Message from the Chair

Oliver F. Adunka MD / William H. Saunders MD Endowed Professor
Vice Chairman for Clinical Operations
Director, Otology, Neurotology & Cranial Base Surgery
Department Otolaryngology, Head & Neck Surgery
& Neurosurgery
The Ohio State University Wexner Medical Center / oliver.adunka@osumc.edu

It was great to see so many of you in person during our May CI2022 conference in Washington DC. The ACI Alliance Conference Program Committee did a fantastic job organizing an engaging conference with many exciting topics. I would like to specifically thank Drs. Lisa Park and Matthew Bush, along with the members of the Program Committee for their hard work. Together and in a collaborative fashion, they have assembled a multidisciplinary program that mirrors the constituency of our organization. We were extremely excited to have a diverse group of invited speakers to cover a broad range of topics. Some comments made by attendees in the follow-up survey include:

• The content of this meeting offered numerous novel topics and was quite different than previous meetings.
• The emphasis on (Re)habilitation, such as with the Rehab Connect Forum, was very relevant and necessary.
• I appreciated the discussions regarding the need for change, tools to provide efficiency without jeopardizing patient care, and updates on both SSD and pitch-matching.
• I liked that the topics covered including some areas that haven’t been seen so much in the past (i.e., health disparities, emotional/psych-social health of CI recipients).
• I loved the Stump the Experts panel! The keynotes were fantastic!

With the conference in our rear-view mirror, it’s time to focus back on some of the ACI Alliance core businesses. As a reminder, the ACI Alliance is a not-for-profit membership organization created with the purpose of eliminating barriers to cochlear implantation by sponsoring research, driving heightened awareness and advocating for improved access for patients of all ages across the US. While utilization rates have slightly increased, we need to continue to remind ourselves that we have a long way to go. This is especially pertinent in the face of the recent CMS announcement of a proposed coverage expansion of cochlear implants under Medicare, which was led by Drs. Zwolan and Buchman, two previous leaders within the organization who continue to contribute in important ways. Such positive changes will also expand the potential constituency of our organization.

Given this ever-changing landscape, we felt a need to modernize our organization’s strategic plan. While this plan has been updated periodically, we are embarking on an important update from that original effort that will guide the ACI Alliance into the next phase of its existence. As part of this process, we are soliciting input from current and previous leadership, our supporters, and, of course, our members. Please be on the lookout for specific communications as we are eager to hear your feedback.

Again, it was great to see everyone in Washington DC and we look forward to another great year where we can advance cochlear implant related research, advocacy, and awareness. Lastly, I would like to paraphrase a comment made by one of the cochlear implant industry leaders who remarked on the enormous breadth and depth of the issues the Alliance is dealing with. She further commented that there is nothing like this organization anywhere else in the world and how much our organization has grown and matured over the past decade. While it is certainly reassuring to hear such positive feedback, we realize that we will need to continue to mature and adapt as our field changes. As such, I hope that you can help us shape the future of the American Cochlear Implant Alliance.
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Lights, camera, action! Late Spring and Summertime bring the big blockbuster movies to the silver screen. The sights, sounds, and celebrities leave summertime moviegoers with plenty of thrills and chills. The ACI Alliance recently wrapped up our blockbuster event of the year, CI2022, in May in Washington, DC and it was a huge success. This event provided the cochlear implant community with a star-studded program featuring cutting edge research and technology updates. Attendees were able to channel their inner superhero as the Incredible Hulk, Lou Ferrigno, connected his inspiring story with a call to increase public awareness of cochlear implantation. Our Niparko Memorial Lecturer, Dr. Rene Gifford, and keynote speakers, Drs. Sarah Bowe and Sumit Agrawal, were our red-carpet celebrated guests and provided engaging and eye-opening presentations. As we’ve persevered through the virtual valleys of pandemic meetings, this 4-day in-person meeting was a true crowd pleaser and evidence that the CI community is back and stronger than ever.

As your CI Program Committee, we’re just starting to come down from the excitement of this in-person meeting. It was such a pleasure to collaborate, share, and debate with everyone again. An event like CI2022 doesn’t occur without an immense amount of effort. Thank you to everyone who helped make CI2022 such a success. We’d like to recognize our fantastic Board of Directors and the CI2022 Program Committee who spent hundreds of hours planning and producing this conference. The CI2022 Program Committee was co-chaired by Dr. Lisa Park from the
University of North Carolina Chapel Hill and Dr. Matthew Bush from the University of Kentucky. We also extend our deep gratitude to our Executive Director, Donna Sorkin, who is our conference compass and always kept our efforts on track. Last, but not least, we are grateful for the CI community who attended and/or contributed content to this meeting. We received over 340 stellar abstracts from 31 countries and 150 different institutions. Over 1200 of you joined us in person and 195 of our colleagues joined us virtually. This conference would never have been possible without these brilliant abstracts and the bright and shining faces of the attendees. Even though the conference has concluded, we are excited to promote the successes of this event as we feature recorded content from the conference on the ACI Alliance website and look forward to seeing top abstracts featured in a special supplement in Otology & Neurotology.
ACI Alliance hasn’t stopped to rest and is already at work planning our next big event, CI2023. We are pleased to announce that the CI2023 Program Committee is co-chaired by Drs. Kara Leyzac AuD, PhD from the Medical University of South Carolina and Aaron Moberly MD of The Ohio State University. The Program Committee, which is composed of a diverse transdisciplinary group of experts in cochlear implantation, has begun to develop an even more action-packed sequel to CI2022. The CI2023 meeting will occur June 7-10, 2023, in Dallas. The abstract site will open in August 2022 and the content of this event will be exciting and will appeal to a broad CI audience. Start making plans now to attend next year’s ACI Alliance blockbuster event in Dallas!
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The long-awaited proposed coverage expansion for cochlear implants was published on July 6. In addition to reviewing the October 27, 2020 complete and formal request with related research documentation, CMS conducted its own internal technology assessment. The Decision Summary includes reviews of published studies, a consensus statement, and a professional society guideline. Public comments provided further support for the expansion.

