

**Advisory Board Meeting
Wednesday, May 11, 2011**

Meeting Summary

Members: Barb Schweitzer (ND), Leslie Himstedt (AR), Amy Brower (SD), Lucy Fossen (SD), Julie Luedtke (NE), JoAnn Bolick (AR), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Holly Johnson (AR), and Sharon Vaz (OK) **Guests:** Jill Shuger (HRSA), Karen Eveans (NE), Barb Hemmelman (SD) and Barb Jackson (NE) **HRCC:** Klaas Wierenga, Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
NBS Clearinghouse report	<p>Karen Eveans provided a detailed update of the NBS Clearinghouse. Highlights include:</p> <ul style="list-style-type: none"> • A NBS Quality Indicators project is underway, with a focus on STFU and Lab, but not LTFU. The project is being coordinated by HRSA, Genetic Alliance and APHL. A preliminary report is to be provided to SACHDNC during the September 2011 meeting. • NBS Clearinghouse website—still running the beta version. New information about specific conditions has been added. Increased used of twitter and other social media to increase traffic to the website. BlenderBox was the company awarded the contract to develop the new site: babysfirsttest.org. Anticipated go live date is September 2011. • NBS Clearinghouse Work Groups: <ul style="list-style-type: none"> ○ Materials Group—has a continuing discussion on how to keep information up to date ○ Public Education—is focused on identifying key NBS topics • \$25,000 Challenge Grant award winners were: March of Dimes, NYMAC, Hawaii Department of Health and APHL. Each project is designed to be completed in six months. <p>Klaas Wierenga asked if the NBS Clearinghouse was using Facebook and was it linked to the website? Karen was unsure. Sharon Vaz commented that Genetic Alliance has a Facebook page.</p> <p>Julie Luedtke asked why the NBS Clearinghouse website didn't just link to the state program web pages for NBS info, as the states will likely have the most up to date</p>	

	<p>information. She also inquired if other video vignettes by other organizations, like Save Babies were being included. And what about other credible sources of information, that may not have obvious ties to Federal funding?</p>	
<p>Strategic Planning</p>	<p>Barb Jackson will be assisting the HRCC and the Collaborative as a whole with strategic planning for the next five years and the upcoming competing renewal. Barb said that the strategic planning will be in 3 phases:</p> <p>Phase One:</p> <ul style="list-style-type: none"> • Brainstorm SWOT (Strengths, Weakness, Opportunities and Threats) • Revisit mission and vision statements <p>Phase Two:</p> <ul style="list-style-type: none"> • Send SWOT, Mission, Vision (Draft) and Values (Draft) to general collaborative membership to review and suggest edits. In addition have them generate a list of priority areas. • Send out the edited priority areas and have the general collaborative identify their top areas. This will be conducted via SurveyMonkey. <p>Phase Three:</p> <ul style="list-style-type: none"> • Annual meeting presentation • Round robin discussion to develop actions for top themes for competing renewal <p>SWOT discussion: Broad themes from conversations with State Genetic Coordinators were included on the handout to begin the discussion. See attached SWOT handout to review comments from Advisory Board members.</p>	<p>Email will be sent to the Advisory Board and general Heartland membership for further info and feedback on the SWOT</p>
<p>Telehealth meeting report</p>	<p>Lori Williamson submitted a written report to the Advisory Board via email, which included information about telemedicine in the other regions. After the conclusion of the American Telemedicine Association meeting the NCC Telehealth work group met which provided a great opportunity to share and discuss areas of interest and potential future opportunities.</p>	

<p>SACHDNC meeting report</p>	<p>Heartland representatives in attendance: Barb Schweitzer (ND), Carol Johnson (IA), Amy Brower (SD) and Lori Williamson (OK). Lori Williamson submitted her unofficial notes from the meeting in written form to the Advisory Board via email. She reiterated her notes are not official and encouraged to everyone to visit www.hrsa.gov/heritabledisorderscommittee/ for the official minutes from the committee.</p> <p>Highlights:</p> <ul style="list-style-type: none"> • A new manuscript has been accepted for publication regarding DBS storage, retention and research. • CCCHD not ready to be adopted due to implementation concerns 	<p>The HRCC will notify the Advisory Board when the official meeting minutes are available online.</p>
<p>State Legislative Updates</p>	<p>A new standing agenda item for the Advisory Board, resulting from a survey circulated by the NCC and legislative updates are a standing agenda item on the PD/PM/NCC monthly calls.</p> <ul style="list-style-type: none"> • North Dakota—State Legislature requested ND DOH to add “genetic/metabolic disease” to NBS notifications • South Dakota—nothing to report • Nebraska—now requires mandatory blood lead levels before kindergarten for all children, parents can opt out. Exploring legislation for genetic counseling licensure in the next session • Oklahoma—introduced a bill for an adult sickle cell center • Arkansas—state required to establish an adult sickle cell center • Missouri—CCCHD screening passed in the state house; create a sickle cell task force and provide coordination for an umbilical cord blood storage • Iowa—DOH to develop materials to educate parents about umbilical cord blood storage; currently facing a state budget standoff • Kansas—no one on call to report 	
<p>Other</p>	<p>Sharon Vaz inquired about the status of the Advisory Board nominations.</p>	<p>Update from the nominating committee will be on the June agenda</p>
<p>Next Meetings</p>	<p style="text-align: center;">**Heartland Annual Meeting** August 24-26, 2011 Bismarck, North Dakota</p>	<p>June 8, 2011--2:00 pm July 13, 2011—2:00 pm</p>