MESSAGE FROM THE CHAIR

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Expanding indications for cochlear implantation is a hot topic right now, not only in the US but in many countries around the world. Over the past few months, I’ve traveled to four continents to discuss cochlear implant access including expanding indications. Most recently, I attended the Asia Pacific Symposium on Cochlear Implants (APSCI) 2019 Conference in Tokyo over Thanksgiving week. I quickly realized that we have a lot of work to do in the US in this area.

While at APSCI, I served on a panel of 8 clinicians from 8 countries. Each of us presented our current CI candidacy criteria. As you may imagine, many of the audience members were surprised to learn that the US is not the world leader in expanding indications for cochlear implants. Not only has pediatric candidacy remained relatively unchanged since 2010 (with the exception of single-sided deafness) but adult candidacy in the US is more restrictive than that in other countries around the world. The US CI utilization rate has not grown the way one would expect—thus our efforts to improve CI access through awareness and education must be expanded.

The overarching theme for CI2020 International, our conference in March, is timely and will provide a unique opportunity for us to learn from each other and from our colleagues around the world. I, for one, am excited to see what the future holds in this area.

Leo Tolstoy said, “Everyone thinks of changing the world, but no one thinks of changing himself.” I urge each of you to think about what you can personally do to contribute to this important topic. We have a lot of work to do, friends! ■
The planning is over and we’re ready for you. Our CI2020 Scientific Chairs have assembled an exciting and robust program, offering a variety of keynote lectures, panel discussions, and podium and poster presentations discussing research on cochlear implant and other implantable technologies across the age continuum. The final program with listed titles and speakers is now posted: https://www.acialliance.org/page/CI2020

What’s new in Orlando?
• A first ever focus on expanding indications for cochlear implants in children and adults
• More keynotes (SIX! Plus the John Niparko Memorial Lecture)
• (Re)Habilitation Connect Forum. From Data to Delivery: Implementing Research-Based Intervention. An afternoon concurrent session devoted entirely to pediatric and adolescent topics plus Continue the Conversation reception. The full (Re)Hab Connect Forum program is published on the website: https://www.acialliance.org/page/CI2020
• More interactive sessions and more time devoted to discussion
• Inductive loop assistive listening in main ballroom to enhance listening for attendees with hearing loss
• Climbing the Ladder to Success: Audiology Professional Development. This panel discussion of CI audiology experts will discuss their stories of professional development and answer questions. There will be opportunities for mentors and mentees to connect.
CI2020  continued from page 2

What hasn't changed that you're looking for?

• Superlative speakers from around the globe and across the continuum of care
• Interactive opportunities before, during and after presentations
• Exhibit hall with products and services you care about
• Poster session—all in one place with poster highlights for a limited number of sessions immediately before
• A fantastic reception on Thursday night to engage and party with your colleagues
• Breakfast satellite sessions each morning with talks by our industry partners
• Wednesday afternoon satellite sessions given by our industry partners
• Captioning at every conference session including all concurrent sessions
• Continuing Education Credits. Specific hours to be provided for each continuing education program provider will depend upon the final conference program.

A similar educational program was offered at the CI2019 Pediatric Symposium and the hours provided were:

• AAA: Up to 2.15 CEUs/1.40 Tier 1 CEUs
• ASHA: Up to 2.15 ASHA CEUs
• AG Bell: Up to 21.5 LSLS CEUs
• ACS: Up to 14.00 AMA PRA Category 1 Credits

The John Niparko Memorial Lecture will be given by Konstantina Stankovic, MD, PhD on degeneration and regeneration of the inner ear. Dr. Stankovic is Chief, Division of Otology and Neurotology and Director of the Molecular Neurotology and Biotechnology Lab at Massachusetts Eye and Ear Infirmary, Harvard University. continued on page 4
Division of Otology and Neurotology and Director of the Molecular Neurotology and Biotechnology Lab at Massachusetts Eye and Ear Infirmary, Harvard University.

Six additional Keynote Speakers will speak:

Oliver Adunka, MD (USA) on electric-acoustic stimulation in adult cochlear implant recipients
Matthew Carlson, MD (USA) on early cochlear implantation in children
Teresa Ching, PhD (Australia) on language development in pediatric cochlear implant recipients
Bruce Gantz, MD (USA) on measures beyond those conducted in the sound booth to assess the effectiveness of cochlear implant use
René Gifford, PhD (USA) on bimodal and bilateral cochlear implantation
Paul van de Heyning, MD, PhD (Belgium) on cognition and cochlear implantation

Thank you to our CI2020 Scientific Program Chairs

University of North Carolina School of Medicine:
Kevin D. Brown MD/PhD, Associate Professor & Chief of Division of Otology, Medical Director Children’s Cochlear Implant Center
Margaret Dillon AuD, Research Associate Professor, Director of Cochlear Implant Clinical Research
Harold C. Pillsbury III MD, Emeritus Chair, Department of Otolaryngology – Head and Neck Surgery and Neurosurgery

CI2020 in Orlando

Registration


Discount Rates for Members
CI2020 Member Discount Codes were mailed to each Member Organization’s point of contact or directly to professional members. If you need your code, contact Jessica Houk at jhouk@acialliance.org.

