

Answers about lung transplants – they're all inside



JOHNS HOPKINS
MEDICINE

Sharing Expertise, Saving Lives

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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JOHNS HOPKINS
M E D I C I N E

Sharing Expertise, Saving Lives

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.

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



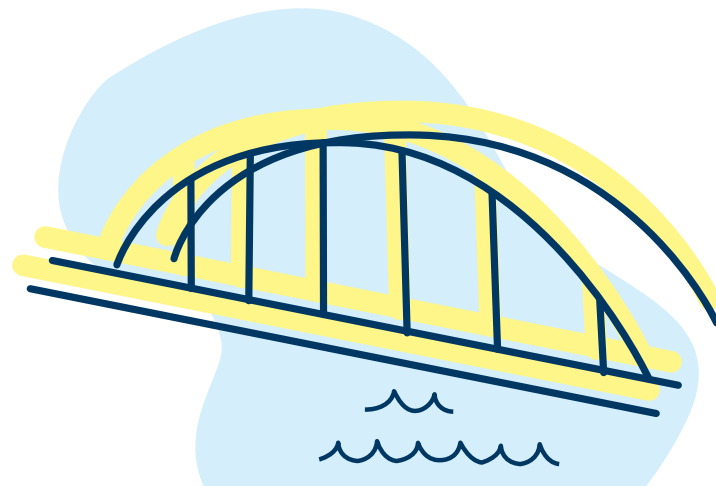
Anil Singh, MD

AHN Pulmonologist

8 | YOUR TRANSPLANT TEAM

The Expertise You Need Here in Pittsburgh

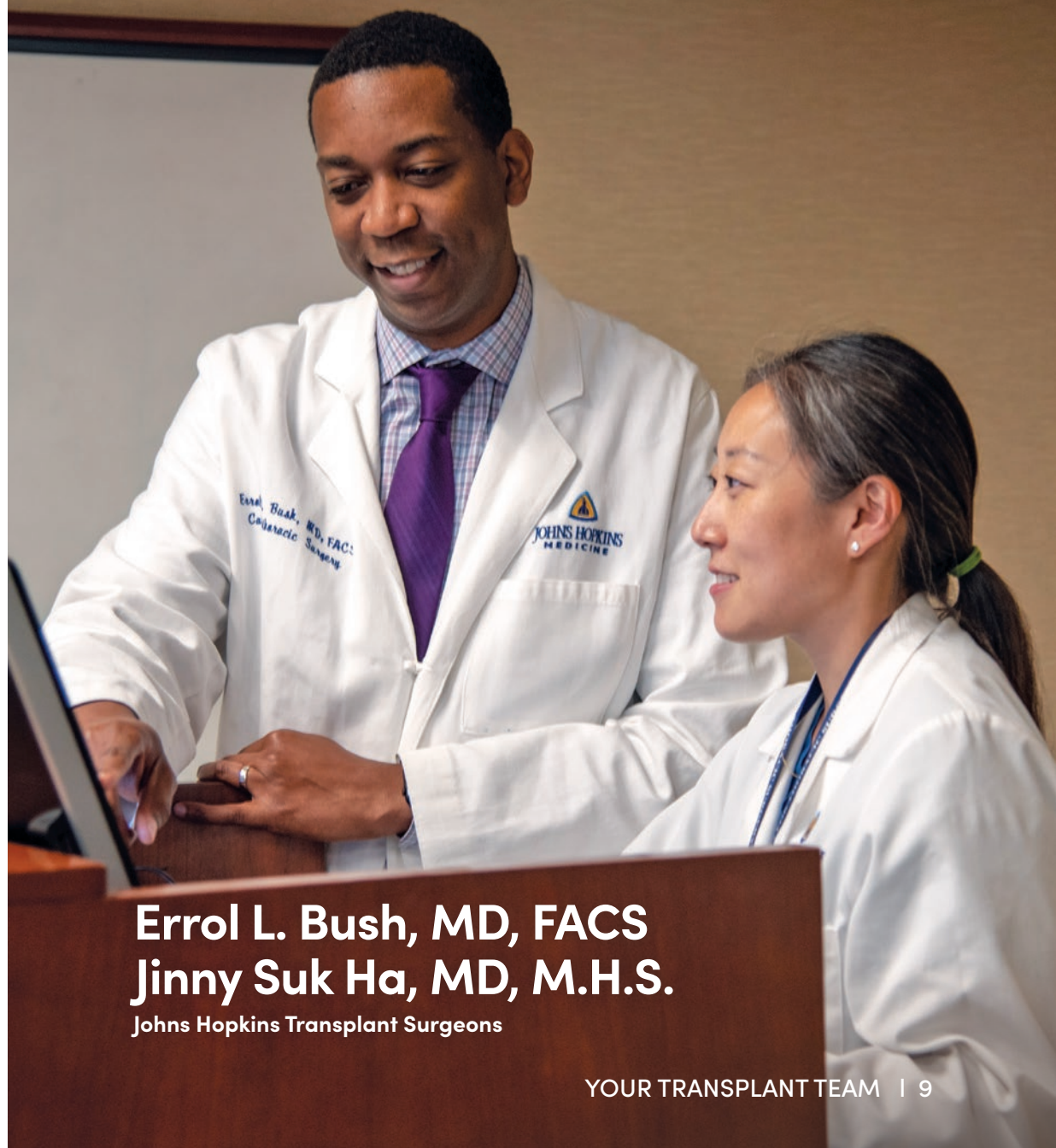
Dr. Singh is your lung specialist here in Pittsburgh. He'll order all of the tests and exams you'll need in order to determine your eligibility for transplant and work closely with the specialists at The Johns Hopkins Hospital throughout the entire process.



