S T A T E  O F  N E W  Y O R K

190

2013-2014 Regular Sessions

I N  S E N A T E

(PREFILED)

January 9, 2013

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:

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.

S 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 DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS DISEASE CARRIERS;

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

(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.

S 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.

S 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.

S 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

BE PAYABLE, AFTER SUBMISSION OF A VOUCHER CERTIFIED BY THE COMMISSIONER, UPON AUDIT AND WARRANT OF THE COMPTROLLER FROM MONEYS MADE AVAILABLE FOR SUCH PURPOSE BY APPROPRIATION.

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

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

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

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

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

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

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

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

(F) FOR MAKING SUCH REPORTS IN SUCH FORM AND CONTAINING SUCH INFORMATION AS THE COMMISSIONER MAY, BY REGULATION, REASONABLY REQUIRE.

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

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

(B) GIVE PRIORITY TO PROGRAMS OPERATING IN AREAS WHICH THE COMMISSIONER DETERMINES TO HAVE THE GREATEST NUMBER OF PERSONS IN NEED OF THE SCREENING AND COUNSELING SERVICES PROVIDED UNDER SUCH PROGRAMS.

S 2774-B. CONFIDENTIALITY OF INFORMATION. ALL TEST RESULTS, MEDICAL RECORDS AND ANY OTHER INFORMATION REGARDING FAMILIAL DYSAUTONOMIA, CANAVAN'S DISEASE AND TAY-SACHS DISEASE SCREENING OR COUNSELING ACQUIRED OR MADE BY A PUBLIC OR PRIVATE ENTITY OR AN INDIVIDUAL UNDER THIS ARTI-

CLE SHALL BE KEPT CONFIDENTIAL, AND SHALL NOT BE ADMISSIBLE AS EVIDENCE IN AN ACTION OR PROCEEDING IN ANY COURT OR BEFORE ANY OTHER TRIBUNAL, BOARD, AGENCY OR PERSON; PROVIDED, HOWEVER, THAT THE PROVISIONS OF THIS SECTION SHALL NOT APPLY TO:

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

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

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

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

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

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

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

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

S 2. This act shall take effect on the one hundred eightieth day after it shall have become a law, provided, however, that 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 and directed to be made and completed on or before such effective date.