



A Resource Guide to Finding a Living Donor

RWJBarnabas
HEALTH

**Cooperman Barnabas
Medical Center**
Renal and Pancreas Transplant Division

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The benefits of living donation

It is important for you and your loved ones to understand the many benefits of a living donor kidney transplant. After you understand the benefits of living donation, then it's important to educate yourself about living donation, living donor transplant options, and ways to find a living donor.

We developed this guide to provide you with an understanding and education about living donation as well as provide you with ideas and tools to find a living donor.

The Living Donor Institute at Cooperman Barnabas Medical Center offers a highly specialized and experienced team to assist you. We have extensive experience in working with both transplant recipients and living donors, and we would like to help make the process easier for you as you consider a living donor kidney transplant.

There are many benefits of receiving a kidney from a living donor:

- Living donor kidney transplant offers better outcomes for kidney patients. There is less chance of rejection and a greater chance of the kidney working longer.
- There is an improved quality of life for the recipient.
- Living donation can reduce your time on dialysis. Dialysis can take a toll on your health and life expectancy, restrict your diet, and cause a great deal of stress on the whole family. Receiving a kidney transplant before needing dialysis is ideal and can happen with a living donor.
- It can help you avoid years of waiting for a deceased donor organ.
- A live donor kidney can last nearly twice as long as a deceased donor kidney.
- The living donor transplant can be done when both you and the donor are in the best physical and emotional health possible. This leads to better outcomes.
- During a living donor transplant, the kidney will be placed into your body as soon as it is removed from the living donor. This means the kidney is deprived of blood supply for only a short time. This results in the transplanted kidney working right away. A kidney from someone who has died is usually preserved for several hours or more before it is transplanted and therefore, after transplant it may take several days to work.

These are all important reasons to consider a transplant from a living donor.

The facts about living donation

By simply understanding the basic facts about living donation, you will be in a better position to help others who may be willing or interested in donating to you. Your transplant team will be there to help you with difficult questions that may be asked by potential donors.

There are strict criteria that the transplant center will follow in determining whether a person can be a living donor.

Some factors that may disqualify a person from being a living donor:

- Age greater than 75 or younger than 18
- Heart, liver, kidney or lung disease
- Recent history of cancer
- Active infection
- Diabetes Mellitus
- Significant obesity
- Heavy cigarette, alcohol or drug abuse
- Evidence of violation of federal law (illegal financial arrangement between donor and recipient)
- Evidence of donor coercion (donor feels pressured to donate)
- Untreated psychiatric condition
- Mentally incapable of giving informed consent

The transplant team will also consider many other factors when deciding whether a particular person can be a living kidney donor.

Once a donor is cleared by the transplant team to proceed with donation, it is important for you and the donor to be assured of the following facts:

- Medical costs related to the donor evaluation and donor surgery should be covered by the recipient's insurance.
- There are potential grants to assist with donor travel expenses, lodging expenses, and lost wages for eligible patients.
- Donor surgery is usually performed laparoscopically which is "minimally invasive." In traditional "open" surgery the surgeon uses a single incision to enter into the abdomen. Laparoscopic surgery uses several small incisions and one slightly larger incision to remove the kidney. This system allows the surgeon to perform the same operation as traditional surgery but with smaller incisions.
- Compared to traditional open surgery, patients often experience less pain, a shorter recovery, and less scarring with laparoscopic surgery.
- The donor is generally hospitalized for 1-2 days and recovery is expected to last 2- 4 weeks.
- An independent living donor advocate will be assigned to each donor, to protect the donor's needs and interests throughout the evaluation and donation process.

