PATIENT & CAREGIVER EDUCATION

Leniolisib

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

Joenja

What is this drug used for?

- It is used to treat activated phosphoinositide 3-kinase delta syndrome (APDS).

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.
- If your child takes any drugs (prescription or OTC, natural products, vitamins) that must not be taken with this drug, like certain drugs that are used for HIV, infections, seizures, and others. There are many drugs that must not be taken with this drug.

If your child is breast-feeding a baby:

- Be sure your child does not breast-feed a baby while taking this drug and for 1 week 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.
- Talk with the doctor before your child gets any vaccines. Use of some vaccines with this drug may make the vaccine not work as well.
- If giving this drug to a child younger than 12 years old and the child's weight changes, talk with the doctor. The dose of this drug may need to be changed.

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.
- A pregnancy test will be done to show that your child is NOT pregnant before starting this drug. If your child gets pregnant while taking this drug, call the doctor right away.
- If your child may become pregnant, have your child use birth control while taking this drug and for 1 week after the last dose. If your child gets pregnant, call the doctor right away.

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.
- A fast heartbeat.
- Fever.

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:

For all patients taking this drug:

- Headache.
- Stuffy nose.
- Diarrhea.
- Hair loss.
- Eczema or other skin irritation.
- Back pain.
- Neck pain.
- Weight gain.

Children younger than 12 years old:

- Stomach pain.
- Cough.
- Signs of a common cold.

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.

- Give this drug with or without food.
- Give doses about 12 hours apart.
- If your child throws up within 1 hour after taking this drug, give another dose as soon as possible. If your child throws up more than 1 hour after taking this drug, do not give another dose. Give your child's next dose at the normal time.

What do I do if my child misses a dose?

- Give a missed dose as soon as you think about it.
- If you miss giving a dose by more than 6 hours, skip the missed dose and go back to your child's normal time.
- Do not give 2 doses at the same time or extra doses.

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

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

- 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.

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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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