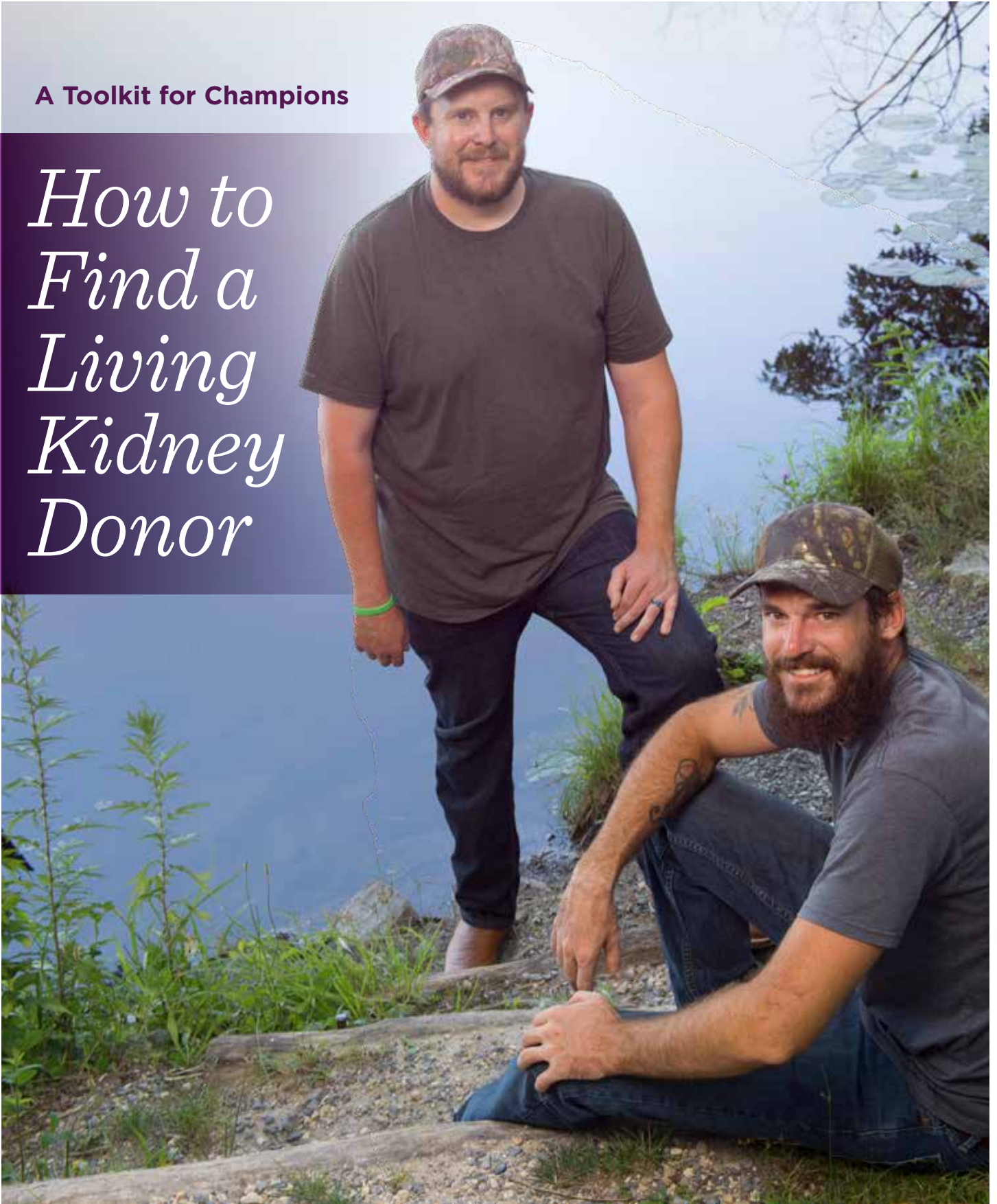


A Toolkit for Champions

How to Find a Living Kidney Donor



A step-by-step guide to help you launch the search

UPMC | HARRISBURG





Kidney Transplant Services at UPMC Harrisburg

Since the creation of UPMC Harrisburg Kidney Transplant Services in 2000, more than 1,300 life-saving kidney transplants have been performed on individuals of all ages throughout central Pennsylvania.

As part of UPMC Transplant Services, one of the leading transplant centers in the country, we provide compassionate and expert patient-centered care. Our services range from thorough evaluations to world-class treatment at every stage of the transplant process. Our surgeons are distinguished by their surgical innovation, research, technological advancements, and contributions to new knowledge.

Our experienced kidney transplant team — surgeons, nephrologists, nurse practitioners, transplant coordinators, nursing staff, social workers, financial coordinators, and other professionals — provides our patients, living donors, and their families with pioneering care and hope for the future. It is our honor to serve you.

To learn more about UPMC Harrisburg Kidney Transplant Services or to schedule an appointment, call **877-778-6110** or visit **UPMC.com/CentralPaTransplant**.



UPMC Harrisburg
Kidney Transplant Services
205 S. Front St.
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With Thanks: We are grateful to the UPMC Harrisburg patients who share their kidney transplant experiences in this booklet. Their personal stories are a powerful tool for raising awareness about and offering valuable insight into kidney transplantation. *Photos by Stephen Moyer Photography.*

On the Cover: Frank Blemler is back to doing the things he loves — thanks to his brother Jonathan and the team at UPMC Harrisburg Transplant Services. On Jan 22, 2019, Frank received one of Jonathan's kidneys during a living-donor transplant. *Photo by Stephen Moyer Photography.*

About This Toolkit

Finding a living kidney donor is a journey — one that can be physically and emotionally overwhelming to a person who needs a kidney transplant. But having a Champion like you on that journey can make all the difference.

