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15TH Australian & New Zealand HAEMOPHILIA CONFERENCE

Life Challenges

Brisbane, 8-10 October 2009 www.haemophilia.org.au

The 15TH Australian & New Zealand Haemophilia Conference will be held at The Sebel, King George Square, Brisbane from 8-10 October 2009.

Our 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.

The Conference Program Committee is chaired by Dr James Daly of Royal Hobart Hospital in Tasmania. The committee has representatives from all clinical disciplines and community representatives from both Australia and New Zealand. Program topics have been selected to cover a range of interests and experiences. The program includes topics of importance for people who provide care and treatment to the bleeding disorders community, as well as for the people who use services.

We already have a list of excellent speakers for the conference. Dr Michael Carr-Gregg who is one Australia's highest profile psychologists will speak on parenting, adolescence and mental health. Dr Paula Bolton-Maggs who is a consultant haematologist in the United Kingdom will bring her clinical experiences of treating people with bleeding disorders over many years. Kathy Mulder is a Canadian physiotherapist with extensive experience and a passion for helping people with bleeding disorders learn more about how to care for themselves, and understand the importance of physiotherapy in comprehensive care teams.

There will also be sessions on the treatment and care of children and adults with bleeding disorders, gene therapy and new treatments, inhibitors and the complexities of

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Contents

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Continued from page 1

15TH AUSTRALIAN & NEW ZEALAND HAEMOPHILIA CONFERENCE

ageing, youth, women's health, hepatitis C and HIV. There will be lively discussions about the cost of treatment and care and issues that impact on access to care and treatment throughout the world.

Youth delegates at the conference

The conference program will be of interest to people of all ages, and youth delegates aged 15 and over are encouraged to attend. Youth will participate in the mainstream program, but youth registration will also cover participation in adventure activities arranged only for youth delegates at the conference.

Abseiling the Kangaroo Point Cliffs

All registered youth delegates will be able to attend the abseiling activity on Thursday 8 October in the late afternoon. Youth will be advised of the full details after they have registered so they can arrange suitable flight arrival times. Abseiling is covered in the youth registration fee, however the box must be ticked to ensure a place.

Who should attend the conference?

- People with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners
- Youth – topics relevant to youth will be integrated throughout the program
- Health professionals – doctors, nurses, physiotherapists, counsellors and other health care providers
- Treatment product producers, suppliers and service providers
- Policy makers and government officials
- Haemophilia Foundation volunteers and staff

Sponsorship

Sponsorship packages are still available. Contact HFA for details if your organisation wishes to participate in this exciting education event.

Exhibition Area

An excellent space is available throughout the conference for exhibitors to showcase new developments, ideas and successes.

Registration

Registrations are now open for the conference. Use the enclosed registration form or register online at www.haemophilia.org.au/conferences.

Registration includes admission to all plenary and concurrent sessions, conference satchel, abstract book, Welcome & Exhibition Opening on Thursday evening, and morning/ afternoon tea and lunch on Friday and Saturday.

Early bird draw

If you book and pay for your registration by 31 July you will go into the draw to win the following prizes courtesy of Brisbane Marketing –

- 1st - 2 nights' accommodation at The Sebel Citigate valued at $400
- 2nd - 2 nights' accommodation at The Sebel Citigate valued at $400
- 3rd - Double pass to climb the Brisbane Story Bridge valued up to $198

This article by Mark W Skinner, World Federation of Hemophilia (WFH) President, was published in *Hemophilia World*, December 2008, Vol 15 No 3, the newsletter of WFH. The Report on the Annual Global Survey 2007 is available on the WFH website at www.wfh.org.

WFH GLOBAL SURVEY MARKS AN IMPRESSIVE DECADE

Mark W Skinner

Ten years ago, the WFH initiated the annual global survey to track key indicators of the level of care and treatment for people with bleeding disorders around the world. The survey is based on the hard work of our member organisations, which every year provide information on the state of care in their countries: demographics, available health resources and treatment products, and the prevalence of complications such as HIV, hepatitis C (HCV), and inhibitors.

Over the years, the quantity and quality of the data reported to the WFH has steadily improved. Today 60 per cent of reporting countries provide data based upon a patient registry. No other data source provides the scale, scope, and reliability of the WFH global survey.

Today, the WFH annual global survey has become an invaluable and widely cited resource on standards of treatment and is used for healthcare planning for people with bleeding disorders. Using data from the WFH global survey, we can demonstrate the quantifiable and significant impact of WFH development programs.

More patients identified

The numbers tell an astonishing story of the increase in identified patients as well as the health status of people with bleeding disorders around the world. Since 1998, the WFH survey has recorded a 107 per cent increase in the number of patients identified. The number of countries participating in the survey has grown from 69 to 105. Over the years, the survey has also expanded to include new areas of data collection including von Willebrand disease, rare factor deficiencies, and inherited platelet function disorders.

Greater demand for products

Another measurement of the continued improvement in care is the steady, significant increase in the availability of clotting factor concentrates. Globally, the use of clotting factor concentrates has increased considerably in the last decade. One way to evaluate factor usage is by dividing the total number of international units of clotting factor concentrates consumed in a country by the number of its total population (IUs per capita). Although this does not tell us the health outcomes for individual patients, it is a useful way to compare how much a country invests in its treatment and care system for people with bleeding disorders overall.

