

DIVISION OF ABDOMINAL TRANSPLANT SURGERY 717-531-6092 or 1-800-525-5395

:: HOW TO CONTACT THE TRANSPLANT OFFICE

PLEASE CALL YOUR SPECIFIC COORDINATOR DURING OFFICE HOURS FOR ALL ROUTINE CARE AND/OR QUESTIONS. REFER TO THEIR BUSINESS CARD OR CALL 717-531-6092 AND REQUEST TO SPEAK WITH YOUR COORDINATOR.

Location: Penn State Health Milton S. Hershey Medical Center

Penn State College of Medicine

Telephone: 717-531-6092 or 1-800-525-5395 **Fax:** 717-531-0124 or 717-531-3717

Address: Penn State Health Milton S. Hershey Medical Center

Division of Transplantation Mail Code H062, RM 3190

500 University Drive Hershey, PA 17033-0850

Office Hours: 8:00 a.m. to 5:00 p.m. / Monday through Friday

Contact information after Hours for Emergencies Only!

While waiting for a transplant:

Your referring doctor will continue to manage your care until you receive a transplant.

After you receive your transplant:

Holidays, evenings, and weekends Call 717-531-8521 and ask for the kidney transplant coordinator on-call.

:: TABLE OF CONTENTS

Introduction	4
Your Transplant Team	6
Pre-Transplant	
•	
Options for Treatment	
Dialysis	
Transplantation	
Deceased Donors vs. Living Donors	
Deceased Donor Organ Distribution	
Living Donors	
Donor Surgery	
Potential Living Donors	
(What do I Tell Someone Who Wants to be a Donor for Me?)	10
Evaluation Process	20
How do I get on the Transplant List?	20
Testing	23
Waiting for Your Transplant	26
Transplant Procedure and Recovery	29
Receiving the Call and Getting a Transplant	
Arriving at The Hospital	
To The Operating Room	
Immediately After Surgery	31
Post Transplant Care	33
Life After Transplant – Staying Healthy	34
Your Care at Home	
Stents	
General Guidelines	36

PATIENT INFORMATION GUIDE :: KIDNEY TRANSPLANT

Vaccines
Medical Identification
Daily Medical Tasks
Other Post-Transplant Care
Daily Hygiene
Exercise
Sexual Activity and Birth Control
Pregnancy After Transplant
Your Diet
Hydration
Potassium in Food
Foods High in Calcium
Rejection and Infection Post Transplant54
Treatment for Rejection/Infection
Complications58
Medications59
Other Less Commonly Used Immunosuppression Medications 78
Post-Discharge Clinic Visits96
World-Class Care
When Should I Call the Transplant Team?
Writing to Your Donor Family
Patient Diary
Additional Resources112
Glossary of Important Terms

:: INTRODUCTION

Welcome to the Abdominal Transplantation Program of the Penn State Health Milton S. Hershey Medical Center. Like many individuals beginning the evaluation process for an organ transplant, you may have a number of questions and concerns. We encourage you to read this entire guide and to ask questions of your doctors, nurses, and other staff if there is something you do not understand. As your transplant team, we are aware that you and your family have likely encountered a great deal of stress and numerous hurdles related to your health. Living with serious health issues involves a number of physical, emotional, and financial changes. We are available to support you through this process as you gather information and face upcoming decisions.

Please keep this guide handy and place all of your correspondence regarding the transplant process in this guide. You must bring this guide with you when you are called in for your actual transplant, as we will need to review the post-transplant care with you at that time. It will help you to know what to expect in each step of the process if you read the entire guide.

The guide provides a brief discussion of how a healthy organ functions normally, what happens when that organ is damaged, and specific information about the Abdominal Transplant Program at the Penn State Health Milton S. Hershey Medical Center. It also describes the evaluation and selection process for an organ transplant, the wait for a donor organ, the operation and immediate post-operative period. Of particular importance is information regarding what you should do after transplantation. It is necessary to learn about your medicines and how to maintain good health with a newly transplanted organ. Being well-informed about how you can take good care of yourself before and after the transplant is a vital part of your recovery process. Remember, if you have any questions, call your transplant coordinator, who is available Monday through Friday from 8:00 a.m. to 4:00 p.m.

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You also may call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.

Thank you for choosing the Penn State Health Milton S. Hershey Medical Center to learn more about organ transplantation.

:: YOUR TRANSPLANT TEAM

TRANSPLANT SURGEONS

Our transplant surgeons have advanced training in surgery (e.g., heart surgery, liver surgery, abdominal surgery, etc.). The surgeon will meet with you before the transplant surgery to determine, with the help of other members of the medical team, whether transplant is the best treatment for you. The surgeon will speak to you about the risks and benefits of the surgery and answer any questions you may have about the surgery or about the follow-up care. The surgeon will perform the transplant surgery and oversee all aspects of your care during your hospital stay and the first year after your transplant.

TRANSPLANT NEPHROLOGISTS

The transplant nephrologist specializes in the medical treatment of kidney disorders and works with the transplant team to ensure optimal functioning of the new kidney. This physician completes a physical examination prior to transplant surgery to assess the risks and benefits of surgery. The nephrologist will discuss any medical issues with you and your family. The transplant nephrologist monitors all non-surgical aspects of your care. In cooperation with the transplant surgeon, he or she will adjust your medications after the surgery, while you are in the hospital, and later, in the clinic. He or she will monitor your kidney function to identify any problems—such as hypertension (high blood pressure) and diabetes—while you are in the hospital.

TRANSPLANT NURSE PRACTITIONERS/PHYSICIAN ASSISTANTS

Our transplant Nurse Practitioners (NPs) and Physician Assistants (PAs) are advanced practice clinicians who have received training in the care of transplant patients. The NPs and PAs work closely with the transplant surgeon to monitor your recovery and care for you during the first year after transplant. In cooperation with the transplant surgeon, the NPs or PAs will monitor your incision, laboratory values and response to immunosuppression. They also perform kidney transplant biopsies to check for rejection.

TRANSPLANT COORDINATORS

Your transplant coordinator is your main source of contact with the transplant team.

The coordinator is a highly trained registered nurse who is an integral part of your transplant process both before and after transplant.

Before transplant, your coordinator guides you through the education and workup process and is your contact person for any questions or concerns you have while awaiting transplant. After transplant, your care is transferred to a post-transplant coordinator who educates you on how to care for yourself and how to take your medications properly. The coordinator also reviews your lab work in conjunction with our physicians and answers any questions that may arise.

TRANSPLANT SOCIAL WORKERS

The transplant social workers provide support, education, counseling, and assistance throughout the evaluation and transplant process. They assist patients and families as they adjust to life with a chronic illness, living with a transplant, and resuming life after a transplant. Social work services are available for all pre- and post-transplant patients and their families, as well as for living organ donors.

TRANSPLANT FINANCIAL COUNSELOR

The transplant financial counselor reviews your insurance coverage and explains what coverage you have available for transplant and medications after transplant. The counselor also makes recommendations for additional coverage to minimize your out-of-pocket expense after transplant.

TRANSPLANT DIETITIAN

Our transplant dietitian offers nutrition counseling for patients awaiting transplant, post-transplant patients, and living donors. Nutrition support is tailored to meet the needs of each patient.

TRANSPLANT PHARMACIST

Our transplant pharmacist has an in-depth knowledge of transplant-related medications. The pharmacist educates patients on immunosuppressive medications, side effects of medications, and proper dosing.

TRANSPLANT OFFICE ASSISTANTS

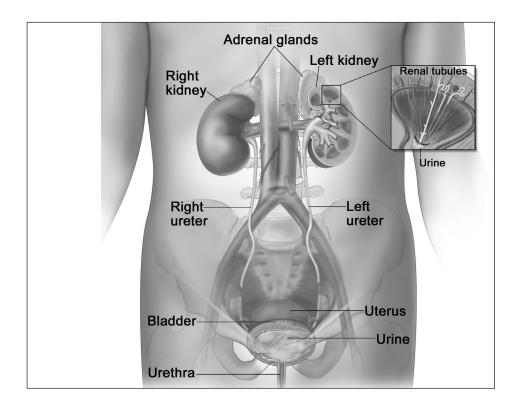
Our transplant office assistants work closely with our transplant coordinators providing administrative support such as answering phone calls, scheduling, entering test results and patient information.

:: PRE-TRANSPLANT

HOW DO KIDNEYS WORK?

KIDNEY

Your kidneys are two bean-shaped organs located on either side of your spine, just below your ribs. Each kidney is about the size of your fist.



FUNCTION OF KIDNEYS

- Filter your blood—your kidneys remove toxins and waste products, that are produced by normal body activities such as breathing, eating, and exercise.
- Produce hormones—these hormones help regulate your blood pressure and red blood cell production.
- Fluid and electrolyte management—your kidneys help remove extra fluid, or keep fluid in your body if it is needed, as well as maintain salt and acid levels.

The kidneys may stop functioning due to a problem that happens immediately (acute kidney failure) or a condition that extends over time (chronic kidney disease). Decreased kidney function could be related to a chronic disease, such as diabetes, or high blood pressure, or it could be from a problem you had from birth. Generally, kidney disease affects both kidneys, and there are often no symptoms until you have had the disease for some time.

When the kidneys have not been working correctly, the waste products and fluids they normally remove start to build up. This results in the signs and symptoms of kidney disease, which can include:

- Fluid retention—puffiness in the face, swelling in the hands and feet
- A change in urination (more or less frequent, painful, or difficult)
- Shortness of breath
- Mental confusion
- Abnormal blood or urine test results
- Tiredness or excessive fatigue

:: OPTIONS FOR TREATMENT

If kidney disease progresses to kidney failure (end-stage renal disease) there are two options for treatment: dialysis or transplant.

DIALYSIS

There are two different types of dialysis, hemodialysis, and peritoneal dialysis. Both have advantages and disadvantages. Your kidney doctor should discuss both types with you and help you decide which one would be the best option, should you need to start dialysis. That decision is best made between you and your kidney doctor, since that doctor is the one who can best evaluate how your kidney disease is making you feel.

TRANSPLANTATION

While there are many different types of transplants, we focus on only a few types in this guide that are related to kidney transplant. The kidney transplant can come from a deceased donor or from a living donor.

DECEASED DONORS VS LIVING DONORS

Kidney transplants can come from either deceased or living donors.

DECEASED DONORS

Deceased donors are people who are being kept alive on life support, and their families have decided to allow their organs to be used to help save the lives of others. There are several types of deceased donors:

Standard Criteria Donor or SCD:

This is a healthy person who experiences brain death. Several tests are done to confirm that these potential donors do not have any blood flow to their brain and no longer have brain function. Once that determination is made, the family can be approached to make the decision about whether or not to donate the person's organs.

Donation after Death or DCD kidneys:

These kidneys are from donors who have experienced catastrophic head injuries such that they will not be able to live any form of meaningful life. Along with the doctors, the family makes the decision to remove life support and allow the person to die. Once the decision has been made to withdraw support, the family is then approached to discuss organ donation. After the family has consented, the patient is brought to the operating room and life support is withdrawn. The patient must not have a pulse for a minimum of five minutes and must not have any sign of a heart rhythm on their heart monitor. The organ recovery teams do not come into the operating room until the patient is pronounced dead to prevent any concern for improper treatment of the donor in any way.

Expanded Criteria Donors or ECD kidneys:

These kidneys are from donors who are older, have died from a stroke, or have had a history of mild hypertension (high blood pressure) but who do not have any signs of kidney damage. These kidneys are then given to older recipients.

DECEASED DONOR ORGAN DISTRIBUTION

(How is it decided who gets an organ when they become available?)

Deceased donor kidneys are distributed based on a point system. Potential recipients on the transplant list are given points based on the following criteria:

- Time on the transplant list or time since date of first dialysis
- Antigen or tissue matching
- **Percentage of reactive antibody** levels (**PRA**s) (highly sensitized patients receive priority)
- Age (those less than 18 years old receive priority)
- Prior living donors also receive priority

Every time there is a deceased donor, a new list is run of potential transplant patients. Where you fall on that list will depend on how well you match with that particular donor. Additional information on how kidneys are distributed may be found in the pamphlet "Questions and Answers for Transplant Candidates about Kidney Allocation".

ADDRESSING THE ORGAN DONOR SHORTAGE

The shortage of organ donors and the ever-increasing number of people on the transplant waiting list has prompted the transplant community to consider different types of organ donors to meet the needs of our patients on the waiting list:

Donors at increased risk

Receiving any donor organ carries a risk of disease transmission despite appropriate screening and negative findings. The Public Health Service has identified donors at increased risk of transmitting infectious disease. These infections include HIV, Hepatitis C, and Hepatitis B. Donors at increased risk include:

- People who have had sex with a person known or suspected to have HIV, or Hepatitis B or C in the last 12 months.
- Men who have had sex with other men in the last 12 months and women who have had sex with one of these men.
- People who have had sex in exchange for drugs or money and anyone who has had sex with one of these individuals.
- People who have abused IV drugs or have had sex with someone who has abused IV drugs in the last 12 months.
- People who have been in jail for more than 72 hours in the last 12 months.
- People who have had multiple blood transfusions which caused dilution of their blood.
- People who have been on dialysis during the last 12 months (increased risk of Hepatitis C only).

- People whose medical and social history cannot be obtained.
- A child less than or equal to 18 months of age who was born to a mother known to be infected or at increased risk for HIV, Hepatitis B or C.
- A child who has been breastfed within the last 12 months and the mother is known to be infected or at increased risk for HIV, Hepatitis B or C.

