

**Advisory Board Meeting
Wednesday, June 8, 2011**

Meeting Summary

Members: JoAnn Bolick (AR), Jackie Whitfield (AR), Kim Piper (IA), Michelle Black (KS), Sharmini Rogers (MO), Barb Schweitzer (ND), Mary Riske (ND), Lucy Fossen (SD), **Guests:** Darlene Bergeleen (SD), Barb Hemmelman (SD), Jill Shuger (HRSA), Barb Jackson (NE), John Mulvihill (OK) and Mark Smith (NE) **HRCC:** Brad Schaefer, Lori Williamson, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
Genetic Systems Assessment Project update	<p>John Mulvihill reported that the GSA project is on schedule. The Kansas City meeting in April helped prioritize the final measures. An abstract was submitted to the International Congress in Human Genetics (ICHG) meeting in October. Expect final version in about a month. Then three months for Heartland states to implement.</p> <p>Mulvihill asked the group if this will be ready to “go national” in the competing cycle, based on implementation in Heartland? Jill Shuger commented that it should be added to the agenda for the monthly calls with the NCC. Lori Williamson asked if it was premature since it has not been implemented in Heartland. Mulvihill responded that given the timing of funding cycles, this may be the right time to get it on the plate. Brad Schaefer commented this is the time to peak interest in the tool. Mulvihill would be prepared to present an update at the November PD/PM meeting.</p>	
Advocate DBS statement	<p>Mark Smith commented that the purpose of the Advocate’s statement is to wholly support DBS screening, storage and research by the states. The statement can serve as a fall back for collaborative members as documentation of parents’ support of the state NBS programs. It shows that parents feel this is an important issue that needs to keep moving forward. The advocates continue to stand by their work.</p> <p>Sharmini Rogers had submitted comments via email, indicating that she feels that broad information is better, with fewer specifics, since each state has its own laws and regulations.</p> <p>Jill Shuger commented that it may be of interest of the Preserving NBS organization.</p>	

<p>Strategic Planning update</p>	<p>a. Draft Values Statement--See attachment. Lori Williamson commented that a vote is not needed as now is the time for review and feedback. Barb Jackson said a more final version will be included with the online survey. Jill Shuger said that priorities will be gleaned from the regions to be included in the competing renewal guidance. Lori indicated that these are specific values to Heartland, not just the Genetic Services Branch and are broad values for the region. Barb commented that this list of values creates a baseline which will shift based on the response to the guidance.</p> <p>b. Draft Vision Statement—See attached. Lori Williamson thanked the ad hoc group which worked quickly and efficiently to draft several options for members to review. Sharmini commented that she liked #2 and the terms, “seamless network”, indicating a transition. Jackie Whitfield said that she had reviewed the options with Dr Patricia Scott and they both liked #2.</p>	
<p>Advisory Board nominations</p>	<p>Kim Piper said the ad hoc group reviewed the nominees and did additional recruitment. Factors they considered were: experience, background and distribution of members by state. All nominees have been contacted (except Joni Bosch). See attached for list of nominees.</p> <p>Brad Schaefer called for a vote of the Advisory Board members present and none were opposed the nominees.</p>	<p>The HRCC will draft a letter to the new members and invited them to the Annual meeting. Thank you letters will also be sent to the members who have terms are up.</p>
<p>PD/PM/NCC/HRSA meeting report</p>	<p>The mid-year meeting of the PD/PM/NCC/HRSA took place June 6th in Chicago. The overall themes of the meeting were:</p> <ul style="list-style-type: none"> • Medical Home (AAP) • Transition (National Health Care Transition Center) • Evaluation (Data Resource) • Advocacy (Sickle Cell) <p>And centers of expertise presented in all these areas.</p> <p>Jill commented the all budgets for the collaboratives will be funded at their full requested amounts, but there will be no awards for supplemental funds that had been requested. Each region has also been granted a one-month no cost extension.</p>	
<p>State Legislative updates</p>	<p>Arkansas reported that the state legislature has allocated funding for an adult sickle cell clinic at the University of Arkansas for Medical Sciences.</p>	

Heartland Genetics and Newborn Screening Collaborative

Other	Travel to Bismarck for the annual meeting will likely be more expensive than previous years, so clear instructions will be given to funded attendees regarding the travel-related expenses that will be covered this year.	
Next Meetings	July 13, 2011—2:00 pm August 10, 2011—2:00 pm Heartland Annual Meeting—August 24-26, 2011—Bismarck, ND	