

## **Why Choose Tampa General Hospital?**

Lung transplantation has grown steadily in the last 15 years and more than 10,000 lung transplants have been performed worldwide. But, the demand far exceeds the numbers now being listed.

Tampa General Hospital's Lung Transplant Program is the result of over three years of preparation, bringing together almost 30 years of physician experience and 28 years of transplant experience throughout the hospital system.



Transplantation is a team effort.

Our success depends on a multidisciplinary approach to patient care. Our team consists of pulmonologists, surgeons, immunology and infectious disease specialists, nurses, dieticians, rehabilitation specialists, social workers, respiratory therapists, financial counselors, pharmacists and chaplains. We at TGH are dedicated to providing the best possible services to the potential lung recipient.

When looking at a Transplant Center, one should consider not just statistics but the quality and dedication of the team that will be providing your care before, during and after the transplant. One should also consider the availability of family, friends or others to help during this time. The cost of living in the area where the hospital is located is another important question.

### **Table of Contents**

#### **Pre-Evaluation Phase**

#### **Evaluation Phase**

#### **Activation and Surgery**

#### **Postoperative Care-CSU and 8A**

#### **Ready To Go Home**

#### **Appendix**

#### **Pre-Evaluation Phase**

#### **What is lung failure (end-stage lung disease)?**

The body needs a certain amount of oxygen to function normally. The amount of blood and oxygen needed changes when a person is resting or exercising. Lung failure means that your lungs cannot supply enough oxygenated blood to your body for the activities of daily living.

Lung failure is called emphysema or COPD, Chronic Obstructive Pulmonary Disease (with or without A1AT deficiency).

It can also be caused by other diseases such as Pulmonary Fibrosis, Cystic Fibrosis, Primary Pulmonary Hypertension.

This failure can have a sudden onset but usually is insidious in nature, which means it occurs gradually over time. The body compensates until it reaches a point where the person becomes symptomatic with activity and even at rest.

### **General Considerations:**

The primary indication for lung transplantation is irreversible. End-stage lung disease is expected to result in death within 1-2 years with no other viable treatment alternatives.

Patients should have significant limitations in functional capacity (activities of daily living) that decrease their quality of life. For each disease state, patients with a high risk for dying without transplantation (life expectancy less than 2 years) should be considered.

Lung transplantation should be discussed early in the course of their disease and not as a “last ditch effort”. In fact, if someone waits too long they may not survive to transplant. This also allows the team to maximize their rehabilitation potential prior to requiring the transplant. It has been shown that those patients who have maximized their rehab potential have significantly better outcomes post transplant.

Waiting list time for a donor lung can outlast life expectancy; therefore, timing is crucial to allow the patient to survive until transplantation.

It is common to feel anxious, depressed or even angry about your condition. There are hundreds of thousands of Americans with lung problems. A positive attitude can help you live better with lung failure. It is very important to share your emotions and fears with family and learn about strategies to manage your illness.

### **Symptoms of lung failure:**

The common symptom of lung failure is shortness of breath - described as a feeling of “air hunger” that causes distress and anxiousness during activities of daily living (ADL’s) and often at night while lying flat. This limitation creates a cycle that leads to increasing limitation due to inactivity.

During the evaluation phase, the patient will undergo stress testing to not only evaluate the severity of their disease but prescribe a program of pulmonary rehabilitation using additional oxygen that will maximize their physical ability. This also leads to a more successful post-operative course.

**Fatigue:**

Lung failure prior to being diagnosed is often labeled as just “getting older” or being “out of condition”. However, this fatigue does not go away and also leads to a vicious cycle of further inactivity, as sense of loss and depression due to inability to perform ADL’s.

Fact: getting into pulmonary rehabilitation with supplemental oxygen often improves your sense of well-being as well as increasing your ability to do more physical activities.

**Loss of appetite:**

Many patients with lung failure have difficulty maintaining an adequate dietary intake. Just the simple act of eating can be tiring. The diaphragm becomes distended, pushing on the stomach, leading to a sense of fullness.

The use of accessory muscles to breathe increases the body’s demand for oxygen leading to increased caloric requirements.

**Fact:** Consulting with a dietician to assist with maximizing your intake will add to your sense of well being.

**Swollen ankles:**

Swelling, especially of the lower extremities, occurs due to sitting or standing for prolonged periods. This is due to your heart being over-stressed from having to pump harder to supply oxygen to your vital organs.

Fact: this leads to increased nighttime urination from the heart pumping more fluid through the kidneys while the body is at rest.

**What you can do about lung failure:**

You are a part of the team of doctors, nurses, and other health professionals. This means that you will be expected to be:

Motivated to do those things that have been prescribed by your health care team, including taking prescribed medications.

Actively involved in a pulmonary rehabilitation program.

Following your diet to either maintain/improve/or even to lose weight.

Keeping your appointments with your health care team.

Compliant with your treatment program.

**Fact:** Motivation and compliance are two very important criteria in evaluating patients for potential lung transplantation.

## **Criteria for Lung Transplant at TGH**

These guidelines generally follow the “International Guidelines for the Selection of Lung Transplant Candidates” (J. Heart Lung Transplant, 1998; 17:703-709), which have been endorsed by the International Society of Heart and Lung Transplantation, the American Society of Transplantation, The American Thoracic Society, the European Respiratory Society and the Thoracic Society of Australia and New Zealand.

### **General Considerations:**

Evidence of pulmonary parenchymal or pulmonary vascular disease that results in significant limitations of functional ability such the patient’s current physical activity levels are insufficient to maintain a satisfactory quality of life.

Within each disease category, patients with a high predicted risk of mortality (i.e.: > than 20-30% within 1 year) should be considered for transplantation independent of any symptomatic limitations.

All conventional medical and surgical therapies for the patient’s pulmonary disease should be considered and either tired and proven ineffective or deemed unlikely to be of any benefit.

There should be no other significant life-threatening or life-limiting medical problems apart from pulmonary disease.

The patient should have a good rehabilitation potential and have a high likelihood of complying with a complex medical regimen over the long-term.

### **Disease specific considerations:**

Emphysema/ Chronic Obstructive Pulmonary Disease (COPD) with or without A1AT:

COPD is the most common indication for lung transplantation in the U.S. In general, pulmonary function studies and the presence or absence of clinical evidence of right ventricular dysfunction (cor pulmonale) have provided the most helpful guidelines in deciding when to refer a patient for lung transplantation. Medical studies of the natural history of COPD, patients with an FEV1 between 20%-30% predicted and no evidence of cor pulmonale, have an expected survival of approximately 65% at two years. Patients with cor pulmonale, even with an FEV1 greater than 30% predicted, have an expected survival of only 44%.

Patients with A1AT Emphysema are a unique subgroup of COPD patients with a somewhat better prognosis. In spite of FEV1 Less than or equal to 25% of predicted, their life expectancy is approximately six years. In these patients the presence of cor pulmonale, degree of exercise-induced hypoxia and respiratory limitation to exercise (class 4 or 5 dyspnea) are probably the best guidelines for determining the optimal timing of referral.

**Referral guidelines for this condition:**

FEV1 less than 30% predicted

there is clinical evidence of right ventricular dysfunction

presence of hypercapnia (PaCO<sub>2</sub> greater than 55mm/Hg) is a consideration for referral

These patients, in general, require only single lung transplantation. Exceptions may be made for younger (<45 years ) with extreme hyperinflation or who have significant pulmonary hypertension.

**Pulmonary Fibrosis:**

This is a major indication for lung transplantation. Ideally, the patient should have isolated pulmonary disease (ie; idiopathic pulmonary fibrosis, occupational lung disease, and histiocytosis X). Patients with chemotherapy and/or radiation therapy for cured neoplastic disease (e.g. Hodgkin's ), prior bone marrow transplant, systemic diseases (collagen vascular, sarcoidosis or lymphangioleiomyomatosis) are considered on a case by case basis.

Even with aggressive treatment, many patients continue to deteriorate with progressive declines in pulmonary function, chest radiography and functional capacity until they die usually from respiratory failure. The natural history can be variable, with some remaining stable for long periods while others deteriorate rapidly. In some series, the average survival from onset of symptoms was 4 years.

Many patients are either misdiagnosed initially or delay seeking medical attention until their symptoms are moderate or even severe. On average, once symptoms are severe the one-year survival is only 40%.

**Referral guidelines for this condition:**

When the FVC or DLCO is less than 70% of predicted. If the patient is asymptomatic, but the definitive diagnosis has been made, frequent follow-up evaluations are essential to assess the rate of functional decline. In this case, a 10% or greater decrease in FVC, a 20% or greater decrease in DLCO, or a 5mm/Hg or greater increase in alveolar-arterial O<sub>2</sub> gradient from baseline values in evidence of progression and referral is appropriate.

Presence of pulmonary hypertension and right ventricular dysfunction should also be sought, since this has a very poor prognostic indication. Gamma-interferon (Intermune) was shown to be of benefit in one recent clinical study and this therapy should now be considered for all appropriate candidates.

## **Cystic Fibrosis:**

This disease represents a unique challenge to the transplant team. As a group they are:

- Younger
- Usually do not have pre-existing risk such as atherosclerosis, degenerative disease and neoplasia. They are more likely to suffer the effects of chronic malnutrition secondary to pancreatic insufficiency, increased tissue catabolism from frequent pulmonary sepsis, renal insufficiency from frequent courses of nephrotoxic antibiotics and insulin dependent diabetes.
- Chronic colonization by resistant organisms such as *Pseudomonas* sp., *B. cepacia*.
- The natural history of CF is variable; however, most patients will die from their pulmonary disease.

Guidelines for determining appropriate time to refer for lung transplant include:

- Frequency of acute exacerbation
- Functional capacity
- Results of serial pulmonary function studies (PFT)
- FEV1 is less than 30% predicted or the PaO<sub>2</sub> is less than 55mm/Hg on room air or PaCO<sub>2</sub> is greater than 50mm/Hg
- Patients on a steady and fairly rapid decline in PFT's in spite of maximal therapy should be referred early based on projected lung functions at the current rate of decline
- Female gender appears to confer a higher risk of 2-year mortality at any given level of pulmonary dysfunction so that they should be referred earlier
- Patients on a steady and fairly rapid decline in PFT's in spite of maximal therapy should be referred early based on projected lung functions at the current rate of decline
- Female gender appears to confer a higher risk of 2-year mortality at any given level of pulmonary dysfunction so that they should be referred earlier

## **Other forms of Bronchiectasis:**

Patients with other forms of bronchiectasis ( immotile cilia, Kartagener's syndrome, etc) share many of the clinical features of cystic fibrosis and undergo similar considerations in determining suitability and timing of transfer. The exception being agammaglobulinemia all have been able to undergo successful lung transplants.

**Guidelines:**

All patients with recurrent airway sepsis require bilateral lung transplantation. Burkholderia cepacia is an absolute contraindication for transplant at this time.

**Pulmonary Hypertension:**

Patients with predominant pulmonary vascular disease are another major category for lung transplant consideration. There are two major subgroups:

- Those with primary pulmonary hypertension (PPH)
- Those with congenital heart disease and Eisenmenger's physiology

There are a variety of effective pulmonary vasodilators (prostaglandins, endothelin antagonists, nitric oxide) that are now available or will be in the near future. Trials of vasodilator therapy should be attempted in all candidates and referrals for transplantation limited to those who either fail to respond or require progressively increasing doses.

**Guidelines for Referral:**

The NHI pulmonary hypertension data survival equation predicts a less than 70% change of survival for patients based on a specific formula. Based on this data, the hemodynamic guidelines for referral with PPH diagnosis are: mean pulmonary artery pressure greater than 55 mm/Hg or mean right atrial pressure greater than 15mm/Hg or cardiac index less than 2.0 L/min/m<sup>2</sup>.

Patients with persistent class III or IV symptoms in spite of escalating doses of prostaglandin should also be referred.

