

# OPTN Pediatric Transplantation Committee Meeting Minutes April 16, 2019 Richmond, Virginia

# George Mazariegos, MD, Chair Evelyn Hsu, MD, Vice Chair

## Introduction

The Pediatric Transplantation Committee (the Committee) met in Richmond, Virginia on 04/16/19 to discuss the following agenda items:

- 1. Introduction to UNOS Research Department and Its Role in Committee Support
- 2. Project Type
- 3. Welcome to Richmond
- 4. Committee Project Survey Review and Prioritization
- 5. Collaborative Improvement
- 6. Pediatric Bylaws Update and Toolkit
- 7. Pediatric Liver Allocation ABO Prioritization
- 8. KAS Update
- 9. Committee Updates
- 10. Service Recognition and Incoming Roster
- 11. Open Discussion

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

## 1. Introduction to UNOS Research Department and Its Role in Committee Support

UNOS staff presented information on the role of the UNOS Research Department and how it can be used to support the work of the Committee.

## Summary of discussion:

UNOS staff explained how UNOS collects data as the OPTN Contractor. UNOS research analysts support OPTN committees by providing data analysis during the policy making process and by developing new technologies for future data analysis. The UNOS Research Department monitors policy changes post-implementation. Research analysts also help fulfill Committee data requests. UNOS staff outlined the process for submitting Committee data requests and non-Committee data requests.

A Committee member asked what the difference is between OPTN data analysis and the Scientific Registry of Transplant Recipients (SRTR). UNOS staff stated that the SRTR is responsible for modelling of future policies, while the OPTN provides more descriptive data and outcomes analysis. In addition, the SRTR provides regular reports on transplant data and outcomes. The UNOS Research Department has the ability to help Committee members with research and publications. UNOS staff outlined how the process of requesting data for a publication works. The Chair asked how the Committee could use the UNOS Research Department in prioritizing the Committee's next projects. UNOS staff stated that they would be able to fulfill the Committee's data requests which could help prioritize projects.

The Vice Chair asked if the UNOS Research Department is able to provide data on only the requestor's transplant center or if they could also provide de-identified data from other centers. UNOS staff stated that individuals from member institutions can get a Standard Transplant

Analysis and Research (STAR) file at no cost, but other data or individuals from non-member institutions may need to pay. Data on organ offers is different and typically is only provided on the institution that is requesting the organ offer data. UNOS staff further stated that they should be able to provide any aggregate data that the OPTN collects.

## Next steps:

No next steps were identified.

## 2. Project Type

UNOS Staff presented information on the different types of projects that the Committee could pursue.

## **Summary of discussion:**

UNOS staff stated that there are a multitude of project options outside of the typical policy development process. UNOS staff presented the following project options:

- 1. Policy Development: This would be the standard process used to develop new OPTN policies.
- 2. IT Customer Council: This project path would involve changes to IT programming but would not include a policy change.
- 3. Collaboration with other committees: This option would involve providing input on other committee's projects.
- 4. Communication and Education: This would include the creation of guidance documents or white papers, which do not change any member requirements.
- 5. Collaborative Improvement Project: The Committee would work with the UNOS Collaborative Improvement (CI) team to implement a voluntary improvement project that does not change any member requirements.

The Chair asked for examples of projects that went through the IT Customer Council. UNOS staff stated that this type of project would include any IT project that does not change member requirements. For example, this could be how data is entered or how offers are accepted. The Chair then asked about the current project portfolio and where there is room for a new project within the OPTN's strategic plan. UNOS staff stated that all proposed projects are evaluated for their potential benefit to the transplant community and where they fit into the five strategic goals of the OPTN. Resources are then allocated based on the five strategic goals. Currently, improving equity in access is over-allocated, but increasing number of transplants and increasing safety are the most under-allocated. There is also a lot of interest from the transplant community on increasing system efficiency. The Vice Chair asked how resources would be allocated within the different project paths. UNOS staff stated that much of this allocation is set by department budgets which are created by the OPTN Finance Committee. However, the OPTN is working on making the process for choosing projects more comprehensive. UNOS staff also noted that the new contract calls for more collaborative improvement projects.

