

**Advisory Board  
Teleconference  
April 14, 2008  
2:30 – 3:30 p.m.**

**Board Members:** Lucy Fossen (SD); Leslie Himsted (AR); Kim Piper (IA); Mary Riske (ND); Jamey Kendall (KS); Larry Weatherford (OK); Amy Brower (NE); Becky Bailey (ND)

**Regional Coordinating Center Staff:** John Mulvihill, Lori Williamson, (OK), Kyna Byerly, (MO), Roxane Joens-Matre (IA)

**Other Attendees:** Sharon Vaz (OK)

**Meeting Summary**

Agenda Item	Discussion points	Action Steps
Web Site Graphic Design	Design #1 recommended by web site design working group	Design #1 approved by board
Lay Advocate Pilot Project Review Recommendations	The proposed review process and modified review form were discussed and several issues raised. Weighting of input discussed. Proposed: primary reviewer (content expert): 40%; Second reviewer (outside) 30%; Advocate Review: 30%	Documents with discussed changes to be sent to entire board for review and further input before final decision
Pilot Projects 2007/2008	Two proposals received for review. Awaiting review from a reviewer.	Williamson will send out final scores and comments for board decision on funding
Genetics Report Card— <b>NEW NAME: Genetics Systems Assessment</b>	Work Group Meeting, Chicago, Hyatt Regency O’Hare May 19 – 20, 2008 State Genetics Coordinators invited to join Work Group	Letters of invite forthcoming.
Association Public Health Laboratories NBS and Genetic Testing Symposium conference	Consider submitting abstract November 3-6, 2008 San Antonio, TX	

*Heartland Regional Genetics and Newborn Screening Collaborative*

<b>Agenda Item</b>	<b>Discussion points</b>	<b>Action Steps</b>
Report on Advocate Conference	Lay Advocate Work Group met successfully March 14-15 in Kansas City. See Lay Advocate Workgroup page for more information	
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	
Regional Conference	September 10-12, 2008, Sioux Falls SD. Holiday Inn chosen for location. Planning committee to meet re: agenda. Dr. Hoyme unable to attend due to birth of grandchild	Contact planning committee member or Kyna with ideas for topics or speakers.
Genetic Alliance Grant application	Heartland will not be submitting an application. There are at least three applications being submitted from our region.	
NBS Exchange Program	Project underway. Arlena Pugliese resigned as project leader; Barb Schweitzer volunteered. ND has visited IA; AR has plans underway to visit NE. Participant teleconference call to be scheduled to discuss post-visit evaluation.	
Other Business	Kim Piper attended first Sarah Lawrence Public Health Genetics module. Plans to do a cost/benefit analysis of adding Krabbe disease to NBS panel as capstone project.	
	Mulvihill announced that rare diseases grant RFP is out. University of OK intends to apply regarding urogenital abnormalities.	Mulvihill to send RFA to the list-serve.