



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

Calling

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Donna L. Sorkin, *Editor*

CI 2015 DC Emerging Issues Symposium Brings Together Cochlear Implant Clinicians and Scientists

Donna L. Sorkin, MA, *Executive Director, ACI Alliance*



The upcoming CI Symposium will explore recent research and clinical guidance on topics that are changing our field through expanded indications and improved patient outcomes. An overriding symposium theme is serving a broader population of children and adults than ever before. ABIs, hearing preservation in cochlear implantation, and CI in single-sided deafness will be examined. Improving outcomes in children and adults will be discussed from the perspective of medical/surgical, audiological, therapeutic and educational approaches.

Six emerging issues will receive special focus; the specifics of each, including the speakers and talk titles, are on the conference website at www.CI2015dc.org under **Emerging Issues**. In addition, we received many exciting podium and poster submissions from clinicians and scientists from the US and around the world on broad-ranging CI topics. The podium and poster sessions will be featured each afternoon of the conference and after the Saturday morning plenary. We have included more time for discussion panels and audience participation throughout the 2½ days. Interactive

twilight sessions on difficult cases will be organized for surgeons, audiologists, and speech pathologists/educators. Details on these afternoon sessions will be posted soon.



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Donna L Sorkin, MA, Ex Officio Board Member
Executive Director

CI 2015 EMERGING ISSUES SYMPOSIUM *continued from page 1*

A freewheeling, interdisciplinary discussion on **Hearing Restoration and Neuroscience** will feature three distinguished scientists whose seminal work on cochlear implants intersects brain science topics. David Pisoni, Blake Wilson and Fan-Gang Zeng will participate in the Saturday morning Synergy event. This unique feature will be moderated by technology pioneer Vinton Cerf, widely known as one of the "Fathers of the Internet." Dr. Cerf has received numerous honors from countries around the world, including the Presidential Medal of Freedom—the highest civilian award in America. He has a personal interest in this topic; his wife Sigrid was deafened in childhood and has bilateral cochlear implants.

ACI Alliance on the Hill will be held on Wednesday beginning with a briefing and brunch for participants at 11:30 AM. After the briefing, advocates will be taken to Capitol Hill in buses. ACI Alliance on the Hill is limited to 150 member advocates and pre-registration is required. We will hold one pre-conference telephone briefing approximately two weeks in advance of the conference. Those who participated in 2013 are encouraged to sign up again; we will arrange for you to revisit some of the same offices, helping to strengthen relationships. All preparations will be made for participants by our ACI Alliance public affairs consultants. For more information, please review the article by Peter Thomas and Sara Rosta on page 3.

Each morning at 7:30 AM, Sponsor Breakfast Symposia will be held on topics that are specific to each company's technology. CEUs will be offered. Attendees are asked to sign up as part of registration so that we may plan for attendance.

A unique after-conference program is offered. You won't want to miss out on a private visit to The River School and a VIP tour of the limited exhibit *Hear My Voice: Alexander Graham Bell and the Origins of Recorded Sound* at the Smithsonian National Museum of American History.

Details on all of the above are available on the conference website at www.CI2015dc as well as on our ACI Alliance site www.ACIAAlliance.org.

Early registration rates for CI2015 DC end August 21. Individuals who are Professional or Organizational Members at the time of the conference will receive a considerable discount on conference registration. Don't miss this most extraordinary cochlear implant gathering! ■



The Importance of Advocacy to Advance ACI Alliance's Goals

Peter Thomas, JD and Sara Rosta, MA, *Government Affairs Counsel to the ACI Alliance, Powers, Pyles, Sutter & Verville PC*

ACI Alliance on the Hill will serve as an opportunity for cochlear implant clinicians, scientists and consumers to educate Congressional offices on the importance and implications of the CI intervention. Attendees as well as consumer and parent members are strongly encouraged to take part in this organized advocacy effort. We request participation from professional members of ACI Alliance, who are involved in the provision or study of cochlear implantation as a physician, audiologist, speech pathologist, other clinical provider, educator, or researcher. We also strongly encourage consumer/parent ACI Alliance members to be a part of the advocacy day.

