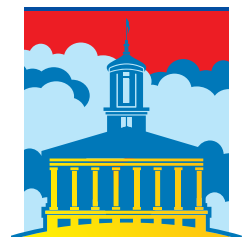


Advocating for Cochlear Implant Access: ACI Alliance Toolkit for Action



2021 Edition

acialliance.org



ADVOCACY

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ACI Alliance Advocates during the 2018 ACI Alliance on the Hill. From left: Amy McConkey Robbins (Former ACI Alliance Board Member from IN), Nichole Westin (ACI Alliance Governmental Affairs Manager), Hill staffer, Naomi Horton and Michelle Barrett (both ACI Alliance IN State Champions) and Former Congresswoman Susan Brooks (R, IN-5th)



“THROUGHOUT THE PAST FOUR YEARS, I HAD THE OPPORTUNITY TO WITNESS HOW BILLS ARE PASSED INTO LAW. SIGNIFICANT DECISIONS WERE MADE REGARDING THE LIVES OF CONSTITUENTS WITHOUT THE STAKEHOLDERS EVER BEING MADE AWARE THAT LIFE- AND PROFESSION-ALTERING DECISIONS WERE BEING MADE ON THEIR BEHALF. OFTEN, THESE DECISIONS WERE MADE BY INDIVIDUALS WHO HAD NO IDEA OF HOW THEY WOULD AFFECT LIVES AND PROFESSIONS.” -- Lori Bobson PhD, Aural Habilitation Program, University of Virginia Cochlear Implant Team

What is Advocacy?

Advocacy is an activity by an individual or group that aims to influence decisions by government officials via education and other means. Anyone can be an effective advocate. You already have the most important and valuable tool you need: your story. No one understands the ins and outs of cochlear implants (CI) better than our members. By translating those experiences to policymakers, you can play a critical role in shaping legislation and policy for families, consumers, and the medical community. Our policy goals change and develop depending on the current situation, but our core value is to ensure access to all who need a cochlear implant are able to obtain one as easily as feasible. We also support research into advancing this advanced hearing technology.

To achieve our shared goals, a robust and coordinated grassroots advocacy effort is vital. This toolkit highlights the many different ways to advocate. These actions can be undertaken with your local and state appointed and elected representatives as well with those who represent you in Washington, DC. Some advocacy techniques are as simple as sending out a tweet while others might take a bit more work. Taken together, the outreach and contact that you undertake to government officials is beneficial. When we do this together with others, the impact is amplified. Our collective voices will influence policies that have the potential to affect ongoing positive change for cochlear implant access. We hope you will join us.

For more information on ACI Alliance advocacy efforts, please visit our website at <https://www.acialliance.org/page/AdvocacyInitiatives>.

Constructs for Cochlear Implant Advocacy

The landscape for cochlear implant advocacy is complicated. Some issues in the US are addressed at the federal level while others are state related. As is the case for many laws, once legislation is passed, regulations must be developed. Advocates span a range of professionals in the field as well as adult consumers and parents of children with hearing loss. CI candidacy criteria are different for adults and children and are also dependent upon the individual's age within those two broad coverage categories. For example, the FDA guidelines differ depending upon the age of the child. Insurance type (e.g., Medicare, Medicaid, private health insurance) impacts coverage patterns. All of this makes for a complicated system that may be hard to negotiate. Knowledge and understanding of this complexity governs and impacts our advocacy strategies. The figure below, constructs for Cochlear Implant Advocacy outlines this complexity.

CONSTRUCTS FOR COCHLEAR IMPLANT ADVOCACY

The landscape of public policy is complicated:



LAWS & REGULATIONS

Some issues are addressed at the federal level, others at the state level. Once a law is passed, regulations must be developed.



ADVOCATES: VARIOUS PERSPECTIVES

Professionals, consumers, and parents can all be advocates.



CI CANDIDACY: ADULTS & CHILDREN

Converge patterns are different for adults and children. Older adults under Medicare are covered for CIs, but the candidacy criteria are more stringent than for younger adults.



