



# Pre-Transplant Patient Education

Brought to you by your Heart Transplant Team

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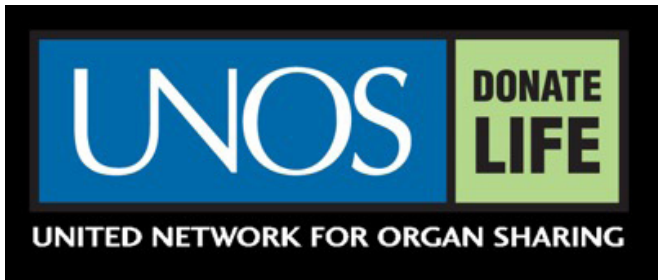
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Please feel free to ask us anything at any time. Remember, the more you learn now, especially about the immunosuppression medications, the better you will be prepared for transplant.



# Providence Heart Transplant

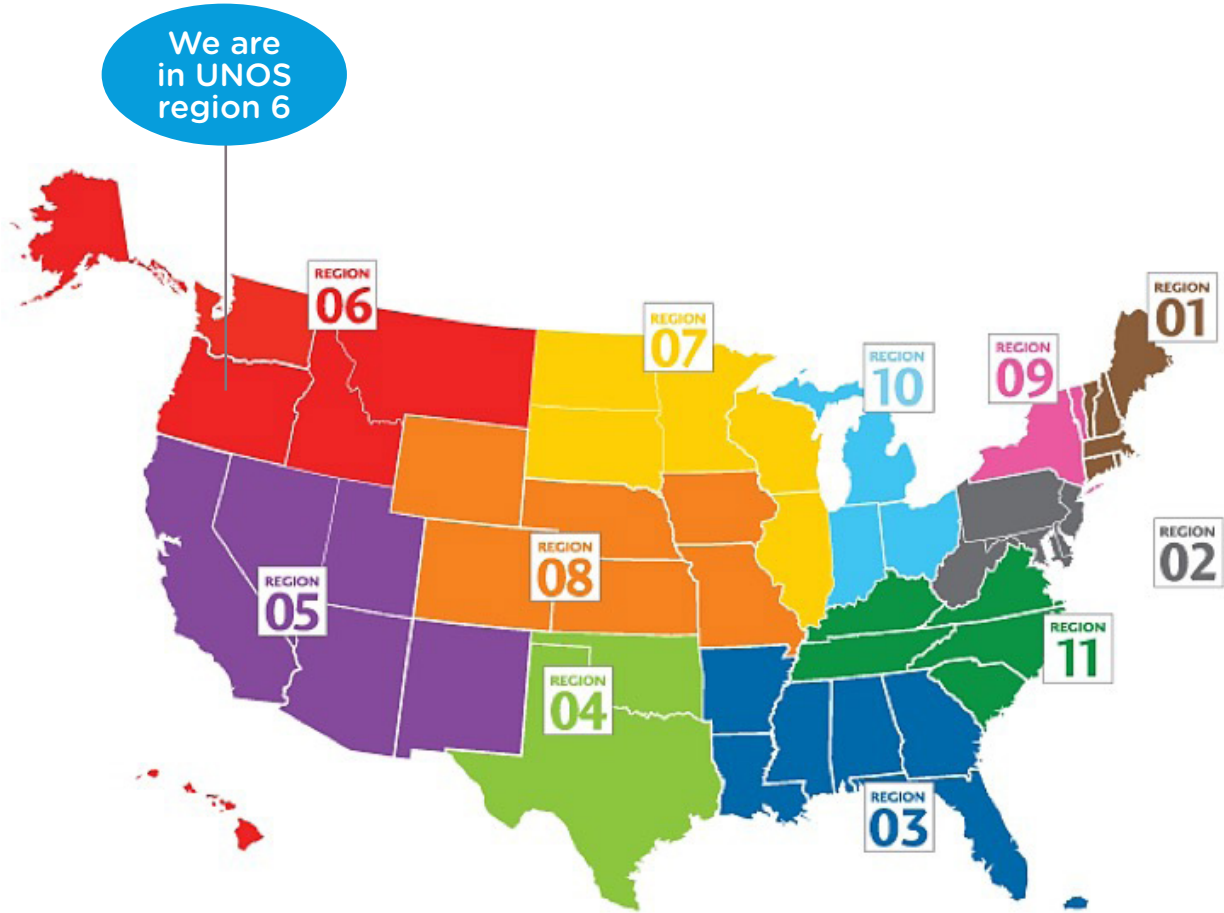
United Network of Organ Sharing (UNOS)



- On average, 3,400 Heart Transplants are performed in the United States each year
- There is a large waitlist for a life-saving heart transplant
- Any data related to heart transplant in the United States can be found here: <https://unos.org/data/>
- Data about any outcomes for a transplant program can be found here: <https://www.srtr.org/>
- A copy of our program's selection criteria for heart transplant is provided in the pre-transplant section of the education binder

# Our Heart Transplant Program


The Providence St. Vincent Medical Center’s heart transplant program is fully certified by CMS (Centers for Medicare and Medicaid Services) and UNOS (United Network for Organ Sharing).



