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Sickle cell disease – a silent killer

Johannesburg, June 19, 2019 – Sickle cell disease (SCD) is one of the major silent killers of infants and children in the developing world, particularly in sub-Saharan Africa, where an estimated 50 – 90 percent of infants born with SCD will die before their fifth birthday.
While simple public health measures such as newborn screening, vaccinations, and early interventions have been proven to greatly improve childhood survival in several countries, SCD continues to be a major global public health issue with the United Nations designating it as global health problem requiring urgent action by member countries and other relevant stakeholders [1].

Novartis spokesperson, Dr. Gary Sopher, says: "Sickle cell disease is a chronic, lifelong, genetic blood disorder that impacts millions of people globally and can take an extreme emotional, physical, and financial toll on patients and their families— but, no one really talks about it."
"Persistent stigmas can cause sickle cell patients to experience feelings of depression and anxiety. Every day, people can endure the painful and life-threatening symptoms of sickle cell disease in the shadows of fear, stigma and isolation."

Medical research literature defines SCD as one of the most common genetic blood disorders in the world; a chronic, lifelong, debilitating disease that can range in clinical severity. It affects the shape of red blood cells and can make blood cells stickier than usual. When blood cells stick to one another they can form clusters in the bloodstream. These clusters can block the flow of blood and oxygen and cause damage to the blood vessels and organs. When blood cell clusters get big enough, they can block the blood flow and lead to a painful crisis. Sickle cell pain crises disrupt patients' lives physically, socially, and emotionally—and can worsen long-term health.

SCD symptoms include chronic pain, recurrent acute pain episodes, severe anemia, enlarged spleen and increased risk of recurrent infections, acute chest syndrome, stroke (clinical and silent), headache, dizziness and seizures, eye problems, including blindness; heart disease; kidney and liver problems, priapism, pale skin and jaundice (yellowing of the skin or eyes).

[1] https://www.hematology.org/Newsroom/Press-Releases/2018/8687.aspx

Importantly, education about the disease has been identified as one of the key interventions. To remove the stigma and improve understanding of SCD, Novartis has partnered with Dr. Alexander Kumar, a world-renowned documentarian and storyteller, to help tell the story of SCD in a relatable and visually powerful way – with a major focus in sub-Saharan Africa where the stigma is rife, and the disease is most prevalent.

In a series of photos, essays, and videos that showcase the faces of SCD and how it impacts their surrounding communities – from their caregivers to their physicians – Novartis hopes to capture the reality of living with sickle cell disease to not only inspire support and companion, but to also help empower those living with the disease beyond the stigma.
Too often, patients with SCD experience shortened lifespans, living only to their 40s. However, early diagnosis, ongoing patient education and awareness and simple medical care, including access to blood transfusions and hospital treatment, can all improve patients' life expectancy.

Latest estimates indicate that millions of patients worldwide live with the SCD and approximately 300,000 babies are born annually with SCD and approximately 300 million people worldwide have the sickle cell trait. The disease impacts many different populations around the world, but disproportionately affects people from Sub-Saharan Africa. It also is common among people with ancestry from South America, Central America, and India, as well as several Mediterranean countries, such as Italy and Turkey, and other populations.

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References:
1. https://www.hematology.org/Newsroom/Press-Releases/2018/8687.aspx

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