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Recomendaciones de la Sociedad Iberoamericana de Neonatología (SIBEN®) para los "Cuidados Transdisciplinarios y Humanizados para el Recién Nacido y su Familia": XIV CONSENSO CLINICO de SIBEN
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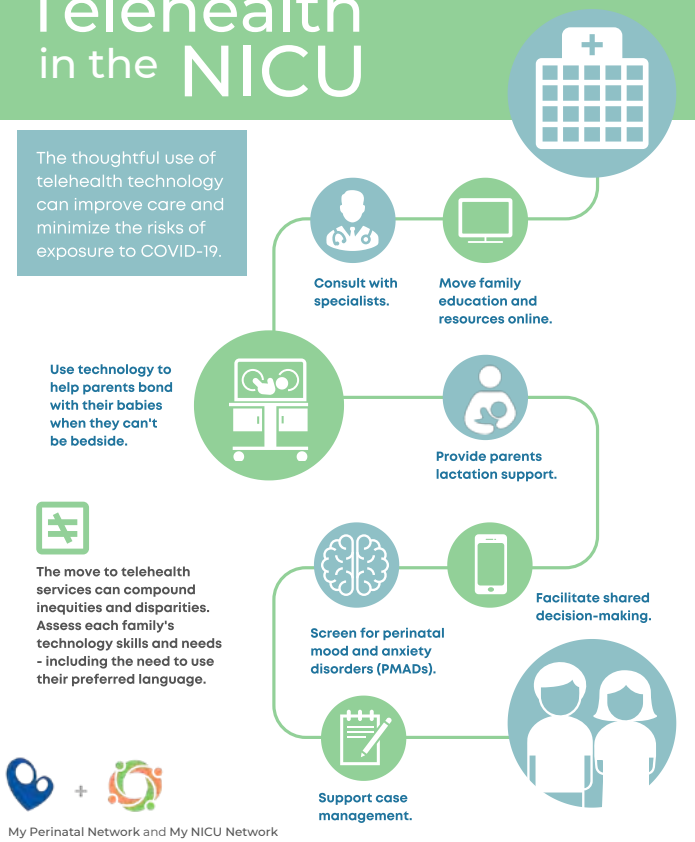
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Telehealth in the NICU

The thoughtful use of telehealth technology can improve care and minimize the risks of exposure to COVID-19.



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Recomendaciones de la Sociedad Iberoamericana de Neonatología (SIBEN®) para los "Cuidados Transdisciplinarios y Humanizados para el Recién Nacido y su Familia": XIV CONSENSO CLINICO de SIBEN

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"Es imperioso un cambio cultural en las unidades de hospitalización neonatal Iberoamericanas, que garantice el respeto de los derechos de los neonatos y sus familias durante la internación, con equidad en los diferentes niveles de atención, sin diferencias por áreas geográficas o nivel socioeconómico."

Resumen

Es imperioso un cambio cultural en las unidades de hospitalización neonatal Iberoamericanas, que garantice el respeto de los derechos de los neonatos y sus familias durante la internación, con equidad en los diferentes niveles de atención, sin diferencias por áreas geográficas o nivel socioeconómico. Es ineludible capacitarnos y mejorar las competencias del equipo de salud desde los gestores hasta los profesionales asistenciales para brindar Cuidados transdisciplinarios y humanizados (CTH) para el recién nacido y su familia. Existe suficiente evidencia que los CTH impactan positivamente los desenlaces finales de los recién nacidos y sus familias y cuando sus familias están involucradas en el cuidado de su bebé hospitalizado.

*El presente trabajo resume los resultados del XIV Consenso Clínico de **SIBEN**® de "Cuidados transdisciplinarios y humanizados para el recién nacido y su familia", en el cual colaboraron 50 miembros de **SIBEN**®, neonatólogos y licenciados en enfermería de 14 países de Iberoamérica que participaron activamente durante el 2023, antes, durante y después de la reunión presencial que se llevó a cabo en Mar de Plata, Argentina en noviembre del 2023. El presente artículo responde a preguntas formuladas con base a la mejor evidencia disponible actualmente y describe recomendaciones de significación clínica para lograr brindar realmente cuidados transdisciplinarios y humanizados (CTH).*

Introducción:

En el siglo XIX, las muertes infantiles eran consideradas parte del orden natural (1). En 1802, se fundó el primer hospital pediátrico en París, L'Hôpital des Enfants Malades, que promovía la lactancia materna y las necesidades emocionales de los niños. (1,2).

La neonatología surgió en el siglo XX gracias a los avances tecnológicos que incrementaron la supervivencia neonatal, pero con reducción de la participación parental. Investigaciones, como las del "Citizen's Committee for Children of New York City", y el "informe Platt" en el Reino Unido influyeron en la aceptación de la presencia de los padres en los hospitales, demostrando que su presencia no aumentaba las tasas de infección (2). Spitz acuñó el término "hospitalismo" para describir los efectos negativos del confinamiento hospitalario prolongado (3). En el decenio de 1980 se introdujo el modelo de cuidado neonatal centrado en la familia, demostrando su eficacia en la atención del prematuro.

En 1984, el Parlamento Europeo aprobó la Carta de los Derechos de los Pacientes y, en 1986 aprobó la Carta Europea de los Niños Hospitalizados, que reconocía 23 derechos, incluyendo el de estar acompañados por sus padres o cuidadores principales el mayor tiempo posible (4). Esta carta, fue adoptada por organismos internacionales como la OMS y UNICEF. Los países occidentales comenzaron a aliviar las restricciones de visita para los padres desde 1990 (2,5).

"Es imperioso un cambio cultural en las unidades de hospitalización neonatal Iberoamericanas, que garantice el respeto de los derechos de los neonatos y sus familias durante la internación, con equidad en los diferentes niveles de atención, sin diferencias por áreas geográficas o nivel socioeconómico."

En Iberoamérica, para el 2016, no todas las unidades de neonatología contaban con las condiciones adecuadas para implementar los CTH. Un estudio de la Sociedad Iberoamericana de Neonatología (SIBEN®) (6) reveló que el 63% de las unidades ofrecían espacio para que las madres se quedaran con sus hijos (el 27% durante la noche), y en el 60% de los casos existían restricciones horarias para las visitas de los padres. Esto demuestra la necesidad de un cambio cultural en las UCIN Iberoamericanas para garantizar el respeto de los derechos de los neonatos y sus familias durante la hospitalización.

Concepto, principios de los cuidados transdisciplinarios y humanizados (CTH) para el recién nacido y su familia

En los últimos años diferentes denominaciones incorporan a la familia en el cuidado del recién nacido hospitalizado. Consideramos que este cuidado es brindado por muchas disciplinas al recién nacido (RN) y su familia, de manera integrada, simultánea, sin jerarquías, organizada, según las necesidades del neonato y sobre todo de manera humanizada; por ello SIBEN denomina a este modelo de atención **"Cuidados transdisciplinarios y humanizados (CTH) para el recién nacido y su familia".**

Los CTH para el RN y su familia con enfoque integral, enfatizan la participación familiar, el respeto por sus necesidades y una comunicación transparente (7). Estas intervenciones reducen el estrés neonatal, favorecen su desarrollo, refuerzan el rol de la familia como cuidadora, mejoran el vínculo familiar y la calidad del cuidado (7-10).

"Los CTH tienen como principios fundamentales: respeto, honrar la diversidad de las familias; flexibilidad, intercambio de información, sin tecnicismos médicos participación y toma de decisiones y colaboración entre el paciente, familia y proveedores de atención médica, permitir el empoderamiento de la familia para descubrir sus fortalezas (5,7)."

Los CTH tienen como **principios** fundamentales: respeto, honrar la diversidad de las familias; flexibilidad, intercambio de información, sin tecnicismos médicos participación y toma de decisiones y colaboración entre el paciente, familia y proveedores de atención médica, permitir el empoderamiento de la familia para descubrir sus fortalezas (5,7).

Niveles de intervención en el CTH para el recién nacido y su familia: (2, 11)

1. **Primer nivel**: Apoyo a los padres mediante intervenciones psicoeducativas, de comunicación y ambientales, para ayudarlos a sobrellevar la hospitalización y prepararlos para el seguimiento del RN.
2. **Segundo nivel**: Intervenciones brindadas por los padres, enfocadas en mejorar el desarrollo y recuperación del RN, con beneficios tanto psicológicos como físicos para los padres, quienes reciben educación del equipo clínico.
3. **Tercer nivel**: Modelos de atención colaborativa, donde los padres se involucran plenamente en la atención del RN.

Elementos del CTH (12)

De acuerdo con la evidencia científica disponible actualmente, consensuamos los siguientes elementos:

- Reconocimiento de la familia como parte importante e imprescindible en el cuidado del neonato hospitalizado.
- Participación constante de la familia en la toma de decisiones, así como de los procedimientos que se realicen.
- Facilitar la colaboración familiar/profesional en todos los niveles de atención.
- Comunicación e intercambio de información en todo momento por parte del personal de salud hacia la familia.
- Reconocimiento de la diversidad familiar incluyendo etnia, nivel socioeconómico, educativo, racial, geográfico etc., evitando así los juicios de valor.
- Incorporar modelos que aporten al aprendizaje de los padres en cuanto al cuidado de sus hijos, mediante cursos y programas de educación.
- Acceso libre en todo momento y que la familia pueda estar siempre al cuidado de su hijo.
- Creación de redes de apoyo familiares.
- Reconocer en las familias sus fortalezas, sentimientos, emociones, preocupaciones, sus capacidades para ayudar y aportar y de esa manera validarlos, reconociéndolos como parte importante, fundamental e imprescindible en el cuidado de los RN.
- Facilitar en lo posible la estancia de los padres mediante un espacio de comodidad para que estén cerca de su hijo el mayor tiempo posible.

"En 2011 en el libro Cuidados Neonatales, Descubriendo la Vida de un Recién Nacido Enfermo de Sola, A (62) se introduce y enfatiza el concepto de que: "los padres no son visita" y que NO debería haber horarios limitados para que una madre esté con su bebé que está en la unidad de cuidado intensivo neonatal (UCIN)."

En 2011 en el libro Cuidados Neonatales, Descubriendo la Vida de un Recién Nacido Enfermo de Sola, A (62) se introduce y enfatiza el concepto de que: *"los padres no son visita"* y que NO debería haber horarios limitados para que una madre esté con su bebé que está en la unidad de cuidado intensivo neonatal (UCIN).

Cambios, beneficios y herramientas para poder realizar los CTH

Es necesario **cambiar** de la atención estándar a los CTH para mejorar la calidad de atención de cada neonato en los servicios de hospitalización y sus familias (6,8,9).

- ✓ promueven el desarrollo neurológico y físico del recién nacido

- ✓ humanizan los cuidados
- ✓ reducen el estrés
- ✓ mejoran la salud
- ✓ mejoran la adherencia a tratamientos
- ✓ facilitan la lactancia materna
- ✓ optimizan los cuidados al alta y la transición al hogar
- ✓ aumentan la calidad de los cuidados
- ✓ elevan la satisfacción parental (1)
- ✓ A continuación, algunas estrategias imprescindibles para lograrlo (13,14).

1. **Información y sensibilización**: Promover los beneficios de los CTH mediante programas dirigidos a equipos médicos, familias y responsables de políticas públicas.
2. **Capacitación del personal**: Implementar talleres, cursos y pasantías para formar al personal en CTH.
3. **Involucrar a los padres desde el inicio**: Fomentar su presencia y participación en procedimientos médicos y cuidados diarios para fortalecer el vínculo afectivo.
4. **Empoderar a los padres**: Brindarles herramientas y capacitación para que participen activamente en la toma de decisiones sobre la salud del bebé.
5. **Adecuar los espacios físicos**: Diseñar áreas que permitan la permanencia de los padres cerca de sus hijos.
6. **Apoyo emocional continuo**: Ofrecer programas de apoyo psicológico para ayudar a las familias a manejar el estrés y las dificultades emocionales.
7. **Planificación y evaluación**: Asegurar una implementación gradual con ajustes constantes y la colaboración de profesionales, padres y la comunidad, para lograr una atención más humana y efectiva (15).

Algunas **herramientas** para promover la participación de los padres en la atención neonatal incluyen (20, 21):

a) ***Kit* de bienvenida:** Contiene información educativa sobre cuidados neonatales, recursos educativos y guía para la participación de los padres.

b) **Contacto piel con piel:** mejora la estabilidad térmica, facilita la lactancia y reduce el estrés en padres e hijos (17,18).

c) **Diario de cuidados:** Los padres registran actividades cotidianas del bebé, como alimentación, cambios de pañal, y procedimientos, que les permite sentirse más comprometidos con su cuidado y evaluar su avance como cuidadores.

d) **Programa de participación en rondas médicas**: Los padres pueden discutir el estado y tratamiento del bebé, hacer preguntas y expresar preocupaciones.

e) **Clases y talleres de capacitación**: Se proporcionan recursos educativos impresos sobre cuidados neonatales y desarrollo infantil.

f) **Aplicaciones móviles y plataformas en línea:** Permiten a los padres acceder a información actualizada sobre el estado de su bebé, programar visitas y comunicarse con el personal médico (11).

g) **Grupos de apoyo y asesoramiento psicológico:** Facilitan la ayuda mutua entre padres, compartir experiencias e involucrarse en el cuidado de sus hijos.

"La inclusión de la familia en el cuidado del neonato hospitalizado es una práctica humanizada y recomendada, aunque no siempre se implementa en todas las unidades neonatales (22, 23). Algunos profesionales consideran que la presencia de los padres no es necesaria, argumentando que pueden generar ansiedad, no estar preparados para procedimientos invasivos, o que el espacio físico es insuficiente. Además, la falta de conocimiento sobre cuidados centrados en la familia y barreras normativas institucionales afectan negativamente el cuidado del bebé y su familia (24)."

Dificultades u obstáculos en el proceso de los CTH

La inclusión de la familia en el cuidado del neonato hospitalizado es una práctica humanizada y recomendada, aunque no siempre se implementa en todas las unidades neonatales (22, 23). Algunos profesionales consideran que la presencia de los padres no es necesaria, argumentando que pueden generar ansiedad, no estar preparados para procedimientos invasivos, o que el espacio físico es insuficiente. Además, la falta de conocimiento sobre cuidados centrados en la familia y barreras normativas institucionales afectan negativamente el cuidado del bebé y su familia (24).

Contacto piel con piel

El contacto piel con piel (CPP) tiene orígenes ancestrales, en diferentes culturas y épocas, siendo una práctica común entre madres y sus bebés sanos o enfermos. En forma protocolizada comenzó en la década de 1970 en Bogotá, Colombia, el calor corporal materno permitió estabilizar fisiológicamente y proporcionar comodidad y seguridad a los neonatos. A partir de 1990, el éxito de esta práctica se difundió y se adoptó en varios países como una opción de atención neonatal (25).

El CPP es beneficioso tanto para el RN de término como prematuros, aplicado inmediatamente después del parto, durante la primera hora de vida postnatal, durante la hospitalización e inclusive en el domicilio (25-27). Se asocia con disminución de

síntomas depresivos en el posparto materno, mejor perspectiva sobre la maternidad, intrínseca y extrínsecamente gratificante, especialmente al ser capaz de cuidar de su bebé (25). Se han reportado niveles de cortisol salival materno más bajo en mediciones de una semana y un mes posparto. (28)

Además, estudios recientes han mostrado una prolongación significativa de la lactancia a los seis meses (5,08 meses frente a 2,05 meses) (29). Otros hallazgos destacan beneficios adicionales, como el aumento de peso del RN, reducción del tiempo de hospitalización, fortalecimiento del vínculo madre-hijo y contribución al desarrollo global del RN (30,31).

Los CTH y ventajas en la lactancia materna:

Los CTH incluyen el concepto de **"*unidades de puertas abiertas*"** las 24 horas, donde se alienta a los padres a estar presentes durante las tomas de leche materna y participar en la alimentación, ya sea directamente del pecho o mediante leche extraída. Este enfoque favorece el vínculo, la analgesia, el neurodesarrollo y, especialmente, la producción de leche y la lactancia materna.

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Los CTH y la satisfacción de la familia:

Los padres de los RN hospitalizados pueden experimentar estrés agudo o postraumático, afectando su salud física, psicológica y social, así como su relación con sus hijos. La confianza de los padres aumenta cuando tienen conocimiento sobre cómo actuar y el impacto de sus acciones en la salud de su bebé (26,33,34,36).

Cuando se establecen los CTH, se reconoce a la familia como referencia permanente en la vida del niño incluso durante su hospitalización. Los miembros de la familia se involucran en los cuidados, forman tempranamente parte de éstos y participan en la toma de decisiones respecto a su hijo promoviendo el vínculo padres-hijo (26,32).

Las dimensiones de la atención neonatal más importantes para los padres son: seguridad, cuidado, comunicación, información, educación, ambiente, seguimiento, manejo del dolor y participación (37).

En este sentido SIBEN® recomienda:

1. Cambiar el paradigma y mejorar las habilidades de comunicación del personal sanitario para satisfacer las necesidades de la familia respecto a la enfermedad, tratamiento y recuperación del neonato.
2. Fomentar la empatía, accesibilidad y confidencialidad en la comunicación con las familias, aumentando su participación en decisiones sobre los cuidados y tratamiento. Además, considerar el funcionamiento familiar como apoyo crucial durante lla hospitalización del RN.
3. Aplicar CTH desde el ingreso del RN, integrando a la familia como cuidadores activos y competentes de su hijo.

"El equipo de salud neonatal en la UCIN se enfoca en preservar la vida de los RN mediante intervenciones terapéuticas (38,39). Cuando los padres enfrentan la pérdida de un bebé, el duelo que experimentan requiere de acompañamiento compasivo por equipos multidisciplinarios que presten atención a aspectos psicológicos, emocionales, y espirituales de la familia, ofrezcan empatía y respeten a los padres, para mitigar su dolor (38,40)."

La satisfacción de la familia ayuda a transitar el duelo:

El equipo de salud neonatal en la UCIN se enfoca en preservar la vida de los RN mediante intervenciones terapéuticas (38,39). Cuando los padres enfrentan la pérdida de un bebé, el duelo que experimentan requiere de acompañamiento compasivo por equipos multidisciplinarios que presten atención a aspectos psicológicos, emocionales, y espirituales de la familia, ofrezcan empatía y respeten a los padres, para mitigar su dolor (38,40).

Infraestructura para la realización de los CTH para el recién nacido y su familia:

La recomendación de la Organización Mundial de la Salud (OMS) de contar con la presencia de los padres las 24 horas en la UCIN, ha motivado la construcción de unidades neonatales con habitaciones privadas que fomentan estas indicaciones. (41)

La implementación y uso de habitaciones privadas en UCIN como recomendación, data de1990 aproximadamente. (42)

Impacto y ventajas en el recién nacido de las habitaciones privadas. (43-51)

- **Reducción de infecciones.** Disminuye a diseminación de infecciones nosocomiales y posibilita la sectorización de pacientes colonizados por microorganismos potencialmente patógenos

- **Mayor aumento de peso.** Los prematuros que permanecieron en habitaciones privadas con sus padres a corto plazo tuvieron mayor tasa de aumento de peso durante la internación.
- **Menos dolor.** verificando un menor número de procedimientos y puntuaciones del dolor más bajas en los niños en habitaciones privadas, en comparación con los niños en habitaciones compartidas.
- **Mejores resultados neuroconductuales.** Hubo significativamente menos estrés fisiológico, hipertonicidad y letargo en los niños en habitaciones privadas.
- **Menor niveles de ruido.** En el modelo de UCIN compartida se encontraron 20 decibeles más elevados.
- **Menor número de días de hospitalización.** M*ás niños fueron dados de alta* tempranamente.
- **Aumento de la lactancia materna.** El 90% logro lactancia materna en habitaciones privadas en comparación con sólo el 66% de compartidas.
- **Menos episodios de apneas.** En el grupo estratificado en la escala PEMR (por sus siglas en inglés: *Physician's Estimate of Mortality Risk*) se observó una disminución del 57 % de eventos totales de apnea en los neonatos prematuros.
- **Reducción en el costo directo.**
- **Reducción de la iluminación**. Se compararon neonatos internados en habitaciones abiertas y privadas de UCIN del *Sanford Children's Hospital* en Sioux Falls-USA, y se mostró reducción de la iluminación, fue de 48,4 lux y solamente 6,4 lux en las privadas ($p < 0,05$) con mayor tiempo de sueño en los neonatos.
- **Post-alta: menor consultas y hospitalizaciones.** Al comparar 2 grupos de prematuros (<34 semanas) se encontraron con menores tasas de re-hospitalización y de solicitudes de atención médica al alta.
- **Mayores puntuaciones cognitivas.** En seguimiento a los 18 meses que compararon las puntuaciones cognitivas del lenguaje y motor de Bayley III en salas privadas y en salas compartidas en prematuros menores de 30 semanas de edad gestacional. Los bebés con alta participación materna en ambas UCIN tuvieron mayores puntuaciones cognitivas.

Desventajas y riesgos de las habitaciones privadas:

Los tipos y frecuencias óptimas de estimulaciones para el desarrollo del cerebro muy prematuro son desconocidos, pero el aislamiento de estos niños en habitaciones privadas relativamente oscuras y silenciosas puede estar yendo en la dirección equivocada (16)**.** Sin embargo, el estímulo auditivo, como las voces de los padres, es considerado positivo en el entorno de la UCIN, asociándose a mejores resultados motores y de lenguaje. Por ello se enfatiza la necesidad de mayor permanencia y participación de los padres en la sala unifamiliar, ya que de lo contrario este aspecto puede ser considerado potencialmente una desventaja. (52)

Las enfermeras de las UCIN presentan más riesgos de fatiga, ansiedad y depresión que las enfermeras de salas generales. El *burnout* en enfermeras neonatales sigue representando un problema. (53-55)

"Posición de SIBEN®. No hay evidencia científica que justifique separar a los padres del RN críticamente enfermo o que requiere una reanimación cardiopulmonar avanzada. Por el contrario, numerosos estudios reportan los efectos beneficiosos para los padres, familia e inclusive su enfoque en relación con la atención recibida, siempre respetando la decisión de dicha participación de los padres; siempre acompañados con personal sanitario que les explique la situación, lo que están viendo."

¿Es recomendable la presencia de la familia durante la reanimación neonatal u otro procedimiento invasivo?

RESPUESTA: SI. Se debe aceptar la presencia de los padres o familiares durante un procedimiento en la sala de internación y no pedirles que abandonen la sala si ellos desean estar allí. (57-58)

Posición de SIBEN®. No hay evidencia científica que justifique separar a los padres del RN críticamente enfermo o que requiere una reanimación cardiopulmonar avanzada. Por el contrario, numerosos estudios reportan los efectos beneficiosos para los padres, familia e inclusive su enfoque en relación con la atención recibida, siempre respetando la decisión de dicha participación de los padres; siempre acompañados con personal sanitario que les explique la situación, lo que están viendo.

Es recomendable, luego de la presencia de los padres durante la reanimación realizar el análisis conjunto con la presencia de ellos, retroalimentar para explicar los procedimientos realizados, aclarar sus dudas y también tomar sus observaciones y enfoques en la mejora de la calidad de los procedimientos realizados en nuestras unidades.

Un concepto filosófico a tener en cuenta es el siguiente que deja sentada una posición al respecto: "*Es así que desde la Antropología se puede notar que a lo largo de la historia de la Humanidad las mujeres buscaron asistencia para el momento del parto, mientras el resto de los mamíferos lo hacen en soledad. Se considera que esto es debido a la complejidad que implica la bipedestación, la cavidad pelviana y el perímetro cefálico humano".* **(59)**

Recomendaciones para implementar estos cuidados transdisciplinarios en las Unidades Neonatales:

- **La importancia de los nombres: Nombre del RN y sus padres.**

Es sumamente importante conocer y referirse a la madre, padre y RN por su nombre. Nunca llamarlo o referirse al recién nacido como: ***"el bebé de la incubadora número tal"***.

- **El arte de la comunicación. La importancia de saber escuchar y hacerse entender.**

  Usar lenguaje sencillo y claro, comprobar que ha sido comprendido lo expresado, especialmente escuchar las inquietudes de la familia alentándoles a realizar preguntas y expresar emociones. Respetar las creencias y costumbres culturales, religiosas de la familia.

- **Somos parte de un mismo equipo – "Los Padres No Son Visitas"** (6)**. La importancia de fomentar, facilitar y acompañar la participación de la madre/familia. Fomentar el contacto piel con piel.**

  También debemos considerar la realización de la práctica por parte de los hermanos o hermanas del RN, abuelos y abuelas, o persona que se designe, con la autorización de sus madres y/o padres**.**

- **Interpretar más allá de las palabras. La importancia de los sentimientos y el apoyo a la salud mental**

  Los profesionales de la salud tendrían que identificar situaciones en donde la madre expresa cansancio, angustia, desesperanza, tristeza, frustración, depresión, llanto, etc.

- **No están solos. La importancia de la red de apoyo de pares, y asociaciones de padres (como FAMISIBEN)** (60)

En el 2021 SIBEN® dentro del grupo de trabajo de FAMISIBEN redactó algunas recomendaciones para padres de neonatos en UCIN, disponibles en formato digital en su página web https://sites.google.com/siben.net/famisiben/ en forma gratuita para familiares, cuidadores, profesionales de la salud y público en general (26.)

En la **tabla 1** se resumen algunas recomendaciones del manuscrito de FAMISIBEN.

Preguntas comunes para implementar los CTH en UCIN:

a. ¿Hay que prohibir el chupete? **Respuesta: NO.** ¿Por qué?

La succión no nutritiva (SNN) es una parte importante de la fisiología del desarrollo infantil. Basados en la evidencia disponible, los autores del "Mini Consenso Clínico de SIBEN / 2021" recomiendan iniciar la estimulación con un chupete (SNN) a las 28-29 semanas de edad gestacional. Los centros que **"prohíben o vedan"** para bebes prematuros el uso del chupete, chupón, chupo, tete o como sea llamado, deben revisar dicha imposición y saber que eso no es ser amigo, sino todo lo contrario (61).

b. ¿Hay que hacer sentir a la madre bienvenida los 1440 minutos de cada día? **Respuesta: SÍ.**

"Los padres no son visita" (62)**.** Los CTH para la familia, favorecen la reducción del estrés de los padres y una relación más positiva entre éstos y el recién nacido.

"Debemos favorecer la permanencia de la madre o padre cerca al bebé aún en la UCIN; las madres y padres en una sala de RN unifamiliares están más involucrados en el cuidado de su bebé, incluido el contacto piel con piel en comparación con las madres de la UCIN abierta, y eso mejoró el crecimiento infantil y neurodesarrollo (46)."

c. ¿La madre **puede permanecer las 24 horas dentro del hospital donde está la UCIN? Respuesta: SÍ.**

Debemos favorecer la permanencia de la madre o padre cerca al bebé aún en la UCIN; las madres y padres en una sala de RN unifamiliares están más involucrados en el cuidado de su bebé, incluido el contacto piel con piel en comparación con las madres de la UCIN abierta, y eso mejoró el crecimiento infantil y neurodesarrollo (46).

d. ¿Existe un tiempo mínimo o máximo para la permanencia de por lo menos un padre en la UCIN? **Respuesta: NO.**

Existe evidencia de que la separación de pacientes hospitalizados altera la dinámica de cuidado de los padres y afecta a todos los miembros del grupo familiar (63)**.**

e. ¿El familiar (madre, padre o quien la madre indique) podrá participar en la UCIN en el cuidado? **Respuesta: SÍ.**

La participación de la familia es un elemento clave en el desarrollo físico, cognitivo y psicosocial de todos los bebés, incluidos los que se encuentran en la UCIN (64)**.**

f. ¿Cuáles son los beneficios de realizar una toma de muestra de sangre, colocación de una vacuna, canalización de vena periférica u otro procedimiento que genera dolor, con el bebé anidado, en brazos y succionando?

En el Consenso Clínico de SIBEN® sobre el abordaje diagnóstico y terapéutico del dolor y el estrés en el recién nacido (65), recomienda la succión no nutritiva cuando se realizan procedimientos que causan dolor leve a moderado. La lactancia materna se considera el tratamiento de primera elección por su seguridad, facilidad de administración y disponibilidad, además de sus múltiples beneficios, que han sido ampliamente estudiados tanto a nivel nutricional como inmunológico**.**

g. ¿Cuál es el rol de las "escuelas para padres" en los CTH para el recién nacido y la familia?

Las escuelas son un espacio de formación para padres y madres que tiene como roles:

1. Permitir una participación consciente y activa de los padres en el cuidado neonatal.

Tabla 1 ¿Qué necesito conocer cuando mi hijo/hija está internado/a en una Unidad Neonatal? [26] · Adaptado de FAMIDERECHOS-SIBEN
https://sites.google.com/siben.net/famisiben/fami-derechos-a-la-manera-de-siben

El alimento es calor, amor, miradas, estímulo, contacto piel a piel y es parte de la construcción del vínculo. Los cuidados que madres, padres y familias puedan brindarle a su bebé pueden variar según el estado de salud del bebé y el funcionamiento del servicio. En conjunto con el acompañamiento de los profesionales, las familias son parte del equipo:

- Participando del cambiado de pañales, del aseo, del baño, al elegir y cambiar la ropa del bebé, al cambiar las sábanas, al controlar la temperatura, a ayudar a posicionarlo correctamente, entre otros.
- Sosteniendo o realizando contacto con el bebé durante algunos procedimientos o intervenciones en el caso de que los cuidadores así lo deseen.
- Sosteniendo en brazos al bebé fuera de la incubadora.
- Calmando al bebé cuando este lo necesite.
- Participando en su alimentación, ya sea por sonda, mamadera o mediante la lactancia; asimismo la extracción y recolección de leche materna es una tarea importantísima y única que puede hacer la mamá por su bebé. En conclusión, madres, padres y familias podrán acompañar y participar en el momento de la alimentación cualquiera sea la manera en que esta se administra.
- Con la mirada. Las mamás y los papás también “cuidan” cuando observan a su bebé, conociendo y reconociendo de a poco las señales y necesidades de su hijo/a: qué le gusta, qué no, si tiene sueño, si está animado, etc.
- Solicitando a los profesionales toda la información que crean necesaria. Es importante que no tengan miedo de preguntar lo que no sepan o pedir a los profesionales que les enseñen a hacer lo que no saben o no se animan. A veces puede ser de ayuda anotar las preguntas en una hoja para no olvidarse lo que va surgiendo durante el día, y a veces en el encuentro con el profesional, por la ansiedad o los nervios se puede olvidar.



Tabla 1 ¿Qué necesito conocer cuando mi hijo/hija está internado/a en una Unidad Neonatal?

Adaptado www.siben.net. Con autorización

2. Enseñar a los padres sobre los estados fisiológicos y biorritmos del niño y sus mecanismos de adaptación.

3. Ofrecer conocimientos para el cuidado post alta del RN.

4. Instruir sobre los beneficios de la lactancia materna y alimentación del recién nacido.

5. Enseñar y promover el contacto piel con piel.

6. Enseñar a los padres sobre la higiene, cuidados y administración de medicamentos.

7. Enseñar signos de alarma prevención de infecciones y reanimación cardiopulmonar del lactante.

8. Dotar de herramientas para trabajar en estimulación del desarrollo psicomotor, formas de estimulación y emociones esperables del RN en diferentes circunstancias que aseguren un adecuado crecimiento y desarrollo de los niños.

h. ¿Cuáles son las acciones claves que son imprescindibles y esenciales para que existan CTH**?**

1. Primero y fundamental, es necesario un cambio de paradigma, asociado a un plan educativo teórico/ práctico para todo el personal, que le proporcione herramientas y habilidades específicas para fomentar el cambio.

2. Lograr la participación multidisciplinaria de todo el personal del área de neonatología, sin voces disonantes o contrarias ("nadie rema en contra").

3. Hay que reconocer que no es suficiente sólo con hablar de este tipo de cuidados neonatales, ya que los desafíos que deben enfrentarse y superarse para implementar CTH en la acción son muchos y en diferentes ámbitos

4. Modificar el ambiente: lo importante es contar con áreas, oficinas y espacios para conversar en privado con los padres y la familia.

5. Asociar en la tarea a los administradores y financieros del área de salud.

"En diversas UCIN, aún en muchos hospitales certificados como amigos de la madre y el niño", se siguen separando a las madres de sus bebés, y además hay poco o nulo espacio para las madres, y no siempre se proporciona una silla o una cama al lado de la incubadora del recién nacido (66)."

i. ¿En la UCI**N de una institución certificada como "amigo de la madre y el niño" se practican CTH para el cuidado del recién nacido y su familia?**

En diversas UCIN, aún en muchos hospitales certificados como amigos de la madre y el niño", se siguen separando a las madres de sus bebés, y además hay poco o nulo espacio para las madres, y no siempre se proporciona una silla o una cama al lado de la incubadora del recién nacido (66).

Puntos clave de SIBEN® acerca los CTH en la UCIN:

- Existe una plasticidad estructural del cerebro en respuesta a la estimulación auditiva materna.
- La calidad de las experiencias influencia significativamente el cerebro y la función y estructura del sistema nervioso central en desarrollo.
- La presencia de la familia en el cuidado neonatal tiene efectos beneficiosos incluyendo mejor vínculo del RN con su familia y la mejoría en la calidad de los cuidados.
- Hay que enfatizar que "los padres no son visitas".
- Transición "suave" del medio hospitalario al domicilio: sin apuros y sin presiones. idealmente con internación conjunta prealta, sobre todo en hospitalizaciones prolongadas de más de 3 semanas.
- El llevar a la práctica acciones y hechos concretos y cotidianos (*no solamente palabras o documentos*) como los comentados en el presente manuscrito, son muy útiles para lograr los mejores resultados
- Llevar a cabo periódicamente autoevaluación crítica y continua de todo el equipo dedicado al bienestar neonatal.

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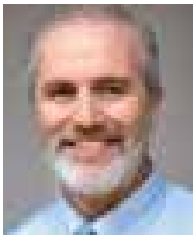
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Recomendaciones de SIBEN acerca de los cuidados transdisciplinarios y humanizados en la UCIN

Edición María José Pleitez

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Recommendations of the Iberoamerican Society of Neonatology (SIBEN®) for "Transdisciplinary and Humanized care for the Newborn and the Family": XIV SIBEN CLINICAL CONSENSUS (English Version)

Jorge Pleitez Navarrete, MD, Carmen Dávila-Aliaga, MD, Lordes Lemus-Varela, MD, María Teresa Montes Bueno MT, Cristian Muñoz, MD, Augusto Sola, MD, Sergio Golombek, MD, and participants of the XIV SIBEN Clinical Consensus of the Iberoamerican Society of Neonatology (SIBEN)

"A cultural change in Iberoamerican neonatal hospitalization units is imperative to guarantee respect for the rights of newborns and their families during hospitalization, with equity at different levels of care, without differences based on geographic areas or socioeconomic level."

Abstract:

A cultural change in Iberoamerican neonatal hospitalization units is imperative to guarantee respect for the rights of newborns and their families during hospitalization, with equity at different levels of care, without differences based on geographic areas or socioeconomic level. It is essential to train and improve the competencies of the health team, from managers to healthcare professionals, to provide transdisciplinary and humanized care (CTH) for newborns and their families. There is sufficient evidence that CTH positively impacts the outcomes of newborns and their families when their families are involved in the care of their hospitalized babies.

This paper summarizes the results of the XIV SIBEN® Clinical Consensus on "Transdisciplinary and humanized care for newborns and their families," in which 50 SIBEN® members, neonatologists, and nursing graduates from 14 Iberoamerican countries actively participated during 2023, before, during and after the face-to-face meeting held in Mar de Plata, Argentina in November 2023. This article answers questions based on the best available evidence and describes recommendations of clinical significance for truly providing transdisciplinary and humanized care (CTH).

Introduction:

In the 19th century, infant deaths were considered part of the natural order 1. In 1802, the first pediatric hospital, L'Hôpital des Enfants Malades, was founded in Paris, which promoted breastfeeding and the emotional needs of children (1, 2).

Neonatology emerged in the 20th century owing to technological advances that increased neonatal survival but with reduced parental involvement. Research, such as the "Citizens' Committee for Children of New York City" and the "Platt Report" in the United Kingdom, influenced the acceptance of parental presence in hospitals, demonstrating that their presence did not increase infection rates (2). Spitz coined the term "hospitalism" to describe the adverse effects of prolonged hospital confinement (3). In the 1980s, the family-centered model of neonatal care was introduced, demonstrating its effectiveness in caring for premature infants.

In 1984, the European Parliament approved the Charter of Patients' Rights. In 1986, it adopted the European Charter for Hospitalized Children, which recognized 23 rights, including the right to be accompanied by their parents or primary caregivers for as long as possible (4). This charter was adopted by international organizations such as the WHO and UNICEF. Western countries began to ease visitation restrictions on parents as early as 1990 (2, 5).

"Not all neonatology units in Ibero-America had adequate conditions to implement CTH by 2016. A study by the Ibero-American Society of Neonatology (SIBEN®) (6) revealed that 63% of the units offered space for mothers to stay with their infants (27% overnight), and in 60% of cases, there were time restrictions for parental visits."

Not all neonatology units in Ibero-America had adequate conditions to implement CTH by 2016. A study by the Ibero-American Society of Neonatology (SIBEN®) (6) revealed that 63% of the units offered space for mothers to stay with their infants (27% overnight), and in 60% of cases, there were time restrictions for parental visits. This demonstrates the need for a cultural change in Ibero-American NICUs to guarantee respect for the rights of neonates and their families during hospitalization.

Concept and principles of transdisciplinary humanized care (CTH) for newborns and families

In recent years, different denominations have incorporated families into the care of hospitalized newborns. We consider that this care is provided by many disciplines to the newborn (NB) and its family in an integrated, simultaneous, non-hierarchical, organized manner, according to the needs of the newborn and, above all, in a humanized way; therefore, SIBEN calls this model

of care **"Transdisciplinary Humanized Care (CTH) for the newborn and its family."**

With a comprehensive approach, the CTH for the NB and its family emphasizes family participation, respect for their needs, and transparent communication (7). These interventions reduce neonatal stress, favor their development, reinforce the family's caregiver role, and improve family bonding and quality of care (7-10).

The fundamental **principles** of CTH are respect, honoring families' diversity, flexibility, exchange of information, no medical terminology, participation and decision-making, collaboration between the patient, family, and health care providers, and family empowerment to discover their strengths (5, 7).

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Levels of Intervention of CTH for the Newborn and Family : (2, 11)

- **First level:** Support parents through psychoeducational, communication, and environmental interventions to help them cope with hospitalization and prepare them for the newborn's follow-up.
- **Second level:** Interventions provided by the parents focused on improving the development and recovery of the newborn, with psychological and physical benefits for parents who received education from the clinical team.
- **Third level:** Collaborative care models, where parents are fully involved in newborn care.

Elements of CTH (12)

According to the currently available scientific evidence, we agree with the following elements:

- Recognition of the family as an important and indispensable part of the care of hospitalized neonates
- Constant participation of the family in decision-making, as well as the procedures carried out
- Facilitate family/professional collaboration at all levels of care.
- Communication and exchange of information by health personnel at all times with the family.
- Recognition of family diversity, including ethnicity, socioeconomic, educational, racial, geographic, etc., thus avoiding value judgments.
- Incorporate models that contribute to parents' learning regarding the care of their children through courses and educational programs.
- Unrestricted access at all times and the family can always be involved in the care of their child
- Creation of family support networks.
- Recognize the family's strengths, feelings, emotions, concerns, and ability to help and contribute, thus validating them as an important, fundamental, and indispensable part of the NB's care.
- Facilitate the parents' stay as much as possible by providing a comfortable space for them to be close to their child for as long as possible.

In 2011, the book Neonatal Care, Discovering the Life of a Sick Newborn by Sola, A (62). introduces and emphasizes the concept that: "parents are not visitors" and that there should not be limited hours for a mother to be with her baby who is in the neonatal intensive care unit (NICU).

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Changes, benefits, and tools for performing CTH:

- ✓ promote the newborn's neurological and physical development
- ✓ humanize care
- ✓ reduce stress
- ✓ improve health
- ✓ improve adherence to treatment
- ✓ facilitate breastfeeding
- ✓ optimize discharge care and transition to home care
- ✓ increase the quality of care
- ✓ increase parental satisfaction (1)

The following are some essential strategies to achieve this objective (13,14):

1. **Information and awareness-raising:** Promote the benefits of BFHC through programs aimed at medical teams, families, and public policymakers.
2. **Staff training:** Implementation of workshops, courses, and internships to train staff in CTH.
3. **Involve parents from the beginning:** Encourage their presence and participation in medical procedures and daily care to strengthen bonding.
4. **Empower parents:** Provide them with tools and training so that they can actively participate in making decisions about their babies' health.
5. **Adapt physical spaces:** Design areas that allow parents to stay close to their children.
6. **Ongoing emotional support:** Offer psychological support programs to help families manage stress and emotional difficulties.
7. **Planning and evaluation:** Ensure gradual implementation with constant adjustments and collaboration of professionals, parents, and the community to achieve more humane and effective care (15).

Some **tools** to promote parental involvement in neonatal care include (20, 21):

a) **Welcome Kit:** This kit contains educational information on neonatal care, educational resources, and guidance for parental involvement.

b) **Skin-to-skin contact**: improves thermal stability, facilitates breastfeeding, and reduces stress in parents and infants (7,18).

c) **Care diary:** Parents record the baby's daily activities, such as feeding, diaper changes, and procedures, which allows them to feel more engaged in their care and evaluate their progress as caregivers.

d) **Medical rounds participation program:** Parents can discuss the baby's condition and treatment, ask questions, and express concerns.

e) **Training classes and workshops:** Educational resources on neonatal care and child development are provided.

f) **Mobile applications and online platforms:** Allow parents to access up-to-date information on their baby's condition, schedule visits, and communicate with medical staff**.**

g) **Support groups and counseling:** Facilitate mutual support among parents, share experiences, and get involved in their child's care.

Difficulties or obstacles in the CTH process:

Including the family in the care of the hospitalized neonate is a humanized and recommended practice, although it is not always implemented in all neonatal units (22, 23). Some professionals consider that the presence of parents is not necessary, arguing that they may generate anxiety, not be prepared for invasive procedures, or that the physical space is insufficient. In addition, lack of knowledge about family-centered care and institutional regulatory barriers negatively affect the care of the infant and family (24).

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Skin to skin contact:

Skin-to-skin contact (SSC) has ancestral origins in different cultures and times, and it is a common practice between mothers and their healthy or sick babies. In protocolized form, it began in the 1970s in Bogota, Colombia; the maternal body heat allowed it to stabilize physiologically and provide comfort and security to neonates. Since 1990, the success of this practice has spread, and it has been adopted in several countries as a neonatal care option (25).

SSC is beneficial for both term and preterm newborns, and it is applied immediately after delivery, during the first hour of postnatal life, during hospitalization, and even at home (25-27). It is associated with decreased maternal postpartum depressive symptoms, improved perspective on motherhood, and intrinsic and extrinsic gratification, especially being able to care for her baby (25). Lower maternal salivary cortisol levels have been reported at one week and one month postpartum (28).

In addition, recent studies have shown a significant prolongation of breastfeeding at six months (5.08 months vs. 2.05 months) (29). Other findings highlight additional benefits, such as increased weight gain of the NB, reduction of hospitalization time, strengthening of the mother-child bond, and contribution to the overall development of the NB (30,31).

CTH and the advantages of breastfeeding

CTH includes the concept of 24-hour **"open-door units"** where fathers are encouraged to be present during breastfeeding and participate in feeding, either directly from the breast or by expressed milk. This approach promotes bonding, analgesia, neurodevelopment, milk production, and breastfeeding.

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CTH and family satisfaction:

Parents of hospitalized NBs may experience acute or post-traumatic stress, affecting their physical, psychological, and social health, as well as their relationship with their children. Parents' confidence increases when they know how to act and the impact of their actions on their infant's health (26, 33, 34, 36).

When CTHs are established, the family is recognized as a permanent reference in the child's life, even during hospitalization. Family members become involved in the care, take an early part in it, and participate in decision-making regarding their child, promoting the parent-child bond (26, 32).

The most important dimensions of neonatal care for parents are safety, care, communication, information, education, environment, monitoring, pain management, and participation (37).

SIBEN® recommends:

1. Change the paradigm and improve the communication skills of healthcare personnel to meet the family's needs regarding the illness, treatment, and recovery of the neonate.
2. Encourage empathy, accessibility, and confidentiality in communication with families, increasing their participation in decisions about care and treatment. In addition, family functioning is considered to be crucial support during the newborn's hospitalization.
3. Apply CTH from the admission of the newborn, integrating the family as active and competent caregivers of their child.

Family satisfaction helps in dealing with grief.

The NICU neonatal health team focuses on preserving the newborn's life through therapeutic interventions (38,39). When parents face the loss of an infant, the grief they experience requires compassionate accompaniment by multidisciplinary teams that pay attention to psychological, emotional, and spiritual aspects of the family and offer empathy and respect for the parents to mitigate their pain (38,40).

Infrastructure to Implement CTH for the Newborn and Family

The World Health Organization (WHO) recommendation of 24-hour parental presence in the NICU has motivated the construction of neonatal units with private rooms, encouraging these indications. (41)

The implementation and use of private rooms in the NICU as a recommendation dates back to approximately 1990. (42)

Impact and Advantages of private rooms for the newborn. (43-51)

- **Reduction of infections.** Decreases the spread of nosocomial infections and makes the isolation of patients colonized by potentially pathogenic microorganisms possible.
- **Increased weight gain.** Preterm infants who remained in private rooms with their parents in the short term had a higher rate of weight gain during hospitalization.
- **Less pain,** with fewer procedures and lower pain scores in infants in private rooms compared to infants in shared rooms.
- **Better neurobehavioral outcomes.** Infants in private rooms had significantly less physiological stress, hypertonicity, and lethargy.
- **Lower noise levels**. In the shared NICU model, 20 decibels were found to be 20 decibels higher.
- **Fewer days of hospitalization.** More infants were discharged early.
- **Increased breastfeeding.** 90% achieved breastfeeding in private rooms compared to only 66% in shared.
- **Fewer episodes of apnea**. In the group stratified on the PEMR (Physician's Estimate of Mortality Risk) scale, there was a 57% decrease in total apnea events in preterm infants.
- **Reduction in direct cost.**
- **Reduction in illumination**. Neonates admitted in open and private NICU rooms at Sanford Children's Hospital in Sioux Falls, USA, were compared, and a reduction in illumination was shown: 48.4 lux and only 6.4 lux in private rooms ($p < 0.05$), with longer sleep time in neonates.
- **Post-discharge: fewer consultations and hospitalizations.** Comparing two groups of preterm infants (<34 weeks), it was found that they had lower rates of rehospitalization and requests for medical care at discharge.
- **Higher cognitive scores.** At an 18-month follow-up, Bayley III cognitive language and motor scores were compared in private and shared rooms in preterm infants under 30 weeks of gestational age. Infants with high maternal involvement in both NICUs had improved cognitive scores.

Disadvantages and risks of private rooms

The optimal types and frequencies of stimulation for very preterm brain development are unknown. Still, the isolation of these infants in relatively dark and quiet private rooms may be going in the wrong direction (16). However, auditory stimulation, such as parental voices, is considered positive in the NICU environment, being associated with better motor and language outcomes. Therefore, the need for greater parental permanence and involvement in the single-family room is emphasized, as otherwise, this aspect may be considered a disadvantage. (52)

NICU nurses are at greater risk of fatigue, anxiety, and depression than nurses in general wards. Burnout in neonatal nurses continues to be a problem. (53-55)

Is family presence during neonatal resuscitation or other invasive procedures advisable?

ANSWER: YES. Parents or family members should be welcome to be present during an inpatient procedure and should not be asked to leave the room if they wish to be there. (57-58)

SIBEN® Position. There is no scientific evidence to justify separating parents from critically ill NBs or those requiring advanced cardiopulmonary resuscitation. On the contrary, numerous studies report the beneficial effects on the parents, family, and even their approach concerning the care received. They always respect the parents' decision to participate and are accompanied by health personnel who explain the situation and what they are seeing.

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It is advisable, after the presence of the parents during the resuscitation, to carry out a joint analysis with their presence, to provide feedback to explain the procedures performed, to clarify their doubts, and also to consider their observations and concerns to improve the quality of the procedures performed in our units.

A philosophical concept to be taken into account is the following, which establishes a position in this regard: *"Thus, from Anthropology, it can be noted that throughout the history of mankind, women have sought assistance at the time of childbirth, while the rest of mammals do it alone. It is considered that this is due to the complexity implied by the bipedestation, the pelvic cavity, and the human cephalic perimeter."* (59)

Recommendations to implement transdisciplinary care in Neonatal Units:

- **The importance of names: the name of the NB and his/her parents.**

  Knowing and referring to the mother, father, and newborn by name is essential. Never call or refer to the newborn as**: "the baby in incubator number such and such".**

- **The art of communication. The importance of listening and making yourself understood.**

  Use simple and straightforward language to ensure that what has been expressed has been understood, especially when listening to the family's concerns and encouraging them to ask questions and express emotions. Respect the family's cultural and religious beliefs and customs.

- **We are part of the same team—"Parents Are Not Visitors" (6). The importance of encouraging, facilitating, and accompanying the participation of the mother and family. Encourage skin-to-skin contact.**

  We should also consider the participation of the newborn's brothers or sisters, grandfathers and grandmothers, or other designated persons, with the authorization of their mothers and/or fathers.

- **Interpreting beyond words. The importance of feelings and mental health support.**

  Health care professionals should identify situations where the mother expresses fatigue, anguish, hopelessness, sadness, frustration, depression, crying, etc.

- **They are not alone. The importance of the peer support network and parent associations (such as FAMISIBEN) (60**)

In 2021, SIBEN®, with the FAMISIBEN working group, drafted recommendations for parents of neonates in the NICU. These recommendations are available in digital format on its website, https://sites.google.com/siben.net/famisiben/, free of charge for family members, caregivers, health professionals, and the general public (26).

Table 1 summarizes some recommendations from the FAMISIBEN manuscript.

Common questions for implementing CTH in the NICU:

a. Should the pacifier be banned? Answer: NO. Why?

Non-nutritive sucking (NNS) is an integral part of infant developmental physiology. Based on the available evidence, the "SIBEN Mini Clinical Consensus / 2021" authors recommend initiating stimulation with a pacifier (NNS) at 28-29 weeks gestational age. Centers that **"prohibit or forbid"** the use of pacifiers, teats, or whatever it is referred to should review this restriction and know that this is not baby-friendly but quite the opposite (61).

b. Should the mother be made to feel welcome for 1440 minutes each day? Answer: YES

"Parents are not visitors." (62) CTH for the family promotes stress reduction for the parents and a more positive relationship between the parents and the newborn.

c. Can the mother stay 24 hours a day in the hospital where the NICU is located? Answer: YES.

We should encourage the mother or father to stay close to the baby even in the NICU; mothers and fathers in single-family nurseries care more for their baby, including skin-to-skin

contact compared to mothers in the open NICU, improving infant growth and neurodevelopmental outcomes. (46)

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d. Is there a minimum or maximum length of stay for at least one parent in the NICU? Answer: NO.

There is evidence that the separation of hospitalized patients alters the dynamics of parental care and affects all family group members (63).

e. Will the family member (mother, father, or whoever the mother indicates) be able to participate in NICU care? Answer: YES.

Family involvement is a key element in all infants' physical, cognitive and psychosocial development, including those in the NICU (64).

f. What are the benefits of performing a blood sampling, vaccine placement, peripheral vein cannulation, or other pain-generating procedure with the infant nestled, held, and sucking?

The SIBEN® Clinical Consensus on the diagnostic and therapeutic approach to pain and stress in the newborn (65) recommends non-nutritive sucking when performing procedures that cause mild to moderate pain. Breastfeeding is considered the first-choice treatment because of its safety, ease of administration, and availability, in addition to its multiple benefits, which have been extensively studied both nutritionally and immunologically.

g. What is the role of the "schools for parents" in the CTH for the newborn and the family?

The schools are a training space for parents whose roles are as follows:

1. To allow conscious and active participation of parents in neonatal care.
2. Teach parents about the child's physiological states, biorhythms, and adaptation mechanisms.
3. To offer knowledge for post-discharge care of the newborn.
4. To instruct on the benefits of breastfeeding and newborn feeding.
5. To teach and promote skin-to-skin contact.
6. Teach parents about hygiene, care, and medication administration.
7. To teach warning signs, infection prevention, and infant cardiopulmonary resuscitation.
8. Provide tools to work on psychomotor development stimulation, forms of stimulation, and expected emotions of the newborn in different circumstances to ensure adequate growth and development of children.

h. What key actions are indispensable and essential for CTH to exist?

1. First and foremost, a paradigm shift is necessary, associated with a theoretical/practical educational plan for all personnel, providing them with specific tools and skills to promote change.
2. Achieving the multidisciplinary participation of all neonatology staff without dissonant or opposing voices ("everyone cooperates").
3. It must be recognized that discussing this type of neonatal care is not enough since implementing CTH in action requires facing and overcoming many challenges in different areas.
4. Modify the environment: It is essential to have areas, offices, and spaces for private conversations with parents and family.
5. Partnering with health care administrators and financiers in the task.

"In many NICUs, even in many hospitals certified as "mother-friendly", mothers are still separated from their babies, and there is little or no space for mothers, and a chair or bed is not always provided next to the newborn's incubator (66)."

i. In the NICU of an institution certified as "mother and child friendly," is CTH practiced for the care of the newborn and its family?

In many NICUs, even in many hospitals certified as "mother-friendly", mothers are still separated from their babies, and there is little or no space for mothers, and a chair or bed is not always provided next to the newborn's incubator (66).

Key points from SIBEN® about CTHs in the NICU:

- The brain's structural plasticity is in response to maternal auditory stimulation.
- The quality of experience significantly influences the brain and the function and structure of the developing central nervous system.

Table 1 What do I need to know when my son/daughter is hospitalized? in the Neonatal Intensive Care Unit? [26] · Adapted from FAMIDERECHOS-SIBEN
https://sites.google.com/siben.net/famisiben/fami-derechos-a-la-manera-de-siben

Food is warmth, love, looking, stimulation, skin-to-skin contact, and is part of bonding.
cThe care that mothers, fathers, and families can provide their
babies may vary depending on the baby's health and the functioning of the service. Together with the support of professionals, families are part of the team::

- Participating in diaper changing, grooming, bathing, choosing and changing the baby's clothes, changing sheets, monitoring the baby's temperature, helping to position the baby correctly, among others.
- Holding or making contact with the baby during some procedures or interventions if the caregivers so desire.
- Holding the baby outside the incubator.
- Soothing the baby when needed.
- Participating in feeding, whether through a tube, bottle, or breastfeeding. Expressing and collecting breast milk is also a very important and unique task that a mother can do for her baby. In conclusion, mothers, fathers, and families can accompany and participate in feeding time, regardless of how it is administered.
- With their eyes. Mothers and fathers also "care" when they observe their baby, gradually learning and recognizing their child's signals and needs: what they like, what they don't, if they are sleepy, if they are active, etc.
- By asking professionals for all the information they deem necessary. It is important not to be afraid to ask questions they don't know or to ask professionals to teach them how to do things they don't know or don't dare to do. Sometimes it can be helpful to write down questions on a sheet of paper so you don't forget what comes up during the day, because sometimes the meeting with the professional can be forgotten due to anxiety or nerves.



Tabla 1 What is necessary to know when my Child is in the Neonatal Intensive Care Unit? Adaptado www.siben.net. Con autorización

- The presence of the family in neonatal care has beneficial effects, including improved bonding of the NB with the family and improved quality of care.
- It should be emphasized that **"parents are not visitors."**
- Smooth transition from the hospital environment to the home: no rush and no pressure. Ideally, this occurs during pre-hospitalization, especially in prolonged hospitalizations of more than three weeks.
- Setting concrete, everyday actions and deeds (*not just words or documents*) into practice, such as those discussed in this manuscript, is very useful in achieving the best results.
- Periodically carry out critical and continuous self-evaluation of the neonatal team.

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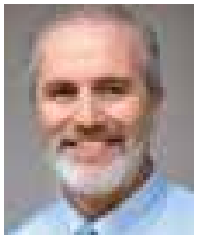
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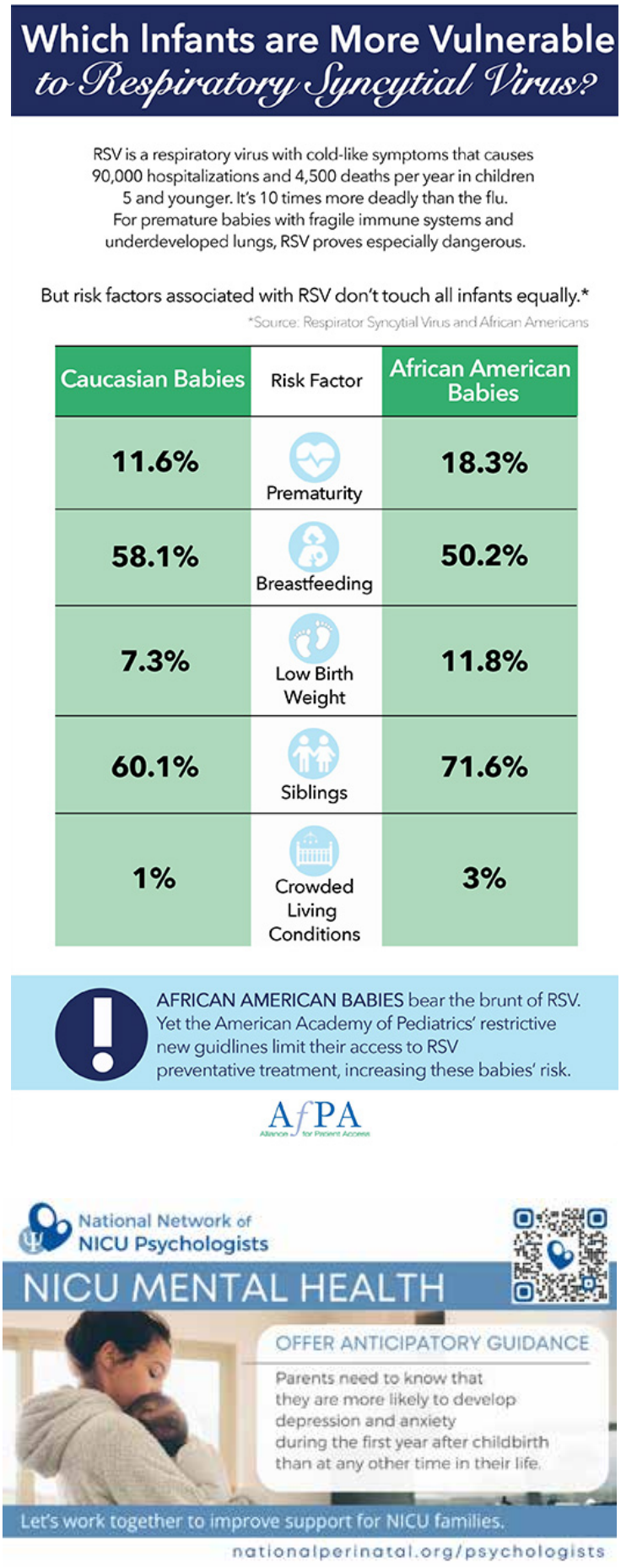
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Freedom And Its Consequences

Rob Graham, R.R.T./N.R.C.P.

I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.

