

## Case Studies

# Fostering Better Outcomes for Treating Sickle Cell Disease

From 2014-2017, NICHQ served as the National Coordination Center for the [Sickle Cell Disease Treatment Demonstration Program](#), an initiative funded by the Health Resources Services Administration. NICHQ worked with four regional coordinating centers to: improve access to care by increasing the number of providers treating patients with SCD; increase the number of providers prescribing hydroxyurea; and increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD.

Approximately 100,000 Americans live with sickle cell disease (SCD). Those with the inherited blood disorder face a lifelong battle with pain, infection and other serious health problems that can affect every organ in the body. Previously considered a pediatric condition, medical advancements and improvements in care mean children with SCD are now living into adulthood. However, due to an insufficient number of specialized medical centers and trained providers, many with SCD struggle to receive quality healthcare across their lifespan.

## Our Approach

NICHQ's efforts as the National Coordinating Center (NCC) marked the first time in U.S. history that improvements in SCD care were tackled on a large, regional and national scale. This effort launched an innovative approach where each Regional Coordinating Center (RCC)—Heartland, Midwest, Northeast and Pacific—developed regional networks of care and implemented unique strategies to increase provider knowledge around SCD. NICHQ led network-wide measurement activities and coordinated the sharing of best practices for all improvement work. Alongside collecting national data, NICHQ developed common measures for RCCs to compare data captured in state “registries,” ensuring that results could be measured collectively and comparatively.

## The Results

As a result of the initiatives:

- Four new SCD regional clinics opened in high need areas
- All four regions increasing hydroxyurea use—a treatment therapy—among patients with SCD
- Over 200 providers engaging in telehealth and telementoring sessions
- Nearly 7,000 patients with SCD contributed information to electronic health registries
- Nearly 11,000 patients with SCD received care through SCDTDP regional networks, reflecting a nearly 30 percent increase in those receiving care
- Developed a Compendium of Tools and Materials with promising practices and strategies for improving sickle cell disease support. [Find out more.](#)
- Created a model protocol of high-leverage changes that lead to process improvements, for clinicians, nurses, allied health professionals, community-based organizations and public health agencies. [Find out more.](#)

Read the full 2017 Congressional Report [here](#).



## **Results Webinar: Strategies and Next Steps for Improving Sickle Cell Disease**

Find out lessons learned and recommendations stemming from this national program focused on improving the quality and access to care for patients with sickle cell disease. Grantees shared their on-the-ground efforts to create systems change and make a difference in the lives of children and adults with sickle cell disease.

[Click here](#) for a free webinar recording.



## **Impact**

The effort's success is defined not only by its initial results, but by the enduring impact it will have on the SCD community through the systems it put in place. Thousands more patients with SCD are already receiving quality care and hundreds of providers now have the confidence and skills to provide quality treatment. The resources, clinics, learning centers and networks now available ensure sustained improvement. As the number of knowledgeable providers continues to grow and barriers to care are removed, the amount of SCD patients benefiting from quality, coordinated care will continue to multiply.

**Looking for a change agent to enhance your initiative?**

**Contact us to get started!**