Pediatric Kidney Transplant Program

Information for Transplant Patients and their Families:
What You And Your Child Need to Know About Kidney Transplantation

In Cooperation with The Rogosin Institute

You have the power to Donate Life®

In Cooperation with The Rogosin Institute
We know that having a transplant can be an overwhelming experience due to your child’s recent surgery, new medications, and new monitoring requirements.

We hope that this booklet will help to answer some questions that you and your child may have as well as provide a basic guide to maintaining your child’s health and your child’s transplant for as long as possible!

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Congratulations on your child’s transplant!

We look forward to seeing you and your child at their post-transplant follow-up visits so that we can work together to help your child keep their new transplant functioning for many years to come!

CONTACTING YOUR CHILD’S NEPHROLOGY TEAM

Clinic Location:
NewYork-Presbyterian Hospital/Weill Cornell Medical Center
505 East 70th Street
Helmsley Building
New York, NY 10065

Contacting Us:
To schedule or change an appointment, please call (646) 962-4324. If the clinic is closed and you have an issue that requires immediate attention, please call (646) 962-4324 to speak with the doctor on-call.

CONTACTING YOUR CHILD’S TRANSPLANT TEAM

Clinic Location:
NewYork-Presbyterian Hospital/Weill Cornell Medical Center
520 East 70th Street
Starr Building – 8th floor (make 2 right turns off of elevator)
New York, NY 10065

Contacting Us:
To schedule or change an appointment, please call (212) 746-3020

If you are experiencing a medical emergency (such as chest pain, difficulty breathing, bleeding), call 911
Your transplant team is here to support you and your child and provide you with guidance in managing your child’s health.

However, YOU AND YOUR CHILD are the most important members of our team. It is your responsibility for making sure your child is taking their medications, for monitoring their fluid intake and blood pressure, and for coming to their follow-up visits described below. All of these things will help ensure that your child’s transplant continues to function for as long as possible.

Post-Transplant Follow-Up Visit Schedule

Below is the schedule of clinic visits that you should expect to attend now that your child has received a transplant.

<table>
<thead>
<tr>
<th></th>
<th>1st Month</th>
<th>Months 2 and 3</th>
<th>Months 4 to 6</th>
<th>Months 6 to 12</th>
<th>Years 1 to 3</th>
<th>After Year 3</th>
</tr>
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<tr>
<td><strong>Your Nephrology Doctor</strong></td>
<td>Twice a week</td>
<td>Once a week</td>
<td>Once a month</td>
<td>Every 3 months</td>
<td>Every 3 months</td>
<td>Every 6 months</td>
</tr>
</tbody>
</table>

Your child will see the transplant surgery team at least once after their transplant.
Preparing for Your Child’s Clinic Visit

1. Please arrive on time for your clinic appointments!

2. Please bring this booklet, your child’s tracking chart, and your child’s current list of medications to all clinic visits. Please bring your child’s pill box and medication bottles to the first visit after transplant.

3. Please do not give your child their Tacrolimus (Prograf®) dose or their Mycophenolate Mofetil (Cellcept®) the morning of the visit, but bring it with you so they can take it after their blood has been drawn.

4. Don’t forget to fill out your child’s monitoring diary every day so your transplant team can see how your child has been doing at home.
The job of your immune system is to protect you from outside invaders such as bacteria and viruses that can cause infection. The immune system is very complicated and views a transplanted organ as a foreign invader, which is why your child will need to take medications that suppress their immune system to protect their transplant from rejection.

Each medicine works in a different way, and plays an important role in protecting the transplant.

Rejection sometimes occurs even if your child is taking their medication as directed. Most rejection episodes can be reversed by additional medications and/or higher doses of their current medications for a brief period of time. Having an episode of rejection does not mean your child will lose the transplant. However, rejection does cause damage to the transplant and can reduce the long-term survival of the transplanted organ. In some cases, severe rejection can lead to transplant loss.

Therefore, it is important for your child to take all of their medications as directed to protect the transplant for as long as possible.

Detailed descriptions about the medications your child will take to protect their transplant from rejection can be found on pages 22 to 24.
Transplant recipients may be at higher risk of developing infection because they are taking medications to suppress the immune system, which also affect the body’s ability to fight infection. Here are the best ways to protect your child from infection:

**# 1 Practice Good Hand Hygiene**
Make sure your child washes their hands often with soap and water or alcohol-based cleanser (such as Purell). Have your child wash their hands again any time before eating throughout the day.

**# 2 Give Your Child Their Preventative Medications**
For the first several months after your child’s transplant, they will be taking three medications (described on page 22) that protect them from the most common infections seen in transplant recipients.

**# 3 Avoid People Who Are Sick**
We know it may be difficult to totally avoid people who are sick, but by having your child avoid close contact and washing their hands often, you can reduce the chance that they will get sick.