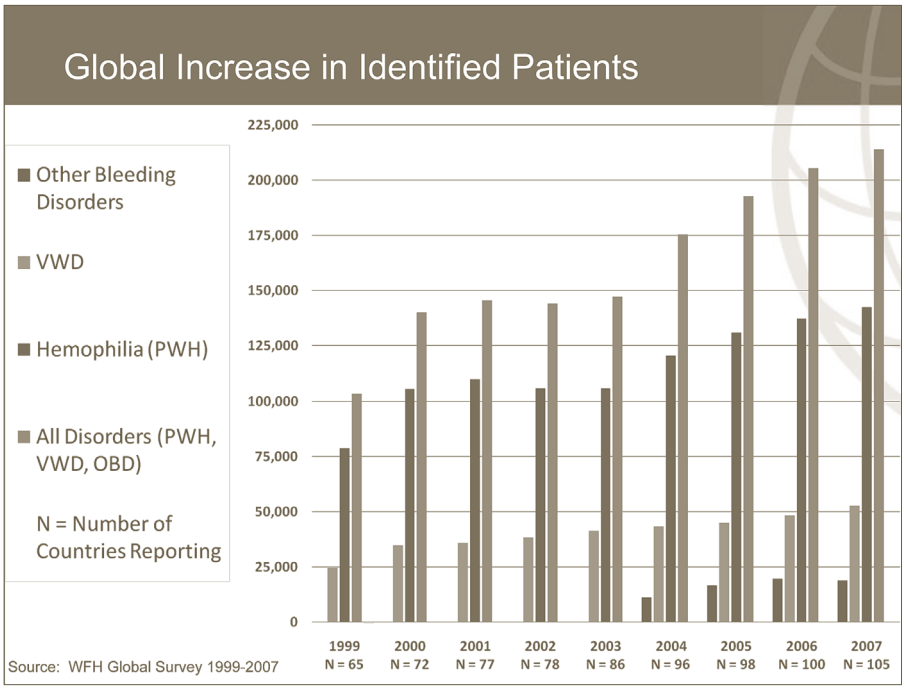
Russia is a noteworthy success story. In 2001, Russia was using 0.14 IUs per capita. In 2004, the country entered the WFH Global Alliance for Progress (GAP) project. By 2007, per capita usage had increased to 1.6 IUs and Russia is now impressively on track to use 3.3 IUs in 2008.

Growth in factor usage has been significant across the economic spectrum. Between 2001 and 2007, emerging economies with per capital gross domestic product (GDP) between US$2,000 and $10,000 increased factor VIII use by 62 per cent. Factor IX usage in those countries doubled in the same time period. In 2007, as another example, countries with per capital GDP over US$10,000 used an average of 4.8 IUs per capita.

However, increases in demand have put pressure on the global market and the availability of both plasma derived and recombinant clotting factors. The fact is that every IU that is produced today is quickly sold and consumed. The situation today suggests there is a growing need for more concentrates.

The steady increase in availability of recombinant products has helped to supply the world demand. Plasma derived clotting factor supplies have not grown as quickly, partly because the supply of quality plasma is a scarce resource and increasing the quantity is a slow and expensive process.

We can take great pride in knowing that the WFH global survey has become the leading source for comprehensive data on the care and treatment for people with bleeding disorders worldwide. The data trends also provide great reason for hope in what we will achieve together in the years ahead.



Our thanks to Annie Marment and Brendan Egan of Physiotherapy Department, Royal Children's Hospital, Victoria, for this article. Brendan is Co-Chair of Australian and New Zealand Physiotherapy Haemophilia Group.

PHYSIOTHERAPY UPDATE: DELAYED ONSET MUSCLE SORENESS

Annie Marment and Brendan Egan

Due to the availability of sufficient supplies of blood products and treatment prophylaxis in Australia people with haemophilia and other bleeding disorders are participating in more sports, and at an intensity not previously seen. Along with the possibility of experiencing a bleeding episode, participants may also experience sporting injuries and other sport and activity related ailments.

This update will talk about Delayed Onset Muscle Soreness (DOMS), a very regular occurrence for sports people. For those who have gone for their first run of the summer after a winter of TV-watching, or played a game of tennis for the first time in years, DOMS is the muscle soreness felt 1-3 days post the activity.

DOMS occurs after exercise and there are several different theories for the mechanism of DOMS which include lactic acid build-up, muscle spasm, connective tissue damage, and inflammation. Latest research concedes that an integration of two or more theories is more likely to explain muscle soreness.

There are many factors that can have an influence on DOMS, including the intensity, type and duration of exercise. Studies have shown that eccentric exercise is more likely to cause DOMS. Eccentric exercise (or eccentric muscle contraction) is where the muscle tension increases (contracts) whilst the muscle gets longer. This is what happens with quadriceps (thigh muscle) when lowered into a squatting position.

Running and the stop-starting of most sports are good examples of activities that will provide eccentric exercise for you.

Many research articles have been written looking into DOMS and types of recovery methods which include:

- Stretching
- Massage
- Hot/cold baths
- Active light exercise

There is a lack of good quality 'gold standard' research which provides limited evidence for the effectiveness of recovery methods in reducing DOMS. There is poor evidence to support passive types of recovery which is most often used by professional sports teams.

Some of the positive research looking into DOMS has shown that a 15 minute warm-up and cool-down reduced injury in dancers (Malliou et al, 2007).

And more promising is the recent research supporting the use of active light exercise in recovery from DOMS. A recent review of current literature shows that the most appropriate and effective recovery mode after dynamic muscle fatigue is light, active exercise (Mika et al, 2007).

What does this mean?

- A 15 minute warm-up and cool-down can help to reduce the risk of injury during exercise sessions.
- Light, active exercise with minimal resistance such as cycling with minimal resistance or light water-based exercise can help in the recovery from DOMS. (Think of football teams down the beach the next morning wading through the water or at the pool post-game cooling down.)