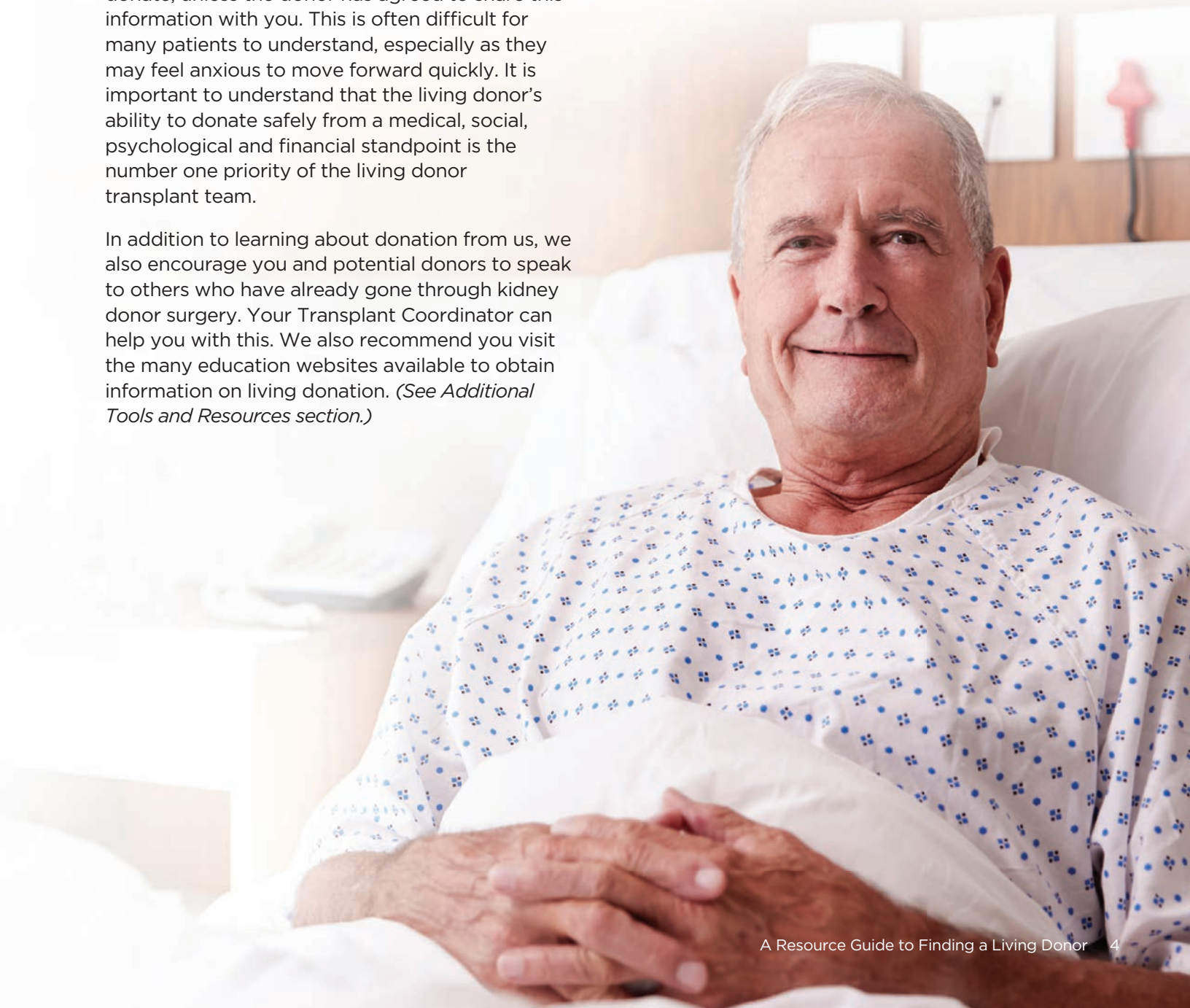
Additionally, donors can expect to:

- Undergo a thorough education process by the transplant team about all of the risks and benefits of living donation.
- Go through comprehensive medical testing.
- Return to a normal lifestyle and live a healthy life with one kidney.
- Have medical follow-up at least once per year with their healthcare provider.
- Avoid contact sports such as football or boxing.
- Feel an extreme sense of fulfillment after giving the ultimate gift.

