



Donna L. Sorkin, Editor

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Gene Therapy: What's our role in the evolving clinical offerings?

Message from the Chair

MESSAGE FROM THE CHAIR

Andrea D. Warner-Czyz PhD

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Scientists have worked on gene therapy for hearing loss for decades, but global interest has piqued in the past six months due to the publication of results from clinical trials around the world. No doubt, you have received links from family and friends about children for whom gene therapy has restored their hearing. For example, the Children's Hospital of Philadelphia announced in January 2024 initial results for a child born with profound level of hearing in both ears whose hearing improved to mild-moderate levels after receiving investigational gene therapy. The latest viral story features Opal Sandy, a toddler diagnosed with auditory neuropathy in the United Kingdom, who received gene therapy before her first birthday and now has near-normal hearing in her treated ear, just six months later. Although the American Cochlear Implant Alliance

focuses on implantable auditory technology, our mission supports the provision of comprehensive information on evolving options to improve communication and quality of life in children and adults who are deaf and hard of hearing. As clinicians and researchers, we need to educate ourselves as to the role of gene therapy as a treatment option for individuals who are deaf and hard of hearing—who is a candidate, how does it work, what do outcomes suggest, and which variables we still need to examine—and our role in guiding patient queries in this new landscape.

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University Hospitals Cleveland Medical

Donna L Sorkin MA

Executive Director
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MESSAGE FROM THE CHAIR *continued from page 1*

First, we should know which patients who are deaf and hard of hearing qualify for gene therapy. Current clinical trials focus on children born with bilateral severe to profound levels of hearing related to nonsyndromic auditory neuropathy spectrum disorder (DFNB9), a rare condition that constitutes 1 to 10% of those with hearing loss (Vignesh et al., 2016). Auditory neuropathy spectrum disorder has heterogeneous etiologies (e.g., defect in the inner hair cells, pre- or post-synapse between the inner hair cells and the spiral ganglion neurons, or demyelination or axonal loss in the auditory nerve). Current candidates for gene therapy must have two non-functioning copies of the OTOF gene, which encodes otoferlin—a calcium sensory protein that underlies transmission of sound information between the inner hair cells and the afferent fibers of the spiral ganglion cells of the auditory nerve. Despite not having the otoferlin protein, the rest of the inner ear functions normally (i.e., functional outer hair cells and spiral ganglion neurons). Inclusion criteria for gene therapy clinical trials also often specify presence of otoacoustic emissions and/or the cochlear microphonic paired with absent or abnormal auditory brainstem response in at least one ear (that does not have a cochlear implant).

Pharmacological therapy to be explored at a concurrent session in Vancouver

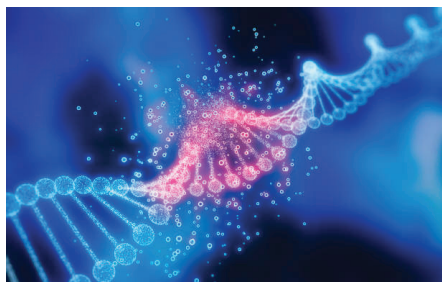
Please join us for a concurrent session on pharmacological therapy on Saturday morning at the CI2024 conference in Vancouver to learn more about gene therapy and its potential as an option for therapeutic intervention for individuals who are deaf and hard of hearing.

The goal of gene therapy is to introduce a healthy copy of the OTOF gene to the cochlea to allow the inner hair cells to regain the function of the otoferlin protein, thereby restoring afferent synapses affording transmission of neural information from the cochlea to the primary auditory neurons in the spiral ganglion. Although the companies pioneering this gene therapy differ in many ways (e.g., surgical approaches, viral particles), they all involve gene replacement with a functional copy of the OTOF gene encased in a modified non-disease-causing virus (e.g., adeno-associated viral vector, or AAV). Injecting dual AAV vectors directly into the fluid-filled cochlea via the round window membrane yields the most efficient delivery to the inner ear (Landegger et al., 2017). Multiple pre-clinical studies using otoferlin knockout mice demonstrate recovery of hearing using AAV vectors to deliver the OTOF gene to the cochlea.

To date, four teams (presented in alphabetical order)—Akouos, Fudan University, Regeneron, and Southeast University/Otovia Therapeutics—have developed otoferlin-based gene therapy and reported on five clinical trials in a total of seventeen children (Lv et al., 2024; Qi et al., 2024). Chronologic age at study enrollment ranged from 10 months to 11 years with results reported between 1 and 6 months post-injection of a single dose. Most of the clinical trials administer the OTOF-based gene therapy to one ear, although two clinical trials implemented bilateral gene therapy in six children. Overall, 16 of 17 children

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exhibited recovery of hearing as evidenced from changes in pure-tone or auditory brainstem response thresholds from profound levels (>95 dB) to mild-moderate levels (e.g., 30-58 dB) or, in a few cases, severe levels (~80 dB). Most children showed improved auditory skill development, with some able to repeat words or localize sounds. No studies reported serious adverse events related to gene therapy.



Results from the clinical trials seem promising overall, with more than 90% of children with auditory neuropathy in the OTOF-based gene therapy clinical trials showing improved auditory skills post-treatment. However, the results also highlight the variability in outcomes from partial to full recovery of hearing—a sentiment shared by bioethicist Dr. Teresa Blankmeyer Burke in a webinar sponsored by Gallaudet University. She recognized that gene therapy may change hearing status to become medically hard of hearing, but it is not a cure. That is, children who receive gene therapy will still need to prioritize support for optimal auditory access aiding development of language, speech, and psychosocial skills.