UPMC Harrisburg Kidney Transplant Services created this booklet to explain the critical role you will play as a Champion. It also includes the information you need to help introduce potential donors to the living kidney donation process.

What Does a Champion Do?

A Champion helps lead the search for a living kidney donor. You may be a spouse, family member, friend, neighbor, coworker, or anyone willing to tell the compelling story of someone awaiting a kidney transplant.

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For additional support and to connect with other Champions, join the Living Donor Champion Support Group. Visit **Facebook.com/groups/livingdonorchampion**.



Step 1

Understanding the Living Kidney Donation Process at UPMC Harrisburg

David and Ray's Story

David didn't know much about kidney disease until doctors said he would likely need a kidney transplant. For David, 73, the transplant waiting list wasn't a good option. When doctors at UPMC Harrisburg encouraged him to find a living donor, he jumped into action. For Ray, the decision to donate a kidney to his father-in-law was an easy one: he wants David to live and thrive for his grandchildren.



“Making the decision to donate a kidney to my dad was a rather simple one. I knew if I ended up being a match, that was all the inspiration I’d need to take the next step. Life has a way of making complex decisions rather simple when you are listening.”

Pamela Morrissey



Learning About Living Donation

People on the kidney transplant waiting list can remain there until a deceased donor organ becomes available. But the wait is often long and uncertain. There is another option: living donation.

As a Champion for someone who needs a new kidney, it’s important to learn as much as you can about the living donor procedure. We’ll start with the basics and then dive a little deeper into kidney transplants.

Living-Donor Kidney Transplants

Medical advancements in surgery and follow-up care now allow people to donate a kidney to help a relative, friend, or even a stranger who is need of a transplant. Having a living kidney donor can help avoid what is typically a five-year wait for a suitable kidney.

Kidney transplants also are possible through a living-donor kidney paired exchange. Any living kidney donor can participate in a paired exchange, which can save the lives of several people facing kidney failure.

Benefits of Living Donation

There are benefits for both the recipient and the donor.

For the recipient, getting a living donation:

- Reduces time on the waiting list.
- Shortens time on the waiting list for other people in need.
- Improves odds of long-term recovery by allowing the surgery to be performed when the recipient is healthier.
- Allows for the surgery to be scheduled at a time that is convenient for both the donor and the recipient.
- Increases the existing organ supply, helping to save more adults and children waiting for life-saving transplants.

For the donor, being a living donor:

- Provides the opportunity to save a life.
- Contributes to the lives of the recipient and their loved ones in a very meaningful way.
- Includes a no-cost, comprehensive medical and psychosocial evaluation that can reveal unknown medical problems.



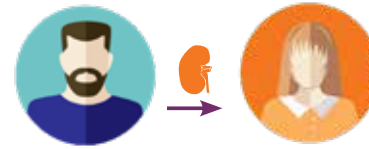
Ross and Jenna's Story

As soon as Jenna learned her husband needed a kidney transplant, she was ready to donate one of hers. Although she wasn't a match, Jenna was part of a five-paired exchange that resulted in a life-saving transplant for Ross at UPMC Harrisburg. "While I didn't receive Jenna's kidney, someone else who needed it did. And I got someone else's kidney," says Ross. Jenna says it was an "amazing blessing" to be part of a paired donation that helped Ross and four others. "I'm back to being active with our two kids, and it's a blessing to be able to see them grow up with their father in such good health," she says.

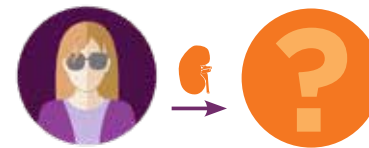
3 Types of Living Donation

There are three categories of living donation:

- **Directed Donation:** The donor chooses the person who is to receive their kidney.

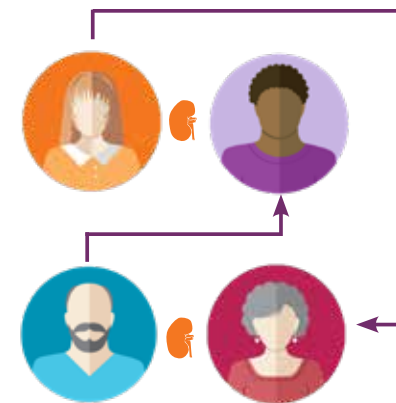


- **Nondirected Donation:** When the donor is neither related to nor known by the person in need, the recipient is determined primarily by medical compatibility.



- **Paired Exchange Donation:** For a kidney transplant to be successful, the donor and recipient must have compatible blood types. They also should be similar in body size and stature. If a living kidney donor is found to be incompatible with their intended recipient, the paired exchange program is a worthwhile option to consider.

A paired exchange matches an incompatible donor/recipient pair with another incompatible donor/recipient pair. By arranging the "swap," two life-saving transplants can take place.



Requirements of Living Donation

"I chose to be an organ donor because often when people are hurting there is nothing you can do to help. This was one way I could help."

Heather Eck

To be considered as a living donor, individuals must be at least 18 years of age, in good health, and not have:



Liver disease



Cancers or other diseases that could complicate the surgery



Diabetes



Heart disease

Unsure if someone will qualify as a living donor?

Have them contact UPMC Harrisburg Kidney Transplant Services at 877-778-6110.

