



Introduction

Welcome to the Lung and Heart-Lung Transplant Center at UC San Diego Health. This guide will help answer many of the questions you may have about the transplant process.

Lung and Heart-Lung Transplant have become good treatment options for carefully chosen patients with end-stage heart and lung disease who have not benefited from other therapies. UC San Diego Health's Lung and Heart-Lung Transplant Program began in 1989 under the direction of the internationally renowned cardiothoracic surgeon, Dr. Stuart W. Jamieson. Since then hundreds of transplants have been performed for many local, national and international patients with excellent outcomes. In 2011, UC San Diego Health opened the state-of-the-art Sulpizio Cardiovascular Center where heart and lung transplants are now performed.

Education of the transplant patient is a continuous process. This guide is meant to give a brief overview of our program and our transplant process. It is important for you to know as much as possible about the process so you can help make the best decision about your health care.

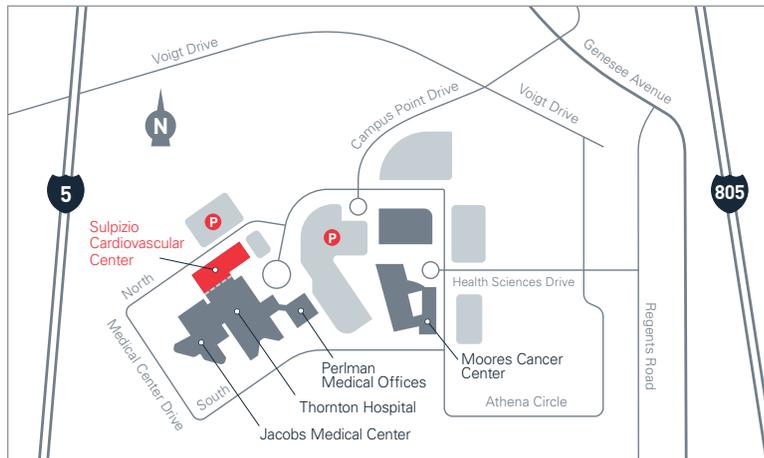
We want to make sure you get the best care possible. If you have any questions, please contact us.

T: 858-657-5050

F: 858-657-7636

health.ucsd.edu/transplant

Locations and Parking



UC San Diego Health – La Jolla
Sulpizio Cardiovascular Center
9434 Medical Center Drive
La Jolla, CA 92037

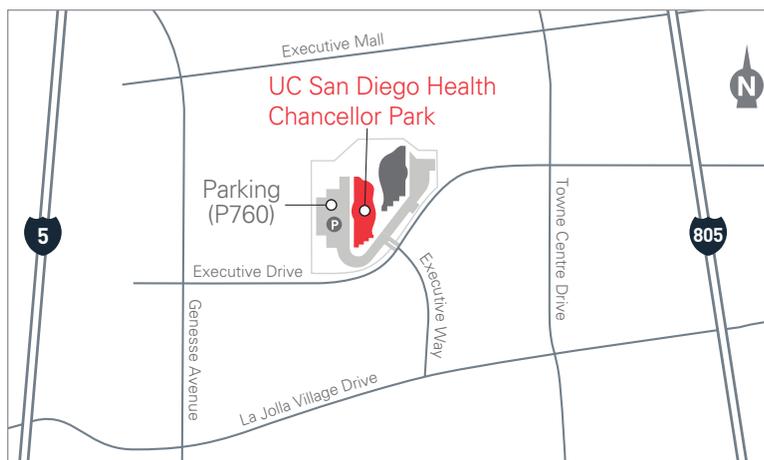
Complimentary disabled parking is available in meters and accessible spaces when you display a valid placard or license plate. Valet parking *is not free* even with a disabled placard.

Patients and visitors can park in lot 751 in front of Thornton Hospital or the East Campus parking structure next to Sulpizio Cardiovascular Center. If the parking lot or structure is full, please use the overflow parking in lot 702 off Voigt Drive and take a free shuttle.

- First 30 minutes free, \$4 for the first two hours, up to \$8 maximum per day

Valet parking is available weekdays in front of Thornton Hospital from 8:30 a.m. to 4:30 p.m.

