# Becoming a Living Liver Donor

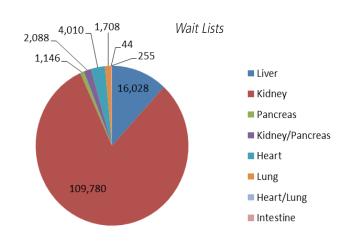
# Welcome to the Transplant Institute at Beth Israel Deaconess Medical Center!

Liver transplantation is a surgical operation in which a donated human liver is placed into a person whose liver is failing. A transplanted liver comes from either a deceased organ donor or a living donor. The liver transplant program at Beth Israel Deaconess Medical Center began in 1983, when New England's first liver transplant was performed at the New England Deaconess Hospital, and New England's first living-donor liver transplant was performed at BIDMC in 1998. Since UNOS began collecting data in 1988, our transplant team has performed over 420 liver transplants. The physicians at our Institute have been pioneers in both the treatment of liver diseases and liver transplantation.

Enclosed in this booklet you will find information regarding your living liver donation. We hope this information will help answer the many questions you may have regarding your upcoming appointments and the weeks to follow. Please bring this booklet with you to all of your appointments during your evaluation; this information will be reviewed with you by the living donor coordinator. Please write down any questions you may have in the space provided at the end of this booklet. This will help you to remember to discuss them with the members of the donor team.

# GREAT NEED FOR DONOR ORGANS

Many thousands of people with liver disease are on the national waiting list for a liver transplant and are waiting for a donor organ to become available. Unfortunately, there are not enough organs to fulfill this demand. As of January 2, 2015, there were over 16,000 people waiting for a deceased donor liver transplant. There are approximately 6,000 liver transplants performed annually in the United States. This organ shortage has led to the development of an innovative and complex procedure, which entails using a living donor's portion of liver for transplantation. A living donor is able to donate a portion of his/her liver to someone in need of a liver transplant because the liver is the only organ that can regenerate and will grow back to nearly 100% of its size in a short amount of time.



# WHAT IS LIVING DONOR LIVER TRANSPLANTATION?

Living Donor Liver Transplantation (LDLT) is a surgical procedure that was developed as a result of the national shortage of organs from deceased donors. LDLT involves the removal of the recipient's *entire* native liver (the one he or she was born with) and replacing it with a *portion* of the living donor's liver. The remaining liver of the donor will regenerate to a normal functional volume within weeks after the donation. The recipient's transplanted liver also will regenerate to almost full size in several weeks.

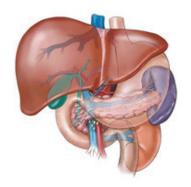
LDLT is possible because liver tissue has the unique ability to regenerate, or re-grow. The first LDLT was performed in 1989 and involved a parent donating a segment of liver to their child. The more technically demanding surgery that allowed a larger portion of the liver to be obtained from a donor and transplanted successfully into an adult developed over the next 10 years.

While Adult-to-Adult LDLT originated in Europe, this surgical innovation was adopted in the United States in 1997. In 1998, Dr. Robert Fisher, now Chief of Transplant at Beth Israel Deaconess Medical Center, performed the second adult-to-adult living donor liver transplant in the country when he was a surgeon at the Medical College of Virginia.

# **ABOUT YOUR LIVER**

The liver is the largest solid organ in the body. It serves many functions. These four are the most important:

- The liver receives all of the blood and nutrients absorbed from the intestine, and processes these nutrients. Any toxins absorbed from the intestine are neutralized in the liver.
- The liver produces bile that is emptied into the intestine through bile ducts that connect the liver to the intestine. The bile is required to help the intestines digest food that you eat, especially foods with a higher fat content.
- The liver produces almost all of the proteins found in your body. These proteins help your body perform many of its important functions like helping your blood to clot after you cut yourself, and helping your body to fight off infection.
- The liver detoxifies waste products produced by muscle and other organs. It also metabolizes drugs.



