OPTN Patient Affairs Committee
Meeting Minutes
August 20, 2019
Chicago, Illinois

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Introduction

The Patient Affairs Committee (PAC) met via Citrix in Chicago, IL on 08/20/2019 to discuss the following agenda items:

1. Education & Orientation: Scientific Registry of Transplant Recipients (SRTR)
2. Proposal Review: Eliminate the Use of DSA and Region in Pancreas Distribution
3. Proposal Review: Continuous Distribution of Lungs
4. Modifying OPTN Proposals for the General Public
5. Initiative to Update Criteria on Increase Risk Organ Donors
6. Proposal Review: Eliminate the Use of DSA and Region in Kidney Distribution
7. Update to PAC Charge

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

1. Education & Orientation: Scientific Registry of Transplant Recipients (SRTR)

SRTR staff presented an overview of their organization, including key roles and responsibilities, how they support the OPTN policy development process, and how SRTR develops their data reports regarding organ transplantation and donation.

Summary of discussion:

In response to the presentation, one Committee members questioned how the SRTR was distributing the information about their organization and their role to the general community. SRTR acknowledge they have not done extensive education with the general community about their organization, however they are currently planning to interface the information in their presentation onto their website. SRTR is focused on creating more information available to the community and patients, along with improving material accessibility and readability. Another point brought up was not only the general lack of knowledge that lower socioeconomic status patients would have when presented with the information, but also that SRTR has a low social media presence at this time. In response, SRTR staff stated that most medical decision making is not logical, but rather emotional. Furthermore, SRTR staff have not found research indicating a correlation between understanding data information and level of education. In this sense, there are certain cognitive processes (such as the use of data visualizations) that can help people across socioeconomic statuses understand the SRTR information and data.

Another Committee member asked whether community members can access specific transplant hospital outcomes data, because this may assist in helping the community choose between listing at certain hospitals. Currently, the SRTR is working to make program-specific reports (PSRs) more understandable, which has caused a fair bit on controversy due to this information being made public. Yet despite transplant hospital being uncomfortable with the public display of their data, SRTR staff reiterated that their primary stakeholder is the patient and general community, and that they are

working to improve the understandability of their data. In response, a PAC member did confirm that though patients access the data, they do not understand it.

Furthermore, there was a suggestion from one PAC member to include extended graft survival rates (2 years, 3 years, 5 years etc.) because this may help patients make more informed decisions. In response, traditionally transplant programs have argued that their responsibility for graft survival is limited to 1 year, though 3 year and 5 year data is available.

2. Proposal Review: Eliminate the Use of DSA and Region in Pancreas Distribution

The Vice Chair of the OPTN Pancreas Committee presented their current proposal out for public comment for feedback from the PAC.

Summary of discussion:

Below is a summary of the Committee's feedback on the pancreas proposal:

- We agree that the maximum reasonable travel distance should be selected, which in the modelling outlined in the proposal is 500 NM, in order to reduce inequities in access to transplants based on geographic location, socioeconomic status or minority status, while still maintaining integrity and quality of the organ or islet, reducing discards or loss of organ, and reduce waitlist mortality. From modelling studies reported in the proposal, 500 NM is the most reasonable choice, however, we do feel it will be especially important to continue monitoring these metrics carefully at intervals noted in the evaluations section.
- We agree that proximity points should be applied both inside and outside the 500 NM circle in order to accomplish the goal of broader distribution for improved equity while still protecting efficiency with minimized travel distance. Modelling supports this effect of proximity points, but some of us still questioned how efficiently these proximity points would achieve this, further emphasizing the importance of frequent reevaluation of outcomes after the proposal is implemented.
- Issues regarding behavior of programs in a new system should be addressed directly to transplant programs and OPO's—this includes concerns about programs being reluctant to accept organs from a farther distance or from a program they have not worked with before. Forging these new relationships may need proactive support from the OPTN. Education of the public, candidates or families is not specifically addressed in the proposal nor is there any consideration of who would be in charge of this education (transplant hospitals?). Pediatric transplantation was not addressed in the proposal, so some clarification about whether this policy would apply to pediatrics is needed. Further, some clarification of how organs are classified as pancreas alone, kidney/pancreas or kidney alone should be clarified.
- We agree that the 150 NM circle makes sense in order to maintain broad distribution and efficiency, as well aligning with kidney import backup for consistency and standardized clarity.
- The secondary circle would likely introduce further travel and preservation stresses for an organ with the clock ticking down, so we do not support it.
- Since pancreas programs are few in number and we would like to encourage further program development, it makes sense to include more programs in the qualification for facilitated offers with the proposed 2 imports in 2 years suggestion.
- It will directly impact candidates by expanding access to transplants geographically with wider distribution, and if modelling predictions bear out, increase access to underserved populations.

