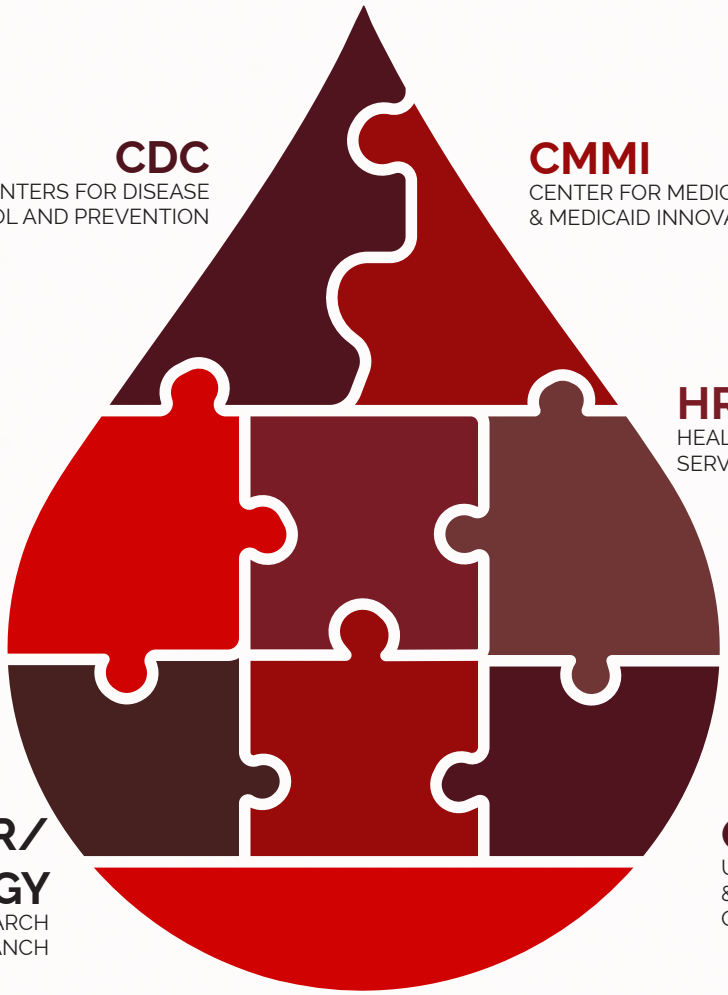
MANY PIECES. ONE MISSION.

HHS Contributions to Sickle Cell Disease

The U.S. Department of Health & Human Services' (HHS) agencies each contribute unique expertise, programs, and resources that fit together to strengthen the federal response to sickle cell disease (SCD). From advancing research and innovation to improving care, informing public health, supporting data exchange, enhancing therapies, and fostering collaboration, each contribution plays an essential role. Together, these efforts create a more coordinated, comprehensive system of support for individuals living with SCD, their families, healthcare providers, researchers, and communities.



CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

CMMI
CENTER FOR MEDICARE & MEDICAID INNOVATION

HRSA
HEALTH RESOURCES & SERVICES ADMINISTRATION

FDA
FOOD AND DRUG ADMINISTRATION

NHGRI
NATIONAL INSTITUTES OF HEALTH/NATIONAL HUMAN GENOME RESEARCH INSTITUTE

NHLBI/DBDR
DIVISION OF BLOOD DISEASES AND RESOURCES

NHLBI/DIR/ HEMATOLOGY
DIVISION OF INTRAMURAL RESEARCH (DIR)/HEMATOLOGY BRANCH

OMH
U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES OFFICE OF MINORITY HEALTH

ONC
OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY

OMH U.S. Department of Health and Human Services Office of Minority Health

1-833-762-4900
minorityhealthinfo@hhs.gov
minorityhealth.hhs.gov

Populations Served

	Individuals Living with Sickle Cell Disease		Caregivers		Healthcare Professionals		Health System Administration
	Community-Based Organizations		Researchers		Policymakers		State and Local Governments

Centers for Disease Control and Prevention (CDC)

The CDC supports the Sickle Cell Data Collection (SCDC) program which collects health information about people with SCD to assess the long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. For more information visit: cdc.gov/sickle-cell/scdc/index.html

Populations Served

Centers for Medicare & Medicaid Services (CMS)/Center for Medicare and Medicaid Innovation (CMMI)