# Organ Availability

While the number of transplants continues to increase each year, the number of patients in need of transplant is high. On average there are over 110,000 patients waiting for an organ transplant in the United States every year.

 **2021: 11th consecutive record-breaking year**

Heart  **4.3%** | 2021: 3,817 | 2020: 3,658

**More than 13,800**  
deceased donors in 2021

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**2021 donors, deceased and living**

**20,398**

*Total Donors January - December 2021 as of 01/12/2022*

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**2021 transplants**

**41,354**

*Total Transplants January - December 2021 as of 01/12/2022*

# Benefits of Heart Transplantation

- Enhance quality of life
- Resume daily life activities (ADLs)
- More freedom of travel
- Provide a chance for long-term survival
- Return to hobbies and activities you enjoy



# Risks of Heart Transplantation

- Infections
- Rejection
- Graft Failure
- Narrowed Heart Arteries (Cardiac Allograft Vasculopathy)
- Diabetes
- High Blood Pressure
- Cancer
- Surgical Complications

Each specialist on the multidisciplinary team will review all risks and benefits in detail with you.





# Barriers to Heart Transplant

Sometimes during the evaluation process previously unrecognized conditions are discovered. The transplant team will refer you to the appropriate providers for treatment. Sometimes the evaluation is paused while the condition is treated. Certain conditions make Advanced Heart Failure therapies too risky.

- Active infection
- Damage to other organs that can't be reversed
- Active or recent malignancy
- High sensitization
- High chance of dying with surgery
- Anatomy that makes transplant too high risk
- Active drug use
- Active alcohol abuse
- Active tobacco use
- Inadequate social support
- Body mass index >38
- Non-adherence to medical regimen
- Severe peripheral vascular disease or diabetes
- Anytime the medical team feels the risk of transplant would be greater than the benefit
- Need for additional social support

You will receive a copy of our centers inclusion and exclusion criteria for heart transplant during the evaluation.

# Barriers to Heart Transplant

## Substance Abuse

We recommend that you do not use:

- Alcohol
- Tobacco
- Illegal drugs

You must abstain from tobacco, marijuana, and illegal drugs to remain eligible for heart transplant. A positive screening test while active on the transplant list will result in your status becoming inactive and the team will discuss options with you in clinic.



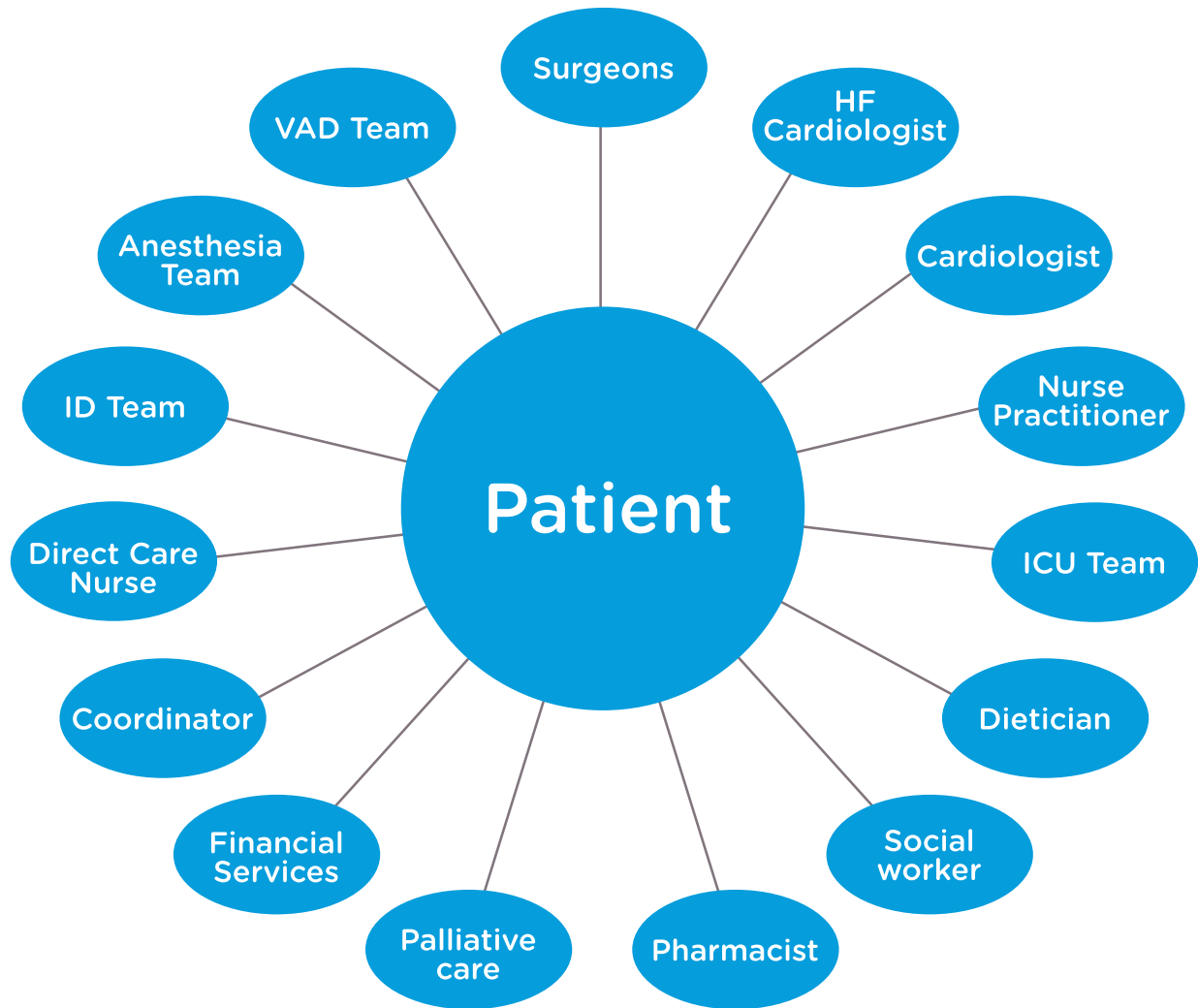
# Educational Acknowledgment/ Consent Review

