Welcome to the Living Donor Liver Transplant Program

The Living Donor Team at Cleveland Clinic is here to help you have a successful transplant and give the gift of life. We have designed an extensive teaching program to help you learn about the living donation process, as well as your individual health needs and medical care before and after liver transplant donation.

Living Donor Liver Transplantation offers a better chance when time matters. Cleveland Clinic’s Living Liver Donor program is the only one in Ohio performing both adult and pediatric living donor liver transplants.

Outcomes for living donation at Cleveland Clinic are among the best in the country. To learn how Cleveland Clinic is ranked compared with other national transplant centers, visit the U.S. Transplant Scientific Registry of Transplant Recipients at www.srtr.org.

For more information about the Liver Transplant Living Donation Program at Cleveland Clinic please visit www.clevelandclinic.org/liver/living-donor-clinic.
THE LIVER TRANSPLANT PROGRAM

Cleveland Clinic’s liver transplant program is an important part of a broad medical and surgical strategy to manage all patients with liver disease with the therapy best suited to that patient. Experts in all areas of liver disease take part in the evaluation, management, treatment and follow-up of these patients.

Cleveland Clinic’s liver transplant program is a member of the Ohio Solid Organ Transplant Consortium (OSOTC) and UNOS, meeting all their requirements for liver transplantation. Our program is approved by Medicare for liver transplant and also has OPTN/UNOS full approval for live liver donation.

THE LIVING DONOR ADVOCATE TEAM

The Living Donor Advocate team functions separately from the organ recipient group. The team consists of independent, unbiased transplant professionals working on behalf of the donor who focus on protecting the safety and welfare of potential living organ donors. Members of the team include: Hepatology, Surgery, Nursing, Bioethics, Behavioral Health, Social Work, and an Independent Living Donor Advocate.

LIVING DONOR LIVER TRANSPLANTATION

In living donor liver transplantation a portion of a donor’s healthy liver is transplanted into a recipient in need. Living donor liver transplantation is possible because the liver, unlike any other organ in the body, has the ability to regenerate (regrow). Most regeneration of both the donor’s and recipient’s livers occurs within the first 8 weeks. More than two decades ago, surgeons around the world began to perform these procedures using adult donors for children who needed transplants. The surgical team at the Cleveland Clinic has pioneered and perfected the use of living donors in both pediatric and adult recipients.

BENEFITS TO BECOMING A LIVING LIVER DONOR

Typically, organs for transplantation are obtained from deceased donors, after their families give permission. Unfortunately, there are not enough deceased donor organs available for everyone who needs a transplant and, as a result, the number of patients on the transplant waiting list continues to grow. Because of this organ shortage, patients waiting for a liver may die or become too sick to undergo a transplant. Living donor liver transplantation is an important option for many patients on the waiting list. Finding a living donor from a healthy adult (relative, friend, or altruistic donor) shortens waiting time, increases long term transplant success, and frees up a liver for a patient on the waiting list who does not have this option.

POTENTIAL RISKS TO LIVING DONATION

At Cleveland Clinic, donor safety is our main priority. Our team will evaluate all the potential risks and discuss them with you before the procedure. As with any major surgery performed under general anesthesia, complications such as bleeding, infection, heart complications, blood clots, stroke, and even in rare cases, death are possible.

POTENTIAL FINANCIAL ASPECTS

The recipient’s insurance will cover all of the donor’s evaluation, surgery, hospitalization and follow-up care costs. Potential financial risks with being a living donor may include; personal expenses for travel, housing and lost wages. Your transplant coordinator will discuss with you during your evaluation possible options for financial assistance. Please see the RESOURCES page for more information regarding financial assistance.
WHAT POTENTIAL LIVING DONORS NEED TO KNOW

All potential donors will undergo a complete medical and psychosocial evaluation. Not everyone is suitable or eligible to become a living liver donor based on a number of factors such as: pre-existing medical conditions, psychosocial concerns, or liver size. Donating an organ is a personal decision that should only be made after becoming fully informed about its potential risks and benefits.

