

MINUTES

Draft

Oklahoma Genetics Advisory Council

September 20, 2007

Oklahoma State Department of Health, RM 806

Oklahoma City, Oklahoma

13 Council Members Present: Barbara Neas, John Mulvihill, Susan Hassed, Laurie Applekamp, Nancy Carpenter, Danny Cavett, Melissa Craft, Dewey Scheid, Larry Weatherford, Sohail Khan for Melissa Gower, Heather Poole for Dr Lynn Mitchell, Adolfo Garnica and Andrew Wagner.

12 Council Members Absent: Mary Heinrichs, Representative Al Lindley, Joan Cain, Kayse Shrum, Linda Terrell, Patti Davis, James Lewis, Carole Keener, James Coldwell, Dana Stone, Dalora Schafer and Tara Lorg.

7 Ex-officio Members Present: John Corpolongo, Pam King, Patricia Burk, Sharon Vaz, Terry Geisler, Kay Pearson and Paula Vann.

9 Ex-officio Members Absent: Karen Hylton, Jeff Mathewson, Edd Rhoades, Jim Struby, Adeline Yerkes, Terry Johnsen, D.J. Gutierrez, Theresa Steckel and Suzanna Dooley.

32 Visitors: Cynthia and Erin Hookham, Jae Lindsay Chaloner, Mallory Martin, Dennis Pollock, Tonya McCallister, Rand Thompson, Jessica Mester, Louis Worley, Gina Bryan, Nena West, Susan Palmer, Linda Wilson, Tricia Nolan, Solomon Nolan, Mike Chapman, Melissa Hall, Julie Keith, Elise Austin, Erin Valentine, Brittney Ogez, Mary Beth Wilhelm, Debbie Kline, Lori Williamson, Erica Cole, Alice Maloy, Samantha Day, Valentine Dalili, Ashley Ethriedge, Mary Monks, Belinda Rogers and Ragina Munguia.

Welcome – Dr. Barbara Nees

Dr. Neas called the meeting to order. Contents of the meeting packet and minutes were reviewed and approved. The “Women’s Health Appraisal” forms in English and Spanish were discussed. The NCCCollaborator handout was provided on expanding genetic and newborn screening services in multifaceted partnerships. A handout about the accomplishments by OGAC was provided.

Family Story

The Hookham family drove from southern Illinois to tell their family story. The Newborn Screening Program diagnosed Erin Hookham with a thyroid abnormality 18 years ago. Erin’s mother thought she had a perfectly healthy child when she was born, however at 2 weeks of age she started on Synthroid when testing revealed a thyroid deficiency. Further testing revealed that she was born without a thyroid gland. Erin has had normal physical and mental growth because of early intervention and medication at one month of age. Most children born at that time with thyroid problems were not caught until they were 2- 4 months old and suffered long term consequences of later diagnosis.

One problem the family faced was the many different opinions on how and when to administer synthroid. The family felt that moving to Oklahoma was a blessing because it meant the abnormality was diagnosed early and they had access to good doctors. Erin feels fortunate because she has to deal just blood work and pills and not the long term consequences of late diagnosis. She is living a normal life and can follow her dreams. The family thanked everyone for taking the time to care if babies are screened because it does make a difference.

Accomplishments “8 years of OGAC and the impact of State Genetics Plan 2002-2007”

Dr. Neas discussed the collage of pictures and the handout of accomplishments commemorating OGAC. “Milestones of OGAC” chronologically highlights accomplishments from 1998 to present. The discussion highlighted the Gingerbread men cookie cut outs that are given to the legislators at the annual Genetics day at the Capitol. Ideas that originally evolved by OGAC as part of system change are still present and are continuing to evolve. A major accomplishment of OGAC was mandating expansion of Newborn Screening by the Board of Health earlier this month. Pam reported that there have been 25 council meetings and 146 committee meetings since the inception of OGAC. The first chair of OGAC, Dr. Carpenter, remembered the first meetings and said it was gratifying to see how many people would eventually participate.

Dr. Mulvihill thanked Pam King for her work with OGAC and she received a standing ovation. Pam thanked Dr. Mulvihill and all of the many others who have made OGAC a success.

OGAC Committee/Genetics Program:

Dr. Neas welcomed the students from the LEND Committee. Dr. Brandt was instrumental in calling for a vote to have the committee formed.

OGAC Executive Committee & Policy: Met August 24 by conference call to plan the OGAC meeting.

POLICY: Dr. Mulvihill- Policy committee met on the September 14th. Genetic Counselor Licensure and supervision of Temporary Genetic Counselors was discussed. The Oklahoma Healthcare Authority has a ruling on the governor’s desk for signature to reimburse Genetic Counselors for prenatal counseling. It is anticipated that the GINA bill will pass after a meeting between Senator Kennedy and Senator Coburn last week. The committee will continue to work on ways to monitor future legislative issues. Dr. Brandt’s passing has left a huge gap in our ability to monitor and influence legislation. Termination of pregnancy and cord blood banking legislation are issues that could come up in the next session. The white paper on storage of newborn screening dried blood spots was discussed. Garry McKee is returning as OSDH laboratory director.

GECO: Sharon Vaz reported they have not met.

Evaluation: Barbara Neas reported subgroups have been meeting and evaluating collected data.

