The interdisciplinary nature of the American Cochlear Implant (ACI) Alliance differentiates it from many other organizations. ACI Alliance unites an array of professionals—surgeons, audiologists, speech-language pathologists, psychologists, social workers, educators, and researchers—as well as parent and consumer advocates—to advance access to cochlear implantation for individuals for whom hearing aids do not provide adequate access to sound or communication benefit.

Our collaborations across disciplines extend to partnerships with organizations in adjacent areas. We always have had congenial connections with other associations focused on speech, language, and hearing. The past few years have reinforced the value of these partnerships as well as connections with other disability-related groups. Below, I reflect on four ways in which we have highlighted the “alliance” part of our name by working with other organizations in hearing health and related fields.

Presentations at others’ conferences. As chair of the Audiology: Implantables Committee for the 2023 American Speech-Language Hearing Association (ASHA) convention, I worked with an interdisciplinary committee of researchers, clinicians, and students to select presentations that brought issues related to cochlear implantation to a broader audience. Two invited talks focused on expanded indications across the
MESSAGE FROM THE CHAIR  continued from page 1

continuum of hearing technology, with Drs. Aaron Moberly and Camille Dunn presenting on adult-based considerations and Drs. Shannon Hammill and Jordan McNair covering pediatric-related issues. Donna Sorkin, Shannon Hammill, and Ginger Mullin discussed underlying barriers to pediatric audiology, from loss to follow-up to creative strategies to overcome these barriers, in a two-part series. Drs. Aaron Moberly and Sara Mamo explored the other end of the lifespan in their talk about the effects of age, cognition, and hearing loss on diagnostics and rehabilitation. Drs. Camille Dunn and Jordan McNair rounded out our headliners with a class on tips and tricks for cochlear implant MAPping. Providing accessible information on implants to a broader audience marks one way to cross-pollinate our field.

ACI Alliance also has a long-standing history with the American Neurotology Society (ANS). The strength of the bond between our two organizations stems from our aligned missions to improve public healthcare through education and information, particularly related to access, research, and funding for cochlear implantation.

The American Academy of Audiology has encouraged our members to submit talks on aspects of cochlear implantation of interest to audiologists in and out of CI. Our members have presented Grand Rounds and a range of sessions providing audiologists with guidance on how to advise patients about CI candidacy and timing.

Endorsement of position statements. Another way to show solidarity across professional organizations is through endorsement of position statements and clinical practice guidelines. ACI Alliance and the American Academy of Audiology (AAA) have critically reviewed each other’s guidelines, resulting in five supported documents. AAA endorsed all four ACI Alliance Task Force Guidelines on cochlear implant candidacy across the lifespan, with The Hearing Review recognizing AAA’s endorsement of Zeitler et al.’s adult implant candidacy guideline as one of the magazine’s top 10 stories in December 2023 and Ear and Hearing awarding Readers’ Choice recognition to three candidacy papers. Our Board of Directors voted to endorse the American Academy of Audiology Position Statement on Early Identification of CMV in Newborns authored by Kettler et al. The mutual support between ACI Alliance and AAA bolsters our impact on the field.

Collaboration to promote outcomes. ACI Alliance engages in activities with others interested in hearing healthcare. For instance, we collaborated with parents of children who are deaf and hard of hearing, adults with hearing differences, and professionals in the field of pediatric hearing loss to develop evidence-based materials supporting the benefits of listening for development and clinical practice guidelines. ACI Alliance and the American Academy of Audiology are through endorsement of position statements and clinical practice guidelines. ACI Alliance and the American Academy of Audiology have critically reviewed each other’s guidelines, resulting in five supported documents. AAA endorsed all four ACI Alliance Task Force Guidelines on cochlear implant candidacy across the lifespan, with The Hearing Review recognizing AAA’s endorsement of Zeitler et al.’s adult implant candidacy guideline as one of the magazine’s top 10 stories in December 2023 and Ear and Hearing awarding Readers’ Choice recognition to three candidacy papers. Our Board of Directors voted to endorse the American Academy of Audiology Position Statement on Early Identification of CMV in Newborns authored by Kettler et al. The mutual support between ACI Alliance and AAA bolsters our impact on the field.

Collaboration to promote outcomes. ACI Alliance engages in activities with others interested in hearing healthcare. For instance, we collaborated with parents of children who are deaf and hard of hearing, adults with hearing differences, and professionals in the field of pediatric hearing loss to develop evidence-based materials supporting the benefits of listening for development and clinical practice guidelines. ACI Alliance and the American Academy of Audiology have critically reviewed each other’s guidelines, resulting in five supported documents. AAA endorsed all four ACI Alliance Task Force Guidelines on cochlear implant candidacy across the lifespan, with The Hearing Review recognizing AAA’s endorsement of Zeitler et al.’s adult implant candidacy guideline as one of the magazine’s top 10 stories in December 2023 and Ear and Hearing awarding Readers’ Choice recognition to three candidacy papers. Our Board of Directors voted to endorse the American Academy of Audiology Position Statement on Early Identification of CMV in Newborns authored by Kettler et al. The mutual support between ACI Alliance and AAA bolsters our impact on the field.

Other hearing-related collaborations include Partner Membership in the OPTION Schools network and membership in the World Hearing Forum. We recently joined OPTION Schools, Inc., as a partner member. OPTION is an international non-profit organization that fosters connections and provides
resources to the public, policymakers, and professionals working with children who are deaf and hard of hearing. Our focus on worldwide awareness of hearing health extends to our membership in the World Hearing Forum, which runs the campaign for World Hearing Day (March 3, 2024) as part of the World Health Organization.

We also promote reciprocal support across a variety of disability groups including Friends of the Congressional Hearing Health Caucus, the Independence through Enhancement of Medicare and Medicaid (ITEM) Coalition, and the Habilitation Benefits Coalition (HAB) (see https://www.acialliance.org/page/Coalitions&Collaborations). For example, we supported the ITEM Coalition’s successful push for the National Council on Disability to support Medicare coverage for elevated seats for power wheelchairs.

