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# Advancing Access to Hearing Healthcare: Yes, You Can Advocate for Positive Change

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## Donna Sorkin, MA

Donna Sorkin, MA is the executive director of the American Cochlear Implant Alliance, a non-profit organization working to expand access to cochlear implants through research, advocacy and awareness. Prior to joining ACI Alliance in late 2012, Donna was Vice President of Consumer Affairs for Cochlear Americas where she led public policy initiatives and activities aimed at the broad life needs of cochlear implant users including insurance practices, habilitation, and educational needs of children with cochlear implants. Ms. Sorkin was previously the executive director of Hearing Loss Association of America and the AG Bell Association for the Deaf and Hard of Hearing. She has served on federal, corporate and university boards including the U.S. Access Board, the National Institute on Deafness, NIH and Gallaudet University. She holds a Masters from Harvard's Kennedy School.



## Nichole Westin, MA

Nichole Westin MA has been the Government Affairs Manager at the ACI Alliance since 2018. She has worked in advocacy since 1998 when she began her career working for the U.S. Senate. Ms. Westin has successfully managed campaigns at both the federal and state levels on issues ranging from export sales to payroll taxes to school nutrition. Ms. Westin enjoys using her experience within the federal government and other non-profits to educate people on being effective advocates for their priority policy issues.



- **Presenter Disclosure:**
  - Donna Sorkin: Financial: Donna Sorkin is employed by the American Cochlear implant Alliance. She received an honorarium for this presentation. Non-financial: Donna Sorkin has no relevant non-financial relationships to disclose.
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# Agenda

- Introduction
- What is advocacy and who can be an effective advocate?
- Advocacy process and tools in hearing healthcare
- Federal and State Laws and Regulations
- 2021 ACI Alliance Advocacy Issues
- Case Studies
- Questions and Answers

# Why another organization in hearing health?

- Membership organization focused on cochlear implantation and access to care
- Members are audiologists, physicians, speech pathologists, educators and others on CI teams + consumers/parents, advocates
- Website designed for those in and out of CI
- Highly collaborative with other organizations
- Welcome your involvement!

[www.acialliance.org](http://www.acialliance.org)

<https://www.facebook.com/ACIALLIANCE.ORG/>

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# American Cochlear Implant Alliance

- Mission: Advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness
- Address factors contributing to underutilization of cochlear implants
- Our objective today: Share information to help patients and professionals engage in advocacy

# Learning Outcomes

After this course, participants will be able to

- Identify mechanisms for becoming involved in legislative or regulatory processes that impact patient access and delivery of hearing care services.
- Describe ways in which they can assist patients to self-advocate in activities that may improve insurance coverage, educational support for children who are deaf and hard of hearing, workplace access, awareness about cochlear implant benefits, and other issues.
- Describe current and near-term public policy issues in hearing care, especially cochlear implantation.

# What is advocacy and who can be an effective advocate?

- Activity by an individual or group that aims to influence decisions within political, economic or social institutions
- Can include publications and research to educate government officials and the public
- Many activities qualify
  - Media campaigns
  - Public speaking
  - Visits to legislators or administrative staff in government
  - Lobbying (aimed at a specific issue or proposal)

# Why is advocacy important?

- Can bring about a positive difference in people's lives
- Helps people feel empowered if we enable them to advocate for an important cause
- Opportunity for professionals to contribute their expertise and experiences
- Our government encourages self advocacy, individual advocacy and group advocacy
- Legislators listen to people
  - They also listen to special interest groups when the argument is compelling

# Research on Advocacy shows...

- Advocacy organizations have a central role in advocating
- Take advantage of rare policy window of opportunities
  - When problems, proposals and politics line up
  - COVID-19 has created policy windows for telehealth, health insurance expansion, etc.
  - Policy windows are often short lived
  - While harder, they can also be created via social and media pressure

# Research on Advocacy shows...

- Advocacy messages need to frame and respond to the political environment
- By understanding key steps, advocates are better equipped to affect positive policy change

## Sources:

- Cullerton, et al. (2018) Effective advocacy strategies for influencing government nutrition policy: a conceptual model, *The International Journal of Behavioral Nutrition and Physical Activity*
- Farrer, et al. (2015) Advocacy for Health Equity: A Synthesis Review, *Millbank Quarterly*

# Everyone is Doing It!

Advocacy is listed as key priority of:

- ACI Alliance
- American Nursing Association
- ASHA
- AAA
- Michael J Fox Foundation
- American Medical Association
- AAO-HNS
- And many, many, more



# An Effective Hearing Health Advocate

- Demonstrates knowledge and passion
- Wants to improve services/access for patients
- Can be consumer, parent or family, HH professional
- Collaborates with others in state, local or national orgs
- Contacts policy makers via in-person visits (post COVID), emails, calls, tweets (paper is out!)





