



101ST GENERAL ASSEMBLY

State of Illinois

2019 and 2020

HB4742

Introduced 2/18/2020, by Rep. Mary E. Flowers - LaToya Greenwood, William Davis and La Shawn K. Ford

SYNOPSIS AS INTRODUCED:

New Act

30 ILCS 105/5

from Ch. 127, par. 141

30 ILCS 105/5.930 new

Creates the Sickle Cell Prevention, Care, and Treatment Program Act. Requires the Department of Healthcare and Family Services to establish a program for the purpose of providing 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; (2) develop standards for determining eligibility for individuals requesting care and treatment for sickle cell disease under the program; and (3) make available grants to groups and organizations who meet the eligibility standards set by the Department. Provides that the highest priority for grants shall be accorded 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 that have a higher population of sickle cell disease patients. Provides that the program must: (i) increase access to health care, mental health resources, and pain management therapies for individuals with sickle cell disease; (ii) provide counseling to any individual, at no cost, concerning sickle cell disease and the sickle cell trait; (iii) provide for the establishment of additional sickle cell disease infusion centers; and (iv) provide for the development of a sickle cell disease educational outreach program. 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. Amends the State Finance Act. Creates the Sickle Cell Chronic Disease Fund.

LRB101 17826 KTG 69811 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning public aid.

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 Sickie
5 Cell Prevention, Care, and Treatment Program Act.

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

7 "Department" means the Department of Healthcare and Family
8 Services.

9 "Program" means the Sickie Cell Prevention, Care, and
10 Treatment Program.

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

16 Section 15. Grants; eligibility standards.

17 (a) The Department shall do the following:

18 (1) Develop the following:

19 (A) Application criteria and standards of
20 eligibility for groups or organizations who apply for
21 funds under the program.

1 (B) Standards for determining eligibility for
2 individuals requesting care and treatment for sickle
3 cell disease under the program.

4 (2) Make available grants to groups and organizations
5 who meet the eligibility standards set by the Department.
6 However:

7 (A) the highest priority for grants shall be
8 accorded to established sickle cell disease
9 community-based organizations throughout Illinois; and

10 (B) priority shall also be given to ensuring the
11 establishment of sickle cell disease centers in
12 underserved areas that have a higher population of
13 sickle cell disease patients.

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

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

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

22 (6) Assist in the development and expansion of care for
23 the treatment of individuals with sickle cell disease,
24 particularly for adults, including the following types of
25 care:

26 (A) Self-administered.

1 (B) Preventive.

2 (C) Home care.

3 (D) Other evidence-based medical procedures and
4 techniques designed to provide maximum control over
5 sickling episodes typical of occurring to an
6 individual with the disease.

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

9 (b) The program must provide for the following:

10 (1) Increased access to health care for individuals
11 with sickle cell disease, with services provided either:

12 (A) directly through the Department; or

13 (B) indirectly through a contract with health care
14 providers, municipal health departments, or
15 community-based organizations.

16 (2) Establishment of additional sickle cell disease
17 infusion centers.

18 (3) Increased access to mental health resources and
19 pain management therapies for individuals with sickle cell
20 disease, with services provided either:

21 (A) directly through the Department; or

22 (B) indirectly through a contract with health care
23 providers, municipal health departments, or
24 community-based organizations.

25 (4) Counseling to any individual, at no cost,
26 concerning sickle cell disease and sickle cell trait, and

1 the characteristics, symptoms, and treatment of the
2 disease, with services provided either:

3 (A) directly through the Department; or

4 (B) indirectly through a contract with health care
5 providers, municipal health departments, or
6 community-based organizations.

7 (5) The development of a sickle cell disease
8 educational outreach program that includes the
9 dissemination of educational materials to the following
10 concerning sickle cell disease and sickle cell trait:

11 (A) Medical residents.

12 (B) Immigrants.

13 (C) Schools and universities.

14 (D) Businesses.

15 (c) The counseling described in paragraph (4) of subsection
16 (b) may consist of any of the following:

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

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

22 (A) Social service counseling.

23 (B) Psychological counseling.

24 (C) Psychiatric counseling.

25 (d) The Department may contract with an entity to implement
26 the sickle cell disease educational outreach program described

1 in paragraph (5) of subsection (b).

2 Section 20. Sickle Cell Chronic Disease Fund.

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

7 (b) The Fund shall consist of:

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

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

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

12 (c) The restrictions on special funds provided in
13 subsections (b) and (c) of Section 5 of the State Finance Act
14 do not apply to the Fund.

15 Section 25. Study.

16 (a) Before July 1, 2021, and on a biennial basis
17 thereafter, the Department, with the assistance of:

18 (1) the Center for Minority Health Services;

19 (2) health care providers that treat individuals with
20 sickle cell disease;

21 (3) individuals diagnosed with sickle cell disease;

22 (4) representatives of community-based organizations
23 that serve individuals with sickle cell disease; and

24 (5) data collected via newborn screening for sickle

1 cell disease;
2 shall perform a study to determine the prevalence, impact, and
3 needs of individuals with sickle cell disease and the sickle
4 cell trait in Illinois.

5 (b) The study must include the following:

6 (1) The prevalence, by geographic location, of
7 individuals diagnosed with sickle cell disease in
8 Illinois.

9 (2) The prevalence, by geographic location, of
10 individuals diagnosed as sickle cell trait carriers in
11 Illinois.

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

14 (4) The location and capacity of the following for the
15 treatment of sickle cell disease and sickle cell trait
16 carriers:

17 (A) Treatment centers.

18 (B) Clinics.

19 (C) Community-based social service organizations.

20 (D) Medical specialists.

21 (5) The unmet medical, psychological, and social needs
22 encountered by individuals in Illinois with sickle cell
23 disease.

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

26 (7) Recommendations for actions to address any

1 shortcomings in the State identified under this Section.

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

4 Section 30. The State Finance Act is amended by changing
5 Section 5 and by adding Section 5.930 as follows:

6 (30 ILCS 105/5) (from Ch. 127, par. 141)

7 Sec. 5. Special funds.

8 (a) There are special funds in the State Treasury
9 designated as specified in the Sections which succeed this
10 Section 5 and precede Section 6.

11 (b) Except as provided in the Illinois Motor Vehicle Theft
12 Prevention and Insurance Verification Act, when any special
13 fund in the State Treasury is discontinued by an Act of the
14 General Assembly, any balance remaining therein on the
15 effective date of such Act shall be transferred to the General
16 Revenue Fund, or to such other fund as such Act shall provide.
17 Warrants outstanding against such discontinued fund at the time
18 of the transfer of any such balance therein shall be paid out
19 of the fund to which the transfer was made.

20 (c) When any special fund in the State Treasury has been
21 inactive for 18 months or longer, the fund is automatically
22 terminated by operation of law and the balance remaining in
23 such fund shall be transferred by the Comptroller to the
24 General Revenue Fund. When a special fund has been terminated

1 by operation of law as provided in this Section, the General
2 Assembly shall repeal or amend all Sections of the statutes
3 creating or otherwise referring to that fund.

4 The Comptroller shall be allowed the discretion to maintain
5 or dissolve any federal trust fund which has been inactive for
6 18 months or longer.

7 (d) (Blank).

8 (e) (Blank).

9 (f) The restrictions on special funds provided in
10 subsections (b) and (c) do not apply to the Sickle Cell Chronic
11 Disease Fund.

12 (Source: P.A. 100-373, eff. 1-1-18.)

13 (30 ILCS 105/5.930 new)

14 Sec. 5.930. The Sickle Cell Chronic Disease Fund.