Liver
Transplantation

A Handbook for Patients
& Their Families
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Contact Information

My Post-Transplant Coordinator is ____________________________________________
local: (503) 494-________
toll-free: 800-452-1369 ext. ______

Transplant Office local:
Monday-Friday 8:00 am to 4:00 pm
(503) 494-8500
toll-free: 800-452-1369 ext. 8500
fax: (503) 494-4492

Urgent Issues DURING Office Hours
Monday-Friday 8:00 am to 4:00 pm
(503) 494-8500
Ask to speak with a post-transplant coordinator

Urgent Issues AFTER Office Hours
Nights, Weekends, Holidays
local: (503) 494-8311
toll-free: 800-452-1369

Tell the operator you are a kidney transplant patient and that you need to talk to the Liver transplant nurse on call. Please remember, the nurse is on call for EMERGENCIES ONLY.

________________________________________
OHSU Pharmacy (503) 494-7993
OHSU Laboratory (503) 494-7383
OHSU MyChart (503) 494-5252

________________________________________
Mailing Address
Oregon Health & Science University
Clinical Transplant Services
Liver Transplant Program
Mail Code: CB569 • 3181 SW Sam Jackson Park Road
Portland, Oregon 97239-2966
Pre Transplant

Liver Transplant Team

At OHSU we approach your care as a team. The team consists of highly trained professionals all working together towards your wellbeing. The members of the team include doctors, nurses and pharmacists, psychologists, social workers, and dieticians. During your evaluation you will have the opportunity to meet many members of the transplant team. You must bring your support person to the evaluation. It is very important for you both to meet the members of the Liver Transplant Team.

**Transplant Surgeon:** This is a doctor skilled in transplant surgery and will be the one to actually perform your transplant operation. After the operation the surgeon will care for you on a daily basis. The surgeon will make changes in your treatment and order new tests based on your progress.

**Hepatologist:** This doctor is skilled in diagnosing and treating liver disease. The Hepatologist works together with the surgeons to manage your liver disease prior to the surgery. The Hepatologist will also follow your progress after the surgery.

**House Staff:** Oregon Health & Sciences University is a teaching hospital. This means providers such as interns, residents and a hepatology fellow are assigned to your care. They work under the supervision of your transplant physician and hepatologist.

**Advanced Practice Nurse and Physician Assistants:** These providers function as liver transplant specialists.

**Transplant Nurse Coordinator:** The transplant coordinators are registered nurses. They are responsible for coordinating all the elements of your care. The long-term goal of the nurse coordinator is to teach you how to take charge of your own care so you can lead a productive lifestyle.

**Social Worker:** The transplant social worker will meet with you to discuss housing needs, insurance issues, financial concerns, and disability. They will also provide emotional support and counseling as well as referrals to community agencies.

**Nutritionist:** The nutritionist works with you and your physician to develop a nutritional program to meet your special needs before and after transplant and counsel you on the appropriate diet.

**Pharmacist:** The pharmacist assists the transplant team in managing the dose, side effects, and interactions of your medications. After transplant, prior to discharge the pharmacist will assist the nursing staff in educating you about your medications. You will have the opportunity to practice setting up your medications prior to going home.
**Psychologist:** The transplant psychologist can assist you in exploring your feelings, and offer insight into ways to manage your feelings and stress surrounding transplantation. Addiction issues will be addressed if appropriate.

**Pastoral Services:** Pastoral counselors are available for spiritual counseling if desired.

**Research Coordinators:** In order to find new approaches to transplantation, research must be conducted. At any time during your transplant experience you may be approached to participate in a research study. Participation is voluntary.

**Primary Care Physician (PCP) and Referring Physician:** You will need to rely on these doctors for your general medical needs before transplant. A referral to the liver transplant program does not mean a transfer of total care and your referring physician will assist with your care up to the time of transplant. The liver transplant team will work closely with these physicians. After transplant it is especially important for you to work closely with your PCP to care for your general medical needs not related to your new liver. Now is the time to establish a solid relationship with your PCP.

**Others:** There are many other individuals who work with the transplant team. You may interact with any of them during the course of your transplant experience. The goal of the transplant team is to provide a successful transplant experience for you.

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**YOU and YOUR SUPPORT!**

You and your support are the most important members of the transplant team. The other members of the team will depend on you to participate in your care. Sharing your physical, emotional and social needs will help shape your treatment program before and after transplant.

You are responsible for:
1. Assuming responsibility for making and attending clinic appointments.
2. Getting your lab work done and faxed to the Liver Transplant Office.
3. Complying with medical treatments.
4. Taking care of **you** before and after transplant.
Important Facts for OHSU Patients

Financial Information

It is important for you to have a full understanding of what your insurance benefits cover and what expenses are your responsibility. Terms and coverage for transplant vary widely among insurance companies. Read your policy and talk to the insurance company benefits office to understand your coverage. Many insurance companies have a co-payment for services or a deductible. Some insurance companies have a lifetime maximum on transplant benefits and caps on medication coverage.

Medications can create a financial strain on the patient after transplant. These medications are required for the rest of your life. It is very important that you understand what kind of medication coverage your insurance benefits offer. Have a clear understanding of what medication costs are your responsibility. Other costs to consider are food and lodging for distant patients and their families when here in Portland and transportation to and from the transplant center. Also consider ‘lost time’ that your employer does not pay for when you are away from work.

The transplant social worker and financial counselors will help you with any questions you have regarding the costs of transplant.
Advance Directive

The Advanced Directive is your opportunity to identify a health care representative. A health care representative will make health care decisions for you in the event you cannot make them yourself. It is also your opportunity to define the extent of medical intervention that will be administered if your medical condition becomes very serious. You may change your directive at any time. Simply notify the Social Worker and she will ensure the amended document is correctly forwarded.

For the purpose of liver transplantation it is necessary that you complete the following sections of the Advanced Directive, and return to the Liver Transplant Social worker.

Part B - (The Appointment of a Health Care Representative). For married couples this usually is a spouse. Your representative may be a sibling, parent, adult child or close friend. It is most important that the representative knows your wishes and be able to advocate for you in a difficult situation.

Part C- Not necessary to complete, but you may wish to discuss with your family.

Part D- (Witnessed Signature)

Part E- (Representative Signature) This section documents that your representative accepts the responsibility of being your health care representative.
The Liver and How It Works

The transplant doctors and coordinators will help you understand your specific liver disease during the evaluation process. The American Liver Foundation has information about the various types of liver disease. Their address, website, and phone number are in the back of this booklet.

Remember: For general health concerns you should be seen by your local provider. The liver transplant team can assist with liver disease specific problems as described in this chapter.

How It Works

The liver is the largest internal organ in your body. An average adult liver weighs approximately three to four pounds. The liver is located in the right side of the abdomen just beneath the diaphragm and behind the lower ribs. The liver has a right and a left lobe. The main blood vessels of the liver are the hepatic and portal veins, inferior vena cava, and the hepatic artery. Beneath the liver lies the gallbladder, which is the reservoir for bile. The pancreas also lies below the liver and produces enzymes that aid in digestion.

The liver is responsible for many of the body’s metabolic and manufacturing functions, including:

1. The metabolism of carbohydrates into glucose (sugar) so your body can use it for energy.
2. Detoxification (cleaning) of harmful substances from the body, this includes alcohol, drugs and other by-products from what you eat and drink.
3. Production of bile, a yellow-green substance that helps your body absorb fats.
4. Metabolism of basic proteins (amino acids) to ensure proper ammonia and levels are maintained.
5. Production of proteins, including proteins that aid in blood clotting.
7. Filtering blood to remove bacteria and other particles.
8. Storage of minerals and vitamins for your body’s use later on.
9. Host defense to assist in fighting infection

End Stage Liver Disease

Due to the complex functions of the liver even the smallest disturbance in any of the functions has a profound effect on the body.

Disease Symptoms

- Abnormal clearance of bile
- Jaundice (yellow color of skin & eyes)
- Clay colored stool & dark urine
- Pruritus (itching)
- Decreased blood flow through the liver from cirrhosis (liver scarring)
- Varices (enlarged vessels in throat, esophagus & stomach)
- Hemorrhoids
- Ascites (abdominal fluid buildup) & edema
- Accumulation of bile salts
- Inflammation of the liver
- Abdominal pain & fever
- Impaired glucose & glucagon metabolism
- Fatigue and weakness & high blood sugar
- Reduced clotting factor production
- Bleeding, bruising easily
- Impaired protein metabolism
- Encephalopathy (confusion) & insomnia

There are many diseases that can cause liver failure. The following are some of the most common causes of liver failure in adults.

Viral Hepatitis
Prolonged inflammation of the liver due to viral infection. Patients with chronic hepatitis may develop cirrhosis, portal hypertension and/or cancer. Liver failure may occur within five years. Symptoms of Chronic Viral Hepatitis can be described as flu-like symptoms and may include fever, fatigue, anemia, pruritus (itching), abdominal pain, jaundice, clay colored stools and dark colored urine, anorexia, nausea and vomiting, varices, ascites, bruising, and prolonged bleeding.

Hepatitis A (HAV)
This disease is transmitted by drinking water or eating food contaminated with fecal matter containing the virus. Shellfish is also frequently a source. Most people recover from the infection within six months and do not require a liver transplant.

Hepatitis B (HAV)
Transmission is through infected blood and other body fluids such as semen, vagina secretions, breast milk, saliva and open sores. A high-risk history includes blood transfusions or exposures through needle sticks, IV drug use, multiple sex partners, or sexual intercourse with an infected person. Most people fight off the infection themselves; however 5-10% of those infected progress to be a chronic carrier and may eventually develop liver disease and cirrhosis. Liver transplant is a viable option for treating the symptoms of hepatitis B. Those transplanted will receive special treatments before and after transplant to keep the virus under better control.

Hepatitis C (HCV)
Previously known as non-A, non-B hepatitis, HCV was identified in 1989 and by 1990 the test was available to identify those infected. HCV is transmitted through exposure to blood infected with the virus. A high-risk history includes blood transfusions, IV drug users sharing needles, tattoos, snorting cocaine, and multiple sexual partners. There are a variety of medications that are approved for treatment of HCV, and work for some of people that are infected.

Alcoholic Cirrhosis
Damage occurs to the liver cells from alcohol and scar tissue forms. Individuals who develop liver damage from alcohol should stop using alcohol immediately. In many cases the liver function will improve within six months. Continued use of alcohol will result in further cirrhosis, and increasing symptoms of liver disease and failure. Liver damage can develop from alcohol even if a person is not an alcoholic. Women are much more sensitive to alcohol, and suffer the long-term effects of continued drinking sooner than men. Liver transplant is the only option if liver failure develops from alcoholic cirrhosis.

If you have liver disease and are still drinking, stop!
Even if you do not have alcoholic cirrhosis, alcohol can increase the effects of your liver disease. For example, if people with hepatitis C drink alcohol, they will advance to end stage liver disease faster than those who do not drink. **Persons continuing to drink alcohol are not eligible for transplant.**

Symptoms from Alcoholic Cirrhosis may include: jaundice, weight loss, ascites (fluid around the abdomen), enlargement of the spleen, edema (fluid) in the legs, encephalopathy (confusion), GI bleeding.

**Primary Biliary Cirrhosis (PBC)**
Slow progressive destruction of the bile ducts that interferes with the excretion of bile from the liver. Substances normally excreted in the bile build up in the blood. Inflammation results and eventually will cause scarring and cirrhosis. The initial cause of PBC is unknown. However, disturbances of the immune system and hormones may play a part. Women are affected 10 times more than men. Symptoms include itching, fatigue, jaundice, fluid accumulation and darkening skin.

**Primary Sclerosing Cholangitis (PSC)**
Bile ducts inside and outside the liver become narrowed due to inflammation and scarring causing bile to build up in the liver. The result is damage of the liver cells. PSC is more common in men than women. Seventy per cent of the patients also have inflammatory bowel disease. Symptoms include fatigue, itching, jaundice, and fever and chills from infection in the bile ducts.

**Autoimmune Hepatitis**
Progressive inflammation of the liver associated with an abnormality of the immune system. Seventy per cent of the patients with autoimmune hepatitis are women. Treatment with Prednisone and Imuran has been shown to decrease symptoms. Symptoms include fatigue, abdominal discomfort, jaundice, aching joints, itching, spider angiomas on the skin, ascites, and encephalopathy.

**Alpha-1 Antitrypsin Deficiency**
Alpha-1 antitrypsin is a protein made by the liver and is important in preventing the breakdown of enzymes in various organs of the body. Adults with this deficiency may also suffer from emphysema. Symptoms from alpha-1 antitrypsin include fatigue, poor appetite, ascites and edema, jaundice, itching, nosebleeds, bruising and varices.

**Wilson's Disease**
The liver fails to rid the body of copper resulting in excessive amounts of copper in the liver, brain and other organs. Wilson's disease is an inherited disorder and is a chronic progressive disease. However, it can also cause acute fulminate hepatitis in which the liver failure progresses rapidly. Other symptoms of Wilson's disease include mental difficulties, unsteady walk, kidney damage and copper in the eyes known as Kayser-Fleischer rings.

**Hemochromatosis**
An inherited metabolic error in which the body absorbs more iron than the body needs. The iron is stored in the liver, and cirrhosis can develop. Individuals with hemochromatosis usually have bronze to slate gray appearing skin. This condition can affect the heart in the form of abnormal rhythms, or congestive failure. A liver biopsy sent for iron quantity levels and a blood test help to diagnose hemochromatosis.
Hepatoma
A malignant tumor in the liver. Sometimes it is possible to surgically remove the tumor. The tumor must be relatively small for transplant to be a successful option. Special treatment to prevent further growth may be done prior to liver transplant.

When to Seek Medical Attention
You should seek immediate medical attention if you experience any of the following liver failure symptoms:
- Vomiting blood or coffee ground-like material
- Blood in your stools or black tar-like stools
- Weight gain of more than 4 pounds in a week
- Shortness of breath
- Confused thinking
- Fever over 100.4 degrees F

Liver Failure Medications
Your providers try to minimize your symptoms of liver failure by prescribing medications that control specific side effects. The more commonly prescribed medications are outlined below. If you have any questions regarding these medications, please talk to your physician or nurse.

Lactulose
This is a laxative used to prevent and treat encephalopathy. It decreases the pH in the colon making it difficult for the intestine to absorb ammonia. This decreases the ammonia circulating in your blood and improves mental function.
The dose of Lactulose varies by patient, but is designed to produce 3 to 5 soft stools a day.

Rifaximin
This is an antibiotic, which destroys bacteria and reduces toxins in the intestine. It is used to help treat encephalopathy.

Furosemide (Lasix)
This is used to decrease the build up of extra fluid in the feet, ankles, legs and abdomen. Lasix can deplete potassium from the blood stream. Your potassium level is monitored when you are on Lasix and you may require a potassium supplement.

Spironolactone (Aldactone)
This is also used to decrease the build up of extra fluid, without depleting the potassium from the blood. Aldactone can cause gynecomastia (breast swelling) and tenderness. It may also result in high blood potassium levels.

Propranolol (Inderal)
This medication decreases the pressure in the blood vessels and thus prevent esophageal varices and gastric varices (enlarged blood vessels of the esophagus and stomach). This helps to prevent hemorrhage of these vessels.
Zinc Sulfate
This is a nutritional supplement that replaces zinc in your body. Zinc promotes healing and protects against infection. Liver disease can cause zinc deficiency.

