Global mortality from sickle cell disease may be nearly 11 times higher than previously believed, says the Commission of world experts on sickle cell disorders.

According to the Advisory Commission published in The Lancet Haematology journal on July 11 by sickle cell disease experts from around the world, over half a million babies were born with sickle cell disease in 2021.

The Commission highlights how newborn screening for sickle cell disease can lead to babies with the disease receiving life-changing treatment before symptoms develop and calls for all babies worldwide to be tested for sickle cell disease by 2025 to prevent long-term complications of the disease.

The study revealed a strikingly high contribution of sickle cell to all-cause mortality that is not apparent when each death is assigned to only a single cause.

The study suggests there were 376,000 global sickle cell-related deaths in 2021, compared to 34,400 cause-specific deaths.

The study shows the global mortality burden from sickle cell disease may be nearly 11 times higher than previously estimated.

Dr. Biree Andemariam, director of the New England Sickle Cell Institute at UConn Health, noted in the published report, “We note the seriousness of the global burden of sickle cell disease and the inequalities in diagnosis and basic clinical care.”

According to the Commission of global experts, reducing the burden of sickle cell disease requires substantial financial and political commitment to improving data collection, diagnosis, treatment and training.

“The commission gives succinct recommendations on how countries can mobilize at all levels—government, health system, community– to improve health outcomes within short and realistic timeframes,” says Andemariam. “This will positively impact the lives of millions of patients and families living with sickle cell disease worldwide.”

“The number of deaths due to sickle cell disease is increasing globally,” says Dr Frédéric Piel of Imperial College London who chaired the Commission.

Dr. Piel adds, “The changes identified in our Commission are achievable and will improve the lives of people with sickle cell disease worldwide.”

Further, it also shines a light on sickle cell disease inequity globally. It also shines a light on the lack of clinical trials aimed at developing novel treatments.

The Commission further says that in the context of increasing global inequalities, partly driven by racism, previous calls for action on sickle cell have been largely ineffective. There is an urgent need for all people with sickle cell to have access to minimum specific health care no matter where they live. It is also necessary to prioritize and increase funding for research on all aspects of the disease.