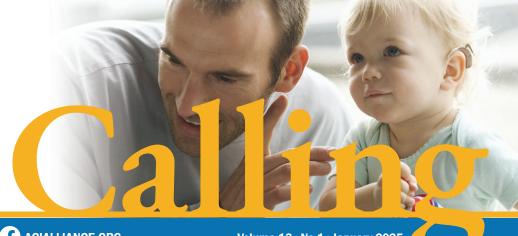


AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.









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Donna L. Sorkin, Editor

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Message from the Chair

Andrea D. Warner-Czyz PhD

Department of Speech, Language, and Hearing

The University of Texas at Dallas

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he American Cochlear Implant Alliance (ACI Alliance) prides itself on its diversity relative to professional discipline. We relish involvement

from clinicians at all levels: from students, residents, and fellows to early career clinicians and researchers to more established professionals. The Alliance also encourages engagement from cochlear implant manufacturers as well as cochlear implant recipients and their families. The interconnections among our members create a unique and powerful combination of knowledge and experience to support our organization's mission focused on research, advocacy, and awareness. Questions arise relative to how to become more involved in the organization. This may look different at different career stages.

As a student, resident, or fellow, this may mean contributing to clinical or research presentations at the annual conference. These individuals may apply for a student scholarship or enter the student poster competition. Students, residents, and fellows may learn more

about ACI Alliance from the resources and webinars available on our website.

Involvement as an early career professional looks a bit different because these individuals benefit from interactions with colleagues at the same and at senior levels. I recently learned about the Early Career group (formerly the Young Members Group) of the American Neurotology Society (ANS). This group, formed ten years ago, supports networking, collaboration, learning, and professional growth for those in the initial stages of their careers. At their September meeting in Miami, ANS hosted a social gathering for the group that inspired them as early career neurotologists. The get-together aimed to ensure younger surgeons had awareness of opportunities to get involved in the ACI Alliance via committees and advocacy efforts. Several members of both organizations - including ACI Alliance Board members Maura Cosetti, Dan Zeitler, and Matt Bush, among others - became engaged in advocacy efforts over the years, starting early in their careers.

When I attended this ANS Early Career group gathering, it made me think about ways in which the ACI Alliance encourages involvement of early career professionals in our organization. We have several committees that welcome engagement from professionals at all career stages. For example, the Scientific Program Committee encourages participation from clinicians across the care continuum, educators, and scientists to develop the program for our annual conferences. This

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Parents of Children with CI FB Group

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Brittney Sprouse AuD, PASC

Director, Audiology and Newborn Hearing Screening University of Chicago Medicine

Donna L. Sorkin MAEx Officio Board Member
Executive Director

MESSAGE FROM THE CHAIR continued from page 1

committee affords an excellent opportunity for networking in different disciplines, geographical areas, and with varied levels of expertise—a boon for individuals regardless of their career state. Esther Vivas from the Emory University School of Medicine and Keri Colio from Rady Children's Hospital San Diego co-lead this diverse group for the 2025 conference.

We have two committees focused on supporting student participation and early career involvement. The Student Scholarship Committee selects students, residents, and fellows to receive an award that covers conference registration, a travel stipend, and a one-year student membership. The Student Scholarship committee, chaired by Melissa Sweeney from the Callier Center for Communication Disorders, includes audiologists, speech-language pathologists, and surgeons. The Student Poster Competition Judging Committee, chaired by Lisa Park of the University of North Carolina, culls through posters by undergraduate students, graduate students, residents, and fellows to select the best submissions at the annual conference.

Advocacy provides another way in which individuals at all levels can join in the ACI Alliance's efforts. We educate and encourage policymakers and payers to support expansion of access to cochlear implants. Participation opportunities include our State Champion program (a member network) that works with our staff to proactively advocate for public policy changes to improve CI access at the state and national levels. State Champions work on expanding coverage under Medicaid and private insurance, passing CMV screening laws, and encouraging provision of unbiased, comprehensive information about early intervention. Our network for CI recipients and parents (CI CAN) recently provided input to their Congressional representatives to address airline access issues being considered by the US Department of Transportation. (See Nichole Westin's column below for details.)

I initially pitched this column as ways in which early career professionals can increase their involvement with our organization. Upon deeper reflection, though, professionals at all levels as well as parents and adult recipients can contribute to these committees and advocacy efforts. We need input from experienced surgeons, audiologists, speech-language pathologists, mental health professionals, educators, and consumers to keep our organization as pioneers in the cochlear implant field. We need interconnections not only across disciplines, but also across levels of experience to foster development of our early career professionals, as well as students, residents, and fellows. In summary, it is never too early or too late to become more engaged with the ACI Alliance.



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CI2025 Boston: Conference on Cochlear Implants April 30-March 3, 2025





Keri Colio AuD | Co-Chair Cl2025 Boston Program Committee Rady Children's Hospital San Diego

Esther X. Vivas MD | Co-Chair Cl2025 Boston Program Committee Emory University





Keri Colio AuD

Esther X. Vivas MD

s committee chairs for the Cl2025 Boston meeting, we are excited to welcome you to what promises to be an inspiring, groundbreaking, and highly collaborative event. Set against the vibrant backdrop of Boston, one of the nation's most historic and innovative cities, Cl2025 will take place from April 30 to May 3, 2025.

Every CI meeting provides an unparalleled opportunity for professionals, researchers, industry partners, and individuals from across the cochlear implant community to come together, share knowledge, and advance our field. CI2025 will be no exception. This year, we have worked diligently to design a program that not only reflects the latest advancements in hearing healthcare but also anticipates the future of cochlear implantation and auditory science.

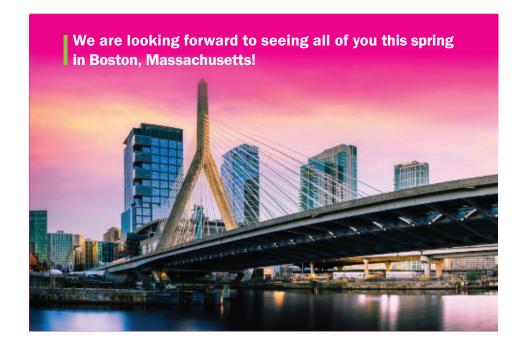
Boston, renowned for its blend of rich history and cutting-edge innovation, is the ideal setting for Cl2025. As a city steeped in medical and scientific achievement, it offers a fitting venue for us to explore the intersection of technology, research, and clinical practice. The city's dynamic energy mirrors the excitement and progress that define our field, making it the perfect environment for inspiring

discussions and breakthrough discoveries.

