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NEONATOLOGY TODAY

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NICUs and March of Dimes Partner to Offer Support to Families across the Nation

By Laura Miller, BA; Scott D. Berns, MD, MPH, FAAP

For parents, having a baby hospitalized in a NICU can be frightening, confusing and overwhelming. Thrust into a world full of unfamiliar sounds, equipment and terminology, parental hopes and dreams change dramatically. With hundreds of thousands of babies born prematurely or critically ill in the United States each year, teams of highly trained doctors and nurses know what it takes to care for these newborns in intensive care nurseries. Their expertise means everything to their tiny patients. Their care and compassion toward the parents and family can be a lifeline when it seems hope is nowhere to be found.

To ease parents' heartache and fear, the March of Dimes developed NICU Family Support® to work in partnership with hospitals to provide information and comfort to families during the NICU hospitalization of their newborn; during the transition home; and in the event of a newborn death. In addition to educating parents and families, the program also contributes to the professional development of NICU staff and promotes the philosophy of family-centered care throughout the NICU.

Guided by former NICU families, the NICU staff, and an on-site NICU Family Support Specialist with personal and/or professional NICU experience, the program addresses the needs of parents, siblings, grandparents and other family members. Each family receives a *Parent Care Kit*, a set of comforting and engaging educational materials that describe the staff, equipment, procedures and conditions they may en-

Nineteen-year-old Ian Miller just finished his first semester of his freshman year at Pittsburg State University in Pittsburg, Kansas, where he is studying secondary English education with a minor in sociology. He was selected as a member of the Presidential Emerging Leaders Program. What is so special about this? It is always considered an honor, but when you consider that Ian began his life thirteen weeks prematurely, as a two-pound, four-ounce baby, the significance is even greater. He and his twin brother Alex spent six months in the NICU in 1991.

The side effects of prematurity have been long-lasting: Ian has cerebral palsy and a ventriculoperitoneal shunt due to a grade III brain bleed. After discharge from the NICU, Alex was re-admitted to the PICU five times before passing away prior to his first birthday.

"We didn't know what the future held for our boys. All we knew for sure was, our life was going to be forever changed," recalled his father, Kelly. "While we were in the NICU we couldn't look even one day into the future; we couldn't imagine a normal life ahead of us. To think about one of them attending preschool, let alone college, was far beyond our imagination."

counter in the NICU, and the emotions they may experience. Included is a baby journal that enables parents to record difficult moments and celebratory milestones in the NICU.

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The Specialist oversees and implements customized programs and parent education hours that serve the needs of the NICU and its families, facilitating parent-infant bonding and participation in baby care. Activities include parent-to-parent support, provision of photo keepsakes, scrapbooking events, support for siblings, and discharge preparation that promotes safety at home and health in subsequent pregnancies.

Begun in 2001, NICU Family Support services are now offered in more than 107 hospitals. While all NICU Family Support sites have similar key components, each one meets the unique needs in its partner NICU. Some sites are staffed and managed by local March of Dimes chapters while License Programs are staffed and managed by partner hospitals. Other hospitals provide support through the NICU Family Support Center, a computer kiosk or computer-on-wheels that enables families to access several March of Dimes and hospital websites. Participation in the national March of Dimes network of sites enables an active and stimulating exchange of innovations and problem-solving through online message boards and a dynamic, educational webinar series.

“Our relationship with the March of Dimes is invaluable and our families rely on the NICU Family Support program throughout their stay. It is one of the critical programs in place at Helen DeVos Children’s Hospital that allows us to deliver the highest quality of care to our babies and their families,” says Dr. Steve Gelfand, Neonatologist at DeVos Children’s Hospital in Grand Rapids, Michigan.

The Children’s Hospital NICU in Aurora, Colorado, was one of three original NICU Family Support pilot sites and provides care to babies in a seven-state region. The NICU Family Support team provides out-of-town families with the information they need to feel connected to their babies and to participate in their care. In addition it offers special activities for Spanish-speaking families, lifting barriers and helping families feel more comfortable during the emotional ups and downs of the NICU experience. No matter what the situation is, “NICU Family Support gives parents the chance to celebrate the

“Begun in 2001, NICU Family Support services are now offered in more than 107 hospitals. While all NICU Family Support sites have similar key components, each one meets the unique needs in its partner NICU. Some sites are staffed and managed by local March of Dimes chapters while License Programs are staffed and managed by partner hospitals. Other hospitals provide support through the NICU Family Support Center, a computer kiosk or computer-on-wheels that enables families to access several March of Dimes and hospital websites.”

birth of their baby,” says Michele Provost, who has been the March of Dimes NICU Family Support Specialist in Aurora since 2004. “We help parents focus on the fact that they have a new family member, not only a critically ill baby. Our materials say ‘Congratulations,’ a word that family and friends do not think to say and parents do not expect to hear in intensive care. We also have a powerful opportunity to bring families together, to comfort each other and see that they are not alone.”

