



A University Health System & UT Health Science Center Partnership | San Antonio

A Patient's Guide to Lung Transplant

Welcome to the University Transplant Center at University Hospital, in partnership with the University of Texas Health Science Center at San Antonio (UTHSCSA). This guide will help to answer many of the questions you may have about lung transplantation.

Program Overview

The Lung Transplant Program at University Hospital was established in 1987 by a pioneer in lung transplantation, Dr. J. Kent Trinkle. Since that time, we have performed the first lung transplant in North America for the treatment of emphysema, the first heart/double lung transplant in San Antonio and the first single lung transplant in the world for pulmonary hypertension. Every patient referred to our program benefits from our strong history of research, education, creative innovation, comprehensive medical expertise and surgical excellence.

Program Achievements

We have performed over 500 lung transplants since the inception of our program, and we have transplanted some of the longest surviving lung transplant patients in the nation.

Please refer to the Scientific Registry for Transplant Recipients for our most current survival outcomes at SRTR.org.

Lung Disease

Lung Disease Diagnosis

A lung transplant may be needed for the following diseases:

Interstitial Lung Diseases

- Idiopathic Pulmonary Fibrosis (IPF)
- Sarcoidosis
- Hypersensitivity Pneumonitis
- Pulmonary Manifestations of Collagen Vascular Disease
- Eosinophilic Granuloma
- Lymphangiomyomatosis (LAM)

Pulmonary Vascular Disorders

- Primary Pulmonary Hypertension (PPH)

