STATE OF SICKLE CELL DISEASE | 2016 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.

While there's no widely available cure for SCD, care is obtainable. But that care is inconsistent in the United States and wholly absent in large parts of the world. To understand where SCD care stands today, the American Society of Hematology (ASH) has polled individuals with SCD, health care providers, and global health leaders. Though advances have been made, their scores show us that we have much to do to improve the state of care for those living with SCD.

ACCESS TO CARE (U.S.)

CURRENT STATE

In the United States, access to appropriate care is limited by a number of factors including health insurance, availability of knowledgeable health care providers, provider experience, geography, economic status, and co-existing conditions. Additionally, the transition from pediatric to adult care can be especially challenging, and the focus needs to shift from acute care of complications to a chronic care model.

GOALS FOR THE FUTURE

- Develop evidence-based guidelines and coordinated health care delivery models to ensure that individuals with SCD can access quality care regardless of age, location, and socioeconomic status.

TRAINING AND PROFESSIONAL EDUCATION

CURRENT STATE

There are not enough health care providers with comprehensive knowledge and expertise to care for people with SCD. The unpredictable and often persistent nature of the pain and complications associated with SCD poses a difficult challenge for providers, especially those inexperienced with treating people with this disease. Many family physicians feel they do not have adequate background in SCD management, making it essential to train more providers.

GOALS FOR THE FUTURE

- Increase the number of providers able to care for those with SCD by educating clinicians to treat symptoms and complications while encouraging medical trainees to pursue careers in SCD care.

RESEARCH AND CLINICAL TRIALS

CURRENT STATE

There is only one FDA-approved treatment (hydroxyurea) for adults with SCD — it is often used off-label in children. Hydroxyurea is under-prescribed in the United States and largely unavailable abroad. This, coupled with limited funding to research and test new cures, severely limits the care individuals can receive.

GOALS FOR THE FUTURE

- Invest in strategies to expand use of existing treatments, develop novel therapies, and strengthen curative options while accelerating their discovery.

GLOBAL ISSUES

CURRENT STATE

SCD is a major killer of infants and children in the developing world, especially in Africa and India where the disease is more common. A lack of resources has limited global progress in increasing awareness and education of SCD.

GOALS FOR THE FUTURE

- Expand newborn screening and early intervention programs, increase SCD awareness and education, and improve access to quality care in developing regions.

For a more detailed look at the state of SCD, and how a coalition of groups with an interest in SCD are working to improve care worldwide, visit scdcoalition.org