What You Need to Know about Donating a Kidney

Introduction

At UCSF, the majority of organs for transplantation are obtained from people who have died and whose families have given permission for their organs to be donated. However, there are not enough of these deceased donor organs available for everyone who needs one. As a result, an increasing number of patients are being added to the national deceased transplant waiting list. Nationally, as of October 2019, there are more than 102,965 patients on the national kidney transplant waiting list, with more being added each day. In 2018, 21,167 patients received a kidney transplant, 2,486 of these transplants were completed in California. Some patients may die while on the waiting list or become too sick to undergo transplant because of the organ shortage.

These facts prove that living donor kidney transplantation is an important alternative as a patient can receive a kidney from a relative or friend, and not need to wait for a deceased donor organ to become available. Since the 1950's, surgeons around the world have performed living donor kidney transplants.

Surgeons at UCSF have performed living donor transplants since 1963. Living donor kidney transplantation is achievable because we are born with two kidneys. A person can live a healthy life with one kidney, which is why this alternative is possible. The kidney is surgically removed from a live donor and transplanted into a recipient.

Q: *What are the advantages of donating a kidney?*
A: Kidney transplant is the best treatment for kidney disease, and living donor kidney transplants give the best longevity and kidney function to the recipient. As a donor, you may be improving the quality of a recipient's life.

Q: *What are the general requirements to become a living donor?*
A: You **must**:

- Be at least 18 years old
- Not have any major medical or psychiatric illness
- Not be pregnant or intend to get pregnant for at least one year after surgery
- Not be overweight. You may still be considered a potential donor if you can achieve the acceptable weight.
- Not be actively smoking. If you currently smoke, you **must** quit at least 6 weeks prior to surgery and it is recommended that you never smoke again.
- Not be actively using illegal drugs
- Be able to understand the risks of this surgery

You will not be excluded from donating because of lack of personal insurance; however, it is in your best interest to secure health insurance prior to donation. For a more detailed description of insurance questions regarding your coverage as a donor, please refer to section **"Will my evaluation, testing and surgery be covered by medical insurance?"** in this booklet.

Follow our instructions for short and long-term follow-up medical care.

Q: *Does the donor need to be related to the recipient?*
A: No. Blood relation is not necessary between the donor and the recipient.

Q: *If the donor is related to the recipient, will the recipient experience less rejection?*
A: The relationship between donor and recipient may not change the risk of rejection. Related donors may be more genetically similar to the recipient, but with our potent medications given to recipients after surgery to prevent rejection, a biologically unrelated donor kidney can offer the same survival advantage as related donors.

Q: *Will the recipient be removed from the deceased donor transplant waiting list if a potential living donor is being evaluated for possible donation?*
A: No changes are made to the recipient's status on the deceased donor waiting list.

Evaluation

Q: *What are the first steps in the evaluation process?*
A: The steps are:

1. Complete an online health questionnaire at www.ucdonor.org
2. Provide Blood & Urine samples for testing
3. Review Health questionnaire and blood/urine results with Nurse Coordinator and discuss suitability to move forward with the "Donor Work-Up" process

Q: *Why is the questionnaire important?*
A: The medical questionnaire will tell the Transplant Coordinator of any medical problems that may affect your ability to donate. Please take your time in completing this questionnaire; do not leave any questions blank and make sure all the information is correct. Some questions, such as family history, may require the help of other family members. You need to be truthful about your personal habits.

Questions, such as smoking, alcohol or drug history, can be quite sensitive. Hiding information will be **dangerous** to you or the recipient.

Q: *Will my questionnaire & lab results be kept confidential?*
A: The questionnaire and all lab results are considered confidential. Only the health professionals on the Transplant Team will use this information and it will not be shared with the recipient or others. It is confidential.

Q: *What does the "donor work-up" process include?*
A: We will need you to obtain additional blood and urine tests, a chest X-ray and an EKG. You will also have an evaluation completed by one of our nephrologists (kidney doctor) and our social worker.
If these tests suggest that you can be a donor, we will schedule you for a CT Angiogram to make sure that you have two healthy kidneys. Other tests and/or consultations may also be necessary, depending on your personal medical history.

Q: *May I get my evaluation done by my own doctor?*

A: The evaluation process will require visits to UCSF and in general most of the testing will be done here (except for the initial blood and urine tests that can be performed locally). An exception to this policy is if an insurance carrier may prefer that some tests be done at a local designated facility. However, we insist that the most crucial testing be completed at UCSF. Tests are billed to the recipient's insurance except standard health maintenance (e.g. age appropriate colonoscopy, mammograms, PAP smears etc).

Some portions of the initial evaluation can be done near your home if you reside outside of California. Our Transplant Team Practice Coordinators will help guide you through this process.

Q: *What is the purpose of the evaluation process?*

A: The purpose of the evaluation is to make sure that your kidneys are normal and that you do not have any medical or psychiatric illness that would make this procedure risky or difficult for you. We also want to make sure you do not have any medical conditions that could be transmitted to the recipient. Finally, we want to make sure that you are becoming a donor voluntarily and no one is pressuring you to donate. To complete the donor evaluation, numerous tests and consultations are required over a period of several days to several months.

Q: *What takes place during the evaluation?*

A: In general, the donor work-up involves a full medical history and physical examination, including cardiovascular, cancer and viral (Hepatitis, HIV, etc) screening. A physician does the medical evaluation. This doctor serves as a "donor advocate" physician and looks at the donor overall health status with only the donor's interests in mind.

Q: *Do I need to fast before my appointments?*

A: It may be necessary for you to fast for some of the tests and you will be instructed to do so. While fasting, you can only have water to drink, absolutely no other food or drinks.

Q: *Will my evaluation be covered by medical insurance?*

A: The recipient's insurance will generally cover you for the donor testing and nephrectomy (the donation surgery); however, we strongly recommended that you have your own health insurance.

Donating a kidney may be considered a pre-existing condition to some insurance companies if you apply for health insurance after donating. A pre-existing clause may apply by way of a waiting period for coverage or denial of individual insurance coverage. Generally a pre-existing condition may not apply through a group insurance plan.

If you are not insured, we recommend that you contact an insurance broker for more details regarding pre-existing conditions as a donor and obtaining insurance for yourself.

