

# Newborn Screening Advisory Committee

**FINAL APPROVED**

## Meeting Minutes

Tuesday, February 6, 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 provided welcoming remarks 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, February 6, 2024 meeting.**

Member Name	Attended
<b>Kaashif Ahmad, M.D., M.B.B.S., M.S.C.</b>	Yes
<b>Beryl (Pam) Andrews</b>	Yes
<b>Khrystal Davis, J.D.</b>	Yes
<b>Titilope Fasipe, M.D., Ph.D.</b>	Yes
<b>Melissa Frei-Jones, M.D., M.S.C.I., Chair</b>	Yes
<b>Alice Gong, M.D.</b>	No
<b>Charleta Guillory, M.D., M.P.H.</b>	Yes
<b>Tiffany McKee-Garrett, M.D., Vice-Chair</b>	Yes
<b>Barbra Novak, Ph.D., C.C.C.-A.</b>	Yes
<b>Fernando Scaglia, M.D.</b>	No
<b>Joseph Schneider, M.D.</b>	Yes
<b>Michael Speer, M.D.</b>	Yes

Member Name	Attended
Elizabeth (Kaili) Stehel, M.D.	Yes

## **Agenda Item 2. Consideration of March 24, 2023, July 28, 2023, and November 13, 2023, draft meeting minutes**

Ms. Thompson recommended a single member vote to approve all the meeting minutes under consideration. Dr. Frei-Jones called for any changes to the March 24, 2023, July 28, 2023, and November 13, 2023, meeting minutes. Hearing none, Dr. Frei-Jones called for an amended motion to approve the March 24, 2023, July 28, 2023, and November 13, 2023, draft meeting minutes.

### **Motion:**

Dr. Speer moved to approve the March 24, 2023, draft meeting minutes as presented. Dr. Guillory seconded the motion. Dr. Speer amended his motion to approve the March 24, 2023, July 28, 2023, and November 13, 2023, draft meeting minutes as presented. Dr. Schneider seconded the amended motion. Ms. Thompson conducted a roll call vote and announced the motion carries with eight yeas (Dr. Ahmad, Dr. Fasipe, Dr. Frei-Jones, Dr. Guillory, Dr. Novak, Dr. Schneider, Dr. Speer, and Dr. Stehel), zero nays, and zero abstentions.

## **Agenda Item 3. Membership update**

Dr. Frei-Jones stated a membership solicitation will be posted soon.

### **Member discussion:**

Members asked for notification of eligibility to reapply.

### **Action item:**

Program staff will email current members regarding eligibility to reapply.

## **Agenda Item 4. DSHS Newborn Screening (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 Susan Tanksley, Ph.D., Deputy Laboratory Director, DSHS Laboratory, and Deputy Associate Commissioner, Public Health Laboratory Division, DSHS, to provide DSHS NBS Program updates.

### **Presentation highlights included:**

- Parent letter changes;

- Long-term form update discussions with specialists;
- Specialist meetings overview;
- Grant updates;
- Second newborn screen collection barrier issues and plans to address them;
- NBS Program conference change from genetics focus to newborn screening;
- Future annual data updates timeline;
- NBS Unit social media presence development;
- New conditions implementation progress;
- Laboratory newborn screening fee increase; and
- Current DSHS Laboratory project updates:
- Congenital hypothyroidism algorithm change, implementation and data collection and evaluation;
- Cystic fibrosis and metabolic screening instrumentation changes;
- Laboratory implementation status of Pompe, Mucopolysaccharidosis type 1, Mucopolysaccharidosis type 2, and Guanidinoacetate methyltransferase deficiency, four Recommended Uniform Screening Panel (RUSP) disorders not currently screened for in Texas;
- Laboratory renovations; and
- Krabbe and Duchenne muscular dystrophy RUSP status updates.

**Member discussion:**

- Electronic provider messaging regarding abnormal congenital adrenal hyperplasia and cystic fibrosis screens;
- Parent letter content and purpose clarification;
- If laboratory construction affects screening volume;
- Second screen barrier issue:
  - ▶ Possibly tied to providers not having awareness of birth hospitals and outpatient laboratories culture change;
  - ▶ Spreading awareness through Texas Pediatric Society (TPS) or Texas Academy of Family Physicians;
  - ▶ Availability of list of second newborn screening-friendly facilities for cities;

- ▶ Task force or subcommittee formation to identify solutions for different scenarios; and
- ▶ Best method for Program to address issue:
  - ◇ Ask TPS members to work on an announcement to raise pediatrician awareness; and
  - ◇ Ask NBSAC members to raise awareness at each of their institutions and check for places who can do second screens.
- Short-term and long-term follow-up form changes;
- Creation of a Texas road map to add tests for conditions not on the RUSP; and
- TPS NBSAC representation.