**Participation in community education.** We have forged partnerships with Audiology Online (part of the Continued online learning network) and Hearing First to share knowledge with professionals and parents (in the case of Hearing First). Audiology Online has more than 25 courses created in partnership with ACI Alliance, with topics ranging from candidacy considerations to optimizing outcomes to quality of life instruments for this population. Hearing First and ACI Alliance publicize each other’s materials, seminars, and events to enhance cross-referencing to interested parties across our separate but intertwined networks. These examples celebrate different ways we advocate for dissemination of accurate and updated information about cochlear implants.

The International Hearing Society (IHS) is the organization of hearing instrument specialists. For the past several years we have supported the organization’s educational activities by providing content on cochlear implants and when to refer for a candidacy evaluation including a well-attended lunch-time virtual workshop, participation in state conferences, and development of CE content for the IHS magazine.

ACI Alliance has a strong network of professionals, but we can extend our impact by partnering with other organizations focused on common themes. These intersections and interactions are relevant for clinical, research, and societal impact. By working together, can we make the largest difference for the people who need it most—our patients.
Cochlear Implants Designed for Your Patients

Take surgical planning and electrode selection to the next level.

Our next level looks like closest to natural hearing. 
What's yours look like?

Only MED-EL offers OTOPLAN—an innovative software providing you with detailed, precise anatomical and audiological information for preoperative and postoperative analyses.

After surgery, use OTOPLAN modeling to pinpoint the exact position of each electrode and adjust the implant settings to complement the electrode's actual fit.

With OTOPLAN:

- Compare different electrode arrays
- Identify each electrode contact
- Get your patient as close as possible to natural hearing

Learn more about OTOPLAN: go.medel.com/ACIA
The ACI Alliances Conference Program Committee has been in full force preparing for the 2024 ACI Alliance meeting in Vancouver, British Columbia. (Committee Members are listed on page 7.) We are thrilled to be working with an outstanding and motivated committee of audiologists, physicians, scientists, speech language pathologists, psychologists, and educators in the planning of our annual conference. The diversity of our committee reflects the ACI Alliance commitment to address the multidisciplinary nature of our field and the critical role of each discipline in patient outcomes. Be sure to get your passports ready so that you can enjoy both the clinical and scientific atmosphere of the conference, as well as the wonderful sights of Vancouver.

Just as it takes a village to raise a child, it takes a team to enable the

continued on page 6

See you this summer in Vancouver, British Columbia!
development of an outstanding cochlear implant recipient. Further, as clinicians and scientists, we understand that measures such as word recognition, language development, and etiology of hearing loss are important to assess in cochlear implant users as they affect outcomes of implantation. However, it is essential that we recognize there are a multitude of additional factors beyond these measures, directly and indirectly related to the patient. While we all seek an improvement in our patients’ quality of life, what more can we do to facilitate the patient journey? We seek to have our conference sub-themes address these elements, really drilling down to several important underlying factors contributing to patient outcomes. As a reminder, our sub-themes are:

1. Successful Pathways to Cochlear Implantation: A Global Perspective
2. Optimized Models for Cochlear Implant Workflow
3. Effects of the COVID Pandemic on Cochlear Implant Outcomes
4. Socio-emotional Health in Cochlear Implant Users
5. Listening Impacts on Literacy and Learning in Children with Cochlear Implants
6. CI in Single Sided Deafness for Adults and Children: Candidacy, Provision, Outcomes
7. CI Provision at Both Ends of the Age Spectrum: Under 6 months and over 90

Several of these sub-themes move beyond the direct measures of the ear and highlight our main theme of Cochlear Implantation: Facilitating the Patient Journey. These sub-themes address accessibility to cochlear implants (sub-themes 1, 2, 3), socio and environmental factors (sub-themes 4, 5), as well as the

continued on page 7
analytic development of CI delivery models to unique populations, (sub-themes 6, 7)—all of which impact patient outcomes. While the individual is paramount, we hope to explore factors related to the proverbial village that can help improve delivery and outcomes in cochlear implant recipients.

We were excited to see many hundreds of abstracts addressing all of these themes, demonstrating that we as a field recognize the critical importance of looking beyond the ear to evaluate the underlying factors contributing to patient outcomes. While the Conference Program Committee continues to plan for an exciting and thought-provoking CI 2024 International, we hope the meeting further motivates our field to think beyond the ear and improve the patient journey, and ultimately improve hearing healthcare.
(Re)habilitation Connect Forum

Building the New

Amy Lynn Birath AuD, CCC-A/SLP, LSLS Cert. AVEd
Moog Center for Deaf Education
Member, Board of Directors, ACI Alliance

“The secret of change is to focus all of your energy, not on fighting the old, but on building the new.”
—Socrates

If you assumed this quote was from the ancient Greek philosopher, that would be a fair assumption. However, these words actually were spoken by a gas station attendant named Socrates in Dan Millman’s Way of the Peaceful Warrior. Regardless, when thinking about (re)habilitation, these words come to mind.

This year’s (Re)Habilitation Connect Forum special session will be a combination of presentations focused on building the new through pediatric habilitation and adult rehabilitation. The Forum will explore variabilities in outcomes for pediatric cochlear implant recipients and possible approaches or intervention strategies to address such, as well as ways to develop and include rehabilitation in adult cochlear implant programs, the lack of evidence in this area, and how to move the needle in the right direction. As previously promised, all included presentations will be taken directly from the abstract submissions for CI2024. Thanks to every (re)hab-minded professional who submitted. You have made it possible for us to have this robust and engaging learning experience.

Following our afternoon special session, Hearing First has graciously agreed to once again host Continuing the Conversation – a happy hour where the (Re)Habilitation Connect Forum presenters and attendees can interact and delve even deeper into the Forum topics. This is an opportunity not to be missed. Whether you identify as an educator, a coordinator, a psychologist, a counselor, a speech-language pathologist, a facilitator, an audiologist, an interventionist, a physician, a habilitationist, a rehabilitationist, a philosopher, a gas station attendant or as any person interested in building the new with the children and adults we serve through discussion of research and best practices, we hope you will join us for this exciting (Re)Habilitation Connect Forum in Vancouver.

