

OPTN Patient Affairs Committee

Meeting Summary

March 30, 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 03/30/2022 to discuss the following agenda items:

1. Discuss Analytical Hierarchy Process (AHP) values exercise

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

1. Discuss Analytical Hierarchy Process (AHP) values exercise

The Committee provided a patient perspective to lend context to specific results of the AHP values exercise. This exercise is aiding in the development of the continuous distribution of kidneys & pancreata.

Summary of discussion:

A member noted that the general public placed more weight on pediatric, prior living donor, and waiting time attributes. The member suggested that may be due to those attributes being more easily understandable compared to the other more clinical attributes.

Prior Living Donor Attribute

Another member stated that the reason that they rated prior living donor very high is because it is very important that living donors have a safety net should they ever need a kidney in the future. Additionally, the member stated that it would not be fair to take away prior living donor priority since individuals have previously been informed of this priority.

A member stated that a prior living donor should receive higher priority should they be medically urgent. The member stated that a prior living donor should not be placed above a candidate that might be in more need of an organ than the prior living donor. Another member responded that medically urgent in the context of kidneys is not as important as other organs due to dialysis options.

The Vice Chair stated that the data shows that the number of prior living donors who need future transplant is very small. The Vice Chair added that prior living donor priority is important from a recruitment standpoint. Another member agreed.

The Living Donor Committee Chair stated that living donors are often not their own best advocates, and agree that sicker candidates be placed above themselves. Another member agreed. The Living Donor Committee Chair stated that the Living Donor Committee and the Ethics Committee previously discussed prior living donor priority and ultimately concluded that all prior living donors should receive very high priority. The Living Donor Committee Chair emphasized that potential living donors often have to convince their family of their choice, and prior living donor priority helps.

Waiting Time Attribute

A member suggested the Kidney & Pancreas Committees consider combining candidate biology and waiting time into a single attribute. The member added that individuals receiving dialysis would most likely rank waiting time as an important attribute. Another member added that they struggled with rating waiting time as the concept seemed over simplified. A member stated that waiting time is difficult to consider as a standalone attribute given it impacts a lot of the other attributes and outcomes.

Another member stated that dialysis should not be considered a replacement for transplant; it is a bridge to get to transplant. The member stated that it would be interesting to see how the results of the AHP exercise would differ if dialysis was not an element.

The Vice Chair stated it is important to understand whether a medically urgent candidate will have the best use of an organ. Another member agreed and added that consideration needs to be made to transplant candidates who will live the longest, such as pediatric patients.

Another member stated support for the linear approach if there is a general preference among patient to prefer long term outcomes, and if there is a diminished change of long term outcomes with wait time.

A member suggested the Kidney & Pancreas Committees may consider using dialysis as a function of wait time.

Pediatric and Prior Living Donor Attributes

A member supported ranking prior living donors above pediatric candidates. The member stated that the gift of a living donor should take priority. Additionally, the member explained that since the number of prior living donors who need a future transplant is so small, it may not be that impactful to pediatric candidates. Other members agreed.

A member stated the prior living donor priority helps as a marketing effort to have more people become living donors. A Living Donor Committee member stated that besides it being a marketing effort, it is simply the right thing to do. The member explained that living donors undertake a selfless act and it is the right action to prioritize them should they ever need an organ in the future.

Other Feedback

A member emphasized that it is necessary to continue to receive input from the general public who are waiting for a kidney transplant. The member stated that the Committee is not representative of those individuals who are on the kidney waiting list. Members agreed.

The Committee requested to participate in the AHP exercise a second time, as they believe their rankings would change based on the information discussed during the meeting.

Next steps:

The feedback will be relayed to the Kidney & Pancreas Committees as they make their determination for attribute weighting in the context of continuous distribution.

Upcoming Meetings

- April 19, 2022 (teleconference)
- May 17, 2022 (teleconference)
- June 21, 2022 (teleconference)

Attendance

- **Committee Members**
 - Anita Patel
 - Christopher Woody
 - Chris Yanakos
 - Darnell Waun
 - Diego Acero
 - Eric Tanis
 - Garrett Erdle
 - James Sharrock
 - Julie Spear
 - Justin Wilkerson
 - Justine Van Der Pool
 - Kenny Laferriere
 - Kristen Ramsay
 - Molly McCarthy
 - Sejal Patel
- **HRSA Representatives**
 - Jim Bowman
 - Raelene Skerda
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alison Wilhelm
 - Darren Stewart
 - James Alcorn
 - Kaitlin Swanner
 - Kayla Temple
 - Kim Uccellini
 - Lauren Mauk
 - Lauren Motley
 - Lindsay Larkin
 - Meghan McDermott
 - Rebecca Brookman
 - Ross Walton
 - Sara Rose Wells
- **Other Attendees**
 - Heather Hunt
 - Mark Payson