Table 1 Family-centered care characteristics and their importance in the NICU: pre- and post-implementation

Characteristic	Importance pre-implementation		Importance post-implementation	
	Important or extremely important (%)	Completely or somewhat important (%)	Important or extremely important (%)	Completely or somewhat important (%)
Open and honest communication between professionals and parents on medical and ethical issues.	84.1	3.0	91.6	0.9
Sharing information and the meaning of the information with the parents	82.2	3.9	93.3	1.8
Involvement of parents in decision making	73.5	4.3	84.6	1.8
A partnership between professionals and parents in the provision of care	70.6	7.0	83.3	3.5
The development of policies and programs to promote parenting skills and family involvement	67.4	8.9	89.9	0.9

Abbreviation NICU, neonatal intensive care unit. P ≤ 0.001 for each characteristic

Cooper, L. G, Gooding, J. S., Gallagher, J., Sternesky, L., Ledsky, R., Berns, S. D. (2007). Impact of a family-centered care initiative on NICU care, staff and families. *Journal of Perinatology*, 27, 32-S37.

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During a NICU Family Support Parent Education class in Fairfax, Virginia, parents are encouraged to hold a preemie-sized baby doll with ventilator tubing while sitting in a zero-gravity chair.

At Children's National Medical Center in Washington, D.C., NICU Family Support touches the lives of approximately 600 families a year and offers an extraordinary array of parent activities and parent education hours. In one model program, hospital leaders, NICU staff and the March of Dimes NICU Family Support team created a video to educate NICU professionals about the family perspective titled: "Lasting Impressions: the Impact of Family Stories." The video was one of several developments in the Children's National project that led to their receipt of the first annual March of Dimes NICU Family Support Project of the Year Award for 2009.

"The March of Dimes has set the standard for NICU family support across the nation," says Dr. Billie Short, MD, Chief, Division of Neonatology. "The program has been a model for the hospital-wide family support program, and I am proud that our site has been a model for others around the country as well." Through the NICU Family Support program, the NICU expanded the hospital's previous visitation policy from a fairly closed

March of Dimes NICU Family Support®

- 1. Assessment:** Prior to program implementation, a comprehensive assessment of family support services in the partnering hospital's NICU is conducted. Staff surveys, interviews with former NICU parents and a review of family support materials are undertaken to identify strengths as well as areas for growth and opportunity.
- 2. On-Site Seminars:** A series of four-hour staff trainings on family-centered neonatal care are delivered by national trainers from the March of Dimes. Content covers many areas including: effectively working with families in crisis, improving communication and impact through sensitive language choice, and techniques for professionals to reduce feelings of caregiver burnout. CEUs are provided. All staff from the hospital's NICU, OB, Mother/Baby, Ante Partum, High Risk and Women/Children's departments are encouraged to attend.
- 3. Print Materials:** Comforting, educational booklets and pamphlets are available to all parents and family members in the NICU, including a baby journal and materials that identify equipment, procedures, medical conditions, types of professionals and common emotions that a parent may encounter throughout their baby's hospitalization.
- 4. Network:** Membership in a national network of more than 70 NICU Family Support sites to exchange ideas, innovations and solutions to common challenges.
- 5. Assessment Report:** Following the Assessment and on-site seminar, the partnering hospital receives a written report including recommendations for program implementation.
- 6. NICU Family Support Center:** Computer kiosk support service located in the NICU waiting room, at bedside, in the form of center-on-wheels. Access to the hospital website, March of Dimes website, and ShareYourStory.org is available.

unit to 24/7 open parent access, where families are encouraged to attend rounds and



A father in Little Rock, Arkansas, holds his baby skin-to-skin. The NICU Family Support site in Arkansas began implementing the "Close to Me" Module in 2010 with the goal of increasing the onset and frequency of skin-to-skin holding experiences for the hospital's NICU families.

where sibling visitation for children under age six has been expanded. Dr. Short attributes the long-term partnership with the March of Dimes as a significant factor in achieving Magnet Nursing Status.

"NICU Family Support has been fully integrated into the newborn intensive care unit," says Christina Lloyd, RNC-NIC, MS, who has served as the March of Dimes NICU Family Support Specialist for five years. The NICU at Children's National was also a pilot site for the new NICU Family Support *Close to Me* program, which focuses on promoting skin-to-skin holding in the NICU so that it happens earlier and more often. Lloyd enhanced the staff classroom component of *Close to Me* by bringing the team to the bedside to observe an actual kangaroo care transfer from incubator to parent. Denise Craven, RN, the NICU's clinical instructor shared, "Through NICU Family Support *Close to Me*, we have definitely seen an increase in the confidence of our newly graduated nurses to promote skin-to-skin care in our NICU."

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In 2007, March of Dimes introduced a technology-based support service to NICU families in the hospital: the NICU Family Support Center. These on-site resource kiosks provide families with immediate access to print and online information. Families use the Center by searching for information on procedures and conditions common in the NICU on both the March of Dimes and hospital web sites. Families can also connect with and gain support from other families via ShareYourStory.org, the safe and monitored March of Dimes online community for NICU families. Hospitals that have installed the Centers report high levels of family satisfaction with the service, with families logging into the Centers for an average of four minutes per visit. As of August 2010, forty-two NICU Family Support Centers were in place and over 13,000 families had access to print and online information and comfort through this service. NICU families utilize a Center an average of nearly 150 times a month.