Current testing methods can detect HIV within five to six days of exposure, Hepatitis C within three to five days of exposure, and Hepatitis B within 20–22 days of exposure.

The risk of transmission of infectious disease is extremely low:

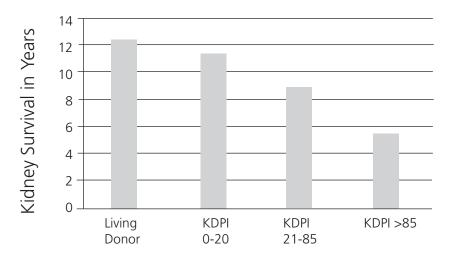
TYPE OF DONOR	RISK OF HIV TRANSMISSION	RISK OF HEPATITIS C TRANSMISSION	
IV Drug Abuser	Less than 0.1%	Less than 0.3%	
Commercial Sex Worker	Less than 0.1%	Less than 0.12%	
Multiple Blood Products	Less than 0.1%	Less than 0.1%	

In comparison, the risk of dying from a traffic accident is <u>twice more</u> likely than risk of dying from HIV or Hepatitis C infection from transplant. And, the risk of acquiring Hepatitis C on hemodialysis is 0.34% per year.

You will always be informed if the donor is considered increased risk. If you chose not to accept a donor at increased risk, your status on the transplant waiting list will not change.

DONOR WITH KIDNEY DONOR PROFILE INDEX (KDPI) SCORE GREATER THAN 85%

- KDPI is derived from Age, Height, Weight, Race, DM, HTN, Cause of Death, Serum Creatinine, HCV status and DCD status.
- KDPI is a number that represents likelihood of deceased donor renal allograft survival post-transplant.
- Lower KDPI is associated with longer function.
- Higher KDPI is associated with shorter estimated function.
- Kidney with KDPI of 20% is expected to have shorter longevity than 20% kidneys recovered during last year and longer function than 80%.
- Kidneys with a KDPI score >85% are only offered to individuals who choose this option.



LIVING DONORS

Living Donor Kidney Transplantation occurs when a person steps forward to be a donor for someone who needs a kidney transplant. That person may be a family member, a friend, a co-worker or an anonymous donor (someone that the recipient does not know). The donor chooses to give one of their own kidneys to you. The first step when receiving a transplant from a living donor is to determine if the prospective donor has a compatible blood type. The table below lists compatible blood types:

COMPATIBLE BLOOD TYPES:

Recipient's blood type	Donor's blood type
A	A or O
В	B or O
O	O
AB	A, B, AB or O

Rh factors (+, -) do NOT need to match

PAIRED KIDNEY DONATION

If a prospective donor is not a compatible blood type, paired kidney donor exchange may be an option. Pairs of incompatible donors and recipients may be entered into this program to "swap" kidneys. Many times a chain of swaps is formed.

ADVANTAGES

There are several advantages to receiving a kidney from a living donor:

- 1. **Shorter waiting time:** You do not have to wait on the list for several years before receiving your transplant. Often it can happen in as little as a few months.
- 2. **It is a scheduled surgery:** Living donor transplants are scheduled. This allows both you and the donor to plan for childcare, absences from work, and other concerns.
- 3. **Shorter time without blood flow for the kidney:** A living donor kidney usually begins to work immediately because it goes without blood flow for a shorter time than a deceased donor transplant. Consequently, there is a very low occurrence of **ATN (acute tubular necrosis)** in living donor transplants. ATN is a reversible kidney condition that results from the kidney being outside of the body without blood flow and it usually resolves on its own in a few weeks.
- 4. **Slightly decreased risk of rejection:** Because living donor transplants spend less time outside the body, they also tend to have a slightly lower risk of rejection.
- 5. **More available donors for those on the list:** Utilizing a living donor that is available for you widens the pool of deceased donors for those who have no living donors.

DONOR SURGERY

The donor is able to have the surgery performed in one of two ways:

Laparoscopic – Laparoscopic donor nephrectomy (kidney removal) uses small cameras and instruments (through five very small incisions on the abdomen) to free the kidney, which is then removed through a small incision that is a few inches below the donor's belly button. A kidney removed by this approach results in less pain and discomfort for the donor, a very short hospital stay (one to two days), and a rapid return to normal activity. Most donors are ready to return to work and normal activity within four to eight weeks after surgery. This is the most common type of donor surgery.

Open – This approach is used only in the event that the surgeon finds that the kidney is in jeopardy of being damaged using the laparoscopic approach, or if the donor's life becomes jeopardized in some way. This approach uses an incision that runs along the lower edge of the rib cage from the middle of the abdomen to the back on the side from which the kidney is to be removed. It can be a painful incision after the donor wakes up from surgery, and the donor will often have a seven- to 10-day hospital stay with an eight- to 12-week recovery period.

POTENTIAL LIVING DONORS

(What do I tell someone who wants to be a donor for me?)

Potential donors MUST call our office to initiate the donor evaluation process.

We cannot call them to start this process—they need to establish that they are doing this out of their own willingness to donate. Please give possible donors the number to our office so they can call us for the initial screening (800-525-5395). Potential donors should be between the ages of 21 and 70. They should not have a history of diabetes, uncontrolled high blood pressure, or kidney disease themselves. A dedicated donor advocate team will work with the donor to ensure that all of the donor's rights are respected.

A very thorough workup is completed for a living donor to make sure that it is safe for the donor to function with just one kidney. Donors also may need to have a psychological evaluation to be sure that they completely understand the risks associated with the surgery. **Please remember:** If we find that a potential donor is at risk either now or at any time in the future by donating a kidney, we will **NOT** be able to proceed with that person as a living donor. After the surgery, donors require a recovery period, but are able to return fully to their normal activities.

:: EVALUATION PROCESS

HOW DO I GET ON THE TRANSPLANT LIST?

You are not listed for transplant until all four steps listed below are completed. Once a decision has been made about your listing status, you will be notified by our office.

To be considered for transplantation, several steps must be completed. Please keep track of when you complete each step.

Step 1: Evaluation in transplant clinic

This four- to five-hour appointment includes transplant education, a medical history review, a physical exam, a social evaluation, blood tests for tissue typing and viral screens, and a financial/insurance coverage review. Your medical history and testing that were completed prior to your visit will be reviewed, as well as the papers that you mailed to us in advance of your visit.

Eval	luation	appointment d	ate:

Step 2: Completion of required tests/procedures

During your initial appointment, the transplant coordinator will review what tests and procedures are needed to determine if you are a candidate for a transplant. These include any additional tests requested by the transplant team and testing previously requested that has not been completed.

These tests may be done close to your home or at the Hershey Medical Center depending on your preference or insurance requirements.

These tests must be completed with the results sent to the transplant office for your transplant coordinator to view before

you can be listed for transplant. The sooner they are completed, the sooner it can be decided if you are a candidate for a kidney transplant. The reports from these studies provide us with information so we can determine if a transplant is truly the best option for you. These tests also may identify potential problems before they occur. This information will allow us to take care of you safely before, during, and after your transplant.

Completion	date of	studies	requested:	
------------	---------	---------	------------	--

CALL YOUR COORDINATOR TO NOTIFY THEM THAT YOUR STUDIES ARE COMPLETED.

Step 3: Review of test results by coordinator

All test results are reviewed by your coordinator. If there are any questions about the results, your coordinator will discuss this with one of the transplant nephrologists and let you know if additional testing is needed. If you have completed all testing and have not heard from your coordinator about being reviewed for listing, please contact our office.

Step 4: Decision for listing by selection committee

Once your coordinator has determined that all of the requested testing is completed, your case is reviewed by our selection committee. The entire transplant team participates to be sure that you are able to move ahead with transplant listing. After the decision is made, you and your kidney doctor are notified, and if you are approved, you are added to the waiting list. If there are any concerns raised during the meeting, either additional testing will be ordered and your case can be re-presented at a later meeting or you will be advised of the reason or reasons that we feel that you cannot be listed for transplant.

DATE PLACED ON THE TRANSPLANT WAITING LIST:

You will receive a letter from our office after you have been placed on the transplant waiting list with the date that you were listed. Please keep this letter in your transplant patient guide.

:: TESTING

The following is a list of basic tests that may be required for transplant listing.

• Chest X-Ray:

This is a picture of your lungs and lower respiratory tract that identifies any abnormalities. (**Must be repeated annually.**)

CT Scan of Abdomen and Pelvis:

This is a radiology study that evaluates the liver, gall bladder, and native kidneys for abnormalities.

• EKG (electrocardiogram):

The EKG shows heart function and reveals any past damage.

Echocardiogram:

This test checks the heart structures and heart valves. (**Done every one to three years depending on cardiac risk.**)

• Cardiac Stress Test:

This test shows how your heart functions under stress (similar to how it will need to work during and immediately after your transplant surgery). There are several types of stress tests. The one that is best suited for you based on your health and history will be ordered. (Cardiac studies may be required annually depending on your cardiac risk classification.)

Dental Exam:

This examination detects any infections, cavities, or gum disease, any of which may be a source of infection after transplant.

Gynecologic Tests (Females):

A gynecologic exam and pap smear (for those aged 18 or older and/or who are sexually active) are needed. (Must be repeated every one to five years depending on results.)

• Mammogram (Females):

This is a radiology study to screen for breast cancer (aged 40 or older and/or with a family history of breast cancer). (**Must be repeated annually.**)

• Colonoscopy:

This is a cancer screening test done to rule out colon cancer (men and women aged 50 or older or who have a family history of colon cancer). (**Must be repeated every five to 10 years.**)

• Labs:

These tests include blood counts, kidney function, liver function, viral testing, HIV, hepatitis, blood typing, **tissue typing**, urinalysis, 24-hour urine collection (if not on dialysis).

• Vaccines:

PPD (TB exposure), Pneumovax, Hepatitis B series, flu vaccine (there are varying schedules for each vaccine – ask your coordinator).

NAME OF TEST	DATE	LOCATION: NAME, STREET, CITY, ZIP
CT Scan		
Cardiac Stress Test		
Chest X-Ray		
Colonoscopy		
Echocardiogram		
EKG		
Gyn Exam/Pap Smear		
Mammogram		
PPD		
ABO (Blood Type)		
Vaccines		

:: WAITING FOR YOUR TRANSPLANT

WHAT DO I NEED TO DO TO BE SURE I AM READY FOR A KIDNEY TRANSPLANT WHEN I GET THE CALL?

Waiting on the list for that phone call can be the one of the most difficult times for transplants patients. **The average wait time for a deceased donor transplant in this region is approximately five to six years.** Please keep in mind that this is an average. Some people do not wait as long, while some will wait longer. We are unable to determine exactly how long you will need to wait for a transplant.

This waiting time may be very frustrating. You can find support and encouragement during this time at several places. Speak to your dialysis support group and dialysis social worker, become or stay involved in social activities such as participating at a local church, and contact your transplant coordinator or transplant social worker. Depression is not uncommon among people waiting for transplant. Please let your primary care doctors know how you are handling the stress of your situation so they can advise you about options for stress management. Let people help you when they offer. While it may be hard to say "yes" when others offer help, it may help save you a little time and energy and allow them to be involved with your care.

Several things are **extremely important** to remember, once you are on the list:

- **I. Stay Healthy:** The healthier you are going into transplant surgery, the better and more quickly you will recover and return to a more normal lifestyle. The following suggestions are **strongly recommended** to have a successful transplant:
 - See your primary care doctor on a regular basis.
 - **Quit smoking** if you don't smoke currently don't start!
 - Exercise as much as your doctor advises.
 - Keep your weight as close to normal as possible being overweight can increase the risk for infection at the time of transplant, cause poor wound healing, or even contribute to the loss of the transplant organ. If you gain too much weight and your body mass index (BMI) increases above our listing criteria, you could be taken off the transplant list.
 - Follow your diet to prevent additional health complications.
 - Keep your routine health screens up to date (i.e., gynecologic exams, prostate exams, and dental exams).
 - Return to see us on a **yearly** basis—we will schedule you for follow-up visits and request testing annually (see testing list.) If we do not have these test results, your transplant may be delayed or postponed.

**Note: If we do not have current testing or if you are in the hospital for surgery or infection we may change your listing to "inactive" or "status 7". This does not remove you from the transplant list, but you will not be considered for any organ offers until we make your status "active" again. If you are told that your listing is status 7, please be sure that you know the reason(s) and work on resolving the issues so that you may be returned to active status.

- **II. Keep Us Informed:** It is **very important** that you call us when any of the following occurs:
 - Changes of name, address, or phone numbers
 - Change of insurance carrier
 - Change of doctor or dialysis unit
 - Change of type of dialysis
 - Any hospital admissions
 - Any infections that are treated with antibiotics
 - Any surgical procedures

We will send a patient information update every six months to obtain any new or changed information you may have forgotten to tell us. Please review this form, make any changes or corrections, and mail it back to us **as soon as possible**. Telling us of any changes as soon as they occur will help us be able to contact you quickly when a donor organ becomes available for you.

- III. Be Available: It is extremely important that we are able to contact you when a kidney becomes available. We usually have up to only one hour to reach you when we receive a kidney offer for you. Please make sure we have any and all phone numbers where you can be reached.
- **IV. Send Blood:** While you are on the transplant waiting list, you must send us one tube of your blood every two or four weeks. This blood is used to do your **antibody** screen **(PRA)** as well as place you on test trays with blood from potential donor organs. Without current blood, your transplant may be postponed or delayed. A prescription to have this blood work done will be enclosed with the letter you receive from our office when you are placed on the transplant waiting list.

