

Advisory Board Meeting
Monday, July 12, 2010
9:45-10:45 am—Conference Call

Meeting Summary

Members: Barb Schweitzer (ND), Amy Brower (SD), Lucy Fossen (SD), Jamey Kendall (KS), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Holly Johnson (AR), and Larry Weatherford (OK) **Guests:** JoAnn Bolick (AR), Annette Arnold (AR), Darlene Bergeleen (SD), and Barb Hemmelman (SD)

HRCC: John Mulvihill, Brad Schaefer, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
Welcome/Attendance		
Highlights from NCC/RC/PD Meeting	<p>Dr Schaefer and Shona Whitehead attended the face-to-face meeting in Chicago on June 7th. Schaefer said the take-aways from the meeting were:</p> <ul style="list-style-type: none"> • No major changes on the horizon • Federal commitment to the collaboratives is solid • There is a focus on medical transition, an area Heartland is already pursuing with a new formed transition work group <p>He also indicated that Heartland is well position among the other collaboratives and that we should continue doing strong work.</p>	
Heartland Collaborative Status Update	<p>A conference call was held in early June with HRSA to discuss the transfer of the grant to Arkansas, where it became clear that doing and actual transfer this project year was going to be more difficult than initially thought. Three options were presented, but none were particularly appealing. Dr Schaefer proposed a 4th option, which was to leave the grant at OUHSC, add Dr Klaas Wierenga as co-Director (handling administrative and budget issues) along with Dr Schaefer as the other co-Director, responsible for programmatic and leadership areas, as well as being the “face of the Collaborative.” Dr Mulvihill would remain as an advisor to Schaefer and Wierenga.</p> <p>Day-to-day management and work would be conducted as it currently is being done. Whitehead and Mary Ann Coffman will continue in their current areas of responsibility. Schaefer plans to hire Lori Williamson as a University of Arkansas</p>	

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	<p>employee and she will work with some work groups and state genetics coordinators. This structure will remain in place until the next competitive renewal, in not quite two years. While this arrangement may not be the ideal situation, but is the best to keep work and projects moving forward and to retain the current funding without jeopardizing loss of carry-over.</p> <p>Schaefer asked if anyone on the call had any objections to the new leadership structure or hiring Lori Williamson. No objections were made.</p> <p>Dr Mulvihill reminded that everyone that the guidance for the competitive renewal will be written during this project year, so now is the time begin submitting suggestions to HRSA for potential inclusion in the guidance.</p>	
Annual Meeting	<p>Overview of draft agenda--The draft agenda was sent in advance of the call. Dr Mulvihill reviewed overall agenda with the group. Sharmini Rogers asked about funding for EHDI representatives to attend and would they have work group meeting? Mary Riske asked about have roundtable discussions and Kim Piper responded that the planning committee decided to not include them this year. Julie Miller commented that advocates should not be treated as guests during the NBS and Clinical Services work group meetings, but as contributing members. Mulvihill indicated that the advocates have their own work group meeting at a separate time to allow for their participation in the other work group meetings.</p> <p>Advisory Board agenda--Suggestions from the group include:</p> <ul style="list-style-type: none"> • Mission and Vision statement, governance and by-laws • Core members and addition of new members • Term limits for Advisory Board members • Rotation for Heartland funded attendees to the SACHDNC meetings • Pilot project application review 	<p>If any gaps are seen in the agenda, please send comments to Shona Whitehead at shona-whitehead@ouhsc.edu.</p> <p>Items for the Advisory Board agenda should also be sent to shona-whitehead@ouhsc.edu</p> <p>A call for volunteers to attend SACHDNC meetings in the next year will be sent, so Heartland is well represented.</p>
Heartland Pilot Projects Program	<p>The plan for is to release the pilot project application in October with applications due in early December and a letter of intent request due in early November. Letters of intent are requested so that project descriptions can be sent to HRSA and appropriate reviewers selected. Anticipated completion of review and scoring would be done by end of January with awardees notified around the same time. Funding</p>	

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	<p>would begin June 1, 2011, with maximum project length of 12 months a budget of \$45,000. This also allows the projects to be funded in the base budget and not carry-forward.</p> <p>The pilot projects are ideal incubators for potential national projects. However, the focus of the projects should be less basic research and more demonstration or translation projects.</p>	
Other	<p>Mary Ann Coffman gave an update on the transition work group. The first meeting was held in early July. The next steps are to conduct a survey of current transition activities within the region. Assistance with survey development will be provided by Dr Wendy Parent (KS). Survey results and development of goals and objects will be the main focus of the face-to-face meeting in Des Moines. HRSA has indicated interest in the preliminary project ideas.</p> <p>Kim Piper commented that there has been an increase in requests from college athletes and parent for NBS results (which can be at least 18 years old), since the NCAA began recommending that all student athletes in tiers 1, 2 and 3 know their sickle cell trait status. This has put a strain on resources, as most of these results are not in the electronic database, and require a search through a log book. Iowa’s assistant attorney general has recommended that after Iowa receives a written request for the newborn screening results, they may release the hemoglobinopathy results to the student or parent (if student <18 years old) with a “disclaimer” that the results are screening results, and if definitive results are required, the student should contact their health care provider. Iowa is considering charging a fee for the requests.</p> <p>Sharmini Rogers indicated that MO too had many inquiries and had consulted its general counsel and was advised to get clarification from the NCAA that they were requesting confirmation results on sickle cell trait and not the screening results and if so, MO then can put out a blanket statement that they do not provide confirmatory results and the athlete needs to get tested through their primary care physician. Dr Mulvihill said this might be an opportunity to document these experiences, including the cost burdens, allocation of resources, and successes.</p> <p>Kim Piper sent a follow-up email the Advisory Board that included the following</p>	

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	information: “a link to a presentation re: NCAA and sickle cell testing recommendations. Click on the Tuesday luncheon session by Lanetta Jordan. This was a plenary session at the National Conference on Blood Disorders and Public Health last March. http://www.blooddisordersconference.com/ .”	
Next Meeting	Save the Date: Heartland Annual Meeting—September 22-24, 2010—Des Moines	Monday, August 9th at 9:45 am