

What to expect when having a Living Donor Kidney Transplant Operation



Transplant Manitoba: Pediatric Kidney Program
Section of Nephrology
Children's Hospital of Winnipeg
2021

Welcome,

This booklet is being given to you because you have completed a kidney transplant workup and are ready and safe for a living donor kidney transplant.

This booklet will help you understand what to expect when you are getting ready to come to the hospital for a living donor kidney transplant.

Please take some time to read this booklet.

There is space at the end of each section in this booklet for you to write any questions you may have.

If you have any questions about what to expect when you come for a transplant operation, please call us at any time. We will be happy to go over the information in this booklet and answer any questions.

You can call the Pediatric Transplant Coordinator at 204- 787- 4842 or Toll free at 1-877-499-8774 –extension 74842 with questions you may have. The coordinator will meet with you at any time you need to have questions or concerns answered.

The Transplant Manitoba – Pediatric Kidney Program Team

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A quick review of living donor transplant

What is a living donor kidney transplant?

- Living donor kidneys come from a person who:
 - Is alive and who has agreed to be a kidney donor.
 - Has had a donor workup and is deemed safe to donate one of their kidneys to you.
 - In children and youth, living donor kidneys usually come from a parent but could also come from another relative, like a grandparent, an aunt or uncle and at times a sibling.

Sometimes, a living donor may be someone you don't know.

 - Is at least 18 years of age.
 - Has a blood group and HLA that are a good match to you.
 - Is in excellent health and has 2 kidneys of their own.
- Once a living donor has had a workup and is cleared to transplant a kidney, their information is shared with the pediatric team so we can book a safe transplant.
- Living donor transplants are planned and booked at a time that is agreed upon with all of those involved.



What is a Pre-emptive transplant?

A pre-emptive transplant just means the person gets the kidney transplant before they start on dialysis. This is the goal for our program. A pre-emptive transplant is not always possible.

How do the doctors know the kidney is right for me?

- We will always try to find the best kidney for you.
- Living donors have a workup to make sure they are healthy enough to give a kidney to you.
- The Transplant Manitoba- Pediatric Kidney program accepts kidneys that are **blood group compatible**, are of **good quality**, and are at least a **2 HLA antigen match**. The antigens we match are called DR and DQ.
- If your kidney is coming from a parent, you will be at least a 3-antigen match. This is because you get half of your antigens from your mom and the other half from your dad.
- You can match more antigens but the minimum match from a parent is a 3-antigen match.
- The better the match, the more likely the body will accept the kidney. You will still need to take medicine to help your body accept the kidney no matter what the match.

Do you remember what blood group you are and which blood group you can get a kidney from?

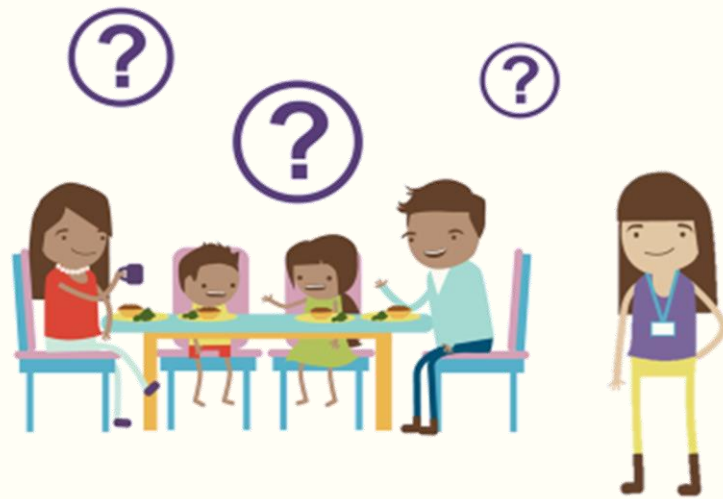
Your Blood Group	Compatible Blood Groups
A	A & O
B	B & O
AB	A, B, AB, & O
O	O

You can get a kidney from any person that is a blood match or has a compatible blood group.

