



GLOBAL ACTION, LOCAL IMPACT: EMPOWERING COMMUNITIES FOR EFFECTIVE SELF-ADVOCACY

World Sickle Cell Day, observed annually on June 19th, adopts the 2025 theme: "**Global Action, Local Impact: Empowering Communities for Effective Self-Advocacy.**" This theme calls for a transformative approach that places affected communities at the center of advocacy and care delivery. It emphasizes the critical need to empower patients, families, and communities to actively shape policies, programs, and services that directly impact their lives. Despite growing awareness and medical advances, sickle cell disease remains one of the most neglected genetic disorders, affecting millions worldwide but continuing to receive disproportionately limited attention and resources.

In Nigeria, sickle cell disease represents a major public health challenge. The country bears the highest burden globally, with an estimated 150,000 children born with sickle cell disease annually¹, accounting for approximately 50% of global births with the condition. With a carrier prevalence estimated at 20–30%, nearly 40 million Nigerians carry the sickle cell trait². The disease contributes to about 8% of under-five mortality, with many affected children not surviving beyond their fifth birthday due to inadequate access to comprehensive care³. These figures only partially capture the deep physical, emotional, and economic toll on families who face recurring crises, frequent hospitalizations, and the lifelong management of a chronic condition within a resource-constrained healthcare system.

The theme's focus on community empowerment and self-advocacy addresses a critical gap in the response to sickle cell disease. Far too often, individuals and families are passive recipients of care rather than active partners in developing and implementing solutions. Cultural stigma, widespread misconceptions, and limited platforms for engagement have historically excluded the voices of those living with the disease. This marginalization perpetuates cycles of discrimination in education, employment, and social participation, while hindering the creation of patient-centered policies and programs that could significantly improve quality of life and survival.

Fortunately, recent advances in sickle cell disease management offer real hope for transformation. Disease-modifying therapies, improved newborn screening technologies, and comprehensive care models have made it increasingly possible for individuals to live well with the condition. Gene therapy breakthroughs and novel medications like voxelotor and crizanlizumab represent paradigm shifts in treatment. However, most Nigerian patients are unable to access these innovations due to high costs, inadequate infrastructure, and limited advocacy for equitable access. Community-led advocacy is essential to bridge this gap and ensure that scientific progress translates into tangible improvements for all affected individuals—regardless of socioeconomic status or geographic location.



To realize this vision, Nigeria must invest in building strong patient advocacy networks and community support systems. Establishing and empowering sickle cell associations at national, state, and local levels will provide platforms for collective action, peer education, and unified advocacy. Training programs that equip patients and caregivers with knowledge of their rights, available services, and advocacy tools will enhance their ability to engage meaningfully with policymakers, healthcare providers, and society. Additionally, digital platforms and social media campaigns can amplify patient voices, challenge stigma, and mobilize support, creating virtual communities that transcend physical boundaries.

At the same time, the healthcare system must be strengthened to support these advocacy efforts. Expanding newborn screening programs, establishing specialized clinics, and integrating comprehensive sickle cell care into primary healthcare are critical. Training healthcare workers in patient-centered communication, effective pain management, and crisis prevention will not only improve care but also build trust between communities and health providers. Implementing patient registries, standard treatment guidelines, and quality improvement programs will ensure that advocacy is grounded in robust data and best practices.

A multi-sectoral approach is essential to sustaining these efforts. Government commitment to implementing national sickle cell policies, ensuring sustainable financing, and eliminating discrimination in education and employment settings will demonstrate true political will. Partnerships with civil society, faith-based organizations, traditional leaders, and the private sector will extend the reach and effectiveness of advocacy. Meanwhile, international collaboration and knowledge-sharing can help Nigeria adopt proven strategies and ensure that its communities contribute to and benefit from global progress in managing sickle cell disease.

As we commemorate World Sickle Cell Day 2025, let us recognize that lasting change requires a shift from charity-based interventions to a rights-based approach—one that positions affected individuals as leaders and decision-makers. By investing in community empowerment, amplifying patient voices, and building inclusive platforms for advocacy, we can transform the landscape of sickle cell disease care in Nigeria and across the globe.

Now is the time to act. Together, we can ensure that every voice is heard, every life is valued, and no one faces sickle cell disease alone.

¹ [https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026\(24\)00183-2/abstract](https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026(24)00183-2/abstract)

² Federal Ministry of Health Nigeria. National Guideline for the control and management of Sickle cell disease at <http://www.health.gov.ng/doc/SCDGuideline.pdf>

³ Stephen N, Nden N, Gusen NJ, Kumzhi PR, Gaknung B, Auta DA. Prevalence of sickle cell disease among children attending plateau u specialist hospital, Jos, Nigeria. *Acta Med Int.* 2018;5:20–23. doi: 10.4103/ami.ami_60_17