Conference podium and poster presentations will cover a range of cochlear implant and hearing science topics with special emphasis on the conference themes, which are listed above in the article by Program Chairs Viral Tejani and Jacob Hunter.
CI2024 International Keynote Speakers

**Featured Sessions**

**Ruth Litovsky PhD** will deliver the annual Niparko Memorial Lecture on “Successful Pathways to Outcomes in Bilateral Cochlear Implantation.” The Niparko lecture was established to recognize Dr. John K. Niparko’s enduring commitment to cochlear implant research and clinical care and honor his significant contributions to the field.

Dr. Litovsky is the Oros Family Chair in the Department of Communicative Sciences and Disorders at the University of Wisconsin – Madison. She has a joint appointment in the Division of Otolaryngology in the Department of Surgery, and serves as the Academic Associate Dean for the Division of Natural, Physical and Mathematical Sciences in the College of Letters and Science.

**Jill B. Firszt PhD** will deliver a Keynote on “Cochlear Implantation of Individuals with Asymmetric Hearing Loss and Single Sided Deafness: Results, Expectations and Gaps in Knowledge.”

Dr. Firszt is a Professor in the Department of Otolaryngology-Head & Neck Surgery and Director of the Cochlear Implant Program at Washington University School of Medicine in St. Louis. She is also Adjunct Professor in the Program in Audiology and Communication Sciences at Central Institute for the Deaf at Washington University. She was an early clinician-scientist to explore cochlear implants for SSD and asymmetric hearing loss.

**Andrej Kral, MD, PhD** will deliver the keynote “Maturation of the Auditory System Requires Auditory Experience within an Early Critical Period.”

Dr. Andrej Kral is Chair of Auditory Neuroscience at the Clinics of Otolaryngology, Hannover Medical School and heads the Department of Experimental Otology. Dr. Kral specializes in auditory neurophysiology in animals (rodents, cats) and humans. His research interests include hearing loss, central effects of deafness, brain development and plasticity, neuroscience of cochlear implants and technology of neuroprosthetics.
Meeting Details: Member Discount Codes and Student Opportunities

Jessica Houk MBA
Manager of Information Technology and Membership Services / ACI Alliance
jhouk@acialliance.org

One of the many perks of having an organizational membership is that you may include up to 50 additional members in your account with no additional charge. These members will be included in our emails, added to our directory, allowed full access to our e-magazine Calling, and approved to post open job positions on our site. Please take advantage of this by adding more members to your account. https://www.acialliance.org/page/MemberCenter

This will be increasingly important as our emails and notifications on the upcoming CI2024 Vancouver conference. There is a significant member discount to attend the conference. Members in our directory have received an email with their specific organizational code to use. These emails were sent to your organization’s Point of Contact (POC). If you need the code or do not know the POC for your organization, please email jhouk@acialliance.org. Please refer to the rate chart, found here: https://www.acialliance.org/page/ci2024registration.

The organization must be in good standing during the registration process and through the conference timeframe. Please work with the Point of Contact for your organization to add additional members to the account or send jhouk@acialliance.org an email and I will update your organizational member account.

Members can find colleagues from other member organizations in the member directory. To protect the privacy of our members, you must log into your account to access this feature. To access the directory, look under the Members tab, and click on directory. https://www.acialliance.org/page/Directory

Student Opportunities
Student Scholarships, Reduced Rates, Poster Competition, and SIG

We offer student scholarships for complimentary registration at the meeting. Students competed via an application that was reviewed by a committee. Students applying for scholarships were encouraged to submit Posters and participate in the Student Poster Competition. This year’s student scholarship recipients have been released. Congratulations to all! https://www.acialliance.org/page/CI2024Students

All students who submitted a poster abstract prior to the October 18 deadline and were accepted through the review process, are eligible to compete in the Student Poster Competition. Posters will be judged on:

- Content/Poster Organization & Preparation
- Display Appearance
- Originality and Merit
- Oral Discussion/Knowledge & Presentation

Special Interest Groups
ACI Alliance established Special Interest Groups (SIGs) at last year’s CI 2023 conference in Dallas. This was well received and will continue this year in Vancouver. More information to follow, stay tuned!
REMOTE PROGRAMMING

Expand your reach and offer your patients virtual cochlear implant programming appointments!
• The only app for complete remote CI programming
• The world’s first app for programming CI + hearing aid

Learn more at AdvancedBionics.com
Over the past 35 years, cochlear implant candidacy criteria have expanded to include children and adults with more residual hearing, including those who have profound hearing loss on only one side. Cochlear implantation in SSD or asymmetric hearing loss (AHL) became more commonplace a decade ago when research and clinical practice recognized the important benefits for both children and adults. Insurance remained hit or miss and typically required the CI clinic to seek coverage via appeals. With the 2019 and 2021 Food and Drug Administration (FDA) expansion of manufacturer CI criteria to include single-sided deafness, more patients with private insurance have been able to gain coverage. ACI Alliance conducted research on health insurance coverage in SSD or AHL (Sorkin et al, Otolgy & Neurotology 2023) and found that two-thirds of our member organizations were able to secure coverage most of the time though it nearly always took an appeal and a good bit of time by CI clinicians.

The specifics of coverage are still too restrictive in many private insurance policies—particularly for children—for whom the FDA manufacturer criteria specified CI in SSD for children over 5 years of age. Some insurers continue to decline children under age 5, even with appeals. The next article in this magazine is a detailed account of how one clinic, University of Michigan Medicine, was able to work with a private insurer in their state to successfully address the coverage challenge for children under age 5 with SSD.

