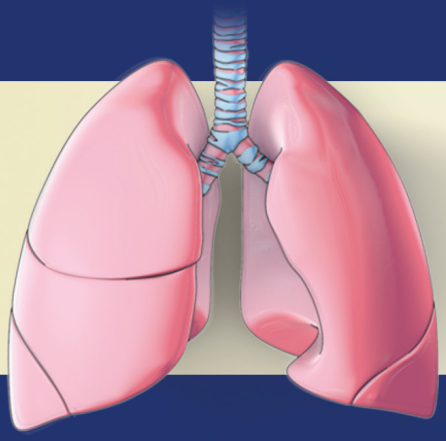
Emory Lung Transplant Program

Journey to Transplantation



YOUR TRANSPLANT GUIDE

EMORY
TRANSPLANT CENTER

Making a difference in the lives
of our patients and our community.

Table of Contents

The most important information you may ever read 2
Why you may need a lung transplant 3
Healthy Lungs 3
Failing Lungs 3
Types of Lung Transplants 4
History of Lung Transplantation 4
Your transplant evaluation 5
Tests 5
Meeting the Team 5
Financial Considerations 8
Before Your Evaluation 8
During Your Evaluation 8
Billing 9
Sample Questions to ask your Insurance Company 10
Waiting for your transplant 12
The Waiting List 12
Your Status on the List 12
The Lung Allocation System 12
Finding a Donor 13
Anxiety Is Normal 13
Dealing with Stress 14
Going to the hospital 15
The Phone Call 15
Leaving for the Hospital 15
Arriving at the Hospital 15
The Lung Transplant Surgery 16
What Happens After Surgery 18
Deep Breathing and Coughing 18
Possible complications after transplant 19
Acute Rejection 19
Infection 20
Bronchiolitis Obliterans Syndrome (BOS) 20
Hypertension/High Blood Pressure 20
Post-Transplant Diabetes 21
Cytomegalovirus (CMV) 21
Medications 22
Learning about Your Medications 22
Where to Get Your Medications 22
Frequently Used Medications 23
Other helpful information 28
Mason Guest House 28
The Mentor Project 28
JumpStart 29
Helpful Web Sites for the Lung Transplant Patient 29

The most important information you may ever read

Now that you are considering a lung transplant, your recovery may depend on your understanding of what to expect before, during and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel free to jot down notes in the margins and ask questions about anything you do not understand or concerns you might have.

At Emory University Hospital, we consider lung transplantation when conventional medication and surgery cannot improve the function of your failing lungs. Transplantation offers many people the chance not only to survive, but to return to a more normal, productive lifestyle.

The Emory lung transplant team seeks to thoroughly educate every candidate about transplantation. Post-transplant management can be difficult and demanding. You and your family must completely understand the risks, limitations and benefits of transplantation before you can make an informed decision concerning this procedure.

It is important to understand that a lung transplant does not "cure" your lung disease. You will need daily medication and rigorous follow-up care by the transplant team for the rest of your life.

The Emory lung transplant team is committed to helping you if you are committed to the demands and requirements of transplantation. Your attitude about surgery and recovery and your participation in your care will play a vital role in the ultimate success of your lung transplant.

Why you may need a lung transplant

HEALTHY LUNGS

The lungs provide your entire body with oxygen and remove carbon dioxide. The lungs are elastic, cone-shaped organs, located in the chest within a protective cage of 12 pairs of ribs and the intercostal muscles between the ribs. The lungs also are supported by the neck muscles and by the diaphragm, the muscle that separates the chest cavity from the abdominal cavity. The right lung, which is larger than the left, is divided into three lobes: upper, middle and lower. The left lung, which is somewhat narrower than the right to accommodate the heart, is divided into two lobes: upper and lower. Each lung is surrounded by two protective layers of tissue called pleura that seal the lungs in an airtight cavity.

The trachea, or windpipe, branches into two mainstem bronchi, resembling an inverted tree-like structure. Each mainstem bronchi divides into five lobar bronchi, which further branch into the bronchioles, the alveolar ducts and, finally, the alveoli. The branches become smaller and smaller as they spread out. The smallest branches end in about 300 million tiny sacs called alveoli, which are the basic units of gas exchange.

Blood that is to be oxygenated in the lungs travels from the right ventricle of the heart into the pulmonary arteries, which bring blood to the alveoli. Gas exchange occurs between the alveoli and tiny blood vessels called capillaries. Oxygen passes from the alveoli into the blood, and carbon dioxide, a waste product of metabolism, leaves that blood to enter the alveoli, and is thereby removed from the body. Freshly oxygenated blood returns through the pulmonary veins to the left atrium of the heart, where it is pumped out and distributed throughout the body.

FAILING LUNGS

People need lung transplants when their lungs can no longer perform their vital function of exchanging oxygen and carbon dioxide. Lung transplant candidates have end-stage lung disease and are expected to live less than two years. They often require continuous supplemental oxygen and are extremely fatigued from an insufficient supply. Their lungs are too diseased to be managed medically, and no other kind of surgery will help them.

Several different diseases can lead to end-stage lung failure. Chronic obstructive pulmonary disease (COPD) can be caused by asthma, chronic bronchitis and emphysema. Alpha-1-Antitrypsin Deficiency, a hereditary condition causing the lack of a protein needed for healthy lungs, is responsible for some cases of emphysema. Interstitial lung diseases include idiopathic pulmonary fibrosis,

sarcoidosis, eosinophilic granuloma, Goodpasture's syndrome, idiopathic pulmonary hemosiderosis and Wegener's granulomatosis. Two airway diseases that can lead to end-stage lung disease are bronchiectasis and cystic fibrosis. Primary pulmonary hypertension is a progressive disease that causes high blood pressure of the pulmonary vessels in the lung and can be a life-threatening condition.

TYPES OF LUNG TRANSPLANTS

You may require either a single, double or heart-lung transplant. Your doctor will discuss which type of transplant is recommended for your condition.

HISTORY OF LUNG TRANSPLANTATION

Lung transplant is a treatment, not a cure, for end-stage lung disease. The first human lung transplant was performed by James Hardy, MD, at the University of Mississippi in 1963 for an isolated cancer of the lung. The patient lived for 18 days and died of kidney failure. Between 1963 and 1980, about 44 transplants were performed at medical centers around the world with no real success. Most of these transplants were performed on debilitated patients as "rescue" attempts after they became ventilator-dependent. Only two recipients lived longer than one month.

This disappointing start contributed to a halt in lung transplantation until cyclosporine was introduced in the early 1980s. Heart-lung transplantation was performed successfully in 1981 at Stanford University and became the only option for lung transplantation until it became commonplace in the late 1980s.

