Social gatherings and our ability to effectively communicate with our family and friends are a hallmark feature of the approaching holiday season. Proper communication remains critical for our well-being during these times, but the internet and other data sources often do not provide accurate information for folks suffering from substantial levels of hearing loss. As the only multi-disciplinary organization solely dedicated to cochlear implantation, it is a critical role of the ACI Alliance to provide accurate, scientific and evidence-based information that is unbiased on a broad range of CI topics relevant to diverse audiences including the general public and those seeking a cochlear implant, healthcare professionals within and outside of the hearing field, and administrators including insurance professionals and government officials.

As such, we have been focusing heavily on our visibility on the World Wide Web and our efforts have helped to make us the leading trusted source of cochlear implant information. We recently began reviewing the accuracy of others’ resources and one of those is the state Early Hearing Detection and Intervention (EHDI) websites as parents have told us how important such data sources are for decision-making. (Please see a related article on page 13 in this issue of Calling.) We have further entered conversations on different media events with regards to hearing.

continued on page 2
MESSAGE FROM THE CHAIR  continued from page 1

loss and cochlear implantation—as Donna Sorkin did on the inaccuracies and misleading portrayals in the recent feature film *Sound of Metal*. Similarly, we have several ongoing grassroots efforts to improve the information landscape on cochlear implantation across multiple related or sometimes unrelated, but well frequented, Internet-based knowledge sources.

In addition, considerable variation exists across the medical and audiologic communities regarding determination of cochlear implant (CI) candidacy. While criteria exist from the FDA for children and adults and from CMS for Medicare beneficiaries, different clinics and even providers within the same clinic use varying protocols to determine CI candidacy in different age groups and also considering factors other than hearing status. Recently, the FDA has expressed interest in engaging with CI thought leaders across the country and we have been asked to help shape this conversation which will take place early next year. We hope that this dialogue, along with others, will help us expand indication criteria beyond what is currently approved—and make cochlear implantation available to a broader patient base.

For information on the FDA Virtual Workshop, please go to page 13.

Correspondingly, the ACI Alliance Board of Directors commissioned four papers to provide clinical guidelines for cochlear implant candidacy in children and adults with bilateral hearing loss and those with single-sided deafness. Multi-disciplinary task forces were appointed to develop these guidelines and I am very pleased to announce this set of AudiologyOnline seminars, as they will provide insight into four 2022 ACI Alliance Candidacy Guidelines. I would like to acknowledge the following individuals and their outstanding leadership on each of these four documents, which also included other authors: Andrea Warner Czyz PhD, Associate Professor, Callier Center for Communication Disorders, University of Texas at Dallas (CI candidacy in children), Sandra Prentiss PhD, Associate Professor, University of Miami Miller School of Medicine (CI candidacy in adults), Lisa Park AuD, Assistant Professor, UNC Department of Otolaryngology/Head & Neck Surgery (pediatric CI candidacy in single sided deafness and asymmetric hearing loss), and Margaret Dillon AuD, Associate Professor, Director of Cochlear Implant Research, UNC Department of Otolaryngology/Head & Neck Surgery (adult CI candidacy with single sided deafness and asymmetric hearing loss).

I would also like to thank our previous Chair Dr. Meredith Holcomb for her guidance and mentorship for these articles as well as Donna Sorkin’s tireless work during this process. More on these articles can be found in this issue.

I also would like to point out that we have added a section in *Calling* highlighting the members of the Board of Directors. In this issue we introduce Andrea Warner Czyz PhD and John Dornhoffer MD with their short summaries about themselves and will continue to feature two members of our board during each publication. Further, I would like to welcome Barbara Mellert MPH to the Board of Directors. As a parent of two young adult sons with cochlear implants, we look forward to Barbara’s contributions to our cause and her perspective. You can read more on her captivating story [here](#).