Multivitamin
A nutritional supplement to replace important vitamins and minerals in your body. A prenatal vitamin is commonly prescribed due to the extra minerals it contains.

Pain Medication
Individuals with liver disease may be on medications prescribed for pain. Narcotics in general are not the best choice for patients with liver disease. Narcotics can increase confusion and encephalopathy and cause patients to be admitted to the hospital for treatment of these conditions. It is preferable to take Tylenol no more than 1.5 grams in a 24 hour period, and not more than 4 times a week. Aspirin or ibuprofen are not recommended for patients with liver disease because they are blood thinners and can cause gastrointestinal bleeding. If you do receive narcotics, the transplant team requires that you obtain them from one source, either your local physician or the liver transplant program. Also consider other approaches to pain management such as ice, heat, physical therapy, or further consultation with a specialist.

Note: The transplant team is concerned about abusive use of pain medications. If abuse is suspected further investigation will occur, and a patient could be denied liver transplant.

Herbal Medications
Do not take any herbal medications pre or post-transplant. They are not regulated so the amount of active ingredients and contaminants are not known.

Transplant Evaluation

The Work-Up
Your doctor has referred you to Oregon Health & Science University (OHSU) for liver transplant evaluation. Not everyone with liver disease should or can have a transplant. The evaluation process will help us find out whether liver transplantation is the best option for you.

The evaluation usually requires a 3-4 day stay in Portland if you do not live locally. The evaluation is done on an outpatient basis unless you are critically ill and require hospitalization. You will attend a class that will teach you about transplantation and review information from the pre-transplant packet. You will also have the opportunity to ask questions. During the evaluation you will have appointments with many specialists in addition to members of the liver transplant team. You will also have lab work and diagnostic tests performed. The tests vary for each person but in most cases they include the following:

Electrocardiogram (EKG)
This test tracks the electrical impulses of your heart. It checks the rhythms in your heart, and can help us to determine the overall health of your heart.
Echocardiogram
This test also checks the health of your heart. Similar to the ultrasound, the echocardiogram checks the health of the chambers of your heart, the valves, vessels and blood flow.

Dobutamine Stress Test
Dobutamine is a drug that is administered intravenously and causes your heart to react like it would during physical activity. Pictures are taken of your heart. This will show how your heart responds during a stressful situation, such as a liver transplant.

Chest X-ray
This is a picture of your heart, lungs, rib cage and surrounding muscle, tissue and lymph nodes. It will help us identify heart disease, lung disease or other problems in your chest.

Pulmonary Function Test
This is a breathing test which measures the capacity of your lungs by having you breathe in and blow out through a special tube. A blood sample may be drawn from an artery in your arm. This will measure your lung’s ability to carry oxygen and remove carbon dioxide from your bloodstream.

Abdominal Imaging:
CT Scan or MRI: You will have one of these scans done during your evaluation. The CT is a computerized image and the MRI is a magnetic image. Both of these scans will show the shape and size of the abdominal organs, major blood vessels, and help to identify if tumors or cancer are present.

Ultrasound: This test uses sound waves to create a picture of the liver and other organs. It can also tell us if the large vessels that flow to and from your liver are open.

Blood Work
The laboratory will draw many tubes of blood on the first day of your evaluation. Some of the tests will help the team understand the status of your liver disease. Other tests check for viral infections, past infection, HIV, tumor and cancer markers, vitamins and minerals. Your blood type will be determined at this time.

Bone Densitometry
This is a scan that shows the density (strength) of your bones and will indicate if you have low bone mass or osteoporosis. Calcium and vitamin D are important supplements that should be taken before and after liver transplant.
Other Testing
These tests may be recommended for some patients depending on the type of liver disease, before being listed for a liver transplant.

A. Liver Biopsy
   This is a procedure in which a small piece of your liver is taken with a special needle. A liver biopsy can help determine the type of liver disease you have and how much cirrhosis or damage there may be. It also can identify increased iron deposits in your liver.

B. Colonoscopy
   A special tube with a camera is passed through your rectum into your large intestine to check for bowel disease, masses, bleeding, internal hemorrhoids and polyps.

C. Endoscopy/EGD
   This procedure uses a special scope to look into your throat, stomach and small bowel to find out if you have any enlarged blood vessels or ulcers. You will be sedated during this procedure.

D. CT Chest without contrast
   This is a cat scan of the chest that will help show more details than a chest X-ray and is used to rule out spread of cancer in the chest.

E. Nuclear Medicine Bone Scan
   A type of contrast is given intravenously and is used to evaluate for spread of cancer to the bones.

Health Maintenance Testing
A. Dental Evaluation yearly to identify (and treat) presence of active infection in teeth or gums.
B. Screening Colonoscopy at age 50 (if normal, usually every 10 years)
C. PSA lab test every 2 years (unless abnormal) for men age 50 or over
D. Mammogram yearly for women age 40 and over
E. Pap smear
   a. Women age 21-29 screen every 2 years
   b. Women age 30 and over screen every 3 years after 3 consecutive normal tests
   c. Women age 65-70 end screening after 3 or more consecutive normal tests with no abnormal tests within the last 10 years.
Updated Testing Prior to Transplant
Some patients may be on the list for several years waiting for a liver transplant. It is important that you maintain the recommended health maintenance schedule. As you approach the top of the transplant waitlist, you will need to provide the current health maintenance testing as outlined above in order to stay active on the waitlist. Current cardiac testing will be required if it has been over 1 year since your initial transplant evaluation and this will be arranged by the transplant office.

Recommended Vaccinations Prior to Transplant
The Transplant Team recommends that you are up to date with certain vaccinations before receiving a transplant. Please review the recommendations below and plan to discuss these with your primary care physician (PCP) who will determine any contraindications (pregnancy etc) and who will administer as needed.

Pneumococcal (Pneumovax)
1. PCV 13 (prime boost approach) followed by another pneumovax PPSV23 vaccination at >= 8 weeks. Repeat the PPSV23 again 5 years later.
2. If the Pneumovax (PPSV23) was given as the first vaccine, then wait 1 year or more and get the PCV 13 vaccination. Repeat the PPSV23 again in 5 years.

Tetanus- Diptheria
1. Tetanus-diptheria every 10 years.
2. (When referred for transplant, the team may recommend an update earlier than 10 years in order for you to be current during the waiting time and early post transplant period.)

Pertussis
Once in adulthood. This can be given with tetanus-diptheria as Tdap

Hepatitis A
1. Two injections, 6 months apart
2. If not immune, repeat the series
3. If still not immune after 2 full series of injections, do not repeat again

Hepatitis B
1. Three injections, second dose at 1 or 2 months, 3rd dose at 6 months
2. If not immune, repeat the series with a double dose with each injection
3. If still not immune after 2 full series of injections, do not repeat again

Varicella (Live-attenuated)
For patients that are VZV negative (have not had chicken pox AND are seronegative with negative VZV IgG), so long as there are no contraindications to liver virus vaccination (eg., not on immune suppression, NOT POST – TRANSPLANT) proceed with VZV vaccination (Varivax): 2 injections, separated by at least a month, then check titer 4 weeks after the last injection. If titer is still negative, give a 3rd vaccine, then check titer again 4 weeks later. If titer is still negative, patient should be instructed to notify the transplant team if they are EVER exposed to chicken pox or herpes zoster. This is a liver virus vaccine, so patient must wait at least 4 weeks after receiving this vaccine to proceed to transplant.
Zoster (Live-attenuated)
1. This can be given prior to transplant to help prevent the severity of herpes zoster infection, commonly known as shingles.
2. Protocol: For patients that have had chicken pox (or are known to be VZV seropositive). Zostavax can be given to patients age >= 50 to decrease the incidence of herpes zoster, so long as there are no contraindications to live virus vaccination (eg., not on immune suppression, NOT POST-TRANSPLANT). This is a live vaccine so you cannot receive a transplant for 4 weeks after this vaccine and you cannot ever receive this vaccine after transplant.

Measles (Live-attenuated)
1. This blood test will be done at the time of your transplant evaluation and the transplant team will give you and your PCP advice if you need to be vaccinated.
2. Protocol: Check the MMR titer (this will be done at the time of your transplant evaluation). If the titers are negative for any of the 3: measles, mumps, or rubella, then a booster shot will be recommended so long as there are no contraindications to live virus vaccination (eg., not on immune suppression, NOT POST-TRANSPLANT). This is a live vaccine, so you cannot receive a transplant for 4 weeks after receiving this vaccine and you cannot ever receive this vaccine after transplant.

HPV
Recommended but not required for females ages 9-26.

Types of Donors
The Transplant Team is very interested in choosing the best possible donor for your transplant. Just as there are a wide variety of medical conditions present in the general population, there are also those present in the donor population. The surgeons will discuss with you the types of donors that would be appropriate or not appropriate for you when you meet with them during the transplant evaluation.
Candidacy

After all the tests and consults are completed, your case is presented to the Liver Transplant Committee meeting which is held once a week. Members of the liver transplant team are present and your case is discussed. There are two decisions to be made at this time.

FIRST it will be decided if you meet criteria for a liver transplant. Criteria for candidacy include, but are not limited to:

- The presence of end stage liver disease, which cannot be cured by other medical treatments.
- Negative HIV test.
- At least 6 months abstinence from alcohol and substance abuse.
- Stable, sober support system, such as family or friends.
- Full understanding of the transplant process.
- Ability to understand and demonstrate compliance with the medical care required.
- No active infections.
- No active cancer, with the exception of some liver tumors.
- No other medical conditions that will interfere with your recovery from a transplant (such as heart or lung disease).

SECOND the team will decide your candidate category. Categories of candidacy include:

- Accepted For Liver Transplant
  This person meets criteria for transplant and will be listed for transplant unless something is discovered in the testing that is a contraindication for transplant.

- Deferred For Liver Transplant
  The person does not currently meet criteria for transplant and further testing and or treatment is necessary. Examples: a medical problem that needs further evaluation or specific treatment, counseling, or treatment for past alcohol or drug abuse. When the requirements are completed, the case will be represented at Selection Committee.

- Denied For Liver Transplant
  The person does not currently meet criteria either due to medical or psychosocial reasons. Sometimes patients in this category may be re-referred once they meet criteria.

In light of all these guidelines, the selection of a specific patient will be based on the merit of the individual's candidacy. The team will work with patients on an individual basis to establish their candidacy. It is important to remember that the team relies on you to assume responsibility for coming to appointments and completing all of the recommendations from Liver Transplant Committee. Individuals who make the choice not to follow through with the recommendations from Selection Conference may be declined due to poor compliance.

The coordinators and secretarial staff in the liver transplant office will work with you to schedule appointments for recommended studies and appointments.
Waiting For Liver Transplant

We realize that waiting for your transplant is very stressful. People who are waiting on the list are prioritized for medical need, body size, and blood type. Even though the waiting is difficult, there are things to do while you wait.

Maximize your health - follow the recommended nutrition and exercise programs and lose weight if needed. Get on with your life - continue working if possible and stay involved with as many activities as possible. Start or restart hobbies or activities. Get prepared - pack a hospital bag and make housing arrangements if you do not live in the Portland area.

The Waiting List

Once all of the recommendations from Selection Conference are completed and you are an acceptable candidate, we will be able to pursue getting insurance authorization for your liver transplant. Your insurance company will need to review your case, and give authorization for the transplant procedure. Once we receive authorization from your insurance company and hospital administration, you will be placed on the liver transplant waiting list.

UNOS

All transplant centers are part of a computerized organ-sharing network that is governed by the United Network for Organ Sharing (UNOS). UNOS is responsible for regulating the listing of patients and the allocation of organs.

All patients are placed on the national waiting list. The patients listed at transplant centers have local and regional priority. Below is a list of the geographic areas that contribute to the local and regional groups.

- **National**: Entire United States
- **Regional**: Alaska, Washington, Oregon, Montana, Idaho and Hawaii
- **Local**: Oregon, Southern Washington and Southwestern Idaho

Livers for transplant must match for body size and blood type. When you are placed on our local list, you will be put into your blood type subgroup: A, B, AB or O. Within that group you will be placed according to the severity of your liver disease based on the MELD system.
MELD / PELD

The MELD is a system of prioritizing patients waiting for liver transplant. It is a statistical formula that determines that the patient with the greatest need will have the highest priority for the next available liver. The MELD (Model for End Stage Liver Disease) is used for adults and the PELD (Pediatric End Stage Liver Disease Model) is used for pediatric patients. The MELD calculates a number between 6 (less ill) and 40 (gravely ill) and is derived from a formula using three lab values: bilirubin, creatinine (kidney function), and the PT or INR (ability to clot blood).

The PELD is used for candidates under the age of 18 and uses the same lab values to determine a number score, as well as other factors specific to growth and development. PELD scores may range higher or lower than MELD scores.

The MELD/PELD will vary with each lab draw. It is mandatory for patients to have lab work done at least every three months to maintain correct placement on the waiting list. Failure to do so will result in your score reverting to your last lowest score until we receive current lab work and can update your MELD/PELD score.

It is important to understand that during your wait for transplant your condition could deteriorate to the point you would no longer survive transplantation, and therefore would no longer be a candidate. The Liver Transplant Team will do everything possible to keep your status active.

Waiting Times

Waiting times depend on your blood type and the number of donors available and are therefore difficult to predict. If you have questions regarding your waiting time once you are listed please talk to the transplant coordinator.

Where to Wait

If you do not live in Oregon, it may be necessary for you to come to Portland to wait for your transplant. When you are listed, the transplant team will watch as you move up on the list. When you are likely to be called for transplant you will be notified to come to Portland. You must arrive at the transplant center within 6 hours from the time you are called in for transplant. If you cannot be here within that amount of time, you need to make arrangements to temporarily move to the Portland area.

OHSU candidates who do need to stay in Portland while waiting for transplant should plan for housing for approximately 2 or more months prior to liver transplant. Our Social Worker can give you suggestions for low cost housing.

Meld Exceptions:

Sometimes a MELD exception is granted by the UNOS Regional Review Board to award a higher MELD score to a patient. The most common exception given is for liver cancer that meets specific criteria. This is called the hepatocellular carcinoma (HCC) MELD exception. A patient can receive 22 points for the HCC MELD Exception. The MELD points increase every 3 months while waiting for a liver transplant. Your transplant team will decide if you are eligible to receive a MELD exception.
Getting the Call for Transplant

While you wait for your transplant, you will need to be available at all times by having accurate mobile and home phone numbers. If your number changes, it is imperative that you communicate this to the Liver Transplant Office staff. Keep the following numbers with you at all times:

**OHSU Liver Transplant Office 503-494-8500**  
**After Hours & Toll-Free 1-800-452-1369, x48500**

When the time comes for you to receive your transplant, the nurse coordinators will first call your home. If we do not reach you, we will use your cell number. You will experience many feelings of excitement, relief, and/or fear. We recommend you have someone drive you to the hospital. Check in at the OHSU South Hospital 9th floor admitting desk. You will then go to the 4A to be prepared for surgery.

Some important facts to remember are: Do not eat or drink anything once you have received the call to come to the hospital. There is always a chance that the transplant may be canceled if the liver is not acceptable.

