2021 Sickle Cell Task Force Annual Report

As Required by

Texas Health and Safety Code,

Section 52.0007

Sickle Cell Task Force

December 2021

Table of Contents

Executive Summary

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

The purpose of the Task Force is to study and advise the Department of State Health Services (DSHS) on implementing the 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 determines is appropriate.

The Task Force was established by the 86th Legislature in 2019. This is the Task Force's second legislative report.

In addition to describing Task Force activities, this report outlines the Task Force's proposed actions for implementing the Sickle Cell Advisory Committee's 2018 recommendations.

- Use existing agency framework to promote annual sickle cell awareness campaigns.
- Design an awareness campaign on sickle cell trait and sickle cell disease education in collaboration with Texas colleges and universities.
- Publish an annual Texas sickle cell report based on data from the DSHS Newborn Screening Unit, the DSHS Texas Syndromic Surveillance System, and the DSHS Center for Health Statistics.
- Establish and maintain a universal sickle cell data collection system.
- Facilitate collaboration with the Health and Human Services Commission (HHSC) Medicaid and Children's Health Insurance Program (Medicaid & CHIP) Services to study current sickle cell clinical care guidelines.
- Facilitate collaboration with HHSC Medicaid & CHIP Services to study the feasibility of integrating non-pharmacological alternatives into care packages of bundled services for patients with sickle cell disease.

1. Introduction

The Sickle Cell Task Force (Task Force) was established in accordance with House Bill 3405, 86th Legislature, Regular Session, 2019, and promulgated under the Texas Health and Safety Code (HSC), Chapter 50 (now HSC Chapter 52 per House Bill 3607, 87th Legislature, Regular Session, 2021). Statute directs the Executive Commissioner of the Health and Human Services Commission (HHSC) to establish and maintain a task force to raise awareness of sickle cell disease and sickle cell trait. In August 2019, HHSC Executive Commissioner delegated the creation and administrative support of the Task Force to the Department of State Health Services (DSHS).

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

Sickle cell disease (SCD) is one of the most difficult and stressful chronic diseases to manage. Reducing health care barriers and disparities will improve the quality of primary care services received by individuals with SCD. SCD is an inherited disorder of abnormal hemoglobin synthesis that is associated with pain and progressive multi-organ damage with significant impact on the patient's quality of life. The disease is associated with adjustment difficulties such as depression and anxiety.[1]

More than one thousand babies in the United States are born with SCD every year.[2] The Centers for Disease Control and Prevention (CDC), the National Center on Birth Defects and Developmental Disabilities, and the Division of Blood Disorders

---

[1] Mackey, Michelle Noble. *Understanding Parents' Disease-Managing Strategies for Children With Sickle Cell Disease*. Dissertation. Walden University; 2019. *Walden Dissertations and Doctoral Studies*. 6610. https://scholarworks.waldenu.edu/dissertations/6610

[2] Sickle Cell Disease Association of America. The Pain Community. http://www.sicklecelldisease.org/strategic-partners/the-pain-community. Published July 11, 2019. Accessed August 9, 2021.

consider SCD a significant health and global concern.[3] Newborns diagnosed with SCD are reported to DSHS's Newborn Screening program, but there are no statewide SCD surveillance programs in Texas.[4] Managing SCD and utilizing health services is difficult for people living with this chronic illness.

Raising public awareness of SCD and sickle cell trait (SCT) involves engaging the attention of the community, alerting health care workers, and working with local, state, and federal agencies. These entities must understand the importance of working in unity to help solve problems with health care disparities for individuals with SCD/SCT.

The Task Force is required to prepare and submit to the Governor and the Legislature an annual written report that summarizes the Task Force's work and includes any recommended actions or policy changes endorsed by the Task Force no later than December 1 each year.

In accordance with Texas Health and Safety Code, Chapter 52, this report outlines the following:

- A summary of the Task Force's activities during 2020-2021,
- Plans for future work, and
- Proposed actions for implementing the Sickle Cell Advisory Committee's 2018 recommendations.

[3] Centers for Disease Control and Prevention. About CDC's Work on Sickle Cell Disease. https://www.cdc.gov/ncbddd/sicklecell/about.html. Published December 16, 2020. Accessed August 9, 2021.

