MSK Kids

PATIENT & CAREGIVER EDUCATION

Tocilizumab

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

Actemra; Actemra ACTPen

Brand Names: Canada

Actemra

Warning

- This drug may raise the chance of infection, including severe infections. Sometimes severe infections have led to death. Most people who had these infections were taking other drugs to lower the immune system like methotrexate or steroid drugs. If your child has any infection, is taking antibiotics now or in the recent past, or has had many infections, talk with your child's doctor.
- 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. Your child will also be watched while taking this drug for signs of TB. Tell the doctor right away if your child feels sick or weak, or has fever, night sweats, or abnormal weight loss.

What is this drug used for?

- It is used to treat some types of arthritis.
- It is used to treat cytokine release syndrome (CRS).
- It is used in certain people to treat COVID-19.

- 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 has liver disease or raised liver enzymes.
- If your child has an infection.
- If your child has a low platelet count or a low white blood cell count.
- 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?

All products:

- 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.
- Your child may have more chance of getting infections. Have your child wash hands often. Avoid crowds and people with infections, colds, or flu.
- If your child has high blood sugar (diabetes), talk with the doctor. Your child may be more likely to get infections.
- If your child has had hepatitis B before or carries the virus, talk with your child’s doctor. This drug can cause the virus to become active again.
- Hepatitis B testing needs to be done as you were told by the doctor. Talk with the doctor.
- Drugs that may suppress the immune system like this drug may raise the risk of cancer. If you have questions, talk with the doctor.
- Have your child’s blood work and other lab tests checked as you have been told by the doctor.

- If possible, make sure all vaccines are up to date before treatment with 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.
- Your child may bleed more easily. Make sure your child is careful and avoids injury. Be sure your child has a soft toothbrush.
- Treatment with this drug may lead to higher cholesterol and triglycerides. The effect of these changes on heart health is not known. Talk with the doctor.
- If your child's weight changes, talk with the doctor. The dose of this drug may need to be changed.
- Liver problems have happened with this drug. Sometimes, this has been severe and has led to a liver transplant or death. If you have questions, talk with the doctor.

If your child is or may be sexually active:

- Birth control pills and other hormone-based birth control may not work as well to prevent pregnancy. Be sure your child uses some other kind of birth control also, like a condom, when taking this drug.

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

- This drug may cause harm to the unborn baby if your child takes it during pregnancy. If your child is pregnant or gets pregnant while taking this drug, call the doctor right away.
- If your child used this drug while pregnant, tell the baby's doctor.
- Tell the doctor if your child is breast-feeding a baby. You will need to talk about any risks to the baby.

Infusion:

- Some people have unsafe allergic effects or bad side effects during the infusion or within 24 hours of the infusion. Talk with the doctor.

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. Rarely, some allergic reactions have been deadly.

- 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 bleeding like throwing up or coughing up blood; vomit that looks like coffee grounds; blood in the urine; black, red, or tarry stools; bleeding from the gums; abnormal vaginal bleeding; bruises without a cause or that get bigger; or bleeding you cannot stop.
- Signs of liver problems like dark urine, tiredness, decreased appetite, upset stomach or stomach pain, light-colored stools, throwing up, or yellow skin or eyes.
- Signs of high or low blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- Feeling very tired or weak.
- Warm, red, or painful skin or sores on the body.

- A skin lump or growth.
- Change in color or size of a mole.
- Shortness of breath.
- Chest pain or pressure.
- Not able to pass urine or change in how much urine is passed.
- It is not known how this drug may affect some nervous system problems. However, multiple sclerosis (MS) and certain other nerve problems have rarely happened in people taking this drug. Call the doctor right away if your child has an abnormal burning, numbness, or tingling feeling; muscle stiffness or weakness; change in bladder or bowel habits; or change in eyesight.
- Tears in the stomach or bowel wall have happened in certain people taking this drug. Call your child’s doctor right away if your child has swelling or pain in the stomach that is very bad, gets worse, or does not go away. Call your child’s doctor right away if your child throws up blood or has throw up that looks like coffee grounds; upset stomach or throwing up that does not go away; or black, tarry, or bloody stools.

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:

- Headache.
- Signs of a common cold.
- Nose or throat irritation.
- Irritation where the shot is given.
- Diarrhea or constipation.
- Anxiety.

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.

Prefilled syringes and auto-injectors:

- It is given as a shot into the fatty part of the skin.
- If you will be giving your child the shot, your child’s doctor or nurse will teach you how to give the shot.
- Take this drug out of the refrigerator and let it come to room temperature before you use it. Be sure you know how long to leave it at room temperature. Do not heat or microwave.
- 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.
- Move the site where you give the shot with each shot.
- Do not give into a mole, scar, or skin that is irritated, tender, bruised, red, hard, or broken.
- 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.

Infusion:

- 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?
Prefilled syringes and auto-injectors:

- Store in a refrigerator. Do not freeze.
- Store in the outer carton to protect from light.
- Keep dry.
- If needed, you may store at room temperature for up to 14 days. Write down the date you take this drug out of the refrigerator. If stored at room temperature and not used within 14 days, throw this drug away.
- Protect from heat.

Infusion:

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

All products:

- 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 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 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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