After Your Child’s Kidney Transplant
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Dear transplant recipient and family,

Congratulations! Your child has had a kidney transplant. This booklet tells you and your family what you need to know to take care of the transplant. You and your family are the only ones that can do this.

While you are in the hospital you will have many questions about your transplant. Your transplant team will help you answer those questions.

This transplant booklet is yours to keep. It includes information about staying healthy, food to eat, medicines, signs of problems and what to do about them, and getting ready to go home. There is room in this booklet for you to write notes and questions. The information here will guide you when you get home. However, you may also call us if you need to speak with someone.

Sincerely,

Your Kidney Transplant Team
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In the Hospital

Where does my child go after the ICU?
1 to 2 days after surgery your child will move from the ICU to a regular nursing unit. The nurses will help your child recover from surgery and teach you and your child how to care for the new kidney.

Can my child have visitors?
— Parents can visit at any time. One parent may spend the night with the child.
— Friends and family may visit you from 11:00 AM to 8:00 PM each day.
— If the room is too crowded for the child to rest or be cared for, the nurse may ask some visitors to leave.
— During the winter the hospital does not allow visitors under 12 years old. The rules will be posted in the hospital and on the website (www.phoenixchildrens.com).
— Visitors who think they have a cold or flu are asked to stay away until they are well.
— Cut flowers and plants potted in soil cannot be in the room. The hospital does not allow latex balloons.

What will it be like on the nursing unit?
We will measure your child’s temperature, pulse, and blood pressure (also called vital signs) often. Every morning your child will be weighed and blood will be drawn for testing.

Why do you do these so early in the morning?
Your doctors and nurses understand it may be hard to get out of bed very early to be weighed and have blood drawn. However, the doctors need to know your child’s weight, vital signs, and blood test results in order to plan your child’s care.

What is I & O?
I & O means intake and output. Every liquid that enters your child’s body (either by IV or mouth) and every liquid that leaves your child’s body (such as urine, loose stool, or vomit) will be measured and written down. Ask your nurse to show you how to measure and record your child’s I & O.
When will my child’s IV be removed?
The nurse will remove your child’s IV when your doctor decides he or she no longer needs IV fluids or IV medicines. In most cases, IV fluids are stopped 5 to 7 days after surgery.

What other tubes will my child have?
Your child’s bladder catheter will still be in place to drain urine. The surgery site will heal faster if the bladder isn’t full. Even with the catheter in, your child may feel the need to urinate. This is normal. The nurse will check your child’s bladder catheter often.

Your child may have drain bulbs near the incision. These take fluid away from the kidney transplant. Your nurse will pin them to your child’s gown so they do not hang, pull, or catch on something. Your child’s doctor will decide when to take out the drains.

What will happen in the hospital?
The nurses will help your child get more active. Your child will get out of bed, sit in a chair, and walk about your room as much as possible. The nurse will help your child take deep breaths and cough. Your child will be shown how to fill his or her lungs with air using a special tool (spirometer). After a few days, your child can walk in the halls. Your child will need to wear a mask when out of your room to keep him or her from catching germs from others in the hospital. It may feel odd to walk with tubes and drains, but moving will help your child heal faster.

The nutritionist will come to see how well your child is eating. The nutritionist will help your child choose foods that he or she will enjoy eating.

What about my child’s bowels?
Moving, eating healthy foods, and drinking enough fluids will help your child have his or her first bowel movement after surgery. If your child’s stool is watery or loose, tell your nurse.

When will my child’s bladder catheter be removed?
Your child’s doctor will decide when the bladder catheter can be taken out. It is usually 4 or 5 days after surgery. After the tube comes out, the nurse will give your child a container to collect and measure the urine. While in the hospital,
your child must always use this container so we can measure how much urine the kidney is making. Children wearing diapers must have all wet diapers weighted before they are thrown out. On the day the tube is removed, the nurse will ask your child to urinate often, to be sure all is working well.

**Will my child have blood in the urine?**
Your child may have blood in the urine for a few days after surgery. The nurse will check your child’s bladder catheter often. If you notice dark red urine or clots, tell your child’s nurse and doctor.

**When will my child be able to shower?**
Ask your doctor when your child can begin taking showers. Use regular soap. Do not put lotions, ointments, or powders on your child’s incision unless the doctor tells you to. Your child should not soak in a bathtub.

**What about my child’s medicine?**
In the ICU, many of your child’s medicines are given through the IV. As your child gets better, more medicine will be given as liquids and pills that can be taken by mouth or G-tube. Some medicines can only be given by IV.

**How will I learn about the transplant medicines?**
When a medicine is brought to your child, the nurse will tell you and your family its name, when your child takes it, and why it is important. You will also find some information later in this booklet. By the time you go home the transplant coordinator will make sure you know about all of your child’s medicines.

*When a medicine is brought to your child, the nurse will tell you and your family about it.*
Getting ready to go home: Discharge Planning

What is discharge planning?
From the day your child comes into the hospital, we are getting you ready to take care of your child at home. This is called discharge planning. Discharge planning includes knowing how to take care of your child at home, recognizing problems, knowing how to respond, and learning how to keep your child healthy at home.

Who will help me get ready to take my child home?
Your transplant team will teach you what you need to know to get ready to leave the hospital. This team includes your child, your family, the pediatric nephrologist, transplant coordinator, unit nurses, nutritionist, social worker, and case manager. You are the most important member of this team.

When does the transplant doctor see my child after we leave the hospital?
After kidney transplants, children need to come back to see the doctor regularly, to see how they are doing and get prescriptions for medicine.