# THE DECISION TO DONATE

The decision to donate a portion of your liver is an individual, voluntary act. When making the decision to donate, you may experience mixed feelings. Of course you'd like to help someone in need, but what does it mean for you?

#### How does living donation affect the donor?

Because the liver is the only organ that can fully regenerate and grow back to almost 100% of its size in a very small amount of time, living donors can donate a part of their liver to the recipient, and return to their normal lives in a short period of time.

# Suppose I decide against being a living donor?

If at any time during the evaluation process you decide that you cannot move forward in the donor evaluation process, the donor team will fully support you in your decision. The decision to become a living donor is voluntary and should be free from internal or family pressures. As an individual, you have the right to decide that liver donation is not for you. If you choose not to donate, your decision will be respected. You will be offered time to discuss your decision and have your questions answered, specifically with respect to alternate therapies for your intended recipient and possible consequences of your decision. Always remember, the donor evaluation is confidential; regardless of the reason for your decision to withdraw from the evaluation process, it will remain confidential between the donor team and you.

# How much does living donation cost? Who pays?

All medical expenses that are related to the evaluation of a potential donor, the transplant operation and hospitalization, and the required follow-up care of the potential donor are paid for completely by the potential recipient's insurance coverage. As a potential donor, you should not see any bills related to your medical evaluation, hospitalization, or post-hospital care. Typically, no other costs (i.e., travel expenses, time off from work, non-medical bills, etc.) are covered by the recipient's insurance company or by the hospital. Some employers may allow this time to be taken as sick leave/short term disability.

# What are the advantages of living liver donation?

- Shortens the waiting time for transplant
- Allows the donor and recipient to know when the surgeries will occur so they can prepare in advance
- Improves the chance for a successful transplant because the donated liver segment is able to be connected quickly to restore blood flow to the organ

#### Are transplants from living donors always successful?

It is important to understand that although living donor liver transplants are highly successful, problems may occur. These issues include:

"Small for size" syndrome

Infection

Primary graft non-function

Rejection

Narrowing of blood vessel or bile duct

• Recurrence of the original liver disease

The decision to become a living liver donor is complex, and it is essential that you discuss this decision with your family, your intended recipient, and the donor team. You need to learn as much as possible about the procedure before you proceed with donation.

# TYPES OF DONORS

**Living Related Donor** — A living related donor is any healthy blood relative of the recipient. Donors can be brothers or sisters, parents, children over 18 years of age, or other blood relatives such as aunts, uncles, cousins, half brothers or sisters, nieces or nephews.

**Living Unrelated Donor** — A living unrelated donor is a healthy individual who is emotionally close to, but not related by blood to the transplant candidate. These donors may be spouses, in-laws, close friends, co-workers, neighbors, or other acquaintances.

**"Good Samaritan" Donor** — A "Good Samaritan" donor, also known as a non-directed donor, is a living donor who is not related to or known by the recipient, but makes the donation purely out of selfless motives. This type of donation is also referred to as anonymous, altruistic, altruistic stranger, or stranger-to-stranger living donation. Individuals considering this option should contact the Transplant Institute at Beth Israel Deaconess Medical Center to discuss the possibility of becoming a donor.

# WHAT IS THE FIRST STEP?

- 1. The person you want to donate to must be on the liver transplant waiting list in order to start your donor evaluation.
- **2.** You must have a compatible blood type. The graph below will help you to know if you are compatible:

DONOR	RECIPIENT			
Α	A, AB			
В	B, AB			
0	O, A, B, AB			
AB	AB			

Blood group "O" is the universal donor; Blood group "AB" is the universal recipient.

- **3.** You must be between the ages of 18 and 55 and in good health.
- **4.** It is important to be approximately the same height and weight as the recipient.
- **5.** Contact the donor coordinator so that an initial telephone health screening can be done. Please have a list of questions ready to discuss with the coordinator when you call. The telephone screening may take up to 45 minutes.