- It is not clear how this policy will be presented to the public in a clear, concise manner, and by whom. The metrics outlined for reevaluation did not include tracking of transportation costs and monitoring of preservation times in relation to changes in transport distance. In order to facilitate understanding by the general public of the proposal and its significance, an introductory section outlining the history that led to this proposal would provide important context. In addition, a glossary for transplant-specific terminology would be helpful for patient readers. We would like to acknowledge that the new "Proposal at a Glance" section is a positive addition to the document, providing a clear, concise, user-friendly entry into the topic. The writing is uncomplicated and to the point with a tone that will be inviting to the general public to encourage joining the discussion.
- We recommend approval of this proposal with some additional attention to clarifying some of the details noted in the questions above. This is an important step in the development of a continuous allocation system. Further, this policy more closely approaches satisfaction of the Final Rule requirement that organ allocation shall not be based on a candidate's place of residence or listing. The policy has been designed with modelling to avoid unnecessary organ loss and promote efficient placement by limiting travel distance with proximity points. It also intends to improve access for historically underserved populations including certain minorities and lower socioeconomic status groups. Finally, it is in compliance with NOTA with a neutral effect on waitlist mortality and broadening of distribution of pancreata while increasing potential pancreas utilization and reducing potential impact of long preservation times on post-transplant mortality.

In response, the presenter replied that they will work on who will present the public comment to the general community, including more national webinars, regional meetings, and outreach to other organizations. Also, the OPTN Professional Education and the Communications team are engaged with the Pancreas Committee and are working to develop new trainings and social media campaigns. Furthermore, currently pediatric patients are not included in pancreas allocation because of the small amount of patients. However, the OPTN Pancreas Committee will be focusing their upcoming work on a project that looks to address pediatric pancreas patients.

One PAC member was concerned about islet transplants, including the specific training and standards set for each islet program. This member was concerned that patients needing an islet would be in direct competition with patients needing a pancreas. In response, the presenter replied that islets make a small portion of transplants, and that the purpose of this proposal is mainly to remove DSA and region. Also, the OPTN does not track data about islet transplants, and they are not considered a standing organ. Lastly, a PAC member asked if the Pancreas Committee performed any modeling for separate pancreas and separate kidneys, and whether the turndown rejection rate was modeled. In response, the presenter clarified that no separate modeling was done between kidneys and pancreas, and that some of the models did show a decrease in kidney transplants because of an increase in kidney/pancreas transplants. However, there was still concern that kidney-alone patients would be disadvantaged and that there would be no specific monitoring on kidney-alone patients. One PAC member encouraged the presenter to review the white papers and guidance documents already published in order to ensure that correct language is used moving forward.

The PAC voted on this proposal and the results are as follows: Strongly support (31%), Support (54%), Neutral/Abstain (8%), Oppose (8%), Strongly Oppose (0%).

3. Proposal Review: Continuous Distribution of Lungs

The Chair of the OPTN Thoracic Committee presented their current proposal out for public comment for feedback from the PAC.

Summary of discussion:

Below is a summary of the Committee's feedback on the continuous distribution of lungs concept paper:

