



AMERICAN COCHLEAR IMPLANT ALLIANCE

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Donna L. Sorkin, Editor

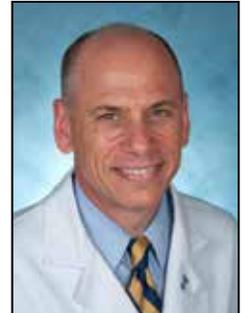
MESSAGE FROM THE CHAIR

Craig B. Buchman, MD, Chair, ACI Alliance

Vice Chairman for Clinical Affairs

Chief, Division of Otolaryngology, Neurotology, Skull Base Surgery

UNC Otolaryngology/Head and Neck Surgery



Happy New Year! As the New Year is upon us, I feel a palpable sense that we are beginning to hit our stride at the American Cochlear Implant Alliance (ACI Alliance). Our Annual Meeting in Nashville last month was a resounding success and a beautiful example of the strength of our organization. Under the leadership of David Haynes, Rene Gifford, Alejandro Rivas, and the Vanderbilt team, nearly 1,100 registrants from the United States and abroad participated in a program that highlighted the breadth of interest in our field.

What I have noticed over the years is that our meetings have evolved. They are no longer about proving that cochlear implants work. Happily, those days are behind us. Rather, we now are seeing compelling presentations on molecular biology of the inner ear, objective measures and stimulation strategies to optimize performance, and the emergence of distance education programs that promise to improve patient outcomes. More amazing is that children and adults with complex additional challenges are now routinely benefitting from cochlear implants. The registrants reported that this was our best meeting ever. We all owe a debt of gratitude to the Vanderbilt team for a job exceedingly well done!

Beyond the meeting, it gives me great pride to report that we are continuing to deliver on our mission to *Advance Access to the gift of Hearing provided by Cochlear Implantation through Research, Advocacy and Awareness*. I invite you to review our strategic plan and accomplishments on our new website (<http://www.acialliance.org>). Some substantive highlights include:

- Enrolling the first patients in a Centers for Medicare and Medicaid Services (CMS)-approved study to broaden candidacy criteria for cochlear implants for individuals

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Message from the Chair

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over age 65; (Details on this study are provided elsewhere in this issue of *Calling*.)

- Active involvement of our State Champions in grass roots advocacy. Based on their analysis of state “Essential Health Benefits,” we have determined that cochlear implants are currently covered by Marketplace Plans under the Affordable Care Act;
- Collaborating with others in the field, ACI Alliance aggressively worked to reverse a CMS-proposed rule that would have eliminated Medicare coverage of Osseointegrated Implants. Our efforts included meeting with elected and appointed officials and submitting detailed comments on why Osseointegrated Implants do not meet the Medicare definition of hearing aids (which are not covered by Medicare).

I feel a renewed sense of energy for what the coming year will bring. Importantly, there will be ripe opportunities for you to get involved. Mark your calendars now for the Emerging Issues in Cochlear Implantation meeting in Washington, DC on Oct 15-17, 2015. Together, we will explore research and clinical implications across the continuum of care for delivering cochlear implants to those in need. We will again feature an advocacy opportunity “ACI Alliance on the Hill” on the day preceding the start of the Symposium. Sign up and we will train you and arrange for you and other advocates to meet with your state’s representatives on Capitol Hill. Together we can provide the message on how our national government can take steps to improve access to cochlear implantation. ■

Make Plans to Attend CI 2015 DC: An Emerging Issues Symposium

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

Building on the success of our recent Nashville conference with Vanderbilt (see page 4) and our first *Emerging Issues Symposium* in October 2013 (<http://www.acialliance.org/?CI2013>) we will convene a second symposium focused on a limited number of topics that may expand candidacy and improve outcomes in appropriate patients on October 15-17, 2015 at the historic and elegant Omni Shoreham Hotel in Washington, DC.

