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

This past week I gave a 45-minute session about cochlear implantation at the Minnesota Academy of Family Physicians Spring Refresher meeting. It was not my usual audience, so I was not sure what to expect but they were engaged and encouraged me (rather us!) to communicate more with them. Since CI is such a narrow topic it may be easier to get on the podium with the broader subject of hearing loss. Our staff is keeping an up-to-date listing of primary care organizations and meetings in each state, making that part of the process easy. (Contact Susan Thomas, sthomas@acialliance.org for information on your state.) We discussed the general lack of awareness and difficulty in recognizing who is a CI candidate. The recently completed ACI Alliance Adult Clinical Guidance (see page 4) document http://www.acialliance.org/page/AdultCandidacy is one way to provide concise, basic information to providers. The attendees I spoke with encouraged us to present at Family Practice meetings and also publish in their primary journals. Given the broad knowledge base needed to be a family medicine physician, they benefit most from review type articles that highlight key points. I encourage you to consider submitting.

We have two research projects we are co-sponsoring. The request for proposals for a study to better understand the quality of life impact of cochlear implantation closed on April 24. I anticipate we will have some outstanding proposals to review. This grant is possible through a unique collaboration with Advanced Bionics, Cochlear, MED-EL, Oticon Medical, and the ACI Alliance. I hope that this can be a model we use again in order to make meaningful progress on the most important issues affecting our patients and industry. The second research project is a collaborative effort with the American Hearing Research Foundation and will focus on

continued on page 2
MESSAGE FROM THE CHAIR  continued from page 1

developing a plan to update the Project Hope study and address the societal cost of severe to profound hearing loss today. More on both of these research efforts is available below.

Wishing all a wonderful spring—yes, it is spring in Minnesota now.

ACI Alliance Research

Revised Medicare Indications
Our mission identifies three elements that comprise our work: Research, Advocacy and Awareness. ACI Alliance now has one major research project underway—Evaluation of Revised Indications for Cochlear Implant Candidacy for Adults under Medicare. Information about that study is available here: http://www.acialliance.org/page/MedicareExpansion. It is hoped that this study will provide outcomes data that will result in a decision by CMS to expand CI candidacy for Medicare beneficiaries.

Quality of Life Outcomes Measures
A second area of research was announced on February 21 with our announcement of a funding opportunity in Quality of Life Outcomes Measures of Cochlear Implantation. We are delighted that a strong set of proposals was submitted by distinguished scientists and clinicians. A committee of the ACI Alliance Board of Directors will review the proposals with an award expected by June 1, 2017. For more information on this important new initiative, view the announcement http://www.acialliance.org/page/QOLMeasures.

New Research Opportunity: Societal Costs of Severe-Profound Hearing Loss
We are excited to announce a new Call for Research Proposals: Planning for a Study on the Societal Costs of Hearing Loss. American Cochlear Implant Alliance will partner with the American Hearing Research Foundation (AHRF) to offer funding for a $25,000 research grant on the societal costs of deafness. It is intended that the grant recipient will explore and recommend a detailed plan for updating the seminal Project HOPE study published in 2000 (Mohr PE et al, The Societal Costs of Severe to Profound Hearing Loss in the United States, International Journal of Technology Assessment in Health Care, 2000;16(4):1120-35. This grant is intended to support the planning of a future study to address societal costs of severe-profound hearing loss.

The proposed study should review and summarize comparable studies completed for other interventions and the impact on healthcare access. Issues that should be considered include (but are not be limited to):

- Population to be studied (adults, children or both)
- Data collection plan
- Method for demonstrating cost effectiveness
- Personnel
- Budget and timeline to undertake a future study

continued on page 3
Submissions for this grant will be made via our partner, American Hearing Research Foundation, using their grant submission process. The link where the research will be described is: http://american-hearing.org/research-grants/

The link for the AHRF grant application guidelines is http://american-hearing.org/research-grants/grant-application-guidelines/

If you have questions regarding this grant, contact Donna Sorkin at dsorkin@acialliance.org. If you have questions about the grant submission process, address them to Joan Wincentsen at Joan@American-Hearing.org.

