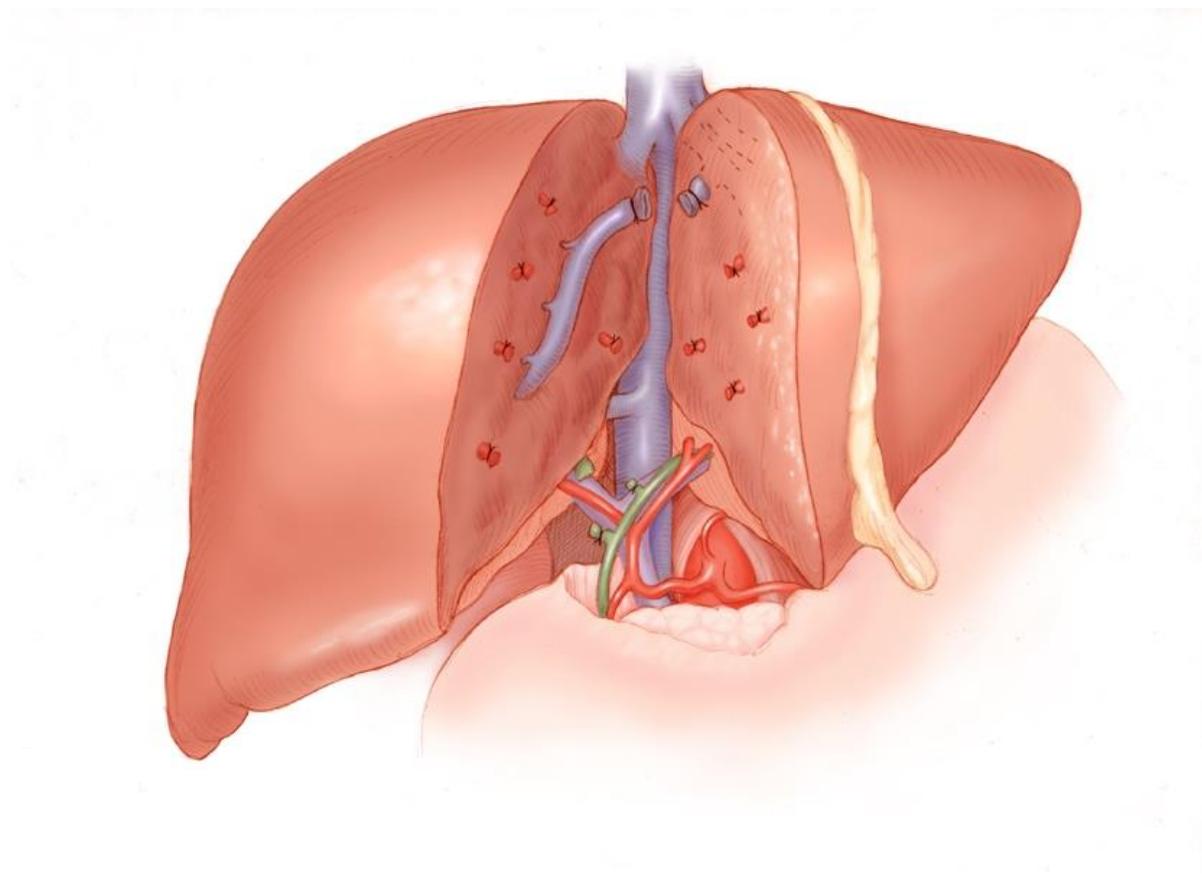


# A PATIENTS GUIDE TO LIVING LIVER DONATION



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## **Introduction**

Donating part of your liver can be a priceless gift, but it must not be undertaken without serious thought. We recommend you begin the evaluation with an open mind and listen carefully to all the members of the living donor team, read this guidebook and research it carefully. Discuss it with people close to you as well. This is a completely voluntary procedure and at no point should you feel coerced or obligated to undergo surgery.

Living donation will not provide any benefit to you except the knowledge that you have tried to save a life, although occasionally the evaluation process may uncover an illness that you may not have known about. The benefit to the recipient is that he or she can be transplanted sooner in a controlled situation prior to the development of acute life threatening complications and further progression of the liver disease. The outcome of the living donor liver transplant is not guaranteed. Its benefit is the timing of the operation, which is likely sooner than waiting for a deceased donor. Having a living donor evaluation will in no way effect the recipient's placement on the waiting list.

A potential recipient of a live donor liver transplant must 1) be deemed a candidate for a deceased donor liver transplant, 2) meet our current listing requirements and 3) be listed with UNOS (United Network for Organ Sharing). Adult patients who have fulminant hepatic failure (acute liver failure) or who are critically ill may not be eligible to receive a live donor transplant because a partial liver transplant may be too small. Living donation must be performed when the recipient is still well enough survive with a partial liver.

**Donor criteria for live liver donation: In order to be evaluated for living donation the potential donor must meet the following requirements:**

