

**OPTN/UNOS PATIENT AFFAIRS COMMITTEE  
INTERIM REPORT**

**Chicago Illinois**

May 22, 2012

I. Legislative Update

The Committee received an introduction to new proposed legislation to encourage Living Donation. The bill proposes to provide reimbursement for lost wages to living donors who meet certain financial eligibility requirements. Reimbursement would:

- Be capped at \$3000 per donor
- Only be available to persons without income while recovering after donation
- Not be available to persons accessing employee benefits such as sick or vacation benefits while recovering

Eligibility verification would be managed through the transplant program in a manner similar to the travel and subsistence reimbursement program currently in existence.

Section 301 of the National Organ Transplant Act (NOTA) of 1984 prohibits the sale or purchase of organs within the United States. Such actions are punishable by 5 years in prison and up to \$50,000 in fines. NOTA does specify three exceptions, whereby exchange of resources for transplant may be acceptable:

- Travel
- Subsistence
- Lost Wages

The Organ Donation Recovery and Improvement Act (ODRIA) established the authority and legislative parameters to provide reimbursement of living donors for travel and reimbursement. ODRIA neglected to include reimbursement for lost wages.

Data on potential Medicare savings in dialysis costs from the KPD Pilot Project have established that living donation benefits patients while also generating healthcare cost savings. The bill estimates up to \$24 million in Medicare savings on dialysis costs if 100 new living donors were brought into the system each year. Over 10 years this amounts to \$24.4 billion in Medicare savings, while also offering the health benefits of early transplant from living donors to transplant candidates.

The Committee noted the following potential unintended consequences to this bill:

- Low income persons may be tempted to donate to receive the financial reimbursement, and later feel they have been disenfranchised in some way

- Persons with resources may feel that they are being penalized for having resources, and thereby choose not to donate

The Committee felt these two issues could be appropriately addressed during the living donor evaluation. Individual committee members expressed interest in contacting the members of the Congressional Caucus in support of the bill.

## II. Overview of the Transplant Provider Survey

The Committee received a presentation entitled *Increasing Dialysis Patients' Access to Transplant Education* from Dr. Amy Waterman, Associate Professor of Medicine with Washington University, St. Louis MO and Vice-Chair of the OPTN Living Donor Committee. The presentation summarized the results of Dr. Waterman's study of both patient and dialysis centers factors that limit dialysis patient access to transplant education. Dr. Waterman surveyed 506 African American dialysis patients and 462 Caucasian dialysis patients in 117 dialysis centers regarding their knowledge and perceptions of transplant. The goal of the study was to identify barriers to transplant education within the dialysis population. The study found the following disparities along racial lines:

Compared to Whites, minorities were less likely:

- To have received deceased or living donor transplants
- To be placed on the waiting list
- To be referred and to present for transplant evaluation
- To be educated about deceased and living donor transplant

The following barriers to transplant education were identified:

- Patient factors;
  - Fears about transplant
  - Poor knowledge about transplant
  - Racial disparities
- Healthcare System factors
  - Inconsistent transplant referrals
  - Insufficient transplant education
  - Weak partnerships between transplant centers and dialysis centers

Dr. Waterman then conducted a randomized controlled trial to assess whether improved transplant education in dialysis centers could improve patients:

- Informed decision making
- Discussion about transplant with family members
- Pursuit of transplant

The resultant data lead to the development of the Explore Transplant Education Curriculum, which is now being used to educate dialysis providers across the country.

The Committee related a very emotional response to the racial disparities highlighted by the study data. The Committee resonated with the need for increased transplant education for dialysis patients. The following avenues were suggested as ways of promoting transplant education:

- Incorporating transplant education into Vascular Access Clinic
- Using data from the study to justify additional dialysis outreach positions in transplant centers
- Increased partnering with education/outreach programs that target the minority community
- Establishing measurable benchmarks for transplant education within dialysis units, for e.g. a percentage of patients must receive pre-emptive transplants, or be transplanted within 2 years of initial dialysis date
- Mandate that every dialysis patient under age 70 have documentation of a completed transplant evaluation
- Partnership with Accountable Care Organizations to promote transplant education in dialysis units.

A Committee Member reported a 400% increase in referrals and a 300% increase in transplant volume after implementing Explore Transplant as part of their dialysis outreach program. The Committee supported collaboration between transplant centers and dialysis units as a significant component of effective transplant education.

### III. Patient Notification

The Committee received a presentation reviewing work with Patient Notification in the last 24 months. This included a plain language rewrite of the OPTN Contractor Patient Information Letter and feedback on the rewrite of the Patient Notification requirement within the Policy Rewrite process. Transplant Centers are required to provide the OPTN Contractor Patient Information Letter to patients:

- Within 10 business days of being placed on the waiting list
- Within 10 business days of completion of the evaluation when the patient will not be placed on the waiting list
- Within 10 business days of removal from the waiting list for reasons other than transplant or death.

There are other instances where patient notification within the OPTN. These include, but are not limited to:

- Corrective Action
- MPSC Action
- Member placed on probation

- Member not in good standing
- Temporary Inactivation of a center

Living Donors are required to receive the UNOS Patient Services Line Phone Number. Transplant Centers are not required to provide the Patient Information Letter to living donor candidates. The decision as to when living donor candidates receive the Patient Information Letter is left to the individual transplant center.

