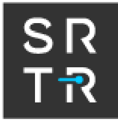
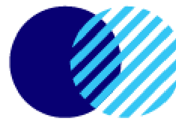


SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS


LIVING DONOR COLLECTIVE

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Potential Living Donor Registration Form

Provider and Donor Candidate Overview

1. Donor Center: _____________
2. Living Donor Collective (LDC) ID number: _____________
3. Date of initial in-clinic screening for living donation: ______________
4. Candidate's SSN#: _____________________
  4a. If the Candidate does not have SSN#, please provide Organ Procurement and Transplantation Network (OPTN) registration number: ____________________
5. Candidate's date of birth: _______________________________________
6. Organ the Candidate is considering donating:

- o Liver
- o Kidney

7. Donor Candidate's relationship to recipient/Living donation type:

- o Biological, blood related Parent
- o Biological, blood related Child
- o Biological, blood related Identical Twin
- o Biological, blood related Full Sibling
- o Biological, blood related Half Sibling
- o Biological, blood related Other Relative
- o Non-Biological, Spouse
- o Non-Biological, Life Partner
- o Non-Biological, Unrelated: Paired Donation
- o Non-Biological, Unrelated: Non-Directed Donation (Anonymous)
- o Non-Biological, Living/Deceased Donation
- o Non-Biological, Unrelated: Domino
- o Non-Biological, Other Unrelated Directed Donation
- o Non-Biological, Other

Donor Candidate Contact Information

8. Donor Candidate Last Name: _____________________________
  8a. Donor Candidate's First Name: ______________
  8b. Donor Candidate's Middle Initial: ____________

Public Burden Statement: The purpose of this data collection is to track long-term health outcomes for living organ donors. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this information collection is 0906-0034, and it is valid until XX/XX/XXXX. This information collection is voluntary. Public reporting burden for this collection of information is estimated to average .27 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 14N136B, Rockville, Maryland, 20857 or paperwork@hrsa.gov.

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9. Address line 1: ______________________________________

- **9a. Address line 2:**____
- **9b. City:** ___________________
- **9c. State or Country:** __________
- **9d. Zip Code:** _______________________

10. Is Mailing Address the same as above?

- o Yes
- o No

If No, please provide mailing address:

- **10a. Mailing Address line 1:** __________________________
- **10b. Mailing Address line 2:** ___________________________
- **10c. City:** ___________________
- **10d. State or Country:** _________
- **10e. Zip Code:** _______________________

11. Primary Phone: _______________________
12. Secondary Phone: _____________________________
13. Primary Email: ______________________________
14. Secondary Email: ______________________________
15. Candidate's preferred method of contact:

- o Primary phone
  - o Text
  - o Voice
- o Secondary phone
- o Primary email
- o Secondary email
- o Postal Mail
- o Other, **Specify:**___________________
- o Social Media: **Specify:**_____________ (Facebook, Twitter, Instagram, etc.)

Whom may we contact if we cannot reach the donor candidate? (This individual will only be contacted to obtain the donor candidate's contact information; no other information will be shared.)

- **16. Other Contact – Name (First, MI, Last):** ____________________________
- **17. Address line 1:** __________________________
- **17a. Address line 2:** __________________________
- **17b. City:** ______________________________
- **17c. State:** ______________________________
- **17d. Zip Code:** ______________________________
- **18. Primary phone:** __________________________
- **19. Secondary phone:** __________________________
- **20. Email:** ___________________________
- **21. Contact's relationship to the donor candidate:** ___________________

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Donor Candidate Demographic Information:

22. Sex:
- o Male
- o Female

23. Marital status at time of screening:
- o Single
- o Married
- o Divorced
- o Separated
- o Life Partner
- o Widowed
- o Unknown

24. Ethnicity/Race (please select all origins that apply and specify for each broader category):
- ▪ American Indian or Alaska Native
  - o American Indian
  - o Eskimo
  - o Aleutian
  - o Alaska Indian
  - o American Indian or Alaska Native: Other
  - o American Indian or Alaska Native: Not Specified/Unknown
- ▪ Asian
  - o Asian Indian/Indian Sub-Continent
  - o Chinese
  - o Filipino
  - o Japanese
  - o Korean
  - o Vietnamese
  - o Asian: Other
  - o Asian: Not Specified/Unknown
- ▪ Black or African American
  - o African American
  - o African (Continental)
  - o West Indian
  - o Haitian
  - o Black or African American: Other
  - o Black or African American: Not Specified/Unknown
- ▪ Hispanic/Latino
- ▪ Mexican
  - o Puerto Rican (Mainland)
  - o Puerto Rican (Island)
  - o Cuban

