

HOUSE No. 3614

The Commonwealth of Massachusetts

PRESENTED BY:

Edward F. Coppinger

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

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

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
<i>Edward F. Coppinger</i>	<i>10th Suffolk</i>	<i>1/18/2023</i>
<i>Adam Scanlon</i>	<i>14th Bristol</i>	<i>1/19/2023</i>

HOUSE No. 3614

By Representative Coppinger of Boston, a 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. Public Health.

The Commonwealth of Massachusetts

**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 establish a Parkinson's disease registry for the collection of
17 information necessary to determine the incidence and prevalence of Parkinson's disease and
18 Parkinsonisms in the commonwealth.

19 (c) There shall be within the department a Parkinson's disease registry advisory
20 committee to advise and assist in the development, implementation and progress of the
21 Parkinson's disease registry established in subsection (a). The committee shall review and submit
22 recommendations on: (i) what data shall be collected, including, but not limited to, demographic
23 information and data by areas and regions of the commonwealth, with specific data from urban,
24 low and median income communities and minority communities of the commonwealth; (ii) the
25 means of collecting and disseminating such data; (iii) how to ensure privacy and confidentiality
26 of such data; (iv) the purpose, design and functionality of the registry; and (v) the
27 implementation of the registry. The committee shall recommend to the department any
28 information deemed necessary and appropriate for the statistical identification and planning for
29 treatment and education of health care providers and persons diagnosed with Parkinson's disease.

30 The committee shall consist of the commissioner, or a designee, and 10 members to be
31 appointed by the commissioner as follows: 3 physicians, 1 of whom shall be a general
32 neurologist, 1 of whom shall be a movement disorder specialist and 1 of whom shall be a
33 primary care physician; 1 health informaticist; 2 population health researchers familiar with

34 registries; 2 Parkinson's disease researchers; and 2 persons diagnosed with Parkinson's disease.
35 The committee shall meet at least bi-annually to assess registry progress and recommend
36 changes.

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

40 (e) All patients diagnosed with Parkinson's disease or related Parkinsonisms, as
41 advised by an Advisory Committee, shall be provided a notice in writing and orally regarding the
42 collection of information and patient data on Parkinson's disease. Patients who do not wish to
43 participate in the collection of data for purposes of research in this registry shall affirmatively
44 opt-out in writing after an opportunity to review the documents and ask questions. No patient
45 shall be forced to participate in this registry. Patients may change their participation status at any
46 time by submitting a request in writing.

47 (f) The department shall establish a system for the collection and dissemination of
48 information determining the incidence and prevalence of Parkinson's disease and related
49 Parkinsonisms, as advised by the advisory committee. The department shall designate
50 Parkinson's disease and related Parkinsonisms as advised by the advisory committee as diseases
51 required to be reported in the state or any part of the state.

52 All cases of Parkinson's disease diagnosed or treated in the commonwealth shall be
53 reported to the department. However, the mere incidence of a patient with Parkinson's shall be
54 the sole required information for this registry for any patient who chooses not to participate. For

55 the subset of patients who choose not to participate, no further data shall be reported to the
56 registry.

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

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

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

65 (g) The department shall provide notification of the mandatory reporting of
66 Parkinson's disease and Parkinsonism on its website and may also provide that information to
67 professional associations representing physicians, nurse practitioners, and hospitals at least 90
68 days prior to requiring information be reported.

69 (h) Any hospital, facility, physician, surgeon, physician assistant or nurse practitioner
70 who diagnoses or is responsible for providing primary treatment to Parkinson's disease or
71 Parkinsonism patients shall report each case of Parkinson's disease and Parkinsonisms, as
72 required by subsection (e), to the department in a format prescribed by the department. The
73 Department shall be authorized to enter into data sharing contracts with data reporting entities
74 and their associated electronic medical record systems vendors to securely and confidentially
75 receive information related to Parkinson's disease testing, diagnosis and treatment.

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

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

85 ii. provide documentation to the department that demonstrates to the department's
86 satisfaction that the entity has established the procedures and ability to maintain the
87 confidentiality of the information.

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

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

95 i. Provided the security of confidentiality has been documented, the furnishing of
96 confidential information to the department or its authorized representative in accordance with

97 this section shall not expose any person, agency or entity furnishing information to liability, and
98 shall not be considered a waiver of any privilege or a violation of a confidential relationship.

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

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

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

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

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

116 SECTION 2.

117 On or before December 21, 2024, and every year thereafter, the Department shall report
118 to the House Committee on Ways and Means, the Senate Committee on Ways and Means, and
119 the Joint Committee on Public Health, a yearly program summary update on the incidents and
120 prevalence of Parkinson's in the state by county, how many records have been included and
121 reported into the registry, and demographic information such as patients by age, gender and race.
122 This yearly report shall also be published in a downloadable format on the Department's
123 webpage or designated Massachusetts Parkinson's Research Registry webpage.

124 SECTION 3.

125 The Department shall create and maintain a webpage titled "an overview from the
126 Massachusetts Parkinson's Research Registry" within the Department's public information
127 website to allow public access to information related to the registry, a yearly program summary,
128 and any other relevant or helpful information related to the registry as deemed necessary by the
129 Parkinson's Disease Registry Advisory Committee. This information may be published in any
130 form deemed appropriate by the Department.

131 This section will take effect January 1, 2025.