"'We hold that the greatest right in the world is the right to be wrong, that in the exercise thereof, people have an inviolable right to express their unbridled thoughts on all topics and personalities, being liable only for abusing that right.' William Randolph Hearst"

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I was in my car a few weeks ago chatting with a young man I had hired to do some work. Eventually, politics came up, as it invariably does in any conversation involving me (be warned). I replied to his comment with the age-old axiom: "Those who do not learn from history are doomed to repeat it." After a moment of silence, he said, "I've never heard that before." I was gobsmacked.

We have unparalleled, instantaneous access to information yet an equally unparalleled level of ignorance (albeit sometimes willful). In a few hours, we can now travel distances that once took many perilous months, yet we are increasingly disconnected from each other. It is the paradox of our time, the scourge of unregulated social media, and a sometimes flawed interpretation of a concept dear to us all -- freedom.

In Canada, the Charter of Rights and Freedoms protects our right to self-expression, including free speech. The former is broader in scope and affords *more* protection than America's First Amendment (1); other sections of the Charter of Rights and Freedoms cover other First Amendment protections. Unlike the American Constitution, the Canadian document contains a "notwithstanding" clause that allows a government (Provincial or Federal) to nullify some (not all) parts of the Charter it deems to impede potential actions or legislation. It is meant to be a temporary measure and must be renewed every five years (2).

Neither America's founding fathers nor Canada's late Right Honourable Pierre Elliot Trudeau (who delivered the Canadian Charter), or those whose combined efforts penned it, could have imagined the wild west that is modern social media. In our efforts to protect "freedom," we have, in effect, become slaves to it.

Mass disinformation campaigns have cultivated a large and growing segment of the population who are, in effect, unconsciously incompetent. They not only do not realise they are wrong, they vehemently believe they are right. It is a dangerous state of mind, and is being purposely exploited for nefarious reasons.

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Artificial "intelligence," at least in the short term, will exacerbate the problem in a most insidious way. Many will believe something is factual because AI has deemed it to be so, but AI not only makes mistakes, it can also be manipulated to provide biased answers and/or to search incompletely.

For example, my column in March's edition of Neonatology Today was run through ChatGPT for evaluation. ChatGPT flagged four points as unsupported or untrue. Three flags were removed when the program was told where and what to search for to validate the statements, and the fourth was easily verified in 30 seconds with a simple Google® search. I was surprised, although I really should not have been.

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The First Amendment and the Canadian Charter protect a free press through freedom of expression. Arguably, these protections assume the role of a free press is to find and present the truth and to offer unbiased, impartial analysis and scrutiny of all aspects of governments, policies, elected officials, and the judiciary.

"News is what people don't want you to print. Everything thing else is ads." William Randolph Hearst

However, what happens when powerful, well-funded groups with self-serving agendas *are* the press? Their Constitutionally protected status gives them carte blanche to flood media of all types with *their* spin on events virtually unchallenged. Billionaires such as Jeff Bezos, Rupert Murdoch, and Michael Bloomberg, to name a few, own or control vast media conglomerates.

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"*When free discussion is denied, hardening of the arteries of democracy has set in, free institutions are, but a lifeless form and the death of the republic is at hand.*" William Randolph Hearst

The recent blatant undermining of journalistic freedom and integrity by Bezos at The Washington Post is an extreme example of undue influence. Sometimes, that influence is less obvious. In an article on billionaire ownership of media (3), The New York Times neglected to name its majority shareholder, Mexican billionaire Carlos Slim Helu, never mind that the Ochs-Sulzberger family essentially controls it.

Then there are Elon Musk and Mark Zuckerberg, who arguably control the largest media platforms in history. Through their respective companies, each is manipulating algorithms not just to steer public opinion but to influence elections, more often than not in a decidedly "right" direction, while suppressing posts considered "left." Such a danger is that their actions have come under scrutiny by jurisdictions from America to the European Union, the latter considering legal action. Mr. Hearst's quote has been turned on its ear; those not wanting something printed can now prevent printing.

When Marchall McLuhan wrote the now famous "The media is the message," the first line of his 1964 book "Understanding Media: The Extensions of Man" (4), he surely could not imagine what the message would become.

Moreover, here we are. All of us! I am not here today to rub American's noses in what has happened during the past 100 days, tempting though it may be. Canada has just had its own Federal election, and most of you know that Mark Carney is now our Prime Minister, albeit with a minority government (5).

Mark Carney's C.V. is stellar and has been named one of the top 100 most influential men in the world, the twenty-first in fact (6). His main rival was (and is) the Conservative Party of Canada (CPC) leader Pierre Poilievre. Herein lies a disturbing similarity between our two countries.

19,583,016 Canadians, representing just over 68% of eligible voters, cast ballots, which is historically a relatively high number. 8,594,352 votes (≈44%) were cast for the party of the Prime Minister, the Liberal Party of Canada (LPC), while 8,108,338 (≈41%) cast votes for the CPC. A third party, the Bloc Quebecois (BC), which runs candidates in Quebec only, received 1,237,057 (≈6%) of cast ballots and holds the "balance of power" in the House of Commons.

Why is this concerning? As is the case in the US, Canadian Supreme Court Judges are appointed by the government on the day vacancies arise. To many, but for bronzer and orange hair, Mr. Poilievre *is* Donald Trump. We all know what happened to the US Supreme Court and the decisions it has since made. The overturning of Roe v Wade was and is a travesty, but the "Citizens United" ruling has the potential to overturn democracy itself.

Poilievre's campaign featured 3-word, misleading slogans with no substance, and his policy platform was released just before the election on April 28, 2025. The numbers above defy logic for many reasons.

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Although climate change and the environment were conspicuously absent in the LPC and CPC campaigns (Donald Trump is up-staging most issues), 60-70+% of Canadians are concerned about them (7). In 2021, the CPC voted down a resolution declaring climate change is real (8), and the previous CPC government, led by former PM Stephen Harper, forbade meteorologists and government scientists from mentioning climate change (9).

The majority of Canadians either entirely or mainly support freedom of choice when it comes to abortion (10). Mr. Poilievre states that he will not reopen the abortion debate (so did Trump) (11). There is currently no abortion legislation in Canada, but each of his party's MPs may "vote their conscience" on the issue, as well as on the definition of marriage, euthanasia, and other socially charged issues. Here, the devil is in the details. As of

2023, there were no pro-choice MPs in the CPC caucus (12), and Conservative rhetoric over trans rights echoes that of the current American administration (13). The CPC is also supported by the evangelical movement (14).

From January 22 to February 23, 2022, a group called "the trucker convoy or freedom convoy" occupied the streets of downtown Ottawa (Canada's capital). Their goal was to overthrow the "supposed" dictatorship of former PM Justin Trudeau (who was leading a minority government; see reference 5), to end all COVID-19 mandates and mitigations, and to restore "freedom" to Canada. Ironically, their actions severely restricted the freedoms of Ottawa residents. Swastikas and confederate flags were seen, as was Pierre Poilievre. He handed out doughnuts and coffee. While, thankfully, nobody was killed during the occupation, your January 6 only lasted a day, and even Donald Trump did not hand out coffee to the insurrectionists!

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During his campaign, Poilievre promised to end all vaccine mandates, defund Canada's public broadcaster (the CBC), end "Woke" ideology, and slash environmental protections so severely it would make Trump jealous (15). He would do away with safe consumption sites (16), and his promise to cut taxes did not mention how to preserve vital services simultaneously. The majority of his platform would, directly or indirectly, harm public health.

Poilievre repeatedly said that Canada is "broken" (yet it is consistently ranked in the top 10 countries in the world) (17) and is plagued with crime (yet it was just named the second safest country in the world) (18). He also promised to restore Canadian's "freedom" (even vowing to go so far as to override the Charter of Rights and Freedoms to do so (19)). Make that make sense! Canada ranks enviably high on the list of the freest countries in the world (20).

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Before he began to state his intentions to annex Canada publicly, 55% of Poilievre supporters approved of Trump and would vote for him if they could (21).

And what was the position of the media? Mainstream Canadian media rarely rebutted his claims. His press conferences were carefully staged before chosen "journalists," who were given pre-selected questions to ask. Journalists were not even permitted on his plane during the official election campaign.

The last CPC government changed the rules governing foreign ownership of our media. Consequently, the vast majority of Canadian media is now owned by primarily extreme, right-leaning American hedge funds. Despite his promises to do away with the entity, the fact that the CBC was equally silent is perplexing.

Finally, ChatGPT has named Pierre Poilievre as the number one spreader of disinformation in Canada (22). Were it not for Donald Trump's musings on the legitimacy of our "Home and Native Land," we would be swearing in Prime Minister Pierre Poilievre. At least he lost his seat and could not speak in the House of Commons until he won a bi-election that was yet to be held.

So, despite our collective but ever so polite smugness after your disastrous election results (having narrowly escaped a train wreck of our own), it seems the veneer of our self-proclaimed superiority is too thin for comfort.

But we are free for now.

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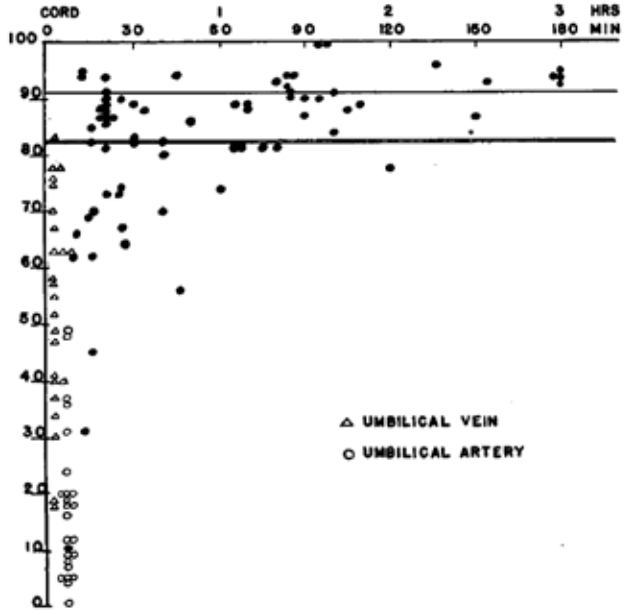
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"Dr. Clement (Clem) Smith was a neonatologist for many years before the terms neonatology and neonatologist were coined by Dr. Alexander Shaffer in 1960."

Dr. Clement (Clem) Smith was a neonatologist for many years before the terms neonatology and neonatologist were coined by Dr. Alexander Shaffer in 1960. (1) He was born in 1901 in Ann Arbor, Michigan, where his father was a Professor of English and Vice President of the University of Michigan. (2) His first love was literature and poetry, and he was a lifelong friend of Robert Frost. After receiving a Master's Degree in English, he studied medicine and was awarded his degree in 1928. He interned at University Hospital in Ann Arbor and then moved to Boston in 1931, where he trained at Boston Children's Hospital. His love of newborn medicine commenced in 1937 when he moved to the Lying-In Hospital and assumed leadership of the newborn nurseries. From his reminiscence published 35 years later, "Dr. Irving and his staff gave me—a young pediatrician (of all things!)—the run of the place, and they gave me between one and two meters of laboratory bench to call my own. This may not seem much, but it was probably 20% of all the nonservice laboratory space in that hospital…Dr. Stuart Clifford, who shared with me the hospitality of the obstetrical staff, offered me the freedom of the premature infant nursery, then under his pediatric direction." (3)

Dr. Smith embarked on a series of seminal studies of neonatal respiratory physiology. In collaboration with Dr. Eugene Kaplan,

Figure 1. Increase in neonatal blood oxygenation saturation versus umbilical saturations in the first hours of life. Black dots are neonatal values (4).



he developed a microcolorimetric method to measure oxygen saturation on 0.2 mL of blood obtained by heel stick. (4) They showed that newborn term infants rapidly increased saturation levels compared to those in the umbilical vessels (Figure 1) and that premature infants did so less rapidly. An early investigation studied the maximal negative intrapulmonary pressure that newborn infants could generate, up to -40 cm H_2O. (5) He then devised an improved seal for a body plethysmograph and studied respiratory rate, tidal volume and minute ventilation, and intraesophageal pressure changes as an index of intrapleural pressure changes in babies. (6–8) Then, he studied these variables in infants with

Figure 2. Pressure-volume loops for an infant with respiratory distress at 2 and 10 days of age (9).

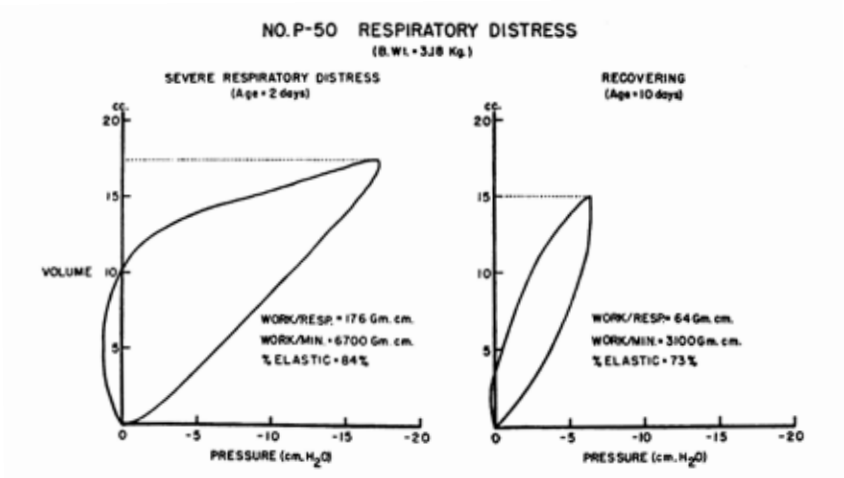


FIG. 5. PRESSURE-VOLUME LOOPS FOR INFANT WITH RESPIRATORY DISTRESS
The marked increase in pulmonary work during respiratory distress is apparent. There is no increase in inspiratory flow resistance although the expiratory flow resistance is increased as a result of the grunting respiration.

respiratory distress syndrome (RDS) and showed much increased intraesophageal pressure changes in those with RDS, along with other abnormalities (Figure 2). (9) Other studies investigated the alveolar-arterial oxygen and carbon dioxide gradients in healthy and ill newborns. (10, 11) Further studies on various aspects of respiratory physiology were also published. (12–14)

"He then devised an improved seal for a body plethysmograph and studied respiratory rate, tidal volume and minute ventilation, and intraesophageal pressure changes as an index of intrapleural pressure changes in babies. Then, he studied these variables in infants with respiratory distress syndrome (RDS) and showed much increased intraesophageal pressure changes in those with RDS, along with other abnormalities (Figure 2)."

The results of these studies and morbidity and mortality statistics have been presented in lectures and review articles over the years. (15, 16) Dr. Smith published a fascinating article in *Scientific American* entitled "The First Breath" that beautifully summarized his studies on this perilous transition from fetal to neonatal life (Figure 3). (17) A review published on my seventh birthday in the *New England Journal of Medicine* summarized the state of the art in respiratory support for sick infants. (18)

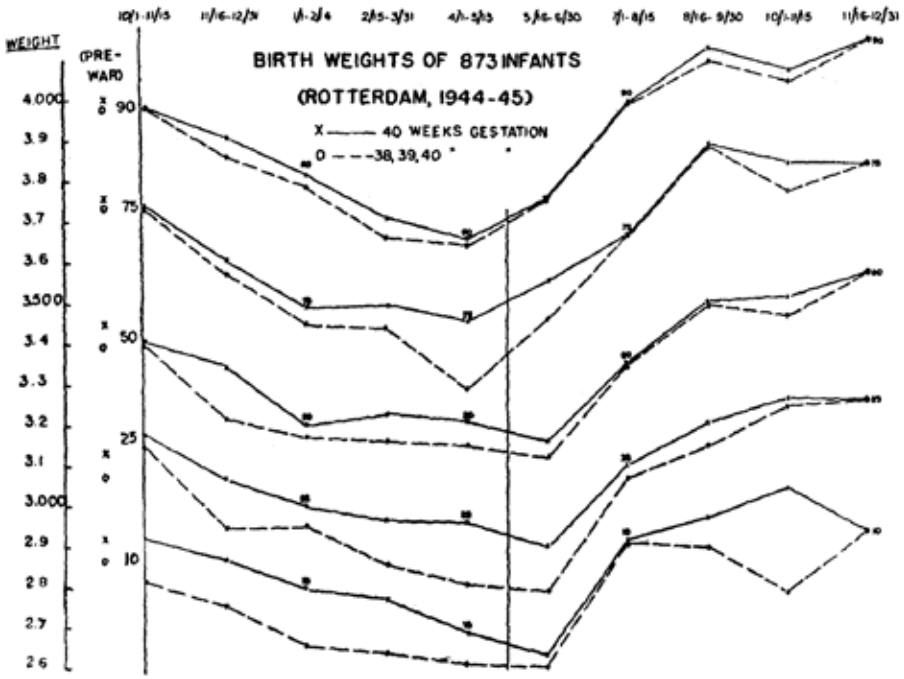
Figure 3. Pressure volume curves for the first three breaths of a term infant (17).



Dr. Smith also had an abiding interest in the fetus. An early study investigated the effects of maternal anesthesia on maternal and fetal oxygenation. (19) He compared the effects of ether, nitrous oxide, and cyclopropane and concluded that cyclopropane was "perhaps less safe for the infant than the clinical appearance of the mother would indicate." He also studied the effects of other obstetrical processes on the outcome of the infant and emphasized the need for obstetricians and pediatricians to work together to improve outcomes. (20) The "Hunger Winter" of 1944 into 1945, close to the end of World War 2, offered an opportunity to study the effect of extreme malnutrition on the fetus and newborn. This was brought about by the Nazi blockade of Dutch cities, which engendered the transient starvation of urban residents. Dr. Smith showed the profound impact of this on the birthweights of infants born during this period (Figure 4). (21) He lectured on the "Potentialities and Limitations of Prenatal Pediatrics." (22) Another series of lectures was summarized in a fascinating publication entitled "In the Valley of the Shadow of Birth." (23)

Dr. Smith made other important contributions to newborn care; in retrospect, some were not so wise. He pioneered the use of umbilical artery catheters and attempted unsuccessfully to treat babies with respiratory distress syndrome with hyperbaric oxygen. (24, 25) An exhaustive study of hyaline membrane formation in 509 autopsies concluded that they were not formed from vernix

Figure 4. Birthweight of babies born before, during, and after the "Hunger Winter" of 1944-5 in Rotterdam, Holland (21).



or meconium but resulted from "concentrated protein of aspirated amniotic fluid," which we now know to be erroneous. (26) In 1964, Dr. Smith published an editorial noting that excess oxygen in the blood was a likely cause of what is now known as retinopathy of prematurity and stated, "Were constant monitoring of the arterial pO_2 feasible, it might be possible to keep the pO_2 between 65 and 85 mm Hg." (27) Fortunately, this is now a reality and his recommendations were remarkably prescient. A later study (with several co-authors who would go on to legendary careers of their own) investigated endogenous carbon monoxide production from hemoglobin destruction in normal and erythroblastic infants.(28) Erythroblastic infants were found to have greatly increased CO production and the authors established the red blood cell survival time in normal infants to be a mean of 88 days, a number we still use today.

"In 1964, Dr. Smith published an editorial noting that excess oxygen in the blood was a likely cause of what is now known as retinopathy of prematurity and stated, 'Were constant monitoring of the arterial pO_2 feasible, it might be possible to keep the pO_2 between 65 and 85 mm Hg.' Fortunately, this is now a reality and his recommendations were remarkably prescient."

On the not-so-wise in retrospect side, Dr. Smith, along with many others at the time, advocated for withholding fluids and feeds from premature infants for up to several days. (29, 30) The argument was that premature infants had excess body water at birth, so early fluid administration was not needed and that withholding feeds would reduce the risk of aspiration. He stated, "Our observations do suggest to us that we need not hurry in the administration of foods or fluids after premature birth, and we assume that removal of the very real danger of food aspiration by delay in feeding makes the critical period a little safer, even when the nursing service is as skilled at gavage technique as ours has learned to be." (23) In the same publication, he wrote, "If we could find a way of preventing premature delivery, what a number of problems would be solved!"

The first of several editions of his *Physiology of the Newborn Infant* was published in 1945 as one of the first comprehensive tomes on the neonate. (31) Dr. Smith served as Editor-in-Chief of *Pediatrics* for 11 years and was President of the American Pediatric Society, the oldest and most prestigious pediatric society. He received numerous accolades for his pioneering work, including being the first recipient of the Apgar Award in 1975, followed by the Howland Award, the highest award given by the American Pediatric Society a year later. He trained dozens of fellows, many of whom went on to distinguished careers, including my primary mentor, Dr. George Cassady, who established the Regional Newborn Intensive Care Unit here at University of Alabama at Birmingham in the 1970s. Multiple obituaries lauded his exceptional contributions when he died in 1988, a few of which are referenced herein. (2, 32, 33)

"The first of several editions of his* Physiology of the Newborn Infant *was published in 1945 as one of the first comprehensive tomes on the neonate. Dr. Smith served as Editor-in-Chief of Pediatrics for 11 years and was President of the American Pediatric Society, the oldest and most prestigious pediatric society."

All of us involved in the care of newborn infants owe a tremendous debt of gratitude to Dr. Clement Andrew Smith for his profound and enduring contributions to what has come to be known as Neonatology. He was truly a pioneer in our field. (33)



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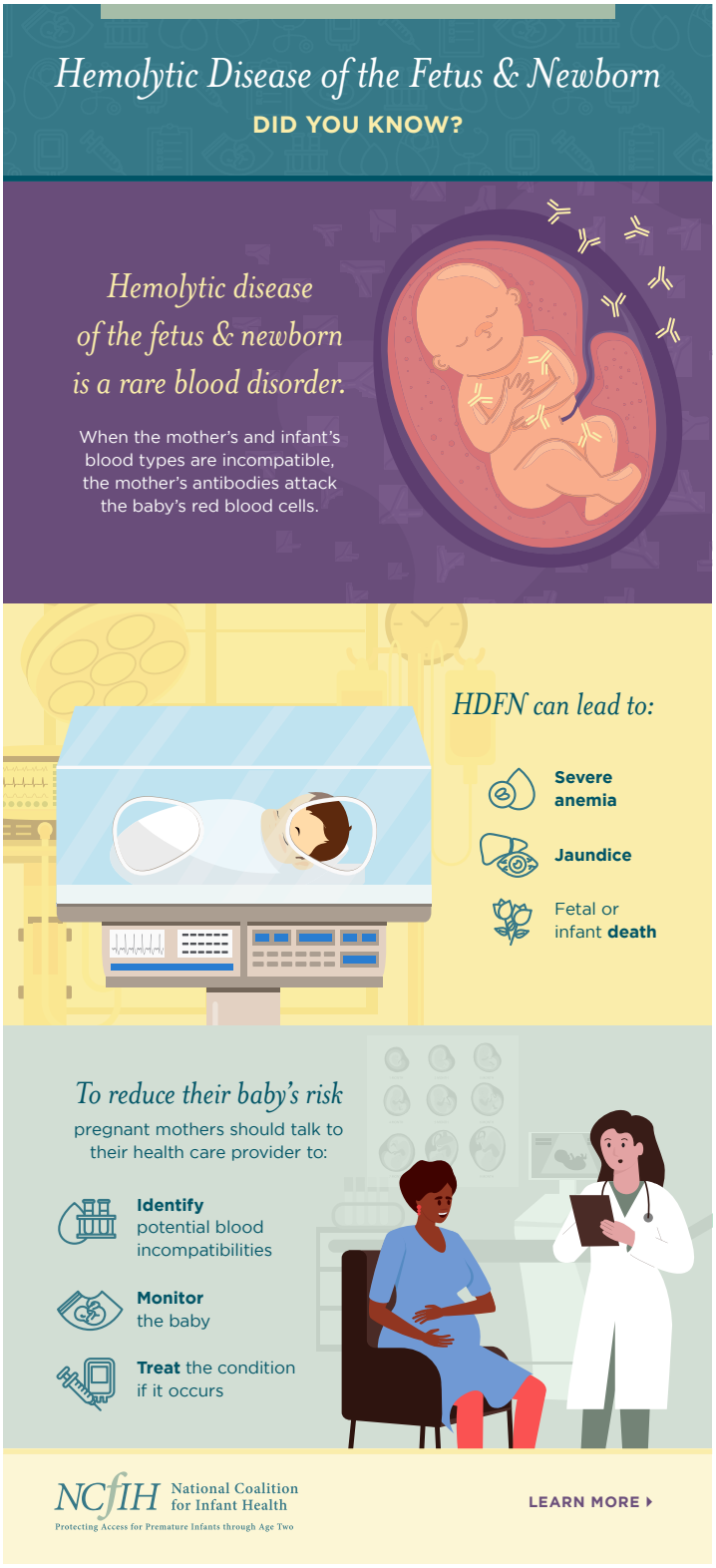
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The Quiet Dismantling of "Safe to Sleep" is a Deadly Betrayal of Our Babies

Jess Daigle, MD, Mitchell Goldstein, MD, MBA, CML

It is hard to overstate what a crib, a firm mattress, and a simple message can do. Since the early 1990s, the "Back to Sleep" campaign—later renamed "Safe to Sleep"—has helped cut infant deaths from Sudden Infant Death Syndrome (SIDS) and other sleep-related causes by more than half. For over 30 years, this campaign gave families a clear, life-saving message: place your baby on their back, alone, in a crib with a firm mattress—no pillows, no blankets, no stuffed animals. (1)

"For over 30 years, this campaign gave families a clear, life-saving message: place your baby on their back, alone, in a crib with a firm mattress—no pillows, no blankets, no stuffed animals. (1)"

It worked. It saved lives. So why is one of the most effective public health campaigns of the last half-century being quietly dismantled?

On April 1, 2025, the National Institute of Child Health and Human Development (NICHD) shut down the communications office that had managed Safe to Sleep for three decades. The team behind it was placed on administrative leave, and all public engagement came to a halt. NIH has tried to offer reassurances, saying the campaign still "exists," but without infrastructure, staff, or outreach, the heart of it is gone. (2)

And babies will die because of it.

"Every year, more than 3,000 babies in the U.S. die from sleep-related causes. (3) That is eight babies—every single day. And these deaths are not mysterious. We know the risk factors. We know how to prevent them. But knowledge does not spread on its own."

Why It Matters:

Every year, more than 3,000 babies in the U.S. die from sleep-related causes. (3) That is eight babies—every single day. And these deaths are not mysterious. We know the risk factors. We know how to prevent them. But knowledge does not spread on its own. It requires education, trust, access, and consistency—especially in communities facing historical neglect or systemic barriers to care.

That is what Safe to Sleep did so well. It did not just print pamphlets. It built trust. It partnered with hospitals, WIC programs, churches, doulas, community groups, and pediatricians. (4, 5) It offered materials in different languages and met families where they were. It acknowledged that culture matters. It understood that how we deliver a message is just as important as the message itself. (1)

And now? That entire structure has vanished—with no replacement and no explanation.

"Let us call this what it is: part of a larger, deeply troubling trend of disinvestment in maternal and infant health. Public health is being politicized, and programs that have saved countless lives are being defunded in silence. When maternal mortality and infant death rates are rising, this kind of decision is not just shortsighted—it is dangerous. (6)"

A Pattern of Disinvestment:

Let us call this what it is: part of a larger, deeply troubling trend of disinvestment in maternal and infant health. Public health is being politicized, and programs that have saved countless lives are being defunded in silence. When maternal mortality and infant death rates are rising, this kind of decision is not just shortsighted—it is dangerous. (6)

The harm will not be evenly felt either. Black infants are already more than twice as likely to die from sleep-related causes compared to white infants. (4) Families living in poverty may not have access to safe cribs, may be forced to co-sleep out of necessity, or may never receive clear, culturally relevant education. Without a federally coordinated campaign, the burden falls to nonprofits and frontline providers—many of whom are already overstretched and underfunded. (5)

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What We Need Now:

We do not need less. We need more.

- Restore full federal funding for Safe to Sleep, including staffing, communications, and resources.
- Expand access to safe sleep surfaces through Medicaid, WIC, and community-based programs.
- Regulate and remove dangerous sleep products from the market.
- Support community-led education efforts that are culturally sensitive and family-centered.
- Fund more research on the social and structural factors that drive disparities in sleep-related infant deaths.

"This is not about politics—it is about prevention. And babies should never be collateral damage in a budget debate. This campaign helped caregivers protect their most vulnerable family members for three decades. Now, at a time when we need it most, it has been dismantled without warning or accountability."

We have already proven that this model works. Instead of letting it die quietly, we should be expanding it.

This Is a Moral Imperative:

This is not about politics—it is about prevention. And babies should never be collateral damage in a budget debate. This campaign helped caregivers protect their most vulnerable family members for three decades. Now, at a time when we need it most, it has been dismantled without warning or accountability.

We owe it to every family who never got the chance to hear this message—and to every baby who still can be saved—to speak up to push for transparency, to demand action. (2, 3)

Because silence on this issue is not neutral, it is deadly.

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Kangaroo Care Day (May 15): A Global Call to Action for Connection, Safety, and Healing

Yamile Jackson, PhD, PE, PMP

Every year on May 15, hospitals and communities worldwide come together to celebrate Kangaroo Care Day. It's a day rooted in science, connection, and the belief that human presence is healing. But for me, it's personal. It's also my son Zachary's birthday.

> *"I didn't set out to start a movement. I was just a mother trying to save her child."*

I didn't set out to start a movement. I was just a mother trying to save her child.

Zachary arrived 12 weeks early. On May 15, 2001, in Houston, Texas, I gave birth to our son, weighing less than 2 pounds. He spent five months in two NICUs, fighting to survive. In those early days, a nurse gently told me that babies like Zach often develop an aversion to touch as they grow. I imagined it was because, like all of us, babies learn through association, and if every touch is painful, touch itself becomes something to fear. I didn't want that to be his story. I wanted his body to learn that human connection could feel safe, calming, and comforting. And that would begin with me.

Larry and I held Zach skin-to-skin from his second day of life, and I held him every day. It was how we became parents—through our presence, warmth, and love.

> *"The incubator lost heat. But I had already learned that my body could warm him. As soon as we arrived, I held Zach against my skin and watched his temperature rise after being cold for 4 hours. His vital signs stabilized, and we calmed each other."*

Three weeks after he was born, when Tropical Storm Allison flooded the hospital and knocked out power, all his life-support machines failed. Larry received a crash course on how to bag him, and he would take turns with the staff every 30 minutes. The incubator lost heat. But I had already learned that my body could warm him. As soon as we arrived, I held Zach against my skin and watched his temperature rise after being cold for 4 hours. His vital signs stabilized, and we calmed each other.

"When machines fail, human presence prevails."

That moment didn't just save his life; it reshaped mine. It revealed the power of touch, the science of closeness, and the urgent need to make this care possible for every baby, everywhere.

I founded Kangaroo Care Day on Zach's 10th birthday to honor Zach's survival and promote safe, nurturing, trauma-informed skin-to-skin care worldwide. The day directly results from the first of the three core gaps I identified through research and lived experience: lack of awareness, standardized safety, and measurement systems to track, analyze, and improve care.

> *"I founded Kangaroo Care Day on Zach's 10th birthday to honor Zach's survival and promote safe, nurturing, trauma-informed skin-to-skin care worldwide. The day directly results from the first of the three core gaps I identified through research and lived experience: lack of awareness, standardized safety, and measurement systems to track, analyze, and improve care."*

As the movement has grown, so has our understanding of what it takes to make this care not only possible, but standard. Kangaroo Care Day continues to grow thanks to the dedication of clinicians, parents, researchers, and advocates worldwide who believe in zero separation from the very beginning. Parent organizations worldwide share their stories and strategies, creating a ripple effect that uplifts and informs families everywhere. As Kangaroo Care sessions lengthen—as they should—the risks also increase, particularly if parents become distracted or drowsy. That's why I developed a simple safety test that any team can use:

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Kangaroo Care Day

Project Plan



15th May 2025

Skin-to-skin Care | The right of every baby | Kangaroo Care Day (May 15)

by Yamile Jackson, PhD, PE, PMP
info@kangaroo.care

kangaroo care day 2025 www.kangaroo.care

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Some Useful Links

kangaroo care day 2025 www.kangaroo.care

Join the global movement
https://kangaroo.care/pages/join-the-kangaroo-care-community

Registered your team at
https://kangaroo.care/blogs/globalkc/2025-team-registration

Setting Up Your Team on The Zaky® APP Web Portal
https://kangaroo.care/pages/the-zaky-app-instructions-for-the-team-leader

Questions about Kangaroo Care Day (May 15), The Zaky APP or the 24 hour Kangaroo-a-thon?
https://thezaky.com/pages/contact_us

If a parent is fully reclined, can they sit upright without using their hands, and the baby remains safe, secure, and easily accessible?

If the answer is no, the setup may not provide adequate support, particularly if the parent becomes drowsy or falls asleep. This isn't about placing more pressure on parents; it's about removing barriers and creating safety systems that adapt to the realities of hospital life. Babies receiving Kangaroo Care are often connected to IV lines, feeding tubes, monitors, and respiratory equipment, making secure positioning and quiet, individualized access essential for safety and continuity of care. And while parents are often the ones holding, anyone with a healthy chest and a compassionate presence can be a healing surface—because, as I frequently say, a caring chest is better than a mattress.

"But awareness alone isn't enough. That's why Kangaroo Care Day offers free tools and resources at www.kangaroo.care to support clinicians and families around the world—because no one should have to choose between love and safety. Among these is a free 5-phase Project Plan that helps teams prepare, implement, and improve safe Kangaroo Care practices while planning meaningful celebrations for Kangaroo Care Day."

But awareness alone isn't enough. That's why Kangaroo Care Day offers free tools and resources at www.kangaroo.care to support clinicians and families around the world—because no one should have to choose between love and safety. Among these is a free 5-phase Project Plan that helps teams prepare, implement, and improve safe Kangaroo Care practices while planning meaningful celebrations for Kangaroo Care Day. Kangaroo Care is also a globally endorsed public health strategy—low-cost, evidence-based, and proven to reduce mortality and support neurodevelopment in high-resource and low-resource settings.

This year, on May 15, we invite the world to wear green to raise awareness, celebrate connection, and commit to giving every baby the safest, most loving start possible. No matter where you are—whether in a high-tech NICU in the United States, holding your baby skin-to-skin in a village clinic in Africa, or on an island in the Mediterranean—this practice is for everyone. Together, let's make Kangaroo Care not just a beautiful moment, but a universal reality. And let's work to make every day a Kangaroo Care Day.

With deep gratitude,

Yamile C. Jackson, PhD, PE, PMP

Founder, Kangaroo Care Day (May 15)

Mother of Zachary

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About the Author: Yamile C. Jackson, PhD, PE, PMP, is a former NICU parent and the safety and ergonomics engineer behind The Zaky®. She founded Nurtured by Design, Inc., and Kangaroo Care Day (May 15) in honor of her son Zachary. Her work has inspired a global movement for zero separation, Family-Centered developmental care, neuroprotection, and safe kangaroo care implementation.

***Disclosure:** Yamile C. Jackson, PhD, PE, PMP, is an ergonomics, safety, and risk engineer and the chief executive officer, Nurtured by Design, Sugar Land, TX. Nurtured by Design is a company that sells a range of family-centered, trauma-informed developmental care products, including devices to facilitate skin-to-skin care. Dr. Jackson holds a patent for such a device (The Zaky ZAK) and receives royalties for her company's products. Nurtured by Design did not provide any funds or compensation for this work.*

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Planning and Executing Kangaroo Care Day (May 15)



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1. INITIATION PHASE: DEFINING THE PROJECT

kangaroo care day 2025 May 15th
www.kangaroo.care

WHAT - Define the Purpose
Clarify the scope of your celebration.
Explain how it supports your unit's or organization's mission and values.
Set a clear purpose to guide planning and activities.
Keep it meaningful, achievable, and focused on impact.

WHO – Define Roles and Gain Support
Assign a project lead to coordinate efforts.
Clarify roles for each team member involved.
Engage leadership and secure interdisciplinary support.
Build a collaborative team to sustain momentum.

WHERE – Identify Locations
List the units participating in the celebration.
Specify where each activity will happen (e.g., NICU, PICU, bedside, hallway, lounge).
Ensure locations are accessible and suitable for families and staff.
Plan spaces for displays, education, and celebration moments.

WHEN - Set the date(s)
Decide if your celebration will be on May 15, or extend over a week or the whole month.
Outline a clear timeline for planning, activities, and data collection.
Include key deadlines and milestones.
Communicate the schedule with your team and families.

WHY – Establish Goals and Metrics
Identify specific, measurable outcomes. Examples:
- Increase total kangaroo care duration by 25%
- Increase number of sessions per baby by 50%
- Each baby is held at least one hour per day
- Reduce time from birth to first hold by one day
- Provide a 30-minute KC training for all staff and parents by May 15.

HOW – Define Your Activities
- Plan meaningful and engaging activities that align with your goals and setting, and consider what works best for your team and families.
- Plan for everyone to wear green on May 15!
- Track Kangaroo Care using your preferred system—on paper, in your EHR, or with The Zaky® APP.
- Choose what works best for your team and families.

Need ideas? Browse inspiration and activity suggestions at: kangaroo.care/blogs/kangaroo-care-day

DOWNLOAD FREE

2. PLANNING PHASE: DEVELOP ROADMAP

kangaroo care day 2025 www.kangaroo.care

SCHEDULE
Create schedule and milestones.
Encourage interdisciplinary collaboration: nurses, therapists, physicians, lactation consultants, admin, volunteers,and parents.

COMMUNICATION:
Develop communication plans, connect with the hospital's marketing deparment for media coverage, email invitation and request appropriate staff, management, and hospital support.

Assign Responsibilities
Define who is responsible for each task and set clear deadlines.
Include roles for promotion, tracking, data, communication, setting up the account on The Zaky APP, etc.
Engage interdisciplinary staff & secure leadership support.
Use a shared checklist or calendar to stay organized.

Set budget or seek donations.
Reach out to parent organizations, foundations, fundraisers, businesses in your town. More ideas: https://kangaroo.care/blogs/kangaroo-care-day/fundraisingideas

Gather materials:
Collect posters, t-shirts, banners, awards, info sheets, The Zaky ZAKs, quotes, and certificates.
Set up your team on The Zaky WEB APP and invite parents via The Zaky MOBILE APP.
Print one tracking card per baby per day for manual logging.
Display invitations and certificates around the unit to boost excitement and participation.

Plan for risks:
Examples: low participation, staffing, data gaps, parents not interested in participating.
Higher holding duration means risks increase. Use The Zaky ZAK® for safe, prolonged skin-to-skin holding. Email yamile@thezaky.com for more info.

DOWNLOAD FREE

3. EXECUTION: LAUNCH AND OPERATE

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Kick-off with Excitement
Launch the event with team briefings, posters, and positive energy to set the tone.

Celebrate Daily Wins
Share progress and milestones to keep momentum and morale high.

Encourage Daily Kangaroo Care
Motivate families and staff to prioritize skin-to-skin holding every day.

Recognize Contributions
Acknowledge the dedication of both staff and families throughout the day.

Track Every Session
Parents can log their time using the bedside Tracking Card or The Zaky® APP.

Execute Risk Control Strategies
Execute roles for monitoring sessions, perform routine visual checks, and communicate clear emergency response steps. These actions help create a safe, supportive environment that promotes confident participation and minimizes risks throughout Kangaroo Care Day.

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4. MONITORING AND CONTROLLING

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Review progress vs. goals regularly.
Compare your actual participation and outcomes against the original goals (e.g., number of holds, time to first hold, total skin-to-skin minutes) to see what's working and where improvements are needed.

Celebrate mini-milestones to boost morale.
Acknowledge progress along the way, such as a record number of holds in a day or a parent's first successful kangaroo care session. Small wins keep spirits high.

Gather feedback from staff and families.
Invite honest input through brief surveys or informal conversations to understand what's going well and what could be improved.

Track participation and data using The Zaky APP or manual tracking cards.
Use digital or manual tools to log each baby's kangaroo care sessions, measuring impact and providing data for future improvements.

Identify barriers and adjust strategies.
If you notice obstacles—like time constraints, staffing issues, or parent hesitancy—work with your team to find creative, trauma-informed solutions.

Share updates and success stories during team huddles or bulletin boards.
Keep everyone connected and inspired by highlighting achievements, memorable moments, or quotes from parents and staff.

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CLOSING PHASE: CELEBRATE AND EVALUATE

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Complete data collection and summarize results.
Gather all tracking cards, app data, and participation metrics to evaluate the reach and outcomes of your efforts.

Debrief lessons learned.
Reflect as a team on what worked well, what could be improved, and any unexpected insights that arose. Utilize this knowledge to enhance future kangaroo care initiatives throughout the year.

Share success stories and visual highlights.
Showcase meaningful moments through photos, quotes, and stories from families and staff—help others see the heart behind the numbers.

Compare with previous years and plan ahead:
Evaluate your progress year-over-year to identify trends, improvements, or areas for growth. Begin outlining ideas for the next Kangaroo Care Day while it's still fresh.

Thank contributors and participants
Acknowledge the time, love, and dedication of everyone involved—parents, nurses, leadership, and volunteers. Gratitude strengthens your community.

Submit your evaluation or Kangaroo-a-thon Results

https://kangaroo.care/pages/evaluation

The Zaky APP

Are you ready for a friendly competition?
Our team is hosting a
Multi-Team Kangaroo-a-thon!
Only Team Leaders may join with the Contest Code and in The Zaky® web APP.

Contest Name: 2025 24-Hour Kangaroo-a-thon
Host Team Name: Kangaroo Care Day (May 15)
Host Team Leader: KangarooCareDay
Host Team Leader email: Info@kangaroo.care
Host Team Location: Sugar Land, Texas, USA
Contest Dates are in the time zone of the Host-Team Location (check your local time):
Start: 12:00 AM May 15, 2025, CDT
End: 11:59 PM May 15, 2025, CDT

TEAM LEADERS:
- ✓ Login at www.thezaky.app
- ✓ Join using CONTEST CODE: C617923

PARENTS AND COACHES:
- ✓ If you are part of the team, then you automatically participate in this and any contest scheduled by your Team Leader.
- ✓ To join a team, ask your leader for the Team Code
- ✓ Visit www.thezaky.app for more information.

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kangaroo care day May 15th
www.kangaroo.care
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The Zaky® is a Registered Mark by Nurtured by Design. The Zaky® app was developed by Nurtured by Design with a grant from the Bill and Melinda Gates Foundation® to increase awareness, implementation, practice, and safety of kangaroo care globally. Available in English, Spanish, and French.

Team Leaders Join the 2025 24-Hour Global Kangaroo-a-thon:

We invite Team Leaders to join our 24-hour global Kangaroo-a-thon — celebrating connection, healing, and the power of skin-to-skin care across the world!
To join our Kangaroo-a-thon, use this

Contest Code: C617923

If you prefer, you can also:

- Create your own Kangaroo-a-thon contest (a One-Team or Multi-Team Contest)
- Join another team's Kangaroo-a-thon using a contest code provided by their Team Leader

Let's work together to support babies and families—one embrace at a time!

#KangarooCareDay #KangarooCare #Kangarooathon

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The Indirect Impact of **RSV**

NCfIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two

OVERVIEW



RSV impacts not only infants and young children, but also entire families.

The National Coalition for Infant Health and the Alliance for Patient Access sought to examine the multifaceted burden that RSV places on families and to identify potential policy solutions.

Two surveys were conducted, one of parents who had at least one child contract RSV and one of health care providers who treat infants and children with RSV.

Both surveys were conducted with YouGov, a global public opinion and data company. Parents and providers were recruited from a pool of pre-selected respondents to ensure they met the survey's requirements. Participants received an honorarium.

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV



67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties



67% worked in an outpatient facility

33% worked in a hospital

RESULTS

FINANCIAL BURDEN

More than ⅔ of parents said the costs of RSV posed a financial burden or financial crisis.

7% of parents said they were fired as a result of caring for their child with RSV.

32% of parents reported losing potential income while their child had RSV.

EMOTIONAL BURDEN

68% of parents said watching their child suffer affected their mental health.

69% of parents felt guilty that they could not do more to prevent their child's RSV.

When parents found out there was no treatment for RSV, only supportive care:

- **48%** felt angry
- **46%** felt helpless

SOCIAL BURDEN

43% of parents had never heard of RSV before finding out their child was sick.

54% of parents had to rely on family and friends for sibling care, transportation and other responsibilities.

42% of parents said they struggled to care for their other children when one faced RSV.

RESULTS

PARENT EDUCATION & AWARENESS

86% of providers said they include RSV education as part of routine care.

99% of providers agreed that parents need more information about RSV.

TREATMENT CHALLENGES

Nearly ⅓ of providers have been reluctant to test for RSV because no treatment exists.

48% of providers said it was difficult to decide whether to send an infant or child with RSV to the emergency room.

92% agreed that if an immunization were available, it should be added to the Vaccines for Children program's list of pediatric vaccines.

MISCONCEPTIONS

A majority of providers (60%) explained that around 50% or more of the babies they see hospitalized for RSV were born healthy, despite many people thinking severe RSV only impacts premature infants or those with preexisting conditions.

CONCLUSION

Both surveys highlighted that the burden of RSV extends well beyond its physical symptoms.

The virus may lead to:

- **Long-lasting health challenges** for babies and young children
- **Financial, social and emotional burdens** for families
- **Frustration for providers,** who lack a cure or viable preventive interventions

This burden is not experienced by the few. Most infants and children contract RSV by the time they are two, and challenges that accompany RSV may impact anyone who has been affected.

Moving forward, the many burdens of RSV demonstrate the need for:

- **More RSV education**
- **Research and innovation** for preventive interventions
- **Access to prevention and treatment** for all babies and children

The challenges caused by RSV can reach far and wide, and its indirect impacts often leave families struggling.

infanthealth.org

Peer Reviewed

Leading Through the Storm: Strategies for Thriving in Times of Change and Uncertainty

Rody Azar, MHA, RRT-NPS

Abstract:

Effective leadership has never been more critical in a world increasingly defined by volatility, uncertainty, complexity, and ambiguity (VUCA). Organizations are constantly challenged by evolving technologies, economic disruptions, global crises, and shifting workforce expectations. In such a climate, leaders must move beyond traditional management approaches and embrace strategies that foster their teams' resilience, trust, and adaptability. This paper explores how leaders can guide organizations through change and uncertainty while maintaining high performance and team morale.

"Effective leadership has never been more critical in a world increasingly defined by volatility, uncertainty, complexity, and ambiguity (VUCA). Organizations are constantly challenged by evolving technologies, economic disruptions, global crises, and shifting workforce expectations. In such a climate, leaders must move beyond traditional management approaches and embrace strategies that foster their teams' resilience, trust, and adaptability."

By drawing on current research, practical examples, and expert insights, the paper identifies five essential leadership qualities: visionary thinking, emotional intelligence, decisiveness, transparency, and adaptability, and offers five actionable strategies that leaders can implement immediately to support and empower their teams. From creating psychological safety to modeling resilience, each strategy is designed to build stronger, more agile teams prepared to thrive in disruption.

Whether navigating a company-wide transformation, responding to global challenges, or preparing for what comes next, this paper provides a practical roadmap to help you lead with confidence and clarity. If you are ready to turn uncertainty into an opportunity for growth for you and your team, read on. The future may be uncertain, but your leadership does not have to be.

Introduction:

In today's volatile, uncertain, complex, and ambiguous (VUCA) environment, change is not the exception but the rule. Organizations across all industries face rapid technological advancements, shifting market dynamics, global crises, and changing employee expectations. In such circumstances, leadership is pivotal in navigating uncertainty and guiding teams to perform at their best. Effective leadership during periods of change is not just about making decisions; it is about fostering resilience, maintaining trust, and inspiring forward momentum. This paper explores effective leadership qualities in uncertain times, supported by literature and case examples, and outlines five actionable strategies leaders can implement to sustain high performance and morale.

Understanding Change and Uncertainty:

Change introduces ambiguity that can impact an organization's culture, operations, and people, whether planned or unexpected. Uncertainty often causes anxiety, lowers morale, and leads to resistance. A McKinsey & Company report found that 70% of change initiatives fail due to employee resistance and lack of leadership support (1). The leader's role in these times is to steer the organization toward a new vision and mitigate the psychological and emotional impacts of change on individuals and teams.

"Uncertainty often causes anxiety, lowers morale, and leads to resistance. A McKinsey & Company report found that 70% of change initiatives fail due to employee resistance and lack of leadership support. The leader's role in these times is to steer the organization toward a new vision and mitigate the psychological and emotional impacts of change on individuals and teams."

Qualities of Effective Leaders During Change:

Effective leaders, during periods of uncertainty, distinguish themselves by the decisions they make and how they carry themselves and inspire others. These leaders cultivate essential traits that foster trust, motivation, and a forward-looking mindset. Below is an expanded view of five critical qualities that define effective leadership during change:

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1. **Visionary Thinking:** Leaders who thrive in uncertain times can envision a compelling future and articulate it in a way that inspires others. Visionary thinking involves looking beyond immediate obstacles and imagining long-term possibilities. These leaders help their teams understand the "why" behind the change and connect daily actions to broader organizational goals. Vision provides a sense of purpose amid chaos, essential for motivation and focus. A well-communicated vision acts as a compass that guides decision-making and fosters alignment, even when the path forward is complex or ambiguous. For example, during major organizational restructurings, visionary leaders reframe the narrative around opportunity and innovation rather than loss and disruption. They do not shy away from reality but offer hope anchored in strategy.

"Visionary thinking involves looking beyond immediate obstacles and imagining long-term possibilities. These leaders help their teams understand the "why" behind the change and connect daily actions to broader organizational goals. Vision provides a sense of purpose amid chaos, essential for motivation and focus. A well-communicated vision acts as a compass that guides decision-making and fosters alignment, even when the path forward is complex or ambiguous."

2. **Emotional Intelligence:** Emotional intelligence (EI) encompasses self-awareness, self-regulation, empathy, and social skills, all crucial in navigating the human side of change. Leaders with high emotional intelligence can recognize and manage their emotions appropriately, which helps maintain composure under pressure. More importantly, they are sensitive to how change affects others. They respond with empathy, validating concerns and fears without being dismissive. Empathetic leadership helps build psychological safety, deepens interpersonal trust, and improves team dynamics. During transitions, emotionally intelligent leaders adapt their communication style to individual needs, provide personalized support, and foster inclusive discussions. This human-centered approach strengthens engagement and loyalty even amid uncertainty.

"Empathetic leadership helps build psychological safety, deepens interpersonal trust, and improves team dynamics."

3. **Decisiveness:** Indecision during change can erode confidence and paralyze progress. Effective leaders must make timely decisions based on available information, even when that information is incomplete. Decisiveness in this context does not imply impulsiveness; rather, it reflects a leader's ability to assess risks, seek relevant input, and commit to action.

   When decisions are delayed, uncertainty compounds and teams may become demotivated or disengaged. Conversely, clear decisions create momentum and demonstrate leadership presence. Decisive leaders are also willing to course-correct when needed, modeling agility and humility.

   For instance, during the early days of the COVID-19 pandemic, leaders who acted quickly to transition to remote work, even without perfect systems in place, were better able to stabilize operations and reassure employees than those who waited for complete clarity.

"When decisions are delayed, uncertainty compounds and teams may become demotivated or disengaged. Conversely, clear decisions create momentum and demonstrate leadership presence. Decisive leaders are also willing to course-correct when needed, modeling agility and humility."

4. **Transparency:** In uncertain times, the absence of information can be more damaging than unwelcome news. Transparency involves open and honest communication about challenges, progress, setbacks, and plans. Transparent leaders do not sugarcoat reality but frame it constructively and maintain a dialogue with their teams. They communicate what they know, what they do not, and what they are doing to find answers.

   This openness builds credibility and prevents rumors from filling informational voids. When leaders are transparent, employees feel more respected and involved. It also encourages a culture of accountability and fosters collective problem-solving. Transparency is crucial during organizational changes such as layoffs, mergers, or restructuring when speculation can lead to fear and disengagement.

"When leaders are transparent, employees feel more respected and involved. It also encourages a culture of accountability and fosters collective problem-solving."

5. **Adaptability:** The most essential trait in a changing environment, adaptability, refers to a leader's ability to remain flexible and responsive in the face of evolving circumstances. Adaptable leaders view change as a challenge rather than a threat. They are willing to pivot strategies, experiment with innovative approaches, and encourage innovation. They also help their teams build resilience by modeling a cheerful

outlook toward change and embracing continuous learning.

Adaptable leaders are not rigidly attached to past successes or fixed plans. Instead, they evaluate what works, solicit feedback, and refine their tactics in real time. This openness to change ensures that the organization remains agile and responsive, which is crucial in today's fast-paced world.

One strong example of adaptable leadership can be seen in industries like retail and hospitality, where consumer expectations shifted dramatically during the pandemic. Leaders who quickly adopted digital tools, delivery models, and new service strategies were able to sustain business and keep teams motivated through challenging transitions.

"Adaptable leaders view change as a challenge rather than a threat. They are willing to pivot strategies, experiment with innovative approaches, and encourage innovation. They also help their teams build resilience by modeling a cheerful outlook toward change and embracing continuous learning."

Five Actionable Leadership Strategies:

To lead effectively through change and uncertainty, leaders can take the following actions:

1. **Creating Psychological Safety:**

   Psychological safety, the belief that one can speak up without fear of punishment or embarrassment, is essential for high-performing teams. Employees may hesitate to express concerns, suggest ideas, or ask questions during uncertain times. Leaders can foster this environment by:

   - Encouraging open dialogue in team meetings.
   - Actively listening without immediate judgment.
   - Acknowledging their uncertainties and learning from others.

2. **Communicate with Clarity and Consistency**

   Effective communication becomes even more critical during times of upheaval. Rumors, misinformation, and lack of direction can exacerbate anxiety. Leaders must:

   - Communicate frequently and through multiple channels.
   - Be honest about what is known and unknown.
   - Reinforce organizational values and the team's role in achieving the vision.
   - Regular updates, Q&A sessions, and one-on-one check-ins can help team members feel informed and connected.

3. **Empower Teams Through Shared Ownership**

   Instead of top-down mandates, teams are involved in co-creating solutions and decision-making. This fosters a sense of ownership and accountability, enhancing motivation and reducing resistance. Leaders should:

   - Set clear objectives but allow flexibility in execution.
   - Recognize and celebrate team contributions.
   - Delegate meaningful responsibilities.

4. **Prioritize Well-being and Morale**

   Change often leads to burnout and disengagement. Effective leaders recognize that performance is linked to well-being. Leaders can:

   - Promote work-life balance through flexible schedules or mental health days.
   - Publicly appreciate the effort and small wins.
   - Offer access to support resources such as coaching or counseling.

5. **Model Resilience and Optimism:**

   Teams often take their emotional cues from leaders. Leaders who remain composed and optimistic while acknowledging challenges set the tone for the team's response. This includes:

   - Demonstrating a growth mindset.
   - Sharing stories of perseverance and past successes.
   - Practicing gratitude and encouraging others to do the same.

   Resilient leaders are not those who avoid adversity but face it with clarity, courage, and compassion.

Challenges Leaders Face:

Even the best leaders encounter obstacles in uncertain times:

- Resistance to Change: Often rooted in fear of the unknown or perceived loss of control.
- Decision Fatigue: Constantly making high-stakes decisions with limited information can be exhausting.
- Maintaining Culture Remotely: Fostering connection and alignment requires intentional effort in virtual settings.
- Balancing Short-Term and Long-Term Goals: Leaders must address immediate needs without losing sight of strategic priorities.

By acknowledging these challenges, leaders can proactively develop strategies to mitigate them.

The Role of Leadership Development:

Organizations should invest in leadership development programs that prepare leaders for uncertainty. These programs should include:

- Training in emotional intelligence and change management.
- Scenario planning and crisis simulations.
- Coaching and peer mentoring.

Leadership is not static; it evolves with the environment. Ongoing development ensures that leaders are equipped to respond effectively to emerging challenges.

Conclusion:

In an age of relentless disruption and accelerating change, leadership is not just about operational oversight; it is about human connection, emotional steadiness, and the ability to inspire forward momentum in the face of the unknown. As organizations grapple with external pressures like economic instability, technological transformation, and shifting workforce dynamics, leaders are increasingly called to serve as beacons of clarity and resilience.

This paper has highlighted five essential qualities, visionary thinking, emotional intelligence, decisiveness, transparency, and adaptability, which set effective leaders apart during times of uncertainty. These qualities are not innate; they can be cultivated through self-reflection, feedback, and ongoing development. Moreover, leadership is not a solo act. It involves fostering environments where teams feel safe, supported, and empowered to rise to challenges together.

The five actionable strategies outlined, creating psychological safety, communicating, empowering teams through shared ownership, prioritizing well-being, and modeling resilience, serve as practical tools for guiding teams through turbulence while maintaining high morale and performance. These strategies help bridge the gap between uncertainty and opportunity, allowing organizations to survive and thrive through change.

Effective leadership in uncertain times is less about having all the answers and more about asking the right questions, creating space for dialogue, and inspiring confidence in the collective journey ahead. Leaders who invest in trust, transparency, and team empowerment foster more innovative, cohesive, and resilient cultures.

"Effective leadership in uncertain times is less about having all the answers and more about asking the right questions, creating space for dialogue, and inspiring confidence in the collective journey ahead. Leaders who invest in trust, transparency, and team empowerment foster more innovative, cohesive, and resilient cultures."

Final Thought for Leaders: As you guide your team through uncertainty, ask yourself this: *Am I being the kind of leader I would want to follow if everything around me were changing?*

Because in times of transformation, how you lead does not just determine the outcome of a project; it defines the character of your organization for years to come.

