

Living Liver Donor Champion

Toolkit

University of Washington Medical Center

Liver Transplant Program

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About This Toolkit

We developed this toolkit to teach living liver donor champions about living liver donation and to provide guidance to living donor champions on how to become effective spokespeople for their loved ones who are in need of liver transplant. This toolkit explains the benefits of living donor liver transplant, the living liver donor evaluation process, and the important role of the living liver donor champion.

A living liver donor champion is someone who is ready to take up the charge to teach others about the liver patient's liver condition. The living donor champion shares the story of the patient's need for a living donor liver transplant.

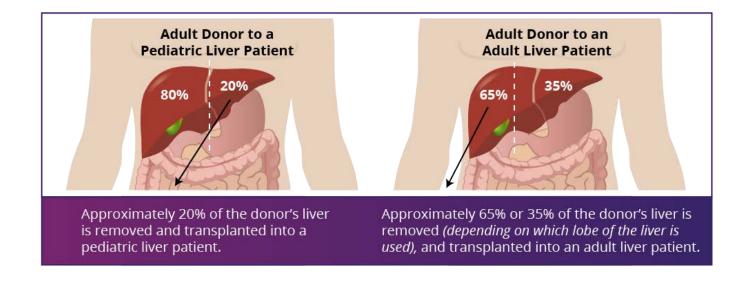
Please read this toolkit carefully. If you want to learn more about becoming a living liver donor champion, please email our **UW Medicine Living Liver Donor Champion Program:** liverdonorchampion@uw.edu.

Thank you for your interest in becoming a living liver donor champion and learning how you can help someone in need of liver transplant.

What is Living Donor Liver Transplant?

Most liver transplants use a whole or partial liver that is donated by the family of a deceased person. But in living donor liver transplant, the surgeon removes part of the liver from a healthy person for transplant into the patient with liver disease (the recipient). The recipient's whole diseased liver is removed.

The liver has the amazing ability to regenerate (regrow) quickly. This is why both the donor and recipient can readily recover after a living donor liver transplant. Most of the liver regrowth happens within three weeks of surgery. By three months after surgery, the donor's liver has regrown to about 90% of its original size.



Why is Living Liver Donation Needed?

There are not enough livers donated by deceased donors to meet the needs of everyone who needs a liver transplant. In the U.S., there are over 12,000 patients currently on the liver transplant waitlist. About one in five of these patients will die before getting a transplant.

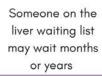
Patients on the waitlist often wait a long time before getting a transplant. By the time they receive a transplant, many recipients are very ill. This slows their healing after transplant surgery.

Living donor liver transplant offers these benefits:

- A much shorter time for the liver patient on the waitlist. The transplant can be done soon after the living liver donor completes their evaluation.
- Easier recovery. With a shorter waiting time, the recipient is more likely to be stronger and in better health at the time of transplant. This helps them heal more quickly after surgery.
- **Scheduling.** We can schedule the donation and the transplant surgeries at a time that works best for both the donor and the recipient.
- Higher quality organ. The liver from a living donor is of high quality. Many of the livers from deceased donors are less than ideal for a variety of reasons. We also may not have the deceased donor's full health history.
- **Better outcomes.** Transplants using a liver from a living donor often have better outcomes than those using a liver from a deceased donor.

WHY ONE SHOULD CONSIDER BEING A LIVING LIVER DONOR







Living Donor Liver Transplant is a Gift of a Lifetime



The liver from a living donor is a higher quality organ



In the U.S. one in five people will die while waiting for a life saving liver transplant



By 3 months after donor surgery the donor's liver has regrown to about 90% of its original size

The recipient's insurance covers the cost of the pre-donation evaluations, surgery, in-hospital recovery, and follow-up care





Easier recovery for the recipient with a shorter waiting time for a transplant



Surgery scheduling can occur at a convenient time for both the donor and recipient



Percentage of donors who say they would donate again

Who Can Become a Living Liver Donor

Volunteering to donate part of the liver with the goal of saving another person's life is an important decision. The first step for the potential donor is to first learn as much as possible about living donation and what it involves.