Patients with congenital heart disease and Eisenmenger's often enjoy a better survival, albeit at the expense of cyanosis even, than would be predicted on the basis of their hemodynamics. The usual guidelines for this sub-group are based on worsening of the functional classification and level of cyanosis.

The optimal procedure for patients with PPH is still controversial. Success has been demonstrated with single and bilateral lung transplantation. TGH preference is to perform bilateral whenever feasible.

Patients with congenital heart disease and Eisenmenger's undergo simultaneous lung transplantation and correction of their defect.

There is also a small sub-group of patients with collagen-vascular disease, systemic sclerosis and related conditions who may merit consideration. These will be evaluated on a case by case basis.

## **Retransplantation:**

Most commonly performed for chronic rejection or bronchiolitis obliterans, has been controversial in view of the limited availability of donor lungs and the historically poor results of retransplantation.

Analysis of results of retransplantation (Annals Thor. Surg. 1998; 65: 227-234) in 230 patients from 47 centers worldwide, with almost two-thirds for bronchiolitis obliterans, show that results were very similar to first-time transplants. Two of the major risk factors for mortality were mechanical ventilation prior to transplant and the experience of the transplant center with retransplantation.

## **Guidelines:**

TGH policy will be to carefully assess patients and consider retransplantation provided there are no significant contraindications.

## **Evaluation Phase for Lung Transplantation at TGH:**

The process of transplantation evaluation begins with a referral from the primary physician's office to the transplant center.

### **Basic information to be obtained includes:**

- Patient Demographics
- Insurance Information
- Clinical Data-such as History/Physicals, Consult Reports, Procedures, Xrays, PFT's, ABG's, any other pertinent laboratory data

Once this data is available, it will be reviewed by the transplant team to determine if the patient meets the minimum criteria for transplant evaluation. Then, the formal evaluation process will begin. Based on the reported data from other active transplant centers, about 30% of those referred will qualify for an evaluation and that 50% of those actually undergoing an evaluation would be eventually listed for transplantation.

The evaluation process is fairly rigorous and begins on Monday with the clinic evaluation and usually can be completed over 2-3 days, depending on circumstances. By the following Monday afternoon the results of all testing will be reviewed by the Medical Review Board, to determine final dispensation. This will then be relayed to the referring physician and the patient.

### **The options are:**

- Not a candidate due to medical and/or psychosocial contraindications.
- Recommend more conventional therapy prior to proceeding to transplantation.
- Recommend additional testing to help delineate a real of potential problem.
- Recommend immediate activation for transplantation.



- Recommend additional therapeutic interventions that will allow patient to become a candidate.

Once the patient is listed and remains on the active list, he or she will be instructed to contact their primary care physician/pulmonologist if they experience a decline in their respiratory status. The transplant center needs to have ongoing updated information regarding any changes (hospital admissions at their “home” hospital, significant changes in medical condition, or insurance coverage) that may prohibit the patient from receiving a lung at any time. There are no provisions for consideration of the severity of pulmonary disease in the listing or the status of a patient on the lung transplant list. Patients receive lungs based on their accrued time on the active list.

Pulmonologists and other physicians on the transplant team will care for those patients who have relocated to the area, or who do not have a pulmonologist caring for their pulmonary condition. If the patient requires admission, they will be cared for by the physicians on the transplant team at TGH. Summaries of their office visits and hospitalizations will be sent to the referring physician.

**Initial screening studies for any abnormal findings:**

**Laboratory:**

CBC w/ differential	Thyroid Panel w/ TSH
PT/PTT/INR	Prealbumin Level
CMP, fasting	24 hour urine for creatinine clearance
HDL profile	Urinalysis C&S
Liver Function Panel	Stool guaiac for occult blood

- Radiological Testing will evaluate your lungs and chest and identify any abnormalities other than your diseased lungs.
- Chest x-ray PA & Lat
- Chest CT- high resolution non-contrast
- Abdominal Sonogram-evaluate for gall stones/biliary tree/aorta size/kidney
- Flex-sigmoidoscopy (colonoscopy if over 50 years)

**Pulmonary Evaluation-to determine the severity of your lung disease:**

- Complete Pulmonary Function Studies w/ Arterial Blood Gas
- 6-minute walk test
- Quantitative Ventilation Perfusion Scan
- VO2 (pulmonary stress test)

**Cardiac Evaluation-to determine if your heart is healthy to undergo transplantation:**

- 12-lead EKG
- Echocardiogram

- Stress Testing
- Muga Scan
- Cardiac Catheterization

**Infectious Disease Evaluation to evaluate your immune system and exposure history:**

- TB skin test
- Candida control skin test
- Viral Antibody Panel and HIV testing
- Initiate Hepatitis A & B Vaccine series injections

**Additionally there will be gender specific tests:**

- Mammogram/Pelvic w/PAP
- Birth Control Counseling
- PSA (prostate specific antigen) for males over 50
- Dental Exam
- Routine Eye Exam

**Social/Psychological Evaluation:**

- Social Worker
- Psychologist

You must be evaluated by our multi-disciplinary team to be considered for a lung transplant. Prior to formal evaluation, your medical insurance coverage for transplant expenses will be verified. Many of your evaluation tests can be performed by an outside facility/primary care physician. However, there are certain tests that are sensitive/specific in nature that will need to be done at the transplant center. This will be discussed with you prior to initiating testing and after obtaining the necessary authorization from your insurance provider.

**Pre-transplant Testing:**

- Laboratory work: blood is tested to look at many different functions within your body such as liver, kidney, immune system, infection and blood type. You will also have skin testing for exposure to TB and candida. You will have your urine tested and stool tests for the presence of any blood.
- Males will need a PSA if over 55.
- Chest x-ray: this will tell your doctors if your lungs and respiratory tract are healthy and will determine the size of your heart.

- CT scan of your chest: is a special computerized test that provides a more detailed picture of your lung and the chest wall. This is to rule out any cancers, and to see the severity of lung disease.
- Quantitative Ventilation/Perfusion (V/Q) scan: this test will show how much air movement (ventilation) and blood flow (perfusion) goes to each lung. This is used to rule out pulmonary emboli and to see which lung gets the best blood flow and ventilation. This information helps in deciding which lung to transplant, in the case of single lung transplantation, and which lung to do first in the case of bilateral lung transplantation.
- Cardiovascular studies: a cardiac catheterization is done to assess the right ventricular size and function. These studies may include:
  - Electrocardiogram (EKG or ECG): this will reveal how well your heart is working and may reveal heart damage that was previously unsuspected. Right and/or Left heart catheterization is when a catheter is placed into your heart chambers and the pressures are measured as well as looking at your arteries for any signs of thickening.
  - MUGA scan: a small amount of tracer solution is injected into a vein. A special camera tracks the movement of the tracer solution to determine heart movement and pumping strength.
  - Pulmonary Function Test: you will be asked to breathe into a tube attached to a measuring device, which will reveal how well your lungs are working. A blood test will be taken to determine your blood's capacity to carry oxygen, ABG (arterial blood gas).
  - Pulmonary Stress Test (VO<sub>2</sub>): this test looks at heart and lung functions. You will be asked to walk on a treadmill, attached to a breathing monitor. This test determines if you have other limitations to exercise.
  - Six-minute walk test: You will simply walk for 6 minutes to see how far (in feet) you can go in 6 minutes. You will be able to use your oxygen and your oxygen level and heart rate will be monitored.
- Dental and Vision: You will also need to have your eyes tested for baseline and to detect for glaucoma and a dental exam for potential sources of infection (caries or gum disease).
- Gynecology/ Pap Smear: for female patients to rule out malignancies and a mammogram if over 45. Females of childbearing age will also receive birth control counseling.
- The social worker, dietitian, financial and psychological counselor as indicated will also evaluate you.

## **Activation and the Surgery:**

Once your records are obtained, you will be contacted by a transplant coordinator to set up the initial appointment, to meet the team, discuss transplantation, ask questions, and be provided information regarding TGH Lung Transplant Program.

## **Transplant Team Members**

### **Your Pharmacist:**

Medication will become a regular part of your life before and after your surgery so get to know your pharmacist. He or she can tell you everything you need to know about the drugs you will be taking, including immunosuppressive medications that will help prevent your body from rejecting your new lung. Don't hesitate to ask questions!

### **Pulmonologist:**

You will see this doctor during the clinic evaluation and follow-up. They will evaluate your clinical findings and continue to supervise your post-operative course.

### **Surgeon:**

Usually you will meet one of several surgeons qualified to perform lung transplantation. They will determine if there are any other problems or issues from the surgery standpoint that might adversely affect the outcome.

### **Infectious Disease Physician:**

Remaining infection free is an important element of your transplant. This physician will determine what antibiotics to give you before surgery and what antibiotics to give you if you should develop an infection.

### **Transplant Coordinator:**

A registered nurse will coordinate all events leading up to and following surgery (scheduling testing, working the Lifelink (organ procurement organization), contacting you when a donor lung is located and education before and after transplant regarding your care/medications/activity. A coordinator will also be available for any emergencies that cannot be handled by your primary care physician.

### **Nursing Staff:**

The staff taking care of you post-operatively has special training in caring for transplant patients.

They will also assist in helping you understand your medications, side effects, necessary monitoring of your blood levels and the physical rehab that will help to ensure a successful outcome.

### **Respiratory Therapist:**

The staff will make sure you are taking your inhaled medications correctly as well as assist in your rehab and monitoring your oxygenation. They will also instruct you while you are in the hospital on your home monitoring requirements.

### **Dietician:**

Following your doctor's orders, a registered dietician will assist in evaluating your caloric needs and developing a diet that will assist in the healing process, promote health and avoidance of unnecessary weight gain (or loss) before and after surgery. This diet will likely include limits on fluid intake initially, encourage low fat, cholesterol and sodium. Proper nutrition can speed recovery and help you stay healthy.

### **Social Worker:**

Will be available to assist you and your family/support system through this process. You will have been evaluated during your initial work-up phase to identify any potential issues. They will also assist with any issues such as medication, home equipment, lodging, etc.

### **Medical Review Board:**

Once the members of your transplant team have had a chance to meet you, your medical information will be presented to the Medical Review Board. The Medical Review Board consists of a transplant medical director, infectious disease doctor, pulmonologist, cardiac surgeon and cardiologist, infectious disease physician, transplant coordinator and a social worker. The Medical Review Board discusses your case and determines if your best medical option is a lung transplant. When the decision is made you will be notified.

### **Where You Fit In:**

Once again, YOU are the most important member of your Transplant team. To a certain extent, all the other team members will try to respond to your cues. Your physical, emotional and practical needs will help to determine your pre and post transplant treatment program.

### **Activation:**

You are matched to a donor based on your blood type, height and weight. Once you are placed on the lung transplant waiting list, you will be soon in the lung transplant clinic by your transplant pulmonologist every 4-6 weeks.

When you are listed for lung, you will be placed on the list as either:

**Active:** Ready and waiting for a lung

Inactive: you are not active due to a medical or other condition that would prevent you from having a transplant at the time. If you should become ill or your respiratory symptoms worsen and you need to be hospitalized at a hospital other than your transplant center, please ask your attending physician to call the Lung Transplant Office. This may also happen if you need to travel far from the transplant center for an emergency and would be unable to reach the hospital in time for a transplant.

Even though you are activated on the transplant list, you may be removed from the transplant list temporarily or permanently due to any of the following:

Your condition changes where you no longer meet criteria for transplantation. When a person's condition becomes so critical a transplant may not guarantee survival or quality of life. You are non-compliant with the instructions from your transplant physician or transplant team member. You have changes in your insurance as it relates to transplant coverage. It is your responsibility to review your transplant coverage with your insurance carrier. If your insurance carrier or level or transplant coverage has or will change, you must inform the transplant office immediately.

A "pre-authorization" from your insurance for your visits and transplant surgery must be current and accurate at all times. If the pre-authorization is not done because you have neglected to tell us important information, you will be responsible to pay "out of pocket" for charges not covered by insurance. This could be several thousands of dollars.

