



Welcome

To the  Scripps  
Transplant Family

As one of Southern California's premier transplant centers, and the first in San Diego to complete three-way and international kidney exchanges, we are honored that you have chosen to join our transplant family. Since 1994, Scripps Organ Transplantation Program has been helping patients with end-stage kidney disease through our kidney transplant program. Today, our kidney transplant program continues to have success rates that match or exceed the national average.

The transplant evaluation and transplant process can be a difficult time for you and your family. We are here to help guide you along the way.

With decades of experience and leadership, Scripps transplant surgeons and support teams offer you and your loved ones compassionate, expert care along every step of your journey.

This guidebook is intended to help you throughout the process. It is full of helpful information for you and your family.

Scripps Center for Organ & Cell  
Transplantation located at:

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[www.scripps.org/transplant](http://www.scripps.org/transplant)



Scan Me

We are  
here  
for you!



**Transplant Office: (858) 554-4310**

*Hours: Monday-Friday 8am to 5pm*

**After hours: (858) 554-9100**

*(Hospital Operator)*

**Transplant Scheduler: (858) 554-4310**

**Transplant Fax: (858) 554-4311**

### Our Mailing Address

*(Letters, outside medical reports, films, insurance forms etc.):*

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You will meet a lot of new people through the transplant process. Use this space to save business cards to help along the way.

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REMOVE TO EXPOSE ADHESIVE

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## Welcome to the Scripps Center for Organ & Cell Transplantation

We are happy you have chosen us as your transplant center. Our Transplant Team is looking forward to working with you and your family.

Our team is here to provide you with the *best* care possible. Please let us know how we can help you or your family. Scripps Clinic and Scripps Green Hospital have been recognized as one of the *leading* healthcare providers in the nation.

Patients and their caregivers often describe the transplant process as being one of the greatest personal challenges of their lives. It is important to understand that this is a challenge you can meet. Remember, there are many people who have been down this road before you. If they could encourage you now, their message would be simple: You can do it!

Most of our patients react to the prospect of transplantation with a mixture of hope and fear (concern/uncertainty). To overcome your fears, it is important to understand what the transplant process entails. Your transplant team will teach you a general idea of what to expect and support you and your family through the process.

Many patients and family members may experience some emotional ups and downs during the transplant process. This is, of course, a normal part of the journey. If you start to feel especially down at some point during the process, please let the transplant team know about it. They can help you make it through your most difficult days. Don't hesitate to take advantage of the help that is available through support groups and mentoring programs. In addition, your transplant social worker is always available to talk things over.

Use this guide as a reference to assist you in your transplant experience. You may want to bring your guide with you to clinic visits before transplant and we do ask that you bring it with you when you are called in for transplant. The transplant staff will use it to teach you and your family all about your care.

*Thank you again for choosing Scripps Center for Organ & Cell Transplantation.*

### Scripps Mission Statement

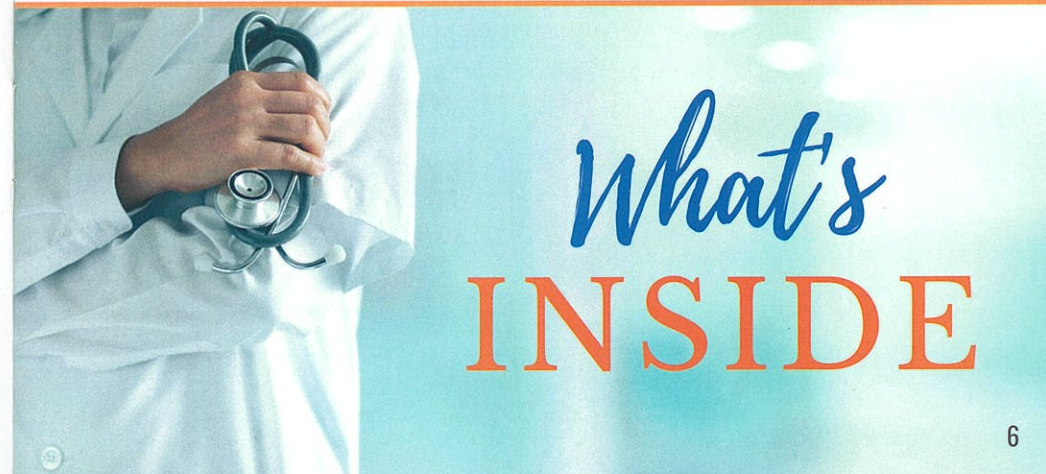
Scripps strives to provide superior health services in a caring environment and to make a positive, measurable difference in the health of individuals in the communities we serve.

We devote our resources to delivering quality, safe, cost effective, socially responsible health care services.

We advance clinical research, community health education, education of physicians and health care professionals and sponsor graduate medical education.

We collaborate with others to deliver the continuum of care that improves the health of our community.

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# Understanding Your Transplant

## Let's take a closer look

The kidneys are two bean-shaped organs located just below the rib cage on either side of the spine. They filter waste and excess fluids from the blood and eliminate these from the body in the form of urine. Kidneys also control the body's chemical balance, assist in creating new red blood cells, and regulate blood pressure. If a kidney is damaged due to illness or injury, it can lead to kidney failure, and harmful amounts of waste and fluid can build up in the body. Most people can live with just one functioning kidney, but if both kidneys are damaged, a process known as dialysis will have to replace the function of your kidneys. This process is ongoing until your kidney function improves, or when a transplant is deemed necessary.



During a kidney transplant, a donor kidney is surgically placed in the lower abdomen near the major veins and arteries in the pelvis. The new kidney will begin to clean the blood at different intervals depending on the patient. Some transplanted organs might take a little while to start working properly. The damaged kidneys are often left in place unless they are badly infected or enlarged from polycystic kidney disease.



# Your TEAM

Transplant is a complex process and requires a team of knowledgeable and experienced healthcare providers. Throughout the transplant evaluation process, you will meet with many members of our team. Scripps is proud to have an amazing group of healthcare professionals working with our transplant patients.

The Transplant Team includes your caregiver, family and friends, a group of highly dedicated professionals, and most importantly *you*, the transplant recipient.

### Recipient

You are the most important part of this transplant equation, so we want to keep you as prepared as possible. Here are a few tips to follow in order to be successful on this journey:

- Ask questions about your care and treatment.
- Share information about yourself, which may affect your care.
- Accept responsibility for learning how to meet your health care needs.
- Learn all about your medications.
- Show up to all of your appointments
- Take care of your mental health and well being
- Do as much as you can for yourself and remain as independent as possible.

### Caregiver

Your caregiver(s) will also have an active role. The caregiver is the primary person identified to help you through the transplant process. Most often, this is a spouse, partner, family member, or long-term friend. The caregiver role is described in detail in the Social Services section.

### Transplant Nephrologist

The transplant nephrologist is a doctor specializing in kidney diseases and medical management of kidney transplants. If your main health problem is kidney disease, a transplant nephrologist will evaluate you at the first clinic visit and will help your primary care doctor and dialysis center take care of you before, during, and after your kidney transplant. He or she helps manage your kidney-related medical problems and makes recommendations to your primary care doctor about your care.

### Transplant Surgical Team

A Transplant Surgeon will evaluate you before surgery and will perform your transplant surgery. Members of our transplant surgical team will visit you daily while in the hospital, examine you, manage your surgical issues, and discuss your care with you. After the transplant, the surgical team will see you in clinic for the first month or so after your transplant and review the results of your post-transplant testing. The surgical transplant team is comprised of Transplant Surgeons, transplant specialized Physician Assistants, Nurse Practitioners, Residents, and Fellows who may also be involved in your pre and post-transplant care.

### Complex Case Manager (Nurse Coordinator)

Your complex case managers are registered nurses who coordinate all your pre- and post-transplant events. You will be contacted by your pre-transplant coordinator by phone after your initial visits are complete.

Your pre and post-transplant coordinators teach you about your transplant and your new medications, help manage your follow-up care, and are the first people to call with questions or problems that you or your family might have. The coordinator will communicate your questions and concerns to the appropriate team members during the pre-transplant evaluation as well as after your hospitalization.

