



KIDNEY TRANSPLANT PROGRAM

After your transplant



Duke Transplant Center

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Welcome to Duke Kidney/Pancreas Transplant Center!

We are glad that you have chosen Duke to provide your transplant care.

Duke Transplant Center

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Durham, NC 27710

My transplant surgeons: _____

My transplant nephrologists: _____

My transplant coordinator: _____

Congratulations

Congratulations on your new kidney transplant! This booklet has important information, including specific guidelines on how to take care of yourself once you arrive home. The transplant coordinators, doctors, nurses and pharmacists will review the material with you.

It is necessary that you understand how to take care of yourself and your new kidney before you are released from the hospital. You must know which medications to take, at what time, what amount and for what reason. You must also know the signs and symptoms that could indicate problems with your transplant, how to watch for them, and how to report them.

You will be responsible for monitoring your health at home and for keeping daily records. You must bring these records with you to each follow-up appointment at the transplant clinic. This will allow us to monitor your condition with you, and to be on the lookout for any problems that may occur.

The Duke Kidney Transplant Team knows that going through a kidney transplant can be a trying time, and we want to help you through this process. Please let us know any way we can help ease your transition to a well-functioning transplant. We look forward to working closely with you.

What to Expect during Transplant Admission

During your hospitalization, you will be cared for by a team of doctors, nurses, transplant coordinators, pharmacists, social workers and dietitians. You will be in the hospital for approximately 4-6 days after a kidney transplant. The kidney transplant surgery itself takes about four hours. An incision will be made in your lower abdomen on either the right or left side. Your own kidneys will not be removed. The transplanted kidney will be attached to your blood vessels and bladder. Then the incision will be closed and you will be taken to the recovery area.

You will have an IV line that the nurses will use to give you fluids and medications. You will have a catheter in your bladder to drain urine; this will stay in place for three days. You may have a drain placed inside your abdomen at the time of surgery; this surgeon will decide when it is appropriate for your drain to be removed. You may have a stent placed in your bladder to aid in draining urine from the transplanted kidney to your bladder. The stent will be removed 4-6 weeks after transplant as an outpatient procedure.

While you are in the hospital, you will receive some IV medications to help prevent rejection. Your vital signs and blood sugar levels will be checked frequently. Your nurses will be carefully recording the amount of urine you are making, IV fluids you are receiving, and oral fluids you are drinking.

You will be given a device called an incentive spirometer to help exercise your lungs. Your nurse will instruct you on how to use it properly. You will need to use the incentive spirometer every hour to help keep your lungs functioning properly and to prevent pneumonia. It is very important that you are out of bed and walking in the hallway at least three times per day. Your nurse will help you do this in a safe manner.

You will have blood drawn every morning to check on your kidney function and to make sure your blood cell counts are stable. A kidney ultrasound may be ordered to check the blood flow in your transplanted kidney. A bladder scan may be performed after your urinary catheter is removed to make sure your bladder is emptying properly. Some patients require dialysis treatments after transplant while waiting for the new kidney to work. This is a common occurrence and does not indicate the long term function of your new kidney.

Prior to discharge from the hospital, you and your caregiver will need to complete education sessions with a pharmacist, a dietitian, a diabetes educator, and a transplant coordinator. Each of these team members will come by your hospital room to arrange a time to for teaching when your caregiver can also be present. In these teaching sessions, you will review all aspects of post-transplant care and will have the opportunity to ask any questions you may have.

Immune System

The immune system is your body's defense against something foreign or unknown that enters your body. The immune system is made of cells and antibodies that work together to protect your body. When your immune system detects a foreign substance, these cells and antibodies work together to respond to that foreign substance. The immune system response attacks the foreign substance and learns how to fight that foreign substance again in the future.

Your transplanted organ is new and foreign to your body. Under normal circumstances, a healthy immune system will attack a transplanted organ. This is called the **immune response**. Preventing this natural response of the body's immune system is called **immunosuppression**. Immunosuppression is important to allow the kidney transplant to work as well as possible for as long as possible. Immunosuppressant medications are given in order to lower your immune response.

In order for immunosuppression to work, your body needs to have just the right level of medicine at all times. Your health care provider will tell you exactly how much medicine to take and exactly when to take it. In the early days after transplant, we will be making frequent changes to your doses. It is important to follow your health care provider's instructions. Failing to make a medication change or missing a single dose can open a window for rejection to take place.

You will always need to take immunosuppressant medications.

Rejection

Transplant rejection occurs when your immune system attacks the new transplanted organ. Your transplanted kidney is foreign to your body and your immune system is trained to recognize and attack all foreign intruders. Transplant rejection can cause severe damage to the transplanted organ. There are different forms of rejection; some rejection is caused by cells in the immune system, some rejection is caused by antibodies in the immune system.

Acute rejection is the most common form of rejection and is typically reversible. Acute rejection occurs when the body recognizes the kidney as foreign and begins to attack it. Early diagnosis and treatment are essential in treatment of rejection.

Symptoms of rejection include weight gain, swelling, and decrease in urine output, pain at the transplant site, fever or flu-like symptoms (chills, nausea, tiredness, body aches). However, many people have **no** symptoms of rejection.

Blood tests will be ordered routinely to evaluate the function of your transplanted kidney. If the transplant team notices an increase in your creatinine, an ultrasound of the kidney may be ordered to evaluate blood flow to the transplanted kidney.

A kidney biopsy will be needed to determine if rejection is taking place. During a kidney biopsy, you are given an injection of a numbing medication into your abdomen around your kidney. A small piece of tissue will be taken from your transplanted kidney with a needle. A pathologist will look at that sample of tissue under a microscope. Results of the biopsy will be ready in 24 to 36 hours.

If transplant rejection is diagnosed, your health care provider will inform you of the necessary treatment. You may need to be admitted to the hospital for IV medications to help stop your immune system from rejecting the transplanted organ. Prompt diagnosis and treatment are required to prevent permanent damage to the kidney. Without prompt treatment, your kidney may not work as well or last as long.

