MESSAGE FROM THE CHAIR

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Dear Friends and Supporters of American Cochlear Implant Alliance,

Understanding the impact of cochlear implants in someone’s life has been the driving force in my career. Having worked with cochlear implants for over 20 years, I often take the power of restoring someone’s hearing for granted. While the science of hearing and the engineering aspects of the device drew me into the field, it soon became clear to be how truly magical it is to provide the gift of hearing and the hope of spoken communication to so many adults, children, and their families. I know that we all share this passion for cochlear implants. As such, it is a true honor and privilege to serve as the next Chair of the Board of Directors of American Cochlear Implant Alliance. I would also like to thank Dr. Meredith Holcomb for her decisive leadership during the past few years as our organization has grown tremendously. Further, it is important to emphasize the multi-disciplinary endeavor that we all thrive on and that has been exemplified by Dr. Holcomb’s appointment as the first Audiologist leading our organization. We really appreciate her passion and leadership.

It may be timely to also acknowledge past Chairs and members of the board. Specifically, we are fortunate to have both a Board of Directors as well as ACI Alliance staff that feel equally passionate about cochlear implants. We share this passion with an ever-increasing group of followers—not just in the United States but also internationally. As our organization continues to grow and mature, it seems pertinent that we set continued on page 2
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an example for other parts of the world and continue to focus on our roots of advocacy, awareness, and education. Most countries lack an organization primarily chartered to advocate for the strong multi-disciplinary efforts required for a successful cochlear implant program. Rather, each professional group includes cochlear implants into their (scientific) meetings without a dedicated and unified forum to bring the various professional groups and consumers together as one. Thus, I have high hopes that we can set an example for other parts of the world to create similar organizations we can ultimately collaborate with.

Speaking of which, it was great to see so many of you for such a strong turnout at CI2021 Virtual. It was especially exciting to see so many students, trainees, and fellows in attendance. We would like to continue this growth trend; creating a pipeline for young professionals interested in cochlear implantation is critical on so many levels. We need to continue the expansion of our grass-roots efforts to spread the word on cochlear implantation. Outreach efforts to primary care offices, the hearing healthcare community, and others is meaningful and worthwhile. As an organization, ACI Alliance is here to help and we are committed and ready to support these efforts on a broader level.

I continue to be disappointed by the media’s portrayal of cochlear implantation. While the struggles of hearing loss and the associated communication deficits along with the social isolation of hearing impairment are well portrayed in the film Sound of Metal, there were inaccuracies associated with cochlear implantation. Donna Sorkin, our Executive Director, wrote editorial on the topic which we published and she continues to be interviewed by publications on the film’s portrayal of hearing loss generally and on CI specifically: https://www.acialliance.org/page/SoundofMetal

I encourage you to take a read and continue our quest to educate the public on the importance of hearing and the ability of cochlear implants to restore the sense of hearing.

Lastly, as our country is emerging from the challenges of a pandemic, we hope that the difficulties of face mask-based communication are soon behind us. For individuals with hearing loss, masks have provided additional challenges that further emphasize the importance of hearing. As such, our upcoming meeting next May seems like a unique opportunity to bring our multidisciplinary teams together in person and continue to exchange experiences and knowledge, raise awareness, and advocate on Capitol Hill for the gift of hearing through cochlear implantation.
MY LAST COLUMN

Meredith A. Holcomb AuD
Immediate Past Chair, ACI Alliance Board of Directors
Director, Hearing Implant Program
Associate Professor, Department of Otolaryngology
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Does anyone else hear David Bowie singing “Ch-ch-ch-ch-changes!” in their head or is it just me? The world is opening back up, masks are literally coming off, travel is on the horizon, and in-person conference plans are in full motion. This also means my new normal includes a different role in the Alliance and a fall and winter calendar filling up with weekends and work meetings in other cities. While this should be exciting, it is instead a bit unsettling and scary as I think I grew far too comfortable hunkered down in my bubble in Miami and attached to my role as the COVID-19 Pandemic Chair of the American Alliance Board of Directors.

As someone who struggles with anxiety, change has never been my friend. But I recognize that it is time for each of us to embrace our new normal, our new schedules, our new roles, and our new experiences. And, I hope we will be better clinicians, better friends, and better humans from the lessons we have learned, professionally and personally, during the pandemic.

