

HOUSE No. 4567

The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES, April 22, 2024.

The committee on Public Health, to whom was referred the petition (accompanied by bill, House, No. 3614) of Edward F. Coppinger and Adam Scanlon relative to the Parkinson's disease registry and improving outcomes for individuals with Parkinson's disease, reports recommending that the accompanying bill (House, No. 4567) ought to pass.

For the committee,

MARJORIE C. DECKER.

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**In the One Hundred and Ninety-Third General Court
(2023-2024)**

An Act to improve outcomes for individuals with Parkinson’s disease.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 SECTION 1. Chapter 111 of the General Laws is hereby amended by striking Section
2 243 and inserting in place thereof the following new section: -

3 Section 243: Parkinson’s disease registry

4 (a) As used in this section, the following words shall, unless the context clearly
5 requires otherwise, have the following meanings:

6 “Parkinson’s disease”, a chronic and progressive neurologic disorder resulting from
7 deficiency of the neurotransmitter dopamine as the consequence of specific degenerative changes
8 in the area of the brain called the basal ganglia. It is characterized by tremor at rest, slow
9 movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.

10 “Parkinsonisms”, related conditions that causes a combination of the movement
11 abnormalities seen in Parkinson's disease — such as tremor at rest, slow movement, muscle
12 rigidity, impaired speech or muscle stiffness — which often overlap with and can evolve from

13 what appears to be Parkinson's disease. Example Parkinsonisms of particular interest include,
14 but are not exclusive to, the following: Multiple System Atrophy (MSA), Dementia with Lewy
15 Bodies (DLB), Corticobasal Degeneration (CBD), and Progressive Supranuclear Palsy (PSP).

16 (b) The department shall, subject to appropriation, establish a registry to record cases
17 of Parkinson's and Parkinsonisms that occur in residents of the commonwealth, and such
18 information concerning these cases as it shall deem necessary and appropriate in order to
19 determine the incidence and prevalence of such diseases.

20 (c) The registry and system of collection and dissemination of information shall be
21 under the direction of the commissioner, who may enter into contracts, grants or other
22 agreements as are necessary for the conduct of the program.

23 (d) All patients diagnosed with Parkinson's disease or related Parkinsonisms shall be
24 provided a notice in writing and orally regarding the collection of information and patient data
25 on Parkinson's disease and related Parkinsonisms. Patients who do not wish to participate in the
26 collection of data for purposes of research in this registry shall affirmatively opt-out in writing
27 after an opportunity to review the documents and ask questions. No patient shall be forced to
28 participate in this registry. Patients may change their participation status at any time by
29 submitting a request in writing.

30 (e) The department shall establish a system for the collection and dissemination of
31 information determining the incidence and prevalence of Parkinson's disease and related
32 Parkinsonisms, as advised by the advisory committee. The department shall designate
33 Parkinson's disease and related Parkinsonisms as diseases required to be reported in the state or
34 any part of the state.

35 All cases of Parkinson’s disease and related Parkinsonisms diagnosed or treated in the
36 commonwealth shall be reported to the department. However, the mere incidence of a patient
37 with Parkinson’s disease or a related Parkinsonism shall be the sole required information for this
38 registry for any patient who chooses not to participate. For the subset of patients who choose not
39 to participate, no further data shall be reported to the registry.

40 The department may create, review and revise a list of data points required as part of
41 mandated Parkinson’s disease reporting under this Section.

42 i. This list shall include, but not be limited to, necessary triggering diagnostic
43 conditions, consistent with the latest International Statistical Classification of Diseases and
44 Related Health Problems, and resulting case data including, but not limited to, diagnosis,
45 treatment and survival.

46 ii. The department may implement and administer this subdivision through a
47 bulletin, or similar instruction, to providers without taking regulatory action.

48 (f) The department shall provide notification of the mandatory reporting of
49 Parkinson’s disease and Parkinsonism on its website and may also provide that information to
50 professional associations representing physicians, nurse practitioners, and hospitals at least 90
51 days prior to requiring information be reported.