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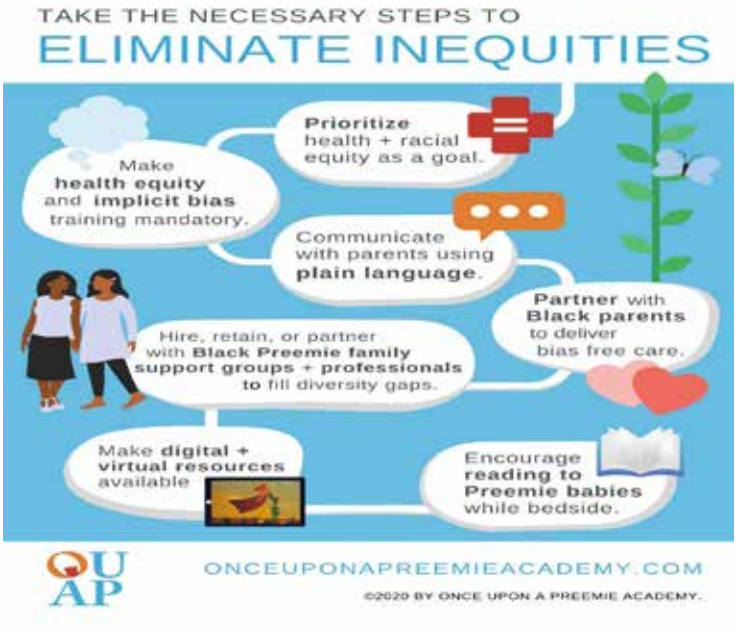
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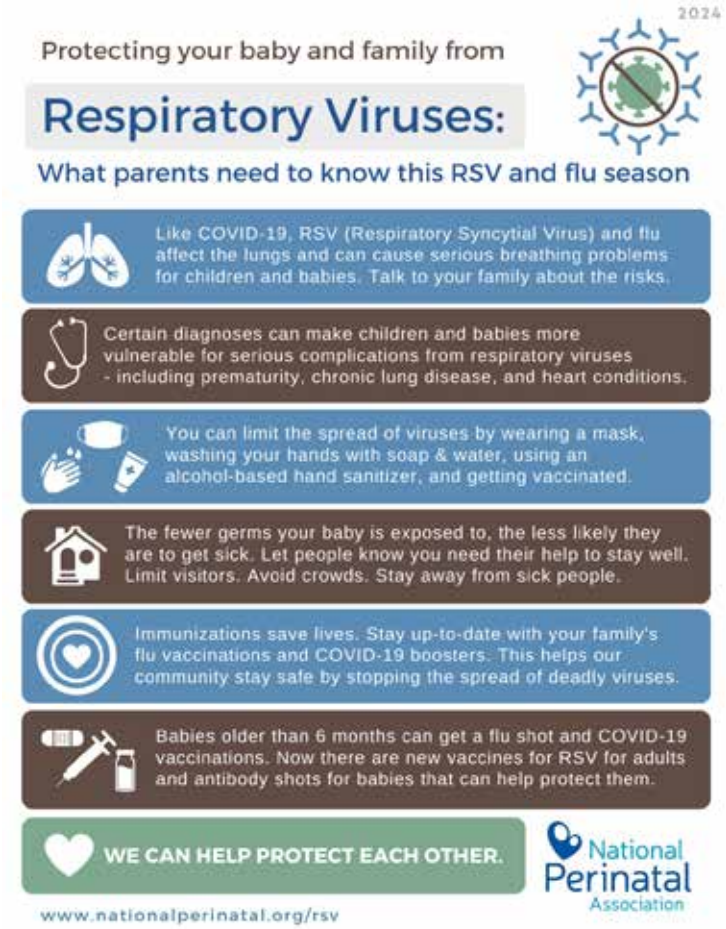
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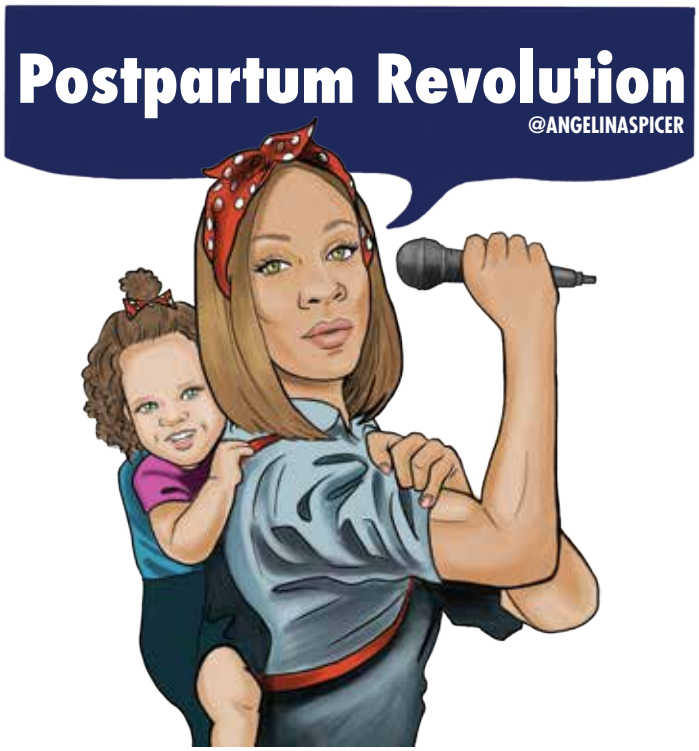


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Ethics and Wellness: The Quiet Weight of Criticism

Mitchell Goldstein, MD, MBA, CML, Steffi Khurana, MD, T. Allen Merritt, MD, MHA

"Criticism is easy to give but hard to take. It can slip off the tongue in a moment of frustration and settle with weight on the heart of the one who receives it. Criticism is inevitable in every workplace, every relationship, and every field of service, especially in fields marked by high stakes and human fragility."

Criticism is easy to give but hard to take. It can slip off the tongue in a moment of frustration and settle with weight on the heart of the one who receives it. Criticism is inevitable in every workplace, every relationship, and every field of service, especially in fields marked by high stakes and human fragility. What makes the difference is how we wield it and how we receive it. (1-3)

There is a kind of criticism that comes with a steady hand and clear intent—a type of feedback offered with kindness and grounded in fact, with suggestions for improvement. This is the kind that builds bridges, not walls. It points out flaws not to shame but to improve, not to hurt but to heal. Constructive criticism is a gift—often uncomfortable to receive but invaluable when it opens the door to progress. (3-5) In medicine, we must master the art of delivering and receiving constructive criticism. It is crucial to acknowledge generational differences, just as we recognize cultural and racial differences and perceptions of commentary in our criticism. (6, 7)

"However, there is another kind of criticism. The kind born of frustration. It is the kind that lashes out not because it is necessarily wrong but because it makes the recipient feel powerless. This situation is hard to reconcile, especially when the frustration of the one who gives it mirrors the struggle of the one on the receiving end. (4, 8, 9)"

However, there is another kind of criticism. The kind born of frustration. It is the kind that lashes out not because it is necessarily wrong but because it makes the recipient feel powerless. This situation is hard to reconcile, especially when the frustration of the one who gives it mirrors the struggle of the one on the receiving end. (4, 8, 9) When both sides are grappling with the same problem, the same barriers, the same exhaustion, criticism becomes a mirror.

In such moments, it is crucial to ask whether this criticism is rooted in anger or truth. This is an essential distinction between "constructive criticism" and "complaint," "impatience," or "possibility." (7, 10) If it is based on fact, offered with humility, and presented with a vision of how to move forward, then it may still be difficult, but it is worthwhile. However, if it stems from an inability to cure a problem beyond anyone's control, it risks becoming demoralizing noise instead of meaningful guidance. Is the criticism given to the individual it is meant for directly, or is it being treated and talked about as a "gossip"? (3-5)

"Being in the wrong place, with the wrong tools or structures, is not a moral failing. (2, 6, 10) It often takes courage and a clear conscience to offer constructive criticism as a learning tool to the individual, and it must be handled with respect for them for it to be received well. It is not a fair reason to blame an individual."

Furthermore, what about those who face criticism despite working under daunting conditions—limited resources, misaligned partnerships, or systemic challenges that stifle change? Being in the wrong place, with the wrong tools or structures, is not a moral failing. (2, 6, 10) It often takes courage and a clear conscience to offer constructive criticism as a learning tool to the individual, and it must be handled with respect for them for it to be received well. It is not a fair reason to blame an individual. Instead, it is a call to look together, constructively and compassionately, for a solution—not the most expedient solution, not the one that pleases at first glance, but the one that truly moves us forward without deepening harm. (1, 7)

"The most effective criticism comes with understanding what it hopes to achieve. If no good outcome is possible, then excessive criticism only creates division. It becomes scapegoating, and scapegoating helps no one. (5)"

We must remind ourselves that criticism is not a sport, not a power play, and not a tool that, like any tool, can build or destroy. (6) The

most effective criticism comes with understanding what it hopes to achieve. If no good outcome is possible, then excessive criticism only creates division. It becomes scapegoating, and scapegoating helps no one. (5)

Ultimately, progress does not come from assigning blame but from aligning efforts with well-intentioned and genuine suggestions for improvement. If we seek better outcomes—for our systems, teams, patients, and families—then we must start not with accusations but with empathy, not harshness but shared resolve. (3)

Understanding and recognizing common concerns is the only way to negotiate a real pathway to success. While that path is rarely straightforward, it is always worth the effort.

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INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT



SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS

- Are the baby and family central to the mission, values, environment, practice & care delivery of IFCDC in the unit?
- Are the parents of each baby fully integrated into the team and treated as essential partners in decision-making and care of the infant?
- What are the strategies and measurements used to improve and sustain IFCDC in the unit?

POSITIONING & TOUCH FOR THE NEWBORN



- Are the positioning plans therapeutic and individualized, given the care needs and development of the baby?
- Are the positioning and touch guidelines continually reviewed by the team, including the parents, and adapted to meet the changing comfort needs of the baby?



SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

- Can the team confidently describe the "voice" or behavioral communication of the baby?
- Are the baby's unique patterns of rest, sleep, and activity documented by the team and protected in the plan of care?

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS



- Is the practice of skin-to-skin contact supported and adjusted to the comfort needs of each baby, parent, & family member?
- Are the parents & family members supported to interact with the baby to calm, soothe, & connect?



REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

- Are parents supported to be present and interactive during stressful procedures to provide non-pharmacologic comfort measures for the baby?
- Are there sufficient specialty professionals to support the wellbeing of the team, including parents, families, and staff? Examples include mental health, social, cultural, & spiritual specialists.

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY



- Are the desires of the m/other central to the feeding plan? Is this consistently reflected in documentation with input of the m/other?
- Does the feeding management plan demonstrate a feeding & nutrition continuum from in-hospital care through the transition to home & home care?

WANT TO KNOW MORE ABOUT THE STANDARDS AND RECOMMENDATIONS?
VISIT: HTTPS://NICUDESIGN.ND.EDU/NICU-CARE-STANDARDS/

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Barium in Appendix – A Case Report

Joseph B. Philips, III, MD, FAAP

"Baby Boy J. was born at 24 weeks gestation to a primiparous mother with no prenatal complications other than preterm labor treated with two doses of betamethasone. His Apgar scores were 6 and 8 at one and 5 minutes, respectively. Continuous positive airway pressure (CPAP) was administered in the delivery room, and he was admitted to the NICU, breathing spontaneously on CPAP with 35% oxygen. He weaned off CPAP on day 3 and remained on nasal cannula oxygen for two weeks before weaning to room air."

Baby Boy J. was born at 24 weeks gestation to a primiparous mother with no prenatal complications other than preterm labor treated with two doses of betamethasone. His Apgar scores were 6 and 8 at one and 5 minutes, respectively. Continuous positive airway pressure (CPAP) was administered in the delivery room, and he was admitted to the NICU, breathing spontaneously on CPAP with 35% oxygen. He weaned off CPAP on day 3 and remained on nasal cannula oxygen for two weeks before weaning to room air.

Enteral feedings were begun with colostrum swabs on day two and mother's milk on day 3. Full feeds were achieved by day 6, and a human milk fortifier was added on day 10. He was transferred to our step-down unit at two weeks and had an uneventful course until three weeks of age when he developed abdominal distension and bloody stools. An abdominal X-ray revealed pneumatosis intestinalis and necrotizing enterocolitis (NEC) was diagnosed. He was made NPO and placed on antibiotics and total parenteral nutrition for 10 days. Enteral feeds were then reintroduced and increased over several days without incident. Two weeks later, he developed abdominal distention and emesis and was suspected of having a post-NEC stricture. A contrast enema was normal, and an upper GI series with small bowel follow-through was unremarkable, except for the residual contrast found in the appendix, as shown in the attached image (Figure 1). His hospital course thereafter was uneventful, and he was discharged home at 37 weeks, adjusted for post-conceptual age.

"Two weeks later, he developed abdominal distention and emesis and was suspected of having a post-NEC stricture. A contrast enema was normal, and an upper GI series with small bowel follow-through was unremarkable, except for the residual contrast found in the appendix, as shown in the attached image. His hospital course thereafter was uneventful, and he was discharged home at 37 weeks, adjusted for post-conceptual age."

Disclosures: *The author has no disclosure.*

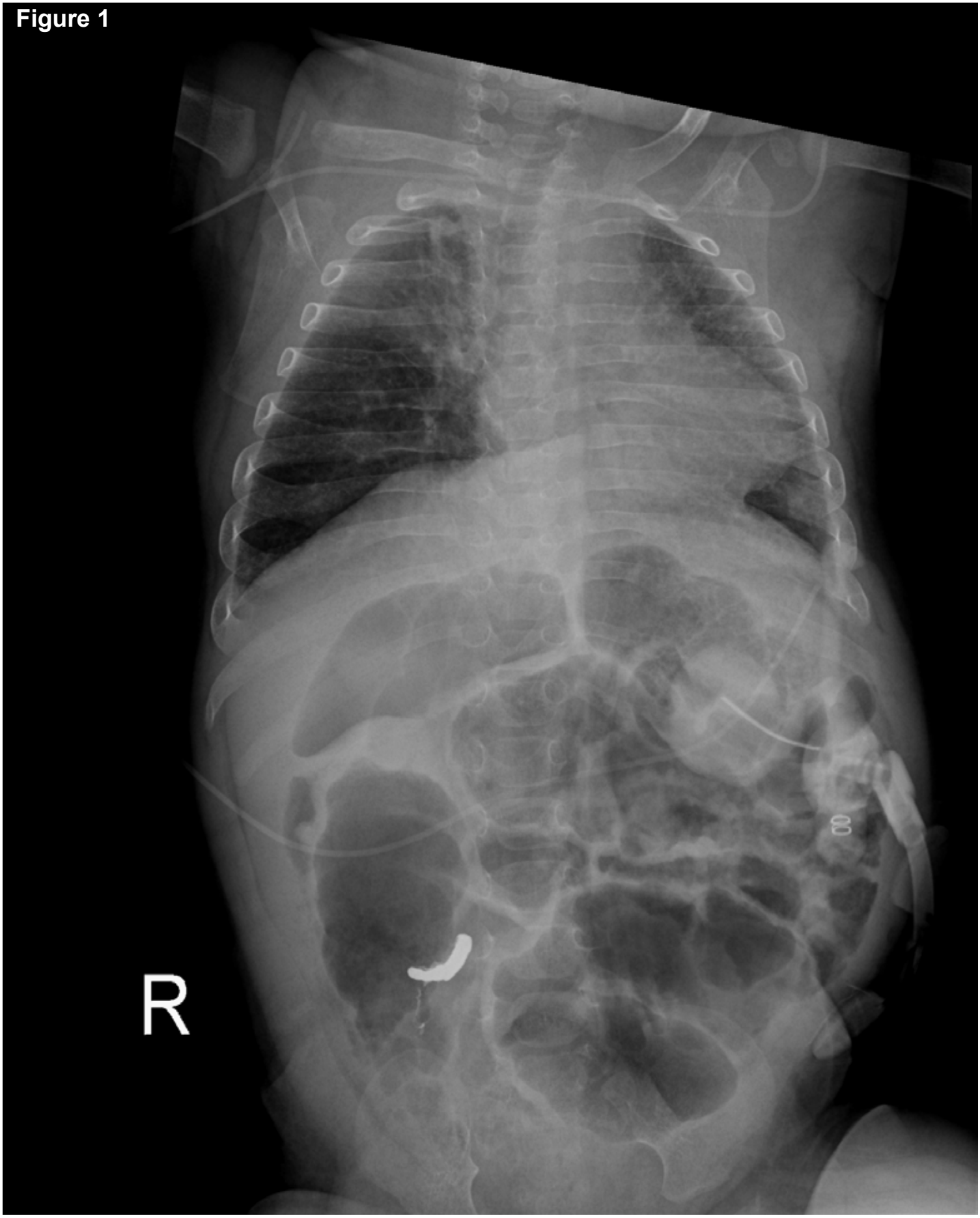
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University of Alabama at Birmingham
Email: jphilips@uabmc.edu

Figure 1



Brilliant! Dr. Bell bridges the journey from grief to growth. This is classic wisdom on healing from our heartbreaks and ultimately enjoying a fulfilling life.

– Christine Theard, M.D.

Post-Traumatic Thriving

The Art, Science, & Stories of Resilience



Randall Bell, Ph.D.

First Candle Launches Safe Sleep Education Program in NICUs

Destiny Stokes, MPH

Saving babies. Supporting families.

First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.

"First Candle's Let's Talk Community Chats program is based on the conviction that effectively reaching families about safe sleep and breastfeeding requires meeting them where they are, especially in communities where the risk of sleep-related infant deaths may be higher."

First Candle's Let's Talk Community Chats program is based on the conviction that effectively reaching families about safe sleep and breastfeeding requires meeting them where they are, especially in communities where the risk of sleep-related infant deaths may be higher.

One such community is that of families caring for a premature baby. Research[1] (1) has shown that babies born between 24 to 27 weeks may have a more than three times higher chance than babies born full term of dying before their first birthday of a sudden unexpected infant death (SUID), which includes Sudden Infant Death Syndrome (SIDS), Accidental Suffocation and Strangulation in Bed (ASSB), and unknown causes.

With that in mind, First Candle has initiated a Let's Talk Community Chats pilot within the Neonatal Intensive Care Unit (NICU) at Grady Memorial Hospital in Atlanta, Georgia, this year. This is designed to educate and support families on safe sleep practices and breastfeeding, aiming to prevent SUID in this higher-risk population.

" It engages families in familiar settings through First Candle-trained facilitators, including community peers such as fathers, grandparents, caregivers, and doulas. This approach creates a collaborative environment to discuss safe sleep practices, breastfeeding, and families' unique challenges regarding infant care."

Program Overview:

Launched in Harlem in 2022, Let's Talk Community Chats has expanded into multiple Atlanta communities. It engages families in familiar settings through First Candle-trained facilitators, including community peers such as fathers, grandparents, caregivers, and doulas. This approach creates a collaborative environment to discuss safe sleep practices, breastfeeding, and families' unique challenges regarding infant care.

"Grady's Level III NICU, which manages over 700 admissions annually and holds the Baby Friendly designation, is an ideal setting for this program."

A Collaborative Effort at Grady:

Grady's Level III NICU, which manages over 700 admissions annually and holds the Baby Friendly designation, is an ideal setting for this program. Dr. Mattie Wolf, a neonatologist at Grady

About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year.

and Assistant Professor of Pediatrics in the Division of Neonatal-Perinatal Medicine at Emory University School of Medicine & Children's Healthcare of Atlanta, explains:

"We are thrilled to expand our ongoing efforts surrounding safe sleep in the Grady NICU by bringing Let's Talk Community Chat to our families. This is especially important given the significantly higher rates of SUID among premature babies and our commitment to ensuring optimal health for all Grady infants, both during their NICU stay and after discharge.

A National Vision:

Partnering with Grady is a first step in growing this phase of the program around the country.

"We are honored to partner with Grady as the pilot site for Let's Talk Community Chats in NICU units," says First Candle Executive Director and CEO Alison Jacobson. "Grady's leadership immediately recognized its transformative potential for critical support and education to NICU parents.

"By leveraging the voices of trained peer mentors who truly understand their journey, we're creating a unique avenue to empower parents during one of the most challenging times in their lives. This partnership marks an important step toward expanding this vital resource nationwide."

"Participants received vital resources, including breastfeeding support pillows, swaddles, diapers, and informational handouts. Discussion ranged from safe sleep practices to housing, maternal mental health, and breastfeeding. The session also underscored the need for safe sleep resources, as seen by requests for bassinets."

Pilot Session Highlights

The inaugural session engaged 13 families and was led by three First Candle-trained facilitators. Participants received vital resources, including breastfeeding support pillows, swaddles, diapers, and informational handouts. Discussion ranged from safe sleep practices to housing, maternal mental health, and breastfeeding. The session also underscored the need for safe sleep resources, as seen by requests for bassinets.

Results from post-event surveys from birth givers (N=9) indicated strongly positive outcomes:

- *Comfort & Support*: 100% felt comfortable and supported, with cultural values respected.
- *Concerns Addressed*: All had their specific questions fully addressed.
- *Increased Confidence*: Respondents expressed increased confidence in applying safe sleep practices.
- *Helpful information*: All found the breastfeeding information helpful or very helpful.
- *Relevant Resources*: Every participant deemed the products and recommendations relevant to their needs.

Key takeaways emphasized three critical safe sleep practices: consistently placing the baby on their back, keeping soft objects away from the sleep area, and ensuring the baby sleeps separately. Seven respondents confirmed they had developed a safe sleep plan for their baby at home.

"The program plays a significant role in creating a safe and supportive space for parents, particularly those in the NICU," says facilitator TE Dupree Thompson. "Important discussions take place about topics impacting parents' lives. These include lactation support, recognizing signs of adequate feeding, safe practices like tobacco use prevention, handwashing, and changing clothes before handling the baby.

"There has also been a focus on maintaining strong relationships between parents, encouraging quality time as a couple, and providing resources for housing, domestic violence assistance, and counseling. Let's Talk offers vital guidance and emotional support, helping to alleviate stress for parents navigating the challenges of having a baby in the NICU."

"By integrating culturally relevant, community-driven education into the NICU setting, the program empowers parents during one of the most challenging periods of their lives. As the program expands, First Candle and its partners will continue to refine and enhance their approach to ensure every family has access to the resources and support they need for safe, healthy infant care."

Looking Ahead:

The collaboration with Grady solidifies First Candle's commitment to support NICU families. By integrating culturally relevant, community-driven education into the NICU setting, the program empowers parents during one of the most challenging periods of their lives. As the program expands, First Candle and its partners will continue to refine and enhance their approach to ensure every family has access to the resources and support they need for safe, healthy infant care.

More information about the program is available by emailing alison@firstcandle.org. #

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1. https://firstcandle.org/lets-talk-community-chats/

About First Candle: First Candle, based in New Canaan, CT, is a 501 (c) (3) organization committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year.

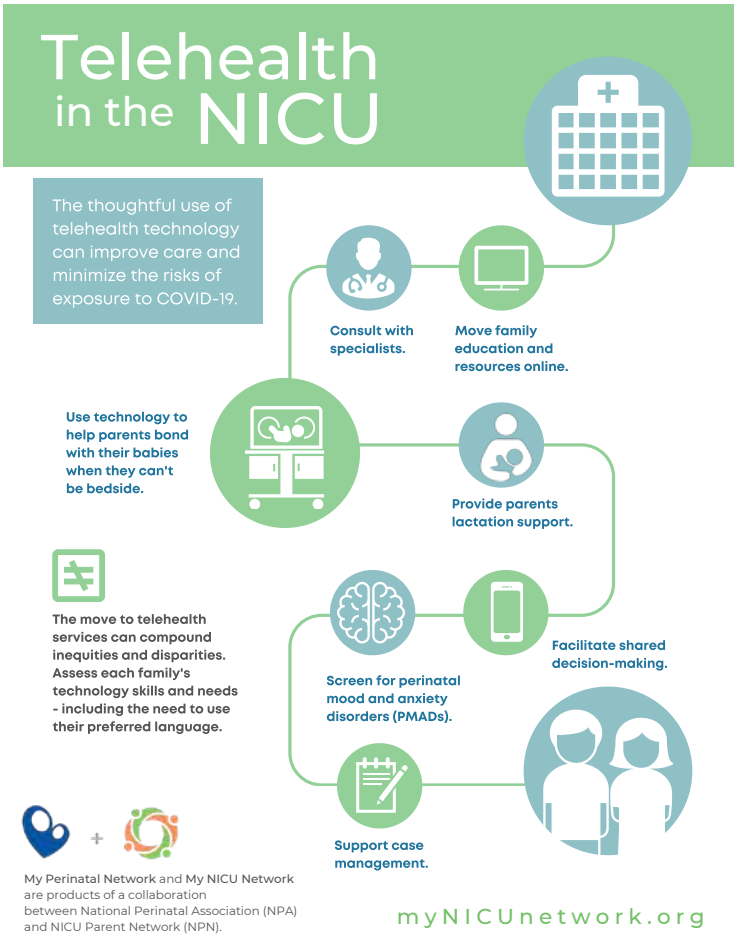
Disclosure: *The author is the Program Director of First Candle, a Connecticut-based not-for-profit 501(c3) corporation.*

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Advancing Neonatal-Perinatal Care: April Update: Your More-Than-Monthly #SONPM Update — Keeping You in the Loop!

Clara H. Song, MD, FAAP

"Your more-than-monthly update from SONPM to keep us all connected and informed!"

Your more-than-monthly update from SONPM to keep us all connected and informed!

Quick Links & Highlights:

- Check the #AAPneonatal Calendar for upcoming events, webinars, and deadlines.
- Browse the #AAPneo Photo Gallery for SONPM event highlights. *(Password: SONPMc3 to download pics)*
- And ICYMI — SONPM is celebrating **50 years**!

Happy Day-Before-May!

1. #BabiesNeedScience Campaign Launches at #PAS2025!

Join neonatologists, clinicians, educators, scientists, advocates, and families in supporting science that helps babies thrive.

The #BabiesNeedScience campaign is running on Instagram and Twitter—and will continue until we protect funding for essential research.

Tell us: *How do YOU use science to help babies?* Share your story via social or email!

We've already been highlighted in TWO #PAS2025 attendee emails. Should we keep this going through the NCE? Inquiring minds want to know.





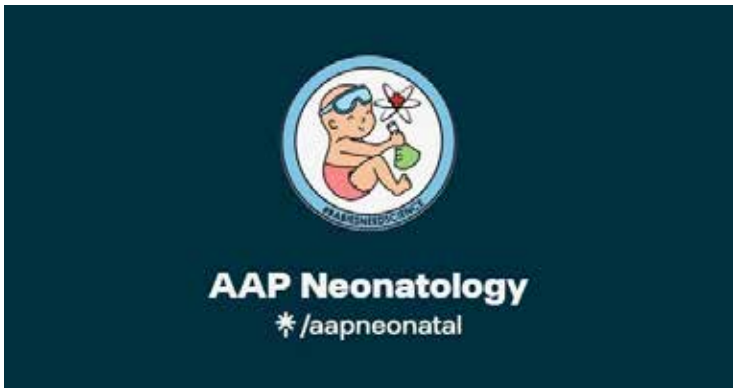
The @AAPneonatal #VideoCrew is on the ground at PAS capturing your stories—don't be shy when you see the cameras!

AAP Neonatology on Instagram & Facebook | Linktree

Join the #BabiesNeedScience campaign

2. Spring 2025 AAP Advocacy Report

You won't believe how much is going on—this update is packed with current efforts from across the Academy. Read the report here





3. Neonatal Hospitalists Webinar: Newborn Billing

From the Subcommittee on Neonatal Hospitalists of the Section on Hospital Medicine (SOHM):
May 1, 2025 | 2:00 PM CST (12 PM PST / 3 PM EST)

Register for the webinar

Recording will be posted soon after at www.NewbornPHM.com

More info: AAP Hospital Medicine

4. Call for QIEAG Chair Applications

The AAP's Quality Improvement Education Advisory Group (QIEAG) is seeking a new chair to begin January 1, 2026.

Applicants must:

- Be an FAAP with previous AAP education/global health leadership experience
- Commit 3–4 hours/month, attend calls, and one in-person meeting annually
- Submit materials by **May 28, 2025**

Questions? Contact Lisa Donato at ldonato@aap.org | 630-626-6723

See Chair Responsibilities & Apply

5. NRP Research Grant Applications Due May 2!

From AAP NRP – Four grant opportunities available for U.S. and Canadian researchers focused on optimizing care in the delivery room:

- **Human Factors or Education Grant** (up to $15,000)
- **Young Investigator Award** (up to $15,000)
- **Research Grant Program** (up to $50,000)
- **Jeanette Zaichkin Nursing Grant** (up to $10,000)

Apply here

6. Equity, Diversity, and Inclusion (EDI) Excellence Award Nominations

The AAP is accepting nominations for the **2025 EDI Excellence Award**, honoring pediatricians advancing equity in child health and workforce diversity.

Deadline: June 4, 2025

Submit materials to sdiederich@aap.org

Award includes conference travel and presentation at the AAP National Conference.

7. 2025 SONPM Awardees & NCE h-Program in Denver!

Join us on **September 27, 2025, in Denver as we celebrate our SONPM honorees at the NCE h-Program, which this year focuses** on **neonatal pain and brain development**.

Awardees:

- *Virginia Apgar Award*: Dr. Satyan Lakshminrusimha (UC Davis)
- *Avroy Fanaroff Education Award*: Dr. Heather French (CHOP)



- *Maria Delivoria-Papadopoulos Landmark Award*: Dr. Rich Molteni (University of Washington, Joint Commission)

📰 More awardee details coming soon in the next SONPM newsletter.

Meanwhile, your SONPM Executive Committee is hard at work—reviewing policies, reports, subgroup budgets, strategic grants, and nominations. Most importantly, we're laying the foundation for **NICU-specific payment advocacy** with support from AAP!

Because we believe:

Fair payment ➡ better salary-to-FTE ratios ➡ improved staffing ➡ lower burnout ➡ stronger workforce ➡ a healthier future for neonatology.

What do you think?

Until next time 🤍 — we're here for you. Stay connected!

On behalf of your #SONPMexec comm:

Past Chair Munish Gupta @munishguptamd

District 1 Rep Wendy Timpson @TimpsonWendy

D2 Shetal Shah @NICUBatman

D3 Michael Posencheg @MikePosencheg

D4 Misty Good @mistygoodlab

D5 Craig Nankervis

D6 Josh Petrikin @jepetrikin

D7 John Loyd

D8 Jessica Davidson @JessDavMD

D9 & Chair Elect Alexis Davis @AlexisDNeoMD

D10 Ravi Patel @ravimpatelmd

Of Counsel Marilyn Escobedo @Mokcita

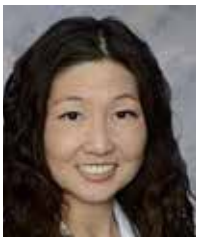
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Chair Clara Song @songMD

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Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine
Lean Six Sigma Black Belt
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Call for Nominations!

Section on Neonatal-Perinatal Medicine Executive Committee: District Representatives from Districts III, VI, and IX

One of the most significant opportunities to engage with the Section on Neonatal-Perinatal Medicine (SONPM) is to serve on the SONPM Executive Committee (EC). The EC consists of one representative from each of the 10 AAP Districts, in addition to chair, chair-elect, past-chair, of-counsel advisor, and AAP section manager (currently Jim Couto). District representatives serve 3-year terms, and are eligible to serve a second term.

District representatives to the EC are responsible for representing all neonatologists working in their AAP districts. The district representative is a liaison between district neonatologists and the SONPM, providing members direct input into SONPM and conveying section activities and opportunities back to the members. More specifically, responsibilities of EC members include the following:

Within executive committee and SONPM broadly:

1. Attend two **required** EC meetings annually, at Scottsdale spring workshop and at NCE;
2. Attend the full SONPM program at Scottsdale spring workshop and NCE meetings annually;
3. Participate in periodic virtual SONPM EC meetings (generally once or twice per month);
4. Review and score abstract submissions to NCE and review poster and oral presentations at NCE meeting, including scoring for SONPM Young Investigator Award;
5. Suggest and select annual SONPM honorary lecturers, including the Cone, Merenstein, Butterfield and Silverman speakers;
6. Solicit and review nominations for annual SONPM awards, including the Apgar, Education, Landmark and Pioneer awards, and select awardees;
7. Participate in planning and execution of national meetings, including section program at NCE, Scottsdale conference, and NeoPREP;
8. Review applications and determine awardees for the Section Strategic Grant Program, currently offered every two years;
9. Review and provide feedback on AAP policy statements, clinical reports, and guidelines as they pertain to newborn care;
10. Participate in and support AAP and SONPM advocacy efforts, including AAP Days of Action;
11. Participate in section committees, groups, and task forces based on interest and need;
12. Participate in SONPM strategic leadership, including implementation of goals of strategic plan; and
13. Participate in SONPM administration, including maintenance and updating of section manual of operations and section budget planning.

Within district:

1. Solicit updates from district members for inclusion in section newsletter twice annually;
2. Allocate annual SONPM district grants by soliciting and evaluating grant proposals;
3. Provide regular updates to district members on relevant aspects of section activities;
4. Provide regular updates to section on district activities and needs of district members;
5. Actively participate in district activities, including attendance at regional conferences; and
6. Encourage AAP and SONPM membership from representative's district, including trainees.

The core executive committee is a productive group! Participation on the executive committee does require a commitment of time and effort, but it is a highly rewarding experience.

Letters to the Editor

Letter to the Editor: "A Case of Wiedemann-Rautenstrauch Syndrome With Fatal Hyperkalemic Renal Failure"

Dear Editor,

Concerning "*A Case of Wiedemann-Rautenstrauch Syndrome With Fatal Hyperkalemic Renal Failure*," I would like to extend my appreciation to Dr. Mohamed Ghamry and colleagues for conducting a thorough review of this case and contributing to our clinical understanding of an extremely rare genetic disorder. This is an essential contribution to the literature, as fewer than 100 cases of WRS have been published, and it will allow physicians to be aware of possible renal anomalies and complications in neonates.

"This case report is the first to discuss hyperkalemic renal failure in a neonate with WRS and effectively describe the course of this complication. An especially noteworthy aspect of this article is its comparison of the physical features of the novel case to previously published cases."

Wiedemann-Rautenstrauch syndrome is a rare, autosomal recessive syndrome with a wide range of phenotypic variability, caused by mutations in the POL3RA gene, which encodes a subunit of RNA polymerase (2). This case report is the first to discuss hyperkalemic renal failure in a neonate with WRS and effectively describe the course of this complication. An especially noteworthy aspect of this article is its comparison of the physical features of the novel case to previously published cases. This allows the reader to understand the clinical variability of WRS and reinforces the idea that ongoing research and documentation of rare cases are crucial in aiding future diagnoses and treatment plans.

A critical area in advancing this piece is comparing the management of the current case to previous cases, such as medical and surgical interventions, and how early the treatments were initiated. For instance, a previous study highlighting five cases of WRS highlighted treatments in each case, ranging from placing a ventriculoperitoneal shunt for hydrocephalus and administering alendronate for osteoporosis (3). This further highlights the clinical variability and treatment management, emphasizing that the disease can present in many different ways. It further reinforces that a thorough assessment of all patient organ systems is essential.

Another area of advancement would be to include the prenatal course of the mother. Although it was mentioned that the case was positive for consanguinity, knowledge of prenatal care would aid the reader in understanding if there were any signs of intrauterine growth restriction on imaging. Additionally, possible anomalies of the renal and urinary system may have been seen on imaging if the mother received regular prenatal care. Furthermore, a thorough assessment of the parents' family history is also beneficial in understanding the patient's condition. Previous reports have included the mother's family history, which was positive for two uncles dying of unknown causes before 20 days of life, which not only reinforces the hereditary nature of the condition but can also aid in identifying related conditions in future pregnancies (4).

"A critical area in advancing this piece is comparing the management of the current case to previous cases, such as medical and surgical interventions, and how early the treatments were initiated. For instance, a previous study highlighting five cases of WRS highlighted treatments in each case, ranging from placing a ventriculoperitoneal shunt for hydrocephalus and administering alendronate for osteoporosis (3)"

Dr. Ghamry and colleagues have put together a comprehensive report of the fatal nature of hyperkalemia renal failure in a patient with Wiedemann-Rautenstrauch Syndrome.

"Being the first case ever to report a renal cause of death in this genetic syndrome, this piece expands on the clinical variability of WRS. Also, it identifies a greater area of exploration for future studies. Multidisciplinary care is crucial to such a syndrome, where various physiological systems are affected simultaneously, requiring care from many specialties."

Being the first case ever to report a renal cause of death in this genetic syndrome, this piece expands on the clinical variability of WRS. Also, it identifies a greater area of exploration for future studies. Multidisciplinary care is crucial to such a syndrome, where various physiological systems are affected simultaneously, requiring care from many specialties. I support future research and documentation of this condition's diagnosis modality and treatment management to improve patient prognosis.

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Sincerely,

Stephanie Yeganyan MSIII, Kevin Kafaja MSIII, Amisha Kumar MSIII, Jhennis Megan Lacsamana MSIII, Selene Nguyen MSIII

Western University of Health Sciences Pomona, CA

Dear Stephanie Yeganyan MSIII, Kevin Kafaja MSIII, Amisha Kumar MSIII, Jhennis Megan Lacsamana MSIII, Selene Nguyen MSIII:

We sincerely thank the authors of this Letter to the Editor for the thoughtful and detailed commentary on "A Case of Wiedemann-Rautenstrauch Syndrome With Fatal Hyperkalemic Renal Failure" by Dr. Mohamed Ghamry and colleagues. The feedback highlights the critical role that rare disease case reports play in expanding our collective clinical understanding, particularly when they uncover new and unexpected complications such as those described in this case.

"The striking phenotypic variability and its genetic etiology in the POLR3A gene make clinical recognition and management uniquely challenging. In this context, the report by Dr. Ghamry et al. is both timely and significant, adding to the growing body of knowledge with a novel clinical manifestation—hyperkalemic renal failure—that has not been previously described as a cause of death in WRS."

Wiedemann-Rautenstrauch Syndrome (WRS) is a profoundly rare and complex autosomal recessive disorder, and as you noted, fewer than 100 cases have been documented in the literature to date. The striking phenotypic variability and its genetic etiology in the POLR3A gene make clinical recognition and management uniquely challenging. In this context, the report by Dr. Ghamry et al. is both timely and significant, adding to the growing body of knowledge with a novel clinical manifestation—hyperkalemic renal failure—that has not been previously described as a cause of death in WRS.

We appreciate your emphasis on the value of comparing this newly described case to prior reports, especially concerning variations in management approaches. As you observed, other documented cases have included interventions such as ventriculoperitoneal shunt placement for hydrocephalus or the use of medications like alendronate for osteoporosis. These cases underscore the extent to which WRS may affect multiple organ systems and the importance of tailored, multidisciplinary interventions. Encouraging future authors to include explicit comparisons to past treatment strategies and outcomes could help illuminate patterns in disease trajectory and support the development of more structured management frameworks for these patients.

Your point about including a more detailed prenatal history is particularly well taken. In many rare congenital disorders, prenatal findings—such as intrauterine growth restriction or anomalies visible on ultrasound—can provide early diagnostic clues and help counsel families about potential outcomes. The suggestion to explore prenatal imaging findings in this context, particularly regarding the renal and urinary systems, is meaningful. When paired with a comprehensive family history, these elements can help clinicians better understand the hereditary nature of the disease and assess recurrence risk in future pregnancies. Indeed, in autosomal recessive syndromes like WRS, consanguinity and previously unexplained neonatal deaths in the family are critical pieces of the diagnostic puzzle.

"When paired with a comprehensive family history, these elements can help clinicians better understand the hereditary nature of the disease and assess recurrence risk in future pregnancies. Indeed, in autosomal recessive syndromes like WRS, consanguinity and previously unexplained neonatal deaths in the family are critical pieces of the diagnostic puzzle."

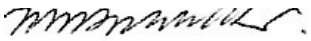
This case also prompts us to reflect on the importance of early and proactive renal evaluation in neonates with syndromic features. Hyperkalemia in the neonatal period is a life-threatening condition, and recognizing syndromes where renal involvement might be an underappreciated risk is vital. Including renal function assessments early in the workup of infants with suspected WRS—or similar progeroid syndromes—may prove to be life-saving, and we hope this report draws needed attention to that possibility.

Finally, we wholeheartedly agree with your closing remarks regarding the necessity of multidisciplinary care in syndromes like WRS, where neurologic, skeletal, endocrine, renal, and other systems may all be affected simultaneously. Neonatologists, geneticists, nephrologists, endocrinologists, palliative care teams, and other specialists must work together to ensure comprehensive care. Just as significant is continued investment in research and case documentation to define the spectrum of disease better and improve the precision of our diagnoses and interventions.

We applaud your engagement with this vital work and advocacy for thoughtful, thorough case documentation and interpretation. Letters such as these help foster a deeper and more nuanced

conversation within the neonatal and genetic medicine communities and support the mission of journals like Neonatology Today to disseminate clinically meaningful and practice-shaping information. We welcome continued dialogue on this and other topics at the intersection of rare disease, neonatal care, and genomic medicine.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today March, 2025)

There were no reported erratum for March, 2025.

Corrections can be sent directly to LomaLindaPublishingCompany@gmail.com. The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from www.neonatologytoday.net.

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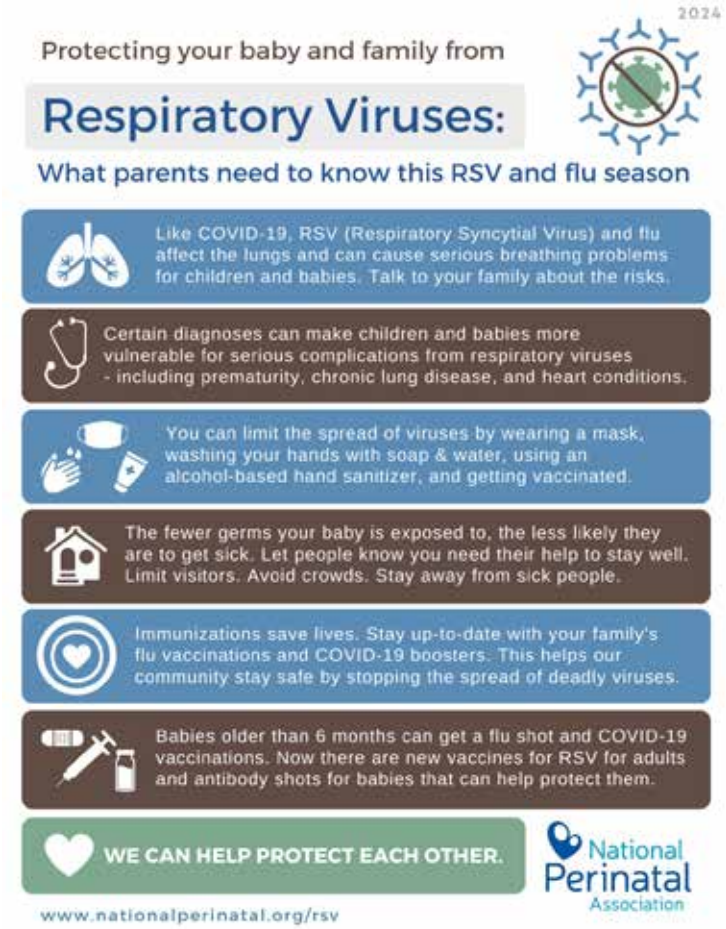
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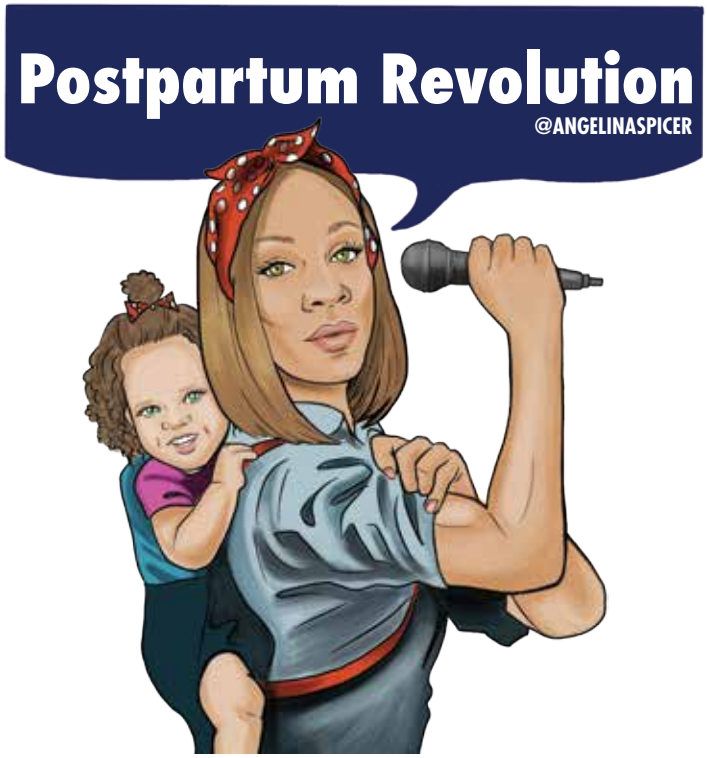
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Gravens by Design: Brighter Beginnings: Why Light in the NICU Matters

James M. Greenberg, MD

Introduction:

At birth, all neonates encounter an array of new environmental conditions requiring initiation of transitional adjustments (Table 1). Immediate concerns include shifting from placental support to endogenous pulmonary and gastrointestinal systems to achieve oxygen transport, metabolic activity, and energy homeostasis. The full-term infant is well-equipped to transition with basic supportive care consisting of drying, skin-to-skin contact, and timely access to nutritional substrates (ideally colostrum). The newborn must also adjust to dramatic changes in sensory stimulation. Neonates born before term and/or those with concurrent illness are required to make the transition to the extra-uterine environment with underdeveloped, overtaxed resources.

Light:

Among the environmental transformations managed by the newborn is exposure to light. At delivery, the preterm infant transitions from an intrauterine environment of low (but not absent) light intensity that also provides circadian cues from the mother. The quality, duration, and spectrum of environmental lighting in the NICU are highly variable. At times, it is very intense and typically lacks correlation with natural daylight's timing and spectral content. In many NICU environments, lighting conditions are often subdued with minimal circadian stimulation. A recent systematic review (1) states that interruption of maternal signaling of fetal rhythms following a preterm delivery, followed by exposure to an environment that lacks day-night cycles because of continuous near darkness (Fig. 1), and/or continuous bright light, could adversely affect the development of circadian rhythms.

New information about light sensing has emerged over the past decade, demanding a reevaluation of current practice. Here, we introduce novel aspects of light sensing with compelling implications for newborn health and wellness. We also discuss

Figure 1: Current practice in many NICUs includes using isolette covers to decrease environmental light exposure. Continuous low-light conditions minimize access to circadian cues and may compromise the development of circadian entrainment needed for optimal growth and feeding.



Table 1: The Newborn Transition

Environmental Condition	Fetal → Neonatal
Oxygen tension	Typical PaO_2 30mmHg → 75–100 mmHg
Temperature	Stable thermal environment → variable environment with higher losses to the environment
Nutrition	Constant substrate delivery from placenta → episodic delivery from gut
Microbiome	Essentially sterile gut → rapid microbial colonization
Sound	Stable auditory environment dominated by maternal blood flow, bowel sounds, muted external input → direct, variable auditory stimulation
Light	Low intensity, complemented by maternal circadian information → highly variable intensity and spectrum

how we might incorporate this new knowledge into a NICU environment to optimize growth and development.

We use the term "light" for the portion of the electromagnetic radiation detected by the retina and transduced by the central nervous system to establish vision (Fig. 2). Visible daylight includes a continuum of wavelengths we perceive as colors. Multiple wavelengths of light are typically perceived as white light. The quality of white light is a function of many variables, including the distribution and intensity of emitted wavelengths. Sunlight includes a continuous sequence of wavelengths ranging from 380 (violet) to 850 (red) nm (Fig. 3).

Opsin Proteins:

Light is detected in virtually all vertebrate animals by a specific class of proteins called opsins, discovered in the early 20th century. In the 1950s, George Wald determined the function of the opsins mediating vision, which led to his receipt of the Nobel Prize for Physiology or Medicine in 1967. Figure 4 depicts the structure and functional properties of opsin proteins.

Figure 2: Light is electromagnetic radiation we perceive and sense through our visual system. White light is a collection of multiple wavelengths of electromagnetic radiation that can be divided by projection through a prism. The wavelengths of visible light range from 380 nm (violet) to 850 nm (red). Information about the wavelengths of light detected by the opsin proteins in the retina is sent to the brain's occipital cortex and further processed to create perception of color, hue, and saturation.

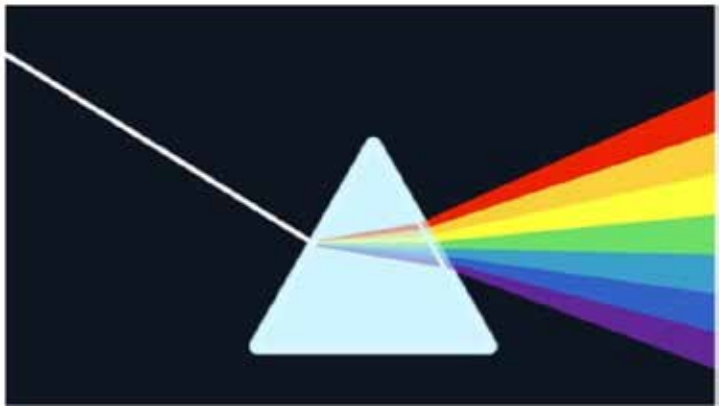


Figure 3: The spectrum of sunlight perceived by the retina is a continuous progression of wavelengths. This lighting environment has been the norm across all vertebrate evolutionary time.

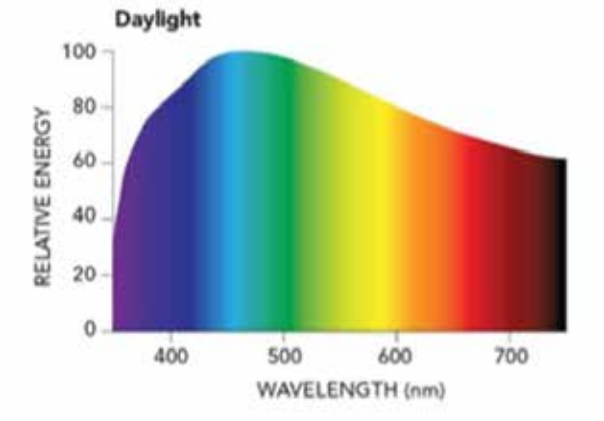
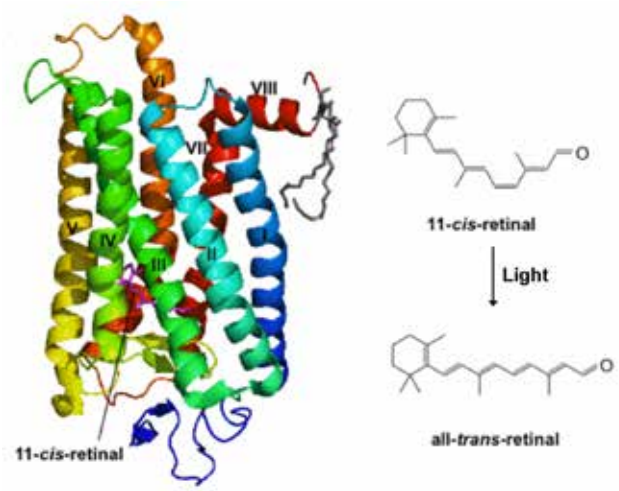


Figure 4: The tertiary structure of rhodopsin (OPN2). The protein incorporates the small molecule chromophore, 11-*cis*-retinal. Photons with wavelength ranges specific to a given opsin interact with the retina. The opsin catalyzes the conversion of the 11-*cis* to the all-*trans* isomer, leading to signal transduction.



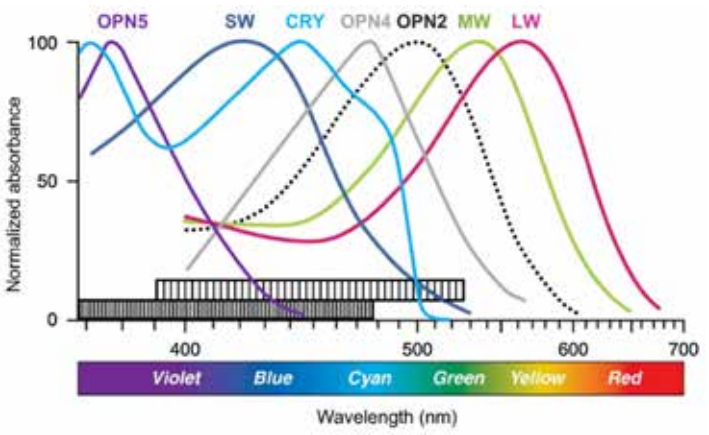
We now know that humans possess nine opsin proteins. Four are found in the retina and support vision. Rhodopsin (OPN2) is present in rod cells, while the others, OPN1SW, OPN1MW, and OPN1LW, are present in the cone cells. Each opsin detects light across a specific range of wavelengths (Fig. 5). Transduction begins when a photon in the appropriate wavelength range interacts with 11-*cis*-retinol, a vitamin A derivative embedded within the opsin protein. The opsin catalyzes a conformational change to all-*trans* retinol, which stimulates the opsin to initiate an action potential propagated in a series of steps from the retina through the brain to the occipital cortex. There, the signal is further processed to create the sensory perception we understand as sight. Two additional opsins catalyze the conversion of all-*trans* retinal back to 11-*cis* retinal to complete the visual transduction cycle.

"Light is detected in virtually all vertebrate animals by a specific class of proteins called opsins, discovered in the early 20th century. In the 1950s, George Wald determined the function of the opsins mediating vision, which led to his receipt of the Nobel Prize for Physiology or Medicine in 1967."

The Non-Visual Opsins:

The three additional opsins, OPN3, OPN4, and OPN5, were discovered in the early 21st century. (3) These are now collectively known as non-visual opsins, light-sensing proteins expressed in non-retinal tissues such as skin, fat, the central nervous system, and gonads. As with the visual opsins, these proteins are activated by specific wavelengths of light (Table 2).

Figure 5: Each opsin is sensitive to a specific range of wavelengths in the electromagnetic spectrum. OPN2 (rhodopsin) is present in the rod photoreceptors of the retina. OPN1LW, OPN1MW, and OPN1SW are responsible for color perception in the cone photoreceptors of the retina. OPN3 (encephalopsin), OPN4 (melanopsin), and OPN5 (neuropsin) are non-visual opsins found in specific cells within the eye, such as IPRGs, as well as an array of extraocular locations within the central nervous system, skin, and other metabolically important tissues such as brown and white fat.



We must consider non-visual opsins in the context of the human experience of light. Modern humans appeared approximately 200,000 years ago. Until the late 19th century, the sun was the primary source of light exposure. Artificial sources, such as candlelight, only provided very dim illumination. The invention of incandescent lighting led to an explosion of indoor lighting installations. As lighting technology improved, humans made a dramatic transition to indoor living. Today, the typical person residing in the developed world spends more than 90% of their time indoors. This change in behavior means that humans no longer encounter sunlight as their primary light source. While indoor lighting may seem no different than light from the sun, several crucial differences exist. First, the spectral content of indoor light lacks many wavelengths generated by the sun (Fig. 6), most notably the wavelengths producing violet and blue light (380–450 nm). Modern window glass is also opaque to these wavelengths. Therefore, indoor light sources do not reliably activate the non-visual opsins, especially OPN5. Further, standard indoor light sources do not vary spectral content across the day. This contrasts with sunlight, which varies consistently from dawn through midday to sunset. Spectral variation and lighting duration associated with seasonal variation are also absent indoors.

"The three additional opsins, OPN3, OPN4, and OPN5, were discovered in the early 21st century. These are now collectively known as non-visual opsins, light-sensing proteins expressed in non-retinal tissues such as skin, fat, the central nervous system, and gonads. As with the visual opsins, these proteins are activated by specific wavelengths of light (Table 2)."

It is helpful to consider these dramatic changes in our modern indoor lighting environments from an evolutionary standpoint. All human opsin proteins display strong evolutionary conservation. (4). OPN5 is remarkably stable with minimal amino acid substitutions over time, implying a crucial function for these proteins. A large and growing body of evidence now demonstrates that these non-visual light-sensing proteins play an active role in physiologic pathways supporting circadian entrainment, energy homeostasis, metabolic activity, and visual development. The implied significance for health and wellness is compelling. Below, we present some evidence supporting the biological importance of non-visual opsins, emphasizing the neonatal population.

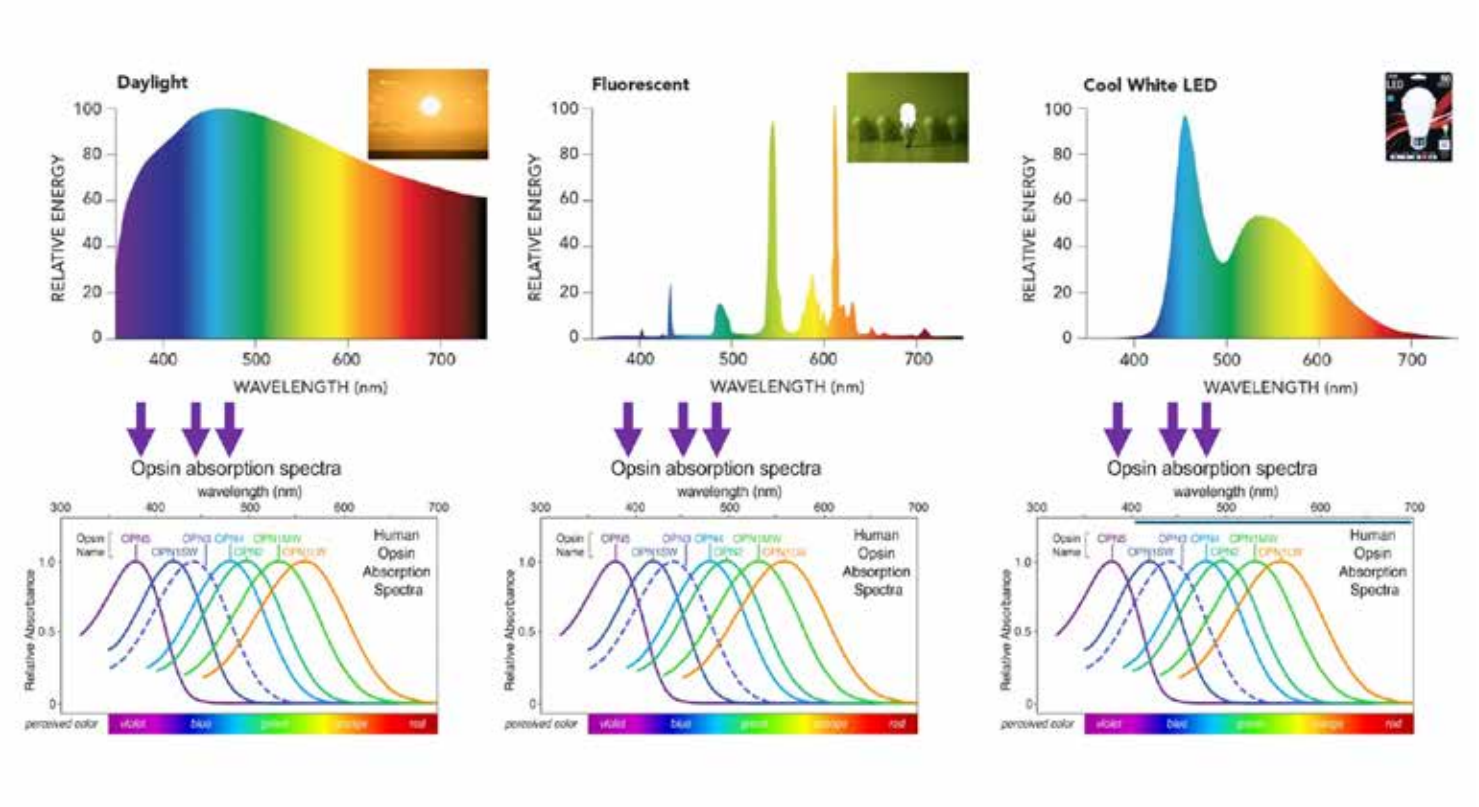
Circadian Entrainment:

Circadian entrainment refers to a collection of biochemical pathways, physiologic processes, and behavior that align with the 24-hour light/dark cycle caused by the rotation of the

Table 2: The Opsin Proteins

Name	Wavelength Range, Comments
OPN2 (rhodopsin)	450–600 nm, rod photoreceptors
OPN1LW (longwave cone opsin)	500–750 nm, cone photoreceptors
OPN1MW (mediumwave cone opsin)	450–650, nm cone photoreceptors
OPN1SW (shortwave cone opsin)	400–500, nm cone photoreceptors
OPN3 (encephalopsin)	peak absorption 450 nm, non-visual
OPN4 (melanopsin)	peak absorption 480 nm, non-visual
OPN5 (neuropsin)	peak absorption 380 nm, non-visual
RRH (peropsin)	450–550, nm, supports opsin function
RGR (retinal G-protein coupled receptor)	380–470, nm, supports the regeneration of 11-*cis*-retinal

Figure 6: Spectra for daylight compared with light generated from artificial sources. Note that fluorescent lighting produces a modest collection of wavelengths that are still perceived as white. A cool color temperature LED generates a broader array of wavelengths. However, fluorescent lighting does not generate light wavelengths that activate OPN3 and OPN4, while neither source produces wavelengths capable of stimulating OPN5 (purple arrows).



