The Honorable Brett Guthrie
Chair
Subcommittee on Health
House Energy and Commerce Committee
United States House of Representatives
Washington, DC 20515

The Honorable Anna Eshoo
Ranking Member
Subcommittee on Health
House Energy and Commerce Committee
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**June 14, 2023**

Dear Chair Guthrie and Ranking Member Eshoo,

Sick Cells is a national sickle cell disease organization with the mission of elevating the voices of the sickle cell community to ultimately influence decision-makers and project positive change.[1] Sick Cells works with a wide variety of stakeholders including individuals and families living with sickle cell disease (SCD), medical providers, payers, manufacturers, government agencies, academic research centers, and other community-based organizations. Our vision is to ignite public interest in SCD, humanize the disease, inspire the public to take action, and empower the SCD community to share their stories to know that they are not alone.

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.[2] 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. Because of the lack of 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.

Sick Cells is pleased to see the Committee hold a hearing on important legislation that will impact the lives of tens of thousands Americans living with SCD. This population has historically been overlooked in federal funding, access to life-saving treatments, and cures. We applaud Representative Burgess, Davis, and Carter for their introduction of the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023* and truly appreciate their continued support of the SCD community's priorities.

The federal government, through legislation and program funding, is uniquely positioned to support and address the needs of the sickle cell disease community and design and coordinate a longitudinal

[1] "About Us." *Sick Cells*, 8 Feb. 2023, sickcells.org/.
[2] "Data & Statistics on Sickle Cell Disease." *Centers for Disease Control and Prevention*, 2 May 2022, www.cdc.gov/ncbddd/sicklecell/data.html#:~:text=SCD%20occurs%20among%20about%201,sickle%20cell%20trait%20(SCT).

understanding of the SCD community to improve health outcomes, quality of life, and reduce the cost of care.

There is an opportunity to build on the current efforts and (1) expand identification of individuals living with SCD through the CDC Sickle Cell Data Collection (SCDC) Program; and (2) enhance education about SCD and improve on quality of care through ECHO program and provide much-needed funding and support to federally qualified healthcare centers and community-based organization who directly serve the community through HRSA's programming.

Despite important advances in federal priorities for SCD, health disparities in the treatment of individuals with sickle cell in the United States continue. The financial and economic burden for an individual with SCD is unimaginably costly. The average annual cost caring for a child with SCD with insurance can cost up to $10,000. As an insured adult with SCD, the annual cost can be three-times as much as a child costing $30,000, annually.[3] An individual with SCD in America will pay four-times as much as an adult without a chronic condition in out-of-pocket expenses, totaling up to $44,000 in their lifetime.[4] Furthermore, the lack of coordination and proper preventative care provided by the medical system results in roughly $2.98 billion in annual healthcare costs.[5] The COVID-19 health crisis has only exacerbated the disparities and inequities found in the SCD community.

To date, there still is not a universal standard of care for people living with SCD. Furthermore, individuals with SCD have less access to comprehensive care than others living with genetic disorders, such as hemophilia and cystic fibrosis. Project ECHO and other educational efforts are designed to improve knowledge about care administration for individuals with SCD. While the intention of the education programs is clear, there is a disconnect in coordination between the existing federal programs and a need for more robust funding. Therefore, barriers still exist to quality healthcare.

With much innovation, including cutting-edge treatments like gene therapy for SCD on the horizon, this legislation provides an opportunity to enhance resources to programs that work towards improving access to care. Sick Cells hopes to see improved coordination among the services offered through the federal government. Each service builds upon the next, thus resulting in the services leaving individuals from the SCD community behind, when the services are not aligned.

In 2018, the SCD community unified in our request to pass the *Sickle Cell Disease and other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act*. We worked closely with the same key champions who are still supporting us today. We were overjoyed to see Public Law No. 115-327. In 2020, the 116th Congress made history by being the first Congress to appropriate $2 million funding

[3] Kauf, Teresa L., et al. "The Cost of Health Care for Children and Adults with Sickle Cell Disease." *American Journal of Hematology*, vol. 84, no. 6, 2009, pp. 323–327, https://doi.org/10.1002/ajh.21408

[4] Johnson, Kate M., et al. "Lifetime Medical Costs Attributable to Sickle Cell Disease among Nonelderly Individuals with Commercial Insurance." Blood Advances, vol. 7, no. 3, 2023, pp. 365–374, https://doi.org/10.1182/bloodadvances.2021006281.

[5] Huo, J, et al. "The Economic Burden of Sickle Cell Disease in the United States." *Value in Health*, vol. 21, 2018, https://doi.org/10.1016/j.jval.2018.07.826.

towards the SCDC Program. These steps were important steps to begin addressing the disparities the SCD community has faced for over 110 years. Nonetheless, more action is needed to address the challenges of SCD, and Sick Cells is happy to continue to help the Committee to develop and enact policies to ultimately solve these challenges.

The sickle cell community continues to advocate for robust funding for the SCDC Program as there is a historical need for this data collection. Improvements for the SCD community require a longitudinal understanding of the unique needs of the patient with ongoing coordination of care and services. Prior to the expansion of the data collection program, Georgia and California were the first and only two states to be actively collecting SCD data. Currently, the SCDC program has expanded to 11 states, however these states do not cover the majority of the Americans living with SCD. The total 13 states only address 35% of the national SCD population and excludes individuals that identify as non-African-American or Native American.[6]

The ongoing support of funding SCD-related programs roughly impacts 100,000 Americans who unfortunately are slipping through the cracks of a system; a system that we are confident is capable of making the much-needed change that the sickle cell disease community requires to eliminate health disparities and save lives.

**We thank you for including the sickle cell disease community in important advances in public health policy.** As leaders in the SCD space, we are looking forward to working with you, members of the Energy and Commerce Committee, and our Champions on this matter. If you have any questions, please contact **Emma Andelson** at **eandelson@sickcells.org** or **Ashley Valentine** at **avalentine@sickcells.org**.

[6] Snyder, Angela B., et al. "Surveillance for Sickle Cell Disease — Sickle Cell Data Collection Program, Two States, 2004–2018." *MMWR. Surveillance Summaries*, vol. 71, no. 9, 2022, pp. 1–18, https://doi.org/10.15585/mmwr.ss7109a1.