

Advisory Board Meeting
Monday, January 26, 2009—2:30-3:30 pm
Summary

Attendees: Barb Schweitzer (ND), Leslie Himstedt (AR), Majed Dasouki (KS), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Mary Riske (ND), Sharmini Rogers (MO), Holly Johnson (AR), Brad Schaefer (AR)

Guests: Annette Arnold (AR), Barbara Jackson (NE)

RCC Staff: John Mulvihill, Lori Williamson, Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Meeting summary accepted as recorded.
NCC/HRSA Meeting Update	<ol style="list-style-type: none">1. Mike Watson announced that the NCC/ACMG is receiving a sole source grant for the Newborn Screening Translational Resource Network (NBSTRN) from NICHD. It will create a nationwide co-hort of NBS outcomes for lifetime tracking in all states willing to participate. A planning meeting is scheduled for April 2009, but the invitees have not yet been announced. The RCCs requested that they be kept informed of progress and meeting dates. Lori Williamson has requested details from Judith Benkendorf regarding the April meeting.2. Legislation—Two bills have recently passed Congress and were signed by the President.<ol style="list-style-type: none">a. Newborn Screening Save Lives Act was passed and is waiting for appropriations.b. S. 1810-Prenatally and Postnatally Diagnosed Conditions Awareness Act-once it also receives appropriations grants will be available. http://www.opencongress.org/bill/110-s1810/show	

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	<p>Missouri also recently passed a bill to disseminate information regarding birth defects</p> <p>3. Genetic System Assessment (GSA)—meeting was held to discuss the current status of the GSA project. Feedback encourages the inclusion of previous tools into the current project. A face to face meeting of the GSA Expert Panel will need to be held in late May to refine the measures list through a revised Delphi process.</p>	
Budget Priorities	<p>Please refer to document “Potential Activities for FY09-10”. An updated and annotated version will be distributed with the meeting summary.</p> <p>List was organized based on the four Heartland goals. Please rank based on project priority within the goals 1 being highest and 5 the lowest. If you think the item should be removed, please indicate with an X.</p>	<p>Please rank the projects in the “Potential Activities for FY09-10” document and submit the rankings to Shona at shona-whitehead@ouhsc.edu by Friday, February 6, 2009.</p>
Evaluation plan	<p>The evaluation plan keeps the Heartland goals and HRSA goals separate in separate documents. However, the HRSA goals are linked with the Heartland goals and should help with reporting outcomes.</p> <p>Amy Brower would like to see language added to the plan that would move goals to future years in the event that goals are not met in the given time frame.</p> <p>Advisory Board members are asked to review the evaluation plan and provide feedback.</p>	<p>Please send suggestions or edits to Barbara Jackson at bjjackso@unmc.edu by Wednesday, February 11, 2009.</p>

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Mid-Year Meeting	<p>A Mid-Year Work group meeting was initially penciled in on the calendar based on verbal feedback given to Lori over the past two years. However, based on a survey of work group members, not enough would be able to attend on the selected dates to justify the meeting.</p> <p>Majed Dasouki asked if there were any pressing items for the agenda and Lori Williamson indicated that the following items were planned for the plenary sessions:</p> <ol style="list-style-type: none"> 1. Evaluation plan – are we asking the questions that we really want to ask? 2. Begin collecting qualitative data. 3. Time to discuss organized collaborative research and collaborative grant applications. <p>Williamson was not aware of pressing agenda items for the work groups that would be expedited or enhanced by meeting face-to-face.</p> <p>It was suggested in order to maximize the time of the attendees that a work group meeting could be “piggy backed” with the GSA Expert Panel meeting in May. Another suggestion was to have a meeting in conjunction with the NBS Workshop in Lincoln, NE on April 30 and May 1, 2009.</p>	<p>The Mid-Year Meeting scheduled for February 23-24, 2009 has been cancelled.</p> <p>Heartland RCC will explore future dates for a face-to-face Advisory Board meeting or a working meeting of board and core members to address the 3 agenda items.</p>
Newsletter Topics	<p>In order to meeting the needs of the collaborative members, the RCC would like to have timely and informative articles included in the quarterly Heartland e-news. Therefore we would like suggestions from the Advisory Board for future topics.</p> <p>Based on our HRSA Office of Performance Review report and action plan we will have a “how to “series starting later in the year. Suggestions from the group included: implications of the recent legislation, an overview of the new NBSTRN project announced at the NCC meeting, and articles related to the four Heartland Collaborative goals.</p>	<p>Please send suggestions for topics for the Heartland e-news to Shona at shona-whitehead@ouhsc.edu.</p>

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Meeting schedule	Several Advisory Board members have indicated that they are unavailable to attend this meeting on current day or time. The RCC will send a Doodle Poll to the Advisory Board members to determine the time that the most number of Board members are available.	Please respond to the Doodle Poll by Wednesday, February 11, 2009 . The link to the poll is: http://www.doodle.com/qarvn52g5g7gme5k The poll will close Wednesday, February 11, 2009
Next meeting		Date to be announced based on feedback from Doodle Poll. No February Meeting.