

MINUTES

Draft

Oklahoma Genetics Advisory Council

January 17, 2008

Oklahoma State Department of Health, RM 806

Oklahoma City, Oklahoma

16 Council Members Present: Barbara Neas, John Mulvihill, Carole Keener, Belinda Rogers for Laurie Applekamp, Danny Cavett, Representative Al Lindley, Dewey Scheid, Larry Weatherford, Sohail Khan for Melissa Gower, Heather Poole for Dr Lynn Mitchell, Joan Cain, Linda Terrell, Mary Rindler, Tara Lorg, Susan Hassed and Andrew Wagner.

9 Council Members Absent: Kayse Shrum, Patti Davis, James Lewis, James Coldwell, Dana Stone, Melissa Craft, Nancy Carpenter, Dalora Scheafer and Adolfo Garnica

9 Ex-officio Members Present: John Corpolongo, Pam King, Patricia Burk, Sharon Vaz, Terry Geisler, Garry McKee, Kay Pearson, Theresa Steckel and Suzanna Dooley.

7 Ex-officio Members Absent: Karen Hylton, Edd Rhoades, Jim Struby, Adeline Yerkes, Paula Vann, Terry Johnsen and Dedric Anderson

14 Visitors: Dennis Pollock, Tyler Whitehead, Soheila Haddad, Mallory Martin, Jean Lea Spitz, Cheryl Freeman, Julie Keith, Elise Austin, Erin Valentine, Brittney Ogez, Debbie Kline, Lori Williamson, Erica Cole and Ragina Munguia.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order. Contents of the meeting packet and minutes were reviewed and approved. Dr. Neas reviewed the educational documents. The minutes were approved.

Family Story

Sharon Vaz introduced Dennis Pollock to the group. He was born with Alpha-1 Antitrypsin deficiency. The deficiency is an inherited disorder that can cause lung disease in adults and liver disease in adults and children. Mr. Pollock went to seven doctors in seven years trying to get a correct diagnosis. He was misdiagnosed with adult onset asthma until age 33, when he was correctly diagnosed by Dr. Cox in Lawton. The doctor told him to “quit his job” and this led to a period of depression and concerns about how he would support his family. On August 2, 2004 he had a double lung transplant at the University of Baylor in Dallas. After the transplant, his life turned around and he is now a spokesman for the deficiency. An affected person can reduce their chance of getting the disease by two-thirds if they choose a lifestyle that protects their lungs. Unfortunately, many doctors do not even want to test for the deficiency and testing is often done anonymously because insurance coverage is a problem. Mr. Pollock supports the GINA Bill and works with the Alpha-1 Association.

OGAC Executive Committee & Policy: The committee met by telephone a month before OGAC to set the agenda.

POLICY: Dr. Mulvihill- Policy committee met on the January 14th. The white paper on storage of newborn screening dried blood spots was discussed. Other issues discussed were PKU formula coverage, Autism treatment insurance coverage and monitoring of future legislative issues. Senator Gumm is introducing legislation seeking to create a cord blood bank in Oklahoma funded by public dollars and private contributions at the cost of \$1.00 per citizen. The bill may be in partnership with the Oklahoma Blood Institute. Pam King has heard from several parents that legislation may be proposed seeking a tax credit for families to assist them in paying for PKU formula.

GECO: Mary Rindler - “Genetics Day” at the capitol is March 26, 2008. The council agreed the event should be continued each year to advocate specific issues and promote general education. It also gives parents an opportunity to be heard and seen by the Legislature. Senator Al Lindley said legislators look forward to the event. DNA day is April 15th at OCCC. Mary asked for assistance in publicizing the event which will include a dance group from Washington DC called the “Ferocious Beauty – Genome”. GECO will also speak at a “Daughters of the American Revolution” conference, August 21-23rd and GECO is applying for a grant.

Evaluation: Barbara Neas reported subgroups have been meeting and evaluating collected data. They have finished Phase I and will report at the next meeting.

Family Advisory: Tara Lorg reported they met by phone. They have several new members. Four volunteers are needed for DNA Day to set on a panel and answer questions. They are collecting family stories for Genetics Day at the Capitol. The group is considering updating the FAC website to make it more user friendly. The web page is paid for by GECO for several more years. They discussed linking the website with other state agencies. They discussed the need to update the booklet “Alphabet Soup”, a book of acronyms and their meanings. They are working with Heather Pike on finding mentors for specific genetic disorders. They are planning to hold monthly meetings.

