

MINUTES

Draft

Oklahoma Genetics Advisory Council

May 15, 2008

Tulsa Youth Services Center

Tulsa, Oklahoma

13 Council Members Present: Barbara Neas, John Mulvihill, James Coldwell, James Lewis, Carole Keener, Melissa Craft, Nancy Carpenter, Laurie Applekamp, Larry Weatherford, Heather Poole for Dr Lynn Mitchell, Dr.Rupa DeSilva for Dana Stone, Susan Hassed and Andrew Wagner.

12 Council Members Absent: Kayse Shrum, Patti Davis, Dalora Scheafer, Adolfo Garnica, Danny Cavett, Representative Al Lindley, Melissa Gower, Joan Cain, Linda Terrell, Mary Rindler, Tara Lorg, and Dewey Scheid

5 Ex-officio Members Present: John Corpolongo, Patricia Burk, Sharon Vaz, Kay Pearson, and Theresa Steckel.

10 Ex-officio Members Absent: Karen Hylton, Edd Rhoades, Jim Struby, Adeline Yerkes, Paula Vann, Terry Johnsen, Dedric Anderson, Terry Geisler, Garry McKee and Suzanna Dooley

10 Visitors: Mary Monks, Tracy Schaeffer, Fred Schaeffer, Jean Kidd, Russell LaCour, Ashley Ethriedge, Clara Van Hosen, Michael Kayser, Kay Romero, and Cheryl Freeman.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order. Dr. Neas asked presenters to give a brief outline of their topic and not to use acronyms due to the diverse audience. Contents of the meeting packet and minutes were reviewed and approved. E-mail Sharon Vaz for additional copies.

Family Story

Cheryl Freeman introduced Russell LaCour who presented the family Story. Mr. LaCour is a parent of a child with Sickle Cell disease, a copy editor for the Tulsa World Newspaper and a member of the Oklahoma Sickle Cell Advisory Council. His 8- year old son, Adam, has Sickle Cell Disease. Adam is a normal child until he has a pain crisis and has been hospitalized many times. His pain can be so severe that morphine only works for a few hours. Often the hospital emergency room staff isn't adequately trained to treat his pain episodes. Mr. LaCour misses time from work when Adam is in pain. Adam also misses school and could benefit from more support from the school system. Adam's parents have to be careful not be overly protective or overcompensate for Adam's illness. Mr. LaCour is thankful that both him and his wife work and have good insurance and transportation. They appreciate the support they get from the Sickle Cell Association. He feels that educating the public about Sickle Cell Disease is critical such as was done during Black History month last February. He thanked OGAC for the opportunity to speak.

Cheryl Freeman gave an update on the 5-year needs assessment plan for Sickle Cell Disease.

OGAC Committee/Genetics Program:

OGAC Executive Committee: The committee met last month. The meeting focused on legislative issues and the directive on genetic testing.

POLICY: Dr. Mulvihill- Policy committee did not meet. OGAC still has an informal network to track legislation. The white paper on storage of newborn screening dried blood spots is still on the agenda for the next policy meeting. John Corpolongo provided the following state legislation update. Two bills were signed this week. HB3060- authorizing a public cord blood bank contingent on state appropriation and private funding. Cost is estimated to be 3-4 million and Senator Gumm is seeking private donations. A maternity education outreach program is specified in the bill. The bill also provides an option for a contractual arrangement with another state's public cord blood bank if Oklahoma is not able to fund one. OGAC attendees are encouraged to read the bill and provide input. Storage will be a major issue. HB3126- creating the Advancement in Stem Cell Cures and Therapies Act. OSDH is to set up a tracking network on the kind of research defined in the legislation and what is permissible and a report to the legislature. Sharon Vaz will be involved in behalf of our agency on both bills. A bill requiring hyperbilirubenemia be added to the Birth Defects Registry was not heard. Nick's law, a bill proposing legislation requiring insurers to cover intervention and treatment for children on the autism spectrum has been taken up by a national advocacy group. Dr. Neas suggested that the policy committee continue to work on improving methods of informing OGAC of legislative issues.

GECO: Sharon Vaz - "Genetics Day" at the capitol on March 26, 2008 was very successful. Three hundred students participated in DNA day, April 15th at OCCC. The "Family Advisory Committee" family panel was very informative. GECO provided genetic toolkits to high school science teachers. The "Ferocious Beauty – Genome" dance performance was impressive. GECO applied for a grant last week and will speak at the "Daughters of the American Revolution" state convention about family health history August 21-23rd.

