WEST VIRGINIA CODE: §16-5DD-1

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

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

(b) These terms are defined:

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

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

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

(d) All patients diagnosed with Parkinson's disease or related Parkinsonisms, as advised by an Advisory Committee, shall be provided a notice 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. A patient may not be forced to participate in this registry.

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

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

(B) Determine what data shall be collected; and

(C) Generally, advise WVU.

(2) Membership of the committee may include:

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

(B) A movement disorder specialist;

(C) A primary care physician;

(D) A physician informaticist;

(E) Parkinson's disease patients;

(F) Public health staff;

(G) Population health researchers familiar with registries;

(H) Parkinson's disease researchers; and

(I) Anyone else West Virginia University deems necessary.

(f) Parkinson's disease and related Parkinsonisms shall be reported, but 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, further data may not be reported to the registry.

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

(h) West Virginia University 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 West Virginia University that demonstrates to the university's satisfaction that the entity has established the procedures and ability to maintain the confidentiality of the information.

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(i) 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.

(j) 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.

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

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

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

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

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