

Saint Barnabas Medical Center

RWJBarnabas
HEALTH

Living Donor Institute

Welcome to the Living Donor Institute.

Thank you for your interest in living kidney donation.

Enclosed, please find:

- (1) a brochure with information on living kidney donation
- (2) a Referral Form, and
- (3) an optional & voluntary research questionnaire (Donor Survey #1).

Please complete and return the Referral Form. The research questionnaire is completely optional and voluntary (see the research questionnaire for an explanation).

You can return the completed Referral Form (and research questionnaire) by mail, using the envelope provided, or by fax, to 973-322-2273.

Once we receive your Referral Form, it will be reviewed by a Transplant Coordinator. A Transplant Coordinator is a Registered Nurse with expertise in kidney transplantation and living donation. The Transplant Coordinator will then call you to discuss the information that you provided in the Referral Form. During this call, the Transplant Coordinator will:

- (1) Review the overall education and evaluation process for donation, and
- (2) Answer any questions that you have.

If you prefer to discuss living donation with a Transplant Coordinator prior to completing these forms, then please call 973-322-5346.

Thank you for choosing Saint Barnabas Medical Center. We look forward to hearing from you soon.

The Living Donor Institute Team

Main number: 973-322-5346

Fax: 973-322-2273

**SAINT BARNABAS MEDICAL CENTER
LIVING DONOR REFERRAL FORM**

LEGAL NAME _____ SS# _____

DOB _____ AGE _____ SEX _____ RACE _____ RELIGION _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

HOME PHONE _____ CELL PHONE _____

HEIGHT _____

WEIGHT _____

CAN WE LEAVE MESSAGES ON YOUR HOME PHONE MACHINE? _____ CELL PHONE? _____

EMAIL ADDRESS _____ CAN WE COMMUNICATE WITH YOU BY EMAIL? _____

WHAT IS THE BEST WAY TO REACH YOU? (home phone/cell phone/email) _____

MARITAL STATUS: ____Single ____Married ____ Divorced ____Widowed ____Separated ____Other

CHILDREN (ages) _____ OCCUPATION: _____

ARE YOU TAKING ANY MEDICATIONS? _____ WHAT ARE THEY? _____

MEDICAL/SURGICAL HISTORY: _____

DO ANY MEMBERS OF YOUR FAMILY HAVE DIABETES OR KIDNEY DISEASE? _____

ALLERGIES _____ BLOOD TYPE (if known) _____

HAVE YOU EVER HAD ANY OF THE FOLLOWING? **Please circle if YES**

Kidney Infection	Kidney Stones	Blood in the urine	Liver disease/ Hepatitis
Blood Disorder/Anemia	Cancer	Lung disease	Heart Problems
High Blood Pressure	Stroke	Drug/Alcohol Abuse	Psychiatric Problems
Diabetes/High blood sugar			

Check Box if YES:

☐ I do not have a recipient and want to learn about non-directed kidney donation to someone in need of a kidney transplant

☐ I have a recipient that I want to donate to: Recipient's Name: _____

Your relationship with recipient (i.e. how do you know them/for how long) _____

☐ If my recipient receives a kidney transplant from another living donor, I may be interested in learning about non-directed living kidney donation.

**If returning by mail send to: SBMC Living Donor Institute, 94 Old Short Hills Road, EW Suite 302, Livingston NJ 07039
or FAX to 973-322-2273**

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DONOR SURVEY #1

Date: _____ Name: _____

The Renal and Pancreas Transplant Division at Saint Barnabas Medical Center is conducting a study to better understand people's knowledge and opinions about living donation. This survey is voluntary and optional. Your answers will be confidential. Your answers will NOT be shared with the doctors and nurses of the Living Donor Institute or with the person to whom you may donate. Your responses are for research purposes only and will not be used as part of your evaluation. Your answers and participation (or non-participation) will not affect whether you can donate a kidney. If you choose to participate, for each question, please check the box that best describes you. There are no "right" or "wrong" answers.