For the first month after leaving the hospital, your child will need to return to the outpatient transplant clinic 3 times each week. You will need to bring your child’s Prograf, Rapamune, or Cyclosporine to the appointment to give your child after blood is drawn for testing. Your child should take all the other medicines before coming to the appointment, unless the transplant team says not to.

At each visit to the clinic, the transplant coordinator and the pediatric nephrologist will see your child, and blood will be tested. These tests will look at your child’s kidney function and measure your child’s level of Prograf, Rapamune, or Cyclosporine. You may also meet with the nutritionist, social worker, or financial counselor on these visits, if you need to. If you live far from the hospital, your child can leave the area and go home after one or two months. How long your child stays depends on how well he or she does after the transplant.
After the first month, your child will need to come back to see the doctor for regular blood tests.

**Why can’t I give my child Prograf, Rapamune, or Cyclosporine before coming in for my appointment?**
Blood will be drawn to check the amount of Prograf, Rapamune, or Cyclosporine in your child’s blood. If your child takes Prograf, Rapamune, or Cyclosporine just before having blood drawn, the test will not be accurate.

**What should I bring to my child’s appointment?**
- Your child’s medicine list
- The log with your child’s weight, temperature, and blood pressure.
- Your child’s Prograf, Rapamune, or Cyclosporine to give after blood is drawn.
- A list of any questions you want to ask the doctor or transplant nurse.

**What will I need to know to take care of my child at home?**
You and your transplant team will talk about all the things you need to know:
- What to check every day (daily monitoring)
- When to call the transplant team
- Medicines
- What problems can happen: rejection and infection
- Activity
- Staying healthy
- Nutrition
- Social services
- Follow-up

**How will we learn it all before we go home?**
Learning about your transplant is like a part-time job that doesn’t end. The transplant team will help you learn in ways that are best for you. Your team will give you written information to take home with you.

**What to check every day (Daily Monitoring)**
— Take your child’s temperature.
If your child feels sick or too warm, take your child’s temperature.
If the temperature is 100 degrees or higher, call your child’s transplant doctor or coordinator.
(You will need a thermometer at home.)
Once each day, before your child takes blood pressure medicine — measure your child’s blood pressure.
(You will need a machine to measure your child’s blood pressure at home.)

Write the temperature, and blood pressure on the log each day.

Will I have to measure what my child drinks and urinates at home?
No. Your child should drink normally with meals, and drink an extra _______ ounces of water each day.

A good way to tell if your child is drinking enough water is to check the color of the urine.
— If the urine is clear to light yellow in color, your child is drinking enough water.
— If the urine is medium to dark yellow, your child should drink more to prevent getting too dry (dehydration).

What problems should I call the transplant doctor or nurse about?
• Fever of 100 degrees F or higher.
• New swelling in hands, feet, legs, arms, or eyelids.
• Flu like symptoms: joint aches, dizzy, weak, very tired, sick to the stomach, throwing up, loose stools, or headache.
• Passing urine burns.
• Dark urine.
• Less urine output.
• Pain over the kidney.
• If your child cannot take his or her medicines.
• Cough or shortness of breath.
• Blood in urine or stool.
• Cold sores or ulcers on lips or mouth.
• Any mole that changes color or starts to bleed.
• A sore on your body that does not heal.
• A lump in your child’s breast, armpit, neck, groin, or testicles.
• Any new rash.
• Swelling, pus or fluid coming from the incision, tenderness, or opening of your transplant incision.
What phone number do I call to reach the doctor or nurse?
Call 602-546-0965 Monday-Friday between 8:30 AM-4:30 PM and ask to speak with the transplant coordinator. Any other time, you will reach the operator and ask for the kidney doctor on call to be paged.
## My Child’s Log

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Medicines

After the transplant, your child will need to take medicine every day for the rest of his or her life. This can be hard to do at times, but it is very important.

Your child needs to take medicines every day to keep the body from rejecting the new kidney. These medicines are called immunosuppressive medications.

Your child also needs to take medicine every day to fight off germs (prevent infections).

Some children need other medicines, too, to stay healthy.

What happens if my child doesn’t take these medications every day?
Taking too little medicine may let your child’s body reject the transplanted kidney. Too much medicine may hurt the kidney and makes it hard for your child’s body to fight infection.

Do not stop, start, or change your child’s medication unless your doctor or transplant coordinator tells you to.

What happens if my child is sick and cannot take his or her medicine?
If your child is sick to the stomach or is throwing up and cannot take medicine, call your doctor or transplant coordinator.

If your child has more than 4 loose stools in 24 hours, call your doctor or transplant coordinator.
What will I need to know about each medicine?
• Name
• What the medicine is for
• How much to give
• When to give it
• Possible side effects
• When to call the doctor

How will I learn about my child’s medicines?
You will get a list of your child’s medicines. Before you leave the hospital, your transplant coordinator and nurse will make sure you understand how and when to give each medicine.

How will I get my child’s medicines?
Your transplant coordinator and social worker will help you find a drug store (pharmacy) that works with your insurance company. Your prescriptions will be sent to that drug store. Before you leave the hospital, a family member or friend will need to pick up your child’s medicines and bring them to the hospital. Your transplant coordinator will talk to you about each of the medicines before you go home.

When we are home, what do I do if we run out of medicine?
Before you are out of medicine, call your drug store to ask for a refill. If there are no refills left, ask them to call the transplant center at 602-546-0965 or fax a refill request to 602-546-4701. At your next appointment, you can ask your doctor or transplant coordinator for new prescriptions.

