

WEST VIRGINIA LEGISLATURE

2022 REGULAR SESSION

Committee Substitute

for

House Bill 4276

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

[Originating in the Committee on Health and Human
Resources; Reported on January 18, 2022]

1 A BILL to amend the Code of West Virginia, 1931, as amended, by adding thereto a new article,
2 designated §16-5DD-1, all relating to the collection of data relating to Parkinson’s Disease;
3 providing for definitions; providing a notice requirement; allowing for West Virginia
4 University to enter into agreements regarding this data collection; and allowing for the
5 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 shall 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 agreements
16 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 in writing and orally regarding the collection

19 of information and patient data on Parkinson's disease. Patients who do not wish to participate in
20 the collection of data for purposes of research in this registry shall affirmatively opt-out in writing
21 after an opportunity to review the documents and ask questions. A patient may not be forced to
22 participate 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;

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

27 (C) Generally, advise WVU.

28 (2) Membership of the committee may include:

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

30 (B) A movement disorder specialist;

31 (C) A primary care physician;

32 (D) A physician informaticist;

33 (E) Parkinson's patients;

34 (F) Public health staff;

35 (G) Population health researchers familiar with registries;

36 (H) Parkinson's disease researchers; and

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

38 (f) West Virginia University shall establish a system for the collection and dissemination of
39 information determining the incidence and prevalence of Parkinson's disease and related
40 Parkinsonisms, as advised by an Advisory Committee.

41 (g) Parkinson's disease and related Parkinsonisms shall be reported, but the mere
42 incidence of a patient with Parkinson's shall be the sole required information for this registry for
43 any patient who chooses not to participate. For the subset of patients who choose not to
44 participate, further data may not be reported to the registry.

45 (h) (1) West Virginia University may create, review and revise a list of data points required
46 as part of mandated Parkinson's disease reporting under this section. This list may include:

47 (A) Necessary triggering diagnostic conditions, consistent with the latest International
48 Statistical Classification of Diseases and Related Health Problems; and

49 (B) Resulting case data; including diagnosis, treatment and survival.

50 (2) West Virginia University may implement and administer this subsection through a
51 bulletin, or similar instruction, to health care providers.

52 (i) West Virginia University shall provide notification of the mandatory reporting of
53 Parkinson's disease and Parkinsonism on its website and shall also provide that information to
54 associations representing physicians and hospitals and directly to the boards regulating health
55 care professionals at least 180 days prior to requiring information be reported.

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

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

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

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

75 (l) Except as otherwise provided in this section, all information collected pursuant to this
76 section shall be confidential. For purposes of this section, this information shall be referred to as
77 confidential information. To ensure privacy, West Virginia University shall implement a coding
78 system that removes any identifying information about the patient.

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

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

86 (o) West Virginia University shall maintain an accurate record of all persons who are given
87 access to confidential information. The record shall include: The name of the person authorizing
88 access; name, title, address, and organizational affiliation of persons given access; dates of
89 access; and the specific purpose for which information is to be used. The record of access shall
90 be open to public inspection during normal operating hours of the university.

91 (p) Notwithstanding any other law, the confidential information shall not be available for
92 subpoena, shall not be disclosed, discoverable or compelled to be produced in any civil, criminal,
93 administrative or other proceeding. The confidential information shall not be deemed admissible
94 as evidence in any civil, criminal, administrative or other tribunal or court for any reason. This

95 subsection does not prohibit the publication by West Virginia University of reports and statistical
96 compilations that do not in any way identify individual cases or individual sources of information.
97 Notwithstanding the restrictions in this subsection, the individual to whom the information pertains
98 shall have access to his or her own information.

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

NOTE: The purpose of this bill is to permit West Virginia University to create a Parkinson's disease registry. The bill provides for certain definitions. The bill provides for a notice requirement. The bill allows for West Virginia University to enter into agreements regarding this data collection. Finally, the bill allows for the maintaining of certain records.

Strike-throughs indicate language that would be stricken from a heading or the present law, and underscoring indicates new language that would be added.