



Finding a **Living Donor**

A toolkit for kidney
patients and champions



SSMHealth.

Saint Louis University Hospital

Transplants aren't just life-saving, they're *life changing.*



My match
is my hero,
she's also
my wife.

Josh & Kristi's Story

Their bond goes beyond marriage.

Josh was born battling kidney disease and has been fighting ever since. In 2008, he had a transplant with a kidney that was donated from his sister, but after six years it failed. For the next several years, Josh struggled on dialysis.

Josh's wife Kristi is a nurse, so he was able to do some of his dialysis procedures at home while they waited for a donor kidney. As Josh remained on dialysis, they looked for a path toward healing. That's when they discovered the SLUCare transplant specialists at SSM Health Saint Louis University Hospital.

Now, they just needed a donor. Many friends and family came forward excited to help, but whether it was for personal or health reasons they all fell through. Josh had been very reluctant to have Kristi get tested to

see if she was a match, as he didn't want to put her at any risk. Kristi was steadfast and wanted to get the tests done. She struggled seeing her husband in so much pain and discomfort. It was a few days later she learned she was a match and could donate!

In February 2017, Kristi donated one of her kidneys to Josh. Kristi's recovery went well. She spent two days in the hospital, was taking short walks outside within a week, and went back to work as a nurse four weeks after her donation surgery. Josh did well too, it just took a little longer. He was weak at first, but was taking short walks within a week. By two months, he was back attending church with Kristi and doing a few light activities. Finally, after three to four months, Josh returned to his job as a construction worker.

But the happy news didn't end there. For years, Josh was told he wouldn't be able to have children because of his various health conditions. So when the couple discovered two months after the transplant that they were expecting their first child, they were elated. Josh and Kristi are proud parents of a beautiful baby boy named Hunter Joshua.

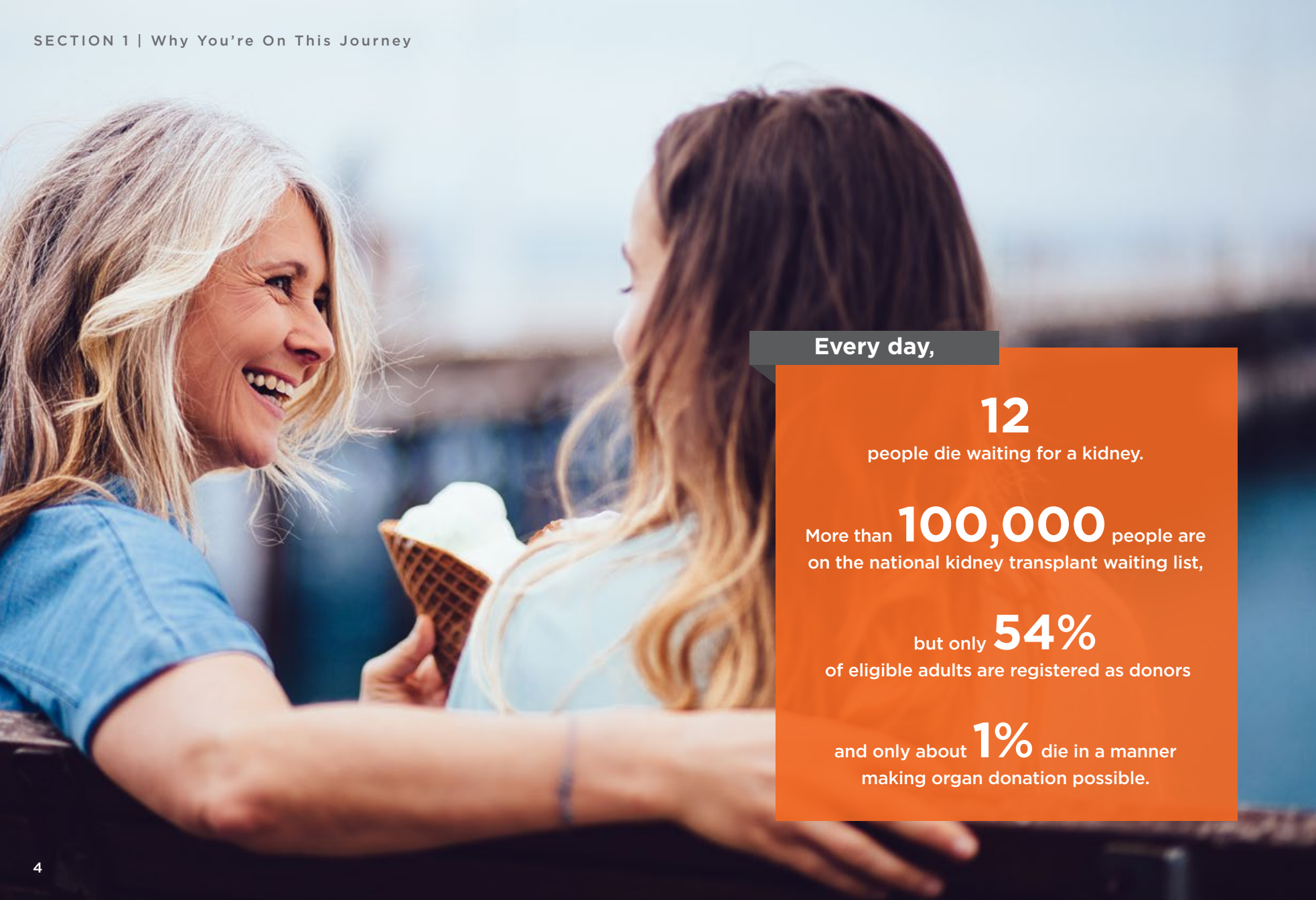




Table of Contents

Section 1 – A Challenging Position: Why You’re On This Journey	4
Section 2 – Kidney Champion: Resources.....	6
Section 3 – The Process for Recipients and Donors.....	24
Section 4 – Answer Guide: True or False.....	30





Every day,

12

people die waiting for a kidney.