Earth. Circadian activity is a hallmark of virtually all multicellular organisms, including humans. At its core, circadian entrainment supports survival by using environmental cues provided by light to optimize activity crucial for food access, safety from predators, and reproductive success. In humans, the suprachiasmatic nucleus (SCN) located in the hypothalamus serves as a master clock, receiving environmental cues such as light via the retinohypothalamic (RHT) tract through intrinsically photosensitive retinal ganglion (IPRG) cells present in the eye. Note that IPRGs use OPN4 as their primary light receptor. Further, every cell expresses a set of circadian "clock" genes. These genes express transcription factors that oscillate on a 24-hour schedule. These cell-autonomous clocks influence various local tissue-level functions but are influenced or entrained through projections from the SCN. Misalignment of environmental cues processed by the SCN with the endogenous clock oscillations is the basis for the physiologic dysfunction seen with jet lag or shift work.

The SCN is functional in the fetus by mid-gestation and is synchronized by signals from the mother through maternal eating patterns and activity. Direct environmental stimulation may also play a role. Specific transplacental signals include melatonin and cortisol. The fetal RHT is fully developed by 36 weeks of gestation. Therefore, the fetus is designed to process time-of-day information from the mother. Of interest, there is evidence that maternal shift work may predispose to preterm birth and other complications of pregnancy. (5) With a preterm delivery, the maternal circadian cues received by the fetus are abruptly cut off. Instead, the neonate is exposed to a chaotic array of environmental information present in the typical NICU. It is likely that the ability of the preterm neonate to achieve circadian entrainment in this environment is compromised, which may lead to short—and long-term developmental and physiological dysfunction.

"A large and growing body of evidence now demonstrates that these non-visual light-sensing proteins play an active role in physiologic pathways supporting circadian entrainment, energy homeostasis, metabolic activity, and visual development. The implied significance for health and wellness is compelling."

Two systematic reviews of cycled lighting in the NICU (1, 6) note the potential value of cycled lighting in the NICU. In some studies, circadian variables such as heart rate and temperature were more stable. Other studies showed better clinical outcomes, such as weight gain or length of stay, with cycled lighting. A few studies failed to demonstrate any significant value. However, the overall trend suggests that NICU lighting should emulate a standard 24-hour light/dark cycle. All studies are hampered by small study populations derived from single centers, variable eligibility

criteria, and inconsistent primary outcome variables. Further, the lighting conditions varied among the studies (or were not stated). Finally, none of the studies considered the spectral quality of the light exposure. Given that OPN4 is the key photoreceptor for environmental circadian information, there is a clear need to include full-spectrum lighting capable of stimulating OPN4 (and perhaps other nonvisual opsins) in future studies.

"With a preterm delivery, the maternal circadian cues received by the fetus are abruptly cut off. Instead, the neonate is exposed to a chaotic array of environmental information present in the typical NICU. It is likely that the ability of the preterm neonate to achieve circadian entrainment in this environment is compromised, which may lead to short—and long-term developmental and physiological dysfunction."

Additional evidence regarding the importance of full-spectrum lighting for circadian entrainment comes from a recent study. (7) These investigators found that the number of mouse rod photoreceptors in the retina is directly influenced by a light-dependent pathway mediated by OPN4 in IPRGs. They correlated their findings using human transcriptome data, demonstrating that key components of the mouse pathway are active during human fetal eye development. The clinical consequences of altering rod photoreceptor number in the retina remain to be determined. It is plausible that such changes could have long-term implications for visual competence. The results clearly emphasize the need to define the optimal lighting environment for the preterm neonate.

"However, the overall trend suggests that NICU lighting should emulate a standard 24-hour light/dark cycle. All studies are hampered by small study populations derived from single centers, variable eligibility criteria, and inconsistent primary outcome variables. Further, the lighting conditions varied among the studies (or were not stated). Finally, none of the studies considered the spectral quality of the light exposure."

Vascular Development

Two preclinical studies (8) demonstrate the central role of OPN4 and OPN5 in retinal vascular development. Rao et al. (9) studied how OPN4 regulates neuron number in the developing retina. This determines oxygen demand, modulating vascular endothelial growth factor A (VEGF-A), stimulating vascular growth. In contrast, OPN5 photoactivation suppresses dopamine release in the retina, suppressing signaling through the vascular endothelial growth factor receptor-2 (VEGFR-2). Thus, photoactivation of OPN4 and OPN5 must be balanced for stable retinal vascularization. The implications for the pathogenesis of retinopathy of prematurity are intriguing. The spectral quality of environmental light may impact retinal vascular development, especially in the preterm infant. These studies also suggest that continuous dim lighting conditions may not be best for preterms.

"The spectral quality of environmental light may impact retinal vascular development, especially in the preterm infant. These studies also suggest that continuous dim lighting conditions may not be best for preterms."

Metabolism

As noted above, light sensing by the nonvisual opsin OPN4 is central to circadian entrainment. OPN4 also participates in ocular development. The presence of non-visual opsins in metabolic tissues raises fascinating questions about potential roles for metabolic health and wellness. There is strong evidence for light-sensing by non-visual opsins in central nervous system structures involved in metabolic regulation and tissues such as white and brown fat. In preclinical models, the data are remarkably compelling. Newborn mice reared in the absence of violet light display a hypermetabolic phenotype driven by activation of brown fat thermogenesis. The same effect is observed in mice lacking the OPN5 gene, demonstrating that light signaling through OPN5 directs brown fat metabolic activity. (10) Conversely, lacking the blue wavelengths needed to activate OPN3 signaling leads to low body temperature and a concurrent decline in white fat lipolytic activity. As with the OPN5 effect, mice lacking the OPN3 gene display the same phenotype. (11)

"While there is much to learn from additional research, it is reasonable to mandate cycled lighting as standard in the NICU. It is also logical to focus on the quality of NICU lighting. As we learn more about the non-visual opsins, light emulating the visual spectrum of sunlight is an important consideration."

What Does This Mean for the NICU?

A large body of evidence consistently points to the biomedical importance of light exposure and the compelling need to consider

the quality and intensity of light in the NICU. The intense evolutionary conservation of the opsin proteins over millions of years tells us that meaningful consequences are associated with the dramatic changes in light exposure that accompany modern life. The preclinical data in relevant animal models are robust and consistent. Human clinical studies show consistent findings but suffer from study design and feasibility challenges. We can overcome these barriers by developing operational full-spectrum lighting systems in the NICU. While there is much to learn from additional research, it is reasonable to mandate cycled lighting as standard in the NICU. It is also logical to focus on the quality of NICU lighting. As we learn more about the non-visual opsins, light emulating the visual spectrum of sunlight is an important consideration. Future studies will help us understand the key wavelengths, intensity, and timing most beneficial for our patients.

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Disclosure: *There are no conflicts of interests to disclose.*

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Review Committee for Pediatrics (RC-Peds) Nominee Qualifications

To qualify to be nominated to the RC-Peds for this position, the candidate:

- must be a board-certified pediatrician or pediatric subspecialist with a background in education and expertise in graduate medical education.
- should have at least three years of experience as a program director of an ACGME-accredited pediatrics residency program or pediatric subspecialty fellowship or three years of experience as a designated institutional official. The nominee's program must be in good standing with a status of Continued Accreditation.
- must have a current or past association with graduate medical education.
- should participate in major specialty societies.
- must be skilled in the use of computers (communication with staff is primarily through email, and members will use electronic systems for receipt of agenda materials, program reviews, reimbursement of expenses, and peer evaluations).
- must demonstrate fairness, the ability to work collaboratively, and express views clearly and concisely.
- must be able to attend an observation meeting, April 10-11, 2025, prior to the start of the term.
- must devote sufficient time to prepare for and participate in three RC meetings per year (January, April, and September), two-three days per meeting, as well as contribute to RC-Peds subcommittee work as assigned.
- ideally, will not hold the same subspecialty certifications as the members of the RC-Peds at the time of appointment. The RC-Peds strives to maintain a balance of specialties; it is preferable that individuals from the following specialties are not nominated:
    - General Pediatrics
    - Internal-Medicine Pediatrics
    - Pediatric Hospital Medicine
    - Pediatric Emergency Medicine
    - Neonatal-Perinatal Medicine
    - Pediatric Critical Care Medicine
    - Pediatric Endocrinology
- must not be at the same institution as any member of the RC-Peds at the time of appointment.
    - *Same-Institution Disqualification: Although the RC-Peds may have multiple members from the same state, they may not be from the same institution. Accordingly, individuals must not be nominated from the following institutions:*
        - UC Davis (Davis, CA)
        - Stanford University (Stanford, CA)
        - University of Colorado (Aurora, CO)
        - Advocate Children's Hospital (Park Ridge, IL)
        - Mayo Clinic (Rochester, MN)
        - Columbia University College of Physicians & Surgeons (Yonkers, NY)
        - Goryeb Children's Hospital-Atlantic Health System (Morristown, NJ)
        - University of North Carolina School of Medicine (Chapel Hill, NC)
        - Cincinnati Children’s Hospital Medical Center (Cincinnati, OH)
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that clogs their nose and lungs, making it hard to breathe

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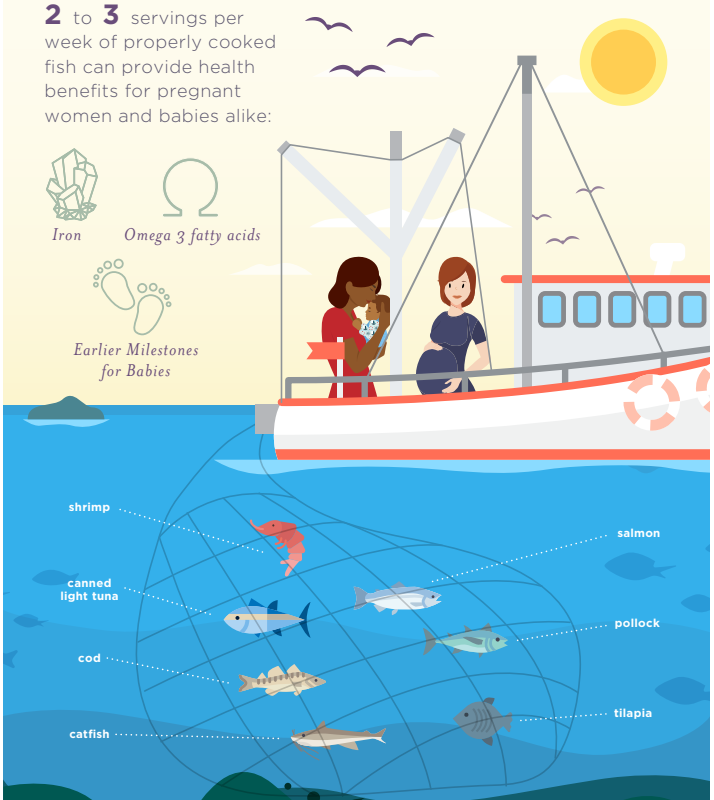
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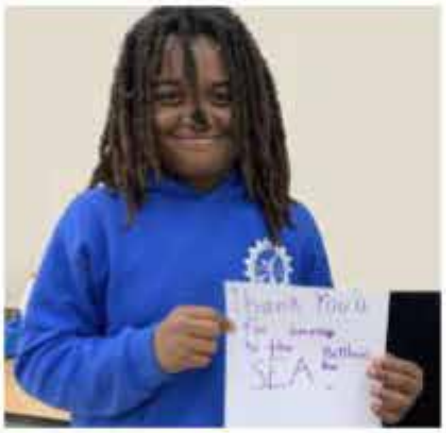


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Navigating toward Neonatology: Interview with Dr. Jay Goldsmith

Benjamin Hopkins, DO, Jay Goldsmith, MD

"Welcome back to another installment. My name is Benjamin Hopkins, and I am currently a post-grad year one pediatric resident at the University of California, San Francisco—Fresno. When 'I grow up,' I want to be a Neonatologist. Look at previous months' journals for my earlier articles and follow along with this column as I navigate my way to becoming a neonatologist."

Welcome back to another installment. My name is Benjamin Hopkins, and I am currently a post-grad year one pediatric resident at the University of California, San Francisco—Fresno. When I grow up, I want to be a Neonatologist. Look at previous months' journals for my earlier articles and follow along with this column as I navigate my way to becoming a neonatologist.

I am nearing the end of my residency intern year. I have recently rotated through newborns, night shifts, and the pediatric ward, where I can better understand generalized pediatric care and increase my autonomy in patient management. I have been fortunate to work closely with senior residents and attendings who care deeply for each patient they see.

I had the privilege of speaking with Dr. Jay Goldsmith, a clinical professor of pediatrics at Tulane University, a practicing neonatologist, and an author. We discussed what we should encourage future neonatologists to be involved in, how he got into Neonatology, some of his past research, and what he is currently doing in neonatal research.

1. What qualities are most essential to excel as a neonatologist?

It's almost every area, but certainly, with patients, you have to be very detail-oriented. It's not a 30,000-foot view. You've got to be down in the very granular aspects of baby's care. Every little thing you change will have an effect, so knowing those details is crucial in ensuring that your impact is the outcome you want and not something else.

2. What would you encourage a future neonatologist to prioritize and be involved in?

"...with patients, you have to be very detail-oriented. It's not a 30,000-foot view. You've got to be down in the very granular aspects of baby's care."

One is that Neonatology is a specific area of a baby's life, yet it affects their entire life. Recognize that what you do profoundly affects many years in that person's life, maybe a lifetime, and their family.

"Neonatology is a specific area of a baby's life, yet it affects their entire life. Recognize that what you do profoundly affects many years in that person's life, maybe a lifetime, and their family."

When I was in residency, a mentor gave me some great advice, and he said that neonatologists should be farmers and not firefighters. A farmer plants the crop and then harvests it, and if he does something wrong during that period, the crop isn't as good. I remember that as unique; no one had ever said that to me. Many academic programs have follow-up clinics, especially for the first two years of life. The families and other providers look to the neonatologists to help them through the first several months after the NICU stay. Suppose you look at certain significant studies, specifically those conducted by the NRN (neonatal research network). Part of almost every study, especially the prospective blinded study, is looking at outcomes. As a neonatologist taking care of babies during their first hospitalization, whether up to a month or up to six months, 500 or 5000 grams, you need to be aware of the outcomes of your treatment. As they leave the NICU on discharge, the outcomes in 18 to 22 months, in five to six years, and even as older children and adults should inform your care and make a difference in some of your judgments.

Another important thing is to understand the unique physiology of babies. Few drugs have been created specifically for babies; most of the baby drugs, the drugs we use in Neonatology, have come from older people, even adults, and we've altered their dosing. Surfactant is one drug that we created only for babies, and maybe one or two others, but there are not many.

"...given the limited amount of time in neonatal training in residency, you need to be proficient in procedures by the time you enter your fellowship. Only 20 to 30% of graduating third-year residents can intubate a baby.."

The third thing is that, given the limited amount of time in neonatal training in residency, you need to be proficient in procedures by the time you enter your fellowship. Only 20 to 30% of graduating third-year residents can intubate a baby. When you get to a fellowship and the first night you're on call, and in some fellowship

programs, you may be there by yourself without an attending, you need to be able to do the procedures, especially intubation, in an emergency. I tell all my residents at Tulane that if they're going into a neonatal fellowship, they should concentrate on procedures and even take a month of anesthesia elective.

3. What caused you to pursue a career in Neonatology?

It's a funny story. I have always wanted to be a pediatrician. My pediatrician was not related to me, but who I loved and who would let me listen with a stethoscope and use the reflex hammer in the office. I called him Uncle John; I never questioned when I was 3, 4, or 5 years old that I would be a pediatrician like Uncle John.

I never changed, and when I got to my residency at the University of California in San Francisco, I got hepatitis and meningitis. I got many more viral diseases, for which they did a bone marrow biopsy. They thought I had leukemia, but it turned out to be a viral suppression of my bone marrow. I met with the ID doctor, who said, "You can't be a pediatrician. You get everything the kids have; we can't figure out what it is, but you have some immune defects." He says, "Pick something in Pediatrics, a fellowship that doesn't have active viruses every day."

There were three cradles of Neonatology in the United States in the 1970s: one was at Boston, one was at Vanderbilt, and one was at UC San Francisco. I was at UC San Francisco, and George Gregory was there; he designed his first paper on CPAP. Louis Diamond was there, and he did the first exchange transfusion. The first catheterized baby for a PDA was done there. It was an incredible place for Neonatology; it was unbelievable that so many of the fathers and mothers of Neonatology were there, so I picked Neonatology. Once I knew I was going to be in Neonatology, I got involved with the respiratory group at UC San Francisco, which included George Gregory, who is an anesthesiologist and received the Apgar award, and Bill Tully, who received the Apgar award, was a pulmonologist. The first boards in Neonatology were not given until 1975, so I did this before there were even boards. Neonatology was a new specialty, so I'm one of the older Neonatologists still practicing.

"There were three cradles of Neonatology in the United States in the 1970s: one was at Boston, one was at Vanderbilt, and one was at UC San Francisco. I was at UC San Francisco, and George Gregory was there; he designed his first paper on CPAP. Louis Diamond was there, and he did the first exchange transfusion. The first catheterized baby for a PDA was done there. It was an incredible place for Neonatology; it was unbelievable that so many of the fathers and mothers of Neonatology were there, so I picked Neonatology."

When I was in residency at UC San Francisco from 1970 to 1972, and then in 1973, I went over to Oakland Children's for a Chief Residency. We spent nine months in the NICU out of 36 months, and now residencies have only two or three months in the whole three years. There's a big difference. Back then, everybody got intubated if they were delivered with meconium. We don't do that anymore. There was a program at Stanford in UC where you extubated and re-intubated everybody every two days because we're afraid the tubes would get plugged. You got very good at the procedures, especially intubation procedures.

"We spent nine months in the NICU out of 36 months, and now residencies have only two or three months in the whole three years. There's a big difference. Back then, everybody got intubated if they were delivered with meconium. We don't do that anymore. There was a program at Stanford in UC where you extubated and re-intubated everybody every two days because we're afraid the tubes would get plugged. You got very good at the procedures, especially intubation procedures."

And in 1973, I went to Oakland Children's and met with Dr. Grumbach, the chair at UC San Francisco, to tell him I was leaving. I said, "Dr. Grumbach, I've been here for two years. I've seen 50 or 60 cases of diabetes insipidus, but I haven't seen a single case of diabetes mellitus, and I think I need to get more general pediatric training." When I got over there, and I became Chief Resident, they were supposed to have a neonatologist come and take over their unit, and a month before he was supposed to show up, he sent him a letter and said, "I can't come." Dr. Duffy, the CMO, called me and said, "You have some spirit. You went to UC San Francisco, and you're in charge of the NICU."

At the end of the year, the first Greater San Francisco Neonatology Society was formed by June Brady, and they had a meeting. June called me and said, "Dr. Goldsmith, I understand you've been running the nursery at Oakland Children's. We're going to have a meeting of the neonatal group here in the greater San Francisco area. Would you like to come?" I said, "Of course, I'd love to come. I'd be honored."

She told me to bring a few slides of what we've been doing because we will discuss transport. We had done over 600 transports in that first year. I worked with Bob Cometto, who ran a transport service, and we designed a transport incubator.

Everyone came to a restaurant in San Francisco and got up and spoke about their transport systems. UC San Francisco had this transport system and had transported 90 babies. June got up and talked about Children's Hospital San Francisco, where they assembled an 18-wheeler that could deliver a newborn inside; it would travel, and they had done a couple dozen. Next, a guy from Sacramento came, and he said they had contacted *Ironsides*, a television show, and figured out how to do a lift so they could have

a lift on the back of their ambulance. It would lift the incubator, which was too heavy, into the ambulance so that nobody would hurt their back. When the meeting ended, June stopped and said, "Dr. Goldsmith, do you have anything to tell us about what you've been doing at Oakland?" I said, "I've got a couple of slides," and I got up, and I said, "We've transported 620 babies, "and June got up and went crazy and said, "You don't even have a neonatologist, how'd you be doing that?" We were on the east side of the bay where all the babies were being born, and once we opened up and said we had transport, they called us, and they didn't ask me who the neonatologist was; they called us. So we went and did over 600 transports, far more than anybody else had done, and we did it without a neonatologist. By the time I left to go to my fellowship, my real fellowship, we had a neonatologist.

4. What has inspired you to focus on your current education topics?

We got involved early on in respiratory care. Dr. Gregory and Dr. Tully wrote a book about respiratory care, but it wasn't practical for how to run the machines. Then, Dr. Fanaroff wrote this famous book *Care of the High-risk Neonate*, which came out in 1972 and was one of the largest-selling medical textbooks ever. They have sold 40,000 copies, which is unbelievable for a medical textbook. Usually, they sell between 5,000 and 10,000. I looked at that and noticed he only had a single chapter on respiratory care. So, we took that chapter and expanded it to a whole textbook. In 1981, we put out the first textbook on respiratory care. Marshall Klaus was the first editor, and Av Fanaroff was the second editor. We got Marshall to write the preface. We tried to use their format with the same editors, and I hardly wrote any of it. I acted as a traffic cop and tried to get people who knew the field to write. We just signed a contract two months ago to do the eighth edition. That's mainly what we've been doing regarding respiratory care, including intubation and ventilator management. As the textbook has evolved, it's become more disease-specific, but the initial textbook was about how to turn the dials of the machines. You need to make sure it has longevity, so in the last edition, we brought on two young editors, and as we step away, these two, Suresh Gautham and Martin Keszler, will take it forward.

"In 1981, we put out the first textbook on respiratory care. Marshall Klaus was the first editor, and Av Fanaroff was the second editor. We got Marshall to write the preface."

5. What are you currently working on?

More mentoring of some of the younger people and some of their projects. A lot of the projects now have to do with outcomes, follow up some with drug babies withdrawing, and new programs to treat babies with drug withdrawal. Still, they're more the projects the younger people want; I'm no longer setting the agenda for research projects. If they have a project and they want me to help mentor them, I will do that. I can offer them a perspective. You want to publish in the highest impact factor journal. So a resident or a fellow comes to me and says, "We're writing this paper," and I say, "Where do you want to submit it? Do you know how hard it is to get in there and what the impact factor is?" We often go from impact factors that are pretty high and get refused, and we have to say, okay, it's time to look at a lower impact factor in a journal.

6. Should we track medical students toward Neonatology because of the decreased opportunity to get pediatric residents interested in the field?

We have about 36 residents, and we get about one a year who goes into Neonatology. In terms of medical students going into pediatrics, generally, when I have four medical students, I'm always trying to convince them to go into pediatrics. It's challenging, and in recent years, it hasn't been as popular as before. We do our best to teach and be models and mentors to get some students into pediatrics. From our medical school, we generally have 25 or 30 each year going into pediatrics, but we would like more. I have one graduating residency this year, and I tend to take too much interest in those people; I want to prepare them for their fellowship years. One of the interesting things about Neonatology is that it brings together so many aspects of what brings people to be physicians. Jeb Randolph, a famous pediatric surgeon, said after I told him I was in Neonatology, "Oh, you're just a surgeon who can't stand the sight of blood."

"...you have to have cognitive knowledge, and...you also do procedures. You have to understand physiology and have a good understanding of pharmacology."

There's something about being a neonatologist; you have to have cognitive knowledge, and then, differing from what most pediatricians do, you also do procedures. You have to understand physiology and have a good understanding of pharmacology. There is not much of a common diagnosis, such as a kid with an ear infection. The other aspect is ethics, especially at the beginning of life or the edge of viability in 22 to 24 weeks, and ethical considerations. Ethics is the opposite of what much medicine is considered; medicine is often a hard science, while ethics is more similar to philosophy. We need to consider this because this is one of the areas of medicine where ethical treatment, management, and parental desires are paramount. After all, it's a brand-new newborn. We need to consider long-term life expectancy and being in a critical care situation. So, I'm grateful to the ethics board, palliative care team, and social worker for focusing on those aspects of patient care. *Answers are paraphrased from video/voice calls.

"The other aspect is ethics...Ethics is the opposite of what much medicine is considered; medicine is often a hard science, while ethics is more similar to philosophy. We need to consider this because this is one of the areas of medicine where ethical treatment, management, and parental desires are paramount."

Disclosures: *No disclosures are noted.*

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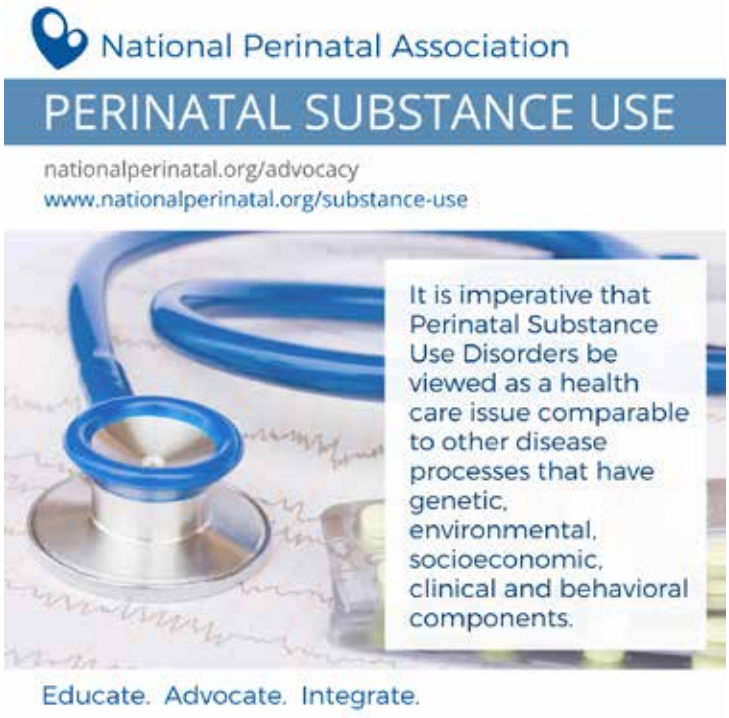
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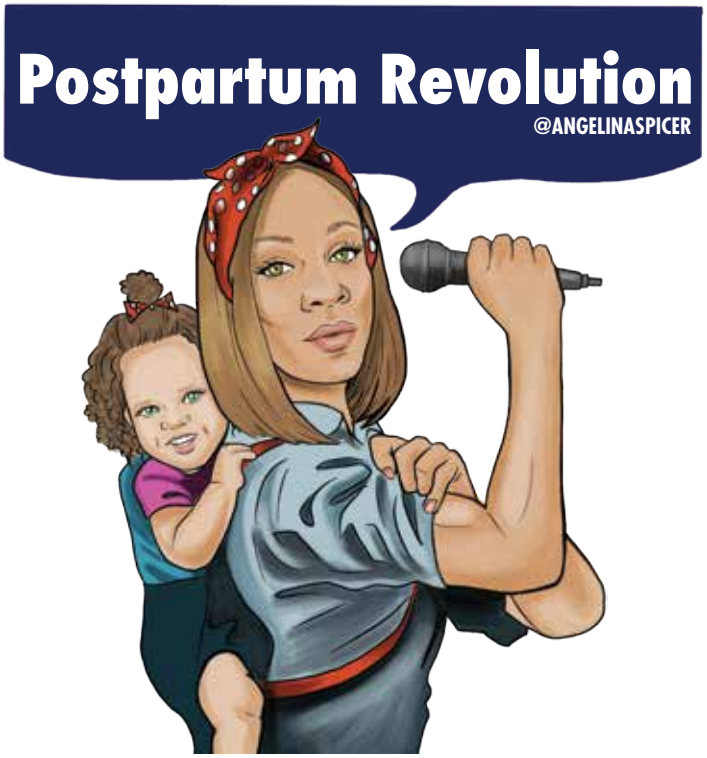
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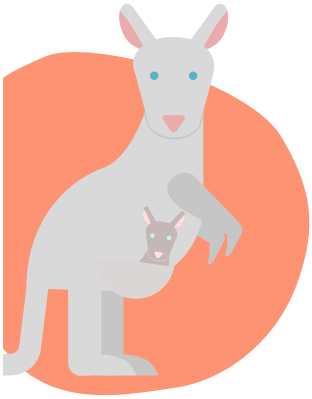
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WE ARE GRATEFUL TO BAYLOR COLLEGE OF MEDICINE, ISABEL DAVIS CENTER FOR SAFE CHILDREN AND TEXAS CHILDREN'S HOSPITAL FOR MAKING ISPID HOUSTON 2025 POSSIBLE



SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.





PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there



National Perinatal Association

nicuparentnetwork.org

NPN NICU PARENT NETWORK

nationalperinatal.org/skin-to-skin

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+ Dawn Godbolt, Ph.D.
National Birth Equity Collaborative



+ Chavis A. Patterson, Ph.D.
Children's Hospital of Philadelphia



+ Shanté Nixon
Connect2NICU



+ Deidre McDaniel, MSW, LCSW
Health Equity Resources and Strategies



+ Dalia Feltman, MD, MA, FAAP
Univ. of Chicago Pritzker School of Medicine



+ Terri Major- Kincade, MD, MPH
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Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5th RSV Vaccines for the World Conference in Accra, Ghana.

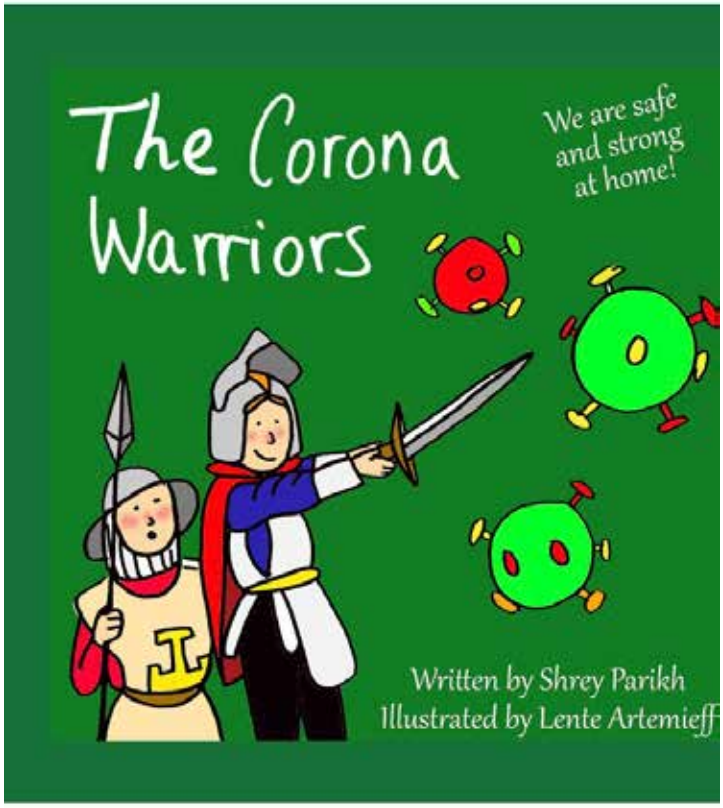
They have produced a personal video entitled "*Why we should all know about RSV*" about Simone van Wyck, a mother who lost her son due to RSV. The video is available at www.rsvgold.com/awareness and can also be watched using the QR code on this page. Please share the video with your colleagues, family, and friends to help raise awareness about this global health problem.

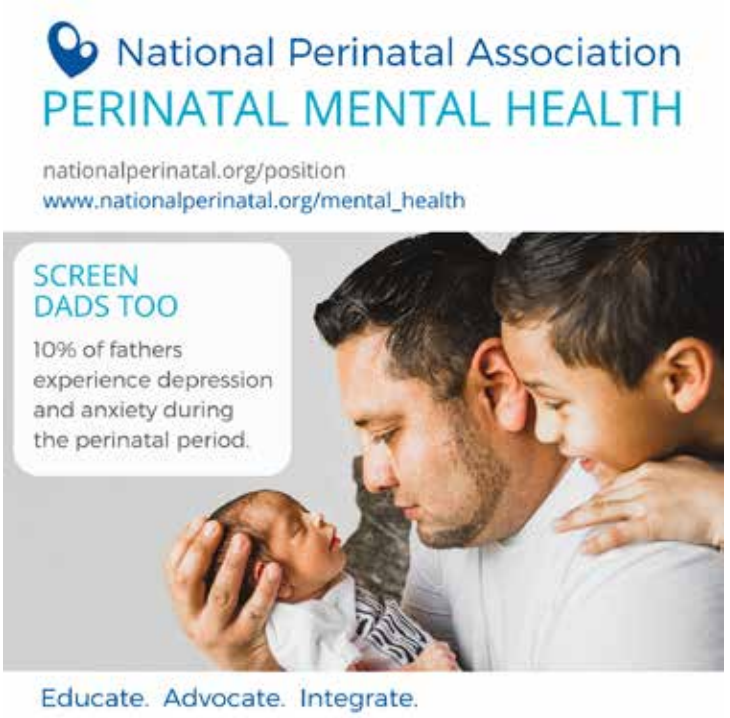


RSV GOLD

A Global Mortality Database for Children with RSV Infection

The RSV awareness video was produced in collaboration with the Bill & Melinda Gates Foundation



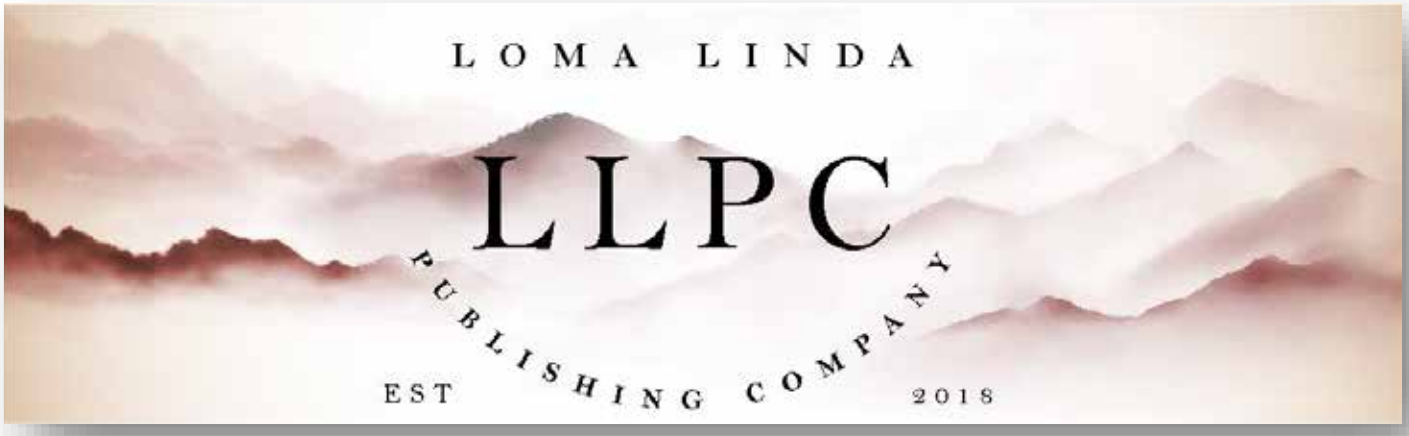


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Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

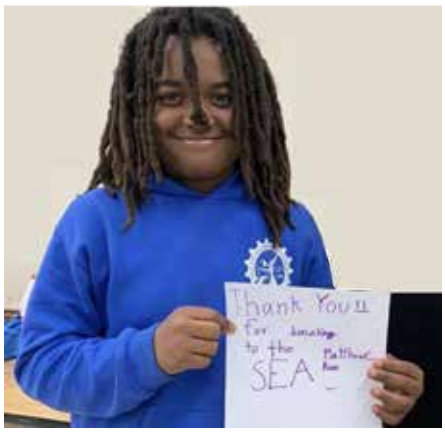


Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

Make a Difference in the Life of a Student in Need Today!
Please visit emilyshane.org

Sponsor a Child in the SEA Program

The average cost for the program to provide a mentor/ tutor for one child is listed below.



1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

The Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) Program is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.

Peer Reviewed

National Coalition for Infant Health: Impact and Burden of Thyroid Disease in the Asia-Pacific Region

Susan Hepworth, Lindsay Cox, MPM, Suzanne Staebler, DNP, NNP-BC

NATIONAL COALITION for Infant Health

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

"Summary of the Thyroid Disease Roundtable in Singapore February 2025"



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IMPACT AND BURDEN OF THYROID DISEASE

in the Asia-Pacific Region



Summary of the Thyroid Disease Roundtable in Singapore

FEBRUARY 2025

GAfPA
Global Alliance for Patient Access

NATIONAL COALITION for Infant Health



Introduction

Thyroid disease is a condition that affects the production of hormones that regulate metabolism, heart rate and other bodily functions. In infants and young children, it is particularly key in modulating growth and neurodevelopment. There are two main types of thyroid disease—hypothyroidism and hyperthyroidism—resulting in either too little or too much production of hormones. Thyroid disease is the second most common endocrine disorder affecting reproductive-age women, and they are five to eight times more likely than men to be affected with thyroid issues.[1]

On February 12, 2025, the Global Alliance for Patient Access and National Coalition for Infant Health co-hosted a roundtable meeting in Singapore to discuss the burden and impact of hypothyroidism on maternal and infant health in Asia Pacific. Convening healthcare experts and patient advocates from the region, the meeting highlighted four key points:

- **Hypothyroidism poses a major threat,** especially to maternal and infant health in the Asia-Pacific region.
- **Access barriers,** such as stigma and low prioritization, negatively impact patient health outcomes.
- **Timely screening, diagnosis and treatment** are crucial to long-term health, especially for at-risk populations.
- **Prioritizing thyroid disease among global health policymakers** will lead to a healthier population.

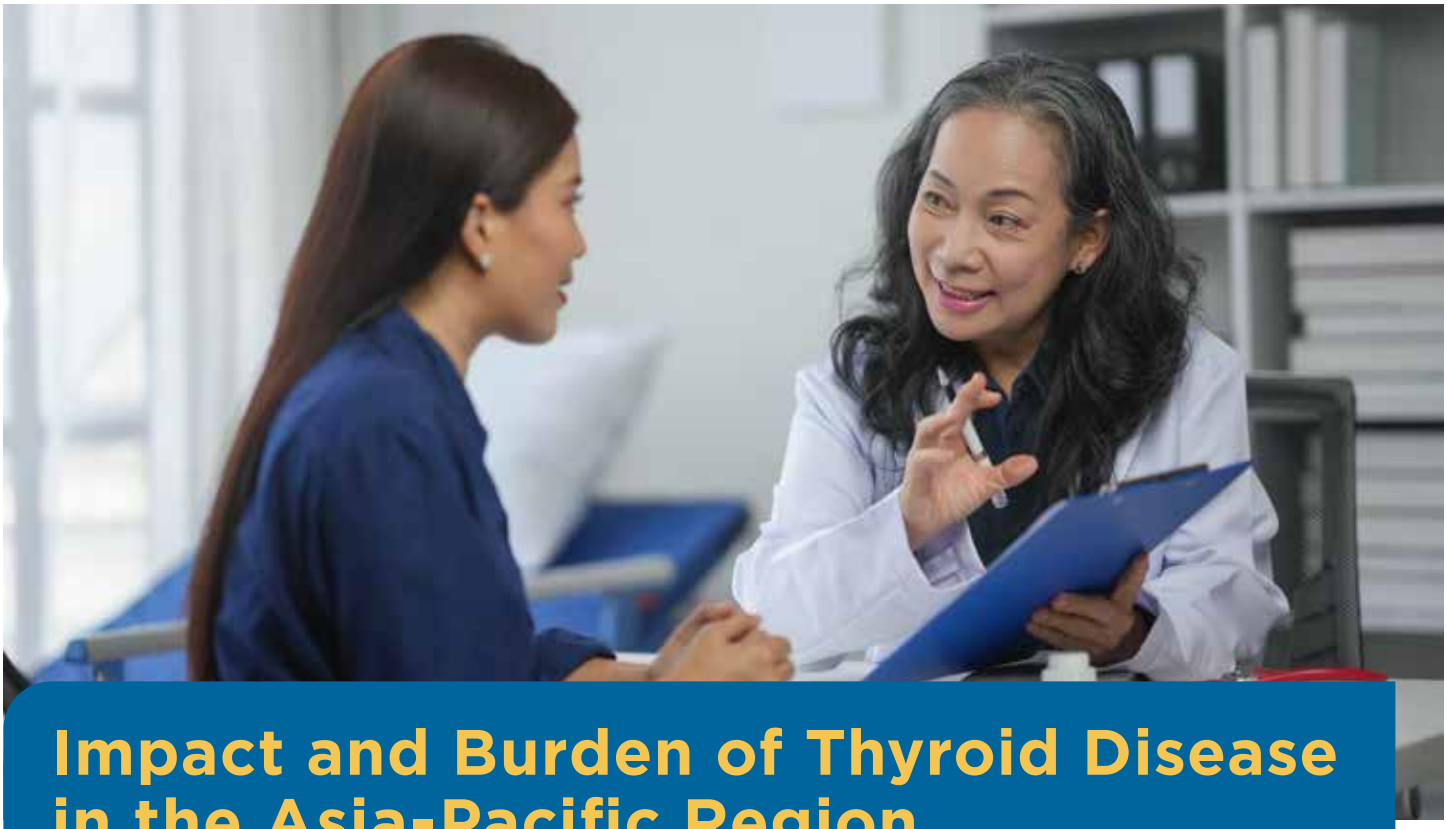


Understanding Hypothyroidism

Hypothyroidism, also called underactive thyroid, is a type of thyroid disease where the thyroid gland does not produce enough thyroid hormone, which can lead to slowing of the body's functions, impacting all levels of cellular metabolism. This includes heart rate, body temperature regulation, and metabolic processes.

During pregnancy, untreated hypothyroidism can lead to preterm birth, miscarriage, pregnancy-induced hypertension, or low birth weight in the infant. The developing fetus also relies on the mother's thyroid hormones for proper growth and development throughout gestation. Without these crucial hormones, fetal growth—especially brain growth—is delayed and can lead to life-long challenges including intellectual disabilities and impaired motor function.[2]

Congenital hypothyroidism can occur when the thyroid does not form correctly in utero or when there is dysfunction of the hypothalamus or pituitary glands. If not diagnosed promptly, congenital hypothyroidism can lead to growth problems and neurodevelopmental disabilities. Babies born to mothers with thyroid disease or those born to mothers in iodine-deficient regions have increased risk of congenital hypothyroidism.



Impact and Burden of Thyroid Disease in the Asia-Pacific Region

The prevalence of hypothyroidism in the Asia-Pacific region is higher compared to the rest of the world, affecting an estimated 11% of adults compared to 2-4% elsewhere. For pregnant women, prevalence is also higher in the region, with approximately 13% suffering from thyroid disease, compared to 5-7% of expectant mothers globally. The region also sees 5-7 in every 10,000 babies born with thyroid diseases, compared to the global average of 3 in every 10,000 births.[3]

The roundtable meeting highlighted how improved screening, diagnosis, treatment and prevention can lead to better patient outcomes in the Asia-Pacific region.

Prevention

The most cost-effective means of preventing hypothyroidism is through salt iodization. Additional iodine fortification is especially important during pregnancy, with intake requirements increasing by over 50%. Insufficient iodine intake during pregnancy can affect the infants' neurological development.[6]

Early Detection and Targeted Screenings

Targeting high-risk groups, such as pregnant women, has been shown to help improve overall detection of thyroid disease. When integrated into existing programs and services, thyroid screenings are more efficient and cost-effective.[4]

"Early detection of thyroid disorders is crucial for improving health outcomes."

-Tjokorda Gde Dalem Pemayun, MD, PhD

Universal screening for maternal thyroid disease has not yet been adopted in the region. For instance, in Malaysia, the screening is a targeted case-finding approach towards maternal hypothyroidism, whereby pregnant women are only screened when they have additional risk factors, such as a family history of thyroid dysfunction.[5]

While universal newborn screening is more widely adopted throughout the region, it is still not available in many countries. In fact, it is estimated that only one in three babies globally receives congenital hypothyroidism screening. Early detection within the first few months of life is critical to reducing long-term consequences.

Diagnosis

In adults, symptoms can vary from person to person and mimic those of other health conditions, so thyroid patients are often underdiagnosed or misdiagnosed. Thyroid levels, via blood sampling, are needed to confirm a diagnosis. Imaging via ultrasound may also be indicated if goiter or other dysfunction is suspected.

Treatment

Hypothyroidism is easily treated and most commonly involves taking a daily hormone replacement tablet. Hyperthyroidism may also require medication with possible ablation or surgical removal of the thyroid. Due to the worsening of long-term consequences as symptoms progress in both mothers and infants, detecting thyroid disease early and treating as soon as possible is key to improving patient outcomes.



Barriers to Education, Screening and Treatment

Roundtable participants highlighted three main barriers impacting thyroid care in Asia Pacific.

System barriers

Systemic barriers include policies or practices that can hinder access to care.

- Lack of awareness and education among healthcare providers
- Lack of universal screening early in pregnancy for maternal thyroid disease
- No universal newborn screening in many jurisdictions for congenital hypothyroidism, although adoption and acceptance of such programs is greater than for maternal screening
- Access to specialists or sites of care, especially in rural areas
- General system bias toward treatment rather than prevention

Programs do exist to address some of these systemic barriers. For example, in Indonesia, the Thyroid RAISE Program brings multiple stakeholders together to improve healthcare professionals' ability to screen and diagnose thyroid disorders in high-risk populations. The program is expected to increase access to hypothyroidism treatment by 5.5 times by 2030.[7] And in 2024, the WHO issued a resolution strongly supporting newborn screening.[8]



Patient and cultural barriers

Religion, cultural practices and belief systems can impact access to care.

- Stigma of accessing "free" care; or for the family of a newborn facing health issues
- Suspicion about new programs and tests
- Deference to healthcare providers / not wanting to ask questions or raise concerns of current health issues or symptoms
- Normalization of ill health
- Costs and insurance coverage

Aimed at addressing some of these barriers, a Nepalese program set up a free thyroid screening clinic inside a local temple. Of the 124 attendees screened, 24 were found positive for thyroid-related issues. Participants also received important education about thyroid disease prevention, treatment and management. This program showed how taking a hyper-local approach was effective in reaching patients and breaking through cultural barriers.



Healthcare provider barriers

Education and awareness among healthcare providers also plays a role in the screening, diagnosis and treatment of hypothyroidism.

- Lack of medical school education focused on thyroid disease
- Limited time with patients due to overburdened healthcare systems
- Healthcare workforce shortages
- Insufficient or inconsistent communication between multi-disciplinary care teams

Integrating thyroid disease into medical and nursing education courses as well as clinical training opportunities for healthcare providers are ways to help improve overall thyroid literacy and close the gaps that exist in screening, diagnosis and treatment.

Prioritizing Thyroid Disease Among International Stakeholders

Thyroid disease states are chronic conditions that place an immense burden on patients, families, healthcare providers, governments and healthcare systems. Roundtable participants agreed that thyroid disease should be elevated as a priority for global policymakers. For example, formal recognition as a noncommunicable disease by the World Health Organization could ensure better access to education, screening, diagnosis and treatment, improving outcomes for patients in Asia Pacific and across the world.

It is estimated that 1.6 billion people globally are at risk for thyroid disorders. Participants also noted an official recognition of a Global Thyroid Disease Awareness Day by the WHO could help to elevate awareness and improve outcomes.

Informing and educating national and international health leaders on the need for prioritization is an important step in ultimately influencing the WHO to recognize thyroid disease as an NCD.

Conclusions



Thyroid function has a large-scale impact on overall health. Significant variation in hormone levels may have a debilitating impact on our most vulnerable populations, with women of child-bearing age and infants at particular risk for long-term health impacts.

Patients, advocates, policymakers and healthcare providers must come together to ensure:

- ✔ Greater education and awareness of thyroid disease risks, symptoms and diagnostic studies.
- ✔ Universal thyroid screening for pregnant women.
- ✔ Inclusion of congenital hypothyroidism into widely adopted and accepted newborn screening programs.
- ✔ Prioritization of thyroid disease among global policymakers.

Doing so will reduce barriers to education, screening and treatment of thyroid disease and improve patients' lives.

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GAfPA
Global Alliance for Patient Access

The Global Alliance for Patient Access is an international platform for healthcare providers and patient advocates to inform policy dialogue about patient-centered care.

GAfPA.org

NATIONAL COALITION for Infant Health

The National Coalition for Infant Health is a collaborative of professional, clinical, community and family support organizations. The coalition focuses on education and advocacy promoting patient-centered care for all infants – whether born preterm or full term – and their families.

InfantHealth.org

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Pita Tosca Indonesia

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Disclosures: The authors have no relevant disclosures.

NT

National Coalition for Infant Health Values (SANE)

Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

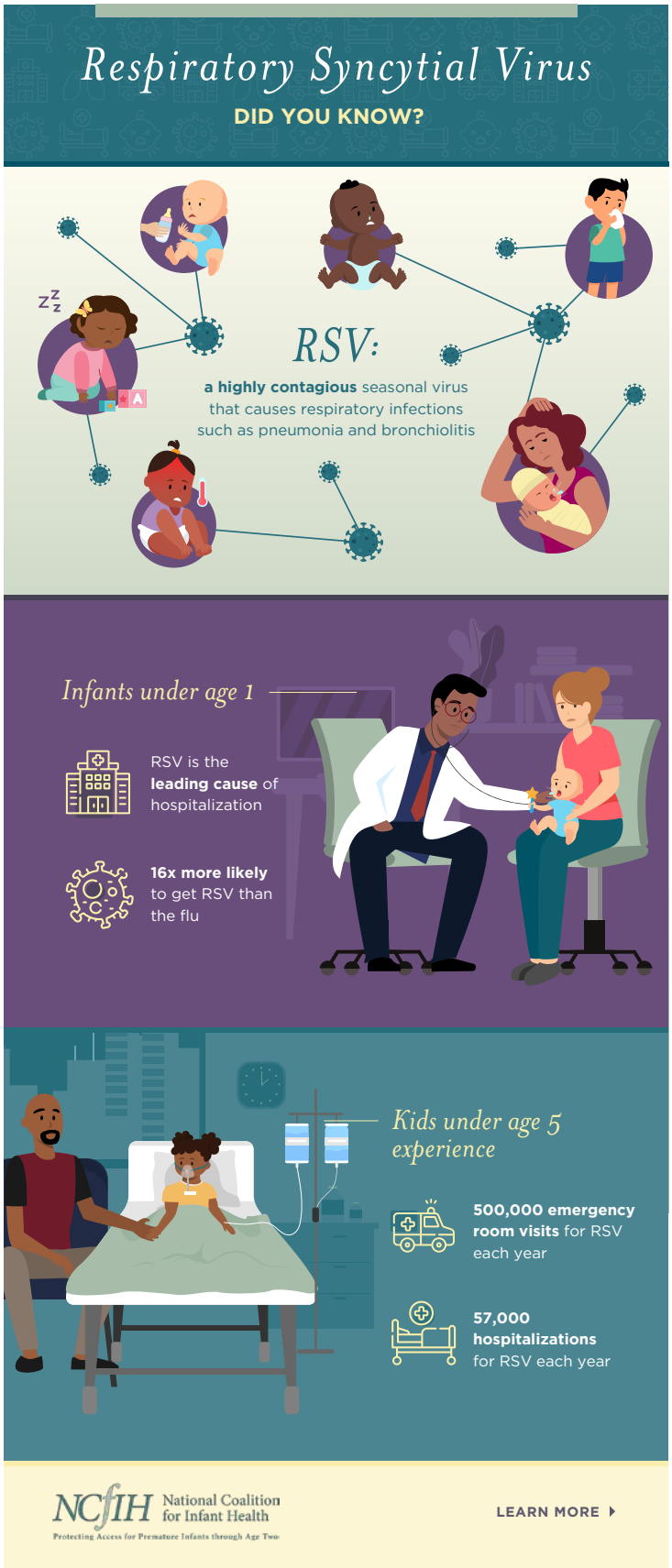
Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

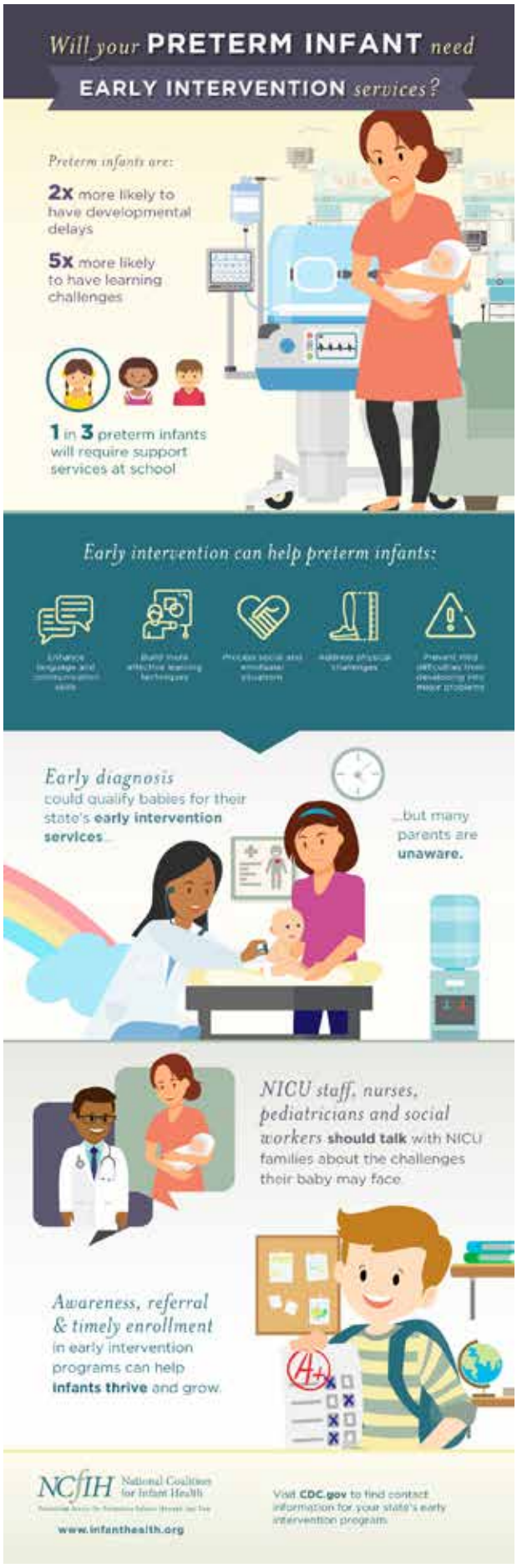
Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equity. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.






Will your PRETERM INFANT need
EARLY INTERVENTION services?
Preterm infants are:
2x more likely to have developmental delays
5x more likely to have learning challenges
1 in 3 preterm infants will require support services at school
Early intervention can help preterm infants:
Early diagnosis could qualify babies for their state's early intervention services...but many parents are unaware.
NICU staff, nurses, pediatricians and social workers should talk with NICU families about the challenges their baby may face.
Awareness, referral & timely enrollment in early intervention programs can help infants thrive and grow.
NCFIH National Coalition for Infant Health
www.infanthealth.org
Visit CDC.gov to find contact information for your state's early intervention program.


WHY INFANTS NEED THE
Vitamin K Shot
Newborn babies need vitamin K to help with proper blood clotting and protect them from vitamin K deficiency bleeding.
This type of bleeding is dangerous and can lead to:
Internal bleeding, including in the brain and other organs
Brain damage
Death
One out of every five babies with vitamin K deficiency bleeding dies.
Babies don't get vitamin K from their moms before they are born.
But vitamin K deficiency bleeding is easily preventable with a shot at birth.
Newborns who do not get a vitamin K shot are 81 times more likely to develop severe bleeding.
The vitamin K shot is:
Safe and effective
Routinely given to newborns
Recommended by the American Academy of Pediatrics
Not a vaccine
Protect infants from life-threatening bleeding with a vitamin K shot at birth.
National Coalition for Infant Health

Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications



Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.



Reduce Your Use

There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- Use smaller amounts
- Use less often
- Learn how to use safer

Reducing or quitting smoking is a good place to start. Set your goals, then ask for help.
One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.



Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery



Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

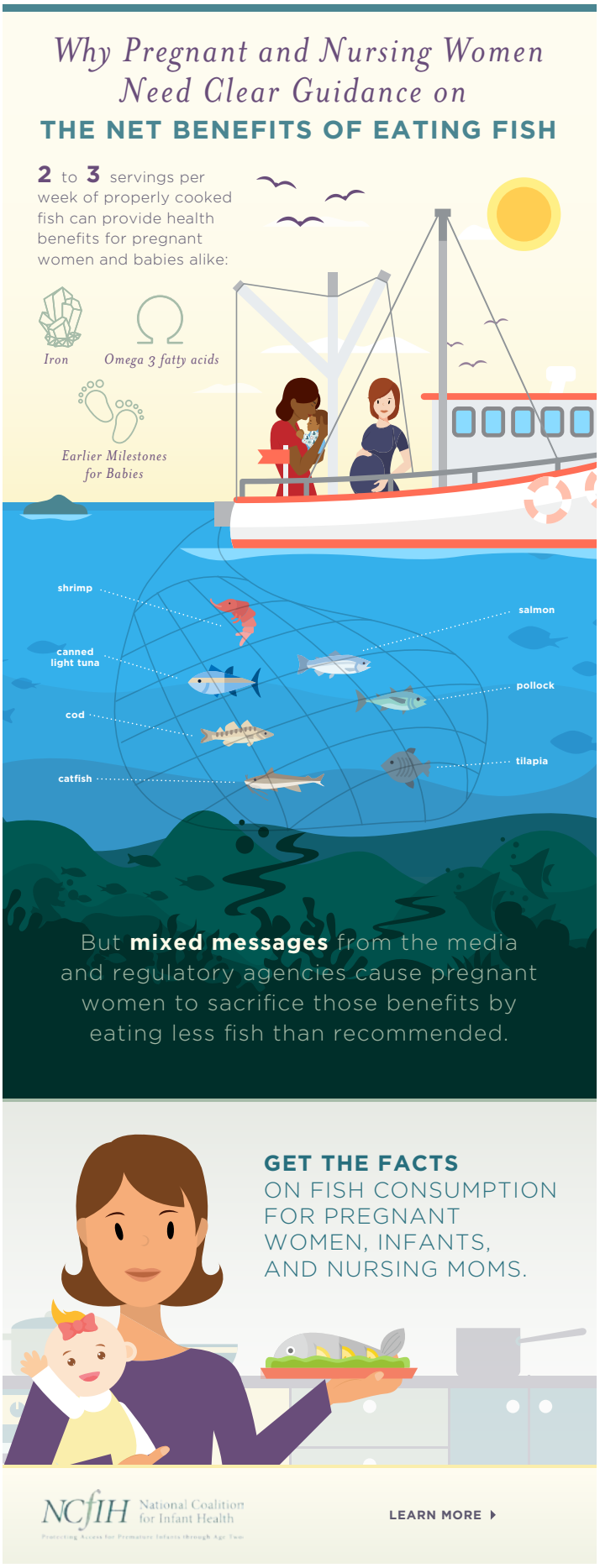
- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- Surround yourself with people who care

Your Health Matters

Academy of Perinatal Harm Reduction

National Perinatal Association

www.perinatalharmreduction.org | www.nationalperinatal.org



SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA





EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

- **S** EEK PARTICIPATION
- **H** ELP EXPLORE OPTIONS
- **A** SSESS PREFERENCES
- **R** EACH A DECISION
- **E** VALUATE THE DECISION





TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY



NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.

nann.org nationalperinatal.org

National Association of Neonatal Nurses

National Perinatal Association

Fragile Infant Forums for Implementation of IFCDC Standards: Alignment of The Occupational Therapy Practice Framework and the IFCDC Standards, Competencies and Best Practices

Rosemarie Bigsby, ScD, OTR/L, FAOTA; Jennifer Hofherr MS, OTR/L, CNT; and Debra Paul, BS, OTR/L



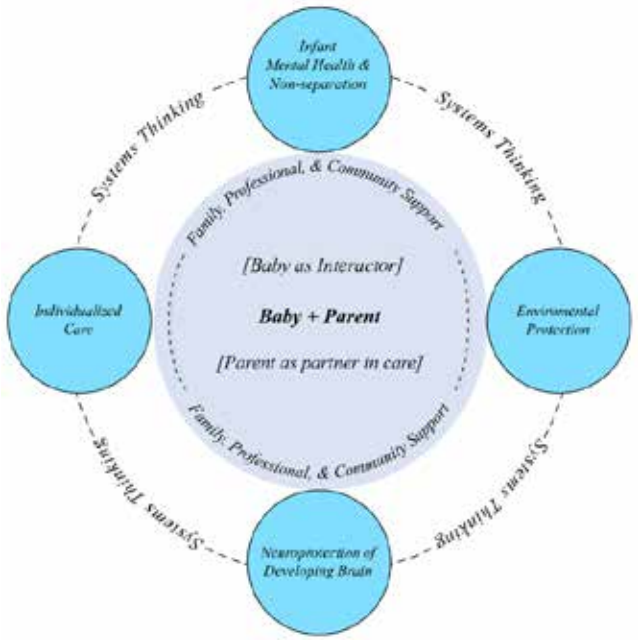
***"This article describes the principles and conceptual models shared by the Standards, Competencies, and Recommended Best Practices for Infant and Family-Centered Developmental Care in the Intensive Care Unit (2020) (https://nicudesign.nd.edu/nicu-care-standards/ifcdc) and the* Occupational Therapy Practice Framework: Domain and Process."**

Developmentally supportive care practices in the NICU have evolved in parallel with the growing evidence base for occupational therapy practice (1) and the availability of updated standards for developmentally supportive care (2, 3). Occupational therapy practitioners (OTPs) have a long history of supporting high-risk infants and families as members of the neonatal intensive care unit (NICU) team, as well as in follow-up care and early intervention. Additionally, a literature review reveals decades of contributions by occupational therapists to education, research, and development of clinical practice standards for developmentally supportive care in the NICU (4–10). This article describes the principles and conceptual models shared by the Standards, Competencies, and Recommended Best Practices for Infant and Family-Centered Developmental Care in the Intensive Care Unit (2020) (https://nicudesign.nd.edu/nicu-care-standards/ifcdc) and *Occupational Therapy Practice Framework: Domain and Process* (11). Recent reviews and studies from the occupational therapy literature are also highlighted, showing congruence with the Infant and Family-Centered Developmental Care (IFCDC) standards.

