STATE OF NEW YORK

5873

2025-2026 Regular Sessions

IN ASSEMBLY

February 24, 2025

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

AN ACT to amend the public health law, in relation to requiring persons and parents of children who test positive for sickle cell disease are informed of such diagnosis and provided with educational materials, establishes a registry of persons with sickle cell disease, and requires the department of health issue an annual report on sickle cell disease

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 1-C
SICKLE CELL DISEASE

Section 2415. Sickle cell disease detection and education.
2416. Sickle cell disease registry.
2417. Annual reports.

§ 2415. Sickle cell disease detection and education. 1. When an infant or child tested for sickle cell disease, either under section twenty-five hundred-a of this chapter or for any other purpose, is found to have such disease, the entity which performed the testing shall notify the administrative officer or other person in charge of the institution caring for the infant or child and document the findings to the sickle cell disease registry established under section twenty-four hundred sixteen of this title. Such administrative officer or other person in charge of the institution caring for the infant or child upon receiving such notification shall inform the physician caring for such infant or child and provide the parents of such child with educational pamphlets created by the department concerning sickle cell disease. Such pamphlets shall include, but not be limited to:

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

(a) the availability and benefits of genetic counseling performed by a licensed genetic counselor.

(b) information concerning the fact that one or both of the parents carries sickle cell trait and the risk that other children born to the parents may carry sickle cell trait or may be born with sickle cell disease.

(c) information about counseling, intervention, and educational services.

2. When a person is diagnosed with sickle cell disease, the diagnosing physician shall document the findings to the sickle cell disease registry established under section twenty-four hundred sixteen of this title and provide such person with educational pamphlets created by the department concerning sickle cell disease. Such pamphlets shall include, but not be limited to:

(a) the availability and benefits of genetic counseling performed by a licensed genetic counselor.

(b) information concerning the fact that one or both of the parents of someone with sickle cell disease carries the sickle cell trait and the risk that children born to such parents may carry sickle cell trait or may be born with sickle cell disease.

(c) information about counseling, intervention, and educational services.

3. Information provided to the sickle cell disease registry under this section shall be provided in the form and manner prescribed by the department.

§ 2416. Sickle cell disease registry. 1. The department of health shall establish a sickle cell disease registry, hereinafter referred to as the "registry", which shall consist of:

(a) a record of individuals in this state who have been diagnosed with sickle cell trait.

(b) any other information regarding individuals who have been diagnosed with sickle cell trait that the commissioner considers necessary and appropriate for inclusion on the registry.

(c) educational materials and training materials and programs for both the public and healthcare providers.

2. The registry shall:

(a) provide information to persons diagnosed with sickle cell disease and, where such person is under the age of eighteen, such person's parents about counseling, intervention, and educational services.

(b) notify the parents of patients who are listed in the registry that follow-up consultations with a physician may be beneficial for children diagnosed with sickle cell trait. Such notifications shall occur: (i) at least once when the patient is in early adolescence, when the patient may begin to participate in strenuous athletic activities that could result in adverse symptoms for a person with sickle cell trait; (ii) at least once during later adolescence, when the patient should be made aware of the reproductive implications of sickle cell trait; and (iii) at such other intervals as may be required by the commissioner.

(c) notify registered persons upon reaching the age of eighteen that such person has sickle cell disease and any information the registry provides persons upon being first diagnosed with sickle cell disease.

(d) in collaboration with experts, develop a surveillance and public awareness campaign regarding the importance of knowing one's sickle cell trait status and to gain knowledge on sickle cell disease for all racial and ethnic groups in New York state. Such campaign shall encourage the medical community, in co-ordination with local governments and other state entities, to work to ensure that all individuals are made aware of their sickle cell trait status by developing a common strategy for dissemination of screening results, education, and counseling to all unserved and underserved at risk members of the population.

(e) publish on the department's website educational materials and training materials and programs for both the public and healthcare providers.

3. To facilitate the operations of the registry, the commissioner shall develop guidelines to:

(a) obtain information regarding individuals diagnosed with sickle cell trait from health care facilities.

(b) protect the confidentiality of the individuals in accordance with The Health Insurance Portability and Accountability Act of 1996.

(c) ensure that the registry is developed in a manner consistent with the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191), regulations adopted under that Act, and other applicable laws and regulations governing disclosure of health information.

4. Physicians licensed under article one hundred thirty-one of the education law shall attend bi-annual continuing education training by the registry. The registry shall revise medical school curriculum on the related effects of sickle cell trait as well as sickle cell disease.

§ 2417. Annual reports. On or before the first day of February each year, the commissioner shall provide a written report on the information obtained under this title to the temporary president of the senate, speaker of the assembly, chair of the senate finance committee, chair of the assembly ways and means committee, chair of the senate committee on health, chair of the assembly health committee and the public.

§ 2. This act shall take effect on the ninetieth day after it shall have become a law. Effective immediately, the addition, amendment and/or repeal of any rule or regulation necessary for the implementation of this act on its effective date are authorized to be made and completed on or before such effective date.