2022 Sickle Cell Task Force Annual Report

As Required by
Texas Health and Safety Code,
Section 52.0007

Sickle Cell Task Force

December 2022

Administrative Support Provided by
Department of State Health Services

Table of Contents

Executive Summary

Texas Health and Safety Code, Section 52.0007, requires the Sickle Cell Task Force (Task Force) to submit a report to the Governor and the Legislature by December 1 of each year. The report is required to summarize Task Force work and include any recommended actions or policy changes. The 86th Legislature established the Task Force in 2019. This is the Task Force's third annual legislative report.

The purpose of the Task Force is to study and advise the Texas Department of State Health Services (DSHS) on implementing recommendations made in the 2018 Sickle Cell Advisory Committee Report published by the Sickle Cell Advisory Committee (abolished on September 1, 2018) or any other report the Executive Commissioner of the Health and Human Services Commission (HHSC) determines is appropriate.

This report highlights Task Force work with DSHS to implement the Sickle Cell Advisory Committee's 2018 recommendations regarding a statewide public awareness campaign, development of statewide sickle cell disease surveillance, collaboration with community health workers, and partnering with Medicaid/Medicare managed care and accountable care organizations.

The Task Force proposes the following recommended actions for 2022:

- Increase Task Force membership from seven to at least 15.
- Extend the Task Force beyond August 31, 2025.
- Identify funding for statewide awareness activities.
- Develop Partnerships to allow Texas to apply to the Centers for Disease Control and Prevention's Sickle Cell Data Collection Program.
- Develop comprehensive medical home models.
- Evaluate options to increase Medicaid and Children's Health Insurance Program (CHIP) eligibility for individuals diagnosed with sickle cell disease to age 26.
- Publish an annual Texas sickle cell surveillance report.
- Establish and maintain a universal sickle cell data collection system.

1. Introduction

The Task Force was established in accordance with Texas Health and Safety Code Chapter 52. Statute directs the Texas HHSC's Executive Commissioner to establish and maintain a task force to raise awareness of sickle cell disease (SCD) and sickle cell trait (SCT). In August 2019, the HHSC Executive Commissioner delegated the creation and administrative support of the Task Force to DSHS.

The purpose of the Task Force is to study and advise DSHS on implementing 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.

More than one thousand babies are born in the U.S. with SCD every year.[1] The Centers for Disease Control and Prevention, the National Center on Birth Defects and Developmental Disabilities, and the Division of Blood Disorders consider SCD a significant health and global concern.[2] Texas newborns with SCD are identified through the DSHS Newborn Screening program, but there are no statewide SCD surveillance programs in Texas.[3] Managing SCD and utilizing health services is difficult for people living with this chronic illness.

Health and Safety Code, Section 52.0007, requires the Task Force to prepare and submit an annual written report to the Governor and the Legislature by December 1. The report summarizes the Task Force's work and includes any recommended actions or policy changes endorsed by the Task Force.

In accordance with statute, this report outlines the following:

- A summary of Task Force activities in 2021-2022;
- Plans for future work; and

[1] American Academy of Pediatrics. Sickle Cell Disease: Information for Parents. healthychildren.org/English/health-issues/conditions/chronic/Pages/Sickle-Cell-Disease-in-Children.aspx. Published September 16, 2019. Accessed August 16, 2022.
[2] Centers for Disease Control and Prevention. About CDC's Work on Sickle Cell Disease. cdc.gov/ncbddd/sicklecell/about.html. Published December 16, 2020. Accessed August 16, 2022.
[3] Texas Department of State Health Services. Screened Disorders. dshs.texas.gov/newborn/screened_disorders.aspx. Updated May 14, 2022. Accessed August 16, 2022.

- Proposed actions for implementing the 2018 Sickle Cell Advisory Committee recommendations.

