

**OPTN/UNOS Pediatric Transplantation Committee
Meeting Minutes
June 21, 2017
Conference Call**

**William Mahle, M.D., Chair
George Mazariegos, M.D., Vice Chair**

Introduction

The Pediatric Transplantation Committee met via teleconference on June 21, 2017 to discuss the following agenda items:

1. SRTR Program Specific Reporting
2. Transition Subcommittee Update
3. Update on project to Reduce Pediatric Liver Waitlist Mortality
4. New Project Discussion
5. Member recognition

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

1. SRTR Program Specific Reporting

Colleagues from the Scientific Registry of Transplant Recipients (SRTR) requested an opportunity to address the Committee regarding a conflict in data reporting re: pediatric transplant recipients.

Summary of discussion:

Jodi Smith, M.D., Nicholas Salkowski, Ph.D., Andrew Wey Ph.D., and Jon Snyder, Ph.D. from the SRTR shared a brief presentation with the Committee. The SRTR stratifies several metrics through the program specific reports (PSRs) by pediatric status, including:

- Transplant Rate
- Waitlist Mortality
- Post-transplant survival

Based on the historical reporting practices, there is some concern that the definitions of pediatric status are inconsistent and may generate confusion for those individuals reviewing SRTR data sets. This situation became more apparent with changes to the SRTR website. Dr. Smith profiled the differences between the definitions and issues at hand. The current definitions include:

Pre-transplant Metrics: Pediatric status determined by age at the beginning of the evaluation window (calendar year)

Post-transplant Metrics: Pediatric status determined by the age at transplant

Dr. Smith then shared the issues with this approach:

1. 'Pediatric' candidates could be 'adult' recipients – a candidate in the pediatric component of the PSRs for pre-transplant outcomes can then appear in the adult component for post-transplant outcomes if the candidate ages past 18 years old prior to the transplant.
2. SRTR has received feedback indicating that the definition generates confusion when evaluating programs in the public reports.

Dr. Smith shared a sampling of SRTR website data for pediatric liver transplant programs to illustrate the issue. Dr. Smith emphasized, this issue only presents when a patient less than 18 years old is registered for a transplant, then ages to 18 years old or more when they receive a transplant. The same situation exists for other pediatric transplant programs.

Based on this discrepancy in definitions, the SRTR proposes to use the age at listing for both pre and post-transplant metrics. The intent of these changes is to:

- Having a standard definition will avoid confusing situations when presenting data for primarily pediatric hospitals
- Adhering to an intent-to-treat principle suggests evaluating outcomes from the time of listing
 - An older pediatric patient is interested in the outcomes of similar candidates listed at the program
 - Defining pediatric status as age at transplant may obscure relevant post-transplant outcomes to prospective pediatric candidates

SRTR representatives are reaching out to stakeholders for input. This has included:

- OPTN/UNOS Membership and Professional Standards Committee (MPSC) leadership did not have a strong opinion but wanted any change to be clearly communicated to ensure that there are not any negative implications for MPSC review
 - SRTR will communicate any change months in advance
- Informally discussed with Stuart Sweet, M.D. (OPTN/UNOS President)
 - Dr. Sweet suggested engaging the pediatric committee for their advice.
- Formally discussed with SRTR Scientific Visiting Committee (SVC)
 - Did not have concerns but recommended consulting the pediatric committee
- Any change would be vetted with Center for Medicare/Medicaid Services (CMS) due to a potential impact on evaluations

The Chair thanked Dr. Smith for her presentation and opened the floor to questions. Several members of the Committee asked what, if any, impact this change in definition would have on a candidate's status on the Waiting List. Drs. Smith and Salkowski responded that changes to the definition for data reporting would not impact a candidate's status on the Waiting List, or retaining pediatric priority for those candidates that are registered prior to age 18 but are transplanted after age 18. The pediatric priority for organ allocation is dependent on OPTN policy and would not be associated with transplant outcomes reporting.

