

NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists

Volume 8 / Issue 5
May 2013

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NEONATOLOGY TODAY

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ISSN: 1932-7129 (print); 1932-7137 (online).
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Corporate Offices:

8100 Leaward Way,
PO Box 444
Manzanita, OR 97130 USA

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Westerly, RI 02891 USA

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Telemedicine: Advantages and Future Applications – Q & A with Drs. Helen Mintz-Hittner and Thomas C. Lee

Medical prevention and screening programs in general are not always given the same attention as surgical programs, and professionals are always searching for innovative means to reach a larger population and prevent serious consequences. As communications technology continues to expand and evolve, telemedicine is playing an increasingly important role in the logistics and execution of healthcare strategy. There are enormous potential benefits within ophthalmology to expand screening, education and tele-mentoring not just to remote rural communities and developing countries, but also within urban regions.

Q: Why is telemedicine becoming indispensable for Retinopathy of Prematurity (ROP) screening?

A: Dr. Helen Mintz-Hittner: ROP is the leading cause of childhood blindness in the United States and studies have shown that early treatment of high-risk pre-threshold ROP significantly reduces unfavorable outcomes.¹ New screening guidelines implemented in 2013² effectively raise the number of infants eligible for screening from 60,000 to 80,000 in the United States alone. Unfortunately, this follows a general decrease in the number of pediatric ophthalmologists willing and able to conduct the ROP screenings.³ Many hospitals are forced to operate without an ROP screener, and if a baby meets the criteria for screening, weighing less than 1500 grams and having oxygen, it has to be transferred or the hospital is subject to a lawsuit if ROP develops.

Transferring babies is not something to take lightly. Mothers in particular are often torn between new babies that need to bond with them and other children at home that cannot be left. Now pediatric units can send me the pictures they capture using Clarity Medical's RetCam, and if I see just a small indication of ROP, I ask them to repeat the images again in a few days. If I see something that is significant ROP, I have them transfer the baby. This allows the majority of babies to stay in their home nursery, close to their family and support system, and feed and grow. Because of telemedicine and RetCam, I have only had to transfer one baby.

A: Dr. Lee: Level 3 Neonatal Intensive Care Units (NICUs) can't have a license if they do not have an ophthalmologist who can screen and treat ROP. In 2006 and 2007, the city of Las Vegas, which had four NICUs, lost their screener and treater. They had to find someone or shut down all four NICU's. They found a screener, but he wasn't comfortable doing the treatment. So if he saw a patient he was worried about, that patient would be imaged with the RetCam and then the files were emailed to me. Then based on those images, the decision would be made whether or not to fly the patient in a medical air transport out to Los Angeles to my hospital. During that whole year, we covered the entire city of Las Vegas for advanced ROP, and the only way we were able to do that was through telemedicine.

Q: Can telemedicine be instrumental in attaining a second opinion?

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References: 1. Barrett-Reis B, et al. *Pediatrics*. 2000;106:581-588. 2. Erickson T, Gill G, Chan GM. *J Perinatol*. 2012:1-3. 3. Lawrence RA, Lawrence RM. *Breastfeeding: A Guide for the Medical Professional*. 6th ed. St. Louis, MO: Elsevier Mosby, Inc; 2005:147.

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A: Dr. Mintz-Hittner: I have had situations where a colleague isn't quite sure what they are seeing and they are able to send me pictures. I can help them determine the pathology and if they need to transfer a baby or not. We also use this technology in clinical studies. In most cases, the consensus of at least two ophthalmologists is needed to initiate treatment. Telemedicine is a good way to make sure you are making the right diagnosis at the appropriate time.

A: Dr. Lee: One of the main criteria for determining whether a child needs to be treated for ROP is the presence of Plus Disease. A 2007 study showed 22 ROP experts wide-angle retinal images and asked them to identify plus disease.³ The study concluded that accuracy of diagnosis, even among experts, is imperfect. The heterogeneity within the community is very high and, even among experts for ROP, we can't always agree. By using telemedicine, more than one person can screen patients, thus diminishing the risk that you miss something or under-call a pathology. I think it can be useful with any retinal or anterior segment issues. Ophthalmic disease is uniquely amenable to telemedicine because so much of what we do with the eye is based on images we take, which can be shared.

Q: What about the use of telemedicine in education or telementoring?

A: Dr. Lee: There are many aspects of telemedicine which, although it sounds very attractive, can end up being very unrealistic depending on what you're asking the telemedicine platform to do. Where it does work is from an educational standpoint. We have a telemedicine distance learning program in Armenia in collaboration with the Armenian Eye Care Project, where it works phenomenally well. We are also planning to mentor the Armenian physicians remotely in the operating room using off-the-shelf technology to stream the video signal from an intraocular endoscope. The Armenian surgeon would have a Bluetooth headset; I would log into their endoscopic unit and then walk them through the surgery remotely from Los Angeles.

A: Dr. Mintz-Hittner: The younger people who do not have as much expertise will send images to someone who has been doing it longer to get a second opinion, that's done all the time, much like radiologists do. I teach all the time, and I'm always showing pictures of



RetCam 3 from Clarity Medical Systems.

one disease or another. I'll take pictures of an abnormal ear or chin and show other abnormalities that are part of the syndrome.

Q: Why is there a shortage of pediatric ophthalmologists who are willing to screen and treat these patients?

A: Dr. Mintz-Hittner: Low reimbursement with considerable time expenditure (repetitive exams are necessary especially in high risk, advancing cases), excessive travel requirements, and medico-legal risks due to late diagnosis, poor outcomes, and difficulties in getting complete follow-up; all contribute to the decline of professionals. In developing countries, the incidence of ROP can be as high as 30% of all preterm births (often including infants weighing more than 2500 grams at birth, and 34 weeks gestational age) and the financial and professional resources to provide high level care are even lower.³ Additionally, in the most remote areas, where they are screening one or two babies a week, there are usually not pediatric ophthalmologists available to go into the hospitals, or it's not worth their time because they don't find enough pathology. Telemedicine gets all of these patients covered without having a

pediatric ophthalmologist go there--the neonatologist, nurses, or any trained technician can do imaging.

A: Dr. Lee: A retina surgeon or pediatric ophthalmologist in the office can see 30 patients in one afternoon, which generates a lot of income, depending on the reimbursement system. If they have to go to the hospital for screenings, they have to drive there, park their car, get to the NICU, repeatedly wash their hands, wear gloves and perhaps gowns, examine a patient, a non-compliant baby who is squirming, and often for minimal reimbursement. On top of that, if you were to make a mistake, it's a very unforgiving disease and a child could go blind in 48-72 hours if you miss the treatment window. If a child goes blind, jury awards for ROP are some of the highest in our field. This is why there's a deficit of ROP screeners. That deficit has driven the deployment of telemedicine. The only way to get infants access to these doctors is telemedicine.

Q: Where do you feel telemedicine will go in the future?

A: Dr. Mintz-Hittner: Telemedicine models are being tested for all types of screening, corneal and lens opacities, anterior segment abnormalities including glaucoma, vitreous abnormalities and important genetic and sporadic retinal and optic nerve abnormalities. A group of 10 optometrists in rural Canada is examining patients and then forwarding the imaging and clinical information to specialists in Alberta.⁵ In the first year of the study, 28 patients were evaluated via a telemedicine system and only four had to be referred to a glaucoma specialist. Without telemedicine, it is likely that all 28 would have had to travel for a consultative screening. In the cases of ROP and glaucoma, telemedicine is used to determine whether future screening is necessary, not what treatment to use.

A: Dr. Lee: As bandwidth increases and as these platforms become more ubiquitous, I think telemedicine is going to mature, and although we haven't seen a lot of movement in this space, I think that will change in the next five years. Your smart phone has the ability to take a highly sensitive and dynamic-range of images. In theory, if a pediatrician saw a dermatologic lesion and wanted to set up a telemedicine consultation with a dermatologist he or she could probably do that with his or her cell phone. The technology is good enough



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and it's that ubiquitous, and I think you are going to see a lot of pressure to start using these in a medical setting.