Family Advisory: Sharon Vaz – Tara Lorg attended a Saturday conference of the Oklahoma Family Network. The flyer provided in the packet was developed. Families are encouraged to the join the committee.

Adult: Melissa Craft- Committee met last week. The committee is still working on the Autoimmune Project. They are developing a descriptive exploratory pilot that examines the assessment of autoimmune disorders during general genetic counseling in a research way. They are ultimately looking at intervention by working with chronic disease to provide resources and support.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner- reported the Oklahoma Birth Defects program was nominated by the National Birth Defects Registry Network for outstanding achievement for their preconception project. Healthy Mothers Healthy Babies is in the process of organizing a statewide coalition. A strategic planning summit is planned June 10-11, 2008 in Tulsa. The committee plans to be part of the planning aspect in implementing HB 3060. The NIH- National Children's Study will earmark 105 counties throughout the United States to follow children from prenatal to age twenty looking for markers for diabetes, hypertension, environmental factors etc. Cleveland and Comanche counties in Oklahoma will receive funding for the study.

Newborn Screening Program and Pediatrics: Theresa Steckel- reported that the Newborn Screening video from the March of Dimes has been copied and will soon be distributed to Children First nurses. Newborn Screening expansion will start with Amino Acids disorders being reported by the end of May, Fatty Acid Oxidation disorders by July 2008, Organic Acid disorders by September 2008 and Biotinidase Deficiency to be announced. John Corpolongo reported another newborn screening nurse will start in June and another scientist has been hired in the lab to assist with follow-up. Paula Vann has been assigned as a special population nurse for newborn screening. Dr. Kayser introduced, Kay Romero, the new adult dietitian at St. Francis. Dr. Mulvihill suggested that the newborn screening committee address general Hypothyroidism due to the many unanswered questions about the abnormality. Currently the newborn screening program monitors babies with the disorder for two years. Theresa introduced Tracy Schaeffer, the new endocrine nurse at OUHSC.

Student Committee Update: Sharon Vaz reported they have not met. The new executive secretary for the committee will be Patricia Burk and she will report at the next OGAC Meeting.

Heartland Update: Theresa Steckel- Heartland sponsored a newborn screening lab disaster preparedness training in April and Tonya McCallister from the OSDH lab attended. Oklahoma currently has a back-up lab that tests could be sent to during a disaster. Louisiana had to send their newborn screening tests to Iowa after the hurricane and has just recently re-opened their lab. Dr. Mulvihill reported that the "Heartland Regional Genetics and Newborn Screening Collaborative Annual Conference" will be held Sept 11-12, 2008 in Sioux Falls, SD. Another Heartland activity is the genetics report card "Genetics System Assessment" to see how states are doing on genetic services. A meeting is scheduled in Chicago next week to discuss infrastructure

Legislative Update-National and State Update – Heather Poole did a comparison between the national and state GINA Act. Printed summaries were provided in the packet for comparisons and both formats are very similar. Insurance companies can't require genetic testing or use genetic testing information for the purpose of determining coverage. However, if you have manifestation of a genetic disease you can be denied coverage. Both the state and national GINA act addresses the ability for individuals to participate in research projects where the information will remain confidential. National legislation considers family history as genetic information and does not allow it to be used against you. Oklahoma's legislation does allow family history to be used against you.

Direct to Consumer Testing- Overview: Nancy Carpenter- JAMA handout was provided in the packet. Traditionally, a health care provider has only done genetic testing, however, direct to consumer genetic testing is now being marketed directly to consumers. Many ads don't accurately portray the ability to predict risks. Without a health care provider the consumer may misunderstand the genetic results and diseases may be missed. There is no monitoring of laboratory quality to insure the accuracy of the testing. Two advisory committees requested that the Health and Human Services Secretary address the need for additional oversight. In 2006 a warning was issued to consumers "Home Genetic Test- a Healthy Dose of Skepticism." Melissa Craft suggested that OGAC continue to address this important issue. The policy committee will follow-up on Oklahoma's regulations.

Evaluation Overview: Dr. Neas provided a two-page handout and discussed this year's evaluation of the five-year plan for OGAC. OGAC has made commendable progress in meeting the plan and now we need a new direction and new needs assessment. She suggested forming a new committee or partnering with other committees. There are many new issues that were not pertinent five years ago. OGAC is nearing its tenth anniversary.

Chair & Public Comments- None.

Adjournment – The next meeting will be September 18 in Oklahoma City.