

Navigating Your Transplant Journey with Confidence

Lung Transplant Education

Welcome

Our commitment is to provide the highest quality of care you can trust. We are here to help take care of you before, during and after your transplant.

We will listen and provide guidance and answers when you need them most. We are your partner in this journey, and we are here to support you every step of the way.

Because we believe you deserve extraordinary care.



| General Office Information

- Lung Transplant business hours
 - 8 a.m. – 4 p.m. | Monday – Friday
(Phones are off 11:30 a.m. – 12:30 p.m. for lunch)
- After-hours support line / Answering Service
 - Supported by our Cardiothoracic Call Team
 - Non-urgent
 - Urgent
 - Do NOT Delay a 911 call



Refer to page 52 of the Patient Guide for the Lung Transplant Office contact information

Agenda

- Meet your Lung Transplant Team
- Paperwork
- Being added to the Waitlist
- Transplant
- Change of Lifestyle
- Medications
- What to do with your Gift
- Lung Transplantation Patient Guide



Meet Your Lung Transplant Team

|Your Lung Transplant Team



Stephanie Cochran | Pre Lung Coordinator



Beth Schubert | Pre Lung Coordinator



Wanda Panus | Pre Lung Coordinator



Masina Scavuzzo | Pre Lung Coordinator.

Transplant Consents

Transplant Consents

There will be multiple consents to sign

- Consents for surgery
- Bronchoscopies
- Research studies
- Blood
- Hepatitis C



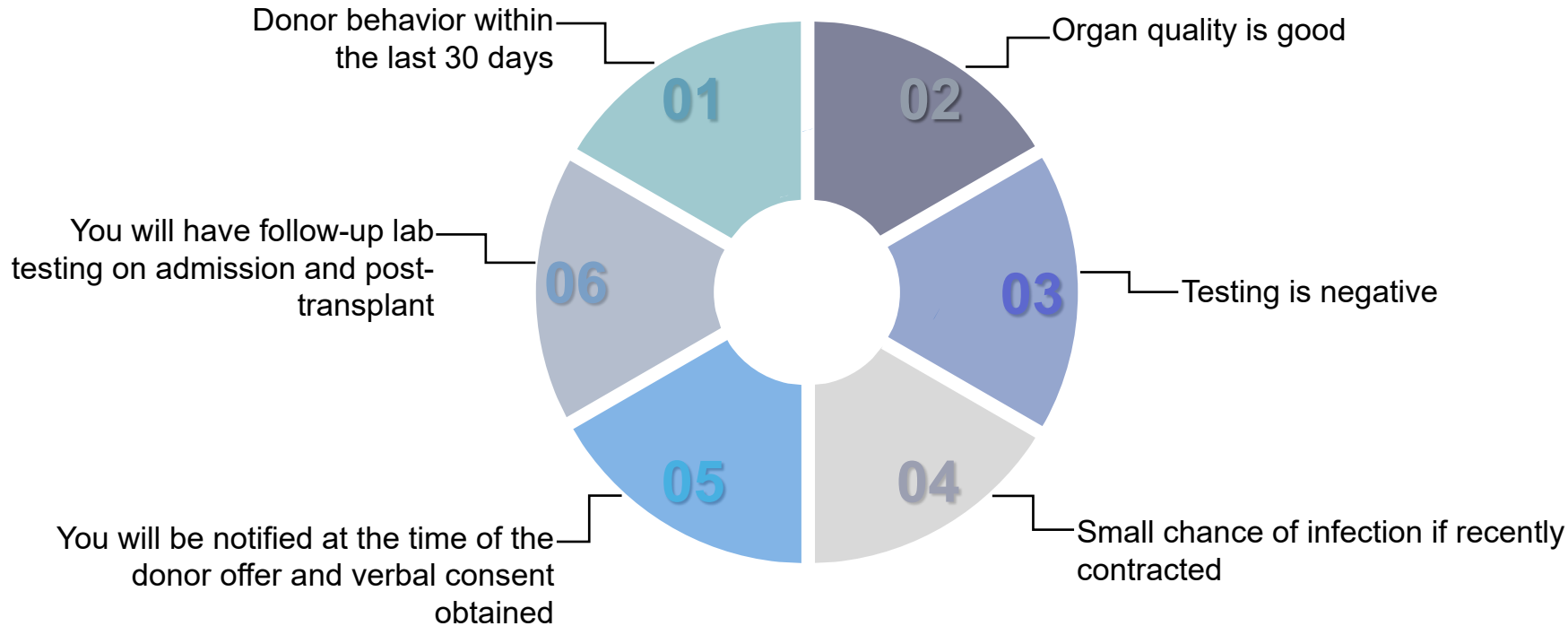
| Hepatitis C Donors

- Considering these donors may increase your opportunities to receive a transplant sooner
- Special consent is required for you to receive offers from this type of donor
- Our transplant center is one of many centers that have successfully performed a transplant with a hepatitis C donor

