

LIVER PAIRED DONATION

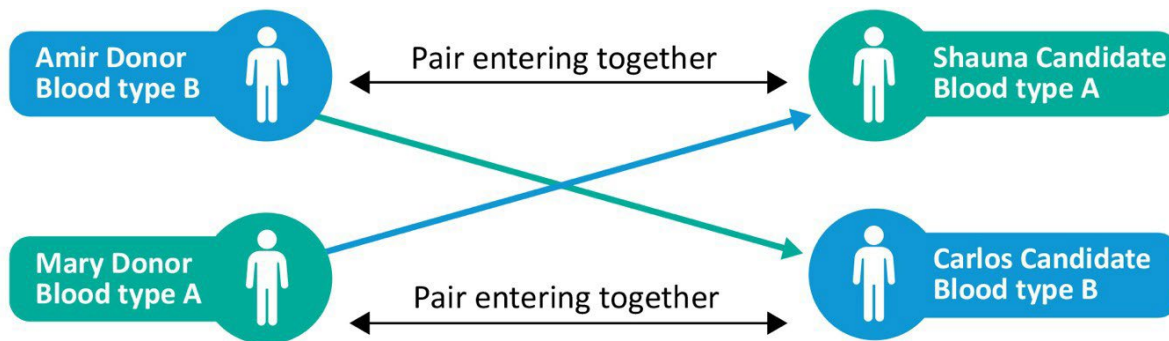
UNOS Liver paired Donation Pilot Program Frequently Asked Questions

What is liver paired donation?

Liver paired donation, also called liver swap, matches donor and candidate pairs with other pairs across the country. Some pairs enter because they do not match each other as they had hoped. Others enter to find a better match. Even pairs that match each other can enter a swap. Having matched pairs join can help to find more swaps for everyone.

Here is an example:

Amir wants to donate part of his liver to Shauna, but they do not match. Mary wants to donate to Carlos, but they do not match. Mary is a match for Shauna, and Amir matches Carlos. Swapping donors and candidates in this case allows both transplants to happen. This is liver paired donation.



What is the United Network for Sharing Liver Paired Donation Pilot Program?

UNOS is the mission-driven non-profit serving as the nation's transplant system under contract with the federal government. UNOS is sponsoring the Liver Paired Donation Pilot Program (Pilot Program). The Pilot Program's goal is to increase the number of living liver transplants. Liver transplant surgeons and other experts in transplant worked together to create this program. Although swapping livers is new, transplant programs have been doing it with kidneys since 2002. The living liver donation programs in the Pilot Program are the most experienced in the country. Together these hospitals have performed hundreds of living liver transplants over the years.

What are the benefits of taking part in a liver swap?

- The transplant may last longer and the candidate may have a better chance of long-term survival
- Candidates may not have to wait as long for a transplant, decreasing their risk of dying while awaiting transplantation
- Candidates can have surgery while they are healthier and better able to withstand surgery
- Each donor helps their loved one
- Each donor and candidate can help other patients receive a transplant

Why is a national swap program needed?

Some transplant hospitals swap livers within their own hospitals. The Pilot Program will test if having a national, multi-hospital swap program will increase the number of living liver donor transplants across the country.

What are the basic steps in the Pilot Program process?

The transplant team approves the candidate and donor for the program. During approval, the transplant team reviews how swapping livers works with donors and candidates and answer all questions. Once approved, the transplant team registers the donor and candidate into the program. Once registered, a computer system looks for potential swaps.

Who can participate in the Pilot Program?

Candidates and donors must enter the Pilot Program together as a pair. The transplant team will approve both the donor and candidate for the Pilot Program. All transplant programs in the pilot follow the same minimum standards for approving candidates and donors. Some programs may have additional approval requirements above the standard.

If the pair is a good fit for a liver swap, their transplant team enters them into the Pilot Program.

All candidates must:

- Be at least 12 years old and eligible to receive a liver transplant
- Be accepted for liver transplantation and registered for a deceased donor transplant
- Have a lab MELD score no greater than 25 at the time of entry into the program
- Not need an emergent liver transplant
- Enter the program with a willing and suitable living donor
- Consent to participate in the program

All potential living donors must:

- Be at least 18 years old
- Complete a series of medical and psychosocial evaluations to determine if they are eligible to donate a part of their liver

- Enter the program with a known candidate
- In the case of a non-directed donor, the donor must be willing to enter the program with a candidate unknown to them
- Consent to participate in the program

What are the costs to joining the Pilot Program?

There is no cost to either the donor or the candidate to register for the program. In addition, potential donors and candidates will not receive payments if they participate in the program.

What is the chance of finding a swap and how long will it take?

Since swapping livers between different transplant programs is new, it is unknown how long it will take to find a swap. The Pilot Program hopes to answer this question. Factors affecting the chance of finding a swap include:

- *Blood Types:* Donors and candidates with more common blood types will have a greater chance of finding a swap and a greater chance of finding a swap sooner
- *Size of liver needed:* It may take longer to find a matched donor for a candidate that needs a larger piece of liver
- *The number of pairs registered in the Pilot Program:* The greater the number of pairs in the program, the quicker candidates and donors will swap

How are candidate/donor pairs matched-up?

