

**Newborn Screening Advisory Committee
Meeting Minutes
October 11, 2019
10:30 a.m.**

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

Table 1: Newborn Screening Advisory Committee member attendance at the Friday, October 11, 2019 meeting.

MEMBER NAME	IN ATTENDANCE
Beryl (Pam) Andrews	YES
Nancy Beck, M.D.	YES
Khrystal Davis	YES
Titilope Fasipe, M.D., Ph.D.	NO
Melissa Frei-Jones, M.D.	YES
Alice Gong, M.D.	YES
Charleta Guillory, M.D., M.P.H.	YES
Tiffany McKee-Garrett, M.D.	YES
Scott McLean, M.D.	YES
Joseph Schneider, M.D.	YES
Michael Speer, M.D.	YES
Elizabeth (Kaili) Stehel, M.D.	BY PHONE
Linda Zediana, R.N.	NO

Table 2: Newborn Screening Advisory Committee guest attendance at the Friday, October 11, 2019 meeting.

GUEST NAME and ORGANIZATION	IN ATTENDANCE
Terese Finitzo, OZ	YES
Alexa Mason	YES
Kellie Dees, TPS	YES

Agenda Item 1: Welcome and Introductions

Dr. Charleta Guillory, Chair of the Newborn Screening Advisory Committee, convened the meeting at 10:32 a.m. Dr. Guillory greeted everyone, introduced herself, and requested members, staff, and the public in the room introduce themselves. Dr. Guillory acknowledged Ms. Tiffany House as an outgoing member of the committee and announced the appointment of a new member, Ms. Khrystal Davis.

Agenda Item 2: Committee Business Logistics

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

Agenda Item 3: Review and Approve Meeting Minutes for July 12, 2019

Ms. Gutierrez requested a motion to approve the July 12, 2019 meeting minutes.

MOTION: Dr. Michael Speer made a motion to approve the July 12, 2019 meeting minutes. Dr. Joseph Schneider seconded. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections and one abstention by Dr. Scott McLean.

Agenda Item 4: Presiding Officer Election

Ms. Gutierrez read the Adoption of Procedure for Election of Officers and Officer Election Process in its entirety to members.

MOTION: Dr. Michael Speer made a motion to adopt the Procedure for Election of Officers. Dr. Joseph Schneider seconded. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections and no abstentions.

After the adoption of the Procedure for Election of Officers, Ms. Gutierrez read the duties of the Chair and Vice Chair. Ms. Gutierrez opened the floor to nominations for Chair. Ms. Gutierrez read for the record members who have been nominated and accepted their nomination through email prior to the meeting.

Nominees who have accepted their nomination for Chair:

- Dr. Joseph Schneider
- Dr. Alice Gong

No other nominations were made. Dr. Joseph Schneider requested to withdraw his acceptance of nomination. Nominations were closed. Ms. Gutierrez read the adopted language for single nominee for record. Ms. Gutierrez requested a motion to approve the election of Dr. Alice Gong for Chair by acclamation.

MOTION: Dr. Michael Speer made a motion to approve of the election of Dr. Alice Gong for Chair. Dr. Joseph Schneider seconded. A roll call vote was taken for Dr. Elizabeth (Kaili) Stehel who was in favor of the motion. A voice vote was taken for members in the room. All members in attendance of the current meeting were in favor. The motion carried with no objections and no abstentions. Members who were absent during the Chair Election were:

- Dr. Titilope Fasipe
- Ms. Linda Zediana

Dr. Gong was congratulated and gave an acceptance speech. Dr. Gong thanked Dr. Charleta Guillory for her leadership and commitment. Dr. Guillory reciprocated her appreciation for Dr. Gong.

Ms. Gutierrez opened the floor for nomination of Vice Chair. Ms. Gutierrez read for the record members who have been nominated and accepted their nomination through email prior to the meeting.

