

# STATE OF NEW YORK

5605--A

2021-2022 Regular Sessions

## IN SENATE

March 12, 2021

Introduced by Sens. SANDERS, BROOKS, KENNEDY, KRUEGER, MAYER, MYRIE, RAMOS, SEPULVEDA, SKOUFIS -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law, in relation to creating the sickle cell disease detection and education program

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. Article 24 of the public health law is amended by adding a  
2 new title 1-C to read as follows:

### TITLE I-C

#### SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM

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4  
5 Section 2415. Sickle cell disease detection and education program;  
6 establishment.

7 2416. Grants to approved organizations.

8 2417. Grants to community-based organizations.

9 2418. Annual report.

10 2419. Advisory council.

11 § 2415. Sickle cell disease detection and education program; estab-  
12 lishment. 1. There is hereby created within the department the sickle  
13 cell disease detection and education program, hereafter referred to in  
14 this title as the "sickle cell disease services program" or "the  
15 program", to promote screening and detection of sickle cell disease,  
16 especially among unserved or underserved populations; to educate the  
17 public regarding sickle cell disease and the benefits of early  
18 detection; and to provide counseling and referral services. For purposes  
19 of this title, "unserved or underserved populations" means people having  
20 inadequate access and financial resources to obtain sickle cell disease  
21 screening and detection services, including people who lack health  
22 coverage or whose health coverage is inadequate or who cannot meet the

EXPLANATION--Matter in italics (underscored) is new; matter in brackets  
[-] is old law to be omitted.

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1 financial requirements of their coverage for accessing detection  
2 services.

3 2. The program shall include:

4 (a) establishment of a statewide public education and outreach  
5 campaign to publicize evidence based sickle cell disease screening,  
6 detection and education services. The campaign shall include: general  
7 community education, outreach to specific underserved populations,  
8 evidence based clinical sickle cell disease screening services, and an  
9 informational summary that shall include an explanation of the impor-  
10 tance of clinical examinations and what to expect during clinical exam-  
11 inations and sickle cell disease screening services;

12 (b) provision of grants to approved organizations under sections twenty-  
13 four hundred sixteen and twenty-four hundred seventeen of this title;

14 (c) compilation of data concerning the program and dissemination of  
15 such data to the public; and

16 (d) development of health care professional education programs includ-  
17 ing the benefits of early detection of sickle cell disease and clinical  
18 examinations, the recommended frequency of clinical examinations and  
19 sickle cell disease screening services, and professionally recognized  
20 best practices guidelines.

21 § 2416. Grants to approved organizations. 1. The commissioner shall  
22 make grants within the amounts appropriated to approved organizations  
23 for the provision of services relating to the evidence based screening  
24 and detection of sickle cell disease as part of this program. The  
25 services shall include but not be limited to:

26 (a) promotion and provision of early detection of sickle cell disease,  
27 including clinical examinations and sickle cell disease screening  
28 services;

29 (b) provision of counseling and information on treatment options and  
30 referral for appropriate medical treatment;

31 (c) dissemination of information to unserved and underserved popu-  
32 lations, to the general public and to health care professionals concern-  
33 ing sickle cell disease, the benefits of early detection and treatment,  
34 and the availability of sickle cell disease screening services;

35 (d) identification of local sickle cell disease screening services  
36 within the approved organization's region;

37 (e) provision of information, counseling and referral services to  
38 individuals diagnosed with sickle cell disease; and

39 (f) provision of information regarding the availability of medical  
40 assistance, including medical assistance under title eleven of article  
41 five of the social services law, to an individual who requires treatment  
42 for sickle cell disease.

43 2. The commissioner shall give notice and provide opportunity to  
44 submit applications for grants under the program. In order to be consid-  
45 ered for a grant, an applicant must show evidence of the following,  
46 relating to the services the applicant proposes to provide:

47 (a) ability to provide and to ensure consistent and quality services  
48 under the program;

49 (b) expertise in providing the service;

50 (c) capacity to coordinate services with physicians, hospitals and  
51 other appropriate local institutions or agencies;

52 (d) ability to provide the service to unserved or underserved popu-  
53 lations; and

54 (e) ability to provide the service in accordance with the standards  
55 specified in subdivision three of this section.