- Many things can impact the efficiency management of organ placement, and the phrase "efficient management" of organ placement is broad enough to include virtually every aspect of transplant. If the points-based framework includes all elements affecting medical urgency, outcomes, and patient access in the calculation of the scores of those factors, efficient management becomes merely a question of the allocation and delivery mechanics and related expense. A points-based system can accommodate multiple factors related to efficiency and will more directly connect those factors with these Final Rule provisions.
- To facilitate understanding and communication across the transplant community, an idea posed by a Committee member included the points-based system being constructed so that the composite allocation score for each organ would be expressed on a scale format (unique to each organ system). Overall, a transparent points-based system that leads to greater equity in the distribution of organs among those who have been accepted as candidates may result in higher patient and patient family satisfaction
- The concept paper discussed the factors that would need to be incorporated. Other factors that should be incorporated include the following: medical urgency, age/size, waiting time, sensitization, patient's access to a transplanted organ; time on the waitlist; quality of the donor organ; length of time from procurement of organ to implantation; and the utilization of "best practices" throughout the transplant process and aftercare. The group believed adult versus pediatric factors should be also be integrated.
- Ultimately, this would impact candidates directly, recipients indirectly, and family members of recipients or donors indirectly. Candidates will have more equity in receiving an organ. Recipients may be negatively or positively impacted, as wait times would play a factor. However, it should be noted that recipients might benefit from less organ rejection due to better organ matching. Family members of recipients or donors may benefit due to their loved one receiving a better organ match (presenting less challenges post-transplant).
- From a patient perspective, the group was divided on how they felt about the language used throughout the concept paper. The basics of classification-based framework and points-based framework were clear, but the document as a whole presented confusing material from a patient's perspective, including the definitions it provided (such as the word "efficiency").
- Group consensus was that they recommend the PAC support this proposal. The principles outlined in this proposal are specific and intended to alter the way transplantation throughout the United States is conducted. The current system, though effective, needs improvement. In order to effectively make the necessary improvements that would ensure a more equitable distribution of these limited resources, structural changes must be made. The existing framework does not demonstrate the flexibility to take advantage of new technological advancements in medicine, thereby enabling greater access to patients who are precluded due to geography and other criteria. This proposal offers a much more flexible framework that changes with future medical advancements and offers a more level "playing field" when it comes to receiving an organ donation. It will facilitate elimination of artificial geographical and other barriers inherent in the classification system and identification of the most important elements of an efficient and effective system.

- Below are the Committee's questions regarding the concept paper and the Thoracic Chair's responses:
    - What are some reasons as to why would anyone oppose this system?
        - Members are concerned about the numerous details involved in creating a continuous distribution system. The Chair commented that it will take time to weigh different factors and incorporate all the feedback from members.
    - Is there a way to add intangibles, like focus on wellness and technology, to the process?
        - One of the advantages of this type of system is its flexibility and adaptability to adding in new factors. There is a challenge for ensuring that those factors are tangible and are aligned with the OPTN Final Rule.
    - Is it fair to include actuarial data into the algorithm (in reference to best practices and maintaining a dynamic and ongoing database)?
        - The LAS score specifically looks at post-transplant outcomes, but there might be an advantage at differentiating this score from the overall composite score in the future.
    - Request for an easy to understand definition of who is a "sensitized " patient. It's stated in the proposal that "a patient who might have trouble getting an organ," but don't most patients fall into this category?
        - The Thoracic Committee has considered the topic of "sensitized candidates", but has not reached a definite conclusion. There is room for improvement in the current allocation system, and the Thoracic Committee will look into this further in order to make sure no patients are disadvantaged.
    - What is the definition of a vulnerable population (cautious of discrimination accusations in the legal climate)?
        - Vulnerable populations are an important consideration (such as rural populations). The Thoracic Committee will evaluate and monitor for any disadvantages in this system, including in any future modeling.
    - Is there any data available on the use of drones (e.g., cost, reliability, distance that they can cover, speed, and potential loss of the organ)?
        - Right now, there is no data available on drones. However, this could impact and change the efficiency of the overall system. The advantage of continuous distribution is that changes to efficiency can be accounted for more easily in the future.
    - Request for additional details on how the numbering system and allocation will work, including will it be simple enough to track, explain to patients, and keep updated in the system?
        - It may be easier to explain to patients once there is an actual policy proposal out for public comment. However, it was noted that candidates would not be receiving an organ offer until they are given a composite score. Furthermore, each organ offer will require a re-calculation of a candidate's score.
    - One element that might be considered efficiency, but not mentioned in the paper, is the problem created by transplant center rejection of previously allocated organs, and reallocation of such organs. Should a secondary formula be available to manage such circumstances so as to maximize use of such organs?
        - The Thoracic Committee has been working on this topic. It is relatively rare that organs are re-allocated after the donor is in the operating room, and there are more concrete ischemic times.

  - Should perfusion boxes be a consideration for implantation in this framework due to their advancement in medical practices and technological systems? Would the utilization of perfusion boxes aid in the delay of the ischemic quality of the organ?
    - Right now, there is no data available on perfusion boxes. However, this could impact and change ischemic time of the overall system. The advantage of continuous distribution is that any changes can be accounted for more easily in the future.
  - How would the proposed system deal with candidates who need multi-organ transplants?
    - The proposed system will not necessarily deal with this directly, but if scores could be standardized across organs, then this may allow a more accurate portrayal of a candidate's medical urgency.
  - If a patient is on the waitlist for a lung transplant, are there things they can do to improve their Lung Allocation Score (i.e., is this score static or could it be dynamic)?
    - The LAS score is dynamic, and is updated whenever new data is taken and documented (there should be no difference under a continuous distribution system).