Physician Profiles

Helen Mintz-Hittner, MD



Helen Mintz-Hittner, MD is Professor of Ophthalmology and Visual Science at the Robert Cizik Eye Clinic University of Texas Health Science Center-Houston Medical School. Dr. Mintz-Hittner earned her bachelor's at Rice University (Phi Beta Kappa) graduating with High Honors and received her MD from Baylor College of Medicine (Alpha Omega Alpha) where she graduated with Honors. She completed her internship and ophthalmology residency at Baylor College of Medicine. She completed her pediatric ophthalmology fellowship as a Heed Fellow at Texas Children's Hospital. She has focused her research on multiple aspects of Retinopathy of Prematurity (ROP), and has

authored multiple articles on ROP throughout her career, which spans 39 years. She is currently the principal investigator of BEAT-ROP, a prospective, randomized, multi-center clinical trial comparing laser to Bevacizumab therapies for ROP. This clinical trial is intended to allow follow-up for 7 to 10 years. The study has published its preliminary results six months following completion of these interventions for Stage 3+ ROP--in the *New England Journal of Medicine* in February 2011. At the *American Association of Pediatric Ophthalmology and Strabismus* meeting in Boston on April 6th, the two-year refractive outcomes comparing laser to Bevacizumab for ROP will be presented and published shortly thereafter. Dr. Mintz-Hittner has been published in many publications regarding her studies and experience in pediatric ophthalmology. She has been published in multiple peer review journals, as well in *The Wall Street Journal*, *The Houston Chronicle*, Reuters, Science News, EyeNet, and *The American Academy of Pediatrics*, to name a few.

Dr. Thomas C. Lee



Dr. Thomas C. Lee is the Director of the Retina Institute in The Vision Center at Children's Hospital Los Angeles. He came to Children's Hospital in 2006 from New York-Presbyterian Hospital / Cornell University, where he was Director of the Pediatric Retina Service, and Associate Director of the Robert M. Ellsworth Ocular Oncology Center. Dr. Lee earned his bachelor's Degree at Johns Hopkins University and received his MD from Cornell University where he graduated with Honors in Research as a Howard Hughes Scholar. He completed his ophthalmology residency at Cornell and then went to Harvard

Medical School as a Heed Fellow where he studied retinal stem cells and the role they play in cancer. He completed his retina fellowship at Massachusetts Eye and Ear Infirmary, Harvard Medical School before



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A: “Dr. Lee: As bandwidth increases and as these platforms become more ubiquitous, I think telemedicine is going to mature, and although we haven’t seen a lot of movement in this space, I think that will change in the next five years.”

returning to Cornell where he was a Fred Gluck Scholar. He held the position of Associate Director of the Robert M. Ellsworth Ocular Oncology Center at Cornell until being recruited to Children’s Hospital Los Angeles.

References

1. Good W, ETROP Cooperative Group. Final results of the retinopathy of prematurity (ETROP) randomized trial. *Trans Am Ophthalmol Soc.* 2004 December; 102:233-250.
2. American Academy of Pediatrics Section on Ophthalmology, American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus, and American Association of Certified Orthoptists. Policy Statement: Screening Examination of Premature Infants for Retinopathy of Prematurity. 2013 January; 131:189-195.
3. Gergely K, Gerinic A. Retinopathy of prematurity – epidemics, incidence, prevalence, blindness. Faculty of Medicine, Comenius University. Found online at: <http://www.bmj.sk/2010/11109-10.pdf>.
4. Gelman R, Jiang L, Du Y, Martinez-Perez ME, Flynn JT, Chiang, MF. Plus Disease in Retinopathy of Prematurity: Pilot study of computer-based and expert diagnosis. *J AAPOS.* 2007 December; 11(6): 532-540.
5. Data presented at the Association for Research in Vision and Ophthalmology annual meeting, Ft. Lauderdale FL, May 2010. Found online: <http://eyeworld.org/article.php?sid=580>.

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- Paediatric And Neonatal Intensive Care Nursing; Reducing Healthcare Associated Infections - *Gerri Sefton, UK*
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- Metabolism, Endocrinology And Nutrition: The Acute Stress Response - *Metabolic And Hormonal Alterations - Koen Joosten, Rotterdam, The Netherlands and George Briassoulis, Greece*
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Immortal Bird: A Cautionary Tale for Pediatric Physicians

By John W. Moore, MD, MPH

I received an email from Marty Stein, a senior developmental pediatrician at Rady Children's Hospital, asking me whether I had come across the book, *Immortal Bird* by Doron Weber. Marty said that it brought up a number of serious communication issues between the patient's family and the physicians who cared for him, as well as communication and relationship issues among the pediatric specialists and surgeons. "Did the issues raised in the book ring true?" he asked me. I looked at reviews of the book, which were mostly positive, read the book and decided it not only "rings true", but is also an excellent teaching tool for those of us caring for cardiac patients.

The book begins with a quote from "Ode to a Nightingale" by John Keats. The first line of which is "Thou wast not born for death, Immortal Bird!" The very line embodies the deep love and profound loss felt by Doron Weber after the death of his son Damon.

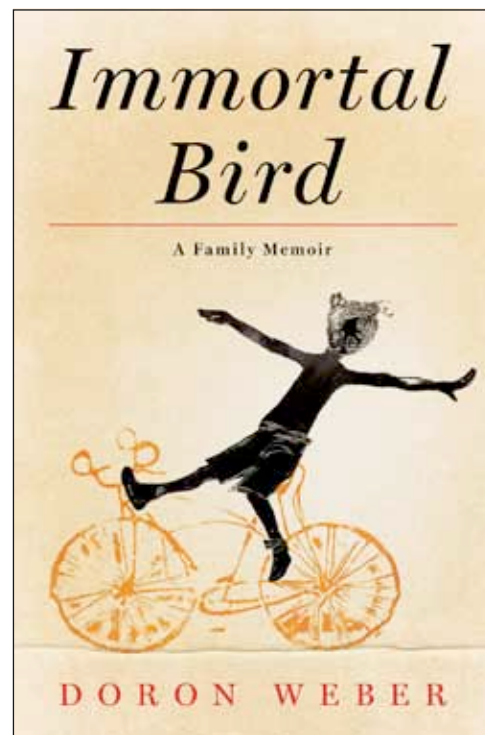
Immortal Bird was not written for a professional audience, so many medical details of Damon Weber's case are missing or obscure. It appears that the boy's underlying heart condition is AV canal defect, probably in the context of a Heterotaxy Syndrome. He was cared for at Columbia in the 1990's and early 2000's. Dr. Jan Quaegebeur performed his initial surgeries, including Fontan completion. From ages four to twelve, Damon grew normally, was medication-free and his cardiologist "marvels at his progress." But, his parents began to notice that his abdomen looked "paunchy" and that he stopped growing. At first, his cardiologist reassured Damon's parents that he was fine. Soon thereafter, Damon revealed to his father that he had swollen testicles and, ultimately, it became clear that he had a ruptured hernia, an enlarged liver and had developed Protein-Losing Enteropathy (PLE). Overtime, he was treated with medications and a special diet. His PLE progressed, and Dr. William Hellenbrand created a fenestration in the catheterization lab. Damon also received albumin and IVIG infusions. He was treated with steroids, and heparin therapy was considered. Although each of these therapies provided temporary improvements, the PLE was relentless.

Damon eventually was listed for and had a heart transplant performed by Dr. Jonathon Chen. The Columbia pediatric transplant team, given the pseudonyms of Drs. Mason, Davis, Becker and Sanford, orches-

trated his pre- and post-transplant care. Damon survived transplantation and left the hospital. Soon thereafter he developed fever, other systemic symptoms, thrombocytopenia, and liver dysfunction. The transplant team treated him for early rejection with a boosted immunosuppressive regime, in spite of a negative biopsy and an Epstein—Barr Virus mismatch. He died shortly thereafter from something Weber calls fulminate Post-Transplant Lymphoproliferative Disorder (PTLD), but as described, sounds more like viral sepsis and multi-organ failure. Damon lived 16 years.

My feelings as I read this book were complicated. Doron Weber's name-dropping, sense of entitlement and privileges, initially put me off. I almost put the book down after reading only the first few chapters. I felt that Weber would have nothing to say about my patients from less affluent and less sophisticated middle and lower class families. I read further mainly because I wanted to respond to Marty. What unfolded was a deeply moving story of a father's love for his son and of the father's arduous and unsuccessful battle to save his son's life. During this struggle, Weber lost trust in most of his son's doctors and felt abandoned by or isolated from many of them. He contacted a number of additional institutions, looking for better treatment options. His attempt to manage his son's care did not build bridges with the physicians at Columbia. Ultimately, in spite of a heart transplant, all efforts were in vain and, eventually, Damon dies. In the epilogue, Weber explained that he was so angry and so distraught about his son's care that he initiated "an all-out hunt for justice" in the form of a malpractice suit. Damon's medical records, shipped to an off-site facility are "lost", further fueling Doron's anger and grief. He pours his grief into the memoir.

