

FIRST REGULAR SESSION

HOUSE BILL NO. 822

102ND GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVE SMITH (155).

1898H.011

DANA RADEMAN MILLER, Chief Clerk

AN ACT

To amend chapter 191, RSMo, by adding thereto eight new sections relating to the Missouri Parkinson's disease registry act.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Chapter 191, RSMo, is amended by adding thereto eight new sections, to
2 be known as sections 191.1820, 191.1825, 191.1830, 191.1835, 191.1840, 191.1845,
3 191.1850, and 191.1855, to read as follows:

**191.1820. 1. Sections 191.1820 to 191.1855 shall be known and may be cited as
2 the "Missouri Parkinson's Disease Registry Act".**

3 2. For purposes of sections 191.1820 to 191.1855, the following terms mean:

**4 (1) "Advisory committee", the Parkinson's disease registry advisory committee
5 established in section 191.1830 to assist in the development and implementation of the
6 registry;**

**7 (2) "Medical university", the University of Missouri and any other medical
8 research university in the state that enters into a memorandum of understanding with
9 the University of Missouri if deemed appropriate by the University of Missouri;**

**10 (3) "Parkinson's disease", a chronic and progressive neurologic disorder that:
11 (a) Results from deficiency of the neurotransmitter dopamine as the
12 consequence of specific degenerative changes in the area of the brain called the basal
13 ganglia;**

**14 (b) Is characterized by tremor at rest, slow movements, muscle rigidity, stooped
15 posture, and unsteady or shuffling gait; and**

EXPLANATION — Matter enclosed in bold-faced brackets ~~thus~~ in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

16 (c) Includes motor and nonmotor symptoms and side effects including, but not
17 limited to, autonomic dysfunction, thinking and mood changes, and other physical
18 changes;

19 (4) "Parkinsonism", any condition that causes a combination of the movement
20 abnormalities observed in Parkinson's disease, such as tremor at rest, slow movement,
21 muscle rigidity, impaired speech, or muscle stiffness, with symptoms often overlapping,
22 and that may evolve from what appears to be Parkinson's disease. The term
23 "parkinsonism" shall include, but not be limited to, multiple system atrophy, dementia
24 with Lewy bodies, corticobasal degeneration, and progressive supranuclear palsy;

25 (5) "Registry", the registry established by the medical university in section
26 191.1825.

191.1825. 1. Beginning January 1, 2024, the medical university shall establish a
2 registry to collect data on the incidence of Parkinson's disease in Missouri and other
3 epidemiological data as required in sections 191.1820 to 191.1855. The database and
4 system of collection and dissemination of information shall be under the direction of the
5 medical university. The medical university may enter into contracts, grants, or other
6 agreements as are necessary for the implementation of the registry.

7 2. The registry shall become functional and able to collect reporting data twelve
8 months after the effective date of this section.

9 3. All patients diagnosed with Parkinson's disease or parkinsonism, as
10 determined by the advice of the advisory committee, shall be notified in writing and
11 orally about the collection of information and patient data on Parkinson's disease and
12 parkinsonism. If a patient does not wish to participate in the collection of data for
13 purposes of research in the registry, the patient shall affirmatively opt out in writing
14 after an opportunity to review relevant documents and ask questions. No patient shall
15 be forced to participate in the registry.

191.1830. 1. Within ninety days of the effective date of this section, the medical
2 university shall establish the "Parkinson's Disease Registry Advisory Committee",
3 which shall assist in the development and implementation of the registry, determine the
4 data to be collected, and generally advise the medical university.

5 2. The committee shall be composed of at least the following members:

- 6 (1) A neurologist;
- 7 (2) A movement disorder specialist;
- 8 (3) A primary care provider;
- 9 (4) A physician informaticist;
- 10 (5) A patient living with Parkinson's disease;
- 11 (6) A public health professional;

- 12 (7) A population health researcher familiar with registries; and
13 (8) A Parkinson's disease researcher.

191.1835. 1. The medical university shall establish, with the advice of the
2 advisory committee, a system for the collection and dissemination of information
3 determining the incidence and prevalence of Parkinson's disease and parkinsonism.

4 2. (1) Parkinson's disease and parkinsonism shall be designated as diseases
5 required to be reported to the registry. Beginning twelve months after the effective date
6 of this section, all cases of Parkinson's disease and parkinsonism diagnosed or treated in
7 this state shall be reported to the registry.

8 (2) Notwithstanding the provisions of subdivision (1) of this subsection, the mere
9 incidence of a patient with Parkinson's disease or parkinsonism shall be the sole
10 required information for the registry for any patient who chooses not to participate as
11 described in section 191.1825. No further data shall be reported to the registry for
12 patients who choose not to participate.

