

Hear! Hear!



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

fhsr.org

FALL 2013

Helping Families Cope with Diagnosis of Hearing Loss

Learning that their child has profound hearing loss is difficult for any family. It was particularly devastating for Stephanie and Mark Fellingner, whose then 2-year-old son, Teddy, had already undergone open heart surgery and, ultimately, a heart transplant at Ann & Robert H. Lurie Children's Hospital of Chicago.

But just as Teddy was getting physically stronger and needed fewer doctors' appointments, it also became apparent to his parents that he wasn't responding to sound the way he used to. Teddy underwent a hearing test, and the results indicated he had profound bilateral sensory neural hearing loss.

"I remember thinking, 'What more could be given to this child to overcome?'" says Stephanie. "And then we met Anne."

Anne Murphy, the social worker for Lurie Children's Audiology Department and Cochlear Implant Program, is uniquely qualified to help families like the Fellingners learn to become advocates for their children. In the last year alone, Anne, whose position is supported by the Foundation for Hearing and Speech Rehabilitation, met with 192

families of children either newly diagnosed with hearing loss or who are scheduled for or have already undergone cochlear implantation surgery. Because a child's hearing loss can result in a broad and complex range of issues, Anne conducts detailed psychosocial assessments of nearly 50 families each year, and discusses their goals and expectations for their child's hearing. This information helps Anne provide the best support and resources for each family.

"Parents find it very helpful to talk about their child with someone who understands the barriers and obstacles they will face raising their child," says Anne. "Often I see parents of babies who have failed their newborn hearing screening and were just diagnosed with hearing loss. Just think of all the adjustments and changes parents are going through when adding a new child to their family. Then they receive a diagnosis of hearing loss for their baby. Fortunately, we can refer parents to a number of resources for help."

Stephanie says Anne's help was invaluable. "Anne was like a calm in the storm," she says. "Right from the start she explained
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Devastated after their son Teddy was diagnosed with profound hearing loss not long after undergoing a heart transplant, the Fellingner family found Audiology and Cochlear Implant Social Worker Anne Murphy's assistance invaluable.

Giving Children a Chance to Reach Their Full Potential



Nancy M. Young, MD

On a personal level, it is the services highlighted in this newsletter provided by Anne, Stacy and Stephanie of which I am most proud. Families of children with hearing loss face many emotional, financial and social challenges — not only at the time of diagnosis, but also as their child matures and changes, and as unexpected events arise in family life. Parents face the additional challenge of finding the best therapies and education for their child. The differences in philosophy among therapists and schools make these decisions difficult. I am so grateful to FHSR for enabling us

to provide critical information and support to families.

In addition to providing truly comprehensive clinical care, we are conducting research to understand how to improve the hearing and spoken language achieved by our children with cochlear implants. In the past year we published our results in two special populations of implanted children: those with Usher's Syndrome, the leading cause of deaf-blindness in the United States; and children with deficiency of the nerve of hearing, a population often deemed non-

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“Cheers for Ears” Celebrates the Joy of Music

Hosted by FHSR, “Cheers for Ears” was celebrated on March 10, 2013 at Lurie Children’s with more than 160 children, families, FHSR board members and supporters attending the event. Billed as “A Fun Musical Celebration for the Whole Family,” the event featured a performance by Rhythm Revolution, who encouraged participants to join in on percussion instruments in one of the interactive drumming circles. In the spirit of learning and celebration, the performance provided an understanding of and appreciation for hearing and music perception by children affected by hearing loss, including cochlear implant recipients. See page 4 for details on the next “Cheers for Ears” event, to be held on March 11, 2014.



Giving Children... (continued from page 1)

candidates for this intervention. Ongoing research focuses on computer-based auditory training to improve cochlear implant outcomes, and magnet resonance imaging of brain structure and function to enable prediction of cochlear implant outcomes.

The number and complexity of children served by Lurie Children’s audiologists and the Cochlear Implant Program continues to grow each year. Lurie Children’s is the largest and most experienced provider of auditory brainstem evoked response testing for infants who fail newborn hearing screening, as well as the largest provider of hearing aids for children in Illinois. Many of the children we serve initially benefit from hearing aids. However, all of our audiologists are educated in identifying potential cochlear implant candidates. They take great pride in their ability to recognize and refer these children for additional evaluations if hearing aids alone are not enough to keep children’s development on track. Early intervention after a change in hearing is beneficial at any age!

The children we serve deserve the opportunity to achieve their full potential — please help them by supporting FHSR.

Nancy M. Young, MD

Head, Section of Otology and Neurotology

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

Team FHSR and Lurie Children’s A-Team Get Moving!

Thanks to your generous support, the combined efforts of Team FHSR, led by FHSR Board member Ellen Babbitt, and Lurie Children’s Audiology Department’s A-Team, raised more than \$10,000 at Lurie Children’s Move for the Kids 5K Run/Walk. The proceeds were directed to the Audiology Department and the Cochlear Implant Program. Team FHSR included a number of families of children who have undergone cochlear implantation at Lurie Children’s.



Ensuring Success in the Classroom

Last year, Eduardo Venalanzo was struggling with his spoken language at his public school. He had undergone cochlear implantation surgery at Lurie Children's when he was 3, and now, at age 9, he was in a mainstream class. His school's speech language pathologist recommended placing him in an all-deaf classroom, where the students used sign language. The school's audiologist disagreed, as did Eduardo's mom, Maria Perez.

"I didn't think it was the right setting for Eduardo," says Maria, whose younger son, Esteban, 5, also has bilateral cochlear implants. "I wanted him to use spoken language at school."