INSURANCE TYPES

All of the main types of insurance (Medicare, Medicaid, private, and VA) cover CIs, but they may cover them differently. And within the private insurance system, different insurers cover them differently.

The Legislative Process

Knowing when and how to impact the political process is essential to advocacy. While each state legislative body has different rules, overall there are similar points to influence the political process across the 50 states. States' processes are similar to those followed in the federal legislative process. The following graphic provides a primer on the key elements that can delay or deny a bill.

The Legislation

- Bipartisan/bicameral bills are easiest to pass
- Federal legislation published on congress.gov and state bills on state websites

THE COMMITTEE

- Committee Chairs hold power to table or pass bills
- Contact Chairs and Committee Members about position on bill
- For State level hearings, anyone can usually testify. Invite only for Federal Hearings

THE CHAMBER

- If voted out of Committee, it will pass to the Chamber for debates and vote.
- Contact local representative to ask to support or oppose
- Floor votes often happen within days or hours of Committee Vote

Repeat the Process

- Bills must pass both Chambers
- Sometimes similar bills are introduced in nottin both Chambers, but often the process starts in just one.
- The Committee and Chamber must repeat in the Second Chamber

BECOMING LAW

- If passed in both Chambers, the bill moves to the President/Governor who then can sign into law or veto.
- Some states do not require the Governor to sign a law for it to become law.
- Once law, the agency with oversight then implements the law if funding is provided

The US Regulatory Process: Putting Laws to Work

Most people understand that Congress passes laws and those laws govern our country in diverse ways. However, laws often do not include all the details needed to explain how an individual, business, state or local government, or others should implement the law. In order to make the laws work on a day-to-day level, Congress authorizes certain government agencies to develop regulations.

Regulations set specific requirements within the structure of a law. For example, a regulation issued by the U.S. Department of

Education on the Individuals with Disabilities Education Act (IDEA) lays out what should be included in an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP) including when a child transitions from an IEP to an IFSP. When federal agencies create regulations, they follow a very specific rulemaking process. This process ensures transparency and gives members of the public an opportunity to provide input on the content of the rules.

Step 1: The Agency Develops a Regulation as a Proposed Rule

- The agency researches the issues and, if necessary, proposes a regulation.
- To improve the regulations and to mitigate the risk of the rules being challenged in court, agencies often engage stakeholders in the rulemaking process. They can do this formally and/or informally. Agencies informally engage stakeholders by contacting organizations or individuals they know and gathering their input at various times in the process such as before rules are drafted or sometimes during the drafting process.
- To engage stakeholders formally, agencies post an Advance Notice of Proposed Rulemaking in the Federal Register, printed and available at www.regulations.gov. Such a posting is usually reserved for complex rules.

Step 2: Agency Proposes the Rule

- After researching the issue at hand and soliciting input from stakeholders, federal employees draft the new rule.
- After the appropriate levels of agency management approve the proposed rules, the agency submits a Notice of Proposed Rulemaking to the Federal Register. The notice has several parts:
 - Summary: A statement describing the issue the proposed rule addresses and how the rule addresses the issue.
 - Dates: The date when the public comment period closes.
 - Addresses: The methods by which a citizen or group may comment on the proposed rules.
 - Supplementary Information: A discussion of the benefits of the proposed rule, key data and other information used in rule writing, explanation of public policy choices made and citation of legal authority to enact the proposed rule.

Step 3: Public Comment

- The public comment period gives citizens and interest groups the opportunity to make known their opinions about a proposed rule. The public comment period is critical to the rulemaking process.
- Comment periods typically run for 30 to 60 days, but can sometimes be more than 180 days. Extended comment periods are given for complex rules.
- Agencies prefer to receive comments through www.regulations.gov for rule commenting. Electronic submissions help agencies keep track of the comments.