[4] Department of State Health Services. Screened Disorders. https://dshs.texas.gov/newborn/screened_disorders.aspx. Updated May 28, 2021. Accessed August 9, 2021.

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). The two-year Advisory Committee developed a set of recommendations for the Texas Legislature, one of which was the establishment of a Sickle Cell Task Force (Task Force) to continue the Advisory Committee's work. Although the Advisory Committee ended in 2018, new legislation established the Task Force the following year in 2019. The Task Force has worked with the Department of State Health Services (DSHS) over the past two years to further explore implementation of the remaining Advisory Committee's 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 United States (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.[5] Though SCD was previously associated with high mortality in young children, advances in treatment and preventive care have led to lower death rates. Today, more than 90 percent of children with SCD survive to adulthood.

However, 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

[5] Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. Global burden of sickle cell anaemia 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

SCD. Survival rates of adults with SCD have changed very little in the past 30 years.[6]

In 2021, the Centers for Medicare and Medicaid Services (CMS) attempted to address the data gap for people living with SCD in the U.S., publishing the first ever comprehensive report on state-level health care utilization and health characteristics of people with SCD receiving Medicaid and Children's Health Insurance Program (Medicaid & CHIP) services. In the CMS report, which examined data from 2017, Texas had 2,604 Medicaid & CHIP beneficiaries with SCD. Only Florida, Georgia, and New York had more beneficiaries with SCD. The report encompassed 41,995 individuals with SCD, almost half the nation's reported population of 90,000 to 100,000.

The report highlights a considerable discrepancy between recommended therapy and therapy individuals received. They found only 36 percent of patients with SCD between the ages of 2-16 years 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.[7]

The report 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 2 years of age had received the appropriate vaccinations, including the 13-valent pneumococcal vaccine.[7] 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 4-year-olds with at least 300 days of prescriptions).[7]

---

[6] 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

[7] 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 January 15, 2021.

The CMS report also highlighted factors that contribute to the health care costs of SCD hospitalizations and emergency department visits. The report shows 77 percent of beneficiaries with SCD had at least one emergency department visit compared to just 34 percent of beneficiaries without SCD, and 48 percent had at least one hospital stay compared to 6 percent of beneficiaries without SCD.[7]

Gaps in care also exist for individuals with SCD because of documented disparities in health care funding, research dollar awards, specialist care access, and the slow 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 medical therapies approved than patients with SCD during the same time period.[8]

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.[8] For SCD, the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection Program had funding to support two states, Georgia and California, from 2005 to 2016, and seven states are receiving funding to participate in 2021 (Minnesota, Wisconsin, Michigan, Indiana, Alabama, Tennessee, and North Carolina).[9] This is still an under-representation 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*

---

[8] 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 6, 2021.

[9] Centers for Disease Control and Prevention. Sickle Cell Data Collection (SCDC) Program. cdc.gov/ncbddd/hemoglobinopathies/scdc.html. Published April 2, 2021. Accessed August 9, 2021.

Strategic Plan and Blueprint for Action. The strategic plan sets forth a vision to 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.[10]

Texas demonstrated a commitment to these efforts through the Advisory Committee, and the Task Force is examining these eight areas for Texas. The Task Force is positioned to be a key player in these efforts moving forward.

The Task Force is made up of seven members appointed by the Health and Human Services Commission Executive Commissioner and is required to meet three times per year. Membership includes physicians specializing in hematology, members of community-based organizations who serve those with SCD, 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.

[10] 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. https://www.nap.edu/read/25632/chapter/1. Accessed August 6, 2021.

3. Task Force Actions and Future Work

As required by statute, the following summarizes the Sickle Cell Task Force's (Task Force) work. The Task Force was established by the 86th Legislature in 2019, and, as such, this is the Task Force's second legislative report. A summary of the Task Force's actions for 2019-2020, including the establishing of Task Force milestones, can be found in the *2020 Sickle Cell Task Force Annual Report*.

Much of the Task Force's work in its second year focused on 2020 milestone objectives.

Task Force Actions (2020-2021)

During the second year of operation, the Task Force held four meetings. Second-year accomplishments included the creation of a social media campaign for Sickle Cell Awareness Month that operated throughout September 2020 (Appendix B). Meeting minutes can be reviewed on the Task Force's webpage dshs.texas.gov/newborn/committees/SCTF-Business.aspx.

