

Timeliness 2.0 Workgroup



FEBRUARY 12, 2016 Meeting

**Co-chairs:
Cathy Wicklund
Kellie Kelm**

MEMBERSHIP



Cathy Wicklund, co-chair	Kellie Kelm, co-chair
Susan Tanksley, Texas PH Lab, APHL	Beth Tarini, pediatrician, researcher
Stephen McDonough, pediatrician	Dieter Matern, Mayo
Klaas Wierenga, pediatrician, geneticist	Ed McCabe, March of Dimes
Amy Gaviligio, Follow up, Minnesota	Emily Drake, Association of Women's Health, Obstetrics and Neonatal Nurses (AWHONN)
Bob Ostrander – family physician, AAFP	Erica Wright, Follow up, Colorado
George Dizikes, Tennessee Dept of Health	Stan Berberich, Iowa NBS Lab
Bill Morris, parent	Cate Walsh Vockley, genetic counselor
Joseph Bocchini, pediatrician, SACHDNC Chair	Neil MacVicar, parent, MHA Service Corp.
APHL	

CHARGE



- Optimize successful strategies to address NBS specimen collection and transport
- Collect and disseminate timeliness specific practices from state NBS programs, including programs that have implemented efficiencies in collection, transport, screening and follow-up.
- Investigate strategies for improved standardization of communication of NBS results to providers and families

OPTIMIZE SUCCESSFUL STRATEGIES TO ADDRESS NBS SPECIMEN COLLECTION AND TRANSPORT AND COLLECT AND DISSEMINATE TIMELINESS SPECIFIC PRACTICES FROM STATE NBS PROGRAMS:



- Gather success stories from states/hospitals, etc.
 - Write up a white paper that has a “tool box” of strategies gathered from the success stories.
 - Partner with other stakeholder groups (e.g. AHA, ANA) to raise awareness by disseminating success stories. Best strategy may be webinars/information sharing from those groups to their members.
- Joint commission – still an interest
- Get updates from other timeliness efforts (e.g., NewSTEPs 360, March of Dimes)
- See the new timeliness data (NewSTEPs) to assess parts of the process that need more attention

INVESTIGATE STRATEGIES FOR IMPROVED STANDARDIZATION OF COMMUNICATION OF NBS RESULTS TO PROVIDERS AND FAMILIES



- Will come back to this charge when we get timeliness data (NewSTEPs)
- The new timeliness data will be the first available to include metrics from collection through 12 months of age, including result to PCP and confirmatory diagnosis
- Several possible projects in this space but they depend on the data and the areas of need