Step 4: Consideration of Comments and Issuance of a Final Rule

- After comments are reviewed, the regulation is revised and a final rule is issued.
- The final rule is published in the Federal Register and on the agency's website.
- The final step is for affected communities to begin utilizing the rule and for enforcement to begin.

Building Relationships with Key Officials and Staff

Establishing relationships with elected and appointed officials is the foundation of advocacy. While developing such relationships may seem intimidating, it can be relatively easy to accomplish. Policymakers in both state governments and in Washington, DC want to know their constituents and better understand their concerns. They want to hear from you more than hearing from ACI Alliance staff. By reaching out regularly and sharing your story, you can develop a rapport and educate these individuals on your living life with and benefiting from a CI. Don't minimize critical connections with the staffers who work on health issues as they advise legislators on policies related to regulation, legislation, and research funding as well as the impact of policies on access to care. Relationships with staffers may sometimes move your goals further along than a single meeting with a representative.

There are many ways to begin these relationships. Different people have different styles; some people want to take time to compose an email and others prefer to pick up the phone. Choose what works best for you and what you feel comfortable doing. The most important thing is to find a way to tell your story and to keep reaching out in a positive manner.

If you are speaking about a specific bill, be sure to mention the bill's number so the staffers know what you're referencing. The ACI Alliance will inform you of the bills that matter for our policy goals. The website www.Congress.gov can help you locate a federal bill. Your state legislative website lists those for your state. Leave your contact information so the staffer can update you with the member's position or any action taken. Be courteous. Regardless of where your policymaker stands on the issue(s) you're discussing, always be polite and patient. The following tips can help you get started.



“ADVOCACY PROVIDES A FORUM TO NETWORK AND WORK COLLABORATIVELY WITH OTHER PROFESSIONALS AND STAKEHOLDERS ON ISSUES THAT ARE PERTINENT TO ALL OF US. FOR EXAMPLE, TELEHEALTH, CMV ADVOCACY, COVERAGE FOR SSD, AND PARENT CHOICE.” -- *Christine Brown AuD, Cochlear Implant Audiologist, Bill Wilkerson Center, Vanderbilt University*

ACI Alliance Executive Director Donna Sorkin visits office of Congresswoman Debbie Dingell (D, MI-12th) with advocates from collaborating hearing healthcare organizations. From left: Donna Sorkin, Maura Farrell (American Academy of Otolaryngology-HNS), Richard Gurgel (University of Utah), Alissa Parady (International Hearing Society), Susan Pilch (American Academy of Audiology), Ian Windmill (Cincinnati Children's Hospital Medical Center).

Sharing Your Story

When emailing, calling or meeting with your local or federal representatives and their staff, it's important to talk about your experience with CIs. Many have never heard of anyone who works with or uses one, so you are often their gateway into this issue. Sharing your story puts a face on the issues that are important to our community, and it helps legislators understand how their actions and votes impact their constituents. It's a good idea to jot down a few points to help frame your personal story. Why did you choose to get a CI. If you are professional in the field, why do support patients with cochlear implants? What successes have you seen? What's been the most frustrating part for your patients or yourself or a family member? How can the representative best help you?

Sending Emails

Using email is an effective way to make your priorities known to legislators and administrators at all levels. In fact, we encourage this communication option over sending traditional paper mail due to long-standing delays for the offices of elected officials and periodic problems with other concerns. Emails are also easier to share with colleagues and others.

You can quickly send legislators pre-drafted emails on important policy issues by visiting their websites. They read all constituent correspondence and convey your messages to their members. Compose your own message or use examples provide in ACI Alliance Advocacy Alerts.

Meeting in Person with Federal Representatives

Meeting with lawmakers in person allows you to share your story face-to-face. It gives members and their staff an opportunity to ask questions and have an in-depth conversation about the matters that are important to you. Periodically ACI Alliance hosts a day of visits on Capitol Hill that we hope you will participate in. We also encourage you to visit with your legislator while they are in your home state. Visits conducted in home districts typically allow for a longer meeting, permitting you to have more time to share your story. Here are some tips for meeting with your legislators:

Before the Meeting

- Schedule an appointment. You should schedule a meeting in the district office closest to you. Many officials have electronic meeting request forms on their websites or you can call the office directly to ask for an appointment.

