

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 from the wait list for reasons other than transplantation or death.

Rationale

- 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

- UNetSM Programming
- Educational Efforts

Supporting Literature

Temporary Inactive Status on Renal Transplant Waiting List: Causes, Risk Factors, and Outcomes. Safi, S., Zimmerman, B. and Kalil, R. Transplantation Proceedings (2012), 44, 1236-1240.

- 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

Lack of Listing Status Awareness: Results of a Single-Center Survey of Hemodialysis Patients. Gillespie, A., Hammer, H., Lee, J., Nnewihe, C., Gordon, J., and Silva, P. American Journal of Transplantation (2011), 11: 1522-1526.

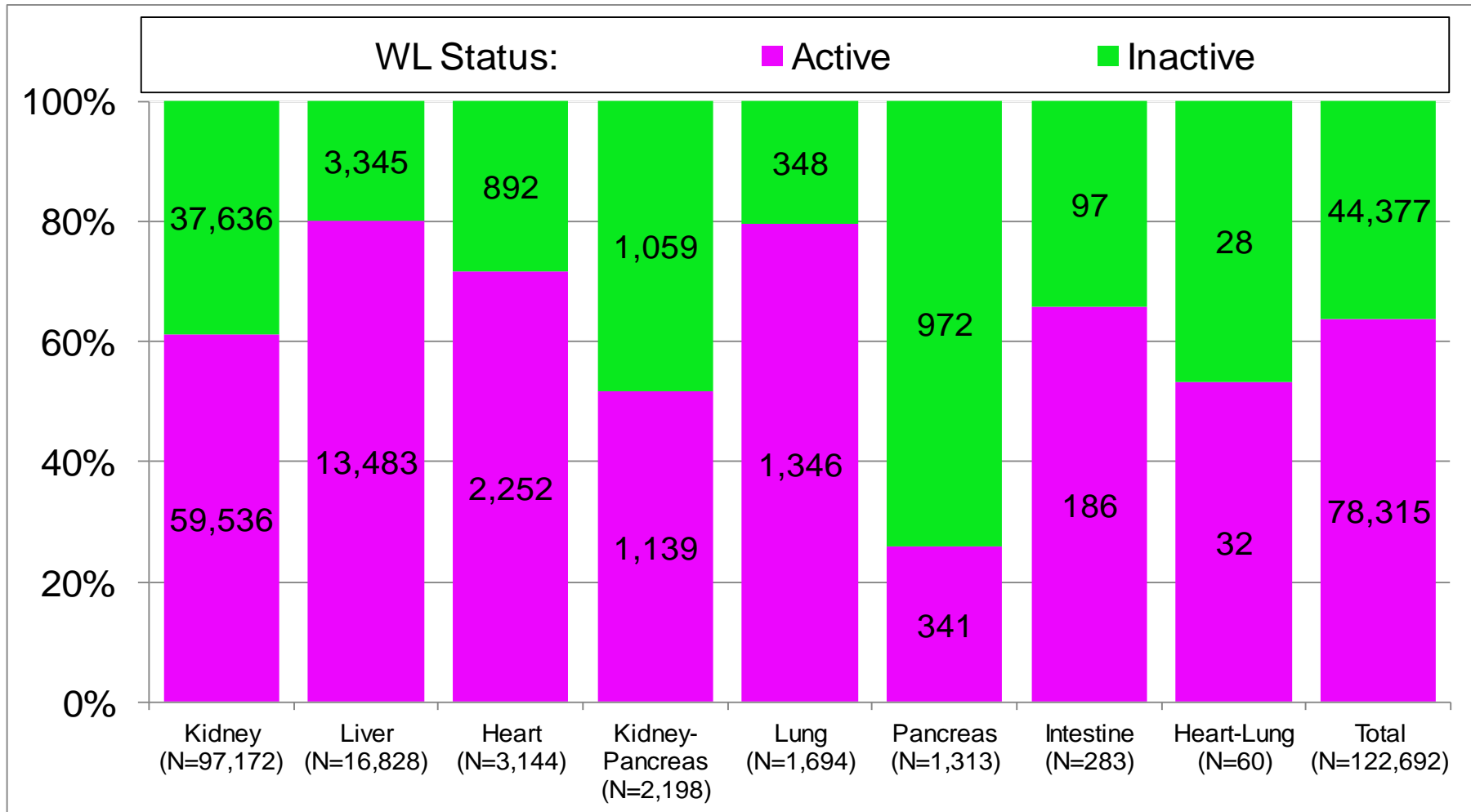
- Survey of dialysis patients in an urban dialysis center in a predominantly African American population
- 53% of candidates undergoing workup were unaware of their listing status
- 89% of those candidates mistakenly believed they were on the active wait list