Be sure your dialysis unit has a copy of this prescription.

:: TRANSPLANT PROCEDURE & RECOVERY

RECEIVING THE CALL AND GETTING A TRANSPLANT – HAVING A PLAN IN PLACE

Be prepared! You never know when you will get a call that an organ is available for you. Be sure you have worked out details such as:

- Transportation: Who will drive you to the hospital?
- Who will watch or care for your children/parents/pets?
- Who will watch your house /get your mail while you are in the hospital?
- When you are called with an available organ offer, the coordinator will review several things:
 - A brief medical/physical review: This is done to ensure that it is safe to proceed with the transplant.
 - Review instructions: The coordinator will give you specific instructions about coming to the hospital.
 - The coordinator will let you know if you are allowed to eat or drink anything after you have received a call about an available organ. You must have an empty stomach to have surgery.

** Bring all current medications and insurance cards with you to the hospital **

To avoid wasting available organs, there are always several patients being cross matched for each organ. Cross matching is the final step prior to getting a transplant – your cells and the potential donor cells are placed together to see if your body has a reaction to the donor cells. The cross match must be compatible (no reaction occurs between your cells and the donor's cells) before you can receive the transplant. This procedure takes anywhere from five to eight hours to complete.

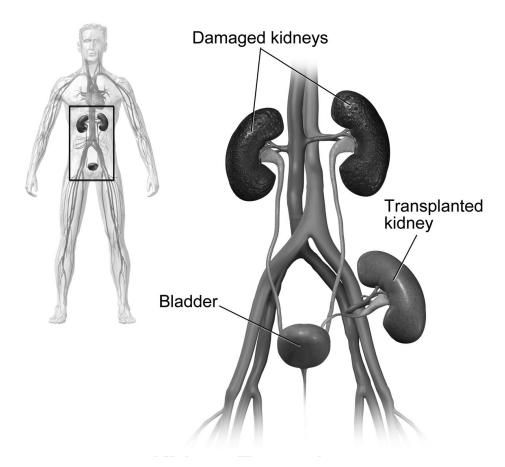
There may be times when you will be asked to come to the hospital, but will not receive a transplant as the cross match is incompatible (a reaction between the donor cells and your cells occurs) or there is someone ahead of you who is a better match for the donor kidney. While this process is frustrating, it is necessary to be sure that every organ has at least one patient who will be ready to receive the transplant.

ARRIVING AT THE HOSPITAL

When you arrive at the hospital, report directly to the admissions office. After you are in your hospital room, there will be a great deal of activity. You will have blood drawn, a complete physical, an EKG, a chest x-ray, and an IV placed to prepare you to go to the operating room.

TO THE OPERATING ROOM

- Your transplant operation will take between two and four hours.
- Your transplanted kidney will be placed in your abdomen on the lower front side. This will allow us easy access to your newly transplanted kidney for ultrasound or biopsy if necessary (see picture).
- Your incision will be between six to eight inches long.
- Your transplanted kidney is connected to your bladder, as well as to the main artery and veins that extend into your leg.
- In most cases, your natural (native) kidneys do not need to be removed. If a native nephrectomy (kidney removal) is required, your transplant coordinator and surgeon will discuss the procedure with you.



IMMEDIATELY AFTER SURGERY

You will wake up in the post-anesthesia recovery unit (PACU), where you will stay for approximately two to three hours. During this time, your heart rate, blood pressure, and urinary output will be monitored closely.

You will go to the surgical ICU post-op. You will have a special IV inserted near your collarbone (it will be inserted while you are asleep in the operating room). This catheter allows us to monitor your fluid levels and give you fluids and medications as needed.

You will have a Foley catheter inserted into your bladder. This will allow us to watch your urine output closely.

Each patient's hospital stay varies based on that individual's needs. Most patients are in the hospital for approximately five to seven days after transplant. During this time, the transplant coordinators will educate you and your family about how to care for yourself and the newly transplanted organ or organs.

:: POST-TRANSPLANT CARE

THIS PART OF THE GUIDE REVIEWS THE CARE AFTER TRANSPLANT

Although transplant may seem a long way off at this time, you need to read about your care after transplant. Deciding if you are able to comply with this care after transplant is an important part of your decision process in determining if transplant is the right treatment of choice for you

:: PLEASE NOTE: WHEN YOU DECIDE THAT TRANSPLANT IS THE BEST TREATMENT FOR YOU, YOU ARE AGREEING TO:

- TAKE THE MEDICATIONS AS PRESCRIBED
- COME TO CLINIC AS SCHEDULED
- GET YOUR BLOOD WORK AS REQUESTED
- COME TO THE HOSPITAL FOR BIOPSIES AND PROCEDURES AS NEEDED AFTER TRANSPLANT
- RETURN OUR CALLS IN A TIMELY MANNER

:: LIFE AFTER TRANSPLANT - STAYING HEALTHY

After receiving a transplant, there are several things you must do to keep that transplant working. Please read these carefully. If you do not think you are able to comply with these requirements, transplantation may not be a good option for you.

- 1. **Take Your Medications:** You will have to take these medications every day at the same time each day because they will not be able to protect your transplant otherwise. They prevent your body from rejecting (destroying) your transplanted organ. We have included information in the following pages on several medications you will take.
- **2. Get Blood Drawn:** Initially after transplant, you will need to have blood drawn frequently (twice a week). This allows us to keep a very close watch on the function of your transplanted organ. The blood tests allow us to identify changes before they become a big problem and affect your transplanted organ. The more time that passes from your transplant date, the less frequently you will need to get blood drawn.
- **3. Return to Clinic:** Once you are discharged from the hospital, you will need to return to our post-transplant clinic for follow-up and care. For the first six weeks post-transplant you will be scheduled weekly. Your clinic visits will become less frequent unless you are having complications. Please refer to the schedule on page 99 of this guide.
- **4. Measure your blood pressure, temperature, weight, and glucose daily:** This information helps you monitor for signs and symptoms of infection and rejection. You will be given levels to report immediately to us if they are too high or too low. Otherwise, you will need to keep a log of your reading, and bring the log to the clinic when you have appointments.

Receiving a transplant is a very precious gift. It is your responsibility to take excellent care of your transplanted organ. We are here to help you do that in every way we can. If a patient loses a transplanted organ due to poor care, that patient may not be considered for another transplant.

:: YOUR CARE AT HOME

Provided there are no complications, you will be allowed to go home four to seven days after surgery. Before you leave the hospital, you must have a thorough understanding of what you need to do to take care of yourself at home. The nurses and transplant coordinator will instruct you on how to care for your new kidney and how to take your medicines. A dietician will give you diet instructions, and a social worker will visit you as needed.

POSTOPERATIVE GUIDELINES

When you leave the hospital, you will have the responsibility for monitoring your health and avoiding infection. Follow the guidelines below in the immediate postoperative stage of your transplant:

- **No** heavy lifting, no lifting of anything over 10 pounds, and no aerobic activity for the first 12 weeks.
- No driving for two weeks from the transplant date.
- **No** tub baths for four weeks; showers are permissible.
- **Do not** go near anyone who has a cold, the flu, or who does not feel well until that person is free of symptoms.

:: STENTS

A plastic catheter is placed in your ureter during the transplant surgery. The purpose of the stent is to make sure the ureter remains open, allowing urine to flow from the kidney to the bladder during the healing process. The stent should be removed around six weeks post transplant.

You will be given an appointment with urology to have the stent removed on an outpatient basis at the Hershey Outpatient Surgery Center (HOSC), 717-520-8200. This building is located one block from the Hershey Medical Center.

Call 717-520-8200 the day before your appointment to get the exact time to report for your stent removal.

:: GENERAL GUIDELINES

The following guidelines should always be observed and should become a natural part of your lifestyle:

• **Avoid** mold. Dust generated from construction sites may contain fungi. If you breathe in a large amount of fungi, it is possible that you could get a serious infection. In general, avoid construction sites, do not undertake renovation work in your home without consulting the transplant team, and avoid barns and sheds due to dust that may contain fungi. If you must be exposed to any of these sites, you must wear a mask that is sensitive enough to protect against tuberculosis (please ask our staff for assistance if you need a mask).

- **Do not** handle pet waste. It is advisable not to have birds or turtles as pets, as their waste contains a high level of germs. If you have a pet, make sure a veterinarian carefully screens it.
- Shower or bathe daily. **Wash your hands with antibacterial soap** before meals and after using the bathroom.
- Wash all fruits and vegetables thoroughly as molds and fungi may be present on their skins.
- Minor injuries, such as cuts and scrapes, should be washed immediately with soap and water. If they do not heal well, call your physician.
- Report any suspicious lumps or growths in armpits, groin, or elsewhere on your body to your physician.
- Always tell physicians or dentists about your transplant before undergoing any procedures (e.g., minor surgical procedures), including routine teeth cleaning.
- A healthy diet, exercise, and plenty of rest will help you avoid illness.
- **DO NOT SMOKE!** Smoking places you at even greater risk of developing lung infections.

:: VACCINES

Wait six months after your transplant date before receiving any immunizations.

You must <u>never receive a live or weakened virus</u> vaccine after the transplant.

Examples of these vaccines are small pox, yellow fever, measles, mumps, rubella, and the oral polio vaccine. This type of vaccination is, in essence, giving you a small dose of the actual virus which, in you, could result in a serious complication.

Immunizations that are acceptable are dead or inactivated virus vaccines. Examples of these are flu, diphtheria-tetanus (as a booster only), the mantoux (TB) test, and the pneumococcal vaccine. A tetanus booster is good for 10 years. Transplant recipients may also receive the Hepatitis B vaccine series. That series is a recombinant virus, which is essentially a synthetic virus and is safe for you to receive. Whether or not you opt to receive these vaccines needs to be determined on an individual basis according to your preferences and your risk factors. For example, if you have routinely received a "flu shot" every year, then you probably will want to continue doing so after you pass the six-month point of your transplant. If you have never received the "flu shot" in the past and remained healthy, it is probably not necessary to get the vaccine now. If you are a health care worker, you will need to get the Hepatitis B vaccine. Follow your primary care physician's advice and if you have any questions, call the transplant office.

Transplant recipients who have young children or who are around young children on a regular basis should be aware of the vaccines that the children are receiving. If possible, children who have immediate contact with the transplant recipient should have the inactivated poliovirus vaccine (IPV) rather than the oral poliovirus vaccine (OPV). If you are exposed to any childhood diseases that you had as a child or if you received a vaccine for that disease prior to transplant, you most likely will be immune to that disease. Just monitor for signs and symptoms of the disease; as we do not give any prophylaxis medication routinely for exposure. If you did not have a certain disease or were not vaccinated for it, please call the transplant office.

:: MEDICAL IDENTIFICATION

It is recommended that you wear a medical alert bracelet or necklace that identifies you as a transplant patient. In case of an accident, it is helpful and important for health care personnel to know that you have had a transplant. A pamphlet is included in your information packet to order this identification.

:: DAILY MEDICAL TASKS

You must take your weight on a daily basis and your blood pressure and temperature twice a day and record them on the chart at the end of this guide.

- Take your temperature in the morning and in the evening. Call the transplant team if your temperature rises above 100° F. Do not take medication to lower your temperature unless instructed to do so by your transplant physician.
- Check your weight every morning before breakfast, after you have gone to the bathroom. An increase in weight may mean that you are retaining fluids, or that you may need to control your calories
- Take your blood pressure every morning and evening. If the top number is consistently greater than 180 or if the bottom number is consistently greater than 90 report it to the transplant team.

:: OTHER POST-TRANSPLANT CARE

You will want to keep up to date with all your routine health maintenance, such as yearly flu vaccines, and pneumonia vaccines as recommended. You also should be sure to keep up to date with regular cancer screenings that are appropriate for your age, including pap smears, mammograms, prostate exams, and colonoscopies.

:: DAILY HYGIENE

DENTAL CARE

Dental care is very important after your transplant. That care includes brushing your teeth after every meal, daily flossing, and gum stimulation. Use Mycelex® or Nystatin® as prescribed. Mycelex and Nystatin prevent yeast infections in the mouth.

Regular dental check-ups should be scheduled every six months or more frequently if recommended by your dentist. You do not need preventative antibiotics for a routine dental visit because of your transplant. If you have been prescribed preventative antibiotics due to another condition, you will still need to take that medication. Do not go to the dentist within the first six months after transplant if at all possible. If you have an abscess or other dental issues within that time frame, however, please have it evaluated by a dentist.

In addition to daily dental care also check in and around your mouth for bleeding gums, lumps, blisters, cold sores, and other signs of infection. Report any unusual findings to the transplant coordinator, such as overgrowth of the gums (hyperplasia), as this is a side effect of the medication.

HAIR CARE

Hair growth and condition may be affected by the medications you take post transplant. For example, Imuran and Prograf can cause hair loss.

If you experience increased body hair growth, which may be of particular concern for women, cream removers (Surgicream) may be used with caution. First, test your skin for irritation by applying the cream to a small area. Be especially careful around the lips and eyes. Permanent hair removal with electrolysis may be done after your prednisone dose is reduced to 10 mg per day or less.

SKIN CARE

The medications you take may increase your susceptibility to skin problems, such as sun sensitivity, dry skin, and acne.

Your increased sensitivity to the sun means you will burn more easily, even if you have never experienced this before. Always wear a sunscreen with SPF 15 or higher on all exposed skin before going outside. Make it a habit to wear sunscreen every day, and always wear a hat that shades your face. The rays that can cause skin damage and skin cancer are present even on cloudy days. Avoid exposure between peak hours of 10 a.m. and 3 p.m. if at all possible.

