Health and Human Services

Sickle Cell Task Force

February 2, 2026

This summary contains supplemental information from reliable sources where that information provides clarity to the issues being discussed. Power Point tables used in the presentations may also be used in this summary. Names of individuals may be misspelled but every attempt has been made to ensure accuracy. Tables and Text have been used from executive and legislative agencies and departments' presentations and publications.

Sickle Cell Task Force raises public awareness of sickle cell disease and sickle cell trait.

Texas Health and Safety Code, Chapter 52, directs the Texas Health and Human Services (HHSC) Executive Commissioner to establish and maintain a task force to raise awareness of sickle cell disease and sickle cell trait. The purpose of the Sickle Cell Task Force is to study and advise the department on implementing the recommendations made in the 2018 Sickle Cell Advisory Committee Report published by the Sickle Cell Advisory Committee or any other report the executive commissioner determines is appropriate.

Presiding Chair Titilope Fasipe, M.D., Ph.D.	Houston	Representative of a health-related institution	2023	6/5
Melissa Frei-Jones, M.D., M.S.C.I.	San Antonio	Physician specializing in hematology	2024	8
André Harris, M.S.W.	Houston	Member of the public who has sickle cell disease (SCD) or is a parent of a person with SCD or sickle cell trait (SCT)	2025	6/5
Justin Luong, Pharm.D.	Austin	Representative of Health and Human Services Commission	TBD	00
Alecia Nero, M.D., M.S.C.S.	Dallas	Physician specializing in hematology	2024	2/3
Presiding Vice-Chair Marqué Reed-Shackelford	Houston	Member of the public who has SCD or is a parent of a person with SCD or SCT	2023	6/5
Linda Wade	Austin	Member from a community-based organization with experience addressing the needs of individuals with SCD	2024	7
Vacant		Member from a community-based organization with experience addressing the needs of individuals with SCD		
Vacant		Member of the public who has SCD or is a parent of a person with SCD or SCT		
Vacant		Texas Education Agency representative		
Vacant		Texas Health and Human Services Commission representative		
Vacant		Physician with experience addressing the needs of individuals with SCD or SCT		
Vacant		Researcher from a public health-related or academic institution with experience addressing SCD or SCT		
Vacant		Health care professional with experience addressing the needs of individuals with SCD or SCT		

1. Call to order, roll call, and welcoming remarks. The meeting was convened by Titilope Fasipe, Chair. Dr. Justin Huang was welcomed as a new member and provided background as a licensed pharmacist and Medicaid formulary manager. A quorum was present.

2. Consideration of December 12, 2025, draft meeting minutes. The minutes were approved as drafted.

3. Hemoglobinopathy testing methods and variant identification. Omar Ordonez, B.S. Micr, Hemoglobinopathy Screening Group Manager.

Summary. Omar Ordonez (DSHS) presented updates on infant hemoglobinopathy screening methods (IEF and HPLC), including a new comparative chart. Each infant is screened twice—newborn and follow-up specimens—with manual processes currently dominating the workflow. The goal is to transition to more automated methods, considering HPLC, IEF, and capillary electrophoresis, with the commitment to dual-method screening being maintained. Discussion on variant detectability, with clarifications that some variants may appear similar across methods but are flagged for further testing. Current cost analysis and workflow efficiency is under evaluation; timeline for changes is expected to span years. Further stakeholder consultation and cross-state comparisons are ongoing.

Presentation

The Hemoglobinopathy Screening Group screens each infant twice. There are two methods for screening:

- Primary screen method is Isoelectric Focusing (IEF) where the total volume of approximately 750,000 screens per year. Abnormal results are retested on IEF. Approximately 100 specimens are retested per day.
- Secondary method is High Performance Liquid Chromatography (HPLC). Some abnormal results will be tested on HPLC (all specimens with S or E trait, bad measures, or clinically significant results). Volume approximately 50 specimens per day.

Current testing is manual. The goal is to move to a more automated process while addressing concerns about reportable variants.

Staff will continue to run hemoglobinopathy testing using two methods. There are several options regarding what those two methods can be.

- HPLC can be used as the primary and IEF as the secondary.
- Capillary Electrophoresis (CE) could also be used as the primary, while familiar technologies like IEF and HPLC are used as the secondary.

