PATIENT & CAREGIVER EDUCATION

Rilonacept

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

Arcalyst

What is this drug used for?

- It is used to treat cryopyrin-associated periodic syndromes (CAPS).
- It is used to help control symptoms of deficiency of interleukin-1 receptor antagonist (DIRA).
- It is used to treat recurrent pericarditis (RP).

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 has an infection.

- If your child is taking any of these drugs: Abatacept, adalimumab, anakinra, certolizumab, etanercept, golimumab, infliximab, or rituximab.

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 blood work checked as you have been told by the doctor. Talk with the doctor.
- This drug may cause high cholesterol and triglyceride levels. Talk with the doctor.
- Your child may have more chance of getting an infection. Some infections have been deadly. Have your

child wash hands often. Have your child stay away from people with infections, colds, or flu.

- TB (tuberculosis) has been seen in patients started on this drug. These patients were exposed to TB in the past, but never got the infection. The doctor may test to see if your child has been exposed to TB before starting this drug.
- Talk with the doctor before your child gets any vaccines. Use of some vaccines with this drug may either raise the chance of very bad infection or make the vaccine not work as well.
- Drugs that may suppress the immune system like this drug may raise the risk of cancer. If you have questions, talk with the doctor.
- This drug may affect growth in children and teens in some cases. They may need regular growth checks. Talk with the doctor.

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:

- 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.
- Numbness or tingling.

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:

- Pain, redness, swelling, or other reaction where the injection was given.
- Signs of a common cold.
- Cough.
- Runny or stuffy nose.
- Ear infection.

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 a shot into the fatty part of the skin on the top of the thigh, belly area, or upper arm.
- If you will be giving your child the shot, your child's doctor or nurse will teach you how to give the shot.
- Wash your hands before and after use.
- This drug needs to be mixed before use. Follow how to mix as you were told by the doctor.

- Do not use if the solution is cloudy, leaking, or has particles.
- This drug is colorless to a faint yellow. Do not use if the solution changes color.
- If the dose is more than 1 injection, give the injections into 2 different places.
- Move the site where you give the shot with each shot.
- Do not give into tender, bruised, red, or hard skin.
- Do not give into skin within 2 inches (5 cm) of the belly button.
- Throw away any part of the opened vial not used after the shot is given.
- Throw away needles in a needle/sharp disposal box. Do not reuse needles or other items. When the box is full, follow all local rules for getting rid of it. Talk with a doctor or pharmacist if you have any questions.

What do I do if my child misses a dose?

- If it is within 7 days of the missed dose, give the missed dose and return to your child's regular schedule.
- If it has been more than 7 days since the missed dose, give a missed dose and start a new schedule based on when the dose is given.

- If you are not sure what to do if your child misses a dose, call the doctor.

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

- Store unopened vials in a refrigerator. Do not freeze.
- Store in the original container to protect from light.
- After mixing, you may store at room temperature for up to 3 hours. Protect from light.
- 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.

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.
- 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.

- 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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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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