

**OPTN Patient Affairs Committee  
Meeting Summary  
June 18, 2024  
Conference Call**

**Garrett W. Erdle, Chair  
Molly J. McCarthy, Vice Chair**

## **Introduction**

The Patient Affairs Committee met via WebEx teleconference on June 18, 2024, to discuss the following agenda items:

1. Welcome and Announcements
2. Patient Awareness of Listing Status (PALS) Project Update
3. Update on Preliminary SRTR Data Request Related to Inactive Status
4. American Transplant Congress 2024 Takeaways
5. Recognize Outgoing Members and Changing Roles
6. Public Forum

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

### **1. Welcome and Announcements**

The Chair welcomed attendees to this last call of the committee term, sharing that he attended the OPTN Board of Directors meeting earlier today. The emphasis of this Board meeting was noted as the business of transplantation rather than the medicine of transplantation today, with OPOs and programs sharing their experiences and successes.

### **2. Patient Awareness of Listing Status (PALS) Project Update**

No decisions were made, but Committee is supportive of project moving forward.

Recognizing the distinction between inactive status and waitlist status efforts, the Chair talked about reframing the proposed inactive status notification policy effort to more broadly allow candidates to be aware of their overall status on the waitlist (active versus inactive). Concern was shared by some Committee members after the May 2024 call that the desire to understand more about available data regarding inactive status was being co-mingled with the proposed project- narrowing its scope.

#### Summary of discussion:

The Committee was concerned about the large number of candidates at inactive status at any point. Of the nearly 104,000 candidates currently on the wait list, over 45,500 are currently inactive, with the bulk of these inactive candidates awaiting kidney transplant. The Committee has heard anecdotal stories of individuals unaware of their inactive status. There is a desire to pursue a means for candidates to ascertain their wait list status (inactive or inactive) in real time.

While at the Board of Directors meeting, the Chair shared that he spoke with fellow chairs of other OPTN committees (Ethics, Data Advisory, Living Donor, Minority Affairs, and Transplant Coordinators) to seek their support for this effort. To date, all are generally supportive of candidates having access to this

information in real time. While some highlighted areas of resistance that will probably be encountered in advancing this project, they also provided thoughts on how to overcome that resistance. The Chair has scheduled calls with Kidney and Transplant Administrators Committee leadership to have similar conversations.

The Chair referenced a recent email from a past PAC member, noting the need for waitlist status to be available to candidates. This was a concern during her term and remains one today, but technology has improved. This email was noted as marking a full circle moment. Acknowledging the number of organs that were not transplanted in 2023, the Chair believes that having more candidates active on the waiting list may result in decreasing nonuse and increasing the number of transplants.

The Committee will determine the next steps. They perceive a simple solution- is patient active or inactive on the website. While there are other elements that could be included here, this was seen as a simple win that provides clarity and transparency to patients.

The proposed project will go to the Policy Oversight Committee for consideration when ready and looked at as part of the overall portfolio of projects. The Chair understood patient focused initiatives to be more front and center in light of resource limitations for the organization noted during the Board meeting.

#### Next Steps:

A work group will be put together to focus on next steps, including simple objectives and bullet points, to advance this proposed effort to the Policy Oversight Committee for review and approval. The Committee's goal is to take this to the Policy Oversight Committee by the end of the summer. Tome

### **3. Update on Preliminary SRTR Data Request Related to Inactive Status**

Committee members supported submission of the data request, pending final approval by Committee leadership.

A Committee member shared that the draft data analysis to be presented is the culmination of over a year's worth of inquiries and reviewing requests to better understand inactive status reporting.

#### Summary of presentation:

SRTR Contractor staff outlined the analysis plan developed based on input from the PAC's informal workgroup to date. The research question derived from these discussions is disparities in the use of inactive status in adult kidney candidates. Information will be reviewed by social determinants, examples of which include sex, race, educational attainment, insurance type, region, and other patient characteristics. The Committee wishes to understand who gets made inactive and when- and how long it takes for these individuals to reach or return to active status. Official work on running the desired analyses will begin once a data request is submitted to both SRTR and HRSA. Today's meeting is focused on seeking Committee support for the plan outlined based upon workgroup comment.

A three-pronged approach was proposed to capture the patient journey in different phases:

1. Time from listing to first activations
  - a. Are certain patient subgroups inactivated faster than other patient subgroups?
2. Time from listing at inactive status to first activation
  - a. Are certain patient subgroups made active more quickly than other patient subgroups?
  - b. Especially relevant for inactivation due to "incomplete workup"
3. Time from inactivation (at any point) to next activation

- a. Once inactive, do certain patient subgroups stay inactive longer than other patients?

The proposed models will consider all patient characteristics simultaneously. This will allow the SRTR to estimate outcomes (e.g. time to first inactivation) for each patient subgroup with all else being equal. For example, time to first inactivation for Black and non-Black patients with the same BMI, waiting time, age, sex, level of education, insurance, etc. in order to understand the question (for example) of whether Black race is independently associated with time to first inactivation above and beyond what can be explained by other patient factors.

The following characteristics will be used:

- Age at listing
- Sex at birth
- Race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian/Pacific Islander, White)
- Ethnicity (Hispanic or Latino – yes/no)
- Educational attainment
- Working for income (yes/no)
- Insurance type (private, Medicaid, Medicare)
- BMI at listing
- Region of the listing center
- Total waiting time (listing or dialysis)

The proposed cohort for this analysis includes adults aged 18 years and up listed for kidney and kidney pancreas transplant on any day from January 1, 2022, through December 31, 2023. This would include candidates listed before January 1, 2022. This sample would focus on current waitlist practices- the most recent two years of data, but could be extended to June 30, 2024, if desired, providing a 2.5-year snapshot.