Alignment of Occupational Therapy Practice Framework and the IFCDC Standards, Competencies, and Best Practices:

The IFCDC Core Principles provide a foundation for developmentally supportive NICU practice, as illustrated in the IFCDC Concept Model (Figure 1): Baby and parent are at the model's core, with parents as partners in care and the baby as communicator/interactor with caregivers. They are appropriately surrounded by professional and community support. When designing specific guidelines and procedures for developmentally supportive care, systems thinking ties the foundational pillars of developmental support (Infant Mental Health & Non-Separation, Neuroprotection of the Developing Brain, Individualized Care, and Environmental Protection) together, so that no single principle is implemented in isolation

Figure 1. Conceptual IFCDC Model



Six practice domains contribute to the growing evidence base supporting IFCDC as a valid approach to NICU care (12). The IFCDC Standards associated with the practice domains

include evidence-based competencies for NICU team members (including parents), recommended action/implementation items for best practices, and examples of metrics/measures that NICU teams can utilize to evaluate their success. Each practice domain emphasizes the vital role of parents and family in implementing a neuroprotective approach to care. This approach is individualized to meet the needs and tolerances of each infant and the needs and preferences of the parents. To implement these recommendations effectively, the interprofessional team must continually adjust the NICU care plan based on each infant's behavior, which communicates their sensory input and stress threshold. This includes accommodating the infant's medical condition and recognizing the parents' and family's unique priorities and desires.

"Six practice domains contribute to the growing evidence base supporting IFCDC as a valid approach to NICU care. The IFCDC Standards associated with the practice domains include evidence-based competencies for NICU team members (including parents), recommended action/implementation items for best practices, and examples of metrics/measures that NICU teams can utilize to evaluate their success."

The Practice Domains for the IFCDC Standards are:

- Systems Thinking in Complex Adaptive Systems
- Positioning and Touch for the Newborn
- Sleep and Arousal Interventions for the Newborn
- Skin to Skin Contact with Intimate Family Members
- Reducing and Managing Pain and Stress in Infants and Families
- Management of Feeding, Eating, and Nutrition Delivery

Both the IFCDC principles and practice domains are in close alignment with the American Occupational Therapy Association (AOTA)'s publication *Occupational Therapy Practice Framework: Domain and Process* (11), AOTA's white papers on the specialized knowledge and skills required for OTPs in the NICU (7), and the role of occupational therapists in the NICU (8). In particular, the occupational therapy evidence-based practice domains are areas of NICU practice where occupational therapists routinely engage in assessment, intervention, and research.

The Occupational Therapy Practice Framework: Domain and Process:

The primary focus of occupational therapy is to promote the capacity to participate as fully as possible in purposeful, meaningful activities that are integral to each individual's specific age and stage of life. In other words, the *domain* of occupational therapy is to assist in fulfilling occupational roles that address the individual's self-identified needs and values. Identifying individual strengths and challenges to participation within the performance context is an ongoing component of the occupational therapy *process*.

Individuals experiencing illness or dysregulation in medical, neurodevelopmental, musculoskeletal, physiological, cognitive, psychological, or social-emotional functions, or other circumstances that disrupt their ability to perform their occupational roles may benefit from occupational therapy services. Careful observation, age and stage-related functional evaluation, focused client-family centered interventions, and a process-oriented analytical approach to assessment and intervention are foundational to achieving the desired functional outcomes. Figure 2 demonstrates the multifaceted Occupational Therapy Domain and Process model with several areas consistent with IFCDC Principles.

"Both the IFCDC principles and practice domains are in close alignment with the American Occupational Therapy Association (AOTA)'s publication Occupational Therapy Practice Framework: Domain and Process, AOTA's white papers on the specialized knowledge and skills required for OTPs in the NICU, and the role of occupational therapists in the NICU. In particular, the occupational therapy evidence-based practice domains are areas of NICU practice where occupational therapists routinely engage in assessment, intervention, and research."

Integral to the transaction among the components of the occupational therapy domain (infant, family, contextual, performance, and co-occupational factors) and process components (evaluation, intervention, and outcomes) is the overarching pursuit of "health, well-being, and participation in life through engagement in occupation" (11 p. 5).

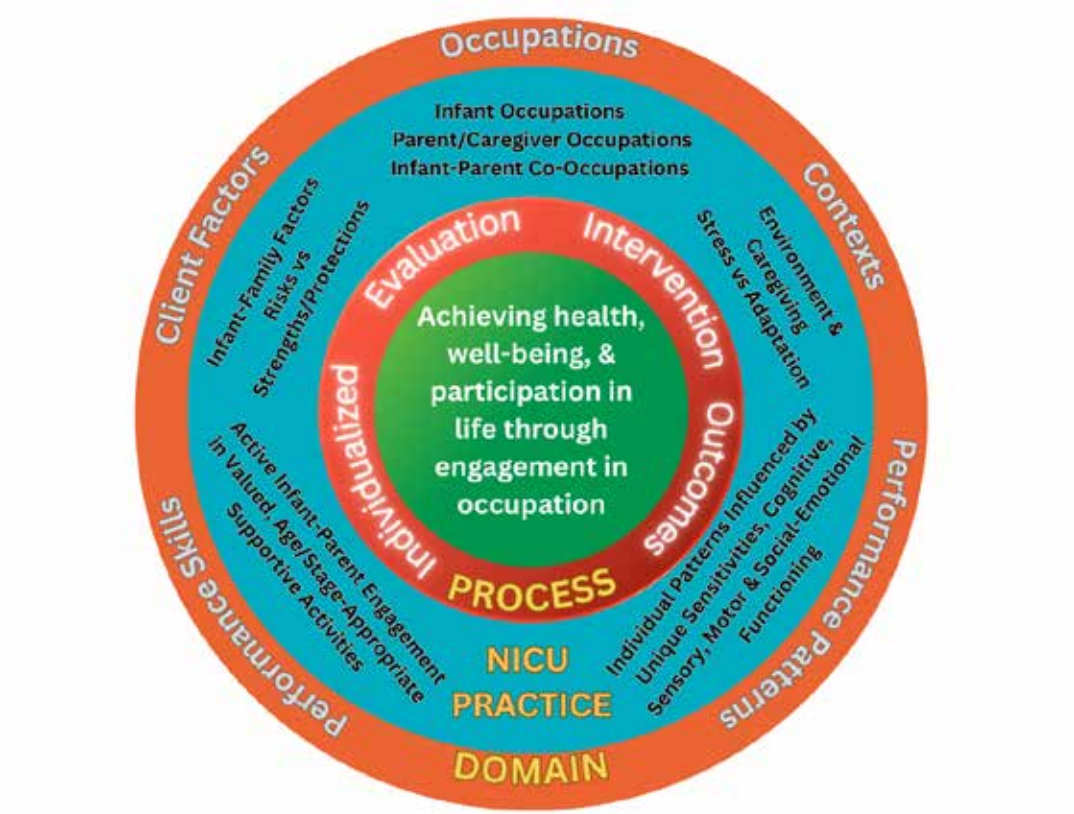
Cornerstones of Occupational Therapy NICU Practice:

The cornerstones of occupational therapy practice are core values and beliefs rooted in occupation, knowledge of and expertise in the therapeutic use of occupation, professional behaviors and dispositions, and therapeutic use of self.

Contributors to the integrity of those cornerstones (11 p. 6) are also integral to NICU practice, including:

- client-centered practice,

Figure 2. Occupational Therapy Domain and Process Model (2020). Adapted to include elements of NICU practice, used with permission.



- clinical and professional reasoning,
- competencies for practice,
- cultural humility,
- ethics,
- evidence-informed practice,
- inter- and intraprofessional collaborations,
- leadership,
- lifelong learning,
- micro and macro systems knowledge,
- occupation-based practice,
- professionalism,
- professional advocacy,
- self-advocacy,
- self-reflection, and
- theory-based practice.

Many value-based contributors to occupational therapy practice are consistent with the IFCDC Systems Thinking in Complex Systems Standards.

Identifying Barriers and Contributors to Successful Infant-Parent Co-Occupations

"The primary focus of occupational therapy is to promote the capacity to participate as fully as possible in purposeful, meaningful activities that are integral to each individual's specific age and stage of life."

The context for NICU care includes factors related to the infant, the family, and the NICU environment, including infant and family factors that may influence capacity for engagement in developmentally supportive care (13). Such infant and family factors frequently exist on a continuum, representing barriers (degrees of risk) or contributors (protection) to successful engagement and participation. Many elements that could impose varying degrees of risk or stress include fetal prenatal and perinatal conditions, family physical and mental health, family dynamics, gestational age at birth, infant medical acuity, characteristics of the NICU environment and the home or socio-economic factors such as family education, income and access to necessary resources by family and staff (14). Elements that may contribute to healthier infant-family outcomes also exist on a continuum. They include parent availability for participation and level of engagement, sensitivity of parents and caregivers to

the infant's physiologic stability, and behavioral communication. Preparedness for discharge from the NICU and parent resiliency may also contribute to healthier outcomes (15).

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To demonstrate the continuum of protection and/or risk in infant and parent occupations in the NICU, the following evidence-based studies that coincide with the IFCDC standards are described. Cardin (9) used thematic analysis of semi-structured interviews and infant-parent observations to develop a matrix of typical *parent occupations* (e.g., providing practical, instrumental support to meet a routine need, such as diapering), *infant occupations* (e.g., looking, listening, seeking attention), and *parent-infant co-occupations* (e.g., skin-to-skin holding, face-to-face interaction, engaging in synchronous feedings together, where the parent is following infant behavioral and physiologic cues). Parent comments reveal the richness of infant-parent co-occupations and reflect their inherent synchronous quality, co-sensitivity, and potential to enhance infant-parent connection and competency.

In addition to identifying common barriers to co-occupations, Stovall, et al., (10) identified contributors to successful co-occupations, including family-centered NICU design, good communication with NICU staff, physical contact with infant, parental involvement in caregiving, positive psychological wellness of parents, parenting education and peer support, and establishing new parental roles (i.e., stressing the importance of caregiving that only parents can provide, such as providing breast milk and skin to skin holding). These elements represent opportunities for evidence-based NICU-based interventions (15–17) and can strengthen occupational performance among infants, their families, and NICU caregivers. Thus, infant growth and development, as well as infant-parent emotional connection, can be enhanced.

Occupational Therapy Domain, Process, and Core Values Consistent with IFCDC Principles:

Systems Thinking in Complex Adaptive Systems

The NICU is a complex medical environment where life-saving care converges with life-altering events, capable of profoundly impacting newborns, their parents, and families, and the interprofessional medical staff caring for them. The IFCDC Standards for Systems Thinking in Complex Environments provide a dynamic systems framework for hospitals and NICU teams, including families and occupational therapy practitioners. They aim to address risk factors and enhance supports to work toward optimal infant-family outcomes. The transactional systems model that is described in *Occupational Therapy Practice Framework: Domain and Process* (11) and utilized by occupational therapy practitioners in the NICU (8) and elsewhere is an example of systems thinking.

Occupational therapy practitioners utilize a systems approach that includes analyzing performance patterns, adapting task sensory-motor demands, and modifying aspects of the performance context. This approach can enhance skills and functional performance.

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Strategies for implementation of the Standards for Systems Thinking in Complex Environments include a variety of elements, including:

- A commitment to individualized IFCDC at every level of the organization
- Analysis of existing procedures and standards using logic models to identify strengths and gaps in the model of service delivery
- Reflection on current practice concerning best practice recommendations
- Prioritizing staff and parent education to establish initial competencies
- Utilizing metrics and measures to assess competency
- Providing regularly scheduled, updated education
- Routine repeated measures to ensure fidelity to the established organizational commitment

The NICU occupational therapy practitioner possesses a comprehensive understanding of how these multidimensional environmental context elements can affect the physical and emotional well-being of both the infant and the family, both in the short and long term (18–19).

Infants as active communicators

Infant occupations have been defined as participation in any task or activity valued and expected by the infant's family or the NICU culture. Infant occupations can be further defined by their developmental function: procuring/soliciting care (e.g., communicating the need to be fed or to be soothed), socially

interacting, and exploring (e.g., engaging the senses to learn about the environment) (20). Co-occupations are shared, interdependent, transactional relationships in which each member of the dyad influences the actions of the other (9). Recognizing infants as active participants in their care enhances parents' ability to engage in co-regulatory interactions with their infants, in other words, co-occupations. "Shared physicality, shared emotionality, and shared intentionality" (21, p.151) are hallmarks of co-occupational relationships. Significantly, when infants and parents are engaged in co-occupations, parents recognize infants as active communicators and participants in their care, and infants look to parents for sensitive responses to their behavior.

Parents as partners in the care of their baby

From the moment an infant requiring NICU care is born, challenges to family participation in their baby's care begin. Ensuring the physiologic stability and well-being of newborns and their mothers is paramount while at the same time facilitating each parent's parental role (22). Partnering with parents to promote their role in caring for their baby is an expected standard of care across disciplines.

Parents may experience a loss of previous occupational roles (e.g., professional standing, engagement in relationships, and even leisure activities) that are personally meaningful and fulfilling to them during their infant's prolonged NICU stay. Occupational therapy practitioners may address these as part of their interventions with parents as part of their supportive care (23). Co-occupational supports can function as protective factors for the infant and family (16), improving infant and family outcomes (24,17).

Family, professional, and community support

The IFCDC standards recommend that perinatal and NICU teams train together to establish a shared mental model of care and include interprofessional simulation training (25). Parents should be provided with early preparation for the challenges they are likely to face.

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Promotion of infant-parent co-occupations can be enhanced in the NICU by assisting parents and other staff in several ways. The OTP on the NICU team partners with parents and other interprofessional caregivers to make practice domain assessments and to recommend possible next steps in the care plan. Attention to the infant's physiologic and behavioral communication, and respect for signs of stress, pain, and/or comfort enable parents and caregivers to modify the infant's care accordingly. These modifications can enhance the infant's neuro-behavioral and physiologic organization and energy conservation while optimizing the potential for infant-parent comfort and connection.

Although interventions by occupational therapy practitioners in the NICU are rarely "hands-on," they are most often planned and performed in concert with rather than to the infant patients, their parents, and their interprofessional caregivers, in keeping with IFCDC Standards (22). Examples of co-occupational caregiving activities may include participation in:

- two-person caregiving (facilitated tucking)
- skin-to-skin or in-arms holding during procedures
- soothing
- feeding
- bathing
- regulating states of sleep and states of arousal to participate in infant-caregiver interaction

These interactive caregiving experiences may benefit from the OTP's performance analysis and modification of the performance context (sensory, motor, and psychosocial components) in collaboration with the NICU team (parents and interprofessionals).

"Parent interviews and/or assessments (e.g., Clinical Interview for Parents of High-Risk Infants [CLIP]) can be used in collaboration with other professionals to better understand parents' impressions of the NICU environment. The results can further inform the occupational therapy process, providing valuable insights into parents' capacity for coping with the stress of having a baby in the NICU, as well as their self-identified values, hopes, and preferences."

Perceived barriers to parent participation in their baby's care may contribute to feelings of helplessness and depression among NICU parents (26). OTPs often utilize additional collaboration with mental health practitioners to learn parents' priorities and unexpressed concerns. Parent interviews and/or assessments (e.g., Clinical Interview for Parents of High-Risk Infants [CLIP] [27]) can be used in collaboration with other professionals to better understand parents' impressions of the NICU environment. The results can further inform the occupational therapy process, providing valuable insights into parents' capacity for coping with the stress of having a baby in the NICU, as well as their self-identified values, hopes, and preferences.

Consistency in family participation and parent education throughout the NICU stay and during the transition home is

emphasized, as these practices strengthen family competencies, reinforce their role as the constant in the infant's life, and establish trust between families, the NICU interprofessional team and community service providers following discharge (28–31). Thus, OTPs are among several key interprofessional team members with the knowledge and expertise to positively impact both short and long-term developmental and infant-parent social-emotional outcomes.

"The IFCDC practice domains (articulated in a previous section) detail the evidence-based rationale, best practices, competencies, implementation strategies and metrics/measurements required to achieve optimal Infant and Family-Centered Developmental Care. All are within the practice domain of occupational therapy in the NICU."

Alignment of IFCDC Domains of Practice and Occupational Therapy Practice in the NICU:

The IFCDC practice domains (articulated in a previous section) detail the evidence-based rationale, best practices, competencies, implementation strategies and metrics/measurements required to achieve optimal Infant and Family-Centered Developmental Care. All are within the practice domain of occupational therapy in the NICU.

Introducing co-occupational caregiving experiences, such as those described in the practice domains, requires careful preparation and planning. Factors that must be considered include:

- Specific analysis of the degree of organization of states of arousal (e.g., ability to sustain a quiet alert state)
- Postural/motor capacities (e.g., head control, muscle tone)
- Type of sensory input (e.g., gustatory, touch, vestibular, auditory, or visual)
- Timing, intensity, and duration of the experience
- Physiological regulation and energy requirements
- Skills required by the infant (32), as well as the parent or staff member

Joint observations with parents and caregivers, including anticipatory guidance concerning the developmental significance of certain aspects of infants' states of arousal and behavioral communication before, during, and after caregiving interactions, are integral to the occupational therapy evaluation and intervention process (33). These types of observations also are hallmarks of current, evidence-based interprofessional approaches to NICU assessment and intervention, such as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (34), Family Nurture Intervention (FNI) (35), Family Integrated Care (FiCare) (36), and Close Collaboration With Parents (37, 38). These approaches are based upon shared observations, including the use of validated assessments such as NIDCAP (39) and APIB (40). NNNS (33, 41, 42), parents and professionals can partner to plan individualized care plans. Standardized therapy intervention programs have demonstrated limited impact on infant neurobehavioral outcomes (i.e., lower lethargy scores on the NNNS) and reduced parent anxiety scores (43). In contrast, individualized approaches to assessment, education, and intervention with and by parents have been demonstrated to be related to improved long-term parent sensitivity, parental role identity and satisfaction, and infant neurodevelopmental, motor, cognitive, social emotional, and executive functioning outcomes (44, 45, 12, 46, 47).

"Joint observations with parents and caregivers, including anticipatory guidance concerning the developmental significance of certain aspects of infants' states of arousal and behavioral communication before, during, and after caregiving interactions, are integral to the occupational therapy evaluation and intervention process. These types of observations also are hallmarks of current, evidence-based interprofessional approaches to NICU assessment and intervention"

Conclusion:

The IFCDC Conceptual Model, Standards, Competencies, and Best Practices provide specific, evidence-based recommendations for implementation and success measures consistent with Occupational Therapy's Practice Framework: Domain and Process and core values. The alignment is particularly demonstrated in the IFCDC principles of complex systems thinking, parent partnership, the infant as an active communicator, family/caregiver, and community support. The occupational therapy practitioner applies a holistic, transactional systems model toward enhancing co-occupational performance of infants and caregivers, within the context of the complex NICU care environment, showing the importance of occupational therapy's contributions to the NICU team.

The ultimate goals of occupational therapy practice in the NICU are to strengthen infant-parent relationships through participation in essential caregiving activities and to adapt components of activities to ensure individualized, developmentally supportive care. Caregiving approaches are adapted to optimize the baby's comfort and stability and to enhance infant/parent participation and competency in performing their occupational roles. Occupational therapy practitioners strive to achieve a level of challenge consistent with individual infant and family capacities and priorities while ensuring safety, comfort, and caregiver

confidence and competence. These points of emphasis illustrate a synergy between the IFCDC Standards, Competencies, and Best Practices and occupational therapy practices in intensive care for babies and families.

"The ultimate goals of occupational therapy practice in the NICU are to strengthen infant-parent relationships through participation in essential caregiving activities and to adapt components of activities to ensure individualized, developmentally supportive care."

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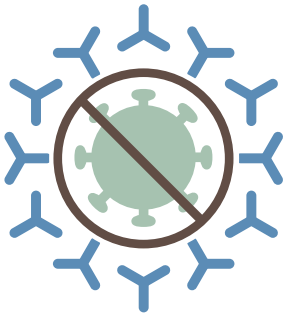
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You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

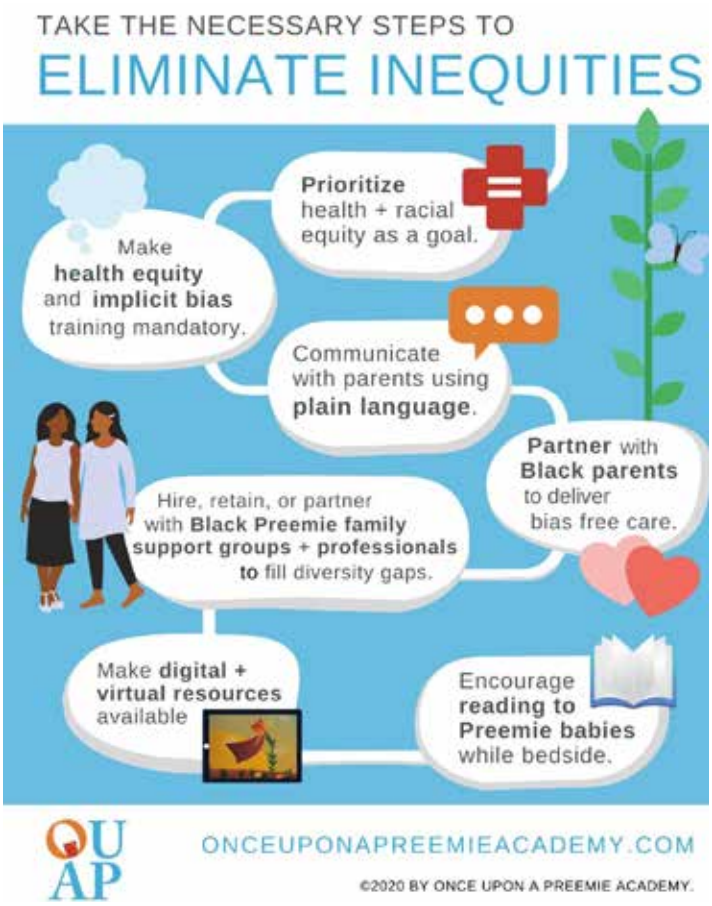
Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.

WE CAN HELP PROTECT EACH OTHER.

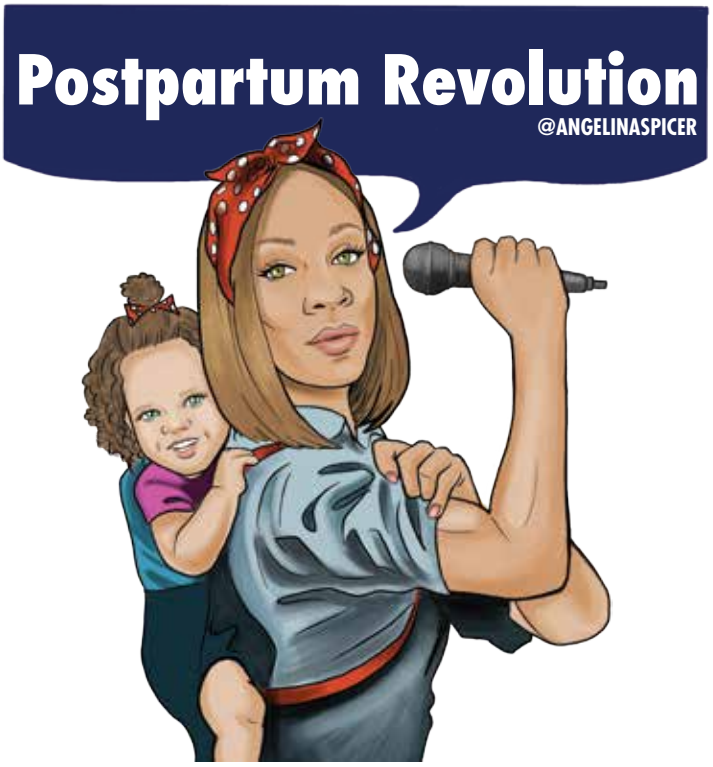
National Perinatal Association

www.nationalperinatal.org/rsv



The Gap Baby: An RSV Story





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COVID-19

National Network of NICU Psychologists
FREE for our NICU COMMUNITY
- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



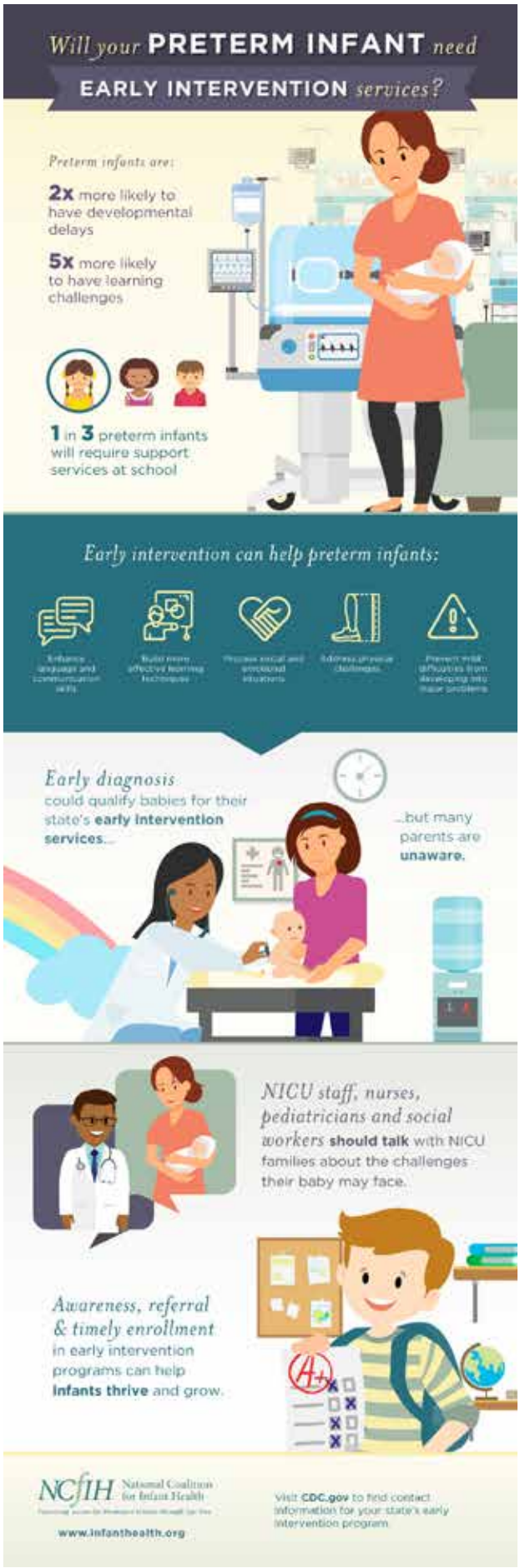
Download at www.nationalperinatal.org/psychologists

The National Urea Cycle Disorders Foundation



The NUCDF is a non-profit organization dedicated to the identification, treatment and cure of urea cycle disorders. NUCDF is a nationally-recognized resource of information and education for families and healthcare professionals.

www.nucdf.org | Phone: (626) 578-0833



Neonatology Today's Digital Presence

Neonatology Today's now has a digital presence. The site is operational now and defines the future look of our digital web presence. By clicking on this https://www.neonatologytoday.org/web/., researchers can download individual manuscripts both in digital format and as part of the original PDF (print journal). While the PDF version of Neonatology Today will continue in its present form, we envision that the entire website will be migrated to this format in the next several months. We encourage you to take a look, "kick the wheels," and let us know where we still need to improve.. We are working towards making the website more functional for subscribers, reviewers, authors and anyone else. Although we have not yet applied for inclusion in the National Library of Medicine Database (Pub-Med), this new format meets several of the important metrics for this ultimate goal. As of December, 2020, NT has its own account with CrossRef and will assign DOI to all published material.

As we indicated last month, we look forward to a number of new features as well.

1. An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.
3. An archive search will be available for journals older than 2012.
4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

Neonatology Today will continue to promote our Academic True Open Model (ATOM), never a charge to publish and never a charge to subscribe.

If there are any questions about the new website, please email Dr. Chou directly at:

fu-sheng.chou@neonatologytoday.net

Readers can also follow

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Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

Hemolytic disease of the fetus & newborn is a rare blood disorder.

When the mother's and infant's blood types are incompatible, the mother's antibodies attack the baby's red blood cells.





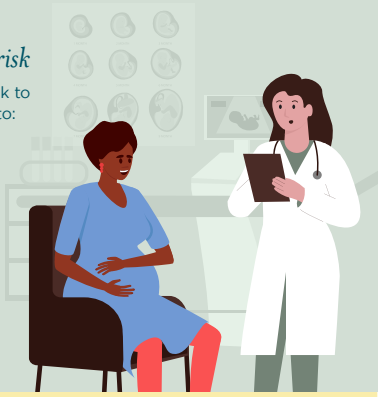
HDFN can lead to:

- **Severe anemia**
- **Jaundice**
- Fetal or infant **death**

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

- **Identify** potential blood incompatibilities
- **Monitor** the baby
- **Treat** the condition if it occurs



NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

LEARN MORE ▸

Which Infants are More Vulnerable *to Respiratory Syncytial Virus?*

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

AfPA Alliance for Patient Access

COVID-19

FREE for our NICU COMMUNITY

- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



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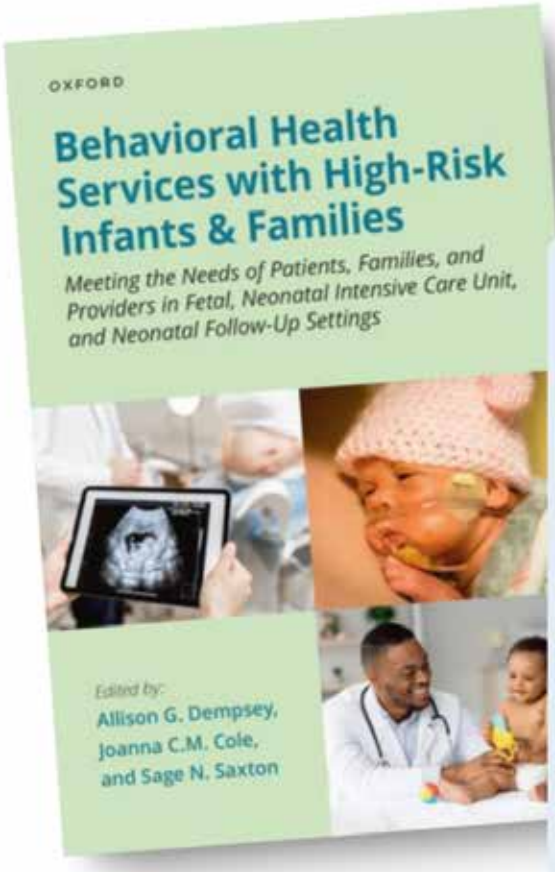
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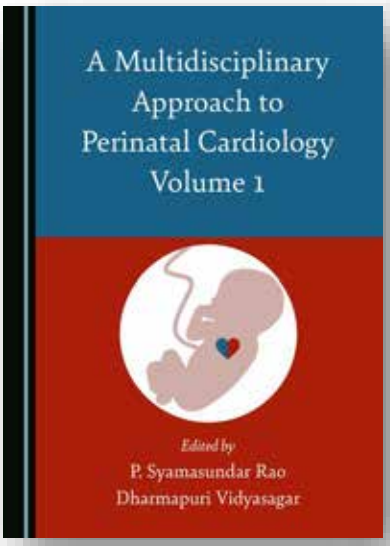
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A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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£99.99

Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

About the Editors

Dr P. Syamasundar Rao, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

Dr Dharmapuri Vidyasagar, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars website, where you can also access a free 30-page sample.

My NICU Network
My Perinatal Network

National Perinatal Association + NICU Parent Network

Online L&D Staff Education Program

Caring for Pregnant Patients & Their Families:

Providing Psychosocial Support During Pregnancy, Labor and Delivery

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Continuing education credits provided by

pac-lac

About the Program

- **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.

- **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.

- **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.

- **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

Program Objectives

- Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.
- Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.
- Define ways to support pregnant patients with high-risk conditions during the antepartum period.
- Describe obstetric violence, including ways that providers may contribute to a patient's experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.
- Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.
- Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.
- Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.

PROGRAM CONTENT



COMMUNICATION SKILLS CEUs offered: 1

Learn principles of trauma-informed care, use of universal precautions, how to support LGBTQ patients, obtaining informed consent, engaging in joint decision-making, delivering bad news, dealing with challenging patients.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, St. John's Regional Medical Center, Oxnard, CA; Karen Saxer, CNM, MSN, University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC; Tracy Pella, Co-Founder & President, Connected Forever, Tecumseh, NE.



PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

Identify risk factors for and differential diagnosis of PMADs (perinatal mood and anxiety disorders), particularly perinatal depression and/or anxiety and posttraumatic stress syndrome. Learn the adverse effects of maternal depression on infant and child development, and the importance of screening for and treating PMADs.

Faculty: Linda Baker, PsyD, psychologist at Unstuck Therapy, LLC, Denver, CO; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Brittany Boet, Founder of Bryce's NICU Project, San Antonio, TX.



PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

Identify psychosocial challenges facing high risk OB patients, and define how to provide support for them, whether they are inpatient or outpatient. Recognize when palliative care is a reasonable option to present to pregnant patients and their families.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPROM Foundation, Denver, CO.



PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients' experience of trauma; learn how to mitigate patients' trauma, and how to provide support during the process of labor and delivery.

Faculty: Sara Detlefs, MD, Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX; Jerry Ballas, MD, MPH, Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA; MaryLou Martin, MSN, RNC-NIC, CKC, Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC; Claire Hartman, RN, IBCLC, Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX; Erin Thatcher, Founder and Executive Director of The PPROM Foundation, Denver, CO.



PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients' experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don't get to go home with them.

Faculty: Amanda Brown, CNM, University of North Carolina Hospital, Chapel Hill, NC; ; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.



SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

Faculty: Cheryl Milford, EdS, Consulting NICU and Developmental Psychologist, Director of Development, National Perinatal Association, Huntington Beach, CA; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Erin Thatcher, BA, Founder and Executive Director, The PPROM Foundation, Denver, CO

Cost

- RNs: $10/CEU; $60 for the full program
- Physicians, licensed clinical social workers (LCSWs), licensed marriage and family therapists (LMFTs): $35/CEU; $210 for the full program
- Although PACLAC cannot award CEs for certified nurse midwives, they can submit certificates to their own professional organization to request credit. $35/CEU; $210 for the full program

Contact help@myperinatalnetwork.org to learn more.

Faculty

Linda Baker, PsyD
Psychologist at Unstuck Therapy, LLC, Denver, CO.

Jerasimos (Jerry) Ballas, MD, MPH
Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA.

Amanda Brown, CNM, MSN, MPH
University of North Carolina-Chapel Hill Hospitals, Chapel Hill, NC.

Sara Detlefs, MD
Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX.

Sue L. Hall, MD, MSW, FAAP
Neonatologist, Ventura, CA.

Claire Hartman, RN, IBCLC
Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC.

MaryLou Martin, MSN, RNC-NIC, CKC
Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC.

Cheryl Milford, EdS.
Former NICU and Developmental psychologist, in memoriam.

Karen Saxer, CNM, MSN
University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC.

Amina White, MD, MA
Clinical Associate Professor, Department of Obstetrics and Gynecology, University of North Carolina, Chapel Hill, NC.

Parent/Patient Contributers:

Brittany Boet
Founder, Bryce's NICU Project, San Antonio, TX.

Angela Davids
Founder, Keep 'Em Cookin', Baltimore, MD.

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Tracy Pella, MA
Co-Founder and President, Connected Forever, Tecumseh, NE.

Erin Thatcher, BA
Founder and Executive Director, The PPROM Foundation, Denver, CO.

CANCELLATIONS AND REFUNDS

- For Individual Subscribers:
  - If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
  - If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to help@myperinatalnetwork.com and individually approved.
- For Institutional Subscribers:
  - After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
  - Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

For Physicians: This activity has been planned and implemented in accordance with the Institute for Medical Quality and the California Medical Association's CME Accreditation Standards (IMQ/CMA) through the Joint Providership of the Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) and the National Perinatal Association. PAC/LAC is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing education for physicians. PAC/LAC takes responsibility for the content, quality and scientific integrity of this CME activity. PAC/LAC designates this activity for a maximum of 6 *AMA PRA Category 1 Credit(s)TM*. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the *CMA Certification in Continuing Medical Education*.

For Nurses: The Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing Provider CEP 5862. When taken as a whole, this program is approved for 7 contact hours of continuing education credit.

For CAMFT: Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LMFTs and LCSWs. CE Provider #128542. PAC/LAC maintains responsibility for the program and its content. Program meets the qualifications for 6 hours of continuing education credit for LMFTs and LCSWs as required by the California Board of Behavioral Sciences. You can reach us at help@myperinatalnetwork.org.

SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- **HORIZONTAL INFECTION**
- **SEPARATION AND TRAUMA**





EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

- **S** EEK PARTICIPATION
- **H** ELP EXPLORE OPTIONS
- **A** SSESS PREFERENCES
- **R** EACH A DECISION
- **E** VALUATE THE DECISION





TRAUMA-INFORMED

Both parents and providers are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

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Coping with COVID-19





A viral pandemic

A racial pandemic within a viral pandemic









Will mental illness be the next inevitable pandemic?

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NICU Parent Network

My Perinatal Network and My NICU Network
are products of a collaboration between NPA and NPN.
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Alliance for Patient Access: Regardless of the Season, RSV Vaccine Remains Important for Infants

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.

AfPA | Alliance for Patient Access

IfPA | Institute for Patient Access

"Respiratory virus season may be past its peak, but the flu, COVID-19, and respiratory syncytial virus all continue to pose risks to vulnerable infants."

Respiratory virus season may be past its peak, but the flu, COVID-19, and respiratory syncytial virus all continue to pose risks to vulnerable infants.

However, most eligible for vaccines to moderate these potentially deadly diseases have not received them. (1) Experts emphasize that getting vaccinated is not too late.

Protecting the Most Vulnerable:

Newborns and young infants face heightened risks from respiratory infections, including severe illness caused by respiratory syncytial virus. Fortunately, there are also multiple options for reducing the risk.

An RSV vaccine given to pregnant mothers offers critical protection to infants during the first few months of life. The immunity transferred from vaccinated mothers significantly minimizes their newborns' risk of severe respiratory illnesses.

"Moreover, for infants whose mothers do not receive the maternal RSV vaccine or those born prematurely or with underlying health conditions, a monoclonal antibody immunization can offer them an additional layer of protection."

Moreover, for infants whose mothers do not receive the maternal RSV vaccine or those born prematurely or with underlying health conditions, a monoclonal antibody immunization can offer them an additional layer of protection. These antibodies are designed to prevent severe infection and reduce the chances of hospitalization and death by 80-95%. (2)

The Role of Vaccines:

The Centers for Disease Control and Prevention recommends several vaccines for infants' first year of life to protect them from preventable illness. (3)

Even at the end of the season, the importance of immunization remains high. Immunization remains one of the most effective tools for reducing severe illness and protecting vulnerable populations, especially infants, from infectious diseases.

"Even at the end of the season, the importance of immunization remains high. Immunization remains one of the most effective tools for reducing severe illness and protecting vulnerable populations, especially infants, from infectious diseases."

By preventing hospitalizations, immunization reduces strain on health systems and communities. At the family level, preventive measures provide protection and peace of mind during a challenging, illness-filled season.

Policymakers Should Speak Up:

While healthcare providers should recommend vaccines for those at most significant risk, policymakers play a role in raising awareness about the safety and efficacy of vaccines.

By sharing information about the benefits of immunization for both infants and pregnant women, policymakers can encourage healthier communities. (4, 5)

Vaccinations and preventive treatments remain crucial in safeguarding the health of the youngest and most vulnerable.

References:

1. https://www.cdc.gov/respiratory-viruses/data/vaccination-trends.html
2. https://www.merck.com/news/mercks-clesrovimab-mk-1654-an-investigational-respiratory-syncytial-virus-rsv-preventative-monoclonal-antibody-significantly-reduced-incidence-of-rsv-disease-and-hospitalization-in-heal/
3. https://www.cdc.gov/vaccines/hcp/imz-schedules/child-adolescent-age.html
4. https://www.cdc.gov/vaccines/imz-schedules/child-easyread.html
5. https://www.cdc.gov/vaccines-pregnancy/about/index.html

Disclosure: *Josie Cooper is the Executive Director of the Alliance for Patient Access. This article was also published at healthpolicytoday.org.*

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Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms[1]
- Reduce disease transmission[3]
- Reduce risk of mortality[2]
- Make communities healthier and safer[4]

Understanding the Options

COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.

mRNA VACCINES

New to market, but research has been ongoing since the 1990s.

HOW THEY WORK: **Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.**

PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.[5]

Safe and Sound

COVID vaccines have been:

- **Thoroughly tested** through multi-phase trials with tens of thousands of participants[6]
- **Proven safe and effective** for adults as well as children[7]
- **Vetted and approved** by the US FDA and EMA and endorsed by the WHO[8-10]

Get Your Jab

Vaccines are available at your:

- **Doctor's office**
- **Neighborhood pharmacy**
- **Community health center**



Talk to your **health care provider** or **pharmacist** about which vaccine is right for you.

1. https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
3. https://www.nejm.org/doi/full/10.1056/nejmc2107717
4. https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683
5. https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html
6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
7. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
8. https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines
9. https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19/covid-19-vaccines-authorised
10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf

GAfPA Global Alliance for Patient Access

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Still a **Preemie?**

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

Just like preemies born much earlier, these "late preterm" infants can face:

Jaundice | Feeding issues | Respiratory problems

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**



Born preterm at a "normal" weight?

STILL A PREEMIE

Though these babies look healthy, they can still have complications and require NICU care.

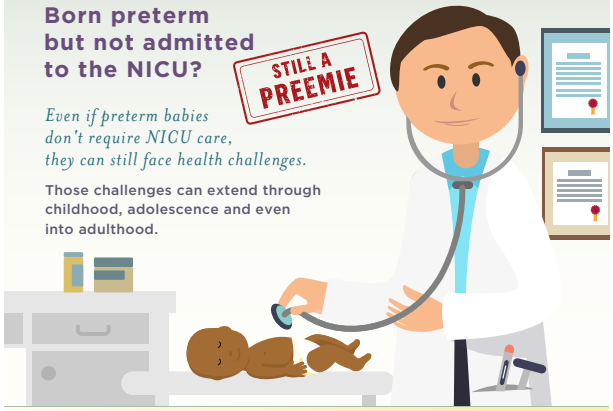
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.



Some Preemies

- Will spend weeks in the hospital
- Will have lifelong health problems
- Are disadvantaged from birth

All Preemies

- Face health risks
- Deserve appropriate health coverage
- Need access to proper health care

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

The Gap Baby: An RSV Story



A collaborative of professional, clinical, community health, and family support organizations improving the lives of premature infants and their families through education and advocacy.



The National Coalition for Infant Health advocates for:

- **Access to an exclusive human milk diet** for premature infants
- **Increased emotional support resources** for parents and caregivers suffering from PTSD/PPD
- **Access to RSV preventive treatment** for all premature infants as indicated on the FDA label
- **Clear, science-based nutrition guidelines** for pregnant and breastfeeding mothers
- **Safe, accurate medical devices** and products designed for the special needs of NICU patients

www.infanthealth.org

iCAN's April Highlights: Empowerment in Full Bloom

Sabina Schmidt Goldstein-Becerra

iCAN
International Children's Advisory Network

Get involved today and Join the iCAN Parent Council!

"On average, our youth are ages 8-18 years old, most of whom are living with chronic, rare, and complicated diagnoses, though a few of our youth have no medical diagnoses or medical conditions. iCAN values and understands that all patients, even the youngest, often have ideas that can help improve their healthcare experiences."

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide consortium of 40 KIDS' (Kids Impacting Disease through Science) advisory groups spanning four continents, including one virtual chapter, iCAN's dedicated youth member groups work in unison around the world to provide a voice for children and families in medicine, research, science, and innovation, to foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research. On average, our youth are ages 8-18 years old, most of whom are living with chronic, rare, and complicated diagnoses, though a few of our youth have no medical diagnoses or medical conditions. iCAN values and understands that all patients, even the youngest, often have ideas that can help improve their healthcare experiences. To foster diversity, all children from anywhere may freely join iCAN. iCAN also supports young adults and the voice of parents, many of whom have young people who cannot share their voices.

"We continue to be a collaboration between the American Academy of Pediatrics (AAP) Section on Advances in Therapeutics and Technology (SOATT), Georgia Institute of Technology (the GT Pediatric Innovation Network), local AAP Chapters, children's hospitals, local academia, and other nonprofits."

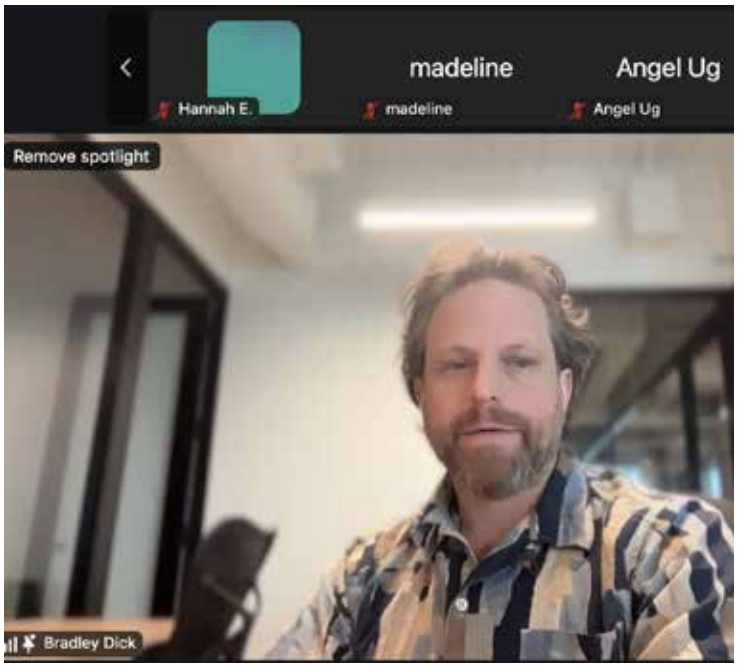
We continue to be a collaboration between the American Academy of Pediatrics (AAP) Section on Advances in Therapeutics and Technology (SOATT), Georgia Institute of Technology (the GT Pediatric Innovation Network), local AAP Chapters, children's hospitals, local academia, and other nonprofits. We aim to get our youth where they need to be to have their voices heard. Our amazing youth make a difference in pediatric healthcare through interactions with industry, by presenting original research at conferences, by innovating new solutions, by empowering the pediatric patient voice in healthcare worldwide, and by telling their stories at conferences and to organizations like the FDA, iACT, NIH, NORD, CDC, and AAP. Whether you are a patient, family member, healthcare professional, or supporter of the cause, we welcome you to visit our website at icanresearch.org to learn more about our mission, various programs, and initiatives. Join us to ensure that every child's voice is heard and that their unique experiences are taken into account to improve healthcare outcomes for all pediatric patients.

"Whether you are a patient, family member, healthcare professional, or supporter of the cause, we welcome you to visit our website at icanresearch.org to learn more about our mission, various programs, and initiatives."

Number of Projects with Kids and Parents Sharing Their Voices from January 2025 to April 2025: 8

Bradley, Co-Founder of zerodivide.ai, Champions Innovation Rooted in Empathy

Click Here to Watch the Full Episode



On April 26, Bradley, the co-founder of zerodivide.ai, joined our "Ask the Experts" session, a one-of-a-kind opportunity that brought iCAN Kids — children from all around the globe — together with leading innovators. Bradley's contribution was more than just an expert presentation; it was a heartfelt exchange of ideas, experiences, and vision, leaving a lasting impact on the participants.

zerodivide.ai, the organization Bradley co-founded, is dedicated to advancing technology for individuals with intellectual and developmental needs (I/DD). Their mission is to develop cutting-edge tools that empower people to live independently and express themselves authentically. However, for Bradley, this work is not just a professional goal — it's a personal mission. He shared with the audience that his inspiration comes from his son's journey with autism, a journey that drives everything he does at zerodivide.ai.

"zerodivide.ai, the organization Bradley co-founded, is dedicated to advancing technology for individuals with intellectual and developmental needs (I/DD). Their mission is to develop cutting-edge tools that empower people to live independently and express themselves authentically."

"Helping people find their voice isn't just a goal — it's a mission," Bradley shared during the session. "It's about giving people the chance to express themselves, to be heard, and to live life on their own terms."

These words resonated deeply with the iCAN Kids who tuned in from across the globe. For many, it was a powerful reminder that technology's true potential goes beyond just solving technical problems — it's about enabling individuals to live on their own terms. In a session where themes of independence, innovation, and meeting the needs of all were front and center, Bradley underscored that the best technological solutions are not those that do things for individuals but those that help them do things for themselves.

"It's not about creating technology that does things for them," he emphasized. "It's about creating technology that empowers them to do things for themselves."

This empowering perspective struck a chord with the attendees, as it framed technology not as a tool of dependency but as a partner in fostering autonomy. Bradley's message was clear: technology should not replace human capability but enhance it, allowing individuals to express their creativity, live independently, and contribute to society on their terms.

Bradley's insights also delved into the role of artificial intelligence (AI) in this process, sparking further reflection among the participants. While AI is often lauded for its potential to revolutionize industries, Bradley offered a balanced perspective on its limitations, reminding everyone that AI can support and enhance human creativity but can never replace the essence of what makes us human.

"AI can predict. It can enhance. But it can't create a Monet. It can't compose a Beethoven symphony," Bradley said. "The true spark — the true creativity — comes from people."

"This statement served as a timely reminder that while technology is advancing at an unprecedented pace, human creativity and ingenuity drive actual progress. AI, Bradley pointed out, should be viewed as a tool to amplify that creativity, not a replacement for it."

This statement served as a timely reminder that while technology is advancing at an unprecedented pace, human creativity and ingenuity drive actual progress. AI, Bradley pointed out, should be viewed as a tool to amplify that creativity, not a replacement for it. This shift in mindset is vital for ensuring that innovation remains aligned with human values and needs.

Bradley's leadership and vision for zerodivide.ai are truly monumental. He is not just building technology for innovation; he is creating tools that allow people to express themselves, embrace independence, and live fuller lives. His work is a testament to empathy's power in driving meaningful technological change.

Through his work, Bradley continues to impact lives in profound

ways, reminding us that the most effective innovations are those that are rooted in understanding, compassion, and a deep respect for human dignity.

If you are inspired by Bradley's message and want to be a featured speaker in one of our future sessions, do not hesitate to reach out! We always seek passionate individuals making a difference to share their knowledge and insights with the iCAN Kids.

Don't miss the opportunity to hear more about how zerodivide.ai is changing lives and why Bradley's approach to technology is setting a new standard for what it means to include everyone. Watch Bradley's full Ask the Experts session from 4/26 by clicking on the link above and learn how technology, when designed with empathy, can help create a world that empowers all.

Watch Bradley's Full Ask the Experts Session from 4/26

Want to be part of our next Ask the Experts session?

Please reach out to sabina@icanresearch.org.

Mark your calendars- iCAN invites you to another installment of *Ask the Experts* on May 3!

CP Strong: Finding Power in Your Story

Register Here



Upcoming Ask the Experts Session with Katy Gaastra

This May, we are honored to welcome Katy Gaastra, Founder and Executive Director of *Cerebral Palsy Strong* (CPstrong), to lead our next *Ask the Experts* (ATE) session. Join us for what promises to be a powerful conversation about the strength found in personal storytelling and the deep connections that can form through shared experiences.

"This May, we are honored to welcome Katy Gaastra, Founder and Executive Director of Cerebral Palsy Strong (CPstrong), to lead our next Ask the Experts (ATE) session. Join us for what promises to be a powerful conversation about the strength found in personal storytelling and the deep connections that can form through shared experiences."

Session

Details:

Date: Saturday, May 3, 2025

Time: 8:00 AM PST / 11:00 AM EST

Session Title: *CP Strong: Finding Power in Your Story*

Guest Speaker: Katy Gaastra

About Katy Gaastra

Katy Gaastra is a passionate advocate, storyteller, and community builder. As the founder of *Cerebral Palsy Strong*—a nonprofit organization led by and for adults with disabilities—Katy has created a space where individuals with disabilities, chronic illnesses, and rare diseases can unite, share their journeys, and find empowerment through connection.

Katy's professional path bridges both for-profit and nonprofit sectors, with significant experience in brand strategy, marketing communications, and community engagement. She earned her Bachelor of Arts in Liberal Arts from Soka University of America and a Master's in Media and Public Engagement from the University of Colorado, Boulder. Her work reflects a deep understanding of how authentic storytelling can shift narratives, dismantle isolation, and build lasting movements for change.

At CPStrong, Katy champions the idea that every story holds the potential to inspire resilience, solidarity, and healing. Through sharing her own experiences and uplifting the voices of others, she continues to transform the way we think about community and strength.

Whether you live with a condition, support someone who does, or are passionate about the power of human stories, this session promises to be an inspiring and unforgettable experience.

We hope to see you there!

iCAN KIDS Spotlight



Youth Spotlight: *Voices in Care*

A KIDS Central Ohio Initiative Amplifying Teen Voices in Healthcare

Teens from KIDS Central Ohio are making waves in the healthcare space—one episode at a time. Meet Tarun, Afraz, and Aayush, the passionate young minds behind *Voices in Care*, a new podcast initiative created in collaboration with iCAN. This team is committed to reimagining what youth participation in healthcare looks like—by ensuring young voices are heard, respected, and acted upon.

Launched as part of iCAN's KIDS Spotlight Series, *Voices in Care* provides a platform for teens to speak candidly about pressing issues in pediatric healthcare, research, and innovation. Through honest and insightful conversations, they aim to break down complex topics, challenge assumptions, and offer real-world solutions that families, educators, clinicians, and policymakers can act on.

Podcast Episodes

Episode 1: The Pediatric Mental Health Crisis & Interventions

In the debut episode, the team explores one of the most urgent challenges in pediatric healthcare today: rising mental health concerns among youth. From social media stress to professional care gaps, they highlight the root causes and the innovative interventions needed to create safer, more supportive environments for kids and teens.

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Episode 2: Pediatric Healthcare in the U.S.

This powerful episode takes a deep dive into disparities in pediatric care across the country. The team tackles tough topics—like rural hospital closures, insurance gaps, and cultural barriers—while exploring bold, practical solutions such as telehealth and community-based care models.

"The team tackles tough topics—like rural hospital closures, insurance gaps, and cultural barriers—while exploring bold, practical solutions such as telehealth and community-based care models."

Listen. Share. Act. Follow *Voices in Care* —and stay tuned for more inspiring episodes coming soon.

Grant Spotlight: KIDS Virtual Member Sanjana Awarded Wellness Grant from Hershey and YSA

NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com



We are excited to announce that Sanjana, a standout youth member from KIDS Virtual, has received a $250 grant through The Hershey Heartwarming Project in partnership with Youth Service America (YSA). This grant will support her youth-led initiative, which promotes personal wellness and health within her community.

Sanjana's project focuses on helping students understand the importance of both mental and physical well-being and encouraging them to apply these values throughout their lives. She aims to inspire students to invest in their personal growth and foster a positive impact in their schools and neighborhoods through wellness activities, resources, and tools.

With the support of Hershey and YSA, Sanjana's initiative is poised to promote youth wellness and inspire lasting change in her community.

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Congratulations to Sanjana on this remarkable achievement, and thank you to Hershey and YSA for their belief in the power of youth leadership.

