



AMERICAN COCHLEAR IMPLANT ALLIANCE

*Research. Advocacy. Awareness.*



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**Donna L. Sorkin, Editor**

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## Message from the Chair

### **Daniel M. Zeitler, MD FACS**

*Co-Director, Listen for Life Cochlear Implant Center*

*Director Research and Academics*

*Otology/Neurotology & Skull Base Surgery, Department of Otolaryngology-HNS*

*Virginia Mason Franciscan Health*

*Clinical Assistant Professor - University of Washington School of Medicine*

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**A**s the newly elected Chair of the Board of the American Cochlear Implant Alliance, I write to you today with a sense of urgency and optimism. A time of growing awareness, and growing responsibility. Pride in how far we've come, and a deep concern about how far we still have to go.

We are witnessing the real-time normalization of cochlear implants

as a transformative treatment for children and adults with significant hearing loss, which now includes diagnoses such as unilateral profound hearing loss and asymmetric hearing loss. We are implanting young children before they can even learn to talk to provide them with all of the opportunities their normal hearing peers are afforded. This progress reflects years of advocacy, education, and research. The progress in the field of hearing health has been unequivocal and we must be heartened by the steady growth. However, awareness is only the first step. Access remains an urgent challenge we must all confront together. Barriers that have been unnecessarily (and in some cases unintentionally) erected for certain groups of patients threaten to turn this medical progress into a privilege for some rather than a right for all.

Recently, a pediatric otolaryngologist shared with me an opinion piece he wrote that was published in the *New England Journal of Medicine* entitled "Breaking the Sacred Promise". This article brings into sharp focus the ethical obligation we all have to ensure access to hearing healthcare for all individuals, regardless of age, socioeconomic status, demographic variables, or insurance coverage. It serves as a reminder that the promise of restoring hearing is not fulfilled until it is equitably fulfilled. As the author states, the work we all do is distilled down to a simple and sacred promise: "I will use my knowledge and skills to solve previously unsolvable problems, and improve the life of the patient".

*continued on page 2*

## ACI Alliance Board of Directors

**Daniel M. Zeitler MD**, *Chair of the Board*  
Co-Director Listen for Life Hearing Implant Center  
Director, Research and Academics  
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Audiology and Newborn Hearing Screening  
University of Chicago Medicine

**Donna L. Sorkin MA**  
Ex Officio Board Member  
Executive Director

## MESSAGE FROM THE CHAIR *continued from page 1*

This article compelled me to ask: what promise are we making to ALL individuals living with hearing loss—and are we keeping it?

Too many families like the one in the article still face heartbreaking denials of insurance coverage for their children despite meeting all required clinical indications. Medicare beneficiaries—specifically older adults with hearing loss that falls outside of traditional labeling—are excluded from receiving the care they need and are banished to a life of silence, isolation, depression, and reduced quality of life despite indisputable evidence of the benefits of implantation in this population simply because they do not fit outdated labeling criteria. Summed up, these patients are denied life-changing technology because policy hasn't yet caught up with science. This is not just a healthcare issue, this is an equity issue. These inequities are not just statistics—they are stories proving the consequences of untreated hearing loss reach across lifespans, affecting individuals, families, and communities.

The mission of ACI Alliance has never been more vital. We are committed to amplifying the voices of those affected, advancing research, and advocating tirelessly for policy change. We all must believe in a future where hearing is not a luxury, but a fundamental part of living fully, and one that should never be denied. But we cannot do it alone. Whether you are a legislator, a clinician, a parent, a person with hearing loss, or someone who believes in equitable healthcare, we invite you to stand with us. Share your story. Support our advocacy. Help us ensure that no one is left behind simply because the system has failed to keep up.

Together, we can honor the sacred promise of hearing—and keep it. ■



Board of Directors meeting in Boston.

# CI2025 Boston: Collaborating to Advance Cochlear Implant Access

## Donna L. Sorkin MA

Executive Director  
ACI Alliance

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The CI2025 Boston conference brought together nearly 1200 clinicians, professionals and advocates from the US and around the world. We welcomed colleagues from North and South America—with especially strong attendance from Argentina, Mexico and Canada—but also like-minded CI professionals from Europe, Asia, the Middle East, and Australia. There was a surge of interest and excitement from professionals who support post CI care from various disciplines—educators, speech-language pathologists, and psychologists—in addition to the strong participation of audiologists and other CI medical team members. Students joined us in force with 110 student attendees sharing their research and meeting together to discuss mentorship and career path. Remarkably, over one-third of attendees this year were attending the CI conference for the first time!

