

Newborn Screening Advisory Committee

FINAL APPROVED Meeting Minutes

Monday, November 13, 2023

1:00 p.m.

Virtual Site -Teams Meeting Platform

In Person Site - North Austin Complex, Rooms 1.401-1.404, First Floor
4601 W. Guadalupe Street, Austin, Texas 78751

Agenda Item 1. Call to order, roll call, and welcoming remarks

Khrystal Davis, J.D., Presiding Chair, called the Newborn Screening Advisory Committee (NBSAC) meeting to order at 1:01 p.m.

Ms. Davis announced they will table the March 24, 2023, and July 28, 2023, draft meeting minutes for consideration at the next meeting, and turned the floor over to Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office, Texas Health and Human Services Commission (HHSC).

Ms. Thompson read the logistical announcements and stated the meeting was being conducted with the Texas open Meetings Act. Ms. Thompson conducted the member roll call and announced the presence of quorum.

Ms. Davis then introduced the Texas Department of State Health Services (DSHS) staff present.

Table 1. NBSAC member attendance at the Monday, November 13, 2023 meeting.

Member Name	Attended
Kaashif Ahmad, M.D., M.B.B.S., M.S.C.	Yes
Beryl (Pam) Andrews	No
Khrystal Davis, J.D.	Yes
Titilope Fasipe, M.D., Ph.D.	Yes
Melissa Frei-Jones, M.D., M.S.C.I., Vice-Chair	Yes
Alice Gong, M.D.	Yes
Charleta Guillory, M.D., M.P.H.	Yes
Tiffany McKee-Garrett, M.D.	Yes
Barbra Novak, Ph.D., C.C.C.-A.	Yes
Fernando Scaglia, M.D.	Yes

Member Name	Attended
Joseph Schneider, M.D.	Yes
Michael Speer, M.D., Chair	Yes
Elizabeth (Kaili) Stehel, M.D.	Yes

Agenda Item 2. Consideration of July 8, 2022, October 24, 2022, March 24, 2023, and July 28, 2023, draft meeting minutes

Ms. Davis asked members to refer to the draft meeting minutes the Newborn Screening (NBS) program liaison emailed them and called for any edits. Hearing none, Ms. Davis called for a motion to approve the July 8, 2022, and October 23, 2022, draft meeting minutes.

Motion:

- Dr. Speer moved to approve the July 8, 2022, and October 23, 2022, meeting minutes as presented. Dr. Schneider seconded the motion. Ms. Thompson conducted a roll call vote, and the NBSAC members passed the motion by a majority vote with 12 yeas (Dr. Ahmad, Ms. Davis, Dr. Fasipe, Dr. Frei-Jones, Dr. Gong, Dr. Guillory, Dr. McKee-Garrett, Dr. Novak, Dr. Scaglia, Dr. Schneider, Dr. Speer, and Dr. Stehel), zero nays, and zero abstentions.

Agenda Item 3. Presiding officer election

Ms. Davis turned the floor over to Ms. Thompson to conduct votes to adopt election procedure and elect a new chair and vice-chair.

A. Presiding officer term review/B. Election procedure adoption

Ms. Thompson reminded members they received a copy of the election procedure and read the handout, "Adoption of Procedure for Election of Officers and Officer Election Process," to members in its entirety. Ms. Thompson called for a motion and a second to approve the election procedure.

Motion:

- Dr. Speer moved to approve the procedure. Dr. Scaglia seconded the motion. Ms. Thompson conducted a roll call vote, and the NBSAC members passed the motion with an 11 yeas majority vote (Dr. Ahmad, Ms. Davis, Dr. Fasipe, Dr. Frei-Jones, Dr. Gong, Dr. Guillory, Dr. McKee-Garrett, Dr. Novak, Dr. Scaglia, Dr. Schneider, and Dr. Speer), zero nays, and one abstention (Dr. Stehel).

C. Chair election

Ms. Thompson read for the record each member who received a nomination for chair prior to the meeting and the member who made the nomination.

Chair nominees:

- Dr. Melissa Frei-Jones was nominated by Dr. Speer.

Ms. Thompson opened the floor for other nominations for the office of chair. Hearing none, Ms. Thompson called for a motion to approve election of the single nominee, Dr. Frei-Jones, for the office of chair by unanimous consent or acclamation.

Motion:

- Ms. Davis moved to approve election of Dr. Frei-Jones to the office of chair. Dr. Scaglia seconded the motion. Ms. Thompson conducted a roll call vote, and the NBSAC members passed the motion by a majority vote with 11 yeas (Dr. Ahmad, Ms. Davis, Dr. Fasipe, Dr. Gong, Dr. Guillory, Dr. McKee-Garrett, Dr. Novak, Dr. Scaglia, Dr. Schneider, Dr. Speer, and Dr. Stehel), zero nays, and one abstention (Dr. Frei-Jones).