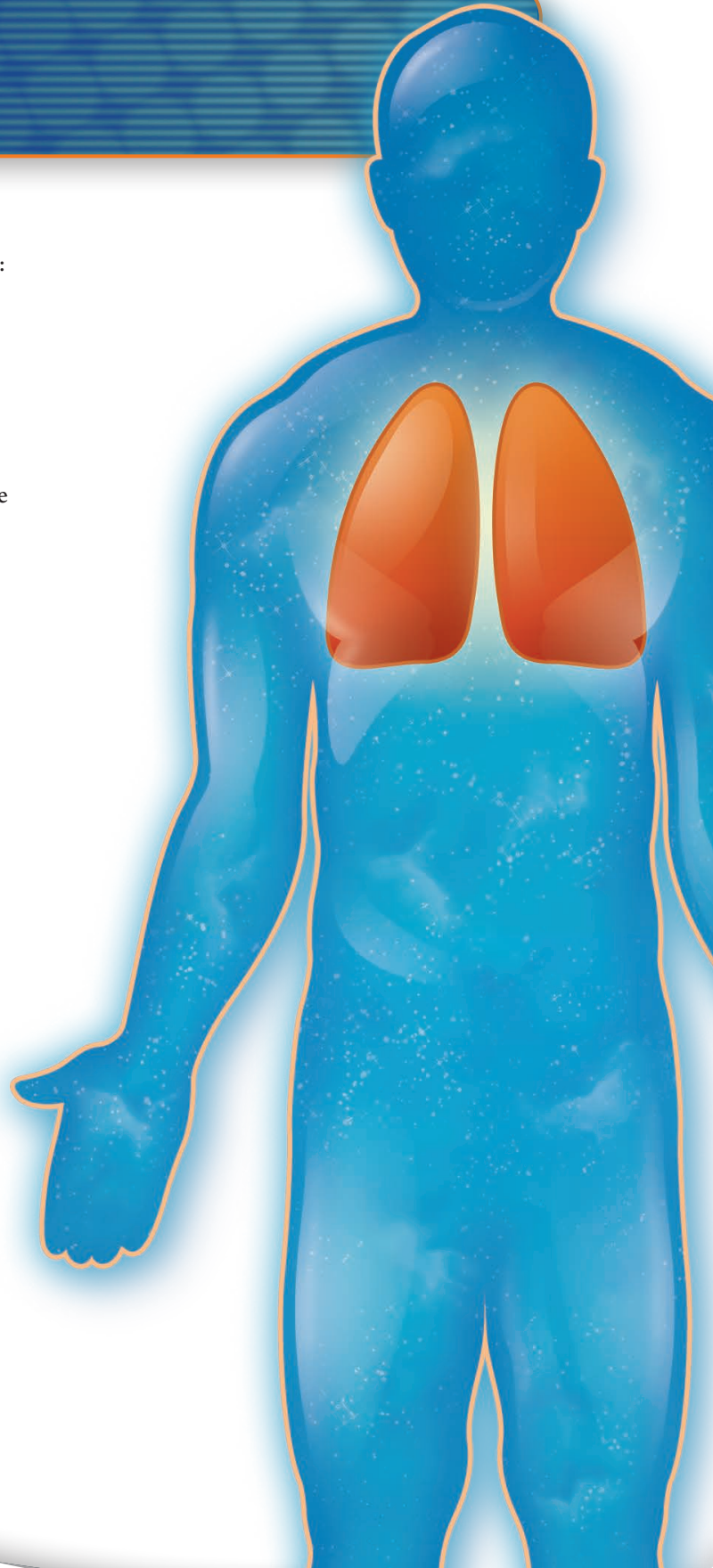
Obstructive Lung Diseases

- Chronic Obstructive Pulmonary Disease (COPD)/ Emphysema
- Alpha 1 Antitrypsin Deficiency

Bronchiectasis

- Cystic Fibrosis

Other rare conditions may be considered for lung transplantation.



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Transplant Candidate Selection

Generally, in order to be considered for lung transplantation, you must have the following:

- Advanced lung disease
- Failed all possible medical therapies available
- High risk of death in one to two years
- Poor quality of life secondary to lung disease

Reasons not to transplant:

- Active Cancer
- Hepatitis B
- Hepatitis C with proven cirrhosis by liver biopsy
- Current substance abuse:
 - Tobacco, alcohol and illicit drugs (6 months abstinence is required before beginning the pre-transplant evaluation)
- Absence of consistent or reliable social support
- Non-compliance with prescribed medications/medical regimen
- HIV Infection
- Dysfunction of other major organ systems
- Unresolved psychosocial issues or uncontrolled psychiatric illness
- Body Mass Index (BMI) >30 or <17. BMI is calculated using height and weight



Brenda Hardin
Lung Transplant Recipient
2009

Knowledge is Power

Facing a life-threatening illness can cause a range of emotions, including fear, anxiety, depression, anger, denial and helplessness.

The more you learn about your disease and lung transplantation, the more comfortable you will feel with the decision you will make. The choice to have a transplant is yours. This educational guide is designed to provide you and your social support with the knowledge necessary to make an informed decision regarding lung transplantation.

How will your transplant candidacy be evaluated?

While you may be referred to a transplant center by your Pulmonologist or personal physician, this does not mean that you are automatically accepted as a transplant candidate. Initially, you will be seen in our Transplant Clinic by our Transplant Team. Your medical records and radiology films will be reviewed. We will also ask you to do a 6-minute walk test during this visit. The physician will then visit with you to discuss your medical history and do a physical examination. If the physician determines you are a candidate to start the transplant testing, the Transplant Nurse Coordinator will schedule the tests which will begin within about two weeks from this visit.

These tests may include:

Heart

- **Catheterization** – During this procedure, a catheter is passed through a large artery in your groin area to the heart and dye is injected into the coronary arteries while an x-ray is taken. This exam measures the internal blood pressure of the heart, assesses blood supply to the heart muscle, views the coronary arteries and the aorta, and measures the oxygen level in the blood.
- **Electrocardiogram (EKG or ECG)** – Determines heart electrical activity. It is a 10 minute procedure that provides information about the rate and rhythm of your heart.
- **Echocardiogram (ultrasound)** – Assesses the structure and function of the heart to include the aorta, valves, chambers and wall motion of your heart.

Lungs

- **Ventilation-perfusion lung scan** to determine blood and air supply to the lungs (requires an injection of “tracer” into a vein).
- **Pulmonary function tests** to measure lung efficiency in breathing (requires inhaling/exhaling into a metered device).
- **Chest x-ray:** used to evaluate organs and structures within the chest for symptoms of disease. The areas of the chest that are looked at are lungs, ribs, heart and the contours of the great vessels of your chest.
- **Chest CT scan** to get a two dimensional x-ray of your lungs. It uses horizontal slices of your chest and the computer projection of these pictures. It assists with the detection of problems that might not have been found on chest x-ray. Occasionally, injected contrast is used with this study.
- **6-minute walk test.**
- **SNIFF test** is used to determine the function of the diaphragm.