56 Applications shall be made on forms provided by the commissioner.

1 3. The commissioner shall develop standards for the implementation of  
2 grants under the program by approved organizations, which shall ensure  
3 the following:

4 (a) integration of the approved organization with existing health care  
5 providers;

6 (b) maximizing third party reimbursement;

7 (c) provision of services to unserved or underserved populations.

8 4. Within the amounts of state or federal funds appropriated for the  
9 program, approved organizations may be authorized by the department to  
10 provide such services for populations served under this title. Services  
11 may include evidence based screening, patient education, counseling,  
12 follow-up and referral.

13 § 2417. Grants to community-based organizations. 1. The commissioner  
14 shall make grants within amounts appropriated for community-based organ-  
15 izations to provide post diagnosis counseling, education and outreach  
16 programs for persons diagnosed with sickle cell disease based upon  
17 criteria to be developed by the commissioner.

18 2. For the purposes of this section, "community-based organizations"  
19 shall mean free-standing organizations in which sickle cell disease  
20 survivors hold significant decision-making responsibility, and which  
21 offer a broad range of sickle cell disease education and support  
22 services free of charge.

23 3. The commissioner shall provide notice and opportunity for communi-  
24 ty-based organizations to submit applications to provide post-diagnosis  
25 sickle cell disease counseling, education and outreach programs. Such  
26 applications shall be on forms established by the commissioner.

27 4. Every organization receiving grants under this title shall submit  
28 to the commissioner, on or before October first of each year, a report  
29 of such organization's activities, including an assessment of the organ-  
30 ization's programs and such data as the commissioner deems relevant and  
31 necessary to accomplish the purposes of the program.

32 § 2418. Annual report. The commissioner shall submit on or before  
33 December first of each year, an annual report to the governor and the  
34 legislature concerning the operation of the program. The reports shall  
35 include the experience of the program in providing services under this  
36 title. The annual report shall include strategies for implementation of  
37 the sickle cell disease awareness program and for promoting the aware-  
38 ness program to the general public, state and local elected officials,  
39 and various public and private organizations, associations, businesses,  
40 industries, and agencies. Organizations receiving grants under this  
41 title shall provide data and assessments as the commissioner may require  
42 for the report. The report shall include any recommendations for addi-  
43 tional action to respond to the incidence of sickle cell disease in this  
44 state.

45 § 2419. Advisory council. 1. There is hereby established in the  
46 department the sickle cell disease detection and education program advi-  
47 sory council, for the purpose of advising the commissioner with regard  
48 to the program.

49 2. The advisory council shall advise and make recommendations to the  
50 commissioner regarding the promotion and implementation of programs  
51 under this title.

52 3. The commissioner shall appoint twenty-one voting members of the  
53 advisory council, which shall include representation of health care  
54 professionals, consumers, patients, with one voting member who shall be  
55 a person who has or has had sickle cell disease. The commissioner shall  
56 appoint one member as a chairperson. The members of the council shall

1 receive no compensation for their services, but shall be allowed their  
2 actual and necessary expenses incurred in performance of their duties.

3 4. A majority of the appointed voting membership of the board shall  
4 constitute a quorum.

5 5. The advisory council shall meet at least twice a year, at the  
6 request of the department.

7 § 2. Subdivision 1 of section 207 of the public health law is amended  
8 by adding a new paragraph (p) to read as follows:

9 (p) sickle cell disease including but not limited to screening,  
10 prevention, and treatment information. The program shall include an  
11 advisory council under this section that shall include patients with  
12 sickle cell disease and their families and health care providers  
13 specializing in treating sickle cell disease, among others.

14 § 3. This act shall take effect immediately.