Organ Selection & Matching

The surgeons are particular about what organs they use for transplant. Any time during the day the surgeons may receive a call to notify them of a potential donor. At this time the donor is worked up with several blood studies, diagnostic studies, and an extensive medical and social history. If the donor meets the criteria as a safe candidate for donation, the surgeons procure (remove/retrieve) the organ. This is the operation the surgeons perform to remove the organ from the donor and prepare it for liver transplant. The final decision to use the organ takes place during the procurement when the surgeon has the opportunity to actually see the liver. If at any time during the procurement process the organ appears to be unsuitable, the surgeons will not use it for transplantation.

Matching for liver transplantation is dependent on two factors.

1. **Blood Type**  
   Livers are matched by blood type. In very rare cases a different blood type may be used to save the life of a critically ill patient. This is a rare exception. The vast majority of transplants are done by matching the donor blood type to the recipient’s blood type.

2. **Body Size**  
   It is very difficult to put the liver of a very large person into the body of a small person and vice versa. The surgeons will look at the body size of the donor and try to match that closely to the body size of the recipient. Unlike kidney or bone marrow transplant, liver transplant does not require tissue typing for a successful transplant.

3. **Unrelated Donor**  
   Unlike kidney or bone marrow transplant, liver transplant does not require tissue typing for a successful transplant.
Due to the matching process for liver transplant, the candidate first on the list is not always the one to receive the transplant. We can tell you when you are getting closer to the top, and estimate when your transplant may occur. A patient’s place on the list can change every day as people renew their MELD scores. Expect to wait for some time to receive your transplant.

Remember: During your wait for transplant your condition could deteriorate to the point you would no longer survive transplant, and therefore would no longer be a candidate.

All of the members of the transplant team are working hard to get you on the waiting list and transplanted as quickly as possible. We advise patient to take this time to promote physical and emotional health. If possible, do not turn your back on your favorite hobbies or activities. You may want to consider starting a new hobby or restarting old ones. Walking is an excellent way to promote your physical wellbeing. Talk to your physicians regarding additional information on physical activity and emotional wellness.
Your Transplant Surgery

Once you have been called in for your liver transplant surgery, your emotions may feel like a roller coaster, and everything seems like a blur. It is important for you to have this day planned out ahead of time. How will I get to the hospital? Where do I go? What do I bring? Prepare for all of this ahead of time.

When you get the call for your transplant, you need to arrive at OHSU South Hospital 9th floor Admitting. You will then go to 4A where the nurses and doctors will prepare you for the surgery. The time before the surgery is very busy. A resident, intern, or PA will perform a physical examination and take a complete history. Please bring a complete list of all your medications. At this time you will be asked to sign one or more consent forms giving your permission to the surgeons to perform the surgery.

In addition to the physical, you will receive a chest x-ray, EKG, and blood tests. The nurses will start an intravenous line (IV) for antibiotics to prevent infection. Finally, you will need to scrub twice with a special antibacterial soap prior to going to the operating room.

The Operating Room

When it is time, the nurses will take you to the operating room. Once you are placed under anesthesia the transplant team goes to work. Your abdomen will be scrubbed again. Several different lines and tubes are placed.

A. Endotracheal Tube (ET tube)
   This is a tube placed in the airway (trachea) that is connected to the ventilator. The ventilator breathes for you while you are under the effects of the anesthesia. Your throat may be sore after transplant.

B. Central Venous Catheter (CVC)
   This is a large IV line that is placed in one of the vessels in your neck. This line is used for giving you medication, fluids and blood products.

C. Urinary Catheter
   This is a drainage tube that is inserted into your urinary bladder. It drains your urine into a bag. This helps the doctors and nurses evaluate your fluid status, electrolytes, and kidney function.

D. Nasogastric Tube (NG tube)
   This tube is passed through one of your nostrils, down your throat and into your stomach. It is used for keeping air out of your stomach while you are on the ventilator. We also use it to keep the acidity of your stomach balanced. The nurses can also give medications down this tube.

E. Jackson Pratt Drains (JP drains)
   The surgeons place these drains around your surgical site when they have completed the transplant surgery. The drains have attached large clear bulbs, which catch the blood and fluid that is collecting around your surgical site. Draining this fluid helps to prevent swelling and infection.

F. Bile Drainage Tube (rarely used)
   This is used to drain bile from the biliary tree. This drainage tube is connected to a collection container immediately after surgery. Once the drainage slows down and you are stable the tube is capped. This tube stays in for weeks and will be removed during one of your clinic visits.
**Incision**

The surgical incision for liver transplant is very large. Most often the incision goes across your abdomen in a “Mercedes Benz™” shape, extending up towards your chest. Once the incision is made the surgeon will proceed with removing your old liver, leaving parts of your major blood vessels and bile ducts. The new liver is inserted and attached to the vessels and bile duct. During the surgery you may receive transfusions of blood, platelets, and fresh frozen plasma. You are placed on a monitor that tracks your heart rate, arterial and venous pressure, and respiratory rate. In addition, your blood is sent to the lab frequently to monitor your chemistries, blood counts and clotting factors.

**Length of Surgery**

The average length of time for a liver transplant is 8 hours and may vary from less than 6 hours to more than 13 hours. The length of time does not predict the success of the surgery. Patients with a past history of abdominal surgery usually take longer during liver transplant because of old scar tissue present in the abdominal cavity. When the surgery is complete, the surgeons close your incision. The incision is closed on the outside with staples. The staples stay in place for at least three weeks and are removed during one of your clinic visits. After the incision is closed and you are stable you will be taken back to the ICU.

While you are in surgery, your family and friends can wait in the nearby waiting room. If the operating room nurses have time they may come out during the surgery to give you a progress report. One identified spokesperson for the family is helpful when communicating to the nursing staff. The spokesperson passes on information to the rest of the family and anyone calling to see how you are doing.

**Your POST Operative Course**

**Surgical Intensive Care Unit (SICU)**

You will wake up from the transplant operation in the Surgical Intensive Care Unit on 7A. The sights and sounds may seem strange to you. You will be attached to many tubes, IV lines, and monitors as described in the previous chapter.

The average length of stay in the SICU is 2 days. This will vary depending on how you respond to the surgery, how quickly you recover from the anesthetic, and how sick you were prior to the transplant.

When you wake up you may experience some confusion due to the anesthetic. Nights and days can begin to blend together. It is not uncommon for your sleep pattern to be interrupted. However, sleeping medications are used infrequently because you will already be on many medications and your new liver is just beginning to work.
When you are stable, the doctors will remove some of the monitors, intravenous (IV) lines, and tubes.

A. Endotracheal Tube (ET tube) - As soon as your body has metabolized the anesthetic, and you are able to breathe on your own the ET tube will be removed, this usually occurs within 24 hours. It is common to have a sore throat after this tube is taken out.

B. Urine Catheter/ Suture Lines - The urine catheter might be removed in the SICU if the surgeons feel your kidneys are working well. The nurses will continue to measure your urine until you go home from the hospital. The suture line should be kept clean and dry. When you are stable you will be transferred to the Transplant Unit.

C. Nasogastric Tube (NG tube) - As soon as your stomach and bowels begin working and you are able to pass gas, this tube will be removed from your nose.

D. Jackson Pratt Drains (JP Drains) These drainage tubes are removed as the amount of fluid draining into them decreases to a very small amount.

E. Central Venous Catheter (CVC) - This is usually the last line to be removed. It may be removed on the day of your discharge.

Liver Transplant Unit (4A)

The average length of stay on the Transplant Unit is 5-8 days. This makes your total hospitalization stay approximately 10 days. This varies depending on your overall post-transplant recovery course.

After your surgery you may feel many different emotions. Many people feel relief that it is over. It is not uncommon to feel depressed or anxious after the surgery. All these emotions are common and most people feel a little of each.

While you are on the Transplant Unit you have some important responsibilities before you can be discharged.

Eating - When you are permitted to eat you will start with clear liquids. If that is tolerated, you will move slowly to solid foods.

Daily Activities - The nurses will expect you to take part in your own care such as brushing your teeth, bathing, combing your hair, shaving, etc. These activities will help make you feel better.

Walking - You will need help at first, but your strength will increase gradually. Walking helps your body get back into shape, and heal faster. The goal is to walk at least 4 times a day.

Learning - You will learn all about your new liver, how to take care of it, how to prevent infection, your medications, and your clinic and lab schedule. The coordinators, pharmacists and nurses will teach you how to take care of yourself now that you have your new liver. You will receive a Post-Transplant Manual. THIS IS YOUR LIFE LONG GUIDE and continue to refer to it forever. The transplant team expects you and your social support to read the manual during your hospital stay. The Transplant Coordinator and the pharmacist will come to your room to review the content of the manual, answer questions, and review your medications. Prior to your discharge, you and your support will need to complete a worksheet on the information you learned.
Coughing and Deep Breathing - Your nurse will show you how to perform coughing, deep breathing exercises, and the incentive spirometer. This “blowball” machine should be used 10 times per hour while awake. These exercises aid in preventing pneumonia and will speed your recovery.

Liver Transplant Unit Visitors
The liver transplant team encourages visits from your family and friends. Because of the risk of infection, you should caution your friends and family not to visit if they have a cold, flu or some other infectious disease. In addition everyone should use frequent hand washing. For the family and friends that cannot visit it is helpful to have a spokesperson for the group. The spokesperson is the one who gets the current updates and passes the information along. This helps keep the nursing staff from having to take time away from your care to answer a number of phone calls.

Discharge
As you can imagine there is a lot to pull together. The Transplant Team will work very hard to get you discharged, but we depend on you to do your part as well. You need to study your manual, practice with your medications, and follow the medical orders from the physician and nurses.

If you do not live in the Portland area you will need to make arrangements to stay. This is because your progress requires close supervision. Even though you may be stable enough to leave the hospital, you will still need frequent follow up and frequent lab work. It is important for you to be nearby (up to 3 months post-transplant) in case of complications after surgery. The transplant team also wants you to get your lab work done in Portland. This helps the team keep your medication doses stable.

The Transplant Team will discharge you when:
- You are physically stable
- You know your medications and can set up each dose.
- You know your clinic and lab schedule
- You pass the discharge review worksheet (reviewed by the coordinators)
- You have arrangements for a place to stay when leaving the hospital.

OHSU Distant Patients
The Transplant Team expects you to stay in the Portland area for up to 3 months after your transplant. During that time the physicians will decide when you are stable enough to go home.

At the end of 2-3 months you will return to your local provider for care. The transplant team will continue to monitor your liver function, and medication levels through routine lab work. We will work with your local provider to help manage your care. You will have regular follow-up visits during the first year post transplant and then annually.
Post Transplant – Discharge to Follow Up Care

Please review the following guidelines. If you have any questions or concerns after you leave the hospital, please call the Liver Transplant Coordinator during office hours which are 8:00 a.m. to 4:30 p.m. Pacific Time. Leave a detailed message with your return phone number if the nurse is not immediately available to take your call.

Liver Transplant Office Phone Numbers
OHSU, Local: 503-494-8500
OHSU Toll-free: 1-800-452-1369, ext.4-8500

Lab Schedule

You will need to have labs drawn on a regular basis for the rest of your life. Remind your lab to fax the results directly to our office at 503-494-5292 the same day your lab work is drawn. Any change to your lab frequency will need to be discussed with your coordinator or physician.

For the first month following transplant you will have your labs drawn twice a week on Mondays and Thursdays.

This schedule maybe adjusted based on individual needs.

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<thead>
<tr>
<th>Months After Transplant</th>
<th>Lab Schedule</th>
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<tbody>
<tr>
<td>1</td>
<td>Monday and Thursday</td>
</tr>
<tr>
<td>2-6</td>
<td>Every Monday</td>
</tr>
<tr>
<td>7-12</td>
<td>Every Other Monday</td>
</tr>
<tr>
<td>After 1 year</td>
<td>1st Monday of every month</td>
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The OHSU outpatient lab is located in the Physicians Pavilion on the third floor. Patients are to have their blood drawn each week on Monday and Thursday. After one month or when your lab schedule changes, your labs should be drawn on Mondays to make sure that there is enough time for the results to be sent to our office and reviewed. If there are any medication changes, additional labs or other studies needed because of your lab results, a coordinator will call you. You will NOT be called if there are no changes to be made. If you wish, you can arrange with the laboratory for results to be sent to you so that you can monitor your test results directly.
You can also sign up for OHSU’s “MyChart” while at an OHSU office visit. MyChart gives you easy online access to your lab test results, medical history and medical appointments. It also gives you the ability to send non-urgent messages to your health care providers.

**Clinic Visits**

After you are discharged from the hospital you will be closely followed at the Liver Transplant Clinic. At each clinic visit the provider will decide when you will need to return for your next office visit based on your rate of recovery.

Transplant Clinic is held in the mornings on Tuesdays and Fridays on the second floor of the Physician’s Pavilion.

When you have recovered sufficiently you will return to your Primary Care Physician for your routine health care (usually a couple months after transplant). Please call to schedule a follow up visit with your doctor as soon as possible after your return home. Our office will be sending an informational packet regarding your transplant episode for your Primary Care Physician to review. The Liver Transplant Department will continue to follow you for life regarding your liver transplant issues. You should continue to see a doctor on a regular basis.

You will need to be seen annually in the Liver Transplant Clinic.

**Complications**

Due to the nature of your transplant surgery and the medications you will take after transplant you are at risk for potential complications. Getting your lab work on time and coming to clinic helps us to recognize signs and symptoms of complications early. The sooner we are able to diagnose a complication, the sooner and easier we can treat it. It is important for you to notify the Transplant Coordinators if you are experiencing complications.

**Treatment for Surgical Complications**

If the complication is related to wound healing, your incision may open and you should call the transplant team right away. If the complication is related to one of the surgical connections, you would first need to have the suspected site evaluated through ultrasound, angiogram or ERCP (a type of endoscopic procedure). Once the problem site is known the physicians may be able to correct it with a simple stent that keeps the connection open. The site may require surgical repair.
When To Call The Nurse

It is important to remember that if you experience any signs and symptoms of complications you should call your Transplant Coordinator.

Appropriate times to call the on-call nurse coordinator: You should call the on call coordinator if you think you need to see a provider immediately or need to be hospitalized. Some examples are:

- Fever of >100.4 degrees F, (38C).
- Severe abdominal pain
- Vomiting that prevents you from taking your medications, food, or fluids.
- Blood in your stools, or vomiting blood.

Examples of inappropriate calls to the on call coordinator:

- Not being able to sleep.
- Medication refills. Medications are not refilled after office hours.
- Lab and study results.
- Waiting several days when you are sick, and finally calling after office hours. Call as soon as you feel the symptoms.

Please remember that the coordinators are not in the office when they are on call. Call 911 when you are having a TRUE medical emergency. If you have issues that need attention please try to call during office hours.

Rejection

Rejection is the process by which your body recognizes your transplanted liver as a foreign protein (not a part of your DNA or tissue type). The body responds with the immune system which is its natural defense against foreign proteins. The immune system is very complicated and made of many things including your white blood cells, which are your fighter cells in your body. In rejection, these cells can attack your transplanted liver. If rejection is not treated, your new liver will be damaged.

Signs and Symptoms Of Rejection

When you have rejection you may experience abdominal pain, fever, increasing weakness or fatigue, changes in the color of your stool and urine. However, if you are getting your lab work on time, it is most likely you will not be feeling any symptoms. We usually see changes in your liver function tests even before you experience symptoms.

