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Continuous Quality Improvement Pre-Conference at NEO
Feb. 18, 2015; Orlando, FL USA
www.neoconference.com

NEO: The Conference for Neonatology
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3rd International Neonatal & Maternal Immunization Symposium (INMIS)
Mar. 4-5, 2015; Gambia
<http://inmis.org>

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Partnering with Parents: Family-Centered Coordinated Care at Women & Infants Hospital of Rhode Island

By Nichole Aguiar, LCSW; Shannon Sullivan, LICSW; Jennifer Silva, FRS; Melissa O'Donnell, LICSW; Betty Vohr, MD

Patient- and family-centered care as a partnership that includes family members and health care staff is recognized by Healthy People 2020 as integral to patient health, satisfaction, and health care quality.¹ Women & Infants Hospital of Rhode Island, a tertiary care, 80-bed, single-family room Neonatal Intensive Care Unit (NICU) that cares for more than 1,200 high risk premature and term infants annually, strongly embraces this concept. The NICU partners with the hospital's Neonatal Follow-up Program which was established in 1974 to provide comprehensive, multidisciplinary support and evaluation for NICU graduates. All high-risk NICU graduates are referred for longitudinal assessment and support. The NICU staff and Neonatal Follow-Up team work together closely with the March of Dimes, the NICU Family Advisory Council, and the Partnering with Parents Program. All share a philosophical model to provide patient- and family-centered care.

Patient- and family-centered care^{2,3} is a redefinition of the relationships between staff and patients. People are treated the way they wish to be treated: with respect for their values, preferences and needs. Patient care encounters are expanded to involve patients and families. The principles of patient- and family-centered care,³ both nationally and at Women & Infants, include:

- **Dignity and Respect** - Patient and family knowledge, values, beliefs and cultural

backgrounds are valued and incorporated into the planning and delivery of care.

- **Information Sharing** - Patients and families are given timely, accurate information so they can effectively participate in the decision-making process.
- **Participation** - Patients and families are encouraged to participate in their care and decision-making at the level they choose.
- **Collaboration** - Hospital staff collaborate with patients and families in policy and program development, implementation, and evaluation; facility design; and professional education.

“Patient- and family-centered care^{2,3} is a redefinition of the relationships between staff and patients. People are treated the way they wish to be treated, respecting their values, preferences and needs. Patient care encounters are expanded to involve patients and families.”

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- Neonatal Nephrology
- Neonatal Infectious Diseases
- Central Nervous System



Patient- and family-centered care is embodied in the multidisciplinary team's relationship with each other, patients and families. This includes patient-centered rounds, where parents are invited to both participate in and contribute to the daily multidisciplinary rounds. Patient-centered rounds enable parents and all clinical members of the team to be active and contributing members of the care team.

The NICU at Women and Infants Hospital of Rhode Island has been fortunate to partner with the March of Dimes in promoting family-centered neonatal care. March of Dimes NICU Family Support® provides information and comfort to families experiencing the hospitalization of their baby in a NICU. Since 2001, the program has been providing support and education to families with sick newborns and supporting hospital initiatives to further family-centered care practices. The goals of NICU Family Support are to provide information and comfort to families during the NICU stay, the transition home, and in the event of a newborn death; provide staff education on topics related to neonatal family-centered care; and promote the philosophy of family-centered care. www.marchofdimes.org/nicu.

Women & Infants Hospital of Rhode Island is one of 130 hospitals in the U.S. that offers March of Dimes NICU Family Support. Nationally, the program offers services to more than 90,000 families each year. Activities provided through the program include parent-to-parent support, print and online education and innovative programs for parents, siblings and grandparents, all with the purpose of providing comfort, information and critical health care messages to families in crisis.

In 2013, the Rhode Island March of Dimes NICU Family Support program at Women & Infants provided nearly 1,000 Parent Care Kits with education materials specifically designed to support families during a NICU stay. The program hosted 110 NICU Family Support parent hours and activities attended by 1,290 individuals with the goal of educating and comforting families. In addition, over 200 families participated in the Journey Jewel Program designed to help families create a visual story of their infant's progress in the NICU. Babies "earn" beads that correspond with milestones met or procedures endured during their NICU stay. Families utilize beads to make a keepsake bracelet to document their NICU Journey.

NICU Family Advisory Council

The mission of the NICU Family Advisory Council is to form a partnership between NICU families and NICU staff in order to advocate for a care environment that is developmentally supportive and family-centered. The key role of the Council is to provide the perspective of NICU families in the development of policies and procedures that promote an optimal healing environment for babies, and support families and staff. The NICU Council is comprised of parents and family members with prior experience in our NICU. Council members partner with current NICU leadership and staff to enhance the NICU environment for newborns and their families. Established in 2006, the NICU Family Advisory Council has played an important role in advising on the planning and design the new NICU, helping revise the NICU family visitation and parent presence policy, and always advocating for patients and families.

Partnering with Parents Program

To further improve outcomes and reduce unnecessary re-hospitalizations and emergency room visits, Women & Infants has created an expanded medical home care team which provides individualized family-centered care, support and education once infants transition home. In 2006, Women & Infants partnered with the March of Dimes and was awarded a pilot grant to provide enhanced transitional support to these infants. Since that time, the services have continued to grow and evolve through additional grant opportunities, securing contracts with private insurers and, in July 2011, Women & Infants was awarded a three-year Innovation Challenge grant from the Centers for Medicare & Medicaid Services, Center for Medicare and Medicaid Innovation. The Partnering with Parents program was initially structured to provide enhanced transitional support to all Rhode Island preterm infants cared for in the NICU for five or more days. These services have expanded to include infants residing in Massachusetts and Connecticut, as well as full-term infants requiring NICU care in Rhode Island.