The first lung transplant associated with prolonged postoperative survival was performed by Joel Cooper, MD, at the Toronto General Hospital in 1983. The patient received a right lung transplant for idiopathic pulmonary fibrosis and survived for more than six and a half years before succumbing to renal failure. In 1986, Dr. Cooper performed the first successful double lung transplant. Results continue to improve because of better medications and treatment of infection and rejection. The main limiting factor today is the limited supply of donor organs.

In 1993, Emory established the only lung transplantation program in the state of Georgia, with the primary mission of serving those residents of Georgia suffering from otherwise untreatable complex lung diseases. Our patient survival rates are consistent with national averages.

Your transplant evaluation

Your primary doctor or pulmonologist may refer you for evaluation if your lung function is very low (determined by a pulmonary function test) and he or she thinks no other medical or surgical therapy will help you. Your medical records will be sent to us for review. If an evaluation is necessary, you will come for an outpatient visit with a transplant pulmonologist and nurse coordinator. During this visit, you will be interviewed, examined and counseled about what we think is the best plan for your care. This may or may not include full evaluation for lung transplantation. The realities of having and living with a lung transplant are explained and discussed. If it is decided to proceed with more evaluation, an additional two to three days of inpatient or outpatient testing will be needed.

TESTS

The evaluation visit consists of meeting many different people who will perform different tests. Tests may include:

- Ventilation/perfusion lung scan (VQ scan)
- Chest X-ray (CXR)
- Computed tomography (Chest CT)
- Six-minute walk test
- EKG (electrocardiogram)
- Abdominal ultrasound
- Bone density scan
- Pulmonary function test (PFT)
- Echocardiogram
- Heart catheterization
- Blood testing
- Urine testing
- Psychological evaluation

MEETING THE TEAM

It is important that you meet all the members of the lung transplant team during your evaluation. Each brings special knowledge that will help you during the various phases of the transplant process. The transplant team reviews the results of your evaluation. A plan of care is presented to you for consideration. This may or may not include the next step in the transplantation process – being placed on the waiting list for a donor lung or lungs.

Transplant Surgeon

The transplant surgeon will perform your lung transplant surgery and will be in charge of your care immediately following your surgery. The transplant surgeon will also follow your progress as needed after you are discharged from the hospital.

Transplant Pulmonologist

The transplant pulmonologist will provide overall supervision of your medical care and, while you are on the waiting list, should be kept informed of your condition and consulted by your local pulmonologist. He or she may see you occasionally while you wait for a donor lung or lungs and, for the first few months after transplant, will see you routinely to perform bronchoscopies, adjust your medications and monitor your progress.

You will see the transplant pulmonologist less frequently as time goes by, except if you experience problems. A pulmonologist is available 24 hours a day for urgent problems that may occur after hours. Once you have returned home, your local physicians need to be aware of your transplant and consult the transplant pulmonologist as needed.

Transplant Coordinator

The transplant coordinator is a bachelor's-prepared registered nurse who is specially trained to care for patients before and after lung transplantation. The coordinator will help arrange your evaluation, teach you and your family about transplantation, and follow your progress in the hospital and at each clinic visit after you are discharged. The transplant coordinator will help answer your questions and provide support for you and your family.

Social Worker

A social worker is available for supportive counseling for you and your family during this challenging and stressful time. If you need information about local housing, fund-raising or other transplant issues, the transplant social worker will assist you.

Financial Coordinator

The financial coordinator will help you understand the cost of transplantation and your insurance benefits. He or she can answer questions about insurance coverage and help you contact the appropriate personnel regarding these questions.

Psychiatrist

A psychiatrist will meet with you to obtain a general mental health history. He or she may recommend counseling to deal with emotional needs or issues, such as depression or alcohol, drug or tobacco use, that might affect the outcome of

the transplant. A psychiatrist will meet with you following your transplantion to continually monitor your mental health and assist with any needs that may develop.

Clinical Nutritionist

Our clinical nutritionist will see you before and after your transplant to evaluate your diet and to help you maintain a healthy weight and healthy lungs. After your transplant, it is not uncommon to have difficulty maintaining your weight, blood pressure and blood sugar. Eating a balanced, nutritious diet is very important, but can be challenging at times. The nutritionist will be available to see you regularly after your transplant to discuss these issues.

Pharmacist

The transplant pharmacist may begin working with you the day you transfer to the surgery floor. It is important for you to clearly understand your medications and how each affects your body. The pharmacist will explain the actions, dosages and side effects of your medications. The pharmacist will be available during each hospitalization to answer questions about your medications.

Physical Therapist

A physical therapist may help pre-transplant patients understand post-transplant exercises that may be prescribed by the transplant pulmonologist. He or she is specially trained to help you regain your strength after surgery and will refer you to a pulmonary rehabilitation program in the early weeks after transplant. Exercise is important to your recovery. It can reduce complications after transplant surgery, improve your endurance and help you maintain a healthy lifestyle.

Chaplain

Transplantation often raises many spiritual issues. A chaplain will visit with you while you are at Emory University Hospital and is on call 24 hours a day. The chaplain can help you and your family deal with conflicting emotions and difficult spiritual questions that are often associated with transplantation.

Staff Nurses

Staff nurses are responsible for monitoring your day-to-day progress, as well as optimizing your environment for a smooth recovery. They will teach you how to monitor your vital signs, look for signs and symptoms of infection and care for your incision site once you go home.

FINANCIAL QUESTIONS?

Call the financial coordinator at 1-855-366-7989.

DISABILITY QUESTIONS?

Call the social worker for lung transplantation at 1-855-366-7989.

FINANCIAL CONSIDERATIONS

The following information regarding the financial costs of lung transplantation will help you begin financial planning. You will need to know how much your insurance will pay for the lung transplant and for immunosuppressant medications. It is unlikely that one single source will cover all of these costs. Often it is necessary to draw on savings accounts, investments, federal and private assistance options and monies from fund-raising efforts.

BEFORE YOUR EVALUATION

Before you come to Emory for your evaluation, call your insurance company's case manager to see if your insurance covers lung transplantation. (See sample questions to ask.) Get a copy of your benefits for lung transplantation, including deductible and copayment amounts.

