

## **OPTN Liver and Intestinal Transplantation Committee**

### **Meeting Summary**

**December 12, 2019**

### **Conference Call**

**James Trotter, MD, Chair**

**James Pomposelli, MD, PhD, Vice Chair**

#### **Introduction**

The Liver and Intestinal Transplantation Committee (the Committee) met via Citrix GoTo teleconference on 12/12/2019 to discuss the following agenda items:

1. Society for Pediatric Liver Transplantation (SPLIT) Survey Review
2. Other Outstanding Items

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

#### **1. Society for Pediatric Liver Transplantation (SPLIT) Survey Review**

##### Data summary:

Emily Perito and Evelyn Hsu from the SPLIT Advocacy Committee presented the results of a survey that SPLIT conducted to evaluate the impact of the NLRB on the pediatric liver transplant community. It was a qualitative survey of SPLIT members, and there were 30 respondents. The survey was anonymous, and most responses were free text.

Respondents perceived more denials than before the implementation of the NLRB. Top reasons received for denials were that the exception did not provide enough information, did not meet the criteria in the guidance, or that the program was asking for too many points. Some respondents thought that it was important for the reviewers to know the region in order to determine whether the points were appropriate. Survey responses varied widely on whether they believed programs were actually asking for too many points. There was also a suggestion to reveal the requested score in relation to MMA<sub>T</sub> in addition to MPa<sub>T</sub>.

Some respondents also mentioned that the pediatric guidance document was not as comprehensive as it could be, and that some reviewers were reluctant to approve an exception request that was not covered in the guidance. A list of specific pediatric guidance topics that might be helpful to cover in the guidance document was presented.

There were also some suggestions for best practices for successful exceptions.

##### Summary of discussion:

Subcommittee members were interested in the range of responses, and thought education for how to review cases, and what kind of scores to request would be helpful. The subcommittee discussed that this might demonstrate that there is room for improvement of the PELD calculation, although it is difficult to tell how much of the large numbers of exceptions is driven by existing exceptions, and how much is because the calculation is not reflective of severity. Similarly, increasing PELD scores might be useful for increasing pediatric candidate access to adult donors and increasing the frequency of splitting livers.

The subcommittee discussed the improvements to pediatric candidate access that are expected with the implementation of Acuity Circles, and expressed a desire to pursue implementation of that priority independently of Acuity Circles if implementation of those changes are further delayed.

A subcommittee asked about the qualifications of reviewers on the pediatric NLRB. Although the programs that participate must be pediatric programs, there are no specific requirements for who they appoint to the NLRB. There is a learning curve for reviewing cases though. Some subcommittee members expressed an interest in encouraging a high level of experience on the pediatric NLRB in particular.

The subcommittee was interested in using some of the lessons learned from this survey and other feedback in future education and updates for the NLRB members.

The subcommittee expressed an interest in bringing more definition to PELD scores above 40, since those are only prioritizing between PELD candidates, and not relative to adult candidates. However, the subcommittee thought it would be better for that to be considered and be a recommendation from the pediatric committee.

The subcommittee was sensitive to the impact of both MMaT and MPaT on access for pediatric candidates, but was hopeful that once Acuity Circles takes effect, the MPaT will be the more important factor.

#### Next steps:

1. The subcommittee will form a small group to discuss areas of the pediatric guidance that could be improved. This would likely include a statement about how to use it when the diagnosis isn't covered in addition to adding information on less common diagnoses.
2. Some of the information will be incorporated into the Pediatric Committee update at the regional meetings.
3. A workgroup will be formed to evaluate whether PELD needs to be revised.
4. Something will be scheduled as a placeholder to determine if there is a need to revisit broader distribution of pediatric livers if there is not a favorable decision in the Acuity Circles litigation in January.

## **2. Other Outstanding Items**

### ART Team Leader

The subcommittee expressed an interest in appointing a member of the ART from the Liver Committee (initially) or who has self-identifies as interested and has a certain level of experience once the NLRB has matured (such as at least 2 years of service on the NLRB). It would be important that these leaders be invested and involved. This leader would need to be trained in advance of their term. This education could be presented on a call for the first few, but may eventually be able to be something that the leader could review on their own.

The leader could vote or not, and would have an opportunity to attend a call the month before their term to observe so that the first call of the month is not their first experience with an ART call.

This would not necessarily require an update to the guidelines prior to implementation of the change, but it would be ideal to update the guidelines to reflect the change.

### "Test" for NLRB Reviewers

The subcommittee discussed the best way to educate reviewers using sample cases. This will be incorporated into the NLRB training required at the beginning of each term. The cases will be fictitious but based on real problem cases and provide feedback on the most useful kinds of feedback.

The subcommittee requested information on whether there are outlier reviewers who are always voting yes or no, or often out of the majority.

#### **Upcoming Meetings**

- January 9, 2020
- February 13, 2020

