

**Heartland Regional Council on Genetics
Semi-Annual Meeting
Teleconference Minutes
May 3, 2007
3:45 – 5:00 PM (CDT)**

Members Present: Butler, Copeland, Egger, Fossen, Hopkins, Kahler, Kendall, Kenney, Kussman, Leeker, Martsof, Miller, Mulvihill, Neas, Orten, Peck, Piper, Riske, Rogers, F Schaefer, Schweitzer, Stein, Weatherford, R Williamson, Willige, and Vogel.

Ex Officio: Byerly, Williamson, Mike Watson (NCC)

Agenda Item	Discussion/Conclusion	Recommendations/Action
March Executive committee minutes	No changes to March minutes.	
Regional Coordinating Center (RCC) activity	Williamson reported major activities are continued technical assistance and committee support . Revised budget for carry-forward funds was submitted due to HRSA cutting that budget by \$80,000. RCC visited ND and IA this year. Purpose of the state visits are: a) to better understand the states in our collaborative; b) identify resources and stakeholders to connect with the collaborative; c) promote the collaborative; and d) gather ideas for collaborative projects or for projects that will promote infrastructure development in the state. Awarded a scholarship to Jamie Kim for the Sarah Lawrence Public Health Genomics certificate program. Four applications were received. Based on the response, we plan to offer the scholarship next year. University of MN is now offering a program, which we will also consider. We will be revising the website next project year and will be putting the job up for bid. No word on funding for next project year as of yet. If fully funded, major new activities include genetics report card, telemetabolic rounds, laminated card with treatment plan for metabolic clinics, and MO and NE participating in transition from pediatric to adult care project.	Notify RCC (hrcc@ouhsc.edu) if you can recommend an excellent website design company.
NCC update	Mike Watson, director of the National Coordinating Center (NCC) reviewed their activities, most of which center around work groups (evaluation, telegenetics, disaster, geospatial mapping, data collection, and long-term follow-up (LTFU)). The NCC and ACMG produced the ACTsheets this year, which are available on the ACMG website (http://www.acmg.net). For details of the NCC activities, please see their website: http://www.nccrcg.org/ .	

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Committee Reports	Advocates: Willige reported that the advocates reviewed pilot project applications. The NBS committee has asked the advocacy group for project ideas. Advocates are planning a ½ day training on September 5, 2007 (day before the Heartland meeting). Advocates will be mounting bios on their webpage.	
	Clinical services: Stein reported that the committee has completed the literature review for the “how to” resource manual for telegenetics services. <u>Next meeting: 5/21 at 9AM.</u>	
	Education: The committee has nearly completed the family health history toolkit, targeting genealogy groups. Utah Department of Health is allowing us to use and adapt many of their materials. Once the toolkit is completed, the committee will notify the state genetics coordinators for their assistance in disseminating it. All of these materials will also be available on the Heartland family health history website: www.heartlandfamilyhistory.org/ .	
	Laboratory: Schaefer reported that main focus this year had been disaster preparedness. This culminated in a HRSA application. Also, the NBS laboratorians on the committee are moving to the NBS committee because of their unique issues and focus.	
	Newborn Screening: Copeland reported that committee is working on standard language re: transfused babies. Committee will try to meet at APHL meeting in Michigan next week.	
	Policy: Weatherford reported that committee is continuing work on Genetics Education Day toolkit and blood spot retention white paper.	
	Research: Three pilot projects were recommended for funding in this most recent cycle. They will be posted to the website on Monday (5/7/07). Patrick Hopkins also reported on completion of last cycle’s pilot project: the IA/MO NBS meeting. The meeting was deemed successful. Approximately 20 people from laboratory and follow-up attended. The focus was implementation of expanded newborn screening.	
State Advisory Committee Updates	Arkansas: Vogel reported that AR’s committee has met once this past year. Their focus is increased parent involvement. AR passed expanded screening; anticipated start date is July 2008.	
	Iowa: Piper reported for new chair, Trout, that IA’s committee has about 25 members that meet quarterly. Their group has representative stakeholder groups (consumers, parents, laboratorians, professional groups, all genetics programs). Provide advice to state health department.	
	Kansas: Kenney reported that expanded NBS passed the legislature and they intend to get the core panel up by July 2008. Currently, KS is conducting a provider survey regarding genetics referrals. Cord blood bank legislation also passed. Unrelated to KS update, Kenney announced a “Genetics for providers” training available on CD through the AAP.	
	Missouri: MO’s council consists of 15 members, nominated by the Governor and approved by the legislature. The council reports to the Department of Health and Senior Services.	
	Nebraska: Miller reported that their council meets quarterly and has 20-25 members (parents, pediatricians, lab, neonatology); Pediatrx attends but is not a voting member.	
	North Dakota: Martsolf reported that their committee is currently focused on completing the ND State Genetics plan.	
	Oklahoma: Neas reported that the group, called OGAC, meets three times a year and advises the commissioner of health. OGAC consists of 28 members. There are 7 committees .	