Lurie Children's Campaign
for every child

Impact Report

Prepared for
The Foundation for Hearing and Speech Resources –
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Ann & Robert H. Lurie Children's Hospital of Chicago®
Stanley Manne Children's Research Institute℠

Ann & Robert H. Lurie Children's Hospital is honored that you share our vision to provide comprehensive care for young patients with hearing loss. With your support, the Audiology Department and Cochlear Implant Program remain among the top pediatric programs in the country that provide treatment and advocacy for children from birth until they transition to adult care. We are pleased to inform you about activities over the past year.

Delivering the Best Care

Lurie Children's pediatric audiology team excels at meeting the unique challenges in the care of each child and is intensifying research to bring forth better treatments. Known internationally for advancing leading-edge care, Nancy Young, MD, the Lillian S. Wells Professor in Pediatric Otolaryngology, is medical director of the hospital's Audiology and Cochlear Implant Programs and has grown our program into the world's largest. To date, experts have completed more than 2,220 cochlear implantations. In the last year—a time like no other due to the pandemic—our attention to children's needs remained unwavering and 115 implantations were performed.

Mom Lindsey with daughter Emma, 2, and Dr. Young, pre-pandemic

Protecting patients, families and staff from viral spread required new care protocols and safety measures for everyone in the hospital. Despite these added precautions that required extra time to prepare for each patient visit and procedure, Lurie Children's Section of Otology/Neurotology maintained the service necessary for every child who needed our expertise, diagnosing 194 children with permanent hearing loss and initiating treatments in the last fiscal year.

In addition to our main hospital, Lurie Children's conducts outpatient general audiology services in Westchester, Northbrook and Skokie. In the last year, these locations proved very important for patient families who were hesitant to come downtown but still needed care for their child. In addition, telehealth remained an essential way to reach patients. Our aural habilitation specialists continued to provide listening and spoken language therapy via this secure connection, and Dr. Young and Stephen Hoff, MD, also used this platform to visit patient families who are established in our program when an examination of the ear was not necessary.

Honoring the impact she has made in the field at Lurie Children's and globally, Dr. Young received the 2021 Women in Otolaryngology Helen F. Krause, MD Trailblazer award in July, given in recognition of individuals who further the interest of women in otolaryngology.

Expanding Cutting-Edge Care

Lurie Children's is the only pediatric hospital in Illinois and one of the few in the nation to offer HearLab, a new type of clinical evaluation to improve management of children with hearing loss who use amplification. This technology measures cortical brain responses to amplified speech sounds and is particularly useful in analyzing very young children and other children who are difficult to evaluate for other reasons, including auditory neuropathy, developmental delays and behavioral disorders. HearLab points our experts in the right direction to identify auditory thresholds, which is valuable information to determine each child's care plan to improve hearing. In some cases, the answer may involve adjusting a hearing aid, and in other cases the answer can be more complicated—but without HearLab, the right treatment can be extremely difficult to identify in some patients.

Due to the Cochlear Implant Program's extensive expertise and desire to serve more children, the team is serving a new group of patients with single-sided deafness or asymmetric hearing loss. More candidates for this surgery are coming to Lurie Children's for evaluation. Thus far, we have performed implantation for 22 patients with single-sided deafness.

In addition, Lurie Children's remains the largest provider in Illinois of auditory brainstem response (ABR) tests. In 2021, we conducted 334 sedated tests and 195 natural sleep tests, a marked increase in tests over the prior year. This test provides an objective, reliable means of diagnosing hearing loss in infants and young children, as well as older children with developmental challenges, for whom testing with behavioral methods is not accurate.

Loaner Hearing Aid Program

Aided by your generosity, Lurie Children's was able to provide loaner hearing aids to patients. In order to provide only top-quality hearing aids, we continuously cull our device stock and remove older ones from our inventory. Hearing aids that are loaned out are important for patients to bridge the gap between evaluation and actual cochlear implantation and while children have their hearing aids repaired or replaced. Over the course of FY21, 200 hearing aids were lent out to 150 patients who were all grateful for this opportunity to have a device temporarily.

Advocating for Children in School:

Hart Family Cochlear Implant Education Coordinator

Over the past year, remote learning and other circumstances posed difficulties for children with hearing loss, Jen Haney, MA, DT-H, the Hart Family Cochlear Implant Education Coordinator, has been a true patient champion, constantly in contact with families and schools to identify each child's set of strengths and areas of need so patients have appropriate supports in place. In FY21, Jen assisted 192 students, conducted 47 meetings with school staff to help patients, and attended 14 conferences.

Being a student is central to the lives and identities of children. Jen aids families, provides information on appropriate accommodations necessary at school, and assists in amending students' IEPs if necessary in order to optimize their learning. She has been a key resource for parents, education professionals and therapists who needed to adapt to virtual learning and in-person learning with protective safety measures in place. Thinking innovatively, Jen has guided students and schools to adopt new strategies that led to improved learning and obtaining vital resources. Below are some of the insights and guidance for resources that Jen has provided to teachers, students and families, bringing comfort and workable solutions during this difficult time:

- Clear masks, if preferred by students, who rely more heavily on facial cues
- Captioning for lesson materials, such as videos and live lessons, at no cost
- Recording lessons and/or providing notes for students who have difficulty keeping up with content/taking notes while listening to lessons
- Instruction for teachers for on-screen placement of interpreters for optimal impact
- Creating a blog post at the beginning of the school year for FHSR to provide guidance for effective learning when students returned in person
- Troubleshooting to ensure assistive listening devices were available to patients and set up on home computers
- Addressing or revising a child's listening-based IEP goals
- Instruction for therapists on parent coaching techniques and strategies that improve telehealth visits.

