Introduction to Haemophilia

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IRISH HAEMOPHILIA SOCIETY LTD
Cumann Haemifile Na hEireann

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Introduction

Haemophilia is a condition in which a person's blood does not clot properly. A person with haemophilia will not bleed any faster than anyone else following an injury, but they can bleed for longer. Most bleeding in haemophilia occurs internally into the joints or muscles. The joints that are most often affected are the knee, ankle and elbow. Repeated bleeding without prompt treatment can damage a joint permanently. External bleeding such as cuts or scrapes are not usually serious and can be easily controlled.

Haemophilia is usually an inherited condition. In 70% of all cases, there is a family history. In about 30% of cases, there is no family history; the condition is the result of a recent genetic change in the mother or baby. Therefore, haemophilia can occur in any family.

Types of Haemophilia

There are two types of haemophilia: haemophilia A and haemophilia B. People with haemophilia A have reduced levels of a protein called factor eight (written as FVIII). People with haemophilia B have reduced levels of a protein called factor nine (FIX).

Haemophilia is considered to be a rare disorder. The incidence of haemophilia A in the general population is about 1 in 10,000 (therefore about 1 in 5,000 males). The incidence of haemophilia B is about 1 in 50,000 (1 in 100,000 males). Both types of haemophilia share the same symptoms and inheritance pattern. (See *The inheritance of haemophilia* on page 7). There are currently 930 people with haemophilia in Ireland.

Did you know?

Haemophilia A and B are in the family of inherited bleeding disorders. These include von Willebrand disorder, rare factor deficiencies and platelet function disorders. Their symptoms and treatment are somewhat different compared to haemophilia.

Degrees of severity

The severity of haemophilia is related to the degree of deficiency of the relevant clotting factor in the blood. There are three levels: mild, moderate and severe.

- A person with over 5% but less than 40% of normal activity is described as having mild haemophilia.
- A person with between 1% and 5% of normal clotting activity is described as having moderate haemophilia.
- A person with less than 1% of normal clotting activity is described as having severe haemophilia.

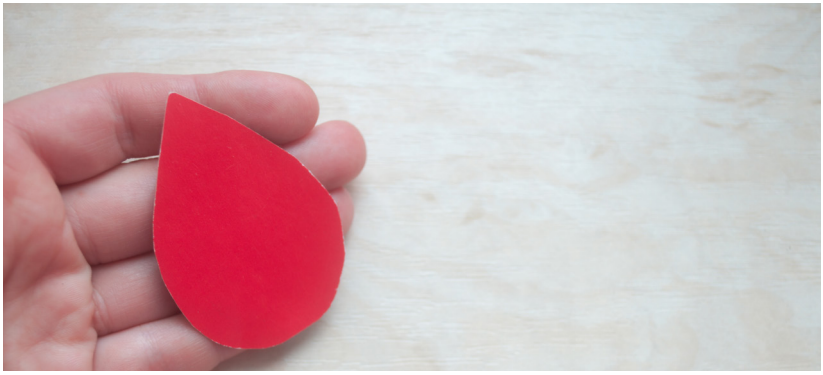
These percentages, however, do not tell the whole story. Some people with mild or moderate factor levels can have a more severe bleeding tendency. Others with a severe factor level may not suffer severe bleeding symptoms.

Degree of Severity

Mild Haemophilia	Moderate Haemophilia	Severe Haemophilia
Factor levels of 5-40% of normal	Factor levels of 1-5% of normal	Factor levels less than 1% of normal

Did you know?

The severity of haemophilia does not change during a person's lifetime. People in the same family inherit the same level of severity of haemophilia.

