Pulmonary Fibrosis Foundation™

Preparing for a lung transplant

WHAT TO EXPECT

FIND IT FAST

For more information, contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or pcc@pulmonaryfibrosis.org.

Understanding and planning for lung transplant

Lung transplant—surgery to remove a damaged or diseased lung and replace it with a healthy lung from a deceased donor—is a life-saving treatment for people with late-stage lung disease after other treatments have been exhausted. Studies demonstrate that lung transplantation is associated with a significant improvement in quality of life. Pulmonary fibrosis (PF) is one of the diseases for which lung transplant is an option; some of the others include chronic obstructive pulmonary disease (COPD), cystic fibrosis, pulmonary arterial hypertension, and sarcoidosis.

Learning about and preparing for lung transplant can be an overwhelming process. This booklet is designed to help PF patients considering lung transplant learn what's involved and how to get started. Referral and transplantation criteria can vary by transplant center.

RECEIVING A REFERRAL

A referral for a unilateral (single) or bilateral (double) lung transplant will come from your primary care physician or pulmonologist (lung doctor). Transplants are a specialized type of surgery performed at a limited number of medical centers across the country, referred to in this booklet as transplant centers. If lung transplantation is thought to be appropriate for your care, your physician will discuss this with you and refer you to one or more of these centers.

The window for referral is important. While lung transplants are designed to address late-stage lung disease, referral should happen early. Early referral helps patients prepare physically and mentally for transplantation, maximizing their ability to recover smoothly. It also assures all necessary medical tests are completed when patients have enough physical reserve to undergo rigorous testing.

THE EVALUATION PROCESS

If you've received a referral from your physician, you'll be extensively evaluated by a transplant center to determine whether you meet the candidacy requirements for lung transplant.

Selecting a transplant center

Although your doctor will refer you to a specific transplant center, you may also select a center on your own. When evaluating a transplant center, check with your health insurance provider to verify which centers are covered under your plan.

Consider the number of lung transplants a center performs each year, as well as transplant survival rates, by reviewing databases maintained by the Scientific Registry of Transplant Recipients (SRTR) at **www.srtr.org**. You may also want to ask about additional services that may be provided by a transplant center, such as support groups, assistance with travel arrangements, or help finding housing for your recovery period. Your transplant center will be a lifelong partner, so it's very important to consider location and distance from home.

Two-way communication

During the evaluation, the transplant team will ask you a lot of questions—but you and your family will also want answers. It's easy to get overloaded with information, so write down any questions or concerns you have before your visits.

Preparing for evaluation

Before you go in for your medical evaluation, there are several steps you should take to ensure you're in the best possible position to be accepted as a transplant candidate:

- **Demonstrate compliance.** For you to be an optimal candidate for lung transplantation, all your other organ systems have to be functioning adequately. Your transplant team will want to see a habit of compliance with your medical care. Make sure your physicals, vaccinations, and dental care are up to date. If you have comorbidities (other diseases in addition to your lung disease), take your medications as prescribed, keep follow-up healthcare appointments, and follow any recommended medical diets.
- **Exercise.** Transplant centers require a minimum level of endurance, which can take time to build up. Get started on your plan now. If oxygen needs or access issues prevent you from enrolling in exercise programs at a gym, ask your healthcare provider if a referral for pulmonary rehabilitation is available to you. Always talk with your provider before beginning a new exercise routine.
- **Meet weight requirements.** Studies demonstrate that outcomes are better when patients are at an ideal weight. All transplant centers have a minimum and maximum body mass index (BMI) for transplant. Maximum BMI criteria vary per center, but are usually 30-35. If you need to lose weight, focus on portion control and increasing your activity level. Ask your healthcare provider for referrals to a medical weight loss clinic or dietitian consultation.
- **Stay substance-free and tobacco-free.** You must not use narcotics, THC, illicit drugs, or alcohol. You also must be tobacco-free (usually for at least six months) to begin a transplant evaluation. This includes nicotine replacement therapies like patches, gum, and vaping. The transplant team may test your blood at any time during the evaluation process.
- **Have a strong support system.** Most centers require patients to identify two to three caregivers who can provide combined continual support during the pre- and post-transplant period. Caregivers may be family members, friends, and neighbors, as long as they can drive and are willing to learn to help care for a transplant patient.

