

# Lung Transplant Diary



Name:

Transplant Date:



**HARVARD MEDICAL SCHOOL**  
**TEACHING HOSPITAL**

## IMPORTANT PHONE NUMBERS

- **Pulmonologist (Transplant Doctor) On-Call**

After hours and on weekends: call the BWH page operator at 617-732-6660 for a live operator. Please ask for the on-call transplant pulmonologist to be paged to your phone number.

- **Karen Tsveybel RN, CCTC,  
Inpatient Lung Transplant Coordinator and Outpatient Heart/Lung Coordinator**

Office phone number (617) 525-9471

To page dial (617) 732-5656 Beeper Number: 12713

- **Jessica Mongello RN, Outpatient Lung Transplant Coordinator**

Patients whose last name begins with: **A-D**

Office phone number (617) 732-7299

Will respond to messages and phone calls within 24 hours or one business day.

- **Stacia Meadowcroft RN, Outpatient Lung Transplant Coordinator**

Patients whose last name begins with: **E-K**

Office phone number (617) 278-0369

Will respond to messages and phone calls within 24 hours or one business day.

- **Meagan Frenette RN, Outpatient Lung Transplant Coordinator**

Patients whose last name begins with: **L-P**

Office phone number (617) 732-4005

Will respond to messages and phone calls within 24 hours or one business day.

- **Linda Cronin RN, Outpatient Lung Transplant Coordinator**

Patients whose last name begins with: **Q-Z**

Office phone number (617) 732-5971

Will respond to messages and phone calls within 24 hours or one business day.

- **Ellen Modi RN and Deborah Valenza-Glennon RN,  
per-diem Lung Transplant Coordinators**

Patients in pre-transplant clinic, post-transplant clinic, or inpatient.

## **IMPORTANT PHONE NUMBERS**

- **Post Transplant Administrative Coordinators**

Office phone number (617) 732-7269  
To make appointments, schedule tests, etc.

- **Carmel Owens, Financial Coordinator**

Office phone number (617) 525-9724

- **Angela Lombardo, Social Worker**

Office phone number- Care Coordination Dept. 617-525-1376  
To page dial (617) 732-5656 Beeper Number: 37276

- **Samantha Pearlstein, Social Worker**

Office phone number- Care Coordination Dept. 617-525-8142  
To page dial (617) 732-5656 Beeper Number: 32699

- **Keri Townsend, Pharm.D Transplant Pharmacist**

Office phone number (617) 525-8901  
To page dial (617) 732-5656 Beeper Number: 15364

## **MEDICAL MANAGEMENT**

## Precautions

You will receive medications that are necessary to prevent your body from rejecting your new lungs. These drugs decrease your body's ability to fight infections. You will be assigned to a private room while in the hospital. These are specially designed rooms with filters built in to protect you from infections, and to your exposure to other people.

You will be on "precautions." This means that everyone entering your room will wear a mask, gown, and gloves, for at least 7 days after your transplant. Your visitors are limited to immediate family or significant others during this time. Anyone with a cold, flu or any ailment that could put you at risk for infection will not be allowed to go into the room. Flowers and fruit baskets will not be allowed in your room.

Good hand washing is the most effective way to stop the spread of bacteria and prevent infection. This includes family, hospital staff, all visitors, as well as yourself. Your nurse can instruct you and your family on proper hand washing.

***When you leave your room for any reason, you must wear a mask.***

## Chest Tubes and Pleural Drains

After transplant, you will have multiple tubes attached to your chest draining excess fluid from around your lung(s). This will in turn help your new lungs re-expand in your chest and help you to breathe better. Some people go home with these drains still in place as it is perfectly safe and manageable.

At home you will be responsible for draining the fluid as directed and recording the amount drained, as well as the color of the fluid. The accuracy of these numbers will help to determine when these drains can be removed.

Prior to leaving the hospital, your nurse will go over how to drain, measure, and record the amount of fluid. Also, when you get home, your Visiting Nurse will be able to help you to initially manage and answer questions you may have about the drains.

## **Respiratory Care**

For lung optimization, it is important for you to **COUGH, WALK, and DEEP BREATHE**. These are essential for expansion of your new lung/s.

A nurse or respiratory therapist will visit you two to three times a day. He/she listens to your lungs and performs chest physical therapy (CPT). CPT consists of tapping and vibrating your chest while you lay in different positions in bed. CPT also involves teaching you to take deep breaths and cough effectively. You will receive CPT frequently from both the therapists and the nurses taking care of you.

The respiratory therapist and the nurse will help you to walk three to five times every day. As you recover, you will walk independently. The more you walk, the more you increase the blood supply to your new lung, and the stronger you become! This will prove to be the most important aspect of your recovery and will be given the priority it demands.

## **Physical Therapy**

Physical therapy will begin as early as 1-2 days after your surgery. The goal of physical therapy is to improve your movement, increase your functioning and relieve pain. This is essential to your recovery after your transplant. It will assist you in preventing pulmonary complications and the side effects of your medications that can cause muscle weakness.

The therapist will first evaluate your strength, coordination, range of motion, pain, breathing techniques, and mobility. The therapist will carefully monitor your cardiopulmonary status (heart rate, blood pressure, respiratory rate, and oxygen saturation), during activity. Initially you will have many lines (I.V.'s, heart monitor, chest tubes, epidural). The nurse and therapist will assist you in moving with all above mentioned lines. At this time, you will be started on an individualized exercise program, which will progress rapidly from in bed to sitting and finally standing. This will assist you in increasing your strength and endurance. Activity will help you in clearing your secretions as well as improving your breathing pattern.

Once you can get out of bed and are walking short distances, you will begin an exercise program and be monitored throughout your individualized program. It is expected that you participate daily to help prevent pulmonary complications and expedite your discharge to home. Your goals prior to discharge will be to be out of bed during the day, to walk and climb stairs independently, and to have a well-established exercise program.

By the time of discharge, we anticipate you will be independent in all routine activities of daily living, independent in walking to allow you to get to your appointments, and able to climb the stairs. You will have an exercise program designed for you to continue at home every day. If you are not fully independent in these activities, you may require a transition to an inpatient rehab facility for to continue working on these goals. We have selected a few local facilities and have trained them to care for our transplant patients.

Following discharge, you will be expected to follow up with outpatient rehab to continue with your rehab program once you have recovered from transplant.

## Prevention of Blood Clots

Blood clots are extremely common following lung transplant surgery and can lead to further complications including pulmonary embolism, a blood clot in your lung. To prevent these complications early ambulation is essential. Another measure we take to prevent blood clots is to give an injectable blood thinning medication called enoxaparin (Lovenox). You will work with your nurse to learn how to self-inject this medication prior to discharge. Most patients require this medication for approximately 1-month post-transplant. Should you have any procedures while you are on this medication, please ask for instructions regarding stopping this medication prior to your procedure.

## Diabetes

Some of the medications you take after transplant may cause diabetes. Diabetes is an increased level of sugar in the blood. During your hospital stay your blood sugars will be closely monitored and most patients will be discharged home with a glucometer and injectable insulin to continue to monitor and treat elevated blood sugars.

Signs of diabetes may include:

1. excessive thirst
2. increased urination
3. blurred vision
4. confusion

Call your transplant team if you have any of these signs. Early detection can result in reversal or reduction of high blood sugar.

In some cases, blood sugar can be reduced by weight loss, careful diet, and exercise. You may need an oral diabetes drug or insulin injections. If you get diabetes, you will be given special teaching about how to deal with this problem.

If you do go home with the instructions to measure your blood sugars, please record each reading in your diary and bring them with you to clinic. It is important we are monitoring those numbers so we can adjust your medications appropriately.

## **Post-Transplant Bone Health**

One common side effect after having a transplant is a condition called osteoporosis. This condition can also be referred to as “thinning of the bones.” This is caused by the medications you are required to take that suppress your immune system.

To prevent osteoporosis, maintain a diet rich in calcium, found in milk, dairy products, and dark green leafy vegetables. After transplant, you will take supplemental calcium and vitamin D, unless contra-indicated. Regular weight bearing exercise, such as walking, will help to prevent osteoporosis as it promotes bone growth.

After discharge most patients will be scheduled to receive an infusion called “Reclast” to help build bone strength while on high doses of prednisone. Reclast is given once a year. If a transplant team member recommends you receive this infusion you will be able to receive the infusion here at BWH or at your home hospital. If your insurance does not approve this medication, you will receive an oral alternative. You will also have routine bone mineral density tests to determine if you will need ongoing treatment and may also need to be referred to endocrine if more management is warranted.

You will need to call and set-up your own infusion appointment at BWH outpatient infusion center p 617-732-9983. When calling to schedule your appointment, you will need to give your name, medical record number, and the name of the medication: Reclast.

Please speak with and inform your outpatient coordinator if you plan on scheduling your appointment. Your coordinator information can be found on page 1 of this manual.



## **Preventing Infection Following Lung Transplantation:**

### **Frequently Asked Questions**

#### **Why worry about infections?**

After a lung transplant, you will need to take medications that prevent your body from rejecting your new lung(s). These medications are very important for you to take, but they can also make it harder for your body to fight off germs that cause infections. There are some things that you can do to help keep from getting sick.

#### **Where do these infections come from?**

- Some infections are caused by “reactivation” of viruses that have been in your body for years from past infections. These viruses usually don’t cause problems until your immune system is weakened. Some examples include viruses that cause cold sores (Herpes simplex virus), shingles (Varicella zoster virus), and CMV infections such as pneumonia (cytomegalovirus). These viruses can also sometimes reactivate in the transplanted lung and cause infections. You will receive medications to prevent reactivation of these viruses.
- Some infections are passed along to you by other people (such as influenza).
- Some infections come from germs from other things like food, animals, or dirt.

#### **How can I protect myself from infection?**

- Stay healthy, get plenty of sleep, drink enough fluids and eat a balanced diet.
- Make sure that you follow all your lung transplant team’s instructions for taking medications. If you have any questions about medications, please ask your lung transplant providers- they’ll be happy to answer.
- Wash your hands often:
  - Washing your hands either with an alcohol-based hand sanitizer or with soap and water is very important to prevent infections.
  - Wash your hands when they are dirty and at the following times:
    - Before preparing food to eat
    - After touching raw meat like chicken or steak
    - Before eating
    - After using the restroom
    - After changing a baby’s diaper
    - After touching animals such as dogs and cats
    - After going outdoors or to a public place
    - Before and after touching catheters or wounds
- Ask people who touch you to wash their hands. People can make you sick by bringing in germs from the outside. Don’t be afraid to ask them to wash their hands. This includes doctors, nurses, other healthcare professionals, family members (including children), and visitors.

### **Skin and mouth care:**

Some medication such as prednisone can increase your chance of getting skin and mouth infections.

- Shower daily, but do not scrub your incision while it is healing. If your skin becomes dry, use a lotion to soften your skin and prevent cracking (do not apply directly to your incision).
- Brush your teeth. Use a soft toothbrush. If you are unable to brush your teeth, use an antibacterial mouth rinse such as Peridex.
- You will receive a mouth wash called nystatin to swish and swallow four times daily to prevent an infection called thrush while on high dose prednisone.
- If you develop blisters or sores in your mouth, let your lung transplant team know.
- Check with your doctor before having dental work done.
- Clean cuts and scrapes with soap and water and cover with a bandage.

### **Keep your living area clean:**

Before leaving the hospital, plan to clean where you will be staying. We recommend:

- Cleaning heating and air-conditioning vents and routinely changing the filters.
- Removing visible mold and mildew from bathrooms.
- Clean your house weekly, especially your sleeping area. This should include vacuuming carpets. It is best if you're not in the same room while this is going on; if you are, we suggest that you wear a mask during the cleaning.
- If you use a humidifier, clean it daily with a dilute solution of bleach then rinse before refilling the water tank.
- Avoid poorly ventilated spaces such as unfinished basement areas and attics that can be moldy or dusty. If you must spend time in these places, wear a mask.
- Avoid smoke-filled environments. No fireplaces, campfires etc.

