Three Months Post Transplant
“Going Home”
Check List

- Identified local Primary Care MD
- “Take home” packet to give to local MD
- Provide us with contact information for local MD
- Have current Med Action Plan
- Outside lab requisition for standing orders
- Provide us with contact information for local lab
- Provide us with contact information for local pharmacy
- Review of side effects of medications by pharmacist
- Review of contact numbers to reach transplant team
- Review of symptoms to call and report to transplant nurses
- Review of health records-including vital signs, blood sugar readings-
  
  *make sure blood sugar readings are pre-meals

- Review by Dietician
- Review by Social Worker
- Never leave the clinic without scheduling next return appointment
- Cardiac Rehab/ Long Term Exercise program
Don’t Forget!

• Remember to NOT take your prograf and cellcept prior to morning lab work. Make sure you took your evening dose the night before. Ideally, these medications should be taken every 12 hours. When we ask for “good trough levels,” it means to draw your blood work 12 hrs. after your evening dose and then take your morning medication right after labs are drawn.

• Wear your mask whenever you visit Stanford, especially in the car and after you leave.

• When instructed to stop itraconazole (sporonox), have weekly lab work for at least 1 month to monitor levels.

• Try to walk at least 30 minutes a day

• Eat low saturated-fat, low cholesterol, low sodium diet as directed

• Have contact phone numbers in wallet or cellphone of nurse coordinators to call if any signs or symptoms of rejection and infection occur.
Masks

Preferred when visiting Stanford even after 3 months

Approved after 3 months—but does not filter out aspergillus—(a common fungus) WEAR AT YOUR OWN RISK!
Rejection

• **Possible** signs of rejection include shortness of breath, feeling dizzy, fatigue, sudden weight gain, swollen ankles, low blood pressure, mild fever, fast heart rate or skipping heart beats, etc.. rejection can also have **NO** symptoms.

• The symptoms listed above can be caused by many other things besides rejection.

• Your job is not to determine whether you are rejecting but to let us know about the symptoms so we can figure out what is going on.
Infection

• Fever (can be slight)
• Shaking chills
• Redness or swelling of your incisions or chest tube sites or the presence of drainage or pus
• Nausea and/or vomiting
• Confusion
• Diarrhea
• Shortness of breath
• Cough, especially if it is productive
• Pain not relieved by your prescribed pain medication
• Generalized lack of energy or increased fatigue
Gentle Reminders

• Once sternal precautions have been cleared by your MD’s--you may resume driving.
• Continue to observe sternal precautions for lifting until cleared.
• Call nurse coordinators when you need medication refills at least 2 weeks prior to running out. Insurance issues contribute significant delays in obtaining refills. Call sooner than later!!!
• Update financial coordinator with insurance updates and changes. Suzanne Tegio 650-498-6334.
• Call your social worker for coping skills, insurance issues and patient assistance services.
• Call Admitting department 650-723-6221 to update your contact information (primary phone number, phone and address changes, emergency contacts etc.).
Contacting Your Donor Family

Although the decision to write your donor family is very personal, many transplant recipients want to know about the person who donated the organ they received. If you choose to write to your donor family, the following guidelines may make the process easier. Please wait at least 6 months before contacting your donor’s family to allow them time to grieve. The donor family may contact you before the six months though.

Confidentiality

Although there is no law that a donor’s family and the organ recipient cannot meet and know each other’s names, all Organ Procurement Organizations (OPO’s) have policies to protect the privacy of both parties.

Writing Your Letter

What information should I include?

• Your first name only
• The state where you live
• Recognize the donor family’s generosity and thank them for their gift
• Describe how long you waited for a transplant and how the wait affected you and your family
Donor Letter Cont.

Writing Your Letter
What information should I include?
• Explain how the transplant has improved your health and changed your life
• Describe the impact of your transplant on your own family
• Explain what has happened in your life since the transplant
• Mention if you are married, have children, grandchildren, hobbies or interests
Donor Letter Cont.

What information should NOT be included?

