

**Advisory Board Meeting  
Monday, March 9, 2009—2:00-3:00 pm  
Summary**

**Attendees:** Barb Schweitzer (ND), Leslie Himstedt (AR), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Kim Piper (IA), Mary Riske (ND), Holly Johnson (AR), Brad Schaefer (AR), Sharon Vaz (OK), Kayla Tinker (SD)

**RCC Staff:** John Mulvihill, Lori Williamson, Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Accepted as recorded
Non-Competitive Renewal	<p>Thank you to all the Advisory Board members who submitted project rankings. It was then easy to identify two priority projects per Heartland goal. (The results of the rankings are attached.) The major projects that are included are:</p> <ul style="list-style-type: none"> <li>• Back-up testing project (in its 3<sup>rd</sup> year and will include all the Heartland states)</li> <li>• Genetic Systems Assessment (in its 3<sup>rd</sup> year and will finalize the tool and then pilot the tool)</li> <li>• Sarah Lawrence Scholarship (may have some cost share with the recipient in 2010)</li> <li>• Heartland Annual Meeting</li> <li>• Website hosting and maintenance</li> </ul> <p>Other ranked activities that have low-cost will be included in the plan for next year.</p> <p>Budget and narrative are due to the OUHSC Office of Research Administration by Wednesday, March 18, 2009.</p> <p>NIH Challenge Grant—Lori will be hosting a call to discuss a possible</p>	

Agenda Item	Discussion	Action
	Heartland RCC application for funding. See below for more details.	
Newborn Screening Translational Research Network (NBSTRN)	<p>The NBSTRN will be a national cohort of children identified by NBS. The coordinating center will be the ACMG, but be separate from the regional collaboratives. A planning meeting of the NBSTRN will be held on April 16-17, which John Mulvihill has been invited to attend, although it is unclear if he is invited to represent Heartland. A meeting of “state NBS representatives” will be held April 6-7. However there is no representation from any Heartland state included on the roster of invitees, despite Heartland RC’s objections.</p> <p>If your state is interested in participating in the NBSTRN, please contact the ACMG directly.</p> <p>Sharon Vaz—attended the February 2009 ACHDNC meeting as both a representative of Heartland and the Oklahoma State Dept. of Health. She indicated she asked about the unbalanced representation of NBS state programs and did not receive a clear answer.</p> <p>Amy Brower, an ACHDNC committee member, agrees with Sharon, the representation from state NBS programs is unbalanced. She assumed that the NBSTRN would work along with the regional collaboratives to take advantage of the synergy created by the regions. It seems that opportunities will be missed by not working more closely with the regional collaboratives. Adding SCID to NBS panel was denied based on one states pilot. Had multiple states worked together through the RC network, enough babies would have been screened to provide sufficient evidence pro or con. This is only one example of how NBSTRN can benefit by working with the RCs.</p> <p>Lori Williamson—Regional Project Managers have met and will be communicating with Mike Watson about the contribution the RCs can make.. In addition, information about the upcoming April meetings is attached.</p> <p>Be prepared for a future call, possibly on short notice, to discuss each states involvement. For success, NBSTRN will need buy-in from state health departments, state NBS labs and programs, and metabolic</p>	<p>If your state is interested in participating in the NBSTRN, please contact the ACMG directly.</p> <p>Mike Watson at <a href="mailto:mwatson@acmg.net">mwatson@acmg.net</a> or 301-634-7127</p> <p>Michelle Puryear at <a href="mailto:mpuryear@hrsa.gov">mpuryear@hrsa.gov</a> or 301-443-1080</p>

*Heartland Genetics and Newborn Screening Collaborative*

Agenda Item	Discussion	Action
	geneticists.	
Report on the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) meeting	<p>Sharon Vaz—the committee reviewed IRB process and NBS sample storage</p> <p>Amy Brower—Krabbe to be reviewed for next committee hearing and there was discussion about informed consent and the development of a national IRB for NBS research</p>	
Annual Meeting	<p>The Little Rock Convention &amp; Visitors Bureau is assisting with gathering RFPs from hotels in Little Rock.</p> <p>The next meeting of the conference planning committee will be held in the next few weeks.</p> <p>A draft agenda will available for review at the April Advisory Board Meeting.</p>	<p>Advisory Board to meet evening of 9/16/09. Main sessions to be held September 17-18 in Little Rock, AR.</p> <p>Please send suggestions for speakers, topics or other agenda items to Shona at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>.</p>
NIH Challenge Grant	Lori Williamson will be hosting two calls to discuss opportunities for the RCC to submit an application that will help meet the needs of the region. Areas for possible projects include: NBS and genomics education, health information technology, and rural health care delivery of genetic services.	<p>Conference Calls:</p> <p><b>Monday, March 23<sup>rd</sup> at 3:00 pm</b> Participant Call-in: (888) 422-7124 Participant Code: 749760</p> <p><b>Tuesday, March 24<sup>th</sup> at 4:00 pm</b> Participant Call-in: (888) 422-7124 Participant Code: 749760</p> <p>Please contact Lori at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a> or Shona at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> if interested in participating.</p>
Authorizations for recent legislation	<p>NBS Saves Lives Act—\$218 million for 2008-2013</p> <p>Prenatal and Postnatal Diagnosed Conditions Awareness Act--\$19 million for 2009-2013</p>	
Next meeting		Monday, April 13, 2009