### **Stay away from dirt and plants:**

- Germs, such as mold and fungus are found in dirt and on plants. These germs can cause serious infections in persons with a weakened immune system that can be difficult to treat.
- No gardening or activities that stir up dirt such as turning soil, mulching, raking, or cutting grass for one year after transplant. Stay indoors with the windows closed when these activities are going on. If yard work is unavoidable, a mask and gloves should be worn. It's unknown whether using a mask will protect you against these infections.

### **Caution for what you eat and drink:**

Germs that cause infection can be in the food you eat. You need to be careful about how you prepare food. Here are some steps to keeping food safe:

- **Clean:** Wash hands, utensils, and surfaces with hot soapy water before and after food preparation, and especially after preparing meat, poultry, eggs or seafood. Be sure to wash fresh fruits and vegetables thoroughly.
- Don't share dishes, glasses or eating utensils.
- **Separate:** Keep raw meat, poultry, eggs, and seafood away from ready-to-eat foods.

- Do not place cooked food on an unwashed plate where raw meat, poultry, eggs, or seafood has been.
- **Cook:** Cook foods thoroughly. Use a food thermometer to check the internal temperature of meat.
  - Cook meat until it is no longer pink, and the juices run clear.
  - Cook eggs until they are firm (no runny yolk).
  - Bring sauces, soups, and gravies to a boil when reheating.
  - Avoid eating uncooked deli foods such as cold cuts.
- **Chill:** Keep cold foods cold. Refrigerate or freeze foods that may spoil. Refrigerate leftovers within 2 hours and make sure the refrigerator temperature is no higher than 40°F and the freezer temperature is 0°F. Never thaw food at room temperature, thaw food in the refrigerator or microwave.
- Municipal tap water is generally safe. Avoid well water if possible unless the water quality is tested frequently.
- Avoid unpasteurized milk, cheese, and vegetable or fruit juices.

### **Pet safety:**

Pets are important to many people but can sometimes pass infections to humans. Make sure to talk to your doctor about pet safety.

- Do not handle animal waste. Don't clean litter boxes, animal cages, or fish tanks.
- Do not adopt sick or stray pets or pets less than 6 months old.
- Do not have birds or reptiles as pets during and after the transplantation.

### **Travel:**

- Your chance of getting an infection is higher in certain areas of world (including certain parts of the U.S.). Talk to your transplant team before traveling to see whether you need to take any special precautions.
- Avoid travel to areas of the world where you would be unable to receive special medical care for patients with weakened immune systems.
- Talk to your transplant team before receiving travel vaccinations. Some vaccines recommended for travel can't be given to transplant recipients.
- Don't buy food from sidewalk vendors. Depending on where you travel, it may be safest to drink only bottled carbonated beverages and to avoid ice cubes.

**Contact your transplant team if you develop any symptoms of infection:**

You should always feel free to call the team about your symptoms and they can determine whether you need evaluation or treatment.

- If you have any of these symptoms, call your transplant team:
  - Fever over 100.5°F
  - Cough, stuffy nose, scratchy throat, earache
  - Chest pain or shortness of breath
  - Diarrhea or vomiting lasting longer than 3 days, loss of appetite, weight loss
  - Chills, night sweats,
  - Skin rash
  - Mouth or genital sores
  - Difficulty or pain with urination
  - Dizziness or headache
  - Pain or redness at a wound or catheter site

## Addressing Your General Healthcare Needs

### Health Maintenance:

You should continue to see your primary care physician (PCP) yearly for routine physical examinations. You should also contact your PCP and local pulmonologist at or about 3 months after your transplant for follow-up and updating of your medical information. Your PCP and local pulmonologist are important resources for you and your transplant team, and we will rely on them to help us take care of you after your transplant. Prior to starting you on any new medication, your local physician should contact the transplant team to make sure the new medication will not interact with anything you are already taking.

**Women** should undergo routine pelvic examinations with PAP smears with your local physician as recommended. You should perform breast self-examination monthly. You should also undergo yearly mammograms if age appropriate as recommended by your PCP.

**Men** should perform monthly testicular self-exams. Prostate cancer screening if age appropriate should be performed as recommended by your PCP.

Both men and women should undergo colon cancer screening if age appropriate as recommended by your PCP.

### Skin Care:

Transplant patients are at an increased risk for developing skin cancer because of sun exposure. Skin cancers are caused by the ultraviolet rays from the sun. These rays are present even when it is cloudy. Patients are instructed on the following steps to protect against harmful ultraviolet rays: Always wear sun block and lip block with a SPF of 30 or higher. Wear clothing that is protective, such as hats and long-sleeved shirts. Wear sunglasses when outside during the day. Report any changes in your skin, such as a change in a mole or a wart, or appearance of any new growth. You should have a full body skin check performed annually by a dermatologist.

Generally, you should shower or bathe as often as necessary to keep your skin clean. Most soaps are safe for use.

Prednisone can cause acne on your face, chest, shoulders or back. Cyclosporine can make your skin oily. If acne develops, wash the area three times a day with mild soap, scrubbing gently with a clean, wet washcloth. Rinse the soap completely from your skin to leave it clean. Any benzoyl peroxide solution may be used. To prevent infection, do not pick at or touch the pimples. Report any acne that may be infected. The acne should clear as your prednisone dose is decreased. You may require treatment from a dermatologist if the acne is severe.

To avoid acne:

- Keep your hands away from your face and avoid rubbing the area
- Limit the use of cosmetics
- Do not scrub your skin vigorously
- Avoid soaps that contain creams and oils

## **Hair Care:**

Prednisone will probably change the condition of your hair. Permanent hair dyes, wave lotions and bleach may cause your hair to become brittle and break. It is recommended that you wait until your prednisone dosage is at 20 mg per day or lower before having permanent or coloring to your hair (dye color may not take with high dose prednisone). Tell your hairdresser that you are taking prednisone before any hair treatments.

Unwanted hair growth or loss may result from your medication regimen. Hair removal cream (depilatory) can be used for excessive facial hair. Be sure to follow directions carefully to avoid eye or lip irritation. Excess hair can also be bleached with a 50% peroxide solution. Waxing and electrolysis are other options. Do not alter your medications due to excess hair growth or loss. Speak with your care team if this becomes a problem for you.

## **Dental Care:**

Continue with your daily routine of dental hygiene by brushing and flossing. You should have regular dental check-ups every six months. Dental surgery should be postponed until at least 6 months after your transplant if possible. Please notify the team if you need to have dental surgery. In some cases, you will need to take a prophylactic antibiotic, prior to surgery. You will not need prophylactic antibiotics for routine visits and cleanings. Please inform your dentist that you are taking a bisphosphonate (Reclast) for your bone health.

## **Sexual Activity:**

Sexual activity may be resumed, as able, approximately 6 weeks following surgery. Your recovery process will impact how soon you feel ready for sexual activity. You should discuss this with your providers during your clinic visit. Your transplant may affect your sexual functioning. Certain medications can also interfere with sexual functioning. Some people avoid sexual activity because they are afraid of hurting their new lungs, or of infection. If you have any of these concerns, please discuss them with your transplant team. Since you are immunosuppressed, it is **ESSENTIAL** that you practice safe sex, because of an increased risk of acquiring a sexually transmitted disease. Please see your PCP for routine testing for STDs. You **MUST** use contraception to prevent unplanned pregnancy as well. Please feel free to address questions/concerns to the transplant team.

## **Pregnancy:**

The immune suppressing medications that you take after transplant are teratogenic, meaning that they can injure a fetus before the fetus is born. As highlighted in previous sections of this book, to preserve your lung function, it is imperative that you not stop these medications for any period of time, even for the purpose of pregnancy. Moreover, the impact of pregnancy on your lung function remains unclear. Pregnancy has the potential to worsen your lung function, a decline that may not be reversible. For this reason, the **BWH Lung Transplant Program discourages pregnancy for women after lung transplantation in the strongest terms**. The impact of immune suppressing medications on male fertility and fetuses born of men on these medications is also unclear.

We strongly encourage the use of proven contraception methods for patients who have undergone lung transplantation. If you are a woman of childbearing age someone will speak with about risks regarding pregnancy and immunosuppressant therapy and appropriate contraception. If you have further questions about pregnancy and childbearing after lung transplantation, please discuss them with the lung transplant team in advance of listing for transplant. The pursuit of in-vitro fertilization (IVF) or other assisted methods of childbearing should also be discussed with the team at the start of your evaluation for transplant. These techniques can impact upon your lung health and upon your ability to be active on the transplant list and should be discussed at the earliest appropriate time in the transplant process.

## **GOING HOME**



## The Transition Home

Now that you have had your lung transplant and are preparing to go home, it is important to recognize your new responsibilities. The transplant team will continue your lung care. This team includes the pulmonologists, the surgeon, the social worker, the nurse coordinators, the pharmacist, the administrative coordinators, and the lung transplant nurse practitioner.

At this point though, the most important member of the team is you! Without your active support, the team's best efforts cannot succeed. As the lifetime caretaker of your new lung, you will need to:

- Make sure you have a healthy daily schedule that includes a good diet and regular exercise.
- Follow your medication schedule & know each medication dose, frequency, and its use
- Check and document your weight, temperature, spirometry, oxygen saturations, blood pressure and heart rate daily and as needed. You are responsible for starting this during your hospital stay and continuing at home.
- Keep all your scheduled clinic appointments.
- Make sure all your doctors, your dentists and your pharmacist know about your medications and your current condition.
- No sleeping on your side until 3-6 months post-transplant.
- No driving for 3-6 months but depending on your health it could be even longer than 6 months, however the timeframe is usually between 3-6 months.
- No lifting > 8lbs for the first 14 weeks post-transplant.

The initial time at home can be quite busy. There will be many scheduled and unscheduled appointments with pulmonologists, visiting nurses, physical therapists, and your primary care doctor. It is also important that you prepare yourself for the likelihood of readmission. Almost every patient is readmitted for medication regulation, intravenous antibiotic therapy, and various treatments for infection and rejection. It is not uncommon for patients to experience rejection during their first-year post transplant, requiring readmission to the hospital for increased immunosuppression, mainly corticosteroids such as prednisone, for treatment.

It is natural to experience a range of emotions after transplantation, even in the absence of complications. You have just undergone a major life event and are learning to live with a new and unusual set of circumstances. Joy, guilt, anxiety, depression, and frustration are all common emotions after transplantation, and you may experience one or all these feelings at different times. Your transplant team is here to help you through these changes and can provide resources to help you manage them. Please let us know if you are uncomfortable in any way, and we will work to help you.

## Communication with the Transplant Team

Having a lung transplant and taking the medications needed to prevent rejection puts you at risk for several problems. It is important for you to follow the instructions that will help prevent or lessen the problems. After discharge, you will be responsible for monitoring your health and calling the transplant team should problems arise.

The information contained in this education book describes issues related to the lung transplant process and regaining your health and strength. The road to recovery can be long. Each person has different concerns or issues related to his or her own individual lifestyle. If you have any questions or concerns, please write them down and feel free to address these questions to your nurse coordinator or any member of the transplant team before you go home or at your next follow-up visit.

We encourage all patients to use Patient Gateway to communicate. This is a more efficient way to communicate questions, but it is NOT for urgent symptoms (low oxygen levels, new shortness of breath, new cough, or fevers etc.). If you have new symptoms, this requires a phone call. If you have new urgent symptoms outside of business hours, page the transplant doctor on call.

Please do not wait until the end of day to contact the team as you will not get a response until the following day.