I am happy to report the Alliance used the time during my leadership to expand organizational memberships, State Champions and advocacy efforts, research initiatives, and CI education. I am incredibly proud of how hard the organization worked to progress the Alliance’s mission that was established 10 years ago. Our founding members were adamant about forming a group that would greatly improve CI access, CI awareness and CI research, and I believe we are successfully meeting those goals. I have no doubt my good friend, and new Chair, Dr. Oliver Adunka, will continue to lead the ACI Alliance well with innovative initiatives that are on the horizon. I am excited to see what he has in store for all of us!

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Lastly, I want you to know I have loved serving you as Chair the past two years. It is not lost on me that you took a huge chance on a young audiologist, who was in the middle of moving to a new state to lead a new CI team, to serve in this capacity, and for that I am forever grateful. Thank you to the Board of Directors, my industry friends, my University of Miami family, each of you, and my wing woman Donna for supporting me through this crazy adventure. This experience will forever be one of the proudest moments of my career. But as the saying goes… all good things must come to an end!

American Cochlear Implant Alliance Membership Elects New Board Leadership

ACI Alliance membership elected a new Board Member, Barbara T. Mellert, and a new Chair of the Board of Directors, Oliver Adunka, during CI2021.

Dr. Adunka is a Professor and Director of Otology, Neurotology and Cranial Base Surgery, Department of Otalaryngology-Head and Neck Surgery at Ohio State University Nationwide Children’s Hospital, and previously served as treasurer of the board of directors.

Barbara Mellert MPH provides Information, Technology and Consulting at Dartmouth College and volunteers as Administrator for Parents of Children with Cochlear Implants Facebook group. She is the parent of two adult children with cochlear implants.

ACI Alliance is grateful to Meredith Holcomb AuD, Director of Hearing Implants and Associate Professor at University of Miami Miller School of Medicine for her service as the immediate past Chair of ACI Alliance during an especially challenging two years. Dr. Holcomb will continue to serve on the board of directors for another year.

ACI Alliance is thankful to Andrew G. Shuman MD, Associate Professor in the Department of Otolaryngology–Head and Neck Surgery at the University of Michigan Medical School for his service on the Board of Directors. Dr. Shuman, a parent of two young children with cochlear implants, recently ended six years of board service.

If you are interested in serving on the board or nominating someone else to serve on the board, you can find more information at www.acialliance.org/page/BODForm2020. ACI Alliance welcomes and encourages nominations from or for any individual who would have a positive impact on ACI Alliance from a leadership standpoint and has relevant cochlear implant experience. The Board of Directors is designed to reflect the diversity and mission of the organization by including surgeons, audiologists, speech-language pathologists, educators of children with hearing loss, and other professionals on cochlear implant teams or from school settings, as well as parents and consumers.
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Hi Jay how are you doing on the history essay? I’m almost done, but I need to work on the citations and clean it up a bit too talk to you later.
It took a village! We wish to thank everyone who helped make the ACI Alliance’s CI2021 Virtual meeting a record-breaking success. Despite challenges associated with the pandemic and restrictions surrounding in-person meetings, we felt very fortunate to have over 1400 conference registrants from around the world, making this the largest annual conference in the US to date. We were also delighted to receive over 350 high-quality original abstract submissions, nine of which were selected for the first ACI Alliance “Best Abstract” awards. These papers will be featured in an upcoming special supplement in Otology & Neurotology: CI2021 Proceedings of the Annual Symposium of the American Cochlear Implant Alliance.

Also new for CI2021, this past meeting was not organized by a single center, but instead was organized by a geographically and specialty diverse program committee comprised of audiologists, surgeons, therapists and educators. CI2021 was chaired by Matthew Carlson MD, from Mayo Clinic and Sarah Sydlowski AuD, PhD, MBA from Cleveland Clinic, and included committee members from 15 distinct cochlear implant and other programs from across the country and world.

We are excited to announce that Matthew Bush MD, PhD, MBA from University of Kentucky Medical Center and Lisa Park AuD from University of North Carolina Chapel Hill will chair the CI2022 Program Committee, scheduled for May 18–21, 2022 in Washington D.C. We look forward to another outstanding conference in 2022, bringing us all together to share advances in basic, translational, and multidisciplinary clinical research to better serve the patients who entrust us with their care.

