MSK Kids

PATIENT & CAREGIVER EDUCATION

Sapropterin

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

Javygtor; Kuvan

Brand Names: Canada

Kuvan; REDDY-Sapropterin

What is this drug used for?

- It is used to treat phenylketonuria (PKU).

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.

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’s blood work and other lab tests checked as you have been told by the doctor.
- Talk with the doctor if your child has a fever or is sick. Your child’s dose may need to be changed.
- Have your child follow the diet plan your child’s doctor told you about.
- Some people have had low blood phenylalanine levels with this drug. The chance is raised in children younger than 7 years of age. Blood levels that are too low for a long time may lead to very bad health problems. 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.
- Dizziness or passing out.

- Flushing.
- Cough.
- Shortness of breath.
- Fidgeting, moving around too much, or talking too much.
- Chest pain or pressure.
- Passing urine more often.
- Seizures.
- Swelling in the arms or legs.
- Feeling agitated.
- Stomach or bowel problems have happened with this drug. If not treated, these can lead to severe health problems like stomach or bowel ulcers or bleeding. Call the doctor right away if your child has throat or stomach pain, severe upset stomach or throwing up, trouble swallowing, or decreased appetite. Call the doctor right away if your child throws up blood; has throw up that looks like coffee grounds; or has 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.
- Diarrhea, upset stomach, or throwing up.
- Signs of a common cold.
- Joint pain.

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.

Tablets:

- Give this drug at the same time of day.
- Give with a meal.
- This drug may be swallowed whole or mixed in water or apple juice.
- If mixing the tablets, mix with $^{1}/_{2}$ to 1 cup (4 to 8 ounces/120 to 240 mL) of water or apple juice. Have your child drink within 15 minutes of mixing. It may take a few minutes for the tablets to dissolve. You may stir or crush the tablets to help the tablets dissolve faster. Rinse glass with more juice or water and have your child drink.
- This drug may not dissolve all the way. You may see small pieces floating on the top of the water or apple juice. This is normal and safe to swallow.
- This drug may also be crushed and mixed in a small amount of soft food like applesauce or pudding.

Powder packet:

- Give this drug at the same time of day.
- Give with a meal.
- Do not open until you are ready to use.
- Be sure you know what the dose of this drug is. Be sure you know which types of packets to use to make up the dose. Talk to the doctor if you are not sure.
- Empty packet in water or apple juice as you have been told. Mix well and have your child drink within 30 minutes of mixing.
- This drug may also be mixed in a small amount of soft food like applesauce or pudding.

What do I do if my child misses a dose?

- Give a missed dose as soon as you think about it on the same day your child missed the dose.
- If it is the next day, skip the missed dose and go back to your child’s normal time.
- Do not give 2 doses on the same day.

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

All products:

- Store at room temperature in a dry place. Do not store in a bathroom.
- 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.

Tablets:

- Store in original container.
- Keep lid tightly closed.

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.

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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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