

The Nicoletti Kidney Transplant Center  
At the Jefferson Transplant Institute

## **Kidney Champion Resource Guide**

# Helping to Find the Next Hero



**Jefferson Health®**

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HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

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## What are Kidneys and Why Do They Fail?

The kidneys are bean shaped organs that are located on each side of the backbone. Almost everyone was born with two. You only need one functioning kidney to live a healthy life.

The kidneys help to regulate many of the body's functions. They are involved in the regulation of blood pressure, fluid and electrolytes, and the acid/base balance in the blood.

The kidneys serve as a filter, sending extra fluid and unwanted waste products out of the body through the urine. Each kidney contains about a million little filtering units called nephrons. Inside each nephron, special blood vessels called a glomerulus work like a strainer, keeping blood cells and other substances that the body needs, while letting extra fluid, waste products, and other unwanted things out of the body in the form of urine.

The kidneys also make hormones that are needed for different functions in the body.

Kidneys often fail due to health problems that cause kidney damage over the course of many months or years. The most common causes of Chronic Kidney Failure are diabetes and high blood pressure. Other causes include immune diseases like lupus, and hereditary diseases.

Unfortunately, when kidneys fail, a person may experience a number of symptoms such as lethargy, weakness, shortness of breath, swelling, anemia, loss of appetite, congestive heart failure, fatal heart rhythm, inflammation of the heart lining, and other life threatening conditions. If left untreated, kidney failure could lead to death.

Treatment for kidney failure includes dialysis or kidney transplant. Transplant has been universally seen as a more desirable treatment for patients as they are able to return to a more normal life, they no longer experience kidney failure symptoms if their transplant is functioning, and life expectancy has been shown to be much greater overall. Live donor transplants work better and last longer than deceased donor transplants for a number of reasons.

## How Many People are Waiting and How Waiting Works?

When a patient decides to pursue kidney transplant, they must be evaluated at a transplant program to make sure that they are a good candidate for transplant. The evaluation includes a thorough medical, surgical, and psychosocial review. If it is determined that a patient can be transplanted safely, they are either placed on the deceased donor waitlist or their living donors are evaluated for donation and surgery is scheduled.

Currently there are nearly 100,000 people waiting for a kidney in the United States. This includes Jefferson Health's waitlist of hundreds of candidates. Waiting time varies by the area of the country you live in, the potential recipient's blood type, and how difficult they may be to match because of previous blood transfusions, transplants, or pregnancies. Without a living donor, most patients can expect to wait for many years before they are able to receive a kidney transplant.

## How Does Someone Become a Live Donor?

When someone is willing to donate one of their kidneys, they contact the transplant program. They can do this in a number of ways. They may come to a transplant appointment with their intended recipient, call the transplant program, or they can fill out the online referral form and send it in via email.

Once we are aware of someone's interest we will begin the evaluation process. The evaluation includes blood tests to determine blood type and compatibility, a medical, surgical, and psychosocial evaluation, some imaging of the abdomen, and a visit with the donor advocate. If the donor has any health conditions, there may be other consultations needed, to ensure that it is safe to donate. There is no cost to the donor for the evaluation and surgery.

If it is safe to donate, and the donor is compatible with their intended recipient, then surgery is scheduled on a date that is good for both the donor and the recipient.

If it is safe to donate, and the donor is incompatible, we will encourage the pair to enroll in a registry that will coordinate a donor "swap" with another incompatible donor and recipient pair. For more information about donor registries, donor chains, and paired donation, please ask the transplant team or visit our webpage at [Jefferson.edu/Transplant](https://www.jefferson.edu/Transplant).

## Who Makes a Good Donor?

Living donors are volunteers who are physically healthy, and who do not have kidney disease or significant risk of developing kidney disease later in life. Donors do not have to be the same race, age, or gender as the intended recipient, and do not have to be related by blood.

## A Living Donor Nephrectomy (Kidney Removal Surgery)

The nephrectomy is performed under general anesthesia and usually takes about 3 hours. The surgery is usually performed laparoscopically. The patient will likely have 3-4 small incisions in the abdomen for the camera and surgical instruments and one larger incision where the kidney is removed from the abdomen. Sometimes it is necessary in the operating room to change the surgery to an open procedure with a larger incision. The patient will have an IV tube placed in their arm and a urinary catheter, a flexible plastic tube used to drain urine from your bladder, in place after surgery. The urinary catheter is usually removed within 24 hours after surgery.

Most donors remain in the hospital for 2-5 days. Patients will be discharged with a prescription for pain medication and will probably feel more tired than usual after the surgery. During the healing period of approximately 2-8 weeks patients should not perform strenuous work or lift more than ten pounds.

## A Kidney Transplant Operation

The transplant surgery is performed under general anesthesia and usually takes 3-6 hours. The kidney is placed in a different location than the existing kidneys and the existing kidneys are usually not removed unless they pose a health threat to the recipient. The transplanted kidney is placed in the front (anterior) part of the lower abdomen, in the pelvis.