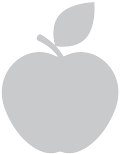
Medical evaluation

Because lung transplant is a major procedure, the medical evaluation process is lengthy and complex. You'll meet with members of a team including a transplant pulmonologist, transplant surgeon, nurse coordinator, psychologist, social worker, physical therapist, finance coordinator, and others. These meetings may take place during several visits that extend over weeks or months.

Transplant centers want to ensure that the candidates they select will benefit from transplantation and have good long-term outcomes. The evaluation starts with assessing your pulmonary health to ensure that you're sick enough to warrant transplantation. The evaluation also ensures that other organ systems such as your heart, kidney, and liver are healthy enough to tolerate surgery and post-transplant medical therapies. The evaluation team will also consider psychological health, your family and social support, motivation, and financial circumstances. You'll take numerous tests, which may include:

- Pulmonary function tests
- Chest X-ray
- CT scan of the chest
- Cardiac stress test
- Echocardiogram (to assess heart structure and function)
- Cardiac catheterization (to make sure your coronary arteries are not "clogged")
- Bone mineral density test
- Complete blood count (CBC)
- Blood tests for kidney and liver function
- Screening for infectious diseases such as tuberculosis, HIV, Hepatitis B, and Hepatitis C—if you have one of these diseases, it must be well-managed
- Screenings for certain age-appropriate cancers (colon, prostate, breast cancer, cervical cancer, etc.)
- Screening for gastroesophageal reflux (GERD) and effective esophageal movement
- Blood type/antibodies present test

For brief descriptions of these tests, see the glossary on page 10.



Best health practices

Even if you're found not to be a candidate for transplant or decide not to pursue one, your general well-being will be better if you follow the tips listed at left above. Get started today to enjoy improved health that helps you manage your PF.

ISSUES WITH CANDIDACY

A number of medical and social circumstances may prevent patients from being candidates for lung transplant. Your transplant center will have a list of absolute contraindications (definite disqualifiers) and relative contraindications (conditions which may or may not be disqualifiers). There are also some special considerations that may affect your candidacy.

Generally, patients may not be accepted as candidates for lung transplant if certain conditions are present, including:

- Significant dysfunction of another major organ system, including the heart, liver, kidney, or brain (unless a combined organ transplant can be considered and performed)
- Significant coronary heart disease that isn't responsive to treatment
- A recent history of certain cancers
- Current or recent tobacco or nicotine use (within six months of evaluation)
- Recent drug or alcohol abuse or dependence (within six months of evaluation)
- Obesity (usually a body mass index, or BMI, of 30 or more, but this can vary per medical center)
- Lack of a social support system
- Uncontrolled psychiatric disorders
- A history of noncompliance with medications and other health instructions
- Partial noncompliance with medications and other health instructions
- Past chest surgery
- Ventilator dependency
- Connective tissue/autoimmune disease (this will depend on the transplant center)

Because transplant centers may differ in what they view as contraindications to transplantation, it's important to have a frank discussion regarding your candidacy with the transplant team, rather than making assumptions.

Other considerations

Certain disorders warrant special review before lung transplant is considered. Esophageal motor disorders and gastroesophageal reflux disease (GERD) are common in lung transplant patients both before and after surgery and may contribute to the body's rejection of the new lung.

Connective tissue disease-related interstitial lung disease (CTD-ILD) was previously thought to be a contraindication for lung transplant, but some patients with CTD-ILD are now undergoing successful transplants. Patients with CTD-ILD are considered for evaluation on a case-by-case basis, depending on the transplant center and health status of the patient.

If you have any of these conditions, your transplant team will discuss how they might affect your eligibility or treatment approach.

THE WAITING LIST

At the end of your evaluation, the transplant team will determine whether you're a candidate for a lung transplant. If so, your name will be placed on the lung transplant waiting list.

