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Donna L. Sorkin, *Editor*

MESSAGE FROM THE CHAIR

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As we enter this holiday season, it seems more than appropriate to express gratitude to each of you for your continued support of the American Cochlear Implant Alliance. We had a record number of virtual attendees for the CI2020 Online Conference. Our consumer membership increased and a new group, CI CAN, was formed to advocate for improved access to cochlear implantation. (See page 7 for more details.) Most of our Organizational Members renewed their memberships and remained "on the map" despite uncertain financial times at their institutions. The State Champions saw a rise in the number of providers and others who expressed desire to be on the front lines in their respective states. The ACI Alliance received an important grant from Oberkotter Foundation which provided the opportunity for the Research Committee to then approve funding for *Cost Effectiveness of Early Identification and Intervention: Impact of Pediatric Cochlear Implantation,* which is an extremely important topic. The Research Committee is now in the midst of deciding who will be awarded the Telehealth Innovation Grant. Lastly, the CI Conference Program Committee is working full steam ahead with preparation and planning for CI2021 Virtually, and we are thrilled with the topics and speakers secured for the line-up so far.

While ACI Alliance is pushing forward with many initiatives, we do realize that this year has taken a toll on all of us in some capacity. We made it through most of 2020, we survived the election, we saw the end of Mercury in retrograde. And, while COVID-19 is still prevalent in all aspects of our lives, somehow, we have adapted to the "new normal" and continued to serve our patients with hearing loss in an impactful way.

continued on page 2

MESSAGE FROM THE CHAIR *continued from page 1*

During this time of Thanksgiving, we each deserve to take a few moments to honor ourselves as providers, as family members, and as friends to the many people in our lives who depend on us. One of my favorite TV episodes from *Parks and Recreation* is "Treat Yo' Self Day." Characters Donna Meagle and Tom Haverford devoted one day every fall to treating themselves to lavish gifts, delicious food, and self-care simply for surviving the previous 365 days. Honestly, I think we all deserve a little "Treat Yo' Self Day" soon.

The ACI Alliance Board of Directors and I wish you and your loved ones a safe, healthy, and joyful Thanksgiving and holiday season. Cheers to 2021! ■

A Tight 2020 Election Leaves the Future of Health Care Policy Unclear

Peter Thomas J.D., Governmental Affairs Counsel to ACI Alliance
Taryn Couture, Director of Governmental Relations
Joe Nahra, Director of Governmental Relations
Powers Pyles Sutter & Verville PC


Peter Thomas J.D.


Joe Nahra


Taryn Couture

On Tuesday, November 3, Americans took to the polls to vote for the next President of the United States, 35 Senate seats, and all 435 House seats. As many expected, due to the increase in early and mail-in voting, a record number of Americans voted, and the end results in several races remain unclear. At the time of this writing (November 9), Joe Biden has been named President-Elect by several news sources, while tight races in several states remain too close to call. Legal challenges create additional uncertainty.

Several House and Senate seats remain undecided as well, but it appears that Democrats will maintain control of the House and Republicans are likely to maintain control of the Senate, both with a slimmer majority than in the 116th Congress. A split Congress will have a significant impact on any future health care policies, potentially slowing the next President's legislative agenda, but opening the door for further executive action.

While the country waits to see a firm resolution of the Presidential race, there are a few key seats that have already been called in both the Senate and the House.

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HEALTH CARE POLICY *from page 2*

Senate

In the Senate, Democrats flipped two seats, including Arizona, where former astronaut Mark Kelly (D-AZ) defeated Sen. Martha McSally (R-AZ) in a special election for former Sen. John McCain's seat, and Colorado, where John Hickenlooper (D-CO), who served as the governor from 2011-2019, won his election against incumbent Sen. Cory Gardner (R-CO). Republicans gained one seat in Alabama with Tommy Tuberville (R-AL) defeating Sen. Doug Jones (D-AL). Other vulnerable Republicans successfully fended off challengers in key states, including Sen. Susan Collins (R-ME) in Maine and Joni Ernst (R-IA) in Iowa. The Senate will also add another health care professional, with Roger Marshall (R-KS), an OB/GYN physician, defeating Barbara Bollier (D-KS) to take former Sen. Pat Roberts' seat in Kansas.

Ultimately, Democratic hopes for a "blue wave" to retake control of the Senate did not materialize, though both incumbents in Georgia will likely face runoff elections on January 5, 2021, which will determine which party controls the Senate. Whatever the results, an increased focus on bipartisan compromise is likely.

House

Democrats are expected to maintain their majority in the House; however, races in some districts were much tighter than expected, and Democrats lost some key seats. Of note, Rep. Donna Shalala (D-FL), former secretary of Health and Human Services, lost her election to Maria Elvira Salazar (R-FL), and Rep. Collin Peterson (D-MN), the most senior representative from Minnesota, was defeated by Michelle Fischbach (R-MN).

