

**OPTN Patient Affairs Committee
Meeting Summary
January 17, 2023
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 01/17/2023 to discuss the following agenda items:

1. Regional Meeting Preparation
2. Active OPTN Portfolio: Where projects fall along the transplant journey subway map
3. Project Discussion

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

1. Regional Meeting Preparation

The Committee was informed of upcoming regional meetings¹ and provided an overview of the Committee's regional meeting presentation.

Summary of discussion:

A member stated that more dialogue needs to be encouraged between the Committee and the broader transplant community. The member suggested that the next regional meetings should expand the short presentation to be an active dialogue between Committee members and members of the region.

Next steps:

The Committee will receive meeting invitations for additional preparation.

2. Active OPTN Portfolio: Where projects fall along the transplant journey subway map

The Committee reviewed the active OPTN portfolio and where the current projects align with stops along the transplant journey subway map.²

Summary of discussion:

The Chair asked if there are opportunities to collect long-term survival data. Staff responded that transplant programs are required to follow-up with transplant recipients annually, and that data is submitted to the OPTN. Staff added that the OPTN Living Donor Committee is actively discussing long-term living donor data collection.

¹ OPTN Regions, more information available at <https://optn.transplant.hrsa.gov/about/regions/>.

² Scientific Registry of Transplant Recipients, 2022 Consensus Conference Workbook. Transplant system, page 8. Available at https://www.srtr.org/media/1568/cc-workbook_final_2.pdf.

3. Project Discussion

The Committee discussed potential projects. Staff noted that the Committee may pursue its own project or continue to focus primarily on providing feedback on other projects.

Summary of discussion:

A member expressed interest in a project that addresses patient notification. The member advocated the Committee address standardizing notification to transplant candidates and transplant recipients. The member stated that individuals should be informed of anything of significance that affects their health. The member requested more information on timelines for project development and implementation. Staff noted that project timelines depend on the type of project. For example, policy development projects may take longer than development of OPTN resources and guidance.

Another member agreed that patient notification is important. The member emphasized that patient notification is imperative to make sure individuals understand what is happening. The member added that some resources, such as *What Every Patient Needs to Know*,³ is shared too late in the transplant process. The member stated that informational resources need to be provided by primary care physicians. The member stated that there is a lack of education for pre-transplant patients.

A member noted that notification of inactivation is often performed verbally and in writing by the transplant program. Staff noted that notification of temporary inactivation is not a policy requirement. Staff added that notification of removal from the waiting list for reason other than transplant or death is required.⁴

A member expressed interest in the topic of transportation of deceased donor organs. The member asked if this topic falls under the purview of the OPTN. Staff responded that the OPTN is looking at where the OPTN may be able to have an impact on transportation of organs within the scope of its authority .

The Chair asked if there is data on the number of active and inactive transplant candidates. Staff noted that OPTN data as of January 16, 2023 shows that there are 89,169 total transplant candidates waiting for a kidney, and 47,736 of those transplant candidates are listed as active on the waitlist. Members noted that number of inactive transplant candidates waiting for a kidney appears to be high. The Chair asked if the number for active and inactive transplant candidates fluctuates. A member responded the number of active and inactive transplant candidates fluctuates. The member noted that there are a number of reasons a transplant candidate may be inactive, such as having an infection, being unable to be reached, or being very sick and in the intensive care unit (ICU). Another member noted it is frightening a transplant candidate can be inactivated due to the transplant program being unable to contact the transplant candidate, because transplant programs may not be making significant efforts to contact the transplant candidate.

The member stated this is disheartening and the patient notification requirements should be changed. The member asked how patients are notified. The member noted that some people do not accept certified mail. A member responded that mail is sent, if that information is available, but communication often occurs through the hospital system and e-mails.

Another member mentioned that, separate from the patient notification process, organ procurement organizations will send multiple organ offers in order to have back-up acceptances in place. The Chair

³ *What Every Patient Needs to Know*, Available at <https://unos.org/wp-content/uploads/Brochure-113-What-every-patient-needs-to-know.pdf>.

⁴ OPTN Policy 3.5: Patient Notification, Table 3-2: Transplant Hospital Patient Notification Requirements, as of January 2023. Available at https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf.

asked if inactive transplant candidates receive organ offers. The member responded that inactive transplant candidates are unable to receive organ offers.

The Chair noted that they have developed a list of the top project ideas that have arisen from Committee members.

Next steps:

The Chair will disseminate the list of project ideas to the Committee. The Chair requested the Committee members consider what they wish to be the future work of the Committee. The Committee will continue these discussions during the upcoming meeting.

Upcoming Meetings

- February 21, 2023 (Chicago, IL)
- March 21, 2023 (teleconference)
- April 18, 2023 (teleconference)

Attendance

- **Committee Members**
 - Calvin Henry
 - Dana Hong
 - Eric Tanis
 - Garrett Erdle
 - Julie Spear
 - Kenny Laferriere
 - Kristen Ramsay
 - Lorrinda Gray-Davis
 - Molly McCarthy
 - Sejal Patel
 - Steven Weitzen
- **HRSA Representatives**
 - Jim Bowman
 - Mesmin Germain
 - Marilyn Levi
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Bridgette Huff
 - Kaitlin Swanner
 - Kim Uccellini
 - Meghan McDermott
 - Roger Brown
 - Sara Rose Wells
 - Tina Rhoades