# THE UCSF KIDNEY TRANSPLANT PROGRAM

## An Introduction for Patients and Their Families

*It is the policy of UCSF Medical Center not to engage in discrimination against or harassment of any patient or potential patient on the basis of race, color, national origin, religion, sex, physical or mental disability, medical condition, ancestry, marital status, age, sexual orientation, or citizenship. UCSF Medical Center has adopted an internal grievance procedure providing for prompt and equitable resolution of complaints alleging any action prohibited by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973. Any person who believes she/he has been subjected to discrimination on the basis of disability, in violation of the policy above, may file a grievance with the Compliance Coordinator (Director of Patient Relations) within 30 days of the date the person filing the grievance becomes aware of the alleged discriminatory action.*

Kidney transplantation is an important life-saving option available to patients with end-stage renal disease. The University of California, San Francisco Kidney Transplant Program was established in 1964 and is the most experienced program of its kind in the world, producing outstanding results and innovations in the field of transplantation. Each year more than 200 kidney transplantations are performed here and more than 1000 patients are referred annually for evaluation to determine whether transplantation is a suitable treatment option.

The program's commitment to quality comprehensive care for patients and their families is supported by a multidisciplinary healthcare team as well as state-of-the-art technology. Continuity of care is maintained by nurse specialists who coordinate the everyday care of patients throughout the transplant process. Support services include a nutritionist, exercise physiologists, social workers, and chaplains. UCSF's multidisciplinary approach to kidney transplantation has served as a model for transplant programs through-out the world. The vast array of resources available at UCSF enables the team to tailor each patient's care, whether pediatric or adult, to his/her specific medical needs. UCSF is a multicultural environment with the availability of a bilingual staff. For patients requiring dialysis treatment, a dialysis unit on the kidney transplant nursing floor allows convenient access.

## *Distinctive features of the ucsf kidney transplant program:*

### Multidisciplinary Care With Exercise Physiology Services

In addition to providing an outstanding team of experienced transplant surgeons, physicians, nurse specialists, nutritionists, and social workers, UCSF is the only transplant program in the country that includes exercise physiologists to assist in the important process of post-transplant recovery.

### Renowned Research

UCSF is a world leader in medical research aimed at reducing the probability of organ rejection and improving the success of transplantation. As a result, transplant patients have access to clinical protocols for immunosuppressive drugs not else-where available. Currently, there are multiple research activities involving available drugs-Neoral (cyclosporine), Prograf (FK506), and CellCept (mycophenolate mofetil). There are also research trials involving new immunosuppressive agents—Rapamycin and Humanized Anti-TAC antibody (HAT). A dedicated in-house immunogenetics laboratory, one of the largest of its kind in the U.S., engages in tissue studies to help prevent and treat rejection. Furthermore, important advances in islet cell transplantation for diabetes are being made so that this treatment can be applied in the near future.

### Living Donor Transplantation

Complementing the 200 solitary kidney transplants completed each year, approximately 100 patients per year undergo living donor transplantation—an increasingly important part of the kidney transplant program given the shortage of cadaver organs.

### Combined Kidney-Pancreas Transplantation

Typically, 15 to 20 patients per year undergo a combined kidney-pancreas transplant procedure for the treatment of end-stage renal disease secondary to diabetes mellitus.

### Pediatric Transplantation

Pediatric patients are cared for by a specialized team of pediatric nephrologists, surgeons, and coordinators specifically trained in the care of children. In addition, the program utilizes UCSF's Child Life Services, which offer informational and emotional support to children and their families in preparation for transplant surgery.

This booklet is designed to help you and your family understand the kidney transplantation process—through evaluation, surgery, and post-transplantation. Also included is information about the wide range of support services available at UCSF to you and your family.

We recognize that kidney transplantation is a complex procedure with many issues. We encourage you and your family to ask any questions you might have.

We gratefully dedicate this publication to our donors and recipients for their exceptional strength and courage and for inspiring advances in transplantation that will bring an even greater promise of life and health to our future patients.

