STATE OF NEW YORK

1813

2023-2024 Regular Sessions

IN ASSEMBLY

January 23, 2023

Introduced by M. of A. DINOWITZ, L. 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:

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

§ 206-c. 1. Program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling. The commissioner shall establish within the department, within amounts appropriated therefor, a program for familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling for the purposes of establishing voluntary familial dysautonomia, Canavan's disease and Tay-Sachs disease screening and counseling programs, primarily through other existing health programs.

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

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

(b) operate 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.

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

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3. The participation by any individual in any program under this section 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. 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 section 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 subdivision shall not apply to:

(a) such information as the patient, or his or her guardian, consents to be released; or

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

(c) such information as is released by written order of a court of competent jurisdiction, 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:

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

(ii) 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 paragraph, 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.

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

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

(r) Familial dysautonomia, Canavan's disease and Tay-Sachs disease education, screening, and counseling.

§ 3. This act shall take effect on the one hundred eightieth day after it shall have become a law. 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 to be made and completed on or before such effective date.