



等待移植

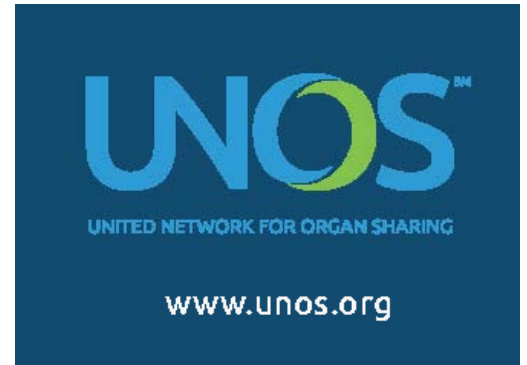
肾脏/胰脏移植

在完成评估并且接受您做移植后、您就可以列入等候器官移植的排名。本章节就是为您解释等候名单、及在被通知来医院做移植之前的等待期间您可以做的事项。

何谓排名？

等候器官移植的排名是由联合器官共享机构(UNOS)主管的一个电子数据库。联合器官共享机构(UNOS)、是一由联邦支持的非营利机构、监管美国、波多黎加的移植轮候名册。

如您要由遗体捐赠的肾脏或胰脏、您必须在此名册上排期。



等候器官移植的排名是由联合器官共享机构(UNOS)主管的一个名册。

我如何才能被排名？

我们会将您个人的资讯-姓名、血型及组织型态-输入联合器官共享机构(UNOS)的电脑系统、将您的名字加入排期名册上。

这名册是如何操作的？

当有遗体捐赠肾脏或胰脏时、所有在名册上等待肾脏、胰脏移植的病者都会与捐赠者相配。电脑会列出与此肾脏或胰脏最相配的病者名字。再加上其它如排期的时间、您的年龄、是否属敏感(请参看第2页)也都是考量的因素。

谁会获得移植？

谁会获得移植是根据：

- 血型及人类白细胞抗原 (HLA)与捐赠者最相配者。
- 排期时间的长短(等待最长久者有优先权)
 - 如您在排名之前已开始肾透析:您的等待时间可以追溯到您开始透析的那一天。如您在2年前开始透析今天开始排名、您就已经有2年的等待时间。

- **如您在排名之前尚未做肾透析:**当您估计的肾小球滤过率（GFR）为 **20 毫升 / 分钟**或更低时，您的等待时间就开始了。这可以由血液测试或尿液测试来测量。
- **如您估计的肾小球滤过率（GFR）高于 20 毫升 / 分钟：**您可以列入肾脏移植等待排名、但您将“暂停”。就是您的等待时间不会开始计时、直到您的肾小球滤过率（GFR）降到 **20 毫升 / 分钟（GFR）**。当您的肾小球滤过率（GFR）**GFR 达到 20 毫升 / 分钟**或更低时、请告诉您的联系护士。我们会让您“激活”、如此您可以开始积存等待时间。
- 年龄(年轻的优先)。
- 他们是否敏感。会敏感的人在他们的**群体反应性抗体（PRA）**测试中得分高。
 - 敏感是指您的血液中有抗体对抗许多潜在的捐赠器官。您可以因怀孕、输血或其他移植而提高敏感度。
 - 如您有敏感、可能很难找到您的身体会接受的肾脏或胰脏。因此、您在等待排名上比其他没有敏感的人占优先。
 - 群体反应性抗体（PRA）是 **99%**的患者可以接受整个地区捐赠者的移植。
 - 群体反应性抗体（PRA）是 **100%**的患者可以接受全国捐赠者的移植、而非仅限于我们当地的移植区。
 - 请参阅本讲义“组织配对(in chapter 5)”一章有关有群体反应性抗体（PRA）及人类白细胞抗原（HLAs）的详细资讯。

我在排名册上排第几？

名册上并无等级、顺序如排第一，第二或第三等等。是否接受到器官的决定是要看有没有能匹配的捐赠者。器官、及接受移植者是基于两者间医疗上的匹配、及已经排名等待的时间而定。