2. Background

In 2016, the Texas Legislature established the Sickle Cell Advisory Committee (Advisory Committee) to raise awareness of sickle cell disease (SCD) and sickle cell trait (SCT) in Texas. The two-year Advisory Committee developed a set of recommendations, including one to establish a Sickle Cell Task Force to continue the Advisory Committee's work. When the Advisory Committee ended in 2018, new legislation established the Task Force in 2019. The Task Force worked with DSHS over the past three years to further explore implementation of the Advisory Committee recommendations regarding:

- A statewide public awareness campaign;
- Development of statewide SCD surveillance;
- Collaboration with community health workers; and
- Partnering with Medicaid/Medicare managed care and accountable care organizations.

Since the first description of sickled red blood cells in medical literature over a century ago, SCD has been recognized as one of the most common inherited blood disorders in the U.S., with millions affected worldwide. In fact, the number of people with SCD in the U.S. is expected to grow by 30 percent by 2050, making the work of the Task Force even more timely.[4] Although SCD was previously associated with high mortality in young children, advances in treatment and preventive care have led to improved survival. Today, more than 90 percent of children with SCD survive to adulthood. When many of these children reach the age of transition from pediatric to adult care, they are unable to find adult specialists or centers with expertise in SCD. Unfortunately, survival rates for adults with SCD have changed little in the past 30 years.[5]

In 2021, the Centers for Medicare and Medicaid Services (CMS) published the first comprehensive data-focused report on state-level health care utilization and health characteristics for people with SCD receiving Medicaid and Children's Health Insurance Program (CHIP) services. In the CMS report, which examined 2017 data,

[4] Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. Global Burden of Sickle Cell Anemia in Children Under Five, 2010–2050: Modelling based on DEMOGRAPHICS, excess mortality, and interventions. PLoS Medicine. 2013;10(7). doi:10.1371/journal.pmed.1001484

[5] Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. Blood. 2010;115(17):3447-3452. doi:10.1182/blood-2009-07-233700

Texas had the fourth highest number of Medicaid and CHIP beneficiaries with SCD (2,604) after Florida, Georgia, and New York. The report encompassed 41,995 individuals with SCD, which is almost half the reported national population of individuals with SCD.[6]

The report found a considerable discrepancy between recommended and actual therapy received, highlighted low rates of annual stroke screening in children, low utilization of disease-modifying therapy, hydroxyurea, in both children and adults as well as a lack of vaccinations and antibiotic prophylaxis. They found only 36 percent of patients with SCD between the ages of 2-16 received an annual stroke screen or transcranial doppler ultrasound. The screen and the ultrasound are the main testing methods for identifying children at risk of stroke, a common severe morbidity of SCD. They also found that prescriptions for the most well-known disease-modifying therapy, hydroxyurea, were extremely low at 37 percent of children and 35 percent of adults. Young children with SCD are 300 times more likely to develop an invasive pneumococcal infection than children without SCD, and the report found only 59 percent of children under age 2 had received the appropriate vaccinations, including the 13-valent pneumococcal vaccine. The other mainstay of infection prevention is antibiotic prophylaxis with daily oral penicillin, which the report found was extremely low (only 11 percent of 15-month-olds to age 4 with at least 300 days of prescriptions).[6]

The CMS report also identified high health care costs associated with SCD due to increased utilization of emergency services and hospitalizations.[6] 2015 studies show the national financial impact includes $2.98 billion in annual direct costs for adults with SCD and $60.8 billion in direct costs for children with SCD.[7] A National Institutes of Health study determined $1.7 million as the average cost insurers pay per individual with SCD in a retrospective study of 2008-2018 commercial claims data.[8] Estimated direct costs to individuals with SCD was $30,000 annually for an

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[6] Wilson-Frederick, S., M. Hulihan, A. Mangum, T. Khan, M. Geibel, R. Malsberger, S. Verghese, R. Borck, R. Fox, and M. Rosenbach. Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017. Baltimore, MD: Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services, 2021. medicaid.gov/medicaid/quality-of-care/downloads/scd-rpt-jan-2021.pdf. Published January 2021. Accessed August 16, 2022.

