

Living Donor

A Social Media Toolkit for Champions

A journey you don't make alone.



UPMC
LIFE CHANGING MEDICINE





About This Toolkit

Finding a living donor is a journey. This lifesaving procedure is made possible in part by advancements in medicine. But every procedure depends on the compassion of people who are willing to share their lives to save those in need.

This booklet will act as a guide to understanding living donor transplants. Not only does it cover how the process works, it takes a closer look at the role of an often overlooked, but highly important participant in this lifesaving journey — the Champion.

The Benefits of a Living Donor Champion

A Champion may be a friend, family member, coworker, or anyone else who is willing to provide emotional support for someone on the transplant waiting list.

Asking someone to become a living donor is a challenge and can be an overwhelming task. With the help of a living donor Champion, finding a donor becomes more manageable.



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Step 1

Understanding the Living Donation Process



Jeanne's Story

When Jeanne's husband underwent a living-donor liver transplant, she was by his side throughout the entire process. A few years later, a friend called her looking for advice, as her husband needed a kidney transplant. Jeanne knew immediately that she wanted to help her friend, especially since she knew how difficult it was to see someone go through it. She scheduled her pre-donation evaluation and was determined to be a medical match. After a successful surgery, Jeanne felt even better, knowing she saved someone's life the same way someone saved her husband's life. And all it took was one phone call.



*“But honestly,
I just could not imagine
not helping her, and I
knew she would do the
same for me.”*

Jeremy Monteverde

Donor for his mother, Kathy



Learning about Living Donation

Many people on the liver or kidney transplant waiting list think that they must remain on the transplant waiting list until a deceased donor organ becomes available. But, there is another option: living donation.

As a Champion for a loved one, you will need to know as much about the procedure as you can. We'll start with the basics and dive a little deeper with both liver and kidney transplants.

Living-Donor Liver Transplant

There are thousands of people on the waiting list for a liver transplant. Unfortunately, many people waiting on the list won't receive a transplant in time because there are not enough deceased-donor livers available.

Because the liver can regenerate, or regrow, living-liver donation is possible — and a lifesaving alternative to waiting on the list.

Living-Donor Kidney Transplant

Advances in surgery and care allow people to donate a kidney to help relatives, friends, or even strangers in need of a transplant. Having a living-kidney donor can help a patient avoid the typical wait times of up to several years for a suitable kidney.

Kidney transplants are also made possible through kidney donor chains. A chain starts with an altruistic donor and has the potential to save and improve the lives of people facing kidney failure.

Benefits of Living Donation

There are benefits for both the recipient and the donor.

For the recipient:

- Increases the existing overall organ supply, helping to save more of the men, women, and children who are currently waiting for lifesaving transplants.
- Reduces the time on the waiting list.
- Shortens the time on the waiting list for other people in need.
- Improves odds of long-term recovery by allowing the surgery to be performed before the condition worsens, 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.

For the donor:

- Provides the opportunity to save a life.
- Gives the opportunity to contribute to the recipient's life — and the lives of the recipient's loved ones — in a very meaningful and lifelong way.

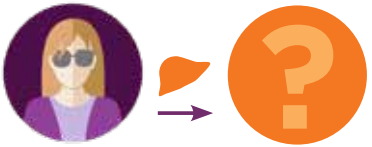
Types of Living Donation

There are three categories of living donation:

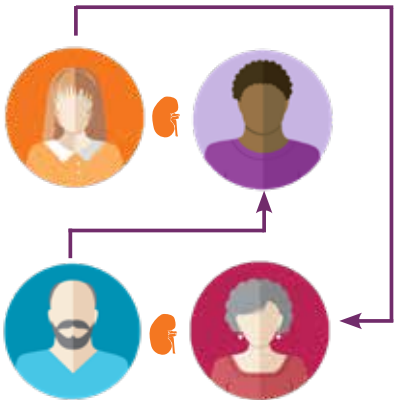
- **Directed Donation:** This is when the donor specifically chooses who will receive their living donation.



