

AMERICAN COCHLEAR IMPLANT ALLIANCE

Research. Advocacy. Awareness.

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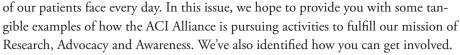
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MESSAGE FROM THE INTERIM CHAIR

Craig B. Buchman, MD, Interim Chair, ACI Alliance Vice Chairman for Clinical Affairs UNC Otolaryngology/Head and Neck Surgery

he American Cochlear Implant Alliance has been hard at work to remove the barriers to cochlear implantation that many



Here in North Carolina, working with the ACI Alliance, we are scheduled to meet with our national elected officials to share information about our cochlear implant program and let them see first-hand the dramatic benefits we are having on patients' lives. We will also discuss the challenges clinicians around the country face in trying to deliver these benefits. We want to focus on the opportunity that Early Intervention services can provide in ensuring families have comprehensive information to make informed decisions as well as appropriate support to follow through on their choices.



We are working on awareness in broader ways as well. We were delighted to have provided encouragement and background for a Today Show segment on cochlear implantation that aired on July 23. View it here: http://www.today.com/health/deafwoman-hears-her-baby-granddaughter-laugh-first-time-live-6C10717122. A reception and private screening of the new dramatic film 95 Decibels, followed by an interactive discussion with the director, crew, and actors will be held on Thursday evening, October 24 at CI 2013. Based on a true story, the film explores the obstacles families face when their child is diagnosed with

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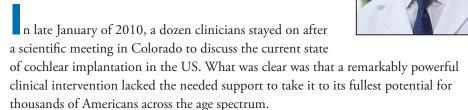
severe to profound hearing loss. To view the trailer for the film, go to: http:// www.youtube.com/watch?v=9oWFxeXM90M. ACI Alliance will continue to promote the film, which we think provides important awareness.

One critical element that is needed to insure access under the Affordable Care Act is recognition of cochlear implantation as an Essential Health Benefit in state plans. We are collaborating with State Champions, providing them with information and support, so that we can achieve this goal. On the research front, Terry Zwolan and John Niparko have been tirelessly working to finalize the details of our CMS proposal to extend the auditory indications for cochlear implantation in adults. This exciting study, which is discussed in an article below, will also pilot a patient registry for the purposes of tracking patient and device outcomes, a process we hope to expand nationally in the future.

Finally, I am looking forward to seeing you in Washington, D.C. for CI2013 on October 24-26. An exciting program has been put together that will help us all learn more about the emerging trends in our vibrant field. Thank you for your support.

MESSAGE FROM THE FOUNDING CHAIR

John K. Niparko, MD, Founding Chair, ACI Alliance Tiber Alpert Professor and Chair Department of Otolaryngology-Head & Neck Surgery President, USC Care University of Southern California



The reasons for this situation? Much has been written. There is a well recognized need for greater insight globally, and a greater will to commit the needed resources up front. Indeed, there was and remains persistently low awareness of candidates who could benefit from implantation, there are steep financial hurdles to developing programmatic support of implants, and there remains a lack of needed professionals and services to guide optimal outcomes. And as we face these challenges, a looming irony is that important societal gains in managing deafness can come from relatively small, early investment.

In recent decades, efforts have been organized to markedly change the landscape for those requiring care for conditions such as AIDS, diabetes and breast cancer. These efforts gathered, and are now supported by a sensitized and now concerned public. We are inspired by these efforts and need to understand how important it is to pursue focused advocacy in enlightening societal views.

In early discussions, it became apparent that organizational support of cochlear implantation—though clearly within the portfolio of many consumer and professional organizations—lacked focus. An overwhelming conclusion of that 2010 meeting was that an organization should be launched to provide specific advocacy to improve access to, and awareness of cochlear implantation. The group decided to call itself an alliance, and the ACI Alliance was born.

