

## Heartland Education Workgroup Meeting

September 6, 2007

### Annual Heartland Regional Genetics and Newborn Screening Collaborative Meeting

#### Recommendations for Education Workgroup Projects:

- Genealogy collaboration – finish the existing project of providing FHH toolkits to the various Genealogy groups in the state. (State Genetic Coordinators).
- “Just in time” information for pediatricians (online with CMEs) – end May 31, 2008...concise, user friendly form...two clicks – Project that the RCC would like the education committee to work on.
  - a. Approach the AAP orgs in each state to get buy in for the project.
  - b. Evaluate existing resources available i.e. Gene Reviews, Other educational sites that can provide information to Pediatricians quickly. Two clicks away by computer.
- Combine State’s information/education – send state info to Sharon – state by state presentation of information available.
  - a. What has been done already so that we do not have to reinvent the wheel?  
Eg Nebraska has NBS brochures translated in to various languages
  - b. Oklahoma has brochures on Breast cancer and Colon cancer screening
  - c. National Resources available – but we don’t necessarily all know what they are.
  - d. Genetic education modules available. Eg Christina Trout has developed genetics education modules for nurses.
- Physicians information/guidelines – genetic services available, analyze family health history, what are families finding out
  - a. Help physicians decide what is important in Family health histories once they are completed and brought in to the physicians office
  - b. Genetic red flags
- Website reference/Education Resources from Heartland Website for providers/parent (including parent-to-parent/young adults contact)
- Contact National organizations to find out what is being developed. Eg NCHPEG is developing one page summaries of different genetic conditions for physicians
- Ultimate goal is to develop a webcast specific for each Heartland state so that information relevant to the state can be disseminated. Genetic services, support group information etc.
- Family advisory group will find out family to family support information for their state.

#### Core Membership:

2 year membership

Teleconference calls every 4-6 weeks

Active participation on a project

Attendance at mid-year face-to-face meeting

Possible nomination to national work group

Short-term Goal: (By May 31, 2008)

Send Results to Sharon re: State resources

Send State's Parent-to-Parent Group List (Lay Advocates to do)

Long-Term Goal:

CME training for Physicians

NEXT MEETING (Phone call):

Thursday, Oct 4, 1:15 pm - 2pm

Discuss Resources, difficulties

\*\* Meetings First Thursday of every month