## 2023 International Patient Advocacy Group Meeting



## **ADVOCACY BEST PRACTICES**

Maynard Friesz, Vice President, Advocacy, Cure SMA (U.S.)



## **Shared Challenge**

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





## **Our Advocacy Philosophy**

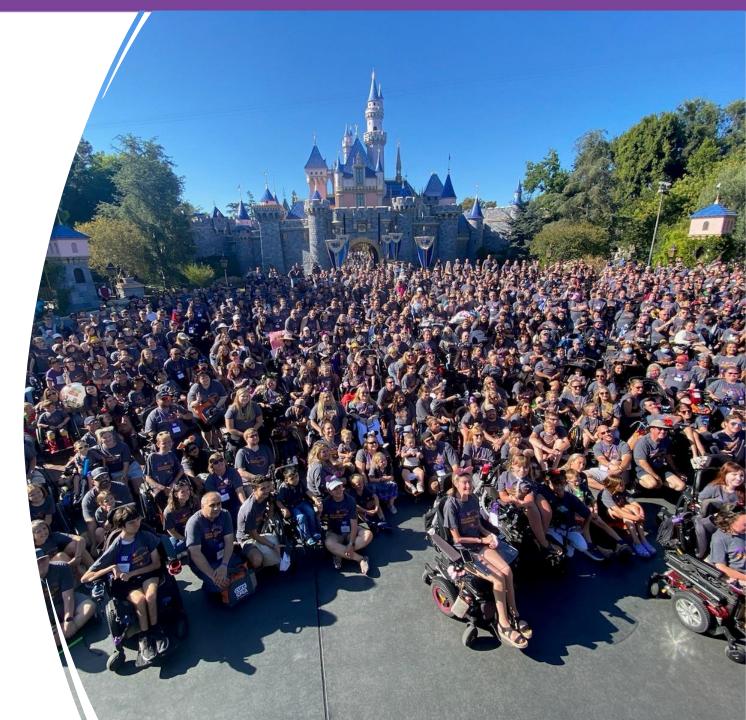
- Influence (don't fight) the system
- Lead with our strengths
- Positivity breeds success





## **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**



