



Organ and Tissue Donation Workgroup
September 25, 2013 Meeting Notes
108 Cherry Street Burlington, VT

Participants: Kate Devine and Jennifer DeMaroney, FAHC; Matthew Boger, NEOB; Jim Carter, TDN; Steven Kind and Michael Thibault, CDT; Jeff Knight, Funeral Homes; Mike Scollins; Commissioner Harry Chen and Dawn Philibert, VDH; Mike Smith, DMV (by phone).

Welcome and Review of Charge

Dr. Chen opened the meeting by welcoming former and new members. Introductions were made and Dr. Chen acknowledged that two positions on the workgroup are appointed by the Governor: Jeff Knight of White River Junction, representing funeral homes, and Jim Carter, representing a family of a deceased person whose organs were donated. Dr. Chen reviewed the charge of the group as stated in Act 32 (2013), emphasizing the focus on live donations

Update on Past Actions and Accomplishments

Dawn reviewed the key work of the preceding workgroup highlighting the following:

- Governor’s Proclamation of April as Donate Life Month; Ceremony in his Statehouse Office
- April event at South Burlington DMV office to celebrate Donate Life month and thank staff for the information they provide to potential donors
- Focus on increasing organ donors by DMV implementing new electronic system which requires license applicants to respond “yes or no” to a question about organ donation

Other activities and updates were discussed by the group, including:

- Jim Carter reported that 2014 VT Driver’s Ed Manual will have information about organ donation inside the front cover. Thanks to DMV for its willingness to make this happen. Mat reported that he is working to have the same notice included in the *Parents’ Supervised Driving Program* book for VT.
- Dr. Chen asked about the status of having a link on the Donate Life web-page to a web page about live donations. A discussion of this ensued. There is no registry for live donations, and the information is specific to the regional transplant center. FAHC has been working on a landing page, but it is not ready yet. Mike Thibault of CDT offered to take responsibility for working with FAHC on this.
- The role of funeral homes in promoting donation was acknowledged.

Status of Registered Donors

Mat and Mike Smith reviewed and discussed the data on donations in VT:

Web Registry as of 9/24/13	6,651	10.9% of registrants
DMV Registry as of 9/24/13	54,354	89.1% of registrants
Total Registrants as of 9/24/13	61,005	12 % of 16+ population

There was a discussion of the monthly variation for DMV donor registrations with an acknowledgement that it will take many months to see determine any patterns or trends. Mike Smith reminded the group that it will actually take 4 years to do so, as this time period will

capture all licensed drivers who must return to have their photos taken. Other observations or comments were:

- Vermont has not yet reached the mark of 50% of people who are asked to indicate willingness to donate and respond “yes”
- NEOB has implemented an ambassador program in 3 DMV districts, linking a person experienced with donation with a DMV office to offer encouragement. More are planned.
- Workgroup members applauded the great work of the DMV to make organ donation a high profile issue in local offices. DMV leadership and staff were praised by all.
- Steven Kind asked if DMV could target messages to people who have not chosen to become organ donors. Mike Smith said there is sensitivity about government using DMV information in ways such as this. The question was then raised about whether or not DMV could include information about donation in license application mailers. Dr. Chen asked Steve and Mike to explore this for the group.
- Mike Smith reported that non-licensed drivers (e.g. youth with permits) can now register as donors.
- Mike Scollins commented that he would like to see some consideration of having questions on the driver’s license application about willingness to become a live donor.

Live Kidney Donation in Vermont- Kate DeVine, FAHC Transplant Coordinator

Kate offered a presentation of live kidney donation at FACH, and some of the opportunities and challenges related to this form of donation (See Power-Point presentation). A discussion followed about the following:

- The gap between those waiting for a kidney and those donating a kidney is widening.
- Risk to donor is less than in childbirth
- 50% of living donors are not registered as organ donors!
- FAHC has recently seen between 5 and 16 live donors per year; 100 Vermonters are waiting for a kidney.
- There is some concern about how being a donor could affect life or disability insurance status.
- Mike Scollins mentioned that the Vermont Kidney Association is encouraging people to mention organ donation in obituaries.

Next Steps for Workgroup

Given the meeting discussion, Dr. Chen outlined three specific next steps for workgroup members:

1. Kate and Mike should work with Dawn to identify strategies for increasing live donations
2. Mike Thibault will work with FAHC and others to create link from Donate Life website to landing page about live donation
3. Steve Kind and Mike Smith will brainstorm about practical ways to provide information about donation in advance to Vermonters who are due to renew their licenses in person.

The Workgroup agreed to meet again in late October.