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**SENATE BILL NO. 119** Offered January 11, 2006

Prefiled January 9, 2006

A BILL to amend and reenact §§ 32.1-292.2 and 32.1-297.1 of the Code of Virginia, relating to the Virginia Donor Registry.

Patrons—Howell, Cuccinelli and Ticer; Delegates: Amundson, Callahan, Moran, Plum, Rust, Scott, J.M., Sickles and Watts

## Referred to Committee on Education and Health

Whereas, in past years, the organ procurement organizations and eye banks of Virginia were required to contact the Virginia State Police to have the Department of Motor Vehicles (DMV) records checked for organ and tissue donor designations; however, in 2000, the General Assembly mandated the establishment of an organ and tissue donor registry by the Virginia Transplant Council; and

Whereas, requiring two years to develop, online services were, remarkably, initiated shortly thereafter in 2003, thus allowing Virginians to register online as organ and tissue donors; and

Whereas, with the budget crisis of 2003, the Virginia Transplant Council lost its funding and its staff while still retaining its statutory responsibilities for the maintenance of the donor registry; and

Whereas, the members of the Virginia Transplant Council have continued to share the costs of maintaining the organ and tissue donor registry; however, funds to maintain the valuable services of the organ and tissue donor registry will soon be depleted, leaving the registry dormant, its usefulness to deteriorate, and eventually causing its closure; and

Whereas, the donor registry has saved money by eliminating the need to contact the State Police for information held by the Department of Motor Vehicles, thereby freeing up law-enforcement officers for important public safety functions; and

Whereas, analysis of registry data proves that, since its initiation, the donor registry has saved lives by increasing donations and improving family acceptance of organ and tissue donation when the loved one has made an easily ascertainable and verifiable decision; now, therefore,

Be it enacted by the General Assembly of Virginia:

1. That §§ 32.1-292.2 and 32.1-297.1 of the Code of Virginia are amended and reenacted as follows:

§ 32.1-292.2. The Virginia Donor Registry.

A. In order to save lives by reducing the shortage of organs and tissues for transplantation and to implement cost savings for patients and various state agencies by eliminating needless bureaucracy, there is hereby established the Virginia Donor Registry (hereinafter referred to as "the Registry"), which shall be created, compiled, maintained, and modified as necessary by the Virginia Transplant Council in accordance with the regulations of the Board of Health and the administration of an Organ and Tissue Donor Registry for the Commonwealth to be administered by the Department of Health. The registry shall maintain, and update as needed, the pertinent Pertinent information on all Virginians who have indicated a willingness to donate organs and tissues in accordance with § 32.1-290 shall be compiled, maintained and modified as necessary in the Registry by the Virginia Transplant Council.

- B. The Registry and all information therein shall be confidential and subject to access only by personnel of the Department of Health and designated organ procurement organizations, eye banks, and tissue banks, operating in or serving Virginia and which that are members of the Virginia Transplant Council, for the purpose of identifying and determining the suitability of a potential donor according to the provisions of subdivision B 4 of § 32.1-127 or subsection F of § 46.2-342.
  - C. The purpose of the Registry shall include, but not be limited to:
- 1. Providing a means of recovering an anatomical gift for transplantation or research as authorized by § 32.1-295 and subsection F of § 46.2-342; and
- 2. Collecting data to develop and evaluate the effectiveness of educational initiatives promoting organ, eye, and tissue donation that are conducted or coordinated by the Virginia Transplant Council or its members.
- D. The Board, in consultation with the Virginia Transplant Council, shall promulgate regulations necessary to create, compile, maintain, modify as necessary, and administer the organ and tissue donor registry Virginia Donor Registry. The regulations shall include, but not be limited to:
- 1. Recording the data subject's full name, address, sex, birth date, age, driver's license number or unique identifying number, and other pertinent identifying personal information;
  - 2. Delegating authority to Authorizing the Virginia Transplant Council to analyze Registry data under

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research protocols directed toward determination and identification of means that are designed to identify and assess the effectiveness of mechanisms to promote and increase organ, eye, and tissue donation within the Commonwealth; and

- 3. Providing that any Virginian whose name has been placed in the registry may have his name deleted by filing an appropriate form with the Virginia Transplant Council or in accordance with subsections E and F of § 32.1-290 or subsection G of § 46.2-342.
  - § 32.1-297.1. The Virginia Transplant Council.
- A. For the purpose of advising the Board, conducting educational and informational activities and coordinating such activities as they relate to organ, tissue, and eye donation, procurement, and transplantation efforts in the Commonwealth, there is hereby established The Virginia Transplant Council (hereinafter referred to as the "Council"). The Council shall also is hereby established to fulfill the following duties:
- 1. To create, compile, maintain, and modify as necessary the Virginia Donor Registry established in § 32.1-292.2 in accordance with the regulations of the Board of Health and the administration of the Department of Health;
- 2. To conduct public education and information services relating to organ, tissue, and eye donation in the Commonwealth;
  - 3. To coordinate organ, tissue, and eye donation activities in the Commonwealth;
- 4. To provide a forum for discussion among its members of any issues of which it may be apprised that could impact the effectiveness of its activities and the relationship between the public and its members; and
- 5. To advise the Board and Department of Health concerning organ, tissue, and eye donation activities, procurement, and transplantation efforts in Virginia.