LIVING DONOR CRITERIA

- The ideal candidate is between the ages of 18 and 60
- Compatible Blood Type
- Physically and psychologically healthy & without a history of drug or alcohol dependence
- Understand the risks of the surgery and provide informed consent
- Proof of medical insurance
- Sufficient family, caregiver, social & economic support

<table>
<thead>
<tr>
<th>Recipient Blood Type</th>
<th>Donor Blood Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>A</td>
<td>A or O</td>
</tr>
<tr>
<td>B</td>
<td>B or O</td>
</tr>
<tr>
<td>AB</td>
<td>A, B, AB or O</td>
</tr>
</tbody>
</table>
THE EVALUATION PROCESS

The decision to become a living donor begins with an evaluation to make sure that your liver is normal and large enough, and that you do not have any medical or psychiatric disorders that would make this procedure more risky or difficult for you. We also want to make sure you do not have any medical conditions that could be passed on to the recipient. Finally, we want to make sure that you are becoming a donor voluntarily, and that no one is pressuring you to do this. It is best that our team, as opposed to your own doctor, performs all tests and examinations. For insurance and billing reasons, the evaluation must be done at Cleveland Clinic.

Step One
Once you know your blood type, you can visit the Cleveland Clinic Living Donor website to fill out your personal information at: http://my.clevelandclinic.org/services/transplant-center/transplant-programs/liver-transplant-program/living-donor-clinic
Or call the Living Donor office at 216-444-1976 to speak with a member of the living donor transplant team. During that call, we will collect demographic information (your age, personal and family history, etc.) and you will have a chance to ask questions. Once you confirm that you would like to proceed with a living donor evaluation, you will then be contacted by a transplant nurse coordinator who will take your full medical history and discuss the living donor liver transplant process. Your case will be reviewed by a liver surgeon. If the surgeon feels that you meet the criteria to be considered as a living donor, you will then be contacted to schedule your evaluation. Once the evaluation is scheduled, the Living Donor Advocate will contact you prior to your scheduled evaluation.

Step Two
A thorough evaluation is scheduled to make sure that your liver is normal and to make sure that you do not have any medical or psychiatric illness that would make the procedure risky for you or your recipient. During the evaluation a number of tests and consultations will take place over several days. You will have labs drawn, consults with the medical team and have imaging studies of your abdomen to measure the size of your liver and to look at the liver’s anatomy and blood vessels. The medical doctor and surgeon will review your full medical history, complete a physical exam, and inform you of potential risks and complications.

Step Three
Other tests or consultations also may be necessary, depending on the results of your initial evaluation. For example, you may need a liver biopsy, in which a small piece of your liver is removed and studied. This would be scheduled on a different day. Depending on the type of additional testing needed, there may be times when steps 1 to 3 are combined. This can be discussed with your transplant nurse coordinator during step 1.

The Decision
Once you have completed all the necessary tests, the transplant team will meet to review the test results. The team includes physicians, nurse coordinators, a psychiatrist, an ethicist, social workers, living donor advocate and any specialists who took part in your evaluation. In our decision-making, we put the well-being of the donor ahead of anything else. Your safety is our top priority.
THE SURGERY

HOW IS THE PROCEDURE DONE?
Before performing the actual surgery, many images – including 3D images – of the donor’s liver are analyzed. The surgeons determine the precise size of the donor’s liver, blood vessel anatomy, the exact section of the liver to be removed, and calculate how much liver is needed to allow the transplant recipient to survive. At least 30 percent of the living donor’s liver must remain in the donor. It is possible to safely donate the left or right lobe. A smaller portion of the left lobe, called the left lateral segment, is used if the liver transplant recipient is a small child. During the surgery, the donor’s gallbladder is also removed. The surgery takes approximately 6 hours to perform.