Hotel
Book your stay at the Hyatt Regency Orlando, an iconic hotel in the heart of everything Orlando has to offer. All conferences/events will be held at the Hyatt. Space is limited and reservations received after February 17 or after the block fills, are subject to availability. http://ci2020orlando.org/site/index.php/hotel-travel/headquarters-hotel

Travel Discounts

More details on the conference website: www.CI2020orlando.org
MRI examinations can be stressful, but they are common and a necessary part of life. At Advanced Bionics we believe that MRI procedures should be hassle free for all cochlear implant patients. That is why we developed the HiRes™ Ultra 3D cochlear implant, which is compatible with 3.0 Tesla MRI with the multi-magnet assembly left in place.

AdvancedBionics.com
Please contact your AB representative for availability in your area.
ACI Alliance Participates in First WHO World Hearing Forum

Donna L. Sorkin MA, Executive Director, ACI Alliance

On December 4–5, 2019, I joined hearing health advocates from around the world at the first World Hearing Forum in Geneva. The aim of the forum is to promote and support action for hearing care through global advocacy and to provide a platform where stakeholders can work together in a cohesive manner to achieve the goal of accessible hearing care for all. It was exciting to work with colleagues from the United States and around the globe on this worthy effort. I was particularly interested in the potential benefit of having an important and highly regarded organization—the World Health Organization—focusing on hearing healthcare.

The Forum will: issue a report on key hearing priorities, involve well-known individuals as champions to increase attention to hearing health, promote its agenda during World Hearing Day, and take steps to make listening safe. ACI Alliance Members participated in the World Hearing Forum as key contributors. Among the participants were: Blake Wilson (Duke), James Saunders (Dartmouth and Coalition for Global Hearing Health), Patrick D’haese (MED-EL, Austria) and Julie Ligeti (Cochlear Ltd, Australia).

ACI Alliance Member Joanne Travers Coaches Parents

We are pleased to recognize the work of a member working in the international arena. Joanne Travers is the founder of Partners for a Greater Voice www.greatervoice.com, which provides coaching to empower caregivers of children with hearing loss. Joanne and her volunteers have conducted parent programs around the world. She will join us in Orlando as a podium presenter and with an exhibit hall booth where you will also be able to view and purchase her new book Coaching and Empowering Caregivers of Children with Hearing Loss: An Approach to Foster Well-Being.
Introducing the Cochlear™ Nucleus® Profile™ Plus with Slim Modiolar Electrode (CI632)

- MRI at 1.5T and 3.0T\(^1\) without head wrap or magnet removal\(^1\)
- Thin implant design for natural and low-profile appearance\(^2\)
- Most reliable cochlear implant\(^3,4,5\)
- Improved hearing performance with close proximity to the modiolus\(^6\)
- Focused stimulation of hearing nerve
- Ultra-slim and atraumatic electrode

Cochlear Delivers the Complete Solution

Profile Plus is available with Slim Modiolar (CI632), Slim Straight (CI622) and Contour Advance (CI612) electrode arrays.

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1. MRI Guidelines D774756

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The ACI Alliance State Champions Program drives our organizational advocacy efforts. Our State Champions are clinicians, educators, parents, and consumers who have direct knowledge and experience with key issues that impact on cochlear implant access and awareness. The early concerns about the consequences of state LEAD-K legislation led us to actively oppose these state bills and organize a multi-organizational Parent Choice alliance, which has been critical to our overall success. Other topics that were identified by our State Champions were Medicaid service restrictions such as therapy caps and reimbursement for surgery and services under Medicaid, and veterans’ access to cochlear implantation via the VA health care system.

Our State Champions urged us to add a new initiative: advocacy and awareness related to the Cytomegalovirus (CMV) and its impact on hearing loss in children. Encouraged by the Board of Directors, we are moving forward to explore how we might positively impact national and state awareness about the effect of congenital CMV on incidence of hearing loss in infants. We are in contact with the National CMV Foundation (which is exhibiting at our upcoming conference) regarding how we might collaborate.

Incidence of CMV Exposure in Newborns
CMV affects approximately 1 in every 200 births in the United States and it is the most common cause of non-hereditary hearing loss, responsible for hearing loss in 1 in 5 hearing-impaired children with no other known risk factor or cause. Hearing loss related to CMV may not be present at birth, but rather delayed in onset, in which case it is typically missed by newborn hearing screening. CMV related hearing loss may fluctuate or progress during childhood.

