

Heartland Education Workgroup
 Thursday, Nov. 1, 2007
DRAFT Conference call Summary

Members present: Barb Schweitzer (ND), Michael Kayser (OK), Jeanne Egger (NE), Patricia Burk (OK), Jayne Brown (ND), Lori Williamson (OK-Regional Coordinating Center (RCC) Staff), Kyna Byerly (MO-RCC Staff)

Item	Discussion	Action
Welcome / Introduction / Review of minutes	Lori Williamson facilitated for Sharon Vaz, who was unable to attend. Oct. minutes approved.	October minutes posted to web site
Primary care provider (PCP)“Just in time” Education Project <ul style="list-style-type: none"> • American Association Pediatrics (AAP) • American Association Family Physicians (AAFP) calls 	Calls with AAP regional offices being arranged (2 times). Call with AAFP will be rescheduled to allow attendance of AAFP staff member assigned to National Genomics project Work group.	RCC will send out dates and call in info for calls with AAP/AAFP when finalized. Members are welcome to attend.
<ul style="list-style-type: none"> • Utah MedHome Portal Collaboration: PCP Education link to Diagnosis modules 	Lori is working with Chuck Norlin on collaborating with this Utah project. Web site http://medhomeportal.org/ reviewed. Diagnosis modules already written on several disorders; discussed linking to these modules for PCP education project; contributing content on one disorder for an additional module. Most felt this would be a good collaboration, and that completing one module could be done by May 31 st .	Members to review Utah MedHome Portal website and diagnosis modules; reply to group with opinions on collaboration and possibility to complete one additional module by May 31
Utah MedHome Portal Collaboration: Other items	The Utah group is interested in creating “mirror portals” for other states. This would involve tailoring the entire site, particularly resource data, to the specific state. Standardized resource databases exist which can possibly be used. They have also applied to Mountain States for money to increase the NBS info available, and to tailor only the NBS pages for other states.	

Heartland Regional Genetics and Newborn Screening Collaborative

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Discussion of collection of educational resources received	Jayne Brown reports she is collecting info on support groups in her state. It was unclear to those on call exactly what resources were to be reported for this collection; assigning members responsible for each state discussed but not done due to attendance.	Previous item: Lori will provide contact information of the ACHDGDNC education workgroup for collaboration Clarify resources to be collected and identify members to work on each state.
Genetic Alliance Publication: Understanding Genetics: A Guide for Patients and Professionals	Lori requests that members review: Do we want to consider tailoring this to our region or states? http://www.geneticalliance.org/ Document in "Publications" section	Review document and reply to group
ND Family Health History Promotion	Jayne Brown reports ND is promoting Family History Day, including a proclamation from the governor, a magazine article, and is referring to the Heartland Family Health History web site and toll free number	Jayne Brown to send RCC the proclamation and article.
Next meeting		Dec. 6, 2007 1:15 pm