Lung Allocation Score (LAS)

Given to each patient who is added to the waiting list, the LAS directs donated organs to the people who will most benefit from a transplant. This calculation tries to predict the likelihood of survival in the next year without a lung transplant, and the likelihood of survival one year following lung transplantation. Some of the factors used in calculating the score are your age, oxygen requirement, pulmonary function test results, distance walked in six minutes, and type of lung disease you have. Learn more at **unos.org/wp-content/uploads/unos/Lung_Patient.pdf.**

Individuals with higher scores receive priority when a compatible lung becomes available. If some of these factors change while you're on the waiting list, your transplant team will update your LAS.

The organ matching and delivery process

In the United States, organ procurement and transplantation are coordinated by the U.S. Department of Health and Human Services' Organ Procurement and Transplantation Network (OPTN), which is currently managed by the United Network for Organ Sharing (UNOS).

When patients are placed on the waiting list, they're registered in a centralized, national computer network that links all donors and transplant candidates. The UNOS Organ Center, which assists with the matching, sharing, and transportation of organs via this computer network, is staffed 24 hours a day throughout the year.

When donor organs are identified, the computer matching program immediately generates a list of potential recipients ranked according to objective criteria like blood type, medical urgency, time on the waiting list, and distance between donor and recipient. Other factors that are considered include donor height and antibodies, which could influence organ compatibility. Ethnicity, gender, religion, and financial status are *not* part of the computer matching system.

Once the transplant surgeon for a matched recipient approves the lung, it's transported to the recipient's hospital at the same time the patient is being prepared for surgery.

Special-category donors

All donor organs are screened for communicable diseases such as HIV, Hepatitis B, and Hepatitis C prior to transplant. If donors engaged in high-risk activities—including intravenous drug use, sex work, exposure to HIV, and increased risk for Hepatitis B or C infections—prior to their deaths, they may falsely test negative because their bodies had not yet formed high levels of antibodies to these infections.

The lung transplant community still uses donor lungs from high-risk individuals. The risk of contracting these infections is low (less than 2%), and there are currently not enough donor lungs available (about 15% of patients die waiting for a suitable lung to become available). If a lung transplant recipient were to contract HIV, Hepatitis B, or Hepatitis C, these are all treatable conditions. In fact, donors with known Hepatitis C are intentionally being used at certain centers because there are now highly effective medications to cure this disease. Your transplant center will have in-depth discussions with you and your family about use of high-risk donors.

You have the right to decline a donor that meets high-risk criteria. Remember, transplant centers only offer donor lungs they feel are of high enough quality to allow recipients to thrive.

Tight timeframe

UNOS divides the U.S. into 11 geographic regions of between two and seven states each for the allocation of organs. However, because lungs have less time to be successfully transplanted than many other organs, a radius from the donor hospital, rather than a region, is the primary geographic guideline for allocating lungs.

PREPARING FOR "THE CALL"

Wait times

The average time on the waiting list for patients with idiopathic pulmonary fibrosis (IPF) is three to six months, but an individual patient's wait time is dependent on how advanced the disease is at the time of listing. It's not possible to predict how long a patient will wait before a compatible lung becomes available. Some patients wait a few days; other times, the wait is many years, depending on the LAS. If your blood type is less common, you are very tall or very short, or you have high levels of antibodies against tissues received from others (due to a history of pregnancy, blood transfusions, or prior transplantation), it may take longer to find a suitable match.

If there's a problem with the donor lung or if you have an infection, the surgery cannot be performed. About one-fifth of all planned lung transplants are canceled the first time. If this happens, you must wait for another compatible organ to become available. Although they can be disappointing, these "dry runs" are common: most patients have at least one while waiting for a transplant.

Ready at a moment's notice

Lungs must be transplanted soon after donation, so timing is critical. Because you may receive the call at any time day or night, you and your support person must be ready at a moment's notice to leave for your transplant center. Your preparations should be complete *before* your name is added to the list.

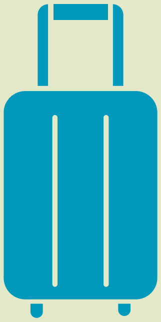
You must be able to travel to your transplant center within a specified amount of time, typically several hours. If you live too far away to reach the center within that timeframe, your transplant team will ask you to relocate to a residence nearer the center while you're on the waiting list.

Answer incoming calls and voicemails as soon as you receive them, even if you don't recognize the number. Inform your transplant team right away if any of your phone numbers change. If your team can't reach you, they may move on to another patient on the list.