您可能比某位病人在排名上等得更久、但是下一个肾脏或胰脏却没给您、因为它与另一位病人更为匹配。但也可能您比其它等候得久的人先得到、因为器官与您较为匹配。

除非接到全国器官共享组织(UNOS)的书面通知、您不会被排名册上除名。

我要等多久？

我们无法预测您等待移植的时间。但是、您的移植团队可以根据您的血型为您提供“一般”等待的时间。（有关可能影响您等待时间的其他事项，请参阅“组织配对”一章。）

请注意、一旦上了等待的排名、就可能在白天或晚上随时通知您来做移植。

我可以在多个名册上排名吗？

所有华盛顿州的移植项目是用同样的名册。在西雅图或斯波坎地区的另一个中心排名并不会改变您的等待时间。事实上、在华大医疗中心排名、就不可在同一个区域的其他移植中心排名。

但是、您如在美国其他地区的移植中心排名、就可能改变您的等候时间。请上联合器官共享机构 (UNOS) 的网站 www.unos.org 查看全国各个不同地区的等待时间。虽然您已在华大医疗中心 UWMC 完成评估、但您如到其他移植中心排名、可能还需要到这些移植中心做移植的评估。

在等待期间该做的事

- 每年至少与您的移植联系人打一次电话、可能订在您生日那天、以便提醒要联系我们。此外、如您健康状况或生活习惯有重大改变时、也务必与我们联系
- 下列事项有改变时请与移植联系人联系：
 - 您的电话号码
 - 地址
 - 健康状况(近期住院或感染)
 - 财物状况(包括健保的改变)
 - 您计划外出
 - 选择性(可事先安排)的手术
- 您个人的事件都已作了安排：
 - 作了预设医疗指示及遗嘱。
 - 如有需要、填妥病假申请表或贷款延期表格。
 - 为您的小孩或宠物安排人照顾。

如您对这些事项需要帮助时、请与我们联系。

- 做周年度的体检。可包括心脏负荷测试、心脏的评估、巴氏抹片测试、乳房 X 光检查、肠镜、及其他移植组要求您做的测试。
- **重要事项:**每月按时作接受遗体捐赠所需的抽血、以便做人类白细胞抗原 (HLA) 测试。如没有您当前的血液样本、您可能会错过一次移植的机会。
 - 会将所需要的试管寄给您
 - 如您在做透析、请将包裹带给透析中心。如果您不做透析、则请您当地的化验室以获取每月的血液样本。

- 遵照您与转诊医生设置的保健计划。例如、做透析、定期去看医生、按医嘱服用药物。
- 观察您的液体增加及磷的指标。 这有助于您在排名表上保持活跃状态。
- 保持健康的生活习惯：
 - 吃得健康。
 - 充足的休息。
 - 处理压力。
 - 如有需要、减轻体重。
 - 遵循常规的锻炼计划、保持身体强壮。

保持最佳的身心健康状态是非常重要的。您所服用的药物可能会削弱肌肉的能力。因此您务必在移植前把健康调整到最佳状态。可能营养师或理疗师可帮助您实现目标。

- 不要抽烟、也不要滥用酒精或毒品。 如您需要帮助戒酒、烟或吸毒、请告诉我们。 我们可以帮助您找到戒烟、酒及毒品的计划。
- 如您是女性、请制定一份您将在移植手术后使用的避孕计划。 有两个非常重要的原因；您至少必须避免在手术后 1 年内怀孕：
 - 怀孕会影响您的移植成功。
 - 移植药物可导致婴儿先天性缺陷
- 学习有关肾脏或肾脏/胰脏移植的更多信息。 多提问。 请阅读此讲义（参见“资讯”一章）。
- 选定您将用那一家药房。您也可以了解一下邮购的可能性、这可为您省些钱。
- 评估您的保险的涵盖范围及个人财务状况：
 - 了解移植的所有费用。
 - 准确地知道您健保计划涵盖的内容、包括外地就诊的运作及涵盖。
- 如您住在普吉特海湾地区之外、请作一个来西雅图的计划。 您的计划应包括如何来西雅图以及您在西雅图的住处。 您可计划在移植后留在西雅图地区至少 3 至 4 周。 您需要在上午 7:30 来医院做多次的后续门诊。
- **设置一个在西雅图的支持系统。**
 - 如您来自其他城市、请计划让家人及朋友与您同住在西雅图。 如需要协助、请告诉我们的员工。
 - 如您住在西雅图、当您接受移植手术后、您仍需要一个支持计划。

