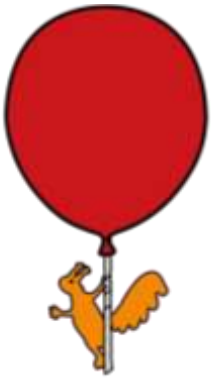


Alder Hey Children's NHS Foundation Trust

Inherited Bleeding Disorders (IBD) Team

Carriers for Haemophilia

Information for Carriers and Potential Carriers

Introduction

This leaflet aims to provide you with general information about being a carrier for haemophilia and why it is important for some women and girls to be tested. If you are ever worried about your child please contact your IBD Team or take your child to the Accident and Emergency Department.

Carriers for Haemophilia

What is Haemophilia?

Haemophilia is an inherited bleeding disorder in which there is an absence or reduction in one of the clotting factors. Haemophilia is known to be an x linked recessive disorder. This means that women are carriers for the gene but most of the symptoms manifest in males.

Some carriers for haemophilia do have symptoms which can be troublesome, these may include nose and gum bleeds, heavy periods and very occasionally bleeding into muscles and joints. People with haemophilia and those who are carriers tend to bleed for longer but not faster than others.

There are two main types of Haemophilia:

- Haemophilia A: The reduction or absence of clotting Factor VIII (8)
- Haemophilia B: The reduction or absence of clotting Factor IX (9)

Why do I need to know if I am a carrier for Haemophilia?

We may recommend that you are tested for your haemophilia carrier status if you have a family history of Haemophilia A or B; for example if your brother or another male relative on your mum's side of the family has haemophilia, or if your mum knows she is a carrier for haemophilia.

We may recommend testing if you have been referred by your GP or another doctor to the inherited bleeding disorders (IBD) team because you have a history of bleeding, bruising or heavy periods.

We think knowing that you are a carrier for Haemophilia can be helpful as

- it can help to explain troublesome symptoms you may have and help us to advise on how best to manage these symptoms
- it can help if you need surgery or dental treatment so that you can let the surgeon or dentist know and we can advise them on the best treatment to prevent increased bleeding
- if you choose to have children in the future you can receive informed advice about pregnancy and your baby can receive the best possible care.

What questions will I be asked at my appointment?

We will ask some questions about your “bleeding history”. You and your carer will be asked if you bruise or bleed easily, about problems with any surgical or dental procedures, or of any difficulties with menstrual periods. You may not be able to answer all these questions and we understand this. You will also be asked if other family members are known to have been diagnosed with haemophilia or if they are affected by any bleeding or bruising. As well as asking you questions we will take some blood to check how the blood is clotting. Examples of bleeding symptoms include

- Heavy and prolonged bleeding during menstrual periods
- Easy bruising
- Prolonged bleeding after cuts and grazes
- Prolonged bleeding after dental procedures
- Increased bleeding following accidents or injury

What does the test for being a carrier for Haemophilia A or B involve?

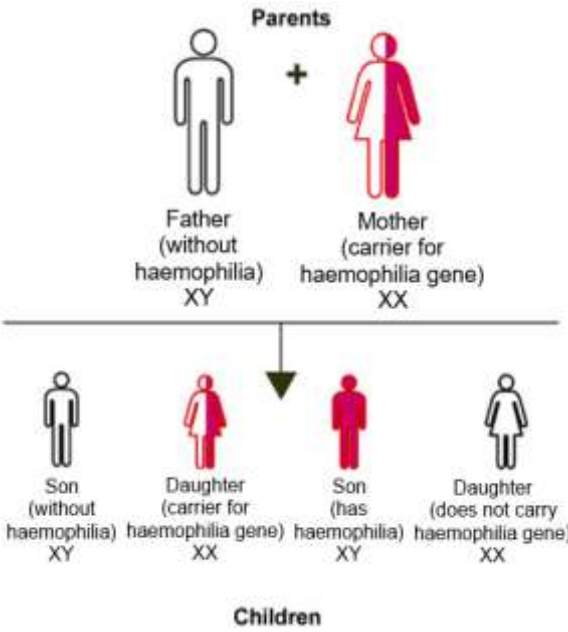
A small sample of blood is taken and sent to the laboratory at Alder Hey to check the Factor VIII or IX levels; normal level is above 50%.

