



Donna L. Sorkin, *Editor*

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Message from the Chair

MESSAGE FROM THE CHAIR

Andrea D. Warner-Czyz PhD

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The University of Texas at Dallas

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Staying within our comfort zone helps to build self-assurance and limit stress, but stepping outside areas of familiarity provides a different set of benefits

such as boosting knowledge, expanding experiences, and increasing resilience. Conferences afford an excellent venue to push ourselves to attend sessions on topics outside our area of expertise and network with researchers, clinicians, educators and other stakeholders from around the world.

The American Cochlear Implant Alliance conference in Vancouver exemplifies the varied opportunities available at professional meetings. Drs. Jake Hunter and Viral Tejani led this year's scientific program committee to craft a conference highlighting exciting presenters, novel topics, and multiple networking opportunities. I would be remiss not to mention the sensational sessions by Niparko Memorial Lecturer Dr. Ruth Litovsky and keynote speakers Drs. Jill Firszt, Andrej Kral, and Debara Tucci. These esteemed colleagues updated attendees on cochlear implantation in individuals with bilateral

and single-sided deafness, implant considerations related to development of the auditory system, and public health implications relative to broader hearing healthcare. Sessions spanned interdisciplinary topics from surgical techniques and issues to assessment, mapping, rehabilitation, and outcomes across the lifespan to disparities and inequities in service delivery. Attendees also had several occasions to interact via Special Interest Group luncheons and receptions.

I tend to review conference programs ahead of time and select sessions related to my areas of expertise. However, thanks to the scientific program committee, I had the incredible opportunity to co-moderate a session called Electrode Array Design. This session featured five surgeons from around the world discussing innovative changes to the internal device—hydrogel coating, drug eluting electrodes, shape memory polymers—to minimize insertion trauma and enhance outcomes in cochlear implant recipients. Attending this session increased my appreciation for the intricacies of the electrode array and the pioneering methods in which my colleagues are moving the field forward. Moderating this session also reminded me of the benefits of taking advantage of the interdisciplinary focus of the American Cochlear Implant Alliance conferences.

Just as I encourage you to learn from others by attending diverse sessions and conferences, I urge you to submit abstracts to share your experiences from clinical, research, and service

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Donna L. Sorkin MA

Ex Officio Board Member
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MESSAGE FROM THE CHAIR *continued from page 1*

delivery considerations related to development of the auditory system, and public health implications relative to broader hearing healthcare. Sessions spanned interdisciplinary topics from surgical techniques and issues to assessment, mapping, rehabilitation, and outcomes across the lifespan to disparities and inequities in service delivery. Attendees also had several occasions to interact via Special Interest Group luncheons and receptions. I tend to review conference programs ahead of time and select sessions related to my areas of expertise. However, thanks to the scientific program committee, I had the incredible opportunity to co-moderate a session called Electrode Array Design. This session featured talks by five surgeons from around the world discussing innovative changes to the internal device– hydrogel coating, drug eluting electrodes, shape memory polymers – to minimize insertion trauma and enhance outcomes in cochlear implant recipients. Attending this session increased my appreciation for the intricacies of the electrode array and the pioneering methods in which my colleagues are moving the field forward. Moderating this session also reminded me of the benefits of taking advantage of interdisciplinary focus of the American Cochlear Implant Alliance conference.

In addition to taking part in sessions outside your comfort zone, consider attending different conferences or webinars than your usual array of meetings to gain new perspectives that could enrich your clinical service delivery or research program. For instance, Hearing First offers an array of virtual learning experiences centered on audiology, listening and spoken language, and collaboration and counseling designed for professionals and parents. Course topics for live and self-study sessions include psychological and social aspects of hearing loss in children, assessment and management of children with single-sided deafness, and genetics and hearing loss.

The American Speech-Language-Hearing Association (ASHA) Convention in Seattle December 5-7 includes nearly 20 podiums or posters on cochlear implants across the lifespan. Of course I enjoy and learn from sessions on implantables, but my favorite session ever at an ASHA convention focused on real-time imaging of beatboxing. The speaker not only explained the sounds from an anatomical and physiological perspective, but also engaged the audience by having them mimic a drum machine with their mouth and voice. The point is that we should support unique chances to learn from experts both within and outside our areas of expertise.

As much as I appreciate the importance of diversifying attendance at conferences to educate ourselves on alternative viewpoints, I also value the consistency of attending conferences. With Vancouver just in the rearview mirror, we look ahead to our conference in Boston from April 30 to May 3, 2025. Drs. Esther Vivas and Keri Colio head an amazing scientific program committee comprised of respected surgeons, audiologists, scientists, speech-language pathologists, and educators from across North America. Themes of next year's meeting include candidacy, access, outcomes across the lifespan, CI in special populations (i.e., asymmetric hearing loss, congenital cytomegalovirus), and topics from an international perspective.

Just as I encourage you to learn from others by attending diverse sessions and conferences, I urge you to submit abstracts to share your experiences from clinical, research, and service delivery perspectives with others in the cochlear implant field. The abstract submission portal for the 2025 meeting closes on October 9. Thank you for your contributions to our next conference, which will allow us to step outside our comfort zone to learn more about global and interdisciplinary aspects of cochlear implantation. ■



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CI2025 Boston: Conference on Cochlear Implants

April 30-March 3, 2025

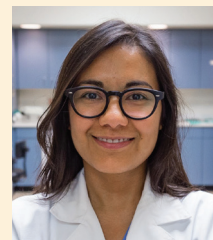


Keri Colio AuD | Co-Chair
CI2025 Boston Program Committee
Rady Children's Hospital San Diego

Esther X. Vivas MD | Co-Chair
CI2025 Boston Program Committee
Emory University



Keri Colio AuD



Esther X. Vivas MD

We are thrilled to invite you to CI2025 Boston, which promises to be a landmark event for our community. As Program Committee Co-Chairs, we are excited to share that this year's conference will feature cutting-edge presentations, groundbreaking research, and interactive panels that will delve into the latest advancements in cochlear implant technology.

