As we celebrate our 10th birthday, our Executive Director, Donna Sorkin, has written a great article summarizing the accomplishments of the ACI Alliance at this milestone birthday.

The ACI Alliance was founded with the intent to eliminate barriers to cochlear implantation and to make this groundbreaking intervention available to many more candidates.

As Donna points out, we have made great strides with regards to the number of cochlear implants performed in the US. ACI Alliance members can take pride in our efforts together. An often-cited estimate of 5% CI utilization was based on 2010 data that was published in a 2013 research study Donna completed. A more recent calculation using traditional candidacy criteria was reported at the CI2021 Virtual conference by Dr. Ashley Nassiri. In 2015, approximately 13% of patients with bilateral severe-to-profound sensorineural hearing loss had undergone implantation, an improvement from 11% two years prior.

While these numbers and their trajectory are encouraging, we continue to struggle with relatively low penetration rates. By comparison, some western European
countries such as Germany perform roughly twice as many cochlear implants per capita when compared to us. While it is certainly encouraging to see that greater penetration numbers are possible, it also highlights the potential detrimental effect of our healthcare system on access.

However, these may also highlight the fact that low penetration rates may not be due to a single issue but are likely multifactorial starting with the invisible nature of hearing loss and the often-stigmatized disability. While financial incentives are often quoted as a driving factor for low penetration rates, I believe educational efforts may be our biggest opportunity for growth.

It may be difficult to provide the proper hearing intervention to most candidates in this country. However, the ACI Alliance was founded on the goal, which was supported by each member of the Founders Board: John Niparko MD and Terry Zwolan PhD (Co-Chairs), Thomas Balkany MD, Alice Holmes PhD, Craig Buchman MD, William Luxford MD, Teresa Caraway PhD, Marilyn Neault PhD, Jill Firszt PhD, J. Thomas Roland MD, Bruce Gantz MD, Jay Rubinstein MD/PhD, Rene Gifford PhD, James Saunders MD/MS, Donald Goldberg PhD, Susan Waltzman PhD, David Haynes MD, Kathryn Wilson MA, Ronald Hoffman MD, and Nancy Young MD.

The current leadership of the ACI Alliance strives to continue the passion of our Founders Board building upon the same mission of improving access to cochlear implantation through research, advocacy, and awareness. I can certainly speak for my own passion for cochlear implantation as a main driving force of my professional career.

In addition, the ACI Alliance Founders recognized that individual efforts pertaining to cochlear implant advocacy and awareness were likely to be less successful than joint efforts, especially when multiple professional groups come together and join forces. Alliance in our name underscores this belief in working collaboratively with others wherever we can find common ground.

Therefore, I would like to call on all members to reach out to us so we can explore creative ways to enhance our mission. It is my firm belief that structured and frequent advocacy, education, and outreach will ultimately continue to show results and help spread the word on the lifechanging effects of cochlear implantation. By performing these activities, we should not forget the many positive downstream effects of cochlear implantation on, for example, social re-integration in adults. In pediatrics, the opportunity to pursue spoken language and educational benefits (including literacy) have been shown to be greatly enhanced via cochlear implants. If you are not familiar with our website, I encourage you to explore and learn more about the resources and information we provide for patients, their families, and professionals.

Finally, I would like to express my gratitude for your support of our organization and the great cause we all serve. I can say that the passion to enhance patients’ lives via cochlear implantation that our Board of Directors, the ACI Alliance staff, and our constituents demonstrate will ultimately lead to positive changes for the field including the communities we serve, our patients, and the diverse group of professionals helping patients enhance their communication abilities. Ultimately, this passion will continue to push our agenda forward and make cochlear implants available to a broader candidate pool.
A powerful hearing experience with excellent sound quality in a variety of situations and built-in connectivity solutions

Effortless comfort and convenience with its ergonomically designed housing and accessories

Ultimate ease of use for staying connected with the world around you throughout the day

Visit us at AdvancedBionics.com/naidacim and start your journey to better hearing today.

CONNECT WITH THE MOMENTS YOU LOVE
Founding of American Cochlear Implant Alliance: Top Ten Accomplishments in Ten Years

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

In 2010, a small group of CI clinicians gathered to consider how they might advance access to cochlear implantation. It was determined that without a dedicated organization, cochlear implantation would continue to fall behind priorities at the major organizations in the field of hearing loss. The American Cochlear Implant (ACI) Alliance was formally incorporated as a nonprofit organization in October 2011 with a specific mission on CI access through research, advocacy, and awareness. A Founder’s Board comprised of thought leaders in the field guided the establishment of the organization. (See page 5)

Now at the ten-year mark, let’s think about what we have accomplished since our founding. The following “Top Ten” represent broad, unique and important organizational accomplishments. Of course, we proudly point to the improvement in utilization rates discussed by Dr. Adunka above while acknowledging we are still not reaching the majority of people who could benefit.