Enhanced transition support services are geared toward recognizing that many NICU graduates go home with a spectrum of special health care needs such as oxygen, monitors, ventilators, medica-



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cians, specialty care providers, visiting nurses, Early Intervention, the Rhode Island Parent Information Network, the Rhode Island Quality Institute, March of Dimes, insurance providers, and various state agencies. The goal of the program remains to continue to improve the transition home for fragile infants by providing comprehensive support and education to families and improving the overall health and well-being of these infants.

“Partnering with Parents is staffed by physicians, nurse practitioners, clinical social workers and family resource specialists. A unique component of these services is offering an opportunity for NICU families to connect with other former NICU parents, as the family resource specialists are former NICU parents themselves.”



NICU Family Support® Bright Space® for Siblings

An evaluation of family-centered care practices and policies in 2013 identified an area for improvement in the care model that involved the Neonatal Follow-up Clinic. The Follow-Up Program has nearly 1,500 patient visits per year, and parents often return with infants who have multiple special health care needs and lengthy appointments. In addition, families often bring young siblings with them who need to wait while their NICU sibling is being evaluated. The siblings have their own adjustments and, at times, are distressed. Brothers and sisters of newborns hospitalized in a NICU often feel disconnected and, at times, even pushed to the side while parents cope with the worry and uncertainty about their NICU baby's health.

The March of Dimes proposed that the families of babies and children being seen in Women & Infants' Neonatal Follow-Up Clinic have an educational and developmentally appropriate space to promote self-healing through play. Through an innovative partnership between March of Dimes and the Bright Horizons Foundation for Children, a Bright Space®, the signature program of the Bright Horizons Foundation for Children, was funded to create a warm, enriching playroom that gives children and families a special place to relax and have fun with a library, interactive and developmentally appropriate toys, an art cart, and decorations including vintage toys and art work. The Bright Space® at Women & Infants offers hope and inspiration. This Rhode Island NICU Family Support Bright Space® for Siblings is the first to open in a neonatal developmental follow-up clinic.

From day one, the Bright Space® has been a success with both children and families, and time seems to fly by when families come for a visit. There are children who enjoy the play area so

tion, special formulas, and multiple follow-up care appointments. In addition, many of the families face significant social, emotional, and economic stressors. By providing families with education, multidisciplinary support, 24-hour physician call access, linkages to community resources, and developmental monitoring, they are better able to navigate the ongoing complexities accompanying their child's special health care needs.

Partnering with Parents is staffed by physicians, nurse practitioners, clinical social workers and family resource specialists. A unique component of these services is offering an opportunity for NICU families to connect with other former NICU parents, as the family resource specialists are former NICU parents themselves. In addition, the program forms strong community partnerships to best support families and works closely with primary care physi-



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much that they need to be coaxed to leave at the end of the visit. March of Dimes chose Women & Infants as one of eight Bright Spaces for NICU Siblings in the United States because of the long-standing partnership between the hospital and the local March of Dimes chapter. Mark Marcantano, President and Chief Operating Officer of Women & Infants Hospital, summed up the Bright Space® addition this way, "As a patient- and family-centered hospital, we are excited to create an enriching educational and play facility for NICU graduates, and the siblings and families of our most fragile infants."

"The Partnering with Parents program was initially structured to provide enhanced transitional support to all Rhode Island preterm infants cared for in the NICU for five or more days. These services have expanded to include infants residing in Massachusetts and Connecticut, as well as full-term infants requiring NICU care in Rhode Island."

In summary, patient- and family-centered care has been enhanced in Women & Infants Hospital NICU and Follow-Up Program with the addition of the new Bright Space® for Siblings.

This augmentation of care, which is the first to extend to siblings, would not have been possible without the strong Women & Infants Hospital partnerships with March of Dimes and the Bright Horizons Foundation for Children.

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Letters to the Editor

Neonatology Today welcomes and encourages Letters to the Editor. If you have comments or topics you would like to address, please send an email to: LTE@Neonate.biz and let us know if you would like your comment published or not.

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- The main text of the article should be written in informal style using correct English. The final manuscript may be between 400-4,000 words, and contain pictures, graphs, charts and tables. Accepted manuscripts will be published within 1-3 months of receipt. Abbreviations which are commonplace in pediatric cardiology or in the lay literature may be used.
- Comprehensive references are not required. We recommend that you provide only the most important and relevant references using the standard format.
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Guidelines Help Increase Survival Rate of Babies Born Early

Edward G. Shepherd, MD

For the last decade, prematurity has been the leading cause of infant mortality in the United States. As a result of prematurity, many infants enter the world too early with a small chance of survival. In fact, just a generation ago, the survival rate for extremely premature babies, sometimes called small babies, was dismal. Many people doubted that babies born before 27 weeks could survive, and even if they did, most assumed that these children were certain to face nearly insurmountable medical and developmental problems throughout their lives.

In 2004, our multidisciplinary team of doctors, nurses, therapists, social workers, respiratory therapists, nutritionists and other staff set out with an ambitious, but simple goal; we aimed to prove that, at Nationwide Children's Hospital, every small baby has enormous potential for a rewarding life. The end product was a new set of guidelines for care for our most vulnerable patients, i.e. those babies born earlier than 27 weeks of pregnancy, with the goal of increasing both their survival rate and their chance of normal development. These guidelines are all-encompassing, and regulate everything: from humidity levels in babies' isolettes to oxygen levels in their blood, from the way their skin is treated to the nutrients they're given.

Then, we took a look at who was caring for those babies and brought in more specialists, including cardiologists, developmental pediatricians, and families of former small babies to create the most dedicated, multi-disciplinary care possible.

