

7976

I N   S E N A T E

May 27, 2010

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Introduced by Sen. SQUADRON -- read twice and ordered printed, and when printed to be committed 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 article  
2     27-DDD to read as follows:

3                                   ARTICLE   27-DDD

4             PROGRAM FOR FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE  
5             AND TAY-SACHS DISEASE SCREENING AND COUNSELING  
6     SECTION 2770. LEGISLATIVE FINDINGS AND DECLARATION OF PURPOSE.  
7             2771. PROGRAM FOR FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND  
8             TAY-SACHS DISEASE SCREENING AND COUNSELING.  
9             2772. COMMISSIONER; FUNCTIONS, POWERS AND DUTIES.  
10            2773. COSTS.  
11            2774. VOLUNTARY PARTICIPATION.  
12            2774-A. APPLICATION; ADMINISTRATION AS TO GRANTS AND CONTRACTS.  
13            2774-B. CONFIDENTIALITY OF INFORMATION.  
14            2774-C. REPORTS.

15     S 2770.     LEGISLATIVE FINDINGS AND DECLARATION OF PURPOSE.    1. THE  
16     LEGISLATURE HEREBY FINDS AND DECLARES:

17     (A) THAT FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS  
18     DISEASE ARE DEBILITATING, INHERITABLE DISEASES THAT HAVE AFFECTED MANY  
19     CITIZENS OF THE STATE;

20     (B) THAT FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS  
21     DISEASE ARE DEADLY AND TRAGIC BURDENS WHICH ARE LIKELY TO STRIKE  
22     ONE-FOURTH OF THE CHILDREN BORN TO PARENTS BOTH OF WHOM ARE FAMILIAL  
23     DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS DISEASE CARRIERS;

24     (C) THAT EFFORTS WITH RESPECT TO FAMILIAL DYSAUTONOMIA, CANAVAN'S  
25     DISEASE AND TAY-SACHS DISEASE MUST BE DIRECTED TOWARD THE EDUCATION,  
26     SCREENING, AND COUNSELING OF CARRIERS OF FAMILIAL DYSAUTONOMIA,  
27     CANAVAN'S DISEASE AND TAY-SACHS DISEASE;

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

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1 (D) THAT SIMPLE AND INEXPENSIVE SCREENING TESTS HAVE BEEN DEvised  
2 WHICH IDENTIFY THOSE WHO HAVE THE DISEASES OR ARE FAMILIAL DYSAUTONOMIA,  
3 CANAVAN'S DISEASE AND TAY-SACHS DISEASE CARRIERS;

4 (E) THAT PROGRAMS WITH RESPECT TO FAMILIAL DYSAUTONOMIA, CANAVAN'S  
5 DISEASE AND TAY-SACHS DISEASE MUST BE BASED ENTIRELY UPON THE VOLUNTARY  
6 COOPERATION OF THE INDIVIDUALS INVOLVED;

7 (F) THAT THE APPLICATION OF METHODS OF SCREENING AND COUNSELING WITH  
8 RESPECT TO FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS  
9 DISEASE DESERVE THE HIGHEST PRIORITY; AND

10 (G) THAT THE ESTABLISHMENT OF FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE  
11 AND TAY-SACHS DISEASE EDUCATION, SCREENING, AND COUNSELING PROGRAMS WILL  
12 BE COST BENEFICIAL TO THE CITIZENS OF THE STATE.

13 2. IN ORDER TO PRESERVE AND PROTECT THE PUBLIC HEALTH AND WELFARE, THE  
14 LEGISLATURE HEREBY DECLARES AS ITS PURPOSE THE ESTABLISHMENT OF A  
15 PROGRAM FOR FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS  
16 DISEASE SCREENING AND COUNSELING.

