

TALKING ABOUT TRANSPLANTATION

Questions & Answers
for **Transplant**
Candidates about
Multiple Listing and
Waiting Time Transfer



UNITED NETWORK FOR ORGAN SHARING

What are the OPTN and UNOS?

The Organ Procurement and Transplantation Network (OPTN) links all of the professionals involved in the nation's organ donation and transplantation system. The OPTN also strives to make more organs available and increase patient access for transplants. 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 review new advances and research and use this information to improve organ transplant policies to best serve patients needing transplants. All transplant programs and organ procurement organizations are members of the OPTN and agree to follow its policies.

How am I listed for a transplant?

If you have a condition leading to organ failure, your doctor may recommend you for an organ transplant. To become a transplant candidate, you must be evaluated and accepted by a transplant hospital. It is up to each center to decide whether or not it will accept someone as a transplant candidate.

How am I considered for organs from deceased donors?

You are considered for available organs based on a combination of medical facts entered into a computerized matching program. These factors include blood and tissue type, medical urgency, body size, distance between the donor and transplant hospital and time spent waiting for a transplant.

The distance between the donor and transplant hospital is important because the less time the organ must be preserved outside the donor's body, the better the chance that it will function when transplanted. There are three levels considered:

- **local.** This is usually the area served by the local organ procurement organization (OPO) where the donation occurs. There are 58 OPOs nationwide. These areas are often statewide but can be smaller (such as a large city or part of a state) or larger (a multi-state area). Your transplant center can tell you what your local area is.
- **region or zone.** If there are no suitable local matches, organs are offered to patients at transplant centers in a wider area. Kidneys, livers, pancreases and intestinal organs are first offered within one of 11 regions of the United States. Heart and lung offers are considered for candidates within 500 miles of the donor site, then 1,000 miles, then 1,500 miles.
- **nationwide.** If there are no matches in the local area or region, organs will be offered to anyone in the United States who is a potential match.

What is multiple listing?

Multiple listing involves registering at two or more transplant centers.

Since candidates at centers local to the donor hospital are usually considered ahead of those who are more distant, multiple listing may increase your chances of receiving a local organ offer.

Could multiple listing shorten my waiting time for a transplant?

Some studies suggest multiple listing can shorten the average waiting times of kidney transplant candidates by several months. This does not guarantee that every multiple-listed patient will have a shorter waiting time.

Many factors affect how long you might wait for a transplant. Of course, not enough organs are donated each year to meet everyone's needs. Everyone in the transplant community shares the goal of increasing organ donation to save and enhance more lives.

Other waiting time factors include how urgent the patient is and how closely the donor and candidate match on body size and blood type. Some kidney and pancreas candidates have a "highly sensitized" immune system because of earlier transplants, pregnancy or multiple blood transfusions. Highly sensitized patients will only be good matches for a limited number of organ offers, so they often wait longer than non-sensitized candidates.

Are there any restrictions?

OPTN policy allows multiple listing. It will still be up to the individual center to decide whether to accept you as a candidate. You probably would not benefit from listing at multiple centers in the same local allocation area (which is usually the OPO). This is because waiting time priority is first calculated among candidates at all hospitals within the local donation area, not for each hospital individually.

Some transplant programs may not accept multiple-listed patients. Others may set their own requirements for multiple-listed candidates. If you are considering multiple listing, you should ask the transplant team how they handle such requests.

What is involved in multiple listing?

As with any transplant listing, you must be considered and accepted by a transplant center. This involves completing an evaluation and agreeing to meet any conditions set by the program (for example, ability to come to the hospital within a certain time if you are called for an organ offer).

You might check with your insurance provider to see if they will reimburse the cost of additional evaluations. You should also consider other costs associated with listing that insurance may not cover. For example, you may need to pay for travel and lodging if the center is further from your home. You should also find out whether your post-transplant medical care will be provided at the center

or can be transferred to a facility closer to your home. In addition, you would need to maintain current lab results and contact information for each transplant program where you list. Each program will need current information should they receive an organ offer for you. Through the OPTN database your center can know if you are multiple-listed but may not know the other hospital(s) where you are listed.

If I list at more than one center, how is my waiting time considered?

As soon as a center accepts you as a transplant candidate, your “waiting time” begins. Depending on the organ you need, waiting time may be a factor in matching you for an organ offer. Waiting time is a more important factor for certain organ types such as kidney and pancreas. It is less of a factor with heart, liver, and intestinal organs. For these organs more priority is given for factors such as medical urgency.

If you are a lung transplant candidate age 12 or older, waiting time will not be used at all in matching you with organ offers. Lung transplant priority is given for a combination of medical urgency and expected post-transplant survival. Waiting time is a factor for lung transplant candidates age 11 and younger.

The longest amount of time you have waited at any center is called your *primary waiting time*. If you list at multiple centers, your waiting time at each center will start from the date that center listed you. OPTN policy allows you to transfer your primary waiting time to another center where you are listed, or switch time waited at different programs. (For example, if you have waited 9 months at Center A and 6 months at Center B, you could switch your time to have 6 months at Center A and 9 months at Center B.)

You are not allowed to add up or split your total waiting time among multiple centers. (Again, assume you have waited 9 months at Center A and 6 months at Center B. You could not assume you have 15 total months of waiting time and assign 5 months to Center A and 10 months to Center B.)

Any request to transfer or switch waiting time must be approved by the transplant center(s) involved. Most transplant programs require a written request to swap or transfer waiting time, which will then be considered by the transplant team.

If I do not multiple-list but transfer my care to another hospital, what happens?

If you want to end your listing at one program and transfer to another, your primary waiting time can be transferred as long as you coordinate with both programs. The new transplant program will probably ask you to request in writing to transfer the waiting time. Keep in mind that if you end your listing at one program *before* another program formally accepts you, *you may risk losing all previous waiting time*.

Sometimes a transplant program may inactivate for a period of time (for example, to replace a key member of the transplant team who leaves) or close its operations. If this happens, the OPTN requires that the program contact you and provide for your continuing care. If the inactivation is short-term you may choose to remain listed until the program becomes active again, but you will not receive organ offers during that time. If the program closes, the staff will work with you to arrange care at another center without loss of your primary waiting time.

Where can I get additional information?

You should first contact the staff of the transplant program where you are listed or want to be listed. They will have the most specific information about how they handle requests for multiple listing and/or waiting time transfer. They will also make any needed arrangements with UNOS.

UNOS maintains a web site, Transplant Living, which contains extensive information for transplant candidates and recipients as well as their family members. The address is www.transplantliving.org. You may also wish to visit the OPTN web site at www.optn.org.

UNOS also maintains a toll-free phone information line for transplant candidates, recipients and family members. The number for Patient Services is 1-888-894-6361.

*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.*



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www.unos.org

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Note to transplant candidates/family members:

In accordance with OPTN Policy 3.2.3, your transplant center is required to provide you with written information about multiple listing and transfer of waiting time. Your signature below confirms that your center provided you this booklet. Your center will keep this form on file to document compliance with this policy.

I have received the booklet Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer.

Signature of Transplant Candidate/Family Member

Printed Name of Transplant Candidate

Date Received

Signature of Transplant Center Staff Member Providing Booklet