Our program will feature a robust lineup of keynote speakers, panel discussions, and podium and poster presentations, ensuring that every attendee—from seasoned professionals to early-career clinicians and researchers—has access to the tools and knowledge needed to enhance their practice and drive forward the science of cochlear implantation. Among the highlights, we are particularly excited about:

- Keynote Presentations by
 Visionary Leaders: CI2025
 will showcase thought
 leaders from around the
 globe, addressing critical
 topics ranging from emerging
 technologies to the challenges
 and opportunities in global
 hearing health equity. Expect
 insights that will challenge
 conventional thinking and
 inspire innovation.
- Presentations: Participants
 will have the opportunity to
 refine their expertise in areas

 continued on page 5



Cl2025 BOSTON continued from page 4

such as surgical techniques, patient counseling, and device programming through dynamic and engaging formats.

- Cutting-Edge Research
 Presentations: As always, the
 CI meeting is a platform for
 unveiling the latest research
 in cochlear implantation.
 Abstracts presented at CI2025
 will cover groundbreaking
 studies, real-world outcomes,
 and interdisciplinary
 approaches to improving
 patient care.
- Networking Opportunities:
 One of the hallmarks of CI
 meetings is the chance to
 connect with peers, mentors,
 and collaborators. Whether at
 formal networking sessions,
 social events, or informal
 meetups, attendees will
 have ample opportunities to
 forge new connections and
 strengthen existing ones.
- A Focus on the Patient
 Perspective: In keeping
 with the tradition of patient centered care, Cl2025 will
 highlight the voices of cochlear
 implant recipients and their
 families, emphasizing the
 human impact of our work
 and guiding us toward more
 inclusive, compassionate care.

We are delighted to announce that Dr. Nancy M. Young has been selected as the Niparko Memorial Lecturer for Cl2025.
Nancy M. Young, MD, FACS, FAAP, is the Lillian S. Wells Professor of Pediatric Otolaryngology at Northwestern University Feinberg School of Medicine and Fellow of the Knowles Hearing Center of Northwestern. She is Head of the Section of Otology and Neurotology in the Division of Otolaryngology and serves as Medical Director of Audiology & the Cochlear Implant

continued on page 6



Schedule at a Glance

Conference Dates

Wednesday, April 30 - Saturday, May 3, 2025

Conference Website

https://ci2025boston.org (links to abstracts, registration, hotel, updates)

Early bird registration rates through March 12, 2025

ACI Alliance Detailed Information

www.acialliance.org/page/Cl2025

Hotels and Meeting Venue

https://ci2025boston.org/meeting-hotel-venue Conference Headquarters Hotel: Omni Boston Hotel

at the Seaport

Group Rates Expire: Monday, April 7, 2025

Welcome & Opening Session with Niparko Lecture

Thursday, May 1, 2025 / 8:45-9:50

CI Manufacturer Satellite Symposia

Wednesday, April 30

1:00 PM - 2:15 PM | Advanced Bionics

2:45 PM - 4:00 PM | MED-EL

4:30 PM - 5:45 PM | Cochlear

CI Manufacturer Breakfast Symposia each day 7:30-8:30 AM

Thursday (Advanced Bionics), Friday (Cochlear), Saturday (MED-EL)

Poster Exhibit Session

Thursday, May 1, 2025, 5:00-6:00 PM

Welcome Reception

Thursday, May 1, 2025, 6:00-7:15 PM

ACI Alliance Research, Advocacy and Awareness Initiatives: Moving the Field Forward

Friday, May 2, 2025, 8:40-9:30 AM

Visit Mass Eye and Ear Following conference close

(see flyer on page 6 for details) Saturday May 3, 2025, 1:00-3:30 PM



Cl2025 BOSTON continued from page 5

Programs at the Ann and Robert H. Lurie Children's Hospital of Chicago. Dr. Young is President-elect of the American Otological Society, a member of the Board of Directors of the Hearing Health Foundation, and a founding board member of the ACI Alliance. We look forward to her insightful and inspiring lecture in Boston entitled "Language Prediction to Improve Outcomes for Children with Cochlear Implants."



Nancy M. Young, MD, FACS, FAAP

The meeting will delve into some of the most pressing issues in our field today. How can we ensure equitable access to

cochlear implants for all who need them? What role will artificial intelligence and machine learning play in the future of auditory rehabilitation? How can we foster interdisciplinary collaboration to address complex challenges in hearing healthcare? These questions and more will be at the forefront of our discussions in Boston.

As committee chairs, we are particularly excited about the collaborative spirit that defines CI meetings. It is always inspiring to see clinicians, scientists, educators, and industry professionals come together with a shared commitment to improving the lives of individuals with hearing loss. CI2025 will build on this tradition, creating an environment where ideas can flourish, partnerships can thrive, and solutions to real-world challenges can emerge.

We are also excited to explore Boston with you! Beyond the conference sessions, the city offers a wealth of experiences, from

walking the historic Freedom Trail to visiting world-class museums and enjoying fresh seafood at its iconic waterfront. We encourage attendees to take full advantage of everything Boston has to offer.

CI2025 Boston is more than just a meeting-it is a celebration of our collective achievements and a springboard for future innovation in cochlear implantation. We are honored to be part of this journey

with you and look forward to the energy, insights, and collaboration that the meeting will undoubtedly bring.

Mark your calendars for April 30 to May 3, 2025, and join us in Boston for an unforgettable experience. Together, let's continue to advance the field of cochlear implantation and make a lasting impact on the lives of those we serve.







Visit Mass Eye and Ear Immediately Following CI2025 Boston Saturday May 3, 1-3:30 PM

Sign Up to Reserve Your Place on "The Field Trip"—Space Limited to First 40

Mass Eye and Ear is an international facility and home to the world's largest hearing and vision research centers. Participants on this visit will have the opportunity to interact with researchers and visit labs to learn about two unique topics: implantable microphone technology and the Temporal Bone Lab.