Continuing your care while you wait

Being in the best possible physical shape at the time of your surgery will help with your recovery and transition to a more active life. Most transplant centers enroll patients on their waiting lists in pulmonary rehabilitation and exercise programs. You'll need to continue these programs after your transplant.

Continue treatment with your primary care physician and/or pulmonologist while you wait. You'll also return to your transplant center periodically so your team can review changes in your health or update tests. If you begin to feel sicker or your health changes in any way, let your team know immediately, so that they can optimize your care and adjust your lung allocation score appropriately.



Packed up, ready to go

Once you're on the waiting list, keep a bag packed with items you'll need for your hospital stay, including enough medication for several days. Also, be sure you can take enough oxygen for the trip and a possible return home, in case the transplant is not able to happen for some reason.

THE SURGERY

Before and during the procedure

When you get the call that a potentially compatible lung is available for you, you'll need to go straight to the hospital without eating or drinking anything. Before surgery, your transplant team will check your vital signs and perform tests including a chest X-ray, electrocardiogram (EKG), and blood analysis. You'll be asked to sign a consent form. Your family can stay with you for most of the time before you go to the operating room.

While you're being prepared for the procedure, your transplant team is in close contact to ensure that the donor lung is right for you. If it's not compatible, the surgery will be canceled. If the donor lung is a match, you'll be taken to the operating room. The anesthesiologist will give you medicines to ensure you're unconscious and don't feel pain throughout the procedure.

A single-lung transplant surgery usually takes four to six hours; a double-lung transplant typically requires eight to 12 hours. After making a cut in your chest to remove your diseased lung, your surgeon will connect the donor lung to its main airway and the blood vessels to the new lung and your heart.

First stage of recovery

After the surgery, you'll be cared for in the intensive care unit (ICU). You'll be on a ventilator (breathing machine) until you can breathe on your own. Usually, patients can breathe without the ventilator within 24-48 hours after surgery, but sometimes patients may need to use the ventilator for days or even weeks. While you're in the ICU, drains (chest tubes) will remove any fluid that collects around your lungs and heart. You'll also be administered antimicrobials to prevent infection and immunosuppressant medications to ensure that your body's immune system doesn't attack the "foreign" lung or lungs, which is called acute rejection.

Sometimes patients develop severe hypoxemia—a below-normal level of oxygen in the blood—during the first stage of recovery. This can happen for several reasons, including infection, redistribution of body fluid into the lung, early rejection, or an inflammatory reaction that occurs when blood flow to the donor lung is absent during transport, called primary graft dysfunction (PGD).

Primary graft dysfunction can occur in up to 10-25% of lung transplant patients. In severe cases of hypoxemia, extracorporeal membrane oxygenation, or ECMO, may be used to support patients until donor lung function recovers. ECMO is a temporary life support machine that allows for oxygenation and removal of carbon dioxide from the blood when the lungs are too inflamed to support gas exchange. It can also provide blood pressure support if cardiac function is temporarily decreased due to stress from the surgery.

As you recover, you'll feel some pain at your incision site. Your healthcare team will help you manage this discomfort using different pain medications, including acetaminophen (Tylenol), non-narcotic pain medications, and small doses of narcotic medications as needed. Adequate pain management early on helps patients cough, breathe, and walk to allow a new lung to fully inflate. Your discomfort should gradually decrease over a few days.

After you leave the ICU, you'll be moved to a transplant unit. Total hospitalization for a typical patient is one to two weeks, but this may be extended if problems occur during recovery. During your hospital stay, your care team will focus on starting immune-suppressing drugs to prevent your body from rejecting the new lung. The most common of these medications are tacrolimus (sometimes cyclosporine), mycophenolate mofetil (sometimes azathioprine), and prednisone. You'll also work with a physical therapist to be out of bed and walking as soon as possible. You may also work with a respiratory therapist, occupational therapist, and speech therapist during your recovery.

TRANSPLANT OUTCOMES

Lung transplants can significantly improve recipients' quality of life. After recovering, patients can breathe better. Most don't need oxygen support and can be more active than they were before surgery. Some people continue to work and travel.

