

10/24/12 Meeting Summary Organ and Tissue Donation Workgroup

Present: Harry Chen, MD, Commissioner of Health; Matt Boger, NEOB; Steven Kind, CDT; Arthur Magnaghi; Shannon Fasset, DMV; James Carter; Michael Scollins, MD; Antonio DiCarlo, MD; Katherine Devine, FAHC; Michael Thibault, CDT; Dixie Henry, VDH; Madeleine Mongan, VMS

Dr. Chen welcomed the workgroup members. There were no comments on the 9/18/12 meeting summary.

Live Organ Donation

The group discussed the current infrastructure in place for those seeking information about live organ donation. Generally, the goal is to have an intermediary source of information for those with initial inquiries and for those who are interested in additional information to then link them to the transplant center.

The group discussed whether information about both live and deceased organ donation should be included in the same materials or same resource. For example, the National Kidney Association website does provide information about both live and deceased organ donation on its website and has a nice presentation that distinguishes between them. The Donate Life website is a good resource already in place for deceased organ donation. Steve Kind, Matthew Boger and Katherine Devine agreed to work on a plan to make live donor information and links to local and national resources available on the Donate Life webpage, as well. They will present their recommendations to the group at the next meeting.

Additional topics relating to live organ donation included:

- The value of the State promoting organ donation by including information on State websites (such as at DMV). Recognizing donors and families of donors through a ceremony with State officials, for example, may be another way the State can promote donation.
- Currently, the focus for DMV is on registering deceased organ donors through the driver's license process and this should not be expanded at this time to include live organ donation.
- Some transplant centers offer limited insurance policies for live donors.
- Health reform may help cover medical expenses for Vermont donors in the future.
- The VDH logo may be added to the Donate Life website to show the Department's support and setting that up should be coordinated with the VDH communications office.
- VMS would be glad to put information in their newsletter and also could consider a Continuing Medical Education Panel on organ donation at one of their meetings.

April is Donate Life month and the group agreed that planning activities around that time to promote live and deceased organ donation would be beneficial. It also is expected that the DMV system for registering deceased organ donation will be available for regular

driver's licenses by then (in addition to the enhanced driver's licenses, as is currently available.) Promotional efforts at that time should include information about the launch of the DMV system.

DMV Driver's Manual

At the last meeting, the group agreed to draft some language for promoting organ donation to be published by DMV in the driver's manual. It appears there is space inside the front cover and DMV agreed to do that in future publications of the manual. The group discussed the target audience for the manual and Matthew Boger agreed to redraft the language to be more directed to the teens using the manual, with links to more information, for this group to consider at the next meeting.

Matthew Boger also agreed to draft a letter for this group to review at the next meeting to be from this group and go out to driver's education classes with the video about organ donation. Using the video in the driver's education classes assures the message is delivered appropriately for the audience.

The instructors who provide driver's education receive annual training. The organ procurement organizations could do a presentation at their annual event on organ donation to train the instructors on this topic, so they could present this information in their classes. Matthew Boger agreed to reach out to DMV to further explore this opportunity.

Legislative Report

The group discussed the specific topics assigned by the legislature.

1) Coordination of efforts of public and private entities to promote organ donation in the state.

- 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.
- April promotional events, e.g. ceremony with State officials to honor donors and their families, public service announcements, DMV launch of the new system
- VMS efforts through their newsletter, continuing medical education
- Information in the driver's manual and training driver's education instructors

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

This will be accomplished with the launch of the new DMV system to register organ donors through the regular driver's license process, in addition to the currently active registration through the enhanced driver's license process.

3) Establishing goals and strategies for increasing donation rates for both deceased and live donation (including how we will assess where we are now and how we will know if activities to promote organ donation registration are successful).

There is data available to the organ procurement organizations and to FAHC to do this and Vermont could create a dashboard with reasonable metrics that shows the goal and progress to date. At this time, the national score card shows Vermont at the bottom. With the launch of the 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 will be discussed (e.g. Donate Life website, dashboard on Health Department website or other.) There is already a lot of information available and this should not be redundant.

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 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, promotional events, dashboard, websites, data analysis, etc. is required, then some resources would be needed.

***Future meeting date: December 14, – 10AM, Vermont Department of Health, Conference room 3B (and call-in capability available)
(NOTE: This meeting was rescheduled from November 29).***