1. The recipient is:

- | | |
|---|---|
| <input type="checkbox"/> My parent | <input type="checkbox"/> Another relative, not related biologically |
| <input type="checkbox"/> My child | <input type="checkbox"/> My friend or acquaintance |
| <input type="checkbox"/> My brother or sister | <input type="checkbox"/> The next patient needing a kidney, chosen by the transplant center |
| <input type="checkbox"/> Another blood or biological relative | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> My spouse or life partner | |

2. Who was the first person to let you know that the recipient needed a kidney transplant?

- | | |
|---|---|
| <input type="checkbox"/> My recipient | <input type="checkbox"/> A medical professional |
| <input type="checkbox"/> Someone in my recipient's family | <input type="checkbox"/> No one, I found out myself |
| <input type="checkbox"/> Someone else who knew my recipient | <input type="checkbox"/> Other: _____ |

3. How did you first find out the recipient needed a kidney transplant?

- | | |
|---|---|
| <input type="checkbox"/> In an in-person conversation | <input type="checkbox"/> Through a social media post (such as Facebook) |
| <input type="checkbox"/> In a telephone conversation | <input type="checkbox"/> I don't remember |
| <input type="checkbox"/> In an email or letter | <input type="checkbox"/> Other: _____ |

4. After you found out the recipient needed a kidney transplant, how much time did you take before you decided to be tested as a potential living donor?

- | | |
|--|---|
| <input type="checkbox"/> No time at all, I decided immediately | <input type="checkbox"/> 2 to 6 months |
| <input type="checkbox"/> 1 to 7 days | <input type="checkbox"/> 6 months to 1 year |
| <input type="checkbox"/> 8 days to 1 month | <input type="checkbox"/> More than 1 year |

Place a checkmark in the box that best describes you.

5. Before today, how much time have you spent...

	No time at all	Less than 1 hour	1-2 hours	2 or more hours
Reading brochures or websites to learn about living donation?				
Watching DVDs or videos on the internet about transplant or living donation?				
Talking to your recipient about potentially donating?				
Talking to close family members and friends, other than the recipient, about potentially donating?				
Talking to medical professionals about potentially donating?				

Place a checkmark in the box that best describes you.

6. How important are each of these statements to you when deciding to be tested as a potential kidney donor?	Not at all important	Slightly important	Important	Extremely important
By donating, I could make someone's life better.				
My spiritual or personal beliefs suggest that I should help others.				
Donating could help my recipient live longer and have the freedom to do what is important.				
Donating will make me feel proud of myself.				
I believe that donating will benefit the recipient's entire family.				
I believe that I should help my family and friends.				

To donate a kidney, a person needs to:

- Be willing to donate a kidney
- Take actions to see if he/she can donate a kidney
- Be approved by the transplant center to donate

7. How ready are you to take actions to see if you can donate a kidney? Check only one.

- ☐ I am not considering taking actions to see if I can donate a kidney
- ☐ I am still deciding whether I will take actions to see if I can donate a kidney
- ☐ I am planning to take actions to see if I can donate a kidney
- ☐ I am taking actions to see if I can donate a kidney

Place a checkmark in the box that best describes you.

8. Here are a list of actions people sometimes take. For each action, check if you have already done this, are planning to do this, or don't plan to do this.	I've already done this	I'm planning to do this	I don't plan to do this
Read information or watch videos on the internet about being a living donor.			
Talk to people you trust about the risks and benefits of donating.			
Talk to the kidney patient about why you want to donate a kidney.			
Call or contact the transplant center to begin donor evaluation.			
Complete and return the transplant center's donor medical forms.			
Go to the transplant center to meet the donation team.			
Complete all medical tests requested by the donation team.			
Think through how to cover your family and work responsibilities when you are in the hospital and recovering from donation.			

9. Is there someone important in your life who does not want you to donate?

- ☐ Yes ☐ No

10. People in my community support me donating.

- ☐ Strongly Agree
 ☐ Disagree
- ☐ Agree
 ☐ Strongly Disagree
- ☐ Neither Agree nor Disagree

11. I sometimes wish the transplant recipient would get a kidney from someone else instead of from me.

- ☐ Strongly Agree
 ☐ Disagree
- ☐ Agree
 ☐ Strongly Disagree
- ☐ Neither Agree nor Disagree

12. Before they start the donor evaluation, people know different amounts about living kidney donation. For each statement, check how much you agree or disagree.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I know what tests I might have to go through to be evaluated as a living donor.					
I know what the expected recovery from living donor surgery might be like.					
I know what risks I might face if I donated a kidney.					
I know what donation-related costs I might have as a living donor.					
I know how donating a kidney might benefit my recipient's health and life.					
I can make an informed decision today about whether to donate my kidney.					

13. In general, in the past 7 days...

	Never	Rarely	Sometimes	Usually	Always
I felt anxious.					
I found it hard to focus on anything other than my anxiety.					
My worries overwhelmed me.					
I felt uneasy.					

