



National
Kidney
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October 3, 2018

Public Comment Coordinator
United Network for Organ Sharing
700 North 4th Street
Richmond, VA 23218

Re: Public Comment: Fall 2018

To Whom it May Concern:

The National Kidney Foundation is pleased to offer comments on the following Fall proposed policies generated by the Organ Procurement and Transplantation Network (OPTN) and United Network for Organ Sharing (UNOS). The National Kidney Foundation is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the US. In addition, the National Kidney Foundation has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI).

1. Addressing HLA Typing Errors

Summary: <https://optn.transplant.hrsa.gov/governance/public-comment/addressing-hla-typing-errors/>

As the Histocompatibility Committee highlights, while human leukocyte antigen (HLA) typing errors occur infrequently even one error can be catastrophic and result in death of the recipient, failed transplant, and organ wastage due to inappropriately matched donors. The National Kidney Foundation appreciates the recommendations of the Committee for a two-step authentication of HLA type. We support this proposal as an interim step to reduce future errors. However, we recognize that human error will continue and that the only way to prevent HLA typing errors is to improve technology by allowing for interoperability of software programs from the labs to UNET and transplant programs so that data can be automatically uploaded. We recognize not all transplant programs are using the same software package, and we call on OPTN to work with the transplant community to take

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immediate steps towards automatic uploading of HLA type to reduce this significant risk to patient safety and lost organs.

2. Pediatric Transition and Transfer Guidance Document

Summary: <https://optn.transplant.hrsa.gov/governance/public-comment/pediatric-transition-and-transfer-guidance-document/>

The National Kidney Foundation appreciates the issuing of this guidance to highlight best practices in assisting pediatric patients to adult post-transplant care. This is a persistent challenge for young adults who are also going through many life changes on top of the need to manage their own medical care. There are many best practices in this guidance that if implemented are likely to make this transition easier on young adults, such as having a multidisciplinary transition team, teaching young adults to be self-advocates, and assessing transition readiness rather than a required handoff at age 18.

The National Kidney Foundation recommends that UNOS also conduct a webinar series for transplant programs to share successful strategies with others. We recommend including patient perspectives in this series and have members of our Kidney Advocacy Committee who would be willing to share their stories and experiences as part of this series.

3. Frameworks for Organ Distribution

Summary: <https://optn.transplant.hrsa.gov/governance/public-comment/frameworks-for-organ-distribution/>

The National Kidney Foundation recognizes the importance and significant difficulty that the Ad Hoc Geography Committee has to recommend a single framework that can be used across organs. Each of these frameworks have pros and cons to them. The National Kidney Foundation supports a solution that will improve equality, efficiency and transparency in organ allocation. Most recently African Americans have seen an increase in transplantation that has been attributed to the current kidney allocation policy that was updated in 2014. Any modification in organ distribution policy must enhance access to transplantation for minority populations and those with low socioeconomic status as these groups have not historically had equal access to transplants.

Sincerely,
Tonya L. Saffer

Tonya L. Saffer, MPH
Vice President for Health Policy