# Arizona Office of Newborn Screening Parent Partnerships



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**Presenting To** 

NewSTEPS (APHL) | STFU Stakeholders

By

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### **Considerations**

- **Involve** agency experts like OCSHCN
- Include Parent to Parent (P2P) organizations in planning
  - ☐ Raising Special Kids
- Add disorder specific organizations to stakeholder list
- **Don't forget** to compensate families for their time/expertise
- And include parents in the decision making processes wherever possible



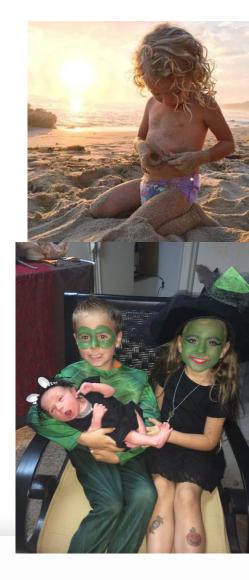
## The Value of Family Involvement

### Disorder specific examples

- 1. CCHD—Mended Little Hearts
- 2. SCID—SCID Angels for Life
- 3. Hearing—Hands & Voices

### **Promotional opportunities**

- AZ babies in our marketing / media campaigns
  - Brochures / posters
  - Website
- AZ family stories
  - 50 Years in NBS
  - Monthly updates to Parent website
- Attend kids camps



## **2018 Staff Meeting Kickoff**

- > Setting tone for the year
- Opportunity to include all staff
  - —teambuilding
- ➤ Even though co-located, the lab, case management, demographics and education teams don't always socialize
- ➤ Sharing the stories linked everyone from a sample to a family experience



### **The Power of Champions**

- Parents who knew the value of their story but didn't know how or where to share it
- Brought together families with different disorders
  - Connections were in some cases national but missing local connections
    - Uniqueness of every family situation
      - ❖ No one-size-fits-all
  - Not every family is ready to hear the news the same way at the same time
    - Puts a face/family to a sample number





### **Close With a Story**

A Mom who served as Executive Director for Quest to Cure...a parent Sickle Cell Disease support organization

### **And a Question**

What would you like us to know so that we can better support families who are served by the Newborn Screening Program?

# **Questions?**

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