Once the care teams were set and guidelines put into place, we applied the new method to over 200 babies from December 2004 to August 2008. The average baby in this study was born at just 24 weeks, the most fragile of all small babies. Despite this, survival rates surged.

The study, published in the *Journal of Neonatal-Perinatal Medicine*, showed that in just three and a half years, the guidelines helped boost small baby survival rates at Nationwide Children's to 78%. Today, those numbers continue to climb to almost 90%.

In fact, we recently held a Small Baby Reunion (as we do every other year) to

"The study...showed that in just three and a half years, the guidelines helped boost small baby survival rates at Nationwide Children's to 78%. Today, those numbers continue to climb to almost 90%."

celebrate small baby graduates with their families and our NICU staff. We welcomed back more than 100 children who overcame tremendous odds with the help of the small baby program and shared memories of the children we once cared for with families and friends. The event reminded us of how the guidelines continue to have a significant impact on the progress of these children and their families.

The care a baby gets in the first hour of life can make a huge difference in that child's health for the rest of his or her life. Since hundreds of doctors, nurses and specialists interact with that child before he or she goes home, we want to ensure that we're caring for that baby in the most effective ways possible. Getting each member of the care team on the same page and creating consistent care for each child is just what these guidelines are intended to do. We're working to give each small baby the chance to make remarkable strides, and to grow up healthy and happy.

For more information on National Children's Hospital's Small Bay Program and guidelines go to: <http://www.nationwidechildrens.org/small-baby-guidelines>

About the Author

Edward G. Shepherd, MD, is the Section Chief of Neonatology at Nationwide Children's Hospital and an Assistant Professor of Clinical Pediatrics at The Ohio State University College of Medicine. Dr. Shepherd is responsible for the care of all babies cared for in our 254 bed NICU system. Dr. Shepherd's clinical interests



Callista and Ryan Dammann, and daughter, Cami Dammann.

have led to his research focus on bronchopulmonary dysplasia (BPD) and developmental care, and he is currently involved in several studies of the diagnosis and progression of BPD as well as the best developmental care for infants so afflicted. Dr. Shepherd regularly presents invited lectures, most recently focusing on the presentation, diagnosis and management of small babies and the avoidance and management of complications.

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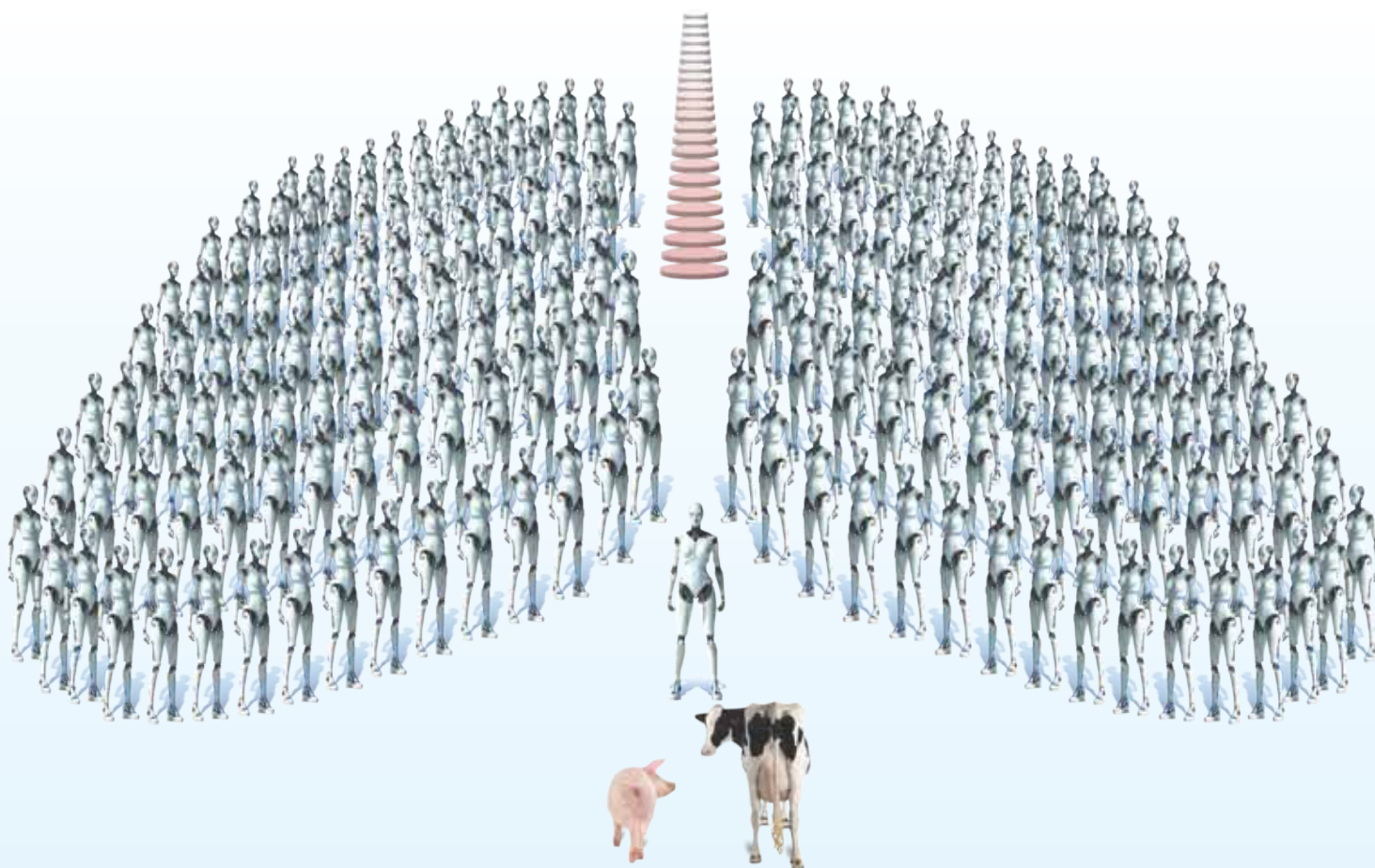


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INDICATION

SURFAXIN® (lucinactant) Intratracheal Suspension is approved by the FDA for the prevention of respiratory distress syndrome (RDS) in premature infants at high risk for RDS.