# Meeting US Rep Susan Brooks (IN-5)



# 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

Coverage 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.



# ACI Alliance Advocacy Networks

## State Champions

- Founded same year as ACI Alliance
- Come from across continuum of care – surgeons, SLPs, Audiologists, consumers, parents.
- Provide us w/ background on state and national issues impacting CI

## CI CAN Consumer Advocacy Network

- Launched in 2020
- Enhance/enlarge our efforts with first-hand knowledge of CI recipients and families
- Personal stories make the difference in positively impacting decision-makers



In 2019, ANA asked members:  
Why do you hesitate to advocate?

- Perceived lack of public speaking skills
- Don't understand the political process
- Don't understand link between regulations and process

Most organizations have ways to address these issues

Jurns C. "Policy Advocacy Motivators and Barriers: Research Results and Applications." *OJIN: The Online Journal of Issues in Nursing*, Vol. 24, No. 3. September 6, 2019.

# Why advocate?

- What challenges did you and your colleagues encounter?
- What challenges do you see patients and others facing?
- What worked well and should be replicated?
- How has CI (or hearing aids or bone-anchored devices) improved life of your patients?
- How can you help those who come behind you?

# Use a Research Base

- Using scientific research (supported by personal stories) generates the best connection with policy makers
- From the outset, our mission combined research, advocacy and awareness
- Important when demonstrating outcomes with a medical intervention
- Example: Cost effectiveness of CI in children
  - Still referencing JAMA study published in 2000
  - Update underway

# Common Advocacy Tools

- Advocacy Software
  - Track legislation, send alerts, and email to officials
  - Easy to use / rapidly respond from anywhere
- Position Papers/Statements
  - Forms talking points for an organization on an issue
- Advocacy Toolkits
  - “How” and “what” to help members understand the process and how to get started
- Coalitions
  - Partnering with other groups to push forward change
  - Unlikely partners can make an impact
- Social Media: Facebook and Twitter