Another hearing loss demographic that has been hampered in accessing coverage of CI for SSD and AHL are older adults who rely upon Medicare for their health insurance. Medicare continues to restrict coverage for beneficiaries who don’t meet the criteria for bilateral moderate to profound hearing loss. While there are anecdotal reports of some Medicare Advantage Plans providing coverage for CI for SSD, straight Medicare is not an option for SSD coverage. It is this group of older adults, those reliant upon straight Medicare, which has been completely left out of our changed perspective about the value of providing CI for SSD.

The ACI Alliance Board of Directors has taken on the challenge of exploring (and likely pursuing) a National Coverage Determination (NCD) for CI in single-sided deafness under Medicare. A committee of clinicians experienced in provision of CI for this population and knowledgeable about patient outcomes with CI in SSD was formed to carry out the collection of data and development of an NCD document. We are being aided in the process by the ACI Alliance public affairs advisors—the firm of Powers, Pyles, Sutter & Verville—a Washington DC-based law firm which focuses on healthcare, education, and government relations. Powers supports ACI Alliance on a number of topics and has worked with other healthcare interest groups on the NCD process.

Unlike the NCD that was undertaken to expand candidacy criteria for bilateral deafness, which involved the conduct of a prospective study to demonstrate outcomes for patients with expanded indications (https://www.acialliance.org/page/MedicareExpansion), we plan to submit the NCD request based upon data for older adults who have already received a CI for SSD. We have been encouraged by CMS staff to collect and submit individualized patient data along with published studies on CI in SSD. Our efforts are being led by Maura Cosetti MD with participation by audiologists and physicians: Allison Biever AuD; Kevin Brown MD, PhD; Michael Hoa MD; Meredith Holcomb AuD; Andrea Warner-Czyz PhD; and Daniel Zeitler MD.
There is a strong foundation of scientific literature that demonstrates early cochlear implantation is a safe and effective strategy to optimize listening and spoken language. Cochlear implantation is FDA-approved for children with bilateral profound hearing loss starting at 9 months of age, but the stated criteria in many private insurance plans for individuals with single sided deafness (SSD) states that candidates be 5 years of age or older. This difference in age criteria for single sided and bilateral deafness in insurance plans is not founded in scientific data. Rather, it is likely due to the recent FDA criteria for single-sided or asymmetric deafness.

FDA guidelines regulate the device manufacturer. They provide important information to clinicians but do not regulate the practice of medicine or whether medical services and devices are reimbursed by health insurances. In fact, the FDA website states: “Good medical practice and the best interests of the patient require that physicians use legally available drugs, biologics, and devices according to their best knowledge and judgement.” Following FDA approval, insurers determine whether to “cover” the device. Access to cochlear implantation typically depends on the insurer’s coverage decision and inclusion/exclusion guidelines.

While practicing clinicians’ influence on FDA approvals is often limited, our potential to influence insurer policies is not. Michigan Medicine’s Cochlear Implant program has successfully appealed on an individual case-by-case basis for cochlear implantation for children under age 5 years with SSD for several years. We recently took a broader approach to this issue by advocating for an insurer policy change to specifically include coverage for cochlear implantation for children with SSD under age 5 years. We approached Blue Cross Blue Shield and Blue Care Network of Michigan (BCBS/BCN) because:

- Their coverage for cochlear implantation for children with SSD begins at age 5 years
- They are the payor for a significant portion of our patients
- They stopped allowing voluntary prior authorizations in 2023, effectively halting our ability to appeal for coverage outside the plan’s inclusion guidelines in advance of surgery.

Insurers review medical policies on a periodic basis; policies often include a table outlining policy revisions and the schedule for policy revisions. We learned that this insurer’s policy for cochlear implantation was due for revision in November 2023, so the timing was right to advocate for change. Our team reached out to the insurer via authorization, payer oversight, and revenue cycle contacts at Michigan Medicine to discuss their policy. This required several inquiries to multiple individuals over the span of several months, but eventually we were successful in receiving an invitation to meet with the task force responsible for evaluating the insurer’s cochlear implant coverage policy. The parents of one of our pediatric patients affected by this policy

continued on page 14
were instrumental in securing this first meeting. Task force members included clinical utilization specialists and medical writers.

Recognizing that insurers must balance multiple priorities, we focused on relaying a business case for policy change in addition to providing a strong foundation of convincing medical outcomes. We conveyed to BCBS/BCN that lowering the age of cochlear implant coverage for children with SSD would not increase the number of covered lives; rather the change would allow for the same children to receive a cochlear implant earlier. We cannot expect that insurance policy writers will be content experts in every area in which policies are created. We clarified that congenital profound hearing loss will not improve over time, a child born unable to hear from one ear would become a candidate for cochlear implantation under their existing policy at age 5 years, and outcomes for children worsen as duration of deafness increases. Thus, lowering the age of coverage would not result in increased number of patients covered, but rather, better alignment of their current coverage to optimize performance. Simply stated, we were not asking to implant more kids, just the same kids—earlier. This change would not only optimize outcomes; it would also decrease the administrative burden of appeals for non-covered benefits. The medical basis for earlier implantation was relatively simple to convey; we leaned heavily on the ACI Alliance candidacy statements and related task force documents to summarize current literature supporting cochlear implantation with specific attention to the importance of duration of deafness as a prognostic indicator (Park et al 2022).

https://www.acialliance.org/page/DeterminingCICandidacy

Once we had presented the logic for decreasing the age of coverage for children with SSD, we made specific recommendations on the verbiage of the policy. We advocated for simplification of the coverage policy to encompass implantation for pediatric and adult individuals with bilateral hearing loss, asymmetric hearing loss, and SSD under the same criteria rather than setting separate guidelines for each group. The result, which was adopted by BCBS/BCN of Michigan on Nov 1, 2023, simplifies inclusion guidelines for traditional candidates. An excerpt from the updated policy is shown below:

*Unilateral or Bilateral cochlear implantation with an FDA approved cochlear implant is considered an established, safe, and effective therapy for individuals who are 9 months of age or older and who meet the following criteria:*

Unilateral or bilateral moderate to profound pre- or post-lingual sensorineural hearing loss