Can my child take medicine not prescribed by the transplant doctor?
Your child’s medicine needs change after transplant.
• Do not give your child any medicine, supplement, or herb until the transplant doctor or coordinator says it is all right. They may interfere with your child’s transplant medicine.
• If any other doctor prescribes medicine for your child, tell your transplant doctor or coordinator before you give it.
• Do not give your child any of these medicines unless your transplant doctor or coordinator says it is all right:
  — ibuprofen (Motrin, Advil, or Aleve)
  — medicine to treat loose stools or diarrhea
  — cold medicine, like nose sprays or decongestants (like Sudafed)

Where do I keep my child’s medicines at home?
Keep medicine in a dry place at room temperature, out of reach of children.

What do I do if I cannot pay for my child’s medicine?
Your child must always have his or her medicine. If you do not have money to pay for refills, before you run out of medicine call your social worker at the transplant center for help.
Prograf

Other names: Tacrolimus

Why is it given?
This medicine keeps your child’s body from rejecting the new kidney. Another word for this is immunosuppressant.

What to do
• Give this medicine at the same time every day.
• If you give this medicine twice a day, give it every 12 hours (such as 8 am and 8 pm)
• You may give this medicine with or without food.
• If you give this medicine with food, always give it with food.
• Do not let your child eat grapefruit or drink grapefruit juice.

Things to know about this medicine

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• headaches
• shaking that the child can’t stop (tremors)
• loose stool (diarrhea)
• sick to the stomach (nausea)
• hair loss
• trouble sleeping
• numb hands and feet
• kidney damage
• high blood sugar (diabetes)
• increased chance of getting an infection
Prednisone

Why is it given?
Prednisone is given to help keep your body from rejecting your new kidney. It is a steroid and an immunosuppressant.

What to do:
• Give prednisone with food. If given without food it could upset the stomach.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• hungry
• trouble sleeping
• sweating
• muscle weakness
• mood changes
• trouble healing
• pimples
• stomach ulcers
• high blood sugar
• changes in eye sight
• weak bones if high doses are taken for a long time

Call your doctor right away if your child:
• throws up blood
• has bloody stool
Cellcept

Other names: Mycophenolate Mofetil

Why is it given?
This medicine keeps your child’s body from rejecting the new kidney. Another word for this is immunosuppressant.

What to do:
• Give Cellcept at the same time each day.
• If you give this medicine twice a day, take the doses 12 hours apart (such as 8 am and 8 pm).
• You may give this medicine with or without food.
• If you give this medicine with food, always give it with food.

Things to know about this medicine

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• loose stool (diarrhea)
• sick to the stomach (nausea)
• throwing up (vomiting)
• not hungry (loss of appetite)
• low white cell count

Call your doctor right away if your child:
• has any unusual bruising or bleeding
• has loose stool (diarrhea)
• This medicine is not safe for pregnant women. It can harm the developing baby. Call the transplant center if you think your child is pregnant.
Diflucan

Other names: fluconazole

Why is it given?
This medicine is given to treat or prevent an infection caused by a fungus, such as yeast and Valley Fever. Another word for this is antifungal.

Things to know about this medicine
• Do not change this medicine unless your transplant doctor tells you to.
• This medicine affects the way your child’s body handles the medicine Prograf.
• This medicine may make birth control pills (oral contraceptives) not work well. A person taking this medicine should not take birth control pills.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• loose stool (diarrhea)
• sick to the stomach (nausea)
• throwing up (vomiting)
• rash
• headache
• not hungry (loss of appetite)
• dizzy
• food may taste different

You may ask your nurse or doctor for the handout, Taste Changes, #950
Bactrim

Other names: sulfamethoxazole, trimethoprim

Why is it given?
Bactrim is given to treat or prevent certain lung infections (pneumonia) and urinary tract infections.

Things to know about this medicine
• Tell your child’s doctor if your child is allergic to sulfa. Your child will be given another medicine instead. Children allergic to sulfa should not take Bactrim.

☐ yes  ☐ no  Give Bactrim at bedtime every Monday, Wednesday, and Friday.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• sick to the stomach (nausea)
• throwing up (vomiting)
• not hungry (loss of appetite)
• headache
• upset stomach
• rash
• itching

Call your doctor right away if your child:
• gets a bad rash, especially around the eyes or mouth
Cytovene or Valcyte

Other name: ganciclovir or valganciclovir

Why is it given?
Ganciclovir is used to prevent CMV (cytomegalovirus) disease. Ganciclovir may keep your child from getting CMV or make the illness milder. Valganciclovir is the pill form of ganciclovir.

Things to know about this medicine
• It is best to take this medicine with food.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
• fever
• rash
• shaking that the child can’t stop (tremors)
• confusion
• low white cell count
• kidney damage
Antacids

Other names: such as Pepcid, Zantac, Ranitidine, Prilosec, Omeprazole

Why is it given?

Antacids are given to help prevent stomach upset, ulcers, and heartburn.

Things to know about this medicine
• Give this medication in the evening or at bed time.

What should I do if my child misses a dose of this medicine?
If your child misses a dose, give it as soon as you remember. If it is almost time for the next dose, give only one dose. Do not give two doses to make up for a missed dose. If you have any questions, call the transplant center.