One of the concerns is that in transitioning to these potential new technologies, some variants may no longer be reportable. The following illustrates which method can identify a specific variant.

Hemoglobin Variants Identifiable by Methods

Variant	IEF	HPLC	Capillary
Hb A	Yes	Yes	Yes
Hb F	Yes	Yes	Yes
Hb S	Yes	Yes	Yes
Hb C	Yes	Yes	Yes
Hb D	Yes	Yes	Yes
Hb E	Yes	Yes	Yes
Hb G	Yes	No*	Yes, but requires in-house validation
O-Arab	No	Yes, validated in-house	Yes, but requires in-house validation
Barts	Yes	Yes**	Yes
H-Disease	Yes	Yes***	Unknown
Reported as other	Yes	No	No

* Hb G on HPLC runs in the D window. But can be identified by IEF, if we choose that as our secondary method.
**Barts is identified by FAST retention time (RT) area cutoff > 10%. Note: degradation can slightly elevate the area of the fast band.
***H Disease is identified by FAST RT area cutoff > 25%. Degradation is negligible due to the high area cutoff.

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Discussion

What was the timeline of transition? Staff stated they are doing a cost analysis and are looking at future technologies. We are looking at a timeline of years, not months.

What is the preference for approaches. Staff stated HPLC is first and IEF is second. They have consulted with other states on the efficacy of the approaches.

A "D" in HPLC triggers a follow-up test.

Right now, the current process requires re-testing. Is that still the same and how many retests per day would there be. I assume this is cost neutral. Staff stated on the cost of IEF has been determined. If they switch to a new testing model, would we get different results? Staff stated switching the order would probably be neutral on the outcome. The analyses are still being conducted, however.

4. Medicaid Cell and Gene Therapy Access Model update.

Summary. Dr. Justin Luong reported successful implementation of the CMS Cell and Gene Therapy Access Model, focusing on Casgevy and Lyfgenia for sickle cell disease. The model provides Medicaid clients access to gene therapies and fertility preservation services, with drug manufacturers covering costs for fertility services. He outlined eligibility criteria for both therapies, including age, confirmed sickle cell diagnosis, crisis frequency, previous treatment responses, and clinical status.
Collaboration between manufacturers, the state, and CMS shaped the criteria and there is ongoing monitoring.

Questions addressed regarding criteria origins, recruitment processes, and the continuity of prior authorizations despite Medicaid plan changes. Members expressed optimism about increased access for Texas Medicaid patients and noted ongoing learning around gene therapy processes.

On September 1, 2025, Texas Medicaid began to use the Cell and Gene Therapy (CGT) Access Model that was implemented by the Centers for Medicare & Medicaid Services (CMS) Innovation Center.
The CGT Access Model focuses on the following gene therapies for sickle cell disease:

- Lyfgenia by bluebird bio
- Casgevy by Vertex Pharmaceuticals

These therapies involve the use of chemotherapy and may affect the client's fertility. The model offers clients access to fertility preservation services that would not otherwise be covered by Texas Medicaid. The drug manufacturers will cover the cost of these services.

CGT Access Model:

- CMS: Cell and Gene Therapy Access Model

- CMS: Improved Access to Gene Therapy for Sickle Cell Disease: Maya's Care Journey
- CMS: CMS Expands Access to Lifesaving Gene Therapies Through Innovative State Agreements

For information and enrollment information related to additional client support in navigating through the client's journey, including the fertility preservation services, please see:

- Lyfgenia: my bluebird support
- Casgevy: Vertex Connects

For fee-for-service, providers may contact the following:

- TMHP: Provider Enrollment
- TMHP: Prior Authorization

For managed care, contact the client's MCO using the MCO Search to find contact information for each MCO.

Providers can find more information about gene therapies, eligibility, claims submission, and more on the Texas Vendor Drug Program website.
Email vdp-policy@hhs.texas.gov with comments or questions.