Long-term survival after lung transplant is often complicated by rejection (the body's immune system attacking the lung as though it were a disease) and the side effects of powerful immune-suppressing drugs, among other factors.

However, survival rates have improved significantly in recent years. According to the OPTN and SRTR 2018 Annual Data Report, approximately 89% of lung transplant patients survive at least one year after their surgery. According to the same report, approximately 74% of individuals receiving lung transplants are still alive after three years. There are many factors that contribute to survival post-transplant, including age, disease type, severity of illness at the time of transplant, and procedure type.

For more information on what to expect after transplant, see the Pulmonary Fibrosis Foundation's "Life After Lung Transplant" brochure.

Scarring after transplant?

Many PF patients ask if fibrosis (scarring) will return in transplanted lungs. Medical research shows that in most cases, preexisting fibrosis doesn't appear to recur in donor lungs.

FINANCIAL CONSIDERATIONS

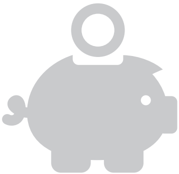
It's important to be prepared for the very high cost of a lung transplant, including some expenses you might not have considered. Although your health insurance may cover many of the costs, you may be fully or partially responsible for some expenses, including:

- Laboratory tests
- Medications, including immune suppression drugs that help prevent organ rejection
- Organ procurement (obtaining the lung from the donor)
- In-hospital stays
- Physical therapy or occupational therapy
- Nonmedical costs such as food, childcare, lost wages, living expenses, or relocating to a residence near the transplant center, if necessary

Most transplant centers have financial coordinators and social workers who can help you navigate and develop a strategy for the financial aspects of lung transplant. Meet with them early in your evaluation process to discuss your financial situation and begin devising a plan.

Patients commonly turn to one or more of these funding sources to help finance a lung transplant:

- **Private insurance.** Read your policy carefully, request preauthorization, and contact your insurance carrier with any questions. Remember that you'll be responsible for deductibles, copays, and any costs exceeding coverage caps.
- **Medicare.** Some of your medical expenses may not be paid by Medicare. Payment is according to a set fee, which may be less than the actual cost of the transplant—so patients covered by Medicare will be required to pay deductibles, copays, and various other expenses. A supplemental or "Medigap" policy can help pay for some of the expenses Medicare doesn't cover. To receive full Medicare benefits for a transplant, your transplant center must be a Medicare-approved facility that meets certain standards.
- **Medicaid.** Most Medicaid programs only cover transplants performed in their state, unless there are no centers in that state that can transplant that organ.
- **Prescription drug assistance programs.** Some pharmaceutical companies provide medications for patients in financial need. To learn more, visit **medicineassistancetool.org.**
- **The Veterans Administration/TRICARE.** If you've been honorably discharged from the military, you may be eligible for VA benefits. Patients who meet certain requirements may be eligible to receive a transplant at a VA medical center. Contact your local VA hospital or office to find out if you qualify. TRICARE, the regionally managed program for active-duty and retired members of the uniformed services, their families, and survivors, may help cover lung and heart-lung transplants. For more information, visit **tricare.mil.**
- **Advocacy groups and charitable organizations.** Some advocacy groups and charitable organizations provide limited financial assistance to transplant patients. For resources that may help cover housing, in-home support, transportation, and medications, visit **transplantliving.org/financing-a-transplant.**
- **Fundraising campaigns.** Some patients carry out fundraising activities, such as events and crowdfunding campaigns, to help finance their transplants. If you're planning a fundraising event, enlist the support of local businesses and other sponsors to promote or contribute.



Caution— fundraising may affect Medicaid

Use caution if you elect to hold a fundraising campaign to help with transplant expenses. If you're on Medicaid, for instance, the money raised may count as income—and disqualify you from Medicaid coverage—if it doesn't go directly to a qualified non-profit account. Consult with a legal advisor and/or your transplant center financial coordinator before beginning fundraising.

CAREGIVER RESPONSIBILITIES

A lung transplant is serious surgery, and caregivers play a key role in providing physical and emotional support before, during, and after the procedure. Caregivers may prepare meals, run errands, help with personal hygiene, ensure medications are taken correctly, assist in communicating with healthcare providers, transport the patient to and from the hospital and provider appointments, and provide companionship and encouragement.