**# 4 Make Sure Your Child Receives the Inactivated Flu Vaccine Every Year**
Transplant recipients should get a flu shot every year to protect them from the influenza virus. In addition, your child should also receive the pneumococcal vaccine every five years, as directed by their nephrology doctor. For any other vaccinations, please check with your child’s nephrology doctor first, since some vaccines contain a live virus, which can be dangerous in a transplant patient. Your child’s doctor can write a letter about which vaccines your child can and cannot receive.

**What is a stent?**
Some patients receiving a kidney transplant have a ureteral stent, which is a tube placed during your child’s transplant surgery to help urine move from the new kidney to the bladder and keep the ureter open while your child is healing from the surgery.

The stent is removed by a urologist at about 6 weeks after transplant – we will assist you in scheduling this appointment. It is important for you to know if your child has a stent and to keep the appointment to have it removed, since keeping the stent in for longer periods of time can lead to infection.
You know your child the best, so you need to take a lead role in letting the transplant team know if something doesn’t “seem right” to you. Below are some examples of the things you should monitor/look out for after your child’s transplant.

**Urine Output**

At home, you should monitor the amount of urine your child makes daily so that you will be able to tell if your child’s urine output changes suddenly.

You should also pay attention to the appearance of your child’s urine. If it is normally clear and yellow, but then if it has blood in it or turns a dark brown color, you should notify the clinic.

**Weight**

Many patients retain fluid after their transplant surgery, causing temporary weight gain. In other cases, patients may become dehydrated due to poor fluid intake, and this can cause weight loss. Patients who are used to limiting fluid intake from being on dialysis sometimes find it difficult to keep up with the fluid requirements after transplant. We recommend that patients weigh themselves every morning when they first wake up and record the weight for review with the team.
Blood Pressure

It is important to monitor your child’s blood pressure after transplant, since both high and low blood pressure can have negative effects on the transplanted organ, and may require changes to their blood pressure medications. High blood pressure can be a side effect of some of the transplant medications, and can also be caused by fluid that has been retained after the transplant surgery.

In the first few months after your child’s transplant, you should check and record their blood pressure twice a day and bring the results to your clinic visits so that we can make any necessary adjustments to their medications. During this time period, you will get an idea of what your child’s new “normal” blood pressure is after transplant. A symptom of high blood pressure is headache, while low blood pressure may cause dizziness or lightheadedness. Report any of these symptoms to your child’s nephrologist.

Temperature

You should take your child’s temperature once per day in the morning, or more frequently if they feel ill. An increase in normal temperature can be a sign of an infection. However, since your child is immunosuppressed, they may not mount a high fever, so you should pay close attention to any other symptoms that they are experiencing (such as chills, malaise, cough, nausea and/or vomiting, or pain, urgency, and/or frequency with urination). If their temperature is 100°F or higher, you should contact your child’s nephrologist for further instructions.
Below are some blood tests that we commonly check after transplant, and an explanation of why it is important that we monitor them.

<table>
<thead>
<tr>
<th>Name of Test</th>
<th>Why Do We Check It</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creatinine</td>
<td>Creatinine is a waste product made by the body that is removed by the kidneys, and we measure the amount of creatinine in your child’s blood to check how well the transplant kidney is functioning.</td>
</tr>
<tr>
<td>Electrolytes</td>
<td>Several electrolytes (such as magnesium, phosphorus, and calcium) will be closely monitored after your child’s transplant since better kidney function may cause low levels of these electrolytes. This may lead to your child needing to take supplements of these electrolytes for a short period of time.</td>
</tr>
<tr>
<td>Glucose</td>
<td>Glucose is another term for blood sugar. After transplant, some patients (both with and without diabetes) will have an increase in their blood sugar levels due to some of the medicines used to protect the transplanted organ from rejection.</td>
</tr>
<tr>
<td>Hemoglobin</td>
<td>Hemoglobin carries oxygen throughout the body to the parts that need it. When your child’s hemoglobin is low, they have anemia, and may feel tired and have lower amounts of energy.</td>
</tr>
<tr>
<td>Platelets</td>
<td>Platelets are cells that help the blood to clot. Some transplant medications may lower your child’s platelet count. A low platelet count may cause your child to bruise more easily or bleed for a longer period of time if they are injured.</td>
</tr>
<tr>
<td>Potassium</td>
<td>Potassium is an important electrolyte in the body that can cause problems if the level goes too high or too low. People with chronic kidney disease and those on dialysis may be used to having a high potassium level. After transplant however, a well-functioning kidney transplant can cause your child’s potassium to go too low. Therefore, we monitor your child’s potassium level closely, and may advise you to change your child’s dietary intake of potassium and/or may give them medication if the level is too low.</td>
</tr>
<tr>
<td>Tacrolimus (Prograf)</td>
<td>Tacrolimus (Prograf®) is one of the medicines most transplant patients take to help protect their transplant from rejection. When your child comes to clinic, we will measure the amount of tacrolimus in their blood to make sure they have a good level and may use this level to adjust the dose of tacrolimus. In order to get an accurate level, your child should not take their morning tacrolimus dose before having blood drawn, but you should bring the medicine with you to clinic and have them take the dose once their blood has been drawn.</td>
</tr>
<tr>
<td>White Blood Cells (WBC’s)</td>
<td>WBC’s are cells of the immune system that help to fight infection. Having a high white blood cell count may be a sign of an infection, while a low WBC count may be a sign that your child’s immune defense is low, putting them at higher risk for infection.</td>
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Nutrition

A well-balanced diet and good nutrition is very important to healing and recovery after your child’s transplant surgery. The transplant nutritionist (also called a dietician) will meet with you and your child once before the transplant and one or more times after the transplant as needed.