Champions of cochlear implant issues maintained their seats in the House,

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ACI Alliance 2021 Major Public Education and Policy Issues

1. CI referral language in proposed Medicare Hearing Aid legislation to suggest that hearing aid providers discuss and refer appropriate patients for a CI evaluation prior to dispensing a Medicare-funded hearing aid
2. Telehealth during *and* after the healthcare emergency in Medicare, Medicaid and private plans
   a. **https://www.acialliance.org/news/528635/ACI-Alliance-provides-comments-on-CMS-Proposed-Rule.htm**
   b. Support of multiple Congressional bills to extend telehealth under Medicare
3. Medicare expansion of candidacy criteria to more closely match FDA and private plans
   a. ACI Alliance sponsored a multi-center clinical trial of adult Medicare beneficiaries to encourage CMS to expand candidacy. Study was completed and published with a change in candidacy expected in 2021.
   b. Assessment of Cochlear Implants for Adult Medicare Beneficiaries Aged 65 Years or Older Who Meet Expanded Indications of Open-Set Sentences Recognition: A Multicenter Nonrandomized Clinical Trial, Zwolan et al. (*JAMA Otolaryngol Head Neck Surg.*) 2020;146(10):933-941. doi:10.1001/jamaoto.2020.2286
4. Veterans access to cochlear implantation continues to be a concern with: (1) an identified need for greater education on CI candidacy and outcomes within the VA audiology community, (2) information on CI not readily available to Veterans, and (3) recognition of the challenges of long distances to VA facilities that provide CI **https://www.acialliance.org/page/Veterans**
5. CI CAN: CI Consumer Advocacy Network launched to add a consumer component to our advocacy activities **https://www.acialliance.org/surveys/?id=CICAN**
6. Initiation of a new study on cost effectiveness of early identification and intervention associated with pediatric CI (See article by Ivette Cejas on page 12)
7. Ensure Parent Choice under early intervention by promoting full access for parents to information on hearing technology and language development options
8. Development and publication of Board of Directors initiated papers on two key topics addressing CI care for children and adults. It is hoped that these papers will provide greater consistency in clinical care, insurance coverage, and public understanding in and out of the hearing care community
   a. Best practices for CI candidacy and evaluation
   b. Cochlear Implantation in Single-Sided Deafness

HEALTH CARE POLICY *from page 4*

including both co-chairs of the Hearing Health Caucus, Reps. David McKinley (R-WV) and Mike Thompson (D-CA). Representative Joe Neguse (D-CO), who introduced legislation in 2019 to ensure that private insurance companies provide coverage for hearing devices, including cochlear implants, also kept his seat.

The Presidency and Health Care Policy

With Congress likely remaining split between Democrat and Republican control, sweeping health care legislation will be difficult to pass, although incremental policy improvements are possible. This potentially opens the door for the next President to develop policy through executive action.

If President Trump is ultimately successful in winning another term, the administration will likely continue its efforts to reduce drug costs, eliminate surprise billing, and broaden Medicare coverage for telehealth. The President is also expected to continue to push for repealing and replacing the Affordable Care Act (ACA) and expanded use of short-term health plans with lower premiums. Regulatory relief and price transparency for health care services would also be expected.

The Biden campaign has expressed interest in adding vision, hearing, and dental benefits to Medicare, lowering the age of Medicare eligibility to 60 (from 65), and allowing Medicare to negotiate drug prices with pharmaceutical companies. A Biden presidency would also work to expand the ACA by creating a new public option for the uninsured to obtain health insurance in order to drive down the cost of health care. These proposals will be difficult to enact in light of the balance of power in the Senate.

Whoever wins the Presidency, health care will remain a hot-button issue, and with a split Congress likely, the executive branch will be a key driver of policy. ■

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CI2021
IT TAKES A VILLAGE

CI2021 Virtual

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

With no travel or large meetings on the horizon for most of us, ACI Alliance is moving ahead with a totally virtual CI conference replacing our Dallas meeting. CI2021 Cochlear Implants in Children and Adults is scheduled for **April 28 – May 1, 2021**. "Cochlear Implantation: It takes a village" will emphasize the importance of a team approach in the management of adult and pediatric CI patients and provide attendees with opportunities to explore current and emerging topics that impact CI outcomes for patients across the lifespan. Expanded indications and management of special needs populations (adults and children) will be explored. Cognition, vestibular assessment, surgical approaches, telehealth, and therapy are also to be emphasized.

Typical Conference Format will be Followed

We expect to follow the format that we usually use at CI conferences beginning with CI company satellite symposia on Wednesday afternoon (April 28). The scientific meeting will open each morning with a plenary session followed by three concurrent sessions. We will have a "lunch" break to give attendees some time away from their screens and then resume with a mix of plenary and concurrent sessions throughout the day. The only major change is no opening reception. Alas! We will make up for the lack of a party the next time we are all gather together in May 2022 in Washington DC. We plan to have a

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CI2021 VIRTUAL *cont. from page 4*

similar format on Friday and a half day (morning) of Saturday sessions.

One of the complaints we always hear from attendees is their frustration at not being able to attend every single concurrent session. With the virtual meeting, we are able to record and offer access to all of the sessions for 30 days. Hence you won't have to make choices this year—you can watch it all.