- **Non-Directed Donation:** This is when the donor is neither related to nor known by the person in need. He or she makes the donation purely out of selfless reasons. The recipient is determined primarily by medical compatibility.



- **Paired Donations (Kidney Only):** This involves at least two pairs of living-kidney donors and transplant candidates who do not have matching blood types. The transplant candidates “trade” donors so that each recipient receives a kidney from the donor with a compatible blood type.



If the UPMC Transplant Selection Committee has medically approved a person for a liver or kidney transplant, he or she should begin talking to family and friends about living donation. The transplant process can start when a potential donor contacts a living donor transplant nurse coordinator. The coordinator will then gather information about the potential donor and answer questions. The evaluation is then scheduled for the donor candidate over the course of a few days.

Requirements of Living Donation

To be an ideal organ donor, a person must meet the following criteria:

Age



18-55
years old



18-69
years old

Health

The person must be in good general health and have no history of:



Liver disease



Heart disease



Diabetes



HIV



Cancers or other diseases that could complicate the surgery

It's important to note that recovery times may vary.

If someone is unsure if he or she qualifies as a living donor, the transplant team can help determine if that person would be a good match.

Motivation



The main reason for donating must be an unselfish desire to help the person in need. There is absolutely no financial compensation that can come as a result of it.

What Happens During a Living-Donor Liver Transplant

During a living-donor liver transplant, a portion of the liver from a healthy donor is removed and transplanted into the recipient.

The potential donor is carefully evaluated before the surgery to determine if he or she can tolerate the operation, and if the one in need will benefit from the donor liver. The evaluation includes:

- Physical and psychological exams for potential donors
- Blood work
- Additional tests

Liver Transplant Process

Here's what to expect:

1

The surgeon will remove 25% to 65% of the donor's liver.



2

The recipient's unhealthy liver will be replaced with a portion of the donor's healthy liver.



3

The donor's liver regenerates.



The recipient's liver regenerates.





The coordinator or surgeon will be able to provide more details about a candidate's specific surgery.

The need for living-liver donors is a big one. 30 million Americans have some form of liver disease.



 = 1 million people

Recovery for Living-Donor Liver Transplant

The liver is one of the few organs that can regenerate. It usually takes about eight to ten weeks for it to grow back to full size. The full recovery of the donor generally takes a few months before he or she is back to his or her previous level of health. **However, it's important to note that recovery times after living-donor liver transplants may vary.**

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What Happens During a Living-Donor Kidney Transplant

During a living-donor kidney transplant, a healthy kidney from a living donor is removed and transplanted into someone with a failing kidney. Often, a kidney transplant can be done through minimally invasive surgery. In most cases, living-donor kidney surgery is conducted with the help of a mini camera.


Prior to transplant surgery, both the donor and person in need undergo a thorough evaluation to determine if a living-donor kidney transplant is the best option. While living donation reduces the recipient’s time on the transplant waiting list, it may not be an appropriate treatment option for everyone.

Kidney Transplant Process


Here is what to expect during this minimally-invasive kidney surgery:

- 1


Surgeons insert a mini camera — called a laparoscope — into the abdomen through tiny incisions.