Some of you may also be interested in whether it is worth the $130+ for a pair of gradient compression garments like the "Skins" brand. The Australian Physiotherapy Association has endorsed the "Skins" product and the "Skins" website does attest to having benefits including reducing DOMS, increasing strength and improving endurance - http://www.skins.net/au/en/Research. A colleague of one of the authors who is an exercise physiologist is not as convinced. However, this same author will tell you anecdotally that the garments have been beneficial to him! Just remember that if you have not gone for a run or participated in a certain activity for some time it is far more beneficial to ease into the activity gradually and to always warm-up and cool-down. This will reduce the chance of bleed, injury and DOMS.

References:

Malliou P, Rokka S, Beneka A, Mavridis G and Godolias G (2007). "Reducing risk of injury due to warm up and cool down in dance aerobic instructors." Journal of Back and Musculoskeletal Rehabilitation 20(1): 29-35.

Mika A, Mika P, Fernhall B and Unnithan V B (2007). "Comparison of recovery strategies on muscle performance after fatiguing exercise." American Journal of Physical Medicine and Rehabilitation 86(6): 474-481.

Professor John Rasko is the Director, Cell & Molecular Therapies, Sydney Cancer Centre, Royal Prince Alfred Hospital, Head of the Gene & Stem Cell Therapy Program at the Centenary Institute and he holds a position at the Faculty of Medicine, University of Sydney in New South Wales.

Although the Haemophilia Foundation Research Fund is relatively small, the Haemophilia Foundation Research Fund Committee has maintained great interest in the benefits of gene therapy research and its promises for haemophilia. In 2003, a small grant of $10,000 was made for some of Prof Rasko's earlier work and in 2008 a further grant of $49,500 from the Research Fund was made as a small contribution to the current work of his group.

HFA invited Professor Rasko to describe some of his work for *National Haemophilia* readers.

DARE WE IMAGINE A CURE FOR HAEMOPHILIA?

Professor John E J Rasko

Well, if other previously 'impossible' ideas have become possible this century, then the answer to this question is: "Yes We Can!" Well …….. maybe.

The delays in delivering the promises of gene therapy for haemophilia have been considerable - but the enthusiasm for this idea has never waned despite widely-reported setbacks. Our bodies were designed to make clotting factor to protect us against bleeding and those living with haemophilia understand precisely the consequences of having to regularly infuse the missing clotting factor in their bodies. What is even worse is the fact that up to three-quarters of those born with haemophilia worldwide do not have regular access to clotting factor and suffer from chronic pain, joint injuries and threat of death.

The dreams, hopes and aims of gene therapy are to introduce the correct version of a missing or dysfunctional gene in order to produce its product forever in the body. The factor is produced in cells, but is secreted so that it circulates in the bloodstream and is available wherever bleeding occurs. Since most clotting factors are produced in the liver naturally, this is a logical (although not essential) location to deliver the gene into. There are two distinct experimental approaches designed to restore clotting factor production in the body: genetic modification of cells outside the body, or direct injection of the gene using molecular technologies based on viruses or DNA-based systems.

My personal optimism for gene therapy stems from the work in dogs performed over the last decade by colleagues in the USA. Beagles born with a naturally-occurring form of haemophilia have essentially been cured after receiving a single injection of virus-based gene therapy into a vessel supplying the liver. The follow-up now extends for many years and the dogs suffer from only mild haemophilia, having been born with clotting factor levels less than one percent of normal.

It seems hard to believe, but the first human clinical trial of gene therapy began over 15 years ago with twins in a province in China. Since then, there have been five distinct clinical trials sponsored by four different companies: Transkaryotic Therapies, Chiron, Avigen and Genstar. The fact that none of these companies continue to work in the area of haemophilia gene therapy reflects the harsh reality of the biotechnology industry. Nonetheless, the most successful clinical gene therapy trial to date was originally sponsored by Avigen for haemophilia B and commenced in 2001 using a virus-based vector called AAV2. With colleagues in the USA, it took about six years to complete the trial and two of the seven individuals treated were Australians! One of these Australians received the highest dose of gene therapy and achieved a plasma factor IX level as high as 12% for many weeks, which eventually waned due to a form of 'rejection' by his body's immune system. Other ongoing studies in the USA and the UK are pursuing a variation on this approach using a virus-based vector with a different coat protein, called AAV8.

Here in Australia we are continuing to pursue the use of gene therapy to treat haemophilia B using a modification of the approach championed by our long-standing colleagues at The Children's Hospital of Philadelphia in the USA. In order to circumvent the immune rejection described above, the same AAV2 system will be used to deliver the haemophilia B gene into the liver – but this time, several months of oral immune suppression will be administered. Of course there are risks, but the hope is that a short course of immune suppression will lead to the long-term persistence of factor IX production. Some of these complex issues are addressed in detail in an upcoming edition of the medical journal *Seminars in Thrombosis and Hemostasis* in a paper entitled "Gene Therapy for Hemophilia: Clinical Trials and Technical Tribulations". No-one doubts the challenges that lie ahead and the likely disappointments or setbacks along the way, but we continue to dare to imagine. Haemophilia Foundation Australia has generously supported this work with some funding and we hope to commence this next clinical trial for eligible individuals with haemophilia B later this year.

People with severe haemophilia B from around Australia who want more information about participating in this clinical trial may contact the Haemophilia Treatment Centre at Royal Prince Alfred Hospital (02) 9515 7013.

Suzanne O'Callaghan is the Policy Officer at Haemophilia Foundation Australia

NEW HFA WEB SITE

Suzanne O'Callaghan

During March 2009 HFA will launch its new web site. There has been a lot of work to redevelop the site and we're very pleased with the results.

What does it look like?

The new design brings a more contemporary look and feel to the web site. For a design motif, we have used the dot from the HFA logo, which represents the missing factor causing bleeding disorders. There are seven buttons on the menu which link to a whole range of information about bleeding disorders and HFA and its activities. To make sure you are kept up to date with what's new, news items are on the home page.