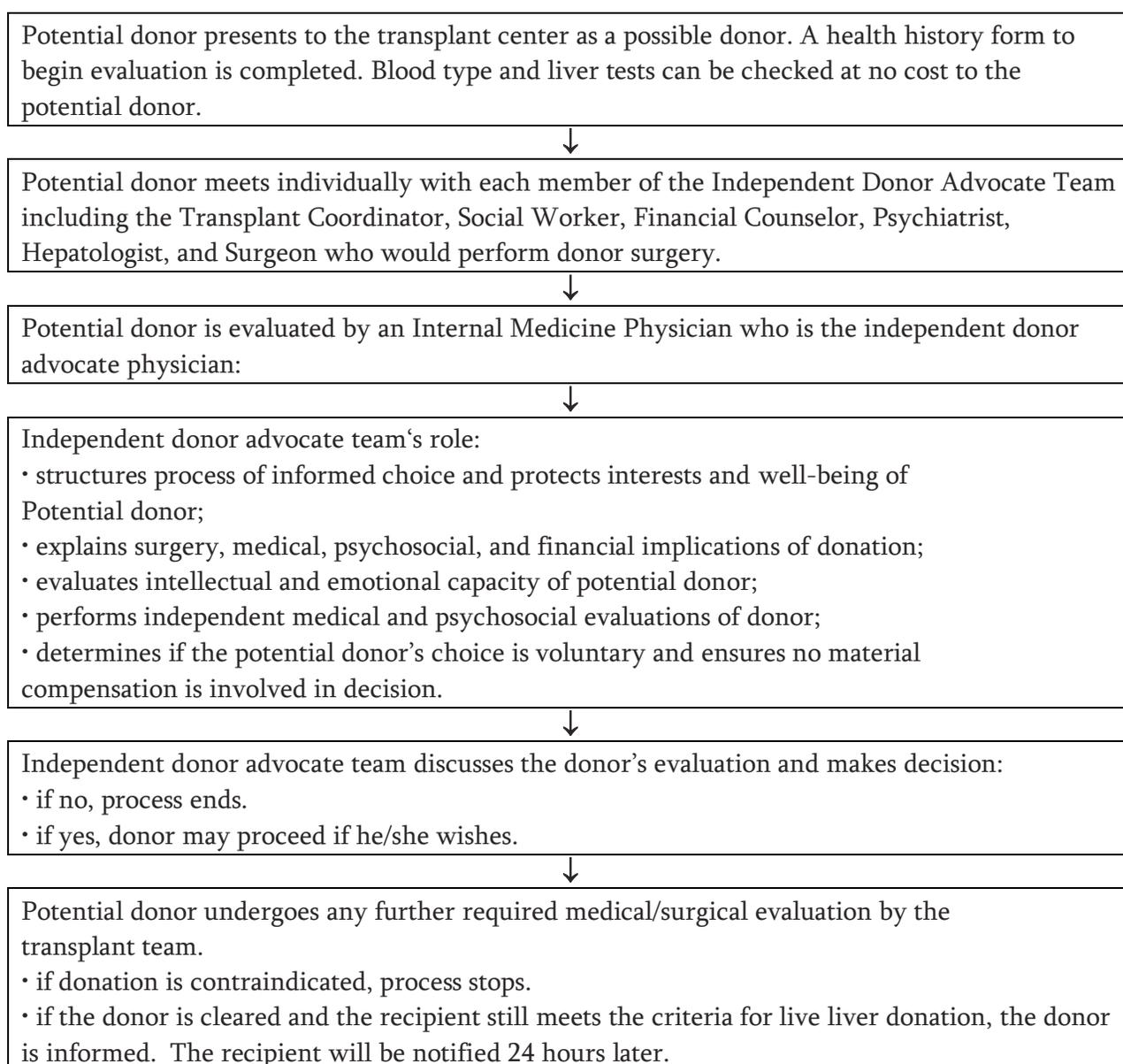
1. A person between the age of 20 and 60.
2. The donor must have a compatible blood type to the recipient.
3. They must be medically healthy and physically fit.
4. They must not have a liver disease or active hepatitis.
5. They must not have severe psychological disorders or active substance abuse.
6. They must not be morbidly obese or have significant fat within their liver.
7. They must not expect to receive payment or material compensation from anyone for their gift.
8. They must not feel coerced or forced to donate.

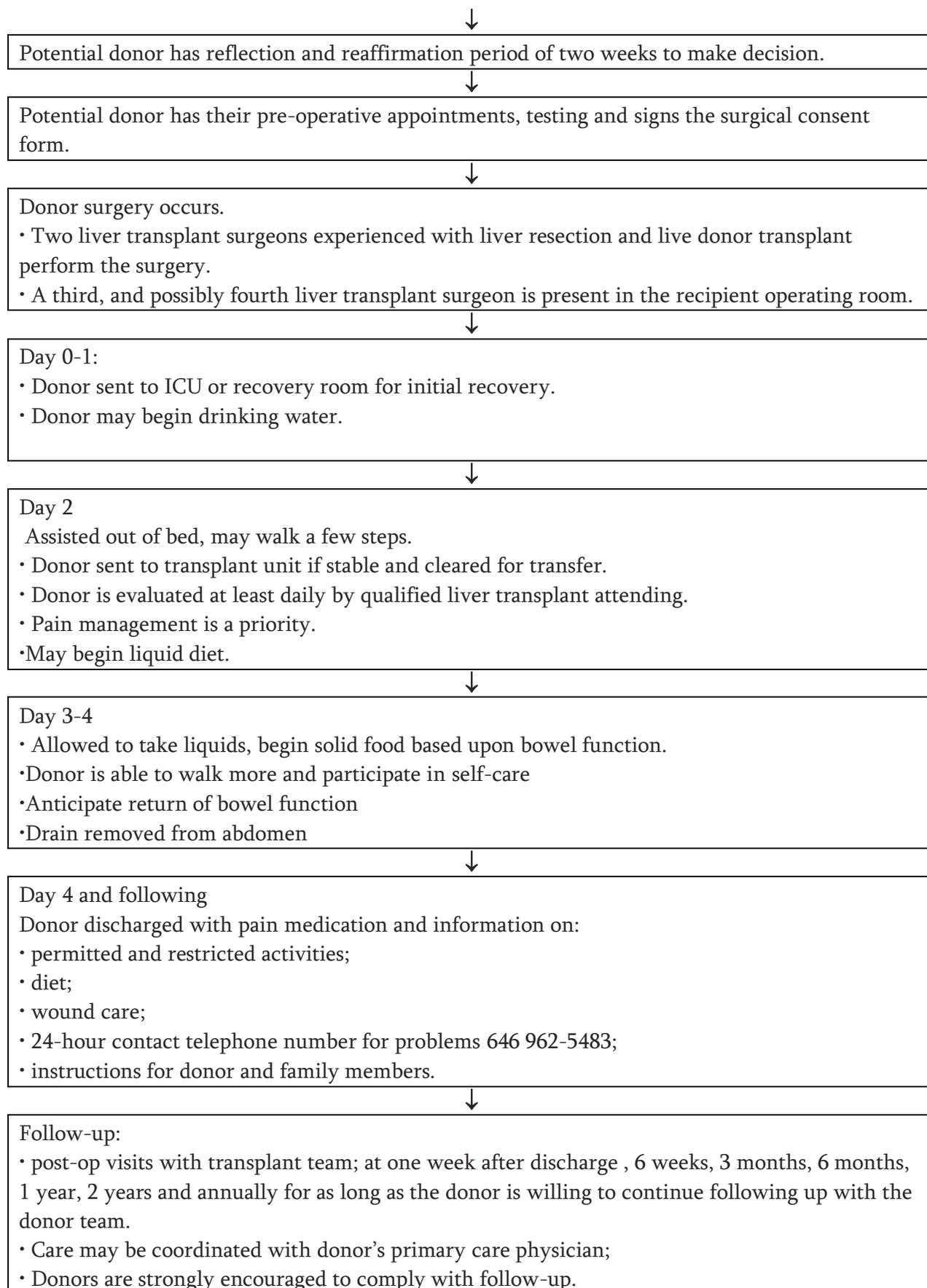
If you are interested in becoming a living liver donor, the first step to beginning the evaluation is to contact the center online or call and speak with the Living Donor Coordinator. It is required that the person who is interested in donating initiates the contact. Only one donor is evaluated at a time. A comprehensive medical and psychosocial evaluation with our living donor team will be scheduled. The living donor team will be concerned solely with your well-being and is not involved with the care of the potential recipient. Only after you are deemed medically well enough to undergo this type of surgery will a surgery be scheduled. It is important to know that you may decide not to donate at any time during the process. The recipient and their team of doctor's will not be informed that it was the donor's decision to end the process. It is never too late to back out!

