

**OPTN/UNOS Pediatric Transplantation Committee**  
**Meeting Minutes**  
**November 6, 2018**  
**Chicago, IL**

**George V. Mazariegos, M.D., Chair**  
**Evelyn K. Hsu, M.D., Vice Chair**

**Introduction**

The Pediatric Transplantation Committee met in Chicago, IL on 11/06/2018 to discuss the following agenda items:

1. Policy Oversight Committee update
2. Implementation Update on the Minimum Training and Experience Requirements for Key Personnel
3. Update on Liver and Intestine Committee proposal
4. Update on OPTN Committee Projects Addressing Use of DSAs or Regions
5. SRTR: Four DSA-Free Models of Heart Allocation: results for pediatric candidates
6. Guidance related to Current Multi-Organ Allocation Policy/White Paper on Multi-organ Allocation
7. National Pediatric Transplant Week 2019
8. SRTR: OPTN Pediatric Committee and Annual Data Reports
9. Committee Project Review and New Project Brainstorming session

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

**1. Policy Oversight Committee update**

The Vice Chair provided an update from recent Policy Oversight Committee (POC) discussions.

Data summary:

The Vice Chair reminded the committee how POC works by assigning a project to one of the five strategic goals and continues to work towards alignment of the project portfolio with the OPTN strategic plan as well as prioritizing resources. In addition at this POC meeting there was discussion about how POC members serve multiple roles for both their committee and as a POC member. They developed project recommendations to the executive committee and reviewed the strategic goals for the OPTN.

The POC helped develop a response to Health Resources and Services Administration (HRSA) about the use of Donation Service Areas (DSA) and Regions; recommended six proposals for public comment and one proposal for special public comment; and reviewed two new committee projects. The latter two projects that were approved were: Clarifications on reporting maintenance dialysis by the Living Donor Committee, and Effective practices for broader organ sharing by Operations and Safety Committee. There are 13 expected proposals coming up in the next year.

The Vice Chair presented a graphic showing projects that the Pediatric Committee had sponsored and how they supported the OPTN Strategic Plan Alignment. Members were shown projects close to implementation and those approved but not yet implemented. The portfolio has room for projects that align with OPTN Strategic Goals to increase the number of transplants; improve waitlisted patient, living donor and transplant recipient outcomes; promote living donor and transplant recipient safety; and promote the efficient management of the OPTN. The portfolio is on track with increasing equity in access to transplant. OPTN/ UNOS staff presented a figure that illustrated the number of projects pediatric committee has done as well as project status from the OPTN/UNOS Committees.

Summary of discussion:

When discussing recent and future work, OPTN/UNOS staff wanted to emphasize the inclusion of the future work slide as a way to identify the priority topics for conference calls. Members were also encouraged to speak up about proposals not just as a pediatric committee member but as members of their respective institutions and professional societies or patient advocacy group.

The Chair discussed which projects would require pediatric input and concluded that the Eliminate the use of DSA and Regions in Kidney and Pancreas distribution and Eliminate the use of DSAs and Regions in Thoracic Distribution were the main ones. Several members brought up ethical implications regarding multi-organ transplant (MOT). OPTN/UNOS staff answered that the Ethics Committee will be sending out a white paper for public comment. Details will be discussed later during the meeting. Members expressed concerns that changes regarding broader sharing and multi-organ could adversely impact pediatric populations and that members need to be involved in these projects so that the pediatric perspective is not discounted.

The Vice Chair gave a brief explanation of the potential Region 8 split liver variance proposal that would allow the remaining liver segment to stay at the program that was allocated the primary portion of the liver.

Next steps:

UNOS staff will research and provide additional information to the Committee about the Region 8 split liver variance proposal.

## **2. Minimum Training and Experience Requirements for Key Personnel- Implementation Update**

UNOS staff updated the Committee on what is known and what is to be determined in planning for the application period and implementation plan for the proposal to establish minimum training and experience requirements for transplant hospitals that register pediatric transplant candidates passed by the OPTN/UNOS Board of Directors (BOD) in 2015..