To begin the education overview, it is important to understand that:

- Although living liver donors are often a family member or friend of the liver patient (emotionally connected to the liver patient), sometimes people who do not know the liver patient may choose to come forward to donate (called an 'anonymous', or 'non-directed', living liver donor).
- Living liver donors must be able to understand all the information regarding the liver donation process and how to use it to make the best decision.
- Living liver donors must be between the ages of 18 and 60 years.
- Living liver donors should be healthy with no major medical or surgical history.

- Living liver donors must have a body mass index (BMI) of 32 kg/m2 or less. The UW Medicine Living Donor Liver Transplant team may provide potential donors with a weight loss goal, as needed.
- Living liver donors cannot have significant alcohol intake or abuse illicit drugs.
- Living liver donors must be free of coercion or external pressure in the decision to donate. In the U.S., the National Organ Transplant Act (NOTA) makes it illegal to buy, sell, or receive financial or other gifts or favors, in exchange for human organs.

What is a Living Liver Donor Champion?

As a living liver donor champion, it is your goal to spread the word about your loved one's liver disease and need for a living donor liver transplant. The living liver donor champion becomes the spokesperson for the liver patient.

Liver patients may, understandably, feel unprepared to find their own living liver donor, including: feeling uncomfortable in discussing their medical diagnoses with other people; being fearful of asking someone to consider living liver donation; feeling too overwhelmed by their own medical needs to take on the process of finding a living liver donor; or just not knowing where or how to start the process of finding a living liver donor.

This is where, you, the living liver donor champion, have the very important role of becoming the voice and advocate for the liver patient.

What is a Living Donor Champion?

- A Living Donor Champion is someone ready to take up the charge to help teach others about the patient's liver condition and their liver transplant options
- The role of Donor Champion is important because it can be difficult for a patient to ask someone to consider living donation
- Many recipients in need of a liver transplant are afraid to reach out, feel embarrassed, or just don't know who to ask or where to start the process
- The Donor Champion does this for the patient
- Donor Champions serve as the patient's spokesperson
 sharing the patient's personal story and educating others about liver disease, living liver donation, liver transplant, and more
 allowing the patient to focus on their own health
- Champions reach out to friends, family, work, school, clubs, faith communities, even strangers – to educate and encourage people to consider living liver donation, increasing the chance that a living donor may be identified
- Living Donor Champions can write letters, send emails, set up a Facebook community page, use Twitter and Instagram to reach potential living liver donors

Welcome to your new role as a Living Liver Donor Champion!

This toolkit will guide you in learning how to be an effective living liver donor champion and share the messages of living liver donation and liver transplant.

The concepts of living liver donation and undergoing liver transplant using a portion of a healthy donor's liver may be unfamiliar to some people.

The UW Medicine Living Liver Donor Champion Program understands that discussions about living donor liver transplant may lead to many questions. We are here to educate you with those answers and supply you with comprehensive educational materials to use to communicate effectively about living liver donation.

Using the information in this Toolkit, your goals as a Living Liver Donor Champion are to:

- Gain knowledge about living donor liver transplant and the living liver donor evaluation process
- · Learn how to talk to someone about living liver donation
- Share the liver patient's story about their liver disease and need for a liver transplant
- · Learn best practices for sharing on social media
- Find potential living liver donors



Who can be a Living Donor Champion?

Anyone willing to help

- A close friend or family member who wants to help, but who may not be able to donate
- A parent or child who is too old or too young to donate
- A colleague or close acquaintance, especially someone who is skilled at communicating
- Someone who has already donated or received a liver transplant, or their family members

Understanding the Living Liver Donation Process

As a living liver donor champion, it is important for you to understand what happens when someone says they are interested in being a living liver donor. Expressing interest does not immediately commit someone to becoming a living liver donor. When someone shows interest in considering living liver donation, they are stepping forward to learn more about the donation process from our living donor liver transplant team. The education process also lets our team learn more about the potential donor.

