
**Report to
The Vermont Legislature**

Organ and Tissue Donation Workgroup Report

In Accordance with Act 32, 2013, Sections 3 and 4
An Act Relating to Anatomical Gifts

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

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Organ and Tissue Donation Workgroup Report

Act 32, 2013, Sections 3 and 4

January 15, 2014

Executive Summary

This report discusses the work and findings of the Organ and Tissue Donation Workgroup, a group authorized in 2013 by Act 32, Sections 3 and 4. During 2013, the Workgroup continued the work of a previous workgroup to increase organ and tissue donation in Vermont.

In January 2013, the Vermont Department of Motor Vehicles (DMV) implemented a new driver's license photo system which, by design, requires applicants to indicate whether, or not, they wish to be entered into the donor registry when they come to a DMV office to renew their license and be photographed. The implementation of this new system was a turning point for registering Vermonters as organ and tissue donors. When this DMV system went live in January 2013, there were 23,110 individuals registered in the Vermont Donor Registry. A year later, that number has increased to 92,182 registered donors in Vermont with 92.3% (85,087) of those registries being identified at the DMV. The Workgroup has acknowledged the hard work and commitment of DMV leadership and staff in registering organ donors.

The Workgroup also studied live kidney donation in Vermont, identifying any potential disincentives for people to become live kidney donors. The group sought information from insurance regulators at the Vermont Department of Financial Regulation, and looked at public policies in other states that offer incentives for kidney donation.

The report concludes with a list of Workgroup plans and further research for 2014. A final report of the Workgroup's findings and recommendations will be written in January, 2015.

Organ and Tissue Donation Workgroup Report

Act 32, 2013, Sections 3 and 4

January 15, 2014

Introduction

In 2013, the Vermont General Assembly passed Act 32, *An Act Relating to Anatomical Gifts*. Among other provisions of this law is the creation of an Organ and Tissue Donation Working Group (Workgroup), chaired by the Commissioner of Health. Sections 3 and 4 of the Act specify the issues to be studied by the group, all of which relate to increasing organ and tissue donation. The Commissioner is charged with reporting on the activities of the Workgroup with an initial status report in January, 2014 and a final report in January, 2015. This report summarizes the activities and accomplishments of the Workgroup in 2013, describes plans for work during 2014 and provides a status report on the development of recommendations for the Governor and the General Assembly.

Background

In 2012, the Legislature passed Act 132, *An Act Relating to Organ and Tissue Donation and Medicaid for Working Persons with Disabilities*. This act created the initial Organ and Tissue Donation Workgroup, chaired by the Commissioner of Health. The Workgroup met three times in 2012 to consider strategies for increasing organ and tissue donation in Vermont, and, as required by Act 132, submitted a report to the legislature in January, 2013. One of the key recommendations of this report was to reauthorize the Workgroup to meet through 2014 in order to advance its work and mission.¹ In 2013, the Legislature followed this recommendation in Act 32. With the exception of organizational representative turnover and the appointment of one new member, the members of the Workgroup formed in 2012 comprise the current Workgroup. The original Workgroup focused on increasing donor designation registrations for deceased donor organs and tissues. The Workgroup reconstituted by Act 32, however, was specifically charged with broadening its focus to study ways for Vermont to increase live organ donations, particularly kidneys.

¹ Vermont Department of Health Website,
<http://www.leg.state.vt.us/reports/2013ExternalReports/285139.pdf>

Different systems and processes exist for a person registering as a future donor of organs or tissue in the event of their death, and a person who is interested in donating a live kidney. The following status report on the Workgroup's work during 2013 includes a discussion of the systems and processes for both deceased donation and living donation.

Increasing Registered Organ and Tissue Donors in Vermont

Historically, Vermonters could indicate their willingness to donate organs and tissues in the event of their death by signing the back of their driver's license or signing a donor card. More recently, and to take advantage of changes in technology, the federally-designated Organ Procurement Organizations (OPOs) serving the state made it possible for Vermonters to register as donors online at www.DonateLifeNewEngland.org and www.DonateLifeVermont. Signing up online made it possible for the OPOs to query the registration database (the New England Donor Registry) to determine a deceased person's donor designation status.