The field still has many unanswered questions relative to gene therapy as a treatment for profound levels of hearing. Which factors serve as risk or protective factors for this treatment? Does implementation within a certain age range yield the best chance at restoration of hearing? Will children maintain improved hearing or will they require redosing, if possible, in the future? Will gene therapy increase vulnerability to damage from excessive noise, ototoxic agents, or aging? How will this work focused on OTOF apply to other genes identified for hearing loss?

Thanks to the diligent collaborative work of scientists and clinicians, our field has made incredible gains in understanding the underpinnings of hearing loss and strategies to address these issues at the level of the gene, but we still have quite a bit of work ahead to address over 150 genes identified for hearing loss. ■

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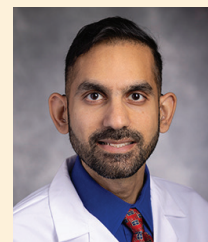
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CI2024 Vancouver: 17th International Conference on Cochlear Implants and Other Implantable Technologies



Jacob B. Hunter MD | Co-Chair
CI2024 Vancouver Program Committee,
Thomas Jefferson University

Viral Tejani AuD, PhD | Co-Chair
CI2024 Vancouver Program Committee,
University Hospitals Cleveland Medical
Center / Case Western Reserve
University



Viral Tejani AuD, PhD



Jacob B. Hunter MD

We are rapidly approaching CI 2024, the ACI Alliance meeting in Vancouver, British Columbia. The CI Conference Scientific Committee is excited at the wide range of science and clinical knowledge that will be shared by our presenters. The podium talks reflect the interdisciplinary nature of our field, centering around clinical outcomes, rehabilitative issues, advances in surgical techniques, and more. Amongst the highlights of this year's international CI conference are three important keynote lectures focusing on bilateral cochlear implantation (Ruth Litovsky PhD), asymmetrical hearing loss and single-sided deafness (Jill Firszt, PhD), and the impact of auditory experience on maturation of the auditory system (Andrej Kral MD, PhD).

We are excited to again offer networking opportunities at special interest groups; see below for details.

We are excited that Debara Tucci MD, MBA, Director of the National Institute on Deafness and Other Communication Disorders (NIDCD), will be attending. This opportunity

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2024 CI Conferences Program Committee

Jacob Hunter MD (Co-Chair); Jefferson Balance and Hearing Center

Viral Tejani AuD, PhD (Co-Chair); University Hospital Cleveland Medical Center/Case Western Reserve University

Ivette Cejas PhD; University of Miami

Keri Collo AuD; Rady Children's Hospital San Diego

Nicholas Deep MD; Mayo Clinic Arizona

Jolie Fainberg AuD; Atlanta Institute for ENT

Karen Gordon PhD; University of Toronto (CA)

Barbara Hecht PhD; Clarke School for Hearing and Speech

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Rebecca Lewis AuD; Nationwide Children's Hospital

Nancy K. Mellon MS; The River School

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Elicia Pillion AuD; Walter Reed Medical Center

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Heidi Slager AuD; University of Michigan

Ellen Thomas MA, SLP, LSLS Cert. AVT; University of Michigan

Esther Vivas MD; Emory University Hospital

Brian Westerberg MD; University of British Columbia (CA)

IT'S NOT TOO LATE TO REGISTER FOR THE CI CONFERENCE.



As of today, there are still rooms left in the hotel block offerings. If you are having difficulty getting a hotel room from the conference block, please contact the hotel directly or reach out to Laura Odato of our staff at LOdato@acialliance.org.

CI2024 VANCOUVER *continued from page 5*

provides much visibility for ACI Alliance and allows NIDCD to see the extraordinary talent within our membership. Dr. Tucci will offer a keynote on cochlear implants and the future of hearing health care on Saturday morning.

We wish to offer special recognition and thanks to the CI Conference Program Committee, an interdisciplinary group of CI clinicians, scientists, and educators from across the care continuum. Our colleagues invested many hours working together to develop the program. They are listed on page 5. Thanks also to the ACI Alliance staff who supported our work, allowing us to focus on developing a unique and timely learning opportunity.

Plan to enjoy all that Vancouver offers after each day's events. With an average high of 72 degrees, the weather should not disappoint. We look forward to welcoming all of our colleagues soon! ■



CI2024
VANCOUVER

Schedule at a Glance

Conference Dates

Wednesday, July 10-13, 2024

Conference Website

www.CI2024vancouver.org (links to abstracts, registration, hotel, updates)

ACI Alliance Detailed Information

<https://www.acialliance.org/page/CI2024>

Hotels and Meeting Venue

<https://ci2024vancouver.org/meeting-venue-and-hotel/>

Vancouver Convention Center

Reservations open at multiple hotels

Group Rates Expire: Friday, June 14, 2024

Welcome & Opening Session with Niparko Lecture

Thursday, July 11, 2024 / 8:45-9:50

CI Manufacturer Satellite Symposia

Wednesday, July 10

1:00 - 2:15 Cochlear: The Future of Hearing Healthcare: Innovations in Patient-Centered Care for Increased Access and Optimized Outcomes.

2:45 - 4:00 Advanced Bionics Empowered Patients, Efficient Practices.

4:30 - 5:45 MED-EL Empowering Auditory Excellence: Insights and Innovations.

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

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

Poster Exhibit Session

Thursday, July 11, 2024, 5:00-6:00 PM

Welcome Reception

Thursday, July 11, 2024, 6:00-7:15 PM

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

Friday, July 12, 2024, 8:40-9:30 AM



Continuing Education Units (CEUs)

We are pleased to announce that the following CEU and CME Accreditation has been secured for eligible participants who wish to claim these credits for the CI2024 Vancouver meeting.