#### Next Steps:

No next steps were identified.

## 3. Welcome to Richmond

The UNOS Chief Executive Officer (CEO) welcomed the Committee to Richmond, VA.

## **Summary of Discussion:**

The Chair asked the UNOS CEO if he thought that the Committee should pursue a project that would either increase the number of transplants or increase safety, as these two strategic goals

are currently under allocated. The UNOS CEO agreed that these two strategic goals would be good places for a new project, but also stated that the ultimate goal of the OPTN is to place each organ with the first candidate on the match run. This is currently unrealistic but the CEO suggested using it as a guide when thinking about which projects to pursue. The goal is to place each organ with the right candidate as quickly as possible.

A Committee member asked what UNOS has done to help educate the transplant community on best practices related to transportation. The CEO stated that the Operations and Safety Committee is working on a guidance document related to transportation. Additionally, the CEO stated that transportation in the field is changing due to new technologies. Specifically, there are emerging technologies to make local procurement more feasible. There are many organs that can be recovered by local teams, but there will still be organs that the transplant team will want to recover themselves. The CEO noted that drones could be used in the future. The American Society of Transplant Surgeons (ASTS) is also convening a group on transportation practices and safety standards.

A Committee member noted that UNOS Labs presented a number of projects related to improving efficiency at a recent OPTN/UNOS Board of Directors (the Board) meeting. The CEO also stated that the OPTN is starting to collect more data on transportation and travel time. Another Committee member was concerned that recent policy changes would increase travel at a time when there is a pilot shortage and less incentive to take part in risky organ procurements. The Committee member was concerned that another transportation accident could occur.

#### Next Steps:

No next steps were identified.

# 4. Committee Project Survey Review and Prioritization

Committee members previously completed a survey about project prioritization. The purpose of the survey was to inform the Committee's decision on which projects to pursue. The Committee discussed the results of the survey.

#### Summary of Discussion:

The Chair presented the list of new project ideas and the results of the survey. The Chair noted that the next Committee project could involve either a policy proposal or a collaborative improvement project. The Committee then discussed some of the ideas in more detail as outlined below.

#### 1. Review Trends in Pediatric Kidney Transplantation:

A Committee member suggested including other metrics in the data review. The other metrics that the Committee member suggested reviewing were the use of high risk donors, the increase in preemptive transplants, the decrease in living donation rates in pediatric kidney transplants, the increased use of the national kidney registry (which could increase living donation rates), and the four year data on the new kidney allocation system (KAS). The Committee member noted that the pediatric sections of the four-year KAS report are not as granular as the Committee would like.

Another Committee member asked if the Committee could review if the use of more increased risk donors has led to a higher rate of hepatitis C transmission. Another Committee member noted that the Kidney-Pancreas Workgroup (KP Workgroup) decided to give pediatric candidates more priority in sequences A and B.

A Committee member felt that they could still get more detailed, historical data on pediatric outcomes under KAS to see if there are any areas that they could improve the

system for pediatric candidates. Another Committee member noted that pediatric outcomes did not improve at the same rate as adult outcomes under KAS, and more detailed data is needed to understand why this was the case. A Committee member was concerned, however, that they would not get this data before the KP Workgroup would submit their modelling request. A Committee member stated that this is not an issue because pediatric candidates will be prioritized in the modelling request based on the KP Workgroup's discussions. However, the Committee could use more data to understand if there are other areas where pediatric candidates are not properly prioritized.