Immunosuppressive medications are very expensive (\$1000-\$2000) per month. Some insurance policies have an annual lifetime maximum coverage for these medications. If your insurance coverage will fall short, then we need to be notified in order to help you look for alternative ways for you to obtain your medications.

**You may be asked to participate in a transplant research study:**

Research studies have been conducted at this center that look at new medications, new equipment or new use of familiar medications. If you meet enrollment criteria for any of these studies, you may be asked to volunteer. You will receive a detailed explanation of the purpose of the study, benefits and risks to you.

If you are an acceptable medical candidate, you will be sent a pager or "beeper" and instructed to keep the beeper with you and turned on 24 hours a day.

**Getting Paged to Receive Your Lung:**

The pager is a "tone only" pager. You may get false alarms. If a lung is offered to you, the coordinator on call will phone your home. If you are not at home or do not answer, you will be "beeped" twice in five minutes.

**If this happens:** Dial: 1-800 505-7769 and ask the operator to page the Lung Transplant Coordinator on call.

When you get the call from the hospital that a donor lung has been located, you will need to be admitted to the hospital as soon as possible. The transplant coordinator will tell you where to go at that time.

**A few pager pointers:**

- Change batteries every three months.
- Check the pager weekly by paging yourself to ensure that the beeper works.
- Please keep the information about the company that sent you the pager. The pagers are provided free of charge and are shared with others waiting for a lung, so it must be sent back as soon as possible after your transplant surgery.
- If you need to travel somewhere your pager doesn't reach, please call the office and leave a number where you can be reached and approximate traveling time to Tampa General Hospital.

**Remember:** Do not eat or drink anything once you receive the call. Bring a list of all your medications and allergies with you.

This is a very exciting time for you, your family and all members of the lung transplant team. It is normal for you to feel anxious and nervous when you receive the call that a lung has been offered to you.

We recommend that in anticipation of a lung offer that you have the following prepared:

- Bag packed with personal items you will want to have while hospitalized. (slippers, shaver, eyeglasses, toothpaste and a new toothbrush)
- A designated driver who will drive you to Tampa General Hospital.
- A friend or family member that is designated as the “hospital contact person” who will be able to notify your friends and family that you are going to Tampa General Hospital for your transplant.

**Before Surgery:**

After you are admitted to the hospital, you will be asked to sign one or more consent forms giving your doctors permission to carry out the surgery and a complete history and physical examination will be conducted. The transplant team wants to make sure your state of health has not changed since your evaluation and that there are no contraindications to performing lung transplant surgery. This means various members of your transplant team will do a few more interviews. The questions may seem repetitive. Try to be patient. In addition, routine chest x-rays, ECG and blood tests will be performed. If any sign of active infection or a significant medical problem is detected, surgery will be cancelled.

If you are able, you will be asked to scrub your body from head to toe. You will be shaved in the area of the surgery. This is done to remove any germs and prevent infection. If you need help with this, your nurse will assist you.

Preparation for surgery involves placing intravenous (IV) lines. The IV lines will help prevent dehydration, monitor your blood pressure and deliver medication at appropriate times during your surgery.

**NOTE:** You will be asked to remove all jewelry, dentures, contact lenses or cosmetics (including nail polish and make-up) to minimize risk of contamination from germs during surgery.

### **The Operation:**

Single lung transplant is performed through either a posterolateral or anterior thoracotomy. The choice of which side to transplant was based on the studies performed during evaluation. The side with the least function is the one this is transplanted for obstructive or restrictive lung disease. In PPH, the side with the most function is transplanted.

Bilateral lung transplantation was initially described using the bilateral transverse thoracotomy approach (clam shell), however, with increasing experience, bilateral anterior thoracotomies, without sternotomy provide excellent exposure, and minimize the morbidity associated with transverse sternotomy. This is performed in a sequential fashion, with the side with the least function being transplanted first.

During the transplant surgery, patients may require cardiopulmonary by-pass to facilitate implantation of the lung(s) and prevent hemodynamic instability, hypoxemia, or hypercarbia.

Once you are prepared for surgery you will be transported on a stretcher to the operating room (OR). Your family may escort you to the doors of the OR. Your family will then be escorted to the Cardiac Surgical Unit (CSU) waiting room. You will find the OR is cool in temperature (ask for a blanket if you feel cold). There will be a lot of equipment, some of which will be used to monitor vital signs during surgery. There will be OR nurses and technicians checking your name bracelet, setting up instrument trays, and ensuring all details are attended to. The best thing you can do is try to relax and prepare for the anesthesiologist to put you to sleep.

Patients will receive immunosuppressive medication prior to and/or during surgery. These medications are designed to suppress, or slow down, your immune system so that it will not actively attempt to reject your new lung. Remember that slight rejection should be expected but rejection does not mean transplant failure. There will be a more detailed description of your immune system, the rejection process, and the medications used to prevent rejection, later in this manual.



### **Your Donor Lung:**

There will be extensive tests performed on your donor's lung to attempt to ensure you receive the best lung possible. Your donor's age is the only information we can share with you. Most lung transplant recipients are very grateful to their donor families and want to express their gratitude. If you choose, you may write a letter to your donor family and give it to your transplant coordinator to forward to the organ procurement agency. This can be done at anytime.

### **Family Waiting Room:**

For your family's convenience, we use the cardiac surgery waiting room which is on the third floor of the hospital. Immediate family member may wait here while surgery is being performed. Your primary surgeon will meet with your family in this waiting area after your surgery is completed.

NOTE: This is a nonsmoking lounge. IF someone must smoke, they must use smoking areas provided outside the hospital. Sleeping in the waiting rooms is not encouraged. If you need local lodging, please contact the Patient/Guest Relations representative or lung coordinator for information on hotels.

### **After Surgery:**

When you wake up from the anesthesia, you will be in the Cardiac Surgery Intensive Care Unit (CSICU). The nurses will be observing isolation technique (wearing masks, gloves, and gowns) to reduce the possibility of infection.

### **Your Immune System:**

White blood cells (WBCs) help make up our immune system. The job of the WBC is to protect us from foreign substances (infection, transplanted organs). When a new lung is transplanted, the immune system views it as a foreign substance and can cause your body to reject it. This is why you must take immunosuppressive drugs (the most common are Prograf, CellCept, and Prednisone). Your immune system has special intelligence or memory cells that will always recognize "foreign" substances; therefore, you will always require immunosuppressive drugs to prevent your body from rejecting your new lung.

The CSICU is a specialized environment where you are more closely monitored than you would be on a regular hospital floor. How long you remain in the CSICU depends on your rate of progress. Your recuperation will be followed carefully. There is a chance of complications but in this protected specialized area the risk of infection is reduced. Your transplant team will determine when it is time for you to be transferred from the CSICU. At certain points in your recovery, it may also be necessary for you to return to the CSICU for specialized monitoring to ensure your best recuperation.

When you first wake up, there will be a tube in your throat leading to your windpipe and lungs. This is called an endotracheal tube. It will be somewhat uncomfortable but it will help you breathe and get the right amount of oxygen. It will be connected to a breathing machine called a

ventilator. You may feel as if you are not getting enough air, but you are; try to relax and let the machine do the work. Your nurse will remind you of this. While you are connected to the ventilator, you will not be able to speak. To communicate with your nurse, you will be able to nod or shake your head yes or no. Again, this may be frustrating but it is a temporary situation until your lungs have expanded and are working well. This should only take a day or two, depending on how well your new lung(s) begin to work. You will also have a tube, which is placed through your nose into your stomach (nasogastric tube). This will keep your stomach from feeling distended. Remember that you will also be very drowsy during this time and will barely be aware of the tubes and lines.

### **PAIN CONTROL:**

Pain management is a priority for the transplant team so that you will be able to Turn, Cough and Deep Breathe and to do it effectively.

Immediately after your transplant, the anesthesiologist will place an epidural catheter (into your spinal area) that will provide your body with medication that will prevent you from having pain. This is like what is used for women during childbirth to prevent the pain during labor and delivery. While you may experience some discomfort, this medication can be adjusted to control your discomfort so that you will be able to cough and deep breathe to prevent mucus from being retained in the new lung(s). As you progress post-operatively, you will be changed over to intravenous and/or oral pain medication.

Other equipment and monitors you or your family may notice are special machines to continuously monitor your heart function, blood pressure, and oxygenation.

The monitor above your bed will continuously read your heart rate and rhythm, blood pressure, oxygen saturation, and the pressures within your heart via the Swan-Ganz catheter that was placed intraoperatively. By monitoring these readings along with your vital signs, weight, intake and output, your transplant team can determine how well your new lung(s) is functioning and your progress.

In the recovery period immediately following surgery, this very sensitive monitoring equipment may occasionally beep or sound an alarm. Try not to be anxious when these alarms sound. These are reminders for the nurses to check one of the machines.

You will have a foley catheter in place. This is a tube that will help you pass urine. It is placed while you are asleep, in surgery. This catheter may seem uncomfortable and make you feel like you need to urinate. If you notice that your bladder is feeling distended, please let your nurse know.

You will also have chest drainage tubes near the bottom of your chest incision that will drain off the fluid and blood that collect after surgery. All tubes and catheters will be removed as you get stronger - a few days to a week after surgery.

## **Coughing and Deep Breathing:**

Once you are awake and breathing on your own, your nurse will ask you to do deep-breathing exercises and to cough. This will further assist your new lung(s) to expand and remove secretions that collect following surgery. This may be uncomfortable, but it is very important. One of the most common complications that occur following lung transplantation is infection. Getting rid of the mucus and congestion on your lungs will help prevent germs from growing.

## **Bronchoscopy and Lung Biopsy:**

This is done to detect any signs of rejection and/or infection in the new lung(s). On the day of your biopsy, you will not have anything to eat or drink after midnight. Before your test begins, the doctor will explain the procedure and have you sign a consent form. You will be given medication to make you drowsy, then a local anesthetic is used to numb the back of your and throat.

A long flexible tube is inserted into your nose or mouth, down your throat and into your lungs. The tube may make you cough or gag a little when it is being passed, but you will be able to breathe easily. Remember: you will be given medication to make this procedure as comfortable as possible.

The tube allows the doctor to see into your lungs to check for infection and/or rejection and to inspect where your new lung/lungs were attached. During the bronchoscopy the doctor will also inject some saline to get “washings”, which are suctioned out and sent for studies. This is called a bronchoalveolar lavage. Also, the doctor will get microscopic samples of your lung tissue to check for rejection. This is called transbronchial lung biopsy.

After your bronchoscopy, you may be very sleepy. You will not be able to eat or drink for several hours until the sedation has worn off and your gag reflex has returned. Your nurse will assess this. When these are done after you have been discharged from the hospital, you will not be permitted to leave the hospital alone. You must have someone with you.

## **Visitors:**

Because of your need for rest and protection from infection, visiting hours are very limited while you are in CSICU. Visitors are limited to healthy, immediate family members and are allowed to visit just three times daily. Your family members may ask a transplant coordinator or call CSICI, 844-7402, for visiting hours.

When your family members visit you in the CSICU, they too will have to observe infection precautions. If they are coughing, sneezing, or feverish OR have been exposed to someone with chicken pox, rubella, measles, TB, they should NOT be visiting. Visitors should be dressed in clean (recently laundered) clothing. Upon entering the CSICU, they need to report to a member on the nursing staff before entering your room. This nurse will instruct them on proper hand washing and use of mask, gloves and gown.

You are at high risk for infection after surgery. Your family must take these precautions with every visitation while you are in the CSICU and on the transplant floor.

One family member must be designated as the ‘hospital contact person’. This person should be the only one to call the hospital for daily updates. This person can then distribute information to other family members. This greatly reduces the number of phone calls and allows the nurse to spend time with you.

**CSICU Telephone Extensions:**     3D1   844- 7402   Rooms D300-316  
  3D2   844- 7539   Rooms D318-334

Ask the nurse or coordinator which extension should be used.