- \$5 service fee, up to maximum of \$10



UC San Diego Health – La Jolla
Chancellor Park
4510 Executive Drive
Suite Plaza 7 (lower level)
San Diego, CA 92121

Park in the lot on the west side of 4510 Executive Drive or the parking structure. Bring your ticket with you. We will validate for the time you are in clinic.



Why You Might Need a Transplant

Any severe lung disease that is getting worse and not responding to medical therapy may benefit from lung and heart-lung transplant.

Lung transplantation may be indicated for different lung diseases such as:

Interstitial Lung Disease

- Idiopathic pulmonary fibrosis (IPF)
- Sarcoidosis
- Hypersensitivity pneumonitis
- Eosinophilic granuloma
- Lymphangioleiomyomatosis (LAM)
- Other interstitial lung disease/fibrosis

Pulmonary Vascular Disorders

- Idiopathic pulmonary arterial hypertension
- Eisenmenger's syndrome

Obstructive Lung Diseases

- Chronic obstructive pulmonary disease (COPD)/Emphysema
- Alpha-1 antitrypsin deficiency

Bronchiectasis

- Cystic fibrosis

Types of Lung Transplants

Single – Replace one diseased lung with a donor lung either right or left side

Double – Sometimes called bilateral (sequential single) lung transplant, both lungs are replaced with donor lungs

Heart-Lung – Both the heart and the two lungs are replaced with donor heart and lungs

Living Lobar Lung – Two living donors related to patient each donates a lobe to recipient (currently it is not performed in our center Transplant Evaluation

While you may be referred to a transplant center by your pulmonologist or primary care physician (PCP), this does not necessarily mean that transplantation is right for you. First, your medical information is reviewed by a transplant pulmonologist (lung doctor). It is important that your doctor forward any pertinent medical information to help us formulate an evaluation plan early on. Our office will then schedule a consultation appointment. In some instances, we find the most efficient way to complete the transplant evaluation testing is for our office to schedule all the testing through UC San Diego Health. If this is not possible due to reasons such as insurance limitations, we will work with your health care provider. These tests may include:

Chest X-ray (CXR) – Provides basic picture of chest and also documents the size of your chest cavity for the new organs.

Chest CT – This special type of X-ray gives the transplant team a more detailed picture of your lungs and the inside of your chest.

Ventilation/perfusion lung scan – Shows how much air movement (ventilation) and blood flow goes to each lung.

Pulmonary function test (PFT) – These tests evaluate how well your lungs and airways work. For lung transplant candidates, there will also be a "6-minute-walk" test and rest and exercise test with arterial blood gas (ABG).



Electrocardiogram (EKG or ECG) – This test records your heart rhythm, shows how fast your heart is beating and whether there are signs of previous heart damage.

Echocardiogram (ECHO) – This test uses sound waves to look at your heart's size and how the heart muscle and valves are working.

Right heart catheterization – This test measures the pressures in your lungs and the heart. It is done by inserting a very small catheter into a large vein in your leg or neck and moving it into the heart. If the pressures are very high, you may be placed on medication to lower the pressure and protect the heart.

Left heart catheterization – If you are over 40 or have any history of heart disease, you may need this test. It tells the transplant team if your heart function and blood supply to the heart muscle are good. During the test, a cardiologist inserts a small catheter into an artery in your groin. The area is numbed before the procedure begins. The catheter will pass through the blood vessel to your heart. Once it is placed in proper position, contrast dye is injected. You may experience a warm sensation when contrast is injected. Pictures of your heart arteries will be taken. You remain awake during the test, but may be given medication to help you relax. After the catheterization procedure, you will be monitored in the recovery room for one to six hours.

Laboratory tests – Blood, urine, stool and sputum

Bone density study – Assess for osteoporosis

Dental and eye examination – You will need dental clearance and a baseline eye examination.

Mammogram/pap smear – Cancer-screening tests for women according to ACOG guidelines

Prostate Exam/PSA – Screening for males over age 50

Colonoscopy – Routine colon cancer screening for patients over age 50

Other Assessments

Social Worker Assessment – You and your family will meet with a transplant social worker who will evaluate your readiness for transplant, and if needed, help you formulate a plan to work through any social or emotional issues that may impact your ability to comply with pre- and post-transplant requirements.