Please remember:

- When in doubt, call!
- If you are thinking about calling, call!
- The transplant team is always available to answer your questions!
- Remember, your Outpatient Nurse Coordinator is your first point of contact for the team during the day and after hours contact the Pulmonologist on-call

## Resources for Managing Your Transplant Health

Should you develop any of the following signs or symptoms, or any others that are of concern to you, please contact the Lung Transplant Team. During weekdays, please contact your Outpatient Lung Transplant Coordinator. **During the evening or on weekends please contact the physician on call by calling the BWH page operator at 617-732-6660 for a live operator. Please ask for the on-call transplant pulmonologist to be paged to your phone number.**

### Warning Signs:

- Any elevation in temperature greater than 1 degree above normal
- A fall in spirometry in either FEV1 or FVC. A drop of more than 10% is significant and you should notify the transplant team.
- A drop in oximetry (oxygen saturations) of more than 2% of normal.
- New or increased difficulty breathing, either at rest or exertion.
- Nausea, vomiting, or diarrhea. These can lead to poor absorption of your medications, so you must notify us promptly if they occur.
- Fatigue
- Sore throat
- Increase in sputum production- or change in color or odor
- Persistent cough
- Inability to clear secretions
- Loss of appetite
- Frequency or burning with urination.
- A cut that does not heal.
- “Just don’t feel well”

For any medical life-threatening emergencies, you need to call 911 and go to the nearest emergency room. Have the physician there call the Lung Transplant physician at the above beeper number. For any emergency you should always call 911 and do not drive yourself to the hospital.

### Wound Care:

Inspect your incision and tube sites every day for signs of infection- these include redness, drainage, increased pain, and/or swelling. Please notify the transplant team if any of these signs of infection occur. The visiting nurse will also be looking for any of these signs of infection. You may continue to wash your incision with soap and water during your daily shower. Pat your incision to wash and dry, do not scrub. However, we do not advise sitting in a bath until your incision is completely healed.

### **Temperature:**

You should be checking your temperature twice daily, at the same time each day in the morning and in the evening. Make sure not to eat or drink anything for 20 minutes before taking your temperature. If your temperature increases more than one degree from your normal you should inform the team. An increase in temperature may indicate infection or rejection. Please be sure to record all results in your diary.

### **Weight:**

Weigh yourself using a digital scale at the same time every day (usually first thing in the morning after you have urinated and before you eat or drink). A trend of increasing weight, or an increase of 6 pounds in one week needs to be reported. This change usually indicates water retention. Please remember to record this information on your log sheets along with your temperature, other vital signs, spirometry, and oximetry.

## Clinic Visits

Professional support persons such as a visiting nurse will visit you when you go home. Appointments for follow-up in the Lung Center C/Transplant clinic along with any other appointments you may need will be made before you are discharged from the hospital.

Initially, you will need to be seen every week at the Lung Transplant Clinic, which is held on either Mondays or Wednesdays, for an indefinite period until your acute issues are addressed. A Pulmonologist or a Nurse Practitioner who is in clinic that week will see you. Just as during your pre-transplant clinic visits, the various pulmonologists involved with lung transplantation will rotate in clinic, and you will see different members of the team on different days. This is also true when you schedule a bronchoscopy; the Pulmonologist who is on service on the day your test is scheduled will do your bronchoscopy.

When you come to clinic after your transplant, please arrive **ONE HOUR PRIOR TO YOUR SCHEDULED APPOINTMENT**. You should first go to the outpatient clinical laboratory at the 45 Francis St. entrance to have your blood drawn. A lab slip will be waiting for you there. You should then walk down the pike towards Lung center C to get your Xray done (across from Lung center C). An order will be entered in the computer for this before you arrive. You must allot enough time to do these tests to ensure you arrive on time to your clinic appointment. Every effort is made to schedule your appointment in a way that is most convenient for you.

**Remember:** Please remember to bring your Tacrolimus (Prograf) or Cyclosporine with you to the clinic appointment. **DO NOT** take your morning dose of Tacrolimus/Cyclosporine before having your blood sample drawn. You need to take the medication **AFTER** your blood work is drawn. It is also very important that you have your blood drawn 12 hours after you have taken your previous dose of Tacrolimus/Cyclosporine from the evening before. If the time interval is greater than or less than 12 hours, it will make your level inaccurate and difficult to adjust. This may require the need to do additional bloodwork.

On days when you are scheduled for follow-up visits, please make sure to bring your diary with your recorded information with you. You will be told about routine lab work (to keep track of your blood count, kidney and liver function, medication levels, etc) or special tests that you might need.

You will undergo lab tests each time you come in for an office visit. These can include blood, urine, and sputum tests. Some of the things the tests look for are:

- Your white blood cell count, which can indicate whether you have an infection or side effects from medication.
- How well your kidneys and liver are working.
- Whether you have enough minerals in your body.
- How much medication (tacrolimus/cyclosporine) is in your blood.
- How much sugar (glucose) is in your blood.
- How well your blood can clot

## Medic Alert Bracelet

You are expected to be an active participant in your health maintenance. You will take medications such as Tacrolimus (Prograf)/Cyclosporine, Prednisone and Azathioprine (Imuran)/Mycophenolate (Cellcept) for the rest of your life. In case of an emergency or other unplanned situation that requires medical attention, it is essential to inform your health care providers that you are taking these medications.

The most effective way of alerting others is by wearing a Medic Alert bracelet or necklace. It is your responsibility to obtain this bracelet. You can order through your local pharmacy or through an online vendor. Once you have received your Medic Alert jewelry, you must make a commitment to wearing it and report to the company if it becomes lost or broken.

When ordering your Medic Alert bracelet or necklace, please include the following information:

1. Your Name
2. 'Lung Transplant'
3. 'CMV Negative Blood Only'

## Wedge Pillow

It is important to keep the head of the bed elevated to prevent aspirating. Aspiration can lead to complications such as infection and/or rejection which may require hospitalizations. In order to prevent aspiration, it is required that you sleep with the head of the bed elevated. This can be done by using a wedge pillow (unless you have an electric bed).

Aspiration Precautions:

- It is very important to keep the head of the bed elevated 30 degrees.
- Do not use pillows. Purchase a wedge pillow that must be 12-inches thick. (This is not covered by insurance).
- Take an H2-Blocker (Nexium, Pepcid, Omeprazole) or PPI (Protonix)
- Eat all meals in upright position (not in bed)
- No eating 2 hours before going to bed.
- Avoid foods high in acidic content.

## Oximetry and Spirometry

A respiratory therapist will teach you how to monitor two parameters: your oxygen level (oxygen saturation) and your lung volumes (spirometry).

Your oxygen saturation is measured with a machine called an oximeter. The oximeter is a small monitor that you place on your fingertip. It reads the percentage of blood saturated with oxygen. Using this monitor enables us to wean you from your oxygen after surgery and allows us to notice problems before they become serious.

To obtain a microspirometer we will provide the name of a medical supplier and a prescription, Remetric Health phone 484-664-7600. You or a family member will then need to arrange for delivery. This is not always covered by insurance and may require an out-of-pocket expense. You may also order through any online vendor or medical supply company if it records the FVC and FEV1. With your microspirometer you will learn how to measure “forced vital capacity” (FVC) which is the amount of air you can force out of your lungs with one breath. The other important measurement is the “forced expiratory volume in one second” (FEV1). The microspirometer records this number as the amount of air exhaled during the first second of your forced exhalation. You will measure the FVC and FEV1 daily and record the values in your diary.

A decrease in your oximetry and/or spirometry may reflect either infection or rejection. Within a few weeks of discharge, you will receive an oximeter and spirometer for home use. It is important for you to be consistent in taking and recording your measurements to help us detect these problems early.

### Helpful Hints for Performing Spirometry at Home

1. Spirometry is effort dependent. Please use the same effort for each try. Performing the test while seated is best.
2. While sitting, get yourself ready by taking a few deep breaths in and out. When ready, take the biggest breath in as possible and place your mouth over the mouthpiece with your lips sealed. Then, blow out as hard and fast as you possibly can.
3. Write down the 2 numbers the machine gives you. They are called FVC and FEV1.
4. Perform this maneuver three different times and write each set of numbers down on scrap paper.
5. To pick the proper set of numbers choose the set with the highest FEV1. Write this set of numbers on your daily log sheet.
6. Please perform your spirometry every morning and record the appropriate set of numbers.

7. Having these numbers logged each day will help you monitor any changes. If you notice a decline of 10% for three consecutive days, please call us. These changes might indicate a new infection or rejection. It will be to your benefit to catch these conditions as soon as possible.

## **Exercise and Recreation**

The goal of your lung transplant is to allow you to return to an active lifestyle and improved quality of life. Incorporation of a regular exercise program that emphasizes both aerobic activity and strength training is one of the surest ways to achieve these goals. In addition, performance of aerobic exercise is one of the most important predictors of the lung function that you achieve after transplant. If you choose to incorporate routine exercise into your life, you will improve how you feel, how active you are, and how well your lungs work after transplant.

When you are discharged, you will continue to participate in the rehabilitation and exercise program that was developed for you. The goal of your rehabilitation is to maximize your muscular strength and endurance so that you can resume an independent life.

Once you are home you must continue to work on increasing your activity level by trying to do a little more each day. Walking is an excellent way of monitoring your progress and improving your strength. Walk every day and gradually increase the length of your walk. Be sure to pace yourself and provide for adequate rest before and after your walk. It is also expected that once your dose of prednisone is 20mg or lower, you will start to participate in Pulmonary Rehab as you did prior to your transplant.

All patients have received nutrition education by a transplant dietitian. Maintaining ideal body weight decreases the risk of complications such as atherosclerosis and osteoporosis. Regular exercise is a necessary weapon against obesity, osteoporosis, diabetes, and hyperlipidemia. Walking is the most economical and beneficial activity. You control your diet and exercise plan, two of the most important factors in your post-transplant outcome!

There are several limitations in your initial transition home to be aware of. These are due to the possible pain medications you may be taking, and to allow your incision from transplant to heal:

- Do not drive until your doctors gives you permission (3-6 months)
- Do not lift anything heavier than 8 lbs. (the weight of a gallon of milk) including children until you are given permission (at least 14 weeks after transplant)
- Do not push or pull anything heavier than 8 lbs. (the weight of a gallon of milk) until you are given permission (at least 14 weeks after transplant)



## **NUTRITION**

## Nutrition After Lung Transplant

Now that you have had a lung transplant, you may be wondering if changes will be made in your diet. It is important to your recovery process to maintain a healthy, well-balanced diet. Your dietitian will assess your individual nutritional needs and determine the number of calories and grams of protein you should be receiving every day while you are in the hospital and when you go home. Remember, you have unique nutritional needs based upon your age, weight status, medical condition, and food preferences. This handout will cover the general guidelines that accompany a lung transplant. Your dietitian and/or doctor will discuss any specific individual nutrition needs with you. Your dietitian will also assist you in planning your individual meal plan.

### **Calories:**

Maintaining your body weight is a good way to be certain that you are getting enough calories every day. You should weigh yourself weekly. If you are underweight, please refer to the pre-transplant handout for tips to increase calories that follows this section. Avoid overeating if you tend to gain weight. If you are overweight, please refer to the section addressing your nutritional needs that follows the section on being underweight. Talk to your dietitian about weight setting goals.

### **Protein:**

The medications you are taking as well as the healing process increase your body's need for protein. For these reasons, you need to pay special attention to getting adequate protein in your diet. Animal products contain the highest quality protein. The best protein choices are lean meats, fish, poultry, eggs (limit 2-3 per week or choose egg substitutes to limit your cholesterol) and dairy products like milk, cheese, and yogurt (choose low fat varieties). Your dietitian will discuss with you just how much protein you need each day. For further suggestions to increase protein please refer to the pre-transplant handout.

### **Salt:**

Since many individuals on steroids and/or immunosuppressant medications have a problem with fluid retention, a no added salt (NAS) diet is recommended. This is because salt contains the mineral sodium which can act like a sponge in the body, holding on to fluid and raising the pressure in your blood vessels.

If you have Cystic Fibrosis, talk to your physicians regarding the appropriate amount of sodium for your diet. Severe limitations on sodium intake can affect the manifestations of CF in your other organs.

General Guidelines for a low sodium diet:

1. Do not add salt at the table.
2. Avoid using salt when cooking. If you do cook with salt, no more than ½ teaspoon should be used per day.