Living Donor Liver Transplantation

- **Right lobe**
  - Adults: Right lobe (60-70%)
  - Small Children: Left lateral segment (15-25%)

- **Left lobe**
  - Adults: Left lobe (30-40%)
Cleveland Clinic has successfully performed the Midwest’s first purely laparoscopic living donor surgery for liver transplantation in an adult recipient. The advanced procedure is available at only a few hospitals worldwide, and Cleveland Clinic is the 2nd U.S. academic medical center to offer this approach for living donor liver transplantation. Unlike open surgery that requires a large incision to access the liver, the laparoscopic procedure is performed with surgical tools and a camera inserted through a few half-inch holes in the abdomen of the living donor. Once the piece of the liver is dissected, the surgeon retrieves the graft through a small incision below the navel. The minimally invasive technique benefits the living donor, who experiences better postoperative recovery and a quicker return to normal life, less pain, smaller scars, and lower risk of an incisional hernia compared with traditional open surgery.

Both open and laparoscopic hepatectomy last approximately 6 hours and are performed using general anesthesia, which means you’ll be asleep during the entire surgery.

One of the main benefits of this procedure is that instead of an 8-20 inch scar that remains after open surgery, patients generally have a scar of about 4 inches. This scar is usually located in the lower abdomen, which tends to be an area that is less painful and less noticeable. In addition, we have observed reduced pain and shorter recovery times after surgery (less than 6 weeks, as opposed to 8-12 weeks for open surgery).

A living donor hepatectomy is a procedure in which a portion of a healthy person’s liver is removed so it may be transplanted to a patient suffering from end-stage liver disease. Due to the liver’s unique ability to regenerate inside the body of both the donor and the recipient, only a portion of the liver is needed for a successful operation. Please note that not every living donor is a candidate for laparoscopic surgery due to their previous medical history.
After surgery you will be transferred to the Surgical Intensive Care Unit (SICU). You will begin to recover from the anesthesia shortly after arriving to the unit and will be monitored closely for signs of immediate or early complications. A dedicated medical team will closely monitor your blood pressure, heart rate, signs of bleeding, and will provide pain control. You will have additional IVs in each arm, a catheter in your bladder, a small tube in your abdomen to drain any blood or bile, and you may have a NG (nasogastric) tube in your nose. You will also have compression stockings around your lower legs to help prevent blood clots. You will be encouraged to sit up in a chair and begin to walk within 24 hours after surgery.

The next day you will be transferred to a regular nursing floor. You will be encouraged to walk several times per day as tolerated. Usually in a day or two you will be able to eat and drink. You will start with clear liquids and gradually increase your diet as tolerated. Your pain will be controlled with IV pain medication to help keep you comfortable and will be transitioned to pill form in preparation for discharge. Once your pain is controlled, you are walking, and eating a regular diet you will be discharged. Your transplant coordinator will meet with you, provide you with discharge instructions, and answer any questions you may have.
FAQ

The Evaluation Visits

Q. Will my recipient be removed from the regular transplant waiting list if I am evaluated?
A. While a potential donor is being evaluated, no changes are made to the recipient’s place on the waiting list. If a deceased donor becomes available for your recipient, your evaluation will be cancelled.

Q. Will my evaluation be covered by medical insurance?
A. The cost of the evaluation, transplant surgery and post-op care will be covered by the recipient’s insurance provider.

Q. Do I need to fast before my appointments?
A. Fasting for at least 12 hours is needed before your first blood work. Please refer to your appointment reminders for all other fasting requirements for a procedure. It is very important that you follow the fasting requirements as the test cannot be completed otherwise.

Q. Should my family come with me to appointments?
A. It is important to have your primary caregiver(s) come with you to your evaluation so they can take part in the process and understand what is involved before you decide to proceed. You and your caregiver will be offered the opportunity to ask questions during your appointments and learn more about the procedure, so you can make an informed decision. We understand that your caregiver may not be able to be present for your entire evaluation, your coordinator will discuss with you which appointments/procedures a caregiver is necessary.