Donors that are Hepatitis C positive

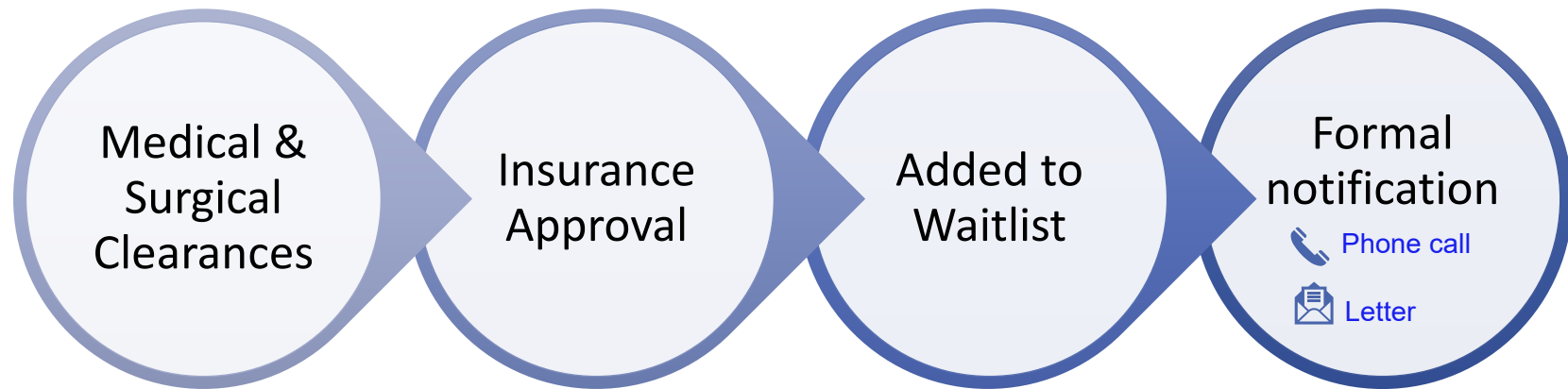
- Hepatitis C is spread by blood-to-blood contact
 - Use condoms when engaging in sexual activity
 - Do not share razors or toothbrushes
- There is chance you will get Hepatitis C after transplant
 - This is monitored by lab work
- Medications are available to cure hepatitis C infection
 - Response to treatment is higher than 98%