Community in Action: KIDS Walter Payton Delivers 10 Care Packages to Ronald McDonald House



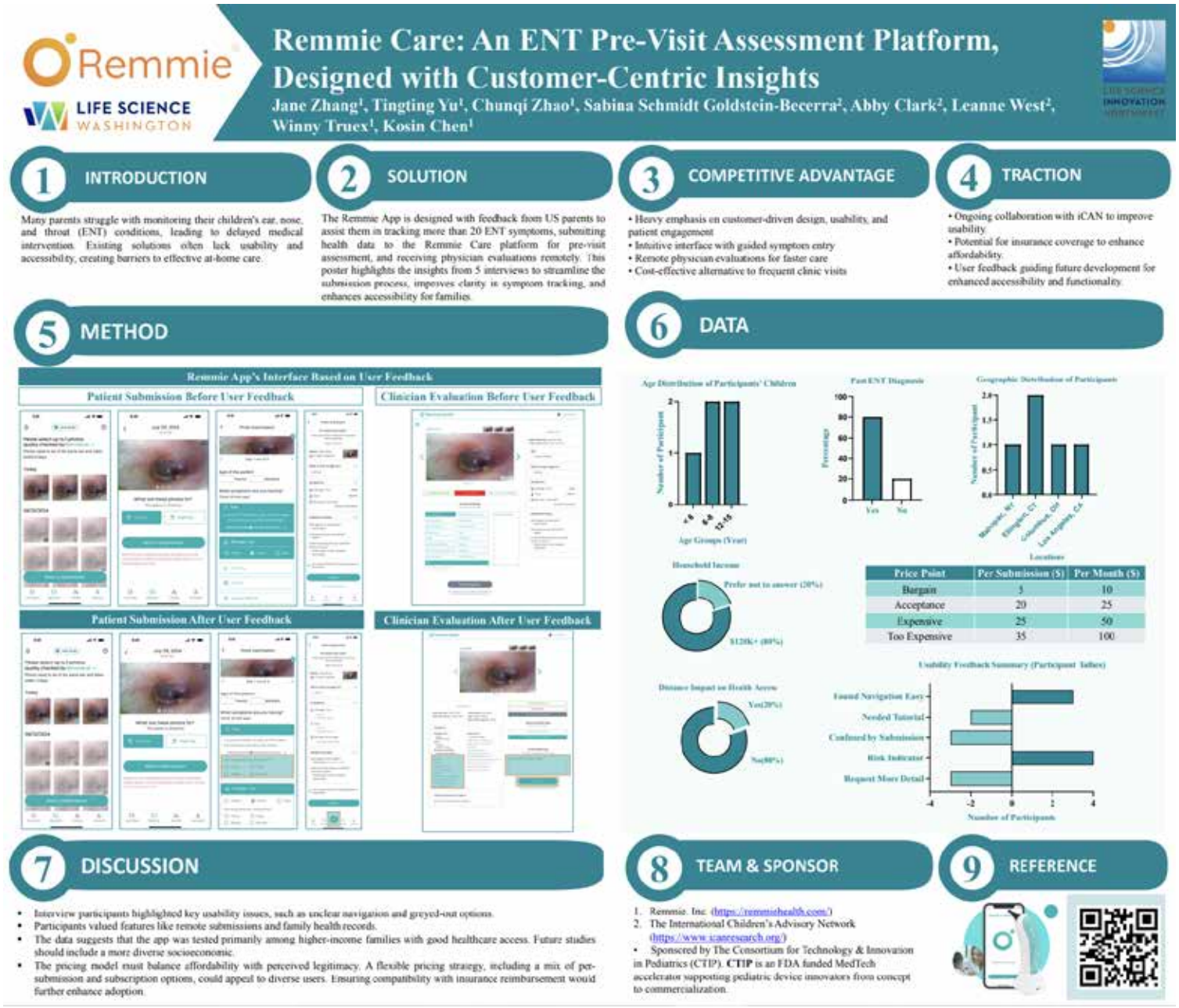
In April, youth members from KIDS Walter Payton completed the iCAN Challenge of 10 by assembling and delivering 10 care packages to the Ronald McDonald House near Lurie Children's Hospital in Chicago. This effort was part of a global challenge encouraging our youth to engage in meaningful acts of service and kindness.

Each care package was designed to comfort families staying at the House. The students included cozy socks, snacks, water bottles, journals, hygiene essentials, stress-relief toys, and handwritten notes of encouragement—small but meaningful items designed to offer relief during difficult times.

The Ronald McDonald House is just steps from Lurie Children's Hospital and provides a safe, welcoming space for families with hospitalized children. With 86 private guest rooms, shared kitchens, daily meals, play areas, and quiet spaces for rest, the House serves as a home away from home and a source of comfort and support for families when needed.

"The Ronald McDonald House is just steps from Lurie Children's Hospital and provides a safe, welcoming space for families with hospitalized children. With 86 private guest rooms, shared kitchens, daily meals, play areas, and quiet spaces for rest, the House serves as a home away from home and a source of comfort and support for families when needed."

During their visit, our members toured the facility with their guide, Nancy, who shared powerful stories about the families served and the importance of the House's work. The visit left a lasting impression on the group, offering insight into how small contributions can have a meaningful impact.



This project reflects KIDS Walter Payton's commitment to making a difference in their community and supporting those going through difficult experiences. The team worked collaboratively, thoughtfully, and with care—demonstrating the values at the heart of the iCAN Challenge of 10.

Thank you to Nancy for the warm and informative tour and everyone who helped make this project possible. Whether donating supplies, assembling packages, or offering encouragement, every contribution helped brighten someone's day.

You can catch the KIDS Walter Payton team on an upcoming episode of *Ask the Experts* this June, where they will share more about their chapter, their recent project, and how they continue to create positive change for others.

How iCAN Helped Bring Parent Voices to the Forefront of Pediatric Health Innovation

At Life Science Innovation Northwest 2025, Remmie Inc.'s presentation on its ENT Pre-Visit Assessment Platform stood out for a powerful reason: it was built with—and for—families. Moreover, the International Children's Advisory Network (iCAN) was at the heart of that effort.

As a global leader in elevating youth and parent perspectives in pediatric healthcare, iCAN partnered with Remmie to ensure that real families shaped the development of the Remmie App—a digital tool designed to help parents monitor their children's ENT symptoms and access remote physician assessments.

Five in-depth interviews with U.S. parents, supported by iCAN, identified pain points in the app's early interface—unclear navigation, confusing submission steps, and lack of guidance. Based on this direct feedback, Remmie redesigned the app to

ICAN
International Children's Advisory Network

ImpactFall 20 Fundraiser 24



improve symptom entry, streamline data sharing, and enhance overall usability.

This collaboration also underscored deeper issues in pediatric care: accessibility, affordability, and the digital divide. While most initial testers came from higher-income households, iCAN and Remmie are committed to expanding outreach to more diverse communities to reflect the full spectrum of family experiences better.

"This collaboration also underscored deeper issues in pediatric care: accessibility, affordability, and the digital divide. While most initial testers came from higher-income households,"

Our ongoing partnership with Remmie is just one example of how iCAN works to ensure that the voices of families—especially those caring for children with chronic, rare, or complex conditions—are not just heard but drive innovation.

By listening to parents, iCAN helped shape a tool that does not just track symptoms—it transforms care.

iCAN's 2025 Annual Summit

Presented by Jumo Health

The Delta Hotel

475 Av. du Président-Kennedy, Montréal, QC H3A 1J7, Canada

July 14-17

Register Here



Get ready for an unforgettable experience at the 2025 iCAN Summit in the vibrant city of Montreal! From July 14-17, join us at the incredible Delta Hotel (Marriott) in the heart of Montreal's entertainment district. This is your chance to be part of a movement shaping the future of pediatric healthcare- providing kids and their families with the opportunity to collaborate with researchers, innovators, clinicians, and industry leaders to drive change in the field from the ground up.

Our annual Summit is a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. We invite you to be part of this life-changing event by contributing in two meaningful ways:

1. Sponsor the 2025 Summit: Your sponsorship will ensure an impactful experience for all attendees.
2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit in Canada. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment.

Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—significantly impacts prioritizing the patient voice and driving positive change. Your generosity and dedication are deeply valued. Let us unite in Canada to create a summit experience that empowers the pediatric community for years to come.

Let us collaborate to make our 2025 Summit even bigger by bringing more kids to share their voices! To contribute to the funding for next year's Summit, please click here to sponsor or donate.

Disclosures: *There are no reported disclosures*

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Want to Strengthen your NICU's Safe Sleep Efforts?
LET'S TALK IN THE NICU: PREPARING FAMILIES FOR SAFE SLEEP AT HOME

HOW CAN ONE CONVERSATION CHANGE EVERYTHING?

Let's Talk Community Chats are now in the NICU—bringing culturally responsive, judgment-free safe sleep and breastfeeding education directly to families before discharge.

Led by **community peers trained by First Candle** and adhering to AAP Guidelines, these sessions empower NICU parents with knowledge, support, and resources to help protect their most vulnerable babies.



Learn how you can bring Let's Talk to your NICU.

Email alison@firstcandle.org for more information

firstcandle
LET'S TALK
Community Chats
IN THE NICU

11TH iCAN SUMMIT

iCAN 2025 Summit!

July 14 -17 (Plus a Celebratory Brunch on the 18th) in Montreal, Canada
The Delta Marriott, 475 Av. du Président-Kennedy, Montréal, QC H3A 1J7, Canada

Presented by Jumo Health, iCAN is excited to celebrate its 11th anniversary in the upcoming 2025 Summit. Get ready for a conference like no other with fun, friends, and awesome learning experiences in healthcare, research, and STEAM!

Registration is Open!

A Miracle in the NICU: Christina's Story of Survival, Strength, and the Power of a Mother's Love

Carolyn TenEyck, RN

"In 1986, when Christina Gagnon was born at just 25 weeks gestation, weighing only one pound and eight ounces, her odds of survival were a sobering 14 percent. A micro preemie born far too soon, she entered the world fighting and has not stopped since."

In 1986, when Christina Gagnon was born at just 25 weeks gestation, weighing only one pound and eight ounces, her odds of survival were a sobering 14 percent. A micro preemie born far too soon, she entered the world fighting and has not stopped since.

Now, nearly four decades later, Christina is a proud board member of GLO Preemies, on the advisory board of the Preemie World Foundation Inc., and a global advocate for NICU families. Her journey has inspired listeners across the UK and Australia through her as a podcast guest, and she earned the prestigious *Miracle Award* from Today is a Good Day, a parent support organization in Pennsylvania.

However, the story of Christina's survival is not defined by modern medical marvels like bedside cameras or discharge planning apps—it is about what it meant to survive *before* those existed. It is about grit, resilience, and the fierce love of a mother determined to defy the odds.

"However, the story of Christina's survival is not defined by modern medical marvels like bedside cameras or discharge planning apps—it is about what it meant to survive before those existed. It is about grit, resilience, and the fierce love of a mother determined to defy the odds."

A Birth No One Expected:

Joyce Gagnon, Christina's mother, had already endured the heartbreak of losing Christina's twin, a boy she named Michael, at 11 weeks. When she began experiencing intense pain and bleeding later in the pregnancy, she knew something was not right—even if doctors insisted otherwise.

"They kept telling me to just keep walking. But I couldn't walk five feet without doubling over," Joyce recalls. Her instincts proved right. Days after a brief getaway to Connecticut, her water broke. What followed was a whirlwind rush to Level III NICU.

"There were people yelling, doctors flying in and out of the room," she said. "It was terrifying."

A Tiny Fighter:

Christina was so small she could fit entirely in her mother's hand—her head resting on Joyce's wrist, her knees hanging over her fingertips. She was frail, her skin grayish-brown, and she was covered in tubes. Joyce was not allowed to hold her. "The only place I could touch her was over her eyebrow," Joyce said. "So I'd pet her gently and sing to her. To this day, when Christina's upset, she still asks me to stroke her eyebrow."

The NICU journey would stretch 212 days—every single one etched in Joyce's memory.

Three Battles with NEC:

Among the countless hurdles Christina faced, one of the most terrifying was *necrotizing enterocolitis (NEC)*—an excruciating condition affecting the intestines. Not once, but three separate times.

"I walked in, and she just looked... different," Joyce said. "I told the nurse, 'She looks shiny.' Her belly was bloated, and she had that glossy look. They did an X-ray and found bowel loops. The doctor said, 'Most adults don't survive this.'"

"Among the countless hurdles Christina faced, one of the most terrifying was necrotizing enterocolitis (NEC)—an excruciating condition affecting the intestines. Not once, but three separate times."

However, Christina did—three times.

Permanent Scars, Unbreakable Spirit:

Not all scars heal invisibly. A blood clot led to gangrene in Christina's foot, resulting in the loss of her toes and leaving her permanently disabled. Nevertheless, Christina, now an adult with a quick wit and a warm smile, will not let it define her.

"I can still walk, run, jump, drive—just a little slower than everyone else," she laughed. "But it's exhausting being handicapped. And you deal with people staring, judging, or questioning if you're really disabled."

"Not all scars heal invisibly. A blood clot led to gangrene in Christina's foot, resulting in the loss of her toes and leaving her permanently disabled. Nevertheless, Christina, now an adult with a quick wit and a warm smile, will not let it define her."

Still, she shares her experience openly, determined to educate others. "If you're going to make a mistake, make it on the side of education," Joyce tells her daughter. "Help them understand."

Life at Home, Interrupted:

The discharge did not bring peace—it brought even more upheaval. On the very day Christina came home, four therapists were waiting at the door unannounced. Physical therapy, occupational therapy, speech, and special education services began immediately.

"No one told us they were coming," Joyce said. "I didn't even get a chance to settle her in before they started working with her."

The Gagnons had little preparation for life after the NICU. Joyce had to re-teach Christina how to suck, curl her tongue, and even sit up—all skills most babies come pre-programmed with.

"The discharge did not bring peace—it brought even more upheaval. On the very day Christina came home, four therapists were waiting at the door unannounced. Physical therapy, occupational therapy, speech, and special education services began immediately."

Then and Now: How Far We Have Come:

Back then, there were no bedside cameras, apps guiding parents through discharge, or coordinated support networks. "Christina was everybody's baby," Joyce said. "I hardly got time alone with her."

Today, parents can rely on organizations like AngelEye Health and apps like NICU2Home to bridge the gap between the NICU and life after. Joyce marvels at the difference: "If I'd had a bedside camera, I would've stared at it all night."

The family remains close to Dr. Kathleen Meyer, Christina's neonatologist, who is proof of the powerful bonds forged in the crisis. "She spoke to me like a colleague," Joyce said. "She knew I was going to fight for my daughter with everything I had."

A Legacy of Love and Advocacy:

Joyce and Christina now advocate together, sharing their story so that other families feel less alone. They remind us how critical support is—not just for tiny patients, but for the parents thrust into chaos, often without a map.

"You're doing a wonderful thing," Joyce said to the AngelEye team. "I wish we'd had you back then. It would've saved so much heartache."

"Today, parents can rely on organizations like AngelEye Health and apps like NICU2Home to bridge the gap between the NICU and life after. Joyce marvels at the difference: 'If I'd had a bedside camera, I would've stared at it all night.'"

Christina is now a celebrated speaker and podcast guest on Dr.'s, Preemie Parents, and other medical-related podcasts as a guest sharing her story. She is also writing her story—literally. A book is in the works. When it hits the shelves, it will carry a message of survival, hope, perseverance, and unwavering love between a mother and her daughter.

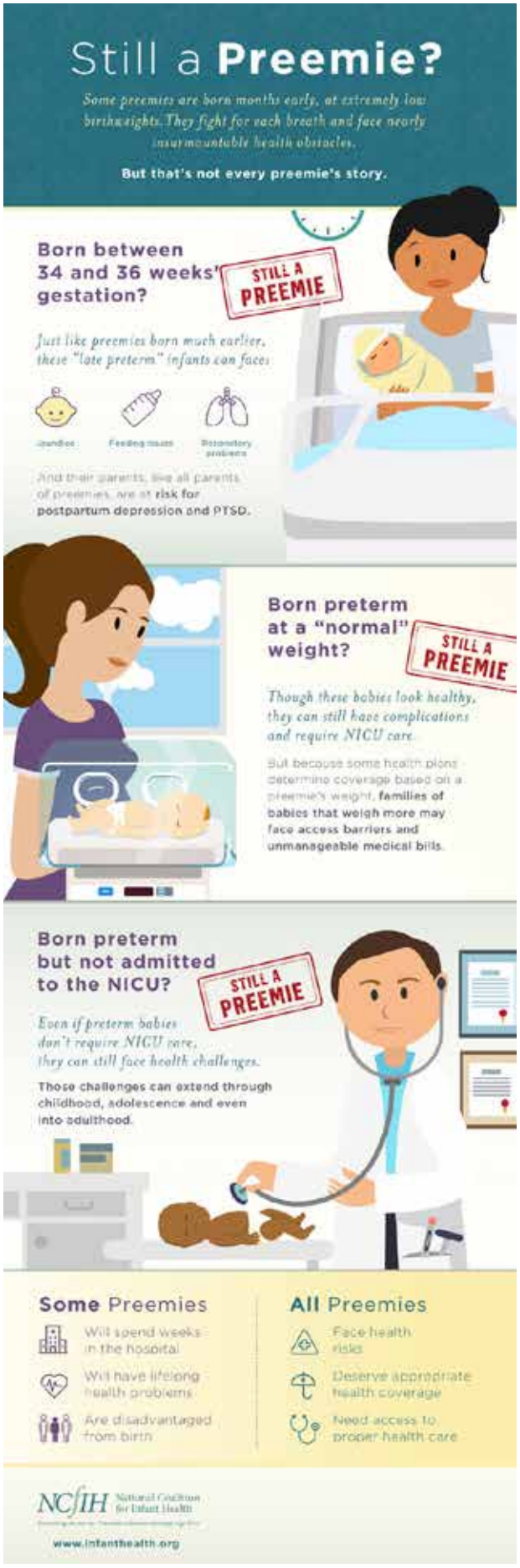
Disclosures: *The authors is Senior Director, Patient & Family Advocacy for AngelEye Health*

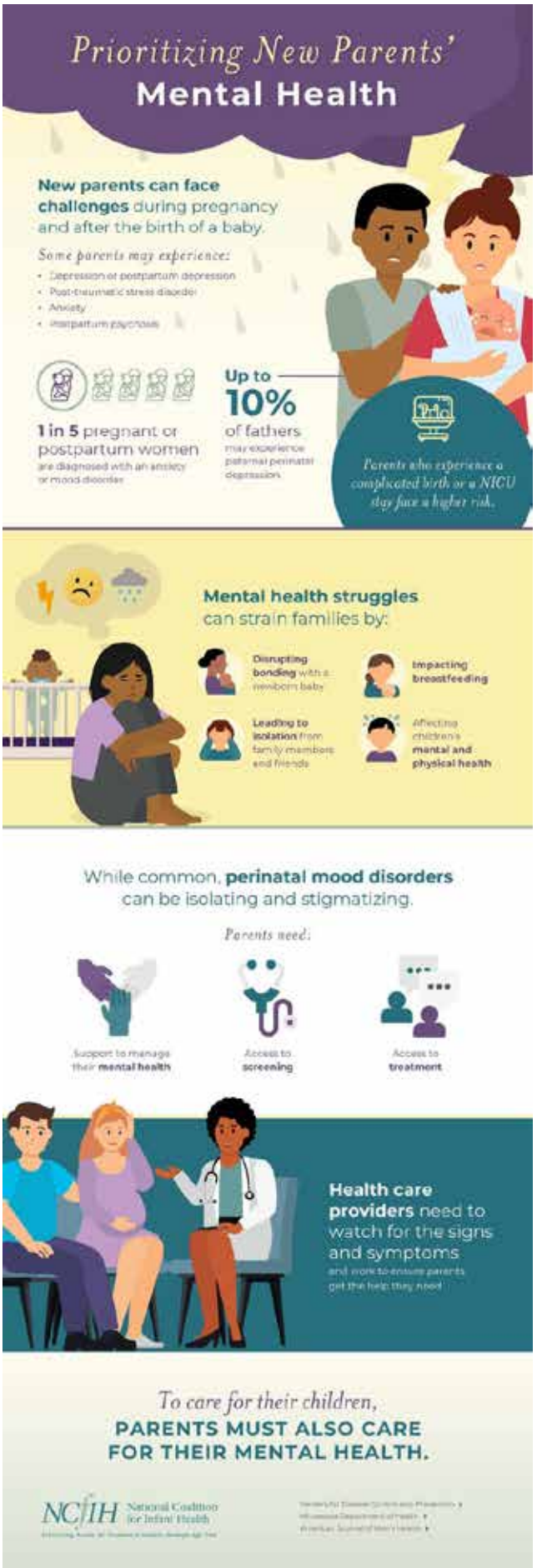
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Corresponding Author



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Senior Director, Patient & Family Advocacy
AngelEye Health
Email: cteneyck@angeleyehealth.com


Still a Preemie?
Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.
But that's not every preemie's story.
Born between 34 and 36 weeks' gestation?
STILL A PREEMIE
Just like preemies born much earlier, these "late preterm" infants can face:
Jaundice
Feeding issues
Respiratory problems
And their parents, like all parents of preemies, are at risk for postpartum depression and PTSD.
Born preterm at a "normal" weight?
STILL A PREEMIE
Though these babies look healthy, they can still have complications and require NICU care.
But because some health plans determine coverage based on a preemie's weight, families of babies that weigh more may face access barriers and unmanageable medical bills.
Born preterm but not admitted to the NICU?
STILL A PREEMIE
Even if preterm babies don't require NICU care, they can still face health challenges.
Those challenges can extend through childhood, adolescence and even into adulthood.
Some Preemies
Will spend weeks in the hospital
Will have lifelong health problems
Are disadvantaged from birth
All Preemies
Face health risks
Deserve appropriate health coverage
Need access to proper health care
NCfIH National Coalition for Infant Health
www.infanthealth.org


Prioritizing New Parents' Mental Health
New parents can face challenges during pregnancy and after the birth of a baby.
Some parents may experience:
Depression or postpartum depression
Post-traumatic stress disorder
Anxiety
Postpartum psychosis
1 in 5 pregnant or postpartum women are diagnosed with an anxiety or mood disorder
Up to 10% of fathers may experience paternal perinatal depression
Parents who experience a complicated birth or a NICU stay face a higher risk.
Mental health struggles can strain families by:
Disrupting bonding with a newborn baby
Impacting breastfeeding
Leading to isolation from family members and friends
Affecting children's mental and physical health
While common, perinatal mood disorders can be isolating and stigmatizing.
Parents need:
Support to manage their mental health
Access to screening
Access to treatment
Health care providers need to watch for the signs and symptoms and work to ensure parents get the help they need
To care for their children,
PARENTS MUST ALSO CARE FOR THEIR MENTAL HEALTH.
NCfIH National Coalition for Infant Health

Join iCAN's Virtual Focus Group!



We warmly welcome all individuals within the age ranges of 8-10 and 12-18, including those with:

- Learning disabilities (example: dyslexia)
- Speech or language disabilities (examples: stuttering, understanding others, hearing)
- Physical disabilities (examples: epilepsy, cystic fibrosis)
- Autism Spectrum Disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD)

Every voice counts!

It's a one-minute survey to see if you qualify for a one-hour focus group to be scheduled at a later date.

Survey Link: bit.ly/icanxkismet

Fill out the recruitment survey now and let your voice be heard! Together, we can make a real difference in pediatric healthcare!

iCAN
International Children's Advisory Network

Education.
Anytime, Anywhere.

Academy of Neonatal Care



The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RT's new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:

www.AcademyofNeonatalCare.org.

Keeping Your Baby Safe
from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little ones from germs and viruses

This year is an especially dangerous cold and flu season - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



Limit Contact with Others



- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.

Provide Protective Immunity

- Hold your baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



Take Care of Yourself

- Stay connected with your family and friends.
- Drink more water and eat healthy foods.
- Seek mental health support.
- Sleep when you can.



Get Immunized

Vaccinations save lives. Protecting your baby from COVID-19, flu and pertussis lowers their risks for complications from respiratory infections.



WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



If you feel sick or are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.
www.nationalperinatal.org/rsv

National Perinatal Association

PROTECT YOUR FAMILY FROM

RESPIRATORY VIRUSES

flu coronavirus pertussis RSV



WASH YOUR HANDS
often with soap and warm water.

GET VACCINATED
for flu and pertussis. Ask about protective injections for RSV.





COVER COUGHS AND SNEEZES.
Sneeze and cough into your elbow.

USE AN ALCOHOL-BASED HAND SANITIZER.





STAY AWAY FROM SICK PEOPLE
Avoid crowds. Protect vulnerable babies and children.

National Perinatal Association

www.nationalperinatal.org

FREE RESOURCES FOR YOUR NICU

Coping During COVID-19

Targeted interventions to improve the mental health of parents, infants, families, and providers

BONDING WITH YOUR BABY



HELPING CHILDREN AND FAMILIES COPE

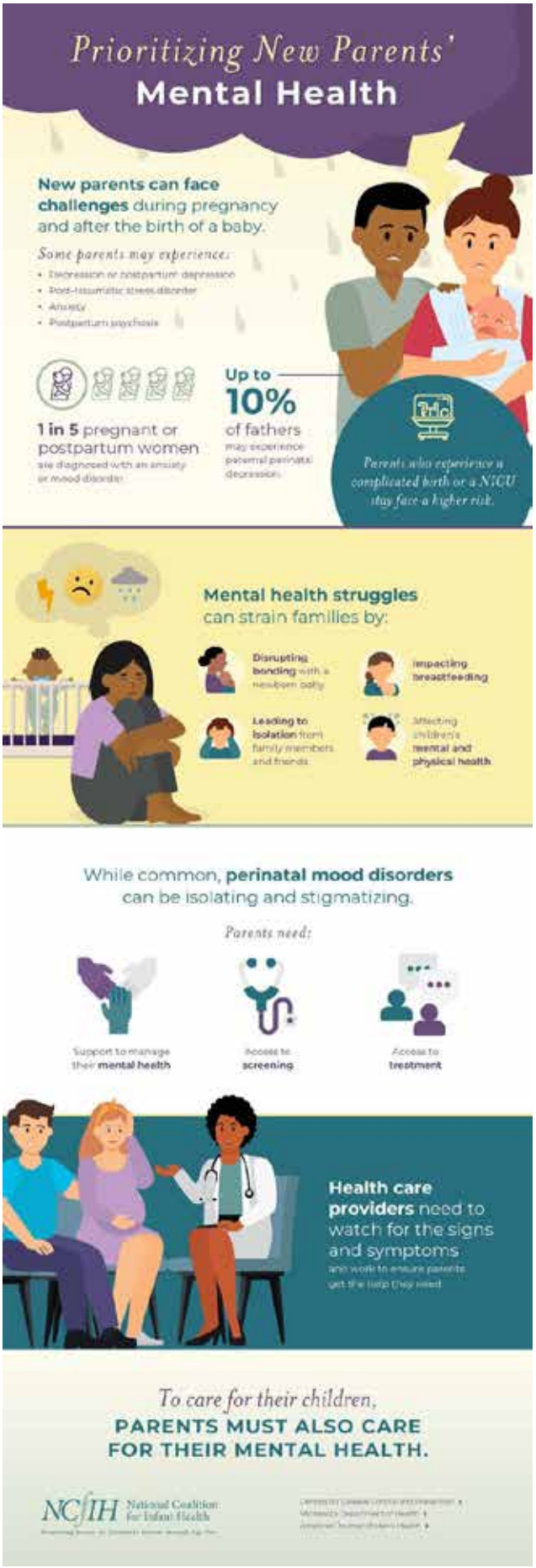


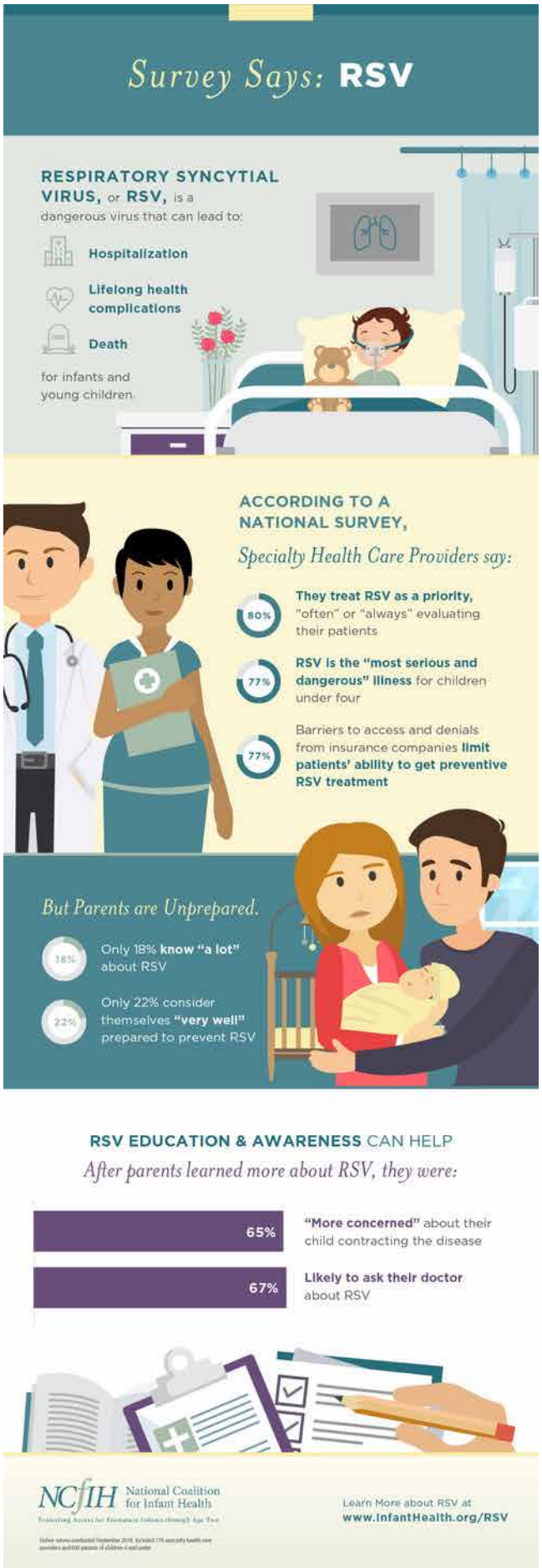
CAREGIVERS NEED CARE TOO



National Network of NICU Psychologists

nationalperinatal.org/psychologists


Prioritizing New Parents' Mental Health
New parents can face challenges during pregnancy and after the birth of a baby.
Some parents may experience:
Depression or postpartum depression
Post-traumatic stress disorder
Anxiety
Postpartum psychosis
1 in 5 pregnant or postpartum women are diagnosed with an anxiety or mood disorder
Up to 10% of fathers may experience paternal perinatal depression
Parents who experience a complicated birth or a NICU stay face a higher risk.
Mental health struggles can strain families by:
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Impacting breastfeeding
Leading to isolation from family members and friends
Affecting children's mental and physical health
While common, perinatal mood disorders can be isolating and stigmatizing.
Parents need:
Support to manage their mental health
Access to screening
Access to treatment
Health care providers need to watch for the signs and symptoms and work to ensure parents get the help they need
To care for their children,
PARENTS MUST ALSO CARE FOR THEIR MENTAL HEALTH.
NCIH National Coalition for Infant Health


Survey Says: RSV
RESPIRATORY SYNCYTIAL VIRUS, or RSV, is a dangerous virus that can lead to:
Hospitalization
Lifelong health complications
Death
for infants and young children
ACCORDING TO A NATIONAL SURVEY,
Specialty Health Care Providers say:
80% They treat RSV as a priority, "often" or "always" evaluating their patients
77% RSV is the "most serious and dangerous" illness for children under four
77% Barriers to access and denials from insurance companies limit patients' ability to get preventive RSV treatment
But Parents are Unprepared.
18% Only 18% know "a lot" about RSV
22% Only 22% consider themselves "very well" prepared to prevent RSV
RSV EDUCATION & AWARENESS CAN HELP
After parents learned more about RSV, they were:
65% "More concerned" about their child contracting the disease
67% Likely to ask their doctor about RSV
NCIH National Coalition for Infant Health
Learn More about RSV at www.InfantHealth.org/RSV

Peer Reviewed

Briefly Legal: Baby Born With Petechiae Not Evaluated—A Missed Case of Congenital Cytomegalovirus

Maureen E. Sims, MD, Barry Schifrin, MD

"A vigorous female infant with a birth weight of 2976 g (slightly < 50%-ile) and head circumference of 33.5 cm (50–75%-ile) was delivered by repeat cesarean section. Apgar scores were 9^1 and 9^5. She was sent to room-in with the mother. The physical examination was unremarkable except for petechiae on her back, trunk, buttocks, and thighs. A CBC was sent and found to have a platelet count of 66 x10^3/mL and 11 x10^3/mL on a repeat."

A 34-year-old G_3P_2 woman with gestational diabetes and Group B streptococcus positive (GBS) cervico-rectal culture developed labor at $39^3/_7$ weeks' gestation. The mother received penicillin for the positive GBS. She had a normal complete blood count (CBC) with a 245 x10^3/mL platelet count. A vigorous female infant with a birth weight of 2976 g (slightly < 50%-ile) and head circumference of 33.5 cm (50–75%-ile) was delivered by repeat cesarean section. Apgar scores were 9^1 and 9^5. She was sent to room-in with the mother. The physical examination was unremarkable except for petechiae on her back, trunk, buttocks, and thighs. A CBC was sent and found to have a platelet count of 66 x10^3/mL and 11 x10^3/mL on a repeat. Because of the thrombocytopenia, the infant was sent to a medical center that had a higher level of care. The platelet counts were serially followed at the referral center and showed improvement. An evaluation for the thrombocytopenia was not performed. She was discharged with a platelet count of 55 x10^3/mL. She passed the hearing screen. Over the next few months, the platelet counts steadily improved and became normal, but increasing concern developed over developmental milestones not being met and head circumference falling off the growth curve. At 5½ months, a seizure disorder developed, which prompted magnetic resonant imaging, which showed increased signals in the periventricular subependymal region suspicious for calcifications, ventricular dilatation with gliotic change, and suspicious for CMV. The liver enzymes were mildly elevated, but the CBC was unremarkable. A PCR of the urine confirmed congenital cytomegalovirus (cCMV). On follow-up, the child is profoundly impaired with microcephaly, sensorineural hearing loss, and difficult-to-control seizures.

"On follow-up, the child is profoundly impaired with microcephaly, sensorineural hearing loss, and difficult-to-control seizures. "

The physicians caring for the child at the referred hospital and in the outpatient clinic were sued for failure to evaluate the thrombocytopenia to implement timely treatment. The case was settled without going to trial.

"Congenital cytomegalovirus (cCMV) infection occurs in approximately 0.5% to 1% of all live births worldwide. This means that out of every 1,000 newborns, 5 to 10 are born with CMV infection, which is the leading cause of nongenetic deafness and learning disability. Eighty-five to 90% of newborns with cCMV are asymptomatic at birth."

Discussion:

Epidemiology:

Human CMV, also known as human herpesvirus 5, is currently the most common intrauterine infection.

Congenital cytomegalovirus (cCMV) infection occurs in approximately 0.5% to 1% of all live births worldwide. This means that out of every 1,000 newborns, 5 to 10 are born with CMV infection, which is the leading cause of nongenetic deafness and learning disability. Eighty-five to 90% of newborns with cCMV are asymptomatic at birth. Of the symptomatic infants with cCMV, they are more likely to have acquired the disease from a primary maternal infection, although symptomatic infections have been reported in women with pre-existing antibodies. Of the 90% who are asymptomatic at birth, 5%–15% have later adverse sequelae. The mortality associated with symptomatic cCMV at birth is 20% to 30%, and two-thirds of survivors have adverse sequelae.

Transmission:

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"Of the 90% who are asymptomatic at birth, 5%–15% have later adverse sequelae. The mortality associated with symptomatic cCMV at birth is 20% to 30%, and two-thirds of survivors have adverse sequelae."

Human CMV is ubiquitous, and its transmission occurs horizontally (by direct person-to-person contact with virus-containing secretions) or vertically (from mother to fetus or infant after birth). Vertical transmission occurs: 1) in utero by transplacental passage of the maternal blood-borne virus; 2) at birth, by passage through an infected genital tract; or 3) following birth via ingestion of CMV-positive human milk. In utero, fetal infection occurs in the pregnant mother with no pre-existing CMV immunity (primary infection) or in those individuals with pre-existing antibodies to CMV either by acquisition of a different viral strain during pregnancy or by reactivation of an existing infection. Congenital infection and associated sequelae can occur irrespective of the trimester, but severe sequelae are associated more commonly with infection acquired during the first trimester. Adverse sequelae occur following both primary and nonprimary infections. Probably more than 75% of infants with cCMV in the United States are born to mothers with nonprimary infection. In terms of acquiring CMV at birth, by passage through an infected genital tract, or from ingestion of CMV-positive human milk, preterm infants <32 weeks' gestation are at greater risk of developing CMV disease than term infants. The incubation period for horizontal (person-to-person) transmitted CMV is variable. For vertical transmission (mother-infant) through milk in preterm infants, the range of CMV viruria is 3–24 weeks, and after infected blood transfusions, it is 3–12 weeks. CMV transmission via human breast milk feeding in <32 weeks' gestation babies may result in a sepsis-like clinical presentation. Mothers may excrete the virus (in the whey portion of milk) even when they are not excreting it elsewhere, such as in urine or saliva. Debate exists as to whether the virus contributes to bronchopulmonary dysplasia.

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Clinical presentation:

The disease manifestation of cCMV infection ranges from mild nonspecific findings to multiorgan involvement, especially of the reticuloendothelial system and CNS. CNS involvement ranges from poor feeding and lethargy to hyper- or hypotonicity, poor suck reflex, microcephaly, seizures, sensorineural hearing loss (SNH), and developmental impairments. Neuroimaging will reveal calcifications, especially in the periventricular area or less commonly in the basal ganglia and cortical or subcortical regions, cortical malformations, cortical atrophy, migration disorders, cerebellar hypoplasia, lenticulostriatal vasculopathy, pseudocysts, and white matter abnormalities, including periventricular leukomalacia. Hepatosplenomegaly and/or abnormal liver function tests may be found. Hyperbilirubinemia occurs in >50%, often persistent with a gradual increase in the direct component. Direct suppression of the megakaryocytes in the bone marrow can result in petechiae and purpura, with thrombocytopenia persisting for weeks. One-third of babies with cCMV have platelet counts <10,000/dL. Anemia, blueberry muffin rash (intradermal hematopoiesis), and leukopenia may be associated with cCMV. Ophthalmologic findings include chorioretinitis, retinal hemorrhage, optic atrophy, strabismus, and cataracts. Diffuse interstitial or necrotizing pneumonitis may develop.

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Diagnosis:

The widespread existence of the virus confounds the diagnosis of CMV disease, the high rate of asymptomatic excretion, the

frequency of reactivation of infections, reinfection with different CMV strains of IgM CMV-specific antibodies in some episodes of reactivation and reinfections, and concurrent infection with other pathogens. Viral DNA can be detected by nucleic acid amplification tests (NAATs) in some tissues, including amniotic fluids. NAAT is an umbrella term that detects genetic material (DNA or RNA) by amplifying it. The most common clinical NAAT is polymerase chain reaction (PCR). CMV PCR detects the presence of CMV DNA and is widely used due to its high sensitivity and specificity. However, its detection does not necessarily indicate acute infection or disease. Its absence means no active infection but does not rule out latent CMV. A quantitative PCR measures viral load and tracks infection progression or response to therapy. Immunofluorescence assays, latex agglutination assays, and enzyme immunoassays (EIA/ELISA) are available for detecting IgG and IgM CMV-specific antigens/antibodies.

"Hepatosplenomegaly and/or abnormal liver function tests may be found. Hyperbilirubinemia occurs in >50%, often persistent with a gradual increase in the direct component. Direct suppression of the megakaryocytes in the bone marrow can result in petechiae and purpura, with thrombocytopenia persisting for weeks. One-third of babies with cCMV have platelet counts <10,000/dL. Anemia, blueberry muffin rash (intradermal hematopoiesis), and leukopenia may be associated with cCMV. Ophthalmologic findings include chorioretinitis, retinal hemorrhage, optic atrophy, strabismus, and cataracts. Diffuse interstitial or necrotizing pneumonitis may develop."

A single serum specimen for IgG antibody testing is helpful for screening for past infection. For diagnosis of suspected recent infection, testing for CMV IgG in paired sera obtained at least 2 weeks apart and testing for IgM in a single serum specimen may be useful. Low-avidity CMV IgG in the presence of CMV IgM in a pregnant person can suggest a more recent infection. Fetal CMV infection can be diagnosed by detecting CMV DNA in amniotic fluid. Congenital infection with CMV requires detecting CMV or CMV DNA in urine, saliva, blood, or CSF obtained within 3 weeks of birth. Detection beyond 3 weeks suggests postnatal acquisition of the virus. PCRs of saliva swab specimens from neonates are >95% sensitive for the identification of cCMV. However, positive saliva test results require confirmation with urine testing because of the potential contamination of CMV in human milk.

"Fetal CMV infection can be diagnosed by detecting CMV DNA in amniotic fluid. Congenital infection with CMV requires detecting CMV or CMV DNA in urine, saliva, blood, or CSF obtained within 3 weeks of birth. Detection beyond 3 weeks suggests postnatal acquisition of the virus."

Treatment:

The mainstay of antiviral treatment of cCMV is intravenous ganciclovir. The oral form, valganciclovir, is equally effective since plasma concentrations are comparable to the intravenous form. Neonates with moderately to severely symptomatic congenital CMV disease with or without central nervous system (CNS) involvement have improved audiologic and neurodevelopmental outcomes at 2 years of age when treated with oral valganciclovir for 6 months. Neonates with isolated sensorineural hearing loss have improved audiologic outcomes when treated with oral valganciclovir for 6 weeks, with treatment begun by at most 13 weeks following birth. Treatment of mildly symptomatic neonates has not been studied. Infants with asymptomatic congenital CMV infection should not receive antiviral treatment outside the confines of a research study. Mildly symptomatic infants with two or fewer transient (e.g., <2 weeks) or clinically insignificant findings (e.g., petechiae, mild hepatomegaly, thrombocytopenia, raised levels of alanine aminotransferase) may be considered on a case by case basis. Asymptomatic babies with no apparent signs to suggest cCMV and normal hearing should not receive medications outside a research protocol. The treatment of preterm infants with cCMV who are determined to have acquired CMV infection at the time of delivery and who develop end-organ disease (e.g., pneumonitis, hepatitis, thrombocytopenia) has not been adequately studied. In the case discussed above, since no evaluation was performed to determine the diagnosis or the timing of its acquisition, this infant did not have the benefit of potential beneficial intervention. If premature infants with cCMV acquired at the time of delivery do receive ganciclovir, a reasonable approach is to treat for 2 weeks and then reassess responsiveness to therapy.

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Prevention:

Several clinical trials are being developed to prevent cCMV, but no CMV vaccine has exceeded 50% efficacy in preventing CMV infections in trial study populations. Transmission of CMV by blood transfusions has been virtually eliminated by the use of CMV antibody-negative donors and the use of leukoreduced blood products. Pasteurization of donated human milk decreases the likelihood of CMV transmission. Freezing human milk at 20°C for the sole purpose of reducing CMV infectivity is not advised because, although it may reduce the viral load of CMV, it does not change the risk of CMV-sepsis-like syndrome, and freezing reduces the bioactivity of human milk.

Screening:

Although a strong case for newborn CMV testing has been proposed for decades, several factors have limited the enthusiasm for universal cCMV screening. First, even though cCMV causes significant disability for some infants, these adverse outcomes are seen in only 15% of newborns; most infants with cCMV are asymptomatic and have normal neurodevelopmental outcomes. The other disorders that are screened on newborns cause significant adverse outcomes. Second, experts have not agreed uniformly regarding the optimal newborn screening tool for cCMV. Although urine PCR has been considered the gold standard for cCMV diagnosis, urine collection is time-intensive, and suboptimal sensitivity is found when using dried blood spots collected on filter paper. Third, the disorders screened should be amenable to a therapeutic intervention. Currently, ganciclovir (or its prodrug, valganciclovir) is reserved for symptomatic children. For asymptomatic infants, no antiviral treatment is warranted.

Over the past many years, public policy, politics, and parental advocacy have intersected and synergized to make universal cCMV screening a reality in 2 states: Minnesota since 2023 and Connecticut, where it is projected to begin in 2025. In addition to Minnesota and Connecticut, New York is conducting universal cCMV screening through a study funded by a National Institutes of Health grant. It will likely incorporate universal cCMV screening into its portfolio after the pilot study period has ended. A pivotal study by Dunn et al. has demonstrated the feasibility of incorporating universal cCMV screening into the infrastructure of a provincial (Ontario) health department screening program.

"The treatment of preterm infants with cCMV who are determined to have acquired CMV infection at the time of delivery and who develop end-organ disease (e.g., pneumonitis, hepatitis, thrombocytopenia) has not been adequately studied. In the case discussed above, since no evaluation was performed to determine the diagnosis or the timing of its acquisition, this infant did not have the benefit of potential beneficial intervention. If premature infants with cCMV acquired at the time of delivery do receive ganciclovir, a reasonable approach is to treat for 2 weeks and then reassess responsiveness to therapy.

Prognosis:

The outcome of cCMV is dependent on many variables: 1) primary versus recurrent maternal infection; 2) early trimester acquisition versus later in pregnancy; 3) during delivery or with breast milk containing CMV; 4) asymptomatic versus symptomatic at birth; 5) preterm versus term; and/or 6) timing of intervention of antiviral therapy.

"Although a strong case for newborn CMV testing has been proposed for decades, several factors have limited the enthusiasm for universal cCMV screening."

Suggested Reading:

1. American Academy of Pediatrics. Red Book: 2024–2027 Report of the Committee on Infectious Diseases (33rd

edition) Eds Kimberlin, DW, Banerjee R, Barnett ED, et al.

2. Chiopris G, Veronese P, Cusenza F, Procaccianti M, Perrone S, Daccò V, Colombo C, Esposito S. Congenital Cytomegalovirus Infection: Update on Diagnosis and Treatment. Microorganisms. 2020 Oct 1;8(10):1516. doi: 10.3390/microorganisms8101516. PMID: 33019752; PMCID: PMC7599523.

3. Dunn JKE, Chakraborty P, Reuvers E, et al. Outcomes of a population-based congenital cytomegalovirus screening program. JAMA Pediatr. Published online January 21, 2025. doi:10.1001/jamapediatrics.2024.5562.

4. Kimberlin DW, Aban I, Peri K, et al. Oral valganciclovir initiated beyond one month of age as treatment of sensorineural hearing loss caused by congenital cytomegalovirus infection: a randomized clinical trial. J Pediatr. 2024; 113934. https://doi.org10.1016/j.peds 2024 113934.

5. Rawlinson WD, Boppana SB, Fowler KB et al. Congenital cytomegalovirus infection in pregnancy and the neonate: consensus recommendations for prevention, diagnosis and therapy. Lancet Infect Dis. 2017;17:2177–88.

6. Schleiss, MR, Congenital Cytomegalovirus Screening Move Ahead JAMA Pediatrics. 2025;179:241–242.

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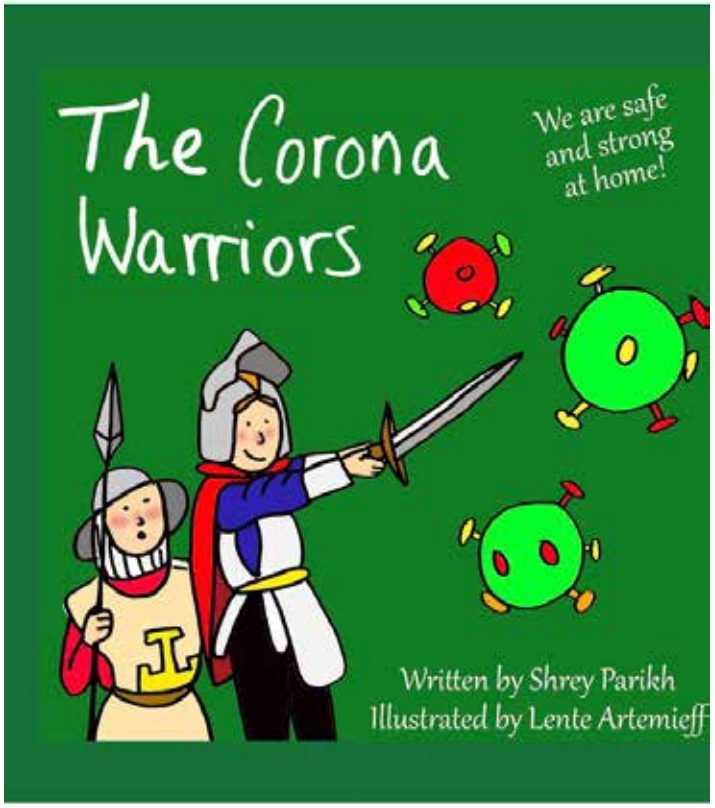
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Will your **PRETERM INFANT** *need* **EARLY INTERVENTION** *services?*

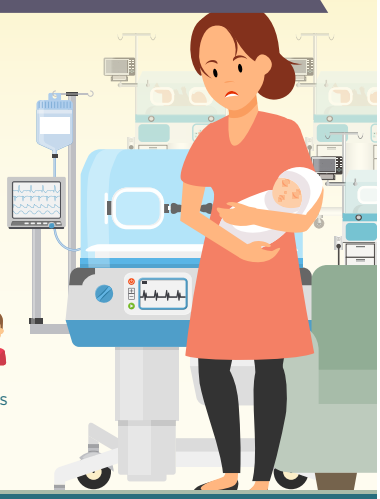
Preterm infants are:

2x more likely to have developmental delays

5x more likely to have learning challenges



1 in **3** preterm infants will require support services at school

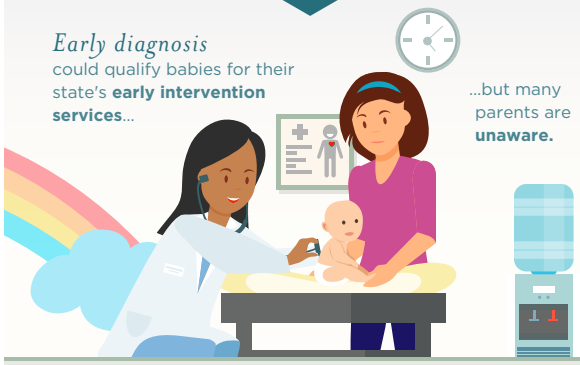


Early intervention can help preterm infants:

- Enhance language and communication skills
- Build more effective learning techniques
- Process social and emotional situations
- Address physical challenges
- Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware.**





NICU staff, nurses, pediatricians and social workers **should talk** with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.



NCFIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

Visit **CDC.gov** to find contact information for your state's early intervention program.

Las nuevas mamás necesitan acceso a la detección y tratamiento para **LA DEPRESIÓN POSPARTO**

1 DE CADA **7** MADRES AFRONTA LA DEPRESIÓN POSPARTO, *experimentando*

- Llanto incontrolable
- Sueño interrumpido
- Ansiedad
- Desplazamientos en los patrones de alimentación
- Ideas de hacerse daño a sí mismas o al bebé
- Distanciamiento de amigos y familiares





Sin embargo, sólo el 15% recibe tratamiento[1]

LA DEPRESIÓN POSTPARTO **NO TRATADA** PUEDE AFECTAR:



- *La salud de la madre*
- *El sueño, la alimentación y el comportamiento del bebé a medida que crece*[2]
- *La capacidad para cuidar de un bebé y sus hermanos*

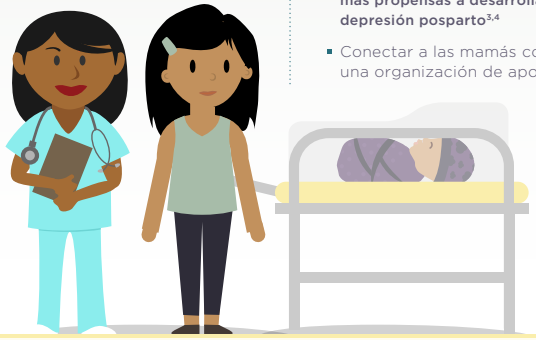
PARA AYUDAR **A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO**

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

- Financiar los esfuerzos de despistaje y diagnostico
- Proteger el acceso al tratamiento

LOS HOSPITALES PUEDEN:

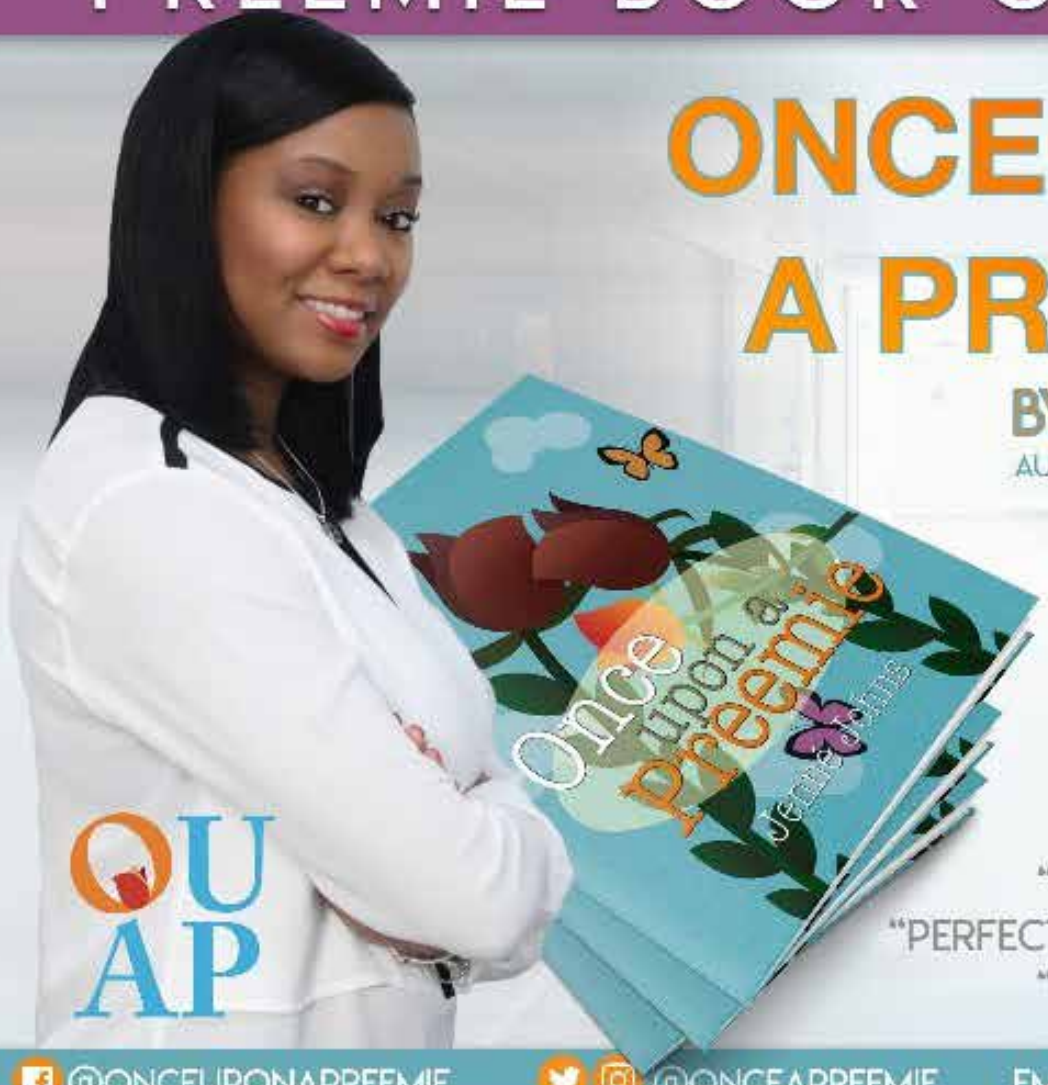
- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión posparto**[3,4]
- Conectar a las mamás con una organización de apoyo



NCFIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

[1] American Psychological Association. Accessible on: http://www.apa.org/pi/women/resources/reports/postpartum-depression.aspx
[2] National Institute of Mental Health. Accessible on: https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml
[3] Journal of Perinatology (2015) 35, 529–536; doi:10.1038/jp.2015.147.
[4] Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. Vigod SN, Villegas L, Dennis CL, Ross LE BJOG. 2010 Apr; 117(5):540-50.

PREEMIE BOOK ON SALE



ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

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NIH *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

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Compiled and Reviewed by Benjamin Hopkins, DO

AAP Fact Checked articles set record straight on measles, vaccines, more

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: **AAP Fact Checked articles set record straight on measles, vaccines, more**

Current as of April 2, 2025

Rumors, false information and confusing statements about science and medicine persist across traditional and social media. A new feature at AAP.org aims to add clarity on topics for pediatricians, parents and media seeking the best information.

Fact Checked, which launched in March, provides facts, evidence and expert comments on vaccines, measles, raw milk, fluoride and abusive head trauma. Additional articles will be added to the library of topics at aap.org/en/news-room/fact-checked.

"We live in a time where everyone has access to an incredible amount of information, yet it is not easy to tell what to trust," said AAP CEO/Executive Vice President Mark Del Monte, J.D. "As a trusted resource for pediatricians, parents and the public, the Academy has a critical responsibility to enter these conversations as the voice of science-backed truth."

Articles on measles and immunizations are especially important as measles outbreaks spread across the U.S. Articles include "The Measles Vaccine is Safe and Effective," "Immunizations Are Essential for Public Health and Child Safety" and "Vitamin A Does Not Prevent Measles."

Each Fact Checked article states a popular source of confusion and explains why that claim is spreading; debunks the claim with facts and the supporting evidence; explains why the issue is important for child health; and ends with a quote from an expert doctor. Links to resources on the topic from the AAP and other organizations also are provided.

The AAP will be sharing Fact Checked articles via social media and other communications.

"Our goal with this innovative project was to address growing topics of misinformation but in a way that was easily accessed and wrapped in truth," Del Monte said. "We want media, members, parents and others to have clear, accurate information delivered by our experts along with additional resources to learn more. In today's digital world, content has to be brief and able to be widely shared."

Tips for parents, caregivers to help console a crying baby

NEWS PROVIDED BY

American Academy of Pediatrics

By Steve Schering

Study: **Tips for parents, caregivers to help console a crying baby**

Current as of April 1, 2025

Hearing a wailing newborn can be hard for parents, but it's normal for newborns to cry for one to four hours a day. Some infants may even cry for more than five hours a day. It's part of adjusting to life outside the womb.

It can be frustrating for parents and caregivers when a baby cries a lot, but there are steps you can take to soothe your infant.

First, understand that crying helps babies communicate what they need. For example, they may be cold, hungry or have a wet diaper. Try warming them up, feeding them and changing their diaper. If they are shrieking or sound panicked, check to see if clothing is making them uncomfortable or if a strand of hair is caught around a finger or toe.

Babies also cry when they are sick. If they have a rectal temperature of 100.4 degrees Fahrenheit (38 degrees Celsius) or higher, contact your pediatrician.

Babies, however, may cry even if they are warm, dry, well-fed and don't have a temperature. Here are some things you can try to soothe your baby:

- Rock the baby in a rocking chair or in your arms.
- Gently stroke the baby's head or pat her back or chest.
- Wrap the baby snugly in a receiving blanket.
- Sing or talk to the baby.
- Play soft music or soft rhythmic noise.
- Walk with the baby in your arms, a stroller or a carriage.
- Burp the baby to relieve any trapped gas bubbles.
- Give the baby a warm bath.

If none of these strategies help and the baby doesn't seem ill, leave the baby alone in a safe location such as a crib. Many babies cry before falling asleep. The crying shouldn't last long if the child is tired.

If you start to feel you cannot handle the situation, set the baby down in a safe location and get help from a family member or friend. Never shake or hit the baby. Shaking an infant can cause blindness, brain damage or even death.

Talk to your pediatrician about other ways to help a crying baby.

For more information, visit HealthyChildren.org.

Probiotic supplements associated with lower mortality rates in Canadian NICUs

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: **Probiotic supplements associated with lower mortality rates in Canadian NICUs**

Current as of April 1, 2025

A retrospective study of more than 32,000 preterm infants admitted to neonatal intensive care units (NICUs) in Canada found the use of probiotics was associated with decreased mortality rates.

The study sought to evaluate the effectiveness of probiotic supplements added to breast milk or formula for infants born before 34 weeks' gestation, including those with an extremely low birth weight (ELBW) of less than 1,000 grams (2.2 pounds).

Of 32,667 eligible infants born at 33 NICUs between Jan. 1, 2016, and Dec. 31, 2022, 18,793 (57.5%) received probiotics and 13,874 (42.5%) did not.