It is important for you and your donor to understand that the donor's evaluation process is separate from the recipient's evaluation process, and confidentiality is maintained at all times. Our donor team focuses on the safety and well-being of the donor before, during, and after surgery.

You, as the recipient, will not be given any information about your donor's evaluation or their medical status, unless the donor specifically informs us that we can share information. If your donor is disqualified by the transplant team, you will not be informed why the donor cannot donate, unless the donor has agreed to share this information with you. This is often difficult for many patients to understand, especially as they may feel anxious to move forward quickly. It is important to understand that the living donor's ability to donate safely from a medical, social, psychological and financial standpoint is the number one priority of the living donor transplant team.

In addition to learning about donation from us, we also encourage you and potential donors to speak to others who have already gone through kidney donor surgery. Your Transplant Coordinator can help you with this. We also recommend you visit the many education websites available to obtain information on living donation. *(See Additional Tools and Resources section.)*



Living donor transplant options



Any healthy individual may be considered as a potential donor. She or he does not need to be a relative. Donors may be spouses, friends, co-workers, acquaintances, or someone who does not even know the recipient. Sometimes complete strangers volunteer to help someone they hear about in need of a transplant. Other people come forward anonymously to donate a kidney to anyone on the waiting list, because they know there is a severe organ shortage.

That being said, it is always best to explore the option of a donor who is genetically related (blood relation) before considering an unrelated or altruistic donor due to the advantage of having the kidney last longer and lessening the possibility of rejection.

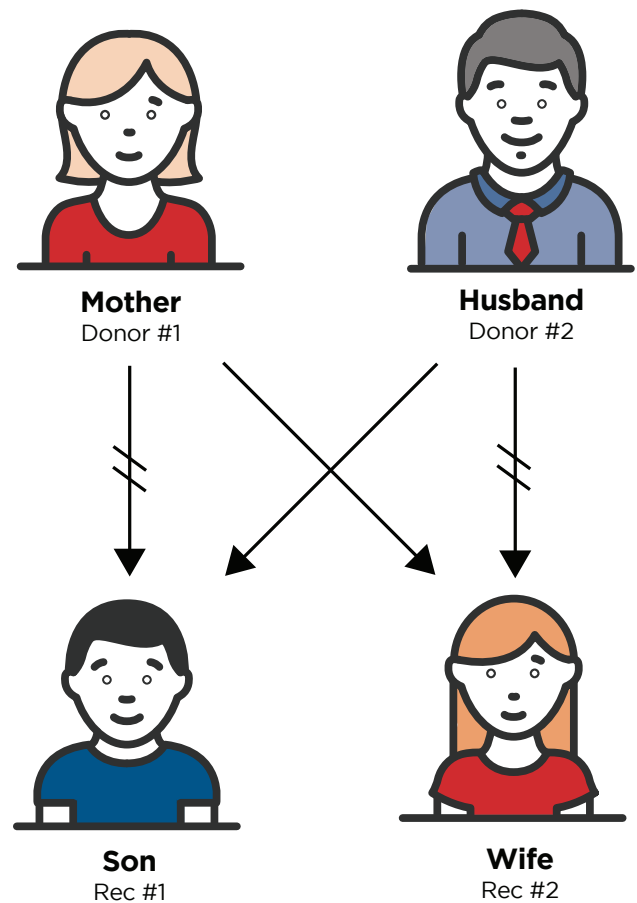
The following ordered list should help you to understand the process of elimination that you should go through in finding a suitable living donor and the transplant team can help you with this.

