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

- Drugs like this one raise the risk of severe meningococcal infections. Life-threatening and deadly meningococcal infections have happened in people treated with drugs like this one. This type of infection can become life-threatening or deadly very fast if not treated early. Your child will need to get a meningococcal vaccine at least 2 weeks before starting this drug unless the doctor tells you otherwise. If your child has had a meningococcal vaccine before, they may need to get another one. Talk with the doctor if you have questions.
- Meningococcal vaccines lower the risk of meningococcal infections but do not prevent all meningococcal infections from happening. Call the doctor right away if your child has 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 child's eyes.
- If your child cannot get a meningococcal vaccine at least 2 weeks before starting this drug, your child will need to take antibiotics as told by the doctor.

What is this drug used for?

- It is used to treat a blood and kidney disease called atypical hemolytic uremic syndrome (aHUS).
- It is used to treat myasthenia gravis.
- It may be given to your child for other reasons. Talk with the doctor.

What do I need to tell the doctor BEFORE my child takes this drug?

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

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

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

What are some things I need to know or do while my child takes this drug?

- Tell all of your child's health care providers that your child is taking this drug. This includes your child's doctors, nurses, pharmacists, and dentists.
- Have your child's blood work and other lab tests checked as you have been told by the 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.
- Have your child wash hands often. Avoid crowds and people with infections, colds, or flu.
- Make sure your child is up to date with all vaccines before treatment with this drug.
- Have your child's patient safety card with you at all times and for 3 months

after drug is stopped.

If your child is pregnant or breast-feeding a baby:

- Talk with the doctor if your child is pregnant, becomes pregnant, or is breast-feeding a baby. You will need to talk about the benefits and risks to your child and the baby.

What are some side effects that I need to call my child's 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 child's doctor or get medical help right away if your child has 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 child's doctor right away if your child has chest pain; trouble breathing; swelling of the face, tongue, or throat; severe dizziness or passing out; or any other bad effects during the infusion or within 1 hour after the infusion.
- Some health problems may happen after this drug is stopped. Your child will need to be watched closely for several weeks after stopping this drug. Follow up with the doctor as you have been told. After your child stops this drug, call the doctor right away if your child has 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; weakness on 1 side of the body, trouble speaking or thinking, change in balance, or change in eyesight; confusion; any bruising or bleeding that is not normal; or seizures.

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 child's doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:

- Constipation, diarrhea, stomach pain, upset stomach, throwing up, or decreased appetite.
- Feeling dizzy, tired, or weak.

- Trouble sleeping.
- Back pain.
- Nose or throat irritation.
- Signs of a common cold.
- Flu-like signs.
- Headache.
- 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 child's doctor. Call your child's doctor for medical advice about side effects.

You may report side effects to your national health agency.

How is this drug best given?

Give this drug as ordered by your child's 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 my child misses a dose?

- Call your child's 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 child's doctor, nurse, or pharmacist about how to store it.

General drug facts

- If your child's symptoms or health problems do not get better or if they become worse, call your child's doctor.
- Do not share your child's drug with others and do not give anyone else's drug to your child.
- 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 child's doctor, nurse, 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, including any risks or benefits regarding use of medications. This information does not endorse any treatments or medications as safe, effective, or approved for treating a specific patient. UpToDate, Inc. and its affiliates disclaim any

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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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