### Transplant Care Coordinator (TCC)

Your Transplant Care Coordinator is your first point of contact in the transplant process. They do an intake and give you instructions on the next steps in the transplant process. You will meet with your TCC as the first consult in your evaluation. They will review the transplant evaluation process and have you sign all required consents. Your TCC will also monitor your progress throughout the evaluation process and while you are listed for transplant.

### Social Worker

You will meet the social worker early in the evaluation process. The social worker will help by reviewing your available resources and ensuring that you are prepared for your transplant. The social worker will have you complete a few questionnaires prior to your first consult. Throughout the transplant process, your social worker will be available for questions, concerns and consultation.

**The rest of the team** - You will meet many other members of our team at different times throughout the process. Other team members include our **transplant schedulers** who will help you manage and schedule most of your appointments. Our **financial coordinators** assist with ensuring all required insurance authorizations are in place. Our **transplant dietician** will meet with you and help develop a nutritional goal for your condition. After your transplant, you will be cared for by our team of critical care and transplant nurses, physical therapists, case managers, and any additional consulting providers that may be indicated such as Infectious Disease, Cardiology, and Endocrinology.

# Transplant EVALUATION



**A transplant evaluation is a complex process. Every patient presents as a unique case, so every evaluation is also unique.**

The transplant evaluation is a series of consults and tests that help determine if you are a suitable candidate for transplant, and if not, determine what needs to be done in order to optimize you to be a suitable candidate. How long it takes to complete your transplant evaluation varies for many reasons, such as your availability when scheduling, or the number of tests and consults you require. Your scheduler and Complex Care Manager will be able to give you a more accurate timeline based on your individual case. Below are steps in the transplant evaluation process:

- **Referral** - Once you and your doctor feel you may be a good transplant candidate, a referral will be initiated. Referrals are typically started by your physician. Sometimes depending on your insurance coverage, you may be able to self-refer for transplant evaluation.
- **Intake** - Once your referral has been received, a Transplant Care Coordinator (TCC) will contact you to collect some additional information and get your permission to request your full medical records so our team can review them. Insurance Authorization for Eval is obtained
- **Consents** - Every evaluation will start with consenting. There are several consents you will need to sign. Your Transplant Care Coordinator will review each consent in depth with you and have you sign. You will be provided a copy of all consents you signed.
- **Testing and Consults** - You will need to complete several tests as part of your evaluation. Evaluation testing includes blood work, imaging, cardiac testing, lung testing, and consults with the transplant nephrologist and surgical team, transplant social worker, transplant dietician, and other consults that may be determined by your transplant physician.
- **Selection Committee** - Once you have completed all evaluation testing, your case will be presented to the Transplant Selection Committee and a determination will be made.
- **Insurance Authorization** - Once approved by the selection committee, our financial coordinators will request authorization for transplant surgery from your insurance carrier.
- **Listing** - Once your insurance company authorizes transplant surgery, you will be listed for transplant with the United Network of Organ Sharing (UNOS). Expect annual evaluations to maintain candidacy on the wait list.

## Medical Records Review

In order to complete your transplant evaluation, the transplant team will need to review all of your previous medical records. If you are a Scripps patient, we will likely have them already. However, if you have not been receiving your care through Scripps, we will need to request these records from your primary physician, and any other hospitals or clinics you have been seen/treated at. You will need to sign a release of information in order for us to obtain these records. If you are unable to obtain your medical records, we are partnered with a company called E-Health Global that will obtain all records from all institutions. They will be in contact with you to sign a release form. This is done at no cost to you and will help move your evaluation more quickly.

## Immunizations

Immunizations help prevent you from getting certain infections. After receiving a transplant, your immune system will not be as strong, so having immunity is more important. Below is a list of immunizations that you should have before receiving a transplant.

- Influenza (The Flu) - You should get this once every 12 months.
- COVID-19 - We recommend you be fully vaccinated according to CDC guidelines
- Hepatitis A - 2 doses
- Hepatitis B - takes 2-3 doses in order to be complete.
- Pneumonia - Within the past 5 years
- Tetanus - Within the past 10 years

## Transplant Education Class

Every patient who goes through transplant evaluation will need to attend one transplant education class. These classes are held once a month and may be virtual or in-person. Classes are also available in Spanish several times a year. Classes typically last between 1-2 hours, and you will have an opportunity to ask questions throughout the class. The purpose of the class is to introduce you and your family to the transplant process. We ask that your primary caregiver joins you when you attend. Your transplant coordinators will assist you in scheduling your class.

## Transplant Evaluation

There are many factors in your medical history and current state of health that must be considered before you can be listed for transplant. It is important that we determine that you are safe to undergo transplant surgery. Your evaluation may reveal certain conditions that need to be corrected before transplantation. In some cases, your evaluation may reveal medical, social, or financial problems that may eliminate you as a transplant candidate. You will only be active on the transplant list after your medical evaluation is complete, you have been medically approved by the transplant selection committee, and financially approved by your insurance carrier.

# Tests & CONSULTS

All exams and tests at Scripps will be scheduled and coordinated by our scheduler. We may accept results from tests done within the last year. Additional tests may be needed if any concerns come up during your initial work-up.

## Testing you will need to complete during evaluation

- **Blood tests** - Measure how different organs such as your liver and kidney are working, look for certain inherited or acquired diseases, and to look for certain infections such as HIV and Hepatitis.
- **Urine tests** - Check your kidney function and evaluate for urinary tract infections (UTIs)
- **Abdominal Imaging** - an ultrasound, CT Scan, or MRI that looks at your liver, kidneys, and other abdominal organs and blood vessels.
- **Chest Imaging** - chest x-ray or a CT scan to look at your lungs.
- **Heart Tests**- Electrocardiogram (EKG), Cardiac Stress Test, and Echocardiogram. Certain patients may also need to have a cardiac angiogram to look at the vessels in their heart.
- **Pulmonary function tests** - Assess your lung function if history of cancer or smoking
- **Mammogram and Pelvic/pap smear** - for female patients
- **Colonoscopy** - to look for early signs of Colon cancer

## People you will see during your evaluation

- Transplant Care Coordinator - Consenting
- Transplant Nephrologist (Kidney Doctor)
- Transplant Surgeon
- Transplant Social Worker
- Transplant Dietician
- Personal Dentist for annual dental clearance

## People you may need to see during your evaluation

- Cardiologist (Heart doctor)
- Pulmonologist (Lung doctor)
- Infectious Disease doctor
- Endocrinologist (if diabetic)
- Ophthalmologist (Eye doctor)
- Psychiatrist
- Neurologist (Brain doctor)
- Vascular Specialist



EVALUATION

# Tissue Matching

## Tissue Matching and Kidney/Pancreas Transplantation

Your body is made up of cells. On the surface of your cells are markers like flags on ships. These markers help your immune system recognize which cells belong there and which don't. That is how your immune system spots infections - it sees markers that don't belong to your cells. In the same way, your immune system can look at your new transplant like a large infection because of the different markers on the cells of the new organ. Once you are medically approved for a transplant and have made the decision to proceed, you will complete more blood tests to look at your immune system. These tests are done to see how similar your cell markers are to those of a potential donor. In general, the more similar and compatible you are, the more likely your body will accept the new organ.

There are 4 tissue matching compatibility tests that are done:

### 1. Blood Type (ABO) compatibility

The most important marker on your cells is your blood type. **Your blood and a donor's blood are typed to make sure they are compatible.** The chart explains which blood types can ordinarily donate to and receive from others.

Blood Type	Can Receive a Kidney From:	Can Donate a Kidney To:
O	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	AB, A, B, O	AB

An ABO compatible donor is required for cadaveric (deceased) kidney or pancreas donation. It is also preferable to have an ABO compatible living donor (pg. 20). In cases where this is not possible, you can also participate in a paired donor exchange or do an incompatible transplant across blood groups. Scripps has an ABO Incompatible Living Donor Program for those patients whose only donor is ABO incompatible. This can be discussed with your nurse coordinator or a transplant surgeon.