Data Summary:

UNOS staff gave an update on the implementation of the 2015 proposal. Members were alerted that they will be receiving information about new key requirements for the primary transplant surgeon and primary transplant physician at pediatric transplant programs. A timeline for implementation was shared. Starting in spring 2019, a notice will be send out to all pediatric transplant programs (as well as any transplant program that has done a pediatric transplant in the last five years). It was stressed that if members think they are not going to apply, then programs need to opt out so that OPTN/UNOS knows that specific programs are not going to be in the first round of applications. Next will be a 90 day application period for programs to fill out and submit their application to UNOS. Staff recommended not to wait the entire 90 day period to fill out the application. This is because when UNOS staff look over the application something might be missing and then the time to respond to additional information requests could put the program over the 90 day deadline. Late applications will be put behind the other applications that were on time and complete. Due to the volume of applications, UNOS staff and the Membership and Standards Professional Committee (MPSC) will need time to review and approve applications. This is anticipated to take approximately 12-18 months. After MPSC approval, applications will be submitted to the OPTN/UNOS BOD for final approval in June or December 2020. UNOS staff also presented information on who to contact with additional questions.

Summary of Discussion:

The timeline was discussed. Several members expressed that they appreciated the advance information. They stressed the importance of spreading it among the transplant community.

Staff and members discussed issues related to implementation communications and materials. UNOS staff clarified that after the implementation, programs would not be able to continue performing pediatric transplants unless they were approved. The policy will also apply to adult programs. UNOS staff added that adult programs can apply for an exception on a case by case basis specifically for heart and liver candidates only. For example if a pediatric candidate is in an adult transplant hospital and is too sick to be moved to a pediatric transplant hospital.

Another member asked: How many times do you have to reapply after the initial approval? UNOS staff clarified that if there are any major changes in personnel, they (personnel) have to meet the requirements but that would not be a reapplication. Another member chimed in stating that in simple terms you would no longer be fulling the requirements. A different member responded by saying that if you meet the

requirements, then you meet them unless that person in that position leaves (e.g. about primary physician/ transplant surgeon). The new person in that position would have to meet the requirements. One member summarized that aside from the exceptions of the teenagers, and the heart and liver cases, if your program is not approved by June/December 2020 and you have a waitlist of pediatric patients, then those patients will have to be transferred to another approved program.

UNOS staff noted that there was outreach in February 2018 to remind the transplant community about the requirements. The goal is to provide proactive notice to avoid programs missing deadlines or not have the case volume needed.

A member expressed that the proposal it is very hard to read, and they would like something in plain language about what is required to better educate the community.

The Vice Chair proposed the idea of a webinar with one slide in simple language and several members agreed with the idea.

UNOS staff mentioned that there was a policy notice and that is supposed to be written in plain language. A member requested that a summary sheet with personnel requirements with required numbers be created to help the proactive education efforts. UNOS staff reminded the group that there have been web based articles in Transplant Pro on the subject and included in the regional slides shown at regional meetings.

A member asked if there was any flexibility on the timeline/ wider period of application due to the potential timing issues for members to meet the requirements. UNOS staff responded by stating they will get back to them as there are several factors involved. Other members spoke about issues with meeting requirements with the recent intestine program requirements implementation and that experienced personnel were asking at the last minute to observe donors in order to meet the requirements.

Another member asked if the Office of Management and Budget (OMB) has to approve the draft of an empty application or the populated application and how this application process will fit into the new OPTN contract. UNOS Staff answered that the OMB approval process applies to UNOS/OPTN because they are a government contractor. Any new application tool needs to go to OMB for review and approval and once that happens the tool can be used to collect transplant program information. It was clarified that the OPTN contract is separate matter and that the OMB process has been always been a requirement. Staff did clarify that they would follow up regarding any potential changes that might impact what is sent for OMB approval. Another member commented that this OMB approval process could affect the time line. UNOS staff acknowledged this concern.

Another member suggested improvements to how proficiency is measured. It was stated that the current measure that a doctor will participate in a surgery is inadequate because they will not actually participate and simply scrubbing in is not satisfactory. This member suggested that you join in "weekly rounding activities or to find a mentor who would be willing to help so that it would be easier to credential and then you could have a usable and, palpable mechanism.