- AG Bell Academy for Listening and Spoken Language - This program has been approved for a maximum of 20.5 CEUs
- American Speech-Language-Hearing Association (ASHA) - This program has been approved for a maximum of 2.05 CEUs
- American Academy of Audiology (AAA) - This program has been approved for a maximum of 2.05 CEUs (1.4 Tier 1 CEUs)
- Through the Joint Providership of the American College of Surgeons this educational activity is approved for 15.25 AMA PRA Category 1 Credits™ (CME)



AG Bell Academy for Listening and Spoken Language

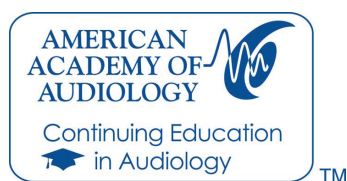
This program has been approved for a maximum of **20.5 CEUs**. AG Bell Academy approval of this course is based on information shared by the approved provider. Views shared by the presenter(s) may not necessarily reflect the views of the AG Bell Academy for Listening and Spoken Language either in part or whole.



American Speech-Language-Hearing Association (ASHA)

American Speech-Language-Hearing Association ASHA CEUs (Professional area, Intermediate level) will be offered for this activity.

The conference will be offered for up to **2.05 ASHA CEUs** (Intermediate Level; Professional Area)



American Academy of Audiology (AAA)

American Cochlear Implant Alliance is approved by the American Academy of Audiology to offer Academy CEUs for this activity. The program is worth a maximum of **2.05 CEUs**. Academy approval of this continuing education activity is based on course content only and does not imply endorsement of course content, specific products, or clinical procedure, or adherence of the event to the Academy's Code of Ethics. Any views that are presented are those of the presenter/CE Provider and not necessarily of the American Academy of Audiology.

Tier 1 CEUs: 1.4

Special Interest Groups (SIGs)

Jessica Houk MBA

Manager of Information Technology and
Membership Services / ACI Alliance

jhouk@acialliance.org



Last year, we introduced three new Special Interest Groups (SIGs) Luncheons during the annual conference. After such a positive outcome, we will continue with the three at CI2024 Vancouver. They will focus on students, adult rehabilitation, and our members with hearing loss. These special interest groups provide a strong community connection that they continue to be popular offerings.

Students, Fellows, Residents

Thursday, July 11th, 12:30 PM

We invite all students, fellows, and residents in attendance at the conference to meet during lunch on Thursday July 11th. Grab a box lunch 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.

This group will be led by:

Miriam R. Smetak MD, MS

Fellow, Otolaryngology & Neurotology
Department of Otolaryngology-Head
& Neck Surgery
Washington University School
of Medicine
smetak@wustl.edu

Katie Berg AuD, PhD, CCC-A

Postdoc Fellow & Cochlear Implant
Audiologist
Vanderbilt University Medical Center
katelyn.a.berg@vanderbilt.edu

[Click here](#) to register.

[Click here](#) for PDF.

Adult Rehabilitation

Thursday, July 11th, 12:30 PM

Welcome existing and new members as we further advance our efforts to explore and expand access to aural rehabilitation for adult cochlear implant recipients. Join CI team members of all specialties to explore our current progress, trends in research, barriers to care and our future plans for this valuable service.

This group will be led by:

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

Speech-Language Pathologist
Mass Eye and Ear
brichlin@meei.harvard.edu

Additional details on the SIG are available in an article below by the group moderator Blair Richlin.

[Click here](#) to register.

[Click here](#) for PDF.

Members with Hearing Loss

Friday, July 12th, 12:30 PM

This special interest group is for hearing health care professionals and researchers with hearing loss.

This will serve as a networking session. We will have a moderated discussion regarding issues affecting us as professionals with hearing loss. We will also explore issues of connectivity of hearing devices (both CIs and hearing aids) with other technologies.

This group will be led by:

Viral Tejani AuD, PhD

Assistant Professor, Otolaryngology-
Head and Neck Surgery
Senior Clinical Research Audiologist,
Cochlear Implant Program
University Hospitals Cleveland
Medical Center / Case Western
Reserve University
Viral.Tejani@UHhospitals.org

James Dornhoffer MD

Otolaryngology-Head and
Neck Surgery
Mayo Clinic

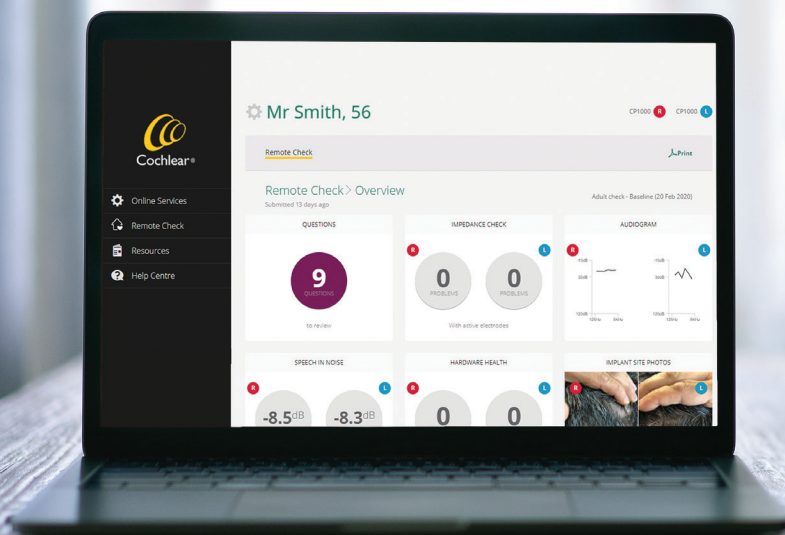
Chad Ruffin MD

Chad Ruffin MD, PLLC
Seattle, WA

[Click here](#) to register.