In order to avoid rejection, take medications exactly as directed by your health care provider. Missing even one dose of your immunosuppressant medication can put you at risk for rejection. Keep all follow-up appointments and get your blood drawn in between your appointments as directed by your health care provider.

Medications

It is mandatory that you have all transplant prescriptions with you before you are discharged from the hospital. The Duke Cancer Center Specialty Pharmacy will be used for your initial prescriptions unless your insurance company mandates another pharmacy be used. If you use a pharmacy outside of Duke, your caregiver must bring all of the prescriptions to the hospital for the transplant team to review before you can be discharged. You will need to pay any copays for your medicines when you pick them up.

Your direct costs for transplant medications are determined by your insurance plan coverage. Insurance plans may cover all or part of the costs of the medications. Any change in your insurance plan may result in changes to the cost associated with your medications. Please obtain detailed information from any new insurance plans before making a change in coverage to avoid unexpected additional medication costs. You should call and review any new insurance plan with your financial coordinator prior to making a change.

Do:

Take your medication according to your most recent medication list from the transplant team.

Store all medications away from heat and direct light. Keep medicines which require refrigeration cold, but not in the freezer.

Keep track of how many refills you have on each medication, call for refills at least one week prior to being out of medications.

Ask your pharmacy to carry your medication in stock. Use one regular pharmacy so they have a record of all of your prescriptions.

Keep a list of your current medications in your wallet/purse/smartphone.

Don't:

Don't rely on the labels on the pill bottles for medication instructions, as medicine direction changes from the transplant providers are common. Always follow the instructions given to you by the transplant team.

Don't take any over-the-counter medications, supplements, or vitamins without checking with the transplant office.

Don't take any prescription medications prescribed by other providers without checking with the transplant office.

Transplant Medications

Taking your transplant medications on time, every day, is an important part of taking care of yourself and your new organ. The chances of side effects and other problems will be lower if you take your transplant medications as ordered. Every medication your doctor prescribes for you is important for your health and the health of your new organ. Stopping any of your medications or even skipping a single dose without guidance from your doctor could harm your new organ.

Generic medications work as well as brand medications in most cases. It is important to stay on the same medicine product. If your pills look different when you refill them at the pharmacy, talk to your pharmacist and transplant provider.

During your hospitalization, you may be given **induction** medications to lower your immune system. These powerful IV medications will lower your immune response to help prevent rejection of your transplanted kidney. Examples of these induction medications are Simulect® (basiliximab), Campath® (alemtuzumab), Thymoglobulin® (antithymocyte globulin) and methylprednisolone.

You will need to take **maintenance** medications to lower your immune system as long as your transplant is working. You can never discontinue these medications, unless instructed to do so by your transplant physician. Stopping or changing the doses of your medications without the approval of your doctor can make you very sick and can result in the loss of your transplanted organ, and possibly lead to death. Examples of these maintenance medications are belatacept, tacrolimus, cyclosporine, mycophenolate, sirolimus, and prednisone.

If you have transplant rejection, your health care provider may increase the doses or change your immunosuppressant medications.

Other Medications

You will be on medications after transplant to help prevent bacterial and viral infections. You will take these medications for 3-12 months after transplant. The length of time for each infection preventing medicine varies between people based on their personal risks of infection. Your transplant team will let you know when to stop taking these medications.

You may also need medications for high blood pressure, high blood sugar, high cholesterol, medications to reduce stomach acid, and for any other health conditions you may have. For a short time after transplant surgery, you may need narcotic pain medications. Follow the instructions of your transplant team when taking all medications.

Tacrolimus (Prograf®, ASTRAGRAF XL®, ENVARUSUS XR®)

What does it do?

Tacrolimus suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Take tacrolimus at the same time every day, 12 hours apart. On lab and clinic days, you will not take your tacrolimus until AFTER your blood tests have been drawn so a tacrolimus level can be checked. You may take your regular dose of tacrolimus after the blood tests have been completed. Do NOT stop taking tacrolimus. There are several brands of tacrolimus capsules and they are NOT equal to each other. Do NOT switch between brands. Contact your pharmacist and transplant coordinator if your tacrolimus pills look different than what you have been taking.

Why is a tacrolimus level important?

Regularly checking tacrolimus levels helps make sure that you are receiving the right dose of medication. Your transplant coordinator will inform you of any dose adjustments that need to be made with your tacrolimus dose. Always follow the dosing instructions given to you by the transplant team. Do not rely on the instructions on your prescription labels because changes to your medication directions can occur more often than prescription refills are needed.

What if I miss a dose?

If you miss a dose and it is still within three hours of the time the dose was due, you may take the dose. If it is more than three hours later than your dose was due, wait and take the next scheduled dose. Do not take double doses. Contact your transplant coordinator if you miss more than one dose.

What should I avoid when taking it?

Do not eat grapefruit or drink any beverages that contain grapefruit because it interferes with tacrolimus in the body. Do not take any medications, vitamins, or supplements prescribed by doctors outside of the transplant team without first checking with your transplant coordinator.

What side effects may I notice from taking it?

Common side effects of tacrolimus include: nausea, headache, mild tremors, increased risk for infections, numbness in hands or feet, hair loss, and increased blood pressure and blood sugar. Severe side effects of tacrolimus include dizziness, blurred vision, ringing in the ears, seizures, and muscle

weakness. Many of the side effects improve after your body gets used to being on tacrolimus. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Mycophenolate (Cellcept® or Myfortic®)

What does it do?

Mycophenolate suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Take mycophenolate at the same time every day, 12 hours apart. Swallow capsules whole and do not crush tablets. Avoid contact with the contents of the capsules or broken tablets. Do NOT stop taking mycophenolate.

What if I miss a dose?

If you miss a dose and it is still within three hours of the time the dose was due, you may take the dose. If it is more than three hours later than your dose was due, then wait and take the next scheduled dose. Do not take double doses. Contact your transplant coordinator if you miss more than one dose.

What should I avoid when taking it?

