

Lurie Children's Campaign

for every child

Impact Report

Foundation for Hearing and Speech Rehabilitation
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 Ann & Robert H. Lurie
Children's Hospital of Chicago®

Stanley Manne
Children's Research Institute™

Thanks to your essential contributions, the Audiology Department and Cochlear Implant Program at Ann & Robert H. Lurie Children's Hospital of Chicago can provide crucial support for children and adolescents with hearing loss. The Foundation for Hearing and Speech Rehabilitation's investment enabled the program to quickly adapt to new ways of providing care, while continuing to transform the lives of patients. With gratitude for your support, we are pleased to present this update.

Superior Care for Children with Hearing Loss

The Lurie Children's pediatric audiology team is among the top in the nation because they rise to the challenge, meeting the unique needs of each child and advancing groundbreaking research. Globally renowned otolaryngologist Nancy Young, MD, Lillian S. Wells Professor in Pediatric Otolaryngology, leads Lurie Children's Cochlear Implant Program and played a major role in making it the world's largest: to date it has performed over 2,100 implantations.

Over the past year, our staff has enhanced their professional competencies and improved access to treatment for more children. Five members of our aural habilitation team achieved advanced certifications through rigorous training that goes well beyond basic licensure requirements. Their new credentials make our program one of the few in the country with this level of expertise for children with hearing loss. Our third clinical outpatient site for general audiology recently opened in Skokie to serve young patients closer to their homes. The Skokie location includes two audiology booths and can accommodate unsedated auditory brainstem response (ABR) tests for newborns and older children with developmental or behavioral challenges. In the future, hearing aids will be dispensed from this new location. Outpatient services are also available in Westchester and Northbrook.

During the COVID-19 pandemic, children's audiology needs remain constant. Like every other area of the hospital, Lurie Children's Section of Otolaryngology/Neurotology was impacted substantially by the

pandemic and implemented additional precautions to keep patients and staff safe. However, despite these challenges, in the past year, we diagnosed and treated 198 additional children with permanent hearing loss and 117 cochlear implantations were accomplished.

Enhancing Clinical Services

Earlier this year, Lurie Children's became one of the first pediatric audiology centers in the country 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 the potential of a child's brain to discern sounds in spoken language. Although implementation of HearLab was delayed by the pandemic, the team conducted this evaluation on infants with Auditory Neuropathy Spectrum Disorder, brainstem auditory pathway dysfunction, and children with developmental delays whose hearing with and without hearing aids may not be accurately assessed through behavioral tests. HearLab can reveal how to best manage a patient's care and point our experts in the right direction to improve a child's hearing. For example, in one recent case of a child whose improvement in hearing could not be evaluated in the sound booth, HearLab demonstrated that the child's brain was not receiving information about certain speech sounds. This situation was resolved by adjusting the child's hearing aid, which would not have been done without the information provided by this advanced technology.

The Cochlear Implant program is one of the few in the U.S. with experience in cochlear implants for children with single-sided deafness. Following last year's FDA approval of the MED-EL Synchrony Cochlear Implant for this patient population, more children with deafness in one ear have had access to this treatment. Lurie Children's is providing education to parents and professionals about this important treatment which improves hearing in background noise and provides awareness of sound location.

Lurie Children's remains the largest provider in Illinois of auditory brainstem response (ABR) tests and conducted 252 tests in FY20. 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. In addition to ABRs done during natural sleep for young infants, this evaluation is done under anesthesia for older infants and children.

The pandemic has posed unique challenges throughout the hospital to continue providing care while keeping patients safe. When innovation became necessary to deliver treatment, our team responded. Our physicians began providing care and counseling by telemedicine. Notably, our Aural Habilitation specialists also began providing listening and spoken language therapy through telehealth, in addition to in-person appointments. Telehealth is done by a live, secure (HIPPA compliant), video and audio link between the therapist. Virtual therapy with younger children is accomplished through coaching of parents on implementing activities to build their child's listening and spoken language skills.