You also may experience bouts of dry skin. Use a mild soap without perfume or deodorants. To soften your skin, you may use Alpha Keri® oil in bath water and Alpha Keri or Lubriderm® skin lotion. You may use any over-the-counter lotion that you prefer.

Some patients may develop acne. To control acne, wash your face and other affected areas at least three times a day with soap, and always use a fresh, clean washcloth. Do not rub or scrub, as this will only increase irritation. Also, do not touch the affected areas. If these measures do not work satisfactorily, try using a lotion containing 10% benzoyl peroxide. If the acne becomes red and infected, consult your physician.

MINOR FIRST AID

To treat cuts, scratches and other minor injuries, wash the area thoroughly with soap and water, apply a mild antiseptic (i.e., Neosporin® or Bacitracin) on a clean, dry bandage, and change the bandage frequently. Check the area daily for infection. If the area becomes swollen and filled with pus, or if you develop a fever, call your physician.

If the cut is large enough to require stitches, remember that you will need antibiotics. Alert the physician who is caring for your injury about your transplant.

CONSTIPATION

Constipation may become a problem due to your surgery and/or pain medications. To prevent or treat constipation, drink plenty of water unless you are on a fluid-restricted diet. Increase the bulk in your diet by eating plenty of fresh fruit and vegetables. Remaining physically active is also an effective way to avoid constipation. You may use most over-the-counter products for constipation.

You also should notify your doctor of stool changes, such as persistent diarrhea or dark, tar-like stools.

:: EXERCISE

To promote general health and prevent muscle deterioration, you should begin an exercise program within days after surgery.

In general, on the **first day after surgery**, you should begin walking in your room and in the hallway. You should increase the time you walk steadily as your condition improves. By the time you leave the hospital, you should be walking up to 30 minutes a day. Gradually increase your time as tolerated.

After six weeks, you may increase your activities and include such things as an exercise bike.

For the **first three months after your surgery**, avoid pulling or straining your abdominal muscles – no heavy lifting or sit-ups. Avoid all contact sports, as well as any activities that are jarring, such as horseback riding, snowmobiling, etc.

You will be able to participate in most activities after three months. Please discuss specific activities with your transplant physician beforehand.

Returning to work will depend on the type of job you have. You may be able to return to work as quickly as four weeks after surgery if you have a desk job and 12 weeks after surgery if your job requires strenuous activity or heavy lifting.

A good exercise program should be part of your daily routine. Only regular exercise will help you build muscle mass and keep your weight at the desired level. **You should exercise at least three nonconsecutive days per week, i.e. Monday, Wednesday, and Friday.** If exercise is difficult to fit into your schedule, a simple activity such as daily walking is sufficient.

Return to normal activity—one of the major goals after transplant is for you to return to a normal lifestyle and activities as soon as possible. This will be a gradual progression, but you will be able to return to work, exercise, and perform many other activities shortly after receiving your transplant.

:: SEXUAL ACTIVITY AND BIRTH CONTROL

It is a good idea to wait four to six weeks after surgery before you have sexual relations. You probably will find that once you are feeling well that you will be more interested in relations than when you were sick. Also, do not worry about hurting the new transplanted organ.

Women should visit their gynecologist soon after leaving the hospital and be placed on the most appropriate regimen of birth control. Menstrual periods usually begin two to 12 months after surgery; however, it is possible to become pregnant before your period starts.

Women aged 40 and younger need to have a pap smear and a breast examination once a year.

While all types of birth control have risks, the best types for transplant patients are birth control pills, condoms, and diaphragms. The intrauterine device [IUD] should not be used.

Keep in mind that the immunosuppressive drugs you take, place you at a greater risk for infection from sexually transmitted diseases, such as AIDS, gonorrhea, syphilis, herpes, etc.

Men should be better able to have an erection after transplant. If you have problems with impotence, it may be because of your blood pressure medication or due to diabetes. If this is the case, your primary care physician may prescribe a different blood pressure medication. Never stop taking blood pressure medication, as high blood pressure places you at risk for stroke.

PREGNANCY AFTER TRANSPLANT

If your kidney is functioning well, and if you do not have problems with high blood pressure, you may try to conceive one year after transplant surgery. You should discuss these plans with your transplant team and nephrologist before trying to become pregnant. Several immunosuppression medications may cause birth defects. We strongly recommend that you use birth control to prevent pregnancy during this time.

:: YOUR DIET

After your transplant, a dietitian will review in detail with you the types of dietary changes you will have to make in order to stay as healthy as possible. In addition, several restrictions will be necessary due to the anti-rejection medications.

The main goals of your diet should be to:

Promote and maintain good nutrition, maintain ideal body weight, control high blood pressure, control blood lipids (cholesterol and triglycerides), and control blood sugar levels.

You should eat only moderate amounts of carbohydrates, sweets, and fats. Use skim milk, limit desserts, and eat fresh fruits and vegetables. Reduce your use of margarine, butter, oil, bread, potatoes, and pasta. Sensible, healthy eating should be your main goal. The dietitian is an important part of the transplant team, and a consultation may be arranged if you are having difficulty with your diet.

You may need to continue to restrict your potassium and phosphorus intake. We have included a guide for food high and low in potassium to assist you in making better food choices.

You should also eat plenty of calcium rich foods. Calcium is an important mineral used to keep your bones and muscles healthy. We have also included a list of high calcium foods.

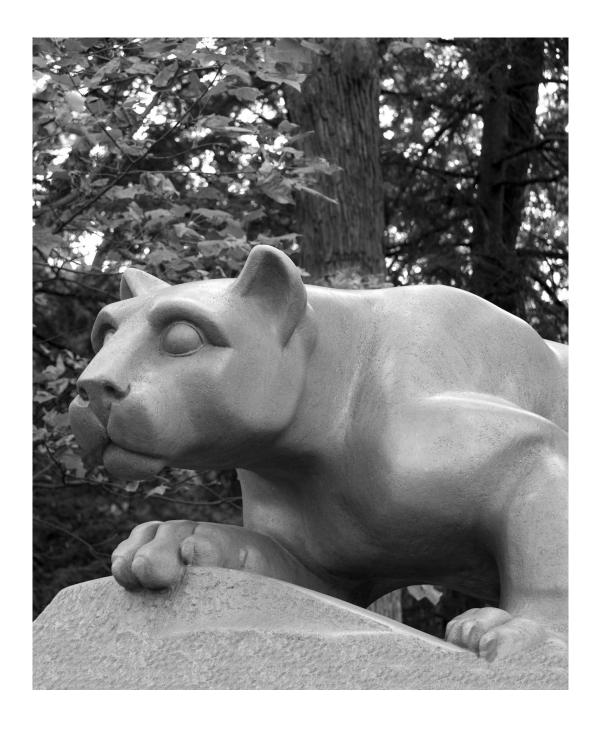
A healthy diet is important for preventing many diseases, not just for controlling diabetes, so follow your transplant team's instructions carefully.

:: HYDRATION

It is important to keep well hydrated. Drinking the appropriate amounts of water each day will keep your creatinine low and help to increase the life of the transplanted kidney. While in the past you may have been on fluid restrictions, you now have a functioning kidney and no longer need to restrict your fluid intake. It is very important to drink eight to 10 cups of liquid each day to keep hydrated. A good indication of hydration is pale, yellow urine. Until you become accustomed to drinking this amount of fluid, it may be helpful to use the same fluid container so you can accurately measure your fluid intake.

Not only is it important to keep your body well-hydrated, it is important to drink the proper beverages. Please avoid excessive use of caffeine. Caffeine is a natural diuretic and can actually make you lose more fluids. Try to drink more **water!** It can be carbonated water, spring water, or flavored water, but at least half of your beverage intake should be water. Milk, milk substitutes and 100% fruit juice are also healthy options. Be aware that **grapefruit juice and pomegranate juice should be avoided** as those beverages can increase the immunosuppression drug levels in your blood. Also, **avoid alcoholic beverages** as you are on potent medications that can be affected by alcohol intake.

There are times when you will need to drink even more than usual. Exercising; dry, cold weather; hot, humid weather; and being ill or having diarrhea can all increase your body's fluid needs.



:: POTASSIUM IN FOOD

HIGH POTASSIUM

Fruits

Apricot, Raw (2 medium)

Dried (5 halves) Avocado (¼ whole)

Banana (½ whole)

Cantaloupe

Dates (5 whole)

Dried Fruits

Figs, Dried

Grapefruit Juice

Honeydew

Kiwi (1 medium)

Mango (1 medium)

Nectarine (1 medium)

Orange (1 medium)

Orange Juice

Papaya (½ whole)

Pomegranate (1 whole)

Pomegranate Juice

Prunes

Prune Juice

Raisins

Vegetables

Artichoke

Bamboo Shoots

Beans, Baked

Beans, Dried

Beans, Refried

Beets, Fresh then Boiled

Black Beans

Broccoli, Cooked

Brussels Sprouts

Butternut Squash

Cabbage, Chinese

Carrots, Raw

Greens, Except Kale

Kohlrabi

Lentils

Legumes

Mushrooms, Canned

Parsnips

Peas, Dried

Potatoes, White and Sweet

Pumpkin

Rutabagas

Spinach,Cooked

Squash, Acorn

Squash, Hubbard

Tomatoes/Tomato Products

Vegetable Juices

Other

Bran/Bran Products

Chocolate (1.5-2 ounces)

Granola

Milk, All Types (1 cup)

Molasses (1 tablespoon)

Nutritional Supplements:

Use only under the

direction of your doctor

or dietitian.

Nuts and Seeds (1 ounce)

Peanut Butter (2 tablespoons)

Salt Substitutes/Lite Salt

Salt-free Broth

Yogurt

The following table lists foods which are low in potassium. A portion is ½ cup unless otherwise noted. Eating more than 1 portion can transform a lower potassium food into a higher potassium food.

LOW POTASSIUM

Fruits	Vegetables	Other
Apple (1 medium)	Alfalfa Sprouts	Bread and Bread Products
Apple Juice	Asparagus (6 spears)	(not whole grains)
Applesauce	Beans, Green or Wax	Cake, Angel, Yellow
Apricots, Canned in Juice	Cabbage, Green and Red	Coffee (limit to 8 ounces)
Blackberries	Carrots, Cooked	Cookies w/o Nuts or Chocolate
Blueberries	Cauliflower	Noodles
Cherries	Celery (1 stalk)	Pasta
Cranberries	Corn, Fresh (½ ear)	Pies without chocolate or
Fruit Cocktail	Frozen (½ cup)	high potassium fruit
Grapes	Cucumber	Rice
Grape Juice	Eggplant	Tea (limit to 16 ounces)
Grapefruit (1/2 whole)	Green Peppers	
Mandarin Oranges	Kale	
Peaches, Fresh (1 small)	Lettuce	
Canned (½ cup)	Mushrooms, Fresh	
Pears, Fresh (1 small)	Okra	
Canned (½ cup)	Onions	
Pineapple	Parsley	
Pineapple Juice	Peas	
Plums (1 whole)	Radish	
Raspberries	Rhubarb	
Strawberries	Squash, Yellow	
Tangerine (1 whole)	Squash, Zucchini	
Watermelon (limit to 1 cup)	Vegetables, Mixed	
	Water Chestnuts, Canned	

Watercress

:: POTASSIUM IN FOOD (Continued)

LEACHING

The process of leaching will help remove potassium from several high-potassium vegetables. It is important to remember that leaching will not remove all of the potassium from the vegetable. If you are instructed to limit your potassium, you must still limit the amount of leached high-potassium vegetables you eat. Ask your dietitian about the amount of leached vegetables that you can safely have in your diet.

How to leach vegetables:

For potatoes, sweet potatoes, carrots, beets, and rutabagas:

- 1. Peel vegetables and slice vegetables 1/8 inch thick.
- 2. Rinse in warm water for several seconds.
- 3. Soak for a minimum of two hours in warm water. Use 10 times the amount of water to the amount of vegetables. If soaking longer, change the water every four hours.
- 4. Rinse vegetables under warm water again for several seconds.
- 5. Cook vegetables with five times the amount of water to the amount of vegetables.

For squash, mushrooms, cauliflower, and frozen greens:

- 1. Allow frozen vegetables to thaw to room temperature and drain.
- 2. Rinse fresh or frozen vegetables in warm water for several seconds.
- 3. Soak for a minimum of two hours in warm water. Use 10 times the amount of water to the amount of vegetables. If soaking longer, change the water every four hours.
- 4. Rinse under warm water again for several seconds.
- 5. Cook the usual way, but with five times the amount of water to the amount of vegetables.

:: FOODS HIGH IN CALCIUM

HOW MUCH DO YOU NEED?

- Healthy adults between the ages of 19 and 50 should aim for 1,000 mg calcium daily.
- Older adults (especially women after menopause) need more calcium because bones lose calcium as we age. After age 50, healthy adults should get 1,200 mg calcium daily.

