



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.



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Carrie Spangler, Editor

Contents

- 1 Message from the Chair
- 2 ACI Alliance Board of Directors
- 3 Using Your Voice
- 6 Dr. Monita Chatterjee Named John Niparko Memorial Lecturer
- 8 Protecting EHDI: The Program Behind Newborn Hearing Screening
- 9 EHDI: Past, Present, and Future
- 10 ACI Alliance Launches Medicaid Advocacy Toolkit
- 12 Empowering Our Voices: From the Kitchen Table to Capitol Hill
- 14 Advancing Medicare Coverage for Single-Sided Deafness and Asymmetric Hearing Loss
- 16 CI2027 Scientific Program Update
- 18 "Don't Be Shy": Lexi on Sports and Self-Advocacy
- 21 Find Your Community: ACI Alliance Special Interest Groups
- 23 ACI Alliance Launches New Internship Pilot Program
- 24 A New Voice for Advocacy: Meet ACI Alliance's First Intern
- 25 Meet Our Board Member: Barbara Mellert MPH

Advertisers

- 5 CapTel
- 15 Cochlear
- 22 MED-EL
- 26 Advanced Bionics

ADVOCACY

Meeting Reflections

Message from the Chair

Daniel M. Zeitler, MD FACS

Co-Director, Listen for Life Cochlear Implant Center

Director, Research and Academics

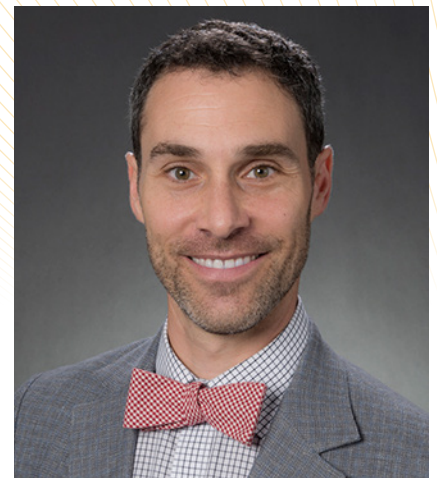
Otology/Neurotology & Skull Base Surgery,

Department of Otolaryngology-HNS

Virginia Mason Franciscan Health

Clinical Assistant Professor – University of Washington School of Medicine

daniel.zeitler@commonspirit.org



Rosh Hashanah, the Jewish New Year, is a season of reflection and renewal—a time to reflect on the year that has passed, celebrate accomplishments, and prepare for the work ahead. I have found myself reflecting on that idea in the context of the American Cochlear Implant Alliance, particularly when I think about one of the central tenets of our mission: **advocacy**. Advocacy is not defined by one meeting, one piece of legislation, or one policy victory. It is the steady work of educating policymakers, building relationships, sharing evidence, and ensuring the experiences of people with hearing loss and their families are part of the conversation. Most importantly, advocacy is a collective effort.

I am particularly proud of the growth of our **State Champions Network**, which now includes 222 Champions representing 49 states and the District of Columbia (if you are from Maine, we need you!). Our State Champions are an essential connection between the ACI Alliance and what is happening locally across the country. I encourage all of our Champions to continue sharing what you are seeing in your states—both successes and challenges. Those experiences help shape our national advocacy efforts.

Our recently launched **Medicaid Advocacy Toolkit** is one way we are helping turn knowledge into action.

continued on page 2

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University of Chicago Medicine

Carrie Spangler, AuD
Executive Director

MESSAGE FROM THE CHAIR *continued from page 1*

The Toolkit provides practical information about Medicaid policy, CI coverage, and opportunities for state-level advocacy. Important expansions for CI coverage have been achieved in Arizona and Washington, with ongoing efforts in several other states. These experiences are invaluable as we work to understand broader trends, identify opportunities to improve access, and address inequities at the policy level.

At the federal level, ACI Alliance remains deeply engaged. We provided written comments and testimony during the **Section 301 tariff proceeding**, advocating for continued duty-free treatment of medical devices and hearing technologies. The final action preserved that treatment, an important outcome for the hearing healthcare community. We also submitted comments to the **Office of Management and Budget** regarding proposed changes to federal financial-assistance rules and their potential implications for federally funded research, public health programs, hearing healthcare innovation, and scientific independence.

We continue to monitor ongoing federal efforts to restructure the Department of Education, including potential transfer of **OSERS and IDEA**-related functions to the Department of Health and Human Services. ACI Alliance is tracking three bills before Congress addressing these issues, and we will continue to engage our State Champions in grassroots advocacy. **EHDI reauthorization** in 2027 will also be an important priority. We are advocating for strong federal support for both the CDC and HRSA components of EHDI and for preservation of the expertise and infrastructure states rely upon. We are already laying the groundwork with congressional champions, and the experiences you are seeing in your states will be critical to that effort.

Lastly, with the help of our allies at Powers Law, we continue our work to pursue expanded **Medicare coverage for cochlear implantation for individuals with single-sided deafness**. We have assembled an incredible, multicentered team of researchers, hearing healthcare professionals, and advocates to advance this effort towards a successful conclusion.

When I look at all these efforts, I am struck by how much of our progress depends on people willing to engage. ACI Alliance can provide the information, the resources, the relationships, and the national voice—but our advocacy is strongest when our entire community participates.

That is particularly meaningful to me as we enter a new year. Renewal is not about starting over; it is about taking what we have learned and using it to move forward with greater purpose. For ACI Alliance, that purpose remains clear: **ensuring people who could benefit from cochlear implantation have meaningful access to it**. I am grateful for the opportunity to serve as Chair, and more importantly for the dedication of everyone who continues to move this mission forward. ■

Humbled and proud,

Daniel M. Zeitler, MD FACS
Chair – Board of Directors, ACI Alliance

Using Your Voice

Carrie Spangler, AuD

Executive Director
ACI Alliance

cspangler@acialliance.org



In the fourth grade, I discovered something important: I didn't know how to use my voice.

I had come in from recess — hot, sweaty, my hearing aids cutting in and out. My teacher began a spelling test, and I was completely lost. I glanced at my neighbor's paper. He raised his hand immediately to tell on me. I was sent to the principal's office, and I didn't say a single word in my own defense. I didn't know how. I didn't know yet that my situation was worth explaining — that there was a story I could tell that would change how people understood what had happened.

That moment has stayed with me ever since. I was embarrassed. I was

met with our industry partners, our Special Interest Groups, our State Champs, and our Parent Advocacy Network. Across every conversation, one theme emerged: advocacy and awareness — at the kitchen table, in the clinic, in the statehouse, and on Capitol Hill — is the thread that runs through everything we do, and it is what nearly every person I spoke with wanted to do more of.

It reflected exactly why we exist. ACI Alliance was built on advocacy, awareness, and research. In 2010, a group of surgeons, audiologists, speech-language pathologists, and industry representatives sat down together around a shared conviction: cochlear implants should be accessible to every person who

“As I step into this role, my job is to make ACI Alliance the place where all those pieces find each other.”



devastated. And somewhere under all of that, I started to understand that advocacy isn't instinct — it's something you have to learn. It can be learned, modeled, and strengthened — but someone has to teach and encourage it. And you have to know your story well enough to tell it.