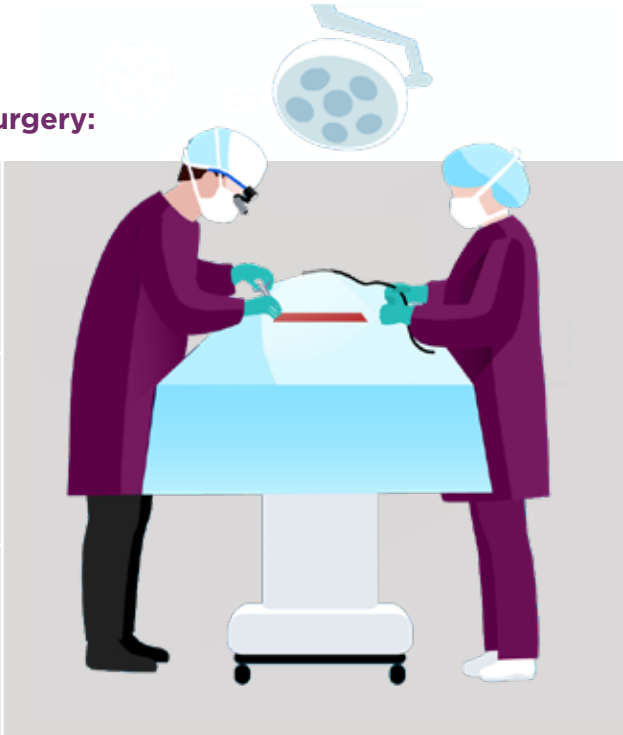

- 2

The camera allows them to visualize and locate the kidney before removing it through a relatively small incision (about three inches).


- 3

The entire operation takes around three hours.





Recovery for Living-Donor Kidney Transplant

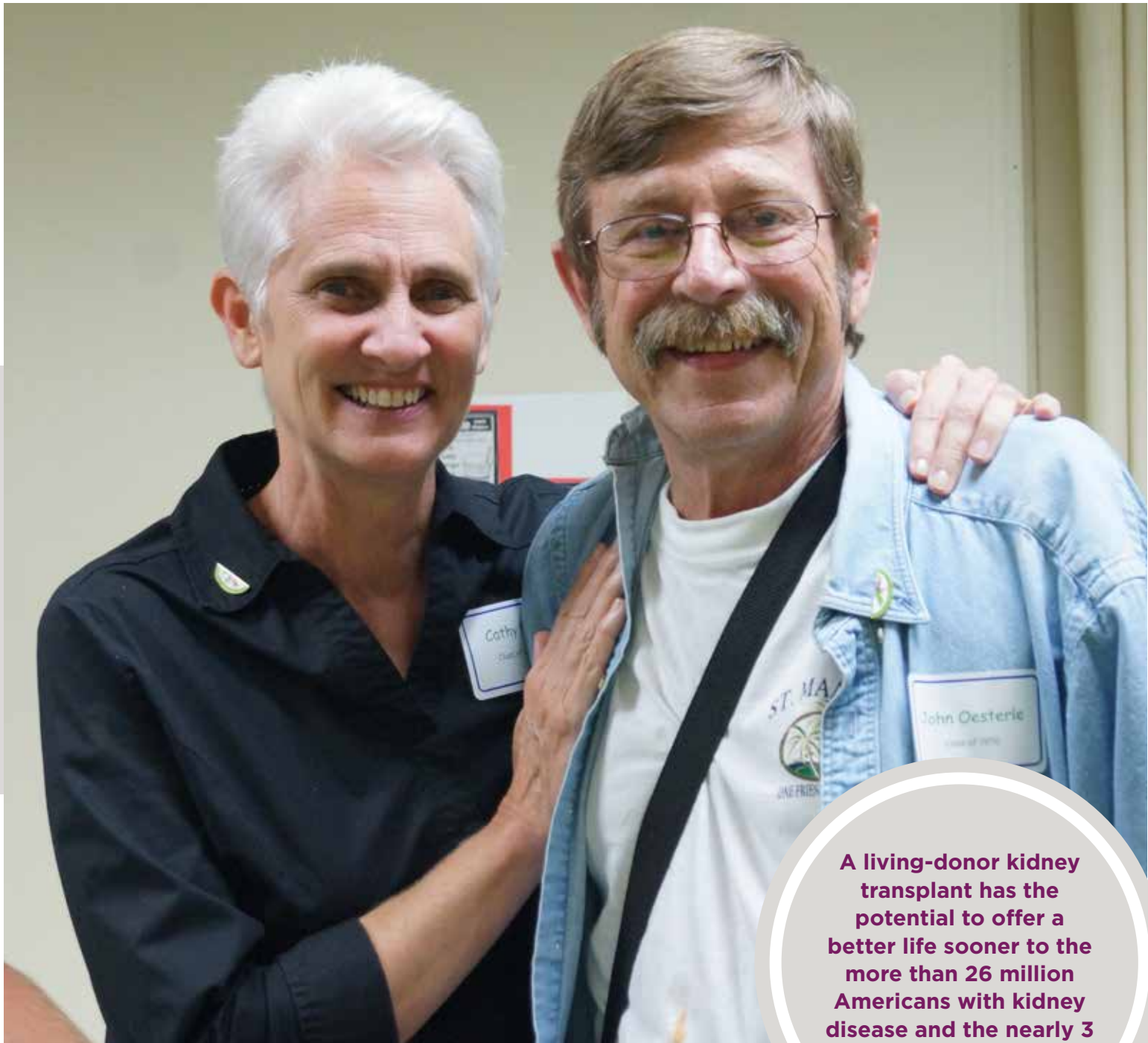
Most kidney donors spend a few days in the hospital to recover. However, we understand that everyone recovers differently, so our kidney transplant team works with each donor to provide a personalized treatment plan that meets their needs after surgery. The full recovery of the donor typically takes a few months before he or she is back to his or her previous level of health and can go back to work. But again, it’s important to note that recovery times after living-donor kidney transplants may vary.