Another member asked where the certification form can be accessed. UNOS staff explained that the form itself has not been approved by OMB yet. Issues about staff remembering and finding documentation of previous surgeries was raised. Another member suggested that instead that a member "should watch a video for 10 minutes on the American Society for Transplantation (ASTS) portal. One member commented that we have not created a pathway that helps everyone gain the needed experience unless they are a fellow at a program that currently has the staff and facilities to provide an avenue to gain the required experience.

Leadership requested a timeline on when they will be getting these materials and stressed the need to have timely reviews to be proactive, make edits, and avoid community criticisms.

#### Next Steps:

UNOS Staff will do the following

- Send out the implementation timeline slides
- Create a plain English document/ webinar about the requirements
- Work with communications and professional education staff regarding community notifications

- Provide an application draft with the list of requirements
- Develop a timeline on getting materials to the Committee for review
- Develop a checklist with information on for each organ and personnel role

### **3. Update on Liver and Intestine Committee proposal**

The Committee received an update on the final proposal recommended to the OPTN/UNOS BOD by the Liver and Intestines (Liver) Committee.

#### Data summary:

The Liver Committee met on Friday, 11/2/2018 to discuss special public comment on their proposal and to finalize the proposal to send to the OPTN/UNOS BOD. The Scientific Registry for Transplant Recipients (SRTR) modeled two different approaches for broader distribution of organs that eliminated use of DSA and region on allocation. The Pediatric Committee was invited to participate in the Liver Committee calls where the modeling was reviewed to give feedback on the pediatric component of the data and listed to the general discussions. The Liver Committee voted to send a proposal using a Broader two circle (B2C) allocation framework with a Model for End-Stage Liver Disease (MELD) sharing threshold of 29. The B2C distances infer two different sharing thresholds based on priority or illness. It resulted in favor for distribution of livers from pediatric donors (less than 18 years old) to give priority to pediatric candidates. The adult liver discussion included a cap for a MELD score exception for candidates older than 18 years old but this would not apply to pediatric candidates as recommended by the Pediatric Committee. There is no plan from Liver Committee leadership to create a cap on MELD/Pediatric End Stage Liver Disease (PELD) score exceptions for pediatric candidates although there will be a MELD cap for adults.

The Chair discussed lessons learned from this process including the value of transparency in the working group; having dialog between the respective committees, leadership and stakeholders; and speaking with one voice on key topics.

#### Summary of discussion:

It was noted that the proposed policy will make allocation more consistent with the Final Rule. It was also noted that organ specific committees will continue evaluation and work towards more optimal and complex solutions that may consider more clinical variables between the donor and the potential recipient over time. The current proposal, however, addresses the immediate need to remove DSAs and regions as allocation units.

The Vice Chair requested a copy of the final proposal and noted that from the pediatric stand point there needs to be clarity with the exceptions and priority for pediatrics. UNOS staff will provide a copy when available. Committee members want to make sure the pediatric perspective is represented as discussed.

A member asked if there was any modeling that was done from a pediatric kidney perspective and if there was an increase in combined kidney and liver transplants. This has been a topic of discussion and UNOS staff noted that from the current data this was not expected. UNOS staff also reviewed the next steps which are proposal consideration by the assigned BOD policy group and then consideration by the full BOD at their December meeting. Pediatric Committee members want to be sure that what the Committee as well as the public has requested from the pediatric perspective is clear.

One member asked about pediatric representation on the Liver Committee. Another member responded that while there was not a large Pediatric Committee presence, pediatric members did participate and voice the pediatric perspective during the Liver Committee meeting calls. There were communications and calls to highlight points such as lack of cap exceptions and pediatric priority. Leadership noted that they were able to help weave the pediatric perspective into the proposed policy through these discussions and communications with the Liver Committee. When the pediatric perspective was presented to the Chair of the Liver Committee as a recommendation, there was no push back.

#### Next steps:

The OPTN/UNOS BOD will consider and vote on the proposal from the Liver Committee at their December 2018 meeting. Implementation is expected to start in early 2019.