ACI Alliance Steps Up Its Advocacy with State Committees

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

ACI Alliance State Champions

The State Champion network was established in 2013 as one of the first programs implemented by the newly organized ACI Alliance as a means of harnessing the knowledge and energy of our members throughout the US, and applying this knowledge and energy to the organization’s advocacy. State Champions are employed at cochlear implant centers, hospitals, non-profit organizations, schools, or independent clinical offices. They represent the full continuum of cochlear implant care as ENTs, audiologists, speech pathologists, educators, and psychologists. Several State Champions are parents of children with cochlear implants or adult CI recipients. We currently have 61 State Champions representing 35 states. http://www.acialliance.org/page/ACIAStateChamps

ACI Alliance advocacy efforts are further strengthened by the Powers firm, a governmental affairs law firm in Washington, DC with special expertise in healthcare, disability, and education. Powers attorneys and legislative staff support ACI Alliance in strategic direction, lobbying, legislative development, and grassroots advocacy. Our Powers experts have authored an article on expected healthcare changes below.

State Champions participate in teleconference briefing calls and may also request one-on-one assistance on specific topics in their state. They attend an in-person meeting to discuss our initiatives at the annual CI conference. Thus far, our State Champion activities have focused on:

- Advancing cochlear implant awareness among national elected and appointed officials
- Pressing for appropriate CI coverage in the Affordable Care Act Marketplace Plans at the state level
- Identifying coverage challenges such as appropriate rehabilitation for children or equipment replacement
- Urging for reauthorization of the national Early Hearing Detection and Intervention (EHDI) Act

State Champions have encouraged ACI Alliance to continue with these key topics and also take on additional issues going forward including ensuring appropriate Medicaid CI coverage in the years ahead. We will continue to encourage parent choice on communication options and the importance of parents having full information about communication and technology options, including cochlear implants.

We are grateful to our State Champions for their contributions and commitment to our work. They are an extraordinary resource for ACI Alliance and the cochlear implant field.

continued on page 4
Advocacy with State Committees continued from page 3

The Future of Member Advocacy

Federal policy is expected to shift in the years ahead with greater decision-making on Medicaid and other programs being decentralized to states. Healthcare officials at HHS and CMS have discussed a move towards Medicaid block grants to states, allowing states more leeway on Medicaid coverage, reductions in Federal funding for Medicaid, and greater reliance on healthcare savings accounts for low and moderate-income people. If these changes are implemented, there will likely be a reduction in Federal funds for Medicaid, forcing states to prioritize healthcare. The cost effectiveness and quality of life benefits of cochlear implantation will necessarily become a key aspect of our advocacy and awareness efforts.

This expected change in federal-state decision-making makes the State Champion network more important than ever. To strengthen and further support the program, we will undertake the following actions:

- Formalize our efforts and create ACI Alliance State Committees for each state
- Create a new full-time staff position of State Advocacy Coordinator to provide more support to our member advocates
- Double the number of State Champions and achieve State Champion coverage in every state with multiple Champs in many states
- Through our new ACI Alliance State Committees, aggressively seek additional volunteer participation—professionals in the CI field as well as parents of children with cochlear implants, adult CI recipients, and others in families to serve as members of the ACI Alliance State Committees. This will take advantage of the energy and excitement of CI beneficiaries.

If you are interested in helping advance our public policy work and serving as a State Champion or on a State Committee, please contact me and express your interest at dsorkin@acialliance.org. If you have patients or parents whom you think would be appropriate for State Committee participation, encourage them to visit our website and see if they might be interested in contributing to our efforts as a state level volunteer advocate.

New Resource from ACI Alliance

Adult Candidacy for Cochlear Implantation: Clinical Guidance

The Board of Directors recently approved a clinical guidance to provide primary care physicians and others in their clinics with information to help them identify and encourage adults who may be candidates for CI to be evaluated at a cochlear implant center. We know that family physicians and internists have a key role in referrals to specialists for patient health concerns. The new resource, which includes a two-page bulleted document as well as a longer version with details and sources, may be viewed and downloaded on the ACI Alliance website under the Cochlear Implant tab/Clinical Guidance http://www.acialliance.org/page/ClinicalGuidance. Printed copies may be ordered by members for distribution at primary care meetings with six weeks notice.
First FDA approved Hybrid Hearing solution to amplify low frequency residual hearing.

For more information visit www.Cochlear.com/US

*The Acoustic Component should only be used when behavioral audiometric thresholds can be obtained and the recipient can provide feedback regarding sound quality.

