

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:

1 Section 1. The public health law is amended by adding a new article 18
2 to read as follows:

ARTICLE 18

PARKINSON'S DISEASE ASSESSMENT PROGRAM

Section 1801. Definitions.

1802. Parkinson's disease registry.

7 § 1801. Definitions. For the purposes of this article: 1. "Parkinson's
8 disease" shall mean a chronic and progressive neurologic disorder
9 resulting from deficiency of the neurotransmitter dopamine as the conse-
10 quence of degenerative, vascular, or inflammatory changes in the area of
11 the brain called the basal ganglia. Such disorder shall be characterized
12 by tremor at rest, slow movements, and rigidity of movement, droopy
13 posture, muscle weakness, and unsteady or shuffling gait; and

14 2. "Facility" shall mean any governmental or private agency, depart-
15 ment, institution, clinic, laboratory, hospital, nursing care facility,
16 health maintenance organization, association or other similar entity
17 that provides medical care.

18 § 1802. Parkinson's disease registry. 1. The department shall conduct
19 a program of epidemiological assessments of the incidence of
20 Parkinson's disease in the state. Such program shall include, but not be
21 limited to, the monitoring of Parkinson's disease associated with
22 suspected chemical agents encountered by the general public both in
23 specific occupations and in the environment generally.

24 2. An attending physician or a person representing or employed by a
25 facility as defined by the commissioner shall report the existence of
26 Parkinson's disease to the department when such physician or other
27 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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1 medication that is used to treat Parkinson's disease or related neuro-
2 logical conditions.

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

5 (i) public health;

6 (ii) specific occupations; and

7 (iii) geographic areas and their interventions and remedies.

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

12 (i) occurrence;

13 (ii) frequency;

14 (iii) incidence; and

15 (iv) concentrations in particular occupations; cause, effect and prog-
16 nosis of Parkinson's disease, and other relevant data and findings with
17 respect thereto.

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

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

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

34 (i) the name of the person authorizing access;

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

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

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

41 6. Persons with a valid scientific interest who are engaged in demo-
42 graphic, epidemiological, or other similar studies related to health who
43 meet qualifications as determined by the department, and who agree, in
44 writing, to maintain confidentiality, may be authorized access to confi-
45 dential information. Any person who, in violation of a written agreement
46 to maintain confidentiality, discloses any information provided pursuant
47 to this section, or who uses information provided pursuant to this
48 section in a manner other than that prescribed by the commissioner, may
49 be denied further access to any confidential information maintained by
50 the department.

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

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

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

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

13 10. The registry shall provide information to supplement the coordi-
14 nating council as provided by section two thousand four-a of this chap-
15 ter. Upon the recommendation of the coordinating council and a majority
16 vote, a designee shall be consulted to attend all council meetings to
17 provide information and analysis of information contained within the
18 Parkinson's disease registry and reports.

19 11. The department, where practicable, shall make available informa-
20 tion regarding research opportunities, clinical trials, or public aware-
21 ness campaigns on its website related to Parkinson's disease research,
22 identification, and treatment.

23 12. The commissioner shall promulgate rules and regulations to imple-
24 ment the provisions of this article.

25 § 2. This act shall take effect immediately.