A Committee member felt that increasing the use of living donation and kidney-paired donation (KPD) for pediatric candidates, as well as more education on high risk organs, could improve outcomes for pediatric candidates. There is much variation in the use of KPD, and many small centers do not participate. Another Committee member noted that the increased transmission of Hepatitis C from increased risk organs was expected to happen, given the increased use of these organs. A Committee member noted that there may also be an increase in unintended transmissions. Another Committee member stated that there is large variation in the group of donors that are classified as high risk, with some having a much higher risk than others. The Committee member felt that there might be a way to better stratify these donors. UNOS staff noted that they do not directly collect the reason why a donor was classified as increased risk, but some indication may be in their electronic health record (EHR).

## 2. Thoracic-Related Projects:

Four of the projects included in the survey were related to thoracic organ transplantation. The Chair asked Committee members involved in thoracic transplantation to provide comments on any of these four projects.

A Committee member stated that the heart allocation system was recently changed so it is probably too early to make any additional changes. The Committee member noted that the early sense is that the new allocation system is not disadvantaging pediatric candidates but it is too early to say for certain and more data is needed.

Another Committee member stated that it is also important to increase the number of donors and the donor utilization rate. The Committee member felt that pursuing a project to increase these two metrics would have a large effect on thoracic pediatric outcomes. The Committee member also noted that there is not great data on the outcomes related to the use of increased risk organs in thoracic transplantation. A different Committee member stated that there are two papers that should be published soon related to high risk donors and donor turndowns, so it is an important and emerging topic. The Committee member suggested waiting for the papers to be published before pursuing a project on this topic.

At a recent International Society for Heart and Lung Transplantation (ISHLT) meeting, there was a presentation on a donor scoring system and its strengths and weaknesses. Some programs are starting to use the scoring system, while others are examining it retrospectively for research purposes. A Committee member suggested having the scoring system presented at an upcoming Committee meeting. There is some debate about the accuracy of the scoring system. Another Committee member noted that there is a current study being done on heart offers and turndowns.

## 3. Non-Organ Specific Projects:

A number of the projects included in the survey were not organ specific. The Chair stated that the project titled, "Establish OPTN Policy Requirement for Transition/Transfer

Protocols," would involve taking the Committee's recent guidance document and moving towards a policy requirement. Another Committee member felt that the project titled, "Promote Care Plan Adherence for Pediatric Recipients," was too broad of a topic.

## a. Risk Tolerance in Pediatric Transplant Programs:

The Chair stated that this project would examine how regulatory oversight impacts behavior at different programs, specifically related to risk tolerance. The Vice Chair felt that this related back to utilizing increased risk donors. Another Committee member noted that the Collaborative Innovation and Improvement Network (COIIN) project also examined this topic. A Committee member suggested that this project also further stratify high risk candidates, so that programs that transplant increased risk candidates are not disadvantaged in their outcomes reporting.

The Chair asked UNOS staff asked what avenue the Committee could take to move forward with a project to risk stratify candidates so that riskier transplants are not as negatively reflected in outcomes reporting. UNOS staff noted that the Membership and Professional Standards Committee (MPSC) would be the group to pursue this change. They have talked about making such a change on a few occasions, and there has been some other community support for this idea.

A Committee member felt that recent OPTN policies have accomplished the opposite of this goal by disincentivizing the utilization of national shares and other higher risk transplant procedures. UNOS staff further stated that the MPSC review process is based around conversation so programs should have the opportunity to explain their behavior.

## 4. Liver-Related Projects:

Two projects in the survey related to livers. The first, which was titled, "Guidance on Early Graft Dysfunction Surveillance to Promote Long-Term Recipient/Graft Survival" was proposed by the Chair, who explained that this project would see if there are long-term trends in the related outcomes. The second liver-related project was titled, "Review Urgent Status Criteria for Pediatric Liver Candidates."

The Vice Chair said that there will be large changes to the allocation system in the coming months, and the changes are expected to be positive for pediatric candidates. However, the Vice Chair still felt it was important to look at the urgent status for pediatric liver candidates. Data shows that there is a difference in mortality rate for Status 1B candidates with a chronic liver disease and other Status 1B candidates. The Vice Chair also noted that it will be even more important to look at the use of increased risk organs, organ utilization, and organ turn-down rates now that more pediatric candidates will be receiving offers.

