

Hear! Hear!



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

fhsr.org

FALL 2015

Expertise in Auditory Neuropathy Spectrum Disorder Care

Delivering an 8th grade commencement speech before 400 fellow students and 1,600 guests is a daunting proposition for any 15-year-old. While admittedly nervous, Marne Sullivan strode to the podium on her graduation day and spoke eloquently about the importance of embracing who you are.

“My main points were, ‘Be yourself and accept yourself, because it’s OK to be different from other people,’” says Marne, who was diagnosed with auditory neuropathy spectrum disorder (ANSD) as a baby, and underwent cochlear implantation when she was 3½. “Different doesn’t just describe being deaf. There are lots of things that can make you different from others.”

Marne was one of the first ANSD patients to receive an implant at Ann & Robert H. Lurie Children’s Hospital of Chicago, whose Audiology and Cochlear Implant Program is one of the largest and most experienced in the U.S. The program is led by Medical Director and surgeon Nancy M. Young, MD, who has performed more than 1,300

cochlear implants. Lurie Children’s is a leader in treating children with ANSD, an uncommon hearing disorder that is difficult to diagnose and requires highly individualized treatment. Its multidisciplinary hearing health care team includes pediatric audiologists, speech therapists, experts in listening and spoken language development, social workers, an education coordinator and hearing aid technician all working together. The team is ideally suited to serve children with ANSD.

A diagnosis of ANSD encompasses a variety of hearing problems due to “misfirings” of the auditory nerve or issues affecting the nerve’s connection with the cochlea. The result is a disorganized transmission of sound to the brain that some patients describe as “static.”

“Unlike typical sensorineural hearing loss, it is not unusual for children with ANSD to pass newborn hearing screenings,” says Dr. Young. “In addition, hearing aids often do not improve these children’s sound



Marne Sullivan, one of the first patients implanted for ANSD at Lurie Children’s, gave the commencement speech at her 8th grade graduation.

awareness or understanding of spoken language, and may even interfere with the child’s ability to hear. Many children suspected of having ANSD are referred to

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Experience “Counts” in Providing Expert Care



Nancy M. Young, MD

As our Audiology and Cochlear Implant Program’s experience has grown, so has our ability to diagnose and treat children with a variety of challenges. Our experience enables us to better counsel parents about their child’s unique situation and what lies ahead. For this reason, many children with hearing loss due to auditory neuropathy spectrum disorder (ANSD), as well as with other complicating conditions, are cared for at Lurie Children’s. Other examples of our expert care not widely available elsewhere include implant surgery to preserve residual hearing using advanced surgical techniques,

and our collaboration with Lurie Children’s Medical Imaging Department, which has made it possible for most implanted children to undergo magnetic resonance imaging without the need for additional surgery.

We also share our clinical experience and the results of our research collaborations with other professionals. Over the past year alone, our staff and research collaborators made presentations at national and international meetings on a wide variety of issues relevant to pediatric cochlear

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Expertise in Auditory Neuropathy Care... (continued from page 1)

Lurie Children's because of our expertise in confirming the diagnosis and in providing the appropriate counseling and multidisciplinary care."

Audiologist and Cochlear Implant Program Coordinator Beth Tournis, Au.D., says a diagnosis of ANSD can only be made using a special protocol during the auditory brainstem response (ABR) testing to distinguish ANSD from other types of hearing loss. Even if this additional testing is performed, many centers don't have the experience necessary to diagnosis ANSD.

"Without the additional protocol and expert interpretation of the abnormal ABR recordings, an accurate diagnosis of ANSD is not possible," she says.

Beth adds that the presentation of ANSD varies widely. "Some patients appear to have near normal awareness of sound, but great difficulty hearing speech in background noise," she says. "Although others function as if they are completely deaf, many detect sound as if a partial hearing loss is present, yet do not hear well with hearing aids or develop speech as children with more typical sensorineural hearing loss do."

Today, Marne, a high school freshman who takes honors classes, has annual follow-ups with Stephanie Yaras, her audiologist since she was four months old.

"To say that we've been thrilled with the entire cochlear implant team at Lurie Children's would be an understatement," says Marne's mom, Molly.