I've thought about that fourth-grade version of myself a lot during my first ninety days as Executive Director of ACI Alliance. These past months were intentional: I spent them listening. I met one-on-one with every board member, connected with partner organization leadership,

can benefit. That conviction became ACI Alliance. It is the most grassroots kind of advocacy — people deciding that something matters enough to build something around it.

Over the years, ACI Alliance has grown into a community that spans the entire cochlear implant team and beyond. Each of you brings an important piece to the puzzle. The surgeon who performs the implant. The audiologist who maps it. The researcher and scientist who advance what's possible. The industry partner who develops and delivers the technology. The

continued on page 4

USING YOUR VOICE *continued from page 3*

therapist, the psychologist, the counselor, the navigator, the nurse, the teacher — every professional and supporter who walks alongside a family through the journey. The parent or caregiver who makes the calls, keeps the appointments, and refuses to stop asking questions. The individual who decides that hearing matters enough to pursue it — and in doing so, makes everything else possible. The State Champ who picks up the phone and calls their legislator. Every piece is essential. The picture isn't complete without all of them.

That starts with voice. Your voice — in a clinical setting, in a school meeting, in a legislator's office. I know what it feels like to not know how to use it. I also know what it looks like when you finally do. After years of advocating for myself as a person who is deaf and hard of

hearing, I started making it a priority to know my legislators before there was a problem. I went to town halls. I requested district meetings. I shared my own experience — what access to

You have that same seat. It doesn't matter what your title is or how long you've been in this work. Being a constituent is enough. Knowing your story is enough. The cochlear

“The puzzle only comes together when we each contribute our piece. What will you do?”

hearing technology had meant to my education, my career, my life. Being a persistent communicator gave me a seat at the table on issues related to hearing health care.

As your Executive Director, I carry that same commitment forward — to keep showing up, keep speaking up, and to amplify every voice in this community.

implant community has one of the most compelling stories in all of healthcare: technology opens the world of sound, families forever changed, adults hearing again for the first time in years, children who learn to listen and communicate and thrive. That story — and the mission to advance access to the gift of hearing through research, advocacy, and awareness — belongs to all of us to tell. ■



USING YOUR VOICE
How to Get Involved with ACI Alliance

"The puzzle only comes together when we each contribute our piece. What will you do?"

☐ Become a State Champion Connect with your legislators before there's a problem. 222 Champions in 49 states are already at work — join them.	☒ Join a Special Interest Group Six SIGs connect professionals around the topics that matter most in CI care. Find the group that fits your work.	☐ Parents & caregivers: add your voice You don't need a policy background — just your family's story. Join the new Parent & Caregiver Advocacy Arm.
☐ Become a member Membership connects you to the full ACI Alliance community — conferences, SIGs, advocacy tools, and the people advancing access to cochlear implants.	☐ Share your story Data shapes policy. Personal stories move it. Your experience with cochlear implants is one of the most powerful tools in advocacy.	☐ Advocate at the state level As policy shifts to states, your local voice matters more than ever. Use the Medicaid Toolkit to know the issues and take action.

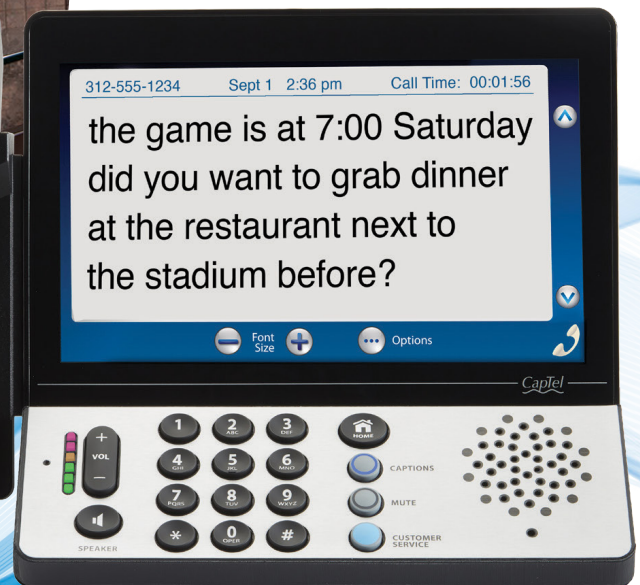
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Honoring a Legacy: Dr. Monita Chatterjee Named 2027 John Niparko Memorial Lecturer

The American Cochlear Implant Alliance is proud to announce that **Dr. Monita Chatterjee**, Professor in the Roxelyn and Richard Pepper Department of Communication Sciences & Disorders at Northwestern University, has been selected as the John Niparko Memorial Lecturer for CI2027. Dr. Chatterjee will deliver the conference keynote in San Diego this May — a moment that will honor Dr. Niparko’s enduring legacy and sharing a frontier of cochlear implant research that is the center of human connection.



A Lecture Built on Shared Purpose

Established by ACI Alliance to recognize Dr. John K. Niparko’s extraordinary contributions to cochlear implant research and clinical care, the annual John Niparko Memorial Lecture is among the most distinguished honors in the field. Dr. Niparko, a founding co-chair of

ACI Alliance’s Board of Directors, devoted his career to improving outcomes for cochlear implant recipients of all ages — and to building the collaborative community that would carry that mission forward.

Dr. Chatterjee, who knew Dr. Niparko through their shared work in the cochlear implant research community, reflects on what this honor means to her:

“I am truly honored and grateful to the ACI Alliance for inviting me to serve as the John Niparko Memorial Lecturer at CI2027. I am fortunate to have met Dr. Niparko several times... Our interactions were always marked by great collegiality and kindness from John, and I remember noticing how profoundly invested he was in the welfare of cochlear implant patients. It means a great deal to me to be able to discuss this work in a lecture that honors John’s memory.”

Listening Beyond Words:

The Science of Emotional Prosody

Dr. Chatterjee has studied auditory and speech perception in cochlear implant users since 1995, bringing to the field a combination of engineering precision and neuroscience. Her training spans electrical engineering at Jadavpur University in Kolkata, India; a PhD in Neuroscience from Syracuse University; and postdoctoral work with Dr. Robert V. Shannon at the House Ear Institute. She has led NIH-funded labs at the House Ear Institute, the University of Maryland, and Boys Town National Research Hospital before joining Northwestern, where she directs the Auditory Prostheses & Perception Laboratory.

At the core of Dr. Chatterjee’s work is a conviction that hearing restoration should support “full emotional and social connection, not just speech comprehension. In recent years, her research has turned to a focus of hearing that is easily overlooked: the ability to read

continued on page 7

HONORING A LEGACY *continued from page 6*

emotion in a person's voice. Through voice pitch, rhythm, and intonation, we communicate a multitude of emotions. For cochlear implant recipients, perceiving these vocal cues can be challenging, with real implications for social connection and quality of life.