Lastly, I wanted to express our gratitude for your continued support of cochlear implantation and the ACI Alliance. We hope you can spend time with loved ones during this holiday season and we look forward to seeing everyone in person during next year’s meeting in May.
A Powerful hearing experience with proven technology platform from the world’s leading pediatric hearing aid, Phonak Sky

Flexibility for a growing child’s adventures with its variety of wearing options and accessories

Ultimate ease of use for staying connected with their world throughout the day

Visit AdvancedBionics.com/skycim and start your child’s journey to better hearing today.
Remember when we were together last in-person as one cochlear implant community? Ah…2019! What fond memories we have of our last in-person meeting in Miami in 2019! The resort attire, tropical breezes, and impactful content, connections, and collaboration seem to be calling out from a pre-COVID era. Three years later we’re ready to step away from our screens and join each other in person once again. It’s been a long road, and we are ready to be reenergized and reconnected to the camaraderie and team-focused care that helps bring hearing to thousands of people around the world.

CI2022 is rapidly approaching, and we want to see you there! This year’s theme, “Emerging Issues in Cochlear Implantation” will commemorate the successes of the past and cast a vision of the future as we reflect on how far we’ve come and how much we can still accomplish. The CI2022 program committee is pleased to share the wonderful lineup of guest speakers, top notch panels, and innovative sessions we have in store:

René Gifford, PhD from Vanderbilt University will be the first audiologist to deliver the Niparko Lecture. Dr. Gifford has been a foundational leader in moving our profession into a groundbreaking and exciting direction. Her keynote, “The Evolution of Cochlear Implant Care” promises to invigorate us all.

Sumit Agrawal, MD from Western University will provide a keynote titled “From Synchrotron to Artificial Intelligence: The Journey to Improve Cochlear Implant Outcomes.” This presentation will expand our understanding of how innovative imaging can impact the way we provide electric stimulation to the cochlea.

We will also kick-off an innovative session on gender equity among hearing healthcare professionals. This unique session is sure to stimulate meaningful discussion and spark your interest in reigniting networking and intersectionality, just in time for our social hour!

The (Re)Habilitation Connect Forum is back with two themes centered around children and adults with cochlear implants. Don’t miss this engaging session which is designed to promote evidence-based (re)habilitation. You’ll learn about cutting edge research impacting therapy and how to put evidence into practice. We can’t wait to reconnect fellow therapy practitioners to share knowledge and support our patients.

A special session on the Childhood Development After Cochlear Implantation (CDaCI) study is also in the works. This session will celebrate the highlights of this groundbreaking 20-year study and how the impactful team-based approach to research opens doors for the future of cochlear implantation.

Many hours of planned program content will provide attendees interdisciplinary and innovative ways to approach cochlear implantation in single-sided deafness, explore challenging cases, build and expand cochlear implant access in your community, apply translational research, and provide quality (re)habilitation care.

We are thrilled to offer a safe and exciting in-person event. Please join us May 18–21 in Washington, DC. Registration opens December 15. We look forward to seeing you there!
Conference Registration/Student Details

Jessica Houk MBA / Manager of Information Technology and Membership Services / ACI Alliance / jhouk@acialliance.org

Advanced registration for CI2022 DC opens December 15, 2021. All professional and student members will receive a specific discount code to be entered during registration. For those with Individual professional or student memberships, member codes were emailed December 8. Check your inbox!

For organizational members, your member code was emailed to the main point of contact for each organization. If you are not sure who your point of contact is, please use our Find a Clinic Map to find your organization. The point of contact is listed for each clinic and that individual has the code for your organization. Please take advantage of the discount when registering for the meeting. To view the registration cost for your member category, view the registration area of the CI2022 DC website.

Student Scholarships
Student Scholarships are intended for full-time students, fellows and postdoctoral scholars who have a clinical or research interest in cochlear implants. Awards will include registration to the meeting, a $120 stipend, and a student membership in ACI Alliance. Applications are due no later than December 17, 2021. Click here to submit your application. Your application will be reviewed by the Student Scholarship Committee and results will be posted January 21.

Watch your inbox for up-to-date information. You can also check the conference website as well as the ACI Alliance site which has a specific area for CI2022 DC.

Please feel free to contact Jessica Houk at jhouk@acialliance.org if you have further questions.

