



September is Infant Mortality Awareness Month! [Click here](#) to learn more.



## National Sickle Cell Awareness Month

September is National Sickle Cell Awareness Month — a month designated by Congress to help focus attention on the need for research and treatment of sickle cell disease. This September, join NICHQ and the Sickle Cell Disease Association of America in recognizing National Sickle Cell Awareness Month, celebrating this year's theme, Sickle Cell Matters 2021. As we continue our work to ensure that all children achieve their optimal health, NICHQ is dedicated to finding innovative responses to the complex health challenges people living with SCD face and creating opportunities for healthcare providers to improve treatment and care.

### **SEPTEMBER IS ALSO NEWBORN SCREENING AWARENESS MONTH**

This month is also an opportunity to share about the connection of newborn screening to children's health outcomes. Newborn screening is an essential public health service that screens babies for serious but treatable medical conditions.

**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.

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](#).

## Help NICHQ Raise Awareness and Improve Care for Patients Living with Sickle Cell Disease

Sickle Cell Disease (SCD), an inherited blood disorder that is more prevalent in individuals of African and Latinx/Hispanic descent, affects approximately 100,000 Americans. 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.

### FAST FACTS ABOUT SICKLE CELL

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

In addition to managing pain and navigating other health challenges, people living with SCD and their families and family caregivers are also often faced with overcoming barriers that lead to missed appointments and reduced quality of care.

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 [#SickleCellMatters2021](#) and [#SickleCellAwarenessMonth](#) to help raise awareness on social media about sickle cell disease and sickle cell trait, and check out the below learning opportunities, discussion guides, and other helpful tools and resources about sickle cell disease.

### [NEW: 9/28 Webinar for Providers](#)

Registration is officially open for our upcoming webinar focusing on developing a strong relationship between sickle cell disease clinics and community organizations that support people living with SCD. [Register today](#) to learn strategies for providers and SCD CBOs to work together to improve conversations and resolve appointment barriers for patients and caregivers.

### View Previous SCD Webinars

Ready to start learning now? Check out the [first](#) and [second](#) webinars in this engaging, interactive series where we share our findings from a series of 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.



## **NEW RESOURCES**

Healthcare professionals can use these newly created discussion guides to help facilitate better conversations with patients.

- [Guide for Community-Based Organizations](#)
- [Guide for Providers to Use with Patients](#)

## **Reducing Missed SCD Appointments and Improving Patient/Provider Relationships**

People living with SCD and their families and caregivers miss critical healthcare appointments for a variety of reasons. According to a 2019 national study, a majority of patients reported missing a clinic appointment in the previous 12 months.

In [disseminating the study results](#), NICHQ interviewed patients, caregivers, and providers – and found that systemic and individual bias and racism contributed to poor patient/provider relationships, which in turn undermined solutions to appointment attendance problems.

While the relationship between patients or caregivers and their providers is not the main problem, improving that partnership can be a big part of the solution.



## Reporting to Congress

As we push to enhance access to services for people living with Sickle Cell Disease and improve and expand provider and patient education, [NICHQ is working with five regional teams from across the country](#) to deliver a comprehensive report to Congress detailing outcomes from the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program.

This project will also produce a Model Protocol that details strategies and lessons learned for improving sickle cell disease care, as well as a Compendium of Tools and Materials that share promising practices for improving sickle cell disease support.