

Sirolimus

Care Team Contact Information: _____

Pharmacy Contact Information: _____

Diagnosis: _____

- This treatment is often used for
 - Graft-versus-host disease (GVHD)
 - Certain types of soft tissue sarcoma
- It may also be used for other reasons.

Goal of Treatment: _____

- Treatment may continue for a certain time period, until it no longer works, or until side effects are no longer controlled.

Treatment Regimen

Treatment Name	How the Treatment Works	How the Treatment is Given
Sirolimus (sih-ROH-lih-mus): Rapamune (RA-puh-MYOON)	For GVHD: Prevents donor immune cells (T-cells) from attacking your body. For soft tissue sarcomas: Slows down or stops the growth of cancer cells by blocking specific proteins that helps them survive.	<ul style="list-style-type: none"> • Tablet(s) taken by mouth. • Solution taken by mouth.

Treatment Administration and Schedule

Your sirolimus dosing instructions:

- Sirolimus comes in 3 tablet strengths (0.5 mg, 1 mg and 2 mg) and 1 solution strength (1 mg/mL). Your care team will tell you which tablets or how many milliliters to take (if using the solution) and may change your dose if needed.
- Your dose is based on many factors, including overall health and diagnosis. Your dose may also be changed to keep the sirolimus level in your blood within a specific range, which will be determined by your care team.
- If using the sirolimus solution, mix with at least 60 mL of water or orange juice. Stir well. Do not use with any other liquids to mix solution. Once solution is mixed, drink immediately and refill cup with another 120 mL of water or orange juice to drink again.
- Take sirolimus with or without food. Take it at the same time and way each day. If you take it with food, always take it with food. If you take it on an empty stomach, always take it on an empty stomach.

Treatment Administration and Schedule (Continued)

- Swallow sirolimus tablets whole. Do not chew, split, or crush sirolimus tablets. Tell your care team if you cannot swallow sirolimus tablets. Your care team can prescribe sirolimus as a solution.
- If you take too much of sirolimus, call your care team right away.

Storage and Handling of Sirolimus

- Store sirolimus tablets at room temperature between 68°F and 77°F (20°C and 25°C) in a dry location away from light.
- Store sirolimus oral solution in the refrigerator between 36°F and 46°F (2°C and 8°C). Protect from light. After a bottle of sirolimus oral solution is opened, it should be used within 1 month. If necessary, bottles of sirolimus oral solution can be stored room temperature up to 77°F (25°C) for up to 15 days.
- If someone else is giving you your medication, they should wear gloves or pour the pills directly from the bottle into the cap, a small cup, or your hand without touching them. They should wash their hands before and after handling the pills.
- People who are or may become pregnant should wear gloves when handling sirolimus.
- Keep sirolimus and all medicines out of the reach of children and pets.
- Ask your care team how to safely throw away any unused sirolimus.

Appointments

Appointments may include regular check-ups with your care team, lab visits, and imaging tests. It's important to keep your appointments whenever you can. If you miss any appointments, call your care provider as soon as possible to reschedule your appointment.

Supportive Care to Prevent and Treat Side Effects

Description	Supportive Care Given at the Clinic or Hospital	Supportive Care Taken at Home
To help lower risk of infections	<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>
Other	<hr/> <hr/> <hr/>	<hr/> <hr/> <hr/>

Common Side Effects

Side Effect	Important Information
<p>Infection (Boxed Warning)</p>	<p>Description: Treatment may increase your chance of getting an infection.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Wash your hands often and bathe regularly. • Avoid crowded places and close contact with people who are sick. • Keep any catheter/port site clean and dry. Follow all instructions provided by your care team. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Fever of 100.4°F (38°C) or higher • Chills • New or worsening cough or sore throat • Painful urination or signs of a urinary infection • Feeling much more tired than usual • Red, swollen, warm, or painful areas on the skin (possible skin infection)
<p>Low Platelet Count (Thrombocytopenia)</p>	<p>Description: Platelets help your blood clot and wounds heal. A low platelet count increases your risk of bruising and bleeding.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Blow your nose gently and avoid picking it. • Brush your teeth gently with a soft toothbrush and keep good oral hygiene. • Use an electric razor for shaving and a nail file instead of nail clippers. • Avoid over-the-counter medicines that can increase bleeding risk (for example, nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen). • Talk with your care team or dentist before medical or dental procedures — you may need to pause treatment. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • A nosebleed lasting more than 5 minutes despite pressure • A cut that continues to bleed • Heavy gum bleeding when brushing or flossing • Sudden or severe headache • Blood in your urine or stool • Blood in your spit after coughing
<p>Low Red Blood Cell (RBC) Count and Hemoglobin (Hgb) (Anemia)</p>	<p>Description: RBCs and Hgb carry oxygen to your body’s tissues and remove carbon dioxide. Low RBC or Hgb (anemia) can make you feel weak, very tired, or look pale.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Aim for 7 to 8 hours of sleep each night. • Do not drive, operate heavy machinery, or do other dangerous activities if you are very tired. • Balance activity and rest — stay as active as you can, but rest when needed. • Eat a balanced diet and follow any nutrition or supplement advice from your care team. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Shortness of breath • Dizziness or fainting • Fast or irregular heartbeats • Sudden or severe headache