Educational Program

The Scientific Program is being planned by the new ACI Alliance Conferences Committee chaired by Matthew Carlson MD and Sarah Sydlowski AuD, PhD, MBA. The Committee, which was selected followed by an open application process, will review the abstract proposals, make decisions about acceptances, and organize the final program. We are accepting abstract submissions for podium and poster presentations until November 15 at 11:59 PM ET. The submission site is here: **http://ci2021.org/site/index.php/scientific-program/abstract-submission**

We have planned a number of special invited speaker sessions including the unique *Rehab Connect* program that had been planned for CI2020. For a preliminary listing of the important panel and speaker line-up, review the CI2021 featured session content on the ACI Alliance website here: **https://www.acialliance.org/page/CI2021**

Continuing Education

We will offer CEU and CME from the same providers that have been offered in the past at CI conferences. The number of educational courses will be similar to that offered at past conferences. Additionally, we are pleased to offer additional CEU hours for the CI2021 virtual conference at no additional cost. Registrants may attend on-demand sessions and claim as many CEU hours as the conference allows through late May 2021. Given that there will be concurrent session offerings for much of the conference (similar to past CI meetings), virtual conference attendees will be able to access sessions that they might have otherwise missed at a physical meeting.

Registration and Cost

The conference registration site will open late November/early December. Pricing will be approximately half of the cost from our CI physical meetings with a significant discount for ACI Alliance Members.

Student Opportunities

Student scholarships will be offered and the popular Student Poster Competition will be offered as ePosters. We are offering student scholarships for complimentary registration at the meeting as part of a competitive application process. The application deadline for scholarships has been extended to December 1. Students applying for scholarship are encouraged to submit ePosters and participate in the Student ePoster Competition. The deadline for poster submissions is the same as the abstract submission timeframe (November 15). We encourage applications and involvement *of students from diverse backgrounds*. **https://www.acialliance.org/page/CI2021**

ACI Alliance Organizational Member Directory

Jessica Houk MBA / *Manager of Information Technology and Membership Services* / *ACI Alliance* / **jhouk@acialliance.org**

One of the many perks of having an Organizational Membership is that an organization may include up to 50 individuals from your entity as members. These members will be included in our emails, added to our directory, allowed full access to our e-magazine, *Calling*, and approved to post open job positions on our site. Conference registration discounts are also available for up to 10 members in typical years. Please take advantage of this by adding more members to your account. **https://www.acialliance.org/members/**

This will be increasingly important to ensure members receive our emails and notifications on the CI2021 virtual conference. There will be a significant member discount to attend this conference. Typically, we only grant up to 10 members per organization to benefit from the organizational discount. However, for CI2021, we will allow any member of the organization to use the discount code. Each member in our directory will receive an email with their specific organizational code to use. Be on the lookout for these emails around the end of November. The organization must be in good standing during

continued on page 13

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We CAN Enhance Our Advocacy Impact with Marketing

Cochlear Implant Consumer Advocacy Network

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

One of the more noteworthy developments from the past few years is the increase in numbers of citizens of all ages participating in the political process. Whether it was record numbers of people voting, sending emails to their Members of Congress, demonstrating on key issues or volunteering with a myriad of campaigns, Americans have a better understanding that their voices can have an impact on important public policy issues.

Since its founding, ACI Alliance has relied on our State Champions to fight for our core policy issues including access to hearing health care, parent choice, and expanding insurance coverage. We have now added the Cochlear Implant Consumer Advocacy Network (CI CAN) to our advocacy efforts. Intended for consumers, parents and other family members as well as those who are part of CI support systems, CI CAN will be positioned to assist our State Champions at the state and federal levels and to bring their own personal stories of how cochlear implants enhance people's lives.

We are pleased at the steady growth of CI CAN with interested individuals joining from all over the country, coming from different paths to the CI community. Interests range and include improving early intervention services in their area, facilitating public and private insurance coverage, and increasing awareness for the CI intervention. These are key issues that ACI Alliance advocated for from our founding; having a consumer advocacy arm will harness their first-hand insights and strengthen our message not only in Washington, but in states and communities around the country.

But the more the merrier! Our professional members can help us reach their patients to raise awareness about CI CAN. When someone connected to ACI Alliance shares information, especially via social media, we immediately see an uptick in CI CAN membership. When Board member Melissa Hall shared information, the number of Florida residents who joined CI CAN doubled. She utilized her personal Facebook and also posted on her clinic Facebook and Instagram accounts. State Champion Elizabeth Rosenzweig from New York shared our Facebook post in CI CAN, which generated interest amongst her followers. Our consumer members have promoted CI CAN among their acquaintances. All such outreach contributes to growth in CI CAN.

An informational brochure by ACI Alliance can be shared and you can view suggestions for its use from members who have already shared it. https://cdn.ymaws.com/www.acialliance.org/resource/resmgr/advocacy/ci_can_flyer.pdf

Please continue to let those who benefit from a CI know that their stories are needed. We know it will help encourage long term positive change for hearing health—we succeed when everyone is involved. ■

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CI CAN
COCHLEAR IMPLANT CONSUMER ADVOCACY NETWORK

Intended for consumers, parents and other family members as well as those who are part of CI support systems, CI CAN will be positioned to assist our State Champions at the state and federal levels and to bring their own personal stories of how cochlear implants enhance people's lives.

