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

It's almost the New Year, so how about a challenge? Our field of CI, similar to the rest of medicine, is slowly evolving but also poised for rapid and unpredictable change. How can we harness advances in other areas to benefit our patients and practices? How could you double or quadruple the number of patients you currently care for and improve outcomes?

Paradoxically the medical profession is oddly predisposed to adhere to intuition, current practices and personal experience rather than be driven by evidenced based processes. Artificial intelligence, machine learning, deep learning can be applied to areas in medicine, including ours. A lot of hype for sure, but there is substance.

continued on page 2
Around the world there are not enough radiologists and pathologists to “read” images and slides. Computers excel at visual pattern recognition and have proven to markedly improve the accuracy and efficiency of radiologists and pathologists. This is resulting not in a gradual evolution of how we care for people but a dramatic “leap” forward.

Dizziness is a common complaint, and patients will see 4-6 providers before an accurate diagnosis and treatment plan is developed. We now have a system that can analyze patient provided survey information and predict the optimal test order and which specialist to see first thus improving efficiency. Early work shows this decreased the number of ENT appointments by 45%.

This same process can be applied to hearing loss. Ultimately, we want to know what type of device (PSAP, hearing aid, CI, other) to recommend and what counseling would be of benefit (tinnitus, noise protection, FM system, rehab for children and adults). Creative change may allow us to accomplish this more efficiently and with better outcomes. Exciting opportunity. Our patients need us to “leap” forward. Think big. Think bold, and let’s have the evidence provide the guidance.

MESSAGE FROM THE CHAIR continued from page 1

CI2019: Pediatric
Don’t Miss It!

The Diplomat Hotel, Hollywood, FL
July 10–13, 2019

Educational Course Directors
Ivette Cejas PhD and Fred Telischi MD
University of Miami Department of Otolaryngology/Ear Institute

T
he Pediatric CI2019 meeting is quickly approaching. We have organized a comprehensive scientific program that addresses both clinical and research innovations in pediatric CI. The CI2019 Pediatric program aims to provide a platform to discuss the common cognitive, social, and emotional challenges experienced by pediatric CI users. The overarching theme will be “Treating the Whole Child.” CI 2019 will target multidisciplinary teams—including otologists, audiologists, speech therapists, educators, and psychologists—to discuss research on best clinical practices and evidenced-based interventions.

continued on page 3
We have several noteworthy keynote speakers including international speaker, Dr. Lizet Ketelaar PhD, who will be discussing Emotional competence and its effect on social functioning in children with cochlear implants. The Saturday morning keynote will be delivered by Elizabeth Pena PhD on What they hear and what they say: Language learning in a bilingual context. This talk will be followed by a session on management of non-English speaking families. During this session, common issues reported by non-bilingual providers will be addressed including: difficulty building rapport with the patient and family, mistrust with the interpreter, limited validated test materials in other spoken languages, poor sound quality/audibility via phone, using formal terminology, and lack of support materials. Our scientific program will be enhanced with panel discussions, networking sessions, and controversial topics. Like what you see so far? Here is a sneak peek for some of the panel discussions:

- **Complex Cases: Multidisciplinary Management.** During this session, four case studies will be presented via a team approach. Cases will be complex and/or involve children with multiple disabilities. Presenters will include surgeons, audiologists, speech pathologists, and others.

- **Moving the Field Forward: Expanding Indications & Special Needs Populations.** The number of deaf children with additional disabilities receiving cochlear implants has increased dramatically along with ever-changing CI candidacy. This session will highlight research on the benefits of CI in this population, evidenced-based early interventions, counseling on realistic expectations, and discussion of how family adaptation may be different for these populations.

- **Beyond the CI: The Role of Therapy, Education, and Family Engagement.** Establishing a positive relationship early in development between the parent-child dyad has been shown to affect a wide range of child outcomes, including linguistic, cognitive, behavioral and social development. This session will target participation from educators, speech and language therapists, and other health care providers. It will not only focus on presenting research on evidenced-based practices, but also discussion of complex cases and therapy strategies that can be implemented across settings.

- **Creative Solutions to Managing the CI program in the Current Healthcare Environment.** Every state and ever CI center has encountered insurance challenges. This session will discuss what some centers are doing to continue successfully running a CI pediatric program within the current healthcare climate.

