MESSAGE FROM THE CHAIR

Colin Driscoll MD, Chair, ACI Alliance
Professor and Chair, Department of Otolaryngology–Head and Neck Surgery
Mayo Clinic, Rochester, MN
driscoll.colin@mayo.edu

Our growing membership brings expanding opportunities to lead and influence. We are now nearly 1500 individuals and institutions representing multiple specialties, all focused on hearing loss and cochlear implantation. We will have a large presence for the ACI Alliance on the Hill event during the upcoming meeting in Washington, DC on March 7, 2018. If you have not yet signed up please take a moment to do so (www.acialliance.org/page/ACIAOnTheHill).

As a collective, we have an enormous amount of experience with the CI process, outcomes, access barriers, and research needs. Have you ever found yourself wondering what everyone else does about some issue? What is best or common practice? Wouldn’t it be great to be able to ask the ACI Alliance membership? We think so and thus have decided to institute a program to allow researchers who are ACI Alliance members to tap this vast wisdom twice a year via survey. ACI Alliance will review and batch submitted surveys and send to the membership, but only twice per year out of respect for your overly taxed email inbox. Participation in any survey is of course voluntary but I hope you will help investigators out with engagement. We expect these projects to lead to presentations at our meetings and to publications for an even broader audience.

I am looking forward to seeing everyone at the CI2018 Emerging Issues symposium in March. Best wishes to you and your family during the holiday season.
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CI2018 DC Emerging Issues Symposium

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www.CI2018DC.org

Donna L. Sorkin MA, Executive Director,
American Cochlear Implant Alliance

John Niparko Memorial Lecture
We are delighted to announce that this year’s John Niparko Lecture will be given by William G. Kronenberger PhD. The topic of his lecture is “Executive Functioning and Language Development in Children with Cochlear Implants.”

Dr. Kronenberger is Professor and Director of the Section of Psychology and Executive Vice Chair of the Department of Psychiatry at Indiana University School of Medicine. He serves as Chief of the Pediatric Psychology Testing Clinic and Co-Chief of the ADHD Clinic at Riley Hospital for Children. Dr. Kronenberger has been an investigator on multiple projects addressing neurocognitive, psychosocial, and spoken language development in children with hearing loss and cochlear implants or hearing aids. He is the author of several tests on these topics.

Four Emerging Issues
Four topics were determined to be pressing issues with regard to access to CI care. These issues have not been explored in depth at other CI meetings. In several instances, we hope that these discussions will help us to determine some appropriate activities and actions going forward. Each issue discussion will begin with presentations by topic experts, followed by a 20 to 30 minute interactive panel with audience participation and Q&A.

William G. Kronenberger PhD
Parental Engagement has a key impact on Pediatric CI Outcomes. Parents and the home routines they create play central roles in a child’s development. Research in pediatric CI outcomes has identified specific ways in which significant caregivers can promote acquisition and growth in spoken language and literacy skills in children with hearing loss. This research also highlights the effectiveness of providing parents and caregivers with specific knowledge and strategies that can be woven into family life to support their child’s communication and literacy development.

Practice Management is one of the most significant issues facing the cochlear implant field today. With approximately 120,000 US CI recipients, clinics must determine how they will continue to serve those who received CIs in the past, along with meeting the demand for new patients, given small increases or even the same number of audiologists in most clinics. CI programs are grappling with innovative strategies and assessing whether and how these techniques affect the quality of care. This session will involve representatives of industry to help assess new industry provided care tools.

Quality of life associated with cochlear implantation is the subject of a major study sponsored by ACI Alliance which seeks to measure and quantify the effects of deafness on adults (i.e., physical, emotional) to fill this gap and improve patient counseling. The conference session will explore the topic across the age spectrum. This topic also impacts health care insurance coverage, which continues to restrict access.