1. A robust public CI informational website. The ACI Alliance website has grown to be a place for the general public to find information on a range of cochlear implant topics that is suitable for consumers, general medical practitioners, and hearing health professionals outside of CI. Two-thirds of the traffic to the site is “organic” meaning people are searching on cochlear implants, steps to a CI, finding a CI clinic, insurance, candidacy and more. The majority of our more than 250 daily visitors are coming to the website for the first time—85%. Though there are other websites with coverage on cochlear implants, ACI Alliance is arguably the most comprehensive, factual, non-commercial resource on CI for the general public but it is also a site providing a focus for ACI Alliance members and the CI community. Some of the inquiries are a bit odd; for example, we receive inquiries via our website or on the telephone about purchasing a part for a sound processor. We help callers determine what brand of CI they have (truly some people don’t know) and then direct them to the right company. Dinner one night was interrupted by a hospital emergency room nurse who wanted to know if a patient could have MRI. We helped the nurse determine which company had manufactured the patient’s CI and provided the 24-hour number to call.

2. Vehicle for CI Community to collaborate. The establishment of ACI Alliance has helped create a CI (and educational) center focus; in the past our field’s collaboration occurred largely through CI manufacturers. We now have an ongoing mechanism for clinicians, scientists, and educators from across the care continuum to come together and collaborate in an ongoing manner.

We have an efficient mechanism for addressing insurance coverage (e.g., single sided deafness), Medicaid coverage and reimbursement, and Medicare candidacy. One of our first national initiatives was organized in 2013 to evaluate expanded CI candidacy in Medicare beneficiaries. (See #7 on page 6) Our advocacy networks described in #4 below are another important example. The CI companies remain important supporters and collaborators.

3. Annual CI Meeting efficiency and broadened outreach. With the move to having the same entity (ACI Alliance) organize the CI conferences each time, continued on page 5.
ACCOMPLISHMENTS continued from page 4

the conference benefitted from operational continuity as well as carry-over from attendees on recommendations for future topics and coverage. In 2021, ACI Alliance implemented a format utilizing a national program committee that provides wide-ranging perspectives around the US and beyond. Public policy is an ongoing part of the discussion at the conferences especially at those meetings held in Washington DC when we arrange for our advocates to meet with Congressional members about our specific CI access issues. Congressional Members often join us. The meeting has grown in size and provides state-of-the-art communication access (for those with hearing loss) as well as growing opportunities for students, fellows and residents, encouraging young investigators to contribute to our field.

4. Dynamic Public Policy Program with CI Advocates around the country. ACI Alliance is the only major organization actively working towards expanding access to cochlear implants in national and state public policies. We have dedicated governmental affairs staff and engage a major DC public affairs firm that helps us reach elected and appointed officials and hone our messages as part of national legislative efforts. The current push to pass hearing aid coverage in Medicare is a good example. We support such coverage of course but the decision to cover only those older adults with severe or profound hearing loss will further confuse those who should be referred for a CI evaluation, a Medicare covered service that would provide greater benefit for someone with a profound hearing loss. ACI Alliance is the only organization that continues to emphasize hearing care across the continuum during the discussions of hearing aid coverage noting that hearing aids are only one part of a set of hearing solutions.

Our State Champions were one of our earliest programs, initiated to provide support for members to address CI coverage in Affordable Care Act Marketplace Plans. This program now involves 143 Champs in 43 states and Washington DC. In 2020, we established the Cochlear Implant Consumer Advocacy Network (CI CAN) for parents, adult consumers, and anyone else who wants to share their stories about CI as part of our advocacy. As this network grows, CI CAN will serve as a powerful force in our advocacy efforts.

5. Parent Choice part of the discussion. There is an ongoing effort by certain interests in the Deaf community to influence policy-making on communication options by erroneously stating that children who are deaf and hard of hearing who are not using sign language are “language deprived.” This is not a research-based statement—it is opinion-driven. ACI Alliance takes no position on the use of ASL or other forms of sign language. We believe that such decisions should be driven by individual family situations. We oppose efforts by some groups to provide misleading information and attempt to force parents to make a specific communication choice for their children. In 2019, ACI Alliance encouraged leading organizations in the field to join with us to collaborate on parent choice initiatives in state and national policies. Prior to organizing the Parent Choice partnership, there was no coordinated effort for the various organizations to work together and provide a coordinated, research-driven response. We have generally been successful in defeating these egregious initiatives designed to denigrate the value of hearing technology. A position paper on Parent Choice was developed and adopted by the Board of Directors, which has helped crystalize our efforts.

continued on page 6
ACCOMPLISHMENTS  from page 5

6. Outreach to Non-CI Audiologists and HA Dispensers to Expand Awareness & Referrals. Consistent referrals to a CI center for a candidacy evaluation are thought by many to be the most important means of improving the current low CI utilization rates. ACI Alliance has initiated multiple efforts to reach hearing care professionals outside of CI who see patients for hearing aid fittings. An annual program with AudiologyOnline (AO) is intended for a broad audiology audience. When the CI2020 International conference was cancelled due to the COVID pandemic, AO stepped up to host the content for a free online conference—an event that reached 1750 audiologists and speech language pathologists and continues to draw a general audience.

