

The background features a large, light orange triangle pointing downwards from the top left. To its left are overlapping geometric shapes in blue, red, and teal. The top right area is white with scattered grey dots. On the right edge, there are three overlapping hexagonal shapes in blue, red, and teal. At the bottom right, there are two overlapping trapezoidal shapes in teal and dark teal.

Health Facts for You



**Your child's
kidney transplant
evaluation**

Welcome to the UW Health Kidney Transplant Program. The team takes pride in building a care plan tailored to your child's needs. We are committed to their success. UW Health is a national and international leader in the field of transplantation. Our program provides care for both adults and children. We offer both deceased and living donor transplantation.

The Kidney

Knowing how the kidneys work will help you understand the transplant process.

What do the kidneys do?

- Filter blood and send it back to the heart
- Balance fluid levels by making urine
- Filter and balance minerals in the blood
- Control blood pressure
- Help to make red blood cells

What are the options if my child's kidneys stop working?

- Dialysis (peritoneal or hemodialysis)
- Transplant (living donor or deceased donor)
- Manage with medicines

After Your Child's Evaluation Testing

When your child's evaluation testing is done, the transplant team reviews and discusses your child's results. There are three possible decisions:

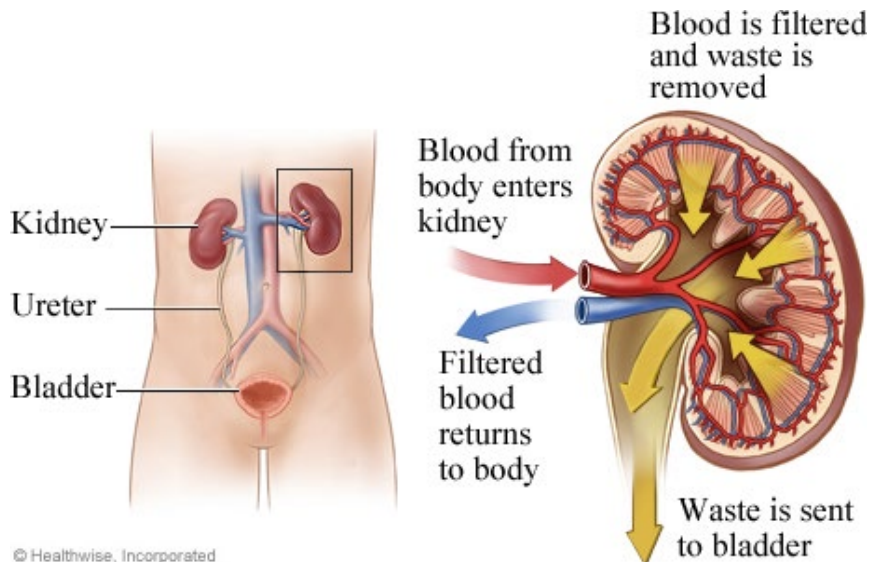
1. Your child is approved to be added to the list. Or,
2. The team feels transplant is NOT the best option. Or,
3. The team needs more testing or information to make the decision.

You will be notified of the decision and next steps.

Where My Child's New Kidney Will Come From

The Organ Shortage

There is a severe shortage of organs for transplant. This means that the wait for a kidney transplant can be months. The UW Transplant Program has long been a leader in trying to find new ways to increase the number of good organs that can be used for transplant. When you are told that your child needs a kidney transplant, you have options as to where the new kidney will come from. It is very important that you explore these options fully.



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Live Donor Kidney Donation		
What?	Who?	Things to Know
This is when a healthy person's kidney is transplanted into the recipient.	Living donors can be related or unrelated.	Patient survival statistics after a living donor kidney transplant are better than those who have had a deceased donor transplant. Other benefits include being able to have a planned surgery and knowing the donor.
Deceased Donor Kidney Donation		
What?	Who?	
Some patients may not have a living donor. They can go on the list to wait for a deceased donor transplant.	Deceased donor kidneys are offered to recipients according to the United Network for Organ Sharing (UNOS) guidelines. The Organ Procurement Organization (OPO) contacts the UW Transplant Program when a kidney is found and tells them who is first on the UNOS list to get the kidney. Below are the types of deceased donor kidneys that patients may be offered.	
Types of Deceased Donor Kidneys		
<p>Donation After Brain Death (Deceased Donor)</p> <p>The most common type of organ donor is a person who has suffered a head injury causing brain death. "Brain death" occurs when the brain doesn't get enough oxygen and the brain stops working. This is often due to trauma or a stroke. Tests are done to tell when someone is brain dead. People who are brain dead are on a breathing machine. The breathing tube and medicines keep the heart beating and supply the organs with blood and oxygen until a transplant team arrives. Once the kidney is removed, it should be transplanted within 24 hours. Kidneys from these types of donors are called "standard donor" kidneys.</p>		
<p>Donation After Circulatory Death (DCD)</p> <p>Sometimes a patient's trauma is so bad that doctors can't save their life, but they are not brain dead. The doctor meets with the family to decide if life support should be stopped. If the family chooses to remove life support, the machines are turned off. Patients may or may not be able to donate. When the patient's heart stops beating, they are declared dead by the doctor. The transplant teams can remove the organs. This is called donation after circulatory death (DCD). The kidney may have some damage due to lack of blood flow. Because of this, kidneys from DCD donors may sometimes take a few days to start working after the transplant. Success rates for patients who get a kidney from a DCD donor are the same as with a brain death donor.</p>		

