



TRANSPLANT PATIENTS

OFFICE HOURS

LAB: 7:30AM-11:30AM

Nurses: Lindsay or Brittany
Direct line: 704-731-6905

MD VISITS: 8:15AM-11:00AM
1:00PM-3:30PM

After Hours: 704-348-2992

OFFICE APPOINTMENTS

Please BRING MEDICATIONS (either medication bottles or list used at home when taking medications) to each visit. Immediately after transplant there are often frequent medication changes and therefore we will review these with you at each visit. Please help us to ensure that the list of medications in the computer matches what you are taking at home. Changes in your meds will be made based on your medication list in our computer.

Newly transplanted patients are generally seen twice a week by a doctor with labs alternating with MD visits. These visits and labs will decrease in frequency as the time since your transplant increases. The doctor will guide you as to your frequency of lab and MD follow-up as you increasingly become more “stable”. Please keep in mind that you MUST have an appointment for both doctor visits and lab visits. The required paperwork for labs is done 48 hours in advance of your appointment.

For the first 6 months to 1 year, depending on your unique situation, you will be seen in the morning clinic. Appointments for this clinic are “first-come, first serve” This is done because patients take their Prograf, Rapamune, or Cyclosporine at 9am and 9pm. Therefore, everyone’s labs must be done at the same time. You will have your labs done and then be seen by the doctor in the order that you present to clinic.

LAB APPOINTMENTS

At the one year mark your appointments will be moved to the afternoon and you will not be able to have your drug level done at those appointments. DO NOT hold your immunosuppressant drugs until you see the doctor in the afternoon. The options for lab draws when you have an afternoon appointment are as follows:

1. Have labs done in our office the same morning of your scheduled afternoon appointment.

You will need a separate appointment for these labs.

2. Have labs done in our office 2-7 days prior to your afternoon appointment
3. Have labs done @ labcorp 2-7 days prior to your afternoon appointment



Transplant labs, if drawn in our office, are reviewed at the end of each day. At that time the physician will determine if there is a need for any medication changes. It is imperative that our office have a minimum of three working numbers to contact you regarding any changes that need to be made. It is your responsibility to contact our office if your contact information changes. The majority of these calls are made from 1-5:30 each afternoon Monday through Friday.

Labs come in to the physician over the computer and as he reviews them he writes orders that are carried out by the nursing staff. Because these labs are reviewed by the physician individually it is common for you to get more than one call from more than one person- do not be alarmed. You will only be called if there are changes to be made- LAB RESULTS THAT DO NOT REQUIRE CHANGES WILL NOT BE CALLED TO YOU. If you would like a copy of your labs and they were drawn in our office, we will be happy to mail them to you within a week. Please notify us by phone or while in the office each time you have labs if you would like to receive a copy.

We encourage you to have your labs drawn at either our office or a local Lab Corp draw station near your home since we are guaranteed the results within one to two days. If you opt to have them done elsewhere we cannot be responsible for obtaining the results. It will be your responsibility to make sure our office receives the results.

QUESTIONS AND CONCERNS

For questions or concerns you may call the above number between the hours of 8am and 5pm Monday through Friday and follow the voice prompts. We attempt to answer all calls immediately. Occasionally you will be prompted to leave a voicemail. If you think your situation is emergent call the main number and press “7”. The operator will page a clinician to assist you. Please **DO NOT LEAVE DUPLICATE MESSAGES** as it will delay the response time.

PRESCRIPTIONS

All prescription refill requests require a minimum of 48 hours. For routine prescription refill request, please notify your pharmacy **FIRST**. They will in turn send a request from their computer to ours. If your insurance company is affiliated with a “mail order” pharmacy, please call our office **2 weeks** in advance so that we can send a new prescription from our computer to their fax.

Prior authorizations can take anywhere from 48-72 hours. If your pharmacy tells you that a medication needs a prior auth. please call to let a nurse know- we will in turn contact our prior auth. department.