Overview of the CGT Access Model

The Cell and Gene Therapy Access Model is a multi-year initiative launched by the Centers for Medicare & Medicaid Services (CMS) to improve access to potentially transformative treatments for patients with rare and severe diseases, particularly sickle cell disease. This model aims to establish outcomes-based agreements between states and manufacturers, ensuring that Medicaid beneficiaries can access these high-cost therapies while managing state healthcare expenditures effectively.
TMHP

Key Features

Implementation Date: The model began on September 1, 2025, allowing Texas Medicaid to participate in both fee-for-service and managed care settings and focuses on Sickle Cell Disease: The initial focus is on gene therapies specifically designed for treating sickle cell disease, which is a genetic blood disorder that significantly impacts patients' quality of life.

Fertility Preservation Services: Unique to this model, clients undergoing gene therapy will have access to fertility preservation services, which are typically not covered by Texas Medicaid. The costs for these services will be covered by drug manufacturers.

Goals and Benefits Improving Access: The CGT Access Model aims to increase access to innovative therapies for patients who often face barriers due to the high costs associated with these treatments.

Outcomes-Based Agreements: The model supports agreements that tie payment to the effectiveness of the therapies, ensuring that states only pay for treatments that deliver promised health outcomes.

Long-Term Cost Management: By improving health outcomes and reducing the burden of severe diseases, the model seeks to lower long-term healthcare costs for state Medicaid programs.

Conclusion

The Texas Medicaid Cell and Gene Therapy Access Model represents a significant step towards enhancing patient access to cutting-edge treatments for sickle cell disease. By focusing on outcomes and providing additional support services, this initiative aims to improve the health and quality of life for affected individuals while managing costs effectively for the state. For more detailed information, providers and interested parties can refer to the Texas Vendor Drug Program website or contact the Texas Health and Human Services Commission.

The update was successfully implemented September 1, 2025 focusing on two gene therapies. Lyfgenia: my bluebird support and Casgevy: Vertex Connects.

As part of the CGT Access Model, the prior authorizations for the gene therapy and related care (i.e., genetic and laboratory testing, prescription) are authorized until the end of the original authorization period regardless of if the client transitions between fee for service and managed care or from amongst MCOs. Additionally, the client must have access to the same qualified treatment center that administered the medication for at least one year after receiving their gene therapy infusion.

Discussion

This is a new world for hematology. What was the eligibility criteria based on? In the model the drug manufacture plays a big role in the baseline criteria, and the state elaborates on that looking at the package insert. This was a collaboration between the state and manufacturer and presented to CMS for approval.

Regarding the stem cell collection phase, this was one of the newest lessons. It was something donor transplant didn't do.

Do we know how many people would be eligible for the model? Staff stated they do not have a specific number but as long as the criteria are met, then Medicaid patients are eligible. Movement from FFS to managed care does not change eligibility.

5. DSHS Newborn Screening Program updates and announcements.

New Sickle Cell Trait brochure 1-66_sicklecelltrait_brochure_english_09_2025.pdf in the Newborn Screening web page

Hemoglobin Specialist Partnership meeting will be happening on March 27, 9:00 am. This is the annual meeting for consultants who provide newborn screening services.

DSHS stated they would like to address the recruitment process for the new model.

Discussion

The brochure should be sent to physicians as well as the parents.

6. Sickle Cell Data Collection and House Bill 107, 89th Texas Legislature, Regular Session, 2025 update. HB00107F.pdf

HB 107 establishing a registry was passed. The registry is unique in that it is an opt-in registry. An assessment is being conducted to establish practices and stakeholder input. The outcome should provide for direction of IT solutions and other policy issues.

Bill Analysis. Sickle cell disease (SCD) is a serious genetic disorder that affects a person's red blood cells, leading to lifelong health complications. In Texas, about 1 in

every 2,000 newborns is born with SCDï¿½primarily impacting African American communities. Despite this, many patients struggle to receive adequate care due limited provider awareness of appropriate diagnosis, and a lack of coordinated statewide data. Without accurate data, efforts to improve treatment, track outcomes, and secure research funding are severely limited.

Texas must establish a centralized, population-based system to collect and maintain accurate records of SCD cases. This registry must be designed to support improved healthcare access, promote early diagnosis, guide policymaking, and ensure medical professionals have the information they need to treat patients effectively. It must also meet strict privacy standards to protect individual health information.

