

# STATE OF NEW YORK

2461

2017-2018 Regular Sessions

## IN ASSEMBLY

January 20, 2017

Introduced by M. of A. DINOWITZ, JAFFEE, HEVESI, ROSENTHAL, WEPRIN --  
Multi-Sponsored by -- M. of A. CURRAN, McKEVITT -- 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 Assem-  
bly, do enact as follows:

Section 1. The public health law is amended by adding a new article  
27-DDD to read as follows:

### ARTICLE 27-DDD

#### PROGRAM FOR FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE

#### AND TAY-SACHS DISEASE SCREENING AND COUNSELING

#### Section 2770. Legislative findings and declaration of purpose.

#### 2771. Program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling.

#### 2772. Commissioner; functions, powers and duties.

#### 2773. Costs.

#### 2774. Voluntary participation.

#### 2774-a. Application; administration as to grants and contracts.

#### 2774-b. Confidentiality of information.

#### 2774-c. Reports.

§ 2770. Legislative findings and declaration of purpose. 1. The  
legislature hereby finds and declares:

(a) that familial dysautonomia, Canavan's disease and Tay-Sachs  
disease are debilitating, inheritable diseases that have affected many  
citizens of the state;

(b) that familial dysautonomia, Canavan's disease and Tay-Sachs  
disease are deadly and tragic burdens which are likely to strike one-  
fourth of the children born to parents both of whom are familial dysau-  
tonomia, Canavan's disease and Tay-Sachs disease carriers;

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

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(c) that efforts with respect to familial dysautonomia, Canavan's disease and Tay-Sachs disease must be directed toward the education, screening, and counseling of carriers of familial dysautonomia, Canavan's disease and Tay-Sachs disease;

(d) that simple and inexpensive screening tests have been devised which identify those who have the diseases or are familial dysautonomia, Canavan's disease and Tay-Sachs disease carriers;

(e) that programs with respect to familial dysautonomia, Canavan's disease and Tay-Sachs disease must be based entirely upon the voluntary cooperation of the individuals involved;

(f) that the application of methods of screening and counseling with respect to familial dysautonomia, Canavan's disease and Tay-Sachs disease deserve the highest priority; and

(g) that the establishment of familial dysautonomia, Canavan's disease and Tay-Sachs disease education, screening, and counseling programs will be cost beneficial to the citizens of the state.

2. In order to preserve and protect the public health and welfare, the legislature hereby declares as its purpose the establishment of a program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling.

§ 2771. Program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling. The commissioner shall establish within the department a program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling for the purposes of:

1. the establishment and operation of voluntary familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling programs, primarily through other existing health programs; and

2. the development of information and educational materials relating to familial dysautonomia, Canavan's disease and Tay-Sachs disease, and the dissemination of such information and materials to persons providing health care and to the public generally.

§ 2772. Commissioner; functions, powers and duties. In carrying out the provisions of this article, the commissioner shall have the following functions, powers and duties:

1. in his or her discretion, to make grants to and enter into contracts with, public and nonprofit private entities for projects for the establishment and operation of voluntary familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling programs;

2. to carry out a program to develop information and educational materials relating to familial dysautonomia, Canavan's disease and Tay-Sachs disease and to disseminate such information and materials to persons providing health care and to the public generally;

3. to make grants to public and nonprofit private entities and to enter into contracts with public and private entities and individuals for the purpose of effectuating the duty prescribed by subdivision two of this section;

4. to adopt, promulgate, amend and rescind suitable rules and regulations to carry out the provisions and purposes of this article; and

5. to exercise and perform such other functions, powers and duties as are contained in this article or as may from time to time be conferred or imposed by law.

§ 2773. Costs. Costs incurred by the commissioner in making payments pursuant to grants and contracts authorized by subdivisions one and three of section twenty-seven hundred seventy-two of this article shall

1 be payable, after submission of a voucher certified by the commissioner,  
2 upon audit and warrant of the comptroller from moneys made available for  
3 such purpose by appropriation.

4 § 2774. Voluntary participation. The participation by any individual  
5 in any program or portion thereof established under this article shall  
6 be wholly voluntary and shall not be a prerequisite to eligibility for  
7 or receipt of any other service or assistance from, or to participation  
8 in, any other program.