CI Conferences Program Committee

Matthew L. Bush MD, PhD, MBA (Co-Chair); University of Kentucky Medical Center

Lisa Park AuD (Co-Chair); University of North Carolina at Chapel Hill

Matthew Carlson MD (Immediate Past Co-Chair); Mayo Clinic

Ivette Cejas PhD; University of Miami

Heather Grantham PhD; Washington University School of Medicine

Ana H. Kim MD; Columbia University Medical Center

Kenneth H. Lee MD, PhD; UT Southwestern Medical Center

Kara Leyzac AuD, PhD; Medical University of SC

Nancy K. Mellon MS; The River School

Aaron Moberly MD; The Ohio State University

Sarah Mowry MD; University Hospitals Cleveland Medical Center

Sandra Prentiss PhD; University of Miami

Bridget Scott-Welch EdD, NBC, LSLS Cert. AVEd; John Tracy Center

Sarah Sydlowski AuD, PhD, MBA (Immediate Past Co-Chair); Cleveland Clinic

Holly Teagle AuD; University of Auckland, New Zealand

Naama Tsach PhD; Naama Tsach Auditory Rehabilitation
Who could have imagined how enthusiastic our members and colleagues from around the world would have been about still another virtual event? One attendee's email to us said it all:

“It was a great conference! With the exception (big) of not seeing people in person, it may have been one of the most efficient programs ever. The ability to go from one "room" and paper to another without having to "find the next room" made it so easy to catch everything you wanted to see/hear. I can only imagine how labor intensive the conference was to present, but the result was excellent!”

When we began planning for CI2021 we had hoped there would be some in-person presence. Of course, it quickly became obvious that would not be the case. We strived to be cognizant of the changes that COVID has necessitated (and facilitated) in CI provision—like telehealth—while taking a broad, long-term look at issues we must address to increase access to cochlear implantation. Our educational content explored challenging topics like assessment and treatment of Spanish speaking patients, whether and when regeneration of hearing will be possible, equity in provision of hearing healthcare, mentorship and mental health of healthcare providers, and sustainability/reimbursement of our current provision model.

The three-hour (Re)Habilitation Connect Forum explored three topics that are often under-addressed including trauma-informed practice, literacy, and transitions after high school. The Forum included a live “Continue the Conversation” with presenters after the formal sessions concluded. As always, the CI company satellite events on Wednesday afternoon were extremely well attended—matching or even exceeding attendance at our in-person conferences. A new feature of the close-out on Saturday was the Multidisciplinary Cochlear Implant Team Video Series, a competitively selected set of 11 short videos from centers and schools around the country. Over 1400 people from around the world were there live for the better part of four days, and it was exciting to have the opportunity to learn and share together.

We were gratified that the reviews were so positive—matching those of some of the most popular in-person CI conferences. There were plenty of suggestions for topics to be explored at future meetings and these have been passed on to the CI Program Committee for consideration at next year’s meeting.

For those who registered for CI2021, the virtual platform will remain open for viewing and CEU claiming until July 1. Take advantage of this opportunity before we close it out!

We are grateful to our CI 2021 Program Committee chaired by Dr. Matthew Carlson and Dr. Sarah Sydowski for their dedication and thoughtful planning of the conference. The Committee devoted many hours to this collaborative planning process, which had such a positive outcome.
AudioStream makes it easy to stream your music directly to your processor. Just slide the AudioStream cover over the SONNET to begin streaming your faves wirelessly from a smartphone or tablet.
Claiming Continuing Education Credits from CI2021

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

Though there were some problems for those verifying and downloading certificates for CEU and CME credits from the virtual platform in May these issues have been resolved. All previously-completed assessment data is available on the platform.

Registered participants who attended live or after the virtual meeting may also continue to view on-demand sessions and complete assessments until July 1, 2021.

Extensions for CEU or CME credit claiming have been confirmed by American Academy of Audiology, AG Bell, American Speech-Language-Hearing Association, and American College of Surgeons (for CME). The virtual platform will remain open until July 1 and claimants may continue to take all courses and seek credits until then.

**CEU claiming instructions:**
You must complete a session evaluation for each session you wish to claim credit for. You may only earn CE credit for sessions that you attend in entirety. You may not receive partial credit for attending a portion of a session.

