



FOR IMMEDIATE RELEASE:

June 21, 2021

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Networking California for Sickle Cell Care Initiative Launches “Neglected No More”

First-of-its-kind state funding in 2019 launched the development of a patient-centered network of care for adults with sickle cell disease, and initiatives to expand workforce, data surveillance, and outreach

SACRAMENTO, CA – Today, on the heels of [World Sickle Cell Day](#), the Networking California for Sickle Cell Care Initiative (NCSCC) launched **Neglected No More**, a public awareness campaign highlighting the Golden State’s groundbreaking continuum of care for adults with sickle cell disease and other innovative solutions spearheaded by the NCSCC to save more lives while reversing decades of mistreatment as a result of systemic racism and neglect.

“This program is only the start of addressing decades of neglect,” said Jennifer Fields, an adult living with sickle cell disease and implementation strategist of the Sickle Cell Disease Foundation. “We can’t dance around the elephant in the room anymore. It’s time to tackle these issues face-to-face with patients and it’s time our voices are finally heard.”

In early 2019, Assemblymember Mike Gipson (D-Carson) led the successful effort to secure first-of-its-kind state-wide funding for adults with sickle cell disease. In late June, Governor Newsom, committed \$15 million for adult sickle cell treatment programs statewide and granted funds to CIBD to create the [NCSCC](#) in partnership with the [Sickle Cell Disease Foundation](#), the nation’s oldest sickle cell disease nonprofit and patient support agency based in San Bernardino County.

“Patients don’t want to be characterized by their disease. Our job, as health care providers, is not to just give them medication but to make sure they can live their lives to the fullest,” said Diane Nugent, MD, founder, president, and medical director of the Center for Inherited Blood Disorders (CIBD), a leading nonprofit specialty clinic based in Orange County. “We’ve come so far, now is not the time to rest – we must keep pushing and that’s what **Neglected No More** is all about.”

Despite COVID-19 pandemic-related challenges, in its first year of the three-year initiative, the NCSCC and its partners have:

- Launched three new, specialized sites in San Diego, Kern, and Sacramento counties to build its network of adult sickle cell disease clinics
- Conducted bias training for physicians and other health care providers
- Initiated innovations to expand the health care workforce of clinicians, community health workers, and new physician assistant graduates who are knowledgeable about sickle cell disease
- Expanded surveillance to better characterize sickle cell disease and its physical, economic, and health services impacts, including on the LatinX population, a neglected group at risk for sickle cell disease
- Strengthened education and awareness of sickle cell disease through competitive grants

“Sickle cell disease causes excruciating episodes of pain. In the emergency room, sickle cell patients are often labeled as ‘pain-med seekers’ and don’t receive the care they deserve,” said Srila Gopal, MD, hematologist, UC San Diego Medical Center. “With this grant support, we’re able to build a committed team and improve on the range of services we can provide, including comprehensive preventative care, same-day infusion-based pain management services, child-to-adult transition services, and more to improve the quality of life in adults with sickle cell disease.”

Sickle cell disease is an inherited blood disorder that affects the ability of red blood cells to carry oxygen. While anyone can inherit the sickle cell trait, the disease disproportionately impacts Black and LatinX communities. Lack of provider education, unconscious bias, poor reimbursement for team based outpatient care, and inadequate research has led to a system of care that grossly undertreats and neglects people with sickle cell disease – resulting in the life expectancy for affected Californians to decline to just 43 years of age.¹² The **Neglected No More** campaign aims to raise awareness around sickle cell disease and elevate patient voices that have been silenced for far too long. Supporters and people with sickle cell disease can follow the campaign on social media through the hashtag, #NeglectedNoMore.

"California's funding for specialized sickle cell treatment centers is long overdue. And even worse, our voices have been ignored," said Mary Brown, president and CEO of the Sickle Cell Disease Foundation. “Our goal is to make sure that the patient voice and perspective is in the heart and center of every single thing we do – Californians with sickle cell disease will be **Neglected No More.**”

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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.

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 the Networking California for Sickle Cell Care Initiative

The Networking California for Sickle Cell Care Initiative (NCSCC) was developed through advocacy and stakeholder engagement supported by data. Learn more by visiting www.sicklecellcare-ca.com.

¹ <https://ca-actionplan.pacificscd.org/wp-content/uploads/2019/01/State-Action-Exec-Sum-rev-12.13.18.pdf>

² <https://pubmed.ncbi.nlm.nih.gov/16267411/>