Making the most of the latest advances in technology and surgical techniques, Lurie Children’s Cochlear Implant Program continues to serve a growing number of children—providing improved hearing, quality of life, and a future full of possibility.

Today implant candidates may have useful hearing of low pitch sounds, but little ability to hear the higher pitch sounds critical to understanding spoken language, especially when background noise is present. Advanced electrode arrays placed into the inner ear with special surgical techniques make it possible to preserve natural lower frequency hearing. New “electro-acoustic” speech processors have hearing aid technology built in to amplify low pitch sounds, while simultaneously providing high pitch hearing with electrical stimulation. The result is children who hear and understand with greater ease.

“In order for children to reap the benefits of this amazing technology, it requires tremendous expertise from the audiologists programming these devices,” explains the program’s Medical Director, surgeon Nancy M. Young, MD. “Fortunately, Lurie Children’s has six experienced pediatric audiologists whose primary role is to evaluate and program implanted children.”

Three-year-old Adam Buresh was diagnosed with hearing loss as an infant. “One of our chief concerns initially about cochlear implants was that Adam would not be able to hear anything unless the processors were on and working correctly,” says Adam’s dad, Chris. “It was a safety issue for us.”

Adam received cochlear implants a year and a half ago. He went from 700 to 1,700 vocalizations a day within three months after his implants were activated.

“He began to communicate verbally more than he ever had before,” says Chris. “And we were thrilled that he maintained so much residual hearing that he was aware of sounds without the processors. That was a huge blessing for us.”

Nine-year-old Hannah Wong experienced progressive hearing loss that was managed with hearing aids until that technology was no longer enough. Before implantation, she

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was increasingly frustrated because she had to concentrate very hard to hear. Despite that effort, she was still missing much of what her teacher and friends were saying. “We were told about new technology that helps retain natural hearing, and we knew Dr. Young was doing more of these procedures,” says Hannah’s dad, Calvin. Hannah had her first implant in November 2015, and her second this past July. She retained significant lower frequency hearing after each surgery, and was fitted with electro-acoustic processors. Her mom, Beth, says Hannah’s progress has been extraordinary. “She started understanding speech right away, and in less than two months Hannah was up to full comprehension,” she says. “It’s been really exciting to see how fast she is progressing.”

After her first implant, Hannah was listening to music on her iPod one day and told her mom, “I can understand the words now, and I used to just like the beat!” Calvin says he and Beth were nervous about the surgery. “But the whole process was so smooth, and the retained hearing has been very impressive,” he says. “We are so thankful for this technology and for the whole team at Lurie Children’s.”

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noise and to help professionals understand the length of time these devices are worn by children. Cochlear implant technology and surgical techniques continue to advance. Hearing preservation is now possible, as illustrated by Adam and Hannah’s stories in this issue. Electro-acoustic speech processors that take advantage of preserved low frequency hearing are now available to a growing number of implanted children. The result is improved understanding of speech with less effort, especially in background noise. Improved ease of listening reduces the significant fatigue and frustration that so many children with hearing loss experience in social and academic settings.

The existence of technology does not guarantee early intervention — which is so critical to improving listening and language outcomes. Parental acceptance of their child’s hearing loss and need for intervention often requires professional counseling and emotional support. Once parents are ready to move ahead, many additional challenges may arise. For example, we are witnessing a dramatic increase in denials from children’s health care payers. Assisting parents with this challenge is time consuming but crucial. Working with early intervention providers and schools unfamiliar with ever-changing technology is also not typically part of standard medical care, but is essential to improving the lives of children with hearing loss.

The need for our social worker and educator has never been greater! These professionals are funded solely by FHSR. They provide direct support to parents and serve as a bridge between Lurie Children’s, community providers of services and the family.

Please give generously to FHSR. Help us to continue to change the outcome for our kids!

Nancy M. Young, MD

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Moving Toward Music with Richard Reed

Please join the FHSR Board as they present legendary blues musician and cochlear implant recipient Richard Reed on Wednesday, February 1, 2017, from 6:30 to 9 p.m. at The Music Center at Columbia College, Chicago. Richard will share his story of hearing loss, implantation and its impact on his life of music. For more information, please visit fhsr.org.
Jennifer Haney, M.Ed., does all she can to eliminate educational barriers for children who receive a cochlear implant at Lurie Children’s. A former teacher of deaf and hard of hearing children who is also an early intervention therapist, Jennifer has special expertise in listening and spoken language development and is fluent in sign language.

