AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

I

119TH CONGRESS
2D SESSION

H. R. 10531

To establish a program to address sickle cell disease and other heritable hemoglobinopathies.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 24, 2026

Ms. ADAMS (for herself, Mr. DAVIS of Illinois, and Mr. IVEY) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

A BILL

To establish a program to address sickle cell disease and other heritable hemoglobinopathies.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Sickle Cell Disease Treatment Centers Act of 2026''.

SEC. 2. ESTABLISHMENT OF SICKLE CELL DISEASE AND OTHER HERITABLE HEMOGLOBINOPATHIES TREATMENT CENTERS.

Subpart I of part D of title III of the Public Health Service Act (42 U.S.C. 254b et seq.) is amended by inserting after section 330P (42 U.S.C. 254c–22) the following:

"SEC. 330Q. SICKLE CELL DISEASE AND OTHER HERITABLE HEMOGLOBINOPATHIES TREATMENT CENTERS.

"(a) DEFINITIONS.—In this section:

"(1) COMMUNITY-BASED ORGANIZATION.—The term 'community-based organization' means a community-based nonprofit organization.

"(2) HUB-AND-SPOKE NETWORK.—The term 'hub-and-spoke network' means a system for delivery of health care services—

"(A) in which a medical hub identifies and manages a medical spoke or network of spokes, to provide comprehensive sickle cell disease care;

"(B) in which such entities serving as spokes—

"(i) may provide sickle cell disease care services; and

"(ii) may increase services over time to meet the definition of medical hubs and connect with new spokes; and

"(C) in which the medical hub and spoke has a partnership with one or more community-based organizations to extend services and outreach to the sickle cell disease community.

"(3) MEDICAL HUB.—The term 'medical hub' means a hospital, clinic, or university health center that—

"(A) provides comprehensive sickle cell disease treatment, which may include medical and surgical treatment, such as provision of stem cell transplants and cell and gene therapies, an outpatient treatment clinic led by a board-certified hematologist, infusion capability, telehealth capability, genetic counseling, access to home care, and a pharmacy;

"(B) has experience serving individuals living with sickle cell disease or other hemoglobinopathies;

"(C) follows consensus-based clinical practice guidelines; and

"(D) may be a grantee or coordinate with grantees of the Sickle Cell Disease Treatment Demonstration Program under section 1106(b).

"(4) SPOKE.—The term 'spoke' means an entity—

"(A) that provides health care services, including—

"(i) a Federally qualified health center, as defined in section 1905(l)(2)(B) of the Social Security Act;

"(ii) a hospital, clinic, or university health center that provides clinical care and has telehealth capability;

"(iii) a primary care provider;

"(iv) an outpatient treatment clinic;

"(v) an infusion center; or

"(vi) other health care providers;

"(B) that has at least 1 collaborative agreement with a medical hub and one or more community-based organizations; and

"(C) that incorporates a community health worker into the care team.

"(b) PROGRAM ESTABLISHED.—The Secretary shall award grants to eligible entities to establish treatment centers using a hub-and-spoke framework (referred to in

this section as 'Sickle Cell Disease Treatment Centers'), for the purposes of—

"(1) promoting access to coordinated, lifelong health care for all patients with sickle cell disease;

"(2) providing support to establish integrated health care teams for patients with sickle cell disease over a patient's lifetime;

"(3) improving the health and well-being of children, youth, and adults with sickle cell disease;

"(4) improving the pediatric-to-adult health care transition;

"(5) collecting and contributing clinical data from States participating in the Sickle Cell Data Collection program of the Centers for Disease Control and Prevention, including the collection of health outcomes and associated complications reported pursuant to such program;

"(6) ensuring that reporting with respect to sickle cell disease includes reporting on all patients with sickle cell disease, including migrating and foreign-born patients; and

"(7) conducting significant public health awareness and education activities with respect to sickle cell disease and sickle cell trait.

