

**Newborn Screening Work Group Meeting**  
**Wednesday, May 27, 2009**  
**3:30-4:30 pm**

**Attendees:** Barb Schweitzer (ND), Jamey Kendall (KS), Julie Miller (NE), Laurie Smith (KS), Leslie Himstedt (AR), Lucy Fossen (SD), Patrick Hopkins (MO), Amy Brower (NE), Debbie Klein (OK), John Adams (Ontario), Julie Raburn (MO), Linda Williams (KS), Sharon Vaz (OK), Sarah Groeneveld (SD) **Guests:** Kim Piper (IA), Patricia Burk (OK)  
**Staff:** Lori Williamson Shona Whitehead

**Meeting Summary:**

Agenda Item	Discussion	Action
Welcome/Attendance		
Supplemental HRSA funding for data system linkage needs assessment	<p>The HRCC should receive notice regarding the supplemental funding request with the NGA for the next project year, possibly by the end of the week.</p> <p>Consultant nominations are still being accepted, whether a person or an entity, to conduct a regional needs assessment for data linkage. The goal is to have several states needs assessed, with preliminary data, in advance of LTFU guidance from HRSA.</p>	<p>Please send consultant nominations to Lori Williamson at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>.</p>
Grant proposal	<p>Usher Syndrome project submitted by Dr. Bill Kimberling—Patricia Burk updated the group on the background of the grant proposal and the project. Dr Kimberling's proposal grew out of his Heartland pilot project (funded by Great Plains) and a roundtable discussion at the 2008 Heartland conference. The proposal includes a new test for Usher syndrome, hoping for early diagnosis in infants who fail initial hearing screening tests, so that there can be early intervention. Proposal includes pre and post genetic counseling, ophthalmology consults and an education component for audiologists, ophthalmologists and genetic counselors. Genetic counseling and travel for families to the closest qualified ophthalmologists will be included. Proposal submitted under NIH stimulus funding, so grant award announcement not expected until September 2009.</p> <p>Dr Kimberling is using the Heartland infrastructure, resulting in 4 states (IA, NE, MO and OK) agreeing to participate and writing letters of support. One additional state, North Dakota, received late approval and hopes to participate.</p> <p>Amy Brower suggested that, if funded, it should be considered for a pilot for uniform panel.</p>	<p>If interested in reading the project abstract, please contact Lori Williamson at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>.</p>

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NBS Workshop Follow-up	<p>Patrick Hopkins and Julie Miller provided a summary of the NBS Workshop and the resulting work group projects. (Full written summary also sent to the group)</p> <ul style="list-style-type: none"> <li>• Emergency Preparedness for both lab and follow up—inter-state and intra-state</li> <li>• Data Collection Form Harmonization—(Julie Miller, Amy Brower and Patrick Hopkins)—Which data do we need? What are the goals/outcomes of harmonizing the forms? Is there potential state or federal impact?</li> <li>• Unsatisfactory Specimen Quality Measures—(Marcia Valbracht, Laura Ross, Leslie Himstedt, Tonya McCallister)—What is each states criteria for unsat? Each state to look/compare an “unsat” to confirm if it truly is “unsat” or could reliable results be returned. Goal to reduce the number of unnecessary repeat screens. A conference call will be set up with all interested in participating to create guidelines for the project.</li> <li>• Transfusion practices—Karen Eveans and Krystal Baumert—A survey to be developed to survey hospitals and blood banks in each state regarding policies about transfusion. A draft survey was distributed to the group. Those interested in working on this project are: Linda Williams, Kim Turner, Barb Schweitzer, Lucy Fossen, Sharon Vaz and Julie Raburn.</li> </ul> <p>Patrick commented that the presentations from Dr Colombo and Amy Brower on CF were very informative. As a result, Sharon Vaz is polling states regarding their cutoffs for CF screening. She will disseminate information once collected.</p>	<p>If interested in participating in any of the projects listed, please contact Shona Whitehead at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>.</p> <p>Conference calls for each project will be arranged in the next few weeks.</p>
Application for Newborn Screening Saves Lives Act	<p>Kim Piper is developing a proposal for the forthcoming, NBS Saves Lives Act funding. The project will expand the “Iowa Family Participation Project,” a HRSA/MCHB project, in the Heartland region.</p> <p>The goal of the project is to ascertain a population’s awareness and perceptions of the NBS program and try to engage the population in the planning, implementation and evaluation of the state NBS program. Project will target populations under-participating in NBS. It will help to identify barriers and how to make it easier to participate.</p> <p>Currently the IA project has worked with Sudanese refugee women, 2 Amish communities, community affiliated with the college of chiropractic in Iowa, adoptive and foster parents and parents of children with false positive screen, true positives and carriers, and parents of children with a diagnosed hearing loss. The expanded project would involve populations the individual State has determined to be underrepresented in the NBS programs.</p> <p>Kim is working with Gene Hallford (OK) since he has experience with town hall meetings</p>	

*Heartland Genetics and Newborn Screening Collaborative*

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	<p>about NBS. In preparation for the funding announcement, Kim Piper will need a snapshot survey from each State, and facilitator from each state, letter of support. If funded each participating state will need state based IRB and/or tribal approvals. Lori Williamson to contact the State Genetic Coordinators next week. Kim Piper will be the PI on this and the HRCC is helping facilitate involvement of the Heartland states.</p>	
IBEM-IS	<p>IBEM-IS is Region IV - Sue Berry's data on long term follow-up data collection project. An initial step is getting IRB approval. Only University of Missouri has accomplished that, and will now get Docsite license and be trained on data entry. Five other centers at various stages of getting IRB, and three are having trouble just getting the subcontract agreement signed.</p> <p>Additional centers have the opportunity to participate if interested, but funding will be included in carry-forward request.</p>	<p>Please contact Lori Williamson, at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>, if interested in participating as it will need to be included in carry forward funding.</p>
Upcoming abstract deadlines	<p>NBS workgroup projects would be appropriate for APHL in 2010. Amy Brower recommends publishing in <i>Genetics in Medicine</i> in addition to submitting the projects that have matured. American Society of Human Genetics deadline is June 2. Genetic Alliance meeting is July 2009 (probably too late to submit, but should be considered for next year). ACMG deadline for March 2010 meeting has past. HRCC will investigate the deadlines for APHA and others. The 2010 APHA call for abstracts will open December 14, 2009 and the deadline for submission is the second week in February 2010.</p> <p>Future deadlines will be added to Heartland calendar.</p> <p>If a poster or oral presentation abstract of one of these group projects is accepted, the Heartland Collaborative will be able to pay for the travel to present it, unless you would already be attending.</p>	<p>Please send any abstract/poster deadline information to Shona Whitehead at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>.</p>
Next meeting		<b>Wednesday, June 12, 2009</b>