In 2022, ACI Alliance will publish organizational guidelines to help clarify the confusion about who is a CI candidate for those in and outside of CI. Individual papers on best practices in determining cochlear implant candidacy in adults and children and companion papers on CI in single sided deafness in adults and children will be published in Ear and Hearing.

Free memberships and educational sessions on CI candidacy and outcomes are offered to members of the International Hearing Society, the organization whose members serve approximately half of US adult hearing aid wearers. Outreach to the American Academy of Family Physicians included two presentations at the annual conference on when to refer patients, what is involved in CI, and typical outcomes.

7. Focused Research Program—Expand Access ▶ Improve Public Understanding of CI Impacts on People. The founders of ACI Alliance emphasized conduct of research to address CI access and public policy concerns. An early research project aimed to examine the impact of providing cochlear implants to Medicare beneficiaries with more residual hearing to determine if older adults had similar outcomes to the younger population. This study was completed with the results supporting a National Coverage Determination from CMS that requests that those covered for a CI Medicare be eligible with hearing aid outcomes similar to those that guide CI for adults younger than 65. Research has been supported on a range of topics that impact public policy including quality of life impacts, cost effectiveness of CI in children, telehealth, and insurance coverage for CI Medicaid and single-sided deafness.

8. Portrayal of Cochlear Implantation. The discussion of cochlear implants in mass media is often inaccurate, negative, and intended to discuss the intervention in an off-putting manner. Popular films such as Sound of Metal (released in 2020) included extensive misinformation (e.g., CI isn’t covered by health insurance, professionals send recipients off without support and guidance, showing large surgical scars that don’t resemble today’s surgery) designed to cast a negative light on the intervention. ACI Alliance actively participates in such discussions—whether the topic is popular film, opinion pieces posing as research in journals, or national public policy on children. Too often hearing care professionals and even consumers are unwilling to step up for fear of being “chastised by Deaf advocates.” We do step up. ACI Alliance is a recognized, credible voice on the facts surrounding cochlear implants. With the creation of a parent/consumer network, our ability to engage in such discussions is enhanced.

9. Insurance Coverage Content for General Public. From its founding, ACI Alliance has sought to change the public discussion on CI coverage for anyone of any age who would benefit and fits candidacy. The organization encourages research and guidance that is intended to demonstrate health and quality of life benefits to advance insurance coverage from public and private institutions. We have developed robust website content with the aim of eliminating the public perception that CI isn’t covered by health insurance. This is shared on our website; directly to candidates, family members, and general health care professionals such as primary care physicians; and during discussions of insurance on online groups. Our website comes up second in Google search on the topic and is one of the most common inquiries we receive via our phone or website info line. We seek to change the public perception that CI is like hearing aids and isn’t covered by insurance as well as the misinformation that exacerbates the problem in film and general media. In the coming year, we will work directly with large insurers who refuse to cover for approved indications.

10. Trusted Source on When and Where to go for a CI. Too often people of all ages fail to move forward because they don’t know when or where
Some of the most basic questions that we respond to are: Where should I go for a CI? Am I too old? Should I wait until I have less hearing? and Won't this preclude future options? The yellow map on the website of CI centers and related providers is a trusted source for people who don’t know where to go and is the second most visited page on the website.

Along with the traditional professional entities in hearing health, ACI Alliance partners with mutually supportive consumer and parent web groups. We are then able to reach and respond to those who are exploring CI or searching for support—a mechanism that is increasingly important in the new Internet world that functions with fluid connections and a different type of membership than was typical in the past.

We’re gratified to have contributed to greater awareness and CI utilization in the United States and will build and expand on what all of us have created with American Cochlear Implant Alliance. Here’s to the next 10 years and even greater awareness of this extraordinary intervention that all of us are so committed to providing to people of all ages who may benefit.
The SYNCHRONY 2 Cochlear Implant System features S-Vector magnet technology. With 25% more magnet strength, it’s the ideal implant for single-unit audio processors.