I'm glad that I read *Immortal Bird*. The book provides a cautionary tale for pediatric cardiologists and other pediatric specialists about how and what to communicate to cardiac patients and their families. Damon, for sure, is one of pediatric cardiology's archetype patients. His case was complicated; he needed careful follow-up; and eventually he needed timely treatment for severe complications of single ventricle and Fontan palliation. His father, a former Rhodes Scholar and boxer, applied his pugilistic spirit to Damon's problems. Like any good parent, he was caring and involved. Unlike most, he felt responsible for his son's care, attending an international PLE medical symposium, making a list of all the known treatments for PLE based on his review of



Immortal Bird: A Family Memoir by Doron Weber. Published by Simon & Schuster - www.SimonandSchuster.com.

the medical literature and labeling this list his "battle plan." Doron Weber was also a hopeless doctor shopper with the means to take his son anywhere for consultation. He sought opinions from four different institutions, numerous individuals and even a Nobel Prize winner. To say the least, he was a complicated and difficult parent. Creating and maintaining a healthy or even an adequate professional alliance with Doron Weber would have been a challenge for any cardiologist.

In the memoir, we have a sad and angry retelling of the course of Damon's treatment. We also learn of a close and loving father's best attempts to cope with an overwhelming situation. We come to know Damon as a bright, talented kid with a flair for acting, who, when on stage, is "like a bird that can only display its full plumage in a native habitat". As for confronting his cardiac issues, his father's description of him as "a brave sixteen-year old boy with a lion's heart" couldn't be more apt. Doron's artful description of Damon, his life, his playfulness, and his implacable spirit engenders affection for him in any reader. His death is a sad ending capable of evoking intense memories of other patients lost.

The book is not without a few light moments. My favorite is when Doron Weber consults with Dr. Alvin Chin at Children's Hospital of Philadelphia (CHOP) to complain about Damon not being properly listed on the Columbia transplant list. Dr. Chin reminds Weber that everyone makes mistakes and that he probably wouldn't do any better at CHOP, because half the CHOP staff trained at Columbia!

There are many important issues raised in this book: Who is responsible for Damon's outpatient care and for his care plan? Is it the "team," the primary cardiologist, and/or the surgeon? How should the child's family be prepared for possible future complications and his uncertain long-term prognosis? Who should educate the family? Furthermore, without agreed upon algorithms for surveillance or treatment, how should Damon's care be managed? How accessible should his cardiologists be to the patient and family? Should they give the family their cell phone numbers and emails? What are the responsibilities of the "on-call" cardiologist? What is the role of the cardiology fellow receiving calls from outpatient families or PCP's about patients? Should care be "handed off" between team members when the child's most identified cardiologist is away or otherwise unavailable? How should his cardiologists react to intrusions or recommendations by VIP's, authorities, or well-know pediatric cardiologists from other programs?

Programmatic and system issues are also raised: Does it make sense to use the ED as a place to evaluate well-known chronically ill cardiology patients or post-transplant patients, or should they be admitted directly to the ward? What is the role of the PICU attending in the care of critically ill cardiac patients who are in the PICU? Who provides and who plans the care in the PICU? Who performs and is responsible for needed procedures (lines, tubes, etc.)? Should there be a CVICU staffed by cardiologist-intensivists? What is the role of the inpatient cardiology fellow? Are there sufficient inpatient cardiology beds available, such that patients like Damon can be properly accommodated? Is there an electronic medical record? How are communications between physicians caring for inpatients occurring? Is critical information exchanged well among practitioners (things like EBV mismatch between donor and recipient)? What is the role of consultants in care planning? Who provides strate-

"Immortal Bird is so loaded with relevant medical and behavioral topics that I decided it merited being the focus of discussion for two sessions of our regular fellowship educational lecture series."

gic direction of care when the patient is sick and in the hospital? Who provides the key communications with the family and the patient? How can a hospital "lose" important patient records?

Immortal Bird is a powerful personal tale of the loss of a child, and it also provides important lessons for the community of pediatric care providers. Damon's story should inspire us to strive for the best possible communications with families and with one another. Review and consideration of the medical issues raised in the book may lead to improvements in the way we care for and treat our patients. I highly recommend that all physicians who care for children read the book.

A Study Guide

Immortal Bird is so loaded with relevant medical and behavioral topics that I decided it merited being the focus of discussion for two sessions of our regular fellowship educational lecture series. I purchased three-dozen used books on Amazon, and provided a copy to each fellow, cardiologist, surgeon, and nurse practitioner in our program. I scheduled one-hour medical and behavioral sessions to occur two months after I distributed the books. I thought that the "readers" among us would finish the book quickly, and word of mouth would take care of the rest. I was right. After two months nearly everyone had read the book, and I was party to many informal discussions about it. By the time the scheduled sessions rose on the calendar, I expected and received large audiences. Marty Stein joined us as well.

Medical Session

In the medical session I reviewed the medical problems encountered by Damon Weber, including PLE, transplantation for failed Fontan, and PTLD. I found the following references to be the most useful and informative:

- Mertens L, Hagler D, Sauer U, et al. Protein-losing enteropathy after the Fontan operation: an international multicenter study. *J Thorac Cardiovasc Surg* 1998;115:1063-1073. (Background, much of my pre-review knowledge came from this report).
- Rychik J. Protein-Losing Enteropathy after Fontan Operation. *Congenit Heart Dis*. 2007;2:288-300. (A slightly dated review, with a sophisticated discussion of factors involved in pathophysiology).
- Meadows J, Jenkins, K. Protein-losing enteropathy: integrating a new disease paradigm into recommendations for prevention and treatment. *Cardiology in the Young* 2011;21:363-377. (The most recent comprehensive review, good references, also a summary of the Boston Children's Hospital experience with PLE).
- Bernstein D, Naftel D, Chin C, et al. Outcome of Listing for Cardiac Transplantation for Failed Fontan. *Circulation* 2006;114:273-280. (Multi-center review of results from pediatric transplant group, provides separate analysis of PLE patients)
- Davies RR, Sorabella RA, Yang J et al. Outcomes after transplantation for "failed" Fontan: A single-institution experience. *J Thorac Cardiovascular Surg* 2012;143:1183-1192. (Review of Columbia's experience, separates PLE patients, includes period when Damon received a transplant).
- Manihot C, Poliack-DarZiv S, Holmes C, et al. Post-transplant lymphoproliferative disorder in pediatric heart transplant recipients. *J Heart Lung Transplant* 2010;29:648-657. (Current experience with PTLD, summary of characteristics, relationship to EVB).

During the medical discussion, my group expressed interest in developing and adapting a common algorithm for surveillance and maintenance care of single ventricle patients after Fontan. We noted that among eleven cardiologists, we had eleven slightly different approaches toward things like monitoring serum albumin and liver function, as well as chronic anticoagulation, use of diuretics and afterload therapy. There was a consensus among us



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“During the medical discussion, my group expressed interest in developing and adapting a common algorithm for surveillance and maintenance care of single ventricle patients after Fontan.”

that a more consistent approach could improve patient care for a variety of reasons.