[7] D. S., PRO26 Cost of illness of Sickle Cell Disease in the US, Payer's Perspective: (CRESCENT)., Value in Health, Volume 24, Supplement 1, 2021, Page S202, ISSN 1098-3015, doi.org/10.1016/j.jval.2021.04.1011.

[8] Kate M Johnson, Boshen Jiao, Scott D Ramsey, M A Bender, Beth Devine, Anirban Basu; Lifetime medical costs attributable to sickle cell disease among nonelderly individuals with commercial insurance. Blood Adv 2022; bloodadvances. 2021006281. doi.org/10.1182/bloodadvances.2021006281. Accessed September 27, 2022.

insured adult and $10,000 for an insured child.[8,9] These costs do not include additional expenses or income loss due to transportation, child care, work absenteeism, unemployment, disability, and unfulfilled degrees.[10]

Gaps in care also exist for individuals with SCD because of documented disparities in health care funding, research dollar awards, specialist care access, and speed of development of new medical therapies. There are discrepancies in both National Institutes of Health and private research funding for SCD when compared to other rarer inherited diseases such as cystic fibrosis (CF). For instance, in 2006 it was first reported that funding for SCD was $1,130 per person with SCD, but CF funding was $9,340 per person with CF. Over time, this difference has continued to widen. In 2020, funding for SCD fell to $914 per person with SCD while funding for CF rose to $10,497 per person with CF. Furthermore, patients with CF had three times more novel therapies approved than patients with SCD during the same time period.[11]

A key driver of health disparities in SCD is the lack of a national surveillance system to characterize the state of health of the population and identify patterns of complications and adherence to treatment guidelines. In contrast, CF has a national organization, the Cystic Fibrosis Foundation, that funds and accredits 130 national CF centers where patients are tracked as part of a national registry.[11] For SCD, the Centers for Disease Control and Prevention's Sickle Cell Data Collection Program had funding to support two states, Georgia and California, from 2005 to 2016, and seven states received funding to participate in 2021 (Minnesota, Wisconsin, Michigan, Indiana, Alabama, Tennessee, and North Carolina).[12] This is still an underrepresentation of the SCD population in the U.S.

In 2020, the National Academies of Sciences, Engineering, and Medicine created a committee to develop a SCD strategic plan, "Addressing Sickle Cell Disease, A Strategic Plan and Blueprint for Action." The strategic plan sets forth a vision to

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[9] Huo J, Xiao H, Garg M, Shah C, Wilkie DJ, Mainous III A. The Economic Burden of Sickle Cell Disease in the United States, Value in Health, Vol. 21, S2 (September 2018).
[10] Holdford D, Vendetti N, Sop DM, Johnson S, Smith WR. Indirect Economic Burden of Sickle Cell Disease. Value Health. 2021 Aug;24(8):1095-1101. doi: 10.1016/j.jval.2021.02.014. PMID: 34372974.
[11] Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity. JAMA Netw Open. 2020;3(3):e201737. Published 2020 Mar 2. doi:10.1001/jamanetworkopen.2020.1737. Accessed August 16, 2022.
[12] Centers for Disease Control and Prevention. Sickle Cell Data Collection (SCDC) Program. cdc.gov/ncbddd/hemoglobinopathies/scdc.html. Published April 2, 2021. Accessed August 16, 2022.

create long, healthy lives for individuals living with SCD by addressing the following eight areas:

- Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span.
- Establish organized systems of care that ensure both clinical and nonclinical supportive services to all persons living with SCD.
- Strengthen the evidence base for interventional and disease management and implement widespread efforts to monitor the quality of SCD care.
- Increase the number of qualified health professionals providing SCD care.
- Improve SCD awareness and strengthen advocacy efforts.
- Address barriers to accessing current and pipeline therapies for SCD.
- Implement efforts to advance understanding of the full impact of SCT on individuals and society.
- Establish and fund a research agenda to inform effective programs and policies across the life span.[13]

The Advisory Committee, and now the Task Force, is positioned to be a key player in guiding Texas in these efforts. The Task Force consists of seven members appointed by the HHSC's Executive Commissioner and is required to meet three times a year per Task Force bylaws. Membership includes physicians specializing in hematology, members of community-based organizations who serve SCD populations, members of the public who have SCD/SCT or are the parent of a child with SCD/SCT, and a representative of a health-related institution. Refer to Appendix A for a list of Task Force members.

