

STATE OF NEW YORK

5803--A

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, McDONOUGH, 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

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:

1 Section 1. The public health law is amended by adding a new article
2 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.

10 § 2010. Definitions. As used in this article, the following terms
11 shall have the following meanings:

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

16 2. "Parkinsonisms" means related conditions that cause a combination
17 of the movement abnormalities seen in Parkinson's disease including, but
18 not limited to, tremor at rest, slow movement, muscle rigidity, impaired
19 speech, or muscle stiffness, which often overlap with and can evolve
20 from what appears to be Parkinson's disease.

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

LBD08983-02-3

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

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

17 § 2012. Establishment of registry. 1. The department shall establish a
18 Parkinson's disease registry for the collection of information on the
19 incidence and prevalence of Parkinson's disease and Parkinsonisms. The
20 department may consult with Parkinson's disease experts, including
21 neurologists, patients living with Parkinson's disease, and Parkinson's
22 disease researchers to assist in the development and implementation of
23 such registry, and to determine what data shall be collected.

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

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

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

40 § 2013. Duties of the department. 1. Parkinson's disease reports and
41 data shall be maintained by the department in a manner suitable for
42 research purposes, and shall be made available to persons as set forth
43 in section two thousand twelve of this article.

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

52 3. The department shall maintain an accurate record of all persons who
53 are given access to the information contained in the Parkinson's disease
54 registry. Such record shall include the name of the person authorizing
55 access, the name, title and organizational affiliation of persons given

1 access, dates of access, and the specific purposes for which information
2 is to be used.

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

8 § 2014. Duties of the commissioner. The commissioner may promulgate
9 any regulations necessary to implement the provisions of this article,
10 including but not limited to:

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

14 2. Prescribing the permissible uses for the information made available
15 under this article; and

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

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