There is no cost (other than transportation over to Mass Eye & Ear-we will group attendees in Ubers), but sign-up is required and attendees must be participants in CI2025.

1:00 Meet at Omni Boston Seaport Hotel location TBD to depart in Ubers 1:30

Arrive Mass Eye & Ear

1:45-2:30 Group A to Temporal Bone Lab, Group B to Implantable Microphones

2:30-3:15 Group A and B switch 3:30

Meet at Mass Eye and Ear for departure back to Omni Boston Seaport Hotel. Attendees may also choose to go elsewhere on their own



(Re)Habilitation Connect Forum Returns for a Fourth Year in Boston

Amy Lynn Birath AuD, CCC-A/SLP, LSLS Cert. AVEd

Pediatric Audiologist/Speech Language Pathologist

Coordinator of Speech-Language Pathology
The Moog Center for Deaf Education



n October 2013, the First Annual Symposium of the American Cochlear Implant Alliance took place in Washington D.C. The focus of Cl2013 was Emerging Issues in Cochlear Implantation with panel discussions on six topics which included "Cochlear Implants in Multiply Involved Children" and "Cochlear Implants in Single-Sided Deafness." At the time, these truly were emerging issues; however, today they are established practices.

For those engaged in (re)habilitation with children and adults in these unique populations, including speech-language pathologists, educators, psychologists, audiologists and others, the need for evidence-based practice guidance and information from experienced practitioners has never been greater. Because of this and because of requests from our (re)hab-minded membership, the (Re)Habilitation Connect Form at CI2025 will focus on outcomes of, and intervention for, children and adults with cochlear implants who have single-sided deafness or asymmetric hearing loss and those with cochlear implants who have hearing loss and additional diagnoses. The research-to-practice format for the Forum, with prominent researchers and experts in the field, will allow attendees to walk away with immediately applicable intervention information. Following the (Re)Habilitation Connect Forum, attendees will be able to meet and engage with the presenters at Continue the Conversation, a happy hour presented by Hearing First, which will allow for further discussion of these important topics in a less formal setting.

Presenters at the (Re)Habilitation Connect Forum will include:

- **Dr. Lori Bobsin**, University of Virginia Health System
- Becky Clem, Cook Children's Medical Center
- Dr. Richard Gurgel, University of Utah Health
- Sandra Hancock, University of North Carolina at Chapel Hill
- Michelle Havlik, UChicago Medicine
- Rebecca Piper, NYU Langone Health
- Blair Richlin, Mass Eye and Ear
- Molly Schoenfeld, The Ear Institute, New York Eye and Ear Infirmary of Mount Sinai
- Adrienne Stewart, The Moog Center for Deaf Education
- **Dr. Brittany Wuebbles**, Central Institute for the Deaf
- Dr. Dan Zeitler, Virginia Mason Medical Center/ University of Washington
- Lindsay Zombek, University Hospitals Cleveland Medical Center

Please join us in Boston on Friday afternoon, May 2, 2025, for this notable opportunity to level up your knowledge and skills regarding intervention with these unique populations.

More Details on CI2025 Boston: Member Discount Codes and SIGs

Jessica Houk MBA

Manager of IT & Membership Services ACI Alliance

jhouk@acialliance.org



12025 Boston Early Bird Member Codes have been emailed out to the organization's primary contact members for distribution. Professional members and students have also received their member codes. Once you begin the registration process, you will see the place to enter the member discount codes in a gray box on the left-hand side of the first page of the conference specific registration page. Make sure you register early and use your member code for the best discount possible. Early Bird rates are in effect through March 12.

We offer many opportunities for networking and learning during the conference outside of the sessions provided. A special interest group (SIG) is a community within a larger organization with a shared interest in advancing a specific area of knowledge, learning or technology where members cooperate to effect or to produce solutions within their field, and may communicate, meet, and organize conferences. We will have several SIG Lunches on both Thursday and Friday. Thursday's will include Adult Rehabilitation and Student Members.

On Thursday at lunchtime, the Adult Rehabilitation SIG will welcome existing and new members as we explore expanding access to aural rehabilitation for adult cochlear implant recipients. Join CI team members of all specialties to review our progress, trends in research, barriers to care and our future plans for this valuable service. Blair Richlin leads this SIG and her article on page 9 has more details.

Other planned SIG meetings include:

 On Thursday at lunchtime, the Students, Fellows, Residents SIG will meet and engage in discussion with recent graduates who can provide guidance on next steps and career goals. This will be a great way to meet other students and early career professionals and learn from those who recently walked in your footsteps.

On Friday at lunchtime, we will offer two SIG opportunities:

- ACI Alliance members with hearing loss will share experiences during a moderated discussion
- Members who are teachers of deaf and hard of hearing children will be led in discussion by Alexandria Mestres MSEd, Deaf and Hard of Hearing Educational Specialist at South Florida Charter Schools and University of Miami Children's Hearing Program. Alexandria's article is below on page 10.

These special interest groups provide a strong community connection, and they continue to be popular offerings. Follow our page for more information and sign up here for a SIG meeting in Boston of interest to you. CI2025 Boston Special Interest Groups - American Cochlear Implant Alliance

Adult Aural Rehabilitation Special Interest Group (SIG) Takes Off

Blair Richlin M.S., CCC-SLP, LSLS AVEd

Speech-Language Pathologist, Mass Eye and Ear

Coordinator, ACI Alliance Adult Rehab SIG

To connect with the SIG:

aciasigadultrehabilitation@gmail.com



The Adult Aural Rehabilitation (AR) Special Interest Group (SIG) is committed to expanding AR services for adult cochlear implant recipients. We believe this can be achieved through collaborative efforts in policy development, increased engagement, and addressing billing and service needs. You can join our group and access our monthly Zoom meetings by completing this form: https://forms.gle/ij37Znx2woaKJpRj8

As excitement builds for the ACI Alliance CI2025 Boston conference, the Adult Rehab SIG reflects on its successful lunch meeting at the CI conference in Vancouver in July 2024. Over 50 professionals from various disciplines attended. It was an excellent opportunity for both long-standing and new members to come together, share ideas, and discuss the latest developments in our field. We expect the CI conference meeting to be an annual in-person opportunity

to supplement our monthly Zoom meetings.

