

JOHNS HOPKINS COMPREHENSIVE TRANSPLANT CENTER

LIVING KIDNEY DONOR PROGRAM



Quiet heroes

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**Donor:** a giver  
a contributor  
a supporter  
a benefactor  
a selfless humanitarian  
a hero

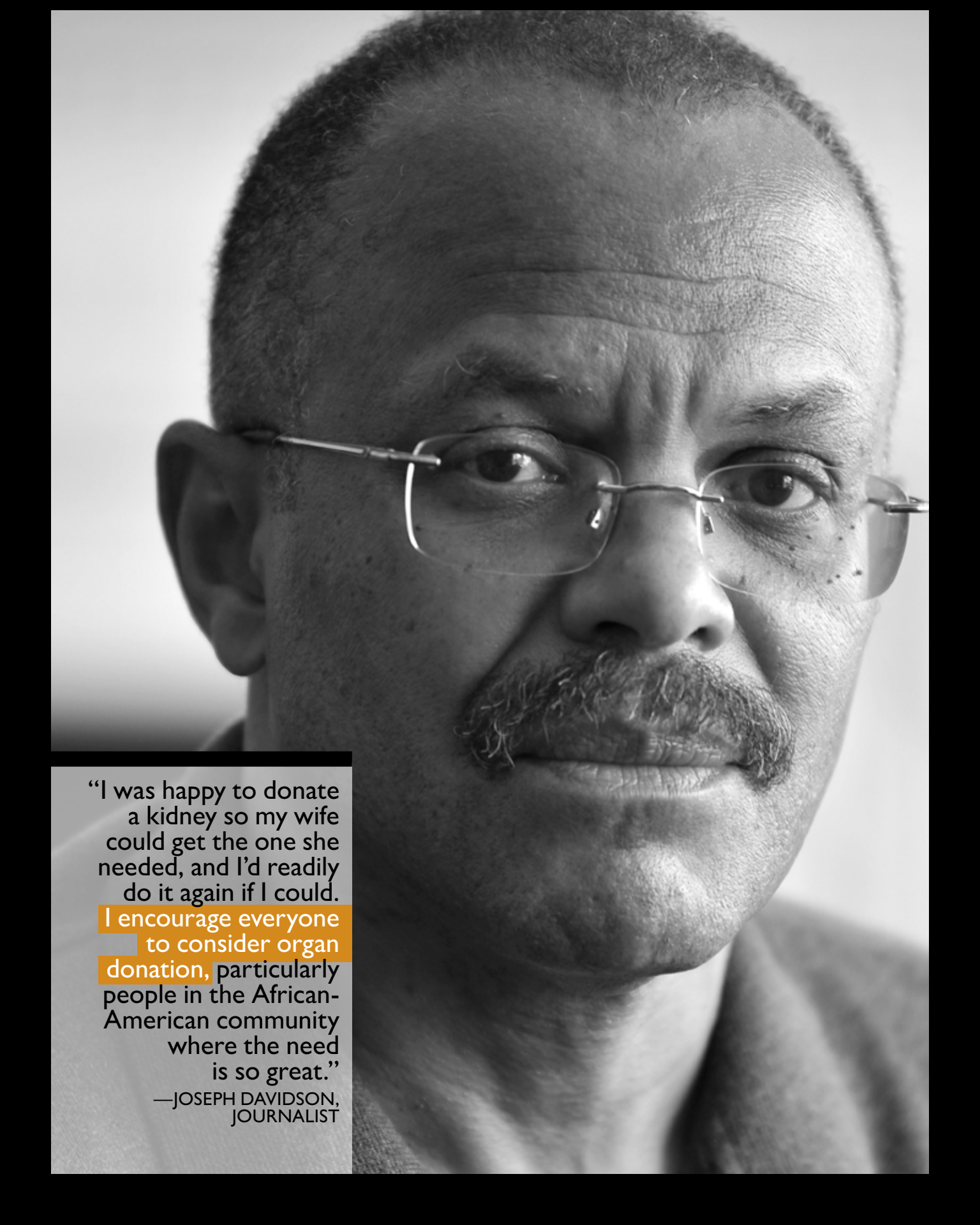
# Quiet heroes

**At The Johns Hopkins Hospital, we're privileged to see heroes everyday. Quiet heroes. The people who save others—related, unrelated, even total strangers—with a living-organ kidney donation.**

