

# Becoming a **Liver Donor**



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## You have the power to save lives – Thank You!

Over 16,000 patients in the U.S. need a liver transplant. There are not enough deceased donor livers to meet the need. Patients in Georgia typically wait 1-2 years for a life-saving transplant; living liver donation is key to address the critical organ shortage.

Piedmont Transplant Institute has been performing living donor liver transplant since 2017. Piedmont is currently the only transplant center in the Southeast actively performing adult-to-adult living donor liver transplants. Our outcomes for living donors and recipients are excellent. Everyone on our team is committed to helping others through successful transplantation!

We are glad that you are interested in becoming part of our program through the gift of liver donation. Our team and this booklet will explain each step of the liver donation process to help you make the decision whether liver donation is right for you. We are here to answer any questions you may have, and will support you during every step of the evaluation.

Thank you for considering changing someone's life by becoming a living liver donor.

"To the world you may be one person, but to one person you may be the world"

- Anonymous

## Why living donor liver transplant?

## There are two treatments for end-stage liver failure. No treatment is a cure.

- · Deceased donor liver transplant
- · Living donor liver transplant

#### **Advantages to living donation**

- Shorter time to transplant for most recipients. The average waiting time to receive a deceased donor liver transplant in Georgia is 1-2 years.
- · Recipient may be able to avoid serious deterioration in health and quality of life
- The transplant is a planned procedure
- · Lower rejection rates
- · Livers from living donors function as well as from deceased donors

## **Donor Qualifications**

Parents, spouses, siblings, adult-aged children, relatives, friends, church members, work colleagues, anonymous individuals can all be donors.

#### A liver donor must:

- Be 18 years or older
- Have a Body Mass Index (BMI) of < 30
- Have no medical problems that would increase the long-term risk of developing liver disease
- Be fully informed of the risk, benefits and alternatives to liver donation and transplantation
- Be competent to understand the risks of liver donation and make an informed decision to donate
- Feel no pressure or coercion to donate
- Have no financial motive for donation
- Understand that there are alternative therapies for the recipient including alternate donors and deceased donor transplant

#### Do I have to be a "match"?

Only a compatible blood type is necessary to be considered for potential liver donation. There are, however, anatomic considerations of the donor liver that will be evaluated prior to donation.

## **Donor Evaluation Process**

During the donor evaluation, we will ensure you are healthy enough to donate. Additionally, you will learn about the potential health, financial and social impact of liver donation to help you make your decision. Information you provide to us is **strictly confidential** and not released to anyone outside of the transplant team. This includes your intended recipient. We cannot discuss your health or test results with them without your permission.

This is an outline of our process before, during and after liver donation. Each step is discussed in further detail.

- Health history and review of family history
- · Blood typing
- · Specialized CT scan and MRI of liver
- Surgeon consult
- Lab work to check liver function and screening for inheritable conditions
- Completion of a 1-2 day clinic visit at Piedmont Hospital
- Review of all testing by the Living Liver Donor Committee to determine donation candidacy
- Pre-operative visit prior to surgery
- Donation surgery
- Follow-up clinic visits in the transplant clinic at 2 weeks, 3 months, 6 months, 12 months, and 24 months postdonation
- Follow-up with your primary care physician annually

#### **Health history questionnaire**

The questionnaire can be done online or printed and mailed to your coordinator. We will review your medical, surgical and social history to determine whether you have any conditions that would preclude liver donation including:

- Surgical History
- Obesity with BMI > 30 (up to 35 considered on case-by-case basis)
- Transmissible disease such as HIV, Hepatitis B or C
- Cancer

- Psychiatric disease
- Current pregnancy
- Use of hormone replacements or oral contraceptives
- Alcohol use history

After completion of the questionnaire, we will review your health history and determine how to proceed. We encourage you to read this booklet before proceeding further. We will assess your interest in liver donation before further testing. We encourage you to ask questions at any time during the process!

#### **Blood typing**

The next step is to check if you and your recipient are a "match". In order to directly donate to your intended recipient, you must have compatible blood types.

Recipient blood type	0	A	В	АВ
Compatible donors	0	A or O	B or O	A, B, AB and O

#### **Liver anatomy**

After verification of blood type compatibility, you will complete a specialized liver MRI and CT. This imaging determines if your anatomy is favorable for donation. The imaging will assess your liver for size, fatty deposits, and anatomy which includes your portal veins, hepatic artery, hepatic veins and bile ducts. The surgeon will see you after your imaging and determine if you are a surgical candidate. If you are a surgical candidate, you will have blood work completed to test for HIV, Hepatitis B and C, screen for inheritable traits, and a drug screen.

