

The Honorable Nancy Pelosi
Speaker of the House
United States House of Representatives
Washington, DC 20515

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
Washington, DC 20515

The Honorable Chuck Schumer
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Lloyd Doggett
Ways and Means Committee, Health
Subcommittee
U.S. House of Representatives
1102 Longworth House Office Building
Washington D.C. 20515

The Honorable Frank Pallone, Jr.
Committee on Energy and Commerce,
Democratic Staff
2125 Rayburn House Office Building
Washington, DC 20515

June 16, 2021

Dear Speaker Pelosi, Leaders McCarthy, Schumer, McConnell, and Chairmen Doggett and Pallone, Jr.,

Sick Cells is a national sickle cell disease organization with the mission of improving the lives of people with sickle cell disease through advocacy. In the spirit of this mission, Sick Cells partners with other organizations to address the needs of the community. For this request, we have collaborated with the Sickle Cell Disease Association of America, its 52 members, and other sickle cell disease grassroots organizations.

Despite important advances in federal priorities for sickle cell disease, three recent New York Times articles highlight the continued disparities in the treatment of individuals with sickle cell disease in the United States. From stories about medical providers failing to order preventative tests to instances of sickle cell being used as a cover for inadmissible police behavior, individuals living with sickle cell disease in the United States continue to be underserved and mistreated. As a community, we request that Congress mandate an annual hearing on the 2020 National Academies of Sciences, Engineering, and Medicine's report on sickle cell disease within the Committee on Energy and Commerce.

Sickle cell disease (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 this country, 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 2018, a bipartisan effort led to the passing of [Public Law No. 115-327](#), the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act. In 2020, the SCD community celebrated the release of a groundbreaking report on sickle cell disease by the National Academies of Sciences, Engineering, and Medicine (NASEM), commissioned by the Office of the Assistant Secretary for Health. **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.**

Based on NASEM's 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 representatives from the following entities as witnesses: the Office of Minority Health; Sick Cells; Sickle Cell Disease Association of America; the American Society of Hematology; a NASEM staff member; and 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.

Signed in Alphabetical order:

Advancing Sickle Cell Advocacy Project, Inc.
American Society of Hematology
Axis Advocacy
Bridging the Gap - Adult Sickle Cell Disease Foundation of Nevada
Cayenne Wellness Center
Citizens For Quality Sickle Cell Care
Dreamsickle Kids Foundation
Foundation for Sickle Cell Disease Research
Kids Conquering Sickle Cell Disease Foundation
Martin Center Sickle Cell Initiative
MTS Sickle Cell Foundation, Inc.
New York State Sickle Cell Advocacy Network, Inc.
Northeast Louisiana Sickle Cell Anemia Foundation
Sick Cells
Sickle Cell Anemia, Inc.
Sickle Cell Association
Sickle Cell Association of Delaware
Sickle Cell Association of Kentuckiana
Sickle Cell Association of Texas Marc Thomas Foundation
Sickle Cell Awareness Foundation Corp. Int.
Sickle Cell Disease Association of America - Miami-Dade County Chapter, Inc
Sickle Cell Disease Association of America - Michigan Chapter
Sickle Cell Disease Association of America - Philadelphia/ Delaware Valley Chapter
Sickle Cell Disease Association of America - West Alabama Chapter, Inc.
Sickle Cell Disease Association of America, Inc
Sickle Cell Disease Association of Illinois
Sickle Cell Reproductive Health Education Directive
Sickle Cell Thalassemia Patients Network
Sickle Cell Warriors, Inc.
Southwest Louisiana Sickle Cell Anemia, Inc.
St. Petersburg Sickle Cell Foundation
Supporters of Families with Sickle Cell Disease, Inc.
The Association for the Prevention of Sickle Cell Disease for Harford and Cecil Counties
The Maryland Sickle Cell Disease Association
The Sickle Cell Association of New Jersey
The Sickle Cell Foundation of Tennessee
TOVA Community Health
Two Tarrer Girls, Inc.
Uriel E. Owens Sickle Cell Disease Association of the Midwest