The Committee did briefly discuss an alternative definition; use of the candidate's age at the beginning of the calendar year of which they are registered on the waiting list. During the discussion, SRTR representatives commented that this approach may make it more challenging to assess the effectiveness of pediatric priority in OPTN policies. Dr. Salkowski was not confident that more complex rules/definitions would result in beneficial gains. For example, there are transplant programs that have diverse clinical experience, and there are those transplant programs that are specialized (e.g.: pediatric or adult care). By capturing data in one cycle by the age (e.g.: a pediatric aged patient) at the beginning of the calendar year, the following cycle could capture a different age (e.g.: an adult aged patient), the data reported at these specialty programs would be confusing to viewers.

Dr. Salkowski noted for the Committee that there is nothing inaccurate in the current calculations. Rather, the proposed definition change is in keeping with the manner in which transplant programs specialize. Members of the Committee generally agreed with the rationale as described. The Chair noted the new minimum training and experience requirements for

pediatric transplant programs on the horizon will make this less of an issue for adult hospitals; this is most relevant to the pediatric hospitals.

Members of the Committee agreed the definitions in use needed to be as accurate as possible. In general, members of the Committee were in favor of the changes in the definitions. The Chair acknowledged there are “pluses and minuses” with any change, though the “pluses” appeared to outweigh the “minuses” in this case. Dr. Smith thanked the Committee for the opportunity to share these proposed definition changes and for their feedback.

Next steps:

- SRTR colleagues will follow-up with the Committee with the points raised during the discussion.
- The Committee requested an update on the final changes in the future.
- Committee members are encouraged to discuss with colleagues at their index institutions and email feedback to the SRTR.

2. Transition Subcommittee Update

An update was provided from the Transition Subcommittee following their conference call on May 23, 2017.

Summary of discussion:

During the May 23, 2017 conference call, UNOS staff responded to a request from the Subcommittee regarding data to help inform decision-making. The data presented centered on Pediatric Lost to Follow-Up Rates at Different Transplant Programs. The concept of this analysis was that “high performing” transplant programs with low lost to follow-up rates could be identified, then surveyed for effective practices. Members did comment that there would be value in surveying both high and sub-optimal performers to identify effective/less effective practices. Further, there would be value in sharing information with the OPTN/UNOS Membership and Professional Standards Committee (MPSC) for any performance improvement considerations.

The Subcommittee previously identified that transplant programs with different case volumes could have varying lost to follow-up rates. The Subcommittee discussed case volume ranges that could correlate with high, medium, and low volume transplant programs. Members held a short discussion on this topic and favored the following:

- High volume – 20 or more kidney transplants per year
- Medium volume – 7-20 kidney transplants per year
- Low volume – less than 5 kidney transplants per year

The Subcommittee felt further consideration of these classifications would be prudent and they would discuss during the next conference call. This will help identify what transplant programs to work with for the survey.

The Subcommittee also discussed individuals that may be most appropriate to complete the survey. Members acknowledged that surgeons and physicians at transplant programs may be unfamiliar with the nuance of OPTN data submission. The Subcommittee also discussed the idea of developing draft survey questions for the next conference call in July 2017.

UNOS staff recommended sections of the guidance be drafted while the online survey is underway. This will eliminate an extended development timeline if these two phases of the project were pursued sequentially.

The Chair thanked UNOS staff for the diligent update and agreed with the work plan to draft the guidance document while the survey was being conducted. He then opened the floor for questions. One member suggested that the survey examine high performers and the geographic or health system considerations that may lead to low lost to follow-up rates. This may outweigh workflow practices or individual performance. Another member asked, is the Subcommittee looking at all organ transplant programs, or a subset of transplant programs? UNOS staff responded that the Subcommittee examined lost to follow-up rates for all organs, but the highest incidence of lost to follow-up following transition was seen in kidney and liver transplant recipients.

Next steps:

- Future Subcommittee calls are planned for July and August 2017. Additional updates will be presented to the Committee in the months ahead.

3. Update on project to Reduce Pediatric Liver Waitlist Mortality

The Chair provided a short update on the status of the Committee's project to *Reduce Pediatric Liver Waitlist Mortality*.

Summary of discussion:

In September 2016, the OPTN/UNOS Executive Committee reviewed the Policy Oversight Committee's recommendation to approve a project to *Reduce Pediatric Liver Waitlist Mortality*. The Executive Committee felt this project had merit, however there were no resources available to pursue the effort.

