

Hear! Hear!



FOUNDATION FOR HEARING AND SPEECH REHABILITATION
An affiliated organization of Ann & Robert H. Lurie Children's Hospital of Chicago

fhsr.org

FALL 2012

Experience Counts: Providing Hope for Children with Hearing Loss

Angel and Jared Berger of South Bend, Indiana, were at their wits' end. Diagnosed with profound hearing loss, their one-year-old daughter, Charlotte, had already been treated at several medical facilities. Various diagnoses were made, and a trial with hearing aids failed to provide much improvement in her hearing.

The family flew to Tampa, Florida, to meet with Charles Berlin, PhD, an expert in auditory neuropathy spectrum disorder, one of several diagnoses that had been made. After tests confirmed Charlotte had the disorder, Dr. Berlin said he felt she was a candidate for cochlear implantation — a treatment that had not been suggested previously.

"We went back to Indiana, and the surgeon disagreed with both Dr. Berlin's diagnosis and his recommendations," says Angel. "Essentially, he said we had wasted our time seeing Dr. Berlin, and recommended another hearing aid trial. I was so frustrated that I just broke down in tears. Fortunately we were referred to Dr. Nancy Young in Chicago."

Nancy M. Young, MD, head of the Section of Otolaryngology and Neurotology at Ann & Robert H. Lurie Children's Hospital of Chicago, has performed more than 1,100 cochlear implantations. She heads a



Children with hearing loss like Charlotte Berger and Osmar Gonzalez are thriving thanks to the expert care they received at Ann & Robert H. Lurie Children's Hospital of Chicago.

multidisciplinary team of 19 professionals with expertise in treating children of all ages, including those with complex auditory and medical conditions. Several of the program's key services and positions are supported by the Foundation for Speech and Hearing Rehabilitation. Dr. Young says she sees a growing number of families whose children were initially treated at other medical centers.

"Hearing loss in infants and young children can be very challenging to diagnose, especially those with more uncommon problems such as auditory neuropathy spectrum disorder or abnormalities of the nerves of hearing or the inner ear," says Dr. Young. "In addition, these children may require special expertise to implant them surgically"
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Empowering Parents Transforms Children's Lives



Nancy M. Young, MD

Sydney's story (see page 3) illustrates how cochlear implantation of a single ear can transform a child's life. Today, most deaf children should have the opportunity to experience the advantages of hearing at a young age. Unfortunately, and despite the availability of advanced technology to diagnosis and manage hearing loss, too many children are not diagnosed accurately or provided with the full benefit of today's treatment options. This problem is especially

true for children who have less common diagnoses or unusual anatomy. Charlotte's and Osmar's stories illustrate just some of the advantages of seeking an opinion from our program, where uncommon problems are typically well within our expertise.

However, what truly sets Lurie Children's audiology and cochlear implant programs apart is the support provided to families by our social worker, Ann Murphy, our hearing
(continued on page 2)

Lurie Children's: New Address, Same Standard of Excellence

On June 9, 2012, Children's Memorial Hospital became Ann & Robert H. Lurie Children's Hospital of Chicago, and moved into its new, state-of-the-art facility downtown. The move allowed the Otolaryngology program to expand its facilities and consolidate them on one floor, enabling the team to serve families in a more timely and efficient manner.

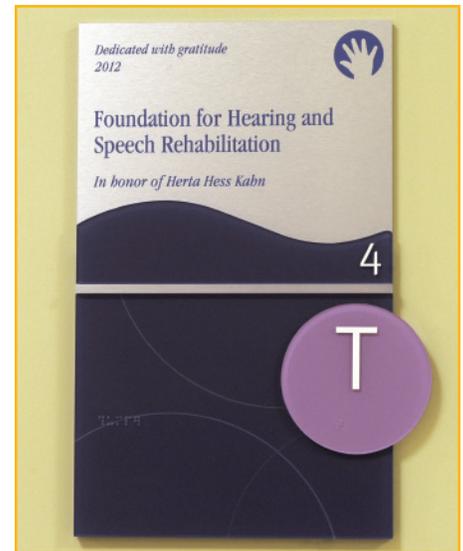
"The move to Lurie Children's has enhanced direct communication among our clinicians in various disciplines who serve children with hearing loss," says cochlear implant coordinator Beth Tournis, AuD. "For the first time, our speech pathologists, audiologists, social worker and the education coordinator all share the same space."