## *Normal kidney functions*

The kidneys are organs whose function is essential to maintain life. Most people are born with two kidneys, located at either side of the spine, behind the abdominal organs and below the rib cage. The kidneys perform several major functions to keep you healthy:

- Filtration of the blood to remove waste products from normal body functions, passing the waste from the body as urine, and returning water and returning water and chemicals back to the body as necessary.
- Regulation of the blood pressure by releasing several hormones.
- Stimulation of the production of red blood cells by releasing the hormone erythropoietin.
- The normal anatomy of the kidneys involves two kidney-bean shaped organs that produce urine. Urine is then carried to the bladder by way of the ureters. The bladder serves as a storehouse for the urine. When the body senses that the bladder is full, the urine is excreted from the bladder through the urethra.

## *Kidney disease*

When the kidneys stop working, renal failure occurs. If this renal failure continues (chronically) end stage renal disease results with accumulation of toxic waste products in the body. In this case, either dialysis or transplantation is required to sustain life.

## *Pre-transplant evaluation*

If you are approaching end stage renal disease or are currently on dialysis, you can learn more about your option for kidney transplantation by setting up an appointment for a pre-transplant evaluation.

During the initial evaluation appointment, you will be interviewed by a transplant coordinator (a nurse specially trained in kidney transplantation) and a kidney transplant physician or surgeon. If possible, it's helpful to have family members or close friends accompany you to the appointment to help understand the significant amount of information you will be receiving about the transplantation process.

## *Scheduling an appointment*

An appointment can be made by you, your referring physician, or a staff member of your dialysis unit by:

- Calling 415/353-1551, or
- Sending a letter requesting an appointment to the transplant service addressed to

The UCSF Kidney Transplant Program

The Medical Center at the University of California, San Francisco

505 Parnassus Avenue, M 884

San Francisco, CA 94143-0116

Once your evaluation appointment is scheduled, you will be sent directions to UCSF and information about parking and convenient short-term lodging.

## *What to bring*

On the day of your evaluation, you need to bring information about family members, including names, addresses, telephone numbers, dates of birth, and past medical histories. Also bring your insurance information, including the insurance company name and policy number. Your referring physician should send a copy of your medical records to the transplant service before your evaluation appointment.

## *Evaluation procedure*

During the evaluation, a transplant coordinator will arrange for a series of tests (see following test information) to be taken to assess your treatment options. In addition, the transplant staff will discuss any medical problems that need to be evaluated before the transplant, such as heart disease, infections, bladder dysfunction, ulcer disease, or obesity. The social worker will meet with you to assess transportation, housing, financial and family support needs with respect to transplant. A financial counselor will meet with you to ensure you understand the covered benefits of your insurance policy. You will have an opportunity to ask any questions you might have. We encourage you to learn as much as possible about the transplant process before making a decision. It's not necessary for you to reach a decision by the end of the session; your decision can be communicated at a later date.

## *Screening tests*

Regardless of the type of kidney transplant you may undergo—living or cadaveric—special blood tests are needed to determine the kind of blood and tissue you have. These test results help to match a donor kidney to your body.

## *Blood Type Testing*

The first test establishes your ABO blood type. There are four blood types: A, B, AB, and 0, and everyone fits into one of these inherited groups. The recipient and donor must have either the same blood type or compatible ones. The list below shows compatible types.

If your blood type is: A

The donor blood type must be: A or O

If your blood type is: B

The donor blood type must be: B or O

It your blood type is: AB (universal recipient)

The donor blood type must be: A, B, AB, or O

If your blood type is: O (universal donor)

The donor blood type must be: O

As indicated, the AB blood type, called the universal recipient, is the easiest to match because that individual accepts all other blood types. Blood type 0, called the universal donor, is the hardest to match. Although people with blood type O can donate to all types, they can only receive kidneys from blood type 0 donors. For example, if a patient with blood type O were transplanted with a kidney from an A donor, the body would recognize the donor kidney as foreign and destroy it. The Rh type (+, -) is not a factor in donor matching.

**Human Leukocyte Antigens (HLA)**

The second test, which is a blood test for human leukocyte antigens (HLA), is called tissue typing. These antigens are substances found on many cells of the body, but are mostly seen on white blood cells. Tissue type likeness between family members may be 100, 50, or 0 percent. The tissue type of all potential donors is considered in donor selection.