OR

Limited or no benefit from hearing aid(s), defined as an aided monosyllabic word score of less than or equal to 50% correct in the ear to be implanted

We followed up after our meeting with a written summary of discussion points, copies of salient literature, and a proposal of a revised coverage policy. The goal of this communication was to make it as easy as possible for the insurer team to incorporate the recommended changes. We credit the BCBS/BCN of Michigan team for embracing external input on their coverage policy, which we anticipate will lead to improved outcomes for patients. We encourage other cochlear implant programs to advocate for improvements in insurance coverage for their patients, in hopes of improving the national landscape for patients with SSD. ■
2023 Summary of Major Organizational Accomplishments

A detailed version of the 2023 Accomplishments (as well as prior years’ listings) may be found on the ACI Alliance website:
https://www.acialliance.org/page/AboutUs

AWARENESS

• Advanced comprehensive public awareness campaign on the 2022 Medicare expansion (via a National Coverage Determination) with diverse audiences to discuss older adults and CI for people of all ages. Published authored articles (cover story in *The Hearing Journal*, articles in the HLAA consumer magazine, the magazine of the International Hearing Society (IHS) for hearing aid dispensers), and provided content for numerous other articles. Conducted a lunch-time virtual course with continuing education credits for IHS members. 
https://www.acialliance.org/page/MedicareExpansion

• The fourth paper in the candidacy series on candidacy bilateral deafness in adults was published in June 2023 in *The Laryngoscope*. 
https://onlinelibrary.wiley.com/doi/full/10.1002/lary.30879 All four candidacy papers were endorsed by the American Academy of Audiology and are available open access with summary infographics. 
https://www.acialliance.org/page/DeterminingCICandidacy

• Published the 50th post for Naama’s *Blog: Cochlear Implant Rehabilitation for Adults*. Blog is #2 in Google search for adult CI rehabilitation. 
https://www.acialliance.org/page/AdultRehab

• Published two “Patient Handouts” in *The Hearing Journal*: Managing Auditory Fatigue and Using the Telephone with a Cochlear Implant.

• ACI Alliance website resources appear on page one of Google search for 66 CI related terms, up from 50 in the prior year. The website is a “featured snippet” for five keywords featured at the top of the search page organically. Examples of page 1 terms include: cochlear implant for older adults, cochlear implant candidacy, steps to a cochlear implant, age limit for cochlear implant, cochlear implant insurance, and Veterans and cochlear implants.

• Two issues of *Calling* magazine were published; the free *Listening* magazine audience grew to 9,000 subscribers. 
https://www.acialliance.org/page/ListeningACIAlliance
*Listening* is a widely used resource for those interested in, but outside of CI care.

• Emphasized hearing health in primary care by facilitating presentations by CI clinicians at state meetings of family physicians. Published editorial on hearing health and primary care.
https://journals.lww.com/thehearingjournal/fulltext/2023/09000/increasing_cochlear_implant_awareness_in_hearing.6.aspx

continued on page 17
2023 SUMMARY OF MAJOR ORGANIZATIONAL ACCOMPLISHMENTS  continued from page 16

- Encouraged global awareness of hearing health as part of The World Hearing Forum’s outreach and stakeholder initiatives.

- Emphasized outreach to the broad audiology community with collaboration with the organizations of audiologists (ASHA, AAA) and presentations on the AudiologyOnline platform. Organized and presented a 5-part series in March 2023 on AudiologyOnline—Adult Assessments in Hearing Healthcare: Working Across the Continuum.
  https://www.acialliance.org/page/AdultCIWebinars2023

- Expanded adult consumer/parent resources with six new recorded webinars for a total of 12 free webinars with over 3500 views; most popular topics are surgery (700 views) and activation (600 views).
  https://www.acialliance.org/page/Webinars

- Developed and re-organized website content to respond to inquiries and public discussion on cochlear implants for children, adults, and advocacy. A needed new resource is Cochlear Implant Misconceptions, which takes on myths often expressed in articles and other media.
  https://www.acialliance.org/page/cimisconceptions

- Organized and presented at a joint January 2023 webinar organized by the American Academy of Pediatrics and the American Society of Pediatric Otolaryngologists with a focus was on understanding and discussing the principles of newborn hearing screening and hearing loss with families.

RESEARCH

- CI2023 Dallas: Emerging Issues in Cochlear Implantation was held May 18-21, 2023 as an in-person meeting. The conference premiered three new Special Interest Groups (SIGs) for adult rehabilitation, student/resident mentorship and support, and needs of hearing health professionals with hearing loss. SIGs have continued to meet.

- An ACI Alliance supported study “Cochlear Implantation and Educational and Quality-of-Life Outcomes in Adolescence” by an interdisciplinary team led by Ivette Cejas PhD was published in JAMA Otolaryngology Head and Neck Surgery in 2023. Children with CIs had better academic performance compared with children without CIs with similar levels of hearing loss and outcomes were similar to typically hearing children. (See page 19 for a summary of the research findings.)
  https://jamanetwork.com/journals/jamaotolaryngology/article-abstract/2806314

- Presented findings on Early Hearing Detection and Intervention (EHDI) websites at the EHDI 2023 Conference and suggested how state EHDI agencies could improve their websites to better support parent decision-making.

ADVOCACY


continued on page 18
and bias in the AAP report and was the only publicly shared comment on the AAP website though other organizations wrote privately, expressing concern. https://publications.aap.org/pediatrics/article/152/3/e2023063288/193755/Hearing-Assessment-in-Infants-Children-and

• Grew State Champion network to 177 members representing 45 states and Washington, DC. State Champions were instrumental in leading efforts for a range of state policy changes.

• Involved consumers and parents via CI CAN (Cochlear Implant Consumer Advocacy Network) in advocacy, engaged them as moderators in webinars, and published their stories.

• Supported member involvement in state LEAD-K bills, which are designed to limit parent choice on communication for children with hearing loss. Led Parent Choice alliance with other organizations in the field, coordinating to address proposals that could limit access to listening and spoken language options for children with hearing loss.

