PATIENT & CAREGIVER EDUCATION

C1 Inhibitor (Human

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

Berinert; Cinryze; Haegarda

Brand Names: Canada

Berinert; Cinryze [DSC]; Haegarda

What is this drug used for?

- It is used to treat swelling attacks in people with hereditary angioedema (HAE).
- It is used to prevent swelling attacks in people with hereditary angioedema (HAE).

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.

This drug may interact with other drugs or health problems.

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?

All products:

- 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.
- The doctor will give you another drug (epinephrine) to use in case of an allergic reaction. Keep it with your child at all times while your child takes this drug. Be sure you know how and when to give it. Get medical help right away after giving epinephrine.
- Blood clots have happened with this drug. The chance may be raised if your child has a certain type of catheter or device in a vein or if your child takes certain drugs like estrogens or androgens. The chance may be raised if your child has ever had heart or blood vessel disease, stroke, thick blood, or a blood clot. The chance may also be raised if your child has not been able to move around for some time. Talk with the doctor.
- This drug is made from human plasma (part of the blood) and may have viruses that may cause disease. This drug is screened, tested, and treated to lower the chance that it carries an infection. Talk with the doctor.
- Talk with the doctor before your child travels. Your child will need to bring enough of this drug for use during travel.
- If your 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:

- Talk with the doctor if your child is pregnant, becomes pregnant, or is breast-feeding a baby. You will need to talk about the benefits and risks to your child and the baby.

Berinert:

- If you gave this drug to treat swelling of the face, lips, tongue, or throat, get medical help right away after giving it.

All other products:

- This drug will not treat HAE attacks. This drug is only used to prevent these health problems. Talk with the doctor to if you have questions about how to treat HAE attacks.

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.
- Very bad dizziness or passing out.
- Change in color of mouth to blue.
- A fast heartbeat.
- Very bad headache.
- Weakness on 1 side of the body, trouble speaking or thinking, change in balance, drooping on one side of the face, or blurred eyesight.
- Call the doctor right away if your child has signs of a blood clot like chest pain or pressure; coughing up blood; shortness of breath; swelling, warmth, numbness, change of color, or pain in a leg or arm; or trouble speaking or swallowing.

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:

Haegarda:

- Irritation where the shot is given.
- Nose or throat irritation.
- Dizziness.

All other products:

- Upset stomach or throwing up.
- Headache.
- Bad taste in your child's mouth.

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.

All products:

- Some products need to be given into a vein. Some products need to be given into the fatty part of the skin. Talk with the doctor or pharmacist if you are not sure how to use this drug.
- If you will be giving your child the shot, your child's doctor or nurse will teach you how to give the shot.

- This drug needs to be mixed before use. Follow how to mix as you were told by the doctor.
- Do not shake.
- If stored in a refrigerator, let this drug come to room temperature before mixing. Do not heat this drug.
- After mixing, be sure you know how long the product is good for and how to store it. Ask the doctor or pharmacist if you are not sure.
- Different brands of this drug may be clear or have a slight color. Be sure you know what your brand needs to look like when ready to use. Do not use if the solution changes color. If you are not sure, talk with the pharmacist.
- Do not use if the solution is cloudy, leaking, or has particles.
- Throw away any part left over after the dose is given.
- Throw away needles in a needle/sharp disposal box. Do not reuse needles or other items. When the box is full, follow all local rules for getting rid of it. Talk with a doctor or pharmacist if you have any questions.

Haegarda:

- Move the site where you give the shot with each shot.

What do I do if my child misses a dose?

Berinert:

- This drug is given on an as needed basis. Do not give to your child more often than told by the doctor.

All other products:

- Give a missed dose as soon as you think about it.
- If it is close to the time for 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 or in a refrigerator. Do not freeze.
- Store in the original container to protect from light.
- After mixing, do not refrigerate or freeze.
- Do not use if it has been frozen.
- 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 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

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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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