

SENATE No. 1245

The Commonwealth of Massachusetts

PRESENTED BY:

Diana DiZoglio, (BY REQUEST)

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 establishing a Parkinson’s disease registry.

PETITION OF:

NAME:

DISTRICT/ADDRESS:

Charles Brown

SENATE No. 1245

By Ms. DiZoglio (by request), a petition (accompanied by bill, Senate, No. 1245) of Charles Brown for legislation to establish a Parkinson’s disease registry. Public Health.

The Commonwealth of Massachusetts

**In the One Hundred and Ninety-First General Court
(2019-2020)**

An Act establishing a Parkinson’s disease registry.

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 adding the
2 following section: –

3 Section 237. (a) The department shall collect data on the incidence of Parkinson’s disease
4 in Massachusetts. For the purposes of this section, “Parkinson’s disease” means a chronic and
5 progressive neurologic disorder resulting from deficiency of the neurotransmitter dopamine as
6 the consequence of degenerative, vascular, or inflammatory changes in the area of the brain
7 called the basal ganglia. It is characterized by tremor at rest, slow movements, rigidity of
8 movement, droopy posture, muscle weakness and unsteady or shuffling gait. The registry and
9 system of collection and dissemination of information shall be under the direction of the
10 commissioner, who may enter into contracts, grants or other agreements as are necessary for the
11 conduct of the program.

12 (b) All patients diagnosed with Parkinson's disease shall be provided a notice in writing
13 and orally regarding the collection of information and patient data on Parkinson's disease.
14 Patients who wish to participate in the collection of data for purposes of research in this registry
15 shall affirmatively do so in writing after an opportunity to review the documents and ask
16 questions. No patient shall be forced to participate in this registry.

17 (c) The department shall establish a system for the collection and dissemination of
18 information determining the incidence and prevalence of Parkinson's disease. The department
19 shall designate Parkinson's disease as a disease required to be reported in the state or any part of
20 the state. All cases of Parkinson's disease diagnosed or treated in Massachusetts shall be reported
21 to the department. However, the mere incidence of a patient with Parkinson's shall be the sole
22 required information for this registry for any patient who chooses not to participate. For the
23 subset of patients who choose not to participate, no further data shall be reported to the registry.

24 (d) The department shall provide notification of the mandatory reporting of Parkinson's
25 disease on its Internet Web site and shall also provide that information to associations
26 representing physicians and hospitals and directly to the board of medicine at least 90 days prior
27 to requiring information be reported.

28 (e) A hospital, facility, physician and surgeon or other health care provider diagnosing or
29 providing treatment to Parkinson's disease patients shall report each case of Parkinson's disease
30 to the department in a format prescribed by the department.

31 (f) Except as otherwise provided in this section, all information collected pursuant to this
32 section shall be confidential. For purposes of this section, this information shall be referred to as
33 confidential information. To ensure privacy, the department shall promulgate a coding system

34 that removes any identifying information about the patient. Patients shall be afforded the option
35 of permitting persons with a valid scientific interest who are engaged in demographic,
36 epidemiological, or other similar studies related to health who meet qualifications as determined
37 by the department, and who agree, in writing, to maintain confidentiality, to access to
38 confidential information collected by the department.

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

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

48 (2) provide documentation to the department that demonstrates to the department's
49 satisfaction that the entity has established the procedures and ability to maintain the
50 confidentiality of the information.

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

54 (i) Provided the security of confidentiality has been documented, [t]he furnishing of
55 confidential information to the department or its authorized representative in accordance with

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

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

63 (k) Notwithstanding any other law, the confidential information shall not be available for
64 subpoena, shall not be disclosed, discoverable or compelled to be produced in any civil, criminal,
65 administrative or other proceeding. The confidential information shall not be deemed admissible
66 as evidence in any civil, criminal, administrative or other tribunal or court for any reason.

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

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

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

75 SECTION 2. Subsection (a) of Section 237 of Chapter 111 of the General Laws shall take
76 effect January 1, 2020.

77 SECTION 3. Subsection (d) of Section 237 of Chapter 111 of the General Laws shall
78 take effect July 1, 2020.