One PAC Committee member asked what the main upcoming issue that the Thoracic Committee will face with a continuous distribution system. The Chair replied that the greatest challenge will be to weigh each of the factors (such as efficiency or medical urgency), and at what LAS scores would teams travel greater distances in order to procure organs. Determining such weighting will require further discussions. This PAC member also asked how the Thoracic Committee would determine whether the policy was effective. The Chair stated that they should know through modeling prior to implementation and in post-implementation evaluations. If the policy did not work, it may not necessarily mean the continuous distribution system failed, but rather how the Committee calculated the composite scores. The Chair supported including community members early in the process so that all voices are heard when developing the policy proposal. Lastly, a PAC member appreciated the dynamic approach of the system, but questioned whether regional review boards would still be needed and if there were any safeguards against Waitlist manipulation. The Chair replied that review boards will still be needed, but that there will always be patients who do not meet the exact policy requirements. In terms of manipulating the system, there are no specific safeguards against this in the concept paper. However, by taking into account more factors, then hopefully this will prevent any manipulation from occurring.

The PAC voted on this proposal and the results are as follows: Strongly support (57%), Support (43%), Neutral/Abstain (0%), Oppose (0%), Strongly Oppose (0%).

4. Modifying OPTN Proposals for the General Public

In response to feedback from the Committee, the OPTN has added a layperson's "at-a-glance" abstract to all public comment proposals. The Committee was asked to share feedback on this abstract. The Committee also previewed commonly used transplant terminology to set-up future discussion on language clarity and sensitivity.

Summary of discussion:

In terms of the laypersons "at-a-glance" abstract, the Committee had the following feedback:

- There was a lack of historical context on OPTN policies featured on the abstract
- A lack of familiarity with OPTN and transplant terminology
  - A Committee member stated that patient populations will not engage with something they do not understand

- There was mixed discussion about the questions included in the abstract. Some Committee members supported the questions at the bottom of the abstract, saying that it helped them navigate and think about the proposal. However, others stated that the questions at the bottom of the abstract were geared more towards professionals, and could be made simpler or more engaging.
    - Examples of simpler questions: Who's going to be advantaged? Who is going to be disadvantaged? How does this impact me?
- A Committee member suggested changing the paragraphs into bulleted lists to ease the abstract's readability.
- The majority of Committee members agreed that the abstract was written to be printed and was not technologically-driven
    - A question posed to the Committee was how they might interface the abstract to make it more interactive and dynamic? A Committee member suggested to include hyperlinked terms and to further leverage technology.
    - One Committee member suggested creating a system whereby when someone accesses the abstract, they can "opt in" to receiving emails from the OPTN
- Many Committee members were concerned that the abstract is only provided in English. As such, it would be difficult to ask a non-native English speaker to read the abstract.
- Most Committee members supported posting the abstract on social media, that way the OPTN can engage with patients and encourage them to learn more about the public comment proposals.

Overall, the Committee was supportive of the proposal "at-a-glance" abstract and thought that with some modifications, the document could help the general community engage and understand the public comment proposals.

Next in the discussion, the Committee previewed commonly used transplant terminology, specifically focusing on language clarity and sensitivity. In summary, PAC members general agreed that the Committee should take the lead in ensuring transplant terminology is sensitive toward donor families, recipients and patients within the OPTN. One Committee member noted that replacing some of the verbiage might make it clearer for patients to understand, though the Committee would need to ensure the language is consistent across multiple patient populations. UNOS staff noted that not all of the terms listed in the document are used in the OPTN, such as the words "harvest" or "cadaveric". In terms of the path forward, a majority of the Committee members supported creating a guidance document or white paper, provided that Donate Life America is not already creating a similar document for public release. HRSA suggested that the Committee and UNOS staff make sure that Donate Life America is not already working on a similar project. The Committee agreed that they should touch base with Donate Life America prior to taking any further steps forward with this project.

Next steps:

UNOS staff will reach out to Donate Life America to find out more about their current project regarding transplant terminology.