The Task Force also met with subject matter experts regarding the 2018 Sickle Cell Advisory Committee (Advisory Committee) recommendations/2020 Task Force milestones. Further, members were assigned to participate in four subcommittees: Public Awareness Campaigns, Medicaid Contracts, Sickle Cell Surveillance, and Legislatively Mandated Report.

The Task Force drafted recommended actions for the Department of State Health Services (DSHS) which are discussed later in this report.

Future Activity

Based on information provided by subject matter experts and discussions within the Task Force, the following represents the plan for future work for fiscal year 2022. To review foundational milestone goals, please see the 2020 Task Force Report.

Membership

Three members ended their two-year term on the Task Force, including the current Chair. The Task Force also received a resignation request from one member. The

Health and Human Services Commission Executive Commissioner will appoint or re-appoint new members as per Task Force Bylaws. The Task Force will also elect a new presiding officer.

Milestones for Developing Public Awareness Campaigns

The Task Force worked with DSHS to develop a public awareness campaign in Texas for September 2021, which is the national and state-designated Sickle Cell Awareness Month. This campaign includes information regarding education on sickle cell disease, the patient experience, and how the public can provide support through blood donations and hemoglobin testing.

In 2022, the Task Force will continue to meet with subject matter experts regarding public awareness campaigns that can be used as a model for Texas. The Task Force plans to partner with community-based organizations to identify resources for the public on the importance of knowing one's hemoglobin type(s), developing family plans with a genetic counselor, and sickle cell awareness. DSHS program staff will work with the Task Force to review and update the list of community-based organizations posted on the DSHS Sickle Cell Resources website (available at dshs.texas.gov/newborn/SCResources.aspx). The Task Force will also consider the development of a campaign that identifies how patients with sickle cell, their family, and the community are coping with the intersection of COVID-19 and the blood disorder.

Milestones for Studying Sickle Cell Surveillance

The Task Force met with agency programs to determine what data elements may be available for Sickle Cell Surveillance. The Task Force worked with the DSHS Texas Syndromic Surveillance (dshs.texas.gov/txs2/default.aspx) System team to draft the first-ever *Sickle Cell Disease in Texas Syndromic Surveillance Systems Report*, which was presented to the Task Force at their August 2021 meeting (available at texashhsc.swagit.com/play/08232021-959). The report includes demographic, geographical, and hospital system-level data for emergency and urgent care visits. The Task Force considered other surveillance data elements that could also be included to make a robust sickle cell report. The Task Force worked with the DSHS Center for Health Statistics to refine surveillance data to include mortality data. The Task Force has identified these components as the basis for the first annual sickle cell data report. During 2022, they will review National Syndromic Surveillance System Program data and sickle cell-specific surveillance systems utilized in other states.

Milestone for Partnering with Medicaid, Medicare, Managed Care Organizations, and Accountable Care Organizations

The Task Force had introductory meetings with the HHSC Medicaid and Children's Health Insurance Program Services (Medicaid & CHIP Services) to share national sickle cell clinical care guidelines. Medicaid & CHIP Services requested ongoing education and discussion at future meetings. In particular, the Task Force wants to address 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.[11, 12] The Task Force will also explore optimizing telemedicine and the development of a tiered recommendation for health care facilities and providers based on level of comprehensive care to improve access to care for individuals with SCD.

Milestones for Working with Community Health Workers

The Task Force will continue to engage with the DSHS Community Health and Wellness Branch to optimize Community Health Worker access to updated education on SCD and SCT, including the development of a lecture or conference. The Task Force will review educational modules by DSHS that provide SCD and SCT education and recommend areas for improvement. The Task Force will also work to understand locations where individuals with SCD seek care for possible targeted educational efforts. Furthermore, the Task Force will review and discuss opportunities for Community Health Worker optimization for high-need areas in Texas.

---

[11] American Society of Hematology. Hydroxyurea for Sickle Cell Disease, Treatment Information from the American Society of Hematology. American Society of Hematology, Patients. https://www.hematology.org/-/media/Hematology/Files/Education/Hydroxyurea-Booklet.pdf. Published February 28, 2019. Accessed August 9, 2021.

