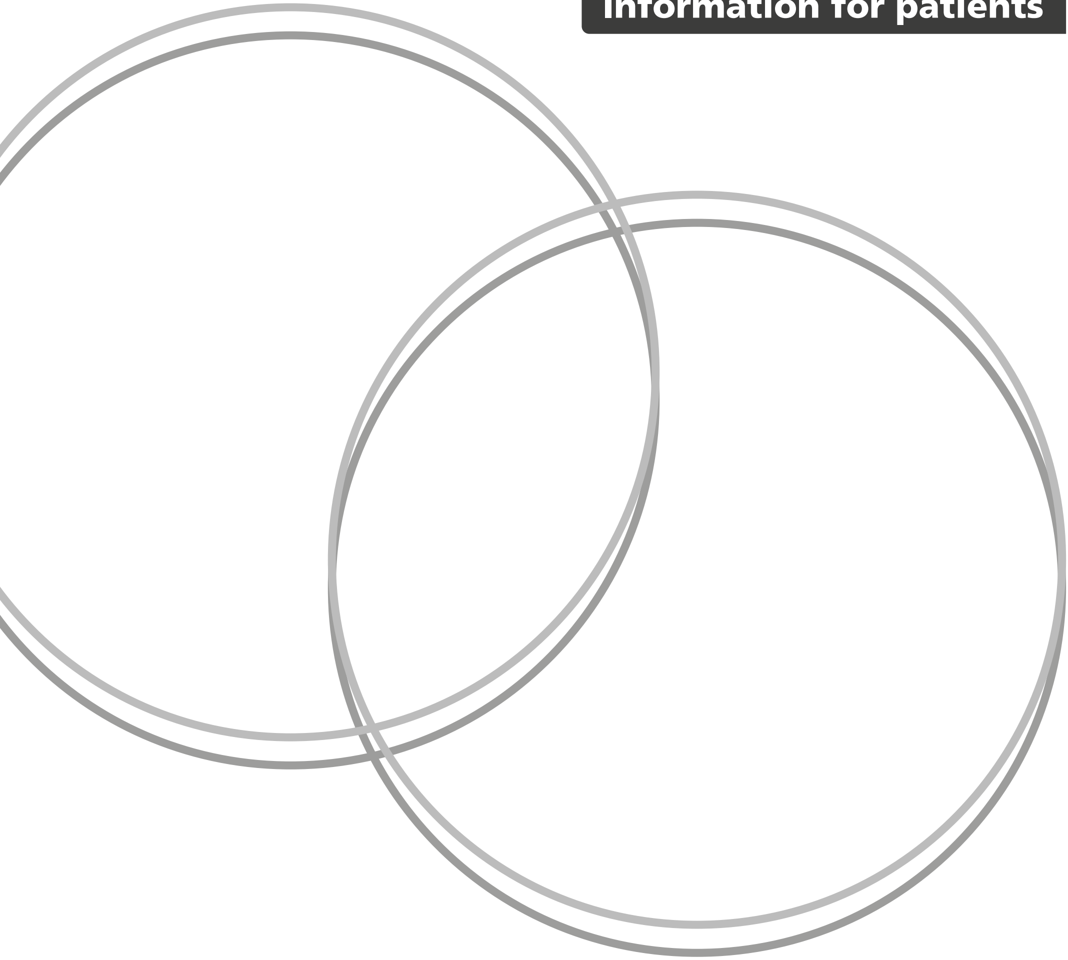
NHS

Oxford University Hospitals
NHS Foundation Trust

Babies with an Inherited Bleeding Disorder

Information for patients



Paediatric Haemostasis Unit

If your baby is known to be or may be affected with an inherited bleeding disorder, they will usually be delivered at the Oxford University Hospitals Women's Centre, under the care of the Silver Star team (the high risk pregnancy service.) This will ensure specific safety measures are in place.

The Paediatric Haemostasis Team will meet with you after delivery to discuss management of your baby should they be affected.

Your baby's care after delivery

After your baby has been born, a blood sample will be taken from the umbilical cord (which connected your baby to you before birth). This blood sample can be tested to check the factor levels in your baby and to confirm if they have the family gene that causes the inherited bleeding disorder (if it is known).