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

implantation. I have had the great privilege to serve as editor of a new book on emerging concepts and best practices entitled, *Pediatric Cochlear Implantation: Learning and the Brain*, which will be published in 2016. My co-editor, Karen Iler Kirk, PhD, and our chapter authors are all leading researchers and clinicians in the field. It is the first book to emphasize new research on the importance of the brain in determining cochlear implant outcomes.

When caring for children with hearing loss, experience "counts" on many levels. The result has been an overwhelming demand for our audiology and cochlear implant services, which continue to expand. We now offer cochlear implant programming, diagnostic audiology and hearing aid fittings at our new outpatient center in Northbrook, in addition to existing programming services at our outpatient center in Westchester and at the main hospital. Diagnostic audiology and hearing aid fittings are also available at outpatient centers in New Lenox and Lake Forest. Hearing therapy provided by speech pathologists certified by the AG Bell Academy, who specialize in listening and spoken language development, is also now available at several locations.

FHSR is critical to our mission to help children to achieve their full potential. Why? FHSR support enables us to help both children and families in ways that transcend the usual role of a medical center. Whether it's providing information about hearing loss and their child's rights, "hands on" coaching for parents to advocate for community-based services, urgent replacement of equipment so that their child may hear, or even a hug, FHSR's support makes all of this possible.

Nancy M. Young, MD

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Tech updates

Here is a brief look at some of the latest developments in cochlear implant technology.

Advanced Bionics knows that talking on the phone is a desired outcome for cochlear implant recipients. AB's Naída CI Q70 processor is now compatible with the Phonak DECT phone for landline use and Phonak EasyCall for Bluetooth cell phones. These accessories allow listeners to hear calls simultaneously in both ears.

MED-EL announces the SYNCHRONY implant, which offers the safest MRI scanning capability on the market. SYNCHRONY is the only implant with a magnet that doesn't need to be removed for a 3.0 Tesla MRI scan, which doctors prefer for its increased resolution. MED-EL says it's the smallest and lightest titanium implant available.

Cochlear Americas introduces the SmartSound® iQ for Cochlear™ Nucleus® 6 cochlear implant users, which automatically adapts to different sound environments. Proven to significantly improve hearing in noise, users no longer have to guess which setting is best — the sound processor will do it for them.

Save the Date for Cheers for Ears



Kids with hearing loss will experience the power of music, as FHSR presents the **5th Annual Cheers for Ears** free family concert on March 6, 2016. Join us for an afternoon of musical entertainment, food and fun for patients and families cared for by Lurie Children's Audiology and Cochlear Implant Program. For more information, please visit fhsr.org.



Social worker Jamie Sanchez (right) visits with audiology patient Maria Ortiz and her mother, also named Maria.

Social Worker Builds Rapport with Spanish-Speaking Families

For parents of children who either need or have undergone cochlear implantation, the journey to improved access to sound can be a long and sometimes overwhelming one. For the approximately 25 percent of families seen by Lurie Children's Audiology and Cochlear Implant Program who are Spanish speaking, the challenges can be even greater.

Thanks to support from the Foundation for Hearing and Speech Rehabilitation, the program includes a Spanish-proficient social worker, Jamie Sanchez.

Jamie works with one of the hospital's Spanish-language interpreters during the initial psycho-social assessments of families with children who are candidates for implantation. As these relationships grow, many of these families become comfortable speaking Spanish with her.

Recently, Jamie sat in on a clinic visit with a teenage girl, who communicates through American Sign Language (ASL), and her Spanish-speaking parents. Although two interpreters were facilitating the dialogue, Jamie's knowledge of Spanish helped with the ease of conversation.

"The family shared that the parents had separated about a year ago," says Jamie. "This combined with a recent transition to high school, contributed to feelings of isolation for the patient. We talked

through the patient's feelings and her parents' desire to connect with their daughter. The family agreed that ongoing therapy could be a great tool, and accepted referrals to therapists close to home who could accommodate their language needs in ASL and Spanish."

Jamie says that in addition to language, there can be cultural considerations with Spanish-speaking families that may impact their relationship with their child's school.

