

Idebenone for Friedreich's ataxia

This leaflet is about the use of Idebenone for Friedreich's ataxia.



This leaflet has been written for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adult patients. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

Name of drug

Idebenone

Why is it important for my child to take this medicine?

Friedreich's ataxia is an inherited disease that gradually damages parts of the nervous system. This causes problems throughout the body but particularly the heart. Taking idebenone regularly will help to prevent or slow down damage to the heart.

What is idebenone available as?


- **Tablets:** 45 mg

When should I give idebenone?

Idebenone is usually given **three times** a day. This should be first thing in the morning, early afternoon and at bedtime. Ideally, these times are at least 4 hours apart.

How much should I give?

Your doctor will work out the amount of idebenone (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?

Your child should have something to eat when they take the tablets.



Tablets should be swallowed with a glass of water, milk or juice. Your child should not chew the tablet.

You can crush the tablet and mix it with a small amount of soft food such as yogurt, jam or mashed potato. Make sure your child swallows it straight away, without chewing.

When should the medicine start working?

The medicine will start working straight away, although you won't be able to see the effects. Your doctor will check your child's heart to see whether idebenone is helping.

What if my child is sick (vomits)?

- If your child is sick less than 30 minutes after having a dose of idebenone, give them the same dose again.
- If your child is sick more than 30 minutes after having a dose of idebenone, you **do not** need to give them another dose. Wait until the next normal dose.

If your child is sick again, seek advice from your GP, pharmacist or hospital. They will decide what to do based on your child's condition and the specific medicine involved.

What if I forget to give it?

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

 **Never give a double dose of idebenone.**


What if I give too much?

If you are concerned that you may have given too much, contact your doctor or local NHS services (111 England and Scotland; 0845 4647 in Wales). 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).

Side-effects you must do something about

 If your child gets a fever (temperature above 38°C), sore throat, rash or mouth ulcers, contact your doctor straight away. This is because idebenone may affect the white blood cells (neutropenia), which makes it harder for your child's body to fight infection.

Other side-effects you need to know about

Your child may get the following side-effects when they first start taking idebenone. They should wear off as your child's body gets used to the medicine. If they are still a problem after a week or so, contact your doctor.

- Your child may have an upset stomach, stomach pain (cramps) and may feel sick or be sick (vomit). Giving each dose with some food may help.
- Your child may get diarrhoea.
- Your child may feel tense, nervous, restless or on edge when they first start taking idebenone.
- They may have difficulty sleeping (insomnia). You can try giving the medicine earlier in the evening.
- They may get a headache.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at <http://www.mhra.gov.uk/yellowcard>.

More information on side-effects can be found in the following leaflet <http://www.medicinesforchildren.org.uk/side-effects-childrens-medicines>

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

- 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.

General advice about medicines

- Try to give medicines at about the same times each day, to help you remember.
- 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 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.



If you think someone else may have taken the medicine by accident, contact your doctor straight away.

- Make sure that you always have enough medicine. Order a new prescription at least 2 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 idebenone and about other medicines used to treat Friedreich's ataxia.

You can also get useful information from:

England – NHS 111

111 - www.nhs.uk

Scotland – NHS 24

111 - www.nhs24.com

Wales/Galw Lechyd Cymru – NHS Direct

0845 4647 - www.nhsdirect.wales.nhs.uk

Northern Ireland – NI Direct

www.nidirect.gov.uk

Ataxia UK

0845 644 0606 - www.ataxia.org.uk

www.medicinesforchildren.org.uk