In spite of the ability to register online, information from other states has demonstrated that the vast majority of individuals who want to register as donors want to do so quickly and easily through the DMV driver's license process. The information on the back of Vermont driver's licenses was not entered into a computerized donor registry so it was not actionable in real time in the event of their death. As a result, many individuals who believed themselves to be donors were not able to be. When a prospective donor's name is entered into the registry, this information can be retrieved in the event of their death. It is routine for a hospital to refer the name of a deceased individual to the OPO which can check the donor registry database to determine if the deceased individual is a registered donor.

The DMV, aware of this situation and committed to improving Vermont's donation system, has had plans to incorporate registration of donation designation status into its electronic license renewal information technology system for several years. Because of challenges in implementing a new enterprise IT system, DMV was not able to register donors until January of 2013. In January 2013, DMV implemented a new drivers' license photo system which, by design, requires applicants to indicate whether, or not, they wish to be entered into the donor registry when they come to a DMV office to renew their license and be photographed. The implementation of this new system was a turning point for registering Vermonters as organ and tissue donors in the event of their deaths.

When the DMV license photo and donor registration system went live in January 2013, there were 23,110 individuals registered in the Vermont Donor Registry. A year later that number has increased to 92,182 registered donors in Vermont with 92.3% (85,087) of those registries being identified at the DMV.

The commitment and willingness of DMV to identify and register prospective donors in 2013 has been outstanding. DMV field office staff has responded positively to the two Organ Procurement Organizations' (New England Organ Bank and Center for Donation and Transplant) training about the importance of donation, and many have embraced the unique opportunity to educate license applicants about the importance of donation. While balancing other job demands, DMV staff have presented the option of donor registration to license applicants without being coercive. The increased numbers of donors attest to this organizational commitment.

In spite of this, Vermont has not yet reached the national goal of 50% of license applicants choosing to register as donors. Organ Procurement Organizations (OPO) uses a metric called Donor Resignation Rates, or DDR, to measure the population rate of opting to register as a donor. The goal for which OPOs strive is that 50% of people approached about registering choose to do so. During 2013, the first year Vermont has had a DMV-linked donor registry, fewer than 50% of those asked if they would like to register did so. The average DDR from January through October 2013 was 34.3%, although June, July, September and October showed a DDR of between 43% and 44%. Whether Vermonters will increase the rate at which they register as donors remains unknown. Continued efforts by the OPOs and other promotional efforts will need to work towards achieving the goal of 50% DDR rate for Vermont.

Another indication of the DMV's commitment to increase registered donors in 2013 was the inclusion of a Donate Life page on the inside front page of the Vermont Driver's Manual. This promotion, targeted toward new licensees, takes advantage of a captive and motivated audience to emphasize the importance of registering as an organ donor. DMV will continue to include this information in a prominent place of each year's manual.

Promoting Live Organ Donation

Act 32 specifically charged the Workgroup with focusing on increasing live organ donation. Because the vast majority of live organs transplanted at Fletcher Allen Health Care are kidneys, the Workgroup's focus during 2013, was live kidney donation and transplant. The system for donating a live kidney is different from registering to be a future deceased organ donor. Individuals interested in becoming live kidney donors express their interest through a transplant center such as FAHC.

The gap between those who are willing to donate a kidney and those who need a kidney is widening. Vermont's tertiary care hospital Fletcher Allen Health Care (FAHC) performed 6 live kidney transplants in 2013, and in previous years has transplanted between 5 and 16 kidneys per year. FAHC is part of the Albany-based Center for Donation and Transplant (CDT), which serves a region including western Vermont, but also provides transplant services to people with End Stage Renal Disease (ESRD) from upstate NY and western MA. Currently, there are 127 individuals on FAHC's waiting list for a kidney donation. The majority of them are Vermonters and are on dialysis while waiting for a kidney. Dialysis costs about \$100,000 per year per individual, while a kidney transplant has a one-time cost of \$125,000.

