

Nirogacestat

Care Team Contact Information: _____

Pharmacy Contact Information: _____

Diagnosis: _____

- This treatment is used for desmoid tumors.
- It may also be used for other reasons.

Goal of Treatment: _____

- Treatment may continue 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
Nirogacestat (NY-roh-GAY-seh-stat): Ogsiveo (og-SIH-vee-oh)	Slows down or stops the growth of cancer cells by blocking a specific protein that helps them survive.	Tablet taken by mouth.

Treatment Administration and Schedule

Your nirogacestat dosing instructions:

- Nirogacestat comes in 2 tablet strengths: 100 mg and 150 mg. Each strength is supplied in blister packs.
- Your dose might differ, but nirogacestat is typically taken as one 150 mg tablet by mouth twice daily.
- Take nirogacestat 2 times a day, with or without food, around the same times each day.
- Swallow nirogacestat tablets whole. Do not break, crush, or chew tablets.
- If you take an antacid medicine, take nirogacestat 2 hours before or 2 hours after taking the antacid.
- Do not change your dose or stop taking nirogacestat unless your care team tells you to.
- Your care team may tell you to change your dose, temporarily stop, or completely stop taking nirogacestat if you develop certain side effects.
- If you vomit after taking a dose or miss a dose of nirogacestat, take your next dose at your regular time. Do not take 2 doses of nirogacestat to make up the dose.
- If you take too much nirogacestat, call your care team or go to the nearest hospital emergency room right away.

Storage and Handling of Nirogacestat

- Store nirogacestat tablets at room temperature between 68°F and 77°F (20°C and 25°C).
- Keep nirogacestat and all medicines out of the reach of children and pets.
- Ask your care team how to safely throw away any unused nirogacestat.

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 an appointment, call your care team as soon as possible to reschedule it.

Supportive Care to Prevent and Treat Side Effects

Description	Supportive Care Taken at Home
To help prevent or treat nausea and vomiting	
Other	

Common Side Effects

Side Effect	Important Information
Fatigue	Description: Fatigue is a constant and sometimes strong feeling of tiredness. Recommendations: - Routine exercise can help reduce fatigue. Talk with your care team to find the right type and amount of activity for you. - Ask family and friends for help with daily tasks and for emotional support. - Try healthy ways to feel better, such as meditation, journaling, yoga, or guided imagery, to reduce anxiety and improve well-being. - Aim for 7 to 8 hours of sleep each night. Limit daytime naps to help you sleep better at night. - Do not drive, operate heavy machinery, or do other potentially dangerous activities if you are very tired. Talk to your care team if you have: - Tiredness that affects your daily life or prevents you from doing normal activities - Tiredness that does not get better with rest - Dizziness or weakness along with severe tiredness
Mouth Sores or Irritation (Mucositis or Stomatitis)	Description: Treatment can irritate the lining of the mouth. In some cases, this can cause redness, sores, pain, and swelling. Recommendations: - Rinse your mouth after meals and at bedtime; rinse more often if sores develop. - Brush your teeth gently with a soft toothbrush or use a cotton swab after meals. - Use a mild, non-alcohol mouth rinse at least 4 times daily (after meals and at bedtime). Example: 1/8 teaspoon salt + 1/4 teaspoon baking soda in 8 oz warm water. - Avoid acidic, hot, spicy, rough, or crunchy foods and drinks that can irritate your mouth. - Avoid tobacco, alcohol, and alcohol-based mouthwash. - Your care team may prescribe medicines or mouth treatments to help with pain and healing. Talk to your care team if you have: - Painful mouth sores or throat pain - Trouble eating or significant weight loss

Nausea and Vomiting	Description: Nausea is an uncomfortable feeling in your stomach or the need to throw up. You may or may not vomit. Recommendations: • Eat smaller, more frequent meals. • Avoid fatty, fried, spicy, or highly sweet foods. • Eat bland foods at room temperature and drink clear liquids. • If you vomit, start with small sips of water, broth, or other clear liquids. If these stay down, try soft foods (such as gelatin, plain cornstarch pudding, yogurt, strained soup, or strained cooked cereal) and gradually return to solid foods. • Your care team may prescribe medicine for these symptoms. Talk to your care team if you have: • Vomiting for more than 24 hours • Nonstop vomiting • Signs of dehydration (very thirsty, dry mouth, dizziness, or dark urine) • Blood in your vomit or vomit that looks like coffee grounds • Severe stomach pain that does not go away after vomiting
Liver Problems	Description: Treatment can cause liver injury. Your care team may check your liver with blood tests before and during treatment. Talk to your care team if you have: • Yellowing of your skin or the white part of your eyes (jaundice) • Severe nausea or vomiting • Pain on the right side of your stomach area (abdomen) • Dark, tea-colored urine • Bleeding or bruising more easily than normal
Diarrhea	Description: Diarrhea is loose, watery stools or more frequent bowel movements than usual. It can cause dehydration and weakness. Recommendations: • Keep track of how often you go to the bathroom each day. • Drink 8 to 10 glasses of water or other fluids daily, unless your care team tells you otherwise. • Eat small meals of mild, low-fiber foods (such as bananas, applesauce, potatoes, chicken, rice, and toast). • If you have diarrhea, avoid high-fiber foods (such as raw vegetables, fruits, and whole grains), gas-producing foods (such as broccoli and beans), dairy (such as milk and yogurt), and spicy, fried, or greasy foods. • Your care team may recommend an antidiarrheal medicine such as loperamide (Imodium). Talk to your care team if you have: • 4 or more bowel movements above your usual number in 24 hours • Dizziness or lightheadedness while having diarrhea • Signs of dehydration (very thirsty, dry mouth, dizziness, or dark urine) • Bloody diarrhea