Additionally, the transplant social worker will review your concerns, discuss the emotional issues related to transplantation, and answer any additional questions. The social worker can provide a variety of helpful resources and assist you in developing your plan for the three-month post-transplant period. Sometimes counseling may be recommended to address certain issues or to provide additional support.

Financial Screening and Insurance – Most insurance companies and medical assistance programs cover transplantation. Our financial advisor will help you determine how the surgery and long-term medications will be paid for. If there are any changes in your insurance at any time during the workup or after listing, please call us immediately.

Additional Tests – The physician may believe additional tests are needed to complete the evaluation.

All the test results will provide the transplant team with a more complete understanding of your health status. The transplant committee will then meet and each member will make recommendations to best manage your health — which may or may not include transplantation.





Meet Your Transplant Team

My Coordinator is:

My Assistant is:

My Social Worker is:

My Dietitian is:

My Pulmonologist is:

If I have questions I should call:

If I have an emergency I should call:





Your Transplant Team — Who We Are

Transplant is a stressful process when you and your family have already faced many medical challenges. We have a competent, caring multidisciplinary transplant team. Please take a minute to get to know your team who will care, assist and cheer for you before and after your transplant.

Transplant Surgeons

A transplant surgeon is a cardiothoracic surgeon with special training in transplant surgery. At the end of your workup evaluation, you will meet with one of the transplant surgeons and have all your surgery related questions answered. He or she will be one of several surgeons that may perform your surgery and follow you during your immediate post-transplant period.

Transplant Pulmonologist and Transplant Cardiologist

A transplant pulmonologist is a medical doctor who specializes in lung disease and has specific training to manage the complex medical issues that may come up after lung transplant. In some cases, you may also meet a transplant cardiologist, who is a medical doctor that specializes in heart disease and has specific training to manage the complex cardiac issues following transplant. Once your transplant work up is completed, the transplant physician will present your case to our transplant committee. If you are listed for transplant, these physicians will monitor your care before, during and after surgery. Your primary care doctor will still be an important part of your care, especially during the pre-transplant phase and for non-transplant related issues post-transplant.

Transplant Coordinators

The transplant coordinators are experienced registered nurses. They are the liaison between you and your physician. There is always one coordinator on call 24/7. They will be getting organ offers, working with the transplant physicians evaluating offers, and contacting you if there is a match right for you. The transplant coordinator will be providing you and your family ongoing teaching during both pre- and post-transplant phases. They work together with the transplant pharmacist to ensure you and your families are comfortable with self-care before getting discharged home after transplant. They continue care for you after transplant. They work with the transplant physician in clinic and address any medical issues as needed between clinic visits.

Transplant Social Workers

All pre-transplant patients will be evaluated by a licensed social worker who identifies needs, problems and discusses your expectations of transplant, as well as the psychosocial issues that may occur after transplant. They will also help you and your family come up with a care plan after your transplant. The social worker also runs support groups to provide support for both patients and their families.

Transplant Financial Coordinator

Significant costs are associated with transplantation including the initial work-up testing as well as post-transplant care. The financial coordinator will verify insurance coverage and benefits and will explain the benefit coverage criteria. Please do not change insurance coverage or carriers until you discuss it with our financial coordinator.

Transplant Pharmacist

The transplant pharmacist works with you and the transplant team to ensure you are on the correct medications after transplant. Additionally, the pharmacist will provide education on how to take your medications and will work to make sure that you are able to get them from the pharmacy.





Transplant Dietitian

Transplant dietitians are registered dietitians who have education and experience in managing nutrition for pre- and post-transplant patients. A transplant dietitian can assess a patient's nutrition status and make recommendations about therapeutic diets and nutritional supplementation.

YOU!

Above all, 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 rules set up by the transplant team. You must maintain a nutritious diet and keep a routine exercise program tailored to your physical ability. Friends and family support is very important too. They provide not only the physical support by taking you to appointments, but also provide the emotional support. Receiving a transplant is a lifetime commitment.