The alternative to living donation is deceased liver donation (previously called cadaveric transplantation), using a liver from a donor who has died. Should you decide not to donate a portion of your liver; the potential recipient will continue to receive care by the liver transplant team at the Center for Liver Disease at New York Presbyterian Hospital. His or her name will remain on the UNOS/ Organ Procurement and Transplantation Network (OPTN) liver transplant waitlist and he or she will wait for a deceased donor organ or another living liver donor to become available. Their position on that list does not change as a result of considering live donation.

The process of evaluation once you call the center is shown below:

### **Live Liver Donation Process**





## **Living Donor Team**

The living donor team is called the IDAT (Independent Donor Advocate Team)

The living donor team is comprised of many people who will meet with you and evaluate and educate you about the process.

They include:

- Donor surgeon
- Hepatologist
- Transplant Coordinator
- Psychiatrist
- Social Worker
- Financial Coordinator
- Internist who is the independent donor advocate

All of the IDAT team members are part of the transplant team except for the Internist and Social Worker. None receive financial gain from participating in the IDAT.

At times you may feel overwhelmed with the information you are receiving from the team members, or you may get tired of repeating your story multiple times but each member plays a critical role in the evaluation process and has important information for you to consider prior to making your decision about donation.

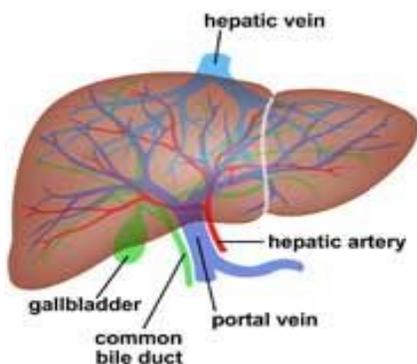
## **Summary of the Donor Evaluation Process**

**Evaluation of the live liver donor is done as an outpatient and is outlined below:**

- 1) **Transplant Coordinator Evaluation & Consultation:** A nurse with training in liver transplantation and donation ensures that all concerns of the potential donor and the donor advocate team are addressed and that the overall process is carried out properly. They will review the Informed Consent with you and answer any questions you may have. Afterward you will be asked to sign the consent if you wish to proceed.
- 2) **Medical Evaluation:** An independent donor advocate who is a medical doctor, and a Hepatologist who is not the primary Hepatologist of the recipient will evaluate the potential donor.
- 3) **Psychiatric evaluation:** The donor psychiatrist evaluates the potential donor for psychiatric illness. Your care partner will accompany you to this appointment.
- 4) **Social Work Evaluation:** The transplant social worker assesses the donor's social support, education level, relationship to recipient, financial status, health insurance, and ability to understand the impact of donation. Your care partner will accompany you to this appointment.
- 5) **Surgical Consultation:** The donor surgeon assesses the donor's surgical risk and reviews the surgery with the potential donor.
- 6) **Independent Internist** A medical doctor, who is outside of the department of surgery, will medically evaluate the potential donor.
- 7) **Laboratory Evaluation:** There are extensive blood tests to rule out medical illnesses, liver diseases, clotting disorders, viral illness, and HIV.
- 8) **Chest x-ray**

- 9) **Electrocardiogram**
- 10) **MRI/MRA of liver or CAT Scan Angiogram of the abdomen with oral and intravenous contrast:**  
These tests show the structure of the liver, its size, anatomy and its blood supply to help the surgical team plan and decide how risky the surgery will be. See Figure 1.

**Figure 1:**



- 11) **Health Care Proxy:** All donors must fill out a health care proxy and submit it to the social worker prior to surgery.
- 12) **Donor Consent Document:** In addition to standard consent form, a donor must review donation consent and sign it with surgeon at pre surgical testing.

**Sample of Additional tests required as indicated:**

- 1) **Mammography:** Within one year for females over 40 years old or strong family history of breast cancer
- 2) **Pap smear:** All females (within one year)
- 3) **Colon Cancer screening;** Stool for guaiac or Colonoscopy: for people over 50.
- 4) **Exercise Stress Thallium Test:** All donors over 50 years old or pertinent history.
- 5) **Subspecialty consultation:** For questionable findings uncovered in routine evaluation.
- 6) **Pulmonary Function Tests:** smoker or history of pulmonary disease.
- 7) **Liver biopsy:** as indicated

**Being Informed to make the right decision for YOU**

You will be asked to give consent on multiple occasions. The first time is when you begin the evaluation and finally when you ultimately decide to undergo surgery. It is the role of the donor team to make sure that all potential donors are fully informed of the risks involved and given ample time to make the right decision for themselves. Listen carefully to the donor team and their description of the surgery, recovery and risks involved. Take the opportunity to attend the educational workshops available and speak with someone who has gone through the process. Knowledge is power and will help you regardless of your decision.