Living donors have helped meet the desperate needs of many transplant patients who have endured long waits for deceased kidney donors. Unfortunately, the number of people waiting for a transplant still far exceeds the number of donors. The transplant team at the Johns Hopkins Hospital Comprehensive Transplant Center is constantly developing new ideas to help transform this deficit. We are persistently working toward advancements in living donation as well as better educating the public on living and deceased organ donation.

Since 1970, The Johns Hopkins Hospital has performed more than one thousand living-donor kidney transplants. In 1995, specialists at Johns Hopkins developed the living-donor surgical procedure called the laparoscopic nephrectomy. Unlike the older method that removed the kidney through a large incision, the laparoscopic nephrectomy uses only four small incisions. This procedure has allowed for shorter hospital stays for living donors and decreased the risk of postoperative infection. Today this technique has become the standard of care not only at Hopkins but at hospitals worldwide.

Our innovation does not stop there. Recognizing the problem of incompatible blood-type donor and recipient matches and sensitized recipients to donor organs, the Johns Hopkins program established the Incompatible Kidney Transplant Program (InKTP). Now, more than ever, almost anyone who is medically eligible can be a living kidney donor. More information about the InKTP program can be found later in this booklet.



“I was happy to donate  
a kidney so my wife  
could get the one she  
needed, and I’d readily  
do it again if I could.

I encourage everyone  
to consider organ  
donation, particularly  
people in the African-  
American community  
where the need  
is so great.”

—JOSEPH DAVIDSON,  
JOURNALIST

## Advantages to Living-Donor Kidney Transplants

There are many advantages to transplant recipients receiving a living-donor kidney transplant. Foremost, is the ability to receive a transplant sooner than they would while awaiting a deceased donor organ.

When people have kidney failure, they don't have many options. They can rely on a dialysis machine to remove waste products from their blood, and they can have their name placed on the transplant waiting list that is maintained by the United Network of Organ Sharing (UNOS) for a deceased donor kidney transplant.

Dialysis can result in long-term health issues. It is time-consuming and limits a person's family and work life. Consequently, kidney transplantation, with its well-documented, high rate of success, is the preferred option for most patients. Long-term survival and quality of life is markedly improved among patients who receive a donor kidney compared with patients who remain on dialysis. Receiving a living donor transplant may also allow a patient to avoid dialysis altogether if the transplant is done when the kidney failure is first found.

Thanks to the many options available to people considering kidney donation, the number of people interested in becoming a living kidney donor has been increasing. That's very good news.

Unlike a deceased donor transplant, the living-donor transplant can be planned ahead of time when the recipient is in better health. Most important of all, the long-term survival rates of living-donor transplants are often higher.

There is one more, very important advantage to living donation—using a living-donor organ frees up a precious deceased donor kidney for someone else who doesn't have a living donor.

At the Johns Hopkins Hospital, we are prepared to help anyone understand how living donation works. We recognize that donating a kidney is a decision that should not be lightly undertaken. We ensure that each donor has a specialized team of doctors, nurses, a special donor advocate, a psychologist and a social worker who support the donor's needs. Their sole focus is that of the donor's health and safety.

There are heroes out there. Quiet ones willing to perform a selfless act of courage, to save a life. At Johns Hopkins, we are dedicated to fulfilling the wish of donors to give the gift of life.

## Choosing to be a Living Donor

### Who can donate?

Living donors can be siblings, parents, relatives, friends, in-laws, neighbors, co-workers, religious service members, even altruistic strangers. Living kidney donors give another person a second chance at life.

A donor must be medically and psychologically healthy, willing to donate and at least 18 years of age. There are certain medical problems that would make you ineligible, such as a cancer, diabetes, kidney or heart disease.