"Sometimes, families will identify their children's behavioral or academic needs, though they are unsure how to access resources within the school system," she says. "We work to empower parents as experts on their children by providing information regarding appropriate contacts within the school, the process of obtaining evaluations and accommodations and reaching out to schools to bridge communication as needed."

Jamie, a former special education teacher in Chicago's Little Village neighborhood, says she gets a lot of satisfaction from building relationships with patient families.

"My primary goal is to help families feel supported in coping with their child's hearing loss," she says. "My ability to speak Spanish helps to build rapport and maintain connections."

Data Logging Technology Offers a True Picture of Implant Use

During an appointment with a 12-year-old patient with bilateral cochlear implants, Lurie Children's audiologist and Audiology and Cochlear Implant Program Coordinator, Beth Tournis, Au.D., asked the boy how his equipment was working. "Oh, everything is fine," he responded. But when Beth downloaded information from the data logging software built into his sound processor, she found something startling: one of the boy's headpieces was falling off an average of 120 times a day. To address these frequent interruptions in his hearing, Beth provided a stronger headpiece magnet.

At his follow up visit, Beth found the number of interruptions caused by the headpiece falling off was reduced to only 10 times a day. "This poor kid was putting the headpiece back on his head 120 times a day in order to hear, and his parents didn't even know!" she says. "Without the data logging technology, we wouldn't have known either."

While data logging technology has been available in hearing aids for about 10 years, it only recently became available for cochlear implants. Beth says this functionality enables audiologists to get an instant snapshot of a number of parameters. These include how many hours a day a patient is listening through their implant and the amount of time the child spends in different listening environments, such as quiet or noisy ones.

"Once we know more about the child's daily listening environment, we can customize programming of their implant system to meet their specific needs," says Beth. "The children and their parents tell us it's made a huge difference. And that's very rewarding."

Payton's Book: "My Cochlear Implants"



Payton Thomas holds her book about life with cochlear implants.

When 6-year-old Payton Thomas was asked by her teacher to write an autobiographical essay for a writing contest, she knew immediately what her topic would be: a typical day in the life of a child with cochlear implants. Her illustrated book, "My CIs," was submitted for a state contest, and she became one of the youngest authors to receive an award at the Illinois Statewide Young Authors Conference in May.

"Every time I make a new friend they point to my head and ask, 'What is that?'" says Payton, who was born with severe to profound deafness and received bilateral implants at Lurie Children's when she was 10 months old. "So I decided to write about how I was born deaf and how my cochlear implants help me hear."

Payton, a first grader who attends a mainstream school in Edwardsville, Illinois, dedicated her book to the hospital's Audiology and Cochlear Implant Program Team. In it she describes a typical day: how she wakes up in the morning not being able to hear until her mom puts on her "ears." Then she decides which decorative stickers to use to accessorize her headpieces.

Even though Payton and her family drive 275 miles for her annual audiology appointments, they don't mind.

"It's a real comfort to know that Lurie Children's has a whole team of physicians, audiologists, education coordinators, social workers and others working together," says Payton's mom, Crystal. "It's especially important when you're a new parent being drawn into the world of hearing loss. We take comfort in knowing that if we need something the team at Lurie Children's is there for us."

A Shared Passion for Helping Others

Building on the rich history established by the founding families of FHSR, Allie and Steve Salzman are making FHSR board work a father-daughter affair. As Co-Chair of the FHSR Board of Directors, Steve was instrumental in forming the new Associate Board, and his daughter, Allie, 26, jumped right into a leadership role as its Co-Chair.

Steve has raised his family with a strong dedication to social justice, and he and Allie have spent many hours participating together in volunteer work. With hearing loss near and

dear to their family, they have channeled their desire to improve the lives of those affected by it into their efforts on behalf of FHSR. This duo, built on mutual respect, also enjoy the extra time they get to spend together through their board service. Steve is the Past-Chair and Allie is serving as Co-Chair of FHSR's Songs for Sound fundraiser on November 12.

The Associate Board is a labor of love for Steve and Allie, and their combined service has doubled the energy of both FHSR boards.

Foundation for Hearing and Speech Rehabilitation is now on FACEBOOK!



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