

**Advisory Board Meeting  
Wednesday, December 8, 2010**

**Meeting Summary**

**Members:** Barb Schweitzer (ND), Leslie Himstedt (AR), Lucy Fossen (SD), Jamey Kendall (KS), Jackie Whitfield (AR), Kim Piper (IA) and Sharmini Rogers (MO)  
**Guests:** JoAnn Bolick (AR), Darlene Bergeleen (SD), Barb Hemmelman (SD), and Barb Jackson (NE) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, and Shona Whitehead

Agenda Item	Discussion	Action
Welcome		
NCC/RC/PD/PM meeting update	<p>Lori Williamson reported that she attended the NCC Publications Work Group meeting on behalf of Shobana Kubendran (Heartland’s official representative). The group is currently working to create a comprehensive bibliography of all publications supported by the regional collaboratives and funded directly by HRSA.</p> <p>The first day of the meeting was spent as a continuation of the strategic planning meeting that Brad Schaefer attended in October, including two small group discussions. A summary of these sessions has not been provided to the attendees. On day two, the topics that were highlighted were health care reform and reaching out to the Federally Qualified Health Centers. No direct insight regarding the upcoming guidance for the final year of this cycle was provided.</p>	<p>The HRCC will follow-up with the NCC regarding the outcomes of the strategic planning sessions.</p>
Advisory Board Charter/ Bylaws	<p>Barb Jackson highlighted the key areas in the draft of the Advisory Board Bylaws, specifically focusing on areas where the HRCC had questions.</p> <p><u>Purpose:</u></p> <ul style="list-style-type: none"> <li>• The Advisory Board is to advise the HRCC on matters related to the collaborative.</li> <li>• Online reporting to HRSA: the HRCC will distribute the new forms to the members, as the official online forms are only accessible by the Program Director and OUHSC grants administration. Regular updates on projects and goals will be provided during Advisory Board meetings.</li> </ul> <p>Klaas Wierenga commented that including the word “approval” could potentially cause the HRCC to be sandwiched between HRSA and the Advisory Board, therefore negatively affecting the partnership among all three. Sharmini Rogers said that “advisory” means providing recommendations and input. Jackson commented that much of the discussion in the ad hoc committee centered on what “oversight” actually means and the group felt that it should remain in the document. It was agreed that “approval” would be removed, but “oversight” would remain. Rogers commented that Advisory Board meeting</p>	<p>The Advisory Board membership will vote to adopt or decline the Advisory Board Bylaws during the January 2011 meeting.</p>

	<p>summaries should reflect the Advisory Board recommendations as a matter of record, so that if the grantee disagrees, all positions are documented.</p> <p><u>Membership:</u></p> <ul style="list-style-type: none"> <li>• 19 voting members; including 8 State Genetics or NBS coordinators, 3 advocates and 8 members at large</li> </ul> <p><u>Members Roles:</u></p> <ul style="list-style-type: none"> <li>• Members have 5 general areas of responsibility</li> <li>• Chair and Chair-elect to be selected by the membership will serve for two years.</li> <li>• Board vacancies to be filled within 6 months</li> <li>• The Chair and Chair-elect will not have a specific role in development of the meeting agendas, but will review meeting summaries.</li> </ul> <p><u>Meetings:</u></p> <ul style="list-style-type: none"> <li>• There should be, at minimum, 10 scheduled meetings each year</li> <li>• A majority, plus one, will constitute a quorum.</li> <li>• Any member can suggest a vote for an item</li> <li>• Members must be in attendance to vote</li> <li>• A quorum must be present in order to conduct vote</li> </ul> <p><u>Bylaws Amendments:</u></p> <ul style="list-style-type: none"> <li>• Amendments can be voted on electronically</li> <li>• 14 days written notice of changes must be provided</li> <li>• Bylaws should be reviewed every two years</li> </ul> <p>Jamey Kendall commented that the ad hoc committee has done very good work in developing this document. The HRCC agreed.</p>	
<p>Pilot Project Application</p>	<p>Williamson addressed the IRB questions that were submitted during the Advisory Board’s final review of the application. She explained that applicants do have to submit to the IRB (where applicable) before funding begins, but full IRB approval is not required before begins.</p> <p>The review and suggested revisions provided by the Advisory Board made pilot project application much strong and more inclusive than in previous years.</p>	<p>The Heartland pilot Project application information will be distributed via the ListServe and available online by 5:00 pm on 12/08/10.</p>

<p>Kelly Leight email</p>	<p>A new coalition is being developed entitled: “Preserving the Future of Newborn Screening” and the regional collaboratives have been asked to join. The coalition is still under development and a decision is not needed at this time. HRSA has indicated that the regional collaboratives can indeed join the coalition, provided they do not engage in lobbying activities.</p> <p>Kim Piper commented that IA has changed to an “opt-out” state for research, so if Heartland chooses to support the Preserving the Future of Newborn Screening coalition, it must be on the caveat that states continue to abide by their state policies.</p>	<p>Williamson or Wierenga will attend this group’s meeting to be held in conjunction with the Secretary’s meeting in January</p>
<p>HRSA Sickle Cell Funding Opportunity</p>	<p>The regional collaboratives were notified of a HRSA funding opportunity for Sickle Cell disease. One of the requirements is that applicants work on some level with the Genetics regional collaboratives. The State Genetics Coordinators were asked if they knew of anyone applying from within Heartland, 7 of the 8 states responded that no one from their state was applying.</p> <p>Sharmini Rogers commented that MO doesn’t have a strong relationship with the Sickle Cell organizations, but other states do, so they would be able to apply for this type of funding.</p> <p>Schaefer commented that it is clear that Heartland will need to increase its contacts among non-geneticist personnel that working in overlapping areas, if not in the next non-competing year, but definitely in the competing cycle.</p>	
<p>Federally Qualified Health Centers</p>	<p>As mentioned earlier in the meeting, it is evident that the regional collaboratives are being encouraged to collaborate with the FQHCs in the region. Williamson asked if the State Genetics Coordinators or NBS coordinators would review the list of FQHCs provided and identify which clinics they work with most often. Rogers commented that she works closely with the FQHCs in MO. Jamey Kendall said she could get in touch with the FQHC coordinator at the state health department. Kim Piper indicated she has no direct interaction with the FQHCs in IA, but works with them through other organizations.</p>	<p>States are asked to identify a contact person for the FQHCs and send the information to Lori Williamson at <a href="mailto:lwdean@uams.edu">lwdean@uams.edu</a>.</p>
<p>Medical Home activities</p>	<p>Schaefer would like to explore and increase medical home activities in the Heartland region. He asked what would be the appropriate forum: an official work group or an ad hoc work group or no formal organization? It was agreed that an ad hoc group would be best.</p>	<p>More information will be provided at a later date.</p>

*Heartland Genetics and Newborn Screening Collaborative*

Non-Competitive renewal projects	Schaefer notified the members that no guidance has been released to date and asked for the members to be thinking if there are any projects that should have a higher priority in the next project year or there any projects that should be removed.	
National Workgroups and NBS Clearinghouse	Williamson said that no nominations for a Heartland representative to the NBS Clearinghouse Advisory Committee have been submitted. It was agreed that an announcement seeking nominations will be made during the next NBS work group meeting. National Work Group discussion tabled for next meeting.	
Heartland Strategic Plan Review	Schaefer notified the members that the Heartland Strategic Plan will be sent to the Advisory Board for review, before the end of the year, in order to be in compliance with the national evaluation measures. He apologized in advance for the short turn-around-time.	
Next Meetings		January 12, 2011 2:00 pm February 9, 2011 2:00 pm