There are some other services that provide financial support for lost wages and travel reimbursement for qualified applicants. The Living Donor Team will help guide you through these services when they are available to you.

Q: *Should the chances for success or failure of the transplant affect my decision to donate?*

A: You are volunteering with extraordinary generosity, to donate your kidney in an attempt to improve another person's quality of life. Before you make this gift, it is important that you understand that while the goal of donation is to improve the health and quality of life of the recipient, there are no absolute guarantees.

Q: *How quickly will I know if I can be a donor?*
A: The process of a full evaluation for donation is involved and can take a number of months from application until surgery. Generally, within 2 weeks of completing every component of the evaluation, we will let you know if you can be a donor. Further tests are sometimes needed which could delay your surgery. This is to ensure that the Transplant Team has all of the information needed to safely clear you for donation. It is important that you allow yourself time to digest the information you are reading here and the additional information you will get when you meet with us.

The decision to donate your kidney is not one you should make lightly. You should consider it very carefully, and discuss it with your family and significant others.

Surgery & Hospital Expectations

Q: *If I am cleared to be a donor, how is it decided when the transplant will take place?*
A: This decision is made jointly by the transplant team, recipient and you. The transplant team, particularly the physicians involved directly in your recipient's care, will determine as accurately as possible the best time to do the transplant, based on the recipient's medical condition. Once we know this, we ask for your input as to what works best for you and try to accommodate you and the recipient's schedule, if possible.

Q: *Once the transplant is scheduled, will it definitely happen?*
A: Unfortunately very little is written in stone. A number of things could happen that could change our plans, and up until the time of surgery plans could be cancelled. For example, your recipient's condition might get worse to the point where they are too sick for the transplant. The recipient or donor might develop an infection or some other condition that would need to be treated before the transplant could be done.

Q: *Do I need to do any special preparation prior to surgery?*
A: The medical evaluation we perform on potential living donors is extremely thorough. Once you have completed your evaluation and it its decide to proceed, there may still be additional testing required. If you opt to donate your own blood in the event of the need for transfusion, we will want you to donate a unit of your blood a couple of weeks prior to your surgery.

Prior to surgery you and your recipient will come to the hospital for a final pre-transplant review and to answer any remaining questions that you may have. You may need to repeat some blood tests if they were done more than 30 days before the surgery. There will be some preoperative test required such as blood samples for blood bank. If time sensitive tests are required, such as COVID tests - your coordinator will help to schedule all of these needs to minimize the number of trips to the hospital.

Q: *Should I stop smoking before my surgery?*
A: You must stop smoking at least 6 weeks prior to surgery, and we recommend that you never smoke again.

Q: *Should I stop drinking alcohol?*
A: If you are going to be a donor, it is advisable that you stop drinking alcohol 2 weeks before surgery. If you have a history of heavy alcohol use, it is very important that you tell our physicians. Alcohol use may not preclude you from being a donor. You should not return to drinking alcohol after surgery until advised that it is safe to do so by the Transplant Team.

Q: *Should I stop taking my medication(s) before the evaluation of the surgery?*
A: You should not stop taking any prescription medication unless advised to do so by a physician. We do not recommend that kidney donors use non-steroidal anti-inflammatory medications (NSAIDs) such as Advil, Motrin, or Ibuprofen during the evaluation phase or after surgery. Medicines that can thin the blood (such as aspirin) should be discussed with your coordinator. A plan will be made if these should be continued or not in the weeks prior to surgery. Women who use certain hormonal birth control medications will be advised to stop taking them 30 days before surgery because of the increased risk of blood clots after surgery. IUDs will not need to be removed.

Q: *Do I need any special diet before surgery?*
A: You can eat and drink normally until noon. You will have a liquid diet from noon until midnight then nothing by mouth until surgery. You will need to take a daily laxative starting 3 days before surgery. If you regularly take any medications, we will give you instructions about taking them.

Q: *When will I be admitted for surgery?*
A: You and the recipient will be admitted to the hospital on the day of the surgery.

Q: *What should I bring with me to the hospital?*
A: Bring only minimal belongings, no valuables & two forms of ID. Because we have your insurance information, there is no need to bring any insurance documentation with you unless we specifically ask you to. Leave all jewelry or other valuables at home or give them to your family for safekeeping. You may want to bring a basic toiletry bag for your use in the hospital.

Q: *How is the kidney removed?*
A: Since 1999 our center has used a laparoscopic technique to remove a kidney for donation. This technique involves four small (1/2 inch) incisions on the left or right side of the abdomen. These small cuts are used to introduce special instruments, which can be used to take out the kidney. In the final step, a 3.5-inch cut is made on the lower abdomen (at the "bikini line") for removal of the kidney. This technique takes about 4 hours. This technique does not require the cutting of any muscle, and the usual hospital stay is approximately 2-3 days, with the possibility of returning to work 4-6 weeks later. You will not know until after the CT angiogram of your kidney if it is possible for you to undergo the laparoscopic procedure. If there is a possibility of an open incision, more information will be shared during your surgical consult.

Q: *How much time passes between removing the kidney from the donor and transplanting it into the recipient?*
A: The operations on the donor and the recipient take place at the same time, in separate operating rooms. There are a few exceptions to this, and will be explained by your coordinator if it applies to your case.

Q: *Will I require a blood transfusion during my surgery?*
A: Blood transfusion during this surgery is uncommon, although it may be necessary. Current data at our center show that less than 1% of our donors have needed a blood transfusion. Your coordinator will go over with you the blood donation options.

Q: *What are some of the possible complications of the donor's operation?*
A: As with any surgery involving general anesthesia, there are possible complications of the anesthesia itself including heart complications, stroke, and blood clot formation in the legs or lungs. There are risks associated with any operation on the abdomen, which are bleeding, infection, and failure of the wound to heal. There is even a risk that you might die. We will discuss these risks with you in more detail during the evaluation process.

Q: *How long will I be in the hospital?*
A: The average hospital stay for donors is 2 days after surgery. Your recipient may have a longer stay.

