

Committee Activity Summary
June 19, 2007

Clinical Services: Telegenetics Resource manual: The committee has completed an extensive literature review, completed an outline decided on the basic structure for the telemedicine resource manual. Members have been assigned to write the first 5 sections, which are to be complete by the July meeting (date to be determined)

On Line Clinical Genetics Resources listings now available. Anne Gramiak from AAP will publicize the Clinical resources web page to AAP members through their newsletter.

Members were also asked to complete the recently finished NCC Telegenetics survey. Next meeting to be scheduled for July.

Cancer sub-committee: Form for collecting info on clinical hereditary cancer resources finalized. Plan to have state representatives collect information by August, with completion prior to September meeting. Next meeting to be scheduled for July.

Policy:

DNA Day toolkit: Workgroup assigned and planning to meet.

NBS Blood spot retention: White paper being drafted by Mulvihill and Rogers.

Summary of genetic counseling licensure efforts obtained from NSGC and disseminated.

Committee will continue to track this issue. MO licensure has run into prohibitive cost issues; going through Dept of Health as OK does is being pursued by Rogers and Kussman.

Next meeting: July 13 9 AM

Lab:

No current projects or meetings scheduled.

Research:

No activity since last pilot project review. Continuing to recruit members, available to assist in Heartland research projects/programs, and planning to assist next pilot project review process.

Newborn Screening

NBS prenatal educational videos distributed to states. Use will be evaluated in 6 months.

Information on NBS for transfused babies (policies and reporting language) has been collected from all states. Workgroup assigned (Lead: Dawn Peck) to review and evaluate for standardization, will report findings back to committee at next meeting.

Total Parenteral Nutrition (TPN) effects on tandem mass spectrometry (TMS) newborn screening: Assigned workgroup (Lead: Patrick Hopkins) to look at individual state policies to recommend best practice for region.

Cystic fibrosis screening practices: Investigating having Heartland involved in national effort.
Next meeting at annual conference in September.

Lay Advocates: Working on

Posting bios to web site

Contacting all members to determine commitment for next cycle

Planning summer training on pilot project review

Developing Lay Advocate specific review process

Planning training at September annual conference

Next meeting: July 11, 4 PM

Education:

Family Health History Toolkit, modified from Utah to reflect Heartland region, final draft complete; being reviewed. Genealogical societies to contact for FHH promotion identified. Article to rural health cooperatives papers on FHH promotion ready for distribution.

Next meeting: July 10, 1:30