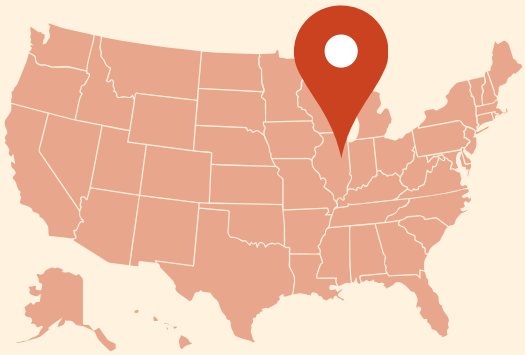
USA SICKLE CELL DISEASE LEGISLATIVE HISTORY

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States, affecting approximately 100,000 Americans. Over the past century, federal policy has evolved from basic disease recognition to research expansion, screening infrastructure, and modernization of treatment access.

1910

First documented U.S. case of sickle cell disease, described in 1910 by Chicago-based physician James Bryan Herrick.



1910 | 1970 | 1980 | 1990

1972 - First Federal SCD Legislation

Passage of the **National Sickle Cell Anemia Control Act**, the first major federal legislation dedicated to SCD that built SCD education, research, screening, and treatment infrastructure.

1980s - 1990s

Federal investment expanded through NIH research programs and the adoption of statewide newborn screening programs, which enabled early diagnosis and improved survival among children born with SCD.

2000

2004

Federal Treatment and Demonstration Programs Established Passage of the Sickle Cell Treatment Act of 2003, which extended Medicaid coverage to certain treatments and services necessary for sickle cell disease patients and allowed the Health Resources and Services Administration (HRSA) to launch a demonstration program to improve access to coordinated, comprehensive care.

2006

Nationwide adoption of newborn screening programs.

2010s

Renewed Congressional Focus Through Appropriations: Congress began directing targeted appropriations within the Labor-Health and Human Services bill to strengthen federal public health engagements in SCD.

2010

2016

The bipartisan Congressional Sickle Cell Disease Caucus was established to provide a dedicated congressional forum focused on advancing federal policy related to SCD by Rep. Danny Davis, Rep. Charles Rangel, and Sen. Tim Scott, who served as early co-chairs and champions for federal engagement on the disease.

2018

National Data Infrastructure Established: The Centers for Disease Control and Prevention (CDC) launched the Sickle Cell Data Collection (SCDC) Program, the first multi-state effort to systematically collect longitudinal data on individuals living with SCD to better understand health outcomes and care utilization.

2019

Expansion of National Surveillance: Congressional appropriations enabled the CDC to expand the SCDC program from initial pilot states to a growing national network. Participating states include Alabama, California, Colorado, Florida, Georgia, Illinois, Indiana, Kentucky, Michigan, Minnesota, New York, North Carolina, Pennsylvania, Tennessee, Virginia, and Wisconsin.

Ongoing Challenges

Despite progress, significant challenges remain, including life expectancy disparities, limited adult care access, reimbursement uncertainty, and persistent stigma in clinical settings. **To ensure that scientific progress translates into continued patient access and improved outcomes:**

- ☑ Support the SCD Comprehensive Care Act (H.R. 5178/S. 721) to expand comprehensive care infrastructure and workforce capacity
- ☑ Increase federal appropriations to SCD research, screening, and treatment
- ☑ Encourage federal coordination and communication on SCD developments

SICK CELLS

About Sick Cells

Sick Cells is a patient-centered advocacy organization that engages policymakers, providers, and community leaders to ensure that individuals living with SCD receive comprehensive, high-quality care. Learn more at sickcells.org.