The excellent program was due to the hard work of the Scientific Program Committee co-chaired by Keri Colio AuD and Esther Vivas MD. [https://cdn.ymaws.com/www.acialliance.org/resource/resmgr/ci2025/CI2025\\_Program\\_Book.pdf](https://cdn.ymaws.com/www.acialliance.org/resource/resmgr/ci2025/CI2025_Program_Book.pdf). In addition to the superlative keynotes by Nancy Young MD and Paul H. Van de Heyning MD, PhD, attendees learned about CI progress at talks on candidacy and care across the age spectrum. Attendees rated sessions on related topics highly including talks on machine learning and AI, parent and caregiver perspectives, barriers to CI, innovations in assessment/training/patient

support and CI in SSD. Panels were well rated with high marks for Stump the Experts, Balancing Ethics and Innovation, Global Hearing Health, and Member Advocacy.

The *(Re)habilitation Connect Forum* was the favorite session for many with strong ratings for both the pediatric and adult sessions which examined topics in a research to practice format. Specific topics explored for both adults and children were CI (1) in SSD and (2) for those with additional diagnoses. We are grateful to Hearing First for sponsoring the lively Continue the Conversation reception for those who participated in Rehab Connect.

The three CI companies each presented twice during the conference: at a Wednesday afternoon satellite symposia and each morning during breakfast. Attendees noted that there were important take-aways for the CI company events with students particularly grateful for the chance to learn about each company's perspective.

A new offering this year allowed selected exhibitors displaying emerging technologies to present for thirty minutes during a special concurrent session. Amazon, IotoMotion, and the two gene therapy companies presented and their talks were all highly rated by attendees. Amazon's summary of their accessibility features is included as a stand-alone article below. Attendees at the Amazon presentation were excited to be able take back information for patients

*continued on page 4*

and also suggest additional uses or offerings for product access.

A new feature of the conference this year was the “field trip” to Mass Eye and Ear Infirmary (MEEI), an international facility and home to one of the world’s largest hearing and vision research centers. Over 50 conference attendees participated in the visit that provided the opportunity to interact with researchers and visit labs to learn about implantable microphone technology, the temporal bone lab, and emerging auditory research and cochlear implants. We are grateful to Julie Arenberg PhD for arranging the visit, which participants raved about.

The attendee survey indicated appreciation for networking opportunities and the chance to learn about a diversity of related topics that they don’t necessarily think about in their day-to-day practice. “It was a great meeting. One of my favorite parts is getting to collaborate with people I don’t see very often.” Indeed, that collaboration and networking with others from a diversity of locations and wide-ranging roles in CI and hearing health is the reason people are drawn to the CI conference and come back to continue the learning. ■

## Amazon Shares Accessibility Products at CI2025

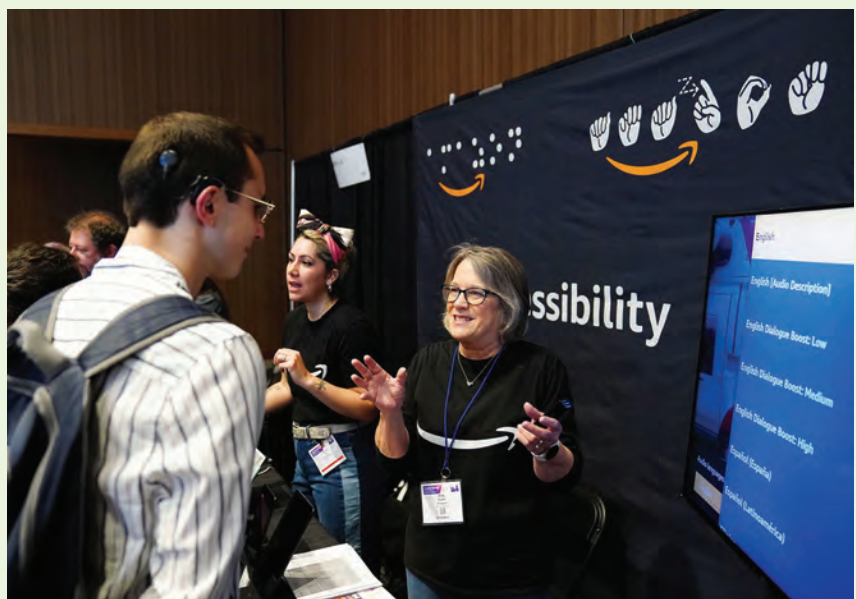
At CI2025 Boston, [Amazon](#) showcased its latest hearing accessibility advances, highlighting how everyday technology can better serve Deaf and Hard-of-Hearing users. Peter Korn, Director of Devices Accessibility, and Lakshmi Ziskin, Senior Accessibility Product Manager for Prime Video, led a session detailing key features across Amazon’s product ecosystem.

