2023 International Patient Advocacy Group Meeting



ADVOCACY BEST PRACTICES

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Shared Challenge

 How do we effectively advocate for the SMA comunity with limited capacity?





Our Advocacy Philosophy

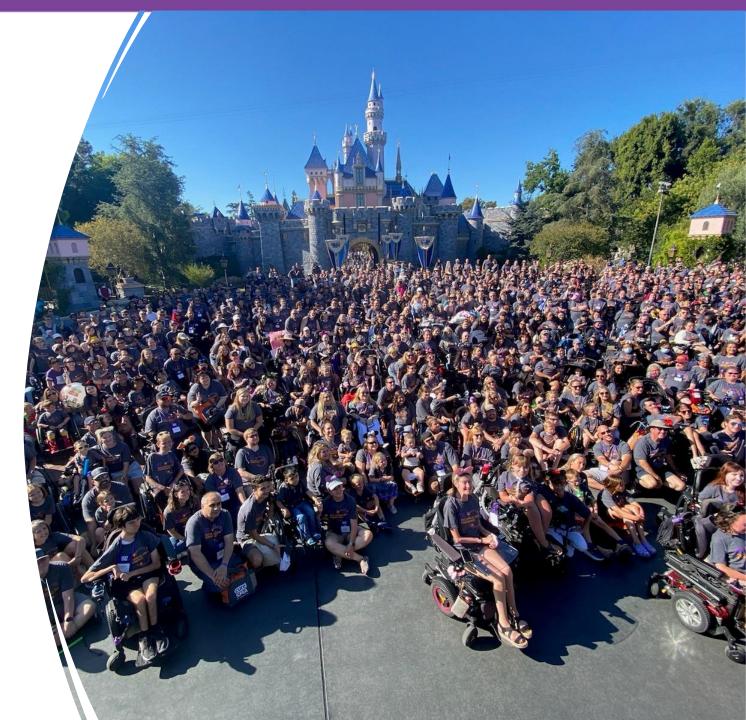
- Influence (don't fight) the system
- Lead with our strengths
- Positivity breeds success





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





Small-to-All Strategy

Newborn Screening of SMA Case Study: Idaho

- Identified Cure SMA Idaho Advocate willing to conduct local advocacy in support of NBS in Idaho
- Mentored Cure SMA Idaho Advocate and supported with letters, testimony, fact sheets, and 1-on-1 advocacy mentoring
- Participated in Legislative Hearing
- Engaged all Idaho Advocates in support of NBS of SMA in Idaho







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 Best Practices Discussion / Q&A