#### **Clinic visit**

If you are determined to be a surgical candidate, you will be scheduled for a 1-2 day clinic visit to the Piedmont Transplant Institute in Atlanta. You will have several tests and consults performed during your visit with us. These may include:

- · EKG to check your heart rhythm
- CXR to screen for lung disease
- Complete history and physical by a transplant liver physician
- Psycho-social evaluation
  - o Psychiatrist
  - o Living donor advocate
  - o Social worker

#### **Additional testing**

- Pulmonary function tests current or prior smokers
- Evaluation by a transplant dietician (candidates with BMI > 30)
- Hematology consult if deemed necessary by hepatologist

#### **Risks of the evaluation process**

- Testing could reveal a reportable infectious disease or serious medical condition that requires follow-up testing
- A genetic condition may be identified that affects your ability to donate
- You can have an allergic reaction to the contrast used in the CT scan (tell us if you have an iodine or shellfish allergy)

#### Long-term medical risks of liver donation

- After liver donation function is affected in less than 5% of the cases.
- The liver will grow to its original size within 2-3 months.
- Although end-stage liver failure is rare in prior living liver donors, they receive priority on the transplant waiting list. Of the more than 5,000 liver donors in the United States between 1999 and 2016, we know of 5 listed for liver transplant.
- Incisional hernia. The risk is less if you follow post-donation lifting restrictions.
- Early detection and treatment of health conditions is key to keeping your remaining liver healthy! Eating a balanced diet, exercising regularly and limited alcohol consumption will also help keep your remaining liver functioning well.
- Risk of blood clots after liver donation: 1/500
- Risk of major complications after living liver donation include pulmonary embolus, liver dysfunction, liver clot, need for liver transplant: 1/1000.

#### **Psychosocial evaluation**

An important part of the evaluation is to help you explore your expectations about liver donation. Considerations about donation that we want you to consider include:

- How will donation impact your relationship with the recipient?
- What do you anticipate your reaction will be before and after donation?
- How will you feel if something happens to the recipient such as rejection, loss of the transplant, or serious complication such as infection or death?
- How well do you feel the recipient will take care of the liver transplant?
- Are you feeling pressure from the recipient or anyone else to donate?

We encourage you to speak openly about your concerns such as these with our living donor coordinator, social worker, living donor advocate, or transplant psychiatrist. We want to address any concern and provide you with the information needed to make your decision. In some cases, it is also helpful to talk to a counselor, religious figure or trusted friend to think through these important considerations.

During the psychosocial evaluation, we will also address financial impact of donation. The recipient's private insurance company or Medicare will pay for the medical cost of the donor evaluation, hospitalization, and post-surgery transplant clinic visits.

There are out-of-pocket expenses that are not reimbursed. There are also important home and work considerations during your period of recovery that may impact your decision to donate. These include:

- Arrangements for your post-operative care: Who will be able to help you at home during your recovery period?
- Who will be able to help you at home during your recovery period?
- Transportation to clinic visits pre and post-donation
- Lodging (out-of-town donors)
- Child and pet care
- Employment: lost time, job security, lost wages
- Impact on health insurance eligibility and premium costs
- Out-of-pocket expenses including prescription medications

The Georgia Transplant Foundation (GTF), through the Donor Assistance Grant, can pay for certain expenses if assistance qualifications are met. These include travel expenses for evaluation and donation (airfare and accommodation), and living expenses while the donor is out of work post-donation. Your coordinator and social worker can provide you with more information about the GTF programs.

It is illegal for a donor to be compensated or paid, directly or indirectly by the recipient, the recipient's family or any other party for donating a portion of your liver.

#### **Cancer screening**

You must be up-to-date with age-appropriate cancer screening in order to donate. These tests must be reviewed before we can approve you to donate. We can help you obtain these tests if needed:

- Colonoscopy report donors 50 years or older
- Mammogram report female donors 40 years or older (study within last 2 years)
- PAP report female donors (result within past 3 years or per gynecology recommendations)

## **Donor Committee Approval**

The testing results obtained during your clinic evaluation will be discussed in Liver Donor Committee after your visit. The committee will decide if you are 1.) approved for donation, 2.) a possible candidate pending review of further testing, or 3.) unable to donate a liver due to medical or psychosocial reasons. Your donor coordinator will discuss the committee decision with you by phone and send you a letter. Your coordinator will assist you in scheduling if additional testing is required.

You can withdraw from the evaluation process or your consent for surgery at any time up until donor surgery. We are here to provide you with the information you need to make this important determination. We support your decisions. You may discover during the clinic evaluation that liver donation is not right for you. We can provide you with a general, non-specific statement that you are not a donor candidate should you decide to withdraw from the process.

## **Preparing for Surgery**

Once approved for donation, transplant surgery is scheduled.

If you are working, arrange for time off work. Most donors return to work 4-6 weeks after surgery (average 4 weeks). Your donor coordinator can assist you in completing FMLA and short-term disability forms.

Approximately one week prior to surgery, you will be seen by a transplant surgeon for a pre-operative exam:

- Review medical history and allergies
- Give instructions on medications the day of surgery
- Obtain pre-operative labs
- Answer questions about the donor hepatectomy surgery

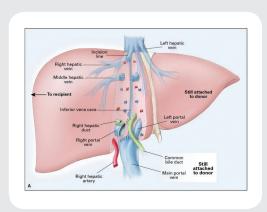
Donors needing lodging the night prior to surgery will be provided a room in the Guest Center. You will not be able to eat or drink anything after midnight prior to your surgery. You will come to Admissions 2 hours prior to your scheduled surgery.