H.B. 107 establishes and maintains a Sickle Cell Disease Registry. The registry will serve as a single, accurate source of information about SCD cases across Texas. It requires health care facilities to report data on SCD cases to the Department of State Health Services (DSHS), and it mandates that all data collection comply with HIPAA, the Occupations Code, and other privacy laws. The bill authorizes DSHS to publish reports, conduct analysis, and provide accessible information to healthcare providers and the public. It also requires DSHS to submit an annual report to the legislature. This bill addresses concerns raised in a prior vetoed version by explicitly ensuring strong data privacy protections.

H.B. 107 amends current law relating to the establishment of the sickle cell disease registry.

Fiscal Note: The Department of State Health Services is required to implement a provision of the bill only if the legislature appropriates money specifically for that purpose. If the legislature does not appropriate money specifically for that purpose, the Department of State Health Services may, but is not required to, implement a provision of the bill using other appropriations available for that purpose.

The bill would make no appropriation but could provide the legal basis for an appropriation of funds to implement the provisions of the bill.

The bill would authorize the Department of State Health Services (DSHS) to establish and maintain a registry of cases of sickle cell disease in the state. Health care facilities would provide data regarding individuals who have been diagnosed with sickle cell disease to DSHS. The Health and Human Services Commission (HHSC) shall adopt rules related to implementation of the registry including ensuring confidentiality and informed consent related to information obtained on individuals for the registry. The bill would require DSHS to submit an annual report on information in the registry to the legislature, and DSHS would be authorized to publish other reports in

cooperation with other sickle cell disease reporting organizations and research institutions.

The analysis assumes DSHS would require 5.0 additional full-time-equivalent positions (FTEs) to establish and maintain the registry. This includes 2.0 FTE Epidemiologist III positions to calculate appropriate statistics, to analyze data quality, and to create reports; a 1.0 FTE Information Specialist IV position to oversee the dissemination of data and reports from the Sickle Cell Registry and to conduct trainings and education for registry users; a 1.0 FTE Program Specialist V position to oversee the Sickle Cell Registry Program and serve as the subject matter expert; and a 1.0 FTE Systems Analyst V position for programming, quality assurance testing, managing system specifications and requirements, and security and updates on the new Sickle Cell Disease Registry system.

Salaries, benefits, and other related costs for the new FTEs total $531,242 in fiscal year 2026 and $746,854 in fiscal year 2027, all from the General Revenue Fund. The lower cost in fiscal year 2026 is attributable to a later start date for the new positions assumed in the first fiscal year and because the Systems Analyst V position would begin as a 0.5 FTE in fiscal year 2026.

DSHS would build a standalone registry system modeled off an existing system to receive lab and provider reports for sickle cell disease. The agency will utilize HHSC information technology (IT) staff augmentation to build the system estimated to total $1,151,652 in fiscal year 2026 and $287,623 in fiscal year 2027, all from the General Revenue Fund.

Other IT costs related to new requirements and components of the new registry include new hardware costs of $350,000 in fiscal year 2026; software licenses costs of $300,000 in fiscal year 2026 and $100,000 in fiscal year 2027; Identity Account Management development and integration costs of $350,000 in fiscal year 2026; Independent Validation and Verification requirement for new IT projects costs of $350,000 in fiscal year 2026; and State Health Analytics and Reporting Platform (SHARP) integration and report development costs of $314,000 in each fiscal year, all from the General Revenue Fund.

Sickle Cell Data Collection (SCDC) Program and Registry
In 2023, the Texas Department of State Health Services (DSHS) applied for and received funding from the Centers for Disease Control and Prevention (CDC) to establish a state sickle cell data collection system that informs sickle cell practices and policies in Texas. Texas SCDC is one of 16 states funded by the CDC.

Texas SCDC is a one-time state data collection effort and is not a state sickle cell disease registry. Texas SCDC serves as the foundation for measuring sickle cell burden in Texas by assessing long-term trends in sickle cell disease diagnosis, treatment, and healthcare access. In the absence of population-based surveillance, Texas SCDC provides information on all individuals with sickle cell disease in Texas, regardless of age, insurance status, or geography.

The goal of Texas SCDC is to collect, maintain, and disseminate high quality sickle cell data that will contribute to improving diagnoses, treatments, survival, and quality of life for all individuals with sickle cell disease in Texas.

