MESSAGE FROM THE CHAIR

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I am excited about the coming year and the future of the ACI Alliance. I have not previously had the privilege to work in an organization with such a diverse and dedicated group of people working towards a singular goal—advance access to hearing provided by cochlear implantation.

Before turning attention to future plans, I would like to congratulate Dr. Julian Nedzelski and Dr. Joseph Chen for organizing and executing a very successful CI2016 International meeting in Toronto. Abstracts and Powerpoint presentations for a number of talks can be found on the ACI Alliance website here http://www.acialliance.org/?page=CI2016

This year we have several significant initiatives planned or underway to improve awareness, access and advance the science. There are many methods by which we can contribute to our mission but one of those can result in great leaps forward—changing laws and policy. Changing the coverage an insurer provides, expanding FDA guidelines, and passing legislation can have wide reaching and sustained effects. Gaining the skills to navigate the political arena is empowering. Our State Champions are a vital component of our outreach efforts. The ACI Alliance has already introduced many into the unfamiliar world of politics and policy. This year we will focus on “advocacy at home” and in 2018 in Washington, D.C. at our annual scientific meeting we will organize another “Alliance on the Hill” effort.

We are expanding our website content as the traffic has continued to build. We will begin a project to post abstracts of important studies with a brief summary of the content in lay language and its importance/relevance to patient care. We plan to expand our list of FAQ’s and help provide clear and logical guidance for complicated...
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issues such as vaccination and MRI scanning. We aim to become a “go-to” site for trusted and relevant information about cochlear implantation.

We will be putting forth our first Request For Proposals (RFP) with funding to support the development of a quality of life survey that can effectively capture the tremendous benefits that our patients experience. We plan to continue to support other focused areas of research that are central to advancing our mission.

In collaboration with CI centers, we will continue to co-host annual CI meetings in North America. I have seen a preliminary program for the CI 2017 Pediatric (July 2017 in San Francisco) from our scientific Chairs Dr. Nik Blevins (Stanford) and Dr. Charles Limb (UCSF). You will not be disappointed by the quality of the program nor the location!

The ACI Alliance could not accomplish its goals without the expertise, dedication and energy that our Executive Director, Donna Sorkin brings to work every day. She keeps us moving forward. Also fundamental to the early success of the organization has been the collaboration and support of the cochlear implant companies. The organization has gained significant strength and stability and will only grow in its ability to break down barriers, advance the science and bring cochlear implants to those in need.

Finally, thank you for your support of ACI Alliance and if you have ideas for improving our organization or executing our mission please do not hesitate to contact me.

ACI Alliance Celebrates Life of Co-Founding Chair John K. Niparko

At the Member Meeting in Toronto, ACI Alliance held a Remembrance of the life and work of Dr. John K. Niparko—an extraordinary contributor to the cochlear implant field. A video of the Remembrance event is available on the website.

http://www.acialliance.org/page/JKNMemorial

To recognize Dr. Niparko’s enduring commitment to cochlear implant research and clinical care and honor his contributions to the field, ACI Alliance established a lecture to be given at the annual ACI Alliance sponsored CI Symposium. The John Niparko Lecture will be the conference keynote on a topic relating to cochlear implantation with the first lecture to be given in San Francisco at the upcoming CI2017 Pediatric Symposium. A fund has been established to help support the annual travel and recognition of the Niparko Lecturer. Contributions are tax-deductible to the extent allowed by US law.
ACI Alliance on the Hill—At Home

Advocating to Your Members of Congress in Your Home Community

Donna L. Sorkin MA, Executive Director, ACI Alliance

As a follow-up to the success of ACI Alliance on the Hill held in Washington, DC, in October 2015, we encourage ACI Alliance members to invite your Members of Congress to visit your clinic or school while they are at home for the long summer recess (July 16–September 6). The purpose is two-fold: (1) To share information about cochlear implantation and the local CI provider presence and (2) To ask your Senators to support the Early Hearing Detection and Intervention (EHDI) Act of 2015, S. 2424. The bill has already passed the House. We earlier provided materials for ACI Alliance on the Hill—At Home, which can be found here. http://www.aci alliance.org/page/Summer2016

The significance of consistent advocacy with federal policy makers cannot be overstated. Making connections with Congressional offices and developing relationships with Members of Congress who may champion CI intervention in the future is essential. The best way to develop Congressional champions is to have them visit your setting (clinic, university, school) to see—firsthand—how you work with CI recipients and the extraordinary outcomes people achieve with the intervention. In this election year, elected officials are looking for district/state-based opportunities to visit constituents; your invitation should be well received.

