

**Advisory Board Meeting  
Wednesday, February 9, 2011**

**Meeting Summary**

**Members:** Jamey Kendall (KS), Julie Luedtke (NE), Sharmini Rogers (MO), Lucy Fossen (SD), Barb Schwietzer (ND), JoAnn Bolick (AR) and Holly Johnson (AR)  
**Guests:**, Barb Hemmelman (SD), Darlene Bergeleen (SD) and Jill Shuger (HRSA) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
Non-Competitive Renewal	<p>Lori Williamson drafted a narrative with some input from the Advisory Board. The following areas need additional input from the Advisory Board:</p> <ul style="list-style-type: none"> <li>• <b>IBEM-IS:</b> Julie Luedtke asked if fees are to be included for data entry. Lori commented that Region 4 submitted an application to the NIH for funding, but awards have not yet been announced.</li> <li>• <b>Telemedicine for Genetics Residents:</b> Barb Schweitzer commented that there are no genetics residents in North Dakota, so she is unsure of the purpose. Lori said this would primarily be a planning year and the project would target residents in training programs or new MDs in genetics. It would teach them to use and set up a telemedicine clinic and to a physical exam. Brad Schaefer also commented the project could provide technical assistance to anyone interested in doing telemedicine. Jill Shuger said this would be a good project that emphasizes the strength and knowledge of telemedicine in the Heartland and Western Regions.</li> <li>• <b>NBS Back-up Testing:</b> What are the next steps? Julie Luedtke said the project should move into long term planning. Sharmini Rogers commented that a drill every year would be ideal. She also thought partnering with other regions would be good. Julie asked about the capacity to back-up more than one state. Lori said all of this would be discussed with Stan Berberich and Patrick Hopkins.</li> <li>• <b>Data Linkage Project:</b> Is the next step for Barb Jackson monitor changes in each state over the next 2-3 years. States have commented that the final reports have not been submitted to the states.</li> <li>• <b>PKU Camp:</b> Heartland is not planning indefinite funding, so it has been recommended to the PI of the pilot project that alternative funding be found. Barb Schweitzer said that she would be interested in helping to plan a camp</li> </ul>	<p>Brad Schaefer and Lori Williamson will revise the draft and send it back by email to the Advisory Board for comments and suggestions.</p>

	<p>for ND, SD and IA. Julie Luedtke suggested that maybe there should be a “north” camp and “south” camp to cover the whole region.</p> <ul style="list-style-type: none"> <li>• NBS Statewide Conference: Lori said that she polled the State Genetics Coordinators to explore the interest level. Out of the responses, 3 options were presented. Julie Luedtke commented that the options could be formed into a logical progression. It will be important to get genetics/NBS on the agenda for a statewide meetings, as it is more effective that holding a separate meeting. The idea of working with PCPs in each state to identify a “chapter champion” and invite them to attend the APHL meeting would be best and simplest to implement. It would also be a way of incorporating Medical Home principles across Heartland. Mary Ann Coffman commented that the transition project will also involve PCPs and pediatricians in the community.</li> <li>• Sarah Lawrence: There is one remaining person who is interested in attending. Should Heartland provide funding and discontinue the scholarship program? Several State Genetics Coordinators commented that they would not be able to attend, even with Heartland funding.</li> </ul>	
Advisory Board Vacancies	<p>With the new Advisory Board structure, there are 8 open at-large positions. Brad Schaefer suggested the current members should move into the open positions. As, co-Program Director, Dr Schaefer will give up his position on the Board. Lori Williamson asked about the other nominees. Klaas Wierenga asked who should fill the spots. The HRCC can help identify candidates, but it is the Advisory Board’s decision. Lori suggested that the nominating committee meet to discuss the nominees. Julie Luedtke asked for 2-3 weeks to have time for the states to have outreach to explore possible candidates. Jamey Kendall asked if the current members should be contacted to see if they are interested in retaining their position. Dr Schaefer said yes, they should be asked.</p>	<p>Shona Whitehead will contact the nominating committee to set up a conference call.</p>
Report from SACHDNC meeting	<p>See included report from Lori Williamson and visit <a href="http://www.hrsa.gov/heritabledisorderscommittee/meetings/2011january/default.htm">http://www.hrsa.gov/heritabledisorderscommittee/meetings/2011january/default.htm</a></p>	
Work Group Leadership	<p>Tabled for next meeting</p>	
<i>Preserving the Future of Newborn Screening</i>	<p>Tabled for next meeting</p>	

Next Meetings		March 9, 2011 2:00 pm April 13, 2011 2:00 pm
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