Dr. Chatterjee describes the questions driving her lab's work:

“Why is it that some children or adults with CIs show excellent performance in our emotion perception tasks, while others experience greater difficulty? In adults, we see age-related decline in emotion perception and are starting to investigate further. In children with CIs, we are very interested in any links between their perception and production of emotional voice patterns. Encouragingly, we see benefits in children's performance as they gain in age and experience with their devices.”

Looking ahead, her team is exploring whether targeted training could improve emotional prosody perception — a question with meaningful therapeutic potential:

“Looking ahead, we would love to know how malleable emotional prosody perception is, and how effective targeted training might be. It's certainly an understudied area and yet so important, underscored by the links that have been shown between emotional prosody perception and quality of life in CI patients.”

A Voice for Equity and Inclusion

Beyond her research, Dr. Chatterjee is the founder of the **BIPOC-CSD Network**, a mentoring network for students, researchers, clinicians, engineers and others working in Communication Sciences and Disorders who identify as Black, Indigenous, and other People of Color. Her commitment to broadening access and representation in the field reflects values that Dr. Niparko himself embodied throughout his career.

Join Us at CI2027

Dr. Chatterjee's keynote lecture will be a highlight of CI2027, taking place **May 12–15, 2027**, in **San Diego, California**. She is eager to share her team's findings — and to hear from the ACI Alliance community in return:

“I hope to highlight both the progress we have made and the many important questions that remain. I'm already looking forward to receiving feedback from the ACI Alliance audience and hearing their perspective on our findings!”

To support the [John Niparko Memorial Lecture Fund](#) and ensure this tradition of honoring excellence in cochlear implant research continues, contributions are welcome. ACI Alliance is a 501(c)(3) nonprofit organization, and donations are tax-deductible to the extent permitted by US law.

[Donate to the John Niparko Memorial Lecture Fund](#)

Learn more about CI2027 and register at ci2027sandiego.org. ■



Protecting EHDI: The Program Behind Newborn Hearing Screening

Monica Yavrom, DDS, MPH

*Government Affairs Manager
American Cochlear Implant Alliance*



More than 98 percent of babies born in the United States are now screened for hearing loss. This remarkable public health achievement, however, tells only part of the Early Hearing Detection and Intervention (EHDI) story. Screening identifies infants who need further evaluation; the EHDI system provides the infrastructure needed to help children move from screening to diagnosis and appropriate early intervention.

EHDI is built around the 1-3-6 benchmarks: screening by one month of age, diagnosis by three months, and enrollment in early intervention by six months for children identified as deaf or hard of hearing. Meeting those benchmarks requires much more than a hospital screening. It requires coordinated state programs, reliable data systems, trained professionals, family engagement, and effective connections among health care and early intervention services.

At the federal level, this work is supported through two distinct but complementary programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). CDC supports the data, tracking, and surveillance infrastructure that helps states follow children from screening through diagnosis and intervention, identify children who may be lost to follow-up, and improve EHDI systems. HRSA supports state implementation, family engagement, provider education, technical assistance, and connections to early intervention and other services.

Understanding these different roles has become increasingly important amid changes in the federal policy landscape. In 2025, broader federal workforce reductions affected CDC programs, including the federal capacity supporting EHDI, raising concerns about the loss of specialized federal expertise and technical assistance. Federal funding for CDC's EHDI activities was subsequently reduced to \$6.8 million in FY2026. Looking ahead to FY2027, the Administration's budget proposes eliminating the HRSA EHDI funding line as part of broader changes within Health and Human Services (HHS). Congressional appropriators have thus far taken a different approach, maintaining funding for EHDI at both HRSA and CDC.

These developments highlight that sustaining EHDI involves more than federal funding alone. ACI Alliance has emphasized to policymakers

the importance of preserving the specialized expertise, data infrastructure, and federal-state support necessary for states to track children from screening through diagnosis and early intervention.

The timing is particularly important because the current EHDI authorization extends through FY2027. Annual appropriations determine how much federal funding EHDI receives, while reauthorization provides Congress with an opportunity to revisit the program's statutory framework and priorities for future years. ACI Alliance is therefore engaged on both tracks as Congress considers FY2027 funding and begins looking toward the program's next reauthorization.

As ACI Alliance prepares for reauthorization, we will continue emphasizing the principles that have contributed to EHDI's success: timely follow-up, strong data systems, family engagement, equitable access to services, and comprehensive, family-centered information.

Ensuring that almost all newborns in the United States receive a hearing screening is an extraordinary public health achievement. But screening is only the beginning. Protecting EHDI means preserving the coordinated system that helps ensure early identification leads to diagnosis, intervention, and meaningful support for children and families. [Read more on EHDI here.](#) ■

EHDI Past, Present, and Future: A Conversation with Linda Hazard, Ed.D



A Conversation with
Linda Hazard, Ed.D,
by Safia Malhotra

“EHDI then expanded into birth to three years of age, which is also the time frame for early intervention services,” said Linda Hazard, Program Director for the Vermont Department of Health’s EHDI program.

After EHDI programs became established, Congress expanded their goals and objectives, adding new initiatives and increasing their age range.

“Babies who are born and diagnosed with hearing differences is one aspect of it,” Hazard explained. “But there’s three to five times as many babies between six months of age and kindergarten age that either have progressive hearing differences or acquired hearing differences.”

The ACI Alliance is prioritizing efforts to protect and strengthen the Early Hearing Detection and Intervention (EHDI) Program and the critical role it plays in connecting children and families with timely services and support. To help explore where EHDI has been, where it stands today, and what lies ahead, ACI Alliance spoke with Linda Hazard, Program Director for the Vermont Department of Health’s EHDI program and an ACI Alliance State Champion.

The following is a summary and highlights from ACI Alliance’s discussion with Linda Hazard.

EHDI: Past, Present, and Future

For children born deaf or hard of hearing, the first months of life can be critical to their language and communication development. Early Hearing Detection and Intervention (EHDI) programs were created to ensure children are identified early and connected with the appropriate services.

EHDI programs grew out of recommendations from the Joint Committee on Infant Hearing (JCIH) in the late 1990s. In 1999, federal EHDI legislation established support for state programs to pursue early identification and intervention.

The system was built around the “1-3-6” benchmarks: screen a baby’s hearing by one month, diagnose hearing loss by three months, and enroll a child in early intervention by six months.

Today, EHDI programs work beyond the initial newborn screening to follow children who may develop hearing loss and connect families with diagnostic testing and early intervention. Programs also work with health care providers and early intervention organizations to ensure children continue receiving support as they grow.

“EHDI programs continue to support the identification of new infants early, ensuring they’re diagnosed and into early intervention,” Hazard said. “But beyond that, we also follow up on those babies that need re-screenings.”

That work depends heavily on federal funding. EHDI programs have historically received funding through the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). Hazard said the two funding sources serve different but equally important purposes, with HRSA supporting work with families and providers and CDC focusing heavily on data collection.

