



March 23, 2021

Dear Congressperson,

On behalf of the sickle cell disease community, we urge you to take action by prioritizing a special oversight hearing on the recommended strategies to improve health care for the approximately 100,000 people in the United States living with sickle cell disease (SCD).

SCD is an inherited blood disorder that disproportionately affects Black and Brown populations in the United States, including roughly 1 in 365 Black and African Americans, and 1 in 14,000 Hispanic Americans. Due to racism and patterns of health inequities in the United States, the SCD population has been marginalized in the realms of research, data collection, education, and access to quality care across the healthcare continuum. Without robust funding for research and treatment, the lives of those living with SCD are approximately 40 years shorter than the average U.S. adult lifespan. Furthermore, the lack of coordination and proper preventative care provided by the medical system results in roughly [\\$2.98 billion](#) in annual healthcare costs. The COVID-19 health crisis has only exacerbated the disparities and inequities found in the SCD community.

In 2020, the National Academies of Sciences, Engineering, and Medicine (NASEM) published a report entitled, "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action." Based on its review of the current needs for treating SCD and input from public comments, the committee developed a strategic plan and blueprint for SCD action and identified strategies and specific actions for improving care and outcomes, including:

- Expansion of nationwide data collection
- Establish national registry
- Provide clinical and nonclinical support through existing health programs (SSA, OMH, etc.)
- Address disparities by reducing barriers to access care and treatment

As you consider the priorities in your work this year, we request that Congress mandate an annual hearing on the NASEM report within the Committee on Energy and Commerce, calling the following witnesses: Admiral Brett Giroir, former Assistant Secretary for Health; Ashley Valentine, Co-founder and President of Sick Cells; a NASEM staff member; a sickle cell disease patient advocate.

The NASEM strategic plan and blueprint for addressing SCD in the United States is an important milestone toward improvement. Now, we need Congress to perform oversight and ensure progress is made to improve care and outcomes for individuals with SCD.

We thank you for including the sickle cell disease community in important advances in public health policy at the federal level. As a community, we are ready to work with all of our members of Congress to implement historic changes in the care and treatment available to those living with SCD in the United States. We are happy to provide insight into the experience of the patient and caregiver community,



which should remain central in the decision-making process. We welcome the opportunity to meet with you to discuss the priorities of the sickle cell community and facilitate engagement with sickle cell disease nonprofits across the country for much-needed change. Please contact Ashley Valentine at avalentine@sickcells.org for inquiries related to the contents of this letter or to schedule a meeting.

We look forward to working with this Congress to transform health outcomes for sickle cell disease patients across the country.

Sincerely,

Ashley Valentine

A handwritten signature in black ink that reads "Ashley Valentine". The signature is written in a cursive style with a large, stylized initial "A".

Co-founder, President
Sick Cells