Other

- **Social Work assessment** to assist you with any non-medical issues and give you important information regarding Medicaid, Medicare and other insurance. They will also provide you with information on psychosocial risk factors post transplant.
- **Dietitian assessment** to evaluate your nutritional status and provide a regimen to follow if you are required to lose or gain weight for the transplant.
- **Laboratory tests** of the blood, urine and sputum.
- **Bone density test** to assess for osteoporosis.
- **Gastrointestinal consult** for patients with scleroderma or gastroesophageal reflux disease (GERD).
- **Gastric emptying study** to assess how quickly and how well your stomach empties its contents. We will also test to see if micro amounts of stomach contents are being aspirated into the lungs.
- **24 hour pH and Manometry study.** The manometry portion of this study evaluates the action of the muscle pressure in the esophagus as well as the muscle valves at the lower end. The pH portion monitors the levels and changes of acid content in the esophagus.
- **Dental exam.** You will need to have a dentist evaluate your teeth.
- **Mammogram/Pap smear** are cancer screenings for women.
- **Colonoscopy** for all patients older than 50 years old or patients with an immediate family history of colon cancer.
- **Additional tests** that physicians may believe are needed to complete a thorough evaluation.

Please keep in mind that the Transplant Pulmonologist will make the recommendation to start the transplant evaluation and to be placed on the lung transplant list, but the final decision is yours. This is a major surgery with its risks and possible complications. Transplantation is a major decision, and patients are encouraged to go home and discuss it with their family/loved ones rather than making a decision during the clinic visit.

A mentor can be provided to you. This will be someone with similar lung disease who had a transplant at our facility.

The Transplant Team

The Transplant Team is a group of health care professionals who are here to assist you before and after your transplant; however, the most important decision maker is YOU.

Transplant Pulmonologists

On your first appointment, you will meet with one of our Transplant Pulmonologists who will determine your candidacy for transplant, review your transplant evaluation and determine if you will be presented before the Transplant Committee. The Transplant Pulmonologist will also monitor your care before and after your lung transplant.

Transplant Surgeons

At the end of your evaluation, you will meet with one of the Lung Transplant Surgeons. This is one of many surgeons that may perform your surgery and follow you during your immediate post-transplant period.

Transplant Coordinators

The Transplant Nurse Coordinator is a registered nurse that is responsible for setting up your transplant evaluation and keeping you informed of your progress. They are the liaison between you and your physician.

Discharge Nurses

After your transplant and during your inpatient period, you will have a Discharge Nurse who will teach you the post-transplant medications, how to take care of the surgical incision and how to protect your transplanted lung(s).

Transplant Clinic

After you are discharged from the hospital, nurses from the Transplant Clinic will monitor your care and be available to answer any of your questions.

Transplant Social Workers

All pre-transplant patients will be evaluated by a social worker who will identify needs, problems and discuss expectations of transplant, discuss psychosocial issues that may occur after transplant, review finances for medications and discuss how you will pay for medication co-pays.

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Dietitian

You will meet with a Dietitian who will discuss your nutritional needs pre- and post-transplant, evaluate your current nutritional status and provide guidance and education as necessary.

Transplant Financial Coordinators

Financial Coordinators will help you obtain pre-authorization for your evaluation and surgery. They can also answer any health care coverage questions. Please do not change insurance coverage or carriers while undergoing the transplant evaluation or while waiting on the transplant list until you discuss it with one of our financial counselors. We are not in network for all insurances, which may result in holding your evaluation or placing you on hold on the transplant list until these issues are resolved.

Transplant Pharmacists

The Transplant Pharmacists will explain and answer questions about your medications. They also work with the specialty pharmacies that carry the medications you will need after transplant.

Your Primary Care Physician (PCP) or Primary Pulmonologist

You will continue to see your PCP before and after your transplant. However, we follow our patients post-transplant on a routine basis. If you have to move to a different city or state, we will help you find care by physicians with lung transplantation experience.

