

World Sickle Cell Day 2020

Standing by people with sickle cell disease and their families

Jun 18, 2020

As the world grapples with the [COVID-19 pandemic](#), we need to continue our efforts to support vulnerable populations, who may be more at risk, such as people with sickle cell disease (SCD).

Sickle cell disease is a hereditary and life-threatening condition that causes ongoing vascular damage and repeated injury to the blood vessels and organs, including the heart and lungs. This lifelong illness often takes an extreme emotional, physical, and financial toll on patients and their families.

Novartis conducted the International Sickle Cell World Assessment Survey (SWAY) to assess the impact SCD has on the daily lives of patients, including the incidence and management of pain crises (called vaso-occlusive crises or VOCs). Here are five things we learned:

SWAY surveyed 2145 patients from 16 countries in Europe, North America, the Middle East and Africa.

A holistic approach to managing sickle cell disease

SCD is a global health problem, yet sub-Saharan Africa bears the highest burden of disease. There is a clear disparity between Africa and other parts of the world, where the condition is managed as a chronic disease.

SCD management requires an integrated, holistic approach. To this end, we took significant steps to expand our Africa Sickle Cell Disease program, which aims to improve the diagnosis and treatment for people with SCD. First launched in [Ghana in November 2019](#), the program is [now expanding to East Africa](#) with launches

planned in Uganda and Tanzania over the next months.

World Sickle Cell Day 2020

Joel has sickle cell disease

Nana has sickle cell disease

Moses has sickle cell disease

Joel has sickle cell disease

Nana has sickle cell disease

Moses has sickle cell disease

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Effective treatment starts with timely diagnosis

Sickle cell disease is recognized by the World Health Organization as a public health priority and a neglected health problem in sub-Saharan Africa. Approximately 80% of individuals with SCD globally are born in sub-Saharan Africa. It is estimated that approximately 1 000 children in Africa are born with SCD every day and more than half will die before they reach the age of five, due to preventable complications. Early diagnosis is the first important step to effective treatment of the disease, but currently only an estimated 4% of children get tested. Novartis partner Hemex Health is working with the Ghana FDA to launch an affordable point of care diagnostic to help improve access to diagnosis.

Additional Resources

[Novartis Global Health: Sickle Cell Disease](#)

[Download sickle cell disease fact sheet](#)

Novartis Social Business (NSB)

NSB supports global public health through novel sustainable business models. Our activities are rooted in local communities, where we work with partners to provide affordable, high-quality medicines against infectious and chronic diseases while strengthening healthcare capacity. Everything we do relies on our network of partners, who share our purpose.

[Learn More](#)

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