So whether you are just entering the field or are considered an expert, please register today to attend this comprehensive meeting. We’ve had a phenomenal number of proposals and the program will be fantastic. We look forward to seeing everyone in Hollywood, Florida. Along with the stellar educational program, we are delighted to share our breathtaking views of the beach, delicious Latin cuisine, and nighttime fun. Don’t forget the dress code will be elegant/casual resort wear. No suits and ties allowed! Bienvenidos a CI2019 Miami!
Supporting Parent Choice for Children Who are Deaf and Hard of Hearing

Donna L. Sorkin MA, Executive Director, ACI Alliance / dsorkin@acialliance.org

On December 8, American Cochlear Implant Alliance published a notable Position Paper, adopted by the ACI Alliance Board of Directors, outlining a rationale and research base for Parent Choice. It would seem implausible that such a paper would be so essential in this timeframe given the extraordinary opportunity available now for children with any level of hearing loss. And yet it is. At the most recent national Early Hearing Detection and Intervention (EHDI) conference held in March 2018 in Denver, Federal officials from the Health Resources and Services Administration (HRSA), on a stage at a plenary conference event, declined to answer a questionnaire from a conference attendee about the agency’s support of parent choice. The session went like this:

Attendee: I want a specific answer to the question does HRSA support parents’ right in decision-making for the education and medical intervention for their children?
Michelle Koplitz (HRSA): HRSA supports full language acquisition for deaf and hard of hearing children. We provide funds to different stakeholder groups. And we support parents having full information before they make decisions on what they want for their children.
Attendee: I’d actually like it stated a little more clearly. Yes, we support parents’ rights to make decisions for their children, yes or no.
Michelle Koplitz (HRSA): I’m actually not going to answer that question.
Attendee: I think that does answer it. Thank you.

Given the lack of support from Federal officials for the fundamental concept of parent choice (as supported in federal legislation) coupled with an aggressive LEAD-K push to pass state laws that would evaluate deaf and hard of hearing children based upon a simplistic comparison with typically hearing children, we felt it was important to provide an evidence-based response. (See Nichole Westin’s article on page 5 for more on LEAD-K.) The Position Paper, which is being used by our State Champion network and others, is available on our website and we urge you share and promote its use. It is available here and is also downloadable: https://www.acialliance.org/page/SupportingParentChoice

New ACI Alliance Staffer is Ready to Help

Hi! My name is Jessica Houk and I joined ACI Alliance as Manager of Information Technology and Membership Services in September. I served as an officer in the US Army for nine years focusing on operations including information technology, communications, and cybersecurity. I left full-time employment in 2014 and I continue to support the US Military as a Major and Cybersecurity Staff Officer in the Reserves. I was particularly interested in a position at ACI Alliance as our work aligns with my desire to work in a mission-based organization. I have two young children, one of which has a unilateral, moderate hearing loss that is helped with amplification. I look forward to working and helping you with your membership questions and concerns.

Jessica Houk MBA, Manager of Information Technology and Membership Services, ACI Alliance / jhouk@acialliance.org
MRI examinations can be stressful, but they are common and a necessary part of life. At Advanced Bionics we believe that MRI procedures should be hassle free for all cochlear implant patients. That is why we developed the HiRes™ Ultra 3D cochlear implant, which is compatible with 3.0 Tesla MRI with the magnet left in place.

AdvancedBionics.com
Please contact your AB representative for availability in your area.
Advocacy for Cochlear Implant Access: Making the Best Use of Your Voice

Nichole Westin MA, Governmental Affairs Manager, ACI Alliance / nwestin@acialliance.org

One of the core principals of American Cochlear Implant Alliance is advocacy. State Champions and our new State Grassroots Committees are working to make the voices of our membership heard by federal and state legislators, policy-makers, and regulators. We utilize a variety of mechanisms to accomplish our goals including in-person meetings, letters, formally submitted comments, and working with collaborative partners. As we prepare for 2019, I would like to share details from our work of the past few months which set the stage for our efforts in the future for promoting 21st century hearing technology.

Medicaid and Cochlear Implants
In our August issue, we discussed our efforts to encourage Maryland Medicaid to provide coverage for qualifying adults needing a CI. Since then, the Maryland Medicaid office replied to our submitted comments and agreed to accept the vast majority of our proposed changes including coverage of both bilateral and unilateral surgeries and improved coverage of replacements for rechargeable batteries. While we disagree with their decision to not specify the processor upgrade policy for Maryland Medicaid, overall we were pleased with the positive changes in adult coverage in Maryland as well as the improvements for children and adults in related services. Our experience in Maryland can be replicated in other states as reviews are underway. You can read our comments here.

