STATE OF NEW YORK

1985--C

2025-2026 Regular Sessions

IN ASSEMBLY

January 14, 2025

Introduced by M. of A. PAULIN, DE LOS SANTOS, BEEPHAN, BORES, EPSTEIN, SAYEGH -- read once and referred to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- again reported from said committee with amendments, ordered reprinted as amended and recommitted to said committee -- reported and referred to the Committee on Codes -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law, in relation to establishing a state frontotemporal degeneration registry

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 20-C to read as follows:

ARTICLE 20-C
STATE FRONTOTEMPORAL DEGENERATION REGISTRY

Section 2015. Definitions.
2016. Duty to report.
2017. Establishment of registry.
2018. Duties of the department.
2019. Duties of the commissioner.

§ 2015. Definitions. As used in this article, the following terms shall have the following meanings:

1. "Frontotemporal degeneration disorders" or "FTD disorders" means a group of clinical disorders caused by progressive nerve cell loss in the brain's frontal lobes and/or temporal lobes which can lead to loss of function in these brain regions, which variably cause deterioration in behavior, personality and/or difficulty with producing or comprehending language, as well as loss of motor control and movement. For the purposes of this title frontotemporal degeneration disorders is the same

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

LBD02004-06-5

as "FTD" and includes, but is not limited to behavioral variant FTD, primary progressive aphasia, corticobasal syndrome, and progressive supranuclear palsy. Some individuals with FTD may also be diagnosed with ALS.

2. "Dementia" means a usually progressive condition marked by the development of multiple cognitive deficits, which may include but is not exclusive to memory impairment, aphasia, and the inability to plan and initiate complex behavior. Dementia has numerous different causes including but not limited to FTD, Alzheimer's disease, Lewy Body Dementia and Vascular Dementia.

§ 2016. Duty to report. 1. Every physician, nurse practitioner, physician assistant and general hospital that diagnoses or is treating a patient diagnosed with FTD disorder shall give notice no later than one hundred eighty days of every case of FTD disorders coming under their care, to the department, in a format to be determined by the commissioner, except as otherwise provided in this article.

2. All patients diagnosed with FTD disorders shall be provided written and verbal notice regarding the collection of information and patient data on FTD disorders. Patients who do not wish to participate in the collection of data shall affirmatively opt-out in writing after ample opportunity to review such notice, provided that, the mere incidence of a patient with an FTD disorder shall be the sole required information for the registry under section two thousand seventeen of this article for any patient who chooses not to participate.

§ 2017. Establishment of registry. 1. The department shall establish a frontotemporal degeneration registry for the collection of information on the rate of clinical diagnoses of FTD disorders. The department shall consult with FTD disorders experts, including neurologists, patients living with FTD disorders, and FTD disorders researchers to assist in the development and implementation of such registry, and to determine what data shall be collected.

2. All information maintained by the department under the provisions of this section shall be confidential except as necessary to carry out the provisions of this section and shall not be released for any other purpose.

3. The department may enter into an agreement to provide data collected in the frontotemporal degeneration registry to the federal Centers for Disease Control and Prevention, or successor agency, to local health officers, or health researchers for the study of FTD disorders for public health and research purposes. Data shall be provided in summary, statistical, aggregate, or other form such that no individual person can be identified.

4. On or before January first, two thousand twenty-seven, the department shall create and maintain a public website called the "New York state frontotemporal degeneration registry" which shall include information on the rate of clinical diagnoses of FTD disorders in the state by county, and demographic information on affected patients.

§ 2018. Duties of the department. 1. FTD disorders reports and data shall be maintained by the department in a manner suitable for research purposes, and shall be made available to persons as set forth in section two thousand seventeen of this article.

2. All information collected under this article shall be confidential insofar as the identity of individual patients is concerned and shall be solely for the purposes as provided in this article. Access to such information shall be limited to authorized employees of the department as well as persons and organizations specified in section two thousand

seventeen of this article with valid scientific interest and qualifications, as determined by the commissioner, who are engaged in demographic, epidemiological, or other similar studies related to public health.

3. The department shall maintain an accurate record of all persons who are given access to the information contained in the frontotemporal degeneration registry. Such record shall include the name of the person authorizing access, the name, title and organizational affiliation of persons given access, dates of access, and the specific purposes for which information is to be used.

4. Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided under this section, or who uses information provided under this section in a manner other than that prescribed by the commissioner, may be denied further access to any confidential information maintained by the department.

§ 2019. Duties of the commissioner. The commissioner may promulgate any regulations necessary to implement the provisions of this article, including but not limited to:

1. establishing the form, content, and manner by which providers shall report FTD disorders information into the registry established under section two thousand seventeen of this article;

2. prescribing the permissible uses for the information made available under this article; and

3. establishing procedures to maintain the confidentiality of information collected by providers and provided to members of the department pursuant to this article. This shall include a procedure to ensure that confidential patient information is deidentified prior to being provided to authorized participants under this article.

§ 2. This act shall take effect on the ninetieth day after it shall have become a law.