

**SICKLE CELL DISEASE  
TREATMENT DEMONSTRATION  
REGIONAL COLLABORATIVES PROGRAM**

*Compendium of  
Tools and Resources*



**SEPTEMBER 2021**

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# Introduction

There are approximately 100,000 people in the United States living with sickle cell disease (SCD). Access to high quality healthcare and services with providers knowledgeable about SCD care is imperative. The Sickle Cell Disease Treatment Demonstration Regional Collaborative Program (SCDTDRCP) is mandated by Congress and funded through the U.S. Health Services Resources Administration (HRSA). More information about the Program can be found in Appendix B of the 2021 Congressional Report.

The materials listed in this compendium offer a range of tools, materials, and resources for providers and care teams in support of the strategies and activities they are using with patients and families to ensure the best quality of life for those with living with SCD. This Compendium of Tools and Materials for SCD resources is the companion piece to the SCDTDRCP 2021 Model Protocol, which details key strategies for improving patient access to high quality care and disease modifying treatments by knowledgeable providers.

## A COMPENDIUM OF HELPFUL TOOLS

All the materials in this compendium are useful tools for providers treating SCD. Some are for sharing with patients to support awareness, self-care management, and shared decision-making. Others are protocols and best practices that primary care, emergent care, and specialists should know and use to serve their Program. During the SCDTDRCP 2018-2021 project, there were many resources and methods for spreading knowledge and awareness of SCD employed.

**Wherever possible, the name of the provider or site contributing the resource is noted in parentheses after the title and link.**

# Provider and Clinician Education and Resources



## Acute Care Resources

### Education Materials and Tools for Providers and Clinics

- [Acute Care Individual Times Tool](#) (OH TDP)
- [Staff training](#): Presentation on sickle cell disease to ED staff (OH TDP)
- [Evaluation survey](#) for presentation to ED staff (OH TDP)
- [CRISIS: Experiences of People with Sickle Cell Disease Seeking Health Care for Pain](#) Video (MD TDP)
- Pediatric ED: [Pain Med Calculator](#) (MA NBSP)
- Pediatric ED: [Nursing In-service - 2012](#) (MA NBSP)
- Pediatric ED: [Nursing In-service - 2014](#) (MA NBSP)
- [APPT Scoring Guide](#) (CA TDP)
- [Fever and Acute Chest Syndrome](#) Best Practices Principles Poster (CA TDP)
- [Priapism in Sickle Cell Disease](#) Best Practices Principles Poster (CA TDP)

### NEED FOR ACUTE CARE RESOURCES

Due to limited general knowledge of sickle cell disease among physicians and lack of access to specialty care, many people with sickle cell disease access medical care through the emergency department. This group of resources and tools is most relevant to providers in the acute care or emergency department setting.

- [CDC's Sickle Cell Data Collection Program: Data Useful in Describing Patterns of Emergency Department Visits by Californians with Sickle Cell Disease \(SCD\)](#)
- [ASH Pocket Guide: Management of Acute Complications of Sickle Cell Disease](#) (University of Illinois, Midwest)
- Sickle Cell Disease Education: [Care of Patients with Sickle Cell Disease for Primary Care Providers and Emergency Room Personnel](#) (Indiana Hemophilia/Thrombosis Center, Inc. (Indiana State STORM))

### Intranasal Fentanyl

- [California SCDTDP ED Protocol for Intranasal Fentanyl](#)
- [ED Protocol Intranasal Fentanyl](#) (CA TDP)
- Pediatric ED: [Intranasal Fentanyl Handout](#) (MA NBSP)
- Kelly GS, Stewart RW, Strouse JJ, Anders JF. Intranasal fentanyl improves time to analgesic delivery in sickle cell pain crises. *American Journal of Emergency Medicine* 2018;36(7):1305-1307

### Pain Action Plans

- [Pain Action Plan](#) - English (CA TDP)
- [Pain Action Plan](#) - Spanish (CA TDP)
- Adult ED: [Individualized Pain Plan](#) (MA NBSP)
- [Individualized Pain Plan for Children with Sickle Cell Disease](#) (PA NBSP/TDP)