- **Genetically (blood) Related Donor**
Examples: mother, father, sister, brother, adult child
- **Unrelated Donor**
Examples: spouse, close friend, in-law
- **Directed Altruistic Donor - Blood Type Compatible**
Example: acquaintance, neighbor, co-worker, church friend, classmate, or someone that is not known to you but has heard of your story and offered to donate

Alternative programs for recipients with incompatible donors

If your donor is not compatible with you, there are many options for you to be able to receive a living donor kidney transplant. The Living Donor Institute at Cooperman Barnabas Medical Center is a national leader in alternative programs for incompatible recipients and donors. Alternative living donor transplant options include:

- **Kidney Paired Donation (KPD) Program:**
Exchange or swapping of kidneys between incompatible recipient/donor pairs so that all recipients receive a compatible living donor kidney transplant. Almost all pairs that are cleared for donation and transplantation can be matched via a KPD transplant.
- **Program for Incompatible Transplants:**
 - **Blood Group Incompatible:** Some blood group A donors can donate directly to their blood group O or B recipients without any additional medical therapy required with excellent outcomes.
 - **Crossmatch (Tissue Type) Incompatibility:** Some blood group compatible pairs are incompatible by crossmatch. Crossmatch incompatible transplantation can be performed on some pairs after the recipient receives medical therapy that allows them to safely accept their incompatible donor's kidney.
- **Compatible Share Program:** An option for compatible pairs who would like to participate in a kidney paired donation. Some pairs may participate in order to find a younger matched donor or improved compatibility match or other advantage. Some pairs may be advised to participate because of an age mismatch (donor is 25 to 30 years older than the recipient) or kidney size/anatomy mismatch (donor kidney or anatomy of kidney is not ideal for recipient) or other reason as explained by the transplant team. Compatible pairs who participate in this program may not only achieve improved outcomes but help other incompatible pairs be transplanted.



How to find a living donor

Patients often ask us for advice on how to talk to family, friends and others about living kidney donation. Asking someone to learn about living donation in order for them to consider donation for you is a major decision and may create a variety of emotions for you, your family, and the potential donor. The following ideas and suggestions may be helpful to you when speaking about living donation with others.

- **Share your story with friends, family, and community.** Many people are private or don't want to bother others with their medical issues. It is important to share your story. Don't assume that family and friends know about your situation. Let others know that you have kidney disease and that you came to the Transplant Center and were told that living donation would likely offer you the best outcome.
- **Talk with your family about who can be your spokesperson or 'champion'.** Often patients find it difficult to let others know of their need for a transplant. Consider identifying a spokesperson or 'champion' who can talk to others on your behalf about your need for a kidney transplant. This person may be a spouse or a close relative who is unable to donate for medical reasons but wants to help you receive a living donor transplant. You and your spokesperson/champion can request a meeting with the Living Donor Institute to learn the facts about living donation and ways to help you find a living donor.
- **Send a letter or email about your need for a living donor to family and friends.** This is a great way to get the word out and share your story. Sample letters are included at the end of this guide for you to customize.
- **Let your community know about your need for a transplant and that living donation would likely provide you with the best outcome.** When family and friends are not available to donate, one of the best sources for living donors is usually a community group or religious congregation that you are involved in. While these individuals do not know you, you still share a connection that bonds

you together. Donors from religious connections tend to be highly motivated and often complete their donor evaluations and go on to successfully donate, either directly to the recipient or through kidney exchange if they are incompatible with their recipient.

- **Say 'yes' to someone who offers to learn about donation and be evaluated.** Many times recipients are hesitant to accept the offer of donation, especially from their adult children. Consider making an appointment for you and your adult children or other interested people to come to the Living Donor Institute in order to learn the real facts about living donation. Don't say no without knowing the facts. Calling to become educated about donation does not obligate you in any way.



Bringing up the topic of donation...

For some people, it may be difficult to raise the topic of donation when speaking with family and friends but in doing so, it will provide an opportunity for a personal discussion. It helps others to learn firsthand about your medical condition and need for a kidney transplant. You may want to set up a group or individual meeting to talk about donation, depending on your situation. For those who live far away, you, a family member, or a friend may need to call, write, or email others to discuss your situation and available treatment options.

