

OPTN/UNOS Patient Affairs Committee - INTERIM REPORT

Conference Call – January 13, 2011

- During the November 15, 2010 PAC meeting the Committee had questions for the Liaison to the Thoracic Committee about heart allocation policy. The Thoracic Liaison was invited to today's conference call to do a presentation on current heart allocation policy. The Liaison provided a written summary of thoracic allocation. The presentation provided an overview of both waitlist and transplant trends across all thoracic organs.

The Committee raised the following questions during the discussion;

- Can wait time be added as a factor in heart allocation?
- Why are there so many inactive candidates?
- What reason or reasons could be attributed to a substantial shift (besides the change in the system from waiting time to score) in the distribution of diagnosis from pre-LAS (>50% Group A) to post-LAS (>50% Group D)?
- Why has there been an increase in lung transplants since the LAS?
- Is there variation due to geography in the number of lung transplants since the LAS?

The Thoracic Liaison will provide answers to the questions as available.

- At the November 15 meeting the committee discussed Medicaid funding cuts in Arizona. Beginning October 1, 2010 lung, pancreas only, pancreas after kidney, heart for non-ischemic cardiomyopathy and liver for diagnosis of hepatitis C were excluded from Medicaid coverage in Arizona. Several committee members stated that other states might be considering changes in Medicaid coverage. The committee requested data to assess how many people are affected or potentially can be affected by changes in Medicaid coverage in the United States. Anna Kucheravaya, Biostatistician and Research Support to the Committee made the following report in response to that request.

On 12/03/10 sixty Arizona residents on Medicaid were waiting for the types of transplants affected by the coverage changes. Nationally about 10% of candidates on the waiting list and 9% of recent transplant recipients reported Medicaid as a primary source of payment. These data indicate that any changes in Medicaid coverage in the United States might affect a significant number of people waiting for transplant.

- The Liaison is working on the Committee Early Evaluation Tool for the Patient Notification Proposal. This document provides a preliminary overview of the proposal that would go out for public comment. The Committee Early Evaluation Tool will be presented to the Executive Committee of the UNOS Board. All Public

Comment proposals must be approved by the Executive Committee before any committee can move forward.

The Plain Language Version of the OPTN Contractor Patient Information Letter, in both English and Spanish has been uploaded to the OPTN website.

<http://optn.transplant.hrsa.gov/resources/professionalResources.asp?index=15>

An announcement will go out to all OPTN Members in the January UNOS E-Newsletter on January 21, 2011. This announcement will be followed up by an email to each individual transplant center. The announcement will inform centers that:

- The new version of the Patient Information Letter (PIL) is available on the web and provide a link to the location
- Centers may begin using the new PIL on January 21, 2011
- Centers have a 90-day window to transition to the new PIL
- All Centers must have implemented the new PIL by April 21, 2011

An article highlighting the personal experience of PAC Member and transplant candidate, Kathe LeBeau appeared in the November/December 2010 UNOS Update. This is the first article in a series of three. The UPDATE series is intended to focus on the personal impact of patient notification.

A webinar on patient notification is being planned for March 2011. The Subcommittee is waiting for confirmation of the actual date. The Webinar will be done in conjunction with DEQ.

- The Subcommittee continues to work on the rewrite of WEP. First drafts all sections except sections 3 and 5 have been completed and are now in the editing process. Sections 3 and 5 are in process. PAC members offered options for underwriting the costs of the rewrite and will email these options to the Liaison.
- The Committee will meet on March 28, 2011 at the O'Hare Hilton for a face-to-face meeting.