[12] Sickle Cell Disease Coalition. Treatment for Sickle Cell Disease. SCD Treatment Flyers. http://www.scdcoalition.org/pdfs/SCDFactSheets-Finalflyers.pdf. Published May 25, 2021. Accessed August 9, 2021

4. 2021 Recommended Actions

Per Health and Safety Code, Chapter 52, the Sickle Cell Task Force (Task Force) is to advise the Department of State Health Services (DSHS) on the implementation of the recommendations in the *2018 Sickle Cell Advisory Committee Report*. Statute also directs the Task Force to include recommended actions or policy changes in this report. As such, the Task Force advises DSHS to consider the following.

1. Utilize existing agency framework to promote annual sickle cell awareness campaigns.

The Task Force and program staff successfully developed two zero-budget sickle cell awareness campaigns in 2020 (Appendix B) and 2021. However, to increase outreach and impact of awareness campaigns, the Task Force recommends that DSHS utilize existing DSHS and Health and Human Services Commission (HHSC) framework to promote annual awareness campaigns focused on sickle cell disease (SCD) and sickle cell trait (SCT). This recommendation is in line with the *2018 Sickle Cell Advisory Committee Report*. The Task Force recommends that the campaigns be modeled after other successful DSHS and HHSC public health awareness campaigns.

2. Design an awareness campaign on SCD and SCT education in collaboration with Texas colleges and universities.

The Task Force recommends that DSHS design an awareness campaign focused on SCD/SCT education and testing and targeting the college and young adult population in Texas. Young adults should know about the inheritance of SCD/SCT, especially if they are starting family planning. This campaign should educate young adults of the importance of obtaining screening for possible carrier status for hemoglobin disorders. The Task Force also recommends that DSHS collaborate with Texas colleges and universities, such as the University of Texas' Human Dimensions of Organizations program, the University of Houston, and Historically Black Colleges and Universities such as the Prairie View A&M University, Texas Southern University, and Paul Quinn University.

3. Publish an annual Texas sickle cell report based on data from the DSHS Newborn Screening Unit, DSHS Texas Syndromic Surveillance System, and the DSHS Center for Health Statistics.

The Task Force recommends the creation and distribution of an annual sickle cell report by DSHS that incorporates available data from the DSHS Texas Syndromic Surveillance System, the DSHS Center for Health Statistics, and DSHS Newborn Screening Unit. 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.

4. Establish and maintain a universal sickle cell data collection system.

The Task Force recommends that 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. Developing this system could be based off the external experience of other states, as described in the American Society of Hematology article titled *Understanding sickle cell disease: impact of surveillance and gaps in knowledge*.[13]

5. Facilitate collaboration with HHSC Medicaid and Children's Health Insurance Program (Medicaid & CHIP) Services to study current sickle cell clinical care guidelines.

The Task Force recommends that DSHS facilitate collaboration between the Task Force and the HHSC Medicaid & CHIP Services to study whether Medicaid's SCD policies and care plans are aligned with national evidence-based clinical care guidelines and quality metrics (See Appendix C). This recommendation will lay the foundation for improved health care outcomes for individuals with SCD and increased provider and public awareness of national guidelines.

---

[13] Mandip Kaur, Mary Brown, Ted W. Love, Alexis Thompson, Marsha Treadwell, Kim Smith-Whitley. Understanding sickle cell disease: impact of surveillance and gaps in knowledge. *Blood Adv* 2020;4(3):496–498. doi:10.1182/bloodadvances.2019001000. https://ashpublications.org/bloodadvances/article/4/3/496/440991/Understanding-sickle-cell-disease-impact-of. Accessed August 20, 2021.

6. Facilitate collaboration with HHSC Medicaid & CHIP Services to study the feasibility of integrating non-pharmacological alternatives into care packages of bundled services for patients with SCD.

