SICKLE CELL DISEASE HEALTH DISPARITIES

Sickle cell disease (SCD) is the world's most common genetic disease, affecting approximately 100,000 people in the United States. As a group, people with SCD experience worse health outcomes compared to other diseases and have access to fewer health resources. This lack of equality is termed a health disparity.

HEALTH OUTCOME DISPARITIES

Health outcomes are the "outcomes or results of a medical condition that directly affects the length or quality of a person's life."



The average
life expectancy
for people with the most
severe form of SCD is
30 years shorter
than that of people without SCD.



Patients with SCD have the highest rate of returning to the hospital within 30 days of being

within 30 days of being discharged compared to other health conditions.



The rate of stroke
in adults (age 35-64 years)
with SCD is
3x higher

than rates in African Americans of similar age without SCD.

HEALTH RESOURCE DISPARITIES

Health resources are "the materials, personnel, facilities, funds, and anything else that can be used for providing health care and services."



The majority of SCD patients are Medicaid beneficiaries.

Less than 70% of doctors in the U.S. accept new Medicaid patients.



Healthcare providers may inaccurately perceive SCD patients as drug-seekers and may doubt their severity of pain. As a result, patients with SCD often experience

longer wait times to see a doctor and to get pain medication

when visiting the emergency department.



The number of physicians

trained and willing to treat SCD patients, especially adult patients,

is limited.

Through a partnership with the Centers for Disease Control and Prevention's Division of Blood Disorders, Tracking California and the Georgia Health Policy Center, the CDC Foundation is implementing the **Sickle Cell Data Collection (SCDC)** program to collect health information about people with SCD to study long-term trends in diagnosis, treatment and healthcare access. The SCDC program aims to use study findings to inform policy and health care changes that decrease health disparities for people with SCD.

The project is receiving funding support from Pfizer Inc., Bioverativ and Global Blood Therapeutics and is active in California and Georgia. Additional support is needed to expand the program to all of the United States to improve the disparate state of SCD.