[Click here](#) for PDF.

If you have any questions on these groups, please email Jessica Houk;
jhouk@acialliance.org. ■



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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.

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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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Adult Rehabilitation Special Interest Group (SIG) to Advance their Work in Vancouver

**Blair Richlin, MS, CCC-SLP,
LSLS Cert. AVEd**

SIG Moderator
Speech-Language Pathologist,
Mass Eye & Ear

brichlin@meei.harvard.edu



Despite previous findings that adults are unfamiliar with cochlear implants (Marinelli et al., 2022), we have the potential for increased and widespread knowledge. Thanks in part to social media and other popular entertainment, CIs are more readily discussed, viewed and “digested” in TikTok sized snacks. CI candidacy criteria has continued to evolve (SSD, we see you). As a result, more ears with severe-profound hearing loss than ever before in the United States may receive sound awareness. However, sound awareness isn’t the end game. CI recipients expect functional listening skills that require more than sound detection. For adult cochlear implant recipients, sound awareness can be transformed with Aural Rehabilitation.



Aural Rehabilitation encompasses services provided by an Speech Language Pathologist (SLP) or Audiologist and includes auditory training, informational counseling/tech support and communication strategies training. At the ACI Alliance CI meeting in 2023 in Dallas, CI team members

of all specialties got together for the first annual Adult Aural Rehabilitation SIG lunch. This year we are excited to welcome existing and new members to the SIG. We hold virtual meetings to discuss current research, trends in practice, barriers to access and care, future research questions and plans for expansion of this valuable service.



You can join our listserv by completing this form:
<https://forms.gle/ij37Znx2woaKJpRj8>



Better yet, join us in person at CI 2024 Vancouver!

Register here:
<https://www.acialliance.org/event/ci2024auralrehab>

Early Hearing Detection and Intervention (EHDI) Programs Undergoing Change: Get Involved to Help Move the Needle in the Right Direction

Donna L. Sorkin MA
Executive Director
American Cochlear Implant Alliance
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Federal legislation to support hearing screening of all newborn children within the first days of life was first passed in 1999 under the leadership of former US Congressman James Walsh of New York. He had been urged by audiologists to take this issue on given the importance of beginning intervention for hearing loss in young children quickly.

been one of the most rewarding advocacy initiatives I have been privileged to be part of in my long career in this extraordinary field. This critical legislation changed the opportunity for children with any level of hearing loss.

Each time the legislation was reauthorized by Congress, we worked to address shortcomings to



I was honored to be part of a Congressional working group drawn from all the major hearing health organizations to develop the newborn hearing screening concept. Pushing the federal legislation forward over the years it took to get to a final bill, collaborating and resolving our differences, and highlighting the important benefits of newborn hearing screening has

improve the program and further enhance lifetime learning and quality of life for children born with hearing loss. Soon after EHDI programs were initiated in states, we recognized the need to spell out the requirement for parent information. I authored the first draft of language that a working

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group tweaked that is now part of EHDI law and is supposed to be a cornerstone of the early intervention process. This language, which was incorporated into the legislation in 2017, stated that families be provided with information that is “accurate, comprehensive, up-to-date and evidence-based to allow families to make important decisions for their children in a timely manner including decisions with respect to the full range of assistive hearing technologies and communication modalities.”

Our ACI Alliance members and others have observed that this aspect of the EHDI federal law is carried out appropriately in some states but not in others. Bias is sometimes inserted by early intervention personnel in programs relative to use of hearing technology and communication modality. As an organization, we take no position relative to communication modality other than emphasizing that families have the information and support that they need to maximize listening and talking in their children who receive cochlear implants. Work that we did and will continue to do emphasizes this important element.

On March 28, the Health Resources and Services Administration (HRSA) made the decision to award the EHDI oversight grant to a new federal contractor, moving away from the coordinator role that had been provided by Dr. Karl White at Utah State University for 24 years to Gallaudet University. We continue to support EHDI and the newly selected contractor—just as we did with Utah State’s National Center for Hearing Assessment and Management. Our commitment to children with hearing loss and their families to have full information, choice of options, and appropriate EHDI services continues.

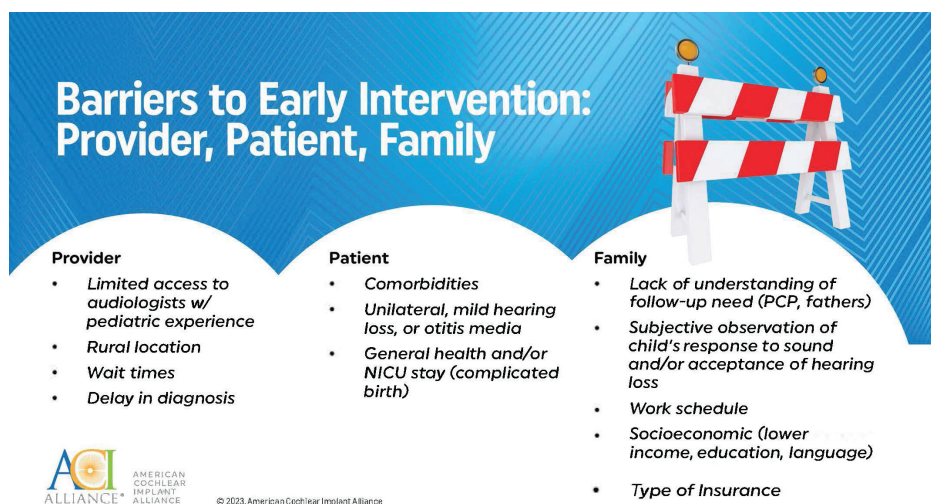
As we move forward in this new era, we have also expressed our support for productively addressing lost to follow-up (LTF)—the process by which children who are identified during hearing screening fall out of the system without a full diagnosis or without receiving early intervention services. As have others, we have explored the barriers and range of reasons why LTF occurs which include family factors like insurance, socio-economic status, and lack of understanding of follow-up need; patient factors such as mild