Friends and Family

A lung transplant is a gift and lifetime commitment. As such, it is a requirement for all patients considering a lung transplant to have established, reliable social support. This can consist of family or friends who have made the commitment with you to manage your lung transplant both pre-transplant and post-transplant. They can help you by driving you to your clinic appointments and taking care of you physically and emotionally after your transplant.

YOU

You are the most important part of this process. The success of your transplant is directly related to your compliance with the medications, clinic visits, and adherence to the rules set up by the Transplant Team. You must maintain a nutritious diet and keep a routine exercise program tailored to your physical abilities.



Charles Holt
Lung Transplant Recipient
2010

Preparing for Transplant

Answer the following questions with your family and/or transplant team:

1) What is my plan to get to the hospital once I am called in for the transplant?

2) If I live more than 2 ½ hours away, I will be required to stay temporarily in San Antonio for a brief period once I am discharged after transplant. What accommodations are available to me?

3) Who will be my primary caregiver while living at home or in temporary lodging?

4) Where will my family stay while I am in the hospital?

5) I will be temporarily restricted from driving. Who will drive me to the weekly appointments during those first three months after transplant?

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6) How will I pay for expenses and who will pay my bills and take care of the household needs (care of pets, home maintenance, etc.) while I am away?

7) Who will take care of my children while I am away from home?

8) How much are my deductibles and co-pays? How much will I be responsible for?

9) How much will I have to pay for my medicines?

10) How will I budget for my co-pays and deductibles?

11) What pharmacy will I use?



Stephen Tyson
Lung Transplant Recipient
2011

Waiting for a Transplant

Once you have completed your transplant evaluation and all test results have been received, the Transplant Team will meet to collectively decide if lung transplantation is an appropriate option for you.

If you had abnormal test results, the Transplant Team may request additional testing before making a final decision. After reviewing those results, they could permanently deny you as a candidate for transplant if they feel it could worsen your overall prognosis or if there are unresolved psychosocial issues. On the other hand, if you are found to be a good candidate the committee will decide if you will be placed on the wait list for a single or double lung transplant.

There are several factors the Team considers when deciding on a single or double lung transplant:

- Type of lung disease
- Severity of lung disease
- Age
- Results of pre-lung transplant evaluation
- Patient symptoms

We do not perform combined heart/lung transplants, nor do we offer living lobar lung transplants at our facility.

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Once the team is in agreement, you will be placed on the lung transplant waiting list.

The waiting list is a nationwide computerized network managed by the United Network for Organ Sharing (UNOS). UNOS is a non-profit, scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN), established by the United States Congress in 1984.

Their duties include:

- Matching donors to recipients and coordinating the organ sharing process 24 hours a day, 365 days a year.
- Maintaining the databases that contain all clinical transplant data for every transplant that occurs in the United States.
- Monitoring every organ match to ensure adherence to UNOS policy and working with the Board of Directors to develop equitable policies that maximize the limited supply of organs.
- Providing assistance to patients, family members and friends, and setting professional standards for efficiency and quality patient care.
- UNOS will calculate a Lung Allocation Score (LAS) that will be assigned to you.

All patients waiting on the lung transplant list are given a Lung Allocation Score (LAS).



Nancy Merriman
Lung Transplant Recipient
2011

Lung Allocation Score

All patients waiting on the lung transplant list are given a Lung Allocation Score (LAS).

Patients in need of lung transplantation will be prioritized by their LAS. The LAS will be used to estimate the urgency of illness and the probability of success after a lung transplant. This information includes lab values, test results and disease diagnosis and is used to calculate a Lung Allocation Score from 0-100 points. The higher the patient's score, the higher their priority on the list. UNOS requires us to update your information and some testing every 6 months. The LAS is designed to change as your lung disease changes. For instance, if your condition should worsen as proven by exams, your Transplant Coordinator will update UNOS. This will probably result in a higher LAS and a higher priority for transplant.

For more information on how you are listed, visit www.UNOS.com.

You are matched to a donor by your blood type and size. Your priority for transplant will depend on your LAS.

Criteria that are not used in the computer matching system are gender, religion, celebrity and financial status.

