

STATE OF NEW YORK

598

2025-2026 Regular Sessions

IN SENATE

(Prefiled)

January 8, 2025

Introduced by Sens. HINCHEY, COONEY, GIANARIS, GONZALEZ -- 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 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. Article 2 of the public health law is amended by adding a new title 9 to read as follows:

TITLE IX
STATE FRONTOTEMPORAL DEGENERATION
REGISTRY

Section 269-a. Definitions.

269-b. Registry established.

269-c. Reports.

269-d. New York state frontotemporal degeneration research registry website.

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

1. "Frontotemporal degeneration" means a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes or its 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. For the purposes of this title frontotemporal degeneration is the same as "FTD".

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 includes but is not limited to FTD, Alzheimer's disease, Lewy Body Dementia and Vascular Dementia.

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

LBD02004-01-5

1 § 269-b. Registry established. 1. The department, in conjunction with
2 the state office for the aging, shall collect data on the incidence of
3 frontotemporal degeneration in this state and other epidemiological
4 data. The registry and system of collection and dissemination of infor-
5 mation shall be under the direction of the commissioner, who may enter
6 into contracts, grants or other agreements as are necessary for the
7 conduct of the registry.

8 2. (a) The department shall, within ninety days of the effective date
9 of this section, establish a frontotemporal degeneration registry advi-
10 sory committee to assist in the development and implementation of the
11 registry; determine what data shall be collected, in addition to the
12 data required by section two hundred sixty-nine-c of this title for
13 annual reports; and generally, advise the department. Following the
14 completion of the registry, the advisory committee shall assist the
15 department with the creation and publication of the reports required by
16 section two hundred sixty-nine-c of this title.

17 (b) Members of the committee shall be selected by the governor, the
18 legislature and the commissioner. The governor, the temporary president
19 of the senate, the speaker of the assembly and the commissioner shall
20 each select two committee members and the minority leaders of the senate
21 and the assembly shall each select one committee member. Membership of
22 the committee shall include:

23 (i) a neurologist;
24 (ii) a speech pathologist;
25 (iii) a primary care provider;
26 (iv) a physician informaticist;
27 (v) a patient living with frontotemporal degeneration;
28 (vi) a caregiver of a patient living with frontotemporal degeneration;
29 (vii) a public health professional;
30 (viii) a population health researcher familiar with registries;
31 (ix) a frontotemporal degeneration researcher;
32 (x) a member of an organization that raises awareness about and
33 promotes research for the treatment of frontotemporal degeneration; and
34 (xi) anyone else the commissioner deems necessary.

35 3. (a) The department shall designate frontotemporal degeneration and
36 related dementias as advised by the advisory committee as dementias
37 required to be reported in the state or any part of the state.

38 (b) The department shall establish a system for the collection and
39 dissemination of information determining the incidence and prevalence of
40 frontotemporal degeneration and related dementias, as advised by the
41 advisory committee.

42 (c) All cases of frontotemporal degeneration diagnosed or treated in
43 this state shall be reported to the department, provided the mere inci-
44 dence of a patient with frontotemporal degeneration shall be the sole
45 required information for this registry for any patient who chooses not
46 to participate. For the subset of patients who choose not to partic-
47 ipate, no further data shall be reported to the registry. The department
48 may create, review and revise a list of data points required as part of
49 mandated frontotemporal degeneration reporting under this section. Such
50 list shall include, but not be limited to necessary triggering diagnos-
51 tic conditions, consistent with the latest International Statistical
52 Classification of Diseases and Related Health Problems, and resulting
53 case data including, but not limited to, diagnosis, treatment and
54 survival. The department may implement and administer this paragraph
55 through a bulletin, or similar instruction, to providers without taking
56 regulatory action.

1 (d) The department shall provide notification of the mandatory report-
2 ing of frontotemporal degeneration and other related dementias on its
3 website and may also provide that information to professional associ-
4 ations representing physicians, nurse practitioners, and hospitals at
5 least ninety days prior to requiring information be reported.

6 (e) A hospital, facility, physician, surgeon, physician assistant and
7 nurse practitioners who diagnose or are treating a patient diagnosed
8 with frontotemporal degeneration or other dementias and have primary
9 responsibility for the treatment and care of the patient for frontotem-
10 poral degeneration or other dementias shall report each case of fronto-
11 temporal degeneration or other dementias to the department in a format
12 prescribed by the department. The department is authorized to enter
13 into data sharing contracts with data reporting entities and their asso-
14 ciated electronic medical record systems vendors to securely and confi-
15 dentially receive information related to frontotemporal degeneration
16 testing, diagnosis and treatment.

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

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

36 (a) obtain approval of their committee for the protection of human
37 subjects established in accordance with Part 46 (commencing with Section
38 46.101) of Title 45 of the Code of Federal Regulations; and

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

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

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

51 (b) Provided the security of confidentiality has been documented, the
52 furnishing of confidential information to the department or its author-
53 ized representative in accordance with this section shall not expose any
54 person, agency or entity furnishing information to liability, and shall
55 not be considered a waiver of any privilege or a violation of a confi-
56 dential relationship.

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

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

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

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

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

24 § 269-c. Reports. 1. On or before January first, two thousand twen-
25 ty-seven, and every year thereafter, the department, in conjunction with
26 the advisory committee, shall report to the legislature and governor a
27 yearly program summary update on the incidence and prevalence of fronto-
28 temporal degeneration in the state. Such report shall include:

29 (a) the incidence and prevalence of frontotemporal degeneration by
30 county;

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

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

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

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

37 (f) a list of resources for the families of patients diagnosed with
38 frontotemporal degeneration and other dementias, which shall include but
39 not be limited to support from the state or federal government, support
40 groups and helplines;

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

43 (h) the average yearly cost of care for a patient with frontotemporal
44 degeneration; and

45 (i) the number of patients with frontotemporal degeneration who had
46 previously received an incorrect diagnosis for their frontotemporal
47 degeneration related symptoms and the amount of time it took to receive
48 the correct diagnosis.

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

52 § 269-d. New York state frontotemporal degeneration research registry
53 website. On or before January first, two thousand twenty-seven, the
54 department shall create and maintain a webpage called the "New York
55 State Frontotemporal Degeneration Research Registry" where the public
56 may view information related to the registry, a yearly program summary,

1 the information required to be included in the yearly reports pursuant
2 to section two hundred sixty-nine-c of this title, and any other rele-
3 vant or helpful information related to the registry as deemed necessary
4 by the advisory council.

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