The presentation focused on innovations including Bluetooth connectivity between [hearing aids and Fire TV](#), [Dual Audio](#), and [Prime Video’s Dialogue Boost feature](#), which enhances spoken dialogue without increasing background noise. The team also demonstrated Alexa’s accessibility features, including [Call Captioning](#), and [Alexa captions](#), designed to make Amazon devices more accessible.

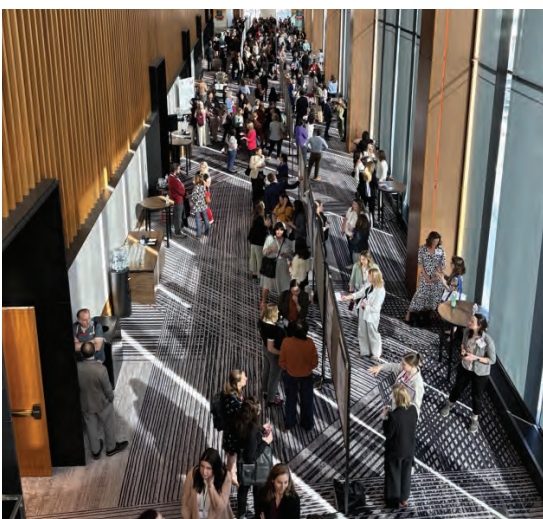
One standout feature that caught audiologists’ attention was the [Kindle app’s Assistive Reader](#), which combines synchronized text and audio. Clinicians noted its potential as a valuable tool for auditory training and language comprehension, particularly for individuals newly fitted with hearing aids or cochlear implants.

Amazon’s presence at CI2025 emphasized their commitment to community feedback and ongoing development of accessible technology solutions. The company continues to build tools that enhance daily experiences for users with hearing loss.

For more information, visit [amazon.com/accessibility](https://amazon.com/accessibility). ■







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# Special Interest Groups Highlight Maturation of ACI Alliance

## Donna L. Sorkin MA

Executive Director  
ACI Alliance

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American Cochlear Implant Alliance began operations thirteen years ago led by a group of clinicians, scientists, educators of children with hearing loss, parents, adult recipients, and others. The objective was to create an entity that would focus on access to cochlear implants and related care. How this would eventually roll out was, like the Bob Dylan film, a complete unknown. In 2012, when I joined the organization as our first executive director, we had only a vague idea of how we would approach the mission. Improving access to cochlear implants has not changed as our core purpose but how we define access and related services has expanded.

In 2012 cochlear implantation in SSD was an “emerging issue,” CI provision to children and adults with other diagnoses was approached with extreme caution, auditory rehabilitation for adults was generally not available, early intervention practices related to CI advisement were unknown, an early CI for a congenitally deaf child was 18 to 24 months, and recipients of all ages were advised that cochlear implants don’t provide access to music. We had 11 organizational members and a handful of parents, adults and other clinicians who joined up to support the cause. We grappled

with how to approach CI coverage under the new insurance plans being offered via the Affordable Care Act—which led us to establish the State Champions Program, which now numbers 215 Champs and continues to grow. The list goes on but certainly, one of the most significant aspects of our organizational growth is the member-driven push to establish and own special interest groups or SIGs allowing members to meet together to explore and take action on important issues. These groups now number four, with three SIGs meeting virtually throughout the year and in-person at the annual

conference. The Adult Rehabilitation SIG collaborated on research which they presented in Boston, and used as a tool to help determine future research and suggestions on best practice in CI care.

Expanding our focus beyond a simple definition of access to cochlear implantation is an important aspect of the organization’s current set of activities. Indeed, these four SIGs demonstrate how ACI Alliance is able to engage with a broader group of individuals and organizations who can help all of us expand knowledge of, and support for, cochlear implant access. ■

## Educators of Children who are Deaf and Hard of Hearing



**Alexandria Mestres MSEd**  
*Deaf and Hard of Hearing Educational Specialist*  
University of Miami

*Children’s Hearing Program*



**Kameron Carden PhD, CCC-SLP, LSLs Cert AVEd**  
*Assistant Professor/  
Director of Clinical Education*

*Communication Sciences and Disorders*  
Samford University School of Health Professionals

The CI2025 conference in Boston brought together a Special Interest Group focused on education for children with hearing loss. This diverse group included teachers of the deaf from school-age programs, early interventionists, college professors from teacher preparation programs, speech-language pathologists, and students preparing to enter the field. Participants came from across the United States as well as international colleagues, enriching the discussions with a broad range of perspectives.