13 3. The medical university may create, review, and revise a list of data points
14 required to be collected as part of the mandated reporting of Parkinson's disease and
15 parkinsonism under this section. Any such list shall include, but not be limited to,
16 necessary triggering diagnostic conditions consistent with the latest International
17 Statistical Classification of Diseases and Related Health Problems and resulting case
18 data on issues including, but not limited to, diagnosis, treatment, and survival.

19 4. At least ninety days before reporting to the registry is required under this
20 section, the medical university shall publish on its website a notice about the mandatory
21 reporting of Parkinson's disease and parkinsonism and may also provide such notice to
22 professional associations representing physicians, nurse practitioners, and hospitals.

23 5. Beginning twelve months after the effective date of this section, any hospital,
24 facility, physician, surgeon, physician assistant, or nurse practitioner diagnosing or
25 responsible for providing primary treatment to patients with Parkinson's disease or
26 patients with parkinsonism shall report each case of Parkinson's disease and each case
27 of parkinsonism to the registry in a format prescribed by the medical university.

28 6. The medical university shall be authorized to enter into data-sharing
29 contracts with data-reporting entities and their associated electronic medical record
30 system vendors to securely and confidentially receive information related to Parkinson's
31 disease testing, diagnosis, and treatment.

32 7. The medical university may implement and administer this section through a
33 bulletin or similar instruction to providers without the need for regulatory action.

191.1840. The medical university may enter into agreements to furnish data
2 collected in the registry to other states' Parkinson's disease registries, federal

3 Parkinson's disease control agencies, local health officers, or health researchers for the
4 study of Parkinson's disease. Before confidential information is disclosed to those
5 agencies, officers, researchers, or out-of-state registries, the requesting entity shall agree
6 in writing to maintain the confidentiality of the information and, if a researcher, shall:

7 (1) Obtain approval of the researcher's institutional review board for the
8 protection of human subjects established in accordance with 45 CFR 46; and

9 (2) Provide documentation to the medical university that demonstrates to the
10 medical university's satisfaction that the researcher has established the procedures and
11 ability to maintain the confidentiality of the information.

191.1845. 1. Except as otherwise provided in sections 191.1820 to 191.1855, all
2 information collected under sections 191.1820 to 191.1855 shall be confidential. For
3 purposes of sections 191.1820 to 191.1855, this information shall be referred to as
4 confidential information.

5 2. To ensure privacy, the medical university shall use a coding system for the
6 registry that removes any identifying information about patients.

7 3. Notwithstanding any other provision of law, a disclosure authorized under
8 sections 191.1820 to 191.1855 shall include only the information necessary for the stated
9 purpose of the requested disclosure, shall be used for the approved purpose, and shall
10 not be further disclosed.

11 4. Provided the security of confidential information has been documented, the
12 furnishing of confidential information to the medical university or its authorized
13 representatives in accordance with sections 191.1820 to 191.1855 shall not expose any
14 person, agency, or entity furnishing the confidential information to liability and shall
15 not be considered a waiver of any privilege or a violation of a confidential relationship.

16 5. The medical university shall maintain an accurate record of all persons given
17 access to confidential information. The record shall include the name of the person
18 authorizing access; the name, title, address, and organizational affiliation of the person
19 given access; dates of access; and the specific purpose for which the confidential
20 information is to be used. The record of access shall be open to public inspection during
21 normal operating hours of the medical university.

22 (1) Notwithstanding any other provision of law, confidential information shall
23 not be available for subpoena and shall not be disclosed, discoverable, or compelled to
24 be produced in any civil, criminal, administrative, or other proceeding. Confidential
25 information shall not be deemed admissible as evidence in any civil, criminal,
26 administrative, or other tribunal or court for any reason.

27 **(2) This subsection shall not be construed to prohibit the publication by the**
28 **medical university of reports and statistical compilations that do not in any way identify**
29 **individual cases or individual sources of information.**

30 **(3) Notwithstanding the restrictions in this subsection, the individual to whom**
31 **the information pertains shall have access to his or her own information.**

191.1850. Sections 191.1820 to 191.1855 do not preempt the authority of facilities
2 **or individuals providing diagnostic or treatment services to patients with Parkinson's**
3 **disease or parkinsonism to maintain their own facility-based registries for Parkinson's**
4 **disease or parkinsonism.**

191.1855. 1. Before January 1, 2025, and before January first every year
2 **thereafter, the medical university shall provide a report to the general assembly that**
3 **includes:**

4 **(1) A program summary update for that year on the incidence and prevalence of**
5 **Parkinson's disease in the state by county;**

6 **(2) The number of records that have been included and reported to the registry;**
7 **and**

8 **(3) Demographic information, such as a breakdown of patients by age, gender,**
9 **and race.**

10 **2. The medical university shall also publish the annual report required under**
11 **this section in a downloadable format on its website or on the registry's webpage.**

✓