When cochlear implants were first introduced, candidacy determination was a straightforward process: patients were expected to have bilateral profound deafness and demonstrate no benefit from hearing aids, which often meant 0% speech recognition. As technology has improved, candidacy has expanded to include patients with greater amounts of residual hearing and greater speech recognition skills. CI Candidacy in 2018 will review recent changes, including the use of contemporary measures to evaluate traditional candidates, medical/surgical considerations when determining CI candidacy, the role that age and cognition play in candidacy considerations, and expansion of candidacy to include patients with SSD and asymmetric hearing losses.

Podium and Poster Presentations
Those who submitted abstracts to give a podium or poster presentation have received notifications. We were very pleased with the number of high quality abstracts submitted. The abstracts are being organized into sections of like topics and will be published soon. Poster submitters can find details about poster preparation and showing times here on the CI2018 DC website: http://www.ci2018dc.org/site/index.php/scientific-program/presenter-resources. The successful poster highlights session that we introduced in San Francisco will be included again on Thursday at 3:40–4:10 PM. This is a chance to hear brief highlights from poster presenters just prior to the poster session on Thursday at 4:10-5:30 PM. We have extended the availability of posters for viewing until Friday at 3:00 PM to provide sufficient time for attendees to access this important conference resource.

Accepting Nominations for the Board of Directors
This coming March 2018, we will present a slate of individuals to be elected to the ACI Alliance Board of Directors. The slate for the Board of Directors will be selected by the Nominating Committee comprised of Holly Teagle AuD (Chair), John Dornhoffer MD, Colin Driscoll MD, and Amy McConkey Robbins MS, LLSL Cert.AVT.

We encourage our membership to participate in this process by considering the nomination of a colleague to serve as a member of the Board of Directors. Nominees should be affiliated with our field and may include physicians, audiologists, speech language pathologists, educators, and others on cochlear implant teams as well as cochlear implant recipients or family members of a recipient. Self-nominations are also encouraged.

Nominating someone is easy—simply fill out the Nominations form https://www.acialliance.org/page/ApplyBOD by the deadline of January 20, 2018. Nominated individuals will be reviewed by the Nominating Committee and the slate will be announced prior to the CI 2018 DC Emerging Issues Symposium. Voting by the ACI Alliance membership will be held at the Member Meeting on Friday, March 9 at 8:30 AM.

Board membership involves a commitment to attend 2 in-person meetings each year as well as 2 to 4 phone meetings each year. Board members are also expected to participate on committees or in activities where their input and expertise can be utilized to advance the organization’s goals.
Student Poster Competition
A new conference feature is a poster competition for student and resident attendees. The poster submission site has been left open for those who wish to participate. The deadline to submit is December 31. A winner and two honorable mentions will be selected and announced on Friday morning, March 9. The winner will receive a $100 cash prize. Winner and honorable mention recipients will be announced in ACI Alliance Calling and provided with a student membership. http://www.ci2018dc.org/site/index.php/scientific-program/abstract-submission

CI Companies Share Technology
CI2018 DC offers important opportunities to interact with our partners, the three CI companies, about their technology and service offerings. Sessions will be held on Wednesday afternoon beginning at 1:00 PM prior to the official conference start and each morning at breakfast symposia at 7:30 AM. CEU credits will be offered.
To register for a CI company event: https://www.acialliance.org/event/2018industrysymposia

Best Parties Ever
The Thursday Reception following the poster presentations is always a favorite way to reconnect with friends and also visit the exhibit hall. This year’s reception starting on Thursday from 5:30-7:00 PM will be no exception. You won’t want to miss the opening party where you can enjoy a glass of wine and some light food, visit exhibits and posters, and chat with colleagues and friends.