How will it be different?

These days people expect to be able to find the information they want from the home page. The new web site menu will drop down so that you can just run your mouse over it until you find the specific information heading you are looking for. News items will have a little introductory blurb so that you know what they are about and can click on them for more. For those who like to see things visually as well as read about them, there will be a lot more images and photos from events included.

If you are registering to participate in an HFA event, like the Red Run Classic or the Haemophilia Conference, or you want to pay or donate online, you want the whole system to be easy and secure. The new web site design updates the online event registration system so that HFA staff can continue to manage events like Red Run Classic and the Haemophilia Conference in-house, using all of the benefits of current web site technology and world's best practice security systems.

And for young people, there is a whole new Kids and Youth section which will have input from the Youth Committee. The design and layout has been developed specially for young people, using comments and feedback from the Youth Committee.

What about the E-news?

The E-News has also gone through a redesign. The new version will be in a magazine style format, so that you can scan all the news at a glance. It will be more colourful, with photos from HFA events and activities. The banner design will be similar to the web site design.

If you don't already receive the HFA E-News through your email, take this opportunity to sign up through the HFA web site. It's easy – just click on the **SIGN UP FOR NEWSLETTER** link and fill in your name and email address.

How did HFA decide the design?

The web site design has been through several revisions with the help of the HFA Web Site Review Panel – thanks to Ann Roberts HFA Executive Board, Dave Bell HFWA, Robert Lamberth HFQ, Pamela Punch HFV and Leonie Mudge, RPAH for their involvement in the Panel. As you would expect when you ask a group of people for their opinions, feedback was fairly diverse. HFA worked with the designer to bring the design closer to something that we believe will have broad appeal, has a good balance of colour and accessibility and aligns with HFA's corporate identity.

Take a look and see what you think! – www.haemophilia.org.au

This article was published on the HFA website on 17 February 2009

VARIANT CREUTZFELDT-JAKOB DISEASE

Health authorities in the United Kingdom recently announced that a man with haemophilia A who died from unrelated causes was found to have evidence of infection with the agent which causes variant Creutzfeldt-Jakob disease (vCJD), the human form of "mad cow disease".

Abnormal prion proteins (the infectious agent causing vCJD) were detected in the spleen during a post mortem, which had been undertaken as part of a UK surveillance study. This is the first time that a person with haemophilia has been found to have any evidence of vCJD infection, although there has been concern that this may occur.

The patient concerned had been treated with UK-produced clotting factor concentrate, which was later identified as having been made from plasma from a donor who developed vCJD after making the donation. Health authorities in the UK have identified this exposure to clotting factor as the most likely source of prion transmission to this patient.

It is important to note this is not the only possible source and the man had other potential risk factors. Whilst there was evidence of abnormal prion proteins, the man did not have vCJD and his death occurred due to unrelated causes. The follow-up investigations are not yet complete.

Although it can never be stated that there is a zero risk of transmission of infectious diseases by clotting factor concentrates, amongst people with haemophilia, it is those who were exposed to concentrates manufactured with UK-sourced plasma between 1980 - 2001 who are thought to be at increased risk of vCJD. Although this risk was considered theoretical and likely to be small, a number of precautions to reduce the risk were put in place and continue to apply.

Firstly from 1998, no UK-sourced plasma has been used in the manufacture of plasma products worldwide. Secondly, blood donors in Australia cannot donate blood to the Australian Red Cross Blood Service if they have resided in the UK between 1980 - 1996 for a total (cumulative) time of six months or more, or have received blood transfusions in the UK since 1 January 1980.

In Australia, recombinant treatment products which are manufactured with little or no human or animal material are used widely by people with haemophilia for their treatment in preference to plasma derived clotting factors. Nevertheless, some people with bleeding disorders still need to use plasma derivatives or choose to do so. Regulators require a number of steps to be taken in plasma derived products registered for use in Australia which result in these products being considered to be of minimal risk of vCJD. This includes donor deferral policies to exclude potentially at risk plasma, and processes and methods to reduce the risk of prions.

HFA is working with Australian health authorities, Australian Haemophilia Centre Directors' Organisation and other organisations to keep aware of the UK situation and will provide further ongoing information to the bleeding disorders community.

People who are concerned about the implications of this information for their own health are encouraged to speak with their haemophilia doctor.

Further information about the UK situation is available from the following web sites:

World Federation of Hemophilia
http://www.wfh.org/index.asp?lang=EN

UK Health Protection Agency News 17 February 2009
http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1234859690542?p=1231252394302

UK Haemophilia Centre Doctors' Organisation
http://www.ukhcdo.org/patientspage.htm

UK Haemophilia Society
http://www.haemophilia.org.uk/index.php?content_id=540

UK Health Protection Agency
http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1195733818681?p=1225960597236

HFA does not give medical advice. This material is provided for general information only. Patients should refer to their treating doctor or haemophilia treatment centre for medical advice and/or advice about the treatment products they use. For details of haemophilia treatment centres contact HFA or visit WFH web site – www.wfh.org.

Professor Albert Farrugia is Senior Director, Global Access, for the Plasma Protein Therapeutics Association (PPTA). The membership of PPTA includes companies which collect plasma and/or manufacture plasma-derived and recombinant therapies around the world. Prof Farrugia has been formerly employed at Therapeutic Goods Administration in Australia, and in a voluntary capacity has served as a Blood Safety Advisor to World Federation of Hemophilia. He has a long working experience across the blood sector. He has been an invited speaker at many HFA national conferences. HFA invited this article for publication in this edition of *National Haemophilia* following inquiries from members about the current thinking of experts in the field.

