

ARKANSAS GENETIC HEALTH COMMITTEE MEETING MINUTES

May 8, 2012

Attendees:

*Bruce Haas
Carol Enderlin
Jackie Whitfield
Stephen Kahler*

Attendees:

*JoAnn Bolick
Kathy Shapley
Patricia Scott
Nancy Holder*

Carol Enderlin called the meeting to order at 3:41 pm. The minutes from the last meeting held on January 31, 2012 were reviewed by committee members. Carol asked for a motion to approve the minutes. A motion was made by Nancy Holder and seconded by Jo Ann Bolick.

Sub-Committee Reports:

Adult Sub-Committee Report:

The Adult-Sub-Committee met on April 10, 2012. Carol Enderlin reported that the committee had two new members to join the adult sub-committee; Julie Kettlewell from Arkansas Foundation for Medical Care and Christina Pettey from UAMS College of Nursing.

Ralph Vogel, past Arkansas Genetic Health Committee Chair, received an award of recognition on March 12, 2012 for his years of service on the Adult Genetics Health Committee at the Arkansas Cancer Summit XIII.

Carla Bell is on the Arkansas Cancer Coalition committee for revision of the State Cancer Plan. Dr. McKelvey or Jill Kelsay will speak at the ACC Quarterly meeting on May 15, 2012.

There is no further progress in collaborating with the Chronic Disease Forum conference planning committee.

The adult sub-committee discussed their upcoming goals for the next year. They are as follows:

- ✦ Consider opportunities to increase public & professional awareness of genetics health
- ✦ Possibly telecommunicating educational offerings
- ✦ Recommend opportunities to partner for educational purposes
- ✦ Suggested topics: pharmacogenetics, pharmacogenomics, personalized medicine, and ethical issues

Newborn Screening Sub-Committee Report:

Jo Ann Bolick gave the Newborn Screening sub-committee report. The last scheduled meeting was held on April 10, 2012 @ 3:00 pm. However, this report is from the January 10, 2012 meeting. The next scheduled meeting is July 10, 2012 @ 3:00 pm. Handouts were given to the committee members of the Newborn Screening Quarterly Update for SFY12 Quarter 2. Please see report attached to the minutes.

Update on SCID Report:

Leslie Himstedt reported that SCID would likely be ready by the end of 2013. Perkin Elmer, the Arkansas newborn screening lab vendor, is working on the kit, which is awaiting patent approval.

Critical Congenital Heart Disease Screening (CCHD) Update:

Dr. William Morrow, a Pediatric Cardiologist provided an update on what's going on with CCHD screening. CCHD has been added to the Secretary Recommended Newborn Screening Panel and Children's Hospital has submitted an application to HRSA for funding of the CCHD screening infrastructure development.

NBS Education Plan Update:

Dr. Patricia Scott reported the NBS brochure is in the process of being printed this month.

Specimen Transport Service Update:

The majority of hospitals are using the courier service for newborn screening specimens as requested. Dr. Patricia Scott reported their findings were that small, rural hospitals were using the courier service, whereas, larger hospitals in were not all using the specimen transport service. Several of the he larger hospitals continue to batch specimens, leading to delayed delivery time. They will be following delivery times to see if there are improvements after a few more months of implementation of the courier service.

Announcements/New Business:

- ✦ Dr. Bob West reported changes in CAH protocol implemented in March.
- ✦ Dr. Gulner Com reported five new adolescent cases of CF in the last month. All five cases had been treated for asthma.
- ✦ Millie Sanford reported that Infant Hearing has a new electronic web based system called ERAVE. The system will be able to link hearing screenings to vital records.

Pediatric Sub-Committee Report:

The Pediatric sub-committee met April 11, 2012. The next scheduled meeting is May 9, 2012 at 1:00pm. At the next meeting, committee members will discuss folic acid education.

The discussion at the meeting included a list of topics and content for the 2012 folic acid campaign. Strategies were discussed that would be beneficial to an audience of women of different ages, healthcare professionals, and others of interest. The committee members discussed the core content for the campaign as follows:

- ✚ Dosage
- ✚ Method of delivery
- ✚ Timing of folic acid supplementation
- ✚ Nutrition
- ✚ Other health benefits of folic acid
- ✚ Other information

New Business/Announcements:

The committee discussed ideas for an Arkansas genetics speaker's bureau. The committee agreed to further discuss the ideas at the next meeting.

Jo Ann Bolick announced the Heartland Annual Conference will be held October 2012 and the Newborn Screening Symposium will be held in May 2013.

Next Scheduled Meeting Date:

The next scheduled meeting will be September 11, 2012 at 3:30 pm Freeway Medical Building, 9th Floor Room 902.

The meeting was adjourned at 4:25 pm.