The probiotic cohort had decreased mortality rates (adjusted odds ratio [aOR], 0.62; 98.3% CI, 0.53-.073) but not decreased rates of necrotizing enterocolitis (NEC) (aOR, 0.92; 98.3% CI, 0.78-1.09) or late-onset sepsis (aOR, 0.90; 98.3% CI, 0.80-1.01).

Of the total dataset, 7,401 infants had ELBW and 2,465 (33.3%) of those received probiotics. In that cohort, probiotics again were found to be associated with decreased mortality rates (aOR, 0.58; 98.3% CI, 0.47-.071) but not decreased NEC (aOR, 0.90; 98.3% CI, 0.71-1.13) or late-onset sepsis (aOR, 1.01; 98.3% CI, 0.86-1.18).

"In the group with a birth weight less than 1,000 g, all-cause death was lower among infants who received probiotics than those in the nonprobiotics group," the authors wrote. "All-cause mortality was comparable between the two groups in the whole cohort."

The authors noted that incidents of probiotic sepsis have prompted federal warnings about probiotic use in NICUs. The study found such incidents to be rare, occurring in 27 infants. Three died within seven days, and probiotic sepsis was considered a possible cause of death in two of them.

"The risk of probiotic sepsis should be weighed against the risks of other interventions that preterm infants are exposed to, such as central venous catheterization," the authors wrote. "Moreover, benefits regarding mortality must also be weighed in the equation."

CDC: Measles cases rise to 884; five new states report cases

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **CDC: Measles cases rise to 884; five new states report cases**

Current as of April 25, 2025

Measles cases have increased to 884 and have been reported in five more states. The data come as a new study predicts 851,000 cases over the next 25 years if vaccination rates stay at current levels.

Confirmed case counts reported Friday by the Centers for Disease Control and Prevention (CDC) rose by about 10.5% from the week before, although experts say they are likely to be undercounted significantly. Roughly 68% of the cases were among children and teenagers.

About 11% of people with measles have been hospitalized this year, and three people have died, including two unvaccinated school-age children in Texas who had no underlying conditions.

Cases were reported in five new states Friday (in bold), bringing the total to 30 jurisdictions with cases this year: Alaska, Arkansas, California, Colorado, Florida, Georgia, Hawaii, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maryland, Michigan, Minnesota, Missouri, Montana, New Jersey, New Mexico, New York City, New York State, Ohio, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Vermont, Virginia and Washington.

The largest of the 11 outbreaks (defined as three or more related cases) this year has been in west Texas. The Texas Department of State Health Services has reported 646 cases of measles as of April 25, an increase of 49 cases since a week ago. Gaines County has reported 393 (60.8%) of the state's total cases. Neighboring Lee County, N.M., has reported 61 of that state's 66 cases. The AAP and CDC recommend ensuring patients are covered with a two-dose measles-mumps-rubella (MMR) vaccination series. Under routine recommendations, the doses are given at ages 12-15 months and 4-6 years. One dose of MMR is 93% effective against measles, and two doses are 97% effective.

Across the U.S., about 97% of measles cases this year have been among people who were unvaccinated or had an unknown vaccination status, according to the CDC.

The outbreaks come as studies show declining rates of MMR vaccination among kindergartners and the rampant spread of misinformation about the safety of vaccines.

Researchers from Stanford University and the Baylor College of Medicine released a study in JAMA Thursday that used modeling to estimate how many measles cases the country could see in the next 25 years under different vaccination scenarios.

At current levels, there could be more than 851,000 cases, 170,000 hospitalizations

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and 2,550 deaths, and measles would be endemic again, according to the models.

If MMR vaccination coverage dropped by 10%, researchers estimated there could be 11.1 million cases over 25 years. However, with a 5% increase in vaccination, there may be about 5,800 cases.

"These findings support the need to continue routine childhood vaccination at high coverage to prevent resurgence of vaccine-preventable infectious diseases in the US," authors wrote.

A new KFF poll found about 78% of parents with children under 18 years are somewhat or very confident in the safety of MMR vaccines. Most parents have read or heard false claims about measles or MMR vaccines with the most common being that MMR vaccines cause autism, according to the poll. About 33% said they believe that false claim is probably or definitely true.

Just under half of parents (48%) know measles cases are higher than in recent years, and about the same percentage are somewhat or very worried, the poll found. Cases are at their second highest level in 25 years, according to CDC data.

Earlier this month, the AAP reached out to congressional leaders, saying the nation is "reaching a breaking point" in its ability to control the outbreaks. It urged them to unequivocally promote vaccination as the only prevention and restore cuts to vaccine-related funding and public health workers.

6 more pediatric flu deaths reported; pertussis cases continue to climb

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: **6 more pediatric flu deaths reported; pertussis cases continue to climb**

Current as of April 25, 2025

Pediatric flu deaths crept closer to an all-time high in a non-pandemic season even as flu-related hospital admissions decreased across all U.S. regions for the week ending April 19, according to the Centers for Disease Control and Prevention (CDC).

The CDC's weekly influenza surveillance report released Friday contained six new pediatric flu deaths that occurred in February and April. That brings the 2024-'25 flu season total of pediatric deaths to 204; last season set a record for a non-pandemic season with 207.

Hospital admissions, outpatient visits and positive tests for the flu continue to decline nationwide, though the CDC expects the disease to circulate for several more weeks.

The hospital admission rate for flu reported Friday was 1.1 per 100,000, a more than 5% decrease from the previous week. The admission rate decreased across all 10 U.S. Department of Health and Human Services regions and reached as low as 0.7 per 100,000 in Region 10, which includes Alaska, Idaho, Oregon and Washington.

Vaccines for the current flu season are still available. The CDC reported Friday that 49% of U.S. children have been vaccinated against the flu this season, up from 48.7% last week.

The CDC recommends that everyone 6 months and older get a flu shot. Protection against the illness typically begins two weeks after administration.

There have been at least 47 million illnesses, 610,000 hospitalizations and 26,000 deaths from the flu in the 2024-'25 season.

No new human cases of avian influenza were reported Friday; there have been 70 cases and one death associated with bird flu reported this year.

Respiratory syncytial virus and COVID-19 activity continue to decline from already low levels. The CDC reports COVID hospitalization rates are at a "very low" level.

More than 400 additional pertussis cases

According to provisional CDC data for the week ending April 19, more than 400 additional cases of pertussis (whooping cough) have been reported in the U.S., bringing the 2025 total to 8,472.

Chad Neilsen, head of infection control and prevention for Nemours Children's Health in Florida, told ABC News on Thursday that the U.S. is on pace for 70,000 cases of whooping cough this year, doubling last year's total.

No new pediatric pertussis deaths have been reported in the last week. The Louisiana Office of the Surgeon General confirmed on March 27 that two infants died of whooping cough within the previous six months, and the Spokane Regional Health District in Washington state reported on Feb. 5 that a child under age 5 died in November 2024.

Vaccination is the best prevention against whooping cough. The immunization schedule calls for the first dose of the diphtheria, tetanus and acellular pertussis (DTaP) vaccine to be given at 2 months of age. Subsequent doses are given at 4 months and 6 months, with boosters at 15-18 months and 4-6 years. A tetanus, diphtheria and pertussis (Tdap) booster is recommended at 11-12 years old.

To prevent adult transmission to babies, people in close contact with infants younger than 1 year should get a booster, and pregnant people should get the vaccine during the third trimester.

Pediatricians united on need to strengthen Medicaid, pediatric workforce, physician well-being

NEWS PROVIDED BY

American Academy of Pediatrics

By AAP President Susan J. Kressly, M.D., FAAP

Study: **Pediatricians united on need to strengthen Medicaid, pediatric workforce, physician well-being**

Current as of April 1, 2025

I often am reminded of Maya Angelou's wisdom in her poem "Human Family": "We are more alike, my friends, than we are unalike." She expands in comment, "And the minute we begin to understand, just the slightest part of that, we recognize ourselves as family."

As I travel around the country and speak with many of you, two things are clear:

While we have unique challenges in our practices and communities, our commitment to the Academy's mission to serve every child grounds our collective

work.

We have more impact when we work together to find common ground and come together enriched by our diverse opinions and priorities.

While there is much work to do and each of us has our interests and priorities, almost every pediatrician I speak with talks about Medicaid, workforce and pediatrician safety and wellness. To fulfill the mission of the Academy, pediatricians need appropriate payment, a strategy for strengthening our workforce and changes to health care delivery.

Medicaid

The face of Medicaid is well-known to us but is not well-appreciated by society at large. We all can champion children when we remind everyone that Medicaid is the single biggest health insurance payer for the nation's children, and nearly half of all infants, children and adolescents in this country are covered by Medicaid or the Children's Health Insurance Program. Coverage varies significantly by state, with 18% of kids in Utah covered, while nearby New Mexico ranks the highest with 71% of children enrolled in a Medicaid program. This variability correlates with several factors, including the level of poverty and state policies. For many pediatricians who serve the poorest communities, lower payments lead to inadequate resources to deliver appropriate care.

For advocacy efforts to be successful, everyone — not just those in health care or policymakers — needs to understand the importance of supporting and strengthening the Medicaid program. The economic strength of every state, military readiness and a healthy workforce depend on healthy children growing into healthy adults. With so many children on Medicaid, the health and strength of the country's future depends on the Medicaid program. Please join the Academy's advocacy efforts in this area. Our voice is stronger when we speak together.

Pediatric workforce

When we look at strategies to strengthen the pediatric workforce, we must start with data. Children make up a declining portion of our population (currently 22% down from 36% in 1960). Every sector is focused on capturing as many of the prospective workers as possible.

We know that any solution to bolster the pediatric workforce has to include reduced debt burden and increased lifetime earnings.

In my opinion, we must plant seeds early to have the pediatric teams we need. We have a unique opportunity: A significant portion of children come through our offices and organizations every day. What are we doing to invite our patients to become our future team members? Do we demonstrate the joy that comes with pediatric care? Do we invite them to dream of working with us?

To spark interest in future pediatricians, we also need support to be successful personally and professionally.

Safety and well-being

Pediatrician safety and well-being starts with feeling respected for who we are: highly trained professionals who have sacrificed much for the privilege of providing excellent health care to infants, children, adolescents and young adults. We come from different backgrounds and have varied interests and expertise, but we all are dedicated to ensuring every child has the best chance of achieving optimal well-being. We also are people whose ability to lead with empathy must start with feeling safe.

If the health care delivery system is not committed to pediatricians, we will not be in a position to bring our best selves to the table, and children and our communities will bear the impact. An investment in pediatricians is an investment in the health of our nation. The children we serve represent 100% of the future.

I look forward to recommendations from the Task Force on Pediatrician Safety and Wellbeing in the months ahead. In the meantime, let's apply what we know from trauma-informed care to our profession. Can we define what adverse pediatric experiences look like? Should we develop strategies for primary, secondary and tertiary prevention to address pediatrician well-being?

Who is your safe, stable, nurturing relationship to help buffer the stress and build resilience? For me, it's you. Meeting and connecting with you and witnessing the amazing work you do for kids in enormously challenging circumstances brings me hope.

Who would you call at 2 a.m. if you needed someone to lean on? If your phone rings in the middle of the night, it might be me.

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Aid cuts threaten fragile progress in ending maternal deaths, UN agencies warn

NEWS PROVIDED BY

World Health Organization

By Laura Keenan, Sara Alhattab, Zina Alam

Study: **Aid cuts threaten fragile progress in ending maternal deaths, UN agencies warn**

Current as of April 7, 2025

Countries must recommit to ending deaths in childbirth amid major headwinds

Women today are more likely than ever to survive pregnancy and childbirth according to a major new report released today, but United Nations (UN) agencies highlight the threat of major backsliding as unprecedented aid cuts take effect around the world.

Released on World Health Day, the UN report, Trends in maternal mortality, shows a 40% global decline in maternal deaths between 2000 and 2023 – largely due to improved access to essential health services. Still, the report reveals that the pace of improvement has slowed significantly since 2016, and that an estimated 260 000 women died in 2023 as a result of complications from pregnancy or childbirth – roughly equivalent to one maternal death every two minutes.

The report comes as humanitarian funding cuts are having severe impacts on essential health care in many parts of the world, forcing countries to roll back vital services for maternal, newborn and child health. These cuts have led to facility closures and loss of health workers, while also disrupting supply chains for lifesaving supplies and medicines such as treatments for haemorrhage, pre-eclampsia and malaria – all leading causes of maternal deaths.

Without urgent action, the agencies warn that pregnant women in multiple

countries will face severe repercussions – particularly those in humanitarian settings where maternal deaths are already alarmingly high.

"While this report shows glimmers of hope, the data also highlights how dangerous pregnancy still is in much of the world today despite the fact that solutions exist to prevent and treat the complications that cause the vast majority of maternal deaths," said Dr Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization (WHO). "In addition to ensuring access to quality maternity care, it will be critical to strengthen the underlying health and reproductive rights of women and girls – factors that underpin their prospects of healthy outcomes during pregnancy and beyond."

The report also provides the first global account of the COVID-19 pandemic's impact on maternal survival. In 2021, an estimated 40 000 more women died due to pregnancy or childbirth – increasing to 322 000 from 282 000 the previous year. This upsurge was linked not only to direct complications caused by COVID-19, but also widespread interruptions to maternity services. This highlights the importance of ensuring such care during pandemics and other emergencies, noting that pregnant women need reliable access to routine services and checks as well as round-the-clock urgent care.

"When a mother dies in pregnancy or childbirth, her baby's life is also at risk. Too often, both are lost to causes we know how to prevent," said UNICEF Executive Director Catherine Russell. "Global funding cuts to health services are putting more pregnant women at risk, especially in the most fragile settings, by limiting their access to essential care during pregnancy and the support they need when giving birth. The world must urgently invest in midwives, nurses, and community health workers to ensure every mother and baby has a chance to survive and thrive."

The report highlights persistent inequalities between regions and countries, as well as uneven progress. With maternal mortality declining by around 40% between 2000 and 2023, sub-Saharan Africa achieved significant gains – and was one of just three UN regions alongside Australia and New Zealand, and Central and Southern Asia, to see significant drops after 2015. However, confronting high rates of poverty and multiple conflicts, the sub-Saharan Africa region still counted for approximately 70% of the global burden of maternal deaths in 2023.

Indicating slowing progress, maternal mortality stagnated in five regions after 2015: Northern Africa and Western Asia, Eastern and South-Eastern Asia, Oceania (excluding Australia and New Zealand), Europe and North America, and Latin America and the Caribbean.

"Access to quality maternal health services is a right, not a privilege, and we all share the urgent responsibility to build well-resourced health systems that safeguard the life of every pregnant woman and newborn," said Dr Natalia Kanem, UNFPA's Executive Director. "By boosting supply chains, the midwifery workforce, and the disaggregated data needed to pinpoint those most at risk, we can and must end the tragedy of preventable maternal deaths and their enormous toll on families and societies."

Pregnant women living in humanitarian emergencies face some of the highest risks globally, according to the report.Nearly two-thirds of global maternal deaths now occur in countries affected by fragility or conflict. For women in these settings, the risks are staggering: a 15-year-old girl faces a 1 in 51 risk of dying from a maternal cause at some point over her lifetime compared to 1 in 593 in more stable countries. The highest risks are in Chad and the Central African Republic (1 in 24), followed by Nigeria (1 in 25), Somalia (1 in 30), and Afghanistan (1 in 40).

Beyond ensuring critical services during pregnancy, childbirth and the postnatal period, the report notes the importance of efforts to enhance women's overall health by improving access to family planning services, as well as preventing underlying health conditions like anaemias, malaria and noncommunicable diseases that increase risks. It will also be critical to ensure girls stay in school and that women and girls have the knowledge and resources to protect their health.

Urgent investment is needed to prevent maternal deaths. The world is currently off-track to meet the UN's Sustainable Development Goal target for maternal survival. Globally, the maternal mortality ratio would need to fall by around 15% each year to meet the 2030 target – significantly increasing from current annual rates of decline of around 1.5%.



Team Behind Critical CDC Maternal and Infant Health Dataset Axed

NEWS PROVIDED BY

MedPage Today

By Rachel Robertson

Study: **Team Behind Critical CDC Maternal and Infant Health Dataset Axed**

Current as of April 9, 2025

As part of the cuts to federal health agencies by the Trump administration, the entire team behind a key CDC dataset for ob/gyn research has been axed.

On April 1, all 17 members of the Pregnancy Risk Assessment Monitoring System (PRAMS) team received a reduction-in-force notice, as did almost the entire Division of Reproductive Health at CDC. They lost access to their laptops shortly after.

Technically, everyone is on administrative leave until June 2, when they have to depart from the CDC.

For nearly four decades, PRAMS has tracked data from a majority of births in the U.S. The CDC's websiteopens in a new tab or window states PRAMS was developed to "reduce infant morbidity and mortality by influencing maternal behaviors before, during, and immediately after live birth." The dataset is often used by health officials to improve maternal and infant health, as well as by researchers to monitor trends and improve patient care.

Isaac Michael, PhD, a mathematical statistician for the PRAMS team, told MedPage Today that his team had just finished up the 2023 data and were about to get started on 2024 data collection when they received the notice.

"We had just gotten caught up, and we were just about to start shifting gears towards making the system more efficient ... and then everything got shut down," he said. "We're going to lose information on cigarettes, on postpartum depression, on healthcare, on mortality rates, on COVID experiences."

PRAMS is "considered the gold standard in survey data collection," Michael said. But to achieve that quality takes time and resources.

"It is slower to get out than some of the other data collections because we have to actually wait until the births occur," he explained. They also look for missing and duplicate records to keep the data clean.

"Our team is not redundant. Our data is not duplicated," he said, noting that since he joined the team 2 years ago they had been working to streamline data analysis and catch up on a data backlog.

Beyond maintaining the PRAMS data, Michael and his colleagues also collaborated with local health departments to assess their maternal health trends and stratify state-specific data based on their specific populations and goals. These partnerships, aimed at tackling disparities and improving maternal and infant outcomes, have taken years to build.

"It's a massive infrastructure, and now it's all been shut down," Michael said.

If PRAMS disappears or tanks in quality, ob/gyns and researchers will feel these effects in their work.

"Losing access to PRAMS surveillance data would be devastating to clinicians, researchers, and patients," Sindhu Srinivas, MD, president of the Society for Maternal-Fetal Medicine, told MedPage Today. "This data is critical because it allows us to monitor and understand emerging issues that impact maternal and child health outcomes."

David Hackney, MD, a maternal-fetal medicine doctor at Case Western Reserve University in Cleveland, agreed that PRAMS is a vital resource for ob/gyn research.

"If you do a quick PubMed search for PRAMS, you come up with voluminous studies that have been done over many years on an extremely wide array of topics -- obesity, diabetes, racial disparities, food insecurity, incarceration," he said. "So if it stops existing, that's a tremendous loss, precisely when we have some of the highest maternal mortalityopens in a new tab or window in the world, [and] some of the highest rates of preterm birth and infant mortality, too."

Compared to other specialties with significant ties to private industry, medical device companies, and pharmaceuticals, ob/gyn has far less outside research funding, he said.

"Obstetrics research tends to be particularly dependent upon the federal government in a way that many other medical fields are not, part of which is we don't have equivalent private or industry research behind us," Hackney explained.

For instance, core research concerns, like preterm birth and preeclampsia, have very little pharmaceutical research. In terms of medical devices, it's mostly just ultrasounds. Hence, ob/gyn researchers tend to be disproportionately dependent upon federal support, grant funding, and federal databases.

"I'm trying to come up with a more intelligent way to say it's really, really bad, but it's quite bad," Hackney said.

Ultimately, Michael said he hopes people across the political spectrum will recognize the value of PRAMS. In fact, he thinks it's an opportunity for Republicans to support mothers, which he thinks would address the common critique that the party only cares about women and babies until birth.

Michael has even started talking about the fact that he voted for Trump this past election, though he said the price he has paid for his vote "hurts like hell."

"There is a lot that I do agree with that the Trump administration is doing. But I do not agree with the team PRAMS getting cut," he said. "I think we fell through the cracks."

HHS Scraps Advisory Committee on Newborn Screening

NEWS PROVIDED BY

MedPage Today

By Jennifer Henderson

Study: **HHS Scraps Advisory Committee on Newborn Screening**

Current as of April 10, 2025

As cuts sweep across federal health agencies, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) has been terminated.

Notably, the ACHDNC, which sits under the Health Resources and Services Administrationopens in a new tab or window, is responsible for the Recommended Uniform Screening Panel (RUSP), a standardized list of dozens of conditionsopens in a new tab or window the HHS secretary recommends states screen for as part of their universal newborn screening programs.

"This is an absolutely essential committee for the life of America's babies," Susan Berry, MD, professor of pediatrics in the division of genetics and metabolism at the University of Minnesota in Minneapolis, who served as a member of the ACHDNC from 2017 to 2020, told MedPage Today. "It's an incredible public health protection, and to lose it is ... heartbreaking. People are shocked and frightened by it."

If the goal is a healthy America, "you want newborn-screened babies [and] the committee is what you need for that," added Berry, who also is director of the National Organization for Rare Disorders (NORD) Rare Disease Centers of Excellence at the University of Minnesota. "We have to have that committee back. It has to be reinstated."

If no action is taken to remedy the loss of the advisory committee, some states may be able to evaluate and determine new conditions that are good candidates to be added to their newborn screening panel while others can not, Allison Herrity, senior policy analyst at NORD, told MedPage Today.

"There are often already health disparities between states that have a large amount of resources for things like this and states that don't," Herrity said. And the termination of the ACHDNC "will just exacerbate those disparities."

The termination comes about 1 month shy of an advisory committee meeting (that had already been delayed earlier this year) to decide whether two conditions -- metachromatic leukodystrophyopens in a new tab or window (MLD) and Duchenne muscular dystrophyopens in a new tab or window (DMD) -- would be added to the RUSP, experts told MedPage Today.

There are new and promising gene therapies for these conditions, and their addition to the screening panel now hangs in the balance, adding to the dismay.

"It's really catastrophic ... that we would not be leveraging all of the great work done on the innovation side to keep these children from the incredible harm that they are facing, and their families," NORD CEO Pamela Gavin told MedPage Today. (Gavin previously released a public statementopens in a new tab or window on the termination of the ACHDNC.)

Many who are advocating for conditions

such as MLD and DMD to be added to the RUSP have been personally affected and want to spare other families from their experiences, Herrity noted.

Author and advocate Maria Kefalas, PhD, lost her daughter to MLD in 2022.

Children with MLD often present around 2 years of age, she said. They lose the ability to walk and talk within months of symptom onset, become paralyzed and feeding-tube dependent, and usually die between the ages of 6 and 10 years.

"My daughter lived until she was 12 years old," Kefalas said. "It was like ALS [amyotrophic lateral sclerosis] and Alzheimer's in a baby."

Kefalas said her daughter had more than 1,700 provider contacts in the 10 years following her diagnosis. Her daughter also was in the intensive care unit multiple times, was intubated, and experienced a C-curve in her body. "And we have the capacity to prevent that from happening," Kefalas said.

Next month, families planned to descend on Rockville, Maryland "to hear what they had been waiting for," that MLD would be added to the RUSP, Kefalas said. "And they just shut it down."

Clinicians have similarly sounded the alarm.

Mira Irons, MD, president of the American College of Medical Genetics and Genomics (ACMG), told MedPage Today in emailed remarks that the ACMG is "deeply concerned" about the termination of the ACHDNC.

"For more than two decades, this committee has played a critical role in safeguarding and advancing the nation's newborn screening system by providing evidence-based recommendations to ensure timely identification and intervention for infants with serious, often life-threatening genetic conditions," Irons said.

"The loss of this independent, expert advisory body threatens to disrupt a process that has had a profound impact on public health and the lives of countless families," Irons added. "The ACHDNC has served as a vital forum for scientific and clinical guidance and has provided a place for patient perspectives to be heard. Newborn screening programs in every state in the U.S. rely on the recommendations developed by ACHDNC."

Irons noted that ACMG developed a list of recommended conditions for newborn screening that was used to create the initial RUSP.

"ACMG remains committed to supporting a strong and effective national newborn screening system and to advocating for the infrastructure necessary to continue improving early detection and care for children with heritable disorders," she added. "We will be advocating for reinstatement of the ACHDNC and are considering ways to ensure that the valuable work of the committee is not lost in the interim."

Each year, newborn screening identifies around 14,000 babies with serious conditions, according to NORD.

The addition of MLD and DMD to the RUSP would identify an estimated 400 to 450 more infants annually that could be treated to prevent life-altering outcomes, including death, the organization contended.

Regarding the termination of the ACHDNC, HHS did not respond to request for comment.

NT



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WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.



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- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
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- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



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Institutional Logic and the Logic of Practice in the High-Reliability Organization (HRO)

Daved van Stralen, MD, FAAP, Sean D. McKay, Element Rescue, LLC, Thomas A. Mercer, RAdm, USN (Retired)

"Organizations have their institutional logic that drives organizational culture. HRO has its unique logic of operations engaging unexpected events. This is a similar situation for corporations that merge with entrepreneurial ventures – how to merge two distinct institutional logics without losing the characteristics necessary to maintain the organization's culture and the venture's agility."

Abstract

Organizations have their institutional logic that drives organizational culture. HRO has its unique logic of operations engaging unexpected events. This is a similar situation for corporations that merge with entrepreneurial ventures – how to merge two distinct institutional logics without losing the characteristics necessary to maintain the organization's culture and the venture's agility.

Introduction

For 35 years, HRO has been studied for its ability to reduce the severity of catastrophic events. Generally, HRO is translated into business terms and made amenable to corporations, the mistranslation washing out the vitality of HRO (1).

A significant reason may lie in institutional logic. Corporations have their institutional logic, which, for the most part, HRO acts as the antithesis. In his paper, we propose the benefit of looking at HRO as a logic of practice that can parallel corporate institutional logics, if not buttress them for rarely encountered events. Lying quietly in the backfield and not washed out, HRO can utilize routine corporate values and actions to engage in time-compressed uncertainty.

Institutional Logics:

Roger Friedland and R. Robert Alford (2) described how institutions have a central logic, a set of practices and symbols that constitute organizing principles within which individuals can work. This *institutional logic* provides individuals with vocabularies of motives and a sense of self.

Through these logics, institutions shape the behavior of their members, while behaviors, in turn, shape institutional logic. This feedback interaction creates the rules of "the game:" understanding institutional logic will influence the competition for power and status (3).

Institutional logic guides classification and categorization, which shape an individual's cognition. Institutional logics affect attention for perception, interpretation, evaluation, and response to environmental situations, as well as decisions about which problems to engage, which solutions to consider, and which solutions to link to a given situation. Institutional logics bridge the gap between the institution's structural perspectives and the microprocess approaches of individuals (3).

Specific types of institutional logic include entrepreneurial and venture logic, the logic of military operations, and the logic of practice found in HROs.

Entrepreneurial Logic

Entrepreneurial logics focus on innovation, creating new markets and technologies, and the pursuit of opportunities (4). Interactions in support organizations expose entrepreneurs to narratives by other members, which convey new entrepreneurial and community logic (5).

"Entrepreneurial logics focus on innovation, creating new markets and technologies, and the pursuit of opportunities (4). Interactions in support organizations expose entrepreneurs to narratives by other members, which convey new entrepreneurial and community logic (5)."

Entrepreneurs tolerate uncertainty, risk, and failure, particularly acceptance of business failure without stigmatization (4, 6). Their narratives communicate stories of past entrepreneurial successes and failures (5). As with HROs, errors and failures convey vital information (7). The entrepreneurial community in Boulder, Colorado, supports entrepreneurs who fail rather than shaming the founders of failed start-ups. Such entrepreneurs are welcomed as advisors and mentors, a deeply ingrained cultural norm (8).

Institutional entrepreneurs have promoted their logic in a dominant corporate logic by using storytelling (9). However, the use of entrepreneurial logic within corporate logic can become misleading. One must not use the achievement of goals of the corporate logic to replace key performance indicators that measure entrepreneurial performance. Goal achievement for venture start-ups do not follow a focused timeline, and entrepreneurial ventures typically lag in revenue production (10).

While it is normal for an organization to have a single institutional

logic, some organizations may have two. For example, corporations have included venture or entrepreneurship logic to enhance corporate innovation or merged with a venture company. This creates a significant divergence between the corporation's institutional logic and the entrepreneurial logic of the venture companies (10).

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The Logic of Military Operations

The USS Carl Vinson and HRO. Codification of HRO developed from military operations. Karlene Roberts and the Berkeley HRO Group initially codified HRO from the crew's performance on the flight and hanger decks of the USS Carl Vinson, the US Navy's second nuclear-powered aircraft carrier (11). During the roughly 30-year period from WWII through the Vietnam War, the US Navy's Pacific Fleet conducted most of the Navy's combat operations, making death a part of operations and creating 'rules written in blood.' When the US Navy's involvement in the Vietnam War ended, the US Navy established additional risk management and safety programs for greater attention to operational readiness.

Captains of a US Navy aircraft carrier are nuclear trained and, by act of the US Congress, must be aviators. Thus, the first *nuclear* aircraft carriers brought together three independent, otherwise disparate domains within a single individual: 1) aerial warfare experience with initiative, improvisation, and flexibility; 2) nuclear propulsion engineering experience with rigor, detail, and conformity to procedures; and 3) previous aircraft squadron and large ship command of complex organizations in demanding circumstances. This remains the standard except for more limited aerial combat experience (12).

The training and professionalism of the nuclear propulsion engineers helped form the basis for increased safety awareness and reliability of operations throughout the carrier and embarked air wing. HRO emerged on the nuclear aircraft carrier by merging the emergency-type responses of aerial combat with the control-operator functions for a nuclear reactor (12).

Military Operations. Military operations occur between the level of strategy and tactics. The operational level bridges and integrates the two levels, between contemplation of abstract knowledge and the mechanical action of tactics using local knowledge. At a practical level, operations are "the proposition of concrete scenarios of action" versus "the presentation of arguments anchored in abstract theories" (13).

Complementary interaction between offensive and defensive actions is essential for developing a dynamic operation. A tactical defense utilizes depth, simultaneous synergy, and operational initiative to give the dynamic properties and operational ability necessary to attain strategic goals (13).

Operations have a time dimension in their logic from present to future, notably missing from most corporate, institutional logic (14). Time as a distinct dimension shifts focus from achieving the ideal performance to continuous responses as new contingencies emerge – "learning by doing." The concept of error as an absolute in performance becomes valued as a continuous learning method (7).

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The Logic of Practice

We engage and enact into uncertainty an ambiguous situation. Within the HRO, this is a shared *logic of practice,* which, in an HRO, becomes the institutional logic (15). Outsiders easily misunderstand the logic of practice as it occurs inside the flux and trajectory of events. Cognition and behaviors become normalized without the necessary access to inner mental states that may have been impaired by stress and threats. What is missed is stress and threat manifested as contingently linked behaviors (1, 16, 17). Detached observation and identification of abstract properties, necessary for scientific objectivity, conceal the situational reasoning and intent of the operator (17-19). The internal logic of individuals' operations becomes unrecognized and inaccessible (20).

Karl Weick (21) described how these "cosmology episodes" collapse sensemaking and leadership. This occurred even with seasoned wildland firefighters during the 1949 Mann Gulch Fire when they mistook a large fire for an ordinary fire and were overtaken by a firestorm. Such abrupt breaches in the environment involve the entire group or organization. In structured, predictable environments, what is rational and logical becomes harmful during a cosmology episode. Actions or events may appear irrational because we do not recognize the system's internal logic. We will likely continue using classical, scientific logic even as the system's internal logic changes.

Boyd's response (22) to disrupting observed reality parallels Weick's sensemaking perspective – operators create what they focus on through repeated cycles. For Weick's sensemaking, the operator distinguishes cues within an ambiguous event to use for enactment toward a resolution that restores the disrupted activity (23, 24).

Two Logics

Institutional logics create a sense of common purpose and unity within the organization. Corporate logic readily becomes the

dominant logic over other logic that exists simultaneously. This does not mean that the dominant corporate institutional logic is persistent. New logic can drive institutional change or become dominant (25). Ann-Kathrin Leiting, Bart Clarysse, and Jana Thiel (10) found significant tensions between the 'corporate culture' and the 'entrepreneurial logic' of the venture capitalists, primarily in more unfocused achievement goals and time lags in the developing revenue stream.

When operators engage within the turbulence and trajectory of events, generating information and knowledge for lessons learned, the dominant corporate logic creates hidden voices (1, 26). The strategic level of analysis, as a fixed-point reference frame outside the flux of events, has a broader view with less confusing nuance. Concepts neatly and rapidly coalesce, partly for organization management and sometimes for the needs of distant regulators and customers. These accounts' speed, putative strength, and familiarity drive them to become the dominant institutional logic. Lost are the experienced hidden voices that capture ephemeral lessons learned (27). As the baseline shifts (28), the subculture *for* dangerous contexts drifts away from the operational level to become lost in the dominant logic (29).

Competing logics create rivalries and conflicts of power. With time, one of the logic outcompetes the other. However, there are situations where competing logics co-exist. It is not clear how competing logics translate into such stability (25). This is a significant problem when HRO, as institutional logic, is brought into an organization with a robust dominant corporate logic.

To qualify as institutional entrepreneurs, individuals must break with existing rules and practices associated with the dominant institutional logic(s) and institutionalize the alternative rules, practices, or logics they are championing (30).

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Healthcare

Introducing the new *business-like healthcare logic* challenged the previously dominant logic of medical professionalism. A healthcare field organized by medical professionalism means the physician-patient relationship guides all service provision, using professional knowledge to determine appropriate patient care. The logic of medical professionalism and business-like health care began competing, each associated with different organizing principles (25).

The intent of the new institutional logic of healthcare is a *business-like model* to increase efficiency. New structures have evolved to increase efficiency and 'do more with less' [Regional Health Authorities Act, SA 1994, c R-9.01, Alberta Government]. The focus of healthcare is now a business-like logic for cost-effective treatment, lowest-cost providers, and customer satisfaction. In the example of Alberta, Canada, the government identified physicians as a significant source of current problems and increased healthcare costs. The Alberta government excluded physicians from positions in the newly created Regional Health Authorities. (25)

"Introducing the new business-like healthcare logic challenged the previously dominant logic of medical professionalism. A healthcare field organized by medical professionalism means the physician-patient relationship guides all service provision, using professional knowledge to determine appropriate patient care. The logic of medical professionalism and business-like health care began competing, each associated with different organizing principles (25)."

The Problem of Two Logics:

Institutional logics are the organizing principles that shape the behavior of members, defining the content and meaning of the organization. Institutional logics provide a link between institutions and action. Institutional change usually follows a new logic for the field (25).

Ventures that do not successfully integrate their institutional logic, *fail to adopt elements from the corporate logic,* and show little interest in giving back to the corporation will become separated from the corporation and are prone to failure. Ventures that take the route of pure assimilation do not succeed either because they do not contribute to the goal of corporate strategic renewal. These interactions operate at the micro level of mechanisms and can guide us during the introduction of a new logic, the HRO logic of practice, into an established dominant logic (10).

The acculturation process means the corporate logic needs to be 'acquired' and understood. The HRO logic of practice is 'anchored' in the corporate logic (10). What we miss here is that HRO operators do not have the lexicon and descriptors to articulate HRO to outsiders with limited experience operating in forcing functions or abrupt catastrophic change—many of whose main challenge is within a white noise environment responding to white noise variance (31).

From a micro-level point of view, actions can be nuanced and less overt in managing rival logic. Such individuals who support a nondominant logic have neither the authority nor the finances to challenge the dominant logic openly. Instead, they focus on the context, developing change strategies as incremental advances toward their goals. Over time, operating 'under the radar' results in new field-level logic (25).

One of the authors (DvS), in association with another physician (Ronal M. Perkin), brought HRO into pediatric training and a children's hospital PICU despite opposition from higher-ranking physicians, administrators, and legal counsel and introduced HRO into EMS (32-34).

Conclusion:

Corporate institutional logic does not recognize the distinctiveness of the HRO logic of practice (1) and the role of moral agency (34). The HRO logic of practice incorporates microlevel self-organization at the point of disruption. Self-organization is an internal logic of practice rather than directed from the outside.

The logic has not been fully elucidated and disseminated as the logic of practice, theory versus practice, and time as a dimension with simultaneous multiple time scales. (1, 14, 15, 35-37). The lexicon is not recognized. Academics have elucidated and characterized institutional logic, yet HRO operators have not. Elucidation and characterization of operational logic (29) is more likely viewed as an oddity or not a fully mature logic.

To introduce HRO as an institutional logic, we must understand how it can support the dominant corporate culture and the unique logic of practice that comprises HRO, so it is not lost through assimilation or co-optation but yes to that 'acculturation.' Corporations and healthcare as a corporate business-like model generally have robust institutional logic.

"Corporate institutional logic does not recognize the distinctiveness of the HRO logic of practice (1) and the role of moral agency (34). The HRO logic of practice incorporates microlevel self-organization at the point of disruption. Self-organization is an internal logic of practice rather than directed from the outside. "

HRO, as an institutional logic, can compete or interfere with corporate logic during routine times with white noise variance. The shift from corporate logic to HRO logic will occur subtly from forcing functions or abruptly from abrupt catastrophic events. Either way, it will often be a lower-ranking member who first engages in the incident.

In corporations, HRO is a secondary, if not subordinate, logic. It is the dominant logic in other organizations, such as the operational military and public safety.

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Different Technology, Same Protective Value

AfPA

https://www.who.int/news-room/feature-stories/detail/how-do-vaccines-work#:~:text=Vaccines%20contain%20weakened%20or%20inactive,rather%20than%20the%20antigen%20itself.

https://static1.squarespace.com/static/5523fcf7e4b0fef011e688e6/t/62445afd0134140ff354f3f6/1648646910485/NCIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf

VACCINES		PREVENTIVE MONOCLONAL ANTIBODIES
Teach the body to create antibodies that fight off a specific disease.		Introduce antibodies that are ready to ward off disease in the body.
By introducing an inactive piece of a disease or proteins that look like the disease, they trigger an immune response, training the body to create antibodies that defeat the disease.	**How does it work?**	Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily available.
Both support the immune system's defenses.		
Many vaccines are readily and easily available. The technology behind vaccines has been around for decades.	**What are the benefits?**	Preventive monoclonal antibodies can provide protection for diseases where there isn't an existing vaccine or there isn't an existing vaccine for certain patient groups.
Both protect against disease and provide a public health benefit by decreasing the burden of disease.		
Polio Measles COVID-19 And more	**What can this immunization protect against?**	RSV COVID-19
Both can provide tailored protection from a variety of diseases.		
Yes	**Is it safe?**	Yes
Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.		

Keeping Your Baby Safe
from respiratory infections

RSV
COVID-19
colds
flu

How to protect your little ones from germs and viruses

Cold and flu season can be dangerous - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based hand sanitizers.



Limit Contact with Others



- Stay home when you can.
- Avoid sick people.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.

Provide Protective Immunity

- Hold your baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



Take Care of Yourself

- Stay connected with your family and friends.
- Drink more water and eat healthy foods.
- Seek mental health support.
- Sleep when you can.



Get Immunized

Vaccinations save lives. Protecting your baby from RSV, COVID-19, flu, and pertussis lowers their risks for complications from respiratory infections.



WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.



If you feel sick or are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop viruses from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.
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How to Care for a Baby with Signs of Withdrawal

Use the Right Words

I was exposed to substances in utero. I am not an addict. And my parent may or may not have a Substance Use Disorder (SUD).

Treat Us as a Dyad

Parents and babies need each other. Help us bond. Whenever possible, provide my care alongside my parents and teach them how to meet my needs.

Support Rooming-In

Babies like me do best in a calm, quiet, dimly-lit room where we can be close to our caregivers.

Promote Kangaroo Care

Skin-to-skin care helps me stabilize and self-regulate. It helps relieve the autonomic symptoms associated with withdrawal, promotes bonding, and helps me sleep.

Try Non-Pharmacological Care

Help me self-soothe. Swaddle me snugly in a flexed position that reminds me of the womb. Offer me a pacifier to suck on. Protect my sleep by "clustering" my care.

Provide Lactation Support

Human milk is important to my gastrointestinal health and breastfeeding is recommended when my parent is HIV-negative and receiving medically-supervised care. Help my family reach our pumping and feeding goals.

Treat My Symptoms

If I am experiencing signs of withdrawal that make it hard for me to eat, sleep, and be soothed, create a care plan to help me wean comfortably.

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Peer Reviewed

Delivery Room Management, I

Scott D. Duncan, MD, MHA

"Attendance at delivery is a frequent occurrence in the life of a neonatologist. Many scenarios require a qualified health professional to be in the delivery room."

Attendance at delivery is a frequent occurrence in the life of a neonatologist. Many scenarios require a qualified health professional to be in the delivery room. The first of a two-part article, a sampling is included below:

"The on-call in-house neonatologist is called for a cesarean section at 6 AM due to failure to progress. Grumbling the whole way to L&D, the OR nurse reminds the neonatologist that the Best Hospital requires a physician to be present for all cesarean deliveries."

Question:

The on-call in-house neonatologist is called for a cesarean section at 6 AM due to failure to progress. Grumbling the whole way to L&D, the OR nurse reminds the neonatologist that the Best Hospital requires a physician to be present for all cesarean deliveries. The cesarean delivery produces a live/viable male infant. The infant is crying and vigorous. After delayed cord clamping, the infant is brought to the warmer, where he is dried, oropharyngeal suctioned, and stimulated. APGAR scores are 8/9, and the infant is taken to the mother for bonding. For the delivery room service, the neonatologist reports:

A. **99464**: Attendance at delivery (when requested by the delivering physician or other qualified healthcare professional) and initial stabilization

B. **99465**: Delivery/birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output

C. **No billable service**



Answer:

C. **No billable service**

Codes **99464-99465** are used to report delivery/birthing room attendance and resuscitation services. Note the phrase "when requested by the delivering physician or other qualified healthcare professional." When healthcare system protocols or guidelines require a qualified health provider to attend a delivery, there is no billable delivery service unless requested by the physician.

"When healthcare system protocols or guidelines require a qualified health provider to attend a delivery, there is no billable delivery service unless requested by the physician."

Question:

True or False. Can 99464 be reported in conjunction with 99460, initial hospital or birthing center care, for the evaluation and management of normal newborn infants?



Answer:

True. 99464 and 99460 are not bundled under National Correct Coding Initiatives; therefore, no modifier is required**.** If reporting 99460, the physician must provide a comprehensive history and physical examination, order any diagnostic tests and interventions, counsel the family, and complete documentation.

"99464 and 99460 are not bundled under National Correct Coding Initiatives; therefore, no modifier is required. If reporting 99460, the physician must provide a comprehensive history and physical examination, order any diagnostic tests and interventions, counsel the family, and complete documentation."

Question:

Dr. Smith requests that the neonatologist attend a cesarean section for a primigravida at 36 completed weeks' gestation with severe pre-eclampsia beginning at 30 weeks gestation and fetal growth restriction. The cesarean delivery produces a live/viable female infant. The infant is limp with occasional respiratory efforts. The infant is brought to the warmer, where she is dried, oropharyngeal suctioned, and stimulated. CPAP is applied due to ongoing cyanosis and moderate intercostal retractions. The infant demonstrates improvement and is subsequently admitted to the NICU for observation. Birthweight is 1830g, less than the 10th percentile. Head circumference and length are above the 10th percentile for gestational age. For the delivery room service, the neonatologist reports:

A. **99464**: Attendance at delivery (when requested by the delivering physician or other qualified healthcare professional) and initial stabilization

B. **99465**: Delivery/birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output

C. **No billable service**



Answer:

A. 99464: Attendance at delivery (when requested by the delivering physician or other qualified healthcare professional) and initial stabilization

99464 is reported when the provider is requested to attend the delivery by the delivering physician in consideration of a newborn who may require immediate intervention. **99464** will include drying, stimulation, suctioning, free-flow O2, HFNC, or CPAP without positive pressure ventilation.

Question:

The correct ICD-10 codes include all the following except:

A. **Z38.01** Single liveborn infant, delivered by cesarean

B. **O14.13:** Severe pre-eclampsia, third trimester

C. **P00.00:** Newborn affected by maternal hypertensive disorders

D. **P05.07:** Newborn light for gestational age, 1750-1999g

E. **P07.39:** Preterm newborn, gestational age 36 completed weeks

Answer:

B. O14.13

O codes are restricted to the maternal chart and are never to be used in the infant's chart! P00-P04 are used when the maternal conditions cause confirmed or potential morbidity with origins in the perinatal period. P00.00 is reflective of maternal hypertensive disorders found in the O chapter, O10-O16 (edema, proteinuria, and hypertensive disorders in pregnancy, childbirth, and the puerperium), excluding O12 (gestational edema and proteinuria without hypertension).

Also note the use of P05.07, which reflects an infant who is light-for-dates, with a weight less than the 10th percentile but a length greater than the 10th percentile. Be aware that low birthweight codes P07.0X and P07.1X should not be coded when using P05 codes.

The sequencing order of the code set would be Z38.01, P05.07, P07.39, and P00.00. Note that the birthweight is coded before the gestational age.

"Attendance at delivery notes requires a written report for proper coding and billing. Documentation must support all code assignments, including appropriate diagnosis. The medical record must include the request for the attendance at the delivery."

Documentation Tip:

Attendance at delivery notes requires a written report for proper coding and billing. Documentation must support all code assignments, including appropriate diagnosis. The medical record must include the request for the attendance at the delivery. If there is no documentation, the attendance at delivery note should include the delivery physician's request and the indication for attending delivery. The note should include interventions in the delivery room, a cursory examination, assignment of APGAR scores, discussion with the referring physician and parents, and the disposition of the infant.

References:

1. Coding for Pediatrics 2025, 30th Edition. American Academy of Pediatrics
2. Current Procedural Terminology 2025, Professional Edition. American Medical Association
3. ICD-10-CM 2025, The Complete Official Codebook. American Medical Association

Biographical Sketch

Dr. Duncan received his undergraduate degree from Transylvania University in Lexington, KY, and completed his medical training at the University of Louisville. He completed a Master's Degree in Healthcare Administration at the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill in 2011. He is a Professor and Division Chief of the Division of Neonatal Medicine at the University of Louisville. Dr. Duncan is a Fellow of the American Academy of Pediatrics and is the Chair of the Coding Committee of the Section on Neonatal-Perinatal Medicine. Dr. Duncan has no conflict of interest.

***Disclosures**: The author has no disclosures*

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2024

Protecting your baby and family from

Respiratory Viruses:

What parents need to know this RSV and flu season

Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.

Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. Now there are new vaccines for RSV for adults and antibody shots for babies that can help protect them.

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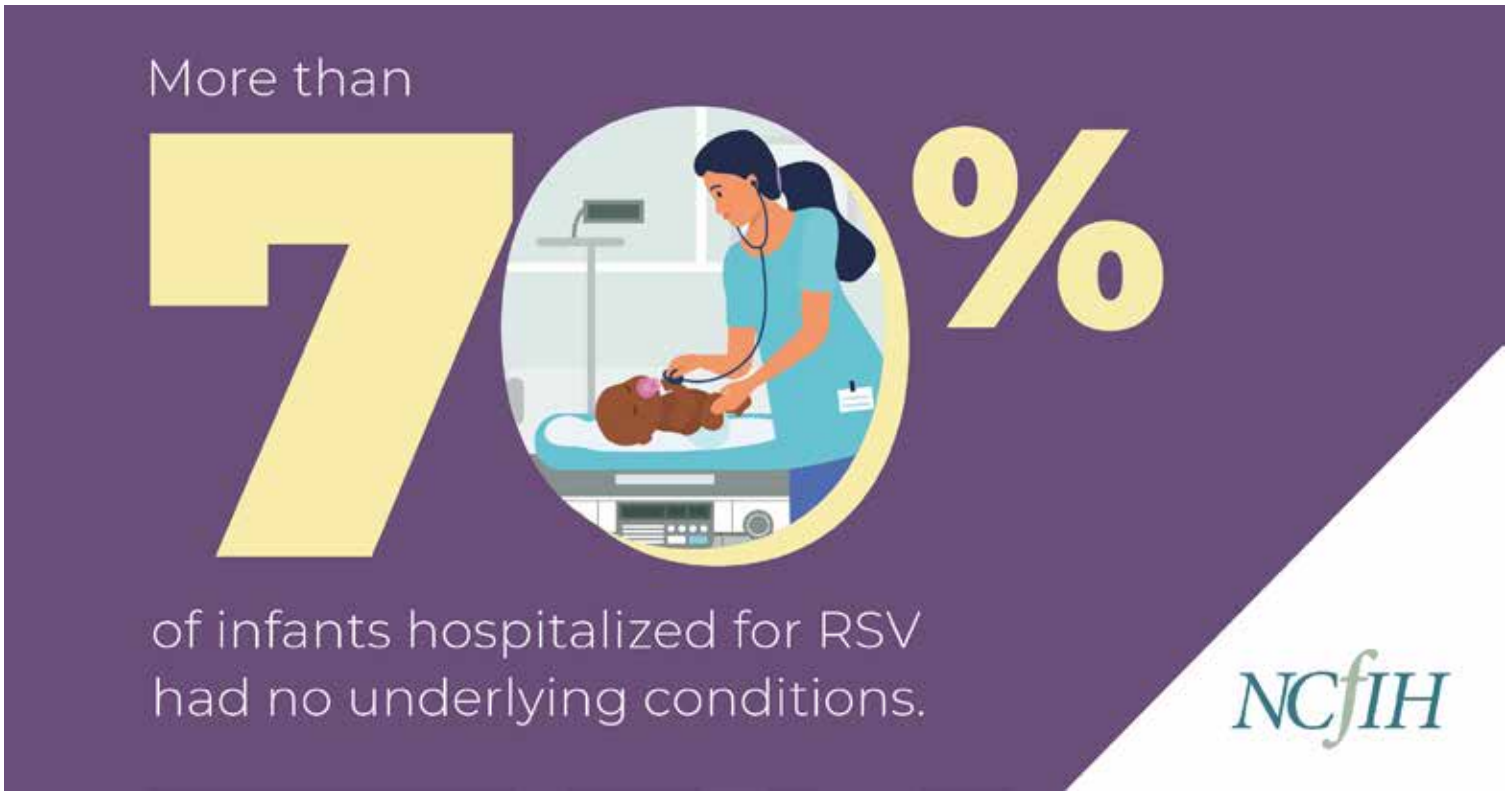
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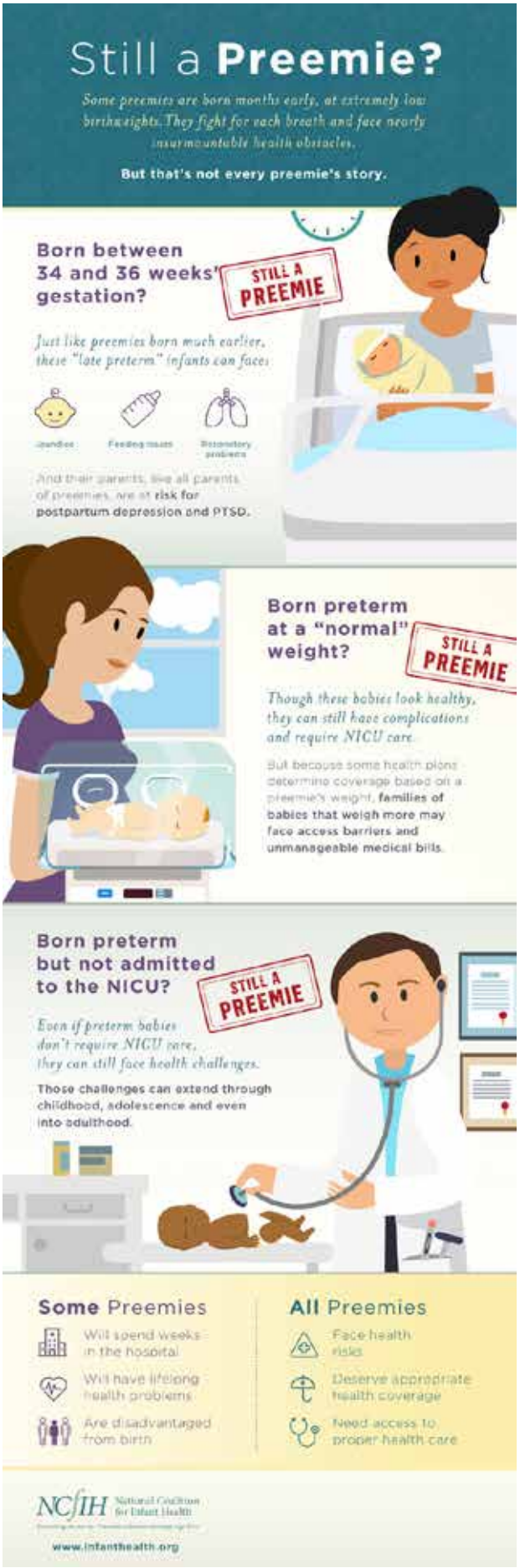
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Still a Preemie?
Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.
But that's not every preemie's story.
Born between 34 and 36 weeks' gestation?
STILL A PREEMIE
Just like preemies born much earlier, these "late preterm" infants can face:
And their parents, like all parents of preemies, are at risk for postpartum depression and PTSD.
Born preterm at a "normal" weight?
STILL A PREEMIE
Though these babies look healthy, they can still have complications and require NICU care.
But because some health plans determine coverage based on a preemie's weight, families of babies that weigh more may face access barriers and unmanageable medical bills.
Born preterm but not admitted to the NICU?
STILL A PREEMIE
Even if preterm babies don't require NICU care, they can still face health challenges.
Those challenges can extend through childhood, adolescence and even into adulthood.
Some Preemies
Will spend weeks in the hospital
Will have lifelong health problems
Are disadvantaged from birth
All Preemies
Face health risks
Deserve appropriate health coverage
Need access to proper health care
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www.infanthealth.org


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Prioritize health + racial equity as a goal.
Make health equity and implicit bias training mandatory.
Communicate with parents using plain language.
Partner with Black parents to deliver bias free care.
Hire, retain, or partner with Black Preemie family support groups + professionals to fill diversity gaps.
Make digital + virtual resources available
Encourage reading to Preemie babies while bedside.
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Pallister-Killian Syndrome: A Case Report of Neonatal Pathogenic Tetrasomy 12p Associated with Congenital QT Prolongation and Multisystem Involvement

Hua Wang M.D., Ph.D

Abstract

Background: *Pallister-Killian syndrome (PKS) is a rare, mosaic genetic disorder caused by tetrasomy of the short arm of chromosome 12. A broad spectrum of clinical findings, including dysmorphic features, hypotonia, and multisystem involvement, characterizes it.*

"Pallister-Killian syndrome (PKS) is a rare, mosaic genetic disorder caused by tetrasomy of the short arm of chromosome 12. A broad spectrum of clinical findings, including dysmorphic features, hypotonia, and multisystem involvement, characterizes it."

Case Presentation: *We report a female neonate born at 36 weeks gestation via cesarean section for breech presentation, who presented with congenital QT prolongation, slow feeding, and respiratory distress. Additional findings included lymphedema, macrocephaly, and dysmorphic facial features. Cardiac imaging demonstrated a mildly dysplastic tricuspid valve with a small patent foramen ovale. Neuroimaging suggested early cerebral atrophy and multiple foci of small hemorrhages. Chromosome microarray analysis performed on a buccal swab revealed a 34.9 Mb pathogenic tetrasomy spanning 12p13.33p11.1, consistent with PKS.*

Conclusion: *This case underscores the phenotypic variability of PKS, and early genetic diagnosis, along with targeted cardiac and neurological evaluations, can help optimize supportive care. Furthermore, the congenital QT prolongation in this patient highlights the potential involvement of genes within the affected region (e.g., CACNA1C) and raises the need for vigilant cardiac monitoring.*

Introduction:

Pallister-Killian syndrome (PKS, OMIM 601803) is a rare, mosaic genetic disorder characterized by the presence of an extra isochromosome composed of the short arm of chromosome 12 (tetrasomy 12p) (1). This chromosomal abnormality arises de novo and exhibits a sporadic inheritance pattern, with mosaicism varying considerably between tissues. Consequently, peripheral blood karyotyping may often yield normal results, complicating the diagnostic process and necessitating alternative tissues—such as skin biopsies or buccal swabs—for accurate detection. Clinically, PKS manifests with a broad spectrum of features, including dysmorphic facial characteristics, hypotonia, developmental delays, and multisystem involvement, which further challenges clinicians in establishing a definitive diagnosis (2).

This case report is noteworthy because, besides exhibiting the classical features of PKS, the patient presents with congenital QT prolongation—a cardiac finding not typically associated with this syndrome. The identification of QT prolongation raises the possibility of the involvement of cardiac genes, such as CACNA1C, located within the affected region of chromosome 12, thereby suggesting a potential expansion of the PKS phenotype.

"This case report is noteworthy because, besides exhibiting the classical features of PKS, the patient presents with congenital QT prolongation—a cardiac finding not typically associated with this syndrome. The identification of QT prolongation raises the possibility of the involvement of cardiac genes, such as CACNA1C, located within the affected region of chromosome 12, thereby suggesting a potential expansion of the PKS phenotype."

Case Description:

This is a 14-day-old female who was born at 36 weeks and 2 days via cesarean section due to breech presentation. Her birth weight was 3425 g (74th%-ile), and she had a head circumference of 36.2 cm (97th%-ile), notable for macrocephaly. Her initial APGAR scores were 7 and 8 at 1 and 5 minutes, respectively. Despite being late preterm, she required admission to the neonatal intensive care unit (NICU) due to respiratory distress, feeding difficulties, and prolonged QT interval on electrocardiogram (ECG).

From birth, the baby demonstrated a constellation of findings that raised concerns about an underlying genetic condition. She exhibited lymphedema of the extremities, abnormal posturing, mildly elevated lactate levels, and intermittent hypoglycemia. Although no overt seizure activity was noted, she experienced abnormal movements, prompting an electroencephalogram (EEG) that ruled out epileptiform activity. Due to her dysmorphic facial features—including a coarse facial appearance, slight hypertelorism, eyes with sparse eyebrows and eyelashes, a short nose with anteverted nostrils, and a thin upper lip—and her systemic complications, a genetics consultation was requested.

As her clinical condition evolved, concerns about cardiac

involvement emerged. An echocardiogram on day 7 of life identified a mildly dysplastic tricuspid valve with mild regurgitation and a small patent foramen ovale (PFO). The significance of these findings remained unclear, but her concurrent ECG abnormalities—including congenital QT prolongation—prompted close cardiac monitoring. Her feeding difficulties persisted, requiring nasogastric support, and she exhibited recurrent tachycardia along with episodes of loose stools, which resolved over the next few days.

"She exhibited lymphedema of the extremities, abnormal posturing, mildly elevated lactate levels, and intermittent hypoglycemia. Although no overt seizure activity was noted, she experienced abnormal movements, prompting an electroencephalogram (EEG) that ruled out epileptiform activity. Due to her dysmorphic facial features—including a coarse facial appearance, slight hypertelorism, eyes with sparse eyebrows and eyelashes, a short nose with anteverted nostrils, and a thin upper lip—and her systemic complications, a genetics consultation was requested."

Neuroimaging findings added further complexity to her clinical picture. A brain MRI revealed prominent cerebral sulci and enlarged bifrontal and bitemporal subarachnoid spaces, suggesting early cerebral atrophy rather than benign enlargement of subarachnoid spaces seen in infancy. Additionally, multiple foci of T1 hyperintensity were observed in the periventricular and subcortical white matter of the bilateral frontal lobes, left corona radiata, and bilateral parieto-occipital regions. These findings raised concerns about prior small hemorrhages, although their etiology remained uncertain. Further systemic evaluation included an abdominal ultrasound, which showed nonspecific increased renal parenchymal echogenicity but was otherwise unremarkable.

