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# INFORMATION TO HELP YOU AFTER YOUR HEART TRANSPLANT

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The Post-Heart Transplant Coordinators and Office Manager will be your contacts after your heart transplant. Please read this handout to learn about follow-up appointments and who and when to call for anything you need after you leave the hospital.

## The Cleveland Clinic Outpatient Post-Heart Transplant Team

### Post-Heart Transplant Coordinators

- Monica Gervais , Nurse Practitioner
- Jacqueline Iammarino, Nurse Practitioner
- Kimberly Jones, Nurse Practitioner
- Lauren Nash, Nurse Practitioner
- Kerri Ross, Registered Nurse
- Crystal Kawczynski, Office Manager



### Heart Transplant Cardiologists

- Chony Albert, MD
- Paulino Alvarez, MD
- Pavan Bhat, MD
- Sanjeeb Bhattacharya, MD
- Andres Carmona-Rubio, MD
- J. Emanuel Finet, MD
- Mazen Hanna, MD
- Andrew Higgins, MD
- Karlee Hoffman, DO
- Eileen Hsich, MD
- Miriam Jacob, MD
- Karen B. James, MD
- Ran Lee, MD
- Michael Martyn MD
- Maria Mountis, DO
- Randall Starling, MD
- Wilson Tang, MD
- Ziad Taimeh, MD
- Preethi William, MD

## Contact Information

Call 911 right away if you have an emergency!



## Heart Transplant Office

Call 216.445.6590 or 800.223.2273, ext. 56590 and leave a message if you:

- Have a medical question or problem that is NOT an emergency
  - Have not gotten biopsy/lab results within 72 business hours
  - Need to schedule or reschedule an appointment or have questions about your appointment.
- Always call the heart transplant office about heart transplant appointments.** Do not call the general Cleveland Clinic appointment line.
- Have any changes to your medications prescribed by other healthcare providers
  - Need a refill for your immunosuppression, blood pressure or cholesterol medications. Please contact your primary health doctor/specialist if you need refills on other medications.
  - Lose your insurance coverage or if you have trouble paying for your medication



**We will return your call within 24 business hours.**

Office hours are Monday-Friday 8:00 a.m. to 5:00 p.m.

During non-business hours and holidays, call 216.444.2200 or 1.800.223.2273 and ask for the heart failure cardiologist on call to be paged. Call back if we do not return your call within an hour.

Heart Transplant Office fax: 216.444.6428

## MyChart

You can use MyChart for non-emergency questions and updates and to request medication renewals. It may take up to 3 business days to get a response.

### Heart Transplant Office Mailing Address

Cleveland Clinic Post-Heart Transplant Office  
9500 Euclid Avenue  
Desk J3-4  
Cleveland, OH 44195

## Post-Heart Transplant Testing Schedule

### Biopsies

Your cardiologist will determine your post-transplant biopsy schedule. A general schedule is:

- **First month after transplant:** One biopsy a week (4 total)
- **Second month after transplant:** One biopsy every other week (2 total)
- **Third to sixth month after transplant:** One biopsy every four weeks
- **Seventh month to one year after transplant:** One biopsy every six to eight weeks



*(continued)*

*(General biopsy schedule, continued)*

- **One year to two years after transplant:** One biopsy every three months
- **Two years to three years after transplant:** One biopsy every four months
- **Three years to five years after transplant:** One biopsy every six months

You will only have biopsies after five years if needed. You will still have office visits every six months.

## **Other testing**

Along with routine biopsies, you will have other tests:

- **Echocardiogram (echo):** One week after your transplant, and then at least once a year
- **Coronary Artery Assessment:** we will check your coronary arteries once a year with either a cardiac catheterization or a stress test

## **Biopsy Appointment Information**

You will see the Nurse Practitioner or your Cardiologist for your heart transplant follow up visits. The Heart Transplant Coordinators will make sure your Cardiologist is updated if you do not see him/her for a visit.

### **IF YOU NEED TO CANCEL OR RESCHEDULE your appointment:**

- Please call the Post-Heart Transplant office: 216.445.6590. DO NOT call the general Cleveland Clinic appointment line.
- You can tell the Cath Lab Scheduler you need to cancel, but you must contact the Post-Heart Transplant Office the next day to reschedule your appointment.

