



Sen. Mattie Hunter

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1 AMENDMENT TO HOUSE BILL 823

2 AMENDMENT NO. _____. Amend House Bill 823, AS AMENDED, by
3 replacing everything after the enacting clause with the
4 following:

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

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

8 "Department" means the Department of Public Health.

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

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

1 Section 15. Grants; eligibility standards.

2 (a) The Department shall do the following:

3 (1) (A) Develop application criteria and standards of
4 eligibility for groups or organizations who apply for funds
5 under the program.

6 (B) Make available grants to groups and organizations
7 who meet the eligibility standards set by the Department.

8 However:

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

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

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

18 (3) Determine policies for the expiration and renewal
19 of grants provided under subparagraph (B) of paragraph (1).

20 (4) Require that all grant funds be used for the
21 purpose of prevention, care, and treatment of sickle cell
22 disease or for educational programs concerning the
23 disease. Grant funds shall be used for one or more of the
24 following purposes:

25 (A) Assisting in the development and expansion of

1 care for the treatment of individuals with sickle cell
2 disease, particularly for adults, including the
3 following types of care:

4 (i) Self-administered care.

5 (ii) Preventive care.

6 (iii) Home care.

7 (iv) Other evidence-based medical procedures
8 and techniques designed to provide maximum control
9 over sickling episodes typical of occurring to an
10 individual with the disease.

11 (B) Increasing access to health care for
12 individuals with sickle cell disease.

13 (C) Establishing additional sickle cell disease
14 infusion centers.

15 (D) Increasing access to mental health resources
16 and pain management therapies for individuals with
17 sickle cell disease.

18 (E) Providing counseling to any individual, at no
19 cost, concerning sickle cell disease and sickle cell
20 trait, and the characteristics, symptoms, and
21 treatment of the disease.

22 (i) The counseling described in this
23 subparagraph (E) may consist of any of the
24 following:

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

1 (II) Psychosocial counseling for an
2 individual who tests positive for sickle cell
3 disease, including any of the following:

4 (aa) Social service counseling.

5 (bb) Psychological counseling.

6 (cc) Psychiatric counseling.

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

11 (A) Medical residents.

12 (B) Immigrants.

13 (C) Schools and universities.

14 (6) Adopt any rules necessary to implement the
15 provisions of this Act.

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

19 Section 20. Sickle Cell Chronic Disease Fund.

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

24 (b) The Fund shall consist of:

25 (1) Any moneys appropriated to the Department for the

1 Sickle Cell Prevention, Care, and Treatment Program.

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

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

4 Section 25. Study.

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

7 (1) the Center for Minority Health Services;

8 (2) health care providers that treat individuals with
9 sickle cell disease;

10 (3) individuals diagnosed with sickle cell disease;

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

13 (5) data collected via newborn screening for sickle
14 cell disease;

15 shall perform a study to determine the prevalence, impact, and
16 needs of individuals with sickle cell disease and the sickle
17 cell trait in Illinois.

18 (b) The study must include the following:

19 (1) The prevalence, by geographic location, of
20 individuals diagnosed with sickle cell disease in
21 Illinois.

22 (2) The prevalence, by geographic location, of
23 individuals diagnosed as sickle cell trait carriers in
24 Illinois.

25 (3) The availability and affordability of screening

1 services in Illinois for the sickle cell trait.

2 (4) The location and capacity of the following for the
3 treatment of sickle cell disease and sickle cell trait
4 carriers:

5 (A) Treatment centers.

6 (B) Clinics.

7 (C) Community-based social service organizations.

8 (D) Medical specialists.

9 (5) The unmet medical, psychological, and social needs
10 encountered by individuals in Illinois with sickle cell
11 disease.

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

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

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

18 Section 30. Implementation subject to appropriation.
19 Implementation of this Act is subject to appropriation.

20 Section 90. The State Finance Act is amended by adding
21 Section 5.930 as follows:

22 (30 ILCS 105/5.930 new)

23 Sec. 5.930. The Sickle Cell Chronic Disease Fund.".