### Pain Assessment

- [Sickle Cell Pain Chart](#) (IL TDP)
- [Pain Assessment Scale](#) (NY NBSP)

### Patient-Controlled Analgesia Pumps

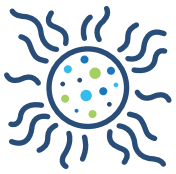
- Pediatric ED: [Patient Controlled Analgesia Handout](#) (MA NBSP)

### Patient Satisfaction Survey

- ED [Patient Satisfaction Survey](#) (MA NBSP)
- [ED Patient Satisfaction Survey](#) (CA TDP)

### Standard Order Sets

- [Acute Chest Syndrome Management Checklist](#) (TN NBSP)
- [Iron Overload Checklist](#) (TN NBSP)
- [Pain Checklist](#) (created by TN NBSP)
- [Stroke Checklist](#) (created by TN NBSP)
- Pediatric ED: [VOE Protocol](#) (MA NBSP)
- [Sickle Cell Pain Initial Order Set Moderate to Severe Pain](#) (CA TDP)
- [Fever in Sickle Cell Disease Algorithm](#) (CA TDP)
- [ED Algorithm for Sickle Cell Disease Pain Management](#) (NJ TDP)
- [Sickle Cell Disease Fever Pathway](#) (Indiana State STORM)
- [Pediatric Sickle Cell Pain Pathway](#) (Indiana State STORM)



## COVID-19

- [Sickle Cell Disease School Letter with COVID updates](#) (Children’s Hospital MN, Midwest)
- [COVID-19 anticoagulation recommendations in children](#) (RCC, Pacific)
- [Safety Measures Checklist for the Re-entry of School During COVID-19](#) (Norton Children’s Medical Group Cancer Institute, Southeast)
- [School Toolkit Cover Letter](#) (Children’s Hospital MN, Midwest)
- [COVID-19 Sickle Cell Registry](#)



## Data Systems

- [Epic EHR Dashboard Elements](#) (Phoenix Children’s Hospital – Phoenix, Pacific)
- [Sickle Cell Trait EHR Counseling Prompt](#) (MA NBSP)



## Educational Materials and Tools for Providers and Clinics

- [Adult Sickle Cell Curriculum](#) (University of Arkansas for Medical Sciences, Heartland/Southwest)
- [Evaluation and Management: Splenic Sequestration](#) (Heartland/Southwest)
- [EMBRACE Presentations](#) (RCC, Southeast)
- [Guidelines to Treat Acute Chest Syndrome \(ACS\)](#) (Heartland/Southwest)
- [Guidelines for Acute Management of Stroke](#) (Heartland/Southwest)

- [Guidelines for Aplastic Crisis](#) (Heartland/Southwest)
- [Guidelines to Treat Fever in SCD](#) (Heartland/Southwest)
- [Perioperative Guidelines for Patients with SCD](#) (Heartland/Southwest)
- [Guidelines for Emergency Treatment of Priapism](#) (Heartland/Southwest)
- [EMBRACE Presentation: Creating a New Sickle Cell Clinic: A Case Study: A few dedicated professionals discuss how and why they created a new county clinic in South Los Angeles](#)
- [Telemedicine Checklist](#) (Medical College of Georgia – Augusta, Southeast)
- [Module: Effective Communication with Patients with Sickle Cell Disease](#)
- [Enhancing Access to Care for Sickle Cell Disease in South Carolina](#) (webinar)
- [Poster Presentation: Provider Bias Training Poster](#) (Jacobi Medical Center, Northeast)

### Hydroxyurea

- [American Society of Hematology’s Hydroxyurea & Transfusion Therapy for Sickle Cell Disease Pocket Guide](#)
- [Boston Medical Center Pediatric Hydroxyurea Dosing Guidelines](#)
- [Hydroxyurea for Sickle Cell Disease: Indications, Dosing and Monitoring Guideline](#) (STORM)
- SiNERGe Webinar: [Helping Patients Adhere to Hydroxyurea Therapy](#)
- SiNERGe Webinar: [A Conversation about Hydroxyurea Part 2](#)
- [EMBRACE presentation: Laboratory and Morphologic Changes During Hydroxyurea Dose Escalation to MTD](#)

### WHAT IS HYDROXYUREA?

The drug hydroxyurea has been life-changing for those who are able to use it (it is not effective for all types of sickle cell disease), yet many people who are eligible are not using hydroxyurea. This group of resources have been used by providers to share information with patients about the benefits and risks of using hydroxyurea.