VARIANT CREUTZFELDT-JAKOB PRODUCTS – WHAT IS THE AUST

Professor Albert Farrugia[1]

On Friday 13 February 2009, an English newspaper announced that a person with haemophilia had been found to have contracted variant Creutzfeldt-Jakob disease (vCJD) when his tissues were examined after autopsy, following death from causes unrelated to vCJD. On Wednesday 18 February the British Health Protection Agency (HPA) confirmed that a patient who had been exposed to a Factor VIII concentrate which had been recalled following the development of vCJD in a contributing donor had been autopsied. The patient died from non vCJD related causes, but autopsy is standard practice on patients who have been exposed to blood products potentially contaminated with vCJD. The autopsy included examination of the patient's spleen for the presence of vCJD prion[2], another standard examination. One specimen out of 24 spleen samples was found to contain the vCJD prion. (The HPA's statement may be accessed at http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1234859690542?p=1231252394302.)

The patient had consumed beef and had also been transfused with blood, two risk factors for developing vCJD. However, the blood transfusions were from donors who had not developed vCJD. The patient was 74 years old when he died, and people who have died from vCJD from dietary exposure have been much younger. This has led the HPA to conclude that the likely source of the vCJD prion in the patient's spleen was the recalled FVIII concentrate. Other investigations are under way.

In many ways, this news, although disturbing and an undoubted source of anxiety for people with haemophilia does not come as a great surprise. It is timely to summarise what we knew about vCJD risk and blood products before this announcement:

1. TSE infectivity exists in blood, and up to 90% of the infectivity resides in the plasma. This is derived from experiments with animals.
2. Similar animal experiments show that plasma products derived from TSE infected plasma can transmit disease when given to other animals. This infectivity can be decreased greatly by the manufacturing process; however, the extent to which this happens varies between products.
3. Transfusion of blood from animals with TSE's – rodents and sheep – transmits the disease to animals given the blood.
4. Transfusions of red cells from donors who subsequently developed vCJD transmitted the disease to patients given the red cells. So far this has happened in four individuals. Three have died from vCJD. The other person died from unrelated causes and the vCJD prion was found in the patient's tissues. This is similar to the case of the person with haemophilia.

The relevant factors in regard to this patient are:

1. He did NOT develop vCJD. The vCJD prion was found in the spleen, and its presence was not extensive. This indicates that this person had a sub-clinical infection. Other studies indicate that up to 1 in 4000 individuals in the UK may have similar infections.
2. He was administered a FVIII concentrate derived from plasma collected from donors in the UK. Included in this plasma was a donation from an individual who subsequently developed vCJD, upon which the concentrate was recalled by the UK authorities.

This is a sad episode in the saga of this strange illness, but not a very surprising one. vCJD prions are infective agents and safety measures are needed to counter them.

DISEASE AND HAEMOPHILIA RALIAN DIMENSION?

Safety measures in Australia

vCJD is a disease which has affected less than 200 people worldwide and the vast majority of them were from the UK. This infection is present, if such is the case, in individuals who reside in the UK. A small proportion of vCJD cases are in non-UK residents who have resided in the UK or visited temporarily.

In 2000, the Therapeutic Goods Administration (TGA) directed the blood provider in Australia to defer blood donors who resided or visited the UK in the period of risk from donating blood. This lost a large number of precious blood donors in Australia. Most were unlikely to pose a risk but this precautionary step removed most of the potential risk from the Australian blood supply.

Irrespective of its involvement in the current case, the concentrate given to the UK patient is known to have negligible clearance capacity. Over the period 2000-2005, the TGA oversaw a program of extensive investigation by companies supplying concentrates in Australia. As a result, concentrates for haemophilia had to undertake one of two precautionary measures:

1. They had to demonstrate considerable potential prion clearance over their manufacture so as to ensure minimal risk to patients; or
2. If such clearance was not demonstrable, the manufacturer was informed that concentrates for the Australian market could only be made from the plasma of donors who had never been exposed to BSE/vCJD through travel outside Australia and New Zealand, two countries which have never experienced BSE.

In addition, the TGA continued to oversee the enhancement of manufacturing processes to remove prions, and in 2007 approved changes in the manufacture of a product subject to the more extensive donor restrictions specified above. These changes resulted in a highly optimised process for the removal of prions, and allowed the travel restrictions to be relaxed to the same level applicable for all other blood products, ie residence in the UK. It must be pointed out that clearance through manufacture is a much more effective way of enhancing concentrate safety than is donor deferral.

As a result of the vCJD epidemic and other non-Australian infectious agent manifestations, the TGA decided in 2002 to take measures to protect the safety of the Australian plasma product supply by requiring the domestic manufacturer to dedicate the fractionation equipment, used to process Australian products, for plasma solely sourced from Australia. Plasma from other countries had to be processed with different equipment. This was considered important in order to counter unknown and possibly robust overseas pathogens.

In 2004, the Australian government agreed to treatment of choice to Australian haemophilia treaters and their patients. Today, most Australians with haemophilia are treated with recombinant products. The patients who still depend on plasma concentrates may be assured about the strong regulatory measures taken over the past decade to minimise the risk of pathogen transmission, including vCJD.

What of the past concentrates? As noted above, vCJD has been primarily localised to the UK donor population so far, and we have only observed one possible sub-clinical infection for a product sourced solely from that population. The situation for Australians is thus not comparable and the risks are commensurately lower. Constant monitoring and vigilance from the regulator and the patient community is essential. In the meantime, Australians with haemophilia should heed the advice of the World Federation of Hemophilia to maintain their clotting factor treatment - http://www.wfh.org/index.asp?lang=EN

References:

1. Albert Farrugia headed the TGA's Blood and Tissues Unit over the period of the implementation of the vCJD measures. None of the opinions or version of events cited in this article is owned by other than the author.

