WORLD COALITION ON
SICKLE CELL DISEASE

SICKLE CELL DISEASE: OPPORTUNITIES FOR ACTION

2023

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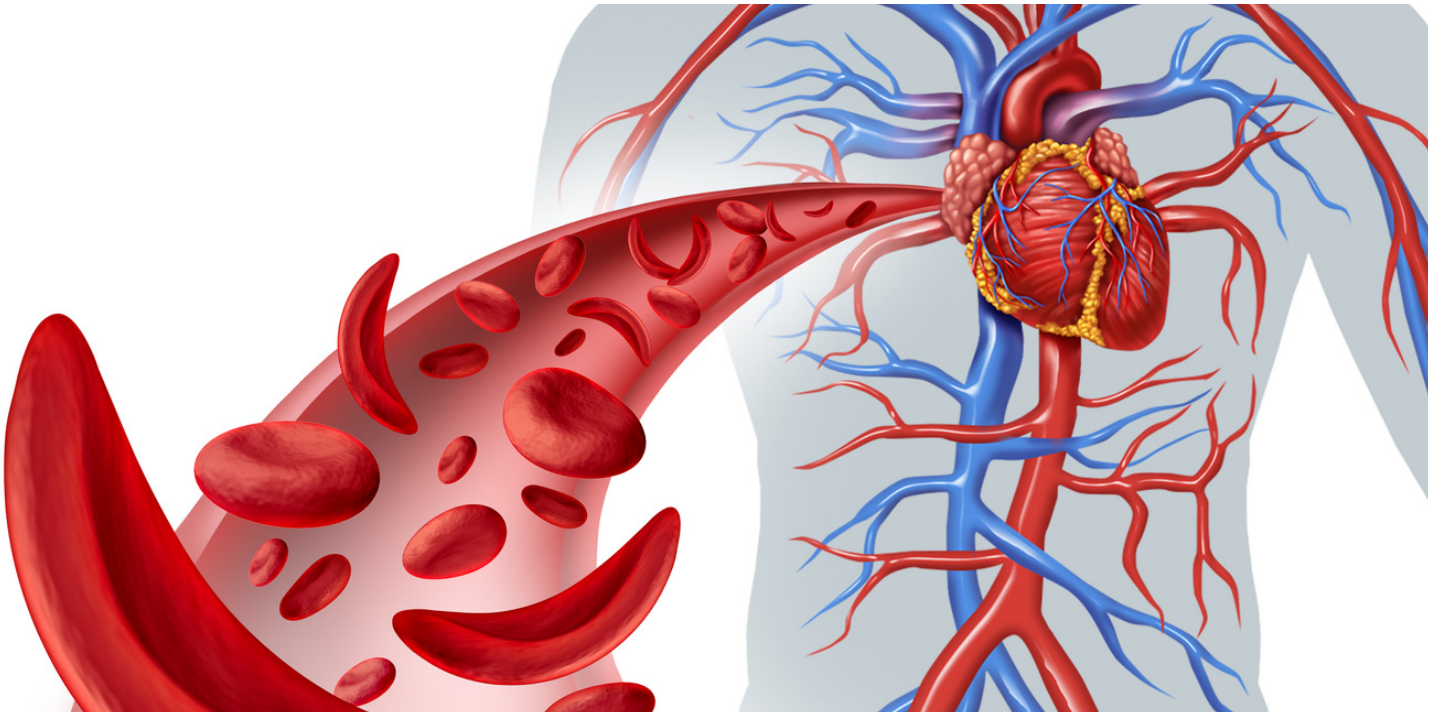
INTRODUCTION

Sickle Cell Disease (SCD) is a genetically inherited, autosomal-recessive disease impacting 7.74 million worldwide.[1] Every year, approximately 515,000 children are born with SCD, with nearly 405,000 of those cases found in Sub-Saharan Africa[2] – a number that is expected to grow.[3] The disease can be extremely lethal, with mortality rates for children under 5 in some communities ranging between 50% to 90%.[4] **While efforts to tackle SCD have gained some momentum in recent years,[5] funding for Sickle Cell Disease initiatives at all levels is not commensurate with the growing global need.** This funding shortfall imperils children's survival, hampers disease awareness, and obstructs the delivery of essential care to those living with SCD.

