

Newborn Screening Advisory Committee

FINAL APPROVED Meeting Minutes

Friday, November 1, 2024

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 1:00 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, November 1, 2024, meeting.

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

Agenda Item 2. Consideration of February 6, 2024, and April 30, 2024, 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 30, 2024, draft meeting minutes.

Motion:

Dr. Joseph Schneider moved to approve the draft minutes from the February 6, 2024, and April 30, 2024, meetings as presented. Dr. Michael Speer seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried. Vote included ten approves (Dr. Kaashif Ahmad, Ms. Pam Andrews, Dr. Melissa Frei-Jones, Dr. Alice Gong, Dr. Charleta Guillory, Dr. Tiffany McKee-Garrett, Dr. Barbra Novak, Dr. Fernando Scaglia, Dr. Schneider, and Dr. Speer), zero disapproves, and zero abstentions.

Agenda Item 3. Member solicitation update

Dr. Frei-Jones gave an update on the NBSAC membership solicitation process. She stated the member appointment process is still underway and Texas Department of State Health Services (DSHS) expects new member appointments by the next meeting in April 2025. Dr. Frei-Jones thanked members for their service, especially the departing members continuing serve until DSHS announces replacements for their positions.

Member discussion:

Members had no questions or comments.

Agenda Item 4. 2024 Newborn Screening (NBS) Program Annual Report update

Dr. Frei-Jones introduced Susan Tanksley, Ph.D., Deputy Laboratory Director, DSHS Laboratory, and Deputy Associate Commissioner, Public Health Laboratory Division, DSHS. Dr. Tanksley referenced the handout, *2024 Newborn Screening Program Annual Report*.

Presentation highlights included:

- Report includes brief overview of NBS.
- Legislatively required when DSHS is not screening for a condition added to the core panel of the Recommended Uniform Screening Panel (RUSP)

- DSHS is not currently screening for five conditions on the core panel:
 - Pompe disease
 - Mucopolysaccharidosis type I (MPS I)
 - Mucopolysaccharidosis type II (MPS II)
 - Krabbe disease
 - Guanidinoacetate methyltransferase (GAMT).
- History of NBS
- Implementation progress
- NBS Preservation Account funding availability
- Current timeline for implementing recommended screens
- Space limitations effects on implementation
- Other conditions under consideration for addition to the RUSP
- Current and projected space in the Austin laboratory building

Member discussion:

- Confirming if GAMT is the last condition to be added and the estimated date
- Congenital Cytomegalovirus status for recommendation to the RUSP by the Advisory Committee on Heritable Disorders in Newborns and Children

Dr. Frei-Jones announced Dr. Titilope Fasipe joined the meeting, and Dr. Fasipe provided an introduction.

Agenda Item 5. DSHS NBS Program updates and announcements

Dr. Frei-Jones introduced Dr. Tanksley, Leslie McKenzie, B.S.N., R.N., Director, NBS Unit, DSHS; and Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, DSHS to provide DSHS NBS Program updates and announcements. Dr. Tanksley, Ms. McKenzie, and Dr. Brown referenced the PowerPoint and handout, *Texas Newborn Screening Program Updates*.

Dr. Tanksley presented Laboratory updates.

Presentation highlights included:

- Laboratory renovations
 - Emergency generator upgrade.

- During shutdowns, the Laboratory will send out a limited number of samples to a reference laboratory.
 - More information will be communicated through listserv and website.
- Current disorder updates: Cystic Fibrosis
 - Testing on new instruments for began 6/3/2024.
 - Method is the same.
 - Expectations for changing the algorithm
- New Disorder Implementation
 - Lysosomal Storage Disorders
 - ◊ Four disorders include Pompe disease, MPS I, MPS II, and Infantile Krabbe Disease.
 - ◊ Impact of laboratory renovation and retrofit delays
 - ◊ New expected implementation date
 - Laboratory building retrofit changes made to date
 - Second-tier testing development
 - Third-tier testing development
 - GAMT implementation
- NBS result report modification and go-live date

Member discussion:

- Plans to address Krabbe second-tier testing time critical concerns
- Clarifying how NBS result report is received from an informatics standpoint
- Billing considerations for additional tiers of testing

Dr. Tanksley turned the floor over to Ms. McKenzie and Dr. Brown to give Clinical Care Coordination updates.

