

**REPORT OF THE  
VIRGINIA DEPARTMENT OF HEALTH**

**VIRGINIA TRANSPLANT COUNCIL  
(VTC) STRATEGIC PLAN**

**TO THE GOVERNOR AND  
THE GENERAL ASSEMBLY OF VIRGINIA**



**SENATE DOCUMENT NO. 17**

**COMMONWEALTH OF VIRGINIA  
RICHMOND  
2000**





# COMMONWEALTH of VIRGINIA

*Department of Health*

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STATE HEALTH COMMISSIONER

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December 14, 1999

TO: The Honorable James S. Gilmore, III

and

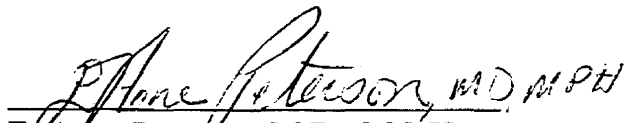
The General Assembly of Virginia

The report contained herein is pursuant to House Joint Resolution 173, agreed to by the 1999 General Assembly.

This report constitutes the response of the Virginia Transplant Council to develop a strategic plan for increasing public awareness of the importance of organ donation, and for evaluating progress toward obtaining a greater number of organ donations from potential donors in the Commonwealth.

The cost to the Virginia Department of Health to conduct this study was \$7,526.73. The study involved 78 staff hours of time. Cost cannot be estimated for the 20 Council members who served voluntarily in creating this report. These members are directors, specialized physicians, and/or CEOs of their individual organizations.

Respectfully Submitted,

  
E. Anne Peterson, M.D., M.P.H.  
State Health Commissioner

**SJR453: Virginia Transplant Council (VTC) Strategic Plan**  
**Executive Summary**

**Purpose:**

As required by Senate Joint Resolution 453 (1999), the Virginia Transplant Council (VTC) is to develop a strategic plan for increasing public awareness of the importance of organ donation, and for evaluating progress toward obtaining a greater number of organ donations from potential donors in the Commonwealth.

**Findings:**

The VTC affirms that citizens of Virginia were not fully aware of their opportunity to designate to be a donor; that accurate information regarding donation and transplantation needed to be provided to citizens for informed decision-making; a lack of inter-organizational trust existed within the VTC; that public opinion on donation seemed unclear and rules for guidelines for behavior were unknown; and that varying definitions of first-person consent negatively influence the procurement process.

**Action Plan:**

In an effort to amass the pending concerns as foreseen by the VTC, it has determined to create a Virginia Donor Registry that will provide easy access to donation intent recorded by DMV. This data would be accessible by the VTC to be used for recovery of organs and tissues and for information and education initiatives. The Joint Commission has offered this registry as a potential legislative option for the 2000 General Session.

VTC also will continue to target its education efforts toward youth to assist them in making an informed decision about donation. In concert with that specialized effort, the VTC will develop an effective internal and external public relations effort that promotes a "team" concept in the healthcare community, which will ultimately enhance the reputation of the VTC as an informational resource and center for donation and transplantation. VTC also will seek to establish a credible method of honoring the right of the donor through the consent process.

VTC hopes that through these united efforts the shortages of eyes, organs, and tissues will be reduced and/or eliminated, and that donation will be an expected behavior and part of the end-of-life decision-making process. With these initiatives in place, the VTC hopes that the Commonwealth of Virginia will position itself as a recognized leader in increasing organ, tissue and eye donation, resulting in increased access to quality transplantation services and shorter waiting times.

## **SJR453: Virginia Transplant Council (VTC) Strategic Plan**

### **I. Mission**

The Virginia Transplant Council exists to promote and coordinate educational and informational activities as related to the organ/tissue/eye donation process and transplantation in the Commonwealth of Virginia.

### **II. Legislative Mandate**

Senate Joint Resolution 453 (1999; see Appendix A) requests the Virginia Transplant Council (VTC) to develop a strategic plan for increasing public awareness of the importance of organ donation, and for evaluating progress towards obtaining a greater number of organ donations from potential donors in the Commonwealth. This plan is to be submitted to the State Board of Health and the Joint Commission on Health Care by October 1, 1999, and shall be submitted to the Governor and the 2000 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

### **III. Background of the Planning Process**

Representative members and non-voting members of the Virginia Transplant Council (VTC) met in June 1999 for a two-day planning session to develop a strategic plan to further increase organ donation in Virginia and to evaluate public awareness of organ donation. The components of the planning included:

- A. Review of the mission of the VTC.
- B. Review of the current operation of VTC.
- C. Identification of the vision of where VTC wants to be.
- D. Identification of the needs of the VTC to achieve its vision.
- E. Identification of strategic directions (high-level actions that move the VTC toward the vision).
- F. Development of a detailed action plan (specific actions for FY 1999-2000 and updated annually).