AND IN BALTIMORE

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.



Errol L. Bush, MD, FACS
Jinny Suk Ha, MD, M.H.S.

Johns Hopkins Transplant Surgeons

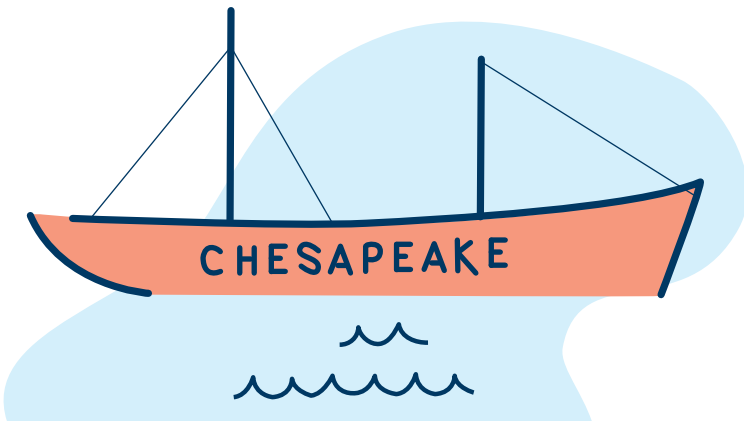


Pali Shah, MD

Johns Hopkins Transplant Pulmonologist

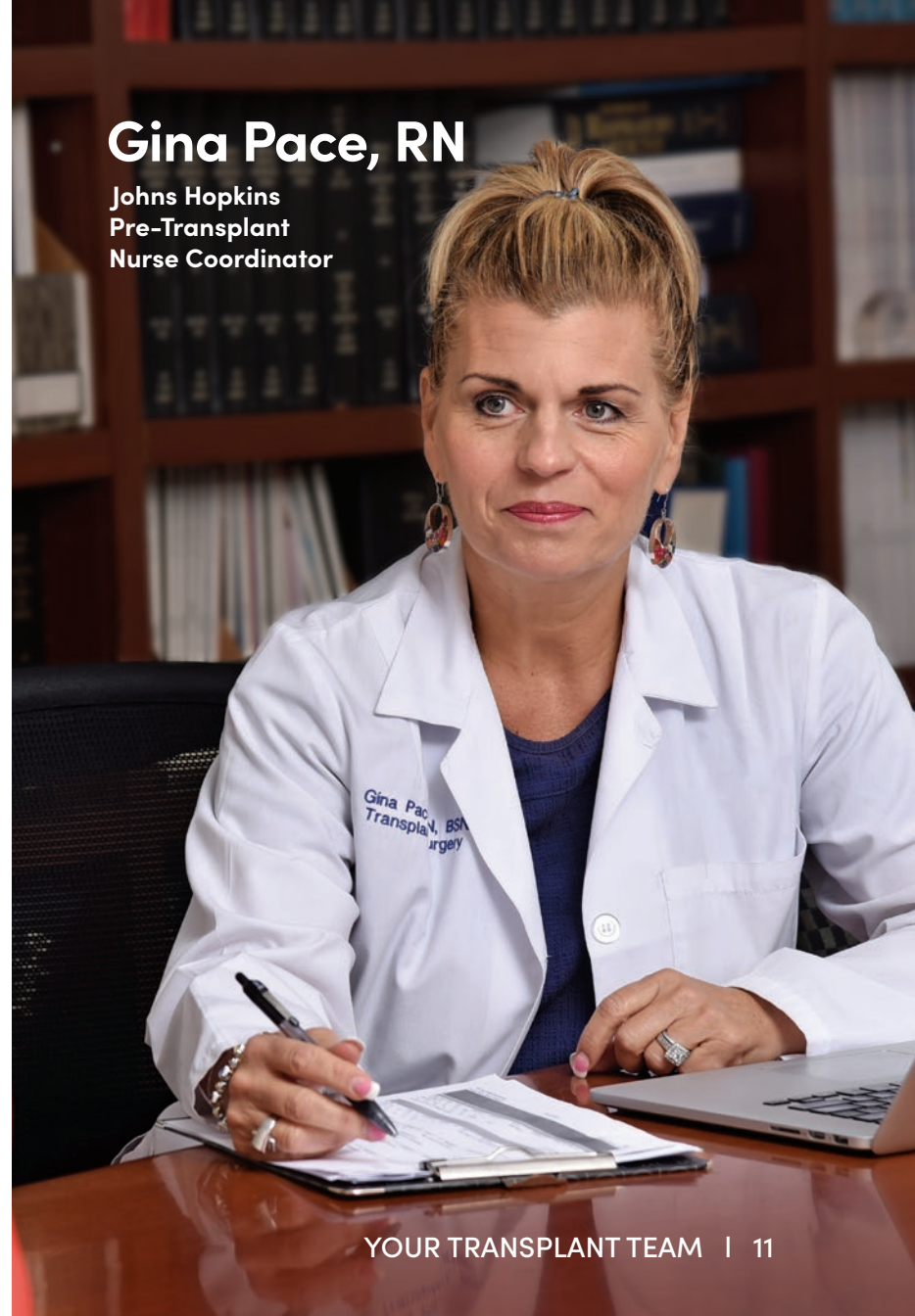
Support Away From Home

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.



Gina Pace, RN

Johns Hopkins
Pre-Transplant
Nurse Coordinator





Marsha Davis, RD, LDN

