

Newborn Screening Advisory Committee

FINAL APPROVED Meeting Minutes

Friday, July 11, 2025

1:00 p.m.

Virtual Site – Teams Meeting Platform

In Person Site – Robert D. Moreton Building, Room M-100, First Floor
1100 W. 49th Street, Austin, Texas 78756

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

Melissa Frei-Jones, M.D., M.S.C.I., Chair, called the Newborn Screening Advisory Committee (NBSAC) meeting to order at 1:01 p.m.

Dr. Frei-Jones welcomed everyone 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 in compliance with the Texas Open Meetings Act. Ms. Thompson conducted the member roll call and announced the presence of quorum.

Table 1. NBSAC member attendance at the Friday, July 11, 2025, meeting.

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

Agenda Item 2. Consideration of November 1, 2024, and April 22, 2025, draft meeting minutes

Dr. Frei-Jones, Chair, reminded members they received a copy of the draft meeting minutes for review and called for any edits or changes. Hearing none, Dr. Frei-Jones called for a motion to approve the February 6, 2024, and April 22, 2025, draft meeting minutes.

Motion:

Dr. Alice Gong provided first motion to approve the draft minutes from the November 1, 2024, and April 22, 2025, meetings as presented.

Dr. Michael Speer seconded the motion.

Ms. Thompson conducted a roll call vote and announced the motion carried vote included ten approvals.

Agenda Item 3. Legislative Updates

Dr. Frei-Jones introduced Alison Hern, Government Affairs staff, who gave an update on DSHS-impacted legislative activities during the 89th Regular Session. Ms. Hern stated the session ended June 2, 2025, and the veto period ended June 22, 2025. Over 9,000 bills were filed, with over 1,100 impacting the Texas Department of State Health Services (DSHS). The Governor signed 1,155 bills and vetoed 26 bills. 140 bills became law without the Governor's signature. Ms. Hern announced new laboratory funding was approved.

Senate Bill 1044, concerning Duchenne's muscular dystrophy, can be implemented after the bill. Funding can be appropriated once additional lab space is obtained, about two years before implementation. The preservation account cannot fund this due to restrictions.

House Bill 107, concerning the sickle cell registry and annual report of sickle cell cases is on hold. DSHS can implement a provision if mandated without funding. DSHS was awarded only \$1 million to implement, but the total cost is \$6.1 million. DSHS will reassess funding availability.

Members discussed the Advisory Committee on Heritable Disorders for Newborns and Children (ACHDNC) status and how to get conditions on the Recommended Uniform Screening Panel (RUSP). There is still a RUSP and since ACHDNC no longer meets, the way to get testing added to a state panel is through legislation. To add

conditions to the RUSP, we are waiting on Federal government direction. One member stated HRSA has the authority to add conditions to the RUSP.

Agenda Item 4. DSHS Newborn Screening Program updates and announcements

Dr. Frei-Jones introduced Dr. Susan Tanksley, Deputy Laboratory Director, DSHS Laboratory, and Deputy Associate Commissioner, Dr. Jessica Brown-Obiora, NBS Medical Director, Dr. Kelly Fegan-Bohm, Community Health Improvement, and Dr. Pawan Vohra, from DSHS Public Health Laboratory Division.

Presentation highlights included:

- General NBS updates, including new screening conditions, electronic case review, the updated critical congenital heart disease toolkit, courier services, and fee increases.
- Members discussed old sample testing, adding courier services to the fee increase, and NBS Clinical Care Coordination putting together a staff list, so providers know which team to contact and at which number. Members also discussed cystic fibrosis repeat testing and potential for future changes.

Agenda Item 5. Sickle Cell Task Force Update

Dr. Frei-Jones introduced Dr. Titilope Fasipe, NBSAC member and Sickle Cell Task Force Chair. Dr. Fasipe discussed highlights from the June 6, 2025, meeting and preparing the end of year report. Additional discussion involved subcommittee reorganization and membership updates.

Action Item:

SCTF will share the 2025 annual report with the NBSAC when the report is ready.

Agenda Item 6. Sickle Cell Data Collection Program Update

Dr. Frei-Jones introduced Dr. Heidi Bojes, Director, DSHS Environmental Epidemiology Disease Registry Section. Dr. Bojes referenced the Sickle Cell Data Collection (SCDC) system as a means to gather information, review sickle cell trends, and healthcare access. The DSHS Institutional Review Board (IRB) application is on the agenda for the next meeting. Through IRB, SCDC can access information obtained and share that information. Current reports are being finalized.

Discussion continued regarding core datasets utilizing NBS data as a base and matching it with other data as allowed.

Agenda Item 7. National Academies of Sciences, Engineering, and Medicine newborn screening committee and report update

- Dr. Frei-Jones re-introduced Dr. Titilope Fasipe. Dr. Fasipe discussed the National Academies of Sciences, Engineering, and Medicine (NASEM) report examined current NBS landscapes with 3.6 million babies screened annually and those needing intervention. Highlights included resource support, public health service, clear laws and policies for protecting dried bloodspot storage and use, evaluating infrastructure, expanding public trust, coordinating research to inform of NBS policy and practice, and ethics involved.
- Discussion from members followed and members would like to know how Texas is doing in comparison to the NASEM report.

Agenda Item 8. Public Comment

Ms. Thompson stated no one registered for public comment.

Agenda Item 9. Action items and future agenda items

Dr. Frei-Jones opened the floor for NBSAC members to discuss future meeting topics and reviewed future agenda items.

Member discussion:

- Standing agenda items
- Meeting minutes
- Bylaws
- Member orientation
- Program updates
- Legislative update on House Bill 107 funding
- NBS Phone Contact List for Providers
- Follow-up on process for babies getting second newborn screens when their families can't afford it.
- Texas Compared to NASEM Report
- Bylaws Review

- Membership update
- Chair and Vice-Chair selection

Dr. Frei-Jones stated the next NBSAC meeting is on November 14, 2025.

Agenda Item 10. Adjournment

Dr. Frei-Jones adjourned the meeting at 3:19 p.m.

Below is the link to the archived video recording of the July 11, 2025, 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 – July 11, 2025, meeting](#)