

# STATE OF NEW YORK

2609

2023-2024 Regular Sessions

## IN ASSEMBLY

January 26, 2023

Introduced by M. of A. HYNDMAN -- read once and referred to the Committee on Health

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:

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

### TITLE I-C

#### SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM

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

2416. Grants to approved organizations.

2417. Grants to community-based organizations.

2418. Annual report.

2419. Advisory council.

§ 2415. Sickle cell disease detection and education program; establishment. 1. There is hereby created within the department the sickle cell disease detection and education program, hereafter referred to in this title as the "sickle cell disease services program" or "the program", to promote screening and detection of sickle cell disease, especially among unserved or underserved populations; to educate the public regarding sickle cell disease and the benefits of early detection; and to provide counseling and referral services. For purposes of this title, "unserved or underserved populations" means people having inadequate access and financial resources to obtain sickle cell disease screening and detection services, including people who lack health coverage or whose health coverage is inadequate or who cannot meet the financial requirements of their coverage for accessing detection services.

2. The program shall include:

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

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

9 (b) provision of grants to approved organizations under sections twen-  
10 ty-four hundred sixteen and twenty-four hundred seventeen of this title;

11 (c) compilation of data concerning the program and dissemination of  
12 such data to the public; and

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

18 § 2416. Grants to approved organizations. 1. The commissioner shall  
19 make grants within the amounts appropriated to approved organizations  
20 for the provision of services relating to the evidence based screening  
21 and detection of sickle cell disease as part of this program. The  
22 services shall include but not be limited to:

23 (a) promotion and provision of early detection of sickle cell disease,  
24 including clinical examinations and sickle cell disease screening  
25 services;

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

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

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

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

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

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

44 (a) ability to provide and to ensure consistent and quality services  
45 under the program;

46 (b) expertise in providing the service;

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

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

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

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

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

1 (a) integration of the approved organization with existing health care  
2 providers;

3 (b) maximizing third party reimbursement;

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

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

10 § 2417. Grants to community-based organizations. 1. The commissioner  
11 shall make grants within amounts appropriated for community-based organ-  
12 izations to provide post diagnosis counseling, education and outreach  
13 programs for persons diagnosed with sickle cell disease based upon  
14 criteria to be developed by the commissioner.

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

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

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

29 § 2418. Annual report. The commissioner shall submit on or before  
30 December first of each year, an annual report to the governor and the  
31 legislature concerning the operation of the program. The reports shall  
32 include the experience of the program in providing services under this  
33 title. The annual report shall include strategies for implementation of  
34 the sickle cell disease awareness program and for promoting the aware-  
35 ness program to the general public, state and local elected officials,  
36 and various public and private organizations, associations, businesses,  
37 industries, and agencies. Organizations receiving grants under this  
38 title shall provide data and assessments as the commissioner may require  
39 for the report. The report shall include any recommendations for addi-  
40 tional action to respond to the incidence of sickle cell disease in this  
41 state.

42 § 2419. Advisory council. 1. There is hereby established in the  
43 department the sickle cell disease detection and education program advi-  
44 sory council, for the purpose of advising the commissioner with regard  
45 to the program.

46 2. The advisory council shall advise and make recommendations to the  
47 commissioner regarding the promotion and implementation of programs  
48 under this title.

49 3. The commissioner shall appoint twenty-one voting members of the  
50 advisory council, which shall include representation of health care  
51 professionals, consumers, patients, with one voting member who shall be  
52 a person who has or has had sickle cell disease. The commissioner shall  
53 appoint one member as a chairperson. The members of the council shall  
54 receive no compensation for their services, but shall be allowed their  
55 actual and necessary expenses incurred in performance of their duties.

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

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

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

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

12    § 3. This act shall take effect immediately.