



AMERICAN COCHLEAR IMPLANT ALLIANCE

*Research. Advocacy. Awareness.*

## **American Cochlear Implant (ACI) Alliance Advocacy** **ACI Alliance State Committees**

### **Background**

The ACI Alliance national office will expand to include a State Advocacy Coordinator dedicated to the support of member advocacy. The new state coordinator will work with the executive director, an individual with extensive experience in public affairs at the local, state, and national levels. ACI Alliance public affairs efforts are further reinforced by the Powers firm, a governmental affairs law firm with special expertise in healthcare, disability, and education. Powers attorneys and legislative staff support ACI Alliance strategic direction, lobbying, legislative development, and grassroots advocacy.

### **State Champions**

The State Champion network was established in 2013 as one of the first programs implemented by the newly organized ACI Alliance as a means of harnessing the knowledge and energy of our members throughout the US, and apply this knowledge and energy to advocacy efforts. State Champions are employed at cochlear implant centers, hospitals, non-profit organizations, schools or independent clinical offices. They represent the full continuum of cochlear implant care as ENTs, audiologists, speech pathologists, educators, and psychologists. Several State Champions are parents of children with cochlear implants or adult CI recipients. We currently have 58 State Champions representing 33 states. Some states have as many as four Champs while others do not yet have one. There is a need to build out the network with multiple Champs in larger states and at least one Champ in each of the 50 states and Washington, DC.

State Champions participate in teleconference briefing calls (approximately 4 per year). Champs may also request one-on-one calls on specific topics in their state. We convene in-person State Champion meetings at the annual US CI conference and have done so since 2013. Capitol Hill visits were arranged on the day preceding CI conferences held in Washington DC in 2013 and 2015. These Hill visits will be repeated in March 2018 at the CI conference being held then. Additionally, Champs were encouraged to invite legislators to their clinics or schools for an initiative called *ACI Alliance on the Hill—At Home* in the Summer/Fall of 2016. Thus far, our State Champion activities have focused on:

- Cochlear implant awareness and understanding of benefit among national elected and appointed officials
- Pressing for appropriate CI coverage in the Affordable Care Act Marketplace Plans at the state level

- Identification of coverage challenges such as appropriate rehabilitation for children or equipment replacement
- Urging for reauthorization of the national Early Hearing Detection and Intervention (EHDI) Act

State Champions have encouraged ACI Alliance to take on additional issues going forward including ensuring appropriate Medicaid coverage in the years ahead. ACI Alliance strongly advocates for parent choice on communication options and the importance of parents having full information about communication and technology options, including cochlear implants. We do not push for one communication modality over another; rather we emphasize support of parents through knowledge and family decision-making.

### **The Future of Member Advocacy**

Federal policy is expected to shift dramatically in the years ahead with greater decision-making on Medicaid and other programs being pushed out to states. Healthcare officials at HHS and CMS have discussed a move towards Medicaid block grants to states, allowing states more leeway on Medicaid coverage, reductions in Federal funding for Medicaid, and greater reliance on healthcare savings accounts for low and moderate-income people. If this transpires, this will likely mean a reduction in Federal funds for Medicaid forcing states to prioritize healthcare. The cost effectiveness and quality of life benefits of cochlear implantation will necessarily become a key aspect of our advocacy and awareness efforts.

This expected change in federal-state decision-making makes the State Champion network more important than ever. To allow a build out of the program, we will undertake the following actions:

- Formalize our efforts and create **ACI Alliance State Committees** for each state.
- Create a new full-time staff position under the direction of the Executive Director to work with our member advocates—**State Advocacy Coordinator**
- Double the number of State Champions and achieve State Champion coverage in every state with multiple Champs in many states
- Through our new ACI Alliance State Committee, aggressively seek additional volunteer participation—especially parents of children with cochlear implants, adult CI recipients, and others in families to serve as members of the ACI Alliance State Committees
- Increase the number of teleconference calls and one-on-one support for our advocacy volunteers
- Develop more guidance materials for State Champs and Committee Members to use
- Increase the number of consumer/parent members of ACI Alliance to allow a significant expansion of the advocacy pool and as a means to take advantage of the energy and excitement of CI beneficiaries
- Tapping into the energy of our expanded consumer membership, create a new parent/consumer role in member advocacy via State Committees, led by State Champions and supported by our national office staff. Committee Members will have their own teleconference briefings and will be invited to meetings organized by our State Champions. They will be asked to write letters, make phone calls, and create awareness via social media.