### **Transplant Unit:**

When your doctors decide you are well enough, you will be transferred to the Transplant Floor (8A). This is a specialized unit on the 8th floor where all transplant recipients are cared for following transfer from CSICU.

You will be in a private room. One healthy family member will be allowed to stay with you overnight in the room if you wish. Visiting hours are typically 8:00a.m.-8:00p.m. Family members still need to wash hands each time they enter your room and to wear masks.

You will be required to wear a mask whenever you leave your hospital room. At this point, you may wish to wear regular clothes (loose fitting, such as a worm up suit) during the day. Personal hygiene is very important post transplant. As your condition permits, we expect you to bathe regularly and use good grooming habits. Frequent hand washing, strict oral hygiene (brush after each meal and snacks), etc., will help to prevent a condition called thrush, which is a white plaque in your oral cavity and can be quite uncomfortable.

### **Pulmonary Rehabilitation:**

As soon as you are alert and off the ventilator, a respiratory therapist or nurse whose specialty is pulmonary rehabilitation will begin working with you. The “step-wise” program begins with range of motion, dangle at the bedside and progresses as tolerated. This should not be as difficult since you will have been in rehab prior to transplant. However, since you have undergone a major surgery, you will be instructed in the specific exercises that will help you regain strength and speed your recovery.

Activity in addition to the pulmonary rehab is encouraged and expected. You will be expected to remain out of bed for extended periods of time and for all meals. If at any time you feel dizzy or short of breath, stop the activity and call for assistance.

### **Nutrition:**

Your nutritional status is very important during your recovery. While in the hospital, you will be on modified cholesterol (fat), low sodium (salt) diet. This diet should be continued at home. The dietitian will instruct you and your family on the elements of a healthy diet. If you have blood sugar (diabetes mellitus), you will receive instruction by a Diabetes Nurse Instructor.

## **Ready To Go Home:**

You should have informed all friends and relatives with colds/flu to send their regards via telephone only. And while hospitalized after surgery, your house should have been cleaned thoroughly. You should have already purchased a box of masks to have available to wear when exposed to crowds or within the hospital/doctor's office.

You should have completed a financial screening, which should enable you to plan financially for your expenses following transplant. Additionally, you should have already initiated any lifestyle changes necessary to meet these new financial demands. If you are less than 60 years of age and not formally retired prior to your illness (you are not working only because of your medical disability), then you should be planning for your return to work within 6-12 months after your discharge home. Patients who are no longer disabled will not be candidates for disability income one year after surgery.

As many of the problems you may encounter postoperatively are not transplant related (broken bones, dental work, vaccination, changes in vision, etc.). You should maintain contact with your primary care physician/internist to continue follow-up care. However, if there is any question as to treatment or medications, then a phone call to your transplant coordinator is justified. You should identify emergency contacts in your local area (911, fire department, etc.) It is recommended that your significant other/primary support system should complete a course in CPR.

## **Discharge:**

After lung transplantation, there are lifestyle changes. It will take a strong commitment on your part to keep you and your new lung(s) healthy. Remember that this is a lifetime commitment but it also offers you the opportunity to have an improved quality of life and certainly offers the hope for an extended life span.

You will be on immunosuppressant medications for the rest of your life to help prevent rejection. There will be frequent clinic visits including bronchoscopies, blood tests, and pulmonary evaluations to monitor for rejection.

Your discharge planning begins when you are accepted for lung transplantation. This includes making sure your insurance will cover the expenses after discharge including your medications and any equipment needed for monitoring your vital signs.

This will include a blood pressure cuff and a hand-held microspirometer (to measure your lung function) as well as a thermometer and accurate scales. Many transplant mail-order pharmacies will provide you with a blood pressure cuff, thermometer and pill box free of charge.

You will need to know where you will get your medications and provide this to your coordinator. This will include the pharmacy name, phone and fax number, and address. This information will need to be kept up to date to prevent and lapses in your medication delivery, especially the anti-rejection medications.

**Blood work:**

Before you go home, you will be given prescriptions for blood work. If you are having tests performed at another facility, other than TGH, make sure they are aware of the need to fax or phone the results to your transplant center. This number will be on the lab request slip.

It is very important to have blood work done on schedule. Initially, this will be weekly, preferably on Monday or Tuesday to avoid the week-ends, and then monthly. It is important that blood work is done before taking your morning dose on immunosuppressant medication.

Remember: It is extremely important for your health and well-being that your blood work is done exactly as ordered, because the immunosuppressant medications can cause damage if the level is too high. If it is too low, it can lead to rejection. The only way to monitor is through blood work.

**IMMUNE SYSTEM AND REJECTION:**

Your body's immune system works to help protect you from infection and disease. The white blood cells are part of the immune system to rid your body of bacteria, viruses and fungi. When you receive new lung(s), this is also identified as a foreign object that is potentially harmful. The body tries to rid your body of this organ through rejection. Everybody will experience rejection at some time. Some will have an episode while still in the hospital and others may experience a month, years or several years after transplant. This is expected. During a rejection episode you may feel bad or some may not even notice the difference. Usually the first bronchoscopy is done while you are still in the hospital, and then, every three months (on average) for the first few years. This is one way to monitor for signs of rejection and infection. The further out from transplant the longer the intervals will become.

Masks - You should always wear a mask when you go to any hospital. For at least 3-6 months post transplant you should wear a mask when inside public areas (churches or malls). You do not need to wear a mask when you are inside or outside your home (unless you are near a construction area). If someone in your household is sick, don't sleep in same room. You or the sick person should wear a mask until symptoms are gone. Wash your hands well and frequently.

**Immunosuppressive Medications:**

You will be taking immunosuppressive medications every day for the rest of your life. Once you are transferred out of the CSICU you will begin the process for discharge. The social worker will again verify your medication insurance coverage where you will get your medications. You will be expected to understand your medication prescription plan. If you have a mail order plan, it is very likely you may be discharged before they arrive and you will need a supply to get you to that point. These medications are not cheap. They can cost up to \$ 12-\$14 per pill depending on what is being prescribed. Again, REMEMBER, you will need to take these to prevent rejection and infection.

You will need to have monthly blood work done to monitor the level of immunosuppressant medication as well to evaluate for any symptoms of toxicity to your other organs from these medications. You will receive a phone call from our office telling what your level was and what if any adjustments need to be made to your medication dose, and when to have your next blood work done. If you do not hear from us within one week from the draw date, please call. Sometimes your lab forgets to send us the results and we may not find this out for several days. However, do not stop taking your medications at any time or change your dose unless cleared by the transplant team.

#### **Treating Rejection:**

If the bronchoscopy reveals a small amount of rejection, the dosage of your immunosuppressant medications may be adjusted and this will be done at home. If the tests show a significant amount of rejection, additional immunosuppressants will be used. Intravenous steroids can be given with home health or in an outpatient setting. However, some medications for rejection may require your being admitted for a few days.

#### **Prescriptions and Over the Counter Medications:**

It is also important that you do not take any other medications that have not been cleared by your transplant team, this includes over the counter medicines, and those prescribed by other doctors. Some prescription medications can change the level of immunosuppressants in your blood or significantly change your white blood cell count.

DO NOT take ibuprofen products such as Advil, Nuprin, Motrin, or Aleve. If you have high blood pressure, check with your post-transplant coordinator before taking Sudafed or Actifed.

#### **Symptoms of Infection:**

If you notice any of these symptoms contact your transplant coordinator.

Cough- if you develop a persistent or productive cough, especially with green or rust colored mucus or a drop of more than 10% in your spirometry readings.

**Spirometry** - this will be a hand-held microspirometer that you will use daily that will measure your lung volumes, which you will keep in your logbook. You will be trained in how to use it right after your transplant and given specific instructions on when to call your transplant coordinator for changes in the readings. You need to contact your insurance provider to see if this will be covered by your DME (Durable Medical Equipment). This device costs between \$300-700.00.

**Temperature** - take your temperature if you do not feel well, when you feel warm, and before you take aspirin or Tylenol. If your temperature is 102 degrees or higher, call your transplant coordinator.

**Cold or flu-like symptoms** - if you develop nausea, vomiting, diarrhea, fatigue or generalized weakness or loss of appetite, call your transplant coordinator.

**Inflamed cut or wound** - if you notice redness, swelling, drainage or a foul odor from a wound, contact your transplant coordinator.

**Shortness of breath** - if you have shortness of breath during activity such as climbing steps or exercising, this is normal. Shortness of breath at rest is not normal, contact your transplant coordinator.

## GOING HOME

You will be expected to keep a daily log of the following:

- Blood pressure
- Heart Rate
- Weight
- Spirometry

Many use a large calendar to record this information, others just use a notebook pad, and some use a diary. Use what works best for you, but you must use something to keep this record!

Daily weights are necessary because you are likely to gain fluid, you will be on a low salt diet, and you may be on a water pill (such as lasix). Weigh first thing in morning, after urinating/bowel movement and before breakfast.

**Changes in blood pressure** - take your blood pressure daily and keep it in your logbook. Once your readings have become stable, you may only need to take it 2-3 times per week unless you are on blood pressure medications. If your blood pressure is unusually low (less than 100/60, wait at least 5 minutes and recheck. If it remains low, contact your transplant coordinator. A low blood pressure over several readings may be a sign of rejection. We expect your blood pressure to be somewhat high, however, if your blood pressure remains high after resting and retaking (greater than 150/100), you will need to contact your transplant coordinator. Check with you insurance if they cover a digital blood pressure cuff. If not you will need to purchase this prior to going home in order to learn to use it.

**Incision Care** - your incision will be “open to air”, no dressing, however, you may still have some staples depending on your recovery and length of stay. You will be given instructions on caring for this incision before you leave the hospital. Generally, you can shower using a mild non-perfumed soap. Use a clean wash cloth and gently cleanse the area. This is all that is generally needed. This is also the time to inspect the incision for any redness, swelling, painful areas or drainage and notify your transplant coordinator.

It is normal to experience some itching, numbness or soreness. However, it is a good idea to have someone assist the first few times you take your shower, since the warmth of the shower and water may cause you to feel dizzy or weak. It is best to try to avoid a hot bathroom and hot water.



**Nutrition** - proper nutrition will help speed healing, recovery, prevent unnecessary weight gain and help lower cholesterol. Fruits and vegetables are encouraged but must be washed. Use the vegetable cleaners on the market or fill sink with water, add 2-3 drops of liquid dish detergent, wash then rinse thoroughly.

You may eat in restaurants but try to avoid going at peak dining hours to avoid crowds. Avoid buffet style served food and salad bars.

Do not eat any raw meat. This includes: sushi, steak tartar and raw oysters.

**Physical Activity** - for the first 2 to 3 months after discharge, avoid any heavy lifting or strenuous arm activities. For example: carry no more than one full grocery bag or about 2 ½ pound weights in each hand. No raking leaves, digging with a shovel. Once your incision has healed, you may swim in a pool or ocean. Swimming in standing water like a lake is not recommended (increased risk for infection). A Jacuzzi less than 99 degrees is fine to use.

Check with your doctors before you return to work or school or prior to beginning an exercise program outside your pulmonary rehab program. You will be expected to begin and maintain your prescribed outpatient pulmonary rehab program. You may get tired and short of breath, but this does not mean you are returning to the level before your transplant. This means that you have become deconditioned and your muscles are out of shape. But, with regular exercise you should notice a gradual increase in your ability to exercise without feeling short of breath or fatigued.

Regular exercise help you control your weight, improve and maintain muscle tone and circulation, increase your self-confidence and independence and well as promoting relaxation after exercise.

Do not try to exercise until at least one hour after meals.

## **Travel**

Dress comfortably in loose fitting clothes. When travelling in a car, plan to stop once an hour, get out and stretch your legs. Be sure to move your legs often while seated, to relax your muscles and help prevent leg swelling.

