

HOUSE BILL No. 1354

DIGEST OF INTRODUCED BILL

Citations Affected: IC 16-46-7.

Synopsis: Sickle cell disease grant program. Requires the state department of health (state department) to do the following concerning the sickle cell disease program (program): (1) Develop standards for determining eligibility for individuals requesting care and treatment for sickle cell disease. (2) Assist in the development and expansion of care for the treatment of individuals with sickle cell disease. (3) Provide financial assistance to individuals with sickle cell disease for specified treatments. Specifies that in awarding grants under the program, the state department shall give priority to establishing sickle cell disease centers in underserved areas with a higher population of individuals with sickle cell disease. Specifies program requirements. Establishes the sickle cell chronic disease fund for purposes of funding the program. Requires the state department, with the assistance of specified groups, to prepare a biennial study of information concerning sickle cell disease in Indiana. Requires the study to be transmitted to the general assembly.

Effective: Upon passage; July 1, 2019.

Porter, Shackelford

January 14, 2019, read first time and referred to Committee on Public Health.



First Regular Session of the 121st General Assembly (2019)

PRINTING CODE. Amendments: Whenever an existing statute (or a section of the Indiana Constitution) is being amended, the text of the existing provision will appear in this style type, additions will appear in **this style type**, and deletions will appear in ~~this style type~~.

Additions: Whenever a new statutory provision is being enacted (or a new constitutional provision adopted), the text of the new provision will appear in **this style type**. Also, the word **NEW** will appear in that style type in the introductory clause of each SECTION that adds a new provision to the Indiana Code or the Indiana Constitution.

Conflict reconciliation: Text in a statute in *this style type* or ~~this style type~~ reconciles conflicts between statutes enacted by the 2018 Regular and Special Session of the General Assembly.

HOUSE BILL No. 1354

A BILL FOR AN ACT to amend the Indiana Code concerning health.

Be it enacted by the General Assembly of the State of Indiana:

- 1 SECTION 1. IC 16-46-7-2 IS AMENDED TO READ AS
- 2 FOLLOWS [EFFECTIVE JULY 1, 2019]: Sec. 2. The state department
- 3 shall establish a program for the purpose of providing ~~funds~~ for the
- 4 prevention, care, and treatment of sickle cell ~~anemia disease~~ and for
- 5 educational programs concerning the disease.
- 6 SECTION 2. IC 16-46-7-8 IS AMENDED TO READ AS
- 7 FOLLOWS [EFFECTIVE JULY 1, 2019]: Sec. 8. **(a)** The state
- 8 department shall do the following:
- 9 (1) Develop **the following:**
- 10 **(A)** Application criteria and standards of eligibility for groups
- 11 or organizations who apply for funds under this program.
- 12 **(B) Standards for determining eligibility for individuals**
- 13 **requesting care and treatment for sickle cell disease under**
- 14 **the program established under this chapter.**
- 15 (2) Make available grants to groups and organizations who meet
- 16 the eligibility standards set by the department. However:
- 17 **(A)** the highest priority for grants shall be accorded to



1 established sickle cell anemia foundation chapters disease
 2 **community based organizations** throughout Indiana; and
 3 **(B) priority shall also be given to ensuring the**
 4 **establishment of sickle cell disease centers in underserved**
 5 **areas that have a higher population of sickle cell disease**
 6 **patients, including the:**

7 **(i) northwest;**

8 **(ii) northeast;**

9 **(iii) south; and**

10 **(iv) southwest;**

11 **regions of Indiana.**

12 (3) Determine the maximum amount available for each grant.

13 (4) Determine policies for expiration and renewal of grants.

14 (5) Require that all grant funds be used for the purpose of
 15 prevention, care, and treatment of sickle cell anemia disease or
 16 for educational programs concerning the disease.

17 **(6) Assist in the development and expansion of care for the**
 18 **treatment of individuals with sickle cell disease, particularly**
 19 **for adults, including the following types of care:**

20 **(A) Self-administered.**

21 **(B) Preventative.**

22 **(C) Home care.**

23 **(D) Other evidence based medical procedures and**
 24 **techniques designed to provide maximum control over**
 25 **sickling episodes typical of occurring to an individual with**
 26 **the disease.**

27 **(7) In order to increase the effectiveness of funds**
 28 **appropriated under this chapter, provide financial assistance**
 29 **to individuals with sickle cell disease for the following**
 30 **treatments of the disease:**

31 **(A) Chronic blood transfusions.**

32 **(B) Hydroxyurea.**

33 **(C) Folic acid.**

34 **(D) Use of other efficacious agents.**

35 ~~(6)~~ **(8) Adopt necessary rules under IC 4-22-2 for the**
 36 **administration of this chapter.**

37 **(b) The program described in section 2 of this chapter must**
 38 **provide for the following:**