CI2022 DC at a Glance

Conference Dates: Wednesday, May 18 – Saturday, May 21, 2022
Conference Website: www.CI2022DC.org (links to abstracts, registration, hotel, updates)
ACI Alliance Detailed Information: https://www.acialliance.org/page/CI2022
Hotel and Meeting Venue: Renaissance Washington DC Downtown
ACI Alliance on the Hill (by application): Wednesday morning, May 18
CI Manufacturer Satellite Symposia: Wednesday, May 18, starting at 1:00 PM
CI Manufacturer Breakfast Symposia: Thursday, Friday, Saturday morning at 7:30 AM
Opening Reception, Exhibits, Posters: Thursday, May 19 (Late afternoon)
Registration Opens: December 15, 2021 (Discounts for Early Registration & Members)
Notification of Acceptances: January 2022
Presenters Must Register: February 15, 2022
Program Published: February 2022

CEU and CME will be offered from the same providers that have been available in the past. Tier 1 Hours for audiologists will be offered.
Become an AudiologyOnline member for 24/7 access to our growing library of 1500+ evidence-based online courses, including 100+ cochlear implant courses. Courses are offered for AAA, ASHA, and IHS CEUs.

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“So much cutting edge research. Especially appreciated how they covered multiple topics from CI referrals to pediatric guidelines to mapping itself. Extremely beneficial and grateful that these presenters shared their expert knowledge.”

– Karson M., AudiologyOnline member
One of the first initiatives undertaken by the newly organized American Cochlear Implant Alliance was a multi-center study to explore outcomes in older adults with greater speech recognition than is allowed under current Medicare criteria. We approached CMS requesting that they partner with us and allow Medicare expanded coverage for individuals who were part of the ACI Alliance study. Principal investigators Terry Zwolan PhD, Craig Buchman MD, and John Niparko MD led the study effort. Historical discussion of what was done is on the ACI Alliance website.

The study assessed outcomes in Medicare beneficiaries with scores that fell between 40 and 60% correct on AzBio sentences in best aided condition when stimuli were presented in quiet at 60 dBA. Study results were published in JAMA Otolaryngology in October 2020 in a paper “Assessment of Cochlear Implants for Adult Medicare Beneficiaries Aged 65 Years or Older Who Meet Expanded Indications of Open-Set Sentence Recognition: A Multicenter Nonrandomized Clinical Trial” by Zwolan et al.

Though the study results were favorable, we have a bit more to do. We have made a formal request to CMS for reconsideration of criteria under a National Coverage Determination (NCD). There is a long list of others in the NCD queue so we are uncertain when our request will be published—the necessary step before the process can proceed.

Of note, once the NCD is published, we will have only 30 days to provide comments and to cite pertinent literature supporting the request, so it is critical that we think now about what we will submit to support the request for expanded criteria.

Comments from CI clinicians who have struggled to provide CI to older adults because of the currently restrictive Medicare criteria as well as those who have been able to gain coverage for 65+ adults are urged to submit. ACI Alliance is monitoring the CMS website and will notify our members immediately once the NCD is published with details on how and where to submit. It is important to reference the specific published findings in the study by Dr. Terry Zwolan and others. For example:

- How does your own clinical experience compare with the proposal to expand Medicare criteria?
- Has your clinic seen improved outcomes in older adults that aligns with the outcomes in younger patients?
- Have older adults with better speech recognition performed better with a CI than those who meet Medicare’s current, more restrictive criteria?
- Discuss the fact that waiting until a patient loses more hearing means that they may never achieve the outcomes of those who receive the technology sooner and the risk associated with waiting.

Please think about the above topics now vis a vis your patients’ experiences so that you will be able to prepare comments quickly to support the NCD. The NCD could open as early as January 2022, so we need to be ready. We will send out an alert once the NCD is published to aid CI clinicians who wish to support the NCD to know what to do. Of course, reach out to me if you have questions or suggestions.

ACI Alliance recognizes the volunteer efforts of those who supported the initiative by participating as study sites and especially the PIs for the study—Drs. Terry Zwolan and Craig Buchman. Participating study sites include: Hearts for Hearing, Johns Hopkins University, Loyola University, Medical College of WI, Medical University of SC, St. Luke’s Mideast Ear Institute, NYU, Ohio State University, Rocky Mountain Ear Center, University of IA, University of Miami, University of Michigan, University of NC, University of PA Health System, University of Southern CA, University of TX Southeastern Medical Center Dallas, University of WA, Vanderbilt University, Washington University St. Louis.
On November 19, the House passed the $1.85 trillion Build Back Better Act, a budget reconciliation bill with several key healthcare, environmental, and educational provisions. Passage of this bill means that Congress is one step closer to passing one of the largest social spending bills in the last decade. Included in the reconciliation bill is language that would expand Medicare coverage of hearing aids for individuals with moderately severe, severe, and profound hearing loss.