The DSHS Sickle Cell Registry is part of the Sickle Cell Data Collection (SCDC) Program, which aims to improve the understanding and treatment of sickle cell disease in Texas. Established with funding from the CDC, the registry collects data on sickle cell disease diagnosis, treatment, and healthcare access, serving as a foundation for measuring sickle cell burden in the state. The goal is to enhance diagnoses, treatments, survival, and quality of life for individuals with sickle cell disease in Texas.

Collection Grant Program. This is the third year of the grant program. They established a core set of people living with the disease. THCIC data has been used, and newborn screening data is linked with hospital discharge data. (THCIC-Texas Health Care Information Collection (THCIC) | Texas DSHS).

Sickle Cell Data Collection Grant includes linkage of newborn screening with hospital data and development of reports on emergency/non-emergency utilization, along with summary infographics.

A Physician list is being updated, and this is an ongoing effort to identify hematologists treating sickle cell patients; input was sought to improve accuracy and capacity-building.

Plans for interactive stakeholder meetings and public reporting; summary docs with a redesigned website to be launched soon.

Discussion

Regarding the list of hematology providers, some do not take Sickle Cell patients. It is appreciated that you are seeking relevant providers that address sickle cell.

There is a problem using the umbrella of oncology/hematology. This can be a problem in rural areas. The list might need to be augmented with other tools and not just physician names.

We have to enable more capacity. Some doctors turn sickle cell patients away. We should focus on identifying potential providers. Is there intent to catalogue all the information including those who do not take sickle cell patients so we can reach out to them. Staff stated that they have a large list at the moment that they are whittling down.

Registry assessment team. If they do a webinar they will reach a broader audience. What is the timeline for that? Staff stated there will have to be a series of meetings to address system issues. The report from the meetings has to be concluded by 11/1 2026.

There was extensive discussion on the opt-in process, data capture challenges, and balancing individual autonomy with programmatic goals.

Regarding the opt-in mechanism of the registry, you will still have data from people who have not opted in, but the consent has to be received before their information can be included in the registry. DSHS stated they would reach out to them to seek the opt-in. They will always have the ability to withdraw their consent.

There was interest in revisiting the opt-in process legislatively because we don't want to half do it because of legal restrictions.

People have reasons to be concerned about research in this demographic (identifying people who did not want to be identified).

7. SCTF subcommittee updates

Medicaid Subcommittee— Meeting quarterly, focusing on member eligibility, education on Medicaid and Medicare/SSDI, and developing recommendations for continuing education updates. Interest in further engagement with federal agencies like CMS.

Action Item: Dr. Justin Luong, HHSC Representative member and Director, DUR Formulary Management, Vendor Drug Program, Medicaid and CHIP Services, HHSC, will provide the criteria used for the CMS CGT Access Model in an update at the February 2, 2026 SCTF meeting.

Public Awareness Campaigns Subcommittee--Reviewed status of previous projects:

- One-pager for community health workers – in progress
- Toolkit or press kit for new media on sickle cell awareness - recommended
- Human Dimensions of Organizations – may not get tractions
- Forming recommendations to request funding for events and public awareness

Review and discuss implementation of 2025 Sickle Cell Task Force Annual Report recommended actions

a. Develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns and identify funding for statewide awareness activities.

b. Texas Department of State Health Services (DSHS) should coordinate with sickle cell community-based organizations to partner with Texas colleges and universities, including medical schools, to create and launch impactful and relevant public awareness campaigns and press releases.

c. DSHS should establish two statewide campaigns per year with an emphasis on September, Sickle Cell Awareness Month, and June 19, World Sickle Cell Day. Potential topics to spotlight include state-specific sickle cell disease (SCD) data, newborn screening, trait or carrier status awareness, and National Collegiate Athletic Association requirements.

d. DSHS should establish a sickle cell awareness calendar to post on the DSHS website and share on relevant email distribution lists to stakeholders.

e. Identification of dedicated, ongoing funding for statewide SCD and sickle cell trait (SCT) awareness activities, including:

- Providing community SCD and SCT education
- Improving detection of individuals with SCD and SCT
- Coordinating service delivery for people with SCD
- Providing training for health professionals regarding SCD and SCT

f. Continue raising awareness in collaboration with public awareness campaign organizations, state agencies, and Texas Health and Human Services Commission (HHSC) Medicaid and Children's Health Insurance Program (CHIP) Services to improve care for individuals with SCD in Texas.