All donors must be:

- Competent
- Willing to donate

- Free of coercion
- Medially and psychosocially stable
- Fully informed of the risks, benefits and alternatives to living donation

To ensure that you completely understand the process and risk, the transplant center will present its experience and program statistics so that you can make an informed choice about donation at this center.

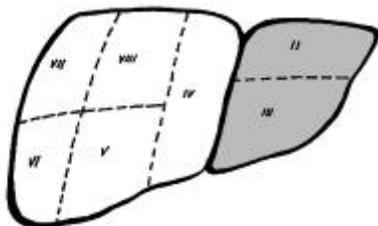
### **Speak to someone who has donated**

No one knows what it is like to be a donor except someone who has done this before. It is strongly encouraged that you speak to a prior donor so you can have firsthand knowledge as to what should be expected; what questions to ask and how to really prepare yourself for the surgery. The Donor team can help you with this.

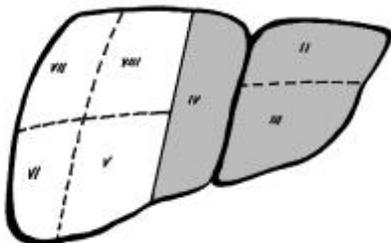
### **The Donor Operation**

Liver donor operations differ depending on whether you are donating to a child or an adult. Donation to a child involves removal of a portion of the smaller left lobe of the liver, while donation to an adult requires removal of a portion of either the smaller left lobe or the larger right lobe depending on your size and the size of the recipient. See Figure 2.

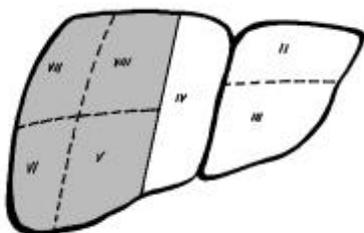
**Figure 2**



**Left lateral segment hepatectomy**



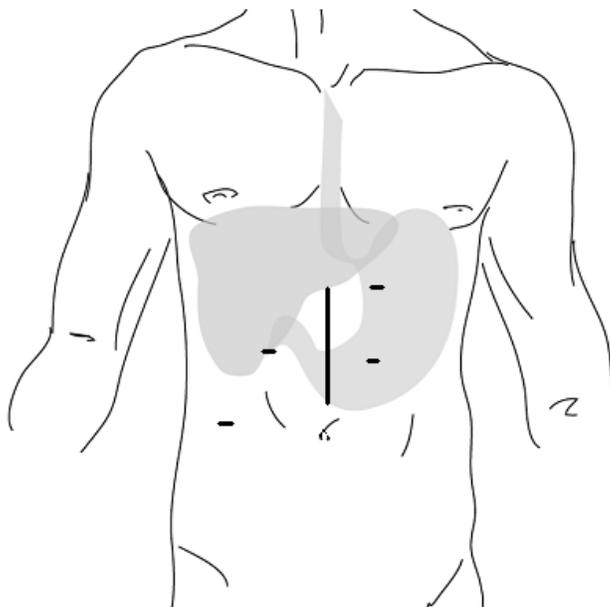
**Left hepatectomy**



**Right hepatectomy**

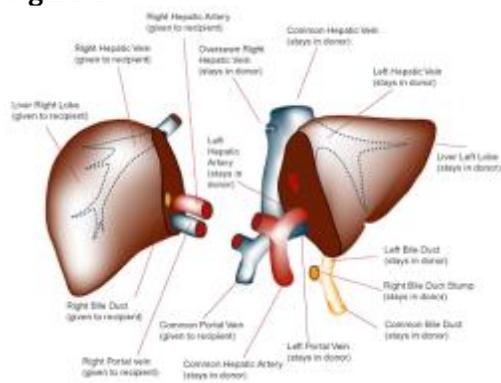
## **Figure 2**

For donation to a small child, the surgery is performed laparoscopically with 5 ports placed into the upper abdomen. The incisions for each port are less than half an inch. The liver graft is removed through a 3-inch incision at the bikini line. For donation to most adults, the surgical incision runs from the breastbone to 1 inch above the navel, which in most people leads to a 6 inch incision (see below). Sometimes the donation to an adult can be performed laparoscopically.



During the surgery, first the liver is exposed, then the proper blood vessels and bile ducts are located, cut, and tied off. Then a segment of liver is dissected out, the cut surfaces are cauterized, and it is removed for transplantation. (See Figure 4)

## **Figure 4**



The donated segment is drained of blood and put on ice to be carried to the operating room where the recipient is with his or her surgical team. The donor then has a rubber tube placed into the new empty space next to the remaining liver, with the other end pulled through a puncture in the skin and attached to a rubber bulb.

This will drain fluid that oozes from the disturbed surfaces in the abdomen and, more importantly, will show us if a bile leak has developed. The surgery usually takes 4-6 hours, regardless of what portion of the liver is being donated.

### **How Long Will It Take to Recover?**

A donor is typically hospitalized for 5-7 days after the hepatectomy and is unable to return to work for 4-8 weeks. The first day after surgery you will be very sore, nauseated, and slightly groggy. On days 2-3 you will still have pain and some nausea as you are switched from IV to oral pain medication and encouraged to walk a little. You should take the medication at least twice a day. Now is not the time to be tough, you need this medication.

By day 4 you start to feel yourself again. You are allowed to eat clear liquids and your bowel function will start to return. After you have a bowel movement, are eating regular food, and have the drainage tube removed from your abdomen, you may be discharged from the hospital. Following discharge, you will be given a prescription for oral pain medicine to take as needed, and you can expect to be moderately fatigued for several weeks.