Originally, state programs received about \$300,000 from HRSA and \$200,000 from CDC. Hazard said CDC funding was recently reduced from approximately \$169,000 to about \$110,000, forcing programs to cut personnel.

continued on page 10

“Less staff means less ability to be able to follow up with families, and also to ensure those families are getting in for the evaluation, the re-screenings, the evaluations, and early intervention services,” Hazard said. “So, it’s going to ultimately impact the timing of when infants are identified.”

Hazard hopes EHDI can rebuild its capacity and restore funding as the program continues to expand. Given EHDI’s long history of bipartisan support, she hopes future federal funding decisions will help restore program capacity and support its continued work.

“I want to see EHDI programs be able to build back up their capacity, because it’s really hard without the funding to do that,” Hazard said. “I would love to see the funding back to \$300,000, \$200,000 because I think that’s realistic with the additional duties.”

For Hazard, continued investment would allow EHDI programs to keep building on more than two decades of work connecting children and families with the services they need.

“If we could restore both the current levels of funding, at least we would be in a better position to continue to provide those services,” Hazard said. ■

ADVOCACY

ACI Alliance Launches Medicaid Advocacy Toolkit



Monica Yavrom, DDS, MPH

Government Affairs Manager

American Cochlear Implant Alliance

ACI Alliance has launched its [Medicaid Toolkit](#), a six-module online resource designed to help clinicians, State Champions, and advocates better understand Medicaid and take action when changes threaten access to cochlear implant care.

Why a Medicaid Toolkit—and Why Now?

Medicaid provides health coverage to nearly 70 million Americans and plays a particularly important role in providing coverage for children. For the cochlear implant community, its importance extends well beyond the initial implant surgery. Medicaid may support the full continuum of care, including evaluation, implantation, audiology

services and programming, rehabilitation, repairs and replacement equipment, and long-term follow-up.

At the same time, Medicaid is entering a period of significant change. Provisions enacted through the One Big Beautiful Bill Act (OBBBA) will affect Medicaid financing, eligibility, and administration, with implementation occurring over several years. While many of these changes originate at the federal level, much of their impact will depend on how individual states respond.

That state-level variation is particularly important for hearing health care. Medicaid is a federal-state partnership, and states have considerable responsibility for administering their programs, establishing coverage and reimbursement policies, contracting with managed care organizations, and implementing prior authorization requirements. As states respond to new fiscal and administrative pressures, access to specialty services such as cochlear implant care could be affected differently across the country. That is exactly why we built this toolkit.

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ACI ALLIANCE LAUNCHES MEDICAID ADVOCACY TOOLKIT *continued from page 10*

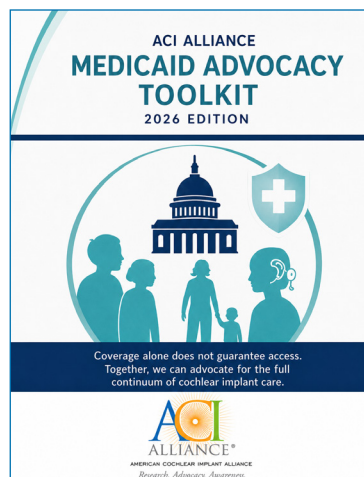
State Champions Have an Important Role

Our State Champions are uniquely positioned to help identify emerging Medicaid issues because they see how policies operate in practice. A change in prior authorization criteria, an unexpected denial from a Medicaid managed care plan, reduced reimbursement, difficulty obtaining replacement equipment, or families losing coverage during eligibility reviews may initially look like an isolated problem. When similar issues begin surfacing across clinics or states, however, they can signal a broader policy trend.

We encourage State Champions, clinicians, and advocates to stay connected with their state Medicaid programs, sign up for provider bulletins and policy updates, and talk with local CI centers about the barriers they are seeing. Just as important, advocates should share significant Medicaid coverage changes or access concerns with ACI Alliance. That information helps us identify trends, determine whether broader advocacy is needed, and engage policymakers when it matters.

A Resource Designed to Grow

The launch of the [Medicaid Toolkit](#) is a starting point, not an endpoint. Medicaid policy varies significantly across states and will continue to evolve, and we intend for the toolkit to grow alongside it, incorporating new resources, state experiences, advocacy examples, and practical tools from the field.



There is no shortage of information about Medicaid, but much of it is dense, technical, and difficult to translate into action. The toolkit takes a different approach: it breaks Medicaid down into plain language while connecting advocates to the agencies, statutes, and source documents behind each topic. Our goal

is straightforward—to give advocates the knowledge and tools to recognize and respond when something affecting cochlear implant access begins to change.

Protecting Medicaid access takes more than understanding policy. It requires clinicians, families, advocates, and policymakers to share information and work together so that people who need cochlear implant care can continue receiving it. As we have said before, the future of hearing health care will be shaped state by state, agency by agency, and decision by decision. Now we have a resource designed to help our community navigate those changes and respond when access is at risk.

Explore the [ACI Alliance Medicaid Toolkit](#). ■

NEW RESOURCE

ACI Alliance

Medicaid Advocacy Toolkit

2026 EDITION

A free, six-module resource to help clinicians, State Champions, and advocates understand Medicaid and protect cochlear implant access as policy shifts to the state level.

☐ Medicaid 101: Understanding the basics

☐ Medicaid & the OBBBA

☐ Medicaid & hearing health care

☐ CI Medicaid coverage & billing

☐ Cochlear implant advocacy

☐ What ACI Alliance can do for you

Empowering Our Voices: From the Kitchen Table to Capitol Hill

By Lauren Vanderbijl and Jessica Salzberg,
Parent Advocacy Network Leaders

Most advocacy in hearing healthcare begins at a kitchen table.

It begins with a referral, a laptop open to a search no parent expected to be making, and a question nobody has yet answered plainly: *what happens now?* Across the country and around the world, families/caregivers sit down to that question and begin working their way through unfamiliar medical systems, technology decisions, and intervention options.

Clinicians, researchers, and audiologists provide essential guidance along the way. But it is families/caregivers who live the daily reality — who celebrate every milestone, who make the calls when a processor fails the week before school starts, and who sit at the table for every IEP meeting.

To advance hearing healthcare and broaden access to cochlear implants (CIs), ACI Alliance must carry those voices further than the kitchen table. That is why we are establishing a dedicated **Parent & Caregiver Advocacy Arm** and inviting families to step forward as active partners in our legislative, regulatory, and educational work.

Why Parent Voices Change Minds

Data and clinical research shape policy. Personal stories move it.

When lawmakers, regulators, and insurers make decisions that affect families, they need to hear from the people who live with the consequences. Parents bring an

authenticity and urgency no report can replicate. A mother describing what early intervention made possible for her daughter, or a father walking a legislative staffer through the months it took to fight for coverage, turns an abstract policy into something a decision-maker can picture.

That is the distance this initiative exists to close: from the kitchen table, where the problem is lived, to the committee room, where it is decided.