Remember that prior to being evaluated for advanced therapies, our team stressed the importance of being educated on the entire process. You have the right to ask any questions and stop the process at any time. We are going to review the listing process for heart transplant and answer questions like:

- What will be expected of me?
- What are the expectations of the transplant team?
- What is UNOS?
- What is CMS?
- What does it mean to be listed?
- What are factors that could affect your wait time?
- What are the risks and benefits of having a heart transplant?
- What happens while I am waiting?
- How long is the surgery?
- How long will I be in the hospital after my transplant?



# Multidisciplinary Approach



# Support Reminder

## What kind of support will I need throughout the evaluation process?

- You cannot go through this process alone
- Survival requires people in your life who are able to give you the support and help you will need
- At least one support person is needed to provide support through your journey as a candidate and recipient post-transplant
- Support person(s) must be active participants in your transplant process



# Support Continued

## Your support person(s) will:

- Learn everything with you about Advanced Heart Failure Therapies and come to all your visits.
- Be present with you at the time of transplant until time of discharge
- Learn how to care for your chest incision as you heal.
- Be ready to go with you to lab, procedure, and clinic appointments
- Learn about all your medicines, be able to help you take them and know what they do, and potential side effects
- Be able to help you fill your pill box, keep track of each medicine you take, and write in your medicine diary
- Help you watch for signs of side effects, organ rejection, or other medical issues



# Blood Types for Heart Transplant



If you complete the evaluation process and the multidisciplinary team feels heart transplant listing is appropriate for you, as a recipient you will be matched with a deceased donor based on your blood type:

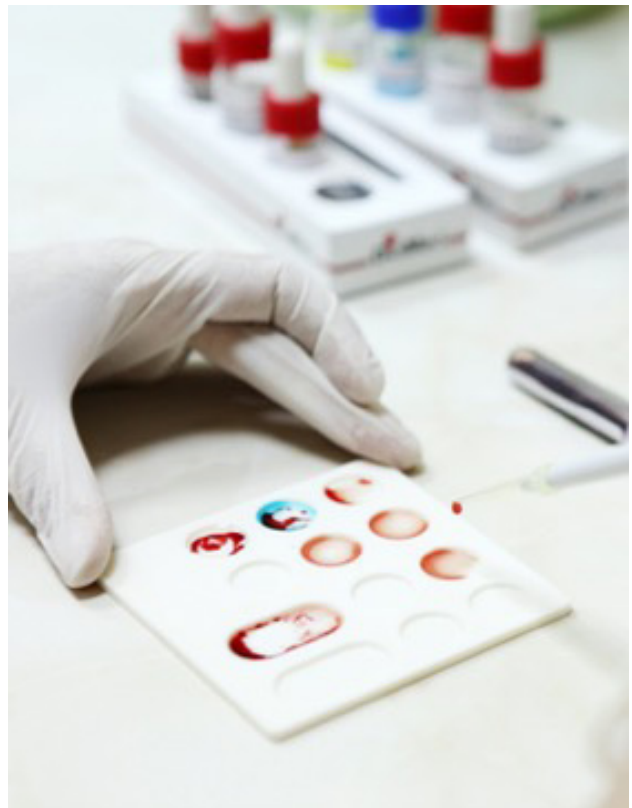
- Blood Type O can only receive a donor heart from blood type O
- Blood type A can receive a donor heart from blood types A and O
- Blood type B can receive a donor heart from blood types B and O
- Blood type AB can receive a donor heart from blood types A, B, AB and O

