PATIENT & CAREGIVER EDUCATION

Sirolimus (Conventional

This information from UpToDate® Lexidrug™ explains what you need to know about this medication, including what it's used for, how to take it, its side effects, and when to call your healthcare provider.

Brand Names: US

Rapamune [DSC]

Brand Names: Canada

Rapamune

Warning

- This drug may raise the chance of very bad and sometimes deadly infections. Talk with the doctor.
- Call your child's doctor right away if your child has any signs of infection like fever, chills, flu-like signs, very bad sore throat, ear or sinus pain, cough, more sputum or change in color of sputum, pain with passing urine, mouth sores, or a wound that will not heal.
- This drug may raise the chance of getting cancer like lymphoma or skin cancer. Call your child's doctor right away if your child has a change in color or size of a mole, a skin lump or growth, a big weight loss, night sweats, or swollen glands.
- This drug is not for use in people who have had liver or lung transplants. Very bad and sometimes deadly problems have happened in these people. Talk with the doctor.

What is this drug used for?

- It is used after a kidney transplant to keep the body from rejecting the kidney.

- It is used to treat a lung disease called lymphangioleiomyomatosis (LAM).
- It may be given to your child for other reasons. Talk with the doctor.

What do I need to tell the doctor BEFORE my child takes this drug?

- If your child is allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell the doctor about the allergy and what signs your child had.
- If your child is taking any of these drugs: Clarithromycin, erythromycin, itraconazole, ketoconazole, rifabutin, rifampin, telithromycin, or voriconazole.
- If your child is taking cannabidiol or a drug like it, or using marijuana, another form of cannabis.

This is not a list of all drugs or health problems that interact with this drug.

Tell the doctor and pharmacist about all of your child's drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe to give this drug with all of your child's other drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking with the doctor.

What are some things I need to know or do while my child takes this drug?

- Tell all of your child's health care providers that your child is taking this drug. This includes your child's doctors, nurses, pharmacists, and dentists.
- High blood pressure has happened with this drug. Have your child's blood pressure checked as you have been told by the doctor.
- This drug may cause high cholesterol and triglyceride levels. Talk with the doctor.
- Have your child's blood work and other lab tests checked as you have been told by the doctor.
- High blood sugar has happened with this drug. This includes diabetes that is new or worse.
- Check your child's blood sugar as you have been told by the doctor.
- Your child may have more chance of getting infections. Have your child wash hands often. Avoid crowds and people with infections, colds, or flu.
- Your child may bleed more easily. Make sure your child is careful and avoids injury. Be sure your child has a soft toothbrush.
- There is a chance of skin cancer. Have your child avoid

lots of sun, sunlamps, and tanning beds. Use sunscreen and dress your child in clothing and eyewear that protects your child from the sun.

- Talk with the doctor before your child gets any vaccines. Use of some vaccines with this drug may either raise the chance of very bad infection or make the vaccine not work as well.
- Avoid giving your child grapefruit and grapefruit juice.

If your child is or may be sexually active:

- This drug may affect fertility. Fertility problems may lead to not being able to get pregnant or father a child. If you plan to get pregnant or father a child, talk with your doctor before taking this drug.
- This drug may cause harm to the unborn baby if your child takes it during pregnancy.
- If your child may become pregnant, birth control must be used while taking this drug and for 12 weeks after your child's last dose. If your child gets pregnant, call the doctor right away.
- Talk with the doctor if your child is breast-feeding a baby or plans to breast-feed a baby.

What are some side effects that I need to call my child's doctor about right away?

WARNING/CAUTION: Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child's doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat.
- Signs of high blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- Signs of low potassium levels like muscle pain or weakness, muscle cramps, or a heartbeat that does not feel normal.
- Signs of high blood sugar like confusion, feeling sleepy, unusual thirst or hunger, passing urine more often, flushing, fast breathing, or breath that smells like fruit.
- Chest pain or pressure.
- A fast heartbeat.
- Feeling very tired or weak.

- Swelling in the arms or legs.
- Any unexplained bruising or bleeding.
- This drug may affect how wounds heal. If your child has surgery, you may need to stop giving this drug before surgery. Start giving it again after surgery as you are told by the doctor. Call the doctor right away if your child has a wound that does not heal or any other wound problems.
- Call the doctor right away if your child has signs of a blood clot like chest pain or pressure; coughing up blood; shortness of breath; swelling, warmth, numbness, change of color, or pain in a leg or arm; or trouble speaking or swallowing.
- Some people have had lung problems with this drug. Sometimes, this has been deadly. Call your child's doctor right away if your child has signs of lung problems like shortness of breath or other trouble breathing, cough that is new or worse, or fever.
- A severe brain problem called progressive multifocal leukoencephalopathy (PML) may happen with this drug. It may cause disability or death. Tell the doctor right away if your child has signs like confusion, memory problems, depression, change in the way your child acts, change in strength on 1 side is greater than the other,

trouble speaking or thinking, change in balance, or change in eyesight.