"About 50% of liver donors feel completely normal and fully recovered at six weeks and almost all donors feel fully recovered at three months after surgery" - Mark Sturdevant, MD, surgical director of the UW Medicine Living Donor Liver Transplant Program.

"Patients with donor champions are five to six times more likely to have someone come forward for evaluation as a living donor, compared to patients who do not have donor champions"
- Kiran Bambha, MD, medical director of the UW Medicine Living Donor Liver Transplant Program.

GETTING STARTED

After calling our Living Liver Donor team, we will ask the potential donor general questions about their health. Potential donors will also speak with an independent donor advocate. This advocate will confirm whether or not it is a good option for the donor to proceed with testing.

FORMAL EVALUATION

During the evaluation, potential donors will meet with a surgeon, liver doctor, social worker, infectious disease specialist, dietitian, and pharmacist. Screening tests wil include; blood tests, heart testing, imaging, and other testing, as needed. If approved as a donor, a surgery dat will be selected.



PREPARING FOR SURGERY

Once the surgery date is confirmed, the donor will finalize plans with family and friends who will serve as caregivers for the donor. Donors will maintain a healthy lifestyle prior to surgery to ensure optimal health the day of the procedure.

DONOR SURGERY

The surgery is called a donor hepatectomy.

The surgeon will remove a safe portion of the donor's liver. The recipient's unhealthy liver is replaced with a portion of the donor's healthy live. The surgery takes about six to eight hours.



HOSPITAL STAY



After surgery, the donor will be closely cared for in the hospital by our experienced team of transplant surgeons and other specialist team members. Most donors stay in the hospital between four to six days.

GETTING BACK TO NORMAL

Everyone recovers at a different pace after major surgery. About half of living donors fee like they are back to normal about six weeks after their donor surgery. The other half feel back to normal over the next several months.



Getting Started Sharing the Patient's Story

The first steps that you, as the living liver donor champion, need to take in order to find a living liver donor are creating and sharing the liver patient's personal story. Start this process by making sure that you, as the donor champion, understand what information and details about their life and liver disease the liver patient is comfortable with you sharing publicly.

Some initial common challenges you may encounter when planning on sharing the patient's story include: "I do not know where to begin", "I have no idea what details to include", "I do not feel comfortable with these conversations".

Think about telling the patient's story in a way that will have a positive impact on the people to whom you are reaching out. When we talk to the general public, we have learned that what truly inspires people to take action are the stories of other people whose lives have been personally touched by liver disease, and the positive impact that living liver donation and transplantation can have on that person's life expectancy and quality of life.



Father and Daughter, Jim (recipient) and Cassandra (living donor)

The key elements of creating an engaging story to share include:

1. Introduction

Identify who the story is about and your role as a living liver donor champion for that person

2. Short explanation of the liver patient's medical condition

Why a living liver donor is needed, offer the reason that liver transplant is necessary

3. The benefit of living donor liver transplantation

Include a few facts about living liver donation. Explain what receiving a living donor liver transplant would mean for the liver patient's life and family. For example, explain how living donor liver transplant would improve the patient's quality of life, increase their life expectancy, allow them more time to spend with family and friends, and allow them to return to a more normal life with improved health.

Consider including personal photos of the patient with their family and friends, including photos of what their life and health was like even before they became ill.

