PATIENT & CAREGIVER EDUCATION

# Eladocagene Exuparvovec

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

Kebilidi

## What is this drug used for?

- It is used to treat aromatic L-amino acid decarboxylase (AADC) deficiency.

## 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 the skull is still growing.

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.
- 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.
- After getting this drug, blood, urine, stools, and other body fluids may have this drug in them. You will need to take special care for 3 weeks after your child gets this drug. Put anything that may have these body fluids on them in a sealed bag and throw it away in household waste. Wear gloves for dressing changes and anybody who may come into contact with these body fluids needs to wash their hands well. If you have questions, talk with your child's doctor.

- A neurosurgery procedure is needed before the use of this drug. Sometimes, health problems have happened within 24 hours of the procedure. Your child will be watched closely after the procedure.
- If your child is of childbearing age, a pregnancy test may need to be done before starting this drug to show that your child is NOT pregnant.

### If your child is or may be sexually active:

- Your child may need to use birth control to prevent pregnancy while taking this drug and for some time after the last dose. Talk with the doctor to see if your child needs to use birth control.
- Tell the doctor if your child is pregnant or becomes pregnant. You will need to talk about the benefits and risks of your child using this drug while pregnant.

### 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 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.
- Severe dizziness or passing out.
- Fever.
- Feeling very tired or weak.
- Trouble controlling body movements has happened within 3 months after the use of this drug. Rarely, this needed to be treated in a hospital. Call your child's doctor right away if your child has trouble controlling body movements (in the face, arm, leg, or whole body); fidgeting, twisting, or squirming movements; head bobbing; or body swaying.

## 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:

- More saliva.
- 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 part of the brain.

## 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 healthcare setting. 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.

## 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 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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