Lung Transplant Committee

Thoracic Surgery Faculty

Stuart W. Jamieson, MB, FRCS, Head of Division
Eugene Golts, MD
Michael Madani, MD
Anthony Perricone, MD
Victor Pretorius, MB

Transplant Pulmonologist Faculty

Kamyar Afshar, DO
Gordon Yung, MD

Transplant Coordinators

Tara Akins, NP
Jaclyn Scholten, NP
Elizabeth Schonhoft, RN

Transplant Social Workers

Leslie Fijolek, LCSW
Holly Hernandez, LCSW

Transplant Financial Advisor

Marylei Icban

Transplant Pharmacist

Ashley Feist, PharmD
Mark Mariski, Pharm D

Transplant Dietitian

Cheri Kaczmarek, RD

Transplant Administrative Staff

La Trecee Evans
Amy Negrillo



Waiting for Your Transplant

The Transplant Waiting List

The waiting list is a nationwide computerized network managed by the United Network for Organ Sharing (UNOS). UNOS is a nonprofit, scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN), which was 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 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.
- For every lung transplant patient, UNOS will calculate a Lung Allocation Score (LAS).

Lung Allocation Score for Lung Candidates

All patients on the lung transplant waiting list carry an LAS. LAS is a score calculated by UNOS based on a patient's disease characteristic, clinical data and testing results. It is used to determine the position of any patient on the waitlist. The higher the score, the higher the patient's priority is on the waitlist. UNOS requires transplant centers to update the information periodically. Some of the testing needs to be repeated every six months. The LAS is designed to change as your lung disease changes and ultimately optimize the use of transplant organs. If there is objective worsening, your transplant coordinator or UNOS data manager will update UNOS. This may result in a higher LAS and a higher priority for transplant.

It is very important to realize that there are many other factors that determine if an organ would be offered to you besides your LAS. Those include blood type, tissue antibody, body weight and size, organ size, organ availability, wait status and wait time. Criteria not used in the organ matching system are gender, religion, celebrity and financial status.

Heart-Lung Candidates

If you are a heart-lung transplant candidate, you will be listed on the heart-lung transplant waitlist.

Multiple Listing

You have the right to be double-listed for a transplant at another center as well as ours. However, each hospital may have its own rules. Generally, each center will require the patient to go through its own transplant evaluation even if the patient is already listed at another hospital. For more information, please call UNOS or visit the website.

888-894-6361
unos.org

While You Are on the Waiting List

- Stay as healthy and active as you can. Ask about pre-transplant pulmonary rehab.
- Join our support group offered to our pre- and post-transplant patients.
- Keep in touch with the transplant team.
- Notify us of any telephone, address or insurance changes.
- 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.
- Always answer your phone, especially when the hospital is calling.



Getting Your Transplant

Receiving “The Call”

A transplant coordinator will call you to let you know we have accepted an offer for you. This call often comes in the middle of the night.

- Do not eat or drink after we call you unless we tell you otherwise. You can take your usual meds, except for aspirin, NSAIDs or blood thinners such as Coumadin or Lovenox shots.
- Inform the transplant coordinator of any recent change in your medical condition such as a recent infection.
- We will ask you to come to the hospital immediately.
- You will be directed by the transplant coordinator where to go upon arrival to hospital. During the daytime, this usually means getting admitted through the admissions office. In the evening and weekends, you may need to go through the emergency room for admission.
- Have a designated driver to bring you. Drive safely!
- Bring your ID and health insurance information with you. Leave valuables at home.
- You will need to have some testing done after your arrival.

What Happens Next?

While you are getting testing done, including blood, urine testing, and CXR, our transplant team will evaluate and monitor the health of the organ and a tentative operating time will be set to perform an on-site evaluation of the donor organ. This involves one or more members of our transplant team going to the donor hospital to visually inspect and physically exam the donor organ. This part of the process typically requires two to three hours. After that, our team will be able to make the final decision of whether the organ is suitable for transplant.

Please note that a significant portion of the organs are turned down at this time.

In order to minimize the period between the organ outside the donor body and transplant recipient body, you may be transferred to the operating room during this time to begin preparation for transplant. This may involve placing “lines” in your wrist, neck or groin area.

In general, we do not give out information about the donor due to patient privacy issues. However, in some cases, your physician may discuss with you specific details of the donor that may affect the transplant. You may be asked to sign additional consent forms to accept the organ. Typically, this involves potential risk of transmitting infectious disease through the donor organ. Although the organs we accept generally have minimal risk of such transmission, we feel that you should be part of that decision.