The CMMI Cell and Gene Therapy (CGT) Access Model is a multi-year, voluntary model for states and manufacturers to test whether a CMS-led approach to developing and administering outcomes-based agreements for CGTs increases Medicaid beneficiaries' access to innovative treatment, improves their health outcomes, and reduces health care costs and burden to state Medicaid programs. The initial focus of the model is on SCD. For more information visit: cms.gov/priorities/innovation/innovation-models/cgt

Populations Served

Food and Drug Administration (FDA)

The FDA's Division of Nonmalignant Hematology (DNH), within the Center for Drug Evaluation and Research (CDER), regulates treatments for non-cancerous blood disorders, reviewing Investigational New Drug applications (INDs), New Drug Applications (NDAs), and Biologics License Applications (BLAs). In parallel, the Center for Biologics Evaluation and Research (CBER), through its Office of Therapeutic Products (OTP), oversees the review and approval of gene therapies for SCD. Since 2018, six disease-modifying SCD therapies have been approved — including gene therapies regulated by CBER/OTP — with multiple clinical trials ongoing. Together, DNH and CBER/OTP actively engage patients, clinicians, and industry to advance safe and effective treatments for this serious condition. For more information visit: fda.gov/about-fda/cder-offices-and-divisions/office-cardiology-hematology-endocrinology-and-nephrology-division-non-malignant-hematology-dnh

Populations Served

Health Resources & Services Administration (HRSA)

HRSA's Sickle Cell Disease Program increases access to quality, coordinated, comprehensive care for individuals with SCD by: 1) increasing the number of clinicians or health professionals knowledgeable about the care of SCD, 2) improving the quality of care provided to individuals with SCD, and 3) improving care coordination with other providers. For more information visit: mchb.hrsa.gov/programs-impact/programs/sickle-cell

Populations Served

National Institutes of Health (NIH)/National Human Genome Research Institute (NHGRI)

NHGRI studies how genes affect SCD, including why symptoms and complications vary from person to person. Researchers also study the associations between nutrition, diet and sickle cell related symptoms. In addition, NHGRI developed educational resources to help people living with SCD and their caregivers better understand their treatment options and make informed healthcare decisions. For more information visit: genome.gov

Populations Served



NIH/National Heart, Lung, and Blood Institute (NHLBI)/ Division of Blood Diseases and Resources (DBDR)

NHLBI's Division of Blood Diseases and Resources (DBDR) supports research to better understand, prevent, and treat blood diseases. It also helps ensure the safety and availability of the nation's blood supply and advances research on stem cells and gene and cell therapies, that may help repair or replace damaged tissues and organs. DBDR supports research on conditions such as SCD, anemia, hemophilia, blood clots, and other blood disorders that affect millions of people in United States. The division also trains future blood scientists, coordinate research efforts, and works with partners across the NHLBI, the NIH, and other federal agencies to promote and improve blood health. For more information visit: nhlbi.nih.gov/about/divisions/division-blood-diseases-and-resources

Populations Served



NHLBI/ Division of Intramural Research (DIR)/Hematology Branch

NHLBI's Hematology Branch, within DIR, conducts laboratory and clinical research on SCD and other blood disorders. The Sickle Cell Genetics and Pathophysiology Laboratory studies why SCD affects people differently and explores targeted treatments. The Cellular and Molecular Therapeutics Laboratory supports research to turn scientific discoveries into cures for SCD, including through stem cell transplantation, gene therapy, and other approaches. Together, these laboratories work to better understand SCD and translate research discoveries into improved treatments and patient care. For more information visit nhlbi.nih.gov/about/intramural-research/hematology

Populations Served



HHS Office of Minority Health (OMH)

HHS OMH leads federal collaboration to improve outcomes for people living with SCD. OMH raises awareness, develops and shares evidence-based educational resources, convenes partners across HHS and beyond, and fosters stakeholder engagement to strengthen coordination. Through these efforts, OMH helps reduce health disparities and enhance the quality of care, information, and support available to individuals and families affected by SCD. For more information visit: minorityhealth.hhs.gov/sickle-cell-disease

Populations Served



The Office of the National Coordinator for Health Information Technology (ONC)

ONC, with the Office of the Assistant Secretary for Planning and Evaluation (ASPE), is developing a United States Core Data for Interoperability Plus (USCDI+) SCD minimum core dataset of standardized data elements to enable consistent, interoperable exchange of SCD information across clinical, public health, and research settings. It improves diagnosis accuracy, emergency care access, surveillance, and data liquidity via strengthening care coordination and outcomes for people living with SCD. For more information visit: healthit.gov

Populations Served

