

MINUTES

Oklahoma Genetics Advisory Council
May 20, 2010
Draft
Tulsa Youth Services Center
Tulsa, OK

10 Council Members Present: Barbara Neas, James Coldwell, John Mulvihill, Andrew Wagner, Nancy Carpenter, James Lewis, Sohail Khan for Melissa Gower, Mike Kayser, Lori Williamson and Jennifer Trevino for Lynn Mitchell.

14 Council Members Absent: Joan Cain, Larry Weatherford, Dewey Scheid, Mary Rindler, Susan Hassed, Danny Cavett, Melissa Craft, Linda Terrell, Tara Lorg, Laurie Applekamp, Grant Cox, Patti Davis, Frank Stone and John Armitage.

6 Ex-officio Members Present: Jennifer Allen, Patricia Burk, Debbie Kline, Tonya McCallister for Garry McKee, Kay Pearson and Sharon Vaz.

11 Ex-officio Members Absent: Paula Vann, Terry Johnsen, Lisa Caton, John Corpolongo, Terry Geisler, Amy Carte, Suzanna Dooley, Karen Hylton, Edd Rhodes, Jim Struby and Linda Thomas.

10 Visitors: Casey Smith, Mary Monks, Joni Bruce, Soheila Haddad, Ashley Ethriedge, Lora Roberts, Debbie Kloker, Janet Mork, Kevin Winters, and Ragina Munguia.

Welcome – Dr. Barbara Neas

Dr. Neas called the meeting to order and welcomed members and visitors. The contents of the meeting packets were reviewed. The minutes from the January 21, 2010 meeting were approved.

Family Story

Lora Roberts introduced Olivia Melton whose son Josiah was diagnosed with Pierre Robin Syndrome and other genetic disorders. He was delivered by an emergency C-section and was in the NICU for six weeks. He had low birth weight and was born with a club foot, u-shaped cleft palate and had a Gastrostomy at four weeks of age. He has Charcot-Marie-Tooth disease adult type, clones on the 2nd chromosome and extremity disorders. He has had numerous genetic tests and surgeries in the last four years. He suffers from low immunity and food allergies. Olivia chose to stay home with him though “it wasn’t really a choice” since his birth father is not very involved in his life. She has to be very organized to maintain Josiah’s eating schedule and his many therapies. He is a sweet spirited child who smiles often and is motivated by music, sounds and lights. He attends the Little Lighthouse and she plans to send him to public school special education classes. Josiah understands more than he can reciprocate and this is frustrating for her. The Sooner Start staff has been a tremendous help and emphasizes that no one really knows what

Josiah can accomplish. She would like to see more education available and more testing and research done. The “in home support waiver” would be very helpful if it becomes available. John Mulvihill mentioned the “all resource” manual Lori Williamson helped develop for several states.

OGAC Committee/Genetics Program:

OGAC Executive Committee

Dr. Neas- Committee met by phone to set the agenda for OGAC.

Genetics Education Committee of Oklahoma (GECO)

Sharon Vaz- reported on “Genetics Day at the Capitol”. Next year it will be planned while other events are going on and a breakfast will be provided. She would like to have new genetic stories to use.

Family Advisory

Joni Bruce reported that the “Joining Forces” meeting on April 9th was a success and had approximately 150 in attendance. The Oklahoma Family Network (OFN) provided travel, lodging and childcare stipends. Attendees were asked to provide a minimum of one outcome to complete by the next conference. OFN representatives visit families in the NICU and asked that families be referred to them.

Adult

Committee has not met.

Birth Defects Registry

Committee has not met. Andrew Wagner reported that the survey on how well obstetric care providers inform patients about the newborn screen is in the approval steps.

Newborn Screening Program and Pediatrics

Dr. Coldwell reported that the committee has not met. The AnnoLite for false/positives is being updated. Casey Smith, Quality Assurance/Data Coordinator for the OSDH Newborn Hearing Screening Program presented on the handout “Failure of Oklahoma Birthing Hospitals to Report Newborn Hearing Screening Results”. He discussed Figures 4 and 5 on the handout and a pilot project that has been initiated with nine hospitals to help hospitals improve their reporting rates. Plans are to include all hospitals that birth more than fifteen babies in a two year period. Sharon Vaz invited any interested ones to join the Audiology Task Force Committee by contacting Patricia Burk. Goals are to include a family member in each sub-committee and educate audiologist. In response to a question from Sohail Khan, Patricia Burk reported that data is linked to the metabolic blood spot form so is not collected by racial groups. Barbara Neas reported on continuing efforts to build the LEND student committee under GECO and encouraging their participation in Newborn Hearing issues. SharonVaz reported that Biotinidase testing is scheduled to start in the fall.

Heartland Update

Sharon Vaz reported that in May, Heartland sent Jennifer Allen to the “2010 Newborn Screening & Genetics Testing Symposium”. Lisa Caton and Paula Vann from the NBS Program also attended. Heartland is preparing for the annual meeting in Iowa this September. The “Transition Project” will be considered and Sharon requested participants and suggestions. Dr. Mulvihill discussed the handout listing Heartland issues, a new manual recently released on how to conduct genetic tele-medicine clinics and a pilot project for Oklahoma kids with PKU to attend camp. Tonya McAlister’s discussed her poster handout which won first place, “The Heartland Good Spot/Bad Spot Project”. The project confirmed the benefits of testing “unsatisfactory” specimens.

Evaluation Committee

The committee has not met but is in the process of pulling information together. Dr. Neas requested two new members.

Policy Committee

Sharon Vaz reported the committee has not met. SB1250 requiring parental consent was signed by the governor. Sharon Vaz was able to convince the legislature to keep “Family Health History” in HB2054. Copies of both bills were provided in the packet. Dr. Mulvihill would like to see blood spots stored for quality assurance.

Heartland Genetics Collaborative/HRSA

Health Information/Long Term Follow up evaluation

Dr. Amy Brower, a medical genetics, discussed her Health Information Technology (HIT) project for Heartland. The project includes the eight Heartland states and how they share information on long-term follow-up and information related to the newborn screen. The “Data Linkage Project” would create a national infrastructure to track outcomes. Included will be standardized language on the federal level and a long term follow-up data base. Newborn screening represents the first interaction of an individual with the health care system and exchange of information between medical entities. Oklahoma and other Heartland states will be in position to apply for federal funding as it becomes available. Concerns were how this information will be managed and the need for informed consent for health information.

Newborn Screening/St John/s IT Project-

Patricia Burk discussed the “data linkage” project in collaboration with CDC and HRSA. Goals are: screening results linking straight to Newborn Hearing using secure CDC software, linking to hospital medical records, and availability of web-based results. Patient information would be automatically populated in the Neometrics system. St. Johns Hospital is participating in the pilot project.

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

Adjournment – The next meeting will be September 16th 2010 in Oklahoma City.