“So many parents and families come into the NICU environment filled with fear and uncertainty about what each day will hold. March of Dimes NICU Family Support is designed to offer light in the darkness - comfort to help families through and information that illuminates the way.”

In 2008, March of Dimes services were expanded to include the NICU Family Support License Program model, which affords hospitals the opportunity to staff and manage the program themselves with materials, expert guidance, training and support from the national March of Dimes team. At St. Charles Medical Center in Bend, Oregon, Dr. John Evered, the NICU Medical Director recognizes the value of supporting families in this way. He states, “This program has enabled

us to connect parents of NICU graduates to parents with babies in the NICU through walks, meals and conversations. We’ve created a Family-Staff Advisory Council to bring family feedback into our planning and decisions. We are connecting parents with counselors to treat depression and Post-Traumatic Stress Disorder.” Sara Mosher, RN, BSN, the NICU Family Support Specialist, has been instrumental in moving the program and support for families forward at St. Charles Medical Center, according to Dr. Evered. The License Program includes a comprehensive written assessment of support services in the partner NICU with recommendations; innovative, family-centered seminars for NICU staff; and expert guidance and support from the national NICU Family Support team.

As the program nears its tenth anniversary, the March of Dimes continues to focus on ensuring the overall quality of the program. Evaluating the impact of its components and expanding programs and materials that could ultimately impact newborn health outcomes is a major focus. While a national evaluation of NICU Family Support (Cooper et al., *Journal of Perinatology*, 2007) demonstrated that the program has a positive impact on the stress level, comfort level and parenting confidence of families and the overall presence of and receptivity to family-centered principles among staff, the March of Dimes continues to build upon and enhance the most vital facets of the program.

March of Dimes is currently working with Vida Health Communications to examine the impact of the *Close to Me* (skin-to-skin) program, developing activities to reduce risk for a subsequent preterm birth, and identifying NICU family-centered trends within the March of Dimes network. A new program targets families whose babies are in the NICU for only a short period of time. March of Dimes focus groups and individual interviews have shown that short-stay families - those with late pre-term birth babies or babies with birth defects or other medical conditions in the NICU less than 14 days - do not always receive the same level of information, support or holding opportunities from NICU staff; NICU Family Support is addressing that through specific programming.

So many parents and families come into the NICU environment filled with fear and uncertainty about what each day will hold. March of Dimes NICU Family Support is designed to offer light in the darkness - comfort to help

families through and information that illuminates the way. It provides a context in which healthy parenthood, attachment and love can unfold now and beyond the NICU doors at home, a place that families can dare to imagine, bolstered by all the support the program has to offer.

To learn more about the March of Dimes NICU Family Support® services, please contact Laura Miller, Manager, March of Dimes NICU Support License Program, at 913-633-2300 or lmiller@marchofdimes.com.

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Corresponding Author

*Laura Miller
National Manager of the NICU Family Support License Program
March of Dimes Foundation
White Plains, NY USA
Phone: 913-633-2300
lmiller@marchofdimes.com*

Laura Miller is the mother of Ian and Isabel, and drew on her experiences in the NICU 19 years ago, followed by the loss of her son Alex, when she joined the March of Dimes in 2005 as the NICU Family Support Specialist at Saint Lukes Hospital in Kansas City, Missouri. Miller is now the National Manager of the NICU Family Support License Program at the March of Dimes Foundation office in White Plains, NY; she focuses on advancing the philosophies and principles of family-centered care through educating NICU staff and neonatologists.

*Scott Berns, MD, MPH, FAAP
Senior VP of Chapter Programs
March of Dimes Foundation
1275 Mamaroneck Ave.
White Plains, NY 10605 USA*

Dr. Berns provides direction in education and community services to all March of Dimes state-based chapters, including DC and Puerto Rico. Berns is board certified in pediatrics and pediatric emergency medicine with a doctorate in public health; in addition to his March of Dimes post, he is Clinical Professor of Pediatrics at the Warren Alpert Medical School at Brown University, Providence, RI.



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Global Neonatology Today: A Monthly Column

By Dharmapuri Vidyasagar, MD, FAAP,
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“The goal of MDG #8 is to create a global partnership for development that would increase the capabilities of countries to achieve all the United Nations Millennium Development Goals (end of poverty and hunger, improved child and maternal health etc.) outlined in my previous columns in Neonatology Today.”

MILLENNIUM DEVELOPMENT GOAL #8 (MDG #8)

The goal of MDG #8 is to create a global partnership for development that would increase the capabilities of countries to achieve all the United Nations Millennium Development Goals (end of poverty and hunger, improved child and maternal health etc.) outlined in my previous columns in *Neonatology Today*. The global partnership would focus on the following targets:

- A non-discriminatory trading and financial system,
- Better export conditions,
- A reduction of indebtedness.