#### 4. Update on OPTN Committee Projects Addressing Use of DSAs or Regions

UNOS staff gave an update on projects by other OPTN committees to amend their respective organ allocation policies to be compliant with the OPTN Final Rule. The Committee will also have an opportunity to review and discuss the Thoracic Simulated Allocation Model (TSAM) report from the SRTR and generate feedback to the Thoracic Committee.

##### Data Summary:

An update Vascularized Composite Allograft (VCA) Committee proposal development was given. Current VCA allocation is within the region of the donor then goes nationally. The recommendation to the BOD will be a 750 nautical mile (nm) radius from the donor hospital as first tier of allocation. This proposal will be going out for spring 2019 public comment (1/22/19-3/22/19). If the committee would like presentation that can be arranged.

For Kidney/Pancreas there were two distribution models listed in the slides. The first was a fixed distance from a donor hospital that had expanding rings of 150 nm, 250 nm, 300 nm, and 500 nm. The second model was a hybrid proximity points model, with a single 500 nm radius from donor hospital that awards points to the candidate based on proximity to the donor. The Kidney/Pancreas Simulated Allocation Model (KPSAM) report is expected on 12/7/18. The Kidney Committee will meet after results are received to review the modeling and finalize their proposal for spring 2019 public comment (1/22/19-3/22/19).

The Thoracic Committee voted on 11/1/18 on their public comment proposal. The recommendation is to replace DSA with a 250 nm radius from donor hospital. The Pediatric Committee has been following development of this proposal and SRTR staff will present the TSAM results to assist the Committee in analyzing the results through the pediatric perspective,

##### Summary of discussion:

One member asked if there is change to allocation then would the VCA allocation table be similar to other allocation tables. UNOS staff noted that the functionally the list is something that needs to be intuitive. The VCA community has expressed that the system for VCA allocation should not be a barrier to VCA donation.

A member asked about the basis for the 750 nm size. UNOS staff responded that the 750 nm takes cold ischemic tolerances into consideration knowing that VCAs are very complex grafts with muscle being the most susceptible tissue. . Initially the VCA Committee considered 500 nm but expanded the size to 750 nm. This was done to expand the potential donor pool. There will have to be dialogue between the OPO and transplant hospital on whether the distance will preclude acceptance.

UNOS staff noted that when the KPSAM is released it will be placed on Basecamp so that Pediatric Committee members can access the modeling and have online discussions. The Chair also asked for volunteers to participate in the Kidney Committee calls to ensure the pediatric perspective is represented. The Committee noted the importance of communicating with each other prior to the call in order to speak with a unified voice.

One member asked if there was any opportunity here to change kidney sequences C and D for children to give them priority. It was further explained that in general pediatric organs should be allocated to pediatric recipients first as happens in liver allocation. They expressed concerns that a pediatric donor with a high KDPI is going to other populations first before pediatric candidates. One member suggested developing a new proposal to address this concern in the future. The Vice Chair noted that this concern has been raised in the past and that the Committee should start a process now that clearly explains why the proposed idea would be best for pediatric candidates. Several members noted that due to the compacted time frame of the proposal it might not be the best time to request these changes. UNOS staff indicated that this issue could be addressed after geography is addressed in kidney allocation policy.

The Committee noted that in past discussions there was disagreement over the numbers that would be impacted if pediatric candidates were placed higher in the sequences. The Chair asked for a member who brought up the proposal to prepare information and a visual to explain the Committee's request. It was noted that in the KPSAM the increase access to kidneys for pediatric candidates was limited by the modeling time frame and complexity of working through these specific issues. Some members asked how

all the organ specific committees are creating their own frameworks that are then supposed to align with the framework being recommended by the Geography Committee. It was noted that these changes are steps and that how to further align frameworks will become part of the next three-year OPTN/UNOS strategic plan to allow for geography changes first to comply with the Final Rule and then to further evaluate and modify policies as needed to move towards the Geography Committee recommendations that will be voted on by the BOD in December 2018.

## **5. SRTR Four DSA- free Models of heart allocation: results for pediatric candidates**

The SRTR presented data related to impacts on the pediatric population for heart allocation without use of DSA.