If the organ is deemed suitable after our procurement team visually inspects it, the transplant surgery will usually begin immediately — taking into account the distance and time the organ needs to be transported between donor hospital and UC San Diego Health.

If we have noted significant issues in the organ on inspection, you will be told the transplant is cancelled and you will be discharged. This is often referred to as a “dry run.” We understand this can be disappointing. Your transplant team is looking out for your best interest and outcome. Please be patient.

Getting the Transplant Surgery

It usually takes four to six hours for single-lung or heart-lung transplants. Double-lung transplants can take up to eight to ten hours. Occasionally, the surgery may be longer, especially if you have had prior chest surgery.

You may have an incision on the right, left or middle of the chest depending on the type of transplant you will receive. Ask your surgeon regarding the surgical approach during your pre-transplant visit. It is uncommon, but sometimes the incision choice can change at the time of transplant to ensure the best outcome.

Your family should wait in the ICU waiting room and give your nurse the best cell phone number to reach them. Your family will be notified as soon as the surgery is done. If the surgeon is unable to locate family members, your family can also call for updates.

858-657-8330

Your Hospital Stay

ICU (Intensive Care Unit)

After your transplant, you will be transferred to the Sulpizio Cardiovascular Center (SCVC) Intensive Care Unit on the third floor where you will be monitored closely for your new lung/heart-lung function as well as possible complications such as bleeding and kidney injury. This requires having various “lines” and “tubes” placed such as:

Breathing tube (ventilator) – This connects you to a breathing machine. It helps you breathe until you are capable of breathing on your own.

Chest tubes – These drainage tubes are inserted into your chest area during the surgery to drain off fluid and/or blood so your new lung can expand fully.

Central line – Commonly placed either around your neck or your groin area, the central line is a slightly bigger IV that serves both as an access port for different types of fluid/meds you may need and as a line to monitor your heart function.

A-Line (arterial line) – Commonly placed on your wrist, it is a small tube placed in an artery to continuously monitor your blood pressure.

Foley catheter – A urinary catheter in your bladder to monitor your urine output.





The effect of anesthesia can take many hours to wear off. Most patients do not remember the first 24–48 hours of their ICU stay. You may wake up feeling a little confused. For your safety, your wrists may be lightly restrained to prevent you from pulling out any tubes or lines. Once the doctor determines that you are strong enough, he/she will try to remove your breathing tube allowing you to breathe on your own. Typically, you will still need supplemental oxygen for a few weeks afterwards while waiting for your lung/heart-lung to recover from surgery. Your doctor may decide to perform a bronchoscopy while you are on a ventilator to help you breath.

In a bronchoscopy procedure, your doctor inserts a small fiber optic tube through your breathing tube so that he/she can visualize the inside of your airways. This procedure will allow your doctor to remove any secretions and/or blood that may obstruct your breathing, as well as to obtain samples to check for infections.

PCU (Progressive Care Unit)

After your doctor determines that you are recovered enough, you will be transferred to the PCU on the SCVC fourth floor. This is a “step-down” unit with private rooms. You are expected to be able to function more independently. In exchange for more intense monitoring you have more autonomy and privacy. As you get better, the IV lines, tubes and catheters will be gradually removed. Physical therapists will be working with you to get your strength back. The transplant coordinator will start post-transplant teaching with you and your family, and the transplant pharmacist will provide you with detailed instructions on your medications. Eventually, you will be discharged from this room when your physician determines you are ready.

Roles of Family and Caregivers During the Hospital Stay

We understand that you may have a lot of family members and friends who want to visit you during your recovery. However, each visitor carries additional risk of spreading infection to you at a time when you are most vulnerable. We therefore ask your family and friends to limit visitation during that time to the minimum. You and your family can discuss with the transplant team the limitations specific to your care.



After Your Transplant

Transplant is a Lifestyle Change

Lung and heart-lung transplantation have the potential to lengthen life expectancy and substantially improve quality of life. However, all post-transplant patients are at risk for developing rejection and other complications and so it is necessary to monitor all patients closely. This includes frequent clinic visits with testing, which can be several times a week.