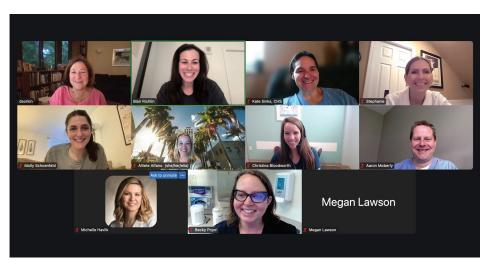
One of the key topics discussed was the initial findings from the Adult Cochlear Implant Recipients' Experience with our Aural Rehabilitation (AR) Survey. Initial results reveal that recipients associate a broad spectrum of services with AR, including learning to listen with a cochlear implant (CI), troubleshooting issues, improving sound quality, and enhancing music perception. Despite these associations, a surprising majority of respondents reported that they have never attended an AR session. The most frequently cited barrier to access was simply that the service was never offered to them. To help us better understand and address these gaps, we encourage you to share the survey with your colleagues, centers, and recipients. The more feedback we gather, the better we can tailor our services to meet the needs of adult CI recipients. Here's the link to the survey: https:// www.surveymonkey.com/r/HK6XZXV



ACI Alliance CI2025
Boston is going to be
a slam dunk for
Rehabilitation! (Boston

is the site of this year's NBA playoffs, with the dates coinciding with Cl2025.) Boston is one of the most vibrant, research-driven cities in the world and the perfect arena for physicians, speech-language pathologists, audiologists, scientists, and educators to network, learn, and discuss. In addition to rehabilitation-focused programming throughout the conference, we are thrilled to announce that the Adult Rehab SIG will host its annual meeting-an incredible opportunity for dynamic, multidisciplinary conversations and collaboration. Cochlear implant team dynamics are a bit like the teamwork of reigning NBA champions, right?

Sign-up for the Adult Rehab SIG lunch meeting at Cl2025 Boston here: https://www.acialliance.org/event/Cl2025auralrehab



Adult AR SIG Zoom meeting in August 2024

Educators of Deaf and Hard of Hearing Children SIG Forming

Alexandria Mestres MSEd

Deaf and Hard of Hearing Educational Specialist at South Florida Charter Schools and University of Miami Children's Hearing Program



Vancouver was an exciting event! Deaf and hard of hearing educators attending the conference had the opportunity to come together as a group and meet with the ChromeBook accessibility team manager from Google. We were able to discuss what digital accessibility means for children that have cochlear implants and use listen and spoken language. This led to broader conversations about supporting the success of deaf and hard of hearing students.

Educators play a key role in the daily life of children with hearing loss. More than 1,000 hours are spent in school every year making connections between deaf and hard of hearing educators, speech and language pathologists. Cochlear implant teams can be instrumental in supporting the success of these children.

With a new special interest group (SIG), educators at this year's CI2025 Boston conference will have an opportunity to come together again and discuss relevant issues impacting children with cochlear implants in school environments. Having this type of group within the ACI Alliance allows us to bridge the gap between clinic, classroom and families in order to ensure that children with hearing loss are getting the support that will lay the foundation for future success. We hope that you will join us this year in Boston for our SIG Lunch meeting!

To sign up, please go to the SIG lunches sign-up area: CI2025 Boston Special Interest Groups - American Cochlear Implant Alliance



Plan Your Trip to Boston!

Visiting Boston in the spring gives CI2025 attendees a great chance to explore and see the historical, educational and scenic city.

Meet Boston works to promote relevant, diverse, and interesting offerings in the city to visitors, and ACI Alliance has teamed up with Meet Boston to offer a website specific to CI2025 attendees that highlights many things the city has offer. The website includes information on the

the hotel is the historic Faneuil Hall Marketplace and Boston Commons and Public Garden.

The CI2025 Meet Boston website also includes information about restaurants, transportation options from the airport and around the city, museums, and sightseeing tours. If you are bringing your family to CI2025, there is a curated list of "25 Things to Do in Boston with Kids," and details on CityPASS tickets and discounts for visiting multiple attractions.



Visit the Cl2025 Meet Boston website at www.meetboston.com/ ci2025/ ■



conference hotel, the Omni Boston Hotel at the Seaport, which is located close to Boston Logan International Airport and situated in the bustling Seaport District, walkable to both restaurants and historic museums and sights. Located just a mile from



Plan Now to Attend Future ACI Alliance Cochlear Implant Conferences



Cl2026 | Chicago May 6-9



Cl2027 | San Diego May 12-15

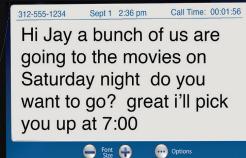


Cl2028 | Orlando April 19-22

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Should all deaf children learn a signed language?

Donna L. Sorkin MA

Executive Director

American Cochlear Implant Alliance

dsorkin@acialliance.org



n late August 2024, The Lancet published an article by ASL advocates Wyatte C. Hall and Julia L. Hecht entitled "Primary health-care practices for deaf children should include early incorporation of a signed language." Hall and Hecht promote the concept that unless children who are deaf utilize sign language, they will be language deprived. Despite The Lancet being a peer-reviewed, highly regarded medical journal with one of the world's highest impact scores, its editors were convinced to publish an opinion piece without references that detail the authors' assertations. The commentary calls up unfortunate perspectives of long ago such as Alexander Graham Bell's writings from 1883 on eugenics and deafness and states "Cochlear implants are not reliable for first language acquisition because they do not facilitate spontaneous language acquisition." That is not necessarily true anymore though it may be the case for late identified children and/or those with a secondary disability or health issue. But neither is learning with ASL necessarily a spontaneous process. At least 90% of children with hearing loss are born to two hearing parents who have no experience with deafness. On average it takes an adult eight years to gain ASL proficiency. To learn enough signs for very basic communication can take a year or more. Most parents new to deafness never gain ASL proficiency. At present 22% of US children are growing up in homes in which English is not spoken (Annie E. Casey Foundation, Kids Count Data Center). Parents will be most comfortable and able to encourage their children to learn in the language of the home—whether that language is English, Spanish, German, ASL or another.