**Action item:**

Rare Diseases Subcommittee will discuss a road map for adding non-RUSP conditions.

**Agenda Item 5. Reportable Conditions Knowledge Management System (RCKMS)**

Dr. Frei-Jones introduced Sepehr Arshadmansab, M.P.H., Health Informatics Specialist, Public Health Informatics and Data (PHID) Unit, Office of Public Health Data Strategy and Modernization, DSHS, to present on the RCKMS. Mr. Arshadmansab referenced the PowerPoint and handout, *Brief Introduction to Electronic Case Reporting at the Texas Department of State Health Services*.

**Presentation highlights included:**

- Electronic Case Reporting (eCR) definition;
- Terms;
- Workflow process map;
- Texas eCR implementation phases one to three timeline;
- DSHS eCR readiness declaration update;
- Elements;
- Number of electronic case reports processed in Texas National Electronic Disease Surveillance System (NEDSS) bar graph;
- Non-COVID electronic case reports in production bar graph;

- Health Care Organizations in eCR production in Texas NEDSS map;
- Public health program expansion to eCR success overview;
- Electronic initial case report processing pathways workflow process map;
- Road map ahead:
  - ▶ Work operational phases;
  - ▶ Administration, policy and oversight;
  - ▶ Communications and training resources building;
  - ▶ Scope expansion to meet Centers for Medicare and Medicaid Services Promoting Interoperability requirements; and
  - ▶ Assessing eCR impact and utility research.
- Summary;
- Feedback; and
- Acknowledgements.

**Member discussion:**

- How newborn screening may fit into the RCKMS;
- How RCKMS will help newborn screening;
- Council of State and Territorial Epidemiologists role in eCR and the RCKMS;
- Making newborn screening a reportable condition may require legislation; and
- How eCR and RCKMS may help long-term follow up.

**Agenda Item 6. Critical congenital heart disease reporting update**

Dr. Frei-Jones introduced Charlie Shumate, Dr.P.H., Program Director, Birth Defects Epidemiology and Surveillance Branch, DSHS; and Rachel Allred, Ph.D., Lead Epidemiologist, Birth Defects Epidemiology and Surveillance Branch, DSHS, to provide a Critical congenital heart disease reporting update. Dr. Shumate and Dr. Allred referenced the PowerPoint and handout, *Birth Defects Epidemiology and Surveillance Program Overview and Electronic Case Reporting*.

**Presentation highlights included:**

- Texas Birth Defects Registry (TBDR) mission and overview;
- TBDR surveillance activity overview;

- What DSHS does with TBDR data;
- TBDR responsiveness to Texan public health issues;
- What DSHS has learned from TBDR;
- What DSHS has learned on survival for a spectrum of defects;
- Recent data modernization development referred to as the Texas Birth Defects Connection Project;
- How eCR data can impact Texas birth defects surveillance;
- RCKMS workflow process map;
- RCKMS birth defect conditions pilot process map;
- RCKMS reportable birth defect conditions process map for Texas Notifiable Conditions list;
- How eCR can help critical congenital heart defect (CCHD) surveillance;
- Receipt of eCR data is one method of receiving a centralized case-finding list;
- How eCR data can impact birth defects surveillance in Texas;
- TBDR levels of potential eCR impact; and
- Future directions.

**Member discussion:**

- Ways NBSAC members may help improve hospital eCR participation;
- Texas Health Services Authority and data quality;
- Addition of all newborn screening disorders to TBDR;
- How infant hearing loss is reported in the TBDR and how it differs from reporting to the Texas Early Hearing Detection and Intervention system;
- If Congenital Cytomegalovirus may be added to the TBDR;
- TBDR Release of Information requirements;
- If the TBDR and electronic medical records creates an opportunity for the state to make sure every baby is screened for CCHD and provide follow up;
- Statewide work on syphilis may require partnership with the TBDR and collaboration with TPS; and
- Removing silos to realize the potential of informatics technologies and what benefits birth defects and newborn screening.

