

ARKANSAS GENETIC HEALTH COMMITTEE MEETING MINUTES

September 11, 2012

Attendees:

Carla Bell
Carol Enderlin
Jackie Whitfield

Attendees:

JoAnn Bolick
Patricia Scott
David Grimes

Carla Bell called the meeting to order at 3:40 pm. The minutes from the last meeting held on May 8, 2012 were reviewed by committee members. Carla asked for a motion to approve the minutes with one minor change. A motion was made by Carla Bell and seconded by Patricia Scott.

Adult Sub-Committee Report:

Dr. Carol Enderlin gave the Adult sub-committee report. The Adult sub-committee has not met since the last meeting, but is in the process of scheduling their next meeting. UAMS Nursing has scheduled Dr. Hackler to give a presentation on Ethics & Genetics on September 19, 2012. Carla Bell is scheduled to give a presentation to UAMS Pediatric Nurse Practitioner students this fall on the importance of assessing family history.

Newborn Screening Sub-Committee Report:

Jo Ann Bolick gave the Newborn Screening sub-committee report. The last scheduled meeting was held on July 10, 2012 @ 3:00 pm. The next scheduled meeting is October 9, 2012 @ 3:00 pm. Handouts were given to the committee members of the Newborn Screening Quarterly Update for SFY12 Quarter 4. Please see report attached to the minutes.

Leslie Himstedt reported there were no new updates on SCID and we are still awaiting FDA approval of the new kits from Perkin Elmer. The Arkansas Department of Health has recommended the newborn screening laws be amended to add newest screenings: SCID & CCHD.

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

Dr. Patricia Scott reported the NBS brochures final English and Spanish versions have been printed and disseminated to all the birthing hospitals in the state of Arkansas. The local health units and ADH MCH programs will be able to order brochures from Central Supply. The brochure has been added to the ADH NBS website and can be downloaded as needed.

Dr. Patricia Scott reported the focus of the specimen transport service has now transitioned to the larger hospitals, which are not using the courier service and continue to batch samples and have delayed delivery times to the PHL. Dr. Scott, Dr. West, and Dr. Schaefer met with lab administrators at Baptist Health Medical Center & St. Vincent Infirmary Medical Center to discuss the importance of timely specimen delivery to the PHL. The next scheduled site visits are at UAMS and Willow Creek Medical Center.

Dr. Kathryn Thrailkill suggested an award incentive to commend hospitals for using the courier service and publicly acknowledging those hospitals for rapid turnaround time in sending the specimens to the laboratory. The incentive award would be a newsletter or posting the top three hospitals on the ADH-NBS website per month or quarter. The committee members agreed to have the award program and it will be called Positive Reinforcement for Hospitals.

Pediatric Sub-Committee Report:

Carla Bell gave the report on the Pediatric sub-committee. Carla Bell reported the Folic Acid campaign was moving along as scheduled. Dr. Brad Schaefer asked the Folic Acid committee to come to a consensus on how the Folic Acid campaign would be promoted. Once a decision is made on how the campaign will be promoted, Dr. Brad Schaefer asked for an estimate of the cost and he will pursue funding opportunities for the folic acid campaign.

New Business/Announcements:

Dr. Patricia Scott added that some of the midwives expressed interest in obtaining copies of the brochure to give to parents, along with training opportunities of how to do a newborn screening test correctly. Carla Bell stated that she belongs to a committee of about 25-30 midwives in Arkansas that meet regularly. Carla Bell said she could take over copies of the brochures to their next meeting and find out if there are other midwives interested in training opportunities.

- The committee agreed to establish an Arkansas genetics speaker's bureau. Carla Bell will present a statement to the committee for the speaker's bureau at the next meeting.
- Jo Ann Bolick and Dr. Patricia Scott will be attending the Heartland Annual Conference which will be held on October 3-5, 2012 in St. Louis, Missouri.
- Jo Ann Bolick has completed the 2010-2011 annual report for ANGELS-NBS and will share it with the group.

Next Scheduled Meeting Date:

The next scheduled meeting will be January 29, 2013 at 3:30 pm Freeway Medical Building, 9th Floor Room 902.

The meeting was adjourned at 4:45 pm.