A financial coordinator will help you consider the financial arrangements you will need to make for transplantation. Call the financial coordinator at 1-855-366-7989 before your evaluation if:

- You have any questions regarding your insurance
- You do not have insurance
- You do not have benefits for transplantation
- You are denied coverage for a transplant

Contact the social worker for lung transplantation at 1-855-366-7989 if:

- You need help applying for disability
- You would like to discuss other financial assistance options

DURING YOUR EVALUATION

Most insurance companies require a review of your evaluation results to see if you meet their criteria for coverage of lung transplantion. For this reason, you will be asked to sign a consent form authorizing Emory to release the medical information from your evaluation to your insurance company.

If you are a candidate for a lung transplant, the lung transplant program will work with you in obtaining approval from your insurance company. If your insurance carrier denies authorization of benefits, the lung transplant program personnel will be happy to write a formal appeal for you. However, please be advised that gaining insurance approval is ultimately your responsibility.

You will meet with a social worker during your evaluation to discuss social issues in detail. You will also meet with the financial coordinator to discuss financial issues during your evaluation.

BILLING

Authorization by your insurance company for medical services provided by Emory does not guarantee full payment of all charges. You will be responsible for the following:

- All deductibles, copayments and non-covered services as outlined in your health plan.
- Any difference between charges and what your insurance carrier pays as "usual and customary charges." Ask your insurer for a copy of its usual and customary charges list and an explanation of how it derives them.

You will receive separate billing statements with separate billing account numbers for Emory University Hospital (inpatient and outpatient hospital services) and the Emory Clinic (inpatient and outpatient doctors' fees and medical services provided by the Emory Clinic). All Emory Clinic charges will be billed on one account. However, you will have several different accounts with Emory University Hospital. The first nine numbers on every hospital account will always be the same; only the last four (4) numbers will change.

Your accounts will include:

- Inpatient admissions (a different account for each admission).
- Specimen accounts (a separate account for lab specimens drawn outside of Emory University Hospital, including those specimens drawn at the Emory Clinic buildings).
- Recurring accounts (outpatient follow-up visits). This account is referred to either as an outpatient recurring or transplant recurring account.

Recurring accounts will remain open for three to six months. Any outpatient hospital charges during that period will be placed on that account. For recurring accounts, the hospital bills your insurance company once a month.

YOU WILL RECEIVE SEPARATE BILLS FROM:

- *Emory University Hospital for inpatient and outpatient hospital services*
- *Emory Clinic for doctors' fees and medical services*

PAYMENT ARRANGEMENTS

Emory University Hospital and the Emory Clinic provide services to you with the expectation that you will pay your bills in full, not your insurer. If you will not be able to pay the balance on your account in full, the hospital and clinic business offices will be happy to work with you to set up payment arrangements. To arrange a payment plan or learn more about Medicare reimbursement, please call the financial coordinator at 1-855-366-7989.

SAMPLE QUESTIONS TO ASK YOUR INSURANCE COMPANY

1. Do I have benefits for lung transplantation?

2. What is my maximum transplant benefit?

3. What is my lifetime maximum benefit? How much have I used toward that maximum?

4. What is my annual maximum benefit? How much have I used toward that maximum?

5. Is organ acquisition covered? If yes, is there any limitation on how much my insurance will pay?

6. Does my insurance plan have "Centers of Excellence" for transplant services? If yes, is Emory University Hospital an approved transplant center? If so, is there a different billing address than the one listed on my insurance card that transplant claims must be sent to? (Note: If there is a different address to submit claims to, please be sure that each time you come to Emory for transplant services, you tell the insurance registration representative the correct address.)

7. What are my deductibles, copayments and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket expenses?

8. What are considered usual and customary charges? How much am I likely to pay?

9. Do I need to obtain authorization or precertification for outpatient office visits and medical services such as pulmonary function studies or bronchoscopies?

10. Are outpatient prescription drugs covered? Specifically, immunosuppressant medications such as Imuran®, CellCept® and Prograf®. How much of the outpatient prescription drug cost is my responsibility? Is there a mail-order pharmacy that I can use that provides a higher level of benefit?

11. Is there a specific nurse case manager who will coordinate my transplant care? If yes, what is his or her name and phone number?

12. Do I have any transportation or lodging benefits?

13. Are ambulance or air ambulance services covered at the time of transplantation?

14. Am I in a preexisting condition period during which care for lung transplantation is not covered? If yes, what conditions need to be met for my transplant to be covered?

Please request a copy of your health insurance policy and bring it with you to your evaluation.

Waiting for your transplant

THE WAITING LIST

If you and the transplant team agree that you are a suitable candidate for transplantation, the team will place your name on a waiting list for a donor lung or lungs. The United Network for Organ Sharing (UNOS) is the national agency that regulates organ transplantation. LifeLink of Georgia facilitates organ donation for the state of Georgia. UNOS, along with LifeLink of Georgia, puts your name on a national computerized transplant waiting list and helps locate donor organs. You may access information on UNOS via the Internet at www.unos.org.

Due to a critical shortage of donor organs, adults can wait up to two years or more before a suitable donor lung is available. Often patients can wait at home during this time.

While you are waiting, you will continue follow-up care with your referring physician. However, it is important that we are always aware of any illnesses that occur, so please inform your coordinator of any illness you may have. Please ask your physician's office to fax us the office notes of all your visits. We would like to see you in our clinic at least every three months.

Finally, if you plan to travel while you are waiting, please inform your coordinator of your travel plans in case there are additional phone numbers we need to contact you.

YOUR STATUS ON THE LIST

You will be listed as an active-status patient on the lung transplant waiting list. When an organ becomes available, the patient with the greatest number of cumulative days spent waiting and with the proper blood group and body size will receive the donor lung.

The longer you are on the list, the more "points" (days on list) you accumulate. Moving closer to the top of the list makes it more likely that you will be transplanted if a donor lung becomes available.

THE LUNG ALLOCATION SYSTEM

In the lung allocation system, every lung transplant candidate age 12 and older will receive an individualized lung allocation score. The lung allocation score is an important factor in determining priority for receiving a lung transplant when a donor lung becomes available. The system determines the order of everyone awaiting a lung transplant by their lung allocation score, blood type and the geographic distance between the candidate and the hospital where the lung donor is located. The lung allocation system uses medical information specific to teach

lung transplant candidate. The information includes lab values, test results and disease diagnosis. This medical information is used to calculate a lung allocation score from 0 to 100 for each transplant candidate. The lung allocation score represents an estimate of the severity if each candidate's illness and his or her chances of success following a lung transplant. All candidates are placed in order for compatible lung offers according to their score. A candidate with a higher lung allocation score receives higher priority for a lung offer when a compatible lung becomes available.