#### **IV. Current Operation**

In 1985 the Virginia General Assembly's Joint Subcommittee Studying Ways to Increase Participation in Organ Donor Programs recommended that the Virginia Transplant Council (VTC) be created to develop and conduct educational activities to improve understanding and acceptance of organ and tissue donation and transplantation in Virginia. The General Assembly established VTC effective July 1, 1986, under the *Code of Virginia* (§32.1-297.1). State funds were appropriated to help support VTC's endeavors.

VTC, a coalition comprised of 15 organizations and experts directly involved in organ and tissue recovery and transplantation, became an official program located in the Office of Family Health Services under the Virginia Department of Health (VDH) in July 1997.

Voting membership of VTC consists of the Virginia Hospital and Healthcare Association and the South-Eastern Organ Procurement Foundation, the Virginia Blood Services, and all organ procurement organizations (OPOs), eye banks, and transplant centers that serve in Virginia. Non-voting members include representatives from the Department of Motor Vehicles (DMV), the United Network for Organ Sharing (UNOS), the Department of Education (DOE), and the National Kidney Foundation of Virginia. VTC is supported by an Executive Director who organizes and staffs all meetings, develops the annual budget, monitors state legislation, and develops and directs statewide public relations activities and projects.

#### **V. Vision of the Virginia Transplant Council (VTC)**

- A. Organ and tissue donation will be a normative part of healthcare.
- B. All Virginians will have access to top quality transplantation services.
- C. VTC's health care industry and efforts will result in shorter waiting times for organ transplantation.
- D. The Commonwealth of Virginia will be a recognized leader in increasing organ, tissue, and eye donation.
- E. Effective statewide educational efforts will allow citizens to make informed decisions about donation.
- F. Through combined public and private resources for organ donation and transplantation lives will be saved and improved.

## VI. Assessment of Needs

### A. Difficulty in Donor Identification and Consent

In 1998 approximately 511 people received a transplant in the Commonwealth while more than 1,800 Virginians were still waiting to receive a transplant. That same year only 112 individuals were organ donors. The demand for organs far outweighs the supply (see table below).

<b>Virginia Transplant Council Donation and Transplantation Statistics</b>					
<b>Year</b>	<b># of Donors</b>	<b># of Organs Donated</b>	<b># of Persons Transplanted</b>	<b># on Waiting List</b>	<b># Died Waiting for Transplant</b>
<b>1998</b>	112	434	511	1,812	130
<b>1997</b>	121	462	458	1,451	111
<b>1996</b>	124	502	551	1,304	119
<b>1995</b>	94	382	450	1,173	86
<b>1994</b>	120	432	460	858	71
<b>1993</b>	110	399	433	651	81
<b>1992</b>	99	325	360	N/A*	N/A

\* (data not available)

Presently, citizens may designate to be a donor on their driver's license when they go to a Department of Motor Vehicles (DMV) Customer Service Center to either obtain or renew a Virginia license. While the population is most easily reached through contact with DMV, the driver's license/record is not advertised as being part of a recognized Virginia Donor Registry. Any change to the license results in a \$5.00 charge to the citizen, which does not allow for easy entry or exit in making a donor decision. The *Code of Virginia* does not permit DMV to release the name, address, or specific age of the citizen--only the gender and age group category in which the citizen is placed. These data are too vague to be utilized for educational purposes. Also, at the hospital setting and in the absence of a license, an organ procurement organization (OPO) must contact the State Police to access the driver's record to discover if the citizen was a donor. No other information, such as an address, may be obtained from the driver's record.

There is a need for a statewide donor center that provides a one-stop shop for donor registration and designation with easy entry and exit for citizens and easy access to donation intent by OPOs and eye banks. Such a center would allow for quicker, more streamlined donor identification, an increase in organ and tissue recovery, improvements in organ and tissue usage, and targeted education efforts by VTC.

There is a need to increase consent rates in Virginia. Definitions of consent continue to vary even to the point of negatively influencing the donation process. For example, the

*Code of Virginia* (§46.2-342) states that the donor designation (driver's license) shall be sufficient legal authority for the removal, following death, of the subject's organ or tissues without additional authority from the donor, or his family or estate. This provision cannot always be carried out by an OPO or eye bank because they also are federally mandated (21CFR1270.21) to conduct a medical history screening interview on the donor by either the next of kin or family physician prior to organ procurement or release of the organ(s) for transplant. Sometimes the next of kin will refuse to provide the history in an effort to thwart the donation process, thus, defying the wishes of the donor.