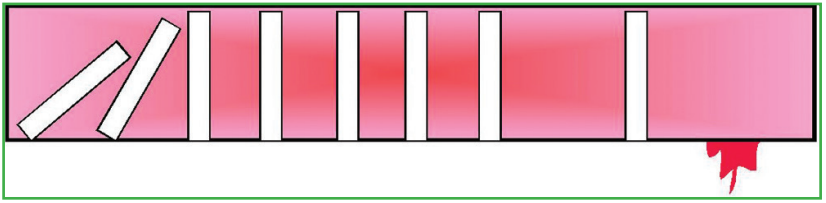


The Clotting Mechanism

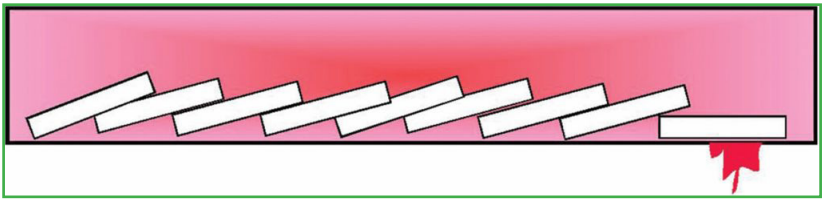
Bleeding is controlled in three ways:

1. Constriction of the blood vessels at the site of the bleeding
2. Gathering of platelets to plug the hole in the blood vessel
3. Clotting factors working in a chain reaction or “domino effect” to form a mesh over the injury and make a permanent clot.

Constriction of blood vessels and platelet function are normal in people with haemophilia. It is the third mechanism that does not work normally. One of the clotting factors, FVIII or FIX, is absent or deficient and the “domino effect” is slowed or stopped and the clot does not form solidly. Without treatment, bleeding continues.



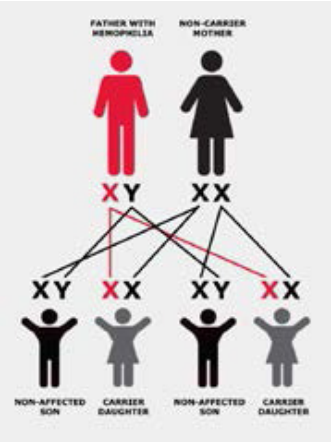
Normal Clotting Mechanism

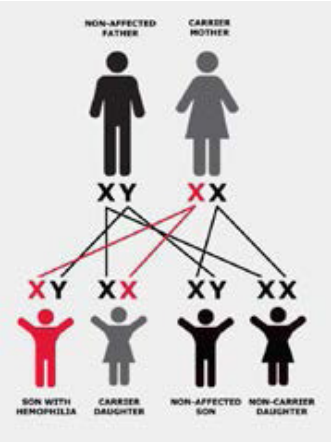


Affected Clotting Mechanism

The Inheritance of Haemophilia

Haemophilia is an inherited condition. The gene responsible for factor VIII and factor IX production is carried on the X chromosome. Females have two X chromosomes; men have an X and a Y. Therefore, men with a haemophilia gene on their X chromosome are necessarily affected. Women who have one affected X chromosome and one normal X chromosome are partially protected; however, many do experience abnormal symptoms of bleeding. Men will transmit haemophilia to their daughters through their X chromosome. Women can transmit the haemophilia gene to both their sons and daughters; however, as they are passing on only one of their two X genes in each case, the chances of transmission are 50%. These women are called *carriers*. The diagrams below may assist in understanding this.





Diagnosis

A simple blood test can be performed prenatally or at birth when there is a history of haemophilia in the family, or if abnormal bleeding occurs after birth and haemophilia is suspected. The blood sample is tested to measure the amount of clotting factor activity in the blood. This will allow the doctor to determine if the person has haemophilia and if so, its type and severity. Low levels of factor VIII indicate haemophilia A, whereas low levels of factor IX indicate haemophilia B.

Cases of severe haemophilia are usually identified in the first year of life. Signs of mild and moderate haemophilia, however, may not show up until the child is a little older.

