

OPTN/UNOS Living Donor Committee
Meeting Minutes
May 9, 2018
Conference Call

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Introduction

The Living Donor Committee met via teleconference on 05/09/2018 to discuss the following agenda items:

1. Project Portfolio Review

The following is a summary of the Committee's discussions.

1. Project Portfolio Review

The OPTN/UNOS Living Donor Committee (LDC) has a number of potential projects in the idea phase. The LDC used this teleconference to discuss these potential projects and to weigh in on future paths forward for committee work. These projects include clarifying maintenance dialysis in policy language, transplant hospital best practices with patient use of social media, and donor self-assessment.

The LDC began with an overview of the issues around maintenance dialysis in policy language. Members have raised questions regarding the meaning of the phrase "begins dialysis" in Policy 18.6. Specifically, it is not currently clear whether the phrase "begins dialysis" requires reporting chronic dialysis representing end-stage renal failure and/or acute dialysis.

In addition, there are several other areas within policy language, TIEDI, and the Patient Safety Portal which refer to the decrease or loss of renal function in a living donor using inconsistent terminology. For example, Policy 18.6.A requires recovery hospitals to report any "living kidney donor who is listed on the kidney wait list or begins dialysis within 2 years after organ donation" as a "living donor event" in the Patient Safety Portal within 72 hours after the hospital is aware of the event. UNOS must then notify HRSA of the event within 24 hours of it being reported through the portal.

The checkbox in the Patient Safety Portal is labeled as "Loss of native organ function." Prior versions of policy included "failure of the living donor's remaining organ function" (February 1, 2014 rewrite version) and "failure of the living donor's native organ function" (January 31, 2014 pre-rewrite version). In these cases, policy 1.2 defined this as "listing for transplant or the need for dialysis in kidney donors" but did not specify acute versus chronic dialysis.

The Living Donor Follow-up (LDF) form reporting (Policy 18.5.A) queries centers about related clinical events at 6 months, 1 year, and 2 years post-donation. Among the choices are "5. Kidney complications" and "6. Maintenance dialysis." Under choice "5. Kidney complications" are the options "Added to UNOS TX candidate waiting list" and "Other, specify." This section does not specifically mention "acute dialysis" as an option.

Regarding the LDF's item "6. Maintenance dialysis," UNet Help documentation offers a definition of "Maintenance dialysis" as "if the donor was on maintenance dialysis (22 sessions in a 3-month period)," but this definition is not codified elsewhere within OPTN/UNOS policy.

Clarifying when transplant hospitals should report chronic versus acute dialysis in the sections of policy and harmonizing terminology on forms will help centers accurately report living donor

events. In addition, greater clarity in reporting will improve safety reviews and the understanding of clinical events after living donation.

Next, an overview of social media and living donation was provided to the LDC. The United States, unlike other countries, has not provided guidance or principles about the use of social media to identify potential living organ donors and related issues. Transplant hospitals have widely disparate approaches to interacting with patients about the use of social media as a communication tool to identify potential living donors. Transplant patients are not uniformly educated about the communication tool in general, about how to use it safely, effectively, and legally, or about the risks and benefits of using it to find a living donor. The wide variation in transplant hospital approaches to discussing the use of social media with patients could increase the disparity between patient populations in access to transplant via living donation. Successful social media campaigns can result in an influx of potential living donors, which creates administrative challenges and opportunities for transplant hospitals.

Finally, the LDC discussed the potential project idea of an online living donor self-assessment tool. Committee members acknowledged that there is a gap regarding one's potential as a living donor when they enter the process. In addition, there is a lack of knowledge about the actual process of living donation and the variability in how center manage these processes. The donor self-assessment tool would provide a means of education on these processes and what potential living donors should expect. It would also provide an opportunity to address center variability early on with potential living donors.

Next Steps:

The LDC will select projects with which to potentially move forward. Upon selecting projects, work will commence to prepare any potential projects for Policy Oversight Committee and Executive Committee review.