More than **100,000** people are on the national kidney transplant waiting list,

but only **54%** of eligible adults are registered as donors

and only about **1%** die in a manner making organ donation possible.

A Challenging Position

Why You're On This Journey

Identify a Kidney Champion

We encourage you to identify a “**Kidney Champion**,” someone who can help teach others about your condition and your transplant options.

Anyone can be your kidney champion. A kidney champion is often someone who wanted to donate a kidney but was ruled-out because of their own health issues, or even children who are too young to donate themselves but want to help a loved one with kidney failure.

Some examples of ways your kidney champion can help include: sending a letter or email to tell people about your condition, hosting a gathering or creating a Facebook page or website. Find more helpful educational material and tools available at ssmhealth.com/transplant.

Sharing your story and your need for an organ donor can seem like an overwhelming process, but our experienced team at the Transplant Center at **SSM Health Saint Louis University Hospital** will be there to help you every step of the way. Contact us today at **314-577-8867** to schedule an appointment or to learn more about what options are available to you.



Josh's wife Kristi is a nurse, so he was able to do some of his dialysis procedures at home while they waited for a donor kidney. As Josh remained on dialysis, they looked for a path toward healing. That's when they discovered the SLUCare transplant specialists at SSM Health Saint Louis University Hospital.

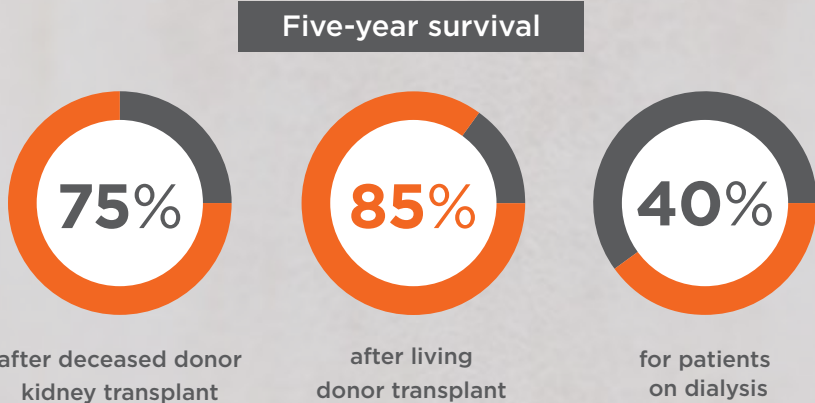
An emotional time

This can be a very *emotional time* for the person in need of a kidney, often times they feel like a burden to their loved ones. As a kidney champion, it's important to provide reassurance to your loved one. Remind them that the challenge is worth pursuing and can be overcome.



Understanding the benefits

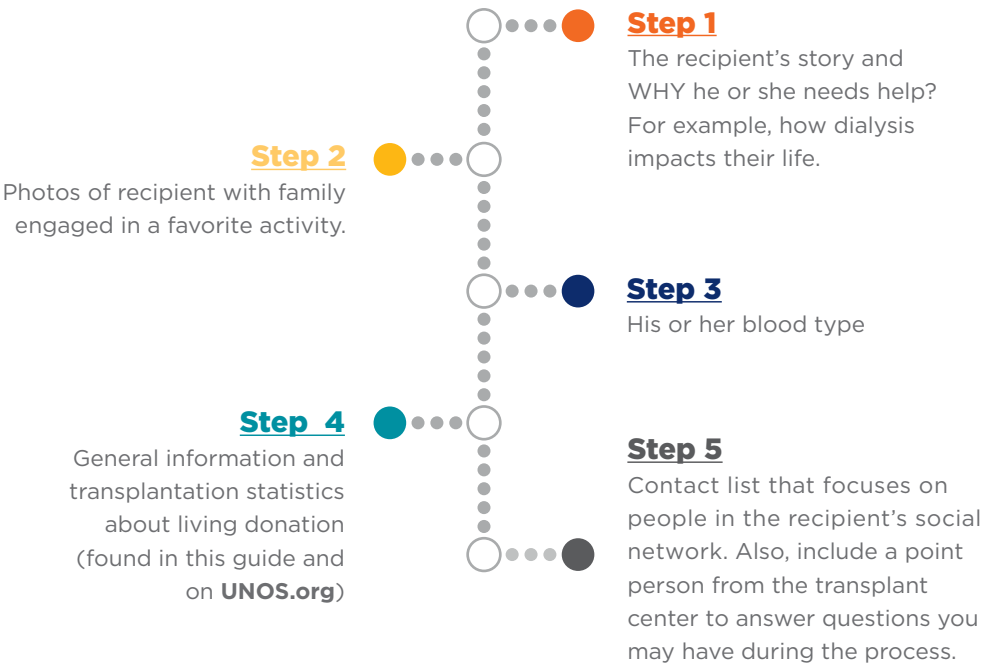
“There are substantial educational barriers in regard to transplants and especially living donor transplants,” says Krista L. Lentine, MD, PhD and medical director of living kidney donation at SLUCare and SSM Health Saint Louis University Hospital. “For example, patients with kidney failure often don’t understand the dramatic improvement in survival with a transplant compared to dialysis. Five-year survival is 75 percent after transplant from a deceased donor and 85 percent with living donor transplant, but only 40 percent for patients on dialysis.”