Behavioral Session

The behavioral session was new territory for me. I had no guidance and little experience. My goal was simply to host an active discussion of issues raised by the author. My method was to raise issues for discussion by reading relevant quotations from the book, such as:

- *I ask Dr. Hayes why she never hinted to me before that anything like this could happen. “Haven’t I always asked for more information about my son?” p. 54.*
- *No one has checked Damon’s albumin for several years, and I have observed what turns out to be PLE symptoms for an indefinite period. p. 60.*
- *She either doesn’t have the facts or won’t discuss them with us. “Trust me, it’s all good.” She said. I begin to worry we are getting a sales pitch. Her language is vague and imparts no real information. p. 214.*
- *I’ve phoned to announce our readiness, at long last, to hand over our son into the care of the pediatric cardiac transplant unit at Columbia—but there’s no one on the other end to receive the news! Nor is anyone on hand to tell us about next steps or to provide the standard set of instructions.... A week later neither Dr. Davis nor Dr. Mason have called back, I send a stronger message, I title my e-mail “Who’s in Charge of Damon Weber?” p. 258.*
- *There were multiple doctors involved: PICU attending, card fellow, more than one cardiologist, the cath doctor to put in lines... “No one is taking responsibility for Damon’s care” p. 312.*

- *“Oh, of course, his donor was EBV positive!” said Dr. Mason. These words tossed out so casually, send me reeling. So she’s known all along, how could she not tell us? Is it possible that she did not communicate such vital information to her colleagues? p. 324.*

It turned out that the group needed little inspiration. After just a few quotes, multiple hands went up. It seemed that nearly everyone had opinions they wanted to express and to discuss. It was interesting that the case specifics in our discussions turned quickly from Damon Weber and Columbia to our patients and our program at Rady Children’s Hospital. John Lamberti, our Chief Surgeon, summarized the conversations by declaring: “I have dealt with similar intense family situations many times during my career!” And, as for the answer to Marty’s question: “Yes, the issues raised in the book do ring true ... and it’s too early to tell whether the book will stimulate positive changes in us or our program.”

Hallway discussions are continuing....

NT



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INOMAX® is a vasodilator, which, in conjunction with ventilatory support and other appropriate agents, is indicated for the treatment of term and near-term (>34 weeks) neonates with hypoxic respiratory failure associated with clinical or echocardiographic evidence of pulmonary hypertension, where it improves oxygenation and reduces the need for extracorporeal membrane oxygenation.

Utilize additional therapies to maximize oxygen delivery with validated ventilation systems.

Reference: 1. Data on file. Hampton, NJ: Ikaria, Inc; 2013.

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INOMAX Important Safety Information

- INOMAX is contraindicated in the treatment of neonates known to be dependent on right-to-left shunting of blood
- Abrupt discontinuation of INOMAX may lead to increasing pulmonary artery pressure and worsening oxygenation even in neonates with no apparent response to nitric oxide for inhalation

Please see Brief Summary of Prescribing Information on adjacent page.

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Brief Summary of Prescribing Information

INDICATIONS AND USAGE

Treatment of Hypoxic Respiratory Failure

INOMax[®] is a vasodilator, which, in conjunction with ventilatory support and other appropriate agents, is indicated for the treatment of term and near-term (>34 weeks) neonates with hypoxic respiratory failure associated with clinical or echocardiographic evidence of pulmonary hypertension, where it improves oxygenation and reduces the need for extracorporeal membrane oxygenation.

Utilize additional therapies to maximize oxygen delivery with validated ventilation systems. In patients with collapsed alveoli, additional therapies might include surfactant and high-frequency oscillatory ventilation.

The safety and effectiveness of INOMax have been established in a population receiving other therapies for hypoxic respiratory failure, including vasodilators, intravenous fluids, bicarbonate therapy, and mechanical ventilation. Different dose regimens for nitric oxide were used in the clinical studies.

Monitor for PaO₂, methemoglobin, and inspired NO₂ during INOMax administration.

CONTRAINDICATIONS

INOMax is contraindicated in the treatment of neonates known to be dependent on right-to-left shunting of blood.

WARNINGS AND PRECAUTIONS

Rebound Pulmonary Hypertension Syndrome following Abrupt Discontinuation

Wean from INOMax. Abrupt discontinuation of INOMax may lead to worsening oxygenation and increasing pulmonary artery pressure, i.e., Rebound Pulmonary Hypertension Syndrome. Signs and symptoms of Rebound Pulmonary Hypertension Syndrome include hypoxemia, systemic hypotension, bradycardia, and decreased cardiac output. If Rebound Pulmonary Hypertension occurs, reinstate INOMax therapy immediately.

Hypoxemia from Methemoglobinemia

Nitric oxide combines with hemoglobin to form methemoglobin, which does not transport oxygen. Methemoglobin levels increase with the dose of INOMax; it can take 8 hours or more before steady-state methemoglobin levels are attained. Monitor methemoglobin and adjust the dose of INOMax to optimize oxygenation.

If methemoglobin levels do not resolve with decrease in dose or discontinuation of INOMax, additional therapy may be warranted to treat methemoglobinemia.

Airway Injury from Nitrogen Dioxide

Nitrogen dioxide (NO₂) forms in gas mixtures containing NO and O₂. Nitrogen dioxide may cause airway inflammation and damage to lung tissues. If the concentration of NO₂ in the breathing circuit exceeds 0.5 ppm, decrease the dose of INOMax.

If there is an unexpected change in NO₂ concentration, when measured in the breathing circuit, then the delivery system should be assessed in accordance with the Nitric Oxide Delivery System O&M Manual troubleshooting section, and the NO₂ analyzer should be recalibrated. The dose of INOMax and/or FIO₂ should be adjusted as appropriate.

Heart Failure

Patients with left ventricular dysfunction treated with INOMax may experience pulmonary edema, increased pulmonary capillary wedge pressure, worsening of left ventricular dysfunction, systemic hypotension, bradycardia and cardiac arrest. Discontinue INOMax while providing symptomatic care.

ADVERSE REACTIONS

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in practice. The adverse reaction information from the clinical studies does, however, provide a basis for identifying the adverse events that appear to be related to drug use and for approximating rates.

Controlled studies have included 325 patients on INOMax doses of 5 to 80 ppm and 251 patients on placebo. Total mortality in the pooled trials was 11% on placebo and 9% on INOMax, a result adequate to exclude INOMax mortality being more than 40% worse than placebo.

In both the NINOS and CINRGI studies, the duration of hospitalization was similar in INOMax and placebo-treated groups.

From all controlled studies, at least 6 months of follow-up is available for 278 patients who received INOMax and 212 patients who received placebo. Among these patients, there was no evidence of an adverse effect of treatment on the need for rehospitalization, special medical services, pulmonary disease, or neurological sequelae.

In the NINOS study, treatment groups were similar with respect to the incidence and severity of intracranial hemorrhage, Grade IV hemorrhage, periventricular leukomalacia, cerebral infarction, seizures requiring anticonvulsant therapy, pulmonary hemorrhage, or gastrointestinal hemorrhage.

In CINRGI, the only adverse reaction (>2% higher incidence on INOMax than on placebo) was hypotension (14% vs. 11%).

Based upon post-marketing experience, accidental exposure to nitric oxide for inhalation in hospital staff has been associated with chest discomfort, dizziness, dry throat, dyspnea, and headache.

OVERDOSAGE

Overdosage with INOMax will be manifest by elevations in methemoglobin and pulmonary toxicities associated with inspired NO₂. Elevated NO₂ may cause acute lung injury. Elevations in methemoglobin reduce the oxygen delivery capacity of the circulation. In clinical studies, NO₂ levels >3 ppm or methemoglobin levels >7% were treated by reducing the dose of, or discontinuing, INOMax.

Methemoglobinemia that does not resolve after reduction or discontinuation of therapy can be treated with intravenous vitamin C, intravenous methylene blue, or blood transfusion, based upon the clinical situation.

DRUG INTERACTIONS

No formal drug-interaction studies have been performed, and a clinically significant interaction with other medications used in the treatment of hypoxic respiratory failure cannot be excluded based on the available data. INOMax has been administered with dopamine, dobutamine, steroids, surfactant, and high-frequency ventilation. Although there are no study data to evaluate the possibility, nitric oxide donor compounds, including sodium nitroprusside and nitroglycerin, may have an additive effect with INOMax on the risk of developing methemoglobinemia. An association between prilocaine and an increased risk of methemoglobinemia, particularly in infants, has specifically been described in a literature case report. This risk is present whether the drugs are administered as oral, parenteral, or topical formulations.

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Neonatology Clinical Trials - From ClinicalTrials.gov

Executive Function in Preterm Born Children: An Integrative Approach from Genetics to Brain Function

This study is not yet open for participant recruitment.

First Received on June 6, 2012. Last Updated on June 7, 2012

Sponsor: University of Zurich

Information provided by (Responsible Party): University of Zurich

ClinicalTrials.gov Identifier: NCT01615523.

