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

I am proud to report a fantastic ending to the year for the ACI Alliance. We gathered in Washington, D.C. to explore Emerging Issues in Cochlear Implantation and we had a banner showing of support for our first hosted meeting! Over 600 attended and learned from the best in our field. In the coming months, highlights of the meeting will be published on our website in an extended abstract format. We are very grateful to the three cochlear implant manufacturers—Advanced Bionics, Cochlear Americas, and MED-EL—for their generous support of CI 2013.

Many of you participated in ACI Alliance on the Hill, an organized effort to educate Congressional Members and staff regarding our mission to advance access to the gift of hearing provided by cochlear implantation. There were many positive stories that emerged from this energizing event which will help us forge relationships with our elected officials and advance our ongoing advocacy and public policy initiatives. We are now collaborating with other organizations in the field and with Congressional Members to develop specific proposals designed to improve the counseling process for parents of deaf children soon after hearing loss is identified. We believe that parents should receive comprehensive, unbiased information about the language development options available for a deaf child and that such information should be available at the earliest possible time.

Two ACI Alliance Members from North Carolina—Kathryn Wilson and Joni Alberg—joined me in Washington, D.C. at a November presentation for Congressional staff sponsored by the group Friends of the Congressional Hearing Health Caucus. We presented on the successful North Carolina model for Early Identification and Intervention for children that fail the Newborn Infant Hearing Screen. We also met with our NC delegation in Washington and in our own state to explore these same...
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Vanderbilt University Medical Center

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issues in depth. Senators Richard Burr and Kay Hagen as well as Representative David Price are committed to improving the counseling process across the country given that appropriate hearing loss management in children improves communication, educational achievement, and employment opportunities and results in overall societal savings. All three elected officials are personally interested in our work; the wheels are set in motion to advance our policy agenda.

As you can see, the Alliance is now a viable organization that is headed in the right direction. At the start of a new year, I want to wish you all a productive 2014 and pay special thanks to Executive Director Donna Sorkin, Vice-Chair Terry Zwolan, and the entire Board of the ACI Alliance for working tirelessly to make the organization successful.

CI 2014 Pediatric in Nashville / December 11–13, 2014

We are delighted to serve as the Program Chairs for the 14th Symposium on Cochlear Implants in Children (CI 2014 Pediatric) in Nashville (TN) December 11–13, 2014. The Departments of Hearing and Speech Sciences and Otolaryngology at Vanderbilt University are developing the scientific program, working collaboratively with the American Cochlear Implant Alliance. This conference is unique in that the multi-disciplinary attendees can discuss and explore the collaborative efforts of otolaryngologists, audiologists, scientists, speech language pathologists, deaf educators, psychologists, social workers and others involved in improving the outcomes of pediatric cochlear implant recipients.

The inaugural ACI Alliance CI 2013 Symposium held in Washington, D.C. this past October was an exciting and valuable event. We will capitalize on this initial effort focusing on pediatric topics. Featured speakers have committed to attend and address current topics such as single-sided deafness, bilateral cochlear implantation, infant language development, intervention targeting bilingual families as well as specific topics like cochlear implant surgery, hearing preservation, and music appreciation. Mark your calendars now to attend the meeting in December 2014. We look forward to experts of all disciplines sharing their respective experiences in research and clinical venues.

We have been able to secure a fantastic venue, The Omni Hotel, in downtown Nashville—Music City U.S.A. The Omni is just steps away from Music Row where most of the music venues in Nashville are located. December is an exciting time to be in Nashville. In addition to the well-known music scene, we have world class shopping, restaurants, sports and historical venues. Nashville offers exceptional entertainment for attendees and their families. We look forward to seeing you in Nashville on December 11–13, 2014!
State Champions Monitor and Advocate for Access

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

One year ago, allied organizations in the field of hearing loss identified cochlear implant coverage under the Affordable Care Act as a top priority for our fledgling organization and also an area that they were not working on. Our sister groups noted that the ACI Alliance was well positioned to take on this concern. Hence we initiated the State Champion Program and recruited leaders to serve as advocates in each state to monitor the rollout and advocate for clear coverage language for the continuum of cochlear implant care—from preoperative assessment all the way through device maintenance. We provide training online as well as regular conference calls and one-on-one support. We also developed the Cochlear Implant Continuum of Care (http://acialliance.org/sites/default/files/files/CI%20Continuum%20of%20Care.pdf) for State Champions to use in explaining the process of cochlear implantation to their state insurance offices.