What has been documented by numerous research studies on the language acquisition process is that there no one "right" way for deaf children to learn language. The world has changed from the bad old days when children with hearing loss were typically not identified with hearing loss until they were 2 to 2 $\frac{1}{2}$ years of age, cochlear implants were not available, and learning to listen and talk with older hearing technology was arduous.

Today over 95% of children with hearing loss are identified in the first month of life and 75% of children who fail the newborn hearing screen are referred into the early intervention system and complete diagnostic testing by 3 months of age. In addition to early identification and availability of cochlear implants at a young age, we have come to appreciate the power of parents to spur their children on using the language of the home and strategies that build upon what families already know. Our job in supporting families is to ensure that they understand that there are options for their deaf child, and to provide them with what they need to be successful in whatever communication option they select for their child.

Our colleagues from the US were frustrated by the misleading *Lancet* opinion piece. We encourage you to get involved in this ongoing discussion. Consider writing to *The Lancet*, another journal, or for a publication in your home community. Get involved in your state's pediatric society or in American

SHOULD ALL DEAF CHILDREN SHOULD LEARN A SIGNED LANGUAGE? continued from page 13

Academy of Pediatrics nationally. Let them know that most deaf and hard of hearing children will learn language on a par with their typically hearing peers when they are identified early, appropriately amplified with modern technology, and encouraged to learn with their families in the language of the home. Note what you do at your clinic to ensure families know that they have options and describe the outcomes you see with a range of approaches.

With a diverse group of language learning experts, ACI Alliance developed our Listening—Language—Literacy infographic. It has been translated in two other languages besides English (Spanish and Japanese) and will soon be available in three more languages. Use this to help you make the case. Engage with primary care providers—especially pediatricians—to provide a balanced, research-based perspective about what families need to help their deaf children acquire language. Let us know if you want to join the ACI Alliance efforts.







Note: Infographic is in all available languages

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

ACI Alliance Position Paper on Screening for Congenital CMV

Kevin D. Brown MD, PhD

Joseph P. Riddle Distinguished Professor of Otolaryngology – Head and Neck Surgery and Neurosurgery

Chief, Division of Otology and Neurotology University of North Carolina School of Medicine

Member of ACI Alliance Board of Directors



ongenital cytomegalovirus (cCMV) occurs in approximately 1 in 200 newborns in the United States, Between 10-15% of newborns will have immediate symptoms of CMV including sensory hearing loss amongst others. Up to another 20% will appear typical at birth but develop subsequent sensory hearing loss. Testing of newborns for cCMV is currently inconsistent across the country, but if performed would permit timely diagnosis, intervention by multidisciplinary teams, avoid unnecessary testing, and allow for surveillance for future complications.

Recognizing the need for more consistent testing in the newborn population for cCMV, the American Cochlear Implant Alliance Board charged three of its members—Kevin D. Brown MD, PhD; Amy Birath AuD; and Britney Sprouse AuD—with developing an interdisciplinary working group to

evaluate the evidence for newborn testing of cCMV. This group was comprised of, and collaborated with, members of the Hearing Committee of the Academy of Otolaryngology – Head and Neck Surgery, as well as the National CMV Foundation. The group consisted of audiologists, speechlanguage specialists, pediatricians, infectious disease specialists, pediatric otolaryngologists and neurotologists.

Together the working group developed a position statement for universal newborn testing for cCMV that was published on the Academy of Otolaryngology website. The working group also prepared a commentary on the evidence that is published in Otolaryngology – Head and Neck Surgery. The working group, together with the American Cochlear Implant Alliance, is hopeful these documents will help prompt and encourage more widespread testing for cCMV in newborns.

References

Position Paper https://cdn.ymaws.com/www.acialliance.org/resource/resmgr/files/CMV Position Statement Dec24.pdf

Article Presented at 2024 AAO-HNSF Annual Meeting (with references available via Google Scholar)

https://aao-hnsfjournals.onlinelibrary.wiley.com/doi/10.1002/ohn.1079

ACI Alliance Website materials on CMV

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

What Lies Ahead in Federal Healthcare Decision-Making?

Peter Thomas JD

Governmental Affairs Counsel to ACI Alliance

Powers Pyles Sutter & Verville PC



Michael BarnettDirector of Governmental Relations
Powers Pyles Sutter & Verville PC



n December 20, after a tumultuous week in Congress marked by three failed attempts and a glimpse of President-Elect Trump's continued influence on Capitol Hill, lawmakers narrowly avoided a government shutdown by approving a short-term funding bill that President Biden signed into law on Saturday, December 21st. The legislation extends current government funding levels through March 14, 2025, allowing the incoming 119th Congress additional time to finalize appropriations for the fiscal year, which ends on September 30, 2025.

The 1,500-page stopgap measure included a number of healthcare provisions. Most importantly, it did not include an increase for payments under the Medicare Physician Fee Schedule to mitigate the finalized 2.8% cut, a priority for ACI Alliance members. The bill did, however, provide a temporary extension—through March 31, 2025—of the telehealth flexibilities granted during the COVID-19 public health emergency, while also including an extension of the Acute Hospital Care at Home initiative. The latter allows certain Medicare-certified hospitals to treat patients with inpatient-level care at home, through the end of March, among other provisions.

The week-long funding saga was marked by intense negotiations and political maneuvering.

An initial bipartisan deal that included, among other provisions, a 2.5% increase in reimbursement

under the Medicare Physician Fee Schedule, a two-year extension of the telehealth flexibilities, a reauthorization of the Traumatic Brain Injury (TBI) Act, and certain Medicare "extenders," was derailed by House conservatives due to opposition expressed by Elon Musk and President-elect Donald Trump. These provisions may be re-negotiated at some point after the 119th Congress is sworn-in in January and will likely be included in the longer-term legislative package that gets considered before the new March 14th government funding deadline.

Subsequent proposals introduced towards the end of last week faced challenges, including demands from President-Elect Trump for debt ceiling extensions and other policy riders. Nevertheless, a compromise was ultimately reached (without the debt ceiling provision), preventing a government shutdown just before the holiday season.