Another Committee member stated that it will be interesting to see how the implementation of the National Liver Review Board (NLRB) impacts pediatric outcomes. Previously, the process for granting exception scores was regionally dependent. Under the NLRB, exception scores will become more objective, but it is unclear how much this will effect outcomes. Under the previous system, exception candidates also received additional points the longer they were on the waitlist, but this is no longer the case under the NLRB. Additionally, the pediatric end-stage liver disease (PELD) score is not considered to be a great indicator of mortality risk for pediatric candidates. The Committee member felt that it will be important to monitor pediatric outcomes under the NLRB. The Committee member mentioned that it may be beneficial to create guidelines for the NLRB to grant additional exception points to certain candidates if it becomes evident that they are being disadvantaged. Another Committee member noted that there

should be better communication towards the parent community about the NLRB because there seems to be a negative perception of the new system from parents of pediatric candidates. The anonymity of the new system is also concerning for some members of the community.

The Vice Chair has been working with the SRTR to look at re-modelling the PELD score to better prioritize pediatric candidates so that pediatric mortality is minimized. The Vice Chair stated that the most efficient way to do this would be to add a set amount of points to the PELD score.

The Chair reminded the group that the NLRB will have a pediatric-specific review board. Another Committee member felt that there could be more objective criteria around the exception scoring system. UNOS staff noted that programs will still be able to request a specific score for their patients through the NLRB. Committee members stated that very few pediatric candidates are transplanted at their laboratory PELD score, which shows that PELD is not a strong predictor of mortality or disease acuity.

A Committee member asked if there are other considerations in the granting of exception scores besides clinical criteria. The Committee member noted that there are regional differences in metrics such as waitlist time and waitlist mortality, and wanted to know if the NLRB will account for these regional differences. The Chair noted that the PELD score only takes into account clinical criteria, but exception scoring will be tied to the unit of allocation.

A Committee member who sits on the thoracic regional review board felt that they may be too lenient in granting exceptions, which then does not allow organs to go to the most urgent candidates.

The Chair asked if it would be a good time to request a descriptive analysis on pediatric waitlist mortality across all organs systems. A Committee member agreed that this would be a good time because the four-year KAS data is just becoming available. A Committee member also noted that much of this data exists in the annual reports, but the Committee may want more detailed data than what are provided in these reports. A Committee member volunteered to collate the relevant data in the annual reports.

## Next Steps:

The Committee will continue to discuss priorities for future projects.

## 5. Collaborative Improvement

UNOS staff from the Organizational Excellence Department presented to the Committee on the opportunity for the group to pursue a CI project.

#### Summary of Discussion:

The purpose of a CI project is to create improvement frameworks that can be spread to other institutions. The high-level process for a CI project is as follows:

- 1. Topic selection
- 2. Recruit subject matter experts
- 3. Develop framework
- 4. Enroll participants and test
- 5. Periodic learning and action periods
- 6. Evaluation of improvement data at an aggregate level
- 7. A final meeting where participants recap and share their experiences from the CI project

The discovery phase of the CI project cycle would include literature and data research, and alpha and beta testing. The three key elements in topic selection are will, ideas, and execution. There must be the will to improve, ideas about alternatives to the status quo, and the ability to execute.

UNOS staff presented a test case for topic selection using Public Health Services (PHS) Increased Risk as the example.

UNOS staff then presented a subset of the larger project list that could be framed as CI projects. These projects included:

- Increase utilization of PHS increased risk organs
- Increase care plan adherence for pediatric recipients
- Evaluate organ offer turn-down/acceptance
- Increase long-term patient/graft survival through effectiveness/efficiency in early graft dysfunction surveillance
- Increase patient/graft survival for pediatric congenital heart disease (CHD) patients
- Reduce suicide ideation/risk
- Increase recipient follow-up efficiency/improve follow-up
- Increase pediatric kidney-paired donation (KPD) transplants
- Increase living donation

UNOS staff then presented on the project selection process and how to create value in a CI project. UNOS staff noted that the new OPTN contract calls for more CI projects and sharing of innovative ideas. UNOS staff also stated that they will incorporate the lessons from the COIIN project in the next CI project. The OPTN plans to launch three or four CI pilot projects and one large scale improvement project each year.