You must not lift greater than 15 lbs. for 4 weeks and you must avoid heavy lifting for 12 weeks (>30lbs). Otherwise, you are encouraged to slowly resume normal activity at your own pace, making sure that you walk daily and stay active. Donors are strongly encouraged to avoid alcohol and any medications or herbal remedies that can be toxic to the liver for six months. Women should avoid pregnancy for one year.

Once you return home, if you develop a fever or have drainage from your incision you should call the transplant office at 646-962-5483. You should shower daily, wash your incision with soap and water, and pat dry. Once dry, apply Neosporin ointment to the incision. You should eat a normal, healthy, well-rounded diet to improve healing. It is best to avoid fatty foods which may cause stomach pain.

The transplant center will follow you closely as you recuperate. You will be seen one week after discharge to assess your condition and check your blood tests. Six weeks after surgery you will return to see the donor team and at three months you will have an MRI of the liver to assess for regeneration. Your six month follow up can be done over the telephone with labs done locally as long as you are not having any issues. One-year post donation you will come in for a follow up and your final MRI to assess the liver's regeneration. We request that you follow up annually thereafter which can be done with us at the Center for Liver Disease or arranged for you to do locally with your primary care physician. New York State requires us to follow you for two years and the transplant team strongly encourages you to comply with follow up recommendations. If you feel ill and need additional follow up, you are encouraged to call the center.

It is also important for you to keep your family doctor abreast of your progress and see him or her annually for a checkup as well. You should provide the donor team the information about your primary care physician so that we may send your reports to your doctor so he or she is fully informed of your care.

## **What are the Risks of liver donation?**

The donor surgery is called a partial hepatectomy, meaning “the surgical removal of a part of the liver.” This surgery is most commonly used to remove benign or malignant liver tumors. Partial hepatectomy can be done safely, and partial hepatectomy in a well person carries less risk than when it is done to treat someone who is sick with liver disease. It is a major surgery, and there are still risks involved, including the risk of death.

With any major abdominal surgery, chronic pain, internal bleeding, infection of the wound or other organs of the body, and injury to other areas in the abdomen, as well as death, are potential risks. Other risks include postoperative fevers, pneumonia, and urinary tract infection.

Patients who have major surgery are also at risk to form blood clots in their legs. These blood clots can break free and travel to the lungs where they cut off the blood supply to a portion of the lungs. This is called pulmonary embolism. Blood clots in the legs occur in about 2% of all major surgeries; 2% of these blood clots will break off and cause pulmonary embolism. We try to prevent blood clots with inflatable sleeves that fit over your calves to keep blood flowing in the legs during surgery. When they do occur, blood clots and/or pulmonary embolism are treated with blood thinners that you need to take for several months and require you to have frequent blood tests. However, a large pulmonary embolism can be fatal.

Major abdominal surgery carries a risk of later bowel obstruction and/or pain due to adhesions. Adhesions are like scars in the abdominal cavity, which can form tight bands or make areas of intestines stick together and get twisted. Obstruction due to adhesions occurs in 5% of major abdominal surgeries and can occur years after the surgery. Sometimes adhesions can cause strangulation of the intestines and life-threatening gangrene. Obstruction from adhesions sometimes fixes itself, but often requires another surgery.

There are also risks that are specific only to this surgery. For the living liver donation, 25-65% of the liver will be removed. Removal of a portion of the liver may cause the remaining liver to not work as well for a short period of time, but it will soon recover and begin to grow back within a few weeks. However, in rare cases, liver failure can result and may require the donor to need a liver transplant. This is a very rare event (about 2 transplants per 1000 living liver donor surgeries). This has never happened at this center. If a living donor has liver failure and in need of a liver transplant they will be placed at the top of the liver transplant waiting list.

If you are having your right lobe removed, your gallbladder will also be removed during this surgery. The gallbladder is not needed for normal function. Some people who have their gallbladder removed have periods of diarrhea, cramping and intolerance to fatty foods, which may last for several months. Think of your gallbladder as a storage unit for bile which is produced in your liver and flows through bile ducts to your gallbladder. Bile is ultimately secreted to your small intestine help digest food. Without your gallbladder, bile will be secreted directly from your liver to your small intestine.

The most common liver complication after surgery is a bile leak. A bile leak occurs when one or more ducts from the liver have not closed entirely after surgery. Bile is irritating to the inner lining of the abdomen and can cause inflammation and scarring. Most bile leaks heal themselves, but

occasionally a leak may require another tube to be placed through the skin to the liver to drain bile into a bag while the liver heals. In rare cases, surgery is required to close the leak. The rate of bile leaks happening across the country ranges from 5-15%.

A long-term complication that can occur is a biliary stricture which is a narrowing of the remaining large ducts that carry bile from the liver to the intestines. Early data shows that such strictures will be rare. They can usually be fixed without surgery by dilating the stricture with a stent (plastic tube) via an endoscopic procedure (through the mouth) or a percutaneous procedure (through the skin).

There are rare complications that can occur involving the blood supply to the liver, both in the arteries and veins. These include strictures and blood clots in these vessels that may occur long after surgery. The MRA or CAT scan that you have before surgery will help the donor surgeon to gauge how risky the surgery might be in this regard.

The most common late complication is the formation of incisional hernias. A hernia forms when the skin has healed, but the underlying muscles and connective tissue have not knit together well. This creates a bulge or “bubble” under the skin when standing. While this can be unsightly, more importantly it has the potential to trap a loop of intestine and strangulate it, which can cause gangrene. For this reason, we often recommend surgery to correct hernias when they occur; in some cases, more than one surgery has been necessary. Hernias can occur in 5-7% of donors. If you are overweight, you may be more likely to develop a hernia. We believe that some hernias may be prevented by avoiding activities that put pressure on the abdomen, such as heavy lifting or straining at stool. The surgeon may place a mesh at the time of surgery to lower the risk of developing a hernia.

Nationwide, the risk of having some type of problem, minor or major, from this surgery is 15-30%. These include infection, hernias and swelling (about 2 in 7 cases). Most problems are minor and get better on their own. Rarely do they require another surgery or procedure.