We are grateful to CMS for the thorough and open manner in which the National Coverage Analysis was conducted. American Cochlear Implant Alliance supports the CMS proposal for Medicare coverage of cochlear implantation when patients derive limited benefit from amplification as defined by test scores of less than or equal to 60% correct in the best-aided listening condition on recorded tests of open-set sentence cognition. The CI community enthusiastically endorsed the CMS proposal with 145 positive comments submitted. We are grateful to our members and particularly to ACI leaders Terry Zwolan PhD and Craig Buchman MD for their ongoing efforts to bring about improved patient access to CI.

**What comes next?**

Confirmation of the coverage expansion proposed on July 6 is expected in the Fall though the final decision is not known until it is published. ACI Alliance is developing materials to inform our various constituencies about the expanded opportunities for Medicare beneficiaries who may benefit including the broad audiology community, hearing health publications, and the general public via major media outlets. We will produce materials that our clinician members may adopt and utilize for outreach to local newspapers, TV, radio, and other sources of information. As the local experts who provide the CI intervention and view first-hand the benefits it provides to patients, you are well positioned to help us expand understanding of who may benefit from a CI and the life-changing nature of the intervention. Additionally, our CI CAN members (CI Consumer Awareness Network) will be encouraged to use the news of Medicare expansion to reach out to local news outlets and share their stories.

We will also be reaching out to Members of Congress who we interacted with during the May ACI Alliance on the Hill regarding the coverage change so that they may be aware of the positive way in which this important initiative concluded. We will thank them for their support of hearing healthcare generally and cochlear implants specifically. Though there is no other legislation impacting hearing at present, it is important to keep our work on access to appropriate care within their viewpoint.

A history of the ACI Alliance effort to expand cochlear implant candidacy under Medicare can be found on the website: [https://www.acialliance.org/page/MedicareExpansion](https://www.acialliance.org/page/MedicareExpansion)
Each year, we highlight our major accomplishments to celebrate what we have done together to expand access to cochlear implants. Highlights appear below; a comprehensive listing is available on the website: [http://www.acialliance.org/page/AboutUs](http://www.acialliance.org/page/AboutUs)

**Awareness**

- **Commissioned four papers:** ACI Alliance Task Force Guidelines for Clinical Assessment and Management of Cochlear Implantation in Children and Adults with Bilateral and Single Sided Deafness. The task forces each covered a specific population and candidacy: Adults with SSD or bilateral moderate-profound hearing loss and Children with SSD or bilateral deafness. Each task force included clinicians from across the care continuum. In 2022, papers on three of the topics published or accepted for publication; one paper in preparation. AudiologyOnline partners with us to provide a forum for presentation to the larger audiology and hearing health community where the papers were discussed. Began collaborations with audiology organizations to further extend dissemination.

- **Listening @ACI Alliance,** a free monthly publication, was launched in September to provide CI information beyond our own membership to consumers, parents, hearing care professionals outside of CI and anyone interested. Strong positive reception helped drive interest such that distribution by year-end was over 8,000.

- Collaborated with AudiologyOnline on a 4-part series: “Expanding Adult Cochlear Implant Access and Outcomes.”

- Interviewed actor and bodybuilder Lou Ferrigno (July), popularly known as The Incredible Hulk, after he received a cochlear implant. Lou discusses his lifelong hearing loss and why he went forward with a cochlear implant at age 69. Video was widely viewed and continues to be a popular resource.

- Created new webinar series—**Tuesday Talks**—to provide information and support for adults with hearing loss, parents, and others. Guest speakers address topics such as “What’s happening at an Adult/Pediatric Mapping,” “Progressive Hearing Loss” and more. Intended as a safe, consumer/parent-friendly opportunity to engage with professionals and other consumers/parents who serve as moderators.


- Expanded web content on adult rehabilitation with Naama’s Blog, addressing an important constituency need. Blog is shared widely with members (who distribute to patients) and to individuals and web groups involved in cochlear implantation and hearing loss generally. The Blog ranks among the top areas of the website and widely sought across the World Wide Web.

