Sickle Cell Task Force (SCTF)

FINAL Meeting Minutes

Monday, June 1, 2026
10:00 a.m.

Virtual Site – Teams Meeting Platform
In-Person Site – Robert 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

Mr. Andre Harris, the Sickle Cell Task Force (SCTF) Co-Chair, presided and called the meeting to order at 10:00 a.m.

Mr. Harris turned the floor over to Ms. Christina Alaniz, Facilitator, Advisory Committee Coordination Office (ACCO), Texas Health and Human Services Commission (HHSC). Ms. Alaniz provided logistical announcements and conducted roll call. With nine members present and three absent, Ms. Alaniz announced the presence of a quorum.

Table 1. SCTF member attendance at the Monday, June 1, 2026, meeting.

Member Name	Attended
Dr. Nwabundo Anusim	**Yes** (joined at 10:39 a.m.)
William (Barney) Fudge *(exoficio)*	**Yes**
André Harris, M.S.W.	**Yes**
Dr. Hyeun Ah Kang	**Yes**
Dr. Justin Luong ("Long"), HHSC	**Yes** (joined late)
Tonya Mitchell	**Yes**
Dr. Olufunke Martin	**Yes**
Dr. Alecia Nero	**Yes**
Dr. Onyebuchi Ononogbu	**Yes**
Ms. Marqué Reed-Shackelford	No
Ms. Linda Thomas-Wade	No
Mr. Henry Westmoreland	**Yes**

Member Name	Attended
Vacant	Member of a community-based organization with experience addressing the needs of individuals with SCD

Agenda Item 2. New Member Introductions

Mr. Harris, SCTF Co-Chair, led the introduction of the new members: Dr. Nwabundo Anusim, a physician with experience addressing the needs of individuals with sickle cell disease (SCD) or sickle cell trait (SCT); William (Barney) Fudge, representative of the Texas Education Agency (TEA); Dr. Hyeun Ah Kang, a researcher from a public health-related or academic institution with experience addressing SCD or SCT; Dr. Olufunke Martin, a physician specializing in hematology; Ms. Tonya Mitchell, representative of a health-related institution; Dr. Onyebuchi Ononogbu, a health care professional with experience addressing the needs of individuals with SCD or SCT; and Mr. Henry Westmoreland, Member of the public who has SCD or is a parent of a person with SCD or SCT.

Action Item:

- One member position for community-based organizations remains vacant. Newborn Screening (NBS) will post member solicitation soon and notify the committee by email. NBS encourages SCTF members to share the solicitation with their community networks.

Discussion: No member discussion or questions.

Agenda Item 3. New Member Orientation

- Ms. Morgan Constantino, Attorney with HHSC, Office of Chief Counsel, Legal Services Division, presented the *"Open Meetings Training Act"*.
    - Key points: Government Code: Title 5. Open Government; Ethics; Subtitle A. Open Government; Chapter 551 Open Meetings. Every meeting of a government body is open to the public, with some exceptions.
- Mr. David Reisman, Chief Ethics Officer, HHS Ethics Office, presented *"Advisory Committee Ethics Overview"* via video recording.
- Ms. Christina Alaniz, Facilitator, ACCO, presented the "*New Member Orientation*" for topics, processes, and approaches.

- Key points: Quorum for the Sickle Cell Task Force is seven members.

- Ms. Leslie McKenzie, B.S.N., R.N., Newborn Screening (NBS) Unit Director, and Dr. Jessca Brown, NBS Physician, presented on "*Texas Newborn Screening Program Overview, Sickle Cell Task Force New Member Orientation*."
  - Key Points: NBS at a Glance, Clinical Care Coordination (CCC), and Texas Early Hearing Detection Intervention (TEHDI)

- Dr. Pawan Vohr and Dr. Susan Tankskey presented on "*Texas NBS Laboratory Overview, Sickle Cell Task Force New Member Orientation*.