3. Avoid packaged and processed foods which contain large amounts of salt and sodium. These include:

1. Smoked, Cured, or Dried Meats and Cheeses

Bacon	Sardines
Ham	Smoke Salmon
Sausage	Hot Dogs
Cold Cuts	Canned Meats
Corned Beef	Cheese, processed (American or spreads)

2. Canned foods/boxed mixes with added sodium  
(Choose low sodium varieties when available)

Canned vegetables, Soups, Pasta dishes  
Boxed pasta, Rice, and Potato mixes with sauces

3. Snacks and Miscellaneous items

Saltines	Cheese Curls
Potato Chips	Salted Popcorn
Pretzels	Salted Nuts

4. Seasonings, Sauces, and Dressings

Salt	Seasoned Salt
Garlic Salt	Onion Salt
Pickles	Meat Tenderizers
Olives	Relish
Ketchup	Soy Sauce

### **Fat and Cholesterol:**

One of the side effects of the medications which you are now taking is that they have the tendency to raise your blood cholesterol level to higher-than-normal levels. To help control your blood cholesterol, it is important to limit the amount of cholesterol, trans fat and saturated fat in your diet. Fat is also a concentrated source of calories, so cutting back on your fat intake can help you control your weight (if weight control is an issue).

### **Suggestions to Limit Saturated Fat and Cholesterol:**

- Limit red meat to 2-3 times a week in 3-to-4-ounce portions. Red meat is beef, lamb, pork, and veal.
- Choose white meats such as chicken, turkey, and fish as protein sources more often than red meat.
- Trim visible fats from meats. Remove poultry skin before eating.
- Limit egg yolks to 3 per week. Use egg whites or egg substitutes instead of whole eggs whenever possible.

- Choose nonfat and low-fat dairy products such as skim or 1% milk, nonfat yogurt and frozen yogurt, low fat or nonfat ice cream or ice milk, and low fat or nonfat cheeses.
- Avoid organ meats such as kidneys, liver, and brain.
- Limit your use of butter and stick margarine. Choose light tub or liquid margarine.
- Avoid frying foods. Prepare by baking, broiling, roasting, or steaming.
- For stir-frying, use a non-stick pan and Pam spray, or use Canola or Olive oil.
- Avoid commercially prepared cookies, cakes, crackers, chips and dips, ice cream, pastries, and salad dressings. Use canola oil rather than butter, lard, or vegetable shortening when making bread products at home.
- Read all labels carefully for the type and amounts of fats they contain.

### **Calcium:**

Osteoporosis is a risk factor after transplant because of medications. It is very important to have adequate calcium intake, 1200 mg per day, either by diet or supplements to help maintain strong bones.

Some of the best sources of calcium are dairy products. For example, one cup of milk can give you 300 mg of calcium. This is 25% of your Daily Value. If dietary fat is a concern, there are many low-fat dairy products from which you can choose.

Other non-dairy dietary sources of calcium include soy products, broccoli, turnip, collard, and mustard greens. If high calcium foods are difficult for you to eat regularly, please ask your doctor or dietitian which calcium supplements are right for you to take. Additional vitamin D supplements are also recommended to help you absorb adequate amounts of calcium.

Additional dietary modifications such as triglyceride, blood glucose control, low potassium and high magnesium guidelines may be necessary because of medications and will be individualized for you by the dietitian.

For **Cystic Fibrosis** patients after transplants: All your life you have been encouraged to gain weight and eat whatever foods appealed to you. Now after lung transplantation caution needs to be taken with weight gain efforts as some of your medications may cause high triglyceride and cholesterol levels. Please see the dietitian for heart healthy ways to increase calories while decreasing saturated fat intake. You may have also consumed foods with high sodium content and at this time it is still allowed but avoid using extra salt at the table and while cooking. For additional questions and suggestions ask the dietitian at clinic or by appointment.

## Lung Transplant Nutrition Care Plan

The information provided on the following pages is intended as a guideline to promote sound nutrition for a long and healthy life. More detailed information is available from your inpatient dietitian. As you are further out from your transplant your special nutrition needs may change. It is important for you to know that you can always have access to a dietitian at Brigham and Women's Hospital. If you live far away, the physician following you in your area can provide you with a referral to a dietitian that is closer to you. Nutrition plays a very important role after transplant and can have a significant impact on your quality of life as well as the success of your transplant.

### **Maintain a healthy weight:**

Keeping your weight within a healthy range will ease stress on your lungs, decrease high blood sugars associated with steroids, and decrease blood pressure. Talk to your doctor or dietitian about a desirable weight for your height after transplant.

**A side effect of the Prednisone that you will be taking is increased appetite. It will be important to keep healthy snacks on hand, and to avoid turning to “junk food” to curb your cravings.**

### **Healthy Snack Ideas:**

Whole Grain (like Wasa, Kavli, or Ak Mak) crackers with “natural” peanut or almond butter. (Natural butters have oil on top and need to be mixed before eating).

Carrots, cherry tomatoes, cucumber, and/or celery sticks with a vinaigrette salad dressing.

Nonfat yogurt

Fresh fruit or vegetables with low-fat cottage cheese

Baked corn chips with fresh salsa or guacamole.

½ whole-wheat tortilla with a few slices of turkey, tomato, avocado

Low salt soup with whole grain crackers

English muffin pizza: ½ whole grain English muffin + tomato sauce + light shredded mozzarella cheese

1 cup of Whole grain cereal with skim/1% milk

Bean dips or Hummus with baked pita chips

Whole grain rice cakes or soy cakes.

### **Meet your body's need for vitamins and minerals:**

Take a multiple vitamin with minerals for at least the first two months after transplant unless instructed not to do so by your transplant doctor or nurse practitioner.

A well balanced diet can usually meet your body's needs for vitamins and minerals in times of good health. Try to consume foods from each of the food groups every day, especially vegetables, fruits, whole grains, and low fat dairy products. If you eat at least five servings of fruit and vegetables per day, you may discontinue your multivitamin two months after transplant.

Although, to ensure you are meeting your body's needs for all vitamins and minerals, you may also continue a daily multivitamin on a regular basis.

Avoid herbal supplements and any other types of over-the-counter nutritional products not approved by the transplant team.

### **Take in adequate calcium:**

Everyone young and old needs calcium in his/her diet to help keep their bones and body healthy. If you don't get enough calcium from the foods and beverages you consume, your body takes calcium from your bones to meet its needs. The Prednisone you are taking causes your body to lose calcium, and over time this can make your bones weak and brittle.

It is recommended that you take in 1,200 mg of Calcium per day. Below you will find the calcium content of food items:

#### **Dairy Foods**

Yogurt, nonfat plain (1 cup) .....	452 mg
Skim milk (1 cup) .....	302 mg
Cheddar cheese (1 oz.) .....	204 mg
Ricotta cheese, part skim (1/4 cup) .....	169 mg
Cottage cheese (1 cup) .....	150 mg

#### **Nondairy Foods**

Tropicana Season's Best Orange Juice plus

Calcium (1 cup) .....

Whole Grain Total Cereal

(1 cup) .....

Pink salmon with bones, sardines

(3 oz. cooked) .....

Collards, frozen

(1/2 cup cooked) .....

Broccoli (1 cup, cooked) .....

Black beans (1 cup) .....

Almonds (1 tbsp.) .....

#### **Soy Products**

Soy yogurt with calcium

(3/4 cup) .....

Soy milk, enriched (1 cup) .....

Tofu, firm or extra firm

(1/4 cup) .....

Soy nuts, roasted/salted

(1/2 cup) .....

## Practice Good Food Safety

Since you are taking immune suppressing drugs, you will be more susceptible to infections and food-borne illnesses. The following recommendations should help to decrease your risk of this potential complication.

- Check expiration dates on all food packaging and consume the product before expiration.
- Wash tops of cans prior to opening.
- Follow package directions for storing items.
- Wash hands with warm soapy water before and after handling any raw foods.
- Thaw frozen foods in the microwave or in the refrigerator. Never thaw or marinate foods on the counter or in the sink.
- Sanitize cutting boards and counters with bleach (1 tablespoon per gallon water). Always clean cutting board after cutting raw meats.
- Never eat raw meat, poultry, seafood, or eggs. Cook eggs until whites are cooked and the yolk thickens
- Cook meats and poultry thoroughly. Use a meat thermometer inserted in the thickest part of the meat to make sure the internal temperature is at least 165 degrees.
- All juices and dairy products should be pasteurized. Avoid fresh squeezed juice, fresh apple cider, and homemade eggnog.
- Avoid sprouts, such as alfalfa, bean, and broccoli sprouts.
- Thoroughly rinse raw fruits and vegetables before eating or using in cooking.
- Avoid eating from street vendors, buffets and salad bars, and food samples at grocery stores. Use caution when eating out at restaurants.
- Use airtight containers to store leftovers. Refrigerate promptly. Do not let food sit at room temperature for more than 2 hours. Discard leftovers after two days in the refrigerator.
- Do not eat hot dogs, luncheon meats, or deli meats, unless they are reheated until steaming hot.
- Avoid getting fluid from hot dog packages on other foods, utensils, and food preparation surfaces, and wash hands after handling hot dogs, luncheon meats, and deli meats.

- Do not eat soft cheeses such as feta, Brie, and Camembert, blue-veined cheeses, or Mexican-style cheeses such as queso blanco, queso fresco, and Panela, unless they have labels that clearly state they are made from pasteurized milk.
- Do not eat refrigerated pâtés or meat spreads. Canned or shelf-stable pâtés and meat spreads may be eaten.
- Do not eat refrigerated smoked seafood, unless it is contained in a cooked dish, such as a casserole. Refrigerated smoked seafood, such as salmon, trout, whitefish, cod, tuna, or mackerel, is most often labeled as "nova-style," "lox," "kippered," "smoked," or "jerky." The fish is found in the refrigerator section or sold at deli counters of grocery stores and delicatessens. Canned or shelf-stable smoked seafood may be eaten.

**Remember, it is always better to err on the side of caution. “When in doubt, throw it out!”**

### **Limit sodium intake**

Some of your transplant medications cause sodium and fluid retention. One way to prevent some of this extra fluid accumulation is by restricting your sodium intake. You may find that you need to adjust your sodium intake depending on how well your body is maintaining your fluid status. If you are taking moderate to high doses of diuretics, are experiencing ankle or leg swelling, or have any other symptoms of too much fluid in your body you may need to be more restrictive with your sodium intake.

- Avoid using salt at the table or in cooking.
- Limit your use of processed foods such as canned goods, convenience foods, fast foods, and foods with more than 300-400 mg of sodium per serving.
- Try alternate flavoring aids such as pepper, spices, lemon and lime juices, fresh herbs, garlic, onion, and other sodium free flavorings.

### **Limit Alcohol**

It is the general recommendation of the transplant team that alcohol consumption be limited to special occasions only. Talk to your doctor before drinking any alcoholic beverages.

### **Questions?**

- Ask your Nurse Practitioner or Physician during your clinic visit.
- **Make an appointment with a dietitian at the Brigham and Women's Nutrition Consultation Service: (617) 732-6054**



## **MEDICATIONS**

## ***Lung Transplant Medications***

### ***Important information about medications***

#### **Important Things to Know About Your Transplant Medications**

- ❖ After your lung transplant, you will need to take medications to prevent rejection for the rest of your life.
- ❖ **Nonadherence (not taking your medications) is the most common reason for transplant rejection.** Try never to miss even one dose of your transplant medications. If you miss a dose of your medicine, call the Transplant Nurses or Pharmacist to ask how to proceed.
- ❖ It is very important to note that doses of your medications may change very often. This is especially true shortly after the transplant. You need to be dedicated to updating your list of current medications and doses and bring that list with you to all clinic visits.
- ❖ Because doses change so often, sometimes the instructions on the prescription bottle may be incorrect. If you are ever confused about how to take your medications, call a member of the transplant team for clarification.
- ❖ Try to establish a schedule. For example, try to take the medications the same time every day. This will help maintain a consistent level of the medications in your body and could help prevent rejection.
- ❖ If you miss a dose and it is almost time for your next dose, skip the missed dose, notify a member of your transplant team, and return to your regular schedule.
- ❖ Never “double-up” on your medications.
- ❖ All medications prescribed by your transplant team play an important role in keeping you healthy.
- ❖ However, along with their benefits, many of these medications can have several side effects and drug interactions. The side effects can be managed, but it is important that you notify the transplant team about any troubling side effects as soon as possible.
- ❖ Do not make changes to your own transplant medications as this can lead to rejection or toxicities. If you have any issues related to medication intolerance, please contact a member of the transplant team.
- ❖ Many of the transplant medications have several drug interactions. Please check with a member of your transplant team when starting a new prescription or over-the-counter medication, as these drugs may impact your transplant medications.