Movie Premiere
A second opportunity to mingle and learn in a very fun setting will occur on Friday at 5:00–6:30 PM when we premiere the new documentary, The Listening Project. The film and champagne reception will be held immediately following the close of conference sessions. The Listening Project features interviews with 12 young adults who were born deaf and diagnosed late.
given the timeframe (prior to newborn hearing screening). Filmmakers Jane Madell and Irene Brodsky have beautifully captured the opportunity afforded by hearing aids, cochlear implants and auditory therapy for children born deaf. This powerful film will be shown first at our conference and followed by a panel discussion with several of those featured in the film as well as the filmmakers. The event is free for registered CI2018 DC attendees. Other interested individuals may attend (space permitting). Refreshments will be served and CART captioning will be provided (and throughout the conference). For more information, http://www.acialliance.org/page/TheListeningProject

Continuing Education
American Cochlear Implant Alliance is an approved continuing education provider for the American Academy of Audiology (AAA), American Speech-Language-Hearing Association (ASHA) and the AG Bell Academy for Listening and Spoken Language. We will offer up to 20 Continuing Education contact hours during the CI2018 DC Emerging Issue Conference. 13.5 hours of Continuing Medical Education (CME) credits will be offered through our meeting planners, the American College of Surgeons. A certificate of participation will be provided to all conference attendees. For information on continuing education at the conference, contact Susan Thomas (sthomas@acialliance.org).

ACI Alliance on the Hill
Our upcoming conference will be held at an ideal time for us to meet with Congressional Members and staff to familiarize them with the extraordinary benefits of cochlear implants as well as access concerns. ACI Alliance on the Hill will be held on Wednesday, March 7—the day before the CI2018 Symposium opens. (CI company pre-conference sessions will also be held on March 7 in the afternoon; participants in the Congressional visits will be unable to attend the Wednesday company events.) Due to the logistics of organizing an event like this, member participation is limited to 100 people.

ACI Alliance will organize the day for our members. We will schedule meetings with Congressional offices, group participants with others from their state, conduct training (both via teleconference two weeks prior and on-site that morning), develop materials and messaging, and provide transportation from the conference hotel to Capitol Hill. This will allow our members to focus on what they know best: the benefits of cochlear implants and what we need to do to ensure full access to care. Our focus this year will be on insurance and the continued availability of Medicaid for the entire continuum of CI care. A secondary issue may be the rollout of the Early Hearing Detection and Intervention Act.

The day will begin with a training lunch at 11AM at the conference hotel (attendance is required to participate in the visits) and end at approximately 4:30 PM. The precise ending time will depend upon the assigned visits for each person. To apply to participate, please review the information and complete an application https://www.acialliance.org/page/ACIAOnTheHill

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As 2017 draws to a close, Congress is facing a slew of issues to address before year end. In addition to the need to authorize funding for the federal government, Congress must also reauthorize the Children’s Health Insurance Program (CHIP) and take action on a package of bipartisan Medicare policies—including possible permanent repeal of the Medicare outpatient therapy caps. Despite a relatively small number of bills passed this year to date, Congress managed to pass a reauthorization of the Early Hearing Detection and Intervention (EHDI) Act, a key ACI Alliance priority.

On October 17, the bipartisan EHDI Act was signed into law, reauthorizing funding and support for early detection, diagnosis, and treatment of hearing loss in newborns, infants, and young children. ACI Alliance strongly supported this legislation, and worked closely with the bill’s champions in the House (Representatives Brett Guthrie, R-KY and Doris Matsui, D-CA) and in the Senate (Senators Rob Portman, R-OH and Tim Kaine, D-VA) to advance the bill through Congress. ACI Alliance worked on language that was incorporated into the legislation that emphasizes the importance of parents receiving accurate and comprehensive information about the hearing technology and communication options available to their child. The bill also expands EHDI-related grants to include children younger than three, in addition to newborns and infants.

Recently, ACI Alliance met with Health Resources and Services Administration (HRSA) officials, who oversee major aspects of the EHDI program, to discuss the implementation of the new law. Additionally, ACI Alliance will soon meet with U.S. Department of Education officials about EHDI implementation.

Funding for CHIP, which provides health care coverage for 9 million low-income children across the country, expired in October when Congress failed to reach an agreement to reauthorize the program. This will eventually lead to disruptions in state CHIP programs, which could impact access to cochlear implants (CIs) and related therapy. Some states have already turned to the federal government for emergency funding assistance to maintain their CHIP programs and 27 more states are likely to run out of funds in the first quarter of FY 2018.