Of infants who have symptomatic congenital CMV, 32.8% will also have or develop hearing loss. Of those who do not have symptoms at birth, an estimated 10% develop hearing loss. There is variability in studies regarding incidence of hearing loss developing, with some indicating as many as 65% of children exposed to CMV will develop hearing loss. The level of hearing loss varies. One estimate is that 2% of children with asymptomatic CMV develop hearing loss severe enough to meet cochlear implant candidacy criteria.

Currently, there is no federal legislation encouraging CMV education or screening and few national research studies. Twelve states have screening or educational laws in place. Typically screening for CMV is conducted after an infant has failed an initial hearing screening. There is no consensus over the most effective method of testing (i.e., blood or urine testing).

Advocacy Goals
Our advocacy goal is to provide guidance to those who wish to advocate for state laws for screening and/or education on the virus. Screening might be part of universal screening at birth or after a failed hearing screening. We hope to increase the number of infants properly diagnosed so that the appropriate intervention and support systems can be implemented as rapidly as possible. As any associated hearing loss is gradual, knowing one’s child had CMV may help parents understand the need for ongoing hearing testing.

We will also strive to raise the level of conversation at the national level including encouraging research on when and how to administer anti-viral drugs for infants identified as having been exposed to CMV. There is some evidence that anti-viral drugs can halt onset of hearing loss though there is no accepted practice on this approach.

To accomplish our efforts, we will need advocates willing to engage with state officials to urge for appropriate legislative options in states. Please contact me at nwestin@acialliance.org if you are interested in becoming a State Champion and working on CMV advocacy.
For the first time, candidates with unilateral hearing loss have an approved option for restoring binaural hearing.

Benefits of binaural hearing with MED-EL cochlear implants:

- Improved speech perception in noise
- Increased sense of spatial awareness or “hearing in stereo”
- Better localization of speech and other environmental sounds
- Reduction in fatigue from listening effort
- Greater participation in social and work activities

Connect with a MED-EL representative to learn more about cochlear implants for SSD:

go.medel.com/ssd-us

*Fine structure coding is not indicated for pre-lingual children in the USA. For information on potential risks and contraindications relating to implantation, please visit www.medel.com/us/isi
A CONSUMER’S PERSPECTIVE

Deaf Pride

Beverly Biderman

Beverly Biderman is a writer living in Toronto. She is a past Chair of the Board of the Canadian Hearing Society, and the author of Wired for Sound: A Journey into Hearing (rev. 2016). Her memoir is the basis for a new opera developed by Carlos Alberto Augusto, “On the Threshold of the Outside World.”

Cochlear implants have become a potent tool in the fight against the pernicious stigma of deafness. Not just against deafness, but the stigma as well.

When I was growing up in the 1950s and 60s, profoundly deaf, I tried to pass as hearing. I was ashamed of my deafness. Mainstreamed with a profound hearing loss, I would bluff, and try to fake it. But now, many years later, instead of ashamed, I am proud to have coped with such a severe disability. I am open about my hearing loss, unashamed.

What has happened in the intervening years? The answer is the life changing technology of cochlear implants. This technology has given me and others a foot up so we can thrive with more ease in a hearing milieu. When I tried to pass in that milieu, the stress was so crushing, the support so absent, that I recall scouring the shelves of my local drugstore for “nerve pills.” I did not know how to advocate on my own behalf, how to ask for the accommodations I needed. My hearing loss was a burden I bore alone in silence, at great personal cost.

That all changed when I received my first cochlear implant in 1993. People were curious about this new technology; they asked questions; they were happy to help me in this amazing adventure in learning to hear. Importantly, I learned how to ask for help. The burden of deafness was not mine alone to bear; I could openly share it.

After the essay at the link below was published in a Canadian newspaper and posted on Facebook, I received a flood of replies that indicated many other cochlear implant recipients and their families had experienced the same change. They felt more open about their deafness and more supported. They told me my story was theirs too. The stigma of deafness has met a powerful foe in cochlear implant technology.

The burden of deafness was not mine alone to bear: I could openly share it.

I have learned from responses to my essay that teenage boys shave their heads to better display the proud markers of their bionic hearing. Cochlear implants are considered “cool.” I have been told that girls proudly affix their receivers on top of their hair rather than hidden beneath it. Parents told me that their children are learning to advocate on their own behalf, and to explain their hearing technology anew each year to their teachers. All this has been gratifying.

I have also heard from people with other disabilities that they have learned that honesty and openness about their disability helps them to thrive. As one correspondent with epilepsy and ADHD said, “You carry everything you’re dealt in life with more strength and acceptance when you’re open about it.”

Amen to that.

https://ottawacitizen.com/opinion/columnists/biderman-learning-not-to-hide-a-disability-was-the-best-lesson-of-all
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