Purpose: Hd-EEG and MRI measures are used to study the maturation of functional networks in order to identify the neural circuits underlying executive and memory processes in children born preterm. It will be determined whether children born preterm with executive function deficits will have an abnormal connectivity between basal ganglia and cortex due to WM injury. Moreover, the development of hd-EEG activity during sleep (coherence and traveling waves) and brain maturation of children and adolescents born preterm will be compared with the respective measures in healthy controls. This is of eminent importance as it helps to understand the nature of executive function and hence, it may help to develop neuroprotective strategies to prevent executive function deficits in these infants.

Condition: Preterm Infants

Intervention: Other: MRI, EEG and cognitive testing

Study Type: Observational

Study Design: Observational Model: Cohort

Time Perspective: Prospective

Estimated Enrollment: 60

Study Start Date: September 2012

Estimated Study Completion Date: December 2015

Estimated Primary Completion Date: December 2015 (Final data collection date for primary outcome measure)

Groups/Cohorts: Children/adolescents born preterm; Control children and adolescents

Assigned Interventions: Other: MRI, EEG and cognitive testing

Sleep EEG and one MRI, executive function testing using Stroop test, BRIEF questionnaire and CantabEclipse

Ages Eligible for Study: 10 Years to 16 Years

Genders Eligible for Study: Both

Accepts Healthy Volunteers: Yes

Sampling Method: Non-Probability Sample

Study Population: Children and adolescents born preterm with their peers as controls

Inclusion criteria: Schoolchildren between 10 and 12 or 14 and 16 (born between 1996 and 1998 or between 2000 and 2002)

Preterm group: born <32 weeks of gestation

Control group: siblings or friends of preterm group in one of the two age groups

Exclusion criteria: Preterm Group: MDI < 85 at 5 years of age; cerebral palsy

Control Group: born <37 weeks of gestation

Locations: University Hospital Zurich, Division of Neonatology, Zurich, ZH, Switzerland, 8091

Investigators: Principal Investigator: Cornelia F Hagmann, MD; cornelia.hagmann@usz.ch

University Hospital Zurich, Division of Neonatology

Responsible Party: University of Zurich

ClinicalTrials.gov Identifier: NCT01615523

Other Study ID Numbers: EF_MRI_EEG

Study First Received: June 6, 2012

Last Updated: June 7, 2012

Health Authority: Switzerland: Swissmedic

ClinicalTrials.gov processed this record on August 29, 2012

For up-to-date information on this trial and others, please visit: www.ClinicalTrials.gov

Prospective Study on Plasma Pro-endothelin-1 in Predicting Bronchopulmonary Dysplasia

This study is currently recruiting participants.

First Received on July 17, 2012. Last Updated on July 18, 2012

Sponsor: University of Zurich

Information provided by (Responsible Party): University of Zurich

ClinicalTrials.gov Identifier: NCT01644981

Purpose: Serial quantitative measurements of plasma pro-endothelin-1 concentrations in very preterm infants. Comparing pro-endothelin-1 with established clinical indices of bronchopulmonary dysplasia (BPD). Hypothesis: Pulmonary-vascular remodeling in infants developing BPD is directly related to circulating pro-endothelin-1, which therefore serves as surrogate marker of BPD.

Condition: Bronchopulmonary Dysplasia

Intervention: Other: blood sampling

Study Type: Observational

Study Design: Observational Model: Cohort Time Perspective: Prospective

Estimated Enrollment: 100

Study Start Date: May 2012

Estimated Study Completion Date: April 2013

Groups/Cohorts: VLBW infants

Assigned Interventions: Other: blood sampling; blood sampling

Ages Eligible for Study: up to 4 Months

Genders Eligible for Study: Both

Accepts Healthy Volunteers: Yes

Sampling Method: Probability Sample

Study Population: VLBW infants

Inclusion criteria: Very preterm infants born before 32 weeks gestational age

Exclusion criteria: Severe fetal malformation, congenital heart defect, inborn syndrome, cardiomyopathy, fetal hydrops

Contact: Philipp Baumann, Physician; philipp.baumann@usz.ch

Contact: Sven Wellmann, MD; sven.wellmann@usz.ch

Locations: University Hospital Zurich, Division of Neonatology; Zurich, ZH, Switzerland, 8091

Principal Investigator: Sven Wellmann, MD; University Hospital Zurich, Division of Neonatology

Responsible Party: University of Zurich

ClinicalTrials.gov Identifier: NCT01644981

Other Study ID Numbers: 1.3 07.10.2011

Study First Received: July 17, 2012

Last Updated: July 18, 2012

Health Authority: Switzerland: 1.3 07.10.2011

ClinicalTrials.gov processed this record on March 14, 2013

For up-to-date information on this trial and others, please visit:
www.ClinicalTrials.gov

Spectral Domain Optical Coherence Tomography Imaging of the Eyes of Neonates (OCT)

This study is currently recruiting participants.

First Received on May 10, 2011. Last Updated on July 27, 2011

Sponsor: University of California, Los Angeles

Collaborator: Los Angeles Biomedical Research Institute

Information provided by: University of California, Los Angeles

ClinicalTrials.gov Identifier: NCT01404247

Purpose: Brief Summary: The purpose of this study is to better characterize the retina and optic nerve in newborns using spectral domain optical coherence tomography (s-oct). This new technology provides a very detailed cross-section picture of the cellular layers in the retina and a 3-dimensional picture of the optic nerve head and the fovea (the center of the retina that provides the most accurate vision). These images have been used by doctors for more than 5 years to help diagnose and treat adults with eye diseases, such as macular degeneration, diabetic retinopathy, retinal detachments, and melanoma. But, it has never been studied in newborns. In newborns, it would potentially help in the diagnoses of glaucoma, optic nerve hypoplasia, foveal hypoplasia, and colobomata among many other disorders. Prior to diagnosing disorders, it is necessary to establish normal values. It is the purpose of this investigation to study the retina and optic nerves in neonates to establish normal values.

After a parent of a normal newborn provides a written consent, the baby will be taken to the Eye Clinic where the instrument is located. The baby

will be swaddled in one or more blankets as needed. The infants will be held in front of the instrument by a nurse. The technician will move the lens of the instrument to about 2 to 4 inches from the baby's eye. The mild light from the instrument will then enter the eye for a few seconds to obtain the desired image. The image can be captured through an immobile eye within 5 seconds. If the baby is fussy, he or she may be given a few drops of a sugar (sucrose) solution on a pacifier for calming. Although the images can usually be secured through a normal pupil, if the pupil is found to be too small, two drops of Cyclomydriol will be placed on the eye for dilation. This is the eye drop used everyday in the Eye Clinic and nursery to dilate the pupils of babies. The dilation will last for about 6 to 10 hours. After the test, the baby will return to the nursery or be discharged home as intended by the Neonatology Division.

There is minimal risk associated with this investigation. The instrument is non-invasive and does not touch the eye. The babies will be swaddled and held by a nurse to prevent any contact with the machine. The eye drop to be used if needed for dilation has been used on babies at Harbor for about 30 years. It has been found to be very safe. The fact that we will study only term (not premature babies) and will apply only two drops if needed should minimize any risk from the eye drop.

An ethical issue to consider is that while the study will provide important information that will undoubtedly help babies in the future, it will probably not benefit the baby being studied. However, if the baby has an undetected retinal or optic nerve problem, the study may reveal it.

Condition: Retinal Diseases; Optic Nerve Diseases

Intervention: Other: Observational: to better characterize the retina and optic nerve in newborns using spectral domain optical coherence tomography (s-oct). Procedure: OCT imaging.

Phase: Phase 1

Study Type: Interventional

Study Design: Allocation: Non-Randomized

Endpoint Classification: Safety/Efficacy Study

Intervention Model: Single Group Assignment

Masking: Open Label

Primary Purpose: Screening

Official Title: Spectral Domain Optical Coherence Tomography Imaging of the Eyes of Neonates

Primary Outcome Measures: Specific eye measurements by SD-OCT, including retinal nerve fiber layer thickness per quadrant, foveal depth, optic cup area and depth, optic nerve/foveal distance and depth of various layers within the retina to determine neonatal baseline values. [Time Frame: 24 months] [Designated as safety issue: Yes] A spreadsheet of the data collected from the study population will be created. The data will be derived from analysis of the images captured by the instrument. Software within the computer of the instrument will provide data from each image including measurements of retinal nerve fiber layer thickness in each quadrant, depth of the fovea, depth and area of the optic cup, distance from the optic nerve to the fovea, and depth of the various layers within the retina. These parameters will be calculated to establish normal values for the first time.

