

A Toolkit for Champions

How to Find a Living Kidney Donor



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

UPMC | HAMOT





Kidney Transplant Services at UPMC Hamot

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 the field.

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 help you through the transplant process.

To learn more about kidney transplant at UPMC Hamot or to schedule an appointment, call **844-426-6822** or visit **UPMCHamot.com/KidneyTransplant**.

UPMC Hamot
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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 Hamot created this booklet to explain the critical role you will play as a Champion. It also includes the information you need to 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 Hamot



Courtney and Matthew's Story

Courtney drove 10 hours from her home in North Carolina to donate one of her kidneys to her older brother, Matthew, at UPMC Hamot. At age 25, Matthew experienced high blood pressure and blurry vision. He was diagnosed with an autoimmune disease, and his kidneys never recovered. After transplant, the siblings recovered together at Matthew's home. Matthew is back to work and feels grateful that his sister's generosity enables him to spend time with his family.





“Now, I spend a lot of time outdoors and can do physical labor at my job that involves roadwork. I can’t thank Courtney enough for giving me the chance to live a full life and to be able to spend time with my family.”

Matthew

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 kidney transplant, 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 in need of a transplant. Having a living kidney donor can help avoid what is typically a five-year wait for a kidney from a deceased donor.

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 donor transplant:

- 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.

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.

- 1** Surgeons insert a mini camera — called a laparoscope — into the abdomen through tiny incisions.
- 2** The camera allows them to visualize and locate the kidney before removing it through a relatively small incision (about 3 inches).
- 3** The entire operation takes around 3 hours.

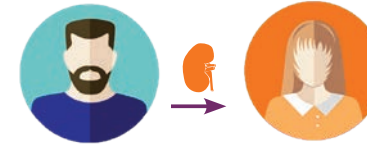
Recovery for Living-Donor Kidney Transplant

Most kidney donors spend one or two days in the hospital. Our kidney transplant team at UPMC Hamot 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.**

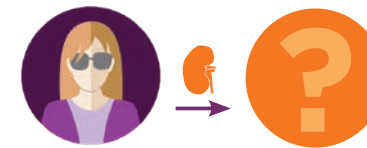
3 Types of Living Donation

There are three categories of living donation:

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

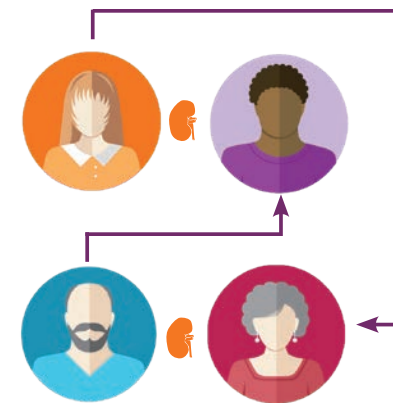


- **Nondirected Donation:** When the donor is neither related to nor known by the person in need, the recipient is determined primarily by medical compatibility.



- **Paired Exchange Donation:** For a kidney transplant to be successful, the donor and recipient must have compatible blood types. 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

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



High blood pressure



Cancers or other diseases that could complicate the surgery



Diabetes



Heart disease

Anyone who is interested in becoming a living donor can register at livingdonorreg.upmc.com/Hamot