Organs Meeting Risk Criteria for possible transmission of HIV, Hepatitis B and Hepatitis C

Your child may be offered an organ from a deceased donor thought to be at more risk for spreading certain infections.

Donors are deemed to meet risk criteria for possible transmission of HIV, Hepatitis B and Hepatitis C based on national guidelines. This may include risk factors such as prostitution, intravenous (IV) drug use, or those with same sex partners. Potential donors have blood tests done to look for viruses such as HIV, Hepatitis B and Hepatitis C. Your child will also be tested for HIV, Hepatitis B and Hepatitis C before transplant. No test is perfect, and false negative results can happen.

There is a small chance (at most, 1 organ in 10,000) that an infection could be passed on. After your child's transplant they will be tested for HIV, Hepatitis B and Hepatitis C. These infections all have good treatment options. We believe that the risks of getting this type of kidney are very small.

Hepatitis C Positive Donors

Hepatitis C is a virus that can damage the liver. We now have medicines to treat and cure this virus, so we can use kidneys from donors who have had or have hepatitis C.

Donors who have had hepatitis C and do not have an active infection are very low risk. If your child receives a kidney from a donor who has had hepatitis C, we will do tests to check for signs of this virus.

Organs from donors with an active hepatitis C infection can be safely used. This is because we now have medicines to treat this virus. Patients who receive a kidney from a donor with an active hepatitis C infection will take medicine to treat the virus. When

placed on the waiting list, the transplant team asks if you are willing to accept a hepatitis C donor kidney. If you agree, you will be required to sign a consent. If you choose not to accept this kidney, your child will not lose their place on the waiting list.

What will we be told about my child's donor?

Privacy laws limit how much we can tell you about your child's donor. We can't tell you the donor's age, gender, or personal health history. The United Network for Organ Sharing (UNOS) distributes the organs. The Organ Procurement Organization (OPO) tells the UW Transplant team when a kidney is found and who is first on the UNOS list to get the kidney.

The OPO carefully screens all would-be donors for any illness that could affect the transplant organ or the patient who gets it. This screening can be limited by time constraints between the time that the donor was injured and when the organ is obtained. The donor's evaluation and screening results may impact your child's care after transplant. This may include the need for other tests or medicines. We believe the risk of these treatments outweighs the risk of waiting for another organ. We use our best knowledge and judgment to make sure every organ we transplant will work and will not harm the person who gets it.

How do I choose?

There are risks and benefits of each type of kidney transplant. Members of the transplant team can tell you more about this topic. They can help you choose the option that may be best for your child.

The Transplant Waitlist

Completing a transplant evaluation does not guarantee being put on the waitlist. After evaluation if you are approved for transplant, you will then be put on the waitlist. UNOS manages the waiting list, matching donor organs to recipients, 24 hours a day, 365 days a year.

Priority is given to patients based on the following:

Blood type

- How well the 6 antigens (genetic markers) match with those of the donor
- The length of time on dialysis
- Age. Pediatric patients (under age 18) receive more points
- Panel Reactive Antibody (PRA) level. This is a blood level that shows how easy or hard it may be to find a suitable donor for a patient based on antibodies a recipient may have.

The patient who has the most points and is found healthy enough for transplant at this time will be called in to receive the transplant. A new list is made for every donor and changes according to the UNOS point system. Everyone's wait time will be different.

Multiple Listings and Transferring of Waiting Time

Multiple listing is when your child is listed for transplant at two (2) or more transplant centers. Multiple listing can increase your child's chances of getting an organ offer. It does not assure a shorter wait time.