  Key points:

  - The Blood Spot Collection Kit fee increased effective January 1, 2026, which includes five more disorders, operational costs, and courier expansion.
    - ◊ Preservation account: The 2019 State Statute established the preservation account. NBS can use dedicated funds to add new conditions, purchase capital assets, complete renovations, or support operations seven days a week.
    - ◊ It cannot use the funds for general operating expenses.
    - ◊ By law, the program is not allowed to charge more than the test costs.
  - Quality improvement projects include the specificity of tests to screen for disorders such as Primary Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Cystic Fibrosis, and Galactosemia.

Discussion:

Mr. Harris inquired about laboratory space and asked whether the lab was finishing renovations on the current space and building another space.

Dr. Tankskey confirmed that crews will complete the current building by December 2026. During the 2025 legislative session, the lab received approval to build an additional building. DSHS is currently completing the signing process with the Texas Facilities Commission. Once approved, DSHS will issue the project for proposal.

After construction is complete, part of the lab will move to the new building, including NBS.

Mr. Harris asked about an abnormal report on SLIDE 21. When a family receives an abnormal report, is the abnormal report sent to providers? Is a copy of the abnormal report also sent to the family? Or is it the provider's responsibility to inform, educate, and support the family?

Dr. Tankskey stated that the lab sends those reports to providers. She explained that once lab reports are final, the lab can send them by mail, electronic messaging, fax, or make abnormal reports available for providers to retrieve from the DSHS website. Electronic messaging places the abnormal report in the patient's health record. When an abnormal result occurs, the NBS information management system creates a case tied to DSHS NBS CCC. For more severe cases, staff contact the provider within 24 hours. Once the health care provider receives the report, the provider can share it with the family. Providers should share results with families, even when the results are normal, because the report confirms that testing occurred. For abnormal results, Dr. Tankskey stated that all of those steps should have occurred.

Mr. Harris confirmed that staff should have identified a family after the report. He then referred to Slides 32 and 33 and asked whether families may request to retain residual dried blood spots for up to 25 years if they opt in. He also asked how families become aware of the opt-in process. Mr. Harris noted that he assumed families opt in through Clinical Care Coordination but requested clarification on how families are informed of that option.

Dr. Tankskey stated that the NBS blood collection kit includes a tear-off information sheet on the first page that staff should give to parents. This sheet provides general information about NBS, explains that parents must opt in to blood spot screening, and outlines the available options for the blood spot. The second sheet serves as the consent form, where parents indicate whether they want the program to retain the blood spot. If parents choose retention, the program keeps the specimen. If parents consent to screening but decline retention, the program eliminates the specimen after two years.

Mr. Harris stated he understands and expressed his reason for understanding the retention blood spot process. He and the committees have expressed concern for individuals with Sickle Cell Trait (SCT). When an individual with SCT reaches high school age for sports or older, or there is the need to provide proof of trait status

for college or military, should it be the educator who explains the significance? Does the parent really know how important it is to know the status?

Dr. Tankskey clarified that the parent consents to the blood being stored. Due to an agency lawsuit, the rule is that the blood spot must be saved for 18 years plus three. The data itself is available. The lab receives requests from adults about their NBS results to determine whether they have SCT. The data is there and the information is not tied to the consent.

- Aimee Millangue, Sickle Cell Task Force Liaison with DSHS, presented on "*Sickle Cell Task Force Overview, New Member Orientation".* Key points:
    - The NBS Unit supports SCTF.
    - SCTF required by Texas Health and Safety Code Chapter 54: To establish and maintain an SCTF to raise awareness of SCD and SCT.
        - In 2015, the Texas Legislature established the Sickle Cell Advisory Committee (SCAC). The SCAC recommended establishing an SCTF to continue committee work. In 2019, House Bill (HB) 3405 of the 86th Legislature, Regular Session, established the SCTF.
        - In 2023, HB 1488, 88th Legislature, Regular Session, expanded SCTF membership from seven to thirteen; expanded required statutory duties; and set the abolishment of the SCTF for August 31, 2035.
    - SCTF Subcommittees include the Medicaid Subcommittee (previously the Medicaid and Contracts Subcommittee), the Legislatively Mandated Report (LMR) Subcommittee (which works on the draft of the annual report), the Public Awareness Campaigns Subcommittee (which works on ideas and recommendations for campaigns), and the Education Subcommittee.
    - Former SCTF subcommittees included the Sickle Cell Surveillance Subcommittee and the Bylaws Subcommittee. The SCTF discontinued the Sickle Cell Surveillance Subcommittee after the Centers for Disease Control and Prevention (CDC) grant ended and state law established the Sickle Cell Registry. The SCTF is currently amending