• Began initiative to explore and suggest research-based communication tools on the benefits of listening for language development in children with hearing loss to address the misinformation being shared by some professionals that unless children use ASL, they will be “language deprived.” The group, now referenced as the Literacy Task Force, developed and disseminated a “Listening—Language—Literacy” infographic that has been widely utilized. Multiple dissemination activities are underway including an editorial in The Hearing Journal entitled “The Power of Parents.” https://www.acialliance.org/news/662649/The-Power-of-Parents--Language-Nutrition.htm

• Expanded advocacy on congenital Cytomegalovirus (cCMV) to advance screening and awareness. Collaborated with National CMV Foundation and other national organizations on state and possible federal legislation. Joined a new multidisciplinary coalition—Connections—focused on CMV legislation and a national guideline for newborn screening.

• Continued work on CI for adults under Medicaid. Washington and South Carolina finalized coverage starting January 1, 2024. Advocates in Georgia, Arizona, Colorado, and Missouri are working for adult coverage.

• Organized task force to pursue CI coverage in SSD under Medicare.

BUILD AN EFFECTIVE ORGANIZATION

• Expanded involvement of students and trainees to encourage CI as a career with scholarships, poster competition, and the new SIG.

• Increased military memberships with plans for specific programming for these members.

• Special interest groups (SIGs) formed with meetings at CI2023 for students/residents, members with hearing loss, and professionals wanting to explore rehabilitation for adults post CI.
What is the award-winning Cochlear™ Nucleus® SmartNav System designed to do for you?

- Electrode Placement Check
- Angular insertion depth
- Speed of insertion
- Impedance
- Advanced and AutoNRT® measurements
- Electrical Stapedius Reflex Threshold (eSRT)
- Automated Implant Registration
- Data transfer to Custom Sound® Pro Fitting software to support MAP creation

As a part of our Connected Care portfolio of surgical care solutions, SmartNav has been designed to enable a streamlined experience from surgery to clinic. Through intraoperative data transfer to Custom Sound Pro, clinicians can be assured surgery has been successful and have a baseline to confidently program patients and help optimize hearing outcomes.2–4

See for yourself! Visit www.cochlear.us/acia-calling and contact your local Cochlear representative today for a SmartNav demo.


This material is intended for health professionals. If you are a consumer, please seek advice from your health professional about treatments for hearing loss. Outcomes may vary, and your health professional will advise you about the factors which could affect your outcome. Always read the instructions for use. Not all products are available in all countries. Please contact your local Cochlear representative for product information.

©Cochlear Limited 2023. All rights reserved. Cochlear, Hear now. And always, Nucleus, Kanso, Baha, Osia, the elliptical logo, and marks bearing an ® or ™ symbol are either trademarks or registered trademarks of the Cochlear group of companies (unless otherwise noted).
Long-Term Educational and Quality of Life Outcomes of Cochlear Implants for Early Implanted Children

Ivette Cejas PhD
Director, Family Support Service / Children’s Hearing Program
Department of Otolaryngology
University of Miami

As one of the few psychologists working as part of a hearing implant team, I have benefited from the multidisciplinary collaboration both clinically and in terms of my research. Some of my earlier work was from the Childhood Development after Cochlear Implantation (CDaCI) study (PI: John Niparko). A multi-site national cohort study on the benefits of pediatric cochlear implantation across six nationally representative cochlear implant programs. This study was funded by the National Institute on Deafness and Other Communication Disorder, NIH for 15 years and allowed us to follow 188 deaf children for 13 years post-implantation. Dr. Niparko’s unique vision for this multidisciplinary team of investigators, including otologists, audiologists, speech and language therapists, and psychologists was at the forefront of pediatric hearing loss care and is what today we would describe as the ideal team for pediatric hearing loss management. Moreover, the CDaCI study was innovative for its time and not only evaluated audiological outcomes, but also assessed the impact on the family, as well as quality of life (QoL) and social, emotional, cognitive, and academic outcomes.

Today, this study that initiated in the 2000s continues to provide valuable data that provides evidence of the long-term benefits of cochlear implantation. Along with the support from the American Cochlear Implant Alliance, I recently published a manuscript, *Cochlear Implantation and Educational and Quality of Life Outcomes in Adolescence* along with my colleagues David Barker, Esteban Petruzzello, Christina Sarangoulis, and Alexandra Quittner. Our multidisciplinary group of investigators of psychologists, health economists, and experts continued on page 20
in modeling worked together to evaluate the differences in academic achievement and quality of life between two cohorts.

Comparisons were conducted between the CDaCI cohort (individuals with cochlear implants) and the National Longitudinal Transition Study-2 cohort, which included individuals with severe to profound hearing loss who did not use cochlear implants. The majority of research to date has focused on the early developmental periods as well as audiological and speech outcomes while this study addressed the long-term educational and quality of life outcomes in adolescents using cochlear implants for over 13 years.

Findings from this study indicate that children with severe to profound hearing loss who use cochlear implants have better educational outcomes and quality of life, regardless of age at implantation, than non-implanted children. Specifically, children in the CDaCI cohort had better educational outcomes in reading, writing (Woodcock Johnson) and quality of life compared to non-implanted children with severe to profound hearing loss. Children implanted prior to 18 months of age had the highest levels of oral language and academic achievement.

Overall, these data provide evidence that children with severe-to-profound hearing loss with CIs can achieve at or above expected levels compared to hearing peers and that the achievement levels are maintained through adolescence. Importantly, these educational outcomes also carried over to quality of life. Adolescents with CIs reported better QoL on the generic PedsQL measure across all subscales compared to the non-implanted comparison samples. Adolescents in the CDaCI cohort reported QoL scores within the same range as normative data for healthy controls on the PedsQL. In general, there were minimal differences observed for the early versus late implantation groups, suggesting that there are benefits in QoL regardless of age at implantation.