### 2. Human Leukocyte Antigen (HLA) Tissue Typing

Another name for these markers on your cells is "antigens." Human leukocyte antigens play a major role in the identification of cells by the immune system. In general, the closer in relation you are to a person the more similar your HLA's are and the more likely your immune system will leave your transplanted organ alone. However, powerful medicines have made this factor less important than in the past.

### 3. Panel of Reactive Antibodies (PRA)

This is a blood test that screens your blood for antibodies against many different donor antigens. It's a test to see how "reactive" or sensitive your immune system is. If you react against a high percentage of these donor cells, you are likely to reject a transplanted organ. Patients with *high PRA have priority* on the waiting list for cadaveric organs because it is more difficult to find a match.

### 4. Cross-match Compatibility

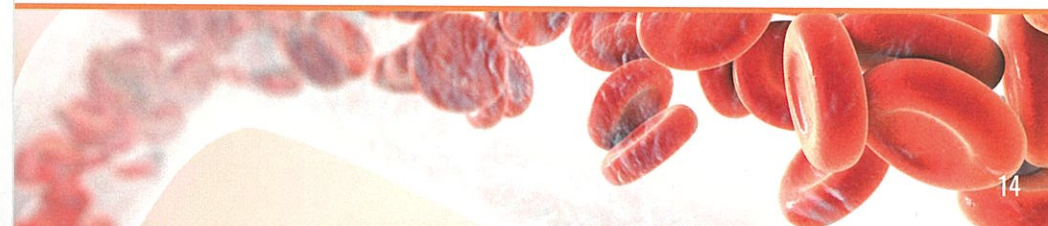
This is a blood test done when a donor organ is available. It checks to see if you have antibodies in your blood that will react strongly with the antigens on the transplanted organ. If there is no reaction (negative cross-match) then you and the donor's organ are compatible. If there are such antibodies, you may have what is called a "positive cross-match."

If you have a positive cross-match with a cadaveric donor, the transplant will be cancelled because your immune system's reaction to that particular organ will be too strong. It will reject the new organ right away. If you have a positive cross-match with a living kidney donor, Scripps has a Cross-Match Positive Desensitization Protocol that may still allow you to be transplanted with that organ. If you have a positive cross-match to your only donor, the transplant team will discuss this option with you.

Things that can change your compatibility and PRA:

- Prior Pregnancies
- Blood Transfusions
- Previous Transplants

If any of these events occur, you may become sensitized, which may make it more difficult to be transplanted. If any of these events occur, contact your transplant coordinator. You may have to repeat your PRA test.





# Who May or May Not Be a Candidate?

The team has to determine if you are an eligible candidate for kidney transplant- having chronic irreversible renal failure that is nearing need for or requiring dialysis. Sometimes a transplant is not in a patient's best interest due to various contraindications.

**Relative Contraindications to Kidney Transplant** (These do not limit you from Transplantation. These conditions will need to be evaluated by your Transplant team)

- Intrarenal infections – infections within the kidney
- Multiple uncorrectable congenital anomalies – abnormal anatomy since birth
- Severe Hypoxemia Due to Right to Left Shunting - lack of enough oxygen due to severe lung damage
- Pulmonary hypertension (mean PA pressure > 35mmHg) – very high pressure in the blood vessels between the heart and the lungs
- Chronic hypotension (low blood pressure)
- Inadequate financial resources
- HIV positive persons
- Body mass index > 35
- Previous transplant
- Recent history of substance abuse
- A history of certain malignancies
- Inability to satisfy post-transplant follow-up
- Frailty that results in poor operative risk
- Deconditioned state
- Phosphorus level, PTH and HgbA1C requirement
- Inability to comply with medical management

**Absolute Contraindications to Kidney Transplant** (These limit you from Transplantation. Please consult your Transplant team if you have any questions)

- Life expectancy < 5 years even with transplant
- Substance abuse & smoking
- Sepsis
- Advanced cardiopulmonary disease – severe heart and/or lung disease
- Inadequate social support mechanisms
- AIDS
- Active nonadherence – failure to follow the team's recommendations on any aspect of your care such as diet, exercise, appointments, medications
- A history of certain malignancies
- Advanced cerebral or peripheral vascular disease

## Selection COMMITTEE

After all tests and consults are completed, your case is presented to the Transplant Selection Committee. Members of the transplant team determine your eligibility based on findings of your evaluation. Your potential contraindications are taken into consideration as well. A decision can fall into one of the below categories:

**Approved:** You have completed your evaluation and you meet criteria for transplant.

- **Active-** You are placed on the waitlist and remain in this status until you receive a transplant, or some new condition develops that requires us to remove you from the waiting list.
- **Inactive Pending-** You are conditionally accepted with the additional pending requirements to complete within a particular timeframe which will be communicated to you. You will not be getting offers until you have completed the pending items.

**Deferred:** You do not currently meet criteria for transplant, but the team is willing to work with you so that you may meet criteria in the future. For example, you may have a medical problem that needs specific treatment, counseling for a psychiatric diagnosis or treatment for past alcohol or drug abuse. If the requirements are completed, you can be presented again. You may be given a time limit to complete these requirements.

**Denied:** You do not meet criteria either due to medical or psychosocial reasons. For example, you may have a cancer or a problem like severe heart disease that makes it unsafe to perform a transplant on you. In addition, if you refuse to stop smoking, using illicit drugs, or do not attend the necessary appointments we require, you may be denied based on poor compliance.



Alcohol and substance use can significantly reduce a patient's chance of a successful transplant. Abstinence from substances such as drugs, alcohol and nicotine greatly increase the likelihood of a successful transplant. As a patient in the Kidney and Pancreas Transplant Program, you are *prohibited* from the overconsumption of alcohol or the use of any medications, supplements, illicit or controlled substances not approved by your transplant physician. This includes but is not limited to marijuana, opiates, amphetamines, cocaine and hallucinogens. Nicotine products of any kind are prohibited. This includes cigarettes, pipes, vapor, nicotine replacement products and chewing tobacco.

### Yearly Re-evaluations

After you have been approved and listed for transplant, the kidney team will have you come back for an annual evaluation with the surgical and social work teams. You will also need to repeat some testing and bloodwork on a yearly basis. Keeping all your appointments as scheduled is crucial.

### Make the Most of Your Waiting Time & Be Prepared for that Call

- Arrange a caregiver for your children and pets.
- Arrange all forms of transportation to and from Scripps (this includes airline, taxi and other sources through friends and family). If you will be traveling to Scripps by airplane, you must check into all available flights to Lindbergh International Airport, Palomar Airport, or Brown Field. Discuss this with a travel agent to make plans in advance. If you have private insurance, you may contact your insurance case manager to ask about travel benefits.
- Plan financially for meals and lodging.
- Contact your insurer about potential reimbursement for lodging and mileage.
- Keep a current and active line of communication available via phone and email.
- Notify your transplant team **immediately** if you have any changes to your address, phone number, insurance, or caregiving plan
- Sign up and get access to the Scripps Patient Portal. A team member can get you set up.
  - For issues, call *Scripps Patient Portal help desk: 888-668-8338*
- We strongly suggest that you obtain an Advance Directive, and a Designation of personal representative, which allows another person to make medical decisions if you cannot make them for yourself. An Advance Directive takes time to prepare so it is wise to do this before you are listed. Sample forms can be sent to your email.
- Talk to your doctor about any doubts or concerns you may have. Maintain a list of ongoing questions for your doctor and transplant care team as you continue with the transplant process. No question is stupid, nor is any concern irrelevant. It is helpful to prepare your list of questions ahead of time and bring them with you to your appointments.
- Keep medically fit by having regular doctor's appointments, dental exams, pap smears, mammograms, or other tests ordered by your primary physician.
- If you are admitted to another hospital, it is very important to inform us as soon as possible or immediately after discharge so we may obtain your medical records. Please note that you may no longer meet the waitlist criteria until we have had an opportunity to review your medical records.
- Learn as much as you can **NOW**- read patient education materials, follow recommendations made by the transplant team, obtain equipment i.e., blood pressure cuff, scale, blood glucose monitor (glucometer)

There are several outcomes that are possible once you are approved for transplant:

- You are transplanted
- Your illness improves or stabilizes, and you are able to defer transplantation for a period of time.
- After Selection Committee Approval, you develop additional complications which prevent transplantation. At this point a transplant would create more risk than benefit for you.