You have the right to be double listed for a transplant at another center as well as ours. You may call UNOS at 1-888-894-6361 for more information.



Christena Crawford
Lung Transplant Recipient
2010

While you are on the waiting list

- Attend our pre-transplant class. A schedule will be given to you. This class is offered to all patients on our transplant list. It runs 3½ hours and provides information about waiting on the transplant list, being called in for the transplant, getting ready for the surgery, hospital stay, and services available to you while inpatient.
- Stay as healthy and active as you can. Ask your Transplant Coordinator about pulmonary rehab pre-transplant.
- Keep in touch with the Transplant Team.
- Notify us of any telephone, address or insurance changes.
- Have a small suitcase packed with toiletries, robe, slippers, etc.
- Contact the Transplant Team if you are going out of town.
- Contact the Transplant Team if you have had a blood transfusion, infection, surgery or any change in your medical condition.
- Carry a cell phone or pager and provide us with as many contact numbers as possible.

Receiving the call to come to the Hospital for a transplant

- A Transplant Coordinator will call you on your cell phone and/or at home.
- We will ask you to come to the hospital immediately.
- Do not eat or drink after we call you unless we tell you otherwise.
- Bring your medications with you.
- Have a designated driver and a back-up transportation plan to the hospital.
- Bring health insurance information.

What Not to Bring

- Money
- Credit cards
- Jewelry
- Flowers, plants or pets
- Fresh fruit or vegetables

Bruce Curry
Lung Transplant Recipient
2010



Your Arrival

Once you arrive to the Emergency Department at University Hospital, report to the 9th Floor Unit

You will have the following examinations:

- Physical examination by one of the doctors
- Blood work
- Chest x-ray
- Electrocardiogram (EKG)

Your transplant could be cancelled if:

- You have any signs of infection
- The donor lung has any problems
- A new/existing medical problem
- Positive nicotine or drug/alcohol test

Your Hospital Stay

The 9th Floor Unit at University Hospital creates an atmosphere dedicated to the compassionate care of the patient and their family.

The unit offers the following:

- Private patient rooms
- Physicians in hospital 24 hours a day, 7 days a week
- Comprehensive multidisciplinary daily medical and surgical care
- State-of-the-art facilities
- Cutting-edge technology
- Bilingual transplant staff

Lung Transplant Surgery

The lung transplant surgery will require 3-4 hours for a single-lung transplant, and 4-8 hours for a double-lung transplant. Additional time may be required if you have had prior chest surgery. The operation begins when the donor lung(s) arrives in the operating room. Your lung is removed and the donor lung is placed in the chest cavity. The surgeon connects the blood vessels to and from the lung (pulmonary artery and pulmonary vein) and the main airway (bronchus) of the donor lung to your airway. The same connections are made for the other lung if you are having a double-lung transplant.

- **Double-lung transplants** are generally done through a transverse sternotomy with bilateral anterolateral thoracotomy “clam-shell” incision. This incision is made through the middle of the chest.
- **Single-lung transplants** are usually done through posterolateral thoracotomy. This incision is made on the right or left side of the chest.

9th Floor Intensive Care Unit

After your transplant surgery, you will go to the 9th Floor Intensive Care Unit where you will be monitored very closely. The effects of anesthesia will take several hours to wear off. Most patients cannot remember the first 24-48 hours of their stay. You will wake up feeling a little confused and your wrists will be lightly restrained to prevent you from pulling out any tubes or lines. You will have IV lines to provide you fluid and necessary medications to keep you stabilized. You will have a breathing tube down your throat. This tube is connected to a ventilator (breathing machine) which will breathe for you until you are capable of breathing on your own. If you have an uncomplicated surgery, you will spend about one day on the breathing machine and about 1-3 days in ICU. You will also have another small tube in your nose that reaches your stomach. This is called a nasogastric (NG) tube. It will help drain the contents of your stomach and prevent nausea. This will be removed once the effects of the anesthesia wear off. You will have drainage tubes coming from your chest called chest tubes. They drain fluid and air. These tubes are connected to suction for a few days to help the lungs re-expand fully. These chest tubes will be removed once you are no longer draining fluid and the lungs are fully expanded. You will have a catheter going to your bladder to monitor your urinary output. Once you are able to go to the bathroom on your own the catheter will be removed.