The nutrition plan you receive will depend on how well your child’s transplant is functioning. Some patients have delayed graft function, which means the kidney is slow to wake-up and that the patient may require dialysis for a period of time after the transplant. In these cases, the patient will likely have similar dietary restrictions as prior to transplant (for example, limiting intake of potassium-rich foods). All patients can benefit from having a low-salt diet after transplant as well.

In other cases, the kidney may work so well that the patient will lose important electrolytes in their urine and may require supplementation of the electrolytes through their diet and/or through medications.

Fluid Intake

It is very important to follow the instructions you receive about how much fluid your child should drink. We know it can be hard for children who were on dialysis to adjust to having to drink a lot of fluid, but just remember how important it is to keep the new kidney happy by giving it fluid.

For patients whose kidney is taking a while to wake-up, they may have to continue on a fluid-restricted diet until the kidney function improves. This is why it is important for you to monitor how much urine your child is making, so we can tell when the kidney is starting to wake-up.
We recognize that it can be hard for children to understand why they have to drink a large amount of fluid. Here are some suggestions to help increase your child’s fluid intake:

- **Have a number of colorful and fun water bottles available.** Let your child pick their favorite container each day.

- **Use silly straws** to encourage consistent drinking throughout the day.

- **Put a slice of lemon, lime or orange in their water** to give it some taste. Let them help squeeze the fruit into their water bottle to get them involved.

- **Keep small water bottles all around the house,** car, backyard, in their room so that water is always readily available.

- **Encourage them to serve themselves water.** Keep a jug on a low shelf in the fridge so they can help themselves.

- **Make popsicles made with mostly water**

- **Have your child chew on ice or add it to their drinks.** Get fun shapes and have them help you freeze it.

- **Be a role model. Drink water in front of your child** as frequently as possible.

- **Teach your child** that their urine should be a very light yellow or clear.

- **Make it a family challenge!** Have a sticker chart and give your child a prize when they do well on their fluid intake.
In general, your child can return to their normal activities as soon as they feel well enough. Your child may be tired and have less energy than before the surgery, so it is important for them to pace themselves and try not to overdo it - moderation is the key!

**Bathing**

It is recommended that your child take a shower, not a bath, until the incision is well-healed. You can let soap and water flow over the incision—do not actively rub the area. The steristrips over the incision will fall off on their own—you should not pull them off yourself. Ask your child’s nephrologist if you have any questions.

**Exercise**

Exercise is a very important activity in maintaining health. After your child’s transplant surgery, it is best to start out slow, perhaps by having them walk or play for 15 to 20 minutes, and gradually increase the time and/or pace as they begin to feel better. Your child should not lift anything heavy for the first 6 weeks after the surgery, and older children and teenagers should not resume workouts with heavier weights until being cleared to do so by their nephrologist. Children and teens with a transplant should never take muscle building supplements.

**Avoiding Crowds**

It is recommended that transplant recipients try to avoid crowded, enclosed spaces for the first 3 months after transplant. For example, patients should try to avoid taking the subway or bus as their means of transportation. Patients may go shopping, to the movies, restaurants, the park, etc.; however, they are advised to go when those places are not their busiest.

**For Teens and Young Adults Who Drive**

Most patients should not drive for about 6 weeks after their transplant. Wearing a seatbelt can irritate the transplant incision. In addition, pain medications taken after the transplant may interfere with your child’s ability to drive safely by causing dizziness, blurred vision, and/or confusion. It is best for you and your child to speak with your transplant team for clearance before beginning to drive again.
Work and/or School

Most patients are able to return to school or work within 3 months of their transplant surgery. Of course, everyone’s recovery is different, so you will have to see how you are feeling as the time nears for you to make the decision to return to work or school.

For younger children who are enrolled in grades 1-12 in the five boroughs, your social worker will help in arranging home instruction with the NYC Board of Education. If your child's school is outside the five boroughs, your social worker and doctor will write a letter to your school to inform them that they must arrange home instruction. For older patients enrolled in college, if your child's transplant occurs during the school year he or she may need to take a leave of absence or defer a semester. Your social worker can assist in writing a letter to your child’s academic institution. We understand that having a kidney transplant during the school year disrupts your child’s education. What should your child’s teacher know? Your Pediatric Nephrology and Transplant Team have put together letters to give to your child's teacher and other school officials to help them better understand the upcoming challenges that your child will face. We have also written a second letter to give to your other children's teachers because we understand that a transplant affects the entire family. Please contact your social worker for a copy of these letters.
Many parents and their children have questions about sexual activity and future family planning. Kidney transplant recipients are able to conceive children of their own. They should inform their doctors when they are thinking about trying to start a family to discuss changes to their medications and the impact on their transplant. Young adults who were previously sexually active can resume sexual activity 2 to 3 weeks after their surgery. Below are some important considerations for both females and males.

