MSK Kids

PATIENT & CAREGIVER EDUCATION

Tisagenlecleucel

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

Kymriah

Brand Names: Canada

Kymriah

Warning

- A very bad health problem called cytokine release syndrome (CRS) has happened with this drug. Sometimes, this has been life-threatening or deadly. This can happen while getting this drug or within 4 weeks after getting this drug. Get medical help right away if your child has signs like chills; confusion; dizziness; feeling tired or weak; fever; headache; passing out; rash; swelling of the face; trouble breathing; very bad muscle or joint pain;

very bad upset stomach, throwing up, or diarrhea; or wheezing.

- Do not give this drug if your child has an infection or any inflammation.
- Nervous system problems have happened after treatment with this drug. Sometimes, these have been very bad or life-threatening. Call your child's doctor right away if your child feels agitated, confused, nervous, or restless. Call your child's doctor right away if your child has anxiety, change in balance, change in eyesight, dizziness or passing out, hallucinations (seeing or hearing things that are not there), headaches, seizures, shakiness, trouble speaking, trouble reading or writing, or new or worse behavior or mood changes.

What is this drug used for?

- It is used to treat a type of leukemia.
- This drug is taken with other drugs. Be sure you know about the warnings, benefits, and risks of these other drugs. Talk with the doctor if you have questions or concerns about any of the drugs.
- 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.

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 is pregnant:

- Do not give this drug to your child during pregnancy.

This drug may interact with other drugs or health problems.

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 avoid tasks or actions that call for alertness for at least 8 weeks after getting this drug. If you have any questions, call your child’s doctor or pharmacist.
- Have blood work checked as you have been told by the doctor. Talk with the doctor.
- This drug may affect certain lab tests. Tell all of your child’s health care providers and lab workers that your child takes this drug.
- 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.
- Your child may bleed more easily. Make sure your child is careful and avoids injury. Be sure your child has a soft toothbrush.
- If your child has had hepatitis B before or carries the virus, talk with your child’s doctor. Drugs like this one can cause the virus to become active. This can lead to

very bad and sometimes deadly liver problems.

- Hepatitis and HIV testing will be done before taking this drug.
- Talk with the doctor before your child gets any vaccines. Some types of vaccines must not be given for at least 6 weeks before starting this drug, during treatment, and for some time after the last dose.
- This drug may add to the chance of getting some types of cancer. Talk with the doctor.
- Do not let your child donate blood, organs, or tissues or cells. Talk with your child’s doctor to see when your child can do these things after getting this drug.
- If your child has an upset stomach or diarrhea, is throwing up, or decreased appetite, talk with the doctor. There may be ways to lower these side effects.
- If your child is of childbearing age, a pregnancy test will need to be done before starting this drug to make sure your child is not pregnant.

If your child is or may be sexually active:

- If your child wants to get pregnant after stopping this drug, talk with the doctor.

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.
- Tell the doctor if your child is breast-feeding a baby. You will need to talk about any risks to 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.

- 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 kidney problems like unable to pass urine, change in how much urine is passed, blood in the urine, or a big weight gain.
- Signs of high or low blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- Signs of electrolyte problems like mood changes; confusion; muscle pain, cramps, or spasms; weakness; shakiness; change in balance; an abnormal heartbeat; seizures; loss of appetite; or severe upset stomach or throwing up.
- Shortness of breath, a big weight gain, or swelling in the arms or legs.

- Fast breathing.
- A fast heartbeat.
- Bad dreams.
- A burning, numbness, or tingling feeling that is not normal.
- Swelling, warmth, numbness, change of color, or pain in a leg or arm.
- Chest pain.
- An immune system problem called hemophagocytic lymphohistiocytosis/macrophage activation syndrome (HLH/MAS) has happened with this drug. HLH/MAS can be life-threatening or deadly. Call the doctor right away if your child feels confused or not alert or has fever, swollen gland, rash, seizures, change in balance, or trouble walking that is new or worse.

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.

- Headache.
- Feeling tired or weak.
- Pain in arms or legs.
- Back, muscle, or joint pain.
- Stuffy nose.
- Weight loss.
- Trouble sleeping.

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.
- Other drugs may be given before this drug to help avoid side effects.

What do I do if my child misses a dose?

- This drug will be given in a health care setting.

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

- This drug will be given in a hospital or doctor’s office. You will not store it at home.

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 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

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Last Reviewed Date

2022-06-20

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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.

Tisagenlecleucel - Last updated on December 12, 2022
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