It is important to understand that your illness may progress while you wait for a transplant. Our team will do everything possible to help you navigate the appropriate steps.

## Transplantation is a Choice

The final decision about transplant is *yours*. A transplant is another form of treatment for the disease which has made you ill. It is not a cure. As of January 2022, there are over 93,000 people waiting for a kidney transplant. If you do not think you can do what is needed before and after the transplant to optimize your outcome, then you should really think about whether it is the right choice for you. The transplant team will respect your decision.

We understand this can be an overwhelming, tiring and stressful time for you and your family. One of the hardest parts about the evaluation process is understanding that you may not be a candidate for transplant. We carefully evaluate all the information gathered during the evaluation to ensure the best medical outcome for you. It may help you to share your thoughts and feelings with someone you trust.



# Social SERVICES

All transplant patients meet with the transplant social worker during the evaluation process. Some patients and families have very specific needs or concerns that can be addressed and discussed with the social worker at any time before or after the transplant.

## The following topics are addressed in detail with the transplant social worker:

- **Housing** - If you come to Scripps from outside San Diego County you will need to make arrangements to stay locally for a period of time after you are discharged from the hospital. The period of time is at least one month but sometimes longer, depending on your condition after transplant. The social worker is a resource to discuss your options. Please request housing materials if you need specific information.

### \*Some Things to Consider\*



- **Hotels** - San Diego is a resort and vacation destination. The cost of lodging can be shocking to patients from out of the area, many of whom may be on disability, fixed incomes and all of whom already pay for housing in their own communities. Hotels closest to the hospital are the most expensive because it is a very upscale area of San Diego. Other areas of San Diego are less expensive and still close enough for frequent follow-up visits. Your concerns and individual circumstances can be discussed with the transplant social worker.
  - You are required to stay at a hotel or lodging where you have full access and use of a kitchen in order to accommodate your new dietary needs during recovery.
- **Automobile Club of California (AAA)** - AAA's travel guide is a good resource for rates and reflects the thorough research that goes into this booklet.

## Online Sources

There are several web sites where you can find hotel discounts. Sometimes good deals can still be found at the last minute, and it is worth a look. A few examples are:

- [www.expedia.com](http://www.expedia.com)
- [www.travelocity.com](http://www.travelocity.com)
- [www.trivago.com](http://www.trivago.com)
- [www.kayak.com](http://www.kayak.com)
- [www.booking.com](http://www.booking.com)
- [www.hotels.com](http://www.hotels.com)
- [www.priceline.com](http://www.priceline.com)

## Friends and Relatives

We encourage you to speak with family or friends in the area to see if you have local resources you may not have considered. Sometimes these people are eager to help transplant patients.

**Trailer or Recreational Vehicle (RV)** - If you have access to a trailer, recreational vehicle or fifth-wheel, rental facilities are available in the community.

**Lodging**-Patients are encouraged to ask their insurance carrier about possible reimbursement benefits related to transplant expenses such as lodging.

**Please feel encouraged to discuss concerns about the following topics with the transplant social worker.**

## Transplant Medications

All transplanted patients take numerous medications after their transplant. These medications are quite expensive. Depending on your insurance coverage, you could face significant out of pocket expenses. The time to discuss your situation and individual needs is before your transplant. There are several assistance programs available to transplant patients for those who qualify.

## Counseling and Support Services

Dealing with chronic illness and going through a transplant can be very stressful, both for the patient and his or her family members. Help is available through support groups and mentoring programs. Please ask your Transplant Social Worker about meetings and services that are available. Refer to our Helpful Resources section for more info. The organ transplant department offers a monthly speaker series.

## Transportation

During the immediate post-surgery period, there are many appointments at Scripps Clinic to carefully monitor your progress. If you anticipate difficulty in getting to Scripps, discuss this with the social worker. Insurance does not pay for routine transportation.

## Finances

Often patients face periods of disability or income interruption. The social worker can be a resource to be sure you have not overlooked any disability or support programs that may exist to assist you.

## Caregivers

Transplanted patients are required to have a caregiver 24 hours/day for **one month**. Identify a primary and secondary caregiver to care for you in San Diego. You will be encouraged to have several caregiving options, as a back-up is often needed.

# Living Donation

A **living donor** is someone who is alive and well and chooses to donate a healthy organ or part of a healthy organ to someone who needs a transplant. The most common organ transplanted from a living donor is the kidney. A living donor is typically a related family member. However, a living donor can also be unrelated, such as a friend or spouse. A living donor can also be altruistic. An **altruistic living donor** is a person who has donated an organ on an anonymous basis to an unknown recipient. Donating an organ can be a very rewarding experience, in that you are helping someone special who is sick and in need.

## \*Advantages of a Live Kidney Donor

Kidney from a person who died	Kidney from a Living Donor
Kidney usually lasts 10-15 years	Kidney lasts longer-usually 15-20 years
Kidney patients usually wait many years to get a transplant	Transplant can happen within 1 year if a matching donor is found
Kidney patients spend more time on dialysis, which can lead to more health problems	Kidney patients spend less time on dialysis, which means fewer health problems
Kidney patients don't know when a kidney may become available.	Surgery can be scheduled at a time that's best for the donor and kidney patient.

\* Source – Explore Transplant (<https://explorettransplant.org>)

The success rate for a living related kidney transplant (LRD) is over 95 percent for the first year. About one half of the LRD transplants have been known to be still functioning after 15 years. The living unrelated kidney transplant (LURD) has a success rate slightly less than the LRD transplant success rate for the first year. Both are greater than the success rate of 90 percent after the first year for a patient who receives a cadaveric kidney transplant (CAD).

# Living Donation Who can Donate?

Potential donors should be:

- Over the age of 18
- In good health
- At a healthy weight
- Free of diabetes
- Normal kidney function
- Non-smoker or willing to stop smoking



**If You Have More Than One Donor...** You may have more than one family member or friend wishing to be evaluated at one time. All interested donors are encouraged to contact the living donor transplant coordinator, as they cannot contact them directly. Your donor must make the initial call to start the process. Every potential living donor for you will be considered for evaluation by the transplant team. It is up to the donor how fast the evaluation will proceed. The living donor coordinator cannot share information with you regarding the process and the results of the donor evaluation.

**If Your Donor is Healthy but Cannot Donate to You...** If your family or friends cannot donate to you because of a positive cross-match or incompatible blood types, you may be eligible for our **Donor Exchange Program**, **ABO Incompatible Protocol**, or **Cross-match Desensitization Protocol**. Contact your transplant coordinator for more information about these programs.

**If You Don't Have a Donor...** Some patients who don't initially have a living donor are not sure where to start in order to get their story heard. Johns Hopkins University (JHU) and Facebook have developed an application, or "app" called *Donor*. Together, the Scripps Center for Organ and Cell Transplantation and JHU are studying the *Donor* app to see if it makes a difference for people who are trying to find a living donor. Once you are signed up, *Donor* takes you through steps to create a short story about your illness and need for organ donation. You then **share your story** on Facebook. Your friends and family can share your story with their network of friends using Facebook, or other social media platforms, like Twitter and Instagram. If you would like to try the *Donor* app and participate in this study, or to receive more information, please contact Scripps Transplant to get in touch with our Living Donor Coordinator.

# Living Donation

## Talking to Potential Donors

### How do I ask someone to donate a kidney to me?

Asking someone to be a living donor is difficult. A shift in thinking from “I need to ask someone” to “I need to inform people about my situation and educate them about organ donation” can help you talk to family members and friends.

