

ARKANSAS GENETIC HEALTH COMMITTEE MEETING MINUTES

January 25, 2011

Attendees:

Bob West
Bruce Haas
Carla Bell
Carmen Paniagua
Jackie Whitfield
JoAnn Bolick

Attendees:

David Grimes
Martha Kuhlmann
Nancy Holder
Ralph Vogel
Carol Enderlin

Ralph Vogel called the meeting to order and asked for introductions of committee members. The minutes for September 14, 2010 meeting were approved by committee members as written.

Revisions of Arkansas Genetics Plan Update:

Carla Bell explained the revisions to the Arkansas Genetics Plan. They are as follows:

- ✓ Statistics of Arkansas Newborn Screening projected cases as of 2009 preliminary data.
- ✓ The number of positive screens compared to other states. (Carla stated through her observation, she noticed as the years go forth, the number of positive screens narrowed.)
- ✓ The laboratory table goals and objectives organized for Essential Public Health Services.
- ✓ Information from sub-committee meeting minutes were added into the table and updated as of 2011. Any changes or additions can be added to the table by the sub-committees.
- ✓ Laws for Arkansas Genetics appendix was not updated, therefore was not included in the document for revisions.
- ✓ Appendix for names of Arkansas Genetic Health Committee members as well as sub-committee members was not included in the revision document. Carla said she did not have that information to make the update. Carla said she would add the information into the revised document once she received the lists.
- ✓ Appendix for 55-65 references that need to be updated on the website was not included in the revised document at this time.

Carla stated that this document would never be a complete document. Revisions will constantly be made as new updates and changes become available. Carla recommended that the document be revised once a year in January. Carla asked for a list of the committee members to be given to her so that she can send an electronic copy of the genetics plan to each committee member via email. The secretary agreed to provide Carla with a list of the committee members.

Ralph stated he thought it would be a good idea to have the revisions done once a year as suggested by Carla. Ralph asked for a motion to adopt the revisions as they are or asked if the committee members would like some time to review the revisions. Carol suggested that the committee members be given time to review the document for any changes or corrections.

Ralph set a deadline for revisions to the genetics plan to be submitted by February 11, 2011. The next Friday, February 18, 2011 is when committee members will vote by email for the revisions to the Arkansas Genetics Plan.

Sub-Committee Reports:

Newborn Screening Sub-Committee Report:

Dr. West gave the Newborn Screening sub-committee report. Since the last Arkansas Genetics Health Committee meeting, Newborn Screening sub-committee has met twice. The next scheduled meeting is April 12, 2011 @ 3:00pm. Dr. West reported on the status of state implementation of SCID & Critical Cyanotic Congenital Heart Disease.

Critical Cyanotic Congenital Heart Disease Report:

At the last meeting Dr. Morrow, a Cardiac Pediatrician gave a presentation on Critical Cyanotic Congenital Heart Disease. In the sub-committee meeting, the committee members agreed it would be good for Dr. Morrow to return for an update on CCCHD.

Arkansas has been selected to be a part of the pilot process for the Critical Cyanotic Congenital Heart Disease newborn screening test. The process is to gather data for one year to show and work out any details before implementing statewide. Dr. West said details were to follow once the test has been implemented on how parents would follow up with their newborns that have tested positive for this disorder.

SCID Report:

Dr. West stated the details were being worked out for the lab method and the cost to each additional test headed off by Immunologist, Dr. Amy Scurlock. The administrative aspect of the disorder would have to be approved by the board of health and legislature. The newborn would be referred to Duke University who are skilled in treating SCID newborns with this disease. Within the last decades, Duke University has performed two hundred bone marrow transplants with good results.

Pediatric Sub-Committee Report:

JoAnn Bolick submitted the Pediatric sub-committee report. The Pediatric sub-committee met November 3, 2010. The next scheduled meeting is March 16, 2011. The pediatric sub-committee meets three times a year. At the January meeting:

- ✓ It was proposed that topics should be sequentially prioritized at each meeting.
- ✓ To have recommendations for each topic to forward to Arkansas Genetic Health Committee and Arkansas Department of Health.

Discussions on recommendations made to Arkansas Genetics Health Committee for medical transition were made. The idea was to collect information, finalize, and revise the proposed recommendations. Those recommendations are as follows:

- ✓ Provide options for sharing questionnaire results of Title V transition results with Arkansas Primary Care Physicians.
- ✓ Arkansas should apply for transition grants with Department of Health and UAMS partners.
- ✓ Professional social workers should be utilized in these efforts.

- ✓ Medicaid regulations should be mandated for EPDST visits, focusing on transition at fourteen or sixteen years old.
- ✓ Educate Arkansas health providers and UAMS staff about medical transition.
- ✓ Implement a joint plan with Department of Education to coordinate educational and medical transitioning.

At the November meeting, the topic of discussion was Congenital Anomalies and the assessment of the environmental care for individuals with congenital anomalies in Arkansas. Recommendations regarding congenital anomalies to the Arkansas Genetics Health Committee are as follows:

- ✓ Develop a second option for folic acid prevention with March of Dimes and UAMS.
- ✓ Promote statewide education of FAS to health care providers and partner with MRFASTC (Midwest Regional FAS Training Center.)

Funding Efforts Proposed:

- ✓ Genetics outreach clinics
- ✓ Tele-genetic services
- ✓ Teratogen information system
- ✓ Pediatric sub-committee and College of Nursing work together in developing a CEU curriculum in genetics and birth defects.

Adult Sub-Committee Report:

Bruce Haas gave the Adult sub-committee report. The Adult sub-committee met October 5, 2010. The next meeting is tentatively planned for late January 2011, time and place is to be announced. The minutes for the Adult sub-committee meeting are awaiting approval. At the last Adult sub-committee meeting, Bruce Haas was voted as the new sub-committee chair/co-chair. Carol will take the meeting minutes and assist Bruce as needed. Discussion of offering core content on education of genetics based on NCHPEG recommendations for interested UAMS staff was suggested. No final decision has been made at this time.

Next Scheduled Meeting Date:

The next scheduled meeting will be **May 10, 2011 at 3:30pm** Freeway Medical Building, 9th Floor Room 902.

The meeting was adjourned at 4:35pm.