

2023

International Patient Advocacy Group Meeting



ADVOCACY BEST PRACTICES

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Shared Challenge

- **How do we effectively advocate for the SMA community with limited capacity?**



Our Advocacy Philosophy

- **Influence (don't fight) the system**
- **Lead with our strengths**
- **Positivity breeds success**



TIP ONE: Expand Your Advocacy Team

- Individuals and Families with SMA
- Healthcare Providers
- Similar Organizations
- Internal Departments & Staff
- Industry / Other Stakeholders



TIP TWO: Determine Outreach Strategy



Common Cure SMA Advocacy Strategies

Small-to-All Advocacy Strategy:

- Start small/targeted, then expand to community-wide outreach

All-Hands-on-Deck Advocacy Strategy:

- Engage entire community from the start



All-Hands-on-Deck Strategy

Newborn Screening Federal Funding Case Study

- Developed online advocacy tools in support of increased newborn screening funds to spur state implementation
- Participated in NBS coalition that includes other national organizations
- Invited entire SMA community to educate their elected leaders about NBS funding



Cure SMA Advocate Resources

- **Do-It-Yourself Video**
- **Fact Sheets**
- **Template Letters**
- **Online Advocacy Tools**

Advocacy Action Center



Support New SMA Research at the National Institutes of Health

Despite the availability of disease-modifying SMA treatments, individuals with SMA continue to face everyday challenges such as muscle weakness, fatigue, severe scoliosis, and joint contractures. The SMA community is united in seeking additional treatments to help address...



Ensure People with SMA can Access Essential Caregiving Services

Many adults with SMA and families of children with SMA struggle to access in-home caregivers, and often do not receive enough Medicaid caregiving hours to live independently and to meet their true everyday needs. In addition, individuals with SMA and their families describe...



Promote Access To Accessible and Affordable Housing For Individuals With Spinal Muscular Atrophy (SMA)

Many individuals with disabilities, including those living with SMA, struggle to find accessible housing that they can afford. While there are public accessible housing programs, there is often insufficient supply of rental vouchers. Working adults with SMA and other...



How to Structure a Congressional Meeting

cure SMA

Advocacy Best Practices Discussion / Q&A

