World Sickle Cell Awareness Day 2024:
Shining the Light in the Catholic Health Network in Uganda

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Every year, on June 19th, Uganda joins the rest of the world to commemorate World Sickle Cell Day, to increase public knowledge, raise awareness and reduce stigma about Sickle Cell Disease. The United Nations General Assembly recognized sickle cell disease (SCD) as a global public health problem due to its increasing burden, particularly in sub-Saharan Africa.

To raise awareness, a resolution was adopted in 2008, designating June 19th as SCD Awareness Day. The international awareness day is observed annually with the goal to increase public knowledge and enhance an understanding of sickle cell disease, and the challenges experienced by patients and their families and caregivers.

In Africa, the majority of children with the most severe form of the disease die before the age of 5 years, usually from an infection or severe blood loss.

In countries such as Cameroon, Republic of Congo, Gabon, Ghana, and Nigeria the Sickle Cell Trait prevalence is between 20% to 30% while in some parts of Uganda it is as high as 25%. Prevalence was highest in the Mid-Northern, North-East, Mid-East and East-Central regions of Uganda, and Sickle Cell Disease prevalence as high as 2 - 2.7% in parts of Mid-East, Central 2 and East Central regions.

A 3-year nation-wide screening survey was conducted between 2015 and 2018, and findings revealed a high prevalence of sickle cell trait and sickle cell disease in Uganda with a crude birth-rate of over 240,000 sickle cell trait births and over 17,000 sickle cell disease births occurring annually in Uganda.

Sickle cell disease disproportionately affects babies in Uganda, and many go un-diagnosed due to lack of deliberate and proactive newborn screening and yet newborn screening lies at the heart of the fight against SCD. Routine newborn screening is needed to save lives and improve care—and as such June 19th *among many other days*—will shed light on SCD through increased public awareness and emphasise the need to have proactive initiatives and efforts to screen and diagnose SCD early—thereby providing appropriate treatment and alleviating social troubles related to the disease, such as chronic ill-health, missed education opportunities, broken families and marriage.

Routine newborn screening for sickle cell disease could have a profound impact in stemming complications and averting loss of life among people diagnosed with the condition.

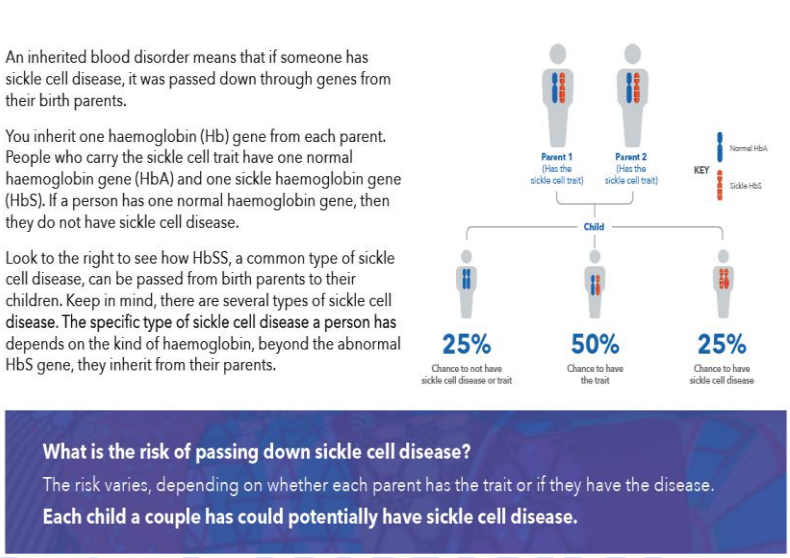
This year, the day is to be commemorated under the theme: "**Shine the Light on Sickle Cell**".

This theme encourages us to increase awareness of the public & community of the burden of SCD disorder, urges health institutions to pay attention to sickle cell disease and anaemia through developing health programs to facilitate access to screening, early diagnosis and appropriate affordable treatment, raising awareness of the importance of pre-marital screening to reduce transmission of sickle cell disease among generations and promoting and supporting research to improve quality of life for those affected.

"*But sickle cell disease should not be looked at in isolation because it affects people's social and economic life,* **Dr. Charles Kiyaga**, The Sickle Cell Program Coordinator in Uganda's Ministry of Health.

"*With first-hand experience conducting nationwide screening services for sickle cell in Uganda,* Kiyaga says *families of children with undiagnosed sickle cell are likely to face dilemmas due to lack of awareness about the disease".*

Sickle cell is a hereditary blood disorder. When a child inherits just one copy of the sickle cell gene, the condition is known as sickle cell trait. People with one copy of the gene have a higher chance of surviving malaria. If a person inherits two sickle cell genes — one from each parent — they can develop sickle cell disease. The condition is characterized by sticky, crescent-shaped red blood cells that block blood flow, leading to reduced oxygen supply and damage to every organ in the body. People living with sickle cell disease may experience intense pain and are highly susceptible to infections particularly invasive pneumococcal infections, acute malaria, and acute splenic sequestration, all of which can be associated with high rates of mortality after a short illness and other serious health issues.



The UGANDA CATHOLIC MEDICAL BUREAU (UCMB) in partnership with NOVARTIS' Health Systems Strengthening (HSS) program are "*shining a light on Sickle Cell Disease*" through the strengthening of screening and early diagnosis of Sickle Cell Disease in selected Catholic Health Network hospitals in Uganda through raising disease awareness among health care workers and health facility clients—through health promotion activities, building appropriate technical expertise and training manpower to enhance newborn screening and incorporate it into routine child health services at hospitals—as well as enhanced pre-marital SCD screening—through Catholic faith activity platforms—*such as during pre-marital counselling sessions* and support management consideration for sustainable sickle cell programs in the hospitals.

Newborn screening entails primary screening for sickle cell disease at birth and enrolment into care programs before the onset of symptoms that could later develop into chronic complications—thereby improving the quality of life for those affected.
Even if the baby is screened and found to be a carrier of a sickle cell, and not actually having the disease, it would help the family prepare the child's future in terms of managing marital choices.

Sickle cell disease and pain crises can affect your work, school, and social lives

Did you know?

For people with sickle cell disease,

1 out of 5

missed days at work
are due to pain crises

The majority of children with sickle cell disease **missed more than**

3 days **of school**

or other activities after being released from an emergency department or hospital

Sickle cell disease can be

isolating

due to pain crises and

long stays at home or hospital

65% of men and women with sickle cell disease report

diminished sexual health,
and nearly all said pain crises were the main reason why

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