**What are some concerns donors have before deciding to donate a kidney?**

Many donors are so comfortable with their decision, they have no concerns, but almost everyone has questions about the donation process. How much discomfort is associated with the surgery? How long will it take to get better? How much time will it take away from work? Will the donor incur any cost?

Some donors express fear. Some even feel guilt about being afraid. Whatever concerns you have, the transplant team is available to help you get the answers you need. Your team can even connect you to a “donor mentor”—someone who has done what you are about to do and who can share their personal experience with you. The team encourages you to learn all you can about donation. Your decision must be the right decision for you.

**How safe is the donor surgery?**

While the laparoscopic technique has made the operation easier for the donor, it is still major surgery. As with any operation, you will have pain and discomfort. There is also a risk of bleeding and infection. Although extremely rare, donor deaths have occurred post-donation for a variety of factors. Factors have included infection, blood clots and bleeding. More common, yet still infrequent, other risks include fever, pneumonia, nausea and urinary tract infections. The risks of living-donor surgery will be discussed throughout your donor evaluation.

**Are there any benefits to living donation for the donor?**

There is no medical benefit to a donation. A possible medical benefit of the evaluation is finding out about a health problem you were not aware of and seeking early treatment. However, giving someone else a second chance at life can be a rewarding experience.

**Members of the Donor Evaluation Team**

An Evaluation Transplant Nurse Coordinator is assigned to every donor. This nurse will guide you through the evaluation process. There are many tests to complete, which he or she will help arrange and coordinate. The nurse coordinator also works closely with transplant surgeons and nephrologists to provide consistent quality care and education as a donor progresses through the evaluation process.

The Johns Hopkins Comprehensive Transplant Center also has an Independent Living Donor Advocate social worker. This role is to help ensure a safe evaluation and care of living donors. The donor advocate provides an additional resource for the donor and the transplant team members. The donor advocate promotes the donor’s best interest and assists the donor in obtaining information and understanding the donation process. You will be able to discuss any questions or concerns about living donation that you may have.

After passing the initial screening, you will be seen in the kidney donor evaluation clinic. There you will meet a transplant surgeon and nephrologist (medical kidney doctor). The transplant surgeon will explain the donor operation and answer any questions you may have regarding the operation. The nephrologist medically evaluates potential donors and will counsel each donor individually regarding the risk for donating a kidney. Together, this team of doctors works to make sure it is safe for you to proceed with kidney donation.

The psychologist and social worker will also provide psychological and psychosocial evaluations to ensure that all potential living donors are suitable from a psychosocial perspective. The psychologist and donor advocate social worker help you and your support network gather information, weigh options and make an informed choice.



**“Friends don’t let friends stay on dialysis. I didn’t, and I’ve been a proud kidney donor since July 20, 2010.”**

—MISTI MYERS,  
PROFESSOR AND PERSONAL TRAINER

Different from other transplanting centers, our team has a dedicated kidney donor follow-up nurse coordinator. This nurse will become your coordinator once you are discharged from the hospital and who specializes in post-donation care.

## Donor Testing and Surgery

One golden rule exists with living donation: Nothing is more important than your health.

Living donation is a process and is done at a pace that is most comfortable to the donor. During all steps of the process, living donors have a nurse coordinator who will be their guide. The living donation process is divided into five phases:

- Initial Call about Living Donation
- Blood and Tissue-Type Matching
- Screening Tests
- Donor Evaluation
- Scheduling the Donor Surgery

## Initial Call about Living Donation

If you are considering living donation, we are prepared to answer any question you may have. We want to make sure that you have all of the information you need as you think about whether donation is right for you. One of the first steps is for you to call the Living Donor Office at 410-614-9345. At this point, you may request more information or get the information you need to schedule the blood test to see if you match the recipient.

## Blood and Tissue-Type Matching

You will have blood drawn to see if you and the recipient have compatible blood types and to check the degree of your genetic matching in what is called a Human Leucocyte Antigens (HLA) test. If your blood type is not compatible with the recipient, it is still possible for you to donate your kidney. Information about Blood Type Incompatible (ABOI) Transplants is covered later in this booklet.

