

## Orbital sclerotherapy: information for families

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**This information sheet explains about orbital sclerotherapy, why it might be suggested and what to expect when your child comes to Great Ormond Street Hospital (GOSH) for the procedure. Sclerotherapy is also used to treat lymphatic malformations and venous malformations elsewhere in the body. Information about these procedures is also available.**

Orbital sclerotherapy is a procedure used to treat a vascular malformation affecting the eye socket (orbit). Usually vascular malformations around the orbit are a collection of small cysts behind the eye. These are congenital, that is, they were present when your child was born. The cysts are filled with a clear fluid similar to the fluid in a blister. A medicine is injected into the malformation, which irritates them encouraging them to scar and shrink.

The cysts have no purpose and can cause problems. The walls of the cysts are quite thin and contain little blood vessels. Occasionally the blood vessels break and cause a clot to form inside the cyst. This can lead to sudden swelling and bruising of the area around the eye, pushing the eyeball forward. This can be painful and the appearance of the bruising can be upsetting. The cysts can also become infected. They can interfere with both the look and function of your child's eye. Sclerotherapy is a way of trying to reduce the size of the cysts so that they are smaller and less troublesome.

Sclerotherapy is carried out in the Department of Radiology by a doctor (radiologist) who specialises in using imaging to carry out procedures.



*Before orbital sclerotherapy*



*After orbital sclerotherapy*

## What happens before the sclerotherapy?

You will already have received information about how to prepare your child for the procedure in your admission letter. You may need to come to GOSH before the sclerotherapy so that your child can have a pre-admission assessment to check that they are well enough. This appointment is usually arranged for the day of the procedure and may involve taking photographs and eye tests.

The person bringing your child to the test should have 'Parental Responsibility' for them. Parental Responsibility refers to the individual who has legal rights, responsibilities, duties, power and authority to make decisions for a child. If the person bringing your child does not have Parental Responsibility, we may have to cancel the test.

An anaesthetist will visit to talk to you about your child's anaesthetic. The specialist eye doctors (ophthalmologists) will review your child during this appointment too.

You will then meet the radiologist who will carry out the procedure. They will explain it in more detail, discuss any questions you may have and ask you to sign a consent form giving permission for your child to have the sclerotherapy. If your child has any medical problems, please tell the doctors.

Many of the studies we perform involve the use of x-rays. Legally, we are obliged to ask any girls over the age of 12 whether there is any chance they might be pregnant. We may ask for a urine or blood sample for pregnancy testing. This is to protect babies in the womb from receiving unnecessary radiation.

## What does the sclerotherapy involve?

Orbital sclerotherapy is carried out while your child is under a general anaesthetic. It is important that your child does not eat or drink

anything for a few hours before the anaesthetic. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure. You will be informed the night before the procedure of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic.

It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.

Once your child is under general anaesthetic, the radiologist will check the malformation using an ultrasound scan. Using the ultrasound scan as a guide, they will insert a small needle through the eyelid into the malformation. If possible, the radiologist will use the needle to drain off some of the fluid inside the cysts.

They will then inject a small amount of contrast liquid through the needle and take an x-ray. This confirms whether it is safe to inject the medicine. They will then inject a very small amount of medicine (sclerosant) through the needle, which irritates and inflames the malformation causing swelling, but this goes down over the next few weeks.

Finally, the radiologist removes the needle. No stitches or dressings are needed – you will only be able to see a few pinpricks in the skin.

## Are there any risks?

Your child will be having sclerotherapy under general anaesthetic. Every anaesthetic carries a risk but this is extremely small. Sclerotherapy causes irritation and swelling, so the area treated will look worse than usual after the procedure. This is usually not a worrying sign as it shows the medicine is working. The area may feel bruised and sore for a few days, but your child will have pain relief.

There is a slightly higher risk of the malformation developing an infection after the procedure. Your child will need a short course of antibiotics if this happens.

As the medicine injected irritates the cysts, they are generally more prone to complications in the first week or two after the procedure. There is a slightly higher risk than usual of the cysts developing blood clots inside them. This causes sudden swelling and bruising, which may be uncomfortable. The swelling can also push your child's eyeball forward, which can be slightly risky for your child's vision.

We keep your child in hospital for one night after the procedure so that we can treat any swelling quickly if it occurs. A significant bleed behind the eye might require another procedure under general anaesthetic to reduce the pressure behind the eye.

