The Leeds Teaching Hospitals NHS Trust

Intralesional bleomycin injection for lymphatic & venous malformations

Information for parents & carers

Leeds Radiology

Vascular Anomalies Service

What is bleomycin?

Bleomycin is a medicine that has been used for many years in the treatment of other illnesses.

Why is my child being offered bleomycin?

Bleomycin is the best type of medicine to help treat your child's malformation.

We have suggested bleomycin for one or more of the following reasons:

- The type of lesion has been shown to respond best to bleomycin
- The lesion is in an area where we would be keen to avoid excessive swelling as a result of treatment e.g. near the eye
- If their previous injections into the lesion have failed to improve their symptoms
- If your child's lesion is close to their skin surface.

Is bleomycin safe?

Bleomycin is a medicine that has been used for many years to treat other conditions, such as cancer.

In a few cases, when it has been used in much higher doses than we would use for sclerotherapy, for example in cancer treatment, and where bleomycin has been injected straight into the bloodstream, it can cause damage and changes to the lungs and how they function. This can happen during treatment or afterwards.

In bleomycin sclerotherapy doses are much lower and the medicine is not given in the same way; not directly into the bloodstream, so the risk is much lower; however, there have been cases reported of lung issues post-bleomycin sclerotherapy.

With this in mind it is important to make sure:

- You inform your child's doctors or dentists that they have been treated with bleomycin before they receive any type of surgery.
- Your child carries a wallet card (we will provide these) or wears a wrist bracelet (e.g., MEDICALERT®) to alert health providers.

We suggest avoiding activities or occupations which use increased oxygen pressure, such as scuba diving, for the rest of their life.

Always tell your doctor if after treatment with bleomycin your child:

- Develops a wheeze
- Develops a cough
- Has a fever
- Feels breathless

You should also let us know if any existing breathing problems get worse. If necessary, their doctor can arrange for your child to have tests to check their lungs.

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 or if your child scratches their skin after treatment. Therefore we will be very careful to put sticky plasters or leads onto parts of the skin that are not noticeable and we may well prescribe your child some anti-allergy tablets (antihistamines).

Assessments carried out before bleomycin sclerotherapy

You will meet a radiology doctor (Interventional Radiologist) in clinic who will explain the procedure in more detail and discuss any questions you may have. You will be asked to sign a consent form; we will talk you through the process so you understand what you are consenting to before giving permission for your child to have their sclerotherapy.

It is important that you know you do not have to make a decision straight away. The reason we see you in clinic and give you patient information sheets such as these is so you can make a well-thought-out decision regarding your child's treatment. If you would like more time to think then please let the doctors know.

There is a section at the end of this information sheet for any thoughts or questions you may have after your meeting with the Interventional Radiologist. Your child will need a pre-admission assessment to check that they are well enough for the procedure and to confirm that their lungs are healthy. If your child has any medical problems, please tell the nurses and doctors. You may well see an anaesthetist at the same time who will talk to you about your child's anaesthetic. This appointment may be booked for several weeks before sclerotherapy or for the day before the procedure.

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.

Follow-up carried out after bleomycin sclerotherapy

We will send a letter to your GP so they are aware of the procedure your child has had.

We will also provide you with an alert card for your child advising medical professionals that they have had intralesional bleomycin.

We will contact you by phone at one, four and eight weeks following your child's treatment when we will assess for expected side effects and to assess to see if your child has a dry cough that hasn't resolved and / or is short of breath.

We will also review your child at an outpatient clinic appointment at three months.

Contact information

Please contact us on the numbers below if your child develops any side effects, such as a continuing dry cough, wheezing chest pain, fever or shortness of breath.

Clinical Nurse Specialists,

Interventional Radiology & Vascular Anomalies,

Leeds Teaching Hospitals NHS Trust (09:00-17:00)

Tel: 0113 392 0930 or 0113 392 0931 (Office)

Secretary

Tel: 0113 392 2860

Email: leedsth-tr.vascularmalformations@nhs.net

If you are concerned out of hours or cannot reach us by the above means then please attend your GP or, if suitable, Accident and Emergency.

Notes

What did you think of your care?

Scan the QR code or visit **bit.ly/nhsleedsfft**

Your views matter

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