

STATE OF NEW YORK

598--A

2025-2026 Regular Sessions

IN SENATE

(Prefiled)

January 8, 2025

Introduced by Sens. HINCHEY, COONEY, FAHY, GIANARIS, GONZALEZ, JACKSON -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- reported favorably from said committee and committed to the Committee on Finance -- 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:

1 Section 1. Article 2 of the public health law is amended by adding a
2 new title 9 to read as follows:

3 TITLE IX

4 STATE FRONTOTEMPORAL DEGENERATION

5 REGISTRY

6 Section 269-a. Definitions.

7 269-b. Registry established.

8 269-c. Reports.

9 269-d. New York state frontotemporal degeneration registry
10 website.

11 § 269-a. Definitions. For the purposes of this title:

12 1. "Frontotemporal degeneration disorders" or "FTD disorders" means a
13 group of clinical disorders caused by progressive nerve cell loss in the
14 brain's frontal lobes and/or temporal lobes which can lead to loss of
15 function in these brain regions, which variably cause deterioration in
16 behavior, personality and/or difficulty with producing or comprehending
17 language, as well as loss of motor control and movement. For the
18 purposes of this title frontotemporal degeneration disorders is the same
19 as "FTD" and includes, but is not limited to behavioral variant FTD,
20 primary progressive aphasia, corticobasal syndrome, and progressive

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

LBD02004-02-5

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 § 269-b. Registry established. 1. The department, in conjunction with
10 the state office for the aging, shall collect data on the incidence of
11 FTD disorders in this state and other epidemiological data. The registry
12 and system of collection and dissemination of information shall be under
13 the direction of the commissioner, who may enter into contracts, grants
14 or other agreements as are necessary for the conduct of the registry.

15 2. (a) The department shall, within ninety days of the effective date
16 of this section, establish a frontotemporal degeneration registry advisory
17 committee to assist in the development and implementation of the
18 registry; determine what data shall be collected, in addition to the
19 data required by section two hundred sixty-nine-c of this title for
20 annual reports; and generally, advise the department. Following the
21 completion of the registry, the advisory committee shall assist the
22 department with the creation and publication of the reports required by
23 section two hundred sixty-nine-c of this title.

24 (b) Members of the committee shall be selected by the governor, the
25 legislature and the commissioner. The governor, the temporary president
26 of the senate, the speaker of the assembly and the commissioner shall
27 each select two committee members and the minority leaders of the senate
28 and the assembly shall each select one committee member. Membership of
29 the committee shall include:

30 (i) a neurologist;

31 (ii) a speech pathologist;

32 (iii) a primary care provider;

33 (iv) a physician informaticist;

34 (v) a patient living with frontotemporal degeneration;

35 (vi) a caregiver of a patient living with frontotemporal degeneration;

36 (vii) a public health professional;

37 (viii) a population health researcher familiar with registries;

38 (ix) a frontotemporal degeneration researcher;

39 (x) a member of an organization that raises awareness about and
40 promotes research for the treatment of frontotemporal degeneration; and

41 (xi) anyone else the commissioner deems necessary.

42 3. (a) The department shall designate FTD disorders as advised by the
43 advisory committee as a clinical diagnoses required to be reported in
44 the state or any part of the state.

45 (b) The department shall establish a system for the collection and
46 dissemination of information determining the rate of clinical diagnoses
47 of FTD disorders, as advised by the advisory committee.

48 (c) All cases of frontotemporal degeneration diagnosed or treated in
49 this state shall be reported to the department, provided the mere inci-
50 dence of a patient with frontotemporal degeneration shall be the sole
51 required information for this registry for any patient who chooses not
52 to participate. For the subset of patients who choose not to partic-
53 ipate, no further data shall be reported to the registry. The department
54 may create, review and revise a list of data points required as part of
55 mandated frontotemporal degeneration reporting under this section. Such
56 list shall include, but not be limited to necessary triggering diagnos-

1 tic conditions, consistent with the latest International Statistical
2 Classification of Diseases and Related Health Problems, and resulting
3 case data including, but not limited to, diagnosis, treatment and
4 survival. The department may implement and administer this paragraph
5 through a bulletin, or similar instruction, to providers without taking
6 regulatory action.

7 (d) The department shall provide notification of the mandatory report-
8 ing of FTD disorders on its website and may also provide that informa-
9 tion to professional associations representing physicians, nurse practi-
10 tioners, and hospitals at least ninety days prior to requiring
11 information be reported.

12 (e) A hospital, facility, physician, surgeon, physician assistant and
13 nurse practitioners who diagnose or are treating a patient diagnosed
14 with an FTD disorder and have primary responsibility for the treatment
15 and care of the patient for an FTD disorder shall report each case of an
16 FTD disorder to the department in a format prescribed by the department.
17 The department is authorized to enter into data sharing contracts with
18 data reporting entities and their associated electronic medical record
19 systems vendors to securely and confidentially receive information
20 related to frontotemporal degeneration testing, diagnosis and treatment.