ACI Alliance and its Washington counsel will make participation in this advocacy effort as easy as possible. We will arrange all House and Senate office meetings for participants and will group participants with other individuals from the same state. Materials and key messages, including meeting talking points, will be developed for participants. Additionally, advocates who can directly reference their own experience with cochlear implantation during meetings will be most effective, regardless of whether one is speaking from the standpoint of a provider or a consumer. Personal stories with respect to the impact of the CI intervention are an important component of increasing the knowledge of Congressional offices on this subject.

The importance of advocacy during **ACI Alliance on the Hill** cannot be overstated. Making connections with Congressional offices and developing relationships with Members of Congress who may champion the CI intervention is essential. The disability community recently lost a major champion, when Senator Harkin (D-IA) retired from Congress last year. Senator Harkin, known for his work on disability rights, including authoring the Americans with Disabilities Act (ADA), sponsoring reauthorizations of the Individuals with Disabilities Education Act (IDEA), as well as being a strong proponent of the Affordable Care Act, served in Congress for several decades and led the Senate Health, Education, Labor, and Pensions (HELP) Committee as Chairman. As such, he advanced many favorable policies for the disability community and, in particular, people with hearing loss, due to his personal investment and understanding of hearing issues because of his brother, Frank's, deafness.

ACI Alliance seeks to build strong ties with Members in both the House and Senate, as well as identify new champions in the disability policy world in terms of hearing health, early intervention, and access to care. In particular, developing Congressional champions that have a personal tie to hearing impairment or the CI intervention is a high priority, whether their experience is first-hand, that of a loved



one, or of a constituent. It is tremendously helpful to have a Representative or Senator deeply care about the issues that we hold dear. Such champions can lead our cause in seeking to advance favorable legislation, and also defend our community when adverse policies are considered.

Congressional champions are not developed easily. We must seek to establish strong personal relationships with many offices in both the House and Senate, keeping in mind that a crucial element in doing so is repeatedly reaching out to your Members of Congress on the issues you care about—the issues of greatest priority to the ACI Alliance. Over time, we can increase the familiarity and knowledge of the CI intervention on Capitol Hill by building solid connections with Congressional office and committee staff. The meetings scheduled for the **ACI Alliance on the Hill** will continue to lay the groundwork for development of long-lasting and effective relations with Congress. For those who participated in the initial ACI Alliance on the Hill in 2013, going back to offices you visited then will be particularly helpful.

Your role in the face-to-face advocacy on October 14 is extremely important. As a community, we must engage with policymakers to effectuate the changes we wish to see. Participate in **ACI Alliance on the Hill** and continue advocacy efforts throughout the year! ■

US Congressional Member Benefits from Cochlear Implant

John K. Niparko MD, *Tiber Alpert Professor & Chair
Tina and Rick Caruso Dept of Otolaryngology-Head & Neck Surgery,
University of Southern CA
Board of Directors, American Cochlear Implant Alliance*

U.S. Congressman David McKinley's office is wallpapered with the images of those he has served with commitment, with challenges faced and battles won. They attest to the Congressman's take-life-by-the-horns, confident style. His dedication to his district and country is clear.

Against that background, I was somewhat surprised by his first comment, "Looking back, without this implant, I didn't know where I was headed." His words evinced the difficulties faced by many with severe to profound hearing loss in America—a future that you and I are trying to brighten.

In early July, Donna Sorkin and I had the opportunity to meet with Congressman McKinley. As a bimodal (HA + CI) listener, he reflected on his 2½ year experience with hearing provided by his cochlear implant.

Congressman McKinley recounted the deep concerns brought on by his progressive hearing loss, the threats that it posed, and how he decided he needed to directly address the circumstances of his hearing loss. In typical fashion, he immediately took to the challenge.

Indeed, he now seems to know where he and his West Virginian constituency are headed. In times that demand bold decision-making and innovative thinking on healthcare, energy and economic policy, it has become all the more important that he maintain his connectivity in listening to others, across meeting tables, restaurants, the House Chambers, and while driving through West Virginia's "Almost Heaven" mountain passes while conferencing calling in his car. With his implant he rarely misses anything now.