## *Lung Transplant Medications* *Immunosuppression- Meds you need to know*

### Tacrolimus (Prograf®, FK506, FK)



**generic name**

**Tacrolimus** - this medication is available as a generic and is available in 0.5mg, 1mg and 5mg capsules



**Trade Name**

**Prograf®**



#### **What is Tacrolimus?**

❖ Tacrolimus suppresses the immune system, which is necessary in lung transplant patients to prevent organ rejection.



#### **How long will I need to take Tacrolimus?**

❖ Tacrolimus is a lifelong medication after lung transplant.



#### **How much Tacrolimus do I take?**

- ❖ Doses are different for each patient, and you will get a dose that is necessary to reach a specific concentration in your blood.
- ❖ We generally start this medication at a low dose in the hospital after the transplant procedure and then slowly increase the dose of the medication up so that we can achieve an adequate level of drug in your blood.
- ❖ You will be required to take blood tests so that we can adjust the dose according to how much of the drug is in your blood.
- ❖ Doses of this medication change often, especially right after the transplant. It is important that you know how much of this medication you are always taking.



#### **How do I take Tacrolimus?**

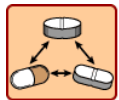
- ❖ Follow your transplant team's instructions carefully.
- ❖ This medication is generally given twice a day (the best way to take it is every 12 hours).
- ❖ You will be asked to take this medication with food to help prevent stomach upset.



#### **Tell me about the special blood tests that I need while I am taking Tacrolimus?**

- ❖ To make sure that you get the appropriate dose of Tacrolimus, it is necessary for the transplant team to check how much of this drug is in your blood.
- ❖ We will check your Tacrolimus blood level every time you come to the outpatient transplant clinic for labs.
- ❖ To successfully check the Tacrolimus level in your blood you must follow several steps:
  1. The night before clinic please take your dose 12 hours before you plan on being at the lab for blood work.

2. The next morning take all morning medications, except for the Tacrolimus, prior to coming to the clinic.
3. Once you arrive at the hospital go to give a blood sample.
4. After you have given the blood sample, take your morning dose of Tacrolimus.
5. Come to clinic ready to tell us your dose of tacrolimus, the time you took your dose the night before clinic and the time your blood sample was taken.
6. It takes 4 – 6 hours for us to get results back, so, if we need to change your Tacrolimus dose, we will call you at home to change your evening dose.



#### **Are there interactions between Tacrolimus and other drugs?**

- ❖ An interaction generally means that one drug may increase or decrease the effect of Tacrolimus.
- ❖ Also, the more medications a person takes, the more likely there will be a drug interaction.
- ❖ Tacrolimus interacts with many prescription and non-prescription medications, as well as some dietary supplements.
- ❖ Please consult with your transplant pulmonologist or transplant pharmacist before starting any new medications because of the potential for drug interactions.



#### **Are there interactions between Tacrolimus and foods or beverages?**

- ❖ It has been shown that grapefruit, grapefruit juice and other foods and beverages that contain grapefruit (for example, the soda Fresca has grapefruit juice in it) can increase the blood level of Tacrolimus.
- ❖ It is recommended that you avoid grapefruit, grapefruit juice and other foods and beverages that contain grapefruit while taking Tacrolimus.



#### **What are some of the more common side effects of Tacrolimus?**

- ❖ Increased creatinine (a measure of kidney function): Tacrolimus, especially at high levels, may increase your creatinine. If this occurs, it may be necessary for us to decrease your dosage. This is one of the major reasons why we will check your Tacrolimus levels so often.
- ❖ Increased blood sugar: some patients who are not diabetic before the transplant may develop difficulties controlling their blood sugars after the transplant. We often have to administer insulin to help control these high blood sugars. This side effect is one that may go away with time.
- ❖ Increased potassium: elevations in potassium levels can be seen in patients who are receiving Tacrolimus. Potassium levels are monitored every time labs are drawn. We can manage high potassium levels by lowering the Tacrolimus dose (if possible) or administering a medication that acts to lower the potassium levels.

- ❖ High blood pressure: high blood pressure is very common after transplantation. Tacrolimus can contribute to this. Several medications are available for use in transplant patients with high blood pressure.
- ❖ High cholesterol: high cholesterol is very common after transplantation. Tacrolimus can contribute to this. Several medications are available for use in transplant patients with high cholesterol.
- ❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take Tacrolimus with food.
- ❖ Hand tremor: Tacrolimus may cause a fine hand tremor in transplant patients and usually occurs in patients with a high blood level. This tremor may go away with time, but if it occurs, please let one of the transplant team members know and, if possible, we can lower the Tacrolimus dose.
- ❖ Hair loss: hair loss occurs in about 20% of patients receiving Tacrolimus. This side effect is generally seen within the 3 months post-transplant, and generally resolves on its own after approximately 6 months.

**NOTES:**

## *Lung Transplant Medications* *Immunosuppression- Meds you need to know*

### **Mycophenolate (CellCept®, Myfortic®, MMF)**



**Mycophenolate** - this medication is available as a generic

- ❖ Mycophenolate mofetil (CellCept®) is available in 250mg capsules & 500mg tablets
- ❖ Mycophenolate sodium (Myfortic®) is available in 180mg & 360mg tablets



**CellCept®, Myfortic®**



**What is Mycophenolate?**

- ❖ Mycophenolate suppresses the immune system but works differently compared to Tacrolimus.



**How long will I need to take Mycophenolate?**

- ❖ Mycophenolate is a lifelong medication following lung transplant.



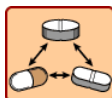
**How much Mycophenolate do I take?**

- ❖ Most patients start by taking 1000mg Cellcept® twice a day.
- ❖ We may decrease the dose or switch you to the sister drug Myfortic® if you experience any side effects.



**How do I take Mycophenolate?**

- ❖ Follow your transplant team's instructions carefully.
- ❖ This medication is generally given twice a day (the best way to take it is every 12 hours).
- ❖ You will be asked to take this medication with food to help prevent stomach upset.



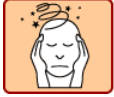
**Are there interactions between Mycophenolate and other drugs?**

- ❖ Mycophenolate does not have as many drug interactions as Tacrolimus, however, there are still some medications that may interact with Mycophenolate.
- ❖ Please consult with your transplant pulmonologists or transplant pharmacist before starting any new medications because of the potential for drug interactions.



**Are there interactions between Mycophenolate and foods or beverages?**

There are no known food or beverage interactions with Mycophenolate.



### **What are some of the more common side effects of Mycophenolate?**

- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection. Decreased white blood cell counts are common in patients taking Mycophenolate. If this side effect occurs, it may require that we reduce your Mycophenolate dosage.
  
- ❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is the most common side effect with Mycophenolate. In order to help prevent this, we will have you take Mycophenolate with food. If this side effect occurs despite taking the Mycophenolate with food, we may split up the doses of this medication (instead of two times a day, we may have you take smaller doses three or four times a day) or lower the total daily dose. Some patients who cannot tolerate the stomach upset or diarrhea from Mycophenolate may be changed to another transplant medication (Myfortic® or Azathioprine) that may cause less stomach or bowel irritation.
  
- ❖ Increased risk during pregnancy: Miscarriage and birth defects have been reported in patients who become pregnant while receiving Mycophenolate. Pregnancy testing and dual contraception are recommended while taking mycophenolate and for at least 6 weeks after discontinuing its use. If you are a female of childbearing age, you will be asked to sign a form acknowledging this risk with mycophenolate.

#### **NOTES:**

## *Lung Transplant Medications* *Immunosuppression- Meds you need to know*

### Prednisone



#### **Prednisone**

- ❖ In general, prednisone is available in 2.5mg, 5mg, 10mg and 20mg tablets



- ❖ This drug is available as a generic and is no longer available as a trade name product.
- ❖ Many pharmaceutical companies make a generic version of this medication; therefore, the pills are available in several different shapes and colors.



#### **What is Prednisone?**

- ❖ Prednisone suppresses the immune system but works differently compared to both Tacrolimus and Mycophenolate.
- ❖ Prednisone is known as a steroid. You may be familiar with this medication, as it can also be used to treat inflammation and pain.



#### **How long will I need to take Prednisone?**

- ❖ Prednisone is a lifelong medication after lung transplant.



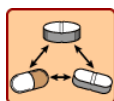
#### **How much Prednisone do I take?**

- ❖ You will be given very high intravenous doses (up to 500 mg) of this medication during and after the transplant procedure.
- ❖ You will be given an individualized steroid taper that you will be asked to follow upon discharge. Over the course of about 4 months your prednisone dose will taper down to 5mg daily, which you will remain on for life.



#### **How do I take Prednisone?**

- ❖ Follow your transplant team's instructions carefully.
- ❖ This medication is generally given once a day in the morning.
- ❖ You will be asked to take this medication with food to help prevent stomach upset.



#### **Are there interactions between Prednisone and other drugs?**

- ❖ Prednisone can interact with many prescription and non-prescription medications, as well as some dietary supplements.
- ❖ Please consult with your transplant nephrologists or transplant pharmacist before starting any new medications because of the potential for drug interactions.



#### **Are there interactions between Prednisone and foods or beverages?**



❖ There are no known interactions with any foods or beverages. However, prednisone may cause retention of sodium (salt), so try to keep your salt intake to a minimum.



### **What are some of the more common side effects of Prednisone?**

❖ Increased blood sugar: some patients who are not diabetic before the transplant may develop difficulties controlling their blood sugars after the transplant. We often have to administer insulin, an injectable medication, to help control these high blood sugars. This side effect is one that may go away with time.

❖ High blood pressure: high blood pressure is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high blood pressure.

❖ High cholesterol: high cholesterol is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high cholesterol.

❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. To help prevent this, we will ask you to take prednisone with food.

❖ Weight gain: prednisone can cause patients to gain weight by two mechanisms. First, it makes people hold onto water; therefore, the more water they hold onto, the heavier they get. Second, this medication can cause an increased appetite in approximately 3% of patients.

❖ Bone loss: osteoporosis is a rare, yet serious side effect of prednisone. Even as little as one dose of prednisone can cause bone loss. If you are maintained on prednisone, it is important to have your bone mineral density checked by your primary care physician. This test should be performed every two to three years in patients who remain on prednisone after the transplant. In order to prevent bone loss, you will be asked to take calcium, vitamin D and a once yearly IV infusion called Reclast.

❖ Night sweats: some patients may experience night sweats while receiving prednisone. This side effect usually takes place with higher doses and goes away with time.

❖ Mood changes: every night we make a similar drug to prednisone in our bodies when we sleep called cortisol. Cortisol helps us deal with stress and our emotions.

When prednisone is prescribed after the transplant, it is not uncommon to see patients develop rapid mood swings (i.e., happy to sad, laughing to crying). This side effect generally disappears after about 5 days of being on the prednisone. It is important that if you have had problems with depression or other psychiatric illnesses in the past that you let the transplant team know if the prednisone is making it worse.

❖ Cataracts: you will be asked to make yearly visits to your eye doctor to make sure that this side effect does not take place.

❖ Acne: a small percentage of patients may develop acne after the administration of prednisone. Good skin hygiene is the best prevention for this, and over-the-counter acne medications may be helpful, but please consult with a transplant team member before starting any medications for acne.

**NOTES:**

## **Other Maintenance Medications**

Our preferred immunosuppressive regimen is Tacrolimus, Mycophenolate and Prednisone.

