

**Advisory Board Meeting
Wednesday, September 14, 2011**

Meeting Summary

Members: JoAnn Bolick (AR), Jackie Whitfield (AR), Stan Berberich (IA), Joni Bosch (IA), Kim Piper (IA), Jamey Kendall (KS) Dawn Peck (MO), Sharmini Rogers (MO), Barb Schweitzer (ND), Jeff Hoffman (NE), Judy Kellogg (OK), Sharon Vaz (OK), Lucy Fossen (SD) **Guests:** Barb Hemmelman (SD), Darlene Bergleen (SD), Patricia Scott (AR), Larry Weatherford (OK) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, and Shona Whitehead

Agenda Item	Discussion	Action
Advocate dried blood spot (DBS) statement	<p>Larry Weatherford requested that he be able to present the newly revised version to the Advisory Board. He gave a bit of background about the statement. He said that it was an advocate-driven initiative. Since the advocates knew that long term storage of DBS had been politicized in other states, they wanted to take the opportunity to educate other parents, as parents, about the important purpose of DBS. The advocates are seeking approval to disseminate their statement on the Heartland website.</p> <p>Sharon Vaz commented that the statement about costs to the family needs to be revised. There is no cost for storage of DBS, but most states charge fees for the actual newborn screen. Sharmini Rogers asked if the advocates would consider modifying the language about consent, since some states do have policies about informed dissent and anonymous samples. She also asked if the document had been reviewed by any lab managers. Lori stated that the paper had been shared with the NBS Work Group but not specifically with lab managers in each state. Stan Berberich commented that this is a useful document as long as it is recognized as education for parents, by parents.</p> <p>Dr Schaefer suggested that suggested revisions be sent to the Advocates for approval and then the Advisory Board can vote to approve.</p>	Draft revisions will be sent to Advocates. Then the final document will sent to Advisory Board for a vote.
SACHDNC public comment	Public comment is encouraged from the states for the upcoming SCHEDNC meeting. Comments must be submitted in writing in advance of the meeting. Jill Shuger has requested that each region submit comments about Dr. Rodney Howell stepping down from his position as chair of the committee.	<p>More information about the SACHDNC meeting can be found: http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/meetings/twentyfifth/index.html Send any comments to Lori.</p>

Chair and Chair-Elect voting results	The Advisory Board Chair is Kim Piper and the Advisory Board Chair Elect is Julie Luedtke. Both had been told of the results before today’s meeting and will assume their responsibilities for the next meeting. Thank you to everyone who participated in the whole process, from nominations to the final vote.	
Collaborative Partners project	An email was sent to the SGCs and NBS Coordinators describing this new initiative. The attached flyer describing the initiative was included with the email. Each state has been asked to identify a primary care provider to attend the upcoming APHL meeting. Once the PCP is identified, the HRCC will contact them to provide logistical information for their travel plans. Some states have already identified a PCP interested in participating.	
Consultant/Work Group/NCC WG liaison reporting rotation	In order to complete the loop of reporting or updating from the Heartland’s representatives and consultants to national or regional projects, the HRCC has decided that a standing agenda item will be added to the Advisory Board agenda to accomplish this needed reporting. The HRCC will contact the liaisons to arrange for their reports to the Advisory Board.	
NBS Clearinghouse Advisory Council report	Baby’sFirstTest.org was officially launched at the beginning of September to coincide with National Newborn Screening Awareness month. (Liz Horn from Genetic Alliance presented about the website at the meeting in Bismarck.) www.babysfirsttest.org	Each state is asked to review the information about their state and send feedback to Karen Eveans or the NBS Clearinghouse directly.
State Legislative updates	<p>Oklahoma—Sharon Vaz said that SCID was to be discussed during the Board of Health retreat, but they ran out of time, so it was tabled for the next meeting.</p> <p>Kansas—Jamey Kendall commented that there have been changes at KDHE, including a reduction in the workforce due to a new early retirement incentive. There is currently no plan to replace the personnel that have retired.</p> <p>Iowa—Kim Piper said she is working with experts to review Iowa’s DBS policies</p> <p>Missouri—Sharmini Rogers said that a state taskforce will be assessing the results of the pilot screening for LSD and planning for full implementation of LSD screening.</p>	
Next Meetings		2:00 pm: Oct. 12, 2011 2:00 pm: Nov. 9, 2011 2:00 pm: Dec. 14, 201