**Research**

- Conducted CI2021 for Children and Adults: It Takes a Village (April 28-May 1, 2021) following the format of prior in-person CI meetings with keynotes, podium sessions, live panel discussions, posters, and CI company satellite events—all virtually. 1350 virtual participants attended in real-time or viewed the meeting as a recording. The scientific program was, for the first time, determined by a geographically and specialty diverse group of audiologists, physicians, therapists, and educators.

- Served on the Planning Committee for the FDA organized workshop “Cochlear Implants, Innovation, Research and Advancement (CIRCA) Virtual Workshop” to be held live February 1-2, 2022. Worked collaboratively with the FDA to determine topics and speakers for virtual workshop attendees from government, industry, academia, professional societies, and the clinical field (patients, physicians, and medical professionals).
Advocacy

- Grew State Champion program to 142 Champs representing 44 states and DC by year end. State Champions are clinicians from across the care continuum, educators, parents, consumers, and other advocates for cochlear implant access. Utilized software tools to maximize opportunities for their involvement and impact.
- Expanded consumer advocacy/awareness arm: CI Consumer Advocacy Network (CI CAN)
- Reviewed 51 EHDI state and DC websites to determine if legislatively mandated parent information is provided. Developed paper on findings for a peer reviewed journal (accepted and to be published in 2022).
- Initiated efforts in three states to improve access to Medicaid for cochlear implantation. All are moving forward with likely favorable outcomes.
- Surveyed members on insurance access for SSD with outcomes to be published in the *Journal of Early Hearing Detection and Intervention* late 2022. Continue to respond to public inquiries regarding SSD coverage.
- Supported State Champion efforts to educate and inform state legislators about Parent Choice during LEAD-K legislation discussions, collaborating with other organizations.
- Surveyed members on insurance access for SSD with outcomes to be published in the *Journal of Early Hearing Detection and Intervention* late 2022. Continue to respond to public inquiries regarding SSD coverage.

Build an Effective Organization

- Increased total number of Organizational members to 106 by year-end (up from 101 the prior year). National membership included nearly 2000 active members comprised of professionals, students, adult consumers, veterans/military, and parent members—a 46% increase over the prior year.
- Grew State Champion program to 142 Champs representing 44 states and DC by year end. State Champions are clinicians from across the care continuum, educators, parents, consumers, and other advocates for cochlear implant access. Utilized software tools to maximize opportunities for their involvement and impact.
- Expande
For the first time since 2019, ACI Alliance Champs were able to meet in person—with many new faces present! During our in-person dinner, we discussed what has happened over the past few years and where we aim to go in terms of advocacy at both the state and national levels. We also discussed the success of our Virtual Hill Advocacy Day which was held prior to the CI Conference on May 4. Although our State Champions missed the excitement of being physically “on the Hill,” everyone felt that the virtual option was efficient and effective.

Protecting Family Options for Choice

One of the more critical points discussed by the State Champions meetings is the growing scope of state and local bills that could negatively impact parent choice on options for their children with hearing loss. While in the past we were often able to defeat these bills, there is a growing wave that requires a pivot. During the 2022 state legislative year, our State Champs have worked with other local advocates from our partner organizations to offer amended legislative language to address our concerns about limiting parent choice in these bills.

We also joined other hearing health organizations in opposing a proposed resolution before the Los Angeles Unified School District that would place all young children in an ASL setting unless parents knew to opt out. Our concern is that these bills, particularly the Los Angeles Resolution eliminates the assessment and options discussion that is central to the early intervention process. Two important Federal laws: Early Hearing Detection and Intervention (EHDI) and IDEA emphasize that the educational system must protect the unique needs of a child and their family. Our letter to the LA Unified School District can be found here.

We face a growing perspective that ASL must be used by every deaf or hard of hearing child regardless of type and level of hearing loss, family preference, and child specific needs. Our State Champs continue to work to educate policy makers on the need for parent choice, which is underscored by federal law. Public and governmental entities are bombarded with warnings of “language deprivation” unless children with hearing loss have access to visual language—preferably ASL.

Other Issues

We are working to expand Medicaid to cover adults in Washington State. Several State Champs have expressed interest in pursuing such expansion initiatives in their own states. A lesson we are capitalizing on is that partnerships with local organizations are important; indeed, Rome doesn’t shift policy in a day (or a year). Additionally, we heard from Champs that there are concerns about State Medicaid Programs not appropriately reimbursing for pre-approved procedures. We will continue to explore the scope of this issue which can affect a clinic’s ability to offer CI.

Insurance denials for SSD continue to be an issue for some clinics. We presented on the results of an ACI Alliance survey at CI2022; the survey outcomes will be developed as a paper. We also updated a list of resources for clinics to utilize during the appeal process, which can be found here.
Virtual Hill Day

While we had planned for our visits with Congressional offices to be in person, the realities of COVID and Hill operations dictated that these be carried out virtually. With the experience and expertise of our public affairs staff at the Powers Law firm, we held 38 substantive meetings with House and Senate Offices involving 29 State Champions from around the country. The focus was on our top three advocacy issues for 2022:

- Reauthorization of the Early Hearing Detection and Intervention (EHDI) Act in the Senate
- Medicare National Coverage Determination to expand access to CI
- Making Medicare telehealth waivers provided during COVID-19 permanent

With regard to the third topic (telehealth), we emphasized the need for audiologists and speech-language-pathologists to be able to offer telehealth services in the longer term as a way to extend access.