We now have 25 states with one or more active State Champions in place. We are looking for individuals who wish to be involved as leaders in the remaining 25 states. State Champions have met with their insurance offices, clarified coverage language, advocated for “Gold Standard Language” for their state’s Essential Health Benefits, and provided support to clinicians as well as patients trying to negotiate the sign-up process.

Our efforts on the ACA are aided by our Public Affairs Consultant, Theresa Morgan. Theresa’s update report on the healthcare law appears on page 8. Our State Champions will monitor the ACA rollout and provide us with input for national level activities. For a listing of State Champions, please go to: http://acialliance.org/sites/default/files/files/LatestStateChampions%20Sheet1.pdf

If you are a member of ACI Alliance and are interested in becoming a State Champion, please send an email to our national office (info@acialliance.org) indicating your interest.
CI 2013 Conference Highlights

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

CI 2013 provided a unique opportunity for attendees to focus on six emerging topics in the field of cochlear implantation. Attendees noted they benefitted from the examination of topics by clinicians and scientists from across the continuum of care.

The interactive discussions following the formal talks allowed audience members to interact in an in-depth manner and helped identify challenging clinical issues and research gaps. Many presenters allowed their Powerpoint presentations to be posted; these are available at: https://www.acialliance.org/member/CI2013ProgramBook

Conference proceedings are being developed in an extended abstract format. These will be published in print and also available electronically on the ACI Alliance website.

We are grateful to the National Institute on Deafness and Other Communication Disorders, NIH for their funding support of the conference and related materials that allow us to expand our educational outreach.

Opening General Session

Major General Robert Hedelund, USMC a helicopter pilot, instructor and Marine Corps leader with numerous overseas deployments, joined ACI Alliance at the Opening Ceremony. Major General Hedelund is currently the commanding officer of the Naval Air Stations in North and South Carolina responsible for the combat readiness of 44 squadrons. He was previously director of Marine and Family Programs and hence is familiar with hearing loss, acknowledging that it is the number one disability for men and women who have served in active duty. Although post-traumatic stress disorder has received more attention, in fact the VA numbers indicate that auditory injuries are growing rapidly with incidence of 29 of 1,000 soldiers reporting hearing loss. Those numbers will grow in the decades ahead. Hedelund commented that “I don’t think any young man or woman joining the Marine Corps thinks that in 4 years or in 40 years, you will come away from your experience serving your country deaf.”

ACI Alliance sought media coverage of the opening ceremony as well as other conference content to expand general awareness about deafness and cochlear implants. We were pleased to have stimulated three excellent mainstream media articles—two on deafness and cochlear implants among military personnel and a third documenting the benefits of cochlear implants for older adults.

**ACI Alliance on the Hill**

American Cochlear Implant Alliance conducted the first ever cochlear implant public policy day on Capitol Hill on October 24. Nearly 90 ACI Alliance members from 22 states joined together to expand awareness among our national elected officials. Information was also conveyed regarding the importance of early intervention and the need for improved advisement for parents of young children who have been identified with hearing loss. On Thursday, prior to the official opening of CI2013, an early morning training meeting was conducted. Each advocate was grouped with others from his or her state, provided with handout materials and messaging, and assigned a schedule of meetings with Senate and House Congressional offices. Clinicians urged legislators to visit their clinics (in their home states or even home districts) to learn more.

