

**OPTN/UNOS Minority Affairs Committee
Descriptive Data Request**

Final Report:
***Update on Prior Living Donors Who Were Subsequently Placed
on the Waiting List***

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Minority Affairs Committee Meeting by Teleconference Call
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Background/Purpose

Over the past years, living donation rates have substantially increased. The MAC expressed an interest in examining data that pertain to safety of living donation, particularly, with respect to individuals who have donated their organ and were subsequently placed on the waiting list due to end stage organ failure.

At the May 12, 2006 meeting the Committee was presented with information on 117 prior living kidney donors and 3 prior living liver donors who were subsequently placed on the kidney and liver waiting lists. The Committee is ultimately interested in determining if the rate of being placed on the waiting list within 5-6 years is higher for previous living kidney donors who are Blacks as compared to non-Blacks.

It was noted that CMS data will be useful to determine whether some of the previous living donors are on maintenance dialysis without necessarily being placed on the waiting list.

Note: UNOS, as the OPTN contractor, has signed a data use agreement which would allow OPTN staff to access CMS data for such purposes. The OPTN has not yet received the CMS data, but has been working through HRSA to receive it.

Committee Request

Contingent upon the receipt of CMS data, UNOS will link the CMS and OPTN database to determine if individuals who have donated their kidney subsequently received maintenance dialysis, and examine the limitations of the CMS data.

Otherwise, provide updated data on individuals who have donated their organ and ended up on the wait list due to end stage organ failure. The data should include demographics (age, gender, ethnicity), cause of end stage organ failure, years after donation, whether they have received a transplant or not, and patient status.

Data and Methods

As of September 13, 2006, the OPTN has not received CMS data. Therefore, the present report is still limited to individuals who have previously donated either kidney or liver and were subsequently placed on the waiting list. Starting on September 9, 1996, prior living kidney donors who were subsequently placed on the kidney waiting list may request four additional points with the appropriate documentation to the OPTN.

For kidney analysis, we included candidates ever on the OPTN kidney waiting list between 1/1/1996 and 5/31/2006, and who were indicated as a previous donor, or had a prior living donation record in the OPTN living donor database as matched by SSN. For liver analysis, candidates ever on the OPTN liver waiting list between 4/1/1996 and 5/31/2006, and had a prior living donation record in the OPTN living donor database as matched by SSN were included. Note that living donor SSN was not collected prior to 4/1/1994 by the OPTN, and therefore SSN matching could not be performed for living donors recovered prior to 4/1/1994.

When available, information on age at donation and years between donation and listing is summarized. Basic waiting list demographics and waiting list outcomes of these candidates are also summarized. Relationship between the donors and the recipients, diagnosis of the recipients and diagnosis of the donors at the time of listing were ascertained on previous living donors who were found through linking the OPTN living donor and wait list databases by SSN.

The Social Security Death Master File (SSDMF) is used to ascertain extra waiting list and post-transplant deaths.

Information provided in this report is based the OPTN data as of August 25, 2006.

Results

Kidney:

There were 121 previous living kidney donors who were on the kidney waiting list (WL), between 1/1/1996 and 5/31/2006. Note that since the majority of these candidates donated prior to the inception of the OPTN in 1987 or prior to 4/1/1994, their demographics and clinical characteristics at the time of donation can not be ascertained. For those cases we could not link with the OPTN data, some additional data on date of donation was obtained through phone calls to the transplant centers and from documentation provided to the OPTN in support of requests for donation points.

Table 1 summarizes age at donation and years between donation and first listing.

- Of the 98 candidates with known age at donation, 65 (66.3%) donated their kidney between the age 18 and 34, 27 (27.6%) donated between the age of 35 and 49, and 6 (6.1%) donated between the age of 50 and 64. The median and mean age at donation was 32 and 32.1 years, respectively.
- Of the 98 candidates with known time of donation, 41 (41.8%) were placed on the WL between 16 and 25 years post-donation, 18 (18.4%) were placed on the WL 26 years or more post-donation, 15 (15.3%) between 11 and 15 years post-donation, 14 (14.3%) between 6 and 10 years, and 10 (10.2%) within 5 years of donation. The median and mean years from donation to listing were 18 and 17.8 years, respectively.

