

The First Steps

- ✓ Your healthcare providers will refer you for an evaluation. They may refer you to a specific transplant center or to multiple centers. You can talk to many centers but need to choose just one.
- ✓ When choosing a transplant center, there are multiple factors to consider, including:
 - ☐ The center's expertise, experience, and patient outcomes; the Scientific Registry of Transplant Recipients has a search engine with relevant information, which is available here.
 - ☐ You might prefer a center close to your current home for convenience, or you might choose a center farther from your home if you are willing to relocate for a significant amount of time.
 - ☐ Your health insurance coverage and costs for tests, surgery, hospital stays, and transportation.
 - ☐ The availability of at least one person who can support you through the transplant process.
- ✓ Your first contact from the transplant center will be with the Transplant Coordinator. This is the point person who will schedule your appointments and tests. Be on time and bring family or friends to every appointment. Punctuality and social support can influence eligibility for a transplant.

The Evaluation will be Thorough

The transplant team will look at many factors when determining your eligibility for a transplant.

✓ Severity of Lung Disease

- ☐ A lung Composite Allocation Score (CAS) is calculated as part of the lung transplant evaluation. CAS is based on type of lung disease, need for supplemental oxygen, 6-minute walk distance, and other aspects of your health that affect your risk of death without a lung transplant.
- ☐ Individuals with severe, life-threatening lung disease are considered more urgently.
- Diagnostic tests will be used to assess your lungs. These tests may include X-rays, ultrasound procedures, computed tomography (CT scan), pulmonary function tests, and lung biopsy.

✓ Overall Health

- ☐ Individuals may not be eligible for a transplant if they have other serious health problems like active cancer, severe heart disease, or uncontrolled infections. In Alpha-1, liver disease plays a role in whether an individual is eligible for a lung transplant.
- □ Various tests will be used to examine your heart and lungs to ensure that you can handle anesthesia and surgery. You will need to get a cardiac stress test and cardiac catheterization.
- ☐ Blood tests are performed to help determine a good donor match.

✓ Substance Use

☐ Most transplant centers require patients to be abstinent from smoking and pain medications for at least six months. If needed, counseling or treatment programs may be recommended.

✓ Mental Health and Social Support

☐ A mental health evaluation helps ensure that the patient can handle the emotional and psychological stress of transplant and recovery. It is also important to ensure that family or friends are available to support the patient before and after surgery.

It Can be a Long Process

- ✓ The evaluation process can take several months. Once completed, the transplant team will meet to review the findings and decide whether you are a good candidate for a lung transplant.
- Transplant centers have different eligibility guidelines, including age restrictions. While you might not qualify for a transplant at one center, you may qualify at another. Most tests will transfer to another center, so keep good records of results. A new center will want to meet you and your caregiver.
- ✓ Eligible candidates will be required to participate in pulmonary rehabilitation before and after the transplant. You must walk the day after surgery; early walking helps transplant survival.

Additional Resources

- ✓ Chapter 9 of AlphaNet's Big Fat Reference Guide (BFRG) focuses on lung transplants. Anyone can access <u>AlphaNet's BFRG</u>. AlphaNet Subscribers can access the BFRG through their <u>Subscriber Portal</u>.
- ✓ AlphaNet has created several One-Pagers that focus on lung health, which are available <u>here</u>.
- ✓ The Scientific Registry of Transplant Recipients has a search engine with information about lung transplant centers and their success rates, which is available here.