

Questions and Answers About the Change in Lung Allocation Policy

Information for Patients and their Families

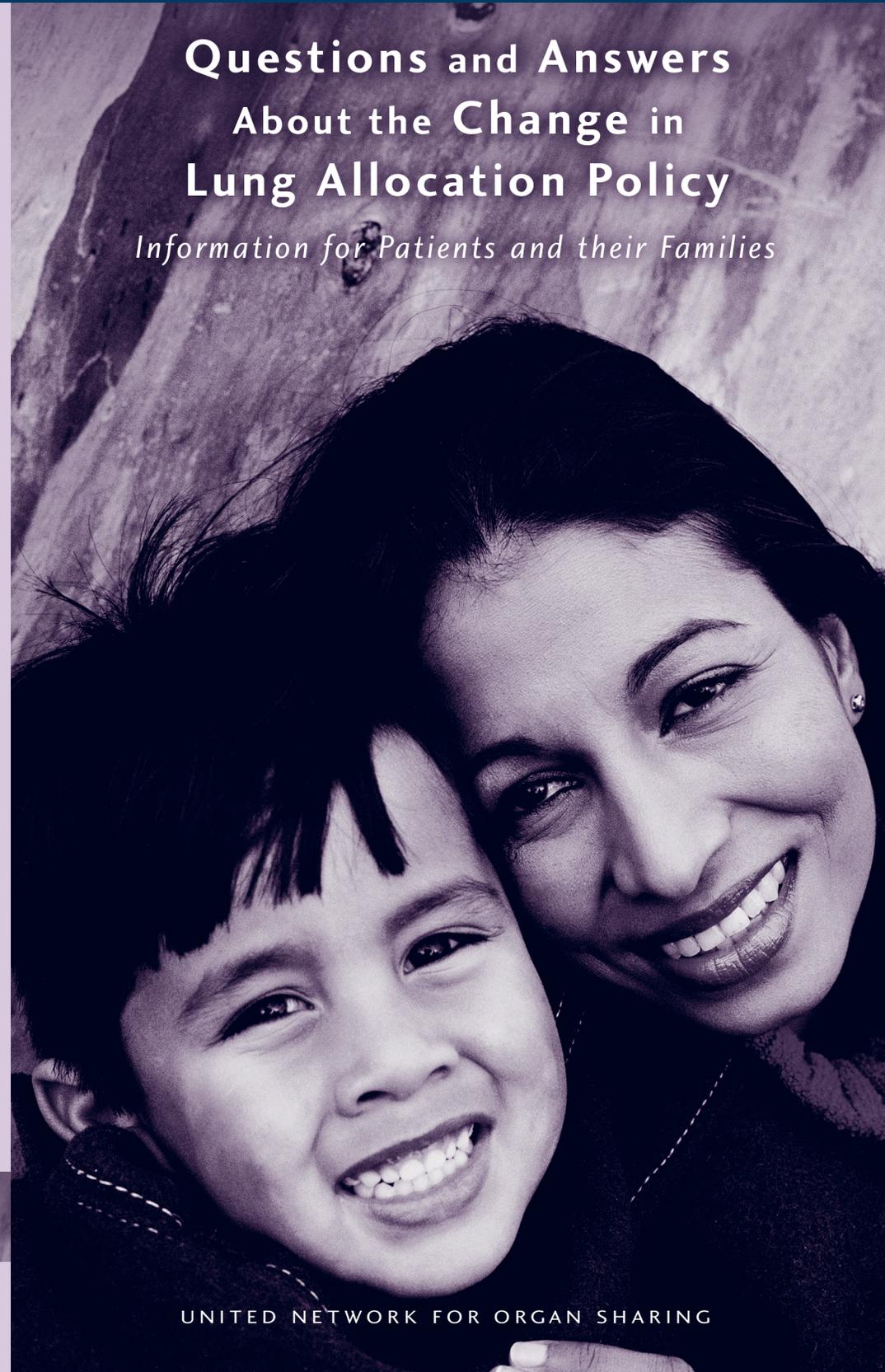
*The UNOS mission is to advance organ availability and transplantation
by uniting and supporting its communities for the benefit of patients
through education, technology and policy development.*

Questions and Answers

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UNITED NETWORK FOR ORGAN SHARING



Effective in the Spring of 2005, U.S. lung allocation policy will change significantly. The new system prioritizes lung transplant candidates for lung offers by assigning them a lung allocation score. This score is based on each patient's individual medical information. It reflects both the seriousness of each patient's medical condition before transplant and his or her likelihood of success after a transplant.