The sclerotherapy procedure involves treating the tissues at the back of the eye socket which are very close to the optic nerve (the nerve that allows the eye to see). There is a very small risk that the treatment may damage the nerve and affect your child's vision. In rare cases, this may be permanent. The eye doctors (ophthalmologists) will keep a close check on your child's vision after the procedure.

## **Are there any alternatives to orbital sclerotherapy?**

Sclerotherapy seems to be the best treatment option for vascular malformations around the eye as it carries lower risks than open surgery. It does not cause any visible scarring and the malformation is less likely to grow back after treatment. However, as every child with a vascular malformation around the eye is different, sclerotherapy may not always be the best option. Sometimes a combination of sclerotherapy and surgery might be suggested. Your ophthalmologist

will explain the options for treatment suitable for your child.

## **What happens afterwards?**

Your child will return to the ward after they have recovered from the anaesthetic. Some children feel sick and vomit after a general anaesthetic. Your child may have a headache or sore throat or feel dizzy, but these side effects are usually short-lived and not severe. Your child can start eating and drinking as normal once they feel like it.

Your child's eye will almost certainly look worse after the procedure as the bruising and swelling last for a few days. The treated area will feel uncomfortable afterwards but children's pain relief medicine is usually enough to deal with any pain.

The doctors will come to check your child's progress on the ward and will give you some information about what they have done during the procedure.

The specialist eye doctors will check your child's eye in clinic the next day, before you go home.

## **Going home**

You will be able to go home once the doctors are happy that your child is recovering well.

The swelling around your child's eye should start to go down after a week or two. The eye is often completely closed for a few days. Bruising around the eye can be quite severe and last several weeks. Sometimes the bruise can extend onto the white part of the eye and here it looks bright red. This can look painful but is quite normal. The bruising can take quite a long time to fade. Sometimes there can be clear fluid leaking from the eye for a few days; this is not a worry.

These after effects are expected and show that the medicine is working. Most children only need regular pain relief medicine, such as paracetamol or ibuprofen, for a few days. Your child will be fine

to go back to school when they are comfortable but should not doing any PE or sport until the swelling has started to settle down.

The swelling should start to go down within a week but the effects of the treatment, such as a decrease in the size of the malformation, may not be obvious for several months.

Lymphatic malformations are prone to small bleeds into the cysts from the tiny surrounding blood vessels. Most of the time, this is not a problem. Your child's malformation may have shown signs of this in the past, such as sudden swelling or bruising. Sclerotherapy of the malformation may trigger another bleed in the days or weeks following treatment but this is extremely rare.

If a large clot forms behind the eyeball itself, it can push the eye forward and cause stress on the optic nerve. If your child usually has good vision in that eye, a large blood clot has the potential to damage the vision in that eye if the pressure is not relieved, for instance by a small operation to release the pressure behind the eye.

Often, the eye doctors may decide to let the swelling settle slowly on its own. If the eye is pushed forward, the eyelids may not be able to close and this will leave the front of the eye unprotected, so your child may need to be given eye drops to use until the swelling settles. If sudden severe swelling happens, your child needs to be reviewed urgently by an eye doctor. You need to contact your local hospital eye team about this.

Your child may have had an infection in their eye in the past, though this is rare with orbital

malformations. Infections are rare after sclerotherapy but if the eye area is very hot, red and painful, with a persistent thick yellow discharge from the eye, you should contact your local hospital eye team about this.

You should call the hospital if:

- Your child is in a lot of pain and pain relief does not seem to help
- The area around the eye suddenly swells and looks bruised and the eyeball is pushed forward
- The treated area is unusually hot, red and painful and your child is generally unwell with a high temperature or not eating or drinking as usual
- Your child complains of a sudden change in their vision (eyesight)

## What happens next?

Your child will have a routine outpatient appointment a few weeks after the treatment. We will send you a letter with the planned date of the outpatient appointment or next treatment session.

Your child might need several sclerotherapy procedures to reduce the malformation. As sclerotherapy causes significant swelling and discomfort, it is safer to carry out several smaller treatments limiting the side-effects each time.

Sclerotherapy will not 'cure' the malformation but it should shrink it significantly. Occasionally children need to have further sclerotherapy as they get older and some may need surgery to tidy up any loose skin or treat underlying eye problems.

## Useful numbers

- Interventional Radiology department: 020 7829 7943
- Eye Clinic: 020 7405 9200 ext 5353 Out of hours, call 020 7405 9200 and ask for the On-call Doctor for Ophthalmology