Boston, with its rich history of innovation, provides the perfect backdrop for us to come together, exchange ideas, and learn from leading experts and industry pioneers. This conference is not just an opportunity to expand our knowledge but also a chance to strengthen our collective efforts in shaping the future of hearing health.

We look forward to welcoming you to what we know will be an inspiring and impactful event!

What can you expect?

There will be a mix of session types with important keynote talks, podium sessions on a range of current and future CI concerns, interactive discussion panels, and poster presentations.

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Anticipated Session Topics (not limited to):

- Cochlear implant candidacy and outcomes in asymmetric hearing loss
- What can be done to improve CI access to underserved pediatric and adult populations
- Maximizing CI outcomes at both ends of the age spectrum
- Accessibility for cochlear implant and hearing aid users to other technologies
- Delivery Models for CI and related hearing services
- Electrode array, robotics, hearing preservation, surgical topics
- The future of gene therapy for children and adults with hearing loss
- Cochlear implants in the hearing health continuum: the US and around the world
- Early intervention challenges and opportunities / serving children in educational settings
- Access to hearing health by children with congenital CMV
- Listening, Language, Literacy in children with hearing loss
- Adult and pediatric (re)habilitation for adults and children with bilateral and unilateral deafness as well as those with other diagnoses

Student Opportunities: Scholarships, Posters, Poster Competition

We welcome full-time students, fellows, and postdoctoral scholars who have a clinical or research interest in cochlear implants to participate in the meeting. Student opportunities include the student scholarship program, participation as a scientific poster presenter (abstract submission and approval required), and eligibility for the student poster competition. Help us distribute the student information to all who are eligible.

Scholarships for full-time students, fellows and postdoctoral scholars who have a clinical or research interest in cochlear implants are awarded for our annual CI Symposium. Selected awardees receive waived registration expense to the meeting, a \$120 travel stipend, and complimentary student membership in American Cochlear Implant Alliance.

*The deadline to submit a CI2025 **Student Scholarship Application** is December 1, 2024.*

Apply here: [CI2025 Boston Student Scholarship Application \(jotform.com\)](https://ci2025boston.org/Student-Scholarship-Application/jotform.com)

Student Poster Competition

All students who submit a poster abstract prior to October 9, 2024 (deadline for all abstract submissions) and are 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

Abstract Submissions for CI2025 Boston Open Through October 9th

Submit your research for CI2025 Boston. Abstract submissions are open through Wednesday, October 9. We welcome submissions related to cochlear implant research and clinical care across the lifespan.
<https://ci2025boston.org/>

During the abstract submission process, select “Yes” for: “This abstract should be entered into the Student Poster Competition.” Opting in for the student poster competition is in the Abstract Submission Additional Details section.



Poster presenters must participate with a printed poster. The Poster Exhibit Session will be held on Thursday afternoon of the

conference (at the conference location at Omni Seaport) in advance of the Welcome Reception. Presenters must set up their poster early on Thursday to allow maximum viewing by attendees throughout the day. Posters are to remain on display through Friday afternoon. Authors are required to be present at their poster during the Poster Exhibit Session when attendees may interact directly with poster presenters on their research while enjoying refreshments during a dedicated session. Specific exhibit details will be published in early March. Poster Format Requirements are available now in the presenter area of the conference website.

www.CI2025boston.org

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We are looking forward to seeing all of you next spring in Boston, Massachusetts!



Field Trip to Mass Eye & Ear Otopathology Laboratory / Eaton- Peabody Laboratories

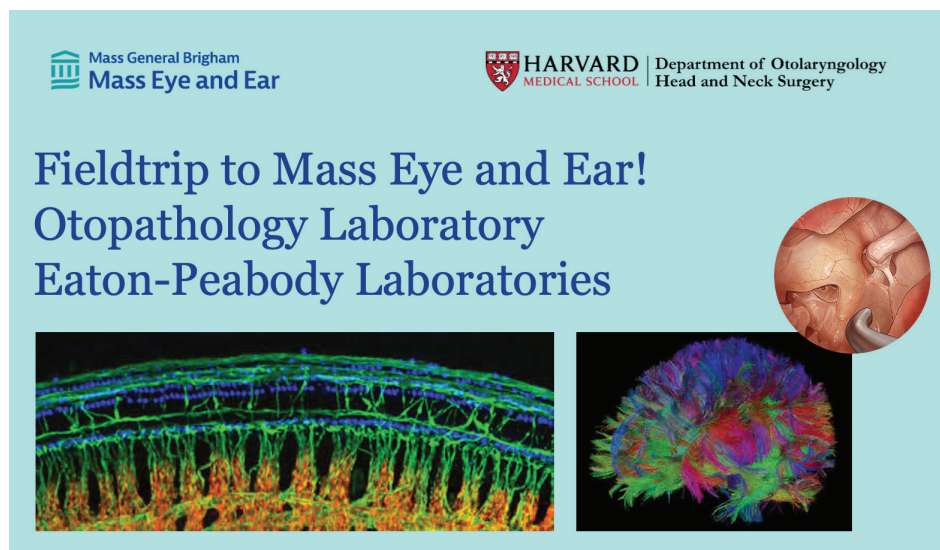
After the conference concludes, there will be an opportunity to visit the Otopathology Laboratory at Harvard Mass Eye and Ear, a basic and translational human temporal bone pathology laboratory with a mission to improve the diagnosis and treatment of disorders causing hearing loss and balance dysfunction. Current research is focused on cochlear implants, auditory brainstem pathology, vestibular dysfunction, and otosclerosis. The visit is free and will begin at 2:00, lasting about 90 minutes. Plan now to stay and visit this world recognized research facility. Sign-up available soon.