There are two ways to complete a session assessment:

1. Click on the “Assessment” button on the bottom right of the screen while in the session page. A dropdown box will pop up; select the credit you would like to claim, and then take the assessment.

OR:

2. From the “select provider” dropdown, choose the credit type you which to claim. A list of each session you attended—with the corresponding credit option—will appear. You will need to take an assessment for each session from which you wish to claim credit.

Once you have taken all of the assessments for the Continuing Education type you would like to claim, click “View Certificate” to download your certificate. The certificate will show the total number of accumulated credits for each credit type.

For those seeking multiple credit types:
- Select a new credit type from the “select provider” dropdown. If you already completed the session assessment previously for another type of credit you will not need to do so again. Click “View Certificate” to download your certificate. The certificate will show the total number of accumulated credits for each credit type.

**For those seeking Tier 1 Credits:**
- Individuals seeking Tier 1 CE hours must attend at least 3 hours of sessions offering Tier 1 Specialty Hours per ABA rules. Sessions offering Tier 1 hours are designated as such in the Program Guide. Tier 1 continuing education hours apply only for participants who are certified by the American Board of Audiology.

If you provided the appropriate Membership/Account/License numbers during the conference registration process, your hours will be reported back to the relevant accreditor. We will contact you if additional information or clarification is required.

Please note each association’s guidelines for acceptance of conference credit hours may differ, and you should consult the appropriate professional association for CE verification. If you have questions regarding CEUs, please contact Jessica Houk at jhouk@acialliance.org.

For a Certificate of Attendance: Visit the Resource Page of the conference platform to download a printable Certificate of Attendance. This certificate does not confer continuing education credits but may be helpful to attendees in other respects such as reimbursement from an employer.
Plans are underway for our next CI conference in May 2022. May is a magical month to visit our nation's capital and our conference location in Washington is right in the heart of the city. The weather is spectacular with sunny days and average highs of 75 and lows of 58. (That's 44 Centigrade—for our friends from outside the US.) The flowers will be in full bloom and the theater schedule is in full swing. Save the date for the meeting and stay for the weekend. We will publish a listing of events that attendees (and their guests) might like to make reservations for in the coming months. Washington is our ACI Alliance home city and we are thrilled to help our members and friends fully enjoy the cultural amenities, wonderful restaurants, and iconic sights. It goes without saying there will be a killer scientific program. As in prior years, there will be plenaries as well as three concurrent sessions to allow attendees to pursue a wide array of cochlear implant and related content. We are exploring how to incorporate more virtual elements into an in-person conference and will announce those plans soon.

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Students, residents and fellows are encouraged. Last year's virtual meeting had the greatest number of students and trainees ever at a CI conference. We want to continue that trend and will offer scholarship opportunities and a student poster competition.
# Key Dates (Tentative)

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<td><strong>ACI Alliance on the Hill</strong> (by application)</td>
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<td><strong>CI Manufacturer Satellite Symposia</strong></td>
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**CEUs**

CEU and CME will be offered from the same providers that have been available in the past.

Tier 1 Hours for audiologists will be offered.

Certificate of Participation for all attendees.
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4. The Cochlear Baha 6 Max Sound Processor, with battery compartment excluded, is dust and water resistant to level IP68 of the International Standard IEC60529. Refer to the relevant user guide for more information.

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With CI2021 wrapped, we are already looking ahead to CI2022 which will take place in Washington, DC in May 2022. Once again, we will take advantage of our location in the nation’s Capitol to organize ACI Alliance on the Hill to visit with Members of Congress and their staff. (We took our members to the Hill at prior DC meetings in 2013, 2015, and 2018.) On May 18, 2022, our State Champions and other interested ACI Alliance Members will discuss the leading issues of the time and educate policy-makers on the benefits of cochlear implantation.

In 2018, nearly 100 of our members participated in ACI Alliance on the Hill to discuss cochlear implants generally, CI provision as an Essential Health Benefit under Medicare and Medicaid, and CI access for Veterans. The discussions were fruitful and informative with many reporting back that they felt heard by the Congressional Members and staff. As a brand-new member of the ACI Alliance team, it was a pleasure for me to watch our members explain what a cochlear implant is, the surgical and rehab process and hear the stories of quality of life benefits.