The prospective recipient and all interested family members and non-relatives can make the appropriate arrangements with the transplant team to have the tissue typing test done. No special preparation is required and results are available within two weeks. Pre-packaged kits with specific instructions about how to collect and return blood samples are available for mailing to out-of-town relatives. The necessary blood can be drawn at a local physician's office or hospital laboratory and sent back to the transplant service via ovennight mail.

**Crossmatch**

Throughout your life your body makes substances called antibodies that act to destroy foreign materials. You may make antibodies each time you have an infection, are pregnant, have a blood transfusion, or undergo a kidney transplant. If you have antibodies to the donor kidney, your body will destroy the kidney. For this reason, when a donor kidney is available for you, we conduct a test to insure that you do not already have antibodies to the donor. This test is called a crossmatch.

The crossmatch is done by mixing your blood with cells from your donor. If the crossmatch is positive, it means that you have antibodies against the donor and should not receive this particular kidney. lf the crossmatch is negative, it means you do not have antibodies to the donor and that you are eligible to receive this kidney. Crossmatches are obtained several times during preparation for a living-related donor transplant, particularly if donor-specific blood transfusions are employed. A final crossmatch also is performed within 48 hours before the transplant.

**Serology**

Testing is conducted for potentially transmissible diseases, such as HIV (human immunodeficiency virus), hepatitis, and CMV (cytomegalovirus).

## *Support groups*

It's common to feel overwhelmed when faced with the possibility of a kidney transplant. To help discuss your feelings and hear about others' experiences, you will have an opportunity to attend support groups during the evaluation process.

These groups help patients and their families waiting for a transplant avoid feelings of isolation by providing a small "community" that forms a bridge between dialysis and the transplant experience. They also provide information about life after the transplant within a discussion format with participation by staff physicians, social workers, exercise physiologists, and transplant coordinators.

## *The kidney transplantation decision*

Following the pre-transplant evaluation process, you will have the opportunity to discuss your specific illness and treatment options with the kidney transplant program staff to help you make an informed decision about your care. Many people believe that kidney transplantation can provide a better quality of life than dialysis. To help determine the best course of treatment for you, there are several factors to consider, including your medical circumstance, the donor possibilities for your situation, age, and your personal lifestyle choice. Transplantation offers a life free of dialysis but also includes the risk of surgery, organ rejection, and the side effects of immunosuppressive medication.

## *Decision-making factors*

**The Transplant Recipient**

People suffering from a variety of causes of end-stage renal disease consider transplantation. The most common causes include glomerulonephritis, diabetes mellitus, severe anatomical problems of the urinary tract, nephrosclerosis (high blood pressure), and polycystic kidney disease.

Some kidney patients consider transplantation after they've begun dialysis, but if you prefer, transplantation can he considered before you start dialysis. In some circumstances, dialysis patients with additional severe medical problems such as cancer or active infections may he considered unsuitable transplant candidates.

After all the factors and features of your case are reviewed by the consulting transplant physician and nurse, your case is presented in detail at our combined, multidisciplinary patient care conference held weekly. All staff surgeons, nephrologists, transplant nurses, social workers and financial counselors are present and have input about your case. If more additional tests

are needed to assess your health, they may be recommended. (On occasion, the conference may decide that kidney transplantation is too risky for you and may lead to worse health than remaining on dialysis. These types of decisions are discussed in full with your own physician who will then relay this information to you. We can also answer any questions you might have regarding such a negative recommendation — if it occurs.)

**Donor Options**

Kidneys for transplantation come from two different sources: a living donor or a cadaver donor.

**The Living Donor**

Sometimes family members, including brothers, sisters, parents, children (18 years or older), uncles, aunts, cousins, or a spouse or close friend may wish to donate a kidney. That person is called a "living donor." He/she must be in excellent health, well-informed about transplantation, and able to give informed consent. Any healthy person can donate a kidney safely.

When a living person donates a kidney, his/her remaining kidney will hypertrophy (enlarge) as it takes over the function of the donated kidney. Donors will not require medication or special diets once they have recovered from surgery. As with any major operation, a potential for complications exists; however, kidney donors have the same life expectancy, general health, kidney function, and activities as healthy non-donors. Donating a kidney does not interfere with a woman's ability to have children. Potential donors whose occupations require extreme physical exertion need to discuss this with the transplant staff.

