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HAEMOPHILIA FOUNDATION AUSTRALIA



Health and wellbeing into the future – the decade ahead

Haemophilia Awareness Week • 9-15 October 2011

HAEMOPHILIA AWARENESS WEEK – 9 15 OCTOBER 2011

During Haemophilia Awareness Week Haemophilia Foundation Australia (HFA), State and Territory Haemophilia Foundations, health professionals, community groups and family and friends around the country work together to raise awareness about inherited bleeding disorders.

The theme this year is **“health and wellbeing into the future – the decade ahead”**. What does it actually mean to live with a bleeding disorder? People from the bleeding disorders community share the experiences of living with a bleeding disorder or of being a parent to a child with a bleeding disorder – the challenges faced every day, the reality of living with a lifelong disorder, what can be done about improving health and wellbeing into the future and most importantly – celebrating the ways we overcome these challenges as a community.

For Haemophilia Awareness Week promotional resources and personal stories, see the HFA website – www.haemophilia.org.au

BACKGROUND INFORMATION

Inherited bleeding disorders include haemophilia, Von Willebrand Disorder and other rare factor deficiencies.

Haemophilia

Haemophilia is a rare inherited bleeding disorder. Haemophilia occurs when people don't have enough of an essential clotting factor in their blood to control bleeding or it doesn't work properly. This clotting factor is a protein known as either factor VIII (8) or factor IX (9), depending on the type of haemophilia. Haemophilia is not curable and can be life threatening if not treated promptly and effectively. Bleeding is mostly internal, often into muscles and joints and sometimes organs. Without effective treatment over time the bleeding can cause damage to muscles and joints, resulting in pain, arthritis, disability and mobility problems and reduced quality of life.

About 2000 people in Australia have haemophilia. As the condition is inherited, it occurs in families. However, in one-third of cases it appears in families with no previous history of the disorder. The haemophilia gene is passed down from parent to child through generations. Men with haemophilia will

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• NATIONAL MEMBER ORGANISATION OF THE WORLD FEDERATION OF HAEMOPHILIA

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pass the gene on to their daughters but not their sons. Women who carry the haemophilia gene can pass the gene on to their sons and daughters. Their sons with the gene will have haemophilia.

Although women can carry the gene, only very rarely do they have haemophilia. However, some may also experience bleeding problems. If girls or women have bleeding symptoms, they may bruise easily and bleed a lot during dental surgery or extractions or other surgery. They may have heavy menstrual bleeding and sometimes have bleeding problems during and after childbirth.

Haemophilia is found in all races and socio-economic groups – the most famous woman to carry the gene was Queen Victoria of England.

With appropriate treatment bleeding can usually be stopped. Young people who have been treated all their lives with clotting factor are likely to live a relatively normal life. Unfortunately older people with bleeding disorders may not have had access to optimal amounts of clotting factor when they were younger and may live with the long term effects of chronic bleeding. With better access to treatment, people are now living into their senior years with haemophilia. This brings new challenges to be faced, as the understanding of the impact of ageing on haemophilia grows. A small number of people also develop antibodies (“inhibitors”) after treatment, which make treatment less effective. If their inhibitors cannot be resolved, they may experience joint and muscle damage and arthritis from a young age.

Treatment is with replacement clotting factor treatments injected intravenously up to 2-3 times every week. Treatment can aim to prevent bleeding episodes or “bleeds” (“prophylaxis”), or to treat bleeds as they occur (“on-demand”). In Australia blood clotting factor products are produced from either human blood plasma or ‘recombinant’ or synthetic product manufactured commercially in laboratories.

Von Willebrand disorder

Von Willebrand disorder (VWD) is another inherited bleeding disorder caused when there is not enough of the von Willebrand clotting factor in a person's blood, or it doesn't work properly. Both women and men can have VWD and can pass it on to their children. It is more common than haemophilia but people with VWD usually have a mild form. Many people have such mild symptoms they are not aware they have the disorder. Common symptoms include frequent or prolonged nose bleeds, easy bruising, very heavy or long menstrual periods, prolonged bleeding with minor cuts, bleeding from the gums and prolonged bleeding after injury, surgery or dental work. It is thought that many Australians with VWD are undiagnosed. Others only realize they have a bleeding problem when they have heavy bleeding after a serious accident or a dental or surgical procedure. However, some people have severe VWD with frequent bleeding episodes and joint and muscle bleeds.

Most people do not need treatment unless they have surgery or an injury or heavy bleeding with menstrual periods. If people have severe VWD they may need preventive treatment or regular treatment, as do people with severe haemophilia. Some people with VWD can only be treated with clotting factor VIII concentrates made from human plasma, while others can be treated with synthetic hormones. Antifibrinolytic drugs such as tranexamic acid can also be used to reduce bleeding.

Diagnosis and treatment of VWD are complex and require a range of specialist laboratory, medical and counseling services. If people think they have a bleeding problem, it is important to be referred to a specialist Haemophilia Centre or Service. These are at some major hospitals and have a team of health professionals with expertise in bleeding disorders, including VWD.

Apart from haemophilia and VWD disorder, there are also other rare blood clotting factor deficiencies. These are caused when a particular factor or protein in the blood that helps blood to clot is lower than normal, missing or doesn't work properly.

Haemophilia Foundation Australia

HFA represents people with haemophilia, Von Willebrand disorder and other related bleeding disorders and their families. HFA is committed to improving treatment and care through representation and advocacy, education and the promotion of research. HFA supports a network of State and Territory Foundations in Australia.

As a National Member Organisation of the World Federation of Hemophilia, HFA participates in international efforts to improve access to care and treatment for people with bleeding disorders around the world.

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