As soon as the Transplant Manitoba living donor program has cleared your donor and you are ready for a transplant, we will talk to you about booking a transplant operation.

Pediatric living donor transplants are usually done once per month on a Thursday. We will let you know what dates we have available to do your transplant.

Any Questions?



My Questions about Living Donor Transplant:

Tests and appointments I will have before the transplant?

- Getting ready for a living donor transplant involves many tests and appointments. We know you have already had many tests and appointments during your workup. These final tests are the last steps to get you ready for the transplant operation.
- All the tests and appointments are done to make sure you are safe for transplant.
- Testing includes your final flow cross match with your donor, urine and blood tests, and a chest x-ray. If you are on peritoneal dialysis (PD), there will be some tests of your PD fluid.
- Appointments include seeing the surgeon for a final consent, seeing the pre-admission clinic, meeting the post-transplant pharmacist for teaching, having your final chronic kidney disease/dialysis clinic visit and having some final teaching with your transplant coordinator.
- At times there may be other tests or appointments. Your transplant team will let you know if there are extra tests or appointments.
- These tests and appointments usually take place during the final 2-3 weeks before your transplant operation is booked.
- Your transplant coordinator will arrange all the tests and appointments and give you a letter with the dates and times. If you have any questions about the information in the letter, please call the transplant coordinator.
- *This can be a busy and stressful time for you and your donor. If you, or anyone in your family, need to talk to a social worker or the transplant team, contact us and we are happy to help.*



So, Let's get started!

What happens when I go to the pre-admit Clinic (PAC)?

- The pre-admit clinic is also called the PAC. The PAC is where you will be seen for your anesthesia appointment.
- At the PAC you will meet the anesthesia doctor. This is the doctor who gives you special medicine during your surgery.
- The PAC nurses and doctors will ask you questions about your medical and surgical history. They will examine your body and explain what you can expect when you come for your transplant surgery.
- They may ask you to do some extra blood tests.
- They will take you on a tour of the operating room, if you are interested.

What happens when I go to see the transplant surgeon?

- The transplant surgeon will review the risks to getting the transplant operation and get a surgical consent signed.
- If you have a peritoneal dialysis (PD) catheter in place, it will be removed at the time of the transplant. The surgeon will also get consent for the PD catheter removal at this appointment.
- Feel free to ask the surgeon any questions or concerns you may have before you sign the consent form.



What happens when I have my final flow cross match?

- The final flow cross match is a blood test done to make sure your body will accept the kidney from your donor.
- It is a blood test that is done with you and your donor at the same time.
- Depending on your age, you may have your blood drawn at Children’s Hospital or the transplant immunology lab.
- You and your donor will have blood taken by the transplant immunology lab. The lab takes the blood and mixes it together to do a cross match test.
 - If your test result is negative, it means it is safe to go ahead with the transplant.
 - If your test result is positive, it means it is not safe to have a transplant. It is extremely rare that a final flow cross match test is positive if the virtual and initial cross matches are negative. If the final flow cross match is positive, the transplant team will discuss the results and what is to be done next.
- After your final flow cross match, the transplant coordinator will meet with you and your family to review the final steps and answer any questions you may have. You will also meet the transplant pharmacist who will talk to you about your transplant medicines.



Transplant medicine information

How do my transplant medicines help my transplant?

- Medicines for transplant help to protect the kidney by dampening down the immune system to help prevent rejection. The medicines act like a blanket and hide the kidney from the immune system. This makes it harder for the immune system to find and attack the kidney.
 - Remember, the immune system’s job is to find and destroy things in your body that do not belong—like a transplant kidney. Taking your medicine makes it harder for the immune system to “see” the transplant kidney and protects the kidney from rejection.

When do I start my transplant medicines?