Through collaborative dialogue, the group identified several common concerns among professionals supporting children with hearing

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## SPECIAL INTEREST GROUPS *continued from page 8*

loss. One major topic was ensuring that children with cochlear implants receive the necessary support services. Discussions addressed educational outcomes, eligibility criteria, and the importance of providing parents with comprehensive information during early intervention. These conversations highlighted the critical need for coordinated efforts to support children's development effectively.

Another significant theme was the growing teacher shortage and the decline in teacher preparation programs nationwide. Many regions are already experiencing the impact of this shortage, which poses challenges to maintaining quality education for children who are deaf or hard of hearing. Participants expressed concern about this trend and explored strategies to attract and retain qualified educators.

The group also discussed uncertainties surrounding federal funding for K-12 and postsecondary education. Concerns about resource availability underscored the importance of advocacy and strategic planning to secure sustained support for educational programs.

Throughout the conference, members shared resources and ideas, reaching a consensus that collaboration among professionals is essential to ensuring the continued success of children with hearing loss. The group, supported by ACI Alliance, has taken an important step forward in fostering ongoing cooperation. They plan to continue meeting virtually and look forward to reconvening at CI2026 in Chicago, strengthening their commitment to this vital work. ■



## Members with Hearing Loss



**Viral Tejani AuD, PhD**  
*Assistant Professor,  
Otolaryngology-Head  
and Neck Surgery  
Case Western Reserve  
University School  
of Medicine*

*Senior Research Audiologist &  
Subdivision Leader, Cochlear Implant  
Program  
University Hospitals Cleveland  
Medical Center*



**Elaine Smolen PhD,  
CED, LSLS Cert. AVE**  
*Visiting Assistant  
Professor  
Deaf and Hard of  
Hearing Education  
Teachers College,  
Columbia University*

*Columbia University*

**T**he ACI Alliance Professionals with Hearing Loss SIG hosted its third annual meeting at CI2025 Boston. Our group has been growing since our initial meeting three years ago, with 40 members now in the SIG! This year, SIG attendees participated in breakout groups and engaged in spirited discussions on issues affecting their professional training, ranging from need for accessibility to limited understanding by typically hearing colleagues regarding their challenges—despite these colleagues being in the field themselves (e.g., Atcherson & Yoder, 2002).

Our members span from trainees to established professionals. They represent different facets of our profession including audiologists, speech-language pathologists, physicians, scientists, teachers of the deaf, and psychologists. Our primary goals are to serve as a safe space for our colleagues in ACI Alliance who have hearing loss and

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## SPECIAL INTEREST GROUPS *continued from page 9*

to serve as a support system as they address accessibility-related challenges and navigate inter-professional relationships. As the group expands, we have immediate

goals of establishing a mentorship program and hosting virtual meetings in between the annual SIG meetings at ACI Alliance. We will also advocate for accessibility

as we collaborate with ACI Alliance leadership and are grateful for their support as we grow our SIG and address these important topics.

If you are an ACI Alliance member with hearing loss (or know one) and are interested in joining the SIG, please contact Elaine Smolen ([es3519@tc.columbia.edu](mailto:es3519@tc.columbia.edu)) and Viral Tejani ([viral.tejani@UHhospitals.org](mailto:viral.tejani@UHhospitals.org)) to be added to the list-serv.

The virtual summer meeting for professionals with hearing loss for is scheduled for July 10th 8:30-9:30 pm EST. Registration and details can be found at <https://teacherscollege.zoom.us/j/9876543210>.

**Reference:** Atcherson SR and Yoder SY (2002). On the Irony of Audiology. *Audiol. Today* 14 (5), 38.



## Adult Aural Rehabilitation



**Blair Richlin MS,**  
*Speech-Language  
Pathologist, Mass Eye  
an Ear*

**T**he Special Interest Group for Adult Aural Rehabilitation had a successful annual in-person lunch meeting at CI2025 in Boston! Our multidisciplinary lunch hosted over 50 professionals from the US, internationally and the online group continues to expand. As a result of the ongoing collaboration between our members, we ran our first research study to better understand how CI recipients are being offered and receiving AR services. The results were shared via a poster at CI2025 and we continue working on the manuscript in development.

