Introduction

The National Liver Review Board (NLRB) Subcommittee (the Subcommittee) met via teleconference on 6/11/2020 to discuss the following agenda items:

1. Qualitative Pediatric Data Request
2. Changes to Pediatric Guidance

The following is a summary of the Subcommittee’s discussions.

1. Qualitative Pediatric Data Request

The Subcommittee reviewed available data on pediatric exception requests.

Summary of Data

The Subcommittee reviewed the number and percent of pediatric exception requests by case outcome and application type. The data concluded:

- Since NLRB implementation, 207 (26%) exception forms were denied by the Pediatric NLRB
- Per reviewer comments, the most common reasons for denial were requesting too many MELD or PELD exception points and submitting insufficient information
- Adding additional guidance for providers who are submitting exceptions to the pediatric NLRB may ensure children receive exception approvals as needed

Summary of Discussion

Subcommittee members expressed interest in learning more about those requests that are initially denied for submitting insufficient information and then approved on appeal. The Subcommittee is also interested in looking at the specific MELD or PELD scores that transplant programs are requesting. The Subcommittee hopes to understand these denial reasons to help inform guidance for requesting an exception.

Next Steps

A new data request will be drafted for the Subcommittee’s approval.

2. Changes to Pediatric Guidance

Members of the OPTN Pediatric Committee presented suggested modifications to the pediatric NLRB guidance.

Summary of Data
The presenters recommended modifications to the following areas of pediatric NLRB guidance:

- Portal hypertension
- Failure to thrive/growth guidelines
- Metabolic liver disease
- Conclusion

Summary of Discussion

Regarding the proposed changes to portal hypertension, the Subcommittee recognized there may be overlap with the policy work currently being discussed as part of the PELD/Status 1B Workgroup. The Subcommittee was generally supportive of the other proposed changes.

Next Steps

The Subcommittee members will continue to review the proposed changes to the pediatric NLRB guidance language and offer feedback. The proposed changes will be incorporated into a formal draft of guidance changes for Subcommittee review at the next meeting.

Upcoming Meetings

- July 9