

ARKANSAS GENETIC HEALTH COMMITTEE

NEWBORN SCREENING SUB-COMMITTEE MEETING MINUTES

July 10, 2012

Attendees:

Bob West
Jackie Whitfield
Leslie Himstedt
Millie Sanford
Sarah Eroh
Kathryn Thrailkill

Attendees:

JoAnn Bolick
Com Gulner
Patricia Scott
Robert Saylor
Chad Rodgers
Jason Ketcher

JoAnn Bolick called the meeting to order and asked for introductions of committee members. Jason Ketcher is the newest member to join the committee. Jason is the Newborn Screening Coordinator liaison between UAMS & ADH.

The minutes from the last meeting held on April 10, 2012 were reviewed by committee members. JoAnn asked for a motion to approve the minutes. A motion was made by Leslie Himstedt to approve the minutes, with one minor change. All committee members approved the minutes with the change.

Newborn Screening Quarterly Report:

Handouts were given to committee members of the Newborn Screening Quarterly Update for SFY12 Quarter 4. Dr. West reported in the fourth quarter the following:

- ✚ Congenital Adrenal Hyperplasia- 0 cases reported
- ✚ Cystic Fibrosis- 2 cases reported
- ✚ Biotinidase Deficiency- 2 cases reported
- ✚ Amino Acid Disorders- 1 case reported
- ✚ Organic Acidemias- 0 cases reported
- ✚ Fatty Acid Oxidation Defects- 0 cases reported
- ✚ Congenital Hypothyroidism- 7 cases reported
- ✚ Galactosemia- 0 cases reported
- ✚ Hemoglobinopathies- 6 presumed cases reported (5 presumed sickle cell and 1 presumed sickle Hb C disease)

Update on SCID Screening:

Leslie Himstedt reported there were no updates at this time. Perkin Elmer is scheduled to have the SCID screening kit ready and FDA approved by the end of 2013. Dr. West added that the Arkansas Department of Health will recommend amending the newborn screening laws to give the Board of Health authority to add other screenings, including SCID & CCHD.

NBS Education Plan Update/NBS Program Brochure:

Dr. Patricia Scott presented the final English and Spanish versions of the Newborn Screening brochure to committee members. The brochures will be disseminated in the next few weeks to all birthing hospitals within the state of Arkansas. The brochures will also be kept in central supply for ordering by local health units and ADH MCH programs, and has been uploaded to the ADH NBS website. Mary Jean Gresham, the nurse educator, will also take brochures with her on site visits to the hospitals.

Dr. Scott and Dr. West reported that Arkansas received two federally funded early childhood home visitation grants. One supports the ADH home visitation program, the Nurse Family Partnership, that provides RN home visits to low income first time mothers. The other funds the Home Visiting Network. ADH is the lead agency and the office will be housed at ACH. The network consists of several partner agencies in Arkansas that deal with home visitation. The focus is on expansion and evaluation of home visitation services. The network is also developing a Home Visiting Training Institute for home visitors to ensure consistent skills and professional development.

Specimen Transport Service Update:

Dr. Patricia Scott reported the specimen transport is improving. The smaller rural hospitals are using the courier service, but most of the larger hospitals were not using the courier service. Based on the current specimen delivery time data, Dr. Scott said the focus would be on the large, urban hospitals not using the courier service. Dr. Scott, Dr. West, and Dr. Schaefer scheduled site visits with lab administrators at Baptist Health Medical Center & St. Vincent Infirmary Medical Center to discuss the importance of using the courier service. The hospital site visits went well and administrators were committed to improving the transporting of the specimens. The next site visits are scheduled with UAMS and Willow Creek.

Dr. Kathryn Thrailkill suggested the idea of coming up with an award incentive to commend hospitals for using the courier service. Dr. Thrailkill said the award incentive would be a way of motivating and publicly acknowledging the hospitals for rapid turnaround time in submitting the specimens to the laboratory quickly. Dr. Thrailkill suggested starting a newsletter or posting the top three hospitals on the ADH-NBS website per month or quarter.

Dr. Patricia Scott stated those ideas were being considered. Mary Jean Gresham, the nurse educator, brings a data sheet to the hospital site visits to keep the hospitals informed of the areas that are lacking, as well as the areas of improvement. Dr. Scott and JoAnn Bolick thought it would be a good idea to further explore the ideas suggested by Dr. Thrailkill. JoAnn Bolick asked committee members for suggestions on what the award incentive would be called. Suggestions were Quality Improvement Reward System, Certificate Appreciation, and Positive Reinforcement for Hospitals. The committee agreed to call the award incentive Positive Reinforcement for Hospitals. This item will be added to the next meeting's agenda for further discussion.

Update of CCHD Screening (Grant Application):

In Diane McDaniel's absence, JoAnn Bolick gave the update on the CCHD screening grant application. Arkansas Children's Hospital submitted a grant application for newborn screening for CCHD in January, but received notification in May they were not selected to receive grant funding. ACH is still moving forward with developing an infrastructure and has a website that has resources and information for hospitals and providers. There are 5-7 hospitals that have voluntarily started newborn screening for CCHD. Some of these hospitals include UAMS, ACH, St. Vincent Infirmary Medical Center, and Baptist Medical Center. JoAnn Bolick passed around information about CCHD regarding the states of Georgia, Texas, and Indiana. Indiana started a state mandate on January 1, 2012.

Announcements/New Business:

- ✚ Dr. Gulner Com will do a presentation at the January 8, 2013 meeting on Cystic Fibrosis Metabolic Syndrome.
- ✚ Heartland Genetics & Newborn Screening Collaborative annual Conference will be October 3-5, 2012.
- ✚ ANGELS-NBS is working on an Annual Report for 2010-2011.

Next Scheduled Meeting Date:

JoAnn announced the next scheduled meeting would be October 9, 2012 at 3:00pm Freeway Medical Building, 9th Floor Room 902. Please email Paula Jackson with any items to be placed on the agenda.

The meeting was adjourned at 4:10pm