We use the HLA test to predict the likelihood of your kidney being accepted by the recipient. We mix, or crossmatch, both of your blood cells. If the recipient’s cells “kill” your donor cells, the crossmatch is positive. If not, it’s negative. A negative crossmatch means it’s unlikely that your kidney will be rejected. A positive crossmatch means that your recipient will most likely have problems receiving your donated kidney and, in most cases, donation will not be possible.

## Screening Tests

During screening, we will ask you to have blood work and urine tests done. You’ll collect a 24-hour urine specimen that will show how well your kidneys are working. Your blood will be checked to see what viruses you may have been exposed to in the past. You will be asked to provide blood pressure readings. Women must also provide the results of a current pap smear and mammogram. All donors 50 years and older

are required to have a colonoscopy. More tests may be added based on the results of this initial screening. If you don't live close to Johns Hopkins Hospital, these tests can be done in your local area.

## One-Day Donor Evaluation

If problems are not discovered during screening, a One-Day Donor Evaluation is set up at Johns Hopkins Hospital. You'll meet with your living donor team: your Nephrologist, Surgeon, Coordinator, Psychologist and the Living Donor Social Worker/Donor Advocate. We encourage you to bring a family member to meet with your living-donor team too—this should be your significant other or the person who will most likely be helping you during your surgical recovery.

During the evaluation, we will perform a chest X-ray, an EKG and a 3-D CT scan of your kidneys. This evaluation takes the entire day, so if your traveling distance is more than 3 hours, we suggest you come to Baltimore the night before. Ask your transplant coordinator for a housing and hotel list.

Sometimes additional testing is requested at your donor evaluation appointment. This information will be communicated to you and assistance will be provided in scheduling. Once all of the testing is completed and reviewed, your case will be presented to our Transplant Committee. It is the committee's responsibility to review a donor's evaluation and determine whether that person is a candidate who is able to donate a kidney.

## Scheduling the Donor Surgery

The Transplant Committee will review the results of your tests. If your evaluation shows you would be a good donor and you wish to proceed, a surgical date will be set in preparation for the transplant.

In most circumstances, the transplant is scheduled four to six weeks in advance. This allows you to arrange time away from work, child care, school schedules and other daily responsibilities.

Donors are usually in the hospital for two days after their surgery. Donors should plan to stay in town for one week after discharge.

Two weeks before your surgery, a visit is scheduled for both the donor and recipient at our Preoperative Evaluation Center. A final crossmatch will be done one week prior to surgery to make sure the recipient has not developed antibodies that could affect the acceptance of the transplant.

## Donation/Transplant

On the day of surgery, you and the recipient will be asked to come to the preoperative surgical area to prepare for surgery. The surgical team will take your blood pressure, heart rate and temperature. Your past medical history will be reviewed and an IV started. You'll meet your surgeon and the anesthesiologist who will care for you during your operation. You'll have plenty of time to ask any last-minute questions. Finally, you'll be asked to review and sign the surgical consent form.

Your surgery is called a Donor Nephrectomy and takes approximately four hours.





“My Mom gave life to me; I’m just grateful that I was given the opportunity to do the same for her.”

In the end, the most gratifying aspect of being a donor has been to witness the way my dad has so lovingly and painstakingly cared for her since the transplant operation.”

—CARMEN BLAKE,  
NURSE

“I love my daughter and am so proud of how she has borne up under her kidney disease all these years. All this cost me was a couple weeks of time, such a small price to pay for her to have a better life.”