Our study highlighted at or above expected levels of performance in language and academic achievement for children who received early identification and intervention. Our follow-up study, funded by ACI Alliance, will discuss how hearing loss and cochlear implantation affect educational attainment and earning, and will provide lifetime and societal cost estimates for individuals with severe to profound hearing loss with and without cochlear implants.

Editor’s Note: This study is an important input to our efforts to argue for parental choice and support of communication options for children who are deaf and hard of hearing. The study referenced in the above article is: Cejas I, Barker DH, Petruzzello E, Sarangouls CM, Quittner AL. Cochlear Implantation and Educational and Quality-of-Life Outcomes in Adolescence. JAMA Oto Head Neck Surg. 2023; 149(8):708-715.
In 2023, the ACI Alliance State Champions network grew to over 170 members in 45 states and Washington, DC. As this network of clinicians, CI recipients, families, educators and others expands, so does our ability to impact public policy issues. State Champions were instrumental in supporting key policy changes this year and supporting educational efforts at the state and federal levels. Our successes built on the foundation laid in previous years, which will continue pathways to improvements in access for the cochlear implant community in the future.

An area that saw important successes this year was expansion of Medicaid to cover CI for adults. Arizona was close to reinstating coverage early in 2023, and advocates there have begun meeting with sponsors to begin the process again in 2024. Georgia will pilot a one-year program to cover parts and services for adults who were implanted as children under Medicaid. This short-term change will, we hope, provide a path forward for Georgia Champs to make parts coverage permanent and provide a “foot in the door” for coverage of adult CI surgery. As of January 1, Washington and South Carolina joined the majority of states covering adults under Medicaid. Our effective South Carolina Champs expect to see this adult coverage include CI in SSD! Colorado and Missouri have taken steps to start the process to attain adult coverage in 2024.

We expanded advocacy efforts on cCMV screening and awareness. ACI Alliance supported efforts of State Champion network who wish to promote legislation in their state by providing research, bill text examples, letters, and sharing of information between states. In collaboration with the National CMV Foundation and other associations on generating interest and support for a federal bill that will hopefully be introduced in the House and Senate in 2024. States that passed CMV screening legislation in 2023 are Texas (targeted) and Connecticut (universal). Legislation is ongoing in Massachusetts and Michigan and work continues in Maryland and Delaware.

Public policy has its share of frustrations and setbacks do occur. Two bills (MT and MO) that could limit information parents receive on language and technology passed despite the strong efforts of a group of advocates. Our Champions and their partners continue to maintain that access to language should not be limited to only one path and that all information presented to families must be unbiased and support their decision as required by federal laws. We were pleased to learn that the 2022 Los Angeles School Board resolution that would have limited communication choice was not implemented due to legal concerns that it violated IDEA law. ACI Alliance and others had publicly opposed that measure and communicated directly with the school board.

Our Champions are also essential in helping us pinpoint emerging issues. One such issue is the continued denial of SSD coverage despite FDA approval. Our work resulted in United altering its coverage to include this benefit and a growing number of Blue Cross plans are doing the same. But this effort will be on going for the foreseeable future including the work with CMS to expand Medicare coverage for this benefit.

The above items are just a glimpse of the work our advocacy networks accomplished in 2023. They as well as our consumer network, CI CAN, utilized our action alert platform to send over 150 messages to Congress on a number of federal bills. These include passing Ally’s Act, fully funding IDEA, the Air Carrier Access Amendments Act (ACAAA) and more. Our Action Alert page is found on our website at https://www.acialliance.org/page/actionalerts.

I have no doubt that 2024 will also be an incredibly busy year for ACI Alliance and our advocates. Each state and federal legislator we meet with, each piece of information that is shared, every Action Alert sent is yet another brick that paves the road to our collective successes. If your state is lacking adult coverage for CI—or if there is another topic that needs to be addressed—please let us know.

If you want to be involved, join our network and future advocacy efforts! For more details, contact me at nwestin@acialliance.org.
The World Hearing Forum (WHF) hosted a hybrid in-person and virtual meeting for stakeholders and members in Geneva, Switzerland on November 27-29, 2023. The WHF is an initiative of the World Health Organization, founded in 2018 to support a World Health Assembly resolution that encourages all countries to include ear and hearing care within their national health systems. The WHF is a diverse body of government and non-government organizations, professional societies, parent groups, academic institutions, and other ear and hearing care stakeholders.

As a founding member of the World Hearing Forum, ACI Alliance was pleased to attend and participate virtually to discuss important topics on hearing health care, World Hearing Day, and related topics. The three-day meeting was attended by individuals representing organizations around the globe and included breakout sessions on various topics. Discussions included global societal perceptions of hearing loss and brainstorming on how to better integrate hearing healthcare into primary care across the lifespan.

The meeting participants also discussed the campaign details for World Hearing Day. World Hearing Day is March 3, 2024, and the theme is “Changing Mindsets: Let’s make ear and hearing care a reality for all!” More information is available on the WHO website, and we encourage all ACI Alliance members and organizations to participate: www.who.int/campaigns/world-hearing-day/2024.

On the last day of the meeting, participation was limited to WHF member organizations whereas the first two days included other non-member participants. During this session, WHF members discussed organizational and membership issues related to the World Hearing Forum, as well as WHF priorities and the path ahead. Members of the WHF can participate in different working groups with a particular focus, including member engagement; changemakers; external relations; “Make Listening Safe”; and “World Hearing Day.” Each of those topical groups met during the Friday meeting to discuss the work ahead and select new leadership.

After the initial launch of the World Hearing Forum in December 2019 (which was attended in person by ACI Alliance Executive Director Donna Sorkin), we have continued to participate and contribute virtually. ACI Alliance recently renewed our membership with the WHF through 2025. We look forward to our continued involvement in the World Hearing Forum and the important work ahead to expand access to hearing health globally.

Details about our membership and work with the WHF are available on our website at www.acialliance.org/page/WHO.
Listening → Language → Literacy for All Deaf and Hard of Hearing Children

Donna L. Sorkin MA
Executive Director, ACI Alliance
dsorkin@acialliance.org

At CI2023 in Dallas, we launched the initial product of Listening → Language → Literacy, an initiative begun by individuals who support families of children who are deaf and hard of hearing. The task force completed a 6-month collaborative process to develop research-based messages on the benefits of listening for language development and literacy designed to support and motivate others to get involved.