39 **(1) Increased access to health care for individuals with sickle**
 40 **cell disease, with services provided either:**

41 **(A) directly through the state department; or**

42 **(B) indirectly through a contract with health care**



- 1 providers, municipal health departments, or community
 2 based organizations.
- 3 (2) Establishment of an adult sickle cell disease infusion
 4 center.
- 5 (3) Increased access to mental health resources and pain
 6 management therapies for individuals with sickle cell disease,
 7 with services provided either:
- 8 (A) directly through the state department; or
 9 (B) indirectly through a contract with health care
 10 providers, municipal health departments, or community
 11 based organizations.
- 12 (4) Counseling to any individual, at no cost, concerning sickle
 13 cell disease and sickle cell trait, and the characteristics,
 14 symptoms, and treatment of the disease, with services
 15 provided either:
- 16 (A) directly through the state department; or
 17 (B) indirectly through a contract with health care
 18 providers, municipal health departments, or community
 19 based organizations.
- 20 (5) The development of a sickle cell disease educational
 21 outreach program that includes the dissemination of
 22 educational materials to the following concerning sickle cell
 23 disease and sickle cell trait:
- 24 (A) Medical residents.
 25 (B) Immigrants.
 26 (C) Schools and universities.
 27 (D) Businesses.
- 28 (c) The counseling described in subsection (b)(4) may consist of
 29 any of the following:
- 30 (1) Genetic counseling for an individual who tests positive for
 31 sickle cell trait.
 32 (2) Psychosocial counseling for an individual who tests
 33 positive for sickle cell disease, including any of the following:
- 34 (A) Social service counseling.
 35 (B) Psychological counseling.
 36 (C) Psychiatric counseling.
- 37 (d) The state department may contract with an entity to
 38 implement the sickle cell disease educational outreach program
 39 described in subsection (b)(5).
- 40 SECTION 3. IC 16-46-7-9 IS ADDED TO THE INDIANA CODE
 41 AS A NEW SECTION TO READ AS FOLLOWS [EFFECTIVE JULY
 42 1, 2019]: Sec. 9. (a) The sickle cell chronic disease fund is



1 established for the purpose of carrying out the provisions of this
2 chapter. The fund shall be administered by the state department.

3 (b) The fund consists of the following:

- 4 (1) Appropriations from the general assembly.
5 (2) Amounts, if any, distributed to the fund from the Indiana
6 tobacco master settlement agreement fund.
7 (3) Gifts, bequests, and other sources of funding.
8 (4) Interest accrued under this section.

9 (c) The expenses of administering the fund shall be paid from
10 money in the fund.

11 (d) The treasurer of state shall invest the money in the fund not
12 currently needed to meet the obligations of the fund in the same
13 manner as other public money may be invested. Interest that
14 accrues from these investments shall be deposited in the fund.

15 (e) Money in the fund at the end of a state fiscal year does not
16 revert to the state general fund.

17 SECTION 4. IC 16-46-7-10 IS ADDED TO THE INDIANA CODE
18 AS A NEW SECTION TO READ AS FOLLOWS [EFFECTIVE
19 UPON PASSAGE]: **Sec. 10. (a) Before July 1, 2019, and on a
20 biennial basis thereafter, the state department, with the assistance
21 of:**

- 22 (1) the Indiana minority health coalition;
23 (2) health care providers that treat individuals with sickle cell
24 disease;
25 (3) individuals diagnosed with sickle cell disease; and
26 (4) representatives of community based organizations that
27 serve individuals with sickle cell disease;

28 shall perform a study to determine the prevalence, impact, and
29 needs of individuals with sickle cell disease and sickle cell trait in
30 Indiana.

31 (b) The study must include the following:

- 32 (1) The prevalence, by geographic location, of individuals
33 diagnosed with sickle cell disease in Indiana.
34 (2) The prevalence, by geographic location, of individuals
35 diagnosed as sickle cell trait carriers in Indiana.
36 (3) The availability and affordability of screening services in
37 Indiana for sickle cell trait.
38 (4) The location and capacity of the following for the
39 treatment of sickle cell disease and sickle cell trait carriers:
40 (A) Treatment centers.
41 (B) Clinics.
42 (C) Community based social service organizations.



- 1 **(D) Medical specialists.**
- 2 **(5) The unmet medical, psychological, and social needs**
- 3 **encountered by individuals in Indiana with sickle cell disease.**
- 4 **(6) The underserved areas of Indiana for the treatment of**
- 5 **sickle cell disease.**
- 6 **(7) Recommendations for actions to address any shortcomings**
- 7 **in Indiana identified under this section.**
- 8 **(c) The state department shall transmit a study performed**
- 9 **under this section in an electronic format under IC 5-14-6 to the**
- 10 **general assembly.**
- 11 **SECTION 5. An emergency is declared for this act.**