**The Hybrid L24 Implant is approved in the US for adults ages 18 and older.
Organizational Membership in ACI Alliance

Susan Thomas MA, Outreach Director

Organizational membership with ACI Alliance is designed for teams of professionals working in cochlear implant centers, clinics, non-profits, educational institutions, associations and other organizations. Our existing Organizational Members (http://www.acialliance.org/search/custom.asp?id=2365) are university centers, hospitals, private clinics, educational institutions, and nonprofit entities.

Membership benefits are extended to all employees on the organizational account. Benefits include:

- Listing as an ACI Alliance Organization in the homepage tab allowing the public to view your own entry as recognition of your leadership as an important provider of cochlear implant clinical, educational or other services. This resource allows potential patients, primary care physicians, and other professionals to easily contact your organization.
- Online Membership Directory—Unlimited listings in and access to the online Professional Membership Directory, allowing you to identify your peers by organization and individual listings.
- Conference Discounts—Up to ten members of each organization receive discounts on registration for American Cochlear Implant Alliance sponsored conferences and meetings (including the upcoming 15th Symposium on Cochlear Implants in Children CI2017 Pediatric Meeting in San Francisco).
- Career Center—Free listings in the ACI Alliance website Career Center.
- ACI Alliance Electronic Mailings—ACI Alliance Calling and other updates on our activities and initiatives sent to all members of your organization.
- Board of Directors Election—All members of your organization have the opportunity to vote at the annual meetings for the American Cochlear Implant Alliance Board of Directors and Chairperson slate.

Consider joining ACI Alliance as an organizational member. It is a simplified, cost-effective way for you to provide your entire staff with the benefits of membership and brings public recognition of your organization’s commitment to ACI Alliance.

ACI Alliance Organizational Members (68)
Confidence over the Phone

Captions confirm every word they hear.

CapTel® Captioned Telephones show word-for-word captions of everything a caller says over the phone. It's like closed captions on TV, only for phone calls. CapTel restores a patient's confidence in talking over the telephone, knowing they can confirm what they are hearing just by reading the captions.

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Give your patients the confidence of knowing what is said - every word, every call.
We are proud to present our final conference update before the upcoming CI2017 Pediatric meeting in San Francisco (July 26–29, 2017)! Through the coordinated efforts of our teams at Stanford University and the University of California San Francisco, we have assembled a terrific program that we believe reflects the spirit of technological innovation and multidisciplinary collaboration in the San Francisco Bay Area.

The overall emphasis on this year’s meeting will center around worldwide efforts underway to improve performance and outcomes for pediatric CI users. There are six primary themes this year: (1) Music: Improving Perception and Appreciation; (2) Technology: Improving CI Results in an Increasingly Interconnected World; (3) Cognition: Improving Our Understanding of Language Development and Central Plasticity; (4) Outcomes: Improving the Use of Metrics for Success; (5) Indications: Improving Hearing in Expanded Populations; (6) Delivery: Improving Efficacy, Availability, and Efficiency in CI Care.

We had a high number of submissions for the conference, and as a result, competition for the limited number of podium presentations was very rigorous. We anticipate an extraordinarily high-quality scientific program, both for podium and poster sessions. We are honored to have five renowned keynote speakers whose presentations will serve as program highlights: Dr. Monita Chatterjee, Dr. Michael Merzenich, Dr. Charley Della Santina, Dr. Anne Fernald and Dr. Bruce Gantz. You can view their talk descriptions, as well as the full conference program, here: http://ci2017sf.org/site/index.php/scientific-program/scientific-program

Dr. Gantz will be speaking as the Inaugural John Niparko Memorial Lecturer, presented as a loving tribute to a true giant in the field of cochlear implantation whose presence is deeply missed. We have planned over 100 podium and 250 poster presentations as well as a new segment featuring brief highlights given by selected poster presenters just prior to the Thursday afternoon poster session. Following the poster session, all are invited to attend the Welcome Reception on Thursday evening in the Exhibit Hall to connect with colleagues and enjoy beverages and hors d’oeuvres. Seven panels addressing timely topics will be interspersed throughout the 2 ½ days for those who want to...
be part of a highly interactive format. Capping off the meeting will be a stellar technology panel on Saturday morning, which will be moderated by Internet pioneer Vint Cerf [https://en.wikipedia.org/wiki/Vint_Cerf] with leaders from Google, Verily, and Dolby—all major companies at the forefront of innovation on information technology, healthcare, and next-generation audio.

