



103RD GENERAL ASSEMBLY

State of Illinois

2023 and 2024

HB1024

Introduced 1/12/2023, by Rep. Mary E. Flowers

SYNOPSIS AS INTRODUCED:

New Act
30 ILCS 105/5.990 new

Creates the Sickle Cell Prevention, Care, and Treatment Program Act. Requires the Department of Public Health to establish a grant program for the prevention, care, and treatment of sickle cell disease and for educational programs concerning the disease. Requires the Department to: (1) develop application criteria and standards of eligibility for groups or organizations that apply for funds under the program; and (2) make available grants to groups and organizations that meet the eligibility standards set by the Department. Provides that the highest priority for grants shall be given to established sickle cell disease community-based organizations, and priority shall be given to ensuring the establishment of sickle cell disease centers in underserved areas with a higher population of sickle cell disease patients. Requires the Department to determine the maximum amount available for each grant; determine policies for the expiration and renewal of grants; require that all grant funds be used for the purpose of prevention, care, and treatment of sickle cell disease or for educational programs concerning the disease; and develop a sickle cell disease educational outreach program that includes the dissemination of educational materials to specified persons and institutions. Permits the Department to contract with an entity to implement the outreach program. Requires the Department to adopt rules. Requires the Department to conduct a study to determine the prevalence, impact, and needs of individuals with sickle cell disease and the sickle cell trait in Illinois. Provides that implementation of the Act is subject to appropriation. Amends the State Finance Act. Creates the Sickle Cell Chronic Disease Fund.

LRB103 04905 CPF 49915 b

1 AN ACT concerning public health.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

4 Section 1. Short title. This Act may be cited as the Sickle
5 Cell Prevention, Care, and Treatment Program Act.

6 Section 5. Definitions. As used in this Act:

7 "Department" means the Department of Public Health.

8 "Program" means the Sickle Cell Prevention, Care, and
9 Treatment Program.

10 Section 10. Sickle Cell Prevention, Care, and Treatment
11 Program. The Department shall establish a grant program for
12 the purpose of providing for the prevention, care, and
13 treatment of sickle cell disease and for educational programs
14 concerning the disease.

15 Section 15. Grants; eligibility standards.

16 (a) The Department shall do the following:

17 (1) (A) Develop application criteria and standards of
18 eligibility for groups or organizations that apply for
19 funds under the program.

20 (B) Make available grants to groups and organizations
21 that meet the eligibility standards set by the Department.

1 However:

2 (i) the highest priority for grants shall be
3 accorded to established sickle cell disease
4 community-based organizations throughout Illinois; and

5 (ii) priority shall also be given to ensuring the
6 establishment of sickle cell disease centers in
7 underserved areas that have a higher population of
8 sickle cell disease patients.

9 (2) Determine the maximum amount available for each
10 grant provided under subparagraph (B) of paragraph (1).

11 (3) Determine policies for the expiration and renewal
12 of grants provided under subparagraph (B) of paragraph
13 (1).

14 (4) Require that all grant funds be used for the
15 purpose of prevention, care, and treatment of sickle cell
16 disease or for educational programs concerning the
17 disease. Grant funds shall be used for one or more of the
18 following purposes:

19 (A) Assisting in the development and expansion of
20 care for the treatment of individuals with sickle cell
21 disease, particularly for adults, including the
22 following types of care:

23 (i) Self-administered care.

24 (ii) Preventive care.

25 (iii) Home care.

26 (iv) Other evidence-based medical procedures

1 and techniques designed to provide maximum control
2 over sickling episodes typical of occurring to an
3 individual with the disease.

4 (B) Increasing access to health care for
5 individuals with sickle cell disease.

6 (C) Establishing additional sickle cell disease
7 infusion centers.

8 (D) Increasing access to mental health resources
9 and pain management therapies for individuals with
10 sickle cell disease.

11 (E) Providing counseling to any individual, at no
12 cost, concerning sickle cell disease and the sickle
13 cell trait, and the characteristics, symptoms, and
14 treatment of the disease.

15 (i) The counseling described in this
16 subparagraph (E) may consist of any of the
17 following:

18 (I) Genetic counseling for an individual
19 who tests positive for the sickle cell trait.

20 (II) Psychosocial counseling for an
21 individual who tests positive for sickle cell
22 disease, including any of the following:

23 (aa) Social service counseling.

24 (bb) Psychological counseling.

25 (cc) Psychiatric counseling.

26 (5) Develop a sickle cell disease educational outreach

1 program that includes the dissemination of educational
2 materials to the following concerning sickle cell disease
3 and the sickle cell trait:

4 (A) Medical residents.

5 (B) Immigrants.

6 (C) Schools and universities.

7 (6) Adopt any rules necessary to implement the
8 provisions of this Act.

9 (b) The Department may contract with an entity to
10 implement the sickle cell disease educational outreach program
11 described in paragraph (5) of subsection (a).

12 Section 20. Sickle Cell Chronic Disease Fund.

13 (a) The Sickle Cell Chronic Disease Fund is created as a
14 special fund in the State treasury for the purpose of carrying
15 out the provisions of this Act and for no other purpose. The
16 Fund shall be administered by the Department.

17 (b) The Fund shall consist of:

18 (1) Any moneys appropriated to the Department for the
19 Sickle Cell Prevention, Care, and Treatment Program.

20 (2) Gifts, bequests, and other sources of funding.

21 (3) All interest earned on moneys in the Fund.

22 Section 25. Study.

23 (a) Before July 1, 2024, and on a biennial basis
24 thereafter, the Department, with the assistance of:

- 1 (1) the Center for Minority Health Services;
- 2 (2) health care providers that treat individuals with
- 3 sickle cell disease;
- 4 (3) individuals diagnosed with sickle cell disease;
- 5 (4) representatives of community-based organizations
- 6 that serve individuals with sickle cell disease; and
- 7 (5) data collected via newborn screening for sickle
- 8 cell disease;

9 shall perform a study to determine the prevalence, impact, and
10 needs of individuals with sickle cell disease and the sickle
11 cell trait in Illinois.

12 (b) The study must include the following:

13 (1) The prevalence, by geographic location, of
14 individuals diagnosed with sickle cell disease in
15 Illinois.

16 (2) The prevalence, by geographic location, of
17 individuals diagnosed as sickle cell trait carriers in
18 Illinois.

19 (3) The availability and affordability of screening
20 services in Illinois for the sickle cell trait.

21 (4) The location and capacity of the following for the
22 treatment of sickle cell disease and sickle cell trait
23 carriers:

24 (A) Treatment centers.

25 (B) Clinics.

26 (C) Community-based social service organizations.

1 (D) Medical specialists.

2 (5) The unmet medical, psychological, and social needs
3 encountered by individuals in Illinois with sickle cell
4 disease.

5 (6) The underserved areas of Illinois for the
6 treatment of sickle cell disease.

7 (7) Recommendations for actions to address any
8 shortcomings in the State identified under this Section.

9 (c) The Department shall submit a report on the study
10 performed under this Section to the General Assembly.

11 Section 30. Implementation subject to appropriation.
12 Implementation of this Act is subject to appropriation.

13 Section 90. The State Finance Act is amended by adding
14 Section 5.990 as follows:

15 (30 ILCS 105/5.990 new)

16 Sec. 5.990. The Sickle Cell Chronic Disease Fund.