[13] National Academies of Sciences, Engineering, and Medicine. *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action*. Washington, DC: The National Academies Press; 2020. doi:10.17226/25632. nap.nationalacademies.org/read/25632/chapter/1. Accessed August 11, 2022.

3. Task Force Actions and Future Work

As required by Texas Health and Safety Code, Chapter 52, the following summarizes the Task Force progress on the 2018 Sickle Cell Advisory Committee recommendations, 2020 Task Force milestones, and 2021 Task Force recommended actions.

During the third year of operations, the Task Force held four meetings. The Task Force has four subcommittees: Public Awareness Campaigns, Medicaid Contracts, Sickle Cell Surveillance, and the Legislatively Mandated Report. Each subcommittee met with subject matter experts regarding Task Force 2020 milestones and 2021 recommended actions.

Summary of Progress

Establish a Sickle Cell Task Force

In 2019, the 86th Texas Legislature established the Task Force. The 2018 Sickle Cell Advisory Committee's recommendations and the 2020 and 2021 Sickle Cell Task Force Annual Reports summarize the Task Force's prior actions. This is the third Task Force legislative report.

Develop Statewide Sickle Cell Awareness Campaigns

The Task Force worked with DSHS to develop a Texas public awareness campaign in September 2021 (Appendix B) and, utilizing existing agency framework, relaunched the campaign in September 2022 for national and state-designated Sickle Cell Awareness Month to promote annual sickle cell awareness. This campaign included sickle cell disease (SCD) education information, the patient experience, and how the public can provide support through blood donations and hemoglobin testing.

The Task Force also submitted a project proposal to work with the University of Texas Human Dimensions of Organizations (HDO) Program for the fall 2022 semester. The proposed or selected project is designed to increase SCD and sickle cell trait (SCT) awareness across the state.

The Task Force will meet with subject matter experts, including HDO and sickle cell community-based organizations, regarding impactful and relevant public awareness

campaigns and press releases. The goal is to have at least two campaigns per year with emphasis on September Sickle Cell Awareness Month and June 19, 2023 World Sickle Cell Day. Planned spotlight areas include state specific SCD data, recognition of newborn screening, trait/carrier status awareness, and National Collegiate Athletic Association requirements. Per these requirements, students must provide sickle cell trait status for participation in athletics due to increased risk of complications associated with physical activity.

Begin Statewide Sickle Cell Surveillance Throughout the Lifespan

The Task Force met with programs to identify available data for Texas sickle cell surveillance and further delineate a surveillance structure to recommend to DSHS. The Task Force met with the Texas Center for Health Outcomes Research & Education, associated with the University of Texas College of Pharmacy, to understand their SCD research history and experience. The Task Force also met with the Center for Health Care Data (CHCD) at the University of Texas Health Science Center in Houston, School of Public Health. In 2021, CHCD was tasked by the Texas Legislature (as directed by Insurance Code, Chapter 38) with developing the Texas All Payor Claims Database. Sickle cell surveillance systems need data from all payor claims databases, which will provide missing SCD population-based information, and collaboration with CHCD is important to attain the sickle cell surveillance goal. CHCD also presented initial sickle cell claims data they are able to access in Texas, which is posted online at the Health of Texas Dashboard.