We are looking forward to having you join us in San Francisco for what will be an exciting conference full of insights, thought-provoking conversation, and new collaborations—see you at CI2017!

Other CI2017 Details: Career Fair, Continuing Education and Satellite Symposia Career Fair

We are pleased to announce the return of the ACI Alliance Career Fair in San Francisco on Friday, July 28 at 5:30 p.m. We invite you to take advantage of this opportunity to promote your organization to cochlear implant professionals, recent graduates, and current students attending the upcoming conference.

Participation is free of charge though participants, both those offering and those seeking jobs, must be registered for the conference. Organizations meeting with applicants will be provided with a table and two chairs for on-site interviews on Friday. We will publicize your position opening(s) on-site and if provided in advance, in our website Career Center.

If you are interested in participating as an interviewer or interviewee, please visit [http://www.acialliance.org/page/CareerFairInterest](http://www.acialliance.org/page/CareerFairInterest).

Do you have an opening that you hope to fill prior to the July meeting? Members may post positions at any time on the ACI Alliance website (Career Center tab under Member Center). This service is free for organizational members and there is a small fee as a professional member. Visit now to see what CI jobs are currently available ([http://www.acialliance.org/networking/](http://www.acialliance.org/networking/)).

Continuing Education

The 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 Continuing Education Credits from the above three organizations at the upcoming CI2017 Pediatric Symposium. Continuing Medical Education (CME) credits will also be offered through our Meeting Planners, the American College of Surgeons. A certificate of participation is provided for all conference attendees.

We will be offering American Board of Audiology Tier 1 Specialty Credits for a number of sessions during CI2017. To receive Tier 1 credits, attendees must attend at least two sessions of the three Wednesday afternoon Corporate Satellite Symposia per ABA rules stating continuing education activities must be a minimum duration of 3 hours. To register for Wednesday afternoon corporate symposia, visit [https://acialliance.site-ym.com/events/register.aspx?id=856282](https://acialliance.site-ym.com/events/register.aspx?id=856282).

For information on Continuing Education at the conference, contact Susan Thomas ([stomas@acialliance.org](mailto:stomas@acialliance.org)).

Corporate Satellite Symposia

Satellite symposia will be held throughout the conference. Wednesday afternoon Corporate symposia begin at 12. Breakfast symposia will be held each morning at 7:30 a.m. Please review the schedule and registration information on the conference website ([http://www.ci2017sf.org/site/index.php/exhibit-sponsors/ci2017-industry-events](http://www.ci2017sf.org/site/index.php/exhibit-sponsors/ci2017-industry-events)). CE credits will be offered for these sessions, but CME credits will not be available.

ACI Alliance Adult Blog for Patients and CI Teams

Naama Tiach PhD, Blog Coordinator, ACI Alliance

Whether someone has undergone cochlear implantation as an adult or (s)he is an adult CI candidate, the ACI Alliance Blog provides helpful and sympathetic information. We encourage you to share this resource with patients.

The blog addresses the benefits, as well as, the challenges faced by CI recipients. The 23 posts written to date cover wide-ranging topics including auditory training tools for home practice, music, attentive listening, CI for adults with congenital hearing loss, expectations and goals, and much more.

As an audiologist and speech pathologist, I have had a range of experiences in working with adults (and children) who are at different stages in their CI journey. I write many of the blog posts but also solicit postings from other professionals and consumers. Our latest blog contributor is Miranda Myers, a college student who received a CI as a young child. All of our host writers share their exceptional professional and personal insights. We invite you to join our blog readers’ community!

Find us here (under the Member Center area of the ACI Alliance website): [http://www.acialliance.org/blog-post/1334356/Cochlear-Implant-Rehabilitation-for-Adults](http://www.acialliance.org/blog-post/1334356/Cochlear-Implant-Rehabilitation-for-Adults). Watch for our blasts announcing a new blog post.
The federal government is currently considering significant policy changes to several major health care programs. With Republicans controlling the House, Senate, and the White House, it is likely that some of these proposals will be implemented, and may impact access to cochlear implantation (CI). Increasingly, it appears that health policy decision-making may shift further toward the states. We provide a brief overview below of these health care policy proposals and how they could impact ACI Alliance members and CI patients.

