

Newborn Screening Advisory Committee

FINAL APPROVED Meeting Minutes

Tuesday, April 22, 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

Tiffany McKee-Garrett, M.D., Vice-Chair, called the Newborn Screening Advisory Committee (NBSAC) meeting to order at 1:01 p.m. and welcomed attendees.

Dr. McKee-Garrett announced the tabling of agenda items 2 and 7 and turned the floor over to Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office, Texas Health and Human Services Commission (HHSC).

Ms. Thompson stated the meeting was being conducted in compliance with the Texas Open Meetings Act and read the logistical announcements. Ms. Thompson conducted the member roll call and announced the presence of quorum.

Table 1. NBSAC member attendance at the Tuesday, April 22, 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	No
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, draft meeting minutes - Tabled

Agenda Item 3. Member solicitation update

Dr. McKee-Garrett announced the Newborn Screening (NBS) Program staff will address the member solicitation update during agenda item 4.

Agenda Item 4. Texas Department of State Health Services (DSHS) NBS Program updates and announcements

Dr. McKee-Garrett introduced DSHS NBS Program staff to provide NBS Program updates and announcements.

NBSAC membership solicitation update

Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, DSHS, gave a membership solicitation update.

Highlights included:

- New member solicitation still under review.
- Current membership roster will remain active until DSHS appoints new members.
- NBS Program staff will notify current members of the appointments.

a. Laboratory updates

Pawan Vohra, Ph.D., M.B.A, Director, Medical Screening Unit, Public Health Laboratory Division, DSHS, and Susan Tanksley, Ph.D., Deputy Laboratory Director, Texas Public Health Laboratory, and Deputy Associate Commissioner, Public Health Laboratory Division, DSHS, provided updates and referenced the PowerPoint and handout, *Texas Newborn Screening Program Updates, April 22, 2025*.

Highlights included:

- New disorder implementation
 - Lysosomal diseases
 - ◇ Pompe disease
 - ◇ Mucopolysaccharidosis type I (MPS I)
 - ◇ Mucopolysaccharidosis type II (MPS II)
 - ◇ Infantile Krabbe disease

- ◊ Expected implementation in June 2025.
- ▶ Laboratory building renovations and retrofit
 - ◊ Completed activities
 - ◊ Impact of delays
- ▶ New instrument installation
 - ◊ Types of instruments
 - ◊ Purpose
 - ◊ Installation status
- ▶ Screening tests overview and implementation status
 - ◊ First-tier tests
 - Amino acid and Acylcarnitine
 - Lysosomal diseases
 - ◊ Second-tier tests
 - Krabbe disease
 - MPS I
 - MPS II
 - ◊ Third-tier tests for Lysosomal diseases
- ▶ Transition from Sanger Sequencing to Next Generation Sequencing (NGS)
 - ◊ NGS Core lab
 - ◊ Workflow process map overview
- ▶ Guanidinoacetate Methyltransferase Deficiency (also known as GAMT)
 - ◊ Building retrofit status
 - ◊ Testing overview
 - ◊ Expected implementation in Winter 2025.
- Lab Developed Tests federal regulation changes.
- New laboratory generator installation status
- United States Postal Service shipping delays:
 - ▶ Impacts
 - ▶ Courier hub creation for affected public health regions.

- New NBS by Whole Genome Sequencing (NBSxWGS) Collaboratory Research Opportunity

b. Clinical Care Coordination (CCC) Updates

Jessica Brown-Obiora, M.D., M.P.H., Medical Director and Leslie McKenzie, B.S.N., R.N., Director, NBS Unit, DSHS provided CCC updates and referenced the PowerPoint and handout, *Texas Newborn Screening Program Updates, April 22, 2025*.

Highlights included:

- New disorder implementation progress:
 - ▶ Meeting held February 27-28.
 - ▶ ACT and FACT sheet preparation status
 - ▶ New CCC team plans and composition
- Advisory Committee on Heritable Disorders of Newborns and Children (ACHDNC) termination announcement and Recommended Uniform Screening Panel (RUSP) status
- New American Academy of Pediatrics Critical Congenital Heart Disease (CCHD) guideline implementation:
 - ▶ New CCHD algorithm and card,
 - ▶ New toolkit items,
 - ▶ New reporting form,
 - ▶ Updating CCHD Texas Health Steps training, and
 - ▶ Presenting an update at the 2025 Texas Newborn Screening Summit.
- 2025 Texas Newborn Screening Summit
 - ▶ Date
 - ▶ Locations
 - ▶ Agenda topics
 - ▶ Audience
 - ▶ Registration link and QR code for sharing
- 2022-2024 NBS bloodspot diagnosed case data for RUSP conditions.