A partial list of what has transpired since the June launch follows with more events and projects on the way. We encourage our members and others in our community who support listening to take on this important effort to dispel inaccuracies regarding outcomes for children who are deaf and hard of hearing. The initiative emphasizes the critical role of parents and other family members in supporting children in using the language of the home—whether that be English, Spanish, ASL, or another.


- Parent Information Center of Delaware offered a webinar on Listening Language and Literacy on improving reading outcomes for children with hearing loss. I was pleased to join Delaware reading experts Roberta Golinkoff and Dianne Nichols.

- “Opening Doors—Unlocking Potential,” The Commonwealth of Virginia’s Conference in Deaf and Hard of Hearing Education will feature language and literacy at the summer 2024 event for parents and professionals.

- Led by bilingual audiologist Alejandra Ullauri AuD, the Listening → Language → Literacy infographic will be translated into Spanish and disseminated to professionals and families.

- Partnering with AudiologyOnline, ACI Alliance will present a two-part series “The Power of Parents” featuring Dana Suskind MD and Karl White PhD. https://www.acialliance.org/page/CIWebinars2024

- Listening Impacts on Literacy and Learning in Children with Cochlear Implants is one of the conference themes for CI2024 Vancouver: 17th International Conference on Cochlear Implants and Other Implantable Technologies, taking place in July. A number of presentations will focus on this key topic in Vancouver.

- “Long-Term Educational and Quality of Life Outcomes of Cochlear Implants for Early Implanted Children” was published in 2023 (Cejas, JAMA Oto). This recent study provides important findings on literacy impacts of cochlear implants for children when CI is provided at an early age.

- “Language Nutrition: The Key Role of Parents in Fostering Language and Literacy” will be presented at the upcoming Early Hearing Detection and Intervention conference in March 2024.

- “Do our societal and educational systems value listening for children who are deaf and hard of hearing?” will be presented at the upcoming conference of the American Academy of Audiology in April 2024. With partners in the field, I will be exploring how we support listening for children with hearing loss. Where are the strong points in the educational system and where are we failing? What are the perceptions of opportunity for deaf and hard of hearing children? How can all of us improve public understanding of the value of hearing technology and support services under early intervention and education?

We have an ambitious program of outreach planned on this topic. Please contact me if you want to get involved! For updates on the work of our partners in the community, visit www.acialliance.org/page/listeninglanguageliteracy.
Participation in the ACI Alliance Medicare Expansion Study Changed My Life!

Ann Liming

I first learned about cochlear implants (CIs) from my older sister, who was diagnosed with hearing loss when we were in high school. After high school, my sister was fit with a hearing aid but she continued to lose her hearing after she had a child. She eventually received a cochlear implant and told me that it changed her life.

I got involved in the Hearing Loss Association of America chapter in Grand Rapids (MI) and learned more about CIs through that group including learning directly from several people about the life-changing benefits of a cochlear implant. When I was evaluated for a cochlear implant, I did not qualify (for having too much hearing), and it was frustrating to have conversations with others who would urge me to consider a cochlear implant when I knew I didn’t qualify for the device under existing Medicare criteria.

During this time, I visited an out-of-state friend who also had hearing loss and realized just how hard it was for her to communicate. If she were doing dishes, cooking, or any activity with noise we couldn’t speak with each other at all. I would occasionally forget this and initiate a conversation with her, but quickly realized she wasn’t able to hear me. This made me realize the frustration my own friends must feel trying to have conversations with me, so after my trip I went home and asked my friends what it was like to communicate with me. I was met with dead silence from my friends and realized I needed to get another evaluation for a cochlear implant.

While I still did not qualify at that time, I learned about the Medicare coverage expansion study during my evaluation and was able to join the study.

As I prepared for my activation, I thought about conversations I’d had with my sister about what voices sounded like with a cochlear implant. She said that it “sounds like everybody else” but when my audiologist (Terry Zwolan PhD) activated my cochlear implant my first thought was this is awful. I quickly realized there was a learning curve and an adjustment period to get to my new normal. At Dr. Zwolan’s recommendation, I listened to audiobooks and remember looking through the rehab programs and apps that were recommended before my mapping appointments to make sure I was aware of all of her recommended options. Gradually my cochlear implant became my new normal through this process.

I currently have one cochlear implant and use a hearing aid in my other ear and am currently considering a second cochlear implant. I am astonished that I can’t hear well at all with my hearing aid alone, but when I use it with my implant everything is better. A second cochlear implant has been suggested for me and I am currently weighing my options since my cochlear implant has allowed me to start playing the piano again and I am not sure I want to change my current situation.

One of my long-term frustrations had been hearing from other people how wonderful their experience had been with a CI, but not qualifying for one myself for so long. My CI is very visible since she I wear my hair short. Hence, I find myself regularly talking about my hearing loss and my cochlear implant with people I see in stores and around town. I always tell people if they need a CI and qualify for it, not to put it off.

I still have some issues with hearing on the phone with some voices and accents, but I love that I have the confidence in most situations to make and receive phone calls. That, for me, is a miracle. I also love the new features of my cochlear implant including the linkage to Bluetooth. I love to help others learn to utilize all the features and accessories of their hearing technology.

I was a nurse and feel disappointed when some people won’t even think about a CI for various reasons. I want to share my story because my CI is a gift to me. I was thrilled to be a part of the Medicare expansion study and help others have access to this extraordinary technology.

Ann (right) talks with her niece
Confidence over the phone
Captions confirm every word they hear

CapTel® Captioned Telephones show captions of everything a caller says over the phone. It’s like closed captions on TV, only for phone calls. CapTel restores a patient’s confidence in talking over the telephone, knowing they can confirm what they hear just by reading the captions.

1-800-233-9130
captel.com