Adult: Pam King reported the committee met January 10th and discussed the Healthy and Ready to Work initiative. It was recommended that a committee be established at the last OGAC meeting. Possible chairs were discussed and OGAC members will vote on the issue later in the meeting. The committee will work on the Autoimmune Project. Sharon Vaz located a guideline published on the web by Emory’s genetics department that gave the incidence of recurrence in family members for different disorders. The committee recommended that the list be forwarded to Dr. Judith James at OMRF to review for accuracy so that a link may be included on the OSDH Genetics Program website. The committee recommended that OGAC and its subcommittees be educated about the availability of different genetic/genomic testing methodologies and implications to the public.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner reported they have not met since the last meeting. January is “Birth Defects Prevention” month and OSDH sent out a press release and brochure to all County Health Departments. A poster highlighting Birth Defects Prevention is in the basement lobby of the Health

Department. OGAC watched a Newborn Screening video from the March of Dimes targeting expectant parents. The video will be used in OB/GYN's offices to educate parents. The video can be reproduced and the first focus will be on low-income areas. Theresa Steckel said Heartland has provided funds nationally for states to distribute the video. Theresa will work with the Children First program to show the video to new parents. Andrew discussed the article from ACOG in the educational packet. The article discusses Newborn Screening and encourages obstetricians to be better educated on screening and be prepared to answer questions from parents. The article includes the Newborn Screening Panel: Core Panel and secondary targets from ACMG. Heartland Regional is providing a loose-leaf notebook of OTIS (Organization of Teratology Information Service) fact sheets that health personnel can consult for their patients. More information can be received from the OTIS web site. Nebraska will be sending out the OTIS binders through a grant they received from Heartland.

Newborn Screening Program and Pediatrics: Theresa Steckel reported that Newborn Screening is in the process of expansion. Emergency rules were approved last September and formal rules are to be approved the 1st week of February. Perkin Elmer is here installing the Software and training the lab. It is anticipated that the first group of disorders will be tested for by this fall. Pam introduced Dr. Garry McKee, who has returned to OSDH as Chief of the Laboratory.

Student Committee Update: Sharon Vaz reported they have not met. Sharon asked the Genetic Counseling students to work with the student committee and the LEND group.

Heartland Update: Sharon attended the "Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children" January 13-15th in Washington DC. They discussed data base collections to share across state lines. Two disorders they are considering adding is SCID and Pompe disease. She also attended the Cystic Fibrosis Educational Update. Oklahoma is very progressive in comparison to other states because we have follow-up and genetic counseling. Dr. Mulvihill said this year's annual Heartland Meeting would be September 11-12 in Sioux Falls, SD.

Transition Committee Vote – A vote was approved to create a separate transition committee. The committee will focus on addressing transition of youths who have pediatric chronic health conditions into adult medical homes and independent living. This has become an issue as children with special health care needs (CSHCN) are starting to live into adulthood. Dr. Cain has worked very hard to integrate exposure to pediatrics in the residency programs. They are in the process of doing a survey of the first 20 patients they have transitioned. They are also surveying medical school graduates to see how well they were trained in genetic conditions. A function of the committee will be to work with other transition groups.

Hearing Screening and Genetic Testing: The speaker that was scheduled to speak could not make it. Sharon Vaz reported that she has heard that newborns at Baptist Hospital are being tested for hearing mutations. Further information will be available at the next meeting.

Genetics Program and New Direction: Dr. Neas discussed the explosion of genetic testing available to private citizens. She is concerned that ethical issues are not being addressed. She suggested OGAC have a future presentation and overview of the types of testing programs available. Pam said the Genetics Program would like to focus on issues beyond NBS. She suggested a needs assessment at the next meeting to prioritize the complex issues of where the genetics program should go in the next five years. Dr. Mulvihill suggested a mini SWOT analysis at the next meeting. The evaluation committee will work with Sharon to coordinate the needs assessment or SWOT analysis. Linda Terrell recommended the World Café Model be used.

Chair & Public Comments- Dr. Neas asked for public comments. Dr. Mulvihill reported that Victor McKusick, a genetics professor at John Hopkins University School of medicine, won the Japan Prize for medical genetics and genomics. Carole Keener discussed the college of nursing website. Pam King is retiring January 31, 2008 and this is her last OGAC meeting. Pam thanked everyone for her experience with OGAC and the commitment of all the members. John Corpolongo thanked Pam for her hard work and said she will be greatly missed. Pam received a standing ovation and a picture of OGAC members was taken.

Adjournment – The next meeting will be May 15 in Tulsa.