

## Advisory Board Teleconference

March 10, 2008

2:30-3:30

**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

Agenda Item	Discussion Points	Action Steps
NCC/HRSA Update	NCC/PI call discussed topic of genetics interfacing with Native Americans. A project in Mtn States was featured. NARCH has three centers in the Heartland IA- Family participation project trying to connect with Native American tribe also ND- Jayne Brown, Good Health tv aired on reservations, discussing information to disseminate through that resource	
Non-competitive Renewal	Submitted; will know something about contingencies and funding in mid-May	
Sarah Lawrence Scholarship	Piper and Rogers awarded the full scholarship for FY07-08 and FY08-09	
Hiring Administrative Person	In process	
External Evaluator	Met March 6-7, Discussed common measures; introduced Dr. Roxanne Joens-Matre from Des Moines University	
Pilot Projects for 2007-2008	Received 6 letters on intent, but only 2 applications	Send Lori email if interested in being reviewer
Website redesign	Moving quickly; Working with professional group	Will have alternative designs to look at and review with group

<b>Agenda Item</b>	<b>Discussion Points</b>	<b>Action Steps</b>
Williamson/Chou attended quality meeting 3/1-3/2	Mountain/Western States and ACMG Quality SIG involved in QI for individual providers They are seeking volunteers to pilot Each of the three regions is looking at a different aspect: Mountain States- QI at provider level Western States- Patient center and consumer aspect Heartland- Genetics system in a state	Report Card Work Group will meet May 19-20; location TBD. All state genetics coordinators invited to participate.
APHL conference	November 3-6, 2008, San Antonio, TX- NBS and Genetic Testing Symposium Hoping to go beyond lab screening and follow-up Hoping to draw broader audience	States contributing to Piero's project will meet at that meeting
Report on lab training (APHL)	Sarah from AR lab attended; glad she went, everyone offered assistance as AR expands screening	
Report on Coordinator Training (NNSGRC)	Training was very helpful; should not be limited to follow-up staff only Should consider having annually rather than on as needed basis	Let Brad Therrell know feedback about wanting annual training
Update on Projects: PWS diagnosis module	Several sections drafted; being reviewed by Utah	
Update on Projects: TBN metabolic disorder diagnosis module	Would like to choose one NBS disorder that will be new in most of our states to write up module Will need writers for new module	
Update on Projects: Telegenetics Guide	In process Document describes how to set up a telegenetics program	
Update on Projects: Collection of educational resources	Contacting genetic counselors in Heartland on what information they give to patients Collecting support group information, local information that clinicians give to families	Absence of information may lead to projects of what is needed in Heartland

<b>Agenda Item</b>	<b>Discussion Points</b>	<b>Action Steps</b>
Update on Projects: Advocacy	Meeting March 14-15 in Kansas City Trying to identify parent-to-parent and advocate groups locally in each state New Lay advocate member- Jayne Nelson, ND	
Update on Projects: Genetics Report Card	Dinner meeting in Phoenix 3-13 at ACMG Broaden discussion with national leaders Work group meeting in late May, state coordinators who want to be involved will be welcome to be involved	Conference call with state coordinators to update
Other Business	Regional Conference- September 11-12; Sioux Falls, SD Suggestions or volunteers for planning committee welcome  Website should list job opening within Heartland	
Next Meeting	Second Monday @ 2:30	Monday April 14, 2:30-3:30