

118TH CONGRESS  
2D SESSION

# H. R. 9872

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

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 27, 2024

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

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## A BILL

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

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Sickle Cell Disease  
5 Treatment Centers Act of 2024”.

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

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

7 **“SEC. 330Q. SICKLE CELL DISEASE AND OTHER HERITABLE**  
8 **HEMOGLOBINOPATHIES TREATMENT CEN-**  
9 **TERS.**

10 “(a) DEFINITIONS.—In this section:

11 “(1) COMMUNITY-BASED ORGANIZATION.—The  
12 term ‘community-based organization’ means a com-  
13 munity-based nonprofit organization.

14 “(2) HUB-AND-SPOKE NETWORK.—The term  
15 ‘hub-and-spoke network’ means a system for delivery  
16 of health care services—

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

21 “(B) in which such entities serving as  
22 spokes—

23 “(i) may provide sickle cell disease  
24 care services; and

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

4           “(C) in which the medical hub and spoke  
5           has a partnership with one or more community-  
6           based organizations to extend services and out-  
7           reach to the sickle cell disease community.

8           “(3) MEDICAL HUB.—The term ‘medical hub’  
9           means a hospital, clinic, or university health center  
10          that—

11           “(A) provides comprehensive sickle cell dis-  
12           ease treatment, which may include medical and  
13           surgical treatment, such as provision of stem  
14           cell transplants and cell and gene therapies, an  
15           outpatient treatment clinic led by a board-cer-  
16           tified hematologist, infusion capability, tele-  
17           health capability, genetic counseling, access to  
18           home care, and a pharmacy;

19           “(B) has experience serving individuals liv-  
20           ing with sickle cell disease or other  
21           hemoglobinopathies;

22           “(C) follows consensus-based clinical prac-  
23           tice guidelines; and

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

4           “(4) SPOKE.—The term ‘spoke’ means an enti-  
5           ty—

6           “(A) that provides health care services, in-  
7           cluding—

8                   “(i) a Federally-qualified health cen-  
9                   ter, as defined in section 1905(l)(2)(B) of  
10                  the Social Security Act;

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

14                   “(iii) a primary care provider;

15                   “(iv) an outpatient treatment clinic;

16                   “(v) an infusion center; or

17                   “(vi) other health care providers;

18           “(B) that has at least 1 collaborative  
19           agreement with a medical hub and one or more  
20           community-based organization; and

21           “(C) that incorporates a community health  
22           worker into the care team.

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

1 this section as ‘Sickle Cell Disease Treatment Centers’),  
2 for the purposes of—

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

5 “(2) providing support to establish integrated  
6 health care teams for patients with sickle cell disease  
7 over a patient’s lifetime;

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

10 “(4) improving the pediatric-to-adult health  
11 care transition;

12 “(5) collecting and contributing clinical data  
13 from States participating in the Sickle Cell Data  
14 Collection program of the Centers for Disease Con-  
15 trol and Prevention, including the collection of  
16 health outcomes and associated complications re-  
17 ported pursuant to such program;

18 “(6) ensuring that reporting with respect to  
19 sickle cell disease includes reporting on all patients  
20 with sickle cell disease, including migrating and for-  
21 eign-born patients; and

22 “(7) conducting significant public health aware-  
23 ness and education activities with respect to sickle  
24 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—

- 1 “(i) primary care;  
2 “(ii) specialty care;  
3 “(iii) pain management;  
4 “(iv) mental health services;  
5 “(v) genetic counseling services; and  
6 “(vi) other providers.

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

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

12 “(G) Providing a dedicated sickle cell ex-  
13 pert at the medical hub to assist in overseeing  
14 care of sickle cell disease patients at spokes and  
15 to advise the community-based organization.

16 “(H) Educating health care providers on  
17 social determinants of health and implicit bias  
18 that may affect quality of care and life for pa-  
19 tients with sickle cell disease, trait, or other  
20 hemoglobinopathies.

21 “(I) Providing telehealth appointments to  
22 patients when appropriate and facilitating ac-  
23 cess to telehealth services for sickle cell disease  
24 patients to the extent feasible.

