

Sickle Cell Disease:

Increasing Access and Improving Care

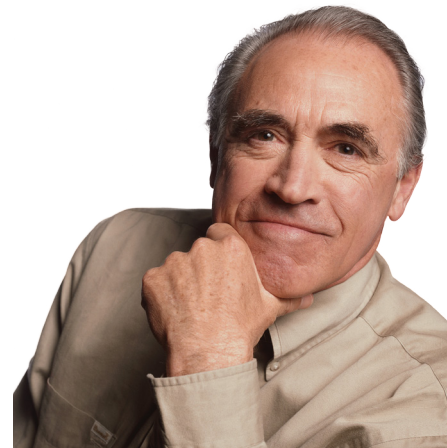


Sickle cell disease affects millions of people worldwide. It is most common among people from Africa, Mediterranean countries, the Arabian Peninsula, India, South America, Central America, and the Caribbean. An estimated 70,000-100,000 Americans live with Sickle Cell Disease (SCD) in the United States and more than 3.5 million Americans have Sickle Cell Trait (SCT). SCT occurs in 1 in 12 African Americans.

- Advances in health care have increased life expectancy for individuals with SCD, but much more needs to be done to expand access, improve health care and health outcomes.
- Better coordination and collaboration can significantly improve SCD care through enhanced public health data about the burden of disease, reliable access to quality care and services, development of new therapies, and biomedical and behavioral research.

Secretary Sebelius has charged the Department of Health and Human Services (HHS) with making SCD a priority. These HHS operating and staff divisions are developing the SCD Initiative:

- Agency for Healthcare Research and Quality
- Centers for Disease Control and Prevention
- Centers for Medicare & Medicaid Services
- Food and Drug Administration
- Health Resources and Services Administration
- National Institutes of Health
- Office of Minority Health
- Office of the Assistant Secretary for Planning and Evaluation





HHS' SCD Initiative

HHS will take specific actions to improve the health of people with SCD:

- Improve the care of adults and children with SCD through development and dissemination of evidence-based guidelines.
- Identify measures of quality of care for individuals with SCD and incorporate them into quality improvement programs at HHS.
- Increase the availability of medical homes to improve access to quality routine care by knowledgeable providers, and specialty care.
- Provide State Medicaid officials, health care providers, patients, families, and advocacy groups with information about federal matching funds for education and services related to SCD care and treatment.
- Create a comprehensive database of individuals with SCD to facilitate the monitoring of health outcomes and clinical research always respecting and protecting patient privacy.
- Work with the pharmaceutical industry and academic investigators to increase the development of effective treatments for patients with SCD.
- Support research to improve health care for people with SCD — including pain and disease management.
- Support research to understand the clinical implications for individuals with sickle cell trait.
- Engage national and community-based sickle cell advocacy organizations, and SCD experts in discussions as HHS actions progress.



For additional information on Sickle Cell Disease, please visit
http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhatIs.html or http://www.nhlbi.nih.gov/new/sicklecellQ_A.htm.
<http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=4>

If you have additional questions, please contact the Office of Minority Health at 1-800-444-6472