21 4. All patients diagnosed with an FTD disorder, as advised by the
22 advisory committee, shall be provided a notice in writing and orally
23 regarding the collection of information and patient data on frontotempo-
24 ral degeneration. Patients who do not wish to participate in the
25 collection of data for purposes of research in this registry shall
26 affirmatively opt-out in writing after an opportunity to review the
27 documents and ask questions. The patient's caregiver may opt-out on the
28 patient's behalf, if the patient is unable to do so of their own accord.
29 No patient shall be required to participate in this registry.

30 5. The department may enter into agreements to furnish data collected
31 in this registry to other states' frontotemporal degeneration regis-
32 tries, federal frontotemporal degeneration control agencies, local
33 health officers, or health researchers for the study of frontotemporal
34 degeneration. Before confidential information is disclosed to those
35 agencies, officers, researchers, or out-of-state registries, the
36 requesting entity shall agree in writing to maintain the confidentiality
37 of the information, and in the case of researchers, shall also do both
38 of the following:

39 (a) obtain approval of their committee for the protection of human
40 subjects established in accordance with Part 46 (commencing with Section
41 46.101) of Title 45 of the Code of Federal Regulations; and

42 (b) provide documentation to the department that demonstrates to the
43 department's satisfaction that the entity has established the procedures
44 and ability to maintain the confidentiality of the information.

45 6. Except as otherwise provided in this section, all information
46 collected pursuant to this section shall be confidential. For purposes
47 of this section, this information shall be referred to as confidential
48 information. To ensure privacy, the department shall promulgate a coding
49 system that removes any identifying information about the patient.

50 7. (a) Notwithstanding any other law, a disclosure authorized by this
51 section shall include only the information necessary for the stated
52 purpose of the requested disclosure, used for the approved purpose, and
53 not be further disclosed.

54 (b) Provided the security of confidentiality has been documented, the
55 furnishing of confidential information to the department or its author-
56 ized representative in accordance with this section shall not expose any

1 person, agency or entity furnishing information to liability, and shall
2 not be considered a waiver of any privilege or a violation of a confi-
3 dential relationship.

4 (c) The department shall maintain an accurate record of all persons
5 who are given access to confidential information. The record shall
6 include: the name of the person authorizing access; name, title,
7 address, and organizational affiliation of persons given access; dates
8 of access; and the specific purpose for which information is to be used.
9 The record of access shall be open to public inspection during normal
10 operating hours of the department.

11 (d) Notwithstanding any other law, confidential information shall not
12 be available for subpoena, shall not be disclosed, discoverable or
13 compelled to be produced in any civil, criminal, administrative or other
14 proceeding. Confidential information shall not be deemed admissible as
15 evidence in any civil, criminal, administrative or other tribunal or
16 court for any reason.

17 (e) This subdivision does not prohibit the publication by the depart-
18 ment of reports and statistical compilations that do not in any way
19 identify individual cases or individual sources of information.

20 (f) Notwithstanding the restrictions in this subdivision, the individ-
21 ual to whom the information pertains shall have access to such individ-
22 ual's own information.

23 8. This section does not preempt the authority of facilities or indi-
24 viduals providing diagnostic or treatment services to patients with
25 frontotemporal degeneration to maintain their own facility-based fronto-
26 temporal degeneration registries.

27 § 269-c. Reports. 1. On or before January first, two thousand twen-
28 ty-seven, and every year thereafter, the department, in conjunction with
29 the advisory committee, shall report to the legislature and governor a
30 yearly program summary update on the rate of clinical diagnoses of FTD
31 disorders in the state. Such report shall include:

32 (a) the incidence and prevalence of frontotemporal degeneration by
33 county;

34 (b) how many records have been included and reported into the regis-
35 try;

36 (c) demographic information such as patients by age, gender and race;

37 (d) the number of new diagnoses in the preceding year;

38 (e) a summary of advancements in the treatment and newly developed
39 treatments of frontotemporal degeneration;

40 (f) a list of resources for the families of patients diagnosed with an
41 FTD disorder, which shall include but not be limited to support from the
42 state or federal government, support groups and helplines;

43 (g) the resources available for the care of patients with frontotempo-
44 ral degeneration by region;

45 (h) information related to the cost of care for patients who have been
46 diagnosed with an FTD disorder; and

47 (i) the number of patients diagnosed with an FTD disorder who had
48 previously received an incorrect diagnosis for their frontotemporal
49 degeneration related symptoms and the amount of time it took to receive
50 the FTD disorder diagnosis.

51 2. The yearly report shall be published in a downloadable format on
52 the department's website and the designated New York state frontotempo-
53 ral degeneration registry website.

54 § 269-d. New York state frontotemporal degeneration registry website.
55 On or before January first, two thousand twenty-seven, the department
56 shall create and maintain a webpage called the "New York State Fronto-

1 temporal Degeneration Registry" where the public may view information
2 related to the registry, a yearly program summary, the information
3 required to be included in the yearly reports pursuant to section two
4 hundred sixty-nine-c of this title, and any other relevant or helpful
5 information related to the registry as deemed necessary by the advisory
6 council.

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