

# Sirolimus Protein-Bound Particles

Care Team Contact Information: \_\_\_\_\_

Pharmacy Contact Information: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

- This treatment is often used for malignant perivascular epithelioid cell tumors (PEComa), but it may also be used for other uses.

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 Protein-Bound Particles (sih-ROH-lih-mus PROH-teen-bownd PAR-tih-kulz): Fyarro (fy-AR-oh)	Slows down or stops the growth of cancer cells by blocking specific proteins that help them survive.	Infusion given into a vein.

**Treatment Administration and Schedule:** Treatment is typically repeated every 3 weeks. This length of time is called a “cycle”.

- You will receive sirolimus protein-bound particles on Days 1 and 8 of each cycle.
- Your care team may monitor you after your treatment.

Treatment Name	Cycle 1								Next Cycle
	Day 1	Day 2	Day 3	...	Day 8	Day 9	...	Day 21	
Sirolimus Protein-Bound Particles	✓				✓				✓

**Appointments:** Appointments may include regular check-ups with your care team, treatment appointments, 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 prevent or treat nausea and vomiting		
To help prevent mouth sores		
Other		

## Common Side Effects

Side Effect	Important Information
Low White Blood Cell (WBC) Count and Increased Risk of Infection	<p>Description: WBCs help protect the body against infections. If you have a low WBC count, you may be at a higher risk of infection.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Wash your hands and bathe regularly.</li> <li>Avoid crowded places.</li> <li>Stay away from people who are sick.</li> <li>Your care team may prescribe a drug that promotes the growth of WBCs.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Fever of 100.4 °F (38°C) or higher</li> <li>Chills</li> <li>Cough</li> <li>Sore throat</li> <li>Painful urination</li> <li>Tiredness that is worse than normal</li> <li>Skin infections (red, swollen, or painful areas)</li> </ul>
Low Platelet Count	<p>Description: Platelets help the blood clot and heal wounds. If you have low platelet counts, you are at a higher risk of bruising and bleeding.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Blow your nose gently and avoid picking it.</li> <li>Brush your teeth gently with a soft toothbrush and maintain good oral hygiene.</li> <li>Use an electric razor for shaving and a nail file instead of nail clippers.</li> <li>Avoid over-the-counter medications that may increase the risk of bleeding, such as NSAIDs.</li> <li>Talk with your care team or dentist before medical or dental procedures, as you may need to pause your treatment.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Nosebleed lasting over 5 minutes despite pressure</li> <li>Cut that continues to bleed</li> <li>Significant gum bleeding when flossing or brushing</li> <li>Severe headaches</li> <li>Blood in your urine or stool</li> <li>Blood in your spit after a cough</li> </ul>
Low Red Blood Cell (RBC) Count and Hemoglobin (Hgb)	<p>Description: RBCs and Hgb help bring oxygen to your body's tissues and take away carbon dioxide. If you have low RBC counts or Hgb, you may feel weak, tired, or look pale.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Get 7 to 8 hours of sleep each night.</li> <li>Avoid operating heavy machinery when tired.</li> <li>Balance work and rest, staying active but resting when needed.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Shortness of breath</li> <li>Dizziness</li> <li>Fast or abnormal heartbeats</li> <li>Severe headache</li> </ul>

Fatigue	<p>Description: Fatigue is a constant and sometimes strong feeling of tiredness.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Routine exercise has been shown to decrease levels of fatigue. Work with your care team to find the right type of exercise for you.</li> <li>Ask your family and friends for help with daily tasks and emotional support.</li> <li>Try healthy ways to feel better, like meditation, writing in a journal, doing yoga, and using guided imagery to lower anxiety and feel good.</li> <li>Make a regular sleep schedule and limit naps during the day so you can sleep better at night, aiming for 7 to 8 hours of sleep.</li> <li>Don't use heavy machines or do things that need your full attention if you're very tired to avoid accidents.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Tiredness that affects your daily life</li> <li>Tiredness all the time, and it doesn't get better with rest</li> <li>Dizziness and weakness, along with being tired</li> </ul>
Swollen Arms, Hands, Feet, Ankles, Face, or Other Parts of the Body	<p>Description: Swelling and fluid retention can occur in different areas of the body, like the arms, hands, feet, ankles, or face. You might notice areas feel puffy or tighter than usual.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Keep a daily log of swelling and note any changes in size or location.</li> <li>Elevate swollen limbs when resting.</li> <li>Limit salt intake.</li> <li>Stay active with regular, gentle exercises.</li> <li>Avoid prolonged periods of sitting or standing without movement.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Swelling that suddenly worsens or spreads to other areas</li> <li>Pain, redness, or warmth in the affected area</li> <li>Signs of shortness of breath or difficulty breathing</li> <li>Swelling is persistent and does not improve with home management</li> <li>Unexpected weight gain</li> </ul> <p>Note: Your care team may ask you to contact them if your weight increases by a certain amount over a certain time period</p>