How to Help ACI Alliance Grow CI CAN

- Share the flyer on your own or your organization's website, Facebook or other social media pages so patients and family members can pursue additional details from ACI Alliance
- Continue to share ACI Alliance social media posts on CI CAN
- Print the flyer to distribute in the waiting room
- Discuss the initiative with patients and provide the flyer to those you think would be interested in the program

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New Staff Member to Focus on ACI Alliance Operations and Marketing

Laura Odato MPP, *Director of Operations and Marketing / ACI Alliance* / **Lodato@acialliance.org**

I am thrilled to join ACI Alliance as the Director of Operations and Marketing to help advance the mission and promote the incredible work and resources that the team has already developed. Prior to joining ACI Alliance, I worked in Washington, DC within the think tank community as well as the executive and legislative branches of our federal government doing outreach, liaison and communications work.

One of our main priorities in this new role is expanding the reach of ACI Alliance research and advocacy work to a broader audience using social media. Facebook, Twitter and LinkedIn have great tools we are utilizing to make sure we post content that resonates with our various audiences. With an increasing number of parents and adult recipients in our membership, we also encourage this key segment of our membership to share with those who can benefit from the important information we post every week. All of you have audiences that we hope to reach.

On Facebook, there is a large and active community of CI recipients and parents of children with CIs who use that platform to share information and make recommendations based on their experiences. In June of this year, we created an informational graphic discussing face shields as a return to school option for teachers and their students who have hearing loss. It quickly went "viral," reaching over 48,000 Facebook members. That post was shared almost 300 times.

The ACI Alliance Twitter account is the most dynamic of the three social media platforms we use, and we use it primarily to share timely news and to help publicize the research, events and news of our membership and allied organizations. In October, we were excited to share that Disney had included a model with a cochlear implant in their holiday catalogue. That tweet did extremely well as it appealed to a broad population. Eye-catching images pop out to Twitter users who are scrolling quickly through their timeline.

On LinkedIn, we have a chance to share new and relevant resources with the mostly professional audience on that platform. In August, we flagged for our followers the myriad resources on CI insurance coverage on our website. That post did well because periodically flagging resources that are useful for medical providers and clinics to share with their patients is an excellent use of material we have already created.

In the future, we will continue to expand our audience and study how parents, patients, and clinics interact with our social media so we can post material that is most useful to them. Fortunately, there are still many untapped audiences, partnerships and ways to communicate that we've yet to explore!

We hope you will follow us and be inspired to share our posts and resources with your patients, students, and colleagues. Please feel free to reach out to me at **Lodato@acialliance.org** with any ideas and suggestions for our social media pages. ■

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LinkedIn:
www.linkedin.com/company/acialliance/

Twitter: @acialliance

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Nucleus 7
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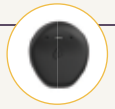

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* The Cochlear Nucleus 7 and Kanso 2 sound processors are compatible with Apple and Android devices, for compatibility information visit www.cochlear.com/compatibility

** The Kanso 2 Sound Processor is dust and water resistant to level of IP68 of the International Standard IEC60529. The Cochlear Nucleus 7 Sound Processor when worn with rechargeable batteries is dust and water resistant to the level of IP57. The Kanso 2 Sound Processor or Nucleus 7 Sound Processor with Aqua+ is dust and water resistant to level of IP68 of the International Standard IEC60529. This water protection rating means that the sound processor with the Aqua+ can be continuously submerged under water to a depth of up to 3 meters (9 feet and 9 inches) for up to 2 hours. The Aqua+ accessory should be used when participating in prolonged water activities.

Celebrating Veterans

Nichole Westin MA and **Laura Odato MPP** / *ACI Alliance Staff*

Working with Veterans and Veterans' advocacy organizations has been an exciting initiative for ACI Alliance. Hearing loss is one of the most common injuries suffered by active duty service members and veterans, with over 1,306,000 veterans having received disability compensation for hearing loss in 2019 (US Department of Veterans Affairs, **https://www.benefits.va.gov/REPORTS/abr/docs/2019-compensation.pdf**). Utilization of cochlear implants by individuals likely to be CI candidates and receiving hearing services in the VHA system in 2019 was less than that for adults in the general hearing health system who received CI by a factor of one-sixth. This comparison was based on an ACI Alliance-developed methodology described here: **https://www.acialliance.org/page/Veterans**

ACI Alliance worked with a number of Veterans who shared their stories for our website on getting CIs through the VA, and their experiences are rife with opportunities to improve the process for others who may benefit from a CI. Included below are brief clips from their full stories that we published.

DAVID WALKER served as a Captain in the U.S. Navy in the surface and diving community. After receiving his first hearing aids while still on active duty, it only took three months from the recommendation from his VA primary care physician to his CI surgery. His experience highlights the critical role of an informed primary care physician in supporting one's hearing journey. By recognizing the signs and referring him on to CI clinicians, his primary care doctor helped facilitate the process of obtaining a cochlear implant. Once in the CI system, he was pleased with his care and the flexibility his VA clinic showed for follow-up care.

Capt. David Walker (left) with his friend, Carl, who was killed in Iraq.