The targets of MDG #8 are outlined below.

Target 8.A:

Develop further an open, rule-based, predictable, non-discriminatory trading and financial system. This includes a commitment to good governance, development and poverty reduction – both nationally and internationally.

Target 8.B:

Address the special needs of the least developed countries including:

- Tariff and quota free access for the least developed countries' exports;
- Enhanced program of debt relief for heavily indebted poor countries (HIPC) and cancellation of official bilateral debt;
- And more generous official development assistance (ODA) for countries committed to poverty reduction.

Target 8.C:

Address the special needs of landlocked developing countries and small island developing States (through the Programme of Action for the Sustainable Development of Small Island Developing States and the outcome of the twenty-second special session of the United Nations General Assembly).

Target 8.D:

Deal comprehensively with the debt problems of developing countries through national and international measures in order to make debt sustainable in the long-term. Some of the indicators listed below are monitored separately for the least developed countries (LDCs), Africa, landlocked developing countries and small island developing states.

Target 8.E:

In cooperation with pharmaceutical companies, provide access to affordable essential drugs in developing countries. Increasing the proportion of the population with access to affordable essential drugs on a sustainable basis.

Target 8.F:

In cooperation with the private sector, make available the benefits of new technologies, especially information and communications. Increase telephone lines per 100 population, cellular subscribers per 100 population, Internet users per 100 population

What Progress is Being Made in Regard to MDG #8?

There are several areas where progress is noticeable. They include:

1. In communication systems, use of mobile phones has more than doubled in low income countries, and continues to increase; broadband technology needs to continue its penetration as well.
2. The debt relief programs have drastically reduced short-term debt burden of many low income countries. But long-term debt remains high.
3. The share of official development assistance (ODA) will need to increase programmable aid.
4. In 2005, G-8 leaders agreed to increase the annual aid allocations to developing countries. But overall, there has been a decline in aid.
5. The average tariffs imposed by industrial countries on least developed countries agricultural, textile, and clothing products have fallen.
6. The overall reduction of tariffs benefit production and exporting sectors of all LDCs.

Success Stories

There are numerous success stories in many developing countries. Please visit sites of United Nations - www.un.org, World Bank Group - www.worldbank.org and the United Nations Children's Fund (UNICEF) - www.unicef.org for more information.

There is much more to be done and, **“The Clock is Ticking!”**

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Dharmapuri Vidyasagar, MD, FAAP,
FCCM
University of Illinois at Chicago
Professor Emeritus Pediatrics
Division of Neonatology
Phone: +1.312.996.4185
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Neonatal Cardiac Rhabdomyoma in Twin Boys

By Samir Atmani, MD

Introduction

Symptomatic cardiac rhabdomyomas and obstructive diffuse forms constitute a rare entity at birth. They are associated with tuberous sclerosis of Bourneville (TSB) in about two thirds of cases. The diagnosis is based on the ultrasound and the prognosis depends on their localization. We report a diffuse and obstructive form of TSB in a twin.



Figure 1: Numerous achromic spots on lower limbs.

Observation

We reported cases of Ayman and Ahmed respectively full-term twin neonates of consanguineous parents. Upon birth, they presented with both perioral cyanosis and respiratory distress. At admission, SaO₂ was at 77% in the first twin, and 70% in the second, with signs of respiratory inconsistency. The cardiac examination revealed a continual murmur in both cases, in addition to pulmonary systolic murmur in the second case. Both infants had hypo-pigmented and achromic spots remarkable on the lower limbs, at the abdominal level and the chest (six spots on the first case, and 8 spots on second) [Figure 1]. After oxygenation treatment using oxygen mask, SaO₂ had improved and became respectively 98% in the first case, and 97% in the second. The Thoracic radiography objectified a diffuse bronchial infiltration both twins.

In both twins, the ultrasound exploration demonstrated a PDA and numerous small lesions disseminate in the two ventricles with a large obstructive mass measuring 2 cm suspended in right outflow truck and the pulmonary valve within the second twin [Figure 2]. The cerebral CT-scan showed typical Bourneville tuberous sclerosis lesion.

Antibiotic and propanolol treatments were started immediately. Progressively, the first case status improved, whereas, the second infant died suddenly, probably by pulmonary trunk obstruction.

At three months of life, the surviving twin developed epilepsy, which is now controlled successfully by sodium vaproate. The clinical follow-up showed non-recurrent symptoms and serial ultrasound examination showed a decreased tumor mass.