2. Prions are believed to be the infective entities in the diseases called Transmissible Spongiform Encephalopathies, which include bovine spongiform encephalopathy (BSE) which affects cattle and vCJD, which is believed to be the human form of BSE.

TREATAWARE UPDATE

Treataware is the National Association of People Living with HIV/AIDS (NAPWA) campaign to provide the latest HIV treatment information for the community.

The *Treataware* 1800 phone line has been discontinued. However, the other services – the website www.treataware.info, which includes the HIV clinical trials database, and the free booklet G*etting the Best HIV Care* – will continue to be available.

If you would like more information or a copy of the free booklet, contact your Haemophilia Social Worker/Counsellor or your local AIDS Council.

Suzanne O'Callaghan is the Policy Officer at Haemophilia Foundation Australia

HEPATITIS AWARENESS WEEK, 18-24 MAY 2009

Suzanne O'Callaghan

World Hepatitis Day will occur on May 19 2009. Once again the global theme is *Am I number 12*? (ie 1 in 12 people in the world have hepatitis B or hepatitis C).

HFA is represented on the World Hepatitis Day National Implementation Committee convened by Hepatitis Australia. We have been working with the Committee to make sure we can translate the global theme into a national theme that can include and recognise people with bleeding disorders – the international focus is on awareness and testing. The Committee agreed that a variation of the theme could be *"I am number 12: this is my story"* to acknowledge the special and different story of people with bleeding disorders.

How is this meaningful to people with bleeding disorders?

HFA's Hepatitis Awareness Week Working Group (Dave Bell - HFWA, Robert Lamberth - HFQ, Pamela Punch – HFV, Erin James - HFA Youth Committee) has developed a national theme that focuses on hepatitis C issues from the point of view of the bleeding disorders community - but with a world perspective.

The HFA national theme is: *I am number 12 – I am part of a world community with hepatitis C but this is my story.* The aim is to

- tell the particular story of having a bleeding disorder and hepatitis C
- look at issues in telling someone else you have hepatitis C
- supporting someone with a bleeding disorder who tells you they have hepatitis C.

AM I NUMBER 12?.ORG

Why tell the bleeding disorders story?

One result of the HFA hepatitis C needs assessment was to realise how few people in the general community in Australia know about or understand what the hepatitis C experience has been like for the bleeding disorders community.

It is a difficult story to tell in some ways. People with bleeding disorders are often very private and saw enough discrimination in the HIV epidemic to be cautious about hepatitis C. Understandably, few will discuss their hepatitis C openly if they are affected by it. We were very fortunate that some people came forward to tell their story for the *Double Whammy* Report and the Evaluation. The *Double Whammy* Report has been circulated widely in the bleeding disorders community, to hepatitis and HIV agencies, health professionals and government. The Report was also taken up by some Hepatitis Councils – the Hepatitis C Council of SA did a very powerful 8-page spread in their magazine featuring Paul Bonner, the President of Haemophilia Foundation South Australia, and his story of growing up with haemophilia and hepatitis C.

It's a story that needs to be told sensitively and carefully – but in a way that gets the point across. Hepatitis C impacted on the whole bleeding disorders community whether people acquired it or not. If not you, perhaps it was your brother, father, uncle, mother, mate who acquired hepatitis C – and perhaps HIV as well – from treatment products they had been using to improve their health. It's hard for your average person in the street to understand what that experience has been like without hearing it from the people who have lived through it – what it was like to find out, trying to manage your life and stay positive while dealing with the gradually increasing load of health problems and the financial difficulties that result, keeping it to yourself, perhaps being lucky enough not to have symptoms, or even to clear it - or perhaps not.

HFA Hepatitis Awareness Week Resources

This year for Hepatitis Awareness Week HFA will produce a set of stories on hepatitis C – some will be quotes taken from *Double Whammy*, others will be the entire personal story of an individual. These will go on the HFA web site and some will be published in *National Haemophilia* and shared with state/territory Foundations to publish if they wish.

HFA will also produce some fact sheets on telling other people you have hepatitis C and supporting someone who tells you they have hepatitis C.

Hepatitis Council Resources

Hepatitis Australia will release some national resources such as stickers, posters and bookmarks closer to the date. Local Hepatitis Councils will also be running activities such as picnics, lunches, street stalls and concerts – contact them for more information.

If you would like more information about Hepatitis Awareness Week or the HFA stories and fact sheets, please contact Suzanne O'Callaghan on 03 9885 7800 or s.ocallaghan@haemophilia.org.au.

World Hepatitis Day web site – www.worldhepatitisday.org

This article on recovering from treatment was published in *Good Liver*, Spring 2008, the newsletter of Hepatitis C Victoria.

Many people with bleeding disorders and hepatitis C find that the time after their hepatitis C treatment finishes can have its own challenges. During the consultation for the HFA hepatitis C needs assessment (*Double Whammy* Report) many people discussed the need for continuing support and advice after treatment. Garry Sattell, the Community Participation Coordinator at Hepatitis C Victoria, looks at some of the issues and strategies to deal with them.

HEALTH AND WELLBEING

Garry Sattell

The six months after treatment is for many people a time of recovery and recuperation and is often a period of mixed emotions and uncertainty.

When people contact us on the HepC Infoline during this time, it's not uncommon for them to be feeling anxious about their health because of the slowness of their recovery after treatment. They speak of hopefulness that the treatment will be successful but also of not wanting to get their hopes up in case they are disappointed. For others, it can be a challenging time and it often depends on whether they have been able to complete the treatment or have had to stop treatment because of adverse side effects.