Johns Hopkins Lung Transplant Dietitian

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

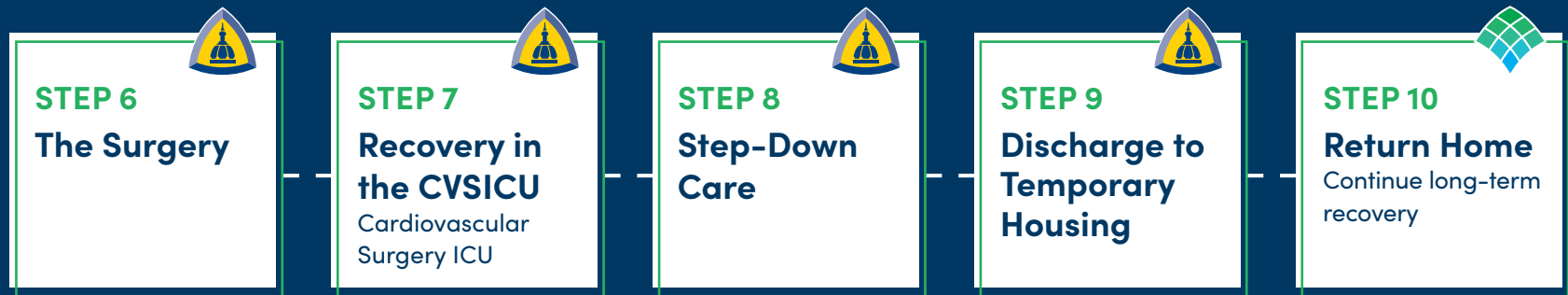
Johns Hopkins Transplant Social Worker

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:



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:

- 1 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.
- 2 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.
- 3 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