UW Health allows multiple listing. Your child needs an evaluation at each transplant center. Each transplant center then decides whether to accept your child on their waiting

list. You should check with your insurance to see if they cover more than one evaluation. Keep your child's health information and contact information updated at each transplant center where you are listed.

Many things affect wait times for transplant. You can transfer your primary waiting time to another transplant center, or switch time between transplant centers. You cannot split your total waiting time among multiple transplant centers. Your child's transplant care will be done at the center where the transplant happens. To learn more about multiple listing or transferring waiting times, contact the transplant center where your child is listed or want to be listed. For more information: https://unos.org/wp-content/uploads/unos/Multiple_Listing.pdf

When to Call

Waiting for your child's transplant may take many months or years or may happen very quickly. Your child may go through many health changes during this time. It is vital to keep the transplant team informed of any changes in your child's health status.

Examples of things that you should call about include your child:

- Taking antibiotics or having an active infection
- Being started on a new medicine
- Getting a blood transfusion
- Being hospitalized or going to the emergency room
- Having a significant change in health status
- Having a change in insurance coverage
- Having changes in contact information (such as phone number or address)
- Having changes in primary care provider information

- Having changes in support person or plan
- Planning to travel away from home
- Receiving a transplant at another center

The transplant team needs to be up to date on this information. This will help to ensure that your child is in the best condition for transplant. Some medicine changes or hospitalizations could change your child's status on the waitlist. It is vital that you contact the team with any health changes.

Staying Healthy Before Transplant

Taking care of your child's health is very important while waiting. It is expected that your child will take all medicines as directed by their doctor and attend all appointments. Your child should also follow a healthy nutrition plan.

Nutrition

Nutrition plays a key role in the transplant process. Eating well and being at a healthy weight may help your child recover faster after surgery. After surgery, your child's body needs enough nutrition to promote healing, fight and prevent infection, and gain back weight they may have lost. Transplant medicines can lower your child's appetite or change their sense of taste. In the long-term, good nutrition plays a key role in keeping your child healthy.

Getting the Call

When your child is on the waiting list, the transplant team should be able to reach you at any time of the day, any day of the week. If the transplant team contacts you and you are not available to return the call up to 30 minutes from the first phone call attempt, the team will move on to the next potential recipient.

You need to have a plan ready for when the call comes.

- How will you get to American Family Children's Hospital?
- Who will come with you and your child?
- Who will take care of things at home while you are in the hospital, such as your other children, pets, etc.?

Getting to the Hospital Quickly

When you get the call, you have a short amount of time to gather your things and make final arrangements. As a rule, the sooner you can get to the hospital, the better. Your safety when traveling is important, so be careful on your way here. The transplant is often done within 24 hours of the call.

The Organ Allocation Specialist will call you if an organ becomes available. You will be asked:

- To have your child stop eating and drinking
- About your child's current health status
- About your child's recent immunizations, illnesses, infections and medicines
- To come to American Family Children's Hospital **or** to keep a phone available, but to wait at home until you are called again.

It is very important that family and friends are involved in the planning process. Be sure they know that you need to be reachable at all times. They should also know the plan for you to bring your child to the hospital when you get the call. You will need to make plans for the care of your pets, other children, work duties, and other responsibilities ahead of time. Being prepared will help to lower your stress.

There may be times when the donor organ becomes unsuitable for transplant. In an event of one of these “dry runs” your child will be discharged home to wait until another donor becomes available.

What to Bring to the Hospital

You need to be prepared when you get the call. This call can come anytime, day or night. Be sure your cell phone is on and ready to call in case of delay or questions (608-263-6400 or 1-800-323-8942).

Plan to bring these items:

<input type="checkbox"/> All medicine bottles and list of medicines
<input type="checkbox"/> Insurance/ Medicare/Medicaid cards
<input type="checkbox"/> Contact information for your child’s pediatrician or primary care physician (family doctor)
<input type="checkbox"/> Name/phone number of local pharmacy
<input type="checkbox"/> Form of payment for medicines at discharge
<input type="checkbox"/> Special toys, security/comfort items for your child
<input type="checkbox"/> Loose fitting clothing for your child, socks, shoes or slippers that cover the feet
<input type="checkbox"/> Personal toiletries or comfort items (hygiene or entertainment related)

Please do not bring large amounts of cash, credit cards, jewelry or valuable items.

