

**Education Workgroup
Annual Meeting--Sioux Falls, SD
Friday, September 12, 2008**

Facilitator: Sharon Vaz

Core Members: Kim Piper, Patricia Burk, Holly Johnson **Attendance:** James O'Leary, Jason Flanagan, Chuck Norlin, Julie Briggs, Julie Rayburn, Lisa Mofle, Michelle Leeker, Lisa Sanderson

- I. Introductions
- II. Membership/Core Membership
 - a. Request for any members who like to Facilitate in future
 - b. Update of who wants to be Core Members
 - c. Suggestions about future meetings
 - i. Holly Johnson – Advocacy group has had success with a Yahoo Group to contact with members. Michelle Leeker confirmed that it is helpful for those who cannot attend phone conferences due to day jobs. Will consider for the future.
- III. Utah MedHome Portal Collaboration on Web-based PCP Education Project
 - a. Review of overall plan for executive and function of project
 - i. Diagnostic Modules
 1. Current Activities
 - a. Down Syndrome
 - b. Neurofibromatosis
 - c. Hurlers Syndrome
 - d. Duchenne Muscular Dystrophy
 2. Under Construction:
 - a. Prader Willi
 - b. MCAD
 - c. Fragile X
 3. Future Additions/Suggestions:
 - a. Hearing Loss - update, suggest and CME questions
 - b. Core Panel Disorders – possibly lump into groups or making a skeleton of each section and carryover to each disorder within group (Amino Acids, Fatty Acid Oxidation, Organic Acid)
 - c. Spinal Muscular Atrophy
 - d. Link to Genetic Alliance and disorders
 - ii. AAP/AAFP collaboration
 - iii. CME/CEU credits
 1. ACMG agreed to provide CMEs for our regional + Utah
 2. CEU credits for other professions: Nurses, Social Workers

- IV. Nursing Genetics Education
 - a. Collaborating with University of Iowa's School of Nursing re: Nursing Educational Resources and Ideas for broader
 - i. Supporting Iowa's program
 - b. Ideas for broader regional collaboration
 - i. Look into:
 - 1. Other sites outside the Heartland Region who are also doing this type of training (i.e. John Hopkins, etc)
 - 2. Available resources and how they can overlap and fill gap
 - 3. Cost differences between programs
 - 4. Cross-listing Online Genetic Courses used for Heartland Genetic Counselors and making them available for Nurses

- V. Resources Education Resources
 - a. Collected Resources – everyone to view and provide feedback
 - b. Heartland Website Education Sections (Family and Professionals)
 - c. Suggestions to check the Parent Training and Information Centers & Family-to-Family Health and Information Centers