Member discussion:

- Clarifying case count requirements for RUSP condition data suppression.
- NBSxWGS Collaboratory Research Opportunity
 - ▶ Separation from the state's newborn screening testing
 - ▶ Potential impact on babies
 - ▶ NBSAC member involvement
 - ▶ Consent process responsibilities
 - ▶ State versus Collaboratory site participation
 - ▶ Community Advisory Board make up
 - ▶ Timeline
- If the DSHS Laboratory will perform Krabbe second-tier tests for psychosine levels in-house or through a reference laboratory due to its time sensitivity.
- DSHS back up plans if efforts to establish a reference laboratory contract fall through so they can prevent a Lysosomal disease testing implementation delay.
- Opportunity for NBSAC member feedback on ACT and FACT sheets.
- If the NBS Program followed up on the babies who had specimens too old to test due to shipping delays.
- The Secretary of U.S. Health and Human Services still has the authority to add conditions to the RUSP, and the NBS Program is awaiting further guidance.
- Status of conditions under ACHDNC evidence review.
- Reviewing RUSP conditions not yet implemented in Texas.

Dr. McKee-Garrett announced Dr. Charleta Guillory joined the meeting at 1:12 p.m.

Agenda Item 5. Sickle Cell Task Force update

Dr. McKee-Garrett turned the floor over to Titilope Fasipe, M.D., Ph.D., Sickle Cell Task Force Chair, to provide a Sickle Cell Task Force update.

Highlights included:

- Plans for next meeting in May.
- Addition of new members is pending.

- The Sickle Cell Task Force Annual Report came out in December and is publicly available.

Member discussion:

Members did not have questions or comments.

Agenda Item 6. Sickle Cell Data Collection (SCDC) Program update

Dr. McKee-Garrett 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.

Highlights included:

- Reviewing CDC cooperative agreement history and purpose.
- Current activities:
 - ▶ Submitting Year 3 Non-competitive renewal application, which includes:
 - ◇ Continuing Year 2 activities, and
 - ◇ New contracted projects.
 - ▶ Undergoing the agency contract implementation process
- Status of:
 - ▶ Developing a SCDC system and conducting analyses on collected data, which includes:
 - ◇ Establishing a core dataset of individuals with sickle cell disease based on NBS data.
 - ◇ Matching core dataset with other DSHS programs' administrative datasets to fill in missing information or verify existing information.
 - ◇ Getting Institutional Review Board approval to work with identifiable information.
 - ▶ Data project evaluating deidentified hospital discharge data from Texas Health Care Information Collection.
 - ◇ Project gives them a chance to get familiar with the dataset before they receive the data with identifiable information.
 - ◇ They will publish and share report online once agency completes review and approves.

- ▶ Academic partner contracted projects
 - ◇ UT Health-Houston – Evaluating All-payer Claims 2022-2024 data
 - ◇ University of Texas at Austin, School of Communication – Developing educational modules and handouts for awareness among college and university students
- Past Multi-Disciplinary Team quarterly meeting presentations
 - ▶ Medicaid
 - ▶ Community-based organizations
 - ◇ Supporting Our Sicklers (also known as S.O.S.)
 - ◇ Sickle Cell Association of Texas Marc Thomas Foundation
- SCDC Program website
 - ▶ Launch date
 - ▶ Content
 - ◇ Sickle cell disease information
 - ◇ SCDC information
 - ◇ Photo blog
 - ◇ Resources
- Addition of a summer intern to SCDC Program staff to expand photo blog into a series highlighting the diversity of the sickle cell community

Member discussion:

- Project timelines
- CDC staffing impact and communications on grant activities

Agenda Item 7. Rare Diseases Subcommittee Reporting - Tabled

Agenda Item 8. Public Comment

Ms. Thompson stated no one registered for public comment.

Agenda Item 9. Action items and future agenda items

Dr. McKee-Garrett stated the next NBSAC meeting is on Friday, July 11, 2025, and she opened the floor for NBSAC members to discuss future meeting topics and agenda items.

Member discussion:

- Reviewing National Academies of Science, Engineering, and Medicine (NASEM) Newborn Screening Current Landscape and Future Directions Committee report and sharing webinar link
- Electronic case reporting (eCR) updates from NBS and Birth Defects programs before the end of 2025
- Supporting addition of NBS trigger conditions to eCR by the Council of State and Territorial Epidemiologists
- Inclusion of NBS data in the DSHS data modernization process
- Efforts to make matching NBS data to birth certificates a best practice
- Status of new NBSAC members and current members
- Status of matching NBS data to birth certificates to find out if all babies born in Texas get newborn screens as an agenda item
- Outpatient clinic newborn screen collection process update
- Testing process for babies if clinic is unable to purchase NBS cards
- NBSxWGS research opportunity update
- Texas NBS Program plans to address what is happening on the federal level
- Clarifying if implementation of current RUSP conditions will move forward
- Legislative session overview and update

Dr. McKee-Garrett asked members to email the advisory committee liaison if they have additional topics for the next meeting.

Agenda Item 10. Adjournment

Dr. McKee-Garrett adjourned the meeting at 2:37 p.m.

Below is the link to the archived video recording of the April 22, 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 – April 22, 2025 meeting](#)