9th Floor Acute Care Unit

After you are stabilized, you will be sent to the Acute Care Unit. The total average length of your stay from the time after your surgery is approximately 10 days. As you get better, the IVs, tubes and catheters are removed. You may or may not be on oxygen at this point. Your progress will be monitored. Physical Therapists will be working with you to determine your strength and ability to go home as opposed to being admitted to our rehabilitation unit. The Discharge Nurses will be providing you with detailed information on your medications and daily care routine. They will be getting you ready to go home.

After Your Transplant

What happens after discharge?

All post-lung transplant patients are at high risk for developing rejection and/or infection during the first three months after their transplant. It is necessary to monitor all patients closely during this period. You will be required to come to the Transplant Clinic once a week for the first three months. During these Clinic visits you will have blood work drawn, pulmonary function tests, chest x-rays, and visits with your Transplant Pulmonologists. If the recovery is uneventful during the first three months, trips to the Transplant Clinic will become less frequent. You will also be following instructions for self-monitoring of your weight, blood pressure, pulse, temperature, lung function, and, if you are diabetic, blood sugar. Of primary importance, you will be instructed not to smoke, to limit your use of alcohol and to follow a good nutrition plan. As soon as your physicians believe you are able, you will start a program of exercise rehabilitation. This may be conducted at the medical center or at a rehabilitation facility under the supervision of your physicians.

Medications After Transplantation

The body tries to dispose of anything that it considers foreign. After your lung transplant, your body will try to reject your transplanted lung(s). In order to prevent rejection, we will give you medications called immunosuppressant medications. These medications help the body control the cells that will try to reject your transplanted lung(s). These medications suppress your immune system; this is the system in your body that helps fight infection; therefore, you may be more susceptible to infections. We will also give you medications that will help your body fight infections. You will be taking more medications post transplant than you did pre-transplant. This medication will be prescribed for the rest of your life unless otherwise instructed by the Transplant Physician.

You must take all your medications exactly the way the doctor orders them. Each one of the medicines help you keep your transplanted lung(s) healthy. If you stop taking your medications, you will reject your transplanted lung(s).

Harold Morrison
Lung Transplant Recipient
2012



Complying with Transplant Treatment

Compliance with your medication regimen is imperative to the success of your transplant. To make this transplant successful you will be responsible for the following:

- Scheduling and attending Clinic appointments
- Eating and avoiding certain foods and beverages
- Taking medications daily as prescribed
- Losing or gaining weight as directed by your Transplant Physician
- Monitoring your fluid intake and blood pressure
- Stopping the use of illegal substances, tobacco and abusing alcohol
- Attending pulmonary rehab as recommended by your Transplant Physician

Occasionally, some patients are found to be non-compliant with their medical regimen. When that happens they have problems with:

- Getting placed on the lung transplant list
- The body rejecting the transplanted lung
- Being removed from the transplant list
- Poorer quality of life
- Worsening physical health
- Death

These are a few situations that keep patients from complying with their medical regimen:

- Medication side effects
- Miscommunication between patient and medical team
- Anxiety, depression or poor coping skills
- No social support (friends or family) to help with daily needs
- Memory problems
- Inadequate funds or insurance coverage

Karen Holly Julian
Lung Transplant Recipient
2011



Establishing a good working relationship with your Transplant Team and making sure the lines of communication are open and clear are very important. This can help to avoid confusion about what is expected of you and can also help to avoid unintentional non-compliance. Here are some recommendations to help with compliance:

- Write down your question before you come to the Clinic visit to make sure all of your unanswered questions are addressed. Write down their answers.
- If your Transplant Team is making recommendations to change the doses on your medications or scheduling you for tests and you are having memory problems, please ask them to write down all instructions for you.
- Share your care plan with the person taking care of you at home so they are aware of the changes or additions being made.
- Fill all of your prescriptions on time.
- Always call your Transplant Team if you have any questions regarding your medical regimen. It is better to clear up any questions than make a mistake.
- Never be too proud to ask for help.
- Ask for psychological support if necessary.