## Hydroxyurea (continued)

- [Journal Article: Improved Hydroxyurea Effect With the Use of Text Messaging in Children With Sickle Cell Anemia](#) (TN TDP)
- Crosby, L. E., Shook, L. M., Ware, R. E. and Brinkman, W. B. (2015), [Shared decision making for hydroxyurea treatment initiation in children with sickle cell anemia. \*Pediatric Blood & Cancer\*; 62: 184–185. doi: 10.1002/pbc.25124](#)

## Immunizations

- [Vaccinations in SCD](#) (see October 19, 2018)
- [ACH Immunizations by Age](#)
- [NHLBI immunization guidelines](#) (see pg. 29)

## Journal Articles

- [Shook LM, Farrell CB, Kalinyak KA, et al. Translating sickle cell guidelines into practice for primary care providers with Project ECHO®. \*Med Educ Online\*. 2016; 21:33616.](#)
- [Whiteman LN, Haywood C, Lanzkron S, Strouse JJ, Feldman L, Stewart RW. Primary Care Providers' Comfort Levels in Caring for Patients with Sickle Cell Disease. \*South Med J\*. 2015;108\(9\):531-536.](#)

## Pain Management

- [ED Pain Management Protocol \(Adult\)](#) (Jacobi Medical Center, Northeast)
- [Pediatric Pain Medication Algorithm](#) (Jacobi Medical Center, Northeast)
- [Sickle Cell Pain in the Emergency Department: A Guide to Improving Care](#) (NICHQ)

## Point-of-Care Resources

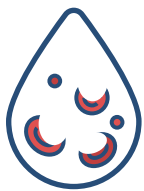
- [Electronic evidence-based, primary care Platform: Dynamed Plus](#)
- [Online global medical news: Medscape](#)
- [Evidence-based, point-of-care clinical decision support system: Essential Evidence Plus](#)
- [STORM HU Clinical Decision Tool](#) (contact [storm@cchmc.org](mailto:storm@cchmc.org) for information)

## Project ECHO®

- [Sickle Cell Treatment & Outcomes Research in the Midwest TeleECHO Clinics](#)
- [STORM TeleECHO Clinic Pamphlet](#)
- [Project ECHO for Sickle Cell Disease \(SiNERGE\)](#)
- [SCD Training and Mentoring Program \(STAMP\) \(PSCRC\)](#)
- [Washington University School of Medicine TeleECHO clinic](#)
- [Journal Articles](#)
  - [Shook LM, Farrell CB, Kalinyak KA, Nelson SC, Hardesty B, Saving K, Whitten-Shurney W, Panepinto J, Crosby LE, and Ware RE.\(2016\) Using Telementoring to Improve Sickle Cell Disease Care in the Midwest, \*Medical Education Online\*, Nov 24;21:33616. 27887664](#)

## Trait Resources

- [Sickle Cell Trait Pre-Clinic Review](#) (IL TDP)
- [Sickle Cell Trait Provider CME Training](#) (MA NBSP)
- [Screening and Trait Counseling Screening Algorithm](#) (MA NBSP)



