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MEDIA UPDATE

Novartis expands Africa Sickle Cell Disease program to Uganda and Tanzania

- *New collaborations aim to reduce the burden of sickle cell disease (SCD) in East Africa and improve access to high quality care*
- *Program continues progress in Ghana with more than 2000 patients being treated with hydroxyurea in 11 treatment centers across the country*
- *Novartis plans to roll the program out to a total of 10 African countries by 2022*
- *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*[1]

Basel, Switzerland, June 18, 2020 – Today, Novartis and its partners announced the expansion of the Africa Sickle Cell Disease program to East Africa with the signature of two new memoranda of understanding with the Ministries of Health of Uganda and Tanzania. The program, first launched in Ghana in November 2019, aims to improve and extend the lives of people with sickle cell disease (SCD) in sub-Saharan Africa, with plans to reach a total of 10 countries by 2022.

“In this time of worldwide uncertainty, it is even more important to support people living with chronic conditions like sickle cell disease,” said Dr. Patrice Matchaba, Group Head of Global Health & Corporate Responsibility at Novartis. “We are excited to join forces with the Ministries of Health of Uganda and Tanzania and local partners to reimagine treatment and care for people with sickle cell disease.”

Within the scope of these public-private partnerships, Novartis and its partners have agreed to explore collaboration opportunities aimed at tackling the growing burden of SCD in their countries. The partners intend to develop and implement a comprehensive approach that includes making diagnosis and treatment available, accessible and affordable for patients and their families; promoting scientific research, training and education; and pursuing robust monitoring and evaluation of the program. As a next step, Novartis plans to work with the respective Ministries of Health to further define the scope of each collaboration and explore opportunities for additional partnerships.

In Ghana, the program is already making progress with more than 2000 patients being treated with hydroxyurea in 11 treatment centers across the country. To date, Novartis has delivered more than 60 000 treatments of hydroxyurea in Ghana, helping ensure SCD patients have uninterrupted access to treatment during the global pandemic. At the same time, Novartis has registered the medicine for the treatment of SCD in Uganda, Tanzania and Kenya. Hydroxyurea is a commonly used medicine for patients with SCD in developed countries, and

is approved for use in both adults and children. A recent study, published in the *New England Journal of Medicine*[2], indicates that hydroxyurea is effective and safe in children with SCD in sub-Saharan Africa and reduces the incidence of pain events (vaso-occlusive crises), malaria, blood transfusions, and death.

In addition, Novartis has signed a memorandum of understanding with the University of Ghana with the intent to collaborate on promoting education, research, advocacy and capacity building to advance Ghana's national health agenda to improve the health and well-being of people with SCD. At the same time, we are continuing our efforts to develop a child-friendly formulation of hydroxyurea and have announced plans to conduct two clinical trials in Ghana and Kenya for its next-generation treatment for SCD, crizanlizumab. Crizanlizumab, a novel targeted biologic therapy, is approved in a number of countries to reduce the number of pain crises in people with SCD. The trials are expected to start in 2020; this will be the first time that a biologic therapy, which is not a vaccine, enters multicenter clinical trials in sub-Saharan Africa (excluding South Africa).[3]

"As we fight the COVID-19 pandemic in Africa, we cannot lose sight of other health priorities for the region, including sickle cell disease," said Dr. Charles Kiyaga, Sickle Cell Program Head at the Ministry of Health in Uganda. "Such partnerships between the public and private sector are necessary to help accelerate progress in SCD prevention and management for the benefit of the patients, their families and communities."

Sickle cell disease is recognized by the World Health Organization as a public health priority and a neglected health problem in sub-Saharan Africa, which carries approximately 80% of the global disease burden.[4] In countries in West, Central and East Africa, the prevalence of the sickle cell gene is between 10 to 30%, while in some areas it is as high as 45%.[5] It is estimated that approximately 1 000 children in Africa are born with SCD every day and more than half die before they reach five years of age.[1] This is due primarily to a lack of early diagnosis through newborn screening, penicillin prophylaxis, parental education, and comprehensive care. In resource-poor countries, more than 90% of children with SCD do not survive to adulthood.[6]

About Sickle Cell Disease
Sickle cell disease is a complex and debilitating, genetic blood disorder that goes beyond sickle-shaped red blood cells. The disease is associated with chronic inflammation, causing higher levels of cell adhesion proteins, which make both the blood vessels and certain blood cells stickier and prone to multicellular interactions, or clusters, in the bloodstream.[7,8] This environment can lead to the acute episodes of pain known as sickle cell pain crises, or vaso-occlusive crises, as well as life-threatening complications.[7,9] SCD is a lifelong illness that can put an emotional, physical, and financial burden on patients and their families.[10,11]

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