Shared Barriers Across the Hearing Loss Continuum

ACI Alliance specializes in cochlear implantation, but the systemic barriers families encounter are shared across the wider hearing loss community. Whatever technology and supports a child uses, the obstacles look remarkably similar. A dedicated parent arm creates a unified voice on the issues that reach every family:

- **Early Hearing Detection and Intervention (EHDI).** Ensuring every child identified through newborn hearing screening receives timely follow-up and complete information about the services and technology available to them — work made more urgent by the reauthorization now before Congress.
- **Educational rights and transitions.** Protecting access to robust Individualized Education Programs and 504 plans, and ensuring support carries forward as children move between grades and schools.
- **Insurance and healthcare access.** Challenging coverage barriers so every child has consistent access to audiological care, device upgrades, and therapy services.



The Vanderbijl family



The Salzberg family

continued on page 13

- **Parent networks.** Connecting families to share practical knowledge, reduce isolation, and strengthen advocacy close to home.

Honoring Family Choice

Respect for family autonomy sits at the center of this work. Every child is different, and every family's path is their own. The Parent & Caregiver Advocacy Arm exists to strengthen families in advocating for the choices they have made alongside their medical and educational teams.

Building the Confidence to Speak

Ask a family whether hearing health policy matters to their family and the answer comes immediately. Ask whether they see themselves as an advocate and it comes more slowly. *I'm not a policy person. I wouldn't know what to say.*

That hesitation — not any lack of conviction — is the biggest reason parent voices go unheard where these decisions are made. Advocacy is a skill, not a credential: parents already hold what no one else can bring, and what they lack is only the preparation to deliver it.

Ready to Add Your Voice?

The Parent & Caregiver Advocacy Arm is now forming, and families at every stage are welcome.

You do not need a policy background, a prepared speech, or any experience with legislators. You need what you already have — your family's story — and we will help you with the rest.

Parent/Caregiver Membership — Annual Fee: \$10

Parent/Caregiver membership is designed for parents, caregivers, family members, and loved ones of children and adults with hearing loss.

[Join as a Parent/Caregiver](#)

For questions contact:

Jessica Houk

Manager of IT & Membership Services

jhouk@acialliance.org



The Advocacy Arm supplies that — training in how state and federal policy is actually made, plain-language briefings on the issues in play, and help shaping years of experience into impactful dialogue. Families start close to home: a school meeting, a state EHDI advisory council, a visit to a district office.

Confidence grows with repetition.

From the Kitchen Table to Capitol Hill

Much of what determines a family's access is now decided at the state level — in Medicaid agencies, EHDI programs, insurance departments, and state legislatures — while EHDI reauthorization remains before Congress. Both arenas need parent voices, and neither is as far from the kitchen table as it looks.

Join Us

Progress happens when clinical expertise and family leadership work together. Whether you are weeks into this journey or years down the road, your perspective matters — and you do not need to arrive already knowing how this works.

We invite parents, caregivers, and family advocates to help us grow this initiative. Together we can break down barriers, shape policy, and build a future in which every child with cochlear implants has what they need to thrive. ■

Advancing Medicare Coverage for Single-Sided Deafness and Asymmetric Hearing Loss



Maura Cosetti, MD

Professor, Departments of Otolaryngology-Head and Neck Surgery and Neurosurgery

Icahn School of Medicine at Mount Sinai

Director, Ear Institute, NYEE of Mount Sinai



Nathalie Chouery, AuD

Sr. Clinical Research Coordinator

Department of Otolaryngology, Mount Sinai Icahn School of Medicine

Work continues to advance a request for the Centers for Medicare & Medicaid Services (CMS) to reconsider the National Coverage Determination (NCD) for cochlear implantation in individuals with single-sided deafness (SSD) and asymmetric hearing loss (AHL). The goal is to better align Medicare coverage with current evidence and clinical practice by moving toward an ear-specific, rather than bilateral, definition of cochlear implant candidacy.

An initial NCD reconsideration request was submitted to CMS in 2024, following several years of evidence development and collaboration across cochlear implant centers.

CMS subsequently provided valuable feedback, including the need for a stronger published evidence base and clearer data specific to the Medicare-aged population. The request was withdrawn to allow the group to address these concerns before resubmission.

Since then, considerable progress has been made. Multi-site data have contributed to peer-reviewed publications examining outcomes of cochlear implantation for SSD and AHL, and additional work has focused specifically on adults aged 65 years and older. As a result, the evidence available today is substantially stronger and more directly relevant to

Medicare beneficiaries than at the time of the initial submission.

Following further discussion with CMS in 2026, the request and supporting materials have been revised to incorporate the feedback received. The project team plans to submit an updated draft NCD reconsideration request to CMS by the end of 2026, an important next step toward formal resubmission.

As the process moves forward, there will be an important role for the broader cochlear implant community. If CMS formally opens the NCD for reconsideration, clinicians, researchers, patients, and other stakeholders will have an opportunity to provide input during the public comment period. The ACI Alliance will keep members informed of the project's progress and share opportunities for engagement as they arise. ■



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Review the latest Cochlear Nucleus System reliability data:
www.cochlear.us/acia-calling

1. Cochlear Limited. Cochlear™ Nucleus® System Reliability Report Volume 24. December 2025.

* Cochlear Limited. D1712883 V1 2026-03. Cochlear Nucleus Reliability Report (Simplified) Volume 24, December 2025.

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

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CI2027 Scientific Program Update



Michael S. Harris, MD

Associate Professor, Department of
Otolaryngology & Communication Sciences,
Department of Neurological Surgery
Chief, Division of Otolaryngology & Neurologic
Skull Base Surgery
Medical Director, Koss Cochlear Implant Program
Medical College of Wisconsin



Michael S. Harris, MD

Alejandra Ullauri AuD, MPH

Founder
Audiology En Español



Alejandra Ullauri AuD, MPH

Planning is well underway for the American Cochlear Implant Alliance (ACI Alliance) [2027 meeting in San Diego](#), and we are excited about a number of changes to this year's program. Our goal has been to preserve what makes the ACI Alliance meeting special while creating new opportunities to learn, exchange ideas, and bring together an even broader cochlear implant community.

One of the most visible changes will be an expanded surgical program. New surgical video sessions will emphasize operative technique, challenging cases, and surgical decision-making, providing an opportunity to learn not only what was done, but why. At the same time, we are expanding opportunities to highlight new science through a longer podium presentation format (15-20 minutes) in addition to the traditional shorter form podium presentations. Additional research podium sessions will provide more investigators the opportunity to present their work in an oral format and create greater space for discussion of emerging research.

We are also planning several special sessions looking toward where our field is headed next. The interface between genetic and emerging

hearing-restoration therapies and cochlear implants will have a prominent place in the program. Rapid advances in molecular diagnosis and genetic therapy are beginning to change how we think about hearing loss and its treatment. These sessions will explore what these developments mean for clinicians, researchers, and patients, as well as how they may ultimately intersect with cochlear implantation.



Another major goal for San Diego is to strengthen ACI Alliance's connections throughout the Americas. We are developing programming that brings additional Latin American perspectives into the meeting and creates opportunities for greater collaboration across countries and disciplines. For the first time, Spanish-language captions will also be available, an important step toward making the scientific program accessible to a broader audience.