Our Medicaid advocacy efforts continued when Chair Colin Driscoll flew to Washington, DC to join ACI Alliance staff for a meeting at CMS followed by four meetings with key Committee staff of both parties in both the US House and US Senate. Discussion centered on five key points: (1) low reimbursement, (2) restrictive equipment upgrade policies, (3) complexity added by usage of MCOs, (4) caps and complicated waiver processes for therapy and (5) difficulty obtaining authorization for surgery and related services. These topics were pulled from our recent member survey on Medicaid which is pending publication in early January 2018.

One of the issues that struck a nerve with both CMS and Hill staffers were therapy caps and complicated waiver processes for pediatric speech therapy. Since the meetings, we have reached back out to CI clinicians to discuss their experiences and have supplemented that information with extensive research on published state policies. If you have struggled with this issue in your state, please contact me as your story will help us make changes.

Working with Legislative Sponsors
Every year, thousands of bills are introduced into the US Congress and state legislative bodies, but only a fraction of them become law. The ACI Alliance keeps an eye out for any bill that impacts on access to care or services for children or adults who are deaf or hard of hearing. In December, we submitted comments to the Washington, DC City Council in support of a bill that would

continued on page 6
require movie theaters to provide open captioning during peak times at least four times a week.

Along with other organizations in the field of hearing loss, we recently met with key sponsors of HR 1120, “Alice Cogswell and Anne Sullivan Macy Act.” We support most of the components of the proposed legislation and its objective of supporting needs of children in educational settings. We are concerned about one element of the proposed bill that would discourage states from addressing changes in educational needs; if a state school for the deaf and/or blind were closed because of declining enrollments and/or different priorities for students, that state would lose Federal funding associated with the school’s funding and could not reprogram the funds to meet current educational needs and desires of families. We met with the sponsors to discuss our concerns and show our support for educational programming that reflects the needs and desires of today’s students.

**LEAD-K**

While we often use our collective voice to support good policies, we have been encouraged by our State Champions to oppose a movement that would implement processes that could hamper provision of appropriate services for young children who are deaf and hard of hearing. Over the past few years, the group Language Equality & Acquisition for Deaf Kids (LEAD-K) has pushed for states to pass legislation that we and other organizations believe will hamper family choice by promoting ASL for all children—regardless of the family’s perspective and the language development program that they are pursuing for their child.

Since 2016, seven states have enacted such laws while over a dozen efforts have been stopped or delayed. Our State Champions urged us to proactively address these initiatives by providing tools and guidance. Please review Donna’s article on page 4 on the new Position Paper on Parent Choice, which is intended to address the LEAD-K efforts. Given that we expect the 2019 state legislative sessions to see multiple LEAD-K bills introduced, we have developed a number of tools that will be helpful. Our State Champions will lead state level efforts against LEAD-K laws; they welcome involvement by others—professionals in hearing health care as well as parents. Check the listing of State Champions in your state or contact me directly at nwestin@acialliance.org. Advocacy is more important than ever and we hope you will join us in making our voices heard.

---

**ACI Alliance Resource**

**Adult Candidacy for Cochlear Implantation: Clinical Guidance**

This clinical guidance provides 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 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.
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 hear just by reading the captions.

A no-cost CapTel phone is available for your patients with hearing loss.

REQUIREMENTS: Hearing Loss, High Speed Internet, Dial-tone.
No-Cost Phone with valid third-party certification is subject to change without notice. Terms and conditions may apply. FEDERAL LAW PROHIBITS ANYONE BUT REGISTERED USERS WITH HEARING LOSS FROM USING INTERNET PROTOCOL (IP) CAPTIONED TELEPHONES WITH THE CAPTIONS TURNED ON. IP Captioned Telephone Service may use a live operator. The operator generates captions of what the other party to the call says. These captions are then sent to your phone. There is a cost for each minute of captions generated, paid from a federally-administered fund. No cost is passed on to the CapTel user for using the service. CapTel captioning service is intended exclusively for individuals with hearing loss. CapTel® is a registered trademark of Ultratec, Inc. The Bluetooth® word mark and logos are registered trademarks owned by Bluetooth SIG, Inc. (v1.5 7-18)
As 2018 winds down, ACI Alliance has been busy advocating for Medicaid coverage and access for cochlear implants, and closely monitoring the new Congressional outlook following November’s elections.

