Introduction

This leaflet aims to provide you with general information about children with mild bleeding disorders. If you are ever worried about your child please contact your IBD Team or take your child to the Accident and Emergency Department.

Mild Inherited Bleeding Disorders (IBD)

Why was my child referred to the Inherited Bleeding Disorders (IBD) Team?

Your child may have been referred to the IBD Team for investigations because you or someone else is concerned that they are bruising or bleeding more than expected, or because another family member has a diagnosis of an IBD.

Where did my child’s inherited bleeding disorder come from?

Inherited bleeding disorders are rare. Sometimes there can be a family history of the disorder; however your child may be the first in the family to be affected.

How is the diagnosis made?

The diagnosis is made by taking a “bleeding history”. You will be asked if your child bruises or bleeds easily and about problems with any surgery or dental procedures.

Sometimes if the bleeding disorder is fairly mild the symptoms may not be noticed until they are older. If your child is very young, you may not be able to answer some of these questions and we understand this.

You will also be asked if other family members 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. Sometimes these blood tests will need to be repeated as the levels can fluctuate. Further blood tests, which may include looking at the genes involved with clotting can help us to discover where the inherited bleeding disorder has come from, give you accurate information and advice, as well as how to manage your child’s disorder. Genetic tests can only be undertaken with consent.

We may also advise you if other family members need to have investigations to see if they are affected.
How does blood clot?

Clotting factors are proteins in the blood that control bleeding.

When a blood vessel is injured, the walls of the blood vessel contract to limit the flow of blood to the damaged area. Then, small blood cells called platelets stick to the site of injury and spread along the surface of the blood vessel to stop the bleeding.

At the same time, chemical signals are released from small sacs inside the platelets that attract other cells to the area and make them clump together to form what is called a platelet plug.

On the surface of these activated platelets, many different clotting factors work together in a series of complex chemical reactions (known as the coagulation cascade) to form a fibrin clot. The clot acts like a mesh to stop the bleeding.

Coagulation factors circulate in the blood in an inactive form. When a blood vessel is injured, the coagulation cascade is initiated and each coagulation factor is activated in a specific order to lead to the formation of the blood clot. Where one or more of the clotting factors is reduced or not working properly the coagulation cascade is affected slowing the time for the fibrin clot to form.

Signs and symptoms of mild IBD

- Bruising (more than other children)
- Bleeding gums
- Prolonged bleeding from cuts
- Nosebleeds
- Heavy periods
- Bleeding after surgery or dental extractions

Children with mild IBD have few day to day problems relating to their IBD but may require some treatment for injuries, surgery and dental extractions. The most common symptoms in IBD are bleeding from the nose and mouth (mucosal bleeding).
When should we ask for advice?

If you are worried about your child, please try to contact the IBD Team on the numbers provided. However if it is out of hours, and you have been unsuccessful, please do not wait at home for a response but attend the Accident and Emergency Department. Make sure you tell them on arrival that your child has a mild bleeding disorder.

- Has a significant head injury with:
  - Babies: any signs of high pitched crying increased sleepiness decreased alertness, reduced feeding or vomiting.
  - Older children: any signs of visual disturbances, loss of consciousness, severe or ongoing headache, loss of coordination, tiredness and decreased alertness, difficulty in thinking or severe or persistent vomiting
- Has a prolonged nosebleed which does not seem to be slowing after 10-15 minutes
- Has a loose tooth that is bleeding and has not stopped within a reasonable amount of time
- Is having a heavy period that is causing problems

Please let us know if your child needs surgery or dental extractions. It is important for us to know so that we can make a simple plan to make sure the procedure runs smoothly.

Can my child join in with sports?

Yes, most sports are encouraged as they can help to make your child’s muscles stronger. Contact sports such as rugby, mixed martial arts and boxing should be avoided, tag rugby can be participated in. Other sports including football, swimming, dancing, basketball and cycling are encouraged and your child should be allowed to join in.

Who do I tell?

It is helpful for other healthcare professionals to know, including your GP and Health Visitor.

Child minder, play group, nursery and schools need to know, as do the leaders of any club or groups. We routinely visit schools to talk to teachers and lunchtime staff and provide them with written information.

You might find it helpful to tell friends about having a mild bleeding disorder so that they can support you and so that if your child develops bruises while playing with their children they can understand why.

How often will we see the IBD Team?

We will see you or speak to you as often as you would like. We know that lots of questions or worries do not wait for a clinic appointments.

Routinely we will see you with your child at diagnosis and then in clinic for primary immunisations. We give all immunisations just under the skin. This is a good time for us to get to know you, and for you to get to know the team and for you to ask any questions. After this we will see you in clinic first at 6-12 monthly intervals. You might feel happier coming more often and this can be easily arranged.

Medicines that should be avoided:

Please avoid using pain killers known as NSAIDs including ibuprofen, naproxen and diclofenac as these interfere with the way the blood clots by affecting the function of platelets, NSAIDs can also irritate the lining of the stomach, causing bleeding. You can give your child paracetamol if he needs a painkiller or something to reduce a temperature
Links
The Haemophilia Society website: https://haemophilia.org.uk/
Alder Hey Children’s NHS Foundation Trust: https://alderhey.nhs.uk/

Contact Information
Haematology Nurses: 8.30am-5.00pm 0151 252 5070 with answer machine. Queries will be reviewed by the end of the next working day.
Nicki Mackett: 07584 234 526 nicki.mackett@nhs.net
Catherine Benfield: 07876 132 163 catherine.benfield@nhs.net

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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