FINDING A DONOR

Every effort will be made to find a donor quickly. The wait for a donor depends on your blood type and body size. To find a donor match for you, we look at two things:

- You and the donor must have compatible blood types.
- You and the donor must be height-compatible.

Many families ask questions about the age of the donor and how the donor died. The transplant team cannot give out any information to you about the donor, nor do we give any information about you or your family to the donor family. The donor family has been promised that this information will be kept confidential.

We do encourage you to write a letter to the donor family without revealing your identity. If you choose to write a letter, the transplant coordinator will send it to LifeLink of Georgia, who will then forward it to the donor family.

ANXIETY IS NORMAL

Everyone has a different experience with transplantation. You may encounter personal, physical, psychological, spiritual or financial stresses during each phase of lung transplantation.

During transplant evaluation, waiting for the transplant and after the transplant, you may feel discouraged, afraid, anxious, sad or depressed. It is normal to worry that you might die before an organ becomes available. Members of your family may also experience emotional distress related to your illness and worry about the risk of death before transplantation.

Post-transplant life can be a challenge too, even if you are highly motivated and well-adjusted. Complications are likely for most recipients and may require treatment and hospital stays that interfere with daily life. As a transplant recipient, you will also be recovering from surgery and taking new medications that may cause extremes in your emotions. It is common to experience anxiety, depression and anger after your transplant. These feelings may improve as you get further from your transplant, but often they do not. You need to share these feelings with your transplant team so we can help you.

LUNG TRANSPLANT SUPPORT GROUP

Contact: Wendy Wyche

wendy.wyche@emoryhealthcare.org

DEALING WITH STRESS

Many transplant candidates report that keeping a positive attitude about the situation helps. Other helpful coping strategies during the waiting period include getting involved in activities and seeking support from others.

Simply talking with someone may help put your feelings into perspective and relieve stress and anxiety. Check with your social worker for the times and places of support group meetings in your area. There are also other organizations that can provide support, including the Mentor Project, Second Wind Lung Transplantation Association (national and local chapters) and the Georgia Transplant Foundation (GTF). Please see the "Other Helpful Information" section of this book for more details.

While you can expect these brief periods of discouragement, they should not affect your usual daily activities. If these feelings occur frequently (for longer than a week or two) or begin to interfere with your daily activities, let your doctor and coordinator know.

Our goal as the transplant team is to help you openly explore and discuss your feelings at any time during the transplant process. Please do not hesitate to call us.

Going to the hospital

THE PHONE CALL

When a donor lung becomes available, a transplant coordinator from the call center will call you using the phone list you provided to your pre-transplant coordinator. If we cannot get in touch with you at the first number you have provided, we will continue to call the other phone numbers on the list you have provided. Please call us back within five to ten minutes.

We will tell you that we have a potential donor, and then ask how you have been feeling. If you have a fever, vomiting or diarrhea, we may not be able to perform the transplant. The most important thing you can do while waiting for a transplant is to seek treatment quickly if you become ill, so that you will be ready at any time should a donor lung become available.

Receiving a call does not always mean the transplant will occur. We will tell you that we have a potential donor. The surgeon examines each donor organ and may find that the organ is not strong or healthy. If the donor organ is not functioning well, we will not preform the transplant. This does not happen often, but it is a possibility.

LEAVING FOR THE HOSPITAL

You need to leave your house within 15 to 30 minutes of our call so that you can arrive at Emory as soon as possible. If you have difficulty driving to the hospital, please call the coordinator and we will try to help you get here safely. We would not want you to miss a chance for a new lung because, for instance, your car broke down.

If you have arranged to fly here, you will need to contact the air ambulance service immediately for departure and arrival times and then tell your coordinator. With this information, we can anticipate when you will arrive at Emory.

ARRIVING AT THE HOSPITAL

When you arrive at Emory University Hospital, please drive to the valet entrance on Clifton Road, then go directly to admissions located on the second floor of the hospital. They will direct you to your room, where you will be prepared for surgery. This time may be very hectic. We will take your vital signs, perform a chest X-ray and EKG, weigh you and do blood tests. You will also receive some medication by mouth and through a vein before going to the operating room. You may have to wait in your hospital room for up to 24 hours before you are taken to the operating room. This all depends on how long it takes to get your donor lungs to Emory. Single lung transplant surgery will last approximately four hours. Bilateral lung transplant surgery will last approximately six to eight hours.

Your family can wait in a special waiting room in the hospital while the surgery is taking place. This is also the place where an operating room nurse may talk with your family during surgery, most likely calling them by phone to provide status reports during the transplant. The surgeon will also look for your family in this waiting room after the surgery.

THE LUNG TRANSPLANT SURGERY

After arriving in the operating room, you will receive general anesthesia and be put to sleep. You may be placed on a heart-lung machine (cardiopulmonary bypass) that will handle the functions of your heart and lungs while the surgeon is working on both your old and new lungs. You will also have a breathing tube in your throat, called an endotracheal tube. This tube is connected to a machine called a ventilator, which will breathe for you during and after the operation.

If you are having a single lung transplant, you will have a thoracotomy incision either on your right or your left side, depending on which lung is being replaced. After the donor lung arrives in the operating room, the surgeon will remove your diseased lung. You will be ventilated using your other lung. If your remaining lung is not able to exchange enough oxygen, the surgeon may place you on cardiopulmonary bypass. Your blood will be filtered through a machine outside your body that puts oxygen into your blood and removes carbon dioxide.

Three connections will be used to attach your new lung. These connections are called anastomoses. First, the main bronchus from the donor lung is attached to your bronchus. Then, the blood vessels are attached: first the pulmonary artery, and then the pulmonary veins. Finally, the incision is closed and you will be taken to the intensive care unit, where you will be asleep for approximately 12 to 24 hours.

If both your lungs are transplanted (a bilateral transplant), the surgeon will make an incision below each breast, called an anterior thoracotomy, or an incision that goes from your right side to your left side at the base of your breasts. This is called a transverse sternotomy incision. In a bilateral lung transplant, each lung is replaced separately. The surgeon begins by removing the lung with the poorest function. You will be ventilated using your remaining lung unless partial cardiopulmonary bypass is needed. Once your first lung is removed, a donor lung will be attached using three connections. The donor bronchus is attached to your main bronchus, then the blood vessels are attached: first the pulmonary artery, then the pulmonary veins. Your second diseased lung is removed and the other new lung is attached in the same way as the first one. Once the second lung is completely connected, blood flow is restored. Finally, your incision is closed and you are taken to the intensive care unit (ICU). With either incision, nerves can be cut, resulting in various degrees of decreased sensation.

Various tubes and monitoring equipment will be used to monitor how well your lungs and body are recovering after surgery.