5. Initiative to Update Criteria on Increase Risk Organ Donors

The CDC gave an update on their efforts to revise the criteria used to identify organ donors that may be at increased risk of having undetected HIV, Hepatitis B (HBV) or Hepatitis C (HCV). The goal of these revisions is to increase the number of organ transplants in the U.S. by aligning health policy with recent advances in disease detection and treatment.

Summary of discussion:

In response to the presentation, one Committee member stated that if physicians are not comfortable with increased risk patients, then the patient community will not accept these changes. In response, the speaker acknowledged that in an ideal world, each hospital would have an infection disease specialist to provide robust education with the transplant team. However, this is not reality, and may not be feasible for smaller transplant programs. Instead, transplant programs should ensure that there are robust infection protocols in place. Another Committee member asked for more clarity regarding the changing increased risk donor designation criteria. The speaker clarified which criteria would be updated under this proposal. Another Committee member was concerned whether any Hepatitis C donors had transmitted the disease to any recipients. In response, the speaker clarified that they excluded any "known" disease transmissions during the data analysis. Furthermore, the speaker highlighted CDC data that showed the number of unknown transmissions of HBV and HCV between the years 2014 to 2017. There was concern from a member about follow-up care and treatments available to patients whom contract HBV or HCV. Though there is still a desire to prevent transmission, the speaker stated that this fear of disease transmission is decreasing because of available testing or treatments available. Also, the goal of these guidelines are to bring the recommendations up to date with current therapies and testing out in the medical community.

Another Committee member was concerned about the lack of guidance for other diseases, such as Zika or West Nile disease. This member encouraged the development of an infection module encompassing all types of donor infections. Though this is out of scope for this particular project, the speaker agreed that this should be done by transplant hospitals. To note, though the CDC agrees that such education should be pursued, there is no singular, standardized test for these rarer diseases, and would be difficult to make systematic recommendations.

In terms of next steps, the proposal will soon be released for public comment. When the proposal is released, the OPTN Disease Transmission Advisory Committee (DTAC) will work with volunteers from the PAC to develop an overall OPTN response. The plan is that these recommendations would not be published until April or May 2020.

Next steps:

UNOS staff will follow-up with Committee members when public comment opens for this proposal.

6. Proposal Review: Eliminate the Use of DSA and Region in Kidney Distribution

The policy analyst for the OPTN Kidney Committee presented their current proposal out for public comment for feedback from the PAC.

Summary of discussion:

Below is a summary of the Committee's feedback on the kidney proposal:

- Historically, PAC supports the goal of continuous distribution. Evolving away from DSA, a 30+ year old policy, complies with the Final Rule but a concentric circle distribution method is also much easier for the Patient community to understand. Patients will likely defer to the experts when it comes to making the final decision on circle size but do want the circle to be as large as is operationally feasible. Patients will understand that transportation time may impact the health of an organ so there is a potential for too large of a circle.
- We understand the move away from DSA will require a new way of doing business for the various parties along the value chain, proximity points appear to be a way of "easing" into a new policy. Yes, proximity points are appropriate inside the 500NM circle. There is

uncertainty if they are required outside the 500NM circle. Over time, might the policy allow for the removal of proximity points? Recognizing that over time, as the Transplant Community successfully adapts to the change in policy, might we scale back the deployment of proximity points? Would this afford an easier transition towards the ultimate goal of continuous distribution?

