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## **First-of-its-kind Sickle Cell Disease Network Exceeds Goals in Providing Care to Historically Neglected Community**

*Annual report highlights success in building a comprehensive network of Adult Sickle Cell Disease clinics in California*

**SACRAMENTO, CA** – Today, [Networking California for Sickle Cell Care](#) released its 2020-2021 Annual [Report](#), underscoring the incredible progress made to-date in building the state’s first and only network of specialized Sickle Cell Disease clinics. These clinics not only address long-standing needs but will also improve access to quality care, preventative monitoring, and state of the art treatment for adults with Sickle Cell Disease. Data from the [Tracking California Data Project](#) revealed that Californians living with Sickle Cell Disease have a much shorter life expectancy -- only 43 years -- compared to 61 years for other states and the national average of 78 years. This distressing 20-year discrepancy in life expectancy for Californians with Sickle Cell Disease is primarily due to the absence of preventative services and knowledgeable multi-disciplinary care for adults throughout the state.

In 2019, Assemblymember Mike Gipson (D-Carson) introduced legislation to address this crisis. [AB 1105 \(Gipson\)](#) proposed building a network of adult clinics throughout California, which was achieved in Governor Newsom’s 2019 Budget Act, and led to the creation of Networking California for Sickle Cell Care.

“What the Network has quickly accomplished in bringing quality care to Californians with Sickle Cell Disease is nothing short of astounding,” said Assemblymember Mike Gipson (D-Carson), a champion of Sickle Cell Disease awareness and treatment. “With the Network comes hope but our work is not yet done. We must continue to push forward and fight for Californians with Sickle Cell Disease, so they receive the care that they have long needed and deserved.”

The Network’s 2020-2021 Annual [Report](#) highlighted four major areas of progress:

### **Building a Regional Network of Adult Sickle Cell Disease Clinics**

The Network surpassed its goal of developing five Sickle Cell Disease clinics in three years. Two years into the three-year scope of the project, the Network welcomed eleven adult Sickle Cell Disease clinics located in Alameda, Fresno, Kern, Los Angeles, Orange, Sacramento, San Bernardino, San Diego, and San Mateo counties. ([Interactive Clinical Map](#))

These clinics provide comprehensive team-based care to meet physical, social, and behavioral health needs. Each clinic team is comprised of a multi-disciplinary staff who have expertise in Sickle Cell Disease care and includes a community health worker certified in Sickle Cell Disease who is employed and supervised by the [Sickle Cell Disease Foundation](#).

### **Workforce Development**

To create sustainable systems of care, the Network continued to expand the healthcare workforce of clinicians, including physicians, advanced practice providers, community health workers, and students who are knowledgeable about Sickle Cell Disease.

The Network's novel remote mini-credential course in Sickle Cell Disease, first piloted for physician assistant students, graduated its first two student cohorts. The third physician assistant cohort begins Fall 2021. The Network also successfully initiated a similar course for nurse practitioner students. Upon completing the course, they will obtain a specialty certificate in Sickle Cell Disease as well.

The Network conducted workforce development through the following programs:

- Building the Advanced Practice Provider Knowledge: Students and Licensed Clinicians
- Clinical Rotations at Network Sickle Cell Centers
- Educating Community Clinicians: Sickle Cell Boot Camps
- Developing Capacity at Community-Based Organizations
- Community Health Worker Training
- Policy: Promoting Access to Advanced Practice Providers and Community Health Workers

### **Expanding Surveillance**

Through active patient engagement and leadership, the Network is collecting real world data and evidence to drive culturally competent treatment, create value added care plans, improve outcomes, and establish best practices. This marks the first time Sickle Cell Disease data has been collected in this way in California – and the nation. This data is essential to providing commercial insurers, Medi-Cal, and Medicare the information they need to support these services and keep Californians with Sickle Cell Disease out of the hospital, emergency rooms, and infusion centers.

During its second year, the Network began to see the true extent of the need for adults with Sickle Cell Disease and the challenges they face in accessing evidence informed, multi-disciplinary team-based care. The brutal truths:

- The initial estimate of 6,000 Californians living with Sickle Cell Disease is *closer to 9,000*
- Mental and behavioral health needs are not being addressed, and are vastly undertreated
- There is a far greater need for community health workers to connect affected individuals with local resources

### **Enhancing Outreach and Education**

The Network engaged community-based organizations and community health workers to facilitate access to adult Sickle Cell clinics statewide. In addition, the Network provided outreach and education grants to the Los Angeles Chapter of the National Association of Hispanic Nurses (NAHN/LA) and the University of California, San Francisco in Fresno (UCSF Fresno). These Network grants address three main areas of need in the California Sickle Cell Disease population:

- Emergency room education
- Pain management
- Quality of life

“Our patients are at the heart and center of everything we do – they have spoken, and the Network is listening,” said Mary Brown, President and CEO, [Sickle Cell Disease Foundation](#). “With the creation and success of the Network, California has started a movement that we hope will influence Sickle Cell Disease care delivery beyond our borders and will help to bring equitable care to patients and their families nationwide.”

As it became clear that the COVID-19 pandemic's isolation and increasing economic hardships were severely impacting Sickle Cell Disease patients and their families, in 2021, the Network requested additional funding from the California Legislature. This Fall, an additional \$1.5 million dollars was allocated to the Network to add behavioral health services and additional community health workers to each clinic team. New funding will also

help support data streaming to enhance connectivity among the Network's clinics, patients, and community health workers.

For more information, including clinic locations, visit [www.sicklecellcare-ca.com](http://www.sicklecellcare-ca.com).

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**About the Center for Inherited Blood Disorders**

*The Center for Inherited Blood Disorders (CIBD) has cared for hundreds of children and adults in Southern California, offering a safety net clinic that provides health care services specifically to patients with inherited blood disorders. CIBD has been able to increase access to care for those who are economically challenged by providing medical care regardless of ability to pay. CIBD is also a national leader in directing federal initiatives to promote regional blood disorder networks that provide team-based clinical care and uniformly track health outcomes. Learn more by visiting [www.cibd-ca.org](http://www.cibd-ca.org).*

**About the Sickle Cell Disease Foundation**

*The mission of the Sickle Cell Disease Foundation (SCDF) is to provide life-enhancing education, services, and programs for individuals living with sickle cell disease. SCDF broadens public awareness, delivers effective advocacy initiatives, and promotes innovative therapies to ultimately find a cure. Learn more by visiting [www.scdfc.org](http://www.scdfc.org).*

**About Networking California for Sickle Cell Care**

*Networking California for Sickle Cell Care (NCSCC) was developed through advocacy and stakeholder engagement supported by data. Learn more by visiting [www.sicklecellcare-ca.com](http://www.sicklecellcare-ca.com).*