Answers about lung transplants — they’re all inside
Here’s what you’ll learn

There’s a lot of things you should know about lung transplants. This booklet is a great starting point to understanding what it means to be evaluated for lung transplant candidacy. Your doctors, nurses, and other caregivers will give you lots of information and guidance along the way.

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We’ve teamed up with Johns Hopkins Medicine

World-renowned transplant expertise matched with outstanding patient care.

Allegheny Health Network’s collaboration with Johns Hopkins combines a team of AHN specialists here in Pittsburgh with lung transplant leaders at The Johns Hopkins Hospital in Baltimore. Lung transplants can be very complicated, so we’ve created a coordinated process to manage all of the necessary tests, exams, and transplant team members and guide you from your initial evaluation through your recovery.

OUR RELATIONSHIP MAKES A HUGE DIFFERENCE FOR YOUR HEALTH:

25 years pioneering lung transplant leadership

Shorter waits than national average*

High success rates with few lifestyle limitations

* Wait times vary for each patient based on a number of factors. United Network for Organ Sharing, or UNOS, oversees the distribution of transplant organs in the U.S. and maintains all organ waiting lists.

Sharing Expertise, Saving Lives
YOUR TRANSPLANT TEAM

Introducing
Your Transplant Team

YOUR TRANSPLANT COORDINATOR: A FRIEND BY YOUR SIDE

You’ll have an entire team of people to support you. Your lung transplant coordinator will work closely with you to make sure all of your tests and exams are scheduled as they’re needed throughout the evaluation process. And he will help develop a transportation plan to get you to and from appointments at Johns Hopkins Hospital — and the transplant procedure itself.

You can call your AHN lung transplant coordinator anytime at (412) 442-2541.

Kevin Nauer, RN
AHN Lung Transplant Coordinator
Arranges testing, evaluation, and transportation.
Dr. Singh is your lung specialist here in Pittsburgh. He’ll order all of the tests and exams you’ll need in order to determine your eligibility for transplant and work closely with the specialists at The Johns Hopkins Hospital throughout the entire process.

The lung transplant specialists at Johns Hopkins include transplant pulmonologists who will work with you during the evaluation and follow-up processes in Baltimore.

Your Johns Hopkins Hospital transplant surgeon will meet with you at your appointments along the way to explain the procedure and its risks and benefits to you and your loved ones. He or she will also answer any questions you may have about any aspect of the procedure.
Gina, along with the Johns Hopkins team, will work with you and your loved ones to arrange the tests and exams you’ll need at Johns Hopkins. They’ll make sure the Johns Hopkins team has all the information they need in order to consider you as a transplant candidate and will help educate you about the transplant procedure and recovery afterward.
Your Johns Hopkins Support Team

Your transplant will be life-changing in many ways. Our support staff will work with you and your loved ones to make sure you’re prepared for them. The team will:

- Make sure you’re receiving the right nutrition so you maintain a healthy weight.
- Find temporary housing for you in Baltimore so you’re close by for follow-up care after your discharge.
- Ensure that your insurance will cover the transplant.
- Help you work through the stress of going through such a major procedure.

Allyson Smith Mitchell, LCSW-C
Johns Hopkins Transplant Social Worker
Here’s How the Process Works

You’ll go through an extensive evaluation to make sure that a lung transplant is right for you. You’ll need lab tests, screenings, meetings with different health care workers, and other appointments. But your dedicated transplant coordinators will guide you through every step of the process:

**STEP 1**
Lab Tests & Screenings at AHN

**STEP 2**
Evaluation at Johns Hopkins Hospital

**STEP 3**
Transplant Team Meeting

**STEP 4**
The Waiting List
Avg. wait 2 months

**STEP 5**
Getting the Call
Travel to Baltimore

**STEP 6**
The Surgery

**STEP 7**
Recovery in the CVICU
Cardiovascular Surgery ICU

**STEP 8**
Step-Down Care

**STEP 9**
Discharge to Temporary Housing

**STEP 10**
Return Home
Continue long-term recovery

The time frames used in this booklet are only examples. Every transplant patient is different, so you will likely spend more time on some steps and less time on others.

*Times can vary based on a number of factors.*
STEP 1
Lab Tests and Screenings at AHN
When your lung specialist determines that you may be a good candidate for a transplant, your lung transplant coordinator will contact you to schedule your initial evaluation here in Pittsburgh. You’ll have a variety of tests, including:
- Blood work and urine testing.
- Heart, lung, and bone imaging.
- Swallowing tests.
- Heart and lung function tests.

STEP 2
Testing at The Johns Hopkins Hospital in Baltimore
Your AHN pulmonologist will review your results with a Johns Hopkins transplant specialist and determine whether or not transplant is your best option and, if so, to continue the evaluation in Baltimore. Your AHN transplant coordinator will work with you to travel to The Johns Hopkins Hospital for two days for additional exams and tests, where you will meet with:
- Transplant specialists.
- Nutritionist.
- Social worker.

STEP 3
Transplant Team Meeting
Once you’ve completed all of your initial tests and exams at AHN and Johns Hopkins, the transplant team will meet to discuss the results of your evaluation. They will make one of three decisions:

You are listed as a transplant candidate for one or two new lungs.
Your team makes sure your insurance will cover the cost of the transplant and will coordinate transportation for your follow-up appointments and surgery at The Johns Hopkins Hospital.

You need additional time or tests or care before a decision can be made.
Your team will let you know when you will need to be listed, and your coordinator will schedule any additional appointments you need so the team can make a decision.

