A Miami Children's Hospital Community Update, April 2005

THE REGION'S BEST HOPE FOR NEWBORNS IN NEED

They come from across continents and oceans as well as from hospitals just a few miles away. They are among the most medically fragile newborns in the world and Miami Children's Hospital's Neonatal Intensive Care Unit (NICU) is considered their best hope.

In the past 20 years, more than 10,000 premature and critically ill babies from throughout Florida and Central and South America have been transported to the Miami Children's NICU. "We receive newborns whose medical conditions present special challenges, either because of severe prematurity or because of serious complications or diseases specific to the neonate," said Dr. Barry Chandler, Director of Neonatology.

Outfitted with the most current technology and the most experienced specialists and nursing staff, the hospital is the "go to" place for children like De'Najia Moore who was born in November of 2000 requiring immediate corrective surgery, as much of her gastrointestinal tract was exposed at birth. Similarly, doctors transferred Jennifer Nebel, born at 23 weeks gestation and weighing only 14 ounces, to Miami Children's knowing such a tiny neonate would need the best of care.

De'Najia and Jennifer are thriving today, thanks to the exceptional skills and experience of the NICU team—backed by the full spectrum of pediatric sub-specialists available at MCH to support the care of critically ill children.

Even as it cares for approximately 900 of the region's most critically ill newborns per year, Miami Children's NICU maintains one of the best survival rates among NICUs nationwide—98 percent.

Expanding International Leadership

To support advancements in neonatal care worldwide, the Miami Children's NICU team has assumed a leadership role throughout the Americas and beyond. Dr. Amed Soliz, Head of the NICU, is leading the newly formed Ibero-American Society of Neonatology, an organization that brings together



Dr. Barry Chandler, Director of Neonatology with De'Najia Moore neonatology specialists from Spain and North, Central and South America to share knowledge and support research.

Currently, Miami Children's is involved in research to evaluate use of the drug Viagra to support the care of neonates with respiratory or cardiac failure. In the United States,

inhaled nitric oxide—a very expensive treatment—is employed to help neonates with these deficits. "Viagra has great potential to serve as an affordable alternative to nitric oxide. It could have a significant impact on neonatal survival in South and Central America," said Dr. Chandler.

In other international outreach, Dr. Soliz was recently tapped by the World Health Organization (WHO) to conduct an investigation of a recent bacterial outbreak in a South American hospital.

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Unit Expansion Planned

To ensure that the NICU facility keeps pace with its reputation for care excellence, the Neonatal Intensive Care Unit is slated for an expansion. When the work is complete, the unit will feature private rooms for each patient with sleep-in facilities for the family, as well as an intra-unit surgical suite.

"Once the expansion is complete, the unit will rival the facilities of any in the country," said Dr. Chandler. "We think Florida families deserve the best and look forward to offering a unit that features enhanced comfort and privacy to match our clinical excellence."

FAMILY-CENTERED CARE AT MIAMI CHILDREN'S

At Miami Children's Hospital, a family-centered care approach is incorporated into all aspects of care delivery. What is family-centered care? It is a philosophy or approach to care in which patients and families are active participants of the healthcare team.

"We value the experience and perspectives of the family and include them in all aspects of care decision making," said Janet Bell-Taylor, Director of Patient Family Services.



The staff at Miami Children's fully encourages families to stay with their children around the clock, with sleeping accommodations available in all but the critical care units. An open dialogue between care professionals and the family is maintained throughout each child's stay.

To further promote family involvement, the hospital's many playrooms are open to siblings and family members to ensure that family relationships are maintained throughout the child's hospitalization. Siblings admitted to the playrooms must be at least 3 years of age and in good health.

Other offerings that support family-centered care include the following:

- *The Family Advisory Council:* The council, composed of families of current and former patients, makes recommendations for strengthening family-centered care practices and enhancing overall services.
- *Teen Council:* The council, composed of current and former patients, provides feedback and guidance relative to programs and services.
- Saturday Presurgical Orientation: These sessions provide patients and families opportunities to learn about what to expect, meet care staff and ask questions in advance of a scheduled surgery.
- *Sibshops:* This support group for siblings of children with special needs provides opportunities for the siblings to share personal feelings, experiences and concerns while taking part in fun activities.
- Family Resource Center: This center serves the health information needs of parents and family members, offering materials on parenting and childhood diseases. It includes a library, magazines, videotapes and other audiovisual material and Internet access.
- Parent Resource Specialist: Through a partnership with Parent to Parent of Miami, the hospital offers services of a parent resource specialist to provide information, support and referrals to families of children with disabilities.

CALENDAR

Safe Sitter, 9 am to 4 pm, May 7 and 14

Prepares 11- to 13-year-olds to baby sit safely. The class teaches developmentally appropriate activities, feeding and bedtime routines to help teens and preteens care for babies and young children. For more information, call the Department of Preventive Medicine at 305-666-6511, ext. 2516.

SibShops

Monthly fun-filled sessions for siblings of children with special needs. The program provides opportunities for children to share personal feelings, experiences and concerns, while taking part in activities such as cooking, art projects and games. For more information, call 305-669-7142.

THEY DEPEND ON US, WE DEPEND ON YOU

Miami Children's Hospital is a private, non-profit pediatric hospital. Donations to the hospital can be made through Miami Children's Hospital Foundation, a separately incorporated 501(c)(3) charitable foundation. To contact the Foundation, please call 305-666-2889 or visit www.mchf.org.



For a physician referral or more information on Miami Children's Hospital and its services call 305-MCH-4KIDs (305-624-4543) or visit www.mch.com.