Although the treatment itself is over, it will be another six months before it can be confirmed as successful. It is not uncommon to find that callers have some adjustment to make about how they're feeling now and how they thought they would be feeling after treatment. Some people call us to ask if it's normal to be feeling the way they are and they often present with a wide range of symptoms and lingering side effects. Like the treatment itself, recovery from treatment is often a very individual experience with a wide range of experiences from person to person. However, for most the return to ordinary life and wellness without the side effects of treatment is a slower process than they expected.

During and after treatment it may be difficult to distinguish between the symptoms of illness and the treatment side effects. On completion of treatment, this can still be a challenge. It's important to advise your doctor or nurse about any lingering symptoms of ill health as you may have other conditions or illness that have been overlooked. Not all of your symptoms may be related to hepatitis C or your treatment.

For those people who stop treatment because of adverse physical or emotional side effects, or if their treatment is discontinued because of non-response it can be a time of disappointment and of coming to terms with their feelings about failed or unsuccessful treatment. Most people don't make the decision to undertake treatment lightly and they often have a range of important reasons why they decided to do it. Coming to terms with the 'failure' of treatment and its ramifications can be daunting and we often encourage people to speak with a counselor to help them move on.

Believe it or not, some people have challenges dealing with successful treatment. Having hepatitis C is often a large part of people's lives and can become part of their identity; for some of these people not having hepatitis C can take time for them to get used to the idea that they no longer have it.

During and after treatment it may be difficult to distinguish between the symptoms of illness and the treatment side effects.

Some people are so over the moon that their treatment is over they start tackling aspects of their lives that they may not be entirely happy with, making wholesale changes. For some of these people the euphoria is sometimes short lived as they attempt too much too quickly, and find themselves overstretched, fatigued and unsure about how to move forward.

Sometimes it's important to talk to people about taking things slowly. It can be important to take the time to recover from treatment, regain strength and come to terms with the outcome of treatment before taking on the rest of their lives.

Whatever your experience of moving on after treatment is, it's important for you to know that help is available.

Sometimes we may recommend you speak with a counselor. For some people the transition from being on treatment to post-treatment can be a challenging time emotionally. Many people experience emotional or psychological side effects during treatment and your emotions may continue to fluctuate for some time after treatment finishes.

If you're concerned about your recovery from treatment you can call us on the HepC Infoline. We can talk about what other people have experienced and advise you on looking after yourself, eating well and getting enough rest and exercise as you recover your strength and return to health. You are welcome to come along to our support group; our members are only too happy to share their experiences and to help you to make decisions about what is best for you. Sometimes talking with people who have had a similar experience can help a great deal.

Moving on after treatment?
Happy recovery!

All state and territory Hepatitis Councils provide an information and support telephone service on hepatitis C. For contact details of your local Hepatitis Council, go to http://www.hepatitisaustralia.com/contacts/ or phone the national HepC Infoline on 1300 437 222.

For other information about services and support for people with bleeding disorders and hepatitis C near you, talk to your Haemophilia Social Worker/Counsellor, your Haemophilia Centre, your state/territory Haemophilia Foundation or HFA.

It's important to talk to people about taking things slowly.

An increasing number of families are caring for their elderly relatives at home. Nutrition is of particular importance to the two million (approx) Australians aged 70 and over. This article is reprinted from *Super Food Ideas*, December 2008/January 2009, Issue 99, published by News Magazines. The author, Nicole Senior, is nutrition editor.

AGED CARING

Nicole Senior

Build 'em up

In this day and age of weight gain and obsession with dieting, it's easy to forget that for the frail elderly, 'eating light' can be a recipe for disaster. The challenge for many aged people is eating more kilojoules, not less, and avoiding malnutrition and unwanted weight loss.

Malnutrition – the causes

Ill health can dramatically affect appetite, and food and nutrients may not be as well absorbed. Ageing itself can also affect taste, chewing and digestion. Medical treatments and medications can cause nausea, heartburn and constipation, and having physical limitations can mean preparing a meal becomes a chore. Poor mental health can also affect nutritional status. The loss of a partner or chronic illness can lead to depression and a lack of interest in food. In turn, malnutrition itself can cause mood swings, apathy and a loss of physical strength, thus creating a vicious cycle.

Malnutrition – what to look for

- Loss of appetite
- Weight loss
- Loss of physical strength
- Apathy/loss of interest in usual activities
- Confusion and poor memory
- Slow wound healing
- Frequent infections (low immunity)

What about cholesterol and diabetes?

Many family members worry about giving their frail elderly relatives high-fat, high-sugar foods in case it exacerbates existing health conditions. Don't worry. In general, fat and sugar content is not relevant when you are trying to stop unwanted weight loss and malnutrition.

Vitamin D

A 70-year old needs three times more vitamin D than a person of 40. Ensure the elderly get some safe sunshine each day (not between 10am and 2pm) to make vitamin D in the skin, as well as plenty of vitamin D-containing foods such as oily fish, fortified dairy foods and margarine.

Consult a dietitian

Nutritional therapy is effective in improving the health and well-being of the elderly. Whether your loved one is in care or at home, referral to a dietitian can help. Dietitians can assess health status and food environment, and provide a tailored nutritional care plan.

