

STATE OF NEW YORK

5803

2023-2024 Regular Sessions

IN ASSEMBLY

March 23, 2023

Introduced by M. of A. PAULIN -- read once and referred to the Committee on Health

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. Article 2 of the public health law is amended by adding a
2 new title 9 to read as follows:

3 TITLE IX

4 STATE PARKINSON'S DISEASE REGISTRY

5 Section 269-a. Definitions.

6 269-b. Registry established.

7 269-c. Reports.

8 269-d. New York state Parkinson's disease research registry
9 website.

10 § 269-a. Definitions. For the purposes of this title:

11 1. "Parkinson's disease" means a chronic and progressive neurologic
12 disorder resulting from deficiency of the neurotransmitter dopamine as
13 the consequence of specific degenerative changes in the area of the
14 brain called the basal ganglia. It is characterized by tremor at rest,
15 slow movements, muscle rigidity, stooped posture, and unsteady or shuf-
16 fling gait.

17 2. "Parkinsonisms" means related conditions that cause a combination
18 of the movement abnormalities seen in Parkinson's disease, such as trem-
19 or at rest, slow movement, muscle rigidity, impaired speech or muscle
20 stiffness, which often overlap with and can evolve from what appears to
21 be Parkinson's disease. Parkinsonisms include, but are not exclusive to,
22 the following: Multiple System Atrophy (MSA), Dementia with Lewy Bodies
23 (DLB), Corticobasal Degeneration (CBD), and Progressive Supranuclear
24 Palsy (PSP).

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

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1 § 269-b. Registry established. 1. The department shall collect data on
2 the incidence of Parkinson's disease in this state and other epidemio-
3 logical data. The registry and system of collection and dissemination of
4 information shall be under the direction of the commissioner, who may
5 enter into contracts, grants or other agreements as are necessary for
6 the conduct of the registry.

7 2. (a) The department shall, within ninety days of the effective date
8 of this section, establish a Parkinson's disease registry advisory
9 committee to assist in the development and implementation of the regis-
10 try; determine what data shall be collected; and generally, advise the
11 department.

12 (b) The commissioner shall select the members of the committee.
13 Membership of the committee shall include:

14 (i) a neurologist;

15 (ii) a movement disorder specialist;

16 (iii) a primary care provider;

17 (iv) a physician informaticist;

18 (v) a patient living with Parkinson's disease;

19 (vi) a public health professional;

20 (vii) a population health researcher familiar with registries;

21 (viii) a Parkinson's disease researcher; and

22 (ix) anyone else the commissioner deems necessary.

23 3. (a) The department shall designate Parkinson's disease and related
24 Parkinsonisms as advised by the advisory committee as diseases required
25 to be reported in the state or any part of the state.

26 (b) The department shall establish a system for the collection and
27 dissemination of information determining the incidence and prevalence of
28 Parkinson's disease and related Parkinsonisms, as advised by the advi-
29 sory committee.

30 (c) All cases of Parkinson's disease diagnosed or treated in this
31 state shall be reported to the department, provided the mere incidence
32 of a patient with Parkinson's disease shall be the sole required infor-
33 mation for this registry for any patient who chooses not to participate.
34 For the subset of patients who choose not to participate, no further
35 data shall be reported to the registry. The department may create,
36 review and revise a list of data points required as part of mandated
37 Parkinson's disease reporting under this section. Such list shall
38 include, but not be limited to necessary triggering diagnostic condi-
39 tions, consistent with the latest International Statistical Classifica-
40 tion of Diseases and Related Health Problems, and resulting case data
41 including, but not limited to, diagnosis, treatment and survival. The
42 department may implement and administer this paragraph through a bulle-
43 tin, or similar instruction, to providers without taking regulatory
44 action.

45 (d) The department shall provide notification of the mandatory report-
46 ing of Parkinson's disease and Parkinsonisms on its website and may also
47 provide that information to professional associations representing
48 physicians, nurse practitioners, and hospitals at least ninety days
49 prior to requiring information be reported.

