

**Advisory Board  
Teleconference  
February 11, 2008  
2:30 – 3:30 p.m.**

**Board Members:** Barb Schweitzer (ND); Majed Dasouki (KS); Lucy Fossen (SD); Leslie Himsted (AR); Kim Piper (IA); Julie Miller (NE); Holly Johnson (AR); Mary Riske (ND); Jamey Kendall (KS); JoAnn Bolick (AR)

**Regional Coordinating Center Staff:** Lori Williamson, Project Manager (OK), Kyna Byerly, Assistant Project Manager (MO)

**Other Attendees:** Bev Duffel (SD); Jamie Kim (KS); Ralph Vogel (AR); Sharon Vaz (OK); Kayla Tinker (SD)

**Meeting Summary**

| <b>Agenda Item</b>  | <b>Discussion points</b>   | <b>Action Steps</b>  |
|---|--|--|
| Sarah Lawrence Scholarship  | 4 applicants; 3 well qualified contenders; evaluation committee did not reach a decision. Waiting on 5th reviewer. Board input mixed: stick to one award, take into account state needs, prioritize to state genetics coordinators, offer multiple partial awards.   | Board to provide input on awarding scholarship to RCC by February 13. RCC to make final decision on award. |
| Hiring External Evaluator   | Evaluator hired, team meeting March  |  |
| Hiring Administrative Person  | Applications being reviewed.   |  |
| Pilot Projects 2007/2008  | States applying for pilot projects; 4 letters of intent received   | Deadline for proposals Feb 29  |
| Vaz attended Advisory Committee on Heritable Disorders and Genetic Conditions in Newborns and Children (ACHDGCNC) | Education Sub-cmte: bringing together all resources<br>Follow up treatment Sub-cmte: Payment/access to medical foods;<br>LTFU white paper: defining LTFU, look at roles and responsibilities.<br><br>MCHB website has meeting minutes ( <a href="http://www.hrsa.gov/heritabledisorderscommittee/meetings/2008january/default.htm">http://www.hrsa.gov/heritabledisorderscommittee/meetings/2008january/default.htm</a> ).<br><br>Applications for additions to NBS recommended core panel: SCID, Krabbe, Pompe. |  |
| Non-competitive renewal   | Final narrative due Thurs, 14th  | Review sections upon request   |

*Heartland Regional Genetics and Newborn Screening Collaborative*

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|---|--|--|
| Update on Projects: Primary Care provider on-line education project     | Authors from Clinical Services led by Merlin Butler progressing on writing content for Prader Willi Syndrome module<br>Fragile X: Brad Schafer editing existing content<br>RCC to identify and set up CME/CEU provider; Education/Lay Advocate collecting resources; Education to review modules and write questions for CME/CEU |  |
| Update on Projects: Telegenetics guide                                  | From Clinical Services workgroup: March 3 deadline. Then to Advocate Workgroup, RCC for final review; to NCC workgroup and states in April   |  |
| Update on Projects: KS-NE Telemed partnership                           | On hold. Reevaluate after KS implements expanded screening. A need may remain in Western KS.   |  |
| Update on Projects: Disaster preparedness                               | IA/MO drills planned Feb/March<br>Workshop planned April 17/18 in Missouri   |  |
| Update on Projects: Advocacy  | March Meeting in Kansas City planned   |  |
| Update on Projects: Family Health History                               | Tool kit distribution to Genealogy groups via state genetics coordinators<br>NE published article in Sept. 2007 rural electric cooperative magazine  |  |
| Update on Projects: Emergency Cards for kids with metabolic conditions  | Machines out<br>Usage tracking tool done<br>Working on evaluation for families   |  |
| Update on Projects: NBS training opportunities                          | AR, ND, KS, IA, OK, to coordinator and lab training with APHL/NNBS   |  |
| Update on Projects: Previously funded pilot projects and other projects | Current pilot projects:<br>MSUD 126 people tested; Expanded into IL finished by May 31<br>NF parental stress underway-changing methods<br>Town hall meeting NBS-going slowly OK/AR proceeding<br>Teratogen-no update provided<br>Other projects: ND state plan at printer  |  |
| Website   | Care Source/Illumin角度 chosen as vendor. Forming workgroup to give input in design process -Work via email and web to give input on proposed designs.   | Contact RCC if interested in participating in Web Site Redesign work group |

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|--------------------|--|------------------------------------|
| Other items        | 3 manuscripts submitted or in progress (2 on PWS; 1 on DS)<br><br>NBS Exchange Program (Arlena Pugliese leader on that project)<br><br>Region 3 metabolic/Nutrition conference April 24-25<br><br>Annual conference SD Sept 11-12, 2008<br><br>Report Card Project: Workgroup to meet May 19-20; Steering committee to meet 3/13 at ACMG |                                    |
| Next meeting       | Second Mondays at <b>2:30 PM</b>   | <b>Monday, March 10, 2:30-3:30</b> |