

SENATE No. 1344

The Commonwealth of Massachusetts

PRESENTED BY:

John J. Cronin

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:

John J. Cronin

DISTRICT/ADDRESS:

Worcester and Middlesex

SENATE No. 1344

By Mr. Cronin, a petition (accompanied by bill, Senate, No. 1344) of John J. Cronin for legislation to improve 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 requires
5 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 (a) 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 (b) 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 (c) The registry and system of collection and dissemination of information shall be under
38 the direction of the commissioner, who may enter into contracts, grants or other agreements as
39 are necessary for the conduct of the program.

40 (d) All patients diagnosed with Parkinson's disease or related Parkinsonisms, as advised
41 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 (e) 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 conditions,
60 consistent with the latest International Statistical Classification of Diseases and Related Health
61 Problems, and resulting case data including, but not limited to, diagnosis, treatment and survival.

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

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

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

75 (h) The department may enter into agreements to furnish data collected in this registry to
76 other states’ Parkinson’s disease registries, federal Parkinson’s disease control agencies, local
77 health officers, or health researchers for the study of Parkinson’s disease. Before confidential
78 information is disclosed to those agencies, officers, researchers, or out-of-state registries, the

79 requesting entity shall agree in writing to maintain the confidentiality of the information, and in
80 the case of researchers, shall also do both of the following:

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

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

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

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

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

98 (k) The department shall maintain an accurate record of all persons who are given access
99 to confidential information. The record shall include: the name of the person authorizing access;

100 name, title, address, and organizational affiliation of persons given access; dates of access; and
101 the specific purpose for which information is to be used. The record of access shall be open to
102 public inspection during normal operating hours of the department.

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

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

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

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

115 SECTION 2. On or before December 21, 2024, and every year thereafter, the Department
116 shall report to the House Committee on Ways and Means, the Senate Committee on Ways and
117 Means, and the Joint Committee on Public Health, a yearly program summary update on the
118 incidents and prevalence of Parkinson's in the state by county, how many records have been
119 included and reported into the registry, and demographic information such as patients by age,
120 gender and race. This yearly report shall also be published in a downloadable format on the
121 Department's webpage or designated Massachusetts Parkinson's Research Registry webpage.

122 SECTION 3. The Department shall create and maintain a webpage titled “an overview
123 from the Massachusetts Parkinson’s Research Registry” within the Department’s public
124 information website to allow public access to information related to the registry, a yearly
125 program summary, and any other relevant or helpful information related to the registry as
126 deemed necessary by the Parkinson’s Disease Registry Advisory Committee. This information
127 may be published in any form deemed appropriate by the Department.

128 This section will take effect January 1, 2025.