### Data summary:

SRTR staff presented some Thoracic Simulated Allocation Model (TSAM) results regarding the impact on pediatric heart candidates. The TSAM was done as part of overall modeling to remove DSA from heart allocation. Four models were completed and compared to current allocation policy allocation. When the study was conducted, the new rules for adult heart allocation were not yet implemented and those rules did go into effect on 10/18/18. The first two models used allocation units of 150 nm, 250 nm, and 500 nm. One had broader sharing and the other did not. The population used were candidates, recipients and donors from July 1, 2009 to June 30<sup>th</sup>, 2011. The outputs modeled were transplant counts and rates, waitlist death counts and rates, post-transplant death counts and rates, and donor-recipient distances. The data is presented in an overall group and by subgroup, as well as summarized across 10 simulation runs. No statistical significance tests were performed.

Data show the minimum, maximum and average data across 10 simulation runs. Results were largely similar for waitlist death counts and rates, transplant counts and rates, post-transplant counts and rates, and increased organ travel distance with increased first circle size.

In the model of DSA, 150 nm, 250 nm, and 500 nm, first offers of adult donor organs go to adult status 1 and 2 and pediatric status 1A candidates go out to 1000 nm. Subsequent orderings for those candidates are similarly incremented. Lastly 500 nm-B; Adult status 1 and 2 and pediatric status 1A candidates are no longer eligible for broader sharing. Offer orders are by 1) status 1 adults and status 1A children within 500 nm, 2) status 2 adults within 500 nm, and 3) status 3 adults within 500 nm.

Transplants rate and counts by pediatric age group within each age groups were similar across the simulations. The pediatric transplant rate is higher than adults. The same data by pediatric status alone showed that status 1A had an increased transplant rate with the 500 nm-A and 500 nm-B models compared to DSA first. Status 1B and 2 had rates and counts similar across all simulations.

Waitlist mortality rates and counts by pediatric age group were shown. The highest waitlist mortality was observed among the youngest children. The waitlist mortality rate and counts were similar across simulation models including when done by pediatric status alone. For status 1b and 2 the waitlist mortality rates were very low. The data showed that that patients in these groups wait longer for transplant instead of dying on the list.

One-year post-transplant mortality and counts by pediatric age group were shown. In each age group, the SRTR noted similar mortality rates and counts across all simulations. When done by pediatric status, there is an increase in the number of post-transplant deaths in 1A patients when first unit of allocation is 500 nm but the rates are similar. This is because there are more status 1A transplants at 500 nm which is why the rate remains similar but post-transplant deaths increased. For status 1B and 2, rates and counts were similar across all simulations.

Median organ travel distance using nm by pediatric age group was reviewed. Due to sharing rules, median organ travel distance is usually higher in pediatrics than adults. Modeling shows an increase in distance for all pediatric age groups with the first unit of allocation at 500nm. If done by pediatric status, then the larger the circle the further the distance traveled.

In summary, there were not a lot of changes except in the pediatric status group. More specifically for status 1A, there was a difference in 500 nm-A and 500 nm-B models.

### Summary of discussion:

Member commented that the highest mortality rate for young children was sad but they questioned if it is independent of donor practices. The SRTR staff answered that pediatrics have priority. Another member responded that they did not model adults, and pediatric doctors are willing to go further for hearts and therefore data do not show anything new. It is believed that the new allocation system is working and reflecting working conditions already. Another member asked about the status 1A and another member responded that it is a large group with differing diagnoses that are not competing for the same heart.

The need to clarify what the data shows was discussed so that patients, parents, and families will not be confused or misinterpret the results. Members stated it would be helpful to have the modeling data reports in plain language. It was also noted that data by region and data on adult congenital heart transplant would be helpful. UNOS staff clarified that additional modeling is not planned.

## **6. White Paper on Multi-organ Allocation**

UNOS staff updated the Committee on an Ethics Committee project to draft a white paper on multi-organ allocation.