CALCIUM PER SERVING

30	0	ma

Cheese, Low-fat natural

(1.5 ounces)

i.e. Cheddar, Mozzarella,

and Swiss

Cheese, Processed (2 ounces)

i.e. American

Macaroni and Cheese (1 cup)

Milk, Fat-free (1 cup)

Low-fat (1 cup)

Chocolate (1 cup)

Buttermilk (1 cup)

Orange Juice, Calcium-fortified

(1 cup)

Pudding, Ready-to-eat (1 cup)

Yogurt, Fat-free (1 cup)

Low-fat (1 cup)

200 mg

Cereal, Calcium-fortified (1 cup) Cheese, feta (1 ounce)

Salmon, Canned w/ Soft Bones

(3 ounces)

Sardines w/ Soft Bones (3 ounces)

150 mg

Bread, Calcium-fortified (1 slice) Cheese, Cottage (1 cup)

Tofu, Made w/ calcium (1 cup)

Muffin, English (1 muffin) Soybeans (1/2 cup)

100 mg

Almonds (1/4 cup)

Greens, Cooked (1/2 cup)

Beet Greens, Turnip Greens

Kale, Collards, and Spinach

Ice Cream/Frozen Yogurt (1/2 cup)

50 mg

Beans, Canned White (1/2 cup)

Broccoli, Cooked (1/2 cup)

Potato, Baked Sweet (1 medium)

Orange (1 medium)

:: REJECTION AND INFECTION POST TRANSPLANT

REJECTION

The biggest problem facing all transplant patients is the possibility of rejection. Rejection is the body's attempt to get rid of a foreign substance, in this case your new kidney. There are several kinds of rejection, and they can be a common and life-long issue.

- **Hyperacute** This severe form of rejection happens within minutes or hours after transplant surgery. The new kidney must then be removed. This form of rejection is very rare.
- **Acute** This is the most common type of rejection, and while it can happen any time, it occurs more frequently during the first six months after transplant.
- *Chronic* This type of rejection can happen at any time, including years after the transplant.

Most rejections that happen shortly after surgery can be treated medically. If you have rejection symptoms, call the transplant office right away. The faster you receive treatment, the more successful the treatment is likely to be.

Several signs of rejection are:

- Fever above 100.4° F
- Swelling or tenderness over the new kidney
- Flu-like symptoms
- Elevated blood sugar levels
- Fatigue/weakness

It also is important to remember that you may experience rejection without any obvious signs or symptoms. **That is why it is so important to have your blood tested on a regular basis.** If we feel that you are experiencing rejection, you may need to have your kidney biopsied. This can be done on an outpatient basis. If it is determined that you are in rejection, you may need to have IV medication to reverse the rejection. Depending on the severity of the rejection, you may need to be admitted to the hospital.

The highest risk of rejection is during the first six months after the transplant surgery. It takes time to get your immunosuppression medication at the right level. Your weekly blood work will give us information on the level of medication in your bloodstream and the activity of your immune system to help us maintain appropriate levels of immunosuppression. Until you have completely recovered from the surgery, you may have frequent medication changes the first few months as your system becomes acclimated to the new organ and the new medication. Taking your medication in the proper doses at the proper times is the best defense against rejection. Even with doing this, you may still have rejection episodes, but without taking your medication properly you **will** have a rejection episode.

INFECTION

The medications you take to prevent rejection also place you at greater risk for infection, as they suppress your immune system. Common areas for infection are your lungs, bladder, or the incision site. You will be on medication for the first six months to help decrease your risk of getting an infection. Be sure to tell your family and friends that anyone who is ill or not feeling well should not come to visit. As a reminder, here are the signs and symptoms of infection that you should watch for and report to your transplant team:

- Fever above 100.4° F
- Cold or flu-like symptoms
- Sore throat

- Skin rash or sores
- Sores in or around the mouth
- A cough that lasts longer than three days
- Shortness of breath with the cough, or sputum that is green or yellow
- Pain or burning with urination
- Blood or blood clots in the urine or the urine becomes cloudy or foul-smelling
- Redness, swelling, or secretion of pus or fluids at the incision cite

There are also "opportunistic infections" that can occur. These are very common viral or bacterial infections, and people are routinely exposed to them. These infections can cause problems for you once your immune system has become compromised by the immunosuppression medication. You will be on medication to protect you from several of these infections, but at times this protection may not be sufficient to prevent you from getting the actual infection. Some of these infections are the cytomegalovirus (CMV), BK virus, pneumocystis pneumonia, and yeast infections.

You will be tested on a regular basis for these infections and may need to have treatment. Treatment may consist of intravenous medication given on an inpatient or outpatient basis. Several types of infections need special medication to help clear them and the treatment could require numerous visits to the clinic and the outpatient infusion area.

:: TREATMENT FOR REJECTION / INFECTION

As mentioned previously, you may need to have a biopsy or be admitted for treatment of rejection or infection. Your coordinator will check your blood work, and if there are any abnormalities, the coordinator will review your results with one of our physicians. This may result in a call to you requesting that you come to the hospital the next day for a biopsy of your transplanted organ. While blood work helps us monitor the organ function, a biopsy is the most definitive way to determine exactly what is happening with the organ.

During a biopsy, you first have an ultrasound exam to determine the precise location of your transplanted organ. You then receive a local anesthetic in the area over the organ. Once the area is numb, a biopsy gun is used to shoot a hollow needle into the organ and obtain a tiny piece of tissue from the transplanted organ. This tissue is checked at the bedside by a pathology technician to ensure that it is an adequate specimen. At times, they may need to obtain two or three specimens to ensure a good analysis of the organ. Once they are sure they have a good specimen, they send it to the pathology lab to be analyzed for signs of rejection. You often are requested to stay at the hospital or in the area until we have final results from the pathologist. **Plan to be at the hospital for a full day.** Depending on the pathology results, it may be necessary for you to be admitted for treatment. It is important that a rejection episode is treated as soon as possible to minimize damage to the transplanted organ.

Be prepared to be admitted for treatment of rejection or infection, as many of the treatments involve medication that is administered by intravenous therapy. While these complications can occur at any time, the first three months after transplant is the period of highest risk for recurrent biopsies and admissions. Depending on the type of rejection that is diagnosed, you may need to have multiple treatments of plasmapheresis in conjunction with IV medication. Please understand that our goal is to keep you and your transplanted organ as healthy as possible.

:: COMPLICATIONS

PARTIAL GRAFT FUNCTION

Occasionally, a kidney transplant will not function at 100% capacity, and patients may require continued dialysis after the transplant. This may be temporary or permanent.

DIABETES

Several of the immunosuppression medications you take may cause diabetes. Diabetes is an increased level of glucose (sugar) in your blood. Signs of diabetes may include extreme thirst, frequent urination, blurred vision, and confusion. Call your transplant coordinator if you notice any of these signs. Your blood glucose levels will be monitored to help detect any problems early.

If you should develop diabetes, you will be instructed on how to deal with this problem. In some cases, diet, weight loss, and exercise can control it. Some patients require oral hypoglycemic medications or insulin to help control their diabetes.

HIGH BLOOD PRESSURE

High blood pressure also is a common side effect of several of the medications you take. You may need an additional medication to control your blood pressure. Following your vital signs schedule carefully will help detect high blood pressure and allow early treatment to avoid complications. Call your transplant coordinator if your blood pressure consistently reads higher than 140/90. The goal for blood pressure is in the 120 over 70-80 range.

:: MEDICATIONS

IMMUNOSUPPRESSIVE (ANTI-REJECTION) MEDICATIONS

After transplant, our body's normal response to something that it sees as foreign or "not me," such as a new organ, is for the immune system to try to attack it. This is known as rejection. In order for that new organ to not be rejected, we must give you medicines to decrease your immune system response and make it not recognize that new organ as foreign. Unfortunately, your body will **never** get used to having the new organ, so you will need to stay on these medicines **for the rest of your life**, although you most likely will be able to decrease the doses over time.

NOT TAKING THESE MEDICINES IS A LEADING CAUSE OF LOSING A TRANSPLANTED ORGAN

While hospitalized, you will be instructed by the pharmacist, your nurses, and the transplant coordinator as to what medicines to take, what each medicine does, and common side effects of each. All medications for the first month will be ordered for you and sent to the hospital. These medications will be sent home with you when you leave the hospital. You must become familiar with the names, dosages, and recording of all your medications. The number and dosage of the medicines will be lowered as you improve. Never stop taking any medication without talking to the transplant team.

Side Effects: These medications can have potential side effects, but the side effects that patients experience vary greatly. These can be anywhere from a few side effects for a short period of time, to many side effects for the life of your transplant.

Several drugs can cause side effects in patients taking anti-rejection medications. You should contact your transplant coordinator before taking any new, routine medicines to make sure that there are no interactions with your current medications or potentially harmful side effects.

:: RULES FOR MEDICATIONS

- Take the prescribed doses each day on time.
- If you forget to take your medicine at the appointed time and remember it later, take it as soon as you remember. Then take the next dose at the appointed time.
- If you cannot remember if you took the medicine, do not take an extra dose, but do take the next dose at the appointed time. **DO NOT take twice as much medicine.**
- Keep medicines in tightly closed bottles and out of the reach of children.
- Store medicines in a cabinet at room temperature and outside of the bathroom to avoid moisture.
- **NEVER** run out of medicine. Refill your prescriptions well ahead of time.
- Plan ahead for vacations and holidays. Take extra medication with you when traveling. Do not put medicines in your luggage because the temperatures vary, or your luggage could be lost.

Other Medications

- Please check with our office if another doctor starts you on a new medication to be sure that it will not interfere with any of your transplant medications.
- For headache or pain you may take acetaminophen (Tylenol®) Regular or Extra-Strength.
- **DO NOT TAKE** Ibuprofen (Advil®, Motrin®), Naproxen (Aleve®), or aspirin (Excedrin®).
- **Avoid** herbal supplements.
- Please check with our office before starting over-the-counter (OTC) medications, supplements, herbal supplements, or vitamins.

- If you are having trouble with side effects, contact our office. We often can change your medication schedule or even the medication you are taking to help ease some of the side effects.
- **Never stop** or change your medications unless directed by your transplant center.

At the time of surgery, you will receive one of the following:

• Thymoglobulin® [Anti-thymocyte Globulin (Rabbit)]

- Given intravenously in the operating room and then for three to five days thereafter.
- Infusion takes at least six hours.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), nausea, vomiting, low blood pressure, allergic reactions, low white blood cell count, decreased platelet count, and higher risk of infection and cancer.

• Campath® (Alemtuzemab)

- Given intravenously as a one-time dose in the operating room.
- Infusion takes at least two hours.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), shortness of breath, fluid in your lungs, allergic reactions, low blood pressure, low white blood cell count, decreased platelet count, anemia, and higher risk of infection and cancer.

• Simulect® (Basiliximab)

- Given intravenously in the operating room, then repeated four days after surgery.
- Infusion takes at least 20 minutes.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), shortness of breath, allergic reactions, and higher risk of infection and cancer.

You may also be given the following medication at the time of surgery. This medication will continue as a life-long medication.

• Belatacept® (Nulojix)

- Given intravenously in the operating room, then repeated on day five, 10, 14, and then every two weeks.
- Infusion takes at least 30 minutes.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), shortness of breath, allergic reactions, high blood pressure, low white blood cell count, anemia, diarrhea, edema/swelling, and higher risk of infection and cancer.

:: MEDICATIONS USED TO TREAT REJECTION

Thymoglobulin® [Anti-thymocyte Globulin (Rabbit)]

- Given through an IV for three to seven days.
- Infusion takes at least six hours.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), nausea, vomiting, low blood pressure, allergic reactions, low white blood cell count, decreased platelet count, and higher risk of infection and cancer.

Campath® (Alemtuzemab)

- Given through an IV as a one-time dose.
- Infusion takes at least two hours.
- Possible side effects are flu-like symptoms (fever, chills, muscle aches), shortness of breath, allergic reaction, low blood pressure, low white blood cell count, decreased platelet count, anemia and higher risk of infection and cancer.

Immunoglobulin®, Intravenous (IVIG)

- Given through an IV as a one-time dose.
- Infusion takes at least eight hours.

Rituximab® (Rituxan)

- Given through an IV as a one-time dose.
- Infusion takes at least six hours.
- Possible side effects are infustion-related reactions including swelling, difficulty breathing, chills, dizziness, fever, headache, high or low blood pressure, muscle aches, nausea, rash, and vomiting.

Plasmapheresis®

- Similar to dialysis, but is used to remove antibodies from your blood that are causing rejection instead of removing toxins.
- The procedure takes about three to four hours.

:: POST-TRANSPLANT MEDICATIONS

The following is a list of several of the main immunosuppressive medications that you will take after transplant and cost range.

1. Steroids (prednisone, methylprednisolone, Solu-Medrol®) – Generally, on a taper schedule (slowly decrease the dose overtime)

Cost: \$4 – \$15 a month without drug coverage from insurance

- **2. Tacrolimus** (Prograf®) **OR Cyclosporine** (Neoral®, Gengraf)
 - **Tacrolimus** (Prograf®)

 Cost: \$850 \$1700 per month without drug coverage from insurance
 - **Cyclosporine** (Neoral®)

 Cost: \$700 \$1850 per month without drug coverage from insurance
- **3. Mycophenolate mofetil** (CellCept®) **OR Mycophenolic acid, delayed release** (Myfortic®)
 - **Mycophenolate mofetil** (CellCept®)

 Cost: \$400 \$500 per month without drug coverage from insurance
 - Mycophenolic acid, delayed release (Myfortic®)
 Cost: \$500 \$1500 per month at other pharmacies without drug coverage from insurance

Medications you will be on to prevent infections:

These medicines will be taken for six months to a year after transplant.