Q: *Will I have a scar after the surgery?*
A: In most cases, the incision heals quickly; leaving a visible scar that fades over time. If a wound infection develops, you may be left with a wider scar that will be more obvious. Occasionally, people develop what is called a keloid, which is the over-growing or over-healing of the skin and results in a raised scar. Kelois can be corrected by plastic surgery. However, this corrective cosmetic surgery is unlikely to be covered by your recipient's insurance.

Q: *Will I have much pain after the surgery?*
A: You should anticipate having pain after this surgery. Your post-operative care team will work with you to evaluate your pain level and they will provide adequate medication so that you can tolerate getting out of bed and moving around.

You should expect to be uncomfortable for at least the first week. You will begin to have less pain as each day goes by. Most donors say that they still had a significant amount of discomfort for 1-2 weeks after the surgery.

Donors have experienced "trapped gas" as being a very painful part of recovery, and the best treatment of this issue is moving around.

Q: *What kind of pain management will I receive?*
A: Opioids are generally prescribed for management of post-operative pain. A side effect of opioids is drowsiness. Opioids can affect your breathing, may cause nausea, and/or constipation. Your inpatient care team will try to get the right balance of pain medication. The goal is to make you comfortable, not drowsy, so you can do your deep breathing exercises, cough and walk. A prescription for pain medication will be provided to you before you leave the hospital for pain control at home. If you have prolonged, severe pain when at home, you should contact the Transplant team to discuss this with them.

Q: *Will I have any tubes or drains in me after the surgery?*
A: You will have one or two intravenous lines in you during and after the surgery so we can give you fluids to keep you hydrated and give you medications. You will also have a catheter (drainage tube) in your bladder so we can monitor how your kidneys are working during and after the surgery. Having the catheter in your bladder also means that you will not need to get up to the bathroom immediately after your surgery. The tubes and intravenous lines are removed before you go home.

Q: *Will I be in the same room as my recipient after the surgery?*
A: No, the recipient generally goes to the same floor but in a different room.

Q: *How soon will I be able to eat and drink after my surgery?*
A: As soon as your intestines start to work again, you will be able to begin to eat and drink again. If you do not have nausea or vomiting with sips of water, you will be able to progress to clear fluids and then to a regular diet.

Discharge & Follow-Up

Q: *Will I have a normal life after surgery?*
A: We expect that most patients will return to a normal life within 2-3 months after surgery, if they do not experience any serious complications. You should be able to return to work within this timeframe, depending on how physically demanding your job is.

Q: *How long will I be off work?*
A: The minimum amount of time you should allow yourself to recover is 4-6 weeks. Because people recover differently, you may need as long as 8-12 weeks. We prefer that you be in a position (both financially and from a job security perspective) to be able to take 8 weeks off from work, should you need it.

Q: *Will I be entitled to disability pay?*

A: You may be entitled for disability pay if you have paid into the State Disability System or have disability benefits through your employer. Contact your employer's Human Resources Department to discuss your benefits and to obtain answers to your questions. If you have State Disability Benefits be certain to request an application before you are discharged.

You may qualify for programs that offer wage, travel and reimbursement of expenses. We can provide you information on eligibility requirements during your evaluation

Q: *When can I restart my birth control pills?*

A: We advise you to wait for at least one month.

Q: *Will I need to come back to the hospital for check-ups?*

A: This surgery is considered a major surgical procedure and you will need to be closely monitored to ensure your recovery is progressing. You will need a follow-up appointment a week after discharge from the hospital. These appointments will be covered by the recipient's health insurance and will be reviewed by the Donor Financial Counselor. It is important that you set-up a checkup with your primary health care provider soon after discharge. You will also require an annual medical checkup with your local provider for the rest of your life. We recommend you have your own health insurance coverage to cover these costs.

You will be required to have blood drawn at 6 months, 1year and 2 years after donation for follow-up. All general health maintenance is provided by your primary health care provider.

Q: *Must I remain close to the UCSF hospital after my surgery?*

A: You need to remain close to UCSF for at least 2 weeks after your surgery. You also need to be able to return to UCSF if you experience any problems during your recovery. We recommend that you have a relative or friend stay with you. This is important during the time immediately after you leave the hospital.

Q: *Will I need to take any medications after I donate a kidney?*

A: You may require medication for pain and it will be supplied with a limited prescription upon discharge. If you develop a wound infection you may also require antibiotics. Most of the time discharge medications are covered under the recipient's health insurance.

If you require additional medications beyond the amount provided at discharge, your transplant team provider will write the prescriptions. You will need to use your pharmacy insurance coverage or pay the retail cost. We do not anticipate that you will require any long-term medications specifically related to the kidney donation.

It is very important that you set up a follow-up appointment with your primary care provider soon after discharge.

Q: *Will I need a nurse to take care of me when I leave the hospital?*

A: This is a very big operation, however you should not need any professional nursing care at home. You will be tired and weak so you will need a friend or family member to do your food shopping, perhaps cook your meals and generally be available should you need them. You cannot lift anything over 10 pounds for 4-6weeks after surgery in order to prevent a hernia. It is also nice to have some company when you first come home from the hospital. You should have someone available to drive you to any follow-up appointments while you are taking any pain medication.

Q: *When will my sutures be removed?*

A: Usually the wound is closed with sutures beneath your skin. These sutures dissolve and do not require removal. You will get detailed instructions to care for your Incision site before discharge from the hospital.

Q: *When will I be able to drive after my surgery?*
A: We advise you not to drive for at least the first 2-3 weeks after surgery. You must be physically and mentally strong with normal reflexes, and not experiencing any abdominal pain or discomfort before you decide to drive. You should not be taking any medication that can affect your mental alertness. Pain medications containing narcotics (like Norco, Percocet or Tylenol with codeine and oxycodone) can affect your mental alertness and you should not drive if you are taking these types of pain medications.

Q: *When can I resume physical activities?*
A: If you are feeling well and are not having any complications, you may begin to return to your normal exercise activities. Begin slowly and build up your strength and stamina such as walking outdoors for at least 20 minutes per day. You will need to avoid any heavy lifting (greater than 10 pounds) for the first 4-6 weeks until your abdomen has completely healed.