The Chair spoke with UNOS staff on the status of this "hold" in June 2017. UNOS staff explained that the OPTN/UNOS Liver and Intestine Committee's effort to revise the liver allocation system continued to consume a great deal of OPTN and non-OPTN resources. Thus, the Committee's project to *Reduce Pediatric Liver Waitlist Mortality* needed to remain on hold for the next several months. UNOS staff will have a better understanding of the timeline after the Executive Committee's conference call in July 2017. Thereafter, it would be prudent to have an update discussion with Liver Committee leadership.

After the update, the Chair opened the floor for discussion. One member asked, did this project indeed need to go back to POC for re-approval? UNOS staff explained that by the Executive Committee "approving to on-hold" prevented the need to re-litigate the merits of the project or pull new data to assess or show a problem. Other members of the Committee verbalized their assurance by this update and were optimistic for a more definitive timeline in August 2017.

Next steps:

- UNOS staff will participate in the forthcoming POC and Executive Committee calls in July 2017. The Committee will be kept apprised of further developments.

4. New Project Discussion

The Chair coordinated a brief update on new projects identified during the in-person meeting in April 2017.

Summary of discussion:

The list of project ideas (both existing and new ideas) were shared with the Committee:

- Existing ideas
 - Promote living donation (caution advised, Living Donor Committee handling)
 - Encourage use of increased risk donor organs (DTAC handling)
 - Living donation to pediatric candidates (ongoing discussions, gaps in data identified)

- Clinical criteria for pediatric liver/kidney transplantation (this may be a good project for the Committee – need to keep the OPTN/UNOS Kidney Transplantation Committee apprised of progress in this area)
- Transplant outcomes in pediatric congenital heart disease
- New ideas
 - Assess for Disadvantaged Patients in the Current Heart Allocation System (can collaborate with Thoracic Committee on post-implementation monitoring)
 - Reduce Incidence of Suicide Among Transplant Recipients
 - Prioritize Pediatric Kidney Candidates
 - Separation of Pediatric Kidney Outcome Data From Adult Outcome Data
 - Increasing split liver transplant when the index program is an adult program (likely can addressed in existing proposal on pediatric liver waitlist mortality)

UNOS staff then asked the Committee to prioritize a “short list” of projects.

- Clinical criteria for pediatric liver/kidney transplantation
- Transplant outcomes in pediatric congenital heart disease
- Reduce Incidence of suicide among transplant recipients
- Prioritize pediatric kidney candidates
- Separation of pediatric kidney outcome data from adult outcome data

An online survey will be sent to members following the call.

Next steps:

- UNOS staff will send an online survey to all members. The results of this survey will be shared with the Committee in August 2017.

5. Member recognition

The Chair recognized members whose terms were concluding in June 2017. This included:

- Manuel Rodriguez, M.D.
- Kyle Soltys, M.D.
- Gregory Abrahamian, M.D.
- Shikha Sundaram, M.D.
- Thomas Nakagawa, M.D.
- Eileen Brewer, M.D.
- David M. McMullan, M.D.

The Chair then introduced new members that would be joining the Committee in July 2017. This included:

- Khashayar Vakili, M.D. – Boston Children’s Hospital
- Rachael Ryan, RN, B.S.N. – Children’s Hospital of Philadelphia
- Tamir Miloh, M.D. – Texas Children’s Hospital
- Amira Al-Uzri, M.D. – Oregon Health and Science Univ.
- Priya Verghese, M.D., M.P.H. – Univ. of Minnesota
- Arika Hoffman, M.D. – Univ. of Nebraska
- Melissa Nugent, RN, B.S.N., CCRN, CCTC – Texas Children’s Hospital
- John Renz, M.D. – Univ. of Chicago

With no further business to discuss, the conference call was adjourned.

Upcoming Meetings

- July 19, 2017 (Transition Subcommittee conference call)
- August 8, 2017 (Transition Subcommittee conference call)
- August 16, 2017 (full committee conference call)
- September 20, 2017 (full committee conference call)
- October 12, 2017 (Chicago, IL)
- November 15, 2017 (full committee conference call)
- December 20, 2017 (full committee conference call)
- January 17, 2018 (full committee conference call)
- February 21, 2018 (full committee conference call)
- March 21, 2018 (full committee conference call)
- April 12, 2018 (Chicago, IL)
- May 16, 2018 (full committee conference call)
- June 20, 2018 (full committee conference call)