

NotJustYou Foundation

Speaker: Ufuoma Muwhe

Panel #1: Reparations, Sustainable Development & Economic Justice

My name is Ufuoma Muwhe, and 25 years ago I was born with the debilitating chronic illness that is Sickle Cell Disease. After living 18 years of pain and prejudice, I am happy to share that I was able to undergo a Stem Cell Transplant that cured me of my disease.

Whilst I celebrate this milestone, I remain cognizant of the many, like my mother's little sister, who lost the battle with this disease.

So today, I am coming to you as the Executive Director of NotJustYou, a Sickle Cell Support Organization I founded as the solution to the stigma, strife, and systemic challenges associated with the disease.

Research underscores the staggering prevalence of SCD, occurring at least 30 times more in Black individuals than any other race, with over 65% of cases concentrated in Sub-Saharan Africa. Tragically, the lack of adequate resources has led to an estimated 30,000+ deaths annually.

In Canada, approximately 6,000 individuals are documented living with SCD, but we expect this number to have increased significantly considering the influx of new immigrants of African descent to the country.

Sickle cell disease is a public health concern and health equity issue because it disproportionately affects people of African descent.

Those affected by this diseases are subject to many health disparities and inequities, such as:

- Delays in **diagnosis**
- Limited access to **specialty care**
- **Insufficient resources** for managing their condition

Today, my recommendation is that if we want to do the work of protecting people of African descent, then we need to start by allocating resources towards mitigating sickle cell disease.

Addressing these health disparities requires a multi-faceted approach that includes increased investment in *research, education, advocacy, and policy changes* aimed at reducing inequities and improving health outcomes for people of African descent.