

**Advisory Board Meeting  
Wednesday, April 13, 2011**

**Meeting Summary**

**Members:** Barb Schweitzer (ND), Majed Dasouki (KS), Amy Brower (SD), Lucy Fossen (SD), Jamey Kendall (KS), Jackie Whitfield (AR), JoAnn Bolick (AR), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Holly Johnson (AR), and Sharon Vaz (OK) **Guests:** Barb Jackson (NE) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
Advocate Position Statement	<p>Julie Luedtke submitted a comment via email before the meeting: “I would recommend the information refer people to their State’s Newborn Screening Program instead of the genetic centers. The program’s are the ones most familiar with the blood spot storage and use policies and procedures“. Barb Schweitzer commented that with the new edits and the one additional edit to make, it is over all a good document. Lucy Fossen said that SD doesn’t store DBS cards and has no provision to do so. Klaas Wierenga commented that a document like this moves the conversation about DBS forward. Amy Brower suggested that a “preamble” be written by the Advisory Board that also includes info from national reports and FAQs about state storage policies. Lori Williamson said that the advocates wanted to create something “by parents, for parents”. Majed Dasouki commented that this type of statement is proactive and can encourage parents to ask questions of the state programs and legislatures. Sharon Vaz said she is ready for any potential calls from parents or state legislators. Jamey Kendall commented that it important and valuable to have the state programs involved in the conversation about DBS.</p> <p>Once a final version is completed it will be sent to the Advisory Board by email for approval.</p>	<p>Amy Brower will draft a “preamble” and send it to Shona Whitehead so it can be distributed to Advisory Board members for input.</p>
Heartland updates	<p><i>Data Linkage Project</i>—Amy Brower has provided hard copies of the draft report to 5 states and will email the remaining 3 states. Conference calls are being scheduled with the states to discuss the reports and make edits. A summary report of all the results will be provided to the HRCC.</p> <p><i>GSA meeting</i>—A face to face meeting of the GSA Steering Committee and Expert Panel was held in Kansas City, MO April 6-7. Much of the time was spent reviewing</p>	

	<p>the current measures and assigning scoring weights to each measure. A preliminary timeline to begin initial implementation in the Heartland states in the next 4-5 months was developed.</p> <p><i>NBS Workshop</i>—All but one of the Heartland states was represented through the 35+ attendees at the NBS workshop in Kansas City, MO April 7-8. Speaker presentations included: steps to implement LSD screening in MO, pilot study results in screening for SCID and effective long term follow-up in NBS programs. Amy Brower commented that attendees were able to hear from national leaders in these areas. Lori Williamson said that all the speakers and content was excellent. Some PowerPoint presentations will be available in the next few weeks.</p> <p><u>Work Groups</u></p> <p><i>Advocates</i>—The Advocate Work Group is beginning to develop a project around individual health plans for children and youth with genetic conditions. The project is in its infancy, so goals and objectives are still being discussed. Long-term this project could potentially be coordinated with the transition pilot project.</p> <p><i>Clinical Services</i>—The survey of clinical services in the region is basically complete and the distribution list is being developed. State Genetics Coordinators will have an opportunity to review the distribution list. Some additional questions about Medical Home may be added to the survey.</p> <p><i>EHDI</i>—The state EHDI coordinators have met once by phone and face to face at a national EHDI conference. The next steps are to discuss additional members to invite to the group and to set a regular meeting schedule.</p> <p><i>Medical Home</i>—This group had an initial conference call April 7<sup>th</sup>. The group is comprised of a variety of participants, including geneticists, genetic counselors, pediatricians and public health representatives.</p> <p><i>NBS</i>—Wrapped up face to face meeting last week and is exploring evaluation of performance measure tools for NBS programs.</p> <p><i>Transition</i>—The project is progressing quickly, 2 clinical centers have been identified and are working with Dr Laura Pickler and the National Health Care</p>	
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	<p>Transition Center. A face to face meeting of the clinical leads will take place April 27<sup>th</sup> in Oklahoma City and a June project meeting with Dr Pickler in Denver. IRB application being finalized and parent or youth advocate are being selected.</p> <p><i>Strategic Planning</i>—Lori Williamson and Barb Jackson are mapping out a plan to being strategic planning for the upcoming competitive renewal. Two proposals will be presented to the Heartland Leadership Team April 14<sup>th</sup> and will be discussed with the Advisory Board in May.</p>	
<i>Preserving the Future of Newborn Screening</i>	<p>Barb Schweitzer commented that Kelley Leight was helpful as new legislation in ND was been discussed.</p> <p>Advisory Board members voted verbally (10 yes, 0 opposed, 1 unsure) to approve the Heartland Collaborative in joining the coalition.</p>	Lori Williamson will contact Kelley Leight to notify her of the Advisory Board’s decision.
Other	<p>Advisory Board Nominations—does the nomination committee need to re-convene to discuss the current and new submissions? Time has elapsed since they approved the original nominations and did not take into consideration the recently approved by-laws. Nomination committee is: Jamey Kendall, Kim Piper and Barb Schweitzer.</p>	Shona Whitehead will contact the nomination committee for a conference call and the recommendations will be discussed during the May 2011 Advisory Board meeting.
Next Meetings		<p>May 11, 2011--2:00 pm</p> <p>June 8, 2011--2:00 pm</p>