1. Valganciclovir (Valcyte®)

Cost: \$1500 – \$5000 per month without drug coverage from insurance

2. Acyclovir

Cost: \$20 – \$50 per month without drug coverage from insurance

3. Sulfamethoxazole/Trimethoprim (BactrimTM SS)

Cost: \$4 – \$15 per month without drug coverage from insurance

4. Nystatin

Cost: \$30 – \$200 per month without drug coverage from insurance

5. Clotrimazole Troche (Mycelex)

Cost: \$30 – \$60 per month without drug coverage from insurance

You may still need to be on medicines for other conditions such as:

- Medicine to decrease indigestion Prilosec[®], Prevacid[®], Zantac[®], or Pepcid[®]
- Blood pressure medication for high blood pressure
- Low-dose aspirin
- Water pills
- Thyroid medicine, if you were taking it before your transplant
- Medicine for treatment of diabetes or high blood sugar
- Injections to increase your red blood cell count
- Injections to increase your white blood cell count
- Pain relief medications
- Stool softeners

:: PREDNISONE

- Use: Prevent rejection
- Some possible side effects:
 As with all medications, prednisone has side effects. Most of these side effects are treatable; do not stop taking prednisone because of its side effects. Talk to your transplant physician about appropriate treatment.
 - Mood swings
 - Increased in blood sugar
 - Insomnia, abnormal dreams
 - Depression or other mental symptoms
 - Ulcers and/or indigestion
 - Increased appetite
 - Salt and water retention (Edema)
 - Increased fatty deposits, especially in the face, "moon face"
 - Thinning skin
 - Delay in wound healing
 - Bone and joint changes such as osteoporosis
 - Increased sensitivity to the sun
 - Acne
 - High blood pressure
 - Blurry vision do not obtain new glasses until on a stable dose
 - Cataract
 - Glaucoma

- Available as a 5 mg, 10 mg, and 20 mg tablet.
- Usually taken once a day.

Taper schedule

- Dose will be slowly decreased over time .
- You may be given a taper schedule to follow or you may be instructed in clinic when to decrease your dose.
- Keep in a cool dark place at room temperature.
- Always wash your hands before taking your medicine.
- If dose is vomited within one hour of taking medication, repeat dose.

:: YOU WILL BE ON EITHER TACROLIMUS OR CYCLOSPORINE, BUT YOU SHOULD NEVER BE TAKING BOTH AT THE SAME TIME

:: TACROLIMUS (PROGRAF, GENERICS, ASTAGRAF XL, ENVARSUS XR))

- Use: Prevent rejection
- Monitor blood levels
 - On days of blood work or clinic, wait to take medication until after blood draw.
 - Prescribed amount can change according to the measured drug level in your blood.
 - If your dose needs to be changed, you will be contacted.
 - Continue to take your medication as prescribed unless you are contacted.

Interactions

- Many medication interactions. Please check with your transplant coordinator when starting a new medication by a doctor other than your transplant surgeon.
- **Do NOT** eat/drink grapefruit, grapefruit juice, plummelo, pomegranate juice, grapefruit soda or Earl Gray tea. These will increase your tacrolimus level.

Some possible side effects:

As with all medications, tacrolimus has side effects. Most of these side effects are treatable; **do not** stop taking tacrolimus because of its side effects. Talk to your transplant physician about appropriate treatment.

- High blood pressure
- Tremor
- Numbness or tingling in hands and feet
- Kidney toxicity
- Insomnia
- Headache
- Nausea
- Diarrhea
- Hair loss (Alopecia)
- Depression or other mental symptoms
- Increase in blood sugar
- Electrolyte changes: low magnesium, low phosphorus, high potassium

Availability

- Prograf is usually taken twice a day, doses 12 hours apart. It is available as 0.5 mg, 1 mg, and 5 mg capsules (brand or generic).
- Astagraf XL is a long acting tacrolimus product that is given once a day. It is available as 0.5 mg, 1 mg, and 5 mg capsules.
- Envarsus XR is a long acting tacrolimus product that is given once a day. It is available as 0.75 mg, 1 mg, and 4 mg capsules.
- Please talk with your coordinator before changing brands of your tacrolimus.
- Keep in a cool dark place at room temperature.

- Always wash your hands before taking your medicine.
- If dose is vomited within one hour of taking medication, repeat dose.
- Call your transplant coordinator if vomiting or diarrhea persists.

:: CYCLOSPORINE MODIFIED (NEORAL, GENGRAF®, GENERIC)

- Use: Prevent rejection
- Monitor blood levels
 - On days of blood work or clinic, wait to take medication until after blood draw.
 - Prescribed amount can change according to the measured drug level in your blood.
 - If your dose needs to be changed, you will be contacted.
 - Continue to take your medication as prescribed unless you are contacted.

Interactions

- Many medication interactions. Please check with your transplant coordinator when starting a new medication by a doctor other than your transplant surgeon.
- **Do NOT** eat/drink grapefruit, grapefruit juice, plummelo, pomegranate juice, grapefruit soda or Earl Gray tea. These will increase your cyclosporine level.

- Some possible side effects:
 - As with all medications, cyclosporine has side effects. Most of these side effects are treatable; **do not** stop taking cyclosporine because of its side effects. Talk to your transplant physician about appropriate treatment.
 - High blood pressure
 - High cholesterol and/or triglycerides
 - Tremor
 - Numbness or tingling in hands or feet
 - Kidney toxicity
 - Insomnia
 - Headache
 - Increased hair growth (hirsutism)
 - Swollen or increased growth of gums (gingival hyperplasia)—regular brushing, flossing, and dental visits help to prevent
 - Depression or other mental symptoms
 - Electrolyte changes: low magnesium, low phosphorus, high potassium
- Available as 25 mg and 100 mg capsules (brand or generic). Also available as an oral solution 100 mg/mL.
- Please talk with your coordinator before changing brands of your cyclosporine.
- Usually taken twice a day. Doses taken 12 hours apart.
- Do NOT take tablets out of package until ready to take. They may not work as well if put in the pill box or left sitting out.
- Keep in a cool dark place at room temperature.
- Always wash your hands before taking your medicine.
- If dose is vomited within one hour of taking medication, repeat dose.
- Call your transplant coordinator if vomiting or diarrhea persists.

:: MYCOPHENOLATE MOFETIL (CELLCEPT, GENERICS) MYCOPENOLIC ACID, DELAYED RELEASE (MYFORTIC)

- Use: Prevent rejection
- Interactions
 - Products containing magnesium, calcium, or aluminum, may decrease
 the blood levels of mycopenolate mofetil or mycophenolic acid, delayed
 release. If possible, separate doses by at least two hours.
 - Antacids and sevelamer (Renvela, Renagel) may decrease the blood levels of mycophenolate mofetil or mycophenolic acid, delayed release. If possible, separate doses by at least two hours.
 - **Hormonal contraceptives:** mycophenolate mofetil or mycophenolic acid, delayed release decrease the effectiveness (making them work not as well) of hormonal contraceptives including oral contraceptives, "the pill". An additional form of birth control must be used. See pregnancy section.
- Some possible side effects:
 - Nausea, vomiting
 - Diarrhea
 - Decreased white blood cell count
 - Increased risk of infection
 - Increased risk of developing Lymphoma's and other malignancies, especially of the skin

- Usually taken twice a day.
- Store at room temperature.
- If you miss a dose of mycophenolate (CellCept) or Mycophenolic acid, delayed release (Mycortic) or are unsure if you took one of your daily doses, do not take a double dose. Call your transplant coordinator.
- Available as:
 - Mycopenolate mofetil (CellCept, generic) 250 mg capsule, 500 mg tablet, 200 mg/mL oral suspension. Do NOT crush, chew, or split capsules or tablets.
 - Mycopenolic acid, delayed release (Myfortic) 180 mg tablet, 360 mg tablet. **Do NOT** crush, chew, or split tablets.
- Birth control and Pregnancy

TALK TO YOUR DOCTOR IF YOU ARE PREGNANT OR TRYING TO BECOME PREGNANT.

BIRTH CONTROL OPTIONS

- You must always use acceptable birth control
 - Before stating mycophenolate
 - During your entire treatment with mycophenolate
 - For six weeks after you stop taking mycophenolate
- Unless you choose not to have sexual intercourse with a man at any time (abstienece), you must always use two different types of acceptable birth control at the same time. You need to use more than one method of birth control at the same time.

- Mycophenolate could reduce the effectiveness of hormonal methods of birth control. (The "pill" may not work as well).
 - Hormonal methods of birth control must be used with a barrier method because studies show that mycophenolate decrease blood levels of certain hormones in the oral contraceptive pill. It is possible that mycophenolate could reduce the effectiveness of the oral contraceptive pill.
- The effectiveness of other hormone methods (like the patch, the ring, the shot, and the implant) may also be reduced while you are taking mycophenolate.
- Birth control options:

1. Methods to use Alone

- Tubal sterilization
- Patient's partner had a vasectomy

OR

2. Choose One Hormone Method AND One Barrier Method

Hormone Methods AND (choose one)

Estrogen and Progesterone

- Oral contraceptive pill
- Transdermal patch
- Vaginal ring

Progesterone-only

- Injection
- Implant

Barrier Methods (choose one)

- Diaphram with spermicide
- Cervical cap with spermicide
- Contraceptive sponge
- Male condom
- Female condom

OR

3. Choose One One Barrier Method From Each Column (must choose two methods)

Barrier Methods AND Barrier Methods (choose one) (choose one)

- Diaphram with spermicide
- Cervical cap with spermicide
- Contraceptive sponge

- Male condom
- Female condom

:: OTHER LESS COMMONLY USED IMMUNOSUPPRESSION DRUGS

:: SIROLIMUS (RAPAMUNE®)

- Use: Prevent rejection
- Monitor blood levels
 - On days of blood work or clinic, wait to take medication until after blood draw.
 - Prescribed amount can change according to the measured drug level in your blood.
 - If your dose needs to be changed, you will be contacted.
 - Continue to take your medication as prescribed unless you are contacted.

Interactions

- Many medication interactions. Please check with your transplant coordinator when starting a new medication by a doctor other than your transplant surgeon.
- If taking with cyclsporine, take sirolimus four hours after morning dose of cyclosporine.
- **Do NOT** eat/drink grapefruit, grapefruit juice, plummelo, pomegranate juice, grapefruit soda or Earl Gray tea. These will increase your sirolimus level.

- Some possible side effects:
 - As with all medications, sirolimus has side effects. Most of these side effects are treatable; **do not** stop taking sirolimus because of its side effects. Talk to your transplant physician about appropriate treatment.
 - High cholesterol and/or triglycerides
 - High blood pressure
 - Swelling in legs
 - Acne
 - Headache
 - Insomnia
 - Diarrhea
 - Low platelet count, low white blood cell count, or anemia
 - Muscle/joint aches and pains
 - Delay in wound healing
 - Mouth ulcers
 - Increased risk of infection
- Available as 0.5 mg and 1 mg and 2 mg tablets.
- Usually taken once a day.
- Keep in a cool dark place at room temperature.
- Always wash your hands before taking your medicine.
- If dose is vomited within one hour of taking medication, repeat dose.
- Call your transplant coordinator if vomiting or diarrhea persists.

:: AZATHIOPRINE (IMURAN)

- Use: Prevent rejection
- Interactions
 - Many medication interactions. Please check with your transplant coordinator when starting a new medication by a doctor other than your transplant surgeon.
- Some possible side effects:

As with all medications, azathioprine has side effects. Most of these side effects are treatable; **do not** stop taking azathioprine because of its side effects. Talk to your transplant physician about appropriate treatment.

- Low platelet treatment
- Low white blood cell count
- Anemia
- Pain in joints
- Nausea, vomiting
- Diarrhea
- Hair loss
- Increased risk of infection
- Available as 50 mg tablets.
- Usually taken once a day. May take with food to decrease stomach upset.
- Keep in a cool dark place at room temperature.
- Always wash your hands before taking your medicine.

- If dose is vomited within one hour of taking medication, repeat dose.
- Call your transplant coordinator if vomiting or diarrhea persists.

:: EVEROLIMUS (ZORTRESS)

- Use: Prevent rejection
- Monitor blood levels
 - On days of blood work or clinic, wait to take medication until after blood draw.
 - Prescribed amount can change according to the measured drug level in your blood.
 - If your dose needs to be changed, you will be contacted.
 - Continue to take your medication as prescribed unless you are contacted.

Interactions

- Many medication interactions. Please check with your transplant coordinator when starting a new medication by a doctor other than your transplant surgeon.
- **Do NOT** eat/drink grapefruit, grapefruit juice, plummelo, pomegranate juice, grapefruit soda or Earl Gray tea. These will increase your everolimus level.

- Some possible side effects:
 - As with all medications, everolimus has side effects. Most of these side effects are treatable; **do not** stop taking everolimus because of its side effects. Talk to your transplant physician about appropriate treatment.
 - Decreased appetite, taste changes
 - Mouth sores
 - High cholesterol and/or triglycerides
 - High blood pressure
 - Skin problems: Dry, itchy skin; rash, acne
 - Headache
 - Insomnia
 - Nausea, vomiting, diarrhea, or constipation
 - Electrolyte changes: decrease in phosphorus, bicarbonate, calcium, potassium and/or sodium
 - Low platelet count, low white blood cell count, or anemia
 - Muscle aches and pains
 - Increased risk of infection
- Available as 0.25 mg, 0.5 mg, and 0.75 mg tablets.
 - **Do NOT** crush, chew, or split tablets. Swallow tablets whole.
 - **Do NOT** take tablets out of package until ready to take. They may not work as well if put in the pill box or left sitting out.
- Usually taken twice daily 12 hours apart. May be taken with or without food, but be consistent.
- Keep in a cool dark place at room temperature.