UNOS staff then explained the algorithm for OPTN CI projects. The algorithm starts with project scoping, which is supported by data analysis and a determination of the community desire for the project. The project will then undergo a value factor analysis, before it is shared with a larger group. If the project is not approved, it could still become policy or an educational resource.

The Chair asked if there is transparency in data sharing in the early phase of the project life cycle. UNOS staff stated that the data get shared more broadly once the project gets approved and it is clear who the participants with effective practices are. At this point, there is more sharing of data and best practices between participating organizations.

UNOS staff stated that the CI team is committed to moving forward with a CI project with the Committee.

UNOS staff then explained value factor analysis, which is an approach to prioritize projects. Value factor analysis is used at the beginning of the life cycle to understand the potential impact of the project and at the end of the project to determine next steps. The Committee will use a value factor analysis to help decide which project to pursue. UNOS staff noted that value is subjective and varies between different stakeholders.

The value factor analysis developed by the UNOS CI staff seeks to evaluate a project across two domains and a number of factors within each domain. The two domains are "Benefit (Quality)" and "Challenge". The Benefit (Quality) factors are community desire, system wide impact, and efficient. The Challenge factors are member commitment, change endeavor, and measurability. Each factor is scored from one to five. UNOS staff clarified that efficiency refers to the elimination of waste and non-value added processes.

A Committee member was concerned that system wide impact would be measured primarily by the number of organs transplanted, which is not specific to the pediatric population. The Chair clarified that system-wide impact actually refers to the size of the impact on the transplant community. For example, minimal system impact would be a project just focusing on one organ or only affects a few OPOs. A full system impact would include the entire OPO and transplant community.

The scores for each of the Benefit (Quality) factors and the Challenge factors are then summed and the value factor ratio is calculated by dividing the total score of the Benefit (Quality) factors by the total score of the Challenge factors. The project with the highest value factor ratio is given priority if there is choice between multiple projects.

A Committee member asked if this framework for value factor analysis has been validated. UNOS staff stated that the framework has been validated but the specific factors have not been. The Committee member was concerned that important information may be lost by the simplicity of the framework.

The Chair asked about the timeline for initiating a CI project. UNOS staff stated that data gathering and literature research will be done for three or four projects. Based on that information, the Committee would complete a value factor analysis for the projects. By June or July of 2019, the Committee would then formally initiate the CI project. From there, the timeframe for the CI project is flexible so that there is sufficient time to complete and analyze the project.

A Committee member asked UNOS staff to speak more about the idea of pursuing a crossorgan project as opposed to a single-organ project. UNOS staff stated that the Committee could choose either type of project and noted that the most important thing is to identify a project that fits the will and desire of the pediatric community.

A Committee member was concerned that there could be a level of discoordination between community desire and the other factors. The community may have a strong desire for something that the Committee does not think is a good project to pursue. Conversely, a project that may have a large impact, may not reflect community desire. UNOS staff reminded the group that value differs between stakeholders. The Vice Chair reiterated that the Committee must consider the balance between system-wide impact and community desire.

The Committee then discussed the list of potential CI projects provided above. The Committee decided that the project to evaluate organ offer turndowns would try to decrease the number of offer turndowns. UNOS staff noted that this would still be a broad topic, so it should be specific to a certain type of organ offer turndown. The Vice Chair noted that there is not good data on organ offer turndowns, so it is difficult to properly scope this topic. UNOS staff stated that gathering this data could be part of the initial project evaluation.

