

Subcommittee on Treatment and Follow up

Advisory Committee on Heritable Disorders in Newborns and Children



SAFER • HEALTHIER • PEOPLE™

Subcommittee Members

- Alan Hinman
- Jill Levy Fisch
- Celia Kaye
- Susan Berry
- James Figge
- Carl Cooley
- Fred Lorey
- Coleen Boyle
- Denise Dougherty
- Christopher Kus
- Alex Kemper
- Brad Therrell
- Jill Shuger



Update of Activities (1)

- Long Term Follow up (LTFU):
 - Overarching questions –
 - ◆ Chris Kus et al. taking the lead on developing a white paper
 - ◆ NCQA – quality measures to address the “overarching questions”

Update of Activities (2)

- LTFU (con't)
 - Presentations from CDC/HRSA/NIH funded LTFU projects
 - ◆ Common data elements across states
- Medical Foods survey
 - MK Kinney analyzing 3 state survey
 - ◆ APHL abstract



Short-term Follow Up Issues

(Freedenberg, Kaye, Therrell)

- *State mandated reporting*
- Routine linkage with birth certificates
 - A minority of states link routinely
 - Several include the NBS serial number as a field on the birth certificate
 - This field is not included on the U.S. standard birth certificate

Proposed Recommendation

“Newborn screening is an essential core public health activity required in every state. In order to facilitate verification that every child has received screening, the ACHDNC requests that the U.S. *model birth certificate* include a field for capturing the serial number of the initial newborn screening blood collection form [using the format described in the Clinical Laboratory Standards Institute LA4-A5]”

- Send this recommendation to the NCVHS (Natl Committee on Vital and Health Statistics)
- CDC/HRSA or FU&T subcommittee work with NCVHS to develop field specifications