Kidney Champion Resources

A great place to start.

To help share your loved one’s story and need for an organ donor, start by gathering some key information. These include:



To be an effective champion,

you’ll need to use as many channels as possible. These essential tools can help you spread the word about your loved one’s need for a transplant. Communication channels include (but are not limited to):

- Social Media
- Digital Resources
- Non-Digital Resources
- The Living Donor Transplant Team

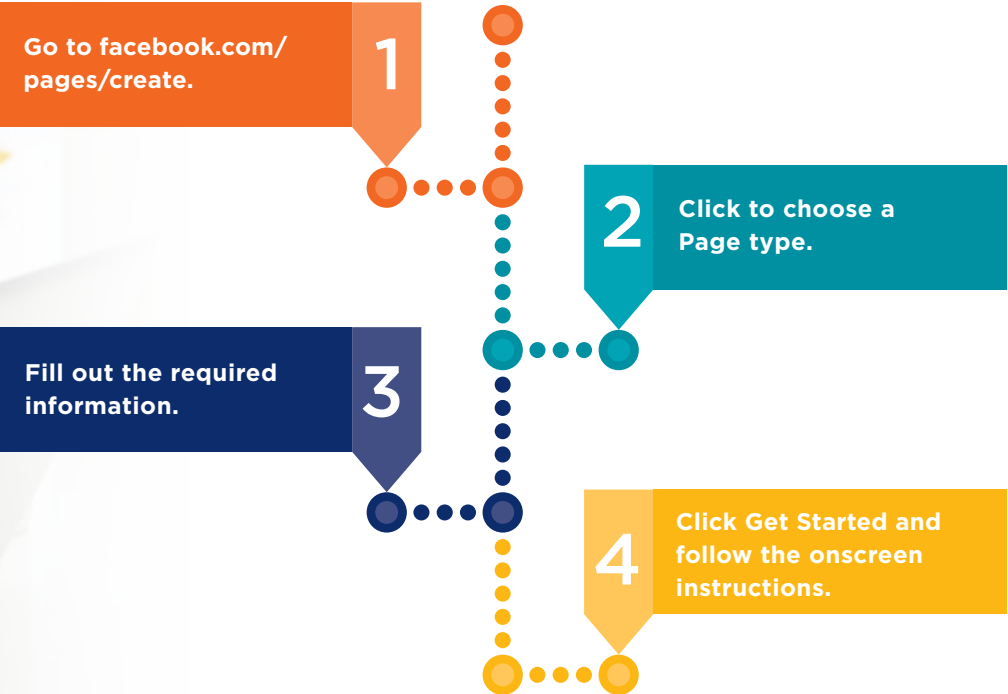


Social Media



It's *simple* to create and start sharing a story.

Creating a Facebook Page





Creating a Group Page on Facebook

1

Click in the top right of Facebook and select **Create Group**.

2

Enter your group name, add group members and then choose the privacy setting.

3

Click **Create**.

Once you create your group, you personalize it by uploading a cover photo and adding a description.

How to share the recipient's story.

- ▶ Tap the camera icon or swipe right from anywhere in News Feed to use the camera.
- ▶ Tap at the bottom of the screen to take a photo or tap and hold to record a video. **You can also:**
 - Tap **Text** to share a text post with a colored background.
 - Tap **Live** to start a Live video. Live videos are available in your story until you end the broadcast.
 - Tap the wand icon or swipe up to take a photo or video with face filters or other camera effects.
 - Tap the photo icon to upload a photo from your camera roll.

- ▶ Tap **Aa** to add text, the art icon to add a sticker or the draw icon to draw on your photo or video. Tap **Effects** to add other creative effects to your photo or video.
- ▶ Tap **Next**, then tap **Your Story**. **You can also:**
 - Make a post.
 - Tap settings to change Your Story privacy.
 - Send to specific people.

You can also share to Your Story when you create a post on Facebook.



Best Practices - Facebook

- ▶ Always use a photo or a video
- Don't overwhelm people with too many posts
- Respond to comments in a friendly and timely manner.
- Follow, mention and tag relevant people and organizations

Outline for sharing your need for a donor

Opening

Convey your wish to share a topic that is important. Include reassurance that individuals can contact the transplant center to ask questions about donation privately, without any obligation.

The Who

Explain for whom you're making the request.

The What

Provide a brief summary of the patient's journey with kidney failure.

The Why

Explain why transplant will improve the patient's health compared to dialysis.