- During recesses, members' calendars fill up very quickly. Look to book several weeks in advance. The scheduler will ask you about the purpose of your visit. Tell them the issues you will discuss, keeping it to 2-3 issues at most.
- Members always bring a staffer to constituent meetings, so by sharing your issues ahead of time you may help ensure the person working on health and research topics will be present. In many cases, the legislator will not attend the appointment and you'll be told you're meeting with the health staffer. Speaking with staff is as important as speaking with a member because they play a significant role in shaping the lawmaker's policies.
- Determine what you'll say. Use talking points to plan what you'll say in your meeting. If available, print handouts to bring to your appointment and leave with your member and/or their staff. Obtain related documents from ACI Alliance.

During the Meeting

- Be patient. Lawmakers and their staff often have very tight schedules. It's not uncommon for the member to be late or for your meeting to be interrupted. Don't be insulted if you are asked to speak in the hallway or while walking between rooms.
- Show off your CI! If you are a CI professional, try to bring a sample cochlear implant for someone to have a sense of what they work. If you are an adult recipient or family member and are comfortable doing so, show off your CI!
- Remain flexible. Prepare to meet with your elected official or their staff. Treat both with equal respect. If the member arrives in the middle of the appointment, continue the conversation and allow them to ask questions if needed. If you discover your legislator is not able to join the meeting, don't be discouraged. Remember, educating staffers on your needs is critical.
- Stay focused. Limit your conversation to one or two policy issues and be specific about the positions you'd like your legislator to take. Have your key requests organized so you can present them concisely.
- Be honest. It's okay if you don't know the answer to a question. Offer to figure it out and get back to the staffer. Your lawmaker may not support the issues you cover in your meeting, but they could be your ally on future topics. Do not discuss elections or campaign support and respect the member's political views. Say thank you and leave educational materials. Express your gratitude and leave copies of the educational handouts so the office can review the issues again. Take the staffer's business card so you can stay in touch.

"IN GENERAL, PARENTS AND CANDIDATES WON'T ASK US MANY MEDICAL QUESTIONS. THEY MORE OFTEN WANT TO KNOW, 'DID THE SURGERY HURT?', AND ESPECIALLY, 'WHAT DOES IT SOUND LIKE?'. YOUR FIRSTHAND KNOWLEDGE OFFERS AN INVALUABLE PERSPECTIVE."

-- Richard Reed, CI Recipient, ACI Alliance Rhode Island State Champion and Musician

After the Meeting

- Follow up. There are many ways to share your thanks after a congressional meeting. You can send an email to your lawmaker and their staff summarizing the issues you discussed and expressing your gratitude for the visit. Or, you can tweet at your member and thank them for their time. Legislators are often eager to take pictures with their constituents during meetings, so feel free to ask for a shot and then attach it to your tweet!

Meeting in Person with State Representatives

The tips above can easily be modified for in person meetings with state officials. Contact information for officials is often on the State Legislative website. Many officials are often in their home districts—some more than in the state capitol. As each state is unique in how many days they are in session, we recommend doing a bit of research before reaching out to your representatives. When your state body is in session, you can often meet with officials at the capital building though this differs by state. For instance, some states require you to request a meeting via a legislative page who will deliver it to the member on the chamber floor. Whether you are able to meet with someone at an office or standing in a hallway, the tenets of framing your story and policy request remain the same.

Another key consideration for state government is that one may be able testify for or against bills simply by showing up at a hearing. Both professionals and consumers should consider providing testimony during a hearing on a critical bill as experiences from your unique point of view can shift the momentum of a bill in an instant.