to moderate hearing loss and minimization of the need for follow-up; and provider factors such as limited access to audiologists with pediatric experience.

Our dedicated State Champions want to help. At our upcoming State Champs meeting in Vancouver, they will be encouraged to get involved in their state’s Early Intervention Program via advisory boards or other input mechanisms. We will be providing ongoing training and information on the most common barriers to early intervention for childhood hearing loss, and how we can work together with other organizations to effect critical change. We believe that resolving such barriers is one key tactic to improve family access to the early intervention process.

We have been told by HRSA that their intent is to begin a process of assessing language acquisition and cognitive status of children with hearing loss as part of the early intervention system. As clinicians, we understand the complexity of such testing in children who have a range of hearing loss characteristics and other issues. Most early intervention programs do not have the personnel to carry this out appropriately. Further, we don’t believe that tests for language acquisition—in and of themselves—will improve the lost to follow-up dilemma and could exacerbate existing issues relative to family counseling.

American Cochlear Implant Alliance and our partners in the hearing health community are committed to supporting families through EHDI programs. Please consider getting involved and adding your voice to our endeavors. ■



Barriers to Early Intervention: Provider, Patient, Family

Provider	Patient	Family
- Limited access to audiologists w/ pediatric experience - Rural location - Wait times - Delay in diagnosis	- Comorbidities - Unilateral, mild hearing loss, or otitis media - General health and/or NICU stay (complicated birth)	- Lack of understanding of follow-up need (PCP, fathers) - Subjective observation of child's response to sound and/or acceptance of hearing loss - Work schedule - Socioeconomic (lower income, education, language) - Type of Insurance

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Advocacy Update

Nichole J. Westin MA

Director of Governmental Affairs
ACI Alliance

nwestin@acialliance.org



The Stop CMV Act

Earlier this year, S.3864/H.R.7542, the Stop CMV Act, was introduced in the U.S. Congress. Our thanks to:

- Original sponsors, Senators Richard Blumenthal (D-CT), Chris Murphy (D-CT), and Roger Marshall (R-KS) in the Senate
- Representatives Mike Lawler (R-NY) and Greg Landsman (D-OH) in the House.



State Champions Meeting in Dallas, June 2023

This legislation has been a long time coming and begins the process of establishing nationwide congenital Cytomegalovirus (cCMV) screening. None of this would have been possible without the efforts and support of the National CMV Foundation, ASHA, ACI Alliance, and other hearing health partner organizations.

As many of you know, cCMV affects approximately 1 per 200 births in the United States and is the most common cause of non-hereditary hearing loss. Infants are infected due to exposure of the mother who often is unaware they had cCMV due to the mild, cold-like symptoms in adults.

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Improving Adult CI Access to Medicaid

Problem: Removing restrictive regulations around access to CI by State Medicaid Programs

Medicaid is a joint US federal/state program that provides insurance for specified medical costs for individuals who meet income criteria. Although most state Medicaid policies cover cochlear implant for adults, some do not. While the federal government has general rules that all state Medicaid programs must follow, each state runs its own program and can set its own criteria for inclusion. Therefore, eligibility requirements and benefits vary state by state.

Solution: Advocate in those states via the legislative and/or regulatory route(s) to address adult coverage

Outcome: By combining expertise from ACI Alliance staff, State Champions and local public policy experts, the organization has seen success in expanding adult CI coverage under Medicaid. Each advocacy path is unique given variations in state governments requiring tailored approaches. Due to these efforts, three states have changed their policies. Maryland changed its policy via the regulatory route (2018), South Carolina amended its state policy similarly (2023), and Washington State pursued a combination of regulatory and legislative approaches (2023).

Missouri came very close to passing legislation this year but ran out of time. Georgia has temporary coverage for CI parts and replacements, but not yet surgery. Arizona came close to new legislation in 2022, but work continues in the state. Colorado and Arkansas have also begun initial conversations in how best to effect change in their states.

Key Lessons for Advocacy: A clear understanding of the politics in each state is necessary to achieve positive change. Some states have made the change without the need for legislation, while legislation was necessary in others. It is important to assemble a broad coalition of supporters to demonstrate the importance of the issue. The combination of expertise, many voices, and clear goals help deliver positive outcomes.

ADVOCACY UPDATE *continued from page 13*

cCMV is responsible for hearing loss in 1 in 5 children who have no other known risk factor or cause. Hearing loss related to cCMV may not be present at birth, but rather delayed in onset and hence would be missed by newborn hearing screening and may fluctuate or progress during childhood.