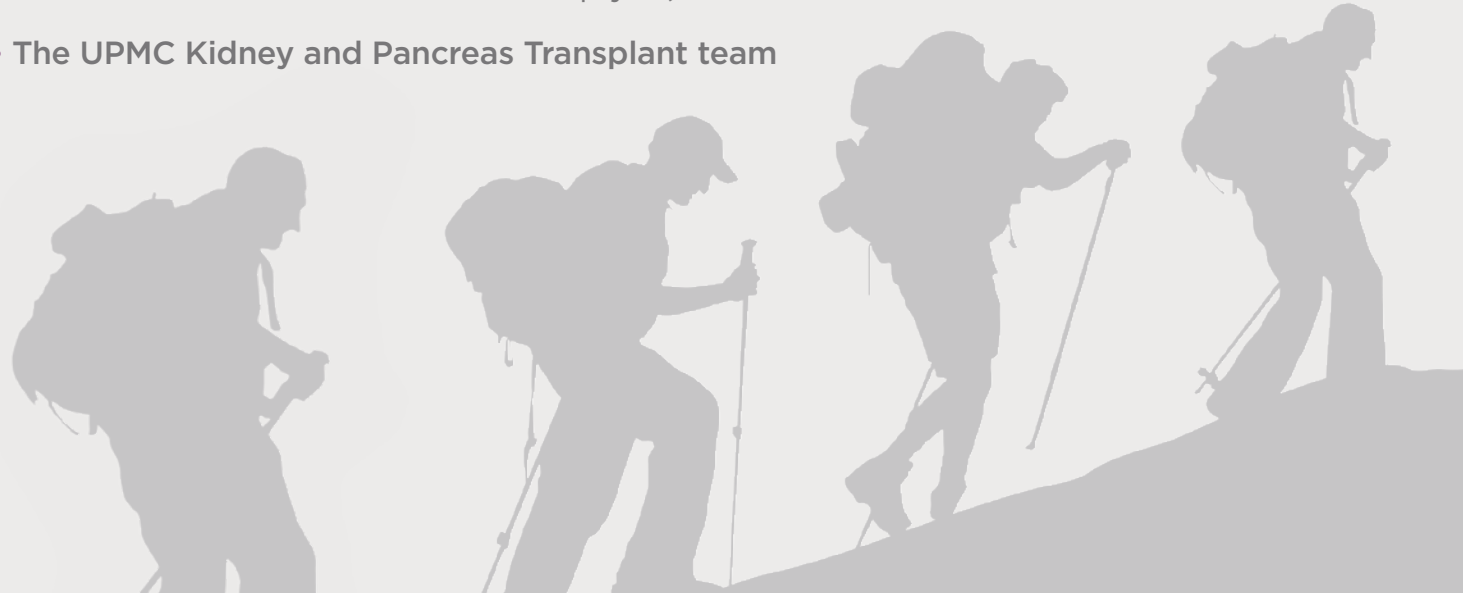
Motivation



The main reason for donating must be an unselfish desire to help a person in need. It is illegal to buy or sell organs.

As a living 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 and Pancreas Transplant 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.



Step 3

Starting the Conversation About Living Donation

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, every moment is critical. Many people will want to support this person's journey. But it is the Champion who plays the most crucial role, which includes:

- **Spreading the word about living donation, and always including the website where potential donors can register.**
- **Offering ongoing support and motivation for the person waiting for a transplant.**
- **Reaching out to as many people as possible to help find a 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.**



Bringing Up Living Donation

You don't need to ask anyone to donate a kidney. 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 life-saving 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 speaking with others about living donation. 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. Instead of asking others for a kidney, share it as an update. Consider using a script like this: 'My dad needs to have a kidney transplant, and his best option is to find a living donor. Please help me to spread the word. Anyone interested should register at livingdonorreg.upmc.com/Hamot'.

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 Hamot 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



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.

If you are already familiar with Facebook, skip ahead to our Posting Pointers on page 20 and look for this location icon.



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:

Always include the recipient's full first and last name, along with the donor registration site, livingdonorreg.upmc.com/Hamot.

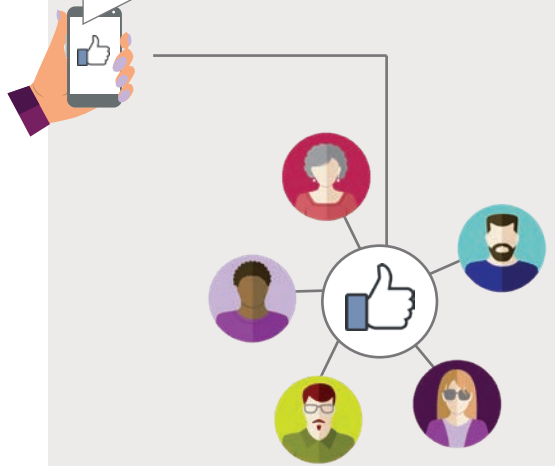
If you're new to Facebook, keep in mind that the more you use it, the more comfortable you'll be with it. In other words, be patient with your own learning curve.