So far in the United States, the mortality rate (death) has been about 0.2% or 2 deaths in about 1000 donors. No living liver donors have died in this center.

### **General Anesthesia**

This surgery will be done under general anesthesia. There are a number of known possible risks with any surgery performed under general anesthesia. An anesthesiologist will explain these to you in detail.

### **Blood Transfusions**

You may need blood transfusions during this surgery, although this is uncommon. The incidence of transfusion is about 1 in 100 cases.

### **Post-Surgical Course/Discomforts**

Drains will be placed in your body to help you heal, to be removed before you are discharged from the hospital. There is a chance that you could be placed on a machine to help you breathe after surgery. You will feel pain (for example: gas pains, sore throat, soreness, backaches, etc.) after the surgery.

**Regeneration:** Success of living liver donation is partially due to the liver's natural ability to regenerate. Regeneration occurs rapidly in both the donor and the recipient. Even within the first seven days after surgery significant regeneration has occurred and within six weeks the liver sections in both the donor and recipient have grown to 80% of the size of a normal liver. However, growth then slows down and eventually stops, so that at one year the liver is still about 10% smaller than its original size. Liver function in the donor returns to normal levels within four weeks, with complete normalization of blood liver function tests by 12 weeks post-donation.

### **Understanding Organ Allocation in the United States**

Since all potential recipients of living donors are also listed with UNOS (The United Network for Organ Sharing), if for some reason living donation does not go forward the recipient will still be eligible for a deceased donor. In addition, if the recipient's name comes up for an organ prior to the living donor surgery, deceased donation would take precedence. Organ allocation is maintained by UNOS, a non-profit charitable organization that operates the Organ Procurement and Transplantation Network (OPTN) under federal contract. On an ongoing basis, the OPTN/UNOS continuously evaluates new advances and research and adapts these into new organ transplant policies to better serve patients awaiting transplants.

As part of this process, UNOS developed a system for prioritizing patients waiting for liver transplant based on statistical formulas that are very accurate for predicting who is most likely to die soon from liver disease. The MELD (Model for End Stage Liver Disease) is used for adult patients and the PELD (Pediatric End Stage Disease Model) is used for pediatric patients.

Meld is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), that is used to allocate deceased donors. It gives each individual a "score" based on how urgently he or she needs a liver transplant within the next three months. The number is calculated by a formula using three routine lab test results:

- Bilirubin: measures how effectively the liver excretes bile.
- INR (prothrombin time): measures the liver's ability to make blood clotting factors.
- Creatinine: measures kidney function. (Impaired kidney function is often associated with severe liver disease)

A patient's score may go up and down over time depending on the status of his or her liver disease. Many patients will have their MELD score assessed a number of times while they are on the waiting list. This will help us ensure that donated livers go to the patients in greatest need at that moment. It is important to remember that if the MELD score is too high and the patient is critically ill they may not be able to get a living donor organ (partial liver) because they are too ill and need the liver mass of a whole organ. If someone presents with acute liver failure and is critically ill, they qualify for a Status 1 on the waiting list and they get additional priority. Adults who are Status 1 may be too sick to receive a living donor organ. This is due to the urgency of their need for transplantation and need for a whole organ with larger mass.

Candidates under the age of 18 are placed in categories according to the PELD scoring system. It is similar to MELD but uses some different criteria to recognize specific growth and development needs

of children. PELD scores may also range higher or lower than the range of the MELD scores. The measures are as follows:

- Bilirubin: measures how effectively the liver excretes bile.
- INR (prothrombin time): measures the liver's ability to make blood-clotting factors.
- Albumin: measures the liver's ability to maintain nutrition.
- Growth failure
- Whether the child is less than one-year-old

A pediatric patient's score fluctuates as well during any given time period. Critically ill children can also qualify as a status one, meaning more urgent. Often a living donor is considered in this instance providing that the child is not too ill and that the size of the potential living donor is adequate to support the child.

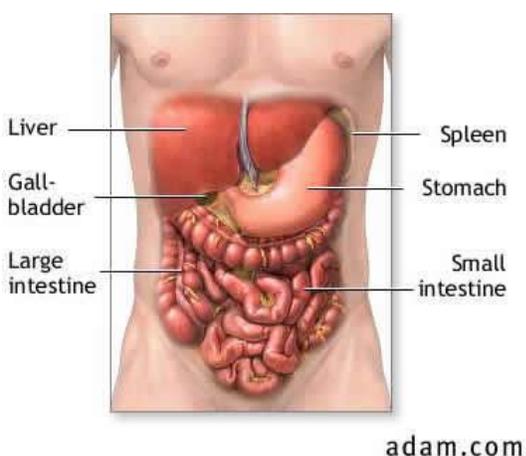
Research shows that MELD/PELD formula is very accurate in predicting most liver patients short-term risk of dying without a transplant but the accuracy of the formula is impeded when patients develop ascites (fluid in the abdomen) or encephalopathy (confusion and disorientation) or certain liver disorders, like hepatopulmonary syndrome or cholangitis. These patients often are disadvantaged by the current system. There is a regional review board in which transplant centers can go to appeal for additional points on the list for certain patients. This often is a motivating factor to consider living donation. In addition, there is no formula to predict long term mortality while waiting.

If a patient is currently disadvantaged by the current allocation system, they may also consider Expanded Criteria Donation (ECD). This is when they agree to accept an organ that likely comes from outside New York State and has been turned down by that region for various reasons. These organs may carry increased risk to the recipient but may be considered in patients whose risk of dying while waiting is high.

We suggest you take organ allocation and your particular family member's condition into account when considering living donation. You may want to speak with the recipient's team as well about their particular risk. This is strongly encouraged.

