

**Advisory Board Meeting
Monday, May 11, 2009—2:30-3:30 pm
Summary**

Attendees: Barb Schweitzer (ND), Leslie Himstedt (AR), Lucy Fossen (SD), Jamey Kendall (KS), Jackie Whitfield (AR), Mary Riske (ND), Sharmini Rogers (MO), Holly Johnson (AR) and Larry Weatherford (OK). **Guests:** JoAnn Bolick (AR), Kayla Tinker (SD), Barb Jackson (NE), Annette Arnold (AR), and Patrick Hopkins (MO)

RCC Staff: John Mulvihill, Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Accepted as recorded
Collaborative Research	<p>Collaborative research is becoming a high priority with HRSA, including publications and presentations.</p> <ul style="list-style-type: none"> a. <i>Neurofibromatosis Department of Defense</i>—an OU researcher who has worked previously with John Mulvihill, Dr Teasdale, submitted a Department of Defense grant which aims to provided increased education to primary care providers who treat adults with NF. He will use the Heartland infrastructure to partner with clinical centers to deliver the educational intervention. b. <i>Usher Syndrome</i>—an NIH Challenge Grant submitted by Dr Bill Kimberling in Iowa. The project will provide Usher syndrome screening to infants who fail the first or second newborn hearing screening. Infants who test positive with have early access to ophthalmologist and genetic counseling. Dr Kimberling is also utilizing the Heartland infrastructure. c. <i>University of Iowa</i>—Two grant proposals submitted. HRCC provided letters of support for both. If funded laboratories and clinicians in Heartland would be contacted. d. <i>NBS Underserved Population</i>—An expansion of pilot project of Kim Piper and Gene Hallford that will explore opportunities to create dialog with fringe populations that may be resistant to NBS. e. <i>Genetic Alliance</i>—potential project with Genetic Alliance and another regional collaborative. 	

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	<p>It has been an exciting and busy six weeks supporting research funding opportunities and fostering collaboration.</p>	
<p>Genetic Systems Assessment (GSA) Project Update</p>	<p>The GSA project has been a base funded project for over two years, which has the goal of developing a tool, based not only on previous tools, but also recent literature, that will measure quality of genetic services in four areas: Public Health, Clinical Services, Lab and Training.</p> <p>The GSA Expert Panel was convened for a one day meeting at the DFW airport. Members of the Expert Panel represent the NCC, HRSA, Heartland state genetic coordinators, advocates and others in key service areas. The goal of the meeting was to complete a Delphi process of reducing the number of potential measures from 62 to 24. The subsequent rankings resulted in median score of 4.7 out of 5 for the top measures.</p> <p>The first of two sequential pilot tests will occur in Hawaii, followed by Oregon in Fall/Winter 2009. Implementation in Heartland is planned for Summer 2010.</p> <p>A presentation of the GSA project progress, including the Delphi process, is planned for the Annual Meeting in Little Rock, AR in September.</p>	
<p>NBS Workshop Report</p>	<p>Report by Patrick Hopkins--3rd annual meeting of the NBS lab and follow-up staff. The 1.5 day meeting began with an update from each state of progress and setbacks over the past year. Two guest speakers—Dr John Colombo and Dr Amy Brower spoke about cystic fibrosis. Emergency preparedness was discussed next, including the Heartland Back-up project and follow-up and tracking. The group collectively spent time discussing ways to potentially harmonize patient collection forms. This project will continue during NBS work group conference calls. The remainder of the meeting focused on the unsatisfactory specimens. This discussion resulted in two projects for the attendees: the lab staff in each state will conduct comparative tests on specimens and the follow-up staff will work on protocols for obtaining new samples after the first are determined to be unsatisfactory.</p> <p>Lori Williamson asked if the nature of these meetings is informative or good enough for a poster. To her knowledge, no other region hosts meetings of this type. Barb Jackson indicated that the meeting structure, which included didactic presentations, group involvement and action items for the</p>	

Heartland Genetics and Newborn Screening Collaborative

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	attendees to work on until the next meeting, was beneficial. She was able to collect qualitative data for the annual report. She also said that those who have attended the NBS workshop and participated in the NBS Program Exchange indicated it was very beneficial to their programs.	
Annual Meeting	The agenda is coming together; there are a few items to clarify before a draft is distributed to the Advisory Board. The meeting location in Little Rock should be finalized within the next week.	Please send any agenda ideas to Shona Whitehead at shona-whitehead@ouhsc.edu .
NBSTRN	ACMG has been awarded \$10 million to be the coordinating center of the Newborn Screening Translational Research Network (NBSTRN). It is currently assumed that not all states will be invited to participate, but the ground rules are still being determined. It is assumed that states that currently retain dried blood spots (DBS) for an extend period of time will be invited to participate. The ACMG recently released a statement encouraging all states to begin retaining DBS. The ACMG statement is attached.	
Announcements	<p>Congratulations to Jamey Kendall who will be attending the Sarah Lawrence Public Health Genomics course in June. The Kansas Department of Health and Environment is paying for Jamey to attend.</p> <p><i>Abstract or Poster Deadlines</i> 5/15/09--National Society of Genetic Counselors 28th Annual Education Conference 5/15/09--Southwest Conference on Disability 6/02/09--American Society of Human Genetics Annual Meeting 6/19/09--Association of University Centers on Disabilities Annual Meeting</p>	
Next meeting	Upcoming Heartland Meetings: Heartland Annual Meeting—September 16-18—Little Rock, AR	Monday, June 8, 2009