Presentation highlights included:

- First annual NBS Education Conference recap
 - Turnout
 - Continuing education credits offered
 - Feedback received

- ▶ Areas to reevaluate
- ▶ 2025 conference planning
- ▶ Clinician survey went live
- Clinician survey
 - ▶ Goal
 - ▶ Takeaways so far
 - ◇ Space for more NBS education in a variety of professions, especially non-clinical roles
 - ◇ Knowledge check shows area for improvement for when to collect screen
 - ◇ Most participants have not experienced barriers to providing care to infants with abnormal screens.
 - ◇ Link
- NBS Awareness month activities completed during September 2024
- Plans for 60th anniversary during NBS Awareness month in September 2025
- Member solicitations updates for NBSAC and Sickie Cell Task Force
- Requesting feedback from NBSAC members, colleagues, and parents on how to best reach out to parents on NBS education

Member discussion:

- Ideas to connect to parents:
 - ▶ Form partnerships to target audience at Neonatal Intensive Care Units and Mother and Baby Units
 - ▶ Texas Pediatric Society webinars for providers and parents
- Has the NBS Program seen an uptick in parent refusals

Agenda Item 6. Sickie Cell Task Force update

Dr. Frei-Jones turned the floor over to Dr. Fasipe, the Sickie Cell Task Force (SCTF) Chair, to provide a SCTF update. Dr. Fasipe gave the status of the 2024 SCTF annual report and described the 2023-2024 SCTF activities. Dr. Fasipe added the SCTF is working on carrying out legislation. Dr. Frei-Jones summarized the legislation.

Action Item:

SCTF will share the 2024 annual report with the NBSAC when the report is ready.

Member discussion:

Members had no questions or comments.

Agenda Item 7. Sickle Cell Data Collection (SCDC) Program update

Dr. Frei-Jones introduced Heidi Bojes, Ph.D., Director, Environmental Epidemiology and Disease Registries Section, DSHS, and Principal Investigator, Centers for Disease Control and Prevention (CDC) SCDC Program grant, to provide a SCDC update.

Presentation highlights included:

- A review grant details and purpose
- Progress on Texas SCDC goals:
 - DSHS Institutional Review Board (IRB) application status
 - Establishment of a core data set based on NBS data after is pending IRB approval
 - Link core data set with other administrative data sets
 - Exploration of other data projects with deidentified information until core data set established
- CDC SCDC Program Annual Meeting and Sickle Cell Disease Summit
- Changes to quarterly meetings and next meeting date
- Photo blog featuring advocate posted online

Member discussion:

- Photo blog required by CDC
- Clarification on type of data and aggregation
- NBS Clinical Care Coordination's follow up and data collection on patients identified with sickle cell disease
- Public health benefits of identifiable data and data linkage

Agenda Item 8. NBSAC Bylaws review

Dr. Frei-Jones stated the NBSAC Bylaws must be reviewed every two years and opened the floor for discussion.

Member discussion:

- Language on the number of times the NBSAC must meet a year must be changed.

Agenda Item 9. NBSAC member informatics goals discussion

Dr. Frei-Jones opened the floor for discussion.

Member discussion:

- Twelve conditions for Critical Congenital Heart Disease (CCHD)
- Electronic case reporting (ECR)
- Birth defects
- Ending use of paper forms
- More accurate case reporting for CCHD
- ECR for screening results
- Timing of reporting compared to real time

Agenda Item 10. Public Comment

Ms. Thompson stated no one registered for public comment.

Agenda Item 11. Action items and future agenda items

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

Member discussion:

- Standing agenda items
- Meeting minutes
- Bylaws
- Member orientation
- Program updates
- Rare Disease Subcommittee
- Informatics data update
- Testimony from public advocates

Dr. Frei-Jones stated the next NBSAC meeting is on April 4, 2025.

Agenda Item 12. Adjournment

Dr. Frei-Jones adjourned the meeting at 2:56 p.m.

Below is the link to the archived video recording of the November 1, 2024 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 1, 2024 meeting](#)