MESSAGE FROM THE EXECUTIVE DIRECTOR

Focusing on Member Advocacy to Bring About Positive Change

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

An important theme of this issue of ACI Alliance Calling is our organizational focus on member advocacy to bring about positive change in access to cochlear implantation. Visiting with legislative offices and state officials may not seem to be our expertise but in fact it is our knowledge of cochlear implants and the impact that they have on children and adults that makes us effective advocates. Nearly 90 ACI Alliance advocates arrived early at the October 2015 CI conference so that they could participate in our Capitol Hill visits. Based on the post conference survey, this was a rewarding and valuable element of the conference experience with many commenters noting that they hoped ACI Alliance would organize more advocacy days.

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Congressman David McKinley from WV, a CI recipient, was traveling the day of the conference. He sent his encouragement via a video in which he urged ACI Alliance members to reach out to their legislators. His video is posted here: http://www.acialliance.org/?page=AdvocateinCongress. We were joined at the Opening Session by Bobby Silverstein, a highly respected and accomplished public affairs professional. Bobby emphasized that because we are experts in the CI field, rather than public affairs authorities, we are effective advocates.

Besides our Capitol Hill visits and follow-up contact designed to urge for passage of the Early Hearing Detection and Intervention Act, ACI Alliance has developed a position paper on pediatric therapy that can be used by clinicians and families to make a strong case for appropriate insurance coverage for children. The research-based paper is discussed on page 7 by board member Amy McConkey Robbins; Amy served on the paper writing committee. With our State Champions, we will be utilizing the paper to press for improvements in therapy coverage in Federal and state insurance plans.

We urge you to join with us to urge for change. Together we can bring about greater awareness and improved access to care.

Thank you for your support as a member of ACI Alliance. On behalf of the ACI Alliance Board of Directors, I wish you a wonderful holiday season and a healthy and happy 2016.
We, in collaboration with ACI Alliance, invite you to attend the upcoming 14th International Conference on Cochlear Implants and other Implantable Auditory Prostheses in Toronto, Canada, May 12–14, 2016. Several themes will be highlighted: brain plasticity, adult auditory rehabilitation strategies, musicality, and the aging process with implications for cochlear implantation. Featured speakers and multiple panels addressing the current status of relevant issues have been struck. A mini symposium entitled “Cochlear Implants Meet Regenerative Biology” with participation by acknowledged authorities in the area of basic science research has been formalized. Continuing education credits will be available from the US clinical societies for surgeons, audiologists, speech pathologists, educators and therapists. For more information on this topic, please visit the conference website.

We are delighted to have received a record number of abstracts for podium and poster presentations from around the world, ensuring a strong scientific program. We will also address the issue of cochlear implant access and needed advocacy. The venue is the Sheraton Centre in downtown Toronto easily accessible to wherever you wish to go outside of the Symposium in our pedestrian friendly city with its wonderful restaurants, cultural amenities and historical sights. Registration is open and we encourage you to book your hotel early. For those of you who have not had the opportunity to visit our city, rest assured you will find the experience to be a memorable one. See you in Toronto! For more information and to register, visit www.CI2016Toronto.org.
American Cochlear Implant Alliance members, joined by our counterparts from around the world, gathered in Washington, D.C., October 15–17 for Emerging Issues in Cochlear Implantation—our second such symposium.

Six topics received focused attention while other submitted topics were discussed during afternoon podium and poster sessions. A recurring theme was the positive effect of advances in technology—beyond traditional cochlear implants—allowing clinicians to better address the needs of children and adults with a wide range of hearing losses and other issues.

Cochlear implant companies offered breakfast talks on their technologies each morning to crowded session rooms. The exhibit area allowed opportunities for companies and institutions to share information on hearing implants (both CI and other), professional services and products, Federal government programs and non-profit/educational offerings.

Twilight sessions on difficult cases in the areas of medical/surgical, audiology and therapy/education allowed in-depth exploration of challenging clinical topics with panel discussion and audience participation. Attendee feedback indicated that the difficult cases sessions were an especially welcome addition to the educational program.

We took full advantage of being in Washington, D.C. by pressing forward on our public policy agenda. ACI Alliance on the Hill brought together 90 advocates who attended training and then descended upon Capitol Hill for visits to Congressional offices to discuss cochlear implantation and the importance of early access to CI for deaf children. (See “Advocacy to Advance ACI Alliance Goals” below.)

The Opening General Session featured Robert “Bobby” Silverstein, a public affairs leader in disability, education and health policy for over 30 years and the behind the scenes author of the landmark Americans with Disabilities Act of 1990. Bobby urged our members to get involved in affecting national policy stating that as skilled and knowledgeable clinicians, educators, parents/consumers, ACI Members have credibility with legislators. “Effort and courage are not enough without purpose and direction.” He encouraged our members to share stories about the impact of cochlear implants on the lives of those who have received them.