If you are in a situation where you may be changing or losing your insurance please notify us well in advance so we can initiate any patient assistance programs that may be available to you. Please keep in mind that we generally do not have samples of your immunosuppressant medications (Prograf, Cyclosporine, Cellcept, Myfortic, Prednisone, and Rapamune).



FORMS

We require a minimum of 7-14 business days to complete forms. Please leave forms at our front desk or mail them to our medical records department. We complete FMLA and short-term disability related to your transplant. We DO NOT complete long term disability forms as kidney transplantation is not a condition requiring long-term disability. There may be a charge for completion of forms.

PRIMARY CARE PHYSICIAN

We encourage all transplant patients to have a primary care physician (PCP) to manage your health care issues that are not transplant related. Please schedule a physical with your PCP approximately 3-6 months after your transplant to update them on all that has changed. If you do not have a PCP we will be glad to recommend one to you.

DENTAL APPOINTMENTS

Kidney transplant patients requiring pre-dental antibiotics are only those who also have mechanical heart valves. Please let us know if your dental office requires written clearance.

REQUEST FOR INFORMATION/ HIPAA REQUIREMENTS

We will be glad to provide records to any physician from which you are receiving treatment. HIPPA laws dictate that we must have your consent in writing in order to obtain your medical information from other providers or send information to your other doctors. Please complete a ROI form if you would like us to be able to share information.



8 Questions and 8 Answers about BK Nephropathy (a.k.a. Polyoma virus nephropathy, or PVN) in Kidney Transplant Patients

1. What is PVN, and why is it called “BK”?

The BK virus is a virus originally described in the transplanted ureter of a kidney transplant recipient in 1971. “BK” was the patient’s initials, and became the moniker of the virus itself. BK is a virus that is believed to live in the lining of the bladder and/or the lining of the ureter of a transplanted kidney. Most people (80% by some estimates) are at least exposed to BK by age 18. In patients with a normal immune system, it causes no known disease. In a small fraction of kidney transplant patients on immunosuppression, the virus reactivates and replicates and can cause damage to the transplanted ureter, or more commonly, damage to the transplanted kidney itself.

2. How did I get it?

Not sure. You may have had it in your bladder, or it may have been present but inactive in the transplanted kidney. Sometimes, the immunosuppression necessary to prevent your immune system from rejecting your kidney will also prevent your immune system from preventing the virus from replicating.

3. What can PVN do to my body?

The BK virus, in the vast majority of cases, only damages the kidney transplant. Although the virus travels in the bloodstream, there have only been a handful of cases in the literature of disease in other organs from the BK virus, and those cases are controversial. PVN can, but does not always, lead to the loss of your kidney.

4. Will I always be at risk for developing PVN?

PVN is thought to be a disease of over-immunosuppression, in most cases. If you had several rejections in the past requiring more aggressive immunosuppression, or if you had a lot of immunosuppression at the beginning of your transplant because of concerns for risk of rejection, you may be at higher risk of developing PVN. The timeframe for developing pVN is quite variable.

5. How will you know if I have PVN?

After your transplant, your transplant nephrologist will be checking your blood regularly for evidence of the virus. This test is called a BK-PCR, a test which counts the number of copies of the BK virus in your blood. Some centers also test the urine for this, but we do not find this very useful. There are no specific symptoms of BK-infection. This is not like a urinary tract infection, where you might have blood in your urine, or pain with urination, or fever. The diagnosis is often picked up by a blood test, and your doctor may order this in the setting where your creatinine is elevated. Often, you will need a biopsy of your transplant to confirm the diagnosis, so you can be treated correctly. Your doctor may also order it as a screening test, without any particular suspicion that you have the disease, so that it can be identified and caught early.