the bylaws and may reestablish the Bylaws Subcommittee once it finalizes the amendments.

- Current SCTF members or agency staff may invite former SCTF members to participate as an SME at the next public meeting.

- **Discussion:** No member discussion or questions.

Agenda Item 4. The SCTF dismissed for lunch at 12:40 p.m.

Mr. Andre Harris, Co-Chair, presided and called the SCTF meeting to order at 1:40 p.m.

Ms. Alaniz conducted a roll call with nine members present and three absent. Members absent in the afternoon were Dr. Anusim, Ms. Reed-Shackelford, and Ms. Thomas-Wade. Ms. Alaniz announced the presence of a quorum.

Agenda Item 5. Acknowledgment of former SCTF Members

Mr. Harris thanked the former members for their service. Two former members, Dr. Melissa Frei-Jones and Dr. Titalope Fasipe, continued to serve on the committee until the state filled their positions. Dr. Frei-Jones served as a physician specializing in hematology. She served on the SCTF since 2019 and participated in subcommittees, including the former Sickle Cell Surveillance Subcommittee and the Medicaid Subcommittee. Dr. Fasipe served as a representative of a health-related institution. She also joined the SCTF as an initial member in 2019, served as chair, and participated in the Medicaid Subcommittee and the Legislatively Mandated Report Subcommittee.

Discussion: No member discussion or questions.

Agenda Item 6. Consideration of February 2, 2026, draft meeting minutes

Mr. Harris asked members to refer to their email or meeting packets for February 2, 2026, draft meeting minutes and called for any edits. Hearing none, Mr. Harris called for a motion to approve the February 2, 2026, draft meeting minutes.

Motion:

Dr. Onyebuchi Ononogbu moved to approve the February 2, 2026, draft minutes. Dr. Hyeun Ah Kang seconded the motion. Ms. Alaniz conducted a roll call vote and announced the motion carried by a majority vote with nine yeas (Dr. Anusim, Mr. Fudge, Mr. Harris, Dr. Kang, Dr. Luong, Ms. Mitchell, Martin, Dr. Nero, Dr. Ononogbu, and Mr. Westmoreland), zero disapproves, and zero abstentions.

Agenda Item 7. DSHS Newborn Screening (NBS) Program updates and announcements

Mr. Harris yielded the floor to Ms. McKenzie and Dr. Brown for NBS Program Updates. Dr. Brown presented.

Presentation highlights included:

- After-hours contact information when an infant screen is not readily available for providers to contact a 24-hour line: 512-776-7318.
- The purpose of CCC.
- 2025 Texas NBS Statistics:
    - ► As of April 30, 2026, NBS received 754,886 total specimens, identified 25,274 abnormal test results, diagnosed 1,252 infants, and identified 5,807 infants with SCT.
    - ► For Recommended Uniform Screening Panel (RUSP) diagnosed cases, Sickle Cell Anemia (SCA) totaled approximately 521 cases. SCA ranked No. 2, and sometimes No. 3, among diagnosed conditions. Sickle Cell Disease (SCD) totaled 229 cases.
        - ◊ For core and secondary conditions by race and ethnicity, African American or Black infants represented the largest group among core conditions. However, the data also represented every race and ethnicity among core conditions. Secondary conditions showed the same pattern.
        - ◊ Sickling hemoglobinopathies showed similar results, with all races and ethnicities represented. Every Public Health Region had at least one child diagnosed with hemoglobinopathies.
        - ◊ Every Public Health Region has at least one child with diagnosed hemoglobinopathies.
    - ► For SCT notification, the CCC team does not follow SCT cases due to staffing limitations. However, the laboratory sends a mailer to the

provider with the result and includes a letter notifying parents about an informational brochure on SCT and available resources.