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, devices more than five years old were recently removed from our inventory this year. For this reason, FHSR's donation this year to this program was especially welcome. Your donation was used to purchase 10 additional hearing aids that helped us fulfill the greatest needs for patients. In the past year, about 25 percent of hearing aids were loaned to patients undergoing evaluation for cochlear implants and the rest helped children hear while their hearing aids were being repaired or replaced. Our loaner hearing aid program was very active as aids were loaned 328 times to children during the past year. We hope to add additional types of hearing aids to our stock in the future including CROS technology for children with single-sided deafness, super power, and bone conduction hearing devices.

Ellie's Story: Reaching for the Sky

Ellie Graeber never let the profound hearing impairment in both of her ears get in the way of her goals. Ellie wore hearing aids until she was 5, when Dr. Young performed her first implant surgery. At that time, implantation of both ears was not yet being done. For years, Ellie functioned with a cochlear implant on her left ear and a hearing aid on her right ear.

Growing up, she did not let her hearing impairment hold her back: she was the only girl on the football team and became a star basketball player in high school. At age 14, Ellie received the implant in her right ear. To help improve her hearing after surgery, she watched TV with captions to help train her newly implanted ear to understand words she hadn't been able to before. Her hearing in her right ear improved greatly, and so did her ability to understand what people were saying in noisy situations.

As a teen, Ellie dreamed about becoming a flight attendant, specifically for Southwest Airlines. When she turned 20, she applied for the position, stating in her cover letter that her life's greatest accomplishment was overcoming her hearing loss.

Ellie officially became a Southwest Airlines flight attendant in October 2019, a feat accomplished by less than 5 percent of applicants. "It's my dream coming true," she said. At her training graduation ceremony, Ellie received the airline's "Warrior Spirit" award, presented to the trainee who "best exemplifies striving to be the best, displaying a sense of urgency and never giving up." She credits her "awesome audiologist," Beth Tournis, AuD, CCC-A, at Lurie Children's for helping her achieve her dreams.



"Don't let anybody tell what you can or cannot do. It may require hard work, but it's 100 percent worth it." - Ellie

Research Highlights

Demonstrating exemplary leadership, Dr. Young was recently elected to the American Otological Society (AOS) Council, the leadership body of the organization. AOS is the second oldest medical society in the U.S. and a leading organization supporting groundbreaking hearing science and translation into medical practice. Dr. Young will serve eight years on the Council, including five years as Education-Director and one year as President. AOS was instrumental in establishing the fields of otology and neurotology and has awarded grants that enabled many scientists to move their research forward with funding from the National Institutes of Health (NIH). Her involvement with AOS started in 2007, when she became the tenth women surgeon to join the society.

In October 2020, Dr. Young was among a select group of national experts who spoke at Duke University's prestigious virtual conference "Harnessing the Power of Artificial Intelligence in Otolaryngology & the Communication Sciences." She presented on her global research collaborative to use machine learning algorithms to improve language acquisition following cochlear implantation. Dr. Young is principal investigator in this study to develop predictive models of language acquisition for patients with cochlear implants based on pre-surgical brain scans. The long-term goal of this research is to develop custom brain-based therapy programs to improve language development. Dr. Young is submitting a grant application to the NIH to expand the study to more sites, to build models to predict language outcome in Spanish speaking children and to assess the effectiveness of a specific type of therapy for implanted children.

During infancy, a baby's brain and auditory system is rapidly growing, and cognitive and physical abilities are being developed. Some babies are not helped by hearing aids and require cochlear implants to perceive and produce sound and speech. However, many children do not receive implants until after they are 1 year old. Dr. Young is leading a multicenter FDA clinical trial to make cochlear implants an option for infants 7 to 11 months of age and other children with a broader range of hearing difficulties. To date, nine infants have received bilateral implants by Dr. Young and Stephen Hoff, MD, and at other medical centers involved in this ongoing FDA clinical trial.