- You will be given a prescription for several medicines, including Tacrolimus and Mycophenolate. **DO NOT START ANY OF THESE MEDICINES UNTIL YOU HAVE BEEN TOLD TO DO SO BY THE TRANSPLANT TEAM.**
- Pick your medicines up at the pharmacy and bring them with you when you come for your final flow cross match appointment.
- The pharmacist will meet with you to talk about the medicines. The pharmacist will let you know when to take the medicine, how to take it, what foods/drinks to avoid and what to do if you miss a medicine or if you are sick and cannot take your medicine.
- After the final flow cross match results are back, the transplant team will let you know which medicines to take and when to take them.
- *Transplant medicines Tacrolimus and Mycophenolate are taken twice daily at 8:00 am and 8:00 pm. It is very important that you take your medicines every day, at the same time and in the same way to help protect your kidney from rejection.*
 - Rejection means your immune system is trying to get rid of your transplanted kidney. Your medicines help prevent rejection.
- Do not stop any of your routine medicines unless told to stop by your CKD or transplant team.

What other tests will I have?

- If you still pee, we will ask you to do a 24-hour urine collection.
- We will also ask you to collect a pee sample to send to the lab to make sure you do not have an infection.
- We will do a chest x-ray to make sure you do not have a chest infection.
- We will do a blood test to check the amount of immune medicine in your blood. This test is done a few days after your final flow cross match and before your transplant.

What happens at my final CKD clinic visits?

- The Tuesday before the transplant, you will come to the CKD/dialysis clinic for one final visit. The doctor will do a physical exam, review all the test results and make sure you are safe and ready for admission to hospital the next day.
- You will have final teaching and a chance to ask any questions you may have.
- You can see the social worker if you would like to have someone to talk to about your feelings or concerns.

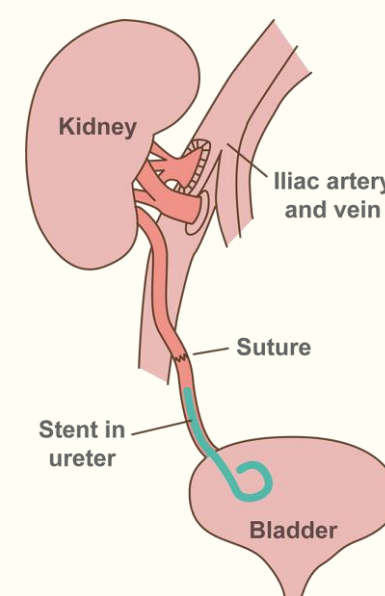
What happens when I get to ward CK5?

- You will be admitted to the ward CK5 at 1 pm the day before the operation.
- Bring any comfort items such as pajamas, stuffy, and toiletry supplies with you for your hospital stay.
- When you arrive on CK5, you will be admitted to the ward and be seen by the nurse and many medical persons, such as medical students, residents and doctors. You may see the anesthesia doctor, who will talk about the operation again. You may also see the transplant surgeon on the ward or in the operating room.
- You will have your height and weight checked.
- Your blood pressure, heart rate, breathing rate and oxygen level will be checked – these are called your “vital signs”.
- An intravenous (IV) will be started for fluids and medicine. Any final blood tests will be taken, if needed.
- You will continue to take your immune suppressing medicine Tacrolimus. You will also start some of the other immune suppressing medicines, such as Mycophenolate and a special type of steroid called methylprednisolone by IV. These medicines help to prepare your body to accept the kidney.
- You may have dialysis. If you are on peritoneal dialysis, you will have your dialysis overnight. Your abdomen will be left empty (no last fill) before going to the operating room. If you are on hemodialysis, you may have a treatment before going to the operating room.
- You cannot eat or drink anything unless advised by the transplant team.
- If you are big enough, you will have special socks called TEDs placed on your legs just before going to the operating room. These are used to help prevent clots in the legs. The TEDs will stay on until you are up and walking around after the transplant.
- There are many things to do to get you ready for the operation. Many people find this waiting time very emotional. It is normal to feel nervous and afraid. We are here to help. We can answer any questions you may have. Having a friend or family member as a support person is helpful.