The First Signs of Haemophilia

Common first signs are:

- Bleeding from the umbilical cord at birth
- Bleeding after blood draws
- Bleeding in the mouth (tongue, gums, cheeks) or when teething
- Bleeding after dental work
- Swelling after childhood vaccinations
- Bruising when a child begins to crawl or walk, often for no apparent reason
- Bleeding into muscles, especially the calf, forearm, and iliopsoas (near the hip)
- Bleeding into joints, especially the knee, ankle and elbow.

Signs to watch out for are:

- The child being reluctant to move or bend the affected limb/ joint.
- The child crying and complaining of pain in the affected joint/ limb.
- Swelling and heat in the affected joint or limb.

The Main Sites of Bleeding

Joints and muscles

The most common type of bleeding in haemophilia is internal bleeding into joints or muscles. This bleeding may occur after a bang, twist or strain or without any obvious cause. Joint bleeds are uncommon in the first three years of life.

Bleeding can occur in any joint; however, the most common joints affected are the knee, ankle and elbow. For the person with haemophilia, the tiny breaks in the blood vessels in joints may re-bleed as a result of normal everyday activity. These bleeds are sometimes described as “spontaneous” because it is impossible to identify a cause. Repeated or untreated bleeding into joints can cause permanent damage such as joint stiffness, arthritis and chronic pain. With treatment, this pattern of repeated bleeding can be controlled and long-term damage avoided.

Bleeding can occur in all muscles. The most common muscles affected are the calf, forearm and iliopsoas, a muscle near the hip. If not treated, bleeding in these muscles can cause serious and permanent damage to the nearby nerves.

Pain and stiffness around a joint or muscle is an indication that a person with haemophilia is having a bleed. The affected area may feel warm to the touch. If left untreated, swelling will worsen and pain may become excruciating. Limping is a sign of a bleed in a lower limb. Reluctance to use an arm in a normal way is a sign of bleeding in the elbow, wrist or forearm.

In addition to coagulation products (see Treatment on page 16), five additional home treatments for bleeding into the joints and muscles are:

- Protection
- Rest
- Ice
- Compression
- Elevation

This is called PRICE.

Bruising, soft tissue bleeds

Soft tissue bruises commonly occur in people with haemophilia, especially toddlers. Deeper bleeding in the soft tissues can be felt as a hard lump, but without any discolouration. They occur as a result of a bang or fall. Although these may look serious, they usually do not require any treatment. Sometimes if the lump or bruise is increasing in size and is causing pain, treatment may be recommended.

Cuts and abrasions

Small cuts and abrasions usually cause no more trouble in a person with haemophilia than in anyone else. When they occur, disinfect and cover them with a plaster and bandage. Apply pressure for a few minutes. Deep cuts that may need stitching will need treatment at a haemophilia centre.

Nosebleeds

Nosebleeds are more common in some people with haemophilia but not all. Tilt the head forward and pinch the bridge of the nose below the bone for 10-20 minutes and/or put an icepack on the bridge of the nose for not more than 5 minutes.

Mouth and Tongue Bleeds

Babies and small children often bite their tongue or the insides of their cheeks. Bleeding can also occur when children teethe. These bleeds can be hard to control because clots that form are washed away by saliva or knocked off by the tongue or food.

- Apply firm pressure to the site of the bleed. Use a popsicle or ice to help slow bleeding and relieve pain.
- Give your child only soft foods (yogurt, pudding, custard, etc.) and avoid giving crunchy and chewy food until the injury heals.
- Avoid giving hot fluids and hot food for several days to a week, until the injury heals.
- Call your treatment centre if bleeding persists.

Minor Head Injuries

Head bumps are especially common in young children at the toddler stage who are just learning to walk and run, and who are unsteady on their feet. Toddlers often bump into doors, walls and furniture. Often the child is not upset by the injury — he doesn't even cry — and there is no bruise or cut caused by the bump.

More Serious Sites of Bleeding

Any bleeding in the head, neck, chest or abdomen can be life-threatening. Fortunately, these types of bleeding are very rare. If such bleeding is suspected, immediate medical assistance is needed.