Each of six topics will be explored by a panel of clinician or research experts from across the continuum of care, allowing time for discussion after each set of prepared talks. Based on attendee feedback from the 2013 Symposium, we will also be soliciting submissions for podium talks and posters. The abstract submission website will open on/around March 1, 2015. More information, including details on Registration and hotel accommodations, will be posted on the ACI Alliance website and via Twitter @acialliance. Once active, the conference website will be located at www.CI2015DC.org. There will be a significant conference discount for those who are ACI Alliance professional members, either through their Organization or as Individuals.

The six emerging issues are:

- Auditory Brainstem Implants in Children
- Trends in Objective Measures for Cochlear Implantation
- Expanded Indications for Cochlear Implants
- Quality of Life and Cost-Effectiveness of Cochlear Implantation
- Literacy and Cochlear Implants: Outcomes and Intervention Strategies
- Cochlear Implant Connectivity to Other Technologies

To view the preliminary program, visit our website at: <http://www.acialliance.org/?page=CI2015>

On Wednesday, October 14 just prior to the start of the CI2015 official program, we will again organize ACI Alliance on the Hill. This is an opportunity for our members to visit with their national elected officials. Participants must sign up for this advocacy initiative in advance so that we may group you with others in your state and arrange for visits with Members of Congress. Together with our public affairs consultants, we will hold an on-site luncheon briefing beginning at 12 Noon on Wednesday just prior to leaving by bus for Capitol Hill. Telephone briefings will also be held two weeks prior to the Hill event. Plan now to arrive in Washington in time for this important opportunity to impact on national public policies that affect access to cochlear implantation. ■



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State Champions Meet in Nashville

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

ACI Alliance State Champions met in Nashville to discuss our work, which thus far has largely related to assessing coverage of cochlear implantation under Affordable Care Act Marketplace plans. We also discussed branching out to other topics. Our findings indicate that while Marketplace Plans do cover CI, we have thus far seen few patients come through who are accessing their insurance coverage through the Marketplace Plans. The concerns that we have relate to limitations on the number of therapy sessions available under such plans, which are typically limited to 30 sessions per year—regardless of the age of the patient. Such limits, which are often referred to as “therapy caps,” are increasingly common in private insurance plans as well.

To share our concerns on this topic, ACI Alliance provided written comments to the US Department of Health and Human Services and to the US Office of Personnel Management. Several of our State Champions submitted comments as CI clinicians. We emphasized the critical need for appropriate follow-up care post CI surgery. You may view our comments on the ACI Alliance website.

Our lively discussion in Nashville also addressed our focus going forward. We explored two topics that impede access to care: (1) *Low Medicaid payment rates* for cochlear implant surgery and follow-up services and (2) *The need for language in the Reauthorization of the Early Hearing Detection and Intervention Act of 2015 to address the lack of information provided to families on technology and communications options for a young child with hearing loss.*

With regard to the issue of low Medicaid payment, we will develop materials that can be utilized by State Champions who wish to lead initiatives in their own states to address Medicaid payment and coverage concerns. Our Washington, DC State Champions have already initiated such a process involving clinicians, educators, and families.

With regard to the issue of parent information, CI clinicians continue to see children arrive at their clinics who were identified deaf at birth but enter the CI process late because families were not given information regarding cochlear implants as part of early intervention advisement. US pediatric CI utilization rates are half of comparable rates in Western Europe, largely because families do not receive the information they need to make informed and timely choices for their children. ACI Alliance has joined with other organizations in the hearing health field to address this concern.

Our advocacy efforts have been greatly advanced by these dedicated individuals working at the State level. Most of our meetings are held in the evening via teleconference. We will hold an in-person meeting at the upcoming CI2015 DC Symposium. For a listing of our State Champions, visit <https://acialliance.site-ym.com/?ACIAState-Champs>. If you are interested in serving, please contact me at dsorkin@acialliance.org. ■



ACI Alliance State Champions met at CI2014 in Nashville to plan future initiatives.



