CORPORATE ADVISORY COUNCIL

WHO WE ARE

Sick Cells is a sickle cell disease (SCD) advocacy nonprofit founded in 2017. **Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience.** In highlighting the grave disparities this community faces, we hope to influence decision-makers and propel change.

Since 2017, Sick Cells has soared at activating the SCD community to advocate across the healthcare continuum and storytelling for change.

KEY ACCOMPLISHMENTS

2021

- **Prepared 22 advocates to testify** at state-level Medicaid Drug Utilization Review Board meetings.
- Ran the **largest COVID-19 community response coalition** - Project SCoVID and the Community Hub.

2022

- **Recruited 76 new Ambassadors across 25 states.**
- Hosted the only SCD Hill Day, with over **72 meetings, 53 Ambassadors, and 20 states represented.**
- Translated blogs into Spanish and conducted **groundbreaking community-participatory research within the Hispanic population living with SCD.**

2023

- **Prepared 100 advocates for 148 Hill meetings representing 28 states** during the National SCD Policy Forum, with a total of **221 event attendees**.
- **Prepared advocates** to testify at the US Food and Drug Administration Advisory Committee meeting for the groundbreaking CRISPR gene therapy.
- **Led the SCD community** in the value assessment for gene therapy by the Institutes of Clinical and Economic Review.

2024

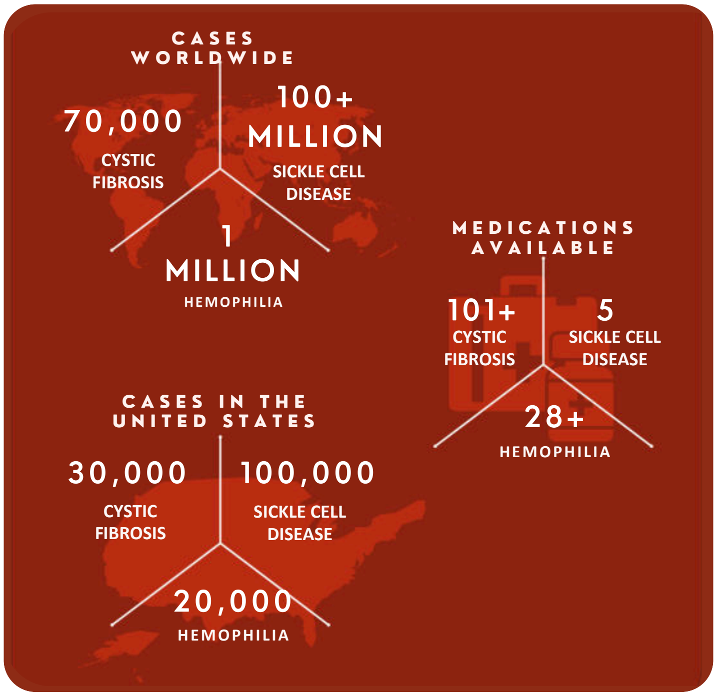
- **Prepared 206 advocates for 106 Hill meetings** representing **28 states** during the SCD Policy Forum, with a total of **230 event attendees.**
- Worked closely with the **Centers for Medicaid and Medicare Innovation (CMMI)** on the Cell and Gene Therapy (CGT) Access Model
- **Prepared a total of 45** (since 2020) advocates to testify at DURB meetings.
- Hosted the Coverage for SCD Summit, with **150 attendees**, including **11 state Medicaids, 8 Commercial payer organizations.**

WHY SICKLE CELL DISEASE

Sickle cell disease (SCD) was discovered in 1910 and is the largest genetic blood disorder in the world. **Research shows that while SCD patients suffer from this condition, they die faster from healthcare disparities rather that the disease itself.**

SCD and the population it touches is an important population to engage with in order to close the gap on health disparities and advance care and research within under-served populations.

Organizations can learn a great deal by engaging with the SCD community and utilizing the available research on the impacts of health disparities on healthcare derived from the SCD experience.



SCD, like Cystic Fibrosis and Hemophilia, are rare genetic disorders caused by a single gene mutation. However, **the disparity between the number of individuals affected by each disease and the number of available medications places SCD at a disadvantage,** particularly in ensuring that patients have access to the medications they need. This highlights the critical importance of this work.

ACCESSIBILITY TO CLINICAL TRIALS AND OTHER HEALTHCARE SYSTEMS. SCD affects individuals of various backgrounds. Ensuring that clinical trials accurately reflect the communities they impact — and prioritize accessibility, is critical to their success.