Motivation

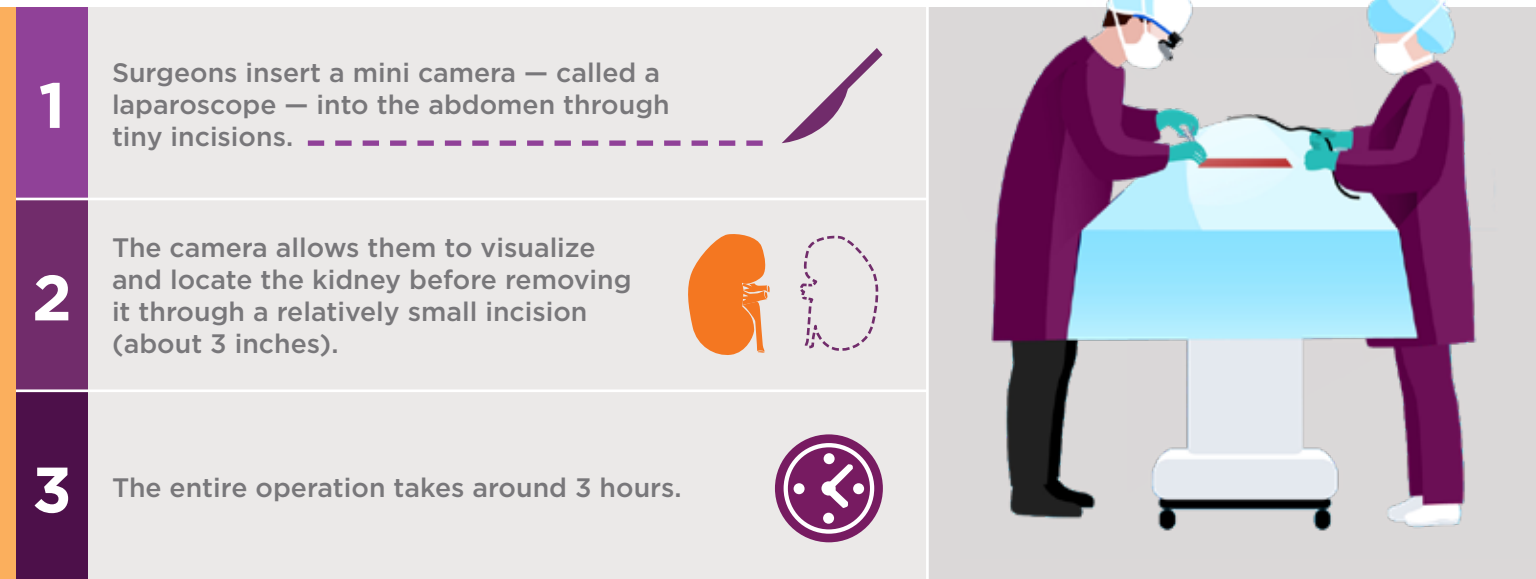


The main reason for donating must be an unselfish desire to help a person in need. Absolutely no financial compensation is involved.

What Happens During a Living-Donor Kidney Transplant

During a living-donor kidney transplant, a healthy kidney is removed from the donor and transplanted into someone whose kidney is failing.

In most cases, the donor kidney is removed during a minimally invasive surgical procedure that involves making several very small incisions on the abdomen.



Recovery for Living-Donor Kidney Transplant

Most kidney donors spend one or two days in the hospital. Our kidney transplant team at UPMC Harrisburg works with every donor to develop a personalized postoperative treatment plan. It typically takes a few months for donors to fully return to their previous level of health. **But recovery times after living-donor kidney transplants can vary.**