## **The evening before your biopsy**

The Cath Lab Scheduler will call you the evening before your biopsy to confirm your appointment. **If you do not get a call by 5:00 p.m., call 216.445.6727.**

**Although the scheduler may give you a time for your biopsy, please arrive at 7:30 a.m. on the day of appointment.**

- Do not eat after midnight!



## **The day of your biopsy**

- Please bring snacks to eat after your biopsy and all the medications you need to take during the day. Do not take any medications before you have your blood drawn!

## **Your appointment includes four steps:**

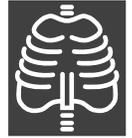
### **Step #1: Go to the J1-1 Admitting Desk at 7:30 A.M.**

- Confirm your insurance authorization and get your ID bracelet
- Make sure we have the correct contact information for all doctors who should get information from our office. Please also tell the Post-Heart Transplant office about any changes.

## **Step #2: Go to J1-4 for lab tests, an EKG and chest X-ray**

### **Tacrolimus (Prograf) testing**

You must have your blood drawn 12 hours after you take your tacrolimus (Prograf). This is so we have the right information to make any needed changes to your dose. **It is best to have your blood drawn exactly 12 hours after you take the medication, but it is OK to have it drawn 30 minutes earlier or later.** For example, if you take the medication at 8:00 p.m. the night before your biopsy appointment, you can have your blood drawn between 7:30 a.m. and 8:30 a.m., but try to have it drawn exactly at 8:00 a.m.



Please let the heart transplant office know if you have any questions about this process. **Please follow these instructions for every visit and for blood tests needed between visits.**

Take your morning dose of immunosuppression medication with just a few sips of water after your lab work is done.

## **Step #3: Go to J2-1 for your biopsy**

If you are not able to be seen at your scheduled time, you may ask the J2-1 desk receptionist to page the transplant coordinator you are scheduled to see and ask if you can have your office visit before your biopsy.

## **Step #4: Go to J3-4 - the Heart Transplant/Heart Failure Department**

The last step in your appointment is to see a Post-Heart Transplant Coordinator. Please know that your appointment time is a place holder. We see patients in the order they come into the clinic. We will do everything we can to help you be seen as quickly as possible. But, we sometimes need to see emergency patients right away.

## **After your biopsy**

The Post-Heart Transplant Coordinator you saw during your visit will contact you the day of your visit only if we need to talk to you right away about the biopsy results or make changes to your medications. Otherwise, your Coordinator will contact you within a few days of your visit to review the results, your medications and give you your next appointment date.

### **Interpretation of Heart Biopsies**

A pathologist will use a microscope to examine the tissue taken from your heart. The tissue is graded using a scale developed by The International Society of Heart and Lung Transplantation. Depending on the grade, you may or may not need treatment.

<b>Grade</b>	<b>Interpretation</b>	<b>Treatment Needed?</b>
0	No rejection	No
1R	Mild rejection	No
2R	Moderate rejection	Yes
3R	Severe rejection	Yes

## **Blood tests between biopsy appointments**

Your post-heart transplant coordinator will let you know when you need to have blood work between biopsy appointments. **Please follow the same instructions for your blood test as you do for your biopsy appointment blood test. Call the transplant office to let us know you have had your blood test(s).**



**If you live locally**, the post-heart transplant coordinator will put the order in for you to have your blood drawn at any Cleveland Clinic lab.

**If you do not live near a Cleveland Clinic lab:** You will get a “Standing Order” for blood tests before you leave Cleveland Clinic. You will get a mailer kit to ship the tacrolimus (Prograf) level to Cleveland Clinic for processing. Please give the standing order and mailer to the lab. If you need blood drawn for a basic metabolic panel (BMP) or complete blood count (CBC), please have your local lab process them and fax the results to the transplant Office at 216.444.6428.

## Self-Monitoring

Part of your care after your transplant includes self-monitoring. These steps will help identify problems with your new heart. Use the records on the next pages to write down the information, and bring them with you to every appointment.

### Heart Rate: Check your heart rate twice a day.

A normal resting heart rate after a heart transplant can range from 90 to 120.