The sounds of a morning jog. **IT’S THE LITTLE THINGS** that make it a memory.

go.medel.com/ACIA

For information on potential risks and contraindications relating to implantation, please visit www.medel.com/us/si-cochlear-implant-systems/
Greetings, friends! The crises and the challenges of the last 18 months have tested our resolve and resilience; thus, we look to 2022 with high hopes and expectations. As we emerge from this sustained storm of adversity, we look forward with excitement to our next annual meeting: CI2022 DC: Emerging Issues in Cochlear Implantation. It is with great enthusiasm that we invite you, the cochlear implant community, to participate in and contribute to this important meeting. This conference will focus on the “emerging issues” facing our patients, research teams, educational programs, and clinical operations as we emerge from such difficult times.

As your CI2022 conference program committee co-chairs, we have had the immense privilege of collaborating with the ACI Alliance Program Committee, who represent some of the brightest minds in our field, to craft a conference program that will celebrate the successes of the past, rejuvenate our shared passion for the gifts of hearing and communication, and provide clarity on the emerging issues facing the cochlear implant community. This conference will commemorate the 10-year anniversary of the ACI Alliance and 40 years of progress in cochlear implantation. Through novel sessions, expert panels, invited speakers, and peer-selected podium and poster presentations, we will highlight the following four emerging issues:

- **Results May Vary: Mechanisms Underlying the Broad Range of CI Performance:** This theme is focused on examining the factors influencing performance and novel ways for cochlear implant teams to address the wide range of cochlear implant outcomes.

- **Grassroots Expansion of Cochlear Implantation:** Through this theme, we plan to provide attendees up-to-date information on issues related to increasing access to cochlear implantation. Content will focus on finding ways to care for broader and more diverse populations with special attention given to building community partnerships, connecting with primary care providers, and supporting cochlear implant programs in private practice settings.

- **What’s New in Clinical Trials and Translational Research:** Attendees will be offered a high yield overview of cutting-edge translational research as studies are brought from the bench lab to the bedside and from clinical practices to population health.

- **Rethinking (Re)habilitation and Education:** This theme will feature advances, variations, and critical transitions in rehabilitation services and the educational resources for adults and children. Special attention will be placed on the services and developing needs of patients with single sided deafness.

The abstract submission website is currently open and we welcome you to submit abstracts across a broad range of categories that include telehealth, basic research, surgical and medical considerations, audiology, rehabilitation and education, behavioral health services, technology, economics/public policy/practice management, and even a miscellaneous category for anything else related to cochlear implantation. We hope to see submissions that highlight collaborative and transdisciplinary means to bring the most up-to-date care to patients.

The global pandemic has given us perspective on how easily we have taken our cochlear implant community for granted. We need each other and this conference is designed to help us reclaim that sense of community. With that in mind, we couldn't be any more excited to welcome you to CI2022 as we emerge from these challenging times into a brighter tomorrow.
American Cochlear Implant Alliance invites students, residents, and fellows with an interest in hearing loss and auditory implants to attend CI2022 DC: Emerging Issues in Cochlear Implants. Students will receive a reduced registration rate and ACI Alliance is offering scholarship opportunities as part of a competitive process for a limited number of students, residents, and fellows. Scholarship awards will include registration, a $120 travel stipend to help offset expenses for in-person attendees, and a complimentary membership to ACI Alliance until the date of the students’ program completion. Scholarship recipients are required to attend the conference in full. Application forms are now available here.

A Student Poster Competition will be held for those enrolled in an undergraduate, graduate, residency, or fellowship program. An academic adviser or another university official must verify student/resident status. Students may enter a poster abstract for the competition as part of the CI2022 DC Call for Abstracts. Click here or visit the conference site to review additional details and to submit your poster abstract. Posters will be judged on:

- Content/Poster Organization and Preparation
- Display Appearance
- Originality and Merit
- Oral Discussion/Knowledge and Presentation
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.

Featuring Bluetooth® Wireless Technology

CapTel2400i

www.CapTel.com/ci
1-800-233-9130

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. and any use of such marks by Ultratec, Inc. is under license. (v1.6 10-19)
Medicare Expansion and Reconciliation

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

Expanding Medicare was a frequent campaign promise made on the 2020 election trail, and Democrats, who now have control over the House, Senate and White House are hoping to make good on that promise through the budget reconciliation process.

The budget reconciliation process allows Democrats to pass legislation through the Senate with a simple majority as long as the bill addresses spending, revenue, or the federal debt limit. The House and Senate are currently considering a $3.5 trillion budget reconciliation package that focuses on health care, childcare, and climate initiatives. The draft reconciliation package in the House includes Medicare expansion provisions that would expand Medicare coverage for dental, vision hearing.

Medicare Expansion Language for Hearing Aids and Impact on Cochlear Implant Referrals
On September 7 and September 9, the House Ways and Means Committee and the House Energy and Commerce Committee, both of which have jurisdiction over Medicare, released reconciliation legislative language, respectively, that included Medicare expansion for hearing aids. The legislative language proposed to cover hearing aids under Medicare for the first time, but would only cover hearing aids for people with severe or profound hearing loss in order to limit the cost of this new benefit.