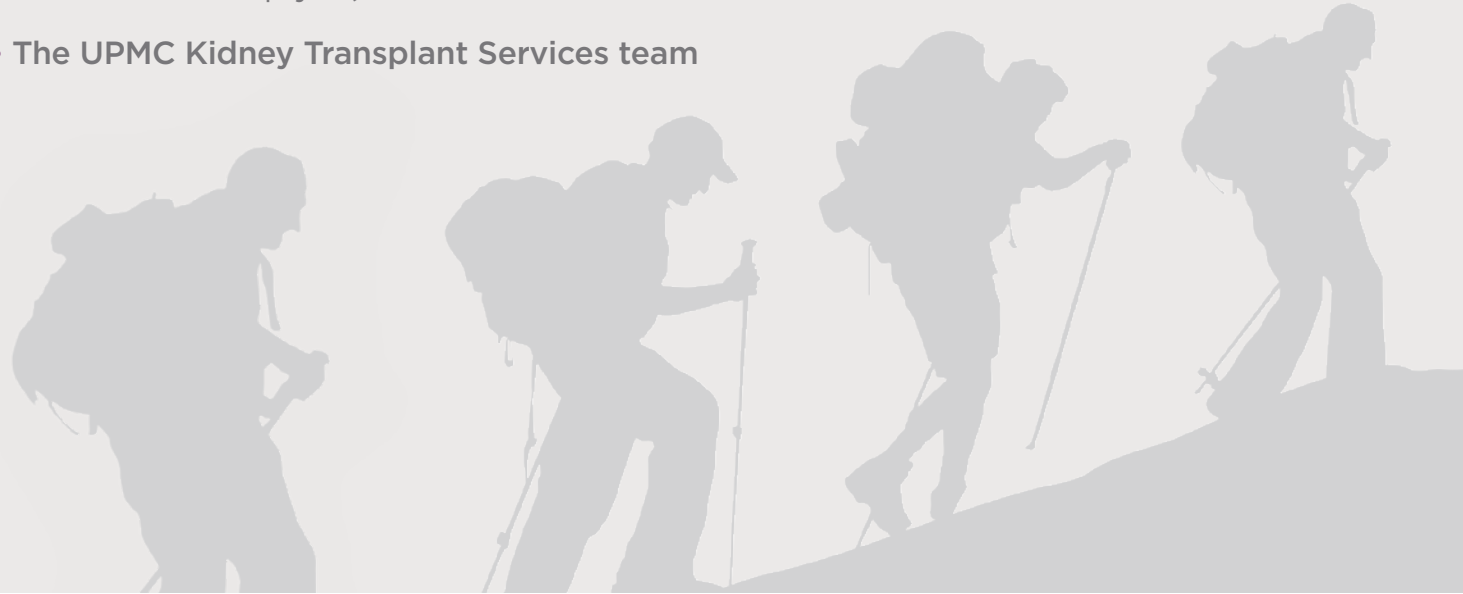


Brandon and Angie's Story

Polycystic kidney disease runs in Brandon's family. His sister and Angie were good friends in high school. When Brandon's sister needed her transplant, Angie got tested at UPMC Harrisburg and was a match. However, another donor came forward who was a better match. When Angie learned that Brandon needed a kidney donor, she was tested again — and found to be his exact match. Donating a kidney was a relatively simple thing to do considering the huge impact it had on Brandon's life.

As a living kidney donor Champion, you are not alone on this journey. Traveling with you are:

- The person waiting for a transplant
- The donor
- The caregiver (if that is someone other than you)
- **Champion partners** (family, friends, and others who volunteer their time and effort to help you)
- The UPMC Kidney Transplant Services team



Step 2

Why You're on This Journey

Regardless of the type of living donor transplant that is performed, one of the major benefits for the person in need is that it reduces time spent on the waiting list.



“The Champion Program was wonderful in the fact that it gave Joe’s need for a living donor a voice.”

Pam St. Clair

Champion for her husband, Joe, about how the Champion program made it easier for her to talk to potential donors.



The Living Donor Champion

Now that you understand the living donor transplant process, let’s talk about your own role as a Champion.

When a loved one is waiting for a transplant, their life hangs in the balance. Many people will want to support this person’s journey. But it is the Champion who plays the most crucial role, which includes:

- Finding a living donor.
- Offering ongoing support and motivation for the person waiting for a transplant.
- Reaching out to as many people as possible to help find a suitable living donor.
- Providing direction and motivation throughout the journey.

Your job as a Champion is vital because:

- The person in need of a transplant is often too sick to take on this task and must concentrate on staying as healthy as possible.
- It is often emotionally difficult for someone who needs a transplant to share the need and ask for help.
- Without a living donor, the patient will likely wait longer to receive a transplant and only get sicker.

Your task as the Champion is to spread the word as far as you can and to reach as many eyes, ears, and hearts as possible. Being a Champion can be challenging. It’s important to fully commit yourself to this journey. Doing so can have a profound impact on the life you’re helping to save — and your own.

An offer from a potential donor may come when you least expect it. On the other hand, a potential donor may not come forward immediately. Be patient and stay focused.

And you don’t have to do this alone when you enlist the help of Champion Partners. While not everyone can be a living donor, anyone can support your efforts to find a donor by becoming a Champion Partner.

Champion Partners can make a positive impact by:

- Becoming advocates.
- Sharing the recipient’s story.
- Helping in any way to find a donor.

