

Arizona Office of Newborn Screening Parent Partnerships



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Presenting To

NewSTEPS (APHL) | STFU Stakeholders

By

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ARIZONA DEPARTMENT
OF HEALTH SERVICES

Health and Wellness for all Arizonans

www.aznewborn.com

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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