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Historic State Funding for Sickle Cell Disease Brings Comprehensive Care to Patients in San Diego

Expanded sickle cell disease program at UC San Diego Health is one of just three centers in the state providing multi-disciplinary care for adult sickle cell disease patients

SAN DIEGO, CA – Today UC San Diego Health held a virtual grand opening of its comprehensive sickle cell disease clinic, marking another step forward in California’s efforts to expand sickle cell disease services and improve care. In the absence of sickle cell centers, preventable pain crises and other complications frequently lead to emergency room visits and hospitalizations at an estimated cost of \$2.4 billion per year in this country.

Made possible by first-time funding through legislation sponsored by Assemblymember Mike Gipson (D-Carson) and included in Governor Gavin Newsom’s 2019 Budget Act, UC San Diego Health’s expanded services are led by Srila Gopal, MD, hematologist, at UC San Diego Medical Center. The clinic provides multi-disciplinary care to local patients with sickle cell disease. This care includes specialists trained to treat sickle cell disease and prevent or reduce its complications, same-day infusion urgent care, pain management, outpatient appointments, child-to-adult transition services, coordination with related specialties, coordination with clinical trials, linkage with a local Community Health Worker who has extensive training and certification in sickle cell disease, and community outreach and education.

“UC San Diego Health’s expanded center will help ensure additional care and resources are dedicated to addressing the poor health outcomes and premature deaths experienced by what has been a historically underserved population of patients,” said Diane Nugent, MD, founder, president, and medical director of the Center for Inherited Blood Disorders. “We are so grateful to Assemblymember Gipson for leading the charge in making sickle cell disease treatment a priority and to Governor Newsom for including critical funding for increased services and care in the state budget.”

While anyone can inherit the sickle cell trait, the disease disproportionately impacts Black and Latino communities. The lack of medical education and inadequate research has led to a system of care that undertreats patients with sickle cell disease. Health outcomes for the vast majority of diseases have improved over the years while life expectancy for those with sickle cell disease has declined to just 43 years of age.¹ In California, patients with sickle cell disease experience higher incidents of emergency room visits and hospitalizations, as well as more deaths at younger ages, and at higher rates than in other states.

"As a person with sickle cell disease, it's critically important that our voices are heard. When silenced, how can we effectively create programs that will impact the people who need it most?" said Jennifer Fields, an adult living with sickle cell disease and implementation strategist of the Sickle Cell Disease Foundation of California. "Many patients are so traumatized by their past treatment in ERs or other healthcare settings they

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

are afraid to seek medical care. This new network is changing the way patients with sickle cell disease, like myself, will receive care by putting the patient's best interest at heart," said Fields.

The 2019 legislation and funding allocation created the [Networking California for Sickle Cell Care Initiative \(NCSCC\)](#) and directs \$15 million to expand services in several counties throughout the state by creating at least five new centers in priority areas. Of the \$15 million, the program granted the Center for Inherited Blood Disorders and the Sickle Cell Disease Foundation of California \$14.4 million to improve access to treatment and comprehensive services over a three-year period. The remaining \$600,000 will expand the Sickle Cell Data Collection Program to better understand long-term trends in diagnosis, treatment, healthcare utilization, and access for Californians living with sickle cell disease.

"Hospitals and clinics must be safe spaces for our patients," said Mary Brown, president and CEO of the Sickle Cell Disease Foundation of California. "Inequitable treatment based on race has led to unconscious judgements and implicit biases, even in well-intentioned clinicians, that can negatively impact the care and treatment of patients with sickle cell disease. California's funding for specialized sickle cell treatment centers is long overdue."

Sickle cell disease is an inherited blood disorder that affects the ability of red blood cells to carry oxygen. Usually diagnosed at birth, the disease is a lifelong condition that can cause debilitating and deadly symptoms including chronic pain, stroke, lung tissue damage, chronic pulmonary hypertension, chronic kidney and liver disease, and chronic bacterial infections. Sickle cell disease is best treated through a multi-disciplinary approach including regular blood transfusions, antibiotics, pain management, and psychosocial supports.

"For far too long, funding for sickle cell disease was put on the back burner while Californians needlessly suffered," said Assemblymember Mike Gipson, a champion of sickle cell disease awareness and treatment. "Through increased funding and the work of NCSCC partners, the state will now have more health professionals trained in this complex condition and patients will receive enhanced access to the local, comprehensive services needed to maintain health and quality of life."

Over the next two years, the NCSCC Initiative will continue to enhance sickle cell disease care by:

- Expanding access to specialty care and improving quality of care by establishing a network of sickle cell disease centers and community organizations in counties where the largest numbers of adults with sickle cell disease live
- Enhancing care coordination through workforce development of both clinicians and community health workers
- Expanding surveillance to monitor disease prevalence, healthcare utilization, complications, and costs
- Conducting outreach and awareness on sickle cell disease

UC San Diego Health is one of two new specialized sickle cell clinics in the state, following the Jeffrey Smith Adult Sickle Cell Clinic at the MLK Jr. Outpatient Center in Los Angeles.

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 of California

The mission of the Sickle Cell Disease Foundation of California (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.

About the Networking California for Sickle Cell Care

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.

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