Department of Legislative Services Maryland General Assembly

2015 Session

FISCAL AND POLICY NOTE

House Bill 118 (Delegate Morhaim) Health and Government Operations

Task Force to Study Presumed Consent Organ Donation in Maryland

This bill establishes the Task Force to Study Presumed Consent Organ Donation in Maryland. The task force must make recommendations regarding the establishment of a presumed consent organ donation system in the State and address how such a system would increase organ donation rates. Interim findings and recommendations to the Governor and the General Assembly are due by June 1, 2016, and final findings and recommendations are due June 1, 2017. The Department of Health and Mental Hygiene (DHMH) must provide staff for the task force.

The bill takes effect June 1, 2015, and terminates July 31, 2017.

Fiscal Summary

State Effect: Minimal increase in general fund expenditures for DHMH in FY 2016 and 2017 only for administrative expenses associated with the task force. Staffing can be provided using existing budgeted resources. Revenues are not affected.

Local Effect: None.

Small Business Effect: None.

Analysis

Bill Summary: The task force includes members of the General Assembly, the Secretary of Health and Mental Hygiene (or the Secretary's designee), and various stakeholders, including the Motor Vehicle Administration (MVA) and Donate Life Maryland (DLMD).

A member of the task force may not receive compensation but is entitled to reimbursement for standard travel expenses as provided in the State budget.

The task force must study (1) the impact of establishing a system of presumed consent organ donation in the State on organ donation rates; (2) comparisons of organ donation rates in countries before and after the introduction of a presumed consent law and comparisons of organ donation rates in countries with and without presumed consent laws; (3) available data on the attitudes of the public, professionals, and other stakeholders regarding presumed consent organ donation; (4) the feasibility of establishing a system of presumed consent organ donation; (6) the medical, legal, ethical, economic, and social issues relating to presumed consent organ donation; and (7) how new health technology could support a presumed consent organ donation system.

Current Law: Individuals in Maryland choose to designate themselves as donors – generally either by registering directly on the Maryland donor registry (at <u>www.donatelifemaryland.org</u>) or having a designation (a heart symbol) added to their driver's license or identification card in a transaction with MVA. The designation is sufficient legal authority for the removal of a body organ or part on the death of the donor.

DLMD maintains and operates the *registry* for the State, in which individuals commit to becoming an organ, eye, and/or tissue donor securely online. The registry ensures every effort will be made to honor donors' wishes when they die, and DLMD is available to take calls 24 hours a day, 7 days a week. DLMD has an information-sharing program with MVA so all donor designation records can be stored in a central and secure place. All registrants, including those who register themselves online, have a unique identifier in the registry (their driver's license or identification number) and may change their status as a donor – even obtaining a corrected driver's license or identification card without payment of a fee (if only obtained for that purpose). More than 2.6 million Marylanders have designated themselves as donors.

The Maryland Revised Uniform Anatomical Gift Act (Title 4, Subtitle 5 of the Estates and Trusts Article) governs donations of all or part of a human body (that take effect after the donor's death) for the purpose of transplantation, therapy, research, training, or education. Among other things, the Act specifies:

• who may make an anatomical gift during the life of a donor (taking effect after the donor's death) and how a donor may make a gift, including by a "document of gift," defined as a donor card or other record such as a statement or symbol on a driver's license, identification card, or donor registry;

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- the classifications of individuals, in order of priority, who may make an anatomical gift of a donor's body or part after the donor's death;
- how an anatomical gift may be revoked or amended and how an individual may indicate a refusal to make an anatomical gift of the individual's body or part;
- the relation between, and priorities of, actions taken by the donor and other authorized persons, with respect to making, amending, revoking, or refusing an anatomical gift; and
- the resolution of conflicts between an advance directive and an anatomical gift.

The persons eligible to make an anatomical gift during the life of the donor include an adult donor; a minor who is emancipated or eligible to apply for a driver's license; an agent of a donor (unless prohibited by a power of attorney for health care or other record); a parent of a donor, if the donor is an unemancipated minor; or a guardian of a donor. Directions given by a person authorized to make, amend, revoke, or refuse to make an anatomical gift of a decedent's body or part must be recorded in the decedent's medical record.

Background: Presumed consent, also known as an opt-out system, means that unless the deceased has expressed a wish in life *not* to be an organ donor, then consent is assumed. Presumed consent systems can be divided into what is known as a "hard opt-out" where the family is not consulted or a "soft opt-out" when the family's wishes are considered in the same manner as with an opt-in system. Residents would likely have to expressly opt out of organ donation, for example, when they applied for a driver's license or State identification card, as opposed to the current system, in which they can volunteer to opt in. No state currently operates a presumed consent system; however, many countries do, particularly those in Europe.

The organ donor *procurement program* is managed by the Living Legacy Foundation of Maryland (LLF), which coordinates with all hospitals in the State for the procurement of organs. In accordance with State and federal regulations, hospitals in Maryland must contact LLF when a patient dies or death is imminent. LLF reviews the potential donor's medical status and assesses his or her potential suitability as a donor; as appropriate, a family services coordinator discusses donation options with the family. The process encompasses determining whether the patient had made an autonomous decision to designate his or her wish to be a donor through a document of gift (a designation on the driver's license, inclusion in the donor registry, an advance directive, or a living will). If so, the family is provided a disclosure form, outlining the steps in the process. If the patient was not designated as a donor, the coordinator reviews the organs and tissues

which the patient *could* donate and, if authorization is given, completes an authorization form with the legal next of kin. Regardless, a thorough physical exam must be conducted and a medical/social history obtained to ensure the safety and suitability of the organs and tissues being considered for donation.

If organ donation is authorized, LLF works collaboratively with the hospital staff to manage the critical care medical and nursing needs of the donor, while conducting further evaluation and testing to determine which organs are suitable for transplant. (A donor family does not incur any financial costs related to the evaluation and recovery of organs and tissues.) The medical information about the organ donor is sent to the United Network for Organ Sharing (UNOS), which operates a centralized computer system to match the donor's characteristics to those of waiting recipients. UNOS allocates organs based on algorithms (which factor in blood type, severity of illness, time waiting, and distance between the donor hospital and potential recipient), but tissues are allocated based on medical need.

Although the rates of organ donor designation have increased in the United States, the need for transplants continues to outpace available organs. According to the U.S. Department of Health and Human Services (HHS), more than 120 million people in the United States have signed up to be an organ donor and an average of 79 people receive an organ transplant each day. However, HHS reports that 18 people die each day while on the waiting list for an organ and that, as of January 27, 2014, 123,251 Americans are waiting for an organ, 3,551 of whom are on the waiting list in Maryland.

According to the 2014 National Donor Designation Report Card from the organization Donate Life America, Maryland ranked twenty-eighth among states with a 54% donor designation share, which is the number of designated donors as a percentage of all state residents age 18 or older.

State Expenditures: DHMH indicates that one part-time (50%) contractual program administrator I is needed to staff the task force (at an annualized cost of \$27,008) at the Vital Statistics Administration. The Department of Legislative Services disagrees and notes that staffing can likely be handled within existing budgeted resources. General fund expenditures for DHMH increase by a minimal amount for administrative expenses associated with the task force, including reimbursement for task force members.

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Department of Health and Mental Hygiene, Maryland Department of Transportation, Donate Life Maryland, Living Legacy Foundation, U.S. Department of Health and Human Services, Department of Legislative Services

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