

Clinical Services Committee Minutes  
September 29, 2006  
Heartland Regional Genetics & Newborn Screening Collaborative  
Omaha, NE

Members Present: Quinn Stein, Brad Schaefer, Blaine Bendure, Kim Keppler, Anne Gramiak, Mary Riske  
Members Absent: Lisa Butterfield, Melissa Craft, Amy Brower, Dawn Peck, Sara Haslag, Sara Copeland,  
Sharon McMillan

- I. Introductions were made.
- II. Quinn/Blaine reported that information about the Clinical Services Committee is posted on the Heartland website. This includes the names and contact information of the committee members, as well as minutes of the meeting. Since the initial meeting in October, 2005, two teleconference calls have occurred, one in February and one in May, 2006. It is of note that “Gene Tests” is interested in adding our directory information to their website for further utilization by professionals.
- III. Project Updates
  - a. Regional Heartland Clinical Genetic Services Directory development
    - i. Still need surveys returned from the states of Missouri, Iowa, and Kansas. State genetic coordinators from these states will be contacted and given a deadline of October 31, 2006.
    - ii. Blaine will consult his IT department to determine the most efficient way to post and access the data entered on each state.
    - iii. States not submitting their information by October 31, 2006 will be listed as no information available.
    - iv. The state information on the Heartland website will be updated every 6 months (in February and September) via an e-mail to each clinical services committee member and the State Genetic Coordinators generated by the secretary.
    - v. Our directory information has also already been shared with the Heartland Cancer Genetics Committee to assist them in locating resources within the Region.
    - vi. Quinn will also forward a copy of our survey form to Judith Benkendorf at the National Coordinating Center.
  - b. Telemedicine Survey
    - i. Blaine reported surveys were completed a little differently from each state. Some additional items may need to be added to the survey in the future.
    - ii. Still need surveys returned from Missouri and Kansas. The State Genetic Coordinators will be contacted. An October 31, 2006 deadline will be utilized.
    - iii. Nebraska, Arkansas, and Missouri are currently utilizing telemedicine for providing genetic services. Discussion followed on how it is working in these states with special emphasis on how they are being funded. Those three states have the hardware – but there are technical differences in usage.
- IV. Goals for the next 5 years
  - a. Complete directory
    - i. Collect remaining clinical services information needed by October 31, 2006.
    - ii. Have all information posted on the website.
    - iii. Update information every 6 months (February and September).
    - iv. Continue sharing information with Gene Tests as requested.
    - v. Market the state information to the primary care providers in each of our respective states.
  - b. Expand the Telemedicine Project
    - i. Collect remaining telemedicine surveys and compile the information addressing what is currently available in each State and what is needed.

- ii. Describe what is unique about providing genetic services via telemedicine and determine the special needs of utilizing this type of technology.
  - iii. Develop a plan for experienced committee members to offer technical assistance to other states wanting to start offering genetic services by telemedicine.
  - iv. Evaluate the telemedicine services being provided in the Heartland Region, collaborating with others already doing research in this area.
  - v. Once sites established region-wide, collaborate with the advocate committee.
- c. Other Ideas
- i. Market AAP modules in genetics to primary care providers.
  - ii. Develop continuing education modules for transitions from pediatrics to adult health.
  - iii. Recruitment of more primary care providers on this committee.
  - iv. Further discussion of funding resources for consumers needing genetic testing without insurance.

Submitted by:

Mary Risko  
Secretary Clinical Services Committee

If you do not wish to be on this Committee or have changed Committees, please let me know so I can delete your name.