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

5           “(K) Providing social work services or  
6 community health worker services in coordina-  
7 tion with one or more community-based organi-  
8 zations.

9           “(L) Collecting and distributing data as  
10 required by the National Sickle Cell Disease  
11 Coordinating Center established under sub-  
12 section (f) or otherwise required by the Sec-  
13 retary.

14           “(M) Engaging in quality improvement  
15 with respect to such standards of care for  
16 health and quality of life outcomes among sickle  
17 cell disease patients as the Secretary may re-  
18 quire.

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

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



1 uals with sickle cell trait, sickle cell disease pa-  
2 tients, caregivers, and health care providers.

3 “(B) Providing support in addressing so-  
4 cial determinants of health, such as food insecu-  
5 rity, housing insecurity, and access to education  
6 and transportation.

7 “(C) Providing social work services or com-  
8 munity health worker services in coordination  
9 with a medical hub or spoke.

10 “(D) Testing or coordinating testing for  
11 individuals at-risk for sickle cell trait and indi-  
12 viduals with sickle cell trait that increase the  
13 likelihood of having a child with sickle cell dis-  
14 ease, including through coordination with a ge-  
15 netic counselor.

16 “(E) Engaging in quality improvement  
17 with respect to standards of care or health and  
18 quality of life outcomes among sickle cell dis-  
19 ease patients, as identified by the Secretary.

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

23 “(A) Collaborating with a medical hub to  
24 coordinate and support care for sickle cell dis-  
25 ease patients.

1           “(B) Providing standards of care as devel-  
2           oped in coordination with the medical hub.

3           “(C) Providing primary care services, ge-  
4           netic counseling, or specialty care.

5           “(D) Providing telehealth appointments, as  
6           appropriate.

7           “(E) Providing medical or surgical treat-  
8           ment.

9           “(F) Implementing individual care plans.

10          “(G) Providing social work services or  
11          community health worker services in coordina-  
12          tion with one or more community-based organi-  
13          zations.

14          “(H) Collecting and distributing data as  
15          required by the National Sickle Cell Disease  
16          Coordinating Center established under sub-  
17          section (f).

18          “(4) ADDITIONAL USES OF FUNDS.—In addi-  
19          tion to the uses of funds described in paragraphs  
20          (1), (2), and (3), an eligible entity selected to receive  
21          a grant under this section may use funds received  
22          through the grant—

23                 “(A) to identify and secure resources for  
24                 ensuring reimbursement under, for the State in-  
25                 volved, the State plan under title XIX of the

1 Social Security Act (or a waiver of such plan),  
2 State child health plan under title XXI of such  
3 Act (or a waiver of such plan), and other health  
4 programs for the prevention and treatment of  
5 sickle cell disease, including by working with  
6 community-based sickle cell disease organiza-  
7 tions and other nonprofit entities;

8 “(B) to assist sickle cell disease patients  
9 with accessing appropriate health insurance, in-  
10 cluding—

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

15 “(ii) by working with community-  
16 based sickle cell disease organizations and  
17 other nonprofit entities; and

18 “(iii) by helping sickle cell disease pa-  
19 tients know their rights with insurance  
20 programs;

21 “(C) to facilitate access to telehealth serv-  
22 ices for sickle cell disease patients and individ-  
23 uals with sickle cell trait, to the extent feasible;

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

1 teachers and school personnel, and correctional  
2 institutional personnel, on the care of individ-  
3 uals with sickle cell disease or trait in health  
4 care settings and other appropriate settings, in-  
5 cluding schools and prisons;

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

12 “(F) to facilitate access to sickle cell trait  
13 testing and genetic counseling.

14 “(e) APPLICATION; SELECTION.—

15 “(1) APPLICATION.—An eligible entity desiring  
16 a grant under this section shall submit an applica-  
17 tion to the Secretary at such time, in such manner,  
18 and containing such information as the Secretary  
19 may require, including a description of how the hub-  
20 and-spoke entity and community-based organization  
21 will collaborate in carrying out the activities de-  
22 scribed in subsection (c).

