

# Eculizumab

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

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

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

- This treatment is often used for paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS). 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
Eculizumab (ek-yoo-LIH-zoo-mab): Soliris (soh-LAYR-is), Bkemv, Ephysql	Prevents red blood cells from being destroyed.	Infusion given into a vein.

## Treatment Administration and Schedule

- Adults will usually receive an eculizumab infusion
  - Weekly for 5 weeks, then
  - Every 2 weeks.
- Children less than 18 years of age, your care team will decide how often you will receive eculizumab depending on your age and body weight.
- After each infusion, you may be monitored for at least 1 hour for infusion-related reactions.

**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	_____	_____
Other	_____	_____

## Common Side Effects

Side Effect	Important Information
<b>Meningococcal Infections (Boxed Warning)</b>	<p>Description: Eculizumab increases your chance of getting serious meningococcal infections caused by <i>Neisseria meningitidis</i> bacteria. Meningococcal infections may quickly become life-threatening or cause death if not recognized and treated early.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>You must complete or update your meningococcal vaccine(s) at least 2 weeks before your first dose of eculizumab.</li> <li>If you have not completed your meningococcal vaccines and eculizumab must be started right away, you should receive the required vaccine(s) as soon as possible.</li> <li>If you have not been vaccinated and eculizumab must be started right away, you should also receive antibiotics to take for as long as your healthcare provider tells you.</li> <li>If you had a meningococcal vaccine in the past, you might need additional vaccines before starting eculizumab. Your healthcare provider will decide if you need additional meningococcal vaccines.</li> <li>Meningococcal vaccines do not prevent all meningococcal infections.</li> <li>Your care team will give you a Patient Safety Card about the risk of serious meningococcal infection. Carry it with you at all times during treatment and for 3 months after your last dose of eculizumab. Your risk of meningococcal infection may continue for several weeks after your last dose of eculizumab. It is important to show this card to any healthcare provider who treats you. This will help them diagnose and treat you quickly.</li> </ul> <p>Call your care team or get emergency medical care right away if you get any of these signs and symptoms of a serious meningococcal infection:</p> <ul style="list-style-type: none"> <li>Fever of 100.4°F (38°C) or higher</li> <li>Fever with high heart rate</li> <li>Headache and fever</li> <li>Confusion</li> <li>Muscle aches with flu-like symptoms</li> <li>Fever and a rash</li> <li>Headache with nausea or vomiting</li> <li>Headache with a stiff neck or stiff back</li> <li>Eyes sensitive to light</li> </ul>

Other Types of Serious Infections	<p>Description: Eculizumab may also increase the risk of other types of serious infections caused by encapsulated bacteria, including <i>Streptococcus pneumoniae</i>, <i>Haemophilus influenzae</i>, and <i>Neisseria gonorrhoeae</i>.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>If your child is treated with eculizumab, your child should receive vaccines against <i>Streptococcus pneumoniae</i> and <i>Haemophilus influenzae</i> type b (Hib).</li> <li>Certain people may be at risk of serious infections with gonorrhea. Talk to your care team about whether you are at risk for gonorrhea infection, about gonorrhea prevention, and regular testing.</li> <li>Certain fungal infections (aspergillus) may also happen if you take eculizumab and have a weak immune system or a low white blood cell count.</li> </ul>	Talk to your care team if you have:	<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 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>	Talk to your care team if you have:	<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>
Stomach-Area (Abdominal) Pain	<p>Description: Abdominal pain is when you feel discomfort or pain in the belly area.</p> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Severe abdominal pain</li> </ul>		
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>	Talk to your care team if you have:	<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>
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>
Headache	<p>Description: A headache can cause you to feel pain or discomfort in your head, making it hard to concentrate or feel your best.</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Keep a headache diary to track the frequency, duration, intensity, and triggers of your headaches.</li> <li>Stay hydrated by drinking plenty of water, as dehydration can contribute to headaches.</li> <li>Apply a cold or warm compress to your forehead or neck to help ease headache pain.</li> <li>Get adequate sleep (7-8 hours per night) and establish a regular sleep schedule.</li> <li>Limit caffeine intake.</li> <li>Your care team may recommend medicine for headaches.</li> </ul>	<p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Severe headache</li> <li>More frequent headaches</li> <li>Dizziness or light-headedness</li> <li>Confusion</li> <li>Vision changes</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>
Pain or Swelling of Your Nose or Throat	<p>Description: Treatment can cause pain or swelling of your nose or throat (nasopharyngitis).</p> <p>Recommendations:</p> <ul style="list-style-type: none"> <li>Wash your hands often.</li> <li>Avoid being around people who are sick.</li> <li>Drink 8 to 10 glasses of water or other fluids each day, unless your care team tells you otherwise.</li> <li>Get 7-8 hours of sleep each night.</li> <li>Your care team may recommend medicines (such as decongestants) for symptom relief.</li> </ul> <p>Talk to your care team if you have:</p> <ul style="list-style-type: none"> <li>Runny or stuffy nose</li> <li>Sore throat</li> </ul>

### Select Rare Side Effects

Side Effect	Talk to Your Care Team if You Have Any of These Signs or Symptoms
Infusion-Related 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, 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.
- It is **not known** if eculizumab will **harm your unborn baby**.
- It is **not known** if eculizumab **passes into your breast milk**. Waiting for at least 2 weeks postpartum to resume therapy may minimize transfer to the infant.

### 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.

- 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.

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