

MINUTES

Oklahoma Genetics Advisory Council
January 21, 2010
Draft
Oklahoma State Department of Health
Oklahoma City, OK

12 Council Members Present: Barbara Neas, James Coldwell, Danny Cavett, Melissa Craft, Susan Hassed, Mary Rindler, Dewey Scheid, Larry Weatherford, Andrew Wagner, Delphine Dorsey for Joan Cain, Lori Williamson and Jennifer Trevino for Lynn Mitchell.

12 Council Members Absent: John Mulvihill, Linda Terrell, Nancy Carpenter, Mike Kayser, Melissa Gower, Tara Lorg, Laurie Applekamp, Grant Cox, James Lewis, Patti Davis, Frank Stone and John Armitage.

9 Ex-officio Members Present: Jennifer Allen, Lisa Caton, John Corpolongo, Terry Geisler, Terry Johnsen, Debbie Kline and Tonya McCallister for Garry McKee, Kay Pearson, Paula Vann and Sharon Vaz.

7 Ex-officio Members Absent: Patricia Burk, Amy Carte, Suzanna Dooley, Karen Hylton, Edd Rhodes, Jim Struby and Linda Thomas.

17 Visitors: Jennifer Trevino, Casey Smith, Cheryl Barr, Mary Monks, Joni Bruce, Ashley Taylor, Ashley Davis, Chunyan Wang, Ashley Schierer, Paniltria Premkuman, Soheila Haddad, Melissa Hall, Delphine Dorsey, Neala Bab, Erica Cole, Julie Keith and Jennifer Fisher.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order and welcomed members and visitors. The contents of the meeting packets were reviewed.

Overview of Genetic Service Assessment- (Heartland Regional Genetics and Newborn Screening Collaborative)

Dr. Ann F. Chou, assistant professor with the College of Public Health and College of Medicine, presented on her collaborative project: **Genetic Systems Assessment**. Her team, along with a national panel of experts, is developing a series of reportable measures to assess the quality of genetic services. It has been shown that performance improves when quality measurements are reported either publicly or privately. States could use the reports to help make informed decisions when negotiating contracts, developing incentives programs or for cross state comparisons.

Family Story

Joni Bruce introduced Jennifer Fisher whose son Blake has Cornelia de Lange Syndrome (CdLS). He was born at 28 weeks gestation weighing 2 lbs, 13 oz, and was in the NICU for a month and a half. When he wasn't growing as normal preemies do, his pediatrician took the time to investigate the cause. He was diagnosed with CdLS at 18 months of age. Due to the rarity of the syndrome – only seven children in the state of Oklahoma are currently diagnosed with CdLS – Ms. Fisher was given the worst possible prognosis; she was told her son wouldn't live to be six years old, would be severely mentally retarded, totally deaf and blind, and that he would never walk or talk. Blake is now 14-years-old, expected to live well into adulthood, can hear, see, walk and talk. He is considered high functional for the syndrome. Blake has excelled in the Special Olympics State Games where he both swims and bowls.

Blake does not have many of the common issues associated with CdLS such as heart defects, bowel abnormalities, missing limbs or missing portions of limbs. He did, however, suffer from reflux and seizures. He had a Nissen wrap to alleviate his reflux, and he quit having seizures when he was 4-years-old.

One difficulty faced by the family was fighting the school system to get the care Blake needed. His school was not providing speech therapy as required, so Ms. Fisher was paying \$180 a week for a therapist to work with Blake. Another difficulty has been general ignorance of CdLS on the part of health care workers.

The family has had to deal with strangers who have been cruel because of Blake's handicap. It is in this area Ms. Fisher feels the public health community can best help children with special needs by educating people, especially school-aged children, and encouraging more integration in the schools.

Legislative Overview

Mark Newman, Director of the Office of State and Federal Policy/OSDH, presented the council with the legislative update. Current proposed legislation contains a great deal of emphasis in postnatal education for parents of newborn children by hospitals and health departments, and there is also significant emphasis placed on education for children with special or high needs.

SB1250: the question was asked of Mr. Newman whether this bill would affect the newborn screening program in any way, and the answer was "no". Sen. Jonathon Nichols, the author of SB1250, has expressed no concern over the Newborn Screening program. He not only supports the Newborn Screening program but also its expansion to more tests. His concern is the blood spot being used for research without parental consent. Texas was holding newborn screening samples for research purposes without parental consent and was ultimately held liable. In response, 30 states are proposing similar bills restricting storage.

Umbilical Cord Blood Bank: the issue of a public cord blood bank is still being discussed, but it is cost prohibitive at this time. Cost estimates range from \$3.5 million to \$5 million per year. As a means of lowering the costs, Oklahoma will probably join other states in establishing a regional bank.

FY10 Budget: Negotiations for the budget are underway. Mr. Newman informed the council that Oklahoma is the only state that requires the house, senate, and governor to submit a budget and then the three parties negotiate for the final budget.

OGAC Committee/Genetics Program:

OGAC Executive Committee

Dr. Neas explained that the role of the executive committee is to meet and discuss the agenda for upcoming OGAC meetings and to discuss any lingering issues. Part of the committee discussion centered on “Genetics Day at the Capital”. The executive committee feels it is very important to educate the legislature regarding genetics. One idea is to work with families of affected children to educate the public and the legislature on services needed.

Genetics Education Committee of Oklahoma (GECO)

Mary Rindler reported the committee has not met since the last meeting. Different ideas were discussed on educating school children. Larry Weatherford recounted the story of how his son gave a presentation to his classmates to educate them on cystic fibrosis. The Oklahoma Directors of Special Services was suggested as a resource; they represent almost every special education director for public schools in the state.

Family Advisory

Joni Bruce reported the Family Advisory Committee and the Oklahoma Family Network are having a meeting on April 9th called “Joining Forces”. It is a meeting for creating partnerships between professionals and parents. This meeting will focus on strategic planning. It is by invitation only, so if any members are interested in going, contact Sharon Vaz.

Adult

Melissa Craft reported the committee is working on a Familial Hypercholesterolemia Brochure. It may be another year before it is ready.

Birth Defects Registry

Andrew Wagner and Sharon Vaz have met. They discussed storage of newborn screening blood spots and the obstetric provider survey on educating parents about newborn screening. Sharon would like to see the committee approach the legislature about providing funds for prenatal education for parents instead of just postnatal education. She plans to discuss the issue with Mark Newman.

Newborn Screening Program

Dr. Coldwell reported that testing for biotinidase deficiency will begin by May at the latest.

Heartland Update

Lori Williamson's last day with Heartland was January 15, 2010, so there are no updates.

Evaluation Committee

The committee has not met but is in the process of pulling information together.

Policy Committee

The committee received a legislative update from Mark Newman.

Chair & Public Comments- Dr. Neas thanked everyone for attending the meeting.

Adjournment – The next meeting will be May 20, 2010 in Tulsa.