Nominees who have accepted their nomination for Vice Chair:

- Dr. Joseph Schneider
- Dr. Melissa Frei-Jones
- Dr. Michael Speer

No other nominations were made. Nominations were closed. Ms. Gutierrez gave the nominees two minutes each to offer a qualifications speech. After nominees gave their qualifications speech, Ms. Gutierrez noted for the record the two new officers will assume command after the current meeting. Ms. Gutierrez asked Dr. Guillory which method she preferred for the election of Vice Chair. Dr. Guillory stated ballot vote. Ms. Gutierrez notified members a ballot with their name on it has been placed by their microphone. Ms. Gutierrez collected the ballots and tallied the votes.

Vote for Vice Chair Tally:

- Dr. Joseph Schneider was voted for by:
 - Ms. Khrystal Davis
 - Dr. Melissa Frei-Jones
 - Ms. Beryl (Pam) Andrews
- Dr. Melissa Frei-Jones was voted for by:
 - Dr. Elizabeth (Kaili) Stehel
- Dr. Michael Speer was voted for by:
 - Dr. Michael Speer
 - Dr. Tiffany McKee-Garrett
 - Dr. Alice Gong
 - Dr. Charleta Guillory
 - Dr. Scott McLean
 - Dr. Joseph Schneider
 - Dr. Nancy Louise Beck

Ms. Gutierrez announced the new Vice Chair, Dr. Michael Speer. Dr. Speer was congratulated and gave an acceptance speech. Dr. Guillory and Dr. Gong acknowledged Dr. Speer for his dedication to the committee. Dr. Schneider offered a concession speech.

Agenda Item 5: Sickle Cell Subcommittee Reporting

Dr. Guillory introduced and turned the floor over to Dr. Frei-Jones. Dr. Frei-Jones referenced the PowerPoint and handout, *Sickle Cell Subcommittee Meeting Minutes September 17, 2019*.

Dr. Frei-Jones stated the subcommittee had a conference call to discuss the Sickle Cell Task Force and the Hemoglobinopathy Consultants Lists.

Members discussed:

- Application solicitation for the Sickle Cell Task Force
- Updating documentation distributed with newborn screening test result notifications
 - The subcommittee can assist program staff with updating the Hemoglobinopathy Consultants List more frequently to maintain the accuracy of pediatric providers' information
 - Adding a list of adult providers as a resource for long-term follow up and for individuals transitioning out of pediatric care
 - Developing a list of adult endocrinologists and the services they provide

MOTION: Dr. Michael Speer made a motion to approve the action items of the subcommittee. Dr. Joseph Schneider seconded. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections and no abstentions.

Agenda Item 6: Newborn Hearing Screening in Neonatal Intensive Care Unit (NICU) Subcommittee Reporting

Dr. Guillory introduced and turned the floor over to Dr. Tiffany McKee-Garrett, Subcommittee Chair. Dr. McKee-Garrett referenced the PowerPoint and handout, *Best Practices for Hearing Screening in Texas NICUs*.

Members discussed:

- The Texas Early Hearing Detection and Intervention (TEHDI) Management Information System (system) capturing gestational age data and determining whether new procedures are effective
- The data in the TEHDI system being deidentified as per parental consent
- The duration of the pilot project at Texas Children's Hospital
- Conveying the motion to the Texas Collaborative for Healthy Mothers and Babies (TCHMB), Texas Pediatric Society (TPS), and other organizations to include the Perinatal Advisory Council
 - Members will draft a letter for distribution and send it to the program for review
- The subcommittee to review the draft standards in a year to assess outcome
- The full committee charging the subcommittee with forming a group of external subject matter experts
- Focusing on insufficient audiological support and clinical decision support

MOTION: Dr. Alice Gong made a motion to accept the proposed subcommittee recommendations as a draft guideline for trial use as a full committee with an amendment to the PowerPoint. Dr. Michael Speer seconded the motion. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections nor abstentions.

MOTION: Dr. Alice Gong made a motion to charge the subcommittee with organizing a group to investigate implementation of the draft guidelines for trial use. Dr. Michael Speer seconded the motion. A roll call vote was taken for members

over the phone. A voice vote was taken for members in the room. The motion carried with no objections nor abstentions.