Contact by Telephone

Phone calls remain another way to engage. Lawmakers tally how many calls for or against they get on a particular policy or bill. When contacting your member by phone, it may be helpful to:

- Plan ahead. Identify yourself. State your name and that you are a constituent. Ask to speak to the staffer who handles health issues. If this individual is unavailable, leave a message.
- Stay on topic. Use talking points to guide your call.
- Keep it short. Staffers have busy schedules and they will appreciate your recognition of their time.

Attending Town Halls

Another place to engage with your representatives is at scheduled town halls or local events. At these public forums, federal and state lawmakers are able to hear from many constituents at once. Social media engagement, including posting quotes from your legislator and pictures of the event, is acceptable and often encouraged. (This may be done in person and/or virtually.) To find town halls in your area, visit your members' websites, join their mailing lists, follow on social media, and check local news outlets.

When attending a town hall, consider these steps:

- Prepare a question. Keep your question brief as you may not get much time at the microphone. Tell your story. Adding a sentence or two about why the topic is personally important to you can really make an impact.
- Be respectful. Town hall meeting discussions can get heated. Remain calm and polite when speaking to your legislator, their staff and other attendees.
- Go in groups. There is power in numbers. Ask your community members to attend with you. Every person doesn't need to ask a question, but a larger show of support from more constituents can make an impression.
- Find staffers. Everyone will want to talk directly to the elected official, but speaking to the right staff person can also be very effective. Before or after the town hall, approach a staffer and ask who's in charge of health issues. Connect with the correct person, ask for their email address, and follow up with more information.
- Follow up! Reinforce your presence and comments by email or phone shortly after the town hall meeting. Lawmakers and staff conduct many events throughout the year so it's important to remind them of who you are and what you're asking for.

Site Visits

One of the best ways to demonstrate the positive impact of cochlear implantation on people is to invite legislators to visit your clinic or school. Site visits can be more effective than a meeting, as these give your elected representative a firsthand look at how the technology is provided—including evaluation, surgery, mapping and therapy. Site visits also help you demonstrate your expertise and share the personal experiences of your patients. Adult consumers and family members can assist by attending, telling their own stories and answering questions on the benefits they have seen in their own lives.

- Invite your representative. It's best to invite them during a break in the legislative schedule or during a recess. Try to schedule the visit a few months out as their schedules can fill up quickly. Be flexible. The office should help you with any media advisory or coordination.
- Plan out the visit. What do you want them to see? Who should they talk to? We suggest fellow clinicians and parents/consumers who use CIs. Observing a mapping or therapy session can be interesting and informative for them.
- Share about the visit on social media. Make sure to take a picture of the elected official visiting your program and tweet the picture at the elected official. This provides an opportunity to thank publicly the elected official. If the elected official retweets the picture from his or her account, that's great publicity for your program!
- As always, send a thank you note.

Using Social Media

When it comes to advocacy, social media platforms, such as Facebook and Twitter, can be powerful tools. Most lawmakers, advocates and policy groups are active on social media and it can be the best way these days to attract their notice. Using your computer, tablet or smartphone, you can inspire others, engage with the advocacy community and interact with elected officials.

Your personal social media account is the best place to feature your advocacy work online. For professionals, consider using your company's media accounts to reach colleagues and patients. Through your own network of contacts, you can exert a tremendous amount of influence and drive progress. Facebook is particularly good for getting others to email their lawmakers and participate in local events, like town halls. Twitter is an ideal space for sharing images of meetings with your lawmakers. And use the hashtags and tag your members!

Create Your Own Post

Posting on social media is a key way to give your followers more insight into what policy issues matter most to you, highlight CI-related policy news or get the attention of your elected officials.

Facebook

- Keep your message concise when writing about a petition or piece of legislation.
- Point out specifically what interests you about what you're posting and encourage your friends to get involved.

