Concept note

OCTOBER 31 - NOVEMBER 2, 2019
LAGOS, NIGERIA
Introduction

Globally, and in Africa, the growing burden of sickle cell disease is undeniable. Sickle cell disease (SCD) is one of the world’s most common genetic diseases, affecting an increasing number of people but is still relatively unknown to the wider public. It poses a significant public health problem notably in sub-Saharan Africa, the Middle East, parts of India, the Caribbean, and Brazil.

According to the World Health Organization (WHO), an estimated 300,000 children are born annually with sickle cell disease worldwide, and over 75% of the affected children are born in Africa where over 1000 babies are born with the disease everyday and about 50-90% of these children die before age 5. More than half of the world’s SCD population live in Africa, which accounts for about 66% of the estimated 120 million people in the world living with the disease. Besides the very high prevalence rates, Africa also accounts for high under-5 mortality rates due to preventable complications. This is largely due to non-existent newborn screening and early intervention facilities and lack of access to basic healthcare.

The impact of SCD on affected communities cannot be overstated, it ranges from causing high morbidity and mortality, to reducing the quality of life, and imposing a high socio-economic burden on individuals, families and health systems. Although developments in recent years has seen SCD recognized by both the United Nations (UN) and the WHO as a disease of major and growing importance, it is still considered to be one of the most neglected tropical disease in Africa and the world and remains virtually invisible on the global health agenda. This is largely due to inadequate advocacy, lack of reliable ground data and inadequate political will. Improving on these will require local and international partnerships and cross-border collaborations between SCD experts, funding/donor agencies, governments and industry.

Presently, there is little to no mechanism anywhere in Africa and the world for ALL stakeholders - especially those in affected communities, in government and policy development, in implementation, program finance, and in research - to gather, connect and share information and recommendations to collaboratively reach a consensus and to build impact-oriented frameworks for a collective action against sickle cell.

The inaugural African Congress on Sickle Cell Disease aims to address this gap and more.
The African Congress on Sickle Cell Disease

The African Congress on Sickle Cell Disease (ACSCD) will take place for three days from 31 October - 2 November 2019 at the prestigious Landmark Center, Victoria Island, Lagos, Nigeria.

The conference will bring together government representatives, inter-governmental organizations, leaders of industry, civil society, academic institutions, donors, the private sector, media and people living with sickle cell themselves from across Africa and rest of the world with aligned interest in exploring sustainable solutions to the challenges of sickle cell disease and also individuals and organizations who are committed to not just the patient/caregiver experience, but also committed to overcoming sickle cell disease in Africa.

The overall goal of the conference is to facilitate active exchange of information among scientists, researchers, policy makers and other key stakeholders, to highlight challenges and opportunities, and enhance strategies to further sickle cell control.

The theme of the Conference is “Overcoming Sickle Cell Disease – Power of the collective voice”. It is pillared by two key words, “Overcome” and “Collective”, essentially holding up the main objective of the conference, which is to collectively explore high-impact and actionable methods to overcome sickle cell disease in Africa. The conference will be both political and technical, with debates, speeches and interactive sessions featuring government officials, private sector and sickle cell experts engaged in exploring innovative ways to address the challenges and further sickle cell control.

Therefore success will be achieved from our ability to work together, network, share best practices and challenge each other to identify innovative ways to addressing the challenges of sickle cell disease. It is time to seize the opportunities presented before us, to connect, collaborate and drive impact.

This, essentially, is the Power of the Collective Voice.

As part of the conference deliverable, experts will draft a working document on sickle cell control in the African context, drawing on broad experiences and numerous contributions from other experts. The recommendation from the conference will be included in the working document and participants will discuss key actions to be carried out collectively and individually to achieve sustained impact on sickle cell control efforts.

Objectives

The main objective of this conference is to provide a platform to enhance the understanding of the current state of sickle cell in Africa, the challenges and opportunities building on the experiences of key actors in the Africa region as well as other regions of the world, and to collectively explore and discover innovative approaches and best practices for effective sickle cell control.

The objectives of the Conference are to:

- Provide a platform for a wide range of stakeholders to exchange on the current status and future perspectives of SCD
- Identify ways to raise the profile of SCD as a global health priority and to articulate the essential elements
on a continental strategy to increase awareness, resource mobilizing and cross-border partnerships
- To explore the effects and outcomes of Universal Health Coverage on SCD.
- To promote ways of accelerating the implementation of policies for the attainment of SDG target 3
- Mobilize a broader base of stakeholders in support of prevention and control measures across Africa and beyond.

**Structure and Format of the Conference**

The conference will aim at balancing panel sessions with interactive parallel sessions and create opportunity for maximizing interaction between participants.

The conference structure includes
1. **Plenary sessions and interactive panels with Q&As** from the floor: to set the scene, prepare participants and stimulate discussions.
2. **Thematic sessions**: to discuss challenges, gaps and recommendations related to sickle cell control in Africa
3. **Innovative sessions and Project hubs**: to discuss promising and innovative practices and projects
4. A ‘Sickle Cell in Focus’ area that will host **parallel sessions** with options for classic panel discussions, short talk model followed by exchanges between participants and presenters.
5. **African Cafe / Workshops**: to discuss policies, projects and methodologies being implemented at the local level

Up to 3 sessions may be running in parallel, providing participants a wide range of possibilities to meet, learn or get inspired in each of the themes.

**What To Look Forward To**

**Women Overcoming Sickle Cell (WOSC)**

The Women Overcoming Sickle Cell Symposium will focus on sickle cell disease in women and highlight key issues affecting women that has never been addressed before on any stage. A first for Nigeria and Africa, this one-day one-of-a-kind event will focus on what it means to be a woman living with sickle cell and also acknowledge women luminaries with sickle cell and women-led sickle cell representative organizations who have contributed tremendously to tackling sickle cell through high impact advocacy, treatment and community commitment on the African Continent.

- A unique platform for women to exchange knowledge, experiences and stories on successes in self-care and survival
- Highlight women-specific challenges with sickle cell and proffer informed solutions and recommendations
- Connect aspiring women leaders in sickle cell with mentors and experts from the African Region and beyond

**Africa Sickle Cell Leaders’ Summit (Meeting)**

Set to become a major annual high-level meeting dedicated exclusively to furthering national, regional and global sickle cell control, this invitation-only event will bring together key decision makers from the African Region and around the world to inform policies, best practices and further cross-border collaborations. It will encourage timely debates on emerging issues related to sickle cell and proffer informed solutions to its effect. Themed “Consolidating Regional Efforts For Effective Sickle Cell Control”, the Leaders’ Summit Meeting will examine the
status quo of sickle cell disease in Africa with a view on scaling up implementation of prevention and awareness strategies and putting sickle cell at the forefront of the African and global health agenda. It will convene health, government, philanthropic and corporate leaders from the African Region and beyond.

**Key Stakeholders**
- International Ministries of Health, education and finance from the African Region
- Multilateral, donor agencies and institutions (e.g., WHO, the World Bank, etc.)
- Researchers, academia, independent experts
- Corporates, other private sector players
- Non-governmental organizations and civil society organizations

**Participants**
The conference will include the participation of Government representatives, Private Sector representatives, Academia, Research Institutes and Think Tanks, Independent experts and researchers

**Partners**
The organizers will reach out to a wide range of key partners to make this event as successful and inclusive as possible

**Online discussions and social networks**
The ACSCD team will be active online prior to and during the event, notably through the hashtags #ACSCD2019 and #OvercomingSCD on twitter and linkedin.

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