The Affordable Care Act (ACA), a signature achievement of President Barack Obama’s presidency, faces its most significant threat with the advent of the new Republican Congress and Administration. Most recently, the House of Representatives has put forth legislation to repeal and replace the ACA; however, that legislation, at least initially, encountered resistance and is currently being renegotiated. The House bill, as written and amended in late March, is entitled the American Health Care Act (AHCA), and would make several significant policy changes. It would transform the Medicaid program from an entitlement program into a capped financing system; repeal Medicaid expansion by 2020; and make significant changes to financing and coverage rules surrounding private health insurance.

Recently, additional proposals to change insurance coverage rules surrounding essential health benefits (EHBs), pre-existing conditions, and premium rating practices have emerged as possible additions to the renegotiated bill, AHCA—and these potential amendments to it—shifts much of the responsibility for health insurance coverage rules and financing to the states, which would assume more prominent roles in coverage and access to care.

While cochlear implants are currently covered by over 90% of commercial health plans, possible changes to EHBs and/or removal of their protections could result in some commercial plans reducing coverage of a variety of rehabilitative and habilitative therapies and devices, such as cochlear implants and related follow-up care. The proposed changes to Medicaid could prove particularly challenging, as Medicaid covers a significant amount of CI-related services and treatments for the pediatric population. Additional challenges include possible penalties for not maintaining continuous coverage, removal of some employer coverage requirements, and reductions in premium tax credits that help low-income individuals and families afford coverage, including coverage of CI.

ACI Alliance is taking action to address these threats to CI coverage and reimbursement. The Alliance will be meeting with House and Senate Medicaid staff responsible for Medicaid issues to promote the importance of continued access, coverage, and reimbursement of CI. ACI Alliance Members can participate by working together with ACI Alliance and participating in State Committees (described above). There will be opportunities to participate in state level meetings to promote CI coverage, reimbursement, and the value of this benefit at a time of transformation of authority back to the states. For more information on becoming involved with your state as either a State Champion or State Committee member, please contact Donna Sorkin, Executive Director of the ACI Alliance, at dsorkin@acialliance.org.

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Electric Acoustic Stimulation is the combination of two technologies: a cochlear implant for the high frequencies, and acoustic amplification for the low frequencies.

The new SYNCHRONY EAS System combines the lightweight SONNET EAS Audio Processor with the unparalleled MRI safety* you get with the SYNCHRONY Cochlear Implant.

Together, the two technologies cover the full range of hearing.

SYNCHRONY EAS System is approved for MRI scanning at 1.5T and 3.0T without magnet removal. Please ensure that all conditions described in the IFU for scanning are followed. For MRI scanning instructions and information on potential risks and contraindications relating to implantation, please visit www.medel.com/us/isi-cochlear-implant-systems/
Major Organizational Accomplishments 2016

Research

- Continued multi-center study for CMS with the aim of expanding candidacy under Medicare. Ten study sites added to boost enrollment, bringing the total to 20.
- Published RFP to provide funding for the development and validation of Quality of Life instruments targeted to cochlear implant recipients. http://www.acialliance.org/page/QOLMeasures


Awareness

- Conducted programs in collaboration with Hearing Loss Association of America (HLAA) to provide greater understanding of candidacy, residual hearing, hearing aid use, insurance and outcomes associated with cochlear implantation in adults:
- Informational sessions for consumers given by local CI clinicians at HLAA chapter meetings
- Outreach to local non-CI audiologists
- Content development for HLAA publications


Conducted collaborative initiatives to improve understanding of CI candidacy and outcomes with hearing care professionals outside of cochlear implantation.


Conducted collaborative initiatives to improve understanding of CI candidacy and outcomes with hearing care professionals outside of cochlear implantation.

Advocacy

- Collaborated to advance reauthorization of the Early Hearing Detection and Intervention Act (expected to pass Spring 2017).
- Continued expansion of ACI Alliance State Champion program http://www.acialliance.org/page/ACIAStateChamps
- Organized ACI Alliance on the Hill—At Home during Summer/Fall 2016 to encourage visits by Congressional Members to member CI clinics and schools.

Build an Effective Organization

- Grew total number of active 2016 members to 1016, a 21% increase. Total number of Organizational Members grew to 66.
- Continued expansion of social media with website, introduction of Facebook https://www.facebook.com/ACIALLIANCE.ORG/ and Twitter @acialliance
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.