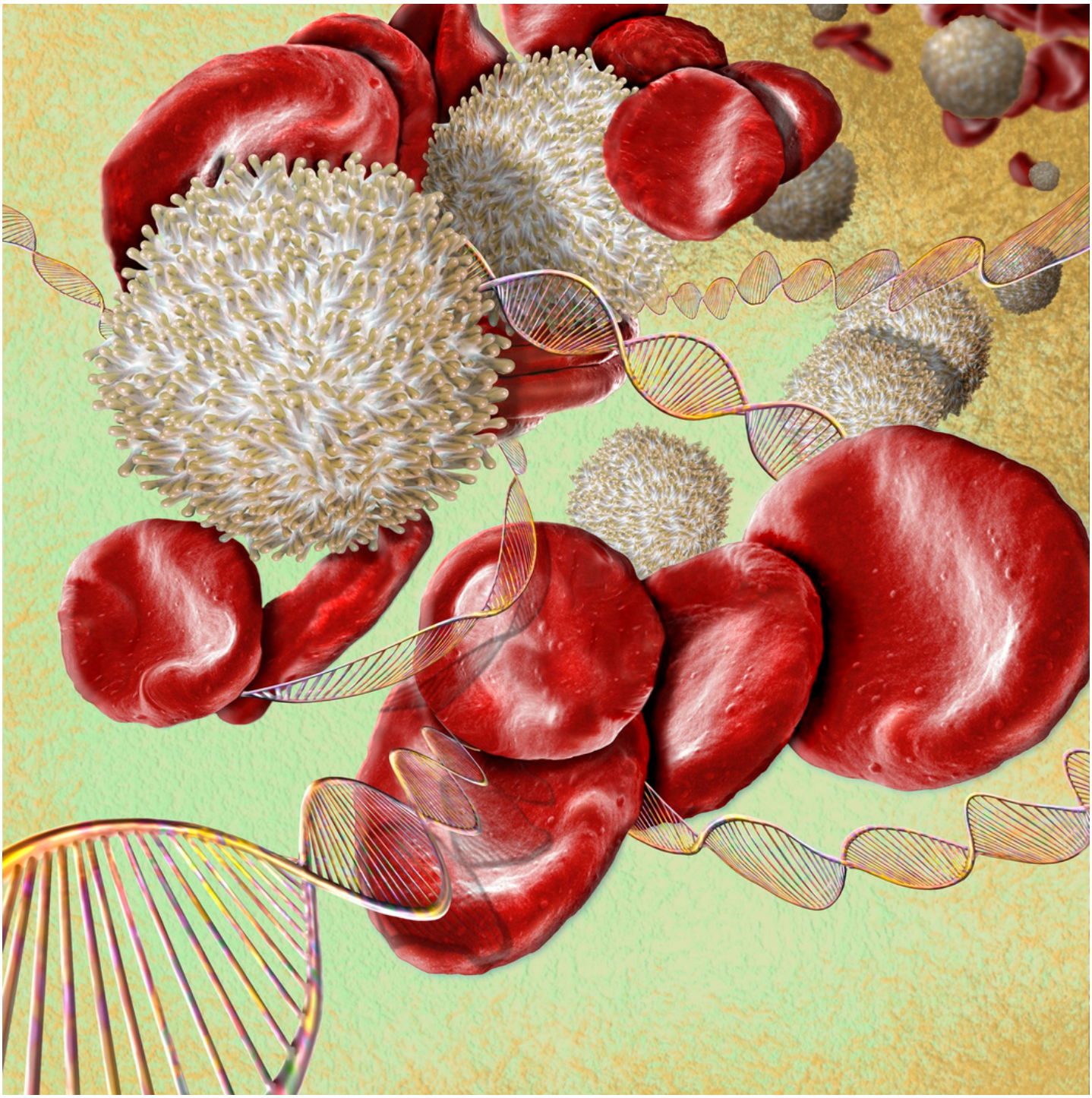
Today, many high-burden countries still struggle to mobilize the resources needed to properly and effectively implement critical SCD programs. Governments face additional challenges to improving SCD outcomes, including inadequate healthcare capacity and infrastructure, limited awareness about the disease, difficulty ensuring that SCD treatments are both accessible and affordable for patients, and insufficient funding for research and universal screening.[6]

Stakeholders from across sectors can improve SCD outcomes at the population level via the provision of treatment and care, and, in the future, via curative approaches such as gene therapy and other innovations. Though cross-sector collaboration will be necessary, governments must take seriously their responsibility to craft policy and prioritize specific actions to make progress against the disease. In line with



recommendations from The Lancet Haematology Commission on Sickle Cell Disease,[7] this paper conceptualizes five priority actions policymakers should take to accelerate efforts in combatting Sickle Cell Disease at the global, regional, and national levels. In addition, it details the biological origins of Sickle Cell Disease, denotes SCD's human, financial, and economic impact on patients and communities, and examines the current funding landscape and ongoing efforts to combat and contain the disease.

