



September is National Infant Mortality Awareness Month! [Find out more](#) about

NICHQ's work to reduce infant mortality and how you can be involved as a public health professional or family/caregiver advocate.



## September is for Sickle Cell Awareness

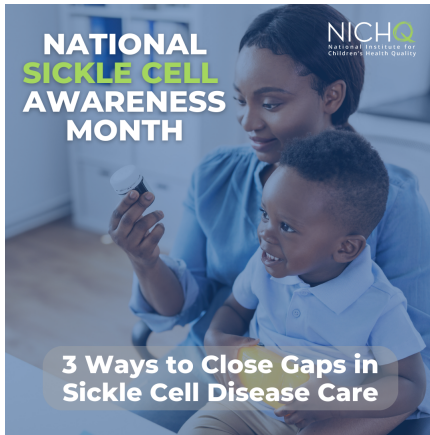
Each September, we join the chorus of families and community-based organizations that support them in raising awareness about sickle cell disease (SCD).

### FAST FACTS ABOUT SICKLE CELL

1. About **1 in 13** African Americans carry the sickle cell trait.
2. There are approximately **2,000** babies born with SCD annually in the U.S.
3. Most states screen for SCD along with **29 of the 35** conditions recommended by the Advisory Committee on Heritable Disorders in Newborns and Children.

NICHQ joins the Sickle Cell Disease Association of America (SCDAA) to help focus attention on the need for research and treatment of sickle cell disease during September. The theme for 2023 is Sickle Cell Matters.

Sickle cell disease (SCD), an inherited blood disorder that is more prevalent in people of African and Latinx/Hispanic descent, affects approximately 100,000 Americans, and sickle cell trait affects an estimated 2 million individuals. People living with SCD experience acute pain crises, dangerous infections, and other serious health problems that can damage every organ in the body, requiring providers who are knowledgeable and understanding.



NICHQ has been committed to improving care for patients with

SCD for more than 10 years, including being the National Coordinating Center (NCC) for a recently funded Health Resources and Services Administration (HRSA) project, the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program (SCDTDRCP). [Read recommendations from NICHQ projects for strategies to close gaps in SCD care.](#)

As we continue our work to ensure that all children achieve their optimal health, NICHQ is dedicated to creating opportunities for healthcare providers to improve treatment and care for people living with this complex condition.

Join our efforts to bring attention to the unique experiences and challenges of people living with SCD and the variety of resources available to health care professionals! Use the hashtags #SickleCellAwarenessMonth and #SickleCellMatters2022 to help raise awareness on social media about sickle cell disease and sickle cell trait, and check out these helpful tools and resources.

## Resources for SCD Care Providers



### **Reducing Missed Appointments**

According to a 2019 national study, a majority of patients reported missing a clinic appointment in the previous 12 months. NICHQ interviewed patients, caregivers, and providers – and [found](#) that systemic and individual bias and racism contributed to poor patient/provider relationships, which undermined solutions to appointment attendance problems.

NICHQ developed a collection of [helpful resources to improve appointment challenges](#).



### **NICHQ Report to Congress, Model Protocol, and More**

- In 2021, NICHQ released a comprehensive [Report to Congress](#) that detailed findings from the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program. Check out the [impact of coordinating centers](#) that served people across the nation living with sickle cell disease.
- 
- Read a [Model Protocol](#) that includes best practices for caring for people with sickle cell disease and details strategies and lessons learned from the 2017-2021 SCDRCTDP.
- Browse a [Compendium of Tools and Materials](#) that share helpful resources and promising practices for improving sickle cell disease support.



### **Learn On Demand**

Check out an engaging, interactive webinar series where we share our findings from interviews with patients and providers, and panelists model conversations among providers, families, and advocates about reasons for and solutions to missed sickle cell disease healthcare appointments.

- Webinar 1: [Increasing Appointment Attendance: A Vital Opportunity to Improve Health Outcomes for Those Living with Sickle Cell Disease](#)
- Webinar 2: [Conversations to Improve Patient/Provider Relationships and Increase Appointment Attendance](#)
- Webinar 3: [Connecting Providers and Community-Based Organizations to Improve SCD Appointment Attendance](#)

### **Attend SCDA's Social Parties**

Follow [@NICHQ](#) and join the conversation with [@SCDAOrg](#) on X on September 18, 20 and 22 as they partner with advocacy, corporate and federal organizations to share victories and exciting information about the latest happenings in the sickle cell community. Together, we will use this time to learn and celebrate with others across the country.

### **Share on Social Media**

Join us and fellow SCD advocates in celebrating National Sickle Cell Awareness Month on social media. We've compiled a social media toolkit with ready-to-use graphics and copy to help you

get started. [Access our online toolkit](#), share on your social accounts, and tag @NICHQ so we can amplify your reach. Be sure to include the hashtags #SickleCellAwarenessMonth and #SickleCellMatters2023 with your posts!



## NICHQ's Work in Sickle Cell Disease

NICHQ's work supporting access to care, use of disease-modifying therapies, and quality improvement in sickle cell disease has spanned decades. Here are our most recent projects that focus on SCD.

- [Improving Sickle Cell Disease Care: Hemoglobinopathies National Coordinating Center \(HNCC\)](#)
- [Sickle Cell Disease Treatment Demonstration Regional Collaborative Program National Coordinating Center](#)
- [Disseminating Results: Missed Sickle Cell Disease Clinic Appointments and the Health Belief Model](#)



## National Newborn Screening Month

Newborn screening is an essential public health service that screens babies for serious but treatable medical conditions – empowering families and caregivers to seek support. One of the most important parts of mitigating negative health impacts for those living with SCD is to start monitoring and disease-modifying therapies early on. Newborn screening has a strong connection to improving children's health outcomes.

**Most states screen for 29 of the 35 conditions** recommended by the [Advisory Committee on Heritable Disorders in Newborns and Children](#), including sickle cell and other rare diseases. Although these conditions are rare, each year more than 5,000 babies are identified with a newborn screening condition.

**Now available in Spanish!** Explore [HRSA's Newborn Screening Information Center](#). NICHQ partnered with a national expert in newborn screening to develop the website, which delivers general as well as state-specific newborn screening information.

Use our helpful action kit for [Improving Follow-Up After Newborn Screening](#).