Key messages included:

- The process of hearing restoration via cochlear implants for children and adults
- Proven cost effectiveness, particularly in children but also in adults
- Newborn hearing screening provides a critical opportunity for starting the process of listening with a cochlear implant at an early time in a child’s life, when it can be most effective
- Parents need comprehensive, unbiased information to make informed choices for their children but only 30% of parents with a deaf child learn of his or her possible candidacy from early intervention personnel
- Cochlear implant utilization is low among eligible children and many come to the intervention too late to realize the greatest benefit

Advocates are following up to encourage visits by national legislators to their clinics or schools. Further, we are collaborating with other organizations on specific proposals for improving the parental advisement process. These will be shared more widely soon.

ACI Alliance was an early promoter of the new short film, *95 Decibels*, given its importance as a powerful educational tool for mainstreamed audiences. Based on the true story of a family’s experience when their daughter was diagnosed as profoundly deaf, it explores their fears and the obstacles they faced as they pursued a cochlear implant for their deaf daughter.

The film was shown at CI2013 followed by a discussion with writer/director Lisa Reznik, cast, early intervention experts, and Miranda Meyers—the 16-year old student who was the inspiration for the film. Audience members were excited

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by the participation of Goran Visnijc, a professional actor best known for his long-running role as Dr. Luka Kovac in the TV series *ER*. Capitol Hill staff were invited to attend. The film is touring at film festivals around the United States and at other special venues. It is available for purchase at [www.95Decibels.com](http://www.95Decibels.com).

**Closing General Session**

At the closing Plenary Session, attendees welcomed Dr. James Battey, Director of the National Institute on Deafness and Other Communication Disorders (NIDCD), NIH. Dr. Battey reviewed the wide-ranging research portfolio supported by NIDCD including extensive work to advance cochlear implants.

**Lasker-DeBakey Clinical Medical Research Award**

Though many awards have been given to scientists who have dedicated their lives to developing and improving cochlear implants, the Lasker Award for Clinical Medical Research given to three individuals in September 2013 is the most significant prize that has ever been awarded in the field. Drs. Blake Wilson, Ingeborg Hochmair and Graeme Clark shared the award for their individual contributions to the field ([http://www.laskerfoundation.org/awards/2013clinical.htm](http://www.laskerfoundation.org/awards/2013clinical.htm)).

ACI Alliance Members were elated to honor the Lasker recipients at the CI2013 Opening Session. Drs. Wilson and Hochmair attended in person while Dr. Graeme Clark sent a special video from Australia. We are delighted to share Dr. Wilson’s conference remarks here.
The Significance of the 2013 Lasker–DeBakey Clinical Medical Research Award for the Field of Cochlear Implants and for Fulfilling the Mission of ACI Alliance

Blake S. Wilson, DSc, Co-Director, Duke Hearing Center, Duke University Medical Center Adjunct Professor, Departments of Surgery, Electrical and Computer Engineering, and Biomedical Engineering, Duke University

The Lasker Award is a spectacular recognition of our field and the power of technology and teamwork to produce the first substantial restoration of a human sense using a medical intervention. In general, the Lasker Awards are second only to the Nobel Prize in Physiology or Medicine in recognizing advances in medicine and medical science. Indeed, fully a third of the Lasker Laureates go on to win the Nobel Prize at a later time. For example, all three winners of this year’s Nobel Prize in Physiology or Medicine are prior winners of a Lasker Award. The Lasker Awards have become known as “America’s Nobel.”

The award for the cochlear implant has increased and will continue to increase tremendously awareness of what this marvelous technology can do. I am 100 percent confident that the Lasker Award will be used in Congressional testimony by the NIH and other organizations—including ACI Alliance—and that that message will produce action.

Increasing awareness is one of the principal purposes of ACI Alliance and I hope and expect that the Lasker Award will give the Alliance a highly favorable tailwind in achieving that noble purpose. Greater awareness is needed. Thus far, about 320,000 persons have received a cochlear implant in one or both ears. Various estimates indicate that as many as 25 million persons worldwide could benefit from a cochlear implant; only about 1 or 2 percent of the population who could benefit actually has received a cochlear implant. To me, this is an astonishing number, given the efficacy of the treatment.