IMPORTANT SAFETY INFORMATION

SURFAXIN (lucinactant) Intratracheal Suspension is intended for intratracheal use only. The administration of exogenous surfactants, including SURFAXIN, can rapidly affect oxygenation and lung compliance. SURFAXIN should be administered only by clinicians trained and experienced with intubation, ventilator management, and general care of premature infants in a highly supervised clinical setting. Infants receiving SURFAXIN should receive frequent clinical assessments so that oxygen and ventilatory support can be modified to respond to changes in respiratory status.

Most common adverse reactions associated with the use of SURFAXIN are endotracheal tube reflux, pallor, endotracheal tube obstruction, and need for dose interruption. During SURFAXIN administration, if bradycardia, oxygen desaturation, endotracheal tube reflux, or airway obstruction occurs, administration should be interrupted and the infant's clinical condition assessed and stabilized. Overall the incidence of administration-related adverse events did not appear to be associated with an increased incidence of serious complications or mortality relative to the comparator surfactants.

SURFAXIN is not indicated for use in acute respiratory distress syndrome (ARDS).

For more information about SURFAXIN, please visit www.SURFAXIN.com and see accompanying brief summary of prescribing information on the next page.

BRIEF SUMMARY OF PRESCRIBING INFORMATION

Please see package insert for full prescribing information.

INDICATIONS AND USAGE

SURFAXIN is indicated for the prevention of respiratory distress syndrome (RDS) in premature infants at high risk for RDS.

CONTRAINDICATIONS

None.

WARNINGS AND PRECAUTIONS

Acute Changes in Lung Compliance

Administration of exogenous surfactants, including SURFAXIN, can rapidly affect lung compliance and oxygenation. SURFAXIN should be administered only by clinicians trained and experienced in the resuscitation, intubation, stabilization, and ventilatory management of premature infants in a clinical setting with the capacity to care for critically ill neonates. Infants receiving SURFAXIN should receive frequent clinical assessments so that oxygen and ventilatory support can be modified to respond to changes in respiratory status.

Administration-Related Adverse Reactions

Frequently occurring adverse reactions related to the administration of SURFAXIN include bradycardia, oxygen desaturation, reflux of drug into the endotracheal tube (ETT), and airway/ETT obstruction.

To report SUSPECTED ADVERSE REACTIONS, contact Discovery Laboratories, Inc. at 1-877-SURFAXIN or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Increased Serious Adverse Reactions in Adults with Acute Respiratory Distress Syndrome (ARDS)

Adults with ARDS who received lucinactant via segmental bronchoscopic lavage had an increased incidence of death, multi-organ failure, sepsis, anoxic encephalopathy, renal failure, hypoxia, pneumothorax, hypotension, and pulmonary embolism. SURFAXIN is not indicated for use in ARDS.

Clinical Trials Experience

The efficacy and safety of SURFAXIN for the prevention of RDS in premature infants was demonstrated in a single randomized, double-blind, multicenter, active-controlled, multi-dose study involving 1294 premature infants (Study 1). Infants weighed between 600 g and 1250 g at birth and were 32 weeks or less in gestational age. Infants were randomized to receive 1 of 3 surfactants, SURFAXIN (N = 524), colfosceril palmitate (N = 506), or beractant (N = 258). Co-primary endpoints were the incidence of RDS (defined as having a chest x-ray consistent with RDS and an $FiO_2 \geq 0.30$) at 24 hours and RDS-related mortality at 14 days. The primary comparison of interest was between SURFAXIN and colfosceril palmitate with the intent of demonstrating superiority. Beractant served as an additional active comparator. Compared to colfosceril palmitate, SURFAXIN demonstrated a statistically significant improvement in both RDS at 24 hours and RDS-related mortality through Day 14. A second multicenter, double-blind, active-controlled study involving 252 premature infants was also conducted to support the safety of SURFAXIN (Study 2). Infants weighed between 600 g and 1250 g and were less than 29 weeks in gestational age. Infants were randomized to receive 1 of 2 surfactants, SURFAXIN (N = 119) or poractant alfa (N = 124).

The safety data described below reflect exposure to SURFAXIN administered intratracheally to infants at a dose of 5.8 mL per kg (up to 4 doses) in either 4 aliquots (Study 1) or 2 aliquots (Study 2) in 643 premature infants.

Comparator surfactants colfosceril palmitate and beractant were administered at the recommended doses (5.0 and 4.0 mL per kg, respectively) while the first dose of poractant alfa administered (2.2 mL per kg) was less than the recommended dose of 2.5 mL per kg. Any subsequent doses of poractant alfa were at the recommended 1.25 mL per kg dose.

Overall, the incidence of administration-related adverse reactions was higher in infants who received SURFAXIN compared to other surfactants (Table 1) and resulted in a greater proportion of infants treated with SURFAXIN who experienced administration-related oxygen desaturation and bradycardia. For Study 1, oxygen desaturation was reported in 17%, 9%, and 13% and bradycardia for 5%, 2%, and 3% of infants treated with SURFAXIN, colfosceril palmitate, and beractant, respectively. For Study 2, oxygen desaturation was reported in 8% and 2% and bradycardia in 3% and 2% of infants treated with SURFAXIN and poractant alfa, respectively.