Do not drive a car until you have returned for your first checkup and the doctor has cleared you. Wearing a seatbelt is allowed/required. Once cleared, you may want to practice driving first in an empty parking lot since your muscles, especially in your neck, may be tight and limit your turning ability.

## **Other Do's and Don'ts**

Do not change filters in air conditioners or furnaces. The dust in the filter may contain molds and fungi. It is recommended that these filters be changed according to recommended guidelines.

## **Pets**

There is no restriction on having pets. You are not permitted to change cat box litter or birdcage liners. These may expose you to toxoplasmosis.

## **Sexual Relations**

You may resume sexual relations when you feel comfortable. You may need to adjust positions initially due to the surgical incision. Also, you may feel more energy in the morning after a good night's sleep or after a nap. This will not harm your new lung(s).

## **Smoking**

Smoking is a major risk factor in lung and heart disease. It causes your blood vessels to constrict your heart to beat faster and harder to pump blood through constricted vessels and cause your blood pressure to elevate.

Smoking damages lung tissue, leads to coughing and breathing problems. It causes mucus to collect and build up, and when you are unable to clear your lungs of this extra mucus, lung infections can develop especially when you are taking immunosuppressive medications. This includes second hand smoke.

## **Clinic Visits**

You will be asked to return to the Lung Transplant Clinic at TGH short stay center 2-H for clinic visits. During this visit you may have a chest X-ray and pulmonary function tests (PFT). Your transplant coordinator and pulmonologist will see you. You may also be scheduled for a bronchoscopy.

## **Medic Alert Identification**

You should order and wear a bracelet or pendant. This identifies you and as lung transplant recipient and could be lifesaving in an emergency. You can get a brochure at any drugstore.

## **Primary Physicians**

Before you are discharged, we will need the name, address, and phone numbers of your physicians that you follow at home. We will work with them to keep them up to date on our progress and care at TGH and ask that you have them keep us updated on any visits you have with them. It is expected that over time they will resume your primary care and we will see you only for transplant related issues. And, we will always be available for consultation should there be any questions related to your plan of care by your primary physicians.

## **Emotional Issues**

Having a lung transplant is a stressful event both physically and emotionally. You and your family may find themselves overwhelmed by the adjustments that need to be made. It may seem a bit overwhelming at the time of discharge, but hopefully, we will have provided you enough instruction and education that this will become part of your everyday routine. Before surgery, you were sick for a long time. You think that after transplant you would be cured and feel better quickly. Please try to be patient with your recovery process. Your weakness is the result of deconditioning.

Recovery takes from 2 to 6 months after surgery. During this time you will be getting used to your medication schedule, increasing your exercise program, eating healthy meals and snacks. But, you will also be able to do many things you were not able to do before getting your new lung(s).

Your family and friends may find this time of adjustment difficult. They may ask you why you are not glad just to be alive. You may still think of yourself as being sick and expect them to care for you but we expect you to become independent and will expect your family to encourage you to do things for yourself. You may find yourself in disagreement over what you expect and what they are expected to do for you. This may lead to arguments. If you can all sit down and have an open and honest discussion, doing so may ease the strain during this period.

If you wonder that you may take on the personality or trait of your donated lung(s) person, that does not happen. It is only an organ of tissue. Many transplant recipients report these kinds of difficulties, that even though they thought they were prepared, they still felt somewhat overwhelmed. But most report feeling back to themselves by their first anniversary. Many say talking with other transplant recipients is helpful and this can be arranged through support groups and national organizations.

## **Follow-up Schedule:**

### **After discharge home, you are monitored for:**

- Rejection
- Infection
- Lung function
- Hypertension (high blood pressure)
- Problems related to steroids
- Morbid obesity
- High blood sugars/ diabetes
- Osteoporosis
- Malignancy (cancer)
- Coronary artery disease

You are given scheduled appointments to attend the Lung Transplant Outpatient Clinic. The primary goal of the clinic visit is:

- Patient/ support system education
- Surveillance for episodes of rejection
- Surveillance for infectious complications
- Medication adjustments
- Monitoring organ systems (blood work)

**Clinic visits for Bronchoscopy within the first year are usually scheduled as follows:**

Bronchoscopy at weeks 3, 5, 8, 12 then months 6, 9, 12 if stable

Should you have rejection or an inconclusive bronchoscopy, we may need to schedule additional biopsy dates. There may also be occasions that you will be scheduled for a clinic visit without a planned biopsy. This could be in follow-up to a rejection treatment, to evaluate a resolving infection, or to assess a new problem.

**What does Rejection Feel Like?**

Rejection can happen at any time. It usually happens when your immunosuppressive drugs are decreased or your weight changes.

**Things you might feel with rejection are:**

- Fever (100.0 degrees or higher)
- Blood pressure less than 90/60
- Decrease in FEV1/FVC (more than 10%)
- Being tired or nervous or a vague feeling of fatigue
- Not able to exercise as much as previously, increased shortness of breath

**Signs of Lung failure:**

- Shortness of breath
- Swollen ankles
- Foamy cough
- Bluish color nails and lips
- Weight gain of 3 pounds in one day
- Dizzy, lightheaded
- Feeling “ill” or any change in the way you feel

The sooner you report any of these symptoms the easier it will be to take care of them.

If you feel any of these symptoms, call your transplant coordinator immediately.  
If your symptoms are such that you need immediate assistance, then you need to call 911.

## **Your Medication**

As stated earlier, transplant recipients will take immunosuppressive medications for as long as they have a transplanted organ. This is an “absolute” must to help prevent rejection. Many recipients will be taking additional medications after their transplant.

A person who does not take their medicine as prescribed is “noncompliant”. Noncompliance is the third major cause of transplant failure. This is why it is so important for you to take your medicine exactly as prescribed by your doctor and to continue visits with your physician. It is your most important job after your transplant. Your team trusts you to do it correctly.

A medication chart has been included at the end of this section so that you can keep a record of your daily medication intake. Bring this sheet with you to all your clinic appointments. This is your responsibility. We also have space for your transplant team to use in order to provide you with specific instructions on how and when to take your medications.

You may use another form (such as a calendar or diary or notebook) to keep this information and instruction. **Remember:** *You are expected to follow these instructions exactly.*

Never skip a dose or change the amount of drug unless specifically instructed to do so by your physician or Transplant coordinator. Should you forget to take your medication, or if you happen to vomit a dose or have diarrhea more than twice a day, contact your Transplant coordinator for advice. Do not make a decision to change, repeat, or skip a dose on your own.

## **Pharmacy:**

Prior to discharge from the hospital, you will need to decide which pharmacy will be dispensing your medications. If you are using a neighborhood pharmacy, it is important that you or a family member call that pharmacy to determine if they have Prograf and CellCept in stock. They are very expensive, so many pharmacies do not have ready stock. Most can order and receive the drug in a few days. Planning ahead is crucial. Some of our patients use mail order pharmacies. You may ask the transplant social worker or coordinator for more details.

It is important that you wear a “Medic Alert” bracelet concerning your transplantation. It is very important that your bracelet state that you have had a lung transplant, the date of transplant, any allergies and if you have other medical problems such as diabetes. This will enable any physician who sees you in an emergency to know your special needs. To obtain this bracelet, call toll free 800 344 3226 or write to Medic Alert, Turlock, Ca. 95381.

## **DO's and DON'Ts concerning your medications:**

### **DO:**

- Learn the names of your drugs and why you take each medication
- Take all medication as directed
- Keep all medication in original container with labeling that show name, dosage and expiration date
- Report all side effects (nausea, vomiting, diarrhea) to your Transplant Team
- Keep medications out of the reach of children
- 

### **DON'T:**

- If you miss a dose, **DO NOT** double the next dose. Take the next dose as directed, and notify the Transplant Team about the omission.
- **DO NOT** take any other medication without checking with the Transplant Team, including medications that may be prescribed by a doctor other than your transplant physician. This applies to over-the-counter remedies such as cough/cold preparations, aspirin, asthma products, etc.
- **DO NOT** keep medications in the bathroom cabinet where they can be exposed to moisture.

If you experience drug side effects, they will be most noticeable during the first year after your transplant, when drug dosages are highest. Many of these side effects are temporary and should diminish with time.

Refer to Appendix A for a list of the most commonly used medications/ side effects.

If your blood work (including Prograf) levels are run at Smith/Kline, you must have your blood drawn at least one week before your appointment. Prograf levels must be processed at Tampa General Hospital, or a laboratory near you that processes Prograf Prograf levels using the same procedure as Tampa General Hospital (Smith/Kline Laboratories may be utilized). You may have your blood drawn elsewhere but a 5 cc purple top tube must be overnight expressed to:

***Tampa General Hospital  
Transplant Services, Room E-406  
Davis Islands  
Tampa, Florida 33606***

Please be advised that postal regulations require proper packaging for mailing specimens. Your post office can provide you with containers. The cost of mailing your blood is your expense; your insurance does not cover this.

Remember: if you need Prograf level drawn, do not take your Prograf on the morning your blood is being drawn. Once your blood is drawn, you may take your Prograf.

Copies of your lab work drawn at Tampa General Hospital can be requested through Medical Records, (813- 844-7525 or by asking the coordinator for a copy at your next clinic visit.

## **Contacting the Coordinator**

### **Patient Phone calls:**

The transplant office receives over 70 patient calls a day. The clinical coordinators are responsible for patient medical issues. The coordinators are in the hospital Monday-Friday 8:00am-4:00pm. After hours a coordinator is available on pager for EMERGENCIES via the hospital operator. If you have a true medical emergency that needs immediate attention, you must call 911.

### **Medical Problems:**

**EMERGENCY:** Call 911 if what you are experiencing is a true EMERGENCY. Your family can call the Transplant Office after calling 911. Please have the ER physician call us with a report or if they have any questions regarding your transplant/medications.

### **Urgent Problems:**

You must speak to the secretary to give her the initial information and she will then contact the appropriate coordinator. After hours, the coordinator on call will be responsible for addressing your concerns. Please do not leave a voice mail if this is an urgent matter. You need to leave the message with the secretary or hospital operator to contact the on-call coordinator.

Please have the following information available when you call:

- Patient name and phone number
- Reason for your call, including symptoms, weight, blood pressure, temperature, spirometry readings and any concerns.

### **Non Urgent Problems:**

If you have a problem to discuss with a coordinator or you have follow-up information that has been requested, you can leave a voice mail message with the nature of the phone call and times you will be available for the coordinator to return your call. We will make every attempt to return these calls the same day.

### **Medication Renewals:**

Use the pharmacy phone mail line. Call several days before your prescription runs out. If a written prescription is needed, call 10 days ahead.

**To speak with a physician or coordinator after office hours for urgent matters:**

- Call (813) 844 7137 or 1-800-505-7769.
- Hold the line and you will be connected to the hospital operator
- Ask for the transplant coordinator on call
- Hospital operator will take your name and phone number, then you can hang up
- Operator will then page the coordinator, who will phone into the hospital from home to answer your call

When the coordinator calls you back, they will need to know your concerns, specific details regarding all vital signs (temperature, blood pressure, pulse) and weight. Be prepared to discuss any recent episodes of rejection or infection, the treatment given, how long ago, and the time of onset of this new set of symptoms necessitating the emergency (that is why it is important to keep a logbook of your daily activities). If you do not receive a return phone call within 15 minutes, please call the operator again.

Please remember, Transplant Coordinators do not staff the hospital 24 hours a day. Calls after office hours, on week-ends and holidays are covered by an on-call coordinator, who is not at the hospital and is available for EMERGENGIES ONLY.

If you are unable to reach the coordinator through the Transplant Office number, then call (813) 844-7000, which is the direct Tampa General Hospital operator line.

**Transplant Office Staff:**

***Karen Bush, Data Coordinator***

The data coordinator is available to help you with insurance issues. If you have HMO/PPO insurance and if you require a referral/precertification to be seen at Tampa General Hospital (please obtain the referral/precert). A referral or precert number is required for any exam, biopsy, stress test, or any other testing you require. This is the claim was submitted to the wrong insurance company. They are also involved with evaluating patient status and pagers.

