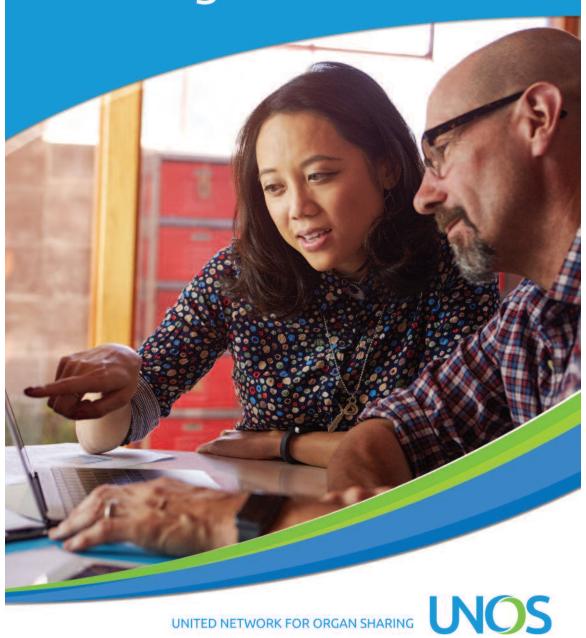
TALKING ABOUT TRANSPLANTATION

Frequently Asked Questions about

# Multiple Listing and Waiting Time Transfer



#### Who are UNOS and the OPTN?

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that manages the nation's transplant system — known as the Organ Procurement and Transplantation Network (OPTN) — under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants.

All transplant programs and organ procurement organizations throughout the country are OPTN/UNOS members and are obligated to follow the policies the OPTN creates for allocating organs.

#### 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 hospital 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 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 program 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 hospitals 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 hospitals. Since candidates at hospitals 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 hospital to decide whether to accept you as a candidate. You probably would not benefit from listing at multiple hospitals in the same local allocation area. 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 hospital. 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).

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 hospital is further from your home. You should also find out whether your post-transplant medical care will be provided

at the transplant hospital or can be transferred to a facility closer to your home. In addition, you 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 program 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 hospital, how is my waiting time considered?

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.

If you are listed for a kidney transplant, your waiting time will be calculated from when you start dialysis to treat kidney failure. Your waiting time will be the same at each transplant program where you list, as long as each program has the same information about when you started dialysis.

If you are listed for any other organ type, your waiting time at each hospital will start from the date that program listed you. The longest amount of time you have waited at any hospital is called your primary waiting time.

OPTN policy allows you to transfer your primary waiting time to another hospital, or to switch time between programs. (For example, if you have waited 9 months at Hospital A and 6 months at Hospital B, you could switch to have 6 months at Hospital A and 9 months at Hospital B).

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

Any request to transfer or switch waiting time must be approved by the transplant programs(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 hospital 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 hospital 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.transplant.hrsa.gov.

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*.

#### Note to transplant candidates/family members:

In accordance with OPTN policy, your transplant center is required to provide you with written information about multiple listing and transferal 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 *Frequently Asked Questions about Multiple Listing and Waiting Time Transfer.* 

Transplant candidate/family member	Date received
Transplant candidate/family member (printed)	
Transplant center staff providing booklet	

Our 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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