



February 17, 2015

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## HOUSE BILL No. 1329

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DIGEST OF HB 1329 (Updated February 16, 2015 1:11 pm - DI 77)

**Citations Affected:** IC 16-46.

**Synopsis:** Sickle cell disease grant program. Adds specific requirements to the sickle cell program of the state department of health (department). Requires the department to establish sickle cell disease centers in various regions of Indiana. Requires the department to conduct a study concerning certain aspects of sickle cell disease and treatment.

**Effective:** July 1, 2015.

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**Porter, Clere, Brown C, Frizzell**

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January 13, 2015, read first time and referred to Committee on Public Health.  
February 16, 2015, amended, reported — Do Pass. Referred to Committee on Ways and Means pursuant to Rule 127.

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HB 1329—LS 6870/DI 77





February 17, 2015

First Regular Session of the 119th General Assembly (2015)

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 2014 Regular Session and 2014 Second Regular Technical Session of the General Assembly.

## HOUSE BILL No. 1329

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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, 2015]: Sec. 2. **(a)** The state  
3 department shall establish a **sickle cell** program for the purpose of  
4 providing funds for the prevention, care, and treatment of sickle cell  
5 **anemia disease** and for educational programs concerning the disease.  
6 **(b) The sickle cell program established under subsection (a)**  
7 **must be funded by the Indiana sickle cell chronic disease fund and**  
8 **must include the following services:**  
9 **(1) Ensure access to blood tests for sickle cell disease and**  
10 **sickle cell trait to any at risk person who requests a test.**  
11 **(2) Ensure access to counseling and advice to any at risk**  
12 **person who requests counseling for sickle cell disease and**  
13 **sickle cell trait, its characteristics, symptoms, traits, effects,**  
14 **and treatment. The counseling provided must consist of the**  
15 **following:**

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- 1           **(A) Genetic counseling for a person who tests positive for**  
 2           **sickle cell trait.**  
 3           **(B) Psychosocial counseling for a person who tests positive**  
 4           **for sickle cell disease, which may include social service**  
 5           **counseling, psychological counseling, and psychiatric**  
 6           **counseling.**  
 7           **(3) Help ensure access to financial assistance to any person**  
 8           **with sickle cell disease who is financially challenged as a result**  
 9           **of the disease and who:**  
 10           **(A) requires continuing treatment with chronic blood**  
 11           **transfusions to avoid strokes, extensive hospitalization, and**  
 12           **other effects associated with the critical, chronic pain, and**  
 13           **sickling condition;**  
 14           **(B) is unable to pay for the entire cost of the services on a**  
 15           **continuing basis despite the existence of various types of**  
 16           **assistance, including medical insurance coverage, the**  
 17           **Indiana check up plan (as amend under IC 12-15-44.2-22),**  
 18           **Medicare, Medicaid, government assistance programs, and**  
 19           **private charitable assistance programs; and**  
 20           **(C) is a resident of Indiana.**  
 21           **(4) Ensure the implementation of a sickle cell disease medical**  
 22           **provider educational outreach program, including the**  
 23           **dissemination of medical educational materials about sickle**  
 24           **cell disease and sickle cell trait to appropriate health care**  
 25           **providers, including physicians, nurses, hospitals, and health**  
 26           **clinics.**  
 27           **(5) Ensure implementation of a sickle cell disease educational**  
 28           **outreach program, including the dissemination of educational**  
 29           **materials about sickle cell disease and sickle cell trait to the**  
 30           **general public and through various institutions, including**  
 31           **businesses, schools, and universities.**  
 32           **(c) The services required under subsection (b) must be provided**  
 33           **by:**  
 34           **(1) the state department; or**  
 35           **(2) private service providers, local health departments, or**  
 36           **community based organizations that have contracted with the**  
 37           **state department.**  
 38           SECTION 2. IC 16-46-7-8 IS AMENDED TO READ AS  
 39           FOLLOWS [EFFECTIVE JULY 1, 2015]: Sec. 8. The state department  
 40           shall do the following:  
 41           (1) Develop application criteria and standards of eligibility for  
 42           groups or organizations who apply for funds under this program.



