

Newborn Screening Advisory Committee (NBSAC)
FINAL APPROVED Meeting Minutes
Friday, July 28, 2023
1:00 p.m.

Virtual Site: Microsoft Teams Meeting Platform

In Person Meeting Site: Robert D. Moreton Building, Public Hearing Room M-100
1100 West 49th Street, Austin, Texas 78756

Agenda Item 1: Welcome, introductions, and logistical announcements

Dr. Michael Speer, NBSAC Chair, called the meeting to order at 1:09 p.m. He welcomed committee members, staff and members of the public.

Ms. Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office, Office of Policy and Rules, Texas Health and Human Services Commission (HHSC) announced the meeting was being conducted in accordance with the Texas Open Meetings Act, conducted roll call, and noted the presence of a quorum.

Table 1. Newborn Screening Advisory Committee member attendance at the July 28, 2023 meeting.

Member Name	In Attendance ^{1,2}
Kaashif Ahmad, M.D., M.B.B.S., M.S.C.	No
Beryl (Pam) Andrews	Yes
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.	No
Fernando Scaglia, M.D.	Yes
Joseph Schneider, M.D.	Yes
Michael Speer, M.D., Chair	Yes
Elizabeth (Kaili) Stehel, M.D.	Yes

¹ Yes indicates member attended the meeting.

² No indicates the member did not attend the meeting.

Agenda Item 2: Consideration of July 8, 2022, draft meeting minutes and October 24, 2022, draft meeting minutes – TABLED

Prior to the meeting start, Dr. Speer announced the NBSAC would table Agenda Item 2: Consideration of the July 8, 2022, draft meeting minutes and October 24, 2022, draft meeting minutes for the next meeting.

Agenda Item 3: Legislative update

Dr. Speer introduced Ms. Amanda Brant, Deputy Director, Government Affairs, Texas Department of State Health Services (DSHS), to provide an update on the 88th Legislature, Regular Session, 2023.

Highlights of the presentation included:

- DSHS tracked hundreds of bills with potential agency or public health impact;
- DSHS will complete implementation plans for bills that went into effect;
- The legislature filed, changed, and amended several bills impacting newborn screening (NBS);
- House Bill (H.B.) 2478 was passed and signed into law. It impacts NBS legislative report requirements, NBS Preservation Account funding, and allows but doesn't require NBS Preservation Account funds to operate the NBS lab seven days a week, and impacts confirmatory Congenital Cytomegalovirus (CMV) testing requirements;
- DSHS will go through the rulemaking process during bill implementation;
- H.B. 181 passed but was vetoed by the governor. It would have required DSHS to establish a sickle cell registry for individuals diagnosed with sickle cell disease; and
- H.B. 1488 was passed and signed into law. It relates to sickle cell disease, impacts several agencies, changes Sickle Cell Task Force composition, and changes reporting requirements.

Members discussed:

- H.B. 2478 legislative intent and report requirements;
- Seeking clarification from bill authors;
- Newborn Screening Preservation Account initial fund sources;
- CMV confirmatory testing requirement may create challenges; and
- If DSHS will seek stakeholder input on H.B. 2478 implementation.

Action items:

- Ms. Brant will follow up on member questions and provide bill copies, summaries, and implementation plan details to Ms. Aimee Millangue,

Advisory Committee Liaison and Ombudsman, NBS Unit, DSHS, to distribute to members.

Agenda Item 4: Program updates – Department of State Health Services

Dr. Speer introduced Dr. Susan Tanksley, Deputy Director, DSHS Laboratory, to provide NBS Program updates for the NBS Laboratory and NBS Unit.

Highlights of the presentation included:

- Current and upcoming laboratory renovations;
- Laboratory fee increase plans;
- Congenital hypothyroidism screening pilot project status and new algorithm implementation timeline;
- NBS Program goals for the new Propel Grant awarded by Health Resources Services Administration;
- Laboratory staff retirement news; and
- NBS laboratory and clinical care coordination job openings and postings.

Members discussed:

- Seven-day laboratory work week legislation;
- New congenital hypothyroidism screening algorithm concerns;
- Their appreciation of Dr. Rachel Lee and Dr. Debra Freedenberg;
- If the Propel Grant plans include an opportunity to replace handwriting with bar codes;
- How the NBS Program will take part in DSHS data modernization efforts;
- NBS and vital statistics data linking; and
- Critical Congenital Heart Disease (CCHD) screening case reporting.

Action items:

- Dr. Tanksley stated they will look at congenital hypothyroidism data to address member concerns; and
- Ms. Karen Hess, Director, NBS Unit, DSHS, will share any information the NBS Program finds related to adding CCHD to reportable cases.

Agenda Item 5: Future condition implementation updates

Dr. Speer introduced Dr. Tanksley to provide future condition implementation updates.