The Time

After an initial conversation, offer ways to contact you for more information or contact the transplant center directly.*

The Closing

Thank the individual for taking the time to read your post.

**The transplant center will never share information about a donation inquiry without permission.*

Making the most impact through social media connections.

Initial appeal post

Group Name (Josh's Journey for a Kidney)

I have a life-changing request. Most of you know my husband Josh. He has been on dialysis for the last six years and we found out that he is need of yet another kidney transplant. It's a lot to ask, but would anyone be interested in learning more about being a living donor? A donor can lead a totally normal life with one kidney. Send me a private message if you would like to learn more.

Found a donor post

Group Name (Josh's Journey for a Kidney)

Just wanted to give a huge shout out to everyone for all the love, prayers and support. It means more than you will ever know. Josh is heading to the hospital for some more testing, but is in good spirits and believes we will find a living donor soon. Thank you to all who have been tested. We truly appreciate your willingness to help. Spread the word to all your friends and family – they could be a match!

Life event post

Group Name (Josh's Journey for a Kidney)

We celebrated Josh's 34th birthday yesterday, surrounded by family and dear friends. The search for a kidney donor continues and Josh's spirits are good as he is already planning his birthday party for next year. The best gift ever would be a new kidney. Help us find a living donor. **#Livingdonorsrock**

Found a donor post

Group Name (Josh's Journey for a Kidney)

This is the BEST DAY EVER. We're so excited to tell everyone that we have found a match for Josh. And you're never going to believe who it is? ME! THANK YOU to everyone for all your support over the last six months. We'll keep you updated as we move closer to surgery. **#donatelife**

Other social media channels

Twitter

Twitter is also a great platform for sharing information and spreading the word about living organ donation. Connecting with other advocates and organizations can enhance your reach.

Best Practices

- ▶ • 280 characters or less
- Use photos and videos
- Include relevant hashtags, such as **#organdonation**
#livingdonor
#donatelife
- Ask questions of your audience to encourage support and participation
- Connect and engage with important advocacy groups
- Post often and engage with your followers

Instagram

Instagram allows you to tell a story and share compelling visuals to highlight an important cause. The more unique the photo and heartfelt the narrative, the more likely you are to move people to help.

Best Practices

- ▶ • Share compelling, colorful and unique photos
- Use relevant hashtags, such as **#organdonation**
#livingdonor
#donatelife
- Tell your story and be genuine!

Social Suggestions

Photos

Videos

Shares & Likes

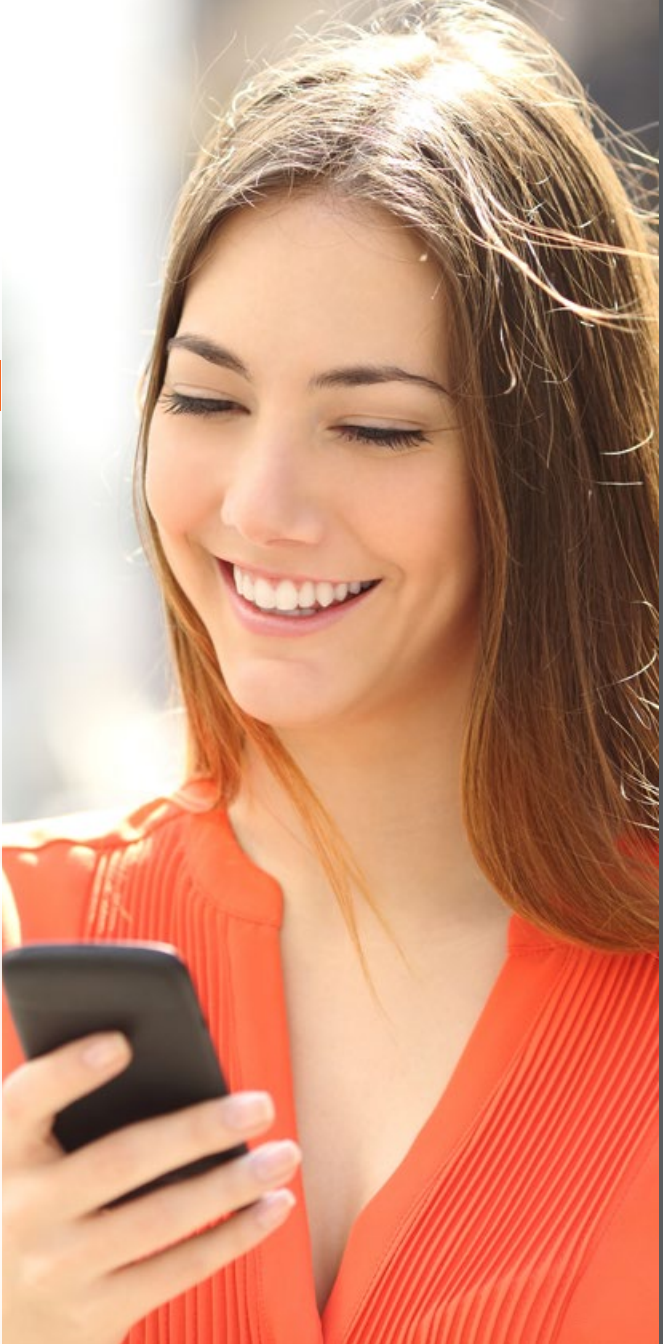
Responses

Motivational Posts

Personal Experiences

Livestream

Hashtags



Security and Privacy Recommendations

Remind users to be selective about what they decide to share.