14th Symposium on
**COCHLEAR
IMPLANTS
in Children**
Vanderbilt University
Medical Center, Nashville



CI 2014 Attendees Caught the Nashville Vibe

David Haynes MD
*CI 2014 Pediatric Educational Course Director
Vice Chair and Chief Academic Officer
Otolaryngology, Neurosurgery and Hearing
Cochlear Implant Program Director
Vanderbilt University Medical Center*



American Cochlear Implant Alliance and Vanderbilt University Medical Center collaborated on the 14th Symposium on Cochlear Implants in Children on December 11-13, 2014 in Nashville (TN). The meeting was, by all accounts, a huge success. Nearly 1100 attendees from 43 countries met to share information over the three-day conference. Together with my course co-directors Rene Gifford PhD and Alejandro Rivas MD and others from the Vanderbilt team, we were gratified at the enthusiastic response to the educational program presented by over 200 invited and submitted speakers. Poster sessions each afternoon provided additional learning and sharing opportunities for the multidisciplinary group from across the continuum of care. And we also had some fun (and music)—outside of the scientific program—along the way.

Tennessee distiller Jack Daniels provided an opportunity for attendees to learn first hand from the company's Master Distiller and then have a taste of three popular whisky blends.

Sessions each day focused on wide-ranging topics in cochlear implantation and related hearing devices, early intervention, educational issues, music perception and appreciation, surgical issues, device design, clinical management, expanding indications, bilingual families, and access to care. A new format in the exhibit hall combining exhibit booths with tech suites provided greater opportunity for attendees to explore elements of the cochlear implant technology with representatives of the three implant manufacturers. Wide ranging companies joined us in the exhibit hall providing an opportunity for attendees to visit with company representatives of surgical equipment, other hearing implants and technologies, and businesses providing services for children.

At the Member Meeting, the leadership of the American Cochlear Implant Alliance presented on the organization's progress over the past year and members voted on a new slate of Board Members.

Session materials used by featured speakers are posted in the CI2014 area of the ACI Alliance website at <http://www.acialliance.org/?CI2014>. You may even find yourself (or someone you know) in the Photo Gallery!

All of us at Vanderbilt worked hard at assembling the program and we were gratified at the response. We thank the symposium attendees and leadership of the ACI Alliance for your collaboration in this important learning opportunity for all of us. We are also extremely appreciative of the support of the three main sponsors: Advanced Bionics, Cochlear Americas, and MED-EL. ■





Michael Douglas, Principal of the Mama Lere Hearing School, co-moderated the Opening Plenary.



Country music singer Lauren Alaina and the children of the Mama Lere Hearing School at Vanderbilt welcomed attendees at a lively Opening Session.



Attendees at a Morning Plenary



The poster sessions were important learning opportunities.



Conference Chair David Haynes and others from the Vanderbilt Program Committee

Grateful thanks to conference photographer Connelly Crowe (<http://cccfotographie.com/>)



Howard Francis of Johns Hopkins takes advantage of Exhibit Hall learning opportunities.

Study Underway to Examine Expansion of Medicare Criteria for Cochlear Implants in Adults Age 65+

Subjects Being Sought

Teresa Zwolan, PhD, Director, University of Michigan Cochlear Implant Program and Vice Chair, American Cochlear Implant Alliance



At present, candidacy criteria for cochlear implantation followed by the Centers for Medicare and Medicaid Services (CMS) are more stringent than the FDA guidelines typically followed by most implant centers and also by the majority of health insurance plans. This has resulted in an unfortunate access barrier; older adults do not have the same access to the benefits of cochlear implantation, which may help them remain active and contribute to their overall health status.

The American Cochlear Implant Alliance is conducting a CMS-approved Coverage with Evidence (CED) study to evaluate expansion of CMS candidacy criteria to include adults with better pre-operative speech recognition skills. Presently, CMS indications state that cochlear implantation may be covered for treatment of bilateral pre- or post-linguistic sensorineural moderate to profound hearing loss in individuals who demonstrate limited benefit from amplification as defined by test scores of less than or equal to 40% correct in the best-aided listening condition on tape-recorded tests of open-set sentence recognition. The purpose of this study is to evaluate the safety and efficacy of currently available multichannel cochlear implant systems using expanded CMS criteria that includes newly implanted adults who score up to 60% correct on HINT sentences preoperatively in their best aided condition.