Commitment to Follow-Up Care

Your child’s care after a transplant is for their entire lifetime. This long-term care includes:

- Biopsies
- Labs and other tests
- Medicines
- Transplant Clinic visits

Keeping the Commitment

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan.
- Call the transplant office about any new problems or symptoms related to your child’s transplant or about any new medicines or tests they have.
- Take all prescription medicines as directed.
- Follow the diet and exercise plan advised by your transplant doctor.
- Go to your child’s clinic visits.
- Get your child’s lab draws and biopsies.
- Talk with your child about not abusing their body by smoking, vaping, drinking alcohol, or using non-prescribed medicines (including those prescribed to someone else) and herbals.

Appointments

The follow-up schedule is intense for the first few months. Labs and biopsies are done to check for rejection. This can happen when your child’s immune system attacks their new kidney. During a biopsy, tissue samples are taken from the kidney. If a biopsy is done because your child’s kidney is not showing normal function, it may be somewhat urgent. You may need to make plans to come to American Family Children’s Hospital without much warning.



Primary Care Visits

Your child must have a primary care provider to address routine health issues. This might include well child visits, vaccinations, minor infections and illnesses, and regular health maintenance. Plan to see them shortly after transplant.

We want your child to live a healthy life after transplant. We will work closely with your child's doctor to provide the best care. We work together to advise you about your child's diet, exercise, and other health needs. The Transplant Team will manage your child's transplant medicines and address any transplant issues.

Health Concerns After Surgery

After transplant, children can live a long, healthy, and productive life. The main issues are the **increased risks of infection and rejection**. To prevent infections, wash your hands and your child's often and wear a mask at times. Sometimes, it is best to avoid crowded places, areas with poor ventilation, or people who may be contagious. We will talk about when they can return to school.

The risk of rejection is greatest the first 6 – 12 months after transplant. It is common to have a rejection. This is the body's normal immune response to "foreign" tissue. When rejection occurs, we need to adjust your child's medicines to decrease their immune system further.

Types of Medicine After Transplant

You will need to know what medicines your child is taking, why your child is taking them, and the dose prescribed. Not giving your child's medicines correctly can lead to rejection and other health problems.



Immunosuppressive Medicines (Anti-rejection Drugs)

Immunosuppressants, also called "anti-rejection medicines," block or suppress your immune system. They are used to prevent rejection of new organs. All transplant patients take these medicines for the **rest of their lives**. There are different kinds. Often, your child will be on more than one kind. Your child's transplant doctor will decide which ones your child will need. Your child will need to take these multiple times a day.

These may include:

- Prednisone (corticosteroids)
- Tacrolimus (Prograf[®], Astagraf XL[®], Envarsus XR[®])
- Cyclosporine (Neoral[®], Gengraf[®], or other generic brand)
- Mycophenolate (Myfortic[®] or Cellcept[®])

Anti-infection Medicines

Anti-infection medicines prevent common infections after transplant. You may need other medicines too based on the type of donor. You may need medicines to prevent:

- **Bacterial** infections of the bladder and lung.
- **Viral infections such as CMV or herpes (cold sores).**
- **Fungal** infections.

Most patients take other medicines to prevent stomach ulcers, control blood pressure and cholesterol, and supplements to support your bones and general health. You may also develop diabetes from the transplant medicines and need insulin or other medicines to manage blood sugar levels.

Some of these medicines are temporary but many are life-long. You may need opioid pain medicines right after surgery. You will

not be able to take NSAID medicine after transplant.

Some children have high blood pressure after their transplant. They may need medicine to treat this. They may also develop diabetes and need insulin or other medicines to manage blood sugar levels. Your child may need opioid pain medicines right after the transplant.

Vaccines

Timing of when your child receives a vaccine can impact when they can receive a transplant. Your child must be screened for conditions or medicines that might make the vaccines unsafe because of their immune system. **No one who has had a transplant should be given a live vaccine.** (Varicella (Varivax[®]), Influenza, intranasal live vaccine, Measles, Mumps, Rubella (MMR), Rotavirus). Because of your child's potential transplant their vaccine schedule may be different than other children.

The list below includes general guidelines. Your situation may be different. Other vaccines may be required. Your child's providers will discuss these with you on an individual basis. **Always talk with your coordinator before your child gets any vaccines.**

Vaccines to Get Before Transplant

- Inactivated influenza, injected
- COVID-19 booster
- Hepatitis B
- Hepatitis A
- Diphtheria/Tetanus/ Pertussis (Tdap, DTaP, Td or DT)
- Polio, inactivated
- Pneumococcal polysaccharide or conjugate
- Human papillomavirus (HPV) (for ages 9-26)
- Varicella zoster (Shingrix[®])

Other Vaccines to Discuss with Your Provider

- Quadrivalent meningococcal conjugate or polysaccharide
- Haemophilus influenzae type b
- Measles, Mumps, Rubella (MMR)
- Travel vaccines

Activity Levels

Most children can go back to their normal activities relatively quickly. It will take some time to gain strength and endurance. Keeping up with an age-appropriate exercise routine after recovering from surgery is the best way to manage your child's weight and improve your child's well-being.

