



AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

Calling

August 2014 • Vol 2, No 2

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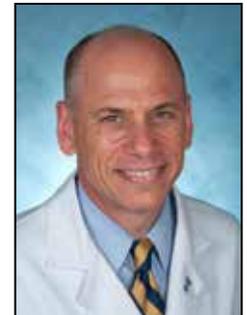
MESSAGE FROM THE CHAIR

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



We hope everyone is having a wonderful summer! Here at the ACI Alliance, we have been hard at work on a number of initiatives to improve access for patients in need of cochlear implants. To this end, Nancy Young MD, Medical Director of the Cochlear Implant Program at Lurie Children's Hospital of Chicago, hosted the Board of Directors Meeting in Chicago in March of this year. There, we spent the weekend updating our Strategic Plan by checking off some of our accomplishments and refocusing our efforts in areas of need. Please see the sidebar on page 2 for a Summary of the updated Strategic Plan.

On the research front, we identified the need for new chairs of our research committee. After a number of very highly qualified individuals were considered, we were fortunate to attract two longtime leaders in the field: Karen Kirk PhD from the University of Illinois and Howard Francis MD from Johns Hopkins University as our Research Committee Co-chairs. We couldn't be happier with their acceptance of the position and we expect great things from their committee going forward. Also on the research front, Terry Zwolan PhD, ACI Alliance Co-Chair, has been working tirelessly with our ten research sites on the CMS study to extend cochlear implant indications in the Medicare population. For more information on the CMS Study, please refer to Terry's articles in prior editions of *Calling* (posted on the website).

A recent development in the field of implantable devices has caught our attention and advocacy efforts. On June 29, CMS proposed to stop covering all implantable auditory devices except for cochlear implants and auditory brainstem implants (regulation §411.15(d)(1)). This decision, if not overturned, would adversely affect patients receiving auditory osseointegrated implants and make future approval for other emerging auditory devices more difficult, if not impossible. More broadly, private payers would

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ACI Alliance Strategic Plan Summary 2013-2016

Update Approved by Board of Directors on June 9, 2014

Message from the Chair

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likely follow suit. What can you do to help? CMS is accepting comments regarding this proposed ruling change until September 2, 2014. We need your prompt action to oppose the ruling and keep these implants available for our patients. At the ACI Alliance, we have partnered with other stakeholders to conduct meetings with CMS and draft comments to oppose this ruling. We have also met with Members of Congress and asked for their help in opposing this change. Guidance for our members to use in writing your own comments is posted in the Advocacy section of the ACI Alliance website. The guidance was also sent to all of our members.

We are all very excited that the 14th Symposium on Cochlear Implants in Children is rapidly approaching in December 11-13, 2014. Dr. David Haynes and his team at Vanderbilt have been hard at work, assembling the best scientific program we have seen. This meeting will surely provide a fantastic mix of topics that all of us can learn from. Please join us at the meeting and share in the exchange. Please visit www.ci2014usa.com for more information and to register for the meeting now. We look forward to seeing you there! ■

Goals

1. Encourage and support research on candidacy, criteria and the broad impacts of cochlear implants for children and adults
2. Advance awareness of best practices related to cochlear implants among patients and their families, clinicians including primary care doctors and other health professionals, early interventionists, educators, policy-makers, payers and the general public
3. Educate and encourage policy-makers and payers to take steps that expand access to cochlear implants
4. Build an effective, sustainable organization

Research

1. Complete a Centers for Medicare and Medicaid (CMS) Services study in 2017 to evaluate the safety and efficacy of cochlear implantation under expanded guidelines for Medicare patients
2. Spearhead planning for a national Cochlear Implant Patient Registry which would provide clinicians and scientists with important research opportunities relating to cochlear implantation in patients of all ages
3. Highlight the need for a Societal Costs of Hearing Loss study modeled after the Project Hope study published in 2000