**Table 1. Age at Donation and Years from Donation to First Listing
Kidney Waiting List Candidates Indicated to be a Previous Living Kidney Donor
Candidates Ever Waiting During 1/1/1996-5/31/2006**

	N	%
Age at Donation (Years)		
○ Unknown	23	-
○ 18-34	65	66.3
○ 35-49	27	27.6
○ 50-64	6	6.1
Total	121	100.0
- Median Age at Donation	32	
- Mean Age at Donation	32.1	
Years from Donation to First Listing		
○ Unknown	23	-
○ 0-5	10	10.2
○ 6-10	14	14.3
○ 11-15	15	15.3
○ 16-25	41	41.8
○ 26+	18	18.4
Total	121	100.0
- Median	18	
- Mean	17.8	

Table 2 summarizes basic waiting list demographics and clinical characteristics of these 121 previous living kidney donors at the time of the listing, as well as the waiting list outcome and patient status after transplant (for those who had received a transplant):

- Twenty one (17.4%) of these 121 previous living donors were placed on the kidney WL in 2005, 17 (14.0%) in 2002, and 11 (9.1%) in 1998, 1999 and 2003. The earliest year of listing was 1993 and the most recent was in 2006.
- Seventy-eight (64.5%) of these candidates were male, and 43 (35.5%) were female.
- Fifty-two (43.0%) of these previous donors were White, 51 (42.1%) were Black, 12 (9.9%) were Hispanic, and 2 (1.7%) each for Asian, American Indian/Alaska Natives and multiracial.
- Forty-nine (40.5%) of these previous donors were between 50 and 64 years old at time of listing, 48 (39.7%) were between 35 and 49 years old, and 12 (9.9%) were between 18 and 34 years and 65+.
- Thirty-two (26.4%) had been on the kidney WL for less than 3 months, 26 (21.5%) for >2 years, 23 (19.0%) for 1-2 years, 21 (17.4%) for 6-12 months, and 19 (15.7%) for 3-6 months.
- The three most common waiting list diagnoses were glomerular diseases - N=30 (24.8%), hypertensive nephrosclerosis – N=23 (19.0%), and diabetes – N=13 (10.7%).
- A total of 102 (84.2%) of these candidates have received a deceased donor kidney transplant, 5 (4.1%) received a living donor transplant, 3 (2.5%) died on the WL, 2 (1.7%) were too sick to transplant, 1 (0.8%) were removed for being too well, 1 (0.8%) transferred to another center, and 7 (5.8%) were still waiting for a transplant.
- Of the 107 candidates who had received a transplant, 102 (95.3%) were still alive and 5 (4.7%) died post-transplant.

**Table 2. Basic WL Demographics and Clinical Characteristics
Kidney WL Candidates Indicated to be a Previous Living Kidney Donor Candidates Ever Waiting
During 1/1/1996-5/31/ 2006 (N=121)**

	N	%
Year Listed		
1993	1	0.8
1994	3	2.5
1995	3	2.5
1996	3	2.5
1997	6	5.0
1998	11	9.1
1999	11	9.1
2000	10	8.3
2001	8	6.6
2002	17	14.0
2003	11	9.1
2004	8	6.6
2005	21	17.4
2006	8	6.6
Donor Gender		
Female	43	35.5
Male	78	64.5
Donor Ethnicity		
White	52	43.0
Black	51	42.1
Hispanic	12	9.9
Asian	2	1.7
American Indian/Alaska Native	2	1.7
Multiracial	2	1.7
Age at Listing		
18-34	12	9.9
35-49	48	39.7
50-64	49	40.5
65+	12	9.9

	N	%
Waiting Time		
< 3 Months	32	26.4
3 – 6 Months	19	15.7
6 – 12 Months	21	17.4
1 – 2 Years	23	19.0
> 2 Years	26	21.5
Diagnosis at Listing		
Diabetes	13	10.7
Glomerular Diseases	30	24.8
Hypertensive Nephrosclerosis	23	19.0
Neoplasms	5	4.1
Not Reported/Unknown	1	0.8
Renovascular and Other Vascular Diseases	8	6.6
Retransplant/Graft Failure	6	5.0
Tubular and Interstitial Diseases	7	5.8
Unknown/Not Reported	22	18.2
Outcome of Registration		
Still Waiting	7	5.8
Deceased Donor tx, removed by tx center	95	78.5
Two Deceased Donor Transplants	4	3.3
One Deceased, One Living Donor Transplant	1	0.8
Deceased Donor Transplant, Relisted, Still Waiting	1	0.8
Too Well, Relisted, Deceased Donor Transplant	1	0.8
Refused transplant	1	0.8
Transferred to another center	1	0.8
Died	3	2.5
Candidate condition deteriorated, too sick to tx	2	1.7
Living Donor tx, removed by tx center	5	4.1
Patient Received a Transplant		
No	14	-
Yes - Alive	102	95.3
- Died	5	4.7
TOTAL	121	100.0

The relationship between the donors and the recipients, diagnosis of the recipients and diagnosis of the donors at the time of listing were ascertained on 29 previous living kidney donors who were found through linking the OPTN living donor and wait list databases by SSN. This information is listed in Table 3 below.