Regardless of what happens long-term with the fiscal year 2025 appropriations package, which will be passed one way or another, next year will inevitably be difficult due to the reconciliation process and potential cuts to Medicaid and even Medicare, despite President-Elect Trump's commitment not to cut Medicare or Social Security during his campaign.

ACI Alliance staff will continue to closely monitor this situation going into next year and provide members with updates as events of importance occur.

Advocacy Via the Regulatory Process: Change Happens in Multiple Ways

Nichole J. Westin MADirector of Governmental Affairs
ACI Alliance

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ne of the most under-appreciated aspects of governmental policy-setting is the importance of the regulatory process and its impact on the lives of Americans. In 2024, the federal government published two final rules that impacts cochlear implant (CI) users. Both are a direct result of years of advocacy efforts not only by ACI Alliance but also by our hearing health partners.

FCC Rule on Hearing Technology and Phones

In October 2024, the Federal Communications Commission (FCC) approved an order requiring that all handset models (e.g., mobile smartphones and handsets for landlines) must be compatible with hearing aids via Bluetooth and other technology. With this change, those who utilize hearing technology such as hearing aids and Cls will have access to all the same mobile phone models that are available to every consumer. The rule also covers handsfree devices and landline phones.

Under current FCC rules, only 85% of wireless phones are required to be compatible with hearing technology permitting phone manufacturers to include up to 15% of non-hearing aid compatible handsets in their portfolios. A Bluetooth coupling requirement was included in the rule and ensures more universal connectivity between mobile handsets and hearing technology by encouraging handset manufacturers to move away from proprietary Bluetooth coupling standards. Currently, most phones can only connect directly to the hearing technology via proprietary Bluetooth technology.

While pairing technology has seen great improvement in the last few years, this rule has been a longtime coming as accessibility for those with hearing loss has lagged behind communication technology jumps. With this rule in place, that will no longer be the case.

Airline Travel Accessibility Rules

In December 2024, the U.S. Department of Transportation issued the final rule to strengthen regulation implementing the Air Carrier Access Act as required by the FAA Reauthorization Act of 2024. While the rule primarily focuses on protecting those who utilize wheelchairs and scooters, we are pleased that it stressed training for all staff on noticing and accommodating those with hearing and visual loss as well as requiring flexibility.

Specifically, the regulation states:

(i) You (the airline) must ensure employees and contractors are trained on appropriate ways to communicate and interact with passengers with disabilities, including persons with physical, sensory, speech, mental, intellectual, or emotional disabilities (e.g., communicating directly with the individual with a disability instead of to the travel companion/interpreter).

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(ii) You must also ensure such employees and contractors are trained to recognize requests for effective communication accommodation from individuals who have disabilities impacting communication (e.g., hearing or vision impaired individuals, non-verbal individuals), and to use the most common methods for communicating with these individuals that are readily available, such as writing notes or taking care to enunciate clearly, for example. Training in sign language is not required.

ACI Alliance met with Congressional staff multiple times on airline access issues, and we also encouraged our consumer advocacy network (CI CAN) to contact their Members of Congress via Action Alerts. These personal stories on the complications of flying with a hearing loss are impactful. We will continue to advocate for our members on other travel issues such as captioning announcements.

Additional Federal Efforts

We also continued to advocate for Medicare telehealth permanency for audiologist and SLPs. While CMS has extended the coverage through 2024 via pressure during the rule-making process, Congressional action is required to make it permanent. As noted above in the article by Peter Thomas and Michael Barnett, Congressional funding bill provided a temporary extension—through March 31, 2025—of the telehealth flexibilities. In December, we joined other members of the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition sending letter supporting legislation to address significant Medicare Cuts to durable medical equipment reimbursement in addition to several issues that broadly support the disability community.

The regulatory process impacts the day-to-day lives of the CI patient community. Decisions finalized in 2024 will provide improvements for many. Interested in joining ACI Alliance Advocacy efforts as a State Champ? Contact me at nwestin@acialliance.org.



Good Stuff on the ACI Alliance Website

Laura Odato MPP

Director of Operations and Marketing ACI Alliance

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CI2024 Vancouver Videos Available

ach of our cochlear implant conferences features content spanning a wide range of topics relating to cochlear implant outcomes, surgery, candidacy, rehabilitation, and more. To allow attendees to take a second look at selected lectures or see a few of the sessions that they may have



missed, we have made videos of the keynotes, some of the panels, and a few concurrent sessions. There are presentations to view on pediatric and adolescent outcomes, telehealth, disparities and inequities in clinical care, and the ever popular "Stump the Experts" panel.

We also publish Powerpoints for those presenters who gave permission to post their talk materials. This should also entice others who were not present in Vancouver to attend the upcoming Boston meeting!

Cl2024 Vancouver conference content is now available. We encourage anyone who was not able to join us in Vancouver or anyone who missed a session to visit and share the website to review these important and educational presentations.

Among the presentations available to watch are:

- Dr. Ruth Litovsky's John Niparko Memorial lecture "Successful Pathways to Outcomes in Bilateral Cochlear Implantation"
- Dr. Andrej Kral's keynote lecture "Maturation of the Auditory System Requires Auditory Experience Within an Early Critical Period"
- Dr. Jill Firszt's keynote lecture
 "Cochlear Implantation of
 Individuals with Asymmetric
 Hearing Loss and Single Sided
 Deafness: Results, Expectations
 and Gaps in Knowledge"
- (Re)Habilitation Connect Forum Part 1 Pediatrics

 (Re)Habilitation Connect Forum Part 2 Adults

These selected presentations from Cl2024 are available at https://www.acialliance.org/page/conferences.

CI Resource Portals

We understand how important it is to make relevant, accurate information on cochlear implants easily accessible on our website. To facilitate this, we've organized resources into four portals found at the top of the ACI Alliance website for four audiences—Adults, Parents, Hearing Health Professionals (outside of CI), and Primary Care Physicians.

The Adults portal covers information most queried by adults seeking information for themselves or a family member, including candidacy, surgery, and insurance. https://www.acialliance.org/page/AdultsPortal

For Parents, the portal covers similar topics and includes information on what happens after surgery, facilitating listening and spoken language, and frequently asked questions page. https://www.acialliance.org/page/Parents



GOOD STUFF continued from page 19

The Hearing Health Professionals portal provides information relevant to hearing care professionals who may not specialize in cochlear implantation, with a focus on how and when to refer a patient for a Cl evaluation.