The proposed bipartisan, bicameral bill would authorize new funding to incentivize hospitals and other health care entities that care for children to screen babies for cCMV within the first 21 days after birth. The bill also supports funding to collect data on cCMV and to assist in the education and training of health care providers, patients, and the public. Finally, the legislation directs the National Institutes of Health to conduct research into congenital cCMV. The bill was structured to resemble the original newborn hearing screening legislation that was passed in 1999.

With a federal bill introduced, what's next? The reality is that it could be several years for passage of the legislation. During a recent question-and-answer session with Senator Marshall, he stated he expects it to take five years or more before a bill is signed into law. This is common for Congressional legislation and the simple fact a bill exists is a significant step forward. The proposed legislation

provides a rallying point around which advocates can educate Members and their staff as well as make specific asks for co-sponsoring the legislation. Once a bill has been introduced, it is also easier to reintroduce the bill every two years when a new Congress is elected.

One of the best and easiest ways to shine a spotlight on the importance of this legislation is by contacting your Members of Congress and asking them to support the bill. ACI Alliance has set up an Action Alert which allows you to do so with a few clicks of the button. You can find it by [clicking here](#). The more organizations and individuals that support the legislation, the more likely Congress is to consider passage.

The impact of cCMV on infants and families is a significant problem. Having a federally supported screening program will ensure that those affected are able to access necessary medical care and interventions at an earlier date. The Stop CMV Act is the first step in that direction. We will continue to work with our partners on passage and on legislation at the state level.

For more information on ACI Alliance advocacy efforts and the State Champion network, contact Nichole Westin at nwestin@acialliance.org. ■

Donate to the Work of ACI Alliance

As a 501(c)3 organization, ACI Alliance is able to receive tax-deductible contributions to advance our mission. We are grateful to each of our donors for supporting activities that help us increase access to cochlear implantation through research, advocacy, and awareness.

Through this process, we have been able to communicate with families who have organized donations in honor of a relative who has passed away and learned their stories of how a cochlear implant changed families' lives. Some families have chosen to share their stories on our website and we encourage our members to take time to read them.

Donations helped fund the Dr. John K. Niparko Memorial Lecture, dedicated to his enduring commitment to cochlear implant research and clinical care and an integral part of the annual CI conference.

Some members have supported our mission by donating honoraria they earned for joint projects with ACI Alliance. Recently, Dr. Allison Biever, an audiologist at Rocky Mountain Ear Center, donated her honorarium from presenting an online course in May 2024 on adult SSD candidacy and outcomes.

You can learn more about donations, as well as information on how to contribute, on our website at www.acialliance.org/page/donations. ■



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ACI Alliance Resources and Support

Laura Odató MPP

Director of Operations and Marketing
ACI Alliance

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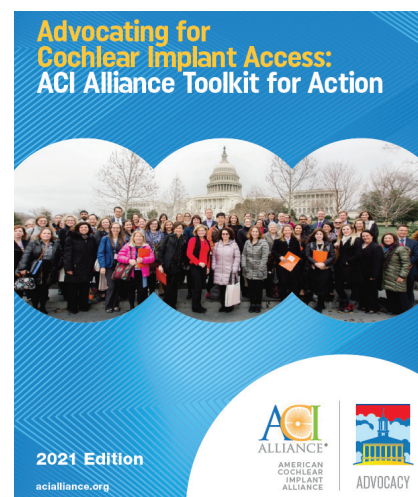


Resources to Share: A Collection of CI Information for Patients, Parents, and Other Professionals

ACI Alliance has made it a priority to develop resources to make it easier for our members to share information about cochlear implantation with others. If you've recently attended an ACI Alliance conference, you most likely saw the organizational resources table with a variety of handouts designed to share with patients, families, and other professionals. Examples of some of these resources include:

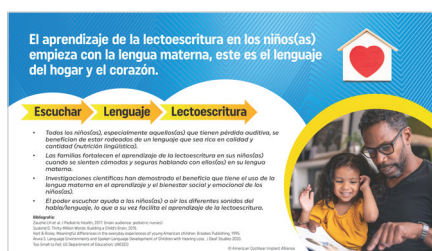
- Candidacy infographics for children and adults with bilateral or single-sided deafness
- Cards with general CI information
- Resources for specific groups (i.e., parents of children with hearing loss)
- Opportunities for CI users to get more involved with the ACI Alliance consumer community
- Patient Tips for cochlear implant users

Some resources were developed for specific organizational campaigns such as the Listening—Language—



Literacy initiative. Last year we published an infographic on this campaign in English, and thanks to the work of Alejandra Ullauri AuD, MPH and Mariana Mejía Turnbull AuD, we recently published a Spanish language translation thereby reaching new audiences. We encourage members to download and print these free infographics from our website as a double-sided card. Some members have placed them on their own websites with links to ours and others have printed them out large scale to post in their clinic.

Our resources are designed to be easy to download and print; we are happy to work with members on larger printing projects. The full list of resources can be found on our website (www.acialliance.org/page/resourcestoshare). Please reach out to Laura Odató at lodato@acialliance.org with questions. ■



Meet the ACI Alliance Board of Directors



Camille Dunn PhD

Director of Cochlear Implants
Department of Otolaryngology
Head and Neck Surgery
University of Iowa

My name is Camille Dunn. I've had the privilege of working in the cochlear implant profession since earning my doctorate degree at the University of Nebraska in 2003. My ambition to get engaged in this field began when I was younger. My brother has a developmental delay, and when he was younger, a speech pathologist would visit our home and work with him on speech and language development. I was always captivated by this, and after she would leave, I would play "speech" with my brother, pretending to be a speech therapist.

