

Heartland Clinical Services Committee Minutes  
November 16, 2005  
Per Conference Call

Members Present: Blaine Bendure (AR), Quinn Stein (SD), Judy Welch (IA), Melissa Craft (OK), Anne Gramiak (AAP), Jeannie Egger (OK Lay Advocate) , Mary Riske (ND)  
Regional Coordinating Center Staff: Kyna Byerly

- I. **Introductions:** Judy Welch from Iowa will be replacing Sharon McMillan on this Committee. Welcome Judy!
- II **Minutes** of the September 2006 Meeting in Omaha were approved. A list of members of this Committee and their contact information are available on the Heartland Website, as well as previous Meeting Minutes.
- III **Cancer Services Subcommittee report** – Melissa reported that Minutes from the November 30 teleconference will be on the Heartland website. She reviewed the 3 year plan for the Committee. Year 1 includes: Locating all the Cancer Resources in each of the 8 States and with a comprehensive list of expertise. NCI has some of this data already and will cross check with that list. Representatives from South Dakota and Iowa are still needed on this Committee. Activities of years 2 & 3 will focus on bridging identified gaps in service and developing a tool kit of what is available. There were questions about overlap with the Clinical Services Directory that is being developed. Melissa stated that her resource information would be more detailed and not the same.
- IV **Regional Coordinating Center report** – Kyna reported that guidance is out for the Heartland 5 yr competitive renewal grant. It is due Jan 5, 2007 with a possible 1 week extension. There are also 2 supplemental competitive grants for an additional \$500,000, total, addressing: 1) newborn screening and long term follow up, and 2) lab quality assurance. Dr. Mulvihill has draft outlines that are open for comment, and he needs to recruit people to help write sections. Lori needs information on our ongoing projects and what the funding needs will be. The next Heartland annual meeting will be in Oklahoma City in September, the 6<sup>th</sup> & 7<sup>th</sup> with an alternate date of September 27<sup>th</sup> and 28<sup>th</sup>.
- V. **Clinical Services Intake Forms**  
The Clinical Intake Forms are in- the deadline was October 31. Missouri and Kansas are still not in. Discussion followed as to how to enter all of the data collected on to the Heartland website. It was agreed to send the information to Kyna and she will convert it to a PDF file for the website. State information will be updated twice a year in Feb. and Aug. Each state coordinator will be sent a notice by this secretary to check the current info and any changes should be sent to Quinn to add to the website. This Committee is also collaborating with Gene Tests to put our State Directory information on their website. South Dakota and Arkansas are already done and North .Dakota will be next.

**VI. Telegenetics Intake Forms**

The collected intake forms have been submitted as an abstract to the American Telemedicine Conference. A summary of what is available in each State will be posted as a Table on the Heartland website. Please send comments.

**Telegenetics Resource Manual**

Brad Schaefer offered to take the lead on this project. There was discussion about how to fund, staff, equip, and utilize models that are already out there. There have been published papers and poster presentations on this topic. Kim will take the lead on gathering information and summarize what literature is available. Anne, Melissa, Blaine, and Judy will help review the collected articles. More specifically, Melissa and Blaine will review the psycho-social aspects, and Judy the goals and outcomes. A timeline of two to three months was discussed for the literature review. There is a website <https://www.telegenetics.net> to check out too if interested.

**VIII. Other**

Blaine asked if anyone was familiar with a service on line called “Gene Scene” which addresses family history and general information about genetic counseling.

**Next Meeting** – February 23, 2007 via Teleconference at 9:00AM.

Respectfully Submitted  
Mary Riske