***Judy Dery, Secretary, 8:00a,-4:30pm***

Judy is the person you will speak to when calling the office. She is the contact person for changes in your address and/or phone number. If you are changing your primary care physician/cardiologist, then please call this information in to her. She will assure that your clinic visit information is sent to the appropriate physician.

***Laura White, Social Worker, 8:00am-4:30pm***

Laura is the social worker for Transplant Services. She is the contact person for drug assistance programs. She is the resource for COBRA, Medicare, and the Medically Needy Program. Please call if you anticipate losing insurance coverage, so she can assist you in maintaining



medical coverage. She can also assist patients with the Vocational Rehabilitation process. She will assist with billing issues that involve the lab or radiology. All other billing issues should go through the Tampa General Hospital Billing Department.

## **Clinic Day**

### **In preparation for your clinic visits:**

- Bring a correct updated list of your medications, bring your logbook with your documented daily weight, temperature, blood pressure, spirometry readings (FEV1/FVC).
- ***DO NOT eat your breakfast*** until after your labs are drawn in clinic.
- Do not take your immunosuppressant prior to clinic. After your blood is drawn you can take your medicine.
- Bring all your medications that you will need to be taking that day ( we don't have them in the clinic.
- If you are a diabetic, do not take your morning insulin injection or pills until instructed to do so by the clinic staff when breakfast has been ordered for you. You may then take the diabetic medications as prescribed.
- If you are taking a blood thinner medication such as coumadin or heparin, you will be instructed what to do if we are doing any testing (bronchoscopy).
- Obtain precertification from the insurance company
- If you are scheduled for a bronchoscopy, you will be given specific instructions (nothing to eat after midnight, etc.)

The transplant clinic is located on the second floor (2-H, short stay center) at Tampa General Hospital in the East Pavilion. After registering at the admissions office in the main lobby, go will be directed to the elevators next to McDonald's to the second floor.

The clinic is held routinely Monday-Friday. A coordinator makes the appropriate arrangements for each patient by pre-scheduling all the diagnostic tests. A physical exam, laboratory studies (CMP, CBC, Immunosuppressant level), chest x-ray and bronchoscopy are the routine diagnostic studies performed.

Please anticipate a 2-4 hour stay for a routine visit and 6-8 hour stay for a bronchoscopy. Make all your transportation arrangements accordingly. But, also be prepared to stay longer or be admitted should we discover a problem requiring further evaluation.

The infectious disease, cardiology, and surgical physicians on the team make themselves available for consultations within the Transplant Clinic setting. However, other specialty physicians (such as gastroenterologists, nephrologists, dermatologists, urologists, orthopedics, gynecologists, and oncologists - hematologists) are not available on short notice. Should you be referred to be seen by any of these physicians, you are responsible for making your own appointment as soon as possible. The Transplant Office will be glad to provide this specialist with a synopsis of your clinical history and current status. Please inform the Transplant Office as to the date and time of your appointment, and where to send the clinical synopsis. You may choose to be seen in the Tampa area, in which case the coordinator can supply you with

physician's names and phone numbers. If you choose to be seen by a specialist in your local area, we advise you to contact your local primary physician for a referral.

### **Biopsy Results:**

The team receives your biopsy results after 3p.m. the day following your bronchoscopy. Results are reported to you after that time.

If your biopsy is showing rejection, you will be contacted by a coordinator with instructions. Rejection may or may not require admission to the hospital. Please do not call our office before that time, unless there is a problem. Again, you will be contacted by a coordinator if you are having rejection and require treatment, or if there are changes being made in your medications.

### **Laboratory results:**

When lab work is ordered for you, you may need to have your blood drawn and processed through your local doctor. Have the results faxed to TGH Transplant Services at 813-844-4016 at least two days prior to your appointment. If you have HMO/PPO insurance, please ask your HMO/PPO physician where your lab work must be done. Blood specimens sent to TGH should only be drawn Monday, Tuesday, or Wednesday.

### **Immunosuppressive Medications & Their Side Effects:**

#### *Neoral (Cyclosporine)*

Neoral is a potent immunosuppressive drug used to prevent transplant rejection. Because of this drug, transplantation is now a therapeutic option for an increasing number of patients. In general, Neoral has given transplant recipients a new "lease on life" free from the restrictions of chronic, disabling disease and the serious side effects of high doses of Prednisone. The doses of Neoral are adjusted according to your weight, kidney function, and the amount of the drug measured in your blood stream.

As with any medication, you may experience some side effects while taking Neoral. Side effects are more common initially, when your dose is higher, and they usually subside as your dose is reduced over time. If you notice any side effects, do not be alarmed; simply report them to your physician but do not stop taking your Neoral without your transplant physician's consent. Your blood will be tested frequently to monitor Neoral levels in order to minimize the risk of liver and kidney dysfunction.

#### **The most common side effects of Neoral are:**

- Signs of kidney dysfunction such as a decrease in urine output, fever, or swollen hands and feet.
- Tremor (a slight shaking of the hands).
- Growth of excessive body hair (thicker hairs).
- High blood pressure
- Swollen or bleeding gums

- Headache

A small number of patients experience one or more of the following effects as well - - stomach discomfort (cramps, nausea, and/or vomiting), diarrhea, acne, flushing, convulsions, decreased white blood count, breast enlargement in males, sinusitis, and a burning or tingling sensation on the skin, especially on the fingers and toes.

### ***Prograf (FK 506, Tacrolimus)***

FK 506 is an immunosuppressant medication that is used instead of Neoral to prevent transplant rejection. FK 506 is similar to Neoral in that it is adjusted according to your weight, kidney function, and the amount of the drug measured in your blood stream.

The most common side effects of FK 506 are:

- Signs of kidney dysfunction such as a decrease in urine output, fever, or swollen hands and feet.
- High blood pressure
- Diabetes
- Headache
- Tremor (a slight shaking of the hands).

### ***PREDNISONE/MEDROL***

Prednisone is a corticosteroid, or steroid hormone, similar to one your body produces naturally. It is given with other medications to prevent rejection.

After transplant surgery, your Prednisone dose will be quickly reduced to approximately 20 mg daily. Then over the following months, the dose will be slowly decreased. The goal, when possible, is to be able to stop Prednisone therapy while keeping you free of rejection. During periods of rejection, the dosage may be increased for a few days and then gradually lowered. If rejection is severe, Prednisone may be given intravenously.

A usual maintenance dose is 5 to 10 mg twice a day. Prednisone is usually supplied as 5 mg, 10 mg, or 20 mg tablets that can be broken in half if necessary.

### **SIDE EFFECTS**

The side effects of Prednisone are also related to the dose of the drug and may subside or decrease as your dosage is reduced. Again, you may or may not develop any or all of these side effects, but you should be aware that they can occur. Report any of these side effects to your physician:

- Swelling of the face, hands, or ankles. This will be noticeable by puffy cheeks or a “full” face. At first you may be alarmed at the difference in your appearance. This too will resolve as your dose is lowered.

- Stomach irritation that could lead to bleeding ulcers. You may be advised to take an antacid between meals and to take your dose with a meal, rather than on an empty stomach.
- Weight gain due to an increase in appetite or fluid retention.
- Heightened risk of infection due to suppression of the immune system. This risk is greatest in the early months after your transplant, when your dose is relatively high.
- Diabetes known as “steroid-induced diabetes” may occur with high doses of Prednisone. If you have diabetes to begin with, your insulin requirements will be increased.
- Skin changes including slower healing, more delicate skin, rash or acne on the face, chest and back, increased hair growth, easy bruising, and stretch marks. In addition, your skin will be more sensitive to the sun. Use a strong (SPF 15) sunscreen.
- Muscle Weakness
- Osteoporosis a weakening of the bone which can lead to compression fractures of the vertebral column.
- Fluid imbalance including potassium loss. You may need to take oral potassium supplements.
- Mood swings that may make you feel fine one minute and blue the next.
- Cataracts an eye condition that decreases clarity of vision. To help decrease your risk, regular visits to your eye doctor (ophthalmologist) are recommended.

**Note:** Because long-term use of Prednisone affects the functioning of your adrenal glands (which produce adrenaline) NEVER discontinue this medication abruptly. The Prednisone dosage must be gradually tapered over time. Also, because of the effect on the adrenal glands, you may need more Prednisone during stress. Your transplant physician will advise you about any dosage adjustments.

### ***CELL-CEPT (Mycophenolate Mofetil)***

This drug is an immunosuppressive drug. It comes in 250 mg and 500 mg capsules, and stops the inflammatory response that is a part of rejection. This drug is used in combination with Neoral and Prednisone. Take Cell-Cept as directed by your physician one hour before or two hours after a meal.

The side effects of Cell-Cept include increased risk of infection and diarrhea and stomach upset.

### ***IMURAN (Azathioprine)***

This drug is also an immunosuppressant. It comes in 50 mg tablets, which may be broken for smaller doses. Some transplant centers prescribe this drug along with Neoral and Prednisone. As with all medications, take Imuran as directed by your physician.

The side effects of Imuran include an increased risk of infection, nausea and vomiting, mild hair loss, decreased white blood cell count, as well as other blood abnormalities. There is also a possibility of liver dysfunction. Report any signs of jaundice (yellowing of the skin) to your transplant physician.

### ***MONOCLONAL ANTIBODY (Orthoclone okt3)***

This is a medication given intravenously for the treatment of severe rejection. It is used alone or with other medications. The medication is given over 10-14 days. The most common potential side effect of OKT 3 is a fever that occurs approximately 30-60 minutes after the drug is given.

Some other common medications you may be taking after your transplant.

### **Antihypertensives (Norvasc, Procardia, Capoten, Cardizem)**

**Purpose:** To lower blood pressure – remember, a common side effect of Neoral is high blood pressure.

**Possible Side Effects:** Range from edema (ankle swelling), nausea, fatigue, headache, cough, or dizziness.

### ***LASIX (furosemide)***

**Purpose:** To eliminate excess fluid from the body.

**Possible Side Effects:** Weakness, dizziness, nausea or muscle cramps.

### ***PEPCID (famotidine)***

**Purpose:** Used to prevent or treat stomach and duodenal ulcers which may be caused by Prednisone. This drug is usually discontinued when prednisone is discontinued.

**Possible Side Effects:** Dizziness, headache, diarrhea, or constipation.

### **ACYCLOVIR (Zovirax)**

**Purpose:** To prevent or treat infections caused by the herpes simplex virus.

**Possible Side Effects:** Nausea, vomiting, headaches, or fatigue.

Generally this drug will be discontinued six months after your transplant when your immune system is better able to fight infections.

### ***SEPTRA***

**Purpose:** To prevent a certain kind of pneumonia (pneumocystis) that can attack people who are immunosuppressed.

**Possible Side Effects:** Nausea, vomiting, or depression.

Generally this drug will be discontinued six months after your transplant when your immune system is better able to prevent pneumocystis pneumonia.

### ***ECOTRIN (enteric coated aspirin)***

**Purpose:** To help prevent clogging of blood vessels.

**Possible Side Effects:** Upset stomach or prolonged bleeding time.

### ***MYCELEX TROCHE***

**Purpose:** Used to treat or prevent mouth sores – must remain in mouth until dissolved – should not be chewed or swallowed whole.

Generally discontinued six months after your transplant.

### **CLINIC DAY**

The outpatient clinic is located at Tampa General Hospital on the second floor of the East Pavilion. After registering at the Admissions Office in the main lobby, take the elevators next to McDonald's to the second floor and turn left.

The clinic is held routinely on Mondays. A coordinator makes the appropriate arrangements for each patient by pre-scheduling all the diagnostic tests. A physical exam, laboratory studies (CMP, CBC with differential, and Tacrolimus level), chest x-ray, and lung biopsy are the routine diagnostic studies performed.