We reviewed with Congressman McKinley national data that support American Cochlear Implant Alliance's primary aims—findings that demonstrate constraints in access to implants and disparities in the support of services that facilitate spoken communication after cochlear implantation. He offered guidance in making our message clear and forceful. He also offered strategies for us to bring legislative remedies to those areas of immense, unmet need in access to services and devices.

This Congressman has restored his powerful talent to communicate, and knows well the importance of access to effective hearing. This man of the people is a powerful spokesperson and champion. In classic McKinley fashion, he's determined to use his own experience to shape a brighter future for Americans who face the stony path he has taken. With us, he intends to help smooth the way. ■



John K. Niparko MD with U.S. Congressman David McKinley

Update on CMS Study to Explore Expansion of CI Criteria for Medicare Beneficiaries

Teresa Zwolan, PhD, Director, University of Michigan Cochlear Implant Program



ACI Alliance is sponsoring a study to investigate expansion of CI candidacy criteria used by the Centers for Medicare and Medicaid Services (CMS).

To date, 10 subjects have undergone baseline testing, 3 subjects have been implanted, and 1 subject has met the 6-month mark for data collection. Patients have begun to contact us directly regarding possible participation as there is great interest in the study.

Please consider referring candidates who do not meet traditional Medicare criteria for inclusion in this study. If you refer a patient to a participating center and they are accepted into the study, we will co-manage the patient with you and transfer his/her care back to your center following completion of the study 1 year post-activation.

This study is needed because many Medicare beneficiaries who meet FDA indications are unable to receive a cochlear implant. Presently, CMS limits candidacy to those who have test scores of less than or equal to 40% correct in best-aided listening condition on tape-recorded tests of open-set sentence recognition. If included in this study, patients may score up to 60% correct on HINT sentences. As a Coverage with Evidence Development (CED), this study may result in an expansion of CMS cochlear implant criteria.

Inclusion criteria for the study are:

- 65 years of age or older
- Bilateral moderate-to-profound sensorineural hearing loss in the low frequencies (up to 1000 Hz) and profound sensorineural hearing loss in the high frequencies (3000 Hz and above)
- Best aided sentence score in quiet between 40 – 60% correct on recorded HINT sentences
- Scores on above exceed current Medicare guideline of less than 40% on recorded sentences
- Spoken English as primary language
- Cognitive ability to use auditory clues and willingness to undergo rehabilitation
- Freedom from middle ear infection and acoustic areas of the central nervous system
- No medical contraindications for surgery

Ten centers are involved:

- University of Michigan
- University of Iowa
- Johns Hopkins University
- University of Miami
- New York University School of Medicine
- University of North Carolina
- University of Southern California
- Vanderbilt University
- University of Washington
- Washington University School of Medicine

Activities are underway to increase awareness about this study:

- Study is registered on clinicaltrials.gov: <https://clinicaltrials.gov/ct2/show/NCT02075229>
- Donna Sorkin and Terry Zwolan presented on the study at the Hearing Loss Association of America (HLAA) conference in St. Louis in June 2015
- Terry Zwolan and Donna Sorkin gave an Audiology Online webinar for professionals in May 2015 as a means to inform professionals about the study and encourage clinicians to refer appropriate patients
- Study will be discussed in an upcoming article to appear in *The Hearing Journal*
- Craig Buchman, Amy McConkey Robbins, Terry Zwolan and Donna Sorkin will present on cochlear implant candidacy at the 2015 ASHA Convention in Denver

For information, please contact Donna Sorkin (dsorkin@acialliance.org) or Terry Zwolan (Zwolan@umich.edu). ■



AMERICAN COCHLEAR IMPLANT ALLIANCE

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ACI Alliance Member Center

ACI Alliance Governance

We would like to give special thanks to Teresa Caraway for her leadership as the organization's first chair of the Nominations Committee and to Katherine Wilson, Rene' Gifford, and Susan Waltzman for their service on this committee. The work of these dedicated professionals helped shape the current structure and content of our Board of Directors. Terry Zwolan has taken over as Chair of the Nominations Committee. She is working with ACI Alliance members to form a new Nominations Committee. This committee works to ensure Board membership includes a variety of members with consideration given to achieving board diversity in areas of expertise; we want our board to reflect our membership and include surgeons, audiologists, speech pathologists, educators, parents, and recipients and to also achieve diversity in terms of gender and geographic location.