Treatment for Rejection

Anti-rejection medications are used to prevent rejection. This class of drugs is called immunosuppressant medications and will be discussed in the next section. If you experience rejection, we use this same class of medications to try to stop the rejection. We can only diagnose rejection with a liver biopsy. You may need to come to Portland for the biopsy and treatment, depending on how far out from transplant you are.
Infection

When anti-rejection drugs (immunosuppressant drugs) are used, your body is not able to fight infection as well as before the transplant. The anti-rejection drugs weaken (or suppress) your immune system. If your immune system is weakened you are at greater risk for infection. There are certain things you can do to help prevent infection including washing your hands regularly, limit visits from sick family or friends, wear a mask when in crowds or around construction sites, and take your infection-fighting medications (antibiotics). You will be on these medications for the first 6 months after transplant.

Signs and Symptoms of Infection

You may experience a fever (≥100.4°F, or ≥38°C), body chills and/or a productive cough with greenish mucous, fluid retention and/or weight gain. You may have diarrhea or painful urination. Sometimes symptoms of infection can be as vague as simply not feeling well.

Treatment for Infection

You first need to have your blood, urine and possibly stool cultured to see where the infection might be. If the infection proves sensitive to antibiotics, you will be treated with

One Year Follow up Evaluation

When you reach your first Transplant anniversary there will be several tests that will need to be ordered to help assess your overall health. The Liver Transplant office will work with you and your Primary Care Physician to get these studies completed. Some of the studies can be done locally in your community while other tests are preferred to be done at OHSU.

The following may be ordered for you:
1. Clinic visit
2. Labs: CBC with diff, Comprehensive metabolic panel and immunosuppressant level
3. Urinalysis
4. Ultrasound of the Abdomen
5. Chest X-Ray
6. Protocol testing if you are
Medications

General Information

This section is intended to be a general guide to each medication’s function, proper use, dosage, precautions, and side effects. The information does not cover all aspects of each medication and is not intended as medical advice for individual problems. Its purpose is to give you a general overview. Always follow the instructions given to you by your transplant team.

You will not experience all of the side effects listed for each medication, and over time most side effects decrease.

After you have received your new liver you will be required to take a combination of medications each day for the rest of your life. These medications are essential to prevent liver rejection. You can never stop or miss these medications or you risk rejecting your liver.

Never change your dose of immunosuppressant’s without discussing it with the Transplant Team.

The Transplant Team will always manage your immunosuppression medications. If your primary care physician wants to make any changes to your immunosuppression medications please have him or her contact the Liver Transplant Office first. The dose of your medications can change frequently. After you are home the medication changes will be called to you over the phone. Be sure to write down any changes you are requested to.

It is extremely important that you take your medications at the correct time each day. You may set your schedule around meals and bedtime. It is easy to forget whether you took your pills or not. You may find it helpful to set up a check system.

What you should know about your medications:

The brand name and generic name

Medications are known by two different names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common, non-branded name of that medication. For example, tacrolimus and Prograf® are the same medication. Tacrolimus is the generic name and Prograf® is the brand name. In many cases there are multiple brand names. It is important to not switch between brand names and generic medications for your immunosuppressants.

The purpose or reason for taking each medication

A medication often has more than one use and may be prescribed for different reasons. You should always know why you are taking each medication. For example, fluconazole is a medication used to treat fungus infections, but it can also be used to increase tacrolimus levels.
What each medication looks like
You must be able to recognize each medication by color, shape, and size. Many medications have a similar appearance with only slight differences. They must be looked at closely to be sure the correct medication is being taken. Magnesium oxide, sodium bicarbonate, and some generic forms of Bactrim® are all large, round, white pills. If you look closely, though, you will see some differences.

When to take each medication
Some medications, such as the anti-rejection medications tacrolimus and cyclosporine, must be taken on time twice a day so that the appropriate level of that medication is maintained in your bloodstream. It is important to know what time you need to take each medication. Work with your coordinator and your pharmacist to arrange a medication schedule that is easy to follow with your daily routine.

How to take each medication
You will take most of your medications by swallowing a pill or capsule. Occasionally, a pill may be divided or crushed and mixed with food or liquids. Discuss how to take each of your medications with your coordinator and your pharmacist. Capsules and time release tablets should never be crushed or opened - as a large dose can be absorbed too quickly.

The most common side effects
Every medication has side effects, but these are not experienced by everyone. You should be aware of the most common side effects that each medication may cause.

Any special instructions
Some medications must be taken with food or on an empty stomach or separated from certain medications. Discuss any special instructions for your medications with your pharmacist, or coordinator.

What to do if you are late, miss a dose, or forget to take a dose
If you are very late taking a medication or have skipped a dose, take the next dose as soon as possible. Do not wait and double the next dose. If you have been vomiting or cannot swallow the pills, call your transplant coordinator. After asking you a few questions and considering your current health status, your coordinator will advise you on what to do.

How to order your medications
Your transplant coordinator or transplant pharmacist will help you find the most convenient way to order your medications.

When to order your refills/repeat prescriptions
Phone your pharmacy for refills. The number of refills you have for each medication depends on how long you will be taking the medication, as well as what your insurance coverage will allow. Once the prescription has been submitted to your pharmacy, you may call for refills/ repeat prescriptions.. It is very important to monitor the number of pills you have so you can order your refills in time so that you avoid missing any doses. You should always have at least a 10 day supply of medications.
What is the cost for your medications?
   It is important that you know your financial responsibility for your medications so you can plan ahead. Some medications may be completely covered by insurance, while others have co-pays. Often, insurance companies have a deductible you must meet before their coverage begins. It may be helpful for you or a family member to call your insurance case manager or approved pharmacy provider before your medications are ordered. A toll-free number for “prescriptive authorization” is usually on the back of insurance cards. This contact person should be able to tell you what your cost is for each prescribed medication.

**Immunosuppression Medications**

In order to prevent rejection the doctors will prescribe medications that you will take every day for the rest of your life. These medications are given to keep you alive. Some anti-rejection medications you may receive are listed below.

**Prograf (Tacrolimus)**
   - This medication is used to prevent acute liver rejection and is taken twice a day. The dose may change based on your blood level.
   - Side effects include but are not limited to high blood sugar, tremors, kidney problems, and headache.

**Prednisone**
   - This medication is used to prevent and treat acute liver rejection. You will be started on an IV form of prednisone called Solumedrol immediately after transplant. You will change to oral tablets when you tolerate food. You will receive a taper that will tell you how much prednisone to take on a given day. Most patients will stay on 5 mg. per day for life.
   - Side effects include but are not limited to mood swings, trouble sleeping, fluid and sodium retention, high blood sugar, muscle weakness, bone loss, stomach ulcers, impaired wound healing, acne, cataracts, and glaucoma.

**Azathioprine (Imuran) or Mycophenolate Mofetil (MMF or Cellcept)**
   - These are used to prevent acute rejection. The dose is once or twice a day.
   - Side effects include but are not limited to diarrhea, vomiting, anemia, reduced white blood cells and/or platelets.
**Infection-Fighters**

The anti-rejection medications suppress your immune system, which weakens the body's ability to fight infection. You will be given medications to help prevent infection for about 6 months.

The following are 3 examples of medications you may be taking after transplant to prevent infection.

**Trimethoprim/Sulfamethoxazole (TMP/SMX)**
- Known as Bactrim, Septra or Cotrim, this is a sulfa type drug used to help prevent bacterial infections such as Pneumocystis carinii pneumonia, PCP for short.
- You will take TMP/SMX once a day by mouth.
- If you are allergic to sulfa drugs you will receive Pentamidine once a month or dapsone once a day instead.
- Side effects include but are not limited to nausea, vomiting, rash, itching, or loss of appetite.

**Valganciclovir (Valcyte)**
- This medication is used to prevent viral infections such as CMV, and herpes simplex I & II.
- Side effects include but are not limited to headache, nausea, decreased white blood cells and platelets.

**Fluconazole or Nystatin Liquid**
- These medications are given to prevent fungal infections such as thrush. You will take fluconazole once a week or nystatin 4 times a day after meals and before bedtime.
- Side effects include but are not limited to nausea, vomiting, diarrhea, unpleasant mouth sensations.

**Other Medications**

You will be on other medications to protect your stomach from acids and ulceration. Many patients need insulin; others may require high blood pressure medication. It is not possible to know ahead of time what your needs will be. You will have your own medication list prepared for you by the pharmacist prior to being discharged from the hospital. You will have time during your hospital stay to learn about your drugs and practice taking them as if you were at home. Your nurse will supervise this.

**Medication Refills**

When your care returns to your primary care provider you will continue to have your immunosuppression medications filled by the transplant team. All other medications should be refilled through your local doctor. The transplant team will continue to adjust the dose of your transplant medications.

If you need a medication refill, call your home pharmacy.

Allow at least 2 working days for the refill request to be completed. *Remember: the coordinators do not refill medications after office hours.*
## Prescriptions Do’s & Don’ts

<table>
<thead>
<tr>
<th>Prescriptions Do’s</th>
<th>Prescriptions Don’ts</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Call your regular pharmacy for refills when you have 7 – 10 days of medication remaining.</td>
<td>✓ Expect pain medication to be filled after hours and on the weekends.</td>
</tr>
<tr>
<td>✓ Give your local pharmacist our contact numbers for refills, phone 503-494-8500, fax 503-494-5292.</td>
<td>✓ Run out of medication before getting refills.</td>
</tr>
<tr>
<td>✓ Have your pharmacy contact our office for a new prescription on your anti-rejection medication.</td>
<td>✓ Wait until the weekend or after 4:00 p.m. to call for refills.</td>
</tr>
<tr>
<td>✓ Call the Transplant Office during office hours (8:00 a.m. – 4:30 p.m.) if you have a problem with your immunosuppression prescriptions.</td>
<td></td>
</tr>
<tr>
<td>✓ Keep the name and phone number of your local pharmacy handy.</td>
<td></td>
</tr>
<tr>
<td>✓ Ask for pain medication refills when you are seen in the Transplant Clinic during the initial post op period.</td>
<td></td>
</tr>
<tr>
<td>✓ During the week, if your pharmacy calls, expect a 48-hour turnaround time for your medication to be refilled. If the office is closed such as on a weekend, holiday or after office hours it may take more than 48 hours.</td>
<td></td>
</tr>
<tr>
<td>✓ Remember to take a few extra days’ worth of medication with you when traveling.</td>
<td></td>
</tr>
<tr>
<td>✓ Carry a list of your medicines and dosages in your wallet or purse.</td>
<td></td>
</tr>
<tr>
<td>✓ Try to buy all your medicines from the same pharmacy. Many pharmacies keep a profile on their customers so they can track whether or not a new drug may cause problems if taken the patient’s other medications.</td>
<td></td>
</tr>
</tbody>
</table>

### Prescriptions Do’s

- Call your regular pharmacy for refills when you have 7 – 10 days of medication remaining.
- Give your local pharmacist our contact numbers for refills, phone 503-494-8500, fax 503-494-5292.
- Have your pharmacy contact our office for a new prescription on your anti-rejection medication.
- Call the Transplant Office during office hours (8:00 a.m. – 4:30 p.m.) if you have a problem with your immunosuppression prescriptions.
- Keep the name and phone number of your local pharmacy handy.

### Prescriptions Don’ts

- Run out of medication before getting refills.
- Wait until the weekend or after 4:00 p.m. to call for refills.
### Medication Table

#### Immunosuppressants – To Prevent Rejections

<table>
<thead>
<tr>
<th>Type</th>
<th>Generic</th>
<th>Branded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcineurin Inhibitors</td>
<td>Tacrolimus</td>
<td>Prograf®, FK506</td>
</tr>
<tr>
<td></td>
<td>Cyclosporine</td>
<td>Sandimmune®, Neoral®, Genraf®</td>
</tr>
<tr>
<td>Purine Inhibitors</td>
<td>Azathioprine</td>
<td>Imuran®</td>
</tr>
<tr>
<td></td>
<td>Mycophenolate mofetil</td>
<td>Celcept®, Myfortic®</td>
</tr>
<tr>
<td></td>
<td>Mycophenolic acid</td>
<td></td>
</tr>
<tr>
<td>Steroids</td>
<td>Prednisone</td>
<td>Deltasone®</td>
</tr>
</tbody>
</table>

#### Anti-Infectives – Prevent bacterial, fungal, and viral infections

<table>
<thead>
<tr>
<th>Type</th>
<th>Generic</th>
<th>Branded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics</td>
<td>Sulfamethoxazole/trimethoprim</td>
<td>Bactrim®, Septra®</td>
</tr>
<tr>
<td></td>
<td>(SMX/TMP)</td>
<td></td>
</tr>
<tr>
<td>Antifungals</td>
<td>Fluconazole</td>
<td>Diflucan®</td>
</tr>
<tr>
<td>Antivirals</td>
<td>Valganciclovir</td>
<td>Valcyte®, Zovirax®</td>
</tr>
<tr>
<td></td>
<td>Acyclovir</td>
<td></td>
</tr>
</tbody>
</table>

#### Anti-Hypertensives – Lowers blood pressure

<table>
<thead>
<tr>
<th>Type</th>
<th>Generic</th>
<th>Branded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcium Channel Blocker</td>
<td>Amlodipine</td>
<td>Norvasc®</td>
</tr>
<tr>
<td>Beta Blocker</td>
<td>Metoprolol</td>
<td>Toprol-XL®, Lopressor®</td>
</tr>
</tbody>
</table>

#### Gastric Acid Suppressants – Reduce “Heart burn” symptoms and prevent stomach ulcers

<table>
<thead>
<tr>
<th>Type</th>
<th>Generic</th>
<th>Branded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proton Pump Inhibitor (PPI)</td>
<td>Omeprazole</td>
<td>Prilosec®</td>
</tr>
<tr>
<td>Histamine Receptor Blockers</td>
<td>Famotidine</td>
<td>Pepcid®, Zantac®</td>
</tr>
<tr>
<td></td>
<td>Ranitidine</td>
<td></td>
</tr>
</tbody>
</table>

#### Possible Other Medications

<table>
<thead>
<tr>
<th>Type</th>
<th>Generic</th>
<th>Branded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Medication</td>
<td>Oxycodone</td>
<td>Roxicodone®</td>
</tr>
<tr>
<td>Stool Softeners</td>
<td>Docusate Polyethylene Glycol</td>
<td>Colace®, Miralax®</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supplements</td>
<td>Aspirin</td>
<td>Tums®</td>
</tr>
<tr>
<td></td>
<td>Calcium carbonate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vitamin D</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Magnesium Oxice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Multivitamin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Potassium Chloride</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fludrocortisone</td>
<td>K-Dura</td>
</tr>
</tbody>
</table>

See Medication Appendix for additional details regarding some of these and other medications.
Health Care

Activity

There are few activity restrictions after transplant. We want you to resume your past level of activity in work or play. You should lead an active life. Restrictions in general include, but are not limited to:

1. No lifting of greater than five (5) pounds for three (3) months after transplant to prevent hernias. Remember, a gallon of milk weighs seven pounds!
2. No lifting of greater than 20 pounds for the next three (3) months.
3. No jogging or running for six (6) months after transplant. Do warm up and stretching exercises.
4. Avoid activities that cause you to bounce like horseback riding, snowmobiling and trail or cross country motorcycle riding for 6 months after transplant.
5. Avoid tub baths and swimming until your staples are out and your skin has healed, approximately 4 weeks after your surgery.

These weight restrictions are in place to lower your risk of developing hernias. The outside incision heals in approximately one month, the inside incisions need up to six months to heal.