Please anticipate a 4-6 hour stay in the clinic with each visit. Make all your transportation arrangements (airplane flights, rides with friends or family, etc.) accordingly. But, also be prepared to stay longer or be admitted should we discover a problem requiring further evaluation.

The Infectious Disease, Cardiology, and Surgical physicians on the team make themselves available for consultations within the Transplant Clinic setting. However, other specialty physicians, (such as gastroenterologists, nephrologists, dermatologists, urologists, orthopedics,

gynecologists, oncologists, etc) are not available on short notice. Therefore, should you be referred to be seen by any of these previously mentioned physicians, you are responsible for making your own appointment as soon as possible. The Transplant Office will be glad to provide this specialist with a synopsis of your clinical history and current status. Please inform the Transplant Office as to the date and time of your appointment and where to send the clinical synopsis. You may choose to be seen in the Tampa area, in which case the coordinators can supply you with physician names and phone numbers. If you choose to be seen by a specialist in your local area, we advise you to contact your local primary physician for a referral.

## **BIOPSY RESULTS**

The team receives your biopsy results after 3 pm on Tuesday. Results are made available to you after 3 pm on Tuesday.

Normal biopsy reports are mailed to you. If your biopsy is showing rejection, you will be contacted by a coordinator with instructions. Rejection may or may not require hospital admission.

Please do not call our office before 3 pm on Tuesday for a report, as it will NOT be available. Again, you will only be called by a coordinator if you are having rejection and require treatment or if there are changes being made in your medications.

## **LABORATORY RESULTS/SPECIAL TESTING**

When lab work is ordered for you, you may need to have your blood drawn and processed through your local doctor. Have the results faxed to Tampa General Hospital Transplant Services at (813)844-4016 at least two (2) days prior to your appointment. If you have HMO/PPO insurance, please ask your HMO/PPO physician where your lab work must be done. Blood specimens sent to Tampa General should only be drawn on Monday, Tuesday, or Wednesday.

## Appendix

### ***Acyclovir: Zovirax (brand name)***

**COMMON USES:** Acyclovir is an antiviral drug that is often used after transplantation to prevent CMV (cytomegalovirus); or prevent or treat a herpes infection (cold sores or genital herpes); varicella zoster (shingles); and Epstein-Barr (mononucleosis). This medication cannot give total protection against these viruses, so should you have any symptoms of these viruses, let your transplant coordinator know immediately.

**HOW TO USE THIS MEDICATION:** Dosages can range from 200 to 3200 mg/day, but may be altered in individual cases. (The capsules come in 200 mg, 400 mg, and 800 mg strengths). Drink at least two quarts of liquid daily. To clear up your infection completely, continue taking this medicine for the full course of treatment even if you feel better in a few days. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do **NOT** take two doses at once.

**POSSIBLE SIDE EFFECTS:** Most Common: dizziness, headaches; diarrhea, and nausea/vomiting. Less common: loss of appetite; and rash. Other: tiredness, joint pain; tenderness/swelling or bleeding of the gums.

**CALL YOUR DOCTOR IF YOU EXPERIENCE** Joint pain; persistent or severe headache; dizziness; nausea; vomiting or diarrhea.

### **WARNING:**

**General Warning:** This medication will **NOT** keep you from spreading herpes to others. Therefore, it is best to avoid any sexual activity if either you or your partner has symptoms of herpes.

**Pregnancy/Breast-feeding:** While there is no information to indicate that acyclovir affects a developing fetus, you should avoid pregnancy.

\*Since acyclovir is excreted in human milk, nursing should be avoided.

### ***ITRACONAZOLE: Sporanox (brand name).***

**COMMON USES:** Itraconazole is an anti-fungal agent. It is given to help prevent various fungal infections such as aspergillus and histoplasmosis.

**HOW TO USE THIS MEDICATION:** It comes in capsules of 100 mg. It is recommended that it be taken with food. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once. To clear up the infection completely, continue taking this medicine for the full course of treatment even if you feel better. Since fungal



infections clear slowly, you may have to take this medicine every day for several weeks or months. If you stop taking this medicine too soon, your symptoms may return.

**POSSIBLE SIDE EFFECTS:** Most Common: nausea; vomiting, mild skin rash or swelling. Less Common: loss of appetite, fatigue, headache; yellow discoloration of skin; and dark urine.

**CALL YOUR DOCTOR IF YOU EXPERIENCE UNUSUAL FATIGUE;** yellowing of the skin or eyes; nausea or vomiting; loss of appetite; or dark urine or pale stools.

**WARNING:**

**Drug Interactions:** Itraconazole may increase blood levels of cyclosporine, therefore, it is important to make sure that your cyclosporine levels are monitored while taking this medication.

\*Sporanox is contraindicated with the antihistamine, Seldane (terfenadine), and Hismanol (astemizole); sedatives, or anti-anxiety drugs, triazolam (Halcion), and midazolam (Versed); and the gastrointestinal agent cisapride (Propulsid).

\*Antacids can reduce the amount of itraconazole in your blood, possibly interfering with its effectiveness. Do NOT take this medication with antacids, such as Zantac, Pepcid, Axid, or within two hours of taking an antacid.

**Pregnancy/Breast-Feeding:** The effect of itraconazole on a developing fetus is not known; pregnancy is not recommended. Since itraconazole is excreted in human milk, nursing should be avoided.

*Clotrimazole: Mycelex Troche (brand name)*

**COMMON USES:** Clotrimazole is used as a prophylactic anti-fungal agent. It offers protection against oral candidiasis or thrush.

**HOW TO USE THIS MEDICATION:** Let one lozenge dissolve slowly in your mouth after each meal and before bed. DO NOT chew or swallow whole. . IF YOU MISS A DOSE OF THIS MEDICATION, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. DO NOT take two doses at once. DO not eat or drink anything immediately after taking this medication.

**POSSIBLE SIDE EFFECTS:** Very rare: nausea/vomiting.

**SULFAMETHOXAZOLE/TRIMETHOPRIM:** Bactrim, Septra (brand names)

**COMMON USES:** This medication is used to treat or prevent infections. Specifically, it helps to prevent a pneumonia called pneumocystis carini pneumonia, which you are susceptible to because of your lowered immune system.

**HOW TO USE THIS MEDICATION:** This medication is best taken with a full glass of water to prevent the formation of crystals in the urine. Drink several additional glasses of water daily,

unless otherwise directed by your physician. Drinking extra water will help to prevent unwanted side effects of sulfonamides. This medicine may be taken with food if it upsets your stomach. Dosage is usually one tablet twice a day. Dose may be reduced to one tablet three times a week. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once.

**POSSIBLE SIDE EFFECTS:** Most Common: stomach upset; nausea/vomiting; loss of appetite. Less Common: sensitivity to sunlight; diarrhea; dizziness; headache; skin rash.

**CALL YOUR DOCTOR IF YOU EXPERIENCE** rash; hives; swelling of the tongue; fever; sore throat; joint pain; cough; shortness of breath; vaginal irritation or discharge; paleness; unusual bruising or bleeding; or yellow discoloration of the skin or eyes.

#### **WARNINGS:**

**General Warning:** For many months after you stop taking this medicine you may experience more sensitivity to sunlight or sunlamps, so take proper precautions.

**Drug Interactions:** For people who are allergic to sulfa drugs, there are alternative medications that are given, such as Pentamidine and Cipro.

**Pregnancy/Breast-feeding:** Since sulfamethoxazole/trimethoprim is excreted in human milk, nursing should be avoided.

#### ***GANCICLOVIR: Cytovene (brand name)***

**COMMON USES:** Oral Cytovene is usually given after ganciclovir IV is finished in order to provide protection against CMV infection, especially for transplant recipients of CMV positive donors. The indication for use in solid organ transplantation is relatively new, but so far it seems to be more effective than acyclovir in preventing CMV infections.

Following the directions for taking this medicine provided by your doctor. It is recommended that you take Cytovene with food (to increase bio-availability), and drink plenty of fluids. Cytovene comes in 250 mg capsules. The usual dose is 1 gram 3x/day. Cytovene capsules should not be opened or crushed. . **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. **IF YOU TAKE IT 3X/DAY** and it is almost time for your next dose, take one dose now and another in six hours, and then continue with your regular schedule. It is important to keep all doctor and laboratory appointments while taking this medication since it may lower your resistance to infection, and reduce the number of blood cells needed for clotting. To prevent bleeding, avoid situations where bruising or injury may occur.

**POSSIBLE SIDE EFFECTS:** Most Common: headache; nausea. Common: Fever, diarrhea; abdominal pain; lowered white blood cell count; unusual bleeding or bruising; anemia; decreased kidney function; decreased platelet count; numbness or pain in the hands, arms, legs, or feet; weakness.

**CALL YOUR DOCTOR IF YOU EXPERIENCE** vomiting; fever, chills; cough; sore throat; unusual bleeding or bruising; rash; or confusion.

**WARNINGS:**

**Drug Interactions.** Do not take any over-the-counter medications without the approval of your transplant physician. This includes, but is not limited to, aspirin and other non-steroidal anti-inflammatory drugs such as Advil, Ibuprofen, Nuprin, and Aleve.

\* Mixing ganciclovir with other drugs that can be damaging to the kidneys can increase the rate and extent of damage.

\* Mixing ganciclovir with other antiviral medication can increase the toxic effects of ganciclovir, and should be used together if absolutely necessary.

\* Pregnancy/Breast-Feeding: Pregnancy is not recommended while using Cytovene. Studies in animals have shown it has the potential to impair fetal development.

\* Use of birth control is recommended while taking this medicine. Males receiving this medicine should use a condom during sexual intercourse during treatment, and for 90 days after stopping treatment to avoid passing the drug on to their partner.

\* It is not known if ganciclovir passes into breast milk, but the possible toxic effects of this drug on a nursing infant should be kept in mind.

**Diuretics: Lasix, Bumex (brand names).**

**COMMON USES:** A diuretic is a medication that helps your body get rid of excess fluid, which may be caused by steroids, by making more urine. Often, this causes the patient to urinate more frequently during the night. This, in turn, decreases the amount of fluid (blood) your heart needs to pump. You may have been taking one of these medications before your transplant. After your transplant, you may continue to require a diuretic.

Since the drugs act to increase urine flow, several common sense suggestions can make their use easier. The drug's effect may last from two to twelve hours, so plan your activities so that a bathroom is accessible. If an evening dose of a diuretic is required, take it in the early evening to prevent the inconvenience of excessive urination during sleep hours. Weigh yourself daily and keep a record. In general, large changes in body weight reflect fluid retention or fluid loss.

The following are directions for using these medications provided by your doctor:

**IF YOU MISS A DOSE OF THIS MEDICATION,** take it as soon as possible.

If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.

**DO NOT** take two doses at once. Usually, after your transplant you will **NOT** need to take any potassium supplements with the diuretic even though you may have needed them before.

**POSSIBLE SIDE EFFECTS:**

**Common:** light-headedness; fatigue; indigestion; diarrhea; skin rash; hives. **Less Common:** vomiting; yellowing of the skin and eyes; dermatitis and other skin reactions; and anemia.

## **WARNINGS:**

**General Warnings:** It is important to have your blood pressure and blood electrolyte levels checked frequently when you are taking diuretics. Electrolytes are necessary for the body to work properly. Symptoms such as dryness of the mouth; excessive thirst; muscle aches; nausea; headache; low blood pressure; and fatigue may indicate that electrolyte levels are abnormal.

**Drug Interactions:** Do not take any over-the-counter cough/cold, asthma, or diet medications without asking your transplant physician first.

\*Diuretics may change the sugar metabolism in your body; patients who are diabetic may need to have their medication adjusted.

**GASTROINTESTINAL: *Zantac, Propulsid, Pepcid, Reglan, and Prilosec (brand names)***

**COMMON USES:** These medications are used to treat heartburn, prevent and treat ulcers, treat gastrointestinal reflux, treat nausea and vomiting, as well as to act as an antacid to buffer the acid in your stomach. Prednisone causes increased acid in your stomach, which may cause an ulcer.