The initial costs for living donor surgery, hospitalization, diagnostic tests and evaluation are usually paid by the recipient's insurance. Travel and living expenses are not covered. Insurance coverage will be discussed at the time of your transplant evaluation.

If you have a potential living donor, he/she will meet with one of the transplant physicians and a transplant coordinator during the evaluation process to discuss the possibility of organ donation. Tissue typing and other tests will be performed to determine the potential donor's suitability. In some families several people may be compatible donors. In other families, none of the relatives or non-relatives may be suitable.

**Cadaver Kidney Transplant**

If you do not have a live donor who can donate a kidney, you may receive a cadaver kidney transplant. A cadaveric kidney comes from a person who has suffered brain death. All donors are carefully screened using the most recent technology to prevent any transmissible diseases. The Uniform Anatomical Gift Act allows all of us to consent to organ donation for transplantation at the time of death and allows our families to provide such permission as well. After permission for donation is granted, the kidneys are removed and stored until a recipient has been selected.

If you have decided to undergo a cadaveric kidney transplant and are a medically acceptable candidate, your name will be placed on a cadaver waiting list. From the time your name is placed on the waiting list, a sample of blood for antibody level is sent monthly to UCSF by your dialysis center or by you if you are on home dialysis, continuous ambulatory peritoneal dialysis,

or have not yet started dialysis. The waiting period for a cadaver kidney depends upon the availability of a cadaver donor compatible with your blood type and your antibody level (see insert for more information on cadaver transplant).

When a kidney becomes available and after you have been identified as a potential recipient for that kidney, your referring nephrologist is contacted for medical approval. The transplant service will verify with the referring physician that you have no recent infections or medical problems that would interfere with safe transplantation. The transplant service will inform you when a cadaver kidney is available and will assist in making the arrangements for your transplantation.

## *Factors for Success*

The success rate of a kidney transplant varies somewhat depending on whether the donated kidney is from a relative or from a cadaver. At the end of two years, the success rate (defined as the transplant working well) for recipients of living related donor transplants is 90 to 95 percent and more than 80 percent for recipients of cadaver donor transplants. During each successive year thereafter, the risk of losing the kidney is approximately two to four percent. Most kidney losses are due to rejection, but infections, circulation problems, and a recurrence of the original kidney disease can also cause kidney loss.

## *At the hospital*

Your hospital stay will probably be between 3-10 days depending upon your individual situation. UCSF, you will go When you arrive at UCSF, you will go directly to the kidney transplant unit on the 14th floor of Moffitt Hospital. If you're interested in short-term lodging, the reservationist in Admitting can help you or you can call 415/476-1765 for information.

Adult recipients stay on the Kidney Transplant Unit (KTU) on the 14th floor of Moffitt Hospital. Pediatric recipients stay on the Pediatric Surgical Unit on the 6th floor of Long Hospital.

After arriving on the unit, you will have blood drawn and a chest x-ray and an EKG (electro-cardiogram) performed. A physician will conduct a physical examination, take a medical history, and explain the surgery and its risks to you and your family. You will be required to sign an operative consent form. Depending on the timing of your most recent dialysis and the results of your blood work, you may need to be dialyzed before going to surgery. The nursing statf will assist you in all of your pre-operative prepara≠tions. After all of these procedures are completed, you will be taken to the operating room.

## *Surgery*

Your surgery may last from two to four hours. During the operation, the kidney transplant is placed in your pelvis rather than the usual kidney location in the back. Your own native kidney will remain undisturbed. The artery that carries blood to the kidney and the vein that removes blood from it are surgically connected to two blood vessels already existing in the pelvis. The ureter, or tube that carries urine from the kidney to the bladder, is also transplanted through an incision in the bladder.

After the operation is completed, you will be taken to the recovery room for a few hours and then will return to the Kidney Transplant Unit. The surgeon will inform your family when the procedure is over.

You will be encouraged to get out of bed starting 12 to 24 hours following surgery and to walk around the Kidney Transplant Unit as much as you can. Staff nurses on the unit will help teach you how to take your medications and instruct you about side effects and making changes in your lifestyle.