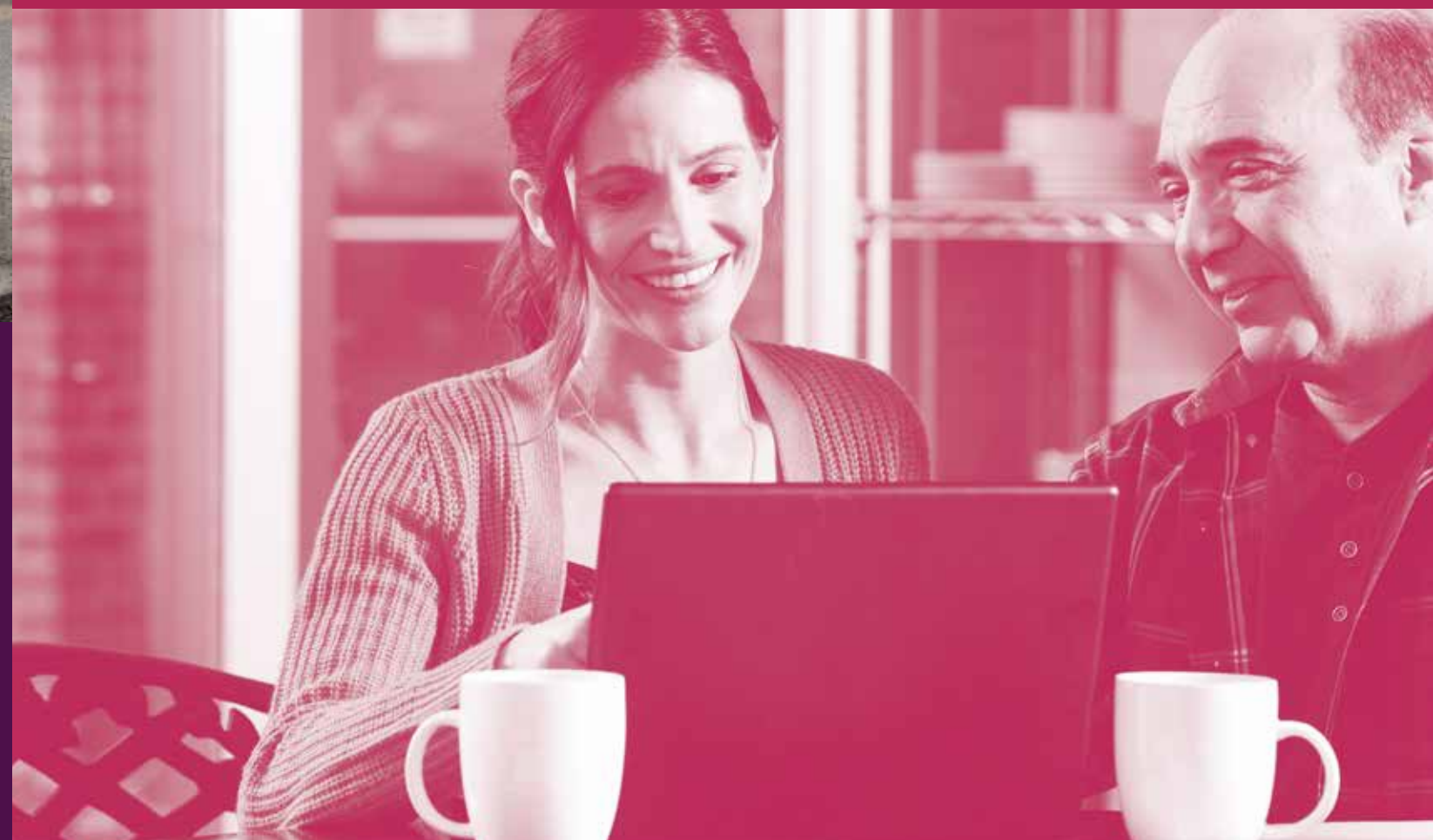
Step 3

Starting the Conversation About Living Donation



Linda and Chanty's Story

After years spent living with kidney disease and being on dialysis, Linda learned she was in severe renal failure and needed a transplant. But 17 months after that diagnosis, she was still waiting for a kidney. That's when her daughters decided to organize a kidney drive through their church — and 18 congregants volunteered. Parishioner Chanty turned out to be a perfect match. Seeing someone else willing to donate was all the encouragement she needed. "I was all in," says Chanty. Both women are doing well and since donating her kidney, Chanty has given birth to two children. "I'm fine and everything works just like it did before," she says.



“My husband’s kidneys failed at a young age, and he was on the transplant list for three years. A year and a half later, I decided I wanted to donate. I love and support him. I donated to give him a new life with our three young children. This transplant has been a blessing for our whole family.”

Buddhi Tamang



Bringing Up Living Donation

Asking someone to be a living donor is a highly emotional request for both the person in need and the kidney donor. For someone waiting for a lifesaving transplant, concerns might include stress or guilt about relying on others for help, the medical risks associated with it, or how he or she will feel if a potential donor doesn’t follow through with the screening process. Other concerns might involve the possible rejection of the organ, how to thank someone for being a living donor, or if there will be any impact on the relationship with the donor.

With that in mind, it might help if you shift your thinking when asking a potential donor. In other words, don’t simply ask someone to donate an organ. Rather, present the situation and offer the option of living donation. That’s why it’s important for you to have confidence in and a firm understanding of the transplant process. By answering questions honestly and directly, you can feel comfortable encouraging someone to consider becoming a living donor.

A good place to start is to make sure you have the information you need to share with potential living donors, including:

- **The person’s story and why help is needed.**
- **General facts and information about living donation.**
- **Photos of the person in need. Showing your loved one in a healthier state is a more positive way to convey why you’re doing this. Let people know that it is not too late to help.**
- **A contact list. Start with those who are closest to the person in need. Include a point person from UPMC Harrisburg Kidney Transplant Services who can answer questions.**
- **Begin by sharing your loved one’s story with people you are most comfortable talking to.**

It is likely the living donor will be someone familiar to you or your loved one. **But only about one in four people evaluated for living donation are eligible candidates.** That’s why it is important to talk with as many friends and family members as possible.



Step 4

Resources for Finding a Living Donor



Patricia and Pierre's Story

When Patricia learned a member of her church needed a kidney, she immediately felt called to become a living donor. Although the mother of three wasn't a match for Pierre, she donated through the paired exchange, or kidney swap, which matches an incompatible donor/recipient pair with another incompatible donor/recipient pair. "I am here today because of her generosity and bravery," says Pierre. Patricia, who has made a full recovery, urges other willing donors to remain on the waiting list even if they are found to be incompatible. "It can help others in need," she says.



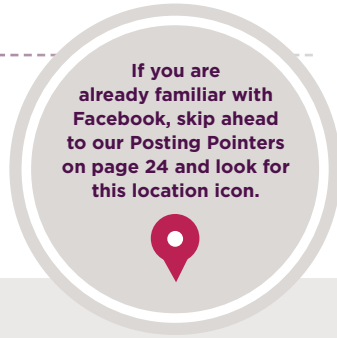
To be an effective Champion, you should use as many channels as possible to communicate the message. This section explains different resources to help you spread the word about your loved one's need broadly and more efficiently.

Social Media

While social media has long been a tool for sharing pictures or personal stories, it is also a growing resource for finding the help people need for serious life issues. Facebook is the most popular and effective social media platform for this type of request. We'll take a look at how that site can help you the most in your role as the Champion.

Creating a Facebook Page

If you don't have a personal Facebook profile, set one up. Don't worry, it's simple and free of charge.

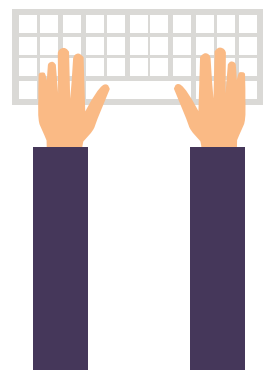


- 1 Go to www.facebook.com.
- 2 If you see the sign-up form, fill out your name, your email address or phone number, a password that you've created and will be able to remember, your birthday, and your gender. If you don't see the form, click **Sign Up**, then fill out the form.
- 3 Click **Sign Up**.

When it comes to your contact list, start with anyone close to the person needing a transplant — this may take a little digging.