- IVs (intravenous tubes) will help you receive fluids and medications. A special IV called a pulmonary artery catheter (Swan-Ganz catheter) in your neck vein will measure the pressures in your heart and lungs and tell the surgeon how well your new lungs are functioning.
- A heart monitor will record your heart rate and rhythm at all times.
- Tubes in your chest near the bottom of your incision and possibly on the sides of your chest will drain the blood and fluid that collect in your chest after the operation. They are usually removed several days after the surgery.
- A small tube in your bladder, called a Foley catheter, will help us measure how well your kidneys are working. This tube will be taken out a couple of days after your surgery, and then you will urinate on your own.
- An epidural catheter may be placed to manage your pain. Later, you will receive pain medication (through your IV tube) that you dose yourself through a special patient-controlled analgesia (PCA) device.

As you begin to recuperate and feel stronger, all the tubes and catheters will be removed.

HOW TO USE THE INCENTIVE SPIROMETER

1. *Assume a comfortable, relaxed sitting position.*
2. *Attach one end of the tubing to the unit and one end to the mouthpiece.*
3. *Slide the pointer to your target volume as instructed by the respiratory therapist or nurse.*
4. *Hold the unit in an upright position.*
5. *Exhale normally, then place your lips tightly on the mouthpiece.*
6. *Breathe in slowly to raise the piston to the target volume.*
7. *Avoid raising your shoulders as you inhale.*
8. *Remove the mouthpiece and hold your breath for about five seconds until the piston falls to the baseline.*
9. *Slowly exhale through your mouth.*
10. *After each breath, cough and breathe deeply. Do not just clear your throat.*
11. *Relax and pace yourself in order to avoid excessive fatigue or dizziness.*
12. *Repeat steps five through nine at least 10 times.*

WHAT HAPPENS AFTER SURGERY

After surgery, you will go to the Cardiothoracic Surgery ICU, where a doctor and nurses are always on hand if you need anything. At first, you will be under the effects of anesthesia. You will have many IVs, special tubes and, initially, a breathing tube. Once you wake up and breathe on your own, the breathing tube will be removed.

When you first wake up, you may feel like you are not getting enough air. It is important to relax and let the ventilator breathe for you. You will not be able to talk while on the ventilator, but you can talk immediately after the ventilator is removed. The ventilator may be very uncomfortable, but the team will work very hard to remove it as soon as your heart and lungs are ready.

You will also hear many different noises. These are normal sounds made by the equipment around you and by people talking.

You will probably look different to your family. You will be pale and possibly swollen and will feel cool to their touch. This will improve after just a few hours in the ICU. You will also still be sleepy and may not remember the first time your family visits.

Your stay in the ICU may be as short as three days or as long as several weeks. You will then be transferred to the thoracic surgery floor, where our nurses and physical therapists will help you regain your strength, teach you how to care for yourself when you go home and prepare you for discharge from the hospital. If all goes well, you can expect to spend two to three weeks on the thoracic surgery floor.

DEEP BREATHING AND COUGHING

Deep breathing and coughing will help expand your lungs and remove lung secretions that have settled during your surgery. A respiratory therapist will show you how to use an incentive spirometer, a device that will help you take deep breaths. You will take the incentive spirometer home with you to use the first four to six weeks after surgery.

Since you will have a chest incision, coughing may be painful. The nurse will teach you how to splint (decrease the pain by holding a pillow or your hands over your incision). Ask the nurse for pain medicine if needed so you can breathe deeply and cough more easily and effectively.

Possible complications after transplant

Most people who receive a lung transplant will develop one or more complications after their surgery. Most of these complications are minor, treatable and no cause for alarm. Your transplant team will help you understand early warning signs, be available to discuss your care and recommend further treatment when necessary.

Donor organs are screened for various diseases in accordance with standards required by the Centers for Disease Control and Prevention (CDC) and UNOS. However, transplant recipients may be at risk for contracting certain diseases from the organ donor, such as various types of infectious diseases and cancers that are not detected during the organ donor screening process.

Some of the most common complications seen after lung transplant are: rejection, infection, bronchiolitis obliterans syndrome (BOS), high blood pressure and diabetes (please see definitions below).

ACUTE REJECTION

Rejection is a natural response of your body's immune system. The immune system acts as the body's defense against foreign invaders such as viruses, bacteria and even some types of cancers. This natural defense system will also recognize a transplanted lung as foreign and try to reject it.

Acute rejection is a cellular reaction that takes place in the tissues of the lung and can be seen under a microscope. Almost all lung transplant patients will have at least one or two episodes of acute rejection in the first year following the transplant. Usually, acute rejection is treated with IV steroids and will require a short inpatient hospitalization.

To help prevent your body from acutely rejecting your new lung, you will take medications called immunosuppressants that will lower your immunity, or defense against foreign agents. These medications, when taken on time and as prescribed, reduce the risk of severe rejection, which can damage the lung. You will take these medications for the rest of your life.

You will have a bronchoscopy at regular intervals so the doctor can look closely at your lungs and take tissue samples to determine if your body is rejecting the new lung or if you are developing an infection.

You may feel good and have no symptoms, yet still be experiencing rejection or infection. That is why we follow your progress so closely after transplant. **If you have any of the symptoms of possible rejection listed to the right, call your transplant coordinator.**

REJECTION WARNING SIGNS

If you have any of these symptoms, call the transplant coordinator:

- *Fever greater than 100.5 degrees Fahrenheit*
- *Excessive tiredness or fatigue*
- *Shortness of breath*
- *Weight gain of more than two to three pounds in 24 hours or more than four to five pounds in two to three days*
- *Loss of appetite, nausea or vomiting*
- *Change in pulse rate or heart rhythm*

INFECTION WARNING SIGNS

If you have any of these symptoms, call the transplant coordinator:

- *Fever, chills or sore throat*
- *Nausea, vomiting or diarrhea*
- *Headache or sinus drainage*
- *Productive cough*
- *Wound redness, swelling or pus*
- *Pain or burning while urinating*

INFECTION

As a lung transplant recipient, you will be more susceptible to infection because you will take immunosuppressant medications to help prevent rejection. The risk of infection from bacteria, viruses and fungi are greatest in the early period following transplant when dosages of medicines are at their highest. That's why it is important to protect yourself from exposure to infections while in the hospital. Here's how:

- Wear a mask whenever you are out in public or in a crowded area.
- Anyone entering your room must wash their hands.
- After transplant, take your temperature three times a day and keep a record in the daily diary that we will provide.
- Avoid large crowds of people in the first month after transplant.
- Avoid people with colds or the flu.
- Carefully clean any cuts or scrapes that you receive with antibacterial soap (such as Safeguard or Dial) and water.
- Always call the transplant coordinator if you suspect an infection or develop a fever.
- See the section on protecting yourself from infection (later in this booklet) because there are several items not included in this list.