Congressional offices were receptive to our concerns. In fact, our virtual visits were so impactful that we are considering making these Virtual Hill Days an annual event for our State Champions.

The More the Merrier

We are proud of the work of our State Champs who work diligently to improve access to cochlear implant care. Over the past few years, our Champs program has continued to grow and now covers most of our 50 states and the District of Columbia. We would love to have you join us and work on these and so many other issues. We welcome ACI Alliance members to be in touch to help us reach our goal of having every state represented during our advocacy efforts. If you are interested in becoming a Champ—whether you are a physician, audiologist, speech-language pathologist, psychologist, social worker, educator, scientist, family member, or CI user, please reach out to me at nwestin@acialliance.org.

States with State Champions
At the suggestion of ACI Alliance, I recently presented at the May 2022 Colorado Academy of Family Physicians Annual Summit in Vail, Colorado. My presentation “Hearing Loss and Dementia—Now Hear This!” included a general discussion of hearing loss, the association of hearing loss with dementia, the role of primary care providers in hearing screening and referrals, and treatment of hearing loss including amplification and implantable technology like cochlear implants.

Like many conferences now, this meeting had both in-person and virtual elements. My talk was well-received with a robust question and answer period and I had a chance to discuss the topic further with attendees during the break.

My participation in this conference is part of a larger ACI Alliance effort to share research and information about hearing loss and cochlear implants with health professionals outside of hearing health. There are several large organizations with national annual meetings and state conferences, like the one I attended in Vail, with professional memberships who can benefit by learning more about hearing loss and when to refer patients to a hearing health professional. The American Academy of Pediatrics, Academy of Family Physicians, and American Nursing Association are all excellent organizations for us to target.

I would encourage others to work with ACI Alliance to find relevant meetings of organizations like these in their state, and work with them to identify opportunities to share our clinical research with other medical professionals. My experience presenting to the Academy of Family Physicians in Colorado was a relevant and productive way to share resources and build relationships to increase awareness of hearing loss and cochlear implantation.

If you are interested in pursuing opportunities to present on CI and hearing loss to primary care physicians in your state, please contact Laura Odato, ACI Alliance Director of Operations and Marketing at LODato@acialliance.org.
Tuesday Talks Return for Fall/Winter/Spring 2022-23

Following the success of the inaugural Tuesday Talks webinar series in Spring 2022, ACI Alliance is pleased to announce new talks beginning in September.

Tuesday Talks are a free, captioned webinar series hosted by ACI Alliance monthly at 12 Noon ET. The content is designed for adults, parents, and others seeking information on cochlear implantation and related topics. Members of the CI CAN consumer network play a pivotal role in each presentation by bringing their own experience with CI to the discussion.

Presentations in the Spring 2022 round were highly rated and well attended. Please share this information with your patients looking for information that is designed to be relevant to their informational needs.

Here’s the line-up of talks beginning September 2022. More courses to be announced.

**SEPTMBER 13**
ABCs of IEPs: Guidance for Parents of Children with Cochlear Implants
John Flanders Esq.
Special Education Lawyer

**OCTOBER 11**
What happens at the CI activation?
Meredith Holcomb AuD
Director, Hearing Implant Program
University of Miami Ear Institute

**NOVEMBER 8**
Cochlear Implants for Veterans: How the VA Provides Coverage and Role of Telehealth
Douglas Hildrew MD
Medical Director, Yale Hearing and Balance Program
Yale School of Medicine
VA Connecticut Healthcare

**DECEMBER 13**
What happens during a CI evaluation for an adult?
Molly Smeal AuD
Clinical and Research Audiologist
University of Miami Ear Institute

**JANUARY 24**
What to Expect at the CI Surgery
Daniel M. Zeitler MD
Co-Director, Listen for Life Center
Virginia Mason Medical Center

**FEBRUARY 21**
A Focus on CMV and Hearing Loss
Cedric Pritchett MD
Medical Director, Cochlear Implant Program
Nemours Children’s Hospital

Sign-up for the Fall/Winter/Spring 2022-2023 series is open on our website.

The recorded captioned courses with audio and video from the first round of Tuesday Talks are now available on the ACI Alliance website. We encourage you to share these resources with patients and families. Previous Tuesday Talks attendees noted that the sessions “really helped me understand mapping and connect the dots,” and the series presented “excellent content and diversity of topics.” The upcoming series recordings will be posted online as they become available.
Student Participation Swells at CI2022

Student involvement at CI2022 was robust, diverse, and added a special element to the conference. Student participants participated in podium sessions, presented scientific posters, and attended sessions throughout the conference. We were delighted to have more students, residents, and fellows in attendance this year than ever before at an ACI Alliance CI Conference—125! We were excited to welcome so many future CI scientists and clinicians to the meeting and hope to see even greater numbers at CI2023 in Dallas.