CEUs at CI2025 Boston

As in past years, we will be offering CEUs for attendees following the timelines and other rules set by CEU providers. To be accredited by these organizations, we must adhere to their timelines. In most cases, that means submitting a final CEU report within 30 days of the conference end date. For us submit accurate reports on time, we must receive completed CEU forms no later than 5 days after the conference has concluded.

We encourage educational professionals to pursue CEUs from conference participation. ACI Alliance will provide the materials needed for attendees to submit to state educational agencies that award continuing educational credits.

For questions on CEUs or process, please contact ACI Alliance staff person Jessica Houk
jhouk@acialliance.org. ■



AMERICAN
COCHLEAR
IMPLANT
ALLIANCE



CI2025 BOSTON



April 30 - May 3, 2025

Accessibility and Connectivity for Children and Adults with Cochlear Implants: It's Not Just About the (CI) Ear(s)

Donna L. Sorkin MA
Executive Director
American Cochlear Implant Alliance
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Over the past 30+ years, cochlear implantation has transitioned from a little known, controversial intervention to a proven means of providing meaningful access to sound for children and adults who derive minimal benefit from traditional amplification. Candidacy criteria were quite narrow initially, gaining insurance coverage could be difficult or impossible for some, and many people doubted that the technology really “worked.” I was privileged to be part of that early wave of individuals who benefitted but were also viewed by some (including my own mother) as guinea pigs for science. When my mother visited me several days after I was activated, she cried because she explained that she thought “it was all a bunch of hooley.” During those early days, the focus was very much on how patients would use the cochlear implant device. Connectivity for the phone was limited to direct plug-in. A separate and somewhat awkward device plugged into my body-worn processor and allowed me to connect to induction loops. To work, it had to be held in a vertical position. I finally figured out I could invert the connector device inside an empty glass to keep it vertical instead of my having to hold it up.

Three decades later things have changed importantly. Federal legislation like the Americans with Disabilities Act and the Telecommunications Act of 1996 placed the burden of addressing connectivity and inclusiveness on federal and state governments and on private companies. With the explosion of technologies and Internet-based products for everyone, the opportunities for inclusion expanded and are truly mind-boggling compared to what was available to me 30 years ago. Companies like Google, Microsoft, Apple, Amazon and others have jumped on the access bandwagon for everyone—including people with hearing loss.

Last summer in Vancouver, we debuted an AI-powered assistive listening solution designed for use with Bluetooth enabled mobile phones—technology that provides hearing accessibility easily and without the need to pick up an extra device (other than one's own mobile phone). Over

the years, I have become increasingly disenchanted with such devices in theaters which are often poorly maintained and provide no benefit to me. Many of our attendees who use cochlear implants, hearing aids, or no hearing device tried Bettear—developers of the technology and enjoyed improved listening at the sessions.

ACI Alliance is planning a unique session on Saturday morning at CI2025 Boston on accessibility and inclusion with representatives of the major tech companies.

There are plenty of other solutions available now or coming soon that will further modernize accessibility and expand inclusion. Clinicians and educators serving children and adults with hearing loss should join in to become knowledgeable and comfortable in supporting their patients and students to access these new options. It's not just about the CI; rather if we want to help people be fully included, we need to support them in knowing how their device connects with other technologies in a range of settings and what else is available more generally that will help them.

To help our members know better how to help their patients and students, ACI Alliance is planning a unique session on Saturday morning at CI2025 Boston on accessibility and inclusion with representatives of the major tech companies. We are thrilled to announce that



Vinton Cerf, Vice President and Chief Internet Evangelist at Google, has confirmed to moderate this session. Cerf is the co-designer of the TCP-IP protocols and the architecture of the Internet and is popularly referenced as one of the “Fathers of the Internet.” Cerf is the recipient of numerous

awards for his work including the US Presidential Medal of Freedom, the Queen Elizabeth Prize for Engineering, the Japan Prize, and many others. He holds 32 honorary degrees. Plan now to stay through for the Saturday conference sessions and attend this exceptional event on Saturday morning. ■

Highlights from CI2024 International in Vancouver, Canada

Donna L. Sorkin MA
Executive Director
American Cochlear Implant Alliance
dsorkin@acialliance.org



Joined by a large international crowd drawn heavily from the Americas—Canada, Latin, and the US—as well as representatives from around the world we celebrated cochlear implant progress, enhanced attention to the diversity of needs for recipients, disparities in CI provision, complex care, CI in SSD, the science behind why early CI is critical in children, service delivery models, the need for attention to (re)habilitation and much more. Keynotes highlighted where the field is today and where it is going.



Attendees noted “the conference was amazing and well organized in the spectacular Vancouver setting.” For some, it was the first time attending a meeting with short scientific talks; one first-timer noted “On the one hand, I wanted more information but on the other the other hand, I was completely immersed during the whole set of

presentations.” We appreciate the attendees who noted “Great job! Big thank you for everything—I even loved the food!” and “The panels were terrific—please include those in the future.”

For many attendees, the keynotes were the most appreciated element of the scientific program. Ruth Litovsky PhD delivered the prestigious John Niparko Lecture highlighting pathways to outcomes in bilateral cochlear implantation. Jill Firszt, a clinical audiologist and respected researcher, presented a keynote on a topic that she has worked on for over a decade.

We asked some attendees to provide us with their perspective on the conference and here’s what they said:



Program Committee Co-Chairs **Viral Tijani and Jacob Hunter**

We had a fun and invigorating time seeing all of our friends and colleagues in Vancouver, as well as exploring the city. The annual ACI Alliance conference is a multifaceted effort involving the program committee, ACI Alliance staff, and all of our colleagues who present and attend on topics ranging from basic science to clinical research. We are grateful to all those involved. We encourage the membership to get involved in ACI Alliance in any capacity to further our mission.