By providing a comprehensive analysis and actionable recommendations, the goals of this paper are twofold: first, to define five concrete actions policymakers can take to increase action on SCD. And second, to argue that cross-sector collaboration and coordination across public, private, and civil society sectors is critical to bring about transformative change in the fight against Sickle Cell Disease.



FIVE FOCUS AREAS FOR POLICYMAKERS

While the fight against Sickle Cell Disease will require action on many fronts, policymakers must implement five key actions to meaningfully accelerate and improve the global response to SCD.

1. Scale Newborn and Infant Screening
2. Integrate SCD Management into Primary Care Services
3. Expand Overall Access to SCD Care
4. Raise Awareness of SCD and Reduce Stigma
5. Facilitate Accelerated Innovation of SCD Treatments, Therapies, and Cures

1. Scale Newborn and Infant Screening

Systematically expanding newborn and infant screening is the single most tangible action policymakers can take to advance the fight against Sickle Cell Disease. According to one seminal study, Newborn Screening and Prophylactic Intervention (NSPI) packages were shown to be a valuable investment in most countries in sub-Saharan Africa, with an average cost per DALY averted of USD 184.[8] In other words, it costs USD 184 to save one year of healthy life with an NSPI package, whereas other health treatments are more expensive. For example, HIV treatments can cost between USD 620 and USD 1000 to save one year of healthy life.[9] Beyond economic advantages, newborn and infant screening can allow for more focused healthcare strategies, for example, by identifying children with the sickle cell trait, who are generally at a reduced risk for severe malaria.[10]

While newborn screening programs are now commonplace in most of the Global North, their presence is sporadic in other parts of the world. In Africa, despite some nations like Benin and Ghana implementing robust screening initiatives,[11] no country has yet fully implemented universal screening programs for Sickle Cell Disease.[12] Due to inadequate screening infrastructure, in some communities, up to 80% of newborns remain undiagnosed.[13] Unfortunately, far too many providers are missing opportunities to test for Sickle Cell Disease when children come in for routine immunizations and semi-annual check-ups.[14]

Without screening, diagnosis of SCD might be delayed until a child presents with symptoms or experiences disease-related complications; these delays in turn can lead to severe health consequences, including death.[15] Early detection, on the other hand, allows providers to execute timely interventions and implement appropriate management and treatment regimens, which can prevent or lessen complications such as Vaso-Occlusive Crises (VOC) and Acute Chest Syndrome (ACS).[16] Screening tools, including innovative, rapid, cost-effective point-of-care devices are essential to scale efforts on early detection.[17] By combining the use of these tools with routine procedures such as vaccinations, countries can create timelier and more efficient interventions at scale.[18]

2. Integrate SCD Management into Primary Care Services

If SCD is not incorporated into primary care services, patients may also face delays in receiving appropriate treatment. Complicating matters further is the fact that patients are often not receiving routine care due to the distance to treatment centers, a lack of available centers, and the economic burden of care-seeking.[19] In many cases, complications resulting from the disease can force patients to resort to emergency services, which can lead to higher out-of-pocket costs and a reduced chance of receiving the optimal treatment.[20] In situations where preventive care is unaffordable and the benefits are not well understood, emergency care tends to become the default, often too late.[21]

While tertiary centers predominantly handle SCD management in most African countries, some efforts are underway on the continent to broaden these vital services to primary and secondary healthcare facilities.[22] However, to ensure that SCD management is fully integrated into all primary care systems, Ministries of Health and other policymakers, in conjunction with administrators, must develop standardized SCD management protocols accessible to all healthcare providers and offer regular training programs to equip these professionals with the latest approaches in SCD care. Furthermore, primary care centers must be equipped with the essential tools, medications, and guidelines needed for managing the disease, ensuring that patients receive consistent care, regardless of which center they visit.[23] Finally, the successful transition of SCD patients from childhood to adulthood necessitates careful collaboration between pediatricians and internists at the primary care level to guarantee continuous, comprehensive care.[24] Ultimately, it is vital that SCD is integrated into the broader health system, rather than being treated as an isolated, vertical program.