These accomplishments are the result of time and energy volunteered from members who are dedicated to expansion of this service. AR doesn't occur in a silo and neither do our initiatives! Synchronous meetings occur via Zoom and asynchronous support/input occur via our google group. Members share and recruit for research studies, support state

and federal initiatives necessary for CI & AR coverage, and facilitate transparent communication for how to evaluate and provide direct AR therapy.

Are you interested in joining the SIG? <https://forms.gle/ij37Znx2woaKJpRj8>

Completion of the form prompts addition to the google group. ■



# Mentorship Luncheon at CI2025 Empowers Students with Career Guidance

## Jessica Houk MBA

Manager of IT & Membership Services  
ACI Alliance

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Students, fellows and residents attending CI2025 Boston had the valuable opportunity to participate in a mentorship luncheon designed to support them as they navigate the early stages of their professional journeys. The event was led by two distinguished mentors:



Nichole Jiam MD



Gabrielle Watson AuD

Nichole Jiam MD, Assistant Professor and Director of the Otolaryngology Innovation Center at the University of California San Francisco, and Gabrielle Watson AuD, an audiologist at the University of Iowa.

Together, they facilitated an engaging and interactive discussion with over 50 students and early career clinicians representing diverse

career paths within the cochlear implant field. The conversation centered on helping students identify and actively pursue their individual career goals. Topics included effective strategies for job searching, resume development, and building meaningful professional networks. The mentors also shared personal stories from their own career paths, offering real-world insights into overcoming challenges and staying motivated throughout the job search process.

In addition to providing practical advice, the luncheon offered students a deeper understanding of the skills and qualities that can distinguish them in a competitive job market. It provided a supportive and welcoming environment for peer connection and professional learning. Overall, the session proved to be both informative and empowering—an invaluable experience for anyone preparing to take the next step in their career. ■





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# Next Up: CI2026 Chicago



## Molly Smeal AuD

Co-Chair, CI2026 Program Committee  
Clinical Audiologist  
Integrated Surgical Institute  
Head and Neck Department  
Cleveland Clinic



Molly Smeal AuD



Kevin Y. Zhan MD

## Kevin Y. Zhan MD

Co-Chair, CI2026 Program Committee  
Assistant Professor of Otolaryngology  
Otology, Neurotology & Skullbase Surgery  
Director, Northwestern Medicine Cochlear  
Implant Program

Following another successful meeting in Boston in 2025, we're bringing you even more of what you loved to CI2026 in Chicago — engaging, thought-provoking discussions, dynamic educational content, and interactive case-based sessions.

We are excited to add more memorable experiences with additional expert panels on complex pediatric and adult cases, thoughtful discussion into nuanced ethical considerations, practice-building seminars to support

program growth of all sizes, advanced audiology programming masterclasses, and much more! This commitment to cutting-edge content and learning is exactly why ACI Alliance hosts the premiere educational and research cochlear implant meeting. Set in the heart of Chicago at the Hyatt Regency

Downtown, you'll be steps away from stunning architecture, the scenic Riverwalk, and the sparkling shores of Lake Michigan.

**Mark your calendars** — this will be our most exciting conference yet! We can't wait to see you there. ■

**We are looking forward to seeing all of you next spring in Chicago, Illinois!**





## Schedule at a Glance

### Conference Dates

Wednesday, May 6 – Saturday, May 9, 2026

### Wednesday, May 6 – Pre-conference Activities

**Thursday, Friday, Saturday, May 7-9** – Scientific Program including keynote speakers, concurrent sessions, panel sessions, and poster exhibits

### Conference Website

[www.ci2026chicago.org](http://www.ci2026chicago.org) (information and links to abstract submissions, registration, hotel, scientific program updates, conference policies)

Abstracts Submissions Open July 1

### ACI Alliance Detailed Information

<https://www.acialliance.org/page/ci2026chicago>

### Hotel and Meeting Venue

[www.ci2026chicago.org/meeting-hotel-venue/](http://www.ci2026chicago.org/meeting-hotel-venue/)

**Conference Headquarters Hotel:** Hyatt Regency Chicago Hotel  
Group Rates Expire: April 13, 2026

### Registration (Opens December, 2025)

[www.ci2026chicago.org/registration/](http://www.ci2026chicago.org/registration/)