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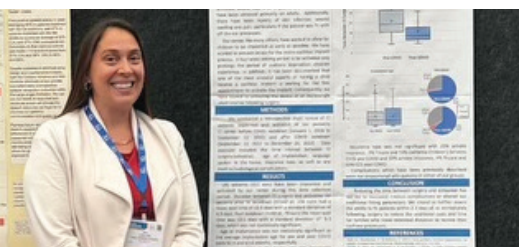
Daniel Zeitler, Conference Presenter, Board of Directors

Cochlear implantation for single-sided deafness has been a passionate project of mine for many years and I am really excited about the efforts that the American Cochlear Implant Alliance is taking to make sure that we get these patients treated with the technology that can benefit them the most. The conference highlighted this topic with a keynote, panel, and podium sessions that provided timely, research-based content.



Meredith Holcomb, Conference Presenter, Former Chair of the Board of Directors

To me, the American Cochlear Implant Alliance is a family. It's a community of people that meet once a year and to learn about cochlear implants and brainstorm about how to make this amazing technology more available and more utilized across the United States. But I think what I love the most about participating in ACI Alliance and in the conference is that everyone is working as a team trying to make a difference.



Keri Colio, CI Conference Program Co-Chair, CI2025 Boston

CI2024 Vancouver was a resounding success, bringing together experts, researchers, and clinicians from around the world. The conference featured insightful presentations on the latest advancements in cochlear implant technology, breakthrough research, and patient experiences. Attendees had the opportunity to engage in dynamic discussions, share knowledge, and explore new possibilities for improving hearing outcomes. The collaborative atmosphere fostered connections and inspired future innovations, making it a truly impactful gathering for the cochlear implant community. The conference inspired me as Program Co-Chair for CI2025 Boston for our work in planning the upcoming CI meeting.



Chris Sutton, Exhibitor (CEO Wavefront Centre, Vancouver)

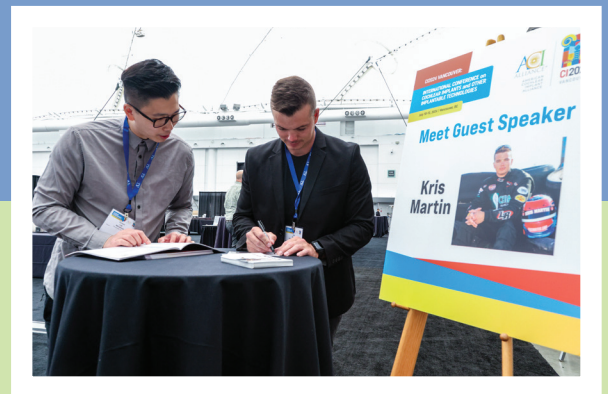
Wavefront Centre for Communication Accessibility provides communication accessibility and hearing health solutions for individuals who are Deaf, DeafBlind, and Hard of Hearing, and we were proud to serve as the audio accessibility partner at CI2024 Vancouver and connect with professionals from around the world who are passionate about hearing healthcare. We are excited to build on these connections from ACI Alliance and return to next year's conference to continue to push the boundaries of what's possible in hearing healthcare and accessibility.

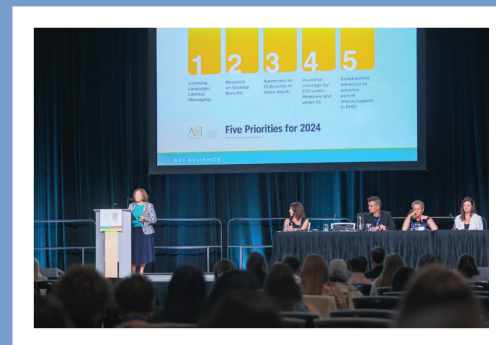


Itamar Gabbay, Exhibitor (Co-Founder and CEO, Bettear)

Having an exhibit booth at CI2024 Vancouver gave us a chance to highlight and explain the Bettear assistive listening technology available during the conference sessions. We spoke with many attendees about their experience using it and were able to use their feedback and provide real time answers to questions they had during their experience using the technology. Our team appreciated learning more about how the technology worked in this large conference setting enabling us to continue our work more effectively.

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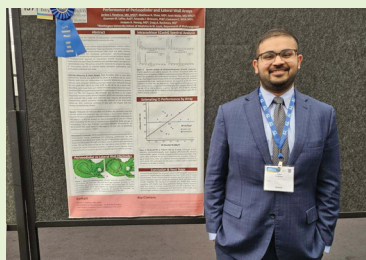


Student Poster Winners Weighed In



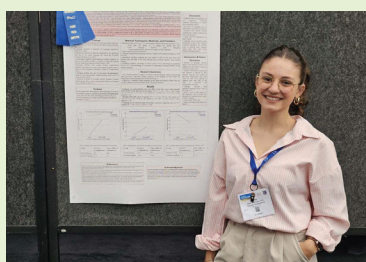
Robel Alemu, Student Poster Winner, University of Toronto

CI2024 Vancouver was my first time attending a conference organized by ACI Alliance. The conference offered informative lectures and engaging expert panels which made for an enriching and educational experience. There were also ample opportunities to have more personal conversations with clinicians and scientists over coffee and refreshments which allowed for sharing of ideas and experiences. As a participant in the student poster competition, I had the opportunity to communicate important findings from my graduate thesis research and engage in insightful discussions with expert judges. My time at CI2024 Vancouver was a positive and memorable experience.



Jordan Varghese, Student Poster Winner, Washington University in St. Louis

It was an honor for our project to be selected as a poster winner and to represent my Otolaryngology Department and Residency Program at Washington University in St. Louis. The conference provided a unique opportunity to meet professionals of diverse backgrounds united in caring for cochlear implant recipients. For anyone involved with improving clinical outcomes for patients with hearing loss, I would recommend attending a future ACI Alliance conference and meeting the incredible community dedicated to this effort.