**+/- (Rh factor) does not matter when matching organ with recipient**

# Compatibility Testing for Heart Transplant

Another important factor the team will need to review if you proceed to transplant listing is sensitization and compatibility. We will look at your immune system to determine what antibodies you may already have and how it relates to you getting a transplant. As a recipient you will be matched with a deceased donor based on your blood type and immune system (HLA) compatibility:

- There is a special lab in Oregon called the Lab of Immunogenetics and Transplantation or LIT
- This special lab test helps determine any immune system risks you may have for matching with a potential donor if you require a transplant. The doctors need to know if your blood is sensitized and may react stronger to a transplant
- The two tests done initially are called PRA and tissue typing, your doctor will explain these
- A crossmatch is done if you proceed to transplant to make sure there are no issues with compatibility





# Donor Organ

Donors are identified by medical professionals and screened by organizations called OPO's (Organ Procurement Organizations). In Oregon the OPO is Pacific Northwest Transplant Bank. When a donor is identified as a potential match, the transplant team is notified.

## Before the transplant both you and the potential donor heart are tested for infectious diseases:

- HIV
- Hepatitis B
- Hepatitis C
- Cytomegalovirus (CMV)
- Epstein-Barr Virus (EBV)
- Syphilis
- Toxoplasmosis
- Coronavirus

Even though donors have many tests to make sure it is safe for the donation to proceed, there is a slight chance of transmission of disease.

## After transplant you will be tested for:

- HIV
- Hepatitis B
- Hepatitis C
- Cytomegalovirus (CMV)

# HCV+/NAT+ Donor

HCV+/NAT+ Donors are donors that had active Hepatitis C (HCV) discovered in their blood during the infectious disease screening process. Prior to 2017 organs from these donors would not have been transplanted. In 2017 advances in the treatment and cure of HCV have led to HCV+/NAT+ donors being utilized for transplant recipients.

Important points to remember:

- HCV +/NAT+ Donors have active Hepatitis C Virus in their blood
- After transplantation, HCV will develop in the transplant recipient's blood
- If you are willing to accept a donor that has active HCV infection, you will be treated after transplant with a medication to cure the HCV
- Medications are 95% effective at curing HCV with the first treatment course
- Accepting an HCV+/NAT+ donor increases the number of donors that may match with you in the UNET system and may decrease the amount of time you wait for a transplant
- You will sign a separate consent agreeing to accept an HCV +/NAT+ donor at the time of listing
- You will sign a separate consent agreeing to accept an HCV +/NAT+ donor at the time of transplant

# Transplant Listing

- Once it is determined that you are an acceptable candidate for Heart Transplant, we will place you on the United Network of Organ Sharing (UNOS) waiting list
- It is important to us that you are committed to wanting a heart transplant and that you understand the possible risks
- Once you have decided to proceed, you will receive a call from your transplant coordinator that you have been placed on the UNOS waiting list. You are not listed until you receive this call from your transplant coordinator
- You will also receive a letter in the mail within ten business days notifying you of the date of listing
- From the time you are placed on the waiting list, **you need to be ready** to receive a transplant at any time
- There is no way to know when a donor heart will become available
- There is a system in place through UNOS to ensure all patients in need of a heart transplant are given fair and equal access to available donor organs
- Once a donor heart is matched for compatible blood type and body size, it is allocated to the sickest patient with the longest waiting time who is closest to the donor heart
- The OPO will notify the transplant team when a heart becomes available
- A transplant coordinator will help arrange everything for your transplant



Providence St. Vincent is fully certified by CMS (Centers for Medicare and Medicaid Services) as an adult heart transplant program.

# Heart Transplant Status

Heart Transplant status or allocation uses criteria based on how sick you are. A new Heart Allocation system was developed in 2018:

- **Status 1 and Status 2**
  - Patient is very ill in the hospital with life support
- **Status 1**
  - VA ECMO
  - Non-dischargeable, surgically implanted, non-endovascular biventricular support device, LVAD
  - Mechanical circulatory support device (MCSD) with life-threatening ventricular arrhythmia or device malfunction
- **Status 2**
  - IABP, TAH, BiVAD/RVAD or VAD
  - V-tach / V-fib, mechanical support not required
  - Percutaneous endovascular MCSD
- **Status 3 and Status 4**
  - Patient may or may not be in the hospital (most LVAD and inotrope dependent patients are Status 4)
- **Status 3**
  - Dischargeable LVAD for discretionary 30 days
  - Multiple inotropes or single high-dose inotrope with continuous hemodynamic monitoring
  - VA ECMO after 7 days; percutaneous endovascular circulatory support device or IABP after 14 days
  - Non-dischargeable, surgically implanted, non-endovascular LVAD after 14 days
  - MCSD with one of the following:
    - device infection
    - right heart failure
    - hemolysis
    - mucosal bleeding
    - pump thrombosis
    - aortic insufficiency