Going Back to School

We encourage children to return to school after having a transplant. Your child's transplant team will talk with you about any activity restrictions and when to plan on return to school or daycare. Support people may be off of work for up to a few months after transplant. The team will help you with return to school paperwork as needed and help to fill out any paperwork you may have.

Coping After Transplant

During the transplant process, it is common to feel anxious, depressed, or frustrated. Stress can cause these feelings and so can your child's medicines. Talk with someone about how you or your child is feeling. The transplant team, your child's nurse, child life staff, or social worker can help your child cope with these emotions. Sharing feelings with loved ones and others may also be helpful. Most areas have support groups for transplant recipients and loved ones. The resources below may also be helpful.

Depression

<http://www.helpstartshere.org/mind-and-spirit/depression>

Anxiety

<http://www.helpstartshere.org/mind-and-spirit/anxiety/about-anxiety-disorders.html>

Coping Emotionally after an Organ Transplant

<http://www.webmd.com/a-to-z-guides/life-after-transplant-coping-emotionally>

Guided Imagery

<https://www.healthjourneys.com/>

Mindfulness Meditation

<https://www.mindfulnesscds.com/>

Mindful meditation may reduce reactions to stress.

Support People

The transplant process can be very tough for support people. Many support people have anxiety during the process. It is important for support persons to take care of themselves during this time.

Keeping Support People Updated

It is a good idea to choose one support person as the primary contact. This person can update other family members and friends about your child's status. Make sure the transplant team has that person's contact information.

Staying Prepared

Make sure your child's transplant team knows how to reach you. Contact your child's transplant coordinator if contact numbers change for you or your support persons.



Have your child's support persons in place. A child's primary support persons are typically their



parent(s)/guardian(s), but may also include a family member or close friend. Choose 1 to 2 adults you feel close with who have the time, health and flexibility to help you and your child through this process

Arrange for your transportation needs to and from appointments and testing.

Learn about transplant and what to expect. As you learn about what

to expect you will feel more comfortable with the process.



- Review transplant materials you are given including resources on the next page.
- Join a transplant support group in person or online.
- If you have questions, contact your child's transplant coordinator.

Who and When to Call

Transplant Nurse Coordinator

Call:

- If you are hospitalized or receive a blood transfusion
- When required evaluation testing complete

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
 - 608-263-1384
-

Social Worker

Call for:

- **Change in support person plan**

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
 - 608-263-1384
-

Financial Counselor

Call for:

- Change in insurance

Contact:

- Monday-Friday, 8:00a.m.-4:30p.m.
 - 608-263-8770
-

Helpful Resources

The resources below may be helpful for transplant patients and their families.

Kidney School

<https://www.kidneyschool.org/>

An online education program for people who want to learn how to manage and live with chronic kidney disease

NKF Peers

<https://www.kidney.org/patients/peers>

Speak with a trained peer mentor who can share their experiences about dialysis, transplant or living kidney donation with you

National Kidney Foundation

<http://www.kidney.org/> and

<http://www.kidneywi.org/>

A nonprofit health organization dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals and families affected by kidney disease and increasing the availability of all organs for transplantation

Know Your Rights

<https://autisticadvocacy.org/policy/toolkits/organs/>

Information to end discrimination in organ transplant.

Scientific Registry of Transplant Recipients

<http://www.srtr.org>

Data on national, regional and center-specific success rates.

Transplant Living

<http://www.transplantliving.org>

A patient education site developed by UNOS. Information on support groups and the costs of transplant can be found here.

UNOS

<http://www.unos.org>

United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system.

UW Health Transplant

<https://www.uwhealth.org/transplant/transplant/10355> or scan the QR code below.

Meet your transplant team, read patient stories, watch educational videos, and more. Information about mentor programs



Transplant Families

<https://www.transplantfamilies.org/>

Provides inspiration, support, and education to families who have children with solid organ or bone marrow transplants.

Starzl Network

<https://starzlnetwork.org/>

Serves to support and unite the global pediatric transplant community and offers educational resources for patients and families.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 4/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8246.