

Newborn Screening Group Meeting
Friday, July 31, 2009
1:00-2:00 pm—Conference Call

Summary

Members: Dawn Peck (MO), Krystal Baumert (NE), Patrick Hopkins (MO), Debbie Klein (OK), Julie Raburn (MO), Karen Eveans (NE). Kim Turner (IA), Stan Berberich (IA), Tonya McCallister (OK), Casey Mullins (OK), Sarah Groeneveld (SD), Annette Arnold (AR)

Staff: Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Agenda for Little Rock Meeting	Members were asked for suggestions for the NBS Work Group meeting in Little Rock. Ideas were: <ul style="list-style-type: none">• Planning for Data Linkage project• Updates on Small Group Projects (unsatisfactory specimens, transfusion practices, blood spot collection form harmonization)• Back-up testing project—discussion of plans for FY 09-10 with the states involved• Review of past projects—which were successful, which were not completed and why; and create list of future projects A draft agenda for the NBS work group meeting is attached.	Please review the attached NBS work group agenda and provide feedback to shona-whitehead@ouhsc.edu by Friday, August 21, 2009.

Agenda Item	Discussion	Action
<p>NBS Workshop Project Updates</p>	<p><i>Transfusion Practices—Karen Eveans and Krystal Baumert</i></p> <ul style="list-style-type: none"> • Goal of project is to compare transfusion practices across the region and see if changes can be made that might affect the approaches taken by LTFU programs • A conference call was held July 14 and draft survey disseminated. All states represented on the call agreed to participate. (ND, SD, NE, MO, KS, IA) • Summary of survey results to be sent to Shona Whitehead by August 11. • Next conference call to be held Monday, August 17. • States not on first conference call can still participate and are asked to bring survey results to Little Rock meeting. • Kim Turner has submitted survey summary. She found that calling ahead worked better than just faxing the survey to the blood banks. <p><i>Unsatisfactory Specimens—Tonya McCallister</i></p> <ul style="list-style-type: none"> • Project guidelines have been discussed via email; the guidelines were agreed upon to minimize the differences in testing format. • Marcia Valbracht has distributed a spreadsheet for documenting data collections and results • However, new CAH guidelines have briefly put the project on hold as labs implement the new guidelines. • Next step is actual testing of specimens. <p><i>Blood Spot Collection Forms—Patrick Hopkins</i></p> <ul style="list-style-type: none"> • Goal of project is to hopefully harmonize the DBS collection forms. • Would like to have a conference call in August • Others are needed to join the project to better represent the region. Those working on the project currently are Julie Miller, Amy Brower and Patrick Hopkins. • Tonya McCallister suggested that both Lab and FU staff be included, if possible. <p>Lori Williamson commented that after these projects are completed, the group determines if the results are worth sharing with other regions or through abstracts or poster submissions.</p>	<p>If interested in joining the DSB Collection Form Harmonization Project contact Patrick Hopkins at Patrick.Hopkins@dhss.mo.gov</p>

Agenda Item	Discussion	Action
IBEM-IS updates	<p>Casey Mullins—Dr Kayser (OK) has received IRB approval and is moving forward on DocSite License.</p> <p>Dawn Peck (MO)—has received IRB approval, consented one patient, awaiting sub-contract from OUHSC to move forward on DocSite License.</p>	
Work Group Facilitation Structure	Is the current work group facilitation structure working? Could it be better? Should work group members facilitate and develop the meeting agendas? Should it stay with the HRCC facilitating and developing the agendas? A combination?	Please send suggestions and feedback to Shona at Shona-Whitehead@ouhsc.edu by Friday, August 28 th .
Next meeting	<p>Preliminary Agenda included with meeting summary.</p> <p>More conference information, including the link for registration can be found: http://www.heartlandcollaborative.org/annualconference/conference09.htm</p>	Heartland Annual Conference—9/16-18/09—Little Rock, AR