We are proud to share that two of our State Champions have jumpstarted the summer program with Congressional visits to their clinics. Read here about what they did. You don’t have to be a State Champion to carry this off successfully and we are happy to help if you have questions.

Barbara McCallahan of Senator Debbie Stabenow’s office (far right) at University of MI visits with CI recipients Jordan and Grace and their mother, hosted by State Champion Casey Stach (center back).

Led by State Champion Casey Stach AuD, the University of Michigan Cochlear Implant Program hosted US Senator Debbie Stabenow’s staff. Using the above noted materials, Dr. Stach organized a visit by Barbara McCallahan, Director of Community Affairs for the Senator, on July 19. Ms. McCallahan reviewed materials sent in advance, including the Early Intervention (EI) bill that is pending in the US Senate. University of Michigan staff discussed the benefits of EI and shared details on hearing aids and cochlear implants and what they provide for a child with hearing loss. They urged that the Senator sign on as a co-sponsor of the EHDI bill.

State Champion Casey Stach also arranged for the Senate staffer to meet families including two siblings, ages 9 and 4. She chatted with the family and learned how early intervention and CI technology changed their lives. Another conversation was with a mother and her 4-year-old son who began his CI journey with an evaluation at 7 weeks of age, then was implanted at 12 months with his first device and at 15 months with his second. Both families were important communicators regarding the importance of early intervention with a cochlear implant.

Casey Stach offers the following advice to those who want to pursue Congressional visits. She began by writing a letter to the Senator via the Senate website and followed up with patient materials including a video of a mapping as the staffer had expressed interest. Having a family present to discuss their experience is key. This was not difficult and was an important experience for everyone!

Connecticut State Champion, Marion Radeen MS, worked with others at CREC Soundbridge to host a visit by US Senator Richard Blumenthal.

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on July 21. CREC provides audiological and educational services to children throughout Connecticut. Families were invited to attend and share their experiences with the Senator including the value of early identification and follow-up services such as those provided by CREC. The Senator had previously signed on as a co-sponsor of the EHDI Bill after contact by our State Champions in Connecticut.

Engage Your Congressional Representatives to Advance Cochlear Implantation

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

The political season is in full swing and that means there is no better time to invite your U.S. Senators and Congressmen to visit your clinic or school. During the remaining months leading up to the national elections in November, candidates are looking for opportunities to interact with their constituents. The timing for you to extend an invitation for a Congressional site visit could not be better.

Building lasting relationships with Congressional champions is critical to advancing favorable policies on cochlear implantation. We hope you will take this opportunity to invite your representatives to tour your facility, educate them on CI policy issues, give them a chance to meet families, and build bridges with your elected representatives.

Our initiative, ACI Alliance on the Hill—At Home, is already paying dividends. The above centers have arranged visits already. We need you to be the next to host your Senators or Congressional Member.

New Web Resources from ACI Alliance

There are several important new web-based resources that are designed to help expand access to CI care. These include:

Health Insurance and Other Mechanisms for CI Coverage
http://www.acialliance.org/page/Insurance

Visit www.acialliance.com to view the page below:

Early Intervention Success Story:
An Interview with the Maes Family

Coming soon: An area of the ACI Alliance website describing the CI Continuum of Care and a Toolbox of infographics for social media
Implications of Insurance Merger Developments on Access to CI

Leif Brierley, Governmental Affairs Consultant to ACI Alliance
Powers, Pyles, Sutter & Verville PC

On Thursday, July 21, 2016, the Department of Justice (DOJ) filed two antitrust lawsuits against two national health insurance companies Anthem, Inc. and Aetna, to block their proposed mergers with Cigna Corp. and Humana, respectively. The lawsuits, filed as related cases but investigated separately, are predicated on the fact that the two deals would harm competition and not result in the efficiencies promised by the insurers, who had been looking to close their combined $82 billion mergers this year.