| Donors with Risk Criteria



Being added to the Waitlist

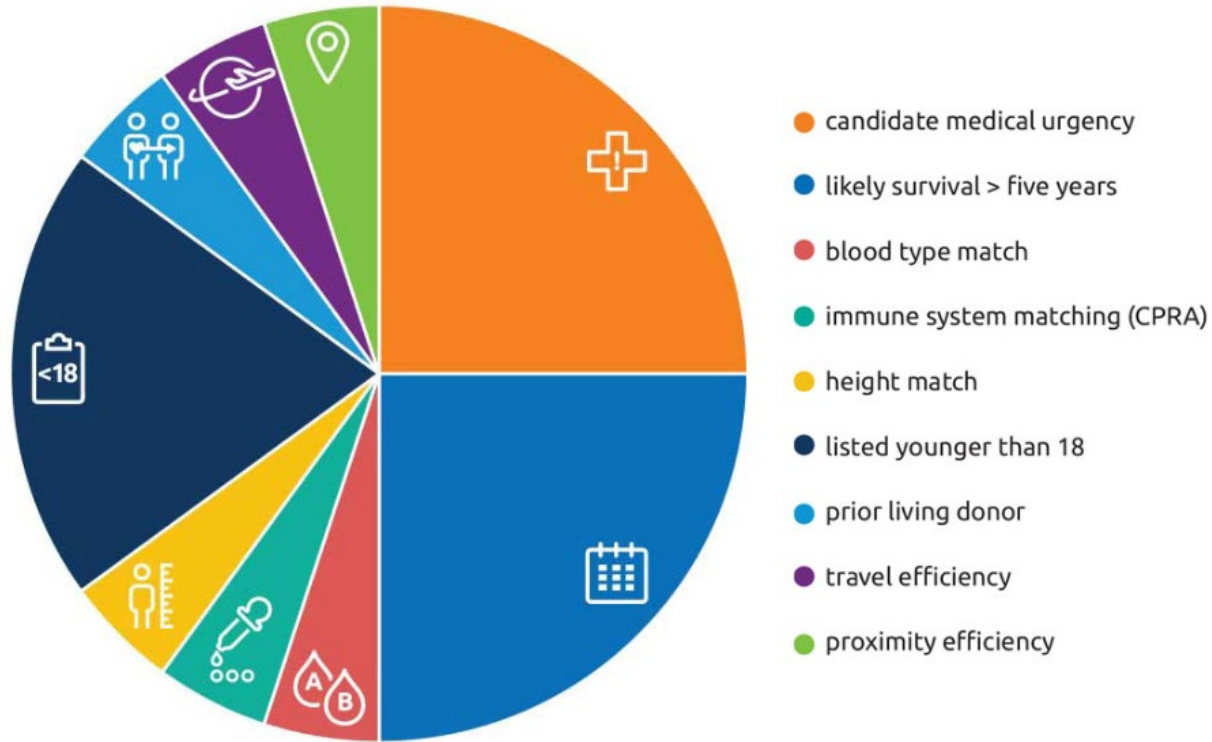
| Being added to the Waitlist



Composite Allocation Score (CAS)

GOAL	PERCENTAGE	ATTRIBUTE(S)	POINTS
Medical urgency	25%	Waitlist survival	25
Post-transplant outcomes	25%	Post-transplant survival	25
Biological disadvantages	15%	Blood type	5
		CPRA	5
		Height	5
Patient access	25%	Pediatrics	20
		Prior living donor	5
CAS Subscore	The CAS Subscore includes points for all goals and attributes that are candidate-based. Placement efficiency, a donor-based attribute, is calculated at the time a candidate appears on a match run.		
Placement efficiency	10%	Travel efficiency	5
		Proximity efficiency	5
Total CAS	100%		100

Composite Allocation Score (CAS) Overview



| While on the Waiting List



| When to Notify Your Transplant Team

Please notify your coordinator at **800.321.4054** when you have changes to your:

- **Health status:** Hospitalizations, emergency room visits, or medical procedures
- **Insurance**
- **Contact information**



Phone number



Address



Emergency contact

| We Want to Know About



Fever

Higher than 101°



Shortness of breath

Increase in shortness of breath or increasing oxygen needs



Respiratory illness

Any respiratory illness or exacerbation requiring antibiotics or boost in steroids



Swelling or weight gain

Increase in swelling of legs or weight gain from fluid retention



Medical changes

Any other medical changes

For life-threatening emergencies, call 911

| Make a Plan for Your Transplant



The call could come at any time – day or night, weekend or holiday

- Please have your phone on and charged
- You may receive a call from a variety of phone numbers
- Caller ID may show a blocked call
- Save the Lung Transplant office phone number as a contact
 - **314.362.5378 | 800.321.4054**



Arrange for someone to drive you to the hospital

- You will not be able to drive 6-8 weeks after surgery
- Reliable transportation and money for parking at the hospital is important



Plan as much as possible

- Identify someone who can care for your pets, children or family members while you are in the hospital



Refer to page 52 of the Patient Guide for the Lung Transplant Office contact information



Getting the Call

When we call you, it's important you leave quickly and safely to get to the hospital

- Be prepared to leave your house within 20 minutes of the call
- Bring oxygen, medications & med list, trilogy, BiPAP or CPAP machines
- Do not eat or drink anything after you are instructed to leave for the hospital
- Time is crucial. Do not shower, wash your hair, etc.
- Bring your photo ID and insurance cards
- Bring your Lung Transplant Patient Guide

We recommend packing a bag and having it ready to go while you are on the waitlist

What to Expect when called in for Transplant

Know Where to Go on Transplant Day

- 1 Park at the **Barnes-Jewish Plaza Garage – Entrance A**
1 Barnes Jewish Hospital Plaza
St. Louis MO, 63110
 - Valet parking is available at select hours
 - Plaza Garage parking is required on weekdays after 9 p.m. and weekends and holidays
- 2 Check-in for registration at **Admitting** on the **main level** of the **Plaza Tower**
- 3 After registration, you will be escorted to your patient room
 - Bloodwork, ECG, chest x-ray (CXR), and a nasal viral swab will be done



| Surgery and Post Transplant Care

SURGERY

- Transplant surgery can take up to 6-8 hours
- Family members will be informed regularly in the waiting area

