

Newborn Screening Advisory Committee

FINAL APPROVED Meeting Minutes

Friday, November 14, 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, presided and 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, Advisory Committee Coordination Office (ACCO) facilitator, 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 with nine members present and four members absent and announced the presence of a quorum.

Table 1. NBSAC member attendance at the Friday, November 14, 2025, meeting.

Member Name	Attended
Kaashif Ahmad, M.D., M.B.B.S., M.S.C.	No
Beryl (Pam) Andrews	Yes
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.	No
Joseph Schneider, M.D.	Yes
Michael Speer, M.D.	Yes
Elizabeth (Kaili) Stehel, M.D.	Yes

Agenda Item 2. Consideration of July 11, 2025, draft meeting minutes

Dr. Melissa 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 July 11, 2025, draft meeting minutes.

Motion:

Dr. Joseph Schneider motioned to approve the draft minutes from the July 11, 2025, meetings as presented. Dr. Michael Speer seconded the motion.

Ms. Jacqueline Thompson, Facilitator, ACCO, HHSC, conducted a roll call vote and announced the motion carried with nine approvals (Ms. Andrews, Dr. Fasipe, Dr. Frei-Jones, Dr. Gong, Dr. Guillory, Dr. McKee-Garrett, Dr. Schneider, Dr. Speer, and Dr. Stehel), zero disapprovals, zero abstentions, and four absences (Dr. Ahmad, Ms. Davis, Dr. Novak, and Dr. Scaglia).

Agenda Item 3. Texas Department of State Health Services (DSHS) Newborn Screening Program updates and announcements

Dr. Melissa Frei-Jones, Chair, introduced Susan Tanksley, Ph.D., Deputy Laboratory Director for Texas Department of State Health Services (DSHS) Laboratory and Deputy Associate Commissioner for the DSHS Public Health Laboratory Division; Pawan Vohra, Ph.D., MBA, Unit Director, Medical Screening Unit, DSHS Public Health Laboratory Division; Jessica Brown Obiora, M.D., M.P.H., Medical Director, DSHS Newborn Screening (NBS) Unit; and Ms. Leslie McKenzie, R.N., B.S.N., Unit Director, DSHS NBS Unit. Dr. Tanksley, Dr. Vohra, Dr. Brown, and Ms. McKenzie referenced the PowerPoint and handout, *Newborn Screening Program Updates, November 14, 2025*.

Presentation highlights included:

- NBS Laboratory updates, including new disorder implementation, quality improvement projects, laboratory courier program, NBS remote data services, electronic test ordering and reporting, NBS and vital statistics data linkage, NBS genomic sequencing, National Institutes of Health (NIH) NBS Whole Genomic Sequencing Collaboratory Project, NBS 2026 fee increase, and laboratory renovations.
- NBS Clinical Care Coordination (CCC) updates, including specialist collaborating partner meetings, CCC contacts list information, electronic case reporting, new disorder implementation, cystic fibrosis testing, Krabbe

Disease prior authorizations, provider survey results, Texas NBS Summit, and DSHS Grand Rounds on NBS.

Member discussion:

- Texas participation in the Genomic Uniform-screening Against Rare Diseases in Newborns (GUARDIAN) Study and the Building Evidence and Collaboration for GenOmics in Nationwide Newborn Screening (BEACONS NBS) initiative.
- Availability of geneticists in Texas and plans to get more geneticists in Texas.
- Analyzing the NBS 2026 fee increase impact on providers' ability to offer second screens for newborns covered by insurance or paying out-of-pocket.
- Medicaid-enrolled providers being required to perform screens as Texas Health Steps providers.
- Texas Administrative Code requirements for fee increase notices.
- Providers having to negotiate with each insurance company on reimbursement rates based on costs and billing codes, which causes a lot of work for providers.
- Quality improvement projects, including the Laboratory's efforts to reduce number of false positives.
- Implementation of new conditions that are dependent on acquiring additional laboratory space, which is expected in five years.
- If some tests can be implemented sooner by sending them out.
- Availability of Texas Laboratory Online (TLO) web portal user access to providers.
- Electronic message reporting is only at 30%, so a lot of reporting still depends on manual data entry.

Agenda Item 4. Sickle Cell Task Force Update

Dr. Melissa Frei-Jones Frei Jones, Chair, introduced Dr. Titilope Fasipe, NBSAC member and Sickle Cell Task Force Chair to provide a Sickle Cell Task Force update.

Presentation highlights included:

- August 19, 2025, meeting and preparing the annual report.
- Finalization, approval, and availability of the 2025 annual report on the DSHS website.