Antacids and vitamin/mineral supplements can interfere with mycophenolate. If your provider prescribes an antacid or vitamin/mineral supplement, take them at least one hour before or two hours after your dose of mycophenolate.

Mycophenolate can cause birth defects and miscarriage. Women of childbearing potential must use two forms of effective birth control while taking mycophenolate. If you are taking mycophenolate and desire to become pregnant in the future, talk with your transplant team. You will need to have your anti-rejection drugs changed by your transplant providers BEFORE you become pregnant.

What side effects may I notice from taking it?

Common side effects of mycophenolate include nausea, vomiting, diarrhea, low white blood cell counts and increased risk for infections. Severe side effects of mycophenolate include blood in urine, blood in bowel movements, difficulty breathing and dizziness. Many of the side effects improve after your body gets used to being on mycophenolate. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Prednisone

What does it do?

Prednisone is a steroid that reduces inflammation and suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Prednisone should be taken once daily in the morning. Taking prednisone with food sometimes lessens stomach upset that some people experience. Your prednisone dose will gradually decrease over time. Follow the dose instructions from the transplant provider carefully. Do NOT stop taking prednisone.

What if I miss a dose?

Since prednisone is taken once daily, you should take it as soon as you remember. If it is almost time for your next dose, do not take a double dose of medication to “catch up”.

What side effects may I notice from taking it?

Common side effects of prednisone include hunger, increased blood sugar and increased blood pressure. Other side effects include sweating at night, heartburn, muscle weakness, increased thirst, irregular heartbeat, unusual tiredness, mood changes, and increased risk of infections. Many of the side effects improve after your body gets used to being on prednisone. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Sirolimus (Rapamune®)

What does it do?

Sirolimus suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Take sirolimus at the same time every day, once daily. On lab and clinic days, you will not take your sirolimus until your blood tests have been drawn so a sirolimus level can be checked. You may take your regular dose of sirolimus after the blood tests have been completed. Do NOT stop taking sirolimus.

Why is a sirolimus level important?

Regularly checking sirolimus levels helps make sure that you are receiving the right dose. Your transplant coordinator will inform you of any adjustments that need to be made with your sirolimus dose. Always follow the dosing instructions given to you by the transplant team. Do not rely on the instructions on your prescription labels because changes to your medication directions can occur more often than prescription refills are needed.

What if I miss a dose?

Since sirolimus is taken once daily, you should take it as soon as you remember. If it is almost time for your next dose, take only that dose. Do not take a double dose of medication to catch up.

What should I avoid when taking it?

Avoid eating grapefruit or drinking any beverages that contain grapefruit. **Many medications interfere with sirolimus.** Do not take any medications, vitamins, or supplements prescribed by doctors outside of the transplant team without first checking with your transplant coordinator.

What side effects may I notice from taking it?

Common side effects of sirolimus are high cholesterol and high triglycerides (blood fats), high blood pressure, stomach upset, trouble healing wounds, mouth sores or ulcers, and increased risk of infections. Many of the side effects improve after your body gets used to being on sirolimus. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Azathioprine (Imuran®)

What does it do?

Azathioprine suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Take azathioprine at the same time every day, once daily. Do NOT stop taking azathioprine.

What if I miss a dose?

Since azathioprine is taken once daily, you should take it as soon as you remember. If it is almost time for your next dose, do not take a double dose in order to “catch up”.

What should I avoid when taking azathioprine?

Many medications interfere with azathioprine and change the amount of azathioprine in your blood. Do not take any medications prescribed by doctors outside of the transplant team without first checking with your transplant coordinator. Always check with your transplant coordinator before taking any over the counter medications, vitamins or supplements.

What side effects may I notice from taking it?

Common side effects of azathioprine include nausea, vomiting, diarrhea, decreased white blood cell counts, and increased risk of infections. Many of the side effects improve after your body gets used to being on azathioprine. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Belatacept (Nulojix®)

What does it do?

Belatacept is an IV medication that suppresses your immune system and helps prevent rejection of your kidney transplant.

How should I take belatacept?

Belatacept is given once every 28 days at an infusion center. The actual infusion takes 30 minutes, though in the outpatient setting we ask that you allow approximately two hours for your infusion appointment. Your first few months of belatacept will be given in the Duke Infusion Center. If you would prefer to switch your infusions to a center closer to your home, that can be arranged through your transplant coordinator. Do NOT stop taking belatacept.

What if I miss a dose of belatacept?

Your belatacept dose must be taken within three days of your scheduled treatment time. Contact your transplant coordinator immediately if you miss a scheduled belatacept infusion. Always make sure you have your next infusion scheduled before you leave the infusion center.

What should I avoid when taking belatacept?

Do not take any medications prescribed by doctors outside of the transplant team without first checking with your transplant coordinator.

What else should I know about belatacept?

All immunosuppressant medicines increase your risk for certain types of cancer. Belatacept specifically increases your risk of developing post-transplant lymphoproliferative disorder (PTLD).

What side effects may I notice from taking it?

Common side effects include fever on the day of the infusion, nausea, vomiting, diarrhea, headache swelling in your legs, and increased risk of infections. Severe side effects include confusion or problems with memory and changes in your mood or behavior. Many of the side effects improve after your body gets used to being on belatacept. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Cyclosporine (Gengraf®, Neoral®, Sandimmune®)

What does it do?

Cyclosporine suppresses your immune system to help prevent rejection of your kidney transplant.

How should I take it?

Cyclosporine should be taken at the same time every day, 12 hours apart. On lab and clinic days, you will not take your cyclosporine until AFTER your blood test have been drawn so a cyclosporine level can be checked. You may take your regular dose after the blood tests have been completed. Do NOT stop taking cyclosporine. There are several brands of cyclosporine capsules and they are NOT equal to each other. Do NOT switch between brands. Contact your pharmacist and transplant coordinator if your cyclosporine pills look different than what you have been taking.

Why is a cyclosporine level important?

Regularly checking cyclosporine levels help make sure that you are receiving the right dose. Your transplant coordinator will inform you of any adjustments that need to be made with your cyclosporine dose. Always follow the dosing instructions given to you by the transplant team. Do not rely on the instructions on your prescription labels because changes to your medications directions can occur more often than prescription refills are needed.