MRI imaging is an increasingly important diagnostic tool for children with cochlear implants, and Dr. Young has validated that children implanted with a device containing a diametric magnet may undergo MRI safely. Children who underwent MRI with this type of magnet within their implant experienced no complications or discomfort and no need for sedation or anesthesia due to the presence of the magnet. This study was published in *The Laryngoscope*. The results contrasted with an earlier study published by Dr. Young in which MRI of children with a standard axial magnet caused magnet displacement or other problems in 30% and in which all children required sedation because of discomfort.

Supporting Children in School:

Hart Family Cochlear Implant Education Coordinator

In FY20, Jen Haney, MA, DT-H, the Hart Family Cochlear Implant Education Coordinator, addressed incredible challenges created by the pandemic and conversion to online learning in schools. Jen was a key resource for parents, education professionals and therapists who suddenly needed to adapt to virtual learning and telehealth. She provided resources and strategies that contributed to effective support for patients during this difficult time.

- Many parents are feeling overwhelmed working full time from home and supporting their child's e-learning. Jen has encouraged parents to make sure their child's learning accommodations are being met and voice concern if children are feeling overwhelmed by school work. Parents are also struggling with detrimental changes in their child's emotions or behavior related to the pandemic. She helps families create routines, schedules, discussions about feelings and positive reinforcement to weather these challenging times.
- Special and general education teachers rely on Jen to help them best support their students. She provides information on assistance such as interpreters, assistive technology, captioning and IEP accommodations that helps students with hearing loss to succeed in e-learning and auditory skill development. As new e-learning resources become available almost daily, Jen is on top of new developments in case they can assist in meeting students' unique needs.
- Early intervention therapists turn to her to provide meaningful sessions to families who are working with their young children. Jen trained to provide telehealth sessions for children ages 0-3 years and is educating other therapists on best practices in this format. She is also helping families whose growing children are transitioning to school and feeling stress that has been heightened by the pandemic.

Part of Jen's mission is to elevate skills in professionals who serve children with hearing loss. She organized, led and participated in several well-attended events to expand knowledge in the field including:

- A "Mind Matters-Fostering Theory of Mind in Children with Hearing Loss" workshop helped pediatric professionals learn to help children with hearing loss develop stronger social-emotional skills. Many children with hearing loss are at risk for deficits in this area. The program featured a speaker from MED-EL Corporation and was attended by more than 100 professionals.
- A pre-pandemic troubleshooting lab at the annual conference of Illinois Teachers of the Deaf and Hard of Hearing gave educators the opportunity to learn about new technology from different cochlear implant manufacturers. A hands-on component instructed participants to

learn how to correct equipment. This lab prepared educators to recognize and address common equipment problems in the classroom that interfere with children's abilities to hear.

- Jen met with numerous organizations serving Illinois children who are deaf or hard of hearing to provide guidance about trainings for parents and professionals, and upcoming community events for patients with cochlear implants. The statewide organizations Jen assisted included the coalition CHOICES for Parents, the Illinois Service Resource Center leadership team and Illinois Teachers of Deaf and Hard of Hearing.
- Jen organized Lurie Day 2020 to educate professionals about early intervention, and 115 attendees registered. Unfortunately, this conference was canceled due to the pandemic. Jen hopes to be able to resume this event when the pandemic is under control.

Gabriel's Story: Success at School

At age 11, Gabriel moved to the United States with his family. He had received cochlear implants at Lurie Children's due to the progression of his hearing loss. Prior to moving to the US, Gabriel was successfully educated in his native spoken language in a classroom with hearing peers. But in the US, his elementary school recommended that he be put in a classroom in which sign language was the primary mode of communication. This recommendation was based upon his inability to communicate with teachers and peers, which was primarily due to his lack of fluency in English, not his hearing loss. Jen helped his family advocate for Gabriel's placement in a classroom for English language learners. She also connected the family with a therapist who provides listening therapy via telehealth in his native language to allow Gabriel's understanding of spoken language to continue to improve.

With Thanks

With help from committed partners like you, Lurie Children's will keep doing everything possible to serve children with hearing loss. The programs supported by the Foundation for Hearing and Speech Rehabilitation have become national models for comprehensive care that has changed the lives of children. Thank you for recognizing the importance of our work for every child with hearing loss.