- 为您接受移植手术的那一天做好准备。因为手术可能会很快发生。如需长时间等待可寻找一些应对的方法。如您在等待时遇到问题、请与我们联系（请参阅“如何应对”一章）。

等待的照顾者

如您是移植患者的照顾者、这对您来说也是一个压力很大的时间。您可以找到其他朋友或家人、在移植后的几周内为您担负照顾的责任、这样您就可以有一些舒缓自己的时间。每天 24 小时照顾某人是一项很艰巨的工作！

请记住；有很多方法可以帮助您所关爱的人：

- 与朋友及家人谈论活体捐赠
- 按时注射疫苗
- 照顾宠物
- 病人移植后、您须时常洗手

接到通知您来接受移植的电话

当有一个适合于您移植的器官时、我们会打电话给您。可以在白天或晚上的任何时间、在一周的任何一天发生。

我们必须在有可用的器官时 1 小时内联系到您。 即使您不在城里、或正参加聚会或参加会议、**我们必须能够在任何时间联系到您。**

如有人总是会知道您在哪里、请确保您也把这个人的电话号码告诉我们。

我们有许多关于当我们打电话给病人来做移植手术时无法联系到的患者的故事。不要重复这故事！务必确保我们能**随时**与您联系。

由于每位患者都是独一无二的、因此与您通过电话后的进展也不一定。您可能被列为首选、或候补来接受器官。当交叉配对的最后结果出来时、我们就可告诉您下一步的计划。

当协调员/联系人致电通知您来接受移植时：

- 我们会告诉您何时到医院、那个部门。
- 如您患有糖尿病并使用胰岛素、并且告诉您不要进食、请向协调员/联系人询问您应使用多少单位的胰岛素。您的剂量将取决于您的手术预期时间而定。大多数情况下、协调员/联系人会告诉您只使用通常剂量的 1/2。

您接到电话后：

- 除非我们另有说明、否则**不要**吃或喝任何东西。做手术时，您的胃需要尽可能是空的。
- 我们会给您足够的时间收拾您需要的物品、及打重要电话的时间、但请尽快安全地到达医院。

事先将您要携带的物件包好

将您的物件包装妥当、随时准备好。 包括您住院所需的个人物品。

也请携带：

- “肾脏/胰脏移植”简介讲义
- 您华大医疗中心的挂号卡
- 健保的资讯
- 有相片的身份证
- 紧急事故联系人的电话号码
- 您所有的药物
- 更换的配件 (如您是做腹膜透析)
- 眼镜、如需要
- 信用卡、如您认为在住院期间需要用钱

您可以要求将您的身份证和信用卡放在医院的保险箱内。

我们还要求您将下列物品带到医院、以确保它们运作良好：

- 量血压计
- 体温计
- 测血糖器、如您需要

请勿携带：

- 首饰
- 贵重物品

您有疑问吗？

我们很重视您的疑问。当有疑问或顾虑时，请致电您的医生或医护人员。

移植科电话：
206.598.3882

Waiting for Transplant

For a kidney/pancreas transplant

After you are done with your evaluation and you have been accepted for transplant, you can be added to the wait list. This chapter explains about the wait list and things you can do until you get called for your transplant.

What is the wait list?

The wait list for organ transplants is a national computer database managed by the United Network for Organ Sharing (UNOS). UNOS is a nonprofit, federally-funded organization. It maintains the transplant list for the entire country. This list contains the name of everyone in the U.S. and Puerto Rico who is waiting for an organ transplant.



The wait list for organ transplants is run by the United Network for Organ Sharing (UNOS).

If you want a kidney or pancreas transplant from a deceased donor, you must be placed on this list.

How do I get on the list?

We will enter your information – your name, blood type, and tissue type – into the UNOS computer system to add you to the wait list.

How does the list work?

When a kidney or pancreas from a deceased donor becomes available, all patients on the list who are waiting for a kidney or pancreas are compared to that donor. The computer makes a list of patients who best match that kidney or pancreas. It also considers how long you have been waiting for a transplant, your age, and *sensitization* (see page 2).

Who gets the transplant?

Who gets the transplant depends on:

- If their blood and tissue type (HLA) matches the donor's.
- How long they have been on the wait list (people who have been waiting longer for transplant have priority).