## General Sickle Cell Disease

- [Health Maintenance and Management of Chronic Complications of Sickle Cell](#) (University of Illinois, Midwest)
- [Management of Acute Complications of Sickle Cell Disease](#) (University of Illinois, Midwest)
- [Sickle Cell Issue Awareness Guide for Providers](#) (University of Illinois, Midwest)
- [SCDAA 2018-2019 Annual Report](#) (Children's Hospital of Michigan – Michigan, Midwest)
- [Educational Presentation on SCD for Primary Care Providers](#) (Children's Hospital of Michigan – Michigan, Midwest)
- [Setting Up a Comprehensive SDC Clinical Program](#) (RCC, Southeast)
- [Help Advance Care for Sickle Cell - Image](#) (Heartland/Southwest)
- [PhenX Toolkit](#)
- [REDCap](#)
- [Texas State Action Plan](#) (Baylor College of Medicine / Texas Children's Hospital, Heartland/Southwest)
- [Pacific RCC State Action Plans](#)
- [Heartland/Southwest State Action Plan](#)
- [Arkansas State Action Plan](#)
- [Iowa State Action Plan](#)
- [Kansas State Action Plan](#)
- [Louisiana State Action Plan](#)
- [Missouri State Action Plan](#)
- [Nebraska State Action Plan](#)
- [Oklahoma State Action Plan](#)

- [Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action](#) (NASEM)
- [Evidence Based Management of Sickle Cell Disease: Expert Panel Report, 2014](#) (NHLBI, NHI)

### Regional Coordinating Centers SCDTDP 2014-2017

- [Sickle Cell Treatment and Outcomes Research in the Midwest](#) (STORM)
- [Pacific Sickle Cell Regional Collaborative](#) (PSCRC)
- [Sickle Cell Improvement in the Northeast Region through Education](#) (SiNERGe)

### Websites

- [American Society of Hematology](#) (Sickle Cell)
- [Centers for Disease Control and Prevention](#) (Sickle Cell)
- [National Heart Lung and Blood Institute](#)
- [National Institute for Children's Health Quality](#)
- [Sickle Cell Disease Association of America](#)
- [American Sickle Cell Anemia Association](#)
- [Sickle Cell Information Center at Emory](#)
- [Sickle Cell Disease Coalition](#)
- [California Sickle Cell Resources](#)
- [PCORI Sickle Cell Project](#)
- [Cincinnati Children's: Sickle Cell Trait](#)
- [Heartland Sickle Cell Disease Network](#)



## Health Maintenance and Tracking

- [Adult Patient Tracking Log](#) (IL TDP)
- [Care Coordination Checklist](#) (IL TDP)
- [Form D.113B.1: Red Blood Cell Exchange and Depletion Standing Orders](#) (RCC, Southeast)
- [BEARS Sleep Screening Tool](#) (Norton Children's Medical Group Cancer Institute, Southeast)
- [Health Maintenance Form](#) (NJ TDP)
- [Pre-appointment Planning Worksheet](#) (University of Illinois, Midwest)
- [Sickle Cell Dashboard Infographics](#) (RCC, Southeast)
- [Sickle Cell Disease Clinic Worksheet](#) (IL TDP)
- [SMART Phrase: Quick summary of relevant sickle cell disease management facts](#) (OH TDP)
- [Colorado Learning Difficulties Questionnaire](#)
- [Transcranial Doppler \(TCD\) Quality Improvement Protocol](#) (Medical College of Georgia – Augusta, Southeast)



## Local Electronic Health Registries

- [SCDTDP Minimum Data Set Data Dictionary](#) (2014-2017)
- [PSCRC Minimum Dataset](#)
- [PSCRC Enrollment and Annual Update Form](#)
- [PSCRC Abbreviated Provider Form](#)
- [COVID-19 Specific SCD Registry](#)



## Mental Health Screening

- [Depression Checklist](#) (TN NBSP)
- [Mental Health Referral Protocol](#) (MO TDP)
- [Patient Referral Satisfaction Survey - Mental Health Services](#) (MO TDP)
- [Mental Health Referral Flowchart](#) (MO TDP)
- [Patient Health Questionnaire - Depression Screening](#) (PHQ9 Copyright © Pfizer Inc. All rights reserved. Reproduced with permission. PRIME-MD® is a trademark of Pfizer Inc.)



## Miscellaneous Journal Articles

- Ballas SK, Vichinsky EP. [Is the Medical Home for Adult Patients with Sickle Cell Disease a Reality or an Illusion?](#) *Hemoglobin*. 2015;39(2):130-133. doi:10.3109/03630269.2015.1023312.
- Hsu LL, Green NS, Donnell Ivy E, et al. [Community health workers as support for sickle cell care.](#) *Am J Prev Med*. 2016;51(1):S87-S98. doi:10.1016/j.amepre.2016.01.016.