Living donation is not as rare as you might think.

47%

of all transplanted organs in the U.S. are from living donors.



A living-donor kidney transplant has the potential to offer a better life sooner to the more than 26 million Americans with kidney disease and the nearly 3 million who may have type 1 diabetes.

John and Cathy’s Story

Best friends for more than 50 years, John and Cathy have always been there for each other. That friendship culminated in 2014 when John needed a kidney transplant and Cathy wanted to help. Today, their bond is stronger than ever. As for John, he is focusing on giving back to those who helped him along the way by spreading awareness of living donation and raising funds to support transplant research.



You'll need to be mindful of everyone who is on this living donation journey. They include:

- The person waiting for a transplant
- The donor
- The caregiver (if he or she is someone other than you)
- Champion partners (family, friends, and others who volunteer their time and effort in helping you)
- The UPMC Living Donor Transplant Team



Kathy and Jeremy's Story

As mother and son, Kathy and Jeremy have always been close. So after they learned she would need a liver transplant, he didn't think twice. Luckily, he was a perfect match. A few months later, Kathy was able to stand by Jeremy's side and dance with him at his wedding. Today, the two have recovered from the transplant and are doing well. Both also believe that more people need to be aware of living donor transplants.

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 2

Why You're On This Journey



“People are always looking for the miracles, but what if we are the miracles?”

Courtney Bost

Living donor for her husband



The Champion

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

Simply put, when a loved one is waiting for a transplant, his or her life hangs in the balance, and the road to recovery may be difficult. While there will be many who will be critical to this person's survival, it is you, the Champion, who will take on perhaps the most crucial role. A Champion's role includes:

- Finding a living donor
- Offering support and motivation for your loved one waiting for a transplant
- Reaching out to as many people as possible to find a suitable living donor
- Providing direction and motivation throughout the journey

The Champion is so vital to the person in need of a transplant because:

- The person in need of a transplant is often too sick — and in the case of a child, too young — to take on this task and must concentrate on staying as healthy as possible.
- Without a donor, the patient is unable to receive a transplant in a timely manner and his or her health will continue to deteriorate.

Your task as the Champion will be to spread the word as far as you can and to reach as many eyes, ears, and, above all, hearts as possible.

It will require you to keep an open mind, since an offer from a potential donor could come when you least expect it. On the other hand, you may also need to be patient, as a potential donor might not immediately come forward.