**Females:**

- **Menstruation:** For girls who have not yet started their menstrual cycle, having a transplant could delay this process. Girls who have already started their menstrual cycle prior to transplant may have an irregular period for some time after transplantation. This should return to a regular cycle in the months following surgery. If your daughter required dialysis prior to transplant their menstrual cycle may have stopped and should resume after transplantation.

- **Use adequate contraception!** For young women who are sexually active, please speak with your nephrology doctor about the best contraceptive method for you, since the best method will vary depending on other medical conditions you may have. To protect yourself against sexually transmitted diseases (STD’s), have your partner use a barrier method such as latex condoms.

- **Pregnancy should be planned!** In general, women who receive a kidney transplant should not become pregnant for at least 1 to 2 years after their transplant. You should speak with your transplant doctor before attempting to become pregnant, since we need to make sure your kidney transplant function is stable. In addition, some transplant medications can be harmful to a developing fetus, so medication adjustments may need to be made prior to you becoming pregnant. This must be done under close supervision of your transplant doctor since you will need to be monitored more closely for rejection.

**Males:**

- **Erectile dysfunction (ED) is a common problem** in men with chronic kidney disease. In many men, this may get better after receiving a transplant, but in some cases, transplant or blood pressure medications may contribute to erectile dysfunction. Please speak with your nephrology doctor, since there are several medications that can help you with erectile dysfunction.

- **Protect yourself from sexually transmitted diseases (STD’s) by using latex condoms.** Speak with your doctor if you are sexually active and have questions about your kidney transplant and sexual activity.
Receiving a transplant can be a very stressful time for your entire family, despite the fact that the transplant is something that you were looking forward to and excited about. A transplant means a big change in your lives and new information to learn, which can be stressful for the whole family.

You and your child may experience family stress, parent-child or recipient-donor conflict, marital conflict, financial concerns, insurance issues, and stress over going back to work or school when the time comes. You are not alone—many patients and families feel these stressors, and it is quite normal to feel some degree of depression and/or anxiety after transplant. Please reach out to the social worker and/or your child’s nephrologist with any issues you are having, and they will assist you and/or refer you to someone who can help you. We can also connect you or your child to other parents and children who have previously been transplanted at our hospital.

We also have a few social events throughout the year where you can meet other children and families who have been transplanted at our center. Please contact your social worker for information about these events.
As a transplant recipient, it is important for your child to receive routine health care outside of the care provided by your transplant team. If you need to find a healthcare provider to visit for the check-ups mentioned below, we would be happy to refer you to someone, just ask!

**Check Your Skin and Visit the Dermatologist**

Skin cancer is the most common type of cancer after transplant and the risk can be 10 times higher than the general population! It is very important for you to routinely check your child’s skin for any problems and to have them visit a dermatologist at least once a year. Some medications that your child will take after transplant can also make their skin more sensitive to the sun and other irritants.

It is also very important that your child wears sunscreen to protect him/her from skin cancer.

Ultraviolet (UV) rays from the sun cause skin cancer, and these UV rays are present even on cloudy days. Protect your child by having them wear sunscreen that is SPF 30 or above as well as lip balm that contains SPF. Transplant patients should not have a tan (unless it is fake, of course)!

**Dental Care**

It is very important for your child to take care of their teeth and mouth after transplant. They should brush their teeth twice a day and don’t forget to floss! If your child has tooth or mouth pain, they should see their dentist immediately, since they may be at higher risk for developing infections. If you have any questions about your child getting dental procedures, ask your nephrologist.
Smoking Cessation

We all know smoking is bad and causes health problems – we have all seen the commercials on TV. But did you know that smoking also shortens the lifespan of a kidney transplant? Many studies have shown that kidney transplant survival is worse in patients who smoke. So is patient survival, due to cardiovascular disease and cancer. Encourage your children to never smoke.

Second-hand smoke is also a serious health risk to children. If anyone in the home currently smokes (even if they only smoke outside), please let us help them quit for your sake and your child’s kidney’s sake! Let your transplant team know that a member of your family is interested in quitting, and we will assist you!

Marijuana and other Recreational Drugs

Marijuana and other recreational drugs are especially contraindicated in transplant patients, and side-effects can be extremely dangerous or even deadly. Even if taken accidentally, please notify your healthcare team immediately!

Other Things to Consider

Maintaining Health & Prescription Insurance

It is very important for you to maintain active health and prescription insurance coverage at all times for your child. Please seek assistance from members of your transplant team if you are having difficulty with your insurance and related financial issues. If you plan to change jobs be sure to speak with your transplant team to ensure that your child will continue to have adequate insurance coverage during this period. Additionally inform us if your child’s insurance coverage changes for any reason. We are here to help so please do not be too proud to let us help you!