A Committee member asked if it would be better to choose a project that crosses organ systems so that there is a higher likely of community interest. The Chair stated that this was a valid idea, but they do not want to rule out an organ specific project yet.

UNOS staff stated that the Committee should decide on their top three or four project choices, then UNOS staff will start to gather relevant data. After the initial data gathering, the Committee can then complete a value factor analysis for each of the projects.

The Chair suggested that the Committee select "Increase utilization of PHS increased risk organs" and "Evaluate organ offer turn-down/acceptance" as potential projects. A Committee member stated that they should look at specific turn down criteria at individual programs for the latter.

One Committee member noted that the "Increase living donation" project could be categorized into more specific subcategories, such as increasing KPD or increasing blood type A to blood type B transplants. UNOS staff stated that each of these subcategories could be a separate project. The Committee would need to look at the data to see which subcategory would most affect living donation. The Committee member felt that it still may be valuable to keep a broad project scope. UNOS staff agreed that it is an important subject that could lend itself to a larger project, but they should consider the data first. Another UNOS staff member noted that incremental change is often the most effective.

The Chair stated that it may be difficult to engage the full transplant community on increasing living donation because not all programs do living donations. Additionally, the Chair was concerned that they would not be able to see an increase in living donations if the project only lasts approximately six months. The Chair then asked if the outcome of the project could be some form of educational resource. UNOS staff stated that CI projects are intended to be measured and evaluated. If the Committee envisions the outcome to be educational, then they can pursue an educational project type. The Committee agreed to keep "Increasing living donation" as a potential project.

The Committee also agreed that the project titled, "Increase recipient follow-up efficiency/improve follow-up" should be considered. A possible measurable outcome of this project would be changes in loss to follow-up after the transition from pediatric to adult care.

The Committee agreed to prioritize the following four CI projects:

- 1. Increase utilization of PHS increase risk organs
- 2. Evaluate organ offer turn-down/acceptance
- 3. Increase recipient follow-up efficiency/improve follow-up
- 4. Increase living donation

UNOS CI staff will meet with UNOS research staff to start figuring out what data is needed to properly scope these four projects. The Chair suggested having Committee members participate in this discussion.

## Next Steps:

UNOS staff will convene to discuss initial data gathering for the four selected projects.

## 6. Pediatric Bylaws Update and Toolkit

Applications for the new bylaws on pediatric components are slated to be distributed in the coming months. Transplant programs that want to perform pediatric transplants once the bylaws are implemented will need to complete an application.

## **Summary of Discussion:**

UNOS staff stated that the application form was submitted to the Office of Management and Budget (OMB) but it has not been approved yet. However, UNOS staff have been working on a toolkit on the OPTN website with a number of resources to help programs through the application process. UNOS staff will be able to update the timeline for the application process once the application form is approved by the OMB. The Chair suggested adding the contact information for someone who could answer questions to the toolkit. UNOS staff clarified that the primary applications provided in the toolkit are the current applications for primary surgeons and primary physicians. They were included in the toolkit because the new bylaws will require primary physicians and surgeons to meet all of these requirements, as well as pediatric-specific requirements.

The Vice Chair asked if the applications for individuals who are already primary physicians or surgeons are on file. The Vice Chair clarified that her question was not about grandfathering these individuals, but rather about having access to the application information, specifically the procedure logs. UNOS staff stated that they would see if these applications are on file.

A Committee member was concerned that older physicians would not be able to find the necessary information to satisfy the bylaw requirements for donor procurements. UNOS staff stated that OPOs or the OPTN may be able to help find this information. Another Committee member was concerned that some physicians may not be able to meet the requirement of attending three procurements and three transplants. Another Committee member noted that she meets all of the pediatric specific requirements, but will not meet the primary surgeon or physician requirements. The Chair stated that Committee members could attend the required procurements or transplants to gain the necessary experience. The Chair reminded the group that the procedure observations do not need to be pediatric patients. The Committee reiterated their concern about making individuals who are already primary personnel reapply to be a primary personnel for a pediatric component. The Vice Chair asked if the Committee could change the bylaws so current primary personnel do not need to reapply. UNOS staff that this would require a bylaw change, which would need full public comment. The Committee was also concerned that individuals who are not currently primary personnel, may now need to meet the primary requirements.

