

March 29<sup>th</sup>, 2022

The Honourable Dr Stephen Amoah  
Member of Parliament for Nhyiaeso  
Ghana

Dear Honourable Amoah,

The undersigned organisations write in response to your recent public comments on sickle cell disease.

Sickle Life is a non-governmental health advocacy organisation with the mission to educate the public about sickle cell disease and empower them to make informed decisions regarding the condition. The Sickle Cell Awareness Initiative (SCAI) is a non-profit initiative that seeks to improve the health and well-being of persons living with sickle cell disease through education, advocacy, research, and support.

SCAI and Sickle Life work with and on behalf of several sickle cell NGOs, PAGs and thousands of persons living with Sickle Cell Disease (SCD) in Ghana. We understand that on Saturday, 26<sup>th</sup> March 2022, you made some comments on SCD while engaging in a conversation on Joy News' current affairs program, Newsfile. During a segment on the state of Ghana's economy, you made the following remarks:

**"Me I see our economy, currency, and those things as a child with Sickle Cell; small push then there is crisis."**

We deem such language as reckless and insensitive, particularly because they drive the stigma and propel associated psychological issues related to the condition. While there are indeed several health and social challenges associated with SCD, you fell short of your mantle when you used your platform to dehumanise the brave warriors who live with SCD by comparing them to a volatile and fragile economy. At a time when there is finally a great deal of national interest in SCD and the government of Ghana is making significant gains in the area of SCD-related issues, your remarks undermine this progress and, frankly, the tireless awareness efforts of organisations like ours. It also threatens to disrupt the investment we have begun to see from your fellow leaders and policymakers.

SCD is a group of inherited red blood cell disorders that affects haemoglobin – the protein that carries oxygen throughout the body. It is characterised by the presence of haemoglobin S in one's body and was first reported by James B. Herrick (1910), who referred to "peculiar elongated and sickle-shaped red blood cells in a case of severe anaemia," hence the name. When a person has two haemoglobin S genes, Haemoglobin SS, the disease is called sickle cell anaemia. This is the most common and severest form of SCD. Haemoglobin SC disease and haemoglobin Sβ thalassemia are two other common forms of SCD. Millions of people are affected by

SCD worldwide. It occurs predominantly in people of African descent. Between 75%-85% of cases occur in Africa. Due to the effects of global migration, it also affects a small number of Hispanics, Asians, Italians, South Americans and Greeks.

On our continent, up to 90% of children born with SCD are expected to die before the age of 5. That is a staggering statistic! Meanwhile, the WHO estimates that **up to 70% of those SCD deaths are preventable with simple, cost-effective interventions**. That should be our focus. Statements like the one you made are not only a distraction from the important work we are doing, but they are harrowing for the men, women, children and families who have to live with the very real and often painful challenges of SCD every day. We request that you publicly retract your comments and take this opportunity to address the millions of stakeholders who will be impacted by them.

Beyond that, we ask you - along with all the country's leaders - to boldly and rightfully lead the charge on intervention efforts for SCD, especially considering the disproportionate impact it has on the constituents you serve.

Our agenda has been and will always be to push for ending the stigmatisation of sickle cell. We share a duty to support everyone living with SCD to enjoy a full and healthy life, free of stigma and limits. To that end, it is imperative that we remain singular and thoughtful in pursuit of our cause. We are more than happy to have further engagements on how we can collaborate to advance a more productive narrative and how positive change can be realised through targeted and deliberate measures.

Thank you.

Signed

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Managing Director  
Sickle Life

Nana Esi Duker-McMartey



Founder  
SCAI

Cc: ALL MEDIA HOUSES

[References & Resources](#)