

**Heartland Regional Council on Genetics  
Executive Committee  
Teleconference Minutes  
January 11, 2007  
4:00 – 5:00 PM (CST)**

**Members Present:** Mulvihill, Bendure, F Schaefer, Kendall, Miller, Piper, Weatherford, Fossen, Copeland, Rogers, and Willige

**Ex Officio:** Byerly, Williamson

<b>Agenda Item</b>	<b>Discussion/Conclusion</b>	<b>Recommendations/Action</b>
<b>Heartland continuation application and priority projects applications</b>	Mulvihill reported that our application featured a “state report card” on genetic services; telemetabolic grand rounds; continued pilot project program and committee funding. We also applied for both priority projects: 1) Laboratory Quality Assurance—MO/IA application for disaster preparedness and Long-term follow-up; 2) IA application to promote data collection in our region; we would also partner with Mountain states and Region 4. (project abstracts were provided in pre-meeting materials and are available on the website).	Place abstracts on Heartland website
<b>Cycle #3 of Pilot Projects</b>	Four letters of intent were submitted; titles of projects were provided in pre-meeting materials. Deadline for applications is Monday 1/29/07 at 5pm.	None
<b>Committee Reports</b>	<b>Advocates:</b> Willige reported that the group is investigating continuing education in advocacy. A lay advocate has volunteered to serve on each committee. The advocates will be contacting committee chairs for input about how best the advocates can contribute to the committee and the collaborative as a whole. Advocates reviewed the NBS parent video/DVD and provided feedback to that working group.	None
	<b>Clinical services:</b> Bendure reported that the committee is completing clinical services and telehealth data collection and compilation. That information will be put on the website and will be linked with GeneTests. An abstract about the telehealth survey was accepted for platform presentation at a national conference in May. The next major activity for the committee is writing a “how to” resource manual for telegenetics services in genetics. <u>Next meeting: 2/23 at 9AM.</u> <b>Cancer sub-committee</b> is working on data collection of hereditary cancer programs in the region, and requests suggestions for members from SD and IA. <u>Next meeting: 1/25 at 4PM.</u>	None  Contact Melissa Craft with names of potential members from IA and/or South Dakota
	<b>Education:</b> The fall family health history campaign consisted of a video press release (developed in OK) sent to TV stations in Heartland and a printed press release sent to newspapers; website for general public created, mostly complete: <a href="http://www.heartlandfamilyhealthhistory.org">www.heartlandfamilyhealthhistory.org</a> and toll free number established for citizens to call and request printed toolkit. Next meeting to be held 1/30/07 to make plans for spring genealogy family health history campaign.	Byerly to continue working on completion of family health history web site
	<b>Laboratory:</b> Schaefer reported he and Colleen Peterson (KS) attended web conference on disaster preparedness November 15, 2006 (see attached reports). Last meeting was 11/30/06 and focused on response to the grant renewal. Next meeting to be scheduled.	None
	<b>Newborn Screening:</b> Copeland and Miller reported that project on newborn screening video for parents is finally nearing completion. Four states selected the March of Dimes video and four states selected the New Jersey video. Evaluation component for this project is being finalized. <u>Next meeting 3/2/07 at 9AM.</u>	None
	<b>Policy:</b> Weatherford reported three new projects—1) assisting states with Genetics Education Day at the Capitol; 2) and evaluation of blood spot retention; and 3) Survey of policy issues identified by other regions and lay advocate groups.	None

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<b>Committee reports, continued</b>	<b>Research</b> —No report	None
<b>RCC Report</b>	Williamson reported. <b>Reimbursements</b> for Omaha meeting were late due to incorrect paperwork being submitted; notify Williamson if you have not yet been reimbursed. OU Pediatrics ITS can no longer support <b>Heartland website</b> . Arrangements are being made to outsource the maintenance and immediate design needs until end of fiscal year. Next fiscal year, open bid process will occur for significant modifications. <b>Staffing</b> changes at RCC: Erica Willis is a graduate student hired through April, and Matt Grim will be joining us soon. Positions will be as follows: Williamson—project manager; Byerly—assistant project manager responsible for conference, website, committees, and directory; Grim—assistant project manager responsible for all Heartland pilot projects and other funded projects subcontracted; Hallford—Evaluator—Exec Sec for Research committee, lead evaluation group, assist committees with evaluation needs; Vaz—Exec Sec for Education committee; Willis—graduate research assistant—schedule teleconferences, assist with directory, duties as assigned. Williamson will be contacting state genetics coordinators regarding <b>involving AAP, AAFP, and Title V</b> in the collaborative as well as <b>visits to your states this spring</b> .	Update website to reflect RCC staff  Williamson/Byerly to contact SGCs re: Title V, AAP, and AAFP and state visits.
<b>Committee membership</b>	Williamson conducted an analysis of committee membership. The results showed that four committees lack representation from all states; several members serve on more than one committee; and that a significant number of committee members do not serve on the council. The latter has implications in that our current structure does not allow their way to be paid to the annual meeting. Changes in committee structure will be discussed again in preparation for the annual meeting, but at this time, Mulvihill stated that the way to become part of the formal council is through committee membership and to continue identifying folks in your state who could contribute to the work performed by these committees	Byerly and Williamson to continue assisting chairs with identifying potential members.
<b>Publications</b>	HRSA encourages publishing work conducted by or funded through the collaborative. Use: <i>“Supported in part by grant U22 MC03962 from the Health Resources Services Administration, Genetic Services Branch, Heartland Regional Genetics and Newborn Screening Collaborative”</i> <u>OR</u> <i>“Funded by grant U22 MC03962 from the Genetics Services Branch, HRSA”</i> to cite the funding source.	None