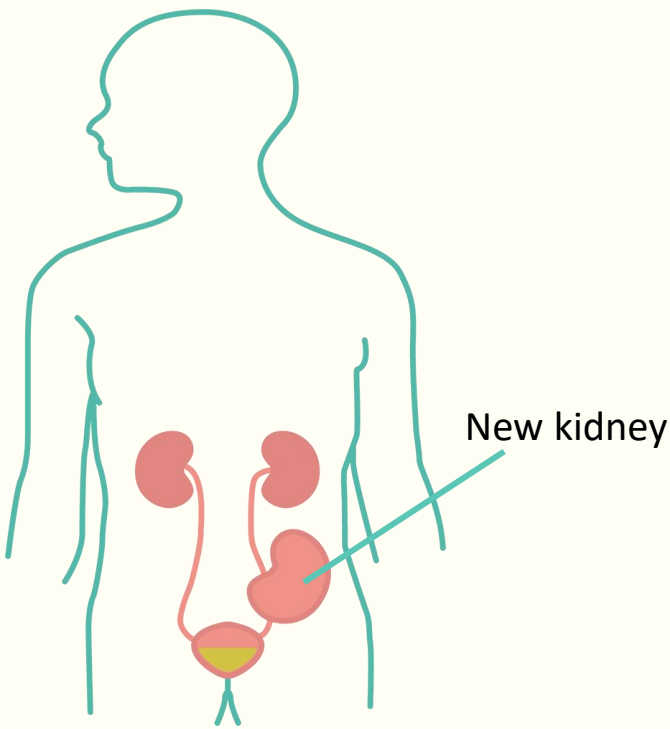
What happens when I go to the operating room?

- Once all the preparations are done and the operating room (OR) is ready, you will be taken to the pediatric OR. Your parent/guardian can come with you to the OR waiting room.
- Usually, you are taken to the OR around 8:30 am.
- In the OR you will be given some medicine to help you fall asleep. Once you are asleep, and cannot feel anything, you will have a small tube placed in your mouth and throat which helps your breathing during the operation. Once the operation is over, the tube is usually taken out. Sometimes, a child will go to the pediatric intensive care unit (PICU) with the tube in place. The medical team will decide when it is safe to take out the tube.
- A urine catheter is inserted into your bladder to collect your pee. This will stay in for a minimum of 5-7 days after the transplant.
- A special IV is put into a vein close to your neck. This is used to give lots of fluids. You will have another IV put into your arm to monitor your arterial blood pressure. You may have a 3rd IV in your arm to give medicine or fluids.
- You will not feel any of this because you are in a special sleep and can't feel pain.
- The OR nurse will put a blood pressure (BP) cuff onto your arm to check your BP. Special sticky pads are placed on your chest to monitor your heart rate. You will have a small clip put onto your finger or toe to check your blood oxygen level.
- When all this preparation is done, the operation starts.
- A transplant operation can take 4-6 hours from start to finish. For complicated surgeries, it could take longer. A small tube called a stent is placed in the ureter during the surgery. This helps prevent the ureter from blocking. The tube will be taken out in a separate operation about 6 weeks after the transplant.
- The waiting time during the surgery is very stressful for families. Parents/Guardians should take some time to go to get something to eat and drink. If you have your support person with you, have them come along to wait with you.
- When the surgery is done, you will be sent to the PICU. You will still have all the IV lines and tubes listed above and, now you will have a dressing over the site of your transplant kidney. There will be a tiny catheter (tube) inserted into the stitch line to give pain medicine. This is called a wound catheter. This catheter will come out in a few days.
- The surgeon will usually come to talk to you about the operation.

