

MINUTES

Draft

Oklahoma Genetics Advisory Council
September 18, 2008
Oklahoma State Department of Health
Oklahoma City, OK

13 Council Members Present: Barbara Neas, John Mulvihill, Al Lindley, Frank Stone, Melissa Craft, Nancy Carpenter, Larry Weatherford, Heather Poole for Dr Lynn Mitchell, Danny Cavett, Dewey Scheid, Linda Terrell, Susan Hased and Andrew Wagner.

12 Council Members Absent: Carole Keener, James Coldwell, James Lewis, Kayse Shrum, Patti Davis, Adolfo Garnica, Laurie Applekamp, Mary Rindler, Melissa Gower, Joan Cain, Tara Lorg, and, Dana Stone.

4 Ex-officio Members Present: John Corpolongo, Sharon Vaz, Kay Pearson, and Paula Vann.

11 Ex-officio Members Absent: Karen Hylton, Edd Rhoades, Jim Struby, Adeline Yerkes, Terry Johnsen, Dedric Anderson, Patricia Burk, Terry Geisler, Garry McKee, Theresa Steckel and Suzanna Dooley.

24 Visitors: Rick & Wanda Felty, Sadie Lewis, Delphine Dorsey, Mary Monks, Debbie Kline, Melissa Hall, Florence Mubich, Elise Austin, Julie Keeth, Kelly Usrey, Whitney McBride, Brittney Ogez, Jae Lindsay Chaloner, Mallory Martin, Lori Williamson, Linda Wilson, Alexandra Tito, Erica Cole, Erin Valentine, Kathy Bogumil, Denny Porter, Jesse Hatfield and Jennifer Allen.

Welcome – Dr. Barbara Neas

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

Family Story

Sharon introduced Rick and Wanda Felty. Wanda Felty presented the family story about their daughter, Kayla, now age 20. When Kayla was born she was in NICU for low blood sugar and at three months of age she was fitted for eyeglasses. At six months of age a pediatric ophthalmologist in Houston diagnosed her with Septo-Optic Dysphasia. They were told she was blind and would have some degree of retardation since the middle part of her brain did not develop. Kayla didn't walk until age two and wasn't talking at age three. At age six she was diagnosed with Autism and at age Ten she begin seeing an endocrinologist who diagnosed her with pan-hypopituitarism. Since Kayla is non-verbal, Wanda can only understand her 25% of the time and she requires a lot of one-on-one assistance. They were forced to begin transitioning her to adult care when her pediatrician passed away. Kayla's conditions require having a physician that can admit her to the hospital immediately when she gets ill. Kayla's school has a contract with a home health agency to monitor her care at school and DHS/DDSD works with her in the home. They are still transitioning to adult care and Wanda is constantly working with hospitals and

doctors to coordinate her treatments. Wanda is concerned about other families with disabled children that don't know how to navigate the medical system.

OGAC Committee/Genetics Program:

OGAC Executive Committee: The committee met by telephone conference. The OGAC committee member elections will be delayed a quarter.

POLICY: Dr. Mulvihill- Policy committee met earlier in the week. Dr. Mulvihill introduced Dr. Denny Porter, a speaker at grand rounds this morning, and Jesse Hatfield, a 1st year graduate student. The minutes were discussed. The draft report on "Long-Term Storage and Retention of Newborn Screening Blood Samples" is ready to be presented to national experts for review along with comments from Nancy Carpenter. Kevin Pipes will continue to be our primary contact for legislative issues. HB3060-providing the establishment of a cord blood bank for Oklahoma was discussed. OSDH is soliciting other blood banks in the region for interest in contracting with Oklahoma. HB 3126-Advancement in Stem Cell Cures and Therapies Act was discussed. The bill advocates stem cell research as long as it is not done on human embryos. Currently no group in Oklahoma is performing stem cell research. There are now 11 licensed genetic counselors. Newborn Screening expansion is moving forward. We need to be vigilant in monitoring legislation affecting Autism. "Direct to Consumer Genetic Testing" is in the news again. Oklahoma does not have laws directly regulating these services so Dr. Mulvihill suggested reviewing New York and California's laws and including it as a future policy agenda item. John Corpolongo attended the interim study on Autism at the capitol this morning. There was very good representation of parents and speakers. The consistent theme was Oklahoma's shortage of service provider experts for children on the autism spectrum, which is a common problem for many states. The committee asked for a summary of the eighteen states that have some form of insurance coverage. John will speak before the legislature next week on the same study for SoonerStart. Senate Bill 1858 "Newborn Screening Saves Lives Act of 2007" has been signed into law at the national level that augments education and outreach about newborn screening and improves coordinated care. The bill is authorized but not appropriated and is an endorsement of NBS. A summary is in the packet.