6. Are there any treatments for PVN?



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Yes, though the approach to treatment for PVN remains controversial, and is tailored to each patient's individual situation. Since PVN is thought to be a problem of over-immunosuppression, the first step is often to reduce (but not eliminate) immunosuppression. This will sometimes permit your immune system to eliminate the virus, but it carries a risk of developing transplant rejection. If you are on a prednisone-sparing protocol, your doctor may elect not to reduce your immunosuppression, and instead, place you on medicines that have been shown to have some promise in reducing and eliminating the virus from your body.

7. That sounds good. What kind of drugs are we talking about, and what are the side-effects? Does anyone get cured from this?

There are two medications often used in the treatment of PVN:

Arava or leflunomide-This pill was originally designed for use in rheumatoid arthritis, but has been shown to have some efficacy in the treatment of PVN. It also has immunosuppressive effects. Arave stays in the body for a very long time (several weeks), so unlike your other immunosuppression medications, drug levels are checked monthly. The main serious side effect of Arave is liver damage, so your doctor will be checking liver tests periodically as well.

Cidofovir-Cidofovir is an older anti-viral medicine that is only given intravenously. In standard doses, it can be quite toxic to the kidney, but in PVN, the doses are much, much smaller. If you are allergic to sulfa, be sure to tell your doctor or nurse, because a sulfa allergy is a contraindication to cidofovir therapy. This is usually given every two weeks for three months.

The duration of therapy is quite variable, and your doctor will be checking labs frequently to follow your progress. And yes, PVN can be cured in some circumstances.

8. I have BK virus in my blood. Do I have PVN?

Not necessarily. There is a difference between viremia and disease. Viremia means that the BK virus is detected in your blood, but doesn't necessarily mean you have damage to your kidney. Your doctor screens for BK regularly, so you may have low virus loads which could go away, or get worse.

9 Questions and 9 Answers about Cytomegalovirus (CMV) infection in Kidney Transplant Patients

1. What is CMV?

CMV is a virus present everywhere in the environment. Many people have been exposed to CMV in the past, but it may have resulted in nothing more than an upper respiratory infection. ***It is NOT contagious.*** However, people with compromised immune system, such as patients on immunosuppression, CMV can be more serious.

2. How did I get it?

In all likelihood, you already had it. Most cases of CMV disease are a result of a reactivation of the virus already in your body. Before the transplant, your immune system kept it suppressed. Sometimes, the immunosuppression necessary to prevent your immune system from rejecting your kidney will also allow the virus to replicate.

3. What can CMV do to my body?

CMV in a transplant patient can cause diseases that range from the mild to the severe. Most commonly, CMV can affect the gut, causing fever, diarrhea, loss of appetite generalized weakness, fatigue, nausea and vomiting. In the more severe (but rare) CMV can cause liver disease, lung disease, and damage to the retina, causing vision problems. There are also studies linking CMV to diabetes after transplantation but the reason why this is so is unclear.

4. Will I always be at risk for developing CMV disease?

You will not always be at the same risk for developing CMV disease. The vast majority of cases occur during the first year after transplant. After that the risk goes down, but never completely disappears.

5. How will you know if I have CMV?

After your transplant your nephrologist will be checking your blood regularly for the virus. This test is called a CMV-PCR, which measures how many copies of the virus are in your bloodstream. Some people have small amounts in their blood, but do not have any evidence of the disease. We call this “CMV viremia.”



Before the transplant you were screened to see if you had previously made antibodies against CMV. If you did, we call this CMV Positive. If not, we call this CMV negative. We also test the donor to see if they made antibodies against CMV. Recipients who did not make antibodies against CMV before transplant and get kidneys from donors who did make antibodies are at higher risk for developing CMV disease after the transplant. So called donor positive, recipient negative patients receive prophylaxis against CMV in the form of a pill called Valcyte. In most circumstances, other patients do not.