Discussion

The cardiac tumors in child and fetus represent about 1% of cardiac disorders diagnosed in-utero. The most frequent histological form in the fetus is the cardiac rhabdomyoma.^{1,2,3} Forty-four cases were rhabdomyomas among a cardiac series of 56 tumors collected along several decades. 60-80% of children with rhabdomyoma are STB.⁴

The diagnosis is evoked by the presence of large echogenic masses, inserted in the cardiac cavities likely blocking the atrio-ventricular outflow and the aortic or pulmonary ejection.^{5,6} They might be single or multiple, either in the interventricular septum or in walls of the two ventricles, or exceptionally in the atrium walls.^{3,5,6}

The prenatal diagnosis using antenatal ultrasound is possible after 22 weeks of amenorrhea.³

Hydrops foetalis, conductive disorders, or hypertrophic cardiomyopathy by massive infiltration are the main prenatal manifestation.⁶ Intrauterine death, as well as sudden death, immediately after birth has attributed to them. After delivery, these tumors are usually asymptomatic,^{6,7} and might be discovered during a routine ultrasound screening in TSB condition.⁶ However infrequently, they could initiate neonatal cardiac deficiency by obstruction or rate/rhythm disorders as Wolf-Parkinson White Syndrome. Also respiratory distress or thrombo-embolic stroke could be the revelator symptom.^{6, 7, 8} The clinical examination could be normal, or associating TSB signs. The cardiac examina-

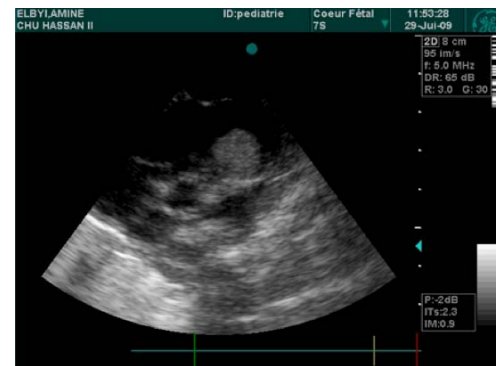
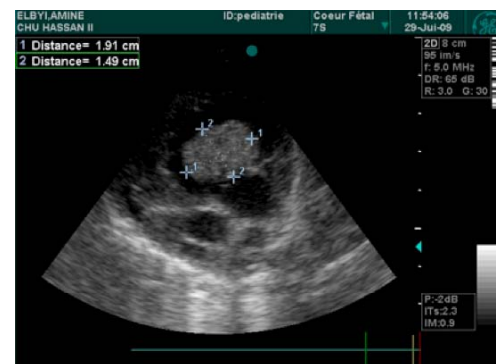
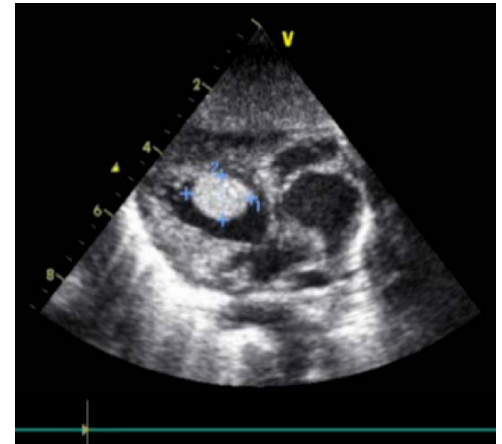


Figure 2 (top); Figure 3 (middle); Figure 4 (bottom): Enormous endocardial mass 2 cm size, appended to the pulmonary outflow truck.

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tion might show systolic pulmonary or aortic murmur such found in the case of the second twin. The thoracic radiography could be normal.

“The clinical manifestations of cardiac rhabdomyomas depend especially on the localization in the heart; they are varied and polymorphic, and often asymptomatic. Particular forms of localization might impair the vital prognosis.”

Doppler-ultrasound is the key diagnostic tool demonstrating the masses, their extension and localization, specifying their number, and assesses their hemodynamic characteristics.⁶

Although difficult to achieve in the neonate, the cardiac MRI allows a better study of the parietal infiltration.^{3,9}

Rhabdomyomas have been known to spontaneously regress. However, serious symptoms may precipitate the need for surgical removal. Such as our second twin, who probably had, acute obstruction of the pulmonary trunk.^{4,7,8,10}

Conclusion

The clinical manifestations of cardiac rhabdomyomas depend especially on the localization in the heart; they are varied and polymorphic, and often asymptomatic. Particular forms of localization might impair the vital prognosis.

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*Samir Atmani, MD
Associate Professor
Pediatric Department
Faculty of Medicine of Fez
BP. 1893; Km 2.200, Sidi Hrazem Rd.
Fez 30000, Morocco*

*Phone: 00212661350780
samir.atmani3@yahoo.fr*

MARCH MEETING FOCUS

California Association of Neonatologists (CAN) and AAP District IX Section on Perinatal Pediatrics

17th Annual Conference Current Topics and Controversies in Perinatal and Neonatal Medicine

March 4-6, 2011 - Coronado Island, Marriott Resort, Coronado, CA USA

www.cme.ucla.edu

Meeting Overview: dedicated to a scientific and practice-oriented discussion of current topics and controversies in perinatal and neonatal medicine. There will be optional pre-conference workshops.