3. Expand Overall Access to Basic SCD Care

Every individual with SCD deserves access to quality healthcare, irrespective of geographical location or financial barriers. Unfortunately, far too many individuals combatting SCD today have difficulties accessing the necessary treatments and support.[25] Following newborn screening, it is imperative to initiate preventive measures. Prophylactic penicillin, started in the first few weeks of life and continued until at least age five, has been shown to significantly reduce the risk of these infections; a landmark U.S. study reported an 84% infection reduction for young children receiving penicillin prophylaxis.[26] Pneumococcal vaccination, too, can prevent infant deaths of bacterial sepsis or severe anemia.[27]

As newborns with SCD mature, the focus shifts to supportive care, providing treatments such as pain medications or, in some cases, malaria prophylaxis.[28] Hydroxyurea, too, has demonstrated clear efficacy in reducing SCD symptoms, decreasing hospitalization rates and the frequency of pain crises and transfusions.[29] Distribution of hydroxyurea must be safe and low-cost in order to improve SCD outcomes, but increasing affordable access to the treatment has been a challenge to date.[30]

Blood transfusions also play a role in the management of Sickle Cell Disease.[31] While they can prevent or alleviate neurological damage or manage Acute Chest Syndrome, their use must be carefully tailored to the individuals to avoid complications.[32]

Although emerging gene therapy solutions offer promise for a curative approach to treating SCD, the high price point, health system resource needs and long-term hospitalization requirements make it inaccessible and burdensome for many patients, particularly those living in sub-Saharan Africa[33] and hard-to-reach areas.[34] As access to curative therapies expands, priority must be given to evidence-based, cost-effective efforts in diagnosis and care. Policymakers should therefore implement measures to broaden the reach of SCD treatments, including by increasing subsidies[35] for diagnostics, expanding targeted telemedicine programs,[36] and making strategic investments in improving overall healthcare infrastructure.[37]

4. Raise Awareness of SCD and Reduce Stigma

As a complex disease with myriad symptoms, treatment and management of SCD is clouded in misunderstandings and misconceptions. In some high-burden countries, SCD is conceived of by some as a supernatural phenomenon – a curse brought upon by enemies.[38] In the United States, where SCD mostly affects African Americans, lack of knowledge about the disease extends to healthcare providers, with only 20.4% of family physicians feeling confident to treat SCD.[39] Additionally, American SCD patients often face prolonged wait times in emergency rooms due to systemic and institutional racism.[40] These prevailing macro factors also influence physicians' attitudes about their own patients; in one study, for example, providers treating SCD patients were more likely to believe their patients were prone to opioid addiction.[41] As a result of these challenges, SCD patients can often suffer from uneven, inadequate, or extremely delayed diagnoses and care.

Improving understanding of the disease and addressing associated stigmas, however, will require a commitment to more robust and sustained awareness campaigns. The

importance of patient advocacy also cannot be overstated; AIDS activism has shown that when individuals mobilize, they can have a considerable impact in shaping national policies.[42] For the broader public, harnessing multimedia campaigns across television, radio, and online platforms can meaningfully improve awareness rate and lower stigma. Creative campaigns such as “artistic activism” can spark awareness about the issue.[43] Grassroots efforts such as community seminars and workshops can further demystify the condition amongst patients and caregivers. Engaging celebrities, faith-based leaders or other prominent figures can amplify SCD campaigns, while collaborations with schools and universities can help increase the likelihood that SCD is better understood by a greater number of individuals from an earlier age. Supplementing these efforts with comprehensive educational materials, like brochures and digital resources, can ensure that all segments of society have access to accurate and person-centered information about SCD. Targeted initiatives, which emphasize the importance of early screening, aimed at expectant parents can also help optimize treatment of the disease.[44]

5. Facilitate Accelerated Innovation of SCD Treatments, Therapies, and Cures

While increasing newborn screening and point-of-care diagnostics and expanding access to treatments like hydroxyurea will help improve outcomes in the coming years,[45] these actions alone will not be sufficient to tackle the growing challenge of SCD. In addition to expanding access to emerging disease-modifying therapies, implementation science approaches can assist with scaling up crucial evidence-based interventions, including prophylaxis for infection and proper hydration.[46]

Rapid advancements in cell phones and wearable devices will further allow for real-time monitoring of SCD patients. Improving access to such technological innovations could not only aid in tracking symptoms and medication routines but might also reduce the need for frequent clinical visits, making caring for patients both more cost-effective and consistent.[47]

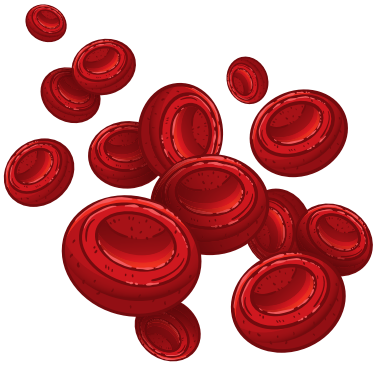
Looking to the future, decisionmakers will need to continue to invest in the development and refinement of curative approaches in the form of oral treatments, Hematopoietic Cell Transplantation (HCT) with Haploidentical Donors,[48] and mRNA-based in vivo gene therapies.[49] More research on gene therapy will be needed, specifically to address the safety concerns associated with base editing and prime editing.[50]