GECO: Sharon Vaz- GECO has not met. They did not get the Genetics Alliance Grant that was applied for but OUHSC did. The alliance will provide us with copies of two booklets, "A Guide to Family History" and "A Guide to Understanding Genetics and Health". Mary Rindler spoke at the "Daughters of the American Revolution" conference in OKC this summer. They are collaborating with the Biotech program at OCCC and science teachers from across the state. Several requests to present to high school students have been received and Sharon may ask the LEND students for help. Heartland Education Workgroup is working on CME's for genetic modules housed at the Utah MedHome Portal. A hand out is provided. Heartland has agreed to fund CME's for physicians who participate in the diagnostic modules. The "Holiday Card" for Thanksgiving will be sent out again this year and Sharon would like suggestions for focus groups. Annual "Genetics Day" at the capitol will be next year. Sharon would like to see

some Oklahoma families' genetic stories included in the next Genetics Alliance report. John Mulvihill discussed the grant they received to educate medical students to encourage their patients to collect family health history. The booklets will be upgraded for next year.

Family Advisory: Sharon Vaz – Has not met. They have been collaborating with the Oklahoma Family Network. There are several mentoring opportunities for families of children that have been recently diagnosed with development disabilities. The website is listed in the minutes. Larry Weatherford said Heartland has been working on medical home issues and on the family resource guide to financial opportunities created by Sookyung Shin. Sharon would like to see the guide piloted across all of the Heartland States. Sharon will request permission to send copies to OGAC and Dr. Mulvihill suggested OGAC assist with printing and distribution.

Adult: Melissa Craft- Committee met last week. They are recruiting more members. Whitney McBride, a first year medical student, may volunteer to join the committee. The committee is still working on the autoimmune disorders. They are still developing a three phase descriptive exploratory pilot that examines the assessment of autoimmune disorders during general genetic counseling in a research way. They recognize their limitations and the need to work with outside consultants.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner- Did not meet over the summer. They attended the “Healthy Mothers Healthy Babies” statewide coalition in June. The preconception committee thru OSDH is working on a draft of the preconception tool. The OSDH Breastfeeding Committee is meeting and the committee is encouraged to consider that babies with metabolic disorders may be better off being fed formula. Sharon has been surveying states with blood banks around Oklahoma in establishing a “virtual” cord blood bank. Colorado, Texas MD Anderson and the Texas Cord Blood Bank have shown interest. Sharon discussed the brochure “Improving Infant Outcomes “ and encouraged all to read it. A task force that is open to statewide participation has been formed aimed at reducing infant mortality in Oklahoma.

Newborn Screening Program and Pediatrics: Sharon Vaz reported that the Metabolic Work Group has been meeting. Theresa Steckel has accepted a position at the College of Nursing. Expansion to fatty acid disorders started Monday and Organic Acids will begin October 20th. Special permission to refill Theresa's position has been requested due to the hiring freeze at OSDH.

Student Committee Update: Patricia Burk was unable to attend due to another conference. Patricia has been in contact with the LEND group.