This committee will work to identify three new members for the ACI Alliance Board of Directors. ACI Alliance members will have the opportunity to vote to approve the slate of new board members during the Member Meeting on October 16 at the CI 2015 Symposium in Washington, D.C. Individuals who wish to suggest individuals for board service may self nominate or nominate others by writing to Terry Zwolan (Zwolan@umich.edu). ■



We are very excited to be co-organizing the upcoming *14th International Symposium on Cochlear Implants and Other Implantable Technologies*, May 11-14, 2016 with the University of Toronto, Sunnybrook Health Sciences.

This meeting is held in North America every four years. Visit our website www.CI2016toronto.org and reserve the date. ■

ACI Alliance Member Directory: Connecting with Your CI Peers

Susan Thomas, MA, *Outreach Director/CE Coordinator, ACI Alliance*



Are you taking full advantage of the benefits associated with being an ACI Alliance Professional or Organizational Member? Likely you know that your Professional or Organizational Membership allows you a significant discount on conference registration. But are you also aware that you have access to an online membership directory that offers valuable networking opportunities? Did you know that you could post job openings for a nominal fee as a Professional Member or for free if you are an Organizational Member? Have you checked out the blog postings on CI2015 DC or visited our Members Share blog?

Organizational Membership allows member institutions to register up to ten individuals for the conference at the member rate though the directory listing is open to an unlimited number of individuals associated with the institution. An important benefit of the Organizational Membership is that the link to listings is open access and highlighted on the homepage of our website under "Find ACI Alliance Organizations" making this an important marketing opportunity for your clinic, school, or university program. Primary care physicians are now referring patients to CI centers listed as Organizations on our website.

Keeping in touch with peers through our online professional membership directory is an important benefit of membership. The directory contains a listing of names, titles, addresses, and contact information for ACI Alliance Professional and Organizational members. Using the directory, professional members may search for other members by name, organization, or location. You can make yourself available as an expert, or find others who are working in similar fields. It's unique as a referral source. Please help enhance the value of this database by updating the information in your membership profile. You can even include a photo.

Our Consumer members have played an important role in ACI Alliance, contributing importantly to our advocacy work. Consumers and parents helped to expand the number of sponsors for the pending Early Intervention legislation and also advocated to retain coverage of Osseointegrated Implants under Medicare last year. Our partnership with Hearing Loss Association of America (HLAA), the consumer organization for adults with hearing loss, has helped expand interest in the CED to examine expanded coverage for adults under Medicare. Consumer involvement in ACI Alliance is an important element of our efforts to expand cochlear implant access and awareness. ■

Organizational Member Listing

INDIANA EAR

Profile Pages More Message Connect

Wall Bio

Last updated: 3/9/2015

Indiana Ear
Organization
ssilva@indianaear.com

PHOTOS

ORGANIZATION INFORMATION

Indiana Ear 260 3875820 (Phone)
9604 Coldwater Road Suite 101 260 7556235 (Fax)
Fort Wayne
United States
46825 United States
[Map]

Description: Indiana Ear is northern Indiana's only dedicated ear subspecialty clinic offering medical, surgical, and rehabilitative care for ear disorders and hearing loss. Dr. Michael Dishser, Neurotologist/Otologist, is the region's only cochlear implant surgeon - offering Cochlear Implant and Hybrid surgical services in northern Indiana and northwest Ohio.