Program Topics Overview:

- CPQCC/CMQCC Pre CAN Workshop 2011
- Neonatology Fellows' Workshop 2011
- Neonatal CPT Coding Update
- Advances in the Management of Pre-Term Labor
- Ethical Issues Around the Care of ELBW W/Infants and Issues Regarding Viability
- Early “Golden Hour” Management of ELBW Infants
- The Nuts and Bolts of Bubble Nasal CPAP
- Controversies Regarding PDA Management
- Chorioamnionitis and BPD Management
- Evidence-Based Drug Therapy to Prevent Bronchopulmonary Dysplasia in ELBW Infants
- Transfusion Related Acute Gut Injury
- Neonatal Resuscitation Program-New Guidelines
- Congenital Diaphragmatic Hernia:Fetus to Infant to Young Adult
- Nutritional Strategies for ELBW Infants
- Catheter Associated BSI's—From Some to None

Keynote Address: “Microarray and Next Generation DNA Sequencing Technology and Its Applications to Healthcare” by Wayne W. Grody, MD, PhD

Course Chairs: Vijay Dhar, MDP; Richard J. Powers, MD; and Udaykumar P. Devaskar, MD

Invited Faculty: David H. Adamkin, MD; William E. Benitz, MD; Dilip R. Bhatt, MD; Ronald I. Clyman, MD; Maurice L. Druzin, MD; Michael Dunn, MD, FRCPC; Neil N. Finer, MD; Wayne W. Grody, MD, PhD; Louis P. Halamek, MD, FAAP; Alan H. Jobe, MD, PhD; Edmund F. La Gamma, MD; John D. Lantos, MD; Barbara K. Schmidt, MD, MSC; Charles J. H. Stolar, MD; David D. Wirtschafter, MD; and Jen-Tien Wung, MD, FCCM

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Medical News, Products & Information

Prenatal Knowledge of Cleft Lip/Palate Shows Little Advantage Over Birth Discovery

Many expectant parents look forward to routine ultrasounds as their first opportunity to “see” their baby. But the ultrasound can reveal that the fetus has unexpected medical conditions, such as a diagnosis of cleft lip and palate. Despite the emotional distress the diagnosis can bring, it can also offer the opportunity to prepare for the child’s future needs. However, a study has found little difference between mothers who were given a prenatal diagnosis of cleft lip and palate and those who discovered the problem at birth.

The authors of the study, which is reported in the September 2010 issue of *The Cleft Palate–Craniofacial Journal* (www.acpa-cpf.org), conducted interviews with 235 mothers of children aged 2 to 7 years with orofacial clefts. Of these children, 46% had been identified prenatally with cleft lip or cleft lip and palate. Overall, prenatal diagnosis is made in about 20% to 30% of pregnancies affected by an orofacial cleft.

Contrary to expectations, few advantages were found for having a prenatal diagnosis. Those with early knowledge of the condition did not report greater satisfaction with information, support, and treatment outcomes, although they had more time to learn and prepare. The two groups did not differ in number of surgeries, expectations for surgeries, complications of surgery, or the quality of care as rated by the mother.

Early planning for a child’s condition could allow parents to seek information and counseling or find resources. An appropriate cleft care team—composed of at least a surgeon, dental professional, and speech professional—could be identified and contacted or organized. Many established cleft care teams hold prenatal consultations with parents expecting a baby with an orofacial cleft.

The one area of the study that did show a significant difference was feeding the newborn child. Infants born with orofacial clefts have unique feeding requirements, and feeding these infants can be difficult and anxiety-provoking for untrained providers and parents. Mothers who were given an early diagnosis reported more positively about providers’ help in making it easier for their infants to feed.

Not only can parents make necessary emotional and medical adjustments with an early diagnosis, but they can also make more practical adjustments. Changes in employment, health insurance, and child care plans may be in order.

The authors acknowledge other questions for which there are not yet answers: whether the early diagnosis might cause greater maternal anxiety, whether being given information about a problem that cannot be corrected prenatally is of any value, and whether the early diagnosis might encourage termination of a pregnancy that shows no other malformations.

Protein Found to Predict Brain Injury in Children on “ECMO” Life Support -Findings May Help Prevent Brain Damage in Vulnerable Patients

Johns Hopkins Children’s Center scientists have discovered that high blood levels of a protein commonly found in the central nervous system can predict brain injury and death in critically ill children on a form of life support called Extra-Corporeal Membrane Oxygenation or ECMO.

ECMO, used to temporarily oxygenate the blood of patients whose heart and lungs are too weak or damaged to do so on their own, is most often used as a last resort because it can increase the risk for brain bleeding, brain swelling, stroke and death in some patients.

A detailed report of the Hopkins team’s findings was published online Nov. 4 in the *Journal Pediatric Critical Care Medicine*.

Following 22 ECMO patients, ranging from two days to 9 years of age, the researchers found that those with abnormally high levels of glial fibrillary acidic protein (GFAP) were 13 times more likely to die and 11 times more likely to suffer brain injury than children with normal GFAP levels. GFAP levels are already used as a marker of neurologic damage in adults who suffer strokes and traumatic brain injuries.