Rejection

The body tries to dispose of anything that it considers foreign. After your transplant, your body will try to reject your transplanted organ. In order to prevent rejection, your transplant team will prescribe for you “immunosuppressant” medication (meaning, suppress the immune response that tries to fight the transplant). These medications help the body control the cells that will try to reject your transplanted organ. There are different types of rejection (acute rejection, chronic rejection, etc.). You can minimize the risk by adhering to the treatment and follow-up plan advised by your transplant team.

Infection

The immunosuppressant you take will make you more susceptible to infection. Your doctor will also give you medications to prevent certain infections. You have an important role in the prevention of infection by following instructions to avoid exposure to infection and immediately reporting any symptoms of infection.

Other Complications After Transplant

Other common complications include diabetes (high blood sugar), hypertension (high blood pressure), hyperlipidemia (high cholesterol), cancer (particularly skin cancer), and kidney and liver dysfunction. Many are related to side effects of certain long-term medications. Again, meticulous care after transplant can minimize the effects of these complications.

Medications After Transplant

You will likely be taking more medications post-transplant than you did pre-transplant, generally including at least three immunosuppressant medications and some other anti-infection medications. The immunosuppressant medications will need to be taken for the rest of your life. You must take all your medications exactly the way they are ordered for you. If you stop taking your medications, you will reject your transplanted organ. Upon your discharge and with each clinic visit, we will help you maintain an up-to-date list of your medications. The following is a sample list of medications you may be prescribed:

Immunosuppressant or “anti-rejection” medication – Suppress/lower immune system to prevent rejection

Steroids – First line of defense for rejection

Antibiotics – Help your body prevent bacterial infections

Antifungal – Help your body prevent fungal infections

Antiviral – Help your body prevent viral infection

Other – Antihypertensive meds, diuretic (water pill), reflux medication, pain medication, vitamins and minerals



Paying for Your Transplant

There are many costs associated with transplant and few patients are able to pay for all of the costs from any single source. You may be able to finance the transplant procedure through the following:

Insurance

You or your family may have health insurance coverage through an employer or a personal policy. Most insurance companies now cover transplant costs. However, the terms and extent of the coverage vary. Most insurance companies require prior authorization (approval) for the organ transplant procedure. Make sure you speak with the financial coordinator here at the lung transplant program to help you with your authorization and be sure you provide them with any changes in your coverage.

COBRA

Insurance coverage may be extended through COBRA, which stands for the Consolidated Omnibus Budget Reconciliation Act of 1985. This is a Federal Law that required certain group health plans to allow participating employees and their dependents to extend their insurance coverage for 18 – 36 months when benefits would otherwise end.

Tricare

This is a government-funded health benefits program for military families of active duty, retired or deceased personnel. Patients must be Tricare-eligible and have pre-authorization for the transplant. Tricare-eligible patients are responsible for all co-pays.

Medicare

This is a federally funded health benefits program available to people who are age 65 or older, have certain disabilities, and other qualifying individuals such as dependents of Medicare beneficiaries. Medicare offers three basic plans for various coverage.

Medi-Cal and Medicaid

This is a state-funded health benefit program for certain low-income people. Individual states determine eligibility and determine what benefits and services are covered.

Social Security

Social Security pays benefits to people who cannot work because they have a medical condition that is expected to last for at least one year or result in death. Federal law requires this very strict definition of disability. While some programs give money to people with partial disability or short-term disability, Social Security does not. Social Security pays disability benefits through two programs: The Social Security Disability Insurance Program (SSDI) and the Supplemental Security Income Program (SSI). There are two ways that you can apply for disability benefits. You may apply online or by calling Social Security.

800-772-1213

More information on Supplemental Security Income (SSI) may be obtained at:

ssa.gov/pubs/11000.html

Information on Social Security Disability Insurance (SSDI) may be obtained at:

ssa.gov/pubs/10029.html#part1



State Disability

California State Disability Insurance (SDI) is a partial wage-replacement plan for California workers. The SDI programs are state-mandated and funded through employee payroll deductions. SDI provides affordable, short-term benefits to eligible workers. Workers covered by SDI are covered by two programs: Disability Insurance and Paid Family Leave Insurance.

[800-480-3287](tel:800-480-3287)

edd.ca.gov/disability/

Fundraising

Patients and families often use public fundraising to help cover expenses not paid by medical insurance or public assistance programs. This may be a key source for financing the transplant.