Cochlear implants (CI) are already covered by Medicare but there is no mention of CI referrals in the bill. Limiting the benefit to only individuals with profound or severe hearing loss raises concerns about how this may impact referrals for CIs. Most individuals with profound hearing loss (close to 100%) are CI candidates and do not demonstrate sufficient benefit from hearing aids. However, hearing aid utilization is highest among people with significant hearing loss: for those with profound hearing loss, hearing aid utilization is an estimated 90%; severe hearing loss is estimated to be 70%. ACI Alliance is working to ensure that by covering hearing aids for those with severe and profound hearing loss, Medicare beneficiaries who can most benefit from CI referrals are more likely to receive them—not less likely.

ACI Alliance Engagement on Medicare Expansion Legislative Language
To improve the opportunity for Medicare hearing aid expansion to benefit the whole hearing health spectrum, including individuals who are appropriate for CI referrals, the ACI Alliance has been working with members and champions on the House Ways and Means and House Energy and Commerce Committees to suggest legislative language that will not limit referrals for evaluations of CI candidacy.

The ACI Alliance is also engaging with key Senate offices, which are beginning the development of their legislative provisions that will be included in the budget reconciliation package, to recommend that their Medicare expansion language does not include limits on hearing aid coverage to just those with severe or profound hearing loss. However, if the Senate also decides to limit hearing aid coverage to decrease the cost of this new benefit, the ACI Alliance will continue its work with key offices to ensure that CI referrals are referenced in the final bill.

Path Forward for Medicare Expansion
The future of Medicare expansion language passing in the House and the Senate remains unclear as Democrats continue to hash out what will be included in the final reconciliation package. The path forward for Medicare expansion being included in the House reconciliation package became a bit more uncertain after drug pricing negotiation language, the savings from which is expected to help pay for the cost of expanding Medicare benefits, failed to pass out of the House Energy and Commerce Committee on September 15. However, Democrats remain confident that drug pricing language will be included in the final reconciliation bill, and are equally confident that expansion of Medicare benefits will also be included.

As Medicare expansion continues to be negotiated and considered for the $3.5 trillion reconciliation package, ACI Alliance will continue to work to ensure that the final language enacted into law does not compromise access to CI referrals.
Recently, we published an Advocacy Toolkit to support our advocacy networks (State Champions and Cochlear Implant Consumer Advocacy Network or CI CAN) as well as others interested in being involved in CI public affairs issues. In the Toolkit, we distinguish between the legislative and regulatory processes. Understanding the mechanics and how and when to interject our concerns and/or support is a key element of effective advocacy. The process of how a bill becomes a law is relatively well known and often discussed—sometimes in singing cartoon form as the Schoolhouse Rock of old. The regulatory process—what happens after a law is passed—has its own set of complicated processes.

Federal Regulations

Most of us understand that the US Congress passes laws that affect our country's governance in diverse ways. However, laws generally do not include all of the details needed to explain how an individual, business, federal, state, or local government is expected to implement a law. Congress authorizes specific governmental agencies to develop regulations for a law. For example, a regulation issued by the U.S. Department of Education regarding the...
Individuals with Disabilities Education Act (IDEA) lays out ground rules for how the process of completing a child’s Individualized Education Plan (IEP) or a family’s Individualized Family Service Plan (IFSP) should be carried out.

When federal agencies create regulations, they follow a very specific rulemaking process. Once a bill has been passed by Congress and signed by the President, the relevant Federal agency drafts and introduces a “proposed rule” that lays out in detail how a bill will be implemented. A public comment period follows allowing citizens, associations, businesses or other interested parties to submit comments on the proposed rule. Once the comment period has closed, the agency considers the input provided. The agency may or may not make changes but this is part of the process before releasing a final rule. You can view the website for submitting comments here [www.regulations.gov](http://www.regulations.gov).

The Centers for Medicare and Medicaid Services (CMS) routinely publish proposed rules on wide-ranging issues as a part of how they provide services, payments, and carry out programs. Recently, CMS published a proposed rule that included reimbursement cuts to multiple providers, including audiologists who perform CI services. ACI Alliance submitted comments disputing the proposed cuts, which you can read [here](http://www.regulations.gov). Last year, we also submitted comments requesting certain billing codes be added to those allowed under telehealth during the current public health emergency and other proposed payment cuts. The regulatory process has a significant impact on how CI clinicians provide services to patients.

Sometimes we ask our members and advocacy networks to help raise the volume on an issue by also submitting comments on a particular proposed rule. When that is the case, we assist by drafting the suggested specifics of our request as well as guidance on how to submit comments. There may soon be opportunities to support our regulatory initiatives relating to Medicare candidacy for CI and telehealth offerings.