The Task Force recommends that DSHS facilitate collaboration between the Task Force and the HHSC Medicaid & CHIP Services, to study the feasibility of integrating non-pharmacological alternatives into care packages of bundled services for patients with SCD, in consultation with providers, to maximize comprehensive pain management. These adjunct therapies should be in line with the *American Society of Hematology's 2020 Guidelines for Sickle Cell Disease: Management of Acute and Chronic Pain*.[14]

[14] Brandow, A. M., Carroll, C. P., Creary, S., Edwards-Elliott, R., Glassberg, J., Hurley, R. W., Kutlar, A., Seisa, M., Stinson, J., Strouse, J. J., Yusuf, F., Zempsky, W., & Lang, E.. American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain. *Blood Adv*. 2020;4(12)2656-2701. doi:10.1182/bloodadvances.2020001851. https://ashpublications.org/bloodadvances/article/4/12/2656/460974/American-Society-of-Hematology-2020-guidelines-for. Accessed August 20, 2021.

5. Conclusion

During the second year of the Sickle Cell Task Force (Task Force), members worked with the Department of State Health Services staff to continue to develop the milestones proposed in the first legislative report. Through regular meetings, input from subject matter experts, and the work of subcommittees, the Task Force was able to recommend the next steps or actions needed to raise public awareness of sickle cell disease (SCD) and sickle cell trait in Texas. The Task Force has identified plans for future work in 2022 to continue raising awareness in collaboration with the Community Health Workers program, public awareness campaign organizations, and the Health and Human Services Commission's Medicaid and Children's Health Insurance Program Services to improve care for patients with SCD in Texas.

List of Acronyms

Acronym	Full Name
CDC	Centers for Disease Control and Prevention
CF	Cystic Fibrosis
CHIP	Children's Health Insurance Program
CHW	Community Health Worker
CMS	Centers for Medicare and Medicaid Services
DSHS	Department of State Health Services
HHSC	Health and Human Services Commission
ICD-10	International Classification of Diseases, Tenth Revision
PHR	Public Health Region
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
TxS2	Texas Syndromic Surveillance System
U.S.	United States

Appendix A. Task Force Members

Table 1. Sickle Cell Task Force Members

Member	Position/Category
Dr. Titilope Fasipe	Representative of a health-related institution
Dr. Melissa Frei-Jones	Physician specializing in hematology
Dr. Michelle N. Mackey, Chair	Member of the public who has sickle cell disease or is the parent of a person with sickle cell disease or trait
Dr. Alecia Nero	Physician specializing in hematology
Ms. 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
Ms. Tonya Prince[a]	Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease

[a] Ms. Tonya Prince resigned June 2021

Appendix B. Public Awareness Campaigns

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

Sickle Cell Awareness Month 2020

The Department of State Health Services (DSHS) Newborn Screening Program worked with DSHS and Health and Human Services (HHS) Communications to promote Sickle Cell Awareness Month in September 2020. Social media posts and articles were published on the respective DSHS and HHSC pages through the month of September.[15] These posts and articles also included links for additional information available on the Newborn Screening Program's homepage (Figure 1) and Sickle Cell Disease webpage (dshs.texas.gov/newborn/sickle.aspx), which received increased unique pageviews in September (Table 1).