When I began college in 1992, I was still intrigued by the treatment my brother had received years earlier and intended to pursue a degree in speech pathology. When I took my aural rehabilitation class, I had no idea that the two-hour lecture on cochlear implants would shape my future profession. I rapidly shifted my concentration to audiology, knowing I wanted to work in the cochlear implant field. After completing my master's degree in Audiology (this was before the AuD), I elected to continue my education and earn my PhD in hearing science with the goal of doing cochlear implant research.

Since 2003, I've had the opportunity and pleasure of working with some of the pioneers of cochlear implants, particularly Dr. Bruce Gantz, at the University of Iowa Cochlear Implant Clinical Research Center. I remember telling my husband that working at Iowa would allow me to gain experience with cochlear implants at a leading cochlear implant program. Because my husband and I grew up in Nebraska and wanted to experience life outside of the Midwest, I assured him we'd only be in Iowa for two or three years. Nearly 22 years later, as Associate Professor and Director of the University of Iowa Cochlear Implant Clinical Research Center, I can't imagine a greater career path. I've been involved in some of the most cutting-edge cochlear implant research, which has resulted in significant advancements in cochlear implant candidacy and outcomes. It has also given me the opportunity to serve organizations such as the American Cochlear Implant Alliance, where I have been on the board for the past six years. It has been humbling and an honor to work with so many outstanding colleagues to keep the Alliance's purpose of increasing access to cochlear implantation through research, advocacy, and awareness.

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ACI Alliance Board of Directors meeting in Dallas, June 2023



Daniel M. Zeitler MD

Co-Director, Listen for Life Center
and CI program
Virginia Mason Franciscan Health
Seattle WA

My journey in the field of cochlear implants, beginning 15 years ago, has been both fulfilling and challenging, humbling and prideful, exciting and frustrating. It is these dichotomies that have helped shape me into the advocate and professional I am today. Over the past four years, I have had the incredible privilege of serving on the American Cochlear Implant Alliance (ACI Alliance) Board of Directors and more importantly I have had the honor of representing the thousands of ACI Alliance members, a group of dedicated professionals along the entire hearing healthcare continuum, united in our mission to advance cochlear implant research, advocacy, accessibility, and awareness. My name is Daniel M. Zeitler, and I am the Co-Director of the Listen for Life Cochlear Implant Center at Virginia Mason Franciscan Health in Seattle, WA and Clinical Assistant Professor at the University of Washington Department of Otolaryngology-Head and Neck Surgery.

There are well-documented and significant disparities among underrepresented and marginalized populations in hearing health care. Central to my vision and career goals is an unwavering commitment to increasing inclusivity and equity in healthcare, specifically in the cochlear implant market. Through active collaboration and cooperation with the staff and board members of the ACI Alliance, we have been able to engage local policymakers, government officials, and relevant stakeholders to push for new policies and initiatives that break down barriers to access. Most recently, our hard work and unrelenting grassroots efforts in Washington resulted in the Washington State Legislature passing a bill requiring state Medicaid to cover cochlear implants for adults. With the help of the ACI Alliance, together we all can amplify the voices that are often unheard and work towards implementing policies that allow everyone, regardless of background or circumstance, equal access to the life-changing effects of cochlear implants.

In my career as a cochlear implant surgeon, I have had the pleasure of spending time not only in the clinic and operating theater, but also working on research projects and clinical trials aiming to further the field's advancements. It is within these realms that I have found my true calling—working tirelessly to improve outcomes for cochlear implant recipients. As an investigator on several multicenter trials exploring expanded indications for cochlear implantation (e.g., single-sided deafness, asymmetric hearing loss), we have harnessed the strength of partnership to explore ways to ensure this incredible technology gets to those patients who need it most. Through my research, and that of other colleagues around the country, we have started championing the use of machine learning in the field of cochlear implantation. Using artificial intelligence and large data analytics, we have the potential to revolutionize how we diagnose, treat, and monitor hearing disorders. From predictive modeling to post-implantation outcomes to personalized rehabilitation plans, the integration of machine learning holds tremendous promise in shaping our future.

The last 40 years in the field of cochlear implantation has been exciting and wildly successful. Together, over the next 40 years, we must continue to navigate the complex landscape of cochlear implant advocacy, research and clinical practice. It is reassuring to know we will be guided by the steadfast commitment to excellence, compassion, innovation, and dedication of the American Cochlear Implant Alliance. It has been, and continues to be, an honor to serve as an ACI Alliance board member. Together with the ACI Alliance, let us all continue to push boundaries, defy expectations, and pave the way for a future where the gift of sound is truly within reach for all who need it, regardless of race, religion, color, or creed. ■

NASCAR Driver Talks Hearing Loss, Racing and Inspiration

Kris Martin



I was born profoundly deaf, which was identified when I was 14 months old. My parents worked to find resources to help me hear, starting with hearing aids and eventually a cochlear implant. In 1992, when I was 8 years old, we found a clinic in Canada near where we lived in London, Ontario. I was evaluated and received my cochlear implant that year.

In school, I wasn't shy in telling my classmates and teachers that it's okay to ask me how my cochlear implant works. I felt like it was my responsibility to show the teachers how to use the FM microphone and remind them to pass it around to the students so I could hear everything that was going on. I always sat in the front row in school and worked hard to make sure I knew what was going on in the classroom. In case the other students were afraid to come up and ask me about my cochlear implant, I went up to them and explained that cochlear implants for deaf people were like glasses for people with vision. Once I explained it to them, they thought

my technology was so cool and some of them wanted to know if they could try it! I don't think you should feel embarrassed about having a cochlear implant and I didn't want the other kids in the class to be afraid or treat me differently than other students.