Family Advisory: Tara Lorg was absent because of a family illness. The Family Advisory Committee provided a sample of the letter of introduction and “Family Advisory Committee Survey” that was mailed to families. Many surveys have been received back and will be reviewed. Tara attended the Heartland Regional Newborn Screening and Genetics Collaborative meeting and met with other families from 28 states. Dr. Mulvihill said that perhaps Family Voices could reprint the survey.

Adult: Melissa Craft reported the committee met and had a vigorous discussion. They have elected to focus on autoimmune diseases, which affects so many families. Dr. Judith James, MD, PhD, a Rheumatologist at OMRF, gave a wonderful presentation on the disease and some of the potential genetic implications. A copy of Dr. James’ presentation is included in the packet. Oklahoma has an opportunity to lead the way in linking the disorder to genetics. Their goal is to research what is currently being done nationally, tie it in with the family history initiative and raise awareness with the public and medical professionals. Melissa asked for volunteers with special expertise or interest to join a sub-committee.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner reported they met by videoconference May 25th. First topic was Preconception Education and how they can best help the women of Oklahoma prepare for pregnancy. They will use the “Women’s Health Appraisal” offered by the OSDH/Birth Defects Program. Kay Pearson discussed how the survey is used with almost 90% of participants benefiting. Many in attendance were impressed with the survey and feel it is an excellent tool. Lori Williamson discussed the companion piece preconception tool “Preventable Birth Defects Curriculum” that has been in place for about six years in numerous states and targets high school students. Another project the committee is planning is a questionnaire to OB providers throughout the state regarding their awareness of newborn screening and how they are explaining it to their patients. The March of Dimes has a DVD that can be shown in OB/GYN’s offices to expectant parents.

Newborn Screening Program: Pam King reported for Dr. Coldwell. Pam discussed the handout on “Oklahoma Newborn Screening Expansion”. The bottom graph shows cases detected since 1991. The Newborn Screening Program’s aggressive follow-up program gets babies on treatment within 5-7 days of age with 100% follow-up for three years. The BOH passed rules for expansion September 13, 2007, which hopefully will start, by May-June 2008. The equipment used to test for MCAD can test for other disorders. When the last disorder Biotinidase Deficiency is added Oklahoma will be in compliance with ACMG requirements. The contract for testing kits is at DCS being signed and MCAD will be moved to the kit when they arrive. It will take 3-5 months to determine what the cutoffs are for Oklahoma babies.

Student Committee Update: Student committee has not met. Sharon Vaz asked for suggestions for the committee to work on. Sharon suggested opening the committee to all students within the state, not just OU. Pam said this would promote genetic careers in young students. Lori Williamson suggested a “boot camp” for genetics.

Genetics Program Update: Sharon Vaz said November is Family Health History Month and the postcards are available to be passed out. Dr. Mulvihill suggested putting the cards in the Sunday paper and Pam suggested modeling the campaign after Kay Pearson's Mother's day campaign for neural tube defects. Sharon introduced, Nena West, the Director over Professional Counselor Licensing at OSDH. The law went into effect last November 1st with the permanent rules being effective June 25th of this year. Rules and regulations are posted on OSDH's website. Her office administers licenses, processes application, issues licenses and enforces the rules. They also provided administrative staff to the advisory committee.

Heartland Update: Lori Williams provided a synopsis of the Heartland Regional Newborn Screening and Genetics Collaborative annual meeting held at the Skirvin Hotel in Oklahoma City this month. Over 100 participants, including the national partners, attended and fifteen states were represented. The regional advocacy group was acknowledged at the meeting. After training the group was anxious to start working and plan to meet again in March. See the Website for activities that have been completed. Our region created the survey on capacity and tele-genetics later used by the national group. They are also working on a survey and manual on how to set up a genetics program and the white paper on storing dried blood spots. Dr. Mulvihill discussed the Heartland Genetics and Newborn Screening Collaborative "report card" on page 8 of the NCCCollaborator handout.

Healthy and Ready to Work - Pam King introduced Mike Chapman, from Children with Special Health Care Needs/DHS, and Louis Worley from Sooner Success/ Child Study Center/OUHSC. Mr. Chapman discussed the SSI program that is funded through Title V funding and supports seven contracts. All contracts have a stipulation that a family member must be represented on the board. The handout "SSI Disabled Children's Program" was provided which explains how to access the services offered to children from birth to age 18. Mr. Worley discussed how the Sooner Success Program assists children with special health care needs by coordinating services and supporting capacity at the local level. A priority for Mr. Worley's program is the health issues related to transition. He is a member of the Oklahoma Transition Counsel, which has an annual Transition Institute to plan ways to meet the needs of youths in the community.

Tribute to Dr. Brandt: The group watched a DVD in tribute to Dr. Brandt. Dr. Brandt's son said his father was getting ready for the OGAC meeting a week before he passed away. Dr. Neas said Dr. Brandt had brought a lot of fun and respect to the group.

Chair & Public Comments-

When Dr. Neas asked for public comments. The family story visitor, Cynthia Hookham, said she was impressed with the meeting and thanked everyone for the wonderful job they have done. Dr. Neas welcomed Laurie Applekamp, who is replacing Randy Hunt for the March of Dimes.

Adjournment – The next meeting will be January 17, 2008 Oklahoma City.