We also encourage you to bring someone close to you to attend your transplant evaluation appointment and class. This person can share information with potential donors.

Sometimes people may know that you are being evaluated for a transplant, but they haven't offered to donate. They may not even be aware that they can donate or maybe they just need information on how to proceed. If they want to learn about donation, an excellent place to start is by providing them with initial information like:

- The email for the Living Donor Institute:
CBMCLivingDonor@rwjbh.org
- The phone number for the Living Donor Institute
973-322-5346
- Our website at **rwjbh.org/ldi**
- Our on-line donor referral (questionnaire)
CBMCLivingDonor.org
- You can also obtain donor questionnaire postcards from the Living Donor Institute that can be given to those who might be interested in donating. Let them know they can contact us for more information about living donation. This does not obligate them in any way and remains confidential. We do not notify recipients or any other individuals of potential donor contacts without their permission. Of course if the potential donor wishes to proceed with the evaluation process after being educated, the recipient must be informed and agreeable to accepting the donation.

What you might say during the discussion...

Tell individuals that the transplant team advised you to meet with them to discuss living donation. You can emphasize the following facts about living donation:

- Improved quality of life for the recipient .
- There is less chance of rejection.
- Greater chance of the kidney working longer.
- Can reduce your time on dialysis or avoid dialysis.
- Can avoid years of waiting for a deceased donor kidney.
- Can last nearly twice as long as a deceased donor kidney.
- The transplant can be done when both you and the donor are in the best physical and emotional health possible. This leads to better outcomes.
- Donors are fully educated and screened carefully by the Living Donor Institute and all conversations are confidential.
- No medical costs to donor.
- The donor evaluation, surgery, and initial donor follow-up appointments are covered by the recipient's health insurance.
- Some donors may also be eligible for help with non-medical donor expenses, such as travel, lodging, and/or lost wages.

(Refer to Sections 1 & 2 of this booklet for more information to share with your friends and family.)

Rather than ask someone to donate a kidney to you, encourage them to call the Living Donor Institute to learn about living donation. A person can only decide if living donation is the right choice for them and their family once they have been fully educated. Encourage them to include their spouse or significant other in the conversations with the Living Donor Institute. Share your feelings. This gives family members and other potential donors the opportunity to share their own thoughts in return.

How to find a living donor *(Continued...)*

Caution...

It is extremely important not to place any emotional or psychological pressure on anyone to donate. Often it is not you (the recipient) but other family members who may be pressuring someone, perhaps unintentionally, to donate. If someone is feeling pressure to donate, this will be discussed during the donor evaluation which may lead to them being disqualified as a donor.

Give it time...

Don't expect potential donors to respond right away after you discuss donation with them. Some people make their decision immediately. Others need time to consider the many issues involved with donation and their own personal situation. Provide them with the information, support, space and the time they may need. It is important for them to comfortably discuss donation with their own immediate family, employer, or others involved in their daily lives.

Direct anyone interested in learning more about donation to contact the Living Donor Institute to discuss their questions or concerns by emailing **CBMCLivingDonor@rwjbh.org** or calling **973-322-5346**. Let them know that they can have a detailed and confidential conversation or meeting with our staff. We will never give information related to a donor discussion to recipients or others. Once a person decides to start the donation process, our transplant team will be there to assist that person through each step of the process.

Making a public plea...

Some patients awaiting transplant may not be able to find a donor among their family and friends. Individuals may have success in finding a donor when they make their need publicly known. In such cases, a recipient, or the family members, may consider going to the general public to seek a donor. Some people have shared their situation and need for a transplant in local newspapers, community or church bulletins, on television, or on the Internet in search of a donor. People have used blogs, social media (e.g. Facebook), or other Web sites to post their requests. While public pleas are becoming more common, they require great consideration and caution. If you plan to make a public request, we recommend that you first let the Transplant Center staff know about your search. We can give you information and guidance that can help you with the process.