Even in the United States, with all of its economic advantages, utilization is only at 6 percent. Obviously, there is some good work to do to bring the gift of hearing to deaf and severely hearing impaired persons.

In many other parts of the world, cost is a barrier to widespread applications of the technology, even though the benefits ultimately far outweigh the cost. The greatest expenses are in providing the appropriate medical infrastructure and care. The cost of the device also plays a role, but that cost is coming down and is not the dominant factor for most countries. Several of us in this room are working to reduce or remove the cost barrier, and to improve hearing health care worldwide, which includes prevention, screening, and treatments in addition to cochlear implants. The global awareness provided by the Lasker Award will help mightily in these efforts.

I note that the prior major recognition of an advance in hearing research or the treatment of losses in hearing was the Nobel Prize to Georg von Békésy in 1961, “for his discoveries of the physical mechanism of stimulation within the cochlea.” The present recognition may be a bit overdue, and does not include key pioneers such as Bill House but I am nonetheless happy that the recognition has arrived. For one thing, it most certainly will enable us to do far more than we could have done otherwise. So now, let’s roll up our sleeves a little bit farther and increase sharply the applications of cochlear implants in the USA and throughout the world.
The Affordable Care Act
Medicaid Expansion and Coverage of Cochlear Implantation

Theresa Morgan, Public Affairs Consultant to ACI Alliance
Legislative Director, Powers Pyles Sutter & Verville, PC

Over the last months of 2013, most health policy stakeholders focused on the private market reforms which started this month under health care reform. States and the Federal government opened, with varying success, a number of “exchanges” across the country to operate as online shopping destinations for individuals and small employers looking to purchase health insurance plans. States and the US Department of Health and Human Services (HHS) certified new insurance products for the marketplaces, reviewing these plans to ensure they meet the new requirements under the Affordable Care Act (ACA). President Obama’s administration was also busy addressing the significant technical problems, which have caused widespread enrollment problems for the 2014 plan year.

What has gotten less national attention as we enter the New Year is the work states continue to undertake to dramatically reform their Medicaid programs. Because of recent budgetary pressures at the local and state levels, many state legislatures and administrations have embarked on changes to expand the use of managed care and have implemented other measures to bring down the cost of health care. For its part, the Federal government has launched a number of state-level demonstrations to coordinate care for “dual eligibles” (individuals who are eligible for both Medicaid and Medicare) and funded programs to provide incentives to states to provide Medicaid services in the community and in the home, rather than in an institution.

In addition, about half of the states will expand Medicaid eligibility in 2014. The ACA encourages states to add a new mandatory eligibility category to their Medicaid program: low income adults who would otherwise not be eligible for Medicaid. For the expansion population, the Federal government will pay 100% of the Medicaid expenses in the first year, and phase down to paying 90% of expenses in future years.

The ACA stipulates that states offer the new eligibly population a benefits package separate from the state benefits plan. States can use existing “benchmark” plan authority to shape a package to the new group. Some states are also using this opportunity to reshape the benefits plan for multiple Medicaid eligibility categories.

By law, when states utilize the existing Medicaid authority to create benchmark or benchmark equivalent plans (now called “Alternative Benefit Plans” or ABPs), these plans must cover Essential Health Benefits (EHBs). EHBs encompass ten broad categories of benefits, including rehabilitative and habilitative services and devices, and are intended to reflect the scope of coverage found in a typical employer plan.

Cochlear implantation is considered an optional service for adults under the Medicaid program. However, as states create ABPs for the new adult population and for other Medicaid eligible groups in the future, it is plausible that CI could become a required benefit when medically necessary because it is covered by most healthcare plans. Indeed, it is a stated goal of the administration that coverage under ABPs reflect similar EHB coverage to that covered under new private plans meeting ACA requirements so as to create greater consistency between the health care delivery mechanisms.