These agencies help with fundraising for transplant. A tax-free account is established with no income penalty for patients with Medi-Cal.

National Foundation for Transplants

[800-489-3863](tel:800-489-3863)

transplants.org

HelpHOPELive

[800-642-8399](tel:800-642-8399)

helpholive.org

Other Financial Resources

There are some other financial resources available to help you manage the costs of your transplant:

National Foundation for Transplant (NFT)

NFT provides services to transplant candidates awaiting organ transplants, as well as patients who have already received transplants. As a nonprofit organization, it shares fundraising expertise and materials. Limited emergency grants may be available for medications and transplant-related expenses.

[888-489-3863](tel:888-489-3863)

transplants.org

Partnership for Prescription Assistance

Many manufacturers provide medications for low-income patients through patient assistance programs. Most programs require that patients meet certain income requirements. This is an online directory that provides details on more than 55 of these programs.

[888-4PPA-NOW \(477-2669\)](tel:888-4PPA-NOW)

pparx.org

Financial Coordinator

These are only brief summaries and are not intended to provide you with complete information about financing your transplant. Our lung transplant program has a dedicated transplant financial coordinator. The financial coordinator helps provide support to you and your family as you face the financial challenges associated with transplant care. Please consider the coordinator your primary contact for your insurance and financial needs. Share your information and concerns so you can best be assisted. Our financial coordinator can be reached at:

[858-657-5050](tel:858-657-5050)



Resources

While your transplant team here at UC San Diego Health is your main resource for your medical needs and any questions or concerns you may have, we also want to make sure you are aware of many other resources in California and the United States that are designed to help support transplant patients just like you. You are not alone in this journey.

Medication Assistance

HealthWell Foundation

800-675-8416

healthwellfoundation.org

NeedyMeds

800-503-6897

needymeds.org

Patient Services, Inc.

800-366-7741

patientservicesinc.org

Partnership for Prescription Assistance

888-4PPA-NOW (477-2669)

pparx.org

Patient Access Network Foundation

866-316-7263

panfoundation.org

Astellas Patient Assistance Program

800-477-6472

astellas.us/therapeutic/product/patients_assistance.html

Vocational/Educational Assistance

The California Department of Rehabilitation's (DOR) vocational rehabilitation services program assists Californians with disabilities to obtain and retain employment and maximize their ability to live independently in their communities. The department develops, purchases, provides, and advocates for programs and services in vocational rehabilitation, habilitation and independent living with a priority on service for persons with the most significant disabilities.

dor.ca.gov/

Assistance for Caregivers

Family Medical Leave Act (FMLA) – FMLA is based on a federal law that authorizes eligible employees up to 12 weeks of paid or unpaid job-protected leave during a “rolling” 12-month period to care for an immediate family member (spouse, child, or parent) with a serious health condition. Other reasons include birth of a child, adoption, or foster care placement and when the employee is unable to work because of a serious health condition. Eligible employees are those who have been employed for a total of at least 12 months who have worked for at least 1,250 hours during the previous 12-month period. The hours do not need to be consecutive hours. Your human resources department has the forms.

Paid Family Leave (PFL) – For California workers covered by State Disability Insurance, PFL insurance provides up to six weeks of benefits for individuals who must take time off to care for a seriously ill child, spouse, parent, or registered domestic partner, or to bond with a new child. Paid Family Leave pays approximately 60 percent of pay for an employed caregiver for up to six weeks per year. Your transplant center has forms.

877-238-4373

edd.ca.gov/Disability/Paid_Family_Leave.htm

In-Home Supportive Services (IHSS) – IHSS provides homemaker and personal care assistance to persons receiving Supplemental Security Income or who have a low income and need aid in the home to remain independent.

800-510-2020

co.san-diego.ca.us/hhsa/programs/ais/inhome_supportive_services/index.html

Southern Caregiver Resource Center – Southern Caregiver Resource Center helps families and communities master the challenges of caring for adults with chronic and disabling conditions.