An immense 3-year effort has gone into developing the mission, governance and an organizational foundation for the ACI Alliance. A logo, its tagline (Research. Advocacy. Awareness), a website, a mission statement, board participation guidelines and bylaws, research proposals, and financial and strategic plans have all been drawn up with care. A talented, dedicated Executive Director was hired and membership drives have been ongoing. Representation from hearing care professionals, consumers, industry, and related professional and consumer societies has been widespread. Guidance from a sister society in the UK (The British Cochlear Implant Group or BCIG) was an early model that fired our imagination of the possibilities. And now, the work of more than 100 motivated providers and consumers has forged a thriving organization that is propelled by a desire to give the gift of sensitive hearing. It is a gift that can and should be accessible to everyone.

Time has passed since that initial meeting, and steady progress has been made in developing a sustainable organization that can carry an important mission forward. I encourage each of you to consider vigorously participating in the Alliance. Your expertise, your leadership, your sweat and passion are the essentials for our continued progress.



Affordable Care Act and Cochlear Implantation

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

uring its recent strategic planning process (see article on page 4), the ACI Alliance Board of Directors was encouraged by our allied organizations in the field as well as by the cochlear implant manufacturers to move forward on activities to ensure that cochlear implantation would be covered under the Affordable Care Act. We have taken two important steps to achieve this coverage goal: (1) We hired a public affairs firm with special expertise in healthcare, disabil-

ity, and coalition building to guide and support our efforts and (2) We

have established a new State Champions program that is intended to put into place a national-wide network of cochlear implant clinicians who are committed to leading insurance activities in their respective states.

As of today, we have 19 states in which one or sometimes two individuals have committed to lead such efforts. The role of these state leaders is to work with state officials to encourage appropriate coverage language for cochlear implants using guidance from ACI Alliance, to serve as a point of contact for the Alliance and for our members who wish to advocate at the state and national levels, and to monitor how the Affordable Care Act is being rolled out in their state and report back regularly so that we can impact on Federal policies as needed. A chart listing our State Champions will be available on the ACI Alliance website under Advocacy Initiatives [http://acialliance.org/ advocacy/advocacy-initiatives] and will be updated regularly. We also welcome clinicians, educators, parents and consumers who would like to be part of our access to care advocacy. If you are interested, please send an email indicating your name, where you live, and a bit about yourself to ACI Alliance Outreach Director Kelly Anderson at **kanderson@acialliance.org**.

Two of our State Champions have already made important contributions in their states. In one case, there was widespread confusion about whether the state's Benchmark Plan for the new state Exchange (under the Affordable Care Act) covered cochlear implantation. Our Champions in that state clarified that it did. In another state, our State Champion has been invited by the state insurance office to provide specific cochlear implant language for the state's Essential Health Benefits plan.

We will also be working with allied organizations in the field on this topic to provide them with information and guidance for their own advocacy on the Affordable Care Act implementation. We welcome your support and involvement!

We will continue to provide updates for this important ACI Alliance initiative. A regular column on the Affordable Care Act and other aspects of insurance access will be authored and shared as a blog by our new public affairs consultant. We are delighted to introduce the first of a regular column by Theresa Morgan of the firm Powers Pyles Sutter & Verville, P.C. Watch for her blog at www.acialliance.org.

ACI Alliance Research on Cochlear Implant **Outcomes in Older Adults**

Teresa Zwolan, PhD

Vice Chair, Board of Directors, ACI Alliance Director, Cochlear Implant Program University of Michigan



he ACI Alliance will foster research that may impact upon access to cochlear implantation by adults and children. The first research project to be undertaken by the organization will evaluate cochlear implant candidacy for older adults and will be undertaken for the Centers for Medicare and Medicaid Services (CMS). At present, the candidacy criteria for Medicare beneficiaries are more stringent than the FDA guidelines.

Individuals age 65 and older face significant communication difficulties and experience serious life impacts when the hearing loss is so advanced that it limits the benefit derived from traditional amplification. While we believe that the older adult population should be carefully evaluated for any surgical intervention, we also trust that there are important health-related and quality-of-life benefits that accrue from providing cochlear implants to this population.