The Task Force also worked with the DSHS Texas Syndromic Surveillance (TxS2) team to add additional data and improve data quality for a second Sickle Cell Disease in Texas Syndromic Surveillance Systems Report, 2021. Syndromic surveillance uses health-related data in real time to provide demographic analysis, which can indicate emerging health trends and potential disease outbreaks. Three syndromic surveillance systems operate in Texas. Data from DSHS Texas Syndromic Surveillance was presented to the Task Force at the August 2022 meeting. Meeting minutes are accessible on the Task Force's webpage.

Partner with Medicaid/Medicare, Managed Care Organizations, and Accountable Care Organizations

The Task Force met with HHSC Medicaid and Children's Health Insurance Program (CHIP) Services and provided national sickle cell clinical care guidelines education

and discussed statewide gaps in accessing comprehensive care for individuals with SCD. The Task Force also addressed opioid policies for individuals with SCD, variations in SCD management based on the healthcare plan, care packages of bundled services for patients with SCD, and access to Federal Drug Administration-approved SCD medications.[14,15]

For 2023, the Task Force intends to discuss and address medical home models for SCD care, variations in SCD management based on the health care plan, lifespan eligibility/waivers, non-pharmacologic/supportive care bundles, and Federal Drug Administration-approved SCD medications. The Task Force will also explore optimizing telemedicine and the development of a tiered recommendation for health care facilities and providers based on the capability to provide comprehensive care for individuals with SCD. The Task Force plans to study the feasibility of a Medicaid and CHIP Services discounted drug plan modeled after the federal 340B Drug Pricing Program to provide outpatient SCD medications to Medicaid-covered entities at significantly lower prices.

Utilize Community Health Workers to Improve Care

The Task Force will review DSHS and HHSC SCD and SCT educational modules and recommend areas for improvement. In addition, the Task Force will continue to engage with the DSHS Community Health and Wellness Branch to boost Community Health Worker access to updated SCD and SCT education, including a lecture or conference development. Furthermore, the Task Force will review and discuss opportunities for Community Health Worker optimization for Texas high-need areas.

[14] American Society of Hematology. Hydroxyurea for Sickle Cell Disease, Treatment Information from the American Society of Hematology. American Society of Hematology, Patients. hematology.org/-/media/Hematology/Files/Education/HydroxyureaBooklet.pdf. Accessed August 16, 2022.
[15] Sickle Cell Disease Coalition. Treatment for Sickle Cell Disease. SCD Treatment Flyers. scdcoalition.org/pdfs/SCDFactSheets-Finalflyers.pdf. Published May 25, 2021. Accessed August 16, 2022.

4. 2022 Recommended Actions

Texas Health and Safety Code, Chapter 52, directs the Task Force to include recommended actions or policy changes in this report. In response, the Task Force advises DSHS to consider the following items to enhance Task Force productivity and complement current progress.

Increase Sickle Cell Task Force Membership from Seven to at Least 15

Statute states the Task Force is comprised of seven members. The Task Force recommends adding more Task Force members to increase subject matter expertise, optimize effectiveness of each subcommittee, and enhance overall Task Force productivity. Recommended new members should include:

- One additional member of the public, who has sickle cell disease (SCD) or sickle cell trait (SCT);
- Two additional members of the public, each of whom is a family member of a person with SCD or SCT;
- Two additional physicians with experience addressing the needs of individuals with SCD and SCT;
- Two researchers from a public health-related or academic institution with experience addressing SCD and SCT; and
- One additional health care professional with experience addressing the needs of individuals with SCD and SCT.

Extend the Sickle Cell Task Force Beyond August 31, 2025

25 Texas Administrative Code, Section 37.420(j), sunsets the Task Force on August 31, 2025. The Task Force anticipates activities related to addressing the 2018 recommendations involve incremental, progressive steps that will likely extend beyond 2025. Therefore, the Task Force recommends extending the timeline beyond the sunset date.

Identify Funding for Statewide Awareness Activities

The Task Force recommends identification of dedicated, ongoing funding for statewide SCD and SCT awareness activities, including:

- Provide community SCD and SCT education;
- Improve detection of individuals with SCD and SCT;
- Coordinate service delivery for people with SCD; and
- Provide training for health professionals regarding SCD and SCT.