<p>High Blood Pressure (Hypertension)</p>	<p>Description: High blood pressure means the force of blood against your artery walls is too high. Treatment can raise your blood pressure or make it harder to control.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Exercise regularly, control your weight, and limit alcohol and salt (sodium). • Take blood pressure medicines as prescribed. Your care team may change your medicines if needed. • Your care team may ask you to check and record your blood pressure at home. Bring readings to appointments. • Follow diet and lifestyle advice from your care team. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Severe or new headaches • Dizziness or lightheadedness • Blurred vision • Trouble breathing • Nosebleeds that do not stop • A pounding sensation in your chest, neck, or ears • Irregular or fast heartbeats • Chest pain or pressure
<p>High Triglyceride Levels (Hypertriglyceridemia)</p>	<p>Description: Triglycerides are a type of fat found in your blood. High triglycerides usually do not cause symptoms, but very high levels may increase your risk for pancreas or heart problems over time.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Adopt a diet low in saturated and trans fats, increase fiber intake, and engage in regular physical activity. • Maintain a healthy weight. • Get regular triglyceride tests and inform the care team of any significant changes. • Do not smoke and limit alcohol consumption. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Symptoms of heart attack or stroke, such as sudden numbness, weakness, or chest pain
<p>Constipation</p>	<p>Description: Constipation means hard, dry stools or fewer bowel movements than normal. It can cause discomfort or pain.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Track how often you have bowel movements each day. • Drink 8 to 10 glasses of fluids daily, unless your care team says otherwise. • Stay active and exercise regularly. • Eat more high-fiber foods (such as raw fruits, vegetables, and whole grains) unless advised otherwise. • Your care team may recommend laxatives such as polyethylene glycol (Miralax) or senna. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Constipation lasting 3 or more days • No bowel movement 48 hours after using a laxative

<p>Pain</p>	<p>Description: Pain is an uncomfortable feeling that can happen anywhere in your body and can vary in intensity. It can be sharp, throbbing, aching, or burning, and it may feel like a discomfort or pressure.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Keep a pain diary to track the frequency, duration, and intensity of your pain. • Your care team may recommend medicines for pain. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Uncontrolled pain
<p>Muscle or Joint Pain</p>	<p>Description: Muscle pain is soreness, aching, cramps, stiffness, tenderness, or weakness in one or more muscles. Joint pain is pain, stiffness, swelling, or reduced movement where two bones meet.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Keep a pain diary: note pain levels, locations, and activities that make it better or worse. • Do gentle exercise (walking, stretching, yoga) to maintain mobility and strength. Check with your care team before starting a new activity. • Use a warm compress for stiff muscles or a cold pack to reduce swelling and numb pain—use what helps the area. • Your care team may recommend or prescribe medicines, including over-the-counter pain relievers. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Pain you cannot control with usual measures • Swelling, redness, or warmth in a joint • New weakness • Trouble walking or moving
<p>Kidney Problems</p>	<p>Description: Treatment can cause kidney problems, including damage to the kidneys and decreased kidney function. Your care team will monitor your kidney function during treatment.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> • Drink 8 to 10 glasses of water each day, unless your care team tells you otherwise. • Your care team may give you fluids and electrolytes with your treatment. <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> • Decrease in your amount of urine • Blood in your urine • Swelling of your ankles • Loss of appetite

