

## **OPTN Pediatric Transplantation Committee**

### **Meeting Summary**

**October 6, 2020**

**Conference Call**

**Evelyn Hsu, MD Chair**

**Emily Perito, MD, Vice Chair**

### **Introduction**

The Pediatric Transplantation Committee (the Committee) met via Citrix GoToTraining teleconference on 10/6/2020 to discuss the following agenda items:

1. Pediatric Bylaws Implementation Update
2. Liver and Pediatric Collaborative
3. Kidney-Pancreas Workgroup Update
4. Collaborative Improvement Update
5. Project Idea Discussion: Mortality Manuscript Update, Ethics-Pediatrics Manuscript Update, KAS Review Manuscript Update

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

#### **1. Pediatric Bylaws Implementation Update**

The Committee were updated on the Pediatric Bylaw implementation and application process.

##### Data summary:

A bylaws change that was sponsored by the Committee and approved by the Board in 2014. The Committee is tasked with overseeing the implementation of the bylaw changes.

There are no changes in the listing practices for Intestine, Pancreas Islets and VCA. The other organ programs are now required to have an approved pediatric component in order to list pediatric patients in compliance with the OPTN bylaws. There is an emergency pathway exception for heart and liver pediatric patients.

However, if a program without a pediatric component begins to list a pediatric patient when no emergency pathway exists, the program will receive an alert that the action is out of compliance with the bylaws and subject to review. The warning banner will persist on the specific candidate listing it involves as long as they fall into noncompliance.

##### Summary of discussion:

The Committee Chair asked if there was a mockup of this process. UNOS staff stated that a mockup was being developed and was awaiting language to be approved. The Committee Chair requested that a presentation of the mockup be presented to the Committee when finalized.

UNOS staff continued by explaining the process for pediatric listings for programs without an approved pediatric component using the emergency pathway. The listing of pediatric candidates is permissible as long as it meets the emergency pathway criteria, if not the program will receive an alert that the action is out of compliance and may be subject to review.

A member asked if a patient could receive an organ despite being out of noncompliance and the system placing a warning on the patient's file. UNOS staff stated that all listed candidates would be able to receive organ offers despite the alert.

The Pediatric Committee decided that pediatric liver and 1A candidates listed at centers without the appropriate pediatric components would be allowed to ride out their existing 1A forms to potentially apply for the emergency membership exception on 1A recertification. Any listing of patients outside of this category (heart, liver, or heart-liver) by programs without a pediatric component would prompt an alert and result in further review.

UNOS Member Quality staff provided an overview of how members would be monitored and efforts to have programs in compliance with the bylaws.

Programs that do not have approved pediatric components should refer their pediatric patients to programs that do. Programs without an approved pediatric component are expected to notify their patients and work to transfer them to programs that have an approved pediatric component. The previous standing of the program will no longer be permissible once the bylaws are implemented. UNOS staff from the Member Quality Department will be working with those programs to make the necessary transitions and monitoring compliance.

The Committee Chair asked when the bylaws would be implemented. UNOS Member Quality staff stated that there are still discussions to be made in the exact implementation date, but it is understood that the changes will be made shortly after the Board meeting in December. These changes are typically done in the morning so as to reduce and disruption in the system. Further information will be provided once confirmed.

A member asked if there would be consideration of notifying patients ahead of time that they could lose their listing due to the programs not being in compliance with pediatric bylaws. UNOS Member Quality staff stated that it is not expected that UNOS have direct communication with patients in this regards. UNOS will have documentation of any notices from the programs who would communicate with their patients.

UNOS Member Quality staff continued by reviewing the number of programs who have opted out or still have outstanding applications with pediatric candidates on the waitlist as of September 30, 2020. There are a total of 28 programs out of 140 who do not currently have an approved application. Those programs will be followed up by the OPTN.

The Committee Chair asked if someone were to transplant a patient before the implementation date, there would not be any review at that time. UNOS Member Quality staff confirmed that this was the case and that transplants will not be considered out of compliance until after the implementation of the new bylaws in December. Any listings after the December implementation date will be alerted and investigated as they would be considered out of compliance at that time.

There were no additional questions or comments.

#### Next Steps:

UNOS staff will continue to update the Committee on the implementation of the pediatric bylaws.

## **2. Liver and Pediatric Collaboration**

The Committee were provided an overview of their collaboration work with the Liver Committee.

Summary of discussion:

The Pediatric Committee is collaborating with the Liver Committee on the Updating Pediatric National Liver Review Boards (NLRB) Guidance as well as being a part of the PELD and Status 1B Workgroup.

To date, the NLRB Subcommittee has continued to evaluate the NLRB Guidance document and incorporate improvements based on community feedback and updated clinical experience. The pediatric guidance document was created to provide guidance to the Pediatric Specialty Board of the NLRB.

The PELD/Status 1B Workgroup was formed in May 2020. The goal of the Workgroup is the re-evaluate the pediatric liver allocation system while specifically evaluating the current criteria for status 1B.