Most transplant centers require potential lung recipients to name at least two people who will be their caregivers while they're on the waiting list and for the rest of their lives after transplant. Caregivers must be adults, nonsmokers, and able to drive. They must also be able to stay at the hospital for long periods during the patient's recovery and transport the patient to and from appointments before and after surgery, as needed.

If a patient is required to move near the transplant center while on the waiting list (see page 4), one or more caregivers may need to relocate, too.

For additional details on caregiver roles after transplant, see the Pulmonary Fibrosis Foundation's "Life After Lung Transplant" brochure.

Choosing caregivers

It's best not to depend on paid caregivers. They may not be covered by insurance after transplant, available for care 24 hours a day and seven days a week, or committed to the lifelong follow-up needed. In fact, most transplant centers don't allow the use of paid caregivers.

GLOSSARY

Bilateral lung transplant: Transplantation of both lungs. Usually performed as a sequential procedure (bilateral sequential transplant), where one lung is transplanted immediately followed by transplantation of the other lung.

Blood type/antibodies present test: A test for classifying an individual's blood type, often used for the purpose of matching patients with potential organ donors.

Body mass index (BMI): A measurement to screen for weight categories that may lead to health problems. BMI is calculated by dividing a person's weight in kilograms by the square of his or her height in meters. Visit www.nhlbi.nih.gov/health/educational/lose_wt/BMI/.

Bone mineral density test: A test using X-rays to measure the amount of minerals (calcium) in a person's bones. This test is important for people who are at risk for osteoporosis (porous and fragile bones), especially women and older adults.

Cardiac catheterization: A procedure used to diagnose and treat certain conditions of the heart and vascular system. A long thin tube called a catheter is inserted into a large blood vessel that leads to the heart.

Cardiac stress test: A test, also called an exercise stress test, that shows how a person's heart works during physical activity. A cardiac stress test usually involves walking on a treadmill or riding a stationary bike while heart rhythm, blood pressure, and breathing are monitored. In some cases, patients may receive a drug that mimics the effects of exercise.

Chest X-ray: An X-ray that produces images of the heart, lungs, airways, and blood vessels, as well as the bones of the spine and chest. A PA/lateral chest X-ray provides a two-dimensional view of the lungs.

Computed tomography (CT) scan: A procedure that uses a combination of X-rays and a computer to create a three- dimensional image of an individual's organs, bones, and other tissues. A CT scan shows more detail than a regular X-ray.

Complete blood count (CBC): A blood test used to evaluate overall health and detect a wide range of disorders. A CBC measures several components of blood, including red blood cells, which carry oxygen; white blood cells, which fight infection; hemoglobin, the oxygen-carrying protein in red blood cells; hematocrit, the proportion of red blood cells to the fluid component, or plasma, in your blood; and platelets, which help with blood clotting.

Connective tissue disease-related interstitial lung disease (CTD-ILD): Lung disease that may develop in some people with a connective tissue disease (also known as rheumatologic, collagen vascular, or autoimmune diseases) such as scleroderma, rheumatoid arthritis, Sjogren's syndrome, systemic lupus erythematosus, polymyositis, or dermatomyositis. CTD-ILD causes inflammation and fibrosis of the lungs. Some patients with ILD may have features of a CTD, but not meet all of the criteria necessary to diagnosis a specific autoimmune disease.

Contraindications: Specific situations in which a drug or procedure should not be used because it may be harmful to the person. An absolute contraindication means use of the drug or procedure could cause a life-threatening situation. A relative contraindication means the benefits may outweigh the risk, but caution should be used.

Echocardiogram: A procedure that uses sound waves to produce images of the heart. Images from an echocardiogram can be used to identify heart disease.

Electrocardiogram (EKG): A test that records the electrical signals in your heart and monitors its activity through sensors (electrodes) attached to your chest and sometimes your limbs.

Esophageal motor disorders: Certain conditions affecting the esophagus (the tube that carries food from the mouth to the stomach). Examples of these disorders are GERD (see separate listing), difficulty swallowing, or a problem with the muscular ring that closes off the esophagus from the stomach.