Once you sign up, you'll need to confirm your email address or phone number. Facebook will then send you either an email or a text message to help you confirm your account. After your page is set up, you can begin requesting friends. We strongly suggest staying with family and friends you know and trust.



Creating a Group Page

If you don't want to use your personal Facebook page in your search for a donor, you can create a group Facebook page specifically for that purpose. Again, it's fairly simple and free of charge. Here's what you do:

- 1 Click the down arrow in the top right of Facebook and select **Create Group**.
- 2 Fill in your group name, those you want to add to your group, and then choose the privacy setting for your group.
- 3 Click **Create**.

Facebook remains a great way to get your message out to your connections, as well as anyone connected to your connections.

Making the Group Easy to Remember

Once you've created a Facebook group page, you can develop an easy-to-remember web address. To create a customized web address for a group that you manage:

- 1 Go to your group and click the ellipses (...) in the top right corner and then select **Edit Group Settings**.
- 2 Next to Web and Email Address, click **Customize Address**.
- 3 Enter an address for your group. The address can't have special characters and can only include letters, numbers, and a period (ex. FindPaulAKidney).
- 4 Click **Customize Address**. This will also create a customized email address that matches the web address.
- 5 If the address you choose is available, it will become your web and group email. If it's taken, you can choose a different address.

Please note: Once you customize your web and email address, you won't be able to change it.

Getting Started

Now that you've set up your Facebook page and know some of the tools that are there to help you, it's time to make your first post. This is when you'll first tell your loved one's story and ask for help. Here are a few tips for crafting a Facebook post, as well as some examples to help inspire you.

Whether you make this appeal through social media or in person, it should follow this outline but in your own style.

AN OPENING:	Convey your desire to start an important conversation and reassure the potential donor that they will not have to make any decisions as a result of it.
THE WHO:	Explain for whom you're making this request.
THE WHAT:	Provide a brief summary of the medical condition that is requiring this transplant.
THE WHY:	Offer the reason why a transplant is necessary.
THE WHEN:	Include a sense of urgency as well as how much time a living donor might need to invest.
A CLOSE:	Ask the potential donor to take the time to think about it, and if he or she is interested in helping, offer ways to contact you for more information.

If you're new to Facebook, keep in mind that the more you use it, the more comfortable you'll be with it. In other words, be patient with your own learning curve.

"Initial Appeal" Post

Group Name
 Okay, here goes — a life-changing request if there ever was any. You all know my dad, Paul. You may also know he has been very sick with kidney disease. Well, we just found out that he will need a kidney transplant. This was tough to hear, but he is hopeful and determined to beat this. We know it's a lot to ask, but would anyone be interested in learning more about being his living donor? Simply put, we need someone soon who is a match and is willing to donate a kidney in order to save his life. Please send me a private message if you would like to talk more or would be interested in helping.

"Update" Post

Group Name
 Hi everyone! Thank you for all the love and support. It certainly means a lot to our family. My dad is headed back to the hospital for some more tests, but his spirits are up. The search is still on for his living donor. A few people have been tested, but we have not found a match yet. Please reach out if you want to learn more and possibly help.

"Life Event" Post

Group Name
 We celebrated dad's 64th today. A great time was had by all. He's still in great spirits as the search for a living donor continues. He's even started talking about where to hold his 65th. Let's find someone to help make it happen. Now THAT would be the ultimate birthday gift.

"Found a Donor" Post

Group Name
 A match has been found! Thank you all so much for your help over the past few months. We are so excited. We are in the process of scheduling his surgery and will let everyone know how it goes.

Posting Pointers



The most important thing to remember when posting is to keep people emotionally invested. Be sure to create the content in your own style, always stay positive, and use these simple tips and tools when documenting this journey to help sustain interest in your story.

Posting Suggestions



Photos – Whether they're of fond memories or recent progress, people love them.



Motivational Posts – Keep everybody's spirits up, including yours.



Videos – More movement than photos and emotionally touching.



Personal Experiences – Share stories about what your loved one is doing beyond this challenge (vacations, good days, etc.) to show that there is so much more life to live.



Shares & Likes – “Share” or “like” someone else's story of a loved one in need and there's a good chance they'll do the same with yours. Also, don't be afraid to take the initiative and encourage people, in a friendly way, to like your page or share your posts.



Tags – Tell your story to more than just your friends. Tell it to your friends' friends.



Livestream – Talk to others and answer their questions (almost) face to face.



Responses – Show your appreciation to those who are participating to whatever extent in helping you to find a donor.



Hashtags – Create catalogues of this challenge so folks can easily find out what's going on.



Acknowledgements – Let others know how individuals have been there for you, no matter how large or small the deed.

How Often and How Long



2 to 3 posts per week – Less than that and people might lose interest. More than that and they may feel overwhelmed.



Keep it short – A post below 250 characters is great. A post below 80 characters is even better.

Note: Don't feel like you need to use all of these pointers. You can just stick to those with which you are most familiar.

Facebook Help Center

If you still have any questions or concerns that this toolkit doesn't cover regarding Facebook, the site has a comprehensive Help Center that covers most issues. Just go to the “down arrow” button on the right-hand side of the toolbar on your page, click on it, and scroll down to “Help.” From there, search for answers to questions or scroll down to “Visit the Help Center.”

Join Us on Facebook

Living Donor Champion Support Group

Another resource on Facebook is the Living Donor Champion Support Group. As a member of the group, you will:

- Learn more about living donation
- Meet and hear stories from other Champions
- Converse with patients on the transplant waiting list and hear from UPMC experts

Please visit [Facebook.com/groups/livingdonorchampion](https://www.facebook.com/groups/livingdonorchampion) to join the group.