858-268-4432

855-730-3703 (Spanish)

caregivercenter.org

Housing

Bannister House – The mission of Bannister Family House is to provide affordable lodging and supportive services for out-of-town families of patients who have come to UC San Diego Medical Center in Hillcrest or Thornton Hospital in La Jolla due to serious injury or illness. It is a haven of comfort and hope for weary families who share similar experiences and concerns in friendly, homelike surroundings close to the hospital. Your transplant social worker will make a referral upon your request.

health.ucsd.edu/bannister

Local Lodging

Many of our patients travel from out of San Diego County to receive care at UC San Diego Health. A list of local hotels is included in this informational binder and can also be obtained by calling one of our transplant social workers.

San Diego Housing Resources Directory – The Housing Resources Directory was prepared by the County of San Diego’s Department of Housing and Community Development to provide residents and the community agencies that serve them with information on housing resources available to low- and moderate-income households. The directory includes information on housing programs, and contact information for organizations that provide support services related to housing, such as credit counseling or mediation services.

sandiegocounty.gov/sdhcd/docs/housing_resource.pdf

Section 8 Public Housing – The San Diego County Housing Authority administers several publicly owned, low-rent housing units in Chula Vista. These rental units are available to low-income families, senior citizens, and disabled persons.

858-694-4801

sdhcd.org

Food Assistance

Supplemental Nutrition Assistance Program (SNAP) – A federal food stamp program. The new name will reflect a focus on nutrition and putting healthy food within reach for low-income households.

<http://www.fns.usda.gov/snap/>

County of San Diego Food Stamp Program – The Food Stamp Program is a federal supplemental nutrition program for families and individuals that meet certain income guidelines. Food stamp benefits help supplement your food budget and allow families to buy nutritious food. You can be working and still qualify for food stamps. If you qualify for food stamps you can use these benefits to purchase food at most grocery stores, convenience stores and food markets. Eligibility to food stamps depends on your household size, assets (in certain circumstances), income and certain living expenses.

sdcountry.ca.gov/hhsa/programs/ssp/food_stamps/index.html



Golden Share – The goal of S.H.A.R.E (self-help and resource exchange) is to help families to save up to 50 percent on their groceries, while encouraging the building of relationships with neighbors in the community.

619-590-1692

goldensharefoods.com

Jacobs & Cushman San Diego Food Bank

– Of San Diego County’s 3.1 million residents, approximately 500,000 people live at or near the federal poverty level. Over 70 percent are children. The Food Bank administers this USDA funded program which provides food packages to low-income individuals and families who meet income guidelines set by the federal government. The Food Bank serves, on average, 400,000 people per month in San Diego County.

866-350-FOOD

sandiegofoodbank.org

Transportation Assistance

Metropolitan Transit System Discounted Fares

– Senior citizens (60+), disabled individuals and Medicare recipients are eligible for a reduced fare on fixed-route buses and trolleys.

619-234-1060

sdmts.com/fares_discounted.asp

MTS Access – Curb-to-curb accessible transportation service for individuals who are unable to “functionally” use regular public bus, trolley, or Coaster services due to a physical or cognitive impairment. Riders must be certified to ride MTS Access. To fill out application, please contact MTS third-party certification contractor, ADA Ride.

877-232-7433

adaride.com

Transplant and Disease-Specific Societies and Organizations

Alpha 1 Foundation – Alpha-1 antitrypsin deficiency
alpha1.org

American Lung Association (ALA)
lung.org

American Thoracic Society (ATS)
thoracic.org

Cystic Fibrosis Foundation
cff.org

Foundation for Sarcoidosis Research
stopsarcoidosis.org

Hermansky-Pudlak Syndrome Network
hpsnetwork.org

Lifesharing Organ Procurement Organization San Diego – A local donate-life organization, with many personal stories from local patients.
lifesharing.org

Pulmonary Fibrosis Foundation
pulmonaryfibrosis.org

Pulmonary Hypertension Association
phassociation.org

Scientific Registry of Transplant Recipients (SRTR) – A website that provides reports and data on solid organ transplantation.
srtr.org

The LAM Foundation –
Lymphangiomyomatosis (LAM)
thelamfoundation.org

UNOS Transplant Living – A website with information and resources for transplant recipients.
transplantliving.org

United Network for Organ Sharing (UNOS)
888-894-6361
unos.org

US Department of Health and Human Services – Access to the Government’s information on organ and tissue donation and transplantation.
organdonor.gov