Early Bird registration rates through March 18, 2026

### CI Manufacturer Pre-Conference Satellite Symposia

Wednesday, May 6

1:00 PM – 2:15 PM

2:45 PM – 4:00 PM

4:30 PM – 5:45 PM

### CI Manufacturer Satellite Symposia each day

**7:30-8:30 AM**

Thursday, Friday, Saturday mornings at 7:30 AM

### State Champions Dinner Meeting

Wednesday, May 6 at 6:00 PM

### Welcome and Opening Session with Niparko Lecture

Thursday, May 7 | 8:45 AM – 9:50 AM

### CI2026 Student Scholarship Application Deadline

December 1, 2025



# Cochlear Implant Connections for Teens with Lexi

## Laura Odató MPP

Director of Operations and Marketing  
ACI Alliance

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**A**CI Alliance is launching a new webinar series Cochlear Implant Connections for Teens, led by Lexi Finigan, a CI recipient and the voice of Cece in the *El Deafo* animated Apple TV series.

Lexi and her family have been involved with ACI Alliance for a number of years, first sharing their story with us when Lexi worked on the *El Deafo* series, and then as active members of the CI CAN advocacy network for families and adult recipients. Lexi and her family were joined us at CI2025 Boston as Lexi opened the conference, sharing her story of how cochlear implants have changed her life and inspired her to give back to the CI community to share what she's learned.

We are pleased to continue this partnership with the initiation of *Cochlear Implant Connections for Teens*. This webinar series is designed for teens to connect, share experiences, and learn from each other and from professionals about their life with cochlear implants. Topics might include talking to friends about your hearing loss and CIs, advocating for yourself, navigating transitions, and becoming comfortable with the changes that all teenagers—with or without hearing loss—must negotiate. Some sessions might provide opportunities to engage with professionals in and out of the field as well with adults who grew up deaf.

The first webinar will take place Tuesday, August 12th from 7-8PM ET. Lexi will lead a discussion on “Back to School” topics, including talking to new teachers and classmates about their hearing loss and discussing accommodations they need to be included. She will

share a Powerpoint that she used with her middle school teachers, and discuss how she approaches these conversations now that she's in high school.



The success of this new webinar series will depend on getting the word out. We encourage you to share our resources or social media posts and let patients and families to know of the opportunity.

For details or to sign up for Cochlear Implant Connections for Teens, visit [www.acialliance.org/page/CIteens](http://www.acialliance.org/page/CIteens). ■



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# Federal/State Legislative Update

## Nichole J. Westin MA

Director of Governmental Affairs  
ACI Alliance

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**D**uring our CI2025 Boston conference, ACI Alliance State Champions held their annual in-person meeting. The discussion centered on responding to the current political environment at the federal and state levels with a special focus on our top policy issues: Early Hearing Detection and Intervention (EHDI) and Medicaid. There was an update on other legislative bills at the state and national levels.

In large part due to the efforts of Missouri State Champion Kate Sinks AuD, Missouri will join the ranks of states that allow Medicaid to cover cochlear implantation for adults. At present, Medicaid covers CI in children in all states due to Federal rules. Dr. Sinks, along with a group of other advocates in her state, worked hard on this initiative over a number of years. Also working hard is Shawn Stevens MD, who is continuing efforts to gain adult Medicaid coverage via state legislation in Arizona.

Screening for congenital CMV legislation was introduced in

Massachusetts and Oregon. The bill in Oregon did not advance before the end of its session, but Massachusetts is still in play. The federal Stop CMV Act needs to be reintroduced in the new Congress and ACI Alliance partnered with other hearing health organizations to promote passage.

LEAD-K is an effort promoted by a group centered in California to prioritize ASL as the communication approach for all children with any level or type of hearing loss. Proponents have encouraged legislation in a number of states causing confusion and conflict in a process that is supposed to provide information on language options to parents in an even, unbiased manner. After a lull in state activity, LEAD-K popped up in the same states as pending congenital CMV legislation and a bill was proposed in Illinois. Discussions with all parties will be ongoing.

With the possibility of shifting federal programs to states,

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continued engagement with policymakers at the state level will be important. State governments will be forced to make decisions at a rapid pace on how to fund and support shifted programs. ACI Alliance will support our members' efforts to educate elected and appointed officials on the importance of ensuring access to hearing health.

