COMMENTARY

blood advances

TO THE EDITOR:

World Coalition on SCD launches, sparking global focus on SCD diagnosis and care

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People living with sickle cell disease (SCD), hematologist advocates, public health professionals, and nongovernment organizations have for years been sounding the alarm that SCD remains nonprioritized and underfunded by public health programs throughout the world. Despite consistent advocacy, sustained momentum in the global SCD response has been difficult to achieve. With the many advances in research and implementation of diagnosis, treatment, and evidence-informed care for SCD, the need is still unmet in most parts of the world, especially in regions with high disease burden. In 2023, a public-private partnership, the World Coalition on SCD, has been launched to officially change the narrative and spark change in the local, national, and global health landscape to finally prioritize this neglected disease.

SCD, an inherited blood disorder, has stark regional differences in individual access to diagnosis and care, and predictable disparities in outcomes. Primarily a disease affecting persons of African or South Asian descent, SCD is an example of the extreme health inequities that exist globally, compounded by socioeconomic factors, such as race, education, stigma, discrimination, and misinformation. In some high-income countries, SCD is included in a panel of disorders screened at birth. When parents of affected children are notified, they are linked to coordinated care by hematologists, pediatricians, and other allied health professionals offering evidence-based interventions, disease-modifying therapies, and potentially curative therapies, such as bone marrow transplant or gene therapy.

This is not the case in low- and middle-income countries (LMICs), particularly in sub-Saharan Africa and India, where resources are constrained and the burden of disease is much greater than in other regions. According to the recent Global Burden of Disease report, in 2021, >500 000 people were born annually with SCD, a majority in sub-Saharan Africa, with SCD being the 11th leading cause of death in children aged <5 years.[1] Without interventions, >50% will not live up to 5 years of age. Studies have shown that SCD causes a significant percentage of mortality among those under 5 years, and many of the key evidence-based interventions are cost effective and can be integrated into broader primary health care programs. The recent Lancet Commission on Global SCD Strategies reinforces that these interventions are well known and the stakeholders are capable, and it is now more important than ever to coordinate a global response to SCD.[2]

In response to the United Nations General Assembly declaring SCD a public health priority in 2008,[3] several projects, programs, and community-based organizations have been able to successfully screen, care, and support persons living with SCD in LMICs. However, these projects have not always translated to sustained, scaled up health system–level change that integrates these efforts into universal health coverage initiatives and other primary care efforts. Other than small efforts housed in noncommunicable disease offices, many nongovernment organizations and research groups, country governments, and domestic, bilateral, and multilateral donors have not been able to coordinate and

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prioritize SCD commensurate to its burden of disease. To achieve the United Nations Sustainable Development Goal 3.2 Ending Preventable Child and Newborn Deaths by 2030, many countries will need to quickly fund and implement SCD interventions.[4] As of 2023, universal newborn screening has not been implemented by any country in sub-Saharan Africa, and there are limited programs to provide care and educate health care providers on SCD treatment.[5]

However, thanks to advocates, shifts are starting to occur. At the August 2022 World Health Organization (WHO) Africa Regional Office regional meeting, Ministers of Health spoke about the need to do more to address SCD in their countries.[6] Global programs to address noncommunicable diseases, such as heart disease, type 1 diabetes, and SCD, are now working with district level hospitals. Even with delays from the COVID-19 pandemic, the fourth Global Congress on SCD was held at Paris, France in June 2022, with advocates calling for global strategies to eliminate SCD. The Indian Government has prioritized eradicating SCD by 2047.[7]

Many broad international activities and networks have been established to strengthen SCD efforts, and this has been done through collaboration among medical scientists, researchers, community-based organizations, and industry partners. Such efforts will be highlighted by the coalition and shared so that others can learn from and adapt such initiatives to their local contexts. The creation of a coalition is vital to best coordinate efforts across broad stakeholders and support national partners in developing multisectoral strategies and fundraising plans via domestic, local, and global funders.

The World Coalition on SCD was initially founded in 2020 under the leadership of the US Department of Health and Human Services, World Bank, and WHO. Stakeholders were dedicated to addressing the SCD burden in LMICs, but the COVID-19 pandemic disrupted the momentum of the coalition and delayed implementation. In 2022, on the sidelines of the Global Congress on SCD, Global Blood Therapeutics, now Pfizer, and the Global SCD Network, convened stakeholders to rebuild the global coalition and recommit to its goals. Core steering committee members agreed to begin revising the coalition's goals, objectives, and governance structure.

From June 2022 to the present, core steering committee members including the American Society of Hematology, Global Alliance of SCD Organizations, Global SCD Network, Novartis, Pfizer, Pierre Fabre Foundation, and WHO Africa Regional Office have connected with broad stakeholders to identify the key priorities of the coalition and how to affect the most change.

The goal of the coalition is to vastly reduce childhood mortality associated with SCD and significantly improve the lives of those living with the disease in LMICs. The coalition seeks to do so by

- engaging country stakeholders, including government, community-based organizations, health care providers, and more, in developing national SCD strategies;
- working with donor communities to mobilize resources to support SCD efforts; and
- acting as a repository of best practices to ensure that quality care can be provided regardless of the geographic location of the individual.

In May 2023, the World Coalition on SCD officially launched on the sidelines of the World Health Assembly in Geneva, Switzerland during an event hosted by Novartis, the Business Council for International Understanding, and the Republic of Uganda Ministry of Health. Government representatives, industry partners, and civil society organizations worked together to showcase the burden of SCD and commit to work to end preventable child deaths by 2030 as part of the United Nations Sustainable Development Goal agenda. Participants also agreed on the need to prioritize targeted, sustainable interventions and how to best mobilize resources to make an impact on the disease.

With the relaunch of the coalition, we are excited to bring more stakeholders together to support our efforts. People living with SCD, medical providers, allied health professionals, advocates, industry partners, private sector, and broader civil society organizations are asked to participate in this endeavor. The coalition is looking for experts to help in developing the templates and diverse goals of country stakeholders into national plans, link health care providers to SCD technical and financial resources, find ways to mobilize further funding for implementation of SCD programs, and to catalyze global advocacy to sustain these efforts. Now more than ever, the coalition will work with a broad range of stakeholders to (1) showcase to government leaders and other global health decision makers the unmet needs; (2) articulate why SCD needs to be prioritized, including sustained funding allocations to support diagnosis and care needs to be rapidly allocated; and (3) calling attention to the importance of education for health care professionals and capacity building support to reach all individuals living with the disease.

More information on our work can be found at the coalition website.[8] We look forward to you joining our collaborative international efforts to address SCD.

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