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of children and adults and also discuss the specific access challenges people face. Bobby ended his talk stating, “Some people dream of worthy accomplishments while others stay awake and do them. Be a doer and get involved in advocacy to bring about needed change.”

Attendees were enthusiastic about the lively Saturday morning synergy plenary on Hearing Restoration and Neuroscience moderated by Internet pioneer Vinton Cerf and featuring three scientists who have contributed importantly to the field: David Pisoni, Blake Wilson and Fan-Gan Zeng. Dr. Cerf began with personal remarks on his wife’s experience with receiving cochlear implants after being deafened since early childhood. The free-wheeling discussion explored wide-ranging topics including:

- The need for research on why some CI recipients perform poorly
- What information the brain needs from a CI to operate optimally
- Improving pitch discrimination, a key component for music and certain tonal languages
- Power consumption as a limitation to widespread CI adoption in Third World countries

Session materials used by the Emerging Issues speakers and other featured talks are posted in the CI2015 area of the ACI Alliance website at http://www.acialliance.org/?page=CI2015. We also hope to offer videos of some sessions, which we expect to place on the website later this winter. Also forthcoming is a proceedings document to be published open electronic access by Cochlear Implants International. Watch the website and follow us on Twitter @acialliance for timely updates.

Musician and CI recipient Richard Reed performed at the Welcome Reception.
ACI Alliance Advocates boarding buses for Capitol Hill visits

Advocacy to Advance ACI Alliance Goals

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

ACI Alliance hosted a Congressional advocacy day on October 14, 2015, the day before the start of the CI2015 DC Symposium. ACI Alliance on the Hill followed a similar advocacy event that was held in October 2013. The day’s activities served as an opportunity for 75 CI clinicians, scientists, educators, parents and consumers to educate over 100 Congressional offices on the importance and implications of cochlear implantation.

ACI Alliance and its Washington counsel arranged all House and Senate office meetings and organized participants into 25 groups, so that individuals from the same state would attend meetings together. ACI Alliance State Champions led nearly every group, so as to maximize their expertise in advocacy. Materials and key messages, including meeting talking points, were developed for participants and shared during a training session prior to traveling to Capitol Hill. ACI Alliance State Champions led many of the visits.

Advocates were instructed to directly reference their own experiences with cochlear implantation during meetings as an effective technique in sharing information, regardless of whether one is speaking from the standpoint of a provider or a consumer. Personal stories with respect to the impact of the CI intervention are an important component of increasing the knowledge of Congressional offices on this subject.

Advocates led meetings with Congressional staff members regarding several topic areas pertinent to cochlear implantation. In the Senate meetings, advocates focused on requesting support for the introduction of the Early Hearing Detection and Intervention (EHDI) Act of 2015, H.R. 1344. EHDI would amend the Public Health Service Act to reauthorize research and public health activities related to early detection, diagnosis, and treatment of hearing loss in newborns and infants. ACI Alliance strongly supports new provisions in this legislation that would ensure parents of children with hearing loss are presented with the full range of treatment options—including cochlear implantation—and that the reauthorization is extended to young children, in addition to newborns and infants. Activities authorized under the bill are conducted by the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH).

The House of Representatives passed the EHDI Reauthorization Act in September 2015; hence meetings there were intended to thank offices for their support and focus on educating Hill staff about the CI intervention, the continuum of care, and appropriate coverage of therapy after surgery.

ACI Alliance seeks to build strong ties with Members in both the House and Senate, as well as identify new champions in the disability policy world in terms of hearing health, early intervention, and access to care. In particular, developing Congressional champions that have a personal tie to hearing impairment or the CI intervention is a high priority, whether their experience is first-hand, that of a loved one, or of a constituent. It is tremendously helpful to have a Representative or Senator who is deeply committed to hearing issues. Such champions can lead our cause in seeking to advance favorable legislation, and also defend cochlear implantation and broader hearing loss issues if adverse policies are being considered.

Congressional champions are not developed easily. It takes time and attention to establish strong personal relationships. Reaching out repeatedly to your representatives is the crucial element in developing these relationships. The October ACI Alliance on the Hill will be followed by future advocacy efforts. Thanks to all who arrived in Washington early to participate. If you are interested in being involved in our ongoing advocacy work, please contact ACI Alliance’s executive director Donna Sorkin at dsorkin@acilalliance.org.
Pediatric Habilitation Position Paper: Responding to ACI Alliance Member Needs

Amy McConkey Robbins MS, LSLS Cert. AVT, ACI Alliance Board Member
Speech Pathologist, Communication Consulting Services

A CI Alliance State Champions systematically examined the Affordable Care Act Marketplace Plans in their respective states to assess coverage for cochlear implantation. It was determined that most Marketplace plans had limitations on the number of covered therapy sessions post cochlear implantation. Most commonly, we saw arbitrary caps of 30 sessions per year—a level of service that is insufficient to meet the needs of many young deaf children who receive cochlear implants and strive to develop spoken language.