Eduardo had another strong advocate on his side — Stacy Simek, Lurie Children's Hart Family Cochlear Implant Education Coordinator, whose position is supported by FHSR. Stacy works directly with teachers and administrators to help determine the most appropriate school placement to allow a child to achieve his or her full potential and in keeping with their family's preferred mode of communication.

"After observing Eduardo in class, it was apparent that there was a gap between the more sophisticated things Eduardo wanted

to express and his ability to express himself using speech," she says.

Stacy spoke with Maria about other school options, including an area private school with a self-contained classroom, where a teacher of the deaf utilized both sign language and oral communication. Depending on their ability level, students were also placed in mainstream classes for part of each day, allowing them to gradually achieve full time placement into a mainstream setting.

Eduardo transferred to the private school last January, and his little brother is now attending kindergarten there.

"The first day of school Eduardo was crying, because he wasn't happy about changing schools," says Maria. "But by the time I picked him up in the afternoon, he said he loved it. Eduardo's speech has improved so much, and I've never seen him so happy. I'm so grateful to Stacy for the help she has given us."

Now in her fifth year on the Cochlear Implant Program team, Stacy has served more than 200 families this year and visited more than 75 schools. She says she's proud of the personal relationships she's developed with the professionals



Brothers Esteban (left) and Eduardo Venalanzo are happy with their school placement, thanks to help from Education Coordinator Stacy Simek.

at the schools, school districts and cooperatives she works with.

"It has evolved to be more of a two-way relationship," she says. "Now we have schools coming to us to discuss the best placement for a particular child. They trust me, and realize that we are all working together to find the best situation for each and every child to succeed."

Helping Families Cope... *(continued from page 1)*

that, while this diagnosis is devastating, there was a plan in place for Teddy. She gave us hope, and reassured us that Teddy would be fine. And he is!"

Teddy ultimately underwent bilateral cochlear implantation surgery at Lurie Children's in July 2012. Today he is an active 3-year-old who loves to laugh and to run, jump and climb on practically anything, and is in a mainstream pre-school class where he is popular with his classmates. As for his ability to hear, Stephanie says Teddy's hearing is "better than my own."

Anne has also worked with Roxana Castillo, the mother of four children under the age of six, including two boys who have had bilateral cochlear implants at Lurie Children's — Adan, 4, and Miguel,

2 ½. As the primary caregiver to four young children, Roxana continues to face challenges. One way Anne was able to provide support was to arrange for a social worker to visit the family on a weekly basis. This year Anne provided more than 320 referrals for assistance from other professionals and organizations.

"The boys are doing well with their implants, but they're not speaking yet, and it can be very difficult at times," says Roxana. "The social worker has helped me deal with the stress, and has helped me in particular with Adan, who wants a lot of attention and gets frustrated when I don't understand what he wants. We also had a bad housing situation, and had all our belongings stolen just two weeks before Christmas in 2011 — including the boys'

hearing aids. Anne put me in touch with Catholic Charities, who helped us find a new apartment. She and (audiologist) Meghan Crimmins also gave us gift cards for groceries and toys. Anne does an awesome job, and always asks me if I need anything. When I'm really stressed out, she'll just look at me and give me a hug."

Anne works closely with the program's audiologists and with Hart Family Cochlear Implant Education Coordinator Stacy Simek, who has visited Adan's school.

"It's very satisfying to hear from families we've been able to help and see that these interventions we've been able to provide have made a difference," says Anne. "I'm also grateful to FHSR for their support in recognizing that our work provides value for the families we work with."

Loaner Hearing Aids Provide Continuity

Nine-year-old Wolfgang Wall is an athletic kid who, according to his mom, Vikki, is always on the move. A few months ago, he had a fall and damaged the hearing aid he uses in his left ear. Without it, Wolfgang, who was diagnosed with hearing loss at age 3, had no access to sound.

Vikki immediately made an appointment with Stephanie Bish, audiology technician for Lurie Children's Pediatric Otolaryngology Program. Stephanie fitted Wolfgang with a loaner hearing aid to use for the week it would take for his own unit to be repaired, and programmed the loaner to accommodate his hearing needs. Wolfgang is an excellent student, and is on par with his hearing classmates at school. Although he benefits from the use of FM amplification systems both at school and at home, being without his hearing aid for even a short period of time could impact his success in the classroom.

"It's important to have loaners available so our patients can continue to stay connected in their academic and social lives," says Stephanie. "It helps them to continue to succeed in life."

Stephanie's position is funded by FHSR, and is an essential component of Lurie Children's audiology and cochlear implant programs. Each year she sees about 1,000 patients who need help with their assistive hearing devices. She also manages the loaner bank of all-digital hearing aids. These loaners are invaluable for patients who are being evaluated for cochlear implantation, have equipment that needs repair or are waiting for financial approval for hearing aids. Stephanie dispensed 111 loaner



Wolfgang Wall is one of the 1,000 patients Audiology Technician Stephanie Bish helps each year.

hearing aids this past year, and an additional 123 devices were dispensed at several of the hospital's satellite locations.

Wolfgang's mom says she's inspired by Stephanie, who was herself diagnosed with hearing loss as a young child and used hearing aids for many years. Stephanie underwent cochlear implantation surgery five years ago.

"Seeing someone like Stephanie inspires me to inspire my son about his future," says Vikki. "She's a busy professional in the real world and is living a full life."

Recent tests have determined that Wolfgang's hearing loss, which had remained stable, is progressing, and he is undergoing evaluation for cochlear implantation.

"Wolfgang takes a very active role in his hearing," says Vikki. "He's a bit worried about the prospect of surgery, but he takes everything in stride. We just want the best quality of life for him as he gets older."



**FHSR is
now on FACEBOOK!**

SAVE THE DATE

**Thursday,
March 11, 2014**

Please join FHSR for a family-friendly event and fun musical celebration. Visit fhsr.org for updates and more information.



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