The Chair stated that there should be more communication for the larger transplant community about the bylaws. UNOS staff reminded the Committee that the timeline is dependent on when the OMB approves the application form. The Chair also asked for more clarity on the turnaround time for when applicants would hear back from the UNOS Member Quality department.

A Committee member stated that the Membership and Professional Standard Committee (MPSC) discussed the Committee creating some form of alternative pathway, such as a letter of attestation, for older physicians to prove the completion of previous procedures. Neither UNOS staff nor the Chair and Vice Chair had heard this discussed before. The Vice Chair was supportive of the letter of attestation pathway. The Vice Chair asked UNOS staff to see if the letter of attestation pathway is real and if it is not, if there is a way to create an alternative approval pathway for more senior physicians.

## Next Steps:

UNOS staff will see if previous primary personnel applications are on file and if there is way to create an alternative approval pathway for more senior physicians under the new bylaws and report back to the Committee.

#### 7. Pediatric Liver Allocation – ABO Prioritization

The Acuity Circles (AC) liver allocation policy is slated to go into effect soon. In general, pediatric recipients are prioritized for pediatric donors. However, this is not the case for blood type O pediatric donors. The OPTN Liver and Intestinal Organ Transplantation Committee (Liver Committee) is considering changing this.

#### Summary of Discussion:

Under the AC policy, pediatric candidates are generally prioritized for organs from pediatric donors. However, organs from blood type O pediatric donors are allocated to all blood type O and blood type B candidates (adult and pediatric) before being offered to any blood type A or blood type AB candidates. The Liver Committee is considering prioritizing blood type A and blood type AB pediatric candidates ahead of adult candidates of any blood type for organs from blood type O pediatric donors.

The Liver Committee wanted to get the Committee's input on this plan and if they should give the same priority to pediatric candidates for organs from adolescent blood type O donors. The Vice Chair was supportive of the change and also suggested prioritizing blood type incompatible pediatric recipients ahead of adult candidates for pediatric donors. The Chair also supported the change and noted that the increased pediatric prioritization would increase utilization of the organs. A Committee member was concerned that adolescent Status 1A candidates would be competing with adult Status 1A candidates for livers at 500 nautical miles (NM). UNOS staff stated that this proposal will likely go out for public comment in the fall. The Committee unanimously supported the increased prioritization for pediatric donors.

## Next Steps:

The Committee's feedback on the proposal will be communicated to the Liver Committee.

#### 8. KAS Update

UNOS staff provided a review of KAS data and an update on current geography efforts.

#### Summary of Discussion:

UNOS staff noted that the KAS update was not a formal committee report, but was only intended to provide a high-level overview of KAS. UNOS staff also stated that the report does not provide detailed information on pediatric outcomes.

UNOS staff stated that the number of transplants has risen, there has been improved equity, the bolus effect stabilized, and utilization rated remained the same. The number of transplants per month has increased. Kidney discard rates have stayed largely the same, except for moderate-to high kidney donor profile index (KDPI) kidneys, which decreased slightly. The percent of deceased donor kidneys going to pediatric candidates has remained the same. There has been an increase in non-local transplants, most of which is explained by the highly-sensitized candidates. There is large variability in transplant rates by donation service area (DSA). Delayed graft function increased slightly.

Based on the two-year KAS report, there was a significant increase in graft survival for pediatric candidates. There was also a slight, although not significant increase, in patient survival. Both increases remained true when stratified across different subcategories.

UNOS staff also noted that the SRTR just released their analysis plan for the current round of modeling for the kidney-pancreas geography project. The modeling report should be available in mid-June. In the second round of modeling, the KP Workgroup decided to move prior living donors and pediatric candidates higher on the match run. Local pediatric candidates were prioritized above 98-99% highly sensitized candidates in sequences A and B.