While kidney and kidney-pancreas candidates will be included here due to similarity in patient population, it was noted that those awaiting other organs have a different waitlist experience, as inactive status is used differently for them.

#### Summary of discussion:

A Committee member noted that this information would not include whether or not the inactive individual was aware of their status, questioning whether this would be a later phase of the project. The Chair noted that the ability for individuals to look up their current waitlist status (inactive vs active) was part of the Committee's PALS project, but that information is not currently available to patients and there is no data on whether notifications are currently completed.

Some concern was raised about including pancreas, as the kidney follows the pancreas in this allocation scenario. It was noted that wait time is still captured similarly to kidney alone list, with people holding more dialysis time holder more wait time accrual. SRTR Contractor staff noted that the kidney-pancreas candidates could be removed from the cohort without significantly impacting the data set.

One member noted concern regarding snapshot data of a time period versus reviewing a larger cohort of a decade's worth of data. There was interest in looking at trends over time. SRTR contractor staff noted that the challenge in looking at longer time periods is the changes to allocation policy over time. Clarification was offered that "snapshot" did not note looking specifically at a point in time, but rather following every adult on the waiting list during that 2 year/2.5 year period of time (regardless of listing date). The recent cohort was suggested due to the number of patients that will fall into this large

window (as listed during this time period). Contractor staff noted that this time window would include people just listed as well as people listed for many years and still waiting for transplant.

A Committee member asked if other patient populations such as pediatrics or other organs might be included in the cohort at a later time or in another review. Recognizing that the kidney provides a much larger sample size, the SRTR Contractor staff noted that certainly other organs or subsets of the population could certainly be reviewed. Kidney was selected as the vast number of inactive status patients are listed for kidney.

The post-COVID sample was noted. A member asked if there was value in looking pre-COVID and post-COVID for comparison on listing practices. It was acknowledged that kidney nonuse has increased in recent years, with a focus on this topic by the Expeditious Task Force. The Contractor staff noted that issues arising post-COVID do not seem to be the result of the pandemic itself at this point but noted that this is speculation.

Next Steps:

OPTN and SRTR contractor staff will finalize the data request and circulate a draft for final approval by the Chair and Vice Chair before submission.

**4. American Transplant Congress 2024 Takeaways**

No decisions were made.
-------------------------

Committee members who attended the 2024 American Transplant Congress in Philadelphia were asked to share any highlights or takeaways that would be of interest to the group. The Committee Chair encouraged Members to attend if their calendars allowed. There is a reduced fee for transplant community (patient) participants.

Summary of discussion:

Members shared the following thoughts:

- One member presented an abstract and a poster during the meeting. Her work focused on the educational needs of pre- and post-transplant patients and psychological support of pre- and post-transplant patients.
- A member was surprised that transplant industry members (drug and device companies) were also talking about waitlist management support and transplant administrative support and the electronic data interchange they are using to assist their patients in these areas (e.g. reminding them that tests are needed to be actively listed as an example). There may be additional help in the larger community related to the PALS project.
- A great opportunity to connect and network. There was a patient summit held during the event. This is a newer offering to get the patients in attendance together.
- There is an opportunity for transplant professionals to learn from the patient experience. Patients attending and giving their input is valuable.
- The conference included an exhibit hall with booths for many donation and transplantation stakeholder organizations and businesses, including the OPTN Expeditious Task Force.

## 5. Recognizing Outgoing Members and Changing Roles

Committee leadership recognized the individuals completing their terms on June 30, 2024, thanking them for their commitment and service. An outgoing member shared her thanks for being allowed to have a voice on the Committee and giving her the confidence to speak from where she stands. Outgoing members shared their thoughts and appreciation for the opportunity to serve the Committee and the patient community.

The outgoing Chair was recognized for his leadership and commitment. He will continue on the Committee for one more year as ex officio past chair.

The new Chair and Vice Chair were congratulated for their terms, starting July 1, 2024.

## 6. Public Forum

### Discussion Summary:

No public forum items were offered for discussion.

### Upcoming Meetings

- July 16, 2024 conference call
- August 20, 2024 conference call
- **September 10, 2024 in person meeting**
- October 15, 2024 conference call
- November 19, 2024 conference call
- December 17, 2024 conference call
- January 21, 2025 conference call
- February 18, 2025 conference call
- **SPRING 2025 in person meeting TBD**
- March 18, 2025 conference call
- April 15, 2025 conference call
- May 20, 2025 conference call
- June 17, 2025 conference call

## June 18, 2024 Attendance

- **Committee Members**
  - Garrett Erdle
  - Molly McCarthy
  - Lorrinda Gray-Davis
  - Densie Abbey
  - Cheri Coleman
  - Tonya Gomez
  - Calvin Henry
  - Andreas Price
  - Cathy Ramage
  - Kristen Ramsey
  - Julie Spear
  - John Sperzel
  - Steven Weitzen
- **HRSA Representatives**
  - Mesmin Germain
- **SRTR Representatives**
  - Katherine Audette
  - Allyson Hart
  - Grace Lyden
- **UNOS Staff**
  - Shandie Covington
  - Desiree Tenenbaum
  - Kimberly Uccellini
  - Jessica Higgins
- **Other**
  - Michael Brown
  - Robert F Johnson
  - Karlett Parra
  - Cody Reynolds