9 § 2774-a. Application; administration as to grants and contracts. 1.  
10 A grant authorized by section twenty-seven hundred seventy-two of this  
11 article may be made upon application to the commissioner at such time,  
12 in such manner, upon such forms, containing and accompanied by such  
13 information, as the commissioner shall deem necessary and, by regu-  
14 lation, prescribe.

15 2. Notwithstanding the provisions of subdivision one of this section,  
16 any application made pursuant to this section shall at least provide:

17 (a) that the programs and activities for which assistance under this  
18 article is sought will be administered by or under the supervision of  
19 the applicant;

20 (b) for strict confidentiality of all test results, medical records,  
21 and other information regarding screening or counseling, except for (i)  
22 such information as the patient (or his or her guardian) consents to be  
23 released; or (ii) statistical data compiled without reference to the  
24 identity of any such patient;

25 (c) for appropriate community representation in the development and  
26 operation of any program funded by a grant under this article;

27 (d) in the case of an application for a grant authorized by subdivi-  
28 sion one of section twenty-seven hundred seventy-two of this article,  
29 assurances satisfactory to the commissioner that (i) the screening and  
30 counseling services to be provided under the program for which the  
31 application is made will be directed first to the blood relatives of  
32 known familial dysautonomia, Canavan's disease or Tay-Sachs disease  
33 victims; and second, to the high-risk population groups in which fami-  
34 lial dysautonomia, Canavan's disease and Tay-Sachs disease occurs with  
35 greatest frequency and especially to those persons in these groups who  
36 are entering their childbearing years; and (ii) appropriate arrangements  
37 have been made to provide genetic counseling to persons found to be  
38 familial dysautonomia, Canavan's disease or Tay-Sachs carriers;

39 (e) for such fiscal control and fund accounting procedures as the  
40 commissioner may deem necessary to assure proper disbursement of and  
41 accounting for funds paid to the applicant pursuant to this article; and

42 (f) for making such reports in such form and containing such informa-  
43 tion as the commissioner may, by regulation, reasonably require.

44 3. In making or entering into any grant or contract pursuant to this  
45 article, the commissioner shall:

46 (a) take into account the number of persons to be served by the  
47 program supported by such grant or contract and the extent to which  
48 rapid and effective use will be made of funds under the grant or  
49 contract; and

50 (b) give priority to programs operating in areas which the commission-  
51 er determines to have the greatest number of persons in need of the  
52 screening and counseling services provided under such programs.

53 § 2774-b. Confidentiality of information. All test results, medical  
54 records and any other information regarding familial dysautonomia,  
55 Canavan's disease and Tay-Sachs disease screening or counseling acquired  
56 or made by a public or private entity or an individual under this arti-

1 cle shall be kept confidential, and shall not be admissible as evidence  
2 in an action or proceeding in any court or before any other tribunal,  
3 board, agency or person; provided, however, that the provisions of this  
4 section shall not apply to:

5 1. such information as the patient, or his or her guardian, consents  
6 to be released; or

7 2. statistical data compiled without reference to the identity of any  
8 such patient; or

9 3. such information as is released by written order of a court of  
10 record, issued by such court after receipt of an application on appro-  
11 priate notice and an opportunity for all relevant parties to be heard,  
12 showing good cause for the following reasons:

13 (a) other ways of obtaining the information are not available or would  
14 be ineffective; and

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

17 In any application brought under this subdivision, unless the court  
18 orders all papers filed under seal, the subject of the record shall be  
19 identified only by fictitious name, and the application and responding  
20 papers shall not contain or otherwise disclose the subject's identity or  
21 other confidential information.

22 § 2774-c. Reports. 1. The commissioner shall prepare and submit to the  
23 governor and the legislature as soon as practicable after the enactment  
24 of this article, but no later than one year following such enactment, a  
25 comprehensive report on the administration of this article.

26 2. Such report shall contain such recommendations for additional  
27 legislation as the commissioner deems necessary.

28 § 2. This act shall take effect on the one hundred eightieth day after  
29 it shall have become a law, provided, however, that effective immediate-  
30 ly, the addition, amendment and/or repeal of any rule or regulation  
31 necessary for the implementation of this act on its effective date are  
32 authorized and directed to be made and completed on or before such  
33 effective date.