These adverse reactions did not appear to be associated with an increased incidence of serious complications or mortality relative to the comparator surfactants (Table 2).

Table 1. Administration-Related Adverse Reactions in SURFAXIN Controlled Clinical Studies^a

	Study 1 ^b			Study 2 ^c	
	SURFAXIN (N = 524)	Colfosceril palmitate (N = 506)	Beractant (N = 258)	SURFAXIN (N = 119)	Poractant alfa (N = 124)
Total Doses Administered	994	1038	444	174	160
Total Number of Events (Events per 100 Doses)					
ETT Reflux	183 (18)	161 (16)	67 (15)	47 (27)	31 (19)
Pallor	88 (9)	46 (4)	38 (9)	18 (10)	7 (4)
Dose Interruption	87 (9)	46 (4)	30 (7)	7 (4)	2 (1)
ETT Obstruction	55 (6)	21 (2)	19 (4)	27 (16)	1 (1)

^a Table includes only infants who received study treatment.

^b Study 1 doses were administered in 4 aliquots.

^c Study 2 doses were administered in 2 aliquots.

Table 2. Common Serious Complications Associated with Prematurity and RDS in SURFAXIN Controlled Clinical Studies Through 36-Weeks Post-Conceptual Age (PCA)

	Study 1			Study 2	
	SURFAXIN (N = 527) %	Colfosceril palmitate (N = 509) %	Beractant (N = 258) %	SURFAXIN (N = 119) %	Poractant alfa (N = 124) %
Apnea	52	52	46	66	75
Intraventricular hemorrhage, all grades	52	57	54	39	38
-Grade 3/4	19	18	21	13	8
Periventricular leukomalacia	10	10	12	4	9
Acquired sepsis	44	44	44	45	52
Patent ductus arteriosus	37	35	37	43	44
Retinopathy of prematurity, all grades	27	26	25	32	31
-Grade 3/4	6	7	6	5	9
Necrotizing enterocolitis, all grades	17	17	19	13	15
-Grade 2/3	6	8	14	8	8
Pulmonary air leak through Day 7, all types	15	17	14	9	7
-Pulmonary interstitial emphysema	9	10	10	3	5
-Pneumothorax	3	4	2	4	1
Pulmonary hemorrhage	10	12	14	6	9

All-cause mortality through 36-weeks PCA was similar regardless of which exogenous surfactant was administered.

Adverse reactions reported in the controlled clinical studies through 36-weeks PCA occurring in at least 10% of infants were anemia, jaundice, metabolic acidosis, oxygen desaturation, hyperglycemia, pneumonia, hyponatremia, hypotension, respiratory acidosis, and bradycardia. These reactions occurred at rates similar to the comparator surfactants.

No assessments for immunogenicity to SURFAXIN were performed in these clinical studies.

Follow-up Evaluations

Twelve-month corrected-age follow-up of 1546 infants enrolled in the 2 controlled clinical studies demonstrated no significant differences in mortality or gross neurologic findings between infants treated with SURFAXIN and those treated with the comparator surfactants (colfosceril palmitate, beractant, or poractant alfa).

OVERDOSAGE

There have been no reports of overdose following the administration of SURFAXIN.

HOW SUPPLIED/STORAGE AND HANDLING

SURFAXIN (lucinactant) Intratracheal Suspension is supplied sterile in single-use, rubber-stoppered, clear glass vials containing 8.5 mL of white suspension (NDC 68628-500-31). One vial per carton.

Store SURFAXIN in a refrigerator at 2° to 8°C (36° to 46°F) and protect from light until ready for use. Do not freeze. Vials are for single use only. Discard any unused portion of SURFAXIN. Discard warmed vials of SURFAXIN if not used within 2 hours of warming.

NT Column: Playing It Safe in a Social World, Social and Mobile Media for the Neonatologist

By Clara H. Song, MD

"Social & Mobile Media for the Neonatologist" by Dr. Song, is a quarterly column in *Neonatology Today*. Dr. Song created and moderates the social media outlets for the American Academy of Pediatrics, Section on Perinatal Pediatrics, as well as the NICU at the Children's Hospital at OU Medical Center. She holds workshops and speaks regionally and nationally on the topic of social communication for the healthcare professional, including: the AAP Perinatal Section Spring meeting, yearly, and the 2011 *NEO: The Conference for Neonatology*.

The virtual, social world wide web can seem like a dangerous place without the regulation of laws and police enforcement. So, why isn't there constant chaos on all the existing social media sites? Short answer: In general, people behave. Social media evolved out of the desire for users to connect and communicate. The intentions, as well as the users, were rooted in a pure, untainted good. Therefore, the social community basically moderates itself to ensure the preservation of good behavior. This self-moderation is more apparent as communities grow in number and strength. To demystify the etiquette encouraged for virtual navigation, one needs to follow a basic rule: Use common sense. That would be the same common sense that is required of us everyday in the our professional lives. Also, remember four P's:

1. Public,
2. Privacy,
3. Permanent,
4. Professional.

Public: The internet was created for everyone to utilize. As such, everything on the world wide web is open for public viewing. Despite the efforts of private security settings, there is always a way to access anything that is posted to the internet at any point in time. So, it's safest to post only those comments, photos and videos that you wouldn't mind anyone viewing, at anytime in any arena. Like they say, post it as if your grandmother could discover it on the front page of the New York Times.

Privacy: Though the web is essentially a public library of information and media, it still behooves us all to monitor privacy settings and policies for each site. This allows for your information to remain limited to a group of web users that you have elected access to your virtual world. Reviewing policies of

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each site will also clarify the ownership of the information and media that you post on that particular site (Who can see my photos? Who owns the videos now that I have posted them on this website - me or the site?). Accounts can be hacked easily and more often these days, so it's even more important that we stay on top of our account and privacy settings.

