PATIENT & CAREGIVER EDUCATION

Rebisufligene Etisparvovec

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

Fayuvi 10.1 to 12kg; Fayuvi 12.1 to 14kg; Fayuvi 14.1 to 16kg; Fayuvi 16.1 to 18kg; Fayuvi 18.1 to 20kg; Fayuvi 2.5 to 3kg; Fayuvi 20.1 to 22kg; Fayuvi 22.1 to 24kg; Fayuvi 24.1 to 26kg; Fayuvi 26.1 to 28kg; Fayuvi 28.1 to 30kg; Fayuvi 3.1 to 4kg; Fayuvi 30.1 to 32kg; Fayuvi 32.1 to 34kg; Fayuvi 34.1 to 36kg; Fayuvi 36.1 to 38kg; Fayuvi 38.1 to 40kg; Fayuvi 4.1 to 5kg; Fayuvi 40.1 to 42kg; Fayuvi 42.1 to 46kg; Fayuvi 46.1 to 50kg; Fayuvi 5.1 to 6kg; Fayuvi 50.1 to 54kg; Fayuvi 54.1 to 58kg; Fayuvi 58.1 to 62kg; Fayuvi 6.1 to 7kg; Fayuvi 62.1 to 66kg; Fayuvi 66.1 to 70kg; Fayuvi 7.1 to 8kg; Fayuvi 8.1 to 9kg; Fayuvi 9.1 to 10kg

What is this drug used for?

- It is used to treat mucopolysaccharidosis type IIIA (MPS IIIA or Sanfilippo syndrome type A).

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 getting a vaccine or has had a vaccine within the last 30 days.
- If your child is taking any drugs that can raise the chance of liver problems. There are many drugs that can do this. Ask the doctor or pharmacist if you

are not sure.

- If your child is pregnant or may be pregnant.

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.
- Have your child's blood work and other lab tests checked as you have been told by the doctor.
- Your child may bleed more easily. This has usually happened within 2 weeks after getting this drug. Make sure your child is careful and avoids injury. Be sure your child has a soft toothbrush.
- This drug may be passed to others through body fluids after the infusion. This happens through blood, saliva, urine, stools, and semen. Talk with the doctor about how to avoid spreading this drug to others. Be sure to wash hands well and dispose of anything that comes into contact with body fluids as you have been told. You will need to do this for 3 months after your child gets this drug.
- There is a chance that this drug could raise the risk of cancer. Talk with the doctor if you have questions.
- If your child's weight changes, talk with the doctor. The dose of this drug may need to be changed.
- A pregnancy test may need to be done to show that your child is NOT pregnant before starting this drug.

If your child is breast-feeding a baby:

- 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 liver problems like dark urine, tiredness, decreased appetite, upset stomach or stomach pain, light-colored stools, throwing up, or yellow skin or eyes.
- Call the doctor right away if your child has any signs of bleeding problems, like bruising; black, tarry, or bloody stools; bleeding gums; blood in the urine; coughing up blood; cuts that take a long time to stop bleeding; feeling dizzy; feeling very tired or weak; nosebleeds; pain or swelling; throwing up blood or throw up that looks like coffee grounds; or very bad headache.
- 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 blood pressure like very bad headache or dizziness, passing out, or change in eyesight.
- Signs of a weak adrenal gland like a severe upset stomach or throwing up, severe dizziness or passing out, muscle weakness, feeling very tired, mood changes, decreased appetite, or weight loss.
- Signs of Cushing's syndrome like weight gain in the upper back or belly,

moon face, severe headache, or slow healing.

- Signs of low potassium levels like muscle pain or weakness, muscle cramps, or a heartbeat that does not feel normal.
- Seizures.
- Behavior problems.
- Feeling very tired or weak.
- Trouble walking.
- Infusion reactions have happened with this drug. Tell the doctor right away if your child has dizziness, passing out, fever, chills, abnormal heartbeat, upset stomach, throwing up, headache, or any other effects during or after the infusion.
- Low white blood cell counts have happened with this drug. This may lead to a higher chance of getting an infection. Call your child's doctor right away if your child has signs of infection like fever, chills, or sore throat.

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:

- Diarrhea.
- Constipation.
- Decreased appetite.
- Muscle spasm.

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.
- A steroid drug like prednisone or prednisolone will be given before and after this drug. Tell the doctor if your child misses a dose of the steroid or throws up after taking it.

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?

- 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 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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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 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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