23 “(2) GEOGRAPHIC DISTRIBUTION.—The Sec-  
24 retary shall award grants under this section, to the  
25 extent practicable, to eligible entities, with a focus

1 on regions where a disproportionate number of pa-  
2 tients with sickle cell disease, individuals with sickle  
3 cell trait, or other heritable hemoglobinopathy pa-  
4 tients per capita reside, and to eligible entities na-  
5 tionwide so that patients can access more com-  
6 prehensive sickle cell disease treatment services no  
7 matter where they reside.

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

11 “(A) include at least one historically black  
12 college or university (defined as a part B insti-  
13 tution under section 322 of the Higher Edu-  
14 cation Act of 1965 (20 U.S.C. 1061)) or minor-  
15 ity serving institution (defined as an eligible in-  
16 stitution under section 371 of such Act (20  
17 U.S.C. 1067q)) that has a medical school, nurs-  
18 ing school, nurse practitioner or physician as-  
19 sistant program, genetic counseling program, or  
20 school of social work;

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

23 “(C) serve a rural area.

24 “(f) NATIONAL SICKLE CELL DISEASE COORDI-  
25 NATING CENTER.—

1           “(1) IN GENERAL.—The Secretary shall estab-  
2           lish, or enter a cooperative agreement with an entity  
3           to establish, the National Sickle Cell Disease Coordi-  
4           nating Center, which shall coordinate the activities  
5           conducted by grantees under this section and carry  
6           out the activities described in paragraph (2).

7           “(2) DUTIES.—The National Sickle Cell Dis-  
8           ease Coordinating Center shall carry out each of the  
9           following activities:

10                   “(A) Advise the Secretary on the design  
11                   and implementation of, and coordinate the in-  
12                   frastructure of, the Sickle Cell Disease Treat-  
13                   ment Centers established under subsection (b),  
14                   including with respect to administrative require-  
15                   ments and ensuring that sickle cell health care  
16                   is available across the United States.

17                   “(B) Develop a national strategy for the  
18                   practice of equitable care, coordinated com-  
19                   prehensive quality care, research and resources  
20                   for patients and health care providers, and  
21                   treatment modality options to improve patient  
22                   outcomes, and submit such national strategy to  
23                   the Secretary.

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

1           tients and routinely update a national needs as-  
2           sessment to improve care for individuals im-  
3           pacted by sickle cell disease.

4           “(D) Coordinate with hub-and-spoke net-  
5           works, patients, researchers, and health care  
6           providers to maintain a comprehensive sickle  
7           cell research, treatment, and national care  
8           strategy.

9           “(E) Establish a rotating panel of stake-  
10          holders, including health care providers, pa-  
11          tients, individuals impacted by sickle cell dis-  
12          ease, allied health professionals, care coordina-  
13          tors, social workers, community health workers,  
14          and sickle cell community-based and advocacy  
15          organizations to advise the Center, provide up-  
16          to-date information and forecasts on status and  
17          plans for improving sickle cell care, treatment,  
18          and access to treatment modalities for individ-  
19          uals and families living with sickle cell disease.

20          “(F) Coordinate and support hub-and-  
21          spoke frameworks.

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

1           “(H) Provide or coordinate technical as-  
2           sistance and support to health care providers,  
3           family members and advocates, public health  
4           professionals, policymakers, and patients that  
5           want to improve access to quality care, tele-  
6           medicine, family planning, health care transi-  
7           tion, and family and community engagement.

8           “(I) Inform and educate the public about  
9           sickle cell disease, sickle cell trait, and options  
10          for quality care.

11          “(g) CDC SICKLE CELL DISEASE DATA COLLECTION  
12          PROGRAM FOR SCD TREATMENT CENTERS.—The Sec-  
13          retary, acting through the Director of the Centers for Dis-  
14          ease Control and Prevention, in coordination with the Na-  
15          tional Sickle Cell Coordinating Center established under  
16          subsection (f), shall carry out the following:

17                 “(1) Collecting, coordinating, monitoring, and  
18                 distributing data, best practices, and findings re-  
19                 garding the activities funded under grants made to  
20                 eligible entities under this section.

