

Transforming adult care for Sickle Cell Disease (SCD) in California

Collaborating to educate policymakers and provide data to fund
Networking for California Sickle Cell Care (NCSCC)



At a Glance

In 2008, only **2 in 10 adults in California** with SCD received care in dedicated centers.

Harnessing data from California's Sickle Cell Data Collection (CA SCDC) Program, the Sickle Cell Disease Foundation (SCDF) and the Center for Inherited Blood Disorders (CIBD) spearheaded advocacy efforts in 2019 to secure legislative funding of \$15M for a network of adult SCD clinics.

This commitment marks a groundbreaking stride in enhancing comprehensive care accessibility for adults with SCD in California.



Stakeholders convene at the California Sickle Cell State Planning Initiative, January 2018

Challenge

Californians with SCD are among our state's most medically vulnerable populations. Knowledgeable preventive outpatient care for adults with SCD is extremely limited. In 2008, CA SCDC found that only 2 in 10 California adults living with SCD received care at a dedicated comprehensive SCD center.

These centers provide diagnosis and treatment for SCD symptoms and complications and access to SCD specialists, including hematologists, pain management experts, psychologists, and social workers.

California's lack of specialized SCD centers leaves some affected adults without any knowledgeable healthcare, and forces most to obtain care in hospital emergency departments. This neglect, a form of systemic racism, causes fragmented care, by inadequately managing the many complex SCD related health needs that affected adults face. Ultimately, this neglect compromises the patient's quality of life and also places a significant strain on the healthcare system.

Approach

Throughout 2018, individuals with SCD, families, clinicians, CA SCDC, advocates, and community organizations developed the California Sickle Cell State Action Plan. This plan identified public health priorities, including increased access to comprehensive care.

Using the Plan's priorities as a basis for action, SCDF and CIBD used the plan and led advocacy efforts to educate policymakers about SCD needs and solutions.



The level of difficulty for patients to access Sickle Cell Disease care three years ago was unacceptable - it was literally costing lives.

Today, patients have access to 12 specialized clinics in their local communities.

As a result, we're reducing the number of preventable ER visits and hospitalizations, saving state resources, and most importantly, saving lives.

- Diane Nugent, MD
Founder and President of CIBD



Impact

In 2019, CA SCDC was invited to present at a legislative briefing on the prevalence, geography, and challenges faced by Californians living with SCD in the state. Assembly Bill 1105, to establish a network of specialized adult SCD centers, expand the workforce of clinicians and community health workers, improve surveillance and data quality, and increase outreach and education, was approved by the Assembly health and appropriations committee, and funded in the Governor's 2019 budget. AB 1105 was informed by CA SCDC's data on patient and provider locations. Between 2019 and 2022, \$14.4 million was awarded to CIBD, which created NCSCC, to implement AB 1105 in partnership with SCDF and CA SCDC.

As of 2024, NCSCC established twelve adult SCD specialty clinics across California, serving 975 adults. In partnership with NCSCC leaders, CA SCDC measures the initiative's impact on healthcare outcomes. Early data show NCSCC has reduced emergency department treatment and release visits by 11%, hospitalizations by 20%, and total hospitalization days by 50% among its clients. Early data also demonstrates that once NCSCC has reached full capacity, it will save the state between \$80 to \$100 million per year.