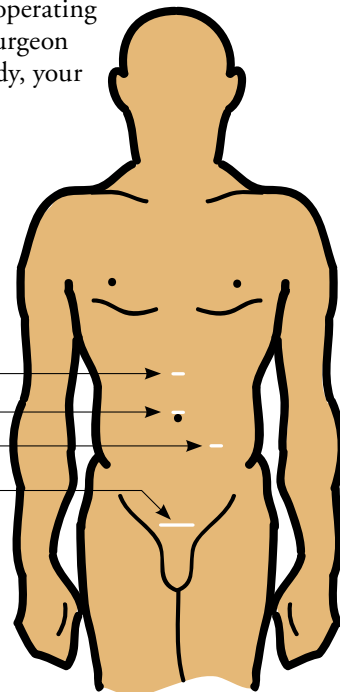
—DR. KENNETH PARK,  
PHYSICIAN



You will be under general anesthesia and asleep during the entire surgery. Once you are asleep, a tube will be placed into your mouth to help you breathe, and a urinary catheter will be placed into your bladder to collect urine.

Most often, your left kidney is removed. Your surgeon makes three small incisions about one-half inch long in your abdominal area (see diagram below). Through one incision, your abdomen is puffed up to make it easier to see the kidney. Through the other incision, a tiny camera and small surgical tools are placed. The kidney will be removed through the fourth incision at the bikini line.

While all this is happening, the recipient is being prepared in another operating room. When the recipient's surgeon reports that everything is ready, your kidney will be removed.



Three small incisions  
each less than ½ inch

2-3-inch incision

## Initial Recovery in the Hospital

You will awake in the recovery room feeling very sleepy. You might also feel a little nauseated. That's normal and due to the anesthesia. Once you are stable, you will be taken to your hospital room.

Your breathing tube will be removed while you are still in the operating room, but the urinary catheter and IV will remain in place for one day after surgery. You can expect to feel puffy from all the fluid you were given during surgery. You will have gained a little weight, because each liter of fluid is equal to 2.2 pounds, but this will drop 1-2 weeks after surgery.

Pain medication is available through an IV or an injection. On the second day after surgery, or once you can tolerate food, you will be given pills to control your pain. You may also have some pain in your shoulders from the gas used to inflate your abdomen.

Soon after surgery, you'll receive a regular diet. You'll also be encouraged to get out of bed. Walking leads to faster recovery and helps prevent infections and blood clots in your legs. By the second postoperative day, if there are no problems, you will be discharged from the hospital.

## Recovery At Home

You will experience some abdominal pain. This pain should be easily relieved with either a prescribed medication or over-the-counter pain relievers. In fact, most donors report they no longer need any medication two weeks or even sooner after surgery.

We recommend that you don't drive for two weeks and don't lift anything heavier than 10 pounds for six weeks. You are encouraged to walk several times a day, both for exercise and to hasten recovery. If you have child care responsibilities, you'll need some assistance during the first week.

You can also expect to feel a variety of emotions from elation to a slight "let down." This is completely normal. You have just experienced an intense emotional and physical event. Be patient with yourself and your progress. Recovery and healing take time.

## Returning to Work

The timing of the donor's return to work is dependent upon the type of work. The return for an office or desk worker may be as soon as 2 to 3 weeks, while a more strenuous worker may need as long as 6 to 8 weeks.

## Follow-up

We ask that our living donors come to a medical appointment after their surgery so we can make sure they are recovering well. Then, we ask them to send medical information to us at regular intervals so that our transplant experts may follow their health. This benefits living donors by providing an enhanced level of safety and attention from living-donor specialists, in addition to the ongoing care they receive from their community-based primary care physician.

## Your Future After Donation

Make no mistake, donating a kidney is no small step. You have to wonder how this is going to affect your health, your future, your life. Here are the answers to the questions we hear the most.

### **Will I be able to live a normal, healthy life after donating a kidney?**

Absolutely. Years of research and follow-up studies with living kidney donors confirm that donating a kidney does not have an adverse effect on future health in any way. It won't shorten your life, or change it, for that matter. Donors lead active lives with only one kidney. They drive, work, exercise, serve in the military and do just about everything they did before. After your initial recovery, we recommend a yearly routine physical by your family physician.

### **Will I be able to get insurance afterwards?**

A national study of insurance carriers found donors had very few problems getting insurance. Only 4 percent had difficulty getting health and life insurance. And only 2 percent had problems getting disability insurance. On rare occasions, donors may be asked to wait from one to three years after donation before being issued a policy. However, we encourage you to have insurance or a way of obtaining annual check-ups after donation. If you have difficulty with insurance, please talk to the transplant office and we will help you with this matter.