A cadaver kidney transplant will occasionally perform as a sleepy kidney, a condition referred to as acute tubular necrosis (ATN). This means that the kidney is temporarily slow in functioning because of being stored and is not filtering the blood adequately. Therefore, you may need dialysis, which will not harm the kidney and may be needed only a few times. If the kidney is slow to function, in most cases, the transplant gains success in two to four weeks.

## *Possible Complications*

Complications can occur with any surgery. Patients undergoing organ transplantation may face additional complications. A few patients have complications immediately following surgery that can include bleeding, infection, or healing problems. Rarely, a patient may have difficulty with blood circulation to the kidney or the flow of urine from the kidney. If any of these problems does occur, your physicians will discuss them with you and your family. It may be necessary for you to go back to surgery to correct the problem. However, these complications do not occur often.

### Rejection

Just as your body fights off bacteria and viruses (germs) that cause illness, it can also resist the presence of foreign tissue. When your body recognizes that the transplant kidney is not the same as your own body tissue, rejection occurs. Rejection is an expected side effect of transplantation and most people who receive a kidney transplant will experience some degree of rejection. Most rejections occur within three months after transplantation, but can occur at any time, even years later. Prompt treatment can reverse the rejection in most cases.

### Medications

Immunosuppressive medications help to prevent and treat rejection. At the present time, they are necessary for the "lifetime" of your transplant. It is important to recognize that while doing "good" they may be associated with

variable and individual side effects. By knowing these side effects ahead of time, you can help minimize these or allow us to care for them should they occur. The doses of these medications and most of the side effects are reduced with time after transplantation.

A combination of medications will be utilized in an effort to avoid rejection of the kidney transplant. Under these circumstances, your physician will instruct you about the appropriate dosage of each medication.

You will take some of the following drugs on a regular basis for as long as you have your transplanted kidney. If you discontinue these medications, rejection will soon occur. It is therefore essential that you know what each medication is used for and how much you should take each day. During your hospital stay you will be instructed in the use of your medications, which are kept at your bedside. Once you are familiar with your medications, you can take them on your own.

### New Immunosuppressive Drugs

UCSF is a world leader in medical research aimed at reducing the probability of organ rejection and improving the success of transplantation. Patients have access to clinical protocols involving the use of new immunosuppressive drugs not elsewhere available.

### Other Medications Used Following Kidney Transplantation

Infection prophylaxis—You will take some additional drugs for the first 3 months in order to prevent viral and certain protozoal infections following your transplant.

Blood pressure medications—High blood pressure may persist following transplantation. The need for high blood pressure medication is evaluated in the hospital as well as in the outpatient clinic.

Antacids—To reduce early post-transplant stomach aches and pains, you will take drugs to prevent extra acidity for the first 3 months.

## *Post-transplant recovery*

### Diet

A renal nutritionist will be available to speak to you concerning any specific dietary needs or requests. A diet class is also offered for patients and their families.

POST-TRANSPLANT SUPPORT

The transplant service social workers visit each recipient, donor, and prospective donor in the hospital and can assist with a wide variety of problems. A social worker will be available to continue to follow you as an outpatient in the transplant clinic.

### Support groups

Support groups are available for patients who have undergone transplant surgery (as well as their family members) who want to discuss issues concerning the post-transplant experience. These groups are led by a psychiatrist and a social worker.

### Outpatient clinic

Typically, patients come to the clinic at UCSF located on the third floor of the Ambulatory Care Center at 400 Parnassus Avenue (across the street from the hospital) for their initial visit after discharge. The time between visits varies with individual needs. At first the visits are twice a week and then fewer in frequency. Between visits some patients see their own physician. Occasionally, special arrangements are made for people who live a distance from UCSF or who have financial limitation. Even years after your transplant, you will continue to need regular checkups to care for your transplanted kidney.

### Resuming daily activities

The recovery period varies with each individual and will depend upon the new kidney's function, the degree of rejection, the amount of medication needed, and complications.

Depending upon your job, you can usually return to work about six to eight weeks after you're discharged from the hospital. Your physician will discuss your activities with you. The social worker in the outpatient clinic will be available to help you with any problems relating to returning to work or to situations at home.