Additionally, policymakers must support the broader SCD innovation pipeline by making increased investments in sickle cell research; SCD grants, which have been shown to be highly effective in recent years, are one type of investment that could be expanded.[51] Decisionmakers must also make investments in research aimed at better understanding the triggers for sickle cell crises, as painful episodes often lead to expensive hospital stays. By proactively identifying the causes of these crises, providers could better manage patients' condition, reduce the need for medical interventions and lower overall care and treatment costs.[52]

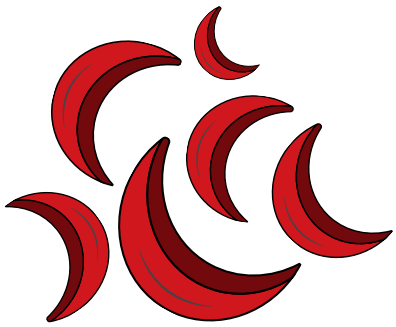
WHAT IS SICKLE CELL DISEASE?

Background

SCD is a genetic blood disorder that affects millions of people worldwide, causing immense pain and suffering, especially in children. The disease originates from a mutation in the gene tasked with hemoglobin production — a protein in red blood cells responsible for oxygen carriage in the body. The mutation culminates in the formation of Hemoglobin S, transforming the typically flexible, donut-like red blood cells into rigid crescent shapes. These malformed cells block capillaries and hamper oxygen delivery to tissues.



Normal Red Blood Cells



Sickled Red Blood Cells

Patients with SCD manifest a plethora of symptoms, primarily acute pain crises, anemia, and increased susceptibility to infections.[53] For children with SCD who survive into adulthood, chronic effects can gradually damage organs such as the lungs, heart, brain, kidneys, and bones.[54] One study found that out of 232 SCD patients who died, over 70% suffered from some form of irreversible organ damage.[55] By their fifth decade, almost half of the remaining patients (48%) showed permanent organ damage.[56] Affected organs can include the kidneys (kidney failure), gallbladders (gallstones), joints (arthritis), skin (open sores), brains (strokes), and eyes (impaired vision).[57]

SCD diagnostic procedures span from prenatal periods to old age. Prenatal testing for people with sickle cell trait or Sickle Cell Disease will include chorionic villus sampling (CVS) and amniocentesis,[58] while newborn screening will involve a heel-prick blood test shortly after birth.[59] From childhood to adulthood, SCD diagnosis can also be done through blood tests, as well as via physical exams or imaging studies, from MRIs to echocardiography.[60] While governments in the U.S. or Europe have made newborn screening mandatory, many nations struggle to incorporate these screenings into regular care processes.[61] Rapid, affordable point-of-care diagnostics can distinguish Sickle Cell Disease from sickle cell trait, where people have one normal and one abnormal hemoglobin gene.

Prevalence & Mortality

SCD predominantly afflicts individuals of African descent, including African Americans, with 1 in 13 being carriers of the sickle cell gene.[62] While its prevalence also extends to individuals from Central and South America, as well as those with Middle Eastern, Asian, Indian and Mediterranean origins,[63] Africa bears the brunt of SCD morbidity and mortality.[64] In affluent regions, patients with SCD may live well into their forties. Conversely, in low- and middle-income resource settings,[65] low awareness and lack of access to affordable care contribute to alarming rates of child mortality.[66]

TREATING SICKLE CELL DISEASE

In low- and middle-income countries (LMICs), the focus on managing Sickle Cell Disease (SCD) centers on early detection, prevention, and comprehensive care. Screening at birth or early in life is crucial, as it enables timely intervention and initiation of preventive measures. Prophylactic penicillin and vaccinations play a vital role in reducing the risk of infections, which are common and potentially severe in SCD patients. Transcranial Doppler (TCD) screenings are also important for identifying children at risk of stroke, allowing for early interventions. Comprehensive care includes proactive monitoring for infections and complications, ensuring that issues are addressed promptly.

While treatments like hydroxyurea remain a cornerstone in managing SCD, understanding and mitigating complication risks through early detection and intervention are essential. Indeed, for nearly two decades, from 1998 to 2017, hydroxyurea was the only FDA-approved treatment for SCD. In recent years, additional medications alleviating some SCD symptoms have been approved. While the emergence of these disease-modifying treatments is encouraging, SCD still lacks a widely available and affordable cure.