What are the OPTN and UNOS?

The Organ Procurement and Transplant Network (OPTN) manages the nation's organ procurement, donation, and transplantation system. The OPTN also works to increase the availability of donor organs and access to donor organs for patients who need them. The United Network for Organ Sharing (UNOS) is a non-profit organization that operates the OPTN under a contract from the federal government. The OPTN and UNOS continuously evaluate new advances and research and use this information to improve organ transplant policies to best serve patients waiting for transplantation. All transplant programs and organ procurement organizations are members of OPTN/UNOS and agree to follow OPTN policies.

What is the current allocation policy?

If you are currently on the lung transplant waiting list, you receive priority for lungs based on the amount of time you have spent on the waiting list, your blood type, and the distance from the donor hospital to your transplant center. Candidates who have waited longer get priority for lung offers over candidates who have not waited as long. The current system does not consider any medical factors that may indicate how sick you currently are or how well you might do following a lung transplant.

How has the policy changed?

Under the new system that will begin in Spring 2005, you and every other lung transplant candidate age 12 and older will receive an individualized *lung allocation score*. All patients in need of lung transplantation will be prioritized by their *lung allocation scores*. Your own *lung allocation score* will determine your priority for receiving a transplant when donor lungs become available.

The new lung allocation system will use medical information from each lung transplant candidate. This information will be used to estimate the urgency of illness and chance of success after a lung transplant. This information includes lab values, test results, and disease diagnosis. This medical information is used

Transplant candidates' lung allocation scores are calculated from the following medical information:

Forced Vital Capacity This is a lung function test that measures the maximum amount of air you can breathe out after you breathe in as deeply as possible. This amount may be lower in patients with lung disease.

Pulmonary Artery Pressure This is the pressure the heart must generate to pump blood through the lungs. This pressure may be high in some patients with serious lung disease.

Oxygen at rest This is the amount of oxygen needed by a patient at rest to maintain adequate oxygen levels in the blood. Patients with severe lung disease may need additional oxygen.

Age This is the candidate's age at the time lungs are offered.

Body Mass Index BMI is a ratio of a patient's weight to height that, when interpreted with other medical test results, helps to evaluate health status.

Insulin dependent diabetes Diabetes may be a predictor of health status in some patients with lung disease.

Functional status The New York Heart Association classifications measure effects that lung disease may have on a patient's function in everyday life.

6-minute walk distance In the 6-minute walk test, a patient is asked to walk as far as they can in 6 minutes. The distance walked is a measure of functional status.

Ventilator use The use of a ventilator to assist breathing may be a measure of disease severity and may affect success after a transplant.

Pulmonary Capillary Wedge Pressure PCW or "Wedge Pressure" is the pressure blood returning to the heart from the lungs must overcome. This pressure can become increased when the heart is not pumping effectively.

Creatinine Creatinine levels are a measure of kidney function. High creatinine levels reflect impaired kidney function, sometimes associated with severe lung disease.

Diagnosis Research has shown that urgency among patients needing a transplant and success after a transplant vary among patients with different lung diseases. Therefore, for every patient, diagnosis factors into the calculation of the lung allocation score.

to calculate a *lung allocation score* from 0 to 100 for each transplant candidate. Candidates are prioritized according to their score: A candidate with a higher score will receive higher priority to be offered lungs when they become available.

Why is this change necessary?

The new lung allocation system was designed as a way to more effectively use the limited number of available donor lungs among patients in need of a transplant and to reduce the number of deaths among transplant candidates. The OPTN designed this lung allocation system by studying scientific data on lung transplantation and by drawing on prior experience with many patients. By prioritizing candidates according to their medical characteristics instead of their waiting time, lungs will be transplanted first to patients who most urgently need them and who will have the greatest chance of success after their transplant.

What does this policy change mean to me?

The new system will be more responsive to your individual medical needs because the new system will use your medical information instead of your waiting time to determine your priority for a lung transplant. Your *lung allocation score* will be based on your own medical information and will reflect the urgency of your illness and your chance of success after a transplant.

How is waiting time counted in the new system?

In the new system, waiting time is not considered when allocating lungs to transplant candidates age 12 and older. These candidates will be prioritized for lung offers based on their *lung allocation scores*.