Awareness

1. Co-design and conduct national and international CI symposia highlighting research, clinical issues, (re)habilitation, quality of life/cost effectiveness, health care policy, and insurance issues
2. Expand the ACI Alliance website to be the premier source of research-based information to support access to cochlear implantation
3. Review and provide input on the accuracy of information provided by others via web-based and other formats

Advocacy

1. Utilize the State Champion program to monitor and impact the rollout of the Affordable Care Act at the state and federal levels vis a vis cochlear implant services
2. Participate in hearing loss and general disability organizations
3. Address the current shortcomings of Early Intervention advisement services to families as they relate to comprehensive, unbiased information on options and technology for parents
4. Lead member advocacy efforts in Washington to expand knowledge about cochlear implants and issues of access
5. In collaboration with other organizations, develop and disseminate multi-disciplinary clinical practice guidelines and undertake efforts that promote cochlear implantation as the standard of care treatment within non-hearing loss disciplines

Build a Sustainable Organization

1. Utilize best practices for board and staff performance
2. Maintain an active committee structure in order to carry out the work of the organization
3. Reach 100 Organizational Members by the end of 2014
4. Carry out a multi-faceted fund development program

ACI Alliance Board of Directors

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Professor and Vice Chair for Clinical Affairs
Director, UNC Ear and Hearing Center
UNC Otolaryngology

Teresa A. Zwolan, PhD, *Vice Chair of the Board*
Professor, Department of Otolaryngology
Director, Cochlear Implant Program
University of Michigan Health System

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Director, University of Miami Ear Institute (FL)

Teresa H. Caraway, PhD,
CCC-SLP, LSLS Cert. AVT
Chair, Nominating Committee
CEO, LSLogic, An Oberkötter Learning
Community

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Medical Director, Midwest Ear Institute (KS)

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Director, Cochlear Implant and
Hearing Loss Research Laboratory
Washington University School of Medicine

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Professor and Head
Department of Otolaryngology–
Head and Neck Surgery
University of Iowa Hospitals and Clinics

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and Hearing and Speech Sciences
Cochlear Implant Program Director
Vanderbilt University Medical Center

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Deaf and Hard of Hearing Educator
Los Angeles

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Clinical Associate Professor
Supervising Audiologist
NYU Cochlear Implant Center

Kathryn Wilson, MA
Director of Embedded Learning
LSLogic, An Oberkötter Learning Community

Jace Wolfe, PhD
Director of Audiology, Hearts for Hearing (OK)

Nancy M. Young, MD, *Secretary*
Medical Director of Audiology and
Cochlear Implant Program
Ann & Robert H. Lurie Children's
Hospital of Chicago

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

A New Website for ACI Alliance

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

We are delighted to announce that ACI Alliance is moving to a new website, which will greatly enhance our opportunity to involve and engage our members in our mission. The website reorganization will also allow us to have a more prominent presence on the Web and reach greater numbers of people outside of the cochlear implant community who are searching for information on the intervention. Lack of awareness about cochlear implants, as well as little knowledge regarding typical outcomes in children and adults, are among the major issues that impede access to care. We want our website to be a credible source of information for those outside of our cochlear implant community including primary care physicians, private insurance industry representatives, and governmental agencies involved in healthcare policy and educational support for children. We will be adding considerable content on aspects of cochlear implantation in the months ahead in order to provide comprehensive cochlear implant resources for our members and others.

A robust member area will allow you to maintain your professional information (including an online CV, if you wish) and choose whether you want this information visible to others. You can also indicate how much you wish for ACI Alliance to contact you. As we develop blogs and other communication vehicles, you can decide whether you wish to be notified when new postings are made.

We are excited about the improved member directory which allows our members to easily locate other members using search by an individual's name, entity (i.e., clinic or school), city, or state. Our Organizational Member information will be more accessible to each of us and also to the public, allowing individuals and primary care physicians to easily find a cochlear implant center.

An important new feature will be the ACI Alliance Career Center where Organizational Members may post the availability of positions, without charge. Individual professional members may also post positions for a charge. Viewing job listings will be open to anyone, regardless of membership in ACI Alliance.