Q. If I am cleared to be a donor, who decides when to do the transplant?
A. This decision is made jointly by the transplant team, by you and by the recipient. The transplant team, especially the physicians caring for your recipient, will determine as accurately as possible the best time to do the transplant, based on the recipient’s medical condition. Once we know this, we will ask you what suits you best, within our limits.

Q. Will my recipient need more testing?
A. The recipient will need to be re-evaluated by the surgeon and will go through a more in-depth examination of blood vessels with venography (a special X-ray).

Pre-Surgery

Q. Is it ok to drink alcohol?
A. It is advised to stop drinking alcohol if you plan to be a living donor. You should not consume any alcohol for six months after donation.

Q. What if I am a smoker?
A. Many experts, including our anesthesiologists, believe that smokers have a higher risk of complications after surgery. Therefore, we very much urge you to stop smoking for at least one to two months before the operation. If you are a current smoker, you will need to undergo a lung function test.

Q. Should I stop taking my medication before the evaluation or the surgery?
A. You should not stop any prescription medication unless your doctor tells you to do so. You should avoid aspirin or non-steroidal medications (such as Advil® or Motrin®) for seven days before a liver biopsy or surgery. These medications affect the ability of the blood to clot and put you at higher risk of bleeding complications. Instead, you may take Tylenol® if needed. Women who take birth control pills or pills for hormone replacement therapy will be advised to stop taking them one month before the surgery and for two-three months after surgery. Taking birth control pills can cause increased risk of blood clots during recovery from surgery.

Q. How long will I be off work?
A. This will depend on the type of procedure you have. If you have the laparoscopic procedure you may be off work for 4 to 12 weeks depending on the type of job you have. If you have the open procedure you may be off work for 8 to 12 weeks. Because people recover differently, with different degrees of fatigue and pain, we will discuss the best timing for you to go back to work during your follow up visits.

Q. Will I be entitled to FMLA or short term disability?
A. It is best to discuss this with your human resources department before you decide to proceed.

Surgery

Q. Do I need to do any special preparation before surgery?
A. The medical evaluation we perform on potential living donors is extremely thorough. You will be scheduled for Final Clearance appointments within 1 week prior to the scheduled transplant surgery. These appointments will be with the transplant surgeon, anesthesiologist, social worker, living donor advocate and transplant coordinator.

Q. Will I have a scar after the incision heals?
A. In most cases, the incision heals quickly, leaving a scar(s) that fades over time, but will always be visible. If a wound infection develops, you may be left with a wider scar that will be more noticeable. Occasionally, people develop what is called “granulation tissue.” This is overgrowing or overhealing of the skin, and it results in a raised scar.
Post-Surgery

Q. How long will I be in the hospital?
A. The average hospital stay for donors is five to seven days. The hospital stay may be longer if you have complications.

Q. Will I be in the same room as my recipient after the surgery?
A. No. You will be in a separate room for your entire hospitalization.

Q. Will I be in the Intensive Care Unit after my surgery?
A. After your surgery, you will be taken to the surgical intensive care unit (SICU) for close observation by the nursing and medical staff. You will remain in the SICU overnight, until you have completely awakened from the anesthesia. Once we see that everything is stable and that you do not have any bleeding or other complications, you will be transferred to a regular nursing floor.

Recovery from Surgery

Q. Will I need to come back to the hospital for check-ups?
A. This procedure is major surgery, and we need to keep track of you very closely at first to make sure everything is OK. You will be scheduled for your first follow-up including lab work, surgeon visit, and if necessary visit with the social worker within 1 week of hospital discharge. You will then be scheduled for follow up and an ultrasound of your liver one week after the first follow up appointment. You will have another check-up at three months with a CT scan of your liver and a final check-up about 12 months after your surgery. In addition to these follow up appointments you will need labs periodically which can be done closer to your home. You may need other appointments as well, depending on how you are feeling. You should have an annual physical exam with your primary care physician after being a living liver donor.