Possible side effects
hard dry stool (constipation)
loose stool (diarrhea)
sick to the stomach (nausea)
throwing up (vomiting)

Call your doctor right away if your child:
• Has stomach aches or heartburn. Your child may need a different antacid.
Other medicines after a transplant over-the-counter and non-prescription

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<th>If your child has</th>
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<td>Runny nose</td>
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<td>Do NOT give decongestants</td>
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<tr>
<td>Headache or body aches</td>
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<td>Do NOT give anti-inflammatory medicines such as Motrin, Aleve, or Ibuprofen. Do not give aspirin unless your transplant team tells you to.</td>
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<td>Sore throat</td>
<td>Chloraseptic spray</td>
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<tr>
<td>Fever</td>
<td>Tylenol</td>
<td>If your child’s fever is more than 100 degrees, call the transplant center.</td>
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Side effects of medicines

It is not easy to get used to the new medicines your child needs to take to prevent rejection and infection. Your child needs to take several medicines every day, and they have side effects. Some of these side effects change the way your child looks and the way your child feels about his or her body.

Will my child experience every side effect listed?
Your child will not get every side effect of every medicine. However, every child gets some side effects. If you know what to expect, you will know what is happening when it happens. Talk to your child’s transplant team to learn how deal with these side effects.

What changes might I see?

Skin Changes
Your child may get pimples on the face (acne). Wash these areas twice a day. Deodorant soap (like Dial) clean and help dry the extra oils on the skin. Do not use soap with oil or cream. These can make acne worse. If acne is a problem for your child, talk to the transplant team.

Your child may have dry skin. Use a mild soap, like Ivory. Use a bath oil, like Keri. After a bath or shower, put lotion on the skin.

Skin problems usually get better when the doses of medicines after transplant are lowered.

Hair Changes
Your child’s hair may get weaker and break more easily. After starting medicine after the transplant, wait a few months before you dye or perm your child’s hair.

Mouth Changes
Your child’s gums may bleed and teeth may become more sensitive to hot and cold foods and drinks. Your child must brush and floss twice a day to prevent infection.

Take your child to the dentist twice a year.
Mood Changes
Your child may be more emotional. Your child may cry or get upset easily. Tell family and friends this may be caused by the new medicine. Help your child talk about feelings to family, friends and the transplant team. Discipline your child the same way all the time, so he or she knows what to expect.

Trouble Sleeping
Your child may have problems falling asleep or staying asleep. Your child will be more tired at night if he or she does not nap during the day. If you care concerned about your child’s trouble sleeping, talk to the transplant team.
Rejection

Rejection is when your child’s immune system attacks the new kidney. If rejection is treated early, there is less damage to the kidney and better results. Know the signs and symptoms of rejection, and if you see them call the transplant team so they can start treatment right away.

What are the signs and symptoms of rejection?
• increasing creatinine  This is a blood test result. Your child will not feel this.

How will the doctor know if my child is rejecting the kidney?
The best way to know is to do a kidney biopsy.

Does rejection mean my child will lose the new kidney?
If rejection is treated early, there is less damage to the kidney and better results. Everyone who starts to reject a transplanted kidney does not definitely lose it.
Infection

Your child will be taking medicine that keeps him or her from rejecting the kidney. This is called immunosuppressive or anti-rejection medicine. A child’s immune system keeps him or her healthy. Your child’s transplant medicines keep the immune system working at a low level. This helps your child’s body accept your new transplant and not reject it. When your child’s immune system is suppressed or working at a low level, he or she has a greater chance of getting an infection. Infections can be caused by viruses, bacteria, or fungus. It is important to know the signs and symptoms of infection. If you see any of these, call the transplant team so treatment can start right away.

What are the signs and symptoms of an infection?
• chills
• fever of 100 degrees or higher
• headache, muscle ache, very tired (flu symptoms)
• cough
• sore throat
• fast heart rate
• swelling, drainage, tenderness, or opening of the transplant incision
• sores in or around the mouth
• urination that burns, is urgent, or more often than usual
• blood in the urine
• low back pain or belly pain

If your child has any of these, call your transplant team right away.

What can we do to prevent infections?
• Your child should wash hands often for 15 seconds with soap and water. Germs can enter the body when hands touch the nose, mouth, or eyes.

• For the first 6 weeks after the transplant, your child should stay away from crowded places, such
as malls, movie theaters, and classrooms.

• Give your child medicines, as prescribed.

• Stay away from people who are sick. Ask friends and family to stay away when they have fevers, sore throats, coughs, or aches.

• Keep your child’s body clean. Wash any cuts or scrapes with soap and water. See your doctor for treatment of more serious wounds. Wear shoes to avoid cuts on your feet.

• Brush and floss your child’s teeth two times each day.

What do we do if a member of our family gets sick?
If someone you live with gets sick, your child has already been exposed to his or her germs. Do not share dishes, cups, glasses, forks, or spoons. Your child should wash his or her hands often. If your child shows the same symptoms as the sick family member, call the transplant team right away.

What if my child is exposed to chicken pox, measles, or mumps?
If your child has had close contact with someone who gets or has been near someone who gets chicken pox, measles, or mumps, call the transplant team right away.
Infections

When your child’s immune system is suppressed or working at a low level, he or she has a greater chance of getting an infection. Here are some infections that children sometimes get after transplant.

CMV (Cytomegalovirus)

What is CMV?
CMV is a common virus. Most people get CMV at some time in their lives. The risk of CMV is highest in the first months after the transplant. For one year after transplant, your child will be given medicine to prevent CMV.

What are the signs and symptoms of CMV?
• tired (fatigue)
• fever of 100 degrees or higher
• headache
• lung infection (pneumonia)

What is the treatment for CMV?
A child with CMV needs medicine by IV (intravenous) or by mouth for several weeks or months. A child with CMV may have to be treated in the hospital.
EBV (Epstein Barr Virus)

What is EBV?
EBV is a common virus. Most people get EBV at some time in their lives. EBV may cause the body to make too many lymphocytes. This can lead to posttransplant lymphoproliferative disorder (PTLD).