The artery that carries blood to the kidney and the vein that carries blood away are surgically connected to an existing artery and vein in the recipient's pelvis. The ureter, or tube, that carries urine from the kidney is connected to the bladder. Most recipients stay in the hospital for 3 -7 days.

## Your Job as a Kidney Champion

We are so grateful that you have agreed to be a kidney champion. You are a hero! As a kidney champion, it is your job to spread the word about your loved one's kidney disease and need for a living donor. It is also your job to clearly direct those interested in live donation to the Jefferson Health Transplant Program, where they can be tested and be given the opportunity to donate. There are several myths and misconceptions about organ transplant and we are hopeful that this resource guide and your kidney champion training will provide you with tools that will help you to correct any misunderstandings you may come up against.

For many, social media is an excellent tool to spread the word. We also recommend email blasts to your family and friends, and speaking at one of your community affiliations such as a church group. You know best how to spread the word amongst your peer groups, friends, work, churches, and other affiliations. We would like to help you with wording, with explanatory language, and with understanding some important do's and don'ts. Wear your kidney champion bracelet with pride and willingly answer questions about it when asked.

## How to Ask Someone to Be a Donor

The first step is to learn everything that you can so that you can answer questions easily. Your kidney champion training session and this resource guide should help you. Our website is another great resource and you can always reach out to the transplant program for any follow-up questions at any time.

The next step is to plan how you will communicate your message. The following is a good checklist for your planning:

- ☐ **large family or friends gatherings**
- ☐ **Facebook**
- ☐ **Twitter**
- ☐ **email to your contacts**
- ☐ **church meetings or church services**
- ☐ **organizations or clubs you belong to**
- ☐ **ask your employer to send an email company-wide or department-wide**
- ☐ **post a flyer at work or in your community**
- ☐ **talk to your volunteer group**

Next, is to put your message on paper and the most important part of your message is the story of your loved one who is in need of a transplant. Everyone's story is compelling. Identify yourself as an advocate and explain why your loved one has kidney disease, how long they have been suffering, and what they are like as a person. It is important for people to connect with the story. It is a good exercise to type up a couple of brief paragraphs to describe this so you can easily use it and share it. We provided some samples for you along with this resource guide.

Finally, your message should include what the interested donor should do. You should include who to contact at the Jefferson Health transplant center, the email address as well as a phone number, and how to access our living donor questionnaire online.

## Do's and Don'ts

### Do:

- Be heartfelt and remember the story should always come first
- Use technology!
- Be understanding when people say no
- Be patient when people have lots of questions
- Expect to be asked awkward questions like "why don't you do it yourself?"
- Allow others to spread the word on your behalf too!
- Practice your message with others to ensure you feel comfortable
- Be prepared to readily provide interested potential donors with contact information for the transplant center

### Don't:

- Coerce people or make them feel bad if they say no. It is a very big thing to ask someone to do, and they must not feel pressured or coerced in any way.
- Offer anything in exchange for donation. Don't bribe someone in any way. It is illegal in the United States to be compensated in any way, monetary or otherwise, for organ donation.
- Feel pressured to know EVERYTHING. Use the transplant center contacts and other resources to help you answer questions.
- Give up your search until a donor is found!

# Resource 1

## Sample Social Media Postings



**Laura Sample**  
3 hrs • 🌐

Family and Friends! As you may know, my sister Mary has suffered from diabetes since she was a teenager. Unfortunately, her condition has progressed to the point that she has chronic kidney failure. Her doctors tell her that she will be starting dialysis next week in order to live! Mary is devastated with this news as is the rest of her family. She fears she can no longer keep her job that she loves as a teacher because of the grueling dialysis schedule. Also, she can no longer enjoy playing with her nieces and nephews since she has been so sick. Mary is one of the kindest people I know and it is so hard to see her sick. The transplant program at Jefferson in Philadelphia is evaluating her to be placed on the kidney waitlist so she can avoid lifelong dialysis. I wish I could give her a kidney myself, but they say I am not a candidate. I am asking any of you who know her or knew of her to consider if you would be willing to give the most ultimate gift of life by considering living kidney donation. Let me know if you want more information about the process, the timeframe, and other details about being a living kidney donor. Or, if you'd prefer, reach out to Mary's transplant coordinator directly at XXXXX@jefferson.edu, or at 1-888-855-6649. If you aren't interested in donating or don't feel that you can, please take a moment to like and share this post for me and, most importantly, for Mary.