I took a similar approach with my racing career, and I've worked hard to show racing officials and other drivers how my technology works. With NASCAR officials, I talked to them about how I hear and communicate during a race with an FM system and went out for a practice time to show them how it works. The other drivers had questions as well, but once the officials and other drivers saw how it works, watched me race and saw that I'm a safe driver who respects other drivers and the rules they let me race!

When I'm not racing, I love speaking with different groups and organizations, especially children with hearing loss. I've worked with the Sound Start program for babies and children with cochlear implants, and it's been rewarding to talk with them about how to help babies and

students with cochlear implants in school. I love talking with the children who often ask me about my story, difficult situations in school, and very often about bullies. I encourage them to follow their dreams in spite of difficulties and setbacks, and tell them that they have the power to choose their own path and pursue their dreams. I tell them to believe in their own hearts and not to worry about other people (including their parents!). It was my dream to race and not my parents, but they followed and supported me. I talk to them about being strong and how it's okay to have a bad day, but if you keep trying to be successful that you'll get better.

I let them know that whatever they want to do, to go for it!

Editor's Note: A video-taped interview with Kris is available on the ACI Alliance website (www.acialliance.org/page/videos). It's a valuable resource for children, families, and professionals. We also look forward to having Kris join us for the Opening Session at CI2024 Vancouver! ■

INTERVIEW WITH KRIS MARTIN



AMERICAN COCHLEAR IMPLANT ALLIANCE

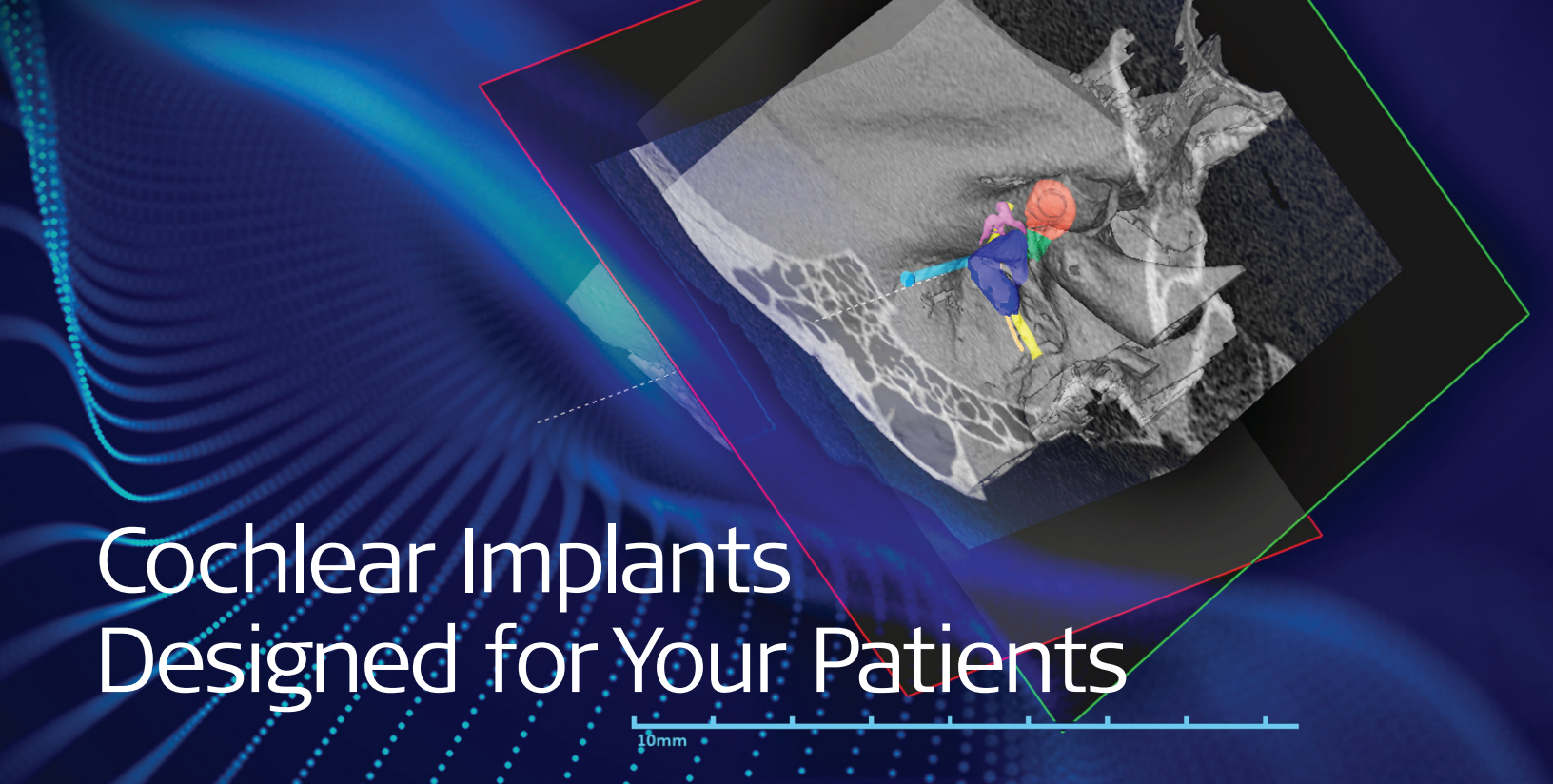
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KRIS MARTIN
NASCAR Race Car Driver
and Motivational Speaker



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