Mouth Irritation and Sores	<p>Description: This treatment can irritate the lining of the mouth. In some cases, this can cause redness, sores, pain, and swelling.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Rinse your mouth after meals and at bedtime, and more often if sores develop.</li> <li>Brush your teeth with a soft toothbrush or cotton swab after meals.</li> <li>Use a mild, non-alcohol mouth rinse at least four times daily (after meals and at bedtime). A simple mixture is 1/8 teaspoon salt and 1/4 teaspoon baking soda in 8 ounces of warm water.</li> <li>Avoid acidic, hot, spicy, or rough foods and drinks that may irritate your mouth.</li> <li>Avoid tobacco, alcohol, and alcohol-based mouthwashes.</li> <li>Your care team may prescribe medicine for these symptoms.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Pain or sores in your mouth or throat</li> </ul>
Taste Changes	<p>Description: Taste changes, such as loss of taste or taste sensitivity, may occur. Foods that used to taste good may no longer be appealing or certain tastes, such as metallic tastes, may become more noticeable.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Choose appealing foods based on appearance and smell.</li> <li>Use plastic utensils if food tastes metallic.</li> <li>Add spices or juices to enhance food flavors.</li> <li>Suck on mints or chew gum to improve taste.</li> <li>Brush your teeth before and after eating with a soft toothbrush.</li> <li>Avoid smoking.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Trouble eating</li> <li>Weight loss</li> </ul>

Low Appetite and Weight Loss	<p>Description: Treatment can cause a low appetite, which means you may not feel like eating much. It's important to eat enough so your body gets the nutrients it needs to heal and stay strong. Eating healthy foods helps you feel better and recover faster.</p> <p>Recommendations:</p> <ul style="list-style-type: none"><li>• Be as active as possible. Do some physical activity before a meal. Before starting an exercise program, talk with your care team.</li><li>• Take note of the times during the day when your appetite is best. Do not limit food when your appetite is good. Eat your largest meal when you feel the most hungry, whether it is breakfast, lunch, or dinner.</li><li>• Eat 5-6 small meals per day and snack anytime.</li><li>• Choose foods high in protein, such as beans, chicken, fish, meat, yogurt, tofu, and eggs. During meals, eat high-protein foods first.</li><li>• Choose foods that are high in calories. Do not select foods that are labeled "low-fat," "fat-free" or "diet."</li><li>• If you feel full quickly when eating, do not drink any liquids 30 minutes before a meal so you have more room for solid food. Then, drink liquids between meals. Choose liquids with extra calories, not diet drinks.</li><li>• Eat a bedtime snack. Choose something easy to digest, such as peanut butter and crackers. If you tend to experience reflux or heartburn, eat at least an hour before lying down.</li><li>• If food is not appealing, try a nutritious beverage, such as a high-protein shake or smoothie, instead of solid food.</li><li>• Ask your care team to recommend a liquid nutrition supplement. Add a scoop of protein powder, yogurt, or ice cream for added protein and calories.</li></ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"><li>• Weight loss</li><li>• No appetite</li><li>• Tiredness</li></ul>
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Nausea and Vomiting	<p>Description: Nausea is an uncomfortable feeling in your stomach or the need to throw up. This may or may not cause vomiting.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Eat smaller, more frequent meals.</li> <li>• Avoid fatty, fried, spicy, or highly sweet foods.</li> <li>• Eat bland foods at room temperature and drink clear liquids.</li> <li>• If you vomit, start with small amounts of water, broth, or other clear liquids when you are ready to eat again. If that stays down, then try soft foods (such as gelatin, plain cornstarch pudding, yogurt, strained soup, or strained cooked cereal). Slowly work up to eating solid food.</li> <li>• Your care team may prescribe medicine for these symptoms.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Vomiting for more than 24 hours</li> <li>• Vomiting that's nonstop</li> <li>• Signs of dehydration (like feeling very thirsty, having a dry mouth, feeling dizzy, or having dark urine)</li> <li>• Blood or coffee-ground-like appearance in your vomit</li> <li>• Bad stomach pain that doesn't go away after vomiting</li> </ul>
Diarrhea	<p>Description: Diarrhea is when you have loose, watery bowel movements more often than usual. The need to use the bathroom may occur urgently.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>• Keep track of how many times you go to the bathroom each day.</li> <li>• Drink 8 to 10 glasses of water or other fluids every day, unless your care team tells you otherwise.</li> <li>• Eat small meals of mild, low-fiber foods like bananas, applesauce, potatoes, chicken, rice, and toast.</li> <li>• Avoid eating foods with high fiber (like raw vegetables, fruits, and whole grains), foods that cause gas (like broccoli and beans), dairy foods (like yogurt and milk), and spicy, fried, and greasy foods.</li> <li>• Your care team may recommend medicine (such as loperamide) for diarrhea.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• 4 or more bowel movements than normal in 24 hours</li> <li>• Dizziness or lightheadedness while having diarrhea</li> <li>• Bloody diarrhea</li> </ul>
Liver Problems	<p>Description: Treatment can harm your liver. This may cause nausea, stomach pain, and bleeding or bruising. It can also turn your skin and eyes yellow and make your urine dark. Lab tests may be performed to monitor liver function.</p> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>• Yellowing of your skin or the whites of your eyes</li> <li>• Severe nausea or vomiting</li> <li>• Pain on the right side of your stomach area (abdomen)</li> <li>• Dark urine (tea colored)</li> <li>• Bleeding or bruising more easily than normal</li> </ul>	