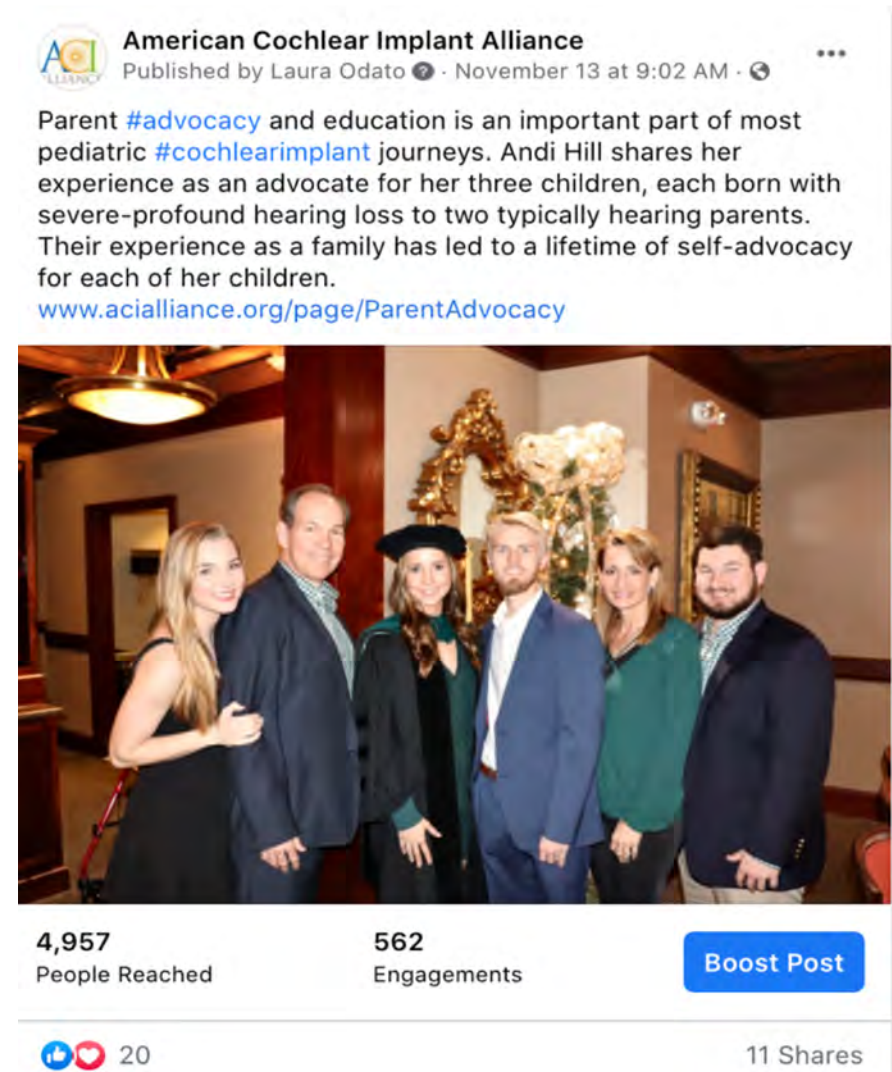
# Social Media as an Advocacy Tool

- Policy-makers have social media accounts
  - Staff dedicated to following and responding
- Tweets reach policy-makers and broader contacts
  - *Annals of Epidemiology* (2015) recommends targeting tweets at key decision-makers on oversight committees
  - Pew Research (2020) found since 2016, typical Member of Congress now tweets twice as often, has nearly three times as many followers, and six times+ as many retweets on posts



# Facebook Example: Sharing Andi Hill's Story

- Parent advocate and State Champ
  - Her story reached 5,400 people on our Facebook with 13 shares
- Helped with outreach to a Federal agency on necessary changes to their website



# Laws, Regulations, and Insurance in Hearing Health

- Concept of Disability
- Education Laws
- General Access Laws
- Insurance Coverage for Hearing Health

# Concept of Disability

- Services and accommodations should be provided to allow a child or an adult access
- Cannot discriminate based on disability
- Laws in US → freedom from discrimination based on disability
- Technologies such as cell phones and broadcast/cable covered
- People are entitled to be included in society → the underpinning of our laws



# Educational Laws: IDEA

- Individuals with Disabilities Education Act (IDEA)
- Federal program requiring state/local aid to address needs of children w/ disabilities in educational settings
  - Provides for IEP (3-21 years) / IFSP (birth-3 years)
- Expertise of professionals vital to demonstrate specific services for a child who is deaf/HoH
  - **Part B:** Children 3-21 / FAPE (free, appropriate public education) / Not: “This is what we offer” / Least restrictive environment
  - **Part C:** Early intervention services addressing needs of family (not just the child) birth-3/ SLP + Audiology, family training, hearing aids, ASL instruction, service coordination, home-based deaf ED
- Professionals have a key role in helping families ensure everything the child needs is spelled out

# Educational Access: Section 504 of Rehab Act

- All entities receiving federal funds must offer services that provide access
- Applies to all public schools + colleges/universities
- Some children performing at grade level categorized as not having an educationally significant hearing loss → not eligible for IEP
- Still must be provided needed services such as FM systems, interpreters, captioning

# Educational Advocacy

- Getting what families desire for their child can be challenging
  - Want to do the right thing for their child
  - Unfamiliar with the process and how to advocate
  - Find themselves on opposite side of the table from “experts” who seem to know what is best for their child
  - Don’t want to rock the boat

# Early Hearing Detection & Intervention Act (EHDI)

- Federal legislation designed to ensure that newborns and young children with HL are identified and receive the care they need
- 98% of infants born in US now have hearing screening
- Problems remaining:
  - Lost to Follow-Up
  - Ensuring families are told of full range of options for their children and provided with the services families desire

<https://mchb.hrsa.gov/maternal-child-health-initiatives/early-hearing-detection-and-intervention.html>





# General Access

- Americans with Disabilities Act (ADA)
  - Covers employment, state & local government, public accommodations (e.g., theaters, hotels), telecommunications (e.g., relay)
- Employers or facilities required to provide "reasonable" accommodations
- Specific process for filing complaints
- Section 504 discussed under Education
  - Also applies to people of all ages and beyond school settings



# Insurance and Advocacy

- Medicare
- Medicaid
- Military/VA
- Private Health Insurance Plans including the Affordable Care Act