- **If you started dialysis before you were added to the wait list:** Your wait time goes back to *the day you started dialysis*. If you started dialysis 2 years ago and are listed today, you already have 2 years of wait time.
- **If you were not on dialysis before you were added to the wait list:** Your wait time begins when your estimated glomerular filtration rate (GFR) is 20 mL/min or less. This is measured either by a blood test or urine test.
- **If your GFR is above 20 mL/minute:** You can be added to the kidney transplant wait list, but you will be “on hold.” This means your wait time will not start to add up until your GFR reaches 20 mL/minute or less. Please tell your nurse coordinator when your GFR reaches 20 mL/minute or less. We will take you off “hold” so that you can start gaining wait time.
- Their age (younger patients have priority).
- Whether or not they are *sensitized*. A person who is sensitized has a high score on their *panel reactive antibody* (PRA) test.
 - Being sensitized means you have antibodies in your blood that could fight against many potential organ donors. You can be sensitized through pregnancy, blood transfusions, or other transplants.
 - If you are sensitized, you could have a harder time finding a kidney or pancreas that your body will accept. Because of this, you are given priority on the wait list over those who are not sensitized.
 - Patients with a PRA of 99% may receive transplants from donors all across the region.
 - Patients with a PRA of 100% may receive transplants from donors all across the country, rather than just our local area.
 - Please see the chapter on “Tissue Matching” for more information on PRA and Human Leukocyte Antigens (HLAs).

Where am I on the wait list?

People are not ranked in an order such as 1st, 2nd, or 3rd on the wait list. The decision about who will receive a transplant is made when a donor organ becomes available. You are given priority based on compatible tissue and blood types between you and the donor, as well as how long you have been on the wait list.

You may end up waiting longer than someone else on the list, simply because a certain kidney or pancreas matches best with that other person. You might also receive a transplant sooner than someone who has waited longer than you because the organ matches best with you.

You will never be removed from the list without receiving written notice from the United Network for Organ Sharing (UNOS).

How long will I wait?

We cannot predict how long your wait for transplant will be. But, your transplant team can give you an “average” wait-list time based on your blood type. (Please see the chapter on “Tissue Matching” for other things that may affect your wait time.)

Remember, once you are active on the wait list, you can be called for transplant at any time, day or night.

Can I be on more than 1 wait list?

All transplant programs in Washington state use the same wait list. Getting on a wait list at another center in the Seattle or Spokane area would not change your wait time. In fact, once you are on UWMC’s wait list, you cannot be listed at another transplant center in this area.

But, being listed with transplant programs in other areas of the U.S. may change your wait time. Visit the UNOS website at www.unos.org to see the wait times for different areas of the country. If you list with other programs, you may need to go to these centers to be evaluated for transplant, even if you have already been evaluated at UWMC.

What to Do While Waiting

- Call your transplant nurse coordinator at least once a year. It’s easiest to do this on a day that you will clearly remember, such as your birthday. Also call if there is a big change in your health status or lifestyle.
- Keep your transplant coordinator updated on:
 - Your phone numbers
 - Address
 - Health status (recent hospital stays or infections)
 - Financial status (including insurance changes)
 - Times when you plan to be out of town
 - *Elective* (planned) surgeries
- Make sure that your personal affairs are in order:
 - Fill out an advance directive and write your will.
 - Complete forms for medical leave or loan deferment, if needed.
 - Arrange caretakers for your children and pets.

Please let us know if you need help with these concerns.

- Have yearly medical checkups. These may include a cardiac stress test, heart evaluation, Pap smear, mammogram, colonoscopy, and other tests that the transplant team has asked you to have.

- **Important:** Keep up to date with your monthly blood samples for deceased donor cross-matching. If the HLA lab does not have your current blood samples, you may miss a chance to have a transplant.
 - Tubes for this testing will be mailed to you.
 - Take the package to dialysis if you are on dialysis, or to a local lab if you are not on dialysis, for your monthly blood sample.
- Follow the healthcare plan you created with your referring doctor. For example, attend dialysis, have regular doctor visits, and take your medicines as prescribed.
- Watch your fluid gains and phosphorus levels. This will help you keep your active status on the list.
- Maintain a healthy lifestyle:
 - Eat healthy foods.
 - Get good rest.
 - Manage your stress.
 - Lose weight if you need to.
 - Follow a regular exercise program to keep your body strong.