### **Can I have children?**

According to research, there is no reason to believe that donating a kidney will affect your ability to become pregnant or father a child. In fact, the data show that almost everyone who tried to have children after donation was successful.

### **What costs will the donor incur?**

The majority of bills related to the donor evaluation, surgery and postoperative follow-up care are taken care of by the recipient's insurance. Some costs that are not covered by private insurance or Medicare include travel costs, lost wages, child care and daily living expenses; but there are a number of resources to help donors with this. That's why it is important that you discuss all of your financial questions with your transplant donor advocate/social worker before the donation process.

“Working as a  
Johns Hopkins  
administrator, I see  
suffering and I see  
miracles every day.

Donating my kidney  
allowed me to relieve  
someone’s suffering  
and to be a part of a  
miracle myself.”

—PAMELA PAULK, VP OF  
HUMAN RESOURCES



## The Incompatible Kidney Transplant Program (InKTP)

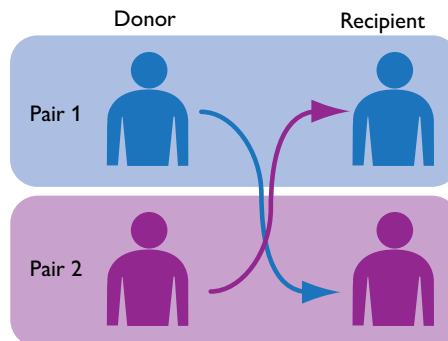
Johns Hopkins is leading the way in innovative strategies for helping people with end-stage renal disease receive a kidney transplant. Through the Incompatible Kidney Transplant Program (InKTP), patients who, previously, had little hope of receiving a living-donor kidney transplant and faced long waiting times for a deceased donor kidney can now be offered four promising opportunities for transplant.

## Blood-Type Incompatible Transplant Program

Now even people with an incompatible blood type with the recipient can donate their kidney. The evaluation and surgery for the donor are just as we explained earlier, but to prevent immediate rejection of the kidney, the recipient's blood must have antibodies to the donor blood-type removed. This is done before the transplant with a process called plasmapheresis. Plasmapheresis removes antibodies from the recipient's blood that would be harmful to the donor kidney. To keep the antibodies from reforming, the recipient's spleen may be removed post transplant if a rejection occurs. This is occasionally done because the spleen is the site where most of the antibody is produced. The patient receives several plasmapheresis treatments postsurgery. Once at home, the patients use the same antirejection medications used for all kidney recipients. Recipients who received blood-type incompatible transplants over the past ten years are experiencing normal kidney function.

## Paired Kidney Exchange Program

This is an exciting program to match blood-type incompatible donors and recipients. For example, a husband needs a kidney and his wife wants to donate, but their blood types are not compatible. Their names are put into a database and their blood types are matched with another living donor and recipient whose blood types are also not compatible. It sounds complicated, but it's really quite simple; (see illustration). Now two people who faced a long wait for a deceased kidney can receive a living-donor kidney transplant instead.



If you know your blood type is incompatible with your recipient, you'll want to find out more about these programs. Just call the transplant office at the number listed at the end of this booklet.

## Highly Sensitized Patient Protocol

People who have had a previous transplant, pregnancy or blood transfusion develop antibodies in their blood that can force an immediate rejection of the transplanted kidney, or cause one sometime after the transplant. These patients are called “highly sensitized.” These patients may wait a very long time for a deceased donor kidney. Many highly sensitized patients have living donors willing to give them a kidney. However, when the recipient’s blood is mixed with the donor’s blood, the highly sensitized recipient’s antibodies act to kill the donor’s cells.

Through the Highly Sensitized Patient Protocol, the recipient’s blood can be cleansed of these antibodies with plasmapheresis. A successful living donor transplant is then possible. The long-term outcomes from this procedure have been very good and patients who receive it double their survival compared to those who remain on the waitlist.

