

Newborn Screening Advisory Committee

Texas Department of State Health Services

1100 W. 49th, Austin, Texas 78756

Moreton Building, M6-653

October 2, 2014

Minutes

Members Present:

William Morris, LVN
Charleta Guillory, MD
Aida Gonzalez
Scott D. McLean, MD
Thomas M. Zellers, MD
Michael Speer, MD
Felicia M. Adams, MSN

Members via Conference Call

Nancy L. Beck, MD
Alice K. Gong, MD

Staff via Conference Call

Debra Freedenberg, MD, PhD,
DSHS Newborn Screening Unit

Staff

David R. Martinez, Department of State Health Services (DSHS),
Newborn Screening Unit Manager
Eugenia Dunham, DSHS, Newborn Screening Support Group Manager
Susan Tanksley, PhD, DSHS, Laboratory Operations Unit Manager
Monica Molina, DSHS, Newborn Screening Unit, Ombudsman, Committee Support
Brendan Reilly, Program Specialist, DSHS Laboratory, Biochemistry & Genetics Branch
Rachel Lee, PhD, Branch Manager, DSHS Laboratory, Biochemistry & Genetics Branch
D'Andra Morin, DSHS Laboratory, DNA Analysis Group
Patricia Hunt, DSHS Laboratory, Metabolic Screening Group
Karen Hess, DSHS, Newborn Screening Genetics Branch Manager
Kurt Wolf, DSHS, Program Specialist

Call to Order

Chairman Morris called to order the October 2, 2014 meeting of the Newborn Screening Advisory Committee at 10:13 am.

Roll Call of Committee Members, Staff and Guests

Chairman Morris asked if everyone would introduce themselves for the benefit of the new members present. Members, staff and guests attending are listed at the beginning of these minutes.

Review and Approval of Minutes

Chairman Morris said that due to the fact that they did not have a quorum for the last few meetings that were teleconference, minutes from the December 20, 2013, March 6, 2014 and June 20, 2014 need to be approved. Chairman Morris asked if everyone had a chance to look over the minutes and if any changes needed to be made. Dr. Speer made a motion to approve all the minutes, Dr. Guillory seconded. Motion passed.

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Newborn Screening Overview and Newborn Screening Program Updates **– Debra Freedenberg, Rachel Lee**

Debra Freedenberg and Rachel Lee gave updates on the newborn screening program and the laboratory. Committee members were given a PowerPoint presentation with detailed information which will not be repeated again in the minutes.

Timeliness of Newborn Screening – Susan Tanksley, Brendan Reilly

Susan Tanksley and Brendan Reilly discussed with the Committee the timeliness of newborn screening. A PowerPoint presentation was shown to the Committee. The topics that were included are as follows:

- Nationwide attention brought by a mother who lost a child with MCAD at 4 days of age
- Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) recommendations related to Newborn Screening (NBS) as of January, 2014/revised recommendations
- NBS system processes
- Timeline for initial specimens and when they should be received by the laboratory
- Timeline for critical conditions
- Quality improvement activities/projects
- Transit Time Workgroup
- Strategy for improvement
- Workgroup initiatives
- DSHS lab courier
- Remote data services
- Laboratory Information Management Systems (LIMS) upgrades
- Interventions needed to achieve more timely results

Biliary Atresia Screening – Dr. Guillory, Dr. Sanjiv Harpavat

Dr. Guillory introduced to the Committee Dr. Sanjiv Harpavat who has done a lot of work in screening babies for biliary atresia using a test that can be done in the hospital. Dr. Harpavat discussed with the Committee biliary atresia which is a rapid and serious disease in infants and presented a PowerPoint presentation, beginning on page 61 of the packet.

- Biliary Atresia
 - #1 reason for pediatric liver transplantation in the U.S. and the world
 - 1:10,000 infants
 - Early intervention = better outcome
 - Hard to diagnose

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Dr. Harpavat stated that a baby looks perfectly normal when born and goes home; then the infant starts to turn yellow, so the parents take the child to the pediatrician who says it is a result of breast feeding and recommends a change to formula. Parents take the baby home, but after about 2 months the baby shows no improvement, so they go back to the pediatrician who now says that something is wrong and the child is diagnosed with the disease. The intervention for this disease is to remove the duct and connect the intestine directly to the liver by an operation called the Kasai procedure. The operation cannot be performed if the disease is diagnosed at 2-3 months of life. Because of this, about 10% of diagnosed infants go directly to liver transplant in the first year of life. The sooner the operation is performed the better the outcome, and the more likely the delay of having to do a liver transplant. The goal is to do this operation within the first 30 days of life. A question asked is “how can this been done when the disease is hard to diagnose and so often missed”? There is a blood test that a lot of children get called a bilirubin test. Dr. Guillory made a motion for the Committee to first support Dr. Harpavat in further collaboration in terms of increasing awareness and increasing data which everyone says we need and second, the Committee work with TMA, TPS, and March of Dimes in terms of educating physicians. Chairman Morris wanted to add to the motion to invite Dr. Harpavat to give more follow up data. Chairman Morris seconded. Motion passed.

Secondary Panel – David R. Martinez

David R. Martinez gave the Committee an update on secondary panel. At the last meeting, the Committee was informed that Dr. Lakey has approved us to move forward to screen for disorders listed on the secondary panel. At the last meeting there were some dependencies on moving forward with the secondary panel, such as the LIMS upgrade, server procurement, and upgrades before we could proceed with the secondary panel. We are still on timeline for 2015 and hoping for completion by late spring. DSHS staff are working with vendors and moving forward with the algorithm and the tests required. Programming is needed with our vendor regarding the clinical care coordination side. DSHS staff are working on letters we need to send regarding the new conditions. DSHS staff are working on ACT/FACT sheets and protocols for the new conditions, as well as trying to get our education materials together. The Committee’s feedback is needed regarding the brochure that has been drafted for metabolic disorders (in your packet). Committee feedback can be sent by e-mail.

Newborn Screening 50th Anniversary – William Morris

Chairman Morris said that he had made some phone calls between December and now and hasn’t been able to get much interest in getting anything together. David Martinez said there was a brochure that was developed by the Association of Public Health Laboratories (APHL) and is something that is available from APHL recognizing 50 years of newborn screening. It is not something that we routinely distribute; however, Mr. Martinez wanted to let the Committee know that it is out there. Additionally, for some of the new members’ information, last year the Texas Newborn Screening Program was recognized nationally for 50 years of screening.

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Department of State Health Services Sunset Commission Updates – David R. Martinez

David R. Martinez stated that the State agencies undergo Sunset Review every 10 years. Mr. Martinez stated that the Health and Human Services Commission is currently going through the review and the report should be released this month. A hearing just like the one that was held for DSHS will take place in November where public testimony will be accepted. The Sunset Advisory Commission will convene again in December to vote on the recommendations and the report. Dr. Guillory asked if the NBS Advisory Committee was impacted. Mr. Martinez stated that the Committee was excluded from the recommendations concerning the Advisory Committees.

Public Comments

None

Agenda Items

- Critical Congenital Heart Defect (CCHD) updates
- Secondary panel updates

Adjournment

The Committee decided that the meetings for 2015 would be held in February, June and October. The dates and location will be determined at a later date. There being no further business, the meeting was adjourned at approximately 2:00 p.m.