

**Newborn Screening Advisory Committee
Meeting Minutes
June 17, 2016 via Conference Call
9:00 a.m. – 1:00 p.m.**

**Texas Department of State Health Services
1100 W. 49th, Austin, Texas 78756
Moreton Building, Conference Room M653**

Table 1: Newborn Screening Advisory Committee member attendance at the Friday, June 17, 2016 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Dr. Alice Gong	P		Dr. Scott D. McLean	P	
Dr. Charleta Guillory	P		Dr. Felicia M. Adams	P	
Dr. Tom Zellers	P		Dr. Elizabeth "Kaili" Stehel	P	
Benna Timperlake	P		Tiffany House	P	
Dr. Nancy Beck	P		Aida Gonzalez, MSN, RN		X
Dr. Michael Speer		X			

Yes: Indicates attended the meeting No: Indicates did not attend the meeting P: Indicates participated by phone

Table 2: Newborn Screening Advisory Committee staff attendance at the Friday, June 17, 2016 meeting.

STAFF NAME	YES	NO	STAFF NAME	YES	NO
David Martinez	X		Karen Hess	X	
Patti Lanfranco	X		Dr. Debra Freedenberg	X	
D'Andra Luna	X		Elizabeth Fitzgerald	X	
Dr. Rachel Lee	X		Leslie Boswell	X	
Brendan Reilly	X		Eugenia Dunham	X	
Michelle Shafer	X		Michelle Shafer	X	
Doug Dittfurth	X				

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Table 3: Newborn Screening Advisory Committee guest attendance at the Friday, June 17, 2016 meeting.

GUEST NAME	YES	NO	GUEST NAME	YES	NO
Rachel Jew	X		Brandy Lee	X	
Shannon Lucas	X		Ashley Juergens	X	
Elisa Seeger	X		James Foerster	X	
Bobby Seeger	X		Jenna Kampfschulte	X	
Mark Vane	X		Kurt Kampfschulte	X	
Dr. Sanjiv Harpavat	P		Julian Kampfschulte	X	
			Leslie Bushell	X	

Yes: Indicates attended the meeting P: Indicates participated by phone No: Indicates did not attend the meeting

Agenda Item 1: Nominate and Elect and Chair and Vice Chair

Dr. Charleta Guillory was nominated and accepted as Chair.

Dr. Alice Gong was nominated and accepted as Vice Chair.

Agenda Item 2: Approval of February 18, 2016 Minutes

MOTION: Dr. Tom Zellers

SECOND: Dr. Scott McLean

Motion carries to approve the February 18, 2016 minutes without correction.

Agenda Item 3: Newborn Screening Fee Increase Update

Dr. Rachel Lee gave an update on the cost of newborn screening activity. Executive Commissioner approved the rule for the fee increase change on May 17, 2016. June 3, 2016 the change was posted for public comment on the website for 30 days. The fee increase will be effective 09/01/2016.

A survey will be sent out to all specialty groups about topics related to billing for telephone consults

\$55.24 is the proposed new fee for newborn screening. Although healthcare providers can bill insurance, there is a concern that many pediatricians are not fully reimbursed for the cost of the newborn screening kits, and many pediatricians absorb the cost. The Committee members suggest looking into costs shifted from the Pediatrician to the Hospital.

Time is critical to update contracts with updated fee information.

Agenda Item 4: Timeliness Projects Update

Brendan Reilly reported on the project workflow redesign. Implementation for this project is July 13, 2016.

Referenced a handout.

Summary: Proposed options for simplified laboratory result reporting that transfers discrete analyte reporting from the current table format to the result reporting statement.

Proposed reporting solution would greatly simplify processes for implementing and maintaining electronic reporting and allow conformance to national standards for electronic reporting. Expansion of electronic reporting

of the results creates significant system efficiencies for both DSHS and healthcare providers.

The main summary of what is being investigated is the timeliness of reporting out of range disorder results.

MOTION: Dr. Alice Gong

SECOND: Ms. Benna Timperlake

Motion carries to recommend the format on page 14 and for result reports.

Karen Hess provided an update on the NewSTEPS 360 grant project. Texas was awarded \$120,000 over the next 3 years. The goals for the grant are: promoting demographic entry through the web application, getting the initial specimens to the lab within 24 hours of collection, and educating and improving practices that help facilitate timeliness including the follow up component.

Agenda Item 5: Data on Births without Newborn Screening

Dr. Rachel Lee researched data on babies that did not get a newborn screening after birth. She shared data with the committee by way of a handout in the packet.

Dr. Debra Freedenberg reported that there is a NewSTEPS site visit the week of June 27, 2016 that will evaluate the newborn screening system in Texas. The team of experts will provide recommendations in a report format.

Agenda Item 6: Newborn Screening for Biliary Atresia

Dr. Sanjiv Harpavat referenced a PowerPoint for his presentation on Biliary Atresia. The advantage of detecting the abnormal bilirubin levels to screen specifically for biliary atresia from the current blood spot card process is we already have a centralized lab (DSHS Lab) that processes blood spot cards.

Dr. Guillory asked Dr. Debra Freedenberg to explain the requirements for making a recommendation to the Advisory Committee on Heritable Disorders in Newborns and Children for inclusion on the Recommended Uniform Screening Panel.

Agenda Item 7: X-Linked Adrenoleukodystrophy (X-ALD)

Ms. Elisa Seeger and Mr. Bobby Seeger from New York showed a video clip of a boy with X-ALD to the Committee as well as notified the Committee of

two federal bills in the Senate and House which mandate all states screen for X-ALD. Two issues: funding, and a mandate vs. recommendation.

MOTION: Dr. Alice Gong.

SECOND: Dr. Elizabeth "Kaili" Stehel.

Motion carries that the Newborn Screening Advisory Committee recommends that screening for X-ALD be placed on the Exceptional Item List with the upcoming Legislative Appropriations Request (LAR).

Agenda Item 8: Newborn Hearing and Early Childhood Intervention Referrals and Follow-Ups

Mr. Doug Dittfurth referred to a PowerPoint to assist him with his update presentation. Committee members verified that the Early Childhood Intervention (ECI) program includes other providers, such as MHMR providers and school-based providers. Additionally, ECI providers can only provide services up through age 35 months.

Agenda Item 9: Public Comment

There was no public comment.

Agenda Item 10: Future Agenda Items

The committee wants data on the pediatricians that are paying for kits so the committee can track to see if the number of kits ordered increases or decreases once the new fee goes into effect.

The committee also wants to track the data on the first screen versus the second screen in linking the newborn screening data.

Additionally, the committee wants to keep X-ALD, Pompe, and MPS1 on the radar.

Add a plan to gather consultant information about the specialist time and reimbursement on the survey.

Agenda Item 11: Adjourn

Chairwoman Dr. Guillory adjourned the meeting at 1:02 p.m.