### Data Summary:

Overall multi-organ transplants (MOT) have increased in the past six years and made up approximately 9% of all transplants in 2017. Previously MOT policies have been done in isolation and not in consideration of the bigger picture. This has created confusion and a lack of transparency. It has introduced the potential to create inequity in the organ distribution process. The white paper focuses on principles of equity and utility. The paper will provide recommendations in 10 to 12 areas. It will address the differences between equity and utility taking into account organ quality, prioritization, subgroups, and how adult MOT affects pediatrics MOT.

The adult MOT can impact pediatric single organ allocation. The white paper draft states that: *Any changes in the allocation system for adult organs has the potential to directly or indirectly affect the allocation of organs among the pediatric patients who may also be candidates for those same organs.* Policies that disadvantage pediatric candidates yet advantage adult MOT violate the ethical principles of equity and utility. The draft white paper states that: *All policies that involve MOT allocation should be reviewed to ensure that they do not have a negative impact upon the number or quality of organs available to pediatric candidates.*

### Summary of discussion:

UNOS staff advised that MOT will not have a separate pediatric paper but that pediatric concerns will be included in the current white paper under development. The Chair asked if there was a data snapshot of MOT by age and organ combinations.

Members questioned what is included in MOT. They indicated that kidney/pancreas pediatric allocation should be included although it is not in the current plan.

Members had several questions for the Ethics Committee. First, they suggested using quality adjusted life years. This is not being done due to the complexity and some members did not think that would work. Second, members asked about the scope of the paper and expressed their desire that all, not just selected, consequences be addressed. Third, the members wanted to make sure that parent opinions are sought out on what should be included. Fourth, several members brought up that getting MOT to occur is very difficult and noted that for some cases the MOT policy is there but OPOs might not follow the policy.

The Vice Chair asked if it was possible to make a stronger statement on MOT. If there is a negative impact on availability of organs to pediatric candidates, then there should be there should be a concurrent policy change to alleviate this issue. The need to be proactive was noted.

UNOS staff explained that the MOT white paper will go out for spring 2019 public comment. The Ethics Committee still has a lot of work and will be soliciting further input from other OPTN/UNOS Committees. It was noted that member scan also give feedback during public comment.

#### Next steps:

UNOS staff will:

- Send out MOT data by pediatric status and adult status by organ type for the past five years.
- Post Basecamp links for members to participate in Ethics Committee meetings

### **7. National Pediatric Transplant Week 2019**

The Committee received a high-level update on the plans for National Pediatric Transplant Week 2019 (April 23-27).

#### Data Summary/Background:

It was noted that last year was the first year of having a national pediatric transplant week but that it was a success. Many in the community provided positive feedback.

#### Summary of discussion:

Plans are to use the same artwork from last year. The Committee would like opinions and ideas on how to share a story about pediatric transplant. There will be a social media tool kit on Basecamp. This year they would like more in-person events at programs to get people more physically engaged. Last year one program did a flash mob and another program made cards. There will be videos to introduce and end the week.

#### Next Steps:

Members were asked to do the following:

- Be a champion for your organization
- Be aware that Donate Life America is putting together a mailing service/contact list and to look for information from them
- Prepare a list of what others have done in the past and share the ideas
- Engage professional associations

### **8. SRTR Annual Data Reports**

SRTR staff briefed the Committee on recent additions to their Annual Data Reports (ADR) regarding pediatric transplant data.

#### Data Summary:

The SRTR is working on presenting pediatric data differently. A year ago SRTR, in collaboration with the Pediatric Committee solicited input on how to improve the pediatric aspect in the ADR. There was significant dialogue on how to better represent pediatric data for each organ. There are changes to the current draft of the ADR based on this collaboration which also led to other project ideas.

A brief summary of modifications were presented. Changes to liver data included how liver 1A and 1B were separated, geography, split liver, percent of transplants by exception for pediatrics vs adults, exceptions by DSA, and the percentage of pediatric donor transplanted into adult recipients. For kidney the following changes were discussed: pediatric specific diagnosing categories, KDPI outcomes, geography, and donor type by age, and acute rejection. For heart, the SRTR made the following changes: refined diagnostic categories, geography, acute rejection and long term survival. For intestine there is a better display of data and breaking out intestine and intestine-liver.