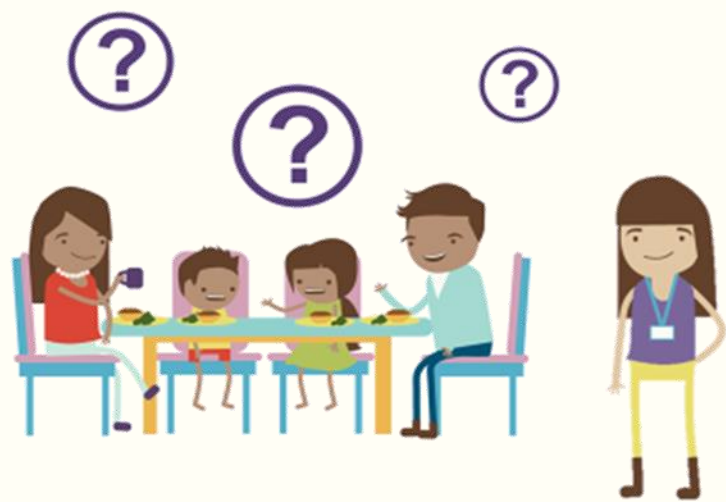


Will the kidney start working right after transplant?

- Kidneys can have cold injury because they are placed on ice after they are taken out of the donor. The ice helps to cool the kidney. Sometimes the cold injury can slow the function of the kidney and it doesn't work right away. If this happens, you may need dialysis for a short time after transplant until the kidney starts to work. This is very rare in living donor kidney transplants.



Any Questions?



My questions about going to CK5 and the OR for surgery:

What happens in the Pediatric Intensive Care Unit (PICU)?

- The PICU is a critical care unit. The staff are specialized in looking after transplant patients and those who are very sick.
- You will be admitted to the PICU right after surgery.
- During this time, you are closely monitored to watch for complications, to provide good pain control and you are given lots of fluids to help the kidney.
- A little bit of pain is expected. You will have a wound catheter that gives pain medicines right to the transplant site. You will also get pain medicines regularly in your IV. At times you may need extra pain medicine ---just ask your nurse for medicine if your pain is not well controlled.
- There are many machines and monitors in the room. The staff use these to help with making sure you are doing well after the transplant. The staff are happy to explain what they are for and why they beep!
- You will be able to drink and eat once it is safe for you. The staff will let you know when it is safe.
- You will continue your transplant medicines (also called immunosuppressive medicines) by IV until you can take them by mouth or tube.
- During this time, your blood will be checked often to make sure your kidney is working, and your transplant medicine levels (drug levels) in your blood are not too high or too low.
- During the time in PICU, you are allowed 1 visitor at a time.
- Most children stay in PICU for 24-48 hours. When it is safe, you will be transferred back to the ward CK5.
- Before you go back to CK5, you may have at least one of your IVs removed. The wound catheter may be removed. Your urine catheter will stay in place. The sticky pads on your chest will be removed.
- The TED stockings will be removed once you are up and walking around.



What happens when I get back to ward CK5?

- When you get back to CK5 you will receive the same medical treatment as you did in PICU. The staff on CK5 are experts in transplant care.
- You will start to take your transplant medicines by mouth.
- Your intake (what you drink) and output (what you pee) will be measured to make sure you are getting enough fluids to keep your kidney safe.
- You will have blood taken every morning BEFORE you take your immunosuppressive medicines. Once your blood test is done, you should take your medicines right away. The blood is tested to make sure you have the right amount of medicine in your body and to make sure your kidney is working well.
- As you get better and can drink, eat, and take all your transplant medicines by mouth, your IVs will be removed. Once you are up and walking, your TED stockings can be removed.
- While you are on CK5, you will have intensive teaching by the post-transplant nurse clinician and the transplant pharmacist to get you ready to safely look after your kidney at home. Ask as many questions as you want to make sure you understand how to safely care for the kidney.
- Most children are discharged from the hospital about 7-10 days after a transplant. If there are concerns about the kidney, you may have to stay longer.



When is it safe to go home?

You will be able to go home when you are safe, and you:

- No longer need IV pain medicines.
- Have had your urine catheter removed.
- Are taking all medicines by mouth or in a tube.
- Are drinking all fluids by mouth or in a tube.
- Can get up and move around.
- Have had all the discharge teaching done.
- Your medicine prescription is ready.

What happens after I go home from the hospital?

Follow-up with the post-transplant team is very important to keep you healthy, to monitor for potential complications and, to keep your kidney safe.

