STATE OF NEW YORK

7431

2025-2026 Regular Sessions

IN SENATE

April 16, 2025

Introduced by Sen. HINCHEY -- 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 advisory committee

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
FRONTOTEMPORAL DEGENERATION ADVISORY COMMITTEE

Section 2020. Frontotemporal degeneration advisory committee.
2021. Reports.

§ 2020. Frontotemporal degeneration advisory committee. 1. The department shall, within ninety days of the effective date of this section, establish a frontotemporal degeneration advisory committee which shall be charged with recommending to the department long range objectives, goals and priorities. It shall also provide advice on the planning, coordination and development of needed services. In making such recommendations, the committee shall review and consider:

(a) rates of clinical diagnosis of frontotemporal degeneration by county;

(b) how many records have been included and reported into the department's frontotemporal degeneration registry;

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

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

(e) advancements in the treatment of frontotemporal degeneration;

(f) the availability and accessibility of resources for the care of patients with frontotemporal degeneration and any disparities that may exist in the regional availability of services;

(g) information related to the cost of care for frontotemporal degeneration disorders; and

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

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(h) frequency of and causes of misdiagnosis related to frontotemporal degeneration disorders.

2. 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. The members of the committee shall receive no compensation for their services, but shall be allowed their actual and necessary expenses incurred in the performance of their duties hereunder, subject to the approval of the commissioner.

§ 2021. Reports. 1. On or before January first, two thousand twenty-seven, 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 rate of clinical diagnoses of frontotemporal degeneration disorders 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 disorder, 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) information related to the cost of care for patients who have been diagnosed with frontotemporal degeneration disorder; and

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

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