

**Advisory Board Meeting
Wednesday, October 7, 2009—4:30-5:30 pm
Summary**

Attendees: Barb Schweitzer (ND), Lucy Fossen (SD), Jamey Kendall (KS), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Larry Weatherford (OK), and Sharon Vaz (OK) **Guests:** Barb Jackson (NE) **RCC Staff:** John Mulvihill, Lori Williamson, Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Mission/Vision Statement ad hoc committee report	<p>The committee is discussing the revised mission statement language via email, and will have a conference call for discussion in November.</p> <p>HRSA does want a vision statement from each region. Not all regions post their statements on their websites, some may be in development.</p> <p>Revisions to vision statement to come after completion of mission statement.</p> <p>The current vision statement has been removed from Heartland website.</p>	<p>HRCC to coordinate conference call for committee and follow up with Ann Chou for sample mission and vision statements and definitions</p>
Work Group Status	<ol style="list-style-type: none"> 1. Education—ad hoc or standing? It was suggested in Little Rock that the Education work group become an ad hoc work group. Most core members serve on other work groups. Concern is that “education” may get lost without a standing committee. Education is a HRSA priority and identified regional need. Julie Miller commented that an aspect of education is already included in all priority projects. Sharmini Rogers said that education is already included in the other work groups. Sharon Vaz indicated that the members should be required to meet as needed. Larry Weatherford said that a similar discussion was had regarding the Policy Committee. The consensus was that the Education Work Group will become an ad hoc work group. 2. EHDI—standing or sub group of NBS? As a self identified group, the EHDI group has requested to be a standing work group. Sharon Vaz believes it should be a standing group. Sharmini Rogers commented that as a standing committee, it continues to keep the EHDI program staff and NBS programs separate. However, Julie Miller commented that there is a drastic difference between the priority work of the EHDI programs and NBS programs. NBS has a large scope. Barb Schweitzer indicated that the ND EHDI coordinator would be interested in 	<p>HRCC to contact Patricia Burk and Jeff Hoffman with the decision and to provide technical assistance.</p>

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	<p>joining the work group. Kim Piper pointed out that IA continues to have travel restrictions and face-to-face meetings maybe difficult to attend. Dr Mulvihill commented that giving the EHDI work group autonomy to “see what they can do” may be a first step. Lori Williamson suggested the Spring 2010 NBS workshop may be an opportunity to bring EHDI and NBS staff together. Consensus was to make EHDI a standing work group and EHDI representatives must be included on the Advisory Board and Advocate Work Group.</p>	
<p>Advisory Board Nominations</p>	<p>Names of nominees have been submitted to the committee. Barb Schweitzer said the committee had questions after the Advisory Board meeting in Little Rock regarding Advisory Board member terms of services, how many members per state and length of service.</p> <p>Nominees are:</p> <ul style="list-style-type: none"> Larry Weatherford—Oklahoma—Advocate Dr. Jakica Tancabelic---Kansas –NBS hematology Dr. C. Maria Riva—Kansas----NBS pulmonary Jeff Hoffman--- Nebraska --- NBS hearing Stan Berberich—Iowa—NBS Laboratory Kim Turner—Iowa—NBS LTFU <p>The goal is have new members in place by the January Advisory Board meeting. The letter of invitation will be sent by HRCC and include information about the development of Advisory Board charter.</p>	<p>HRCC to send committee the current Board member list and Heartland organizational chart</p> <p>The HRCC will send letter of invitation to nominees</p>
<p>ACHDNC Report</p>	<p>Sharon Vaz and Lori Williamson attended the meeting and encourages everyone to download the minutes from the September 2009 meeting when they are available.</p> <p>http://www.hrsa.gov/heritabledisorderscommittee/default.htm</p> <p>Highlights:</p> <ul style="list-style-type: none"> • The subcommittee in LTFU covered overarching topics and will soon be releasing a paper. • Medical Foods Legislation—Sen. Kerry has draft language that will require insurance companies to cover medical foods. • Health Informatics—Public comment is needed on the national NBS coding language standards • NCQA is developing quality measures for NBS and the Heartland GSA project would mesh into a future project. Lori spoke with Ann Chou 	<p>If interested in attending the ACHDNC meeting, please contact Lori Williamson at lori-williamson@ouhsc.edu</p>

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	<p>regarding this and she cautioned Heartland to not “give away” the intellectual property of the GSA tool. NCQA sells their products.</p> <ul style="list-style-type: none"> • Alpha thalassemia • Krabbe—vote was not to add at this time • Preview of Howell and Therrell’s paper—the 1st guideline caused additional discussion. Michele Puryear would like the paper to be reviewed by other agencies before its release • A paper is to be released regarding NBS and health care reform <p>Sharon and Lori also attended the open forum hosted by ACMG, MOD and Genetic Alliance. The webinar is posted on the Genetic Alliance and ACMG websites. Lori recommends that everyone view the webinar. About 250 people were online during the presentation and 60 were there in person.</p> <p>Julie Miller encourages everyone to make public comments when the opportunity arises, since the people developing many guidelines or terminology or reviewing use cases are not “working in the trenches” and need the feedback from those who are on the front line.</p> <p>The HRCC invites interested Advisory Board members to let Lori know if you want to attend the next face-to-face ACHDNC meeting. The previous priority was to send the State Genetics Coordinators. 2010 meeting dates are:</p> <ul style="list-style-type: none"> • Thursday and Friday, January 21-22 • Thursday and Friday, May 13-14 • Thursday and Friday, September 16-17 	
Sarah Lawrence Review Committee	An Advisory Board member is needed to serve on the review committee for the new Sarah Lawrence Scholarship applications. The other committee members are Rachel Grob, Jamie Kim, Kim Piper and Sharmini Rogers. The application deadline is January 15, 2010 so the committee will not meet until end of January 2010.	If you are interested in serving on the review committee please contact Lori Williamson at lori-williamson@ouhsc.edu .
Next meeting	Upcoming Heartland Meetings: 2:30 pm, Monday, November 9, 2009 —Confernce Call	

Attachments: Sharon Vaz’s notes from ACHDNC meeting.