Ms. Thompson announced Dr. Frei-Jones the new NBSAC Chair by unanimous vote and congratulated her. Dr. Frei-Jones gave an acceptance speech.

D. Vice-Chair election

Ms. Thompson read for the record each member who received a nomination for vice-chair prior to the meeting and the member who made the nomination.

Vice-Chair nominees:

- Ms. Pam Andrews was nominated by Dr. Schneider;
- Dr. Tiffany McKee-Garrett was nominated by Dr. Speer; and
- Dr. Schneider was nominated by Dr. Speer.

Ms. Thompson asked Dr. Schneider if he declined the nomination, and he confirmed. Since Ms. Andrews was not at the meeting, Ms. Thompson turned the floor over to Ms. Davis, who read a qualifications statement on Ms. Andrews' behalf. Ms. Thompson turned the floor over to Dr. McKee-Garrett to state her qualifications. After Dr. McKee-Garrett gave her qualifications speech, Ms. Thompson conducted a roll call vote to elect the vice-chair.

Vice-Chair roll call vote tally:

- One vote for Ms. Andrews (Dr. Schneider);
- Ten votes for Dr. McKee-Garrett (Dr. Ahmad, Ms. Davis, Dr. Fasipe, Dr. Frei-Jones, Dr. Gong, Dr. Guillory, Dr. Novak, Dr. Scaglia, Dr. Speer, and Dr. Stehel); and
- One abstention (Dr. McKee-Garrett).

Ms. Thompson announced Dr. McKee-Garrett is the new NBSAC Vice-Chair and congratulated her. Dr. McKee-Garrett gave an acceptance speech.

Agenda Item 4. DSHS NBS Program updates

Ms. Davis introduced Dr. Susan Tanksley, Deputy Director, DSHS Laboratory and Deputy Associate Commissioner, Public Health Laboratory Division, DSHS, to provide DSHS NBS Program updates.

A. NBS Laboratory/B. NBS Unit

Dr. Tanksley introduced Ms. Lori Gabbert Charney, Director, Maternal and Child Health Section, DSHS, and they presented NBS Laboratory and NBS Unit updates.

Presentation highlights include:

- Staff updates:
 - ▶ NBS Unit Director retirement announcement;
 - ▶ New staff member announcements, introductions, and welcome;
 - ▶ New staff speeches:
 - ◇ Dr. Jessica Brown-Obiora, Medical Director, NBS Unit, DSHS;
 - ◇ Ms. Leslie McKenzie, Director, NBS Unit, DSHS; and
 - ◇ Dr. Pawan Vohra, Director, Medical Screening Unit, DSHS Laboratory.
 - ▶ New NBS Unit structure overview;
 - ▶ Thanks to staff for their help during the transition period;
- Laboratory renovations progress;
- Congenital hypothyroidism screening project status and new algorithm implementation date announcement;
- Cystic Fibrosis screening instrument change announcement and implementation process timeline;

- Propel Grant goal and activity overview;
- Recent and upcoming laboratory fee increase rates, dates, and purpose; and
- DSHS staff participation at the October 2023 Association of Public Health Laboratories Newborn Screening Symposium.

Agenda Item 5. Future condition implementation updates

Ms. Davis turned the floor over to Dr. Tanksley to present future condition implementation updates.

Presentation highlights include:

- Implementation status for four Recommended Uniform Screening Panel (RUSP) conditions not screened for in Texas:
 - Pompe;
 - Mucopolysaccharidosis type I;
 - Mucopolysaccharidosis type II;
 - Guanidinoacetate Methyltransferase Deficiency;
- Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) role in recommending conditions for NBS in the United States;
- Krabbe disease, Duchenne Muscular Dystrophy, and Biliary Atresia ACHDNC status; and
- How DSHS could fund implementation for new conditions added to the RUSP.

Members discussed:

- Genetic testing for conditions not on the NBS panel;
- What approach DSHS will take regarding new sequencing capabilities;
- Requesting improvements in how the NBS Program shares results;
- Dr. Shumate in Birth Defects works on electronic case reporting at DSHS;
- Electronic case reporting potential for follow up of conditions such as Critical Congenital Heart Disease (CCHD);
- DSHS work to improve data entry, timeliness and follow up for blood spot, hearing, and CCHD screening; and
- Need for ongoing discussion on the ethics of filtering out data from the Texas NBS test and only looking at results of currently screened conditions.

- Ms. Gabbert Charney responded to Dr. Schneider’s comments and gave an electronic case reporting update related to the Propel Grant.