For Linda, a 7-year-old girl with a complex medical history and a cochlear implant, Jen made sure she was able to learn at school and placed in the best environment for her abilities.

The girl's family, who has socio-economic barriers to care, could not get their daughter to wear the external component of the cochlear implant. Compounding this difficulty, the external device had been lost several times. Jen partnered with the family and school to create a plan to ensure the child had a speech processor that could be kept at school. She also obtained consent from the parents to send any necessary equipment to school so they could assist with troubleshooting as needed. In addition, Jen coached the school's hearing itinerant on goals for Linda's auditory skill development and language targets. Initially, this student was in a special education classroom with hearing peers, but as she made progress by using her cochlear implant and improved her listening and signing skills, she was transferred to a more appropriate program specifically for children with hearing loss. With Jen's oversight, Linda is now wearing her speech processor consistently at school. Jen continues to work with

the family to find ways for this young girl to always wear the device at home as well, so her speech and listening skills can be optimized. (Name changed to protect privacy)

To respond to patient needs with the latest and best guidance, Jen constantly stays informed about new developments in her field and spreads her knowledge to others who care for children with hearing loss. In the last year, she attended virtual conferences in parent coaching to update her knowledge. In addition, she learned from another conference presented by an audiologist about supporting children with hearing disorders when they are at school, including new challenges the pandemic has created. She also gleaned new trends from breakout sessions of the American Cochlear Implant Alliance.

Jen stretched her professional learning by disseminating knowledge to early intervention therapists who help parents enhance interactions and coaching with their children. She also provided online trainings for staffs at individual schools. Jen's expertise has qualified her to play a role in some of the state's leading advocacy organizations for the deaf and hard of hearing community, and also utilize her expertise on the national level. Recently, this has included the CHOICES for Parents Advisory Board, Illinois Service Resource Center Leadership Committee, and the Illinois Joint Commission for Infant Hearing Work Group. She also worked with several cooperatives including NSSEO, SASED, SEDOL, ECHO, SWCCCASE, CASE, as well as educational programs for Child's Voice, Chicago Public Schools and the Archdiocese of Chicago.

Research Highlights

The foundation for better outcomes lies in research, and Drs. Young and Hoff are constantly pursing improvements in pediatric treatments.

The cochlear implant team is leading a multi-institutional FDA clinical trial sponsored by MED-EL corporation. The aim of this study is to expand approved indications to include children with more hearing difficulties and at younger ages. Implantation during infancy would be a life-transforming technology for these children. In Australia, the norm for the average age at surgery is between 6 and 9 months. In the U.S., this treatment may not be covered by public and private insurers, in part because cochlear implants are not FDA-approved for this age range. Dr. Young presented preliminary data from Lurie Children's participation at the American Cochlear Implant Alliance 2021 and the 15th European Symposium on Pediatric Cochlear Implantation.

The implant team is also participating in a multi-center FDA post-market study of the MED-EL cochlear implant for children with single-sided deafness and asymmetric hearing loss. The purpose of this study is to evaluate long-term outcomes of children and adults receiving an implant for these new indications.

Dr. Young leads an international collaboration using artificial intelligence to predict language based on brain structure and function identified by magnetic resonance imaging (MRI). The study involves multiple centers across the U.S. with the goal of predicting language abilities for each individual child. Forecasting individual outcomes is an important first step toward development of language therapy

to optimize learning for English and Spanish-speaking children, in addition to studying the effectiveness of intensive parent-centered therapy for children at risk for poor language development. Results from this work were also presented at the American Cochlear Implant Alliance 2021.

In December, Dr. Young's study in the journal *Otology & Neurotology* reinforced that cochlear implantation clearly benefits children with autism spectrum disorder (ASD) who have hearing loss. The study reported long-term outcomes of the largest number of children with ASD who received a cochlear implant, with mean follow-up of 10.5 years, and found that cochlear implants helped them understand spoken language and enhanced social interactions with their families. The majority (73 percent) of children in the study consistently used their cochlear implant throughout the day, of whom 45 percent developed some understanding of spoken words with hearing alone and without visual cues. Forty-five percent also used spoken language to some degree as part of their overall communication. Eighty-six percent of children followed were reported by parents to have improved social engagement after implantation. Responding to a survey that was part of the study, one parent reported: "Without his implant, he was stuck in his own little world, no sound, no eye contact with others. The implant brought his personality out to us."

Recognizing Dr. Young' extensive research background for patients with hearing loss, the National Institute on Deafness and Other Communication Disorders (NIDCD) asked her to participate in their planning process for the 2022-2027 strategic plan, which will prioritize areas for research.

With Sincere Gratitude

As protectors of children, Lurie Children's is addressing today's most pressing challenges in pediatric audiology. Thank you for championing their needs through your support. Your support is empowering a higher standard of care for these children that will impact the rest of their lives. Thank You!