

Hear! Hear!



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

fhsr.org

FALL 2014

Patient Turned Teacher Pays It Forward

Anna Tess was born with profound hearing loss in both ears. When she was 2½, she underwent her first cochlear implant surgery at Ann & Robert H. Lurie Children's Hospital of Chicago, performed by Nancy M. Young, MD, Medical Director of the hospital's Audiology and Cochlear Implant Program. Anna recently graduated from Illinois State University with a degree in Deaf Education, and is pursuing her master's degree at Vanderbilt University.

My parents say I was terrified the first time my implant was activated. I adjusted quickly though, and started talking soon after that. I communicated orally and with sign language until I was about 5. One day I came home from school with a note that said, "Anna has decided to be completely oral." From first grade on I attended mainstream classes.

I didn't really become aware that I was different until junior high school. I remember wishing that I had a friend who was going through the same experiences. Kids would say things like, "Oh, she can't talk," or "She can't

hear." Thankfully, I had some awesome friends and a lot of people advocating for me. I earned straight As in high school, ran cross country and played soccer and basketball.

My other ear was implanted when I was 19, also by Dr. Young. I had done so well up until then that I never felt the need to get another implant. But after meeting people in college with bilateral implants, I thought, "Well, I might as well try it."

Dr. Young was very honest with me, and said she wasn't sure how much additional benefit I would get. But she said it was ultimately my decision. Two years later, my overall hearing has improved, and I have no regrets about my second implant.

As a student teacher, I've taught students at Child's Voice and Bell Elementary School in Chicago, and at a school in St. Louis. I went into deaf education because I had such great experiences growing up, with so many people supporting me. I want to pay it forward to help other kids, because I know what it's like



Anna (right) tutored fellow Lurie Children's cochlear implant recipient Jenna Harris last summer. Anna is also a member of FHSR's new Junior Board.

to be the only kid in school with hearing loss. I want to say to them, "Yes, you can do this. You may not succeed the first time, but you can do it."

Advances and Challenges in Hearing Healthcare



Nancy M. Young, MD

"It was the best of times, it was the worst of times..."

This opening line from "A Tale of Two Cities" by Charles Dickens captures the contrasts I see unfolding in hearing healthcare. Improving the lives of children with hearing loss continues to evolve in exciting ways. For example, this fall I was invited to speak at two national meetings about single sided deafness. This topic is "hot" in light of advances in hearing aid and auditory implant technologies and the growing evidence of the academic, social

and emotional impact of hearing loss — even when only one ear is affected. The next decade and beyond could be an exciting time, during which we may be able to help a large and neglected group of children for whom effective treatment has not been available.

Healthcare is changing rapidly in other ways. A major restructuring of the way children funded by public aid receive primary care in Illinois is underway. The logistics of these children obtaining access

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Meet FHSR's New Board Members

The Foundation for Hearing and Speech Rehabilitation is pleased to introduce the new members of its Board of Directors.

Amanda Biedron is an audiologist and is the Great Lakes Regional Manager for Advanced Bionics.

"For children with hearing loss, technology alone does not ensure that they reach their full potential. Being a member of the FHSR Board allows me to do what I can to make sure that each child has every opportunity available to them."

Tim Egan serves a dual leadership role in healthcare as President and CEO of Roseland Community Hospital and CEO of the Mobile Care Foundation.

"I have dedicated my professional and personal life to identifying children in need and connecting them with proper healthcare providers. Volunteering and sharing my leadership experience with FHSR is a logical fit for my personal life mission."

Frank Jakosz is a partner in the accounting firm Sikich, LLP, which provides professional audit, tax and consulting services to not-for-profit organizations.

"Having grown up with hearing loss throughout most of my childhood and as an adult, I appreciate the challenges these children face. I am very excited to be a part of an organization that is improving the lives of children affected by hearing and communication disorders."

S. Benjamin Kanter is Associate Chair and Associate Professor in the Department of Audio Arts & Acoustics at Columbia College, where he investigates research and technological advances in the hearing sciences.

"My work involves lecturing on hearing physiology and conservation. As an FHSR Board member, I feel right at home working with others who share a passion for raising the public's awareness of hearing health and rehabilitation."

Kerry Roesch is an audiologist and Area Director for Med-EL Corporation. Since 1991 she has provided support and education for both families of children with hearing loss and professionals in the hearing industry.

"I previously worked as an audiologist in the Cochlear Implant Program at Lurie Children's, and I've maintained a strong interest in supporting FHSR and its efforts on behalf of the hospital's program."

Songs for Sound



FHSR partnered with *Songs for Sound* on a unique event on October 25 at Moonlight Studios in Chicago. Nearly 300 guests enjoyed music from top Nashville songwriters Wendell Mobley, Jim Collins and Andrew Pates. Proceeds will support the Audiology and Cochlear Implant Program at Lurie Children's. Members of FHSR's new Junior Board played a key role in organizing *Songs for Sound*, including securing raffle items, selling tickets and volunteering at the event.



Advances and Challenges... (continued from page 1)

to more specialized hearing healthcare is unclear. I am gravely concerned about continuity of care for children currently under our care and the potential for increased barriers to access for families whose children would best be served by programs providing specialized pediatric care. Experience counts, but only if the children we are trained to serve find their way to us. In addition, several major private insurance carriers have recently implemented more restrictive policies that appear to limit coverage of cochlear implantation for children. These changes will likely result in more children whose treatment is delayed by insurance denials and the appeals process. At worst, some children may never receive medically necessary care. Our social worker and the Hart Family Cochlear Implant Education Coordinator will play an important role in supporting families and helping them to navigate these challenges.