Basic guidelines when making a public plea for a living donor:

- Consider starting your public plea with people that are connected to you in some manner such as friends, community/hobby groups or religious connections as they are more likely to give it serious thought and complete the donor evaluation process. Donors who live a significant distance away (outside the tri-state area) and who don't know you or share no connections to you are not as likely to complete the donor evaluation process.
- First, discuss your idea of creating a public notice with your transplant coordinator before you place such notices. We can help you make sure that any potential donors who respond to your plea are appropriately considered.
- Next, make sure that you have the appropriate permission to post a public notice with the organization involved (i.e. church, school, work etc).
- Direct any potential donors to contact us via our website to complete a donor questionnaire at **CBMCLivingDonor.org**
- Remember that all donors who are considered altruistic to you (donors who do not know you or do not share an emotional relationship with you) must be evaluated at Cooperman Barnabas Medical Center. This makes it very difficult for donors who live a significant distance from the Transplant Center to be evaluated. Potential donors typically make 4 to 5 visits to the Transplant Center during their evaluation process. Their spouse or significant other is required to attend some of these visits. That's why a donor who doesn't know you and who lives a significant distance away from the Transplant Center is not likely to complete their evaluation.
- You, or someone helping you with the search, may want to share basic information about yourself. How much information you want to share is a personal preference. It depends on your comfort level. You may want to discuss your ideas with your coordinator or social worker.
- You may want to include resources that potential donors can check to get more information about donation. This might include our donor web site at rwjbh.org/ldi or other national websites. This will allow them to independently explore information, rather than just hear it from you or the Living Donor Institute. National website suggestions are included in the "Additional Tools and Resource" section of this guide. It is important to know and share with potential donors that the donor team will not inform recipients of who contacts the Living Donor Institute, or release any information about them to the recipient. We respect donor confidentiality at all times. It is up to the potential donor to share information with the recipient if he or she wishes to do so.
- The Living Donor Institute reserves the right to decline donors solicited from certain websites or organizations, such as those that charge money for access to potential living donors.
- The use of Craigslist or other similar sites is strongly discouraged, as these tend to attract people who live very far away and have no connection to you or your family. It is difficult for the Living Donor Institute to determine the motivations of potential donors who are solicited in this way. Instead, patients have the most success finding a living donor when they keep their public pleas local to their own community and affiliations. This avoids disappointments, frustrations and confusion. The goal is to seek potential donors who live within a reasonable distance to the Transplant Center, so they can be evaluated appropriately and can include their family and/or significant other in the evaluation process.

Additional tools and resources

1. Contact the Living Donor Institute if someone is interested in donation:

If you or anybody would like to learn more about living donation, please contact the Living Donor Institute by emailing **CBMCLivingDonor@rwjbh.org** or calling **973-322-5346**. A transplant coordinator will provide detailed information. The coordinator will also have a confidential and personal discussion with the interested individual. Frequently, this information assists a person in deciding whether donation is right for him or her. There is no pressure or obligation to proceed and the discussion always remains confidential. If a caller remains interested, the coordinator will guide him or her how to proceed. The coordinator will also provide additional donor resources that may help the potential donor with their decision. We are always available to guide the potential donor throughout the process.

2. Helpful websites

- Cooperman Barnabas Medical Center Living Donor Institute: **rwjbh.org/ldi**
- National Kidney Foundation: **livingdonors.org**
- American Society of Transplantation: **myast.org**
- Coalition on Donation: **donatelife.net**
- National Living Donor Assistance Center: **livingdonorassistance.org**
- United Network for Organ Sharing (UNOS): **unos.org**
- UNOS-Transplant Living: **transplantliving.org**

For Information specifically related to Costs/Finances and Legislation visit

transplantliving.org/financing-a-transplant/

3. Sample Letters to Family/Close Friends

- a) Letter from Patient's 'Champion'
- b) Letter from Patient Directly
- c) Public Plea