## Pain Management and Health Risks

- [Inpatient Sickle Cell Pain Management Guidelines Presentation](#) (Heartland/Southwest)
- [Emergency Room Pain Algorithm](#) (Heartland/Southwest)
- [Yoga and Mindfulness for Pediatric Inpatients](#) (Heartland/Southwest)
- [Wong-Baker FACES Pain Rating Scale](#)<sup>®</sup>
- [Pain Treatment Guideline](#) (Oregon Health and Science University, Northeast)



## Patient Communication

- [CAMC Sickle Cell Clinic Postcard](#) (Charleston Area Medical Center / West Virginia, Northeast)
- [AHA Sickle Cell - Save the Date 2019](#) (Phoenix Children's Hospital – Phoenix, Pacific)
- [HRSA Telemedicine Patient Survey](#) (Heartland/Southwest)
- [WSCD 2020 Flyer](#) (Phoenix Children's Hospital – Phoenix, Pacific)
- [Pacific Sickle Cell Regional Collaborative Website](#) (Pacific)
- [Regional Updates Newsletters](#) (Pacific)



## Patient Education (Family)

- [The Hope and Destiny Book](#)
- [Authorization for Release of Information Document](#) (Children's Hospital MN, Midwest)
- [Sickle Cell Trait Knowledge Tool](#) (TN NBSP)
- [The Talking Drums Project Community Survey](#) (CA TDP)
- [Readiness Assessment for Parents](#) (Got Transition<sup>®</sup>)
- [Readiness Assessment for Youth](#) (Got Transition<sup>®</sup>)

### Hydroxyurea

- [Keeping You Healthy with Sickle Cell Disease. An educational kit addressing knowledge/beliefs on the use of hydroxyurea](#) (MA NBSP)
- [Treating sickle cell disease: Is hydroxyurea right for your child? \(English\)](#) (PSCRC, STORM, Heartland SCD Network) ([Spanish](#); [French](#))



## Quality Improvement

- [Quality Improvement: Change Packet](#) (RCC, Southeast)
- [Cabana MD, Marsh A, Treadwell MJ, Stemmler P, Rowland M, Bender MA, Bhasin N, Chung JH, Hassell K, Rashid NN, Wong TE. Improving Preventive Care for Children With Sickle Cell Anemia: A Quality Improvement Initiative. Pediatric quality & safety. 2021 Jan;6\(1\).](#)



## Transition

- [Transition Research Brief](#) (Jacobi Medical Center, Northeast)
- [Sickle Cell Transition Curriculum](#) (RCC, Southeast)
- [Got Transition<sup>®</sup> Toolkit](#)  
(National Health Care Transition Family Advisory Group)
- [Florida Health and Transition Services](#)
- [A Program of Transition to Adult Care for Sickle Cell Disease](#)  
Journal Article (ASH)
- [Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents with Sickle Cell Disease, includes Topics, Methods, and Efficacy Measurements \(PDF\)](#) Journal Article (WISCH)
- Journal Articles
  - [Crosby, L. E., Quinn, C. T., & Kalinyak, K. A. \(2015, April 1\). A Biopsychosocial Model for the Management of Patients With Sickle-Cell Disease Transitioning to Adult Medical Care. \*Advances in Therapy\*. Springer Healthcare.](#)
  - Treadwell M, Johnson S, Sisler I, et al. Development of a sickle cell disease readiness for transition assessment. *Int J Adolesc Med Health*. 2016;28(2):193-201. doi:10.1515/ijamh-2015-0010
  - Treadwell M, Johnson S, Sisler I, et al. Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *Int J Adolesc Med Health*. 2015;2015(4):381-388. doi:10.1515/ijamh-2015-0014.