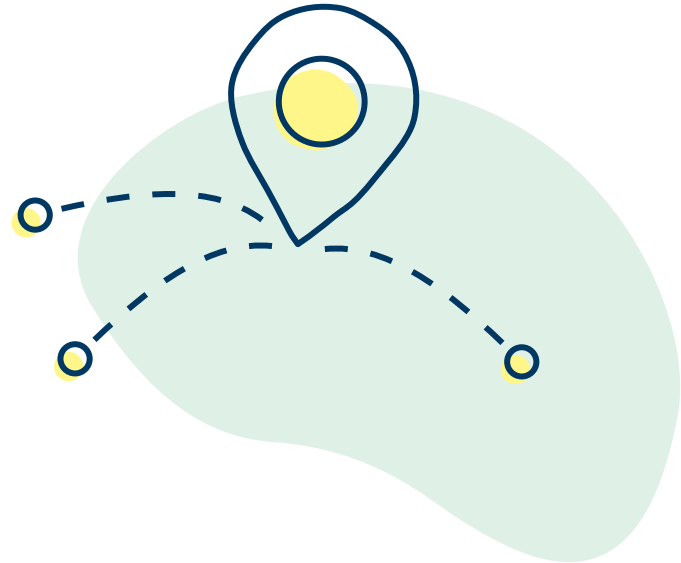
UNOS* uses the results of your transplant evaluation to determine the severity of your illness. They will assign you a lung allocation score (LAS). In general, if you have a higher LAS score, you'll receive higher priority when a compatible lung becomes available.

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.

*United Network for Organ Sharing, or UNOS, oversees the distribution of transplant organs in the U.S. and maintains all organ waiting lists.

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.



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.





Keep These Things in Mind



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.

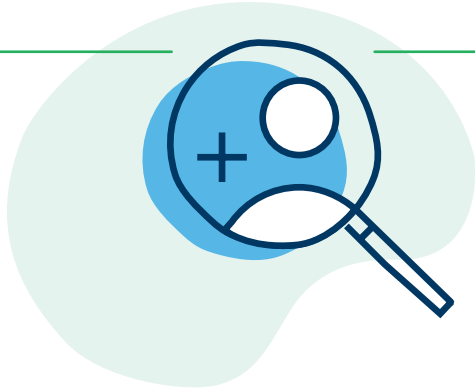
Body Mass Index (BMI): If your BMI is greater than 30, your team will require you to lose weight before your procedure. Your nutritionist will help you make lifestyle changes to help you reach a healthy weight.

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.

You will have a financial advocate on your team. He or she will guide you through any insurance issues you may have throughout the process and will routinely verify whether your insurance covers all aspects of your transplant care.

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



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 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

LANGUAGE ACCESSIBILITY AND NONDISCRIMINATION

Allegheny Health Network (AHN) complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex in its health programs and services. In order to treat individuals in a nondiscriminatory manner, AHN provides free communication aids and language assistance services.

ATTENTION: If you don't speak English, language assistance services, free of charge, are available to you 724-745-6100.

Arabic

ملحوظة: إذا كنت تتحدث أذكر اللغة، فإن خدمات المساعدة اللغوية تتوفر لك بالمجان. اتصل برقم 724-745-6100.

Chinese

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 724-745-6100。

French Creole

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 724-745-6100.

French

ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 724-745-6100.

German

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 724-745-6100.

Gujarati

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 724-745-6100.

Italian

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 724-745-6100.

Korean

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 번으로 전화해 주십시오. 724-745-6100.

Mon-Khmer

ប្រយ័ត្ន: ប្រសិនបើអ្នកនិយាយ ភាសាខ្មែរ, ស្ថាប័ននេះផ្តល់ជូនសេវាភាសា ជាមិនគិតថ្លៃដល់ គ្រប់អ្នកដែលនិយាយភាសាខ្មែរ។ ផ្លូវស៊ី 724-745-6100.

Pennsylvania Dutch

Wann du Deitsch schwetzsch, kannscht du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: call 724-745-6100.

Polish

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 724-745-6100.

Portugese

ATENÇÃO: Se fala português, encontramos disponíveis serviços linguísticos, grátis. Ligue para 724-745-6100.

Russian

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 724-745-6100.

Spanish

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 724-745-6100.

Vietnamese

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 724-745-6100.