1 (2) Make available grants to groups and organizations who meet  
 2 the eligibility standards set by the department. However, the  
 3 highest priority for grants shall be accorded to established sickle  
 4 cell ~~anemia foundation chapters~~ **disease community based**  
 5 **organizations** throughout Indiana. **Priority must be given to**  
 6 **ensuring the support or establishment of sickle cell disease**  
 7 **centers in underserved areas in which there is a higher**  
 8 **population of sickle cell disease patients. The state department**  
 9 **shall seek input from the Indiana Minority Health Coalition**  
 10 **in determining the focus in underserved areas. The state**  
 11 **department shall ensure that each sickle cell center has the**  
 12 **appropriate staffing to provide the services required under**  
 13 **this section.**

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

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

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

19 (6) Adopt necessary rules.

20 SECTION 3. IC 16-46-7-9 IS ADDED TO THE INDIANA CODE  
 21 AS A NEW SECTION TO READ AS FOLLOWS [EFFECTIVE JULY  
 22 1, 2015]: **Sec. 9. The state department may do the following:**

23 (1) **Develop standards for determining eligibility for care and**  
 24 **treatment under the sickle cell disease program established**  
 25 **under this chapter.**

26 (2) **Assist in the development and expansion of programs for**  
 27 **the care and treatment of persons suffering from sickle cell**  
 28 **disease, including the following:**

29 (A) **Self administration.**

30 (B) **Prevention.**

31 (C) **Home care.**

32 (D) **Other medical procedures and techniques designed to**  
 33 **provide maximum control over sickling episodes typical of**  
 34 **the condition.**

35 (3) **Extend financial assistance to persons suffering from**  
 36 **sickle cell disease in obtaining chronic blood transfusions,**  
 37 **hydroxyurea folic acid, and other effective agents to increase**  
 38 **the effectiveness of the funds appropriated to carry out this**  
 39 **chapter.**

40 (4) **Adopt rules necessary to carry out this chapter.**

41 SECTION 4. IC 16-46-7-10 IS ADDED TO THE INDIANA CODE  
 42 AS A NEW SECTION TO READ AS FOLLOWS [EFFECTIVE JULY



1, 2015]: Sec. 10. (a) The state department shall:

2 (1) Conduct a biannual study to determine the prevalence,  
3 impact, and needs of sickle cell disease and sickle cell trait  
4 within Indiana. The study must be conducted with the  
5 assistance of the Indiana Minority Health Coalition, sickle cell  
6 patients, physicians who treat sickle cell patients,  
7 representatives of clinics that treat sickle cell patients, and  
8 representatives of community based social service  
9 organizations that serve the sickle cell population in Indiana.  
10 The first study must be completed by November 30, 2015, and  
11 a report must be submitted to the public health committee of  
12 the Indiana house of representatives and the health and  
13 provider services committee of the Indiana senate.

14 (2) The study in subdivision (1) must determine and document  
15 the following:

16 (A) The prevalence, by location, of sickle cell disease  
17 patients within Indiana.

18 (B) The prevalence, by location, of sickle cell trait carriers  
19 within Indiana.

20 (C) The availability, accessibility and affordability of sickle  
21 cell trait screening services within Indiana.

22 (D) The prevalence, location, and capacity of sickle cell  
23 disease treatment centers, clinics, and medical specialists  
24 within Indiana.

25 (E) The prevalence, location, and capacity of community  
26 based social service organizations serving sickle cell  
27 disease patients and sickle cell trait carriers within  
28 Indiana.

29 (F) The unmet medical and psychosocial needs, if any, that  
30 are encountered by sickle cell disease patients within  
31 Indiana.

32 (G) The areas of Indiana, if any, where sickle cell disease  
33 patients may be underserved with regard to medical  
34 treatment or social service support.