### **EHDI and Medicaid**

Currently, EHDI is facing two issues—the firing of CDC staff who collect and manage key data for EHDI and the zeroing out of HRSA funds under the Administration's proposed budget. (CDC has funding in the budget request and HRSA has staff but no funding for state programs.) The loss of CDC staff and HRSA funding for states would have significant long-term impacts on newborn hearing screening and early intervention. A poll by the National Center for Hearing Assessment and Management at Utah State found that staff in state EHDI programs believe that their programs will be forced to close if federal grant funding disappears. Some hospitals may continue to perform newborn hearing screening but potentially those with budget pressures will cease offering the program especially in rural areas where families rely upon Medicaid.

**A recent Supreme Court decision (A.J.T. v. Osseo Area Schools) may make it easier for parents of children who are deaf or hard of hearing to successfully seek enforcement of their rights under the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act and the American Disabilities Act (ADA). On June 12, a unanimous Supreme Court sided with the family of a child who was denied full access to her education. Law experts agree this will make it easier for families to seek damages and/or ensure full support under disability law. This case emphasizes the need for a federally enforced IDEA as the child in question did receive support in one state but was denied in another once the family relocated. ACI Alliance will continue to provide more details of the impact of the Court decision once such facts and outcomes are known.**

We continue to contact Senate offices as the budget bill has yet to move through the Senate. As a clearer picture of these cuts comes into focus, ACI Alliance will continue to educate members of Congress regarding the impact cuts in EHDI and Medicaid have on children. ACI Alliance staff and State Champions have met with key Congressional offices and we will continue to do so. We have discussed how critical Medicaid is for young children with hearing loss. Our meetings included the leadership offices of Speaker Johnson, House Minority Leader Jeffries, and Senate Majority Leader Thune—as well as many other Members of the House and Senate.

### **Join Our Efforts**

One of the best and easiest ways is to support these efforts is to complete ACI Alliance Action Alerts and share them with your networks. Our EHDI Alert has been sent to Congressional offices nearly 5000 times, which has a significant impact on raising awareness. You can find them all at: <https://www.acialliance.org/page/actionalerts>.

You can also request meetings (virtual is fine!) with Members of Congress to discuss impacts on your clinic, your patients, or your own CI experience. We can help! If you are not yet a State Champion, join our efforts by becoming one. Contact me at [nwestin@acialliance.org](mailto:nwestin@acialliance.org). ■

# An Adult CI User's Perspective

## Musician and CI Recipient Shares Tips for Appreciating Music

**Kelly Flodin,**  
**Advocate and Musician**



I've always loved music. Even as a little kid, I loved the sounds of music, loved catching the groove, loved the way it made me feel. I saved up little bits of money from doing odd jobs and bought myself a guitar, learned a few chords, and started out on what has since become a lifelong fascination with music.

I grew up hearing pretty well, but by my early thirties my hearing had very noticeably declined. It started to impact the way I heard music and I started to adjust how I approached playing music.

With progressive hearing loss there comes a point where many of us just can no longer function in a hearing world, even with the best hearing aids, which is true for music too. I finally hit that point in my mid-fifties. I could not hear well enough to fake it in a band setting anymore. I could still hear some sound, but couldn't understand speech much at all and pretty much quit socializing, avoided going places and doing things, and changed what I did to make a living.

### Crash Course on Cochlear Implants

I was referred for a cochlear implant (CI) evaluation by an audiologist at my hearing aid center who took one look at my audiogram and referred me to MUSC Health Cochlear Implant for evaluation. The only thing that gave me pause was what I read about music appreciation with CIs. I finally decided that hearing and understanding speech, and being able to communicate in everyday life was the most important thing for me. If I qualified for CI, I would do it and roll the dice on what it would do for music.

During my CI evaluation I qualified easily for both ears and we set a surgery date for four weeks later to get my left ear implanted. The night before my surgery, I went up in my little studio and fired up my old Mesa Boogie, grabbed my Les Paul and just played guitar by myself for a few hours, knowing that I would never hear it quite the same ever again.

My surgery went fine and after I healed for a couple weeks, it was activation day and I was able to understand some speech right away. But it was strange, high pitched, alien, and robotic. In a couple months speech and sounds became much more familiar and normal, and I was communicating better than I had in years. The success I was having with my CI made me realize how little useful information my hearing aid ear was giving me, and I decided that going bilateral CI would be the best choice. I got my second CI four months after my first one.

Everything was going great except for the music, which sounded awful and unrecognizable. I had picked up speech quickly, so my CI rehab efforts soon shifted to getting music back. I reached out to a few musicians that had been

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## AN ADULT CI USER'S PERSPECTIVE *continued from page 19*

able to get back to playing music after making the jump to CI, read everything I could find on CI and music appreciation, and talked with my audiologist.