14. How important is religion or spirituality in your life?

- ☐ Very Important
 ☐ I am not religious or spiritual
- ☐ Fairly Important
 ☐ I choose not to answer
- ☐ Not Very Important

15. Do you believe in God or a universal spirit?

- ☐ Yes
 ☐ Not sure
- ☐ No
 ☐ I choose not to answer

16. Are you a member of a church, synagogue or other place of worship?

- ☐ Yes
 ☐ I choose not to answer
- ☐ No

17. In the past year, have you donated blood or platelets?

- ☐ Yes
 ☐ No

18. Do you now, or have you ever, served in the military?

- ☐ Yes
 ☐ No

Place a checkmark in the box that best describes you.

19. For each statement, check how much you agree or disagree	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
People of my race or ethnic group are treated the same as people of other groups by doctors and health care workers.					
People of my race or ethnic group receive the same medical care from doctors and health care workers as people from other groups.					
In most hospitals, people of different races or ethnic groups receive the same kind of care.					

20. What is your current relationship status?

- ☐ Never married
 ☐ Divorced/Separated
☐ Married or have a life partner
 ☐ Widowed

21. Will someone be coming to the transplant center with you when you have your donation medical tests?

- ☐ Yes
 ☐ Don't know
☐ No

22. What is the highest degree or level of school that you have completed?

- ☐ 8th grade or less
 ☐ Associate's or bachelor's degree
☐ Some high school, no degree
 ☐ Some professional or graduate school, no degree
☐ High school degree or equivalent (GED)
 ☐ Professional or graduate degree
☐ Some college credit, no degree

23. Do you have health insurance coverage?

- ☐ Yes
 ☐ No

24. Do you or does anyone in your household own a car or other vehicle?

- ☐ Yes
 ☐ No

25. How will you travel to the transplant center for your medical appointments? Check ALL that apply.

- ☐ Drive or be driven
☐ Take public transportation (bus/train)
☐ Fly

26. How much time will it take to travel from your home to the transplant center?

- ☐ 1 to 30 minutes
 ☐ 1-2 hours
☐ 31 to 60 minutes
 ☐ More than 2 hours

27. The possibility of having to pay for some donation-related costs, like travel or lodging, makes it harder for me to donate.

- ☐ Strongly Agree
 ☐ Disagree
☐ Agree
 ☐ Strongly Disagree
☐ Neither Agree nor Disagree

28. The possibility of having to take time off work for testing and surgery makes it harder for me to donate.

- | | |
|---|--|
| <input type="checkbox"/> Strongly Agree | <input type="checkbox"/> Disagree |
| <input type="checkbox"/> Agree | <input type="checkbox"/> Strongly Disagree |
| <input type="checkbox"/> Neither Agree nor Disagree | <input type="checkbox"/> Not Applicable |

29. What is your annual household income?

- | | |
|--|--|
| <input type="checkbox"/> Less than \$30,000 | <input type="checkbox"/> \$100,000 – \$149,999 |
| <input type="checkbox"/> \$30,000 – \$49,999 | <input type="checkbox"/> \$150,000 or more |
| <input type="checkbox"/> \$50,000 – \$74,999 | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> \$75,000 – \$99,999 | <input type="checkbox"/> Prefer not to answer |

30. Today, if you lost your current income, how long could you and your household continue to live in your current situation?

- | | |
|---|---|
| <input type="checkbox"/> I do not have a current income | <input type="checkbox"/> 7-12 months |
| <input type="checkbox"/> Less than 1 month | <input type="checkbox"/> More than a year |
| <input type="checkbox"/> 1-2 months | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> 3-6 months | |

31. How confident are you filling out medical forms by yourself?

- | | |
|--------------------------------------|---------------------------------------|
| <input type="checkbox"/> Extremely | <input type="checkbox"/> A little bit |
| <input type="checkbox"/> Quite a bit | <input type="checkbox"/> Not at all |
| <input type="checkbox"/> Somewhat | |

32. How often do you need to have someone help you when you read instructions, pamphlets, or other written materials from your doctor or pharmacy?

- | | |
|------------------------------------|---------------------------------|
| <input type="checkbox"/> Always | <input type="checkbox"/> Rarely |
| <input type="checkbox"/> Often | <input type="checkbox"/> Never |
| <input type="checkbox"/> Sometimes | |

33. Did someone help you complete this survey?

- ☐ Yes
☐ No

If YES, how did that person help you? Check all that apply.

- ☐ Read the questions to me
☐ Answered the questions for me
☐ Wrote down the answers I gave
☐ Helped in some other way

***Thank you for taking the time to complete this survey!
Please return it with your Referral Form to the SBMC Living Donor Institute.***