Select Rare Side Effects

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms
Allergic Reactions, Including Anaphylaxis	<p>Get emergency medical help right away if you develop any of the following signs or symptoms:</p> <ul style="list-style-type: none"> • Swelling of your lips, mouth, tongue, or throat • Trouble breathing or swallowing • Raised red areas on your skin (hives) • A very fast heartbeat • You feel dizzy or faint
Lung Problems	<ul style="list-style-type: none"> • Cough • Shortness of breath • Chest pain
Your Body May Hold Too Much Fluid (Fluid Retention) Leading to Swelling (Edema)	<ul style="list-style-type: none"> • Swelling in you face, ams, legs, ankles, or feet • Weight gain from swelling
Veno-Occlusive Disease/Sinusoidal Obstruction Syndrome (VOD/SOS)	<p>In people who are receiving treatment with sirolimus for GVHD, sirolimus can increase the risk of veno-occlusive disease (VOD). VOD, also called sinusoidal obstruction syndrome (SOS), is a serious condition where the tiny blood vessels in the liver become blocked and inflamed. This blockage prevents the liver from filtering waste properly, leading to liver swelling, weight gain, and fluid buildup in the belly.</p> <ul style="list-style-type: none"> • Sudden weight gain • Stomach-area (abdominal) swelling • Discomfort in upper right side of the abdomen (under the ribs) where the liver is located • Yellowing of the skin and the whites of the eyes (jaundice)
Transplant-Associated Thrombotic Microangiopathy (TA-TMA)	<p>If you are taking sirolimus with a calcineurin inhibitor (such as cyclosporine or tacrolimus) for GVHD, you may be at an increased risk of TA-TMA. TA-TMA is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs, and may lead to death.</p> <p>Get medical help right away if you get any of the following signs or symptoms during treatment:</p> <ul style="list-style-type: none"> • Confusion • Weakness • Swelling of arms and legs • Yellowing of skin and eyes • Stomach (abdomen) or back pain • Nausea or vomiting • Feeling sick • Decreased urination
Risk of New Cancers	<p>There is an increased risk of developing new cancers like lymphoma or skin cancer. Talk with your care team about this risk and ask about the signs and symptoms of new cancers.</p>

**Before starting treatment, ask your care team when to call 9-1-1 or seek emergency help.
If you experience any new, worsening, or uncontrolled side effects, contact your care team immediately.**

Intimacy, Pregnancy, and Breastfeeding

- Treatment may **change how you feel about intimacy and your body**. However, physical closeness—such as holding hands and hugging—remains safe. It is common to have questions about intimacy. If needed, talk to your care team for guidance.
- Treatment may **harm an unborn baby**.
 - If you are able to become pregnant, take a pregnancy test before starting treatment.
 - Use an effective method of birth control during treatment and for 12 weeks after your last dose of sirolimus.
 - If you think you might be pregnant or if you become pregnant, tell your care team right away.
 - If your partner is able to become pregnant, use an effective method of birth control—such as condoms—during treatment and for 12 weeks after your last dose of sirolimus.
- Sirolimus **may be safe during breastfeeding**. Talk with your care team if you are breastfeeding or plan to breastfeed.

Additional Information

- **Tell your care team about all the medicines you take**. This includes prescriptions, over-the-counter drugs, vitamins, and herbal products. Before starting any new medicine, supplement, or vaccine, ask your care team first.
 - You should not receive a live vaccine during treatment with sirolimus. Talk with your care team if you have questions about whether a vaccine is a live vaccine.
- **You should not drink grapefruit juice or eat grapefruit during treatment with sirolimus**. Grapefruit may increase the amount of sirolimus in your blood.
- **Wound healing problems**. Wound healing problems have happened in some people who take sirolimus. Tell your care team if you plan to have any surgery before or during treatment with sirolimus.
- **This Patient Education Sheet may not describe all possible side effects**.
Call your care team for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

Notes

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Scan the QR code below to access this education sheet.



Important notice: The Association of Cancer Care Centers (ACCC), Hematology/Oncology Pharmacy Association (HOPA), Network for Collaborative Oncology Development & Advancement, Inc. (NCODA), and Oncology Nursing Society (ONS) have collaborated in gathering information for and developing this patient education guide. This guide represents a brief summary of the medication derived from information provided by the drug manufacturer and other resources.

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