The new space has five sound booths for testing hearing, two more than were previously available. Each of the booths is equipped with an audiometer, otoacoustic emissions unit, tympanometer, video VRA system and an FM transmitter and receiver system. The FM systems for each sound

booth were made possible by donations to FHSR in memory of long-time board member Herta Hess Kahn. The FM system enables the audiologists in the control booth to work seamlessly with the audiologist in the test room with the child. This technology is invaluable when evaluating very young or difficult to test children.

In addition, the two cochlear implant programming rooms are now equipped to program digital hearing aids. Audiology manager Lisa Weber, AuD, says this capability is important, because many recent cochlear implant recipients wear a hearing aid in their opposite ear.

Hearing aid technician Stephanie Bish played an important role in the transition to the new facility as a member of Lurie Children's equipment planning committee. For Stephanie, one important benefit is the presence of a Verifit unit at her desk. "This has allowed us to improve the turnaround time in getting repaired hearing aids back to patients," she says.



In recognition of FHSR's longtime philanthropic support of the Otolaryngology program, a central corridor in the Audiology Department at Lurie Children's is named for the Foundation. The space is comprised of two cochlear implant consultation rooms, two sound booths and two office spaces — each featuring a plaque honoring FHSR.

Empowering... (continued from page 1)

aid technician, Stephanie Bish, and our cochlear implant educator, Stacy Simek. Why are they so pivotal to what we do? The answer lies in the emotional impact of hearing loss and the need for excellent and timely coordinated care across many disciplines. So many families are devastated to learn their child has hearing loss and are unfamiliar with the potential impact on language and intellectual development. Our parents need knowledge and confidence to move forward and become advocates for their child. The additional time and advice these dedicated professionals are able to give to parents and to other professionals in the community are central to achieving our mission of helping each child achieve their full potential.

FHSR support has transformed the lives of so many children with hearing loss. Please give generously to the Foundation so that Ann, Stephanie and Stacy can continue to empower families and enable Lurie Children's to provide the best possible hearing healthcare.

Nancy M. Young, MD

Head, Section of Otolaryngology and Neurology

Medical Director, Audiology and Cochlear Implant Programs

Ann & Robert H. Lurie Children's Hospital of Chicago

Lillian S. Wells Professor of Pediatric Otolaryngology, Northwestern University Feinberg School of Medicine

FHSR Moves for the Kids



Team FHSR participants Tom and Jacquie Clark with their children (from left) Josie, Jeanmarie and Ryan.

Congratulations to our volunteers who braved the rainy weather on May 12 to participate as members of "Team FHSR" in the Move for the Kids 5K Run/Walk to benefit Lurie Children's. Thanks to their efforts, Team FHSR, led by Ellen Babbitt, raised more than \$15,000.

Cochlear Implant Program Featured on PBS

Nancy M. Young, MD, was recently featured on the award-winning PBS television series, *Healthy Body, Healthy Mind*. The segment, "Cochlear Implants: Bringing Back the Joy of Sound," illustrates the impact of implantation on the lives of children and adults. FHSR Board Chair Kristen Van Dyke and her son, Max, are also featured in this episode. To view the program, visit:

itvisus.com/programs/hbhm/episode_2401.asp

Sydney: One Extraordinary Teen

On paper, 17-year-old Sydney Pesko sounds like just another high achieving teen. A suburban Chicago high school senior, Sydney is a National Honor Society member who plays on her school's softball, soccer and tennis teams and plans to study engineering in college. But nothing about Sydney is ordinary. Diagnosed with profound hearing loss in both ears at 13 months of age, Sydney received her first cochlear implant when she was 2-1/2. At that time, newborn hearing screening did not exist and cochlear implants were new technology and only done in one ear.

A week after her diagnosis at Ann & Robert H. Lurie Children's Hospital of Chicago, Sydney was fitted with hearing aids, and began seeing an auditory verbal therapist. While she received some benefit from hearing aids, Sydney's parents, Gina and Christopher, consulted with Nancy M. Young, MD, who confirmed that she was a candidate for a cochlear implant.

After her first implant surgery on her right ear, it took Sydney time to adjust to her improved access to sound.

"At first it was very scary for her, because she was hearing more than she did with her hearing aids," says Gina. "It was nerve-racking, because she didn't want to wear it. Finally, we took a trip to Disney World, and outside the gates we said, 'If you want to go in, you'll have to wear your implant.' After that, she never took it off, and after eight months we could really tell a big difference in her speech."

Sydney has been in mainstream classes throughout school, with minimal accommodations. Her mom says Sydney was initially resistant to suggestions that she undergo implantation of her other ear.

"We had talked about it, and it was always, 'No, no, I don't need it,'" says Gina. "Then she attended a reunion of kids her hearing therapist had worked with. Many of them had bilateral implants and told her, 'You're going to hear so much better. What are you waiting for?' I think that was the turning point for her."