## *Recipient medical expenses*

Your medical insurance typically pays for a kidney transplant just as it normally pays your medical expenses. As a transplant patient, you probably will be eligible for Medicare insurance. Medicare benefits, regardless of your age, cover most of the costs of your kidney transplant. Our social workers are available to answer any questions you may have concerning your insurance coverage. A financial counselor will discuss your insurance situation at the time of your pre-transplant evaluation.

## *Family support*

We encourage patients and their families to attend our transplant support groups, which are facilitated by health care professionals and are described on pages 6 and 14. These sessions are designed to provide you with information that will help you cope with the formidable changes facing you before and after transplantation. Those support group participants who are former transplant recipients can help provide you with the perspective of experience and can offer tips for successful coping strategies. It's often encouraging and educational to hear the stories of those who have "been there."

It's important for both you and your family to understand that transplantation—from the evaluation phase through recovery—requires great physical and emotional stamina. From our years of experience, we have found that the emotional support and practical assistance provided by family members is vital.

Prolonged illness and complex surgical procedures affect family members and loved ones as well as the patient; this is particularly true with kidney disease and transplantation. The most important thing to remember is you're not alone. In the ups and downs that usually occur before and after transplant, many people are available to help you and your family. Discussing your feelings about the transplant process and involving your loved ones in resources offered by the transplant program will help you and them proceed through the recovery process.

## *Glossary*

**Acute Tubular Necrosis (ATN) -** A condition when the tubules (small tubes) of the kidney are damaged by ischemia (decreased blood flow to the kidney). When the tubules are damaged, the blood cannot be filtered correctly.

**Antibodv -** Protein substances developed by the body, usually in response to the presence of antigen that has gained access to the body.

**Antigen -** A substance that causes the formation of antibodies. An antigen may be introduced into the body or it may be formed within the body. Examples are bacteria, bacterial toxins, and foreign blood or tissue cells.

**Bladder -** A storage sac for urine.

**Blood Urea Nitrogen (BUN) -**
A substance found in the blood, lymph, and urine. It is formed in the liver from ammonia derived from the breakdown of protein in digestion.

**Creatinine -** The end product of creatine metabolism. Creatine is a substance that combines with phosphate to provide a high energy source for muscle contraction.

**Diabetes Mellitus -** A disorder of glucose metabolism that causes high blood sugar, resulting from too little production of insulin or the body's inability to use insulin.

**Donor -** One who furnishes blood, tissue, or an organ to be used in another person.

**Foley Catheter -** A urinary catheter equipped with a small balloon near the tip which can be inflated to retain the catheter in the bladder.

**Iliac Artery/Vein -** The renal artery and vein of the transplanted kidney is attached to the iliac artery and vein. The iliac artery supplies the new kidney with blood, and the iliac vein drains the blood away from the new kidney.

**Immune Response** - The body's attempt to protect itself from foreign tissue, such as bacteria, viruses, yeast, or transplanted organs. Immunosuppressive or anti-rejection medicines are used to control this reaction against the transplanted kidney.

**Lymphocytes** - A type of white blood cell. There are two main types of lymphocytes called B and T cells—both play major roles in the human immune response.

**Recipient** - One who receives blood, tissue, or organs provided by a donor.

**Rejection** - The body's attempt to protect itself from foreign tissue such as a new kidney. Immunosuppressive or anti-rejection medicines are used to try to prevent this.

**Renal** - Pertaining to the kidney.

**T-Cells** - A type of lymphocyte (white blood cell). These cells suppress or assist the stimulation of antibody production of B-lymphocytes and can kill tumor and transplant tissue cells.

**Ultrasound** - The use of sound waves from an instrument on the skin to produce a picture of the internal organs, used often to detect urologic abnormalities, obstructions, and kidney size.

**Uremia** - A toxic condition associated with renal failure and the retention in the blood of nitrogenous substances normally excreted by the kidney.

**Ureter** - One of two tiny tubes carrying urine from the kidneys to the bladder, beginning with the pelvis of the kidney and emptying into the base of the bladder.

**Urethra** - The muscular tube that carries urine from the bladder to the outside of the body.