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52 Comments 15 Shares


 Like  Comment  Share




**Suggestion: Add pictures of the patient with friends and family.**






**Kevin Sample**  
5 hrs • 🌐

Hello Family and Friends! I am a kidney champion for my brother-in-law, Tony. That means I agreed to help find him a kidney donor. Some of you may know Tony. For those of you who don't, you should know that Tony is married to my sister Kim. He is an accountant by training but hasn't been able to work in the past two years. He has a grown daughter in college, who he loves dearly. Tony spends three days a week on dialysis and he has been on the kidney waitlist at Jefferson for the past year. His kidneys failed due to a genetic disorder he has called polycystic kidney disease. His daughter, my niece has the same disorder and is unable to donate her kidney. Several of us in the family have also tried to be donors, but unfortunately it has not worked out. Tony would never be able to ask for such a gift. He is quiet and keeps to himself and he rarely ever complains about the pain, discomfort and awful side effects that go along with kidney failure and dialysis. My job as a kidney champion is to find a donor for Tony. I am sharing this post here with the hopes that someone who knows me or him, or even a stranger, may see this and think that they can do this. If you want to learn more about how the process works to be evaluated as a kidney donor, please private message me and I will get back to you right away. If you know you are interested or want to talk to the transplant program directly, please feel free to reach out to the transplant coordinator at XXX@jefferson.edu or at 1- 888-855-6649. If anything, please like and share this post to help me spread the word.



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44 Comments 12 Shares

 Like  Comment  Share

## Resource 2

### Sample Church Group or Volunteer Gathering Speech

Good morning fellow parishioners:

Many of you know me and I am grateful that you are allowing me this time to talk to you about someone dear to me who needs our help; my next door neighbor of nearly 20 years, Jim. Jim lives alone and spends most of his days inside. This is not the same man I met when my husband and I moved our family to the neighborhood and the parish. Jim was the first person to welcome us to the neighborhood. He helped us to unpack, made us feel welcome, and spent the next 20 years as the kindest and giving neighbor one could imagine. He plowed the snow from our driveway when my husband broke his foot. He helped us wrangle up our dogs every time they got loose and darted through the neighborhood. He was always there to help if I went to work and I was afraid I left the stove on. He even helped to teach our youngest how to ride a bike. Jim has always helped me and my family. I am trying to help him.

We don't see much of Jim anymore. He spends two days a week plus a Saturday on kidney dialysis. When he is home, he is too tired to get out much. His kidney failure has affected his ability to work steadily as a plumber and has put serious strain on his finances and his entire life in general. Jim doesn't have a big family. But I consider him to be family.

The reason I am here today is that I am asking this parish of people, who I know to be generous and selfless, to consider kidney donation for someone you probably don't know. It is a big ask. Most of us are born with two kidneys but you only need one to live. I would give one of mine to Jim if I could. The best I could do is spread the word about his need.


Jim is on the kidney transplant waitlist at Jefferson in Philadelphia. He has been waiting since last April and hasn't been called yet for an organ match with a deceased organ donor. If he has a living donor that is evaluated to be a good and safe candidate, he can likely come off the list, come off of dialysis and get his life back. Jefferson has outstanding doctors and surgeons and has been doing living donor transplants for over 40 years now.

There's a lot to know and learn about living kidney donation and I would love to spend some time answering anyone's questions. I will be in the back of the church at the close of services if anyone wants to come to talk to me. If anything, I have flyers that I am hoping you could distribute at your jobs or anywhere you volunteer. Please help me to spread the word for Jim. I know he would do the same for me or for any of us.

Thank you for your time

## Resource 3

### Sample Flyer



# KAREN — NEEDS A — KIDNEY

Meet Karen! Karen O'Toole has dedicated her life as a nurse and to helping others. She is now in need of some help. Karen needs a kidney.

Karen has worked as a family practice nurse in Doylestown for the past 10 years and spends her weekends volunteering at the SPCA of Bucks County.

Karen has suffered from hypertension her entire life and her kidneys are on the brink of complete failure. Karen wants to be able to keep her lifestyle as a beloved family practice nurse and volunteer, but she can't do those things while spending her time on dialysis.

#### How can you help?

Have you ever considered being a living kidney donor? Most of us are born with two kidneys and we only need one to live. Karen's best chance of being transplanted within the next five years is to have a living donor. The evaluation at the Nicoletti Kidney Transplant Center for a live donor is streamlined, patient friendly, and free of any cost to a live donor candidate. There is unlimited education about the process, the procedure, and what you should know and expect.

If you or someone you know is interested in being considered to be a live donor for Karen or someone like her, please call the transplant team at Jefferson at 1-888-855-6649 and let them know. You can also email them at [XXXX.XXXX@jefferson.edu](mailto:XXXX.XXXX@jefferson.edu) or go to their webpage and complete an application form (insert URL here).

**HELP US TO FIND KAREN A KIDNEY! SPREAD THE WORD!**



# Kidney Champion

You are working as a kidney champion for \_\_\_\_\_.

Transplants performed by living donation can last twice as long as deceased donor transplants. Due to the significantly better outcomes, live donation is a better option for transplant. Remember if blood type does not match, there is always the possibility of Paired Donation or Paired Exchange. Please list below individuals that could possibly be living donors.

Name	Phone Number
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____
11. _____	_____
12. _____	_____

