

ARKANSAS GENETIC HEALTH COMMITTEE

NEWBORN SCREENING SUB-COMMITTEE MEETING MINUTES

January 10, 2012

Attendees:

Bob West
Jackie Whitfield
Leslie Himstedt
Millie Sanford
Melissa Alvarado
Kathryn Thrailkill
Diane McDaniel
Ashley Ross

Attendees:

JoAnn Bolick
Com Gulner
Patricia Scott
Terrence R. Love
Chad Rodgers
Erin Berry
William Morrow
Holly Bante

JoAnn Bolick called the meeting to order at 3:00. The minutes from the last meeting held on October 11, 2011 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 and seconded by Jackie Whitfield.

Critical Congenital Heart Disease Screening (CCHD) Update:

Dr. William Morrow, a Pediatric Cardiologist at Arkansas Children's Hospital gave a presentation on newborn screening for CCHD. Dr. Morrow discussed the relevance of why this disorder should be screened for, the updates on the disorder from the national perspective, the implementation of a demonstration program in Arkansas (with a grant opportunity), and the strategies for adding the disorder to Arkansas' Newborn Screening tests and implementing this in Arkansas. . For further information of Dr. Morrow's presentation, please refer to the power point presentation attached.

Newborn Screening Quarterly Report:

Handouts were given to committee members of the Newborn Screening Quarterly Update for SFY12 Quarter 2. Dr. West reported in the second quarter the following:

- ✓ Congenital Adrenal Hyperplasia- 1 case reported
- ✓ Cystic Fibrosis- 1 cases reported
- ✓ Biotinidase Deficiency- 4 cases reported
- ✓ Amino Acid Disorders- 4 cases reported
- ✓ Organic Acidemias- 0 cases reported
- ✓ Fatty Acid Oxidation Defects- 1 case reported
- ✓ Congenital Hypothyroidism- 3 cases reported

- ✓ Galactosemia- 2 cases reported
- ✓ Hemoglobinopathies- 7 cases reported

Update on SCID Screening:

Leslie Himstedt reported she spoke with Linda Carter from Perkin Elmer. A meeting is scheduled for next month. There are no new updates on SCID at this time.

NBS Education Plan Update:

Erin Berry, UAMS Genetic Counseling student introduced a mock up Newborn Screening parent brochure for the state of Arkansas. The brochure was introduced to committee members for their feedback on improvements, changes, and corrections. Erin's goal was to ensure the content in the brochure met the expectations of parents who wanted to know specific information concerning their newborn. Dr. Patricia Scott passed around some examples to committee members of what's currently being used. One brochure is the current Arkansas NBS brochure that is being used, and the other was a parent brochure developed by the National Newborn Screening and Genetics Resource Center, HRSA, and the Academy of Pediatrics. Any feedback concerning the brochure will be sent to Dr. Patricia Scott who will oversee development of the new AR NBS parent brochure.

Specimen Transport Service Update:

Leslie Himstedt stated the majority of hospitals are using the courier service as requested. There are still a few hospitals that are sending the specimens via mail and may be still holding some specimens until there is enough to mail out. Over all, the process is going well. Dr. Scott added it's only been a couple of months since the hospitals began using the courier service. She said we should see significant improvement in those hospitals that haven't began using the courier service. Also, the nurse educator, Mary Jean Gresham, has been visiting the hospitals in the state educating nursery and lab staff on why it is so important to use the courier service to ensure timeliness of specimen delivery.

Announcements/New Business:

Dr. Bob West said that changes will be made to the protocol for CAH. There are some concerns about the second tier (steroid profile) methodology in detecting cases of simple virulizing CAH. We will be reducing reliance on the steroid profile ratio and relying more on the initial 17-OH screening result to help ensure that all forms of the disorder are detected. New cut-offs will be established for birthweights above and below 2500 grams. PCPs will be requested to closely monitor babies with abnormal screening results for clinical and lab findings. Dr. West is hoping to have this protocol implemented later on this month.

Jo Ann reported that the Newborn Screening long term database has started as of January 9, 2012.

Dr. Com Gulner, a pulmonologist at UAMS, reported there will be a meeting with Dr. Brad Schaefer regarding follow-up on sweat tests for newborns with inconclusive results to address all the possibilities. The meeting with Dr. Schaefer will clarify specifics as to what should be done.

Dr. Gulner also reported that five new adolescent CF cases were diagnosed last month. Two of the five were siblings. All had been treated for asthma.

Millie Sanford reported that Infant Hearing continues to work on the electronic web based system, ERAVE. The system began development about three years ago and will be able to link hearing screens to vital records. The system is now being tested internally to work out any discrepancies. The system will then be piloted by some hospitals that have volunteered. It will be available to clinics that provide diagnostic testing and primary care physicians throughout the state. Dr. West added that Dr. Tariq Ali is the new Infant Hearing Program Manager. Dr. Ali is a medical doctor and has his master's degree in Public Health. An invitation to Dr. Ali will be extended to join the newborn screening sub-committee and attend the quarterly meetings.

Next Scheduled Meeting Date:

JoAnn announced the next scheduled meeting would be April 10, 2012 at 3:00pm Freeway Medical Building, 9th Floor Room 902.

The meeting was adjourned at 4:40pm