

**Selected Recommendations of the
OPTN/UNOS Thoracic Organ Transplantation Committee to the
Board of Directors
November 16-17, 2009
Orlando, Florida**

Summary

I. Action Items for Board Consideration

- *Addition of “Other” Field to Lung Diagnosis Data Elements*
To improve accuracy of diagnoses entered for candidates less than 12 years of age, the Committee asks the Board to approve the following programming change: Addition of an “other” data field where centers may enter a diagnosis not already listed in UNetSM. (Item 1, page 3)
- *Reorganization of Hemodynamic Data on the Adult Status 1A Heart Justification Form*
To make data collection requirements clearer and more logical in presentation, the Committee asks the Board to approve the following programming change: Reorganizing fields in the hemodynamic section. (Item 2, page 3)

II. Other Significant Items

- *Implementation of Approved Modification to Policy 3.7.6.1 (Candidates Age 12 and Older): Adding Current Bilirubin and Change (Increase) in Bilirubin as Factors to the Lung Allocation Score*
On October 23, 2009, the Committee will ask the Executive Committee the following: how it should move forward with policy development in the future, especially in light of the concerns expressed by the Board of Directors during its deliberations on implementing recent changes to Policy 3.7.6.1. (Item 3, page 4)
- *Automatic Approval of All Non-Exception Heart Status Justifications that Meet the Medical Urgency Criteria Listed in Policies 3.7.3 (Adult Candidate Status) and 3.7.4 (Pediatric Candidate Status)*
In October, 2009, the Committee will send a letter to the 11 Heart Regional Review Boards informing them of the Committee’s preference for automatic approvals of non-exception heart status justification forms. (Item 4, page 4)

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**Maryl R. Johnson, MD, Chair
Mark L. Barr, MD, Vice-Chair**

This report presents selected recommendations of the Thoracic Organ Transplantation Committee on issues that were discussed at the March 27, 2009 and July 14, 2009 meetings.

1. Addition of “Other” Field to Lung Diagnosis Data Elements

For a lung transplant candidate who is less than 12 years of age, a center cannot enter a diagnosis that is not already programmed in UNetSM. There is no “other” category where the center can enter this diagnosis. (There is an “other” category for lung candidates who receive lung allocation scores (≥ 12). When an “other” diagnosis is entered, the center submits an exception request to the lung review board.)

On February 25, 2009, UNOS staff discussed with the Lung Subcommittee the addition of an “other” field to enter a lung disease diagnosis that is not listed in UNetSM. This discussion was prompted by a center contacting UNOS staff to inquire how to enter a diagnosis not already listed in UNetSM. These contacts have not occurred too frequently, thus laying open the possibility that either the diagnoses listed in UNetSM are complete or that diagnoses that most closely match are being selected. To encourage accuracy in the diagnoses entered, the Lung Subcommittee recommended allowing centers to enter a diagnosis that is not in UNetSM. The Committee discussed and supported this recommendation at its March 27, 2009 meeting.

The Lung Subcommittee discussed this topic again on September 29, 2009. UNOS Staff posed programming questions related to the addition of the “other” field, and queried the Lung Subcommittee’s interest in the following alternatives to adding the “other” field. These alternatives were:

- 1) Add more lung diagnosis codes (rather than adding a new “Other Diagnosis” field); or
- 2) Allow all candidates less than 12 years old to submit an LAS Exception for a “Other Diagnosis”

The Lung Subcommittee maintained its support of adding the “other” text field. After this text field has been added to UNetSM, the Subcommittee commented that it would consider adding to the quantitative diagnosis list those diseases that are frequently entered in the text field.

The Committee asks the Board to consider the following recommendation:

****RESOLVED, that programming to add the lung diagnosis data element “other” for candidates who are less than 12 years of age, as set forth in Exhibit A, is hereby approved, effective pending programming in UNetSM.**

2. Reorganization of Hemodynamic Data on the Adult Heart Status Justification Form

On October 2, 2007, the Committee received a request from a Heart Regional Review Board member to clarify data fields in the heart justification form. The reason for this request is that in some cases, the hemodynamic data are not current or complete. In addition, for some Status 1A justification requests, the location of the “Date of Hemodynamics” field is also confusing.

A Committee member proposed that reorganizing fields in this section would make the data collection requirements clearer and more logical in flow. The Committee agreed.

On October 13, 2009, the Heart Subcommittee met to further discuss this programming topic. Exhibit B is the report of this meeting, and this report includes details on how the Subcommittee would like the heart status exception form revised. At its meeting on November 4, 2009, the Thoracic Committee voted in favor of the Heart Subcommittee's programming recommendation: 18-Supported; 0-Opposed; 0-Abstained .

As of June, 2008, the Board of Directors requested to review all programming items. As such, the Committee asks the Board to consider the following recommendation:

****RESOLVED, that the reorganization of hemodynamic data elements in the adult heart justification form, as set forth on page 9 in Exhibit B, is hereby approved, effective pending programming in UNetSM.**