SICKLE CELL DISEASE PARTNERSHIP

We Stand With Individuals Who Have Sickle Cell Disease

An Urgent Call to Federal Policymakers to Strengthen Access to High-Quality, Equitable Care and Treatment

The Sickle Cell Disease Partnership, representing more than a dozen organizations, is working to improve outcomes for people with Sickle Cell Disease (SCD) by advocating for better access to qualified, trained health care providers, investments in research, and access to existing and emerging therapies. We urge Congress and the administration to prioritize SCD treatment to achieve better, more equitable outcomes for people with SCD and to advance progress to end the most common genetic disease facing our nation.

Today, an estimated 100,000 Americans live with SCD, a rare genetic blood disease that disproportionately affects the African American community. In fact, one in 13 African Americans is born a genetic carrier,[1] making SCD the most common genetic disorder in the United States.[2] Individuals with SCD experience not only the debilitating pain and shortened life expectancies of the disease, but for too long, discrimination in the delivery of care; health disparities; and underinvestment in research, treatments, and the health care infrastructure needed to combat SCD. Communities across the country lack timely, sustained access to high-quality, equitable, coordinated care and treatment.

Sickle Cell Disease by the Numbers

1 in 365
African Americans is born with SCD[3]

1 in 16,300
Hispanic Americans is born with SCD[4]

1 in 13
African Americans is born with Sickle Cell Trait[5]

100
Units of blood an SCD patient may need annually to address complications of the disease[6]

A Strategic Plan and Policy Blueprint for Action

The National Academies of Sciences, Engineering, and Medicine recognized the need for greater attention to SCD in the U.S. and, in September 2020, released *"Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action."*[3] This consensus-based landmark report recommends priorities for federal health care programs, policies, and research. It also identifies specific steps that the administration and Congress put forward a roadmap of recommendations in 2020 to combat SCD, increase treatment options and improve the lives of individuals with SCD nationwide. Its detailed policy platform recommends:

- Establishing a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the lifespan.
- Establishing organized systems of care that ensure both clinical and non-clinical support services to all persons living with SCD.
- Strengthening the evidence base for interventions and disease management and implementing widespread efforts to monitor the quality of SCD care.
- Increasing the number of qualified health professionals providing SCD care.
- Improving SCD awareness and strengthening advocacy efforts through targeted education and strategic partnerships among the U.S. Department of Health and Human Services, health care providers, advocacy groups, community-based organizations, professional associations, and other key stakeholders (e.g., media and state health departments).
- Addressing barriers to accessing current and pipeline therapies for SCD.
- Implementing efforts to advance understanding of the full impact of SCD on individuals and society.
- Creating a research agenda to inform effective programs and policies across the lifespan.

The Sickle Cell Disease Partnership is committed to advancing these policies, addressing systemic inequalities in the treatment of SCD, and ensuring adequate investment to support access to high-quality, equitable care and treatment for individuals with SCD and their families in communities across the nation.

Overcoming Barriers to Care

People living with SCD suffer shortened life expectancy and experience a myriad of debilitating acute and chronic health issues, including pain, fatigue, long-term organ damage, and organ failure, that severely impact their quality of life. Comprehensive, equitable, and high-quality health care, treatment options, and resources for individuals with SCD are lacking, most notably when compared to other rare disorders, such as cystic fibrosis and hemophilia.[4] Existing health disparities and inequities exacerbate the impact of SCD and contribute to the high mortality rate associated with the disease.

Individuals with SCD often report reluctance to using health care services and face discrimination in their patient journey. Far too many individuals with SCD are also more vulnerable to experiencing unmet basic social needs, such as food, housing, and utility insecurity.[5] The COVID-19 pandemic has also focused fresh attention on the importance of addressing long-standing racial inequities, health disparities, socioeconomic barriers, and social determinants of health – all of which have led to worsened outcomes from COVID-19 for people with SCD.

> **“There would be no stronger affirmation of our national commitment to equity and racial justice than to prioritize assistance to those suffering from Sickle Cell Disease.”** [9]
>
> **- Dr. Brett Giroir, Former Assistant Secretary of Health, HHS (2018-2021)**

What Policymakers Can Do

While no one organization or entity can fully address historical barriers and existing challenges, there is an opportunity and a need across our nation’s health care system – in both the private and public sectors – for leaders to collaborate to improve the health of all individuals with SCD.

As a payer, regulator, funder of research and training, and provider, the federal government has a responsibility and an opportunity to help improve the lives of individuals with SCD. There are concrete, actionable opportunities to support timely, sustained access to high-quality, coordinated, and comprehensive care and access to future treatments.

Congress and the Administration should work together to implement the National Academies’ recommendations to improve care and access to treatment for individuals with SCD. As Dr. Victor Dzau, President of the National Academy of Medicine, has said:

> “There is a great urgency to implement the recommendations from the 2020 National Academies report on Addressing Sickle Cell Disease. Investing in pipeline treatments, novel insurance coverage models, improvements in health workforce diversity, and more robust disease surveillance are all necessary interventions to ensure that those with Sickle Cell Disease are provided with effective, efficient and compassionate care – care that is long overdue.”

In recognition of World Sickle Cell Disease Day 2022, the Sickle Cell Disease Partnership issues a call to action to Congress and the administration, urging collaboration with health care organizations to adopt and implement the recommendations of the National Academies report on Sickle Cell Disease.

We stand ready to work with any public policy leader who seeks to advance these consensus-based federal health care policy recommendations to modernize, improve and strengthen our nation's response to Sickle Cell Disease.

[1] https://www.cdc.gov/ncbddd/sicklecell/data.html
[2] https://www.rarediseaseadvisor.com/disease-info-pages/sickle-cell-disease-etiology/
[3] https://www.nationalacademies.org/our-work/addressing-sickle-cell-disease-a-strategic-plan-and-blueprint-for-action
[4] https://publications.aap.org/pediatrics/article-abstract/123/1/407/71999/Models-of-Comprehensive-Multidisciplinary-Care-for
[5] https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-06055-y