Estimated Enrollment: 50

Study Start Date: January 2011

Estimated Study Completion Date: June 2013

Estimated Primary Completion Date: December 2012 (Final data collection date for primary outcome measure)

Arms: Experimental: OCT imaging in neonates

OCT imaging of all neonates, 38-42 weeks, enrolled in this study

Assigned Interventions: Other: Observational: to better characterize the retina and optic nerve in newborns using spectral domain optical

coherence tomography (s-oct). The OCT technician will attempt to image the eyes of neonates. The neonate may be given Cyclomydril ophthalmic solution, if needed for dilation. Cyclomydril dosing for this study is 1 drop every 5 minutes times 2. Procedure: OCT imaging. All newborns meeting eligibility requirements will undergo spectral domain optical coherence tomography imaging in order to better characterize the retina and optic nerve in newborns. Other Name: OCT imaging

Ages Eligible for Study: 38 Weeks to 42 Weeks

Genders Eligible for Study: Both

Accepts Healthy Volunteers: No

Inclusion Criteria:

- Healthy term, gestational age of 38-42 weeks inclusive.
- Able to be transported to the Eye Clinic.
- No longer monitored. On no intravenous or other lines.

Exclusion Criteria:

- History of hyperglycemia in the infant (a blood sugar greater than 100mg%, per Laboratory Policy on Critical Values for infants less than 20 days old).
- Feeding intolerance.
- Green-tinged aspirates/emesis.
- Abdominal distention.
- History of genetic consult indicating any abnormality.
- Any known ocular disorder.

Locations: Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, Torrance, California, US, 90502

Principal Investigator and Contact: Sherwin J. Isenberg, MD; Los Angeles Biomedical Research Institute; Tel: (310) 222-2731; isenberg@ucla.edu

Sponsors and Collaborators: University of California, Los Angeles
Los Angeles Biomedical Research Institute

Principal Investigator: Sherwin J. Isenberg, MD

Responsible Party: Sherwin J. Isenberg, M.D./Principal Investigator, Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center

ClinicalTrials.gov Identifier: [NCT01404247](https://clinicaltrials.gov/ct2/show/study/NCT01404247)

Other Study ID Numbers: 14069-01

Study First Received: May 10, 2011

Last Updated: July 27, 2011

Health Authority: United States: Institutional Review Board

ClinicalTrials.gov processed this record on August 29, 2012

For up-to-date information on this trial and others, please visit:
www.ClinicalTrials.gov



Seeking a BE/BC Clinical Neonatologist and a Neonatal Nurse Practitioner

St. Luke's Children's Hospital in Boise, Idaho, is seeking one BE/BC clinical Neonatologist and one Neonatal Nurse Practitioner to join 7 Neonatologists and 7 NNPs in a long-established Level IIIB NICU. ADC of 37, ~800 admissions/yr. Full complement of Pediatric Subspecialty services, plus 4 MFMs. Modern 61-bed, technologically advanced unit. Level II NICU in Meridian, 12 beds. Highly skilled Maternal-Child Transport Team.

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Medical News, Products & Information

Only One-Third of Parents Follow Doctors' Orders for Kids All of the Time

Newswise — Pediatricians regularly dispense advice to parents of young children during well-child visits, but a new University of Michigan poll shows that many aren't following doctors' orders.

Only one-third of parents (31%) said they follow advice from their child's health care provider all of the time, according to the most recent University of Michigan Mott Children's Hospital National Poll on Children's Health. Thirteen percent said they follow the provider's advice only occasionally.

Parents from lower-income households (<\$60,000 annually) were more than twice as likely to say they follow provider advice occasionally (17%), compared to parents from higher-income households (8%). Black and Hispanic parents are twice as likely to follow provider advice only occasionally (22% and 18%, respectively) compared to white parents (9%).

Most parents (56%) said they follow provider's advice "most of the time."

Parents were asked to choose the areas where they are most and least likely to follow the provider advice. Among parents who follow provider advice only occasionally, the topics on which they are most likely to follow advice are nutrition, going to the dentist, and using car seats/booster seats.

In contrast, these parents are least likely to follow advice on discipline (40%), putting the child to sleep (18%) and watching TV (13%).

"During well-child visits, health care providers give parents and guardians advice about how to keep their kids healthy and safe. This poll suggests that many parents aren't heeding that advice consistently, putting kids at risk for long-lasting health concerns," says Sarah J. Clark, MPH, Associate Director of the Child Health Evaluation and Research (CHEAR) Unit at the University of Michigan and Associate Director of the National Poll on Children's Health.

Clark says that many major health risks for children are closely tied to parenting behaviors. For example, childhood obesity has been linked to parents allowing the over-consumption of sugar-sweetened beverages and excessive TV watching. Sudden Infant Death Syndrome (SIDS) is associated with putting infants to sleep in the prone position.

"Even more concerning is that certain populations (poorer families, non-white families) were more likely to report following advice only occasionally. The children in these populations are known to have higher rates of health problems such as obesity, SIDS, and tooth decay," Clark says.

The poll also showed that parents' ratings of the quality of care offered by their children's healthcare providers are closely linked to whether they follow provider advice, says Matthew M. Davis, MD, MAPP, Director of the C.S. Mott Children's Hospital National Poll on Children's Health.

Among parents who rated their child's provider as "good/fair/poor," Forty-six percent of those parents said they follow provider advice only occasionally, says Davis, who is a pediatrician.

"This poll suggests that parents need to ask for clarification if they are unsure about what the provider is saying, or why it's important. Providers should work on using clear language, asking parents about their concerns, and giving practical examples of what works with children of different ages," says Davis.

See the video here:

www.youtube.com/watch?v=CtdLOvju_FU&feature=youtu.be

Purpose/Funding: The C.S. Mott Children's Hospital National Poll on Children's Health – based at the Child Health Evaluation and Research Unit at the University of Michigan and funded by the Department of Pediatrics and Communicable Diseases and the University of Michigan Health System – is designed to measure major health care issues and trends for U.S. children.

This report presents findings from a nationally representative household survey conducted exclusively by GfK Custom Research, LLC GfK Custom Research, LLC (GfK), for C.S. Mott Children's Hospital via a method used in many published studies. The survey was administered in January 2013 to a randomly selected, stratified group of parents with a child age 0-8 (n=907) from GfK's web-enabled KnowledgePanel® that closely resembles the U.S. population. The sample was subsequently weighted to reflect population figures from the Census Bureau. The survey completion rate was 60% among panel members contacted to participate. The margin of error is ± 2 to 15 percentage points.

Findings from the U-M C.S. Mott Children's Hospital National Poll on Children's Health do not represent the opinions of the investigators or the opinions of the University of Michigan.

Nurse Understaffing Increases Infection Risk in VLBW Babies

Newswise — Very low birth weight infants, those weighing less than 3.25 pounds, account for half of infant deaths in the United States each year, yet a new study released in the March 18th issue of *JAMA-Pediatrics* documents that these critically ill infants do not receive optimal nursing care, which can lead to hospital-acquired infections that double their death rate and may result in long-term developmental issues affecting the quality of their lives as adults.

These vulnerable infants are the highest risk pediatric patients in hospitals and account for half of all infant deaths in the country each year. Hospital-acquired infections afflicted 13.9% of these frail infants in 2009, the last year reported in the study.

The lead authors, based at the University of Medicine and Dentistry of New Jersey- School of Public Health and the University of Pennsylvania School of Nursing, studied very low birth weight infants cared for in 67 Neonatal Intensive Care Units (NICU).

"One-third of NICU infants were understaffed, according to current guidelines. Understaffing varies further across acuity levels with the greatest fraction of understaffed infants (92%) requiring the most complex critical care, translating into a needed 25% increase in the numbers of nurses," wrote co-principal investigators Jeannette A. Rogowski, PhD, the University Professor in Health Economics at the UMDNJ-School of Public Health and Eileen T. Lake, PHD, RN, FAAN, Associate Director of the Center for Health Outcomes and Policy Research at the University of Pennsylvania School of Nursing.

