

**Interim Report of the  
OPTN/UNOS Transplant Coordinators Committee  
Live Meeting  
August 28, 2012**

I. **Agenda** items for the call included: a presentation on how often the unknown fields are used on the data collection (Tiedi) forms; an update on the education & policy working groups; an announcement for upcoming Tiedi Documentation Project working group calls; and, a Living Donor Committee request for assistance to review a document.

II. **Old Business**

Tiedi Documentation Project. Research staff presented data on the rate of unknown response to data elements collected on the transplant recipient follow up (TRF) forms. The committee wanted to know how often the “unknown” field was being utilized and consider a recommendation to remove that option on the forms if it was being used too often as a replacement for information pertinent to patient outcomes. After reviewing the data, it was determined, due to the low number of incidence, that there wasn’t sufficient evidence to remove the field from the form. The committee requested that the principles of data collection is reviewed at its September 24<sup>th</sup> meeting to better understand the rationale for having to fill out fields on the forms that are not clinically relevant as the coordinators feel that most of the data is requested for research purposes only.

Education working group update. Members of TCC and the Patient Affairs Committee (PAC) are collaborating to develop a resource to define what “inactive” vs. “active” status means to patients. Members agreed that there is confusion not only with patients, but also with coordinators and physicians. It was noted that the new Kidney Allocation System will be presented at its September 24<sup>th</sup> meeting to give members an opportunity to ask questions about how these statuses will be handled. In addition, members agree this is a patient issue and there needs to be a policy in place to hold centers accountable for informing their patients of their status.

Policy working group update. Members of the TCC and PAC are collaborating to develop policy on patient notification of having an inactive status. Data was reviewed and members suggest that patients waiting for an abdominal organ should be notified every twelve months if having an inactive status and those waiting for a thoracic organ is notified every six months. The specifics will be outlined at its September 24<sup>th</sup> meeting.

III. **New Business**

Living Donor Committee request. The living donor committee liaison requested that a few members from the TCC review screen shots included in a document to *Require Reporting of Non-utilized and Redirected Living Donor Organs*.

IV. **Meetings**

- The next in-person meeting in Chicago is September 24, 2012.

- The next Tiedi Documentation Working Group Live Meeting is scheduled for September 19<sup>th</sup>. On this call, kidney and liver fields will be reviewed on the transplant candidate registration (TCR) forms.
- The next full committee monthly live meeting is scheduled for October 23<sup>rd</sup>.

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