Main Contact(s): Sarah Silva - Practice Administrator & Cochlear Implant Coordinator

Individual Professional Member Listing

SAPHEARA BY MARVEL

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Sapheara by Marvel
Professional
sthomas@acialliance.org

PROFESSIONAL INFORMATION

The Children's Hearing Center
Super Hero

Profession: Education

PERSONAL INFORMATION

New York
New York
United States

Birthday: 10/18/2014

ADDITIONAL INFORMATION

MORE INFORMATION

I have bilateral cochlear implants. My superpower is my gem necklace. The necklace provides a light source that protects against danger. I work with The Blue Ear and Iron Man to combat bullying, hearing loss, and more.

Thank you to the Children's Hearing Institute for taking the initiative in sponsoring Sapheara and Marvel Entertainment for creating such an engaging role model for kids with cochlear implants.



Begin Your Online Shopping on Our Website

A AmazonSmile is a website operated by Amazon that provides the same shopping features as the main site. When you begin on AmazonSmile, you have the opportunity for the Amazon Foundation to donate 0.5% of your total purchase to support our work. There is no difference in pricing. We have placed the link on our homepage. You can also reach the site directly by keying in AmazonSmile (instead of Amazon) and then designating American Cochlear Implant Alliance Foundation as the donation recipient. ■



Back Issues of ACI Alliance Calling

We have many requests for past issues of our e-magazine. These are available open access under the Member Center tab on the homepage of our website www.acialliance.org. ■

A Consumer's Perspective

Richard Reed, *Rhythm & Blues Musician*

Welcome to the future. Still no flying cars? Ah well. I can't be too disappointed with modern technology. I went deaf at the end of the 20th century, and can hear here in the 21st. My cochlear implant is a time machine that transports me to sounds and songs I thought were lost forever. A few things don't sound like they did before I lost my hearing. How many things don't quite taste, smell, look or feel like they used to? Things change and/or our perceptions change. Our memory goes to work on those perceptions and, hopefully, somewhere along the line we become acclimated. When my fourteen year-old niece gets nostalgic about music, food or school in "the good old days," it's funny to realize she's talking about 2010. Forget the future, the past happens fast. When using a CI at first, that's not such a bad thing. The sooner we get accustomed to this noisy planet, the better.

People ask what things sound like through the CI. I can describe and even imitate activation day. Yes it sounded weird. Imitations and simulations can't capture the more miraculous but mundane-seeming reality of what happened later: most sounds are quite normal now. "That's such an amazing thing," friends say, referring to the CI. So too the brain. Not my brain especially, but everybody's brain. Getting a CI is the first step in a process that should include a reasonable amount of post-activation (re)habilitation. We need to get those synapses snapping. Neuroplasticity is under-appreciated. Spell-check even subjects it to the indignity of the dotted red underline sometimes. Considering all it does for us, neuroplasticity deserves a higher profile, should be at least as well known as crowd-sourcing or virtualization. Hopefully, President Obama's BRAIN Initiative will accomplish for neuroplasticity in America what the ACI Alliance is attempting for CI in research, advocacy and awareness.

As a late-deafened musician, I've got a lot to gain from future CI technologies. Pitch perception is still problematic for CI users, but we haven't let that get in the way of a good time. Music is about more than pitch. It's about more than a lyric, rhythm, chord progression or tone. Any combination of these qualities can add up to a lot more than the sum of its parts. Music only needs to break our hearts in a good way or make us dance. Or both. At first and for quite a while, CI music sounded completely alien. Now, almost 13 years post-activation, it sounds down to Earth again. Like anything worth doing, CI music can be difficult to get right, to do well. We make mistakes. So what? It isn't brain surgery. Some musical mistakes actually end up sounding good. Composers use "happy accidents" all the time.

Sci-fi prognosticators of yesteryear offered scant details as to where we'd park all those flying cars or how to handle extra-terrestrial rush hour with fuel cells running low. The ACI Alliance is working on making the biotech dream of artificial ears (far-fetched just a few years ago) come true for many more Americans. If you're not yet a member of the American Cochlear Implant Alliance, please consider joining. Don't let the CI future start without you. It sounds too cool to miss. ■



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