What if I miss a dose?

If you miss a dose and it is still within three hours of the time the dose was due, you may take the dose. If it is more than three hours later than your dose was due, then wait and take the next scheduled dose. Do not take double doses. Contact your transplant coordinator if you miss more than one dose.

What should I avoid when taking it?

Avoid grapefruit while taking cyclosporine. **Many medications interfere with cyclosporine.** Do not take any medications, vitamins, or supplements prescribed by doctors outside of the transplant team without first checking with your transplant coordinator.

What side effects may I notice from taking it?

Common side effects of cyclosporine include nausea, headache, elevated blood pressure, tremors and increased risk of infections. Other side effects include bleeding or swelling of your gums, vomiting, diarrhea, hair growth, chest pain, irregular heartbeat. Many of the side effects improve over time. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Sulfamethoxazole/Trimethoprim (Bactrim®, Septra®)

What does it do?

Sulfamethoxazole/trimethoprim is an antibiotic used to help prevent bacterial infections, specifically a certain type of pneumonia that can develop in individuals who are taking immunosuppressive medications. You will take this medication three times per week for one year post transplant. If you are allergic to sulfa drugs, you will be given another antibiotic medications to take.

How should I take it?

Take as instructed by the transplant team with a full glass of water. Do not stop taking this medication until directed by the transplant team.

What if I miss a dose?

Take your dose of sulfamethoxazole/trimethoprim as soon as you can. If it is almost time for your next dose, do not take a double dose of medication to “catch up”.

What should I avoid when taking it?

You may be more sensitive to light while taking this medication. Be sure to protect your skin when you are outside by using sunscreen, light colored clothing and a hat.

What side effects may I notice from taking it?

Common side effects of sulfamethoxazole/trimethoprim include nausea and diarrhea. Severe side effects include allergic reactions, difficulty breathing, low red or white blood cell counts, unusual weakness, dizziness, or yellowing of the eyes or skin. Many of the side effects improve after your body gets used to being on sulfamthoxazole/trimethoprim. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Valganciclovir (Valcyte®)

What does it do?

Valganciclovir is an antiviral medicine used to help prevent viral infections after transplant. About 80% of the population has been exposed to a certain virus called cytomegalovirus (CMV) at some point in life. Once exposed, that virus can live quietly in the body for life. When the immune system of someone previously exposed to the virus is suppressed, this virus can flare up and cause problems. Valganciclovir is used after transplant to help prevent either infection (if you were never exposed to CMV but your donor had been) or reactivation of your own CMV.

How should I take it?

Take valganciclovir with food at the same time each day. Take valganciclovir exactly as instructed by the transplant team. Depending on your kidney function, your dose may need to be adjusted.

What if I miss a dose?

If you miss a dose, take it as soon as you can. If it is almost time for your next dose do not take a double dose in order to “catch up”.

What should I avoid when taking it?

Valganciclovir may harm your unborn baby in women, and alter sperm production in men. Both men and women must use effective birth control continuously while taking valganciclovir.

What side effects may I notice from taking it?

Common side effects include stomach upset, nausea, vomiting, unusual weakness, and reduction in your white blood cells. Other side effects include increasing your risk of bleeding by lowering red blood cells and platelets. Many of the side effects improve after your body gets used to being on valganciclovir. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Acyclovir (Zovirax®)

What does it do?

Acyclovir is an antiviral agent used to help prevent a viral infection called Herpes Simplex Virus (HSV) after transplant. You may have been exposed to HSV at some point in your life. Once exposed, that virus can live quietly in the body for life. When your immune system is suppressed, these viruses can flare up and cause problems. You may be on this medication instead of valganciclovir after transplant to help prevent HSV.

How should I take it?

Take acyclovir with food at the same time each day.

What if I miss a dose?

If you miss a dose, take it as soon as you can. If it is almost time for your next dose do not take a double dose in order to “catch up”.

What side effects may I notice from taking it?

Common side effects include rash and lower back pain. Other side effects include blood in urine and unusual bleeding or bruising. Many of the side effects improve after your body gets used to being on acyclovir. Please contact your transplant coordinator regarding any side effects that you are experiencing.

Sample Medication Chart

The following is a **sample** medication chart of medications you may be on after transplant. Your transplant pharmacist will give you a specific list that includes every medication you will need to take prior to your discharge from the hospital.

Transplant Medications	Dose	Number	9am box 1	1pm box 2	5pm box 3	9pm box 4	Helpful Notes
Prograf® (Tacrolimus) Prevents rejection Dr Reddy	3mg	3 x 1 mg capsules	3 mg			3 mg	Hold am dose until after labs. No grape fruit
Myfortic® (Mycophenolate) Prevents rejection	720 mg	4 x 180 mg tablet	720 mg			720 mg	Do not crush, open or chew
Prednisone Prevent rejection	30 mg	6 x 5 mg tablets	30 mg				Take with food
Bactrim DS® (Trimethoprim-Sulfamethoxazole) Prevents bacterial infection	1 tablet	1 tablet (take on Mon., Wed., and Fri.)	1 tab				Take with food
Valcyte® (valganciclovir) Prevents CMV virus	900 mg	2 x 450mg tabs			900 mg		Take with a meal
Aspirin EC Blood thinner	81 mg	1 x 81 mg	81 mg				Report any unusual bleeding
Tramadol Reduces Pain	25 mg	1/2-1 tabs every 4 hours if needed					As needed for pain

