

MINUTES

Oklahoma Genetics Advisory Council
September 16, 2010
Draft
Oklahoma State Department of Health
Oklahoma City, OK

10 Council Members Present: Barbara Neas, Melissa Craft, Susan Hased, Larry Weatherford, Andrew Wagner, Delphine Dorsey for Joan Cain, Lori Williamson, Linda Terrell, Michael Kayser and Nancy Carpenter.

14 Council Members Absent: Laurie Applekamp, John Armitage, Danny Cavett, James Coldwell, Grant Cox, Patti Davis, Melissa Gower, James Lewis, Tara Lorg, John Mulvihill, Mary Rindler, Dewey Scheid, Garth Splinter and Frank Stone.

11 Ex-officio Members Present: Jennifer Allen, Patricia Burk, Ken Cadaret, John Corpolongo, Suzanna Dooley, Terry Geisler, Debbie Kline, Tonya McCallister, Kay Pearson, Paula Vann and Nicole Zitterkopf-Khoury.

10 Ex-officio Members Absent: Amy Carte, Lisa Caton, Karen Hylton, Terry Johnsen, Garry McKee, Lynn Mitchell, Edd Rhoades, Jim Struby, Linda Thomas and Sharon Vaz.

27 Visitors Present

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order and welcomed members, visitors, and genetic counseling and LEND students. The advisory council advises the Commissioner of Health on matters that are pertinent to public health in the area of genetics. The contents of the meeting packet were reviewed. The May 20, 2010 minutes were approved.

Family Story

Dr. Wagner introduced Stephanie Stewart. In preparation for her second child, Stephanie got into shape and took her prenatal vitamins. She got pregnant without any problems and the pregnancy seemed normal. At her 18 week ultrasound it was discovered that her son suffered from Lower Urinary Tract Obstruction (LUTO)* with a favorable prognosis. Testing ruled out a genetic cause. She began six weeks of high risk fetal interventions which included an amniocentesis to drain the bladder, an amnioinfusion to insert fluid to help his lungs develop, and one attempt at fetal shunt surgery. The surgery failed because he moved under the anterior placenta. Multiple attempts to reposition the baby failed and the procedure was terminated due to the risk. At 23 weeks, the prognosis turned from poor to fatal.

The family faced the tough choice of either terminating the pregnancy or carrying to term. Stephanie wondered if her baby was suffering or whether it was morally wrong to terminate. She looked for support networks but found there weren't any so she began her own blog to share

her feelings of anger, sadness and happiness. The blog was followed by 500- 1000 daily readers. Stephanie decided continue to term.

Stephanie went into spontaneous labor at 35 weeks, and Vayden James Stewart was born on May 23, 2009. The family selected comfort care for Vayden who lived for 3 hours and 45 minutes. Both parents were with him till he passed away. The Stewarts feel blessed to have had that time with him and state that they have no “hard feelings toward God or their medical team”. She is grateful for the support of her decision from her medical team, friends, family and online community.

Through her organization “My Very Own Angel”, Stephanie donates 345 teddy bears to metro hospitals to represent the time that Vayden lived. The teddy bears are given to mothers who have lost their babies either in utero or shortly after birth.

* The incidence of LUTO is about 1 in 500 pregnancies.

Fetal Infant Mortality Review – Oklahoma County

Mary Beth Cox thanked Ms. Stewart for her involvement and advocacy in infant mortality. Ms. Cox is a supervisor for the Central Oklahoma Fetal and Infant Mortality Review (FIMR) project.

FIMR is a community based action oriented project to understand infant mortality in the community, why it is happening and to work to reduce infant mortality. There are over 200 FIMR projects across the United States with two in Oklahoma – Oklahoma City and Tulsa. Since 2006, FIMR has reviewed 200 cases, increased reviews from four cases a month to 10, and expanded to two surrounding counties – Cleveland, and Canadian. FIMR reviews 100% of all cases in Oklahoma, Canadian, and Cleveland counties excepting homicides.

The process begins when an infant death occurs. Documents are submitted to the state health department; records are obtained from vital records; nurse’s abstract data from prenatal, labor & delivery, and pediatric records, ambulance, police and autopsy reports; and home interviews are conducted. FIMR has a 44% rate for completing home interviews and this part is considered the most important and enlightening. FIMR brings to the table the voice of the moms whom they have interviewed regarding their experiences; most people do not ever get the opportunity to hear what moms and families are experiencing.

The second part of the process is sending the de-identified information that is collected, abstracted and summarized to the case review team. They develop strategies to implement changes in the community. The team consists of 40-50 members including professionals and community members from the faith based community, hospitals, the March of Dimes, Heartline 211, Mary Mahoney, the child death review board and others. FIMR accepts new members. All FIMR publications can be found at <http://www.cchdoc.com/community/fetal-and-infant-mortality-review>.