- ◊ For SCT cases by race and ethnicity from 2021 to 2025, African American or Black infants represented the largest group. However, every race and ethnicity had SCT representation. Dr. Brown also highlighted Hispanic infants, noting that 6,320 Hispanic infants were born with SCT and the data showed an increasing trend.
- ◊ Every Public Health Region has at least one child with diagnosed SCT.

- NBS will present at several conferences, including the Texas Pediatric Society Annual Meeting in Round Rock, Texas; the Texas Nurse Practitioners Annual Conference in Galveston, Texas; the Texas Academy of Family Physicians Annual Session and Primary Care Summit in The Woodlands, Texas; and the Association of Texas Midwifery Conference in South Padre Island, Texas.

Discussion:

Dr. Kang asked about Slide 7, Hemoglobinopathy Conditions by Race/Ethnicity, DOB 2021-2025 (1 of 2) for NBS Program Updates presentation regarding babies with SCA and asked whether staff could explain the trend from 2024 to 2025, which showed a 30 percent decline.

Dr. Brown clarified that NBS is still receiving case information for 2025. She explained that the information is complete as of the meeting date, but variability remains, and the numbers will likely continue to increase.

Mr. Harris followed up on Dr. Kang's question and asked whether NBS has a timeframe for when the presented data becomes more complete and less variable.

Dr. Brown stated that NBS updates the data as it receives information. She explained that short-term follow-up plays a key role in confirming diagnoses. At the end of the short-term follow-up, NBS receives a letter from the baby's subspecialty physician that either clears or confirms the diagnosis. NBS receives most confirmatory diagnoses quickly, but some diagnoses, including sickle cell disease and other conditions, may take years to confirm.

Agenda Item 8. Sickle Cell Data Collection and House Bill 107, 89th Texas Legislature, Regular Session, 2025 Update

Mr. Harris introduced Dr. Heidi Bojes, Director of the DSHS Environmental Epidemiology Disease Registries (EEDRS) Section and Principal Investigator of the CDC Texas Sickle Cell Disease Data Collection (SCDC) Program Grant. Dr. Bojes provided an update on grant activities and on SCD legislation for an SCD registration.

Presentation highlights included:

- In 2023, the CDC awarded Texas a grant to establish the Sickle Cell Data Collection (SCDC) Program. The program uses multiple linked state-level data sources, including administrative and clinical data, to better understand the nature and extent of SCD. This information helps inform state policies and practices that improve the quality of life for people living with SCD. Texas is one of 16 states that receive funding for the program.
- EEDRS is establishing an SCDC system by using DSHS NBS data and linking it to other DSHS administrative datasets, including hospital discharge records and Vital Statistics records. This approach follows CDC recommendations and aligns with practices used by other states. Because the data includes protected health information, EEDRS sought approval from the DSHS Institutional Review Board (IRB) in August 2025 to use the data.
- With IRB approval, EEDRS received Texas Health Care Information Collection (THCIC) data in 2025. The data included identifiable hospital discharge information for inpatient and outpatient hospital admissions and emergency department visits for people with SCD. In 2026, EEDRS received data from the NBS Program and linked it with Vital Statistics birth records. EEDRS still needs to link hospital discharge information and has requested key variables from NBS and hospital discharge data, which requires an IRB amendment. EEDRS is awaiting IRB approval.
- EEDRS is also working on other data evaluation reports. The team evaluated the public use, de-identified hospital emergency discharge dataset and finalized two reports. One report focuses on emergency department visits for individuals with SCD, and another report focuses on hospital visits for individuals with SCD outside the emergency department. EEDRS posted both reports and a one-page summary document on its website.