Emergency Medical Information Identification

You should make a list of your child’s medications and contact information for their medical team and have them keep it in their phone, book bag, wallet, or locker. Another copy should be given to your child’s school nurse.
Guidelines for Taking Medications

The Basics

- Always maintain and carry a list of your child’s current medications (including the dose, strength and how frequently they take them).
- Make sure your child takes all of their medications exactly as directed at the same time every day. **Do not stop taking or change the dose of any medication without the knowledge and approval of the transplant team.**
- Your child should take all of their transplant medications with food.
- Your child should avoid drinking or eating grapefruit and pomegranate juice and fruit or juices/soda that contain it (such as Sunny Delight, Fresca, Squirt).
- Do not crush or chew tablets or open capsules. If your child is having difficulty swallowing any of the medications, talk to your child’s nephrologist, nurse, or pharmacist for alternative dosage forms.

If Your Child is Sick...

...and they are not able to take their medications and/or keep them down (for example, they are vomiting or have bad diarrhea), please call your child’s nephrologist immediately.

Over-the-Counter Medications

- Do not give your child any over-the-counter medications, vitamins, or herbal supplements/remedies without talking with their nephrologist.
- Your child should **never** take certain over-the-counter pain medications including ibuprofen, Advil, Motrin, naproxen, and Aleve.
- Acetaminophen (Tylenol) is okay to take for pain.

Medications Prescribed

Some medications interact with immunosuppressants. If your child is prescribed a medication by a doctor other than their nephrologist, check with the nephrologist prior to taking them to make sure that it is okay.
You should try very hard to never skip a dose of the transplant medications, but if a dose is accidentally missed:

- Call the nephrologist.
- **Never double-up** on doses if your child accidentally misses a dose of medication.
- For medications your child takes once a day, have your child take it when you remember and then get back on schedule the next day.
- For medications your child takes twice a day, if your child is less than 5 hours late with one dose, have your child take it as soon as you remember and then get back on schedule with the next dose. If your child is more than 5 hours late with one dose, skip it and have your child take the next dose at the next scheduled time. Then stay on schedule.
- If your child takes a medication three or four times a day and misses a dose, skip that one and get back on schedule with the next one.
- **But remember, having your child take the right dose of medications at the right time is very important!**

### Your Child’s Medication Supply

- Call your pharmacist for refills at least 7 days before you are due to run out of your child’s medication.
- Make sure you will have enough medication for your child if you will be away from home.
- Ask for prescriptions for medication refills for your child as needed at your clinic visits.

### Storing Your Child’s

- Store your child’s medications as per the package instructions.
- Store your child’s medications out of the reach of small children.

### About Side Effects

While we list many possible side effects of your child’s medications, your child may experience only a few of them or may not have any. But if you do notice that your child has any of these side effects, always tell your child’s nephrologist.
The key to maintaining a successful transplant is having your child take the anti-rejection medications (also called immunosuppressants) prescribed to them for the rest of their life. Your child will be on many different medications after transplant. These include anti-rejection medications, antibiotics and other medications based on your child’s individual case. On the following pages, we will check-off the medications that your child is taking.

Initially it may seem a little overwhelming, but in time you and your child will become very comfortable with the routine. As time passes the number of medications your child has to take should decrease. Children should be involved in taking their own medication. Help them learn the names, doses, and purpose of each of their medications.

Talk to your health care team about your questions and concerns.

Having trouble paying for your child’s medications?

Talk to your transplant doctor, social worker, or pharmacist immediately if your financial situation changes and you don’t have enough money to afford your child’s medications. Some medications have value cards for co-payment assistance as well as patient assistance programs for free medication based on eligibility. Additionally, some medications have generic formulations available that may lower medication-related costs.
Purpose: Prograf® (Tacrolimus) is an immunosuppressive medicine that helps prevent rejection.

Dosage: The dose we prescribe for your child is based on lab values. The capsule comes in three sizes (see below). A liquid suspension can also be made at select specialty pharmacies for younger children and patients who have difficulty swallowing.

When: Specific doses are taken in the morning and evening approximately 12 hours apart at consistent times each day. Take consistently with food. On mornings of clinic visits and/or days your child’s labs are checked, your child should not take their morning dose of tacrolimus until after their blood is drawn. Remember to bring your child’s tacrolimus with you to clinic.

Precautions: Tacrolimus levels can be changed by some medicines. Before your child takes any new medications contact your child’s nephrologist.

Common Side Effects may include increase in blood pressure, headache, numbness, dizziness, tremor/shakiness, and increase in blood sugar.

Other side effects may include seizures, mental status changes, insomnia, loss of appetite, diarrhea, rash, decreased kidney function, leg cramping, elevated potassium levels, lowered magnesium levels, and hair loss.

Additional Considerations: Tacrolimus is available in both Brand (Prograf) and Generic forms of medication. Your child is on the Sandoz generic form. Generic forms usually look different from the brand and from each other. Call your child’s nephrologist immediately if your child’s medication looks different than as originally filled. Your child should stay on the same generic form but if switched from the Sandoz form to a different generic form, additional blood tests will need to be taken for a period of time and you should notify your child’s nephrologist if you notice any changes (drug-related side effects) after the switch.