- ▶ Respect other’s wishes and privacy before posting
- ▶ Ask before you post anyone’s photo or story
- ▶ Encourage people to check their own privacy settings

Respect everyone’s privacy. If ever there is any doubt at all about posting something or not, ALWAYS be cautious and don’t post it!



Digital Resources

Use all your digital resources available: Facebook, Twitter and Instagram. Between shares, likes and retweets your information and story can reach hundreds or even thousands of potential living donors. Your match could be out there and the more people you reach, the potential for success exponentially increases.



Email Communication

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.

Additionally, a benefit to using email is that you can create a specific address that directly relates to this journey (example: saveJohn@____.com). This can be helpful in the following ways:

- It helps to keep your personal email account more private. If you wanted to share the ways in which someone could contact you, such as a phone number, or home or business address, this would be an appropriate place to do so.
- It can act as an avenue to and from Facebook.
- It creates an "official" appearance.
- It's eye-catching and easier for people to remember.
- It makes the process more manageable for you by not clogging up your personal or business email inboxes.



Finding the knowledge

Use the resources listed here to aid in education, add valuable information to your social media posts and keeping your story top-of-mind.

ssmhealth.com/transplant

SSM Health Saint Louis University Hospital

kidney.org/livingdonation

National Kidney Foundation
Call **855-653-7337** (855-NKF-PEER) or email **nkfpeers@kidney.org** today!
Monday - Friday from 9 am - 5 pm EST
(In English & Spanish)

Get answers and support from other patients, caregivers and living donors in an online forum monitored by NKF.