Given the clinical presentation, the genetics team performed a chromosomal microarray analysis on a buccal swab sample. The microarray analysis was conducted at **Invitae** (test #6913904) using comparative genomic hybridization (CGH) technology. The results showed the presence of *arr[GRCh37] 12p13.33p11.1(164439_34852437)x4*, a 34.9 Mb pathogenic tetrasomy spanning the entire short arm of chromosome 12 (12p13.33p11.1x4), establishing a diagnosis of Pallister-Killian syndrome. This diagnosis explained her dysmorphic features, hypotonia, and multisystem involvement. However, congenital QT prolongation remained an intriguing finding, as this is not a well-recognized feature of PKS. The involvement of genes such as *CACNA1C*, which is located within the duplicated chromosomal region and associated with cardiac conduction disorders, was considered a potential contributor to her ECG abnormalities.

Management and Outcome:

Given the diagnosis of Pallister-Killian syndrome (PKS) and her complex medical presentation, a multidisciplinary care approach was implemented to address her immediate and long-term needs. Management strategies were tailored to mitigate her symptoms, support her development, and monitor for potential complications. Genetic counseling was provided to the family, emphasizing that the condition is not inherited and the recurrence risk is less than 1%. The genetics team recommended confirmatory mosaicism testing via blood karyotype and fluorescence in situ hybridization (FISH) to assess the extent of mosaicism in different tissues.

"The results showed the presence of arr[GRCh37] 12p13.33p11.1(164439_34852437)x4, a 34.9 Mb pathogenic tetrasomy spanning the entire short arm of chromosome 12 (12p13.33p11.1x4), establishing a diagnosis of Pallister-Killian syndrome."

Throughout her hospitalization, the patient showed gradual improvement in respiratory function and stabilization of her cardiac status, allowing for the weaning of respiratory support. Her feeding challenges persisted, but with nutritional support through her G-tube, she demonstrated adequate weight gain. Serial ECGs confirmed that her QT prolongation had resolved, but she remained under cardiology follow-up due to the presence of tricuspid valve dysplasia and a small PFO. Given the potential risk for evolving cardiac complications, periodic echocardiographic surveillance was planned. Neurologically, the patient continued to exhibit hypotonia, prompting early referral for physical and occupational therapy. Plans were also made to reassess her developmental progress at regular intervals and to monitor for potential seizure onset.

Discussion:

Pallister-Killian syndrome (PKS) is a rare mosaic genetic disorder caused by tetrasomy of the short arm of chromosome 12 (12p). It arises from a supernumerary isochromosome 12p, which is not inherited but occurs sporadically due to a post-zygotic chromosomal duplication event. The estimated prevalence of PKS is approximately 1 in 20,000 to 1 in 25,000 live births, though the actual frequency is likely underreported due to difficulties in diagnosing mosaic conditions (3).

The clinical phenotype of PKS is highly variable and often depends on the level of mosaicism in different tissues. Some of the most consistent clinical features include:

- **Dysmorphic facial features:** Coarse facial appearance, high forehead with frontal bossing, sparse scalp hair (particularly in infancy), hypertelorism, upslanting palpebral fissures, a short nose with anteverted nostrils, long philtrum, and thin upper lip
- **Neurological involvement:** Severe hypotonia in infancy, intellectual disability, and developmental delay are hallmark

features. Seizures are reported in up to 40% of cases (3).

"[PKS] arises from a supernumerary isochromosome 12p, which is not inherited but occurs sporadically due to a post-zygotic chromosomal duplication event. The estimated prevalence of PKS is approximately 1 in 20,000 to 1 in 25,000 live births, though the actual frequency is likely underreported due to difficulties in diagnosing mosaic conditions."

- **Growth abnormalities:** Some infants present as large-for-gestational-age (LGA) at birth, but postnatal growth failure is common.
- **Congenital anomalies:**
  - **Cardiac defects:** Atrial septal defects (ASDs), ventricular septal defects (VSDs), bicuspid aortic valve, and aortic dilatation may occur in up to 50% of cases (4).
  - **Gastrointestinal anomalies:** Diaphragmatic hernia is a significant feature seen in some cases, along with gastroesophageal reflux disease (GERD).
  - **Skeletal abnormalities:** short limbs, scoliosis, and joint contractures may be present.
  - **Hearing and vision impairments:** Sensorineural hearing loss and ophthalmologic anomalies, including optic atrophy and strabismus, have been reported (3).

The phenotypic spectrum of PKS is highly variable, with differences in severity, organ involvement, and developmental outcomes. A systematic review of 59 cases by Wilkens et al. (2012) provided one of the most comprehensive clinical characterizations of PKS (3). Their study found that:

- **Hypotonia is the most consistent feature**, seen in nearly all cases, and is the primary cause of motor delay.
- **Cardiac defects were present in 50% of cases**, with ASDs and VSDs being the most common.
- **Seizures were reported in 40% of individuals**, usually beginning in early childhood.
- **Gastroesophageal reflux and feeding difficulties** were frequent, often requiring **G-tube placement** for adequate nutrition.
- **Intellectual disability was nearly universal**, but its severity varied significantly.

Another large cohort study by Karaman et al. (2018) reviewed 15 cases and reinforced that phenotypic variability is linked to the level of mosaicism in different tissues (2). Notably, individuals with higher levels of tetrasomy 12p in fibroblast or buccal samples tended to have more pronounced developmental delays and congenital anomalies. Tilton et al. (2014) specifically examined the cardiac manifestations of PKS, highlighting that valvular abnormalities, septal defects, and cardiomyopathy occur more frequently than previously recognized (4). However, no direct association with congenital QT prolongation was noted, making our case a significant contribution to understanding the expanded cardiac phenotype of PKS.

Diagnostic criteria for PKS rely on clinical findings and confirmatory genetic testing. Given its mosaic nature, standard karyotyping on blood samples is often insufficient. Instead, chromosomal microarray analysis (CMA) or fluorescence in situ hybridization (FISH) using buccal cells or fibroblasts is recommended for accurate diagnosis (2).

The differential diagnosis for PKS includes several genetic syndromes with overlapping features:

- **Trisomy 12p syndrome**: Non-mosaic **full trisomy 12p** can present similarly to PKS, but it is typically associated with **more severe congenital anomalies** and higher mortality in infancy (1).
- **Down syndrome (Trisomy 21)**: Both conditions share facial dysmorphism and hypotonia, but PKS often presents with **sparser scalp hair, larger birth weight, and a distinct craniofacial appearance**.
- **Sotos syndrome**: Features include **macrocephaly, overgrowth, and developmental delay**, similar to PKS. However, Sotos syndrome is caused by **NSD1 mutations** and lacks the isochromosome 12p finding.
- **Beckwith-Wiedemann syndrome (BWS)**: Both syndromes involve **overgrowth features at birth**, but macroglossia, abdominal wall defects, and a predisposition to embryonal tumors characterize BWS.

"Diagnostic criteria for PKS rely on clinical findings and confirmatory genetic testing. Given its mosaic nature, standard karyotyping on blood samples is often insufficient. Instead, chromosomal microarray analysis (CMA) or fluorescence in situ hybridization (FISH) using buccal cells or fibroblasts is recommended for accurate diagnosis."

- **Other chromosomal disorders**, Mosaic **trisomy 8, 9p deletion syndrome, and 18p deletion syndrome,** can present overlapping features, necessitating genetic testing for differentiation (3).

The formation of isochromosome 12p, characteristic of Pallister-Killian syndrome (PKS), is thought to result from errors in chromosome segregation. This leads to an additional abnormal chromosome consisting of two identical short arms (12p) and the

loss of the long arms (12q). Because PKS arises as a de novo mosaic condition, the recurrence risk is considered very low—estimated to be less than 1%—due to its sporadic, post-zygotic origin (2). Parental testing is generally not required for recurrence risk assessment. However, in rare instances, karyotyping or fluorescence in situ hybridization (FISH) analysis of parental samples may be considered to rule out germline mosaicism. In PKS, abnormal cells may be absent or underrepresented in peripheral blood due to selective loss, making standard karyotyping unreliable. Without tissue-specific testing—such as analysis of a buccal swab—this patient's diagnosis might have been missed or delayed, highlighting the critical role of tailored diagnostic approaches in mosaic conditions like PKS.

The management of PKS is multidisciplinary, addressing various medical complications and developmental challenges individually. Due to the rarity of the condition, there is currently no definitive cure, and treatment remains supportive mainly and symptomatic. The standard of care for PKS primarily addresses its multisystem manifestations, including neurologic, cardiac, orthopedic, respiratory, gastrointestinal, and endocrine complications.

What Makes Our Case Unique?

This case aligns with many classical PKS features, including macrocephaly, hypotonia, dysmorphic facial features, and feeding difficulties, but it is noteworthy for the presence of congenital QT prolongation, a finding not commonly reported in PKS.

"The formation of isochromosome 12p, characteristic of Pallister-Killian syndrome (PKS), is thought to result from errors in chromosome segregation. This leads to an additional abnormal chromosome consisting of two identical short arms (12p) and the loss of the long arms (12q). Because PKS arises as a de novo mosaic condition, the recurrence risk is considered very low—estimated to be less than 1%—due to its sporadic, post-zygotic origin."

1. Congenital QT prolongation and potential genetic links

While PKS is associated with cardiac defects, congenital long QT syndrome has not been well-documented in this disorder. One possible explanation for this case's prolonged QT interval is the involvement of CACNA1C, a gene within the duplicated 12p region. Gain-of-function mutations in CACNA1C are known to cause long QT syndrome type 8 (Timothy syndrome), which is associated with arrhythmias, neurodevelopmental delay, and facial dysmorphism—features that overlap with PKS (1). CACNA1C duplication raises new questions about the potential impact of gene dosage on cardiac conduction in PKS patients.

2. Diagnostic challenges and the importance of tissue-specific genetic testing

The initial presentation raised suspicion for Turner syndrome due to her lymphedema, abnormal posturing, and congenital abnormalities. However, traditional karyotyping on blood samples could have missed her diagnosis due to low-level mosaicism. Using a buccal swab for chromosomal microarray analysis was crucial in confirming PKS, reinforcing the importance of tissue-specific testing in mosaic genetic disorders (2).

3. Multisystem involvement and the need for multidisciplinary care

This case underscores the importance of a collaborative, multidisciplinary approach to managing PKS. Her cardiac, neurological, respiratory, and gastrointestinal complications required coordinated care across multiple specialties, including cardiology, neurology, pulmonology, gastroenterology, and genetics. This case highlights the complexity of care in PKS patients and provides valuable insights for clinicians managing similar cases.

Significance and Future Directions

This case contributes novel insights into the cardiac phenotype of PKS and suggests that a subset of patients may have previously unrecognized arrhythmias. If future studies confirm an increased risk of electrophysiological abnormalities in PKS, routine ECG screening could become a standard part of management protocols for these patients.

Additionally, this report challenges the current assumption that PKS is primarily a disorder of structural malformations and neurodevelopmental delay, suggesting that cardiac electrophysiology should be systematically evaluated in affected individuals.

Moving forward, longitudinal studies evaluating cardiac function in PKS patients could determine whether QT prolongation is a transient neonatal finding or a persistent risk factor for arrhythmias. Genomic and transcriptomic analyses of cardiac tissue in PKS may also help identify specific genes on 12p that contribute to electrophysiological disturbances, paving the way for potential therapeutic interventions.

"This case contributes novel insights into the cardiac phenotype of PKS and suggests that a subset of patients may have previously unrecognized arrhythmias. If future studies confirm an increased risk of electrophysiological abnormalities in PKS, routine ECG screening could become a standard part of management protocols for these patients."

Conclusion:

This case report of a neonate with Pallister-Killian syndrome

highlights the complexity of diagnosing mosaic genetic disorders. Identifying a pathogenic tetrasomy of 12p through buccal microarray analysis and multisystem clinical findings—including congenital QT prolongation—underscores the importance of integrating genetic, imaging, and clinical data. A multidisciplinary approach is essential for optimal management, and further studies are warranted to understand better the genotype-phenotype correlations and cardiac implications in PKS.

Key Learning Points and Clinical Pearls

1. **PKS Diagnosis Requires Targeted Genetic Testing:** Given the mosaic nature of PKS, peripheral blood karyotyping may fail to detect tetrasomy 12p, necessitating genetic testing via skin fibroblasts or buccal swab samples when clinical features strongly suggest the diagnosis.
2. **QT Prolongation May Be an Underrecognized Feature of PKS:** While congenital heart defects are known in PKS, this case highlights the importance of ECG screening for possible arrhythmias, including QT prolongation, which could have profound implications.
3. **Multisystem Surveillance is Essential:** Management of PKS should include neurological, orthopedic, respiratory, gastrointestinal, and endocrine evaluations, emphasizing a lifelong multidisciplinary care model to optimize quality of life.
4. **Potential Genetic Contributions to Electrophysiology:** The gene dosage effect of tetrasomy 12p may influence cardiac conduction, warranting further research into the molecular mechanisms underlying cardiac arrhythmias in PKS.
5. **The Role of Early Intervention:** Developmental therapies, nutritional support, and early monitoring of associated complications can improve outcomes in PKS patients, reinforcing the need for proactive rather than reactive medical management.
6. **Management Uncertainty for Cardiac Involvement:** Given the rarity of QT prolongation in PKS, no established guideline exists to monitor or treat this cardiac abnormality in affected individuals. Beta-blockers and close monitoring were employed in this case, but whether QT prolongation in PKS requires long-term antiarrhythmic intervention or pacemaker therapy remains unknown.

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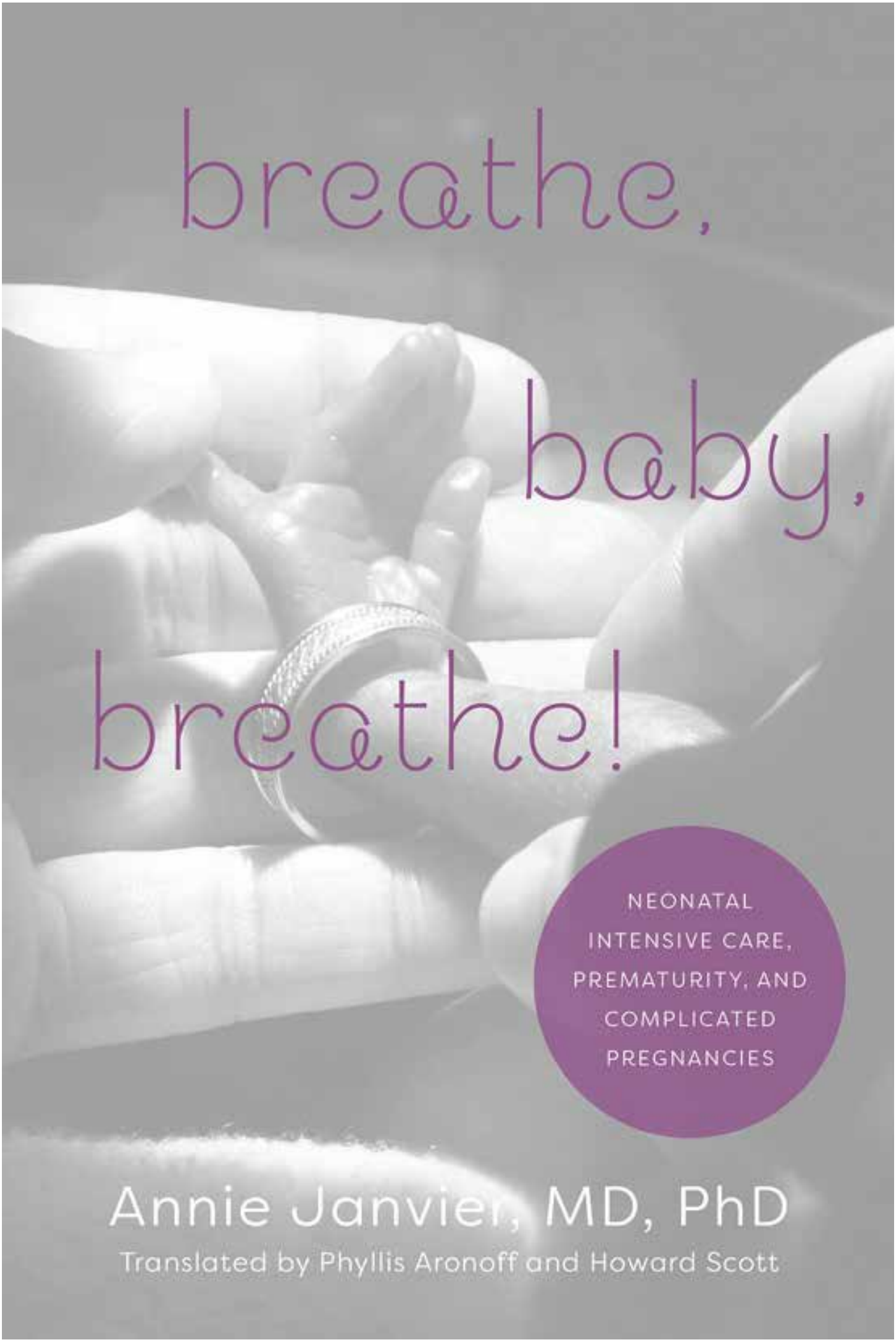
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Figure 2. NANN Product Flyer

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Which Infants are More Vulnerable *to Respiratory Syncytial Virus?*

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

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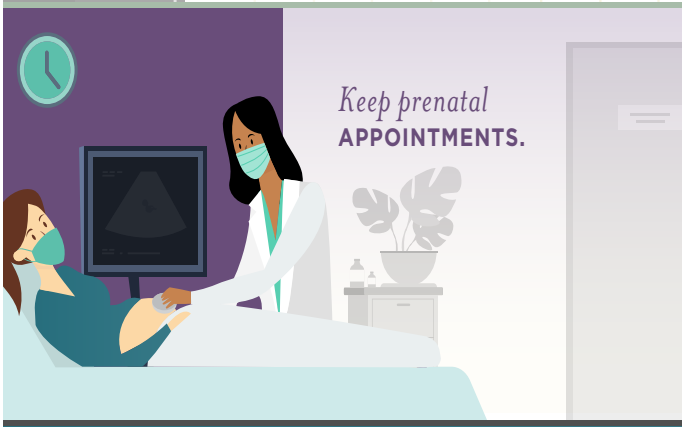
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Family Centered Care: Spring 2025 Newsletter and May Webinar

Morgan Kowalski

"The first international, multicenter collaborative initiative solely dedicated to quality improvement in NICU Family-Centered Care."

Disclosure: *This work is supported by an educational grant from Chiesi Inc. USA and a Seed 1 Partnership Award from Stanford Impact Labs.*

NT

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FCC TASKFORCE

NEWSLETTER

The **first** international, multicenter collaborative initiative solely dedicated to **quality improvement in NICU Family-Centered Care**.

In This Issue

- Supporting Families Beyond Discharge
- March '25 Webinar Summary
- Trauma-Informed Care Corner
- April/May Poll
- Executive Council Update
- FCC Taskforce Information

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Part Four: 'Aria's Journey: Connecting Through Our Shared Humanity'

by Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW, NICU Parent

Content Warning: The following is an artistic interpretation of what being a premature baby could be like. If you've experienced a preterm birth, please take care when reading.

"I get to try something new (again) today! My favorite helper said Mom and Dad are here, and I'm going to try using my mouth to eat. I wonder if that means they will get rid of this thing in my nose. Don't get me wrong, it's way better than when it was in my mouth, but it tickles and makes me sneeze. Don't get me started about when they put it in! Do all people have to have one of these in the beginning? There has got to be a better way! Maybe this mouth thing is it. After Dad changes my diaper, Mom scoops me up onto her chest. I love snuggling with her, but I am super hungry. My helper is talking to Mom and Dad about what we'll be doing. Mom holds me against her in a different way. It's weird, but I'll get used to it. I just really want to eat! It smells like her, and that makes me feel calm. One thing I know is we'll figure this out together, just like everything else!"

Practical tips for facilitating breastfeeding/chestfeeding for the first time:

- Everyone will be nervous, and the baby could be cranky or unsure of what to do. Share your calm! It helps bring the stress down in the room. Normalize the jitters and make a plan together.
- Frame the first feeding at the breast/chest as a shared learning experience. We are all in this together and learning along the way.
- Just like with cue-based interaction, focus on the experience rather than the quantification.
- If your unit has access to a lactation consultant, utilize their support!

For Part One/Aria's birth, catch up here.
For Part Two/Aria's admission, catch up here.
For Part Three/Aria's first time skin-to-skin, catch up here.

SUPPORTING FAMILIES BEYOND DISCHARGE

WITH JESS DAIGLE, MD, FAAP, NICU PARENT

Discharge day is often seen as the happy ending in a NICU story, but for many families it's the beginning of an entirely new chapter. As a physician and a NICU mom, I've come to understand that the journey home is layered with relief, joy, fear, and an invisible weight that is rarely acknowledged outside of NICU walls. **I wish more people knew what it's really like to bring a NICU baby home:**

1. **Discharge doesn't mean the journey is over.** Leaving the NICU is not the end of care—it's a transition. Families are sent home with follow-up appointments, feeding plans, therapy referrals, and lingering questions about their baby's development and future.
2. **You're excited—but terrified.** For weeks (or months), parents have had the safety net of machines, monitors, and medical teams. Home is quieter, but it can also feel lonelier and scarier. Every sound, every missed feeding, every pause in breathing feels high stakes.
3. **Feeding, sleep, and milestones become stressors.** Feeding often remains a challenge due to reflux, fatigue, or coordination issues. Sleep is fragmented, not just because of the baby, but because parents are hypervigilant. And developmental milestones don't feel like boxes to check—they feel like potential red flags.
4. **Grief can sneak in, even where there's joy.** Parents still grieve the birth experience they didn't get, the time they missed while their infant was in the NICU, and the uncertainty they still carry. The NICU experience is traumatic for many, and trauma doesn't disappear at discharge.
5. **Just because we're home doesn't mean we're "fine."** Friends and family often expect things to return to "normal" after discharge. But the truth is, families are still healing—physically, emotionally, and mentally. They need ongoing support, not just congratulations.

As members of the healthcare team, we must recognize that **discharge isn't a destination—it's a handoff. True family-centered care continues beyond the hospital walls.** That means preparing parents not just with supplies and appointments, but with validation, education, and emotional support. **We can empower families by:**

- Normalizing anxiety and emotional shifts after discharge
- Offering resources like parent support groups, therapists, or NICU follow-up clinics
- Collaborating with pediatricians and specialists to ensure seamless care
- Encouraging honest conversations about fears and expectations

NICU parents are doing more than surviving—they're carrying the weight of uncertainty, trauma, and fierce love. When we acknowledge that, we help carry that weight with them. As healthcare professionals, **our compassion doesn't end when a family leaves our unit, it lives in the way we prepare them, follow up with them, and advocate for better systems of support—from hospital to home.**

MARCH '25 WEBINAR SUMMARY

WITH BOB CICCO, MD

Our March Webinar (watch **HERE**) emphasized the need for healthcare professionals and the healthcare system itself to recognize that their roles go far beyond treating the medical conditions that bring a baby and family to the NICU. If we are going to ensure that all babies reach their maximum potential in life, we must do everything possible to provide compassionate care that allows parents and their babies to grow together in their quest towards self actualization.

"Cultivating Compassion: Enhancing NICU Family Experiences and Addressing Bias in Healthcare" with Jess Daigle, MD, FAAP

Jess emphasized quality care is not only meeting the medical needs of babies in the NICU, but **providing compassionate care that addresses families' mental, social, emotional, financial and cultural needs.** The following are some of the many highlights from her talk:

- While a history and physical exam provide medical data, it's equally **important to obtain and understand every family's unique lived experiences in order to effectively partner with them on their NICU journey.**
- Compassion is not the same as empathy. Compassion is not only feeling and understanding another's experience but taking action to help.
- People are not born with or without compassion. **Compassion can be developed and cultivated.**
- The words we use matter. It's important to be respectful and honest when we speak, and to be active listeners who are attentive to what is being said to us.
- Even the best communicators sometimes say things that are hurtful. We should always apologize, even if it just a misunderstanding. It still hurts!
- Everyone has biases! We should not deny our biases but try to understand them and learn how not to make unwarranted assumptions about others.
- Address bias by remembering to **P.A.U.S.E. P**ay attention to your reactions. **A**cknowledge assumptions. **U**nderstand your perspective. **S**eek different viewpoints. **E**xamine & adjust your approach.
- Cultivate compassion by engaging in **C.A.R.E. C**ontinuous self-reflection. **A**sk for feedback. **R**ecognize cultural differences. **E**ngage in mindfulness. For more of Jess' guidelines on cultivating compassion, click here

"Self Actualization: Live Highest Potential as Parents" with Colonel Erick Ridout, USA, Medical Corps (Retired)

Erick's presentation provided a detailed summary of the importance of striving to achieve self actualization and how it can be accomplished for families in the NICU. Some of the vital lessons Erick imparted in his talk include:

- Every healthcare professional should remember: **"We provide care FOR a baby, not TO a baby!"**
- It's not enough to only address physical, developmental, and emotional needs of infants in the NICU. **Healthcare professionals must also support parents by encouraging their ongoing growth in taking care of their baby**, allowing them self actualize.
- **Self actualization is achieved through autonomy** (being in control of our decisions), **mastery** (getting better at something that matters) **and purpose** (finding meaning our lives).
- Self actualization is not just important for parents, but also for healthcare professionals AND babies.
- Autonomy does not mean one has to go it alone. Family-Centered Care requires interdependence of all team members, including parents. With increasing autonomy, there is increasing interdependence and accountability.
- **Babies are not totally dependent - they have a voice. They desire and deserve care that has value to them. Care provided to both babies and families that does not have value is harmful.**

TRAUMA-INFORMED CARE CORNER

REIMAGINING FCC: A TAPESTRY OF TRANSITIONS, CONTEXT, AND CONNECTION

WITH MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

Family-Centered Care is often described as a partnership—one that honors dignity, voice, and collaboration. But how often does that partnership reach beneath the surface, into the lived experiences of families and clinicians navigating uncertain terrain?

In trauma-informed developmental care, we recognize that every NICU admission is more than a medical event—it's a profound transition. Drawing from Afaf Meleis' Transitions Theory, we are reminded that identity, relationships, and roles are in flux—and that **healing requires more than interventions; it requires presence.** Layering in Bronfenbrenner's Ecological Systems Theory, we acknowledge that **care doesn't happen in a vacuum**. Families are shaped by complex systems—policies, cultures, inequities—that ripple through the bedside experience. **Context matters. Language, access, and belonging all shape the story of care.**

And so, FCC must evolve. It must become more than a philosophy—it must become a practice of relational safety. This is where the **B.U.F.F.E.R.™** framework lives: **B**elonging, **U**nderstanding, **F**orgiveness, **F**rameworks, **E**quanimity, and **R**espect. **These aren't soft skills; they are clinical imperatives. They shape trust. They buffer stress. They transform outcomes.**

As we move forward, let us ask:

- What transitions are the families—and staff—moving through?
- What systems support or harm those journeys?
- And how can our care reflect not just what we know, but who we choose to be?

FCC, at its best, is not a checklist—it is a commitment. One that begins with us.



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Thank you for your insights! **To view all of the helpful polls and responses we've received, click here.**

EXECUTIVE COUNCIL UPDATE

WITH MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its first quarterly meeting of 2025 on March 6, with 19 members gathering in person at the Gravens Conference and 6 joining virtually via Zoom!





There was a lot to talk about!

Journal of Perinatology publishes our quality improvement work

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QUALITY IMPROVEMENT ARTICLE OPEN

Improving commitment to family-centered care in the NICU: a multicenter collaborative quality improvement project

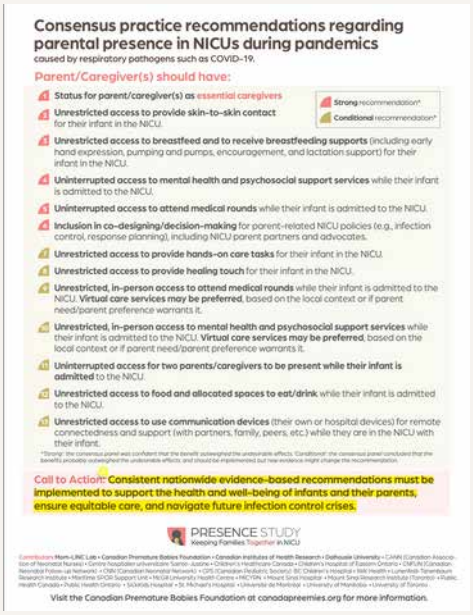
Malathi Balasundaram[1,2✉], Henry C. Lee[3], Laura C. Hedli[1], Kerri Z. Machut[4], Dharshi Sivakumar[1,2], Morgan Kowalski[1], Rafael Mendelsohn[5], Keira Sorrells[6] and Colby Day[7]

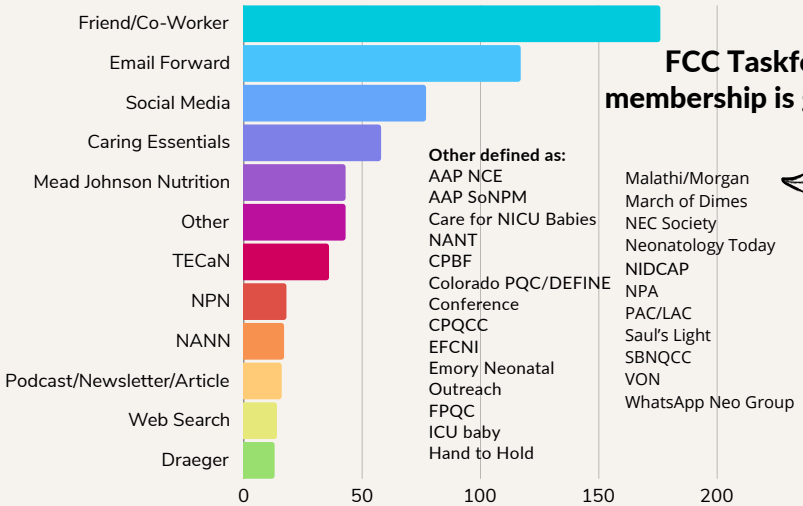
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OBJECTIVE: Despite evidence demonstrating the positive impact of family-centered care (FCC) in the neonatal intensive care unit (NICU), FCC is not standard of care. This multi-center, quality improvement initiative aimed to increase the percentage of NICUs with FCC committees and Family Partnership Councils (FPCs).
STUDY DESIGN: Participating NICUs were divided into small groups for collaborative mentoring. A key driver diagram and Pareto charts evaluated barriers to FCC and directed interventions. The primary outcome measure was development of an FCC committee and/or FPC. Process measures were views of bi-monthly educational webinars, evaluated using Statistical Process Control charts.
RESULT: Across 22 NICUs, the percentage with FCC committees and FPCs increased from 18% to 59% and 18% to 45%, respectively. Average webinar views increased from 28 to 182 views/webinar with clear signal on XmR chart.
CONCLUSION: A collaborative mentoring model and focused education achieved the goal of increasing NICU FCC committees and FPCs.

Journal of Perinatology; https://doi.org/10.1038/s41372-025-02232-1

Presence Study provides guidelines for parental presence in NICUs during pandemics. We're creating a toolkit based on this amazing work!





FCC Taskforce membership is growing!

Other defined as:
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Laura Hedli, MS

Mission Statement

We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

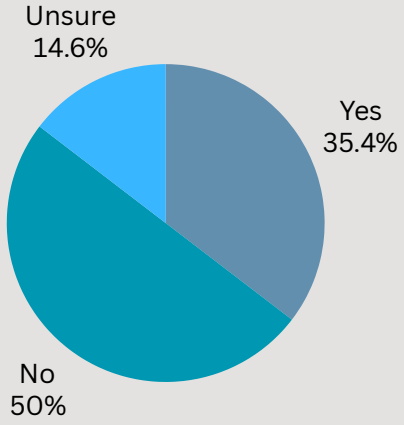
Why We Exist

To address the challenges that exist in implementing FCC practices, we offer free educational webinars with engaging, live Q&A sessions and free monthly office hours sessions.

Our key strength is equal partnership between clinicians and family partners in everything we do.

In a survey of 48 NICUs across the U.S., 65% said they don't have an FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



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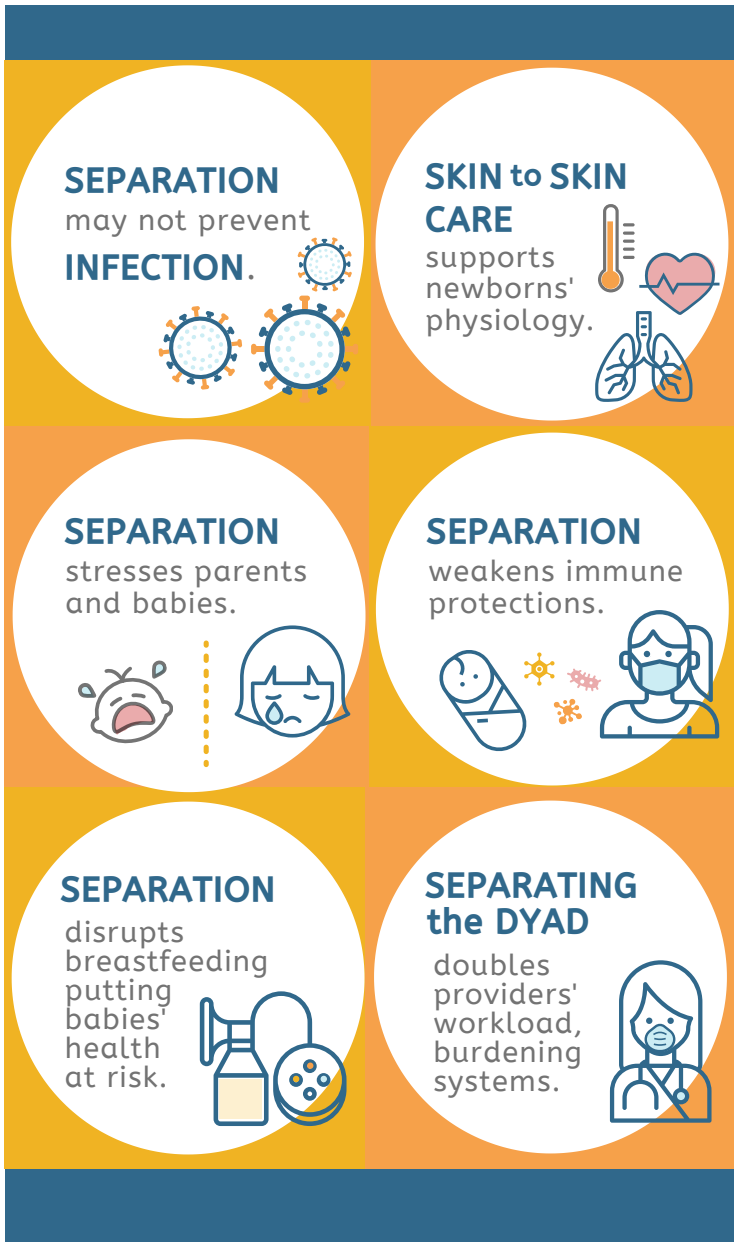
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Should Infants Be Separated from Mothers with COVID-19? First, Do No Harm

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FCC TASKFORCE WEBINAR

May 8th, 2025 | 11-12:30pm PT

From Risk to Reform: Removing the Barriers to Safer Kangaroo Care



Ashley Weber, PhD, RN, RNC-NIC (she/her)
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Department of Population Health,
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Yamile Jackson, PhD, PE, PMP
NICU Parent of Zachary
CEO & Founder, Nurtured by Design
Inventor, The Zaky®
Founder, International Kangaroo Care Awareness Day: May 15th



Engagement of Families in a State-Wide Quality Improvement Initiative on Skin-to-Skin Care in the NICU



Lelis Bauzá Vernon, S.Q.I.L.
NICU Parent of Bobby & Charlie
State Family Leader - Florida Perinatal Quality Collaborative
Family Laison - AAP, ACLC
Faculty Family, Vermont Oxford Network

Susan M. Bowles, DNP, APRN-CNS, RNC-NIC (she/her)
Nurse Consultant, Florida Perinatal Quality Collaborative



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FCC Taskforce Program Overview

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FAMILY-CENTERED CARE TASKFORCE

The Signs & Symptoms of RSV

RESPIRATORY SYNCYTIAL VIRUS

Know the Signs & Symptoms of RSV

- Cough
- Runny Nose
- Struggling to Breathe *(breastbone sinks inward when breathing)*
- Difficulty Eating
- Lethargy
- Wheezing

RESPIRATORY SYNCYTIAL VIRUS
is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

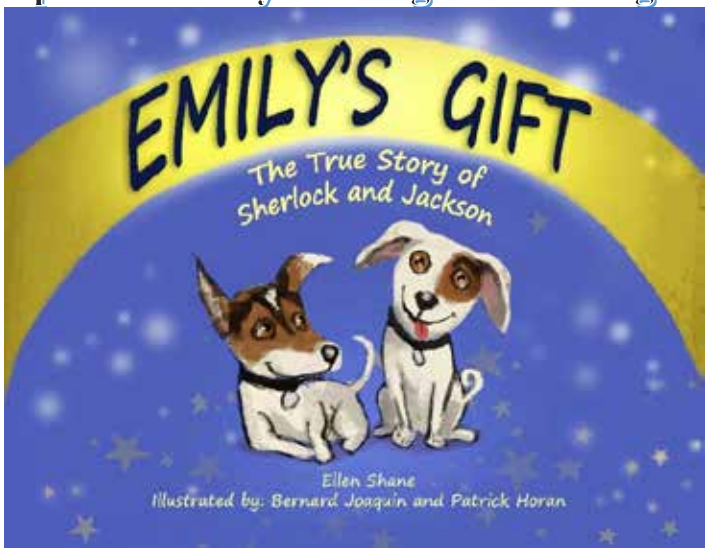
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NCfIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two

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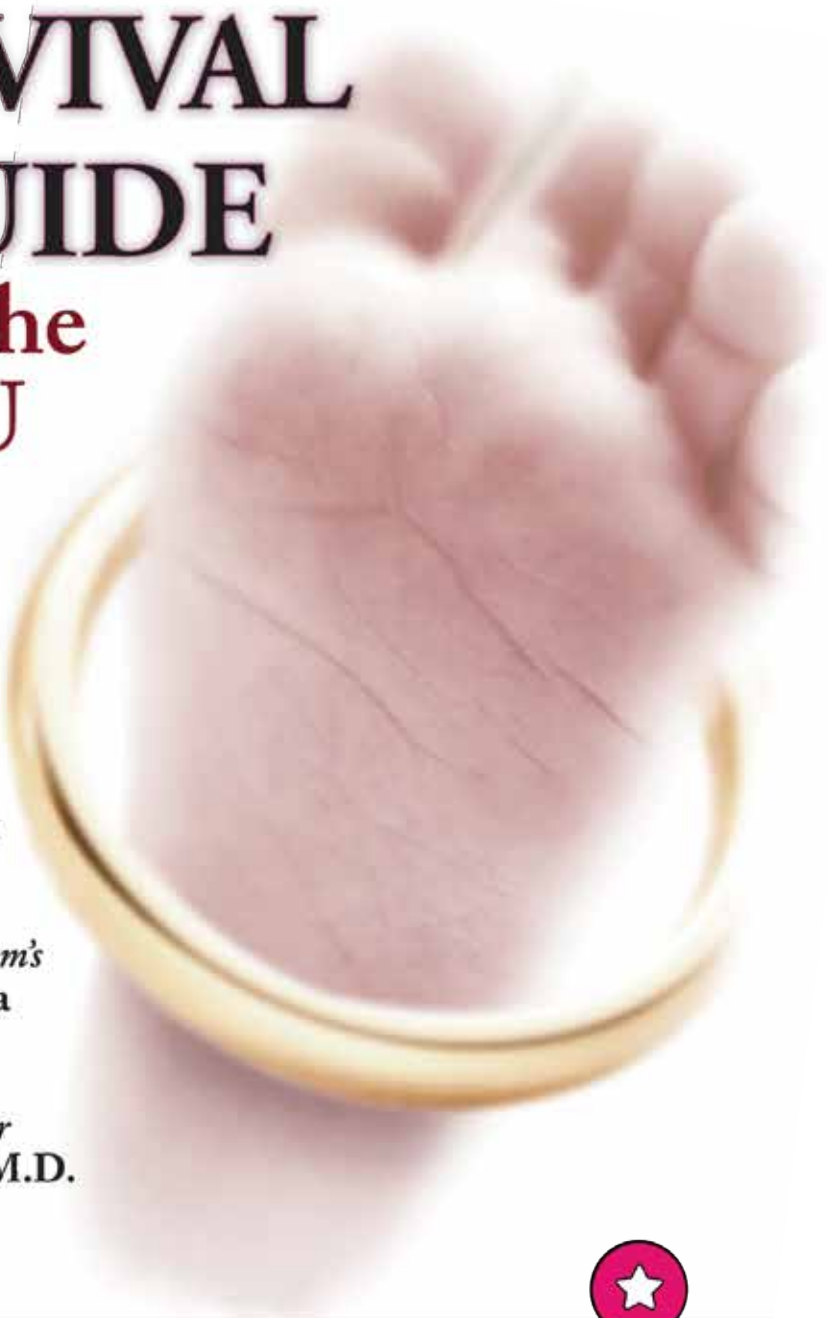




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The Preemie Parent's SURVIVAL GUIDE to the NICU



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Nicole Conn

&

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Deb Discenza

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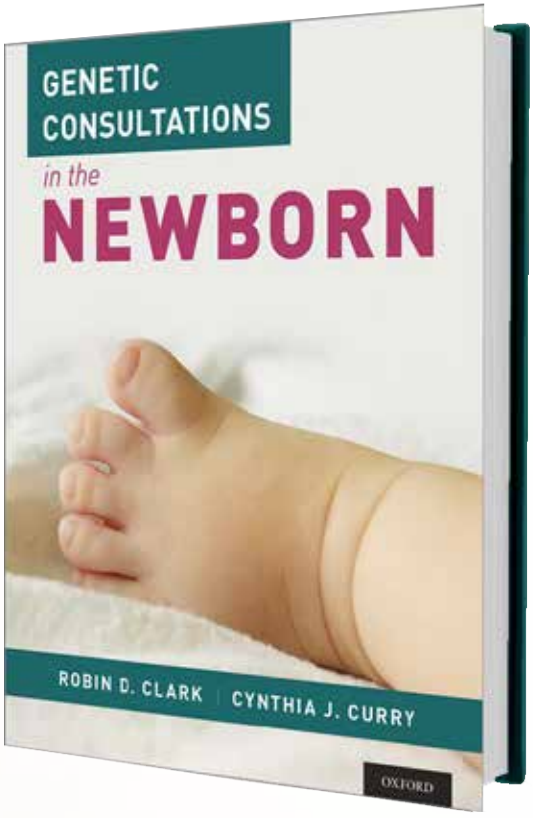
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Clinical Pearl: When It Comes to Neurodevelopmental Outcomes for Extremely Preterm Infants, Parents' Perspectives, Especially Regarding their Babies' Functional Capabilities, are Just as Important

Joseph R. Hageman, MD, Matthew Pellerite, MD, Lolita Alcocer Alkureishi, MD, Mitchell Goldstein, MD, MBA, CML

"I know the title of this month's clinical pearl is long. However, the significance of involving the parental perspectives of the longer-term neurodevelopmental and functional outcomes in the clinical criteria is really important after reviewing the extensive study by Richter and colleagues of the Canadian Neonatal Follow-up Network (CNFUN) and the editorial by Sobotka and Ross (1,2)."

I know the title of this month's clinical pearl is long. However, the significance of involving the parental perspectives of the longer-term neurodevelopmental and functional outcomes in the clinical criteria is really important after reviewing the extensive study by Richter and colleagues of the Canadian Neonatal Follow-up Network (CNFUN) and the editorial by Sobotka and Ross (1,2).

The study involved a multicenter study at 13 clinics of the developmental evaluation at 18-21 months corrected of 1098 preterm infants born at <29 weeks' gestation and asking their parents "whether they considered their child as developing normally, having mild/moderate impairment, or having severe impairment (1)". The investigators then compared the parental answers to this question with the medical classification of neurodevelopmental impairment (NDI) based on Bayley-III cognitive, language, and motor scores (Bayley Scales of Infant and Toddler Development Third Edition scores) and hearing, vision, and cerebral palsy status (1).

The demographic characteristics of this large group of 1098 preterm infants included a mean gestational of 26.1 weeks, a mean birthweight of 919 grams, and were assessed at a mean age of 19.6 months corrected (1).

What is clinically as well as statistically significant is the discrepancy between the parental answers and the formal developmental evaluations of these high-risk preterm infants (1). "Parents were more likely to describe their child's development as normal or less impaired than CNFUN classifications": CNFUN classification-54%, 29%, and 17% were classified as having no NDI, mild-moderate NDI, or severe NDI, respectively, compared to parental classification-67%, 31%, and 2% with no NDI, mild-moderate NDI, or severe NDI (1). Of the 596 children considered to have no NDI, 491 (82%) were also perceived by the parents to have no NDI (1). In the mild-moderate NDI group (CNFUN), the agreement with parents was 42%, and in the severe NDI group (CNFUN), there was only 23 (12%) agreement by the parents (1). Using Cohen's simple k and weighted k, statistically, poor agreement was noted (1). Discrepancies varied by parental education, with "parents who completed postsecondary education and reported as white ethnicity were more likely to agree with CNFUN categorization (58% vs. 46% and 63% vs.55% respectively)" (1).

"Of the 596 children considered to have no NDI, 491 (82%) were also perceived by the parents to have no NDI (1). In the mild-moderate NDI group (CNFUN), the agreement with parents was 42%, and in the severe NDI group (CNFUN), there was only 23 (12%) agreement by the parents (1). Using Cohen's simple k and weighted k, statistically, poor agreement was noted (1). Discrepancies varied by parental education, with "parents who completed postsecondary education and reported as white ethnicity were more likely to agree with CNFUN categorization (58% vs. 46% and 63% vs.55% respectively)" (1)."

When Richter et al. and Sobotka reviewed these important and clinically relevant comparisons, they noted that parents' assessments relied more on the functional capabilities of their toddlers at the time of their developmental assessments, which were not a part of the CNFUN neurodevelopmental classification (1,2). They suggest that the definitions be reviewed and modified with significant inclusion of parental input, especially "functional measures" for infants (1,2). Assessment of children and adults

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with disabilities includes activities of daily living," which is the same as these "functional measures" suggested by the authors of both papers (1-3).

"They suggest that the definitions be reviewed and modified with significant inclusion of parental input, especially "functional measures" for infants (1,2). Assessment of children and adults with disabilities includes activities of daily living," which is the same as these "functional measures" suggested by the authors of both papers (1-3)."

References:

1. Richter LL, Janvier A, Pearce R et al. Parental and medical classification of neurodevelopment in children born preterm. *Pediatrics 2025;155(2):e2024066148.*
2. Sobotka SA and Ross LF. The importance of functional measures and parental input for neurodevelopmental assessment. *Pediatrics 2025;15(2):e202468432.*
3. www.yourkidsot.activities-of-daily-living.com.

Disclosures: *The authors have no disclosures*

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Clinical Pearls are published monthly.

Submission guidelines for "Clinical Pearls":

1250 word limit not including references or title page.

May begin with a brief case summary or example.

Summarize the pearl for emphasis.

No more than 7 references.

Please send your submissions to:

josephhageman6@gmail.com

Corresponding Author



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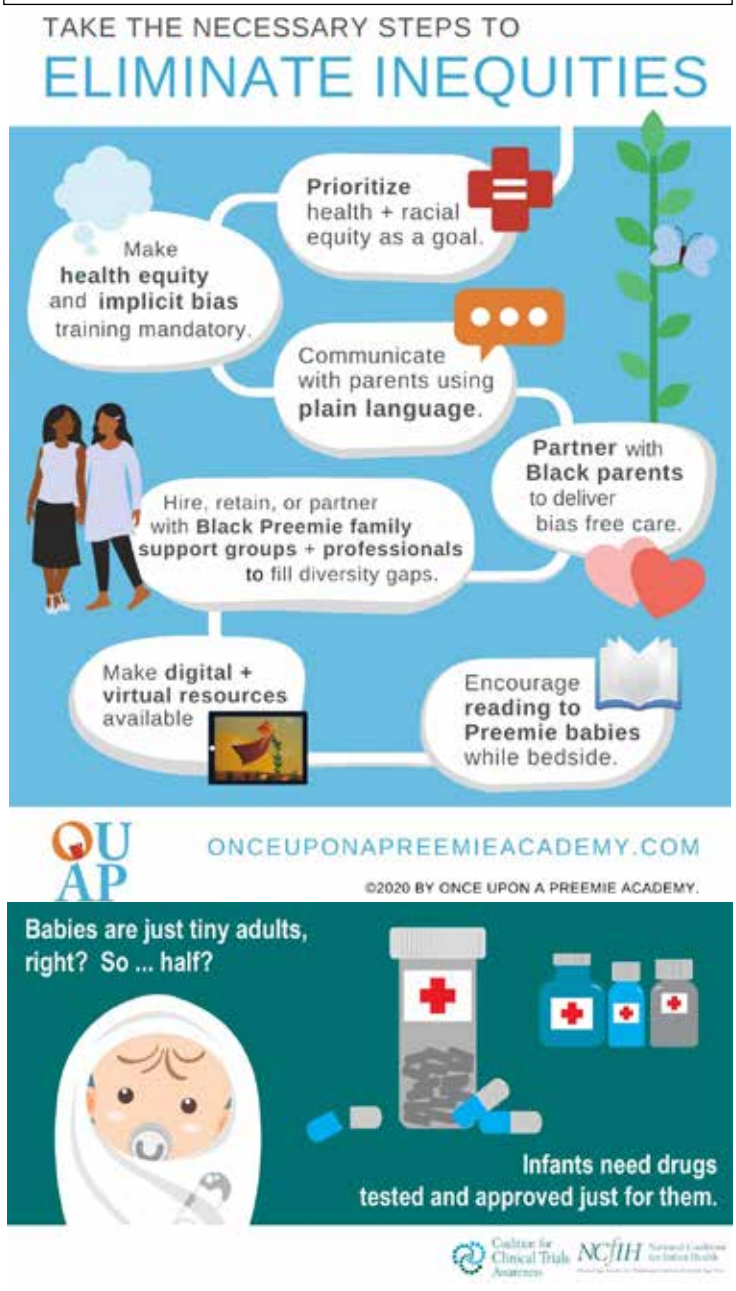
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Which Infants are More Vulnerable *to Respiratory Syncytial Virus?*

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.*

*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	Prematurity	18.3%
58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%

AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

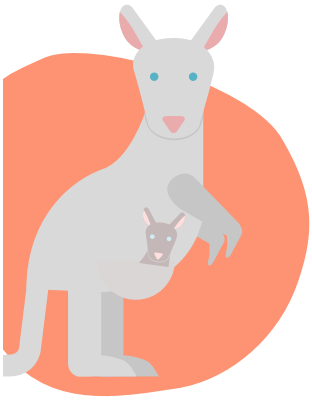
AfPA Alliance for Patient Access

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GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.





PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there



National Perinatal Association

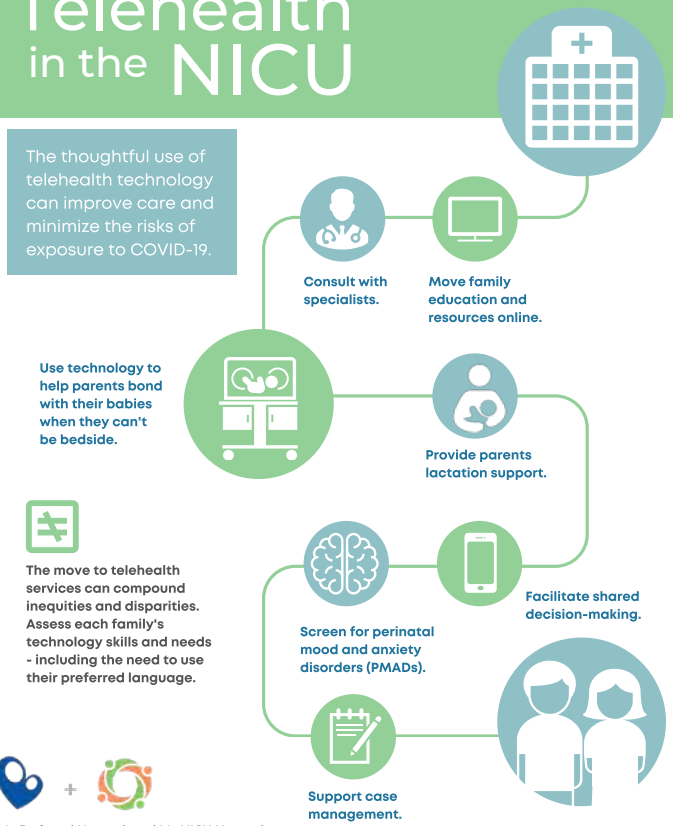
nicuparentnetwork.org

NPN NICU PARENT NETWORK

nationalperinatal.org/skin-to-skin

Telehealth in the NICU

The thoughtful use of telehealth technology can improve care and minimize the risks of exposure to COVID-19.



The move to telehealth services can compound inequities and disparities. Assess each family's technology skills and needs - including the need to use their preferred language.

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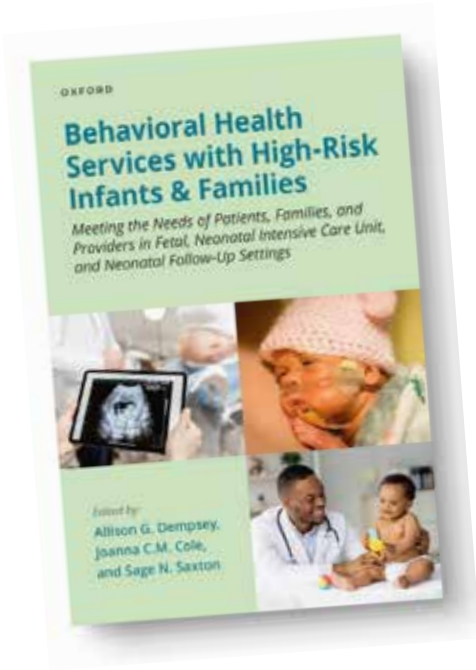
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Jonathan R. Swanson, MD, MSc
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University of Virginia
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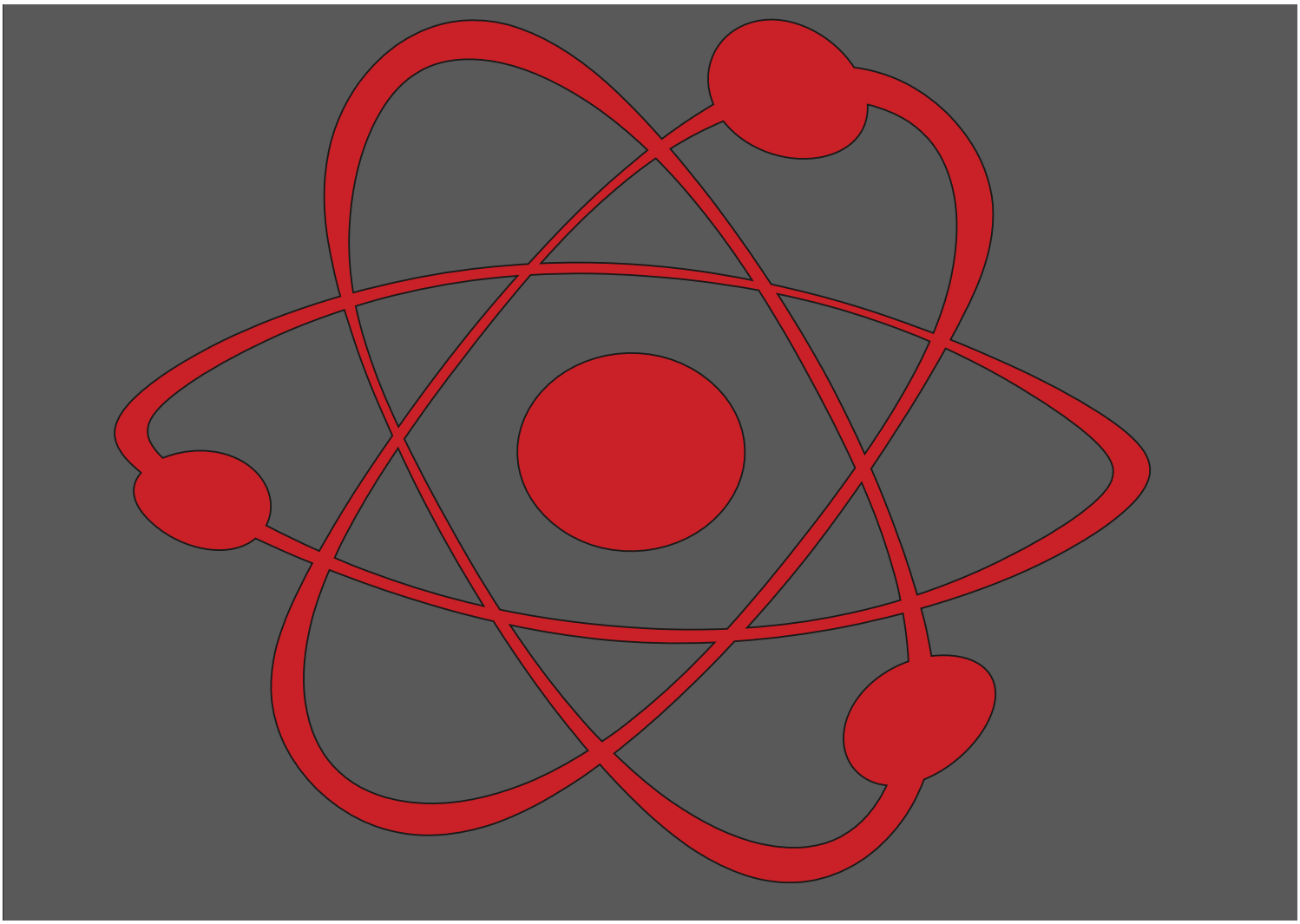
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Colorado Convention Center
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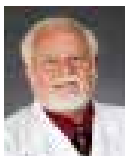
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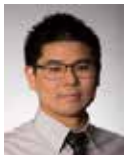
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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. Dr. Zahera Etter provides "Baby Blue Eyes with Mount Fuji in the Background." a For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Rose Garden" done by her son Tim. Our bird is also from Dr. Etter, "la rencontre d'un héron."



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Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to: LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.

5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references. EndNote X9 is suggested.

X9 9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing(a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

NICU Baby's Bill of Rights

1- The Right to Advocacy
My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

2- The Right to My Parents' Care
In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

3- The Right to Bond with My Family
Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

4- The Right to Neuroprotective Care
Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

5- The Right to be Nourished
Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

6- The Right to Personhood
Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

7- The Right to Confident and Competent Care Giving
The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

8- The Right to Family-Centered Care
Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9- The Right to Healthy and Supported Parents
My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

10- The Right to Inclusion and Belonging
Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:

NPN
NICU PARENT NETWORK

NICU Parent Network

Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

*** The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.**

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Invitation to Apply:

Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
2. Reflective questions about if/when to offer seeing or holding of the baby.
    - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.





