



Mercaptamine eye drops for ocular symptoms of cystinosis

This leaflet is about the use of mercaptamine eye drops for ocular (eye) symptoms of cystinosis.



This leaflet has been written specifically about the use of this medicine in children. The information may differ from that provided by the manufacturer. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Name of drug

Mercaptamine eye drops (cysteamine)

Why is it important to take this medicine?

In cystinosis there is an increase in the amount of an amino acid called cystine in the eyes and other organs of the body. The cystine can build up and form crystals in the eyes, which could lead to blindness. Mercaptamine eye drops will reduce the build up of cystine in your child's eyes.

What is mercaptamine available as?

- **Eye drops:** 0.11% (10 mL) and 0.55% (50 mL) available from a special-order manufacturer or specialist importing companies

When should I give mercaptamine?

Mercaptamine eye drops are usually given **four to six** times a day. Ideally, these times are at least 2–4 hours apart. Give the drops at about the same time(s) each day so that this becomes part of your child's daily routine, which will help you to remember.

How much should I give?

Your doctor will work out the amount of mercaptamine eye drops (the dose) that is right for *your* child. The dose will be shown on the medicine label.

 **It is important that you follow your doctor's instructions about how much to give.**

How should I give it?

You may need help from another adult to help give eye drops, especially in small children and babies. One of you can hold the child still and one can give the drops. You may find it helpful to wrap a small child or baby in a blanket to help keep them still.

- Use the eye drops in both eyes, unless your doctor has told you otherwise.
- Wash your hands thoroughly with soap and hot water before and after giving the drops.
- The eye drops are easiest to give when your child is lying down.
- For older children, gently pull the lower lid out and squeeze the bottle gently so that one drop goes into the pocket that is formed.

- In small children and babies, place the drop into the inner corner of the eye (preferably with the eye open, but the liquid will still drain on to the eye even with a closed eye if you can hold your child's head still for a few seconds).



- After giving eye drops, your child should keep the eye closed for as long as they can (5 seconds if possible) so that the eye drop doesn't spill out.
- If you think the drop didn't go into the eye, you can repeat the process but do not try more than twice.
- Try to avoid the tip of the bottle/dropper touching any part of your child's eye if possible.
- Wash your hands again with soap and water.

When should the medicine start working?

Mercaptamine eye drops should start working in a few days and your child's vision should start to improve.

What if my child is sick (vomits)?

You do not need to worry if your child is sick, as the medicine will still work.

What if I forget to give it?

Do not give the missed dose. Just give the next dose as usual.

What if I give too much?

You are unlikely to do harm if you give an extra dose of mercaptamine eye drops.

If your child accidentally swallows mercaptamine, it is unlikely to do harm. However, if you notice any unusual effects or are worried, contact your doctor or NHS Direct (0845 4647 in England and Wales; 08454 24 24 24). Have the medicine or packaging with you if you telephone for advice.

Are there any possible side-effects?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects).

Your child is unlikely to get side-effects with mercaptamine eye drops. Any side-effects that do occur are usually mild and will wear off after a few days.

- Mercaptamine may cause your child to have an unpleasant smell on their breath. This can be masked using breath fresheners.

Can other medicines be given at the same time as mercaptamine?

- You can give your child medicines that contain paracetamol or ibuprofen, unless your doctor has told you not to.
- Check with your doctor or pharmacist before giving any other medicines to your child. This includes herbal or complementary medicines.

Is there anything else I need to know about this medicine?

- Mercaptamine eye drops are manufactured by special-order manufacturers and therefore it may take longer than normal for your local pharmacist to get hold of them. Make sure that you go to your GP for a new prescription at least 3 weeks before you are going to run out.
- A separate leaflet about mercaptamine for nephropathic cystinosis is available on the Medicines for Children website, www.medicinesforchildren.org.uk

General advice about medicines

- Try to give medicines at about the same times each day, to help you remember.
- If you are not sure a medicine is working, contact your doctor but continue to give the medicine as usual in the meantime. Do not give extra doses as you may do harm.
- Only give this medicine to *your* child. Never give it to anyone else, even if their condition appears to be the same, as this could do harm.
- If you think someone else may have taken the medicine by accident, or swallowed some eye drops, contact your doctor.
- Make sure that you always have enough medicine. Order a new prescription at least 3 weeks before you will run out.
- Make sure that the medicine you have at home has not reached the 'best before' or 'use by' date on the packaging. Give old medicines to your pharmacist to dispose of.

Where should I keep this medicine?

- Keep the medicine in a cupboard, away from heat and direct sunlight. It does not need to be kept in the fridge.
- Make sure that children cannot see or reach the medicine.
- Keep the medicine in the container it came in.

Who to contact for more information

Your child's doctor, pharmacist or nurse will be able to give you more information about mercaptamine eye drops and about other medicines used to treat ocular symptoms of cystinosis.

You can also get useful information from:

NHS Direct (England)

0845 4647

www.nhsdirect.nhs.uk

NHS 24 (Scotland)

08454 24 24 24

www.nhs24.com

NHS Direct Wales/Galw Iechyd Cymru

0845 4647

www.nhsdirect.wales.nhs.uk

NI Direct (Northern Ireland)

www.nidirect.gov.uk

Cystinosis Foundation UK

www.cystinosis.org.uk

www.medicinesforchildren.org.uk