

Newborn Screening Advisory Committee

FINAL APPROVED

Meeting Minutes

Tuesday, April 30, 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 1:01 p.m.

Dr. Frei-Jones made two announcements. She stated they will table the February 6, 2024, draft meeting minutes until the next meeting, and they will consider agenda item five before agenda item four. She asked members to hold questions until they have completed both agenda items four and five.

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 Tuesday, April 30, 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

Member Name	Attended
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.	Yes

Agenda Item 2. Consideration of February 6, 2024, draft meeting minutes - Tabled

Agenda Item 3. Membership update

Dr. Frei-Jones gave an update on the NBSAC membership solicitation process. She stated members received an email notice on the number of terms they served and their eligibility to reapply, and she expects the solicitation be posted in the next couple of months.

Member discussion:

Members discussed solicitation and application process.

Members proceeded to agenda item five.

Agenda Item 5. 2022 Newborn Screening (NBS) data overview

Dr. Frei-Jones introduced Leslie McKenzie, B.S.N., R.N., Director, NBS Unit, Texas Department of State Health Services (DSHS), to provide a 2022 NBS data overview. Ms. McKenzie referenced the PowerPoint and handout, *Texas Newborn Screening Diagnosed Cases, 2019 to 2022*.

Presentation highlights included:

- Data information and sources;
- Recommended Uniform Screening Panel (RUSP) versus the Texas NBS Panel; and
- 2019-2022 bloodspot conditions data:
 - ▶ Congenital hypothyroidism was the most frequent infant diagnosis of all the RUSP conditions, followed by sickle cell anemia;
 - ▶ Total diagnosed cases for all RUSP disorders increased from 2019 to 2022; and

- ▶ Total number of blood spot screens received dropped in 2020, the first year of the COVID pandemic.

Member discussion:

Members postponed discussion for agenda item five to after agenda item four.

Members returned to agenda item four.

Agenda Item 4. DSHS NBS Program updates

Dr. Frei-Jones introduced Leslie McKenzie, B.S.N., R.N., Director, NBS Unit, Texas Department of State Health Services (DSHS); Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, DSHS; and Pawan Vohra, Ph.D., M.B.A, Director, Medical Screening Unit, Texas Public Health Laboratory, DSHS, to provide DSHS NBS Program updates.

Presentation highlights included:

- Current disorders;
- New disorder implementation;
- Laboratory-developed tests regulation;
- Second screen issue follow up;
- Specialist Collaborating Partner meetings:
 - ▶ Name change from consultants meetings;
 - ▶ Spinal muscular atrophy group met in March; and
 - ▶ Cystic fibrosis group met in April;
- 2024 Newborn Screening virtual conference;
- Program support of Reportable Conditions Knowledge Management System efforts; and
- Social media outreach.

Member discussion:

- Possible causes of decreased number of newborn screening cards collected and cases from 2019 to 2020;
- Possible cause of increased cystic fibrosis after 2020;
- RUSP conditions not yet on the Texas panel; and

- Second screen data availability.

Action item:

Program will research if cystic fibrosis testing changed from 2020-2022.

Agenda Item 6. Sickle Cell Data Collection (SCDC) 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:

- CDC final budget approval status and funding details;
- Texas SCDC goals;
- Grant activities overview;
- Completed grant activities to date:
 - Multi-disciplinary team March in-person meeting; and
 - Data collection and analysis protocol submission to DSHS Institutional Review Board (IRB).
- IRB review and approval purpose;
- Aggregate data project exploration; and
- Educational outreach activities:
 - Photo blog; and
 - Collaborative video project.

Member discussion:

- Fall data update possibility; and
- IRB approval time estimate.

Agenda Item 7. NBSAC Sickle Cell Subcommittee update

Dr. Frei-Jones gave a Sickle Cell Subcommittee update and lead a member discussion.

Presentation highlights included:

- Subcommittee history; and

- Subcommittee proposal to dissolve subcommittee.

Member discussion:

- Clarifying options to continue Sickle Cell Subcommittee duties and activities;
- If other groups carrying out sickle cell-related work have the same leadership as the subcommittee; and
- Subcommittee appreciation of NBSAC support.

Agenda Item 8. Sickle Cell Task Force (SCTF) update

Dr. Frei-Jones introduced Titilope Fasipe, M.D., Ph.D., SCTF Chair, to provide a SCTF update.

Presentation highlights included:

- SCTF anticipates HHSC will post a call for applications soon;
- House Bill (HB) 1488, 88th Texas Legislature, Regular Session, 2023, added new SCTF members and directives;
- HHSC, DSHS, and SCTF collaboration to reach HB 1488 goals;
- SCTF may dissolve SCTF Sickle Cell Surveillance Subcommittee due to SCDC work duplication; and
- 2024 SCTF legislatively mandated report status.

Member discussion:

Members had no questions or comments for agenda item eight.

Agenda Item 9. Public Comment

Ms. Thompson stated no one registered for public comment.

Agenda Item 10. 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:

- Member work continuation with Texas Pediatric Society to address second screen issues;
- Information and discussion related to second NBS bloodspot screens, such as missed second screen data;

- NBS status within DSHS data integration;
- Road map for adding diseases not on the RUSP; and
- Congenital cytomegalovirus (cCMV).

Future agenda items:

- DSHS NBS Program updates; and
- Annual spring NBS data update.

Action item:

NBS Program staff and Dr. Frei-Jones will discuss appropriate options related to out-of-scope topic discussion prior to next meeting.

Dr. Frei-Jones reminded members to email meeting topic suggestions to Aimee Millangue, Advisory Committee Liaison, NBS Unit, DSHS, prior to the next meeting on July 19, 2024, at 1:00 p.m., in the North Austin Complex.

Agenda Item 12. Adjournment

Dr. Frei-Jones adjourned the meeting at 2:14 p.m.

Below is the link to the archived video recording of the April 30, 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 – April 30, 2024 meeting](#)