50 (e) A hospital, facility, physician, surgeon, physician assistant and
51 nurse practitioners who diagnose or are treating a patient diagnosed
52 with Parkinson's disease or Parkinsonisms and have primary responsibil-
53 ity for the treatment and care of the patient for Parkinson's disease or
54 Parkinsonisms shall report each case of Parkinson's disease and Parkin-
55 sonisms to the department in a format prescribed by the department. The
56 department is authorized to enter into data sharing contracts with data

1 reporting entities and their associated electronic medical record
2 systems vendors to securely and confidentially receive information
3 related to Parkinson's disease testing, diagnosis and treatment.

4 4. All patients diagnosed with Parkinson's disease or Parkinsonisms,
5 as advised by the advisory committee, shall be provided a notice in
6 writing and orally regarding the collection of information and patient
7 data on Parkinson's disease. Patients who do not wish to participate in
8 the collection of data for purposes of research in this registry shall
9 affirmatively opt-out in writing after an opportunity to review the
10 documents and ask questions. No patient shall be forced to participate
11 in this registry.

12 5. The department may enter into agreements to furnish data collected
13 in this registry to other states' Parkinson's disease registries, feder-
14 al Parkinson's disease control agencies, local health officers, or
15 health researchers for the study of Parkinson's disease. Before confi-
16 dential information is disclosed to those agencies, officers, research-
17 ers, or out-of-state registries, the requesting entity shall agree in
18 writing to maintain the confidentiality of the information, and in the
19 case of researchers, shall also do both of the following:

20 (a) obtain approval of their committee for the protection of human
21 subjects established in accordance with Part 46 (commencing with Section
22 46.101) of Title 45 of the Code of Federal Regulations; and

23 (b) provide documentation to the department that demonstrates to the
24 department's satisfaction that the entity has established the procedures
25 and ability to maintain the confidentiality of the information.

26 6. Except as otherwise provided in this section, all information
27 collected pursuant to this section shall be confidential. For purposes
28 of this section, this information shall be referred to as confidential
29 information. To ensure privacy, the department shall promulgate a coding
30 system that removes any identifying information about the patient.

31 7. (a) Notwithstanding any other law, a disclosure authorized by this
32 section shall include only the information necessary for the stated
33 purpose of the requested disclosure, used for the approved purpose, and
34 not be further disclosed.

35 (b) Provided the security of confidentiality has been documented, the
36 furnishing of confidential information to the department or its author-
37 ized representative in accordance with this section shall not expose any
38 person, agency or entity furnishing information to liability, and shall
39 not be considered a waiver of any privilege or a violation of a confi-
40 dential relationship.

41 (c) The department shall maintain an accurate record of all persons
42 who are given access to confidential information. The record shall
43 include: the name of the person authorizing access; name, title,
44 address, and organizational affiliation of persons given access; dates
45 of access; and the specific purpose for which information is to be used.
46 The record of access shall be open to public inspection during normal
47 operating hours of the department.

48 (d) Notwithstanding any other law, confidential information shall not
49 be available for subpoena, shall not be disclosed, discoverable or
50 compelled to be produced in any civil, criminal, administrative or other
51 proceeding. Confidential information shall not be deemed admissible as
52 evidence in any civil, criminal, administrative or other tribunal or
53 court for any reason.

54 (e) This subdivision does not prohibit the publication by the depart-
55 ment of reports and statistical compilations that do not in any way
56 identify individual cases or individual sources of information.

1 (f) Notwithstanding the restrictions in this subdivision, the individ-
2 ual to whom the information pertains shall have access to his or her own
3 information.

4 8. This section does not preempt the authority of facilities or indi-
5 viduals providing diagnostic or treatment services to patients with
6 Parkinson's disease to maintain their own facility-based Parkinson's
7 disease registries.

8 § 269-c. Reports. On or before January first, two thousand twenty-
9 five, and every year thereafter, the department shall report to the
10 legislature and governor a yearly program summary update on the inci-
11 dence and prevalence of Parkinson's disease in the state by county, how
12 many records have been included and reported into the registry, and
13 demographic information such as patients by age, gender and race. This
14 yearly report shall also be published in a downloadable format on the
15 department's website or the designated New York state Parkinson's
16 disease research registry website.

17 § 269-d. New York state Parkinson's disease research registry website.
18 On or before January first, two thousand twenty-five, the department
19 shall create and maintain a webpage called the "New York State
20 Parkinson's Disease Research Registry" where the public may view infor-
21 mation related to the registry, a yearly program summary, and any other
22 relevant or helpful information related to the registry as deemed neces-
23 sary by the advisory council.

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