

9/18/12 Meeting Summary Organ and Tissue Donation Workgroup

Present: Harry Chen, MD, Commissioner of Health; Robert Ide, Commissioner of DMV; Matt Boger, NEOB; Madeleine Mongan, VMS; Steven Kind, CDT; Arthur Magnaghi; Mike Smith, DMV; James Carter; Michael Scollins, MD; Antonio DiCarol, MD; Dixie Henry, VDH

Dr. Chen welcomed the workgroup members and asked if there were comments or revisions on the meeting summary of the 7/25/12 meeting. There were no comments.

Dr. Scollins described the results of his research into live organ donation registry efforts in other jurisdictions. In California, although a law was passed there recently, they have run into some difficulties in implementing the registry. In England, a private organization ran a “Give a kidney, one’s enough” campaign and they are seeing increasing interest in live organ donation, but do not have data at this point.

The group discussed what is needed in Vermont relative to promoting live organ donation. Topics included:

- The need to keep communications separate and clear between deceased organ donation and live organ donation.
- The need for an entry portal where those interested can obtain information and be referred to the lead organization (e.g. FAHC or DHMC).
- The need to identify appropriate channels to reach people, such as through information or video at DMV offices, polling stations, county fairs and other public events.
- Encouraging primary care providers to include information/discussion of organ donation as part of annual exams coordinated with an “Ask your doctor” campaign.
- Promoting changes to Vermont law or employer policies to make it easier for people to be a live donor, such as through paid time off for recovery period, provide health insurance to donors.
- Increase use of social media to reach people, such as through approaching Facebook to expand their deceased donor marker to include live donor information to direct those interested to their health care provider or local transplant hospital.

Dr. Chen asked the workgroup members to draft the components of a plan to identify what we need to make live organ donation work in Vermont and send it to him. The Health Department will combine the recommendations of the members and bring it back to the group for discussion of menu items to propose to the legislature.

The group discussed ideas for a communications campaign to coordinate with the launch of the new DMV system for registering organ donation. Ideas included press releases, inviting state and federal officials to participate in press conferences and special events/information at DMV offices. The DMV will launch its new system as soon as it is

ready and the communications campaign can happen anytime after that, possibly during December.

The group also discussed ideas for promoting organ donation throughout the state in multiple ways and venue, such as by adding information in the driver's manual, by providing general information on a state website with links to the transplant hospitals for specific information. DMV may have a new video screen system in its offices that could include an organ donation video, possibly looping with other messages. Members will draft suggested content, such as for the driver's manual and website, and bring it back to the next group meeting for review and further discussion.

The group did not identify any specific data that is needed at this point other than what will be available to the organ procurement organizations from Statline that is similar to data they already receive from other states.

The group discussed the importance of communication, education and outreach efforts for both deceased and live organ donation campaigns and the need to coordinate those efforts to effectively promote donation and minimize confusion. Some suggestions on how to do this included creating specific staff positions to be the contact points to keep channels open. This could be at a state agency or grass roots organization to facilitate and coordinate a statewide organ donation campaign and should be designed not to duplicate what is done already by organ procurement organizations or with the schools. Funding may be required to support these activities.

The group discussed potential avenues for state support for donation that would require legislative action, including: extending employee benefits, health insurance, paid leave and tax benefits for expenses related to costs incurred or work time lost related to live donation and a voluntary financial donation on a tax return to support donation efforts.

Matt Boger presented information on advisory councils that have been established in other states. Generally, there is no appropriation to support their work, but they are sponsored by a state agency. See attached power point.

Next Steps and topics for discussion at our next meeting:

Group members are requested to send their suggestions to Commissioner Chen by 10/22 for:

1) the components of a plan to identify what we need to make live organ donation work in Vermont; and

2) draft language for inserting in the driver's manual or for a state webpage.

Also, for the October meeting, we will discuss specific recommendations to increase organ donor registration to be included in the Workgroup Report to the legislature regarding:

1) coordination of efforts of public and private entities to promote organ donation in the state;

- 2) the creation of a comprehensive statewide program for organ and tissue donations and transplants;
- 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*) ; and
- 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 specific recommendations from this discussion will be the basis for a draft report for the Workgroup to review and finalize at the November 29 meeting (the final meeting scheduled for this group.)

Future meetings dates: October 24 and November 29 – 10AM, Vermont Department of Health, Conference room 3B (and call-in capability available)