52 (g) Any hospital, facility, physician, surgeon, physician assistant or nurse practitioner
53 who diagnoses or is responsible for providing primary treatment to Parkinson’s disease or
54 Parkinsonism patients shall report each case of Parkinson’s disease and Parkinsonisms, as
55 required by subsection (e), to the department in a format prescribed by the department. The
56 Department shall be authorized to enter into data sharing contracts with data reporting entities

57 and their associated electronic medical record systems vendors to securely and confidentially
58 receive information related to Parkinson's disease testing, diagnosis and treatment.

59 (h) The department may enter into agreements to furnish data collected in this registry to
60 other states' Parkinson's disease registries, federal Parkinson's disease control agencies, local
61 health officers, or health researchers for the study of Parkinson's disease. Before confidential
62 information is disclosed to those agencies, officers, researchers, or out-of-state registries, the
63 requesting entity shall agree in writing to maintain the confidentiality of the information, and in
64 the case of researchers, shall also do both of the following:

65 i. obtain approval of their committee for the protection of human subjects
66 established in accordance with Part 46 (commencing with Section 46.101) of Title 45 of the
67 Code of Federal Regulations; and

68 ii. provide documentation to the department that demonstrates to the department's
69 satisfaction that the entity has established the procedures and ability to maintain the
70 confidentiality of the information.

71 (i) Except as otherwise provided in this section, all information collected pursuant to this
72 section shall be confidential. For purposes of this section, this information shall be referred to as
73 confidential information. To ensure privacy, the department shall promulgate a coding system
74 that removes any identifying information about the patient.

75 (j) Notwithstanding any other law, a disclosure authorized by this section shall include
76 only the information necessary for the stated purpose of the requested disclosure, used for the
77 approved purpose, and not be further disclosed.

78 Provided the security of confidentiality has been documented, the furnishing of
79 confidential information to the department or its authorized representative in accordance with
80 this section shall not expose any person, agency or entity furnishing information to liability, and
81 shall not be considered a waiver of any privilege or a violation of a confidential relationship.

82 (k) The department shall maintain an accurate record of all persons who are given access
83 to confidential information. The record shall include: the name of the person authorizing access;
84 name, title, address, and organizational affiliation of persons given access; dates of access; and
85 the specific purpose for which information is to be used. The record of access shall be open to
86 public inspection during normal operating hours of the department.

87 (l) Notwithstanding any other law, confidential information shall not be available for
88 subpoena, shall not be disclosed, discoverable or compelled to be produced in any civil, criminal,
89 administrative or other proceeding. Confidential information shall not be deemed admissible as
90 evidence in any civil, criminal, administrative or other tribunal or court for any reason.

91 This subsection does not prohibit the publication by the department of reports and
92 statistical compilations that do not in any way identify individual cases or individual sources of
93 information.

94 Notwithstanding the restrictions in this subsection, the individual to whom the
95 information pertains shall have access to his or her own information.

96 (m) This section does not preempt the authority of facilities or individuals providing
97 diagnostic or treatment services to patients with Parkinson's disease or related Parkinsonisms to
98 maintain their own facility-based Parkinson's disease or Parkinsonisms registries.

99 SECTION 2. On or before December 21, 2025, and every year thereafter, the Department
100 shall report to the House Committee on Ways and Means, the Senate Committee on Ways and
101 Means, and the Joint Committee on Public Health, a yearly program summary update on the
102 incidence and prevalence of Parkinson's and related Parkinsonisms in the state by county, how
103 many records have been included and reported into the registry, and demographic information
104 such as patients by age, gender and race. This yearly report shall also be published in a
105 downloadable format on the Department's webpage or designated Massachusetts Parkinson's
106 Research Registry webpage.

107 SECTION 3. The Department shall create and maintain a webpage titled "an overview
108 from the Massachusetts Parkinson's Research Registry" within the Department's public
109 information website to allow public access to information related to the registry, a yearly
110 program summary, and any other relevant or helpful information related to the registry This
111 information may be published in any form deemed appropriate by the Department.

112 This section shall take effect January 1, 2025.