

# STATE OF NEW YORK

9938

## IN ASSEMBLY

April 26, 2024

Introduced by M. of A. PAULIN -- read once and referred 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:

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 research  
10 registry website.

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

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

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

23 § 269-b. Registry established. 1. The department, in conjunction with  
24 the state office for the aging, shall collect data on the incidence of  
25 frontotemporal degeneration in this state and other epidemiological  
26 data. The registry and system of collection and dissemination of infor-  
27 mation shall be under the direction of the commissioner, who may enter  
28 into contracts, grants or other agreements as are necessary for the  
29 conduct of the registry.

30 2. (a) The department shall, within ninety days of the effective date  
31 of this section, establish a frontotemporal degeneration registry advi-

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

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1 sory committee to assist in the development and implementation of the  
2 registry; determine what data shall be collected, in addition to the  
3 data required by section two hundred sixty-nine-c of this title for  
4 annual reports; and generally, advise the department. Following the  
5 completion of the registry, the advisory committee shall assist the  
6 department with the creation and publication of the reports required by  
7 section two hundred sixty-nine-c of this title.

8 (b) Members of the committee shall be selected by the governor, the  
9 legislature and the commissioner. The governor, the temporary president  
10 of the senate, the speaker of the assembly and the commissioner shall  
11 each select two committee members and the minority leaders of the senate  
12 and the assembly shall each select one committee member. Membership of  
13 the committee shall include:

14 (i) a neurologist;  
15 (ii) a speech pathologist;  
16 (iii) a primary care provider;  
17 (iv) a physician informaticist;  
18 (v) a patient living with frontotemporal degeneration;  
19 (vi) a caregiver of a patient living with frontotemporal degeneration;  
20 (vii) a public health professional;  
21 (viii) a population health researcher familiar with registries;  
22 (ix) a frontotemporal degeneration researcher;  
23 (x) a member of an organization that raises awareness about and  
24 promotes research for the treatment of frontotemporal degeneration; and  
25 (xi) anyone else the commissioner deems necessary.

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

29 (b) The department shall establish a system for the collection and  
30 dissemination of information determining the incidence and prevalence of  
31 frontotemporal degeneration and related dementias, as advised by the  
32 advisory committee.

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

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

53 (e) A hospital, facility, physician, surgeon, physician assistant and  
54 nurse practitioners who diagnose or are treating a patient diagnosed  
55 with frontotemporal degeneration or other dementias and have primary  
56 responsibility for the treatment and care of the patient for frontotem-

1 poral degeneration or other dementias shall report each case of fronto-  
2 temporal degeneration or other dementias to the department in a format  
3 prescribed by the department. The department is authorized to enter  
4 into data sharing contracts with data reporting entities and their asso-  
5 ciated electronic medical record systems vendors to securely and confi-  
6 dentially receive information related to frontotemporal degeneration  
7 testing, diagnosis and treatment.

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

18 5. The department may enter into agreements to furnish data collected  
19 in this registry to other states' frontotemporal degeneration regis-  
20 tries, federal frontotemporal degeneration control agencies, local  
21 health officers, or health researchers for the study of frontotemporal  
22 degeneration. Before confidential information is disclosed to those  
23 agencies, officers, researchers, or out-of-state registries, the  
24 requesting entity shall agree in writing to maintain the confidentiality  
25 of the information, and in the case of researchers, shall also do both  
26 of the following:

27 (a) obtain approval of their committee for the protection of human  
28 subjects established in accordance with Part 46 (commencing with Section  
29 46.101) of Title 45 of the Code of Federal Regulations; and

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

33 6. Except as otherwise provided in this section, all information  
34 collected pursuant to this section shall be confidential. For purposes  
35 of this section, this information shall be referred to as confidential  
36 information. To ensure privacy, the department shall promulgate a coding  
37 system that removes any identifying information about the patient.

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

42 (b) Provided the security of confidentiality has been documented, the  
43 furnishing of confidential information to the department or its author-  
44 ized representative in accordance with this section shall not expose any  
45 person, agency or entity furnishing information to liability, and shall  
46 not be considered a waiver of any privilege or a violation of a confi-  
47 dential relationship.

48 (c) The department shall maintain an accurate record of all persons  
49 who are given access to confidential information. The record shall  
50 include: the name of the person authorizing access; name, title,  
51 address, and organizational affiliation of persons given access; dates  
52 of access; and the specific purpose for which information is to be used.  
53 The record of access shall be open to public inspection during normal  
54 operating hours of the department.

55 (d) Notwithstanding any other law, confidential information shall not  
56 be available for subpoena, shall not be disclosed, discoverable or

1 compelled to be produced in any civil, criminal, administrative or other  
2 proceeding. Confidential information shall not be deemed admissible as  
3 evidence in any civil, criminal, administrative or other tribunal or  
4 court for any reason.

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

8 (f) Notwithstanding the restrictions in this subdivision, the individ-  
9 ual to whom the information pertains shall have access to his or her own  
10 information.

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

15 § 269-c. Reports. 1. On or before January first, two thousand twenty-  
16 five, and every year thereafter, the department, in conjunction with  
17 the advisory committee, shall report to the legislature and governor a  
18 yearly program summary update on the incidence and prevalence of fronto-  
19 temporal degeneration in the state. Such report shall include:

20 (a) the incidence and prevalence of frontotemporal degeneration by  
21 county;

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

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

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

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

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

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

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

36 (i) the number of patients with frontotemporal degeneration who had  
37 previously received an incorrect diagnosis for their frontotemporal  
38 degeneration related symptoms and the amount of time it took to receive  
39 the correct diagnosis.

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

43 § 269-d. New York state frontotemporal degeneration research registry  
44 website. On or before January first, two thousand twenty-five, the  
45 department shall create and maintain a webpage called the "New York  
46 State Frontotemporal Degeneration Research Registry" where the public  
47 may view information related to the registry, a yearly program summary,  
48 the information required to be included in the yearly reports pursuant  
49 to section two hundred sixty-nine-c of this title, and any other rele-  
50 vant or helpful information related to the registry as deemed necessary  
51 by the advisory council.

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