Call the Transplant Office if your heart rate is lower than 60 or higher than 120.



### Blood Pressure: Check your blood pressure twice a day.

A common side effect of anti-rejection medication is high blood pressure.

Call the Transplant Office if your blood pressure is higher than 140/90 (systolic/diastolic) or less than 90 systolic.



### Temperature: Check your temperature twice a day.

Immunosuppression medication can increase your risk of infection. It is important to watch for signs of infection and **call the Transplant Office if you have:**

- A temperature higher than 99.5 F (38 C)
- Fever, shaking, chills or excessive sweating
- Fatigue
- More redness or drainage than usual from your incisions
- A cough with phlegm
- Shortness of breath that is worse than normal
- Sore throat or mouth
- Stuffy nose, sinus pain or tenderness along your upper cheekbones or a sinus headache
- Persistent diarrhea or abdominal pain
- Problems with urination, such as pain, burning, constant need to urinate, urinating more often than normal or trouble urinating
- Urine that is bloody, cloudy or foul smelling
- White patches in your mouth or on your tongue



**Weight: Weigh yourself every morning, after you use the bathroom and before you eat breakfast. Use the same scale and wear no clothing or the same clothing each time.**



Call the Transplant Office if you gain 2 pounds within 24 hours or 3 to 5 pounds within a week.















## Medications

You will take medication for the rest of your life after your heart transplant. These medications:

- Prevent your body from rejecting your new heart
- Protect you from infections
- Control side effects



### Please make sure you:

- Know the names of all the medications you take and why you need to take them.
- Have a current list of all medications and supplements you take. Keep this list with you at all times. Bring your medication list with you to every appointment.
- Call the Transplant Office if you have side effects from your medications.
- Refill medications before you are close to running out of them so you always have a supply. Keep track of the number of refills you have left.

**Please take all of your medications exactly as prescribed. Do NOT stop taking any medication without first talking to your transplant team!**

In order to keep your new heart healthy, it is important that you do not miss any doses of your medications. If you miss or skip a dose of your immunosuppressant medication, it can cause rejection.

### Try using one or more of these tools to help you remember to take your medications:

- Pill organizer
- Alarm clock or watch
- Reminder app on your phone
- Medication checklist

### If you miss a dose:

- **If you remember the dose within 6 hours**, take that dose as soon as you remember.

Example: It's 11 a.m., and you forgot to take your tacrolimus at 8:00 a.m.

What to do: Take the forgotten dose now, and take your next dose at the normal time.

- **If you remember after 6 hours**, skip the dose and go back to your normal schedule.

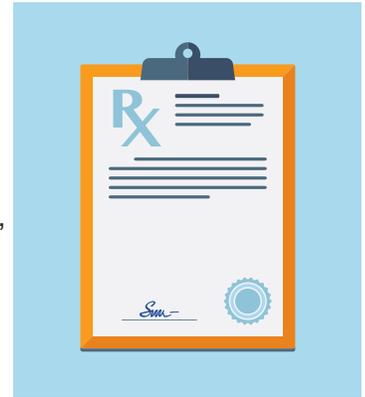
Example: It's 4:00 p.m., and you forgot to take your tacrolimus at 8:00 a.m.

What to do: Skip the forgotten dose and take your 8:00 p.m. dose as scheduled.

**Never take a double dose. If you miss more than one dose, call the transplant office.**

## Medication refill/renewal information

- The transplant office can renew/add refills for your immunosuppression, blood pressure, and cholesterol medications ONLY. Please follow up with your PCP/specialist for refills on other medications.
- You can request renewals by calling the Transplant Office or by sending a MyChart message. If you use MyChart, please include the medication name(s), strength (dosage) of the tablets/capsules, the supply you need (30- or 90-day) and pharmacy information (name and phone number).
- Call the transplant office if your immunosuppression capsules look different than your usual ones or if they are made by a different manufacturer.



