

Heartland Update

October 9, 2007

Submitted by: Lori Williamson, MS, CGC, LGC

1. Annual meeting

- Over 100 in attendance from 15 different states
- Excellent attendance and involvement of work groups: Education, NBS, and Clinical Services
- All work groups are strengthened

Please visit our website for information about upcoming work group meetings, speakers' slides, etc...: <http://heartland.ouhsc.edu> or contact the Regional Coordinating Center: hrcc@ouhsc.edu or 405-271-8685.

2. Activities this year

- Completing activities: telegenetics "how to" manual; white paper on NBS dried blood spots; TPN and transfused babies information;
- New activities: education inventory of resources and capacity; web resource for PCPs; training for KS, AR, OK, and SD laboratories; emergency cards for metabolic patients; Genetics report card; advocacy efforts; disaster preparedness; ND state plan; website enhancements; newsletter

3. Planning for next year

- NBS: Long-term follow-up is an issue that must be addressed in our next year

4. Advisory Committee on Heritable Disorders and Genetic Conditions in Newborns and Children

- The regional coordinating center PI and/or project managers are now required to attend these meetings. Background about this committee is found in their charter:

The Secretary of Health and Human Services (HHS) is directed under section 1111 of the PHS Act to establish an Advisory Committee on Heritable Disorders in Newborns and Children (Committee). HHS has expanded the Committee to include genetic diseases and has renamed the Committee accordingly. The Committee's purpose is to provide to the Secretary advice and recommendations concerning the grants and projects authorized under section 1109 and technical information to develop policies and priorities for this program that will enhance the ability of the State and local health agencies to provide for newborn and child screening, counseling and health care services for newborns and children having or at risk for heritable disorders. Specifically, the Committee shall advise and guide the Secretary regarding the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders. (<http://mchb.hrsa.gov/programs/genetics/committee/charter.htm>)

Minutes from the September meeting are not yet available, but I gathered several pieces of information that will be disseminated to the regional collaborative via the listserv and web site.