17 S 2771. PROGRAM FOR FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-  
18 SACHS DISEASE SCREENING AND COUNSELING. THE COMMISSIONER SHALL ESTAB-  
19 LISH WITHIN THE DEPARTMENT A PROGRAM FOR FAMILIAL DYSAUTONOMIA,  
20 CANAVAN'S DISEASE AND TAY-SACHS DISEASE SCREENING AND COUNSELING FOR THE  
21 PURPOSES OF:

22 1. THE ESTABLISHMENT AND OPERATION OF VOLUNTARY FAMILIAL DYSAUTONOMIA,  
23 CANAVAN'S DISEASE AND TAY-SACHS DISEASE SCREENING AND COUNSELING  
24 PROGRAMS, PRIMARILY THROUGH OTHER EXISTING HEALTH PROGRAMS; AND

25 2. THE DEVELOPMENT OF INFORMATION AND EDUCATIONAL MATERIALS RELATING  
26 TO FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS DISEASE, AND  
27 THE DISSEMINATION OF SUCH INFORMATION AND MATERIALS TO PERSONS PROVIDING  
28 HEALTH CARE AND TO THE PUBLIC GENERALLY.

29 S 2772. COMMISSIONER; FUNCTIONS, POWERS AND DUTIES. IN CARRYING OUT  
30 THE PROVISIONS OF THIS ARTICLE, THE COMMISSIONER SHALL HAVE THE FOLLOW-  
31 ING FUNCTIONS, POWERS AND DUTIES:

32 1. IN HIS OR HER DISCRETION, TO MAKE GRANTS TO AND ENTER INTO  
33 CONTRACTS WITH, PUBLIC AND NONPROFIT PRIVATE ENTITIES FOR PROJECTS FOR  
34 THE ESTABLISHMENT AND OPERATION OF VOLUNTARY FAMILIAL DYSAUTONOMIA,  
35 CANAVAN'S DISEASE AND TAY-SACHS DISEASE SCREENING AND COUNSELING  
36 PROGRAMS;

37 2. TO CARRY OUT A PROGRAM TO DEVELOP INFORMATION AND EDUCATIONAL MATE-  
38 RIALS RELATING TO FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS  
39 DISEASE AND TO DISSEMINATE SUCH INFORMATION AND MATERIALS TO PERSONS  
40 PROVIDING HEALTH CARE AND TO THE PUBLIC GENERALLY;

41 3. TO MAKE GRANTS TO PUBLIC AND NONPROFIT PRIVATE ENTITIES AND TO  
42 ENTER INTO CONTRACTS WITH PUBLIC AND PRIVATE ENTITIES AND INDIVIDUALS  
43 FOR THE PURPOSE OF EFFECTUATING THE DUTY PRESCRIBED BY SUBDIVISION TWO  
44 OF THIS SECTION;

45 4. TO ADOPT, PROMULGATE, AMEND AND RESCIND SUITABLE RULES AND REGU-  
46 LATIONS TO CARRY OUT THE PROVISIONS AND PURPOSES OF THIS ARTICLE; AND

47 5. TO EXERCISE AND PERFORM SUCH OTHER FUNCTIONS, POWERS AND DUTIES AS  
48 ARE CONTAINED IN THIS ARTICLE OR AS MAY FROM TIME TO TIME BE CONFERRED  
49 OR IMPOSED BY LAW.

50 S 2773. COSTS. COSTS INCURRED BY THE COMMISSIONER IN MAKING PAYMENTS  
51 PURSUANT TO GRANTS AND CONTRACTS AUTHORIZED BY SUBDIVISIONS ONE AND  
52 THREE OF SECTION TWENTY-SEVEN HUNDRED SEVENTY-TWO OF THIS ARTICLE SHALL  
53 BE PAYABLE, AFTER SUBMISSION OF A VOUCHER CERTIFIED BY THE COMMISSIONER,  
54 UPON AUDIT AND WARRANT OF THE COMPTROLLER FROM MONEYS MADE AVAILABLE FOR  
55 SUCH PURPOSE BY APPROPRIATION.

1 S 2774. VOLUNTARY PARTICIPATION. THE PARTICIPATION BY ANY INDIVIDUAL  
2 IN ANY PROGRAM OR PORTION THEREOF ESTABLISHED UNDER THIS ARTICLE SHALL  
3 BE WHOLLY VOLUNTARY AND SHALL NOT BE A PREREQUISITE TO ELIGIBILITY FOR  
4 OR RECEIPT OF ANY OTHER SERVICE OR ASSISTANCE FROM, OR TO PARTICIPATION  
5 IN, ANY OTHER PROGRAM.