Instructions for use of the sample templates:

1. Use the template as a guide but be sure to customize all information *highlighted in red*.
2. You can further personalize by adding to or deleting anything that you are not comfortable with or would like to say differently.
3. It is recommended that you keep the letter addressed in a general way (Dear Family/Friends) as this will minimize the person (s) receiving the letter from feeling pressured or singled out.
4. Before finalizing, go back and read the document carefully to make sure it says exactly what you intend. You do not want to give the appearance of a form letter when sending something so important.
5. If you would prefer the templates electronically, please contact the Living Donor Institute by calling **973-322-5346** so that we may assist you.

Sample Letter from Patient's 'Champion'

(Date)

Dear Family/Friends:

I am writing to *(patient's first name)* family and close friends to let you know that *(he/she)* has been diagnosed with Stage 5 Chronic Kidney Disease. Stage 5 means that *(patient's first name)* kidneys have failed. The kidneys help the body to filter blood and get rid of poisons, salt, and water. Without kidneys that work, people can become very sick.

(Patient's first name) doctors have told us that the ideal treatment for kidney failure is a kidney transplant. A kidney for transplant could come from a deceased donor (somebody who has died), but *(patient's first name)* would have to wait about 5-7 years, or even longer, for this kind of transplant. This would mean that *(he/she)* would probably have to spend years on dialysis, where machines would clean *(his/her)* blood for *(him/her)*.

The doctors have said that the best type of kidney transplant is a transplant from a living donor (like a family member or friend). A kidney transplant from a living donor would mean that *(patient's first name)* wouldn't have to wait years for a transplant. A transplant from a living donor also has the best chance of working for many years. Unfortunately, even though I would want to, I cannot donate one of my own kidneys to *(patient's first name)* because *(explain reason and add any additional information about others in the immediate family who may have been ruled out as living donors)*. Because a living donor transplant is *(patient's first name)* best hope, as you can imagine, I was very disappointed to learn that I can't donate a kidney to *(him/her)*.

During *(patient's first name)* evaluation at the Transplant Center, I learned that one of the best ways to help *(patient's first name)* was to become *(his/her)* 'Champion' and let those who are closest to *(him/her)* know about *(his/her)* kidney problems. I learned that in the United States, there are over 100,000 people on the waiting list for a kidney. Each year, only about 16,000 of those patients are fortunate enough to get a kidney transplant from someone who has died and donated their organs. I am hoping that *(patient's first name)* will be able to find a living donor so that he can *(avoid dialysis or come off of dialysis)* and be transplanted soon.

If you would like to learn more about living donation, the staff at *(patient's first name)* Transplant Center is wonderful and available to talk with you confidentially. The Transplant Center at Cooperman Barnabas Medical Center staff can talk to you about the living donation process and what is involved and answer any questions. You can email **CBMCLivingDonor@rwjbh.org** or call **973-322-5346** if you wish to do so. You can also complete a donor questionnaire at **CBMCLivingDonor.org**. Calling for information and education, and completing a donor questionnaire does not obligate you in any way.

In closing, *(patient's first name)* has kidney failure, and any support you can offer to *(him/her)*, no matter how big or small, is appreciated. If *(patient's first name)* can get a kidney transplant from a family member or friend, that would be best for *(his/her)* health. I realize that donating a kidney may not be right for everyone, or it simply might not be the right time. Donating a kidney is a very personal decision that requires not only education about the risks and benefits but also thoughtful consideration and the support of loved ones. I hope that one of *(patient's first name)* family and friends will be able to help *(him/her)*. Thank you in advance for your support.

*(Most Sincerely or Fondly),
(Your Name)*

Attachment: Additional Resources

Additional tools and resources *(Continued...)*

Sample Letter from Patient Directly

(Date)

Dear Family/Friends:

I am writing to my family and close friends to let you know that I have been diagnosed with Stage 5 Chronic Kidney Disease. Stage 5 means that my kidneys have failed. The kidneys help the body to filter blood and get rid of poisons, salt, and water. Without kidneys that work, people can become very sick.