The researchers noted that infection caused four to seven days of longer hospitalization with associated increased costs, notably to Medicaid. "Under recent changes in Medicaid policy, hospitals will no longer be reimbursed for the costs associated with these infections," said Lake. "Sadly, because Medicaid is the largest payer for premature newborns, the additional costs may lead hospitals to further cut the nursing staff,

Continued on page 17

NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists

About Neonatology Today

Neonatology Today (NT) is the leading monthly publication that is available free to qualified Board Certified (BC) neonatologists and perinatologists. Neonatology Today provides timely news and information to BC neonatologists and perinatologists regarding the care of newborns, and the diagnosis and treatment of premature and/or sick infants. In addition, NT publishes special issues, directories, meeting agendas and meeting dailies around key meetings.

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NEO: THE CONFERENCE FOR NEONATOLOGY

FEBRUARY 20-23, 2014

NEO: The Conference for Neonatology addresses cutting edge, yet practical aspects of newborn medicine. Educational sessions are conducted by many of the foremost experts, who address neonatal-perinatal topics for which they have become renowned.

Target audience: All neonatal-perinatal providers, including neonatologists, advanced practitioners and staff nurses.

Topics include:

- Getting Stareted on the Right Foot — The Early Care of the Critically Ill Neonate
- Respiratory Support 2014 — What Do You Do, When Do You Do It?
- Neurological Injury in the Neonate
- Nutrition and the Neonate
- The Fetal Patient

SPECIAL INTERACTIVE SESSION: Surviving the NICU — Parents' Perspectives



SPECIALTY REVIEW IN NEONATOLOGY

FEBRUARY 18-23, 2014

Specialty Review in Neonatology, the leading review of its type in the country, is an intensive and comprehensive review of neonatal medicine. This course is an invaluable learning experience for those preparing for certifying examinations, as well as new or current fellows-in-training seeking an outstanding fundamental pathophysiology course in neonatal-perinatal medicine.

Target audience: Neonatologists, residents, fellows and advanced practitioners.

Topics include:

- Maternal-Fetal Medicine
- Neonatal Respiratory System
- Neonatal Cardiovascular System
- Neonatal Endocrinology
- Neonatal Nephrology
- Neonatal Infectious Diseases
- Central Nervous System

leading to a cycle of infection and mortality that could impact even more of these fragile infants.”

“These are the first data that demonstrate the extent of adherence to national staffing guidelines and the shortfall is dramatic,” said Rogowski. “Fewer nursing hours could lead to less time devoted to cleaning and maintaining intravenous catheters used to deliver medications thus leading to the higher rates of infection.”

The researchers examined data from 67 NICUs involving 4,046 nurses and 10,394 infants in 2008 and 3,645 nurses and 8,804 infants in 2009-2010. The research was funded by the National Institute for Nursing Research and the Robert Wood Johnson Foundation.

The University of Pennsylvania School of Nursing is one of the premier research institutions in nursing, producing new knowledge in geriatrics, pediatrics, oncology, quality-of-life choices, and other areas. Researchers here consistently receive more research funding from the National Institutes of Health than any other private nursing school, and many Master’s programs are ranked first in the country.

iPads Help New Moms Bond with Their Infants in the NICU

Newswise – A new iPad program in the Maxine Dunitz Children’s Health Center at Cedars-Sinai is enabling mothers to bond with their newborns soon after delivery – even when parent and child are hospitalized on different floors.

Moms who are not ambulatory after delivery, perhaps because of a Cesarean section or other complications, are able to see their newborns in the Neonatal Intensive Care Unit due to the new iPad initiative. The program, called *BabyTime*, allows moms to visit with their infants and the medical team over a secured Internet connection.

“*BabyTime* will help bridge communication with the family and the baby’s medical team and is an excellent use of technology to help new mothers bond with their babies, even when they cannot be physically at their babies’ bedside,” said Charles F. Simmons Jr., MD, Chair of the Cedars-Sinai Department of Pediatrics and Ruth and Harry Roman Chair in Neonatology. “When doctors and nurses are treating a newborn in the NICU, mom can be right there asking questions and getting updates, even if she’s on a different floor.”

Simmons estimates that 20 to 30% of mothers who undergo C-sections do not feel well enough to travel from their bed in the Labor and Delivery unit to the NICU for the first 24 to 48 hours.

As soon as the baby is admitted to the Neonatal Intensive Care Unit, an iPad is set up next to the infant’s incubator. A second iPad is delivered to the new mother, who can log onto *BabyTime* twice a day.

“The *BabyTime* program will reduce fear and stress in the new moms as they are able to see their babies and also communicate with the doctors and nurses,” said Selma Braziel, Nurse Manager for the Neonatal Intensive Care Unit.

“*BabyTime* is an excellent marriage of healthcare and technology, allowing us to securely use new technology to keep our patients more informed and more comfortable during their stay,” said Darren Dworkin, senior VP and CIO at Cedars-Sinai.

Rachel Little was one of the first mothers to employ *BabyTime*. After her daughter was born in mid-February by C-section, Little was unable to make her way to the Neonatal Intensive Care Unit, where her infant was being treated. Little was eager to see her baby and hear about her condition.

“Even though I couldn’t hold her, she stopped crying when she heard me talk to her,” Little said.

In turn, Little herself was comforted by being able to hear the physician explain the infant’s condition. “While it’s not the same as being able to hold your baby, it was almost as good,” Little said.

Just a day later, Little was able to bond with her baby the old-fashioned way – face-to-face – when her daughter was released from the NICU.

New Nutritional Recommendations for Preterm Infants Published in Journal of Pediatrics Supplement

“Feeding the Preterm Infant,” a supplement published in the March 2013 edition of *The Journal of Pediatrics* provides new nutritional recommendations for preterm infants. The supplement includes new science about host defenses in preterm infants, unique needs of different subpopulations and guidance to address existing knowledge gaps in preterm infant nutrition. The supplement was developed by 31 international academic neonatal nutrition experts who attended the *Global Neonatal Consensus Symposium* sponsored by Mead Johnson Nutrition.

More than one out of every 10 babies around the world are born premature and preterm birth is the leading cause of infant death in the United States. Despite the critical role nutrition plays in the growth and development of preterm infants, it has been nearly a decade since the publication of the most recent U.S. guidelines on infant nutrition (*Nutrition of the Preterm Infant, Second Edition*). Recent innovations and changes in neonatology have prompted the need to provide updated nutritional recommendations for preterm infants.

The supplement addresses:

- Updated nutritional recommendations for preterm infants (protein, micronutrients and lipids)
- Nutritional needs of specific subpopulations of preterm infants including micropreterm infants, small-for-gestational age infants, late preterm infants and post-discharge infants
- New science about host defenses in preterm infants
- Challenges in translating the latest science to practical application
- Identification of current knowledge gaps in preterm infant nutrition

All supplements published in *The Journal of Pediatrics* are reviewed by a guest editor, one or more outside peer reviewers who are independent of the supplement project and The Journal editor. This process ensures that the supplement lacks bias toward a particular drug or product and has an educational focus.

Physicians Interactive Introduces Omnio - A Customized, Comprehensive iPad App for Medical Professionals

Marlborough, MA – Physicians Interactive (PI), a leading provider of online and mobile clinical resources and solutions for healthcare professionals, announced in March the launch of *Omnio*, a versatile, new app that invigorates the medical app market by unleashing the power of the iPad in a personalized point-of care tool.

The free *Omnio* app is available for download in the App Store: <https://itunes.apple.com/us/app/omnio/id545775601?mt=8>.

From the point of download, *Omnio* connects clinicians to comprehensive drug and disease references and calculators that are essential in their specialty. *Omnio* is easy to expand, connecting users to a worldwide medical marketplace of trusted publishers, allowing them to further customize *Omnio* into the optimal point-of-care companion.

Continued on page 18

Since its mid-December debut in the App Store, word of mouth and social referral among medical professionals have driven *Omnio* to top the charts of free medical apps in the App Store, bolstered by a stellar rating near 5 stars.

“With more than 31 million new entrants coming into the American healthcare system under healthcare reform, clinicians have a pressing need for tools to simplify their workflow,” said Physician Interactive’s CEO and Vice Chairman Donato Tramuto. “Yet, only 5% of medical professionals are satisfied with current medical apps (*July 2012 WorldOne Research Survey*). *Omnio* changes everything, allowing clinicians one-tap access to their favorite mobile tools and serving all the diverse roles clinicians now play. We chose the name *Omnio* because this app will become the omnipresent clinical assistant for the emerging healthcare workflow.”

Omnio is designed to be the modern-day digital black bag for clinicians to keep all their most important “must haves” just a tap away on their iPads. The app was developed with extensive user research to ensure it met the needs of medical professionals who have been frustrated with the limitations of other medical apps.