## Other medication information

- There are many medications and supplements that can interact with your immunosuppression medications, which puts you at risk for rejection or kidney problems. Do not start or stop taking any medication or supplement (prescription or over-the-counter/nonprescription) without first calling the transplant office.
- Do not take non-steroidal anti-inflammatory medication (NSAIDs) (ibuprofen, naproxen, Advil, Motrin, Aleve, etc.) because they can harm your kidneys. If you need to take a pain reliever, acetaminophen (Tylenol) is the preferred medication to use.
- Take laxatives that contain magnesium or aluminum one hour before or two hours after you take Cellcept (mycophenolic acid).
- If you have cold-like symptoms, please call the transplant office so we can add the information to your chart.
- **You can take these medications for relief from cold symptoms:**
  - Diphenhydramine (Benadryl)
  - Loratadine (Claritin)
  - Cetirizine (Zyrtec)
  - Chlorpheniramine (Coricidin HBP)
  - Guaifenesin (Mucinex) and dextromethorphan (Robitussin DM)
  - Saline nasal spray
  - Acetaminophen (Tylenol)
  - **Do not take medications that contain pseudoephedrine or phenylephrine.** These medications often have the letter "D" or "PE" after the name of the medication.
- Do not eat grapefruit, pomegranate, star fruit or anything that contains these, as they can interact with your transplant medications.
- Keep your medications in a cool, dry place and out of the reach of children.
- When you travel, keep your medications with you (not in a checked bag). Bring an extra supply in case your trip is longer than expected.

## Infection prevention

It is important to do everything you can to avoid getting an infection. Your risk of infection is higher after you have a heart transplant because of the anti-rejection medication you must take. If you get an infection, it can be worse than it is for a person who has not had a transplant. Please follow these steps and let us know if you have any questions or concerns.

- Wash your hands
- Avoid contact with anyone who is sick.
- Avoid touching your face.
- Avoid crowded areas.
- Do not use tobacco, and avoid tobacco smoke.
- Do not smoke marijuana, and avoid marijuana.
- If you have pets, talk to your transplant coordinator about ways to safely care for them. Avoid bird droppings.
- Avoid gardening, landscaping and farming.
- Avoid construction sites and other dusty areas.
- Avoid aerosols.
- If you cannot avoid high-risk areas, it is recommended that you wear a mask.
- Do not use hot tubs/Jacuzzis.
- Do not drink water directly from lakes or rivers.
- Do not drink well water that is not frequently screened for bacteria. If you use well water, it needs to be tested for contamination every year.

## Preventing infection when traveling

The Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) offer health information to travelers:

[cdc.gov/travel/destinations/list/](https://www.cdc.gov/travel/destinations/list/)

[who.int](https://www.who.int)

When you take a long-distance trip, drink plenty of water, wear compression stockings and stop/get up to walk for 10 minutes every 90 minutes. Also, remember to keep your medications in your carry-on bag.

## Vaccinations

Make sure you are up to date on all vaccinations.

Get a yearly flu vaccine, unless your healthcare provider tells you not to have one. You cannot have the nasal vaccine after your transplant.

### Avoid live vaccines for:

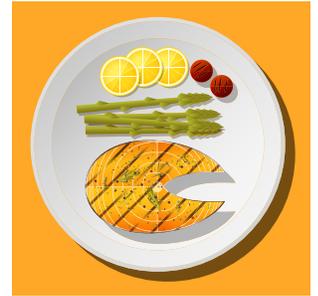
- Measles, mumps, rubella (MMR combined vaccine)
- Rotavirus
- Smallpox
- Chickenpox
- Shingles vaccine (older version – Zostavax)

## Nutrition

You should eat a heart-healthy diet. If you need help choosing foods, please talk to your transplant coordinator, doctor or a registered dietitian.

The Food & Drug Administration (FDA) offers information about food safety for transplant patients:

[fda.gov/food/people-risk-foodborne-illness/food-safety-transplant-recipients](https://www.fda.gov/food/people-risk-foodborne-illness/food-safety-transplant-recipients)



## Corresponding with donor families

It is up to you to decide whether or not to write to the donor family. If you would like to write to them, please refer to the Lifebanc pamphlet for guidance. Please bring your letter to your appointment, and we will send it to Lifebanc.

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*This information is not intended to replace the medical advice of your healthcare provider.  
Please consult your healthcare provider for advice about a specific medical condition or treatment.*

