

MINUTES

Draft

Oklahoma Genetics Advisory Council

May 21, 2009

Youth Services Center

Tulsa, OK

10 Council Members Present: Barbara Neas, Nancy Carpenter, Andrew Wagner, James Coldwell, Laurie Applekamp, Mike Kayser, Annette Johnson for Joan Cain, Melissa Craft, Sohail Khan for Melissa Gower, and Lora Roberts for Tara Lorg.

16 Council Members Absent: Adolfo Garnica, Lori Williamson, Carole Keener, James Lewis, Patti Davis, Dana Stone, Susan Hassed, Dewey Scheid, Frank Stone, John Mulvihill, Mary Rindler, Larry Weatherford, Heather Poole, Danny Cavett, John Armitage, and Linda Terrell.

6 Ex-officio Members Present: John Corpolongo, Sharon Vaz, Kay Pearson, Terry Johnson, Amy Carte, and Debbie Kline for Garry McKee.

8 Ex-officio Members Absent: Suzanna Dooley, Karen Hylton, Edd Rhoades, Jim Struby, Terry Geisler, Linda Thomas, Patricia Burk and Lisa Caton.

7 Visitors: Debbie Kloker, Debbie Earley, Meredith Gatzemeyer, Casey Newman, Kaylee Paulsgrove, Melissa Hall, and Joan Burns.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order. Contents of the meeting packet and minutes were reviewed and approved. Dr. Neas welcomed members and visitors.

Family Story

Sharon Vaz introduced Lora Roberts. Her 10-year old son, Jeremiah, was diagnosed with FG syndrome. He has multiple health issues, including Hydrocephalus, Agenesis of the Corpus Callosum, congenital heart defects, and scoliosis. He was initially diagnosed with a hearing loss and was fitted with hearing aids but it was later discovered that he had a processing problem not an actual hearing loss. He is in school full time in a multi needs class and uses an assistive tech device. He was enrolled in a research project at the Greenwood Genetics Center in South Carolina but has since been discharged from the research protocol. FG syndrome is a syndrome that includes mental retardation, constipation, midline defects and kidney issues. Lora stated that she cofounded a support group for the Tulsa Area for families with children who have rare diseases. They meet every 3rd Saturday at St Francis in the classroom from 10:30 until noon and she provided information cards.

OSDH Newborn Hearing Program and Audiology Program

May is “Better Speech and Hearing Month”. Meredith Gatzemeyer, Joan Burns, Debbie Earley and Casey Newman, Audiologists for the Oklahoma State Department of Health –

Sooner Start and Child Guidance program presented an overview of the OSDH newborn screening hearing program. They discussed how families and newborns are referred to them and what the process is until diagnosis. They stated that one of the biggest problems they have is that most of their clients live in rural areas and that they have no access to genetic services. They also have difficulty with getting genetic counseling appointments because pediatric genetic counseling is not a covered service under Medicaid. The NBHS Program presented at the EDHI Conference in March. A copy of the presentation is provided in the packet

Heartland Genetics Collaborative Hearing Grant

Lori Williamson was unable to attend. Sharon Vaz gave a brief update on the proposed project sponsored by Dr Kimberling in Iowa. The proposal is to offer every family identified with a hearing loss on the newborn screen, genetic testing and pre/post genetic counseling as well as follow-up that have an identifiable mutation. The Oklahoma newborn screening program has agreed to participate if the grant is funded.

OGAC Committee/Genetics Program:

OGAC Executive Committee: The executive committee set the agenda via email. They also included several additional items recommended for discussion, including storage of the Newborn Screening Blood spot cards as well as completing expansion for Biotinidase testing.

Policy: John Corpolongo reported on behalf of the chair of the subcommittee. The policy committee has not met but has scheduled a meeting for August. John updated the Council on legislation that has been passed to allocate funds through the Tobacco Settlement Endowment Trust (TSET) to fund adult stem cell research. There is a possibility that some of the funds may be used to establish an umbilical cord blood bank. Also the Stem cell research database rules have to be resubmitted to the Board of Health because of a legal issue.

GECO: GECO has not met. However, the committee has had several activities. Genetics Day at the Capitol was a success. Several legislators attended and were educated about genetic services available in the state. The committee participated in DNA day activities in Lawton. This was a collaboration of several high schools with Cameron University. The focus of this activity was Sickle cell. Sharon gave the students a talk about the Genetics of Sickle cell disease as well as some of the medical aspects of the disease. The students did a floor activity about mitosis and meiosis and a wet lab on hemoglobin electrophoresis. Sharon also did a STARS training for the Sooner Start providers that was a daylong training and was well attended.

Family Advisory: Sharon Vaz and Lora Roberts reported on the joint activity with GECHO. Joining Forces is an annual conference that is collaboration between professionals and families to encourage collaboration and partnership. Several of the attendees were present at the OGAC meeting and reported that the meeting was very helpful and informative.

Adult: Melissa Craft- Committee met last Thursday the 14th of May. The committee has taken on the task of providing information and writing a brochure for Familial hypercholesterolemia. They have established a plan to do a literature review over the summer and to start working on the brochure.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner- reported on the Title V needs assessment and requested that members of the Council and their contacts fill out the needs assessment. The deadline for filling out the assessment is May 30th.

Newborn Screening Program and Pediatrics: Sharon Vaz reported that the NBS committee has not met but that there is a planned meeting in middle summer to evaluate the data from the expansion. Sharon also provided a review of the ACMG and APHL policy on storage of dried blood spots. She stated that there are discussions at the health department regarding this issue but that the biggest draw back to storage and to expansion to Biotinidase is space. The public health laboratory would like OGAC's support for allocating funds for a new public health laboratory.

Heartland Update: Sharon Vaz reported on the recent NBS meeting in Lincoln, Nebraska with the collaborative states to work on disaster preparedness between the newborn screening labs. One focus of this meeting was to establish a follow up preparedness plan.

Evaluation Committee – They are continuing to work on the evaluation report. Progress is being made and gaps identified. They would welcome volunteers and input from council members.

Chair & Public Comments-

Dr Neas informed the Council of the impending arrival of a Medical Geneticist to the OU Genetics Department, Dr. Klaus from the University of Miami.

Adjournment – The next meeting will be September 17, 2009 in Oklahoma City.