

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

### **Bleomycin sclerotherapy**

This information sheet explains about bleomycin sclerotherapy, why it might be suggested and what to expect when your child comes to Great Ormond Street Hospital (GOSH) for treatment. Bleomycin is one of several different medicines that can be used for sclerotherapy. Information about sclerotherapy in general is available in other factsheets.

## What is bleomycin sclerotherapy and why is it needed?

Bleomycin sclerotherapy is a procedure used to treat some particular types of vascular malformations. It is usually suggested as a treatment for specific kinds of lymphatic malformations (microcystic lymphatic malformations), or when standard sclerotherapy has failed.

Bleomycin may also be useful in superficial malformations where the skin is directly involved as it is less likely to cause skin blistering or scarring. It is also considered for the treatment of malformations in areas where the doctors are keen to avoid swelling, such as behind the eye.

A lymphatic malformation is a collection of small cysts. These malformations 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. Sclerotherapy involves injecting a medicine into the cysts, which irritates them, encouraging them to scar and shrink. The cysts of the lymphatic malformation have no useful 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. This can be painful and the appearance of the bruising can be upsetting. The cysts can also become infected. Microcystic malformations contain millions of very small cysts and usually cause problems because they are bulky, unsightly, or get infected. 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. This information sheet only explains about bleomycin sclerotherapy. For information about other sclerotherapy procedures, see our information sheets available from our department, the Pals Office or our website.



#### What is bleomycin?

Several medicines are used for sclerotherapy. Bleomycin is just one of those options. Bleomycin may be better at shrinking microcystic lymphatic malformations than the other medicines available. It may be useful for treating malformations in areas where swelling may be dangerous, such as near the eye or airway.

Bleomycin is a medicine that has been used for many years to treat other conditions. In a very few cases, when it has been used in much higher doses and has been injected straight into the bloodstream, patients have developed some scarring of their lungs several months later, meaning that they can't take in as big a breath as previously. Sometimes this is permanent.

Doctors think this is extremely unlikely to happen in children where bleomycin is being used for sclerotherapy, as the doses are much, much lower and the medicine is not given in the same way. However, we will check your child's lungs before the procedure, usually using a chest x-ray and some simple breathing tests. This gives a baseline picture of your child's healthy lungs. If we need to test their lungs again later, we have the baseline picture against which to compare the new picture.

Very rarely, bleomycin can cause some discolouration of the skin or nails or make some hair fall out. This usually gets better with time. We think that the skin is more likely to be affected if there are monitoring leads or plasters stuck to the skin at the time of treatment. During your child's procedure, we will be very careful to either put these on parts of the skin that are less noticeable like the sole of the foot or use alternative bandaging.

# 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 will 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 for the procedure and to confirm that their lungs are healthy. This may involve taking blood samples, photographs and other tests to measure lung function. This appointment may be booked for several weeks before sclerotherapy or for the day before the procedure.

You will also meet the radiologist, who will explain the procedure 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. An anaesthetist will visit to talk to you about your child's anaesthetic.

As bleomycin could harm an unborn baby, we will ask all girls aged 12 years or older about their periods and any chance that they could be pregnant. We will also ask for a urine sample to carry out a pregnancy test.

# What does the sclerotherapy involve?

Sclerotherapy is almost always 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 sedation or



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. Fasting times are provided in your admissions letter in broad terms, this is six hours for food (including milk), four hours for breast feeding and two hours for clear fluids before the procedure.

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 and sometimes x-rays. Using the ultrasound scan as a guide, they will insert a small needle through the skin into the malformation. They will then inject the medicine through the needle. 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. The area treated may look a little more swollen than usual after the procedure. The area may feel bruised and sore for a few days, but your child will have pain relief. There is a slight risk of the malformation developing an infection after the treatment. Your child will need a short course of oral antibiotics if this happens. We will give you a letter to take home, explaining to your family doctor (GP) what to prescribe for your child if they get an infection. There is a slightly higher risk than usual of the malformation developing blood clots inside them. This causes sudden swelling and bruising, which may be uncomfortable. If this happens, the bruising will slowly settle. It will not affect how well the treatment works.

Sclerotherapy works for most children but not all of them. Experience helps us understand which malformations are more likely to respond. If the doctors feel that the sclerotherapy treatment has not been very successful, they might suggest surgery, perhaps in combination with further sclerotherapy.

# Are there any alternatives to sclerotherapy?

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

Any bruising and swelling of the malformation will only last for a few days. Some parents say that the discomfort or swelling is more noticeable on day 3 or 4 rather than straight after the procedure. This is normal. Children's pain relief medicine is usually enough to deal with any pain.

You will get an appointment to come back to the hospital so the doctors can check on your child's progress and decide whether the treatment has worked.

### **Going home**

You will be able to go home once the doctors are happy that your child is recovering well. The swelling should start to go down after a few days. They should be able to go back to school after a few days.

The doctors will tell you if your child needs further sclerotherapy procedures and if so, when. Your child might need to have a routine outpatient appointment a few weeks afterward before this decision is made. 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 swelling and discomfort, it is safer to carry out several smaller treatments limiting the 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 improve the final result.



You should call the hospital if:

- Your child is in a lot of pain and pain relief does not seem to help
- 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

### If you have any questions, please telephone the ward from which your child was discharged or one of the numbers below

Interventional Radiology department: 020 7829 7943

Out of hours, call 020 7405 9200 and ask for the On-call Doctor for Dermatology

Compiled by the Interventional Radiology team in collaboration with the Child and Family Information Group

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