The Council shall be staffed by an executive director, who shall be a state employee for all purposes. The Council may shall establish such bylaws as may be necessary for its operation, consistent with state and federal law.

B. The membership of the Council shall consist of the following organizations, each of whom shall have one vote: the Bone Marrow Transplantation Program at Medical College of Virginia Hospitals, the Bone Marrow Program at Virginia Blood Services, the Bone Marrow Transplantation Program at the University of Virginia Medical Center, Carolina Organ Procurement Agency, INOVA Fairfax Hospital, Henrico Doctors' Hospital, LifeNet, Life Resources Regional Donor Center, Lion's Medical Eye Bank and Research Center of Eastern Virginia, Medical College of Virginia Hospitals, Mountain Regional Donor Services; Old Dominion Eye Bank Foundation, Inc., Roanoke Memorial Hospitals, Sentara Norfolk General Hospital, South-Eastern Organ Procurement Foundation, University of Virginia Health Sciences Center System, Virginia Hospital and Healthcare Association, Virginia's Organ Procurement Agency, Virginia Commonwealth University Health System, Washington Regional Transplant Consortium, and any successor organization thereof which remains directly involved in activities related to organ, tissue, or eye donation, procurement, or transplantation in Virginia, and one representative of donor families and one representative of transplant recipients. The Council shall elect, from among its membership, such officers as its bylaws require to serve for the terms established in such bylaws.

The Council shall also elect the representatives of donor families and transplant recipients who shall serve for terms established in the bylaws.

C. In order to provide flexibility and coordination and to prevent duplication of efforts, the Council may agree to extend nonvoting, associate membership on the Council to representatives of other organizations, agencies, or experts, public or private, who (i) are directly involved in or (ii) provide education or information on organ, tissue, or eye donation, procurement, or transplantation. Such membership shall (a) be extended to the Virginia Departments of Education, Health Professions, and Motor Vehicles, and the Virginia Hospital and Healthcare Association; and (b) shall include at least one representative of the faith community and one representative of local public schools; and (c) may be extended to other organizations, agencies, or experts as the Council deems appropriate.

D. In addition to the duties assigned in subsection A, the Council shall (i) advise inform the Board regarding the administration of the Council's activities; (ii) conduct and coordinate professional education and informational activities as they relate to organ, tissue, and eye donation, procurement, and transplantation efforts; and (iii) conduct its activities in consultation and, coordination, and cooperation with other organizations whose goals are related to organ, tissue, or eye donation, procurement, or transplantation including, but not limited to, the End Stage Renal Disease Network of the Virginias, the North American Transplant Coordinators' Organization, the National Kidney Foundation of Virginia, the American Liver Foundation, the United Network for Organ Sharing, the Virginia Heart Association, and successor organizations thereof. To achieve its purposes efficiently and effectively, the Council may conduct its activities in partnership with its member organizations or may contract for services with appropriate parties.

E. The State Board of Health shall be designated the budgetary administrator of the Council and

shall receive such funds as may be provided by the General Assembly in the appropriation act for the operation and administration of the Council. The Board, in consultation with the Commissioner, shall oversee the activities and programs of the Council and shall require the fiscal and substantive reports of the Council to be submitted on or before June 30 of each year.

F. To enable the Council to further its purposes, the Board may, on behalf of the Council, apply for, accept, and expend gifts, grants, or donations from public or private sources. There is hereby created in the state treasury a special nonreverting fund to be known as the Virginia Transplant Council Education Fund (the "Fund") which shall be administered by the Board, in consultation with the Commissioner. The Fund shall be established on the books of the Comptroller as a revolving fund and shall consist of such gifts, grants, or donations as may be received pursuant to this subsection and any moneys appropriated by the General Assembly to support the Council's education and information programs. Moneys remaining in the Fund at the end of each fiscal year shall not revert to the general fund but shall remain in the Fund. Interest earned on such funds shall remain in the Fund and be credited to it.

G. In addition to such other reports as may be required by the Commissioner or the Board, on or before September 30 of each year, the Council shall submit a report on its activities, programs, and funding in the previous fiscal year to the Board.