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HOUSE BILL NO. 2732

House Amendments in [] - January 25, 2007

A *BILL to amend and reenact § 51.5-11 of the Code of Virginia, relating to the brain and spinal cord injury registry.*

Patron Prior to Engrossment—Delegate Englin

Referred to Committee on Health, Welfare and Institutions

Be it enacted by the General Assembly of Virginia:

1. That § 51.5-11 of the Code of Virginia is amended and reenacted as follows:

§ 51.5-11. Central registry; information contained therein to be confidential.

A. The Department shall establish and maintain a central registry of persons who sustain spinal cord injury, *brain injury, or both*, other than through disease, ~~whether or not permanent disability results, and brain injury if permanent disability is likely to result,~~ in order to facilitate the provision of access to appropriate rehabilitation services by the Department and other state agencies to for such persons. The Department, in cooperation with organizations representing persons with disabilities maintained by the central registry, shall establish and pilot a mechanism which utilizes ~~utilize~~ the data maintained by the central registry pursuant to this section to provide client identification; follow-up and outreach; maintain accurate and up-to-date records concerning the client's functional level and need for services; and facilitate better analysis and utilization of ~~to analyze and utilize~~ such data for effective program, policy and fiscal planning purposes.

B. Every hospital and attending physician shall report to the [~~Department Registry~~] by the most expeditious means within ~~thirty~~ 30 days after identification of any person sustaining a brain or spinal cord injury and within seven days after identification of any person sustaining spinal cord injury. The report shall contain the name, age and residence of the person, date and cause of the injury, and such additional information as the Department may deem necessary.

C. Information contained in the registry concerning individuals shall not be subject to the Virginia Freedom of Information Act (§ 2.2-3700 et seq.) and shall be confidential *except* for purposes other than those directly connected with the administration of programs under the Department's jurisdiction or as required by other agencies of the Commonwealth. Information needed for research purposes may be made available to an organization or individual engaged in research only for purposes directly connected with the administration of programs relating to persons with disabilities *brain or spinal cord injuries*, including research for the development of new knowledge or techniques which would be useful in the administration of the program; however, the organization or individual must *investigator shall* furnish satisfactory assurance that the information will be used solely for the purpose for which it is provided, that it will not be released to persons not connected with the study under consideration, and that the final product of the research will not reveal any information that may serve to identify any person about whom information has been obtained through the Department without the written consent of the person, or his legally authorized parent or guardian, and the Department of compliance with Chapter 5.1 (§ 32.1-162.16 et seq.) of Title 32.1 and 45 C.F.R. 46.101 relating to conducting research involving human subjects.

ENGROSSED

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