



## Using CICLOSPORIN after a bone marrow transplant

# Information for families

This information sheet from Great Ormond Street Hospital (GOSH) describes how this medicine is given and some of its possible side effects. Each person reacts differently to medicines so your child will not necessarily experience every side effect mentioned. If you have any questions or concerns, please ask your doctor, nurse or pharmacist or telephone one of the contact numbers of this information sheet.

### What is it for?

**Ciclosporin** is a medicine that is used to treat many different conditions. It belongs to a group of medicines known as immunosuppressive agents. These medicines are used to lower the body's immune response to prevent rejection of organs such as kidneys after a transplant. It is also used both before and after bone marrow transplants.

The prescriber must always specify the brand of ciclosporin because even at the same dose, there are differences in how much actually gets into the body. You must always ensure that you obtain the same brand each time unless your doctor has advised you otherwise.

### Monitoring the level of medicine in the blood

Your child may have a blood test to monitor the amount of medicine in their blood. Doses of the medicine may be changed depending on the result.

### What are the side-effects?

#### **Nausea and vomiting**

Anti-sickness drugs can be given to reduce or prevent these symptoms. Please tell your doctor or nurse if your child's sickness is very bad or continues for more than a few days.

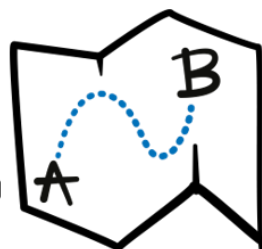
#### **Headache**

These symptoms can be reduced or prevented by giving your child painkillers. Mild painkillers, such as paracetamol, are usually enough to prevent headaches due to ciclosporin. If your child has headaches, please tell your doctor as the dose of ciclosporin may need to be changed.

### How is it given?

Ciclosporin is given by mouth in the form of capsules or liquid. It can also be given as an infusion into a vein (intravenously) through a central venous catheter, implantable port or PICC. It is usually given twice a day. Some children are taking a dose that means they will be given a combination of the liquid and capsules.

The liquid can be mixed with a strong tasting liquid such as orange juice, squash or apple juice to improve the taste. It can also be mixed with water. The liquid should be mixed immediately before taking, rinsing the glass with some more liquid to make sure none of the medicine is left behind. You must always use the same liquid for each dose.



## Excess hair growth

If this concerns your child, please tell your doctor.

## Mild shakes

If your child complains of shakiness or tremor, please tell your doctor, as the dose of ciclosporin may need to be changed.

## Gum overgrowth (gingival hypertrophy)

This is a common problem. However, very thorough teeth cleaning will reduce the overgrowth but does not prevent it. If your child's gums overgrow, it can be treated with intensive cleaning, use of a special spray or gel twice a day or with a small operation.

## Sensitivity to sun

While your child is taking this medicine, they should use an effective sunscreen (SPF 50 or above) and wear a hat whenever outdoors.

## Burning sensation in the feet and hands

Please tell your doctor if your child complains of this, as their ciclosporin dose may need to be changed.

## Altered kidney function

Ciclosporin may cause mild changes to your child's kidney function. This should return to normal when treatment stops. Blood tests may be needed on a regular basis to check how well your child's kidneys are working.

## Increase in blood pressure

This should also return to normal when your child stops treatment. Their blood pressure will be checked on a regular basis and medicine given if needed to lower it.

## Decrease in magnesium levels in the blood

This may mean that your child needs to take magnesium supplements to bring the concentration of magnesium in the blood up to the

right level. Your doctor will decide if this is necessary.

## Secondary cancers

There is a very small chance that some children on long-term ciclosporin might develop a type of tumour. If you feel you need more information about this, please talk to your child's doctor.

## Damage to the unborn baby

Ciclosporin must not be handled or given to patients who may be pregnant or are likely to become pregnant in the near future. This includes anyone who is giving the medicine to your child.

If your daughter is ten years old or older, we will ask her about her periods and any possibility that she could be pregnant. If your daughter is sexually active, she must use a reliable form of contraception.

If you are concerned about any of these side effects, please discuss them with your doctor or pharmacist.