Presently, the only curative treatment is stem cell or bone marrow transplantation, which essentially replaces sickled cells with healthy ones. The specific procedure, hematopoietic stem cell transplantation (HSCT), is intricate and carries significant risks for patients. Thus, treatments like HSCT are only recommended for SCD patients suffering from extreme complications such as strokes, recurrent vas-occlusive crises, recurrent transfusions, and renal damage.[67] Because of the complications and adverse reactions many patients have to these approaches, researchers have been working on innovative, less invasive gene therapy solutions. While these solutions may become a viable alternative in the coming decades, due to their hefty price tags, most patients are unlikely to experience their benefits in the near-term.

UNDERSTANDING THE GLOBAL BURDEN OF SICKLE CELL DISEASE

Human Toll

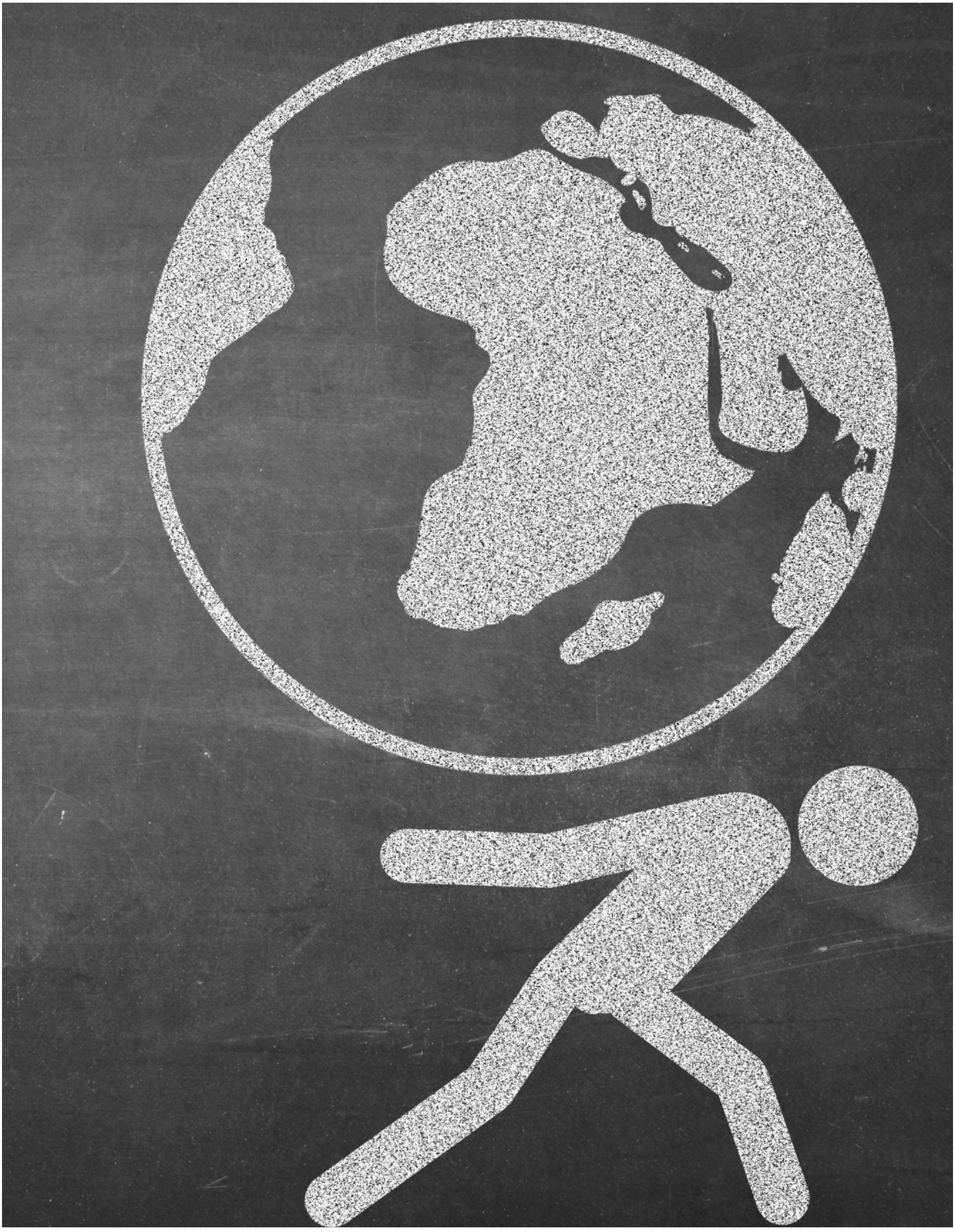
The global burden of SCD is both severe and multi-faceted, impacting individuals and healthcare systems alike. On the individual level, those with SCD face recurring pain, frequent hospital admissions, and lasting organ damage. Many patients struggle with debilitating, long-lasting disabilities. This combination contributes to missed workdays, fewer employment opportunities, and disruptions in education.

