

Newborn Screening Work Group Meeting

Wednesday, November 18, 2009

3:30- 4:30 pm—Conference Call

Summary

Members: Jackie Whitfield (AR), Leslie Himstedt (AR), Linda Williams (KS), Colleen Peterson (KS), Barb Schweitzer (ND) Krystal Baumert (NE), Patrick Hopkins (MO), Karen Eveans (NE), Sharon Vaz (OK), Lucy Fossen (SD), Sarah Groeneveld (SD), JoAnn Bolick (AR), Jamey Kendall (KS), Amy Brower (NE), Tonya McCallister (OK), Casey Mullins (OK), Debbie Klein (OK), John Adams (ON)

Staff: Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Small Group Projects Update	Unsatisfactory Specimens—It was decided on the last project conference call that testing would continue through Nov. 25 th and that data would be submitted to Patrick Hopkins for analysis. Patrick would then draft an abstract for APHL, even though there would be a short turnaround time. Jamey Kendall, Amy Brower and Lori Williamson volunteered to review the abstract before submission.	
Abstract Submission to APHL	<p>Unsatisfactory Specimens—See above</p> <p>Harmonization efforts—Lori Williamson proposed submitting a poster to APHL highlighting harmonization efforts within the region. Item to be included: NBS Program Exchange; Spring NBS meetings; NBS Back-up Testing Project; TPN survey; Transfusion Practices survey; and comparison of DBS card information and lab report information.</p> <p>Back-up Testing Project—to be submitted by Stan Berberich</p>	Abstracts attached to summary.
NBS Summit (December 7-8, 2009)	Genetic Alliance is hosting a NBS summit in the Washington DC area on December 7-8, 2009. Amy Brower will be a presenter. Amy indicated that the regional coordinating centers are part of the target audience of the summit.	More information can be found at www.geneticalliance.org .

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Data Linkage State Assessment	Amy Brower provided an overview of the project. Throughout the project, assessment tools from the CDC, Public Health Informatics Institute (PHII) and AHRQ will be used. Amy is in the process of contacting the first state now. She asks that everyone in all NBS programs to begin thinking about the stakeholders (users, administrators, consumers, clinicians, laboratory staff, etc) and who should attend site visit meetings. Amy is aware of other similar national projects and is making adjustments to the Heartland project. WG members on the call indicated that Spring 2010 would be the best for site visits.	
NBS Spring Workshop	Group was asked to suggest locations for the Spring 2010 NBS meeting. Kansas City, MO was the consensus. No date was officially selected. The each state is to select the attendees (with suggestions from the HRCC and based on budget). Attendees could include: SGC, STFU, LTFU, lab staff or EHDI. Krystal Baumert, Karen Eveans and Sharon Vaz volunteered to serve as a planning committee.	Please send suggested agenda items to Shona at shona-whitehead@ouhsc.edu .
Next meeting	Draft agenda for January 2010 meeting attached.	January 27, 2010--3:30 pm