<table>
<thead>
<tr>
<th>Capsule Size</th>
<th>Color</th>
<th>Photo</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.5 mg</td>
<td>Yellow/White</td>
<td><img src="image" alt="Yellow/White Capsule" /></td>
</tr>
<tr>
<td>1 mg</td>
<td>Brown/White</td>
<td><img src="image" alt="Brown/White Capsule" /></td>
</tr>
<tr>
<td>5 mg</td>
<td>Orange/White</td>
<td><img src="image" alt="Orange/White Capsule" /></td>
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</tbody>
</table>

What does Tacrolimus look like?

Please note that the pictures to the right are for Sandoz generic tacrolimus. Brand Prograf and other generic versions may look different, and you should notify us if your child receives tacrolimus that looks different than originally filled.
When: Specific doses are taken in the morning and evening approximately 12 hours apart at consistent times each day. Always take with food.

Precautions: Antacids such as Maalox and Mylanta can decrease your child’s body’s absorption of Myfortic or CellCept. Your child should never take antacids at the same time as Myfortic or CellCept. Both Myfortic and CellCept can cause birth defects and should not be taken during pregnancy. Women of child bearing potential who are sexually active must use effective contraception while taking Myfortic or CellCept. If considering pregnancy, this must be discussed with the transplant team in advance.

Common Side Effects may include nausea, vomiting, diarrhea, loss of appetite, low white blood cell count, low platelet count, low red blood cell count (anemia).

Additional Considerations for Patients Taking CellCept: Cellcept (Mycophenolate Mofetil) is available in both Brand and Generic forms of medication. There are currently several different companies that make generic forms. Generic forms usually look different from the brand product and from each other. Call your child’s nephrologist immediately if your child’s medication looks different than as originally filled. If your child is switched from one form of medication to another, you should notify your child’s nephrologist if you or your child notice any changes (drug related side effects) after the switch.
**Purpose:** Prednisone is an immunosuppressive medicine that helps prevent rejection.

**Dosage:** Follow instructions per transplant team. The dose of Prednisone will be tapered down over time.

**When:** Specific doses are taken in the morning with breakfast. If your child is taking Prednisone twice a day, have them take the evening dose with dinner. Take consistently with food.

**Common Side Effects** may include stomach pain, water and salt retention, weight gain, increase in blood sugar, blood pressure, and cholesterol, mood swings, insomnia, bone pain, osteoporosis, impaired wound healing, acne, and hair growth. **Other side effects** may include depression, euphoria, irritability, menstrual irregularities, increased risk of infection, joint discomfort, stomach ulcers, “moonface”, eye changes (cataracts), heightened sun sensitivity, nausea, vomiting, and increased appetite.

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**Purpose:** Rapamune is an immunosuppressive medicine that helps prevent rejection. We do not commonly use this medication, unless a patient cannot tolerate one of the standard medications (such as tacrolimus or mycophenolate).

**Dosage:** The dose we prescribe for your child is based on their lab values.

**When:** Specific doses are taken in the morning with breakfast at a consistent time each day, with food. On mornings of clinic visits and/or days your labs are checked, do not have your child take their dose until after their blood is drawn. Remember to bring your child’s Rapamune with you to clinic.

**Precautions:** Rapamune levels can be changed by some medicines. Before your child takes any new medications contact the transplant team.

**Common Side Effects** may include increase in cholesterol and triglycerides, impaired wound healing, low white blood cell count, low platelet count, low red blood cell count (anemia), diarrhea, and leg swelling. **Other side effects** may include increase in blood pressure, rash, bone pain, mouth ulcers, and pneumonitis.
**Purpose:** Used to prevent or treat viral infections. Valcyte prevents or treats cytomegalovirus (CMV) infection that can be found in the blood, gastrointestinal tract, and lungs.

**Dosage:** Dosages vary depending on your child’s kidney function and whether Valcyte is being used for prevention or treatment. Valcyte is available as a 450mg tablet (pink) and a liquid solution (50mg/mL).

If all is going well, your child will take this antiviral medication for only the first 3-6 months after the transplant.

**Side Effects** may include low white blood cell count, low platelet count, abdominal pain, nausea, vomiting, diarrhea, headache, and dizziness.

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**Purpose:** Mycelex and Nystatin are medications that prevent or treat fungal (candida) infections often found in the mouth (thrush). Your child will take only one of these medicines after their transplant.

**Dosage:** Mycelex (clotrimazole) is available as a 10mg Troche (white) and Nystatin is available as a liquid suspension (100,000 units/mL). Your child should suck on the Mycelex troche in their mouth until dissolved. It should never be chewed or swallowed whole. Younger children may be prescribed the Nystatin liquid suspension. Your child should swish and swallow the liquid. Your child should not eat or drink for 30 minutes after taking either of these medications.