In June, just three days after Lurie Children's opened, Dr. Young implanted



Sydney with Nancy M. Young, MD, who implanted Sydney's right ear when she was 2-1/2, and her left when she was 17.

Sydney's other ear, making her the first patient to undergo a cochlear implant at the new hospital. Gina says Sydney is still acclimating to her second implant, and is working hard at identifying words and music with her left ear alone.

"Sydney is a very smart, very driven young lady," says Gina. "For her to have accomplished everything that she has, we couldn't be more proud of her."

Experience Counts... *(continued from page 1)*

and to program them successfully after implantation. In Charlotte's case, a proper diagnosis was essential, as children with auditory neuropathy often do not derive significant benefit from hearing aids."

Dr. Young performed surgery on Charlotte's right ear when she was 19 months old. Angel says that within the first month, Charlotte learned 50 new words and is now, at age two, age appropriate in speech and language. "Coming to Lurie Children's was the best decision we ever made," she says.

Another Lurie Children's success story is four-year-old Osmar Gonzalez, who was previously seen at four other Chicago area medical centers after being diagnosed with severe to profound hearing loss. Osmar was fitted with hearing aids when he was nine months old. His mom, Neima, says the hearing aids provided little benefit, and cochlear implantation surgery on his right ear was scheduled when he was 15 months old at a Chicago area hospital.

"Then we got a call the night before surgery telling us that they were canceling it, because an MRI showed he didn't have an auditory nerve," says Neima. "They said that the only option was sign language. That was just devastating."

Three months later, upon the recommendation of another family with a hearing impaired child, Neima and her husband, Miguel, made an appointment with Denise Thomas, a cochlear implant audiologist at Lurie Children's.

"Denise worked closely with his local therapist who was providing hearing therapy," says Dr. Young, who told the family that cochlear implantation was an option after all. "It became clear that despite the MRI findings, he was hearing some sounds, not just feeling the aids vibrate. So we knew there was a neural connection between the ear and the brain."

Surgery was performed when Osmar was two years old. "After the device was

activated, Osmar rapidly developed good sound detection skills through his cochlear implant," says Denise. "Whether he will develop the ability to understand words and learn to talk is not yet known. Only time will tell."

Today, Osmar is in a total communication preschool class, where he is taught to communicate in sign language and encouraged to listen and talk. He also is seen at Lurie Children's by aural rehabilitation specialist Megan Sullivan and music therapist Rachael Rilingier, who work together to help Osmar develop his listening and spoken language.

"Osmar is trying very hard to use his voice," says Neima. "We talk to him so much that at the end of the day we're hoarse! The other day he woke up and the first thing he wanted was his implant. He put it on and started to smile. That made me very happy."

Hart Family Cochlear Implant Education Coordinator



Stacy Simek, MS, DT-H,
LSLS Cert. AVEEd

Hart Family Cochlear Implant Education Coordinator Stacy Simek continues to expand her work with schools and special education cooperatives throughout the greater Chicago area and Northwest Indiana.

In the past year, she served more than 150 patients from 42 schools representing 22 school districts and cooperatives. Stacy also worked closely with nearly 120 teachers and other professionals, including the Chicago Public Schools' Coordinator of Deaf and Hard of Hearing Services, enabling her to provide the cochlear implant team with status updates on schools attended by Lurie Children's patients. She made several presentations at the Illinois Teachers of Hard of Hearing and Deaf Individuals annual conference.

This year Stacy enhanced her professional skills by becoming a Listening and Spoken Language Specialist Certified Auditory-Verbal Educator through the AG Bell Academy. She is the third member of the implant team to achieve certification.

Audiology Technician



Stephanie Bish

Audiology Technician Stephanie Bish, whose position, like Stacy's, is supported by FHSR, helps patients and their families with their assistive hearing devices, seeing approximately 1,000 patients per year. Additionally, she has over 1,800 patients in her hearing aid database, and manages the lending of more than 150 loaner hearing aids at five locations. All devices are the latest technology, and approximately 100 are out on loan to patients at any given time.

Stephanie is often contacted by parents in urgent situations. Recently a patient's mother called from out of town to report that both of her daughter's hearing aids were broken. Stephanie provided troubleshooting assistance over the phone and arranged for a hearing aid from the loaner bank to be made available for the patient. She then programmed the device and sent it overnight to the family. Needless to say, the family was very appreciative of Stephanie's swift response and assistance.

SAVE THE DATE

Sunday, March 10, 2013

Please join FHSR for a family-friendly event and fun musical celebration.

Visit fhsr.org for updates and more information.



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