STATE OF NEW YORK

7185

IN SENATE

(Prefiled)

January 3, 2018

Introduced by Sen. SERINO -- 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 developing a Parkinson's disease assessment program in the state

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 18 to read as follows:

ARTICLE 18

PARKINSON'S DISEASE ASSESSMENT PROGRAM

Section 1801. Definitions.

1802. Parkinson's disease registry.

§ 1801. Definitions. For the purposes of this article: 1. "Parkinson's disease" shall mean a chronic and progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as the consequence of degenerative, vascular, or inflammatory changes in the area of the brain called the basal ganglia. Such disorder shall be characterized by tremor at rest, slow movements, and rigidity of movement, droopy posture, muscle weakness, and unsteady or shuffling gait; and

2. "Facility" shall mean any governmental or private agency, department, institution, clinic, laboratory, hospital, nursing care facility, health maintenance organization, association or other similar entity that provides medical care.

§ 1802. Parkinson's disease registry. 1. The department shall conduct a program of epidemiological assessments of the incidence of Parkinson's disease in the state. Such program shall include, but not be limited to, the monitoring of Parkinson's disease associated with suspected chemical agents encountered by the general public both in specific occupations and in the environment generally.

2. An attending physician or a person representing or employed by a facility as defined by the commissioner shall report the existence of Parkinson's disease to the department when such physician or other person diagnoses the presence of that illness or a patient is prescribed

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

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medication that is used to treat Parkinson's disease or related neurological conditions.

3. (a) The commissioner shall analyze available incidence data and prepare reports as necessary to identify Parkinson's disease hazards to:

(i) public health;

(ii) specific occupations; and

(iii) geographic areas and their interventions and remedies.

(b) The commissioner shall issue an annual report that shall be designated as a Parkinson's disease report and shall, at a minimum, contain information which the commissioner establishes as necessary to identify, locate and investigate the:

(i) occurrence;

(ii) frequency;

(iii) incidence; and

(iv) concentrations in particular occupations; cause, effect and prognosis of Parkinson's disease, and other relevant data and findings with respect thereto.

(c) Parkinson's disease reports and data shall be maintained by the department in a manner suitable for research purposes, and shall be made available to persons set forth in this article.

4. Notwithstanding any other provisions of law, all information collected pursuant to this article shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes as provided in this article. Access to such information shall be limited to the authorized employees of the department and persons with a valid scientific interest and qualifications, as defined by the commissioner, who are engaged in demographic, epidemioligical or other similar studies related to health, and who agree, in writing, to maintain confidentiality as established by the commissioner.

5. (a) The department shall maintain an accurate record of all persons who are given access to the information contained in such Parkinson's disease reports as established in subdivision three of this section. Such record shall include:

(i) the name of the person authorizing access;

(ii) the name, title, and organizational affiliation of persons given access; and

(iii) dates of access and the specific purpose for which information is to be used.

(b) The record of access shall be open to public inspection during normal operating hours of the department.

6. Persons with a valid scientific interest who are engaged in demographic, epidemiological, or other similar studies related to health who meet qualifications as determined by the department, and who agree, in writing, to maintain confidentiality, may be authorized access to confidential information. Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided pursuant to this section, or who uses information provided pursuant to this section in a manner other than that prescribed by the commissioner, may be denied further access to any confidential information maintained by the department.

7. Notwithstanding any other provisions of law, the department may authorize a New York medical research institution to oversee and maintain the Parkinson's disease registry upon a showing of the ability to collect and analyze information in a timely manner and maintain the confidentiality and privacy of all records housed therein. The commissioner shall remain responsible for ensuring reporting procedures,

privacy compliance, and approval for access to the records are suitable and compliant with all rules and regulations.

8. The commissioner may enter into contracts as are necessary for the conduct of such program and may accept, on behalf of the state, grants of public or private funds for such program.

9. The commissioner may coordinate the Parkinson's disease registry with all other public health registries where practicable, including but not limited to article twenty and section two thousand four hundred one of this chapter, or any other epidemiological assessments conducted by the department to determine public health incidence rates and correlations with environmental factors, geographic locations, or any other statistically relevant information.

10. The registry shall provide information to supplement the coordinating council as provided by section two thousand four-a of this chapter. Upon the recommendation of the coordinating council and a majority vote, a designee shall be consulted to attend all council meetings to provide information and analysis of information contained within the Parkinson's disease registry and reports.

11. The department, where practicable, shall make available information regarding research opportunities, clinical trials, or public awareness campaigns on its website related to Parkinson's disease research, identification, and treatment.

12. The commissioner shall promulgate rules and regulations to implement the provisions of this article.

§ 2. This act shall take effect immediately.