Remember that not everyone will be able to be a living donor. However, everyone can still contribute greatly to this journey by becoming a Champion partner. And not only can they still help, they may want to help. Some of the ways they can continue to make a positive impact on behalf of your loved one include:

- Becoming an advocate
- Sharing their story
- Helping the person in need and/or you with anything involved in finding a donor

In other words, being a Champion for someone in need can be a challenge. So, you should be prepared to fully commit yourself to this journey. However, doing so could have a profoundly positive impact not only on the life you're helping to save, but on yours as well.

Frank and Erica's Story

What would you do for a loved one who was in need of an organ transplant? How far would you go? For one daughter, the answer was simple.

Former DEA agent, Frank, was suffering from end-stage liver disease and needed a lifesaving liver transplant. After being placed on the liver transplant waiting list, he and his wife were introduced to the UPMC Living Donor Champion Program. As a loving father and husband, Frank was hesitant to ask anyone to make the sacrifice and become his living donor. After learning more about living donation, he decided to talk to his family about it.

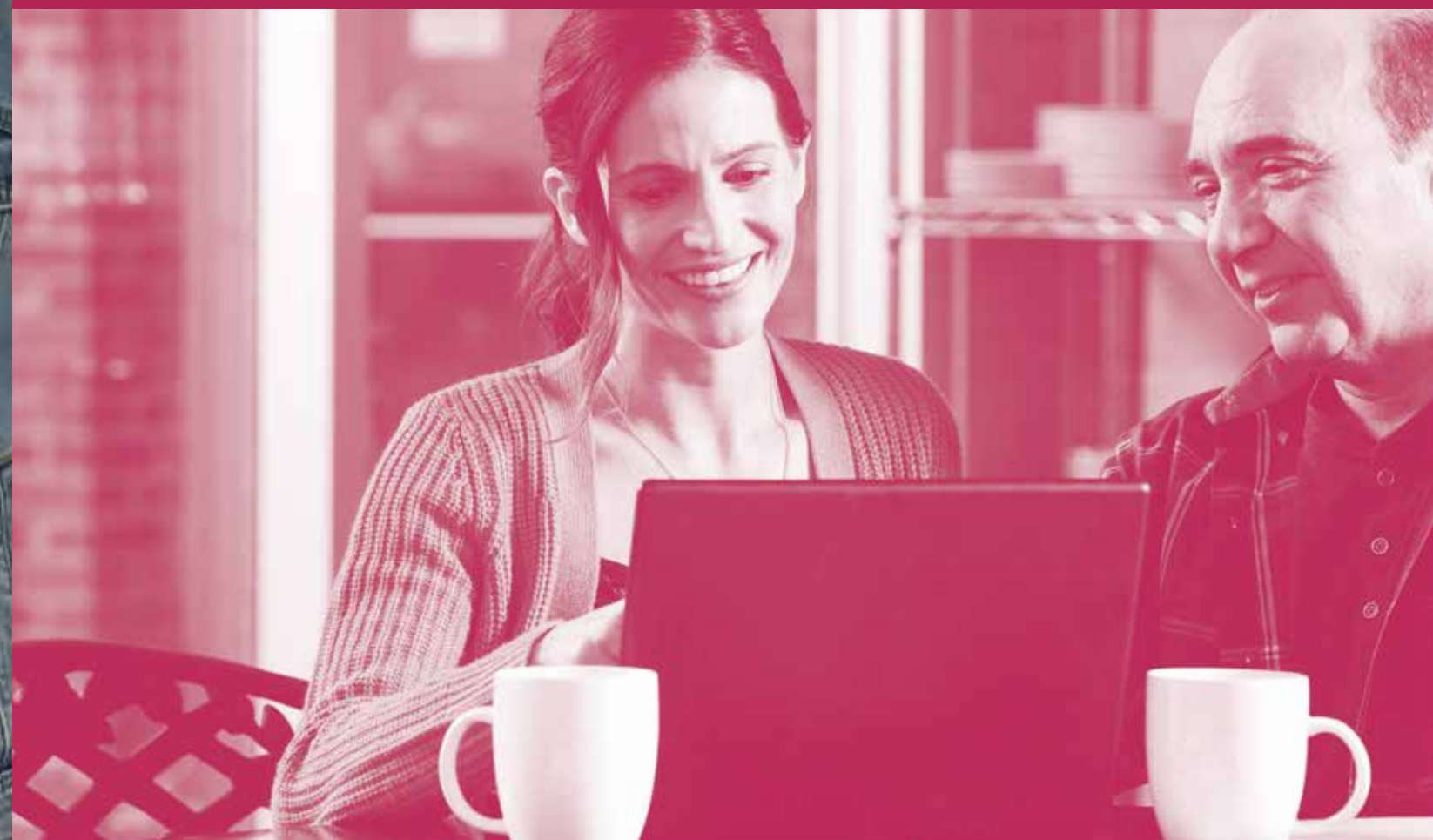
His daughter, Erica, couldn't imagine losing her father. When she learned that she could donate part of her liver, she immediately jumped at the chance to save his life, essentially telling him she would do it no matter what.