Permanent: Every post, pin, tweet and link is permanently cemented into the memory of the web. Of course, anything can be deleted, but it will be archived and accessible. Deleting is like covering up a seashell with sand - you won't see the shell on a glance, but it can always be dug up and exposed.

Professional: I believe that most of us in the neonatal profession maintain a respectable and respectful demeanor in our everyday lives, whether in the unit or in the coffee shop. This same professionalism should just as easily extend to our virtual world on the web. Professional liability risks are just as real on the web. Like whispering private or untoward comments in the elevator, we wouldn't do that in the NICU, or in the elevator for that matter. So, why would we do that on Facebook? People can still hear the whispering.

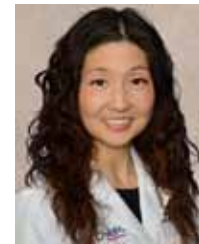
Mother was right when she said, "Think before you speak." Transfer these wise words to the social media use. "Think before you post." Better yet, "Think, pause, review, then post." It only takes an extra few seconds to think and review. Despite the scary notions of exposure and privacy issues, I still believe that the benefits outweigh the risks to us all

by interacting through social communication. So, use the social platforms in whichever way makes your life more efficient, and let the world (wide web) know what a strong social leader like yourself can teach with your knowledge and expertise. Like driving a car and anything that makes our life easier, we just need to follow a few safety rules for everyone's sake.

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The Medium is Not the Message: As of March 2015, Neonatology Today Will be Totally Digital

by Tony Carlson; Richard Koulbanis; John W. Moore, MD

The need for magazines and newsletters to be printed on paper is no longer sacrosanct, and many publications, for a variety of reasons, have gone all digital. After a careful review of trends, existing and emerging technologies, as well as reader demographics, as of March 2015, we have decided to publish *Neonatology Today (NT)* digital only. As of that date, we will no longer print *NT* on paper, except for special issues.

There are a number of factors that went into our decision, including:

- What are the pros and cons for the readers, authors, advertisers, and to *Neonatology Today* itself?
- What are our own subscriber trends, as well as technology trends in the medical field?

Here is what we found:

- A growing number of our subscribers have either requested the digital version, or have asked to change from print to digital.
- For every 1 subscriber asking to subscribe to the paper edition, we receive 10 who want it digitally.

Currently, over 50% of our subscribers are digital only. Virtually, all physicians in today's world use smart phones, tablets and computers for reviewing patient information and accessing available literature. In 2013, the number of physicians with tablets reached 72%,² and we think it's fair to say that two years later, that number is likely to be over 80%. The improvements in tablet technology and increased battery life have made tablets more desirable for physicians to use in a practice or hospital setting. In an article by Dr. Kevin Campbell, he writes, "Many hospitals are now using tablet technology to help physicians and other treatment team members prepare and interact with patients while on the move. With health care reform and cost containment strategies, many hospital systems are looking for ways to streamline care and cut costs. Potential advantages of tablet use include the ability to improve workflow on rounds, reduce staffing requirements, and increase productivity and efficiency without compromising patient outcomes. In many centers, physicians are able to sync their devices wirelessly or via sync stations located throughout the hospital." He further adds, "For physicians, the possible applications of tablet technologies are endless. Ultimately, I believe that these mobile technologies will revolutionize medicine and allow for care to be provided to patients who have previously been underserved. Tablet-based electronic patient encounters are on the horizon. As physicians, we must ensure that we continue to embrace technology and we must not resist change — medicine remains both a science and an art. We must continue to strive to incorporate both technology and human touch into our patient encounters. Change is coming: We must adapt and embrace these technologies in order to provide our patients with the health care and caring that they deserve."³

NT has been publishing both a print and digital version since it was launched in May 2006, and *NT*'s sister publication, *Congenital Cardiology Today (CCT)* since September 2003. We have slowly started to include additional material and information in the digital versions of *NT* and *CCT* that one cannot get in the print edition alone. For example, in a recent article in *CCT* by Dr. Evan Zahn et al,⁴ we linked graphic figures to videos to better help exemplify the case. We plan to enhance *NT* with videos relevant to the articles, as well. In addition, with print we have always been restricted by postal regulations to keep the publication to certain sizes, format and word count. We have had to take into consideration long lead times to print and mail. By going totally digital, significantly less impediments exist. For example, we will start including additional data on the hospitals through links and videos for recruitment advertisers, and the same for industry sponsors. We will include a new column which will focus on upcoming meetings, where we will not just high-

light the meeting, but put readers in direct touch with additional meeting information, possibly video interviews and the course directors via email. We will be able to give the reader a fuller, and better reading and learning experience, so that the reader can access additional relevant information. Since we will no longer be restricted by postal regulations for page sizes, we will make the type larger for easier online reading. And of course, every issue will always be available.

The publication will remain free to NICU professionals, and with the focus on electronic distribution, we will be able to reach more readers both domestically and internationally. We will continue to enhance the publication.

In the past, we have published our digital version in a PDF file because it allowed the reader to read *NT* with the same format as print. Moving forward, we will continue to use this format, but will transition to HTML5, which allows for easy access from any number of computers, operating systems and mobile devices. For those who like to hold, read and feel the paper, the newsletter can be printed locally on one's own printer. For those readers who have not read *Neonatology Today* digitally, every issue ever printed, past and present is available at our website - www.NeonatologyToday.net.

Over the next few of months, we will convert the remaining print subscribers to digital ones. While some readers may be more comfortable with paper and reluctant to change, as our own statistics have born out, many more will look forward to this change; it is the wave of the future. We expect to grow the subscriber base, and build a neonatology community in the coming months and years, incorporating social media as well.