Sofia Machado, Student Poster Winner, University of Houston

The CI2024 conference was a fantastic opportunity to learn about the research being conducted around the world in this field and to connect with other professionals. Participating in the student poster competition was a great way to showcase the research I've been doing at UH and receive important feedback. With so many high-quality research posters presented, being awarded first place in the rehab category was a pleasant surprise. I'm very grateful to have been part of this event in stunning British Columbia.

Content on CI2024 and Past CI Conferences on our Website under Conferences

Did you miss a talk at CI2024 Vancouver that you wanted to see, or were you unable to join us in Vancouver this summer? We will be posting videos of the four keynotes and selected other talks as well as PowerPoint materials (for presenters who gave permission to post their materials).

We have posted materials from every prior ACI Alliance conference from 2013 forward. For each conference, you can find the full program book, selected recorded sessions and PowerPoint materials, podium and poster abstracts, student poster and scholarship winners, and details on that year's Lifetime Achievement Award recipient. While not all conference sessions and materials will be available on the website, the content online is free to watch for both conference attendees and those who were not able to attend. Materials can be found here: www.acialliance.org/page/priorconferences.

Photos from Vancouver are running at the bottom of our website homepage. Take a look and be inspired to come to Boston! ■

What is the award-winning Cochlear™ Nucleus® SmartNav System designed to do for you?

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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.

1. Cochlear Limited. D1840640 Custom Sound Pro User guide.

2. Cochlear Limited. D1657378 ISS1 OCT19. Cochlear Nucleus® SmartNav App user guide (CAM).

3. Cochlear Limited. D1651764 ISS3 FEB20. Cochlear Nucleus® SmartNav App user guide (ROW).

4. Hoth, S, Dziemba OC. The Role of Auditory Evoked Potentials in the Context of Cochlear Implant Provision. Otol Neurotol (2017); 38(10): e522-e530.

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.

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Advocacy in 2024 and Looking Ahead to 2025

Nichole J. Westin MA

Director of Governmental Affairs
ACI Alliance

nwestin@acialliance.org



We advanced a number of positive advocacy efforts for ACI Alliance. With the support of our State Champions, we saw critical changes to insurance coverage, support for Congenital CMV (cCMV) screening and more focused efforts on supporting early intervention. We plan on doing even more in 2025.

Insurance Changes

The year kicked off with two more states, South Carolina and Washington, joining the majority of those that provide Medicaid CI coverage for adults. Efforts continue in Colorado, Arizona, and Missouri. Missouri came close to passage but failed due to political decisions outside of our Champions' control. We are hopeful that coverage of CI in adults will pass in 2025.

UnitedHealthcare announced that starting September 1, 2024 that the insurer will cover cochlear implants for children 6 months of age or older with bilateral sensorineural hearing loss as well as children 9 months of age and older with single-sided deafness. ACI Alliance has been working with United to improve coverage and we are pleased that they moved forward with this decision.

Federal Policy Efforts

The long-awaited introduction of a federal bill on cCMV screening occurred this year. The Stop CMV Act—S. 3864/H.R. 7542. This legislation would authorize new funding to incentivize hospitals and other health care entities that care for children to screen babies for cCMV within the first 21 days after birth. It also authorizes funding to collect data on cCMV and assist in the education and training of health care providers, parents, and the public. It also directs NIH to conduct research on this disease. ACI Alliance supports the national bill and will continue to work on state screening efforts.

ACI Alliance supports the Expanded Telehealth Act which would make permanent telehealth capabilities for audiologists and speech-language pathologists for Medicare beneficiaries. Since COVID, numerous studies have demonstrated the benefits of telehealth with many private insurance companies continuing coverage policies put in place during the pandemic. We are urging both Congress and CMS to make the Medicare waivers permanent.

We submitted a letter to the National Institute on Deafness and Other Communication Disorders (NIDCD), NIH responding to a request for information regarding improving access and affordability for hearing health in adults. Our comments urged the agency to promote awareness of CIs and highlight the positive outcomes for adults. We noted that research has shown that many of those who qualify for a CI are unaware of the intervention and/or the positive outcomes enjoyed by the majority of CI recipients.

To support Congressional bills, visit our Action Alert webpage:

<https://www.acialliance.org/page/actionalerts>

To view our letters to federal agencies, visit our testimony and comments page:

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

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Changes and Barriers to Early Hearing Detection and Intervention (EHDI)

There were changes this year in how EHDI programs are being supported. In March 2024, the Health Resources and Services Administration (HRSA), an agency in the Department of Health and Human Services, announced that state EHDI programs will receive technical assistance in the new funding cycle (April 2024 – March 2029) differently than was the case in the past. Now three different entities (Gallaudet University, American Academy of Pediatrics, and Hands & Voices) are working together as a “National Network” with joint and unique objectives. As of September 1, guidance had been lacking on how state EHDI will be supported in the management of their programs.

ACI Alliance, together with nine other hearing health organizations, sent a letter to HRSA outlining our concerns about the lack of guidance and offering our full support for EHDI programs. Our letter can be found on the comments page link above. In response, Dr. Jeffrey Brosco, Director of the Division of Services for Children with Special Health Needs at the Maternal and Child Health Bureau at HRSA, shared letters clarifying goals and statements from the federal government and grant holders. A joint letter between HRSA, CDC, and the Department of Education highlighted the need for better coordination between these agencies related to EHDI and Part C of IDEA. We will continue to monitor progress on this topic but we were reassured by the changes that are being made to improve inter-agency coordination.

