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Inherited Bleeding Disorders Team

**Inherited Platelet Disorders**

Information for Parents and Carers

**Introduction**

This leaflet aims to provide you with general information about inherited platelet disorders. If you are ever worried about your child please contact your Inherited Bleeding Disorder Team or take your child to the Accident and Emergency Department.

**Inherited Platelet Disorders**

**What are inherited platelet disorders?**

These are platelet disorders which can be passed on from parent to child.

Platelets are blood cells that are involved in helping to stop bleeding; they work in combination with clotting proteins (factors) to form a stable clot at the site of injury. People affected by inherited platelet disorders may bleed for longer but not faster than other people.

**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, about problems with any surgery or dental procedures and any medicines your child is taking. 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 if there are enough platelets, what the platelets look like and how they are working. Sometimes these blood tests will have to be repeated. Further blood tests which may include genetic bloods may also be taken this helps us to provide you with accurate information and also to provide the most effective treatment for your child. Genetic tests can only be undertaken with consent.

**Where did my child’s platelet disorder come from?**

Platelet disorders may be passed down from one or both parents who may have mild symptoms or no symptoms at all. Less commonly a spontaneous genetic error can occur and your child may be the first person in the family to have a platelet disorder. Where there is confirmation of your child’s disorder we will be able to advise you if you or other family members need to attend for investigations.

**What are the symptoms of inherited platelet disorders?**

* Bruising
* Prolonged bleeding post dental extractions
* Prolonged bleeding post-surgery
* Bruising or bleeding after vaccinations
* Nosebleeds
* Bleeding gums
* Heavy periods

Children with platelet disorders have few day to day problems relating to their disorder, bleeding from the nose and mouth (mucosal beading) and heavy periods are the most common symptoms. Some may require treatment for injuries, surgery and dental extractions.

**How should we ask for advice?**

If you are worried about your child please contact the Inherited Bleeding Disorder 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 an inherited platelet disorder and bring along a haemorrhage alert card (if your child has one)

**Situations when you should ask for advice**

If your child:

* 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
* has a heavy or difficult to manage period

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.

**Treatment for inherited platelet disorders**

Use usual first aid for nose and mouth bleeds. Apply pressure to the affected area, for example, where a tooth has fallen out a finger wrapped in gauze pressing firmly over the socket or for nose bleeds firm pressure below the bridge of the nose. Sucking on an ice pop helps both nose and mouth bleeds to slow down as it cools the area.

Currently there is no cure for platelet disorders but there are medicines and treatments available that help to keep symptoms under control

**Tranexamic acid** is helpful for gum bleeds, nose bleeds, dental extractions and periods. It works by helping to stabilise blood clots while the blood vessel repairs itself. It is usually given orally but may be given as an infusion intravenously.

**Platelet transfusion** may be needed for surgery or dental extractions. Platelets come from a donor (similar to blood donation) and are specially matched to your child’s blood type.

**Recombinant VIIa (Novoseven)** this manufactured product mimics the effect of clotting factor VII and works to help form the final fibrin clot allowing damaged blood vessels to heal.

**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 clubs or group your child joins. We routinely visit schools to talk to teachers and lunchtime staff and provide them with written information.

We might advise you to talk to family members who may need to ask a doctor to review if they could be affected by a platelet disorder

You might find it helpful to tell friends about platelet disorders so that they can support you and so that if your child develops bruises while playing they can understand why.

**How often will we see the Inherited Bleeding Disorder 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. Initially we may see you more frequently, by the time your child is five years old we will see you routinely once or twice a year. You might feel happier coming more often 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 they need 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 8.00am-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.

Alder Hey Children’s NHS Foundation Trust

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