Jennifer is the Hart Family Cochlear Implant Education Coordinator, a position supported by FHSR. Since joining the cochlear implant team in December 2015, she has served as an essential bridge between parents, early intervention therapists, teachers and school administrators.

Her role is wide-ranging. Jennifer spends time in the medical center meeting with families, in the classroom observing children and with school-based and early intervention professionals in the community. She teaches educators about integrating auditory skills development techniques into the curriculum. Jennifer is also charged with organizing the “A Day at Lurie Children’s” educational program for community-based professionals working with pre-school and school-aged children.

She meets with parents to discuss their goals for their child after implantation and to provide therapy and educational recommendations. Jennifer develops an initial report that is shared with the family, the school and the implant team to ensure that all stakeholders understand her recommendations.

Making families aware of the best educational options for their child’s specific situation can make all the difference. For example, Jennifer worked with the family of a child whose progressive hearing loss had gone unrecognized for several years. When finally diagnosed, he still had spoken language, but his untreated hearing loss prevented him from developing the academic skills of his third grade hearing peers. He received a cochlear implant and, with Jennifer’s assistance, was placed in an oral education classroom. This setting supports listening, language and academic skills of children with hearing loss until they are ready to succeed in a mainstream class. He has made tremendous progress, and his path in life has been forever changed.

“Being able to meet and support a wide variety of families in varying stages of their child’s journey and assisting in their educational success is very gratifying,” says Jennifer. “Our team here is really amazing.”

With the goal of creating a community for all children with hearing loss, the FHSR’s Associate Board is made up of young professionals dedicated to working with children who are deaf or hard of hearing and include some of the first patients assisted by FHSR programs. This dynamic group of individuals has come together to expand the Foundation’s reach.

“I envision FHSR as a resource for families of children with hearing loss that facilitates a positive sense of community in the Chicagoland area,” says Kora Kilpatrick, an early intervention speech language pathologist and teacher of children who are deaf or hard of hearing.

Echoing this statement, Jamie Davidson, also a teacher of the deaf and hard of hearing and a hearing itinerant, says, “One of the biggest challenges for kids with hearing loss is connecting with other children like them. The FHSR’s Associate Board has the ability to help facilitate the connections between these kids who have similar experiences.”

Alexander Mott, one of the first generation of pediatric cochlear implant recipients, knows firsthand the importance of creating connections with other kids.

“As a pre-teen it really helped me to attend events where there were other cochlear implant users and hearing aid wearers who were my age,” he says. “It made me feel like I was not alone. By serving on the Associate Board, I can help ensure that kids with hearing loss don’t feel isolated, and instead feel like they’re part of a fun, dynamic group.”

FHSR is very excited for the coming year and the outstanding activities driven by this group of engaging adults, including creating family-oriented fundraising events and a mentorship program.
The diagnosis of hearing loss can be fraught with enormous worry and stress for the child’s family. While every member of Lurie Children’s Audiology & Cochlear Implant programs is dedicated to achieving the best possible outcome for each child, social worker Christine Berg, LCSW, focuses on the entire family’s needs.

“I tell families I am here for them, and they are so grateful,” says Christine who, thanks to support from the Foundation for Hearing and Speech Rehabilitation, provides crucial services for these families.

Being present when a child is diagnosed with hearing loss enables Christine to form lasting partnerships with families. She develops a psycho-social assessment of each family to understand the strengths and stressors they are dealing with. This assessment is an essential tool in determining how to best support and work with each family.

“Having a professional who is knowledgeable about hearing loss and social services, and is professionally trained to help families manage stress and become advocates for their children, is invaluable,” says Medical Director, surgeon Nancy M. Young, MD. “Parents are often devastated thinking that the future they had envisioned for their child might not be possible. But the good news is, that future may very well be possible after all. Christine does a great job of providing resources, as well as emotional support, for families.”

Chicago is a very culturally diverse city. Understanding cultural differences may be crucial in gaining parents’ trust. Trust is often the key to parents following through on their child’s treatment plan. For example, one patient’s mother, who came from a country where hearing loss is stigmatized, had great difficulty accepting the diagnosis and the need for her child to wear hearing aids. With Christine’s help, she gradually became more comfortable – which translated into consistent device use with improvement in listening and spoken language, as well as more joy in their relationship.

“It took a long time, but it was a huge victory,” says Christine. “I am an eternal optimist, and I always look for the hopeful. But to see that this family finally was so invested in their child’s care and taking our recommendations was just wonderful.”

Social Worker Christine Berg provides crucial services for families of children diagnosed with hearing loss.