What are the signs and symptoms of EBV?
- fever of 100 degrees or higher
- swollen lymph nodes
- sore throat
- increasing creatinine  This is a blood test result. Your child will not feel this.

What is the treatment for EBV?
A child with EBV may have to take less medicine to suppress the immune system.
Herpes Simplex Virus

What is herpes simplex virus?
Herpes simplex usually infects the skin. It can also infect other body parts, like the eyes or lungs. Herpes can be spread through sex. However, transplant patients may get herpes infections by any contact.

What are the signs and symptoms of herpes simplex virus?
There are two types of herpes simplex:

Type 1 causes
• sores in or around the mouth

Type 2 causes
• sores in or around the genital area
• unusual discharge in females

What is the treatment for herpes simplex virus?
Most herpes simplex infections are mild, but sometimes they can be severe. There is no cure for herpes, but the symptoms can be treated with medicine.

How can we prevent the spread of herpes simplex?
• Keep sores clean and dry.
• After touching a sore, wash your hands with soap and water for 20 seconds.
• Do not kiss someone who has a cold sore.
• Wear clothes that fit loosely, so they don’t rub on the sores and spread the virus.
Shingles (Herpes Zoster)

What are shingles?
Shingles (herpes zoster) are caused by the chicken pox virus (varicella zoster). Even if your child had chicken pox, he or she can still get shingles.

What are the signs and symptoms of shingles?
• rash or small water blisters on the chest, back, or hip
• pain near the rash

What is the treatment for shingles?
Shingles are treated with medicine by IV or mouth.
Chicken Pox (Varicella Zoster)

What are chicken pox?
Chicken pox is an infection caused by the varicella zoster virus.

What are the signs and symptoms of chicken pox?
• itchy rash or small blisters that cover large areas of skin
• fever of 100 degrees or higher

What do I do if my child is exposed to chicken pox?
If your child comes near someone with chicken pox, call your transplant doctor or coordinator.

What is the treatment for chicken pox?
Chicken pox is treated with medicine by IV or mouth.
Candida

What is Candida?
Candida is a fungus or yeast that can cause different infections in transplant patients.

What are the signs and symptoms of Candida?

Thrush
• white patches of painful sore spots in the mouth and throat
• white layer on the tongue
• trouble swallowing

• infection of the tube from the mouth to the stomach (esophagus)
• infection of the vagina, with yellow or white discharge

What is the treatment for Candida?
Candida is usually treated with medicine by mouth. If the infection is severe, your child may need to be in the hospital to get medicine by IV.
Valley Fever (Coccidiomycosis)

What is valley fever?
Valley fever usually infects the lungs and causes pneumonia. However, it can also infect other parts of the body. Valley fever is caused by a fungus found in the soil in the southwestern United States, called coccidiomycosis.

What are the signs and symptoms of valley fever?
• fever of 100 degrees or higher
• cough
• chills

How can I prevent my child from getting valley fever?
• After transplant, your child will be given medicine forever to prevent valley fever. This medicine fluconazole (Diflucan), is given by mouth.
Wound Infections

What is a wound infection?
Bacteria can get into a surgical site and cause a wound infection.

What are the signs and symptoms of a wound infection?
It is normal for the surgical site to have twinges, itching, or numbness for the first two months after surgery.

These are the signs and symptoms of an infection in a wound:
• redness
• swelling
• drainage
• tenderness
• incision opens up
• fever of 100 degrees or higher
• pain at the site

What is the treatment for a wound infection?
• Wound infections are treated with medicine.
Other Tests Your Child May Have

The following scans, x-rays and lab tests may need to be done after your child’s transplant.

Ultrasound
This test looks at the inside of the body using sound waves to see if there are problems with your transplant. An ultrasound test is done in the Radiology department. A gel is put on your child’s skin over the transplant. A probe is moved gently over the skin, and pictures appear on the computer screen for the doctor to view. This test takes about one hour.

Transplant Biopsy
If it looks like your child may be rejecting the transplant, this test is done. A sample of the kidney is taken out through a needle, and looked at under a microscope. Some children may need to get medicine to sedate them before this test is done. The skin is numbed, and the needle is put into the transplanted kidney. The kidney does not feel pain. After this test your child will need to stay in bed for 4 to 6 hours. Your child may have blood in his or her urine for up to 24 hours. This will clear faster if your child drinks more fluid.

Readmissions to the Hospital
Many transplant patients have to go back into the hospital within the first 30 to 90 days after the transplant. The usual reasons for admission are getting too dry (dehydration), possible rejection, or infection.

Laboratory Tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Normal Range</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creatinine</td>
<td>Varies by age</td>
<td>Best measure of how your kidney is working</td>
</tr>
<tr>
<td>Hemoglobin (Hgb)</td>
<td>12 - 16 gms/dl</td>
<td>Red blood cells that carry oxygen through your body.</td>
</tr>
<tr>
<td>Hematocrit (Hct)</td>
<td>36 - 46%</td>
<td>Percentage of red blood cells in your blood</td>
</tr>
<tr>
<td>White blood Cells (WBC)</td>
<td>4 - 10,000</td>
<td>Part of your immune system. Changes may indicate infection.</td>
</tr>
<tr>
<td>Prograf level</td>
<td></td>
<td>The amount of medicine in your blood.</td>
</tr>
<tr>
<td>Cyclosporine level</td>
<td></td>
<td>The dose will be adjusted by your doctor or coordinator.</td>
</tr>
<tr>
<td>Rapamune level</td>
<td>Varies</td>
<td></td>
</tr>
</tbody>
</table>
Activity

Right after surgery your child will have less strength and energy.