Living kidney donations can be achieved in a number of ways. One way is for family and friends of an individual with ESRD to offer a kidney for transplant directly to a named person they know. If it is determined that the prospective donor's kidney is a match for the individual in need, the donor proceeds through a series of rigorous health screenings and interviews to determine if they are healthy enough to donate and fully aware of any psychological or financial consequences of doing so. However, sometimes a willing donor's (Donor A) is healthy enough to donate a kidney but their kidney is not a suitable match for their intended recipient, (Recipient A). There are now systems to match the willing Donor A with a Recipient B, who is a better match, in return for Recipient A receiving a kidney from the Donor B that Recipient B brought to the pairing. This is known as a paired exchange donation. Periodically, someone indicates a willingness to donate a kidney as an altruistic gesture. Assuming they pass the screenings, this donation can set in motion a chain of donations benefiting a number of people. The donation of a kidney to anyone in need, a so-called altruistic donation, can be assigned to a single compatible individual, or launch a chain, benefitting many recipients and optimizing donor-recipient matches. A February 18, 2012 New York Times article profiled a 60 person chain of 30 kidney donations that all started with one altruistic donor.²

² <http://www.nytimes.com/2012/02/19/health/lives-forever-linked-through-kidney-transplant-chain-124.html?pagewanted=all& r=0>

Disincentives for Becoming a Living Kidney Donor

Because the demand for kidneys exceeds the supply, strategies and policies that both promote donation and remove disincentives for donation are needed. In an effort to understand if there are any insurance or regulatory barriers for people to become live organ donors, the Workgroup met with two representatives of the Vermont Department of Financial Regulation (DFR). Because the vast amount of insurance regulation occurs at the state level, the group sought to understand what, if any, insurance barriers exist that would be a disincentive for individuals to offer a kidney for donation. The following summarizes the information presented by the group.

Health Insurance - In its individual and small group insurance market, Vermont has had a policy of Guaranteed Issue of health insurance for many years. So, Vermonters cannot be denied health insurance based on health status. Similarly, Vermont has had a policy of Community Rating for health insurance, a policy that prohibits “rating” (assigning a higher premium) of people with preexisting conditions. Because this is not the case for most states, the Affordable Care Act included a provision that would prohibit health insurance providers from denying coverage to, or rating, people with preexisting conditions. This will remove an impediment to health insurance for many people, and ensures that people who have donated live organs cannot be denied coverage or issued higher rates because of the donation. This law does not apply to those self-insured plans protected by ERISA, such as those benefit plans of large organizations such as UVM or multi-state organizations such as IBM and GE.

Vermont insurance regulations also require that any policy providing coverage for the recipient in a transplant operation shall also provide reimbursement of any medical expenses of a live donor to the extent that benefits remain and are available under the recipient's policy, after benefits for the recipient's own expenses have been paid. (See DFR Regulation 80-1 Sec. 7(A)(9)).

Life Insurance - People who donate live organs have been screened and medically scrutinized before they can be accepted as live organ donors, so their health status is much better than the general population. This does not necessarily mean that insurance companies cannot rate or deny them, but most of the companies consulted acknowledged that the excellent health status of donors enabled them to have coverage at a rate commensurate with other insured people. There are currently no legal barriers in Vermont that prohibit a life insurance provider from denying or rating an individual who has, for example, one functioning kidney as a result of organ donation. One Workgroup member explained that because a

normal clinical sequela of having only one kidney is an increased serum creatinine level, he has heard of cases where individuals were denied or rated for life insurance because of this. David Martini, the DFR representative, acknowledged that there are currently no regulations that would prevent an individual life insurance company from doing this.

Disability Insurance - Disability insurance is typically provided through employers, but any exclusion or rating of organ donors tends to be rare. This is most likely because donors tend to have excellent health status as a result of having been screened for donation. No Vermont regulations would prohibit an insurance company from considering previous donation as a rationale for denying or rating an applicant however.