BRONCHIOLITIS OBLITERANS SYNDROME (BOS)

The most common late complication of lung transplant is the development of bronchiolitis obliterans syndrome (BOS) or obliterative bronchiolitis (OB). OB is an inflammatory disorder of the small airways, that can lead to obstruction and destruction of pulmonary bronchioles. BOS refers to chronic lung rejection. BOS affects up to 50% of lung transplant patients within five years of transplant and is perhaps the main impediment to prolonged survival.

A patient with BOS usually complains of dry or productive cough and progressive difficulty in breathing that is not helped by bronchodilators. The main functional abnormality is airflow obstruction, which is measured by a decline in forced expiratory volume (FEV1). BOS is usually treated with increased doses of immunosuppression medications, which provides improvement in some, but not all, patients. Patients are closely monitored for the development of infections that may be more likely to develop witgh increased immunosuppression.

HYPERTENSION/HIGH BLOOD PRESSURE

Many transplant recipients take medications to control hypertension or high blood pressure, since prednisone and Prograf, two of the medications used to limit rejection, can raise blood pressure.

Blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressure ranges from 100/70 to 130/80. After transplant you

will take your own blood pressure three times a day and keep a record of your numbers in a daily diary we will provide you. We will also provide blood pressure guidelines and will expect you to call us if your blood pressure goes above or below the guidelines. Untreated high blood pressure can eventually damage your heart and other organs.

POST-TRANSPLANT DIABETES

Some of the immunosuppressant medications that you take may increase the likelihood of developing diabetes. Diabetes is an increased level of sugar in your blood. Signs of diabetes may include excessive thirst, frequent urination, blurred vision, drowsiness and confusion. Notify the transplant team if you notice any of these signs.

In some cases, high blood sugar can be reduced and managed through loosing weight, maintaining a healthy diet and exercising regularly. However, you may need an oral diabetes medication or insulin injections. Approximately 75% of our patients go home from the hospital having to administer insulin injections and check their blood sugar regularly. If you get diabetes, our diabetic educator will provide you with special training to help you manage your condition.

CYTOMEGALOVIRUS (CMV)

Cytomegalovirus (CMV) is a very common virus. About 70% of adults have been exposed to CMV at some time. It usually causes a flu-like illness with fever, general body aches and a decreased appetite that lasts for two or three days. Following exposure to the CMV virus, your body forms antibodies in your blood to protect you from future exposures to CMV. This is similar to what happens after you have chicken pox. We are able to perform blood tests to check both the transplant recipient and donor for the presence of CMV antibodies.

Because of the immunosuppressant medications, you will be at risk for infection with CMV follwing transplant. During the first few months, while the immunosuppressant doses are highest and your immune system is especially weak, the CMV virus can "reactivate" or "wake up." A CMV infection can range from one that causes flu-like symptoms to more serious infections involving your stomach and lungs (pneumonia).

If either you or your donor were positive for CMV antibodies you will be given antiviral medications for the first few months after transplant. As your doses of immunosuppressants are lowered over time, your risk of developing CMV will decrease as well and the antiviral medication will be stopped. If you develop an active CMV infection, the antiviral medications will likely be re-started.

FOR THE TRANSPLANT COORDINATOR

Call 1-855-366-7989 and choose option 4 from the menu for lung, then choose option 2 for a financial question.

FOR EMERGENCIES ONLY

After hours, on weekends or on holidays, call 1-855-366-7989 and ask for the lung transplant or pulmonary attending physician on call.

Medications

After your transplant, you will have to take certain medicines for the rest of your life. These medicines are very important and must be taken exactly as prescribed and on time for the transplanted organ to work properly. Failure to do this may result in organ failure and death.

LEARNING ABOUT YOUR MEDICATIONS

While you are in the hospital recovering from your surgery, our pharmacists and nurses will teach you and at least one family member about all of your medications. We will review with you the purpose, dosage and possible side effects of each medicine. To help you feel more comfortable taking these medications, we will ask you to begin administering them and keeping your own medication records in the hospital a few days before your discharge.

All transplant patients initially take Prograf, Imuran or CellCept and prednisone to help prevent rejection of their new organs. The following pages explain what is important to know about these medicines. You may be placed on medications other than these after transplant. Please ask your transplant coordinator or pharmacist for information about those medications.

WHERE TO GET YOUR MEDICATIONS

Soon after your transplant surgery, the coordinator will order your medications from a local specialty pharmacy that will deliver your medications to the hospital prior to your discharge. Once discharged, you may use a pharmacy in your hometown or a mail-order pharmacy. Please try to plan ahead and make these arrangements before you get your transplant.

Prior to your discharge, a coordinator will either call your pharmacy with your prescriptions or provide you with written prescriptions. It is your responsibility to contact your pharmacy when you run low on medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescriptions will usually be for a month's supply, along with three to 11 refills, depending on the medication. We recommend that you keep a one- or two-week supply on hand.

If you are interested in a mail-order pharmacy, please let the coordinator know. If you decide to use a mail-order pharmacy, it is your responsibility to call and set up the service initially, and then the coordinator will call in the prescriptions. Mail-order pharmacies will get medications to you in a few days after you call them, or they can ship them to you routinely every month. When your dosages are reduced later on and you contact them with your new medication dosages, the pharmacy asks us to verify the changed prescriptions. Mail-order pharmacies usually bill your insurance company directly.

If you experience difficulty with the cost of your medications, please do not hesitate to let your coordinator know. We will work together to seek assistance.

FREQUENTLY USED MEDICATIONS

Antirejection medications (immunosuppressants)

You will take immunosuppressants for the rest of your life to protect your new lungs from rejection. Immunosuppressants alter your immune system so that it will not reject your new lungs. These medicines also make you more susceptible to illness and infection. All immunosuppressive drugs cause side effects, but not all of the side effects occur in everyone.

Tacrolimus (Prograf)

Prograf (formerly known as FK-506) is a very potent antirejection drug that comes in 0.5-mg, 1-mg and 5-mg capsules.

Special instructions:

- Must be taken every 12 hours.
- Must be taken one hour before eating or two hours after eating.
- Do not take with other medications.
- Notify your pharmacy several days before discharge so that this drug can be ordered for you.
- Do not consume grapefruit or grapefruit juice while you are on Prograf; the interaction can dangerously increase the medicine's level in your blood.