What types of activities are good for my child?
After your child leaves the hospital, every day he or she should bathe, get dressed, eat, and walk. Your child should notice how his or her body feels, and rest often. If your child is tired, he or she should take a nap.

Walking every day is very important. It will help your child get stronger, feel better, and not gain weight. Exercise can help:
• increase your child’s sense of health and well-being.
• tone and strengthens muscles.
• help build strong bones.
• improve sleep
• improve energy
• lower anxiety
• help to control weight
• improve self-esteem
• lower risk of heart disease

What kinds of activities should my child not do?
For the first 6 weeks after the transplant, your child should not lift anything weighing more than 10 pounds. Your child should not do things that bounce the body, such as horseback riding, aerobics, motorcycle riding, or jogging. Also, your child should not do a lot of bending, stretching, or straining.

What should my child not do, ever, even after 6 weeks?
After a transplant, your child can never participate in football, martial arts, wrestling, boxing, hockey, and lacrosse.

Can my child go swimming?
If your child has IV lines or catheters outside the body, he or she cannot go swimming. When these lines are out, your child can swim in pools, lakes, or oceans.
Can my child go in a hot tub or Jacuzzi?
If your child has IV lines or catheters outside the body, he or she cannot go in a hot tub or Jacuzzi. When these lines are out, your child can go in.

Can my child drive?
• If your child is legally able to drive, ask the transplant team if he or she is allowed to drive.
• Your child should never drive when taking medicine to treat pain.
• Your child must always wear his or her seatbelt.

Can my child travel?
It is much easier to travel after a transplant than it is on dialysis.
• Always pack enough medicine.
• Always carry the medicine. Do not check it with baggage.
• Carry the name and number of your child’s doctor and transplant team.
• If you plan to go to a country that requires immunizations, talk to the transplant team. Your child cannot get any live immunizations, such as varicella, measles, mumps, rubella, oral polio, yellow fever, or rotavirus.
Staying Healthy

What other health care should my child have?
The transplant team will continue to treat your child for issues related to transplant.

For health care that is not related to the transplant, your child should continue to see his or her primary care physician or pediatrician (PCP).

Six months after your child has the transplant, his or her eyes should be checked by an eye doctor (ophthalmologist). Some of the medicines your child is taking can cause changes in the eyes. After that, your child should see an eye doctor once each year.

Infections can start in the teeth and gums, so it is important they are kept healthy. Six months after your child has the transplant, his or her teeth should be checked by a dentist. Tell the dentist your child has had a transplant. If your dentist has any questions, have him or her call the transplant team. Your child should have a dental exam every six months (twice each year).

If your child has been seen by a specialist for a health problem, such as heart disease, your child should continue to see that doctor after the transplant.

Should my child get a flu shot?
Your child should get a flu shot every year. Everyone living in the house with your child who is over 6 months old should also get a flu shot.

Your child and everyone in the house should not get the flu vaccine given in the nose. This is a live virus, and could make your child sick.

What immunizations should my child avoid?
Children who have had transplants should not get any live vaccine. Examples of live vaccines are varicella, measles, mumps, rubella, oral polio, yellow fever, rotavirus, or the flu vaccine given in the nose.
Skin care

The medicine your child takes every day to keep the body from rejecting the new kidney (immunosuppressive medicines) increase your child’s chance of getting skin cancer. It is important to check your child often for changes in the skin.
- Tell your child’s doctor about any skin change that does not go away 2 or 3 weeks after it appears.
- Tell your child’s doctor about any skin change that bleeds, scabs, or seems to be growing.
- Tell your child’s doctor about any moles that bleed, grow, or change color.

To help prevent skin cancer:
- Keep your child out of the sun, especially between 10 am and 4 pm.
- Put sunscreen on your child’s skin every day, even when he or she is not going out into the sun.
- Use sunscreen with an SPF (protection factor) of at least 45.

Can my child smoke?
No. Smoking increases the chance of infection, bronchitis, emphysema, and pneumonia. These conditions can kill people taking immunosuppression medicine. Your child should also avoid second hand smoke.

Should my child wear a Medical Alert bracelet or necklace?
Yes! Your child’s Medical Alert bracelet or necklace should say:
Transplant patient on immunosuppressive medication.
Other health problems, such as high blood pressure, can also be printed on it. Ask your transplant coordinator for information on how to order one.
Nutrition After Transplant

How much water does my child need to drink?
Keeping your new kidney hydrated is very important. Your transplant nutritionist will give you a daily fluid goal and help develop a plan to meet your fluid goals every day. The best kinds of fluids are caffeine-free, such as water, skim milk, crystal light, sugar free Kool-Aid, or light fruit juices. Drinking high calorie beverages may lead to unwanted weight gain.

Your child’s daily fluid goal is ______ ounces.

What foods should my child stay away from?
If your child has high blood pressure, he or she should stay away from food high in salt or sodium. The nutritionist will teach you which foods to stay away from.

Will my child have any diet restrictions after transplant?
If the new kidney does not work right away, your child may need to avoid some foods. Most children will be able to eat more foods than they could before transplant. Your nutritionist will help you with this.

What can my child eat after the kidney transplant?
Transplant medicines may increase your child’s appetite. Food may taste better than it used to. Your child can now enjoy many fruits, vegetables, whole grains, and low fat dairy products. Eating a lot of different foods will help your child get all the vitamins, minerals, and protein needed for wound healing, recovery from surgery, and to help fight infections. Your child may like foods he or she did not like before the transplant. Give your child a lot of different foods to try.

