

**Advisory Board Meeting
Wednesday, September 22, 2010
5:00-8:00 pm—Des Moines, IA**

Meeting Summary

Members: Majed Dasouki (KS), Julie Luedtke (NE), Mary Riske (ND), Lucy Fossen (SD), Jamey Kendall (KS), Sharon Vaz (OK), Barb Schweitzer (ND), Leslie Himstedt (AR), Larry Weatherford (OK), Amy Brower (SD), and Holly Johnson (AR) **Guests:** Barb Jackson (NE), Laurie Smith (KS), Ingrid Larson (KS), Michele Lloyd-Puryear (HRSA), and Gloria Weissman (HRSA) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
<p>Advisory Board Structure</p>	<p>Current status of the funding and staff: Funding is remaining at OUHSC. Drs Schaefer and Wierenga are the co-Program Directors. Lori Williamson is working at University of Arkansas for the Medical Sciences with 50% of her time spent on Heartland. Dr Mulvihill will continue as a Senior Advisor and work on the GSA project. A long-range plan is to work together for the competitive renewal.</p> <p>Michele Puryear commented that, in the past, the Hemophilia Coordinating Centers have changed frequently with success and maybe rotation between the states in the region would be good.</p> <p>Term Limits and Governance: Barb Jackson commented that this was an incomplete action step from the Working Together discussion in Little Rock. The following people volunteered to help develop bylaws: Julie Luedtke, Kim Piper, Sharon Vaz, Sharmini Rogers, Larry Weatherford and Leslie Himstedt. They will meet by phone during Oct, Nov and Dec and have draft bylaws ready to share with the Advisory Board by that time.</p> <p>Meeting Schedule: It was agreed that the new date and time for Advisory Board meetings will be the 2nd Wednesday of each month at 2:00 pm.</p> <p>Heartland Conference 2011: North Dakota is hosting and the meeting will be held in Bismarck, ND. Planning committee volunteers will include: Mary Riske, Barb Schweitzer, Kim Piper and Holly Johnson.</p>	<p>If interested in serving on the planning committee for the 2011 Heartland Confernece please contact Shona Whitehead at shona-whitehead@ouhsc.edu.</p>

	<p>Membership: It may be time to not restrict the Advisory Board membership to the current organizational structure. Other areas to consider are Health Information Technology (HIT), addition of new conditions to the core panel and possibly non-voting industry representatives. There should be rotation of members (with exception of State Genetic Coordinators) and assurance that all states are represented.</p>	
<p>Heartland Projects Update</p>	<p>GSA—Pilot tests planned for Washington State and Maryland in the next 6-9 months. State Plans—All State Genetics plans have been completed (except South Dakota) Med Home Portal—Development of new modules has been delayed but not abandoned Telegenetics—Manual complete and disseminated. Available on Heartland website. Clinics between KS and AR via telemedicine successful. Transition—Pilot project under development and will begin January 1, 2011 LTFU for Hearing Loss—The project in South Dakota has been approved by HRSA and is waiting for funding from the current carry-forward request. Emergency Preparedness—Stan Berberich and Patrick Hopkins have now completed functional back-up testing drills with all applicable Heartland states. Data Linkage—Amy Brower is wrapping up the final report Financial Resources Guide—The project had an unanticipated delay and will be completed in this current project year Pilot Projects—Both projects are underway and are expected to be completed on time. The PKU camp was held in July and the six-month follow-up is the next step.</p>	
<p>SACHDNC Attendees</p>	<p>The HRCC budgeted for Heartland members to attend the meetings, but need guidance on who should attend.</p> <p>Mary Riske commented that Public Health representatives should attend when possible. Mary Ann Coffman said that it is clear that consistency is needed and that it is helpful to learn about current and future projects from a national perspective. Michele Puryear commented that representatives from the regional collaboratives are key for feedback to the committee and continued support. Julie Luedtke suggested that whoever attends should make public comments on behalf of the collaborative and that discussion about the upcoming meetings should be an agenda item on the Advisory Board agenda. Also there should be discussion at the meeting following the SACHDNC meeting. Brad Schaefer said that the plan should be to send Lori Williamson each time for consistency and</p>	

	<p>interaction with other collaborative’s Program Managers who attend and rotate the SGCs where applicable. Lucy Fossen commented even though it is unlikely she will be able to attend, she continues to submit the request to the SD Department of Health management.</p>	
<p>Pilot Project Application</p>	<p>The application for the next round of pilot projects is planned to be release at the end of October. Now is the time to make changes to the application.</p> <p>Klaas Wierenga asked if one of the criteria should be that the project idea be novel or innovative. Julie Luedtke said that some of the states are just “trying to keep up” and do the minimum so that is where help is needed the most. Lori Williamson commented that projects are usually a mix of both national and new projects, not able to be included in base-funding. Gloria Weissman suggested that the language in the application may be too “research” oriented and might discourage service projects from being submitted. Sharon Vaz also commented that results from pilot projects should be more clearly reported back to the collaborative.</p>	
<p>Comments from HRSA and NCC</p>	<p>Michele Puryear: HRSA/MCHB/GSB will be conducting strategic planning over the next year, beginning in October 2010. The goal is to look at a life-course approach and hopes to conceptualize the future goals and priorities. This will be a companion piece to Health People 2020, but for genetics.</p> <p>Gloria Weissman: The Publications Work Group has been re-energized and is creating good collaborations between the regions. Shobana Kubendran, who represents Heartland, has been a good addition to the group.</p>	
<p>Next Meeting</p>	<p>NEW DATE and TIME: 2nd Wednesday of each month at 2:00 pm CDT</p>	<p>October 13, 2010 2:00 pm</p>