Potential side effects:

- Increased risk of infection
- Kidney damage
- Increased potassium level
- Increased blood pressure
- Increased blood sugar
- Nausea, vomiting or poor appetite
- Trembling hands or voice
- Headache
- Difficulty sleeping
- Constipation

Azathioprine (Imuran)

Imuran is an antirejection drug that reduces the number of white blood cells in the body, which attempt to reject a transplanted organ. Imuran is given by vein initially, and later taken once a day in pill form. The dose varies based on test results. Imuran comes in 50-mg tablets.

Special instructions:

- Watch for increased bruising and bleeding. Report these to the transplant team.

Potential side effects:

- Increased risk of infection
- May lower your white blood cell or platelet count
- Increased risk of mouth ulcers
- Liver irritation
- Anemia
- Nightmares
- Nausea, vomiting, diarrhea or upset stomach

IMPORTANT:

Please bring your medications with you in their original bottles to all of your post-transplant clinic visits.

IMPORTANT:

Do NOT take Prograf the morning before your blood draw. Generic medications are okay to take.

Prednisone

Prednisone is a steroid drug that helps prevent and treat organ rejection. The dose of this drug will be slowly decreased over time. Most of the side effects of prednisone are dose-related. As the dose is lowered, the side effects decrease. Prednisone comes in 1-mg, 5-mg, 10-mg, 20-mg and 50-mg tablets.

Special instructions:

- Take with food.
- Monitor your weight and report gains of two pounds or more in 24 hours or more than four to five pounds in two to three days.
- Have your eyes examined annually by an eye doctor.
- Wait four to six months before changing your eyeglass prescription, because prednisone can change your vision.

Potential side effects:

- Stomach irritation
- Cataracts
- Acne
- Muscle weakness
- Blurred vision
- Mood swings
- Sun sensitivity
- Increased appetite/weight gain
- Water retention and round, puffy face
- Weakening of the bones (osteoporosis)
- Fragile skin, including bruising and skin tears
- Night sweats and trouble sleeping
- Increase in blood sugar (diabetes)
- Increased blood pressure (hypertension)

Other antirejection medications that may be used

Mycophenolate mofetil (CellCept)

CellCept is a very potent antirejection medication usually prescribed instead of Imuran. The usual dose of CellCept is 1000-mg to 2000-mg twice a day. CellCept comes in 250- and 500-mg tablets.

Special instructions:

- Must be taken every 12 hours.
- Must be taken on an empty stomach one hour before or two hours after a meal.
- Notify your pharmacy several days before discharge so that this drug can be ordered for you.

Potential side effects:

- Nausea, vomiting or diarrhea
- Constipation
- Leg cramps or weakness
- Headaches
- Increased frequency of urination

Sirolimus (Rapamune®)

Sirolimus (Rapamune) is an antirejection medication often prescribed in combination with a steroid medicine (e.g., prednisone) and cyclosporine (e.g., Neoral® or Sandimmune®). The usual dose is 1- to 3-mg per day. Rapamune comes in 1-mg tablets.

Special instructions:

- Do not consume grapefruit or grapefruit juice during treatment.
- Rapamune is usually taken once a day. It is recommended that Rapamune be taken four hours after taking cyclosporine (Neoral or Sandimmune), but always follow your doctor's instructions.
- Rapamune can be taken either with or without food, but it is very important to take every dose of Rapamune in the same relation to food each day.

Potential side effects:

- Nausea, vomiting or diarrhea
- Constipation
- Headaches
- Increased blood pressure
- Increased cholesterol or triglyceride levels
- Water retention or swelling
- Leg cramps or weakness
- Rash or acne
- Fever

Cyclosporine (Gengraf®)

Cyclosporine is a potent antirejection drug. It is given by vein initially, and later taken in pill form. Cyclosporine comes in 25-mg and 100-mg capsules.

Special instructions:

- Must be taken every 12 hours.
- Do not store capsules out of foil wrappers.
- Do not store in refrigerator or leave in hot sun.
- The capsules have a funny smell. You may take your dose out of the foil and let the capsules stand for five to ten minutes if the smell offends you.
- Take each dose with a full glass of water.
- If possible, take your cyclosporine first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take cyclosporine at the same times each day and an hour before meals since food can alter how cyclosporine gets absorbed in your body.
- Do not consume grapefruit or grapefruit juice while you are on cyclosporine; the interaction can dangerously increase the medicine's level in your blood.

Potential side effects:

- Increased risk of infection
- Kidney damage
- Elevated blood pressure
- Headaches
- Trembling hands or voice
- Tingling of hands or feet
- Increased body hair
- Thickening of gums
- Anemia
- Liver irritation
- Ringing in the ears

TIPS FOR TAKING MEDICATIONS

- *Know the medicines that you are taking and their side effects.*
- *Tell the transplant coordinator if you experience any side effects.*
- *Keep a record of medicines you are taking, including the frequency and dose.*
- *Talk to the transplant coordinator before adding, stopping or changing any medicine, including those prescribed by other physicians such as your local doctor.*
- *Keep medicines in a dry place, away from heat or light, and out of the reach of children.*
- *If you miss a dose, DO NOT double the dose; take the next dose as directed.*
- *If you miss two doses, notify the transplant coordinator.*
- *Do not take any non-steroidal anti-inflammatory drugs (e.g., Advil, Motrin, ibuprofen and Naproxen) as these can cause further damage to your kidneys.*
- *Do not follow the instructions on your prescription bottles.*
- *Follow the instructions for medication dosages and times to take your medications listed on the medication schedule that your transplant pharmacist will give you.*
- *Bring a list of your medications including their frequency and doses, each time you see a health care professional.*

TIPS FOR TAKING MEDICATIONS

(Continued)

- *To prevent possible dangerous interactions, never take over-the-counter medications or herbal remedies unless you first check with the transplant coordinator*
- *Do not take aspirin unless approved by the transplant coordinator as it affects blood-clotting rates. Use other medications such as Tylenol (generic) instead.*

INFECTION PROPHYLAXIS

Antibiotics

The antibiotic trimethoprim-sulfamethoxazole (Bactrim®) is prescribed to prevent a life-threatening pneumonia called *Pneumocystis carinii pneumonia* (PCP).

Potential side effects:

- Nausea or vomiting
- Rash
- Lowered white blood cell count
- Elevated potassium level

Antiviral drugs

Antiviral drugs such as acyclovir (Zovirax®) are prescribed to help prevent and treat herpes-related infections such as fever blisters and shingles.