# Heart Transplant Status

- **Status 4**
    - Dischargeable LVAD without discretionary 30 days
    - Inotropes without hemodynamic monitoring
    - Re-transplant
    - Diagnosis of one of the following:
      - ▾ congenital heart disease (CHD)
      - ▾ ischemic heart disease with intractable angina
      - ▾ hypertrophic cardiomyopathy
      - ▾ restrictive cardiomyopathy
      - ▾ amyloidosis
  - **Status 5 and Status 6**
    - Waiting at home or waiting for dual organ transplant
  - **Status 5**
    - On the waitlist for at least one other organ at the same hospital
  - **Status 6**
    - All remaining active candidates
  - **Status 7**
    - Inactive (on hold)
- \*\* See UNOS handout on Heart Transplant Listing for reference

# Factors Affecting Wait Time

- Listing Status (how sick you are)
- Blood Type (organs are matched by blood type)
- Height and Weight (body type needs to be closely matched)
- Antibody Status (HLA or sensitization)
- Crossmatch may be needed before or after transplant depending on your sensitization. Your provider will discuss this with you prior to transplant



Your physician will help explain the need for crossmatch and whether you are sensitized. You can become sensitized through:

- Pregnancies, LVADs, blood product transfusion, and prior transplants

# Life on the Waiting List

- Blood draw monthly - we use this to crossmatch you with possible donors
- Frequent clinic appointments
  - You will need to be within five hours of St. Vincent Hospital
  - Depending on how ill you become, you may need to be admitted to the hospital to wait for your transplant
  - Your physician will talk with you if admission is needed



- **Remember: your doctor may admit you to the hospital to await transplant or you may need local housing**
  - **If you need local housing our social workers will assist you**
- Contact the heart transplant with any changes to your symptoms or health status
- You are **required** to notify the heart transplant team with any changes to your phone numbers, address or insurance coverage
- Good health maintenance during listing will assist you in staying strong for transplant

# Waiting

If you become sicker while waiting for heart, different strategies can be used to keep your body functioning so that you can still receive a transplant:

## Most Common

- Inotropes (IV medicine to help your heart pump better), some names of the medications used are dobutamine and milrinone

## MCS (Mechanical Circulatory Support)

- Intra-Aortic Balloon Pump (IABP) or Impella-(types of heart pumps that help your heart work better)
- Ventilator (you are very ill and need help breathing)
- ECMO-Extra-Corporeal Membrane Oxygenation (your heart can't pump blood to all your organs and needs total support)
- Ventricular Assist Device-VAD, LVAD, MCS (a type of heart pump that can be placed to help your heart pump more affectively)

\*When listed for a heart transplant at our center, patients need to be open to these options and the transplant physician will discuss this with you. Some of these options can also be used instead of a heart transplant.

- The transplant team always needs to be able to reach you or your support person
- You will have frequent Right Heart Catheterizations (RHC) and follow-up testing to assess your heart function and you could be kept for admission during that time.
- You will also have frequent clinic visits with physician heart team coordinators and lab work to assess how you are doing
- Waiting is hard as we can't tell you when a donor heart will become available, but a social worker and palliative care team are available
- We have resources in place to help you remain positive and hopeful while waiting for heart transplant



# Waiting List Requirements

You will be required to continue to follow with your local doctors for routine medical care:

- Primary Care Physician (PCP) - It's important to maintain a relationship with your primary care provider
- Cardiologist - if you are followed by a local cardiologist, please continue to notify them of your status and maintain a relationship
- Contact the heart transplant team when/if:
  - You visit urgent care, the emergency department, or are hospitalized
  - You are placed on antibiotics, have an illness, fever or infection
  - Insurance coverage, phone numbers, or address changes

Good health maintenance and having a positive outlook during listing will assist you in staying strong for transplant

It is imperative to notify us if:

- You get a cold, develop a fever or have any signs or symptoms of infection
- Have flu like symptoms
- Get a blood transfusion
- Start any new medications
- If your insurance changes
- If your contact numbers change
- Any change in your social situation and support person
- Any time you are concerned, please call the office to speak to your coordinator

**Remember:** Good communication with the transplant team will help you be a successful transplant recipient!

# Removal or Inactivation From the List

While on the Transplant waiting list you could be removed or inactivated.