- EEDRS collaborated with the University of Texas (UT) Health in Houston to evaluate the 2022 and 2023 All-Payors Claims data for public and private insurance plans. The data included medical, pharmacy, dental, patient eligibility, and provider information. The evaluation reviewed population information and health care utilization patterns for people with SCD. EEDRS also posted the UT Health report on its website.
- EEDRS is expanding resources to include educational materials for campus health care providers and students in Texas. These materials will help campus health care providers understand sickle cell disease, the transition from pediatric to adult care, and ways to support students with SCD. The resources include two educational video modules, "Introduction to SCD in College Student Population" and "Vaso-occlusive Crisis and Other SCD Complications," as well as two one-page resource guides, "Introduction to SCD Resources" and "SCD Pain and Crisis Resources." EEDRS also developed a student postcard titled "Heading Off on Your Own with SCD."
- EEDRS will continue collaborating with the UT School of Communication to implement phase two of the education program. The team is currently developing a digital toolkit for college students with SCD. The toolkit includes a medical passport, conversation guide, and a health care transition checklist. Additional resources include a map of hematologists, community-based organizations, and a one-page overview of SCD in Texas. EEDRS is developing these resources in collaboration with healthcare providers, community-based organizations, and people with SCD, as recommended in the Sickle Cell Advisory Report.
- EEDRS continues to work on recommendations from the Sickle Cell Advisory Report, including creating a directory of adult and pediatric hematologists who treat SCD in Texas. EEDRS is completing this work in collaboration with the UT School of Communication and Dr. Kang's group. EEDRS received a list of all licensed hematologists and oncologists from the Texas Medical Board as of November 2025. The team's next step is to contact offices to verify whether the hematologists treat patients with SCD.
- EEDRS also continues to work on electronic case reporting integration for clinical data and the SCD registry. These efforts include conducting an environmental scan, identifying current practices, reviewing other opt-in efforts, developing requirements documents, assessing functionality, and estimating implementation costs. EEDRS is also seeking stakeholder input

from community-based organizations and medical providers. EEDRS will share the final report with leadership and the legislature.

Member discussion: No member discussion or questions.

Agenda Item 9: Sickle Cell Task Force Subcommittee updates

a. Medicaid Subcommittee (Members Mr. Harris)

Mr. Harris provided the Medicaid Subcommittee update. The subcommittee met on April 14, 2026, and discussed Managed Care Organization contract definition changes, the differences between STAR Kids Plus and STAR Kids Medicaid, and the criteria for special health care needs and eligibility.

Dr. Luong provided an update on the Cell and Gene Therapy Access Model and stated that no further action was needed.

The subcommittee also discussed collaboration with managed care plans. Mr. Harris noted that he and Dr. Luong currently serve on the Medicaid Subcommittee and asked SCTF members to volunteer. Dr. Kang, Dr. Onye, Mr. West-Moreland, and Ms. Mitchell joined the Medicaid Subcommittee alongside Dr. Luong and Mr. Harris.

b. Public Awareness Campaigns Subcommittee (Members Dr. Nero, Ms. Reed-Shackelford, Ms. Thomas-Wade) Dr. Nero, subcommittee member, provided the Public Awareness Campaigns Subcommittee update. The subcommittee met to regroup and discuss previous initiatives, future outreach strategies, and ways to increase awareness, engagement, and involvement in sickle cell activities across the state. During the March meeting, Dr. Nero accepted the role of Public Awareness Campaigns Subcommittee Chair. The subcommittee reviewed previous initiatives, including sickle cell education for universities, and discussed ways to share information about sickle cell activities throughout Texas.

The subcommittee suggested adding a calendar to the **NBS** Program website to highlight relevant dates and activities. Members recommended vetting the dates and activities before posting them and establishing a workflow and process for maintaining the calendar. The group has not yet met to review the proposed workflow or process flow but plans to discuss it at a future meeting.

The subcommittee also discussed using the Public Awareness Campaigns Subcommittee as a resource toolkit for community-based organizations. Members decided to pause meetings until new SCTF members joined so the subcommittee could incorporate their input and feedback as it moves activities forward. The subcommittee will also establish a meeting frequency.