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

For Primary Care Physicians, much of the above information is provided with details on what to consider when counseling and referring patients (children and adults) who may benefit from cochlear implants. https://www.acialliance.org/page/PrimaryCarePortal

Stories of CI Recipients

Many find it valuable to learn about the experiences of cochlear implant recipients to to understand what may lie ahead for them. We have collected stories specific to different populations to help people understand what their life might be like after cochlear implantation, with the understanding that each case in unique. We have reallife stories about children, young adults, middle-aged and older adults, veterans, and parents who contribute as advocates for others.

We are grateful to the individuals, families, and parents who choose to share their stories. We encourage you to share these with others and connect us with patients, students, or friends who may want to share their stories with us.

Resources to Share

The website includes a Resources to Share landing page that includes free, downloadable PDFs of postcard and flyer resources relevant to adults and children. These resources are intended for use by



clinic professionals to provide to patients, educators who work with deaf and hard of hearing children, and the candidate population. They are great handouts for the clinic, professional development events and conferences, and on social media.

Resources include the Patient Tips series published in collaboration with The Hearing Journal, candidacy postcards for adults and children, and the Listening—Language—Literacy graphics in multiple languages.

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

Ask the Audiologist Blog

This fall ACI Alliance launched "Ask the Audiologist," a blog designed to allow people who are exploring cochlear implants to have a place to ask questions to help them along the path. The blog avoids addressing topics that are best responded to by the CI team for people who are already part of the CI journey. Drs. Melissa Hall and Cache Pitt have answered questions on diverse topics including using a cochlear

implant on one ear and a hearing aid on the other, how to determine if a patient is a candidate for a cochlear implant, navigating health insurance coverage, and bilateral hearing loss in children.

The blog allows anyone to easily submit a question for Audiologists Hall and Pitt to answer, with the goal of the blog being that it will become an ongoing, reliable and relatively comprehensive resource for the questions we most often receive as an organization.



A blog designed to allow people who are exploring Cochlear Implants to have a place to ask questions to help them along the path.



MELISSA HALL AUD



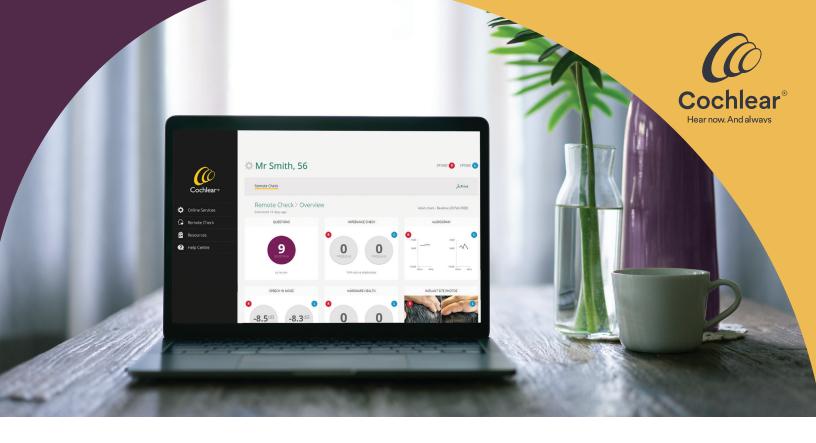
Dr. Melissa Hall earned her Doctor of Audiology from the University of Florida after completing her BA and MA in Communication Sciences and Disorders at the University of Central Florida. She joined the University of Florida as a clinical associate professor teaching audiology courses. Today, she directly serves patients and families, specializing in occhieor implants and other implantable hearing devices.

Dr. Cache Pitt is a Clinical Associate Professor of Audiology and provides clinical supervision to graduate students in Audiology. He went to the University of Wyoming where he earned his Bachelor's and Master's degrees in Audiology. Dr. Pitt began his coreer in audiology at the California Ear institute in Palo Alto, CA where he worked with adults and children with cochlear implants.



We encourage you to share this blog with anyone who may benefit as well as professional colleagues so we can continue to add additional answers and provide consumers another avenue for accurate and up-to-date information on hearing loss and cochlear implants.

www.acialliance.org/page/ask-audiologist-blog



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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.

Remote Check and Remote Assist for Nucleus sound processors are intended for ages 6 and older. Remote Check and Remote Assist features are only visible and accessible if they are enabled by a clinician. Clinicians should consider the suitability of the feature before enabling Remote Check and Remote Assist. Remote Check does not replace clinical care and does not involve remote programming of the sound processor. Only available at clinics that have enrolled in Remote Care.

Your clinician might require payment for a Remote Care session once completed. Clinic must be enrolled in Remote Care to participate.

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Meet the ACI Alliance Board of Directors



Maura Cosetti MD, Director, Ear Institute, New York Eye and Ear Infirmary of Mount Sinai

y name is Maura Cosetti and I am a neurotologist in the Mount Sinai health system in New York, NY. I currently serve as Director of the Ear Institute at the New York Eye and Ear Infirmary (NYEE) of Mount Sinai, leading a highly specialized and comprehensive multidisciplinary team of professionals focused on ear and balance disorders, which includes the Cochlear Implant Program. I am also passionate about teaching and mentoring, and am involved in the otology education of medical students, residents and fellows, including directing the neurotology fellowship program at the Icahn School of Medicine at Sinai.

I have been involved in ACI Alliance since 2012 when I began as a Louisiana State Champion working to improve cochlear implant access for deaf children in the rural South. Over the past 10+ years, I have been continually inspired and invigorated by the dedication of this organization toward the mission of advancing hearing healthcare through research, advocacy and awareness. As a physician and CI surgeon, I have the daily privilege witnessing the tremendous impact that this technology can have on adults and children with hearing loss and their families. Through ACIA, I have witnessed the impact that committed, passionate individuals can make at the local, regional and national level. As a current member of the ACIA board, I am grateful to work with gifted clinicians, dedicated patients and their families, researchers, legislators, and policy makers to improve awareness and access to CI-related care.