ACI Alliance has developed and submitted a study proposal to CMS that will examine and evaluate 90 Medicare-age study participants who experienced hearing loss after learning language to evaluate the safety and efficacy of cochlear implants. These are individuals whose hearing loss falls within the FDA cochlear implant guidelines but do not meet the current Medicare guidelines. We will assess outcomes in various domains for cochlear implantation under revised guidelines for such adults.

An innovative element of the study involves the creation of a new patient registry that will house the patient data for the Medicare study. In future years, the registry will provide a means to conduct a range of research projects relating to cochlear implantation in patients of all ages.

Healthcare Reform Overview: Big Changes in 2014

Theresa Morgan

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

n early 2010, Congress passed and President Obama signed the healthcare reform law entitled the Patient Protection and Affordable Care Act (known as "ACA" for short, and called "Obamacare" by many in the media). A number of the law's provisions took effect almost immediately, such as extending coverage to young adults until the age of twenty-six and prohibitions on insurance plans denying coverage to children with pre-existing conditions. But many of the most significant changes are going into effect in the next six months.

The ACA created a new health insurance marketplace organized into state-based "Exchanges." Health insurance consumers will use Exchanges to compare and purchase insurance plans for plan year 2014 and beyond. Consumers should be able to purchase health insurance coverage for next year on the Exchanges starting on October 1, 2013. Individuals will have the option to purchase plans for themselves or their families. Small businesses will be able to purchase plans for their employees. Some individuals will qualify for federal premium subsidies to help them afford health insurance coverage, and small employers will be eligible for tax credits to encourage them to provide health insurance coverage for their employees.

Individuals who now participate in group plan coverage through a large employer will have the choice to maintain that coverage, unless their employer ceases to offer health insurance benefits in the future. The ACA established fines for certain large employers who fail to offer affordable coverage and whose employees receive tax credits to purchase insurance on an Exchange, though the Administration just recently chose to delay application of those fines until 2015.

Most new insurance plans offered to individuals and small groups for plan year 2014 must cover, at a minimum, some benefits which fall within each of 10 statutorily named categories. These categories include rehabilitative and habilitative services and devices. Which benefits are specifically covered under that category will depend on existing coverage in each state. For example, if cochlear implants are covered by the plan which your state has selected as a base plan from which to determine a minimum benefits floor, then it is likely that all new individual and small group plans in that state will cover cochlear implants in 2014—unless an issuer substitutes another actuarially equivalent benefit for cochlear implantation.

At the same time, many states are expanding their Medicaid program under ACA authority to a new category of eligible, low-income adults. If your state chooses to expand Medicaid, then newly qualified beneficiaries will have a choice to access a Medicaid alternative plan, which covers Essential Health Benefits (EHB), as defined by that state. If cochlear implantation is part of that EHB plan, then the new Medicaid beneficiaries may be able to access what otherwise may be uncovered cochlear implant services under the traditional Medicaid plan in your state.

The upcoming changes are significant and complicated, and ACI Alliance is working with our State Champions to monitor health care reform. There are still many unanswered questions. We know the program will continue to evolve. We will provide updates and welcome information from our members that will help us advocate at the state and federal levels to ensure that health care reform is implemented in a manner that protects and enhances access to cochlear implantation.

Access to Cochlear Implantation

Donna L. Sorkin, MA Executive Director, ACI Alliance

he American Cochlear Implant Alliance organized a recent supplement to the peer-reviewed journal Cochlear Implants International. The journal issue, "Access to Cochlear Implantation," was edited by Donna Sorkin, ACI Alliance's executive director. The issue provides unique insight into access issues in the United States providing comparisons with cochlear implant access in four other countries: Belgium, China, Japan, and the UK.

The reasons for low utilization include low awareness of the benefits in the general population and among health care professionals, both in and out of hearing loss; the lack of specific referral pathways; political issues relative to the Deaf community, particularly in the United States; financial issues relative to provision; the need for widely accepted clinical practices; the lack of timely and comprehensive cost-effectiveness data; and the need for a dedicated organization focused on cochlear implantation. This last topic is discussed by ACI Alliance Founding Chairs John Niparko and Teresa Zwolan, who note that with the organization's launch we hope to better address these access concerns.