- Pediatric priority is supported by the Committee for both inside and outside the 500NM circle.
- Priority points for living donors is supported by the Committee
- Logistic and cost concerns are well documented. Probably the same two concerns identified back in the 1980s when DSAs were first established. Communication: the Patient Community must believe the new policy is in their best interest. Highlighting "why" this new policy will benefit the Patient is critical. Donor families and recipients must have confidence that the new policy is safe and equitable. There must be a common message coming from the Transplant Community or there is a risk of losing Patient support. If the Patient Community has doubts, then operational slowdowns may occur. Communicate, often, the reasons why this benefits the Patient Community.
- Medical urgency should be defined. If urgency is defined, then the results may be measured. There is some concern that "medical urgency" may result in unequal sharing of a national life source. The Patient Community will believe the system is "fair" provided there are documented rules. Currently, medical urgency is defined differently depending on the Region so this policy must make the definition uniform across the nation. The priority points system could be used to determine which of two medically urgent patients should be prioritized (Distance, Age, Dialysis Time, Prior Living Donor status, etc.).
- Time is of the essence under this situation. Broad discretion should be afforded to OPOs but they must document how they chose to allocate, in case questions arise about equity.
- Pleased to see the modeling does not anticipate a reduction in transplantation. Opinions shared include, "financial status may no longer impact access to transplantation," "living donors will appreciate that their prior sacrifice will be acknowledged should they need a transplant in the future" and "this policy will be easier to understand than under DSA."
- The language, illustrations and figures used in the proposal are difficult for the general public to understand. The "Proposal at a Glance" section is a nice summary. Expand in this area. Definitions that the general public may need to know in order to understand more accurately are missing. Might there be electronic links in the proposal for acronyms and medical terms?
- It appears there have been lengthy discussions on potential impacts, positive and negative, and many stakeholders were consulted. The results after the policy change goes into effect will inform us if we are successful of not, however, it seems the professionals present an appropriate policy. Yes, PAC supports this policy. First and foremost, where you live should not hinder access to transplant. This policy change, after 30+ years, points us in the direction towards continuous distribution, a policy supported by the vast majority of PAC.
- There was concern that certain Regions may unfairly frame this proposal as "bad", whereby this proposal should be framed as creating more equity across the entire country.
- There was some confusion about how proximity points are defined in the paper. For example, patients might take the word "proximity" to mean how close one is to getting a transplant, versus "proximity" actually referring to geographical location. UNOS staff agreed to take these comments back to the Kidney Committee.

- It is also important that Regions understand that they still may benefit from this proposal, albeit not at the full 100% they had been doing so previously. In this way, it is important for people to understand equity, and how this proposal can benefit the sickest candidates.
- The issue of water boundaries was spoken about, and a perceived lack of income due to water boundaries. However, SRTR staff commented that circles will still work even though there is water, because there are neither donor nor transplant hospitals in the water.
- One PAC member commented that using the word “may” multiple times gives the proposal an impression of uncertainty.
- One PAC member stated that transplant centers and candidates should look at other opportunities outside of deceased donor organs, such as living donation, especially if there is a change in the number of transplants for that center.

In response, the speaker stated that using proximity points outside of the circle are valuable because it sets up one descending line from the donor hospital. In this way, this is a step in the right direction for eventually implementing continuous distribution. Also, the champion of the patients in this proposal will be the patient representative on the Kidney Committee, along with stakeholder outreach. One attendee at the meeting summarized feedback from the Region 3 meeting, stating that they strongly opposed this proposal due to a large decrease in the number of transplants for certain centers. In response, a PAC member stated that OPTN Regions should focus on the mission of the OPTN, which is to the greatest good and increase transplants. On the otherhand, a PAC member opined that OPO performance needs to be evaluated as well. However, UNOS staff noted that though OPO variability needs to be addressed, this will not necessarily be addressed in this proposal.

The PAC voted on this proposal and the results are as follows: Strongly support (23%), Support (69%), Neutral/Abstain (0%), Oppose (8%), Strongly Oppose (0%).

7. Update to PAC Charge

The PAC Committee discussed modifying or changing their OPTN charge.

Summary of discussion:

UNOS staff presented the current PAC charge and asked if there was any feedback from PAC members. UNOS staff clarified that re-evaluating the charge is not meant to entail a complete rewrite of the statement. Rather, this updating the charge was deemed necessary for all OPTN Committees to do per the Executive Committee. PAC members discussed and agreed that the word “UNOS” be replaced with “OPTN”. Furthermore, most Committee members agreed that the word “donors” should be distinguished between living and deceased and to provide more specificity. Though one Committee member opined that “deceased donors” may not be the correct terminology to use, a donor-family related Committee member supported using the word “deceased” and stated that such a word is not offensive. Therefore, the PAC modified the current charge to this:

"*The Patient Affairs Committee advises the OPTN Board of Directors and other committees about patient and donor family perspectives on OPTN policies and initiatives that originate in other committees. It may work independently or with other Committees, as approved by OPTN leadership, in the development of initiatives and policy proposals with significant import for topics of interest to patients, including transplant access, outcomes, and safety. The committee helps develop and provide input on educational OPTN-related information for transplant candidates, transplant recipients, living and deceased donors and their families, and patient groups*".

Next steps:

The PAC Chair requested that this discussion be had again at their next meeting in September. UNOS staff will submit the modified PAC charge to the Executive Committee for further consideration.

Upcoming Meeting

- September 17, 2019