Legislative Update

Mark Newman, Director of the Office of State and Federal Policy/OSDH, presented the council with the legislative update.

Effective May 10, 2010, senate Bill 1250 prohibits any medical facility from storing or using infant DNA for research without the parents' permission. Sen. Jonathan Nichols is the author of the bill. Responding to lawsuits in other states, he was explicitly targeting the newborn screen bloodspots.

Budget

OSDH took a 7.5% cut this year. The agency took steps to prepare by offering Voluntary out Benefit Offers (VOBOs) – early retirement – and implementing more state car usage. The department of health is no longer a top ten agency receiving state appropriated funds. More funds are coming from the federal government that limits what the agency can and cannot do. OSDH took the largest cuts of all health and human services agencies. Question 744 is on the ballot and will greatly impact future budgets. This year, education was 53.4% of the budget. If 744 passes, education will be 66% or more of the budget. All other state agencies would share the remaining monies. It would go into effect in SFY2012 and be phased in over three years to be fully implemented by 2014. Stimulus funds accounted for \$1.4 billion in one-time monies in a \$6.7 billion budget. The SFY2012 budget will have to absorb the loss of that money. State revenues will be greater this year than last, and if they are greater than 3% or more, state income taxes will be reduced.

OGAC Committee/Genetics Program:

OGAC Executive Committee

The executive committee, Dr. Neas, Nancy Carpenter and Sharon Vaz, met by teleconference to plan the September 16, 2010 OGAC meeting.

Genetics Education Committee of Oklahoma (GECO)

Patricia Burk, Program Coordinator for Newborn Hearing Screening presented.

12,000 babies are born the US each year with hearing loss; 50% have a genetic link but relatively few are being sent for genetic testing/counseling. A brief survey was sent to all audiologists in Oklahoma asking them about their knowledge of the link between genetics and hearing loss. The results can be found in the meeting packet. The Oklahoma Audiology Taskforce (OKAT) has created a genetics subcommittee “to raise awareness within the Oklahoma speech pathology, audiology, and deaf communities regarding the utility of genetic education and evaluation for families of children with hearing loss.” OKAT is seeking to join forces with GECO to create a project for genetic awareness.

Family Advisory

Jennifer Allen, Newborn Screening Nurse Coordinator presented. Jennifer, Joni Bruce and Sharon Vaz met in June. They discussed revising the structure of the family advisory committee with the help of the Oklahoma Family Network. They also discussed the development of a family evaluation and health care transition guide. Sharon attended the Department of Rehabilitation Services' “Joining Forces” conference and they are working on revising some SS

documents. The Family Advisory Committee is working with GECHO to create an alphabet soup directory for families. The Oklahoma Family Network is hosting their "Harvesting Hope" reunion at the Harn Homestead on Sunday. They will have their big fund raiser wine tour on November 6, 2010.

Adult

Melissa Craft reported the committee is working on a Familial Hypercholesterolemia Brochure with the help of Ashley and Melissa Hall. They may go forward with brochure in 2011.

Birth Defects Registry

Andrew Wagner introduced Ashley Davis. She has helped create a survey for all OB/GYN's and family physicians asking when and/or if they inform their patients about newborn screening and their knowledge on newborn screening. Surveys are complete and ready to be mailed.

Newborn Screening Program

Jennifer Allen presented. She discussed the quarterly metabolic work group meetings between Newborn Screening, the Public Health Laboratory and metabolic specialists to review the disorders that were added to the panel two years ago. Biotinidase Deficiency Screening will begin November 1, 2010.

Heartland Update- Oklahoma

Lori Williamson presented. Heartland will have its annual meeting in Des Moines, IA next week. Tonya McCallister will be presenting on the Good Spot/Bad Spot project. Sharon Vaz will co-facilitate the transition workgroup and the newborn screen workgroup. Drs. Kayser and Dr. Wierenga are participating in a national data collection project looking at long term outcomes of children with inherited metabolic disorders. The Oklahoma newborn screening lab participated in the emergency preparedness exchange with Missouri. This project ensures that if disaster strikes, the newborn screening program will continue to operate.

Evaluation Committee

The committee has a new member but will not reconvene until October.

Policy Committee

Ken Cadaret, Chief, Screening & Special Services is new to the committee, and Dr. Mulvihill is currently out of town. No report will be presented at this meeting.

Chair & Public Comments

Dr. Neas discussed with the council members the issue of elections. Due to the budgets cuts and leadership changes at the state health department, the council advised not holding a new election this year to keep the council on track. Dr. Neas suggests putting a nominating committee together now as well as a committee to start looking at new directions and to fill some of the vacant seats. There were no objections at the meeting, and discussions will take place between now and the next meeting. Dr. Neas thanked everyone for attending the meeting.

Adjournment – The next meeting will be January 20, 2011 in Oklahoma City.