## Who should not take ciclosporin (contraindications)?

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

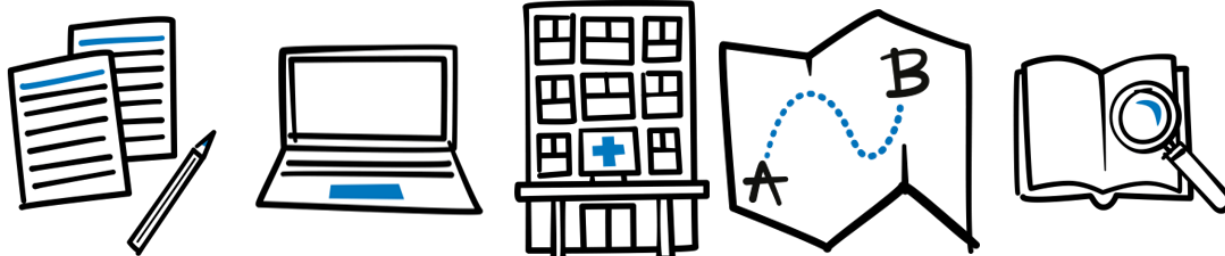
- Malignancy (in non-transplant indications)
- Uncontrolled hypertension (in non-transplant indications)
- Uncontrolled infections (in non-transplant indications)

## Ciclosporin and other medications

Some medicines can interact with ciclosporin,

**Always check with your doctor or pharmacist before giving your child any other medicines, including herbal or complementary medicines.**

The following medicines are known to interact with ciclosporin:



- Grapefruit juice: This can increase in amount of ciclosporin absorbed from the stomach so is best avoided while taking ciclosporin.

Please discuss with your doctor or pharmacist before giving them to your child.

### **Guidance for immunosuppressant medicines**

#### **Chicken pox**

If your child is on ciclosporin and has not had chickenpox but comes into contact with someone who has chicken pox or shingles (either face to face or longer than 15 minutes in the same room), you should report to your doctor immediately as your child may be at risk of developing a more severe form of the infection and may need special treatment.

If your child develops chicken pox or shingles, you should also report to your doctor immediately for medication (antivirals) to be given. If you are unsure whether your child has had chicken pox before starting ciclosporin, their immunity should be checked with a simple blood test at that time and the result entered on the parent-held record.

#### **Immunisations**

Your doctor will advise you if your child should avoid immunisation after transplant. Your child should NOT have any live vaccinations such as MMR, oral polio, chicken pox or BCG while taking

ciclosporin. Inactivated or killed vaccines such as influenza/flu, meningitis C, pneumococcal, hepatitis, Hib, tetanus, diphtheria, whooping cough/pertussis and the killed version of the polio immunisation are permitted if the patient is stable under treatment.

If you have other children who need vaccines while your child is taking ciclosporin, they should have these as normal, but they should also receive the 'killed' or inactivated polio vaccine. If you have any questions about vaccines and immunisations, please ask your doctor.

#### **Important**

- Keep medicines in a safe place where children cannot reach them.
- Keep medicines in a cool, dry place out of direct sunlight and away from heat.
- If your doctor decides to stop treatment with ciclosporin, return any unused medicine to your pharmacist. Do not flush down the toilet or throw it away.
- If you forget to give your child a dose, give it as soon as you remember. Do not give a double dose if it is already time to give the next one.
- Some medicines will need to be ordered by your local pharmacist- ask your GP for another prescription with enough time (when you have about 2 weeks of your medicine left) to ensure you do not run out.

### **For further information please contact:**

**Medicines Information: 020 7829 8608** or via the Medications page on the MyGOSH app (available Monday – Friday, 9am - 5pm excluding Bank Holidays)

GOSH switchboard: 020 7405 9200 or contact your clinical team directly via the MyGOSH app

#### **Disclaimer**

Please read this information sheet from GOSH alongside the patient information leaflet (PIL) provided by the manufacturer. If you do not have a copy of the manufacturer's patient information leaflet please talk to your pharmacist. A few products do not have a marketing authorisation (licence) as a medicine and therefore there is no PIL. For children in particular, there may be conflicts of information between the manufacturer's patient information leaflet (PIL) and guidance provided by GOSH and other healthcare providers. For example, some manufacturers may recommend, in the patient information leaflet, that a medicine is not given to children aged under 12 years. In most cases, this is because the manufacturer will recruit adults to clinical trials in the first instance and therefore the initial marketing authorisation (licence) only covers adults and older children. For new medicines, the manufacturer then has to recruit children and newborns into trials (unless the medicine is not going to be used in children and newborns) and subsequently amend the PIL with the approved information. Older medicines may have been used effectively for many years in children without problems but the manufacturer has not been required to collect data and amend the licence. This does not mean that it is unsafe for children and young people to be prescribed such a medicine 'off-licence/off-label'. However, if you are concerned about any conflicts of information, please discuss with your doctor, nurse or pharmacist.