- Hispanic/Latino: Other
- Hispanic/Latino: Not Specified/Unknown

- Native Hawaiian or Other Pacific Islander
  - Native Hawaiian
  - Guamanian or Chamorro
  - Samoan
  - Native Hawaiian or Other Pacific Islander: Other
  - Native Hawaiian or Other Pacific Islander: Not Specified/Unknown
- White
  - European Descent
  - Arab or Middle Eastern
  - North African (non-Black)
  - White: Other
  - White: Not Specified/Unknown

25. Citizenship:

- U.S. Citizen
- Non-U.S. Citizen/U.S. Resident
- Non-U.S. Citizen/Non-U.S. Resident, Traveled to United States for Reason Other Than Transplant
- Non-U.S. Citizen/Non-U.S. Resident, Traveled to United States for Transplant

26. Highest education level:

- None
- Grade school (0-8)
- High school (9-12) or GED
- Attended college/technical school
- Associate/Bachelor degree
- Post-college graduate degree
- Unknown

27. Does the Candidate have health insurance?

- YES
- NO
- UNKNOWN

28. Is the Candidate working for income?

- YES

  28a. If Yes, please specify (check one):

  - ☐ Working Full Time
  - ☐ Working Part Time due to Disability
  - ☐ Working Part Time due to Insurance Conflict
  - ☐ Working Part Time due to Inability to Find Full Time Work
  - ☐ Working Part Time due to Donor Choice
  - ☐ Working Part Time Reason Unknown
  - ☐ Working, Part Time vs. Full Time Unknown
- NO

28b. If Not Working, please provide reason (check one):

- ☐ Disability
- ☐ Insurance Conflict
- ☐ Inability to Find Work
- ☐ Donor Choice - Homemaker
- ☐ Donor Choice - Student Full Time/Part Time
- ☐ Donor Choice - Retired
- ☐ Donor Choice - Other
- ☐ UNKNOWN

- ▪ UNKNOWN

29. Is donation a financial hardship?

- o YES
- o NO
- o UNKNOWN

Pre-Donation Clinical History

30. History of cigarette use:

- o YES
- o NO

30a. If Yes, choose one:

- o Still smoking
- o Quit 0-5.0 years ago
- o Quit >5.0 years ago

31. Other tobacco or e-cigarette use:

- o YES
- o NO

31a. If Yes, choose one:

- o Still smoking
- o Quit 0-5.0 years ago
- o Quit >5.0 years ago

32. Marijuana use:

- o YES
- o NO

32a. If Yes, choose one:

- o Still smoking
- o Quit 0-5.0 years ago
- o Quit >5.0 years ago

34. History of cancer:

- o NO

- o YES

34a. If Yes, please indicate type (check all that apply):

- ☐ Lip
- ☐ Other oral cavity/pharynx
- ☐ Esophagus
- ☐ Stomach
- ☐ Colon and rectum
- ☐ Anus
- ☐ Liver
- ☐ Pancreas
- ☐ Lung
- ☐ Melanoma
- ☐ Squamous Cell Skin
- ☐ Breast
- ☐ Uterine Cervix
- ☐ Corpus and Uterus
- ☐ Prostate
- ☐ Testis
- ☐ Urinary Bladder
- ☐ Kidney and Renal Pelvis
- ☐ Brain and Other Nervous System
- ☐ Thyroid
- ☐ Hodgkin Lymphoma
- ☐ Non-Hodgkin Lymphoma
- ☐ Myeloma
- ☐ Leukemia
- ☐ Other, **Specify (34b):** ______________________

34c. If Yes, please provide the cancer free interval (years): ____

35. Does the Candidate have diabetes?

- o YES
- o NO
- o UNKNOWN

35a. If Yes, please provide the Candidate's treatment of diabetes (check all that apply):

- ☐ Insulin
- ☐ Oral Hypoglycemic Agent
- ☐ Diet
- ☐ None

36. Is the Candidate currently taking a cholesterol-lowering medication?

- o NO
- o YES
- o UNKNOWN

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36a. If Yes, please indicate medication type (check all that apply):

- ☐ Statin
- ☐ Other cholesterol-lowering medication

37. Has the Candidate ever been told by a health care provider that he/she has hypertension (check one):

- ☐ NO
- ☐ YES
- ☐ UNKNOWN

37a. If Yes, please indicate the how long the Candidate has had hypertension:

- ☐ 0-5 YEARS
- ☐ MORE THAN 5 YEARS
- ☐ UNKNOWN DURATION

37b. If Yes, please indicate how many medications have been used to control blood pressure (check one):

- ☐ None
- ☐ 1 medication for blood pressure
- ☐ 2 medications for blood pressure
- ☐ More than 2 medications for blood pressure
- ☐ UNKNOWN

Pre-Donation Clinical Measurements

38. Height:____ft____in, *or*____cm

39. Weight:____lb., *or*____kg

40. Clinic Blood Pressure at the time of Candidate evaluation:

Systolic:____mm Hg
Diastolic:____mm Hg

41. Total cholesterol:____mg/dL
42. High density lipoprotein (HDL) cholesterol:____mg/dL
43. Low density lipoprotein (LDL) cholesterol:____mg/dL
44. Triglycerides:____mg/dL
45. Fasting blood glucose:____mg/dL

Liver-Specific: Pre-Donation Clinical Information

(Provide only if a liver donor candidate)

Clinical Measurements

L1. Total Bilirubin:____mg/dL

L2. SGOT/AST:____ U/L
L3. SGPT/ALT:____U/L
L4. Alkaline Phosphatase:____units/L
L5. Serum Albumin:____g/dL
L6. Serum Creatinine:____mg/dL
L7. INR: ____
L8. Platelet Count:_______per microliter (mcL)

L9. Was a liver biopsy performed?

