EINPRESSWIRE

Global Sickle Cell Disease Registry: The GANSID Takes A Giant Step Forward

The Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID) advances sickle cell initiatives globally.

Lagos University Teaching Hospital- GANSID meeting

LAGOS, NIGERIA, January 31, 2025 /EINPresswire.com/ -- The Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID) held a hybrid meeting in Lagos, Nigeria on January 23rd, 2025, marking the commencement of a significant initiative by the organization. This gathering brought together key stakeholders to discuss the establishment of a Global Registry for Sickle Cell Disease (SCD) and related initiatives, signaling the first step in a long and ambitious journey to revolutionize SCD care worldwide.

The Importance of a Global Registry

Globally, there is no accurate data on the number of people living with SCD. Even in advanced healthcare settings like the United States, the available statistics are largely guesstimates. Dr. Donnell Ivy, a board member of the Sickle Cell Disease Association of America (SCDAA) and a leading voice in this initiative, emphasized that a comprehensive registry is essential for data-driven advocacy and improved patient outcomes.

The Chief Medical Director of Lagos University Teaching Hospital (LUTH), Prof. Lanre Adeyemo, highlighted the gravity of the SCD burden in Nigeria, which accounts for 33% of the global prevalence. Prof. Adeyemo underscored the importance of data collection and registries in improving health outcomes, commending the small-scale registry already established in partnership with LUTH.

GANSID’s Vision and Approach

Prof. Adekunle Adekile, Chairman of GANSID’s Scientific Working Committee, outlined the organization’s vision of fostering global collaboration and addressing the gaps in SCD care, particularly in low-medium-resource countries. Prof. Adekile stressed that Nigeria must lead efforts to establish an accurate SCD registry, given its significant share of the global burden. He noted that until this is achieved, broader global efforts like the Global Sickle Cell Disease Network (GSCDN) would remain incomplete.

Prof Adekile restated GANSID’s mentorship program and the organization’s plans for clinical trials site standardization. He pointed out that while 75% of newborns with hemoglobin disorders are in low-resource countries, less than 5% of clinical trial centers exist in these regions. This disparity raises questions about healthcare equity and highlights the need for capacity building in Africa.

Patient Registry: Purpose, Benefits, and Challenges

Prof. Titi Adeyemo provided an overview of the purpose, benefits, and challenges of patient registries, drawing from her experience with the Sickle Cell Disorder Registry in Nigeria (SCDRN), established in 2018. She emphasized the necessity of robust data systems to track patients, inform clinical care, and guide research. However, she acknowledged the challenges, including inadequate funding, limited healthcare infrastructure, and low awareness among healthcare professionals.

Local and Global Collaboration

Dr. Abosede Wellington, Desk Officer for SCD Programme, Lagos State Ministry of Health, reaffirmed Lagos State’s commitment to improving healthcare delivery. She outlined plans to establish newborn screening centers across Lagos State to issue cards showing hemoglobin status at birth, integrating SCD screening into immunization clinics. GANSID’s CEO Mrs. Lanre Tunji-Ajayi, MSM commended these efforts and emphasized the importance of collaboration between government agencies, clinicians, and patient organizations.

Advocacy and Leadership

Among the speakers was Public Health Physician Dr. Annette Akinsete, CEO of the Sickle Cell Foundation Nigeria (SCFN) whom LUTH Chief Medical Director, Prof. Lanre Adeyemo described as ‘the foremost advocate for SCD care in Nigeria’. Leading the largest sickle cell organization in Nigeria and one of the biggest globally, Dr. Akinsete commended GANSID for its remarkable understanding of the power of partnership and collaboration. ‘Partnerships like those fostered by GANSID are essential for making meaningful strides in SCD care, especially in countries bearing the highest burden,’ she stated.

SCFN’s collaboration with GANSID underscores the critical role of working hand in hand in tackling inherited blood disorders on a global scale.

The Road Ahead

The meeting concluded with remarks from GANSID's CEO, Mrs. Tunji-Ajayi MSM, who called for sustained conversations and learnings to build a strong foundation for SCD care. She highlighted the need for Nigeria to take leadership in establishing an accurate registry and announced plans for similar meetings in major cities worldwide. Prof. Adekile reminded attendees that progress requires collective efforts, noting that many healthcare professionals remain under-informed about SCD.

Among the attendees were representatives from various SCD organizations in Lagos State, including Mrs. Bimpe Alowonle of Lagos State Public Schools Sickle Cell Club, Maureen Nwachi of the Sickle Cell Advocacy & Management Initiative (SAMI), and Anthony Osegbue of the Sickle Cell and Thalassemia Foundation. Other attendees included Dr. Ije Akinwumi, Dr. Olatinwo of Orilẹ Agege General Hospital, and retired Matron and health activist, Mrs. Theresa Onyejose.

This historic meeting marked a pivotal step toward addressing the long-standing gaps in SCD care and research. GANSID’s initiative demonstrates the power of global partnerships in tackling inherited blood disorders, offering hope for millions of individuals worldwide.

A similar hybrid meeting is scheduled to take place in Maiduguri, Borno State, Nigeria, with others slated for the rest of Africa, Asia, Europe, the Middle East, North and South America, and the Western Pacific.

About the GANSID

The Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID) unites patient organizations, healthcare providers, researchers, and partners to improve outcomes for individuals with inherited blood disorders. Focused on developing global registries, enhancing access to therapies, and promoting equity in care, GANSID empowers patient advocates and clinicians, strengthening capacity in low-medium resource countries. Through global collaboration, it is bridging gaps in healthcare and advancing research for millions worldwide.

Lanre Tunji-Ajayi
GANSID
+1 416-951-6981
email us here