**Hearing Aid Coverage in Build Back Better Act**

The Medicare expansion legislative language will cover hearing assessment services and hearing aids beginning in 2023. Hearing aids will be covered for beneficiaries in need once every five years, and requires that hearing aids will be provided through a written order from an audiologist, physician, or other health professional. Furthermore, as part of the requirement that hearing aids be provided through audiologists, the bill now reclassifies audiologists as practitioners and allows them to be reimbursed for services provided under Medicare.

The legislative language will cover hearing aids under Medicare for the first time, but by limiting the hearing aid benefit to only individuals with moderately severe, severe, or profound hearing loss, there are concerns around how this new legislation will impact referrals for cochlear implants (CIs).

Most individuals with profound hearing loss (close to 100%) are CI candidates and do not demonstrate sufficient benefit from hearing aids, however, hearing aid utilization is highest among people with significant hearing loss.

**Cochlear Implants as Part of the Hearing Health Spectrum**

In an effort to avoid negative impacts to cochlear implant referrals by expanding hearing aid benefits under Medicare, the ACI Alliance has been working to include language for the legislative record that makes it clear that nothing in the hearing aid Medicare expansion provisions in this bill are intended to encourage individuals to receive a hearing aid when a cochlear implant would be a better option. Having language for the record will help to ensure that when the Centers for Medicare and Medicaid Services (CMS) begins to implement the bill, they will draft regulations and guidance documents that are consistent with Congressional intent and will not undermine or block referrals for CI.

The ACI Alliance is now engaging with key Senate offices who are beginning the process of reviewing the House package and updating and developing their own legislative provisions that will be included in the budget reconciliation package. ACI Alliance is focused on Senate offices to encourage them to include language for the record that will clarify the importance of cochlear implants as part of the hearing health spectrum, and clarifying that nothing in the bill should be construed to limit appropriate referrals for evaluation of CI candidacy.

**Next Steps for Build Back Better**

The Senate bill can pass with a simple majority as long as the bill addresses spending, revenue, or the federal debt limit. Democrats in the Senate, however, are working to ensure that some of the more moderate Democrats, including Senator Joe Manchin (D-WV) and Senator Kyrsten Sinema (D-AZ), will support passage of the budget reconciliation bill before bringing it forward for a formal vote. This means that additional negotiations and revisions will most likely take place in the Senate before a final reconciliation bill can be sent to the President for his signature.
Season 2

Hearing Health Today

An educational and thought-provoking podcast series for hearing health professionals

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Presented by Cochlear
It’s been a year since we launched the Cochlear Implant Consumer Advocacy Network (CI CAN)—an advocacy network composed of parents of children with cochlear implants, adults with cochlear implants and others with a strong interest in CI advocacy. Our intent is to enhance the strong advocacy base provided by our State Champions with others interested in advocacy from the CI recipient community. Since the launch, this network has grown to over 100 members from 26 states.

CI CAN members are already having an impact on state and national policy. In Pennsylvania, a bill requiring screening for Cytomegalovirus (CMV) passed the Pennsylvania Senate and will hopefully pass the state House soon. In Connecticut, a bill to require that private insurance cover CI surgery was introduced and the sponsor plans to continue to support this effort in 2022. At the national level, CI CAN members are letting their Members of Congress know that they support making Medicare telehealth waivers permanent. They are also reauthorization of the Early Hearing Detection and Intervention (EHDI) Act and that the program be reauthorized with appropriate funding.

Recently, three CI CAN members participated in a roundtable to discuss their CI journey, local advocacy, and ideas for the future. Kelly Flodin (SC), Julie Olson (WI), and Tim McPherson (PA) had unique hearing loss journeys but they also share similarities including their common belief that advocacy is primarily a local endeavor.