Q: *When can I begin to exercise?*
A: As soon as you wake up from the anesthesia you will begin "exercising". You will need to take deep breaths and cough to make sure you are getting air deep into your lungs. This will help prevent pneumonia. You will also begin to exercise the muscles of your legs by flexing and relaxing them periodically. You will be helped out of bed the day after your surgery and begin walking. We cannot stress enough how important walking is to your recovery. Each day you should be pushing yourself a little bit more. By walking as soon after your surgery as possible, you will help to prevent such complications as blood clots, pneumonia, and muscle wasting. You are encouraged to continue a program of daily walking when you go home. Remember: the goal is to be back to normal health within 2-3 months recovery. Each day you should be pushing yourself a little bit more. By walking as soon after your surgery as possible, you will help to prevent such complications as blood clots, pneumonia, and muscle wasting. You are encouraged to continue a program of daily walking when you go home. Remember: the goal is to be back to your baseline health.

Q: *When can I engage in sexual intercourse?*
A: You will probably want to refrain from sexual intercourse for a couple of weeks until you have less discomfort and are feeling stronger. This decision is based on how you are feeling.

Q: *How long should I wait after surgery to get pregnant?*
A: Female patients should not get pregnant for at least a year from the date of surgery.

Q: *When can I go on vacation or fly?*
A: If we have any concerns about possible complications we will want you to return to UCSF for evaluation and treatment. You should not plan any vacations or trips outside the United States for at least 4 weeks and preferable 8-12 weeks after your surgery. It should be no problem for you to take trips or vacations after 8-12 weeks.

Please read through this information carefully and discuss the "Living Donor Kidney Transplant" option with your family and loved ones. If you have further questions, please call the Transplant Center at (415) 353-1551 or email living.donor@ucsf.edu to connect with a member of the Living Donor Team.

UCSF Medical Center
UCSF Benioff Children's Hospital

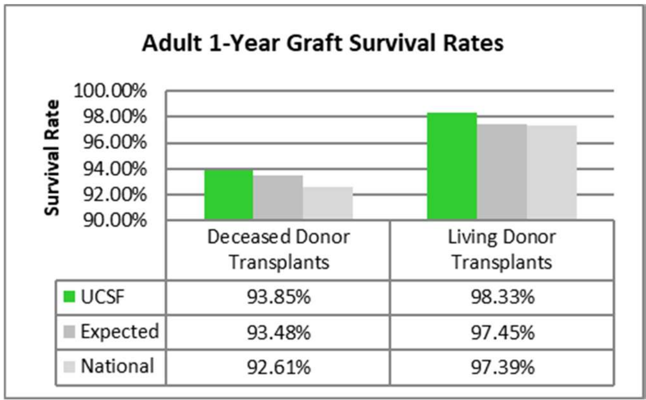
UCSF Kidney Transplant Program SRTR Post-Transplant Outcomes
Fall 2023

What is the SRTR?

The Scientific Registry of Transplant Recipients (SRTR) is an ever-expanding national database of transplant statistics. Data in the registry are collected by the Organ Procurement and Transplantation Network (OPTN) from hospitals and organ procurement organizations (OPOs) across the country. Every six months, SRTR uses the collected data to calculate transplant program specific *graft survival* and *patient survival* statistics that are made available to the public.

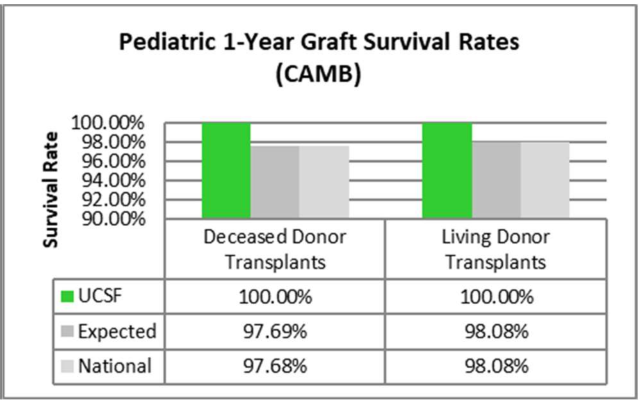
What are UCSF's post-transplant outcomes?

The graphs below include UCSF's *actual* and *expected* outcomes as well as the national average. The SRTR calculates what our *expected* outcomes should be based on many variables that describe how sick or healthy our recipients are, and the quality of the donor organ.



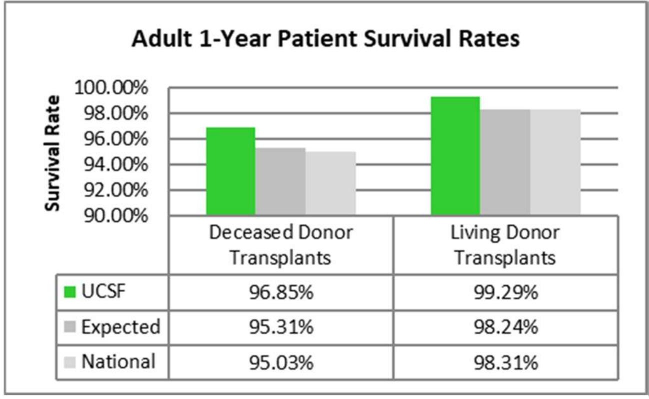
Adult 1-Year Graft Survival Rates

	Deceased Donor Transplants	Living Donor Transplants
UCSF	93.85%	98.33%
Expected	93.48%	97.45%
National	92.61%	97.39%



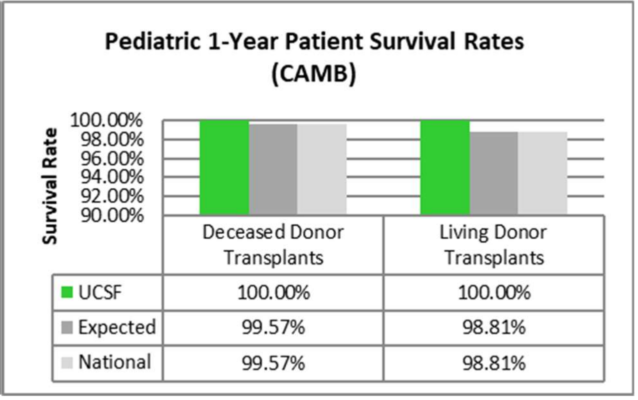
Pediatric 1-Year Graft Survival Rates (CAMB)

	Deceased Donor Transplants	Living Donor Transplants
UCSF	100.00%	100.00%
Expected	97.69%	98.08%
National	97.68%	98.08%



Adult 1-Year Patient Survival Rates

	Deceased Donor Transplants	Living Donor Transplants
UCSF	96.85%	99.29%
Expected	95.31%	98.24%
National	95.03%	98.31%



Pediatric 1-Year Patient Survival Rates (CAMB)

	Deceased Donor Transplants	Living Donor Transplants
UCSF	100.00%	100.00%
Expected	99.57%	98.81%
National	99.57%	98.81%

Do UCSF's outcomes comply with Medicare requirements?

