





**FOR IMMEDIATE RELEASE:** 

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# Historic State Funding for Sickle Cell Disease Enhances Comprehensive Care for Adults in Los Angeles County

UCLA Health joins Networking California for Sickle Cell Care

LOS ANGELES, CA – Today, Networking California for Sickle Cell Care announced the opening of a new clinic to join the state's historic network of specialty Sickle Cell Disease clinics. Located at the UCLA Medical Center Oncology/Hematology in Westwood, UCLA Health is the second Sickle Cell Disease clinic offering multidisciplinary care to adults in the greater Los Angeles area, joining the Jeffrey Smith Sickle Cell Clinic at the MLK Jr. Outpatient Center. The Network is proud to continue serving local Los Angeles patients and improve the overall health of Californians with Sickle Cell Disease (SCD), a medically vulnerable population that has suffered decades of inattention and neglect, leading to poor care, and too many deaths of adults under the age of 40.

"As a provider working daily with patients living with blood disorders, I'm proud that California acted to address the historic neglect faced by California adults living with Sickle Cell Disease," said Diane Nugent, MD, Founder, President, and Medical Director, Center for Inherited Blood Disorders. "Our state has initiated a movement that fundamentally addresses the long journey to establish health equity for patients and families and we hope the Network will influence Sickle Cell care delivery models beyond our borders."

In 2019, the California State Legislature approved funding to establish Networking California for Sickle Cell Care. Since then, the Network has expanded access to specialty care; supported workforce expansion for coordinated health services; conducted surveillance to monitor disease incidence and prevalence; and strengthened education and awareness of SCD through competitive grants. Currently, there are at least 2,100 known patients living with SCD in the Los Angeles area out of an estimated 7,000 in California<sup>1</sup> – and experts say there are likely more. Before California began public health surveillance of SCD, no one knew how many people in the state lived with the disease. Because of Tracking California's work on the California Sickle Cell Data Collection Program, the Network has more recently been able to identify the counties with the largest numbers of patients living with SCD, including Los Angeles County.

"Sickle Cell Disease is the most common inherited blood disorder in the United States, yet California adults were dying early due to the lack of a statewide infrastructure focused on addressing this complex disease," said Mary Brown, President and CEO, Sickle Cell Disease Foundation. "Our partnership with UCLA Health marks the first time in state history that there are two, specialized clinics serving patients with Sickle Cell Disease in one county – this is groundbreaking for a community that has been neglected for far too long."

In the absence of specialized clinics, preventable pain crises and other complications frequently lead to emergency department visits and hospitalizations at an estimated cost of \$2.4 billion per year nationally. A conservative estimate based on Office of Statewide Health Planning and Development (OSHPD) data for 2014-16 indicates the charges for hospitalization and emergency department visits for adults with SCD exceeded \$226 million in California alone.

<sup>&</sup>lt;sup>1</sup> https://www.trackingcalifornia.org/sickle-cell-disease/sickle-cell-disease-in-california

Last year, the Network launched its "Neglected No More" campaign to raise awareness around SCD and elevate patient voices that have been silenced for far too long. Supporters and people with SCD can follow the campaign on social media through the hashtag, #NeglectedNoMore.

## Location and contact information for the new Sickle Cell Clinic at UCLA Health:

100 Medical Plaza, Suite 550 Los Angeles, CA 90095 310-206-6909

In the future, UCLA Health will expand Sickle Cell services in several community clinic locations, including Downtown Los Angeles, Santa Clarita (Valencia) and Redondo Beach.

Clinic services provided by UCLA Health help address the range of health problems faced by adults with Sickle Cell Disease. These include: Primary care including preventive services and management of co-occurring chronic conditions; urgent care including advanced nursing services such as IV fluid and medication infusions; transfusion services and red cell exchange by apheresis; inpatient care; intensive car; bone marrow transplant; stroke screening and treatment; pulmonary disease screening and treatment; orthopedic management for avascular necrosis; neurovascular disease complications treatment; pulmonary hypertension screening and treatment, integrative health/psychosocial support; and Sickle Cell Disease research and therapies, including gene therapy and telehealth resources.

For more information about Sickle Cell Disease and new treatment clinics around the state visit <a href="https://sicklecellcare-ca.com">https://sicklecellcare-ca.com</a>.

## 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 <a href="https://www.cibd-ca.org">www.cibd-ca.org</a>.

## About the Sickle Cell Disease Foundation

The Sickle Cell Disease Foundation (SCDF) was incorporated in 1957 and is the first and oldest Sickle Cell Disease community-based organization of its kind in the nation. As the only organization in California approved to provide Hemoglobin-Trait Counseling Services and direct the Sickle Cell Educator/Counselor Certification Training Course, SCDF provides 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 <a href="www.scdfc.org">www.scdfc.org</a>.

## About Networking California for Sickle Cell Care

Networking California for Sickle Cell Care (Network) is the state's first and only network of specialized adult Sickle Cell Disease clinics. The Network was developed through advocacy and stakeholder engagement supported by data. Learn more by visiting <a href="www.sicklecellcare-ca.com">www.sicklecellcare-ca.com</a>.