

# STATE OF NEW YORK

1304

2019-2020 Regular Sessions

## IN SENATE

January 14, 2019

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

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

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1 Parkinson's disease to the department when such physician or other  
2 person diagnoses the presence of that illness or a patient is prescribed  
3 medication that is used to treat Parkinson's disease or related neuro-  
4 logical conditions.

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

7 (i) public health;

8 (ii) specific occupations; and

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

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

14 (i) occurrence;

15 (ii) frequency;

16 (iii) incidence; and

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

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

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

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

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

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

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

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

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

53 7. Notwithstanding any other provisions of law, the department may  
54 authorize a New York medical research institution to oversee and main-  
55 tain the Parkinson's disease registry upon a showing of the ability to  
56 collect and analyze information in a timely manner and maintain the

1 confidentiality and privacy of all records housed therein. The commis-  
2 sioner shall remain responsible for ensuring reporting procedures,  
3 privacy compliance, and approval for access to the records are suitable  
4 and compliant with all rules and regulations.

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

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

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

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

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

27 § 2. This act shall take effect immediately.