I am so grateful to FHSR for creating and sustaining our social worker and educator positions. These two pivotal team members enable us to support families in ways rarely possible at medical centers. The result is parents who are enabled to advocate for their children, and children who become adults able and willing to contribute to society.

Nancy M. Young, MD

Head, Section of Otolaryngology and Neurotology
Medical Director, Audiology & 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

“A Day at Lurie Children’s” Provides Inspiration

Earlier this year, more than 200 school-based and early intervention professionals who work with children with hearing loss attended separate “A Day at Lurie Children’s” education programs. The program focused on cochlear implantation — in particular what happens at Lurie Children’s before, during and after implant surgery, and how school-based professionals may support these children. Up-to-date information about research being conducted by members of Northwestern University’s Pediatric Cochlear Implant Research Group was also presented. The attendees left with new insights from sessions on a variety of topics, and also participated in behind-the-scenes tours of the hospital.

The “A Day at Lurie Children’s” programs were developed by Hart Family Cochlear Implant Education Coordinator Stacy Simek, whose position is supported by FHSR. The sessions were an outgrowth of a similar event Stacy organized in 2013 for speech language pathologists. After several deaf educators heard about the event, they contacted Stacy about hosting a similar program for teachers.

“I go out to educators’ ‘homes’ all the time to see what they do,” says Stacy, who spends much of her time meeting with teachers and school administrators and observing children with hearing loss in their classrooms. “We thought it would be nice to invite them into our ‘home,’ and the feedback was overwhelmingly positive.”

At the day-long sessions, Stacy explained how she works with families of children with cochlear implants to secure the most appropriate education environment for them. A session focusing upon auditory skill development for children before and after cochlear implantation was led by several implant team speech pathologists who specialize in aural rehabilitation. Beth Tournis, audiologist and Cochlear Implant Program Coordinator, and Anne Murphy, the program’s former social worker, participated in a lively “Q&A” session, and a child life specialist explained how she and other members of the Surgical Services Department



School-based professionals at the “A Day at Lurie Children’s” education day pose with Audiology and Cochlear Implant Program Medical Director Nancy M. Young, MD, after watching her perform cochlear implant surgery via a real-time video feed.

support families on the day of surgery to alleviate their anxiety.

For many, the biggest “wow factor” was provided by a live video feed of a cochlear implant surgery performed by the Audiology and Cochlear Implant Program’s Medical Director, Nancy M. Young, MD. Afterward, Dr. Young was greeted with a standing ovation when she joined the attendees.

Among those cheering was hearing itinerant teacher Tracy Aleckson. “Watching Dr. Young perform surgery was fascinating,” she says. “Many of my students are patients of hers, so getting to meet her was a bonus. Additionally, I learned some new strategies from the speech pathologists to incorporate into my lessons.”

The second “A Day at Lurie Children’s” event, tailored for early intervention providers, was co-sponsored by the State

of Illinois’ Hearing and Vision Early Intervention Outreach (HVEIO) organization. HVEIO’s Program Coordinator, Gail Olson, attended the conference and helped secure sign interpreting services for attendees. The program also featured a presentation on auditory neuropathy spectrum disorder, an uncommon and challenging hearing disorder Lurie Children’s Audiology and Cochlear Implant Programs have special expertise in identifying and managing.

Stacy says the Audiology and Cochlear Implant Programs plan to host similar education days in 2015.

“It’s important for our team to reach out to the professional community to share the latest advances and techniques to improve the lives of children with cochlear implants,” says Stacy. “After all, we’re all working toward the same goal.”

Implants Give Raymond the Gift of Music



Born with severe to profound hearing loss, 11-year-old Raymond Lo loves to play violin.

Eleven-year-old Raymond Lo unpacks his violin and, a bit nervously, begins to play an etude for a small audience in one of the audiology suites at Lurie Children's. While he starts out a bit shaky, Raymond gains confidence as he plays. By the end, the shy 6th grader, who was born deaf, has a huge grin on his face. His mom, Chui Tse, beams with pride at her son, who has made huge strides thanks to his cochlear implants. Raymond is thriving academically in mainstream classes, and communicates orally in both English and Cantonese.

Joining in on the applause is Beth Tournis, Lurie Children's Cochlear Implant Program Coordinator and Raymond's audiologist since he was a toddler. Until today, Beth had never heard him play his violin.

Raymond was diagnosed with severe to profound hearing loss after failing his newborn hearing screening. He was identified early as a candidate for cochlear implantation, and when he was 2½ Raymond underwent

implant surgery on one ear at Lurie Children's.

When Raymond first began playing the violin, he experienced feedback from the hearing aid he used in his other ear, and struggled with his playing. Raymond says his hearing markedly improved after his second ear was implanted when he was 9 years old.

"Now I understand what people are saying better, because it helps me separate sound from noise," he says. "It has also changed the way I play violin, and made me better. Now I'm playing in an orchestra, and I really like it."

For Raymond's mom, what may seem ordinary for most 11-year-olds seems extraordinary for her son.

"Without Dr. Young, Beth and all the specialists at Lurie Children's, Raymond's life may have turned out very differently," says Chiu.

Watch a video of Raymond playing the violin at: <http://youtu.be/KPcC4GVV54s>.



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Video Celebrates FHSR's Legacy

FHSR has produced a new video to increase awareness of the organization in the community. Using archival material, it chronicles the Foundation's history from the early 1950s to the present day. This film pays tribute to key members who had the vision and the drive to address issues facing individuals with hearing loss, at a time when resources and options were limited. Also new is an educational video for families of children with hearing loss about the benefits of cochlear implants and other devices.

**Foundation for Hearing and Speech
Rehabilitation is on FACEBOOK!**

