

## Newborn Screening Work Group Meeting

Wednesday, March 18, 2009

3:30-4:30 pm

**Attendees:** Barb Schweitzer (ND), Krystal Baumert (NE), Lucy Fossen (SD), Patrick Hopkins (MO), Amy Brower (NE), Colleen Peterson (KS), Debbie Klein (OK), Jackie Whitfield (AR), Sharon Vaz (OK), Sarah Groenveld (SD), Annette Arnold (AR)

**Staff:** Lori Williamson and Shona Whitehead

### Meeting Summary:

Agenda Item	Discussion	Action
Welcome/Attendance		
NBS Exchange Program	<p>Post visit PEAS assessments are due in April for those states who conducted visits last Spring. Arkansas has completed their assessment, but North Dakota and Kansas still need to be completed.</p> <p>South Dakota will be visiting Oklahoma at the beginning of April. The PEAS assessments and draft agenda will be reviewed by Lori within the next week.</p>	PEAS post assessment due in April for North Dakota and Kansas.
Budget Priorities for FY 09-10	<p>The Advisory Board was asked to prioritize activities that had been suggested by all the work groups. Lori organized the suggestions under each of the Heartland goals, provided description of the activity and included estimated budget costs. The list not only included new activities but also ongoing and required activities. This was a new process for selecting Heartland activities for the upcoming project year. The results of the Advisory Board rankings are attached.</p> <p>Telemedicine metabolic rounds had been suggested several years ago and modeled after a program conducted by Brad Schaefer when he was in Nebraska. At the time, the project was not supported by HRSA because it didn't include primary care physicians (PCP) or pediatricians. However, the new project would include these physicians.</p> <p>Initial suggestions are to host 3 or 4 sessions the first year to discuss difficult metabolic cases. North Dakota has volunteered to be the first state to participate.</p> <p>This project has many potential benefits including:</p> <ol style="list-style-type: none"><li>1. All states have now implemented expanded NBS</li><li>2. HRSA is pushing regions to more effectively use telehealth technology</li><li>3. This is possibly a meaningful way to reach out to PCPs</li><li>4. Increased dialog can increase awareness of genetic cases among PCPs</li></ol>	Please contact Lori at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a> if you state is interested in participating in the telemedicine metabolic rounds.

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Agenda Item	Discussion	Action
	<p>Items needed for success of the project:</p> <ol style="list-style-type: none"> <li>1. Other states volunteering to participate</li> <li>2. Metabolic consultants, that aren't necessarily from the host state</li> </ol> <p>Annette Arnold commented that PCPs are too busy now, what is the plan to get them to attend?</p> <p>It is not known at this time if CME credit would be available. This project has the potential to be low cost.</p>	
<p>MEMSCIS (<a href="https://memscis.org/home/">https://memscis.org/home/</a>)</p>	<p>Lori discussed the questions raised during the last NBS meeting with Sue Berry.</p> <ul style="list-style-type: none"> <li>• MEMSCIS is a clinical tool—not research, NO IRB needed</li> <li>• Each enrolling center has access to its patients but not those of other centers; MN does NOT have access to any other center's patients, unless a particular family gives MN permission to be contacted</li> <li>• Patients do not enroll themselves, it must be done at an approved center</li> <li>• Patients and nurse coordinator complete forms and enroll onsite</li> <li>• Family must consent separately to be contacted by MN to become further involved with research projects.</li> <li>• Family assigns permissions for access</li> <li>• Website is secure, but is it possible to gain access in case of emergency</li> <li>• Cost to Heartland RC would be cards with password</li> <li>• Templates were originally developed by AAP</li> <li>• Website is hosted by ImageTrend.com</li> </ul> <p>Currently there is no specific activity for Heartland planned.</p>	<p>Contact Sally Hiner at <a href="mailto:shiner@mphi.org">shiner@mphi.org</a> with any additional questions or if you wish to participate.</p>
<p>Report from Stan Berberich</p>	<p>Postponed for next meeting</p>	
<p>NBS Workshop</p>	<p>April 30 and May 1, 2009 at the Embassy Suites in Lincoln, NE. Guest speakers include Amy Brower and John Colombo.</p> <p>Heartland will reimburse up to 3 people per state to attend, plus the state genetics coordinator. Lodging for attendees will be arranged by the RCC based on information on the registration form. If you plan to fly, flight arrangements can be made by the RCC also.</p> <p>Thank you to Stan Berberich, Patrick Hopkins and Julie Miller for their work developing the agenda and selecting guest speakers.</p>	<p>Agenda and registration form attached to summary. Registration deadline is April 20, 2009.</p> <p>Please contact Shona at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> with any questions.</p>

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<b>Agenda Item</b>	<b>Discussion</b>	<b>Action</b>
Cystic Fibrosis Mutation Effort	<p>Amy Brower notified the group about a project called CFTR2 – The Clinical and Functional Translation of CFTR which is an international effort to update clinical and functional information on CFTR mutations. The project is looking for state programs to contribute data/samples or information on clinical features found during CF follow-up.</p> <p>For more information visit: <a href="http://www3.genet.sickkids.on.ca/cftr/app">http://www3.genet.sickkids.on.ca/cftr/app</a></p>	
CLSI	<p>Lucy Fossen asked the group if anyone had read or implemented the new CLSI recommendations for premature and sick newborns. The document is not finalized, but should be in July 2009.</p> <p>Sharon Vaz indicated that at this point OK will not be making any changes since good follow-up currently exists.</p> <p>Lucy commented that SD is also not expecting to make any changes.</p> <p>Krystal Baumert responded that she does expect changes in NS, but the final decision will be made by Julie Miller and her co-chair.</p>	
Collaborative Research Opportunity Conference Calls	<p>Lori Williamson and Amy Brower will be hosting two calls to discuss external funding opportunities. The RCC is serving as facilitator to help states across the region apply for funds. Stimulus grants are due by April 27<sup>th</sup>.</p> <p>Project ideas to be discussed on the calls include:</p> <ul style="list-style-type: none"> <li>• Quality assurance</li> <li>• Translational research</li> <li>• Patient registries</li> <li>• Health Technology</li> <li>• Uncommon disorders research</li> <li>• Underserved populations</li> <li>• Transition</li> </ul> <p>If you have a project idea that you are willing to share, are seeking opportunities to collaborate with other Heartland states, or would like to request technical assistance (writing, reviewing, or budget development) for submitting a grant application, please join one of the two calls.</p>	<p><b>Conference Calls:</b>  <b>Monday, March 23rd at 3:00 pm</b>  Participant Call-in: (888) 422-7124  Participant Code: 749760</p> <p><b>Tuesday, March 24th at 4:00 pm</b>  Participant Call-in: (888) 422-7124  Participant Code: 749760</p>
Next meeting		<b>Wednesday, April 22, 2009</b>