Over the Counter Medications

**Medications presented below are safe to use in kidney transplant patients

** Do NOT use any medications not on this list without contacting the transplant coordinator

Complaint	Over the counter generic name	Some over the counter brand names (others are allowed if they have only the ingredients listed)
Allergies	Diphenhydramine, loratadine, cetirizine, fexofenadine, cromolyn nasal spray	Benadryl®, Claritin®, Zyrtec®, Allegra®, NasalCrom® Avoid: decongestant products with "D" in the name such as Claritin D®, Zyrtec D®, Allegra D®
Congestion	Guaifenesin *Do not use any decongestants like pseudophedrine (Sudafed®) or phenylephrine (Sudafed PE®)*	Mucinex®, Robitussin (plain)®, Tab Tussin 400, Coricidin HBP® Chest Congestion and Cough (contains dextromethorphan too)
Constipation *If lasts for > 3 days or if you have abdominal pain and fever, notify coordinator*	Docusate, senna, bisacodyl, polyethylene glycol 3350 Milk of magnesia *must be separated from transplant meds by at least 2 hours*	Colace®, Senokot®, Dulcolax®, Miralax®, Metamucil® Phillips® Milk of Magnesia
Cough	Dextromethorphan, guaifenesin *Products are available without sugar or alcohol if you are a diabetic*	Robitussin®, Delsym®, Mucinex® With both dextromethorphan and guaifenesin: Robitussin DM®, Coricidin HPB®
Low-grade fever, joint aches, headache *Contact coordinator for temp > 100.4	Acetaminophen Do NOT use ibuprofen (Motrin, Advil) or Naproxen (Aleve). Do not take aspirin unless instructed to do so by transplant physician.	Tylenol® *Do not exceed 3000 mg in 24 hours*
Nausea	Calcium carbonate	Tums®
Sneezing, runny nose	Chlorpheniramine, Chlorpheniramine and acetaminophen	Chlortrimeton® Coricidin HBP® Cold and Flu
Sore throat	Menthol, Benzocaine	Halls®, Chloraseptic®, Vicks®, Ludens®

Infections

Your immune system is the part of your body that is responsible for fighting infection. After your transplant, you will be taking medications to lower your immune system. With a lower immune system, your body has a decreased ability to recognize and destroy foreign substances. You will be more susceptible to infections. You are the most susceptible to infections in the first few months following transplant and for the first month after any rejection treatments.

Common infections that may occur within the first few months after transplant are wound infections, urine infections, lung infections (pneumonia), and reactivation of previous viral infections. You will be monitored in clinic closely for any signs or symptoms of these infections.

Latent Virus Reactivation

A latent virus is a virus that lies dormant (not active) in your body. After transplant, it is possible to have some latent viruses reactivate in your body. These are viruses that you or your transplanted organs were exposed to in the past. Under the setting of immunosuppression these viruses may replicate and cause damage to your body. Viruses that may reactivate include cytomegalovirus (CMV), BK, herpes simplex virus (HSV) and varicella.

You will have labs drawn to check for CMV and BK monthly for your first year post transplant. If these viruses are detected, appropriate adjustments in your immunosuppressant medications will be made and treatments will be ordered if necessary.

BK virus is a virus that can travel to your kidneys and urinary tract. In many people, the virus remains inactive, and symptoms of the infection never occur. BK can be detected in blood work. Most people have no symptoms of BK infection. Late symptoms of BK include blood in your urine, painful urination, and flu-like symptoms. BK is a serious infection that can damage your new kidney and is treated by a reduction of your immunosuppressive medications. If BK is detected in your blood work, your transplant team will inform you of what medication adjustments or treatments are needed. During treatment for any infection, you will be instructed to get frequent labs drawn. Successful recovery requires close monitoring and frequent adjustments so compliance with instructions is vital.

CMV is a very common virus that infects most adults in the US by the time they are 40 years old. Anyone who has had CMV infection can pass it on to others via bodily fluids. CMV can be detected in blood work. Symptoms of CMV include weight loss, diarrhea and fatigue. If CMV is detected in your blood work, your transplant team will inform you of what medication adjustments or treatments are needed. During treatment for any infection, you will be instructed to get frequent labs drawn. Successful recovery requires close monitoring and frequent adjustments so compliance with instructions is vital.

Prevention post-transplant

The best way to avoid infections post-transplant is through prevention. Please limit your exposure to visitors for the first 30 days post-transplant. The more people you are exposed to, the more germs you are exposed to. Avoid large crowds for the first few months post-transplant. Always avoid contact with people with contagious illnesses. Often, colds and other illnesses will last longer than before transplant because of immunosuppression.

Be sure to use **hand sanitizer** or **wash** your hands frequently. Keep hand sanitizer in your car or purse, and keep some easily accessible at home. Make sure kitchen countertops and food preparation surfaces are kept clean. Do not eat or drink after other people or reuse the same drinking glass without washing it daily. The cleaner you can be, the fewer germs you will be exposed to.

Use extra precautions when handling pets or gardening. Please wear gardening gloves when working with soil as numerous fungi and bacteria are present in soil. Please do not handle any animal waste products. Exercise caution with pets while your surgical wound is healing, do not allow pets to jump up on you.

Home Care and Activity

Post-transplant care requires adherence to a strict medical regimen in order to achieve best outcomes. You will be seen in clinic frequently after surgery to monitor recovery from surgery and effects of immunosuppression. It is very important that you keep all of your follow-up appointments and communicate any problems with the transplant team.

Activity post-transplant

While in the hospital, we will expect you to be out of bed within 24 hours after your surgery. You will need to be walking in the hall the day after your surgery. Inactivity increases the chances of medical problems, and slows your recovery from surgery.

You will have some degree of weakness after surgery. At home you should be focused on increasing activity each day while incorporating some rest periods. Exercise strengthens your heart, conditions muscles, reduces stress, helps to reduce high blood pressure, helps to reduce cholesterol, and helps control blood sugar levels. Exercise can prevent some of the side effects of your medications and is one of the best things you can do to help yourself live a longer and healthier life.

Most transplant patients are able to return to a normal activity level post-transplant. Do not let having a transplant restrict healthy exercise. Start slowly and gradually increase your activity, especially in the early post op period (until your wound is healed inside and out). Do not lift more than five pounds or do other activities that require you to bear down for the first 90 days after your surgery. Lifting, pushing, or pulling too much early after transplant may cause hernias to develop. No abdominal or core exercises for the first 90 days post-transplant. Avoid sports or activities that would risk a direct hit to your abdomen. Focus on exercising large muscle groups through walking, treadmill, or using stationary bike. Get your heart rate up for 30 minutes each day.

