

## Advisory Board Meeting Monday, June 8, 2009—2:30-3:30 pm Summary

**Attendees:** Barb Schweitzer (ND), Leslie Himstedt (AR), Majed Dasouki (KS), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Sharmini Rogers (MO), Larry Weatherford (OK), Brad Schaefer (AR), and Sharon Vaz (OK)

**Guests:** Joann Bolick (AR), Annett Arnold (AR), Bev Duffel (SD) and Barb Jackson (NE)

**RCC Staff:** John Mulvihill, Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Accepted as recorded
New Project Year (FY09-10)	<p>New staff—Mary Ann Coffman, who was previously involved with Great Plains, has been hired to serve as a part-time project coordinator for specific projects in FY09-10.</p> <p>As of 6/8/09 the NGA has not been received. <i>UPDATE</i>—NGA was received on 6/9/09, and a copy of the project narrative is attached. It will be discussed in the next meeting.</p>	Please contact Lori Williamson at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a> if you have any questions about the projects.
June 5th NCC/PI Meeting Report	Agenda was focused on helping move important regional projects, which potentially have national implications, to the national level.	
Annual Meeting—Little Rock, AR	<p>Agenda highlights:                      Wednesday 9/16/09—Telegenetics Workshop; Board Meeting                      Thursday 9/17/09—Welcome and overview of services in Arkansas; focus on NBS by discussing state, regional and national activities                      Friday 9/18/09—Updates from the RCC, HRSA, NCC and Work Group meetings.</p> <p>Brad Schaefer—a tour of UAMS will be planned for the afternoon of Friday, 9/18/09 from 3:00-5:00pm. Headcount of those attending will be needed in advance.</p> <p>Online registration coming soon.</p>	<p>Send comments regarding the draft agenda to Lori Williamson at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a> by noon on Tuesday, June 16<sup>th</sup>.</p> <p>Please send any contact information for potential vendors to Shona Whitehead at <a href="mailto:shona-whithead@ouhsc.edu">shona-whithead@ouhsc.edu</a>.</p>

Agenda Item	Discussion	Action
	<p>The Advisory Board members are asked to review the agenda and send comments to Lori Williamson. After comments are reviewed and any necessary changes are made; a final draft will be sent out for approval.</p>	
<p>Agenda items for the face-to-face meeting</p>	<p>A portion of time will be given to Barb Jackson to conduct project evaluation with the Board.</p> <p>Dr Mulvihill suggested that some time could be spent revising the Heartland Vision Statement. Kim Piper suggested that code of ethics could be developed for the region, similar to what Iowa did several years ago. Julie Miller commented that Nebraska created guiding principles for the state program.</p>	<p>Send suggested Advisory Board agenda items to Lori Williamson at <a href="mailto:lori-williamson@ouhsc.edu">lori-williamson@ouhsc.edu</a>.</p>
<p>NBS Saves Lives Act (NBSSLA) Guidance</p>	<p>HRSA release the guidance for NBSSLA funding opportunity. Proposals must be submitted by 7/15/09. Guidance is included with summary.</p> <p>Per the guidance: “this initiative’s activities focus on the use of electronic health information exchange (HIE) to improve the newborn screening system, with attention to both short and long-term follow up.” The goal is to use technology to link data, improve infrastructure to create seamless communication between the NBS lab, primary care physicians (PCP) and the parents.</p> <p>Kim Piper (IA) has already begun writing a proposal that will include newborn hearing, NBS lab and will be working with the Public Health Informatics Institute.</p> <p>Upon request, Brad Schaefer will provide details regarding Arkansas \$5 million funding from Medicare.</p> <p>Sharmini Rogers (MO) commented that they can not apply for external funding, because there is not enough FTE or IT staff to sustain this type of project and the legislature has imposed a hiring freeze.</p> <p>Kim Piper (IA) said they also don’t have the FTE to sustain their proposal, but have partnered with the UIA Hygienic Lab to provide the staff.</p> <p>Sharon Vaz said that Oklahoma also doesn’t have the IT staff to sustain this type of project and that the quick deadline date would prevent exploration of other options.</p> <p>Julie Miller said that Nebraska couldn’t sustain this type of project because the shortage of IT staff.</p>	

*Heartland Genetics and Newborn Screening Collaborative*

<b>Agenda Item</b>	<b>Discussion</b>	<b>Action</b>
	<p>Kim Piper (IA) offered to include expansion into the Heartland as a final step in the project proposal. At a minimum, they hope to include North and South Dakota—states for which they provide NBS currently.</p> <p>Majed Dasouki commented that in Kansas, PCPs can access immunizations through KSWebIZ, but newborn hearing results are on another system. KSWebIZ is the Kansas Immunization Registry.</p>	
Next meeting	<p>The next Advisory Board meeting will be held on either: Monday, July 13, 2009 or Monday, August 10, 2009. The date that will have the most attendees will be selected.</p> <p>Upcoming Heartland Meetings: Heartland Annual Meeting—September 16-18, 2009—Little Rock, AR</p>	<p>Please respond to the Doodle poll indicating your preference. <a href="http://www.doodle.com/kzt2vi68vszeeadp">http://www.doodle.com/kzt2vi68vszeeadp</a></p>