

STATE OF SICKLE CELL DISEASE | 2018 REPORT CARD

Sickle cell disease (SCD) — an inherited disorder that causes a person's red blood cells to become deformed and get stuck in veins, blocking oxygen flow throughout the body — can cause severe pain, stroke, organ failure, and even death.

There is no widely available cure for SCD, and care is inconsistent in the United States and wholly absent in large parts of the world. To highlight the urgent need for change, in 2016 the American Society of Hematology (ASH) issued a report and report card on the state of SCD based on a survey of individuals with SCD, health care providers, and global health leaders. Two years later, SCD stakeholder groups have conducted a follow-up survey to measure progress. The good news is that this 2018 report card suggests we are making progress; however, the scores also indicate that we have much to do to improve the state of care for those living with SCD.

2016 RATING | 3.7



ACCESS TO CARE (U.S.)

POSITIVE CHANGE

Steps are being taken to further identify and address barriers to quality care for children, teens, and adults with SCD. To improve existing efforts, government and nonprofit grants have been awarded to projects nationwide and legislation has been introduced in Congress and in some states.

WHERE WE STILL NEED TO GO...

In the United States, there are too many barriers to quality care: health insurance, provider experience and knowledge, geography, economic status, and co-existing conditions. Children with SCD are not getting the antibiotics they need to prevent complications, people are unable to fill their pain relief prescriptions, and implicit bias remains a barrier to quality care.

2016 RATING | 3.2



TRAINING AND PROFESSIONAL EDUCATION

POSITIVE CHANGE

Education and training programs for community health workers, emergency physicians, pediatricians, hematologists, and other providers who might see a person with SCD have been implemented by several organizations and agencies, including those in the Sickle Cell Disease Coalition. New clinical guidelines for SCD are expected in 2019.

WHERE WE STILL NEED TO GO...

There are not enough health care providers with comprehensive knowledge and expertise to care for individuals with SCD, who suffer from unpredictable and often persistent pain and complications. Consequently, people with SCD are not receiving the standard of care and feel that they are not receiving compassionate care.

2016 RATING | 4.7



RESEARCH AND CLINICAL TRIALS

POSITIVE CHANGE

SCD has become an exciting field of research. Recently, the U.S. Food and Drug Administration approved the first SCD medicine in 20 years. To date, gene therapy, a potentially curative therapy, is currently in active clinical trials. Additionally, over 40 therapies are in the research and development pipeline. Groups in the Sickle Cell Disease Coalition have made progress to increase patient engagement in research and establish registries, a clinical trials network, and a national initiative focused on finding a cure.

WHERE WE STILL NEED TO GO...

Bone marrow transplant is a cure for some individuals with SCD but may not be an option for everyone. Also, there are too few effective treatment options. There has been increased interest and investment in clinical trials, yet there are barriers to patient participation that must be addressed.

2016 RATING | 3.2



GLOBAL ISSUES

POSITIVE CHANGE

Efforts in India and sub-Saharan Africa, where SCD is endemic, are making progress toward increasing newborn screening and improving survival of young children. In Ghana, newborn screening and educational efforts have significantly decreased mortality rates. Nigeria has set a goal to cut deaths from non-communicable diseases by 25 percent by 2025, and India set a world record for screening 7.5 million people for SCD in a single day. Conferences aimed at accelerating progress continue to take place in these regions.

WHERE WE STILL NEED TO GO...

SCD remains a major killer of infants and children in the developing world. Screening, interventions, knowledgeable providers, and medicines remain unavailable to most patients. Increased public awareness is key to improving the global state of SCD.

For a more detailed look at the state of SCD, visit scdcoalition.org/report

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The organizations that endorse the **State of Sickle Cell Disease: 2018 Report Card** include:



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