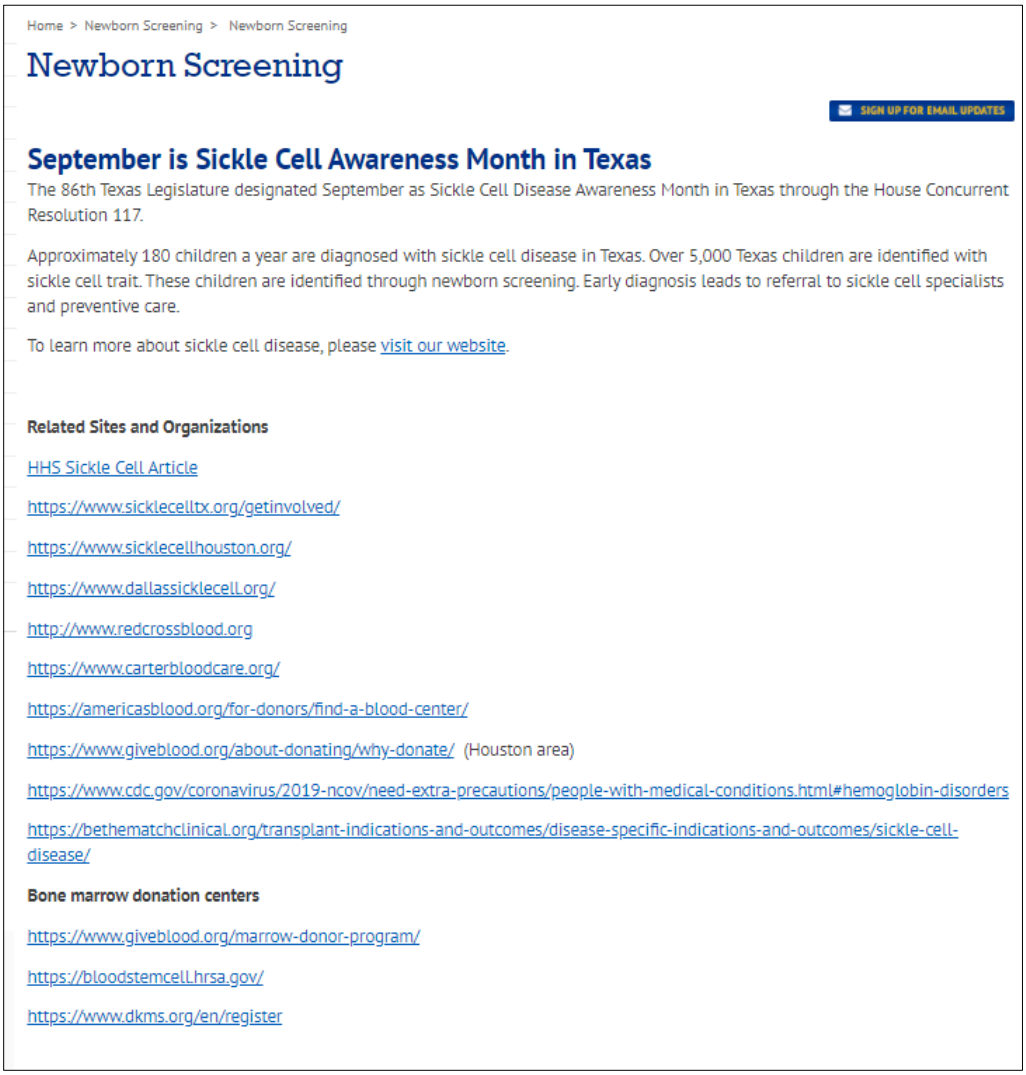
HHS Communications shared posts on social media as follows:

- Texas DSHS Instagram: Tuesday, September 15, 2020 (Link)
- Texas DSHS Facebook: Thursday, September 17, 2020 (Link)
- Texas DSHS Twitter: Friday, September 18, 2020 (Link)
- Texas HHSC Twitter: Monday, September 21, 2021 (Link)

[15] HHSC's announcement is available at hhs.texas.gov/about-hhs/communications-events/news/2020/09/september-marks-sickle-cell-disease-awareness-month-texas.

Website updates for Sickle Cell Awareness Month 2020

Figure 1. Screenshot of the DSHS Newborn Screening Program's website homepage, September 2020



Home > Newborn Screening > Newborn Screening

Newborn Screening

SIGN UP FOR EMAIL UPDATES

September is Sickle Cell Awareness Month in Texas

The 86th Texas Legislature designated September as Sickle Cell Disease Awareness Month in Texas through the House Concurrent Resolution 117.

Approximately 180 children a year are diagnosed with sickle cell disease in Texas. Over 5,000 Texas children are identified with sickle cell trait. These children are identified through newborn screening. Early diagnosis leads to referral to sickle cell specialists and preventive care.

To learn more about sickle cell disease, please visit our website.

Related Sites and Organizations

HHS Sickle Cell Article

https://www.sicklecelltx.org/getinvolved/

https://www.sicklecellhouston.org/

https://www.dallassicklecell.org/

http://www.redcrossblood.org

https://www.carterbloodcare.org/

https://americasblood.org/for-donors/find-a-blood-center/

https://www.giveblood.org/about-donating/why-donate/ (Houston area)

https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#hemoglobin-disorders

https://bethematchclinical.org/transplant-indications-and-outcomes/disease-specific-indications-and-outcomes/sickle-cell-disease/