6 S 2774-A. APPLICATION; ADMINISTRATION AS TO GRANTS AND CONTRACTS. 1.  
7 A GRANT AUTHORIZED BY SECTION TWENTY-SEVEN HUNDRED SEVENTY-TWO OF THIS  
8 ARTICLE MAY BE MADE UPON APPLICATION TO THE COMMISSIONER AT SUCH TIME,  
9 IN SUCH MANNER, UPON SUCH FORMS, CONTAINING AND ACCOMPANIED BY SUCH  
10 INFORMATION, AS THE COMMISSIONER SHALL DEEM NECESSARY AND, BY REGU-  
11 LATION, PRESCRIBE.

12 2. NOTWITHSTANDING THE PROVISIONS OF SUBDIVISION ONE OF THIS SECTION,  
13 ANY APPLICATION MADE PURSUANT TO THIS SECTION SHALL AT LEAST PROVIDE:

14 (A) THAT THE PROGRAMS AND ACTIVITIES FOR WHICH ASSISTANCE UNDER THIS  
15 ARTICLE IS SOUGHT WILL BE ADMINISTERED BY OR UNDER THE SUPERVISION OF  
16 THE APPLICANT;

17 (B) FOR STRICT CONFIDENTIALITY OF ALL TEST RESULTS, MEDICAL RECORDS,  
18 AND OTHER INFORMATION REGARDING SCREENING OR COUNSELING, EXCEPT FOR (I)  
19 SUCH INFORMATION AS THE PATIENT (OR HIS OR HER GUARDIAN) CONSENTS TO BE  
20 RELEASED; OR (II) STATISTICAL DATA COMPILED WITHOUT REFERENCE TO THE  
21 IDENTITY OF ANY SUCH PATIENT;

22 (C) FOR APPROPRIATE COMMUNITY REPRESENTATION IN THE DEVELOPMENT AND  
23 OPERATION OF ANY PROGRAM FUNDED BY A GRANT UNDER THIS ARTICLE;

24 (D) IN THE CASE OF AN APPLICATION FOR A GRANT AUTHORIZED BY SUBDIVI-  
25 SION ONE OF SECTION TWENTY-SEVEN HUNDRED SEVENTY-TWO OF THIS ARTICLE,  
26 ASSURANCES SATISFACTORY TO THE COMMISSIONER THAT (I) THE SCREENING AND  
27 COUNSELING SERVICES TO BE PROVIDED UNDER THE PROGRAM FOR WHICH THE  
28 APPLICATION IS MADE WILL BE DIRECTED FIRST TO THE BLOOD RELATIVES OF  
29 KNOWN FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE OR TAY-SACHS DISEASE  
30 VICTIMS; AND SECOND, TO THE HIGH-RISK POPULATION GROUPS IN WHICH FAMI-  
31 LIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS DISEASE OCCURS WITH  
32 GREATEST FREQUENCY AND ESPECIALLY TO THOSE PERSONS IN THESE GROUPS WHO  
33 ARE ENTERING THEIR CHILDBEARING YEARS; AND (II) APPROPRIATE ARRANGEMENTS  
34 HAVE BEEN MADE TO PROVIDE GENETIC COUNSELING TO PERSONS FOUND TO BE  
35 FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE OR TAY-SACHS CARRIERS;

36 (E) FOR SUCH FISCAL CONTROL AND FUND ACCOUNTING PROCEDURES AS THE  
37 COMMISSIONER MAY DEEM NECESSARY TO ASSURE PROPER DISBURSEMENT OF AND  
38 ACCOUNTING FOR FUNDS PAID TO THE APPLICANT PURSUANT TO THIS ARTICLE; AND

39 (F) FOR MAKING SUCH REPORTS IN SUCH FORM AND CONTAINING SUCH INFORMA-  
40 TION AS THE COMMISSIONER MAY, BY REGULATION, REASONABLY REQUIRE.