A total of ten CI centers are taking part in this study across the U.S. (Study centers are noted in the adjacent table.) Study participants must have the surgery and specific follow-up appointments at one of the designated study sites. However, many study sites have indicated they are willing to work with referring centers to have patients attend non-study appointments at centers closer to their home, and to allow patients to transfer back to their home center once they have completed their obligations to the study one year post-implant.

If you are a hearing health professional who has turned away patients who are good candidates for a CI because they do not meet current CMS criteria to receive a cochlear implant, we would like to ask you to consider referring such patients to this study.

If you (or someone you know) are of Medicare age, presently using hearing aids, and still have difficulty hearing, or if you have been evaluated and told that you have too much hearing for a cochlear implant under Medicare's more stringent criteria, we encourage you to learn more about this study. Studies have found that CI recipients with more residual hearing and shorter periods of deafness at the time of CI tend to have the best outcomes.

For information about this study, contact Donna Sorkin, dsorkin@acialliance.org or visit <https://clinicaltrials.gov/ct2/show/NCT02075229>. Overview Information on this study can also be found in past issues of the ACI Alliance e-magazine, which can be accessed freely in our Member Center area at www.acialliance.org. ■

CI Center Study Sites

Johns Hopkins, New York University, University of Iowa, University of Miami, University of Michigan, University of North Carolina, University of Southern California, Vanderbilt, University of Washington (Seattle), Washington University (St. Louis)

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The Affordable Care Act: Open Enrollment for 2015 and Ongoing Challenges

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

The 2015 open enrollment period in the health insurance exchanges began on November 15, 2014 and ends on February 15, 2015. This is the second open enrollment period under the Affordable Care Act (ACA) and it is considerably shorter than it was last year. During open enrollment, private health insurance can be purchased through the health insurance marketplace in each state. From the period of November 15 to January 9, nearly 6.8 million consumers selected health insurance from the marketplace for coverage in 2015 or were automatically reenrolled in a health care insurance plan.¹ When expanded Medicaid coverage is added, approximately 10 million people will be newly ensured under the ACA. The vast majority of ACA health plans cover cochlear implantation (CI).

Health insurance exchanges (also commonly referred to as “marketplaces”) are used by consumers to shop and contrast available health coverage and select a plan that meets the person’s needs. These plans must comply with ACA requirements and each state’s existing insurance laws. Each state is required to offer an exchange to its residents and may do so by creating and running its own exchange, deferring to the federal government to operate its exchange, or partnering with the federal government to operate its exchange. 15 states, including the District of Columbia, operate their own exchanges, 27 states have health exchanges run by the federal

government, and 9 states have partnered with the federal government to operate their exchanges. All exchanges can be accessed through the website, www.healthcare.gov, which is administered by the federal government.

According to the Centers for Medicare and Medicaid Services (CMS), more affordable options are available during open enrollment this year due to increased competition in the health insurance marketplaces. Approximately 90 percent of consumers will have the option of 3 or more issuers, an increase from 74 percent in 2014.² Consumers will also have an average of 40 health plans to choose from; up from 31 health plans in 2014.³

The ACI Alliance State Champions have been working with state governments tasked with implementing the ACA. Extensive efforts have occurred throughout the past year to raise the importance of CI coverage and State Champions are now in the process of collecting data and stories regarding access to cochlear implant services under the ACA plans. This data and anecdotal information will be shared with state and federal policy makers.

Consumer Access to Health Insurance

New federal insurance requirements are imposed under the ACA on all policies



offered through the exchanges. Consumer protections include the following:

- Nondiscrimination based on health status (such as hearing loss or deafness);
- Guaranteed issue and renewal of insurance;
- No pre-existing condition exclusions;
- No rescission of health plan coverage;
- Modified community rating for premiums;
- Coverage of an essential health benefits package, including coverage of “rehabilitative and habilitative services and devices”;
- Nondiscrimination in health benefit design;
- No lifetime or annual monetary caps on benefits; and,
- Behavioral and mental health parity.