Flodin has had his cochlear implants for about a year though he experienced a long history of personal and family hearing loss. While many of his family members have hearing loss, he is currently the only one who has a CI. Olson received a CI in 2005 and is bimodal, enjoying the benefits of a hearing aid in her contralateral ear. McPherson has utilized CIs since 2000 and has been involved in advocacy through his work as an occupational therapist. The conversation was wide ranging and included the importance of mentoring as advocacy, supporting others by suggesting referrals for a CI evaluation, providing unbiased information to parents and consumers about CIs, and noting that ACI Alliance has information that can assist with all of those areas.

**Mentoring**

At its core, advocacy for our CI CAN members is about sharing stories to have a positive impact. Mentoring falls into that category. Olson is active in another hearing loss organization and has been a mentor in various capacities for many years. She stated that her experiences demonstrate that you need to be a part of the solution if you are finding something a problem. In her case, she realized she would be able to help people. Since then, she has been active in other hearing health groups, runs a CI support group in her home state, and is a mentor at Mayo Clinic Connect. “We need to be clear that we are educating people on our own experiences.”

After he was implanted, Flodin reached out to his referring audiologist to ask how to help and has mentored prospective CI candidates throughout the national level, CI CAN members are letting their Members of Congress

All Advocacy is Local

Nichole Westin MA / Governmental Affairs Manager / ACI Alliance / nwestin@acialliance.org

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South Carolina. Many are worried about what it entails and “if it will work for them” to which he says: “It was a life changing experience for me.” It’s important for people to know that this intervention works. Each time someone shared their story within their community and beyond, more families and adults with hearing loss learn of the benefits of a CI and have access to someone who can help them along the way.

Recommendations for the Future
A common issue that comes up at the local, state, and national level is the issue of potential candidates not being referred for a CI evaluation. ACI Alliance has worked on this with the VA, in Medicare hearing expansion efforts, with collaborative partners, and with other hearing health as well as primary care organizations. Flodin was frustrated at how long it took for his hearing care professional to suggest a CI evaluation and how for years he was told a CI would not work for him. After his surgery, he was able to locate the 60/60 guideline for determining when to refer for a CI evaluation (Zwolan TA, Schwartz-Leyzac, KC, Pleasant T., August 2020). He wanted to know why this information is not utilized more. Olsen shared her frustration on this issue as well. Helping consumers and families know how to advocate and share their success stories is a long-standing goal of ACI Alliance.

Adults may not be aware of options for listening to music as well as suggestions for improving listening (i.e., websites, apps). All three in the roundtable discussion are musicians and Flodin continues to play and considers playing an instrument the best form of rehab saying, “If you don’t have an instrument—get one!” He has utilized many speech apps but he found he progressed the most when he picked up his guitar again, as finding pitches helped him with recognizing speech.

Importance of Education
All three people in the discussion agreed that a national focus on educating the public is critical. They also agreed that many individuals—including and especially policy makers—are unaware of what life is like for CI recipients. McPherson noted “there needs to be awareness of what life is like and the positive outcomes of having a CI.” He also emphasized that broad education on the needs of those with hearing loss should include sharing information on technology tools designed to assist such as captioning, hearing loops in buildings (i.e., concert halls and churches), and FM systems. There is also an abundance of biased and false information out there and sharing ACI Alliance resources on a multitude of issues is helpful, particularly myth busting such as the incorrect notions that “cochlear implants are brain surgery!”

McPherson recommended an advocacy effort focused on retaining employment for those who are deaf or hard of hearing. “Employers need to be educated as to what people with hearing loss can do and what accommodations can be easily implemented for us to be productive members of the work setting. I know that employers are afraid of added expense for just one employee or repercussions from ADA. But so often things can be remedied simply and without fanfare.”

While there are excellent support groups on Facebook, such as Cochlear Implant Experiences and Parents of Children with Cochlear Implants, the trio highlighted that ACI Alliance is in a unique resource to provide information that is consumer-focused, unbiased, and medically accurate to the general public. As their conversation shows, advocacy is not just working to pass laws in Congress, but is often sharing your story at the most local levels. CI CAN was founded in part to capture these stories to better serve the needs of adult consumers and families. These stories help shape approaches to self-advocacy but also our collective advocacy efforts at the state and national level. Our thanks to Kelly, Julie, and Tim for taking time to share their thoughts with us and for their on-going dedication to improving the future for CI users.