By preventing the consolidation of two of the four largest Medicare Advantage plan providers, Aetna and Humana, the DOJ’s lawsuits likely provide relief for Medicare Advantage plan beneficiaries. All four of the plans participate in the individual market across the country to one extent or another. For Medicare Advantage beneficiaries and private insurance enrollees, consolidation of these insurance providers could lead to significantly reduced competition, putting less pressure on the insurers to innovate, provide extended benefits, and keep premiums low.

Attorney General Loretta Lynch echoed these concerns, noting, “If these mergers were to take place, the competition among these insurers that has pushed them to provide lower premiums, higher-quality care and better benefits would be eliminated.” The DOJ further claimed the Anthem-Cigna merger would reduce competition in at least 35 major metropolitan regions and give the combined company excessive bargaining power in negotiating rates with health care providers, including hospitals and doctors.

Aetna, Humana, Anthem, and Cigna have argued that these mergers would benefit consumers through increased efficiencies and expanded reach by the insurers into new markets. Current plan benefits and costs are not expected to be affected. However, in light of DOJ’s lawsuits, Humana announced that they will exit several individual health insurance markets across the country. Humana said they expect their individual health insurance exchange products to cover “no more than 156 counties across 11 states” in 2017, a significant decrease from their 2016 offerings, which were offered in 1,351 counties across 19 states. Additionally, they will discontinue all off-exchange individual market products as well.

These retractions in plan offerings may affect various markets in which these insurers provide coverage. The ACI Alliance is particularly interested in and is closely monitoring coverage of cochlear implants and related rehabilitation.

For now, the DOJ’s suits have been welcomed by most of the patient and health care provider community, most prominently because the actions will prevent the kind of consolidation that could damage competition for consumers, restrict coverage, and reduce rates for providers. As insurers defend these lawsuits and reevaluate their position in the marketplace, the cochlear implant community will need to monitor benefit reductions and marketplace offering changes that insurers may take as they seek to reduce costs and plot their next steps.

CI2017 Conference Program Co-Chairs

Dr. Charles Limb (UCSF), Dr. Nikolas Blevins (Stanford), CI Audiologist Jan Larkey (Stanford), and Donna Sorkin met in July to work on the conference programming.
At Cochlear, we help people hear and be heard.

We empower
people to connect with others and live a full life.

We help transform
the way people understand and treat hearing loss.

We innovate and bring to market a range of implantable hearing solutions that deliver a lifetime of hearing outcomes.
Continuing Education at ACI Alliance Conferences

Susan Thomas MA, Outreach Director

Certificates of Attendance for CI2016 were distributed by email on June 17, 2016. The certificate confirms CE Credits for the professional association(s) that individuals indicated, if allowed by that organization. Each association’s guidelines for acceptance of conference credit hours may differ, and hence those seeking CE Credits should consult the appropriate professional association for CE verification. Continuing Education (CE) submissions to ASHA, AAA and AG Bell for CI2016 have been completed. We will be offering Continuing Education Credits again at the upcoming CI2017 Pediatric Symposium for ASHA, American Academy of Audiology and AG Bell. In addition, CME for physicians will be offered as it was in Toronto. Please contact Susan Thomas (santhomas@acialliance.org) if you have any questions regarding a CE submission.

