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:

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

§ 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.

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

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

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

(i) a neurologist;

(ii) a speech pathologist;

(iii) a primary care provider;

(iv) a physician informaticist;

(v) a patient living with frontotemporal degeneration;

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

(vii) a public health professional;

(viii) a population health researcher familiar with registries;

(ix) a frontotemporal degeneration researcher;

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

(xi) anyone else the commissioner deems necessary.

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

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

(c) All cases of frontotemporal degeneration diagnosed or treated in this state shall be reported to the department, provided the mere incidence of a patient with frontotemporal degeneration shall be the sole required information for this registry for any patient who chooses not to participate. For the subset of patients who choose not to participate, no further data shall be reported to the registry. The department may create, review and revise a list of data points required as part of mandated frontotemporal degeneration reporting under this section. Such list shall include, but not be limited to necessary triggering diagnostic conditions, consistent with the latest International Statistical Classification of Diseases and Related Health Problems, and resulting case data including, but not limited to, diagnosis, treatment and survival. The department may implement and administer this paragraph through a bulletin, or similar instruction, to providers without taking regulatory action.

(d) The department shall provide notification of the mandatory reporting of frontotemporal degeneration and other related dementias on its website and may also provide that information to professional associations representing physicians, nurse practitioners, and hospitals at least ninety days prior to requiring information be reported.

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

poral degeneration or other dementias shall report each case of frontotemporal degeneration or other dementias to the department in a format prescribed by the department. The department is authorized to enter into data sharing contracts with data reporting entities and their associated electronic medical record systems vendors to securely and confidentially receive information related to frontotemporal degeneration testing, diagnosis and treatment.

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

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

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

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

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

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

(b) Provided the security of confidentiality has been documented, the furnishing of confidential information to the department or its authorized representative in accordance with this section shall not expose any person, agency or entity furnishing information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.

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

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

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

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

(f) Notwithstanding the restrictions in this subdivision, the individual to whom the information pertains shall have access to his or her own information.

8. This section does not preempt the authority of facilities or individuals providing diagnostic or treatment services to patients with frontotemporal degeneration to maintain their own facility-based frontotemporal degeneration registries.

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

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

(b) how many records have been included and reported into the registry;

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

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

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

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

(g) the resources available for the care of patients with frontotemporal degeneration by region;

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

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

2. The yearly report shall be published in a downloadable format on the department's website and the designated New York state frontotemporal degeneration research registry website.

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

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