

# **DACHDNC**

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

January 16, 2014

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
- 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)**

**(GSB/Genetic Services Branch)**

**(ISB/Integrated Services Branch)**

## Subcommittee Charge (as it was 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 priorities determined and projects requested/approved by Committee

- Priority A: “Screening program implementation”
- Priority B: “Closing gaps in systems of care”
- Priority C: “Real world impacts and outcomes”

# 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.
- ~~• Project 2 – Ongoing evaluation of CCHD implementation – will work with HRSA-funded Regional Collaboratives~~

# **PRIORITY C: Real world impacts and outcomes**

- Explore the extent to which we can document improved clinical outcomes to determine whether we are realizing the potential of NBS.
- Includes evaluation of the impacts of variability in clinical care, in notification of and action regarding carrier status, in use of EHRs, gaps in services for S Cell Dx patients, etc.

# PRIORITY B: Closing Gaps in Systems of Care

- No specific project (yet) assigned; however Committee specifically asked that roles and responsibilities in LTFU be considered in the following ways:
  - 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 roles and responsibilities.

# Subcommittee Work

## Since Meeting September 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 A

### Screening Program Implementation

**Project** – Assessing challenges of new Point of Care tests. Case study:

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

REPORT TODAY FROM C. KUS

## PRIORITY A

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

- Submitted to Committee for APPROVAL.
  - PUBLICATION - Authorship question.
- 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 A**

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

- **DISCUSSION**
- **DISPOSITION**

## 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
- Discussion

# Report on Old and New Business Subcommittee meeting Jan 16, 2014

- Brief update regarding tracking of integration of NBS and other data systems
- In future Subcommittee meeting, interest in update on transition initiatives
- Possible new projects in line with Committee assigned priorities
  - Explore hospital/birthing centers role in NBS. (? Potential to add value or redundant to ongoing efforts of APHL and others? Would collaborate with ED & TR Subcommittee; possibly convene stakeholder meeting, possibly conduct a survey)
  - Describe landscape of LTFU models used by States and other stakeholders, present case studies of success that can help build bridges between Federal additions to RUSP and state implementation. (Follow-on to Framework project and to another prior effort of subcommittee. Possibly convene stakeholder meeting, possibly conduct survey, work with Regional Genetics Collaboratives and other initiatives, likely to address transition and workforce issues as well as variability by state and by condition. )
  - Out of hospital births and responsibility for newborn screening.
  - Identify and further characterize elements of LTFU requiring specific consideration for “implementability” to help inform expert review (Follow-on to Framework project; but ? possibly redundant to ongoing activity of Committee ?)