Your adult haematologist will discuss this test with you before your baby is born. If you are happy for this to be carried out, your consent for it to be done will be recorded in your maternity notes.

Sometimes the blood sample can clot or be mixed with your blood, which will give incorrect results. If this happens we may then have to take a small blood sample from your baby. We will discuss this with you if it is needed.

It should not be necessary to give your baby haemostatic treatment such as, coagulation factor concentrate after a normal vaginal delivery or caesarean section. If there have been any concerns about bleeding during the delivery this may be necessary, but this will be discussed with you at the time by the Neonatal and Paediatric Haemostasis Team.

The Paediatric Haemostasis team will aim to meet you after your baby has been born. If you are discharged prior to this they will call you to ensure you have their contact details and will arrange a follow-up appointment in 6 weeks. They will be able to discuss any specific queries or concerns you might have and explain the risks your baby may have of bleeding or bruising. You can contact them before the appointment, if you need to.

Vitamin K

All babies, including those with an inherited bleeding disorder, should be given vitamin K at birth. This is routinely given as an injection into a muscle (usually into the thigh muscle), but if your baby is known to be (or possibly may be) affected with a severe or moderate inherited bleeding disorder the **vitamin K should be given by mouth**. It should not be given by injection into the muscle, as this could cause bleeding. **This should be clearly stated in your birth plan**.

Your baby will need 3 doses of oral vitamin K; at birth, when they are 5 days old and at 4 weeks old. The midwifes will ensure the course is completed on your discharge to the community.

Vaccinations

Vaccinations under the skin can cause local irritation and redness. Applying a cool compress or ice pack can help relieve these symptoms. if the leg(s) are very swollen or your child is in pain please can the Paediatric Haemostasis Unit for Advice.

Sometimes we recommend that your child starts an anti-fibrinolytic medication called Tranexamic Acid if swelling has occurred or a large lumpy bruise appears. We will discuss this with you at your initial appointment which will be prior to any scheduled routine immunisations.

Blood tests for your baby

All babies have a heel-prick test (the Guthrie test) around 5 days after birth, which is routine screening used to check for certain conditions. If your baby is known to be (or possibly may be) affected with an inherited bleeding disorder, then pressure should be applied where the heel has been pricked straight after the test has been done. Gentle pressure for a full 5 minutes should be all that is needed to stop any bleeding. This also applies to any other blood tests your baby may have.

Possible brain bleed

One of the rare bleeding problems that can occur is bleeding inside the brain.

A cranial ultrasound may be required prior to your babies discharge. This is a routine scan recommended for all neonates with severe or moderate bleeding disorders. This checks for any subdural bleeding which may have resulted from birth.

Additionally we will give you information on symptoms and signs of a possible brain bleed prior to discharge.

Medication

If your baby has a severe bleeding disorder we may need to supply you with an emergency dose of factor replacement to keep at home. We will discuss this with you prior to discharge.

Review

We will review your baby in clinic around 6 weeks old.

An appointment has been made for your baby at the Paediatric Haemostasis Unit:

An initial appointment and review:

Date: ....

Location: ....

How to contact us

If you have questions about how haemophilia may affect your baby, or about any of the information in this leaflet, please contact the Paediatric Haemostasis Unit.

Paediatric Haemostasis Unit

Telephone: 01865 226 562
(9.00am to 5.00pm, Monday to Friday)

For emergency advice or treatment outside office hours, at weekends and on Bank holidays, please telephone the Oxford University Hospitals switchboard.

Telephone: 0300 304 7777

Ask to speak to the 'on-call Specialist Registrar for Haematology'.

The Specialist Registrar may give you advice over the telephone or, if your child needs treatment, they may ask them to come into Kamran's Ward, which is on Level 0 of the children's hospital at the John Radcliffe Hospital.

Kamrans Ward

Telephone: 01865 234 068 or 01865 234 069

Additional useful information can be found at the following websites

OUH:

Website: www.ouh.nhs.uk/kamrans/haemophilia

The Haemophilia Society:

Website: www.haemophilia.org.uk

The haemophilia society is the only national, independent charity, for all people affected by a bleeding disorder. The website has useful information for patients, families and schools. They organise events such as weekends away for new families. Some parents and patients wish to get involved and find these helpful.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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April 2024
Review: April 2027
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 90036