Develop Partnerships to Allow Texas to Apply to the Centers for Disease Control and Prevention's Sickle Cell Data Collection Program

The Task Force recommends DSHS work with other state agencies and programs such as the University of Texas College of Pharmacy and the Center for Health Data at the University of Texas Health Science Center in Houston - School of Public Health to develop partnerships that will place Texas in a position to apply to become a site in the next funding announcement for the Center for Disease Control and Prevention's Sickle Cell Data Collection Program. Participation in this national system would enhance the care of individuals with SCD in Texas and include Texas as a key member of the national push to improve SCD care.

Develop Comprehensive Medical Home Models

Given the multiple barriers people face accessing high-quality sickle cell care, the Task Force recommends the development of comprehensive sickle cell medical home models for both urban and rural Texas communities.[16] Developing these models can be based off existing state models for patients with complex care needs and also on sickle cell expert recommendations from the American Society of Hematology.[17]

[16] Nowogrodzki, Anna. No adult left behind: bridge the health-care gap for sickle-cell disease. *Nature* 2021 Aug 26;596:S13-S15. doi: doi.org/10.1038/d41586-021-02143-z.
[17] Kanter J, Smith WR, Desai PC, Treadwell M, Andemariam B, Little J, Nugent D, Claster S, Manwani DG, Baker J, Strouse JJ, Osunkwo I, Stewart RW, King A, Shook LM, Roberts JD, Lanzkron S. Building access to care in adult sickle cell disease: defining models of care, essential components, and economic aspects. *Blood Adv*. 2020 Aug 25;4(16):3804-3813. doi: 10.1182/bloodadvances.2020001743. PMID: 32785684; PMCID: PMC7448595.

Evaluate Options to Increase Medicaid and Children's Health Insurance Program Eligibility for Individuals Diagnosed with Sickle Cell Disease to Age 26

Given that SCD is a chronic illness with progressive complications, the Task Force recommends the HHSC evaluate options to increase eligibility of Medicaid and CHIP services for any individual with SCD to age 26 to cover the health care transition period to early adulthood, unless they are eligible for disability coverage.

Publish an Annual Texas Sickle Cell Surveillance Report

The Task Force recommends DSHS create and distribute an annual sickle cell report that incorporates available data from the DSHS Texas Syndromic Surveillance System, the DSHS Center for Health Statistics, the DSHS Newborn Screening Unit, and the new All-Payor Claims Database. Data should include the number of babies born annually with SCD/SCT, as well as demographic characteristics, geographical distribution, hospital utilization data, and mortality data of individuals with SCD.

Establish and Maintain a Universal Sickle Cell Data Collection System

The Task Force recommends DSHS establish and maintain a universal sickle cell data collection system to improve treatment, access, and care to people with SCD in Texas. This system would enhance the data provided in an annual sickle cell report.

5. Conclusion

During its third year, Task Force members worked with DSHS staff to cultivate and advance Task Force milestones and recommended actions developed during the first two years. Through regular meetings, subject matter expert input, and the Task Force subcommittees' work, the Task Force recommends next steps needed to raise public awareness of sickle cell disease (SCD) and sickle cell trait (SCT) in Texas, develop a state-level annual SCD surveillance report, and lay the foundation to participate in nationwide surveillance programs. The Task Force recommends actions and plans for future work in 2023 to continue raising awareness in collaboration with public awareness campaign organizations, state agencies, and the Texas HHSC's Medicaid and Children's Health Insurance Program (CHIP) Services to improve care for individuals with SCD in Texas.

Task Force recommendations are:

- Increase Sickle Cell Task Force membership from seven to at least 15.
- Extend the Sickle Cell Task Force beyond August 31, 2025.
- Identify funding for statewide awareness activities.
- Develop partnerships to allow Texas to apply to the Centers for Disease Control and Prevention's Sickle Cell Data Collection Program.
- Develop comprehensive medical home models.
- Evaluate options to increase Medicaid and CHIP eligibility for individuals diagnosed with sickle cell disease until age 26.
- Publish an annual Texas sickle cell surveillance report.
- Establish and maintain a universal sickle cell data collection system.

