

**Newborn Screening Work Group Meeting  
Wednesday, October 22, 2008  
3:30-4:30 pm**

**Attendees:** Sharon Vaz (OK), Amy Brower (NE), Barb Schweitzer (ND), Colleen Peterson (KS), Debbie Klein (OK), Jamey Kendall (KS), Jennifer Marcy (IA), JoAnn Bolick (AR), John Adams (Advocate), Julie Miller (NE), Julie Raburn-Miller (MO), Karen Evans (NE), Krystal Baumert (NE), Leslie Himstedt (AR), Lucy Fossen (SD), Patrick Hopkins (MO), Sharmini Rogers (MO), Linda Williams (KS), Jennifer Allen (OK), Jackie Whitfield (AR), Janda Jenkins (MO).

**Staff:** Lori Williamson and Shona Whitehead

**Meeting Summary:**

| Agenda Item  | Discussion   | Action   |
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| Report on Advisory Committee on Heritable Disorders in Newborns and Children | Julie Miller added more to her report from the ACHDNC meeting. <ul style="list-style-type: none"> <li>• The working group revised its focus related to everyone's role in LTFU</li> <li>• Status of disorders in consideration for inclusion on core panel                             <ul style="list-style-type: none"> <li>○ Krabbe: Sent to evidence review group, to be voted on in February 2009</li> <li>○ Fabry: Not sent to evidence review group</li> <li>○ SCID; Sent to evidence review group, reviewed, but not voted on</li> <li>○ Pompe: Sent to evidence review group, voted to not include in core panel, because there is no validated test</li> <li>○ Nieman-Pick: Not sent to evidence review group</li> </ul> </li> </ul> |  |
| Utah MedHome Portal Collaboration  | <ol style="list-style-type: none"> <li>a. Jackie Whitfield and Leslie Himstedt agreed that KS, MO, IA and OK had good online information about different disorders. Leslie felt that IA has a good practitioner's manual online as well.</li> <li>b. Additional disorder nominated was MSUD</li> <li>c. Suggested authors are:                             <ul style="list-style-type: none"> <li>• Dr. Brad Schaefer</li> <li>• Dr. Stephen Khaler</li> <li>• Sara Copeland</li> <li>• Charlotte Phillips</li> </ul> </li> </ol>  | <p><b>Work Group members are asked to rank their preferred disorders on a 1-4 scale (1=top choice and 4=last choice)</b></p> <p><b>Disorders are:</b></p> <ul style="list-style-type: none"> <li>• isovaleric academia</li> <li>• pyruvate dehydrogenase deficiency</li> <li>• PKU</li> <li>• MSUD</li> </ul> <p>Please send rankings to <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> by Friday, October 31, 2008.</p> |

| Agenda Item  | Discussion  | Action  |
|--|---|---|
| NBS Exchange Program   | <ul style="list-style-type: none"> <li>a. SD to visit OK in Spring 09</li> <li>b. KS lab to visit IA lab—no date set</li> <li>c. AR lab to visit MO lab—not date set</li> <li>d. MO to visit IA for LTFU—no date set</li> </ul>   | <p>Visits must be conducted before May 31, 2009. And, pre-visit planning (e.g., pre-assessment and agenda) must be completed and reviewed by RC.</p> <p><b>Once dates are confirmed please notify <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>.</b></p> |
| Heartland Back Up Testing Project                                | <ul style="list-style-type: none"> <li>a. Reminder to identify EMAC official in each state                             <ul style="list-style-type: none"> <li>• Contact official</li> <li>• Let official know about potential drills</li> <li>• Julie Miller commented it is important to know the communication chain of command in emergency situations</li> </ul> </li> <li>b. NBS lab meeting—Funding is available, if the meeting is needed.                             <ul style="list-style-type: none"> <li>• Consensus was that meeting would be good. Patrick Hopkins commented that the previous meetings have expanded into a “NBS workshop” and was attended by both lab and LTFU staff to improve harmonization.</li> </ul> </li> </ul>  | <p>Julie Miller in Nebraska indicated they would be willing to be the host state for the NBS workshop this year.</p>  |
| Region 4 “true positive” data collection project (Piero Rinaldo) | <ul style="list-style-type: none"> <li>a. Review of state program reps                             <ul style="list-style-type: none"> <li>• AR—Leslie Himstedt and Jackie Whitfield</li> <li>• IA—Sara Copeland and Kim Turner (submits data)</li> <li>• KS—Colleen Peterson and Linda Williams</li> <li>• MO—Patrick Hopkins (submits data) Julie Rayburn-Miller</li> <li>• NE—Julie Miller and Krystal Baumert (submits data)</li> <li>• ND—Barb Schweitzer (submits data)</li> <li>• OK—Jennifer Allen (submits data) and Tonya McCallister (cut-offs)</li> <li>• SD—Lucy Fossen (submits data)</li> </ul> </li> <li>b. Mayo Clinic Training Program for lab personnel. States that have attended training are: AR, IA, MO and OK. Funding available from Heartland for others to attend.</li> </ul> | <p>KS is interested in attending training in either Dec. 08 or Feb. 09.</p>   |

*Heartland Genetics and Newborn Screening Collaborative*

| <b>Agenda Item</b>  | <b>Discussion</b>   | <b>Action</b>   |
|---|---|---|
| Long term follow up data collection project with Sue Berry (Region 4) | <p>a. Sara Copeland not on call to report about IA's experience with IBEM-IS.</p> <p>b. Heartland can fund additional centers interested in participating in this project. Centers would be expected make database entry every time a patient is seen; participate in scheduled conference calls and in-person meetings. HRCC would pay for license to access the proprietary database, participating centers would receive a "per entry fee" for data entry and cover travel expense for required in-person meetings.</p> <p>It has been reported at a national meeting that some participating states are having problems with IRB approval and are incurring additional expense.</p> | <p>Lori Williamson has already contacted Dr. Kayser in Tulsa and Dawn Peck in Missouri; about participating because of prior interest. <b>She will also contact Quinn Stein in South Dakota.</b></p> <p><b>If interested in participating contact <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>.</b></p> |
| Planning for FY 2009-2010   | <ol style="list-style-type: none"> <li>1. Transition <ul style="list-style-type: none"> <li>• Electronic Health Records (EHR)—what role do they play?</li> </ul> </li> <li>2. Telemedicine <ul style="list-style-type: none"> <li>• Electronic Health Records (EHR)—what role do they play?</li> </ul> </li> <li>3. LTFU</li> <li>4. Storage of cards</li> <li>5. NBS Save Lives Act <ul style="list-style-type: none"> <li>• Are EHRs included under this act?</li> <li>• Some example state programs are included in the language</li> <li>• LTFU data needed</li> </ul> </li> </ol>  | <p><b>Please send any ideas or potential projects to <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>.</b></p> <p><b>Amy Brower to provide a summary of the NBS Saves Lives Act</b></p>   |
| New business  |   |   |
| Next meeting  |   | <p><b>Wednesday, November 19<sup>th</sup></b> (1 week early due to Thanksgiving)</p> <p>Agenda Item suggested: Feedback on APHL NBS workshop on CF</p>  |