The Patient Information Letter provides the recipient with the number to the UNOS Patient Services Phone Line (888/894-6361). Callers can receive help with accessing information on transplant data, transplant policy, location of transplant centers, and patient education resources.

The Committee was asked to respond to the following three questions in an effort to determine how the Committee should move forward with this issue:

- Should transplant centers be required to provide the Patient Information Letter to Living Donors?
- At what point should living donors receive the Patient Information Letter?
- Should transplant centers be required to provide the Patient Information Letter with all OPTN-required correspondence (see the list above for examples)?

The Committee was unanimous in their desire to insure that the Patient Information Letter be provided to living donors. The Committee cited the problems that lack of education raises for patients in all areas of transplantation. Living Donors and recipients of living donor transplants related personal stories of feeling disconnected and not knowing where to turn for information. Transplant Coordinators and Social Workers within the Committee related the positive of the Independent Living Donor Advocate in keeping living donor candidates informed and connected to the transplant system. The Committee persisted in their support of providing the Patient Information Letter to living donor candidates at the time that they enter the transplant system.

The Committee formally voted, by unanimous consent to develop policy language requiring that transplant centers provide the OPTN Contractor Patient Information Letter to living donor candidates at the point that the candidate formally enters the donor evaluation process. The Committee will collaborate with the Living Donor Committee and other interested committee's in this process.

#### IV. Social Media: Opportunity With Caution

In the months prior to today's meeting the committee had shared individual instances of perceived unethical or risky behavior within the arena of social media and transplantation. Based upon these discussions, the Committee received a presentation today on the risks and benefits of social media and its impact within transplantation. Social Media impacts transplantation, both positively and negatively in three distinct areas:

- Sharing information
- Spreading awareness
- Soliciting specific donors

Ethics has been outpaced by the rapid development of technology and the use of social media, leaving a void where existing rules and norms are no longer applicable. Social Media provides a great service by increasing awareness of the need for organ donation. This is especially evidenced by the increased incidence of non-directed donors who are identified through social media contacts. Organ failure is life-threatening. Desperate people take desperate measures. This opens the door to potential coercion and exploitation.

There are also concerns about the ‘beauty contest’ effect within social media. This concept highlights one candidate as opposed to another based upon subjective perceptions about worthiness or attractiveness. This operates in direct opposition to the concept of allocation that is based upon medical need only. This system provides advantages to those who are resourced, attractive, and connected, potentially at the expense of those who do not meet these criteria.

Social Media is a part of the culture. It is not going away. The challenge for the transplant community is to discover ways to use social media in a thoughtful and responsible way, without disadvantaging anyone, or putting anyone at risk.

The Committee highlighted the:

- Benefits of social media in promoting awareness
- Benefits to the entire transplant system when altruistic donors are identified

The Committee also acknowledged:

- The need for cautions for patients and families
- The inability of the OPTN to regulate business practices of companies who use social media
- Actions of families who are desperately seeking donors

The Committee agreed to have a subcommittee review the issues and bring recommendations back to the Committee for further consideration in this area.

#### V. PAC Proposed Work

The Committee briefly reviewed the proposed work for 2012-13. The Committee has completed *What Every Patient Needs to Know*. The Spanish language version is in progress with an expected date of July 2012.

The Committee proposed two new projects to the Policy Oversight Committee for the 2012-13 Committee Year:

*The Teen Adherence Project:* project to develop a comprehensive transplant education program for teens and young adults. A cornerstone of this project would be a Smartphone game that proposes to educate about compliance in transplant. This project is being considered on the transplant consent agenda for the June 2012 Board Meeting.

*Organ Specific – What Every Patient Needs to Know:* The Committee proposed to develop organ specific brochures, highlighting the psychosocial issues unique to each organ. The POC requested data to support this concept. The POC asked the PAC work with Dr. Amy Waterman to develop a study of calls received through the UNOS Patient Services Line to document the different educational needs and experiences of candidates by organ.

Both these projects will be considered by the Board at the June 2012 Board Meeting.

The Committee will continue work on patient notification as previously discussed.

## VI. Public Comment Review

The Committee received presentations on the following proposals. All proposals were approved unanimously.

- Proposal to Revise the Lung Allocation Score System (Thoracic Organ Transplantation Committee)
- Proposal to Establish Kidney Paired Donation (KPD) Policy (Kidney Transplantation Committee)  
*The Committee asked if OPO's can assist in packaging and labeling of organs for KPD based upon their expertise in this area. Per the proposal this practice is acceptable.*
- Proposal to Include Bridge donors in the OPTN Kidney Paired Donation (KPD) Program (Kidney Transplantation Committee)  
*The Committee discussed the potential for bridge donors to refuse to donate if left as a bridge donor indefinitely. After discussion, the Committee agreed that the benefit of starting another chain with a bridge donor outweighs any potential for a bridge donor to drop out.*
- Proposal to Clarify Priority Status for Prior Living Organ Donors who Later require a Kidney Transplant (Kidney Transplantation Committee)

The Committee unanimously supported the Kidney Committee proposal. The Committee had lively discussion about whether this same priority should be offered to any living donor who later needs a transplant of any organ. The Committee agreed to ask the Living Donor Committee to look into policy that will allow this same priority across all organs for living donors of all organs.

The Committee also discussed the potential for priority on the waiting list for persons who have a transplant of a previous organ and now need a kidney transplant. The Committee agreed to request data on the incidence of this situation. The Committee will continue the discussion when the data is presented.