healthunlocked.com/nkf-kidneytransplant

Transplant *Remain anonymous if you wish.*

healthunlocked.com/nkf-donors

Living Donation *Remain anonymous if you wish.*

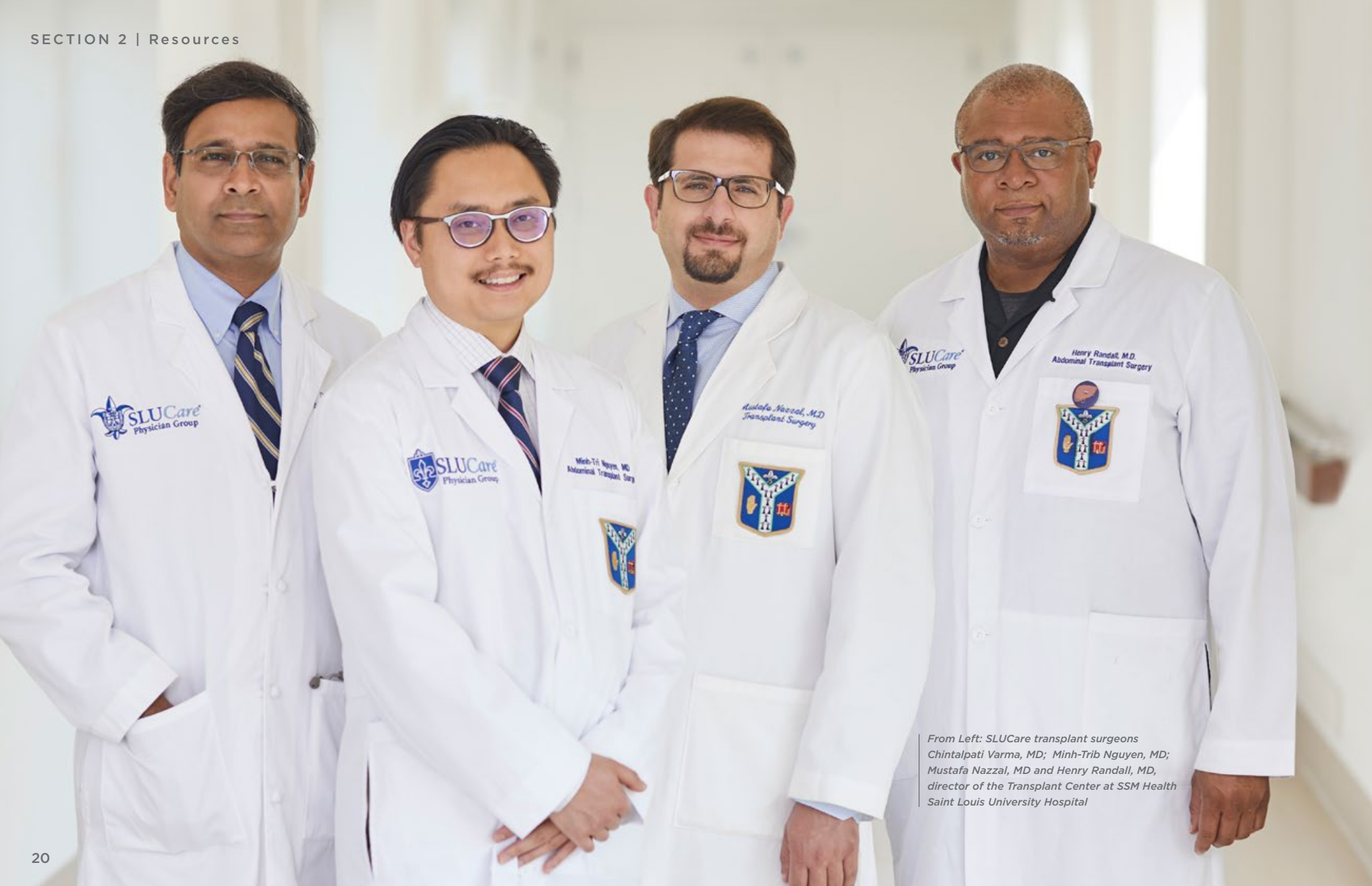
donatelife.net

Donate Life America

unos.org

United Network for Organ Sharing





From Left: SLUCare transplant surgeons Chintalpati Varma, MD; Minh-Trib Nguyen, MD; Mustafa Nazzal, MD and Henry Randall, MD, director of the Transplant Center at SSM Health Saint Louis University Hospital



Transplant Team

Speaking with everyone involved in the transplant search and process provides valuable information and important teaching tools for the kidney donor, patient, and their families and loved ones. Reach out early and often to find answers to all your questions.

Transplant Nurse Coordinator

The Transplant Team

Below is a list of your transplant team that works closely together to care for both transplant patients and living donors. It's important to learn the roles and responsibilities of each caregiver. They're each tasked with supporting kidney patients and living donors in different ways.

- Transplant Nutritionist
- Transplant Pharmacist
- Transplant Social Worker/Psychiatrist
- Living Donor Advocate
- Transplant Nephrologists
- Transplant Surgeon
- Financial Advisor



What If Someone Says “No”

Always *stay positive*. Living donation is not right for everyone. However, sharing your loved one’s story can still spread the word, and may help you find a champion partner. Ways to support the search for an organ donor include:

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



Non-Digital Resources

Resources outside of the digital world



Word of Mouth

Whether it's the occasional phone call with a family member or friend or it's the bumping into of someone familiar at the grocery store, any time spent with someone is another opportunity to advance the journey of finding a donor!

Social Groups and Organizations

Regular gatherings, such as book clubs, church groups, sports leagues and alumni groups 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 living transplant.

Social settings:

- Gym or fitness center
- Work
- Place of worship
- Family or friend gatherings
- School

Non-digital mediums

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

Types of Living Donation



Living donor transplants

The **kidney** is the most commonly transplanted organ from a living donor. One entire kidney is removed and transplanted.

Directed donation

In a directed donation, the donor names the specific person to receive the transplant. This is the most common type of living donation. The donor may be:

- a biological relative, such as a parent, brother, sister or adult child
- a biologically unrelated person who has a personal or social connection with the transplant candidate, such as a spouse or significant other, a friend or a coworker
- a biologically unrelated person who has heard about the transplant candidate's need

Non-directed donation

In non-directed donation, the donor does not name the specific person to get the transplant. The match is arranged based on medical compatibility with a patient in need. Some non-directed donors choose to never meet their recipient. In other cases, the donor and recipient may meet at some time, if they both agree and if the transplant center's policy permits it.

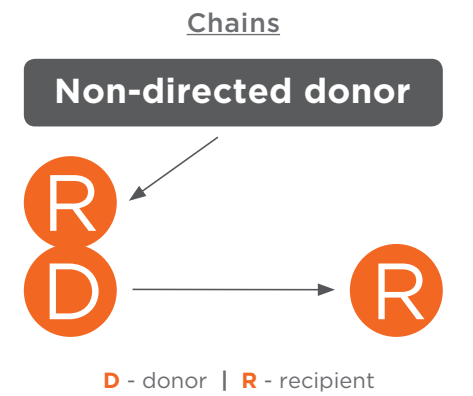
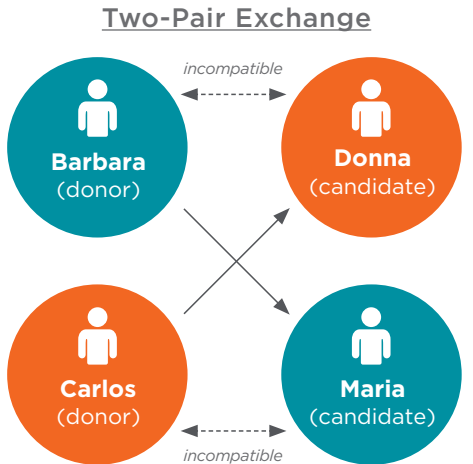


More than **100,000** people are awaiting kidney transplants in the US.

Kidney paired donation

Also called paired kidney exchange, kidney paired donation involves pairs of living donors and transplant candidates who are not biologically compatible with the donor who wants to help them (i.e., based on blood type or the presence of antibodies against donor tissue). Candidates "trade" donors so that each candidate receives a kidney from a compatible donor. For example, in figure 1, Barbara wants to donate to her sister Donna, but they do not have compatible blood types. Carlos wants to donate to his wife Maria, but they are also not blood-type compatible. By "swapping" donors, so that Carlos donates to Donna and Barbara donates to Maria, two transplants are made possible. This type of exchange may involve multiple living kidney donor/transplant candidate pairs.