Sexual activity may be resumed after your incision heals, typically about 30 days post-transplant. Follow safe sex practices to prevent sexually transmitted diseases. Some women do not menstruate when they have kidney failure or once they start dialysis. Menstruation will usually resume after your transplant. It is necessary to use birth control after transplant to prevent pregnancy. Generally, you need to wait at least one year after transplant before attempting to become pregnant. You should discuss this completely with your transplant physician before stopping birth control. Many immunosuppressant medications are harmful to the fetus and can cause significant birth defects.

Do not drive until your staples are out and you are no longer taking any narcotic pain medication. Your doctor will typically clear you for driving a few weeks after your transplant.

Wound care

After your transplant, you are allowed to shower daily. Do not submerge your wound under water (no baths) until your wound is completely healed. Let warm soapy water flow over your transplanted incision, pat dry. Do not use any lotions or powders on the wound. Do not cover the wound unless it is draining. If you need to cover the wound to protect your clothes, use sanitary pads and paper tape to hold in place. These absorb well and are very effective in keeping the skin dry. Staples will be removed approximately three weeks after surgery. Steri-strips (if used) will fall off on their own approximately one week after they are placed.

Blake Drain Care

You may have a drain placed in your abdomen at the time of your kidney transplant to help collect some of the drainage from the surgery. The drain will remain in place until the amount of fluid decreases to 30 mL (about 1 ounce) or less per day. Many times, this drain will be removed prior to your discharge from the hospital. If the output from your drain is greater than 30 mL (about 1 ounce) per day, you will go home with the drain. Empty the bulb by removing the cap and squeezing the contents into a collection container. With the bulb squeezed, replace the cap. Typical drainage is pink tinged but clear; if drainage becomes thick or turns yellow or green, contact the transplant team immediately.

Wound Vac

Sometimes a device called a Wound Vac may be needed to assist with wound healing. This type of device helps promote blood flow to an open wound. Should a Wound Vac be needed after transplant, additional information and home health services will be arranged to help you care for your wound and Wound Vac.

Urinary catheter care

You will have a urinary catheter placed in your bladder at the time of your transplant. Typically, this will remain in place for three days post-transplant. While your catheter is in place, be sure that the urinary drainage bag is kept below the bladder. It is important that anyone handling your urinary catheter bag is using good hand hygiene and strategies to prevent infection and contamination. Sometimes it is necessary for someone to be discharged from the hospital with the catheter still in place. You will be educated on how to care for the catheter prior to discharge.

Diet and fluid intake

Diet and nutrition are very important aspects of everyday care after a kidney transplant. The renal diet you are currently following may no longer apply after your kidney transplant. You will however, need to continue to follow any dietary recommendations that you currently do for other disease processes, such as diabetes. To keep your new kidney and entire body healthy, the transplant team recommends you eat a well-balanced, low-salt, low-fat, low-cholesterol diet. We have included some of this information below, but you will receive a comprehensive education session during your hospitalization with specific nutrition instructions.

- First 6 weeks after transplant
 - You may need to eat smaller amounts of food more frequently (4-6 times per day). Eat a healthy diet with plenty of protein (found in red meat, chicken, & fish, but also in plant sources, like beans, lentils, & nuts) and continue to limit sodium <2300 mg per day.
 - Increase fluid intake by drinking water or unsweetened beverages. You should aim to drink 2-3 liters of fluids each day unless directed otherwise by the transplant team. There may be times when you are advised to limit your fluid intake.
 - If blood glucose levels are high, limit juices to 4 oz. per day. Reduce sugar intake to 28 grams (4 teaspoons) per day. Sugar is hidden in many different places; please get into the habit of reading nutritional labels on the foods you consume. You should avoid sugary drinks such as sodas, sprite and colas. Dietitian appointments are available as needed.
 - Potassium and phosphorus diet restrictions are usually no longer needed with good graft (transplanted kidney) function. However, the transplant team may need to make restrictions for a short period of time.
- Food Safety and Drug: Nutrient Interactions
 - The following foods are **NOT** recommended after transplant due to concerns with decreased immune function:
 - No grapefruit or grapefruit juice, including sodas that may contain this. Examples: Fresca, Sundrop, Sunny Delight, Squirt, Ruby Red Squirt, Citrus Blast.
 - No pomelo fruit
 - No undercooked or raw meat, fish, poultry, or over easy /runny eggs
 - No raw sprouts: alfalfa, bean or other sprouts
 - Wash all raw fruits/vegetables well
 - No unpasteurized (raw) milk or cheeses
 - Cook all deli meats, hot dogs, and luncheon meats to steaming hot
 - No unpasteurized pates or meat spreads
 - Avoid all herbal supplements
 - Avoid buffets

Health Maintenance Post-transplant

Please be sure you are following with a **primary care physician** to receive routine health exams and malignancy screenings, as necessary. Call the transplant coordinator for any new medications prescribed. Women over the age of 40 should have a yearly mammogram and Pap smear. Men over the age of 45 should have a yearly prostate exam. Everyone over the age of 50 should have a colonoscopy. Long term, the transplant team will closely follow your kidney transplant needs, but is not a substitute for your primary care physician.

It is recommended that you to stay up to date with vaccinations, especially the flu and pneumonia vaccines. Vaccinations should be delayed at least 2-6 months following transplant. However, you cannot receive any **live virus vaccines** post-transplant. Examples of live virus vaccines include: intranasal influenza vaccine, measles, mumps, rubella vaccine, oral polio vaccine, varicella vaccine, zoster vaccine. Contact your transplant coordinator prior to vaccine administration to be sure that the vaccine is safe for you. If you are around anyone who has received a live vaccine, avoid all bodily fluids from that person for 14 days after vaccine administration. Live viruses will be shed in bodily fluids for 14 days after administration of the vaccine.