Yes. All transplant programs in the country are closely monitored to assure that we are providing safe and high quality care to our patients. Our outcome data is reviewed every six months and meets Medicare and OPTN requirements.

Where can I go to get more information about transplant outcome data?

You can visit the following websites:

- The Scientific Registry of Transplant Recipients (SRTR) ***www.srtr.org***
- The Organ Procurement and Transplantation Network (OPTN) ***https://optn.transplant.hrsa.gov***

Data source: SRTR Report – Jan 2023 Fall Public Release

UCSF Health
Transplant Service

LIVING DONOR SURGERY

Here is some useful information about the donation process, as well as the risks of kidney donation:

1. Thank you for coming forward to donate a kidney. By donating a kidney, you may potentially improve and extend the life of your recipient. Thank you for this tremendous gift!
2. The history and physical exam today will allow us to evaluate you, the donor, to ensure that you are medically fit to undergo kidney donation.
3. The laboratory tests that you have already completed have been reviewed by a kidney doctor. Any abnormal results on these or future tests will be discussed with you.
4. You are getting a CT (Computerized Tomography) scan with intravenous (IV) contrast (dye) today or at a later date so that the transplant surgeon can look at the anatomy of your kidneys.
    a. 1/5 people have unusual kidney anatomy.
    b. 1/500 people have only one kidney.

    Any abnormalities of the kidney or other organs that are found on this scan will be discussed with you.
5. Later in your evaluation, you will have an opportunity to go through the details of the surgery. Almost all living donor kidneys are now removed **laparoscopically** and the medical term for this is **laparoscopic nephrectomy.** This procedure involves making four very small incisions in the abdomen, into which a small video camera and instruments are inserted. Another incision is made in the lower part of your abdomen; this is where the kidney will come out. The laparoscopic approach has been shown to decrease: 1. length of the hospital stay, 2. post-surgical discomfort, and 3. time to recovery.[1] Rarely (3 in 1000 cases), donors may need a bigger incision in the operating room due to technical difficulties; this is called an open nephrectomy.
6. On the day of surgery, both you and the recipient will likely be on the same floor (in separate rooms). Most donors stay in the hospital for 2-3 days, and the recipients for 3-5 days.
7. After you leave the hospital, you may be taking narcotic pain medications for up to 2 weeks, and during this time you will not be able to drive. You should plan to take 6 weeks off from work or school to fully recover from surgery. During this time, you should not lift anything heavier than 10 pounds.
8. Your transplant coordinator will contact you soon about the results of today's visit. Please call us at any time should you have any questions about kidney donation.

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[1] Davis CL and Delmonico FL. Living donor kidney transplantation: A review of the current practices for the live donor. *JASN* 2005; 16:2098-2110

UCSF Health
Transplant Service

COMPLICATIONS OF LIVING DONOR SURGERY[2]

(Review of 1000 consecutive laparoscopic donor nephrectomies at UCSF)

Short Term Risks

Wound infection (minor)	2 in 100 patients
Bleeding requiring blood transfusion	1 in 200 patients
Urinary tract infection (minor)	4 in 1000 patients
Deep vein thrombosis (blood clot in the leg – could travel to lung)	4 in 1000 patients
Pneumonia (lung infection)	1 in 1000 patients
Donor death	1 in 3500 patients

(The first laparoscopic donor nephrectomy was done at UCSF on November 3, 1999[2])

Long Term Risks

Incisional hernia	2 in 1000 patients
Lifetime Risk of End Stage Kidney Disease in donors	9 in 1000 persons[3]
Lifetime Risk of End Stage Kidney Disease in healthy non-donors	1.4 in 1000 persons[3]
Lifetime Risk of End Stage Kidney Disease in US General Population	33 in 1000 persons[3]

Seeing a Doctor

*****ONCE A YEAR FOR THE REST OF YOUR LIFE with your primary care provider*****

You must have your blood pressure, kidney function (serum creatinine) and urine protein excretion checked every year to minimize your risk of developing high blood pressure and kidney disease.

Donors will be contacted by UCSF at 6 months, 1 and 2 years after donation, and mandated blood and urine testing will be done at the medical center's expense (these can be accomplished locally). You may also choose to come to UCSF for an in-person appointment at those points with a member of the transplant team for follow-up. These do not replace your annual appointments with your PCP.

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[2] Ahearn AJ et al. Experience with laparoscopic donor nephrectomy among more than 1000 cases. *Arch Surg.* 2011: 146(7): 859-864

[3] Muzaale AD et al. Risk of End Stage Renal Disease Following Live Kidney Donation. JAMA 2014; 311:579-586

Created on 2/7/2018

Paired Kidney Exchange

Frequently Asked Questions

What is Paired Kidney Exchange?

Our goal at UCSF is to get each and every recipient with a living donor transplanted. By exchanging or “swapping” kidneys with other donor/recipient pairs, you can help us achieve this goal. Paired Kidney Exchange (PKE) is a transplant option that is available to living donor pairs.

Who can be involved in Paired Kidney Exchange?

Anyone can be involved in PKE. If you have an *incompatible* blood type with your recipient, or if you are *incompatible* due to your recipient’s antibodies (positive crossmatch), PKE is the optimal choice for transplant. In addition, if you are *compatible* with your recipient and want your recipient to receive a kidney from a younger donor, or if you are *compatible* with your recipient and want to help more than recipient get transplanted, you can be participate in PKE.

How are matches found in Paired Kidney Exchange?

We maintain a database of donor/recipient pairs who are in search of a better match. Our team of immunologists, nephrologists, transplant surgeons and coordinators routinely check for potential matches. A software program helps to facilitate this process. We are also involved in a national program in which we can exchange kidneys with other transplant centers, should we not find you a match at UCSF.