In response to what we realized was a trend among many small insurance providers, the ACI Alliance Board of Directors appointed a working committee to develop a position paper on habilitation services needed for children following cochlear implantation. The paper was approved by the Board of Directors on July 27, 2015 and is available at: https://c.ymcdn.com/sites/acialliance. site-ym.com/resource/resmgr/Docs/ACI_Paper_Pediatric_Rehab.pdf.

The writing committee was chaired by then board member Kathryn Wilson and included three other speech pathologists who work with children and their families: Hannah Eskridge, Amy McConkey Robbins and Lindsey Zombek. The charge was to develop an evidence-based recommendation for an appropriate therapy regimen for children with cochlear implants. In reviewing the literature, these clinicians determined that there were significant negative effects of therapy caps including reducing the needed intensity of treatment, creating gaps in a therapy regimen, putting children at risk for regression of skills, ignoring the importance of individualized care for each child, and contradicting knowledge of sensitive period and neuroplasticity in language development.

The committee reviewed both cochlear implant literature and standards for pediatric therapies for other developmental skills and interacted with professional governing bodies to see if there was a template for this type of document. (There was not.) The position paper provides a rationale for therapy based upon evidence from multiple, intersecting sources that constitute five domains of knowledge:

- Clinical Outcomes Research cited the frequency of habilitation for CI children as 1 to 2 hour-long sessions per week.
- Clinical Management Reports estimates the average amount of time CI children need to close the gap between chronological age and language age.
- Neuroplasticity Findings cite evidence of sensitive periods for auditory cortical development.

Best Practices Literature documents a regression of skills that occurs as a result of gaps in service when a child’s therapy cap is reached and a period of months goes by before therapy can be re-initiated.

Health Economics Research demonstrates that children who are denied the benefits of CIs experience a disproportionate shortfall in quality of life, relative to other disease states. The economic impact of lifelong hearing loss is reduced dramatically when interventions such as CI, with appropriate follow-up habilitation, are provided.

The recommendation: 50 to 100 hour-long habilitation sessions are recommended for CI children each year. Professionals delivering habilitation services should have expertise and specialized training in pediatric CI and coordination across the child’s providers is essential. Appropriate care includes an assessment of each child’s unique needs, meaning that some children will need fewer sessions in a year, and some children will need more.

The Position Paper on Pediatric Habilitation can be used by families and clinicians during discussions with insurance providers regarding habilitation needs of children who have received cochlear implants. ACI Alliance will also be utilizing the paper to press for appropriate coverage at the state and national levels via our State Champions and our national advocacy efforts. We welcome ideas from members about how this and other position statements might be useful to our efforts to expand access to appropriate care.
A new Nominating Committee was recently formed. It includes three ACIA Board of Directors members: Terry Zwolan, PhD, John Niparko, MD, Bridget Scott-Weich EdD and two ACI Alliance members: Camille Dunn PhD and Stephanie Scott-Moody MD. The committee was charged with the task of compiling a list of candidates who would be willing and qualified to serve on the Board of Directors. One of the goals of this committee was to select board members who represent a variety of occupations (including surgeons, audiologists, speech-language pathologists, educators, other professionals involved in hearing health care, parent(s) of a child with a cochlear implant, and/or adult cochlear implant recipient), as well as a variety of geographical locations and medical or educational settings.

Thank You to Our Outgoing Board Members for Their Service
Three board members recently completed their terms: William Shapiro AuD, Robert Cullen MD, and Nancy Young MD. We are grateful for the years of service and dedication provided by these individuals. We would like to say a special thank you to Dr. Young for her service as the Board of Directors’ Secretary and to Dr. Shapiro for his work as our Membership Chair.

Welcome to New Board Members
The Nominating Committee received the names of numerous qualified individuals for possible board membership. After careful review and lengthy discussion, the Committee selected three candidates who were well suited and qualified to serve:

Holly Teagle AuD is an audiologist and Assistant Professor at UNC where she serves as Program Director, The Children’s Cochlear Implant Center. Holly will be a valuable asset to the board as she actively works with pediatric cochlear implant patients including those receiving auditory brainstem implants.