Kidney Problems	<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"> <li>Drink 8 to 10 glasses of water or other fluids each day, unless your care team tells you otherwise.</li> <li>Your care team may give you fluids and electrolytes with your treatment.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Decrease in your amount of urine</li> <li>Blood in your urine</li> <li>Swelling of your ankles</li> <li>Loss of appetite</li> </ul>
Muscle and Joint Pain	<p>Description: Muscle pain feels like soreness, aches, cramps, or stiffness in one or more muscles. It may also include tenderness or weakness. Joint pain happens where two bones come together and can feel sharp, dull, throbbing, or burning. It often causes stiffness, swelling, and difficulty moving.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Track your pain levels, areas of discomfort, and any activities that worsen or improve your symptoms.</li> <li>Engage in gentle exercises like walking, stretching, or yoga to maintain mobility and strength, but consult your care team before starting any new exercise routine.</li> <li>Apply a warm compress to relax stiff muscles or use cold packs to reduce swelling and numb pain in affected areas.</li> <li>Your care team may prescribe or recommend medications, including over-the-counter pain relievers.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Uncontrolled muscle or joint pain</li> <li>Swelling, redness, or warmth in the joints</li> <li>Weakness</li> <li>Difficulty walking or moving</li> </ul>
Cough	<p>Description: A cough is a reflex action that forcefully expels air from the lungs to clear the airways of irritants or mucus.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Tell your care team what your cough feels like and when it happens.</li> <li>Use a humidifier and drink plenty of water.</li> <li>Keep your house clean by dusting and vacuuming regularly</li> <li>Avoid exposure to smoke or strong chemicals.</li> <li>Your care team may recommend medicine for cough.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Trouble breathing</li> <li>Chest pain or tightness</li> <li>Coughing up blood</li> </ul>

