

**OPTN Patient Affairs Committee  
Meeting Summary  
March 16, 2021 – 3:00 – 4:00 PM EST  
Conference Call**

**Darnell Waun, M.S.N, Chair  
Garrett Erdle, M.B.A., Vice Chair**

## **Introduction**

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 03/16/2021 to discuss the following agenda items:

1. Educational Panel – Organ Donation and Transplantation: A Conversation About What Really Happens

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

### **1. Educational Panel – Organ Transplantation: A Conversation About What Really Happens**

UNOS staff introduced the panelists – Carolyn Light, MPA, Aneesha Shetty, MD, and Randy Schaffer, MD. UNOS staff provided a brief overview of patient need, waitlist period, living and deceased organ donors, the organ procurement, and the transplantation process.

#### Summary of discussion:

A member asked about the timeline between when the OPO receives a call about an organ and when the patient could receive the organ. A member from an OPO informed the Committee that it could take as long as seven days from when the initial referral is received, but the time of authorization from the donor’s family and time of the recipient’s transplant can be 24-48 hours. Within the 24 to 48-hour time frame, the OPO team does a match run on DonorNet, with each organ type having its own waiting list. Once the organs have been allocated and accepted by the transplant center, the OPO takes the donor to the operating room (OR) and acts as the intermediary between transplant centers from there on out.

A panelist detailed the process of accepting an organ offer which starts with the automatic tissue typing match and then the transplanting physician will look at factors like age, KDPI score, organ size, and organ function. Some of these factors may make a candidate ineligible to receive a particular organ offer but once matched with an organ it is ultimately the patient’s decision to accept or decline the offer. Kidney Donor Profile Index (KPDI) is a score from 0-100 that considers 10 different factors to predict the longevity of the organ, with the lower score indicating a higher organ life.

A member inquired about the informed consent process for Living Donors, specifically regarding the Hippocratic Oath to do no harm with the possibility of harm done as a result of the organ donation. A panelist shared that CMS has very detailed guidelines about informed consent and the potential for physical, financial, or psychosocial consequences. Transplant centers are required to have independent living donor advocates to ensure the donor has had all of their questions answered and give them the opportunity to decide against donation at any time in the process. A member inquired about the potential for donor’s remorse and a panelist shared that the vast majority of donors feel happy with their decision and would partake in the process again, although some people can have harder recoveries or difficulty processing emotionally afterwards. A member shared that if at any point in the process the

transplant team senses any hesitation from the donor the transplant team will provide the donor with a 'medical out' to not harm the relationship between the donor and recipient.

A panelist went on to explain the difference between the terms "DCD" and "DBD." A donation after cardiac death (DCD) occurs when a patient still has some brain activity but is unlikely to live and the family makes an end of life decision. A donation after brain death (DBD) is when a patient is declared brain dead and able to donate their organs. Due to these two deceased donor types, there are limitations on who is eligible to donate their organs.

A member inquired about the process of notifying patients when an organ offer occurs and what types of questions do patients normally ask when determining if they will accept an organ offer. A panelist informed the group that the transplant team will normally only contact the patients who are at the top of the match run and have a higher likelihood of receiving the organ. In terms of questions, recipients often ask about the donor's cause of death, longevity of the organ, how well the organ is matched to them, and what the organ function is. Once patients have a better understanding of the organ, they often ask what the next steps are and timeline to hospital arrival or surgery.

A member inquired about how the change from DSAs will impact the allocation and notification process. The providers on the call were in agreement that the new system will increase the quantity of organ transplantations occurring, reduce organ waste, and hopefully increase accessibility and decrease waitlist mortality.

#### **Upcoming Meetings**

- April 20, 2021
- May 18, 2021
- June 15, 2021

## Attendance

- **Committee Members**
  - Darnell Waun, Chair
  - Garrett Erdle, Vice Chair
  - Anita Patel
  - Chris Yanakos
  - David Skinner
  - Earl Lovell
  - Eric Tanis
  - James Sharrock
  - Julie Siegel
  - Kenny Laferriere
  - Phil Williams
  - Sarah Koohmaraie
  - Stephanie Little
- **HRSA Representatives**
  - Adriana Martinez
  - Jim Bowman
  - Raelene Skerda
- **SRTR Staff**
  - Allyson Hart
  - Katie Audette
- **UNOS Staff**
  - Abby Fox
  - Laura Schmitt
  - Lindsay Larkin
  - Meghan McDermott
  - Sarah Rose Wells
  - Susan Tlusty
- **Other Attendees**
  - Aneesha Shetty
  - Carolyn Light