How much should my child eat?
The number of servings your child should eat from each food group depends on your child’s age. Ask your transplant nutritionist how many servings your child needs.

Grains (choose whole grains in bread, rice, cereal, and pasta)
6 to 11 servings per day
One serving is 1 slice of bread, 1 cup of ready-to-eat cereal, or 1/2 cup cooked cereal, rice, or pasta.
Vegetables
3 to 5 servings per day
One serving is 1/2 cup other vegetables (cooked or raw), 1 cup raw leafy vegetables, or 3/4 cup low-sodium vegetable juice.

Fruit
2 to 4 servings per day
One serving is 1 medium apple, banana, orange, pear; 1/2 cup chopped, cooked, or canned fruit, or 3/4 cup fruit juice.

Milk, Yogurt and Cheese (choose low fat or fat free)
2 to 3 servings per day
One serving is 1 cup of fat free milk or yogurt, or 1 1/2 ounces of cheese.

Meat and Beans (choose lean or low fat)
2 to 3 servings per day
One serving is 2 or 3 ounces of cooked lean meat, poultry, or fish, 1/2 cup cooked dry beans or tofu, 1 egg, 2 tablespoons of peanut butter, or 1/3 cup of nuts.
Should my child take any vitamins, minerals, or herbal supplements?
The best way for your child to get all the nutrients he or she needs is in a healthy, balanced diet. If you want to give your child any vitamins, minerals, or herbal supplements, ask the nutritionist on the transplant team first. Some may interact with transplant medicines.

Do I need to think about food safety?
Yes, food safety is important since your child’s immune system is weakened. Food poisoning could make your child seriously ill.

How can I protect my child from food poisoning?
• Wash your hands before touching food.
• Clean counters and cutting boards often.
• Keep food in the refrigerator or freezer until you are ready to use it.
• Do not let cooked food or leftovers sit outside of the refrigerator for more than 2 hours.
• Cook food to the right temperature.
• Do not serve your child food that looks, smells, or tastes spoiled.

If you have any questions about what foods to choose or how to serve them, talk to your transplant nutritionist.
Living with Changes

What is a transplant social worker?
How can a social worker help me?
Going through a transplant can be stressful for a family. A transplant social worker helps you and your family cope with the stresses that come with a transplant. Your social worker may listen to your problems, and help you find ways to deal with them. You can talk to your social worker about any concerns or problems you have before and after your child gets the transplant. Your social worker can help your family with money issues, give you information, and refer you to organizations in the community that can help. Your social worker’s job is to make sure you and your family have all the information you need to make the transplant work.

What happens during the psychological/social assessment?
Your first meeting with the social worker is part of the Recipient Evaluation Process, and will last 1 or 2 hours. This meeting is called the psychological and social assessment. This meeting is required by the U.S. Government, so it must happen. You and the social worker will talk about personal things that can make the transplant work or not work. This is a good time for you and your family to talk about any concerns you have about getting a transplant and ask questions about the process. Some things you might talk about include:

— Personal and social background. Your child’s age, activity level, school experience, culture, religion, family relationships, and medical history

— Family and friends who can help (support system). The family members and friends who will help care for your child and you after the transplant surgery.

— Ability to follow through. In order for the transplant to work, you and your family have to do many things according to plan. These include giving medicines, staying on a special diet, having dialysis, and keeping appointments.

— Financial status. The ability of your family to pay for your child’s medicines and costs of living during and after the transplant.

— Transportation. How you and your child will get to and from the hospital and doctor visits.
— **Community Resources.** As needed, there may be organizations that can help you and your family with things like rides to and from appointments, paying for services, raising money, or counseling.

— **Your feelings and concerns.** You and your family can talk to the social worker about how you all feel about the transplant, including fears, concerns, and questions you may have.

**What will my child and family feel during the transplant process?**

Children and families have many different feelings during the transplant process. Some may be afraid or frustrated while waiting for their transplant. Some children may feel nervous about going to the hospital and want extra attention. Before the transplant, many parents report feeling worried about the procedures involved, possible complications and risks, and the costs of the transplant.

After their transplant, many children feel very happy and look forward to feeling better. Some families say they feel very grateful toward the person who donated their kidney. If the kidney came from a deceased donor, some families feel sad about the donor’s death and want to know more about the donor. After the transplant, parents may begin to feel lost, ignored, scared and often overwhelmed with all the medicines and follow-up appointments.

When the child begins to heal and life becomes more normal, parents may have trouble getting used to the changes in the family. For example, the child is no longer sick or helpless. The child may do more in school and play more with friends, and may need the parent less. Children may also behave differently. Some of this change is because the child feels better and has more energy. Behavior changes may also be related to medicines.

Your social worker is there to listen to you talk about your feelings, and help in any way possible. If you have any concerns or questions, call your social worker.
Who pays for the kidney transplant?

Kidney transplants are very expensive. When planning a transplant, it is very important to look at insurance and income. Your financial coordinator and social worker will help you with this.

In the beginning, you need to find out how the surgery will be paid for, how to pay for the cost of living if you need to take time off from work to take care of the child, how to get to and from the hospital and appointments, and if you need a place to stay near the hospital.

After the transplant, you will need money for the medicine to keep your child from rejecting the kidney and medicine to prevent infections.

