

# My+LBUSTED

# Is it true people with haemophilia can't play any sports?

**No.** People with haemophilia can safely participate in a wide range of sports. Regular exercise and sport can strengthen muscles and protect joints, preventing injuries and bleeding

episodes. As for everyone, physical activity can help people with haemophilia feel better generally, be with friends and have fun. Likewise, it is important that everyone uses the protective equipment that is appropriate to the sport. Generally, it is recommended that people with haemophilia do not do high contact sports like boxing. They can discuss their sporting goals with their Haemophilia Treatment Centre and work together on their chosen sport.



# My+LBUSTED

# If people with haemophilia cut themselves, will they bleed to death?

**No.** People with haemophilia have blood that doesn't clot properly but with specialised treatment their bleeding can be controlled. Some have treatment to prevent bleeding and rarely have bleeding problems. Without treatment a person with haemophilia does not bleed any faster than anyone else, but bleeding can continue for

**Bleeding Disorders** 

Awareness Month

longer and result in poor healing. Minor cuts and scratches on the skin are not usually a problem. They can be treated by putting on a Band-Aid® and some pressure over the site of the bleeding. If the bleeding does not stop, specialised treatment will be needed so blood can clot normally.

**OCTOBER 2024** 

My+LBUSTED

Are bleeding disorders

**No.** There is absolutely no way bleeding disorders like haemophilia

or von Willebrand disease (VWD)

can be 'caught'. Haemophilia and

VWD are hereditary and caused

by a change to a gene, but they

previous history of the condition.

MUTHBUSTED

sometimes occur in families with no

contagious?





#### Bleeding Disorders Awareness Month OCTOBER 2024

# Myth Busted

#### Is it true only males have haemophilia?

No. Males are more likely to be diagnosed with haemophilia. However, around 20-30% of females with the 'haemophilia' genetic change have bleeding symptoms related to haemophilia. Some of these females may be diagnosed with haemophilia.



#### Bleeding Disorders Awareness Month OCTOBER 2024

# Did you know?

**Von Willebrand disease** (VWD, also known as *von Willebrand disorder*) **is the most common bleeding disorder worldwide.** 

Bleeding problems can vary a lot between people with VWD. Some people experience little or no disruption to their lives unless they have serious injuries or surgery, and others bleed quite often. There can be bleeding problems with all types of VWD. Many people are not aware they have the disorder and are currently undiagnosed.





Bleeding Disorders Awareness Month OCTOBER 2024



#### This can happen because there is a new gene change that occurs by chance during reproduction, before a baby is born.

#### Bleeding Disorders Awareness Month OCTOBER 2024

### Can people with haemophilia travel?

Yes. They just have a little more organising and packing to do. They need to contact their Haemophilia Treatment Centre (HTC) to organise enough treatment product and equipment for the time they are away.

They also need to find out where the nearest HTCs are to where they will be staying.

They may also need documentation to carry medication and treatment equipment through security and customs - it is important to talk to their HTC about this well in advance and allow plenty of time to prepare the documentation.



Bleeding Disorders Awareness Month OCTOBER 2024







# Did you know?

# What does haemophilia B have to do with Christmas?

#### Haemophilia B is also known as Christmas Disease.

It was named after Stephen Christmas – the first person to be diagnosed with the condition in 1952.

Haemophilia B occurs when there is not enough clotting factor IX (9) in the blood. Approximately 1 in 26,000 males have haemophilia B.



# Did you know?

#### Is haemophilia a Royal disease?



Haemophilia is caused by an alteration in the factor VIII (8) or IX (9) gene and can occur in any family.

Haemophilia has often been associated with European royal families and is sometimes called 'The Royal Disease'. This is because several members of the European royal families had haemophilia or carried the gene alteration in the nineteenth and twentieth centuries. Queen Victoria of England (1819-1901) carried the factor IX gene alteration causing haemophilia B. One of her sons had haemophilia and the gene was passed on through some of her children to the English, Prussian, Russian, and Spanish royal families. A famous example of Queen Victoria's decendants with haemophilia was Prince Alexei Romanov, son of the Russian Tsar Nicholas II, and great-grandson of Queen Victoria. No living member of the current royal families of Europe is known to have haemophilia or carry the gene alteration for it.

**Bleeding Disorders** 

Awareness Month



Bleeding Disorders Awareness Month OCTOBER 2024

## Did you know?

Dogs, cats, horses and other animals can have hereditary bleeding disorders.

Von Willebrand disease, haemophilia and other bleeding disorders have all been reported in cats, dogs, horses and other animals. Similar to humans, animals with bleeding disorders will work with a specialised vet to receive treatment, and require extra preparation before medical procedures such as surgery.



When was von Willebrand disease first discovered? Von Willebrand disease (VWD) was

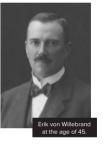
**OCTOBER 2024** 

Did you know?

discovered in 1925 by, and named after, the Finnish doctor Erik von Willebrand. Professor von Willebrand described

this new type of bleeding disorder after observing families living on the Aaland Islands between Sweden and Finland who had bleeding problems.

It is also known as von Willebrand disorder.





Bleeding Disorders Awareness Month OCTOBER 2024

# Did you know?

The World Federation of Hemophilia estimates that over 75% of people living with haemophilia worldwide have not yet been identified and diagnosed.

Identification and diagnosis rates are even lower for women with bleeding disorders and for those with von Willebrand disease (VWD) and other rare bleeding disorders.



Bleeding Disorders Awareness Month OCTOBER 2024



# NEW POSSIBILITIES

Bleeding Disorders Awareness Month OCTOBER 2024



# Did you know?

Factor XI (11) deficiency is the third most common bleeding disorder to affect women.

Factor XI deficiency is the most common of the rare bleeding disorders, estimated at one in 100,000 people, and is the third most common bleeding disorder to affect women after von Willebrand disease and haemophilia.



Bleeding Disorders Awareness Month OCTOBER 2024