### **Understanding the Liver**

The liver is the largest internal organ in the body and plays a vital role in many bodily processes. (See figure 6)



It is located in your upper right part of your abdomen under your rib cage. It performs the following functions:

- Storing energy in the form of sugar
- Storing vitamins, iron, and other minerals
- Making proteins, including blood clotting factors
- Processes worn out blood cells
- Makes bile that helps digest food
- Cleans the blood by breaking down medicines and toxins such as alcohol
- Regenerates its own damaged tissue
- Maintains hormone balance
- Helps in absorption of fat soluble vitamins including A, D, E, K
- Helps the body resist infection by producing immune factors and removing bacteria from the blood.

There are many diseases that can cause a liver to fail. Typically end stage liver disease that requires a liver transplant is from cirrhosis (scarring of the liver). The cause of cirrhosis varies and can be from alcohol abuse, hepatitis B or C, an autoimmune disease, a metabolic disease, or from some unknown reason. Some liver diseases are cured with a transplant others are just treatments for the cirrhosis and the original disease can return to the new liver. Patients who are considered transplant candidates typically have an 80%-90% chance of survival.

It is strongly encouraged that you know the reason the person you are donating to has a liver disease and understand their chance of survival and risk of recurrent disease. This will help you to decide if living donation is right for you. Your donor team can give you some information about this but you may also want to go with the recipient to their medical appointments so you are completely informed about their chance of survival.

## **Preparing to be a Donor**

**LEGAL MATTERS:** Peace of mind during your hospital stay and recovery will be enhanced by planning ahead. It is recommended that you consider making the following advanced directives and legal arrangements:

**Appoint a Health Care Proxy:** Did you know that it is possible to carry out your wishes for medical care even if you cannot answer for yourself? By choosing a person(s) to represent you and to act on your behalf, you will always remain in control of your medical care. Transplant Social Workers will educate you further on appointing a Health Care Proxy. When you submit the Health Care Proxy form, we will make sure that the name of your Health Care Proxy gets entered into the Hospital's computers. Some transplant surgeons and physicians make a completed Health Care Proxy a requirement for surgery to take place. Without a health care proxy, the medical team must turn to your next of kin. For instance, an unmarried adult's next of kin is his or her parent. A separated patient's next of kin is the spouse.

**A Living Will:** A living will specifically states what procedures you want or do not want if you are not able to make your own medical decisions.

**Appoint a Power of Attorney:** Compelling business and legal matters often require patients' attention during hospitalization and recovery. By choosing someone to conduct your affairs, you can reduce stress on you and your family.

**Create a Joint Bank Account:** A family member who has joint access to your bank account will be able to pay bills, deposit and withdraw funds.

**ACCOMMODATIONS:** Your family may be comforted by being able to stay nearby when you are hospitalized. A complete list of hotels is available from your Transplant Social Worker but you may want to consider the following hotels:

**Helmsley Medical Towers** - 1320 York Avenue between East 70<sup>th</sup> and 71<sup>st</sup> Streets, NYC, (212) 472-8400. Rooms may come with kitchenettes. It is accessible to our center by free van service at scheduled times from 16 East 60<sup>th</sup> Street.

**McKeen Pavilion**- Milstein Hospital Building, 9<sup>th</sup> Floor, Columbia University Medical Center. (212)305-5951. Space is limited.

**Crown Plaza** - 401 S. Van Brunt Street, Englewood, NJ 07697 (201) 871-2020

**Holiday Inn George Washington Bridge** – 2339 Route 4 East, Fort Lee, NJ 07024 (201)994-5000

**Radisson Hotel** - Englewood, NJ. (201)871-2020. Ask for the Hospital rate. A shuttle bus transports guests over the George Washington Bridge for a fee.

## **When you go Home**

**DISCHARGE PLANNING:** A transplant social worker coordinates the plans the Medical Team recommends for you once you are well enough to be able to leave our hospital.

On the day of discharge from the hospital, you and your family will receive written instructions on how to provide care for you at home including telephone numbers you can access 24 hours a day to

speak with a doctor on call. Typically, after a hospital stay of 5 to 7 days, you will not require any special nursing care at home. You will be advised to eat a normal diet, to walk around several times a day and to get plenty of rest. You will be unable to drive for 4 weeks following discharge. You will be required to return to the Transplant Clinic for a check-up at two and six weeks, three months and one year after your donation. We will ask that you follow up with your primary care physician and have a telephone follow up with us at 6 months post donation, 2 years post donation and every year thereafter. You always have the option of coming in for these visits if you prefer.

**PSYCHOSOCIAL IMPACT OF DONATION:** Many issues may affect donors and their families from the psychosocial standpoint and should be addressed before a decision to donate is made.

Since abdominal scars from surgery are inevitable, potential donors are strongly advised to evaluate whether scarring will negatively affect their body image and lifestyle. For instance, a donor who is accustomed to wearing a bikini bathing suit at the beach may choose to alter their attire if that would make them feel uncomfortable.

Some donors worry about the possibility that the donated liver might be rejected by the recipient. If that occurs, the recipient would be listed for an emergency donation from a deceased donor. In that case, your donation would not be useful to the recipient or anyone else.

It is also important to consider how you might feel if the recipient died during or after the surgery. Would you be able to accept that possibility as a risk? You might have to manage not only your own recovery from major surgery; but also deal with a grief reaction, not only yours, but that of the recipient's family as well.

Another concern facing donors is that the disease that caused the recipient's liver failure may reoccur and infect the new liver. If the reason for the recipient's liver failure is Hepatitis C, for example, the recipient may have to deal with taking extra medications to combat the virus. Additionally, if your recipient has liver cancer this can reoccur in the new liver.

**PREPARING YOUR FAMILY FOR LIVING DONATION:** Ideally, family members will accompany you to liver transplant education seminars given throughout the year. There, they too, will become familiar with the members of the team who will assist you throughout your medical journey.

In some families, donors may experience fierce objections to the idea of donation, often from a significant other. It is helpful that family members who object to donation be given the opportunity for the donor team to answer their questions and to discuss their objections. Your social worker and psychiatrist often meet with family members individually.

You will need a separate team of caregivers than the recipient. As inpatients, both of you will find comfort in knowing that the other has caregivers devoted to them alone. Make sure that family members know how important it is to help with your transportation to and from the hospital when you are unable to drive. A care partner is someone you have designated to support you through this process and also help take care of you after you have been discharged from the hospital.