We will consider changing the transplant medication you are taking if you develop severe side effects from any of the transplant medications. Changing from one transplant medication to another can increase the risk for rejection. This will only be done when we feel that changing medications will provide you with a benefit moving forward. Below you will find a list of other available transplant medications along with a brief description.

### **Cyclosporine (Neoral<sup>®</sup>, Gengraf<sup>®</sup>, CsA)**

- ❖ Cyclosporine can be used as a substitute for Tacrolimus.
- ❖ This medication is given twice a day, but also requires blood work to determine the appropriate dose for you.
- ❖ Cyclosporine has the same drug-interaction profile as Tacrolimus.
- ❖ The side effects of Cyclosporine are like Tacrolimus, except that Cyclosporine tends to cause more high blood pressure and high cholesterol, but less hand tremor and blood sugar problems.

### **Sirolimus (Rapamune<sup>®</sup>, Rapa)**

- ❖ Sirolimus can be used as a substitute for Mycophenolate.
- ❖ This medication is given once a day, but also requires blood work to determine the appropriate dose for you.
- ❖ Sirolimus has the same drug-interaction profile as Tacrolimus.
- ❖ The side effects of Sirolimus are like Tacrolimus, except that Sirolimus does not cause increased creatinine, but it can cause problems with wound healing, mouth ulcers, breathing difficulties (pneumonitis) and increases in cholesterol and triglycerides.

### **Enteric-Coated Mycophenolate (Myfortic<sup>®</sup>)**

- ❖ Enteric-Coated Mycophenolate is a coated version of Mycophenolate (CellCept<sup>®</sup>) and may be used a substitute for Mycophenolate.
- ❖ The coating may help prevent some of the stomach side effects seen with regular Mycophenolate (just like enteric coated aspirin causes less stomach side effects compared to regular aspirin).
- ❖ This medication is often given twice a day.
- ❖ This medication has the same drug-interactions and side effects as Mycophenolate.

### **Azathioprine (Imuran<sup>®</sup>, AZA)**

- ❖ Azathioprine can be used as a substitute for Mycophenolate.
- ❖ This medication is given once a day.
- ❖ This medication has a significant drug interaction with some medications used to prevent gout.
- ❖ This medication can cause less stomach upset than Mycophenolate.

## *Lung Transplant Medications*

### *Anti-infectives*

#### **Anti-Infectives**

- ❖ Any time a person's immune system is suppressed they are at increased risk for infections.
- ❖ Proper hygiene, especially handwashing, is essential to prevent infections.
- ❖ It is also important to make sure that you have been adequately vaccinated prior to the transplant (i.e., pneumococcal vaccine, flu-vaccine, etc.).
- ❖ To help prevent you from getting an infection after the transplant we will be putting you on two different types of antibiotics.
- ❖ You will receive one medication that is active against a type of pneumonia.
- ❖ Lung transplant patients are at high risk for developing a pneumonia called *Pneumocystis jiroveci* (formerly known as *Pneumocystis carinii* or PCP).
- ❖ This germ is spread in the air and is common all over the world. Since you can't help being exposed to this germ, you will receive a medication to prevent this infection.
- ❖ The most common medication used to prevent this pneumonia is called Bactrim, which is a sulfa-drug.
- ❖ Some patients have an allergy to sulfa-drugs. If you are allergic to Bactrim, you will receive another medication called Mepron or be desensitized to Bactrim.
- ❖ You will receive a second medication that is active against viral infections.
- ❖ Cytomegalovirus or CMV, is a virus that is common in about 70% of Americans.
- ❖ People are usually infected by the time they are 2 years old or during their teenage years.
- ❖ Many people are infected with CMV and don't even know it because CMV usually does not cause long-term problems.
- ❖ CMV is spread through contact with an infected person's body fluids (such as saliva, blood, urine, semen, or breast milk). It can be sexually transmitted or transmitted through an organ transplant.
- ❖ Both you and your donor will be tested to see if you have ever been exposed to this virus.
- ❖ If either you or your donor have been exposed to the CMV virus, then you will receive the medication Valcyte. If neither you nor the donor have ever been exposed, you will receive Valtrex.

## Lung Transplant Medications Anti-infectives

### Antibiotic – Sulfamethoxazole/Trimethoprim (Bactrim<sup>®</sup>, SMZ/TMP)

- ❖ As mentioned above, the most common antibiotic used to prevent *Pneumocystis* pneumonia is called Sulfamethoxazole/Trimethoprim (Bactrim), which is a sulfa-drug.



generic name

**Sulfamethoxazole/Trimethoprim** (also known as SMZ / TMP) - this drug is available as a generic medication and is available as a “single strength (SS)” 400mg/80mg tablet and a “double strength (DS)” 800mg/160mg tablet.



Trade Name

**Bactrim<sup>®</sup>**



**How do I take Sulfamethoxazole/Trimethoprim?**

- ❖ The dose is different for every patient. It is dependent on blood tests at the time of transplant.



**How long will I need to take Sulfamethoxazole/Trimethoprim?**

- ❖ Bactrim is a lifelong medication after lung transplant.



**What are some of the more common side effects from Sulfamethoxazole/Trimethoprim?**

- ❖ Increased creatinine: Sulfamethoxazole/Trimethoprim may increase your creatinine. If this occurs, it may be necessary for us to discontinue this medication early or start you on a different antibiotic.

- ❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.

- ❖ Increased potassium: elevations in potassium levels can be seen in patients who are receiving Sulfamethoxazole/Trimethoprim. Potassium levels are monitored every time labs are drawn. Persistent elevations in potassium may require us to discontinue this medication and start you on a different antibiotic.

- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

- ❖ Sensitivity to the sun: this medication can make your skin more sensitive to the sun and more likely to develop sunburn, even in the winter. Please wear sunscreen when you go out into the sun to help prevent sunburns.

- ❖ Rash: rarely, patients receiving Sulfamethoxazole/Trimethoprim can develop a rash. If this happens to you, please call your one of the transplant team member. You may need to be switched to another antibiotic.

## *Lung Transplant Medications* *Anti-infectives*

### **Antibiotic – Atovaquone (Mepron®)**

❖ For those patients that are allergic to sulfa-drugs, we will use Atovaquone to prevent *Pneumocystis pneumonia*, which is just as effective, but does not cause the allergic reactions that are seen in some patients who take sulfa-drugs.



**generic  
name**

**Atovaquone-** this drug is currently available as a generic medication and only comes as a liquid suspension of 750mg/5mL.



**Trade  
Name**

**Mepron®**



**How do I take Atovaquone?**

❖ You will take 1500 mg (10 mL or 2 teaspoons) once daily.



**How long will I need to take Atovaquone?**

❖ Atovaquone is a lifelong medication after lung transplant.



**What are some of the more common side effects from Atovaquone?**

❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. To help prevent this, we will ask you to take Atovaquone with food.

**NOTES:**

## *Lung Transplant Medications* *Anti-infectives*

### **Antiviral – Valganciclovir (Valcyte®)**

- ❖ If either you or your donor has been exposed to CMV, then you will receive a medication called Valganciclovir, which is very effective at preventing CMV from causing an infection.



**generic name**

**Valganciclovir**- this medication is currently available as a generic and comes as a 450mg tablet.



**Trade Name**

**Valcyte®**



**How do I take Valganciclovir?**

- ❖ The dose of your valganciclovir will be dependent upon your kidney function and may change over time as your kidney function changes.



**How long will I need to take Valganciclovir?**

- ❖ You will be taking this medication for 6-12months following the transplant depending upon your risk of developing the CMV infection.
- ❖ This medication may be restarted after the transplant if we believe you are at increased risk to develop CMV disease, such as after receiving treatment for acute rejection



**What are some of the more common side effects from Valganciclovir?**

- ❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. To help prevent this, we will ask you to take this drug with food.
- ❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

**NOTES:**

*Lung Transplant Medications*  
*Anti-infectives*

**Antiviral – Valacyclovir (Valtrex®)**

❖ If both you and the donor have never been exposed to CMV, then you will receive a medication called Valacyclovir, which is used to prevent an infection from the Herpes Simplex Virus.



**generic name**

**Valacyclovir** - this drug is available as a generic medication and comes as a 500mg tablet.



**Trade Name**

**Valtrex®**



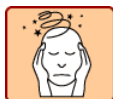
**How do I take Valacyclovir?**

❖ The dose of your valganciclovir will be dependent upon your kidney function and may change over time as your kidney function changes.



**How long will I need to take Valacyclovir?**

❖ You will be taking this medication for 6-12 months following the transplant.  
❖ This medication may be restarted after the transplant if we believe you are at increased risk to develop viral infections, such as after receiving treatment for acute rejection



**What are some of the more common side effects from Valacyclovir?**

❖ Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.

❖ Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

**NOTES:**



***Lung Transplant Medications***  
***Vaccinations***

**Vaccinations**

- ❖ It is important to make sure that you have been adequately vaccinated prior to the transplant (i.e., pneumococcal vaccine, flu-vaccine, etc.).
- ❖ We may not administer any vaccinations within 3 months of the transplant or until your prednisone dose is lowered because you will not respond to the vaccine given the high amount of immunosuppression you will be receiving.
- ❖ However, after the transplant, some vaccines should not be administered to patients on drugs that suppress the immune system. The vaccines that we ask you to avoid are those that come from live viruses.
- ❖ See below for a list of vaccines that are appropriate for patients before and after the transplant procedure. Please discuss the use of vaccines with a member of the transplant team before receiving any vaccinations.
- ❖ You should get the flu vaccine your PCP every year and the pneumococcal vaccine every five years by your PCP. If you are unable to get these vaccines from your PCP, please contact the transplant team.

Vaccine	Recommended for transplant candidates	Recommended for transplant recipients
*Influenza (Flu)	Yes	Yes
Hepatitis B	Yes	Yes
Hepatitis A	Yes	Yes
Tetanus	Yes	Yes
Polio, inactivated	Yes	Yes
<i>S. pneumonia</i>	Yes	Yes
<i>N. meningitides</i>	Yes	Yes
Rabies	Yes	Yes
Varicella	Yes	No
BCG	Yes	No
Papillomavirus (HPV)	Some	Yes (for some patients)
Smallpox	No	No
Anthrax	No	No
Zoster	Some	No

\* Please note that transplant patients should not be given the nasal flu vaccine (FluMist®) because it is a live virus. Also, it is recommended that family members also NOT receive the nasal flu vaccine. If any member of your family (or anyone living in your household) receives a live-virus vaccine, you should do your best to avoid contact with that individual for at least one week (yes, we understand this will be difficult).

## *Lung Transplant Medications*

### *Other commonly used medications*

#### **High Blood Pressure and High Cholesterol Medications**

- ❖ Heart disease is a very serious problem in kidney transplant patients.
- ❖ High blood pressure occurs in nearly 85% of patients after the transplant.
- ❖ High cholesterol occurs in nearly 60% of patients after the transplant.
- ❖ Your blood pressures and cholesterol levels will be monitored very closely after the transplant.
- ❖ It is very important for transplant patients to try to stick to a heart-friendly diet and to try to exercise (walking, biking, swimming, etc.).
- ❖ Proper management of your blood sugars (in patients who have diabetes) and stopping smoking (in patients who smoke) can all help improve your health.

#### **High Cholesterol**

- ❖ The important transplant medication Tacrolimus is known to increase cholesterol, and so is prednisone.
- ❖ The goal “bad cholesterol” (LDL cholesterol) is less than 100.
- ❖ Diet is the first step to try to reduce your cholesterol.
- ❖ Many patients will require medication to lower their cholesterol level.
- ❖ Your transplant team will choose the cholesterol lowering medication that is right for you.
- ❖ When you are on a cholesterol medication, a muscle enzyme test known as “CK” and your liver enzymes will be checked every 3 months, because cholesterol-lowering medications may rarely affect the levels of these lab tests.

#### **High Blood Pressure**

- ❖ The goal blood pressure after the transplant will be less than 130/80. However, if you are a diabetic, the recommended goal blood pressure is at or less than 125/75.
- ❖ Many patients require more than one medication to control their blood pressure.
- ❖ Your transplant team will choose the blood pressure medication(s) that is/are right for you.