- You will be seen in the clinic daily for a week or more. Timing of visits will be discussed with you when you are ready to go home.
- Each day you will have blood and urine testing, a weight, a blood pressure check, a medicine review and, have a checkup with the nurse and transplant doctor. You may also see the pharmacist, dietitian, or social worker.
- After your appointment, the transplant nurse will call you at home to review the results of your blood and urine tests and tell you about any changes to your medicines or other treatments.

How can I keep my kidney healthy?

- There are many things you can do to keep your kidney healthy.
- Research shows that adherence, or sticking to the health care plan, is the most important way to keep your kidney healthy.
- Adherence means taking your medicines on time all the time, drinking your daily fluids, coming to all your appointments and treatments. It also means practicing good self-care such as getting enough rest, exercise and eating well. And it means monitoring for any signs of infection or rejection and letting the transplant team know if you think you have any of these.
- Our goal is to keep you healthy and to keep your kidney healthy and functioning for as long as possible. Most children will need a second kidney transplant in their lives, so a part of your job (and ours) is to work together to keep your first transplant kidney healthy for as long as possible.
- When you are seen in clinic, you will receive ongoing education about how to safely care for your kidney and keep you healthy.



A word about Adherence

Adherence means sticking to the health care plan. Some examples of the health care plan are taking transplant medicine on time, in the same way, every day, drinking the water you need to keep a kidney healthy, and coming to clinic.

Non-adherence means not sticking to the plan of care.

Non-adherence is one of the major reasons why children, and especially teenagers, have rejection and lose their kidneys.

If the kidney is too damaged from rejection it will no longer work.

When the kidney no longer works, the person will have to return to dialysis.

Why is medical adherence important in kidney transplant?

Adherence is important

- a. In keeping your/your child's kidney in good shape and to **prevent rejection** so the kidney will last as long as possible.
- b. To keep you/your child in **the best possible physical, emotional, and social condition** so they can participate fully with family and friends in normal activities of life such as school, family activities and outside interests.
- c. To minimize any risks to you/your child's health.



What does medical adherence include after transplant?

Sticking to the plan of care includes:

- a. Taking all medicines on time, in the same way, every day.
- b. Making sure you drink the amount of water that the transplant doctors have prescribed. This is usually at least 2-3 liters of water per day (more when sick or active).
- c. Coming to all your appointments.
- d. Keeping yourself healthy by washing your hands, getting lots of rest, exercising to avoid gaining lots of weight, and avoiding people who are sick.
- e. Getting your annual flu shot.
- f. Contacting the doctors or nurses when you don't feel well or are worried about your kidney.

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If you have any questions about this information, call the Pediatric Kidney Transplant Coordinator at 204-787-4842 OR Toll free at 1-877-499-8774—extension 74842.



Glossary – what do all those words mean?

ABO - is the short form for blood groups. There are 3 groups: group A, group B and group O.

Adherence (Add-hear-ants) - sticking to something. In transplant this means sticking to the plan of care.

Anesthesia (An-a-th-ee-zee-ah) - is a state of controlled, temporary loss of sensation or awareness that is induced for medical purposes. It may include some or all of analgesia (relief from or prevention of pain), paralysis (muscle relaxation), amnesia (loss of memory), and unconsciousness.

Antibody (Ant-e-bod-e) - antibodies are proteins (Pro-teens) made by your body when something foreign like an antigen or bacteria or virus comes into your body. Antibodies try to destroy these invaders to protect the body against disease

Antigen (Ant-a-gin) - is something unknown to the body that will trigger the immune system to make antibodies. A transplanted kidney is considered a foreign object.

Arterial line - also called an Art line. This is a small tube placed in an artery at the wrist area. It is used to measure blood pressure

Bladder - is a balloon like object found in the abdomen. It collects the urine (pee) that comes from the kidney.

Blood Pressure - is the pressure of the blood within the arteries. It is made by the contraction (squeezing) of the heart muscle. The first (systolic pressure) is measured after the heart contracts and is highest. The second (diastolic pressure) is measured before the heart contracts and lowest.

