

**Newborn Screening Advisory Committee  
Meeting Minutes  
July 16, 2018  
10:30 p.m.**

**Moreton Building, Public Hearing Room M-100  
1100 W. 49<sup>th</sup> Street, Austin, TX 78756**

Table 1: Newborn Screening Advisory Committee member attendance at the Friday, July 16, 2018 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Nancy Beck, M.D.	P		Joseph Schneider, M.D.	X	
Alice Gong, M.D.	X		Michael Speer M.D.	P	
Charleta Guillory, M.D.	X		Elizabeth "Kaili" Stehel, M.D.	P	
Tiffany House, J.D.	P		Benna Timperlake, R.N.	X	
Tiffany McKee-Garrett, M.D.	X		Linda Zediana, RN	X	
Scott McLean, M.D.	X				

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

Table 2: Newborn Screening Advisory Committee guest attendance at the Friday, July 16, 2018 meeting.

GUEST NAME/ORG.	YES	NO	GUEST NAME/ORG.	YES	NO
Barbra Novak, MD, TX Children's Hospital	X		Nora DelBosque, March of Dimes	X	
Kellie Dees, Texas Pediatric Society	X		Mari Bailey, Health Services of North TX	X	
Carriston Hendricks, CCHD Subcommittee Member	X		Mike McBrierty, Biogen	X	
Khrystal Davis, FAST/SMA	X		Tiffany Britton, Caddo Associates	X	
Amanda Deason, CCHD parent	X		Shelbye Almeida, Carthage ISD	X	

**Agenda Item 1: Welcome and Introductions**

Dr. Charleta Guillory, Chair of the Newborn Screening Advisory Committee, convened the meeting at 10:30 a.m. Dr. Guillory greeted everyone and requested Committee members and members of the public introduce themselves.

**Agenda Item 2: Committee Business Logistics**

Dr. Guillory turned the floor over to Ms. Stephanie Gutierrez, Policy & Rules Advisory Committee Coordination Office, HHSC. Ms. Gutierrez reviewed logistics, called roll, and determined quorum.

### **Agenda Item 3: Review and Approval of Minutes for February 16, 2018**

Ms. Gutierrez reminded members they were sent a draft of the minutes through email and inquired whether there were any necessary edits. Dr. Speer stated he would like to add, "Texas Children's Hospital" to the minutes under section seven.

**MOTION:** Dr. Alice Gong motioned to approve the February 16, 2018 meeting minutes with Dr. Joseph Schneider seconding. A roll call vote was taken. The motion carried to approve the February 16, 2018 minutes by unanimous vote.

### **Agenda Item 4: Newborn Screening Advisory Committee Bylaws**

Ms. Gutierrez reviewed the bylaws with the Committee. Committee members discussed:

1. Member Expectations: Training within 90 days of appointment.
2. Subcommittees: Subject Matter Expert
3. Compensation and Travel Reimbursement: For Community representatives and Families

**MOTION:** Dr. Schneider made a motion to adopt the Newborn Screening Advisory Committee bylaws striking the Compensation and Travel Reimbursement section and pending edit of Responsibilities of Members subsection B number seven. Ms. Benna Timperlake seconded the motion. A voice vote was taken. The motion carried by two thirds vote.

**ACTION ITEM:** Ms. Patti Lanfranco will send members on the phone a clean copy of the Members by Statement for them to digitally sign.

**ACTION ITEM:** Ms. Lanfranco will send members the online link to the Open Meetings Act training.

**ACTION ITEM:** Mr. David Martinez will ask leadership for their guidance regarding Compensation and Travel Reimbursement.

### **Agenda Item 5: Newborn Hearing Screening in Neonatal Intensive Care Unit (NICU)**

Dr. Guillory introduced Dr. Barbra Novak, Audiology Texas Children's Hospital, Dr. Terese Finitzo, Texas Early Hearing Detection and Intervention Management Information System Representative, and Eugenia Dunham, Manager of Newborn Screening Support Group.

Dr. Novak referenced the PowerPoint and handout, *Newborn Hearing Screens and the NICU Population*.

Dr. Guillory turned the floor over to Dr. Terese Finitzo. Dr. Finitzo referenced the PowerPoint and handout, *Newborn Hearing Screening in the Neonatal Intensive Care Unit*.

Dr. Guillory requested a subcommittee on Hearing Screening, working with the Texas Pediatric Society and Medicaid subgroups, to work on developing best practices for hearing screens in the Texas NICU population.

Subcommittee Members on Hearing Screening:

1. Dr. Tiffany McKee-Garrett
2. Dr. Alice Gong
3. Ms. Benna Timperlake
4. Dr. Michael Speer
5. Dr. Joseph Schneider

**ACTION ITEM:** Dr. Novak will get data based on gestational age for the Committee.

### **Agenda Item 6: Critical Congenital Heart Disease**

Dr. Guillory introduced Dr. Scott McLean, Subcommittee Chair, Dr. Debra Freedenberg, Medical Director Newborn Screening Unit, and Dr. Charles Shumate, Epidemiologist Birth Defects and Surveillance Branch.