35 (H) Recommendations for actions required to rectify any  
36 identified shortcomings.

37 (b) After completion of each study under this section, the  
38 general assembly may direct the department to implement new  
39 changes to the sickle cell program, including the establishment of  
40 a network of regional sickle cell centers under section 8.3 of this  
41 chapter.



## COMMITTEE REPORT

Mr. Speaker: Your Committee on Public Health, to which was referred House Bill 1329, has had the same under consideration and begs leave to report the same back to the House with the recommendation that said bill be amended as follows:

Page 1, line 6, after "(a)" insert "**must be funded by the Indiana sickle cell chronic disease fund and**".

Page 1, line 8, delete "Provide for free" and insert "**Ensure access to**".

Page 1, line 9, after "any" insert "**at risk**".

Page 1, line 10, delete "Provide for free" and insert "**Ensure access to**".

Page 1, line 10, after "any" insert "**at risk**".

Page 2, line 5, delete "Provide" and insert "**Help ensure access to financial**".

Page 2, line 5, after "disease" insert "**who is financially challenged as a result of the disease and**".

Page 2, line 13, after "coverage," insert "**the Indiana check up plan (as amend under IC 12-15-44.2-22),**".

Page 2, line 17, delete "Provide for the development" and insert "**Ensure the implementation**".

Page 2, line 18, delete "and the development" insert ", **including the**".

Page 2, line 19, delete "and".

Page 2, line 23, delete "Provide for the development" and insert "**Ensure implementation**".

Page 2, line 24, delete "and" and insert ", **including**".

Page 3, line 2, after "the" insert "**support or**".

Page 3, line 4, delete "**At least one (1) sickle cell disease**" and insert "**The state department shall seek input from the Indiana Minority Health Coalition in determining the focus in underserved areas. The state department shall ensure that each sickle cell center has the appropriate staffing to provide the services required under this section.**".

Page 3, delete lines 5 through 6.

Page 3, after line 33, begin a new paragraph and insert:

"SECTION 4. IC 16-46-7-10 IS ADDED TO THE INDIANA CODE AS A NEW SECTION TO READ AS FOLLOWS [EFFECTIVE JULY 1, 2015]: **Sec. 10. (a) The state department shall:**

**(1) Conduct a biannual study to determine the prevalence, impact, and needs of sickle cell disease and sickle cell trait**



within Indiana. The study must be conducted with the assistance of the Indiana Minority Health Coalition, sickle cell patients, physicians who treat sickle cell patients, representatives of clinics that treat sickle cell patients, and representatives of community based social service organizations that serve the sickle cell population in Indiana. The first study must be completed by November 30, 2015, and a report must be submitted to the public health committee of the Indiana house of representatives and the health and provider services committee of the Indiana senate.

(2) The study in subdivision (1) must determine and document the following:

(A) The prevalence, by location, of sickle cell disease patients within Indiana.

(B) The prevalence, by location, of sickle cell trait carriers within Indiana.

(C) The availability, accessibility and affordability of sickle cell trait screening services within Indiana.

(D) The prevalence, location, and capacity of sickle cell disease treatment centers, clinics, and medical specialists within Indiana.

(E) The prevalence, location, and capacity of community based social service organizations serving sickle cell disease patients and sickle cell trait carriers within Indiana.

(F) The unmet medical and psychosocial needs, if any, that are encountered by sickle cell disease patients within Indiana.

(G) The areas of Indiana, if any, where sickle cell disease patients may be underserved with regard to medical treatment or social service support.

(H) Recommendations for actions required to rectify any identified shortcomings.

(b) After completion of each study under this section, the general assembly may direct the department to implement new





**changes to the sickle cell program, including the establishment of a network of regional sickle cell centers under section 8.3 of this chapter."**

Renumber all SECTIONS consecutively.  
and when so amended that said bill do pass.

(Reference is to HB 1329 as introduced.)

CLERE

Committee Vote: yeas 12, nays 0.

