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:

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 not limited to, tremor at rest, slow movement, muscle rigidity, impaired speech, or muscle stiffness, which often overlap with and can evolve 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

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

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

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

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

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

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

§ 2013. Duties of the department. 1. 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 as set forth in section two thousand twelve of this article.

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

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

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

4. Any person who, in violation of a written agreement to maintain confidentiality, discloses any information provided under this section, or who uses information provided under 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.

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

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

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

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

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