Most recently, we have embarked on a journey to improve CI access and secure equitable care for Medicare beneficiaries with post-lingual single-sided deafness (SSD) and asymmetric sensorineural hearing loss (AHL). Evolving changes in CI candidacy have afforded various populations with SSD and AHL access to CI, including adults 65 and older insured outside of Medicare, active-duty military and United States veterans. However, current coverage determinations limit the treatment options for Medicare beneficiaries. With the help of a large partnership of CI clinicians across the country, and the support of ACIA, we are proposing a revision to Medicare coverage that would eliminate the inequity in access currently experienced by Medicare beneficiaries.

As the daughter of a federal judge, I was raised with a long-standing respect for public service and the rule of law. Though I recognized early-on that my future was in the operating room, not the court room, I appreciate the effort and commitment required to influence federal policy, and the potential gravity of these changes on access and equity for hearing impaired individuals. I am optimistic for the future of hearing healthcare, and the many exciting developments in hearing restoration that will be options for our patients in the future. I remain honored to work with the ACI Alliance organization, board and hearing healthcare community to maximize access and awareness to all who may benefit.

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Kenneth Lee MD, PhD, Professor of Otolaryngology, Southwestern Medical Center and Director of the UT Pediatric Cochlear Implant Program at Children's Health Dallas

y name is Kenneth Lee and I was first introduced to cochlear implants as an MD, PhD student working toward a doctorate in neurobiology in the lab of Doug Cotanche, who studied cochlear hair cell regeneration. While I was working on understanding a neurobiological process that restored hearing in deafened birds, I became fascinated with how effective cochlear implants were at providing functional hearing in humans with profound hearing loss. I decided to pursue a career as an otolaryngologist and as a resident at Washington University in St. Louis, I continued to learn about cochlear implants from research leaders in the field such as Margo Skinner. At Wash U, I shifted my research to become more translational and investigated the potential of using axon guidance molecules to direct the outgrowth of spiral ganglion neurons to specific electrons on a cochlear implant array to provide more frequency specific stimulation and improved sound quality.

I am a pediatric otolaryngologist with a focus on otology and treatment of hearing loss in children. I currently serve as the John W. and Rhonda K. Pate Professor of Otolaryngology at UT Southwestern Medical Center in Dallas and the Director of the UT Pediatric Cochlear Implant Program at Children's Health Dallas. I continue to be active in cochlear implant research and recently my efforts have become very translational. My current project is in collaboration with a materials science engineer, and we are developing a novel cochlear implant electrode array with shape memory polymers that is straight at room temperature, but then self-coils to match the turn of the cochlea once inserted and warmed to body temperature. As a result, it can be inserted as a lateral wall array with minimal trauma, but then slowly change shape to become a perimodiolar array for more optimal electrode positioning, and thus, effectively provide the best of both worlds.

One of the highlights of my career is to have the privilege of joining the ACI Alliance Board of Directors. I am honored to work alongside a such an esteemed group of professionals who, while having diverse backgrounds, share the common goals of furthering our understanding of hearing loss and advancing treatment for our patients. In the short amount of time since joining the board, I have already learned so much from my colleagues and am further motivated to push for new discovery, promote quality care, and better advocate for our patients and their families.

An Adult CI User's Perspective

Thrive Through Sound: My Journey with Cochlear Implants

Renee Polanco Lucero PhD, LSLS Cert. AVEd



s a Deafblind Latina educator and Chief Academic Officer at the John Tracy Center, I have spent over two decades championing diversity, equity, and inclusion in deaf education. My personal and professional journeys are deeply intertwined with my experiences as a bilateral cochlear implant (CI) user, shaping both my identity and my mission to empower others.

Diagnosed with moderate hearing loss at age three, my early years were shaped by my family's dedication to ensuring I had the tools and opportunities to succeed. They prioritized access to quality educational experiences-from learning to speak and listen with hearing aids to excelling in general education classrooms. These early efforts laid the foundation for my resilience and adaptability. It wasn't until my 30s that I was diagnosed with Usher Syndrome (type 2), which explained the progressive nature of my hearing loss. By then, I was bimodal, using a hearing aid and one cochlear

implant. While I enjoyed being bimodal, my degenerative visual condition led me to get a second implant in 2021, ensuring better auditory access and maintaining a strong connection to life as my vision declines.

Cochlear implants have been lifechanging, opening new dimensions of communication and interaction. They have allowed me to remain deeply connected to my family, my work, and my community. As a professional in deaf education, they provide me with firsthand insight into the possibilities and complexities of hearing technology, which extends far beyond just the individual user. This technology has a profound ripple effect, impacting the families who navigate these decisions and the professionals who support them on their journey.

In the summer of 2024, I attended my first ACI Alliance conference in Vancouver. It was a remarkable experience to meet other CI users and professionals who share a commitment to advocacy and education. The conference reaffirmed the importance of organizations like the ACI Alliance. whose mission to advance access to the gift of hearing through research, advocacy, and awareness ensures that cochlear implants remain a life-changing option for those who need them. The connections I made and the knowledge I gained strengthened my resolve to continue this important work.

This mission aligns closely with my work at the John Tracy Center,

where we provide parent-centered services locally and globally to children with hearing loss, offering families hope, guidance, and encouragement. Our work emphasizes the importance of empowering families to make informed decisions and helping children thrive in their unique journeys. In my role as the Director of the JTC-Mount St. Mary's University graduate program, I mentor the next generation of teachers of the deaf, emphasizing accessibility and representation as cornerstones of inclusive education. Through this work, I see firsthand how cochlear implants can transform lives, not as a cure, but as a tool for connection and opportunity.

As I reflect on my journey,
I am reminded of my mother's
perspective when she chose
hearing technology and spoken
language as the primary mode of
communication for me. It wasn't
because she thought I was broken,
but because she believed in giving
me access to opportunities that
might otherwise be out of reach.
This belief continues to guide me
as I work to ensure that all children
and families have access to the
resources they need to thrive.

I am profoundly grateful for the community and tools that have supported me along the way. Together, we can continue to advocate for a world where every individual, regardless of hearing level, has the chance to find their voice, connect with others, and flourish.



Remote Care will allow you to support your patients —at any time that is convenient for you.

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