Dr. Martin, Ms. Mitchell, and Dr. Anusum joined the subcommittee alongside Dr. Nero, Ms. Thomas-Wade, and Ms. Reed-Shackleford.

c. Legislatively Mandated Report (LMR) Subcommittee (Dr. Fasipe, Dr. Frei-Jones, and Ms. Reed-Shackelford)

Mr. Harris provided the LMR Subcommittee update. The subcommittee met on May 5, 2026, and discussed changing the annual report frequency from annual to biennial, which may require legislative approval. Members also discussed inviting former members to participate as subject matter experts.

The subcommittee discussed removing the recommendation to update managed care organization contract definitions. Members recommended keeping the periodicity schedule, retaining the Public Awareness Campaign recommendations, and adding a recommendation to request funding for public awareness campaigns.

Mr. Harris and Mr. West-Moreland joined Ms. Reed-Shakelford as members of the LMR Subcommittee.

d. Education Subcommittee (Ms. Thomas-Wade)

Mr. Harris provided the Education Subcommittee update. He noted that the Education Subcommittee paused its meetings until new members committed to serving on the SCTF.

Discussion:

- Mr. Harris invited Mr. Fudge to serve on the Education Subcommittee as the TEA representative. He provided Mr. Fudge with a brief overview of the subcommittee, explaining that it meets quarterly and makes recommendations to the SCTF.
- Mr. Harris also asked Mr. Fudge to serve as a liaison between the SCTF and TEA by informing the subcommittee about SCD education and awareness efforts for K-12 students.

- Dr. Onye and Ms. Mitchell joined the Education Subcommittee alongside Ms. Thomas-Wade, Mr. Harris, and Mr. Fudge, who joined tentatively.

Agenda Item 10. 2026 SCTF Annual Report Development Discussion

Member discussion: No member discussion or questions.

Agenda Item 11. Member Reports

Mr. Harris gave members an opportunity to share updates on clinical partner activities, community-based organizations, and Sickle Cell Warrior activities.

Discussion:

Mr. Harris noted that, in Austin, members will partner with the Red Cross for a Sickle Cell Awareness event in July 2026. He also shared that members are working with other organizations on sickle cell advocacy efforts in the Austin and Houston areas. In September, Houston will host the annual walk for sickle cell awareness.

Dr. Onye shared that her National Institutes of Health- (NIH-) funded sickle cell research recently ended and stated that she looks forward to providing the SCTF with an update in the future. Her research examined the microbiome of sickle cell patients who experienced three or more pain crises within a 12-month period compared with patients who experienced two or fewer pain crises during the same period. She will present the findings once the data becomes available.

Agenda Item 12. Public Comment

Ms. Alaniz, ACCO, HHSC, stated, for the record, that no one pre-registered for public comment and no one registered onsite for public comment.

Agenda Item 13. Action Items and future agenda items

Mr. Harris invited members to submit agenda topics or recommend speakers for the next meeting. He noted that standing agenda items include member reports, NBS Program updates, the SCDC Program update, and subcommittee updates.

Mr. Harris also stated that the SCTF must hold elections for chair and vice chair. The NBS Program sent an email requesting nominations, and nominated members will be asked whether they accept the nomination. Members should respond to the email accordingly.

The SCTF will discuss the 2026 annual LMR report recommendations. SCTF members will vote to adopt the 2026 annual LMR report recommendations and allow the SCTF Chair to edit the LMR report on the members' behalf and vote to approve the 2026 Legislatively Mandated Report.

Mr. Harris announced that the next meeting will take place on August 21, 2026, at 1:00 p.m. in the Moreton Building, Room M-100.

Agenda Item 14. Adjournment

Mr. Harris, Co-Chair, adjourned the SCTF meeting at 3:11 p.m.

The archived video recording of the June 1, 2026, SCTF meeting is available at the link: texashhsc.v3.swagit.com/videos/389597. The public may view and listen to the recording for approximately two years from the posted meeting date, in accordance with the HHSC records retention schedule.