If you have not already switched your subscription to electronic, and would like to do so, simply send an email to: Change@Neonate.biz. Include your name, title, hospital affiliation and work address. If your NICU team members would like to subscribe, they may send an email to: sub@Neonate.biz, also including their name, title, hospital affiliation, and work address.

We would also like to hear from you on what changes you would like to see to enhance our editorial. Send your ideas and requests to: Ideas@Neonate.biz.

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Preterm, Low Birth-Weight Babies May Need New Hips in Adulthood

Researchers from Australia report that low birth weight and preterm birth are linked to increased risk for osteoarthritis (OA)-related hip replacements in adulthood. Findings published in the *American College of Rheumatology (ACR) journal, Arthritis Care & Research*, indicate that low birth weight and pre-term babies were not at greater risk of knee arthroplasty due to OA as adults.

According to the ACR, 27 million Americans over the age of 25 are diagnosed with clinical OA. Symptoms of OA range from mild to severe and include pain, stiffness, and swelling of joints. In fact, OA is the most common cause of disability, with medical evidence reporting OA of the knees and hips totaling 71 million patients lived with disability (2010)—a worldwide increase of 64% since 1990.

Lead investigator, Professor Flavia Cicuttini with the School of Public Health and Preventive Medicine at Monash University and Alfred Hospital in Melbourne, Australia says, "Currently there are no disease-modifying medications available to treat OA, which makes understanding the risk factors associated with OA so important for improving prevention of this disabling disease."

Previous research found that low birth weight and preterm birth have been linked to hypertension, cardiovascular disease, insulin resistance and reduced bone mass in adulthood. With understanding of these adverse outcomes, the research team set out to investigate if low birth weight and preterm birth also played a role in increased risk of joint replacement surgery as adults.

The present study used data from 3,604 participants of the Australian Diabetes, Obesity and Lifestyle Study who were 40 years of age or older at the time data of joint replacement surgeries were collected. Participants provided information about their weight at birth and if they were prematurely delivered. The participants' records were then linked to knee and hip replacements due to OA data (2002-2011) from the Australian Orthopaedic Association National Joint Replacement Registry.

Of the participants, 116 had knee replacement surgery and 75 underwent hip arthroplasty for OA. Low birth weight and preterm birth were linked to increase incidence of hip arthroplasty independent of age, sex, body mass index (BMI), education level, hypertension, diabetes, smoking and physical activity. Researchers found no significant association between low birth weight or preterm birth and knee replacement surgery.

"Our findings suggest that individuals born prematurely or with low birth weight are more likely to need hip replacement surgery for OA in adulthood," concludes Professor Flavia Cicuttini. "While further investigation is needed to confirm these findings, indentifying those at greatest risk for hip OA and providing early interventions may help reduce the incidence of this debilitating disease."

THE NEO MEETING AGENDA AT GLANCE

NEO: The Conference for Neonatology
Feb. 19-22, 2015; Hilton Bonnet Creek, Orlando, FL USA
www.neoconference.com

NEO 2015 will address cutting edge, yet practical aspects of newborn medicine. Educational sessions will be conducted by diverse experts who will address the following neonatal-perinatal topics:

MODERN MANAGEMENT IN VENTILATORY CARE

- Non-invasive Ventilatory Management
- The Effects of Mechanical Ventilation on Other Organ Systems
- Contemporary Care of the Infant with PPHN
- Practical Applications of the SUPPORT Trial – Managing Oxygen in the NICU

BIG DATA IN THE NICU – THE MODERN APPROACH TO IMPROVING NEONATAL OUTCOMES

- Using the EHR in the NICU – Making it Better for Neonates
- Local Collaboratives in Improving Outcomes in the NICU
- CPQCC – The Challenges Moving Forward
- The North Carolina Perinatal Collaborative
- Outliers in the Data Warehouse – What Do You Do?

PHARMACOLOGY IN THE NICU

- The Neonatal Drug Pipeline
- Inhalation Drug Therapy in the NICU
- Antifungals in the NICU – So Now What?

THE NEONATAL BRAIN – INJURY AND OUTCOMES

- The Role of Biomarkers in the Diagnosis and Management of HIE
- Cooling in HIE – Where are We Now, What is the Future?
- The Use of Cord Blood in the Treatment of HIE Injury
- Imaging and Outcomes in the VLBW Infant – Evolving the Care

CURRENT CONCEPTS IN CLINICAL NUTRITION AND PREVENTING NEC

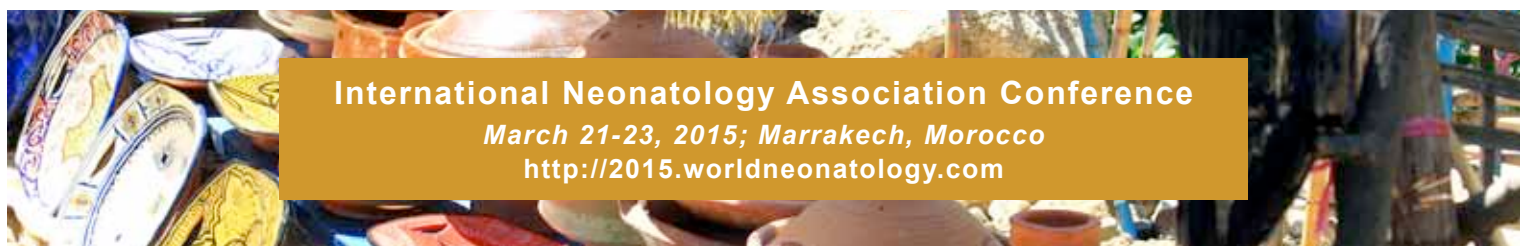
- Optimizing Growth of the Maternal and Donor Human Milk-Fed, Extremely Preterm Infant
- Breathing and Swallowing Mishaps in the Neonate: Aero-Digestive Regulation
- The Role of Probiotics in the Care of the ELBW Infant
- New Thinking About NEC