Head

These can result from a severe bang on the head or fall. A head injury is always serious if the person is knocked unconscious. These injuries should be treated as quickly as possible and the patient should be taken to the nearest haemophilia centre or A&E.

Watch out for:

- A bad or persistent headache
- Blurred vision
- Nausea or vomiting
- Mood or personality changes
- Drowsiness
- Loss of balance or coordination
- Weakness or clumsiness
- Stiffness of the neck
- Loss of consciousness
- Seizures

Neck and throat

If bleeding occurs in the neck or throat, it can press on the airway, making it smaller or closing it completely.

Watch out for:

- Pain in the neck or throat
- Swelling
- Difficulty swallowing
- Difficulty breathing.

Chest injuries

The lungs, heart and major blood vessels are located in the chest cavity. Injury to the chest may cause bleeding in vital organs. Bleeding in the lung tissues forces blood into the spaces that normally contain air. This makes breathing difficult.

Watch out for:

- Pain in the chest
- Difficulty breathing

Abdomen

The stomach, spleen and intestines are just three of the organs found in this cavity. Injury to this area could result in massive bleeding from an organ or major blood vessel.

Watch out for:

- Pain in the abdomen or lower back
- Nausea/vomiting.

If any of these symptoms occur, you must seek medical assistance immediately.

A CAREFUL EYE SHOULD BE KEPT ON THE CHILD FOR AT LEAST 12 HOURS AFTER ANY INJURY THAT MIGHT AFFECT THE HEAD, NECK, CHEST OR ABDOMEN.

Treatment

Haemophilia Treatment Centres

Ireland has a network of very high-quality haemophilia treatment centres. There are three comprehensive care centres in Ireland:

The National Coagulation Centre (NCC) in St. James's Hospital in Dublin.

The Coagulation Centre in Cork University Hospital (CUH).

Children's Health Ireland (CHI) at Crumlin.

These centres offer comprehensive care to children and adults with bleeding disorders, from investigation and diagnosis to long-term management of mild, moderate and severe haemophilia. The multidisciplinary approach includes:

- Nursing
- Physiotherapy and orthopaedic care
- Surgery
- Dental care
- Paediatric care
- Hepatology and infectious diseases
- Obstetrics and gynaecology

- Genetics
- Social work
- Psychosocial support

The three comprehensive care centres support local hospitals where you might receive routine treatment.

There is also one recognised haemophilia treatment centre which offers some services: Galway University Hospital.

Other acute hospitals around the country will keep an emergency supply of haemophilia therapies and treatment can be accessed in an emergency but your comprehensive care centre should be involved. You can contact them using the number on the bleeding disorder alert card, produced by the Society, which will be issued to you on request from your comprehensive care centre.

Treatment depends on the haemophilia type and severity.

Mild Haemophilia A

People with mild haemophilia A, in which bleeding occurs quite rarely, are usually treated only when they have a bleed. Some are able to be treated with desmopressin, a synthetic hormone, which is injected under the skin. Doctors at the haemophilia treatment centre will perform tests to find out if desmopressin works in your child. If not, factor VIII (FVIII), a clotting factor concentrate can be used. This is infused intravenously (into a vein). Quick treatment after a bleed starts is key to avoiding permanent damage.

Did you know?

While people with mild haemophilia may bleed less frequently, their bleeding must be taken just as seriously as bleeding in those with severe haemophilia.

Moderate and Severe Haemophilia A

These more severe forms of haemophilia A, in which bleeding occurs more frequently, are often treated preventatively. This is called *prophylaxis*. There are two kinds of treatment. The most common treatment is with a monoclonal antibody (called Hemlibra or emicizumab) which is infused under the skin once every 1, 2 or 4 weeks. An alternative is FVIII concentrate, which is infused intravenously 2 or 3 times a week.

Both these treatments are safe and very effective at preventing bleeding. Parents can be trained to inject or infuse them at home. Children as young as 7 or 8 years old often learn to inject / infuse themselves.