Medications

- **Immunosuppressant** – or “anti-rejection” – special medications that are designed to suppress (or lower) your immune system
- **Steroids** – first line of defense for rejection
- **Antibiotics** – help your body prevent bacterial infections
- **Antifungals** – help your body prevent fungal infections
- **Antivirals** – help your body prevent viral infections
- **Pain medications**
- **Antihypertensive** – used to treat high-blood pressure
- **Diuretics** – help control fluid “water pill”
- **Vitamins and minerals**
- **Ulcer medications**

Spreading Awareness

Transplantation provides hope to thousands of children and adults with organ failure by giving them a new chance at a healthy and normal life. Transplantation is made possible by the commitment from organ, eye and tissue donors. Unfortunately, the need for donors is much greater than the number of people who donate. You can help spread awareness by sharing your story with those around you and encouraging them to register to become a life-saving donor. Here is how:

Steps to sharing your story

- Introduce yourself and speak about how personal transplantation is to you and your family.
- Share the facts about organ donation. For example, in 2015, 21 people died each day awaiting a life-saving transplant due to a shortage of donors.
- Make it a point to share how important donation is to “life” and how it affects you and your family.
- Encourage others to register online at DonateLifeTexas.org/UHS or complete the donation section on their driver’s license or renewal application form at the DMV.

Facts about donation

- Organ donation is only considered after all efforts to save your life have failed and death has been declared.
- Anyone can register, regardless of age, gender, ethnic background or current health status.
- All major religions support donation.
- There is no cost directly related to donation.
- Donation does not prevent an open casket funeral.

A single donor can improve the lives of more than 50 people through organ, eye, and tissue donation.



Jorge Barrantes
Lung Transplant Recipient
2012

Resources

United Network for Organ Sharing (UNOS)

(888) 894-6361

UNOS.org

American Lung Association

(800) LUNGUSA

Lung.org

US Department of Health and Human Services

U.S. Government Information on Organ Donation and Transplantation

OrganDonor.gov

SmokeFree

A resource to help you quit smoking

(877) 44U-QUIT

SmokeFree.gov

Texas Organ Sharing Alliance (TOSA)

(210) 614-7030

TXOrganSharing.org



Teresa Guilliams
Lung Transplant Recipient
2006, 2008

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Transplant Living

A website with information and resources for transplant recipients

TransplantLiving.org

National Foundation for Transplants

For over 30 years, NFT has offered fundraising assistance for organ and tissue transplant patients across the country

(800) 489-3863

Transplants.org

Second Wind Lung Transplant Association

Patient-run organization that provides information on lung transplantation for patients (and their families) who have had a transplant or who are waiting to have a transplant

(888) 855-9463

2ndwind.org



James Uhls
Lung Transplant Recipient
2011



A University Health System & UT Health Science Center Partnership | San Antonio

General Information

University Hospital

4502 Medical Drive, MS 18
San Antonio, Texas 78229

Office Telephone Numbers:

(210) 567-5777

Toll free: 1-888-336-9633

Fax: (210) 358-8254

Office Hours:

8 a.m. to 5 p.m.

Monday through Friday

Closed on holidays and weekends

Transplant Clinic

4502 Medical Drive
San Antonio, Texas 78229

Clinic Telephone Number:

(210) 358-4500

Clinic Hours:

8 a.m. to 4 p.m.

Monday through Friday

Closed on holidays and weekends

UniversityTransplantCenter.com

Directions

From IH 10 West (northbound):

- Exit Medical Drive/Wurzbach.
- Take Frontage Road to Medical.
- Turn left onto Medical.
- Turn left into University Hospital entrance.
- Follow signs to visitor parking.

From IH 10 West (southbound):

- Exit Wurzbach.
- Turn right onto Wurzbach.
- Turn left on Medical Drive.
- University Hospital is on the right.
- Turn right at second entrance.
- Follow signs to visitor parking.

From NW Loop 410:

- Take Babcock exit.
- Head north on Babcock to Wurzbach (about three miles north of 410).
- Turn right on Wurzbach.
- Turn right onto Medical.
- University Hospital is on the right.
- Turn right at second entrance.
- Follow signs to visitor parking.