21                 “(2) Collecting and maintaining up-to-date data  
22                 on sickle cell disease, including subtypes as applica-  
23                 ble, and their associated health outcomes and com-  
24                 plications, in consultation with States participating  
25                 in the Sickle Cell Data Collection of the Centers for



1 Disease Control and Prevention, including for the  
2 purpose of—

3 “(A) improving national incidence and  
4 prevalence data, including the geographic dis-  
5 tribution of affected individuals;

6 “(B) identifying health disparities impact-  
7 ing individuals born with sickle cell disease, in-  
8 cluding subtypes as applicable, and other  
9 hemoglobinopathies;

10 “(C) assessing the utilization of therapies,  
11 comprehensive complication risk screening, and  
12 strategies to prevent complications resulting  
13 from sickle cell disease and to increase quality  
14 of life; and

15 “(D) evaluating the effects of genetic, envi-  
16 ronmental, behavioral, and other risk factors  
17 that may affect individuals with sickle cell dis-  
18 ease.

19 “(3) Developing educational materials, public  
20 awareness campaigns, or other outreach programs  
21 regarding the inheritance pattern, treatment of, and  
22 prevention of complications from sickle cell disease  
23 and prevalence of sickle cell trait, as well as pro-  
24 grams and activities that will enhance the lives of in-

1 individuals living with sickle cell disease and sickle cell  
2 disease trait.

3 “(h) REQUEST FOR INFORMATION.—Not later than  
4 180 days after the date of enactment of the Sickle Cell  
5 Disease Treatment Centers Act of 2024, and in advance  
6 of each new grant cycle thereafter, the Secretary shall  
7 publish in the Federal Register a request for information  
8 seeking feedback from stakeholders on—

9 “(1) best practices with respect to the establish-  
10 ment and implementation of Sickle Cell Disease  
11 Treatment Centers; and

12 “(2) any other information that the Secretary  
13 may require.

14 “(i) REPORT TO CONGRESS.—

15 “(1) IN GENERAL.—Not later than 3 years  
16 after the date of the enactment of the Sickle Cell  
17 Disease Treatment Centers Act of 2024 and every 5  
18 years thereafter, the Secretary shall submit to the  
19 Committee on Health, Education, Labor, and Pen-  
20 sions and the Committee on Appropriations of the  
21 Senate and the Committee on Energy and Com-  
22 merce and the Committee on Appropriations of the  
23 House of Representatives a report on the impact of  
24 the Sickle Cell Disease Treatment Centers estab-

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

3 “(2) REPORT ELEMENTS.—The report de-  
4 scribed in this section shall include—

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

8 “(B) information about the specific activi-  
9 ties supported by grant funds awarded under  
10 this section with respect to each eligible entity;

11 “(C) the number of sickle cell disease pa-  
12 tients served by grant programs funded under  
13 this section and demographic information about  
14 those patients, including race, sex, gender, geo-  
15 graphic location, and age; and

16 “(D) information about patient experiences  
17 with the hub-and-spoke system and community-  
18 based organizations.

19 “(j) SUPPLEMENT, NOT SUPPLANT.—The activities  
20 under this section shall supplement, not supplant, other-  
21 wise authorized activities of the Department of Health and  
22 Human Services relating to sickle cell disease.

23 “(k) AUTHORIZATION OF APPROPRIATIONS.—

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

1 as may be necessary for fiscal year 2025 and each  
2 fiscal year thereafter.

3 “(2) ALLOCATION TO ACTIVITIES.—Of the  
4 amount appropriated under paragraph (1) for a fis-  
5 cal year—

6 “(A) 70 percent may be awarded to eligible  
7 entities for purposes of supporting the activities  
8 of hub and spoke networks that are a part of  
9 such eligible entities;

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

14 “(C) 5 percent may be used for the estab-  
15 lishment and maintenance of the National Sick-  
16 le Cell Disease Coordinating Center described  
17 in subsection (f); and

18 “(D) 5 percent may be used for the activi-  
19 ties of the Sickle Cell Data Collection program  
20 of the Centers for Disease Control and Preven-  
21 tion described in subsection (g).”.

○