Aside from physical impacts, SCD sufferers also face heightened risks of depression and often remain untreated due to the stigma associated with the disease.[68] In one cross-national study, 60% of patients reported frustration with symptoms.[69] The unpredictable nature of SCD, causing sufferers to experience unexpected bouts of debilitating acute pain, along with the fear of disease progression, can lead to heightened anxiety.[70] A poignant reflection from a sickle cell patient in Nigeria encapsulates these challenges:

> “My life is a constant struggle laced with the uncertainty of whether I am going to witness my next birthday, ever get married or have my own children.”[71]

This struggle is further intensified by disparities in healthcare quality and access. In affluent regions, patients with SCD may live well into their forties, though individuals with SCD are projected to live 22 years less than those without the disease.[72] The situation in LMICs is even more alarming: many children with SCD don’t survive to adulthood, with over 500 succumbing daily due to inadequate newborn screening and limited treatment access.[73]

The poor quality of life of patients with SCD may force them to take difficult decisions with respect to childbearing. One study of Cameroonian patients reported a notably high percentage (40.9%) of patients with severe SCD open to the idea of pregnancy termination.[74]



Financial and Economic Costs

Medical expenses amount to USD 1.6 million for women and USD 1.7 million for men

The financial burden incurred by Sickle Cell Disease is staggering. The average lifetime medical expense for an SCD patient in the U.S. can soar to approximately USD 1.6 million for women and USD 1.7 million for men.[75] Though comprehensive financial data for SCD across Africa is sparse, one study in Nigeria found that, despite the reality that the average household income ranges between USD 27.15 and USD 716.64 per month, the monthly health expenditure for SCD spans from USD 5.43 to USD 466.90.[76]

USD 700,000 is the average income loss of SCD patients in the U.S.

In addition to the direct medical costs of the disease, SCD also has cascading effects on employment and income. A U.S.-based study projected major income losses due to the unrealized earning potential over an SCD's sufferer life, calculated at nearly USD 700,000.[77] The actual number is likely larger, as this figure does not include other societal expenses, like days missed from work due to disability, lost educational opportunities, caregivers' lost workdays, and hospital visits.

Children with SCD miss between 16.3 and 18.2 days of school

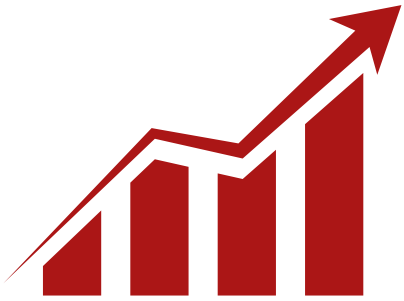
Studies from the U.S. and U.K. demonstrate that children with SCD miss between 16.3 and 18.2 days of school per academic year.[78] The blood disorder not only hampers children's immediate education, but it also has lasting repercussions, with many students facing grade retention or requiring special education.[79] For adults with SCD, the disease significantly affects their employment prospects. One Brazil-based study reported a nearly 50% rate of unemployment among adults with SCD.[80]

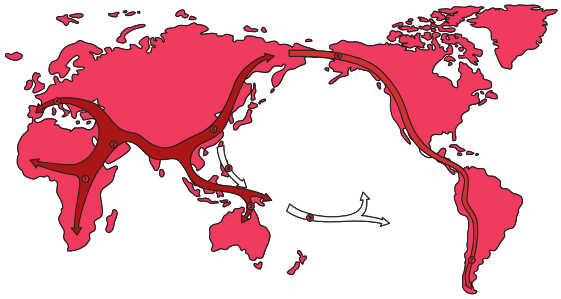
83.3% of SCD caregivers experience income loss

The ripple effect of SCD's financial toll extends to caregivers as well. A study of caregivers of children with SCD in Nigeria found that 83.3% of caregivers mentioned that the dedication required for caregiving for a loved one with SCD resulted in lost income or other financial hardship.[81] Additionally, almost one-fifth (19.6%) of caregivers resorted to borrowing money to cover the costs associated with the disease.[82]