- Some people treated with this drug have had very bad kidney problems caused by a certain viral infection (BK virus). In people who have had a kidney transplant, BK virus infection may cause loss of the kidney. Call the doctor right away if your child has signs of kidney problems like change in the amount of urine passed, trouble passing urine, pain when passing urine, or blood in the urine.
- Very bad and sometimes deadly blood problems like thrombotic thrombocytopenic purpura/hemolytic uremic syndrome (TTP/HUS) have happened with this drug in some people. Call your child's doctor right away if your child feels very tired or weak or has any bruising or bleeding; dark urine or yellow skin or eyes; pale skin; change in the amount of urine passed; change in eyesight; change in strength on 1 side is greater than the other, trouble speaking or thinking, or change in balance; or fever.
- Liver problems have rarely happened with this drug. Sometimes, this has been deadly. Call your child's doctor right away if your child has signs of liver problems like dark urine, tiredness, decreased appetite, upset stomach or stomach pain, light-colored stools, throwing

up, or yellow skin or eyes.

If your child has menstrual periods:

- Period (menstrual) changes.

What are some other side effects of this drug?

All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child's doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:

- Dizziness or headache.
- Constipation, diarrhea, stomach pain, or upset stomach.
- Muscle or joint pain.
- Pimples (acne).
- Nose or throat irritation.
- Mouth irritation or mouth sores.

These are not all of the side effects that may occur. If you have questions about side effects, call your child's doctor. Call your child's doctor for medical advice about side effects.

You may report side effects to your national health agency.

How is this drug best given?

Give this drug as ordered by your child's doctor. Read all information given to you. Follow all instructions closely.

All products:

- Give this drug with or without food but give it the same way each time. Always give with food or always give on an empty stomach.
- Keep giving this drug to your child as you have been told by your child's doctor or other health care provider, even if your child feels well.
- If your child is taking cyclosporine, give it to your child at least 4 hours before giving this drug.

Tablets:

- Have your child swallow whole. Do not let your child chew, break, or crush.
- If your child has trouble swallowing, talk with the doctor.

Oral solution:

- Put at least 2 ounces ($^1/_4$ cup or 60 mL) of water or orange juice into a glass or plastic container. Do not mix with other liquids.
- Measure this drug in the oral dose syringe. Empty drug from syringe into cup. Mix well and have your child drink.

- Fill container again with at least 4 ounces ($^1/_2$ cup or 120 mL) of water or orange juice. Mix well and have your child drink.
- After mixing, give your child's dose right away. Do not store for future use.
- Throw syringe away after use. Do not use the same syringe more than one time.
- If you get this drug on the skin, wash it off right away with soap and water.
- If this drug gets in the eyes, rinse with cool water.

What do I do if my child misses a dose?

- Give a missed dose as soon as you think about it.
- If it is close to the time for your child's next dose, skip the missed dose and go back to your child's normal time.
- Do not give 2 doses at the same time or extra doses.

How do I store and/or throw out this drug?

Tablets:

- Store at room temperature protected from light. Store in a dry place. Do not store in a bathroom.
- Do not take this drug out of the blister pack until you are ready to give this drug to your child. Give this drug right away after opening the blister pack. Do not store the

removed drug for future use.

Oral solution:

- Store in a refrigerator. Do not freeze.
- Protect from light.
- After opening, throw away any part not used after 1 month.
- This drug may also be stored at room temperature. If stored at room temperature, throw away any part not used after 15 days.
- Liquid (solution) may look hazy when refrigerated. Bring to room temperature and shake gently until haze goes away.
- Liquid (solution) in an amber colored syringe (comes with this drug) may be stored at room temperature or in a refrigerator for up to 24 hours.

All products:

- Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be

drug take-back programs in your area.

General drug facts

- If your child's symptoms or health problems do not get better or if they become worse, call your child's doctor.
- Do not share your child's drug with others and do not give anyone else's drug to your child.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your child's doctor, nurse, pharmacist, or other health care provider.
- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

Consumer Information Use and Disclaimer

This generalized information is a limited summary of diagnosis, treatment, and/or medication information. It is not meant to be comprehensive and should be used as a tool to help the user understand and/or assess potential diagnostic and treatment options. It does NOT include all information about conditions, treatments, medications, side effects, or risks that may apply to a specific patient. It is not intended to be medical advice or a substitute for the medical advice, diagnosis, or treatment of a health care

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If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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