Are you interested in joining the effort? We are always looking for advocates to join our efforts! We hope CI clinicians will encourage patients to reach out, and consumers and parents will help spread the word. Please contact Nichole Westin at nwestin@acialliance.org to learn how you, your colleagues, patients, and friends can join our advocacy efforts. For more information on CI CAN and our State Champions, view our noted website content.
The SYNCHRONY 2 Cochlear Implant System features S-Vector magnet technology. With 25% more magnet strength, it's the ideal implant for single-unit audio processors.

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For information on potential risks and contraindications relating to implantation, please visit www.medel.com/us/isi-cochlear-implant-systems/
The World Wide Web as a Key Parent Information Resource

Nichole Westin MA / Governmental Affairs Manager / ACI Alliance / nwestin@acialliance.org

Growth of the Internet as an information resource has provided expanded opportunities for families to easily gather information. The Pew Research Center reported that 72% of mothers sought medical information on the Web during the timeframe March-May 2021, with use highest among those age 18-49. While utilization is slightly lower among certain groups (reduced socio-economic and education), it is still above 75% across race, income and education. State Early Hearing Detection and Intervention (EHDI) websites are an important opportunity for families seeking information on options for their children who have been identified as deaf or hard of hearing and are a requirement for EHDI programs.

ACI Alliance conducted a comprehensive review of the 51 EHDI websites looking at hearing loss, technology, communication options and resources. Of the 51 sites, 26% were rated as “comprehensive,” 35% as “somewhat helpful,” and 39% as “inadequate” (which included four state websites that were not operational at the time of review). ACI Alliance worked with Congressional offices to include language in pending EHDI legislation that would require a GAO study to analyze how information collected through EHDI programs (including state EHDI websites) contributes to access to early intervention services and how such data availability helps or hinders opportunities for children and families. Our intention is that the study will expand opportunities for parents and professionals to work with EHDI programs and for state governments to model the information that best supports families in a comprehensive and unbiased manner. Watch for a report on our findings.

ACI Alliance serves on the Workshop Planning Committee for the CIRCA Workshop.
American Cochlear Implant (ACI) Alliance Guidelines for Cochlear Implant Candidacy in 2022

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

C

onsiderable variation exists across the medical and audiologic communities regarding determination of cochlear implant (CI) candidacy. While criteria exist from the FDA for children and adults and from CMS for Medicare beneficiaries, different clinics and even audiologists within the same clinic use varying protocols to determine CI candidacy in different age groups and also considering factors other than hearing status. To provide guidance on this topic, the ACI Alliance Board of Directors commissioned four papers to provide guidelines for candidacy for children and adults with bilateral hearing loss and for those with single-sided deafness or asymmetric hearing loss. Task forces were appointed to develop the guidelines with membership drawn from across the care continuum to include audiologists, surgeons, speech-language pathologists, and others involved in CI patient care. We expect to publish the four papers in a journal this winter.

To further the dissemination, we are partnering with AudiologyOnline in March 2022 to provide a four-part series to provide insights from the authors on these 2022 ACI Alliance Candidacy Guidelines. Each seminar will be given at 12Noon ET and will offer CEUs and captioning. Seminars will be given by the lead author and, in two instances, an additional task force member. We are grateful to AudiologyOnline for continuing to support the work of ACI Alliance.

AudiologyOnline March 2022 Series

ACI Alliance Guidelines for Determining Cochlear Implant Candidacy

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<th>TITLE</th>
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<tr>
<td>Adults with Bilateral Deafness</td>
<td>Sandra Prentiss PhD</td>
<td>March 2</td>
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<tr>
<td>Children with Bilateral Deafness</td>
<td>Andrea Warner-Czyz PhD</td>
<td>March 9</td>
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<td>Adults with SSD or Asymmetric Hearing Loss</td>
<td>Margaret Dillon AuD</td>
<td>March 16</td>
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<td>Matthew Carlson MD</td>
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<td>Children with SSD or Asymmetric Hearing Loss</td>
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Information on sign-up for the AudiologyOnline webinars will be shared soon.
ACI Alliance is proud to support the upcoming film, Rally Caps, scheduled to open in Spring 2022 to coincide with Major League Baseball’s Opening Day. The film is based on the book written by Jodi Michelle Cutler and Stephen J. Cutler, inspired by Jodi’s experience as a mother of a son with profound bilateral sensorineural hearing loss and a cochlear implant.