**Use this medicine exactly as directed by your physician:**

**IF YOU MISS A DOSE OF THIS MEDICATION,** take it as soon as possible.

If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. DO NOT take two doses at once. Additional antacids may be used with these medications, but check with your transplant coordinator first.

**POSSIBLE SIDE EFFECTS:** nausea/vomiting; constipation/diarrhea; headache; dizziness; and drowsiness.

## **WARNINGS:**

**Drug Interactions:** Antacids have the ability to interfere with the action of antibiotics. You should avoid taking antacids and antibiotics less than two hours apart.

\*Some antacid medications, such as Reglan and Propulsid, may cause drowsiness or dizziness. Do not drive or operate machinery while on these medications. Also, antacids may increase the effects of other depressants or alcohol.

**BLOOD PRESSURE LOWERING MEDICATIONS: *Captopril, Dynarcirc, Cardizem, Procardia, Vasotec (brand names)***

**COMMON USES:** These medications lower blood pressure and are often used in combination with other drugs. Remember high blood pressure is very common when taking cyclosporine and prednisone.

Medications can lower blood pressure in many ways. Some dilate the blood vessels. Others change the kidney's effect to control blood pressure. Still others block part of the nervous system that increases blood pressure.

Your physician will give you information on how to take this medication correctly:

**IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.

**DO NOT** take two doses at once.

It is important that you check your blood pressure daily, and that you take any anti-hypertensive medications exactly as prescribed.

**POSSIBLE SIDE EFFECTS:** headaches; dizziness; fatigue; nausea; joint pains; rash.

**CALL YOUR DOCTOR IF YOU EXPERIENCE** tender, bleeding or swollen gums; irregular heart beat; dizziness; or swelling of the feet or hands.

#### **WARNINGS:**

\*Some of these medications can cause dizziness. Do not drive or operate machinery until you know how you react to this medication.

**ANTI-ANXIETY MEDICATIONS:** *Valium, Buspar, Librum, Atavan, Xanax (brand names)*

**COMMON USES:** These medications are used to help control anxiety in transplant patients, which is often caused by the side effects of prednisone.

Your physician will give you information on how to take these medications when it is prescribed for you:

**IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once. It may take several weeks before the full effect of these medications is noticed.

**POSSIBLE SIDE EFFECTS:** drowsiness; dizziness.

#### **WARNINGS:**

**Drug interactions:** Do not take these medications with alcohol, which can induce drowsiness.

\*Do not take any over-the-counter cough/cold, allergy, sleep aid, or diet medications without asking your transplant physician.

#### **ALCOHOL & TRANSPLANT MEDICATIONS:**

Some of the medications often used by transplant patients are listed here, along with potential interactions with alcohol. Always play it safe and check with your transplant team to learn exactly how your medications interact with alcohol. An occasional glass of wine or beer is usually not a problem.

Lab Tests and Normal Values	Purpose	Problems With Abnormal Results	Factors That Can Change Your Results
White Blood Count (WBC) (4500-11,000 cu/mm)	Tells how many infection fighting cells (white blood cells) are in the blood.	Low Level: can mean too few infection-fighting cells High level: means you may have an infection	Some medicines like Imuran and intravenous Acyclovir can lower your white blood cell count, while others like Prednisone can elevate it.
Hematocrit (HCT) (36.0-46.0%)	Tells how many oxygen carrying red blood cells are in the blood.	Low Level: can make you anemic, tired, and short of breath. High Level: can make your blood thicker and cause problems with clotting.	A lot of bleeding can make your hematocrit go down; blood transfusions make your hematocrit go up.
Platelets (Plt) (150,000-350,000/cu mm)	Tells how many cells that make your blood clot (platelets are in the blood).	Low level: you may bleed more easily. High level: can make your blood very thick and may require that you take a blood thinner.	Liver disease and some medications can cause problems with the platelet count.
Potassium (K+) (3.7-5.5 mEq/L)	Tells how much potassium is in the blood. Potassium helps the heart and other muscles work well.	Low Level: possible problems with the heart beat. High level: possible problems with the heart beat and too much acid in the blood	Kidney failure can increase the level, high levels of acid in the blood can increase the level. Often seen with pancreas transplant. Sodium bicarbonate is used to lower this level; diuretics can cause low levels.
Carbon Dioxide (CO2) 24-30 mEq/L	Reflects the acid balance in your blood.	Low CO2 means too much acid in your blood. Can make you feel tired and short of breath.	Kidney failure or pancreas transplants can decrease the level; sodium bicarbonate tablets can increase the level.
Blood Urea Nitrogen (BUN) (7-22 mg/dl) Creatinine (Cr) (0.5-1.2 mg/dl)	BUN and Creatinine indicate how well a kidney is functioning.	High level: may mean that the kidney is not functioning properly.	High levels can result from kidney failure; high drug levels of Cyclosporin (Sandimmune, Neoral) and Tacrolimus (Prograf) in the blood, or organ rejection; a diet high in protein can increase the BUN.

Magnesium (Mg) (1.3-2.0 mEq/L)	Tells how much magnesium is in your blood. Your body needs magnesium to carry out many of its daily functions.	Low level: can cause muscle weakness; sleepiness and problems with the heartbeat.	Medicines like Cyclosporine and Tacrolimus can cause your magnesium level to go down. Magnesium Oxide helps to keep the level normal; Cipro (antibiotic) can affect the absorption of magnesium, so it should be taken two hours before the magnesium.
Arterial blood gases (ABG) pH 7.35-7.45 pCo2 35- 45 pO2 80-100 O2 Sat 95-100	Tells how well you are getting oxygen and getting rid of carbon dioxide (by-product of metabolism) in your body. It is a measure of the acid-base balance.	There are certain levels that the body maintains as the result of how well your lungs are working and other buffer systems (your kidney) that help to maintain a normal balance.	If you don't get enough oxygen and don't eliminate CO2, because your diseased lung is not capable of exchanging "good air with bad air", you will feel short of breath and anxious.
Lab Tests and Normal Values	Purpose	Problems With Abnormal Results	Factors That Can Change Your Results
Total and Direct Bilirubin (0.2-1.2 mg/dl) Total (0.0-0.4 mg/dl) Direct	Tells how well the liver is working	High Level: may mean that the liver is not working well.	Liver failure causes the levels to rise as the sick liver cannot remove the bilirubin, which is a waste product from the blood.
AST or SGOT (0-35 IU/L) ALT or SGPT (0-31 IU/L) Alk Phosp (30-120 IU/L) GGT (8-51 IU/L) LDH (0-220 IU/L)	Tells that there may be damage to the liver, heart, or bones	High Level: these enzymes are released into the blood if there is damage to the liver or bones. Damage can be a result of rejection or certain medicines.	Liver failure increase the levels; especially ALT or GGT; the bone disease that occurs with kidney failure can increase the alkaline phosphatase; certain medicines such as Imuran can cause AST and ALT to go up.
PT (11.2-13.6 sec) PT (20-31 sec)	Tests the clotting function of the blood.	High level: may mean that your blood is not able to clot or stop bleeding well. Liver failure and medicines can cause this problem.	Liver failure can cause your blood to not clot well. Medicines like Coumadin and Heparin are used to make the blood thin and cause high levels.

Cyclosporine Level, Whole Blood HPLC (150-300 ng/ml) or Tacrolimus Level, Whole Blood TDX (6-15 ng/ml)	Tells how much Cyclosporine or Tacrolimus is in the blood. Both of these medicines prevent rejection.	Low level: can increase the risk of rejection. High Level: can cause problems with other organs in the body like the kidneys and increase the chance of infections.	You should always have your blood drawn 12 hours after your last dose for the best results based on a twice-a-day dosing regimen. Any earlier might make the level high; later might make it low.
Glucose (blood sugar) Fasting (70-115 mg/dl)	Tells how controlled your diabetes is.	Low level: can make you feel faint, cause sweating, nervousness, fast pulse, and a headache. High level: can cause problems such as excessive thirst, fatigue, hunger, and weight loss, and can mean your transplanted pancreas is not working as well as it should.	Acute stress such as the surgery or infection, intravenous fluids with sugar, and steroids can all cause glucose to go up. Too much insulin can cause the glucose to be too low; exercise, severe cold, high fever, and a poor diet can lower the blood sugar level.
Cholesterol (fat-like substance) (<200 mg/dl)	Tells whether there is a problem with the liver. Tells whether you are higher risk for having a heart attack.	High level: can cause narrowing or blockage of blood vessels which may lead to a heart attack. When the liver is not working well, the level may be low.	Eating fatty foods up to 12 hours before the test may cause a high level. A fasting state is often required; certain diseases such as diabetes elevate the level; medicines such as prednisone and Cyclosporine may increase the level; diet and exercise will lower the level; bile tube problems such as blockage can cause a high cholesterol level.
Urine Culture	Tells if there is bacteria causing infection in your urine.	Infection in your urine can cause burning when you urinate; frequent urination; change in color and odor of your urine.	It is important to clean yourself well when obtaining urine samples to get an accurate result.



When deciding to refer a patient for lung transplantation it is important to note that average waiting times for lung transplantation nationally are approximately 18 months and the current U.S. system does not prioritize patients on the waiting list based upon their severity of illness.

Absolute Contraindications:

Presence of one or more of these would exclude patient from consideration:

Infection with HIV.

Age Criteria:

Single lung > 68 years

Bilateral lung > 60 years

Dysfunction of major organs other than the lung:

Severe CNS disease (cerebrovascular injury with major residual deficit, uncontrollable seizures, mental retardation, etc)

Dialysis-dependent renal failure or creatinine clearance < 40ml/min

Significant chronic liver disease with documented evidence of cirrhosis or portal hypertension

Severe gastrointestinal disease including hepatobiliary and pancreatic disease that is not amenable to therapy

Severe ventricular dysfunction (LVEF < 40% or irreversible RV dysfunction) (consider HLT)

Significant coronary artery disease that is not amenable to revascularization (CABG or PTCA) (consider HLT)

Significant valvular heart disease (other than tricuspid insufficiency) that is not amenable to valve repair (consider HLT)

Significant cerebrovascular or peripheral vascular disease that is not amenable to revascularization or repair.

Progressive neuromuscular disease.

Diabetes mellitus with end-organ dysfunction (retinopathy, peripheral neuropathy or nephropathy)

Hepatitis B antigen positivity.

Hepatitis C with either histologic evidence of liver disease or positive PCR indicating presence of hepatitis C DNA.

Active malignancy

Within the last two years with the exception of basal cell and squamous cell carcinoma of the skin

Within the last five years for extracapsular renal tumor, breast cancer stage 2 or higher, colon cancer stage Duke's B or higher and melanoma level III or higher.

Airway colonization with organisms that are pan-resistant to antibiotics.

Substance addiction/use within 6 months (tobacco, alcohol or other illicit drugs)

Presence of major psychosis, inability to understand the procedure & associated risks or well-documented history of failure to comply with medical management

Severe musculoskeletal disease affecting the thorax.

Relative contraindications:

Chronic supra-physiologic (greater than 0.2 mg/kg/day) corticosteroid use of associated with severe systemic manifestations

Symptomatic osteoporosis refractory to therapy

Persistent poor nutritional status (despite program intervention) with evidence of low visceral protein stores (low albumin and/or prealbumin) and weight < 70% of IBW (ideal body weight).

Obesity-body mass index-> 30 despite program intervention.

Invasive mechanical ventilation (assessed on a case by case basis)  
Persistent positive smear for mycobacterium despite therapy.  
Severe deconditioning despite program intervention  
6-minute walk < 600 feet with diagnosis of COPD, cystic fibrosis, or IPF.  
Prior chest surgery( major resection, pleurectomy, thoracoplasty, etc.) resulting in severe pleural disease /thickening.  
Mediastinal fibrosis.  
Inadequate social support structure.