

**ARKANSAS GENETIC HEALTH COMMITTEE MEETING MINUTES**

**September 13, 2011**

**Attendees:**

**Bruce Haas  
Carla Bell  
Carol Enderlin  
Jackie Whitfield  
Ralph Vogel**

**Attendees:**

**JoAnn Bolick  
Bob West  
Martha Kuhlmann  
Patricia Scott  
David Grimes**

Ralph Vogel called the meeting to order at 3:10 pm and asked for introductions of committee members. The minutes for May 10, 2011 meeting were approved by committee members as written.

**Selection of Chairperson & Co-Chairperson:**

Ralph opened the floor for to committee members to nominate a new Chairperson and Co-chairperson. A motion was made by JoAnn Bolick and seconded by Carol Enderlin to nominate Carla Bell as the new Chairperson for the Arkansas Genetics Health Committee. A motion was made by JoAnn Bolick and seconded by Carla Bell to nominate Carol Enderlin as the new Co-chairperson for the Arkansas Genetics Health Committee. All committee members voted in favor of electing Carla Bell and Carol Enderlin. Ralph announced that Carla would take over as Chairperson effective immediately.

**Sub-Committee Reports:**

**Newborn Screening Sub-Committee Report:**

Dr. West gave the Newborn Screening sub-committee report. The next scheduled meeting is October 11, 2011 @ 3:00pm. Handouts were given to the committee members of the Newborn Screening Quarterly Update for SFY11 Quarter 4. Please see report attached to the minutes.

**Update on SCID Report:**

Dr. West reported that Perkin Elmer, the primary vendor for Arkansas's newborn screening laboratory, is pursuing development of an automated immunoassay for SCID that may be FDA-approved and commercially available by the end of 2012.

This method may be more feasible and cost effective for us than PCR, the method currently used by SCID pilot states. Dr. West mentioned that Leslie Himstedt has been working with a Perkin Elmer representative to keep up with test kit development. Dr. West anticipates that Arkansas will be adding SCID screening by late 2012, about the same time that the majority of other states will be adding the screen.

**Performance Evaluation and Assessment Scheme (PEAS):**

Dr. Scott said that she and other committee members have been discussing what needs to be done for some type of self assessment and program evaluation for the Newborn Screening program. A published tool that has been piloted among some other state newborn screening program is the PEAS (Program Evaluation and Assessment Scheme). PEAS was developed as a cooperative agreement between HRSA and the National Newborn Screening and Genetics Resource Center. Dr. Scott stated that this would be timely for us to get started on program evaluation, especially before any new screenings are implemented. There are three sections: Pre-Analytic, Analytic, and Post-Analytic, along with a cross cutting section. Leslie Himstedt will utilize PEAS in the lab and it complements the current CQI process. Dr. Scott said this tool would be a good way to see how we are doing and how we can improve.

**Selection of Sub-Committee Chair:**

Dr. West announced that elections were held at the last meeting for a new NBS Sub-committee Chair and a new Co-Chair. The NBS Sub-Committee unanimously voted to elect JoAnn Bolick as the new NBS Sub-Committee Chair and Dr. Patricia Scott as the new NBS Sub-Committee Co-Chair.

**Heartland Meeting Report:**

Dr. Schaefer, JoAnn Bolick, and Dr. Patricia Scott attended the Heartland Meeting held in Bismarck, North Dakota from August 24-26, 2011. Key topics included long-term follow-up and CQI.

**Pediatric Sub-Committee Report:**

The Pediatric sub-committee met July 6, 2011. The next scheduled meeting is November 2, 2011 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.

They are as follows:

- ✓ Arkansas State Department of Health
- ✓ Arkansas Medicaid
- ✓ Arkansas Children's Hospital
- ✓ UAMS (Department of Pediatrics, Perinatology, Genetics)
- ✓ Heartland's Regional Genetics Collaborative
- ✓ March of Dimes
- ✓ Spina Bifida Association

The Pediatric Sub-Committee will convene an ad hoc meeting inviting key stakeholders to make definitive plans for the campaign. During this meeting, things to be accomplished will include:

- ✓ Request for formal commitments of participation
- ✓ Sources/amounts of financial support
- ✓ Review of materials developed during the last campaign (Information needs to be updated)
- ✓ Review of existing materials from other programs (Adapt for Arkansas)
- ✓ Evaluate need for cultural options (Spanish speaking materials in particular)
- ✓ Specific discussions about the role of social media options
- ✓ Establish a plan for roll-out. Identify priority lines of dissemination. Could include, but not limited to:
  - ✚ Physicians (OB/FP/Pediatric) and Nurses
  - ✚ Schools (Nurses, Nutritionists, Health Educators)
  - ✚ Classic media (TV, Newspapers, Pamphlets)
  - ✚ Social Media

**Action Items:**

Bettye Baxter will share collected information from the last campaign.

- ✓ Dr. Brad Schaefer will distribute to the group

Brad's office will work on scheduling an organizational meeting in early September.

- ✓ Ask committee members to send information on any other key stakeholders that we have not identified to invite.

**Adult Sub-Committee Report:**

The Adult-Sub-Committee did not meet last quarter, but will schedule a meeting for this quarter.

Carol Enderlin mentioned at the last meeting, the Arkansas Genetics committee voted to become a partner of the Arkansas Cancer Coalition. Carol also became a member individually of the Cancer Coalition as well. Dr. West agreed to be the emissary for the Arkansas Cancer Coalition on behalf of the Arkansas Genetics committee. Carol attended the meeting that was held by the Cancer Coalition. She discussed the new genetics plan that Arkansas has in place.

**New Business/Announcements:**

Ralph discussed his involvement with the LEND (Leadership in Education Development on Disabilities) program in the issue of transition. Transition for children with special health care needs from pediatric to adult health care is an important topic for all the Genetics Subcommittees. Ralph encouraged the Subcommittees (especially the Adult Subcommittee) to stay involved with transition issues and collaborate with LEND.

JoAnn Bolick gave additional comments on the Heartland meeting that she, Dr. Patti Scott, and Dr. Schaefer attended in Bismarck, North Dakota. The Newborn Screening Program & Genetics Program Activity centers, for the state of North Dakota, were the topics highlighted at this meeting. Other presentations included, fetal alcohol syndrome, newborn screening long term follow up, metabolic nutrition, and Heartland pilot projects. As of this year, the group has decided to alternate conferences between St. Louis, Missouri and Kansas City, Kansas to cut down on cost. Next year's meeting will be in St. Louis, Missouri. Dr. Scott added that there was a big emphasis on quality improvement nationally. There is a new clearing house for newborn screening, "Babies First Test," ([babysfirsttest.org](http://babysfirsttest.org)).

JoAnn announced that the ACH/UAMS research project, Arkansas Newborn Screening Long Term database received IRB approval.

**Next Scheduled Meeting Date:**

The next scheduled meeting will be **January 31, 2012 at 3:30pm** Freeway Medical Building, 9<sup>th</sup> Floor Room 902.

The meeting was adjourned at 3:55pm.