Margaret Pittman the day her CI was activated

MARGARET PITTMAN served in the U.S. Army as a radio and satellite operator. Ms. Pittman received her first hearing aids through the VA, and her journey to her CI was frustrated by inefficiencies in the referral and Community Care processes. The initial VA clinic she visited did not have a cochlear department and as a result she was referred out for her surgery. Although ultimately a success story for her hearing, Ms. Pittman's experience shows that while the VA Community Care program does work in providing excellent CI services to those who cannot receive them from their local VA, there are still issues that need to be addressed.

Rick Berger as a photojournalist during the Vietnam War and now

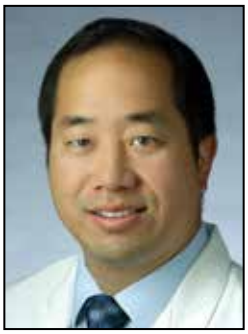
RICK BERGER served in the U.S. Air Force during Vietnam as combat journalist before joining the FBI. He received a CI for single-sided deafness (SSD). He originally received an auditory osseointegrated device with a private surgeon performing the operation. When considering a CI as a replacement, he was informed of his possible VA eligibility. Overall, Mr. Berger is pleased by the service provided by the VA, but says time spent approving the surgery and waiting for it to be scheduled should be shorter. He would also like to see more awareness about the fact that the VA will cover CI surgery for appropriate candidates.

A consistent theme is that Veterans are unaware of the cochlear implant intervention and that the VA will provide CI as a benefit to eligible Veterans. To broaden our reach, ACI Alliance is prioritizing building relationships with Veterans' advocacy organizations including Service Women's Action Network (SWAN) and Disabled American Veterans (DAV). These relationships are key to reaching a large population of Veterans who could benefit from our resources. SWAN now features ACI Alliance as a resource on their website. We are grateful to these organizations for partnering with us.

If you are interested in learning more about this initiative or want to refer a Veteran who has a CI to share their story with us, please contact Nichole Westin at **nwestin@acialliance.org**.

ACI ALLIANCE RESEARCH

Research and the ACI Alliance Mission



Michael Hoa MD / *Associate Professor /Department of Otolaryngology-Head and Neck Surgery / Georgetown University Medical Center / Chair, ACI Alliance Research Committee*

The ACI Alliance Research Committee was recently re-established and energized to provide appropriate oversight of research efforts and initiatives supported by the organization. The ACI Alliance Research Committee membership includes individuals from across the care continuum including Oliver Adunka MD; John L. Dornhoffer MD; Camille Dunn PhD; Hannah Eskridge MSP, CCC-SLP, LSL Cert. AVT; Fred Telischi MD; Andrea Warner-Czyz PhD; and Michael Hoa MD (Chair).

Societal Costs of Severe to Profound Hearing Loss

In the past year, we have developed a committee structure and developed procedures for rigorous scientific review of research initiatives. As its first task, the committee provided research oversight and review of a grant by the Oberkotter Foundation to the American Cochlear Implant Alliance to extend the analyses of the HOPE study which analyzed societal costs of hearing loss among cochlear implant recipients. The American Cochlear Implant Alliance tasked a team of investigators headed by principal investigator Dr. Ivette Cejas and joined by three Co-Investigators with backgrounds in childhood deafness (Dr. Alexandra Quittner), health economics (Dr. Esteban Petruzzello) and social context of health behaviors (Dr. David Barker) to create a grant proposal for this effort. The Research Committee ensured that an appropriate critical review was provided with input to the investigators. The process ultimately resulted in the Oberkotter Foundation agreeing to fund the study under the auspices of the American Cochlear Implant Alliance. Details on the study are provided below in content by Dr. Cejas.

Telehealth Innovation Grant

Our cochlear implant and hearing loss community have not been unscathed by the COVID-19 pandemic. To spur innovation in this environment, the committee with a directive from the ACI Alliance Board of Directors, created an organizational competitive grant application with a focus on telehealth innovations for cochlear implant recipients. The ACI Alliance Telehealth Innovation Funding Opportunity Announcement (FOA) solicited proposals for funding with the aim to fund an innovative proposal from one group of investigators. Multiple grant submissions have been received and a formal NIH-style grant review is under way. We hope that these efforts will establish a strong basis for scientific review of research initiatives and promote rigorous translational science within the organization that will ultimately benefit our patients. ■

Societal Costs of Severe to Profound Hearing Loss and Cost-Utility of Cochlear Implants

Ivette Cejas PhD / *Associate Professor and Director, Family Support Services / University of Miami Department of Otolaryngology / ACI Alliance Conferences Program Committee Member and Co-Chair, Scientific Program for CI2019 Pediatric (Hollywood FL)*

Hearing loss is the most common sensory disorder, with severe to profound hearing loss affecting 1 in 1,000 children born in the United States. Untreated hearing loss negatively affects educational outcomes, employment status and earnings, use of healthcare services, and life expectancy. The Project Hope Study (Mohr et al., 2000) is the most comprehensive examination to date estimating the societal costs of hearing loss as an additional $297,000 over an individual's lifetime. Moreover, for a child with prelingual deafness the estimation exceeds $1 million. This is double the cost associated with strokes, epilepsy, and rheumatoid arthritis. However, the Project Hope study was published in 2000, prior to the wide adoption of cochlear implants as the preferred

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ACI ALLIANCE RESEARCH *continued from page 12*

treatment for bilateral severe to profound hearing loss. The benefits of CIs are well-established and research has consistently shown their positive effect on auditory skills and spoken language abilities. CIs have also been shown to be cost-effective, with greater cost-savings being reported for children implanted earlier (Semenov et al., 2014).