Heartland Update: Sharon Vaz and Dr. Mulvihill attended the Heartland Regional Genetics Collaborative meeting in Sioux Falls last week. There was an interesting presentation on HRTW issues. Dr. Mulvihill discussed the one page summary medical template that should be filled out for complex patients. It is a valuable document for patients in transition to adult care and will allow medical providers to coordinate treatment for those that don't communicate well. He recommended a committee of OGAC consider it for review. If the "Newborn Screening Saves Lives Act" receives funding, Oklahoma entities need to be ready to move for implementation. Dr. Mulvihill discussed the need to be flexible and cooperative with national research efforts to amalgamate rare patients across the United States into research cohort studies. OGAC may need to endorse Oklahoma's bid for a clinical science award with the prospect that OSDH IRB may become the Institutional Review Board (IRB) for the state. About six months ago it was decided that emergency rooms in the Oklahoma City area would have access to a network called "Smart Net" that provides life-saving information about the patient. The Cherokee Nation developed the model in their health system. Sharon discussed the Oklahoma PKU Connection Newsletter and a recent MMWR article.

Transition Committee/HRTW Report – Delphine Dorsey discussed the HRTW Transition Program Update provided in the packet. Currently 69 patients are enrolled in the program. The tables provide information on grade level, education, employment status etc. Thirty-one patients transitioned to adult medical homes between 2002-2008. Having insurance does not make transition to an adult hematologist any easier. Two patients have died since transition from sickle cell disease complications. Preliminary statistics for the post transition telephone survey were discussed. They are planning a minus two-year survey for comparison. The program is working and 93% of transitioned patients have reported satisfaction with the services.

Nominations- Sharon Vaz asked for volunteers from the audience to be on the council. Elections will be held in January 2009 and Barbara Neas' term as chairman is ending.

Direct to Consumer Testing- Overview: Nancy Carpenter- discussed the summary table of the New York and California correspondence with health-related direct-to-consumer genetic testing businesses. The Health Departments in both states have advised testing companies to stop marketing to state residents and that they out of compliance with state laws. Both states have laws regarding licensure of laboratories and lab directors and both states require that clinical and lab tests be ordered by a physician. There has been a federal level effort to emphasize to the Health and Human Services Secretary that there needs to be more oversight on direct- to-consumer testing. Recommendations have been put forth and will be discussed further at an National advisory committee meeting in December. John Corpolongo suggested that OSDH provide a link on the OSDH Genetics website to "Direct- to- Consumer Genetic Testing." providing information from the policy committee. As more research is done, it will be decided if legislation is needed. Dr. Mulvihill suggested contacting Kathy Hudson at the Genetics and Public Policy Center for further direction. Sharon is on the forum of the American Public Health Association and has access to the Genomic form and the policy statements. Complete articles of: "Issues- Federal Neglect: Regulation of Genetic Testing" and "Food and Drug

Law Journal- In Search of a Coherent Framework: Options for FDA Oversight of Genetic Tests” will be provided by Sharon to those that want a copy.

Evaluation Overview: Dr. Neas- Committee is in the process of coordinating the evaluation report for new direction for OGAC. The report will be based on two pieces: all the Logic models used for the state plan and by modifying the Maternal and Child Health State Assessment Tool. OGAC operates so well because of the commitment and support of OSDH. Funding and the NBS program are solid. Wonderful advances have been made by all of the OGAC programs but there is still a lot to do. Educating the healthcare world, legislatures and families will continue to be important. OGAC needs a standardized year-end report mechanism to evaluate progress. Plans are to have something to look at prior to the meeting in January. The committee is open to new members.

Chair & Public Comments- John Corpolongo thanked the following for their hard work: Dr. Neas, on behalf of the commissioner, for her ongoing advisement and support, the students that are the lifeblood of the profession and the future leaders in the health world, the NBS staff, specifically Sharon Vaz, Paula Vann and Jennifer Allen, the OSDH Lab staff, specifically Debbie Kline, Tonya McAlester, Dr. Mathewson and Dr. McKee. The NBS program and expansion would not be successful without their hard work. NBS has not missed a baby in danger of needing treatment in almost four years. John Mulvihill announced that Dr. Victor A. McKusick, the founder of medical genetics, recently passed away. Linda Terrell thanked John Corpolongo for being a “listening ear” when it seemed that the PKU formula provided through DHS could be in jeopardy.

Adjournment – The next meeting will be January 15, 2009 in Oklahoma City.