Across all of these changes, we want the meeting to remain distinctly ACI Alliance: multidisciplinary, clinically relevant, scientifically rigorous, and highly interactive. Audiologists, surgeons, speech-language pathologists, scientists, educators, trainees, industry partners, and others all bring different perspectives to cochlear implant care, and some of the best ideas emerge when those groups are in the same room.

There is much more still to come as the program takes shape, including keynote speakers, special sessions, and opportunities for discussion and collaboration. We hope the new additions will give longtime attendees some fresh reasons to be excited about the meeting while also welcoming people who may not have traditionally thought of ACI Alliance as their meeting.

We look forward to seeing everyone in San Diego in May 2027 and to sharing much more in the months ahead.

Michael Harris, MD & Alejandra Ullauri, AuD, MPH
Co-Chairs, ACI Alliance 2027
Scientific Program Committee ■

CONFERENCE ON COCHLEAR IMPLANTS

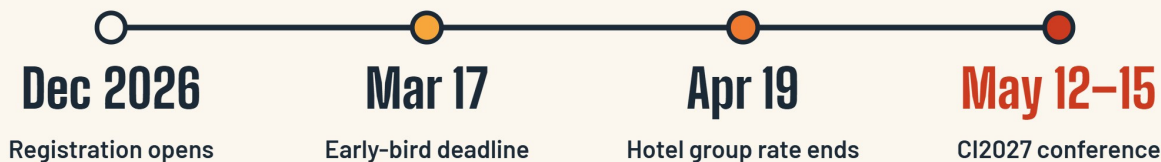
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“Don’t Be Shy”: Lexi on Sports and Self-Advocacy with special guest Valli Gideons

Cochlear Implant Connections for Teens —
webinar recap

Host Lexi Finigan on golf, hearing fatigue, and learning to speak up — with guest Valli Gideons

Lexi Finigan is 17, a high school senior, and five years into a golf game she took up on a whim. She is also the host of ACI Alliance’s Cochlear Implant Connections for Teens series — and she runs it herself, working her own slides and reading the chat aloud. She opened the fourth session in August by asking everyone to name a favorite food. Hers is baklava. The session was captioned and recorded, and is

posted with the rest of the series at acialliance.org/page/CITeens.

Some in the audience would have recognized her voice. Lexi voices Cece, the lead character in the Apple TV+ animated series *Ei Deafo*, adapted from Cece Bell’s best-selling graphic novel about her own childhood hearing loss — a role she auditioned for at 12, after her mother received an email from the University of Miami, where Lexi received her implants. What stayed with her was the book’s central idea. “I thought it was really incredible that a person thought of their deafness as their superpower,” she said at the time.

Her latest [webinar subject was around sports and advocacy!](#)

The Studio Years

From pre-K through fourth grade, most days after school, she danced — ballet, jazz, tap and hip-hop. It was also close to an acoustic worst case: a hard-walled studio that echoed, music at volume, and instructors calling choreography over the top of it.

She had a remote microphone. She almost never used it, and her three reasons are part of her advocacy. It lived on its charging station at school, so it was rarely with her. Her instructors danced alongside the class, and if the microphone fell and broke she would lose it for the rest of the school year. And outdoors it caught every gust of wind — “all I would hear would be the whooshing rather than the instructor”. It was not a logical choice for me at the time.

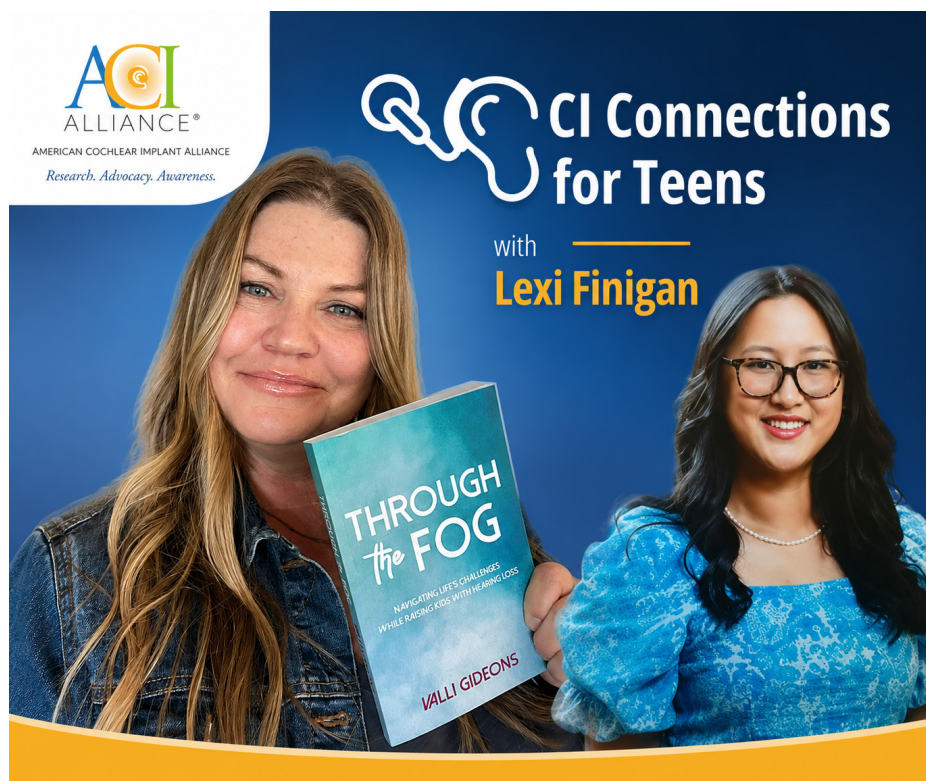
The Thing She Couldn’t Name

Something else was happening in those classes that took her years to understand.

“I was a pretty rowdy kid,” she said, “but usually I was pretty content and well behaved. During dance classes, I just couldn’t get myself to focus. At the time, I couldn’t explain why I tended to misbehave more and get off task constantly.”

In hindsight she realized why: seven hours of school, then straight into three hours of dance in a room she

continued on page 19



could barely hear in. “No wonder I had such a hard time focusing.” She had listening fatigue, and no one had ever explained to her what it was.

Why Golf Works

She came out of the pandemic wanting something new. Her mother suggested golf, partly because it is not a contact sport. One lesson and she was hooked.



“After having a seven-hour day of school and going straight into three hours of dance — no wonder I had such a hard time focusing.”

Five years on, the sport suits her: quiet, non-contact, largely self-directed. What it demands is practical rather than acoustic — mostly heat, sweat and rain, which she manages with a routine she has worked out for herself.

The risks have not vanished. At one tournament a competitor's club slipped out of her hands and travelled to within a yard of Lexi. People were shouting. She did not know they were shouting at her.

What She Would Do Differently

In elementary school, Lexi never pursued accommodation for dance. Everyone knew she had cochlear implants; no one, herself included, turned that into a conversation about what she needed. She wishes now that she had.