Scholarships Offered

Conference scholarships were open to full-time students, residents, fellows, and postdoctoral scholars who have a clinical or research interest in cochlear implants. The scholarship offered registration to the meeting, a $120 stipend, and a student membership in ACI Alliance. Submissions were reviewed by a committee of professionals across the hearing health spectrum. The 66 applicants who submitted a scholarship application spanned the range of clinicians and scientists that comprise the ACI Alliance community. Those chosen for this prestigious award represent a diverse field of individuals from 19 different institutions of higher learning from around the country enrolled in audiology, speech-language pathology, deaf education, linguistics, and medicine.
Student Poster Competition

The Student Poster Competition is an opportunity for students, residents and fellows to submit, display and discuss their research with other conference attendees to gain feedback and build relationships. A total of 99 students participated in the student poster competition, presenting on wide-ranging research topics. Student posters were reviewed by Judging Committee of twelve hearing health professionals from across the care continuum. Three student winners were selected and another three were identified as having important research and awarded Runner-Up status.

Gabriel Brandner, CoM MD Candidate

CI2022 represented many firsts for me. It was simultaneously my first national conference that I was able to attend in-person and first opportunity to present my research on barriers and facilitators to the cochlear implant process. The entire experience was eye-opening to hear live from many of the research-scientists whose work I had read, and to learn from their presentations on the latest innovations and problems facing the cochlear implant community. In particular, advances Dr. Sumit Agrawal and his team have made towards imaging and mapping native cochleae for implantation is undoubtedly going to improve hearing outcomes for implant recipients.

Even more personal was the opportunity to see my mentor, Dr. Ted McRackan, present on the CIQOL-Expectations instrument and its application to patient preoperative counseling. The enthusiastic reception of his work, which I witnessed development of as a medical student at NUSC, gave me perspective on the importance of patient reported outcomes in capturing the wholistic clinical performance of cochlear implants.

CI2022 also gave me the unique opportunity to meet the upcoming generation of providers and network with fellow students and residents from across the country. My main takeaway from the conference was that future patients will benefit from the advocacy work and audiologic advancements discussed this year in Washington DC. The community of advocates, students, PhDs, audiologists, and otolaryngologists that assembled at CI2022 truly represented an interprofessional undertaking that strives to provide excellence in its care for all cochlear implant recipients.

Dr. McRackan added that “experiences, such as those described by Gabriel, can be incredibly formative for young clinician-scientists. A lot of these concepts used in our field can seem abstract when reading research articles and learning about research methodology, but attending conferences makes this far more tangible. I am very proud of Gabriel’s work and thankful for the ACI Alliance for providing the platform to disseminate our research.”

Gabriel Brandner, CoM MD Candidate 2023 from the Medical University of South Carolina (MUSC) was a student poster winner for his research “Facilitators and Barriers to Cochlear Implantation.”
Kristina Bowdrie AuD/PhD

I was a first-time attendee and student poster presenter at this year’s CI2022 Conference. I learned about current work in the field and was able to connect with exceptional members of the ACI Alliance. I also had the opportunity to share my work suggesting that child temperament and the family environment interact to influence spoken receptive language outcomes in children who are deaf and hard-of-hearing. It was such a rewarding experience to engage with so many people who were interested in my project, including the panel of judges.

Dr. Aaron Moberly noted that Kristina’s work “is exciting as it suggests we must expand our perspective as hearing healthcare clinicians beyond just the patient. The ways in which our particular patients interact with their environments, especially their families, impacts their language development. Moreover, personal characteristics of each individual patient, such as temperament, appear to impact how their family environment contributes to development.”

More information about the student poster winners, runners-up, and the Student Poster Judging Committee can be found on our website.

Ankita Patro MD, MS

Dr. Patro is a resident in otolaryngology-head and neck surgery at Vanderbilt University Medical Center. Originally from Texas, she earned degrees in economics and biology at Stanford University before graduating with honors from the Baylor College of Medicine.

Regarding her residency experience, she noted that “Vandy has been the ideal program for me; after my interview day, I knew that I fit perfectly. It combined what I desired in residency—excellent training, meaningful and cutting-edge research, and the ability to lead a balanced life.” Attending the CI conference allowed me to learn more from others in the field. Dr. Patro’s interests include surgical outcomes, medical/resident education, health care delivery, and global health.

Kristina Bowdrie AuD/PhD candidate from The Ohio State University was student poster winner for her research "The Interaction between Temperament and Family-Related Environmental Confusion on Spoken Language"
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Meet the ACI Alliance Board of Directors

Barbara Mellert MPH: An Advocate for Families for Over Two Decades

I’m honored to be the parent representative on the ACI Alliance Board. My husband and I are parents of two adult sons; both have bilateral cochlear implants. Thom, our older son, was born in the pre-newborn hearing screening days so was not diagnosed with his severe/profound hearing loss until he was over three years old. He was fitted with hearing aids and did quite well with them. Our younger son, Sam, was diagnosed with a profound hearing loss at 15 months with similar success as his brother. Fast forward to middle school for our older son. It was clear his hearing had changed so we moved ahead when he was 13 with his first cochlear implant. To say a cochlear implant exceeded our expectations is the understatement of the century! He acclimated quickly and it was obvious from his speech that he was hearing so much more. Sam saw Thom’s experience and wanted that for himself. He received his first implant when he was 11. In short order, insurance began providing coverage for bilateral cochlear implants so both eagerly requested to have their second ear implanted. Both described the experience as being nearly as impactful as receiving their first implant. They noted the benefits of directionality and a richer, deeper sound. Our only regret—looking back—is I wish they’d had their surgeries when they were younger.