PATIENT INFORMATION GUIDE :: KIDNEY TRANSPLANT

- Always wash your hands before taking your medicine.
- If dose is vomited within one hour of taking medication, repeat dose.
- Call your transplant coordinator if vomiting or diarrhea persists.

:: MEDICATIONS TO PREVENT INFECTIONS

:: TRIMETHOPRIM/SULFAMETHOXAZLE (BACTRIM, TMP/SMZ)

- Use: Prevent pneumonias, specifically Pneumocystis jiroveci pneumonia (PCP).
 - Also helps to prevent urinary tract infections and some other infections transplant patients are at high risk of getting.
- Some possible side effects:
 - Nausea, vomiting
 - Loss of appetite
 - Rash
 - Can increase sensitivity to the sun (leading to sunburn); wear sunscreen all year round and wear a hat or cover up as much as possible
- Available as a single strength tablet combination 400 mg SMZ and 80 mg TMP.
- Usually given once a day.
 - May be taken with or without food.
 - Drink at least eight ounces of water when taking the medication.
- You will take this medication for the first year.
- Store at room temperature.

:: ATOVOQUONE (MEPRON)

- Use: Prevent pneumonias, specifically Pneumocystis jiroveci pneumonia (PCP).
- Some possible side effects:
 - Nausea, vomiting
 - Rash
 - Headache
 - Insomnia
- Available as 750 mg/5 mL suspension.
- Usually given once daily. Must be taken with food.
- You will take this medication for the first year.
- Shake gently prior to each use.
- Store at room temperature.

:: VALGANCICLOVIR (VALCYTE)

- Use: Prevent or treat a viral infection called CMV (cytomegalovirus) and herpes infections.
- Some possible side effects:
 - · Nausea, vomiting, or diarrhea
 - Low platelet count, low white blood cell count, or anemia
- Available as a 450 mg tablet.
- Usually taken once a day to prevent infection and twice a day to treat an infection. It is best to take this medication with food.
- You will take this medication for four to six months after transplant to help prevent this infection.
- Store at room temperature.
- May cause a decrease in fertility in men and women.
- Has the potential to cause birth defects in humans.
- Women should use effective contraception during treatment and for 30 days after.
- Men should use barrier contraception during treatment and for 90 days after.

:: ACYCLOVIR (ZOVIRAX)

- Use: Prevent or treat a viral infections with herpes.
- Some possible side effects:
 - Nausea, vomiting, or diarrhea
- Available as a 200 mg tablet, 400 mg tablet.
- Usually taken three times a day to prevent infection. You may take this medication with food or without food.
- You will take this medication for four to six months after transplant to help prevent this infection.
- Store at room temperature.

:: CLOTRIMAZOLE (MYCELEX TROCHE) OR NYSTATIN

- Use: Prevent the occurrence of oral yeast ("thrush") infection, which is common, when large doses of prednisone are taken.
- Some possible side effects:
 - Nausea, vomiting
- **Clotrimazole** is available as a 10 mg troche (Lozenge).
 - Usually taken three times daily.
 - Allow to dissolve slowly over 15 to 30 minutes.
 - **Do NOT** crush, chew, or swallow troches.
 - Do not eat or drink anything for 30 minutes after taking medication.
- **Nystatin** is available as a 100,000 units/1 mL oral suspension.
 - Usually taken three times daily.
 - Shake suspension well before measuring.
 - Swish liquid around mouth for several minutes then swallow.
 - Do not eat or drink anything for 30 minutes after taking medication.
- You will take this medication for three to six months after transplant.
- Store at room temperature.

:: OTHER MEDICATIONS

You may be started on some other medications to treat the side effects of the immunosuppressants or for other medical conditions. A member of the transplant team will explain these medications to you. They may include:

Medication to prevent ulcers and indigestion

- Omeprazole (Prilosec), esomeprazole (Nexium), lansoprazole (Prevacid), pantoprazole (Protonix), ranitidine (Zantac), or famotidine (Pepcid).
- Usually only need for the first two months unless you were on this medication prior to transplant for ulcers or reflux.

Blood pressure medication

- Calcium channel blockers like amlodipine (Naorvasc).
- Beta-blockers like metoprolol (Lopressor®).

Diuretics ("water pill")

• Furosemide (Lasix®), or bumetanide (Bumex®)

Pain relief medications

• Oxycodone or acetaminophen (Tylenol).

Vitamin supplements

- Multivitamin [available other the counter].
- Magnesium, phosphorus, calcium supplements.

Stool softener

• Docusate sodium (Colace®) [available over the counter].

Aspirin

• Aspirin, low dose [available over the counter] (use enteric coated to prevent stomach upset.

:: WARFARIN (COUMADIN®)

WHAT IS WARFARIN?

Commonly referred to as a "blood-thinner", however it is best described as an anticoagulant. Anti means "against" and coagulant means "clotting". Warfarin increases the time it takes for your blood to clot. As a result, warfarin reduces the chances that you will produce blood clots in areas of your body that can be harmful.

WHY DO YOU NEED WARFARIN?

- Clotting disorder = at risk for blood clot formation
- Deep Vein Thrombosis (DVT) = blood clot in a vein
- Pulmonary Embolism (PE) = blood clot in the lung

MONITORING OTHER MEDICATIONS

PT and INR = measures how long it takes for your blood to clot

- Desired INR range is usually two to three
- The higher the INR > the "thinner" the blood > the slower blood will clot

HOW SHOULD YOU TAKE YOUR WARFARIN

- Taken once daily at the same time everyday, evening is usually best.
- Doses will change from time to time depending on you INR.
- If you miss a dose, **NEVER** double the dose to catch up.
- Available as 1 mg, 2 mg, 2.5 mg, 3 mg, 4 mg, 5 mg, 6 mg, 7.5 mg, and 10 mg tablets (tablets may be cut).

OTHER MEDICATIONS

- Do not drink alcohol.
- Do not take any herbal supplements.
- If already taking, be consistent with taking multivitamins or supplements that contain vitamin K.

DIET

- Food can affect how well warfarin works.
- The most important thing to remember is to eat what you would normally eat and do not make any major changes in your diet without contacting your healthcare provider.
- Warfarin works with vitamin K. Foods high in vitamin K may work against warfarin.
- Foods high in vitamin K are usually green leafy vegetables such as broccoli, lettuce, cabbage, spinach, kale, collard greens, soybeans, green tea, and animal liver.

Please call our office or go to the ER if you develop bleeding that does not stop or if you have a fall:

- monthly periods that are heavier than normal
- nosebleeds
- cuts or scrapes
- blood in your urine or stool

:: MEDICATIONS FOR FEMALE PATIENTS

The immunosuppressive drugs you are taking may make you more susceptible to fungal infections of the vagina. Miconazole vaginal creams, suppositories, or ovules known as Monistat® 3 or Monistat 7 or clotrimazole vaginal creams known as Gyne-Lotrimin® 3 or Gyne-Lotrimin 7, are prescribed to treat these common infections. The cream, suppositories, or ovules come with an applicator to insert them into the vagina. If you have any questions about insertion or other matters related to the products and your infection, ask your primary care provider or gynecologist. In order to help prevent infection from recurring, do not have sexual intercourse during the time you are using the medication.

If your symptoms do not resolve within seven days, you need to see your primary care provider or gynecologist. Common side effects of the miconazole or clotimazole vaginal products are irritation around the vaginal area and a skin rash.

:: ADULT COUGH AND COLD PRODUCTS

ANTIHISTAMINE

- Aller-Chlor, Allergy-Time, Chlor-Trimeton Allergy, Chlor-Trimeton, Chlorphen, (Chlorpheniramine)
- Claritin, Alavert, QlearQuil 24 Hour Relief, Triaminic Allerchews (loratidine)
- Zyrtec Allergy, All Day Allergy (cetirizine)
- Allegra Allergy, Allegra 24-HR, Mucinex Allergy (fexofenadine)
- Benadryl (diphenhydramine)

ANTIHISTAMINE AND ANALGESIC COMBINATIONS (chlorpheniramine or diphenhydramine and acetaminophen)

- Coricidin® HBP Cold and Flu (contains acetaminophen)
- Chlor-Trimeton Allergy
- Tylenol® PM (acetaminophen and diphenhydramine)

COUGH SUPPRESSANTS (dextromethorphan)

- Delsym[®]
- Robitussin® 12-hr Cough Relief
- Robitussin Medi Soothers DM
- Robitussin Lingering Cold Long Acting Cough
- NyQuil Cough Suppressant

EXPECTORANT (guaifenesin)

Mucinex

EXPECTORANT AND COUGH SUPPRESSANT COMBINATIONS (dextromethorphan/guaifenesin)

- Coricidin HBP Chest Congestion and Cough
- Mucinex DM
- Mucinex Fast Max DM Max Liquid
- Alka-Seltzer Plus Mucus and Congestion
- Robitussin Cold Cough & Chest Congestion DM (sugar free)
- Robitussin Cold Cough & Chest Congestion DM
- Robitussin Maximum Strength Cough & Congestion DM
- Delsym® Cough & Chest Congestion DM

ANTIHISTAMINE AND COUGH SUPPRESSANT WITH OR WITHOUT ANALGESIC (chlorpheniramine, dextromethorphan, with or without acetaminophen)

- Coricidin HBP Cough and Cold
- Coricidin HBP Maximum Strength Flu (contains acetaminophen)
- Robitussin Maximum Strength Nighttime Cough DM
- NyQuil Cold & Flue Nighttime Relief (contains acetaminophen)
- Alcohol-free NyQuil Cold & Flu (contains acetaminophen)
- Alka-Seltzer Plus Severe Cold & Cough Nighttime (contains acetaminophen)

SORE THROAT

- Chloraseptic® Sore Throat Spray
- Cepacol Sore Throat Spray (sugar free)

OTHER

- Breathe Right® Original, Extra, Advanced, or Clear
- Breathe Right Menthol
- Cool Mist Humidifier
- Vicks Vapor Rub (ointment or cream)
- Saline Nasal Spray

^{*} Products that contain pseudoephedrine or phenylephrine should not be used if you have high blood pressure, coronary artery disease or diabetes mellitus.

:: POST-DISCHARGE CLINIC VISITS

After you have been discharged from the hospital, the transplant team will monitor you very closely for both medical and surgical complications and problems. You must visit the Transplant Surgery outpatient clinic on the Monday after being discharged. You will come to Transplant Clinic according to the schedule outlined under long-term follow-up care.

You will still see your nephrologist and also an endocrinologist if you are diabetic.

We encourage you to make an appointment to see your nephrologist six to eight weeks after the transplant date.

THE OUTPATIENT TRANSPLANT SURGERY CLINIC

Outpatient care for transplant patients is provided in a dedicated suite in the University Physicians Center (UPC II), Suite 3100, Surgical Specialties Clinic. Parking is available in a lot adjacent to the UPC building. The post-transplant clinic is on Mondays from 7:30 a.m. to 11:30 a.m.

When you have a scheduled clinic appointment you will need to have labs drawn before your clinic appointment. Please report to the University Physicians Center Lab (UPC I, Suite 520) for the blood tests. These labs will evaluate your blood count, kidney function, and Prograf level. You **should not** take the Cyclosporine/ Prograf/Rapamune doses until the blood samples have been obtained, and you should not eat breakfast before your lab work.

After your blood work is drawn, you are welcome to go to breakfast (hospital cafeteria, or the café on the second floor of the UPC building) before your clinic appointment. (See next page for directions for breakfast). Please report back to the clinic at your scheduled appointment time.

Bring your medication list and vital signs log to these appointments.

During the visit, please ask any questions and report any concerns, including fever, headache, cough, weight gain and wound drainage.

It is important to remember that rejection may occur with or without symptoms. That is why we draw and test your blood frequently, and why it is crucial that you keep your outpatient appointments. It is not unusual for patients to be readmitted at least once or twice following a transplant.

There is a café on the second floor of the clinic area with a limited selection of items.

The café opens at 7:45 a.m.

:: DIRECTIONS FROM THE CLINIC AREA TO THE HOSPITAL CAFETERIA

HOSPITAL SHUTTLE DIRECTIONS (RECOMMENDED)

Leave the clinic area by the elevator and take it to Floor 1. Get off the elevator, and walk straight ahead to the doors that go outside. Next, take the hospital shuttle to the main entrance of the hospital. Get off at the main entrance of the hospital, and bear to the right following the hallway. When you come to the rotunda (the lion is in the middle), and the cafeteria is straight ahead.

WALKING DIRECTIONS

Leave the clinic area by the elevator, and take it to the first floor. Get off the elevator and turn left, walk over the bridge (the hallway is winding) that connects the clinic to the hospital area. (Once in the hospital area you are on the second floor.) Turn left at the first hallway that turns left.

Take the hallway to the elevators, then take the elevator to Floor 1. Get off the elevator and turn left, then immediately turn right, and proceed down the hallway. Follow to the rotunda (the lion is in the middle), and the cafeteria is on the left-hand side.

Remember to check in at the registration desk for your clinic appointment when you return.

:: LONG-TERM FOLLOW-UP CARE

Lab work Schedule

One to three months post transplant date: Labs every Monday and Thursday

After three months: Your schedule will decrease to once weekly, then every other week, then monthly, then every three months at two years.

Clinic Visits – You may see us more frequently if you have complications.