Dental Health

Follow up with your dentist for regular dental cleanings and check-ups. Unless you have a dental emergency we recommend you wait 6 months after your transplant for routine dental cleanings/procedures. Brush twice per day, floss daily. Notify the transplant team if you notice any mouth sores, ulcers or white patches in your mouth. Inform your transplant coordinator about upcoming dentist appointments as you may need a dose of antibiotics prior to routine dental procedures. Transplant recipients may have a greater risk for developing an oral infection after dental procedures.

Cancers post-transplant

Immunosuppressive medications may increase your risk for developing cancers. Skin cancer and lymphomas (cancers of the lymph glands and white blood cells) are the most common types of cancer seen post-transplant. Help prevent skin cancers by wearing a hat while outside, using sunscreen with SPF 30 or higher, and protecting yourself from the sun. We recommend you see a dermatologist annually for a full body skin exam. Early detection of cancer can be helped by monthly breast exams and testicular exams. PAP smears and skin cancer screenings should be done by your physician every year.

Going back to work

It is our goal to make it possible for patients to work after transplant. Most patients can go back to work about 2-3 months after their transplant. Depending on the type of work you do, you may be able to return to work earlier than three months. Do not return to work until your transplant physician agrees you are ready to return to work.

It may be best to start back to work part-time and eventually move toward full-time work; most patients are more “out of shape” than they realize & cannot immediately work a full day. With your permission, we will assist you in providing your employer or insurance company with the information they require to help you get back to work again. Please let us know if your employer has specific paperwork that will need to be completed.

Patients and their families face a new lifestyle after transplantation that may cause them to feel nervous, stressed, or depressed. Stay in contact with your transplant social worker to aid you in dealing with emotional and psychological changes after transplant.

Caregiving

When you have a kidney transplant, you are required to have a caregiver that will be available to help you in several ways. During your hospitalization, your caregiver will need to be present for multiple education sessions with a pharmacist, dietician, and transplant coordinator. These in depth education sessions will prepare you and your caregiver for all that is required to provide great care after you are discharged. It is the goal of the transplant team that you and your caregiver are confident and prepared to be discharged.

You will need someone to drive you to your weekly clinic appointments for at least the first month after transplant. We also request that your caregiver participate in clinic appointments for your first month post-transplant. There is a lot of new information discussed and medication changes that may be made in clinic.

Once home, you will need your caregiver to provide 24 hours care for at least the first two weeks once you are home. You may need assistance with setting up your weekly pillbox, assistance with household chores and meal preparations, help with wound care, and assistance with keeping track of your logs for clinic.

Clinic Visits

After you leave the hospital, you will be seen frequently in the transplant clinic. You will typically be seen once per week for the first month. You will have appointments with your transplant surgeon, transplant nephrologist, transplant pharmacist and transplant coordinator. Financial coordinators, social workers, dieticians, and transplant psychiatrists are available to meet with you as needed. During clinic, the nephrologist and surgeon who examine you will assess for signs of rejection, illness, and wound healing and general health issues. This is the best time to ask questions about your transplant, medications, or other problems that you have noted.

Lab studies will be checked in clinic, and may be needed in between clinic visits as well. This is a way to monitor for your kidney function and to check your drug levels of your immunosuppressant medications. Labs should be drawn in the morning before you take your morning dose of tacrolimus, sirolimus or cyclosporine. Once your lab results are received, your transplant coordinator will review those results with the transplant nephrologist. Your transplant coordinator will give you a call once all your lab results have been reviewed to discuss any medication adjustments that need to be made.

We will review the records you need to keep for us to review after discharge. These records are extremely important! Not keeping them accurately can delay or negatively impact your recovery from surgery.

Two of the most important determinants of how you will do after a kidney transplant are exclusively under your control: regular clinic attendance and compliance with medications.

Please bring the following things to clinic each visit:

1. Medication list
2. Pillbox with your medications
3. Vital sign log, blood sugar log, intake and output log
4. Caregiver
5. Any questions you may have

Symptoms to report immediately

When to call

1. Fever greater than 100.5 F
2. Nausea or vomiting that lasts for more than 4 hours
3. Diarrhea more than 3 times in one day
4. Inability to take medications or out of medications
5. New pain that is sudden or sharp
6. Drainage from wound that is cloudy, smells bad or becomes thick
7. Painful or difficulty passing urine
8. Weight gain greater than 2 lbs. in one day or 5 lbs. in one week
9. You are admitted to an outside hospital for any reason

Who to call

919-613-7777 – Transplant Office

Use this number during business hours (Monday-Friday, 8am-4:30pm). Please ask to speak to your post-transplant coordinator. If you get a voicemail message and you need to report one of the above problems, do not leave a voicemail. Please proceed to instructions for urgent calls.

919-684-8111 – Duke Hospital Operator

Use this number for urgent calls anytime day or night. Please ask the operator to page the **kidney transplant coordinator on-call**. If you do not get a return call within 15 minutes, please call again.

911 – Emergencies

Use this number for life threatening emergencies such as chest pain or shortness of breath.

Transplant Nurse Coordinators are available 24 hours a day, 7 days a week to help you navigate urgent medical needs. We do not want you waiting until a convenient time to report the symptoms above. Please recognize that the transplant coordinators **on call** are not at the hospital during non-business hours. They are working from home in order to provide assistance for **urgent medical needs**. Routine requests for prescription refills, appointments, and lab orders will need to be handled during business hours by either speaking with your coordinator or leaving a voicemail message. You can also leave messages with our administrative staff that will make certain your coordinator gets the message.

Vital sign monitoring

It is important to keep track of your vital signs to monitor your recovery after transplant. Use the logs at the back of this notebook to keep a written record of your blood pressure, heart rate, temperature, blood sugar and intake/output. Bring the record to each clinic visit until instructed to stop. Recording vital signs is an important way you can help the transplant team help you do well after your kidney transplant.

Blood pressure: Check twice per day, around the time you are taking your medications. Become familiar with your usual blood pressure and pulse rate. Blood pressure readings have two parts; the top number is called the systolic blood pressure and the bottom number is called the diastolic blood pressure. Notify the transplant team with any systolic blood pressure readings greater than 170 or less than 100. Notify the transplant team with any diastolic blood pressure readings greater than 100.

