

**Advisory Board Meeting
Wednesday, October 13, 2010**

Meeting Summary

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

Agenda Item	Discussion	Action
Welcome		
Annual Meeting Wrap-up	<p>Shona Whitehead commented that all the presentations from the speakers in Des Moines are now available on the Heartland website. www.heartlandcollaborative.org. The conference evaluation summary is also online. A majority of expense reimbursements have been processed and checks mailed sometime next week.</p>	
Heartland Coordinating Center Structure	<p>Brad Schaefer announced that he, Dr Wierenga, Lori Williamson, Mary Ann Coffman and Shona Whitehead had a conference call last week to discuss the roles and responsibilities of each person in coordinating and sustaining Heartland projects. Drs Schaefer and Wierenga serve as co-Program Directors and Dr Mulvihill will serve as a senior advisor. A draft of the projects and the HRCC staff contact was sent prior to the meeting.</p> <p>Both Lucy Fossen and Sharon Vaz commented this list will be very helpful. Mary Riske asked if it would be best to contact the person in the first column with questions about that project. Yes, that is the initial plan.</p> <p>Schaefer commented that this is a dynamic list and changes will be made as needed. It was also decided on the call last week; the five HRCC staff will have a conference call every other week to discuss relevant issues or projects.</p> <p>In addition, staff contacts for the Work Groups were also listed. It seems that the committee structure with a committee chair has been revitalized and the volunteer chairs were listed. These chairs are not permanent and can be changed as needed. Lori Williamson will be re-establishing the Education and EHDI work groups if warranted.</p>	<p>Please send any comments, questions or edits of the <i>HRCC Projects and Contacts</i> list to Shona (shona-whitehead@ouhsc.edu) by Monday, October 18.</p>

<p>NBS Clearinghouse</p>	<p>NBS Clearinghouse is funded by HRSA through Genetic Alliance. Lori Williamson is currently serving on the Clearinghouse’s Advisory Council as the representative for NSGC and by default Heartland. However, if there is someone else who is interested in serving as the Heartland representative, nominations are being accepted. The Clearinghouse Advisory Council meets by conference call quarterly for two hours. Previously, 3 state genetics coordinators had expressed interest, so the HRCC would like to confirm this continued interest. Ideally the representative should be a state genetics coordinator or an NBS coordinator. Nominations should be submitted to the HRCC and the Advisory Board will make a decision during the November conference call.</p>	<p>If interested in submitting a nomination, please send the name to Shona at shona-whitehead@ouhsc.edu.</p>
<p>NCC Work Groups</p>	<p>A question has been asked: Who are Heartland’s representatives for the National Work Groups and are they actively reporting back to the Advisory Board or HRCC? Some people from the region may be participating in the work groups, but not as an official Heartland representative. How would the Advisory Board like to receive information about these work groups? Oral report? Written summary? Meeting minutes?</p> <p>Suggestions for reporting included: a paragraph update after each meeting submitted to HRCC; rotate an oral report from each NCC work group at each Advisory Board meeting; update Heartland website with National Work Group information.</p> <p>NCC work group representation as of 6/3/10 is attached.</p> <p>Amy Brower suggested that we include the NBSTRN work groups, as well. Shona will provide Lori with that list. Lori will work to clarify any vacancies, confirm representation, and communicate with designated reps of both the NCC and NBSTRN work groups.</p>	

Other	<p>Charter ad hoc work group—has met and has a working first draft. Follow-up conference call will take place October 20th. A draft may be available for comment by the November Advisory Board call.</p> <p>Barb Jackson also commented that the National Performance Measures data will need to be collected in the next few months. In an attempt to be proactive, Barb will contact Gloria Weissman at the NCC to make sure there are no changes and confirm the timeline.</p>	
Next Meetings	NEW DATE and TIME: 2 nd Wednesday of each month at 2:00 pm CDT	November 10, 2010 2:00 pm December 8, 2010 2:00 pm