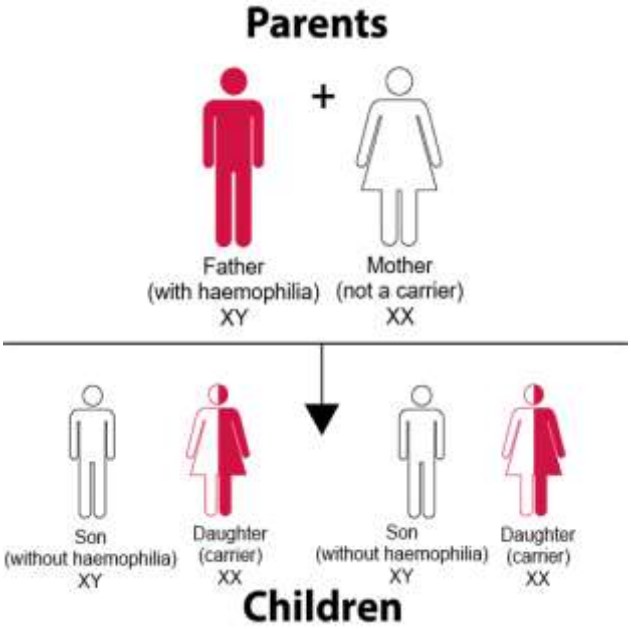
We cannot take blood for genetic testing without your or (in some situations) a parent’s consent.

If you don’t have any bleeding symptoms of your own but do have a family member who has haemophilia we will wait until you are old enough, to understand what the results of this test might mean for you.

Inheritance of Haemophilia

In each pregnancy a carrier for Haemophilia has a 1:2 (50%) risk of passing the affected gene on to her child. A man with haemophilia A cannot have a son affected by haemophilia A or B but his daughters will all be obligate carriers for Haemophilia A or B. We can discuss testing other family members during clinics.





What happens next?

We will make an appointment to see you with the results of your investigations, this is usually between two and three months after the blood tests have been done. Sometimes it is a relief to know that you have a reason for your bruising or bleeding symptoms but it can also leave you with mixed feelings as to what it means for you and what it may mean for you if you decided to have children in the future. We will spend time talking this through with you but can also refer you to the adult Inherited Bleeding Disorders services as well as genetic services so that you can discuss the implications of these results. It may also be helpful for you to see a member of the psychological services team that you can talk through your feelings about your new diagnosis and what it means to you.

Further booklets and information sheets are available from the Haematology Treatment Room waiting area, with further information from the Haemophilia Society.

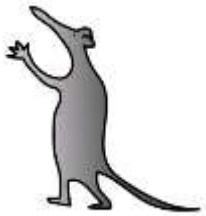
Links

The Haemophilia Society website https://haemophilia.org.uk/

Alder Hey Children's NHS Foundation Trust https://alderhey.nhs.uk/

Contact Information Haematology Nurses 8.00am-5.00pm 0151 252 5070 with answer machine. Queries will be reviewed by the end of the next working day.

Sharon Thind: 07584 234 526 sharon.thind@alderhey.nhs.uk



This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.
This information can be made available in other languages and formats if requested.

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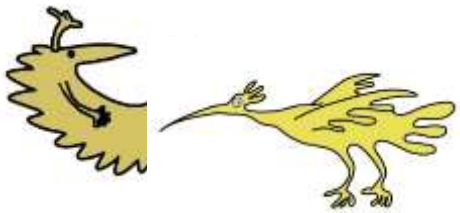

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