Sometimes a non-directed donor can start a "chain" of donations and transplants, allowing more than one transplant to happen through their gift.



D - donor | R - recipient



From Left: SLUCare transplant surgeons Chintalapati Varma, MD and Henry Randall, MD, director of the Transplant Center at SSM Health Saint Louis University Hospital; Jack Martin, kidney transplant recipient; Jennifer Martin, kidney donor; Jane Beckman, non-directed donor and Cody Wooley, RN, Transplant Coordinator, meet and celebrate the successful kidney donor chain that took place at SSM Health Saint Louis University Hospital.

Successful kidney donor chain

After seeing a news story about living organ donation, an inspired Jane Beckman called SSM Health Saint Louis University Hospital to see how she could help. That call helped save two patients struggling on the transplant waiting list.

In the case of Jack Martin, his wife Jennifer was willing to donate and while not compatible with her husband, she was compatible with another patient waiting on the list. As Jane was compatible with Jack, her non-directed donation put pieces in place for a kidney exchange.

In these two transplants, Jane donated to Jack while Jennifer donated to another patient. Their joint story highlights how kidney exchange can change lives.

Kidney Transplant

What Will Take Place

Living donor kidney transplantation

Living donor kidney transplantation occurs when a healthy individual donates one of his or her kidneys to a person with end-stage renal disease, thus sharing the gift of life. Currently, there are more than 100,000 people on the national kidney transplant waiting list in the United States, with 14,000 deceased donor kidney transplants performed in 2017. Many transplant candidates die or become too sick before a deceased donor organ becomes available. Living donor kidney transplantation allows individuals in need to bypass the lengthy waiting list and get on to a longer, healthier life much sooner.

Requirements of living donation

Living donors should be in good overall physical and mental health and older than 18 years of age. Some medical conditions

could prevent individuals from being a living donor. These conditions include uncontrolled high blood pressure, diabetes, cancer, hepatitis, acute infections or a psychiatric condition requiring treatment. Since some donor health conditions could be associated with adverse outcomes for the donor or their recipient, it is important that individuals share all their physical and mental health information. Potential donors must be fully informed of the known risks involved with donating and complete a full medical and psychosocial evaluation. An individual's decision to donate should be completely voluntary and free of pressure.

What happens when a recipient gets a kidney from a living donor?

The donor and patient are admitted to the hospital the morning of the day of surgery. The surgeries take place in series, and each takes several hours.

My match
is my hero,
she's also
my
daughter.

After a successful living kidney donation Trisha and her mom, Kim are grateful for the gift of more time. Kim's transplant eliminated the need for her to go on dialysis or the organ waiting list.



Being a Recipient

There are no additional risks when receiving a living donor kidney transplant, but there are many benefits, including:

- Improved graft survival, with an average transplant lasting 18 to 20 years vs. 8 to 10 years from a deceased donor.
- Shorter time on dialysis before transplantation. Patients are able to get off dialysis sooner or avoid it all together.
- Living donor transplant recipients experience fewer complications after transplant. For example, transplant patients who receive a living donor kidney usually see immediate function of the transplanted organ.
- Better quality of life.
- Living donation allows the procedure to be scheduled at a time that works best for the donor and recipient. Planning the date of transplant surgery in advance also allows optimal attention to medical issues before surgery.

Being a Donor

Being a living donor allows individuals to give the ultimate gift of life to someone in need. Through the act of donation, a healthy person can help a person with end-stage renal failure return to a healthier, more functional life. Potential donors are encouraged to talk with prior donors about their full range of experiences with living donation.

If an individual is interested in being a living donor, contact the Transplant Center at SSM Health Saint Louis University Hospital at **314-577-8867**. Then, after completing a short health history individuals will discuss next steps with a nurse coordinator.



Kidney Transplant Surgery

How to prepare for surgery

One of the benefits of a living donor transplant is that you, your donor and the transplant teams will be able to schedule the surgery at a time that works for you and your living donor.

Scheduling your surgery allows you to:

- ▶ Plan for time away from work
- ▶ Arrange child care
- ▶ Plan transportation to and from the hospital
- ▶ Prepare for your hospital stay, such as pack a bag and collect important papers, like insurance information

The transplant surgery

From the time you’re waiting for surgery to begin, all the way to waking up in recovery, the whole process takes about 4-8 hours.

Before the surgery:

- You’ll do any tests you need 1-2 weeks before surgery.
- You’ll come in the morning of the surgery at about the same time as your donor.
- In the hospital, your transplant team will ask you many questions to prepare you for surgery.
- They may also do a dialysis treatment if you need one.
- Doctors will put an IV in your vein.
- Doctors will retest the kidney to make sure it’s a match before surgery. This is called a crossmatch.
- After anesthesia is administered and you are asleep, the doctor will put a catheter in your bladder, which is a small tube to collect urine after surgery.

During the surgery:

(surgery takes 3-4 hours)

- A machine will help you breathe well during surgery.
- Doctors will place the kidney into your body through a small incision in your lower belly.
- Then they connect your new kidney to your bladder.
- The new kidney starts making urine, often during the surgery.
- A tube will help drain urine from your bladder for a few days after surgery.

