

## PATIENT & CAREGIVER EDUCATION

# Cysteamine (Ophthalmic)

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

Cystadrops; Cystaran

## Brand Names: Canada

Cystadrops

## What is this drug used for?

- It is used to get rid of a protein called cystine from the eye.

## 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?**

- 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 use care when doing tasks that call for clear eyesight.
- Bright lights may bother your child. Have your child wear sunglasses.

### **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.

## **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.
- Change in eyesight, eye pain, or severe eye irritation.

## **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:

- Headache.
- Eye irritation.

- Eye redness.
- Eye is bothered by bright light.
- Blurred eyesight.
- More tears.

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:**

- For the eye only.
- Have your child take out contact lenses before using this drug. Lenses may be put back in 15 minutes after this drug is given. Do not put lenses back in if your child's eyes are irritated or infected.
- Do not touch the container tip to the eye, lid, or other skin. This could lead to bacteria in the drug, which may cause severe eye problems or loss of eyesight.
- Wash your hands before use.
- Tilt your child's head back and drop drug into the eye.
- After use, have your child keep eyes closed. Put pressure on the inside corner of the eye. Do this for 1 to 2 minutes. This keeps the drug in the eye.
- Give your child's last dose of the day at least 30 minutes before bedtime.
- If more than 1 drug is being used in the same eye, use the drugs at least 10 minutes apart.

## **Cystadrops:**

- You will need to prepare the bottle before first use. Follow what you have been told by the doctor or read the package insert.

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

- 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?**

### **Cystadrops:**

- Store unopened bottles in the refrigerator. Do not freeze.
- Each week, take out a new bottle from the refrigerator to use for that week. Store at room temperature.
- Store in the original container to protect from light.
- Store opened bottles at room temperature. Throw away any part not used after 7 days.
- Keep lid tightly closed.

### **Cystaran:**

- Some of these products must be frozen before opening. Some must be stored in the refrigerator before opening. These products are also stored differently after opening. Be sure you know which product you have. Talk with your pharmacist if you have any questions about how to store your drug.

## **Cystaran (frozen before opening):**

- Store unopened bottles in the freezer. Do not take out of the foil wrap until ready to use.
- Each week, take out a new bottle from the freezer to use for that week. Store in a refrigerator or at room temperature.
- Let bottle thaw for 24 hours before using.
- Do not put bottle back in the freezer after thawing.
- Keep lid tightly closed.
- Throw away any part of thawed bottle not used after 7 days.

## **Cystaran (refrigerated before opening):**

- Store unopened bottles in the refrigerator. Do not take out of the foil wrap until ready to use.
- After opening, store at room temperature.
- Keep lid tightly closed.
- Throw away any part of thawed bottle not used after 7 days.

## **All products:**

- 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 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](http://www.mskcc.org/pe) to search our virtual library.

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