If bleeding requires extra treatment while receiving Hemlibra, FVIII can be given.

Mild Haemophilia B

People with mild haemophilia B, in which bleeding occurs quite rarely, are also treated only when they have a bleed. Factor IX (FIX), a clotting factor concentrate, is used. It is infused intravenously (into a vein). Quick treatment after a bleed starts is key to avoiding permanent damage. While bleeding may be less frequent when the severity is mild, it must nevertheless be taken seriously.

Moderate and Severe Haemophilia B

These more severe forms of haemophilia B, in which bleeding occurs more frequently, are also often treated preventatively, with prophylaxis. Extended half-life (EHL) factor IX (FIX), a clotting factor concentrate, is infused intravenously (into a vein), usually once a week or in some cases, every 10 days in every two weeks. If bleeding requires additional treatment, an extra dose of FIX is infused.

FIX is safe and very effective at preventing bleeding. Parents can be trained to infuse it at home. Older children learn to treat themselves.

Port-a-caths

If small children need prophylaxis with FVIII or FIX, it can sometimes be difficult for parents (and even health care providers) to find the veins in the hands or arms. An alternative is to use a port-a-cath. This small device is placed under the skin in the chest and connects directly into the bloodstream. Infusions are made by pushing a special needle through the skin into the port. The port-a-cath is left in place until the child is old enough to access the veins in the hand or arm.

Port-a-caths are now rarely required as many young children are treated with the subcutaenous therapy - hemlibra.

Self-care

Children with haemophilia learn self-care at a very young age. It starts with recognizing bleeds and telling their parents so they can get quick treatment, if needed. They soon start to learn to prepare their treatments. These could be the subcutaneous injections of emicizumab or the intravenous infusions of clotting factor concentrates. There is no definitive age when children should start to do their own injections / infusions; they start when they feel ready. Many learn when they are as young as 7 or 8 years of age.

Mastering all steps of self-care from preparing the treatments, to doing the injections / infusions, to disposing safely of the supplies means that a child is more independent. They are able to go on overnights with friends, on school trips or on visits to relatives without a parent needing to accompany them. This leads to greater self-confidence and feelings of normalcy.

The personnel at the haemophilia treatment centre are experts at training children in their own care.

Inhibitors to Clotting Factor Concentrates

Some people with haemophilia develop an antibody or inhibitor to factor concentrates. The body's own immune system sees FVIII or FIX as foreign and eliminates it soon after infusion. The treatment becomes much less effective at stopping or preventing bleeding.

Inhibitors are more common in severe haemophilia A. They are very rare in mild haemophilia A and in all forms of haemophilia B.

Fortunately, the efficacy of Hemlibra is not affected by an inhibitor. People with a factor VIII inhibitor can continue to receive Hemlibra and control their bleeding.

Treatment for factor IX inhibitors is more complex. Therapies called bypassing agents are used. New treatment options are currently in clinical trials (see later section on research).

Growing up with haemophilia

When a baby is diagnosed with haemophilia, the parents may at first have feelings of disappointment, worry and perhaps guilt. This may be an especially hard time for those who have no family history of the condition. Parents and other members of the extended family need to have the reality of haemophilia carefully, patiently and repeatedly explained to them by members of the haemophilia comprehensive care team. In time, parents may find that the condition is not nearly as bad as they first imagined. The unknown is often more frightening than the reality.

The impact of regular prophylactic treatment on the lives of families with haemophilia needs to be explained. It is important to remember that with good treatment the child with haemophilia has every chance of growing up as an active, fit child who can participate fully in family life, school and later working life.

Because haemophilia is rare, parents may feel isolated and alone and it is very helpful to be put in touch with others in a similar position. Attending meetings and events organised by the Irish Haemophilia Society is one way to meet people who have similar issues.