### **Blood Sugar Medications**

- ❖ High blood sugars are very common after transplantation with new onset diabetes occurring in up to 25-30% of lung transplant recipients, mostly due to medications.
- ❖ Diabetes after transplant is associated with increased risk of heart disease and infection which are serious complications following transplant.
- ❖ Your blood sugars will be monitored very closely after transplant
- ❖ Most patients will be taught how to use and be discharged home with a glucometer, a device that measures blood sugars.
- ❖ If your blood sugars are consistently high after transplant you will be started on insulin, an injectable medication to help lower your blood sugars.
- ❖ Some patients can stop insulin if their sugars improve as the prednisone dose decreases, however some patients may require long term management of blood sugars with insulin or an oral agent.

### **Blood Thinning Medications**

- ❖ Blood clots are very common following lung transplant, occurring in up to 30% of patients.
- ❖ Blood clots can lead to serious complications including pulmonary embolism which could affect the function of your new lung.
- ❖ Ambulation is essential to prevent blood clots. However, after lung transplant most patients are not able to walk enough to prevent blood clots on their own.
- ❖ You will receive an injection called enoxaparin or heparin to help thin the blood to prevent blood clots.
- ❖ You will be discharged on this injectable medication for approximately one-month post-transplant, until we are confident that you are walking enough to prevent blood clots without medication.

## Over the Counter (OTC) Medications & Dietary Supplements

- ❖ Over-the-counter medications and dietary supplements are consumed by millions of American for common illnesses such as aches and pains, stomach upset, diarrhea, the common cold, and others.
- ❖ Many over-the-counter medications are safe for transplant recipients to take, but several are not.
- ❖ If, at any time after the transplant, you want to use an over-the-counter medication, please call your transplant team to make sure that it is OK to take these medications.
- ❖ Some over-the-counter medications are not good to use in lung transplant patients because they can harm the kidney, raise the blood pressure, or have interactions with some of the transplant medications.
- ❖ **Some common over-the-counter medications that should never be taken by lung transplant patients include:**

- ❖ Aches and Pains:
  - Ibuprofen (also called – Motrin, Advil, Haltran, Ultraprin, I-Prin, Menadol, Proprinal)
  - Naproxen (also called – Aleve)
  - Ketoprofen (also called – Orudis KT)
  - Choline salicylate (also called – Arthropan)
  - Magnesium salicylate (also called – Doan’s, Keygesic, Momentum)
  - Sodium salicylate
- ❖ Cough and Cold:
  - Pseudoephedrine (also called – Sudafed)
  - Phenylephrine (also called Sudafed PE)
- ❖ Laxatives:
  - Sodium Phosphates (also called – Fleets Enema, Fleets Phospho-Soda)
- ❖ Anti-Diarrheals
  - Kaolin and Pectin (also called – Kaodene, KaoSpem, Kapectolin)

- ❖ It is important for you to know that many over-the-counter medications contain several different drug combinations. For example, Tylenol Allergy Sinus contains acetaminophen, chlorpheniramine and pseudoephedrine. Because this product contains pseudoephedrine, transplant patients should not use it.
- ❖ Please read over-the-counter medications boxes very carefully, looking specifically for the active ingredients.

- ❖ Call one of your transplant team members if you are confused about what over-the-counter products you can or cannot take.
- ❖ The Food and Drug Administration (FDA) do not approve dietary supplements for use in the United States; therefore, we cannot safely advise our patients to take them.
- ❖ Several dietary supplements have been shown to have severe interactions with transplant medications. For example, St John's Wort has been shown to decrease the blood levels of Tacrolimus, which may cause rejection.
- ❖ Other dietary supplements are known to cause harm to the kidneys, such as chromium and creatine.
- ❖ **Please avoid the use of any dietary supplements unless it is specifically discussed with one of the transplant team members.**

**NOTES:**

## Over-the-Counter Cough and Cold Medications Fact Sheet

### Steps for selecting an OTC cough/cold product:

1. Read the product label. Identify the drug chemical name. This is usually on the back and will give an amount next to it.
2. Check to see if the medication name is on the approved medications list (right). If you are unsure, check with your pharmacist or the transplant team.
3. Do not use products that contain ingredients on the "Not Approved" List

### LOOK AT THE DRUG INGREDIENTS

**Drug Facts**

**Active ingredients (in each caplet)**

Acetaminophen USP 325 mg.....

Dextromethorphan hydrobromide USP 15 mg.....

Phenylephrine hydrochloride USP 5 mg.....

**Uses**

- temporarily relieves
- headache
- minor aches and pains
- minor sore throat

**Drug Facts (continued)**

- nasal and sinus congestion
- cough
- temporarily reduces fever

**Warnings**

**Alcohol Warning:** If you consume 3 or more alcoholic drinks a day, do not take acetaminophen or other pain relievers/fever reducers. **Acetaminophen** can cause liver damage if you drink alcohol and take acetaminophen.

**Do not use**

- with any other product containing acetaminophen
- if you are now taking a prescription monoamine oxidase inhibitor (MAOI), psychiatric, or emotional conditions, or Parkinson's disease, or if you do not know if your prescription drug contains an MAOI, ask a doctor

**Ask a doctor before use if you have**

- heart disease
- high blood pressure
- thyroid disease
- cough that occurs with too much phlegm (mucus)
- trouble swallowing
- cough that lasts or is chronic such as occurs with smoking, asthma, or emphysema

**When using this product** • do not exceed recommended dose

**Stop use and ask a doctor if**

- nervousness, dizziness, or sleeplessness occurs
- fever gets worse or lasts more than 3 days
- new or worse pain, cough or nasal congestion gets worse or lasts more than 7 days
- sore throat is severe, persists for more than 2 days, is accompanied by fever, rash, nausea, or vomiting
- cough comes back or occurs with fever, rash or headache the next day

**If pregnant or breast-feeding, ask a health care professional**

**Keep out of reach of children.**

**Overdose Warning:** Taking more than the recommended dose may cause serious liver damage. In case of overdose, get medical help or contact a Poison Control Center at 1-800-438-2246.

### Approved Medications:

#### Pain Reliever:

- ✓ Acetaminophen (Tylenol®)
  - This drug relieves aches, pains and fever. It should not be taken with alcohol
  - Maximum daily dose is 3000mg- more than this can cause damage to the liver.

#### Antihistamine:

- ✓ Brompheniramine (Dimetapp®)
- ✓ Ceterizine (Zyrtec®)
- ✓ Chlorpheniramine (Chlor-trimeton®)
- ✓ Diphenhydramine (Benadryl®)
- ✓ Fexofenadine (Allegra®)
- ✓ Loratadine (Claritin®)
  - These medications will make you drowsy. Avoid alcohol and driving while taking these medications.
  - These medications may also cause urine retention. Consult a member of the transplant team if this occurs.

#### Cough (please call your nurse coordinator as this may represent an infection):

- ✓ Guaifenesin (Mucinex®)
  - This medication is used to loosen congestion in the chest to help aid in coughing the mucus up.
- ✓ Dextromethorphan
  - This medication is used to suppress or stop a cough.
  - Check with your pharmacist if you are taking anti-depressants or mood stabilizers.
  - Do not take more than 120 mg in one day.

#### Runny Nose:

- ✓ Drink plenty of fluids, especially water
- ✓ Use a humidifier
- ✓ Saline Nasal Spray (Ocean®)

## Approved Medications:

### Decongestants:

- ✓ Saline Nasal Spray (Ocean<sup>®</sup>)
- ✓ Vicks Nasal Inhaler<sup>®</sup>
- ✓ Oxymetazoline Nasal Spray (Afrin<sup>®</sup>)
  - You may only use nasal decongestion sprays.
  - **Do not use the spray for longer than 3 days or the congestion may get worse.**
  - You must monitor your blood pressure if you use oxymetazoline.

### Sore Throat:

- ✓ Drink plenty of fluids especially water.
- ✓ Gargle with salt in warm water.
- ✓ Phenol Spray (Chloraseptic<sup>®</sup>)
- ✓ Throat Lozenges
  - Cough drops are ok, as long as they do not contain any herbal supplements.
  - Cepacol<sup>®</sup>, Chloraseptic<sup>®</sup>, Sucrets<sup>®</sup> are ok.

### Combination Products:

- Generally, combination products should be avoided. Please check with your pharmacist or transplant team for specific product questions. Here is a list of combination products that are OK to take:
  - NyQuil<sup>®</sup> cold and flu (acetaminophen + dextromethorphan + doxylamine)
  - NyQuil<sup>®</sup> cough (dextromethorphan + doxylamine)
  - Robitussin<sup>®</sup> cough and congestion (dextromethorphan + guaifenesin)
  - Tylenol PM<sup>®</sup> (acetaminophen + diphenhydramine)
  - Tylenol<sup>®</sup> Severe Allergy (acetaminophen + diphenhydramine)
  - Tylenol<sup>®</sup> chest congestion (acetaminophen + guaifenesin)

## Not Approved-

### Do Not Take Medications:

- Any generic or store brand product that contains un-approved ingredients.
- Any medication not listed on the approved list without your transplant doctor's approval.
- Any herbal supplements.

### Some examples of products to avoid:

- Airborne<sup>®</sup>
- Alka-Seltzer Plus Cold<sup>®</sup>
- *Aspirin (ok to take for heart protection)*
- Claritin D<sup>®</sup> or Loratadine D (plus pseudoephedrine)
- Cold-eeze<sup>®</sup> products
- DayQuil<sup>®</sup> multi-symptom cold and cough
- DayQuil<sup>®</sup> Sinus
- Ibuprofen (Advil<sup>®</sup>, Motrin<sup>®</sup>)
- Ketoprofen (Orudis<sup>®</sup>)
- Naproxen (Aleve<sup>®</sup>)
- NyQuil<sup>®</sup> Sinus
- Phenylephrine (Sudafed PE<sup>®</sup>)
- Pseudoephedrine (Sudafed<sup>®</sup>)
- Robitussin<sup>®</sup> cough and cold CF
- Robitussin<sup>®</sup> chest congestion PE
- Robitussin<sup>®</sup> cough cold and flu
- Robitussin<sup>®</sup> cough and allergy
- Tylenol<sup>®</sup> Allergy multi-symptom
- Tylenol<sup>®</sup> sinus congestions and pain (regular, day or nighttime formulations)
- Tylenol<sup>®</sup> allergy complete
- Tylenol<sup>®</sup> sinus
- Tylenol<sup>®</sup> Cold Multi-symptom
- Tylenol<sup>®</sup> Cold Congestion
- Theraflu<sup>®</sup> Products
- Vicks<sup>®</sup> 44<sup>®</sup>D cough and head congestion relief
- Zicam<sup>®</sup> Products
- Zinc preparations

***Lung Transplant Medications***  
***Drug Interactions***

**Drug Interactions**

- ❖ The transplant medications have a lot of drug interactions with other prescription and over-the-counter medications, as well as dietary supplements.
- ❖ When one medication interacts with a transplant medication, it may result in increased or decreased exposure to the transplant medication, or it may expose the patient to medications with similar side effects.
- ❖ Some practical examples of drug interactions may include:
  - Tacrolimus and Verapamil (blood pressure medication) = increases in tacrolimus blood levels potentially resulting in tacrolimus toxicity.
  - Tacrolimus and Carbamazepine (medication used to prevent seizures) = decreases in tacrolimus blood levels potentially resulting in rejection of the transplant.
  - Tacrolimus and Ibuprofen (over-the-counter pain medication) = both medications can cause kidney dysfunction and when used together are more likely to cause this side effect.
- ❖ Below is a small list of medications that would interact with your transplant medications and could potentially cause toxicities or rejection of the transplant.
- ❖ Because medications can go by different names before you start ANY new medication you should check with your Transplant Pharmacist or Transplant Pulmonologist.