As part of the website re-launch, we have added a new feature to help us raise funds for ACI Alliance operations.

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



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You shop. Amazon gives.



David S. Haynes, MD
*Professor of Otolaryngology,
Neurosurgery and Hearing
and Speech Sciences
Cochlear Implant
Program Director*



René H. Gifford, PhD
*Assistant Professor, Hearing
and Speech Sciences
Director, Cochlear
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Alejandro Rivas, MD
*Assistant Professor,
Otology and Neurology*

MESSAGE FROM THE CI 2014 PEDIATRIC PROGRAM CO-CHAIRS

CI 2014 Pediatric Update

Preparations for the 14th Pediatric Cochlear Implant Symposium in Nashville on December 11–13, 2014 are proceeding. We had a robust response to abstract submissions and reviews are nearly complete. We will have an exciting program featuring—but is not limited to—the timely topics of auditory brainstem implants, hearing preservation, habilitation, family support, and music appreciation with cochlear implants.

The Omni Hotel is a perfect venue for this meeting in Nashville as it sits in the heart of the downtown music district. The hotel venue is attached to the Music City Hall of Fame and is a short walk from the historic district and world-renowned music venues as well as many of the top restaurants in the world. In addition to an excellent plenary session, panel discussions, podium presentations and invited speakers we will also have a unique poster session after the conclusion of the oral presentations each day. The opening reception on Thursday evening will include a tasting of Tennessee Whiskey being organized for us by the Jack Daniel's Distillery.

Join us for the 14th Pediatric Cochlear Implant Symposium in Nashville, TN on December 11–13! The hotel venue is attached to the Music City Hall of Fame and a short walk from world-renowned music venues!



This is the first pediatric meeting held in the US since 2011 in Chicago, and there will not be another until San Francisco in 2017. We hope you will join us with the world's experts in pediatric hearing loss and cochlear implants in Nashville, Tennessee, December 11–13, 2014.

For more information and to register, please watch the ACI Alliance website (www.ACIAlliance.org), follow us on Twitter @acialliance or visit the conference website directly at www.CI2014usa.com. There is a significant discount in conference registration rates for ACI Alliance members. Special rates are available for Federal government/military personnel and full-time students. Early bird registration ends October 6. ■

The Affordable Care Act: Consumers, States and HHS Prepare for 2015

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



So far this year, over 8 million individuals have selected a health insurance plan through the new Affordable Care Act (ACA) marketplaces. Although the open enrollment period ended a few months ago, individuals experiencing “qualifying life events” (i.e., the birth of a child) may be eligible to enroll during special enrollment periods.

The next open enrollment period for plan year 2015 is scheduled to begin on November 15, 2014 and close on February 15, 2015. Individuals and small businesses can purchase health insurance plans through the online marketplaces (or directly through issuers) that meet the requirements of the ACA.

Currently states which operate their own marketplaces—and the Department of Health and Human Services (HHS) which operates the federal marketplace for states without their own exchanges—are in the process of certifying plans for eligibility to participate in the insurance marketplaces for 2015. Regulators are also in the process of drafting proposed rules to affect the insurance marketplaces in 2016 and beyond. The ACI Alliance State Champions are in the process of collecting data and stories regarding access to cochlear implant services under the ACA plans to share with state and federal policy makers.

Ongoing Challenges

Website Challenges

There remain a number of unresolved issues moving forward as the insurance

marketplaces ramp up for 2015. It is unclear if all of the technical issues with the online marketplaces have been resolved, or if the open enrollment period for plan year 2015 will be plagued with similar problems as was seen in the enrollment period of 2014.

Network Adequacy

Federal regulations have yet to define with any great specificity network adequacy requirements under the new law. At the same time, some providers are skeptical of the new plans and have opted to forgo participating in the new networks, at least in 2014. The result is that plan participants could have insurance coverage but lack access to the specialists they might need or to health care providers in their geographical area.