It is important to *educate yourself*. Having the knowledge about organ donation will give you the confidence to talk about your situation and answer any questions raised by others. Please read the materials in your living donor packet that is provided by your transplant team.

Giving family and friends written donor information from us as well as our Transplant Office phone number is a good place to start.

If talking about living kidney donation is hard for you, ask a close friend or family member to talk to others in the family about your need for a living donor. “I asked my grandmother to spread the word for me to the rest of the family. I knew my grandmother would not be the donor, but she was a great spokesperson. It took the spotlight off me.”

Speak from your heart and take time to listen to the feelings and concerns of your family members or friends. Don't expect potential donors to respond right away. Some people make their decision immediately while others need time to process the details. Keep your options open. Someone may offer to donate when you least expect it.

Be careful not to put pressure on potential donors. Factors in their lives may prevent them from being a kidney donor. Don't expect an answer right away. People will need information, time, support and “space” to decide. They may need time to talk with their own family, employer or others involved in their daily lives.



# Living Donation

## Talking to Potential Donors

### \*Some Things to Consider\*

#### Work

Kidney donation is major surgery with a recovery time of 3-6 weeks. Your family and friends may lose wages if they miss work. Sometimes, this time off can be covered with sick leave and vacation pay or donated time from co-workers. Donors may qualify for special leave under the Family and Medical Leave Act (FMLA). Donors may be eligible for reimbursement of lost wages. Encourage your family and friends to talk to their employer about the types of time-off benefits available.

#### Pregnancy

Pregnancy may create a slightly higher risk for the remaining kidney. Kidney donation should not interfere with a woman's decision to become pregnant later. If the donor should become pregnant it is important to have her obstetrician consult with a nephrologist (kidney doctor) for proper monitoring during pregnancy.

#### Smoking, Nicotine, Drug Use, and Obesity

Smokers who want to be donors must stop smoking at least 60 days before the start of the medical screening process. Donors should not resume smoking after donation as it can have harmful effects on blood pressure and in turn affect long term kidney function.

Individuals who use illegal drugs, or who use moderate amounts of alcohol (more than 1-2 drinks per day) are not appropriate donors because of the increased health risks to both the donor and the recipient. Illicit drug use is a contraindication for donation. Substance abuse of any kind is a contraindication to become a donor.

Donors who have lost weight in order to donate are advised to maintain their lower weights to avoid the damage to their remaining kidney associated with obesity.

#### Emotional Effects

When a family member or loved one is in need of an organ transplant or has been on a waiting list, it can be a difficult and frustrating period. The decision to become a living donor is complex, and it is essential to discuss the decision with family, the recipient (if known), and your doctors to learn as much as possible about the procedure. Most organ donors have been touched by someone close to them in need of an organ. And nearly all organ donors find the outcome of the experience positive and say they would donate again!

# Living Donation

## How Much Will It Cost?

There is no cost to the donor for health screening or surgery related to living kidney donation. The costs for obtaining the initial physical exam should be covered by the annual physical allowance of the potential living donor's insurance policy. If your family member or friend does not have insurance, contact the transplant nurse coordinator.

\*Payment of a potential living kidney donor's medical expenses is limited to tests that are directly related to the required medical work-up. If testing uncovers medical problems that need further evaluation or treatment, the living donor program cannot cover those costs.

By law, *donors may not receive direct payment of any type for their donation.* Donors may, however, be eligible to receive compensation for travel expenses related to donation and for lost income resulting from the donation surgery and recovery. The kidney recipient's insurance will pay the cost of medical expenses for evaluation testing, surgery and hospital stay.

## Resources

- **Explore Transplant** – provides extensive written and video information about who can be a donor, the donor surgery, the risks of live donation and the benefits to the donor of donating a kidney
  - <https://explorettransplant.org/basics-of-kidney-disease/living-donation>
- **American Society of Transplantation** – provides more information about live donation through a medical toolkit for live donation and a financial toolkit to help understand the costs associated with live donation
  - <https://www.myast.org/patient-information/living-donor-toolkit>
- **National Living Donor Assistance Center** – provides resources to help reduce the financial disincentives to live kidney donation
  - <https://www.livingdonorassistance.org>
- **UNOS** – provides information on different types of live donation, including kidney paired donation (donor swaps or donor chains)
  - <https://unos.org/transplant/living-donation>
- **Donate Life America** – Living Donation info, register to be an organ donor, and more
  - <https://www.donatelife.net/>

# Living Donation

## Getting the Process Started



The decision to be a living organ donor is very personal and must be done *voluntarily*. The first step is to have any interested family and friends call our office at 858-554-4310. The Living Donor Coordinator cannot make the initial call to prospective donors. Your donor has to initiate the first contact.



Basic information will be taken, and we will send each donor a packet and application regarding living donation. We are more than happy to talk with potential donors at this point to answer their questions.



The Living Donor nurse coordinator will contact donors who have called us and have them perform a very simple health screening, including a blood typing test and blood pressure monitoring.



Eligible donors will then take part in a more in-depth health screen and laboratory testing to ensure there is minimal risk to the donor. Finally, if the donor is approved, tissue typing (cross-match) is completed and surgery can be scheduled.



Obesity has been shown to lead to high blood pressure, diabetes, and kidney disease. Patients who are overweight may be asked to lose a certain amount of weight before they can be approved as donors.





# Living Donation

## Donor Surgery

Removal of the selected kidney from the donor involves an operation that lasts 2-4 hours. The kidney can be removed in an open procedure or via a laparoscopic method. The open method requires an incision of about two hand breadths long. The laparoscopic approach allows the surgeon to insert instruments into the donor's body through a series of small incisions – usually three around the width of a finger and one the width of a palm just large enough to remove the kidney. At Scripps, most kidney donor surgeries are done laparoscopically. The advantages of laparoscopic surgery are that the donor tends to have less pain, a smaller scar and shorter hospital stay. The donor is usually able to go home after 2-4 days in the hospital.

Depending on the type/location of the incisions that have been made to remove the kidney, the donor can return to full activity after 3-6 weeks. Apart from regular physical check-ups following surgery, there are no medications to take and no restrictions on a normal lifestyle for donors.

### After Donation

Donors are seen in the transplant clinic for follow-up one week after discharge from the hospital. We will send records of the donor's hospital stay and follow-up to their primary physician. Studies so far have not established any increased risk of developing high blood pressure after donating a kidney. However, high blood pressure is extremely prevalent in the American adult population (20-25%), so we ask all kidney donors to have yearly physicals and urine testing for kidney function to check for early signs of high blood pressure. You will need to make sure that you coordinate with your primary care physician after donation.

Donating a kidney does not change your life expectancy. In fact, one study found that kidney donors actually live longer than the general population. This is probably because only healthy people become kidney donors in the first place.

We do follow the donors for two years and require that you complete our health questionnaire and lab work locally at the 6-month, 1-year and 2-year marks. It is important that you maintain your regular visits with your primary care physician as they will be following your annual check-ups and other pre-existing conditions



# Transplant Surgery

### Preparing for an Organ Offer

- A transplant team member will call to tell you when a donor has become available. The first call may not be your transplant call. It is very important that you keep your active phone with you at all times and ensure that it is working properly. Notify your coordinator if you get a new phone number or if you are going to be out of the area for any time.
- You will be given instructions by the transplant coordinator about what to expect and how to prepare for surgery.
- Upon hospital admission, all patients will have more tests (blood tests, chest x-ray, etc.) prior to surgery. These tests include a final cross-match of your blood against the donor's blood, which will determine whether your immune system will accept the kidney or pancreas. Patients who are on dialysis may need a dialysis treatment prior to surgery.
- The medical team will examine you and review medical records to ensure that it will be a safe and optimal surgery.
- The nurse will give you directions about what to do before surgery. If there is a surgery time, you will be asked to take a shower and you may be given an enema. Oral or intravenous medications may be given to prepare you for your surgery.
- Once you get the final clearance to safely proceed with the transplant, you will be taken to the operating room.