Breathing tube - a small tube placed into the throat to help you breathe when you are under anesthesia.

Catheter (Kath-a-ter) - the name for a tube which is put into the body for dialysis. In hemodialysis the catheter is placed into a blood vessel. In peritoneal dialysis the catheter is placed in abdomen.

Dialysis - the process of cleansing and achieving chemical balance in the blood of patients whose kidneys have failed. Dialysis may refer to hemodialysis or peritoneal dialysis (PD)

Donor - the person who gives an organ to another person.

Final flow cross match - the test used to mix blood from a donor and recipient to make sure they match and are safe for transplant.

Graft - an organ or tissue that is transplanted.

Hemodialysis (He- Moe-Di-Al-is-is) - a type of dialysis in which blood is cleaned of wastes by circulating through an apparatus outside the body – you may hear people call it an "artificial kidney"

HLA (human leukocyte antigens) - system is a genetically determined group of markers (antigens) that are present on human blood cells and tissues. They are our genetic make-up and are the way our body identifies itself – they make you who you are.

ICU - short for intensive care unit. A hospital unit that can provide very specialized care

Immunosuppression - medicines that dampen the immune system so it will not attack a transplanted kidney

Immune response - the body's reaction to invasion by any foreign material

Immune system - the system that protects the body from invasion by foreign substances, such as bacteria, viruses, and cancer cells

IV - is short for intravenous. This is a plastic tube that is placed into a vein to give fluids or medicine during transplant

Kidney - one of the two kidney-bean-shaped organs located on both sides of the spine, just above the waist. They rid the body of waste materials and maintain fluid balance by making of urine (pee)

Living Donor (LD) - a person who is alive and who donates an organ for transplant

Match - the compatibility between recipient and donor. In general, the more closely the donor and recipient "match", the greater the chance the transplant will be successful.

Nasal prongs - plastic tubes that are placed under the nose and provide oxygen through holes in the tube.

Nephrologist - A doctor, who studies the kidney, treats kidney disease. A pediatric Nephrologist is a doctor who looks after children and adolescents with kidney disease.

OR - short for operating room.

Peritoneal (Per-it-toe-kneel) dialysis - a way to clean the waste out of the body via the abdomen (tummy).

PICU - short for pediatric intensive care unit. A hospital ward whose staff specializes in caring for the sickest patients.

Recipient (Ree-sip-e-ent) - the person who is getting an organ from another person.

Rejection - an immune response against a kidney, which, if not successfully treated, results in failure of the graft (kidney) to survive.

Sensitized - the development of antibodies by previous exposure to that antigen.

Surgeon - a doctor who performs surgery.

Transplant - an organ (kidney) is taken from the body of one person and put into another person.

TED stockings - special socks that help to prevent blood clots in your legs. These are worn during the transplant operation and until you are up walking around. They are only used if you are big enough. The nurse measures you to see if you are big enough to wear the TEDs.

Ureters (Ur-ra-ter) - the tube that connects the kidney to the bladder. It drains the urine from the kidney to the bladder.

Urethra (Yur- eth-raw) - a tube that drains urine the bladder out of the body.