Because of our positive experiences, I’ve become a passionate advocate for parents who have children with hearing loss so that they understand that they have amazing options. I administer a large Facebook group—Parents of Children with Cochlear Implants—that provides support and factual information in a warm, supportive environment to over 15,000 members. My husband, Hugh, and I were the parent members for the New Hampshire Newborn Hearing Screening Task Force when our sons were younger.

Thom and Sam are doing so well today. Cochlear implants have opened so much for both of them. I am a newly minted mother-in-law! Thom married Noel in May of this year. Thom is a landscape designer living in Seattle. He graduated from Hampshire College in 2015. Sam is now engaged to Shelby. Their wedding is planned for fall of 2023. In addition, Sam recently graduated college summa cum laude with a 4.0 GPA. He was chosen to be the student commencement speaker. When Sam mentioned he was born deaf, you could hear gasps from the audience. Representation matters! Sam begins an MBA program in the fall while also working full time.

I have always had deep respect for the American Cochlear Implant Alliance and am honored to serve on the Board of Directors. The research, advocacy and awareness components are so important. In a world where there’s so much inaccurate information, ACI Alliance is a beacon for reliable, accurate information.

Brittney Sprouse AuD, PASC

I am the director of Audiology at the University of Chicago Medicine (UCM) where I also serve as a pediatric cochlear implant audiologist. I obtained my Doctorate in Audiology from the Northeast Ohio AuD Consortium (University of Akron). From a young age, I knew that I wanted to work with children and first learned of Audiology as an undergraduate while studying elementary education. It was during this time that I learned about children who are deaf and hard of hearing and how to help them reach their academic potential. From that moment on, I knew that pediatric audiology was the right fit for me.

It is a privilege to work with children and families as they navigate their child’s hearing loss journey and for many of my patients, that journey has led to a cochlear implant (CI). At UCM, our team works to continue reducing barriers for access to CI, improving patient outcomes with CI, and continuing efforts in alignment with the mission of ACI Alliance. ACI Alliance is a wonderful organization that is dedicated to increasing awareness, advocacy, and research in cochlear implants. I am thrilled to be a new member of the board of directors and look forward to continuing the work of ACI Alliance.
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Rosie Finigan

Rosie Finigan is a parent member of ACI Alliance and serves on the CI CAN network. Her family is a model for parent ingenuity, resourcefulness, and the power of the human spirit when we allow a child to learn and excel in ways that best meet their unique needs.

Editor’s Note: Try to get through this wonderful narrative in one gulp. If you don’t have time now, it’s also posted on our website here: www.acialliance.org/page/storiesaboutchildren

2022 was special for our family in a few ways. It marked the ten-year anniversary of my daughter Lexi receiving her cochlear implants. By today’s standards, she is considered a late-implantee, receiving her first cochlear implant at 27 months of age, and her second implant a month after her third birthday. My hope is that by sharing her story it gives hope to other families, especially those that feel they might be getting off to a late start.

Adopting a Deaf Child from China

In early 2011 we were a family of three. We had already adopted a little girl from China five years prior, who was six years old at the time. Both myself and my husband are close to our siblings, so we wanted our daughter to have that same experience, and we felt that our family had a lot of love to share. We have many family members here in our community, and several who have a built their family through adoption. We were hoping to adopt another child, but adoption from China at that time was mainly through their special needs program, and there was no guarantee that we would be matched with a child.

After a few years of waiting, we received a file for a little girl with hearing loss. We knew very little about hearing loss. In addition, we live in the Florida Keys, which is rich in beauty but short on services—especially specialized services for children. We were able to consult with an audiologist who confirmed, with the limited medical information we had, that she likely had a profound hearing loss in both ears. We did a lot of research, weighing the fact that we have no deaf community here and no audiology services. I wondered if we could meet her needs as parents, and if our community could provide what she needed to learn, grow and reach her potential.

Finding People and Resources to Help

I remember looking for a sign. I received many. I reached out to an audiologist who had tested my hearing a few years prior, and she was kind enough to read Lexi’s audiogram and offer her expertise. I reached out to parents who had adopted children with hearing loss, and I even was able to speak with parents who adopted children from Lexi’s orphanage. We were blown away by the kindness of strangers and how many people were willing to help and share their experiences and advice to a couple whom they had never met. So, despite the many unknowns in adopting a toddler with several identified medical issues, my husband and I decided that what Lexi needed most was the love of a family, and we would just have to figure the rest out. After all, becoming a parent is such a leap of faith in just about every way.