**State Governments**

State governments may follow a similar path of opening up the governance process to the public once a law is passed, but sometimes changes are implemented without such input. We sometimes find that directly engaging with state agencies can affect change as states may have more flexibility than the federal government. For example, as we discussed in the March 2021 edition of Calling, clinicians may be able to work with your state Medicaid office on issues such as reimbursement for services, coverage of equipment for patients, or expanding coverage. In 2018, ACI Alliance and others worked with State of Maryland staff on the expansion of Medicaid CI coverage to include adults. We submitted [official comments](http://www.regulations.gov) and worked with relevant staff. Adults who are Medicaid beneficiaries in Maryland are now eligible for surgery and the full range of cochlear implant services.

Many of our State Champions have improved Medicaid CI coverage in their state by developing good working relationships with Medicaid staff. Examples include providing documentation and rationale for covering SSD surgeries and increasing the allowed number of therapy sessions for a child post cochlear implantation. Currently, we are working jointly with a state medical association to expand Medicaid coverage to include adults in Washington State. In 2018, the state passed a bill covering hearing aids for adults covered by Medicaid. Unfortunately, the local consumer group neglected to include cochlear implants in their advocacy. We hope to rectify that during our conversations with the appropriate agencies.

ACI Alliance and our advocacy networks submit comments on proposed state regulations as well. In July 2021, Texas Medicaid proposed reimbursement reductions for cochlear implant surgeries. ACI Alliance submitted [written comments](http://www.regulations.gov), as did our Texas State Champions. One State Champ also testified at the hearing regarding the detrimental impact of the proposed cuts. We won’t know if we were successful for a few more months, but we are always ready to engage further with Texas Health and Human Services.

Legislation is just the first step in policy-making. The regulatory process is a critical part of the process as it affects the details of how a law is implemented. If you would like to join us in our advocacy efforts, please contact me at [nwestin@acialliance.org](mailto:nwestin@acialliance.org).
In September 2021, we began distribution of a new (free) monthly online news publication—Listening @ ACI Alliance. Our goal is to expand awareness about cochlear implants and our own research and advocacy activities for a broad audience including the CI patient community, hearing health professionals who are interested in cochlear implants but not intensively involved, and family members and friends who support people with hearing loss. Some readers may choose to be more involved in ACI Alliance.

The distribution list for Listening was built from past CI conference attendees, individuals who queried us via the website, contacts from organizations with whom we collaborate, and anyone who has expressed interest. All ACI Alliance members automatically receive Listening and we encourage our members to let your patients and colleagues know that they may sign up. We’ve been gratified to see the diversity of those who have signed up which includes teachers, hearing healthcare professionals, nurses, parents, grandparents, recipients and others who simply wanted to learn more.

We heard from Listening subscribers after the first issue. We especially enjoyed the communication from our friend Warren Estabrooks—a wonderful teacher, therapist, author, and public speaker from Toronto, known around the world for his joyful way of encouraging therapy professionals to help parents become agents of change for their children with hearing loss.

Please help us get the word out about Listening. Anyone can sign up by visiting this link, and past issues are available here.

“I loved the title. It is ACTIVE and that is what LISTENING is...HEARING is what cochlear implants can provide following the amazing precise surgical work of CI surgeons around the world. Ultimately, however, the goals are for children, in particular, to develop exceptional, exquisite and refined LISTENING skills through the help of their parents and the coaching and guidance of practitioners who are are committed to helping parents realize the desired outcomes of LISTENING and spoken language in their children who are deaf or hard of hearing. This publication “LISTENING” follows a K I S S principle that I prefer to follow.....KEEPING IT SIMPLE AND SPECIFIC, by linking the three major areas of Awareness, Advocacy, and Research to each other and directly to the website of ACI Alliance. LISTENING is off to a stellar start.”

Warren Estabrooks, President & CEO, WE Listen International
Redefining Hearing Loss for the Next Generation

Teresa H. Caraway PhD, CCC-SLP, LSLS Cert. AVT, CEO of Hearing First

Dr. Teresa Caraway supports families and professionals on the Listening and Spoken Language (LSL) journey through awareness, education and community. She was a Founding Board Member of American Cochlear Implant Alliance and served on the Board of Directors for six years. Dr. Caraway was the Founding President of the AG Bell Academy for Listening and Spoken Language and Founder and Executive Co-Director of Hearts for Hearing. ACI Alliance is a frequent collaborator with Hearing First in our outreach and educational efforts.

It wasn’t so long ago that the newborn hearing screening (NHS) wasn’t as widely available as it is today, which meant delays in diagnosis and amplification or implantation. Today, with nearly all babies receiving a NHS shortly after birth and the incredible advances in hearing technology, we find ourselves in a pivotal moment to reduce those delays and provide access to technology and early intervention for children who are deaf or hard of hearing to improve LSL outcomes.

