

STATE OF NEW YORK

2516

2025-2026 Regular Sessions

IN ASSEMBLY

January 17, 2025

Introduced by M. of A. DINOWITZ, ROSENTHAL, HEVESI, WEPRIN -- read once and referred to the Committee on Health

AN ACT to amend the public health law, in relation to the establishment of a program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling

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

1 Section 1. The public health law is amended by adding a new section
2 206-c to read as follows:

3 § 206-c. Program for familial dysautonomia, Canavan's disease and
4 Tay-Sachs disease screening and counseling. 1. The commissioner shall
5 establish within the department, within amounts appropriated therefor, a
6 program for familial dysautonomia, Canavan's disease and Tay-Sachs
7 disease screening and counseling for the purposes of establishing volun-
8 tary familial dysautonomia, Canavan's disease and Tay-Sachs disease
9 screening and counseling programs, primarily through other existing
10 health programs.

11 2. The commissioner may make grants to and enter into contracts with
12 public and nonprofit private entities for the establishment and opera-
13 tion of programs under this section. The commissioner shall promulgate
14 regulations pursuant to this section. In making grants authorized under
15 this section the commissioner shall give priority to programs that:

16 (a) provide services first to blood relatives of known familial
17 dysautonomia, Canavan's disease or Tay-Sachs disease victims, and second
18 to high-risk population groups in which familial dysautonomia, Canavan's
19 disease and Tay-Sachs disease occur with greatest frequency and
20 especially to those persons in such groups who are entering their child-
21 bearing years; and

22 (b) operate in areas which the commissioner determines to have the
23 greatest number of persons in need of the screening and counseling
24 services provided under such programs.

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

LBD04449-01-5

1 3. The participation by any individual in any program under this
2 section shall be wholly voluntary and shall not be a prerequisite to
3 eligibility for, or receipt of, any other service or assistance from, or
4 to participation in, any other program. All test results, medical
5 records and any other information regarding familial dysautonomia,
6 Canavan's disease and Tay-Sachs disease screening or counseling acquired
7 or made by a public or private entity or an individual under this
8 section shall be kept confidential and shall not be admissible as
9 evidence in an action or proceeding in any court or before any other
10 tribunal, board, agency or person; provided, however, that the
11 provisions of this subdivision shall not apply to:

12 (a) such information as the patient, or their guardian, consents to be
13 released; or

14 (b) statistical data compiled without reference to the identity of any
15 such patient; or

16 (c) such information as is released by written order of a court of
17 competent jurisdiction, issued by such court after receipt of an appli-
18 cation on appropriate notice and an opportunity for all relevant parties
19 to be heard, showing good cause for the following reasons:

20 (i) other ways of obtaining the information are not available or would
21 be ineffective; or

22 (ii) there is a reasonable likelihood that the records will disclose
23 information of substantial value in a civil and/or criminal proceeding.

24 In any application brought under this paragraph, unless the court
25 orders all papers filed under seal, the subject of the record shall be
26 identified only by fictitious name, and the application and responding
27 papers shall not contain or otherwise disclose the subject's identity or
28 other confidential information.

29 4. On or before July first, two thousand twenty-seven, the commission-
30 er shall issue a report on the administration of this program to the
31 governor, the temporary president of the senate, the minority leader of
32 the senate, the speaker of the assembly, and the minority leader of the
33 assembly. Such report shall contain such recommendations for additional
34 legislation as the commissioner deems necessary.

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

37 (t) Familial dysautonomia, Canavan's disease and Tay-Sachs disease
38 education, screening, and counseling.

39 § 3. This act shall take effect on the one hundred eightieth day after
40 it shall have become a law. Effective immediately, the addition, amend-
41 ment and/or repeal of any rule or regulation necessary for the implemen-
42 tation of this act on its effective date are authorized to be made and
43 completed on or before such effective date.