Currently, some states are operating on reserve funding or even facing the possibility of having to cancel health coverage for children in their state. While the House has passed legislation to reauthorize the program for five years, the Senate has not acted on its CHIP reauthorization bill to date. However, Senate Finance Committee Chairman Orrin Hatch (R-UT) has vowed to enact CHIP reauthorization as soon as possible.

Finally, legislation to permanently repeal the annual limit on per-patient therapy expenditures under Medicare Part B, commonly known as “therapy caps,” may also be included in a package of bipartisan Medicare provisions. A group of House and Senate leaders introduced legislation to repeal the therapy caps in late October. The legislation would replace caps with a targeted medical review of claims totaling over $3000, relieving patients and providers of some of the bureaucratic burden from the current process. However, the legislation continues to require that services must be shown to be medically necessary, as justified by appropriate documentation in the medical record. Despite the requests of stakeholders, physical therapy (PT) and speech-language pathology (SLP) services do not receive separate $3000 thresholds. They are combined under one cap. Individuals with cochlear implants routinely exceed the current therapy caps, so repeal of the existing cap would be an improvement for CI patients and providers. ACI Alliance will continue advocating on the therapy cap bill and report developments as they occur.
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Everyone remembers certain events that were major landmarks in their life: marriage, a new job, birth of a baby, or—not so happy—death of a loved one. For me, after watching my hearing deteriorate for almost half my life (I’m 82), getting a cochlear implant was one of those major landmarks.

With my new CI, I was no longer isolated. I could converse easily with Joy, my wife. I could talk on the phone. Family get-togethers were once more enjoyable instead of being an onerous ritual. I became more active again in the community; to the surprise of some of my acquaintances, I no longer sat there quietly at meetings but talked up and joined in discussions.

When I decided to get a CI, I kept notes about my experiences and feelings. I wasn’t sure what I planned to do with these memoirs. Maybe it could help to others with hearing loss considering hearing aids or cochlear implants.

With that in mind, I contacted Donna Sorkin and Naama Tsach of ACI Alliance to see if they were interested in what I wrote. Yes, they were. In fact, they wanted to publish it as part of Naama’s Blog on the organization’s website. They felt that we should use my musings as a way to tell older folks that you’re never too old to get a cochlear implant. (And you aren’t. Just ask me.)

After some editing by the ACI Alliance staff, my first segment—The Decision—was ready for publication. I am so appreciative for their wonderful job! You can view my experiences, in a blog format, here:

http://www.acialliance.org/blog-post/1644925/An-Octogenarian-s-CI-Journey

Many people have expressed interest in my CI. A doctor I visited had no idea what it was. When I explained how a CI works, he thought the device might help his father who is getting little benefit from hearing aids. My audiologist asked me if I’d mind answering some questions from a patient who is thinking of getting a CI and I have exchanged several emails with the man.

I’ve since met with others who have questions about hearing, hearing loss, hearing aids, and cochlear implants. A friend who is president of the local Lions Club asked me to give a talk to the Club next month. He says he knows several members who might benefit from cochlear implants as they have great difficulty hearing, even with hearing aids.

I also put a note about my CI on my college class website with a link to the ACI Alliance blog, and will have a short article in the next class newsletter.

What else can I do? Well, our local county has an adult education program. Anyone can suggest a class on a topic they want to teach. We’ve had classes on everything from fly-fishing to geology to French literature. Spring term is coming up soon. It’s about time there was a class on hearing, hearing loss, and technology that can help—including cochlear implants!

*Editor added the title for Bruce’s article. Pay it forward—a goodwill movement popularized by the movie of the same name starring Kevin Spacey and Helen Hunt. The movie concept was that the recipient of a favor did a favor for others, spreading out good deeds. We think Bruce Sloane is “paying it forward.”

Bruce Sloane, M.S., M.A.

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