How does Paired Kidney Exchange work?

Most exchanges involve 2-3 way swaps. In Figure 1: Donor #1 is incompatible with Recipient #1. Donor #2 is incompatible with Recipient #2. Therefore:

1. Donor #1 gives to Recipient #2
2. Donor #2 gives to Recipient #1

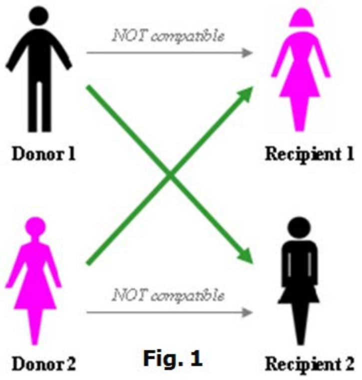
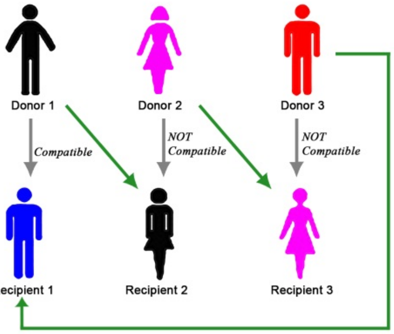


Fig. 1

Fig. 2



In Figure 2: Donor/Recipient #1 are compatible, but recipient is seeking a younger donor. Donor/Recipient #2 are incompatible, as are Donor/Recipient #3. Therefore:

1. Donor #1 gives to Recipient #2
2. Donor #2 then gives to Recipient #3
3. Donor #3 then gives to Recipient #1

(Recipient #1 receives kidney from younger donor, Donor #1 helps multiple people get transplanted.)

Where will my Paired Kidney Exchange surgery take place?

You are our patient. Your surgery will take place at UCSF. Your will have a UCSF surgeon regardless of who receives your kidney. Your recipient will also have a UCSF surgeon regardless of where their donor's kidney is coming from. Neither you nor your recipient will need to travel to take part in Paired Kidney Exchange transplant.

When will my Paired Kidney Exchange surgery take place?

In most cases, your surgery will take place on the very same day as your recipient's surgery. You will never donate prior to your recipient having a match. You and your recipient will be entered into the exchange program as a pair, and therefore matching is done simultaneously.

How long does it take to find a match through Paired Kidney Exchange?

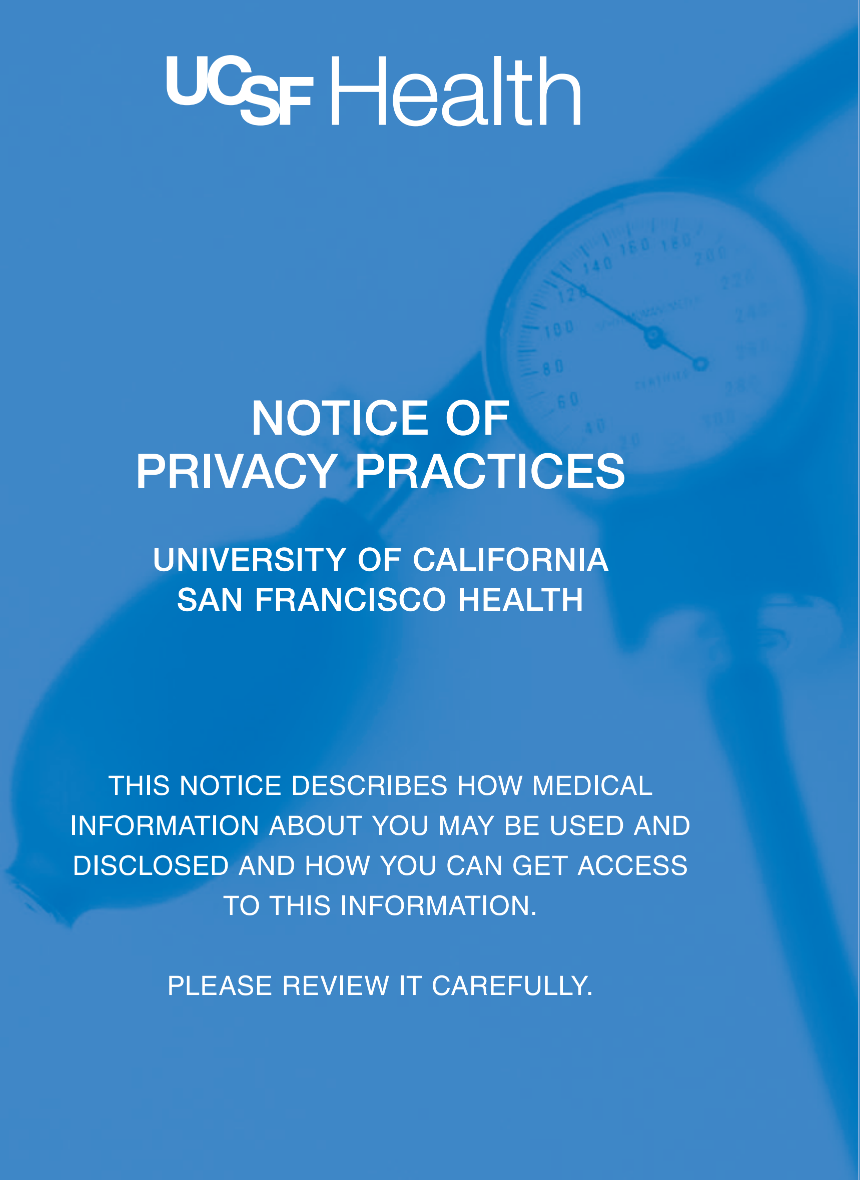
Matching can move very quickly, and you may go to surgery as soon as one month from entering the program. The average wait time is 3-6 months for incompatible pairs. Certain incompatible blood types can wait 12-18 months.

Why would I want to be involved in Paired Kidney Exchange?

