



MTS
SICKLE CELL FOUNDATION, INC.

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CO SPONSOR REQUEST: SICKLE CELL DISEASE TREATMENT CENTERS ACT OF 2022

September 20, 2022

Hello Senator Ossoff,

My name is Mapillar Dahn and I am a resident of our great state of Georgia.

I am also the founder of MTS Sickle Cell Foundation, Inc., a national sickle cell organization that I established in honor of my three beautiful daughters Tully, Deej and Hajar, who all have Sickle Cell Disease.

As one can imagine, life with three children with Sickle Cell Disease is very challenging. Between my three daughters, we've had over 100 blood transfusions, 10 surgeries, 1 stroke, and too many hospitalizations to count. And that's just in the last 10 years.

Sickle cell disease is a very brutal disease and is even more challenging when patients and their families have to struggle outside of the medical environment due to the socio-economic strains that are a direct result of a very unpredictable disease. Because it is a blood disease, its impact can be felt on every part of the body. A person can go blind from it, have a stroke, have organ damage, experience excruciatingly painful episodes called crises, and even die from its complications.

While the life expectancy of patients with SCD has increased with improved childhood treatment, too many Americans lack access to specialized providers with an understanding of chronic care management and a comprehensive care team including primary care and mental health services.

Despite the need for consistent and coordinated treatment, few patients with SCD have access to multidisciplinary care teams. Many health care providers lack the knowledge and resources to address patients' unique health challenges over the course of their life. In addition, many Americans who may have sickle cell trait do not know they have it or do not have access to counseling, and, as a result, may not receive the care they need to respond to these potential complications. Yet, funding for education and treatment for SCD and sickle cell trait is extremely limited compared to that for other disabling chronic diseases.

Comprehensive Care Centers exist across the country, but if a patient does not live nearby, they can face hours of travel and even overnight stays. A patient who needs regular treatment or transfusions, like my daughter Deeji, may need to take days off or miss countless hours of educational hours to access care. Someone who experiences an acute pain episode, like my rising Freshman Tully who is currently attending Oglethorpe University, may have no choice but to go to a local emergency room that is ill-equipped to provide effective treatment.

It is with this backdrop that I write to urge you to cosponsor The Sickle Cell Disease Treatment Centers Act of 2022 (H.R. 8855/S. 4866).

The Sickle Cell Disease Treatment Centers Act of 2022, introduced by Senator Chris Van Hollen (D-Md.), Senator Cory Booker (D-N.J.), Representative Barbara Lee (D-Calif.), and Representative Danny Davis (D-Ill.), would address the unmet needs of patients with SCD, sickle cell trait, and other heritable hemoglobinopathies through the establishment of and funding for a nationwide system of treatment centers as well as much-needed provider and patient training and education resources. The legislation establishes a nationwide network of more than 120 Sickle Cell Disease Treatment Centers based on a hub-and-spoke framework and provides support for 100 community-based organizations, creates a National Coordinating Center to coordinate the National Sickle Cell Disease Treatment Center Program, and authorizes appropriations of \$535,000,000 for fiscal year 2023 and each fiscal year thereafter.

I write to you today as a mother and an advocate for many who feel voiceless and many of whom suffer in silence. The Sickle Cell Disease Treatment Centers Act of 2022 presents an opportunity to boldly tackle the healthcare disparities that exist for over 100,000 Americans and their families who are impacted by this global health issue,

thereby making a significant and meaningful impact to improve the lives of patients with SCD, sickle cell trait, and other heritable hemoglobinopathies. Please co-sponsor The Sickle Cell Disease Treatment Centers Act of 2022 and stand in solidarity with me, my daughters, and the roughly 10,000 Georgia families who are impacted by this life-threatening disease.

I have attached the text of the Sickle Cell Disease Treatment Centers Act as well as a one page summary, however if you have any questions about the legislation, please contact Erika Ninoyu (Congresswoman Barbara Lee's office) at Erika.Ninoyu@mail.house.gov or Shayla Britton (Senator Chris Van Hollen's office) at Shayla_Britton@vanhollen.senate.gov.

Thank you so much for your time, consideration, and for your support.

Sincerely,

Mapillar Dahn