Once we decided to move forward
with the adoption, we set out to learn as much as we could about hearing loss, the options available, modes of communication and where we could obtain services to help Lexi catch up. We also needed to consult other medical specialists for what Lexi may need, as well as how to best foster attachment with a toddler. I realize that in choosing to adopt a child with hearing loss, we did not have a grieving period, and I can only imagine all of the difficult emotions that many parents experience when they are told that their child has hearing loss. International adoption has many challenges but in between the paperwork and the fingerprints we tried to prepare for every possible scenario the best that we could.

During this time, we learned that the University of Miami had a Children’s foundation to help children with hearing loss. I reached out to them and they met with us, (before we even had Lexi!) to tell us about all of the options to help Lexi hear. They kept in touch and once we finally received our dates to travel to China, they were able to schedule us a couple days after we returned home. Lexi was two and a half years old when we adopted her and she had no language other than her ability to give a thumbs up. I often worried about how to soothe her when she couldn’t hear, and how confusing this time must be for her. Surprisingly, communication was not as difficult as I had feared. She watched what we did, would lead our hand to what she needed or would point to what she wanted. It certainly helped having our daughter Mia with us, who was six years of old at the time. Lexi attached to us pretty quickly and seemed so eager to learn. She compensated very well for her lack of hearing. It was clear that although she had been in an orphanage for most of her young life, she was well cared for.

Moving Ahead Quickly to Develop a Team

Two days after we returned home from China, we were in a sound booth at the University of Miami testing her hearing and getting fitted for hearing aids. I remember feeling like we were in a race against time since she was so behind in her language. I was surprised to learn that kids are often implanted after the age of two. There is a ton of research that supports the benefits of early implantation, especially before there is a substantial delay in spoken language. As a results of the research, the recommended age for receiving cochlear implants has been lowered. However, many kids have progressive hearing loss and may not yet be candidates for cochlear implants until they are older, or their hearing loss was not identified until later, or in other cases the loss has been identified but the parents have to battle their insurance company for coverage.

The next couple of months was a whirlwind of appointments. The staff at medical offices came to know me pretty quickly because I would call every day to see if there were cancellations in order to move up appointments. As a working parent who was off on maternity leave, I felt like I was in a race against time as well. Persistence pays off as does having a competent team. After a short hearing aid trial, Lexi received her first cochlear implant about two months after we returned home. We had already begun participating in AVT, and this was good preparation for the work we would need to do at home.

The team at the University of Miami was fabulous and although I felt like I had done enough research to complete a dissertation, when they turn your child’s implants on and give you a suitcase of supplies, it is overwhelming. Chasing after a very spirited toddler trying to keep the processors on her ears is a feat that I am sure every parent can relate to. Of all the support we received from the fabulous team at the University of Miami, the one moment that had the greatest impact on me is when the director of the program looked me in the eye and told me that I can do this. She already knew what we slowly came to realize: we are the expert when it comes to our children, we are the team leaders, we are the teachers and facilitators. I am quite sure that as professionals they knew that the most important role to achieve a successful outcome for the CI child belongs to the family and the family environment in which the child develops. Studies show that
the relationship between the family and the auditory-verbal development potential of the CI child is strong, even if the exact mechanism that contributes to success are not clear.

**Lexi’s CI Turn-On and Maximizing the Opportunity**

It was obvious to us that Lexi was eager to hear and speak. I honestly believe that she didn’t want to miss out on anything. She is a very outgoing, strong-willed child who was eager to learn.

She started to pick up on sounds. One of the first ones was hearing our coffee percolating. We pointed out sounds constantly, narrated everything we were doing, and minimized background noises. She started pointing out new sounds almost every day. She was a tireless child so I just tried to bombard her with as much language as I could. The University of Miami was a three-hour drive for us, so I needed to find ideas for how to best help Lexi at home. We used TeleRehab with an AVT from Central Institute for the Deaf in St. Louis, which was a newer concept at the time. In no way could Lexi sit at a computer for 30 minutes but I quickly realized that these sessions were to teach me as her parent how to best foster her listening and spoken language. One of the silver linings of the COVID pandemic is that it has broadened the availability of teletherapy for AVT and speech services, making them more available and affordable for the families that desperately need these services. I also found so many resources online.

We participated in the John Tracy Clinic’s distance learning program for children with hearing loss and attended their international summer program the following summer right after Lexi’s fourth birthday. This program serves to educate parents on how to best help their child learn to listen and speak. I think many parents, including myself, don’t realize that we must become strong advocates for our children with hearing loss. Many parents at the time blogged about their experiences and I learned so much from them. We used games, picture cards, toys, essentially anything we could to introduce novel words and push the language in. Lexi’s older sister Mia, read many beginner books to her which benefited them both.

**Advocate to Set the Bar High**

In the Summer of 2012, we enrolled Lexi in pre-school. At our first IEP meeting, it was suggested to us that Lexi be placed in a special needs classroom. Another professional suggested that Lexi could use an iPad to supplement her communication. Lexi had just received her second implant so I asked them why on earth would we set the bar low when as far as I was concerned her potential was enormous. We would not let her struggle but we needed to set the bar high and give her a chance to reach for it, while providing her with the services to do just that. I told the team that she has a physical disability not a learning disability; therefore she needed to be in an environment with kids who could model good spoken language. I often wondered what would have happened had I not educated myself to be a strong advocate for Lexi. A month later she started preschool. Although her language was still very limited, I knew that she needed to be immersed in a language rich environment. We taught her some vital words in sign language, and she seemed to be understanding more and more spoken language each day.