UPMC & Donate Life: Living Donor Transplant Facebook page

Visit the **UPMC & Donate Life: Living-Donor Transplant** Facebook page for continuing education about living donation and to keep up to date with the UPMC Living Donor Program.

Recommendations for Security

To keep your privacy during this process, it's important to be selective about what you share. Here are some of the things you should avoid posting when using social media:

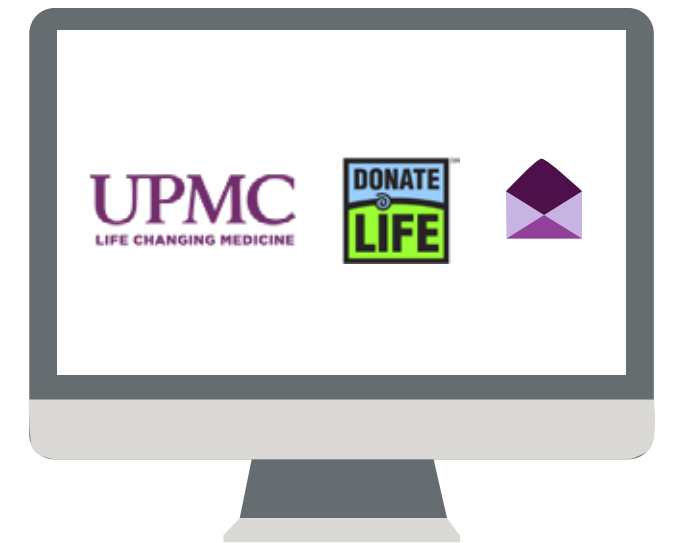
- Personal phone numbers
- Residential addresses
- Personal email addresses
- Family information
- Inappropriate photos
- Any other information that might be considered sensitive

Remember to be respectful of everyone's right to privacy. If there is any doubt about whether or not you should post something, always be cautious and don't post it.

Online Resources

While social media is an effective tool for finding information and getting the word out, it's not the only one you have. There are other tools inside the digital world that can help, including:

- [UPMC.com/CentralPaTransplant](https://www.upmc.com/CentralPaTransplant)
- [Donate Life America \(donatelife.net\)](https://www.donatelife.net)
- [Gift of Life Donor Program \(donors1.org\)](https://www.donors1.org)
- Email can help spread the word through people you know and is a good way to let people know about your loved one's need.



An additional benefit to using email is that you can create a specific address that directly relates to this journey (example: FindPaulAKidney.com). This can be beneficial in a few ways:

- It helps keep your personal email account private. You can provide this email to those trying to contact you instead of your personal one.
- It makes the process more manageable for you by not clogging up your personal or business email inbox.
- It can act as an avenue to and from Facebook.
- It's eye catching and easier for people to remember.
- It creates an official appearance.

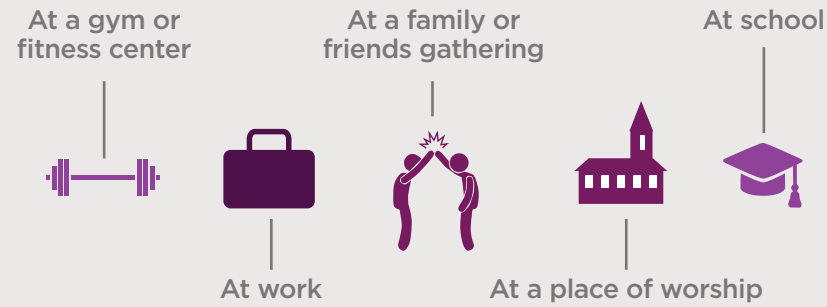
Nondigital Resources

Word of Mouth

Whether it's the occasional phone call with a family member or friend or bumping into someone you know at the grocery store, time spent with others is another opportunity to further the journey to find a suitable donor.

Social Groups

At regular meetings with a book club, recreational sports league, church or alumni group, and others who share a common connection, you can keep informed and up to date on what is happening with the person in need of the transplant. And be sure to talk with people you know or meet.



Nondigital mediums



- Local traditional media (i.e., television, radio, print, etc.)
- Pamphlets
- Business cards

UPMC Living Donor Information Session

As a Living Donor Champion, your job is to support the person in need of a kidney transplant throughout their journey and to take the lead in finding a suitable living donor.

Share your loved one's story by hosting a Living Donor Information Session in the community. You can invite family members, friends, and neighbors to learn about your loved one's need for a living-donor kidney transplant, the donation process, and the criteria for and steps to becoming a living donor.