1 "(c) ELIGIBLE ENTITY.—The term 'eligible entity'
2 means any entity that is comprised of—
3 "(1) a hub-and-spoke network that includes—
4 "(A) a medical hub that is a hospital, clin-
5 ic, or university health center; and
6 "(B) at least 1 spoke working in partner-
7 ship with the medical hub; and
8 "(2) at least 1 community-based nonprofit or-
9 ganization working in a partnership with the hub-
10 and-spoke network.
11 "(d) USE OF FUNDS BY ELIGIBLE ENTITIES.—An
12 eligible entity shall use grant funds received under this
13 section as follows:
14 "(1) MEDICAL HUB.—The medical hub of the
15 eligible entity shall carry out the following:
16 "(A) Operating and administrating costs of
17 operating a hub-and-spoke framework.
18 "(B) Complying with consensus-based sick-
19 le cell disease treatment guidelines, as identified
20 by the Secretary.
21 "(C) Educating health care providers on
22 sickle cell disease treatment standards and pro-
23 tocols.
24 "(D) Providing integrated care manage-
25 ment, which may include—

"(i) primary care;

"(ii) specialty care;

"(iii) pain management;

"(iv) mental health services;

"(v) genetic counseling services; and

"(vi) other services.

"(E) Coordinating specialty care services, whether provided at the medical hub or spoke.

"(F) Coordinating reproductive health and family planning services for patients with sickle cell disease, trait, or other hemoglobinopathies.

"(G) Providing a dedicated sickle cell expert at the medical hub to assist in overseeing care of sickle cell disease patients at spokes and to advise the community-based organization.

"(H) Educating health care providers on social determinants of health and implicit bias that may affect quality of care and life for patients with sickle cell disease, trait, or other hemoglobinopathies.

"(I) Providing telehealth appointments to patients when appropriate and facilitating access to telehealth services for sickle cell disease patients to the extent feasible.

"(J) Implementing pediatric-to-adult health care transition programs for purposes of ensuring coordinated patient graduation from pediatric to adult providers for all patients.

"(K) Providing social work services or community health worker services in coordination with one or more community-based organizations.

"(L) Collecting and distributing data as required by the National Sickle Cell Disease Coordinating Center established under subsection (f) or otherwise required by the Secretary.

"(M) Engaging in quality improvement with respect to such standards of care for health and quality of life outcomes among sickle cell disease patients as the Secretary may require.

"(2) COMMUNITY-BASED ORGANIZATION.—The community-based organization of the eligible entity shall provide or coordinate services to patients and families, which may include the following:

"(A) Providing education and outreach to individuals at-risk for sickle cell trait, individ-

uals with sickle cell trait, sickle cell disease patients, caregivers, and health care providers.

"(B) Providing support in addressing social determinants of health, such as food insecurity, housing insecurity, and access to education and transportation.

"(C) Providing social work services or community health worker services in coordination with a medical hub or spoke.

"(D) Testing or coordinating testing for individuals at risk for sickle cell trait and individuals with sickle cell trait that increase the likelihood of having a child with sickle cell disease, including through coordination with a genetic counselor.

"(E) Engaging in quality improvement with respect to standards of care or health and quality of life outcomes among sickle cell disease patients, as identified by the Secretary.

"(3) SPOKE.—The spokes of the eligible entity shall provide or coordinate each of the following services:

"(A) Collaborating with a medical hub to coordinate and support care for sickle cell disease patients.

"(B) Providing standards of care as developed in coordination with the medical hub.

"(C) Providing primary care services, genetic counseling, or specialty care.

"(D) Providing telehealth appointments, as appropriate.

"(E) Providing medical or surgical treatment.

"(F) Implementing individual care plans.

"(G) Providing social work services or community health worker services in coordination with one or more community-based organizations.

"(H) Collecting and distributing data as required by the National Sickle Cell Disease Coordinating Center established under subsection (f).