Future Challenges

The challenges posed by Sickle Cell Disease could increase in the coming decades if no action is taken. By 2050, the number of newborns with the hemoglobinopathy is expected to rise by 30% globally.[83] Economic and geopolitical crises, coupled with climate change pressures, will likely increase migration flows.[84] As a result, SCD prevalence is likely to shift and increase across geographies. The disparity in care between developed and developing nations will further exacerbate the challenges associated with managing the disease. For instance, hydroxyurea has seen limited adoption in sub-Saharan Africa, driven by a lack of medical professionals in rural areas, inadequate equipment for regular blood checks, and higher acquisition and administration costs.[85]





INTRODUCING THE WORLD COALITION ON SICKLE CELL DISEASE (WCSCD): JUMPSTARTING EFFORTS TO COMBAT SCD

The significant global burden associated with the disease and the clear societal costs of continued inaction underscore the urgent need to take concerted global measures. Making strides against SCD will substantially decrease costs for patients, caregivers, insurers, and providers in the long term.[87] In addition to generating savings, a study examining the economic effects of SCD found that curing the disease could also meaningfully close economic disparities within impacted communities.[88] Beyond economically empowering SCD patients, numerous studies have demonstrated that investments in global health infrastructure generate a wide range of economic benefits. For example, a recent McKinsey report found that that these interventions can boost labor force productivity, thereby increasing GDP in countries with high prevalence of SCD.[89]

But revitalizing the effort to combat SCD in all affected communities will require a reimagined, comprehensive, cross-sectoral global approach. Governments should develop national agendas and create initiatives aligned with the above policies; the life sciences industry should continue R&D into new innovations; international organizations can direct policy priorities and funding toward SCD; and advocates can increase the profile of the disease on national, regional, and global agendas. Additionally, other industry players in sectors with an interest in improving SCD

outcomes – such as energy, mining, telecommunications, hospitality, and finance – will be important voices to both understand and shape systemic approaches that address SCD.

The World Coalition on Sickle Cell Disease (WCSCD) will add unique value by coordinating these stakeholders, facilitating the sharing of best practices, and aligning global efforts with local needs. The Coalition will serve as a cohesive platform for action and support of health systems' strengthening by developing policy guidance, advising policymakers, connecting local and global advocacy moments through targeted convenings and advocacy campaigns, and developing a knowledge repository of up-to-date resources.

Initially founded by the World Health Organization, the World Bank, the U.S. Department of Health and Human Services, and private sector leaders, this new Coalition provides a unique, multi-stakeholder and cross-sectoral platform for elevating SCD globally and enhancing the coordination of programmatic efforts at national and regional levels.

As part of the Coalition's remit, we will work to ensure that the most effective actions to tackle SCD are prioritized. Early detection in newborns and infants, along with mandatory screenings and a well-trained healthcare workforce, are paramount. Further, to ensure consistent and quality care for all SCD patients, the Coalition will advocate for the integration of SCD management into primary healthcare systems. Because comprehensive care would not matter if stigma and awareness are still barriers to seeking it, the Coalition will elevate local advocacy campaigns and tactics to milestone moments within the Global Health calendar. This advocacy will include an emphasis on upskilling physicians and nurses to understand how to diagnose and treat the disease. Finally, we will work with stakeholders at the systems level to ensure that cutting-edge treatments can be accessible and affordable for all communities, regardless of income level.

WCSCD has outlined an ambitious plan for 2024, emphasizing its role as a platform to increase resources, provide policy guidance at country level, and amplify advocacy campaigns on the global stage. A core component of this plan is Resource Mobilization, with strategies in place to boost financial and programmatic support, including a targeted Communications Campaign for resource acquisition. The Secretariat will play a pivotal role in the Coalition's operations, from governance and coordination to member engagement, and it will be responsible for developing policy assets that can inform country governments on how to operationalize SCD commitments.

On the global stage, the Coalition will elevate SCD by actively participating in major global health moments, including prioritizing an event on the continent of Africa. WCSCD will cultivate new partnerships within and outside the SCD ecosystem and take advantage of emerging opportunities to inject the topic into salient discussion and debates. Finally, the Coalition aims to contribute to knowledge sharing on SCD by acting as a repository of expert information, keeping up with the fast pace of innovations. WCSCD's overarching objectives in 2024 are to expand, engage more effectively with existing players in the field of SCD, and elevate the issue on national, regional, and global agendas.

By providing a vehicle for cross-sectoral stakeholders to better mobilize, organize, and advocate for action on Sickle Cell Disease, the WCSCD aspires to jumpstart efforts to combat the disease. We are currently seeking new partners and members, and we look forward to driving meaningful, measurable, and lasting change.

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