Common reasons for removal/inactivation:

- Your heart gets better
- Active infection
- Substance abuse
- Tobacco Abuse
- Your overall health declines
- Not following medications instructions
- Missing appointments with your transplant care team
- Changes in social support
- Weight gain or loss
- You become too sick for transplant
- You need a VAD as a bridge to transplant

## Transplant Event

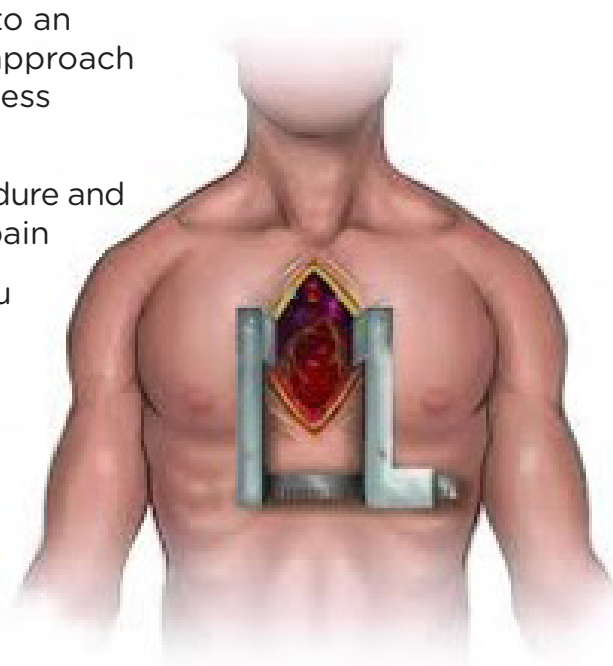
When a heart becomes available, a transplant team member will call you with instructions:

- Do not eat or drink as soon as you receive the call
- Always have a 'go-bag' ready for yourself and your support person
- Be prepared to leave within 30 minutes to travel to hospital
- Bring all of your medications with you
- If you have an VAD, bring all of your VAD equipment with you
- Bring your cellphone and charger
- Report to the designated area of the hospital you were instructed to go to

Emergency contact number: 503-216-1182, ask to have the heart transplant coordinator on call paged.

# Surgery

- The surgical procedure is similar to an open heart surgery. Sternotomy approach is to open the chest and have access to the heart
- You may be in pain after the procedure and the team will treat your surgical pain
- Physical Therapy will work with you afterwards to show you how to properly move
- You will remain in the CICU with chest tubes, breathing tube, pacing wires, multiple IV lines until you are stable
- These invasive lines will be discontinued when your condition begins to improve



All surgeries have risks some of which include:

- Anesthesia Reaction
- Fluid Collection
- Bleeding
- Blood clot
- Stroke
- Infection
- Death
- Rejection

# Dry Run

## What is a Dry Run?

The transplant could be unexpectedly canceled for many reasons:

- Donor complications or instability
- An unexpected issue is uncovered upon admission (infection or underlying problem)
- Crossmatch is incompatible
- The pressures in your lungs are too high
- The most common reason for canceling a transplant is related to the quality of the donor heart and donor instability
- If a dry run happens to you we will explain the reason and you will most likely be discharged from the hospital

If a dry run would happen, it is very unfortunate but it does not effect your status on the waiting list.

# Hospital Course

## Length of hospital stay will be dependent on many factors:

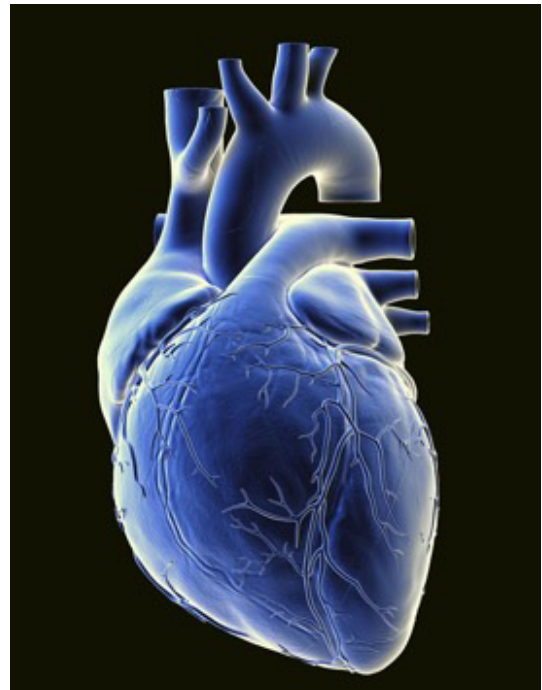
- How sick you are at the time of transplant
- Nutritional status
- Other co-morbidities
- Usual post-op activity - get moving!
- Foley catheter, wound drains, heart pacing wires, chest tube, central line, peripheral IV
- Average hospital stay: 10-14 days
- Discharge Education: 2-3 two hour sessions with a Post-Transplant RN Coordinator
  - Teaching starts early, and your support person(s) must be available throughout the hospital stay to learn medications and post transplant regimen