Although many areas of the ACA have been addressed through regulation,

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¹ <http://www.hhs.gov/healthcare/facts/blog/2015/01/open-enrollment-week-eight.html>

² “Open Enrollment Begins November 15; Consumers Should Visit HealthCare.gov to Preview Their Plan Choices Today.” *Centers for Medicare and Medicaid Services*. 14 Nov. 2014.

³ “Open Enrollment Begins November 15.” 14 Nov. 2014.

Affordable Care Act *from page 7*

there are still several areas of concern, including provider network adequacy, transparency in benefit design, and the contents of the essential health benefits package. The ACI Alliance and the State Champions are tracking limits placed on post CI surgery therapy services and have provided (and will continue to provide) technical assistance to state issuers and regulators on the appropriate coverage for these services under an ACA health insurance plan. The federal government has yet to finalize several aspects of the ACA and is currently in the rule making process, a process in which ACI Alliance is actively engaged.

Supreme Court Challenge

A major wild card in ACA implementation is a U.S. Supreme Court case, *King vs. Burwell*, that is scheduled to be heard in early March and decided in June. The case centers on whether the ACA authorizes federal subsidies to flow through the federal exchange (which covers a total of 36 states) or whether subsidies are limited to those who purchase coverage through state-based exchanges. If the court invalidates subsidies through the federal exchange, the entire ACA insurance market will be thrown into chaos and over 5 million people will lose their health insurance in short order.

Conclusion

ACI Alliance will continue to monitor health care reform implementation, work with its State Champions, its Washington counsel, and to bring challenges and successes to the attention of policy makers at the state and federal levels. To learn more about the ACI Alliance's work regarding the ACA Marketplaces and cochlear implantation, please visit www.acialliance.org. ■

ACI Alliance Establishes Online Career Center

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

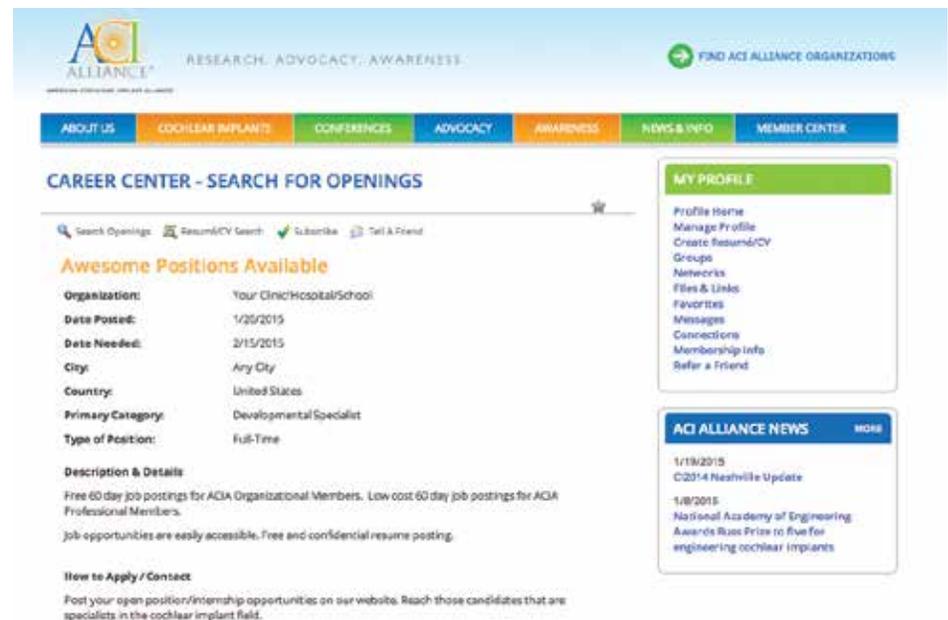


Do you have an employment opportunity at your clinic, school, or university? Do you want to target personnel in the cochlear implant field?

ACI Alliance has created an online resource to help employers reach staff across the continuum of care. You may post a job or internship on the ACI Alliance Career Center. Posting a position is free for Organizational Members. Individual Professional Members may post for a fee. Open positions may be posted for 60 days.

