MINUTES
Draft
Oklahoma Genetics Advisory Council
January 15, 2009
Oklahoma State Department of Health
Oklahoma City, OK

14 Council Members Present**:** Barbara Neas, John Mulvihill, Nancy Carpenter, Larry Weatherford, Heather Poole for Dr Lynn Mitchell, Danny Cavett, Linda Terrell, Andrew Wagner, James Coldwell, Laurie Applekamp, Mary Rindler, Mike Kayser, James Smith for John Armitage, and Lori Williamson.

13 Council Members Absent: Carole Keener, James Lewis, Patti Davis, Adolfo Garnica, Melissa Gower, Joan Cain, Tara Lorg, Dana Stone, Melissa Craft, Susan Hassed, Al Lindley, Dewey Scheid and Frank Stone.

7 Ex-officio Members Present: John Corpolongo, Sharon Vaz, Kay Pearson, Patricia Burk, Suzanna Dooley, Paula Vann and Lisa Caton.

8 Ex-officio Members Absent: Karen Hylton, Edd Rhoades, Jim Struby, Terry Johnsen, Terry Geisler, Garry McKee, Linda Thomas, and Amy Carte.

18 Visitors: Ryan McLaughlin, Humberto Videllieda Susan Palmer, Mary Monks, Melissa Hall, Julie Keeth, Kelly Usrey, Whitney McBride, Jae Lindsay Chaloner, Linda Wilson, Erica Cole, Jennifer Allen, Tonya McCallister, Sue Haddad, Joni Bruce, Ashley Diffin, Ragina Munguia and Belinda Rogers.

Welcome – Dr. Barbara Neas
Dr. Neas called the meeting to order. Contents of the meeting packet and minutes were reviewed and approved. The 2008 Member Directory has been updated. Dr. Neas welcomed three new council members: Lori Williamson, Genetic Counselor, OUHSC, Michael Kayser, Clinical Geneticist and Clinical Biochemical Geneticist, St. Francis Hospital and John Armitage, President and CEO, Oklahoma Blood Institute.

John Corpolongo provided an update on new personnel changes to the Newborn Screening Program: Sharon Vaz - Director of Genetics, Lisa Caton- Quality Assurance Coordinator and Patricia Burk - Coordinator for the Newborn Screening Program.

Family Story

Sharon Vaz introduced Ryan McLaughlin, a former Mrs. Oklahoma. She is a mother to three children. Her three-year old daughter, Ellie Kate, was born with non-ketotic hyperglycinemia. Ellie Kate started school last week and is currently stable. Her daughter's birth encouraged her to get involved in the world of " Newborn Screening." She sits on the board of directors for "Safe Babies Through Screening Foundation". Through Joni Bruce and the Oklahoma Family Network they have established Hope Link, a support group for mothers' of children with rare and undiagnosed disorders.

Currently the support group is local and meets once a month. She provided flyers with the web address and phone numbers and said additional brochures will soon be available.

John Mulvihill mentioned that NIH has established a clinic for patients with undiagnosed patients of all ages.

OGAC Committee/Genetics Program:

OGAC Executive Committee: This committee sets the agenda for OGAC and is continuing to look at licensing issues. They recommend that the policy committee continue to work with Kevin Pipes on legislative issues.

Policy: Dr. Mulvihill- Policy committee met earlier today. HB 3126, which supports stem cell research, was discussed. Draft rules will be introduced at the March 2009 BOH meeting. The new administration will likely be more favorable to this type of research. Nick's bill has been reintroduced as SB 1. The bill proposes funding for behavioral therapy without mentioning genetics. Twenty applications were received at The Oklahoma Genetic Counseling Board to license members of an out-of state genetic counseling company. The committee agreed to do more research to determine the professional standards. This issue is a small part of the licensing across state borders issue or Telehealth. The Genetic Counseling Board will meet to discuss further in order to insure professional standards are met as well as meeting the needs of the citizens of Oklahoma. The importance of using a two-way video during telephone counseling was discussed. Today is the deadline for any legislative submissions. The dried blood spot storage issue was discussed. The draft paper has been slightly revised and may be presented to national leaders for consideration. Dried blood spot storage has become a national issue. Direct to Consumer testing is still a highly visible public issue as shown from a recent New York Times article " My Genome, Myself". At the request of the policy committee, OGAC members showed appreciation for Dr. Cruther's support and wished him success in his future endeavors by passing a motion.

GECO: Mary Heinrichs- GECO has not met. The US Surgeon General's website for Family Health History tool is now interactive and is also available through OSDH's website. Genetics Day at the capitol is March 24th, 2009 and volunteers will be needed. LEND will be added as a subgroup to the GECO Committee.

Family Advisory: Joni Bruce represented Tara Lorg – Joni discussed the sibling support project "Sibshops" that has been established in the Tulsa area. They hope to establish five more Sibshops groups in Oklahoma within a year. The group provides support to the siblings and family of a special needs child. They have 400 mentors and have access to many parent groups that can be matched to provide one-on-one support. She discussed the Title V Conference "Joining Forces: Supporting Family/Professional Partnerships Conference" April 25th, 2009 and a handout was provided in the packet.