Agenda Item 6. NBSAC subcommittee updates

A. Rare Diseases Subcommittee

Ms. Davis, Rare Diseases Subcommittee Chair, provided the update.

Presentation highlights include:

- The subcommittee did not meet between the last and current NBSAC meeting; and
- The subcommittee will meet prior to the next meeting to discuss the process for the NBSAC to recommend screening for conditions not already on the RUSP.

B. Sickle Cell Subcommittee

Ms. Davis stated the subcommittee did not meet and turned the floor over to Dr. Frei-Jones, Sickle Cell Subcommittee Co-Chair, to provide the update.

Presentation highlights include:

- Subcommittee plans include helping to update the long-term follow up form and NBS data;
- Sickle Cell Data Collection (SCDC) grant background; and
- Next meeting agenda includes discussing how the subcommittee may support the state in carrying out the SCDC grant.

Members discussed:

- Dr. Schneider offered to present on how electronic case reporting could significantly help data collection for the Rare Disease Subcommittee and Sickle Cell Subcommittee.

Agenda Item 7. Sickle Cell Task Force (SCTF) update

Ms. Davis turned the floor over to Dr. Fasipe, SCTF Chair, to present a SCTF update.

Presentation highlights include:

- Sickle Cell Subcommittee update overlapping with the SCTF update;

- Expressing excitement over the SCDC grant awarded by the Centers for Disease Control and Prevention and congratulating and thanking everyone who contributed to the accomplishment;
- When the 2023 SCTF Annual Report will be published and a summary of their 2023 recommendations;
- Membership update; and
- 88th Legislature, Regular Session, 2023 update and House Bill 1488 impact.

Members discussed:

- Clarifying what NBS Program data the SCDC grant will need;
- SCDC Program history;
- How the SCTF and its Sickle Cell Surveillance Subcommittee worked to identify data sources and the challenges they faced; and
- If the sickle cell-related legislative bill provides the means for clinicians to follow patients once disease modifying treatments come out.

Break/Roll Call

At 2:26 p.m., Ms. Davis announced a 15-minute break and reconvened the meeting at 2:43 p.m. Ms. Thompson conducted a member roll call and announced the presence of quorum.

Agenda Item 8. Public comment

Ms. Thompson read the public comment logistical announcements and called on members of the public who pre-registered to provide public comment.

Oral public comment:

- **Lesla Brackbill, Director of Advocacy, Leukodystrophy Newborn Screening Action Network**

Ms. Brackbill addressed members on behalf of a family unable to join because of the realities of living with Metachromatic leukodystrophy (MLD) to speak about the importance of screening for MLD. Advocates plan to nominate MLD for the RUSP after the Federal Drug Administration approves a MLD gene therapy. Ms. Brackbill is also a mother of a daughter diagnosed with Krabbe disease and looks forward to the day Texas screens for all LSDs and leukodystrophies to help families receive a diagnosis with hope.

Agenda Item 9. Action items and future agenda items

Ms. Davis opened the floor for NBSAC members to plan and discuss future meeting topics and reviewed a list of proposed agenda items for the next meeting.

List of proposed agenda topics:

- NBSAC goals two-year goal setting and action plan development;
- DSHS program updates;
- Future condition implementation updates;
- Rare Disease Subcommittee report;
- Sickle Cell Subcommittee report;
- SCTF update;
- Reportable Conditions Knowledge Management System and CCHD Presentation from Dr. Charles Shumate, Birth Defects Epidemiology and Surveillance, DSHS (include electronic case reporting and its impact on hospital case reporting);
- Congenital cytomegalovirus (cCMV) testing guidance development and tracking and reporting development; and
- Newborn hearing screening follow up data and cCMV testing.

Member discussion:

- Ms. Gabbert Charney addressed member-proposed cCMV agenda topic requests;
- cCMV bill legislative intent;
- DSHS role in cCMV bill implementation; and
- A hearing screening follow up, test referral, audiologic evaluation, and therapy data request ask.

Action items:

- The NBS Program staff will check hearing screening follow up data availability and provide what can be shared with NBSAC members.
- During their goal setting discussion, NBSAC members will make a list of what they would like DSHS to report to the NBSAC annually and what recommendations they would like to make to DSHS.

Ms. Davis announced the next meeting will take place January 29, 2024 in the Robert D. Moreton Building, Room M-100, First Floor, 1100 W. 49th Street, Austin Texas, 78756.

Agenda Item 10. Adjournment

Ms. Davis adjourned the meeting at 3:08 p.m.

Below is the link to the archived video recording of the November 13, 2023 NBSAC meeting. The public may view and listen to this meeting recording for approximately two years from the date the meeting is posted, in accordance with the HHSC records retention schedule.

[Newborn Screening Advisory Committee – November 13, 2023 meeting](#)