

STATE OF NEW YORK

1985--B

2025-2026 Regular Sessions

IN ASSEMBLY

January 14, 2025

Introduced by M. of A. PAULIN, DE LOS SANTOS, BEEPHAN, BORES, EPSTEIN -- 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

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 as "FTD" and includes, but is not limited to behavioral variant FTD, primary progressive aphasia, corticobasal syndrome, and progressive

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

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1 supranuclear palsy. Some individuals with FTD may also be diagnosed with
2 ALS.

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

9 § 2016. Duty to report. 1. Every physician, nurse practitioner, physi-
10 cian assistant and general hospital that diagnoses or is treating a
11 patient diagnosed with FTD disorder shall give notice no later than one
12 hundred eighty days of every case of FTD disorders coming under their
13 care, to the department, in a format to be determined by the commissioner,
14 except as otherwise provided in this article.

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

23 § 2017. Establishment of registry. 1. The department shall establish a
24 frontotemporal degeneration registry for the collection of information
25 on the incidence and prevalence of FTD disorders. The department may
26 consult with FTD disorders experts, including neurologists, patients
27 living with FTD disorders, and FTD disorders researchers to assist in
28 the development and implementation of such registry, and to determine
29 what data shall be collected.

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

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

41 4. On or before January first, two thousand twenty-eight, the department
42 shall create and maintain a public website called the "New York
43 state frontotemporal degeneration registry" which shall include information
44 on the incidence and prevalence of FTD disorders in the state by
45 county, and demographic information on affected patients.

46 § 2018. Duties of the department. 1. FTD disorders reports and data
47 shall be maintained by the department in a manner suitable for research
48 purposes, and shall be made available to persons as set forth in section
49 two thousand twelve of this chapter.

50 2. All information collected under this article shall be confidential
51 insofar as the identity of individual patients is concerned and shall be
52 solely for the purposes as provided in this article. Access to such
53 information shall be limited to authorized employees of the department
54 as well as persons and organizations defined in section two thousand
55 twelve of this chapter with valid scientific interest and qualifica-

1 tions, as determined by the commissioner, who are engaged in demograph-
2 ic, epidemiological, or other similar studies related to public health.

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

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

14 § 2019. Duties of the commissioner. The commissioner may promulgate
15 any regulations necessary to implement the provisions of this article,
16 including but not limited to:

17 1. establishing the form, content, and manner by which providers shall
18 report FTD disorders information into the registry established under
19 section two thousand twelve of this chapter;

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

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

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