Although preliminary, the team’s findings may pave the way to a much-needed method to monitor the precarious neurologic status of children on ECMO without using imaging tests like ultrasounds or CT scans. Periodic blood tests measuring GFAP levels may be one such tool to monitor brain function and help ward off brain injury and death, the researchers say.

“A simple, fast and easy-to-use test has been needed to monitor, predict and prevent brain damage in children on ECMO because these children are unresponsive or heavily sedated, and doctors cannot easily gauge their neurologic function,” says study lead investigator Melania Bembea, MD, MPH, a pediatric critical-care specialist at Hopkins Children’s.

“Early detection of brain injury can help us prevent further harm by changing medication doses and rapidly weaning the patient from ECMO support,” she adds.

The findings may have implications beyond ECMO, the researchers say, as they offer a way to monitor brain damage in other high-risk situations, including heart surgery and severely premature birth.

“Our long-term goal is to make lifesaving therapies like ECMO and heart surgery safer and more effective by improving protection of the brain, and GFAP and other biomarkers can give us a much-needed benchmark around which we can make these therapies safer,” says senior investigator Allen Everett, MD, a cardiologist at Hopkins Children’s.

In the study, seven of the 22 children on ECMO developed brain bleeding or brain swelling, five of whom died subsequently. These children had much higher peak levels of GFAP than children without brain injury — 5.9 nanograms per milliliter of blood compared to 0.09 in children without brain injury. GFAP levels were also markedly higher among eight of the 22 children in the study who had poor neurologic outcomes after ECMO (3.6 ng/ml) than in those children who had good neurologic outcomes (0.09 ng/ml).

Researchers also measured GFAP levels among healthy children and among newborns without neurologic injuries. Their median GFAP level was 0.055 nanograms per milliliter of blood and as high as 0.436 in some cases. By comparison, overall GFAP levels in children with neurologic injuries were 13 times greater than GFAP levels in healthy children.

The researchers caution that their findings should be replicated in a larger trial with more patients and that future studies must clarify the relationship between a rise in GFAP levels and the onset of brain injury. In the current study, GFAP levels rose sharply in some patients one or two days before their brain damage was discovered on ultrasound.

ECMO is used in about 1,000 children each year. Between 10% and 60% of children who survive ECMO suffer neurologic damage either because of their underlying disease or complications during ECMO therapy, the researchers say.

The research was funded by the National Institutes of Health. Other investigators in the study included William Savage, MD, John Strouse, MD, PhD, Jamie Schwartz, MD, Ernest Graham, Carol Thompson, MBA, MS, all of Hopkins.

Doctors on Facebook Risk Compromising Doctor-Patient Relationship

Doctors with a profile on the social networking site Facebook may be compromising the doctor-patient relationship, because they don’t deploy sufficient privacy settings, indicates



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Children's Mercy Hospitals and Clinics Section of Neonatology is seeking a board eligible/certified Neonatologist. Interest in scholarly pursuit, including education, research, or bio-information systems, would be a plus. The section is large enough to provide multiple responsibilities, allowing opportunities to create and pursue an individualized professional practice pathway.

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research published online in the *Journal of Medical Ethics*.

The authors base their findings on a survey of the Facebook activities of 405 postgraduate trainee doctors (residents and fellows) at Rouen University Hospital in France. Half those sent the questionnaire returned it.

Almost three out of four respondents (73%) said they had a Facebook profile, with eight out of 10

saying they had had a presence on the site for at least a year. Those with a profile tended to be slightly younger than those who didn't.

One in four (24%) logged on to the site several times a day, but almost half (49%) logged on once a day or several times a week. The rest were rather more infrequent users of the site.

Almost half believed that the doctor-patient relationship would be changed if patients discovered their doctor held a Facebook account. But three out of four said this would only happen if the patient was able to access their profile.

Virtually all (97%-99%) displayed sufficient personal information for them to be identified, including their real name and their birth dates. And 91% displayed a personal photo. Just over half displayed their current post (55%) while 59% provided information on their current university training site.

Over half claimed to change at least one of the default privacy settings (61%), but 17% couldn't remember if they had done this. Those who had been on the site for under a year were less likely to limit access to the content of their profile.

While most respondents (85%) said they would automatically refuse a friend request from a patient, one in seven (15%) said they would decide on a case by case basis.

The need to keep a professional distance or the suspicion that the patient was interested in a romantic relationship were the primary reasons given for rejecting the request. Although a high proportion of doctors considered that such interaction might be unethical, this reason came at the bottom of the list.

"This new interaction results in an ethically problematic situation because it is unrelated to direct patient care," say the authors.

"Moreover public availability of information on a doctor's private life may threaten the mutual confidence between doctor and patient if the patient accesses information not intended for them. Doctors must be aware that comments and pictures posted online may be misinterpreted outside their original context and may not accurately reflect their opinions and real-life behavior."