AFTER SURGERY

- Patient will recover in ICU
- Visiting hours are 24/7 after patient is settled
- Patient may require additional support, including:
 - Ventilator
 - Chest tubes
 - IV lines
 - Bypass or ECMO
 - Tracheostomy

HOSPITAL STAY

- Patient will remain in the hospital for approx 2-3 weeks
- Patient will be required to walk on the treadmill for 30 minutes before being discharged



Refer to page 19 of the Patient Guide for post-transplant care

Transplant Complications

- **Transplantation is not a cure but a lifestyle change!**
- Immunosuppression medication allows the transplant organ to function
 - Possible effects of immunosuppression
 - Infections
 - Other disease processes
 - Chronic kidney disease
 - Diabetes
 - Cancer
 - High blood pressure
- If complications arise, bring them to your post-transplant coordinator's attention
- We will tailor your treatment plan to your situation and medical history



Refer to pages 23-24 of the Patient Guide for more information on rejection



Refer to pages 40-50 of the Patient Guide for immunosuppression medicines and page 16 for more information on the specialty pharmacy

Take Your Medications as Directed

- Taking medications as directed is one of the most important parts to ensure you have a successful transplant journey (before and after transplant).
- After transplant, your medications help **prevent rejection** of your new organ and must be taken as prescribed.
- You will need a local pharmacy. This must be setup before transplant.
- A transplant pharmacist will meet with you and your caregiver to discuss medication instructions.
- 3 Immunosuppression medications will be prescribed
 - Prednisone OR methylprednisolone (Solumedrol®)
 - Tacrolimus (Prograf®) OR cyclosporine (Neoral®, GenGraf®)
 - Mycophenolate mofetil (CellCept®) OR mycophenolic acid (Myfortic®) OR azathioprine (Imuran®)
- Additional medications to prevent infections
- Plan and budget for medication expenses

Microspirometry

- Home Microspirometer is a tool that measures lung function
- Record trends post-transplant
- Insurance coverage
 - Medicare and Medicaid do not cover this cost
 - Private insurance may not cover the cost
- Pulmonary rehab will give more detailed instructions when you are discharged from the hospital



Refer to page 26 of the Patient Guide for more information on Microspirometers

Support after Transplant

Post Transplant Follow-up Consultations



Dietitian

- Follows up with you about dietary changes



Social Worker

- Available for patient and caregiver support



Respiratory Therapist

- Daily exercise sessions



Pharmacist

- Review of medications with you before discharge



In-patient Nurse Practitioner (NP) | Post Transplant Coordinator

- Reviews discharge instructions
- Contact person while in the hospital

| Transplant Support



Support Person

- Needs to be with you after transplant
- Can be more than one person. Approval required by transplant team
- Social worker is available for counseling and additional support as needed



Refer to pages 12 & 23 of the Patient Guide for more information on identifying a support person and page 48 for social worker support



Support Group

- Educational meeting and break out sessions available for you and your support person
- Monthly Zoom and in-person meetings are available



Mentor Program

- Post lung transplant patients area available for additional support



Additional Information



Relocation

- You and your support person are required to be in St. Louis for approximately 3 months after transplant
- Will attend Pulmonary Rehab daily Monday – Friday



Returning to the workforce

- You may return to work after 6 months



Pets

- Talk with your Transplant Physician for specifics

****You and your support need to read the Lung Transplant Patient Education Guide***

| Staying Healthy

Post-transplant care is a lifelong commitment

Support your health and wellbeing after your lung transplant.

- Regular exercise
- Lower your blood pressure
- Manage your stress and prevent depression
- Refrain from using nicotine products, marijuana, alcohol and non-transplant approved medicines
- Don't wait to address a problem



| Complete your Annual Exams

- Regular dental visits
- Labs
- Chest X-Ray and EKG
- Cardiac testing
- Other testing based on your medical history
- Cancer screening (American Cancer Society Guidelines)
 - Mammograms and Well-woman exams
 - Colonoscopy
 - Prostate screening



| Helpful Resources



Washington University and Barnes-Jewish Transplant Center

- Lung Transplant Patient Guide
- Lung Transplant Support Group
- Lung Transplant Mentor Program
- Writing a letter to your Donor family

Additional Resources

- Website:
barnesjewish.org/Medical-Services/Transplant/Lung-Transplant
- UNOS Website: unos.org
- transplantliving.org

Thank you!