<b><i>Antibiotics</i></b>	<b><i>Antifungals</i></b>	<b><i>Blood Pressure</i></b>	<b><i>Pain Relievers</i></b>	<b><i>Others</i></b>
- Amikacin - Clarithromycin - Erythromycin - Gentamicin - Isoniazid - Rifampin - Tobramycin	- Amphoterecin B - Fluconazole - Itraconazole - Ketoconazole - Lipid-based Amphotericin B - Posaconazole - Voriconazole	- Diltiazem - Nifedipine - Verapamil	- Celecoxib - Diclofenac - Diflunisal - Etodolac - Fenoprofen - Flurbiprofen - Ibuprofen - Indomethacin - Ketorolac - Meclofenamic Acid - Meloxicam - Naproxen - Piroxicam - Sulindac	- Amiodarone - Calcium - Carbamazepine - Danazol - Magnesium - Metoclopramide - Phenobarbital - Phenytoin - Protease Inhibitors - Sevelamer

***Lung Transplant Medications***  
***Your Medication Schedule***



- ❖ The Transplant Pharmacist will make up a medication schedule that is SPECIFIC for you at the time you are discharged from the hospital after the transplant. An example medication schedule can be seen below. Please carry this schedule with you to all clinic visits and keep it updated as your medications change over time.
- ❖ Your transplant pharmacist would be glad to update the medication schedule for you upon request in the transplant clinics.

Medication	Dose	Use	Morning – w/ food	Afternoon	Evening – w/ food	Bedtime
Tacrolimus (Prograf)	3 mg twice daily <b>12 hours apart</b>	Prevents Rejection	X (3 capsules)			X (3 capsules)
<b><i>On days you come to clinic, do not take the Prograf (tacrolimus) in the morning until after your blood test</i></b>						
Mycophenolate (Cellcept)	1000 mg twice daily	Prevents Rejection	X (4 capsules)			X (4 capsules)
Prednisone	10 mg once daily	Prevents Rejection	X (2 tablets)			
Valcyte (Valganciclovir)	900mg once daily	Antiviral	X (1 tablet)			
Bactrim DS (Sulfamethoxazole/TMP)	1 tablet <b>three times weekly</b>	Antibiotic	X (1 tablet M-W-F)			

**Some Medications that you may get prescriptions for that you will only take “as needed” include:**

- Pain Medications (such as oxycodone, and/or acetaminophen [Tylenol])
- Stool softener (such as docusate)
- Laxative (such as senna or senokot)

**Special Instructions:**

- When you come to the clinic, do not take the Prograf (tacrolimus) in the morning, but bring the pills with you. Come to the clinic and have your blood drawn. Immediately after having your blood drawn, take your morning dose of the Prograf (tacrolimus).
- You will take the Prograf (tacrolimus) twice a day. Please try your best to take the morning and evening doses 12 hours apart from each other. For example, if you take the morning dose at 7 am – try to take the evening dose at 7 pm.
- You will be taking Bactrim (Sulfamethoxazole/TMP) for six to twelve months. After this time, we will discontinue this medication.
- You will be taking Valganciclovir (Valcyte) for six months. After this time, we will discontinue this medication.

## *Lung Transplant Medications Medication Planning for Discharge*

### Obtaining Medications for Discharge

- ❖ Once you have undergone a transplant at BWH, we will begin your discharge which will include extensive medication teaching. Community Walgreens is an outpatient pharmacy that BWH uses to supply all lung transplant patients with an initial supply of maintenance medications.
- ❖ The transplant team will order medication based on the needs of each individual patient. Medications will be delivered to your floor on the day of your discharge. They will be packaged in a black nylon tote with your name and medical record number as an identifier.



#### Included in the CVS Specialty package:

- One plastic, weekly pill organizer
- One pill splitter
- One oral digital thermometer
- One Blood pressure cuff
- Labeled medication bottles

- ❖ Community Walgreens is available to fill future prescriptions, or you can transfer all your prescriptions to your local outpatient or mail-order pharmacy.
- ❖ As a reminder.....
  - If you are down to 5-7 days of medication, please call Community Walgreens to schedule a delivery.
  - They require 3 business days (weekend not included) for a free delivery. All calls should be made before 2pm.
  - There are delivery charges for next day and Saturday delivery.
  - All new prescriptions called in by a doctor's office before 2pm are next day delivery (no charge).
- ❖ You will be asked to call to verify all current personal information, including credit card number for copays, addresses, any changes in insurance, and phone numbers.

**Community Walgreens**  
**21-23 Stanhope Street**  
**Boston, MA 02116**  
**617-375-7969**  
**Fax 617-375-9656**



## **MEDICATION SCHEDULE**























## **FAMILY MEETING / QUESTIONS**

## Family Meeting Outline

### 1. Transition Home

- Changes needed in your home
- Visitors
- Children
- Sick family members or friends

### 2. Responsibilities once your go home:

- Medications
- Daily log sheets (vital signs, spirometry)
- Blood glucose monitoring
- Daily exercise log- Spend 30 minutes of dedicated activity, i.e., treadmill, walking or biking a day.

### 3. Emergencies:

- Wear Medical Alert Bracelet or Necklace
- Identify blood restrictions on the form:
  - i. Lung Transplant
  - ii. CMV Negative Blood Only

### 4. Nursing Services at Home

\*Everyone goes home with VNA initially after transplant.

\* You may also be seen by PT and OT

They will provide help and instructions with:

- Vital Signs
- Wound Care
- Blood sugar monitoring
- Reinforcement of new medications and treatments
- Physical Therapy
- Occupational Therapy

### 5. Infection Control:

- MASK

When you NEED to wear it:

Around crowds, in the hospital, and around anyone that is sick.

How long?

It is very important for the first year and until your Prednisone taper is at a stable dose

(You can purchase masks at a CVS or local pharmacy. However, we will give you some prior to you leaving the hospital)

### 6. Vital Signs:

- Document the following on the diary sheets in your vital sign section of the binder:
  - Blood Pressure
  - O2 Saturation
  - Heart Rate
  - Weight
  - Temperature
- 7. Spirometry:
  - How often: Daily
  - Why: To monitor your lung function. A decline could indicate rejection or infection
  - You may order a micro spirometer of your choice if it records the following values: FVC and FEV1.
  - A company we routinely use and will send an order to is Remetric Health: phone 484-664-7600, fax 484-664-7500
- 8. What symptoms to watch for:
  - Temperature greater than 100.5, new shortness of breath or increase in shortness of breath, new cough, or newly productive cough, nausea vomiting, or any worrisome symptoms
  - Assess your incisions for: redness, swelling, drainage, or increased pain.
- 9. When to call the transplant team:
  - Call for any question or concern. Better to call than not to call.
  - All the important numbers are located in the front section of the diary.
  - Call Coordinators during the daytime hours or call the doctor who is on-call after hours, and on weekends.

#### While At Home Reminders:

- 10. Lifting:
  - No lifting anything greater than 8 pounds; includes pursing and pulling.
  - (While taking prednisone you can feel energetic and stronger, but still no lifting anything greater than the 8-pound limit)
- 11. Pets:
  - No Birds
  - Do not change the cat litter
  - Dogs and Cats are ok to own, however they need to stay updated on all of their shots and grooming
- 12. Pain medicine post-Transplant:
  - Most will go home on oral pain medication
  - Can take Tylenol for discomfort



13. Driving

- No driving for 3-6 months
- No driving while taking narcotics
- No driving until physically able

14. Sexual Activity

- No sexual activity for 6 weeks post-transplant
- If not in monogamous relationship, very important to practice safe sex.

15. Nutrition:

- Low fat, low sodium, and well-balanced diet are important.

16. Alcohol:

- Not recommended

17. Smoking:

- No smoking and no secondhand smoke exposure allowed.

18. Travel

- No travel for the first 6 months.
- Prior to making any travel plans, please be sure to discuss with the team.

19. Work:

- No work for the first 6 months. Then, you may return on a part-time basis. Please discuss with the team prior to resuming work

20. Gardening:

- Refrain from gardening immediately after your transplant and caring for your house plants until your pulmonary MD says it is ok.

21. Aspiration Precautions:

- It is very important to keep the head of the bed elevated 30 degrees.
- Do not use pillows. Purchase a wedge pillow that must be 12-inches thick. (This is not covered by insurance).
- Take an H2-Blocker (Nexium, Pepcid, Omeprazole) or PPI (Protonix)
- No eating 2 hours before going to bed.
- Avoid foods high in acidic content.

## Clinic and Follow-Up appointments and Procedures

### 22. Clinic:

- Clinic appointments are every Monday and Wednesday.
- On the day of your appointment, you need to arrive **one-hour** earlier than your scheduled clinic appointment time. This is so you can have blood work and a chest x-ray prior to your appointment.
- Where to go:
  - i. Blood work: Out- Pt lab at 45 Francis St.
  - ii. Chest X-Ray: On the PIKE between 15 and 45 Francis Street across from Lung Center C.
- What to bring: Diary, list of questions, and morning dose of Tacrolimus or Cyclosporine dose
- Be sure to wear your MASK

Note: Your blood work for you Tacrolimus or Cyclosporine level needs to be drawn 12-hours after you have taken your evening dose. It is very important for you to take your dose 12 hours before your level is drawn. Please bring in your morning dose of Tacrolimus or cyclosporine with you to clinic and take it after your blood has been drawn. No fasting before blood work is needed.

### 23. Bronchoscopies:

- They will be performed at: 1-month, 3-months, 6 months, and 1 year post transplant.
- Arrive 45 minutes before procedure
- Do not eat or drink anything the night before and morning of the procedure.
- If on blood thinners, aspirin, and insulin speak with your outpatient coordinator ahead of time.
- You will need to arrange for a ride home after the test because you cannot drive yourself. If you show up without a ride home your test will be rescheduled for another day.
- You may need to be admitted after if the doctor feels it necessary.
- You may experience hoarseness, fever, and have bloody sputum.

### 24. Outpatient labs:

- You may be asked to get labs drawn on the same day. If getting labs locally, please utilize one of the MGB (Mass General Brigham) labs sites or a Quest lab.

## Family Meeting Transplant Quiz

1. What is my outpatient coordinator's name and phone number?
  - a. Name: \_\_\_\_\_
  - b. Number: \_\_\_\_\_
2. What is the location of my local Quest or MGB (Mass General Brigham) lab site?
  - a. \_\_\_\_\_
3. Hand washing is the number one way to stop the spread of infection. **True or False**
4. Name three side effects of each of the following medications:
  - Tacrolimus
  - Mycophenolate
  - Prednisone
5. List three complications of lung transplant
  - a. \_\_\_\_\_
  - b. \_\_\_\_\_
  - c. \_\_\_\_\_
6. Most patients experience one episode of rejection in the first 12 months post-transplant. **True or False**
7. Three things to focus on after lung transplant is to cough, walk and deep breathe. **True or False**
8. Depression is uncommon after transplant. **True or False**
9. Following transplant my kidney function needs to be watched very closely. **True or False**
10. On clinic days what medication needs to be held until your blood is drawn?
11. If you have an appointment for 10AM, what time do you need to come to clinic?
12. When around crowd's post-transplant a mask is not necessary. **True or False**
13. An accurate medication list with dosage and frequency is required at each clinic visit along with daily weight, temperature, and spirometry. **True or False**
14. Any type of house pet is allowed post-transplant. **True or False**

15. Gardening is not allowed for the first-year post-transplant. **True or False**
16. What is the purpose of daily spirometry?
17. At what times during the first-year post-transplant are bronchoscopies performed?
18. You will have enough time to request a medication refill the day before you run out.  
**True or False**
19. Before a bronchoscopy can you eat and drink?
20. What should you do if a family member or friend is sick?
21. Home physical therapy and pulmonary rehabilitation are important components in post-transplant care. **True or False**
22. When will you be allowed to drive after transplant?
23. Why do you need to elevate the head of your bed post-transplant?
24. After transplant you may need to go to a rehab facility before going home.  
**True or False**
25. Some patients may require glucose monitoring and insulin at home after transplant.  
**True or False**







## **DAILY LOGS**











**Daily Vital Signs and Spirometry**

Day	Time	Weight	Temp	O2 Sat	Blood Pressure	Heart Rate	FVC	FEV1



