The film features a young baseball player who has his dreams of pitching for a little league travel team derailed by a devastating injury on the field. After a long recovery process, he goes off to sleep-away camp where he befriends a deaf catcher who helps him overcome his fear of returning to the mound. We believe Rally Caps is a great story. But we are supportive of the rollout because we believe it will increase awareness of cochlear implants to a broad audience in a way that normalizes CI as a part of a character’s story, rather than making a character’s deafness the story. In early 2022, we will contact ACI Alliance organizational members with information on exciting ways to support Rally Caps with sponsored awareness events at baseball stadiums around the country. ACI Alliance is proud to be listed on the film’s website as a resource on cochlear implants.

Top 2021 ACI Alliance Resources for Awareness and Advocacy
Over the past year, we worked collaboratively to raise awareness on, and support advocacy to advance access to cochlear implants. Here are our top five resource picks.

The Incredible Hulk Gets a CI
In February, actor and bodybuilder Lou Ferrigno, popularly known as The Incredible Hulk, received a cochlear implant. In this conversation with ACI Alliance Executive Director Donna Sorkin, Lou thoughtfully discussed the challenges of his lifelong hearing loss and why he went forward with a cochlear implant at age 69.

Advocacy Toolkit
ACI Alliance provides support to our professional, consumer, and parent members to support their involvement in state and national advocacy. We developed and published the Advocacy Toolkit, bringing together our collective experience and knowledge in one place to help our members advance public policy on CI.

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Sound of Metal
Released in late 2020, this feature film included extensive misinformation on the cochlear implant process. ACI Alliance addressed our members’ issues with the film’s inaccuracies with editorials, interviews with the various media sources, and a Dr. Radio podcast led by a CI surgeon.

Cochlear Implant Patient and Advocate Stories
We are grateful to the patients, parents and advocates who reach out to us throughout the year and generously share their stories. By using our platform to amplify their stories, it is our hope that others who may benefit from a CI might see parallels to their own journey and feel emboldened to move forward.

Cochlear Implants, Awareness, and Disability: An All Americas Perspective
In this series of six videos, five adults from the US and Brazil (each associated with cochlear implants in different ways), discuss benefits, challenges, and lessons learned.
Meet the ACI Alliance Board of Directors

John Dornhoffer MD
I am currently Professor and Chair of the Department of Otolaryngology—Head and Neck Surgery at the University of Arkansas for Medical Sciences (UAMS) in Little Rock, Arkansas. Additionally, I also hold the James Y. Suen Endowed Chair in Otolaryngology and am Director of the Division of Otology and Neurotology at UAMS and Arkansas Children's Hospital, and serve as the Executive Director of the Prosper Meniere Society. I graduated from the University of Kansas School of Medicine and did my residency training in Otolaryngology—Head and Neck Surgery at the University of Arkansas for Medical Sciences and completed Otology/Neurotology fellowships in Germany and Switzerland.

Of particular interest, I am a cochlear implant surgeon with a cochlear implant. I have an autosomal dominant, progressive sensorineural hearing loss that was diagnosed when I was a young child. Fortunately, normal speech development was possible for me. However, as time went on, my high frequency hearing diminished to the point that even the strongest hearing aids were of little help. By the age of 50, I was understanding speech with only low tones remaining in both ears (250 Hz and 500 Hz), corresponding to vowel sounds. I knew it was time to consider getting a cochlear implant when I realized that the patients I was implanting had better hearing than I did. The saga of surgery, programming, and relearning how to hear with an implant has given me valuable insights—especially regarding the neuroplasticity of the human brain—that, I believe, would otherwise be lost to the implant community.

Therefore, I am very passionate about serving on the board of the American Cochlear Implant Alliance as it gives me the opportunity to increase public awareness about cochlear implants, including insurance coverage, and facilitate research on all aspects of implantation.