In late October, ACI Alliance was represented by Board Chair Colin Driscoll, Executive Director Donna Sorkin and Advocacy Manager Nichole Westin at meetings with the Centers for Medicare and Medicaid Services (CMS) and key Congressional staff to discuss Medicaid coverage of cochlear implants and access to CI and related services under the program. The meetings provided a venue for ACI Alliance to raise the profile of CI with key federal officials, including leading staff of the Centers for Medicaid Division of Benefits and Coverage, and the Senate Finance Committee and House Energy & Commerce Committee staff.

In these meetings, ACI Alliance representatives shared concerns about access to CI under Medicaid, and sought feedback from the staffers on how to address those concerns. The meetings resulted in significant interest from both CMS and Congressional staff in ensuring that all states provide access to, and coverage of, cochlear implants and the related services that recipients require. We will continue working closely with these federal officials on addressing this important issue.

Meanwhile, the 2018 Midterm Elections resulted in a return to divided government as the Democratic Party gained enough seats to take control of the US House of Representatives, while the Republican Party maintained and added to their margin in controlling the US Senate. This result has a significant impact on the fate of the Medicaid program. Medicaid reform is still viewed as a necessity, but what form that takes changes dramatically with the House led by Democrats in 2019.

As the 116th Congress convenes in January, House Democratic leaders will likely examine all options to deliver on their campaign promises, including protecting the Affordable Care Act (ACA), especially individuals with pre-existing conditions. House Democrats will also likely conduct oversight of the Administration’s activities, including changes at the regulatory level that have impacted health care. Throughout the past two years, the Trump Administration has issued new regulations to loosen the legal requirements of the ACA. Those regulations have included new types of less-comprehensive health insurance plan offerings, which do not need to adhere to the benefits and coverage rules that the ACA typically requires. This erodes protections for pre-existing conditions as well as coverage of CI under the essential benefit category known as “rehabilitative and habilitative services and devices.”

Recently, the Trump Administration issued new guidance allowing states to apply for waivers of ACA health insurance plan requirements. These changes are premised on the Trump Administration’s stated goal of expanding more affordable coverage options for consumers, but many fear the changes will restrict coverage of critical benefits and limit choices for those with greater-than-average health care needs, such as people with disabilities and chronic conditions, including those requiring CI.

These new types of plans may be of concern to ACI Alliance members, as these plans may be permitted to forego coverage of certain benefits and services associated with CI. Given the makeup of the incoming Congress, House Democrats are limited in their ability to effectively reverse the Trump Administration’s regulatory actions in this area, as any changes approved by the Democratically-controlled House would require the support of the Republican-controlled Senate and White House. These developments could negatively impact access and coverage of cochlear implants over time. ACI Alliance will continue to raise awareness of the impact of these changes on CI access with government policy makers and will closely monitor this situation going forward.
Why RONDO 2?
Easy for Them, Easy for You

With RONDO 2’s wireless charging, there’s no need to open the processor or change batteries—making it incredibly simple to use. The lightweight off-the-ear design is so comfortable it’s easy to forget it’s there. And RONDO 2 adapts to changing listening conditions for optimal hearing on the go.

- Easy to use
- Easy to charge
- Easy to wear

Learn more at www.medel.com/us/RONDO2.
A PARENT’S PERSPECTIVE

Parent Advocate Joins ACI Alliance
State Champions

Melissa K. Chaikof

In 1987, when our first child was born, my husband Elliot and I had no reason to suspect any problems. However, she wasn’t even a week old when I began noticing that she did not startle. Although I voiced my concern at our initial visit with her pediatrician, he dismissed it, telling me I was “an overly anxious new mother who does not understand how newborns react to sound.” When I insisted at her next visit, he referred us for testing, which confirmed our fear. Our daughter had a profound hearing loss. He then became concerned about cerebral palsy, because she also had low muscle tone. Fortunately, that concern proved unfounded, although her gross motor milestones were all late.

Through family connections, we learned of the Auditory-Verbal Approach, which focuses on teaching children who are deaf to use their residual hearing to learn to listen and talk. We opted for powerful hearing aids, which were large, awkward body aids at the time with big buttons sticking out of her ears, and were very happy when, at ten-months of age, she was able to switch to regular behind-the-ear hearing aids. Despite the powerful signal from her aids, though, our daughter did not respond to any sound.

In the summer of 1989, while talking on the phone to an Auditory-Verbal Therapist (AVT) in Canada, our AVT learned about the cochlear implant. While we had heard of it, our audiologist at home in Boston had told us it was something to keep our eye on in the distant future. This AVT, though, told ours that she had a child who also had no residual hearing, and her parents had taken her to New York University for a cochlear implant. This was a year before the FDA approved cochlear implants for children age two and older, and also before the internet. Thus, information was not readily available. Armed with contact information for the team at NYU, though, I called, and we set up an appointment.