You may notice your muscles, especially leg and abdominal muscles, have become weak. Excellent ways to improve the strength of these muscles include walking, bike riding, and swimming. For the first six months after transplant you are not to tighten or strengthen your abdominal core muscles. This time period gives your body time to heal from your surgery.

Use common sense as your guide for any activity after transplant. As you gain strength and endurance, your amount of physical activity will also increase. If you have any questions, please call the Transplant Office.

Try to do a little more physical activity every day. Make physical goals for yourself, for example walking so many steps in a day. Remember do not push yourself so hard that you cannot get up the next day and do it all over again.

After six (6) months, sit-ups and other abdominal exercises will improve the tone of your abdominal muscles.

Diet & Exercise

A common problem with transplant patients is weight gain. It is not uncommon for patients that have had a transplant to gain up to 10-15% of their starting weight.

There are several reasons for this:

• You can eat your favorite foods again.
• You have a much-improved appetite.
• You feel better, so eating is once again a pleasure.

Achieving and maintaining a desirable weight is a major goal of your nutrition care plan. Obesity contributes to high blood pressure, diabetes, and may lead to heart attacks and strokes. It can also affect your self-image.
The bookends for weight management are: exercise and diet.

Some patients complain about a decreased appetite or that food tastes different. This is usually a temporary side effect of the medications. It is important for healing to eat frequent small meals.

Exercise should be a planned program that is done on a regular basis 3-5 times per week for at least 30 minutes. Walking is an excellent way to exercise, is inexpensive, and unless you have a physical problem is easy to do. Studies show that transplant patients who do aerobic exercise 3 times a week for 30 minutes live longer than patients who do not exercise.

Nutrition after Liver Transplant

A positive lifestyle, including well-balanced meals and moderate activity, is very important for your long-term health after a liver transplant. This section of your handbook will talk about food safety, eating well, and exercise.

General Nutrition

Heart healthy eating is very important for anyone living with an organ transplant. The Mediterranean diet is built around using olive oil (or canola or peanut oil) in food preparation. It also emphasizes fish and seafood, as well as poultry, with very lean red meat in smaller amounts. Whole grains, unsalted nuts and seeds, and fresh or frozen fruits and vegetables are stressed.

This is just one approach to enjoyable low fat, low cholesterol meals but it has been shown to protect some transplant recipients from heart disease later.

Protein

In the first 3 months after transplant you need extra protein. To tell you how many grams of protein you need each day: divide your weight in pounds by 2, and then add an additional 50% to that number.

- Meats, Fish, Poultry—about 7 grams of protein per ounce
- Dairy Products—8 grams of protein per cup of milk
- Eggs—about 7 grams of protein each
- Unsalted nuts—about 7 grams or protein per ¼ cup
- Dried beans, lentils, and peas—about 7 grams of protein per ¼ cup cooked
- Soybeans, soy milk, tofu—protein content varies, but is a high quality

Sodium

You should continue to limit your intake of sodium. One of your medications, prednisone, can cause fluid retention. Limiting the salt intake can help control bloating. Remember the words “NO ADDED SALT” and let them guide you when you are at the stove and at the table. The following foods are high in sodium and should be limited or avoided as much as possible:

- Salt (salt is sodium chloride)
- Crackers and snack foods with visible salt
- Cured meats (bacon, ham)
- Luncheon meats
- Canned or dried soups
- Ethnic foods: Chinese, Japanese, Mexican, Italian (it is best to cook these from scratch at home, using lower salt ingredients such as low-sodium soy sauce, or tomato products made with less salt)
• Sauces: Worcestershire, chile, soy, teriyaki
• Prepackaged casseroles
• Macaroni & cheese

Safe Foods and Food Hygiene
The medications used to prevent rejection also suppress your immune system. You are more at risk of picking up a food-borne illness after your transplant. The most important steps to protect yourself include:

1. Safe Food Handling and Preparation
   • Always wash hands well with soap and water and dry thoroughly after using the restroom, before and after handling foods, and before eating
   • Sanitize sinks and chopping boards with 1/2 teaspoon bleach in 2 cups water
   • Separate raw produce from uncooked meats. Use separate cutting boards if possible; and clean cutting utensils between use on fresh produce and animal products.
   • Remove outside leaves of leafy vegetables and rinse leaves individually
   • Rinse all produce under running water
   • Do not eat foods from damaged or broken containers
   • Ground meat must be thoroughly cooked—hamburgers should be well-done

2. AVOID High Risk Foods such as:
   • Raw and/or undercooked fish, other seafood, poultry, and meat
   • Foods containing raw eggs
   • Raw bean sprouts (very high risk for E. Coli)
   • Salad bars and buffet-style meals
   • Soft and semi-soft cheeses
   • Unpasteurized dairy products such milk, cheese, and yogurt made from raw milk

3. Food storage
   • Store eggs in the refrigerator
   • Store raw meats below other foods in the refrigerator
   • Separate raw and cooked foods while purchasing, storing and preparing foods
   • Refrigerate or freeze perishable foods as soon as possible
   • Cover stored foods
   • Do not wait for cooked foods to cool; refrigerate immediately
   • Defrost foods in the refrigerator or microwave – not at room temperature.
   • Do not refreeze uncooked foods that have already been defrosted
   • Leftover foods should be consumed within 48 hours unless frozen

4. Eating out
   • Ask for food to be freshly prepared to your order
   • Avoid salad bars and buffet-style meals
**Sexual Activity**

As with any major surgery, waiting a period of six weeks before engaging in sexual intercourse is a good idea. This time will allow the incision and muscles to heal. If you are sexually active and do not have a steady sexual partner, it is essential to use condoms to reduce the risk of sexually transmitted diseases such as AIDS, syphilis, herpes, hepatitis, gonorrhea and chlamydia.

Women of child bearing potential should use two forms of birth control. Some immunosuppressant’s reduce blood levels of the hormones in the oral contraceptive pill and could reduce its effectiveness. Pregnancy must be discussed with your transplant team prior to conception. Some immunosuppressant’s have been associated with serious birth defects.

**Use of Tobacco & Alcohol**

Do not drink alcoholic beverages. Do not drink “non alcoholic” beverages including “near beers” and wine coolers. Alcohol is metabolized, or broken down, in the liver. Drinking any type of alcoholic beverages can harm your liver. Many of your medications are metabolized by the liver. Liver cells may be destroyed with the additional stress of breaking down alcohol as well as your medications.

Do not smoke or use tobacco products.

Smoking can cause cancer, heart disease, and lung disease. Additionally, smokers may have prolonged respiratory infections because of the effect of smoke on the lungs. Transplant recipients who smoked before transplant are strongly encouraged not to start smoking. Since nicotine is broken down or metabolized by the liver, there is a possibility that some medications, particularly tacrolimus and cyclosporine, may not be metabolized well. Levels of these medications may be lower in smokers. You should never risk losing your healthy liver for cigarettes. Chewing tobacco can lead to neck and mouth cancers. The use of marijuana can cause lung and brain infections from a fungus called Aspergillus.

**Returning to Work**

Some patients have returned to work as quickly as three weeks after their transplant surgery. Most patients are ready to return to work within three months after transplant. When possible, it can be helpful to return on a part-time basis. You can gradually increase your hours as your energy and endurance improves.

**Sun Exposure**

Transplant recipients have an increased risk of developing skin cancer. This risk is up to 65 times greater than in people who have not had a transplant. The medications that transplant recipients take to suppress their immune system cause this increased risk.

Skin and lip cancers are the most common cancers of transplant patients. Since the risk increases with time, you must always protect your skin and lips from the ultraviolet rays of the sun. Apply lotion and lip balm that has sunscreen with an SPF of 30 or greater every day.

- Avoid midday (10 am to 3 pm) sun, when ultraviolet rays are strongest.
- Wear a hat, long sleeves and slacks when outdoors.
• Use a sunscreen lotion and lip balm (>30 SPF) every day (rain or shine) and apply often to exposed areas, especially face, neck and hands.

Remember that sunscreen lotions wash or wear off. Reapply the lotion as needed, especially after swimming.

Immunizations

Avoid vaccines that consist of live viruses such as Sabin oral polio, smallpox, measles, mumps, rubella (MMR), chicken pox, and yellow fever. Receiving a live vaccine may cause serious health complications because a transplant recipient could develop the virus that he/she is being immunized against.

You may receive injectable polio and a TB skin test. It is recommended that you receive the Influenza A & B or “flu” shot every year and pneumovax every five years. You should not get live vaccines such as the nasal mist influenza vaccine (Flu-mist®), the live polio vaccine, the smallpox vaccine, the measles-mumps-rubella vaccine (MMR®), and the live varicella vaccine (Varivax®, Zostavax®).

Do not change diapers of children that have received these immunizations, 3-5 days. It is best to avoid close contact with anyone who has had the oral polio vaccine for up to eight weeks since the virus may shed in their stool and saliva. Transplant recipients who have infants should be sure that their child receives the Salk polio injection. It is also recommended to avoid close contact with a child who has received the chicken pox vaccine. However you do not need to avoid a child who has recently received a MMR.

Get a tetanus booster every 10 years. If you are injured and have not had a tetanus booster within the last 5 years, please contact your primary care physician.

Avoiding Infection

You need to consciously protect yourself from infection by taking the following pre-cautions:

• Wash your hands often. This is the number one way of protecting yourself from infection.
• Keep your hands away from your face and mouth.
• Stay away from people with colds or other infections.
• Avoid close contact with people who have obvious illnesses such as colds and flu.
• Avoid crowded places like stores, movies, restaurants and churches in the first few months, particularly during cold and flu season or when you are highly immune-suppressed.
• Do not share eating utensils, cups, or glasses with others since many viral illnesses are spread through saliva and mucous. Do not share razors or toothbrushes.
• Ask friends to visit only when they are well.
• If you have a wound that requires dressing changes, wash your hands before and after changing the dressing.
• Avoid working in the soil for three (3) months after your transplant. Thereafter, wear gloves. Avoid compost piles, wet leaves, and rotting organic matter. These materials can carry mold that can cause significant respiratory infections.
• Wear a surgical mask if you are near a construction site or in a large crowd until your prednisone dose is down to 10mg a day.
• Avoid handling animal waste and avoid contact with animals that roam outside. Do not clean birdcages, fish tanks, turtle tanks or cat litter boxes. The cat litter box should be covered and taken out of your home before it is changed. Some types of pets should be avoided such as reptiles, turtles, amphibians (frogs), hamsters, and guinea pigs. These animals can carry infections that could cause you to become ill.

Dental Visits

You must have a dental check up every six months to one year. Inform your dentist that you had a liver transplant and are taking immunosuppressant medication. You may need to take an antibiotic before any dental work, cleaning, exam or procedure.

The mouth has a large amount of bacteria in it. The use of an antibiotic helps to decrease the chances of an infection if the mouth or gum tissue is disturbed during dental work.

OHSU transplant program follows the American Heart Association guidelines for pre-procedure antibiotics. Your dentist will decide if you need antibiotics and how long. They may call the Liver Transplant office with any questions.

Pregnancy

In women, ovulation may begin within 1-2 months after transplant for women with well-functioning livers. All women of childbearing age should be advised about the possibility and risks of pregnancy after transplant. Pregnancy is not typically recommended within the first year after a transplant because the risk of rejection is the greatest and immunosuppressive therapy is the most aggressive. It should, however, be planned when organ function and immunosuppressive therapy are stabilized and there is no sign of rejection, hypertension or chronic infection.

If you are considering becoming pregnant, it is important to discuss potential risks with your transplant team.

For men, there are no known risks if your partner becomes pregnant while you are on immunosuppressive mediations. Please discuss with your physician if you are planning on becoming pregnant or your partner is pregnant, while you are on immunosuppressive therapy.
Rejection

Your body’s immune system protects you by recognizing certain foreign substances, such as bacteria and viruses, and destroying them. Unfortunately, the immune system also recognizes your new liver as a foreign substance.

Rejection is an attempt by your immune system to attack the transplanted liver and destroy it. To prevent rejection from occurring, you must take immunosuppressive medications as prescribed for the rest of your life.

In spite of all precautions, rejection episodes can occur. Even while taking immunosuppressant’s, up to 10 - 30% of all liver-transplant recipients will have at least one rejection episode. The first episode often occurs within 3 months of surgery. Changing the dosages of your immunosuppressive medications or adding a new one usually controls rejection.

If detected early, most rejection episodes can be treated successfully.

You should be alert to the signs and symptoms of rejection and inform your transplant team promptly if you have the following:

- fever greater than 100.5° F/38.4° C
- flu-like symptoms such as chills, nausea, vomiting, diarrhea, loss of appetite, headaches, dizziness, body aches, tiredness
- abdominal pain or tenderness

If you do not receive treatment, your symptoms will worsen over time. Later symptoms may be similar to problems you had before transplant and may include:

- dark, tea-colored urine
- confusion
- abdominal swelling with fluid (ascites)
- Jaundice (yellow skin or eyes)
- Dark yellow/orange urine
- Clay colored stools

Any injury to the liver can cause the release of liver enzymes into the bloodstream. An injury to the liver cells could be caused by rejection, infection, or side effects of medications. Measuring the liver function tests (LFTs) regularly and watching the pattern of the results can help your doctor decide what is happening to your liver.

Liver rejection is usually diagnosed by looking at the liver function tests. Your doctor may suspect that you have rejection if any of these numbers are increased from the normal range. This could be confirmed by a liver biopsy. Based on the results, your transplant team will decide the best treatment for you.
How is rejection treated?
Rejection does not mean that you will lose your liver, but early diagnosis and treatment are very important to avoid complications.

Mild to moderate rejection is treated by increasing your immunosuppression and/or your prednisone dose. Sometimes the IV form of prednisone is given for several days. Another way to treat rejection is by adding or combining other anti-rejection medicines such as mycophenolate mofetil, sirolimus, or azathioprine.

Severe rejection requires admission to the hospital for IV administration of stronger agents.

The risk of rejection decreases over time but can occur at any time. Taking good care of yourself, taking your medications as prescribed, and having your blood tests done as requested will help decrease your risk of rejection.

Diagnostic Testing

MRCP (Magnetic resonance cholangiopancreatography)
An MRCP is a special type of Magnetic resonance imaging (MRI) that specifically images the biliary and pancreatic ducts in a non-invasive manner. This test is an excellent tool for visualizing blockages in the ducts and pancreatic cysts. It can also diagnose bile duct stones or tumors.

PTC (Percutaneous transhepatic cholangiography)
A procedure that x-ray's the hepatic and common bile ducts. This procedure is done under local anesthesia by a radiologist. During the exam, a thin needle is inserted through the skin (percutaneous) and through the liver (transhepatic) into a bile duct. Then contrast media is injected, and the bile duct system is outlined. If necessary, a thin, flexible tube (catheter) may be inserted to allow the bile to drain into a collection bag outside the body, or into the small intestine. This procedure is called biliary drainage. Drainage catheters may be placed to divert bile. Stones can be removed, or balloon inserted to dilate strictures (narrowing of a duct or passage)

ERCP (Endoscopic, Retrograde Cholangio Pancreatography)
Endoscopic refers to the use of an instrument called an endoscope - a thin, flexible tube with a tiny video camera and light on the end. The endoscope is used by a highly trained gastroenterologist, to diagnose and treat various problems of the GI tract. The GI tract includes the stomach, intestine, and other parts of the body that are connected to the intestine, such as the liver, pancreas, and gallbladder. Retrograde refers to the direction in which the endoscope is used to inject a liquid enabling X-rays to be taken of the parts of the GI tract called the bile duct system and pancreas. The process of taking these X-rays is known as cholangiopancreatography. Cholangio refers to the bile duct system, pancreas to the pancreas.