Twitter

- To tweet at a member of Congress or state representative, be sure to include their Twitter handle in your post. Use the search box in the top right corner of Twitter to find your lawmaker's page. If your member's handle is the first thing in the tweet, add a period (.) in front of it to ensure all of your followers can see your post. Tweets without the period will be sent directly to lawmakers and won't be visible to all users.
- Use appropriate hashtags in ACI Alliance related tweets.
- Research supports utilizing Twitter for advocacy:
 - *Annals of Epidemiology* (2015) recommends targeting tweets at key decision-makers on oversight committees
 - Pew Research (2020) found that since 2016, the average Member of Congress is tweeting twice as often, has nearly three times as many followers, and sends six times as many retweets on others' posts

Support an ACI Alliance Post

The ACI Alliance's [Facebook page](#) and [Twitter account](#) are frequently updated with information about policy issues and other important information. By sharing, commenting on and liking one of these posts, you can spread the word about the benefits of cochlear implants and become a credible source of information.

Using Traditional Media

While social networking sites can seem ubiquitous, don't forget about the ways in which traditional media (e.g., newspaper, television, radio) can further your advocacy goals. Print publications provide a host of opportunities. With letters to the editor, op-eds and blogs, you can call attention to important policy issues and educate not only the public, but elected and appointed officials as well. Submitting these pieces to a news outlet is easy, and when reporters craft a story they will often pull directly from what you send them. ACI Alliance staff can help you draft a submission or provide data to use making your points.

When writing, remember the key points of:

- Highlight your personal story. Readers want to hear how having a CI or working with patients has impacted your life or the lives of others.
- Add facts. Language from the educational handouts in this toolkit may support your letters, op-eds and blogs.
- Review submission guidelines. Each media outlet is different. Be sure you understand word limits and submission processes before you begin developing your piece.
- Letters to the editor are short commentaries (typically 250 to 300 words) which can be in support of, or opposition to, a newspaper editorial. Such letters may also detail your thoughts in relation to a recently published article.
- Op-eds are persuasive pieces and detail your thoughts and expertise on a particular topic. They often focus on current events or issues relevant to a particular community. Op-eds usually are around 750 words.
- You can publish blogs in many places, including online news publications, your own personal webpage, or on others' websites. They're typically more informal than letters to the editor and op-eds and usually run about 500 words.

ACI Alliance Advocacy Networks

ACI Alliance maintains and supports two advocacy networks in place to promote our efforts to expand access to, and awareness of, cochlear impacts.

- **ACI Alliance State Champions** are from across the entire hearing healthcare continuum (surgeons, speech-language pathologists, audiologists, educators, early intervention specialists, psychologists, social workers), consumers, and parents. Champions not only ensure that ACI Alliance is aware of key advocacy topics, but are also critical in carrying our message to federal and state officials.
- The **Cochlear Implant Consumer Advocacy Network** (CI CAN) provides a voice for recipients and families on important issues regarding their or their family members' care and access. By helping policymakers understand what matters to people and to the process of accessing and providing quality clinical care, our personal stories of living with significant hearing loss is critical to our advocacy success.

If you have questions or are interested in getting involved, please do not hesitate to contact ACI Alliance staff. For more information on ACI Alliance advocacy efforts, please visit our website at <https://www.acialliance.org/page/AdvocacyInitiatives>.

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"THIS EXPERIENCE HAS ALLOWED ME TO ACQUIRE A BETTER UNDERSTANDING OF INSURANCE COVERAGE, LEGISLATIVE ISSUES, AND HOW TO ADVOCATE FOR OUR COCHLEAR IMPLANT PATIENTS AT THE STATE AND NATIONAL LEVELS. "ADDITIONALLY, I HAVE MET SOME AMAZING PROFESSIONALS FROM ALL OVER THE COUNTRY WHO HAVE SHARED THEIR EXPERIENCES WITH ISSUES IN THEIR STATES AND PROVIDED VALUABLE INFORMATION ON HOW TO OVERCOME OBSTACLES RELATED TO THESE ISSUES." -- Casey Stach AuD, Audiologist, University of Michigan Cochlear Implant Program