

Subcommittee on Follow-up and Treatment

Overarching Priorities

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Subcommittee Charge (from 9/25/11)

- ❑ Identifies barriers to post-screening implementation and short and long-term follow-up, including treatment, relevant to newborn screening results**
- ❑ Develops recommendations for overcoming identified barriers in order to improve short and long-term follow-up, including treatment, relevant to newborn screening results**
- ❑ Offers guidance on responsibility for post-screening implementation and short and long-term follow-up, including treatment, relevant to newborn screening results**

Subcommittee Members

- ❑ Susan Berry
- ❑ Robert Bowman
- ❑ Coleen Boyle
- ❑ Christine Brown
- ❑ W. Carl Cooley
- ❑ Denise Dougherty
- ❑ Lisa Feuchtbaum
- ❑ Michelle Fox
- ❑ Alexis Thompson
- Carol Greene
- Charlie Homer
- Celia Kaye
- Alex Kemper
- Chris Kus
- Jana Monaco
- Robert Ostrander
- Brad Therrell
- Andrea Williams

Other experts: Amy Brower, Kathryn Camp, Debra Freedenberg, Nancy Green, Kathy Harris, Cindy Hinton, Amy Hoffman, Rani Singh, Alan Zuckerman

HRSA experts: Jill Shuger, Marie Mann

Priorities

- ❑ **Facilitating screening program implementation and follow-up**
- ❑ **Closing gaps in access to care and services**
- ❑ **Improving clinical outcomes**

Facilitating Screening Program Implementation and Follow-Up

- **Possible case studies or projects:**
 - Ongoing evaluation of CCHD implementation
 - Hearing screening f/u
 - Connecting POC testing with DBS screening

Closing Gaps in Access to Care

- ❑ **Roles and responsibilities in short- and long-term f/u**
 - Recommendations without clear guidance on roles
- ❑ **Challenges and opportunities in the changing health care environment**

Improving clinical outcomes

- ❑ **Challenges of evolving technology and health care system**
- ❑ **Sickle Cell as a condition that could serve as a test case**
 - Gaps between technology and disease management practices
 - “Outstanding interventions but a very frustrated system of I/t care”
 - Variability in SC Trait notification and f/u systems
- ❑ **Consider options for overarching approaches and/or other case studies or comparisons**