Ultrasound with Doppler’s
Ultrasound is a safe and painless procedure that uses sound waves to "see" inside your body. The doppler allows the doctor to evaluate the blood flow through the arteries and veins of your abdomen. The scan can help diagnose obstructions in the blood flow to your liver as well as some problems in the liver.
CT (CAT) scan (Computed Tomography Scan)

CT scans use X-Ray technology and advanced computer analysis to create detailed pictures of your body. A CT can help diagnose problems in the liver, spleen, colon, pancreas, kidneys and other internal organs. Sometimes the exam includes a contrast dye. The dye improves the image quality by highlighting certain structures, such as arteries or the colon, making them more visible on the scan. The contrast is usually given by IV and in some cases may be given orally.

CTA (Computed Tomography Angiography)

CTA uses a Computed tomography (CT or CAT) scanner to create images of blood vessels. Special contrast dye is injected into an IV. The dye highlights the blood vessels and make them easier to see on the X-Ray images.
Health Concerns

What happens after transplantation depends on the organ transplanted and the recipient's specific medical situation. Most patients recover fully, return to work and resume a normal, active life after receiving a new organ. However, there is a possibility of developing unrelated health problems after transplantation. It is important to work closely with your doctor concerning your overall wellness.

Anxiety and Depression

Patients and their families face a new lifestyle after transplantation that may cause them to feel nervous, stressed or depressed. Anxiety and depression post transplant are considered normal. Because emotional and psychological support is a continuing process, ask your social worker about counseling services that can help you and your family deal with these changes. Professionals can help you work through concerns; mood swings; job planning; rehabilitation; family stresses, such as parent-child conflicts, marital conflict or financial concerns, such as questions about Medicare, disability or insurance.

High Cholesterol

Many immunosuppressant drugs can contribute to high cholesterol. This condition therefore affects many transplant recipients. When a patient develops high cholesterol, blood vessels, including the ones attached to the transplanted organ, become clogged, which affects the flow of blood. This slowing of blood flow can affect the success of your transplant and may even lead to heart disease. It is important to talk to your doctor about how to reduce the risk factors of heart disease, including controlling your cholesterol.

High Blood Pressure

High blood pressure (hypertension) is a common condition that is seen in the general population. After transplant, patients who have had high blood pressure may need to continue to be treated for this condition. Sometimes, high blood pressure occurs in patients who have never had any problem with their blood pressure. Hypertension after transplant can be a side effect of medications, particularly the anti-rejections medications. High blood pressure also may occur if the kidneys are not working well.

There are several medications that can be used to treat high blood pressure. They work in different ways to control hypertension. Sometimes patients are prescribed more than one blood pressure medication because the medications work together to control hypertension. Sometimes a diuretic (“water pill”) is needed to work with these medications. Your doctor will prescribe the blood pressure medications that are right for you to control high blood pressure and any complications you may have.
Diabetes

Diabetes is an increased level of sugar in your blood. Some of the immune-suppressive medications that you take may cause diabetes.

If you develop diabetes, you will receive specialized teaching and ongoing follow up about how to deal with this problem.

Symptoms of diabetes may include:
- Increased frequency of urination
- Increased thirst
- blurred vision
- confusion
- extreme hunger
- constant itching
- irritability

What can you do to lower your risk?
- Improve your overall health through diet and exercise.
- If you are overweight, it is important to lose weight to reduce your risk for diabetes.
- Improve your nutrition with a balanced diet. Talk to your dietician, transplant coordinator, and/or physician about the best diet for you.
- Exercise is an important treatment, particularly when combined with a weight loss program and stress reduction.
- Try to reduce stress. You may feel comfortable talking with your social worker, transplant coordinator, and/or physician about any increased stress you are experiencing after your transplant. They can help or refer you for additional counseling and advice.

If left untreated or uncontrolled, diabetes is related to heart disease, stroke, high blood pressure, blindness, kidney disease, and kidney failure. Severe problems with blood flow in small blood vessels also may lead to amputation.

Recurrent Hepatitis C

Unfortunately the hepatitis C virus is found in the blood and not just the liver, so a liver transplant is not a cure. Some people transplanted because of Hepatitis C will have a recurrence of the virus in their blood.

The rate of progression is variable. It is unclear what all increases the rate of progression of the disease, but it is known that treatment of acute rejection has been associated with faster progression. About 25% of patients will develop significant recurrence of hepatitis C (seen on liver biopsy) in the new liver. Some patients will develop symptoms related to the hepatitis C shortly after transplantation. Two things lead to the quick recurrence; a high level of the virus in the blood at the time of transplantation, and the body’s inability to fight the virus because of the immunosuppression. Most people with recurrent hepatitis will develop cirrhosis within five years of their transplant, which is unfortunately much quicker than in non-immunosuppressed people. Luckily a person can live a long time, even with cirrhosis if they take good care of themselves.
There are several different medications used to treat recurrent Hepatitis C disease. How well a person responds to treatment is dependent on the type of hepatitis C (the genotype), the decreased rate of effectiveness with immunosuppression and the high rate of complications and side effects.
Writing Your Donor’s Family

You no doubt are aware that sadness and loss have accompanied the gift of donation you received. And so you like many recipients, may be confused about what to say or do. You may want to express your gratitude, but may feel afraid that you will intrude or add to the donor family’s grief.

This guide is meant to address your concerns and provide you with instructions for corresponding with your donor family.

A Simple “Thank You” Means So Much...
“Thank You,” can say so much to donor families. It can say we deeply appreciate this precious gift. It can say this gift has been worthwhile. It can say someone’s life has been saved, and many people are grateful.

It can say we will always remember your generosity. It can say your loved one did not die without making a difference in this world.

Why Write to your Donor Family?
Experience shows that donor families want to know that their loved one’s gift has been received and it has made a difference in someone’s life. A letter from you can validate the gift of donation and may help them to bear the sorrow of their loss. A letter is not generally thought of as an intrusion as long as you communicate in a sensitive way.

There is no set timeline for corresponding. Some people want to communicate right away; some need time before they are ready.

The Family Resource Program of the Pacific Northwest Transplant Bank and your transplant social worker will facilitate correspondence with your donor family. It is our belief that donor families and recipients have the right to engage in mutually acceptable forms of communication, as they desire, with respect to confidentiality. There is no right or wrong way to approach this communication. And there is no timeline for your decision. The following are general guidelines for you to follow.

Guidelines for Communication
When writing to the donor family, you may:

- Acknowledge and express sympathy for the donor family’s loss.
- Thank the donor family.
- Use simple language.
- Share general information about your life, occupation, family and friends, hobbies and interests.
- Write about the transplant experience, and how it has affected your life.

Letters should remain anonymous. Don’t include last names, addresses, city names, phone numbers, or names of hospitals or physicians.
Place your completed letter in an unsealed envelope. Include a separate sheet of paper with your full name and your date of transplant. Mail the letter and separate sheet to your social worker. Your social worker will then mail your letter with the proper donor identification information to the Pacific Northwest Transplant Bank. They will then forward it to the donor family and send you a note indicating it was sent. The same process is true for any return correspondence from the donor family. The only way that you and your donor family could come to know each other’s identity is if you mutually agree to exchange that information.

**Will the Donor Family Write Back?**
Just as you had to make the decision to write to your donor family, the donor family also needs to decide whether they feel comfortable reading your correspondence and writing back. If you do not receive any return correspondence from the donor family, please remember that the donor family is coping with the loss of their loved one and that individuals handle grief in different ways. Even if they feel unable to communicate with you, they will always know that you cared.

If you need further information about writing to donor families, please call your transplant coordinator, social worker, or the Pacific Northwest Transplant Bank.

**Sample Letter from a Recipient**
We could only imagine the pain that your family went through during your terrible loss. We are very sorry for the loss that you endured. It saddened us even more because our daughter was the same age.

My husband’s biggest goal was to see his only child married. Our daughter was married last Mother’s Day and my husband was in his glory walking her down the aisle. I don’t think there was a dry eye in the room when he danced with her.

Thank you doesn’t seem to say enough, but “Thank you” for raising a son who knew what his gift would mean to others.

**Sample Letters from Donor Families**
I want to thank you for your letter regarding the donation of my husband’s organs and tissue. I’ve shared the information with my son, my husband’s family and our friends. It has given us ALL great pleasure to hear that four different lives were affective as a result of our gift.