#### Summary of discussion:

Several members mentioned that they would like a separate pediatric ADR report. This idea was brought up last year. The case was made that the current reports do not capture pediatric wide concerns. Leadership commented that pediatrics might lose visibility if they had a separate report. One member asked if SRTR could do conditional outcomes across all organs and they indicated that is on their list to complete.



### Next Steps:

SRTR has ongoing work to improve the pediatric component of the ADR. They requested volunteers to continue review and making suggestions for next year's reports.

## **9. Committee Project Review and New Project Brainstorming**

UNOS staff provided an overview of the past Committee work plan and the Committee discussed what new projects should be considered.

### Data Summary/Background:

Staff reviewed the project and policy development processes noting that there are different types of projects. Certain projects, such as policy and guidance, must go out for public comment and be approved by the BOD. There are also other Committee efforts that have a non-BOD path of developing and implementing (e.g. education only projects). All projects must clearly define the problem and what OPTN Strategic Goal will be addressed through the project.

The committee was given a list of priority ideas that the group had compiled before the meeting. These included:

- Clinical Criteria for Simultaneous Pediatric Liver/Kidney Registration
- Priority for Pediatric Kidney Candidates
- Reduce risk of suicide among pediatric transplant recipients
- Transplant outcomes in pediatric congenital heart disease
- Encourage Use of Organs from PHS Increased Risk Donors
- Evaluate Organ Turn-downs
- Update Recipient Follow-up Data Collection
- Assess for Disadvantaged Patients in the Heart Allocation System
- Increase Participation of Pediatric Kidney Programs in Kidney Paired Donation (KPD)
- Review Use of Kidneys from A2B Donors in Pediatric Kidney Candidates

### Summary of Discussion:

The Committee formed three brainstorming groups to come up with potential new projects. They were instructed to consider:

- What is the problem we need to solve
- What data can be sourced to show evidence of the problem
- What is a solution you would propose
- Developing new ideas not on the current list

### Group 1 Ideas:

- Improve graft longevity for kidney recipients. The idea is to look at donors between 11 and 17 years old and address how these organs are allocated including how KAS has changed who is getting these organs
- Improve transition and adherence for all organs. The idea is to look into side effects of medication
- Reevaluate categories for heart and liver allocation. The idea is to examine the impact of technological advantages in heart and the impact on mortality. For liver, the idea is to examine whether the 1b urgency status is too broad.
- Examine developmental abnormality for kidney patients between 1 and 5 years of age and whether they should have prioritization. The idea is that parents have concerns about the short term outcome data and would like more data.

### Group 2 Ideas:

- What drives behavior for transplant programs and transplant physicians
- Split liver: Who is doing it, why, are these program better than average and if so, how they take that extra risk. A possible model to understand how to increase organ use

- Kidney use: Examine if there is an outward migration of pediatric kidneys to adults and publish results
- Guidance on MOT
- Address risk tolerance in pediatric transplant. There is a concern that programs have fear of punishment or lack of payor acceptance which is causing programs to be stuck and not transplant when risks might be tolerable. Another concern is a potential lack of transparency on this issue. The group wants to find out what programs need to help advance the field that might allow additional tolerable risk to be taken to increase pediatric transplantation.

#### Group 3 Ideas:

- Review multi-organ transplant data to assess whether pediatric candidates in need of a solitary organ transplant are being disadvantaged.
- Increase living donation to pediatric candidates.
- Guidance on early graft dysfunction surveillance to promote long-term recipient and graft survival
- Promote care plan compliance for pediatric transplant recipients
- Develop a scoring system to weigh accepting a heart offer versus continuing to remain on the waiting list

Members also requested more orientation about Basecamp and information on how to use the application. They would like to see specific categories for certain organs or proposals in order to make targeted responses. They would like to use the to-do list feature.

#### Next steps:

- Prioritize potential projects discussed.
- Voting will be conducted via an online survey
- Identify key stakeholders for early collaboration
- Begin project development discussion and prepare project to submit to the POC

#### **Upcoming Meetings**

- Conference Calls: 3rd Wednesday of each month from 4-5pm EST
- In-Person Meeting: March 19, 2019 in Richmond, VA at UNOS