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HAEMOPHILIA FOUNDATION AUSTRALIA

October 8, 2009.

15th Australian and New Zealand Haemophilia Conference

Boy oh boy – Life's challenges for people with haemophilia

Affecting approximately 2000 males in Australia, haemophilia is an incurable and potentially life-threatening inherited blood clotting disorder. It is treated with injections of blood clotting products. The good news is that effective and now safe treatment is helping people with haemophilia to live longer. But in the past, some people with haemophilia were exposed to HIV and hepatitis C through their treatments and many developed permanent joint damage from bleeding due to inadequate clotting factor treatment. They continue to live with the consequences of these earlier problems. The state of the art in haemophilia treatment and care will be presented at the 15th Australian & New Zealand Haemophilia Conference in Brisbane from October 8-10, 2009, and which will run in conjunction with Haemophilia Awareness Week – nationally from October 11-18, 2009.

“We’re seeing a relatively new phenomenon,” says Dr Huyen Tran from The Haemophilia Treatment Centre at The Alfred Hospital in Melbourne. “And that’s the elderly person with haemophilia. The availability of clotting factor concentrate over the last several decades and improved medical care provided by specialised haemophilia treatment centres have resulted in an increase in the life expectancy of people with haemophilia to greater than 70,” he claims. Dr Tran will talk about the unique problems that are emerging in people with haemophilia as they age. “In haemophilia, “older” usually means you are over 40. It’s very positive to see people living now into their senior years, but they do have to endure both haemophilia-related health problems such as joint disease and antibodies to treatment known as “inhibitors”, as well as age-related ailments such as cancer and cardiovascular disease.”

Psychologist Dr Michael Carr-Gregg says coping with a chronic illness such as haemophilia at any age is extremely difficult, but during adolescence can be seen as a crisis upon a crisis. “The period of adolescence is characterized by simultaneous physical, psychological, social and sexual transformations. It’s a time of immense psychological challenge for the young person with haemophilia, which can be compounded by the health risks of not complying with their preventive treatment, which happens frequently when they pass from childhood to adolescence,” he says. “One of the most important influences on the adolescent’s care of themselves is support from parents, peers and caregivers. Personalised treatment strategies that recognize and accommodate the young person with haemophilia and his lifestyle are essential.”

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“Many people with haemophilia acquired hepatitis C as a result of blood product treatment in the days before testing for the virus was available,” says Professor Greg Dore from the National Centre in HIV Epidemiology & Clinical Research at the University of NSW. “It’s not easy for them because, apart from the health problems it adds, there’s enormous stigma attached to hepatitis C. The good news is that treatments are better than ever, and new non-invasive methods of determining the extent of liver damage have been developed.” Professor Dore, an international authority on hepatitis C, will talk about the particular problems people with haemophilia face with hepatitis C and treatment possibilities based on the latest research.

“Gene therapy offers great hope to people living with incurable bleeding disorders. The idea of putting the normal haemophilia gene back where it should be is very simple, but we’ve faced several hurdles along the way, most recently due to the immune system,” explains Professor John Rasko who is Director of the Department of Cell and Molecular Therapies at Royal Prince Alfred Hospital. “If we are successful with the current trial of a single injection of gene therapy followed by several months of immune suppression we hope to permanently avoid the risks of factor replacement and cure haemophilia forever.” Professor Rasko is an international leader in gene and stem cell therapy and a grateful past recipient of research funding from the Haemophilia Foundation Australia.

Background

Inherited bleeding disorders include haemophilia and von Willebrand Disorder and other rare factor deficiencies. There are approximately 3600 people diagnosed with inherited bleeding disorders in Australia.

Haemophilia

Haemophilia is a rare inherited bleeding disorder. Haemophilia occurs when blood clotting factors VIII (eight) or IX (nine) are missing in a person’s blood or don’t work properly. It is not curable and can be life threatening if not treated properly. Bleeding is mostly internal into muscles and joints. Over time it can cause damage to muscles and joints, resulting in pain, disability and reduced quality of life.

Haemophilia is an inherited condition and occurs in families. However, however in 1/3 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 pass the gene on to their daughters but not their sons. Women who carry the haemophilia gene can pass the haemophilia gene on to their sons and daughters. 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. 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 normal life. Unfortunately older people with bleeding disorders may not have had access to optimal amounts of clotting factor and may live with the long term effects of chronic bleeding and blood borne viruses. Treatment is with replacement clotting factor treatments injected intravenously up to 2-3 times every week. Blood clotting factor products are produced from either human blood plasma or ‘recombinant’ or synthetic product manufactured commercially in laboratories. Most people with haemophilia in Australia now use recombinant products as a safety precaution.

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. It is thought that many Australians with vWD are undiagnosed as it is more common in a mild form, and most people do not need treatment unless they have surgery or an injury. However, some people have severe vWD with frequent bleeding episodes and joint and muscle bleeds. 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.

Life Challenges: The 15th Australian and New Zealand Haemophilia Conference

October 8-10, 2009, The Sebel Hotel, King George Square, Brisbane QLD

This biennial conference brings together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry representatives. It is a great opportunity to learn more about the care and treatment in Australia and New Zealand and around the world, and what the future holds for the bleeding disorders community.

With sessions on the treatment and care of children and adults with bleeding disorders, inhibitors, and the complexities of ageing, youth, women's health, hepatitis C and HIV, the program will feature presentations on current and future issues affecting people with haemophilia and related inherited bleeding disorders by experts from Australia, New Zealand, USA, the UK and Canada.

There will be lively discussions about the supply and safety of treatment products, the cost of treatment and care, and issues that impact on access to care and treatment in the developed and the developing world. Interesting to all ages, the conference promises to again be an essential roundup of the state of the art in the treatment and care of haemophilia today.

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