Pulse: Your pulse is the number of heart beats per minute. Notify the transplant team with any pulse greater than 120 or less than 60.

Weight: Check your weight once per day, at the same time each day. Notify the transplant team with any weight gain of greater than 2 lbs. in one day or 5 lbs. in one week

Temperature: Check once per day, at the same time each day; notify the transplant team with temperature above 100.5 F. You should also check if you are feeling warm or having unprovoked sweating, as these may be signs of infection.

Blood Sugar: Check your blood sugars before breakfast, before lunch, before dinner and at bedtime. Notify the transplant team if your blood sugar is greater than 400 or less than 70.

Intake and Output: Record how much fluid you take in and how much urine you make. The goal is to drink 2 liters (64 ounces) of mostly water each day. Notify the transplant team if your urine output amount changes drastically from one day to the next.

Monitoring Progress

Please use the following sheets to track your health data. Bring these sheets with you to every clinic appointment. Continue tracking your data until instructed by the transplant team to stop. Please call with any questions or concerns.

The first few weeks after transplant are the most critical, concerns and issues need to be addressed immediately. Various complications can occur after kidney and pancreas transplantation. These may include rejection, infection, technical complications, and recurrence of your original kidney disease. While complications out of your control are always possible, it is important to remember that the single most important factor in the outcome of your transplant is **you**.

The best outcomes occur when you follow your health care team's instructions, monitor yourself for signs of rejection and infection, take your medications as directed, communicate with your coordinator regularly via phone and MyChart, and attend your regularly scheduled appointments. By communicating openly and freely with your team, we can stay on top of any issues and intervene early. Kidney transplantation is a lifelong commitment that will affect every aspect of your life. So take your responsibility seriously and take good care of yourself.

Vital Sign Log

Measure your vital signs each morning and evening and record it in the log below.

Day	Time	1	2	3	4	5	6	7
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	8	9	10	11	12	13	14
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	15	16	17	18	19	20	21
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	22	23	24	25	26	27	28
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	29	30	31				
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							

Vital Sign Log

Measure your vital signs each morning and evening and record it in the log below.

Day	Time	1	2	3	4	5	6	7
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	8	9	10	11	12	13	14
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	15	16	17	18	19	20	21
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	22	23	24	25	26	27	28
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							
Day	Time	29	30	31				
Weight	AM							
Blood Pressure	AM							
Pulse	AM							
Temperature	PM							
Blood Pressure	PM							
Pulse	PM							

Blood Glucose Log

Measure your blood glucose before each meal and record it in the log below. Note the amount of insulin (if any) you gave yourself.

Date	Breakfast		Lunch		Dinner		Bedtime	
	Glucose	Insulin	Glucose	Insulin	Glucose	Insulin	Glucose	Insulin
1								
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3								
4								
5								
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31								

Blood Glucose Log

Measure your blood glucose before each meal and record it in the log below. Note the amount of insulin (if any) you gave yourself.

Date	Breakfast		Lunch		Dinner		Bedtime	
	Glucose	Insulin	Glucose	Insulin	Glucose	Insulin	Glucose	Insulin
1								
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3								
4								
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28								
29								
30								
31								

Intake and Output Log

Measure your oral intake and urine output each day and record it in the log below.

Date	Morning		Afternoon		Evening	
	Oral Intake	Urine Output	Oral Intake	Urine Output	Oral Intake	Urine Output
1						
2						
3						
4						
5						
6						
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Intake and Output Log

Measure your oral intake and urine output each day and record it in the log below.

Date	Morning		Afternoon		Evening	
	Oral Intake	Urine Output	Oral Intake	Urine Output	Oral Intake	Urine Output
1						
2						
3						
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5						
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31						

Drain Output Log

Measure your drain output each day and record it in the log below.

Date	Morning	Afternoon	Evening
1			
2			
3			
4			
5			
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7			
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11			
12			
13			
14			
15			
16			
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19			
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28			
29			
30			
31			

Exercise Log

Record the type of exercise and the number of minutes in the log below.

	Morning		Afternoon		Evening	
	Type	Minutes	Type	Minutes	Type	Minutes
1						
2						
3						
4						
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Resources

We want to help you and your family deal with concerns that may arise after your transplant. Your social worker, transplant coordinator and physician can give you information on resources for your particular needs. The following are a list of websites that may be useful.

Duke University Health System

- www.dukehealth.com

Duke MyChart

- www.dukemychart.org/home

Carolina Donor Services

- www.carolinadonorservices.org

Donate Life

- <https://www.donatelife.net/>

National Kidney Foundation

- www.kidney.org

Explore Transplant

- <https://exploretransplant.org>

United Network for Organ Sharing

- www.unos.org

Medicare

- www.medicare.gov/

My Transplant Life

- www.mytransplantlife.com

Astellas Cares

- www.astellascares.com/transplant

My Med Schedule

- www.mymedschedule.com

National Foundation for Transplants

- www.transplants.org

Glossary

BK – a polyomavirus

Calcium – an electrolyte needed to maintain nerve and muscle function, also needed for bone health

Cholesterol – measures the amount of fats in the blood

CMV - cytomegalovirus

Creatinine – a protein filtered by your kidneys, an indicator of your kidney function

Glucose – measures the amount of sugar in the blood

Hematocrit – measures the percentage of red blood cells in your blood

Hemoglobin –measures the oxygen carrying capacity of red blood cells in your blood

HSV – herpes simplex virus

Magnesium – an electrolyte needed to maintain nerve and muscle function

Phosphorus – an electrolyte needed for energy production within cells, also needed for bone health

Potassium – an electrolyte needed for normal heart and muscle function

Sodium – an electrolyte needed to regulate blood volume and maintain muscle function

Tacrolimus/Cyclosporine/Sirolimus level – the amount of medication detectable in your blood

White blood count – the amount of white blood cells in your blood, changes can indicate infections