List of Acronyms

Acronym	Full Name
CF	Cystic Fibrosis
CHCD	Center for Health Care Data
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare and Medicaid Services
DSHS	Texas Department of State Health Services
HDO	University of Texas Human Dimensions of Organizations Program
HHS	Texas Health and Human Services
HHSC	Texas Health and Human Services Commission
NBS	Newborn Screening
SCD	Sickle Cell Disease
SCDC	Sickle Cell Data Collection Program
SCT	Sickle Cell Trait
TxS2	Texas Syndromic Surveillance System

Appendix A. Sickle Cell Task Force Membership

Table 1. 2021-2022 Sickle Cell Task Force Members

Member Name	Position/Category
Dr. Titilope Fasipe, Chair	Representative of a health-related institution
Dr. Melissa Frei-Jones	Physician specializing in hematology
Ms. Priscilla Hill-Ardoin	Member of the public who has sickle cell disease or is a parent of a person with sickle cell disease or trait
Dr. Dawn D. Johnson	Member from a community-based organization with experience addressing the needs of a individuals with sickle cell disease
Dr. Alecia Nero	Physician specializing in hematology
Mrs. Marqué Reed-Shackelford	Member of the public who has sickle cell disease or is a parent of a person with sickle cell disease or trait
Ms. Alysian Thomas, J.D.	Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease

Appendix B. Public Awareness Campaign

Per House Concurrent Resolution 117, 86th Legislature, 2019, September is Sickle Cell Awareness Month through 2029 in Texas.

Sickle Cell Awareness Month

The Texas DSHS Newborn Screening (NBS) program worked with DSHS and Texas Health and Human Services (HHS) Communications to promote Sickle Cell Awareness Month in September 2021 and 2022. HHS Communications and NBS staff developed a Sickle Cell Awareness Month video featuring Task Force member, Dr. Titilope Fasipe, which DSHS posted on YouTube on September 3, 2021. As of August 2022, the video has 509 views. DSHS and HHS shared this video and other sickle cell information in social media messages and articles published on the respective DSHS and HHS websites and social media accounts.

HHS Communications shared the following social media posts:

- Texas DSHS Facebook
  - September 7, 2021 (Link) – Shared video had 3,100 views as of August 2022
- Texas Health and Human Services Commission (HHSC) Facebook
  - September 5, 2021 (Link)
  - September 14, 2021 (Link) – Shared video had 367 views as of August 2022
- Texas DSHS Twitter
  - September 7, 2021 (Link) – Shared video had 12,300 views as of August 2022
- Texas HHSC Twitter
  - September 5, 2021 (Link)
  - September 7, 2021 (retweet of Texas DSHS September 7 tweet)
  - September 10, 2021 (Link)
  - September 14, 2021 (Link) – Shared video had 462 views as of August 2022
- Texas DSHS Instagram
  - September 7, 2021 (Link) – Shared video had 338 views as of August 2022

Some articles and posts included additional information links available on the Newborn Screening Program's homepage, Sickle Cell Disease webpage, and Sickle Cell Resources webpage. These webpages received an increase in combined unique pageviews. In September 2021, the webpages received 2,288 pageviews compared to 1,732 pageviews in August 2021 and 1,719 pageviews in October 2021, according to Google Analytics statistics provided by the DSHS Web Office.

Additionally, preliminary data for social media posts is available for 2022. HHS Communications shared the following social media posts:

- Texas DSHS Facebook
  - September 1, 2022 (Link)
- Texas DSHS Twitter
  - September 1, 2022 (Link)
  - September 21, 2022 (Link)
- Texas DSHS Instagram
  - September 1, 2022 (Link)