Memorial Sloan Kettering Cancer Center

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 my doctor BEFORE I take this drug?

- If you are allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell your doctor about the allergy and what signs you had.

This drug may interact with other drugs or health problems.

Tell your doctor and pharmacist about all of your drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe for you to take this drug with all of your drugs and health problems. Do not start, stop, or change the dose of any drug without checking

with your doctor.

## What are some things I need to know or do while I take this drug?

### All products:

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- Your doctor will give you another drug (epinephrine) to use in case of an allergic reaction. Keep it with you at all times while taking this drug. Be sure you know how and when to use it. Get medical help right away after using epinephrine.
- Blood clots have happened with this drug. The chance may be raised if you have a certain type of catheter or device in a vein or if you take certain drugs like estrogens or androgens. The chance may be raised if you have ever had heart or blood vessel disease, stroke, thick blood, or a blood clot. The chance may also be raised if you have not been able to move around for some time. Talk with your 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 you travel. You will need to bring enough of this drug for use during travel.
- If your weight changes, talk with your doctor. The dose of this drug may need to be changed.
- Tell your doctor if you are pregnant, plan on getting pregnant, or are breast-feeding. You will need to talk about the benefits and risks to you and the baby.

### Berinert:

- If using this drug to treat swelling of the face, lips, tongue, or throat, get medical help right away after using 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 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 doctor or get medical help right away if you have 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 your doctor right away if you have 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 doctor or get medical help if any of these side effects or any other side effects bother you 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 mouth.

These are not all of the side effects that may occur. If you have questions about side effects, call your doctor. Call your doctor for medical advice about side effects.

You may report side effects to your national health agency.

You may report side effects to the FDA at 1-800-332-1088. You may also report side effects at https://www.fda.gov/medwatch.

## How is this drug best taken?

Use this drug as ordered by your 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 yourself the shot, your 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 I miss a dose?

### Berinert:

- This drug is used on an as needed basis. Do not use more often than told by the doctor.

### All other products:

- Take a missed dose as soon as you think about it.
- If it is close to the time for your next dose, skip the missed dose and go back to your normal time.
- Do not take 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 symptoms or health problems do not get better or if they become worse, call your doctor.
- Do not share your drugs with others and do not take anyone else's drugs.
- 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.
- Some drugs may have another patient information leaflet. Check with your pharmacist. 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.

## 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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