Special focus on young children is advisable. Your social worker will provide you and your children with help on age-appropriate explanations about your hospitalization. Pediatric recipients and their siblings have access to the Child Life Program in the Children's Hospital of New York where specialists will prepare children for surgery from a psychological point of view.

Other donors and caregivers who have completed surgery and recovery are always available to provide you and your family with telephone or email support.

**FINANCIAL CONSIDERATIONS FOR DONORS:** Medical expenses associated with the evaluation and donation are borne by the recipient's health insurance provider. Donors are responsible for out-of-pocket expenses that may include some of the following: parking, transportation costs, telephone, television, possible living expenses after discharge such as hotels, childcare, and medical expenses after the first year.

Due to surgery, donors are advised that health and life insurance companies may increase raise their rates or even deny coverage. Donors are strongly advised to discuss donation with insurance providers in advance of donation.

Although families are allowed assist donors with their out-of-pocket expenses, Federal law prohibits receipt of money or other compensation for a donated organ.

Donors are strongly advised to discuss possible donation with your employer in order to investigate benefits and to develop a financial plan for your hospitalization and recovery. Some employers oppose voluntary medical leave and donors should be advised that they may face not only a possible loss of employment; but also, donation may impact future employment, especially where heavy lifting is required.

New York State now allows living donors to claim up to \$10,000 in expenses from donation.

**DISABILITY INSURANCE:** In New York State there is short-term disability insurance for most full time workers that provides modest replacement income while you are unable to work. New York State Short-term Disability Insurance is accessed by submission of forms filled out by you, your doctor and social worker. A way to obtain a pamphlet and form and to see if you are eligible is to call 718-802-6964. The human resources department at your job may also have forms. Lastly, your employer may have a private disability insurance policy for you on which you might be able to make a claim.

Social Security Disability Income (SSDI) is administered through the Social Security Administration for persons with a work history. If after 26 weeks of short-term disability income or disability without benefits, SSDI may be granted, if, in your doctor's opinion, your disability is expected to last at least 12 months. Evaluation of your work record can be done by contacting your local Social Security Office. Call 800-772-1213 to locate your nearest office and to make an appointment to see a counselor to apply for benefits. Long-term disability from donation is a rare event. Another long-term benefit is Supplemental Security Income. It is granted to low-income disabled or elderly persons without a work record or whose income from SSDI is below the poverty level. Applications are made at your Social Security Office.

**FAMILY AND MEDICAL LEAVE ACT (FMLA):** Federal legislation allows for workers in public or private enterprises of at least 50 employees to be awarded 12 weeks per year of unpaid time off taken all at once or day by day. The leave is granted due to an illness or disability of the employee or a family member. For example, once FMLA is granted, a family member would be eligible to assist you during your hospitalization, recuperation and follow-up medical appointments. The employer would be required to maintain health insurance benefits during the unpaid leave.

**USE OF THE INTERNET:** While the Internet can be a valuable resource for medical information, donors are advised to use the Internet with an awareness sometimes the facts about donation may be sensationalized and distorted. Please contact your donor team with any questions or concerns. UNOS has developed an excellent website for those considering living donation and you are encouraged to review it at [www.UNOS.org](http://www.UNOS.org)

**EDUCATION AND SUPPORT GROUPS:** Please see addendum with for a list of educational and support groups you may wish to attend to prepare for your transplant and to cope with your recovery afterwards.

**RESOURCES:**

*Access-a-Ride:* 877-337-2017 (Low-cost para-transit for medical patients)

*Alianza Dominicana:* 212-740-1967 (Assistance for Spanish-speaking families)

*American Liver Association:* 1-800-223-0179

*Center for Liver Disease and Transplantation, Columbia University Medical Center:* 212-305-9014 or 800-LIVERMD

*Center for Liver Disease and Transplantation, Weill Cornell Medical Center:* 646-962-4040

*Child Health Plus:* 800-431-1914

*Child Life Center:* 212-305-2607 (Conducts pre-admission tours for you and your child)

*Children's Liver Association for Support Services:* 805-255-0353

*Compassionate Friends:* 708-848-9985 (Grief support for families after the death of a child.)

*Disability Claims: New York State* 718-802-6964

*New York Presbyterian Hospital International Services, Weill Cornell:* +1-212-746-9100

*LOLA or Latino Organization for Liver Awareness:* 718-892-8697

*Living Donor Social Work, Columbia University Medical Center, New York Presbyterian Hospital:* 212-305-8083

*National Kidney Foundation:* [www.kidney.org](http://www.kidney.org) for information on living donors) or 1-800-622-9010

*New York Presbyterian Hospital, Cornell Center:* 212-746-5454

Partnership for Caring: [www.partnershipforcaring.org](http://www.partnershipforcaring.org) for downloading advance directive documents.

*Pastoral Care Department (Hospital Chaplains):* 212-746-6971

*Patient Relations Department:* 212-746-5454. It is possible to leave an anonymous complaint. Ask the operator for the Patient Relations Department.

*Public Benefits Resource Center:* 212-614-5591 (Advice on NYC, NYS and Federal Benefits)

*RN Registry:* 212-305-2525 (Private duty nursing for inpatient stay)

*Schweitzer Comprehensive Transplant Center:* 212-305-7600

*Social Work Services, Columbia University Medical Center:* 212-305-2553

*Transplant Recipients International Organization (TRIO):*

New York City Chapter: 718-597-5619, [www.Triom@aol.com](http://www.Triom@aol.com),

Long Island Chapter: 516-248-4532, 516-796-3610

*Transplant Support Organization (TSO):* [www.tso97@optonline.net](http://www.tso97@optonline.net) or [www.transplantsupport.org](http://www.transplantsupport.org), 914-576-6617

*Tobacco Cessation Clinics:* 212-939-6000

*United Network of Organ Sharing:* 1-888-894-6361, [www.unos.org/patient](http://www.unos.org/patient)