## Altruistic Nondirected Donation

It’s one thing to offer a kidney to someone you love, but imagine giving it to someone you don’t even know. That’s exactly what one transplant nurse did in 1998, when Johns Hopkins Hospital performed its first altruistic donor kidney transplant.

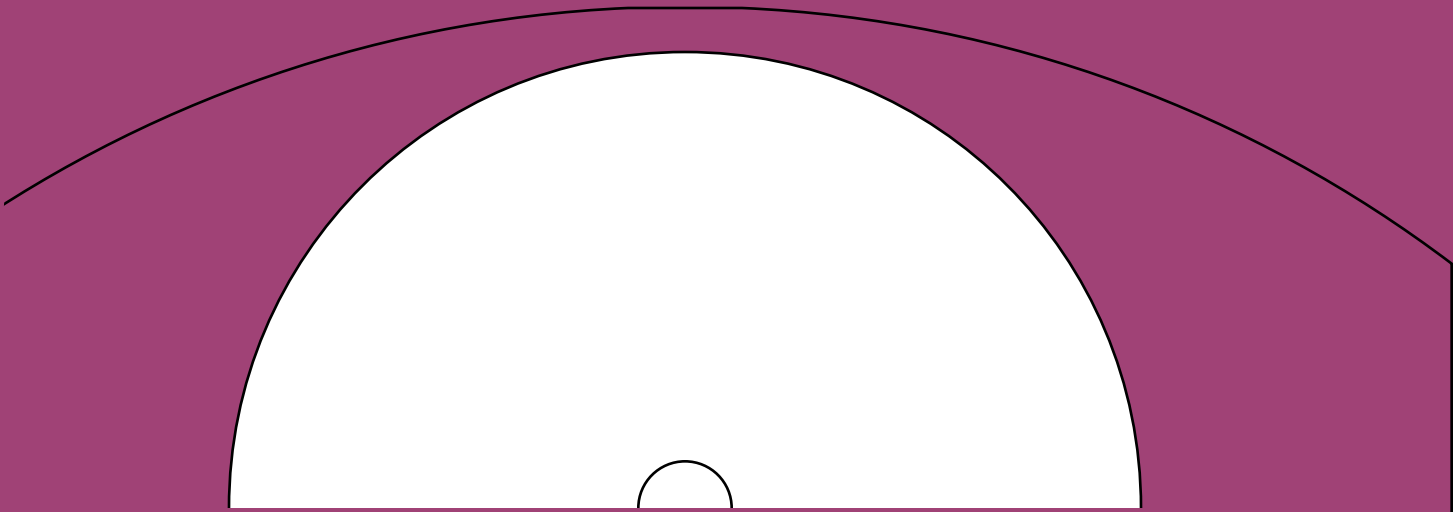
This nurse wanted to show the world that being a living donor was a safe and rewarding way to help the thousands of patients waiting for a kidney. Since her donation, hundreds of people from around the United States and throughout the world have expressed interest in Altruistic Kidney Donation at the Johns Hopkins Hospital.

If you’re thinking of being a living kidney donor, we hope this booklet has given you the basic information you need. As always, the Johns Hopkins Hospital Comprehensive Transplant Center is ready to answer any of your questions.

### COMPREHENSIVE TRANSPLANT CENTER TELEPHONE DIRECTORY

Johns Hopkins Hospital  
Johns Hopkins Comprehensive  
Transplant Center  
720 Rutland Avenue, Turner 36  
Baltimore, Maryland 21205  
Main telephone number: 410-955-5000

Abdominal Transplant Office  
Kidney Living Donor Evaluation Office  
1-888-304-5069 / 410-614-9345  
Fax number: 410-614-6906





**For more information:**

**The Johns Hopkins  
Comprehensive Transplant Center  
410-614-5700  
[hopkinsmedicine.org /transplant](https://hopkinsmedicine.org/transplant)**

The Johns Hopkins Comprehensive Transplant Center would like to thank Mr. & Mrs. Bruce and Susan Ross for their generosity in making *Quiet Heroes* possible. We thank them for their dedication and support to the promotion of living kidney donor education.