4. Basic living liver donor requirements Age, body mass index, overall health

5. Conclusions/expressing gratitude

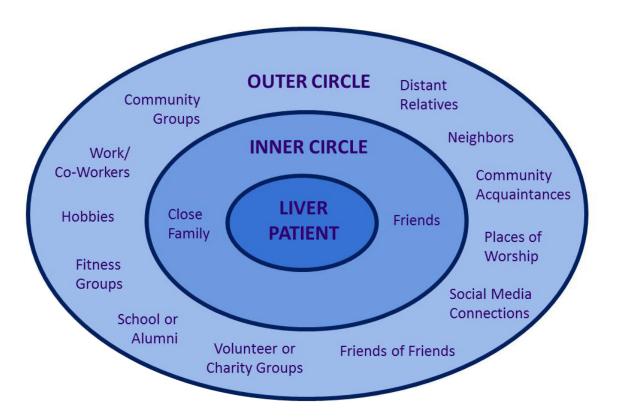
In creating a story, you will want to be sure to thank potential donors for taking the time to learn about living liver donation. Give people the option of contacting either you for more information, or contacting the UW Medicine Living Donor Liver Transplant team directly. Some potential donors may prefer to learn more and/or be tested without telling you. That is okay. Assure people that their information will be kept confidential by our living liver donor team, and that the decision to donate, or not, will be completely up to them and remain confidential. Our living donor liver transplant team will not share any information about donor inquiries or donor evaluations with the donor champion or with the liver patient.

A word around length and timing - if you are sharing your story through writing, keep it to one page or less. If you are sharing your story verbally, especially in a social setting, aim for about five minutes of sharing. Will you be able to cover all the details? Of course not. Allow the person(s) to whom you are speaking to ask questions, which will give you the ability to share more in-depth.

Circles of Conversation

As individuals living in communities and society as a whole, each of us has many difference social connections that link us together and encourage us to communicate with other people. Some of these connections may include family, friends,

acquaintances, classmates, colleagues, neighbors, etc. Our closer community links allow us to extend our circles of communication outward towards other people. The goal of the living liver donor champion is to reach as many people as possible.



Ways to Inspire Living Liver Donation

- **1. Be natural, yet informative.** Share your story in a relaxed and informative way. Allow the listener time to consider your message.
- **2. Keep it positive.** Even though the medical circumstances of needing a liver transplant are often grim, share the hopeful side of receiving a liver transplant.
- 3. Highlight benefits of a liver transplant from a living donor. Explain how living liver donors allow those in need to plan and schedule their transplant when they need it most, but before they become very ill with their liver disease.



Conversation Starters

What to say to potential living liver donors.

Whether it's with one person or many, how you talk with people about living liver donation makes a difference. It will be easier to start the conversation and find the appropriate words to express your emotions by speaking with those closest to you. Each conversation you have will make you more confident to speak with others. If you feel you cannot find the right words to say in person, consider sending an email. Here are some tips and examples to assist you.

Opening the Conversation: Identify the right person to talk to, select an ideal time, and share with the person how long you think the conversation will be.

- "I would like to talk to you about something important.
 Please let me know when you have the time to chat."
- "I wanted to let you know that my (family member/friend)
 needs a liver transplant. They have been waiting for a
 liver transplant for over (specify the approximate # of years
 or months here)."
- "You know my friend, (liver patient's name)? She has liver disease and has spent the last (specify the approximate # of years or months) on the liver transplant waiting list. There are over 12,000 people in the U.S. currently waiting for a liver transplant."
- "I was told that I am not able to donate a portion of my liver to (liver patient's name), so I am trying to spread awareness about his need for a liver transplant and a living liver donor. I am hoping that sharing his story might inspire someone else to possibly serve as a living liver donor."

Conversation Points: Sharing the basics about the gift of living liver donation.

- "Did you know that a person can live a healthy and complete life after donating a portion of their liver?"
- "The evaluation to be a living liver donor is very thorough and paid for the by the recipient's insurance."
- "The living donor liver transplant team will not let a person donate unless they determine that the donor is healthy at the time of the donation and that surgery poses the least possible risk to the donor."
- "The liver doctors shared that a liver transplant from a living liver donor can be scheduled electively, allowing the donor and the recipient more time to prepare for surgery."

