

**Heartland Regional Genetics and Newborn Screening Collaborative  
Clinical Services Work Group  
Teleconference Meeting  
November 9, 2007**

**Members Present:** Quinn Stein (SD), Jeanne Egger (NE), Stacey Montgomery (IA), Robin Troxell (MO), Brad Schaefer (NE), Merlin Butler (MO), Donna Nale (MO), Dana Orten (NE), Jaime Kim (KS), Becky Butler (AR)

**Regional Coordinating Center Team (ex officio):** Kyna Byerly

<b>Agenda Item</b>	<b>Discussion/Conclusion</b>	<b>Recommendation/Action</b>
<b>Old Business: Clinical Services Listing</b>	<b>GeneTests collaboration</b> is proceeding. For all states except MO, all clinics we list that are not in the GeneTests Clinic Directory have been contacted and asked to be added. MO is in process. We still have no listing for Kansas.	States to be asked to review and update listings in Feb., 2008  Jaime Kim to collect KS clinical services info
<b>Telemedicine Resource Manual</b>	Work to date collected; need to review, and identify and collect any missing info or sections; edit final copy.	Email current collected sections and info to group: <b>Done</b> Group to review. Brad and Becky to coordinate collecting any missing info, any rewriting and editing. Final copy to be reviewed at next meeting.
<b>NF Project, Susan Hased Genome disorder project idea</b>	Merlin requested an update on these projects	Brad to contact Hased and Mullins as he is at OU and report back to the group
<b>New Business: Utah MedHome Portal Collaboration</b>	<a href="http://medhomeportal.org/">http://medhomeportal.org/</a> web site reviewed and collaboration discussed: (1) modifying newborn screening pages to reflect regional/state info, (2) creating a “mirror portal” for another state, where entire web site is modified to reflect another state, instead of Utah. (3) Clinical Services to work with Education Work Group to use Utah Diagnosis Modules for primary care provider on line education project. Clinical services to provide content on one new disorder to Utah for creation of a new module as a “trial run” to determine what is involved, logistics, timeline etc. Prader Willi chosen with Merlin Butler to be lead author. Will determine details on further modules after completion of Prader Willi Module.	Regional coordinating center to work with Utah on establishing work scope and logistics of collaboration.  Merlin to review Diagnostic Module guidelines for content, and work with Kyna to identify which sections he will write, and which to recruit other members to write.

<p><b>Transition</b></p>	<p>Transitional care, from pediatric to adult, has been identified as area we want to address during the next fiscal year. We need to develop a plan now for inclusion in next year's funding request, which will be submitted this winter. Identification and review of on-going projects or other initiatives discussed to help identify collaborative projects or ideas for our region.</p> <p>Brad reports ad hoc National Coordinating Center workgroup is doing a national survey of adult care providers as a needs and capacity assessment, and some NBS projects.</p> <p>NE has a federally funded transition project which has produced a resource note book to be used as a tool in transition; currently being converted to DVD. ~20% of the info is NE specific-could be modified to reflect regional or state specific info.</p> <p>Identifying transition projects through Title V or Maternal Child Health or other entities in each state discussed.</p>	<p>Brad to send more info on NE project to group for review</p> <p>Kyna to work with members to identify appropriate contact people in each state to obtain info on regional transition projects.</p> <p>Information on any identified projects to be circulated and review by committee with further discussion at the next meeting</p>
<p>Next Meeting:</p>	<p>2<sup>nd</sup> Friday of the month</p>	<p><b>Friday December 14, 8:30 am</b></p>