



Jargon Buster

Why is it that when you have a bleeding disorder everyone expects you to know what a whole load of complicated medical terms mean? Have a look at our jargon buster to pick the meaning from the meaningless.

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A

Antibody

Your body produces these proteins to fight any substance that it thinks is foreign or dangerous. An inhibitor is when the body produces antibodies to your factor replacement.

Antihemophilic Factor (AHF)

Another term for Factor VIII, which is one of the clotting factors in the blood needed to form fibrin, which in turn helps stop bleeding.

Acquired Haemophilia

Acquired haemophilia is a bleeding disorder which usually develops in later life and can affect both men and women. It is very rare and occurs when the immune system develops antibodies against the body's own clotting factors, usually factor VIII, stopping it from working. This results in a reduced factor level in the blood.

Arthropathy

Chronic joint disease (arthritis) caused by repeated and uncontrolled bleeding into joints. This is the leading cause of disability in people living with haemophilia.

B

Bleeding Disorder

To make a blood clot you need thirteen different factors in the right order. Most bleeding disorders occur when there isn't enough of one particular factor. Different missing factors cause different bleeding disorders.

Bubbling

An unusual, intermittent feeling in a joint or muscle that indicates early stages of bleeding.

C

Christmas Disease

This is the other name for haemophilia B. The condition was first described in 1952 by researchers at Oxford. It is named after Stephen Christmas, a five year old British boy who was the first patient in whom this was recognized to be different from classical haemophilia.

Classical Haemophilia

This is the other name for haemophilia A.

F

Factor

There are lots of different "factors" that help blood clot. You need thirteen in all to make a clot. Most bleeding disorders occur when there isn't enough of one particular factor. Different missing factors cause different bleeding disorders.

Factor IX

Factor IX helps to stop you from bleeding. If you have haemophilia B you will have less factor IX than normal.

Factor VIII

Factor VIII helps to stop you from bleeding. If you have haemophilia A you will have less factor VIII than normal.

G

Genes

Genes are the master planners of the body that tell cells what to do. The 50,000 or so genes in our bodies contain instructions that determine everything physical about us. For example, the colour of your hair. Some genes tell cells to make clotting factors to help blood clot. We get our genes from our parents.

H

Haemophilia

Haemophilia is a bleeding disorder caused by a deficiency in blood clotting factor. The factor deficiency means that blood takes longer to clot, so that a person with haemophilia will bleed for longer than an unaffected person. Usually a hereditary disorder caused by a gene alteration but can occur spontaneously. There are two main types, haemophilia A and haemophilia B.

Haemophilia A

Haemophilia A is when you have a deficiency of factor VIII.

Haemophilia B

Haemophilia B is when you have a deficiency of factor IX.

Hereditary Disorder

A disorder that is genetically passed from parents to their children. Haemophilia and von Willebrand's disease are usually hereditary disorders but occasionally result from spontaneous gene mutations.

I

Inhibitors

These are antibodies in the blood that react to and destroy infused factor more quickly than usual and make clotting more difficult in some people with haemophilia.

M

Mild Haemophilia

People with mild haemophilia have more factor than people with moderate or severe haemophilia, which means that lots of bleeds can stop by themselves.

Moderate Haemophilia

People with moderate haemophilia do have some factor in their blood, and so they might not bleed as often as someone with severe haemophilia.

Mutation

Sometimes there are problems with the genes that result in disease. These problems are known as mutations and cause genetic disorders. They can happen at any time. In the case of haemophilia, a mutation causes a single gene to be altered or missing which affects the level of factor naturally present in your blood.

P

Plasma

The fluid component of blood, which contains platelets, clotting factors, and other proteins.

Platelets

Platelets are the cells in the blood that are involved in the formation of blood clots. When someone has a low level of platelets they will bleed for longer than an average person.

Port (Port-a-Cath)

A device surgically implanted under the chest wall that allows for factor infusions without having to locate an accessible vein.

Prophylaxis

Prophylaxis is treatment that stops you bleeding. This means putting factor in your body 2 or 3 times a week. If you have prophylaxis you should have less bleeds and this means less pain, less time in hospital and more time doing fun things.

R

Recombinant Factor

Factor VIII or Factor IX concentrate created in a laboratory using the human factor gene. These factor concentrates are artificial, ie they don't come from human blood or plasma.

S

Severe Haemophilia

People with severe haemophilia have hardly any factor in their blood, and so they bleed more often than other people with haemophilia, more than once a week sometimes.

Spontaneous Bleed

Sudden, unexpected internal bleeding.

V

von Willebrand Disease (vWD)

Von Willebrand's disease (vWD) is the most common hereditary bleeding disorder in humans, although it can also be acquired as a result of other medical conditions. There are four types of hereditary vWD. It happens because of a lack of von Willebrand factor (vWF). It affects humans and also dogs! The disease was first described by Erik von Willebrand, a Finnish physician who reported a new type of bleeding disorder among island people in Sweden and Finland.

von Willebrand factor (vWf)

Von Willebrand Factor is a protein critical to help blood clot. This glue-like protein, produced by the cells that line the blood vessel walls, interacts with blood cells called platelets to form a plug which prevents the blood from flowing at the site of injury. If you have von Willebrand's Disease it means you have less von Willebrand factor than other people.