The Committee discussed this information and, in doing so, concluded that because many life insurance companies consider previous organ donation to be an indication of excellent health, most do not use this to justify denial of coverage in Vermont. The numbers of willing and eligible donors who would be affected by denied insurance is likely to be small. Nevertheless, the Legislature could prohibit life and disability insurance companies from denying coverage to or rating individuals who have donated a kidney.

There are other economic disincentives associated with live organ donation. Although the medical work up and organ resection surgery are typically covered by the kidney recipient's insurance, there are other costs associated with donation. These include lost wages, travel expenses, childcare, and follow-up health status monitoring.

The pain and inconvenience of becoming a living donor can also be a disincentive. However, most of these surgeries are now, done laparoscopically and the surgery poses less risk than childbirth. There can be considerable discomfort during recovery. And living donors are usually out of work for a month following surgery. No options for removing this disincentive currently exist.

Incentives to Encourage Live Organ Donation

Many states have created incentives for live organ donation in the form of state tax deductions, donor leave laws and other assistance. The National Kidney Foundation offers a list of the laws and donor incentives that currently exist in all states.³

Donor Leave Laws- Because kidney donors must typically be out of work for a month, lost wages are a significant issue for anyone considering donation. The federal government offers 30 paid days to its employees who donate a kidney. Many states have followed suit by offering state employees a similar incentive. Vermont, for example, has a side agreement to its collective bargaining agreement that offers state employees 30 paid days. This benefit was created as a result of advocacy by a state employee who donated a kidney to another state employee. State policies vary in terms of which segment of the workforce is eligible for this incentive.

State Tax Deductions or Credits- Many states offer tax deductions, and occasionally credits, as an incentive for living donors or to cover unreimbursed expenses associated with donation. There is a wide range of these incentives, which are applied to state income taxes, and some states offer tax credits to employers who elect to pay the wages of an employee who donates an organ. Arkansas provides donors a tax deduction and offers employers a tax credit if they pay for donation-related leave.

Although these are examples of state policy initiatives to create incentives for donation, the Workgroup is not yet aware of the effectiveness these initiatives have had on increasing donation. More research will be necessary to determine which incentives have been most effective in increasing donation.

³ https://www.kidney.org/transplantation/livingdonors/pdf/LDTaxDed_Leave.pdf

Conclusion and Workgroup Agenda for 2014

There is more research and discussion for the Workgroup to accomplish during 2014 as it continues to examine strategies for increasing both deceased registered and live organ donation. As in 2013, a Governor's Proclamation of April as Donate Life Month will be scheduled at Governor Shumlin's ceremonial office in the Statehouse. Data on donor registrations will continue to be monitored and analyzed. In addition, the following work and research will be the agenda for the Workgroup during 2014.

1. **Analyze Donor Registration Data** Work with DMV to analyze demographic data on donors who register through the DMV to determine if there are any differences between those who register to donate and those who do not. An understanding of any demographic differences may lead to more effective and targeted promotion strategies.
2. **Research Effectiveness of State Incentives for Living Donation** Continue to research other states' experiences with implementing incentives for live organ donation to determine the effectiveness of these policies. A better understanding of documented outcomes will direct Vermont policy makers in considering future initiatives in Vermont.
3. **Include Donate Life Vermont link on VDH Webpage** The Vermont Department of Health will include a link to the Donate Life website on its new website.
4. **Individual Workgroup members will:**
 - a. Research the feasibility of including information about organ donation in mailed drivers' license applications to educate Vermonters about its importance and increase the likelihood of their registering as donors.
 - b. Create a link on the Donate Life website to a landing page with information about live kidney donation.
 - c. Organize a 2014 Governor's Proclamation of April as Donate Life Month

5. **Continue the Promotion of Organ and Tissue Donation** Consider other methods for:
 - a. Educating Vermonters about the continuing need for organ and tissue donation
 - b. Promoting donor registrations and
 - c. Increasing live kidney donation.
6. **Final Report** A final report to the Governor and Legislature, as required by Act 32, will be written and will include recommendations about continued work needed to increase organ donation.