Staying in great mental and physical shape is very important. The medicines you take may weaken your muscles. You will want to be as healthy and strong as possible if and when you have your transplant. A dietitian or physical therapist may be able to help you with your goals.

- Do not smoke cigarettes and do not abuse alcohol or drugs. If you need help managing your alcohol, cigarette, or drug use, please tell us. We can help you find a program to quit.
- If you are a woman, create a birth control plan that you will use after transplant surgery. There are 2 very important reasons you must avoid becoming pregnant for at least 1 year after surgery:
 - A pregnancy will impact the success of your transplant.
 - Transplant medicine can cause birth defects in the baby.
- Learn more about kidney or kidney/pancreas transplants. Ask questions. Read the handouts you receive (see the chapter on “Resources”).
- Decide what pharmacy you will use to get all your medicines. You may want to look into mail order options, since they may save you money.
- Assess your insurance coverage and personal finances:
 - Learn about all the costs of having a transplant.
 - Find out exactly what your plan covers, including how your plan works when you are outside your hometown area.

- If you live outside the Puget Sound region, make a plan for coming to Seattle. Your plan should cover how you will get to Seattle and where you will stay. Plan to stay in the area for at least 3 to 4 weeks after transplant. You will need to come to the hospital at 7:30 a.m. for follow-up visits on many days.
- **Set up a support system in Seattle.**
 - If you are from out of town, make plans for family and friends to stay with you in Seattle. Ask our staff for help, if needed.
 - If you are from Seattle, you will still need a plan for support if and when you have your transplant.
- Get ready for the day when you are called for transplant. It may happen quickly. Find ways to cope if it takes longer. Ask for help if you are having problems coping while you wait (see the chapter on “Coping”).

For Caregivers Who Wait

If you are the caregiver for a transplant patient, this can be a stressful time for you, too. You may be able to find other friends or family members who will step in for you in the weeks after transplant, so that you can take some time for yourself. Looking after someone 24 hours a day is a tough job!

Keep in mind that there are many ways to help your loved one:

- Talk with friends and family about living donation
- Update your vaccinations
- Take care of the pets
- Wash your hands often after your loved one’s transplant

Getting Called for Transplant

We will call you when there is an organ that will work for your transplant. This can happen at any time of the day or night, on any day of the week.

We must be able to reach you within 1 hour of an organ becoming available. Even if you are out of town, at a party, or at a conference, **we must be able to reach you at ALL times.**

If there is someone who will always know where you are, make sure you give us that person’s phone number, too.

We have many stories about patients who could not be reached when we called them for transplant. Do not be one of these stories! Make sure we are able to reach you **AT ALL TIMES.**

Since each patient is unique, what happens after the phone call will vary. You may be called in as a primary or backup recipient. We will tell you of the plan as soon as the cross-match results are final.

When the coordinator calls you in for transplant:

- We will tell you when and where to arrive at the hospital.
- If you have diabetes and take insulin, and you are told not to eat, ask the coordinator how much insulin you should take. Your dose will depend on the expected time of your surgery. Most times, the coordinator will tell you to take only ½ of your usual dose.

After you receive this call:

- Do **NOT** eat or drink anything, unless we tell you otherwise. Your stomach needs to be as empty as possible when you have surgery.
- We will give you enough time to gather the belongings you will need and make important phone calls, but please try to get to the hospital quickly and safely.

Have Your Bag Packed

Have your bag packed and ready to go at all times. Include personal items you will need for a hospital stay.

Please also bring:

- Your copy of *Your Kidney/Pancreas Transplant Guide*
- Your UWMC clinic card
- Information about your insurance plan
- Photo ID
- A list of emergency contact phone numbers
- All your medicines
- An extra exchange (if you are on peritoneal dialysis)
- Reading glasses, if needed
- Credit card, if you think you will need money during your hospital stay

You can ask to put your photo ID and credit card in the hospital safe.

We also ask that you bring these items with you to the hospital, to make sure they are working well:

- Blood pressure cuff
- Thermometer
- Blood glucose meter, if you use one

Do **not** bring:

- Jewelry
- Valuables

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882