"(4) ADDITIONAL USES OF FUNDS.—In addition to the uses of funds described in paragraphs (1), (2), and (3), an eligible entity selected to receive a grant under this section may use funds received through the grant—

"(A) to identify and secure resources for ensuring reimbursement under, for the State involved, the State plan under title XIX of the

Social Security Act (or a waiver of such plan), State child health plan under title XXI of such Act (or a waiver of such plan), and other health programs for the prevention and treatment of sickle cell disease, including by working with community-based sickle cell disease organizations and other nonprofit entities;

"(B) to assist sickle cell disease patients with accessing appropriate health insurance, including—

"(i) through the payment of insurance premiums and cost-sharing amounts, to the extent otherwise permitted under State and Federal law;

"(ii) by working with community-based sickle cell disease organizations and other nonprofit entities; and

"(iii) by helping sickle cell disease patients know their rights with insurance programs;

"(C) to facilitate access to telehealth services for sickle cell disease patients and individuals with sickle cell trait, to the extent feasible;

"(D) to fund evidence-based programs that provide education to health care providers,

teachers and school personnel, and correctional institutional personnel, on the care of individuals with sickle cell disease or trait in health care settings and other appropriate settings, including schools and prisons;

"(E) to develop a system of social and community supports, including transportation services or travel reimbursement for sickle cell disease patients who do not have, but who need access to, in-person care with the Sickle Cell Disease Treatment Centers; and

"(F) to facilitate access to sickle cell trait testing and genetic counseling.

"(e) APPLICATION; SELECTION.—

"(1) APPLICATION.—An eligible entity desiring a grant under this section shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require, including a description of how the hub-and-spoke entity and community-based organization will collaborate in carrying out the activities described in subsection (d).

"(2) GEOGRAPHIC DISTRIBUTION.—The Secretary shall award grants under this section, to the extent practicable, to eligible entities, with a focus

on regions where a disproportionate number of patients with sickle cell disease, individuals with sickle cell trait, or other heritable hemoglobinopathy patients per capita reside, and to eligible entities nationwide so that patients can access more comprehensive sickle cell disease treatment services no matter where they reside.

"(3) PRIORITIES IN MAKING AWARDS.—In awarding grants under this section, the Secretary may give priority to eligible entities that—

"(A) include at least one historically Black college or university (defined as a part B institution under section 322 of the Higher Education Act of 1965) or minority serving institution (defined as an eligible institution under section 371 of such Act) that has a medical school, nursing school, nurse practitioner or physician assistant program, genetic counseling program, or school of social work;

"(B) serve an area with a high prevalence of sickle cell disease; or

"(C) serve a rural area.

"(f) NATIONAL SICKLE CELL DISEASE COORDINATING CENTER.—

"(1) IN GENERAL.—The Secretary shall establish, or enter a cooperative agreement with an entity to establish, the National Sickle Cell Disease Coordinating Center, which shall coordinate the activities conducted by grantees under this section and carry out the activities described in paragraph (2).

"(2) DUTIES.—The National Sickle Cell Disease Coordinating Center shall carry out each of the following activities:

"(A) Advise the Secretary on the design and implementation of, and coordinate the infrastructure of, the Sickle Cell Disease Treatment Centers established under subsection (b), including with respect to administrative requirements and ensuring that sickle cell health care is available across the United States.

"(B) Develop a national strategy for the practice of equitable care, coordinated comprehensive quality care, research and resources for patients and health care providers, and treatment modality options to improve patient outcomes, and submit such national strategy to the Secretary.

"(C) Coordinate with Federal agencies to improve data collection over the lifespan of pa-

tients and routinely update a national needs assessment to improve care for individuals impacted by sickle cell disease.

"(D) Coordinate with hub-and-spoke networks, patients, researchers, and health care providers to maintain a comprehensive sickle cell research, treatment, and national care strategy.

"(E) Establish a rotating panel of stakeholders, including health care providers, patients, individuals impacted by sickle cell disease, allied health professionals, care coordinators, social workers, community health workers, and sickle cell community-based and advocacy organizations to advise the Center, provide up-to-date information and forecasts on status and plans for improving sickle cell care, treatment, and access to treatment modalities for individuals and families living with sickle cell disease.

"(F) Coordinate and support hub-and-spoke frameworks.

"(G) Support improvement in patient and family-centered care, health outcomes, and care affordability by improving access to care.

"(H) Provide or coordinate technical assistance and support to health care providers, family members and advocates, public health professionals, policymakers, and patients that want to improve access to quality care, telemedicine, family planning, health care transition, and family and community engagement.

