

OPTN Patient Affairs Committee

Meeting Summary

June 21, 2022

Conference Call

Garrett Erdle, MBA, Chair

Molly McCarthy, Vice Chair

Introduction

The OPTN Patient Affairs Committee (the Committee) met via Citrix GoTo Meeting teleconference on 06/21/2022 to discuss the following agenda items:

1. Recognition of Members
2. Provide feedback to Match Run Rules Workgroup
3. Offer Filters: Overview
4. Policy Oversight Committee-reviewed Projects

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

1. Recognition of Members

The Committee recognized the members whose terms end at the end of June, and heard introductions from the incoming members whose terms start in July.

2. Provide feedback to Match Run Rules Workgroup

The Committee discussed the OPTN Operations & Safety Committee's Match Run Rules Workgroup (Workgroup) project. The Committee was asked to comment on whether their transplant programs contacted them about potential organ offers that ultimately went to other candidates, and whether such calls should be limited. The Committee was also asked to provide feedback on how many patients should be contacted for each available organ to confirm availability for transplant. The Workgroup proposed contacting two patients at a time for heart, liver, intestine, pancreas, and VCA, and four patients for lung and kidney.

Summary of discussion:

A member asked how often transplant candidates are not available when they are called with an organ offer. The representative from the Workgroup said that it is about 20 – 30 percent of the time in their personal experience as a transplant coordinator. The representative added that it is also dependent on organ type.

A member noted that cold ischemic time is a very important factor in determining whether to accept an organ. Another member stated that in addition to the Workgroup's proposed framework for organ offer review and acceptance, organ offer filters aim to increase efficiency and decrease cold ischemic time. A member stated that mandating pumping of organs by the organ procurement organizations may also help to mitigate cold ischemic time.

Another member wondered how many candidates are unavailable when offered an organ due to communication issues. The member noted that they had to have their cell phone replaced while they were on the waitlist and it took some time to get the phone up and running, and then the first call they

received on their new phone was the call from their transplant program to come in and receive their transplant. The member noted that a kidney candidate may be on the waitlist for several years, and not checked in with as often as a heart candidate who is hospitalized while on the waitlist. The member stated that confirming availability for more than four kidney candidates may be needed.

Overall, members received 1-7 calls regarding organ offers before receiving a transplant. A member shared their experience of receiving seven calls for kidney offers. The member shared that during one of these calls for a potential kidney offer, they were told there were seventh on the list. The member did not understand why they were contacted in this case and that it was not an enjoyable experience because they were excited at first but ultimately let down. The member stated that calling two backups for kidney offers should be sufficient.

The Vice Chair shared their experience of receiving four calls for kidney offers. The Vice Chair stated that they appreciated the first call they received because it gave them assurance that the process was working. The Vice Chair added that the call allowed them to have a dry run and think more logistically about the preparation that may be needed when their transplant occurred. The Vice Chair added that by the fourth call, they had developed more immunity to the offer. The Vice Chair stated that if they had to choose, they would prefer to have the calls to have assurance they are on the list.

A member stated that transplant professionals should consider the mental health impact that “dry run” organ offers have on transplant candidates. Another member noted that it is often a focus of patient education to prepare candidates to expect multiple calls. Members noted that patients receive varying information from their centers about their priority for transplant. For example, some patients have said they were told by their transplant program that they were #1 in the nation or #2 at their center, even though priority for transplant can vary by match run based on donor factors and distance from the donor hospital.

The Vice Chair asked for more information on the technology side of organ offers and acceptances.

Another member stated there is a national collaborative that is discussing improving organ placement.

Next steps:

The feedback will be relayed to the Workgroup.

3. Offer Filters: Overview

The Committee was provided an overview of offer filters.

Summary of discussion:

The Chair stated that mandatory offer filters may be beneficial to the patient community. The Chair emphasized that evaluating allocation time is necessary to understand the impact and potential improvement.

4. Policy Oversight Committee-reviewed Projects

The Committee reviewed projects under review by the OPTN Policy Oversight Committee (POC).

Summary of discussion:

A summary of OPTN committee projects under review by the POC:

- Ethical Consideration of Normothermic Regional Perfusion (OPTN Ethics Committee)
- Review of Liver Variances in OPTN Policy (OPTN Liver & Intestinal Transplantation Committee)

There were no comments or questions.

Upcoming Meetings

- July 21, 2022 (teleconference)
- August 16, 2022 (teleconference)

Attendance

- **Committee Members**
 - Anita Patel
 - Christopher Woody
 - Chris Yanakos
 - Darnell Waun
 - Diego Acero
 - Earl Lovell
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Spear
 - Justin Wilkerson
 - Justine Van Der Pool
 - Kristen Ramsay
 - Molly McCarthy
 - Sarah Koochmaraie
 - Sejal Patel
- **HRSA Representatives**
 - Jim Bowman
 - Lauren Darensbourg
 - Raleane Skerda
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Joann White
 - Kaitlin Swanner
 - Kim Uccellini
 - Lauren Motley
 - Meghan McDermott
 - Sara Rose Wells
- **Other Attendees**
 - Calvin Henry
 - Dana Hong
 - Jill Campbell
 - Laurel Avery
 - Lorrinda Gray-Davis
 - Steve Weitzen