When: Mycelex is taken in the morning and evening approximately 12 hours apart at consistent times each day. Nystatin is taken four times daily; after each meal and at bedtime. Have your child take this medication last after they have taken all of their other medications.

**Side Effects** may include nausea, vomiting, diarrhea, oral irritation, and chalky taste in mouth (Mycelex).
Other Medications Your Child May Receive After Transplant

Medications to Lower Blood Pressure

**Purpose:** Control blood pressure.

**Dosage:** Vary based on type of medication and on individual need.

**Common Side Effects** may include dizziness, lightheadedness, nausea, headache, flushing, swelling, and fluctuation in heart rate.

BLOOD PRESSURE MEDS
- Procardia XL (nifedipine)
- DynaCirc (isradipine)
- Norvasc (amlodipine)
- Catapres (clonidine)
- Vasotec (enalapril)

Medications to Protect Your Child’s Stomach

**Purpose:** Used to prevent stomach and duodenal ulcers, which can develop when Prednisone doses are high.

**Dosage:** Vary based on medication utilized and kidney function.

**Side Effects** are rare but may include nausea, abdominal pain, diarrhea, headache, low white blood cell count, and low platelet count.

STOMACH MEDS
- Nexium (esomeprazole)
- Prilosec (omeprazole)
- Protonix (pantoprazole)
-Prevacid (lansoprazole)
- Pepcid (famotidine)
- Zantac (ranitidine)

Medication to Prevent Constipation

**Purpose:** Stool softener; used to prevent constipation.

**Dosage:** The usual dose range is 50mg-300mg daily (as a single dose or in divided doses). You may adjust this based on how your child feels. It is best to stay on a maintenance dose to avoid becoming constipated, but if your child has have loose stools or diarrhea, your child should not take this medication.

**Side Effects** are rare but may cause diarrhea.

STOOL SOFTENER
- Colace (docusate sodium, DOK, D.O.S.)
Once your child goes home from the hospital after the transplant, call the pediatric nephrology clinic for further instruction if any of the following occur:

- Weight gain of more than 3 pounds within 24 hours if your child’s weight is over 100 pounds, more than 2 pounds in 24 hours if your child’s weight is between 60 and 100 pounds, or more than 1 pound in 24 hours if your child’s weight is less than 60 pounds
- Decrease in urine output
- Painful urination
- Blood in urine
- Kidney transplant tenderness or pain
- Systolic blood pressure (top number) less than 90 or greater than 140 if your child is older than 6 years of age OR less than 80 or greater than 120 if your child is 6 years of age or younger
- Heart rate less than 60 or greater than 130
- Irregular heart beat or palpitations
- Temperature greater than 100°F
- If diabetic, blood sugar less than 70 or greater than 200
- Dizziness or blackout spells
- Cough, trouble breathing, breathing fast, sore throat, chills, or mucus production
- Any episodes of vomiting
- Diarrhea; greater than 5 episodes within 24 hours
- Blood in bowel movements
- Any unexplained rash
- If you are unable to obtain any of your child’s medications
Below are some websites you may find useful in learning more about life after transplantation

<table>
<thead>
<tr>
<th>Website</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transplant Living</strong></td>
<td>Comprehensive website from the United Network for Organ Sharing that has useful information pertaining to before, during, and after your transplant.</td>
</tr>
<tr>
<td><a href="http://www.transplantliving.org">www.transplantliving.org</a></td>
<td></td>
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<tr>
<td><strong>International Transplant Nurses Society</strong></td>
<td>Great educational brochures on many different topics pertinent to transplant patients that you may find helpful.</td>
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<tr>
<td><strong>National Kidney Foundation</strong></td>
<td>The National Kidney Foundation website contains a variety of educational topics about life after transplantation. Our hospital participates in their annual kidney walk each October with our patients and families.</td>
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<tr>
<td><strong>MedAction Plan/MyMedSchedule</strong></td>
<td>Before you leave the hospital, you will receive a medication list generated using MedAction Plan. Once you get home, you can use their web-based tools to create reminders for yourself related to your medications.</td>
</tr>
<tr>
<td><strong>Transplant Experience</strong></td>
<td>Transplant Experience is a program that transplant candidates and recipients can join to learn more about transplantation and receive educational materials, newsletters, etc.</td>
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<tr>
<td><a href="http://www.transplantexperience.com">www.transplantexperience.com</a></td>
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</tbody>
</table>

Quick Reference: How to Contact Us

- **Transplant Appointments**: (212) 746-3020
- **Pediatric Nephrology Clinic**: (646) 962-4324
- **Off-Hours (answering service)**: (646) 962-4324
- **Emergency**: 911
## Additional Resources

