

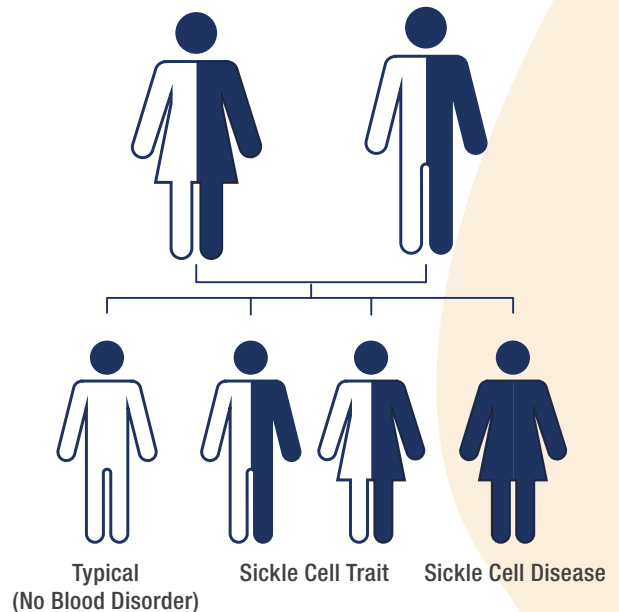
# Sickle Cell Disease and the Maternal and Child Health Bureau

## What is Sickle Cell Disease?

Sickle cell disease (SCD) is an inherited red blood cell condition. Individuals living with SCD have abnormal red blood cells that form into a crescent shape, break easily, clump together, and block blood flow to organs and tissues.

Complications of SCD can result in:

- anemia,
- periodic acute pain episodes, and
- organ damage and other medical complications which can lead to a reduced life expectancy
- decreased quality of life
- fatigue



## What Causes Sickle Cell Disease?

SCD is inherited, meaning people living with SCD are born with the condition because the sickle cell gene is passed on from both parents.

## Sickle Cell Disease in the U.S.

It is estimated that approximately:

**2,000,000**  
Americans have  
sickle cell trait

**100,000**  
are living  
with SCD

Sickle cell disease occurs in:

**1 in 365**  
African-American  
births

**1 in 16,300**  
Hispanic-  
American births

## Care and Treatment for Sickle Cell Disease

- Early entry into evidence-based care including specialty care from SCD specialists reduces complications, improves quality of life, and extends life expectancy for individuals living with SCD.
- Prevention and treatment options include:
  - » Lifestyle and behavior changes
  - » Medical screenings and interventions like vaccines
  - » Specific treatments such as Hydroxyurea to prevent SCD complications
- People living with SCD experience barriers to accessing care and treatment due to lack of access to SCD specialists, discrimination, racism and unmet social factors.

Learn more at <https://mchb.hrsa.gov>

# MCHB and Sickle Cell Disease

Since the 1960s, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) has recognized the significance of early identification and treatment of SCD and has been a leader in supporting community-based organizations (CBOs) and clinics to conduct testing, counseling, and education.

About **25%** of individuals living with SCD are served through MCHB's sickle cell programs

## HRSA-Funded Sickle Cell Disease Programs

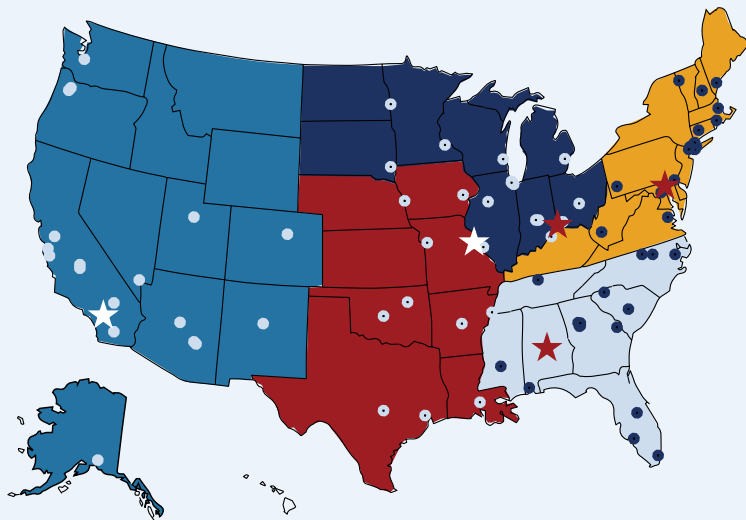
- The Sickle Cell Disease Treatment Demonstration Program (TDP) uses a regional model with a focus on recruitment, outreach, and SCD specific trainings to expand the capacity of providers to deliver evidence-based sickle cell care and support the system of comprehensive care.
- The Sickle Cell Disease Newborn Screening Follow-up Program (FP) works to improve the lives of individuals living with SCD through SCD-based CBOs advocating for and supporting the unmet needs of the SCD population. Annually, approximately 1,000 newborns are identified with SCD through state newborn screening programs.

### Legend

- ☆ Treatment Demonstration Programs
- Follow-up Programs

### Geographical Area

- Southwest
- Northeast
- Midwest
- Pacific
- Southeast



## The Hemoglobinopathies National Coordinating Center (HNCC) Supports the Goals of SCD Programs and Organizations



**Strengthen the system of care** and support services



**Provide education** for patients, families, and clinicians



**Facilitate partnerships** between clinicians, organizations, and other stakeholders



**Provide referrals and linkages** to clinical and community supports

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