

**SENATE . . . . . No. 1245**

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**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:

*Charles Brown*

DISTRICT/ADDRESS:

**SENATE . . . . . No. 1245**

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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.

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**The Commonwealth of Massachusetts**

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**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.