Get Ready for CI 2017 Pediatric 15th Symposium on Cochlear Implants in Children
San Francisco Hilton / July 26–29, 2017

EDUCATIONAL COURSE DIRECTORS
Nikolas Blevins MD, Stanford University School of Medicine
Charles Limb MD, University of California San Francisco

The Organizing Committee, comprised of cochlear implant clinical and research staff from each of our institutions, is excited to partner with ACI Alliance on the upcoming CI 2017 Pediatric symposium. We are developing a dynamic program with a focus on six themes that have the potential to improve pediatric cochlear implantation. These themes are:

- Music: Improving Perception and Appreciation
- Technology: Improving CI Results in an Increasingly Interconnected World
- Cognition: Improving Our Understanding of Language Development and Central Plasticity
- Outcomes: Improving the Use of Metrics for Success
- Indications: Improving Hearing in Expanded Populations
- Delivery: Improving Efficacy, Availability, and Efficiency in CI Care

Plan to attend, participate in the learning activities, and share your work. We are seeking poster and podium proposals; the submission process on the conference website will open on/around October 1. Watch for details on the ACI Alliance website and via email blasts. And don’t forget, in planning your trip, to leave time to enjoy all that San Francisco offers!
Learn how the combination of AB and Phonak technology delivers improved hearing for your patients and easier, more efficient fittings for you. Visit AdvancedBionics.com, or speak to your AB representative.
CI 2016 Toronto / May 11–14, 2016
14th International Conference on Cochlear Implants and Other Implantable Technologies

Thanks to the excellent efforts of the scientific program committee from the University of Toronto, a team led by Drs. Julian Nedzelski and Joseph Chen, the May CI 2016 Conference was outstanding. We enjoyed a record number of enthusiastic attendees at a North American CI meeting representing 66 countries. Keynote addresses every morning covered wide-ranging topics including music perception, the sound of a cochlear implant by SSD patients, auditory cortex plasticity, adult rehabilitation and more.

Presentation materials (including Powerpoints for those who gave permission) as well as the full conference program are available on the ACI Alliance website under the Conferences tab at http://www.acialliance.org/?page=CI2016. Presentations are arranged by topic such as Binaural/Bimodal, Data Logging, Music Training, Outcomes in Older Adults, ABI, EAS and many others.

The panel on single-sided deafness featured Drs. Van de Heyning, Gantz, Arndt, Rajan, and Marx.

The Poster Sessions provided learning opportunities at the end of the day.

Attendees enjoyed lively keynote presentations each morning.

Scientific Program Co-Chair Joseph Chen MD offered introductory comments.

Scientific Program Co-Chair Julian Nedzelski MD (left) and ACI Alliance Board Chair Craig Buchman MD (right) opened the conference.
SYNCHRONY

3.0 Tesla MRI without magnet removal

Cochlear implants will never be the same again. With its revolutionary rotatable magnet design, the SYNCHRONY Cochlear Implant is the only CI able to undergo a 3.0 Tesla MRI without magnet removal. The benefit to your patients?

No discomfort, no additional surgeries, no hearing downtime.

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Neil Maes is the real deal—a child born deaf who was early identified, early implanted with cochlear implants, and part of a family that worked hard at providing him with what he needed to develop spoken language. In May 2016, 11 year old Neil traveled from his home in South Carolina to compete in the Scripps National Spelling Bee in Washington, D.C. Neil was identified with a hearing loss through newborn hearing screening, fit with hearing aids early, and received his first cochlear implant at 11 months of age. His family worked with an auditory verbal therapist and utilized a parent-centered therapy approach emphasizing talking, listening, and play. He has two younger sisters; one is also a cochlear implant recipient. ACI Alliance staff spoke with Neil’s mother, Christy Maes, about their family’s experience with early intervention and their cochlear implant journey.

ACIA: What were you told by early intervention specialists when Neil was first identified with a hearing loss?
CM: We were lucky to work with a number of early intervention specialists who provided us with a lot of information about the different options available for children with hearing loss. We received information on spoken language, sign language, hearing aids and cochlear implants. We were given literature to read including a helpful booklet from the Alexander Graham Bell Association.

ACIA: Were you told about cochlear implants and Neil’s possible candidacy? Who first told you about cochlear implants?
CM: I had a friend, prior to having children, who had a cochlear implant so I was familiar with the technology. Additionally, I’m a nurse and I had some exposure during nursing school. Our early intervention specialist at the SC School for the Deaf and Blind, as well as the audiologist who diagnosed Neil, both brought up Neil’s possible candidacy.