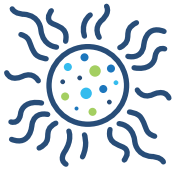
## Webinar Series

- [Making a Smooth Transition from Pediatric to Adult SCD Care: Eliminating Barriers, Enhancing Resources Part I & II \(Webinar Series\)](#) (SiNERGe)
- [CDC's Sickle Cell Data Collection Program: Data Useful in Describing Patterns of Emergency Department Visits by Californians with Sickle Cell Disease \(SCD\)](#) (PSCRC)
- [Genotyping in Hemoglobin Disorders Webinar](#) (STORM)

# Patients and Caregivers

## EDUCATION AND RESOURCES

People living with sickle cell disease often have multiple and complex medical needs, so it is ideal to be able to coordinate care among various specialties. This group of resources is useful for providers, patients, caregivers and representatives of community-based organizations who are involved in coordinating care for patients.



## COVID-19

- [COVID-19 Handout](#) (Heartland/Southwest)
- [COVID-19 Infographic](#) (RCC, Southeast)
- [School Reopening MARAC Recommendations](#) (Children's Hospital MN, Midwest)
- [COVID Tip Sheet](#) (Children's Hospital MN, Midwest)
- [School is Closed Tip Sheet](#) (Children's Hospital MN, Midwest)



## Health Maintenance and Tracking

- [Care Coordination Screening Tool](#) (IL TDP)
- [Well Sickle Checklist](#) (NY NBSP)
- [Patient Event Diary](#) (NY NBSP)
- [Patient Needs Assessment](#) (IL TDP)
- [Sickle Cell Daily Activity Worksheet](#) (Heartland/Southwest)
- [Sickle Cell Disease Youth Acute Pain Functional Ability Questionnaire](#) (Heartland/Southwest)



## Living with SCD (Patients)

- [Yoga and Mindfulness](#) (Heartland/Southwest)
- [Patient Empowerment Toolkit and Instructions for Use](#)  
For questions, [contact Patient Support](#) (Children's Hospital of Michigan – Michigan, Midwest)
- [Tips for Supporting Students with Sickle Cell Disease](#) (CDC)
- [Living Well with Sickle Cell Disease: Tips for Healthy Living](#) ([English](#); [Spanish](#)) (CDC)
- [5 Tips to Prevent Infection](#) (CDC)
- [SAFER Card](#) (Children's Hospital of Michigan – Michigan, Southwest)
- [What You Should Know About Sickle Cell Disease: Nine Steps to Living Well with Sickle Cell Disease in College](#) (CDC)



## Miscellaneous Journal Articles

- Ballas SK, Vichinsky EP. [Is the Medical Home for Adult Patients with Sickle Cell Disease a Reality or an Illusion?](#) *Hemoglobin*. 2015;39(2):130-133. doi:10.3109/03630269.2015.1023312.
- Hsu LL, Green NS, Donnell Ivy E, et al. [Community health workers as support for sickle cell care.](#) *Am J Prev Med*. 2016;51(1):S87-S98. doi:10.1016/j.amepre.2016.01.016.



## Patient Communication

- [Local Resources for Patients with SCD](#) (Phoenix Children's Hospital – Phoenix, Pacific)
- [Pacific Sickle Cell Regional Collaborative Website](#) (Pacific)
- [Regional Updates Newsletters](#) (Pacific)



## Patient Education

- [Pregnancy During Sickle Cell](#) (Heartland/Southwest)
- [Risk of Stroke in Children with SCD](#) (Southeast)
- [Sickle Stroke Screen Pamphlet](#) (Southeast)
- [Disease Education Materials](#)  
(Norton Children's Medical Group Cancer Institute, Southeast)
- [Sickle Cell Disease: Avascular Necrosis \(AVN\)](#)  
(Children's Hospital St. Louis, Heartland SCD Network)
- [Sickle Cell Disease: Bedwetting \(nocturnal enuresis\)](#)  
(Children's Hospital St. Louis, Heartland SCD Network)
- [Sickle Cell Disease: Retinopathy](#)  
(Children's Hospital St. Louis, Heartland SCD Network)
- [Sickle Cell Disease: Gallstones](#)  
(Children's Hospital St. Louis, Heartland SCD Network)
- [Sickle Cell Disease: Priapism](#)  
(Children's Hospital St. Louis, Heartland SCD Network)
- SCD Fact Sheet: What you should know about sickle cell disease  
([English](#)) (CDC) ([French](#))