Rash	<p>Description: Rash can cause symptoms like redness, swelling, and varying bumps, such as small red spots, welts, or patches.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Keep your skin moisturized with creams or lotions to reduce rash and itchiness; wear loose-fitting clothing.</li> <li>Avoid perfumes and colognes, as they may worsen rash symptoms.</li> <li>Limit time spent in heat to prevent worsening symptoms.</li> <li>Avoid sun exposure, especially between 10 AM and 4 PM, to lower the risk of sunburn.</li> <li>Wear long-sleeved clothing with UV protection and broad-brimmed hats.</li> <li>Apply broad-spectrum sunscreen (UVA/UVB) with at least SPF 30 as directed.</li> <li>Use lip balm that contains at least SPF 30.</li> <li>Avoid tanning beds.</li> <li>Your care team may recommend medicines for symptoms.</li> </ul>	Talk to your care team if you have:	<ul style="list-style-type: none"> <li>Rash or itching that continues to worsen</li> </ul>
High Cholesterol and Triglyceride Levels	<p>Description: Treatment can raise the levels of cholesterol and triglycerides in your blood. While cholesterol is needed by the body, high levels can be harmful and may lead to heart issues. 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"> <li>Adopt a diet low in saturated and trans fats, increase fiber intake, and engage in regular physical activity.</li> <li>Maintain a healthy weight.</li> <li>Get regular cholesterol and triglyceride tests and inform the care team of any significant changes.</li> <li>Do not smoke and limit alcohol consumption.</li> </ul>	Talk to your care team if you have:	<ul style="list-style-type: none"> <li>Symptoms of heart attack or stroke, such as sudden numbness, weakness, or chest pain</li> </ul>
Low Blood Potassium and Magnesium	<p>Description: Treatment may decrease the levels of potassium and magnesium in your blood. Your care team will regularly monitor your potassium, magnesium, and other electrolyte levels (salts) throughout your treatment.</p> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Muscle weakness, cramps, tightness, or twitching</li> <li>Loss of appetite, nausea, vomiting, or constipation</li> <li>Frequent headaches or migraines</li> <li>Fatigue</li> <li>Irregular heartbeats</li> </ul>		

## Select Rare Side Effects

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms
Lung Problems	<ul style="list-style-type: none"> <li>Cough</li> <li>Shortness of breath</li> <li>Chest pain</li> </ul>
High Blood Sugar	<ul style="list-style-type: none"> <li>Frequent urination</li> <li>Drowsiness</li> <li>Increased thirst</li> <li>Loss of appetite</li> <li>Blurred vision</li> <li>Fruity smell on your breath</li> <li>Confusion</li> <li>Nausea, vomiting, or stomach pain</li> <li>It becomes harder to control your blood sugar</li> </ul>
Infusion Reactions	<ul style="list-style-type: none"> <li>Chills or shaking</li> <li>Itching, rash, or flushing</li> <li>Trouble breathing or wheezing; tongue-swelling</li> <li>Dizziness or feeling faint</li> <li>Fever of 100.4°F (38°C) or higher</li> <li>Pain in your back or neck</li> </ul>

**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, Fertility, 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 can affect your **ability to have children**. It may damage your reproductive organs or stop them from working. If you are worried about fertility, talk to your care team before starting treatment.
- 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.
  - If you think you might be pregnant or if you become pregnant, tell your care team right away.
  - If your partner(s) could become pregnant, use an effective method of birth control—such as condoms—during treatment and for 12 weeks after your last dose.
- Do NOT breastfeed** during treatment and for 2 weeks after your last dose.

## Handling Body Fluids and Waste

Some drugs you receive may stay in your urine, stool, sweat, or vomit for many days after treatment. Because many cancer drugs are toxic, your body waste may also be dangerous to touch. To help protect yourself, your loved ones, and the environment, **follow these instructions** for at least **12 days** after each dose of **sirolimus protein-bound particles**:

- People who are pregnant should avoid touching anything that may be soiled with body fluids from the patient.
- You can use your usual toilet. Always close the lid and flush to discard all waste. If you have a low-flow toilet, flush twice.
- If the toilet or seat is soiled with urine, stool, or vomit, clean the surface after each use before others use it.
- Wash your hands with soap and water for at least 20 seconds after using the toilet.
- If you need a bedpan, inform your caregiver so they can wear gloves and assist with cleanup. Wash the bedpan with soap and water daily.
- If you cannot control your bladder or bowels, use a disposable pad with a plastic back, a diaper, or a sheet to absorb waste.
- Wash any skin exposed to body waste with soap and water.
- Wash soiled linens or clothing separately from other laundry. If you don't have a washer, place them in a plastic bag until they can be washed.
- Wash your hands with soap and water after touching soiled linens or clothing.

## 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.

- **Do not drink grapefruit juice or eat grapefruit.** Grapefruit may increase the amount of sirolimus in your blood.
- **This Patient Education Sheet may not describe all possible side effects.**

Call your healthcare provider 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.

This guide does not cover all existing information related to the possible uses, directions, doses, precautions, warnings, interactions, adverse effects, or risks associated with this medication and should not substitute for the advice of a qualified healthcare professional. Provision of this guide is for informational purposes only and does not constitute or imply endorsement, recommendation, or favoring of this medication by ACCC, HOPA, NCODA, or ONS, who assume no liability for and cannot ensure the accuracy of the information presented. All decisions related to taking this medication should be made with the guidance and under the direction of a qualified healthcare professional.

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