ALF LIVING DONOR NETWORK™

Fact Sheet & FAQ

What is the ALF Living Donor Network?

American Liver Foundation's (ALF) Living Donor Network is the first-ever non-directed liver donor database; it was created to connect individuals who wish to donate part of their liver with transplant centers nationwide to help patients in need. The ALF Living Donor Network is a pivotal step in addressing the critical shortage of liver donors in the U.S. It not only increases the donor pool but also offers a lifeline to patients who might otherwise face prolonged wait times on a deceased donor list leading to potential decline in health or even death.

What is a non-directed donor?

Most living donors know the person they would like to donate part of their liver to; this is called directed donation. There is, however, an increasing number of individuals who would like to provide the gift of life to someone in need, whom they do not know. These individuals are known as non-directed donors (NDD), formerly called altruistic donors.

Why is there a need for non-directed donors?

With nearly 9,300 people in the U.S. waiting for a liver transplant right now, the need for living donors is great. Approximately 25% of people on the liver transplant list will die waiting due to lack of available organs. Living donor liver transplant offers a solution. It can help increase the number of living donor liver transplants for U.S. adults and children and eliminate the pediatric liver candidate waitlist. Yet, despite being an available treatment option for decades, it continues to lag far behind living donor kidney transplant. According to the Organ Procurement and Transplantation Network (OPTN), in 2024 there were 11,458 liver transplants in the U.S. and only 604, or 5.27% were from living liver donors. That same year living kidney donors made up about 23% of all kidney transplants.

How is ALF filling the gap?

Studies show that public willingness to donate an organ to strangers is growing, with up to 22% of individuals surveyed open to becoming a living donor. However, many transplant centers lack structured outreach for such donors. The ALF Living Donor Network offers non-directed liver donors an easy and secure way to connect with transplant centers across the country.

Our goal is twofold: increase the number of living donor liver transplants for adults and children in the U.S.; and eliminate the pediatric liver candidate waitlist.

Who can register?

The ALF Living Donor Network is voluntary and open to anyone who would like to become a non-directed liver donor. Registrants must be 18 years of age or older and reside in the U.S. **Download the Quick Start Guide here**.

Why should I register?

Non-directed living liver donors can dramatically expand lifesaving liver transplants, especially for patients who cannot find a living donor or a match from family or friends. By registering to become a non-directed liver donor, you have potential to give someone the gift of life.

What will I do?

If you choose to register as a non-directed living liver donor, go to LivingDonorNetwork.liverfoundation.org and click the blue REGISTER NOW button in the top right corner of your screen. You will then complete an online health history questionnaire, consisting of 13 core medical sections. Once you've completed the questionnaire, the system will evaluate your submission to determine eligibility. If eligible, you will be referred to a transplant center for further evaluation. Donors have the ability to choose which transplant center they would like to be referred to as part of the initial questionnaire.

How will my personal data be used?

- The information you share will help us understand if you might be a good match to be a living liver donor.
- Your answers will be compared to the guidelines that transplant programs in the ALF Living Donor Network typically use to evaluate donor candidates.
- This is an early step to see if living donation could be a safe and possible option for you.
- If you seem like a potential match, a transplant center may reach out to you for the next steps.
- Sharing your information doesn't mean you're committing to donate or that you'll definitely be contacted — it just helps us start the process.
- Please view the complete terms of use available on the ALF Living Donor Network site: LivingDonorNetwork.liverfoundation.org.

What if I am not accepted as a donor?

When transplant centers evaluate potential living donors, the donor's health is the number one priority. Transplant centers use certain criteria to ensure a donor's health will not be compromised through the selfless act of organ donation. If you are not accepted as a donor, your journey to help liver patients doesn't have to end there! Your voice is powerful and using it to raise awareness about living donation is one of the most important ways you can help advance the field and help more patients find a match.

Consider sharing ALF's comprehensive <u>Living Donor Liver Transplant Information Center</u> with your social media networks. This free resource includes information for those looking to <u>find a living donor</u>, resources for <u>those considering donation</u>, a complete <u>toolkit</u> with educational information for donors and recipients, and a series of 60-second videos about the living donor liver transplant process. You can also become a <u>Liver Life Advocate®</u> and help us expand access to care and increase living donor protections on Capitol Hill.

Even if you are ineligible to donate a portion of your liver to someone in need, you have already shown such courage and strength to help liver patients! Your voice is powerful—raising awareness about living donation save lives.