Whether you are receiving a kidney, pancreas, or combined kidney and pancreas transplant, your surgeon will review the procedure with you and provide details as to their specific approach chosen.

### The Surgery

In the operating room, you'll be connected to many monitors and IV lines. The anesthesiologist will put you to sleep with general anesthesia through your IV and a mask placed over your nose and mouth. The anesthesiologist monitors you throughout the entire surgery to make sure you are asleep and feeling no pain.

Once asleep, additional lines and tubes are placed for surgery such as a urinary catheter, a nasal suction, a breathing tube, and a central IV line typically in the larger veins of your neck.

The surgery takes about 3 to 8 hours. Your family will be updated intermittently on your progress. After surgery, you will go to the recovery room.

# Transplant Surgery

## Immediately After

From the recovery room, you will be taken to the transplant unit (3 North). Your family will be able to see you in this room.

- Within a few hours, an ultrasound may be performed to look at the blood flow into your transplanted organ(s).
- Your blood sugars will be checked often, and you'll likely have IV insulin for the first few days. You will be started with clear liquids and gradually advance to solid food.
- You will have a PCA (patient-controlled analgesia) pump to self-administer pain medication, as needed, until you can tolerate oral pain medication
- You will be given an Incentive Spirometer (a device that helps you take deep breaths) and will be encouraged to use it every hour to help reduce the risk of breathing complications, such as pneumonia.
- You will be helped out of bed the first morning after surgery. Walking will reduce your risk of developing blood clots, pneumonia, constipation, and bloating. Walking also helps you to recover from surgery faster.
- The catheter that drains your urine (Foley catheter) will stay in place for typically 3 days to give the new connections to the bladder plenty of time to heal.

If you have received a kidney transplant, you may still require dialysis for a number of days after your transplant. This is not unusual as it may take some time for your new kidney to start working properly. If you have received a pancreas transplant, you may still require insulin (usually much less than you required before surgery) until your new pancreas fully recovers.



# Transplant Surgery

## Discharge

On the day of discharge, your transplant coordinator will come to your room to meet with you and your caregiver. They will provide you both with a packet of educational material that will include your future lab/clinic appointment schedule, medication regimen, diet and exercise recommendations, safety precautions, realistic expectations, etc.

- You will be seen in our clinic *twice a week* (Mon/Thurs) for the 1st month, once weekly for the 2nd month, then once every other week for the 3rd month. For this reason, it is important that you and your caregiver are staying **within San Diego for at least 1 month**. These visits will include getting your labs drawn, then seeing our staff in the clinic to ensure that your surgical wounds are healing, and your medications are working properly.
- In certain cases, you may be discharged with a urinary catheter or drain still in place. If this is required, you will be shown how to care for it before you leave. Your drain or catheter will then be removed in clinic. (Don't worry, this will not be painful.)
- If your incision has metal staples, these will be removed in clinic 3 weeks after your surgery.
- Your ureter stent placed during surgery will be pulled out at about 3 to 6 weeks after your surgery. You will also undergo a biopsy of your transplant in clinic approximately one month after your transplant.
  - Both of these procedures are done in clinic, but you should plan to be in the hospital for half a day since you will need to be monitored afterwards for an extended period of time.

### Questions After Discharge

We know the process of transplant involves a lot of detailed information and things to remember. We are here for YOU!

1. There will be an Advanced Practice Clinician (APC) assigned to your care at all times. After you have been transplanted, post-transplant calls will be returned by a transplant coordinator or APC, not by the transplant MD, hepatologist, or nephrologist.
2. For any **non-emergency** questions or concerns, please wait until seen in clinic, or call (858) 554-4310 (Monday-Friday 8am-5pm). Please do not call all of the members of the transplant team to assist you.
3. For any **emergency** questions or concerns after hours and weekends, please call the main hospital number (858) 455-9100 and ask for the coordinator on call.
4. If you are having chest pain, shortness of breath, difficulty breathing or have any other emergent situation, **go to the emergency room or call 911**. Please do not leave a message for the transplant team.



# Medications After Transplant

You'll be taking transplant medications **every day for the rest of your life**. You'll want to know as much as you can about your medications - how they work, what are the side effects, how to pay for them and tips for always remembering to take your medicines at the right time and in the right way.

## Getting Started

Medications are vital to your recovery and the success of the transplant. Keep *all* of your appointments with your doctor and the transplant clinic so that adjustments to your medications can be made as needed and side effects can be minimized.

## Pharmacy Arrangements

The first month's supply of medication will be filled by a local specialty pharmacy and sent to the hospital prior to your discharge. Your prescriptions thereafter can be filled at any pharmacy that accepts your insurance plan. It can be very helpful to use a pharmacy that specializes in medications for transplant patients. If you will be staying temporarily in San Diego after the transplant, you will need to make pharmacy arrangements. Call your insurance company to obtain a list of participating pharmacies near where you plan to stay after discharge from the hospital. Always carry your prescription insurance card with you so you're ready to show it to any pharmacy.

After surgery, you will begin to learn about your medication regimen. The transplant coordinator or pharmacist will begin teaching you about your medications about 2-3 days after surgery. They will give you a medication sheet with the names, doses and times of all your medicines. Always keep an up-to-date medication sheet with you. At first, the number of medications may seem overwhelming, but they will decrease over the next several months. It's a really good idea for family members and/or support persons to learn along with you if you need help managing your medications.

**It is very important not to run out of your medications or skip doses.** Have your prescriptions refilled early and try to give us time (at least one week) to have your medications refilled at your pharmacy. If you need a prescription refilled, please have your pharmacy fax us a request at (858) 554-4311.

If you have problems or questions about your medications after you are discharged, call your transplant nurse coordinator. Between 8 a.m. and 4:30 p.m., please call (858) 554-4310. After hours, please call (858) 455-9100.

# Medications After Transplant

## Why take immunosuppressants?

Immunosuppressants or **anti-rejection drugs** are medications that suppress the body's immune system by decreasing the effects of lymphocytes (a type of white blood cell). This is necessary so that your body's immune system does not recognize the new organ as foreign and defend your body by attacking it with white blood cells. In general, immunosuppression may make the body more susceptible to infections with organisms that normally do not cause infections (opportunistic) and organisms from your environment (colds, flu). Immunosuppression also carries a small risk of developing tumors.

The transplant team uses 2-3 of these drugs in combination. Each drug works by blocking a different pathway in the immune system. Working together they produce better immunosuppression, allow for the use of smaller doses of each drug, and reduce the number and severity of side effects.

Common immunosuppressants used post-transplant include:

- ★ Prograf (Tacrolimus, FK-506),
- Mycophenolate (Cellcept, MMF),
- Sirolimus (Rapamune),
- Azathioprine (Imuran)

It is important that you remember to take these medications daily as prescribed by your doctor to prevent rejection. If you forget whether you took your dose on a given day, call your doctor or transplant nurse coordinator for further instruction. **Do not double your doses.**

Even though you are on maintenance doses of your immunosuppressive medications, rejection may still occur. Acute rejection most often occurs within the first year after transplant and may be successfully reversed by using medication. Rejections are best determined by following your blood test results. **Be sure to keep all appointments for blood tests.**

# Medications After Transplant

## Other Medications

Medications used for transplant patients change over time. You may not be prescribed all medications listed and may also be prescribed medications not listed here.