- o NO
- o YES

L9a. If Yes, please provide % Macro vesicular fat:____ %
L9b. If Yes, please provide % Micro vesicular fat:____%

L10. Was an MRI obtained?

- o NO
- o YES

L10a. If Yes, please provide % Macro vesicular fat:____ %
L10b. If Yes, please provide % Micro vesicular fat:____%

Clinical History

L10. Has the Candidate ever had hepatitis, jaundice or abnormal liver tests, or has the Candidate ever been told by a health care provider that he/she had hepatitis, jaundice or abnormal liver tests?

- o YES
- o NO
- o UNKNOWN

L11. In the past 12 months, how often did the Candidate drink any type of alcoholic beverage? How many days per week, per month, or per year did the Candidate drink? Enter '0' for never.

- o | | days per week, or
- o | | days per month, or
- o | | days per year.
- o Declined or don't know

L 12. In the past 12 months, on those days that the Candidate drank alcoholic beverages, on the average, how many drinks did the Candidate have?

- o | |number of drinks, and if less than 1 drink, enter '1'.
- o Declined or don't know

Kidney-Specific: Pre-Donation Clinical Information

(Provide only if a kidney donor candidate)

Clinical Measurements

K1. Urine albumin. Enter one or more of the following: Albumin-creatinine ratio (mg/g) ________________________________

Albumin excretion (mg/24 h) _______

K2. Serum Uric Acid:____mg/dL

K3. Serum Creatinine:____mg/dL

K4. APOL1 risk if Candidate is Black (check one):

- ☐ 0 risk variants
- ☐ 1 risk variant
- ☐ 2 risk variants
- ☐ Not measured
- ☐ UNKNOWN

Clinical History

K5. Does the Candidate have a family history of kidney disease (check one):

- ☐ NO
- ☐ YES
- ☐ UNKNOWN

K5a. If Yes, please indicate this person's relationship to the Candidate:

- o Biologic parent
- o Child
- o Brother or sister
- o Other blood relative

K5b. If Yes, please indicate the type of kidney disease in the family (check all that apply):

- ☐ Kidney disease known to be caused by diabetes
- ☐ Kidney disease known to be caused by high blood pressure
- ☐ Autosomal dominant polycystic kidney disease (ADPKD or PKD)
- ☐ Alport syndrome or thin basement membrane disease/nephropathy
- ☐ Atypical hemolytic uremic syndrome (aHUS)
- ☐ Fabry disease
- ☐ Familial focal segmental glomerulosclerosis
- ☐ Other hereditary kidney disease
- ☐ None of the above
- ☐ UNKNOWN

K6. Has a health care provider ever told the Candidate that he/she had gout?

- o YES

- o NO
- o UNKNOWN

K7. Does the Candidate have a family history of diabetes (check one):

- ☐ NO
- ☐ YES
- ☐ UNKNOWN

K7a. If Yes, please indicate this person's relationship to the Candidate (check one):

- ☐ Biologic parent
- ☐ Child
- ☐ Brother or sister

K8. Has a health care provider ever told the Candidate that he/she had kidney stones?

- o YES
- o NO
- o UNKNOWN

K8a. If Yes, how many times has the Candidate had a kidney stone (choose one)?

- o 0 (never)
- o 1
- o 2
- o More than 2
- o UNKNOWN

K8b. If Yes, please indicate the most recent kidney stone the Candidate had:

- o < 2 years ago
- o 2-5 years ago
- o 5-10 years ago
- o >10 years ago

K9. If the Candidate is female (per question 22) has the Candidate ever been pregnant?

- o YES
- o NO

If Yes, during any pregnancy:

K9a. Has the Candidate ever been told by a health care provider that she had diabetes, sugar diabetes or gestational diabetes? Please do not include diabetes that the Candidate may have known about before the pregnancy:

- o YES
- o NO
- o UNKNOWN

K9b. Has the Candidate ever been told by a health care provider that she had gestational hypertension?

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- o YES
- o NO
- o UNKNOWN

K9c. Has the Candidate ever been told by a health care provider that she had preeclampsia (hypertension with proteinuria during pregnancy)?

- o YES
- o NO
- o UNKNOWN