

## **OPTN Transplant Coordinators Committee**

### **Meeting Summary**

**May 18, 2023**

**Conference Call**

**Stacy McKean, RN, Chair**

**Natalie Santiago-Blackwell, RN, MSN, Vice Chair**

### **Introduction**

The OPTN Transplant Coordinators Committee (the Committee) met via Citrix GoToMeeting teleconference on 05/18/2023 to discuss the following agenda items:

1. Welcome
2. Living Donor Data Collection Project: Request for Feedback
3. Estimated Glomerular Filtration Rate (eGFR) Implementation: Effective Practices
4. Reminders

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

#### **1. Welcome**

Committee leadership and staff welcomed the Committee members.

#### Summary of discussion:

The Committee members had no questions or comments.

#### **2. Living Donor Data Collection Project: Request for Feedback**

The Vice-Chair of the Living Donor Committee provided information about two projects scheduled to go out for public comment during the Summer 2023 cycle.

#### Presentation Summary:

The Living Donor Committee has two separate, but related, projects.

- Granular Review of OPTN Living Donor Data Collection
  - Updated data collection to ensure accurate data collection on living donors and improve analyses to inform living donation decision-making and evidence-based policy making.
  - A data collection proposal will recommend modifications, removals, and additions of data elements on three OPTN living donor data collection instruments.
    - Additional modifications include restructuring sections for ease of entry and clarity, as well as updates to data definitions via help documentation.
- Collect Living Donor Candidate and Donation Decision Data
  - Purpose: to improve data on long-term outcomes of living donation through a collaboration between the SRTR Living Donor Collective and the OPTN.

#### *Living donor candidate data*

- Collecting this data will allow for data collection on an appropriate comparator group to analyze the risks and benefits attributable to live organ donation.

### *Donation decision data*

- Collecting an approved individual's living donation decision will allow for analysis regarding equitable access to living donation and reasons for not donating.

### *Upstream data collection by the OPTN will help support the SRTR's Living Donor Collective as a national living donor registry*

- With the OPTN collecting front end data, the SRTR's Living Donor Collective can collect downstream data and assess long-term outcomes of living donor candidates and living donors
- The Committee also will discuss realigning current follow-up requirements to mitigate increases in resources

The POC approved a concept paper with the aim to get community feedback. The goals of these projects are to increase efficiency, reduce redundancy, and acquire key data. The concept paper will provide the following:

- Detail potential updates to current OPTN living donor data collection instruments and seek feedback
- Educate community on the Living Donor Collective
- Detail potential data collection on living donor candidates and donation decision and seek feedback
  - Living donor candidate defined as someone who was evaluated at a transplant program
    - This definition will continue to be refined
- Overview how new potential data collection processes support long-term data collection on living donors

Questions for Committee feedback and discussion:

- Feedback on the definition for living donor candidate?
- How does your transplant program define "evaluation" for living donors?
- Preferences on type and amount of data collection on living donor candidates?
- What opportunities might there be to reduce any redundancy or burden in the living donor data collection processes?
- What is your transplant program's process for screening and evaluating living donors?
- Would reducing OPTN living donor follow-up requirements help with allocating resources to collect data on living donor candidates and donation decision?

### Summary of discussion:

A member noted that her transplant center classifies "potential living donors" as those undergoing evaluation and "approved living donors" for those who make it through evaluation and are moving forward with donation. The Living Donor Committee representative supported the use of "approved" to distinguish between those undergoing evaluation and actual living donor candidates.

The Living Donor Committee representative asked about the reasons why an individual would not be approved. A member responded that the top reasons are high body mass index (BMI), diabetes, and hypertension.

A member noted that her transplant center considers everyone that starts the evaluation and selection committee process as a candidate. She added that the 2019 changes to the Centers for Medicare and Medicaid Services (CMS) conditions of participation and interpretive guidelines added clarifications

around the informed consent process for living donors and programs are not allowed to start evaluations until certain parameters are met. The member further added that her transplant program will do an initial screening with medical history before requesting consent and moving forward with the evaluation process.

The Living Donor Committee representative asked members if transplant programs might be willing to provide basic data on potential living donors prior to what is currently required in OPTN policy. A member responded that there might be challenges based on transplant center volume. For example, some programs might only allow one potential donor to be evaluated at one time for a particular recipient while others will evaluate multiple potential donors.

The Living Donor Committee representative acknowledged that living donor follow-up rates are challenging because donors want to get on with their lives after a certain period and don't want to return for appointments and testing.

A member suggested using something similar to the Covid vaccine study that was done where patients could opt in or out to provide information at certain time intervals. This could take some of the data burden off transplant programs. The Living Donor Committee representative noted that the Scientific Registry of Transplant Recipients (SRTR) has the framework and resources to do that work.

A member noted that one challenge with living donation is that occasionally a large number of individuals will come forward offering to donate. This might be due to a media campaign for a kidney, and it puts a great deal of burden on transplant programs to identify which of these individuals are serious about donating an organ.

A member stated that her transplant programs get approximately one thousand referrals for living donation every year. Of those, approximately 120 move forward to the evaluation stage and only 30% of those become donors. So, it does require a significant amount of work for the transplant programs and being required to submit additional data on those that don't become donors would be a burden on transplant programs.

There was no further discussion.

### **3. eGFR Implementation: Best Practices**

UNOS staff provided an overview of the eGFR modification project, including the implementation timeline.

Effective practices shared by the community include:

#### Assessing waiting lists

- eGFR "cutoff"
- Divide list by 1) dialysis and 2) preemptive
- Review active candidates first, then inactive

#### New candidates

- List candidate, then submit modification. A two- step process, completed in one visit.
- Include notification 1 in new patient notification letter

#### Candidate notifications

- Individualized notification for candidate who may be/is eligible
- General notification for candidates who are not eligible

#### If documentation not found in program's record

- ID nephrologist in candidate notification
- Discuss with candidate during clinic time (if able)

#### Strategies to reduce workload

- Call upon additional staff/divide and conquer
- Develop a workflow: staff for each step of process

#### Summary of discussion:

A member noted that her transplant center has gone through their entire waiting list and identified which eGFR calculation was used and were able to change it for a handful of patients. She added that they also changed the eGFR calculation for all their patients to ensure it is race neutral.

A member noted that her transplant program is putting the onus on patients to provide documentation from their nephrologists once they have been notified. She added that several patients who do not qualify for the waiting time modification due to race are requesting that their initial low eGFR be used. Staff responded that they have heard similar feedback and noted that patients need to be reminded that this change was for patients affected by the race inclusive eGFR calculations.

A member noted that her transplant program has received a lot of phone calls with questions mainly due to patients not understanding how the change does or does not affect them. Staff noted there is a plan for a collaborative in July where the community will be able to share best practices.

There was no further discussion.

#### **4. Reminders**

Staff provided a reminder about the next conference call and thanked the committee member for their time.

#### **Upcoming Meeting**

- June 8, 2023 (Teleconference)

## Attendance

- **Committee Members**
  - Stacy McKeon
  - Natalie Santiago Blackwell
  - Angele Lacks
  - Ashley Hamby
  - Ashley Cardenas
  - Donna Campbell
  - Heather Bastardi
  - Jamie Myers
  - Melissa Walker
  - Madison Salazar
  - Stacy Sexton
  - Rachel White
- **HRSA Representatives**
  - Arjun Naik
  - Shelley Grant
- **UNOS Staff**
  - Robert Hunter
  - Ross Walton
  - Meghan McDermott
  - Kelley Poff
- **Other Attendees**
  - Stevan Gonzalez
  - Christine Brenner