

Information on lung transplantation

In collaboration with **NOVARIA**
Swiss Association of
Lung transplantation

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Who stands behind *NOVARIA*

In December 2004, the association was founded by those patients directly involved.

The goals are:

To enhance the exchange of information and cooperative interpersonal relations among its members

To assist the patients and their relatives after surgery

To encourage future transplanted patients by offering information and advice

To interact with national and international organisations with similar goals

To assist and facilitate scientific projects related to lung transplantation

To promote the awareness of the lung transplantation among Suisse people and Suisse physicians

To encourage the donation of organs in Switzerland

To assist in events for information patients about lung transplantation.

Where do you obtain further information about lung transplantation?

Centre for lung transplantation, university hospital, Zurich, coordination of the lung transplantation outpatient clinic

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When does the question of a transplantation of the lungs arise?

Some pulmonary diseases can progress in spite of the best treatment and lead to a severe shortness of breath. Physical exercises then become almost impossible. Those patients are no longer able to lead a "normal" life. When all possible treatments have been tried without any appreciable improvement, a lung transplantation can offer a chance for the most severely sick lung patients.

Are both lungs transplanted?

The transplantation of both lungs is ideal for most diseases. There are very few cases for a unilateral transplantation. The combined procedure, heart and lungs together, is only rarely performed, since both lungs are available for the majority of pulmonary disorders. The physical fitness can well be increased by all methods. The treatment following the surgery and the long term care are independent from the kind of the operation and are the same for every patient.

Who decides on whether a lung transplant is feasible?

The decision for a transplantation must carefully be weighed by the patient and the doctors involved. It is important that both sides are sufficiently informed. The better a patient knows the risks and chances for a successful intervention and, what he has to expect, the better he will be able to make his own decision and to get ready for it. The patient will first be sent by her lung specialist to the primary discussions, which will be held at the centre of lung transplantations. She will receive the detailed explanations from the team of specialists involved in her case, particularly of everything that concerns the operation and will be invited to ask her questions. At the same time, she gets to know the patients, who already breathe with their new lungs. She will hear the story from their perspective. The team of transplant specialists needs all possible information about the candidate to be able to decide, whether the transplantation is the correct method. That includes the picture of the disease, its course during the last months, the disabilities caused by the disorder and eventual comorbidities. Further examinations for an eventual intervention will be performed during a hospitalisation of 2 weeks at the centre.

How long does one have to wait for a new organ and who distributes the organs?

When the results of all the tests are good, and the patient agrees on a lung transplantation, she will be put on a waiting list. At that moment, a transplantation becomes possible at any time. The waiting period, however, cannot be predicted for each individual. It can last from a few months to three years. During that period, the patient has to remain always retrievable (phone, handy, beeper). The organs are announced to the organisation "Swiss transplant" and from there sent to the two centres of transplantation.

What is the success rate of a lung transplantation?

The success of a transplantation cannot be foreseen for every single case. A lot of patients obtain a good physical performance after the transplantation, can practise sports and enjoy a reasonably "normal" life. Some also can hold a full time job, again. The results have steadily become better over the last years thanks to the increasing experience of the two centres in the realm of surgery itself, of anaesthesia, the intensive care unit and the highly specialized long term follow-up. One, therefore, can count on a survival time of one year in 85-90 per cent and of five years of 70 per cent in Switzerland. In the mean time, ten patients could celebrate the tenth birthday of their transplantation in Zurich. There are, however, less favourable courses or only temporary improvements with a deterioration of the physical performance. In addition, side effects of the necessary medicine can occur. There is no safeguard against a failed transplantation for everybody.

What happens after the transplantation?

After surgery, regular medical check-ups at the specialized outpatient clinic are a must for the success of the intervention. The purpose of those visits is to recognize on time a possible rejection, infections and other problems. They, therefore, are the essential condition for the longest possible survival of the new organ. The postsurgical exams include besides the blood test the analysis of the functions of the lungs, radiographs and bronchoscopies, as well. During the bronchoscopy, a thin tube is inserted under local anaesthesia into the trachea and the bronchi to obtain a small sample of mucus and tissue from the lungs.

What do we have to pay attention to during the further course after the transplantation?

The operation is not the end of the treatment. Our body recognizes the transplanted organ as an intruder and tries to get rid of it. That attempt at rejection is normal and happens with every kind of transplantation (kidney, liver, lung or heart). Therefore, everybody with a new organ has to take drugs during her or his entire life to suppress those rejections. But the immunosuppressors do not only decrease the resisting forces of our body, which threaten the new organ, but also the ones helping the human being to defend oneself against infections. That means that all the individuals with a new organ are much more prone to infections than others, and that the infections take a more serious course. Dealing with those problems needs a great specialized medical experience. You find it at the centre for lung transplants. That also is the reason for having the follow-up visits at the out-patient clinic for lung transplants, where a team of doctors, especially trained to treat transplanted patients, takes care of you.

What will you be capable of doing after the transplantation?

The aim of the lung transplantation is to allow the patient to again enjoy a reasonably normal life. That includes a vacation with the family as well as a return to one's hobbies and sports. Equally important is the reinsertion into the professional and social daily activities. Those steps are actively supported by the transplantation program with professional help (social counselling and psychosocial assistance).

Which drugs have to be taken after the transplantation?

The medicine used to prevent a rejection inhibits the resistance of the body (the immune system) and is called immunosuppressant. After a lung transplantation, three different immunosuppressants are prescribed. One of them is cortisone. In addition, drugs preventing infections play a big part. All those drugs have side effects, which need to be treated, too.

Application for individual membership, families and patronage

I wish / we wish from the association NOVARIA to be admitted as a Member.

Individual membership (lung transplant)

An individual membership of NOVARIA is only possible for lung transplant patients and their family members.

The annual amount is CHF 50 .---

As an individual member they have a right to vote and receive a special authorization for the members area on our website.

Family membership

A family membership can be provided by families, spouse / cohabitant who is in the same household.

The annual amount is CHF 50 .---

As a family member they have a right to vote and receive a special authorization for the members area on our website.

Patronage

A patronage can be granted from anyone at NOVARIA. Membership contributions have been fixed from **a contribution of CHF 30 .---** As a patron you will not receive any voting rights or special access to the members area on the website.

I could also imagine being in an active role for example as

I am available as a contact person for affected patient. My contact data can be given in need for this purpose.

Comment: