
**Report to
The Vermont Legislature**

**Report of the Organ and Tissue Donation
Working Group**

**In Accordance with Act 132 (2012 Adj.), Section 5(e)
*An Act Relating to Organ and Tissue Donation and
Medicaid for Working Persons with Disabilities***

Submitted to: Senate Committee on Health and Welfare
Senate Committee on Transportation
House Committee on Health Care
House Committee on Human Services
House Committee on Transportation

Submitted by: Organ and Tissue Donation Working Group

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Report of the Organ and Tissue Donation Working Group

Introduction

This report is submitted to the House Committees on Human Services, on Health care, and on Transportation and to the Senate Committees on Health and Welfare and on Transportation and to the Governor, as required by Act 132 (2012 Adj.) Section 5(e).

Working Group Charge

The Organ and Tissue Donation Working Group was created by Act 132 (2012 Adj.) to make recommendations to the general assembly and the governor relating to organ and tissue donations by January 15, 2013, after which time the working group ceases to exist. The Working Group was asked to develop recommendations regarding:

1. coordination of the efforts of all public and private entities within the state that are involved with the donation and transplantation of human organs and tissues;
2. the creation of a comprehensive statewide program for organ and tissue donations and transplants;
3. the establishment of goals and strategies for increasing donation rates in Vermont of deceased and, where appropriate, live organs and tissues; and
4. a recommendation about whether the department of health should establish an ongoing advisory council on organ and tissue donation.

Working Group Members

The Working Group was convened and chaired by the Commissioner of Health. As provided in Act 132, the members included the Commissioner of Motor Vehicles and representatives of the Vermont Medical Society, the New England Organ Bank, the Center for Donation & Transplant, Fletcher Allen Health Care, Transplant Donor Network, Vermont Kidney Association and an organ recipient.

Working Group Recommendations

The Working Group met on July 25, September 18, October 24 and December 14, 2012. The meeting summaries and other information relating to the Group's work is posted on the Health Department website at:

http://healthvermont.gov/vadr/otd/act132_work_group.aspx

1. Coordination of Efforts of Public and Private Entities

The Working Group reviewed the numerous efforts of public and private entities within the state that are involved with the donation and transplantation of human organs and tissues and recommends the following priority activities to coordinate those efforts:

- April is Donate Life month. The Working Group recommends that public and private entities work together to coordinate promotional activities during April including:
 - Public service announcements
 - Public promotion of the new Department of Motor Vehicles license registration system that will allow organ donation consent to be given through the regular driver's license process (in the same way it is currently available through the enhanced driver's license process.)
 - State officials could have a ceremony to honor organ donors and their families
- DMV will publish information about organ donation in its driver's education manual. DMV will continue to offer information about organ donation at its offices and may be able to include a video on its screen in the offices that would alternate with other messages
- The workgroup, with leadership from NEOB, will provide training on organ donation to driver's education class instructors and schools for inclusion in their training..
- The Health Department will indicate the State's support of organ donation by publishing its logo on the Donate Life website and by expanding information about organ donation on its website.
- The Donate Life website is a known resource for information about deceased organ donation. Working Group members are exploring adding appropriate information on that site about live organ donation. It is important to keep communications clear between deceased and live organ donation to differentiate the processes and to direct those interested to the appropriate source for information. The National Kidney Foundation does provide information on its website about both deceased and live donation.
- Increasing use of social media by all entities promoting organ donation to reach as wide an audience as possible.

In addition, the Working Group recommends additional efforts be explored, including:

- Possible legislative proposals to:
 - Require employers to provide sick leave for 1-2 weeks for live donors.
 - Provide a voluntary contribution through the tax form to support live donor's expenses.
 - Providing health insurance for live donors who do not have insurance.

- Explore opportunities to add information about organ donation to other state forms, for example, state income tax forms, to provide information about and promote organ and tissue donation.
- Encouraging primary care providers to include information/discussion about organ donation as part of annual exams, coordinated with an “Ask your doctor” campaign.
- Expanding opportunities to reach people by coordinating promotional efforts at polling stations, county fairs and other public and school events.
- State agency staff to be the contact point to coordinate public and private entities’ promotional efforts to assure maximum outreach, consistency of message and minimal duplication of efforts.

2) Creation of a comprehensive statewide program for registering organ and tissue donations and transplants.

This will be accomplished with the launch of the upgraded new DMV system to register organ donors through the regular driver’s license process. Organ donation is currently registered through the enhanced driver’s license process. The information registered through the DMV is uploaded to the Statline, the donor registry system used by all the New England states. The launch of the new DMV system will be a focal point of the promotional activities planned for April, 2013 as described above. Alternatively, individuals can register through the Donate Life website and have their information entered into the same Statline database.

3) Establishing goals and strategies for increasing donation rates for both deceased and live donation.

There is a great deal of data available to the organ procurement organizations and to Fletcher Allen Health Care that could be used to assess where we are now, document progress and determine if the activities to promote organ donation registration have been successful in increasing rates. The data could be used to create a dashboard with reasonable metrics that shows the goal and progress to date. At this time, the national score card shows Vermont with the lowest organ donor registration rates of all states. With the launch of the new DMV system, however, it is expected that Vermont’s numbers will increase rapidly. Once the metrics are agreed upon, then the appropriate way to make the information available should be determined and may include making the information available on the Donate Life website or possibly a dashboard on the Health Department website or through another resource. It is important that if this information is published, that it be useful and not be redundant to information already available.

4) Whether the Health Department should establish an ongoing advisory council on organ and tissue donation (including recommendations for how it might be resourced).

The Working Group discussed keeping a permanent advisory council under the Health Commissioner. Those participating in this group are doing so without additional compensation. Depending on the responsibilities of the Council, additional resources may be required. Periodic meetings, such as those this fall, would have little additional costs. If, however, staff support for meetings and for coordinating efforts of public and private entities' promotional events, dashboard, websites, data analysis, or some of the other activities recommended above are implemented, then additional resources would be needed to support that work.

Conclusion

Improving the rates of organ donor registration and providing information and supporting live organ donation in Vermont are critical to improving the lives of Vermonters and others waiting for an organ. The launch of the new DMV system is anticipated to provide a substantial boost in rates for deceased organ donation through the driver's license registration process. The Working Group recommends a number of events and coordinated promotional activities to communicate that this resource is now available and to encourage organ donor registration. At the same time, coordinated messaging may allow the same events and promotional activities to also provide important information about live organ donation.

On a national, regional and state level, data relating to organ donation is readily available. Setting metrics and analyzing available data will allow Vermont to assess efforts to improve organ donation rates in the state.

Finally, the Working Group recommends that an Advisory Council on Organ and Tissue Donation be authorized for a period of 18 months (until July 1, 2014.) The Advisory Council would coordinate the annual April promotional activities and further evaluate the extent of state support needed for this work. If additional work is recommended, then the Advisory Council would issue a report by January 15, 2014 to identify that work and recommend resources to support that work.