“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. Anyone interested in living donation should sign up to donate to Paul Smith at livingdonorreg.upmc.com/Hamot. Please help us to share this message!

Like Comment Share

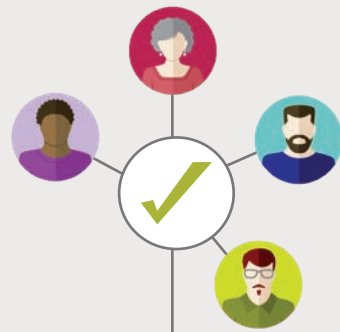


“Update” Post


 **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 continue to share that interested donors should register for Paul Smith at livingdonorreg.upmc.com/Hamot.

Like Comment Share

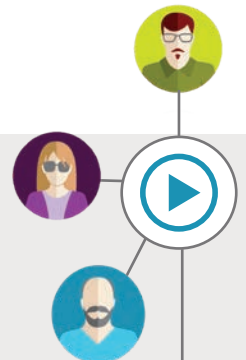


“Life Event” Post

 **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. Anyone interested in living donation should sign up at livingdonorreg.upmc.com/Hamot and enter Paul Smith as the recipient.

Like Comment Share



“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.

Like Comment Share



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:

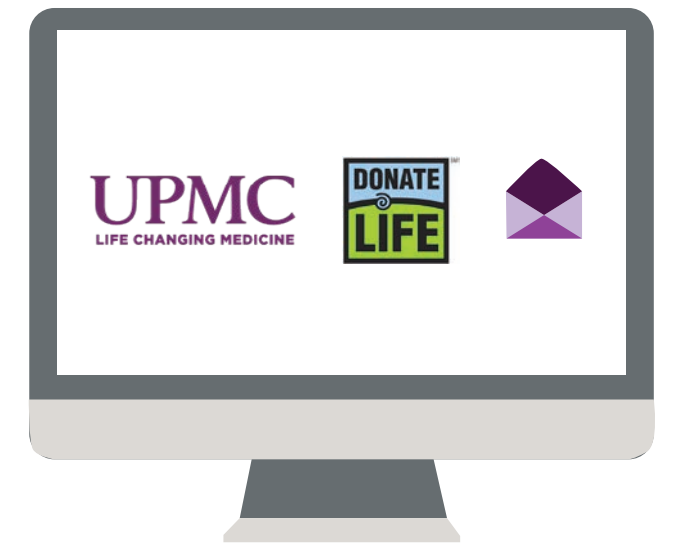
- Personal phone numbers
- Residential addresses
- Personal email addresses
- Family information
- Inappropriate photos
- Any other information that might be considered sensitive

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:

- [UPMCHamot.com/KidneyTransplant](https://www.upmchamot.com/KidneyTransplant)
- [Donate Life America \(donatelife.net\)](https://www.donatelife.net)
- [Center for Organ Recovery and Education \(CORE.org\)](https://www.core.org)
- Email and text messages can help spread the word through people you know and are good ways 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.

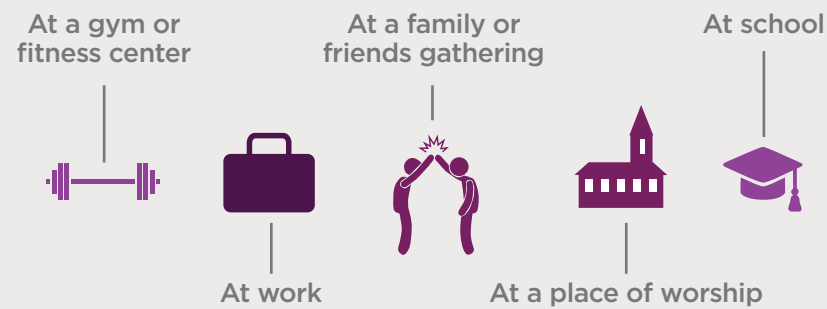
Nondigital Resources

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, religious or alumni group, and others who share a common connection, you can keep people 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
- Yard signs
- T-shirts
- Car magnets
- Tote bags

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 encourage others to register as living donors.