Andrew Shuman MD is an Assistant Professor in the Department of Otolaryngology – Head and Neck Surgery at the University of Michigan. He serves as Chief of the ENT Section of the Surgery Service at the Ann Arbor VA. He additionally serves as Co-Director of the Program in Clinical Ethics in the Center for Bioethics and Social Sciences in Medicine at the University of Michigan. Andy has two children, both of whom have bilateral cochlear implants. He will provide important input to the board, both as an otolaryngologist and as a parent of children who use cochlear implants.

David Haynes MD is Professor within the Department of Otolaryngology/ Hearing and Speech Sciences, Director of the Division of Otology and Neurotology, and Program Director of the Neurotology Fellowship at Vanderbilt University Medical Center. Dr. Haynes served as a non-voting Board Member while serving as Chair of the Scientific Program Committee for the very successful 14th Symposium on Cochlear Implant Implants in Children that took place in Nashville in December 2014. He was appointed as a voting member and will serve as Chair of the Membership committee. Dr. Haynes will provide valuable input both as a CI surgeon and a past chair of a pediatric CI symposium.

Please consider sending us your name or the names of others you feel are qualified and willing to serve either on the Board of Directors or on one of the committees that have been set up to serve the mission of the ACI Alliance.
The ACI Alliance website provides a range of resources for CI professionals as well as for the general medical community. There is also helpful information for consumers and for parents that can be used to educate primary care physicians and insurance providers.

The CI2015 DC Symposium covered a range of CI topics. The presentations are now available on our website at https://acialliance.site-ym.com/?page=CI2015. Materials from previous ACI Alliance conferences are also available under the “Conference” Tab.

The Cochlear Implant tab on the homepage provides general information for candidates, pediatricians, internists, and others as well as resources that can be used to educate insurance professionals such as the Continuum of Care graphic https://cymcdn.com/sites/acialliance.site-ym.com/resource/resmgr/Files/CI_Continuum_of_Care%281%29.pdf.

The ACI Alliance Career Center is a unique resource specifically for CI-related positions. Located under the Membership tab, it is available free to Organizational Members and for a minimal charge for professional members. Access for viewing is freely available to all.

The online membership directory provides direct access to a network of dedicated CI professionals. Searchable by name or locality, the directory provides contact information for ACI Alliance Professional and Organizational members.

The directory is a great networking tool and referral resource. Keep your personal entry up-to-date by logging into your account and selecting Manage Profile on the right side of the webpage.

Visit our website at http://www.acialliance.org/ today and see for yourself the exciting progress we are continuing to make as an Alliance. If you need help with any of these features, don’t hesitate to contact me at sthomas@acialliance.org.
A Family Perspective

Steve, Lee and Anna Rech / Steve is a Board Member, ACI Alliance

The success stories all start with diagnosis, shock and tears—our daughter Anna was identified as profoundly deaf when she was six months old. Then comes the implant and the hard work. I say it’s hard because it takes time, energy and emotion. In hindsight, however, some of our most cherished memories involve post-implant therapy. Towards the middle of the success story there is sometimes a poem. Anna wrote “The Sounds of Silence” when she was in junior high. There is no more compelling reason to advocate for cochlear implants with ACI Alliance than her poem, at least not to us.

The Sounds of Silence By Anna Rech

Imagine a world without sound
Yes, that’s the way it was for me
No good at all, all around
It was like a silent film; I could only see
No airplane roar; no baying of hound
No mother’s voice; no birdsong
Not even that of Jay, Robin or Lark
I couldn’t hear for a year and a half long
And then a man named Graeme Clark
Created a Cochlear Implant that sound traveled along
When my parents heard of it they had me implanted
When I heard an airplane for the first time, I was shocked
at first, and then slowly but most certainly enchanted.
What was my world but truly and absolutely rocked?
There were now sounds in the silence I had so long taken for granted!
The next step for me was long hours of therapy and work:
With people like Nancy Schenk or Shelley Mathay
I kept going and going, working hard; from my job I did not shirk.

Until, at long last, I could say things like “You’re kidding me” or “No way!”
When I was done, I felt I wanted to yell at the silence, “So there!” and smirk.
So now I can hear the wind through my hair
Perhaps outside my window the melody of “Twinkle, Twinkle, Little Star”
Or maybe the villain in a movie cackling in his lair
And now I can chase my dreams, be they close or far
I think that is all well and good, sweet and satisfying and fair.
My road has been very twisting and winding and long
It has taken many a twist and bend and turn
And each has come and gone like the faint last notes of a song.
No matter how big or small, they have all been a chance to learn.
And I did learn. I’ll tell you about it. Just ask me,
“Hey, Anna, can you tell me about your implants?”

Above: Lee and I helped her on freshman move-in day. She looks older, now that she’s a freshman at Wake Forest University. Go Deacs!

Here is a picture of Anna when she heard that airplane.