

ARKANSAS GENETIC HEALTH COMMITTEE MEETING MINUTES

January 31, 2012

Attendees:

*Carmen Paniagua
Carla Bell
Carol Enderlin
Jackie Whitfield
Stephen Kahler*

Attendees:

*JoAnn Bolick
Kathy Shapley
Martha Kuhlmann
Patricia Scott
Nancy Holder*

Carla Bell called the meeting to order at 3:45 pm. Committee members introduced themselves and stated how they became affiliated with the genetics committee. The minutes from the last meeting held on September 13, 2011 were reviewed by committee members. Carla asked for a motion to approve the minutes. A motion was made by Dr. Patricia Scott and seconded by Dr. Stephen Kahler.

Sub-Committee Reports:

Adult Sub-Committee Report:

The Adult-Sub-Committee met on November 18, 2011. Carol Enderlin began the meeting with an introduction of the Cancer Coalition conference planning committee and the Cancer Coalition's State Plan Revision Committee. Carol has met with the Cancer Coalition Summit planning sub-committee several times. The speakers are already planned and are related to health policy and legislation. However, an invitation was extended to the genetics committee to provide a speaker at the quarterly meeting to speak about cancer and genetics. The meeting is scheduled for May 15, 2012.

It has been confirmed that Ralph Vogel has been selected to receive an award for his years of service on the genetics committee and for his work in pediatric cancer. The award will be presented to him at the Awards Ceremony Reception on March 12, 2012 between 5-7 pm. Carol provided registration forms for committee members who would like to attend the ceremony.

The Arkansas Cancer Plan has been outsourced. There will be more information available about the plan in February regarding possible inclusion of information on cancer and genetics.

Carol Enderlin called Dr. Zohoori's office requesting a meeting to discuss how the genetics committee might contribute to the Chronic Disease Forum in the future. She was unsuccessful in reaching him and left a message with his secretary. Carol has not heard back from him at this time.

Newborn Screening Sub-Committee Report:

Dr. West gave the Newborn Screening sub-committee report. The last scheduled meeting was held on January 10, 2012 @ 3:00 pm. However, this report is from the October 11, 2011 meeting. The next scheduled meeting is April 10, 2012 @ 3:00 pm. Handouts were given to the committee members of the Newborn Screening Quarterly Update for SFY12 Quarter 1. Please see report attached to the minutes.

Update on SCID Report:

Jo Ann Bolick reported there were no updates or changes since the last meeting. The start-up of the screening is scheduled for potentially late 2012-2013. There are several states jumping on board with adding the SCID screening, particularly California and Michigan. Jerry Brown, Governor of California, signed the SCID screening into law on October 6, 2011. Also, there was a news release on October 6, 2011, that Michigan has added the SCID screening to the newborn screening panel.

Performance Evaluation and Assessment Scheme (PEAS):

Dr. Patricia Scott gave a brief description of what PEAS is and how it is being implemented in the Newborn Screening Program in Arkansas. PEAS (Program Evaluation and Assessment Scheme), is a published tool that has been piloted among some other state newborn screening programs. There are three sections: Pre-Analytic, Analytic, and Post-Analytic, along with a cross cutting section. Dr. Scott said the lab and the follow-up program are working together on the process and the tool would be a good way to see how we are doing and how we can improve.

As part of the Newborn Screening's education plan, the website has been updated. Some of those changes include adding sites and making the site more readable for parents. A new addition to the website was a new national clearinghouse called babysfirsttest.org. The website is a work in progress. Pediatric Genetics education and outreach to primary care providers is also a part of the education plan. Pediatric Genetics provides education and training to primary care physicians around the state on newborn screening. Training was done at the AHEC's targeting nurses working in PCP offices. Pediatric Genetics will be going back out to offer this same newborn screening training to PCP offices and providing them with posters that show an algorithm outlining steps to take when they are notified by ADH NBS nurses of a baby with an out-of-range NBS result.

Pediatric Sub-Committee Report:

The Pediatric sub-committee met November 2, 2011. The next scheduled meeting is March 21, 2012 at 1:00pm.

The topic of discussion for this meeting was the folic acid campaign. Based on discussion and input, there is a definite need and strong interest in the project. Since the last committee meeting, several sources of monetary support have been identified. Committee members reviewed potential partners & collaborators they would like to invite as participants. The committee reviewed current participants in the campaign. The consensus from committee members is to add to the list of current participants. Those potential participants to be added are:

- ✚ College of Nursing (Carmen Paniagua)
- ✚ Hispanic community (Eddie Ochoa to give suggestions)
- ✚ Parent representative (possibly Julie Mayberry & Rodney Farley)
- ✚ Arkansas Department of Education
- ✚ ACH Media
- ✚ Country extension services
- ✚ WIC
- ✚ FAS (Carol Rangel)
- ✚ Higher Education

At the next meeting, committee members will bring suggestions for the folic acid campaign, such as additional resources and funding, media formatting, and a list of topics and content to include in the campaign.

New Business/Announcements:

Carol Enderlin announced that Bruce Haas is no longer the Program Director/Chairman of the UAMS graduate program in genetic counseling. Bruce requested that someone else from the adult sub-committee volunteer to serve as secretary. No one has volunteered at this time. The adult sub-committee has not scheduled their next meeting.

Dr. Scott discussed the new developments in specimen transport. Some hospitals were already using the courier service to transport microbiology and other specimens to the lab. Dr. Scott drafted a letter to go out to the hospitals offering the courier service. The outreach nurse, Mary Jean Gresham contacted all of the hospital nurseries offering the courier service as well. Mary Jean also reminded them of the rules and regulations for newborn screening law, which states that the specimens should be delivered within 48 hours of collection. The hospitals showed interest in wanting to use the courier service immediately. As of the last meeting, Leslie Himstedt reported that the majority of the hospitals were using the courier service as requested. There are a few hospitals that are still sending the specimens via mail. It's been a few months since the courier service process began. Dr Scott said we should see significant improvement in those hospitals that haven't begun using the courier service. Over all, the process is going well.

The newborn screening sub-committee had a lot of discussion on CCHD. Jo Ann Bolick suggested that the group invite Dr. William Robert Morrow, MD, a pediatric cardiologist at UAMS/ ACH to the January meeting. Dr. Morrow could provide an update to the group about what's going on at the national level for CCHD. The newborn screening sub-committee met on January 10, 2012, and Dr. Morrow gave a presentation on CCHD.

Next Scheduled Meeting Date:

The next scheduled meeting will be May 8, 2012 at 3:30 pm Freeway Medical Building, 9th Floor Room 902.

The meeting was adjourned at 4:48 pm.