

SENATE No. 1421

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. 1421

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.

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

The Commonwealth of Massachusetts

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(i) Provided the security of confidentiality has been documented, [t]he furnishing of 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.