Closing the Conversation: Offer thanks, even if you did not receive the answer you expected. End with sincerity for the opportunity to discuss living liver donation and living donor liver transplant.

- "Thank you for listening and having this conversation with me. If you have any questions, please do not hesitate to ask me, or to reach out to the living liver donor team directly."
- "I appreciate the opportunity to speak with you about this.
 It truly means a lot that you are interested in considering the option of being a living liver donor and open to learning more."
- "Please share this information with anyone you think may be interested in learning more about living liver donation and possibly being evaluated as a living liver donor for (liver patient's name here)."



Samples of Living Liver Donor Champion Emails

Dear (personalize letter),

I am writing to you about my (e.g., friend, family member), (liver patient's name), to let you know about (his/her) current health challenge and how you can help. This is not an easy communication for me to write, but I know that without sending this, someone who might be interested in helping will not have that opportunity.

Please allow me to share a bit about (liver patient's name). (Talk about the patient's work, family, hobbies, volunteer work, involvement with the community and anything that could connect their story with other people.)

(Liver patient's name) has (end stage liver disease) and has been told by the UW Medicine Liver Transplant team that (he/she) has the option to receive a living donor liver transplant. The ability to be transplanted before (he/she) gets critically ill is a big benefit of living liver donation. And patient survival after living donor liver transplant is equal to, or better than, the outcomes experienced in deceased donor liver transplant.

Since I care so much for (liver patient's name), I'm doing everything I can to help find (him/her) a living liver donor. (Give a brief history of patient's health challenges, how long waiting, how many other people have tried to help, etc. Potentially include a picture. If the recipient has made many positive lifestyle changes, mention them. If you yourself are unable to be a living liver donor, consider explaining why).

(Liver patient's name) needs a liver transplant, and we hope you will consider learning more about being a living liver donor. I know this is a big request. But I make it on behalf of someone who devotes every day of (his/her) life to making a difference to (his/her) family and friends. If you can help, please do. If you know anyone who might, please forward this on. Forwarding this to your family, friends, work, school, or any other communities you belong to would be very much appreciated.

If you would like to learn more about living liver donation, please feel free to contact me (insert phone number or email). All conversations are kept confidential. I want to be as helpful as possible. You can also visit www.uwmedicine/ liver-donation. org or contact the UW Medicine Living Donor Liver Transplant team directly at 206-598-0337 or email: liverdonor@uw.edu

Thank you for your care and concern, and for letting me share this with you.

Dear Family and Friends,

Did you know that (*liver patient's name*) is in need of a lifesaving liver transplant? Patients with advanced liver disease across the U.S. who are on the liver transplant waiting list face substantial challenges as they need to wait, often for months or years, for a life-saving liver transplant. Unfortunately, with over 12,000 people on the U.S. liver transplant waiting list, there are simply not enough donated livers from deceased donors, which means that not everyone on the waiting list will survive to receive a life-saving transplant.

Many people do not realize that a liver transplant from a living donor is an important option for people needing a liver transplant. I wish I could donate a portion of my liver to (liver patient's name), but I cannot due to (choose a reason or insert your own: my own health issues, already donated, have a transplant myself, am too young, etc).

Since I cannot assist by donating a portion of my liver, I decided to do the next best thing – I am (liver patient's name) Living Liver Donor Champion, the person who will advocate for (liver patient's name) and teach others about living liver donation in the hope of finding someone who might be willing to consider living liver donation.

Please contact me at (insert your contact information-email or phone #). All conversations are kept confidential. If you would like to learn more about living liver donation, you can also visit www. uwmedicine.org/liver-donation, or contact the UW Medicine Living Donor Liver Transplant team directly at 206-598-0337, or email: liverdonor@uw.edu. Thank you so much



Daughter and Mother, Lauren (living donor) Kris (recipient)

10 Living Liver Donor Champion: **Toolkit**

Best Practices and Tips for Using Social Media

Social media is defined as any website or application that provides online community building and personal interactions. For example, Facebook, Instagram, Twitter, YouTube, TikTok, and blogs allow people to share information via written word, videos, website links, or photography.