The average wait time for a deceased donor kidney is 5-7 years. Without a living donor, two thirds of patients will die or become too sick for transplant. For diabetic patients, only 1 in 10 will receive a transplant if they have to wait on the deceased donor list. Living donor kidney transplants have better outcomes, longer survival, and eliminate long wait times. You can still help your loved one receive a transplant, even if you do not donate to them directly. In addition, you are saving the lives of other recipients by being involved in an exchange. Talk to your coordinator today about Paired Kidney Exchange.

Effective Date: June 1, 2021

UCSF Health



NOTICE OF PRIVACY PRACTICES

UNIVERSITY OF CALIFORNIA SAN FRANCISCO HEALTH

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY.

UCSF Health

UCSF Health is one of the health care components of the University of California. The University of California health care components consist of the UC medical centers, the UC medical groups, clinics and physician offices, the UC schools of medicine and other UC health professional schools. The administrative and operational units supporting the provision of care at all locations listed are also health care components of the University of California.

Our Pledge Regarding Your Health Information

UCSF Health is committed to protecting the privacy of your medical or health information. We are required by law to maintain the privacy of your health information. We will follow the legal duties and privacy practices described in this notice ("Notice").

Your Rights Regarding Your Health information

You have the following rights regarding the health information we maintain about you:

Right to See and Copy. You have the right to see or receive a copy of your health information, with certain exceptions. If we have the information in electronic format, you have the right to obtain your health information in an electronic format if possible. If not, we will work with you to find a way for you to receive the information electronically or as a paper copy. Your request must be made in writing and submitted to:

Health Information Management Services, UCSF Health,
400 Parnassus Ave, Room A88, San Francisco, CA 94143-0308.

You may also submit a request online at:
https://www.ucsfhealth.org/billing-and-insurance/medical-records

If you request a copy of the information, there may be a reasonable, cost-based fee for these services. You may also request that a copy of your health information be released to a third party that you choose.

Your Rights Regarding Your Health information (cont.)

Right to Ask for a Correction. If you feel that your health information is incorrect or incomplete, you may ask us to change or add more information to complete your record. Your request must be made in writing and submitted to: *Patient Relations, UCSF Medical Center, 350 Parnassus Ave., Suite 150, Box 1299, San Francisco, CA 94143-1299, phone: 1-415-353-1936, fax: 1-415-353-8556.* UCSF Benioff Children's Hospital Oakland patients, your request must be made in writing and submitted to: *Patient Advocate, UCSF Benioff Children's Hospital Oakland, 747 52nd Street, Oakland, CA 94609, phone: 1-510-428-3885 ext 5483.* We may say "no" to your request, but we will provide you with a reason why in writing.

Right to Know How We Have Shared Your Health Information. You have the right to request a list (accounting) of the times UCSF Health has shared your health information with others, such as to government agencies. The list will not include any disclosures made for treatment, payment, health care operations, or any disclosure you asked us to make. The request may be for a period covering up to six years before the date you request the list. Your request must be made in writing and submitted to: *Health Information Management Services, UCSF Health, 400 Parnassus Ave, Room A88, San Francisco, CA 94143-0308*. If you request an accounting more than once during a 12-month period, we may charge you a reasonable, cost-based fee.

Right to Ask for Restrictions. You have the right to ask us to limit how we use and share certain health information for treatment, payment, or health care operations. We are not required to agree to your request. If you pay for a service or healthcare item out-of-pocket in full, you can ask us not to share that information for purposes of payment or our operations. Your request must be made in writing and submitted to: *Patient Relations, UCSF Medical Center, 350 Parnassus Ave., Suite 150, Box 1299, San Francisco, CA 94143-1299, phone: 1-415-353-1936, fax: 1-415-353-8556*.

UCSF Benioff Children's Hospital Oakland patients, your request must be made in writing and submitted to: *Patient Advocate, UCSF Benioff Children's Hospital Oakland, 747 52nd Street, Oakland, CA 94609, phone: 1-510-428-3885 ext 5483.*

Right to Ask for Confidential Communications. You have the right to ask that we communicate with you about your health information in a certain way or at a certain location. For example, you may ask that we contact you only through your home phone number or only by mail. You must make your request in writing to: *Patient Relations, UCSF Medical Center, 350 Parnassus Ave., Suite 150, Box 1299, San Francisco, CA 94143-1299, phone: 1-415-353-1936, fax: 1-415-353-8556*.

UCSF Benioff Children's Hospital Oakland patients, your request must be made in writing and submitted to: *Patient Advocate, UCSF Benioff Children's Hospital Oakland, 747 52nd Street, Oakland, CA 94609, phone: 1-510-428-3885 ext 5483.* We will agree to all reasonable requests.

Right to a Paper Copy of This Notice. You can request a paper copy of this Notice at any time, even if you have agreed to receive this Notice electronically. Copies of this Notice are available throughout UCSF Health locations, or you may obtain a copy at our website, **https://www.ucsfhealth.org**.

Right to be Notified of a Breach. You have the right to be notified if we discover a breach that may have compromised the privacy or security of your health information.

How We May Use and Disclose Your Health Information

For Treatment. We use your health information to provide you with treatment or services. We disclose your health information to doctors, nurses, technicians, medical and health sciences students, or other health system personnel involved in your care. We may also share your health information with other non-UCSF Health providers for care or treatment. For example, we may share your health information if you are being referred to another provider at a non-UC Health institution.

For Payment. We use and share your health information to bill or get payment from health plans or other entities. For example, we disclose information to your health plan so it will pay us for your services.

How We May Use and Disclose Your Health Information (cont.)

For Health Care Operations. We use and share your health information to manage your treatment and services, run our business and teaching institution operations, improve your care, and contact you when necessary. For example, your health information may be used to review the quality and safety of our services, or for business planning, management and administrative services. We may also share your health information with an outside company performing services for us such as accreditation, legal, or auditing services. These companies are required by law to keep your health information confidential.

Other Ways We Share Your Health Information

We are permitted or required by law to share your health information in others ways – usually in ways that help the public, such as public health and research. We have to meet many conditions in the law before we can share your information for these reasons.

Hospital Directory. If you are hospitalized, we may include certain information about you in the hospital directory. This is so your family, friends, and clergy can visit you in the hospital and generally know how you are doing. You have the right to object to the release of directory information.

Individuals Involved in Your Care or Payment for Your Care. We may share health information with your family, close friends, or others involved in your care or payment for your care.