ACIA: Were you told that early implantation leads to better outcomes?
CM: Yes. Charles, our early intervention specialist at the SC School for the Deaf and Blind, mentioned the importance of early implantation.

ACIA: Were you directed to your cochlear implant center, Medical University of South Carolina (MUSC)? If not, how did you find out about the center?
CM: Our home in South Carolina is between two cochlear implant centers. I was given information by Charles on both centers and did research on my own. I contacted audiologists at both centers and collected information that helped us make our decision.

ACIA: What guidance did you receive from your pediatrician regarding Neil’s hearing loss?
CM: Neil’s pediatrician wasn’t a big part of our hearing journey. We saw him regularly for well-baby checks and other health issues but our audiologist, the early intervention specialists, and the CI center staff were the ones who we interacted with on Neil’s hearing loss.
ACIA: Did you have any negative experiences with professionals? If so, how did you handle the situation?
CM: We worked with so many great individuals and those are the ones you really remember. However, there was one negative visit from an early intervention specialist at the beginning of our journey. She only focused on the difficulties Neil would encounter with a spoken language approach, none of the positives. She even told me he wouldn’t be able to say his own name—that it would be too difficult. After she left the house, I called the early intervention office and requested that they send someone else next time. I felt it was important to focus on the positives. Parents are the best and first advocates for their child.

ACIA: Was there any information you would you have liked to receive from early intervention specialists before getting to your cochlear implant center at (MUSC)?
CM: Not that I recall. We worked with a number of great early intervention specialists. I was emailing and calling MUSC before we even had our first appointment. I felt like we were well prepared for our first visit.

ACIA: Did Neil wear hearing aids prior to the cochlear implant? How old was he when he received them?
CM: Yes, Neil was fit with hearing aids at about 3 months of age. My understanding, as part of the CI candidacy, was that he needed to wear them for around 6 months to determine if he was receiving meaningful benefit from the hearing aids.

ACIA: When did you start parent-centered therapy? Before Neil received his cochlear implant did he have exposure to language?
CM: We were learning some sign language before we learned that Neil was definitely a candidate for CIs. Once we knew he was a candidate we switched to all auditory-verbal therapy. He was about 6 months old when we started working with an Auditory Verbal Therapist (AVT). We followed the advice from our AVT who advised: “No TV and minimize background noise. Lots of talking and reading.” We began this program even before the cochlear implant. I did a lot of research. I was determined for him to have speech and language. Early interventionists came to the house. We did goal directed play.

ACIA: Is there anything you would like to share about the support you received from MUSC? How do you think MUSC provided support? What particularly helped your family?
CM: They are just such a great team. The audiologists, speech language pathologist and surgeons all work together. It is obvious they care a lot about the child’s outcome. They knew time was of the essence and worked hard to not lose a moment in moving Neil forward. We were lucky that both of our children were perfect candidates. We’ve spent a lot of time at MUSC and they feel like family. They get genuinely excited about our progress and success, like Neil’s competing in the Spelling Bee.

ACIA: Your six-year old daughter also has a hearing loss and uses CIs. Was your experience with early intervention as positive with your daughter?
CM: The same support system was available to us when our daughter was diagnosed. However, we didn’t utilize the early intervention system as much because we already had therapists in place. We jumped right in with MUSC. My daughter had her first visit at two weeks of age with the surgeon who performed Neil’s surgery. She is a pistol and picked up speech and language quickly. Both of them have done well, but hear differently with their CIs. All children learn differently.

ACIA: If you had one piece of advice for the early intervention system, what would it be? What is the most important thing that early intervention can do to help a child along this path?
CM: Don’t assume that anybody knows anything. Offer as much information as possible and accommodate different learning styles. Some people need verbal while other people like written information. I tend to like written as I can go back and re-read and really process what I’ve been given. AG Bell is a great resource. Inform families of their options. Educate, educate, educate! Allow families to make a decision on what is best for their family. Many families find the diagnosis of hearing loss overwhelming and are in denial. They need help with their feelings that this is a negative diagnosis. Still, families need to know that time is of the essence.