PATIENT & CAREGIVER EDUCATION

# Eculizumab

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

Bkemv; Epysqli; Soliris

## Brand Names: Canada

Soliris

## Warning

- This drug raises the risk of severe meningococcal infections. Life-threatening and deadly meningococcal infections have happened in people treated with this type of drug. This type of infection can become life-threatening or deadly very fast and can be deadly if not treated early. You will need to get a meningococcal vaccine at least 2 weeks before starting this drug unless your doctor tells you otherwise. If you have had a meningococcal vaccine before, you may need to get another one. Talk with your doctor if you have questions.
- Meningococcal vaccines lower the risk of meningococcal infections but do not prevent all meningococcal infections from happening. Call your doctor right away if you have signs of a meningococcal infection like headache with upset stomach or throwing up, fever, or stiff neck or back; confusion; fever with or without a rash or fast heartbeat; body aches with flu-like signs; or if light bothers your eyes.
- If you cannot get a meningococcal vaccine at least 2 weeks before starting this drug, you will need to take antibiotics as your doctor tells you.

## What is this drug used for?

- It is used to treat a blood disease called paroxysmal nocturnal hemoglobinuria (PNH).
- It is used to treat a blood and kidney disease called atypical hemolytic uremic syndrome (aHUS).
- It is used to treat myasthenia gravis.
- It is used to treat a health problem called neuromyelitis optica spectrum disorder (NMOSD).

## What do I need to tell my doctor BEFORE I take this drug?

- If you are allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell your doctor about the allergy and what signs you had.
- If you did not get a meningococcal vaccine.
- If you have a meningococcal infection.

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

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

## What are some things I need to know or do while I take this drug?

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- Have your blood work and other lab tests checked as you have been told by your doctor.
- This drug may raise the risk of other severe infections. This includes infections caused by *Streptococcus pneumoniae*, *Neisseria gonorrhoeae*, and *Haemophilus influenzae*. Vaccines can help lower the risk of some of these infections. Talk with the doctor if you have questions.
- Wash hands often. Stay away from people with infections, colds, or flu.
- Make sure you are up to date with all your vaccines before treatment with this drug.
- Have patient safety card with you at all times and for 3 months after drug is stopped.
- Tell your doctor if you are pregnant, plan on getting pregnant, or are breast-

feeding. You will need to talk about the benefits and risks to you and the baby.

## What are some side effects that I need to call my 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 doctor or get medical help right away if you have any of the following signs or symptoms that may be related to a very bad side effect:

### All products:

- 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 infection like fever, chills, very bad sore throat, ear or sinus pain, cough, more sputum or change in color of sputum, pain with passing urine, mouth sores, or wound that will not heal.
- Signs of a urinary tract infection (UTI) like blood in the urine, burning or pain when passing urine, feeling the need to pass urine often or right away, fever, lower stomach pain, or pelvic pain.
- Signs of herpes infections like cold sores, shingles, genital sores, severe headache, confusion, change in eyesight, eye redness, or eye pain.
- Signs of high or low 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.
- Not able to pass urine or change in how much urine is passed.
- A fast heartbeat.
- Swelling in the arms or legs.
- Change in eyesight, eye pain, or severe eye irritation.

- A skin lump or growth.
- Infusion reactions have happened during the infusion. Tell your doctor right away if you have chest pain; trouble breathing; swelling of the face, tongue, or throat; severe dizziness or passing out; or any other bad effects during or within 1 hour after the infusion.
- Some health problems may happen after this drug is stopped. You will need to be watched closely for several weeks to months after you stop this drug. Follow up with your doctor. Call your doctor right away if you have a change in how much urine is passed; dark urine; swelling, warmth, or pain in the leg or arm; chest pain or pressure; coughing up blood; trouble breathing or swallowing; any unexplained bruising or bleeding; seizures; stomach pain; severe dizziness; or passing out. Call your doctor right away if you feel confused, very tired or weak, or have weakness on 1 side of the body, trouble speaking or thinking, change in balance, drooping on 1 side of the face, or change in eyesight. Call your doctor right away if you are not able to get or keep an erection.

### Soliris and Epysqli:

- Bruising.
- A burning, numbness, or tingling feeling that is not normal.
- Cataracts have happened with this drug. Tell the doctor about any change in eyesight.

## 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 doctor or get medical help if any of these side effects or any other side effects bother you or do not go away:

- Headache.
- Nose or throat irritation.
- Signs of a common cold.
- Flu-like signs.

- Back pain.
- Constipation, diarrhea, stomach pain, upset stomach, throwing up, or decreased appetite.
- Feeling dizzy, tired, or weak.
- Trouble sleeping.
- Muscle or joint pain.
- Pain in arms or legs.
- Muscle spasm.
- Hair loss.

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

You may report side effects to your national health agency.

You may report side effects to the FDA at 1-800-332-1088. You may also report side effects at https://www.fda.gov/medwatch.

## How is this drug best taken?

Use this drug as ordered by your doctor. Read all information given to you. Follow all instructions closely.

- It is given as an infusion into a vein over a period of time.

## What do I do if I miss a dose?

- Call your doctor to find out what to do.

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

- If you need to store this drug at home, talk with your doctor, nurse, or pharmacist about how to store it.

## General drug facts

- If your symptoms or health problems do not get better or if they become worse, call your doctor.
- Do not share your drugs with others and do not take anyone else's drugs.
- 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.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your doctor, nurse, pharmacist, or other health care provider.
- This drug comes with an extra patient fact sheet called a Medication Guide. Read it with care. Read it again each time this drug is refilled. If you have any questions about this drug, please talk with the doctor, 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 provider based on the health care provider's examination and assessment of a patient's specific and unique circumstances. Patients must speak with a health care provider for complete information about their health, medical questions, and treatment options,

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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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