One especially interesting finding was the variance in utilization rates by children in the US compared with many European countries. Utilization by eligible children in the US is estimated at 50% compared with 90% or more of children in European countries surveyed. Adult utilization of cochlear implants was 5% or less across all of the five countries examined.

The Access issue of Cochlear Implants International is available free online at http://www.ingentaconnect.com/ content/maney/cii/2013/0000014/ a00101s1.

ACI Alliance Governance

Teresa H. Caraway, PhD

Nominations Committee Chair, ACI Alliance Founder and President, Learning Innovation Associates

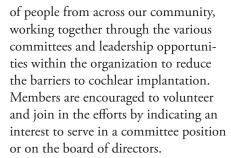
Board Leadership Transition

The Board of Directors of the American Cochlear Implant Alliance unanimously elected Craig A. Buchman, MD, FACS, as the Interim Chair of the Board at its June 2012 meeting. An accomplished surgeon and scholar, Dr. Buchman is the Harold C. Pillsbury Distinguished Professor, the Vice Chairman for Clinical Affairs, and the Chief of Otology/ Neurotology/Skull Base Surgery at the Department of Otolaryngology-Head & Neck Surgery at the University of North Carolina at Chapel Hill. Having served on the Founding Board of Directors of the ACI Alliance, Dr. Buchman accepted the gavel from Founding Chair John K. Niparko, MD on July 1, 2013. Dr. Buchman will be slated as Chair for a vote by the ACI Alliance membership at the October 2013 membership meeting in Washington, D.C. He would be elected to serve for a one-year term of office.

We are grateful to Dr. Niparko, who led the organization from an idea to reality as Founding Chair. Pressing to push forward an idea that he had discussed with others for some ten years, Dr. Niparko worked with Vice Chair Terry Zwolan and others to establish the organization as a not-for-profit 501(c) (3). He led the entire cochlear implant community to get this fledgling organization off to a successful start. We are delighted that Dr. Niparko will continue to serve on the Board of Directors as Immediate Past Chair.

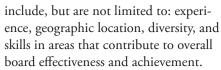
Dr. Buchman takes over an organization that is posed for greatness. He possesses a strong constructive spirit of discontent for the current challenges in the field of cochlear implantation compared to the possibilities. Through Buchman's vision, practical ideas, and willingness to lead, the ACI Alliance is positioned to significantly advance cochlear implantation as the standard of care.

To be successful, ACI Alliance needs the collaborative efforts



Nominating Committee Process

The American Cochlear Implant Alliance by-laws include the requirement for a Nominating Committee to provide leadership, oversight and management of the nomination process, election and annual review of the Board of Directors and officers. The committee consists of both board and non-board members. The Committee is charged with identifying and annually reviewing the appropriate skills and characteristics across professional and consumer disciplines, which are required of Board members to achieve our mission. These factors



The Nominating Committee seeks nominations among both board and non-board members and welcomes suggestions of potential candidates, including self referral. The Nominating Committee recommends nominees for election to the membership based on the number of open positions for that term period. The nominees for the Board of Directors are presented as a slate to the membership at the annual meeting. Members of the Board of Directors can be elected to one-year or two-year terms in order to stagger the rotation of leadership on the Board. No director may serve more than three consecutive two-year terms.

The Nominating Committee is also charged with nominating an individual to serve as Chair of the Board. This nomination is also included on the ballot for the membership vote. All deliberations are made in closed door sessions and nominees are contacted by a member of the nominating committee.

Now is the time to get involved and to volunteer to be a part of this vibrant new organization that is working to make a difference in the lives of those touched by hearing loss!



A Strategic Plan for ACI Alliance

Donna L. Sorkin, MA Executive Director, ACI Alliance

n March 2013, the ACI Alliance Board initiated a process to develop a strategic plan to guide our organization's activities over the next three years. As a new organization with a critical mission and limited resources, we wanted to focus on the most important activities during our initial start-up years.