- **Fluconazole (Diflucan)**- An antifungal antibiotic used to prevent infections with yeast. Typically taken for about 1 month after transplant.
- **Valganciclovir (Valcyte), Ganciclovir (Cytovene), Acyclovir (Zovirax), Valacyclovir (Valtrex)**- Antiviral medications that are used to prevent herpes infections and CMV (Cytomegalovirus) infections. Typically taken for about 2 months after transplant.
- **Trimethoprim/Sulfamethoxazole (Bactrim, Septra, Cotrimoxazole, Trim/Sulfa, TMP/SMZ)** - Antibiotics used to prevent bacterial bladder infections, and lung infections caused by a fungal organism.
- **Famotidine (Pepcid)** - histamine-2 blocker used to neutralize or prevent acid secretion. These are initially needed to prevent stomach upset or injury caused by high doses of anti-rejection medications. Typically taken for about 2 months after transplant.
- **Docusate (Colace), Bisacodyl (Dulcolax), Psyllium (Metamucil), Lactulose (Chronulac, Cephulac, Kristalose)** - Stool softeners and laxatives used to avoid constipation and hard stools after surgery. Important to take while taking pain medications.
- **Amlodipine (Norvasc), Atenolol (Tenormin), Metoprolol (Lopressor, Toprol)** - Anti-hypertension medications used to lower blood pressure after surgery. Controlling blood pressure is important in preventing damage to your new organ.
- **Aspirin** -Anti-platelet medication given to help prevent clotting of blood vessels leading to your new organ. It can also help prevent heart attacks and stroke.
- **Furosemide (Lasix), Bumetanide (Bumex)** - Diuretics "water pills" used to help get rid of excess fluid causing swelling and edema.
- **Multivitamin** - Used following transplant to help supplement your diet.
- **Folic Acid**- synthetic form of Folate, a B-vitamin needed to form healthy cells, including red blood cells
- **Ferrous Sulfate (Iron)** - Used following transplant if you are anemic. Iron helps the body build new red blood cells.
- **Calcium (Tums, Oscar, Citracal)** - Supplement to help prevent bone disease and bone loss.
- **Vitamin D (Cholecalciferol, Calcitrate)** - Needed by the body to help absorb calcium from your diet and supplements.
- **Magnesium (Mag-Ox)** - Used to treat low magnesium levels that can be caused by anti-rejection medications.
- **Hydrocodone/Acetaminophen (Norco)**- narcotic pain medicine

# Paying for MEDICATIONS

Medications after a transplant are too expensive for most patients to afford out-of-pocket. They can run as much as \$12,000 to \$15,000 per year. The costs may decrease over time as some of the medicines are stopped, or your physician lowers the dosages. This is an area where medical insurance can help. Verify your prescription insurance coverage and know what your expected co-pays or deductibles will be. Even with medical insurance, you may have to pay for part of your prescription drugs and other over-the-counter vitamins and supplements.

**Some questions to ask your insurance company about your prescription drug coverage:**

- Does it cover prescriptions at a certain percentage (such as 50, 80 or 90 percent)?
- Do you pay a certain dollar amount co-pay per prescription (such as \$10 per prescription per month)?
- Does your insurance provide different coverage based on whether the drug is a "generic" or a "name brand"? People with transplants are often prescribed name-brand medicines for which no "generic" equivalent exists (such as Prograf and Cellcept). These can be some of the most expensive medicines. Please be aware if your policy requires you to pay a higher co-pay or percentage for name-brand medicines.
- Does your insurance offer a mail-order pharmacy for medicines? These mail-order pharmacies often allow you to obtain a three-month supply of medicines for a lower co-pay than if you went to a local community pharmacy.
- Check with the pharmaceutical company about patient assistant programs and eligibility.

Drug manufacturers offer financial assistance programs for people who cannot afford to buy the medications they have been prescribed. See Social Services or Resources section or ask your social worker for more information.

If you qualify for **Medi-Cal**, it covers most prescriptions that you will need after transplant.

If your insurance coverage is **Medicare**, you will need to make sure you work with your benefits office, our transplant social worker and financial coordinator to make sure you are aware of all changes and coverage pre-transplant and post-transplant for prescription medications.

Mail-order pharmacies that specialize in transplant medications will do all your billing for you, including Medicare. If you have other insurance in addition to Medicare, the mail-order pharmacies will check to see if they can bill that insurance for you, too. Please let us know how we can assist you.

# Paying for TRANSPLANT

*Transplant surgery is expensive. Financial planning and consideration of both your income and insurance will be a key part of your success as a transplant patient. Your planning will require decisions for both the short and long-term. Do this before your surgery to help you avoid unforeseen expenses afterward.*

Your **Financial Coordinator** will provide specialized assistance with questions and/or problems about payment for your transplant care. This person will work closely with your insurance to solve any insurance problems. He/she will be your best resource to determine your transplant costs and answer your financial questions.

It is not unusual for **insurance coverage** to change with time. **If your insurance or financial situation changes, please contact our Financial Coordinator as soon as possible at 858-554-2296 or 858-554-2232.** There *may* be information or programs that may assist you.

**If you are considering a change to your insurance, please discuss the change with your transplant financial coordinator before making any changes.**

Most insurance plans provide benefits for a transplant. There are many different insurance plans, and each have different levels of coverage and limitations. Some plans provide good coverage for your transplant, and others may leave you with large gaps in coverage. Below are some parts of your plan you should check carefully:

- **Inpatient hospital stays** - Does your policy cover inpatient charges at a certain percentage (such as 80 or 90 percent), or do you pay a flat co-pay per day while you are in the hospital? If your policy pays a percentage of the costs, you will have a larger bill to pay.
- **Waiting Periods** - Most insurance plans require that you be covered under the plan for at least one year before it will pay for transplant-related expenses.
- **Skilled Nursing Care** - While the goal is always for you to return home after your transplant, from time to time patients require a short stay in a Skilled Nursing Facility (SNF). It is recommended that you check to see if your policy will pay for SNF care if needed.
- **Coordination of Benefits** - If you are covered by more than one commercial insurance plan, such as through your employer as well as your spouse's employer, you will need to check with the secondary policy to find out its rules on coordination of benefits. This will help you find out how and if the secondary policy will cover expenses left over after your primary coverage pays.

**Medicare** is a health insurance plan administered through the federal government. It is for persons who have been on Social Security Disability for at least two years, are at least 65 years old or are on dialysis for end stage renal disease

There are two parts of Medicare - **Part A** and **Part B**. Part A may cover hospital stays, including a kidney transplant. Part B may cover doctor fees, both inpatient and outpatient, as well as approved outpatient expenses. Medicare has several deductibles and co-pays. With a transplant, these can add up to *thousands of dollars*. Most people with only Medicare coverage *should* consider additional insurance if qualified.

**Medicare Supplements or "Medigap" Policies** supplement your Medicare coverage. Most often they pay the Medicare co-pays and deductibles, but nothing extra. Having Medicare and a supplement will likely cover many transplant costs.

**Medi-Cal** is a health insurance plan for California residents who are very low income and who can be linked to the program. To see if you qualify, apply to your local health and social services office. Your social worker can give you contact information for the office where you apply for benefits.

**The financial staff will work with you to arrange funding for your transplant. Prior to admission for transplantation, funding must be established. Patients who do not have enough insurance coverage will be required to make a financial deposit before being accepted and placed on the transplant list. If you do not have the resources to make this deposit, your social worker can advise you about fundraising activities, etc. Talk with your social worker or financial coordinator for more details.**


## Other transplant-related financial considerations:

### Short-term Issues

- Paying for the medical expenses related to transplant surgery.
- Covering living expenses while staying near the hospital if you normally live outside of the San Diego area (All patients are required to stay within one hour of Scripps Green Hospital for a minimum of one month following transplant surgery.
- Covering living expenses while off work (both before and after transplant).

### Long-term Issues

- Paying for out-of-pocket costs for transplant medicines.
- Covering transportation and living expenses for post-op follow-up care if you normally live outside of the San Diego area.
- Patients living outside of San Diego County may need to plan for long-term accommodations



## Income WHILE OFF WORK

If you are working, your employer might provide short or long-term disability income insurance. After transplantation, you will be medically disabled for at least 6 weeks or longer. You should plan to be off work full time for *at least* 6 weeks, and often longer after your transplant.

### Short-term Disability

This insurance pays a portion of your salary, often around 60 percent, while you are off work for a medical reason. Some, but not all patients have this benefit. Check with your state and/or employer about short term disability benefits. Some states may cover up to 60% of your salary for up to 12 months. Please check with your insurance to verify your coverage.

