

OPTN/UNOS Patient Affairs Committee
Meeting Minutes
August 15, 2017
Conference Call

Kristie Lemmon, MBA, Chair
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Introduction

The Patient Affairs Committee met via Citrix GoToTraining teleconference on 08/15/2017 to discuss the following agenda items:

1. Fall 2017 Public Comment Proposals

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

1. Fall 2017 Public Comment Proposals

The Committee reviewed two proposals out for public comment.

Regional Review Board Guidance for Adult Congenital Heart Disease Exception Requests

The Committee appreciates the Thoracic Committee's efforts to increase equity in access to transplant for adult congenital heart disease candidates by proposing objective exception criteria to standardize the evaluation and award of exception requests for these patients. The new policy has not been implemented yet, so the impact that proposal will have on the ACHD population is unknown. Removing variability in awarding exceptions for ACHD patients will only positively impact this population if Regional Review Boards (RRBs) adopt and follow the guidance which, by the nature of OPTN guidance, is voluntary and not enforceable. This raises the question of how effectively this proposal addresses the heart transplant community's concerns. Most patients do not know about exceptions. How can ACHD patients be assured that this exception is being sought on their behalf by their transplant programs (if appropriate) and that RRBs are utilizing this guidance? This guidance proposal does not address how the transplant community will educate patients about the change. Although the Committee recognized this is an interim measure, they recommend the Thoracic Committee not lose focus of the limitations of this proposal as guidance (versus policy) and the potential impact on the ACHD patient population. The Thoracic Committee answered all questions to the Committee's satisfaction. The Committee moved to support this proposal.

Guidance for Transplant Program Participation in the Transplantation of Non-A1/Non-A1B (A2/A2B) Donor Kidneys into Blood Group B Candidates

The Committee appreciates the Minority Affairs Committee's efforts to increase equity in access to transplant for blood group B candidates by increasing the number of programs participating in the voluntary kidney allocation system (KAS) provision to allow non-A1/non-A1B (A2/A2B) donors to match with blood group B candidates. The Committee acknowledged this would affect a moderate amount of the target population and is likely to provide moderate improvement over current state, if more programs adopt this guidance. Blood type B group candidates would have more organs available with a higher level of minorities being eligible for transplantation and wait list time may be reduced. The Committee inquired whether certain groups may be at a disadvantage; for example, patients who happen to live in a region where there is a lack of lab facilities, patients with low literacy may have difficulty understanding and being able to consent, and it may divert some kidneys from A and AB blood group candidates. The Committee inquired whether MAC had considered patient safety concerns. Patients who receive these transplants

and develop antibody-mediated rejection requiring pheresis will need special consideration with regard to their plasma infusions. Although the scope of the proposal is to educate centers to implement the practice of A2/A2B to B transplants, there should be some education about what can go wrong and how to manage that as those aspects promote patient safety. The proposal includes an education plan for transplant programs, but not for patients. The Committee suggested patient-friendly education and consent form templates would be extremely helpful resources to increase implementation and reduce timeline for activation. The Committee moved to support this proposal.

Upcoming Meeting

- September, 2017