- Continuing partnerships with the HHSC Office of the Medical Director for Medicaid and Children’s Health Insurance Program (CHIP) Services and the DSHS Sickle Cell Data Collection Program (SCDC) to optimize goals with sickle cell disease:
 - Educating Medicaid health plans on approach to sickle cell disease as a disease that requires comprehensive care like other chronic diseases.
 - Looking for opportunities to provide care during transition from pediatric to adult care when individuals lose Medicaid coverage.
 - Updating the Sickle Cell Texas Health Steps module to provide Continuing Medical Education credit.

Agenda Item 5. SCDC and House Bill (HB) 107, 89th Texas Legislature, Regular Session, 2025 update

Dr. Melissa Frei-Jones, Chair, introduced Heidi Bojes, Ph.D., MPH, Director, DSHS Environmental and Disease Registries (EEDRS) Section, and Principal Investigator, Centers for Disease Control and Prevention (CDC) SCDC Program grant, to provide an update on recent sickle cell disease legislation and grant program updates.

Presentation highlights included:

- Sickle cell disease legislation:
 - The passing of HB 107 by the 89th Texas Legislature, Regular Session, 2025, requiring DSHS to establish a sickle cell disease registry.
 - The unique requirements of the registry as an ‘opt-in registry’ requiring consent under statute.
 - The \$1.0 million appropriated to DSHS to implement HB 107 is being used to conduct a registry assessment to establish a roadmap for how DSHS can establish the registry.
- SCDC activity updates:
 - Program is in its third year.
 - Status of establishing a core data set of individuals living with sickle cell disease by using newborn screening data as the base and linking that to various administrative DSHS datasets, such as hospital discharge records and vital records, to fill in missing information and verify existing information.
 - Program received required Institutional Review Board approval to start obtaining data with identifiable information in August 2025.

- ▶ Datasets they have received and expect to receive and the analyses they plan to conduct.
- ▶ Project using de-identified hospital discharge data from emergency department visits from individuals with sickle cell disease in Texas in 2023.
- Development of a complementary report to emergency department visit data report to evaluate non-emergency or hospital visits by individuals with sickle cell disease in 2023.
 - ▶ Collaboration with University of Texas (UT) Health Houston to evaluate 2022-2023 All Payor Claims data to describe the patterns in health care utilization among individuals with sickle cell disease identified in the health care claims database.
 - ▶ Collaboration with UT Austin, School of Communication to develop educational materials for campus health care providers and students in Texas to inform them about sickle cell disease and the transition from pediatric to adult care:
 - ◊ Video educational modules
 - ◊ One-page resource guides accompanying modules
 - ◊ Postcard handout for students
 - ▶ Continuing work on series of photoblogs highlighting diversity of sickle cell disease community to be posted on the DSHS SCDC website and shared through social media.
- The DSHS SCDC website includes the completed reports, projects, and educational materials the agency reviewed and approved.

Member discussion:

- Sharing educational materials with colleges campuses and students.
- Having the opportunity to review approved reports.
- Availability of link to DSHS SCDC website.
- Sickle cell trait information is not included in SCDC because data collection is focused specifically on individuals diagnosed with sickle cell disease.
- Other organizations in the U.S. have created workgroups to look at sickle cell trait and discuss creating separate sickle cell trait registries.

Agenda Item 6. Bylaws review

Dr. Melissa Frei-Jones, Chair, stated that members will have the opportunity to look over the NBSAC bylaws. Members only need to review the bylaws and do not yet need to vote on them.

Member discussion:

- If anyone has recommended changes to the bylaws.
- If DSHS recommends any changes to the bylaws.
- Members should review bylaws and send questions, concerns, and recommendations for changes to the Advisory Committee Liaison by email.
- Vote on bylaws will be at a future meeting.

Agenda Item 7. Public Comment

Ms. Jacqueline Thompson, Facilitator, ACCO, HHSC, stated no one registered for public comment.

Agenda Item 8. Action items and future agenda items

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

Member discussion:

- Getting more new geneticists in Texas.
- Medical student genetic internships.
- New membership appointments.
- History of NBSAC presented by Dr. Alice Gong, Dr. Charleta Guillory, and Dr. Michael Speer.
- NBS Program updates.
- Status of NBS Preservation Account.
- National Institutes of Health study on whole genomic sequencing in public health laboratories – BEACONS_{NBS}.
- Specific topics related to the National Academies of Sciences, Engineering, and Medicine consensus report, *Newborn Screening: Current Landscape and Future Directions*.
- Status of project linking NBS data to vital statistics data.

- Impact of NBS fee increase on small practices.

Dr. Frei-Jones stated the next NBSAC meeting is scheduled for April 17, 2025, at 1 p.m. in Moreton, M-100.

Agenda Item 9. Adjournment

Dr. Frei-Jones adjourned the meeting at 3:17 p.m.

Below is the link to the archived video recording of the November 14, 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 – November 14, 2025, meeting](#)