Although that was one of the hardest moments in my life and one of the toughest decisions I’ve ever made, I can tell you that I am so thankful today for making the RIGHT choice. I wish there was a way to advocate this to the world.

~~~~~~~~~

After saying yes to the question of donating my daughter’s organs, months afterwards I really had reservations. The pain of our loss was more than the joy of sharing. I wondered, was the gift of life given in vain? Until this past week, the question was still in our minds. A beautiful letter which meant so much was sent to us. Pains eased, the joy of sharing became very vivid in our minds. In death as in life, our daughter is helping others. If the same situation happens again, we would not hesitate to share.
Web and Other Resources

These organizations/web sites can provide you with additional information about liver disease and transplant.

American Liver Foundation
1425 Pompton Avenue Cedar Grove, NJ 07009
(800) 223-0179
http://www.liverfoundation.org/

American Organ Transplant Association (AOTA)
P. O. Box 441766
Houston, Texas 77244
(281) 493-2047
http://www.a-o-t-a.org

National Foundation for Transplants
(formerly Organ Transplant Fund)
1102 Brookfield, Suite 200 Memphis, TN 38119
(800) 489-3863
www.transplants.org

Transplant Recipients International Organization
The Northern Brewery 1327 Jones Drive, Suite 105 Ann Arbor, Michigan 48105
(734) 998-7314 http://www.transweb.org

United Network for Organ Sharing (UNOS)
700 North 4th St.
P.O. Box 2484
Richmond, VA 23218
1-888-TXINFO1
http://www.unos.org
Appendix A: Medication Details

TACROLIMUS (PROGRAF®, FK506)

What is it used for?
Tacrolimus is an immunosuppressive medication that is used to prevent or treat acute liver rejection. Tacrolimus may be the only immunosuppressant that is prescribed for you or it may be used with other anti-rejection medications to prevent rejection.

How is it given?
Tacrolimus is available in 0.5 mg, 1 mg, and 5 mg capsules. It is usually dosed twice daily, 12 hours apart. Your dose of tacrolimus will be adjusted based on the level of tacrolimus in your blood, which is measured in lab on a regular basis, as determined by your doctor.

When do I take it?
Take tacrolimus two times a day, 12 hours apart, for life or as determined by your doctor. It is important to take tacrolimus at the same time each day and consistently with or without food.

On a day when your tacrolimus level is to be measured in lab, do not take your morning dose until after your blood has been drawn. Make sure to bring your morning dose with you to the lab. Your blood should be drawn 12 hours (+/- 30 minutes) after your evening dose. For example if you take your tacrolimus at 9:00 p.m. have your blood drawn at 9:00 a.m. and then take your morning dose.

What side effects might I expect?
Side effects may vary and may depend on your tacrolimus levels. Side effects include but are not limited to tremors, muscle cramps, diarrhea, nausea, high blood pressure, headache, numbness and tingling of the hands and feet, insomnia (trouble sleeping), kidney problems, high blood sugar, and high potassium levels.

What else do I need to know?
Do not stop taking tacrolimus unless you are told to do so by your doctor. Take with food to prevent nausea. Store tacrolimus at room temperature (59 to 86 degrees F). Tacrolimus may interact with some commonly used medications and herbs. Please speak with your pharmacist if you have questions regarding interactions with medications and herbs.

Tacrolimus was given the name FK506 when it was a study drug. This name is still commonly used especially when blood is drawn for the drug level.

You should not eat grapefruit or drink grapefruit juice while taking tacrolimus. Chemicals in grapefruit can interfere with the enzymes that break down tacrolimus. Patients who are taking tacrolimus may develop a very high level of their medication if grapefruit is taken at any time of day. All forms of grapefruit and drinks containing a grapefruit juice should be avoided.

Some medications should not be taken with tacrolimus. Your coordinator or pharmacist will explain which medications should not be taken with tacrolimus.
CYCLOSPORINE, MODIFIED (NEORAL®, GENGRAF®)

What is it for?
Cyclosporine is an immunosuppressive medication that is used to prevent or treat acute liver rejection. Cyclosporine may be the only immunosuppressant that is prescribed for you or it may be used with other anti-rejection medications to prevent rejection.

How is it given?
There are many different brands of cyclosporine and it is available in liquid and capsule forms. It is usually dosed twice daily, 12 hours apart. Your dose of cyclosporine will be adjusted based on the level of cyclosporine in your blood, which is measured in lab on a regular basis, as determined by your doctor.

When do I take it?
Take cyclosporine two times a day, 12 hours apart for life or as determined by your doctor. It is important to take cyclosporine at the same time each day and consistently with or without food.

On a day when your cyclosporine level is to be measured in lab, do not take your morning cyclosporine dose until after your blood has been drawn. Make sure to bring your morning dose with you to the lab. Your blood should be drawn 12 hours (+/- 30 minutes) after your evening dose. For example if you take your cyclosporine at 9:00 p.m. have your blood drawn at 9:00 a.m. and then take your morning dose.

What side effects might I experience?
Side effects may vary and may depend on your cyclosporine levels. Side effects include but are not limited to kidney problems, high blood pressure, leg cramps, gum tenderness or inflammation, tremors, headache, high potassium levels, and excess hair growth.

What else do I need to know?
Do not stop taking cyclosporine unless you are told to do so by your doctor. Take with food to prevent nausea. Cyclosporine may interact with some commonly used medications and herbs. Please speak with your pharmacist if you have questions regarding interactions with medications and herbs.

If you take the liquid solution, mix it with milk, chocolate milk, or orange juice to make it taste better. Stir it well and drink it at once. Only mix it in a glass container (not plastic), and rinse the container to make sure you get the full dose. When getting your cyclosporine refilled at the pharmacy make sure they do not switch between Neoral®, Gengraf®, and generic substitutes, they cannot be substituted.

You should not eat grapefruit or drink grapefruit juice while taking cyclosporine. Chemicals in grapefruit can interfere with the enzymes that break down cyclosporine. Patients who are taking cyclosporine may develop a very high level of their medication if grapefruit is taken at any time of day. All forms of grapefruit and drinks containing a significant amount of grapefruit juice should be avoided if you are prescribed cyclosporine.

Cyclosporine capsules and liquid should be stored at room temperature and away from direct sunlight. An opened bottle of cyclosporine liquid may be used for up to two months.
AZATHIOPRINE (IMURAN®)

What is it for?
Azathioprine is an immunosuppressive medication that is used to prevent or treat acute liver rejection. Azathioprine is a “helper” immunosuppressant and may be given with tacrolimus, cyclosporine and prednisone.

How is it given?
Azathioprine is taken orally or intravenously depending on the condition of the patient being treated. Azathioprine is available in 50 mg tablets. It is usually prescribed once daily and should be given at the same time each day, with or without food.

When do I take it?
Take azathioprine every night. Most patients will take this medication for life.

What side effects might I expect?
Azathioprine may lower the number of white blood cells, which fight infection. It may also lower platelets, which help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also be harmful to the liver resulting in an increase in the liver functions tests. It can also cause an inflammation of the pancreas. When taken long-term, azathioprine may increase your risk for developing certain types of cancer such as skin cancer.

What else do I need to know?
If you develop gout and your doctor wants to treat you with allopurinol it is important to explain that you are taking azathioprine. These two drugs together can make your white blood cell count drop to critically low levels that may be result in death.

If you miss a dose of azathioprine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
PREDNISONE (DELTASONE®)

What is it for?
Prednisone is a steroid used to prevent or treat acute liver rejection.

How is it given?
Prednisone is available as many different strength tablets as well as an oral solution. It is usually dosed once a day.

When do I take it?
Take prednisone once daily for life or as determined by your doctor. Prednisone should be taken in the morning. If taken at night, it can affect your sleep.

What side effects might I expect?
Prednisone can have many side effects, but these vary depending on the dose, frequency and duration of your treatment. The most common side effects include: an increased appetite, weight gain, high blood sugar, stomach irritation and/or stomach ulcers, mood changes, irritability, anxiety, and acne. You may also retain fluids which may make your face, hands, and ankles “puffy.” Side effects that can occur with higher dosages over a longer period of time include bruising, high blood pressure, high cholesterol levels in the blood, high blood sugar, muscle weakness, night sweats, bone weakening, delayed wound healing, cataracts, and glaucoma.

What else do I need to know?
Take with food or milk to prevent nausea. Do not abruptly stop taking Prednisone unless you are told to do so by your transplant doctor.

Prednisone may not work as well when taken at the same time as some other medications. Your coordinator or pharmacist will explain which medications should not be taken with prednisone.

Do not drive until your Prednisone dose is down to 10mg a day
What is it for?
Mycophenolate mofetil (Cellcept®), or MMF for short, is an immunosuppressant medication that is used to prevent or treat acute liver rejection. Mycophenolate may be the only immunosuppressant that is prescribed for you or it may be used with other anti-rejection medications to prevent rejection. Mycophenolate sodium (Myfortic®) is a slow release version of the same medication.

How is it given?
Mycophenolate is taken orally or intravenously depending on the condition of the patient being treated. Mycophenolate mofetil (Cellcept®) is available in 250 mg capsules and 500 mg tablets, as well as an oral suspension. Mycophenolate sodium (Myfortic®) is taken orally and is available in 180 mg and 360 mg tablets.

When do I take it?
Take Cellcept or Myfortic twice daily, 12 hours apart. Most patients will take one of these for life.

What side effects might I expect?
Mycophenolate may lower the number of white blood cells, which fight infection. It may also lower platelets, which help your blood clot. Other side effects include but are not limited to nausea, vomiting, loss of appetite, diarrhea, and stomach cramps. When taken long-term, mycophenolate may increase your risk for developing certain types of cancer such as skin cancer.

What else do I need to know?
It is important that you tell your doctor if you are taking any over the counter iron tablet supplements. Report excessive diarrhea to your doctor.

Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled.

If you miss a dose, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.

If you are planning to become pregnant, discuss the use of mycophenolate with your transplant physician and obstetrician/gynecologist. Women of childbearing age should use contraception while on this medication and for six weeks after discontinuing it.

You should avoid receiving live vaccines such as the nasal mist influenza vaccine (Flu-mist®), the live polio vaccine, the smallpox vaccine, the measles-mumps-rubella vaccine (MMR®), and the live varicella vaccine (Varivax®, Zostavax®).
What is it for?
Valganciclovir and acyclovir are antiviral medications that are used to prevent or treat certain viral infections that commonly occur in patients who have a suppressed immune system. Cytomegalovirus (CMV), herpes simplex infections (HSV), and Epstein Barr Virus (EBV) infections are usually treated with valganciclovir or acyclovir.

How is it given?
Valganciclovir is available in 450 mg tablets and as an oral solution. It is taken by mouth usually once or twice a day and should be taken with food. Acyclovir is available in 200 mg, 400 mg, and 800 mg tablets or capsules and as an oral suspension. It is taken by mouth twice a day and can be taken with or without food.

When do I take it?
Take valganciclovir or acyclovir once or twice daily. The amount of time you will need to take valganciclovir or acyclovir after your transplant will depend on your risk for developing a viral infection after transplant. Your pharmacist will instruct you on how long you should take valganciclovir after transplant, either 3, 4, or 6 months. You may be restarted on valganciclovir or acyclovir if you are treated for rejection.

What side effects might I expect?
Side effects may include: diarrhea, nausea, vomiting, headache, pancreatitis, confusion, and seizures. Valganciclovir and acyclovir can affect the white blood cell count and platelet count, but this usually resolves by decreasing the dose or by stopping the medication.

What else do I need to know?
Always take Valganciclovir with food. Drink plenty of fluids to avoid harm to your kidneys.
**FLUCONAZOLE (DIFLUCAN®)**

**What is it for?**
Fluconazole is an antifungal medication that is used to treat or prevent fungal infections, namely thrush. Thrush is a fungal infection in the mouth. It can also be in the esophagus.

**How is it given?**
Fluconazole is available intravenously or orally in 50 mg, 100 mg, 150 mg, and 200 mg tablets, as well as an oral solution and an oral suspension. For prevention, fluconazole is usually taken once a week. For treatment, fluconazole is usually taken once a day.

**When do I take it?**
Fluconazole is taken by mouth once a week, on Mondays for the first 4 months after your transplant surgery. You may be restarted on it if you are treated for rejection.

**What side effects might I expect?**
Side effects include but are not limited to rash, headache, dizziness, nausea, vomiting, abdominal pain, diarrhea, elevated liver enzymes and/or change in ability to taste food.

**What else do I need to know?**
Fluconazole may increase the concentration of some drugs and enhance their effect, thus careful monitoring after completion of treatment is necessary:

- Warfarin (Coumadin®)
- Anti diabetic medication (Glyburide, Glipizide, Glimepiride)
- Phenytoin (Dilantin®)
- Theophylline
- Tacrolimus (Prograf®)
What is it for?
Bactrim® is an antibiotic used to prevent or treat Pneumocystis carinii Pneumonia (PCP). Patients who have a suppressed immune system are at greater risk for this type of pneumonia.

How is it given?
Bactrim® is available as single strength or double strength tablets as well as an oral suspension. It is usually dosed once a day.

When do I take it?
Take Bactrim® once a day for 6 months after your transplant. You may be restarted on it if you are treated for rejection.

What side effects might I expect?
Side effects include but are not limited to photosensitivity or a sunburn-like reaction when exposed to the sunlight, rash, and diarrhea. Other side effects include nausea, vomiting, diarrhea, mouth ulcers, a low red blood cell count (anemia), a low white blood cell count, or a low platelet count. Bactrim® can cause an increase in liver and kidney function tests in some patients.

Patients who are allergic to sulfa drugs will have an allergic reaction to Bactrim® or Septra®. They usually develop a rash, itching, and/or hives. If you are allergic, your transplant doctor will prescribe another medication to prevent PCP.

What else do I need to know?
Bactrim® should be taken with a full glass of water. Drink plenty of fluids while taking Bactrim®.
OMEPRAZOLE (PRILOSEC®)

What is it for?
Omeprazole is a proton pump inhibitor used to treat or prevent ulcers, esophagitis and other conditions caused by too much stomach acid, which can be the result of the use of high dose or a prolonged duration of steroids.

How is it given?
Omeprazole is available in 10 mg, 20 mg, and 40 mg capsules and tablets, and can be compounded into an oral suspension by your pharmacy. It is usually dosed once or twice a day.

When do I take it?
Take at night before going to bed or as directed by your doctor. You may be on this medication for 3 months after your liver transplant surgery. It may be restarted if you are treated for rejection. Some patients may stay on omeprazole for life.

What side effects might I expect?
Side effects are rare but can cause headache, nausea, and diarrhea.

What else do I need to know?
Capsules should be swallowed whole, not chewed, since these capsules contain time-released granules.
AMLODIPINE (NORVASC®)

What is it for?
Amlodipine is in a class of medications called calcium channel blockers that works to reduce blood pressure that may be caused by some immunosuppressant medications. It may be used alone or in addition to other blood pressure reducing medications.

How is it given?
Amlodipine is available in 2.5 mg, 5 mg, and 10 mg tablets. It is usually dosed once a day.

When do I take it?
Take amlodipine once a day. Some patients may stay on amlodipine for life.

What side effects might I expect?
Side effects may include but are not limited to dizziness, fatigue, headaches, abdominal pain, increased swelling in the legs or arms, or flushing. Amlodipine may increase your risk of developing chest pain or a heart attack; therefore you should contact your physician immediately if you are having chest pain while taking amlodipine.

What else do I need to know?
Amlodipine may affect the concentration of some drugs and either enhance or decrease their effect, thus careful monitoring is necessary:
- Cyclosporine (Sandimmune®, Neoral®, Gengraf®)
- Tacrolimus (Prograf®)
- Fluconazole (Diflucan®)
- Amiodarone (Cordarone®)
- Simvastatin (Zocor®)
**METOPROLOL (TOPROL-XL®, LOPRESSOR®)**

**What is it for?**
Metoprolol is in a class of medications called beta blockers that works to reduce blood pressure that may be caused by some immunosuppressant medications. Metoprolol also slows heart rate and may be used for other indications such as irregular heartbeats. It may be used alone or in addition to other blood pressure reducing medications.

**How is it given?**
Metoprolol (Lopressor®) is available intravenously and in 25 mg, 50 mg, and 100 mg tablets and is usually dosed twice a day. Extended release metoprolol (Toprol-XL®) is available in 25 mg, 50 mg, 100 mg, and 200 mg tablets and is usually dosed once a day.

**When do I take it?**
Take metoprolol (Lopressor®) twice a day. Take extended-release metoprolol (Toprol-XL®) once a day with food. Some patients may stay on metoprolol for life.

**What side effects might I expect?**
Side effects may include but are not limited to dizziness, fatigue, shortness of breath, headache, or depression.

**What else do I need to know?**
Metoprolol may mask the symptoms associated with low blood sugar, so if you have diabetes, it is advised to monitor your blood sugars closely. Metoprolol may worsen symptoms associated with asthma. If you have asthma, discuss the use of metoprolol with your transplant physician prior to starting metoprolol.
OXYCODONE (ROXICODONE®)

What is it for?
Oxycodone is used to relieve moderate to severe pain. Oxycodone is in a class of medications called opiate (narcotic) analgesics. It works by changing the way the brain and nervous system respond to pain.

How is it given?
Oxycodone is generally prescribed in 5 mg tablets and is taken orally.

When do I take it?
Take oxycodone if needed every 4 to 6 hours or as directed by your doctor.

What side effects might I expect?
Side effects include but are not limited to drowsiness, dizziness, light-headedness, nausea, vomiting, headache, and constipation.

What else do I need to know?
Avoid alcohol, antihistamines or other drugs that may intensify the drowsiness caused by oxycodone. It can be taken with or without food. Avoid driving or operating heavy machinery while taking oxycodone.

This prescription is not refillable by phone. If you continue to experience pain request new prescriptions during your regular office visits.