Cytogam®

Cytogam is an antiviral drug that helps prevent and treat cytomegalovirus (CMV). It is given by IV every two weeks, for a total of six doses. Cytogam is used to prevent CMV if lung transplant recipients are CMV-positive by blood test or when a CMV-positive organ is implanted into a CMV-negative recipient.

Special instructions:

- Cytogam is administered over two to three hours. Do not administer with other medications.

Potential side effects:

- Decreased white blood cells or platelets

Valganciclovir HCl (Valcyte®)

Valganciclovir (Valcyte) is an anti-viral drug that helps treat and prevent cytomegalovirus (CMV). It is taken orally one to two times a day for six months to a year post-transplant.

Special instructions:

- Do not chew or crush.
- Do not handle without gloves if you are of childbearing age.

Potential side effects:

- Increased sensitivity to light (wear sunscreen that is 50 SPF or higher and a hat with a brim)

ANTIFUNGAL DRUGS

Antifungal drugs such as nystatin (Mycostatin®) are prescribed to help prevent and treat fungal infections of the mouth and throat.

Posaconazole (Noxafil®)

Posaconazole (Noxafil) is a second-line antifungal agent to treat *Aspergillus*. Posaconazole usually comes in 200-mg/5 mL suspension. You will take 5 mL three to four times a day for four to six months following your transplant.

Special instructions:

- Take each dose with a meal and an acidic drink.
- Take all of the posaconazole that your doctor prescribes for you even if you start to feel better.
- Never run out of this medication as it affects your rejection levels.

Potential side effects:

Continue taking posaconazole and talk to your doctor if you experience:

- Blurred vision, increased sensitivity to light or other visual changes
- Nausea or vomiting
- Diarrhea
- Swelling or water retention

REJECTION TREATMENT: IMMUNOSUPPRESSANT DRUGS

Methylprednisolone (Solu-Medrol®), available in IV administration only, treats acute rejection and has side effects similar to prednisone. You will be given three days of IV Solu-Medrol if you develop acute rejection in the hospital.

OTHER MEDICATIONS

Antihypertensives

Antihypertensives are drugs that help control high blood pressure. Among the more commonly prescribed are Lopressor® (metoprolol), Norvasc® (amlodipine) and lisinopril.

Potential side effects:

- Low blood pressure
- Dizziness
- Weakness
- Fatigue
- Sexual dysfunction
- Fluid retention

Mineral-based replacement medications

Magnesium is prescribed to replace this normal body salt that is removed by your kidneys when you take certain immunosuppressive medications.

Other helpful information

MASON GUEST HOUSE

The Mason Guest House is a private retreat that offers low-cost housing for organ transplant candidates, recipients, living donors and families. Guests who book one of the 15 bedrooms, each with a private bath, will find a comfortable bed-and-breakfast environment. Several bedrooms and bathrooms are wheelchair-accessible. Continental breakfast is provided, but guests may cook their own meals. Other amenities include laundry facilities, TVs in the gathering rooms, private phones, a VCR, a stereo and a computer.

The Mason Guest House is a home away from home created to make transplant candidates, recipients and their families feel far away from a hospital environment, yet close enough to feel secure should they need medical assistance. Please call 404-712-5110 for reservations.

THE MENTOR PROJECT

What is the Mentor Project?

The Mentor Project provides one-on-one contact between people living successfully with a transplant and people who are new to the world of transplantation. The project pairs a "veteran" organ transplant recipient, primary caregiver or living donor with someone who is waiting for a transplant, a recent transplant recipient, a family member of a transplant recipient or a living kidney or liver donor. Through these connections, even the smallest questions get answered, experiences are shared and support is provided to both patients and families.

Who are mentors?

Mentors are organ recipients, parents and other supporting family members and living donors who are at least six months out from their transplant date or the transplant date of their loved one. Mentors attend a full day of training to learn how to draw on their personal experiences to address the needs of others they will mentor. Mentors are updated periodically on services and assistance available to families within the transplant community, and the mentor network provides an excellent connection to these resources.

How do I get a mentor?

If you live in Georgia, you can be referred to the Mentor Project by your social worker, transplant coordinator, clinical nurse specialist or physician. A mentor is never assigned without the consent of the potential mentee. Georgia residents may also call the Mentor Project and request a mentor directly. For more information about the Mentor Project, contact the Georgia Transplant Foundation at 1-866-(GATX411) or 770-457-3796.

JUMPSTART

JumpStart is an assistance program that helps Georgia transplant recipients and candidates return to the work environment. JumpStart offers information and training to help the transplant recipient reach career goals.

The objective of JumpStart is to provide transplant recipients and candidates a quick and successful re-entry into the work force. Skilled placement specialists evaluate work needs and provide both necessary skills training and access to the appropriate vocational and rehabilitation services.

JumpStart offers access to the state's vocational rehabilitative services and provides a comprehensive return-to-work program – at no cost to you. The return-to-work program can be the link that helps achieve the ultimate goal of transplantation: returning recipients to a productive lifestyle. Services include:

- Career interest testing and development
- Assistance with Social Security issues
- Information on state vocational rehabilitation services
- Job skills training
- Résumé development and interview training
- Job placement
- Early return-to-work assistance
- Guidance regarding the Americans with Disabilities Act (ADA)
- Post-placement intervention to ensure success

HELPFUL WEBSITES FOR THE LUNG TRANSPLANT PATIENT

Patient information

American Lung Association - lung.org
American Thoracic Society - thoracic.org
Coalition on Donation - donatelife.net
Cystic Fibrosis Foundation - cff.org
Emory Center for the Treatment and Study of Interstitial Lung Disease
www.medicine.emory.edu/divisions/pulmonary/research/interstitial-lung-disease.html
Emory Transplant Center - emoryhealthcare.org/transplant
Georgia Transplant Foundation - gatransplant.org
International Society for Heart & Lung Transplantation - ishlt.org
LifeLink of Georgia - lifelinkfound.org
National Heart, Lung, and Blood Institute - www.nhlbi.nih.gov
Scleroderma Foundation - scleroderma.org
TransWeb: Transplantation and Donation - transweb.org
United Network for Organ Sharing - unos.org
Second Wind Lung Transplant Association - 2ndwind.org
Pulmonary Hypertension Association - phassociation.org

Other helpful websites

American Academy of Family Physicians - familydoctor.org

Health Answers - healthanswers.com

Healthfinder (U.S. government site) - healthfinder.gov

National Library of Medicine (Health Info for Consumers) - nlm.nih.gov

Notes

Notes

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