So what will 2022 look like? Participants will be grouped by home state or topic and all meetings will be scheduled by our public affairs advisors (Powers Pyles Sutter & Verville PC) and ACI Alliance staff. Before participants arrive in DC, we will hold virtual training to fully brief our advocates get up to speed on how to advocate. On the morning of May 18, starting at 8:30 AM, we will kick off with a review of the issues, answer last-minute questions and issue assignments before transportation to take us all to Capitol Hill. And then they are off! Participants will return prior to the start of the afternoon CI company satellite symposia.

What issues will be discussed? As the policy world is shifting, stalling, or jumping ahead based on what is happening at a particular moment in time, it is difficult to pinpoint right now what we will focus on. Who could have predicted the COVID crisis and how it shifted so many issues? Medicare and Medicaid coverage for hearing health continue to be important to us as are Veterans access, and educational needs of children at school. As we get closer, this list will be fine-tuned and shaped by the political environment and our specific issues.

These visits to Capitol Hill are truly a rewarding experience as well as a critical part of our overall advocacy efforts. ACI Alliance staff meet regularly with Congressional offices but it is your stories that make the difference. It is the personal stories of lives changed—from the view of the clinician, the educator, the parent, or the CI user—that shines a light and showcases why access to cochlear implants needs to be improved.

More information on how to be involved in the visits will be provided in the coming months. I am always happy to discuss our advocacy programs and can be reached at nwestin@acialliance.org. We look forward to seeing you next May.
The 2020 elections led to a significant shift in power in both the White House and Congress, and as the President and Congress finally settle into their new roles, and begin to staff up, their policy priorities for the next year become clearer. As in many years, healthcare legislation is taking center stage, particularly as elected officials work to learn lessons from the past year and a half of the public health emergency. The focus on the healthcare policy landscape—and the new Administration and new Congress—means welcome opportunities for the cochlear implant community to review, update, and revive legislative and regulatory targets and priorities.

**Agenda for the 117th Congress and the Biden Administration**

The 2020 elections resulted in Democrats gaining control of the White House and both chambers of Congress. While Democrats retained control of the House, they lost some key elections and reduced their margin of control by ten seats. Democrats also gained control of the Senate, following special elections for both Georgia Senate seats, giving Democrats tight control with a 50-50 split and Vice President Harris breaking a Senate tie. With such tight margins in the House and Senate, the most moderate members of each party wield significant power as key swing votes.

Democrats may choose to use their slim majority to advance difficult-to-pass legislation through the budget reconciliation process. This legislative procedure allows legislation to be passed with a simple majority (51 votes) if it is deemed “germane” to certain tax, spending, and debt limit legislation. Democrats have already used reconciliation to pass the $1.9 trillion *American Rescue Plan Act*, which included billions for vaccines, and an increase to the federal matching rate for spending on Medicaid home and community based services.

With Democrats in control in Congress and the White House, there is a more unified policy platform among the branches, with both President Biden and Congress prioritizing COVID-19 vaccine ramp up and infrastructure investment, including so-called “human infrastructure” through the *American Jobs Plan* and the *American Families Plan*. In addition, Congress is looking to pass telehealth legislation that would make some telehealth extensions permanent after the public health emergency, which may have a particularly important impact on access to care following cochlear implant surgery.

**Hearing Health and the New Congress and Administration**

President Biden is expected to revise or repeal regulations that would ultimately benefit the provision of cochlear implants including rolling back federal regulations and guidelines that were introduced during the Trump Administration that limited the guaranteed coverage of Essential Health Benefits (EHB), including rehabilitation and habilitative services that include cochlear implants. Options for regulatory action include: rolling back guidance that allowed states to implement less comprehensive plan offerings, including short-term limited-duration insurance (STLDI) and association health plans (AHPs); and removing benchmark plan flexibilities that allow states to select another state’s more limited EHB package.