Our State Champions have been tasked with establishing strong, cooperative relationships with their state’s EHDI programs. Each State EHDI program is unique in how it focuses on a range of issues including early intervention, congenital CMV screening, newborn screening, and more. Some of the ways we suggested to connect and support EHDI Coordinators include presenting to key groups, participating on advisory boards, providing technical assistance, and offering to be a resource for families and parents who have questions. In addition, ACI Alliance is exploring avenues to address barriers to access for early intervention services.

Our work for the coming year is shaped by what we have done in 2024. If you are interested in working on any of these issues as a State Champion, please contact Nichole Westin at nwestin@acialliance.org ■



State Champions Dinner held at CI2024 Vancouver

Athletes with Hearing Loss Represent at the Olympics and Paralympics

Laura Odato MPP

Director of Operations and Marketing
ACI Alliance

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The Paris 2024 Olympics games ended in August with remarkable stories of athlete's hard work and perseverance, including deaf and hard of hearing athletes competing from around the globe.

Team USA sprint kayaker Aaron Small has bilateral hearing loss and proudly displayed his blue and green hearing aids during the Olympics, noting that he was excited to compete and "hopes that by being in the Olympics he can be the role model that he wished he had as a child."

British Paralympic swimmer and equestrian Suzanna Hext was injured in a horse-riding accident and represented Great Britain in the Paralympic Games which began in late August. Suzanna received cochlear implants in 2021 and notes "When I say 'life changing' I truly mean it. This has changed my life beyond belief. I put it on in the morning and I smile to myself because there's suddenly sound around me."



Aaron, Suzanna and the many other athletes with hearing loss are a strong reminder that hearing loss is just a part of one's story. By sharing their hearing loss while competing athletically on the Olympic stage, they are demonstrating that their hearing loss is not a limit to what they are able to achieve.

These athletes can be an incredible example for cochlear implant professionals to reference, especially for children, to demonstrate what's

possible. From parents of an infant first receiving their child's hearing loss diagnosis to an adult experiencing hearing loss for the first time, it can feel overwhelming to imagine what's next. The dedication and joy seen in these athletes are powerful reminders of what's possible in everyday life for children and adults with hearing loss. ■

Rally Caps Now Widely Available on Streaming—Representation Matters

Jodi Michelle Cutler

Co-Author, Producer of Rally Caps

<https://rallycapsthemovie.com/>



Jordan Eric Del Dottore was born in Baltimore, Maryland on August 27th, 1996, in a hospital that did not have a Newborn Hearing Screening program. When he was 8 months old, we began telling our pediatrician we were concerned that he was not babbling despite the fact that he was very advanced in his other milestones. Our pediatrician told us not to worry that because Jordan was a child of bilingual parents (my husband was Italian and I was American) this was the cause of his language delay. I repeated my concerns at our 10-month checkup, my pediatrician called me neurotic and told me not to worry.

We moved to Italy when Jordan was 11 months old; one month later our Italian Pediatrician thought something wasn't right, so he sent us for an Audiology consultation. At 12 months of age, in Florence, Jordan was diagnosed with profound bilateral sensorineural hearing loss. The audiologist immediately fitted Jordan with hearing aids, we made an appointment with a local speech therapist, and one month later, Jordan began his journey in a language that was not my own—Italian. I was told that I could not speak English to him (current research indicates that a mother should speak in her native tongue), and because learning Italian was so difficult for me, sign language was not an option. I was overwhelmed.

Jordan and I learned Italian together during his speech therapy sessions with Iris who was my oxygen and life

support system during the first six years of his life as I dealt with whistling hearing aids, various appointments, temper tantrums due to frustration with not being able to communicate, and the people surrounding me who never understood my child. I understood him, though, and we were in our own bubble, struggling to improve language and communication skills.

When Jordan was 7 years old, I heard him playing hide and go seek with one of his friends, and he couldn't understand what she was saying. I heard him bluffing his way through a conversation. He was embarrassed, and I was devastated. I had heard that there was no better possibility to treat profound hearing loss than cochlear implants, and at that moment I decided to make an appointment in Pisa to gather more information.

Jordan received his first cochlear implant when he was eight years old and his second when he was 18, each of which was passed by the Italian National Healthcare System. His cochlear implant transformed his life and his character; he went from being frustrated to being affectionate. He was finally able to have his curious nature satisfied thanks to the access to sound and incidental language provided by his cochlear implant. Because Jordan became more independent, studious, and autonomous, I was able to dedicate my new-found free time to taking care of his baby sister Sofia and the book *Rally Caps* that my dad insisted I help him write.

My dad had a baseball story to tell and suddenly I had a strong deaf character with a cochlear implant to create so that my son could see himself in literature. We published *Rally Caps* in the US in 2007 and in Italy in 2008. The book led to my career in helping other families, offering resources and support, establishing a national pediatric audiology network in Italy, publishing various research articles, and creating a Facebook forum of 15,000 families involved in a hearing loss journey. Helping families is my passion.

As soon as *Rally Caps* was published, my dad began insisting it should become a movie. Insisting is a gentle term for how persistent my father can be when he gets an idea in his head. That determination led to Director Lee

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RALLY CAPS *continued from page 17*

Cipolla, who agreed with my father's vision, transforming the book into a beautiful screenplay. Cipolla demonstrates how debilitating anxiety can be for a young child, while reinforcing how the ability in disability is how our kids with hearing loss can become strong role models.

RALLY CAPS the Film

Starring Academy Award Nominee Judd Hirsch (The Fabelmans), with Carson Minniear (Palmer) and Amy Smart (StarGirl), RALLY CAPS is a coming-of-age, family friendly story written and directed by Lee Cipolla. Based on actual events, adapted from the book by the father-daughter writing team of Stephen J. Cutler and Jodi Michelle Cutler, RALLY CAPS is a heartwarming tale of friendship. A young boy, Jordy, is seriously injured during a youth baseball tryout. At a summer camp he bonds with a deaf boy, Lucas, who had recently had cochlear implant surgery. Their friendship becomes the driving force as the pitcher/catcher duo leads their team in the camp championship game.