A member stated that the collaboration with the Liver Committee is a great effort and helped to provide a larger voice from the Pediatric Committee on allocation policies and processes.

Another member agreed with this and stated that this provides an opportunity for the Pediatric Committee to provide insight and increase the benefits for pediatric patients in these allocation policy changes.

There were no additional questions or comments.

Next Steps:

The Committee will continue to be updated on the development of these projects.

**3. Kidney Pediatric Workgroup Update**

The Committee was updated on the Kidney-Pediatric project.

Summary of discussion:

In the kidney allocation processes, there are various sequences which determine allocation order. The Kidney-Pediatric Workgroup wanted to pursue increased targeted priority for pediatric donor organs.

A member asked what the upper limit of the kilos and the definition of “pediatric donors” means. The Workgroup member stated that donors under 18 years of age are classified as pediatric donors.

A member stated that if these kidneys are still labeled with high KDPI’s, it could be a barrier for transplant surgeons to accept these offers.

The Committee Chair stated that this project should be paired with educational materials that can go out to the community to advise them of these initiatives and policy changes. A member stated that this was a good idea and that there is information on the UNOS website but not in relation to kidney pediatric patients. This would be a good opportunity to do this.

Next Steps:

The Committee will continue to be updated on the progress of this project.

**4. Collaborative Improvement Update**

A UNOS staff member gave a brief overview and update on the progress of a collaborative improvement project.

Summary of discussion:

A member stated that there are 13 programs that have agreed to participate.

The Committee Chair asked what the plans were for this collaborative. UNOS staff stated that this was a discovery effort with a desire to look at this project and improving the framework to aid in other

pediatric projects. There are a number of topics that are being discussed that could be included in this project. The plan is to learn from the transplant community at large in determining timing of projects.

UNOS staff stated that it is helpful to learn where the needs and gaps are present to help in the framework of this project. CMS is looking to embark on a national level effort focused on kidney transplant and UNOS staff are keeping this in mind to ensure that programs are not overburdened.

#### Next Steps:

The Committee will continue to be updated on the progress of this project.

#### **5. Project Idea Discussion: Transplant Mortality Manuscript Update, Ethics-Peds Manuscript Update, KAS Review Manuscript Update**

The Committee discussed project idea updates on manuscripts focused on transplant mortality, ethics-pediatric collaborative effort, and KAS review.

#### Summary of discussion:

##### *Transplant Mortality Manuscript*

The Committee Chair asked for best approaches in developing the manuscript. SRTR staff stated that the Committee can work on what information is available currently. Committee members were encouraged to volunteer if they were interested.

##### *Ethics-Pediatric Manuscript*

The Committee will revisit this project idea with the Ethics Committee to review and update the Ethical Principles of Pediatric Organ Allocation white paper. There was discussion on whether revisions to the white paper would be needed or if there should be an external project where a separate manuscript were developed.

##### *Pediatric KAS Manuscript*

This manuscript will be provided to HRSA for review.

There were no additional comments or questions.

##### *Previously discussed projects*

The Committee Chair reviewed a list of previously discussed projects. Members were asked if there were additional topics that may have come up that would be of interest that the Committee should consider.

A member stated that before the Heart Committee begins work on a Continuous Distribution project, that the pediatric committee should evaluate the system and consider what improvements they would like to propose be incorporated into the new framework.

Another member stated that ABO incompatible listing are an area to evaluate that are mostly limited to patients aged 1-2 years. Additionally, there was agreement in taking a close look at the effects in the changes of the policies especially with new processes for the National Heart Review Board.

The Chair noted that there is interest in pursuing the following projects:

- 1) Broaden ABO compatible transplant criteria
- 2) Taking a look at effects in changes in heart policy on children
- 3) Focus on effects of Pediatric National Heart Review Board

A member stated that another important thing for the Committee to think about are why pediatric kidney transplants have not rebounded, what the problem is, and what the solutions must be.

Another member stated that there should be a focus on monitoring the effects of transplants after the bylaws implementation and monitoring those changes.

Next Steps:

The Committee will continue to discuss project ideas to consider to work on and address.

**Upcoming Meetings**

- November 18, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Abigail Martin
  - Andy Bonham
  - Brian Feingold
  - Caitlin Shearer
  - Douglas Mogul
  - Emily Perito
  - Evelyn Hsu
  - Jennifer Lau
  - Johanna Mishra
  - Joseph Hillenburg
  - Kara Ventura
  - Regino Gonzalez-Peralta
  - Sam Endicott
  - Sara Rasmussen
  - Shellie Mason
  - Walter Andrews
  - Warren Zuckerman
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Chris Folken
  - Jodi Smith
- **UNOS Staff**
  - Beth Overacre
  - Betsy Gans
  - Jean Teotonio
  - Joann White
  - Julia Foutz
  - Kiana Stewart
  - Krissy Laurie
  - Leah Slife
  - Lloyd Board
  - Matt Cafarella
  - Matthew Prentice
  - Nicole Benjamin
  - Roger Vacovsky
- **Other Attendees**
  - Sharon Bartosh