How do I register?

Ready to become a non-directed liver donor and help save a life? Scan the QR code on the last page or visit <u>LivingDonorNetwork.liverfoundation.org</u> to go directly to the ALF Living Donor Network powered by Medsleuth. You may also email us at <u>LivingDonorNetwork@liverfoundation.org</u>.

What is living donor liver transplantation? How is it possible?

Living donor liver transplantation, is a surgical procedure where a healthy person donates a portion of their liver to a child or adult in need. This is possible because the <u>liver is the only organ in the human body that can regenerate</u>—both in the donor and the recipient—within a few months. Learn more about the process in this <u>60-second animated video</u>.

What are the benefits of becoming a living organ donor?

By being a living donor, you have the opportunity to give someone a second chance at life. Not only will you change the course of the recipient's life, but the course of their loved ones' lives as well.

If I qualify as a nondirected living donor candidate, what is the liver transplant evaluation process like? If you qualify as an eligible donor, you will be connected with a transplant center for a full transplant evaluation to ensure optimal safety for you and the recipient which includes:

- Blood tests & imaging to check overall health, liver anatomy and blood type compatibility
- Psychological assessments to confirm you understand your risk and are donating voluntarily
- **Consultations** with hepatologists, transplant surgeons, social workers and sometimes nutritionists to ensure you are a good candidate and have adequate support at home.

What are some potential risks of becoming a living organ donor?

If you are a qualified candidate, your transplant center will go over any specific risk factors you may have during your formal transplant evaluation. The long-term health risks of living donation for someone determined healthy enough to donate are low, however, like any surgery there are some immediate risks which may include:

- Allergic reaction to anesthesia
- Injury to tissues or other organs
- Infection

- Blood clots
- Bleeding
- Pneumonia

May I speak with a living donor to ask questions and learn what to expect?

Yes! <u>Caring Connections—an ALF peer to peer support program</u> can connect you with a living donor mentor. Through ALF's online peer mentoring platform, you are matched, one-to-one, with a trained peer mentor and can communicate safely and securely by messages or video chat. The platform makes it easy to share your questions, experiences, and challenges with a trusted peer who understands what it's like to be in your shoes. To join this free program now head to <u>liverfoundation.org/caringconnections</u>.

If I have donated a kidney, can I still be considered for liver donation? Yes, living liver donation is a viable and safe option after kidney donation. The transplant team will carefully review your medical information and evaluate whether liver donation after kidney donation is an option for you.

Are there costs associated with becoming a living donor? What is covered by insurance?

The recipient's insurance usually covers a living donor's medical expenses, including evaluation, surgery, and follow-up care. However, non-medical costs like travel, lodging, meals, and lost wages are not typically covered. While donors cannot be paid, recipients or charitable programs may help cover these expenses. Organizations such as National Living Donor Assistance Center (NLDAC), which operates the Living Organ Donation Reimbursement Program (LODRP), can currently assist non-directed donors with their travel expenses, lost wages and dependent care, regardless of their recipient's income. Read a summary of the program here, or learn more by watching these two insightful videos: <a href="https://living.nimer.com/living/incommons.co

May I choose my recipient?

Typically non-directed, or altruistic, donors are individuals who give the gift of life to someone they don't know, however, you do have the opportunity within the ALF Living Donor Network to choose between a child or adult transplant center. If you are open to donating to either a child or an adult, centers will aim to allocate the liver lobe to the recipient that needs it the most. Also, if you are aware of a patient actively looking for a living donor (i.e. through an online social media campaign, news article, etc.), you may enter that person's name into your questionnaire.

<u>Note</u>: A donor who identifies a specific recipient may not be able to qualify for the same level of financial assistance from the National Living Donor Assistance Center (NLDAC) as the recipient's income is assessed prior to the donor being approved.

Will my information be shared with the recipient? Is it possible to meet them? Unless you and the recipient agree to exchange information, the process will remain entirely anonymous. If you and your donor choose to meet or exchange emails, your transplant center can help arrange that for you.

What if I change my mind during the process and no longer want to become a living donor?

The decision to become a living donor (or not) is yours to make – you should never be pressured by anyone to donate. Your safety and wellbeing are of utmost importance. Once you are accepted as a donor there are multiple steps along the way to ensure that you are still comfortable in going forward with donation.

To learn more about living donor liver transplants, visit our <u>Living Donor Liver Transplant Information Center</u>. To register to become a living liver donor today, scan the QR code now.



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