Many states are undertaking the ABP process as of January 2014. As 2014 state legislative sessions consider how to approach health care, states that have not yet decided to expand Medicaid will likely have the debate anew. Even in states that have opted to forgo expansion in 2015, there is an opportunity to use the Alternative Benefit Plan process to alter Medicaid coverage for other eligible groups in states.

To expand understanding of the Affordable Care Act and how it may impact access to cochlear implantation, ACI Alliance conducted a one-hour webinar on January 15 in partnership with Audiology Online. The online course was recorded and is available free at: http://www.audiologyonline.com/audiology-ceus/course/expanding-access-to-cochlear-implantation-23615. A follow-up course will be offered in August; watch the website and Twitter @acialliance for details.
ACI Alliance Research on Cochlear Implant Outcomes in Older Adults

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

In 2011, a Medicare Evidence Development and Coverage Advisory Committee (MEDCAC) was convened to discuss the evidence, hear presentations and public comment, and make recommendations concerning the currently available evidence regarding the use of unilateral and bilateral cochlear implant technology for hearing loss.

A summary of this meeting can be found online at http://www.cms.gov/medicare-coverage-database/details/medcac-meeting-details.aspx?MEDCACId=58&fromdb=true.

As part of this meeting, members of the Evidence-Based Practice Center at Tufts University presented the results of their technology assessment performed under contract to AHRQ (Agency for Healthcare Research and Quality) regarding outcomes of adults with unilateral and bilateral cochlear implants.

Additionally, public comment was provided on these topics by hearing healthcare professionals. At the end of the meeting, several questions were posed to the committee. It was concluded that there was insufficient evidence to support the expansion of cochlear implant criteria by the Centers for Medicaid and Medicare Services (CMS) to include bilateral CIs or to expand candidacy to scores up to 60%

CMS did, however, indicate they were willing to consider a Coverage with Evidence Development (CED) study to evaluate expansion of current Medicare criteria.

ACI Alliance offered to take leadership of the CED proposal and three separate proposals were submitted for consideration. In 2013, the CED study was approved to evaluate the use of cochlear implants in Medicare beneficiaries with preoperative hearing test scores on open set sentence tests in quiet that are greater than 40% and less than or equal to 60% correct in the best-aided listening condition.

Ten adult cochlear implant centers have been enrolled in this CED study, which will enroll up to 90 Medicare beneficiaries with postlingual onset of hearing loss. Subjects will be required to have a bilateral moderate to profound hearing loss in the low frequencies (up to 1KHz) and profound sensorineural hearing loss in the high frequencies (3KHz and beyond), and must demonstrate preoperative aided sentence scores in quiet greater than 40% correct but less than 60% correct in the best aided condition on HINT sentences. The study will examine post-implant performance both 6 and 12 months post-activation and will utilize HINT Sentences, AZ Bio Sentences, and CNC Words as outcome measures. The study will also evaluate speech recognition over the phone and changes in quality of life as measured by the Abbreviated Profile of Hearing Aid Benefit (APHAB), Short Form-36 Health Survey, and the Health Utility Index Mark 3.

Participating centers* are in the process of obtaining IRB approval for the study with data collection to begin in early 2014. Popsicube has been engaged by ACI Alliance to assist with data management. We anticipate it will take 18 to 24 months to complete the study. The study may result in development of a nationwide CI registry and expansion of CMS criteria to include patients who score up to 60% correct on sentences, increasing access to cochlear implantation for Medicare beneficiaries nationwide.

*Study sites include Johns Hopkins, New York University, University of Iowa, University of Miami, University of Michigan, University of North Carolina, University of Southern California, Vanderbilt, Virginia Merrill Bloedel Hearing Research Center (University of Washington), and Washington University School of Medicine.
ACI Alliance Governance

Teresa H. Caraway, PhD, CCC-SLP, LSLS Cert. AVT  
Chair, Nominating Committee  
Founder and President, Learning Innovation Associates, LLC

A merican Cochlear Implant Alliance is ringing in 2014 with new Board Members. At CI 2013, the membership elected the Board Chair to a one year term as well as two new Board members for two year terms: Dr. Robert Cullen, an otologist in private practice at Midwest Ear Institute in Kansas City and Dr. Jace Wolfe, Director of Audiology at Hearts for Hearing in Oklahoma City join the Board of Directors. Dr. Craig Buchman, Vice Chairman for Clinical Affairs and Chief of Otology/Neurotology/Skull Base Surgery at UNC Otolaryngology-Head & Neck Surgery was elected Board Chair.

