

Impact Statement

Approximately 100,000 Americans live with sickle cell disease (SCD). One out of every 365 African American children are born with SCD each year, making it one of the most common serious genetic disorders in the United States.¹ 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 SCDDTP award, the National Institute for Children's Health Quality (NICHQ) ran the SCDDTP 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 SCDDTP-funded Regional Coordinating Centers (RCCs).

Specifically, the SCDDTP 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 (HU); 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

All four regions report increases in HU use.

Heartland

Child patients: 12% to 20%

Adult patients: 14.3% to 17.3%

Midwest

All patients: 48% to 69%

Northeast

Child patients: 23% to 34%

Adult patients: 16% to 18%

Pacific

All patients: 29% to 42%

Four states across the country opened clinics for treatment and care of patients with SCD in areas of high need.

In California, more than 1,000 patients with SCD have access to high quality SCD care with the newly opened Adult Sickle Cell Clinic at the Martin Luther King, Jr. Outpatient Center in Los Angeles.

Telementoring and telehealth initiatives increased provider knowledge around treatment of SCD across the country.

More than 200 providers were trained and supported in their care of patients with SCD.

95 Project ECHO^{®2} clinics were held across the country expanding opportunities for provider education.

¹ Sickle Cell Disease (SCD) Data & Statistics. Centers for Disease Control and Prevention; 2016. <https://http://www.cdc.gov/ncbddd/sicklecell/data.html>. Accessed March 2017.

² Project ECHO[®]. 2017; <https://echo.unm.edu>. Accessed Aug. 15, 2017.

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Sickle Cell Disease Treatment Demonstration Program

ACCOMPLISHMENTS

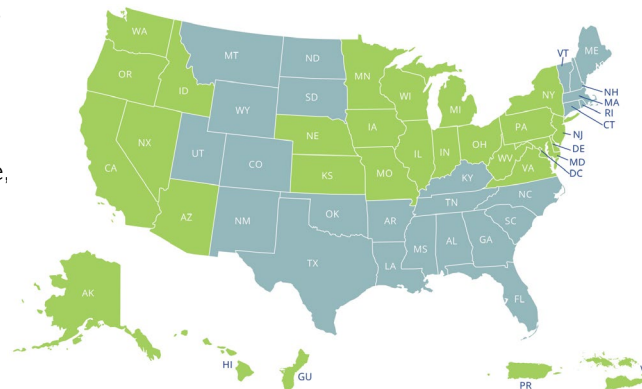
Heartland RCC (IA, KS, MO, NE) established telementoring programs for healthcare providers to address geographic disparities in care access. <https://sicklecell.wustl.edu/>

Midwest RCC (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 RCC (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/index.html>

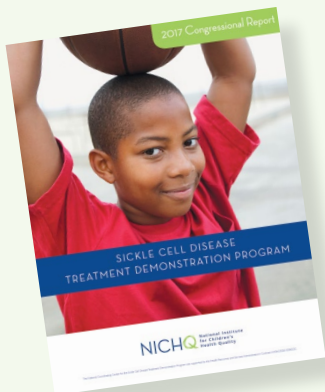
Pacific RCC (AK, AZ, CA, ID, HI, OR, NV, WA, Guam) increased patient access to care with the opening of two new comprehensive centers for SCD care in key urban areas targeting larger concentrations of patients with SCD. <http://pacificscd.org/>

2014-2017 SCDTDP Regions/States Covered



Resources

Learn more from these SCDTDP resources:



Congressional Report

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

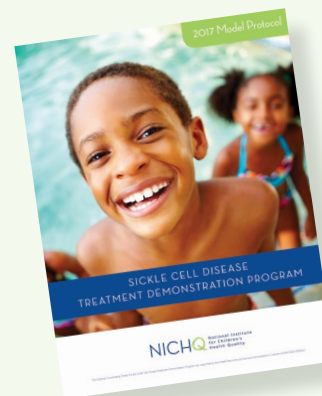
www.nichq.org/resource/congressional-report-2017



Compendium of Tools and Materials

This compendium identifies promising practices and strategies used by RCCs 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



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