Protein in Your Urine and Possible Kidney Problems	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. Your care team may check your urine for protein before and during treatment. They may adjust or stop your treatment if protein is found. Recommendations: • Drink 8 to 10 glasses of water or other fluids each day, unless your care team tells you otherwise. • Your care team may give you fluids and electrolytes with your treatment. Talk to your care team if you have: • Decrease in your amount of urine • Blood in your urine • Swelling of your hands, arms, legs, ankles, or feet • Loss of appetite
Ovarian Problems	Description: People who are able to become pregnant may have ovarian problems and changes in their menstrual cycle during treatment with nirogacestat. Nirogacestat may affect fertility which may affect your ability to have a child. Talk to your care team if you have: • Changes in your menstrual cycle • Hot flashes • Night sweats • Vaginal dryness
Headache	Description: Headaches are pain in your head that can vary in intensity, frequency, and location. Recommendations: • Keep a headache diary to track the frequency, duration, intensity, and triggers of your headaches. • Stay hydrated by drinking plenty of water, as dehydration can contribute to headaches. • Apply a cold or warm compress to your forehead or neck to help ease headache pain. • Get adequate sleep (7 to 8 hours per night) and establish a regular sleep schedule. • Limit caffeine intake. • Your care team may recommend medicine for headaches. Talk to your care team if you have: • Severe headache • More frequent or worsening headaches • Dizziness or feeling faint • Confusion • Changes in vision

Rash or Itchy Skin	Description: Rash or itchy skin can cause redness, swelling, and a variety of bumps or patches (small red spots, welts, blisters, or scaly dry areas). Recommendations: • Keep your skin moisturized with creams or lotions to reduce rash and itchiness. • Wear loose-fitting clothing. • Avoid perfumes and colognes, as they may worsen rash symptoms. • Limit time spent in the heat to prevent worsening symptoms. • Avoid sun exposure, especially between 10 AM and 4 PM, to lower the risk of sunburn. • Wear long-sleeved clothing with ultraviolet (UV) protection and broad-brimmed hats. • Apply broad-spectrum sunscreen (UVA/UVB) with sun protective factor (SPF) 30 or higher as directed. • Use lip balm with SPF 30 or higher. • Avoid tanning beds. • Your care team may recommend medicines for symptoms. Talk to your care team if you have: • Rash or itching that continues to worsen
Changes in Electrolytes and Other Laboratory Results	Description: Treatment may cause low levels of phosphate and potassium in your blood. Your care team will perform blood tests to check for these changes and will treat you if needed. Recommendations: • Your care team may give you medicine to treat low phosphate or low potassium if needed. Talk to your care team if you have: • New or worsening muscle weakness, cramps, or bone pain • Trouble breathing or shortness of breath • Confusion, slurred speech, or severe dizziness • Severe fatigue or inability to perform daily activities • New or worsening muscle weakness or cramps • Irregular, fast, or pounding heartbeat, or chest pain • Severe dizziness, fainting, or lightheadedness • Severe constipation or stomach-area (abdominal) pain

Select Rare Side Effects

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms
Risk of New Non-Melanoma Cancers	There is a risk of developing one or more new cancers during or after treatment. Your care team may do skin exams before and during treatment if you are at risk for skin cancer. Talk with your care team about this risk, and ask about the signs and symptoms to watch for. New or changing skin lesions

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:
 - Your care team will verify your pregnancy status before treatment.
 - Use an effective method of birth control during treatment and for 1 week after your last dose of nirogacestat.
 - If you use a birth control method that contains hormones (for example, birth control pills, injections, or transdermal system patches), an additional barrier method of contraception (for example, diaphragm or condom) is recommended. Birth control methods that contain hormones may not work as well during treatment with nirogacestat. Talk to your care team about birth control methods that may be right for you.
 - 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 1 week after your last dose of nirogacestat.
- Do not breastfeed** during treatment and for 1 week after your last dose of nirogacestat.

- **Tell your care team about all the medicines you take.**

- o Especially tell your care team **if you take antacid medicines, including Proton Pump Inhibitor (PPI) medicines or H2 blockers, during treatment with nirogacestat**. Ask your care team if you are not sure.

- **You should not drink grapefruit juice, eat grapefruit, or eat Seville oranges (often used in marmalades)** during treatment with nirogacestat. These products may increase the amount of nirogacestat in your blood.
- **This Patient Education Sheet may not describe all possible side effects.**

Notes

pg. 8 of 9

ACCC
ASSOCIATION OF CANCER CARE CENTERS



HOPA
Hematology/Oncology
Pharmacy Association



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 to gather information and develop this patient education guide. This guide is a summary of the medication, based on information provided by the drug manufacturer and other sources.

This guide does not cover all information available on the possible uses, directions, doses, precautions, warnings, interactions, adverse effects, or risks associated with this medication. It should not be used as a substitute for the advice of a qualified healthcare professional. The provision of this guide is for informational purposes only. It 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 regarding this medication should be made with the guidance and direction of a qualified healthcare professional.

Permission:

Patient Education Sheets are provided as a free educational resource for patients with cancer and their caregivers in need of concise, easy-to-understand information about cancer therapy. Healthcare providers may copy and distribute the sheets to patients and direct them to the Patient Education Sheets website. However, commercial reproduction or reuse, as well as rebranding or reposting of any type, are strictly prohibited without permission of the copyright holders. Permission requests, including direct linking from Electronic Health Records, and licensing inquiries should be emailed to patienteducationsheets@ncoda.org.

Copyright © 2026 by Network for Collaborative Oncology Development & Advancement, Inc. All rights reserved.

PES-309