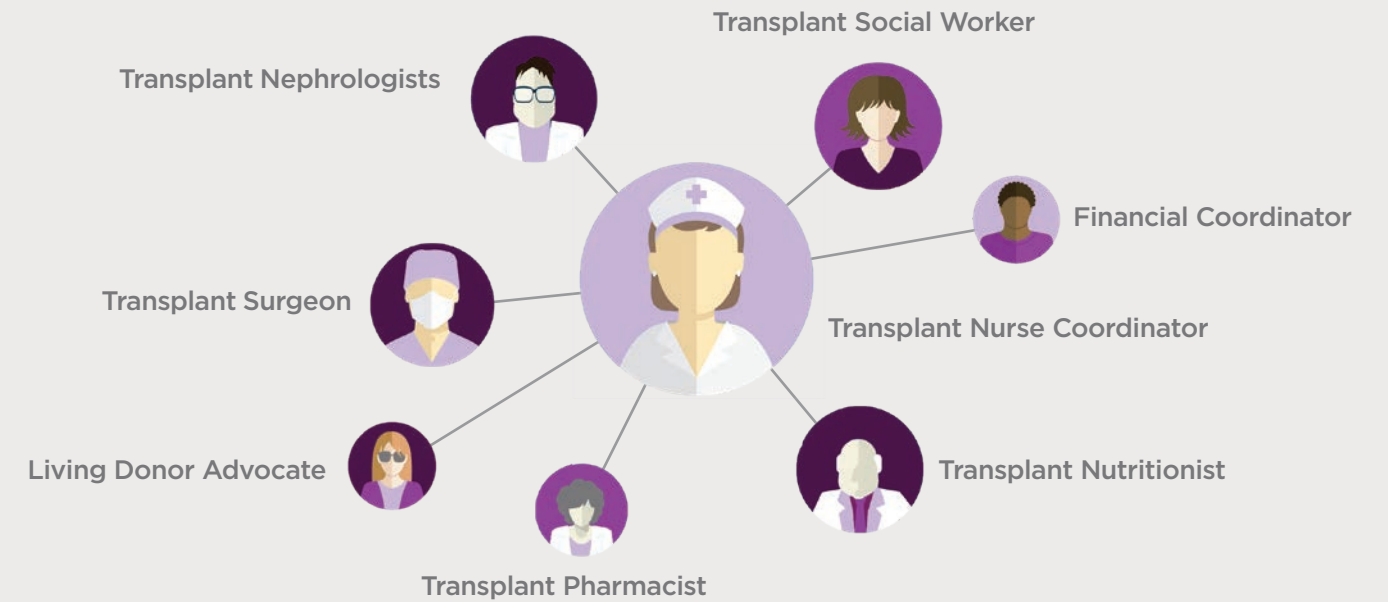
Share your loved one's story by hosting a Living Donor Information Session in the community. You can invite family members, friends, and neighbors to learn about your loved one's need for a living-donor kidney transplant, the donation process, and the criteria for and steps to becoming a living donor.

To help make your event a success, the UPMC Hamot 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.**

For more information, call UPMC Hamot at **844-426-6822**.

The Living Donor Transplant Team



Being a Champion 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 (newspapers), 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. Be sure to include the spelling of the recipient's first and last name, as well as the living donor registration site so the audience can take action. Anyone interested in becoming a living donor should sign up using the recipient's name at livingdonorreg.upmc.com/Hamot.

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 Hamot or to download a pdf of the Champion toolkit, visit **UPMCHamot.com/KidneyTransplant**.