Congress is also acting on legislation that is likely to benefit cochlear implantation. In the last Congress, Representative Debbie Dingell (D-MI) introduced a bill which proposed to provide Medicare coverage for hearing aids for the first time. The bill would have covered beneficiaries with severe and profound hearing loss, but the bill made no mention of referrals of cochlear implants for this same population. The ACI Alliance suggested language for the bill that would have required providers to consider all hearing health options, including referrals for cochlear implants. Ultimately, that bill, which was included in the broader drug pricing bill, the *Elijah E Cummings Lower Drug Prices Act*
Drug Costs Act Now, H.R. 3, passed the House but ultimately did not pass in the Senate. The House has reintroduced H.R. 3 this year, however, that bill did not have any of the previous Medicare benefit language, including coverage for hearing aids.

Representative Dingell introduced a new Hearing Aid bill this year, H.R. 1118, Medicare Hearing Aid Coverage Act. The bill no longer includes limits on hearing aid coverage for just those with severe or profound hearing loss and, instead of including hearing aids as a distinctly covered DME device under Medicare, removes hearing aids from the list of prohibited services for Medicare coverage. This would remove existing exclusions of hearing aid coverage but would not affirmatively establish a hearing aid Medicare benefit. Finally, the bill focuses on directing the U.S. Government Accountability Office (GAO) to conduct a study on the potential impacts of removing the Medicare hearing aid exclusion. This legislative approach addresses many potential cochlear implant concerns raised by the ACI Alliance.

This year is a year of change as the new President and Congress work to sort out their healthcare policy priorities and test what they can pass with a slim majority. Through this year of change, there are clear opportunities to advance policies that benefit the cochlear implant community, and the ACI Alliance continues to work for all of its members to identify and respond to those opportunities.

The ACI Alliance Advocacy Toolkit is now available. It brings together our collective experience and knowledge to help our members impact public policy on cochlear implants. [https://www.acialliance.org/page/AdvocacyToolkit](https://www.acialliance.org/page/AdvocacyToolkit)
Cochlear Implants, Awareness and Disability: An All Americas Perspective

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

In early 2021 CI advocate Paula Pfeifer, founder of Crônicas da Surdez, reached out to Google engineer and “Father of the Internet” Vinton Cerf and his wife and CI recipient Sigrid Cerf as well as ACI Alliance Executive Director Donna Sorkin. Ms. Pfeifer is a bilateral CI recipient and her experience inspired her to found Crônicas da Surdez, an organization focused on CI awareness in South America. Along with her husband, Dr. Luciano Moreira, they proposed the idea of collaborating on a video exploring their experiences with cochlear implants and disability issues.

Vinton and Sigrid Cerf proposed including ACI Alliance Executive Director Donna Sorkin to broaden the conversation with her own experience as a CI recipient as well as her advocacy and ACI Alliance’s efforts to improve awareness and access.

The group of five met remotely in March. The discussion included wide-ranging topics that all five were concerned about such as hearing with cochlear implants and hearing aids, assistive devices, the stigma of hearing loss, strategies for learning to listen with a CI (in Sigrid’s case—listening to over 500 audiobooks), and how new technology has improved their listening experience.

It was notable to all participants how similar their experiences were throughout the process despite coming to it from different countries and different perspectives—as consumers, spouses, professionals, and advocates.

These videos serve as a resource to answer questions that arise as people consider the short and longer-term benefits and challenges of getting a CI. ACI Alliance is excited to share these videos and continue the organization’s mission of raising awareness by sharing honest conversations about both the challenges and life-changing prospects of CIs.

The video series can be found on the ACI Alliance website at www.acialliance.org/page/AllAmericasPerspective.
I’m writing this on the 15th anniversary of the day our younger son, Sam, received his first cochlear implant at the age of 11. Our older son, Thom, received his first six months earlier in November of 2005. In the space of 15 months, both our sons became bilateral recipients. They were among the first in our state to receive bilateral cochlear implants and for both, having cochlear implants was positive and life changing.

A little about us. My husband, Hugh, and I have two sons. Thom was born in New Orleans in 1992, before universal newborn hearing screening was enacted. We moved to New Hampshire in 1994; Sam was born in the Granite State in 1994, also before universal newborn hearing screening. Fast forward to Thom’s three year check-up. I had a doorknob conversation with his pediatrician (you know, when your hand is on the door and you’re ready to leave and you think of one more thing?) about the fact that Thom would seem to ignore me at times. We talked about it and started putting pieces together. My brother has a moderate unilateral loss. He’d done well enough over years. Then there was my mother’s brother with hearing loss but we never thought much about that either—my family owned lumber yards so we thought it likely was related to noise exposure. And my sister’s son? Well, that was due to ear infections. Thom was diagnosed at 3 years, 3 months with severe hearing loss, a retest revealed that initial diagnosis to be correct. He was fitted with hearing aids at 18 months and thrived with them. Thom’s diagnosis led to testing Sam via ABR. Sam had a profound loss, was quickly fitted with hearing aids, and did very well with them also. They both attended our town’s public schools and had excellent supports via their IEP and then 504 plans.