We began the process with a meeting to gain initial input from allied organizations in the field of hearing loss as well as the leadership of the three cochlear implant manufacturers offering products in the US. Attendees at this initial meeting included ACI Alliance Board of Directors and staff; the leadership of: the Alexander Graham Bell Association for the Deaf and Hard of Hearing, American Academy of Audiology, American Academy of Otolaryngology—Head and Neck Surgery, American Speech-Language-Hearing Association, and Hearing Loss Association of America; and presidents of the three cochlear implant companies operating in the US.

The input gained at this initial meeting provided the ACI Alliance Board with needed background on what our allied partners believed were missing elements and/or needed actions to improve access to cochlear implantation. This set the stage for the discussions during a weekend retreat and follow-up work to finalize a strategic plan for the organization. A summary of the strategic plan, which is organized around four broad goals (Research, Advocacy, Awareness, Organizational Development) follows:

American Cochlear Implant Alliance 2013 – 2016 Strategic Plan

MISSION: The mission of the American Cochlear Implant Alliance (ACI Alliance) is to advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness.

PLAN SUMMARY

RESEARCH GOAL: Encourage and support research on candidacy, criteria and the broad impacts of cochlear implants for children and adults.

- Complete a CMS Study by 2015 to evaluate the safety and efficacy of cochlear implantation under expanded candidacy guidelines for Medicarecovered patients.
- Spearhead planning for a national Cochlear Implant Patient Registry
- Update the Societal Costs of Hearing Loss (Project HOPE) Study

AWARENESS GOAL: 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.

- Conduct international CI professional symposia that address basic and emergent research, health, quality of life, clinical practices, rehabilitation, education, policy and reimbursement
- Present at others' conferences and submit articles to medical journals of primary care physicians
- Use the ACI Alliance website and social media as tools to communicate with broad medical and general audiences
- Act on periodic opportunities to gain broad media coverage related to cochlear implants

ADVOCACY GOAL: Educate and encourage policy-makers and payers to take steps that expand access to cochlear implants.

- Advocate at the state and national levels for appropriate inclusion of cochlear implantation under the Affordable Care Act
- Address early intervention advisement practices under Part C of IDEA during the upcoming Congressional Reauthorization hearings to improve parent information and appropriate services for families of children birth to 3 years
- Initiate ACI Alliance on the Hill to involve ACI Alliance members in outreach and advocacy
- Collaborate with other organizations in and out of hearing loss to initiate a process to develop multi-disciplinary clinical practice guidelines
- Determine whether and how cochlear implantation could be made a mandatory service under Medicaid opening up access to appropriate adults in all states

ORGANIZATIONAL DEVELOPMENT GOAL: Build an effective, sustainable organization.

- Implement best practices for Board performance
- Create a rolling 3-year financial projection with requisite investment in staff, outsource services and other capabilities
- Develop marketing and growth plans for membership growth
- Carry out a multi-faceted fund development program

ACI Alliance on the Hill: Join Us!

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

ur cochlear implant community's first ever opportunity to improve knowledge of the CI intervention with elected officials in Washington will be held just prior to the opening of CI 2013 on Thursday morning, October 24. Attendees and consumer/parent members are encouraged to be part of this important advocacy program. Webinars will be held in advance of the conference to provide

an overview of the process and we will also hold a breakfast at 7AM on Thursday morning to provide guidance and handout materials. Attendance at the breakfast will be mandatory for anyone participating in the Congressional meetings.

While we are still finalizing the details, the following is an overview of the program:

Don't Miss CI 2013

There is still time to register to attend CI 2013 in Washington, D.C., October 24-26, 2013. This first stand-alone meeting of the Alliance will bring together cochlear implant clinicians, educators, and government officials to explore the latest research results, discuss the clinical population, and raise questions regarding clinical implications. Each of six 3-hour topical segments will include expert speakers from across the treatment continuum: otologists, audiologists, (re)habilitative clinicians and if appropriate, educators of children with hearing loss. The final hour of each segment will consist of a panel discussion of the speakers and additional participants who can address broader issues in the patient population affected.

