

ASSEMBLY, No. 963

STATE OF NEW JERSEY

219th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2020 SESSION

Sponsored by:

Assemblyman HERB CONAWAY, JR.

District 7 (Burlington)

Assemblyman BENJIE E. WIMBERLY

District 35 (Bergen and Passaic)

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District 33 (Hudson)

Co-Sponsored by:

Assemblywoman Murphy

SYNOPSIS

Establishes central registry for sickle cell trait diagnoses; provides for informational outreach and genetic counseling.

CURRENT VERSION OF TEXT

Introduced Pending Technical Review by Legislative Counsel.



1 **AN ACT** concerning sickle cell trait and supplementing Title 26 of
2 the Revised Statutes.

3

4 **BE IT ENACTED** *by the Senate and General Assembly of the State*
5 *of New Jersey:*

6

7 1. a. If a newborn screening for hereditary disorders performed
8 pursuant to section 4 of P.L.1981, c.502 (C.26:5B-4), P.L.1977,
9 c.321 (C.26:2-110 et seq.), or any other applicable law or regulation
10 detects the presence of sickle cell trait, the laboratory performing
11 the screening shall notify the physician responsible for the
12 newborn's care and shall document the patient's information in the
13 central registry established pursuant to section 2 of
14 P.L. , c. (C.) (pending before the Legislature as this bill)
15 in a manner and on forms prescribed by the Commissioner of
16 Health.

17 b. The physician responsible for the newborn's care shall
18 provide the patient's parents with information concerning the
19 availability and benefits of genetic counseling performed by a
20 genetic counselor licensed pursuant to P.L.2009, c.41 (C.45:9-
21 37.111 et seq.). Genetic counseling concerning a diagnosis of
22 sickle cell trait shall include, but not be limited to, information
23 concerning the fact that one or both of the parents carries sickle cell
24 trait and the risk that other children born to the parents may carry
25 sickle cell trait or may be born with sickle cell disease.

26

27 2. a. The Commissioner of Health shall establish a central
28 registry of patients diagnosed with sickle cell trait. The information
29 in the central registry shall be used for the purposes of compiling
30 statistical information and assisting the provision of follow-up
31 counseling, intervention, and educational services to patients and to
32 the parents of patients who are listed in the registry including, but
33 not limited to, information concerning the availability and benefits
34 of genetic counseling performed by a genetic counselor licensed
35 pursuant to P.L.2009, c.41 (C.45:9-37.111 et seq.).

36 b. The commissioner shall establish a system to notify the
37 parents of patients who are listed in the registry that follow-up
38 consultations with a physician are recommended for children
39 diagnosed with sickle cell trait. Such notifications shall be
40 provided: at least once when the patient is in early adolescence,
41 when the patient may begin to participate in strenuous athletic
42 activities that could result in adverse symptoms for a person with
43 sickle cell trait; at least once during later adolescence, when the
44 patient should be made aware of the reproductive implications of
45 sickle cell trait; and at such other intervals as the commissioner may
46 require.

47 c. The commissioner shall establish a system under which the
48 Department of Health shall make reasonable efforts to notify

1 patients listed in the registry who reach the age of 18 years of the
2 patient's inclusion in the registry and of the availability of
3 educational services, genetic counseling, and other resources that
4 may be beneficial to the patient.

5 d. Information on newborn infants and their families compiled
6 pursuant to this section may be used by the department and agencies
7 designated by the commissioner for the purposes of carrying out
8 this act, but otherwise the information shall be confidential and not
9 divulged or made public so as to disclose the identity of any person
10 to whom it relates, except as provided by law. A person who
11 discloses information in violation of this section is guilty of a
12 disorderly persons offense. Each disclosure made in violation of
13 this section is a separate and actionable offense.

14
15 3. This act shall take effect on the 90th day after the date of
16 enactment.

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19 STATEMENT

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21 This bill requires the Commissioner of Health to establish a
22 central registry of newborn patients diagnosed with sickle cell trait
23 and to provide information about counseling, intervention, and
24 educational services to patients and their parents. Sickle cell trait is
25 the condition of carrying one sickle cell gene, which means the
26 person is at risk for passing the gene on to his children and may be
27 at risk of experiencing certain health complications. A person born
28 with two sickle cell genes has sickle cell disease, an inherited blood
29 disorder most commonly characterized by chronic anemia and
30 periodic episodes of pain.

31 Currently, all children born in New Jersey are screened for a
32 number of genetic and biochemical conditions at birth, including
33 sickle cell anemia. Under the bill, when a patient tests positive for
34 sickle cell trait, the screening laboratory will be required to notify
35 the physician responsible for the newborn's care and document the
36 diagnosis of sickle cell trait in the central registry established under
37 the bill. The physician is to provide the newborn's parents with
38 information concerning the availability and benefits of genetic
39 counseling performed by a licensed genetic counselor. This genetic
40 counseling is to include, at a minimum, information concerning the
41 fact that one or both of the parents carries sickle cell trait and the
42 risk that other children born to the parents may carry sickle cell trait
43 or may be born with sickle cell disease.

44 The bill requires the Commissioner of Health to establish a
45 system to notify the parents of patients who are listed in the registry
46 that follow-up consultations with a physician may be beneficial for
47 children diagnosed with sickle cell trait. Such notifications will be
48 provided: at least once when the patient is in early adolescence,

1 when the patient may begin to participate in strenuous athletic
2 activities that could result in adverse symptoms for a person with
3 sickle cell trait; at least once during later adolescence, when the
4 patient should be made aware of the reproductive implications of
5 sickle cell trait; and at such other intervals as may be required by
6 the commissioner. The bill additionally requires the commissioner
7 to establish a system under which the Department of Health (DOH)
8 would make reasonable efforts to notify patients who have reached
9 the age of 18 years of the patient's inclusion in the registry and of
10 the availability of educational services, genetic counseling, and
11 other resources that may be beneficial to the patient.

12 The information in the central registry established under the bill
13 will be used for the purposes of compiling statistical information
14 and assisting the provision of follow-up counseling, intervention,
15 and educational services to patients and to the parents of patients
16 who are listed in the registry. Central registry information will be
17 confidential, and a person who unlawfully discloses the information
18 will be guilty of a disorderly persons offense, which is punishable
19 by imprisonment for up to six months, a \$1,000 fine, or both. Each
20 unlawful disclosure is a separate and actionable offense.