The SRTR will model 11 different allocation systems. Two of the models incorporate stepwise proximity points. The idea was that within the first circle, it may not matter if the liver is driven 25 NM or 75 NM. So within the smallest circle (150 NM), candidates are assigned the same number of proximity points. Candidates outside this circle but inside 500 NM would be assigned proximity points on a linear basis. This model treats candidates within 150 NM equivalently. The second variation does the same thing, but the innermost circle is 250 NM, which was noted to be the threshold for driving versus flying.

The Chair asked if pediatric candidates were being given any additional priority in sequence C in the modeling. UNOS staff stated that they were only given priority in sequences A and B because they already had priority in these sequences. A Committee member stated that there is no reason to not prioritize pediatric candidates in sequence C, as it would not disadvantage

adults and it would be beneficial for pediatric candidates. UNOS staff noted that the forthcoming en-bloc policy will also give some priority to pediatric candidates for small, pediatric donors.

UNOS staff noted that there was feedback in the first round of public comment to have separate policies for kidney allocation and pancreas allocation. A Committee member stated that even though pediatric prioritization in sequence C was not included in the modeling, it could still be incorporated into the final policy. The Vice Chair agreed and noted that the Committee should be vocal in their support for additional pediatric priority. The Chair asked if UNOS staff had data on the incidence of living kidney donation. UNOS staff did not have that information immediately available.

A Committee member asked for data on the following topics:

- Pediatric mortality by age
- Transplant rate for highly sensitized pediatric candidates by age
- Pediatric transplant rate by age
- Delayed graft function rates by age
- Graft survival by age
- KDPI distribution of pediatric kidney donors by age
- Characteristics of recipients of KDPI>35 kidneys from pediatric donors by age and calculated panel reactive antibodies (CPRA)

UNOS staff suggested submitting the above items as a data request to the OPTN.

## Next Steps:

The Committee will continue to advocate for additional pediatric prioritization. UNOS staff will draft a data request based on the conversation.

## 9. Committee Updates

UNOS staff provided updates on the pertinent work of other OPTN committees.

## **Summary of Discussion:**

## Kidney-Pancreas Work Group

The Chair stated that the Committee should remain involved in the work of the KP Workgroup. The Vice Chair urged the Committee to keep advocating for additional pediatric priority during the workgroup meetings.

## Intellectual Disabilities Work Group

The federal Office of Civil Rights (OCR) is also drafting a document related to individuals with intellectual disabilities. Because of this the Health Resources and Services Administration (HRSA) has asked the OPTN to delay the publication of their guidance document until after the OCR opinion is released. Work is continuing on the project, but the timeline is not set. The OPTN document would need to be consistent with the OCR document.

A Committee member asked when the OPTN may have a draft of the guidance document ready. UNOS staff stated that a draft would not be available prior to the publication of the OCR paper. Another Committee member asked if the OCR paper included discussion of people of all ages. UNOS staff did not have that information. The Committee member noted that people of different ages have different needs.

# Next Steps:

No next steps were identified.

## 10. Service Recognition and Incoming Roster

## Summary of Discussion:

The Chair thanked all Committee members who are completing their term at the end of June and welcomed the new Committee members. There was no additional discussion.

#### Next Steps:

No nest steps were identified.

## 11. Open Discussion

## Summary of Discussion:

Representatives from Donate Life America encouraged Committee Members to participate in National Donate Life Month. UNOS staff presented the regional meeting dates and location for the fall regional meeting cycle. The Chair summarized the key takeaways from the day and asked for volunteers to help identify the relevant data elements for the CI projects.

## Next Steps:

Committee members that volunteered to participate in data collection for CI projects will take part in upcoming meetings with UNOS staff.

## **Upcoming Meeting**

• May 15, 2019 - Teleconference