<table>
<thead>
<tr>
<th>Website</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Kidney and Urology Foundation of America</strong></td>
<td>Comprehensive website aimed to help the kidney, urology, and transplant communities with resources, education, and recent news and events. Many of our children take advantage of their scholarships.</td>
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<tr>
<td>[<a href="http://www.kidneyurology.org/">http://www.kidneyurology.org/</a>]</td>
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<tr>
<td><strong>Make-A-Wish</strong></td>
<td>Children under 18 who are on dialysis or who receive kidney transplants are eligible for Make-A-Wish. This organization recognizes the difficulty of having a chronic, life-long disease and can help make your child’s wish come true.</td>
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<tr>
<td><a href="http://www.wish.org/">http://www.wish.org/</a></td>
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<tr>
<td><strong>Frost Valley Kidney Camp</strong></td>
<td>Frost Valley YMCA invites campers with chronic kidney disease to camp for a life-changing journey. Children who have received kidney transplants or who are on dialysis are able to participate in sleepover summer camp activities alongside their healthy peers.</td>
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<tr>
<td><a href="http://www.frostvalley.org/kidney">www.frostvalley.org/kidney</a></td>
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<td><strong>Donate Life America</strong></td>
<td>Donate Life America is a non-profit national alliance of organizations from the organ and tissue donation field committing to spread the word about the importance of donation. Here you can also join the organ donor registry in any state if you’d like to be a donate life upon your passing.</td>
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<tr>
<td><a href="http://www.donatelife.net">www.donatelife.net</a></td>
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<tr>
<td><strong>New York Organ Donor Network</strong></td>
<td>Offers volunteer opportunities for donors, transplant recipients, and their families to educate others about the importance of donation and transplantation.</td>
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<tr>
<td><a href="http://www.savelivesny.org">www.savelivesny.org</a></td>
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Visit our website for additional news and resources:

- [www.WeillCornellTransplant.org](http://www.WeillCornellTransplant.org)
- [www.facebook.com/CornellTransplant](http://www.facebook.com/CornellTransplant)
- [www.twitter.com/Cornell Kidney](http://www.twitter.com/Cornell Kidney)
WEEKLY TRACKING CHART
PLEASE FILL OUT EACH WEEK AND BRING WITH YOU TO YOUR CHILD’S CLINIC VISITS TO REVIEW WITH YOUR CHILD’S NEPHROLOGY DOCTOR

WEEK #

<table>
<thead>
<tr>
<th>WEEKLY TRACKING CHART</th>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
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<td>TEMPERATURE</td>
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<td>MORNING BLOOD PRESSURE</td>
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<td>EVENING BLOOD PRESSURE</td>
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<td>URINE VOLUME/NUMBER OF TIMES VOIDED</td>
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QUESTIONS FOR YOUR CHILD’S DOCTOR:

QUESTIONS FOR YOUR CHILD’S SOCIAL WORKER:

QUESTIONS FOR YOUR CHILD’S TRANSPLANT SURGEON:
Get Involved!

Join our team at the Annual Fall National Kidney Foundation walk!

Share your story! Inspire others with your transplant journey. We can share it in our social media, website, newsletter, and other outlets.

Support the transplant program! Lindsey celebrated the 1 year anniversary of her kidney transplant and asked attendees to make a contribution in support of NYP/Weill Cornell’s transplant program.

Look out for our pediatric events and support groups for a chance to connect with other young recipients.

Spread the word about the power of organ and tissue donation! Encourage others to consider giving the gift of life upon their passing by joining the donor registry at www.donatelifeline.net. You can also talk about the impact of living kidney donation. In addition, if you’d like any educational materials from our program to share at any events, or would like to discuss getting involved, please contact Jessica Melore at jem9173@nyp.org or (212) 746-3944.
What Can the Weill Cornell Transplant Program Offer You?

An Experienced, High-Volume Kidney and Pancreas Transplant Program

A Dedicated Team of Transplant Professionals

Experience with a Diverse Patient Population
*We transplant people of all ages, races, and with medical conditions such as heart disease, HIV, and Hepatitis C*

Personalization of Immune Therapy
*Thanks to the increasing number of anti-rejection medications available, we are able to personalize the regimens of our patients*

Long History Utilizing Cutting Edge Immune Therapy for Our Patients
*Steroid free maintenance regimen in over 75% of our patients*

New and Exciting Basic Science Research that Can be Applied at Your Bedside
*Non-invasive monitoring for rejection using urine tests*

Among the Largest National Experience with Living Donor Kidney Transplant Chains
*Enabling living donor kidney transplants for people who might otherwise wait a long time for a transplant from a deceased donor*

Largest National Experience with LaparoEndoscopic Single Site Surgery for Living Kidney Donors
*Surgery for Living Kidney Donors Now Uses Just One Incision*

Among the Shortest Waiting Times in the New York Region

Excellent Outcomes for Patient and Transplant

NewYork-Presbyterian is the #1 hospital in the New York metropolitan area, #7 hospital in the U.S., and the #3 kidney disease center in the U.S., according to the U.S. News & World Report 2012 “America’s Best Hospitals Survey”

Contact Us:
Weill Cornell Transplant Center
NewYork-Presbyterian Hospital
Weill Cornell Medical Center
525 East 68th Street, Box 98
New York, NY 10065

Telephone: 212.746.3099
Email: transplant@med.cornell.edu
Website: www.cornellsurgery.org/transplant

Updated 10/18/2013