I would like to introduce the ACI Alliance community to the investigator team: myself—Ivette Cejas, Alexandra L. Quittner, David Barker, and Esteban Petruzzello. We are a research team made up of psychologists, health economists and statisticians that will work in partnership with the American Cochlear Implant Alliance to build upon the currently available research on the societal costs of hearing loss and cost-utility of pediatric cochlear implants. Despite the known benefits of cochlear implants, variability remains in terms of insurance coverage and reimbursement for cochlear implants.

An economic evaluation of CI will provide an opportunity to measure the cost-effectiveness of early identification and intervention to limit the impact on societal costs. The purpose of a cost-utility analysis is to determine the ratio between the cost of a health-related intervention and the benefits, expressed in quality-adjusted life years (QALYs). QALYs are a treatment effectiveness measure that help quantify health states (such as hearing loss or cochlear implantation) that are considered less preferable to full health and allow comparisons over time.

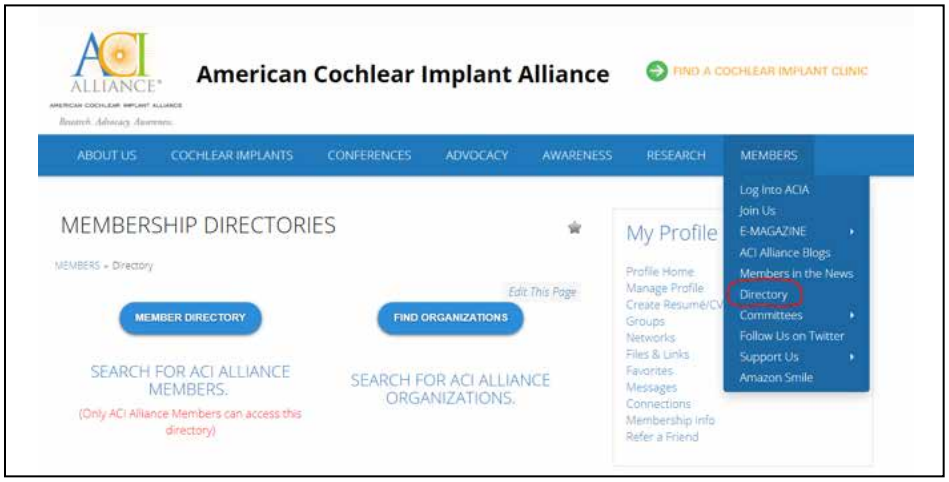
Over the next year we will be obtaining several datasets that capture the educational and medical costs of severe to profound hearing loss and cochlear implantation. We will also be using data from the Childhood Development after Cochlear Implantation (CDaCI), a unique database that captures a comprehensive developmental picture of deaf children receiving cochlear implants from infancy to adolescence/young adulthood.

Although this is no small task, we are up for the challenge. The importance of evidenced-based data as an educational tool regarding the benefits and costs of cochlear implantation is crucial given the uncertainty of healthcare in the future. We feel strongly that this project will help tackle health disparities in cochlear implants and improve access to hearing health care. ■

ACI ALLIANCE ORGANIZATION MEMBER DIRECTORY *cont. from page 5*

the registration process and through the conference timeframe. Please work with the main point of contact for your organization in order to be added to the account or send me an email at **jhouk@acialliance.org**, and I will gladly update your organizational member account.

Members can also find other members/colleagues from different organizations in our member directory. To protect the privacy of our members, you must log into your account to access this feature. To access the directory, look under the Members tab, and click on directory. **https://www.acialliance.org/page/Directory** ■



Student Opportunities for CI2021 Have Been Extended!

Student Scholarships will be offered/ Student ePoster Competition continues

We will offer student scholarships for complimentary registration at the meeting. The application deadline for scholarships has been extended to **December 1**. Students applying for scholarship are encouraged to submit ePosters and to participate in the Student ePoster Competition. We encourage the applications and involvement of students from diverse backgrounds. **https://www.acialliance.org/page/CI2021**

Abstract submission for Podium and ePoster Presentations deadline is **November 15**, and will not be extended. We will have a poster component and will be using an ePoster format. The submission area is here: **http://ci2021.org/site/index.php/scientific-program/abstract-submission** ■

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**Fine structure coding strategies are not indicated for prelingual children in the USA.*

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A PARENT'S PERSPECTIVE

Becoming a Highly Successful Parent Advocate (x 3)

Andi P. Hill, *Parent, Mentor, and Advocate / ACI Alliance / Alabama State Champion / Madison, AL*

I happened to first hear the words "cochlear implant" watching Caitlyn Parton and her parents appear on *60 Minutes* on November 8, 1992. My hometown is a diverse, technologically-rich melting pot on the northern shore of Alabama, 70 miles from Helen Keller's birthplace. My only exposures to deafness prior to my own children's births were from school field trips to Ivy Green and Caitlyn's appearance on *60 Minutes*. In just a little over a year, "Caitlyn's Story" would be far more than memorable and fascinating—it would be highly personal.

