MINUTES OF THE Advisory Council on Organ and Tissue Transplants and Donations

Meeting of November 18, 2015

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

ADVISORY COUNCIL ON ORGAN AND TISSUE TRANSPLANTS AND DONATIONS AGENDA

Wednesday November 18, 2015 1:00PM Conference Room 3A

- 1. Introductions
- 2. Approval of Minutes
- 3. Discussion of Organ Transplant Fund
- 4. Discussion of Organ and Tissue Donor Registration Fund
- 5. Scheduling of next meeting

ADVISORY COUNCIL ON ORGAN AND TISSUE TRANSPLANTS AND DONATIONS

Presented below is a summary of the meeting, including time-keeping, attendance and votes cast.

Date of Meeting: November 18 2015

Beginning Time: 1:00PM Ending Time: 2:30PM

Attendance and Summary of votes

Board Member	Attended
Jennifer Barrelle	Yes
Amie O'Hearn	Yes
Tim Miley	Yes
David Hanlon	No
Sandra Duffy	Yes
Alexandra Glazier	Yes
Ann Linehan	Yes
Dr. Heung Kim	Yes
Dr. Joren Madsen	Yes
Dr. Adel Bozorgzadeh	Yes
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Summary	members attended

Additionally, Matt Boger and Sean Fitzpatrick from the New England Organ Bank attended.

PROCEEDINGS

A regular meeting of the Massachusetts Department of Public Health's Advisory Council on Organ and Tissue Transplants and Donations (Section 2 of Chapter 190 the Acts of 2010) was held on

November 18, 2015 at the Massachusetts Department of Public Health, 250 Washington Street, Conference Room 3A, Boston, Massachusetts 02108.

ITEM 1: Approval of Minutes

There were no changes made to the minutes of December 23, 2014.

Dr. Kim made a motion to approve the minutes, Dr. Madsen seconded that motion, all approved.

ITEM 2. Discussion of Organ Transplant Fund

a. Guidelines and Application

Tim Miley informed members that DPH program staff continued to implement the updated guidelines for the Organ Transplant Fund previously approved by the Council, and that all recipients were submitting full annual applications to become eligible, or renew eligibility, to utilize the fund. Applications are reviewed by a team of staff at DPH before approval for eligibility. Recipients must then submit documentation for reimbursement on a quarterly basis, and this material is reviewed by DPH program and clinical staff to ensure payments from the fund are consistent with usage guidelines.

Matt Boger inquired if the application and instructions could be sent out to the transplant centers. Tim Miley indicated DPH could email the application documents, and would post the documents online for anyone to access and print. Tim also indicated that the program had received applications for new members, primarily for pediatric patients from Boston Children's Hospital. There were also new and existing applicants who were denied as they did not meet the guidelines, generally due to income level.

Dr. Madsen asked if the Council could be provided regular updates on the Fund, including number of recipients (new and existing). Tim Miley indicated this information could be shared by email with Council members outside of formal Council meetings.

ITEM 3. Discussion of Organ & Tissue Donor Registration Fund

a. RFP

There was a discussion about the Request for Proposal (RFP) process to utilize the funds in the Organ and Tissue Donor Registration Fund. Council members expressed urgency for the process to move forward. Tim Miley indicated that DPH program and communications staffers were working to finalize approval of the draft RFP for posting, and intended to post as soon as possible.

Alex Glazier inquired whether the Council could be part of the review process for the RFPs. Tim Miley indicated that DPH intended to have the Council provide input and, if allowed by the procurement process, review submitted proposals before a final vendor is selected. Council members asked to be kept updated on the RFP process.

There was a general discussion on how to identify and reach certain populations that have a lower donor registration rate, which could be incorporated into a public campaign to raise donation rates. Matt Boger indicated that registration data shows a significant decrease in donors registering (or renewing their registration) after age 55.

There was discussion of methods to improve registration rates at Registry of Motor Vehicle (RMV) locations. Matt Boger and Sean Fitzpatrick indicated there was new signage as well as a registration video at RMV locations. Matt Boger also indicated that many of those signing up to be donors through the RMV do so online. Members discussed possibility of having "opt-out" instead of "opt-in" registration, as well as not requiring renewal of donor registration once someone has registered, as methods to improve long-term registration rates.

There was discussion of how to determine why people refuse to register at RMV locations, and the possibility of performing a survey or poll. Sean Fitzpatrick indicated there was Gallup polling data on this topic.

Alexandra Glazier pointed out that the Uniform Anatomical Gift Act allows persons under 18 to indicate they would like to become donors, which becomes effective automatically when they turn 18. There was discussion of potentially altering the RMV form to remove parent/guardian signature that may be unnecessary. Amie O'Hearn indicated RMV's legal staff would look into this issue.

Matt Boger and Sean Fitzpatrick indicated there were federal grant opportunities, which could involve using census block donor registration data to drive hyper-local public awareness campaigns. Sean Fitzpatrick indicated he could provide a link to the census block data, and overlay maps. Key takeaways from this data show that education level, income, and race are closely related to donor registration rates. As an example, the data shows that living in a community with low registration rates has a significantly detrimental effect on one's likelihood to register. Tim Miley raised the possibility of using social pressure messaging, which is also used to increase voting rates and reduce energy usage, as a way to increase donor registration.

ITEM 4. Scheduling of Next Meeting

The Council agreed to schedule the next meeting for the first quarter of 2016. The meeting then adjourned.