Adult: Sharon Vaz- Committee met last Thursday. They are continuing to discuss autoimmune disorders. A genetic counseling student is working on an educational component and online website to submit to the National Society of Genetic Counselors to be used as part of their continuing education. They also plan to develop a tool, guide or brochure to determine the risk for cardio vascular genetics disease. Families often do not have obvious symptoms in their family until someone passes away. Melissa Hall may be recruited for assistance.

Birth Defects Registry, Prenatal Screening and Diagnosis: Andrew Wagner- Did not meet as a committee. Andrew and Sharon attended a meeting discussing the Public Cord Blood Bank issue.

Newborn Screening Program and Pediatrics: James Coldwell, - Group has been meeting. Dr. Coldwell and Susan Hassed reported that Organic Acid Screening is going well. Included in the packet was a copy of the "Oklahoma Health Bulletin", published by OSDH in January 1966. The article discusses the beginning of PKU screening in Oklahoma. Sharon Vaz reported that the biggest issue for the NBS program is premature and sick newborns. She has received a survey concerning proposed guidelines that is due February 17th on what is appropriate for Oklahoma. The Newborn Screening Committee will meet to discuss it further. John Mulvihill and Lori Williams attended the national meeting of the Newborn Screening Heartland Regional Collaborative last week. One issue discussed was the "Newborn Screening Saves Babies Lives Act" which passed last year with no funding. The Newborn Screening Translational Research Network sponsored by the Child Health Institute plans to capture all children caught by newborn screening and follow them for a lifetime. Funding will only be provided to some jurisdictions so Oklahoma will need to be proactive. Another act not passed yet but in the news is the "Prenatally Diagnosed Condition Awareness Act" with the goal to provide information and support for patients receiving a positive test diagnosis.

Student Committee: Patricia Burk- Plans are to add a student section to the GECO Committee and for LEND leadership students to participate in Genetics Day at the Capitol. Educational opportunities will be provided through a pilot program with plans to expand to other OUHSC students and medical students across Oklahoma. LEND being will continue to be a part of GECO due to its transient students.

Heartland Update: Lori Williamson – The heartlandcollaborative.org website is up running. Two issues of the E-Newsletter have been published. They are gearing up for their non-competitive grant renewal. Lori will be working with Genetics Coordinators in each Heartland State to identify service gaps and present them to Sharon Vaz. One major project is the back-up testing project for disaster preparedness between Iowa and Missouri. Disaster preparedness is receiving national attention. The goal is to prepare Heartland States to back each other up in a disaster and to promote harmonization through laboratories. Another project in its early development is the, "Genetics Systems Assessment Project", which provides outcomes for genetic testing as in other professions. The project will be piloted at OSDH at some point. Dr. Mulvihill emphasized the need

for outcome standards for genetic services. Dr. Kayser's Center and six other Heartland states are contributing data.

Evaluation Committee – They are continuing to work on the evaluation report. Progress is being made and gaps identified. They would welcome volunteers and input from council members.

Cord Blood Banking- Dr. James Smith from the Oklahoma Blood Institute presented a slide presentation on Cord Blood Banking. Cord blood, which is rich in stem cells, is typically discarded. It can be used for transplant purposes if it is collected and stored properly. Private storage has not been well supported by the medical profession, thus the need for a public cord blood bank. He indicated it would be to Oklahoma's benefit to have a cord blood bank located in Oklahoma and not in another state. OBI is a non-profit organization. John Corpolongo discussed the legislative activity this year. SB 3060 required OSDH to survey blood banks as to their availability to contract with Oklahoma. The University of Colorado provided the most favorable response. The results of the survey were provided to the legislature as requested. This year, Senator Gumm filed SB17 requesting an appropriation of five million dollars to start a cord blood bank in Oklahoma. A meeting is planned with Senator Gumm next week to discuss further. Funding would be through OSDH and then require a sub-contract with a blood bank entity. The Newsweek article "When Medicine Meets Marketing" was discussed. The possibility for funding may increase with the new administration.

Sharon discussed the upcoming OPHA conference and recommended attendance. Dr. Mulvihill has an article in the OU Medicine Newsletter and Dr. Wagner is also in the newsletter. Sharon discussed the other educational handouts.

Nominations: Barbara Neas has agreed to chair for another year and Melissa Craft has agreed to vice-chair for another year.

Chair & Public Comments- Dr. Neas welcomed the students in attendance.
Dr. Mulvihill mentioned two upcoming conferences. The "Statewide Downs Syndrome Conference", March 7th at the Moore Norman Technology Center and Grand Rounds, Thursday, January 22nd, where Dr. Eric Vilain will speak on "Disorders of Sex Development: New Genes, New Names", Nicholson Auditorium, 8:00 am.

Adjournment – The next meeting will be May 21, 2009 in Tulsa.