



MIAMI  
CHILDREN'S  
HOSPITAL®

THE MARY ANN KNIGHT INTERNATIONAL INSTITUTE OF PEDIATRICS  
FOUNDED AS VARIETY CHILDREN'S HOSPITAL

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# CHILDREN'S HEALTH TALK

A Miami Children's Hospital Community Update, July 2005

## HELPING CHILDREN WITH GENETIC DISORDERS

The visa lottery win that enabled Leidybeth Rodriguez and her family to leave their native Cuba was much more than a ticket out of a troubled country. For Leidybeth, it was a chance for a complete medical turnaround.

Leidybeth has Gaucher disease, a genetic disorder caused by an enzyme deficiency. The disease results in weakness, anemia, the tendency to bruise and bleed, bone degeneration and enlargement of the liver and spleen.

Although Leidybeth was diagnosed at age 7, she did not receive proper management until she arrived in Florida at age 11. The doctors at Miami Children's Hospital placed her on medication that has changed her life.

"Before I had no energy and would lie around all the time," said Leidybeth, a Miami-Dade Community College student who also works at a bank. "There's no way I could work and go to school without this treatment."

### Help for children with genetic disorders

The Division of Clinical Genetics and Metabolism at Miami Children's provides expert diagnosis, counseling and treatment of children with a wide range of conditions. The team commonly evaluates infants and children with developmental delays, unusual facial features, metabolic disorders, seizures, craniofacial anomalies or babies who fail to thrive.

### The regional leader in genetic services

Miami Children's Division of Clinical Genetics and Metabolism is the largest provider of clinical genetic services in the region. The team sees patients from throughout Miami-Dade, Broward, Palm Beach and Monroe counties. Care is offered at Miami Children's Hospital's main campus near Coral Gables as well as at the Miami Children's Hospital Dan Marino Center in Weston.



Dr. Mislen Bauer, Medical Director of the MCH Division of Clinical Genetics and Metabolism, and longtime patient Leidybeth Rodriguez.

### Helping parents plan ahead

The Division of Clinical Genetics and Metabolism also offers genetic counseling to help parents of children with abnormalities plan for future pregnancies. The team gathers detailed information regarding medical and family history, and assesses the risk for potential offspring as well as options for genetic testing.

### Specialty programs and clinics

For children with genetic disorders, the division has developed specialty programs and clinics that offer patients the convenience of care from multiple specialists:

**Neurofibromatosis Center:** This center evaluates and manages children with suspected or confirmed diagnosis for Neurofibromatosis. Families are provided with the most current information related to treatment and research and receive ongoing management.

**Craniofacial Center:** The Division of Clinical Genetics and Metabolism is also home to the region's state-designated Craniofacial Center, which offers care for children with craniofacial anomalies. This program offers diagnosis, management and reconstructive surgery to support the care of children with craniofacial differences.

**Neurogenetic/Metabolic Program:** Children with neurogenetic/metabolic disorders require treatment from many subspecialists. This program – which is offered in association with the hospital's Brain Institute – brings together a broad group of specialists to provide convenient and comprehensive care.

**Lysosomal Storage Disease Center:** The center brings together a broad-based multidisciplinary team to care for children with lysosomal storage disorders, complex diseases that affect many different organs. For more information, call 305-663-8595.

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## MCH INTRODUCES NEW GUEST IDENTIFICATION SYSTEM

As part of its commitment to ensuring the safety of the children in its care, Miami Children's Hospital recently introduced a new guest identification system, through which every visitor, patient, family member or vendor is issued an electronic identification badge upon arrival.



"This system enables us to keep a record of all who enter the facility and their destination. Through it we hope to offer guests and staff peace of mind that we are taking advantage of the latest security advances," said Alan Sheffield, Director of Safety and Security at Miami Children's.

Miami Children's selected the FAST-PASS identification system created by Sisco Identification Solutions of West Palm Beach, Florida, which enables guests to obtain badges quickly and efficiently.

Guests are asked to provide a photo identification upon arrival at any hospital entrance. The identification card is scanned and then an adhesive photo badge is generated for the guest. Children entering the hospital wear badges bearing their parent's name and likeness.

"In our increasingly security-conscious world, it is expected that most hospitals will soon initiate similar systems," said Sheffield. "We are pleased to be at the forefront among South Florida hospitals."

*For a referral to a Miami Children's Hospital physician, please call 888-MCH-DOCS (624-3627).*

## COMMUNITY EDUCATION CALENDAR

### Let's Go Back to School

August 6, 9 am to 1 pm

MCH South Dade Center 17615 SW 97 Avenue (Franjo Road) Prepare your children to go back to school safely. Our Health on Wheels Program will be offering vaccinations for uninsured children and teenagers. An interactive "Stranger Danger" workshop will provide children and parents with information for child protection awareness. Child passenger safety technicians will check your child's seat for defects, recalls, installation and fit. For more information, please call the Division of Preventive Medicine at 305-662-8282.

### CPR Class

August 9, 6 pm to 8 pm

This course in Pediatric CPR teaches parents, grandparents and caregivers how to administer CPR to infants and children. Please call 305-662-8282 for further information.

### New Sibling Class

August 20, 10:30 am to 12:30 pm

This program is designed to prepare children ages 3 to 7 years of age for the arrival of a new brother or sister. Positive sibling skills

will be presented in a fun, interactive way that teaches children about the important contributions they can make as big brothers or sisters. For more information, please call 305-662-8282.

### Infant Massage (4 week series)

Tuesdays beginning on August 23, 6 pm to 8 pm

Infant massage is designed for children ages 0 to 15 months. Our hands-on method ensures that you will learn the art of interactive massage to suit your baby's individual needs and developmental level. Infant massage encourages relaxation for both parent and baby, promotes longer and deeper sleeping patterns and can relieve colic symptoms among other benefits. For more information, please call 305-662-8282.

### Child Passenger Safety

Child safety is our priority. Child passenger safety technicians will check your child's seat for defects, recalls, installation and fit. For more information, please call the Division of Preventive Medicine at 305-663-6800.

### Emergent Language Group for Children with Autism

Thursdays, 4 pm to 4:45 pm

Music therapy is used to promote language development in children with autism. For more information, please call 305-666-6511 ext. 2434.

## NO ONE KNOWS CHILDREN LIKE MIAMI CHILDREN'S.

There's no greater love than a parent's love for a child. It's a love that we at Miami Children's Hospital share. It's why we've been caring for children for over 55 years, longer than any other children's hospital in South Florida.

No matter where you live, no hospital comes close to the kind of pediatric care your child receives at Miami Children's. MCH is renowned throughout the world. Nowhere will you find physicians more experienced, facilities as advanced, or a staff more devoted to children. We're South Florida's only licensed specialty hospital *exclusively* for children. And that means we have an understanding of children's physical and emotional needs that no other hospital can offer. Your child means so much to you. Choose the hospital that truly knows them best, Miami Children's.

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