Improving LSL outcomes is precisely why Hearing First was founded by the Oberkotter Foundation, which has supported opportunities for children who are deaf or hard of hearing to learn to listen and talk for over 35 years. In the past few years, researchers worldwide increasingly studied children with hearing loss. This recent research has shown that excellent outcomes for children are probable when evidence-based, audition-centered hearing healthcare is provided in a timely fashion. The studies support what we’ve known from practice and experience: early access to sound is critical for a baby’s brain development.

Every child deserves the opportunity to benefit from the availability of a newborn hearing screening, advances in technology, and early learning services in their communities. While it’s amazing to witness how far we’ve come in the past 30 years, we continue to look ahead and see what else needs to be done. Together, we can move the needle forward for children with hearing loss to overcome some of the remaining obstacles—specifically around raising awareness and increasing access to appropriate hearing technology.

Empowering Parents

Increased awareness of newborn hearing screening and the importance of hearing for brain development can reduce delays in amplification or implantation from years or months to those critical early weeks. When parents know what’s at stake, they act urgently. One of Hearing First’s goals is to help all children have the opportunity to take advantage of access to sound. With that in mind, we’ve launched a new initiative to raise awareness among expectant moms about newborn hearing health and early brain development. The campaign, continued on page 17...
HEARING LOSS from page 16

Starts Hear, educates soon-to-be parents in the US about the NHS so they’re prepared with next steps should their newborn fail.

Bright and optimistic in design, the campaign taps into parents’ hopes for their child’s future. By linking their dreams with the importance of newborn hearing, parents are encouraged to take swift action in getting the appropriate hearing technology if their baby needs it. In the first six months since launch, the digital media campaign has been viewed more than 107 million times by expectant parents across the country.

We’re not alone in spreading this critical message to expectant parents. Other organizations have joined together to expand the reach of the campaign including American Academy of Audiology, BabyCenter, Brazelton Touchpoints Center, Bright by Text, Reach Out and Read, Thirty Million Words, What to Expect, Zero to Three, and of course American Cochlear Implant Alliance.

Powering Potential
While the campaign raises awareness and reduces delays in diagnosis and implantation, our work doesn’t stop there. After receiving a diagnosis of hearing loss, families begin their LSL journey with the support and expertise from a team of professionals to reach the outcomes they dream of for their child. In an effort to support these families, Hearing First provides free resources and materials for parents, as well as professionals supporting families, through our website, HearingFirst.org, which has recently been refreshed to better meet the needs of both families and professionals alike.

Hearing First is also home to more than 6,000 professionals who use the Professional Learning Community to connect with other colleagues around the globe, helping take their practice to the next level. Free learning experiences provide the chance to earn CEUs so professional teams can stay on the forefront of best practices related to LSL, cochlear implants, and more, while also leveling up their knowledge and skills to improve outcomes. There’s dedicated space for families too with the Family Support Community and a private families-only Facebook group.

These online communities help families connect in a free, safe space to find support from others on this journey as they ask questions, share difficulties, and celebrate wins. We’ve seen how important this is for many families, especially those who may not have the opportunity or access to local resources and camaraderie they need to help their child learn to listen and talk. Hearing First also serves as a source of hope and inspiration by sharing stories from families who have chosen LSL, celebrating their journey and success.

It Takes a Village
We’ve seen what amazing outcomes are not just possible but probable when families and professionals are equipped to best meet the needs of a child with hearing loss. Our efforts can be perfectly summarized by the ACI Alliance CI2021 Virtual conference theme: It Takes a Village. Together, we can power potential for every child who is deaf or hard of hearing. We invite you to learn more about our awareness efforts at Hearing First resources.
Personal Purpose, Professional Passion

Carrie Spangler AuD

Carrie Spangler is the lead educational audiologist at the Summit Educational Service Center in Cuyahoga Falls Ohio. She has over 20 years of professional experience and a lifelong experience of living with hearing loss. She is a wife, mom of two teenagers, blogger, and host of the empowEAR Audiology podcast.

“One day you will tell your story of how you overcame what you went through and it will be someone else’s survival guide.”
—Brene Brown

Let’s take a short step back in my story. I was born with a mild sloping to severe bilateral hearing loss, late identified at the age of 4 years (before Universal Newborn Hearing Screening), and then fitted with my first set of hearing aids shortly thereafter. Going to my neighborhood school and being the “one and only” was not always easy. I was presented with a roller coaster of challenges navigating the hearing world. In hindsight, these formative, developmental years of challenges set the stage for my personal purpose and professional passion; becoming an educational audiologist who is passionate about advocacy and purposeful in sharing my hearing journey story.