Q. Do I need to stay close to the hospital after I am discharged?
A. You need to stay within 1 hour of the Cleveland Clinic for at least two weeks after you are discharged from the hospital. If you have any complications related to the surgery you need to come to the Cleveland Clinic for treatment. If you are from out of town or out of state, your social worker or transplant coordinator will provide you with a list of places available to stay in the area. It is important that you have your caregiver (a friend or relative) stay with you during this time.

Q. Will I need to take any medications after I donate part of my liver?
A. You may get prescriptions for pain medications after your surgery. Other medications may be needed, depending on complications.

Q. When can I begin to exercise?
A. You will be advised to avoid running or abdominal exercises for 3-6 months after surgery. You will need to avoid any heavy lifting for the first 4 weeks, until your abdomen has had time to heal. You should not lift any weights greater than 10 pounds. After 6-8 weeks, if you are feeling well and are not having any complications, you may begin to return to some normal activities, such as low-impact aerobics. Begin slowly and build up gradually. Be cautious with abdominal exercises.

Life After The Donation

Q. If I want to start a family, how long should I wait after surgery to get pregnant?
A. We recommend that you do not become pregnant for at least 1 year after surgery.

Q. When can I restart my birth control pills or replacement therapy?
A. We will discuss with the transplant pharmacist depending on which hormone you are taking.

Q. When will I be able to drive after my surgery?
A. We advise you not to drive for at least the first two to three weeks after surgery. You must be physically and mentally strong, with normal reflexes, and not having any abdominal pain or discomfort before you decide to drive. You must be off all narcotic pain medication such as Percocet or Oxycodeone as these can affect your mental alertness.

Q. Would I be able to donate part of my liver again in the future to someone else?
A. No. Once you donate a portion of your liver, you cannot do so again in the future.

Living Donor Liver Transplant is Lifesaving
MY LIVING DONOR
LIVER TRANSPLANT TEAM

Hepatologist: ______________________________________________________
Surgeon: _________________________________________________________
Liver Transplant Coordinator: ________________________________________
Anesthesiologist: ___________________________________________________
Social Worker: _____________________________________________________
Living Donor Advocate: _____________________________________________
Psychiatrist: ______________________________________________________
Ethics Specialist: __________________________________________________
Other: ___________________________________________________________
Other: _________________________________________________________________

If you have any questions please do not hesitate to contact the liver transplant office during business hours 8 AM – 4:30 PM, Monday thru Friday at 216-444-1976, option 1, option 1 again.

If you have an URGENT matter after 4:30 PM or on the weekends please page the on-call liver transplant coordinator at 216-444-2200. When you speak with the operator please tell them you need the on-call liver transplant coordinator to be paged.

NOTES ________________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
RESOURCES

Cleveland Clinic Liver Transplantation Living Donor Program
my.clevelandclinic.org/departments/transplant/programs/liver/living-donor-clinic

National Living Donor Assistance Center – livingdonorassistance.org
Mission: To reduce the financial disincentives to living organ donation. To this end, we operate a nationwide system that provides reimbursement of travel and subsequent expenses to people being evaluated for and/or undergoing living organ donation. Priority is given to those who could not otherwise afford to donate.

United Network for Organ Sharing (UNOS) – unos.org
Mission: To advance organ availability and transplantation by uniting and supporting or communities for the benefit of patients through education, technology and policy development.

Transplant Living (Division of UNOS) – transplantliving.org
This program provides support and references for transplant patients, their families and their caregivers.
Transplant Recipients International Organization, Inc. triocleveland.org
Mission: TRIO is a nonprofit, international organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education and awareness.

Scientific Registry of Transplant Recipients – srtr.org
Mission: To provide advanced statistical and epidemiological analyses related to solid organ allocation and transplantation in support of the Department of Health and Human Services and its agents in their oversight of the national organ transplantation system.

American Liver Foundation – alf.org
Mission: To facilitate, advocate and promote education, support and resources for the prevention, treatment and cure of liver disease.