

# SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM

2014 - 2017

Approximately 100,000 Americans live with sickle cell disease (SCD). One out of every 365 African American children are born with SCD each year.<sup>†</sup> For much of the 20th century, SCD was considered a pediatric condition, as individuals with SCD did not survive into adulthood. However, with medical advancements and improvements in care, most people with SCD are now living into adulthood. Despite these gains, people living with this illness face a lifelong battle with pain, infection and other serious health problems that can affect every organ in the body.

The Sickle Cell Disease Treatment Demonstration Program (SCDTDP) was funded by Congress in 2004 to improve the care of patients with SCD. In the most recent 2014-2017 SCDTDP award, the National Institute for Children's Health Quality (NICHQ) ran the SCDTDP National Coordinating Center (NCC). As the NCC, NICHQ led network-wide measurement activities and coordinated the sharing of best practices for improvement work done by the four SCDTDP-funded Regional Coordinating Centers.

Specifically, the SCDTDP project aims were 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.



**NICHQ**  
National Institute for  
Children's Health Quality

## MAKING AN IMPACT

### Access to Care

Nearly 11,000 patients with SCD received care by SCDTDP regional networks, reflecting an increase of more than 3,000 patients from baseline.

Four states opened clinics in areas of high need. More than 1,000 more adults have access to high quality care with the newly opened Adult Sickle Cell Clinic at the Martin Luther King, Jr. Outpatient Center in Los Angeles.

### Hydroxyurea Use

#### HEARTLAND

Pediatric patients: 12% to 20%  
Adult patients: 14.3% to 17.3%

#### MIDWEST

All patients: 48% to 69%

#### NORTHEAST

Pediatric patients: 23% to 34%  
Adult patients: 16% to 18%

#### PACIFIC

All patients: 29% to 42%

### Knowledgeable Providers

Telementoring and telehealth initiatives increased provider knowledge across the country.

Nearly 100 Project ECHO® clinics were held expanding opportunities for provider education for more than 200 providers.

<sup>†</sup> Sickle Cell Disease (SCD) Data & Statistics. Centers for Disease Control and Prevention; 2016. <http://www.cdc.gov/ncbddd/sicklecell/data.html> Accessed March 2017.

## ACCOMPLISHMENTS

**Heartland Regional Coordinating Center** (IA, KS, MO, NE) established telementoring programs for healthcare providers to address geographic disparities in care access.

<https://sicklecell.wustl.edu>

**Midwest Regional Coordinating Center** (IL, IN, MI, MN, OH, WI) addressed gaps that affect care, including setting up satellite clinics that connected patients and local providers to staff and resources at larger medical systems with SCD expertise.

<http://sicklestorm.org>

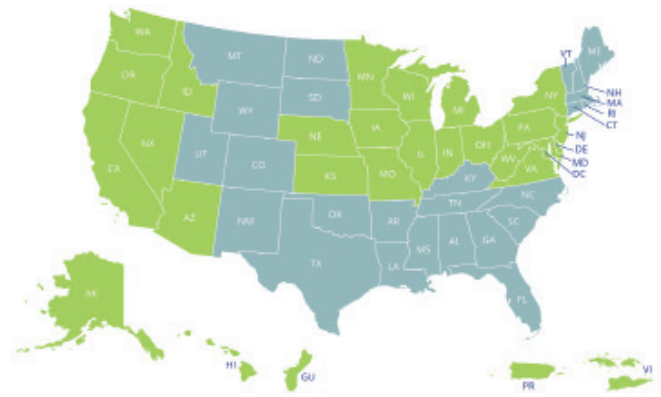
**Northeast Regional Coordinating Center** (DC, MD, NJ, NY, VA, PA, DE, WV, Virgin Islands, Puerto Rico) developed strong relationships with community-based organizations both in individual states and at the regional level to increase patient access to SCD care.

<http://www.hopkinsmedicine.org/Medicine/sickle>

**Pacific Regional Coordinating Center** (AK, AZ, CA, ID, HI, OR, NV, WA, Guam) increased patient access to care with the opening of two new comprehensive centers for SCD care in key urban areas targeting larger concentrations of patients with SCD.

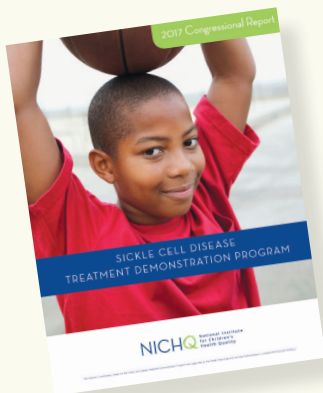
<http://pacificscd.org>

## 2014-2017 SCDTDP Regions/States Covered



■ SCDTDP states

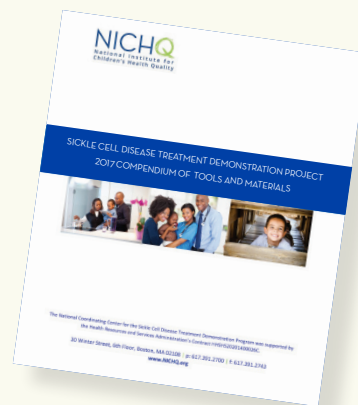
## RESOURCES



### Congressional Report

This report to Congress synthesizes the results and recommendations of the Sickle Cell Disease Treatment Demonstration Program.

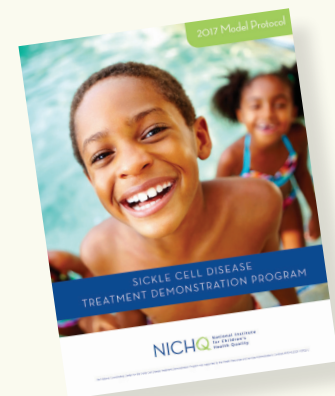
[www.nichq.org/resource/congressional-report-2017](http://www.nichq.org/resource/congressional-report-2017)



### Compendium of Tools and Materials

This compendium identifies promising practices and strategies used by Regional Coordinating Centers to implement changes in their health systems related to improving access to care, increasing use of Hydroxyurea and provider education.

[www.nichq.org/resources/compendium-resources-2017](http://www.nichq.org/resources/compendium-resources-2017)



### Model Protocol

The model protocol provides clinicians, nurses, allied health professionals, community-based organizations and public health agencies with recommendations and strategies to improve care provided to individuals with sickle cell disease.

[www.nichq.org/resources/model-protocol-2017](http://www.nichq.org/resources/model-protocol-2017)