Extracorporeal membrane oxygenation (ECMO): A life support machine that allows for gas exchange outside of the body. ECMO replaces the functions of lungs, and can also provide hemodynamic support (stablilize blood pressure), depending on the configuration.

Gastroesophageal reflux disease (GERD): A condition that occurs when stomach acid flows back into the esophagus (the tube connecting the mouth and stomach). This backwash (acid reflux) can irritate the lining of the esophagus. The presence of GERD may contribute to the body's rejection of a transplanted lung.

Hypoxemia: A below-normal level of oxygen in the blood.

Lung Allocation Score (LAS): A score given to each patient who is added to the lung transplant waiting list to help donated organs reach the people who will most benefit from a transplant. Factors in the LAS include age, oxygen requirement, pulmonary function test results, distance walked in six minutes, and type of lung disease. When a compatible lung becomes available, individuals with higher scores receive priority. The LAS estimates one-year survival on the waitlist versus one-year survival post-transplant, prioritizing waitlist survival twice as much in an effort to prevent patients dying while on the waitlist.

Organ Procurement and Transplant Network (OPTN): A public-private partnership that links all professionals involved in the U.S. donation and transplantation system, as well as individuals who sign organ donor cards, people who comment on policy proposals, volunteers who support donation and transplantation, and many others. The OPTN was created in 1984 under the National Organ Transplant Act. UNOS (see separate listing) is the current OPTN under contract with the U.S. Department of Health and Human Services. Visit optn.transplant.hrsa.gov.

Pulmonary function tests: A series of tests that show how well the lungs are working. The tests measure lung volume, capacity, rates of flow, and gas exchange (the delivery of oxygen from the lungs to the bloodstream and elimination of carbon dioxide from the bloodstream via the lungs).

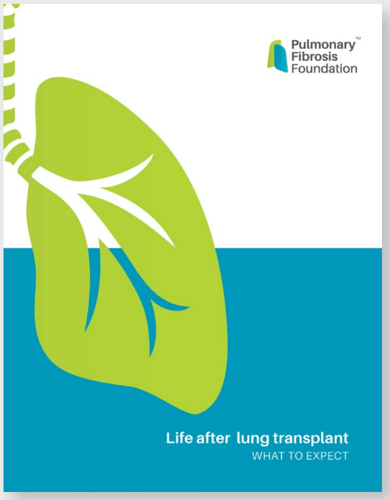
Pulmonary rehabilitation: A supervised program that includes exercise training, health education, and breathing techniques for people with certain lung conditions.

Scientific Registry of Transplant Recipients (SRTR): An organization that supports the transplant community by carrying out data analyses, maintaining databases, and providing informational websites that lead to better patient outcomes. SRTR is administered by the Chronic Disease Research Group of the Hennepin Healthcare Research Institute, with oversight and funding from the U.S. Department of Health and Human Services. Visit **srtr.org**.

Transplant center: One of a limited number of U.S. medical centers that perform lung transplants.

Unilateral lung transplant: Transplantation of a single lung.

United Network for Organ Sharing (UNOS): The private, non-profit organization that manages the nation’s organ transplant system under contract with the federal government. UNOS brings together hundreds of transplant and organ procurement professionals and thousands of volunteers in a system that serves as the model for transplant systems around the world. Visit **unos.org**.



For information on continuing recovery after you return home from the hospital, see the Pulmonary Fibrosis Foundation’s ”Life After Lung Transplant” brochure.

NOTES

STILL HAVE QUESTIONS?

Contact the PFF Patient Communication Center at 844.TalkPFF (844.825.5733) or pcc@pulmonaryfibrosis.org.

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Pulmonary Fibrosis Foundation™

223 W. Jackson Blvd., Suite 350
Chicago, IL 60606

phone: 844.TalkPFF
844.825.5733
help@pulmonaryfibrosis.org

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RESOURCES

To learn more about life after a lung transplant, visit:

- United Network for Organ Sharing at unos.org
- Organ Procurement and Transplant Network at optn.transplant.hrsa.gov
- Scientific Registry of Transplant Recipients at srtr.org

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The PFF gratefully acknowledges the organizations at left and these additional sources for the information contained in this booklet:

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