~~8. Sickle cell trait testing discussion~~ Tabled

9. 2026 SCTF Annual Report development discussion

This item was for members to review the 2025 recommendations and initiate 2026 planning, inviting subcommittees to revisit and update action items.

2025 Recommended Actions

Update Medicaid MCO contract definition of Members with Special Health Care Needs to specifically include SCD as an inclusion criterion. Under Texas's Medicaid-managed care program, contracted MCOs must identify and provide service coordination to members with special health care needs (MSHCN). An MSHCN is a member who

1. Is in one or more of the following groups: pregnant women identified as high risk, members with behavioral health conditions, or members with serious ongoing illness or a chronic complex condition that is anticipated to last for a significant period and requires ongoing therapeutic intervention and evaluation; or
2. Has been identified as MSHCN.

SCD has progressive complications such as pain crises, acute chest syndrome, stroke, and a constant red blood cell shortage. Given that SCD is a chronic illness, the Task Force recommends the state update the MCO contract definition of MSHCN to specifically list SCD as an inclusion criterion. Doing so will ensure that Medicaid recipients with SCD receive the additional services they need to manage the disease, mitigate complications, and prevent additional serious health outcomes.

Evaluate options to increase Medicaid and CHIP eligibility for individuals diagnosed with SCD until age 26 years. The Task Force recommends HHSC evaluate options to increase Medicaid and CHIP services for any individual with SCD. During early

adulthood, individuals with SCD have a higher chance of experiencing an increase in SCD-related complications, such as progressive organ damage and early death. Early adulthood is also a time when individuals with SCD may face a gap in health care coverage if they age out of Medicaid. Many individuals over 18 years old are only eligible for Medicaid if they have a disability and meet income requirements. Having a SCD diagnosis alone is not enough for an individual to be considered disabled. These individuals may not have access to a parent's health insurance plan either, which would provide continuous health care coverage until age 26 years.

Use available resources to study the development of comprehensive medical home models and ways to create and fund comprehensive sickle cell care centers as a quality improvement project. Currently, no standards exist for providing care to patients with SCD. Establishing standards by creating sickle cell care models and comprehensive sickle cell care centers may improve care for patients with SCD. Given multiple barriers people face receiving high-quality sickle cell care, the Task Force recommends studying the development of comprehensive sickle cell medical home models for both urban and rural Texas communities as a quality improvement project. These models can be based off existing state models for patients with complex care needs and on the American Society of Hematology sickle cell expert recommendations. ASH Pocket Guides - Hematology.org

Partner with Medicaid and CHIP Services to pursue SCD-specific quality metrics through one or more of Texas Medicaid's quality improvement programs. The Task Force recommends partnering with Medicaid and CHIP Services to pursue SCD-specific quality metrics. Metrics would include rates of stroke screening, hydroxyurea prescriptions, penicillin prescriptions, etc., through one or more Texas Medicaid quality improvement programs, e.g., External Quality Review Organization. Monitoring these metrics would allow the state to better understand the sickle cell landscape, the treatments provided to sickle cell patients, and any potential gaps in care. See the 2024 External Quality Review of Medicaid and CHIP Managed Care Annual Technical Report as an example. eqro-annual-technical-report-contract-sfy-2024.pdf

Develop sickle cell quality care plans for Medicaid and private payors. To support initiatives to assist managed care plans in promoting timely, evidence informed health care plan services to plan enrollees, the Task Force continues to recommend DSHS collaborate with HHSC to create quality care plans for individuals with SCD to guide Medicaid and private payors in prioritizing and reinforcing access to preventive care

based on national, evidence-based guidelines from the American Society of Hematology and the National Heart, Lung, and Blood Institute at National Institutes of Health. The Task Force continues to work with HHSC Medicaid and CHIP Services and HHSC to explore plan complexities and encourage payors to implement quality care plans as part of their covered benefits and services. Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014 | NHLBI, NIH

Update Texas Health Steps Online Provider Education module on sickle cell disease so it is more comprehensive and is eligible for continuing education (CE) credit. The Task Force recommends updating the Texas Health Steps Online Provider Education module on SCD to reflect most current SCD guidelines and resources. The current module is outdated. A newly revised module could help medical professionals understand sickling disorders and treatment options better. Additionally, it will support health care worker competency and engagement needed for effective treatment and disorder management for affected patients. Adding CE credit would also promote awareness efforts.