41 3. IN MAKING OR ENTERING INTO ANY GRANT OR CONTRACT PURSUANT TO THIS  
42 ARTICLE, THE COMMISSIONER SHALL:

43 (A) TAKE INTO ACCOUNT THE NUMBER OF PERSONS TO BE SERVED BY THE  
44 PROGRAM SUPPORTED BY SUCH GRANT OR CONTRACT AND THE EXTENT TO WHICH  
45 RAPID AND EFFECTIVE USE WILL BE MADE OF FUNDS UNDER THE GRANT OR  
46 CONTRACT; AND

47 (B) GIVE PRIORITY TO PROGRAMS OPERATING IN AREAS WHICH THE COMMISSION-  
48 ER DETERMINES TO HAVE THE GREATEST NUMBER OF PERSONS IN NEED OF THE  
49 SCREENING AND COUNSELING SERVICES PROVIDED UNDER SUCH PROGRAMS.

50 S 2774-B. CONFIDENTIALITY OF INFORMATION. ALL TEST RESULTS, MEDICAL  
51 RECORDS AND ANY OTHER INFORMATION REGARDING FAMILIAL DYSAUTONOMIA,  
52 CANAVAN'S DISEASE AND TAY-SACHS DISEASE SCREENING OR COUNSELING ACQUIRED  
53 OR MADE BY A PUBLIC OR PRIVATE ENTITY OR AN INDIVIDUAL UNDER THIS ARTI-  
54 CLE SHALL BE KEPT CONFIDENTIAL, AND SHALL NOT BE ADMISSIBLE AS EVIDENCE  
55 IN AN ACTION OR PROCEEDING IN ANY COURT OR BEFORE ANY OTHER TRIBUNAL,

1 BOARD, AGENCY OR PERSON; PROVIDED, HOWEVER, THAT THE PROVISIONS OF THIS  
2 SECTION SHALL NOT APPLY TO:

3 1. SUCH INFORMATION AS THE PATIENT, OR HIS OR HER GUARDIAN, CONSENTS  
4 TO BE RELEASED; OR

5 2. STATISTICAL DATA COMPILED WITHOUT REFERENCE TO THE IDENTITY OF ANY  
6 SUCH PATIENT; OR

7 3. SUCH INFORMATION AS IS RELEASED BY WRITTEN ORDER OF A COURT OF  
8 RECORD, ISSUED BY SUCH COURT AFTER RECEIPT OF AN APPLICATION ON APPRO-  
9 PRIATE NOTICE AND AN OPPORTUNITY FOR ALL RELEVANT PARTIES TO BE HEARD,  
10 SHOWING GOOD CAUSE FOR THE FOLLOWING REASONS:

11 (A) OTHER WAYS OF OBTAINING THE INFORMATION ARE NOT AVAILABLE OR WOULD  
12 BE INEFFECTIVE; AND

13 (B) THERE IS A REASONABLE LIKELIHOOD THAT THE RECORDS WILL DISCLOSE  
14 INFORMATION OF SUBSTANTIAL VALUE IN A CIVIL AND/OR CRIMINAL PROCEEDING.

15 IN ANY APPLICATION BROUGHT UNDER THIS SUBDIVISION, UNLESS THE COURT  
16 ORDERS ALL PAPERS FILED UNDER SEAL, THE SUBJECT OF THE RECORD SHALL BE  
17 IDENTIFIED ONLY BY FICTITIOUS NAME, AND THE APPLICATION AND RESPONDING  
18 PAPERS SHALL NOT CONTAIN OR OTHERWISE DISCLOSE THE SUBJECT'S IDENTITY OR  
19 OTHER CONFIDENTIAL INFORMATION.

20 S 2774-C. REPORTS. 1. THE COMMISSIONER SHALL PREPARE AND SUBMIT TO THE  
21 GOVERNOR AND THE LEGISLATURE AS SOON AS PRACTICABLE AFTER THE ENACTMENT  
22 OF THIS ARTICLE, BUT NO LATER THAN ONE YEAR FOLLOWING SUCH ENACTMENT, A  
23 COMPREHENSIVE REPORT ON THE ADMINISTRATION OF THIS ARTICLE.

24 2. SUCH REPORT SHALL CONTAIN SUCH RECOMMENDATIONS FOR ADDITIONAL  
25 LEGISLATION AS THE COMMISSIONER DEEMS NECESSARY.

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