Preterm Infants May Need a Boost

A new study suggests that preterm infants may not be fully protected against invasive pneumococcal disease under the current United Kingdom immunization schedule. The findings are reported in the November issue of the *journal Clinical and Vaccine Immunology*.

The study, conducted by researchers from Newcastle University, began with a survey of UK neonatal intensive care units. The survey

found that preterm infants at increased risk of invasive pneumococcal disease were not being adequately immunized because of a lack of evidence that these infants are protected by the pneumococcal conjugate vaccine.

Preterm babies have significantly less maternally derived antibody than full-term infants. Early effective immunization is therefore especially important to decrease the chances of pneumococcal infection.

"Our study found that in addition to a poor response to serotype 6B, preterm infants had a diminished response to serotype 23F, and several infants remained unprotected to at least one serotype following a booster dose of the vaccine," says Samantha Moss, an author of the report. "These results support the need for a booster dose in the second year of life."

Current vaccination schedules in the UK calls for immunization at 2, 4 and 13 months. Evidence suggests that preterm infants are more likely to remain unprotected following the initial immunization and would therefore benefit from increased monitoring post-primary immunization and, if they are unprotected, to offer them an early booster dose.

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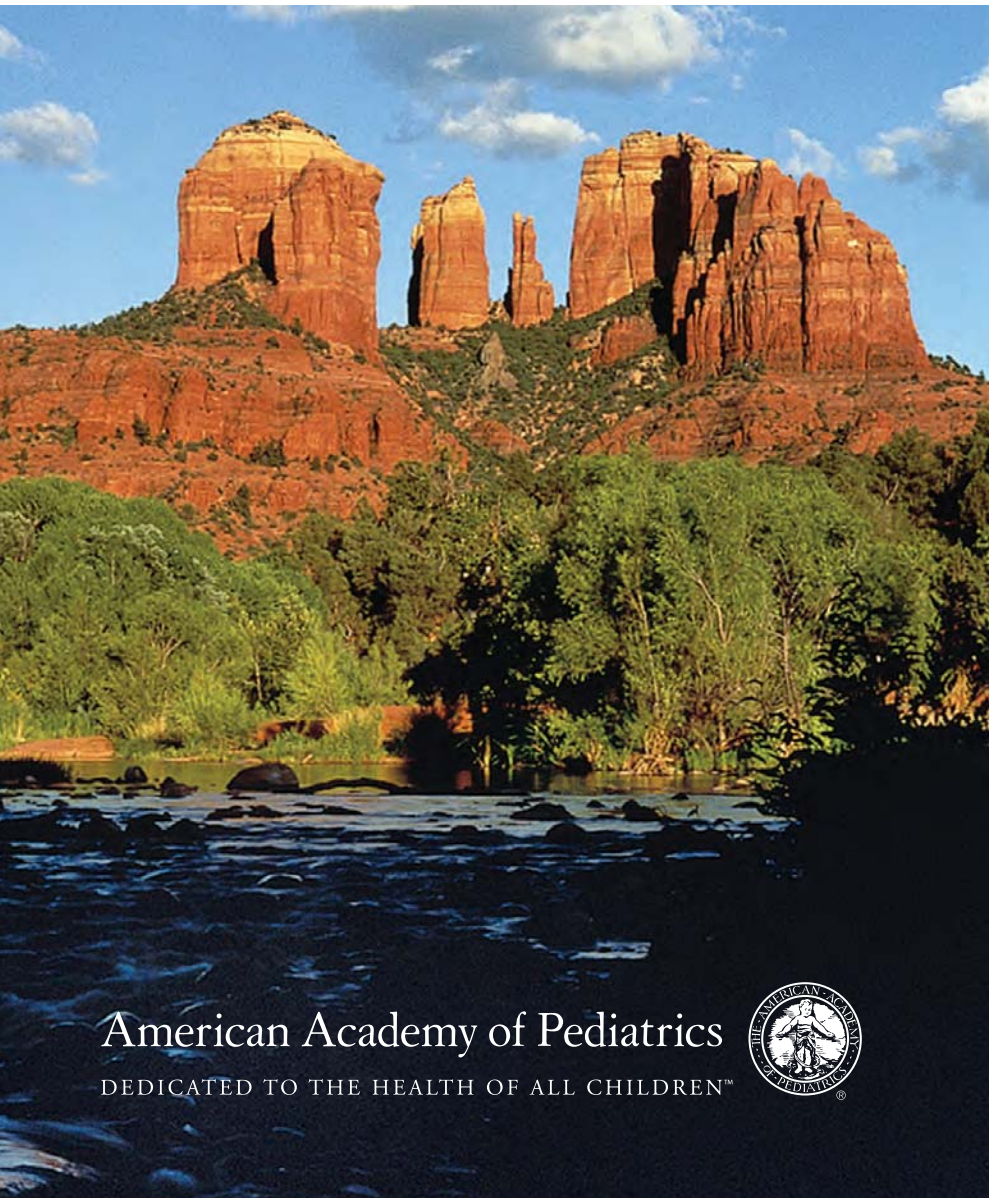
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