The Early Days

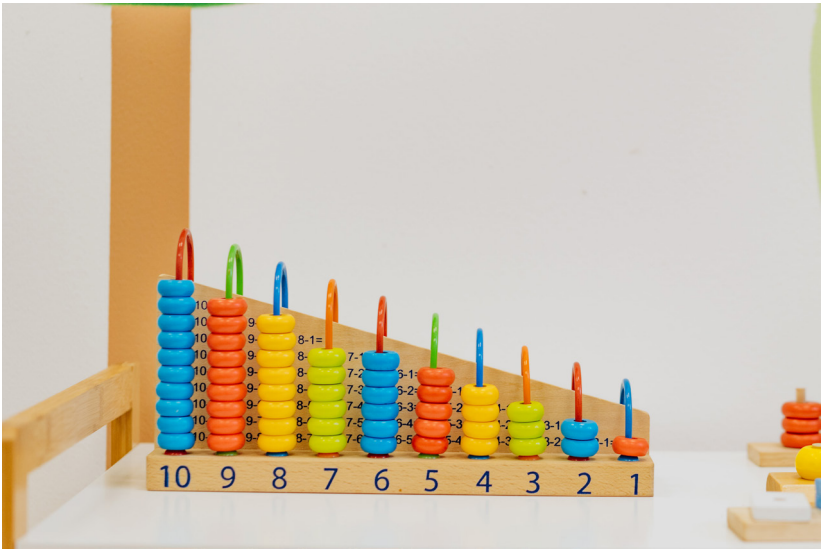
A big worry for parents of a baby with haemophilia is how to recognise when their child has a bleed. (See *The main sites of bleeding* on page 9). If in doubt, you should call your haemophilia treatment centre for advice. With experience and a little vigilance parents will soon learn to recognise the signs and severity of bleeding episodes and learn to respond effectively.

At the Toddler Stage

It is important for the child, siblings and parents that haemophilia does not dominate the life of the family. A child with haemophilia has to learn about the world around him in the same way as any other child. While it is natural for parents to want to offer as much protection as possible, over protection is not in anyone's interest. Helmets and padding are not usually recommended. At the toddler stage, when all children are liable to cut, bump and bruise themselves, careful observation of the child is important. As children get older, they can become more involved in self-care and the recognition of bleeds. Young children with haemophilia very quickly learn to recognise when a bleeding episode is starting in a joint or muscle. They should be encouraged to tell a parent as soon as possible so that treatment can be given, if needed, and disruption to normal life reduced to a minimum. A child should never be blamed for a bleeding episode.

At playgroup, normal play activities present little in the way of problems and the child should be allowed to play alongside the other children. They may get some unsightly bruises, but in general these will not be a serious problem and no treatment will be necessary.

There is no reason why children with a bleeding disorder should not be allowed to use scissors and other sharp instruments. Like any child, they need to learn how to handle this equipment.



School

Haemophilia should not interfere with a child's education. Education is vitally important in today's world as it provides the child with every opportunity to participate fully in activities of a normal life.

Haemophilia is rare, however, so the school personnel and teacher will likely not be familiar with the condition. It is important that parents provide the school with the key information needed. Teachers need to learn to rely on the parents, who have the knowledge, and the child, who knows their own body, in the case of a bleed. Normally, the child with

haemophilia will participate in school activities just like their classmates.

The haemophilia treatment centre and the Irish Haemophilia Society can provide parents with tools to educate school personnel. (See IHS' *Information for Teachers & Playgroup Leaders*.)

There is no need to hide haemophilia or to overdramatise it. School personnel need to have the basic information about the condition at the beginning of the school year so they know what to do and not do in different situations.

Adolescence

Adolescence is an exciting but challenging time of life. In addition to the difficult issues all adolescents have to deal with, those with haemophilia have some additional challenges as they become more independent and make the transition to adulthood, such as:

- Learning to consistently and promptly identify bleeds on their own
- Maintaining infusion supplies
- Making and keeping clinic appointments (or calling to reschedule if necessary)
- Following the recommended treatments as agreed with the medical staff at the centre
- Safely managing self injection / infusion when away from home
- Completing treatment logs at the time of each injection / infusion

- Doing physical fitness exercises as recommended.