Most insurance plans cover kidney transplantation. In many cases, Medicaid (called AHCCCS in Arizona) will also pay for kidney transplants. Medicare may also pay for a transplant, but usually does not cover all the costs. All insurance plans are different and may not pay for everything. The many co-pays for hospitalizations, doctor fees, outpatient clinic visits, tests, and post-transplant medicines can add up to a lot of money. Other ways to help pay for the transplant costs are group health insurance through a parent’s job, Medicaid (AHCCCS), Medicare supplements, or kidney disease programs.

Here are some things to look at with health insurance:
— How much is covered for inpatient hospital stays, including deductibles and co-pays
— If there is a waiting period. Many policies have a one-year waiting period before they cover expenses related to transplantation.
— Coordination of benefits. If the child is covered by more than one insurance policy, the second policy may cover expenses left over after the first insurance company (primary coverage) pays.

The largest cost of the kidney transplant is the immunosuppressive medicines that the child must take for the life of the kidney to prevent rejection. These medicines can cost $1000 to $2000 per month. In addition to medical insurance and Medicare, some other ways to help cover this cost may be:
— Medicaid. A state medical insurance plan for low-income patients. In Arizona, this plan is called AHCCCS. Some states cover all the costs of the transplant medicines, while others may have co-pays or limit how
much they cover.

— State kidney disease programs.

— Drug company patient assistance programs can help lower-income patients with insurance get needed prescriptions drugs. However, it can take four to six weeks to get medicine through these programs. The family will need to pay for medications until the drug company starts to help.

— Military. The dependents of retired veterans and active duty personnel may get medical care through military and VA hospitals. Medicine may also be covered at no charge.

There may be other issues, besides money, that may keep your child from getting a transplant. When this happens, the team will explain the issues to you and help you make a plan to deal with them.
Where can I get more information about kidney transplants?

National Kidney Foundation
www.kidney.org
800-622-9010
The National Kidney Foundation can mail you information.

American Association of Kidney Patients
www.aakp.org
800-749-2257
Information, referral, and advocacy for people with chronic kidney disease.

Life Options Rehabilitation Resource Center
www.lifeoptions.org
800-468-7777
Life Options provides research, education, and outreach to help people living with kidney disease.

Transplant Recipients International Organization (TRIO)
www.trioweb.org
800-TRIO-386
Transplant and organ donation information and resources for transplant candidates, recipients, donors and their families. They have many local chapters.

Transweb
www.transweb.org
A non-profit educational website for the transplant community.

Transplant Health
www.transplanthealth.com
A web-based resource for healthy living for transplant recipients.

The Gift of a Lifetime
www.organtransplants.org
A photo journey about organ donation and transplantation.
Financial Assistance and Information:

Medicare
www.medicare.gov
1-800-MEDICARE
Medicare Part D Prescription Drug Benefit
www.kidneydrugcoverage.org
800-622-9010
Provides information about Medicare Part D Prescription drug coverage.

Needymeds.com
www.needymeds.com
Website with information on patient assistance programs for prescription medications.

Partnership for Prescription Assistance
www.pparx.org
888-477-2669
Prescription drug assistance program.

National Foundation for Transplants
www.transplants.org
800-489-3863
Provides support, advocacy, and financial help to transplant candidates and recipients.

National Transplant Assistance Fund
www.transplantfund.org
800-642-8399
Help with raising money to pay for transplant costs.

Caregiver Information:

Family Caregiver Alliance
www.caregiver.org
800-445-8106
Information, education, services, research and advocacy for those caring for a loved one with a chronic disabling condition.
Now that you’ve read this:

☐ Show your child’s nurse or doctor how you take your child’s temperature. (Check when done.)

☐ Show your child’s nurse or doctor how you take your child’s blood pressure. (Check when done.)

☐ Tell your child’s nurse or doctor what medicines you will give your child, how much, and when. (Check when done.)

☐ Tell your child’s nurse or doctor why your child must always take these medicines. (Check when done.)

☐ Tell your child’s nurse or doctor what you will check every day (daily monitoring). (Check when done.)

☐ Tell your child’s nurse or doctor when you will call the transplant team. (Check when done.)

☐ Tell your child’s nurse or doctor how you will know if your child is rejecting the kidney. (Check when done.)

☐ Tell your child’s nurse or doctor how you will know if your child has an infection. (Check when done.)

☐ Tell your child’s nurse or doctor how active your child can be after the transplant. (Check when done.)

☐ Tell your child’s nurse or doctor what you can do to help your child stay healthy. (Check when done.)

☐ Tell your child’s nurse or doctor what you need to do before your child sees a dentist. (Check when done.)
☐ Tell your child’s nurse or doctor what your child can eat and drink. (Check when done.)

☐ Tell your child’s nurse or doctor what social services you can use. (Check when done.)

☐ Tell your child’s nurse or doctor how you will follow-up with the transplant team. (Check when done.)

If you have any questions or concerns,
☐ call your child’s doctor or ☐ call ______________________

If you want to know more about child health and illness, visit our library at The Emily Center at Phoenix Children’s Hospital
1919 East Thomas Road
Phoenix, AZ 85016
602-546-1400
888-908-5437
www.phoenixchildrens.com
Disclaimer
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Family Review of Handout

Health care providers: Please teach families with this handout. Families: Please let us know what you think of this handout.

Would you say this handout is hard to read? ☐ Yes ☐ No

Would you say this handout is easy to read? ☐ Yes ☐ No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read? ☐ Yes ☐ No

Why or why not?

Would you do anything differently after reading this handout? ☐ Yes ☐ No

If yes, what?

After reading this handout, do you have any questions about the subject? ☐ Yes ☐ No

If yes, what?
Is there anything you don’t like about the drawings? □ Yes □ No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

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Phoenix, AZ 85016-7710

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Thank you for helping us!