The Career Center also can be used by job seekers to post resumes. The system allows someone to specify criteria for and receive updates via email when matching positions are posted the free and confidential (member only access) resume posting service allows the job seeker to control what information can be searched and accessed by employers. As a member, there is no cost to access the positions posted in the Career Center or to post a resume.

To get started, go to the Member Center tab on the ACI Alliance website at www.acialliance.org and click on "Career Center." Contact Susan Thomas if you need help at sthomas@acialliance.org. ■



The screenshot shows the ACI Alliance Career Center website. At the top, there is a navigation bar with tabs for ABOUT US, COCHLEAR IMPLANTS, CONFERENCES, ADVOCACY, AWARENESS, NEWS & INFO, and MEMBER CENTER. Below the navigation bar, the main heading is "CAREER CENTER - SEARCH FOR OPENINGS". There are search filters for "Search Openings", "Resume/CV Search", "Subscribe", and "Tell A Friend". The main content area displays "Awesome Positions Available" with a job listing for "Your Clinic/Hospital/School". The listing includes details such as "Date Posted: 1/25/2015", "Date Needed: 2/15/2015", "City: Any City", "Country: United States", "Primary Category: Developmental Specialist", and "Type of Position: Full-Time". Below the listing, there is a "Description & Details" section and a "How to Apply / Contact" section. On the right side, there is a "MY PROFILE" sidebar with links for Profile Home, Manage Profile, Create Resume/CV, Groups, Networks, Files & Links, Favorites, Messages, Connections, Membership Info, and Refer a Friend. At the bottom right, there is an "ACI ALLIANCE NEWS" sidebar with recent news items.

A Consumer's Perspective

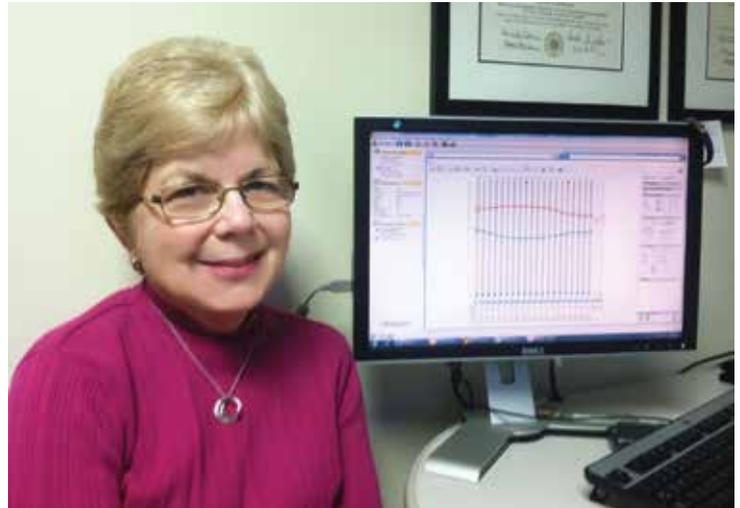
Ann Liming, *Consumer Advocate*

When I learned that I was a candidate for a cochlear implant, I was both happy and relieved. I had not qualified for an implant in the past based on criteria established by Medicare. When my audiologist asked if I would like to participate in a research project to explore whether Medicare candidacy criteria should match that of most other insurance plans there-by allowing for earlier implantation, I thought, "why not?"

Most people who embark on a path to learn if a cochlear implant is the right choice for them conduct some level of research including talking with and observing people who have traveled this same path before them. Even then it is hard to imagine how an implant will impact your own hearing. There is no way to describe the joy of hearing all of the notes played by my musical clock for the first time and being able to identify the tune. I smile when I am reminded that the teakettle whistles and that I can hear when I leave the water running in the sink. Both my friends and I are more relaxed when they do not have to work so hard to include me in conversations or repeat what I have missed. I am much more confident now dealing with sales clerks or placing an order at a fast food restaurant.

While I do not feel like an older person, my chronological age places me in the "middle old age" population. There is an abundance of research supporting the negative impact of hearing loss on older people. It is a major loss to a family network or community at large when older people isolate themselves because they can no longer hear conversations and sounds around them well. Hearing loss can lead to life threatening situations when a person does not hear information. Loneliness, isolation and frustration can take a toll on one's physical health. Recent research shows a possible link between hearing loss and dementia. The cost to family caregivers and society is staggering. It makes sense to implant people while they are still in the "young old age" group and while they have greater capacity to adapt to this new way of hearing.

