

**Advisory Board Meeting  
Monday, August 10, 2009—2:30-3:30 pm  
Summary**

**Attendees:** Barb Schweitzer (ND), Leslie Himstedt (AR), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Jackie Whitfield (AR), Julie Miller (NE), Kim Piper (IA), Larry Weatherford (OK), and Holly Johnson (AR)

**Guests:** Joann Bolick (AR) and Barb Jackson (NE)

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

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Accepted as recorded
Annual Meeting—Little Rock, AR	<p>Review of agenda (attached)</p> <ul style="list-style-type: none"> <li>• Added additional roundtable to involve EHDI staff</li> <li>• NCC update will be given by Gloria Weissman, but will focus on activities of the regions and the national evaluation effort</li> </ul> <p>Additional people have been invited, from each state, (with Heartland paying for travel and lodging) with the thought that they would become work group members replenishing and expanding the overall membership.</p> <p>Conference Information:  <a href="http://www.heartlandcollaborative.org/annualconference/conference09.htm">http://www.heartlandcollaborative.org/annualconference/conference09.htm</a></p>	RCC to send SGCs a list of invitees from their state and a customizable letter to personally invite those same folks, if you want to do so and have time.
Review of Project Narrative	<p>(Narrative Attached) Highlights:</p> <p>Goal 1</p> <ul style="list-style-type: none"> <li>• Region 4 project—All states participating</li> <li>• IBEM-IS—7 centers participating</li> <li>• Metabolic Rounds—report from Mary Ann Coffman at September meeting</li> </ul> <p>Goal 2</p> <ul style="list-style-type: none"> <li>• MedHome Portal Evaluation—need to finish project before we can evaluate</li> <li>• LEND—Lori is working with LEND leaders in OK to introduce the regional collaborative to LEND and promote Genetics becoming part of</li> </ul>	The HRCC will add the FY 09-10 Project Narrative to the website in the next week.

Agenda Item	Discussion	Action
	<p>LEND curricula across the region.</p> <ul style="list-style-type: none"> <li>• Family Resources Guide—Project Lead is Sookyung Shin</li> <li>• Genetics in Nursing Modules—Project Lead is Mary Ann Coffman</li> </ul> <p>Goal 3</p> <ul style="list-style-type: none"> <li>• GSA—in progress; project lead Ann Chou</li> <li>• Evaluation of NBS Exchange—in progress; Barb Jackson</li> <li>• Back-up testing project—in progress; Project Leads are Stan Berberich and Patrick Hopkins</li> <li>• Transition –Project Lead is Mary Ann Coffman</li> <li>• Sarah Lawrence Scholarship Program to be offered later this fall</li> </ul> <p>Goal 4</p> <ul style="list-style-type: none"> <li>• Link with FQHC as suggested by HRSA Office of Performance Review</li> </ul>	
Consultant	<p>Data Linkage Project—Commitment from Amy Brower as a private consultant. This project is result of the \$75,000 in supplemental funding provided by HRSA to conduct a needs assessment and future planning for NBS data linkage in all states.</p> <p>Financial Resources Guide—Advocates believe in the project, but as the project moved forward, they discovered that it would take substantially more time to complete than they could provide. After no objections by the Advocates, Sookyung Shin (who developed the original guide for OK) was selected and has agreed to be the project lead. The HRCC will also provide a GRA (10 hrs/wk) for additional support.</p>	
Agenda for Face to Face Meeting	<p>(Draft agenda attached)</p> <ul style="list-style-type: none"> <li>• Revision of “Vision Statement”</li> <li>• Barb Jackson has developed a survey for Board members to complete in advance of the meeting. It will be an online survey in SurveyMonkey and will be sent in the next few weeks.</li> <li>• Open Mic—provide an opportunity for non-Board members who attend the meeting to ask questions and provide feedback. It was suggested that this might be a good idea for the plenary session as well.</li> </ul>	<p>Please send any “code of ethics” models to Julie Miller and Kim Piper in advance of the conference.</p> <p><a href="mailto:Julie.Miller@nebraska.gov">Julie.Miller@nebraska.gov</a>  <a href="mailto:kpiper@idph.state.ia.us">kpiper@idph.state.ia.us</a></p>
Board Members Terms of Service and Nominations	<p>Rotation of Board members results from a suggestion from HRSA. HRCC is seeking nominations for members whose two-years is expired and for positions that are unfilled. There is an open call for nominations and self nominations are</p>	<p>The HRCC make nomination announcement via the Heartland ListServe in the next week.</p>

*Heartland Genetics and Newborn Screening Collaborative*

<b>Agenda Item</b>	<b>Discussion</b>	<b>Action</b>
	<p>acceptable. Term of service is two calendar years.</p> <p>An ad hoc nomination committee will review the nominations and make recommendations to the Advisory Board and the RCC. Volunteers for the nominating committee are Jamey Kendall, Barb Schweitzer and Kim Piper.</p> <p>Julie Miller suggested that a “charter” of Advisory Board scope, responsibilities and expectations be developed.</p> <p>List of Board Membership attached.</p>	
Next meeting	<p>Upcoming Heartland Meetings: Heartland Annual Meeting—September 16-18, 2009—Little Rock, AR Monday, October 12, 2009 Monday, November 9, 2009</p>	

**Attachments:**

- Annual Meeting Agenda
- Project Narrative (FY 09-10)
- Board Membership List