Dr. McLean referenced the PowerPoint and handout, *Critical Congenital Heart Disease (CCHD)*.

Dr. Guillory turned the floor over to Dr. Freedenberg. Dr. Freedenberg referenced the PowerPoint and handout, *CCHD NBS in Texas 2018*.

Dr. Freedenberg turned the floor over to Dr. Shumate. Dr. Shumate referenced the PowerPoint and handout, *Comparing CCHD Surveillance Systems: Texas Birth Defects Registry and Texas Newborn Screening*.

Dr. Guillory requested the CCHD subcommittee meet to work on guidelines for how to increase reporting in the state of Texas.

Dr. Guillory also requested that DSHS partner with the Texas Pediatric Society to repeat a previous study on birthing hospitals and designees responsible for reporting on CCHD, this time with the help of an epidemiologist.

### **Agenda Item 7: Break**

Dr. Guillory announced a 10-minute break.

### **Agenda Item 8: WORKING LUNCH: Parental Refusals**

Dr. Guillory reconvened the meeting at 1:17 p.m. and introduced Dr. Rachel Lee. Dr. Lee referenced the PowerPoint and handout, *Documenting NBS Parental Refusals*.

### **Agenda Item 9: X-ALD Screening Implementation**

Dr. Guillory turned the floor over to Dr. Lee. Dr. Lee referenced the PowerPoint and handout, *X-ALD Implementation Update*.

Dr. Lee turned the floor over to Ms. Jana Zumbrun, Associate Commissioner for Laboratory and Infectious Disease Services. Ms. Zumbrun notified the Committee that the department has developed a request to the legislature above the base budget to include full implementation of X-ALD. The status of X-ALD is that it has been presented to the acting Executive Commissioner by the DSHS Commissioner.

The increase of fee will be implemented on the go live date, September 2019.

Dr. Freedenberg informed the Committee of a grand round speaker, Dr. Jerry Raymond who will be giving a webinar on X-ALD.

**ACTION ITEM:** Dr. Freedenberg will give the Committee the archived link to the webinar.

### **Agenda Item 10: SMA Screening Cost Analysis**

Dr. Guillory turned the floor over to Dr. Lee. Dr. Lee informed the Committee of the methodology to be used for SMA screening. The methodology will be an add-on to a current screening. The reagent cost will be lower. New instruments will need to be purchased which will require more full time employees. 2.4 million dollars is the cost estimate for total cost. After go live, continuing cost will be 1.4 million per year.

### **Agenda Item 11: Rider 37 Update**

Dr. Guillory turned the floor over to Dr. Lee. Dr. Lee referenced the PowerPoint and handout, *Rider 37 Study Report Updates*.

### **Agenda Item 12: Comprehensive Review of DSHS Public Health Laboratory Budget**

Dr. Guillory introduced and turned the floor over to Dr. Grace Kubin, Director Laboratory Services Section. Dr. Kubin referenced the PowerPoint, *Laboratory Services Section Budget Overview*.

Dr. Guillory stated she would like to call a special meeting to draft a letter to comment on Rider 37. The Public Comment period will be closed July 26, 2018; however, Dr. Kubin stated the letter from the Committee can be included with the study report submission.

Dr. Guillory requested a subcommittee to draft a letter for public comment of Rider 37 from the Committee.

Subcommittee Members to draft a letter for Rider 37:

1. Dr. Joseph Schneider
2. Ms. Linda Zediana
3. Dr. Elizabeth Stehel
4. Dr. Nancy Louise Beck

**ACTION ITEM:** Dr. Kubin will check with Government Affairs regarding the Committee providing public comment as a whole.

**ACTION ITEM:** Dr. Kubin will provide the PowerPoint for her presentation to members.

**ACTION ITEM:** Dr. Guillory will communicate with Ms. Lanfranco to organize a special adhoc meeting.

### **Agenda Item 13: Discussion: Response to Committee Recommendation for Permanent Funding Mechanism for New Conditions**

Dr. Guillory and Dr. Gong relinquished their time.

### **Agenda Item 14: Public Comment**

Dr. Guillory turned the floor over to Ms. Gutierrez. Ms. Gutierrez read Public Comment Logistics to the Committee and announced there are five public comments, four in person and one Ms. Gutierrez will read for the record.

1. Ms. Carriston Hendricks
  - a. Gave an overview of articles
2. Ms. Khrystal Davis
  - a. Read her public comment regarding SMA
3. Ms. Shelbye Almeida
  - a. Offered her services of creating a video for CCHD for public dissemination
4. Ms. Amanda Deason
  - a. Shared her daughter's story with members
5. Ms. Beth Moore
  - a. Submitted written comment distributed to members

### **Agenda Item 15: Future Agenda Items/ Next Meeting Date/Adjournment**

Dr. Guillory noted a survey will be sent to members for future meeting dates. Members expressed interest in the Stakeholder meeting. Dr. Guillory thanked everyone for their contribution and hard work then adjourned the meeting at 3:31 p.m.

**ACTION ITEM:** Ms. Lanfranco will send the Stakeholder meeting materials to Dr. Schneider.

Webcast: <https://texashhsc.swagit.com/play/07162018-1355>