WEST VIRGINIA CODE: §16B-11-7

§16B-11-7. Establishment of a central registry.

(a) To the extent funds are available, the Governing Board of the West Virginia University shall establish an Alzheimer's Disease Registry to collect information concerning Alzheimer's disease and related disorders. The purpose of the registry shall be to provide a central database of information to assist in the development of public policy and planning. The information collected by the registry shall be analyzed to prepare reports and perform studies as necessary when such data identifies information useful in developing policy.

(b) All reporting sources, including hospitals, physicians, facilities, clinics, or other similar units diagnosing or providing treatment or care for Alzheimer's disease and related disorders, shall provide a report of each case to the Alzheimer's Disease Registry in the format specified.

(c) All information reported pursuant to this section is confidential and shall be used only for the purposes set forth herein. A report provided to the Alzheimer's Disease Registry that discloses the identity of the individual being treated shall only be released in accordance with the provisions of the Health Insurance Portability and Accountability Act of 1996. No liability of any kind or character for damages or other relief shall arise or be enforced against any reporting source by reason of having provided the information or material to the Alzheimer's Disease Registry.

(d) The governing board shall propose rules pursuant to the provisions of §29A-3-1 *et seq*. of this code to implement this section. The rules shall include, but not be limited to: (1) The content and design of all forms and reports required by this section; (2) the type of information to be collected and maintained; (3) the procedures for disclosure of nonidentifying data to other appropriate research entities; (4)the manner in which reporting entities or individuals, including families, may be contacted by the registry for additional relevant information; and (5) any other matter necessary to the administration of this section.

WV Legislature