Our oldest daughter, Jessica, was born in 1993—well before Newborn Hearing Screening was available. I suspected something was wrong with her hearing when she was 4 months old. The general consensus of most family members and professionals I summoned the courage to tell was that I was an over-paranoid first-time mother. When Jessica was 8 months old, I told our pediatrician "either she is deaf or I am crazy and one of the two of us needs treatment!" I'll never forget my heart sinking as the audiologist gave us the testing results. I desperately wanted to be wrong and for everyone who thought I was an over-paranoid first-time mother to be right.

The ENT we saw at the time Jessica was diagnosed in 1994 told us a "great" outcome for her was to learn American Sign Language (ASL), read at a "4th-5th grade level upon high school graduation and move away from our family and community to a residential school for the deaf "early in elementary school." We were devastated, grieving, and hopeless. With images of Caitlyn Parton in my mind—dancing and singing, indistinguishable from her hearing peers—I persistently researched other options, none of which were meaningfully present in our state.

We chose the road less traveled at the time: Auditory-Verbal Communication, now known as the Listening and Spoken Language (LSL) communication mode. The long, painful story cut short is that Jessica made little progress, not for lack of qualified therapy or effort, but because she was misdiagnosed. At the urging of our speech-language pathologist who had gone to professional training at the Helen Beebe Speech & Hearing Center, we traveled nearly 1000 miles to finally get an accurate diagnosis: Jessica's hearing loss was severe-profound, not moderate-severe. The first question out of my mouth was "Does that make her a cochlear implant candidate?"

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The Hill family attended a NEEDTOBREATHE concert together—an amazing family memory made possible by cochlear implant technology and LSL.

A PARENT'S PERSPECTIVE

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We traveled to Pennsylvania to learn that there was a new pediatric cochlear implant program in Birmingham (AL) founded by Audie L. Woolley MD. We transferred Jessica's care there and started making weekly 200-mile round trips. Despite the rigid cochlear implant protocols in place at the time, in the fall of 1996, Jessica became Dr. Woolley's 14th CI patient and Alabama's first child with severe-profound hearing loss to hear with CI technology. The copious hours of work we had invested with AVT paid off, and Jessica began to soar.

Before you surmise that Jessica's hearing loss progressed from moderate-severe to severe-profound, let me stop you. Her audiogram is virtually identical to Jared's and Julianne's audiograms, which have been stable from the outset. The chances of two hearing parents with no history of congenital hearing loss having three deaf children is 1.56%, but against all reasonable odds, all three of our children are. The differences in their journeys are astonishing, and shed light on why the 2019 Joint Commission for Infant Hearing (JCIH) Guidelines promote a 1-2-3 standard for infants with congenital hearing loss.

Hill Family Hearing Profiles

Today, the results of our collective labors of love speak for themselves. All of our children are successful cochlear implant users and remarkable human beings by any definition. All graduated from high school with honors, using few accommodations for their deafness. Jessica graduated from college with honors, has her doctorate in physical therapy, and works as a licensed, board-certified physical therapist in a busy outpatient practice. She is Dr. Woolley's first CI patient to receive a graduate degree. Recently married, she and Chris have our first grand-dog, a chocolate lab bundle of happiness. Jared is a college graduate who through resolve and persistence amid a global pandemic, started his own business in a highly specialized market. Julianne is a college sophomore, majoring in Sports Medicine (Pre-Med). She is a Presidential Scholar and part of a distinguished service fellowship. With a busy leadership and social calendar, she finished her freshman year with a 4.0 GPA and has her sights set on medical school, in hopes of one day becoming a pediatric CI surgeon or PA.

For 25 years, I have stepped into the void I experienced when our kids were young. Sharing our family's experiences, educating, mentoring, and advocating for infants and children who are deaf/hard of hearing and their families is my calling. My career has led to everything from founding and serving as the Executive Director for a not-for-profit which supported families faced

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Hill Family Hearing Profiles

Key Milestones	Jessica	Jared	Julianne
Birth Year	1993	1997	2000
Age @ Diagnosis	9 months	Birth	Birth
Newborn Hearing Screening Available?	No	Yes, if elected by parents.	Yes / Not Covered by Ins
Began Auditory Verbal Therapy 1X week with LSLS/Cert AVT	10 months	8 weeks	4 weeks
EHDI Standard Met (Detection / Diagnosis / Intervention):	9 /10-24-33 / 10-24-33	1 - 2 - 2	1 - 1 - 1
Age when Cochlear Implant Candidacy began	24 months	6 months	3 months
FDA Minimum Age for Cochlear Implantation	24 months	18 months	12 months
Age at 1st Cochlear Implant	33 months / 1996	18 months / 1998	8 months / 2001
Cochlear Implant Precedent	1st child with severe-profound SNHL to be implanted in AL.	Youngest CI recipient in AL 1998-2001.	Youngest CI recipient in AL among youngest 3 in US in 2001.
Intervention Required in addition to weekly LSLS / AVT?	Yes	Yes	No
Language & Commuication Development	Significant Delay	Moderate Delay	Slight Delay
Total Years of Early Intervention / Therapy (Active or monitored by LSLS/Cert AVT and receiving IDEA Part C or Part B Services)	***11 years***	***6 years***	***3.5 years***