## **Agenda Item 7. NBSAC subcommittee updates**

### **A. Rare Diseases Subcommittee**

### **B. Sickle Cell Subcommittee**

Dr. Frei-Jones announced no updates from the Rare Diseases Subcommittee and the Sickle Cell Subcommittee because they did not meet.

## **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:**

- The SCTF hopes to reschedule the February meeting to March;
- The SCTF presented House Bill 1488, 88th Texas Legislature, Regular Session, 2023, SCTF and sickle cell disease education updates at a HHSC Medicaid Medical Directors meeting; and
- The SCTF excitement that DSHS received Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program grant to expand sickle cell disease surveillance activities.

### **Member discussion:**

Members did not have questions or comments for agenda item eight.

### **Break/Roll Call**

At 2:58 p.m., Dr. Frei-Jones announced a 15-minute break and reconvened the meeting at 3:13 p.m. Ms. Thompson conducted a member roll call and announced the presence of quorum.

## **Agenda Item 9. SCDC Program update**

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

### **Presentation highlights included:**

- DSHS received the CDC grant with help and support of collaborators;
- Completed project activities recap;

- Specific grant activities included in funding opportunity;
- SCDC purpose and intent;
- SCDC Multi-disciplinary team (MDT) composition and first meeting;
- Staff hiring announcement; and
- Current activities status:
  - March in-person meeting with CDC;
  - Institutional Review Board application;
  - Core data set establishment;
  - All Payor Claims database data linking contract work; and
  - Education and outreach.

**Member discussion:**

- Clarification of SCDC activities;
- Examples of accomplishments of other states; and
- First-year goals for Texas.

**Agenda Item 10. NBSAC goal planning**

Dr. Frei-Jones led members in a NBSAC goal planning discussion.

**Member discussion:**

- RUSP conditions and the Texas screening panel;
- If the NBSAC wants to consider specific disorders in making goals, such as hearing screening;
- Hearing screening long-term goals related to manual data entry and release of information limitations;
- Hearing screening electronic medical record sharing subcommittee formation;
- NBSAC needs to help provide targeted congenital cytomegalovirus (cCMV) screening guidance with respect to failed hearing screens;
- Whether the NBSAC has a mandate to provide education;
- The NBSAC may make recommendations to partner with other state groups who provide education;
- Clarifying DSHS responsibilities in cCMV screening law;



- If the electronic medical record captures CCHD screening results;
- What other non-RUSP conditions to consider;
- CCHD reporting paper form elimination within two years; and
- Work with DSHS to develop a method to use eCR for long-term follow up of birth defects reportable conditions.

**NBSAC two-year goals:**

- Rare Diseases Subcommittee will develop a road map for non-RUSP conditions;
- Explore how to use informatics to support newborn hearing screening and CCHD reporting;
- Identify a process to eliminate or replace paper reporting forms; and
- Work with DSHS and disease consultant groups to develop electronic long-term follow up forms.

**Agenda Item 11. Public comment**

Ms. Thompson announced no one pre-registered to provide public comment.

**Agenda Item 12. Action items and future agenda items**

Dr. Frei-Jones announced members will discuss action and future agenda items.

**Action item:**

Program will email members their terms and eligibility to reapply.

**Member discussion:**

- If NBSAC needs to form a second screen subcommittee;
- If NBSAC needs to form another informatics subcommittee;
- If DSHS can include in their annual data report the number of babies not receiving their CCHD, hearing, and first newborn screens; and
- Cystic fibrosis 72-hour requirement provider message follow up.

**Future agenda items:**

- Program update that includes a second newborn screening issue follow up;
- 2022 data report;
- Rare Diseases Subcommittee and Sickle Cell Subcommittee reports;

- SCDC Program update;
- Sickle Cell Task Force update;
- Goals follow-up discussion; and
- Laboratory update.

Dr. Frei-Jones reminded members to email any ideas or topics to Aimee Millangue, Advisory Committee Liaison, NBS Unit, DSHS, and announced the next meeting on April 30, 2024, at 1:00 p.m., in the Robert Bernstein Building, Room K-100, First Floor.

### **Agenda Item 13. Adjournment**

Dr. Frei-Jones adjourned the meeting at 3:58 p.m.

Below is the link to the archived video recording of the February 6, 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 – February 6, 2024 meeting](#)