# THE DONOR EVALUATION

- 1. The testing to become a liver donor occurs in three phases. Advancing through the donor evaluation may be dependent on acceptable results during the previous phase.
- 2. You will meet with the donor coordinator, hepatologist (medical doctor who specializes in the care of patients with liver disease), and donor social worker to discuss liver donation, undergo a history and physical and psychosocial assessment, and respond to your questions and concerns.
- 3. Laboratory Testing will be done to determine if you have any obvious liver problems, unknown medical conditions, blood clotting disorders, or an incompatible blood type.
- **4.** A Chest X-Ray helps to evaluate the functioning of your lungs. If you are a smoker, you will be asked to stop smoking in order to become a liver donor.
- **5.** An Echocardiogram and Electrocardiogram (ECG) evaluate the function and conduction of your heart. If there is an abnormality with these preliminary tests, you may need a stress test or a more advanced test called a cardiac catheterization, which is rare.
- **6.** The liver is evaluated with a Doppler Ultrasound, which is a picture of your liver to evaluate for fat and the blood flow through your liver.
- 7. A Volumetric MRI is another radiology test done to determine the amount of liver volume you have in various segments of your liver. This will give the donor surgeon information about the size of your liver and whether you have enough volume in the right lobe of your liver to support the recipient's health while still maintaining enough liver volume in the left lobe to support your health after donation. This imaging also looks at the blood vessels and bile ducts that flow through your liver. Finally, this test can identify any fat accumulation in your liver, which might affect your candidacy as a living donor. If there is any indication of fat accumulation, a liver biopsy will be included in your evaluation. (See item 8.)
- **8.** A Liver Biopsy may be performed to evaluate for any fat or abnormalities in your liver. Not every donor needs this procedure. The need for this test will be based on any findings on your lab, ultrasound, and MRI results. We also look at your height and weight ratio; if you are considered obese, a biopsy is indicated regardless of the radiology test results. During this procedure, your side is injected with a numbing medication. Then a large needle is inserted through your right side and a piece of tissue is removed for examination under a microscope. You will require vital sign monitoring and bed rest on your right side for 4 hours after the procedure to monitor for bleeding. Because of this post procedure care, this test often can take the entire day and is scheduled as a single appointment. Please know that you will need someone to drive you home after this procedure.
- **9.** The last procedure is an Angiogram, which takes several hours. This is a procedure in which a large intravenous catheter is placed in a blood vessel in either your arm or leg. A dye solution is injected into the catheter so that the blood supply of your liver can be clearly defined. The donor surgeon will use this test to help determine if it is safe to divide your liver as well as to assist with surgical planning if you are an acceptable living liver donor. Again this procedure is followed by post procedure monitoring. Please know that you will need someone to drive you home after this procedure.
- 10. You will meet with the donor surgeon, who will review all of your testing, discuss your concerns, the risks of surgery, and what to expect during your recovery. We request your spouse, partner, significant other, or other support to be present at this appointment so that all parties involved are able to hear about all aspects of the surgery. Dr Fisher also will examine your abdomen. At this time, he will review with you the consent for the evaluation and you will be asked to sign the consent for the second time at this visit; you will sign this consent again the day before surgery together with the consent for surgery.
- 11. Finally, you will meet with the donor advocate. The donor advocate is a social worker or psychologist who is responsible for advocating for your best interests as a potential living liver donor. She/he will review your understanding of living liver donation, respond to any questions or concerns, and ensure that you remain committed to living liver donation.

**Reminder:** You will need someone to drive you on the days of the liver biopsy and angiogram. If you have an allergy to dye or shellfish, please let the donor coordinator know at the time of your telephone screening.

Based on your health history and interval results during your donor evaluation, additional tests may be required, which would extend the evaluation process.

