

**Clinical Services Work Group**  
 September 12, 2008  
 Annual Heartland Meeting, Sioux Falls SD  
 Summary

**Attendees:** Becky Butler, Jeanne Egger, Merlin Butler, Quinn Stein, Ralph Vogel, Mary Riske Robin Troxell, Donna Nale, Jill Shuger, Lindsey Johnson, Tiffany Lepard **Heartland Staff:** Kyna Byerly

**Meeting Summary:**

Agenda Item	Discussion	Action
<b>Membership</b>	Core and other membership designations were reviewed (see below). Egger, Riske, Butler, Stein, Vogel and Troxell agreed to remain as core members. Current core members Schaefer, Welch and Craft were not present. Butler, Nale and Lindsey to be 'Other' members. Kyna Byerly is resigning from Heartland; Lori Williamson will be facilitating this work group for the time being.	Schaefer, Welch and Craft to notify Lori Williamson if they would like to remain in work group, and in what capacity
<b>Telemedicine Resource Manual Review</b>	<p>Telemedicine was be a roundtable discussion topic at Sioux Falls Conference; see conference web page for more details.</p> <p>Edits and comments received on the manual were discussed. Several issues were identified: how list authors; definition and consistent use of terms "telemedicine" and "telehealth"; inclusion of info on the telemedicine coordinator, inclusion of additional links, resources and contacts from telegenetics programs in our region, inclusion of information on how to perform a genetics exam using telemedicine. Two additional issue raised during review (but not discussed) are: addressing essential supports for technical difficulties, sufficient training, or insufficient technical support staff during clinics, and issues surrounding Access Fees, rights to accessing certain T1 lines, and Federal regulations that have the potential to interfere with how extensively telehealth may be used (raised by NE state genetics coordinator Julie Miller)</p> <p>Plan for finalization and dissemination discussed included: final draft to RCC for review, and then to national telemedicine workgroup. Web formatted version (links for each section, etc) to be posted on Heartland web site, as well as print version file.</p>	<p>Byerly to collate all collected edits and feedback, and send to RCC, as well as Schaefer, Nale and Butler: <b>Done</b></p> <p>RCC to coordinate dissemination.</p>
<b>Primary Care Provider Education Project</b>	<p>After completion of PWS module (see below) the work group discussed continued participation to involve</p> <ol style="list-style-type: none"> <li>1) Nominating disorders for future modules (5 additional planned for the next year); suggestions included FAS (Fetal Alcohol spectrum), DiGeorge, Angelman</li> <li>2) Identifying potential authors or experts on specific disorders in our region. Examples: Meg Hefner in St. Louis: CHARGE syndrome expert; William</li> </ol>	Email nominations of disorders and identified experts to Lori Williamson by <b>October 13</b>

	Kimberling in Omaha: Usher syndrome expert; Gene Hoyme, Sioux Falls: FAS expert The work group will not write another module as a group effort.	
<b>Prader Willi Syndrome (PWS) Module:</b> discussion of completion	PWS authors reviewed and discussed edits. Byerly to send summary to group and Utah. Lori Williamson will help coordinate project now.	Byerly to send summary of discussion of final draft to Utah MedHome portal
<b>Transition</b>	Plenary session included a presentation from Patti Hackett from Healthy and Ready to Work about Transitional Care. However, Hackett was not able to be at work group meeting for further discussion. See conference page on web site for slides and multiple handouts. Ralph Vogel volunteered to lead the Heartland Transition effort, which includes assistance from HRTW, identifying state partners, and disseminating already developed resources.	Follow up teleconference with Patti Hackett to be scheduled.
<b>Next meeting</b>		To be determined

## Defining Clinical Genetic Services Work Group Membership

### Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. Attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

### Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project.