### Important Information to know:

- After surgery is done, the surgeon will come and speak with your support person to update them
- When a heart transplant recipient is recovered, patients will go to the Cardiac Intensive Care Unit (CICU)
- Discharge may be to home or an outside facility if you need more help to recover and get strong
- Discharge is dependent on how well your new heart is functioning and your physical recovery from the surgery
- All of your follow-up testing and appointments will be scheduled before discharge

# Immune System/Rejection

- The body's immune system protects the body from infection
- The cells of the immune system move around the body, checking for anything that looks foreign or different from the body's own cells
- Your immune system may see your donor heart as a foreign object and try to reject it, which can damage the heart
- Occurs when the body's immune cells recognize the transplanted heart as different from the rest of the body and attempt to destroy it
- Every heart transplant recipient receives medications to prevent rejection (immunosuppressants). They must strictly adhere to immunosuppressant drug regimen
- Sometimes, a change in medications will halt rejection if it occurs
- Two types of rejection: Acute Rejection and Chronic Rejection/CAV (cardiac allograft vasculopathy)



# Common Post Transplant Infections

Infectious disease screening is done after transplant:

- Toxoplasmosis
- HIV
- Cytomegalovirus (CMV)
- Varicella
- Herpes Simplex
- Tuberculosis
- Epstein Barr
- COVID 19

## Cytomegalovirus (CMV):

- Usually causes an illness similar to mononucleosis with sore throat, swollen lymph nodes, fatigue, diarrhea, and fever
- A normal immune system keeps the virus in check so it can't do any serious harm and the infection goes away by itself
- The medications you take after transplant (immunosuppressants) make it harder to fight off CMV and other infections

# Rejection Prevention

- Take your immunosuppression consistently every day
- Come to your clinic and biopsy appointments
- Have your labs drawn

The goal of immunosuppression is to balance between rejection and infection. You must take enough to prevent your immune system from attacking your heart while minimizing your risk of developing infections.

## Transplant Medications





# Immunosuppressants

Medications that lower the body's ability to reject a transplanted organ.

Main three:

- Tacrolimus (Prograf)
- Mycophenolate (MMF)/Cellcept/Myfortic
- Prednisone



Tacrolimus (Prograf)



Mycophenolate  
(Cellcept)



Prednisone

Medication images may differ depending on the manufacturer.

# Monitoring Post Transplant

- Follow up lab/clinic/biopsy schedules
- Every day, you'll check and write down:
  - your weight
  - your blood pressure
  - your heart rate
  - your temperature
  - your blood sugar levels
- Monitor your labs
- Take medications exactly as prescribed
- Be a proactive participant and call with concerns!



After Transplant	Clinic	Biopsy and Cath	Labs
1 <sup>st</sup> Month	<b>At least weekly after discharge</b>		
2 <sup>nd</sup> Month	<b>Weekly or every other week</b>		
3 <sup>rd</sup> Month	Monthly w/ECHO		Every other week
4 <sup>th</sup> Month	Monthly w/ECHO	Monthly	Monthly
5 <sup>th</sup> Month	Monthly w/ECHO	Monthly	Monthly
6 <sup>th</sup> Month	Monthly w/ECHO	Monthly	Monthly
7 <sup>th</sup> thru 10 <sup>th</sup> Month	Monthly w/ECHO	Allomap or Biopsy	Monthly
12 <sup>th</sup> Month	Monthly w/ECHO	Biopsy and Angiogram	Monthly
During 2 <sup>nd</sup> year	Every three months for clinic, ECHO, and Allomap or biopsy		

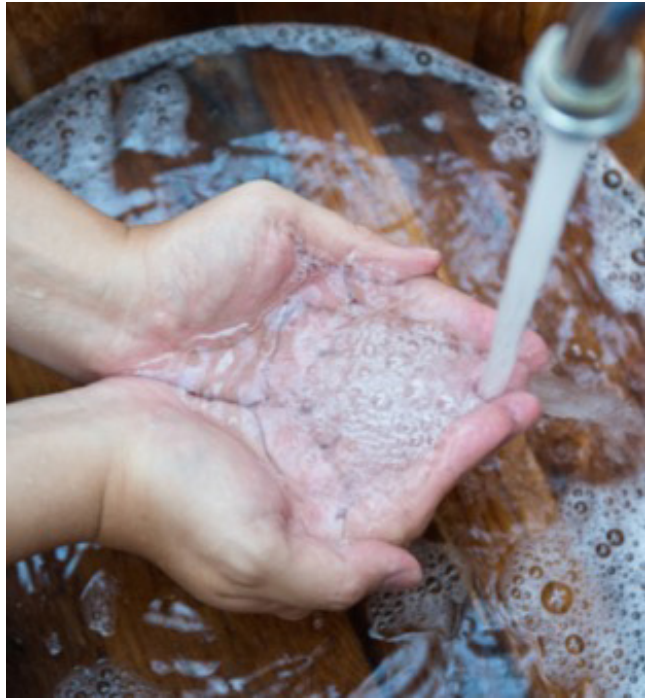
# Lifestyle

- Continue eating a heart healthy diet
- Maintain a healthy weight
- Stay fit and exercise
- Blood pressure and cholesterol control
- No smoking
- Testing as indicated
- Stress Reduction
- Stay involved and in-touch with the team