Producers are Katherine Borda, Amy Williams, William Garcia, Stephen J. Cutler, Jodi Michelle Cutler, Curtis Pride, Eileen Jones, Orien Richman and Gary Sales.

Watching Colten and Noelle Pride, children of Lisa and Curtis Pride (former Major League Baseball outfielder who is Deaf, act in this movie is pure magic. Colten recites the Lucas character, while Noelle recites the character, Niki; both actors have hearing loss. Making the cochlear implant and hearing aid visible and showing how assistive hearing technology promotes inclusion and accessibility for kids with hearing loss leads to smashing stigma. I watched the two young actors interact with the other kids on the set and have the time of their lives, while following every line of every scene under Lee's direction. Representation matters.



I have dedicated the past 27 years of my life to inclusion, accessibility, and cochlear implant advocacy. I have waited with patience and persistence for the day that my deaf son, who uses cochlear implants to hear and speak, would be represented in film. That day has arrived.

Rally Caps was released everywhere on September 10. We greatly appreciate the support of Phonak, Advanced Bionics, and the American Cochlear Implant Alliance in helping us spread the important message that Anything is Possible.

Editor's Note: American Cochlear Implant Alliance was proud to support the rollout of this film, and we will continue to spread the word regarding the powerful messages it conveys—as well it being wonderful entertainment. The film may be accessed via streaming and is now available on Video on Demand! Audiences can watch RALLY CAPS on Amazon, Apple TV, Fandango at Home, and Google Play. ■

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Meet the ACI Alliance Board of Directors



Allison Biever AuD, Director, Rocky Mountain Cochlear Implant Program

My name is Allison Biever and I have been working in the field of cochlear implants since 1992. I am extremely passionate about my work with deaf and hard of hearing individuals that was inspired by my mother's journey with her hearing loss. My mother was born in a rural community in Alberta, Canada. Her hearing loss, which was initially diagnosed as a moderate sensorineural hearing loss, was late identified. She did not receive binaural amplification until she was in her twenties, and I believe, her late identification and intervention limited many opportunities for her. My mom did not work outside the home, and she did not drive. She often felt isolated and depressed, and undoubtedly, her hearing loss was a major reason for feeling isolated socially. It was not until I was in graduate school, when I was exposed to simulations of mild, moderate, severe,

and profound sensorineural hearing losses that I better understood the impact of her hearing loss. My mom's hearing loss progressed, and her communication difficulties increased along with her feelings of isolation.

I recognized that my passion in Audiology was geared towards helping patients with significant hearing loss optimize their communication skills and outcomes. I completed my master's degree in 1992 and am humbled to have begun my career with one of the pioneers in the field, Dr. David Kelsall. In 2005, I completed my AuD from Central Michigan University, where I completed a capstone that examined the impact of residual hearing on pediatric cochlear implant performance. I currently serve as the director of the cochlear implant program at the Rocky Mountain Ear Center, and I cannot imagine a better or more rewarding career.

I have been heavily involved in research and have taught for the Institute for Cochlear Implant Training (ICIT) as well as the University of Colorado. I have proudly served on the LISTEN Foundation's Executive Board, which is a foundation whose mission is to facilitate optimal spoken language outcomes for children who are deaf and hard of hearing. I am excited to serve as a board member for the American Cochlear Implant Alliance and am committed to our mission of increasing access to cochlear implantation and promoting advocacy and awareness about this life changing technology.



Charles Limb MD, Chief, Division of Otology, Neurology and Skull Base Surgery, University of California San Francisco Medical Center

My name is Charles Limb, and I'm a neurotologist at the University of California San Francisco Medical Center. I was born in Brooklyn, New York as the son of two surgeons, although ironically my parents' background in medicine initially turned me off from pursuing a career in surgery. Since the earliest days that I can recall, I was always transfixed by one thing above all else: the world of sound. I have been a musician (saxophone, piano) since childhood, with a deep fascination for all things musical. It is this background that led me on a quest to understand the nature of sound and hearing, which ultimately resulted in my becoming a neurotologist.

I currently serve as the Francis A. Sooy Professor and Chief of Neurotology at the University of California, San Francisco, where I direct the Douglas Grant Cochlear Implant Center. I have been at UCSF for the past ten years. Prior to that, I worked at Johns Hopkins Hospital for 19 years, under the mentorship of Dr. John Niparko, one of the founding members of the ACI Alliance. I also direct the Sound and Music Perception Lab, where we study music perception in cochlear implant users as well as the neural basis for musical perception and production. Music is one of the most challenging acoustic signals for individuals with cochlear implants due to its immense complexity. Beyond providing entertainment, music can serve as a target and a tool by which we can probe the limits of current cochlear implant technology to providing high level hearing restoration.

It has been an absolute privilege to contribute to the field of cochlear implants and to help those who are deaf and hard of hearing. Despite the fact that more than one million people worldwide have cochlear implants, it is remarkable to observe that we are still just at the beginning—there is so much we have left to learn, and so many goals that we have yet to reach for hearing rehabilitation, especially for complex acoustic signals beyond speech, such as music. It is my sincere hope that in the relatively near future we can provide perfect hearing restoration for people who have hearing impairment. I thank you for the honor and opportunity to serve as Board member for the American Cochlear Implant Alliance. ■

A Parent's Perspective

Two Sisters with Progressive Hearing Loss Enjoy the Gift of Hearing Again

Jessica Salzberg

On March 5th, 2019, my dream of becoming a mother came true. My husband, Matthew, and I welcomed our perfectly healthy baby girl into this world. Leah was truly everything we could have imagined and more. The first two years of her life were full of love, joy, and laughter. We were in awe watching our little girl bloom and blossom before our very own eyes. She even became a sister to her little sister, Sophie. She absolutely loved this new role of hers and took it on proudly.