MOTION: Dr. Joseph Schneider made a motion that during the period of evaluation, the subcommittee also evaluate adequacy of audiological support and how to handle it as well as the ability to provide electronic clinical decision support to audiologist and other organizations. Dr. Scott McLean seconded the motion. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections nor abstentions.

ACTION ITEM:

- Dr. Terese Finitzo, OZ Systems, will provide the program with data on false positives for babies that were screened in Australia.
- Dr. Debra Freedenberg, Medical Director, DSHS, Newborn Screening Unit, will provide members with information regarding the availability of follow-up data in the statewide TEHDI system for all babies receiving care in the NICU that have been screened by 34 weeks gestational age.

PUBLIC COMMENT: Dr. Terese Finitzo discussed the TEHDI system and diagnostic testing with members.

Agenda Item 7: Lunch

Dr. Guillory announced a 30-minute lunch break.

Agenda Item 8: Critical Congenital Heart Disease (CCHD) Subcommittee Reporting

Dr. Guillory reconvened the meeting at 1:03 p.m. then introduced and turned the floor over to Dr. Scott McLean, Subcommittee Chair. Dr. McLean referenced the PowerPoint and handout, *Report of the Critical Congenital Heart Disease (CCHD) Subcommittee to the Texas Newborn Screening Advisory Committee (NBSAC)*.

Members discussed:

- How to have abnormal screens reported to the state within 48 hours of completion
- The law to conduct newborn screening for CCHD provides state with no authority to collect CCHD data other than confirmed cases or for enforcement
- How to go about developing measures and oversight for CCHD screening for the sake of quality improvement

MOTION: Dr. Elizabeth Stehel made a motion to support the recommendations of the CCHD subcommittee with a request of a quality improvement mechanism within the CCHD system. Dr. Joseph Schneider seconded the motion.

MOTION: Dr. Scott McLean made a motion to table the motion made by Dr. Stehel. Dr. Michael Speer seconded the motion. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections nor abstentions.

Agenda Item 9: Newborn Screening Consultant (NSC) Fees Subcommittee Reporting

Dr. Guillory turned the floor over to Dr. Scott McLean, Subcommittee Chair. Dr. McLean referenced the handout and PowerPoint, *Report from the NBS Consultants Subcommittee 10/11/2019*.

Members discussed:

- Tracking referrals to specialists
- Tracking volume of telephone consultations by specialists
- Other states' contracting with specialty centers that provide genetic services
- Identifying funding mechanisms, compensation models and resources to support genetic services
- Relieving workload burden of specialists providing telephone consultations

MOTION: Dr. Michael Speer made a motion for the full committee to support the wrap up summary of the NSC Fees subcommittee and encourage their further diligence. Dr. Joseph Schneider seconded the motion. A roll call vote was taken for members over the phone. A voice vote was taken for members in the room. The motion carried with no objections nor abstentions.

Agenda Item 10: Public Comment

Ms. Gutierrez read public comment logistical announcements and called Ms. Kellie Dees to address members.

Ms. Dees, Texas Pediatric Society, Public Health Education Manager, addressed members regarding the newborn screening kit fee increase exacerbating inadequate and insufficient reimbursement for pediatricians.

Agenda Item 11: Future Agenda Items/ Next Meeting Date/ Adjournment

Dr. Guillory opened the floor for discussion of future agenda items.

Members discussed:

- Update on X-linked Adrenoleukodystrophy (X-ALD) testing
- Update on future implementation of Spinal Muscular Atrophy (SMA) screening
- Laboratory testing/newborn screening kit fee increases
- Subcommittee reporting
- Feasibility of tying newborn screening test results to birth records
- Presentation on electronic informatics model for newborn screening data
- Review of Medicaid funds distributed outside of the Newborn Screening program

Dr. Guillory thanked the state newborn screening program staff and Ms. Gutierrez for their support. Dr. Guillory gave an exit speech showing gratitude for members and appreciation for all the work that has taken place on the committee.

Dr. Guillory adjourned the meeting at 2:48 p.m.

Webcast: <https://texashsc.swagit.com/play/10112019-701>