After a successful living-donor liver transplant, Frank and Erica are both back to their healthy and active lifestyles. Without the UPMC Living Donor Champion Program, Frank never would have asked a family member to donate to him, but now he and Erica share something that brings them even closer together than before.



Step 3

Starting the Conversation About Living Donation



“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



Bringing Up Living Donation

Asking someone to be a living donor is a highly emotional request for both the person in need and the 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 possibly 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 up the option of living donation. Having knowledge of the process, as well as the answers to the questions that others might have, will help instill confidence when talking to others about becoming a living donor.

A good place to start is by making sure you’ve assembled all of the information you will need to share with potential donors in order to find a living donor. This includes:

- The person’s story and why he or she needs help.
- His or her blood type.
- 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 reliable contact list. Start with the people closest to the person in need. Also include a point person from the transplant center to handle any questions you might have throughout this journey.

It’s a good idea to start by sharing your loved one’s story with people you both feel comfortable talking to.



Joe and Barb's Story

Joe suffered from elevated liver enzymes and needed a lifesaving liver transplant. His wife, Pam, wanted to help him find a living donor, but didn't know how to begin. After attending a Living Donor Champion Workshop to learn about the best way to find a donor, she set up a Facebook page to spread Joe's story as far as she could.

That page caught the eye of his cousin, Barb. She lived four hours away and had three boys but still traveled from her home in Virginia to be evaluated as a potential living donor.

After a successful living-donor liver transplant, Joe was back to his active lifestyle of kayaking and fishing within a few months. Barb is thankful for the Champion Program giving Joe a chance to get his story out there, allowing her to step up and save his life.

Since only about **one in four people** evaluated for living donation are eligible candidates, it's important to talk with as many friends and family members as possible.



Chances are the living donor will come from someone who is familiar to you and your loved one rather than from someone who isn't.

Step 4

Resources for Finding a Living Donor



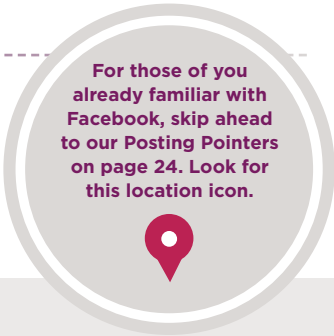
To be an effective Champion, you'll need to use as many channels as possible. This section will explore different resources that can help you spread the word about your loved one's need further and more efficiently.

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 some of life's heavier issues. The most popular and effective social media platform regarding this type of request is Facebook. 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, you'll need to 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 . |



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 you start with, and keep to, 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 . |



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. FindPaulALiver). |
| 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 one, 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 include the reassurance to the potential donor that he or she 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 liver cancer. Well, we just found out that he will need a liver 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 piece of his or her liver 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.