# Medicare CI Coverage

- Medicare covers for beneficiaries who meet candidacy criteria including equipment (and upgrades every 5 years)
- Ongoing effort to broaden candidacy to more closely match FDA
- Traditional Medicare does not cover SSD
- Ambiguous language on bilateral CI is interpreted differently by CI centers
- Hearing aids not covered at present
- No mechanism to advocate for *different* coverage

# Medicaid Overview

- Medicare and Medicaid created in 1965 as part of The Great Society programs
  - Separate programs/operate differently
- Health care for persons of all ages whose income and resources are insufficient to pay for healthcare
- Children covered by Medicaid for CI, hearing aids, therapy in all states
- Adult coverage for hearing health varies by state

# State Medicaid Rules Affect Hearing Access and Nature of Services

- Adult Coverage Varies (whether or not coverage for hearing aids, CI or other care)
- Children (for CI candidacy and aftercare rules such as therapy)
- Reimbursement is poor in many states
- Medicaid coverage policies can be changed (state advocacy)



# Private Health Insurance

- Majority cover cochlear implants for all ages
- Typically follow FDA Guideline
- Aftercare coverage can vary but most cover DME (durable medical equipment)
- Challenges still exist for SSD coverage
- Some insurances cover hearing aids (not many)
- Advocacy (and persistence) can be applied to insurers by physicians, beneficiaries, others

# Choose Your Issues and Focus

*For ACI Alliance, that focus is  
access to cochlear implants*



# ACI Alliance 2021 Policy Issues

- Expanding Public and Private Insurance Coverage for CIs
  - Single-sided deafness
  - Insurance coverage: our most common inquiry
    - Change in a public or private plan can be sought by beneficiaries as well as by physicians. Research outcomes help.
  - Telehealth coverage
- Protecting Parent Choice
  - Ensure parents have access to unbiased information on language options under EHDI
- Cytomegalovirus (CMV) Screening
  - Most common cause for non-hereditary hearing loss
  - Supporting state law efforts on screening to quickly identify infants with CMV

# 2021 Policy Issues Cont'd

- IDEA and EHDI funding/reauthorization
  - Due for reauthorization at the federal level
  - Provide most of legal protections for access to services/education for children
  - Issues with full funding
- Access for Veterans
  - Expand information to Veterans on CI coverage from VA
  - Partnering with Veteran Service Organizations to share information and resources
  - Collected Veterans' stories on CI experience





# Medicare Hearing Aid Bill

- Bill passed by US House Dec 2019
- Inclusion of hearing aids as prosthetics for individuals diagnosed w/ profound or severe hearing loss
- We support hearing aid coverage but have concerns about focus on the population—many of whom would benefit to a greater degree from CI
- Have met with Congressional offices asking that referral language be included in the bill
- May come up in 2021 or beyond as part of larger Medicare legislation

# Case Studies

# 1. Telehealth

- Pre COVID, expanded interest telehealth
  - Rural areas without access to specialists
  - Private insurance companies allowed in some cases
  - Some states (NC) had laws mandating coverage
- Outcomes similar to in-person services
  - ACI Alliance funding research to document outcomes
- Current coverage during pandemic temporary
  - Need legislation to make Medicare flexibility permanent
  - Multiple organizations ready to move a bill this year

## 2. Medicaid Coverage of SSD: W VA Child denied CI

- Mother contacted US Congressman McKinley/ staff forwarded details
- Shared research on outcomes
- We developed/published white paper
- Suggested she contact legal aid for a pro bono attorney
- Final appeal to Board of Medical Services
- Denial overturned and Medicaid funded the CI surgery



## 3. You CAN Change Medicaid

- Most states cover CI in adults (~60%)
- Many inquiries on adult coverage
- Adults in MD complained to Disability Rights MD, contacted us for assistance in expanding coverage
- Provided research on quality of life, impact of employment, lower health care costs overall
- Other clinicians pursuing changes in their state policy regarding Medicaid adult coverage

# References

- Insurance coverage for CI:  
<https://www.acialliance.org/page/Insurance>
- In Support of Insurance Coverage for Cochlear Implantation in Cases of Pediatric Unilateral Hearing Loss:  
<https://www.acialliance.org/page/SingleSided>
- “Education and Access Laws for Children with Hearing Loss,” Sorkin D. in *Pediatric Audiology: Diagnosis, Technology, and Management*, Thieme, 2019.