Lung transplant is not the right treatment for you.
Your AHN and Johns Hopkins lung specialists will discuss the decision with you and explore other treatment.

STEP 4
The Waiting List
You may have heard about a transplant waiting list. You will be placed on the waiting list for The Johns Hopkins Hospital, consisting of individuals in need of transplant within the region.

Determining Your Priority on the Transplant List
UNOS* uses the results of your transplant evaluation to determine the severity of your illness. They will assign you a lung allocation score (LAS). In general, if you have a higher LAS score, you’ll receive higher priority when a compatible lung becomes available.

Your LAS can change based on new exams and testing. It’s important to keep all of your follow-up appointments and let your transplant team know if your health status changes.

Listing at Multiple Medical Centers
Even if you are listed at Johns Hopkins, you can also be listed at another transplant center. Visit the UNOS website for more information about double listing.

*United Network for Organ Sharing, or UNOS, oversees the distribution of transplant organs in the U.S. and maintains all organ waiting lists.
STEP 5
Getting the Call
When a potential organ becomes available, a Johns Hopkins transplant coordinator will call you and your caregiver to come to The Johns Hopkins Hospital. The coordinator will:
- Ask about your current health.
- Give you instructions about where to go and what you can/can’t do until your surgery.
- Notify the AHN transportation team to activate your transportation plan.

You May Have to Return Home
Unfortunately, it may take several calls before the transplant team finds the donor lungs that are a good match. When you receive the call, they may not have all of the necessary information about the donor lungs, but they want you to be ready for the transplant in case the lungs are a good match.
- You’ll be notified as soon as possible if the surgeon determines that the donor lungs aren’t a good match after you’ve received the call. If this happens, you and your caregiver will be able to return home immediately. We know this situation is frustrating. But it’s well worth the wait to ensure you get the right lungs for you — and that the transplant begins as soon as it can when those lungs become available.

STEP 6
The Surgery
You will undergo the transplant surgery in an operating room staffed by your very trained, highly experienced surgical team who will be completely focused on the success of your transplant.

STEP 7
Recovery in the Cardiothoracic Surgery Intensive Care Unit
After surgery, you will spend several days in the Cardiovascular Surgery Intensive Care Unit (CVSICU) for close monitoring by your medical team. For the first 24 to 48 hours, you will be connected to a breathing machine.

STEP 8
Step-Down Care
When you are ready, your team will transfer you to the step-down unit, the Cardiovascular-pulmonary care unit. Here you’ll start physical therapy under close monitoring.

STEP 9
Discharge to Temporary Housing
Once you’ve recovered enough, you will be discharged to the temporary housing you have selected with the Johns Hopkins coordinator, where you will stay for another 8 to 12 weeks.*
During this time, you will continue to recover with the help of your caregiver, family, and friends — still seeing your transplant coordinator, surgeons, and pulmonologist regularly.

STEP 10
Return Home
After 8-12 weeks of care in Baltimore, you will be able to return home to continue your long-term recovery and begin life after your transplant.*

*Times can vary based on a number of factors.
Aside from understanding the transplant process and knowing the kinds of care you will need, there are other important things you should know.

YOU WILL NEED A CAREGIVER

You should choose a family member or close, trusted friend who can help look out for your health during the waiting period and help care for you after the transplant. He or she should come with you for all of your tests and appointments, ask questions, and take notes to help make sure you understand everything that was discussed about your health.

Your caregiver will also travel with you to Baltimore for the duration of your transplant and 8- to 12-week recovery.

YOUR HEALTH MAY AFFECT YOUR TRANSPLANT STATUS

Smoking: You cannot be evaluated for a lung transplant if you have smoked in the last six months, since it can increase the recovery time and the risk of complications. Your transplant team will periodically check to make sure you’re not smoking.

Body Mass Index (BMI): If your BMI is greater than 30, your team will require you to lose weight before your procedure. Your nutritionist will help you make lifestyle changes to help you reach a healthy weight.
WE PUT YOUR HEALTH AND SAFETY FIRST
We screen all transplant organs for infections, cancers, and other diseases based on UNOS and Centers for Disease Control and Prevention (CDC) guidelines. Unfortunately, there is no way to test for all medical conditions, and in rare cases, testing does not detect infections before transplant.

YOUR LIFESTYLE WILL CHANGE
Your transplant will help you regain more normal lung function and allow you to do more of the things you enjoy. You may need to make a few lifestyle changes after your surgery to help you stay healthy. Your medical team will give you more information about this during your evaluation and appointments.

YOU NEED INSURANCE COVERAGE
It's critical that you maintain continuous insurance coverage while you're a transplant candidate. You also need to understand what is covered and whether there are any gaps in your coverage.

If your insurance coverage lapses, your team's financial advocate can assist you as soon as possible. If your coverage lapses, we'll help you find new coverage.

YOU CAN FIND MORE INFORMATION ONLINE
There's more information about lung diseases, transplants, and the organizations that come together to make lung transplants possible:

- Allegheny Health Network Breathing Disorders Center
  AHN.org/specialties/pulmonary-disease
- Johns Hopkins Division of Pulmonary and Critical Care Medicine
  HopkinsMedicine.org/pulmonary
- Johns Hopkins Comprehensive Transplant Center
  HopkinsMedicine.org/transplant
- United Network for Organ Sharing
  UNOS.org
- The Living Legacy Foundation
  TheLLF.org