# Lifestyle

- WASH YOUR HANDS!
- Avoid people with contagious diseases
- For the first 3 months, wear a mask in public places including clinic, lab, and hospital
- Take food precautions
- Practice food safety to avoid foodborne illness
- Don't share food/utensils
- Use gloves when gardening
- Pet considerations; after transplant do not clean litter boxes, bird cages, or fish tanks
- Avoid construction projects both in and outdoors as they can cause infections from the soil and in the building



# Routine Health Maintenance

- Annual Physical with PCP
  - Women: well-woman exam w/ Pap Smear if indicated
  - Men: PSA and prostate exam
- Mammogram
- Colonoscopy at interval recommended by your provider
  - Everyone at age 45 or older must have
- Skin Health: Regular skin checks
  - Stay out of the sun and use sunscreen
  - Visit a dermatologist once a year
- Dental Health: annual exam, cleaning every 6 months
- Eye Health: annual exam for diabetic patients



# Contacting the Transplant Team

- Transplant office is open **Monday-Friday from 8:00 am to 4:30 pm**
- If you are having a scheduling issue or need to contact your outpatient transplant coordinator, **please call (503) 216-1182, option #1**

## Transplant Nurse On-call

- There is a transplant nurse on-call
  - 24 hours per day
  - 7 days per week
  - 365 days per year
- If you are calling for an **urgent problem** during after hours or a holiday, call 503-216-1182, option 1. This will route you to the answering service, ask for the **Transplant Coordinator on-call**



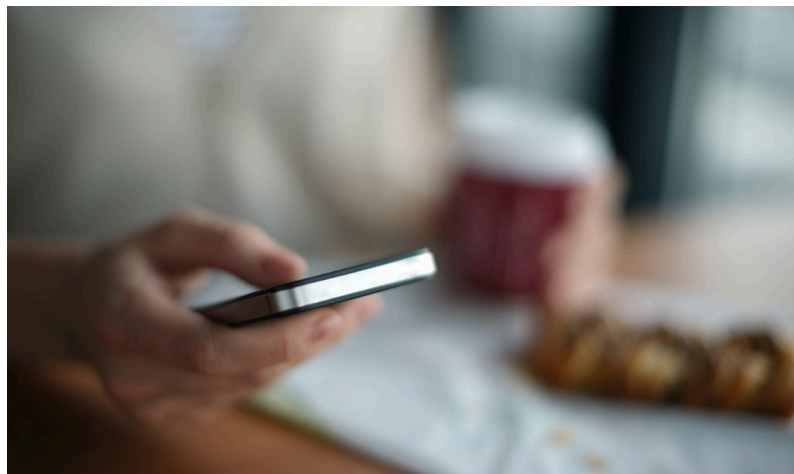
# Additional Resources

## Providence Guest Housing

- Visitors can be good medicine for patients. Friends and family members are welcome to visit patients during their stay at Providence hospitals and medical centers.
- Providence Portland, Providence St. Vincent and Providence Medford medical centers offer on-campus or nearby housing for long-term out-of-town patients and guests.

## Providence Guest Services

- Providence St. Vincent-888-550-1575
- Providence Portland-844-971-7768  
(Available at Providence Portland and St. Vincent Medical Centers)  
The friendly staff of Providence Guest Services can help arrange guest housing or make hotel reservations for out-of-town patients and visitors, give directions and transportation advice, and recommend a local restaurant for a good breakfast, lunch, dinner or snack.
- Make a reservation request



# Providence Heart Transplant



Celebrating our Heart Transplant Patients Successes at our first-annual Heart-to-Heart Picnic in 2019.

## Our Heart Transplant Patients

On Sunday, August 4, 2019, more than 100 patients attended the first-ever Heart-to-Heart picnic at Providence St. Vincent Medical Center to celebrate stories of success and words of inspiration. We love that!

On Wednesday, November 18 2020, we hosted our second annual gathering for our patients. While this year's gathering could not be held in person, our Heart-to-Heart virtual gathering had an incredible turnout with our patients and their caregivers participating with our entire team. It was a delight to "see" everyone come together and have the chance to hear personal stories from the patients.

Our patients are at the center of what we do. It is an honor to serve you and support you in this journey.

- Your Heart Transplant Care Team



## Our Mission

As expressions of God's healing love, witnessed through the ministry of Jesus, we are steadfast in serving all, especially those who are poor and vulnerable.

## Values

Compassion, Dignity, Justice,  
Excellence, Integrity



CARDIAC CLINICAL CARE

