

Subcommittee on Treatment and Follow up

Advisory Committee on Heritable Disorders in Newborns and Children



SAFER • HEALTHIER • PEOPLE™

Subcommittee Members

- Susan Berry
- Robert Bowman
- *Coleen Boyle*
- Christine Brown
- W. Carl Cooley
- *Denise Dougherty*
- Lisa Feuchtbaum
- James Figge
- Michele Fox
- Holly Johnson
- Celia Kaye
- Alex Kemper
- Chris Kus
- Dina Matos
- *Kwaku Ohene-Frempong*
- Brad Therrell



Update of Activities

- Long-term Follow Up:
 - developed a draft white paper with a refined matrix of the “overarching questions”
 - met with NCQA to develop quality measures for the overarching questions
- Medical Foods:
 - Completed survey on costs and reimbursement
 - Data analysis is ongoing



Update of Activities (2)

- Birth certificate and newborn screening linkage
 - Draft of white paper on the current practices in states including recommendations
 - Subcommittee comments
- HIT workgroup collaboration
 - NBS/birth certificate linkage; Quality measures—medical home/care coordination; Contingency planning---family perspective
 - Liaisons – Robert Bowman and Alex Kemper



Update of Activities (3)

- Strategic planning
 - Reviewed and reaffirmed the subcommittee charge
 - Barriers to short and long term follow up
 - Challenges and opportunities
- Presentations by Dr. Arnold
 - Subcommittee recognized the need
 - Well developed practice protocols
 - Timely outcome studies



Discussion and next steps

- Define what are the critical questions
- Define minimum data set
- Identify areas where the lack of standards poses a problem (e.g., case definition)
- “Use Case” for long-term follow up
- *What is the role of the subcommittee work vs. work of the Agencies*