“I didn’t really know how to advocate for myself — and what do I need to succeed,” she said of those years.

Golf has been different. She tells her coaches casually that she has cochlear implants, that sometimes she cannot hear as well, and that she will say so if something makes her uncomfortable. It has not been a problem. Her advice to anyone still in the position she was in at eight years old was brief: “Don’t be shy.”

She plans to play club golf in college rather than compete at varsity level — a deliberate choice, so she can take on a demanding major and still keep the sport on her own terms.

A Parent’s View

Joining Lexi was Valli Gideons, author, founder of the online platform My Battle Call, and mother of two college-age children who use cochlear implants and are both now college athletes. She answered the question she is asked most often — can kids with devices play sports? — with two words: “Heck yeah.”

Her most practical advice concerned coaches, most of whom had never met anyone using hearing technology. Her family wrote a short guide, which her son helped draft, emailed it before each season, and then asked for a meeting before the first practice, never on the day itself. “Catching a coach on the first day of practice is not a good idea.” They brought their children to those meetings, so coaches heard from the athlete directly — and the children heard what advocacy sounds like.

continued on page 20

Sweat, Rain and Sun: What is in Lexi’s Golf Bag?

Five years of tournament golf have produced a routine:

- **A drying box, plugged in and waiting.** After three hours in heat that feels like 105 degrees, sweat collects on the magnets, processors and microphones. The devices go into the dryer while she showers and come out ready.
- **A waterproof jacket with a hood.** Her first line of defense when it rains.
- **An umbrella big enough for her and the clubs.**
- **A visor.** It keeps a surprising amount of rain off.
- **A towel over the head.** For heavier weather, when she wants to be certain nothing is getting wet.

LEXI ON SPORTS AND SELF-ADVOCACY *continued from page 19*

That was always the point. “We always tried hard to model advocacy,” she said, “and then for them to be able to slowly but surely start to advocate for themselves.” Both her children now do it without her. She left parents with one caution: “I think we worry more than the kid often.”



What Carries Them Forward

What any teen gets from a cochlear implant depends on their own hearing history, how long they have used the device, and the support around them — which is why regular audiology follow-up and ongoing therapy continue to matter well into the teenage years.

But the skill both speakers kept returning to is the one no clinic

appointment can supply. As teens move into settings their parents cannot manage for them — a dance studio, a golf course, a college lecture hall — the ability to say plainly what they need becomes the thing that carries. Lexi spent her dance

years without it and her golf years with it, and she is clear about which she would recommend.

Watch the full session — and the rest of the [Cochlear Implant Connections for Teens](#) series [here](#). ■

Where Teens Can Find More

- **Watch this webinar.** The session is recorded, captioned and posted with the rest of the series at acalliance.org/page/CIteens — the Cochlear Implant Connections for Teens hub. Earlier sessions have covered talking to teachers about hearing loss and captioning access for teens.

— Valli Gideons writes at mybattlecall.com.



New Lexi webinar!

 **Nov 23**
at 7:00 PM

CI myths

- ? Can deaf/hh people drive?
- ? Can you get married?
- ? CI surgery is brain surgery...

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acalliance.org/event/ci_teen_myths

Research. Advocacy. Awareness.

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Find Your Community: ACI Alliance Special Interest Groups

Jessica Houk, MBA

Manager of Information Technology
and Membership Services

ACI Alliance

jhouk@acialliance.org



The ACI Alliance Special Interest Groups (SIGs) bring members together around shared interests, professional experiences, and important issues in cochlear implant care. Whether you're a seasoned clinician, an educator, a researcher, or just beginning your career, SIGs offer a space to connect with colleagues who understand your work and share your goals.

SIGs provide opportunities to network, exchange ideas, discuss challenges, and collaborate on research and best practices. They also give members a voice in shaping conversations across the field, from improving access to care to supporting the next generation of professionals. By bringing together people from different disciplines, settings, and backgrounds, SIGs help turn shared experiences into practical solutions that benefit cochlear implant recipients and their families.

Our six SIGs include:

Educators of Children who are Deaf and Hard of Hearing

Connect with educators and professionals working to support the educational needs and outcomes of children with hearing loss. This group offers a forum to discuss classroom strategies, collaboration between schools and clinical teams, and ways to help children with cochlear implants thrive academically and socially.

Members with Hearing Loss

A community for deaf and hard of hearing professionals to connect, share experiences, support mentorship, and discuss accessibility in the workplace. Members bring a unique perspective to the field, and this group creates space to share that insight, support one another, and advocate for inclusive professional environments.

Adult Aural Rehabilitation

Focuses on improving access to and delivery of aural rehabilitation services for adults before and after cochlear implantation. Participants explore approaches that help adult recipients get the most from their devices, along with ways to expand the availability of these services.

Student & Early Professional Network

Supports career development, mentorship, networking, and engagement for students and early-career professionals entering the cochlear implant field. This is a great place to meet peers, learn from experienced colleagues, and build connections that can last throughout your career.

Professionals Working with Spanish-Speaking Patients and Their Families

Brings together clinicians, researchers, and advocates working to improve access, consistency, and quality of CI care for Spanish-speaking patients and families. Members share resources, discuss cultural and linguistic considerations, and work toward more equitable care.

Cochlear Implant Care within Governmental Services

Connects professionals involved in CI care within federal healthcare systems, including services for Veterans and active-duty service members. The group provides an opportunity to discuss the unique processes, challenges, and opportunities of delivering care in these settings.

Why Join a SIG?

Participating in a SIG is one of the most meaningful ways to get involved with the ACI Alliance. Members can build professional relationships, stay current on issues affecting their area of practice, contribute to collaborative projects, and help advance best practices across the cochlear implant community. Many members find that SIGs offer both professional growth and a genuine sense of belonging.

Important: SIG participation is a benefit of ACI Alliance membership. Only ACI Alliance members may participate in these Special Interest Groups, which will all meet during CI2027 San Diego as part of the program. If you're not yet a member, now is a great time to join and take advantage of this opportunity.

Explore the SIGs and find the group that fits your interests:
[ACI Alliance Special Interest Groups](#) ■

THE SOUNDS THEY HEAR TODAY CAN SHAPE THEIR TOMORROW.



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ACI Alliance Launches New Internship Pilot Program

This fall, the ACI Alliance welcomed its first intern as part of a new pilot program designed to introduce college students to the intersection of health policy, journalism, communications, and nonprofit advocacy. The goal of the ACI Alliance Internship Program is to provide students with meaningful, hands-on experience while supporting the organization's advocacy and public awareness priorities.

Our inaugural intern is Safia Malhotra, a junior at American University pursuing dual majors in Journalism and Political Science, with a concentration in Law and Politics. Safia's background made her a strong fit for ACI Alliance's first internship.

The pilot also explores how skills from journalism, communications, and public policy can be applied to health policy advocacy, particularly by translating complex research and policy information into clear, accessible content for a broader audience.