Update the Texas Health Steps Periodicity Schedule to include SCT counseling for teenagers who were diagnosed with SCT at birth or have unknown status. While the Texas newborn screening panel includes testing for SCT, parents may not remember to share the results with their children as they age. The Task Force recommends Health and Human Services update the Texas Health Steps Periodicity Schedule to direct physicians and other medical professionals to provide SCT counseling to teenage patients who screened positive for SCT at birth or have unknown SCT status during a routine adolescent health care visit. Counseling should include SCT education and additional testing, if needed. Education and improved individual awareness of the trait could help adolescents understand potential risks and prepare them prior to family planning decisions. The Task Force recommends state agencies promote this practice through provider education efforts. ths-med-checkup-periodicity-sched.pdf

Study the feasibility of a state-level sickle cell quality rating system for health care facilities. The Task Force recommends studying the feasibility of a state-level sickle cell quality rating system to set SCD standards for quality care. To allow for consumer comparison of health care institutions that provide care to individuals with SCD, a statewide reporting system can collect data to show low-performing and high performing facilities and general compliance history to include allegations and surveyed substantiations. DSHS may use this data for quality improvement efforts at facilities

with higher incidence and reporting rates. Publishing facility history and data reports may aid individuals with SCD in selecting an appropriate provider.

Collaborate with HHSC to incorporate a reporting process for sickle cell care provided by health care facilities into an existing statewide system. The Task Force recommends DSHS collaborate with HHSC to incorporate a reporting process for health care facilities providing sickle cell care into an existing complaint and incident intake system. Patients may report issues with facility care received including hospital emergency departments. Facilities may also self-report. The program area that processes these reports could determine if a regional surveyor should investigate and recommend appropriate corrective actions, if necessary.

Develop partnerships with Texas colleges and universities to create sickle cell awareness campaigns and identify funding for statewide awareness activities. The Task Force recommends DSHS coordinate with sickle cell community-based organizations to partner with Texas colleges and universities, including medical schools, to create and launch impactful and relevant public awareness campaigns and press releases. The goal should be to launch at least two statewide campaigns per year with an emphasis on September, Sickle Cell Awareness Month, and June 19, World Sickle Cell Day. Potential topics to spotlight include state-specific SCD data, newborn screening, trait or carrier status awareness, and National Collegiate Athletic Association requirements. Sickle Cell Trait - NCAA.org

To promote statewide awareness activities, the Task Force could work with DSHS to establish a sickle cell awareness calendar to post on the DSHS website and share on relevant email distribution lists to stakeholders. Community organizations and health care institutions could submit their activities to DSHS. DSHS could consider adding these activities to the calendar along with state-run activities. Additionally, the Task Force recommends the identification of dedicated, ongoing funding for statewide SCD and SCT awareness activities, including:

- Providing community SCD and SCT education;
- Improving detection of individuals with SCD and SCT;
- Coordinating service delivery for people with SCD; and
- Providing training for health professionals regarding SCD and SCT.

Continue to support the efforts of the Texas SCDC Program to expand current data collection activities. Significant progress has been made in bolstering the state's

capacity to conduct sickle cell surveillance. The Task Force supports the activities of the Texas SCDC Program to meet the goals of the CDC grant and recommends continued support towards the realization of a SCD registry.

Discussion.

There was discussion on enhancing public/community engagement beyond formal public comment, with suggestions for improved outreach and feedback mechanisms.

10. Member reports: Clinical partner activities; Community-based organization activities; Sickle cell warrior activities. Members gave brief reports of their experiences since the last meeting.

11. Public comment No public comments were offered

12. Action items and future agenda items.

Future meeting dates: May 15, and August 21, 2026

Agenda Items:

- Standing agenda items
- New Brochure described/discussed above
- Discuss opportunities for executing action for goals
- DSHS community meeting and goals
- HB1488 discussion
- New Member updates and timeline

13. Adjournment. There being no further business, the meeting was adjourned.