

**Clinical Services Work Group**  
**Friday, October 10, 2008**  
**8:30-9:30 am—Conference Call**  
**Summary**

**Attendees:** Donna Nale, Robin Troxell, Becky Butler, Quinn Stein and Mary Riske  
**Heartland Staff:** Lori Williamson, Shona Whitehead

**Meeting Summary:**

Agenda Item	Discussion	Action
Welcome and Attendance		
Telemedicine Resource Manual Project Update	<p>Becky Butler and Donna Nale completed updates and changes from Brad Schaefer and Kyna Byerly. Policies and procedures are separate sections. Sample patient satisfaction forms to be added. An appendix of the state inventory listing collected by Quinn Stein and Blaine Bendure to be added. Becky and Donna commented that it was extremely helpful to have facilitated roundtable at the Sioux Falls meeting because it provided additional insight on what was happening in other states.</p> <p>Suggestions for dissemination (after final review) to be discussed on next call.</p>	<p>Current version to be reviewed by Shona Whitehead, for readability not content. Then will be posted on password-protected section of Heartland website for full committee review.</p> <p>Each state will need to provide weblink to telegenetic clinics in their states. Also needed is the weblink to each state/institutional policy for telemedicine. <b>Please send to Shona Whitehead by November 10.</b></p>
PCP Education Project	<p>The plan is to have the Clinical Services and NBS workgroups nominate disorders that will become additional PCP education modules. AAP and AAFP chapters will also be asked to nominate disorders. Modules will have one or two authors, rather than be a full committee project.</p> <p>Suggested disorders:                      FAS (Gene Hoyme/Quinn Stein)                      Angelman syndrome                      Tuberous sclerosis                      CAH                      T-18                      T-13                      Del 22q</p> <p>Compensation is available to module author(s).</p>	<p>Williamson/Whitehead to re-contact AAP and AAFP chapters. Chapter members will be given a compiled list of disorders to rank in priority of importance, rather than an “open” nomination process.</p>

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<p>Planning for FY 09-10</p>	<p>Project ideas for FY 09-10; either pilot projects or regional projects.                  Suggestions:</p> <ul style="list-style-type: none"> <li>• Transition                     <ul style="list-style-type: none"> <li>○ What is needed in the region?</li> <li>○ Pilot project</li> <li>○ Access to info</li> </ul> </li> <li>• LTFU                     <ul style="list-style-type: none"> <li>○ Needs assessment</li> <li>○ Small demonstration project</li> <li>○ Position states to receive additional future federal funds</li> </ul> </li> <li>• DG Galactosemia                     <ul style="list-style-type: none"> <li>○ Consensus statement for follow-up</li> <li>○ Registry (is data available from Sue Berry's project or should a database be set up within Heartland??)</li> </ul> </li> </ul>	<p>Complied list from all work groups will be reviewed and prioritized by Advisory Board. <b>Please send any suggestions to <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> to be included on the list.</b></p>
<p>Clinical Genetics Services Listings</p>	<p>All states' information received, but may not be categorized. Database search is functional on web.</p> <p>Categories used: Adult Genetics Pediatric; Genetics Metabolic / Biochemical; Genetics Prenatal Genetic Counseling / Diagnosis; Cancer Genetic Counseling / Risk Assessment; Multidisciplinary Clinics; Genetics Laboratory; Other</p>	<p><b>Please review your states listing.</b> (Verify that the listing has an associated category).</p> <p><b>Send any questions or revisions to Shona Whitehead <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>.</b> She will be maintaining and can update/correct as needed.</p>
<p>Other items</p>	<p>Heartland Newsletter—Next issue to include current and applicable information about clinical genetic labs (cytogenetic, molecular, and biochemical). Topics to be covered: billing/insurance/contracts with outside labs, GeneTest, websites and research.</p>	
<p>Next Meeting</p>		<p>November 14, 2008</p>