### Long-term Disability

This insurance pays a portion of your salary, often 60 percent, for as long as you are considered disabled and unable to work. However, you will usually need to be disabled for a minimum length of time, such as 90 days, before benefits will begin.

### Social Security Disability (SSD)

The Social Security Administration (SSA) has its own definition of disability for various illnesses. The application process can take many months. If approved, the monthly amount you receive is based on how much money you have paid into the Social Security system through payroll taxes. SSA must consider you disabled for at least five months before benefits can begin. Also, your disabling condition must be expected to last at least one year to be eligible for SSD. Most transplant patients are not disabled for that long and should not rely on SSD to provide income while off work after a transplant.

### Supplemental Security Income (SSI)

This is a disability income program through the Social Security Administration. The disability rules are the same as for SSD. However, SSI has strict income and financial limits.

If you are already on SSD or SSI prior to your transplant, there is the possibility of losing these benefits afterwards. Depending upon why you were originally declared disabled, Social Security could decide you have recovered enough after your transplant to return to work. This would not happen without a formal review by Social Security.

If you are not eligible for any of the above resources, you will need to plan for the time after a transplant when you are off work. Many people put aside money to help pay bills. Others borrow money from friends and family. Fundraising is also an option. There are charitable organizations that help transplant patients raise funds for uncovered expenses such as medical co-pays, travel, lodging, lost income, etc.

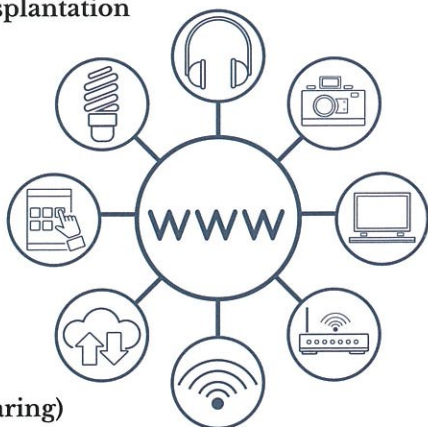
Feel free to reach out to your transplant social worker for more information on fundraising options (Pg. 40)

## NOTES

# Helpful RESOURCES

The Internet is vast, but not necessarily correct or up to date in its information about transplants. **Your transplant team is the best source of information regarding your transplant.** Read all that you can, but please rely on your transplant team for medical decision-making. We have included a list of websites where you can find accurate information on transplantation.

- **Scripps Center for Organ & Cell Transplantation**
  - [www.scripps.org/transplant](http://www.scripps.org/transplant)
  - 858-553-4310
- **National Kidney Foundation**
  - [www.kidney.org](http://www.kidney.org)
  - 800-622-9010
- **The Whittier Institute for Diabetes**
  - [www.whittier.org](http://www.whittier.org)
  - 877-WHITTIER
- **Diabetes Portal**
  - [www.insulinfree.org](http://www.insulinfree.org)
- **UNOS (United Network for Organ Sharing)**
  - [www.unos.org](http://www.unos.org)
- **HRSA (Health Resources & Services Administration)**
  - [www.organdonor.gov](http://www.organdonor.gov)
- **American Association of Kidney Patients: National nonprofit funded by kidney patients**
  - [www.aakp.org](http://www.aakp.org)
- **Donate Life America**
  - [www.donatelife.net](http://www.donatelife.net)
- **Donor Outreach for Veterans (DOVE): Helps veterans seek out living donors.**
  - <https://dovetransplant.org>
- **PEERs Program through the National Kidney Foundation: Speak with a trained peer mentor who can share their experiences about dialysis and transplant.**
  - [www.kidney.org/patients/peers](http://www.kidney.org/patients/peers)



# Fundraising Options

**(The options below do not impact Medi-Cal eligibility)**

Help Hope Live- Support community-based fundraising for unmet medical expenses.

[www.HELPHOPELIVE.org](http://www.HELPHOPELIVE.org) -- 1-800-642-8399

National Foundation for Transplants-Provides fundraising guidance and advocacy for medical and non-medical transplant-related costs.

[www.transplants.org](http://www.transplants.org) -- 800-489-3863

Children's Organ Transplant Association (COTA)-Provides fundraising guidance for ADULTS with single cell genetic disorders such as Polycystic Kidney Disease.

[www.cota.org](http://www.cota.org) -- 1-800-366-2682

American Kidney Fund-Funding for dialysis patients to cover health insurance premiums based on need

[www.kidneyfund.org](http://www.kidneyfund.org)--800-638-8299

American Transplant Foundation-Provides transplant recipients an emergency assistance grant up to \$1,000, based on need, to cover expenses that pose a direct financial barrier to post-transplant care (hotels, groceries, utility bills, etc.)

[www.americantransplantfoundation.org](http://www.americantransplantfoundation.org)

TRIO-Transplant Recipients International Organization-a not-for-profit, international organization that provides Awareness, Support, Education, and Advocacy for transplant candidates, recipients and their families.

[www.trioweb.org](http://www.trioweb.org)

United Network for Organ Sharing (UNOS)-Provides patient support and information.

[www.transplantliving.org](http://www.transplantliving.org)

## Substance Abstinence Support Resources and Mental Health Counseling

*\*\*\*Always check with your insurance company for "preferred providers" to minimize expenses\*\*\**

### San Diego Access and Crisis Line:

*24-hour crisis line and provides mental health provider options.*  
**(888) 724-7240**

### National Suicide Crisis Line

**(800)273-8255**

NAMI (National Alliance on Mental Illness) Helpline

**800-950-NAMI**

Family Health Centers San Diego- accepts Medi-Cal, Medicare + some insurance

**(619) 515-2300**

[www.PsychologyToday.com](http://www.PsychologyToday.com)- a tool to find psychotherapists, psychiatrists, treatment centers and support groups. They provide bios on mental health providers, resources and allow one to filter by need/insurance/location/telehealth or in-person support

Psychiatrists:

[www.sandiegopsychiatricsociety.org/doctor-finder](http://www.sandiegopsychiatricsociety.org/doctor-finder) -- (858) 279-4586

Psychiatrists who accept Medi-Cal:

[www.dhcs.ca.gov/individuals/Pages/MMCDHealthPlanDir.aspx](http://www.dhcs.ca.gov/individuals/Pages/MMCDHealthPlanDir.aspx)

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### Substance/Alcohol Rehabilitation and Treatment Centers options:

Aurora Behavioral Health: 858-487-3200 --  
[www.aurorabehavioral.com](http://www.aurorabehavioral.com)

Family Health Centers of San Diego: 619-515-2588 --  
[www.fhcsd.org](http://www.fhcsd.org)

Hazelden Betty Ford (affiliated with Scripps):  
866-831-5700 -- [www.hazeldenbettyford.org/sandiego](http://www.hazeldenbettyford.org/sandiego)

McAlister Institute - MITE: 619-465-7303

Practical Recovery- SMART Recovery Center: (800) 977-6110

Sharp McDonald Center:  
858-637-6920 -- [www.sharp.com/mcdonald/about-us.cfm](http://www.sharp.com/mcdonald/about-us.cfm)

VA Medical Center San Diego - 858-552-8585

## In-Home Counseling Options:

Doctor-On-Demand  
[www.doctorondemand.com](http://www.doctorondemand.com)

HELP (Home-Based Effective Living Professionals)  
858-481-8827 -- [www.helptherapist.com](http://www.helptherapist.com)

Blue Moon Senior Counseling  
855-241-7160 -- [www.Bluemoonseniorcounseling.com](http://www.Bluemoonseniorcounseling.com)

Psychotherapists  
[www.PsychologyToday.com](http://www.PsychologyToday.com)

### Online substance/alcohol abstinence support links:

#### AA online or in person:

[www.aa-intergroup.org/directory](http://www.aa-intergroup.org/directory)  
[www.aasandiego.org/newzoom.html](http://www.aasandiego.org/newzoom.html)

'In The Rooms' online:  
[www.intherooms.com](http://www.intherooms.com)

'SMART Recovery San Diego' online  
[www.smartrecoverysd.org/meetings](http://www.smartrecoverysd.org/meetings)