- Thirteen of these donors were White, 13 were Black and 3 were Hispanic
- Majority (22) of these donors donated to their full siblings, 5 donated to their parent, one donated to the child, and one donated to an unrelated individual
- Age at donation ranged from 18 to 54 years, and years from donation to listing ranged from 2 to 16 years.
- Diagnosis of the donors at the time of listing and diagnosis of the recipients of these donors are listed in Table 3.

**Table 3. Living Kidney Donors Recovered Since October 1, 1987 and on Kidney Waiting List Since 1996
Information on Living Kidney Donors and their Recipients**

Living Kidney Donors					Recipients	
Ethnicity	Age at Donation/ Listing	Yrs from Donation to Listing	Relation to Recipient	Diagnosis at Listing	Age at Transplant	Diagnosis at Transplant
Hispanic	31/43	12	Full Sibling	Retransplant/Graft Failure	36	Not Reported
White	46/56	9	Full Sibling	Renovascular and Other Vascular Diseases	47	Prune Belly Syndrome
Black	23/40	16	Child	Diabetes	47	Hypertensive Nephrosclerosis
Black	32/43	10	Full Sibling	Other	34	Chronic Glomerulonephritis
White	42/56	14	Full Sibling	Unknown	47	Polycystic Kidneys
Hispanic	21/34	12	Full Sibling	Glomerular Disease	31	Not Reported
White	33/45	11	Full Sibling	Hypertensive Nephrosclerosis	34	Chronic Glomerulonephritis
White	34/48	13	Full Sibling	Hypertensive Nephrosclerosis	31	Hypertensive Nephrosclerosis
Black	37/41	4	Full Sibling	Glomerular Disease	36	Renal Cell Carcinoma
Black	24/29	4	Child	Unknown	39	Hypertensive Nephrosclerosis
Black	34/44	10	Child	Unknown	61	Diabetes-Type I
Black	18/25	7	Full Sibling	Renovascular and Other Vascular Disease	18	Acquired Obstructive Nephropathy
White	29/35	6	Full Sibling	Other	34	Nephritis
Black	22/27	5	Full Sibling	Glomerular Disease	28	Focal Glomerular Sclerosis
White	30/43	13	Unrelated	Glomerular Disease	30	Diabetes-Type I
Black	26/32	5	Full Sibling	Glomerular Disease	37	Hypertensive Nephrosclerosis
White	54/61	6	Full Sibling	Glomerular Disease	59	Focal Glomerular Sclerosis
Black	37/43	5	Full Sibling	Hypertensive	38	Hypertensive Nephrosclerosis

				Nephrosclerosis		
Black	34/36	2	Child	Unknown	61	Focal Glomerular Sclerosis
White	25/30	4	Full Sibling	Retransplant	29	Hemolytic Uremic Syndrome
White	34/41	6	Child	Fibromuscular Dyplasia	61	Hypertensive Nephrosclerosis
Black	40/45	4	Full Sibling	Chronic Pyelonephritis/ Reflux Nephropathy	43	Not Reported
White	50/59	9	Full Sibling	Gout	53	Membranous Glomerulonephritis
Black	30/33	3	Full Sibling	Parvo B19 Infection	28	Retransplant
White	38/44	5	Full Sibling	Malignant Hypertension	40	IGA Nephropathy
Black	34/43	8	Half Sibling	Diabetes – Type II	50	Diabetes – Type I
White	34/41	6	Full Sibling	Focal Glomerular Sclerosis	37	Malignant Hypertension
White	51/57	6	Parent	Unknown	36	Diabetes – Type I
Hispanic	42/52	10	Full Sibling	Renal Cell Carcinoma	40	Membranous Glomerulonephritis

Liver:

Between 4/1/1994 and 5/31/2006, there were 3 prior living liver donors on the liver WL:

- All three were White males between the age of 25 and 55 years at listing.
- One of the donors donated to the blood related half sibling, one to the parent, and one to the spouse.
- Ages of the recipients ranged from 45 to 70.
- Diagnoses of the recipients were cirrhosis cryptogenic (idiopathic), cirrhosis: type C, and secondary biliary cirrhosis: Caroli's disease.
- The three living liver donors were all put on the liver WL within 30 days of donation.
- Diagnoses of the previous donors at time of listing were sub-fulminant hepatic failure due to liver donation, Budd-Chiari syndrome, and other (donation related – partial hepatectomy).
- One of the previous donors died one day after being put on the WL, another candidate received a deceased donor liver transplant within 3 days of listing, and the third candidate was removed from the WL due to condition improved.
- The one previous living liver donor who received a liver transplant was still alive at 4 years post-transplant.