Immediately following the DC conference, the board of directors met and passed a resolution to appoint the Scientific Program Chair of CI 2014 Pediatric as a nonvoting member of the Board. Dr. David Haynes, Professor of Otolaryngology, Neurosurgery and Hearing and Speech Sciences and Cochlear Implant Program Director at Vanderbilt University Medical Center has joined the Board. The creation of this nonvoting seat will provide leadership, stability, and continuity in planning upcoming conferences.

The Nominating Committee comprised of Drs. Rene Gifford, Dr. Susan Waltzman, Terry Zwolan and Kathryn Wilson is charged with projecting and recruiting the Board of Director’s optimal composition in terms of three practical and interrelated dimensions:

• Eligibility requirements  
Board candidates are required to be a member of the organization in good standing.

• Desired competencies  
Board candidates are evaluated as a potential board member for their expertise, interests, and experience. A particular desired competency is that candidates bring governance experience from another organization or prior leadership service in an organization, committee, or work group in the field.

• Diversity criteria  
To avoid insularity or groupthink on the board, criteria were defined to ensure that the board’s composition is balanced and strengthened by differences among members. Race, gender, age, professional and institutional disciplines, size of organizations, geographical regions, and philosophies about the profession and its practice areas are considered.

These three dimensions are used consistently to encourage and screen prospective candidates. The best boards are a mix of characteristics, skills, experiences, and diversity. This ideal board profile is not dictated by a formula. It is driven by the particular and current needs of the organization.

In 2014, the Nominating Committee will continue to examine the major issues facing the organization in the coming years as well as the board member job description. We will also take into account how the current board members fill the requirements identified in the ideal board profile and what will be lost from board members whose terms are ending in 2014. Where are the gaps? Will the board be losing the perspective of a leader from a significant field, institutional size, or geographical area? Will the board no longer have an individual with the experience of a senior executive? Does the board need to add a member who brings more financial expertise, strategic thinking skills, or consumer perspective? These questions will guide the Nominating Committee’s work as we recruit from the talented and capable membership of ACI Alliance.
A Consumer’s Perspective

Arlene Romoff, Author, Speaker, Advocate on Hearing Loss Issues

I’ve been a cochlear implant user for the past 16 years and I can honestly say that I have never taken this gift of hearing for granted. I grew up with normal hearing, losing hearing slowly over a period of 25 years. As the technology advanced, it became evident that a cochlear implant was my last hope of remaining in the hearing world. My first cochlear implant in 1997 gave me my life back. I wanted to share my experience with others, so I wrote my first book, *Hear Again—Back to Life with a Cochlear Implant*. Although the book helped many people, I found that awareness was still a barrier and most people still did not know what cochlear implants were. For this reason, when I went bilateral in 2008, I wrote a second book, *Listening Closely: A Journey to Bilateral Hearing*, describing the benefits of hearing with two “ears,” again hoping to educate others.

I’ve had the opportunity to meet many people over the years while giving talks on my books and have found that a lack of understanding about cochlear implants is still common. I was very pleased to learn about the ACI Alliance and its mission, which dovetails so closely with the goals of my books and presentations. I encourage all clinicians and consumers with a connection to cochlear implants to join this organization. Together, we can work to ensure that parents and adults facing the challenges of deafness have the essential resources needed to access this life-changing technology. I have found these materials, on the Alliance website, to be helpful in explaining the organization to professionals, consumer and parent advocates: [http://acialliance.org/member/why-join-aci-alliance](http://acialliance.org/member/why-join-aci-alliance).