### **MSK Kids**

#### PATIENT & CAREGIVER EDUCATION

### Lonafarnib

This information from Lexicomp<sup>®</sup> 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**

Zokinvy

#### What is this drug used for?

- It is used to lower the risk of death in people who have Hutchinson-Gilford Progeria Syndrome (HGPS).
- It is used to treat certain health problems called processing-deficient Progeroid Laminopathies.

# 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 takes any drugs (prescription or OTC, natural products, vitamins) that must not be taken with this drug, like certain drugs that are used for high cholesterol, HIV, or seizures. There are many drugs that must not be taken with this drug.

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.
- This drug may lower the ability of the bone marrow to make blood cells that the body needs. If blood cell counts get very low, this can lead to bleeding problems, infections, or anemia. If you have questions, talk with the doctor.
- Have blood work checked as you have been told by the doctor. Talk with the doctor.
- Get your child an eye exam as you have been told by the doctor.
- High blood pressure has happened with this drug. Have your child's blood pressure checked as you have been told by the doctor.
- Avoid giving your child grapefruit and grapefruit juice.
- Avoid giving your child Seville oranges.
- As your child grows, your child's doctor may change your child's dose. Give this drug as your child's doctor has told you.
- This drug caused fertility problems in animals. It is not known if it will cause fertility problems in humans. Talk with the doctor.

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

- This drug may cause harm to an unborn baby. Your child must use birth control while taking this drug. If your child gets pregnant, call your child's 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 fluid and electrolyte problems like mood changes, confusion, muscle pain or weakness, fast or abnormal heartbeat, severe dizziness or passing out, increased thirst, seizures, feeling very tired or weak, decreased appetite, unable to pass urine or change in the amount of urine produced, dry mouth, dry eyes, or severe upset stomach or throwing up.
- Signs of high blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- 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.
- Any unexplained bruising or bleeding.
- Not able to pass urine or change in how much urine is passed.
- Change in eyesight.
- Depression.
- Weakness on 1 side of the body, trouble speaking or thinking, change in balance, drooping on one side of the face, or blurred eyesight.

#### 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:

- Stomach pain.
- Decreased appetite.
- Gas.
- Feeling tired or weak.
- Signs of a common cold.
- Back, bone, joint, or muscle pain.
- Weight loss.
- Headache.
- Constipation, diarrhea, throwing up, and upset stomach are common with this drug. If these happen, talk with your child's doctor about ways to lower these side effects. Call your child's doctor right away if any of these effects bother your child, do not go away, or are severe.

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 meals.
- Have your child swallow whole with a full glass of water.
- Do not let your child chew or crush.

- If your child cannot swallow this drug whole, you may mix the contents of the capsule with applesauce, orange juice, or certain other liquids (Ora Blend SF, Ora-Plus). Follow how to mix as you have been told. Give within 10 minutes after mixing. Do not store for future use.
- Do NOT mix with juice that has grapefruit or Seville oranges in it.
- Keep giving this drug to your child as you have been told by your child's doctor or other health care provider, even if your child feels well.

#### What do I do if my child misses a dose?

- Give a missed dose as soon as you think about it, with food.
- If it is less than 8 hours until your child's next dose, 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.
- 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**

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#### **Last Reviewed Date**

2020-11-25

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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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