### Hydroxyurea

- [Hydroxyurea Brochure](#)  
(Children's Hospital of Michigan – Michigan, Midwest)
- [Hydroxyurea White board](#)  
(Children's Hospital of Michigan – Michigan, Midwest)
- [St. Jude Informative Hydroxyurea Pamphlet](#) (St. Jude, Southeast)
- [Hydroxyurea Recurring Brochure](#) (Cincinnati Children's Hospital, Midwest)



## Screening and Trait Resources

### Educational and Counseling Strategies

- [Genes for Teens Brochure](#) (TN TDP)
- [Genes for Parents of Children with Sickle Cell Disease](#) (TN TDP)
- [Trait Counseling Educational Booklet and Presentation](#) (MO TDP)
- [Sickle Cell Trait Counseling Handout](#) (MA NBSP)
- [Sickle Cell Trait Presentation for the Community](#) (MA NBSP)
- [A Parents' Guide to Sickle Cell Disease](#) (MA NBSP)
- [A Parents' Guide to Sickle Cell Trait](#) (MA NBSP)
- [Get Screened to Know Your Sickle Cell Status](#) ([English](#)) (CDC) ([Spanish](#); [French](#))
- [What you should know about Sickle Cell Trait](#) ([English](#)) (CDC) ([Spanish](#); [French](#))
- [What you should know about SCD and Pregnancy](#) ([English](#)) (CDC) ([Spanish](#); [French](#))

### SICKLE CELL TRAIT

Though carriers of the sickle cell trait do not have the same symptoms as those with sickle cell disease, it is important for individuals to know their status and how it can impact them and their families. Individuals often become aware of their status through community health fairs or during pregnancy, when screening for sickle cell disease and general education are offered. This group of resources can be used by providers to educate patients about sickle cell disease, sickle cell trait, and screening.

- [Cincinnati Children's Hospital: Sickle Cell Trait](#) (STORM)
- [Sickle Cell Disease: Contraception](#) (Children's Hospital St. Louis, Heartland SCD Network)
- [Sickle Cell Disease: Pregnancy and Sickle Cell Disease](#) (Children's Hospital St. Louis, Heartland SCD Network)

### Pre- and Post-Tests

- [Pre- and Post-Test for Genetic Counseling and Education](#) (IL NBSP)

### Other

- [Sickle Cell Trait Toolkit](#) (CDC)



## Transition

- [Health Care Transition Timeline for Parents and Caregivers](#) (Got Transition<sup>®</sup>)
- [St. Jude E-learning Transition Platform](#) (Southeast)
- [Pediatric to Adult Health Care Transition: A Family Toolkit](#) (Got Transition<sup>®</sup>)
- [Sickle Cell Transition from age 13 to 15](#) (Johns Hopkins All Children's Hospital, Northeast)
- [Sickle Cell Transition from age 16 to 18](#) (Johns Hopkins All Children's Hospital, Northeast)
- [Sickle Cell Transition from age 19 to 21](#) (Johns Hopkins All Children's Hospital, Northeast)
- [Transition Binder](#) (Children's Hospital MN, Midwest)



## Webinar Series

- [Webinar: Blood Transfusions & Iron Overload](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Understanding Your CBC](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Blood Transfusions & Blood Matching](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Blood Transfusions: How, When, Why](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Hydroxyurea & Sickle Cell Adults](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Hydroxyurea & Sickle Cell Children](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Diagnosis & Treatment of Acute Chest Syndrome](#) (Sickle Cell Community Consortium (SC3), Southeast)
- [Webinar: Bone Health & Avascular Necrosis](#) (Sickle Cell Community Consortium (SC3), Southeast)

These resources were developed through the Sickle Cell Treatment Demonstration Regional Collaboratives Program (2017-2021). As the National Coordinating Center for this regional collaborative, NICHQ freely shares guidance, tools, and resources that teams from around the country have created, tested, or used to improve care for patients with sickle cell disease.

**Source:** National Institute for Children's Health Quality (NICHQ)

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