

STATE OF NEW YORK

5803--B

2023-2024 Regular Sessions

IN ASSEMBLY

March 23, 2023

Introduced by M. of A. PAULIN, GUNTHER, McDONALD, FAHY, STERN, KIM, HYNDMAN, WOERNER, SHIMSKY, CARROLL, DICKENS, McMAHON, SIMON, McDO- NOUGH, RA, DE LOS SANTOS, STIRPE, BUTTENSCHON, SILLITTI, SEAWRIGHT, THIELE, LEVENBERG, HEVESI, MANKTELOW, BRABENEC, JENSEN, DeSTEFANO -- read once and referred to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- recommitted to the Committee on Health in accordance with Assembly Rule 3, sec. 2 -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law, in relation to establishing a state Parkinson's disease registry

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-B to read as follows:

ARTICLE 20-B

STATE PARKINSON'S DISEASE REGISTRY

Section 2010. Definitions.

2011. Duty to report.

2012. Establishment of registry.

2013. Duties of the department.

2014. Duties of the commissioner.

§ 2010. Definitions. As used in this article, the following terms shall have the following meanings:

1. "Parkinson's disease" means a chronic and progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as the consequence of specific degenerative changes in the area of the brain called the basal ganglia.

2. "Parkinsonisms" means related conditions that cause a combination of the movement abnormalities seen in Parkinson's disease including, but

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

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1 not limited to, tremor at rest, slow movement, muscle rigidity, impaired
2 speech, or muscle stiffness, which often overlap with and can evolve
3 from what appears to be Parkinson's disease.

4 § 2011. Duty to report. 1. Every physician, nurse practitioner, physi-
5 cian assistant and general hospital that diagnoses or is treating a
6 patient diagnosed with Parkinson's disease or Parkinsonisms, shall give
7 notice no later than one hundred eighty days of every case of
8 Parkinson's disease coming under their care, to the department, in a
9 format to be determined by the commissioner, except as otherwise
10 provided in this article.

11 2. All patients diagnosed with Parkinson's disease or Parkinsonisms
12 shall be provided written and verbal notice regarding the collection of
13 information and patient data on Parkinson's disease. Patients who do not
14 wish to participate in the collection of data shall affirmatively opt-
15 out in writing after ample opportunity to review such notice, provided
16 that, the mere incidence of a patient with Parkinson's disease shall be
17 the sole required information for the registry under section two thou-
18 sand twelve of this article for any patient who chooses not to partic-
19 ipate.

20 § 2012. Establishment of registry. 1. The department shall establish a
21 Parkinson's disease registry for the collection of information on the
22 incidence and prevalence of Parkinson's disease and Parkinsonisms. The
23 department may consult with Parkinson's disease experts, including
24 neurologists, patients living with Parkinson's disease, and Parkinson's
25 disease researchers to assist in the development and implementation of
26 such registry, and to determine what data shall be collected.

27 2. All information maintained by the department under the provisions
28 of this section shall be confidential except as necessary to carry out
29 the provisions of this section and shall not be released for any other
30 purpose.

31 3. The department may enter into an agreement to provide data
32 collected in the Parkinson's disease registry to the federal Centers for
33 Disease Control and Prevention, or successor agency, to local health
34 officers, or health researchers for the study of Parkinson's disease for
35 public health and research purposes. Data shall be provided in summary,
36 statistical, aggregate, or other form such that no individual person can
37 be identified.

38 4. On or before January first, two thousand twenty-six, the department
39 shall create and maintain a public website called the "New York state
40 Parkinson's disease registry" which shall include information on the
41 incidence and prevalence of Parkinson's disease and Parkinsonisms in the
42 state by county, and demographic information on affected patients.

43 § 2013. Duties of the department. 1. Parkinson's disease reports and
44 data shall be maintained by the department in a manner suitable for
45 research purposes, and shall be made available to persons as set forth
46 in section two thousand twelve of this article.

47 2. All information collected under this article shall be confidential
48 insofar as the identity of individual patients is concerned and shall be
49 used solely for the purposes as provided in this article. Access to such
50 information shall be limited to authorized employees of the department
51 as well as persons and organizations defined in section two thousand
52 twelve of this article with valid scientific interest and qualifica-
53 tions, as determined by the commissioner, who are engaged in demograph-
54 ic, epidemiological, or other similar studies related to public health.

55 3. The department shall maintain an accurate record of all persons who
56 are given access to the information contained in the Parkinson's disease

1 registry. Such record shall include the name of the person authorizing
2 access, the name, title and organizational affiliation of persons given
3 access, dates of access, and the specific purposes for which information
4 is to be used.

5 4. Any person who, in violation of a written agreement to maintain
6 confidentiality, discloses any information provided under this section,
7 or who uses information provided under this section in a manner other
8 than that prescribed by the commissioner, may be denied further access
9 to any confidential information maintained by the department.

10 § 2014. Duties of the commissioner. The commissioner may promulgate
11 any regulations necessary to implement the provisions of this article,
12 including but not limited to:

13 1. Establishing the form, content, and manner by which providers shall
14 report Parkinson's disease information into the registry established
15 under section two thousand twelve of this article;

16 2. Prescribing the permissible uses for the information made available
17 under this article; and

18 3. Establishing procedures to maintain the confidentiality of informa-
19 tion collected by providers and provided to members of the department
20 pursuant to this article. This shall include a procedure to ensure that
21 confidential patient information is deidentified prior to being provided
22 to authorized participants under this article.

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