For many living liver donor champions, social media is an excellent tool to spread the word about living liver donation. Social media lets you share a story with a large network very simply, quickly, and at no cost. Just one message can have an endless reach with shares and likes. Sharing the story of your recipient may increase the likelihood that someone will step forward to consider living liver donation. Additionally, you can keep followers updated and link to other living donation websites.

This living liver donor champion toolkit will assist you with wording, examples of language, and with understanding some of the important elements of a social media campaign.

- Create a Facebook and/or Instagram page that people can "like" and "share" with others
- Share your personal connection to living liver donation and liver transplant
- Post news stories about successful living donations
- Share information about living liver donation
- Post often, stay engaged, and encourage people to share the posts
- Link to the UW Medicine Living Donor Facebook page and to the UW Medicine Transplant Instagram account (see Additional Resources on page 15)
- · Create short videos to help tell the story
- · Raise awareness from other living donation stories

Creating a Facebook Page

One of the most popular and effective social media platforms for Donor Champions to share their message is Facebook. If you do not have a personal Facebook profile, you can easily set one up. It's simple and free of charge.

- 1. Go to facebook.com and click Create New Account
- 2. Enter your name, email or mobile phone number, password, date of birth and gender
- 3. Click Sign Up
- 4. To finish creating your account, you need to confirm your email or mobile phone number

CREATE A GROUP PAGE



If you do not feel comfortable with using your personal Facebook page to promote living donation, you can create a group page.

Find the Facebook Groups page and click Create New Group

A four part pop-up will appear:

- Name your group: (try to make your group name memorable)
- Select your Privacy setting (choose public to increase visibility)
- Choose Visibility setting (select "visible" so anyone can find the group)
- Select friends to add to your new group

Create a Memorable Group Page Name

1. Within your group page, click the ellipses (...) located in the top right corner of the page.



Select Edit Group Settings.

- 2. Scroll to web address, click Customize Address.
- 3. Enter a customized address for your group page so that it can be found more easily. Then click *Customize Address*.

T/-

ADVERTISING & PROMOTION

Facebook is a quick and effective way to get your message out to your connections as well as larger friend networks of all your connections.

FACEBOOK POST EXAMPLE 1:

You can save a life ... living liver donor needed. Just a few weeks ago, (*liver patient's name*) was placed on the liver transplant waiting list, and (*his/her*) best chance of survival lies in the hands of someone willing to be a living liver donor. What can you do?

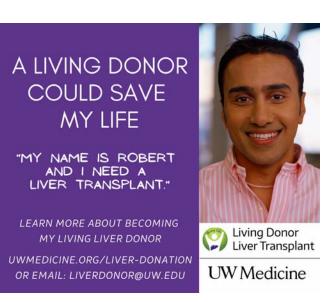
If you are healthy, age 18-60 years and are willing to donate a portion of your liver, you may be able to help (liver patient's name) by becoming a living liver donor. If, after careful consideration, you are interested in more information on the process, please visit **uwmedicine**. **org/liver-donation** or call the UW Medicine Living Donor Liver Transplant team at **206.598.0337**, or email: **liverdonor@uw.edu**. All donor inquiries are kept strictly confidential by the UW Medicine Living Donor Liver Transplant team.

FACEBOOK POST EXAMPLE 2:

My good friend (*liver patient's name*) has been diagnosed with (*name of liver disease*). A number of side effects from this disease have greatly impacted (*his/her*) quality of life in the past few years. And with many hospital stays it was finally decided that a liver transplant is the only way for (*him/her*) to regain a normal quality of life.