After the surgery:

- Doctors will take you to the recovery room or intensive care unit (ICU) after surgery. Nurses and doctors will watch you carefully and give you IV fluids and pain medication. You will also receive anti-rejection medicines right away.
- The day after surgery, your transplant team will have you sitting in a chair and walking to help avoid problems from the surgery. You won’t be able to eat for a few days after surgery.
- After about 2-4 days, your doctors will fine-tune your medication so you can go home.
- Sometimes a kidney takes several hours to several days to start working. You may need dialysis until it starts working.

When you wake up from your surgery, you may:

- Feel pain near the incisions from your surgery until they heal
- Feel like you need to urinate often or very strongly for a few days if you didn’t urinate often before your transplant
- Experience difficulty passing a bowel movement and need medication to help

When you go home from the hospital:

By the time you go home from the hospital, you will start to feel like yourself again. You may feel tired and weak for several weeks.

When you go home:

- Shower daily, wash your incision with soap and water and pat dry
- Eat normal, healthy meals
- Start your normal activities at your own pace, making sure that you walk daily and stay active
- Avoid lifting more than 5 lbs. for 6 weeks, unless your doctor gives you other instructions
- Don’t drive for several weeks

If you get a fever or have fluid leaking from your stitches, call the transplant office and speak to your nurse or doctor.

You’ll need to visit the transplant center for checkups a few times in the first year after the surgery and then once a year after that. Checkups will happen after:

- 2 weeks
- 6 weeks
- 6 months
- 1 year
- Every year for 2-5 more years



Recovery for the Living Donor

Most kidney donors spend a few days in the hospital to recover. However, we understand that everyone recovers differently. Our kidney transplant team works closely with donors to provide a personalized treatment plan that meets their needs after surgery. The full recovery of the donor takes a few months, before feeling like their typical selves.

In 1988, there were only **1,829** living donations performed in the US.



True or False

A kidney donor and recipient must be related by blood.	FALSE	The Truth: A donor and recipient don't have to be related by blood. People can donate to family members, friends or even strangers.
Kidney donors have to take medicine for the rest of their lives.	FALSE	The Truth: A kidney donor will only need pain medication and stool softeners for a short time after surgery. After that time, a donor doesn't have to take medication.
A kidney donor doesn't need the same blood type as the recipient.	TRUE	True! A donor's blood type may not be the same as the recipient's, but it may still work well. For example, a person with type A blood can donate to a person with type AB blood.
A living kidney donor can't be older than 60.	FALSE	The Truth: A living kidney donor can be older than 60 and have no problems from surgery. The kidney from a donor older than 60 can work very well.
A kidney donor will usually be in the hospital for about 2 nights after surgery.	TRUE	True! A kidney donor is usually in the hospital for only two nights. For example, if surgery is on a Tuesday, the donor will most likely leave the hospital on Thursday.

A kidney donor can no longer play sports or exercise.	FALSE	The Truth: A kidney donor should be able to return to regular activities, including sports and exercise, at about 4 to 6 weeks after surgery.
A female kidney donor can get pregnant after donation.	TRUE	True! This is true, although the donor should wait 3-6 months after donation to become pregnant. The body needs time to recover from the surgery and to adjust to living with one kidney before pregnancy.
A kidney donor's sex life will be negatively affected by donation.	FALSE	The Truth: A kidney donor can be sexually active when they feel well enough. Sexual libido won't be affected by donation.
A kidney donor must be about the same age as the recipient.	FALSE	The Truth: Research has shown that transplants can work well when there's an age difference between the donor and recipient.
A kidney donor won't have to change their diet after donation.	TRUE	True! There are no dietary restrictions after donation. A kidney donor can eat anything, but like everyone, should follow a healthy, well-balanced diet.

In 2017 nearly **6,000** transplants were made possible by living donors.





SSMHealth
Saint Louis University Hospital

SLUCare
Physician Group

notes

Grand **New**
SSM Health Saint Louis University Hospital

Coming
September
2020

We're here to help!

If you have identified a potential donor, please visit **[ssmhealth.com/transplant-services/kidney/living-donor-kidney-transplantation](https://www.ssmhealth.com/transplant-services/kidney/living-donor-kidney-transplantation)**

If you have any questions about living donation, please call the Transplant Center at SSM Health Saint Louis University Hospital at **314-577-8867**.

Sources:

National Kidney Foundation: **[kidney.org/livingdonation](https://www.kidney.org/livingdonation)**

SSM Health Saint Louis University Hospital: **[ssmhealth.com/transplant](https://www.ssmhealth.com/transplant)**

American Transplant Foundation: **[americantransplantfoundation.org](https://www.americantransplantfoundation.org)**

Donate Life: **[donatelife.net](https://www.donatelife.net)**

United Network for Organ Sharing: **unos.org**

ENGLISH: SSM Health provides free language assistance services to help you communicate with us in your preferred language for health care. Ask your health care professional or visit **[ssmhealth.com](https://www.ssmhealth.com)**.

Español: SSM Health proporciona servicios de asistencia de idiomas para ayudarle a comunicarse con nosotros en su idioma preferido para obtener atención médica. Pregúntele a su profesional de atención médica o visite **[ssmhealth.com](https://www.ssmhealth.com)**.

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