

103<sup>D</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 3745

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JANUARY 26, 1994

Mr. JEFFERSON (for himself and Mr. FIELDS of Louisiana) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

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. FINDINGS AND PURPOSE.**

4       (a) FINDINGS.—Congress finds that:

5               (1) Sickle Cell Disease is a serious illness that  
6       disproportionately affects African-Americans.

7               (2) Approximately 1 out of every 12 African-  
8       Americans is born with the sickle cell trait, and

1 about 1 out of every 600 is afflicted with Sickle Cell  
2 Disease.

3 (3) Sickle cell conditions also occur in other  
4 United States populations, primarily those of Puerto  
5 Rican, Cuban, southern Italian ancestry and more  
6 recently sickle cell has been found in some Cauca-  
7 sian individuals.

8 (4) Sickle Cell Disease is a painful and dis-  
9 abling disorder which can lead to untimely death  
10 and is caused by inadequate transportation of oxy-  
11 gen due to an abnormal type of hemoglobin molecule  
12 in the red blood cells.

13 (5) Sickle Cell Disease is an inherited disease  
14 which can be transmitted to offspring, particularly if  
15 both parents carry the genetic trait.

16 (6) The sickle cell trait carriers show no sign of  
17 the disease, but statistically, 1 in 4 of their children  
18 will be afflicted with the disease.

19 (7) There is no national research center devoted  
20 to Sickle Cell Disease in the United States.

21 (8) There is no known cure for Sickle Cell Dis-  
22 ease at this time and there is a need for prioritized  
23 and specialized research to find such a cure for this  
24 severely disabling disease.

1           (9) Louisiana's minority population is  
2           1,299,281.

3           (10) Of this number, a suspected 3,248 individ-  
4           uals will have the disease and of those individuals,  
5           25 percent (812 individuals) will have the most  
6           acute and serious stage of Sickle Cell Disease, a  
7           stage that is usually fatal.

8           (11) Some 129,928 individuals in Louisiana will  
9           carry the sickle cell trait.

10          (12) Southern University, located in Baton  
11          Rouge, Louisiana is the largest predominately Afri-  
12          can-American university in the United States.

13          (13) Approximately 16,700 students attend this  
14          112 year old school and Southern graduates are lo-  
15          cated throughout the United States and the world.

16          (14) The State of Louisiana through the Lou-  
17          isiana Legislature and Southern University, has  
18          shown great leadership and committed significant fi-  
19          nancial and personnel resources towards the develop-  
20          ment of a National Center for Sickle Cell Disease  
21          Research.

22          (15) Because Southern University has commit-  
23          ted its resources and personnel to seeing this project  
24          through to its ultimate goal, finding a cure for Sick-  
25          le Cell Disease, and because of Southern Univer-

1       sity's large minority population it is appropriate to  
2       locate the National Center for Sickle Cell Disease  
3       Research at Southern University in Baton Rouge.

4       (b) PURPOSE.—It is the purpose of this Act to estab-  
5       lish a National Center for Sickle Cell Disease at Southern  
6       University in Baton Rouge, Louisiana, that will have the  
7       following objectives—

8               (1) to conduct biomedical research and clinical  
9               investigations designed to find a cure for Sickle Cell  
10              Disease;

11             (2) to conduct a wide variety of human behav-  
12             ioral studies designed to provide new knowledge  
13             about such issues as the effectiveness of various  
14             counseling and education methods, and techniques to  
15             improve coping skills on the part of patients and  
16             their families;

17             (3) to establish collaborative arrangements and  
18             joint research programs and projects with other  
19             Louisiana institutions of higher education, such as  
20             Louisiana State University Medical Centers at New  
21             Orleans and Shreveport and Tulane University Med-  
22             ical Center to conduct clinical trials on anti-sickling  
23             agents;

24             (4) to provide expanded opportunities for fac-  
25             ulty members at the institutions described in para-

1 graph (3) to publish in the three broad areas of  
2 basic biomedical research, psychosocial research and  
3 clinical research;

4 (5) to become a laboratory for training both  
5 graduate and undergraduate students in research  
6 methods and techniques concerning Sickle Cell Dis-  
7 ease; and

8 (6) to develop, promote and implement joint re-  
9 search projects with other public and private higher  
10 education institutions including teaching hospitals  
11 on Sickle Cell Disease.

12 **SEC. 2. NATIONAL CENTER FOR SICKLE CELL DISEASE RE-**  
13 **SEARCH.**

14 (a) GRANT.—The Secretary of Health and Human  
15 Services shall award a grant to the Louisiana Department  
16 of Health and Hospitals for the establishment and con-  
17 struction of the National Center for Sickle Cell Disease  
18 Research at Southern University in Baton Rouge, Louisi-  
19 ana, and for related facilities and equipment at such Cen-  
20 ter. Prior to the awarding of such grant, the State of Lou-  
21 isiana shall certify to the Secretary—

22 (1) that the State of Louisiana has provided  
23 not less than \$7,000,000 to support and operate  
24 such Center; and

1           (2) that the State of Louisiana has developed a  
2           plan to provide funds for the continued operation  
3           and support of such center.

4           (b) AUTHORIZATION OF APPROPRIATIONS.—There is  
5           authorized to be appropriated \$21,000,000 to carry out  
6           the purposes of this Act.

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