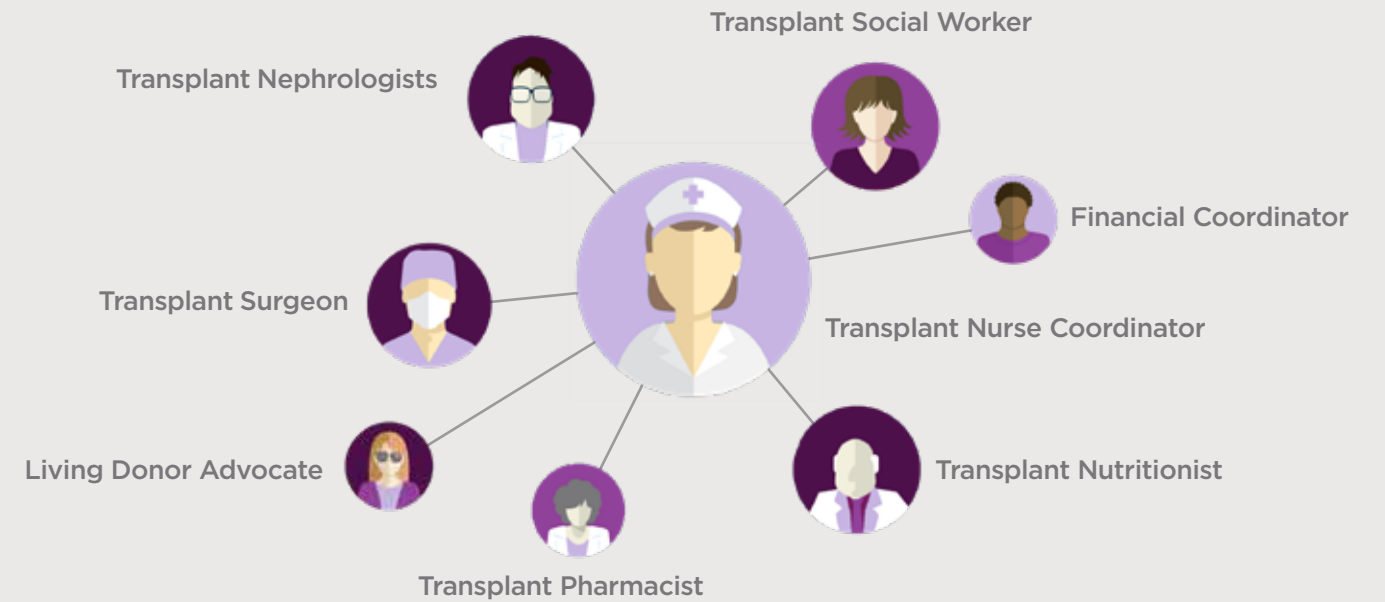
To help make your event a success, the UPMC Harrisburg Kidney Transplant Services team will provide:

- **Material to help plan and promote your event.**
- **Talking points and background information about living donor transplants.**
- **Information about how to register to become a living donor for anyone who would like to help.**

In addition, a member of the UPMC Harrisburg Kidney Transplant Services team will attend your event to provide education and answer questions about the living donation process.

For more information, call UPMC Harrisburg Kidney Transplant Services at **877-778-6110**.

The Living Donor Transplant Team



Being a Champion for a loved one is a rewarding but potentially difficult process. We hope this toolkit is a useful resource in helping you find a living donor for your loved one.

Stay positive all along the way — and never stop sharing their story!

Five Tips for Speaking With Your Local Media About Living Donation



As you begin sharing your story and speaking to your community about living donation, you may catch the attention of local media. Sharing the need for a living donor with local media can be an effective way to raise awareness of living donation and to identify a potential donor.

The media — including print newspapers, local TV stations, radio shows, documentaries, and online outlets — will report your story without charging you.

To work effectively with your local media, keep in mind these **five tips**.



1 Reach Out to Local Outlets

To engage with local media, the first step is to find someone to contact. There's no standard method of contact, but there are a few typical routes:

- Find a local outlet's contact page and call either their general contact number or their tip-line number.
- Perform an internet search for living donation stories from your local media and write down names of the reporters and their organizations. On the organization's website, find contact info for that reporter and send an email or give them a call.
- If you have a friend who had a similar story covered in local media, ask for the contact information of the reporter who wrote/covered the story.

Many reporters are actively searching for local stories and will likely be receptive to your call or email.

2 Do Your Research

When a reporter contacts you, ask some background questions before agreeing to an interview. You'll want to know their name and organization, what kind of news they typically cover, and the type of story they are working on. Your goal is to understand the perspective they will take in the story. If they give an answer that you do not understand, ask follow-up questions for clarification.

Finally, ask when they plan to print or air the story and what they need from you. Knowing the answers to these basic questions will help you take full advantage of this opportunity and develop a relevant message.

3 Prepare and Practice Your Message

Excluding social media, there are three main types of media outlets: print, TV, and radio. Each type takes a different form and has a different audience, requiring different messages.

For print pieces, remember to speak clearly and slowly. People are going to be reading your quotes, so it's best to slow down and say precisely what you mean. On TV, speak in short sentences, keep your demeanor positive, and pay attention to your appearance since people will be able to see you. On radio, your audience only hears your voice so be sure to speak clearly and to keep complex information to a minimum.

Before you participate in an interview, write down two or three short, clear sentences that convey the key points you want your audience to understand. Practice saying these points out loud but don't memorize them. You want to come across as natural as possible.

Emphasize the main points you wrote down by using language that focuses the listener's attention, such as:

- What's important is ...
- The main message I want to communicate is ...
- The reality is ...

4 Only Answer Questions You Feel Comfortable Answering

As reporters develop questions for interviews, they try to be as thorough as possible. Because of this, they may ask questions you feel uncomfortable answering, questions that feel too personal for you or your loved one, or ones that are too technical.

If you don't know the answer to a question, be honest about it. Don't be afraid to decline to answer. When answering any question, remember to speak only for yourself.

5 Share Your Story

Once the reporter has completed your story and posted it online as an article, video, or sound clip, treat it as a new opportunity to share your story through social media. Post a link to it on your Facebook page with a caption that thanks the reporter for helping to share your loved one's story and the need for a transplant. Tell the story at work, in social settings like school and church, and anywhere you want people to hear your loved one's story.

It's possible that a local media story will be the push you need to find your loved one a living donor.

For general inquiries about living donation, members of the media may contact UPMC Media Relations by email at mediarelations@UPMC.edu or by calling **412-647-3555** during business hours.



Help is here.

For information about the living-donor Champion program at UPMC Harrisburg Kidney Transplant Services or to download a pdf of the Champion toolkit, visit [UPMC.com/CentralPaTransplant](https://www.upmc.com/CentralPaTransplant).

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