MSK Kids

PATIENT & CAREGIVER EDUCATION

Ravulizumab

This information from Lexicomp® 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

Ultomiris

Brand Names: Canada

Ultomiris

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 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.

What is this drug used for?

Vials (for IV infusion):

- 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).
- If your child has been given this drug for some other reason, talk with the doctor about the benefits and risks. Talk with the doctor if you have questions or concerns about giving this drug to your child.

On-body Injector:

- This drug is not approved for use in children. However, the doctor may decide the benefits of taking this drug outweigh the risks. If your child has been given this drug, ask the doctor for information about the benefits and risks. Talk with the doctor if you have questions about giving this drug to your child.

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.

If your child is breast-feeding a baby:

- Be sure your child does not breast-feed a baby while taking this drug and for 8 months after the last dose.

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.

- This drug may raise the risk of other severe infections. This includes gonorrhea infections in some people. Talk to your child’s doctor to see if your child has a greater chance of gonorrhea, how to prevent gonorrhea, and if your child needs to get tested.
- 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 a patient safety card with your child at all times and for 8 months after drug is stopped
- Have your child’s blood work and other lab tests checked as you have been told by the doctor.
- If your child’s weight changes, talk with the doctor. The dose of this drug may need to be changed.
- Some health problems may happen after this drug is stopped. Your child will need to be watched closely for several weeks to months after stopping this drug. Follow up with the doctor. 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 or swallowing; any unexplained bruising or bleeding; seizures; stomach pain; severe dizziness; or passing out. Call the doctor right away if your child feels confused, very tired or weak, or has weakness on 1 side of the body, trouble speaking or thinking, change in balance, drooping on one side of the face, or change in eyesight. Call the doctor right away if your child is not able to get or keep an erection.
- If the patient is a child, use this drug with care. The risk of certain severe infections may be raised in children.

If your child is or may be sexually active:

- Your child may need to use birth control to prevent pregnancy while taking this drug and for some time after the last dose. Talk with the doctor to see if your child needs to use birth control.

If your child is pregnant:

- Tell the doctor if your child is pregnant or becomes pregnant. You will need to talk about the benefits and risks of your child using this drug while pregnant.

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:

- 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 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.
- Swelling in the arms or legs.

- Bruising.
- Pain and irritation where this drug goes into the body.
- Swollen gland.
- Infusion reactions have happened during the infusion. Tell the doctor right away if your child has arm or leg pain; back pain; bad taste in the mouth; feeling sleepy; 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.

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:

- Signs of a common cold.
- Nose or throat irritation.
- Headache.
- Constipation, diarrhea, stomach pain, upset stomach, throwing up, or decreased appetite.
- Feeling dizzy, tired, or weak.
- Back, muscle, joint, arm, or leg pain.
- Muscle spasm.
- Anxiety.
- Hair loss.
- Dry skin.

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.

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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 warranty or liability relating to this information or the use thereof. The use of this information is governed by the Terms of Use, available at https://www.wolterskluwer.com/en/know/clinical-effectiveness-terms.

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If you have any questions, contact a member of your care team directly. If you're a patient at MSK and you need to reach a provider after 5 p.m., during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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