SOCIAL DETERMINANTS OF HEALTH. Social determinants of health are the conditions in which people are born, grow, live, work, and age. They include items like socioeconomic status, education level, neighborhood, and employment. Social determinants of health (SDoH) impacts the SCD on employment, schooling and many other factors, strategies to address SDoH are ingrained into all clinical trial and care designs.

EXPERIENCE IN NAVIGATING HEALTHCARE SYSTEMS. Sickle cell disease costs the US Healthcare system $1 billion annually and costs patients $1 million over the course of a lifetime. The SCD population has experience and insight about barriers to access healthcare and the limitations of our current healthcare continuum.

COMPLEX COMORBIDITIES. Comorbidities of SCD reach most spheres of medicine; however, often times SCD patients are not included in research around those comorbidities or do not have access to treatments for them. Engaging in the SCD space can help organizations understand a different perspective on current treatments, barriers to accessing treatment options, and how patients overcome these barriers.

COMMON COMORBIDITIES OF SICKLE CELL DISEASE INCLUDE THE FOLLOWING:

STROKE
ARTHRITIS
SPLENIC SEQUESTRATION
CHRONIC KIDNEY DISEASE
EXTREME PAIN
LEG ULCERS
VISION LOSS
DEEP VEIN THROMBOSIS & PULMONARY EMBOLISM
ORGAN DAMAGE
AVASCULAR NECROSIS (AVN)
ANEMIA

In 2020, **Sick Cells attended a roundtable discussion hosted by the First Lady of the United States** to mark Sickle Cell Awareness Month and discuss the ongoing challenges faced by our community. This roundtable was the first of its kind, and Sick Cells was honored to represent the Sickle Cell Disease community in that space.

Sickle cell **advocates shared their personal stories of living with the disease,** while elected officials listened attentively. Representatives from federal agencies provided updates on their work in the SCD space, outlining the progress made and the additional steps they hope to take.

The First Lady opened the roundtable by reaffirming the goal of finding a cure and then highlighted some of the actions already taken to improve the lives of people with sickle cell. She also acknowledged that **much more work remains to be done.**

WHY PARTNER WITH US

Sick Cells is looking to build strategic partnerships with businesses and corporations that share our vision of eliminating healthcare disparities and improving the lives of the sickle cell community.

Your membership with the Sick Cells CAC will inform your company about health and policy disparities and the landscape, not only for sickle cell disease patients and advocates, but for broader under-served populations. Together we can work towards solutions.

By joining Sick Cells' Corporate Advisory Council, you will have the opportunity to stay informed and receive updates from our organization, recognized as a leader in Sickle Cell Disease community for advocacy and research. You'll also **gain access to our events and programs, as well as connect with our Ambassadors.**

Partnering with Sick Cells to help elevate the Sickle Cell Disease landscape will enable your organization to make **informed decisions that can have a meaningful impact on the SCD community.**

THANK YOU FOR YOUR CONSIDERATION

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MEMBERSHIP BENEFITS

Memberships are for 1 year. Each membership begins the 1st day of the following month joined.

DESCRIPTION	CHAMPION $50,000	FOUNDER $35,000	LEADER $20,000	FRIEND $10,000
REPRESENTATIVES AT 3 ANNUAL MEETINGS	4	3	2	1
ACCESS TO SICK CELLS FOCUS GROUP (Sick Cells will convene 3 - 5 Ambassadors/ Advisory Board members for 1 focus group)	X ONE PER YEAR - VIRTUAL			
SPEAKING OPPORTUNITY FOR SICK CELLS' AMBASSADORS PROGRAM	X	X		
ACCESS TO SICK CELLS NETWORK FOR SHARING ONE (1) SURVEY	X	X		
ACCESS TO SICK CELLS' THOUGHT LEADERSHIP AS A RESOURCE ON HEALTH POLICY ISSUES	X FOUR PER YEAR	X THREE PER YEAR	X TWO PER YEAR	X ONE PER YEAR
COUNCIL SHOW AND TELL	X	X	X	X
RECOGNITION BY TIERS WITH CORPORATE LOGO ON SICK CELLS' WEBSITE	X	X	X	X COMPANY NAME ONLY
SUBSCRIPTION TO COUNCIL QUARTERLY E-NEWSLETTER	X	X	X	X