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Networking California for Sickle Cell Care Holds Inaugural Meeting

California makes history with first and only statewide network of comprehensive Sickle Cell Disease clinics

SACRAMENTO, CA – Today [Networking California for Sickle Cell Care](#) held its inaugural meeting, marking the first time that clinicians from the ten participating Network clinics came together in one virtual “room.” During the meeting, the Network provided an overview of its many [achievements](#) since the June 2019 launch and set the stage for what the Network will accomplish moving forward – saving lives of adults living with Sickle Cell Disease and reversing decades of mistreatment as a result of racism and neglect.

“There are so many advocates, patients, providers, and elected officials we must thank for getting us to this point; however, the Network wouldn’t be a success without each and every one of the clinicians who took a leap of faith in joining this historic Network. Because of the resources provided by the Network, these local clinics are better positioned to improve the quality of care for all Californians living with Sickle Cell Disease,” said Diane Nugent, MD, Founder, President, and Medical Director, Center for Inherited Blood Disorders. “While we know there is a long road ahead, we couldn’t be more proud of what we’ve accomplished so far.”

Established in 2019 as a result of [AB 1105 \(Gipson\)](#), Networking California for Sickle Cell Care has quickly expanded the number of specialized clinics in the state from three to [ten](#). Led by the Orange County-based Center for Inherited Blood Disorders in partnership with the San Bernardino County-based Sickle Cell Disease Foundation, the Network has also:

- Increased the healthcare workforce of clinicians, community health workers, and physician assistant graduates who are knowledgeable about Sickle Cell Disease
- Conducted bias training for physicians and other health care providers
- [Enhanced surveillance](#) to better track Sickle Cell Disease and analyze its physical, economic, and health impacts
- Strengthened education and awareness of Sickle Cell Disease through competitive grants

“After decades of neglect, we’ve finally turned a corner and are now able to successfully and effectively improve care for Californians living with Sickle Cell Disease,” said Mary Brown, President and CEO, Sickle Cell Disease Foundation. “For the patients who have never had their voices heard, who have felt like they’ve been living in the shadows, now is the time to speak up and speak out. We are listening, and our program is going to address your needs to the best of our abilities.”

While anyone can inherit the Sickle Cell trait, the disease disproportionately impacts Black and LatinX communities. Pain is the most common complication of Sickle Cell Disease, and the number one reason that people with Sickle Cell Disease go to the emergency room or hospital. During acute episodes, also called vaso-occlusive crises, patients’ “sickle cells” get trapped in blood vessels, acting like dams that prevent blood from flowing. This causes pain that can start suddenly, be mild to severe, and can last for any length of time. Symptoms also include debilitating inflammation, infections, blood clots, and even premature death.

Prior to the Network's establishment, Californians with Sickle Cell Disease, particularly adults, were among the state's most ignored and medically vulnerable populations. In the absence of specialized clinics, people experiencing acute pain crises were forced to seek help from emergency rooms, which led to worse outcomes due to providers not being trained in how to handle acute pain episodes or racist sentiments like Black patients having higher pain tolerances. These false narratives and the lack of a statewide program focused on this population resulted in the life expectancy for California adults with Sickle Cell Disease being 43 years compared to the nationwide average of 61 years.

"I have experienced no pain as intense as a Sickle Cell crisis," said Jennifer Fields, an adult living with Sickle Cell Disease and Implementation Strategist of the Sickle Cell Disease Foundation. "But I think I speak for all patients in saying what's worse than the pain, is presenting to the emergency room and being met with racism and being treated like drug addicts. I've heard stories of patients that have been given a bus ticket and sent home. It's horrific."

The Network is two years into a three-year pilot program to create a system of adult Sickle Cell Disease clinics that are connected with one another in a hub and spoke model across the state. Clinics have expanded upon existing – but previously fragmented and inadequate services -- in the geographic areas where the largest numbers of adults with Sickle Cell Disease live. As the Network continues to grow, it's leadership also hopes to partner with appropriate Medi-Cal managed care organizations to reach all patients with Sickle Cell Disease and their families for many years to come.

For more information visit <https://sicklecellcare-ca.com>
[Networking California for Sickle Cell Care \(Promo Video\)](#)

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.

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.scdcf.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.