

# **DACHDNC**

## **Follow-Up and Treatment Subcommittee**

September 20, 2013

Carol Greene, MD, Chair

Christopher A. Kus, MD, MPH, Co-Chair

# Follow-Up and Treatment Subcommittee Roster

## OFFICIAL MEMBERS

- Deborah Golant Badawi, MD
- Susan A. Berry, MD
- Robert Bowman, MS
- Coleen Boyle, PhD, MS \*
- Christine S. Brown, MS
- Denise Dougherty, PhD \*
- Carol Greene, MD **Chair +**
- Kathryn Hassell, MD
- Charles, Homer, MD \*
- Celia I. Kaye, MD, PhD
- Alex R. Kemper, MD, MPH, MS
- Christopher A. Kus, MD, MPH **Co-Chair +**
- Sylvia Mann, MS, CGC
- Jana Monaco
- Robert J. Ostrander, MD
- Brad Therrell, PhD
- Alexis Thompson, MD, MPH \*
- Andrea Williams \*

\* **Committee Member**

+ **Organizational Representative**

## OTHER EXPERTS

- Amy Brower, PhD
- Kathryn Camp, MS, RD, CSP
- John Eichwald, MA, FAAA
- Lisa Feuchtbaum, DPH, MPH
- Debra Freedenberg, MD, PhD
- Terese Finitzo, PhD
- Nancy C. Green, MD
- Kathy B. Harris, MBA
- Cindy F. Hinton, PhD, MS, MPH
- Rani Singh, PhD, RD
- Marci Sontag, PhD
- Alan E. Zuckerman, MD, FAAP

## HRSA MCHB DSCSHN

- Irene Forsman, MS, RN **(ISB)**
- Edward (Donnell) Ivy, MD **(GSB)**
- Marie Mann, MD **(ISB)**
- Jill Shuger, ScM **(GSB)**
- Tina Turgel, BSN RN-BC **(GSB)**

**GSB/Genetic Services Branch**

**ISB/Integrated Services Branch**

# Subcommittee Charge Revised September 2011

Engage in a multi-step process that:

- 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 implementation and short- and long-term follow-up, including treatment, relevant to newborn screening results; and
- Offers guidance on responsibility for post-screening implementation and short- and long-term follow-up, including treatment, relevant to newborn screening results.

# Subcommittee Work Since Meeting May 2013

- Monthly phone conference calls
- Focus on priority areas and projects previously vetted/approved by full Committee
- Project development - subcommittee members and other experts formed ad hoc writing groups
- **“PRIORITY A”**: *Some Lessons Learned from Early Hearing Detection and Intervention (EHDI) that may be applicable to Critical Congenital Heart Disease (CCHD) Screening*
- **“PRIORITY C”**: *A Framework for Assessing Outcomes from Newborn Screening: Do we know if we are achieving the promise of NBS?*

## **“PRIORITY B”**

### **Closing Gaps in Systems of Care**

- “Project” – Roles and Responsibilities in LTFU:
- As part of case studies, include focus on learning what are the current (and variable) roles and responsibilities in LTFU for children with hearing impairment or sickle cell (disease or carrier).
- Making sure that all our projects look at Rs & Rs.

**“PRIORITY A”**  
**Screening Program Implementation**

**Project 1** – Assessing challenges of new Point of Care tests. Begin with hearing screening follow-up as a case study – REPORT TODAY FROM C. KUS

**POSSIBLE Project 2** – Ongoing evaluation of CCHD implementation – would involve work with HRSA-funded Regional Genetic Service Collaborative –  
*POSSIBLE PROJECT PREVIOUSLY ENVISIONED BY COMMITTEE AS A TASK FOR THE FU&TX SUB-COMM – FOR DISCUSSION AT END OF FU&TX SUB-COMM REPORT TODAY*

## **“PRIORITY A”**

### ***Some Lessons Learned from Early Hearing Detection and Intervention (EHDI) that may be applicable to Critical Congenital Heart Disease (CCHD) Screening***

- State EHDI and Newborn Bloodspot screening programs are often not well integrated with each other. Public Health Newborn Screening Programs should strive to better integrate their various components.
- The State Health Department should play a leadership role in implementing electronic data systems that utilize standards-based messaging to reduce errors and enhance timeliness in data reporting.
- Screening programs should require child level data for quality improvement efforts.
- Appropriate financial support (federal and state) will be needed to develop, implement and maintain the CCHD screening system.

## “PRIORITY C”

### *A Framework for Assessing Outcomes from Newborn Screening: Do we know if we are achieving the promise of NBS?*

- Not to duplicate efforts occurring at HHS (*or anywhere else*). Focus is on developing key questions and understanding data sources, and to identify gaps. Process:
  1. Create a framework
  2. Use S Cell as example to be test framework and revise as needed until framework includes essential data types and permits mapping of data sources and gaps
  3. Test (and revise) framework against other conditions so that final framework can be applied to future understanding the real world impact of NBS for any condition.



## “PRIORITY C”

### *A Framework for Assessing Outcomes from Newborn Screening: Do we know if we are achieving the promise of NBS?*

- Hinton, Green, Homer, Thompson, and Hassell presented matrices developed to help organize and review -
  - Questions
  - Data sources
- General discussion -
  - Issues, goals, concerns that public/families may have about privacy
  - Use of *and study of use of* EHR
  - Need for HARMONIZATION
  - Need for AVOIDANCE OF DUPLICATION
- Work in progress
- Draft has been provided to Committee for review and comments

# New Business