

**Advisory Board Meeting
Wednesday, October 12, 2011**

Meeting Summary

Members: JoAnn Bolick (AR), Jackie Whitfield (AR), Joni Bosch (IA), Kim Piper (IA), Jamey Kendall (KS), Sharmini Rogers (MO), Barb Schweitzer (ND), Mary Riske (ND), Julie Luedtke (NE), Lucy Fossen (SD) **Guests:** Bryce Heese (MO) **HRCC:** Lori Williamson, and Shona Whitehead

| Agenda Item | Discussion | Action |
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| NCC WG liaison reporting—ACT Sheets | <p>Bryce Heese reported that he attended the September meeting at ACMG which was held to discuss the new ACT sheets specifically for pediatric to adult health care transition services for patient with inborn errors of metabolism detected on the core panel. Joni Bosch asked if any drafts were available for review and Bryce responded, no not yet.</p> <p>The group is working on algorithms for LSDs to help states plan for future LSD screening. Julie Luedtke asked if they were considering doing ACT sheets for all screened conditions. She hopes they will eventually expand to all genetic conditions.</p> | |
| Result of Advocate Statement vote | <p>The quorum of votes, as stipulated in the bylaws, was not met.</p> <p>Kim Piper suggested that the HRCC do a polling vote by email with all the Advisory Board members.</p> | Shona will email each voting board member for a “yes, no, or abstain” response. |
| SACHDNC report | <p>Please see attached summary from Lori. These notes were also reviewed by Kim Piper and Leisha Suckstorf, but should not be interpreted as the official meeting summary.</p> <p>Some speaker presentations are now available on the SACHDNC website. Lori highly recommends reviewing the official meeting summary when it is made available online, especially the presentation about newborn screening and the military contracts.</p> <p>Kim Piper asked if the military is screening for SCID. Julie Luedtke responded yes.</p> <p>Lori indicated that a question was asked, during the SACHDNC meeting, if the military screening panel matches what the state screens for on its required panel. Jamey Kendall indicated that not in all states does the panel match.</p> | |

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| <p>Carry-forward update</p> | <p>It should be finalized later today. The estimate is \$159,000 and most of it is already earmarked for ongoing projects. Some funding for previously submitted pilot projects (which were not funded in the base budget, but scored high) and that began without Heartland funding are now included in the carry-forward. The two projects are the Tri-State Quality Enhancement project in ND, SD and IA and the Parent Support Liaison project in Kansas.</p> | |
| <p>Review of priority areas and strategies</p> | <p>These are items to consider and think about in preparation for the November Advisory Board meeting. The Guidance will be distributed by HRSA November 4th. All of the priority items (from within Heartland and HRSA) will be discussed during this meeting.</p> <p>This list is the culmination of the strategic planning process implemented by barb Jackson over the summer months. These are the top strategies derived from the round-robin strategic planning session that took place in Bismarck. Each priority had more strategies listed (and a master list has been retained), but these are the top strategies and the natural cutoff among the items with the most votes.</p> <p>This list is being presented to all the work groups for input on project development and potential response to the upcoming guidance. The goal is to work smarter and not harder on the next cycle's projects.</p> | |
| <p>State Legislative updates</p> | <p>Kim Piper recommended that states visit the AMCHP website to review the proposals for the future of Title V funding. www.amchp.org</p> | |

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| <p>Other</p> | <p>Lucy Fossen commented that she received an email from Alyssa Johnson, consultant to the NCC, which included a survey about South Dakota’s data collection and use policies. Lucy asked if the other states received similar emails and why the RC was not involved with this project. Lori was not aware of these emails going out to the states.</p> <p>Julie Luedtke said she also received it and asked Alyssa if the NCC had intent to publish the results. Alyssa responded that the results would be summarized into a table for possible distribution to the work groups of the NBSTRN or SACHDNC.</p> <p>Sharmini didn’t receive the email directly, it was sent to another staff person at the MO Dept of Health. All the other Heartland states did receive the email. Each email was tailored specifically for a specific state.</p> <p>Lori will follow up with the NCC at the face-to-face PD/PM meeting in November.</p> | |
| <p>Next Meetings</p> | | <p>2:00 pm: Nov. 9, 2011 2:00 pm: Dec. 14, 201</p> |