- The Pilot Program's computer system matches donors and candidates.
- Blood type, age, donor and candidate size, and liver size and structure all determine if donors and candidates are a good fit.
- The program gives special considerations for the distance between the two matched transplant programs, younger donors, candidates with higher MELD scores, and if the candidate is a prior living donor.
- When all other aspects are equal, the program offers the swap to candidates who have been registered the longest.

What happens after a swap is found?

- A computer at UNOS looks for potential swaps. When a possible swap is found, UNOS offers the swap to transplant team
- The transplant teams decide if the donor is a good fit for their candidate. If they are, the transplant team will accept the offer.
- Donors and candidates who enter the program together always match at the same time.

How is a candidate/donor pair informed of possible swap?

- The candidate's transplant team notifies the donor and candidate pair of the swap after the team confirms the matched donor is a good fit
- Both transplant teams in a swap must accept the offer before they can notify candidate/donor pair of possible swap

How will donors and candidates know that a swap will be a good fit?

The transplant team reviews the donor who matched their candidate to see if they are a good fit.

- They will review the donor medical and psychosocial information and images taken of the liver
- They will talk with staff at the matched donor hospital
- If the donor is traveling to the matched candidate's hospital for donation, the team will meet with the donor. This meeting may be a virtual visit or an in person visit.
- If additional tests are needed to see if the donor is a good fit, the team will order those tests
- The entire transplant team will review the donor as a group to determine if the swap is a good fit
- If at any point the transplant team feels the donor is not a good fit for the candidate, they will decline the offer

What information do matched candidate/donor pairs receive about each other?

- To protect their privacy, donors and candidates receive limited information about each other before surgery.
- Donors and their matched recipients may have the opportunity to communicate or meet after surgeries, only if both agree
- Donors and candidates have the right to remain anonymous if they choose

Where will the donation and transplant take place?

Transplant: The transplant takes place at the transplant hospital where the candidate is registered.

Donation: Transplant teams will discuss the following options with donors:

- Donor travels to candidate's hospital for their surgery
 - This option is the more typical approach
 - You will be provided information about financial assistance to help with travel costs
 - Having the donor travel will decrease the time between donation to transplant surgeries
 - This improves the chance the liver will function immediately after transplant
 - It also decreases travel-related risks to the liver
 - Donors will visit with their matched transplant program prior to surgery to meet the team that will care for them. Meetings may be virtual, in person, or a combination depending on individual circumstances
 - Donors must bring a support person with them when traveling for donation

- Liver is transported to matched candidate's transplant hospital

There may be times when it is okay for the donor to have their surgery at their evaluating hospital and the liver shipped to the candidate hospital

Who decides if a donor will travel or not?

- Transplant teams will discuss the benefits and risks of donors traveling versus shipping livers, and discuss the best option with both donor and candidate
- Donor can decline to travel at any time
- Candidate can decline to accept a shipped liver
- The swap will only move forward if it is agreed that that both donors travel or both livers are shipped

Who will provide medical care for donors after surgery?

When a donor travels, the transplant program that performed their donation will take care of them until they are able to return home.

- The transplant team will request that donor stays local for a certain amount of time after donation to make sure they are safe to travel. This time period will be discussed with the donor prior to surgery
- After returning home, the donor can choose to have their follow-up care at the transplant program that initially evaluated them or where they had surgery
- If a donor does not live near either transplant program, options may be available for follow-up care closer to donor's home

Who pays for the donor's medical care?

The matched recipient's insurance pays for the pre-surgery testing, donor hospitalization and follow-up care.

Can matched pairs meet?

- Identities of matched donors and candidates remain anonymous prior to donation and transplant surgeries. If both donor and recipient agree, they can meet or send letters/email after surgery. Both donor and recipient must be medically stable to meet.
- It may be possible for the candidate to write a card to the donor before the donation and transplant surgeries. The matched donor's transplant team can give the card to the donor after they approve surgery but before the donation occurs.
- After surgery, a donor may receive limited information about the recovery of their matched recipient, and vice versa; however, these updates are not mandatory.

Each transplant hospital will share their policies for donor and candidate communication and meeting. If the policies between the transplant programs differ, the two programs will choose one to follow.

What information does UNOS need to find swaps?

A candidate who joins the Pilot Program must be on the wait list for a deceased donor. All information about the candidate on the wait list will be available for use in the Pilot Program.

Donor information available for use in the Pilot Program includes, but is not limited to name, date of birth, relationship between the potential living donor and their candidate, blood type, height, weight, results of blood tests, imaging of the liver and other medical information helpful to identifying potential swaps.

UNOS will share donor information with the transplant team at the matched candidate's transplant program. Information is stored indefinitely.

How will information remain confidential?

Donor and candidate medical information will remain confidential to the extent required by law.

UNOS and the transplant programs in the pilot will not share donor and candidate information with anyone outside of the UNOS Liver Paired Donation Pilot Program, without clear permission. Access to the UNOS database is through a secure, password-protected system. UNOS offers swaps to transplant programs through secure email.

The potential donor's health insurance may provide the matched candidate with the name of their actual matched donor on an "estimate of benefits" form before surgery. This means that recipients may learn their matched donor's identity. Transplant hospitals will make every effort to keep this from happening.

Once in the Pilot Program, what else can the candidate and potential donor do to stay active?

The candidate and potential donor remain active until their transplant team removes them. Donors and candidates can request to be removed at any time.