There is a need to establish a level of acceptance that organ and tissue donation is a normative part of healthcare and to establish a standardized method of legalized consent that satisfies both state and federal law.

## **B. Citizens Unaware of Opportunity to Donate**

While public support exists for donation, there are numerous disjointed educational efforts about the process within the public arena. Also, myths and misconceptions about donation and transplantation contribute to the populous being skeptical and perhaps fearful of donation. Many individuals are not convinced that transplantation works and leads to productive lifestyles for recipients. There is public confusion about the allocation system and goals of the transplant community.

There is a need to establish public faith in the donation and transplantation process and to provide accurate and easily accessible public information regarding donation and transplantation. Citizens of Virginia are not fully aware of their opportunity to designate to be an organ and tissue donor. Accurate information regarding donation and transplantation needs to be provided to youth, particularly those pursuing a driver's license, who would be asked at their local DMV if they desire to be an organ and tissue donor.

In 1988, the VTC introduced its first donor education curriculum entitled *Organ and Tissue Donation Curriculum Guide* to be voluntarily used in driver's education classes and eighth grade health classes throughout Virginia. This guide was updated in 1994, and again in 1998, to include an accompanying video and to be in compliance with Virginia's Standards of Learning. VTC is working with the Virginia Department of Education in the development and implementation of this new curriculum. This curriculum needs to be standardized for all students in driver's education classes.

## **C. Need to Improve Council Operations**

Since the VTC's inception in 1986, it has sustained a lack of inter-organizational trust. Some members have been unable or perhaps unwilling to commit to VTC tasks over their individual organization's agenda. Also, some individual members had conflicting agendas and messages with other members and VTC. When VTC officially joined the state in July 1997, some members grew fearful of the new role within a state agency,



resigning themselves to the fact that they would be unable to effect change in the transplant community. Sentiments also were voiced that VTC's efforts were relatively unknown in the transplant community and that its work impacted a small number of the population (mainly the transplant recipients). With such a limited budget (less than \$100,000 annually), VTC also worried that its difficulty to measure its educational endeavors may cause some to question its credibility as Virginia's educational source on donation and transplantation.

There is a need for VTC members to renew their commitment to the mission and to speak as one voice via collaboration and to use its diverse membership to improve its internal support base.

## **VII. Plans for FY 1999-2000**

### **Goal I: Improve Organ and Tissue Donor Identification and Consent in Virginia.**

#### **Objective A.**

**Establish a statewide Virginia Donor Registry that will offer easy access to donation intent to be used for educational and procurement purposes.**

#### **Strategies:**

1. Analyze current data in the Virginia DMV database by July 1999.
2. Review/compare other state and territorial registries and legislative initiatives and identify successful models which have resulted in increased donor designation by September 1999.
3. Appoint a Donor Registry Committee (including a DMV representative) by September 1999 to recommend a plan of action that will define the purpose and capabilities of a Virginia registry.
4. Monitor and comment on anticipated legislative language by the Joint Commission on Health Care regarding the implementation of a donor registry.
5. Begin the implementation process of the registry when resources are made available.

#### **Objective B.**

**Increase organ and tissue donation consent rates.**

#### **Strategies:**

1. Establish a Committee for "First-person Consent" by September 1999.

2. Conduct an opinion survey to members of the transplant community to determine current donation consent conditions by October 1999.
3. Plan a consensus conference based on survey results by December 1999.
4. Hold the consensus conference in January 2000.
5. Produce position statement on “First-person Consent” and plan for standard of care by June 2000.

**Goal II: Virginia Citizens Will Make Informed Decisions About Donation and Transplantation.**

**Objective A.**

**Implement a standardized statewide public education curriculum for Driver’s Education classes throughout Virginia working with DOE in preparation for school year 2000.**

**Strategies:**

1. Complete written draft of education curriculum for Virginia driver’s education classes by October 1999.
2. Finalize curriculum video by December 1999.
3. Test curriculum in a Fairfax County Driver’s Education class.
4. Finalize curriculum per test classes by June 2000.
5. Distribute completed curriculum with video by summer 2000.
6. Develop and disseminate questionnaire regarding curriculum usage and report outcomes.
7. Continue to update and market curriculum.

**Objective B.**

**Develop and implement a Public Relations Program.**

**Strategies:**

1. Establish a Public Relations Committee.
2. Develop and launch a VTC Website by December 1999.
3. Develop and conduct a survey to gauge citizen attitudes toward donation and transplantation and compile survey results by December 1999.
4. Place Coalition on Donation/VTC Public Service Announcements and info-releases in every media market of Virginia by January 2000.