My doctors have told me that the ideal treatment for kidney failure is a kidney transplant. A kidney for transplant could come from a deceased donor (somebody who has died), but I would have to wait about 3-5 years, or even longer, for this kind of transplant. This would mean that I would probably have to spend years on dialysis, where machines would clean my blood for me.

The doctors have said that the best type of kidney transplant is a transplant from a living donor (like a family member or friend). A kidney transplant from a living donor would mean that I wouldn't have to wait years for a transplant. A transplant from a living donor also has the best chance of working for many years. Unfortunately, there are no suitable donors in my immediate family.

During my evaluation at the Transplant Center, I learned that one of the best ways to help myself was to make sure that those closest to me know about my situation. I learned that in the United States, there are over 100,000 people on the waiting list for a kidney. Each year, only about 16,000 of those patients are fortunate enough to get a kidney transplant from someone who has died and donated their organs. I am hoping I will be able to find a living donor so that I can *(avoid dialysis or come off of dialysis)* and be transplanted soon so that I may live a longer and with an improved quality of life.

If you would like to learn more about living donation, the staff at my Transplant Center are wonderful and available to talk with you confidentially. The Transplant Center staff at Cooperman Barnabas Medical Center can talk to you about what is involved in the living donation process and answer any questions. You can email **CBMCLivingDonor@rwjbh.org** or call **973-322-5346** if you wish to do so. You can also complete a donor questionnaire at **CBMCLivingDonor.org**. Calling for information and education, and completing a donor questionnaire does not obligate you in any way. Your call and any information regarding your donation process is kept strictly confidential, even from me, unless you consent to share this information.

In closing, I wholeheartedly appreciate any support that you can offer to me, no matter how big or small. If I can get a kidney transplant from a family member or friend, that would be best for my health and my future. I realize that donating a kidney may not be right for everyone, or it simply might not be the right time. I also know that donating a kidney is a very personal decision that requires not only education about the risks and benefits but also thoughtful consideration and the support of loved ones. I hope that one of my family and friends will be able to help me. Thank you in advance for your support.

(Most Sincerely or Fondly),
(Your Name)

Attachment: Additional Resources

Sample Public Plea to Community or Affiliation

My name is *(First Name)* and I have been diagnosed with Stage 5 Chronic Kidney Disease which means that my kidneys have failed and I will need a kidney transplant as soon as possible to avoid the need for lifelong dialysis treatments. *(The next few lines should speak to your involvement with the community or affiliation to whom you are making the plea. For example, I have worked at (Name of Organization) for 15 years and have sought permission from Human Resources to publicize my situation. I am hoping that someone from (Name of Organization) will be able to help.*

Or

I have been a member of (Name of church or synagogue) all of my life and have discussed my situation with (Name of Pastor or Rabbi) to obtain permission to share my situation with the congregation. I am hoping that someone from (Name of Organization) will be able to help.

Next, add a few lines about yourself, sharing as much or as little as you feel comfortable with. For example, I am 36 years old and married to my beautiful wife, (First Name). We have two young children, (Names and ages). I have just started dialysis which has been an enormous struggle for me and for my family because of the many hours I must spend undergoing treatment. Also, I am feeling poorly much of the time which adds to the stress of my illness.

My doctors have told me that a living donor transplant is the ideal treatment option for me. Unfortunately, I do not have any possible living donors within my family and close friends which is why I am making this plea. I am in need of a donor who is in good health and willing to undergo further education and evaluation at Cooperman Barnabas Medical Center. Attached is a list of helpful resources and contact information. Thank you so much for your support.



**Cooperman Barnabas
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Renal and Pancreas Transplant Division

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rwjbh.org/ldi