Bone marrow donation centers

https://www.giveblood.org/marrow-donor-program/

https://bloodstemcell.hrsa.gov/

https://www.dkms.org/en/register

Table 1. Comparison of total unique pageviews of the DSHS Newborn Screening Program's webpages for August, September, and October 2020[a,b,c]

Webpage	Number of unique pageviews August 2020	Number of unique pageviews September 2020	Number of unique pageviews October 2020
All DSHS Newborn Screening Program webpages[d]	7,408	9,144	8,616
DSHS Newborn Screening Program homepage	1,658	1,856	1,784
Sickle Cell Disease	90	310	100
Sickle Cell Disease (Spanish)	11	23	11
Sickle Cell Trait	147	137	109
Sickle Cell Trait (Spanish)	249	268	286
Aplastic Crisis	6	0	1
Aplastic Crisis (Spanish)	35	100	89
Chest Syndrome	0	1	3
Chest Syndrome (Spanish)	0	3	0
Hemoglobin Disorders	243	378	322
Hemoglobin Sickle C Disease	11	3	11
More About Sickle Cell Disease	15	22	11
Pain in the Child with Sickle Cell Disease	0	1	0
Pain in the Child with Sickle Cell Disease (Spanish)	0	0	0
Pneumococcal Infection and Penicillin	1	0	1
Pneumococcal Infection and Penicillin (Spanish)	0	0	0
Priapism	9	13	13
Priapism (Spanish)	8	16	10
Sickle Beta Zero Thalassemia	56	34	42
Sickle Beta Zero Thalassemia (Spanish)	42	43	43
Sickle Beta+ Thalassemia	16	9	12
Sickle Cell Anemia and Stroke	3	8	3
Sickle Cell Anemia and Stroke (Spanish)	5	4	1

Sickle Cell Anemia: A Parent's Guide for the School Age Child	6	9	18
Sickle Cell Anemia: A Parent's Guide for the School Age Child (Spanish)	195	368	293
Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait	207	328	274
Sickle Cell Disease and Sickle Cell Trait	13	9	10
Sickle Cell Disease: A Resource for the Educator	2	1	20
Sickle Cell Resources	84	81	72
Sickle Cell Resources (Spanish)	2	5	4
Splenic Sequestration Crisis	18	22	19
Total unique pageviews for the DSHS Newborn Screening Program's sickle cell webpages	**1,474**	**2,196**	**1,778**

[a] Source: Google Analytics provided by the DSHS Web Office, August 2021

[b] Unique pageviews does not include additional pageviews from the same user in the same session

[c] Data for multiple web addresses that direct to the same webpage have been combined

[d] Includes all web addresses that begin with "dshs.texas.gov/newborn/"

Appendix C. National Sickle Cell Care Guidelines and Reports

2014, *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report*, National Institutes of Health. Full guidelines available at nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease. Summary guide is available at nhlbi.nih.gov/sites/default/files/media/docs/Evd-Bsd_SickleCellDis_Rep2014.pdf.

2017, Pediatric Quality Measures Program, Management of Chronic Conditions – Sickle Cell Treatment, Agency of Healthcare Research and Quality/Centers for Medicare & Medicaid Services. Available at ahrq.gov/pqmp/measures/management-of-chronic-conditions.html.

2019-2020, *Clinical Practice Guidelines on Sickle Cell Disease*, American Society of Hematology. Available at hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/sickle-cell-disease-guidelines.

2020, *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action*, The National Academies of Sciences, Engineering, and Medicine. Available at nationalacademies.org/our-work/addressing-sickle-cell-disease-a-strategic-plan-and-blueprint-for-action.

2020*, At a Glance: Medicaid and CHIP Beneficiaries with Sickle Cell Disease, T-MSIS Analytic Files (TAF) 2017*, Center for Medicaid and Children's Health Insurance Program (CHIP) Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services. Available at medicaid.gov/medicaid/quality-of-care/downloads/sickle-cell-disease-infographic.pdf.

2020*, 2020 Guidelines for Sickle Cell Disease: Management of Acute and Chronic Pain*, American Society of Hematology. Available at ashpublications.org/bloodadvances/article/4/12/2656/460974/American-Society-of-Hematology-2020-guidelines-for.

2021, *Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017*, Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services. Available at medicaid.gov/medicaid/quality-of-care/downloads/scd-rpt-jan-2021.pdf.