The first two years of Leah's life, we watched her dance to music and clap her hands to the rhythm, dance, and babble. When Leah was two and a half years old, she began to attend a preschool in

our community. She adapted and adjusted well and had a love for learning and exploration. About halfway through the school year, I noticed Leah's speech began to plateau and was then beginning to decline. Her articulation and pronunciation sounded muffled, her vocabulary was no longer expanding, and at times she would not respond when her name was called. Her teacher began to have the same observations, and as our concern grew, we took Leah to an ear nose and throat specialist.

Looking for Answers

She was found to have fluid in her ears, and we were told to treat it with saline spray and come back in a few weeks. We did as instructed and when we returned to the doctor we entered the sound booth for testing with an audiologist. She was unable to gather conclusive results, and explained it is rather challenging at this age as the results yielded fair reliability. We left the appointment feeling worried and defeated that we had no clear answers. At the time, we decided to begin speech therapy for Leah twice a week. During her sessions, she was not engaged or focused, which was not in line with her personality. Even at just two and a half, she was a very cooperative little girl and it was unlike her to not be participating in the therapy.

After three months, we were desperate for answers. We scheduled Leah for an auditory brain response test three days after her third birthday. After two hours of holding her hand while she was sedated, the audiologist had results. My husband and I will

never forget her exact words, "I can't believe her speech given the degree of her hearing loss." That day, Leah was diagnosed with bilateral sensorineural hearing loss. We were told she would need hearing aids and educational and speech support, and together we headed home.

My husband and I took our heartbreak and grief and immediately sprung into action mode. We had her fit with hearing aids and followed protocol of scheduling appointments with a pediatric ophthalmologist and geneticist. The day came when Leah received her pretty pink sparkly hearing aids, which we called "super ears." The beginning was a challenge, but in time she adjusted beautifully and appreciated having the gift of hearing.

A Surprising Diagnosis for Our Family

A few months later, the geneticist called with results that we had never expected. He shared that Leah's hearing loss was in fact caused by a genetic mutation (MYO15a) causing progressive hearing loss in early life. We finally had an answer and although it did not change her care, it did mean we now needed to carefully monitor Sophie's hearing. I was pregnant with my third child at the time and we were aware that meant we would need to monitor our new baby as well. Sophie, who also was once a chatterbox who loved music and dancing, began to regress in her speech and language. Now knowing that there was a possibility she might also be affected by hearing loss, our concern grew. We took her to the geneticist and fitted her for hearing aids to be proactive.

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A PARENT'S PERSPECTIVE *continued from page 21*

During the period waiting for results, our third daughter Mila was born. In a time of so much uncertainty, she brought our family love and light. The day she was born, we arranged for the geneticist to test her so we



could be prepared, either way. Three weeks later, the geneticist called my husband with results for both Sophie and Mila. It was found that Sophie had the same genetic hearing loss as Leah, and that Mila was a carrier, just like my husband and I, and therefore is not affected by hearing loss. We began the process all over again. Although it was difficult, we were ready to do whatever we need to do to ensure our girls would live normal, happy, and healthy lives.

Leah and Sophie both attended the school in our community and proudly wore their “super ears” to school. We couldn’t have asked for more love or support from the school administrators or their teachers. We created a team of professionals and speech therapists so the girls received all the support and services that they needed to succeed. Leah and Sophie have speech therapy three days a week, and are such hard working and motivated little girls. We were comforted to know that the girls have each other through this journey, and their little sister as their biggest cheerleader.

Cochlear Implants for Leah and Sophie

We had frequent visits with our audiologist at the Children’s Hearing Program to check their devices and monitor the degree of their hearing loss. Sophie wore her purple hearing aids for three months and Leah wore her pink ones for eight months before sound booth results showed both of them were experiencing a progression in hearing loss. We realized that both girls were now candidates for cochlear implants. At the time of diagnoses, Leah and Sophie presented with moderate to severe hearing loss. Within months, they were both in the severe to profound range.

After back-to-back sedated ABR tests and MRIs, they were both approved as candidates for cochlear implantation. My husband and I did a lot of research, asked a lot of questions, and met with many professionals and specialists. After educating ourselves, we felt in our hearts this was the best option for our girls. ACI Alliance’s work providing resources for families and providers is so important for families during this decision-making process.

After a lot of debate and consideration, we decided to schedule Leah and Sophie’s bilateral cochlear implant surgery

on the same day. On the morning of January 4th, 2023, the next chapter of our story began. Dr. Simon Angeli of University of Miami operated on our girls, back to back. After eight hours of surgery and a twelve-hour day at the hospital, we took them home to heal. We were amazed and inspired by their resilience and how well they recovered.

After three weeks, it was activation day. Dr. Christina Sanchez, our audiologist, activated the girls together. It was a day we will forever remember. Since that very day, our girls have exceeded every single expectation we ever had as their parents. We truly could not be prouder. Leah and Sophie attend the same community preschool and are shining superstars. There is truly nothing these girls can’t do. They love to sing, dance, scooter down the street, play soccer, and do gymnastics. Anything they can dream of, they can do.

It has been the biggest honor and blessing to watch our little girls become who they are today, and we are forever thankful for this life changing technology and the medical experts who have taken care of our family. We know that this is only the beginning for Leah and Sophie, and that together they will change the world.

Editor’s Note: The Salzberg’s story was originally shared in People magazine in June 2024 at <https://people.com/two-sisters-cochlear-implants-exclusive-8670766> The People coverage was an important opportunity to expand public awareness about hearing loss, genetic counseling, and cochlear implantation. We are grateful to the Salzbergs for supporting our mission to expand knowledge and understanding by sharing their journey. ■





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