Adolescents with haemophilia have to decide whom they want to tell about their condition and how much they want to say. Talking about their haemophilia in a matter-of-fact and open manner as a condition they are well able to manage on their own goes a long way to having it accepted by peers.

The experience of dealing with a chronic health condition like haemophilia often leads to young people developing maturity at a younger age and an ability to better deal with life's challenges.

College / Employment

With the treatment available today, a person with haemophilia should not miss out on schooling or education as a result of bleeds or joint damage. The choice of college education and employment, therefore, for someone with a bleeding disorder should not differ from any of their peers.

In each case, the choice of occupation is related firstly to the interests, abilities and skills of the individual and secondly to the severity of haemophilia.

It must be emphasised that the majority of people with haemophilia find and keep satisfactory regular employment.

Home treatment has enabled the person with haemophilia to inject / infuse at home or, if necessary, at their place of employment. This enables normal work attendance and promotes self-confidence and independence.

Physical Activities and Sports

Children with haemophilia should be encouraged to be as active as possible. Physical fitness and strong muscles protect joints from bleeding.

The most important factor in choosing a sport is the child's love for the activity.

Not all sports present the same risk of bleeding. Swimming is considered an ideal by haemophilia doctors. It is very safe and contributes to excellent physical fitness. Playing in warm water allows the exercise of all joints and muscle groups in the body without gravity. No child should grow into adolescence without being able to swim.

Bicycling is also an excellent activity to develop physical fitness.

The suitability for participation in contact sports such as football will depend on a number of factors:

- The child's age (sports become rougher as children get bigger)
- The level of competition (high-level competition involves greater risk)
- The degree of severity of haemophilia
- The prophylactic therapy prescribed
- The condition of the child's joints.

Children and parents should discuss the choice of sports with the physical therapist at the haemophilia treatment centre. Proper precautions—the right equipment, adequate supervision, warm-ups—are especially important.

If it is found that a particular sport causes bleeds, it may be necessary to change to another sport or adjust the prophylactic treatment before taking part.

For further information on sports, please refer to the Irish Haemophilia Society's booklet *SPORT, EXERCISE & HAEMOPHILIA*.

Carriers

Obligate Carriers

In certain cases, a person is an obligate carrier. There can be no doubt. Such cases are:

- A daughter of a man with haemophilia
- A mother with more than one son with haemophilia
- A mother with one son with haemophilia and a blood relative with haemophilia.

Possible Carriers

In other cases, the carrier status is not certain. If a male has haemophilia and there is no history in the family, the females in the family are *possible* carriers. The following family members should be tested for their carrier status: mother, sisters, cousins, aunts and nieces.

It is important for carriers to be aware of their factor levels as treatment may be necessary in childbirth, or at times of severe injury or surgery. When an obligate or potential carrier is pregnant, she should inform her obstetrician of her status.

It should not be assumed that a young girl who has grown up with a father or brother with haemophilia is aware of her possible carrier status. A young girl needs to be given information relevant to her age and using language that she can understand. This information needs to be given on an ongoing basis as she matures to help her understand it at her level. When the time comes for a young girl to be tested for her carrier status, she will need to be given extra support.

Did you know?

If a carrier has a factor level of less than 40%, she will be diagnosed as having mild haemophilia. Moderate or severe haemophilia can occur in females but it is relatively rare.

Genetic Counselling

For obligate or possible carriers, it is advisable to have genetic counselling, preferably before becoming pregnant. Genetic counselling will provide information to enable a woman to make an informed decision in relation to family planning. Genetic counselling and carrier testing is available at the National Centre for Hereditary Coagulation Disorders in St. James's Hospital, Dublin. Tel: 01 – 4162141.