6. Yeah, I'm on Valcyte. What is it? Are there any side effects?

Valcyte is an anti-viral medicine specifically used for CMV. Valcyte stops CMV from replicating, it permits your body to eliminate the body on its own. Valcyte comes in a 450mg tablet; your dose will vary according to your kidney function, and whether you are taking Valcyte to prevent CMV disease or to treat existing CMV. An important side effect of Valcyte is low white blood cell count, so your doctor may be making several changes to your other medications while you are taking it.

Individual patient circumstances may vary. However, if you are taking Valcyte to prevent CMV disease, you will probably be on a lower dose (450-900 mg) for 3 months. If you are taking Valcyte for established CMV you will be taking it for several weeks to months, depending on how long it takes to clear the virus from your system.

7. Are there other treatments for CMV?

Yes, Valcyte is a new form of an older medication called *gancyclovir*. Gancyclovir can be given in pill or IV form. However the pill form of gancyclovir requires taking 15-20 pills a day and is not tolerated well. The IV form needs to be delivered daily for several weeks. IV gancyclovir is sometimes given instead of Valcyte for more serious CMV disease. There are other medications for CMV that are used infrequently, because of side effects, but are also sometimes needed for more serious CMV disease.

8. Will CMV hurt my kidney?

Not directly. Some people believe that CMV can directly affect the kidney, but that is controversial. However, being sick from CMV can sometimes affect your kidney if you become dehydrated or can't take your immunosuppression. Therefore treating it is very important to your overall health and the health of your transplant.



9. Will I get CMV more than once?

Most people will not get CMV more than once, but sometimes relapses occur. One cause of relapse is incomplete treatment of the original disease, so it is very important to take your medications as directed.



Post-Transplant Lab and Clinic Follow-Up Schedule

The following schedule is an outline of the typical lab and medical clinic follow-up visits required after transplant. There may be more lab and office visits necessary if there are significant complications following transplant.

LAB FOLLOW-UP:

- Labs drawn twice weekly for the first 4 weeks following transplant.
- Then labs drawn once weekly through post-transplant month # 6.
- Then labs drawn every other week through post-transplant month # 12.
- Then labs drawn monthly thereafter.

MD FOLLOW-UP:

- **Patients from Charlotte:**
 - Twice weekly for the first 1-2 weeks following transplant.
 - Then once weekly through the first month post-transplant.
 - Then every other week through post-transplant month # 3.
 - Then once monthly through post-transplant month # 6.
 - Then every other month through post-transplant month # 12.
 - Then every 3-4 months thereafter.
- **Patients outside of Charlotte:**
 - Twice weekly for the first 1-2 weeks following transplant.
 - Then once weekly through the first month post-transplant.
 - Then every other week through post-transplant month # 3.
 - Then once monthly through post-transplant month # 6.
 - Then every 3 months through post-transplant month # 12.
 - Then semi-annual visits for 2 years.
 - Transition back to your primary Nephrologist for shared care 6 months after transplant.*



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Name: _____

DOB: _____

The following were discussed at the initial transplant office visit.

	To bring a medication list to EVERY visit
	Not to take immunosuppressant medications before having labs drawn.
	When to go to the emergency room.
	How medication changes will be addressed.
	When and where to call for medication refills.
	The process and charges for completion of any forms.
	When you will be seen in the office, morning vs. afternoon appointments.
	How labs can be obtained at an outpatient lab, (ie: Labcorp, local lab)
	Primary care physician/ Dental appointments/Surgery
	To call with ANY new medications to see if they are safe to take after transplant.
	What is and how we treat CMV/BK
	When the nurses will call me
	Office visit follow-up layout
	Emergency contact/Alternate contact
	Voicemail/Phone call/ After hours

I met with a transplant nurse and we discussed the new transplant patient packet and office policies and procedures as they pertain to me. I have been given the opportunity to ask and have answered any questions I had.

I was provided with a copy of this packet.

Patient signature _____ Date _____

Responsible Party/Relationship _____ Date _____

Transplant nurse signature _____ Date _____