- Do not include your address, city or phone number
- Do not include the name or location of the hospital where the transplant surgery was performed. Or the names of your transplant health care providers
- Use caution when including religious comments, as you do not know the religion of the donor’s family

**Will I hear from the donor’s family?**

You may or may not hear from your donor’s family. Some donor families may feel that writing about their loved one and their decision to donate helps them in their grieving process. Others choose not to write the organ recipient. This is a personal decision and you will not be judged either way.

If the donor family chooses to respond, they will send a letter to the OPO. The OPO will then forward the response to you.
A word from the pharmacist

- If taking tacrolimus, it may be taken with or with out food. However, be consistent as food affects absorption.

- Call before taking any over the counter (OTC) medications, herbal supplements or alternative medications--many interactions

- Do NOT take Non-Steroidal Antinflammatory Drugs (NSAIDs)--motrin, ibuprofen, Aleve naproxen, Advil--may cause serious kidney damage.

- Do not drink grapefruit juice or take St. John’s Wort (a natural mood stabilizer)--interactions

  **Side Effects of Immunosuppression**

  - Tacrolimus (Prograf), Cyclosporine (Sandimmune, Neoral, genraf, cyclosporine modified)
    - Tremors, headaches, confusion, seizures, kidney function damage, high blood pressure, high cholesterol, gum enlargement, hair loss or growth, and skin changes
  
  - Mycophenolate (Cellcept, Myfortic)-- nausea, vomiting, ↓ white blood cell count, anemia

  - Sirolimus (Rapamune), Everolimus (Zortress)--impaired/delayed wound healing, mouth ulcers, increased cholesterol and triglycerides, swelling, and lung or pancreas disease.

  - Prednisone (Deltasone)--psychosis, mood swings, round face (moon face), swelling , diabetes, nervousness, insomnia, stomach ulcers, and osteoporosis (brittle bones).
Diabetes

Low blood sugar and High blood sugar

• **Low** blood sugar is defined as a level <70mg/dl.

• Signs and symptoms of low blood sugar include: hunger, shakiness, nervousness, sweating, dizziness or lightheadedness, sleepiness, confusion, difficulty speaking, anxiety and weakness. If low blood sugar happens at night - you may have nightmares or cry out, night clothes may be damp, and you may experience confusion and irritability upon waking.

• **High** blood sugar is defined as a level of >150mg/dl

• Signs and symptoms of high blood sugar include: thirst, frequent urination, hunger, blurry vision, sleepiness and confusion.

• ***It is very important that you monitor your blood sugars as directed and call if you are experiencing frequent low or high blood sugars. Bring your blood sugar and blood pressure logs to clinic for review with RN’s and MD’s.***
Treating blood sugars

- If you have low blood sugars-take something to increase your blood sugar level quickly. You should take 3 or 4 glucose tablets, taking 1 serving of glucose gel (the amount equal to 15 grams of carbs), ½ cup (4oz) of any fruit juice, ½ of regular soda, 5-6 pieces of hard candy or 1 tablespoon of sugar or honey.

- If you have high blood sugars- observe your symptoms and observe the low glucose diet prescribed by your doctor and dietician.
Nutrition

• Achieve and maintain a healthy weight:
  – Limited saturated fat, sodium and cholesterol intake, consume a plant-based, high fiber diet
  – Review detailed nutrition guidelines in transplant binder
  – Check out the American Heart Association Nutrition Center for more information: http://www.heart.org/HEARTORG/GettingHealthy/NutritionCenter/Nutrition-Center_UCM_001188_SubHomePage.jsp
  – Exercise daily, ideally 45 minutes – 1 hour

• Control your blood sugar levels (if applicable):
  – Consume modest portions of high carbohydrate foods and limit intake of foods with added sugar
  – Check your blood sugars and keep a detailed log as directed by transplant team

• Stay hydrated for healthy kidneys (and weight management!)
  – Drink 8-12 cups daily (2-3 liters) unless otherwise directed by team

• Eat high magnesium foods to maintain normal blood levels (see list in transplant binder)

• Avoid grapefruit and pomelo fruit and juice as it interacts with your transplant medications

• Review any unprescribed supplement products with transplant team prior to consuming them (especially herbal products)

• Contact the transplant Dietitian for more nutrition resources and support:
  – Erin Williams, RD, CNSC ph: 650-723-6200