During those early years I found it very helpful to journal the progress that Lexi was making, keeping track of the words she was saying. I often use the CASL inventory form to keep track of her growth and shared it with her audiologist and AVT when we had follow-up appointments. Because our services were so limited in our island community, we looked for additional summer programs and found ones that provided both of my daughters with fun, engaging opportunities to learn. I saved up so I could take FMLA from work for a month each summer. One summer we went to the Atlanta Speech School’s day camp and another year Lexi participated in a day camp at The River School in Georgetown. I always have believed that each therapist has a different approach and perspective from which we could learn.

**Catching Up Lexi’s Language**

Each year in elementary school Lexi closed the gap a bit more. Her love of reading was a huge factor in teaching her new vocabulary and helping her catch up in her English language skills. By the time she was in third grade she was essentially caught up if not ahead of her peers in several areas. This created yet another challenge to keep her on an IEP. However, I continued to be a gentle but persistent team leader, armed with research and my child’s best interests, prepared to make sure my daughter was able to get what she needed at school in order to be successful. There are so many resources available for parents today, such as the ACI Alliance, Hearing First, AG Bell, and the Face Book group: Parents Children with Cochlear Implants. The parents on this Facebook group are a vast wealth of information and happy to help others who are earlier in their journey. I have also found other helpful FB Pages, such as Lynn A Wood, LSL, AVT. She...
is always posting great ideas and activities to foster language growth.

The good news is that as a parent of a child with hearing loss, you are not alone. Even if your child was implanted late, like Lexi was, there is still so much hope. A study in 2020 suggested that post-op performance of auditory perception and speech intelligibility of CI kids implanted prior to age five was significantly related to the family environment, as well as the educational level of the parents. With so much research about the most successful outcomes being for kids implanted before age two, I was glad to see this study. I think the correlation with a child’s success and the educational level of the parents has so much to do with access to health care and resources, as we have seen with so many other health issues in our country. We need to continue to demand insurance coverage for our kids and expand services to those who really need it. For the parents whose child was implanted after age two, know that there is hope and plenty of potential for your child.

**Parent Engagement Makes the Difference**

Narrating everything you are doing with your toddler, engaging in more interactive conversations with your child, and becoming an advocate comes more naturally to some parents but the good news is these are skills that a parent can learn. More importantly, there are resources to help your family—you just have to look for them. In many areas of life, we sometimes find ourselves needing to compromise or lower our expectations. For our implanted kids however, I think we need to set the bar high and provide them with great opportunities to be in language-rich environments as research shows that this input during the first years after CI implantation strongly predicts later language outcomes.

**Casting Call for El Deafo Lead Character**

In January of 2020, the director of the University of Miami Children’s Hearing Program passed on to us a casting call from a talent agency. They were looking to cast a deaf girl for a voice role. Lexi auditioned for the role and got the part of Cece/El Deafo for the animated series on Apple TV based on the graphic novel “El Deafo” by Cece Bell! After a delay due to the pandemic, the recordings were finally completed in 2021 and the series was released in January of this year. While the whole process was an amazing experience for Lexi, I don’t think Lexi truly understood the impact until I read her the comments from parents and kids online. Parents who wonder if their child can succeed with cochlear implants. Parents like me who just a few short years before wondered if my child could gain the skills to listen and speak, catch up with her peers, attend a school in our community and thrive in a hearing world.

**Becoming an Advocate for Herself and Supporting Other Kids**

Lexi is now a teenager navigating the middle school years. She has become a strong advocate for herself. Her school district was finally able to hire a teacher of the deaf a few years ago. Lexi has learned to be the team leader, telling the IEP team what she needs to be successful. As a girl who is Chinese, adopted, and deaf, she is learning how representation is important in her life, as well as how it can positively affect others. Lexi recently had the opportunity to talk to a group of deaf children across the country on Zoom. It started off with her answering questions about the voice role but then the kids just talked about how they each handled the various challenges in their everyday lives. It was such a positive experience and each of our kids were able to see that we all have challenges, and that they are not alone. Last month we attended an event sponsored by the University of Miami children’s hearing program. Lexi was able to meet with and encourage young kids with CIs early in their journey, telling them that they can do anything they set their mind to.

I often reflect on my daughter’s hearing loss journey. I think many other parents would agree that although it is one I never knew I would be on and there were certainly many days and nights of worry, battles with insurance and school team members, it has been an amazing journey. Through this process I have met the most wonderful people, some of whom I have yet to meet in person and others who have become lifelong friends. It has taught us important lessons and even shaped the path of my older daughter as she plans to go to college to become a pediatric audiologist. As a family, we have witnessed the miracle of modern medicine and what the support of a strong family can do. It’s a powerful combination. So don’t underestimate your ability as a parent to help your child reach their potential. Reach out for help when you need it. There is an entire community of parents who are ready to help and want to pay it forward. Set the bar high and look for the blessings in the journey.

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