SPECIAL INTERACTIVE SESSION

- Surviving the NICU, Parents' Perspectives
- Premie-Parent Alliance Members

LEGENDS OF NEONATOLOGY 2015 HONOREES:

- Philip Sunshine, MD
- John Kattwinkel, MD



International Neonatology Association Conference

March 21-23, 2015; Marrakech, Morocco

<http://2015.worldneonatology.com>

This study was published in *Arthritis Care & Research*. Full citation: "Association of Low Birth Weight and Preterm Birth with the Incidence of Knee and Hip Arthroplasty for Osteoarthritis." Sultana Monira Hussain, Yuanyuan Wang, Anita E. Wluka, Jonathan E. Shaw, Dianna J. Magliano, Stephen Graves and Flavia M. Cicuttini *Arthritis Care and Research*; Published Online: November 3, 2014 (DOI: 10.1002/acr.22475).

<http://doi.wiley.com/10.1002/acr.22475>

Size Matters: Baby's Size at Birth May Predict Risk for Disease Later in Life

A new research report published in the November 2014 issue of *FASEB Journal* suggests that being overweight might be better in the long term than being underweight. Before you reach for that box of Twinkies™, however, it's important to note that this discovery only applies to the weight of newborn babies in relation to risk of future disease.

"These findings support the hypothesis that common long-term variation in the activity of genes established in the womb may underpin links between size at birth and risk for adult disease," said Claire R. Quilter, PhD, study author from the Mammalian Molecular Genetics Group, Department of Pathology at the University of Cambridge in the United Kingdom. "If confirmed, these could be important markers of optimal fetal growth and may be the first step along a path to very early disease prevention in the womb."

Quilter and colleagues set out to determine whether or not there was any truth to the prevailing hypothesis that conditions in the womb that lead to a high birth weight or low birth weight could affect expression of genes in the baby, which in turn, leads to effects that persist into adult life. To do this, scientists looked at DNA derived from the cord blood of newborn babies from mothers with raised glucose levels during late pregnancy and in those babies born following relatively slow growth in the womb that later caught up after birth. Researchers looked for differences in DNA methylation patterns (chemical modifications of DNA known to effect changes in gene activity). Results showed differences in these methylation changes which were specific to boys and girls and to each of the two groups. However, changes were also identified that were common to both groups of babies. Similar overlapping signals were seen in two other groups of babies studied.

"In the age of epigenetics, prenatal care is moving beyond infant survival and into optimizing the health of the baby for his or her entire life," said Gerald Weissmann, MD, Editor-in-Chief of *The FASEB Journal*. "Understanding the epigenetic factors that play a role in a baby's

birthweight will eventually help doctors give the best care and advice to their pregnant patients."

Details: Claire R. Quilter, Wendy N. Cooper, Kerry M. Cliffe, Benjamin M. Skinner, Philippa M. Prentice, LaTasha Nelson, Julien Bauer, Ken K. Ong, Miguel Constância, William L. Lowe, Nabeel A. Affara, and David B. Dunger. Impact on offspring methylation patterns of maternal gestational diabetes mellitus and intrauterine growth restraint suggest common genes and pathways linked to subsequent type 2 diabetes risk. *FASEB J*. November 2014 28:4868-4879; doi:10.1096/fj.14-255240 ; <http://www.fasebj.org/content/28/11/4868.abstract>

Mayo Clinic and Invenshure Launch Oneome™

Mayo Clinic and Invenshure announce the launch of Oneome™, a genomics interpretation company that exports Mayo's extensive pharmacogenomics knowledge in the form of concise, actionable reports to help providers anywhere deliver the right medication at the right time. Oneome™ reports will focus on providing pharmacogenomically driven guidance for medications with high levels of evidence in medical literature. Financial terms of the agreement were not disclosed. Mayo's financial investment in Oneome™ comes from the Mayo Clinic for Individualized Medicine.

"Our own genetic makeup can have a significant impact on how our bodies process and use prescription medication, which in turn affects whether or not a drug works the way our doctor intended," says Oneome™ co-founder John Logan Black, MD, a Mayo Clinic physician and Co-Director of the Personalized Genomics Laboratory in Mayo's Department of Laboratory Medicine and Pathology. "We have developed sophisticated decision algorithms that can help providers use genomic testing to get their prescriptions right the first time."

Individual patients may have minor, but significant variations in hundreds of genes. Some of these can result in potentially life-threatening reactions to a medication that may be perfectly safe for most of the population, while others make prescriptions less effective. Some people, for instance, cannot process the common pain relievers codeine and tramadol, rendering the drugs ineffective against pain. Other people process the drugs too quickly, giving the patient a rapid and dangerous pulse of relief, which may result in accidental overdose. In many cases, a patient's genomic information offers insight into how that person is likely to respond to a particular medication.

"Even some of our most widely prescribed medications don't work the same way in every patient," says Dr. Black. "The same dosage of warfarin can have markedly different effects in

different individuals — this is why patients taking anticoagulants need routine clotting tests."

Invenshure Co-Founder and Oneome™ CEO Troy Kopischke says combining his company's data processing platform with Mayo's pharmacogenomics knowledge base positions Oneome to meet a critical and untapped need in clinical care.

Research and development of the algorithms come from the Mayo Clinic and the Mayo Clinic Center for Individualized Medicine.

Dr. Black has a financial interest in Oneome™, and the technology described herein. The revenue Mayo receives is used to support the clinic's nonprofit mission in patient care, education and research.

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