

Founding of American Cochlear Implant Alliance: Top Ten Accomplishments in Ten Years

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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](http://acialliance.org) 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,

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ACI Alliance website

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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

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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 crystallize our efforts.

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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

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to go. Cochlear implants are viewed as a last resort—something one pursues “at the end of the road.” That reticence is exacerbated by the fact that people don’t know where to go for an evaluation and remain in the hearing aid channel. Misleading information abounds—even from sources that should be reliable; it includes CI isn’t covered by insurance, the CI “brain” surgery is risky, there will be other better options soon such as drug therapy that will restore hearing for all who need it, and residual hearing will be destroyed.

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. ■