"(I) Inform and educate the public about sickle cell disease, sickle cell trait, and options for quality care.

"(g) CDC SICKLE CELL DISEASE DATA COLLECTION PROGRAM FOR SCD TREATMENT CENTERS.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, in coordination with the National Sickle Cell Coordinating Center established under subsection (f), shall carry out the following:

"(1) Collecting, coordinating, monitoring, and distributing data, best practices, and findings regarding the activities funded under grants made to eligible entities under this section.

"(2) Collecting and maintaining up-to-date data on sickle cell disease, including subtypes as applicable, and their associated health outcomes and complications, in consultation with States participating in the Sickle Cell Data Collection of the Centers for

Disease Control and Prevention, including for the purpose of—

"(A) improving national incidence and prevalence data, including the geographic distribution of affected individuals;

"(B) identifying health disparities impacting individuals born with sickle cell disease, including subtypes as applicable, and other hemoglobinopathies;

"(C) assessing the utilization of therapies, comprehensive complication risk screening, and strategies to prevent complications resulting from sickle cell disease and to increase quality of life; and

"(D) evaluating the effects of genetic, environmental, behavioral, and other risk factors that may affect individuals with sickle cell disease.

"(3) Developing educational materials, public awareness campaigns, or other outreach programs regarding the inheritance pattern, treatment of, and prevention of complications from sickle cell disease and prevalence of sickle cell trait, as well as programs and activities that will enhance the lives of in-

dividuals living with sickle cell disease and sickle cell disease trait.

"(h) REQUEST FOR INFORMATION.—Not later than 180 days after the date of enactment of the Sickle Cell Disease Treatment Centers Act of 2026, and in advance of each new grant cycle thereafter, the Secretary shall publish in the Federal Register a request for information seeking feedback from stakeholders on—

"(1) best practices with respect to the establishment and implementation of Sickle Cell Disease Treatment Centers; and

"(2) any other information that the Secretary may require.

"(i) REPORT TO CONGRESS.—

"(1) IN GENERAL.—Not later than 3 years after the date of the enactment of the Sickle Cell Disease Treatment Centers Act of 2026, and every 5 years thereafter, the Secretary shall submit to the Committee on Health, Education, Labor, and Pensions and the Committee on Appropriations of the Senate and the Committee on Energy and Commerce and the Committee on Appropriations of the House of Representatives a report on the impact of the Sickle Cell Disease Treatment Centers estab-

lished under this section on health outcomes for sickle cell disease patients.

"(2) REPORT ELEMENTS.—The report described in this section shall include—

"(A) a summary and description of eligible entities operating a hub-and-spoke system that are receiving grant funds under this section;

"(B) information about the specific activities supported by grant funds awarded under this section with respect to each eligible entity;

"(C) the number of sickle cell disease patients served by grant programs funded under this section and demographic information about those patients, including race, sex, gender, geographic location, and age; and

"(D) information about patient experiences with the hub-and-spoke system and community-based organizations.

"(j) SUPPLEMENT, NOT SUPPLANT.—The activities under this section shall supplement, not supplant, otherwise authorized activities of the Department of Health and Human Services relating to sickle cell disease.

"(k) AUTHORIZATION OF APPROPRIATIONS.—

"(1) IN GENERAL.—To carry out this section, there are authorized to be appropriated such sums

as may be necessary for fiscal year 2027 and each fiscal year thereafter.

"(2) ALLOCATION TO ACTIVITIES.—Of the amount appropriated under paragraph (1) for a fiscal year—

"(A) 70 percent may be awarded to eligible entities for purposes of supporting the activities of hub-and-spoke networks that are a part of such eligible entities;

"(B) 20 percent may be awarded to eligible entities for purposes of supporting the activities of community-based organizations that are a part of such eligible entities;

"(C) 5 percent may be used for the establishment and maintenance of the National Sickle Cell Disease Coordinating Center described in subsection (f); and

"(D) 5 percent may be used for the activities of the Sickle Cell Data Collection program of the Centers for Disease Control and Prevention described in subsection (g).".

○