- *First six weeks after transplant: Every Monday.
- *Six weeks to three months after transplant: Every other Monday.
- *Three months to six months after transplant: Monthly.
- *Six months to one year after transplant: Every eight weeks.
- *One year to two years after transplant: Every four months.
- *Greater than two years after transplant: Every 12 months.

Vital Signs – You may be asked to monitor your vital signs more frequently if you are having complications or blood pressure problems.

Take your blood pressure, weight, and temperature daily for the first month only. Record your vital signs and bring this record to your clinic visits.

:: WORLD-CLASS CARE

The kidney transplant process will not be easy. You will certainly experience your share of stress and anxiety during this difficult period. You will be concerned and will have many questions about your own health and future, as well as the impact the process will have on your family.

The kidney and kidney/pancreas Transplant Program at the Hershey Medical Center is committed to provide you with the best care possible. The entire team is dedicated to give you the emotional and practical support that is necessary to get through the transplant process successfully. With our academic and research expertise, our program offers the latest breakthroughs in transplant science. Those resources, coupled with your firm commitment to follow faithfully the instructions necessary for your recovery, offer you an excellent chance of returning to a normal life.

Again, if you have any questions at all about any point in the process, do not hesitate to contact the transplant team.

OUR MISSION is to provide quality care to our patients and to the members of the community, to improve patient care through excellence and biomedical research, and to educate and train the future academic and practice leaders in American surgery.

:: WHEN YOU SHOULD CALL THE TRANSPLANT TEAM

Your transplant surgeons and coordinators are available by calling the Transplant Office at 1-800-525-5395 or 717-531-6092, Monday through Friday from 8:00 a.m. to 4:00 p.m. No question or concern is trivial, and it is important that you call whenever you have a question, concern, or symptom. Please call with routine questions on a regular business day during office hours and ask to speak with the coordinator assigned to your care.

There is a transplant coordinator on call 24 hours a day, seven days a week. This is reserved for **true emergencies post transplant** that occur after 5 p.m. Monday to Friday, weekends, and holidays. You can contact the coordinator on call by calling 717-531-8521. If you are having a severe emergency, such as chest pain or difficulty breathing, call 911 or go to your local emergency room.

While you are waiting for a transplant, your primary care physician or nephrologist should be contacted first for emergencies. Our office does need to know if you are hospitalized or sick so we can evaluate your current status.

We ask that you continue to see your primary care physician or nephrologist for routine health care such as diabetic management, blood pressure regulation, cardiac management, head colds, gout flare-ups, sore throats, etc. They are familiar with your care in those areas and are usually more accessible than our surgeons. We will gladly consult with any of your physicians regarding your care if they have questions relating to your transplant.

:: WRITING TO YOUR DONOR FAMILY

Once you have received your new kidney, you will have the opportunity to write a letter to the family of your donor. Donor families often express their gratitude in hearing from the recipient of their loved one's kidney. While writing a letter is optional, we encourage all transplant recipients to do so. Everyone recovers at a different rate and is not always up to writing a letter immediately. You can write a letter to your donor family at any time after transplantation. Please see the brochure "Writing to Your Donor" that was given to you after surgery. If you do not receive a brochure, please request one from either your social worker or transplant coordinator.

If you decide to write to your donor family, please omit your name or any other "identifying" information. The letter must remain anonymous in an effort to protect the privacy of both you and the donor family. The transplant team can forward your letter to the local procurement agency, the Gift of Life Donor Program, who will then forward the letter to the appropriate family. Your letter will be screened prior to sending it to the donor family. If the family chooses to respond to your letter, they will follow the same process, submitting a letter to the Gift of Life Donor Program, who will then forward the letter to you after screening it.

TIPS FOR WRITING TO YOUR FAMILY

When writing about yourself:

- Include your first name only (and the first names of the family if you choose to include them).
- Acknowledge the donor's family's loss and thank them for their gift.
- Discuss your family situation such as marital status, children, or grandchildren. Describe the type of transplant that you received. (One donor may have benefited many people).

- Use simple language. Avoid complex medical terms and giving too much detail about your medical history.
- Describe how long you have waited for a transplant. What was the wait like for you and your family?
- Explain how the transplant has improved your health and changed your life. Did you return to work, school, or accept a new job? Did you celebrate another birthday? Did your son or daughter marry? Did you become a parent or grandparent?
- Share your hobbies or interests
- Consider omitting any religious comments, since the religion of the donor family is unknown.

Please sign your first name only. Do not reveal your address, city, phone number, physician's name, or the name of your hospital.

You may or may not hear from the donor family. Several donor families have said that writing about their loved one and their decision to donate helps them in their grieving process. Other donor families, even though they are comfortable with their decision to donate, may prefer privacy and chose not to write.

We thank you for your thoughtfulness. We know the donor families appreciate hearing from recipients. Remember the donor family may still be coping with the loss of their loved one, and individuals manage grief in different ways. While you may be celebrating the anniversary of receiving your transplant, someone else is remembering a loss. Help the family understand the importance of the decision to donate. Let them know that their loved ones will never be forgotten.

Mail to:

Family Support Services Gift of Life Donor Program 401 N. 3rd Street Philadelphia, PA. 19123

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

DATE	WEIGHT	A.M. TEMP.*	A.M. BLOOD PRESSURE**	A.M. PULSE	P.M. TEMP.*	P.M. BLOOD PRESSURE**	P.M. PULSE

^{*} Call if temperature is 100.5° F or above. ** Call if top blood pressure number is over 130, or if the bottom number is over 85.

:: ADDITIONAL RESOURCES

INTERNET RESOURCES

WWW.PENNSTATETRANSPLANT.COM: Website for Hershey Medical Center Transplant Program. Phone: 1-800-525-5395 or 717-531-3716.

WWW.DONORS1.ORG: Gift of Life Donor Organization, Donor Organ Procurement Organization for this region; this is the organization responsible for the distribution of organs in the regions of eastern Pennsylvania, southern New Jersey, and the state of Delaware. Phone: 1-800-DONORS-1.

WWW.UNOS.ORG: United Network for Organ Sharing, the National organization responsible for overseeing the distribution of organs in the United States. Patient information: 1-888-894-6361.

WWW.TRANNEWS.COM: *Transplant news*; a bi-weekly newsletter focusing on developments in organ procurement and transplantation.

WWW.KIDNEY.ORG: Official website for the National Kidney Foundation.

WWW.LIVINGDONORASSISTANCE.ORG: Website with Information on financial assistance for living organ donors.

WWW.TRANSPLANTLIFE.COM: A website established for patients by a pharmaceutical (drug) company known as Astellas. This website was established to specifically help patients deal with issues both before and after transplant.

WWW.HEALTHYTRANSPLANT.COM: This website developed by the American Society of Transplantation specifically to help patients through the transplant process.

WWW.DIABETES.ORG: American Diabetes Association. Phone: 1-800-232-3472.

WWW.AAKP.ORG: American Association of Kidney Patients. Phone: 1-800-638-8299.

WWW.KIDNEYFUND.ORG: American Kidney Fund. Phone: 1-800-638-8299.

SOURCES FOR ADDITIONAL INFORMATION

For more information you may want to contact the following organizations.

National Diabetes Information Clearinghouse

1 Information Way Bethesda, MD 20892-3560 (301) 654-3327

Email: ndic@aerie.com

American Diabetes Association

ADA National Service Center 1660 Duke Street Alexandria, VA 22314 800-232-3472 or (703) 549-1500

Web Page: www.diabetes.org

:: PLAN AHEAD FOR THE OUT-OF-POCKET EXPENSES OF A KIDNEY TRANSPLANT

Here is a list of things that you need to think about as you plan ahead for you kidney transplant.

- 1. There is no lodging available on the grounds of the Penn State Hershey Medical Center. If you and your family need to stay locally you will need to have money saved to pay for lodging. Hotels and motels can be expensive here in Hershey. This is especially true during the tourist season. Get reservations ahead of time if possible.
- 2. Be prepared to have money on hand for spouses and/or other family members to pay for meals. Food is available in the hospital cafeteria. There are fast food restaurants, diners, restaurants, and grocery stores located near the Hershey Medical Center.
- 3. You and your family members may need to make frequent trips to the Hershey Medical Center. You should consider the cost of gasoline and the wear and tear on your vehicle in your planning for kidney transplant.
- 4. Have you planned for the possible loss of income due to lost work time? You will need to plan for how you and your family can best manage financially if you are unable to work for a long period of time. You also need to plant for the loss of work time for your spouse and/or other family members as they take care of you or visit you in the hospital.
- 5. Check your credit cards, loans and/or mortgage to see if you have disability insurance. The disability insurance may make your payments while you are unable to work.

6. There are two organizations that may be able to assist with fund-raising. Feel free to contact them if fund-raising may benefit you and your family. These include:

National Foundation for Transplants 800- 489-3863 www.transplants.org

Help Hope Live 800-642-8399 HelpHOPELive.org

:: ACCOMMODATIONS

Free accommodations for patients:

Parsonage

Available for families of transplant patients based on available space. There is no charge for lodging. Application is made through the transplant social worker.

Hershey Ronald McDonald House

745 W Governor Road 717-533-4001 888-829-3545

There is no charge for lodging, but room availability is limited. A reservations should be made well in advance whenever possible. For pediatric patients and families.

If financial constraints make it difficult to obtain accommodations at an affordable rate, please contact your social worker for assistance.

HOTELS IN THE AREA

America's Best Value Inn 2951 Horseshoe Pike 717-838-4761

Best Western Rt. 422 & Sipe Ave. 717-533-5665

Cocoa Motel 914 Cocoa Ave. 717-534-1243

Comfort Inn 1200 Mae Street 717-566-2050

Days Inn 350 W. Chocolate Ave. 717-534-2162

Econo Lodge Hershey 115 Lucy Ave. 717-533-2515

Fairway Motel 1043 E. Chocolate Ave. 717-533-5179 Hampton Inn 749 E. Chocolate Ave.

717-533-8400

Hershey Lodge 400 E. Hershey Park Dr. 717-533-3311

Hilton Garden Inn 550 E. Main Street 717-566-9292

Holiday Inn Express 610 Walton Ave. 717-220-4085

Howard Johnson 845 E. Chocolate Ave. 717-533-9157

Milton Motel Hershey 1733 E. Chocolate Ave. 717-533-4533 Motel 6

1518 E. Chocolate Ave. 717-533-2384

Red Carpet Inn 210 Hockersville Rd. 717-534-1600

Rio Motel 60 Washington Ave. 717-534-1065

Roadway Inn 43 W. Areba Ave. 717-533-7054

The Warwick Hotel 12 W. Main Street 717-566-9124

White Rose Motel 1060 E Chocolate Ave. 717-533-9876

:: GLOSSARY OF IMPORTANT TERMS

Acute tubular necrosis (ATN) – Reversible kidney damage resulting in delayed kidney function. ATN generally resolves on its own in a few weeks.

Antibody – A protein that is produced by the body's immune system when it detects a foreign substance, such as a transplanted organ.

Antigen – A substance, such as a transplanted organ, that can trigger an immune response; an immune response may be the production of antibodies.

Biopsy – Taking a small tissue sample of the transplanted organ by using a needle so that the sample can be examined under a microscope to look for rejection.

Crossmatch – A test between the donor's blood and the recipient's blood to determine if any reaction occurs. A reaction indicates that the recipient's body would attack the donor's organ immediately if it were transplanted, and means they are incompatible.

Deceased donor – An individual who has died and donated his or her organs for transplant.

Graft – A transplanted organ, such as a kidney or pancreas.

Immune System – The body's natural way to fight infections such as bacteria, viruses, and other foreign substances.

Immunosuppression – Using medication after transplant to lower the body's immune response to foreign bodies to prevent rejection of the new organ.

Living Donor – Someone who donates one of their kidneys to someone else, it could be a relative, friend, or even someone unknown to the donor.

Non-Compliance – Failure by a patient to follow instructions provided by his or her transplant team or center.

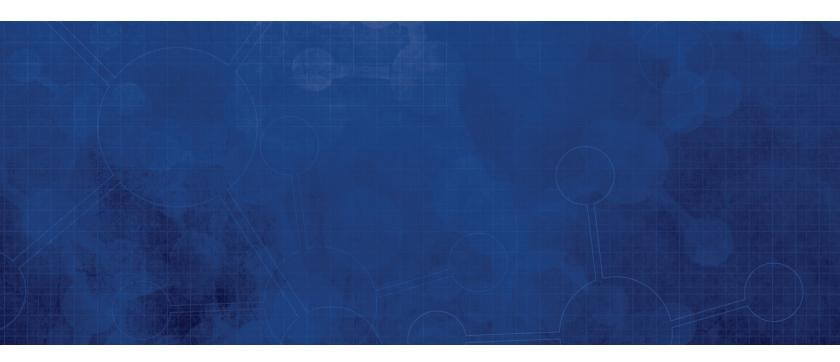
Organ Procurement Organization (OPO) – A local organization responsible for distributing organs to transplant centers in their region. The Gift of Life is our OPO.

Percent of Reactive Antibody (PRA) – The percent of possible donors that your blood is tested against each month that had a reaction (was incompatible). This helps predict how likely you are to be compatible with a potential donor. Patients with high PRA levels may be difficult to match. The PRA level will increase because of previous transplants, blood transfusions, pregnancies, or serious infections.

Rejection – Attempt by the immune system to attack and destroy a transplanted organ. If not treated, rejection will result in loss of the transplanted organ.

Tissue Typing – A test that evaluates how closely a donor's tissue matches that of a recipient.





hmc.pennstatehealth.org/transplant-surgery