Cancer screening is required to be current. These tests are age and gender specific: mammography, pap smear, and colonoscopy. Because these tests are considered routine health maintenance, they are not included in the donor evaluation and should be arranged with the assistance of your local physician. Also, because these tests are done separately from the donor evaluation, they would be covered under your own health insurance.



### RISKS OF SURGERY

Thirty percent of living liver donors will experience a complication as a result of living liver donation.

#### Minor complications may include:

- Wound infection
- Urinary tract infection
- Pneumonia
- Temporary nerve injury numbness/tingling in your fingers/arm
- Skin breakdown this has been seen as hair loss on the back of the head due to positioning during surgery

#### **Serious** complications may include:

- Re-operation due to bleeding or injury to a surrounding organ
- Bile leak
- Blood clot deep vein thrombosis (DVT) or pulmonary embolus (PE)
- Incisional hernia
- Liver failure resulting in the need for a liver transplant

There have been four reported donor deaths in the United States. The risk of dying as a result of living liver donation is 2 in 1000. Liver donors are not at any greater risk of developing liver disease than those in the general population.

# HOSPITAL STAY

- The average hospital stay for the donor is 5-7 days.
- You will recover on the Transplant Unit. The nurses and staff will encourage you to get out of bed to walk, and to exercise your lungs by coughing and breathing deeply.
- You will be given a shot to prevent you from having blood clots in your legs or lungs. You will be taught how to do this at home for approximately six weeks.
- You will experience pain at your incision; the degree of discomfort is very individual and is managed with medications.
- You may experience nausea related to the anesthesia; you will have medicine available to manage this symptom.
- If you have traveled from out of town, we ask that you stay locally for the first two weeks after donor surgery.
- At the end of this booklet there is information on how to get to the hospital. Information on places to stay can be given to you on request.

#### What happens if I am considered an acceptable donor?

The donor coordinator will be in close contact with you throughout your donor evaluation process. Remember that all of your results will have been reviewed by the donor surgeon, Dr. Robert Fisher. Once you have been accepted as a living liver donor, an update on your intended recipient's condition will be requested and a tentative surgical date will be identified.

Pre-operative appointments will include updating your lab work, meeting with anesthesia, pre-operative teaching, and final surgical consent. You will be admitted to the hospital the day prior to surgery.

You may want to consider talking with a previous liver donor; it can be very helpful to discuss his/her experience with them so you may appreciate living donation from the donor's perspective.

The recipient will remain on the national liver transplant waiting list until the day of the scheduled living donation and transplant. If an offer for a deceased donor liver is received prior to the planned surgeries, the Transplant Team will proceed with the deceased donor liver transplant.

# What happens if I am turned down as a donor?

There are several reasons why you could be declined as a living liver donor. These can include, but are not limited to:

- variant anatomy of the liver
- inadequate liver volume
- abnormal liver biopsy
- abnormal lab or test result such as clotting studies or cardiac testing
- evidence of coercion or lack of understanding about living liver donation

- active infection
- active malignancy
- major health issue (heart disease)
- major psychiatric disorder (bipolar disease)

While these issues may or may not affect your overall health, these are issues which would increase your surgical risk beyond that which is acceptable for a donor undergoing elective surgery which does not offer you any clinical benefit. Again, this decision is made after reviewing all of your donor evaluation results. If the donor team feels there is any risk to you at all, you will be declined as a living liver donor. If a medical issue is identified which requires further care, you will be offered a referral for ongoing care.

**Useful Websites** 

www.srtr.org www.liverfoundation.org www.unos.org www.livingdonorassistance.org | www.transplantliving.org | www.asts.org

# **DRIVING DIRECTIONS**

#### From the north (Interstate 95/Route 1)

Cross the Tobin Bridge going south and follow elevated loop merging onto the Leverett Connector. Staying in left lane, follow onto Storrow Drive West.

#### From the north (Interstate 93)

Follow 93 south to Boston and Storrow Drive (Exit 26) and the Leverett Connector. From the left lane, follow onto Storrow Drive West.