Each day will begin with a one-hour general session to explore cochlear implantation from a range of public policy perspectives with participation by elected and appointed officials concerned with health care. Dr. James Battey, Director of the National Institute on Deafness and Other Communication Disorders, NIH, will address the symposium on Saturday morning.

The topics for the symposium are:

- Hearing Preservation
- Implantation of the Very Young
- Implanting Multiply Involved Children
- Cochlear Implants in Single-Sided Deafness
- Cochlear Implantation in Older Adults
- Telehealth and Cochlear Implantation

Continuing Education Units will be offered from ASHA, American Academy of Audiology and AG Bell. Other elements include poster sessions, a presentation each morning organized by a cochlear implant manufacturer, and a reception and private screening of a new dramatic film based on a true story of one family's experience with deafness and the cochlear implant process. We encourage attendees, as well as consumer/parent members of ACI Alliance, to participate in advocacy activities on Thursday morning prior to the Opening. This will be an opportunity to meet with your state's elected officials in Washington about cochlear implants and access to care. See ACI Alliance on the Hill (above article) for more details.

The early bird registration deadline (after which rates will increase) is August 23. For more information and to register, please visit www.ci2013dc.com. Information on hotel accommodations is posted on the conference website.

- Individuals participating should be professional members of ACI Alliance who are involved in the provision or study of cochlear implantation as a physician, other clinical provider, educator, or researcher. We are seeking advocates who can directly reference their own experience with cochlear implantation during our meetings with legislators. We also expect that such professionals will be attending the CI 2013 Symposium. Applications to participate will be sent automatically to all those who are registered for the conference. You may also request the form directly or ask questions about ACI Alliance on the Hill of our Outreach Director, Kelly Anderson:
 - kanderson@acialliance.org.
- We encourage consumer/parent ACI Alliance members to apply to be part of this advocacy. Parent/consumer members do not need to be conference registrants to participate.
- ACI Alliance will arrange appointments for participants. We will group participants with other individuals from the same state.
- Materials and key messages will be developed for participants to use. Advocates can choose which topics they wish to focus on so that they are discussing issues that they feel comfortable with. Participants are encouraged to share their own experiences as CI clinicians, educators, consumers, and parents.

We expect that the topics will be:

- Awareness about cochlear implants and the benefits they provide for children and adults with appropriate levels of hearing loss
- Cost effectiveness of the cochlear implant intervention
- Importance of ensuring access to care via the various health insurance options—public and private
- Challenges that parents of deaf children face when they are not told about their child's possible CI candidacy during the Early Intervention process
- Support for NIH research on cochlear implantation



AMERICAN COCHLEAR IMPLANT ALLIANCE

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ACI Alliance Board of Directors

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



ACI Alliance: Be Part of a Movement!

William Shapiro, AuD, Membership Chair, ACI Alliance Supervising Audiologist, NYU Cochlear Implant Center

he American Cochlear Implant Alliance is a member driven organization. As such, our effectiveness and credibility derives from the collaborative work of clinicians and educators from across the continuum of care combined with the support and involvement of consumer and parent advocates. There is strength in numbers. If you are reading this and are not now a member, please join ACI Alliance as an Organization or an individual professional or consumer.

At present, 27 clinics, companies or other institutions involved in cochlear implantation are supporting ACI Alliance as Organizational Members. A new area of our website at https://www.acialliance.org/organizational-members will highlight member organizations and their offerings. We believe this will provide important visibility demonstrating both the types of providers involved in cochlear implantation as well as the individual institutions themselves, as they endeavor to make themselves known to the candidate population. While we are still building this website resource, what is posted already demonstrates what we are developing.

We are delighted that the number of individuals who are ACI Alliance professional or consumer/parent members is growing and as of today numbers nearly 700. There are numerous opportunities to be part of our activities such as our work on the Affordable Care Act and our ACI Alliance on the Hill outreach. Please add your voice—together we can improve access to this extraordinary technology. Join us at https://www.acialliance. org/membership.