

MINUTES

Oklahoma Genetics Advisory Council
October 15th, 2009
Oklahoma State Department of Health
Oklahoma City, OK

14 Council Members Present: Barbara Neas, John Mulvihill, Mary Rindler, Linda Terrell, Dewey Scheid, Larry Weatherford, Nancy Carpenter, Andrew Wagner, Mike Kayser, Annette Johnson for Joan Cain, Sohail Khan for Melissa Gower, Joni Bruce for Tara Lorg, Lori Williamson and Heather Poole for Lynn Mitchell.

10 Council Members Absent: James Coldwell, Laurie Applekamp, Melissa Craft, Grant Cox, James Lewis, Patti Davis, Susan Hassed, Frank Stone, Danny Cavett, and John Armitage.

10 Ex-officio Members Present: John Corpolongo, Sharon Vaz, Paula Vann, Kay Pearson, Jennifer Allen, Suzanna Dooley, Patricia Burk, Terry Geisler, Terry Johnsen, and Debbie Kline and Tonya McAlester for Garry McKee.

6 Ex-officio Members Absent: Amy Carte, Karen Hylton, Edd Rhoades, Jim Struby, Linda Thomas and Lisa Caton.

22 Visitors: Liz Moore, Sadie Welmor, Erin Davis, Kandace Westphal, Jae Lindsay Chaloner, Julie Keeth, Erica Cole, Ashley Davis, Chunyan Wang, Panithra Pumkumon, Whitney McBride, Kelly Usrey, Russell Gumford, Mary Monks, Ashley Ethridge, Stacey Silagi, Asheley Taylor, Sue Palmer, Diana Houon, Klaas Wierenga Jennifer Butler and Soheila (Sue) Haddad.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order and welcomed members and visitors. The minutes from OGAC meeting 5/21/09 were reviewed and approved.

Family Story

Joni Bruce related a poignant family story about a very young family whose baby was often hospitalized with a metabolic disorder and a heart defect. The Oklahoma Family Network was able to assist the family in obtaining special formula for their baby. Due to the family living in a rural area, special formula was not always easily accessible. The network was able to help them get approved for TEFRA and provided support. The Mom stated that “Foods which cannot be purchased in a grocery store should be considered a medical necessity and should be funded as such.” Joni discussed the copy of H.R. 3263 provided in the packet. The bill states that amounts paid for food for special dietary use, dietary supplements, or medical foods shall be treated as a medical expense. Dr. Neas requested that the policy committee consider how to approach the Commissioner on future legislation related to this topic.

OGAC Committee/Genetics Program:

OGAC Executive Committee: The executive committee set the agenda. Included in the packet are dates for future OGAC meetings.

GECO: Mary Rindler reported the committee met last Monday. They discussed a new theme and tentative days for “Genetics Day” at the Capitol -March 3rd or 10th. Family History Day will target AARP during Thanksgiving this year. They are working on the New York and Mid Atlantic region brochures and updating the Genetic Curriculum Book for science teachers. Patricia Burk met with the LEND students. She suggested having one student leader and dispersing LEND members throughout the OGAC Committees.

Family Advisory: Joni Bruce reported they have developed a “Family Leadership Database” where families share their stories. She related a study that showed pediatricians will treat patients with more empathy after hearing a family story. They offer in-service training and brochures printed by DHS.

Adult: Sharon Vaz reported they met last week. They plan to focus on creating a brochure on Familial Hypercholesterolemia (FH). Partners at the heart hospital will review the contents. Target population areas may include the Scotch-Irish population in Southeastern Oklahoma, West Virginia, Missouri and Arkansas. The committee will bring the Family Health History initiative to federally qualified health centers around the state and Native Americans tribes. Dr. Mulvihill discussed the handout “Family History and Improving Health”.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner reported the committee met. They discussed implementing a survey on how well obstetric care providers inform patients about the newborn screen. Sharon Vaz reported the Oklahoma Tobacco Trust is considering putting funds aside for future stem cell research. Sharon will be completing the first year report on stem cell research to be sent to the Governor and legislative leadership by December 31st.

Newborn Screening Program and Pediatrics: Sharon Vaz reported the metabolic work group has met to review cases.

Heartland Update: Lori Williams attended the annual Heartland Meeting in September. A new workgroup, “Early Hearing Detection and Intervention” has been formed with Patricia Burk as co-chair. This year Oklahoma will be included in the Newborn Screening laboratory back-up testing project drill. A mock disaster will occur and Oklahoma’s specimens will be sent to Missouri’s lab for testing. Eventually all of the eight Heartland States will have participated. The “Genetic Systems Assessment Project” pilot will occur early next year and Dr. Amy Bauer, a PHD Geneticist, has been hired to conduct the evaluations. The Heartland Pilot Project Program is issuing a new RFP due in

early December-see website for more information. The Sarah Lawrence Scholarship has been posted on the Heartland Website.

Evaluation Committee – Barbara Neas reported they are continuing to work on the evaluation report and plan to have a written report by December 1st.

Policy: Dr. Mulvihill reviewed the policy committee minutes and they were approved. The committee membership rolled over. Mark Newman continues to monitor new legislation. Federal ARRAS grant funding is available for a partnership between an academic health center and a community for building infrastructure.

Biotinidase Presentation (Dr. Kayser)

Dr. Kayser reviewed the handout on Biotinidase. Oklahoma is the only state not offering this screening. The disorder is rare and affects approximately 1 in 60,000 infants. PerkinElmer is developing a new FDA approved test kit. Debbie Kline, from the OSDH Lab, reported that they will be ordering the testing equipment soon and plan to be ready to start screening by January 2010.

Long term storage of dried blood spots- Update from town hall meeting and the Advisory Committee on Heritable Disorders in Newborns and Children-

Dr. Mulvihill and Sharon Vaz discussed the six hand-outs from the meeting. The graph of states storing dried blood spots indicates over 50% storing for over 18 yrs and 46% storing for less than three years. OSDH Lab stores for 42 days. Quality Assurance and research opportunities were discussed as valid reasons to store. John Corpolongo suggested that quality assurance could provide a good position to request the Commissioner's approval to store longer. Federal Guidelines are needed before proceeding in order to avoid any constraints on the Newborn Screening Program. Sharon said the Secretary Advisory Committee is taking the draft paper to ACOG. The Policy Committee will continue to research storage issues and track future legislative bills. Dr. Neas requested that the Newborn Screening Committee workgroups add education on storage to their agenda and encouraged all to read the six hand-outs.

Chair & Public Comments-

Dr Neas requested all review the handout "Are electronic health records ready for genomic medicine"? Dr. Mulvihill discussed a grant OUHSC wants to respond to on improving IT interfaces which could help reporting to the Birth Defects Registry. He will follow up with Kay Pearson. Sharon Vaz's long term goal is to get the Newborn Screening Web Base completed for pediatricians to access and she requested OGAC's support. Lori Williamson mentioned that the consultant they have hired will benefit the entire state with the "Data Linkage Assessment Project". Dr. Neas thanked the presenters and the audience. The meeting was adjourned.

Adjournment – The next meeting will be January 21, 2010 in Oklahoma City.