Matching lungs to young patients under age 12 has unique challenges. For this reason, pediatric candidates under age 12 will continue to receive priority for lung offers based on the amount of time they have spent waiting for a transplant.

When will the new system begin?

The new system is expected to take effect in Spring 2005. Before it begins, it will need to be programmed on the national transplant computer system. Six months before the new system begins, transplant centers will be notified so they may examine patients and enter their medical information on the computer system.

What if I am already registered as a lung transplant candidate when the system changes?

If you are currently registered as a lung transplant candidate and your physician decides that a lung transplant is still the right treatment for you, then your transplant team will need to update your medical information on the national registry by the date the new lung allocation system begins. It is important that your information is up to date when the new system begins so that you will receive a *lung allocation score* that accurately reflects your medical condition.

Your transplant center will be given six months notice before the new system takes effect so that your transplant team may evaluate you and your physician may enter your most current information in the system. During this transition period, you should work with your transplant team to schedule a visit to update your medical information.

How am I registered as a lung transplant candidate under the new system?

The new allocation system does not change who can register for a lung transplant. Your transplant team will decide when the time is right for you. When your transplant team decides that you should be registered as a lung transplant candidate, you will need to have a complete transplant work-up. During the transplant work-up, you will participate in a series of medical tests that will give your transplant center the information it needs to register you as a candidate for lung transplantation. This same information will also be used to calculate your *lung allocation score*.

How often should my information be updated?

Your transplant center will be required to update your information. Because the lung allocation system will determine priority for lung offers based on patients' medical information, it is important that your transplant center has your most current information and test results. Your transplant center may update your information on the system at any time your physician thinks it is necessary to reflect a change in your condition. Your transplant center will be required to update your information **at least once every six months**. If your medical information is not kept up to date, it may negatively affect your *lung allocation score*. It will be important for you to work with the team at your transplant center to set up a schedule for visits that will allow you to keep your information up to date.

What if I cannot perform a test to provide the information?

Most of the medical information that is needed to calculate your score comes from diagnostic tests or medical procedures. If your transplant physician decides that you should not perform these tests or undergo these procedures because of the severity of your condition, your physician may request that the best estimate of your medical information be entered on the system instead.

How high must my *lung allocation score* be before I may have a transplant?

There is no specific *lung allocation score* that will guarantee that you receive an offer for donor lungs. When donor lungs become available, a “match run” list is generated by the national transplant computer system to match the lungs with suitable candidates by blood type and the distance from the donor hospital to their transplant center. Candidates registered at transplant centers in the local area around the donor hospital and having a blood type that matches the donor are then prioritized by their *lung allocation scores*. The candidate with the highest *lung allocation score* at that time will receive first priority to be offered the donor lungs. If no appropriate recipient is found among these closest candidates, potential recipients at greater distances from the donor hospital will then be offered the lungs. Of course, you and your physician and surgeon at your transplant center will always have the option to decide whether a lung transplant is the right choice for you at that time or whether the particular lungs being offered are right for you.

Do pediatric patients receive a *lung allocation score*?

All lung transplant candidates age 12 and older will receive a *lung allocation score*. Because of unique challenges in matching lungs to patients under age 12, they will continue to be prioritized based on the amount of time they have spent waiting for a lung transplant.

What if my doctors and I don't agree with my *lung allocation score*?

If your transplant physician or surgeon believes your condition is an exceptional case and that your needs are not being met by the lung allocation system, then your transplant center will have an option to appeal your case to the Lung Review Board. This is a group of transplant physicians and surgeons who will consider the special circumstances of your case and determine what steps to take.

Will the system change again?

As transplant professionals apply this system and learn from it, some changes will likely be required to better meet patients' needs. In fact, this system is designed to be flexible and allow improvements. In transplantation, as in all scientific fields, new studies are taking place all the time to learn how to save more lives and help people live longer and better. Every six months, the lung allocation system will be reviewed and adjustments may be made to the way lung allocation scores are calculated. Your transplant team will keep you informed of changes to the system and what you may need to do.

What if I have more questions?

If you have any questions or concerns, you should contact your transplant team for additional information. You may also contact the UNOS Patient Services Department at 1-888-894-6361. Details about the OPTN, UNOS, allocation policy, and patient informational resources are available on the following Web sites:

www.optn.org • www.unos.org • www.transplantliving.org