**Goal III: Improve Council Operations.**

**Objective A.**

**Identify membership non-involvement and establish dialogue, identifying agendas and strategies to renew their participation within the Council by October 1999. Recruit more membership support from transplant centers and hospitals.**

**Objective B.**

**Pursue alternate funds.**

**Strategies:**

1. Seek funding through federal grants, if available.
2. Pursue funds through private sources.

**Objective C.**

**Hold VTC Conference in May 2000.**

**Strategies:**

1. Create planning committee.
2. Committee finalizes agenda and issues invitations, conducts conference, and evaluates results of conference, and use conference to seek input into VTC's FY 2000-2001 action plans.

**Objective D.**

**VTC establishes working committees: (1) Donor Registry, (2) Public Relations, (3) Annual Meeting, and (4) First-Person Consent.**

**VIII. Funding Needs**

- A. Funding estimate for initial start up cost for the Donor Registry including new hardware and software is \$500,000. Annual maintenance of the registry is \$200,000. (Figures are based upon the Legacy Organ and Tissue Donor Registry in Louisiana, which VTC would like to emulate).
- B. Production and distribution estimates for the driver's education donor curriculum are approximately \$15,000 from VTC budget.
- C. Cost for the implementation of a Public Relations Program survey (\$500) and Website annual maintenance (\$200 annually) from VTC budget.
- D. Increase donation consent rates: total cost estimate of survey, conference, and follow-up \$8,000 (VTC budget).

**APPENDIX A:  
COPY OF RESOLUTION**

**SENATE JOINT RESOLUTION NO. 453**

Offered January 21, 1999

*Requesting the Virginia Transplant Council to develop a strategic plan for increasing public awareness of the importance of organ donation, and for evaluating progress towards obtaining a greater number of organ donations from potential donors in the Commonwealth.*

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Patrons-- Gartlan, Bolling, Lambert, Martin, Schrock, Walker and Woods; Delegates: Baker, Brink, Davies, DeBoer, Diamonstein, Hamilton, Melvin and Morgan

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Referred to Committee on Rules

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WHEREAS, the Joint Commission on Health Care recently performed a review of organ donation issues in the Commonwealth; and

WHEREAS, organ transplantation is an increasingly common and successful medical procedure for improving the lives of individuals suffering from kidney, liver, heart, lung, and pancreatic failure; and

WHEREAS, Virginia is served by five organ procurement organizations (OPOs) and seven transplant centers; and

WHEREAS, the demand for human organs for transplantation far exceeds the available supply such that 1,451 individuals were on transplant waiting lists at Virginia transplant centers during 1997; and

WHEREAS, the number of deaths of individuals who were awaiting an organ transplant increased by 167 percent nationally from 1988 to 1996; and

WHEREAS, 111 individuals died in Virginia during 1997 while awaiting an organ transplant; and

WHEREAS, there were 121 organ donors in Virginia during 1997, representing 22 percent of the potential donors referred to OPOs; and

WHEREAS, the number of organs procured in Virginia during 1997 was 66 per one million population, a rate which was below the national average of 75 organs procured per one million population; and

WHEREAS, Virginia's 18 organ donors per one million population was likewise below the national average of 21 organ donors per one million population during 1997; and

WHEREAS, the Virginia Transplant Council (VTC) is located within the Virginia Department of Health and as such is accountable to the State Health Commissioner and to the State Board of Health; and

WHEREAS, the VTC has statutory responsibility for conducting educational and informational activities, and coordinating such activities as they relate to organ, tissue, and eye donation, procurement, and transplantation efforts within the Commonwealth; and

WHEREAS, the VTC would like to work even more closely than it has in the past with other State agencies, including DMV, in order to promote organ donation in the Commonwealth; and

WHEREAS, efficient and effective organ recovery and transplantation are vital components to the Commonwealth's overall health care delivery system, now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the Virginia Transplant Council be requested to develop, with the involvement of the Virginia Hospital and Healthcare Association, a strategic plan for (i) increasing public awareness of the importance of organ donation, including improved education and outreach functions, and (ii) evaluating progress towards increased public awareness of organ donation, and towards obtaining a greater number of organ donations from potential donors. The strategic plan shall include specific actions to be taken, a timetable for implementing the plan, proposed funding sources, and periodic updates as necessary; and, be it

RESOLVED FURTHER, That the Virginia Transplant Council's strategic plan be submitted to the State Board of Health and the Joint Commission on Health Care by October 1, 1999, and shall be submitted to the Governor and the 2000 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.