The research found that hundreds of apps designed for clinicians on the market today were too overwhelming to manage separately. They often focused on just one function, did not allow clinicians to customize the app for their specialties, and too often failed to provide the relevant information and resources clinicians needed at the point-of-care.

“Clinicians don’t have time to scroll through five screens of medical apps to find the one tool they need,” said Physician Interactive’s Chief Medical Officer and Senior Vice President of Product Management Gautam Gulati, MD, MBA, MPH. “We provide those core tools, for each specialty, then apply the latest design and technology to make it easy to add, swap, drag and drop to customize *Omnio* into their optimal point-of-care resource. Clinicians are coming to *Omnio* to get the latest news in their field, check drug dosing and interactions, review evidence-based guidelines, and perform calculations at the point-of-care. We make it quick and easy for them to access the tools they need.”

Omnio’s free content includes: drug look-up, dosing recommendations, medical calculators, drug interaction, formulary information, disease reference materials, curated specialty news feeds, and much more with ongoing releases of new updates. All the offerings are personalized by profession and specialty to identify the most relevant resources from publishers, peers in healthcare,

and professional associations. Clinicians can bookmark and tag these key resources—which can range from books to medical calculators to entire Web sites—so they are just one tap away on the iPad. With *Omnio*, clinicians can spend less time looking for information and more time practicing medicine.

“I can use *Omnio* on my iPad every day to answer questions specific to my branch of cardiology,” said Jordan Safirstein, MD, FACC, FSCAI, RPVI, who specializes in cardiac and peripheral vascular intervention. “It is personalized information chosen by me that is always accessible on my iPad. This type of functionality is part of the appeal of the iPad—so it’s great to finally have this in a medical app.”

For more information about *Omnio*, please visit www.omnio.com.

Study Finds Healthcare Supply Chain Could Benefit from Using Retailers Best Practices

Newswise — A new survey by researchers at the University of Arkansas indicates that the health-care industry’s supply chain lags behind the retail industry supply chain and could benefit significantly from adopting several of retail’s best practices.

“The retail industry has a long history of adopting automation, complemented by scientific and mathematical models, to improve supply-chain operations,” said Ed Pohl, Associate Professor in the Department of Industrial Engineering. “Conversely, health care has been relatively slow to adopt these methods. Based on survey responses, we believe that considerable efficiency gains might be available to the health-care supply chain through the adoption of best practices from the retail supply chain.”

The researchers found that the retail supply chain has done a better job in the critical area of collaborative planning, forecasting and replenishment, which involves suppliers and retailers – or health-care providers – working together to adopt order forecasting and inventory planning to create an integrated supply-chain network. Also critical, health care is struggling to catch up with retail in the area of scanning technology, which is used to track materials by means of barcodes and RFID technology. The health-care supply chain also is lagging behind retail in professional training and education, specifically the skills associated with materials-management, purchasing and warehousing.

Considering retail’s success, Pohl and faculty colleagues Manuel Rossetti, Heather Nachtmann and postdoctoral fellow Vijith

Varghese conducted the survey to get a better understanding of the gaps between the two supply chains and to learn how the health-care supply chain might benefit from adopting some or all of the best practices used by retail.

The first step involved identifying best practices. The researchers came up with an initial list of 22, based on an extensive literature review and guidance from a steering committee made up of industry leaders. The steering committee scored and ranked all 22 best practices according to their potential impact on business and their associated cost and ease of implementation.

From this ranking, the top 10 best practices were identified and included in the report. In addition to collaborative planning, forecasting and replenishment, scanning technology, and education and training, best practices included:

- centralized purchasing and supply,
- supply chain services reorganization,
- regular cycle counting and stock rotation,
- performance management,
- actual usage inventory management,
- e-commerce,
- data standardization

The researchers’ survey of health-care and retail managers revealed many expected findings and a few surprises, Pohl said. Not surprisingly, higher-revenue respondents – large retail stores and hospitals – were more likely to have implemented best practices. Across both industries, 80% of the respondents thought the identified best practices had a significant or very significant business impact.

A minority (40%) of retail respondents perceived implementation of best practices to be easy or very easy. When compared to the responses from retailers, however, most health-care respondents perceived implementation of best practices to be easy. They also perceived implementation of best practices to be cheaper and require a lower minimum rate of return for many of the practices. Considering that the health-care industry lags behind that of retail in terms of implementing best practices, the researchers were surprised by the responses.

“This may indicate that the health-care industry is underestimating the investment necessary to achieve the full benefits from some of the best practices,” Varghese said.

Overall, retailers led in the implementation of best practices, despite their perception that implementation of the practices is difficult and expensive.

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The study was conducted for the Center for Innovation in Healthcare Logistics at the University of Arkansas. The center is a partnership with industry that leads a nationwide effort to identify and foster system-wide adoption of innovations in health-care supply chain and logistics. The center facilitates collaboration among U of A researchers, health care providers and industrial sponsors. Additional information about the center can be found at cihl.uark.edu.

Rossetti is holder of the John L. Imhoff Endowed Chair in Industrial Engineering.

JAMA Internal Medicine Viewpoint Highlights - Assessing Research Results in the Medical Literature ... Trust, but Verify

In a *Viewpoint*, Robert M. Califf, MD, of Duke University Medical Center, Durham, NC, and colleagues write: "Clinical research should contribute to a generalizable body of evidence that can guide decisions about clinical practice, personal health and health policies. Recently, however, the integrity of the results disseminated in the biomedical literature has been questioned. Critics point to selective omission of important findings from articles and fundamental inaccuracies in those that are published."

"The liberation of information once held in secret has toppled regimes and transformed societal expectations regarding progress and possibilities. Access to data from clinical research should be truly democratized. Until then, however, the data should be trusted but verified. It is time for biomedical science in both industry and academia to catch up to other areas of society," they conclude.

Study Examines Neurodevelopmental Outcomes for Children Born Extremely Preterm

Newswise — Fredrik Serenius, MD, PhD, of Uppsala University, Uppsala, Sweden, and colleagues conducted a study to assess neurological and developmental outcome in extremely preterm (less than 27 gestational weeks) children at 2.5 years.

"A proactive approach to resuscitation and intensive care of extremely preterm infants has increased survival and lowered the gestational age of viability. There are concerns that

increased survival may come at the cost of later neurodevelopmental disability among survivors. Approximately 25% of extremely preterm infants born in the 1990s had a major disability at preschool age, such as impaired mental development, cerebral palsy, blindness, or deafness. More recent studies report decreasing, unchanged, or increasing rates of neurodevelopmental disability at preschool age compared with previous decades," according to background information in the article.

The study included extremely preterm infants born in Sweden between 2004 and 2007. Of 707 live-born infants, 491 (69%) survived to 2.5 years. Survivors were assessed and compared with control infants who were born at term and matched by sex, ethnicity, and municipality. Assessments ended in February 2010 and comparison estimates were adjusted for demographic differences. Cognitive, language, and motor development were assessed. Clinical examination and parental questionnaires were used for diagnosis of cerebral palsy and visual and hearing impairments. Assessments were made by week of gestational age.

At a median (midpoint) age of 30.5 months, 456 of 491 (94%) extremely preterm children were evaluated (41 by chart review only). The researchers found that overall, 42% of extremely preterm children had no disability (compared with 78% of control participants), 31% had mild disability, 16% had moderate disability, and 11% had severe disability. There was an increase in moderate or severe disabilities with decreasing gestational age. Also, the difference in overall outcome between preterm boys and girls was not statistically significant.

"Improved survival did not translate into increasing disability rates, and we like others believe that the neurodevelopmental outcome for extremely preterm children born in the 2000s will be better than for those born in the 1990s. Nevertheless, the impact of prematurity on neurodevelopmental outcome was large, which calls for further improvements in neonatal care, such as better control of infection and postnatal nutrition," the authors write.

"These results are relevant for clinicians counseling families facing extremely preterm birth."

NEONATOLOGY TODAY

© 2013 by Neonatology Today
ISSN: 1932-7129 (print); 1932-7137 (online).

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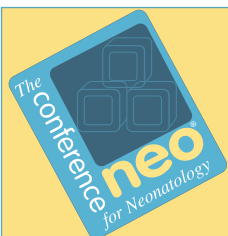
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