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 reach out if you want to learn more and possibly help.

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.

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.



Videos – More movement than photos – and possibly more moving.



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.



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



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



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



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.



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.



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



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

250
↓
80

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. 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.”

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/LivingDonorTransplant](https://www.facebook.com/LivingDonorTransplant) to join the group.

UPMC & Donate Life: Living Donor Transplant Facebook page

Visit the **UPMC & Donate Life: Living-Donor Transplant** Facebook page to learn more about what living donation means and connect with others who have gone through, or are currently going through, the same situation as you and your loved one.

Recommendations for Security

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

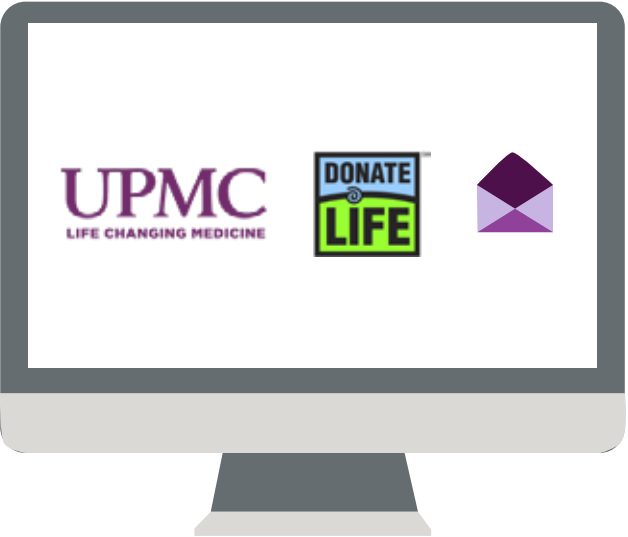
- Personal phone numbers
- Residential addresses
- Personal email addresses
- Family information
- Inappropriate photos
- Any other information that might be considered sensitive

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

Digital 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 others inside the digital world that can help, including:

- [UPMC.com/LivingDonor](https://www.upmc.com/LivingDonor)
- The Donate Life America website, [DonateLife.net](https://www.donatelife.net)
- The Center for Organ Recovery & Education (CORE) website, [CORE.org](https://www.core.org)
- Email – This can help spread the word through specific people you know. Addressing people through email is a way to guarantee that they’ll at least 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: FindPaulALiver@____.com). This can be beneficial in a few ways:

- It helps keep your personal email account private. You can provide that 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.

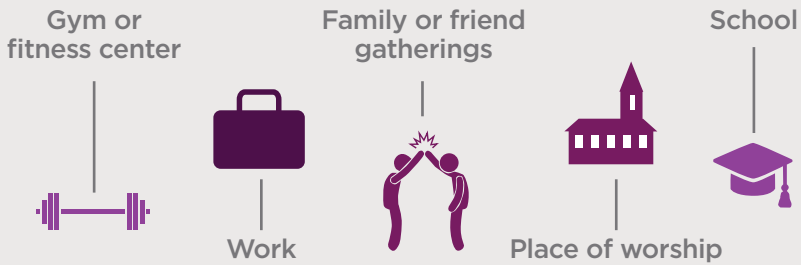
Non-Digital Resources

Word of Mouth

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

Social Groups

Regular gatherings, such as book clubs, recreational sports leagues, church groups, alumni groups, etc., keep those with whom you share a common connection informed and up-to-date on what is happening with the person in need of the transplant.



Non-digital 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 provide support for the person in need throughout the entire journey and to take the lead in finding and securing a suitable living donor.

