Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Iloprost

This information should be read in conjunction with any patient information leaflet provided by the manufacturer. However, please note that this information sheet explains about the use of iloprost in children and young people so may differ from the manufacturer's information.

This information sheet explains about iloprost, how it is given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer every side effect mentioned. If you are concerned about any of these side effects, please ring one of the contact numbers on this information sheet and ask for your doctor, nurse or pharmacist.

What is iloprost?

Iloprost is known as a prostaglandin. It acts by imitating a naturally occurring substance in the body called prostacyclin. It is prescribed at GOSH to treat pulmonary hypertension (high blood pressure in the blood vessels in the lungs). It works by lowering blood pressure by widening the blood vessels in the lungs.

The use of iloprost in children is not currently licensed in the UK. Medicines are often used outside of their license (off-label) in children because trial data is not available for a specific use. Prescribing medicines 'off label' is not necessarily hazardous but should be explained and agreed before use.

How is it given?

Iloprost is available as a 10microgram/ml solution which should be administered via a specific nebuliser called an i-Neb®. The nebuliser changes the solution into a mist which is then inhaled. Breathing in the mist carries the iloprost directly to the blood vessels in the lungs making them widen. Your doctor, nurse or pharmacist will have explained to you how to give the dose before you leave hospital. When using the nebuliser, always make sure the room is well ventilated and that only a mouthpiece is used rather than a mask.

Who should not take iloprost?

People with the following conditions should discuss taking iloprost with their doctor:

- Hypersensitivity to iloprost or any of its ingredients
- Bleeding disorders
- Recent history of stroke or heart attack
- Pregnancy, possibility of pregnancy, trying to become pregnant or breastfeeding

What are the side effects of iloprost?

If any of these side effects are severe or persist for a long time, please tell the Pulmonary Hypertension team:

- Headache
- Dizziness or light-headedness (this may be helped by getting up slowly after sitting or lying down)
- Flushing
- Cough
- Tongue pain or throat irritation
- Wheeze

If any of the following side effects occur, please contact the Pulmonary Hypertension team for advice:

- Chest discomfort
- Muscle or jaw pain
- Coughing of blood or blood stained sputum
- Unexplained or prolonged episodes of bleeding

Some people develop an allergic reaction to iloprost, which may be mild or severe. Signs of a mild reaction include skin rashes and itching, high temperature, shivering, redness of the face, a feeling of dizziness or a headache. If you see any of these signs please report them to a doctor or nurse.

Signs of a severe allergic reaction include any of the above, as well as shortness of breath or chest pain. If you are in hospital and your child shows signs of a severe allergic reaction, call a doctor or nurse immediately. If you are at home, call an ambulance immediately. If your child has a severe reaction to iloprost, subsequent treatment will be changed.

Iloprost and other medicines

Some medicines can interact with iloprost and may alter its effects. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.

- Iloprost should not be taken with the following medicines except upon the advice of your doctor:
- Antihypertensives (blood pressure medicine)
- Anticoagulants and antiplatelets (blood thinning medicine)
- Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen

Useful numbers

GOSH switchboard: 020 7405 9200

Pharmacy medicines information: 020 7829 8608 from Monday to Friday from 9am to 5pm

Pulmonary hypertension team: extension 1664 or 1494 via switchboard

Compiled by the Pharmacy Department and Pulmonary Hypertension team in collaboration with the Child and Family Information Group Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH www.gosh.nhs.uk