

WEST VIRGINIA LEGISLATURE

2022 REGULAR SESSION

ENROLLED

Committee Substitute

for

House Bill 4276

BY DELEGATES ROHRBACH, REED, SUMMERS, TULLY, D.
JEFFRIES, PACK, G. WARD, BATES, JENNINGS, WORRELL,
AND ROWAN

[Passed February 15, 2022; in effect from passage.]

1 AN ACT to amend the Code of West Virginia, 1931, as amended, by adding thereto a new article,
2 designated §16-5DD-1, relating to the collection of data relating to Parkinson's Disease;
3 defining terms; creating a Parkinson's disease registry; providing a notice requirement;
4 allowing for West Virginia University to enter into agreements regarding this data
5 collection; establishing an advisory committee; providing that confidential data shall not
6 be disclosed; and allowing for the maintaining of certain records.

Be it enacted by the Legislature of West Virginia:

ARTICLE 5DD. COLLECTION OF DATA RELATING TO PARKINSON'S DISEASE.

§16-5DD-1. Establishing collection guidelines for Parkinson's disease data.

1 (a) West Virginia University may collect data on the incidence of Parkinson's disease in
2 West Virginia and other epidemiological data as required by this article.

3 (b) These terms are defined:

4 "Parkinson's disease" means a chronic and progressive neurologic disorder resulting from
5 deficiency of the neurotransmitter dopamine as the consequence of specific degenerative
6 changes in the area of the brain called the basal ganglia. It is characterized by tremor at rest, slow
7 movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.

8 "Parkinsonisms" means related conditions that cause a combination of the movement
9 abnormalities seen in Parkinson's disease, such as tremor at rest, slow movement, muscle
10 rigidity, impaired speech or muscle stiffness, which often overlap with and can evolve from what
11 appears to be Parkinson's disease. These include: Multiple System Atrophy (MSA), Dementia
12 with Lewy Bodies (DLB), Corticobasal Degeneration (CBD), and Progressive Supranuclear Palsy
13 (PSP).

14 (c) The registry and system of collection and dissemination of information shall be under
15 the direction of West Virginia University, who may enter into contracts, grants, or other
16 agreements as are necessary for the conduct of the program.

17 (d) All patients diagnosed with Parkinson's disease or related Parkinsonisms, as advised
18 by an Advisory Committee, shall be provided a notice regarding the collection of information and
19 patient data on Parkinson's disease. Patients who do not wish to participate in the collection of
20 data for purposes of research in this registry shall affirmatively opt-out in writing after an
21 opportunity to review the documents and ask questions. A patient may not be forced to participate
22 in this registry.

23 (e) (1) West Virginia University shall establish a Parkinson's Disease Registry Advisory
24 Committee to:

25 (A) Assist in the development and implementation of the registry which may include a
26 system for the collection and dissemination of information determining the incidence and
27 prevalence of Parkinson's disease and related Parkinsonisms;

28 (B) Determine what data shall be collected; and

29 (C) Generally, advise WVU.

30 (2) Membership of the committee may include:

31 (A) Neurologists from WVU, Marshall, and Charleston Area Medical Center;

32 (B) A movement disorder specialist;

33 (C) A primary care physician;

34 (D) A physician informaticist;

35 (E) Parkinson's disease patients;

36 (F) Public health staff;

37 (G) Population health researchers familiar with registries;

38 (H) Parkinson's disease researchers; and

39 (I) Anyone else West Virginia University deems necessary.

40 (f) Parkinson's disease and related Parkinsonisms shall be reported, but the mere
41 incidence of a patient with Parkinson's shall be the sole required information for this registry for

42 any patient who chooses not to participate. For the subset of patients who choose not to
43 participate, further data may not be reported to the registry.

44 (g) A hospital, facility, physician, surgeon, physician assistant, and nurse practitioners, or
45 other health care provider deemed necessary by West Virginia University diagnosing or providing
46 treatment to Parkinson's disease or Parkinsonism patients, shall report each case of Parkinson's
47 disease and Parkinsonisms to West Virginia University in a format prescribed by the university.
48 West Virginia University may enter into data sharing contracts with data reporting entities and
49 their associated electronic medical record systems vendors to securely and confidentially receive
50 information related to Parkinson's disease testing, diagnosis, and treatment.

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

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

60 (2) Provide documentation to West Virginia University that demonstrates to the university's
61 satisfaction that the entity has established the procedures and ability to maintain the confidentiality
62 of the information.

63 (i) Except as otherwise provided in this section, all information collected pursuant to this
64 section shall be confidential. For purposes of this section, this information shall be referred to as
65 confidential information.

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

69 (k) Provided the security of confidentiality has been documented, the furnishing of
70 confidential information to West Virginia University or its authorized representative in accordance
71 with this section shall not expose any person, agency, or entity furnishing information to liability,
72 and shall not be considered a waiver of any privilege or a violation of a confidential relationship.

73 (l) West Virginia University shall maintain an accurate record of all persons who are given
74 access to confidential information. The record shall include the name of the person authorizing
75 access; name, title, address, and organizational affiliation of persons given access; dates of
76 access; and, the specific purpose for which information is to be used. The record of access shall
77 be open to public inspection during normal operating hours of the university.

78 (m) Notwithstanding any other law, the confidential information shall not be available for
79 subpoena, shall not be disclosed, discoverable, or compelled to be produced in any civil, criminal,
80 administrative, or other proceeding. The confidential information shall not be deemed admissible
81 as evidence in any civil, criminal, administrative, or other tribunal or court for any reason. This
82 subsection does not prohibit the publication by West Virginia University of reports and statistical
83 compilations that do not in any way identify individual cases or individual sources of information.
84 Notwithstanding the restrictions in this subsection, the individual to whom the information pertains
85 shall have access to his or her own information.

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

The Joint Committee on Enrolled Bills hereby certifies that the foregoing bill is correctly enrolled.

.....
Chairman, House Committee

.....
Chairman, Senate Committee

Originating in the House.

In effect from passage.

.....
Clerk of the House of Delegates

.....
Clerk of the Senate

.....
Speaker of the House of Delegates

.....
President of the Senate

The within this the.....
day of, 2022.

.....
Governor