Transparency

Health care advocates, consumers and providers alike are finding it a struggle to access current and adequate information on the various plans offered, and the benefits covered by these plans, on various exchanges across the country. Some consumers are reporting that issuers will provide detailed information about benefits coverage only after a consumer is enrolled in a specific plan. Advocates are relying on data regarding essential health benefits benchmark plans that is from 2012.

Essential Health Benefits Definition and Coverage

In part because HHS has opted to

implement essential health benefit (EHB) requirements using a benchmark plan approach and in part because specific plan information is often lacking, it remains a challenge to determine which benefits are covered under the new plans. It is also a challenge to determine which benefit limitations are allowable under the new requirements. The ACI Alliance is tracking limits placed on post CI surgery therapy services and plans to provide guidelines to issuers and regulators on the appropriate coverage for these services under a health insurance plan.

Medicaid Expansion

The ACA allows for states to expand Medicaid eligibility to adults living at 133 percent of the federal poverty level or lower. As of June 2014, 27 states (including Washington, D.C.) are implementing Medicaid expansion in 2014. Indiana, Pennsylvania, and Utah are engaging in an open debate about whether or not to expand Medicaid eligibility in 2015; 21 states have decided to not move forward at this time. Whether or not a state expands Medicaid has critical implications for the low income individuals within that state, and the health care providers who treat them. The ACA also allows for those included in the expansion population to have access to different services than under the traditional state Medicaid plan.

Conclusion

The ACI Alliance will continue to monitor health care reform implementation, and to bring challenges and successes to the attention of policy makers at the state and federal level. To learn more about the ACI Alliance’s work at the state level regarding the ACA Marketplaces and cochlear implantation, please visit www.ACIAlliance.org. Preliminary

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Affordable Care Act

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findings from our State Champions' review of their state's Essential Health Benefits Plans are summarized at right. ■

State Champions Review States' Essential Health Benefits

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

We have State Champions in 31 states monitoring the rollout of the Affordable Care Act in their states. Thus far we have found no stated exclusions for cochlear implantation. Some states mention cochlear implants by name in their EHB plans as a covered service but most make no mention at all. ACI Alliance goals vis a vis the ACA are to ensure that:

- The entire continuum of care is appropriately covered
- Coverage language is clear
- As other carriers come on, ensure that they also cover cochlear implants.

We have not been able to determine if the Benchmark plans cover bilateral cochlear implants as this element of coverage is not explicitly mentioned in the plans. (This does not mean there is no coverage for bilaterals; it means it's not specified.)

One concerning trend is the finding that the majority of Essential Health Benefit Plans reviewed have annual visit limits for therapy. Of the 17 states for which we have definitive responses, 70% have stated therapy limits either for the number of covered visits (typically 30 per year) or for other specific issues. Two state plans had lifetime limits, which are illegal under the new law (and will be addressed by our State Champions).

Recognizing that such limitations are a significant concern for patient outcomes, the ACI Alliance Board of Directors has established a new committee charged with developing a therapy guideline for appropriate therapy for children and adults post cochlear implantation. Kathryn Wilson, a board member and speech language pathologist, has agreed to chair this new committee. It is our hope that such a guideline can then be used by our State Champions, by clinics, and by families to address such limits in insurance plans—both those purchased on the ACA Marketplaces and others. ■



Introduction

Susan Thomas, MA, *ACI Alliance Outreach Director/
Continuing Education Administrator*

I am very excited to join the Alliance and support our mission. As an audiologist with over 20 years of experience, I have seen first hand the profound impact that cochlear implant technology has made on the quality of life for recipients. I'm so proud to be a part of the organization's mission of advancing access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness.

An important part of my work is to support the continuing education aspects of our conferences. The upcoming CI2014 Pediatric Symposium will provide an opportunity to earn continuing education units. ACI Alliance is an approved CEU provider for ASHA, American Academy of Audiology and AG Bell. In addition, the Illinois Early Intervention Training Program has approved our symposium for Early Intervention credit. We expect to provide Continuing Medical Education for physicians; it is pending approval. To obtain continuing education credits, when you register for the symposium please indicate which organization(s) you would like us to submit verification to following the symposium.