Research and Novel Products

It is an exciting time in haemophilia research. In addition to monoclonal antibodies (emicizumab) for people with haemophilia A, with and without inhibitors, and extended half-life FVIII and FIX , which were introduced in Ireland in recent years, more novel products are in the research pipeline.

The first generation of gene therapies has been approved for use for both haemophilia A and B by the European Medicines Agency. They are one-time treatments that offer the potential of replacing prophylactic therapy for an indefinite period.

More potent forms of emicizumab are currently being developed for haemophilia A. These may offer even greater bleed protection.

Three other types of sub-cutaneous treatment for both haemophilia A and B are in clinical trials. These include:

- Anti-tissue factor pathway inhibitors
- Anti-thrombin inhibitor
- Anti-protein C.

While the benefits and risks of these treatments are still under evaluation by the European Medicines Agency, it is very hopeful to see the number and variety of novel treatments for haemophilia in the research pipeline.

What the Irish Haemophilia Society Offers

The Irish Haemophilia Society represents the interests of people with haemophilia, von Willebrand Disorder and other inheritable bleeding disorders. We aim to assist people with bleeding disorders to be positive and proactive with their health and to maximise their quality of life.

The Society was founded in 1968 by members of the medical profession, people with haemophilia, their families and friends who felt the need to provide support and advice for members and to improve the quality of life for people with haemophilia. The Society has grown from an informal and voluntary group of parents of people with haemophilia who wanted a better life for their children, to a confident and professional charity with a committed board and professional staff to deal with the challenges ahead.

Today the Society is vigilant on product safety and the availability of treatment and maintains a strong and united organisation. The Irish Haemophilia Society continues to play a central role in advocating for inheritable bleeding disorders both nationally

and internationally. Nationally, we contribute effectively to the National Haemophilia Council, Haemophilia Product Selection and Monitoring Advisory Board and Consultative Council on Hepatitis C. Our strong presence helps to ensure that people in Ireland have the best possible treatment options. Internationally, we regularly attend and participate at conferences and events organised by the World Federation of Hemophilia (WFH) and the European Haemophilia Consortium (EHC).

We produce various publications, organise information meetings, conferences, regional visits, home and hospital visits and updates on treatment. We have a committed board

and staff, young enthusiastic members, great volunteers and are working in a strategic and planned manner. We have a permanent headquarters and provide services for all categories of members.

One of the central functions of the Irish Haemophilia Society is to facilitate learning and the sharing of information among members. To achieve this, we arrange a number of different information days and conferences throughout the year. We hold an annual Conference and AGM, and annual October Members' Conference, an annual von Willebrand Disorder Information Day and a tri-annual Parents Conference, among others. These conferences and information days bring together medical professionals from across the world and from Ireland who have huge experience and knowledge around inheritable bleeding disorders, as well as members of the Society who have been with us for many years and those who have only just joined us.

Our conferences and information days are heavily subsidised for members or free of charge. At our conferences for families (such as our AGM and October Members' Conference) we run children's programmes parallel to the adult programmes. These programmes group children together by age and involve various activities and games.

Another primary method in which we disseminate information to our members is through publications and other forms of media, such as our bi-weekly online newsletter and our social media channels. We publish a quarterly magazine which includes an update on new treatments, interviews with doctors and members, information about conferences, and more. We also publish a Novel Products Review twice a year, which covers all novel treatments and therapies for people with haemophilia and other inheritable bleeding disorders. The IHS also has

numerous other publications on haemophilia, von Willebrand Disorder, rare bleeding disorders and more.

The Society plays a strong supportive role to people in Ireland with haemophilia and other inheritable bleeding disorders. We do so by systematically contacting members by phone annually, answering informational queries over the phone or directing callers to the relevant person, and physically meeting members who want our support. We organise regional visits several times a year and carry out home visits when asked. We also organise school visits when requested by members, to educate teachers about the child's bleeding disorder.

We remember those who have passed away. We remember and have learned from the tragedies which have befallen our community and we look to the future with confidence and hope.

Notes

This booklet was produced by:

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