Having now reaped some of the joys of hearing better (and I am sure there are many more to come), my response to the invitation to participate in this study has gone from "why not" to "absolutely!" I am thankful for the wisdom, commitment and passion of the professionals in ACI Alliance to take on this research study. As a consumer, it is a privilege to share in important collaborative opportunities provided by ACI Alliance. It is empowering to work alongside professionals to advance access to cochlear implantation. It gives me goose bumps to envision the improved quality of life for older individuals with hearing loss, who with a cochlear implant, can enjoy their older years and continue to make meaningful contributions to their communities. Based on the sounds and conversations that I now hear in only three months since my CI was activated, my participation in this study has taken on new meaning and new life. I would like for all people receiving Medicare who choose a CI as their path to follow, to be able to do so early in their senior years so they can stay connected to people and their communities. ■



Major Organizational Accomplishments 2014



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

Research

- Launched CMS-approved multi-center study to evaluate expansion of CMS candidacy criteria to include adults with better pre-operative speech recognition skills than is currently allowed under Medicare.
- Initiated systematic assessment of cost utility of cochlear implantation, an analysis of 60 studies completed since 1995 with publication expected in 2015.
- Developing consumer/clinician project to expand primary care physician knowledge about cochlear implants for adults.

Awareness

- Collaborated with Vanderbilt University Medical Center on 14th Symposium on Cochlear Implants in Children December 11-13, 2014 with 1100 attendees from around the world.
- Developed, published, and widely distributed CI 2013 Abstract Proceedings in print and electronic formats.
- Published two issues of *ACI Alliance Calling*.
- Achieved mainstream media coverage coinciding with CI2013 DC conference (*NY Times, Bloomberg, Military Times*)
- Launched new website and expanded Twitter with enhanced content for the general public and general healthcare professionals and greater member participation.
- Expanded membership of Organizations by 52% and individuals by 30%.

Advocacy

- Expanded State Champion program to 31 states with periodic group and individual conference calls and documentation to support state level monitoring and action of CI coverage by ACA Marketplace plans.
- Identified therapy caps as a significant issue under the ACA and initiated development of a therapy guideline.
- Submitted comments to CMS and US Office of Personnel Management asking for clarification of the cochlear implant benefit under the ACA Marketplace plans to address arbitrary limits on services (i.e., allowing only one CI per year or limiting the number of mapping or therapy sessions allowed in a given timeframe).
- Undertook aggressive campaign to retain Medicare coverage of Auditory Osseointegrated Implants. Worked organizationally and with other groups to submit comments and provide guidance to our members to facilitate individual input. Met with CMS officials and organized a bi-partisan letter signed by 20 Members of the Congressional Hearing Health Caucus. CMS announced in late 2014 it would retain coverage.
- Conducted ACI Alliance on the Hill at CI2013 to increase visibility of CI among a large group of legislative offices and help our members to establish relationships with their Congressional representatives. Continued follow-up into 2014.
- Under the auspices of the Friends of the Congressional Hearing Health Caucus, collaborated to organize a Congressional staff luncheon on pediatric hearing loss focusing on cochlear implant benefits and shortcomings of the early intervention system vis a vis parent information.
- Developed close relationships with several key Senators and House Members
- Organized Congressional clinic visits.
- Began a collaborative effort with other organizations to include language in the EHDI 2015 reauthorization requiring comprehensive information on technology and communication options be provided to parents of deaf children.
- Assisted specific states with reimbursement challenges (i.e., MassHealth regarding equipment coverage, GA regarding lack of visibility on ACA coverage of CI, Washington DC on Medicaid underpayment)
- Participated in The Ear Foundation (UK) conference and report to Parliament designed to bring about a more sensitive approach to adult hearing loss by the UK's National Health Service. Conducted and presented on a survey of adults regarding workplace effects post cochlear implantation.