

Heartland Executive Committee Meeting

Teleconference

November 2, 2006 3-4 pm

Members Present: Sharmini Rogers, Teresa Willige, Larry Weatherford, Fred Schaefer, Jamey Kendall, Kim Piper, Julie Miller, Blaine Bendure, Lucy Fossen, Sara Copeland, John Mulvihill, Ralph Vogel

Also on the call: Julie Rayburn-Miller (MO NBS Coordinator), Jim Jeffries (MO Department of Health), Kayla Tinker (South Dakota Department of Health), Gene Hallford (RCC staff), Kyna Byerly (RCC staff).

Agenda and Discussion:

1. Conference evaluation: Evaluation summaries are posted on the website (<http://heartland.ouhsc.edu>). Overall, evaluations were favorable.
2. 2007 Annual Meeting: 1st choice: September 6/7; 2nd choice: September 27/28. Next step is checking hotel availability in Oklahoma City.
3. Regular monthly meeting: 1st Thursday of every month at 4pm (NEXT MEETING: **Thursday, January 4, 2007**). We will NOT have a call in December due to the numerous calls we have been having regarding the HRSA grant renewal. **Addendum: Meeting changed to Jan. 11th as grant is due Jan. 5.**
4. Discussion of Heartland response to "priority activities" (see page 12 of the guidance). There are two areas for which we can apply. Funding is for \$250,000 per year for 5 years. Both priority areas relate to newborn screening (NBS).
 - a) Laboratory Quality Assurance Activity: We may partner with Mountain states to contribute data to their **long-term follow-up (LTFU) database**. No details were available at the time of this call. Funding for abstracters and meeting attendance were mentioned as a need, if we are to participate. There is a national coordinating center (NCC) call next week about how the regions might be coordinating projects. The LTFU database will be discussed and you (the HRCG Exec Cmte) will be apprised of those details. **Disaster recovery** was mentioned as another possible bid. Funding would allow our region (and possibly partner with another region) to develop the plans, bring key folks together, and practice executing the plans. A similar idea may be hatched at the national level. We will know more after the NCC call next week. The third idea discussed was a **metabolic/NBS "grand rounds"** via internet/conference call. This project would likely need another region due to small number of metabolic specialists in our region. Due to the rural nature of our states, there may be issues with **receiving lab samples in a timely manner**. Evaluating this aspect of NBS QA might be important. Another very rural region is Mountain States.
 - b) Follow-up Activity: under the sub-heading of "evaluate newborn screening program performance" we discussed an idea that had surfaced in previous phone calls; that is, a state report card for their genetics programs and NBS programs. It seems that the states who want to grow their programs are bottlenecked due to lack of money, lack of personnel, require policy changes, or all of the above. In order to address this at the root cause, we could envision a multi-year project to:
 - a) develop and test a state report card;
 - b) provide a practical educational program for key stakeholders in each state to learn core elements of effecting policy change;
 - c) identify barriers to genetics/NBS growth in states; and
 - d) provide legislator education.

Conference calls prior to this one engaged collaborative members in considering these issues. Other ideas that could be woven into the above ideas include: determining if money can be used to pay for %FTE in the states (e.g. hiring a LTFU coordinator or nurse); 2 states want to address transition to adult issues; harmonizing testing panels in

our region; metabolic telemedicine; harmonizing our reports; creating back-up systems in our region; and linking child health records in states.

Given that there will be more core funding, some of the ideas could be funded through that money, rather than the priority activity money.

The Executive committee will be apprised of any new information after the NCC call and the HRSA call re: the guidance. Once we have that information, the RCC will propose some options for the Exec Cmte to discuss and mutate as needed.

Respectfully submitted,

Lori Williamson, MS, CGC
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