

**SENATE . . . . . No. 1421**

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**The Commonwealth of Massachusetts**

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PRESENTED BY:

***Diana DiZoglio, (BY REQUEST)***

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*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.

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PETITION OF:

NAME:

DISTRICT/ADDRESS:

*Charles Brown*

**SENATE . . . . . No. 1421**

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By Ms. DiZoglio (by request), a petition (accompanied by bill, Senate, No. 1421) of Charles Brown for legislation to establish a Parkinson’s disease registry. Public Health.

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[SIMILAR MATTER FILED IN PREVIOUS SESSION  
SEE SENATE, NO. 1245 OF 2019-2020.]

**The Commonwealth of Massachusetts**

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**In the One Hundred and Ninety-Second General Court  
(2021-2022)**  
\_\_\_\_\_

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 specific degenerative changes in the area of the brain called the basal ganglia.  
7 It is characterized by tremor at rest, slow movements, muscle rigidity, stooped posture, and  
8 unsteady or shuffling gait. “Parkinsonisms” means related conditions that causes a combination  
9 of the movement abnormalities seen in Parkinson's disease — such as tremor at rest, slow  
10 movement, muscle rigidity, impaired speech or muscle stiffness — which often overlap with and

11 can evolve from what appears to be Parkinson's disease. Example Parkinsonisms of particular  
12 interest include, but are not exclusive to, the following: Multiple System Atrophy (MSA),  
13 Dementia with Lewy Bodies (DLB), Corticobasal Degeneration (CBD), and Progressive  
14 Supranuclear Palsy (PSP). The registry and system of collection and dissemination of  
15 information shall be under the direction of the commissioner, who may enter into contracts,  
16 grants or other agreements as are necessary for the conduct of the program.

17 The department shall establish a Parkinson's Disease Registry Advisory Committee to  
18 assist in the development and implementation of the registry; determine what data shall be  
19 collected; and generally, advise the department. Membership of the committee must include  
20 representation from at least general neurologist, movement disorder specialist, primary care  
21 physician, physician informaticists, Parkinson's patients, public health staff, population health  
22 researchers familiar with registries, Parkinson's disease researchers and anyone else the  
23 department deems necessary. The committee should meet at least bi-annually to assess registry  
24 progress and recommend changes.

25 (b) All patients diagnosed with Parkinson's disease or related Parkinsonisms, as advised  
26 by the Advisory Committee, shall be provided a notice in writing and orally regarding the  
27 collection of information and patient data on Parkinson's disease. Patients who do not wish to  
28 participate in the collection of data for purposes of research in this registry shall affirmatively  
29 opt-out in writing after an opportunity to review the documents and ask questions. No patient  
30 shall be forced to participate in this registry.

31 (c) The department shall establish a system for the collection and dissemination of  
32 information determining the incidence and prevalence of Parkinson's disease and related

33 Parkinsonisms, as advised by the Advisory Committee. The department shall designate  
34 Parkinson's disease and related Parkinsonisms as advised by an Advisory Committee as diseases  
35 required to be reported in the state or any part of the state. All cases of Parkinson's disease  
36 diagnosed or treated in Massachusetts shall be reported to the department. However, the mere  
37 incidence of a patient with Parkinson's shall be the sole required information for this registry for  
38 any patient who chooses not to participate. For the subset of patients who choose not to  
39 participate, no further data shall be reported to the registry. The registry shall include  
40 information the department deems necessary and appropriate for the statistical identification and  
41 planning for treatment and education of health care providers and persons diagnosed with  
42 Parkinson's disease and related movement disorders.

43 (d) The department shall provide notification of the mandatory reporting of Parkinson's  
44 disease and Parkinsonism on its Internet Web site and shall also provide that information to  
45 associations representing physicians and hospitals and directly to the board of medicine at least  
46 90 days prior to requiring information be reported.

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

51 (f) Except as otherwise provided in this section, all information collected pursuant to this  
52 section shall be confidential. For purposes of this section, this information shall be referred to as  
53 confidential information. To ensure privacy, the department shall promulgate a coding system  
54 that removes any identifying information about the patient. Patients shall be afforded the option

55 of permitting persons with a valid scientific interest who are engaged in demographic,  
56 epidemiological, or other similar studies related to health who meet qualifications as determined  
57 by the department, and who agree, in writing, to maintain confidentiality, to access to  
58 confidential information collected by the department.

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

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

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

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

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

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

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

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

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

95 SECTION 2. Subsection (a) of Section 237 of Chapter 111 of the General Laws shall take  
96 effect July 1, 2021.

97           SECTION 3. Subsections (b) through (l) of Section 237 of Chapter 111 of the General  
98   Laws shall take effect January 1, 2022.