The purposes of Early Hearing Detection & Intervention (EHDI) and Early Intervention (IDEA Part C) are to reduce the need for special education supports and services later in life. While there was a substantial investment of resources involved in appropriate hearing care and Listening & Spoken Language / Auditory Verbal Therapy services for our children between the ages of 0-11 (the majority was parent-funded), clearly by the information provided below, the investment has a very high rate of return.

Key Educational Milestones	Jessica	Jared	Julianne
Mainstreamed with Appropriate Supports & Services (IEP) starting in:	Preschool	Preschool	Preschool
Appropriate Grade-Level Literacy Scores Achieved:	3rd Grade	2nd Grade	In K = 3rd Grade Level.
No longer qualified for an IEP; SS504 or equivalent instituted beginning:	5th Grade	3rd Grade	Kindergarten
High School Graduate?	Yes, with high honors.	Yes, with honors.	Yes, HS valedictorian.
Gainfully employed or college student?	Yes - BS, DPT	Yes - Busines Owner	Yes - In College

A PARENT'S PERSPECTIVE

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with pediatric hearing loss to leading the development of a Pediatric Audiology center in my home community. Today, I serve on multiple corporate and state advisory boards and guest lecture at the university level.

In 2017-2019, I co-led opposition to divisive LEAD-K legislation which would have been a chokehold to parent choice in my state, which is already plagued by restricted choices for working families who want to pursue technology and LSL due to systemic policy and funding inequalities. I watched two of my three children eloquently testify before our state's House Education Policy Committee. I devoted hundreds of hours developing strategy, researching and writing materials to provide to legislators, communicating with constituents, and presenting in the meetings that followed. It was through this work that I became more deeply connected to ACI Alliance.

Alabama was one of the earliest states targeted by LEAD-K proponents. Sadly, we are last in so many things (except football), but we were one of the first states to develop effective means for opposing divisive and destructive LEAD-K legislation. Through email exchanges with Donna Sorkin three years ago, I provided some of the first written documents to ACI Alliance for effectively opposing LEAD-K. Donna connected me to Nichole Westin, with whom I shared seven different documents outlining strategy and talking points we used in Alabama. I was so encouraged by Nichole's response: "This is impressive. I've been doing this for years and yep—I'd do this." What came next I count as a great honor; Nichole and Donna asked me to serve as Alabama's

Hiking in the North Carolina mountains when Jared was in college—from left: Jared, Julianne, Andi and Steve

State Champion, and in early 2018, I became the first parent to serve as an ACI Alliance State Champion.

Most parents of deaf children don't also happen to be MDs, PhDs, AuDs, SLPs, LSLS Cert. AVTs, or JDs who focus on special education and disability law. As parent advocates, we must gain functional knowledge in all of those areas to be effective in understanding and meeting our children's needs. I was a corporate controller before my kids were born, but I've become a jack of many trades because the people I love dearly needed me to have specialized but varied expertise. Our experiences, with what amounts to a comparative case study in our own home, have given me important insights that may inform future policies.

I wish I could say the state systems and supports available for families like mine changed in the seven years between the births of our oldest and youngest daughters. I wish I could say in the 20 years since Julianne was born, systemic changes have occurred so that all infants who are born deaf or hard of hearing can meet the JCIH 1-2-3 EHDI standard. I wish the JCIH Guidelines were codified to ease systemic barriers families face in engaging rapidly so their children can successfully use technologies like cochlear implants with LSL to hear, speak, listen, and thrive. I wish policies and funding allocations that presently make the ASL communication mode easier to access than others (in most states) had shifted to provide equitable access. I wish national certifying organizations like the American Speech-Language Hearing Association (ASHA) awarded a specialty designation for experienced SLPs who are LSLS Cert. AVTs like they provide to SLPs who are Board Certified Specialists-Child Language (BCS-CL). I wish insurance companies covered hearing aids for all people who have or acquire hearing loss before they can speak, read, and write to communicate. I wish third-party payers provided higher reimbursements to pediatric audiologists, cochlear implant audiologists, and SLPs who are LSLS Cert. AVTs. I wish Medicare, Medicaid, and the VA did more for people with hearing loss of all degrees, and that cochlear implants were recommended by professionals in those agencies far more rapidly and frequently.

In so many places in the national conversation, the incredible impact cochlear implants with LSL can make for children is underrepresented, if at all. For meaningful opportunities for this and the next generation of infants and children with hearing loss, someone has to speak up—if not us, then who? Our stories matter. Our experiences are informative and should have a transformative impact on our policymakers. I'll keep working and speaking up, and I have three incredible, amazing people in my family who speak boldly for themselves, for others, and for cochlear implants. Will you? ■

A longer version of the Hill family story appears here: **https://www.acialliance.org/page/ParentStories**

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