Early in my career, I learned the power of being courageous to tell your story. We all have a story to tell, and it can be one of the strongest ways to bond with others on a personal level as well as advocate for the needs of others. I was given this opportunity back in 1999 when I was asked to testify in front of Ohio’s state legislators advocating for the need for universal newborn hearing screening. I was able to infuse my professional knowledge of benefit of early intervention with my personal experiences of being late identified and needing years of intervention and special education support. This personal (and professional) story grabbed the attention of the legislators, and I was thankful for the courage to stand up on behalf of children in the State of Ohio.

I share this because these experiences gave me the foresight to journal my thoughts, feelings, and emotions early on when I first started thinking about the cochlear implant journey. Through my multiple journal entries, the idea of sharing my story came to fruition with a blog, hearingspanglish.blog (check it out!). In one of the first blog posts, I talk about “unfocused” hearing and how over a few years, I felt my hearing was becoming like a camera lens that is out of focus. Hearing through my hearing aids became more and more of a struggle that I could not ignore. I was putting so much effort into trying to hear and understand that I found myself retreating to solitude more and more and that was not who I was.

Putting on my professional hat, I knew deep inside what my next step needed to be. I began reaching out to my professional connections in the cochlear implant world to ask questions. I took advantage of every opportunity that I had to attend a continuing education event about cochlear implants. I talked to cochlear implant surgeons that I knew, mapping audiologists and my audiology friends who have cochlear implants. These personal and professional connections drove me to schedule an appointment for a cochlear implant consultation.

In July 2019, I had my CI consultation at the Ohio State University Medical Center. After an exhausting several hours of audiology testing, my “unfocused” hearing was confirmed. Audiologically, I was a candidate for a cochlear implant. I also had an appointment on the same day with Dr. Oliver Adunka. He further confirmed that I was a candidate and explained the next steps if this was that path that I wanted to take. I went into this consultation day thinking that I was just there to gather more information. By the end of the appointment, I knew that the cochlear implant decision was the next step in my hearing journey.

The months between July and November was filled with a roller coaster of emotions. I felt excited, scared, nervous, and thrilled to be starting this next step in my hearing journey. Sharing my story allowed me to surround myself with family and friends who were willing to jump onto this roller coaster ride with me and be my greatest supporters.

continued on page 19
I knew I needed to trust and have faith in the process. This was a true test of my patience, perseverance, and positivity. November 15, 2019 was my surgery day and I was blessed with an incredible medical team, CI surgeon, audiologist, and supportive family and friends. I left the hospital the same day to recover at home. December 4 was activation day. I felt like a little kid waiting for Christmas morning! I was fully prepared mentally for the unnatural sounds that I was going to initially hear. My mindset moving forward was that I am running a marathon, not a sprint. Learning to listen was going to take much patience, perseverance, and positivity.

Today, I continue to run in the cochlear implant marathon. Just as running a marathon presents with training, focused mindset, injuries, setbacks, challenges, pacing, and keeping up with your PR (personal record), so does the cochlear implant marathon. I am committed to dedicated time to practice listening, keeping a positive mindset, attending scheduled mappings, and keeping my own PR. When I have a setback in my PR (or hearing journey), I have learned to ask questions of my cochlear implant team so that we can have a better training program for my cochlear implant marathon.

Circling back to the courage to share your story; after receiving my cochlear implant, I decided to join the American Cochlear Implant Alliance as a consumer member and become involved. I was drawn to the mission of the organization to advance access to the gift of hearing provided by cochlear implantation through research, advocacy, and awareness. I know my own cochlear implant marathon has changed my life. I joined the CI CAN (Cochlear Implant Consumer Advocacy Network) and also became an ACI Alliance State Champion for Ohio to share my own personal and professional expertise to positively influence change at the individual, state, and national level. I remembered the impact of being courageous to share my story with Ohio legislators to advocate for support of universal newborn hearing screening; in this next hearing journey chapter I am driven to share my cochlear implant journey story in hopes that someone else will positively benefit.

What will you do with your own personal or professional story to be a survival guide for someone else? ACI Alliance is an organization that provides the toolbox for your story to come alive and play a critical role in shaping the future of children and adults living with significant hearing loss. It is my hope that you find the courage to get involved. Sharing your story and advocacy works!
Unleash your patients’ potential

Cochlear™ CoPilot is an interactive app that gives your patients personalized support, information and interactive activities to help them build communication skills.

✓ Hearing in the real world
  – Communicate in the workplace
  – Support an active lifestyle
  – Manage listening fatigue
  – Enjoy concerts, travel, social occasions and more
  – Find helpful resources
  – And much more...

✓ Build knowledge and skills
  – Easy-to-use instructions
  – Tips for everyday activities
  – How to get the most out of your device
  – Interactive listening activities
  – Insights and support from others

✓ Support when you need it
  – Information all in one place
  – Use at your own pace
  – Interactive, simple to use
  – Use anywhere, anytime

Download Cochlear CoPilot now!