#### From the South Shore (Route 3)

Follow the Southeast Expressway through the I-93 North Tunnel to Storrow Drive West, Exit 26.

#### From the South (Route 24 and Interstate 95)

Follow Route 128 South to Route 3 exit to Southeast Expressway through the I-93 North Tunnel to Storrow Drive West, Exit 26.

Continue on Storrow Drive West to the Fenway/
Kenmore exit. The ramp will fork immediately; bear
left onto the Fenway ramp, then keep right and bear
right twice onto Boylston Street (outbound), and
proceed to intersection of Brookline Avenue (.6 miles)
and Park Drive. Continue straight ahead (slight left)
onto Brookline Avenue. Continue .4 miles to east
campus on your left and .6 miles to west campus on
your right.

#### From the northwest (Route 2)

Follow Route 2 East toward Boston to Fresh Pond Parkway. Cross the Charles River onto Soldiers Field Road, which becomes Storrow Drive East. Continue on Storrow Drive to the Fenway/Kenmore exit. Bear right twice onto Boylston Street (outbound) and follow as above.

#### **West Campus Rosenberg Building**

Continue on Brookline Avenue to the set of lights at the intersection of Brookline and Longwood Avenues (new glass building on the corner). For drop-off, continue on Brookline Avenue and take the first right onto Joslin Place. Follow Joslin place to the top and take a left onto Pilgrim Road and then the first left onto Deaconess Road. The Rosenberg Building will be on the right. There is valet parking at this entrance from 7 am to 7 pm.

(For Rosenberg Building parking only, take a right onto Longwood Avenue and the first left onto Pilgrim Road. Take the first right onto Crossover Street. The Pilgrim Road Garage is located on the right.)

#### The Transplant Institute

110 Francis Street, 7th Floor (Lowry Medical Office Building)

Continue past Deaconess Road and take the next left onto Francis Street. The Lowry Building will be on your right. The garage is attached to the office building. From the first level (handicapped parking), enter the building and go straight through two doors to the elevators. If another level, exit through the door on the building side of the garage and take the stairway either up or down, and exit to the elevators on your left. The Transplant Institute is on the 7th floor, and has a glass-fronted lobby.

#### From the west

Heading east on the Massachusetts Turnpike, take Route 128 South (exit 14) to Route 9 East (exit 20A). Follow Route 9 to the intersection of Brookline Avenue (the Brook House will be on the right). Turn left onto Brookline Avenue and continue about ½ mile to the Riverway.

#### **West Campus Rosenberg Building**

Cross over the Riverway and take the third left, which is Joslin Place. Follow Joslin Place to the top and take a left onto Pilgrim Road and then the first left onto Deaconess Road. The Rosenberg Building will be on the right. There is valet parking from 7 am to 7 pm at this entrance; otherwise, park in the Pilgrim Road Garage or the Lowry Garage.

#### The Transplant Institute

110 Francis Street, 7th Floor (Lowry Medical Office Building)

Cross over the Riverway and take the first left onto Francis Street. The garage to the Lowry Building will be immediately on your left, and is attached to the office building. Take the stairway on the building side either up or down, and exit to the elevators on your left. The Transplant Institute is on the 7th floor, and has a glassfronted lobby.

QUESTIONS:		

NOTES:		

# Thank you!

Thank you for your interest in living liver donation. The donor team is happy to answer any questions you may have during this process. We are working together with the transplant team to help restore the health of your intended recipient. Your inquiry is the first step. Please do not hesitate to call with any questions.

Sincerely,

Denise S. Morin, RN, MSN, CCTC Living Liver Donor Coordinator

Phone: 617-632-9717 Fax: 617-632-9804

# The Transplant Institute at Beth Israel Deaconess Medical Center

110 Francis Street, 7th Floor, Boston, MA 02215

P: 617-632-9700 F: 617-632-9804

bidmc.org/transplant