OPTN/UNOS

Transplant Coordinators Committee

Report to the

OPTN/UNOS Board of Directors

June 24-25, 2013
TCC Project Updates

- Patient Notification – Extended Inactive Status
- Tiedi Documentation
Patient Notification - Extended Inactive Status

- Notify candidates who have been in an inactive status for 12 consecutive months and annually if they remain inactive

- Public Comment - Fall 2013
Rationale

- Transparency of listing status for candidates

- Consistent with rationale behind existing OPTN policy 3.2.7, requiring patient notification:
  - when patient is listed;
  - if the decision after evaluation is to not list; or
  - if the patient is removed for the wait list for reasons other than transplantation or death.
Some patients do not know they are inactive.

Some patients who know they are inactive do not know that inactive means they are ineligible to receive offers.

Just as policy requires patient notification at listing and delisting, policy should require patient notification when inactive status is prolonged.
Alternatives Considered

- UNet\textsuperscript{SM} Programming
- Educational Efforts
Supporting Literature


- Single center study
  - 26% of WL temporarily inactive
  - 65% of those inactive were reactivated at some point, some not until 214 months (~18 years) later
  - 33% of those inactive were never reactivated
  - Patients on the inactive list wait longer for organs and are more likely to die
Supporting Literature


- Survey of dialysis patients in an urban dialysis center in a predominantly African American population
- 53% of candidates undergoing workup were unaware of their listing status
- 89% of those candidates mistakenly believed they were on the active wait list

- Patients should only be listed once their work-up is complete
- A task force should be convened to define the maximum allowable duration of inactivity (1 year)
- Patients should always be aware of their status
- These recommendations would reduce the length of the waiting list, allow renal transplant to be offered to a greater proportion of candidates, and cut overall expenditure on ESRD treatment
Active and Inactive WL Registrations
March 2, 2012, by Organ Type

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>Active</th>
<th>Inactive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>892</td>
<td>37,636</td>
</tr>
<tr>
<td>Liver</td>
<td>3,345</td>
<td>13,483</td>
</tr>
<tr>
<td>Heart</td>
<td>1,059</td>
<td>2,252</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>1,139</td>
<td>1,346</td>
</tr>
<tr>
<td>Lung</td>
<td>972</td>
<td>348</td>
</tr>
<tr>
<td>Pancreas</td>
<td>186</td>
<td>341</td>
</tr>
<tr>
<td>Intestine</td>
<td>97</td>
<td>28</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>32</td>
<td>44,377</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>78,315</td>
</tr>
</tbody>
</table>

WL Status: Active, Inactive

OPTN
Median Time in Most Recent Inactive Status for Inactive Registrations as of March 2, 2012, by Organ and Total Time Waiting

- Kidney
- Liver
- Kidney-Pancreas
- Pancreas
- Heart
- Lung
- Intestine
- Heart-Lung

Median Time in Inactive Status

- 25 yrs
- 20 yrs
- 15 yrs
- 10 yrs
- 5 yrs
- 0 days

Total Time Waiting

- 1 yr
- 5 yrs
- 10 yrs
- 15 yrs
- 20 yrs
- 23 yrs

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Supporting Data

Data presented to the TCC in June 2012 looking at inactive registrations removed for death or being too sick to transplant during 2007-2011 indicate that:

• The vast majority of registrations were removed after having been inactive for 12 months or less.

• However, there were registrations that had been inactive anywhere from 1 to >15 years prior to removal.
# Waiting List on February 28, 2013

<table>
<thead>
<tr>
<th>Organ</th>
<th>Active</th>
<th>Inactive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>26</td>
<td>49.1</td>
<td>27</td>
</tr>
<tr>
<td>Heart</td>
<td>2,530</td>
<td>73.0</td>
<td>936</td>
</tr>
<tr>
<td>Intestine</td>
<td>170</td>
<td>66.7</td>
<td>85</td>
</tr>
<tr>
<td>Kidney</td>
<td>57,229</td>
<td>60.0</td>
<td>38,211</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>1,057</td>
<td>49.7</td>
<td>1,068</td>
</tr>
<tr>
<td>Liver</td>
<td>12,535</td>
<td>79.8</td>
<td>3,181</td>
</tr>
<tr>
<td>Lung</td>
<td>1,311</td>
<td>79.4</td>
<td>341</td>
</tr>
<tr>
<td>Pancreas</td>
<td>332</td>
<td>27.9</td>
<td>857</td>
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<tr>
<td>Pancreas Islet</td>
<td>25</td>
<td>12.2</td>
<td>180</td>
</tr>
</tbody>
</table>
Identify problems with existing data field descriptions on OPTN forms

Identify fields for review by other committees for current relevance or improved description

Approximately 300 fields have been reviewed thus far

The remaining fields will be completed by the end of the year
Listserv

Join the transplant coordinators listserv at

http://groups.yahoo.com/
Questions?

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