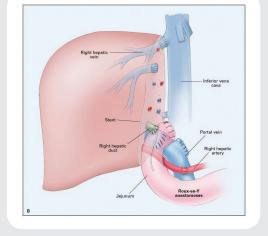


## **Donor Surgery**

#### What can I expect during my hospital stay?

- Liver donor surgery takes about 5-6 hours.
- Surgery is under general anesthesia. An IV is placed in your arm vein to administer intravenous fluids and medications. A central line is also placed to provide additional fluids and medications. A urinary catheter (Foley) is inserted into your bladder to measure your urine output before and after surgery. After intubation, an arterial line is placed for intraoperative monitoring.
- A drain will be placed during surgery to monitor for bile leaks. This should be removed prior to discharge.
- After surgery, you are monitored in the post-operative recovery room and transferred to the intensive care unit for monitoring. The following day, you are transferred to the Transplant Unit.
- Blood tests are done the morning after surgery to ensure your liver function and blood counts are stable.
- The urinary catheter is removed the day after donation.
- You will be able to go home once pain is controlled with pills and you are eating a regular diet. Most donors go home 5-7 days after surgery.





Donor

Recipient

#### What are the surgical risks of liver donation?

- Risks of donation surgery are similar to risks of any general surgery including pain, bleeding, wound infection, urine infection, pneumonia, incisional hernia, injury to other abdominal organs, allergic reaction to anesthesia, and blood clots in the legs. The overall complication rate in donors is 5% or 5/100.
- Approximately 1% or 1/100 donors need a blood transfusion or repeat surgery for bleeding.
- Major, life-threatening complications occur in 0.1% of liver donors, or 1/1,000.
- Getting up and walking as early as the evening of surgery will reduce risk of blood clots in your legs.
- Following exercise and lifting restrictions will reduce your risk of hernia.

#### After you leave the hospital

- You will need a daily injection to prevent blood clots for two weeks after the surgery.
- Pain may last a few weeks but you should experience an improvement in pain within 3-4 days. You will receive prescription pain medication. If the pain is mild, we recommend using plain ibuprofen, (Motrin, Aleve, Advil) and other non-steroidal antiinflammatory medications (NSAIDS).
- The incision was closed with staples. You can shower and let soapy water rinse over the incisions, then pat dry. Please avoid baths and swimming for 4 weeks until your incisions heal.
- Your staples will be removed at your 2-week visit.
- No driving for at least a week. You cannot drive until off prescription pain pills.
- You may feel more tired than normal for 1-2 months after donation.
- You may not lift more than 10 pounds for 6 weeks after donation.
- We will discuss returning to work (if applicable) between 3-6 weeks post-donation during your first clinic visit.
- The donated liver as well as the remnant liver will regenerate to nearly full size within 3-4 months.

#### **Post-donation follow-up**

- We are committed to monitoring the health of our donors. For your safety, you are followed by our center for a minimum of 2 years after donation.
- Clinic visits are at 2 weeks, 3 months, 6 months, 1 year and 2 years after donation. We will test your blood work, check your blood pressure and perform a physical exam.
- Clinical data from these visits is provided to the United Network for Organ Sharing. This helps ensure continued efforts are made to optimize donor outcomes nationally.
- We recommend you maintain a primary care provider who knows of your liver donation and will see you for annual check-ups (recommended for life).
- Any problems you experience related to donation should be reported to our team and documented.

The United Network of Organ Sharing provides a toll-free patient service line to help transplant candidates, recipients, living donors, and family members to understand organ allocation practices and transplantation data. You may call this number to discuss any problem you experience at your transplant center or with the transplant system in general. The toll-free number is 1-888-894-6361.

Piedmont Transplant Institute has a Transplant Surgeon and Hepatologist available 24 hours a day, 7 days a week, 365 days a year. We are always available if you need us. Our toll-free number is 1-888-605-5888.

## **Donor Resources**

#### **Piedmont Transplant Institute**

- piedmont.org/transplant
- Piedmontlivingdonor.org

#### **Financial assistance for donors**

- Georgia Transplant Foundation: www.gatransplant.org (financial assistance tab)
- Living donor assistance program: www.livingdonorassistance.org/

#### **Compare outcomes of specific transplant programs**

• Scientific Registry of Transplant Recipients: www.srtr.org

#### **General information regarding organ transplantation**

- Organ Procurement and Transplantation Network: http://optn.transplant.hrsa.gov/
- United Network for Organ Sharing: www.unos.org
- www.transplantliving.org

## **Meet the Team**

Led by renowned transplant surgeons and hepatologists with decades of collective experience, our multidisciplinary staff takes an integrated approach to care that supports the patient and their caregiver.

Our liver transplant team is an interdisciplinary group that includes psychiatrists, pharmacists, transplant nurses, social workers and dietitians. We work together to formulate a customized treatment plan, ensuring that each patient's medical and psychological needs are appropriately addressed.



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