A living liver donor is the best opportunity to make this drastic improvement in (his/her) life. Since the liver regrows, a healthy person can donate a portion of their liver, and both the donor and the recipient will have a fully regrown liver in about two to three months! Please consider living liver donation and help us spread the word so we can find our miracle donor!

UW Medicine branded templates are available for our Donor Champions to personalize and share on social media. Please email us at: liverdonorchampion@uw.edu for more information.



A LIVING DONOR
COULD SAVE MY LIFE

"My name is Barb and I need a liver transplant."

Learn more about becoming my living liver donor uwmedicine.org/ liver-donation

or email: liverdonor@uw.edu

Living Donor Liver Transplant

UW Medicine

Additional Tips for Using Social Media

- Keep it upbeat. Share the hopeful side of receiving a living donor liver transplant
- Be patient when people have lots of questions
- · Encourage others to spread the message on your behalf, too
- · Once a week, post status updates, pictures, or general living liver donation information to keep those who have liked your page interested
- Make it as easy as possible for people to contact the UW Medicine Living Donor Liver Transplant team for more information. Share our contact information widely.
- Reach our team by phone at : **206.598.0337**, via email: **liverdonor@uw.edu**, or on the web at: uwmedicine.org/ liver-donation

What Not To Share on Social Media

- Avoid sharing sensitive or too personal of information:
- Personal phone numbers
- Residential addresses
- Personal email addresses
- Sensitive family information
- Any other information that might be considered sensitive
- Inappropriate photos
- Do not offer incentives, rewards, or compensation for living donation-this is illegal. All donors are screened for coercion (being pressured for forced to donate).
- Do not provide any medical advice. If a potential donor asks about the details regarding surgery, medication, recovery, etc. encourage them to contact the UW Medicine Living Donor Liver Transplant team for more information.

"A transplant requires just one donor, so keep sharing."

"It may take a village of offers to find an ideal donor. Share your message with someone new at least once a day."

Handling Responses

Keep in mind that asking for a living liver donor takes courage. Remember, it is a big ask. If someone declines interest in living liver donation, this does not mean that the person does not love you or care about your circumstances. In all likelihood, the reasons why someone doesn't donate may have nothing to do with you. It just means that this may not be the right decision at the right time for them. You may find that it's challenging to move on, but it's important to focus on finding someone who is willing and ready to be a living liver donor.

It can be equally challenging to accept when someone says yes. It can feel overwhelming to realize that a potential donor is willing to step up and begin the evaluation process. Be gracious and express your gratitude, regardless of whether it works out.



Additional Resources

There are many organizations where you can find additional information about liver disease, living donation, and organ transplantation. The United Network for Organ Sharing (UNOS) has a toll-free patient services line (1-888-894-6361) where patients, family, or friends, can call to discuss their questions.

In addition, the following organizations offer useful information on their websites:

Explore Living Donation

A website that highlights the living donation and transplant stories of real people: living donors, recipients, family members, and friends.

www.explorelivingdonation.com

UNOS Ambassador

Become a UNOS Ambassador by ordering an Ambassador Kit. The kit includes print and video items you can utilize to educate you community about organ transplant and donation.

unos.org/community/unos-ambassadors

UNOS-Stories of Hope unos.org/transplant/stories-of-hope

UNOS-Transplant Living Donation www.transplantliving.org/living-donation

Donate Life America www.donatelife.net

American Liver Foundation www.liverfoundation.org

American Transplant Foundation www.americantransplantfoundation.org

National Living Donor Assistance Center www.livingdonorassistance.org

UW Medicine Social Media: UW Medicine Transplant Instagram: @UWMedicineTransplant

UW Medicine Living Donor Facebook: @UWMedicineLivingDonorTransplant

University of Washington Medical Center Liver Transplant Program

Box 356175 1959 N.E. Pacific St., Seattle, WA 98195 206.598.0337 liverdonorchampion@uw.edu uwmedicine.org/liver-donation





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