Health Information Exchanges. UCSF Health may participate in one or more health information exchanges (HIE), where we may share your health information, as allowed by law, to other health care providers or entities for coordination of your care. This allows health care providers at different facilities participating in your treatment to have the information needed to treat you.

If you do not want UCSF Health to share your information in an HIE, *you can opt out by completing an opt-out form:* **https://www.ucsfhealth.org/-/media/project/ucsf/ucsf-health/pdf/health_information_exchange_patient_opt-out.pdf** and submitting it to: *Health Information Management Services, UCSF Health, 400 Parnassus Ave., Room A88, San Francisco, CA 94143-0308.*

UCSF Health will agree with your opt-out request as needed to comply with the laws that apply to us. Opting out stops UCSF Health from sharing your information with other health care providers through the HIE; it does not stop other health care providers from sharing your information with UCSF Health, and it does not stop a health care provider that already received your information from keeping it. To stop other health care providers from sharing your information with UCSF Health, you must contact those providers directly. If you opt out, you can choose to resume participation by submitting a written request to: *Health Information Management Services, UCSF Health, 400 Parnassus Ave., Room A88, San Francisco, CA 94143-0308.*

Research. UCSF Health is a research institution. In certain circumstances, we can use or share your information for research without obtaining your authorization. For example, we may use your health information without your authorization for certain research when the research goes through a special review process to protect patient safety, welfare, and confidentiality.

University of California researchers may contact you about your interest in participating in certain research studies. Researchers may only contact you if they have approval to do so under a special review process. If you would like to opt out of receiving information related to research opportunities, please contact *UCSF Research Participant Services at 415-476-9259* or via email at **rps@ucsf.edu**.

Organ and Tissue Donation. If you are an organ donor, we may share your health information with organ procurement organizations.

Coroners, Medical Examiners and Funeral Directors. We may share health information with a coroner, medical examiner, or funeral director when an individual dies. This may be necessary, for example, to identify a deceased person or determine cause of death.

Disaster Relief Efforts. We may share your health information to an entity assisting in a disaster relief effort so that others can be notified about your condition, status and location.

Other Ways We Share Your Health Information (cont.)

Fundraising Activities. We may use the information you provided us to contact you about fundraising programs and events. You can opt out of receiving fundraising information for UCSF Health by contacting us at: **HIPAAOptOut@ucsf.edu**, or 1-888-804-4722, or *Records Manager, UCSF, Box 0248, San Francisco, CA 94143-0248*

As Required By Law. We will disclose your health information when required to do so by federal or state law. For example, we may share your health information with the Department of Health and Human Services if it wants to see that we're complying with federal privacy law.

Respond to Lawsuits and Legal Actions. We can share health information about you in response to a court or administrative order, or in response to a subpoena.

Military and Veterans. If you are or were a member of the armed forces, we may release your health information to military authorities as allowed or required by law.

Inmates. If you are an inmate of a correctional institution or under the custody of law enforcement officials, we may release your health information to the correctional institution as allowed or required by law.

Workers' Compensation. We may use or share your health information for Workers' Compensation or similar programs as allowed or required by law. These programs provide benefits for work-related injuries or illness.

Public Health and Safety. We may disclose your health information for certain situations such as:

- preventing or controlling disease (such as cancer and tuberculosis), injury, or disability
- reporting vital events such as births and deaths
- reporting suspected abuse, neglect, or domestic violence
- preventing or reducing a serious threat to anyone's health or safety
- reporting adverse events or surveillance related to food, medications, or defects or problems with products
- notifying people of recalls, repairs, or replacements of products they may be using
- notifying a person who may have been exposed to a disease or may be at risk of contracting or spreading a disease or condition
- providing limited information to your employer for legally required reporting of an employee's serious injury or death that occurs in the workplace
- providing limited information to your employer for legally required reporting related to medical surveillance of the workplace or work-related illness or injury, including infectious disease prevention and control.

Health Oversight Activities. We may share your health information with governmental, licensing, auditing, and other agencies as allowed or required by law.

Law Enforcement. As allowed or required by law, when certain conditions are met, we may release your health information to law enforcement.

National Security and Intelligence Activities. As required by law, we may share your health information for special government functions such as national security and presidential protective services.

Marketing or Sale of Health information. Most uses and sharing of your health information for marketing purposes or any sale of your health Information are strictly limited and require your written authorization.

Other Uses and Disclosures of Health Information. Other ways we share and use your health information not covered by this Notice will be made only with your written authorization. If you authorize us to use or disclose your health information, you may cancel that authorization, in writing, at any time. However, the cancellation will not apply to information we have already used and disclosed based on the earlier authorization.

Special laws apply to certain kinds of health information considered particularly private or sensitive to a patient. This sensitive information includes psychotherapy notes, sexually transmitted diseases, drug and alcohol abuse treatment records, mental health records, and HIV/AIDS information. When required by law,

Other Ways We Share Your Health Information (cont.)

we will not share this type of information without your written permission. In certain circumstances, a minor's health information may receive additional protections.

Changes to UCSF Health's Privacy Practice and This Notice

We may change the terms of this Notice at any time, and the changes will apply to all health information we have about you. The current Notice will be available upon request, at our locations, and on our website.

Organized Healthcare Arrangements

UCSF Health participates in an Organized Healthcare Arrangement (OHCA) with other healthcare providers. Within the OHCA, member organizations may share your health information for treatment, payment or operations related to the OHCA. For a list of UCSF Health's current OHCA participants, click **https://ohcp.ucsf.edu/OHCA**.

Questions or Complaints

If you have any questions or concerns about this Notice, please contact: *UCSF Health Patient Relations, UCSF Medical Center, 350 Parnassus Ave., Suite 150, Box 1299, San Francisco, CA 94143-1299, phone 1-415-353-1936, fax 1-415-353-8556*, or email **patient.relations@ucsf.edu**. If you feel your rights have been violated, you may file a complaint with UCSF Health. You may also file a complaint with the Secretary of the U.S. Department of Health and Human Services, Office for Civil Rights. You will not be retaliated against for filing a complaint.

Additional Information

Notice of Privacy Practices – Other Languages

a. English
b. Spanish
c. Chinese
d. Russian