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

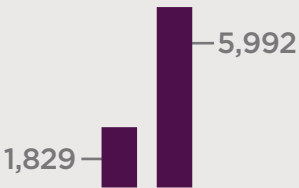
To help make your event a success, the UPMC Living Donor Transplant team will provide:

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

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

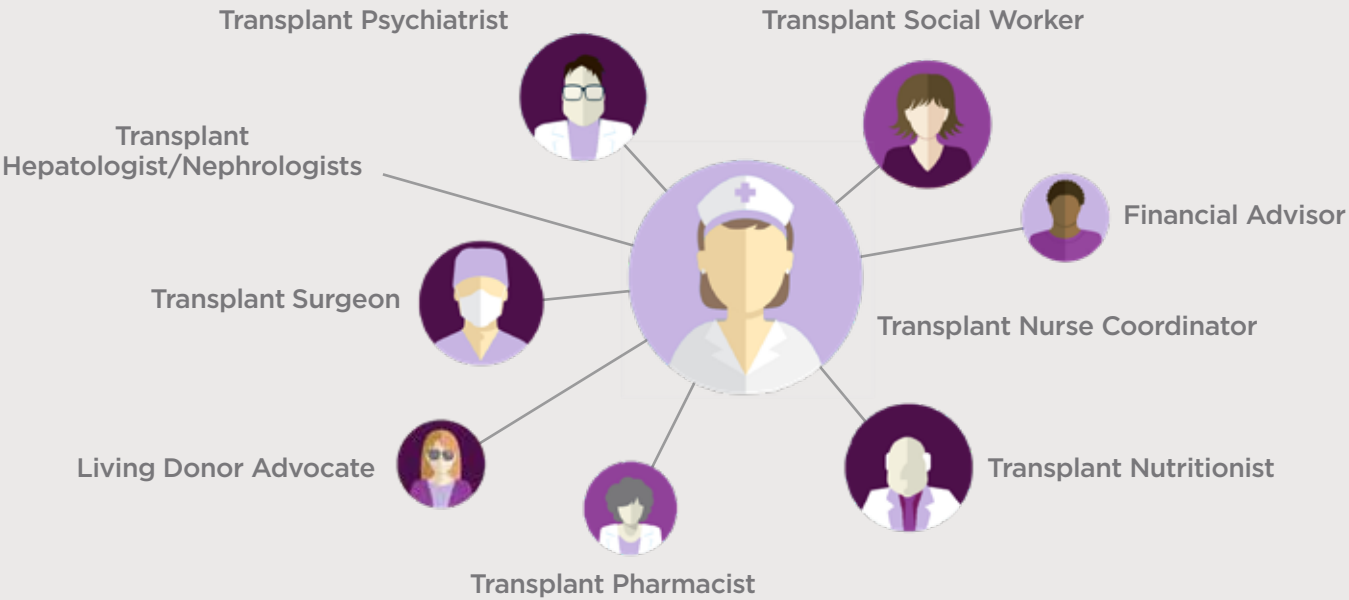
For more information, visit [UPMC.com/LivingDonorCommunity](https://www.upmc.com/LivingDonorCommunity).

In 1988, there were only 1,829 living donations performed in the U.S. By 2015, that number had grown to 5,992.



Source: Health Resources and Services Administration, U.S. Department of Health & Human Services

The Living Donor Transplant Team



Champion Ambassador

As you and your loved one are working to understand the living donation process and identify a living donor, you are also welcome to work with UPMC's Living Donor Champion Ambassador, Donya McCoy.

After becoming a Champion for her daughter Kennedy, Donya now helps other Champions become heroes for their loved ones. Through her role with UPMC, she guides Champions through the transplant journey by sharing tips and advice for how to share their story.

She is available to speak personally with patients and Champions and can provide support through the Champion support group on Facebook.

If you would like to speak with Donya, you can contact her at **412-389-7606** or mccoyd8@upmc.edu.

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

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

Notes:

Notes:



Help is here.

If you have identified a potential donor, please visit
UPMC.com/LivingDonor and click “Register to be a Living Donor”

For any questions about the UPMC Living Donor Champion Program or to download a digital copy of the Champion toolkit, visit **UPMC.com/LivingDonorChampion**.

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