**Medications for Electrolyte Imbalances**

Purpose: Sometimes medications can cause imbalances in the body’s electrolytes. Electrolytes are substances your body needs to maintain fluid balance and to help with other functions of your body. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body. Medications to treat or prevent electrolyte imbalances may be needed for several reasons. Sometimes these imbalances are due to side effects of other medications. For example, a high level of tacrolimus can cause magnesium levels in your blood to be lower than normal. Sometimes imbalances can occur if your kidneys are not working well. If you have a lot of diarrhea because of an infection or as a side effect of a medication, the bicarbonate level in your blood may be low.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Use</th>
<th>Possible Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnesium oxide</td>
<td>To treat or prevent low magnesium levels</td>
<td>Diarrhea, abdominal cramping, muscle weakness, high magnesium level, low blood pressure</td>
</tr>
<tr>
<td>Magnesium gluconate (Magonate®)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fludrocortisone (Florinef®)</td>
<td>To treat or prevent high potassium levels</td>
<td>High blood pressure, edema, headache, rash, low potassium</td>
</tr>
<tr>
<td>Potassium chloride (K-Dur®)</td>
<td>To treat or prevent low potassium levels</td>
<td>High potassium, nausea, vomiting, diarrhea, abdominal pain, muscle weakness, heart</td>
</tr>
<tr>
<td>Calcium carbonate (Tums®)</td>
<td>To treat or prevent low calcium levels and support bone strength</td>
<td>Constipation, intestinal bloating and excess gas</td>
</tr>
</tbody>
</table>
Approved Over-The-Counter (OTC) Medications

- Tylenol® (acetaminophen) 325 mg tablets, 2 tablets every 10 hours as needed for pain.
- Extra Strength Tylenol® (aceta-minophen) 500 mg tablets, 1 tablet every 8 hours as needed for pain.
- Tylenol® (acetaminophen) can be toxic to your liver; do not take more than 1.5 grams (1500 mg) a day. You must be aware of combination drugs that contain Tylenol® (acetaminophen) and make sure you do not take more than 1.5 grams (1500 mg) a day.
- Chlor-Trimeton® (chlorpheniramine) and Benadryl® (diphenhydramine) anti-histamines for cold symptoms (runny nose, itchy eyes), follow directions on the box.
- Claritin® (loratidine), Zyrtec® (cetirizine), and Allegra® (fexofenadine) for seasonal allergies, follow directions on the box.
- Robitussin® (dextromethorphan), Mucinex® (guifenesin), and Mucinex-DM® (guifenesin and dextro-methorphan) for cough, follow the directions on the box.
- Sudafed PE® (phenylephrine), Astelin Nasal Spray® (azelastine), Ocean Nasal Spray® (saline), and Neti Pot for nasal congestion.

Check with your pharmacist before taking any other over the counter medications to see if they adversely interact with your current medications.

- DO NOT TAKE non-steroidal anti-inflammatory drugs (NSAIDs). These include but are not limited to Ibuprofen, Motrin®, Excedrin IB®, Advil®, Naproxen®, Feldene®, and Celebrex®. This kind of medication can injure your kidneys or cause kidney failure! If you are not sure whether you should take a medication that has been prescribed for you, ask your pharmacist.
- DO NOT TAKE aspirin unless it is prescribed by the transplant team.
- DO NOT TAKE Sudafed® (pseudo-ephedrine) unless it is prescribed by the transplant team. Sudafed® can increase blood pressure and cause irregular heart rhythms.
- DO NOT TAKE herbal medications after your liver transplant.

Please notify your coordinator if you are taking any of these medications on a regular basis.
### Appendix B: Laboratory Tests

#### Laboratory Tests that Monitor Liver Function

<table>
<thead>
<tr>
<th>Test</th>
<th>Normal Range*</th>
<th>Function</th>
<th>Indicates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Bilirubin (T Bili)</td>
<td>0.1-1.2</td>
<td>A substance made from the breakdown of hemoglobin; Red blood cells are trapped and destroyed in the spleen as they wear out. When these cells are destroyed, bilirubin is released into the blood. The liver then processes this bilirubin, combines it with another substance, and excretes the bilirubin through bile. Bile flows from the individual liver cells, through the bile ducts, and into the intestine where it leaves the body in the feces. The characteristic brown color of feces is due to bile.</td>
<td>↑ Bile duct obstruction &lt;br&gt; ↑ May be a sign of rejection or infection</td>
</tr>
<tr>
<td>Alkaline phosphatase (Alk Phos)</td>
<td>45-129</td>
<td>An enzyme produced by the liver (and other) cells; elevated blood levels of this substance may indicate abnormal function of the liver or other organs.</td>
<td>↑ Bile duct obstruction &lt;br&gt; ↓ Malnutrition &lt;br&gt; ↑ Liver injury, rejection, biliary obstruction, mononucleosis, pancreatitis, myocardial infarction, severe burns, trauma</td>
</tr>
<tr>
<td>Alanine Transaminase (SGPT or ALT)</td>
<td>9-57</td>
<td>Enzyme which occurs in high concentration in the liver</td>
<td>↑ Liver injury, rejection, myocardial infarction, pancreatitis, trauma</td>
</tr>
<tr>
<td>Aspartate Transaminase (SGOT or AST)</td>
<td>14-44</td>
<td>Enzyme present in tissues with high metabolic activity, including the heart, liver, muscles, kidney, brain, pancreas, lungs</td>
<td>↑ Liver injury, rejection, bile duct obstruction &lt;br&gt; ↓ Malnutrition</td>
</tr>
<tr>
<td>Gamma Glutamyl Transferase (GGT)</td>
<td>9-59</td>
<td>Enzyme present mainly in the liver, kidney, prostate and spleen</td>
<td></td>
</tr>
<tr>
<td>Albumin (Alb)</td>
<td>3.5-5.0</td>
<td>a protein made by the liver that helps maintain fluid balance in the body</td>
<td>↓ Malnutrition &lt;br&gt; ↓ Malnutrition, chronic liver dysfunction</td>
</tr>
<tr>
<td>Total Protein (TP)</td>
<td>6-8.4</td>
<td>Total of multiple types of proteins found in the blood. They are a source of nutrition and a buffer system.</td>
<td></td>
</tr>
<tr>
<td>Test</td>
<td>Normal Range*</td>
<td>Function</td>
<td>Indicates</td>
</tr>
<tr>
<td>---------------------</td>
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<td>--------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Blood Urea Nitrogen (BUN)</td>
<td>7-23</td>
<td>BUN is a product of protein breakdown, or a waste product, normally excreted by the kidney.</td>
<td>↑Kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications</td>
</tr>
<tr>
<td>Creatinine (Cr)</td>
<td>0.6-1.1</td>
<td>Creatinine is a waste product produced by the muscles and released into the blood stream.</td>
<td>↓Liver disease, over-hydration, ↑Kidney dysfunction, side effect of some medications, dehydration</td>
</tr>
<tr>
<td>Sodium (Na)</td>
<td>131-142</td>
<td>A mineral needed by the body to keep body fluids in balance</td>
<td>↓Side effect of diuretics; kidney dysfunction</td>
</tr>
<tr>
<td>Potassium (K+)</td>
<td>3.5-5.0</td>
<td>A mineral required for normal body functioning; important in helping the heart, nerves, and muscles function properly; helps change carbohydrates into energy and in forming proteins</td>
<td>↑Kidney dysfunction, side effect of some medications, ↓Side effect of diuretics; decreased intake, vomiting</td>
</tr>
<tr>
<td>Magnesium (Mg++)</td>
<td>2-2.6</td>
<td>Mineral required for normal bodily function; involved in nerve, skeletal muscle, heart, and cell function; also involved in blood clotting and the metabolism of carbohydrates and proteins</td>
<td>↑Kidney dysfunction, ↓Diarrhea; side effect of medications</td>
</tr>
<tr>
<td>Glucose (Glu)</td>
<td>71-109</td>
<td>A type of sugar in the blood that supplies energy to the cell; glucose levels vary with diet, medications, stress, and organ dysfunction</td>
<td>↑Diabetes, pancreas problem, side effect of some medications, ↓Occurs in liver disease or with thyroid problems</td>
</tr>
<tr>
<td>Calcium (Ca++)</td>
<td>8.4-10.4</td>
<td>A mineral measured in the blood that is required for bone growth and for blood clotting; also needed for the heart and nerves to function</td>
<td>↑High intake of calcium; bone disorders, thyroid problem, ↑Kidney dysfunction, over hydration, problems with the pancreas, severe malnutrition</td>
</tr>
<tr>
<td>Test</td>
<td>Normal Range*</td>
<td>Function</td>
<td>Indicates</td>
</tr>
<tr>
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</tr>
</tbody>
</table>
| White Blood count    | 4.4-10.8      | Cells that fight infection; also involved in the rejection process       | ↑ May indicate infection
| (WBC)                |               |                                                                          | ↑ Side effect of some medications, stress                                  |
| Hematocrit (hct)     | Males 40-54%
Females 37-47% | Measures the percentage of oxygen-containing red blood cell (RBC)        | ↑ May cause blood clotting
|                      |               |                                                                          | ↓ May be a sign of anemia                                                  |
| Hemoglobin (Hgb)     | Males 12-18
Females 12-16 | The oxygen-containing part of the red blood cell (RBC)                   | ↑ May indicate dehydration or a blood disorder
|                      |               |                                                                          | ↓ Can be a sign of anemia                                                  |
| Platelets (Plt)      | 150,000-350,000 | Component of blood that helps stop bleeding                             | ↑ Can make your blood “thick” and lead to clotting
|                      |               |                                                                          | ↓ May be a sign of liver disease, bleeding, anemia                        |
Appendix C: Definitions

**Albumin**
A protein made by the liver that helps maintain fluid balance in the body.

**Alkaline Phosphatase (Alk Phos)**
An enzyme produced by the liver (and other) cells; elevated blood levels of this substance may indicate abnormal function of the liver or other organs.

**Anemia**
Decreased capability of the red blood cells to deliver enough oxygen to the body tissues. It may be caused by a low number of red blood cells, decreased amount of hemoglobin or decreased volume of red blood cells.

**Antacid**
A drug that aids in protecting the digestive system and relieves heartburn and digestive discomfort.

**Antibody**
A protein produced by the body immune system to eliminate foreign substances, such as bacteria.

**B Cells**
A type of lymphocyte, or white blood cell that develops in the spleen that is responsible for the body’s immunity; B cells produce antibodies.

**Bacteria**
Small organism (germ) that can cause disease or infection.

**Bile**
A fluid produced by the liver, stored in the gallbladder, and released into the small intestine to help absorb dietary fats.

**Bile Ducts**
The tubes through which bile flows.

**Bile Leak**
A hole in the bile-duct system that causes bile to spill into the abdominal cavity.

**Biliary Stenosis**
Narrowing or constriction of a bile duct.

**Biliary Tree**
All passageways inside and outside the liver that carry bile to the intestines.

**Bilirubin**
An orange colored substance in bile produced by the breakdown of red blood cells.

**Blood Urea Nitrogen (BUN)**
A test that indicates kidney function. It is a product of protein breakdown normally excreted by the kidneys.

**Cadaveric Donor**
A recently deceased organ donor.

**Calcium**
A mineral measured in the blood that is required for bone growth and for blood clotting; also needed for the heart and nerves to function.

**Cholangiogram**
A test that examines the bile ducts in the liver for any leaks or blockages.

**Cholangitis**
A bacterial infection in the bile ducts.

**Cholestasis**
An accumulation of bile in the liver caused by medications, an injury to the liver, liver disease, total parenteral nutrition (TPN), or gallstones.

**Cholesterol**
A form of fat that performs necessary functions in the body, but can also cause heart disease. Cholesterol is found in animal foods such as meat, fish, poultry, eggs, and dairy products.

**Cirrhosis**
A disease causing irreversible scarring of the liver.

**CMV (Cytomegalovirus)**
A virus infection that is common in transplant recipients; it can affect the lungs and other organs as well; a member of the family of herpes viruses.
Coagulation
The process of blood clotting. The ability to clot is measured by the prothrombin time (PT), partial thromboplastin time (PTT) and platelet count.

Coagulopathy
Decreased ability to clot

Complete Blood Count (CBC)
A blood test that measures components of the blood including hemoglobin (Hgb), hematocrit (Hct), platelets (Plt), and the types of white blood cells (WBC)

Corticosteroids
A category of immunosuppressive medications that includes prednisone and prednisolone.

Creatinine
A substance found in blood and urine; it results from normal body chemical reactions; such as muscle metabolism. High blood creatinine levels are a sign of depressed kidney function.

Diabetes
A disease characterized by high levels of blood sugar.

Diabetic Nephropathy
Kidney disease or damage as a result of diabetes.

Dialysis
A process by which blood is cleaned to restore chemical balance.

Edema
Excess fluid in body tissues; swelling of the ankles, for example, is a sign of edema.

EGD (esophagogastroduodenoscopy)
A diagnostic endoscopic procedure that visualizes the upper part of the GI tract to the duodenum

Electrocardiogram (ECG or EKG)
A recording of the electrical activity of the heart.

Electrolyte
A dissolved mineral such as sodium, potassium, magnesium, etc that helps maintain bodily functions and fluid balance.

Endoscope
A small telescope-like instrument that is used to examine the esophagus, stomach and small intestine.

Endotracheal Tube
A tube inserted through the mouth and into the windpipe to aid a person in breathing.

Enzyme
A protein made in the body and capable of changing a substance from one form to another.

ERCP
Endoscopic retrograde cholangio-pancreatogram; test that examines the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree)

Fibrosis
The presence of fibrous tissue in the liver that causes scarring and liver dysfunction; fibrosis develops into cirrhosis.

Gallbladder
A muscular sac attached to the liver; stores bile. This is removed during transplant.

Gastroenterologist
A doctor who specializes in the diagnosis, treatment, and management of diseases of the digestive system, including the liver

Gastrointestinal (GI)
The tract between the mouth and the rectum, including the intestines and stomach.

Glomerular Filtration Rate (GFR)
A test that determines the level of kidney function.

Glucose
A type of sugar in the blood that supplies energy to the cell; levels vary with diet, medications, stress, and organ dysfunction

Graft
A transplanted tissue or organ, such as a liver or kidney. A graft between humans or the same species with different genetic material is called an allograft. A graft between different species, such as a baboon to human, is called a xenograft.
**Helper T-cell**
The white blood cell that tells the immune system to fight infection or foreign substances, such as transplanted tissue.

**Hematocrit**
Measurement of the amount of red blood cells in the blood.

**Hematoma**
A bruise or swelling caused by the accumulation of blood in tissue.

**Hemoglobin**
A substance in red blood cells containing iron and protein that gives blood its characteristic red color; carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs.

**Hepatic**
Relating to the liver.

**Hepatitis**
Liver inflammation that may be caused by a virus or chemical such as alcohol.

**Hepatologist**
A physician who studies the liver and treats liver disease.

**Hepatomegaly**
An enlarged liver.

**Herpes**
A family of viruses that infect humans: herpes simplex causes lip and genital sores; herpes zoster causes chickenpox and shingles.

**Hirsutism**
Excessive hair growth; a common side effect of cyclosporine seen in both male and female transplant recipients who receive cyclosporine.

**Hypertension**
High blood pressure.

**Hypotension**
Low blood pressure.

**Immune System**
The system that protects the body from invasion by foreign substances, such as bacteria and viruses, and from cancer cells.

**Immunity**
A condition of being able to resist a particular infectious disease.

**Immunosuppression**
Decrease of the body’s immune response, accomplished through the use of certain drugs in order to help prevent or control a rejection following a transplant.

**Immunosuppressive Agents**
Medications taken to prevent rejection of a transplanted organ.

**Insulin**
A hormone produced by the pancreas that regulates blood sugar levels.

**Intravenous (IV)**
Refers to fluids or medications administered to patients directly into a vein via a needle or catheter.

**Jaundice**
Yellowing of the skin and eyes caused by excess bile products in the blood.

**Kidney Failure – Chronic**
Diminished kidney function over time that is irreversible.

**Leukocyte**
A white blood cell that helps fight infection.

**Liver Enzymes**
Substances produced by the liver and released into the blood; these are measured to assess liver function.

**Liver Function Tests (LFTs)**
Blood tests used to determine how well the liver is functioning; includes the ALT, AST, GGT, bilirubin, and alkaline phosphatase.

**Lymphocyte**
Cells produced by the lymph glands that are responsible for immunity and defending the body against infection and foreign substances by producing antibodies and other substances.
MRCP (Magnetic resonance cholangio-pancreatography)
An alternative for Endoscopic retrograde cholangio-pancreatogram; test that examines the drainage system or ducts of the gallbladder, pancreas, and liver (the biliary tree) using an MRI.

Nephrologist
A physician who specializes in diagnosing and treating kidney disease.

Neutrophil
A type of white blood cell.

Platelet
A small blood cell needed for normal blood clotting.

PTLD
Post-transplant lymphoproliferative disease; a wide spectrum of viral disorders associated with the Epstein Barr Virus (EBV) that may range from a self-limiting mononucleosis (“mono”) to a type of lymphoma, or cancer of the lymph nodes; a complication of a suppressed immune system; Treatment includes lowering immunosuppression and administering antiviral medications.

Pneumocystis Carinii Pneumonia (PCP)
A type of pneumonia seen primarily in patients whose immune systems are suppressed.

Potassium
A mineral essential for body function. High potassium levels can irritate the heart. Poor kidney function and side effects of immunosuppresive medication is often associated with high potassium levels.

Prophylactic Medication
Medication taken to help prevent disease

Red Blood Cells
The part of the blood that transports oxygen to body tissues.

Renal
Refers to the kidney.

Rejection
When the immune system attacks the transplant organ (liver, kidney, etc.) to rid the body of it because it is recognized at a foreign object.

Sepsis
A severe infection that has spread to the bloodstream.

Shingles
A herpes virus infection (herpes zoster) causing painful blistering skin eruptions along a nerve track in one area of the body.

Signs
Things you or someone else can see that are determined by measurement, such as an increase in temperature or blood pressure.

Sodium
A mineral needed by the body to keep body fluids in balance.

Stricture or Stenosis
Narrowing of a passage in the body.

Systolic Blood Pressure
The top number when the blood pressure is measured. This is the pressure when the heart muscle contracts.

T Cells
White blood cells that play a major part in rejection.

T-Tube
A tube placed in the bile duct that allows bile to drain into a bag outside the body.

Thrombosis
The development of a blood clot.

Thrush
A fungus infection in the mouth.

Tissue Typing
Identifying a person’s major antigens used to evaluate the match between a donated organ and a potential recipient via a blood test.

Toxins
Waste products in the blood that is poisonous to the body in high concentrations.

Turcotte Tube
A tube placed in the bile duct that allows bile to drain into a bag outside the body.
Ultrasound
A method of picturing internal organs using sound waves. It is often used to detect masses, abscesses, organ size, or blood flow to a transplanted organ.

Urinary Catheter
A soft rubber tube that is inserted into the bladder to drain urine.

Urinary Tract
The body system that produces, transport, stores and eliminates urine. The urinary tract includes the kidneys, ureter’s, bladder and urethra.

United Network for Organ Sharing (UNOS)
The national body that sets policies for organ allocation in order to ensure fairness. UNOS also maintains statistics on different transplant programs and collects scientific data on transplant recipients and donors.

Wean
To slowly withdraw or reduce; immunosuppression, particularly steroids, may be weaned slowly over time in patients who have stable function of the transplanted liver

White Blood Cells
Cells in the blood that fight infection; part of the immune system.