### Learning to Listen to Music

I decided that just hearing music as music, versus playing music, would be the first project. I made a playlist of very simple, familiar songs that I knew by heart. I would put the playlist on random play, and try to identify the songs without looking. It was tough at first, but occasionally a riff or a word would pop out of the noise, music memory would kick in, and I could follow the song along if I concentrated. The more I listened, the more this would happen. This was encouraging, and I started listening to many different genres, and found some translated to CI much better than others. For me, simple stuff with a strong backbeat worked best. Slowly, passively listening to music began to fall into place and it began to be enjoyable once again.

### Becoming a Musician with Cochlear Implants

I got my guitars back out and started playing a little every evening. One thing I noticed right away was that the noise suppression and filters of my CI programs seemed to be interfering with hearing my guitar. I talk with my audiologist and we explored some "open" programs, maps with as much front-end processing turned off as possible. No noise suppression, no auto gain control, no automatic features, no filters at all. It may seem a little counter-intuitive, but this is one of the things I really feel made a big difference in the way I hear music. They were loud and harsh at first, but I could hear my guitar so much better. I started listening to all my

music with them, and soon adapted to them and prefer them for everything ever since.

It immediately became apparent was that my pitch perception was zero. Since I have bilateral CI and no residual hearing, everything I hear is electric and I have no acoustic information at all. So, with the limitations of CI processing, pitch perception is the big hurdle to playing music with CIs. CIs do very well with timing and rhythm. It is up to the brain to come up with new ways to regain a sense of pitch.



I did this by playing very familiar simple scales that I have been playing for decades. I tune my guitar with a tuner to be sure it is correct, then just play that scale over and over up and down the neck every evening. At first it sounded like the same note being played over and over. Then I started hearing very inaccurate intervals. As the weeks and months went by, it began to sound more and more accurate. I moved on to just playing familiar melodies and riffs, and it started being fun again.

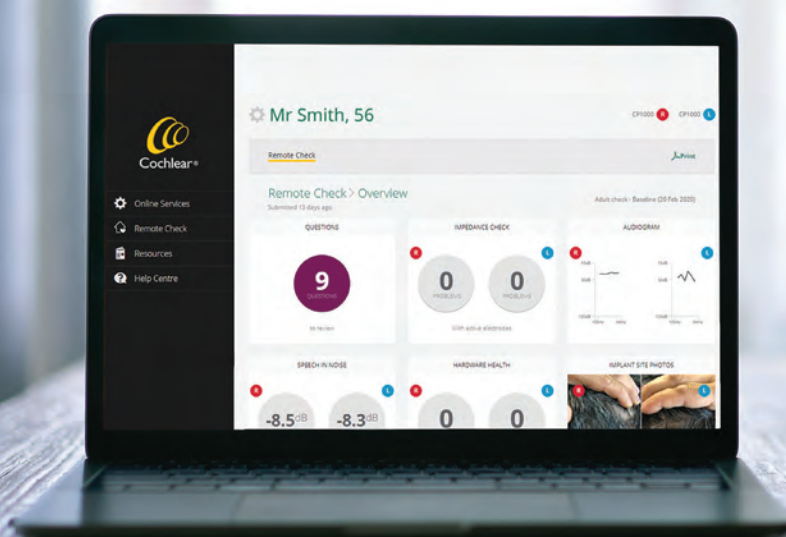
Music is still different than my memories of it from long ago when I could hear well. The dynamic range is compressed, soft things are pretty loud, and loud things are not much louder. Timbre is different, a little less defined, a little harder edged. There can still be pitch confusion, I pay attention a little more to not play out of key. The more complex the music, the harder it is for me to hear what I need hear to play.

### Music Before and After Cochlear Implants: Perspective Matters

If I continually compare what I hear now with my memories of music from long ago when I could hear good, I could be disappointed. But if I compare it to where I was with my old hearing aids just before I made the leap of faith to CIs, then I'm happy with how I hear music now. I'm pretty sure with the way my hearing was disappearing I would have lost music completely by now. So even though it's different, I still get a kick out of music. I no longer try to hear it as I once did, I just try to hear it the best I possibly can with my CIs. And it's been good connecting with other CI candidates and users that are walking this same path with music.

My CIs have been life changing for me. They have allowed me to get back to living my life in a hearing world as I've always known it.

*Read Kelly's full story and other music resources for CI recipients at [www.acialliance.org/page/CIMusic](http://www.acialliance.org/page/CIMusic). ■*



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