

## Advisory Board Meeting Monday, February 8, 2010 Summary

**Attendees (5 members absent):** Barb Schweitzer (ND), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Larry Weatherford (OK), Brad Schaefer (AR) and Sharon Vaz (OK) **Guests:** Barb Jackson (NE) and Jill Shuger (HRSA) **RCC Staff:** John Mulvihill, Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Telemedicine Manual update	After much work by many people the Heartland Telemedicine Manual has been sent to the printer. Once printed it will be disseminated to the other Regional Collaboratives and HRSA. An electronic version will also be available on the Heartland website; initially as a PDF and later a searchable document. Jill Shuger requested that HRSA and NCC be notified once it is finished.	
Pilot project award decision	Based on the scores and priorities and goals of reason and nature, it was decided that the PKU camp and iLibrary proposals would be funded.  Questions were raised about possibly funding a portion of the Family Voices conference proposal, but the consensus was to only fund the top two projects and provide funding for advocates to travel to the Family Voices conference.	Award notices will be sent to the top two projects approved for funding and regrets and project critiques to other project authors.
Prioritization of 2010-2011 Activities	The Board's ranking results were discussed and agree upon. Some projects are not as expensive as others, so it may be possible to include some additional projects that are ongoing.  The Sarah Lawrence scholarship was not ranked high and there are some concerns that the curriculum and program may not be as strong as it once had been. If the program is strengthened it may be worthwhile to consider again next year.	
ACHDNC update	Jamey Kendall's notes were provided in advance of the call. Jill Shuger commented that the official committee minutes will be posted on the committee website <a href="http://www.hrsa.gov/heritabledisorderscommittee/">http://www.hrsa.gov/heritabledisorderscommittee/</a> .  Jamey commented that the committee is recommending to the Secretary that SCID be added to the core uniform screening panel. Amy Brower also suggested reading the sub-committee reports when they are available.  Seats on the Advisory Committee are open and nominees to fill the positions are being accepted. (See attached email)	

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<p>Updates on consultant and work group activities</p>	<p>Data Linkage Assessment Project— Amy Brower                      Site visits are being finalized for the first two states (AR and KS). Methodologies have been confirmed, assessment will be based on metrics from PHII and other LTFU standards. The goal is to complete all states by the end of May, providing a report at the annual meeting in September 2010 and possibly an interim report at the NCC/PD/RC meeting in June 2010. This project may be ready to “go national”.</p> <p>Genetics Education for Nurses--Mary Ann Coffman                      Sandy Daack-Hirsch from the University of Iowa College of Nursing has been selected to help schools of nursing within the region who will be applying for accreditation to expand their genetics and genomics curriculum. She will also help identify a “genetics champion” at each school.</p> <p>Transition—Mary Ann Coffman                      Mary Ann has been in contact with D-70 grantees within the region (particularly MO and KS) to discuss how to collaborate on transition activities. The initial idea is to offer a workshop focused on transition that targets AAP and AAFP members and family advocates.</p> <p>Clinical Genetics Survey—Mary Ann Coffman                      Is developing a survey of clinical genetics services in the region. The Clinical Services work group provided core questions during the annual meeting in September 2009.</p> <p>Med Home Portal/CME/PCP Education—Mary Ann Coffman                      Plans to identify a core group of primary care physicians throughout the region to assist in identifying the three genetic conditions to add to MedHome Portal. This same group of “physician champions” will help develop strong partnership to promote access to quality care for children and youth with genetic conditions. The key is to develop a survey and identify physicians through health professional groups and associations that already work or advocate for CYSHCN.</p> <p>Work Groups—Shona Whitehead                      Advocates—are working on a position statement regarding dried blood spot retention.                      Clinical Services—will be helping Mary Ann finalize and disseminate the survey                      NBS—is planning agenda for Spring workshop                      Education—meets only as needed</p>	

*Heartland Genetics and Newborn Screening Collaborative*

<b>Agenda Item</b>	<b>Discussion</b>	<b>Action</b>
Mission/vision statement	<p>The mission statement has been revised to read:</p> <p><i>The Heartland Genetics and Newborn Screening Collaborative is focused on ensuring the best possible outcome for individuals with heritable disorders and optimizing the health of the population throughout the life cycle by improving understanding and awareness of genetics; expanding access to health care; and translating new findings to improve the quality of care within an eight-state region.</i></p> <p>The committee who revised the statement reviewed the other collaborative's mission statements during the course of their work. The next step is to work on the vision statement.</p>	
Review of board member nominations accepted	<p>Previous nominees were accepted and an additional call for nominees will be sent with the goal of filling the remaining openings. Barb Schweitzer volunteered to continue serving as the NBS Coordinator representative.</p>	<p>The HRCC will notify the nominees of their acceptance and remind Board members of remaining vacancies.</p>
Non-competitive renewal update; Project Director choice	<p>After some discussion, Advisory Board agreed to review a suggestion that John Mulvihill set forth. He agreed to send that suggestion for review.</p> <p>Non-competitive renewal is due March 9 and March 23, 2010.</p>	<p>Mulvihill awaits preview of that suggestion by Michele Puryear.</p>
Next meeting		<p><b>Monday, March 8, 2010 at 2:30 pm</b></p>