Supporting Literature

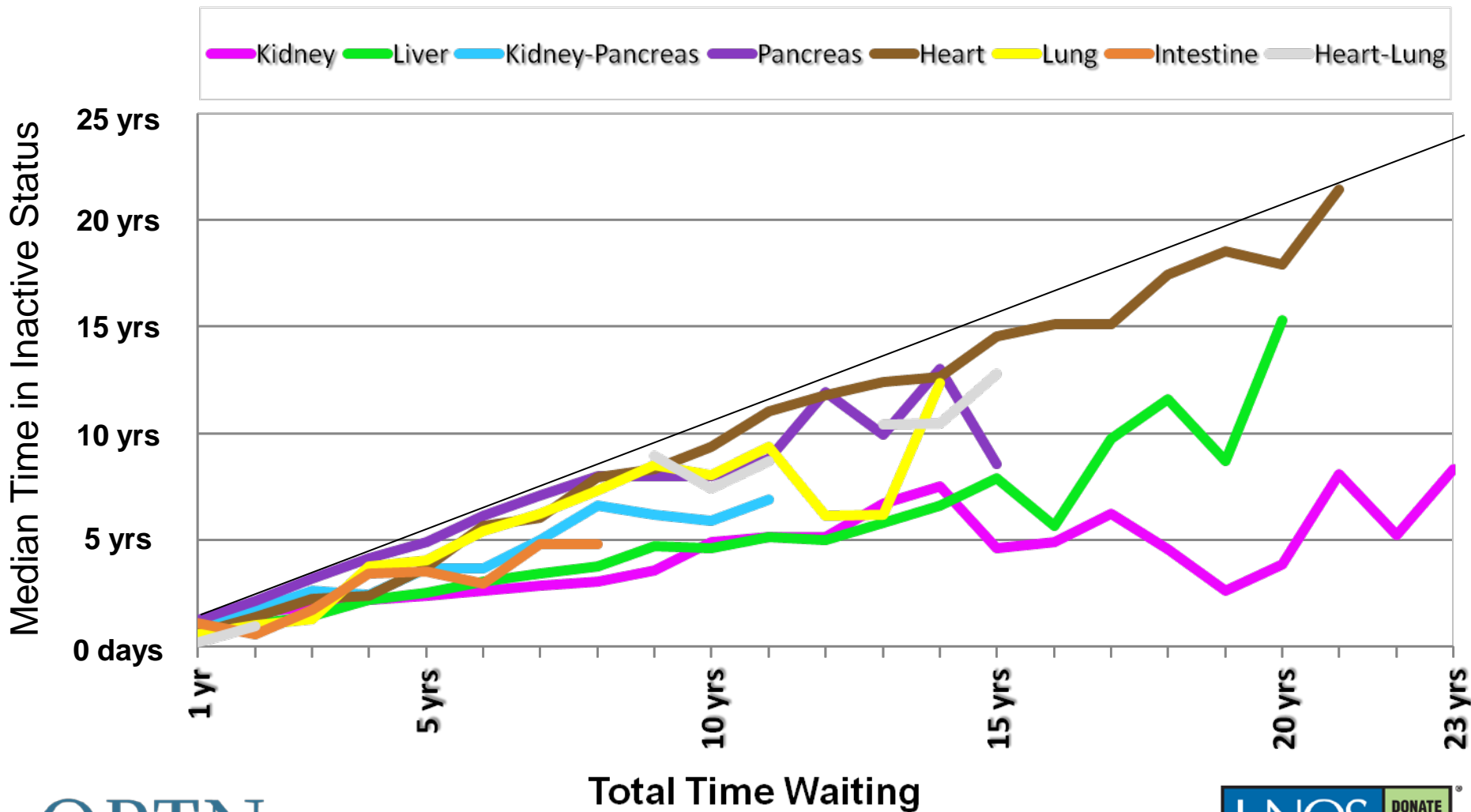
Tackling inactivity on the waiting list for transplantation. F. Berthoux. Nat Rev Nephrol. 2009 Jun;5(6):308-9

- 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



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



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

Organ	Active		Inactive		Total	
	N	%	N	%	N	%
Heart-Lung	26	49.1	27	50.9	53	100.0
Heart	2,530	73.0	936	27.0	3,466	100.0
Intestine	170	66.7	85	33.3	255	100.0
Kidney	57,229	60.0	38,211	40.0	95,440	100.0
Kidney-Pancreas	1,057	49.7	1,068	50.3	2,125	100.0
Liver	12,535	79.8	3,181	20.2	15,716	100.0
Lung	1,311	79.4	341	20.6	1,652	100.0
Pancreas	332	27.9	857	72.1	1,189	100.0
Pancreas Islet	25	12.2	180	87.8	205	100.0

Tiedi Documentation

- 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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