I look forward to working with you and hope to meet you in Nashville. ■



ACI Alliance Governance

Teresa H. Caraway, PhD, CCC-SLP, LSLC Cert. AVT
Chair, Nominating Committee
CEO, LSLogic, An Oberkottler Learning Community



The Board of Directors of ACI Alliance sets the tone and strategic direction of the organization. Effective board leadership and governance helps ensure that the Alliance can operate to its fullest capacity to achieve its mission. Creating an effective board is a continual process that includes recruitment, engagement and development.

Current Nominating Committee members Rene Gifford, Susan Waltzman, Kathryn Wilson, and Terry Zwolan continue to work diligently to create a slate of nominees to be presented at the upcoming annual Member Meeting at the time of CI2014 Pediatric in Nashville December 11–13, 2014.

The Nominating Committee seeks nominations among both board and non-board members and welcomes suggestions of potential candidates, including self-referral. The Nominating Committee strategically considers many factors including but not limited to experience, geographic location, diversity and skills in areas that contribute to overall board effectiveness and achievement. Members of the Board of Directors can be elected to a one or a two year term in order to stagger the rotation of leadership on the Board. No director may serve more than three consecutive two year terms. Additionally, the Nominating Committee is charged with nominating an individual to serve as Chair of the Board and this nomination is also included on the ballot for the membership vote. Deliberations are made in closed door sessions.

Thank you in advance for your assistance in the nomination process. Now is the time to get involved, volunteer, and be part of this vibrant ACI Alliance community which is working to make a difference in the lives of children and adults touched by hearing loss. ■

Member advocates participated in training prior to visiting with Congressional offices for ACI Alliance on the Hill at CI2013 in Washington, DC. Plan to participate in the next ACI Alliance on the Hill at CI2015 (October 2015).





A Parent's Perspective

Lisa Reznik-Meyers, Parent of Miranda, age 17
Writer and Filmmaker

The ACIA Alliance has been a great resource for me as a parent of a teenager who received a cochlear implant when she was two years of age. This new organization brings together the medical-surgical community, educators, government, non-profit organizations, and private industry to expand access to cochlear implant care. The ACI Alliance provides a critical forum for families to share our experiences and collaborate with professionals.

Last year, we wrote and produced *95 Decibels*, a film to help spread awareness about the extraordinary improvement a cochlear implant can make in a child's life. The film addresses the importance of early detection of hearing loss, new technology and post-implant habilitation. In showing the film to groups in different parts of the country and overseas, we've seen that opposition to cochlear implants still exists. We will continue to work to change this perception, as the ACI Alliance does, whenever we can.

My daughter and I participated in ACI Alliance on the Hill held just prior to CI2013 in Washington, DC, an initiative designed to educate Congressional members on the need for better access to the gift of hearing provided cochlear implants. We look forward to continuing our involvement in this important effort to ensure parents receive comprehensive information about language development options for deaf children.

The mission of the ACI Alliance is vital. Parents and teen members will benefit greatly by being involved in this organization, which has been a long-time in the making. I encourage all parents and their teenagers with a connection to cochlear implants to join the ACI Alliance. Together, we can strive to ensure that everyone facing the challenges of deafness is able to benefit from the life-changing technology of cochlear implants. ■

Cochlear Implants International: An Interdisciplinary Journal

COMING SOON: Proceedings of the First Annual Symposium of the American Cochlear Implant Alliance

The abstracts of the CI 2013 Symposium: "Emerging Issues in Cochlear Implantation" will be published in Volume 15.5 of **Cochlear Implants International**, due online in September.

Subscribers to the journal will be able to download the Proceedings at www.maneyonline.com/cim upon publication. An electronic copy will also be freely available on the ACI Alliance website.