Highlights of the presentation included:

- Implementation of the four Recommended Uniform Screening Panel (RUSP) conditions not currently screened for in Texas, which include Pompe,

Mucopolysaccharidosis type I (MPS I), Mucopolysaccharidosis type II (MPS II), and Guanidinoacetate Methyltransferase Deficiency (GAMT);

- Implementation process, activity, and timeline overview;
- Lysosomal storage disorder stakeholder meeting details;
- How Centers for Disease Control and Prevention (CDC) grant funds support implementation activities;

Members discussed:

- Pompe, MPS I, MPS II, and GAMT implementation target date;
- How to help clinicians who receive abnormal test results understand what to do and when more testing will follow to prevent false alarm;
- The laboratory tries to implement additional tiers of testing because of false positives causes medical system burdens; and
- If laboratory improvements will free up additional space for screening non-RUSP conditions in the future, especially with new gene therapies coming out fast.

Agenda Item 6: Newborn Screening Advisory Committee subcommittee reports

A. Rare Diseases Subcommittee

Dr. Speer turned the floor over to Ms. Khrystal Davis, Chair, Rare Diseases Subcommittee Chair, to present a subcommittee report.

Highlights of the presentation included:

- When the Rare Diseases Subcommittee last met;
- Background on Ms. Lisa Otto, a guest the subcommittee invited to their June 9, 2023, meeting;
- An overview of the Noonan syndrome presentation Ms. Otto gave at the subcommittee meeting;
- Overview of the subcommittee member discussion related to Noonan syndrome; and
- The meeting also included a legislative update.

B. Sickle Cell Subcommittee

Dr. Speer turned the floor over to Dr. Melissa Frei-Jones, Sickle Cell Subcommittee Co-chair, to present a subcommittee report.

Highlights of the presentation included:

- When the Sickle Cell Subcommittee last met and who was present;

- An overview of subcommittee discussion at the July 7, 2023 meeting, which included:
 - Comparing their role as a NBSAC subcommittee to the role of the Sickle Cell Task Force;
 - A rundown of new laws and their Sickle Cell Task Force impact;
 - Sickle Cell Subcommittee activities;
 - Status update on a letter of support subcommittee wants to send to the Texas Medical Association (TMA) for their survey help;
 - Background and effects of the National Collegiate Athletic Association sickle cell policy change; and
 - Hemoglobinopathy long-term follow up data reporting.

Members discussed:

- Their support of the subcommittee request for the NBS Program to share long-term follow-up form data;
- If the NBS Program could collect long-term data on sickle cell performance measures; and
- How they could assist with the TMA letter.

Action Items:

- Determine best method to submit the survey support letter to TMA;
- In response to Dr. Alice Gong’s long-term data request question, Ms. Lori Gabbert-Charney, Director, Maternal and Child Health Section, DSHS, advised DSHS will provide the long-term care form data they collect to the committee; and
- NBS lab will provide update on sickle cell newborn screening requests as a result of the NCAA policy change.

Agenda Item 7: Membership update

Dr. Speer advised committee members the NBSAC needs to fill 8 of 13 positions. The solicitation will go out in August 2023. Three member terms will expire in 2025, and three member terms will expire in 2026. A couple of member terms will expire on August 31, 2023. Members will serve until their positions are filled.

Action Items:

- Dr. Speer asked for the list of open positions and the member solicitation to go out to the membership.

Break/Roll Call:

At 2:29 p.m., Dr. Speer announced a 15-minute break and reconvened the meeting at 2:44 p.m. Ms. Thompson conducted a roll call and advised the presence of a quorum.

Agenda Item 8: Public Comment

Ms. Thompson announced no one registered for public comment.

Agenda Item 9: Future agenda items, next meeting date, and adjournment

Dr. Speer advised members of action items and future meeting topics and asked committee members to submit additional agenda topics to committee liaison, Ms. Millangue, before the next meeting. He then opened the floor for member discussion.

Action items:

- NBS Program staff will share with members copies of relevant bills discussed during the meeting, the medical director posting, opportunities for stakeholder feedback; and the list of members and term expirations; and
- DSHS staff will follow up on CCHD screening and reporting details, the finalized version of H.B. 2478, hypothyroidism data and the number of babies not receiving second screens, long-term data report.

List of proposed agenda topics:

- Subcommittee reports;
- Program updates;
- Future conditions implementation;
- Officer elections; and
- Membership appointments.

Members discussed:

- Newborn genome sequencing;
- Electronic case reporting;
- H.B. 2478 requirements for Congenital Cytomegalovirus testing for newborns who failed the hearing test;
- Birth Defects Registry; and
- Including CCHD in the Reportable Conditions Knowledge Management System.

Dr. Speer announced the next meeting will take place on November 3, 2023.

Dr. Speer adjourned the meeting at 2:54 p.m.

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Below is the link to the archived video of the July 28, 2023, NBSAC that will be available for viewing approximately two years from date meeting posted on website and based on the HHSC records retention schedule.

[Newborn Screening Advisory Committee](#)