Learning by Doing

The internship combines substantive project work with experiential learning and professional development. During her first weeks, Safia has been learning about ACI Alliance's mission, cochlear implants and hearing health, the State Champions Network, and the organization's federal and state policy priorities. She is also gaining experience with the different ways ACI Alliance communicates with

its audiences, from Listening and Calling to public education and advocacy communications. Throughout the semester, Safia will contribute to projects that may include translating cochlear implant research and policy into accessible content, reviewing ACI Alliance advocacy resources, developing social media content, and contributing to publications.



From left to right: Carrie Spangler, Executive Director; Monica Yavrom, Government Affairs Manager; and Safia Malhotra, Intern — ACI Alliance

The experience also extends beyond project work. Safia has already had the opportunity to participate in ACI Alliance's Capitol Hill visits, gaining firsthand exposure to congressional advocacy and how legislative priorities are communicated to policymakers. Additional opportunities will include participation in coalition and State Champions meetings

and conversations with clinicians, advocates, and other professionals working in hearing health and public policy.

Building a Program for the Future

At the end of the semester, Safia will share what she worked on, what she learned, and her recommendations for the program. The ACI Alliance will also evaluate which projects and experiences provided the greatest educational value and how the internship might evolve for future students.

The pilot reflects something central to ACI Alliance's work: effective advocacy depends not only on sound policy, but also on the ability to understand complicated issues, communicate them clearly, and help people understand why they matter.

By opening our work to students beginning careers in journalism, public policy, communications, law, and related fields, we hope to provide meaningful professional experience while introducing a new generation to hearing health advocacy and the role nonprofit organizations can play in public policy.

We are excited to welcome Safia as our first intern and to see what we learn together during this inaugural semester. ■

A New Voice for Advocacy: Meet ACI Alliance's First Intern

*Meet ACI Alliance's Intern
by Monica Yavrom*

As Safia Malhotra joins the ACI Alliance this fall as our new intern, we took the opportunity to get to know her better and learn more about her background in journalism, her interest in health policy, and what drew her to advocacy.



She brings an interest in public-service journalism and experience covering politics and local communities.

At American

University, she writes for The Eagle, the university's student-run newspaper. This past summer, Safia worked as one of five full-time reporters at The Lima News in northwest Ohio, covering midterm election campaigns, municipal proceedings, and community events. Before college, she served as editor-in-chief of her high school newsmagazine and was named runner-up for Ohio Student Journalist of the Year.

Safia, you have reported on everything from Flock camera surveillance to local election campaigns. What draws you to stories about institutional accountability, and how do you see that interest showing up in health policy advocacy?

My family is absolutely the reason I have such a passion for holding institutions accountable. I come from a family of hard-working individuals who have fought tooth and nail to get

to where they are today. Growing up, political discourse was part of pretty much every dinner conversation and family reunion. No matter our differences, everyone in my family cares about the same fundamental question: How do we ensure that our institutions work the way they are intended to and protect the interests of everyday Americans?

Health care impacts every American, every day. Some people have access to quality health care, but many do not, and for many families, accessing care can be a significant source of stress. I believe health care is a fundamental human right, just like access to food, water, and shelter. Through organizations such as the ACI Alliance, I believe there is an opportunity to work alongside government and other stakeholders to advance health care policy and help make it more accessible.

Advocacy communications and journalism both involve translating complex information for a public audience, but the goals are different: a reporter aims for objectivity, while an advocate aims for impact. What has felt the most different about that shift so far?

As much as I love journalism, I have really enjoyed this style of writing because I can take a position on issues I care about and communicate with a specific outcome in mind. As a journalist, I work hard to keep my reporting objective, particularly when covering issues I am passionate about. As many of my editors have told me, "We report the facts and allow the public to draw their own conclusions."

I understand why that is so important to journalism and to society, and it's a big part of why I love the field. But I'm also excited about my work with ACI Alliance because I can use my writing to help people understand an issue, recognize why it matters, and hopefully inspire them to take action. Being able to bring more of my own perspective and passion to my writing has been the biggest difference for me so far.

Safia, hearing health and cochlear implant policy are likely new territory for you. What's a question or angle you're most curious to dig into this semester?

I want to dig into the stigma surrounding hearing loss and cochlear implants and explore how we can begin to change the way people think about hearing health.

I've seen people avoid getting the help they need because they're afraid of how others will perceive them. As a society, we've become much more open about talking about mental health, and as that stigma has started to fade, more people seem to feel comfortable recognizing when they need help and seeking it.

I hope we can see that same shift with hearing health and cochlear implants. I am really interested in how we can help make conversations about hearing loss more normal and help people feel comfortable seeking treatment without feeling like there's anything to be ashamed of. ■

Meet Our Board Member: Barbara Mellert MPH



Barbara Mellert MPH

*Information, Technology
& Consulting*

*Dartmouth College
Administrator*

*Parents of Children
with CI FB Group*

I'm honored to serve on the [American Cochlear Implant Alliance board](#) as the parent representative. I'm the mother of two adult sons, both have bilateral cochlear implants that they received as young teens. Prior to implantation, both had hearing aids. They both were mainstreamed in our town's public schools and graduated from college in New England. My younger son has also earned his master's degree. Both have interesting, rewarding jobs and both are married — I love being a mother-in-law. My older son is a landscape/lighting/irrigation designer for a large company in Delaware; my younger son works in safety engineering at a large Naval shipyard.

My husband, Hugh, and I live in a small town in New Hampshire, so often our sons were the only kids with hearing loss in their grade and often in their entire school. Because of that, we had to learn quickly all the ins and outs of hearing loss, the challenges of educating deaf/hard of hearing kids in a mainstream environment, not to mention taking care of hearing equipment for four ears. We learned as we went along — sports was an interesting challenge. How DO you keep your cochlear implant processors on while playing basketball? My husband often served as a coach for various sports.

I quickly realized I needed a mentor and a community of like-minded parents. Our teacher of the deaf at the time let me know about a parent listserv (remember those?) that I joined. It was a mix of parents, D/deaf folks, as well as professionals. And while useful, a group of parents from that listserv formed our own group called Listen-up. It was both a listserv and a webpage with unbiased, accurate information for parents.



The Mellert family

As social media became more popular, I joined a Facebook group called Parents of Children with Cochlear Implants and eventually became one of the admins. We are 21,000 parents strong. It's a parent-only Facebook group with no drama and no judgment. It's wonderful to see parents helping parents with questions we all had — how do I inservice my child's school team? Which brand of cochlear implant do you recommend (we are agnostic to brands, believing all are excellent choices). School placement and communication methods are also often-asked questions.

I was asked to join the board as their parent member in 2019 — a role I gladly accepted. As the only parent member, I've enjoyed bringing a parent perspective to the amazing professionals who are on the board.

One of the Alliance's key tenets is advocacy. Because of that, my husband and I served as the parent members of the NH newborn hearing screening task force that eventually passed. We testified to our legislators. We also served in the Family Faculty program at Dartmouth Medical school. I also serve as an ACI Alliance State Champ for New Hampshire.

My signature tag is "Get involved! The world is run by those who show up." which I heartily believe. ■



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