

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

**Meeting Summary**

**Members:** Kim Piper (IA), Sharon Vaz (OK), Leslie Himstedt (AR), Jamey Kendall (KS), Julie Luedtke (NE), Sharmini Rogers (MO), Lucy Fossen (SD), Barb Schweitzer (ND), JoAnn Bolick (AR) and Holly Johnson (AR) **Guests:** Barb Hemmelman (SD), **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
Pilot Project Review and Selection	<p>(Advisory Board members who were applicants or co-applicants were not involved in the final selection of projects to fund.) A quorum was confirmed, however.</p> <p>Lori explained that two reviews were incomplete. In order to determine how the incomplete score might affect the review, Lori and Shona assigned a mock “perfect” score to the incomplete category. Applying this “best case scenario” did not raise either project’s score to the level of the top two. There remained a clear demarcation between the top two scores and the others. Discussion, questions, and comments were sought.</p> <p>Julie Luedtke was in support of funding the two projects with the highest scores. A vote was conducted by eligible Board members and all voted in favor of funding the top two projects.</p>	The HRCC will announce the projects selected and all applicants will receive copies of their project reviews.
Advocate Position Statement	<p>The Advocates have worked on two statements related to dried blood spots; one for the NBS work group and the other for other parents. Heartland leadership wanted to make sure the Advisory Board was aware of the public statement before it was disseminated.</p> <p>Sharmini Rogers commented that she liked the use of the word “sample” instead of DBS and suggested the language be consistent in both statements. Sharon Vaz said that the confidentiality of information section should be expanded to include state specific information, not just GINA. She also suggested that it should say “at this time there is no cost to the family”. Julie commented that the storage of spots varies by state and research is done with de-identified information and in most instances consent from the parent.</p>	Lori Williamson will make suggested edits and comments to the public statement and it will be returned to the Advocates for discussion during their next work group meeting.

	<p>Klaas Wierenga commented that the statements could be very useful and appreciated the work done by the Advocate Work Group. Lori said the Advocates should be credited with the work they have done and the Advisory Board should be aware of the public statement before it is posted to the Heartland website or more widely distributed.</p> <p>Julie suggested that these comments should be presented to the Advocates and after any update the Advisory Board has the opportunity to review the statement one more time. Lucy Fossen and Kim Piper said that they would both like to review the statement for accurate information about their respective states before the statement is distributed.</p>	
<p>Work Group Leadership</p>	<p>The HRCC is seeking advice from the Advisory Board on the leadership structure for the work groups. Originally the work groups were led by a volunteer chair, but the time demands were too great, so the HRCC then started facilitation of the work groups. During the leadership transition and in preparation for the annual meeting in Des Moines, volunteers were identified to help facilitate the work group meetings and those volunteers were morphed into chairs for the work groups. As a result there was some confusion about roles and responsibilities among the leadership team and the work group members.</p> <p>Julie Luedtke said that when the work groups have specific projects then much work is done, but leadership is needed when a work group has no goal or priorities for new projects. Kim Piper asked how the other collaboratives structure their work groups. Lori commented that it varies by region and some regions are very directive, but Heartland has strived to be more grassroots.</p> <p>Sharon commented that she felt the NBS work group was working fine with its current structure, but was not familiar with the other groups and if there were issues.</p> <p>Brad Schaefer suggested that we keep the current arrangement which seems to be playing out as a hybrid (with chairmen and HRCC guidance) and that the structure is revisited at the next annual meeting.</p>	

<p><i>Preserving the Future of Newborn Screening</i></p>	<p>The regional collaboratives have been approached to join the <i>Preserving the Future of Newborn Screening</i> coalition. Several other regions have joined and HRSA does not disapprove of collaborative involvement. Members wish to look at the website and learn more about the coalition before deciding if Heartland should be a member. <a href="http://www.newbornbloodspots.org">www.newbornbloodspots.org</a></p>	<p>Shona Whitehead will send Kelly Leight’s PowerPoint.</p>
<p>Genetic Alliance Family Health History Grants</p>	<p>Genetic Alliance announced that it would be making six \$40,000 awards for the Family Health History project. If an entity in Heartland is applying for funding, the HRCC will write a letter of support, if appropriate. Application deadline is April 4, 2011.</p>	
<p>Next Meetings</p>	<p style="text-align: center;"><b>**Save the Date**</b> 8<sup>th</sup> Annual Heartland Genetics and NBS Collaborative Conference August 24-26, 2011—Bismarck, ND</p>	<p>April 13, 2011—2:00 pm May 11, 2011—2:00 pm</p>