Fast forward to 2005. Thom was in 6th grade and it became obvious that he needed more in terms of amplification. That’s when his audiologist at the time suggested cochlear implants. We were all shocked initially but agreed we’d learn about them. Our center—Dartmouth-Hitchcock Medical Center in Lebanon NH—had a very thorough path to determine candidacy. Thom had appointments with a developmental pediatrician, a neuropsychologist who specialized in working with deaf/hh kids, a social worker to talk about realistic expectations and next steps, and of course, our ENT and audiologist. Thom received his first CI in November 2005, as mentioned and was activated in December 2005. The results were nothing less than dazzling. When he tested just prior to implantation, his word recognition scores were 4%!—with hearing aids. Three months post activation, he scored 98%! He was on a panel discussion with Heather Whitestone Miss America 1995 in early 2006 3-4 months after activation. We were in a large conference room and he was answering questions posed to him from the back of the room, something he could never have done with hearing aids. Thom received his second CI in December 2006.
Sam saw Thom's success and wanted a cochlear implant as well. After an insurance rejection that our surgeon and audiologist successfully argued, he received his first in May 2006 and his second in February 2007. We definitely kept ENT and audiology busy those months!

Today both our sons are doing very well. Thom graduated from Hampshire College, majoring in theater (with an emphasis on acting). Incredibly creative, he is working towards certification as a landscape designer and works for a small landscape firm in Seattle. Thom is engaged to the wonderful Noel, who is also smart and creative (date to be determined!). Sam lives in eastern New Hampshire, in the southern Lakes region. He and his sweet girlfriend, Shelby, bought a house last July. Sam is working towards his undergrad in business at Granite State College and then plans on continuing at University of New Hampshire in their MBA program. Sam works at UNH in Student Accessibility Services. As he said in his cover letter applying for the job, he had an excellent experience growing up with accommodations and wants to help others do the same.

Our family has always believed in the importance of advocacy—our own and also helping others with information and resources. Hugh and I were the parent members of the New Hampshire Universal Newborn Hearing Screening Task Force to implement the state law, which passed in the early 2000s. Access to accurate information and resources is crucial and especially now with so much on social media, it's even more important. I took over the Facebook group Parents of Children with Cochlear Implants as an information resource for parents who have children with a CI or who are learning about cochlear implants. They receive accurate information in an accepting, non-judgmental environment. Back in the days of listservs, I worked with a group of like-minded parents to start the Listen-up listserv.

Another important aspect of parent advocacy is knowing when to start turning advocacy over to your child. We chose to do that bit by bit; they attended IEP or 504 meetings in late elementary. I remember at the beginning of 8th grade, Sam did an in-service for his teachers in his mainstream public school. He talked about his hearing history. Then he transitioned by saying “and now I’m going to tell you what I need from you so I can be successful in your class.” His English teacher—who was also the high school football coach—was incredibly impressed. After the meeting, his social studies teacher told Sam she’d never had a student with cochlear implants and wanted to let him know if she wasn’t doing something correctly, to let her know.

I recently was honored to join the Board of Directors of the American Cochlear Implant Alliance and hope as the parent member to bring parents’ unique perspective to the group. The ACI Alliance is such an important organization. I’ve directed many parents to the ACI Alliance. The ACI Alliance mission of research, advocacy and awareness is spot on and is near and dear to my own heart. I mentioned before how important advocacy is to our family. It’s so important to me that there’s an organization that echoes my values and beliefs. I appreciate every day that information coming out of ACI Alliance is accurate and is based on sound research. I’ve been a State Champ (representing New Hampshire) for awhile now and find the information given regarding legislative efforts to be extremely helpful. It’s an organization that listens to parents and then acts on that information. Advocacy works!
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