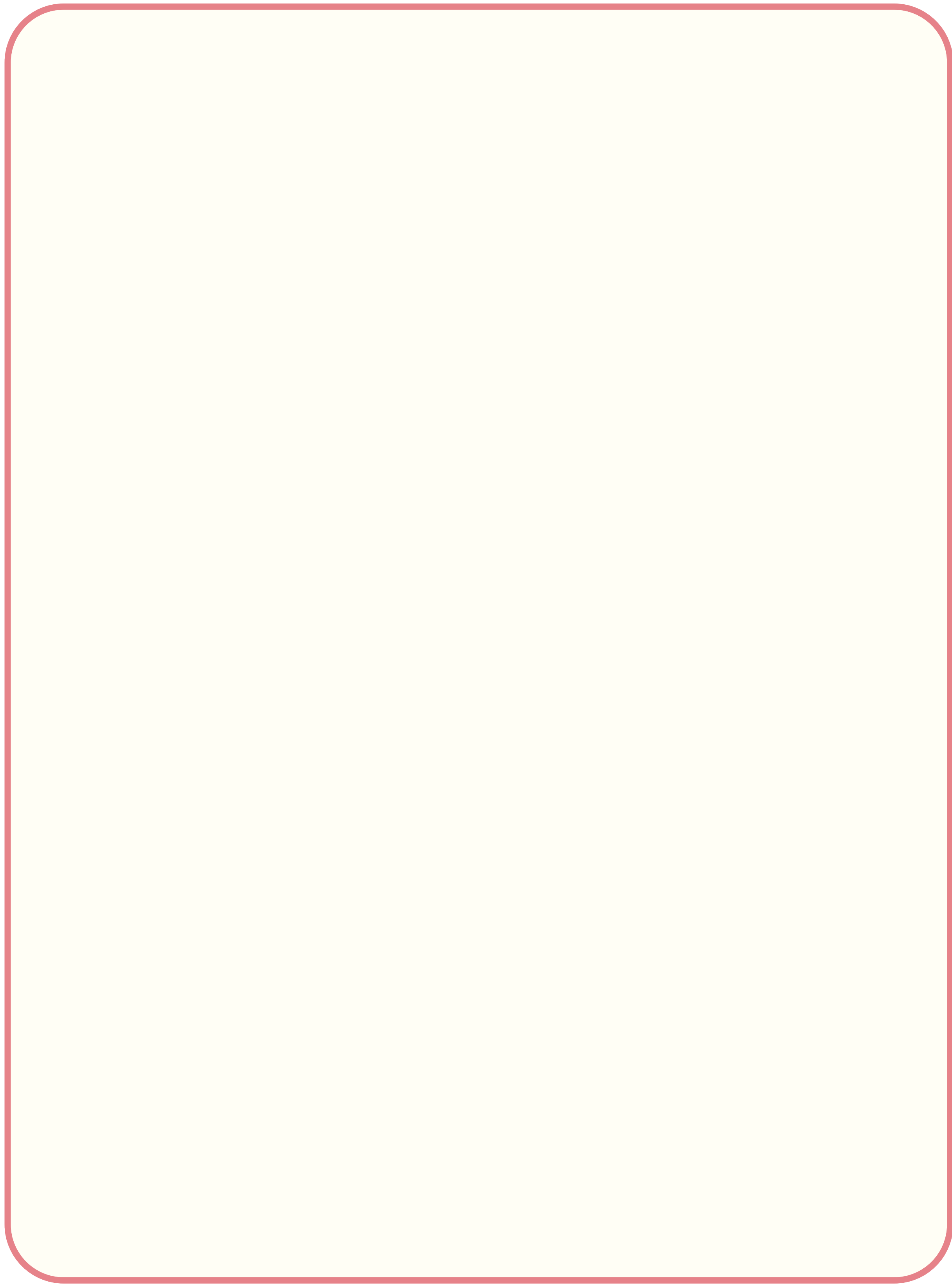
Urine catheter - a plastic tube placed into urethra and then onto the bladder to help urine drain. The urine catheter is attached to a bag so urine can be collected and measured.

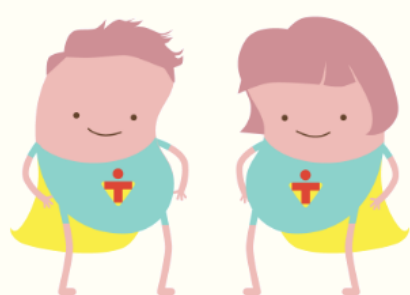
Wound catheter - a small tube placed into the stitch line to give pain medicine.

My final questions about Living Donor Transplants:

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For more information about this resource, please contact Pediatric Nephrology at 204-787-4947 or kidneytwins2@exchange.hsc.mb.ca