Andrea Warner-Czyz PhD
I first learned about cochlear implants in the mid-1990s and started examining early speech production outcomes in young children with cochlear implants as a doctoral student soon thereafter. Now, as an Associate Professor in the Department of Speech, Language, and Hearing at The University of Texas at Dallas, my research continues to focus on the effect of hearing loss on communication skills, social interactions, and quality of life in infants, children, and adolescents who use hearing aids and cochlear implants.

My programmatic research always has embraced an interdisciplinary approach, drawing on not only my own training in audiology, but also the adjacent fields of speech-language pathology, psychology, and otolaryngology. This likely explains my desire to serve on our American Cochlear Implant Alliance Board. I appreciate the open conversations among various professionals from clinic and research on the Board and within our organization, which has influenced how I frame both my research and my teaching.

Serving on the Board also has afforded opportunities to develop new skills such as writing guidelines and policies. For example, I collaborated with a diverse group to generate contemporary guidelines on pediatric cochlear implant candidacy, which we hope will increase the referral of children who are deaf or hard of hearing who could potentially benefit from this auditory technology. Finally, and perhaps most importantly, I feel grateful to work closely with colleagues and friends who share a passion to contribute meaningfully to the organization and the cochlear implant field to benefit clinicians, researchers, patients, and their families.

Barbara Mellert MPH
Parent and family advocate Barbara Mellert joined the ACI Alliance Board of Directors in 2021. Read her inspirational story “Advocating for Your Cochlear Implant Child: It’s not just about the IEP.”
Jennifer Pinney

Jennifer Pinney is a parent member of the ACI Alliance CI CAN network and actively advocates for insurance coverage for hearing implants.

Our daughter Abigail fell from a hammock in June of 2020 when she was almost 2. She fractured her temporal bone causing single sided deafness (SSD). After discovering the SSD several months later, we were referred to a clinic to explore the possibility of a cochlear implant (CI), where it was recommended that we move ahead with a CI.

Unfortunately, we were denied insurance coverage for the cochlear implant. We were insured under a self-funded plan through my husband’s employer that included specific language that excludes cochlear implants for SSD. The insurance plan is written through UMR which is a division of United Healthcare.

We appealed to our insurance company as well as my husband’s employer asking for a special consideration, but both avenues were denied. We were determined to help Abigail even if we had to self-fund the CI, so we asked about the out-of-pocket cost. We got in touch with Hearts for Hearing in Oklahoma, where the staff were competent, kind, and very helpful to us. They referred us to Dr. Stanley Baker, a CI surgeon in Oklahoma, who was able to help us manage the out-of-pocket cost and performed the surgery. Hearts for Hearing was also helpful in lowering the cost of the aftercare, including costs associated with Abigail’s activation day and programming. Our daughter was implanted on August 11, 2021 and activated August 20, 2021.

We are grateful for the generosity of everyone at Hearts for Hearing and to Dr. Baker. Despite their generosity, the insurance denial meant using a significant portion of our family savings, getting a 401k loan, and seeking additional help from charity to help fund Abigail’s implant. The financial stress that this caused had a significant impact on our family.

Just a month after activation, Abigail’s cochlear implant had already changed our lives. Abigail is in a much better mood after school every day as she is no longer experiencing the listening fatigue that she had been struggling with. We also notice that she can hear where sounds are coming from significantly better than before, and that she is also responding to us better.

We chose to implant our daughter after hearing that up to 30% of children with single sided deafness (or even lesser levels of hearing loss) and don’t receive appropriate follow-up support, repeat a grade by the 3rd grade. We did not want her hearing loss to impact her ability to learn in the classroom. We also felt that sound directionality was very important because before the implant, we noticed that when a neighbor turned on their car, she would often look in the opposite direction to see where the noise was coming from. As a safety issue, this was hugely concerning for us as parents.

We are thankful to have this procedure behind us. We chose to share our story because we want to help other families who are advocating for their own children with hearing loss. This process was one of the hardest things we have gone through as a family—to know that we were fully insured and yet to determine that our insurance did not cover our child for something as critical as hearing.
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