In the fall of 1989, we visited NYU and what was known at the time as the League for the Hard of Hearing. The team identified our daughter as a candidate for a CI, although they told us they could not promise that she would hear more than environmental sounds. However, we were bowled over when we met a child at the League who was two years older than our daughter and had had a CI for about a year-and-a-half. She was hearing and speaking like a typical four-year-old. We left New York with renewed hope and an appointment for surgery two months later.

Compared to today, where CI surgery is outpatient, our daughter’s surgery took over four hours, and she was in the hospital for four nights. A month later, we went for her initial stim, which at that time took three days. I will never forget that first day. Each time an electrode was stimulated, she would cry. We were thrilled because we knew it meant she was hearing.

From that point on, we never looked back. Our daughter began to show us that she was hearing two weeks after her initial stim. Two months later, she found her voice and began to try to talk, taking words that she had learned via lipreading and transferring them to the auditory through her newfound hearing. She attended a mainstream preschool and began to pick up language

continued on page 12
from the other children, coming home with expressions that I knew she could only have learned through hearing them.

In 1991, our son was born, and he had normal hearing. The professionals had told us our daughter’s deafness was likely due to a virus I had had during pregnancy, and we were eager to believe that theory. However, in 1995, our third child was born also profoundly deaf, and so we knew we were dealing with genetic deafness, although genetic testing came up empty. She also shared her older sister’s low muscle tone and gross motor delays.

Although the FDA approved pediatric cochlear implants in 1990, we did not want to wait until the then approved age of two. While our older daughter was doing beautifully, she still had a language delay. We made the trip back to NYU in search of an earlier surgery, hoping for 18 months. We were thrilled when our surgeon said he would do it the next month when our daughter was only 15-months-old, making her the youngest CI recipient in the U.S. at that time. The difference that earlier implant made for her was exponential. By age six, she completed Auditory-Verbal therapy with language that tested age level to two years above.

Cochlear implants made an immeasurable difference in our daughters’ lives. Both were mainstreamed in school all the way through, learning at the same pace as their peers with normal hearing. Our older daughter studied French and excelled, winning a state-wide spoken foreign language award in high school. Later, it was her French skills that helped earn her a place in Cameroon in the Peace Corps, where she also had to use her listening and speaking skills to learn Pidgin English in order to communicate with the natives. My younger daughter has become an advocate for CIs, listening and spoken language, and for all with disabilities, working to level the playing field.

In 2006, we came to appreciate our girls’ ability to hear and speak with their CIs even more when, during a routine annual eye exam, we finally learned the cause of their deafness, Usher Syndrome. This diagnosis also explained their low muscle tone as babies and poor balance because Usher Syndrome type 1 also affects the vestibular system. Most significantly, though, it meant that they would both slowly lose their vision because retinitis pigmentosa is part of Usher Syndrome. We are so thankful that we had chosen not just cochlear implants for our girls at a time when they were not the standard of care, but also that we had taught them to use the hearing gained from their CIs to the fullest extent possible so that they would not have a dual sensory loss. I often say that I would sleep better at night if I knew that my girls would always see as well as they hear.

Over the years, by necessity, I became a skilled advocate for my daughters, battling insurance companies and school systems not just for services that they needed but also for their right to communicate through listening and spoken language, a choice that, after much research, my husband and I made for them believing it would work best for our family and a choice that my girls, now adults, are very grateful we made for them. While in more recent years my efforts have taken on a new direction, fundraising for Usher Syndrome research, I recently re-entered the advocacy arena for parents to have the right to make an educated decision about communication options for their children when I became aware of the LEAD-K effort, a movement by some in the Deaf culture to ensure via a law in each state that all babies born deaf be strongly encouraged to learn American Sign Language. Parents should not be pressured on the communication model they wish to pursue with their child; rather our institutions should support parent choice and services to be provided should respect the model parents are pursuing with their chosen educational and medical teams. Thus, I was very pleased to find that the ACI Alliance has organized state groups to advocate for parental rights and parental choice. I have joined this effort and am so very grateful that the organization has taken the lead to ensure that all babies born deaf today have the same options that my girls had when we were first starting on this journey.
Cochlear is proud to offer world-first connectivity for both the Cochlear™ Nucleus® 7 System and Baha® 5 System.

The first hearing implant systems compatible Apple® and Android™ through the Cochlear Nucleus and Baha Smart Apps.

To learn more, visit https://bit.ly/2RMWYPz