#### **MSK Kids**

#### PATIENT & CAREGIVER EDUCATION

## Risdiplam

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** 

Evrysdi

**Brand Names: Canada** 

Evrysdi

#### What is this drug used for?

• It is used to treat spinal muscular atrophy.

# 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.

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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 stop giving this drug without calling the doctor who ordered it for your child.
- If your child's weight changes, talk with the doctor. The dose of this drug may need to be changed.
- This drug may affect being able to father a child. Talk with the doctor.
- If your child is of childbearing age, a pregnancy test will need to be done before starting this drug to make sure your child is not pregnant.

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

- This drug may cause harm to the unborn baby if your child takes it during pregnancy.
- If your child may become pregnant, have your child use birth control while taking this drug and for 1 month after the last dose. If your child becomes pregnant, call the doctor right away.
- If your child's sex partner may become pregnant, birth control may need to be used while taking this drug and for some time after your child's last dose. Talk with the doctor.

#### 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;

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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 a urinary tract infection (UTI) like blood in the urine, burning or pain when passing urine, feeling the need to pass urine often or right away, fever, lower stomach pain, or pelvic pain.
- Shortness of breath.
- Cough.

### 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:

- Mild fever.
- Diarrhea or constipation.
- Throwing up.
- Mouth sores.
- Joint pain.
- Signs of a common cold.

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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 after a meal.
- Give this drug at the same time of day.
- Your pharmacist or other health care provider will need to mix this drug before you get it.
- Measure liquid doses carefully. Use the measuring device that comes with this drug.
- Give the dose within 5 minutes after you draw it into the oral syringe. Do not store this drug in the syringe. If not given within 5 minutes, prepare a new dose.
- Have your child drink water after taking this drug to make sure the dose is fully swallowed.
- Rinse the measuring device with water after each use.

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- If your child is not able to swallow the whole dose or throws up after taking a dose, do not repeat the dose.
  Give the next dose at your child's normal time.
- Those who have feeding tubes may use this drug. Use as you have been told. Flush the feeding tube after this drug is given.
- If you get this drug on the skin, wash it off right away with soap and water.
- If this drug gets in the eyes, rinse with cool water.

### Young children:

- If the patient is an infant who is breast-feeding, give this drug after breast-feeding. Do not mix this drug with formula or milk.
- Have your child sit upright to take a dose. Place the tip of the syringe into the mouth on the inside of the cheek. Gently push the plunger until all the drug is gone. Do not squirt quickly. This could cause choking.

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

- Give a missed dose as soon as you think about it.
- If it has been 6 hours or more since the missed dose, skip the missed dose and go back to your child's normal time.

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• Do not give 2 doses at the same time or extra doses.

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

- Store in a refrigerator. Do not freeze. Throw away any unused part 64 days after this drug was mixed. Talk with your pharmacist if you are not sure when this is.
- If needed, this drug can be stored at room temperature up to 104°F (40°C) for a total of 5 days. This drug can be removed from, and returned to, a refrigerator. If this drug has been kept at room temperature for more than a total of 5 days, throw it away.
- Avoid temperatures higher than 104°F (40°C). Do not take this drug if it has been at a temperature higher than 104°F (40°C).
- Store in the original container to protect from light.
- Store upright with the cap on.
- 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.

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#### **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**

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

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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

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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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