More information

Australian Department of Health and Ageing – www.health.gov.au

Meals on Wheels – www.mealsonwheels.org.au

Tips for keeping the elderly well-fed and healthy

- Consider accessing a meals on wheels service
- Offer frequent, smaller meals – large meals can be off-putting
- Provide nutrient-dense foods and drinks – meat, fish, eggs, milk, cheese, grain foods, vegetables, fruit and fats
- Make foods soft for easy chewing and swallowing – ie, casseroles rather than steak, stewed/ chopped fruit rather than whole
- Give nutritious fluids – milk drinks rather than tea, creamy or blended soup instead of clear broth
- Add extra energy to foods and drinks – extra oil to vegetables, grated cheese on potato, cream in cereal and desserts, sour cream in stews and soup
- Skip low-fat and sugar-free foods – the frail need all the kilojoules they can get
- Consider the use of supplementary foods and drinks such as Sustagen or Ensure – these pack a lot of nutrition into a small and palatable form.

Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group has provided the following comments which might assist people who are caring for older relatives.

OTHER THINGS TO CONSIDER

Many people have had dietary supplements recommended to ensure they are receiving all essential nutrients, eg calcium, vitamin B, vitamin D. These may be in addition to medications prescribed by their doctors. It is important for individuals and carers to be aware of all medications and supplements, and the ways they may interact. I would suggest that if people are taking a range of medications and/or supplements they ask their GP to organise a Home Medicine Review, together with a dietician review. Also as frail people often cannot manage their own footcare, ask the GP about local podiatry services. These may be available through community health centres.

Other resources

For information about local services, including for example:

- a range of allied health care (eg podiatry, dietician)
- household help, home maintenance and modification
- transport and meal services
- special services for dementia
- continence assistance

contact Commonwealth Carelink Centres on freecall 1800 052 222. You will then be connected to your nearest Centre. There are 60 shopfronts nationally, or visit ww.commcarelink.health.gov.au.

Services provided by Commonwealth Carer Respite Centres, freecall 1800 059 059, include:

- information and advice on different support options
- help with organising emergency, short-term or planned breaks
- programs to link carers with other carers
- 24 hour service in times of crises or emergency

Commonwealth Carer Resource Centre: freecall 1800 242 636 for an emergency care kit

National and State Carers Associations: www.carersaustralia.com.au

News for Seniors, a publication of Centrelink, has great information about resources and is published quarterly. To receive a copy call the Retirement Line on 13 23 00 or visit www.centrelink.gov.au and search under 'publication'.

Together, we care

Involving a specialized team in hemophilia care ensures:

- Accurate diagnosis
- Prompt and effective treatment
- Fewer hospitalizations
- Healthy joints and muscles
- Support for families

WORLD HEMOPHILIA DAY

Celebrating 20 years, April 17, 2009

Contact the WFH for further information
Tel: +1 514 875 7944 – Fax : +1 514 875 8916
wfh@wfh.org – www.wfh.org

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FEDERACIÓN MUNDIAL DE HEMOFILIA
Treatment for All

WORLD HAEMOPHILIA DAY 2009

World Haemophilia Day is celebrated on 17 April, the birthday of World Federation of Hemophilia (WFH) founder, Frank Schnabel, who died of AIDS in 1987 as a result of contaminated blood products.

This year marks the 20th anniversary of the celebration of World Haemophilia Day. Haemophilia organisations around the world will come together with their partners in their own countries to raise awareness of bleeding disorders.

The 2009 theme is *Together, we care*, which aims to emphasise the importance of comprehensive care in haemophilia health care delivery. In Australia we have a network of haemophilia treatment centres around the country which provide access to the services of haematologists, nurses, physiotherapists, social workers, orthopaedic surgeons and dentists who work together to provide their care.

For more information about Haemophilia Foundation Australia activities to celebrate World Haemophilia Day go to the HFA website or visit the WFH website, www.wfh.org for further information about resources and materials available for World Haemophilia Day or the work of the World Federation of Hemophilia.

DAMON COURTENAY MEMORIAL ENDOWMENT FUND

Grant Applications 2009

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established as a perpetual Trust to be administered by Haemophilia Foundation Australia in November 1993 by Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

The fund provides funds which can be used for the care, treatment, education and welfare for people with bleeding disorders and/or their families.

Distributions are generally made every 1-2 years. In the past people with bleeding disorders have received support from the fund for training and education, career development, personal development courses, conferences, medical appliances and equipment to help them live more independently.

A distribution of approximately $20,000 will be made in 2009. Applications are invited from people with bleeding disorders, or their family members or the representatives of recognised haemophilia organisations who may make applications on their behalf.

The eligibility guidelines and application form can be downloaded from the HFA website or requested from HFA by telephone 1800 807 173, or by email on hfaust@haemophilia.org.au.

Closing date for applications is 8 May 2009.

THE VISION AND LEADERSHIP AWARDS

The Haemophilia Foundation Australia *Vision and Leadership Awards* were established to enable men and women affected by haemophilia and related bleeding disorders to achieve new goals.

The Awards have been generously sponsored by Wyeth since the awards were first offered in 2007. The awards are managed and administered by HFA and were set up with clear guidelines and an Assessment Panel of experts to consider applications.

Successful applicants have the opportunity to undertake an education activity or project to enhance their personal development or career, or attend a conference or program to develop skills for leadership and participation in the bleeding disorders community.

Applicants can propose an activity or project that will make a difference to their life and use this award opportunity to achieve success or reach a new personal goal or objective.

It is expected that five (5) awards of $2,000 each will be made to people in either of the following categories:

- Young men and women aged 15-25 who have a bleeding disorder or who are affected by bleeding disorders
- Adults aged 26 yrs and over (men or women) with a bleeding disorder or who are affected by a bleeding disorder

The current funding round closes on 31 March, and successful applications will be announced in the next edition of *National Haemophilia*.

Leonie Mudge is Haemophilia Social Worker at the Royal Prince Alfred Hospital, NSW, and is Co-Chair of Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group.

HFNSW VISITS *WAGGA*

Leonie Mudge

Peter Mathews, Executive Officer, Haemophilia Foundation New South Wales, and I made the first of several outreach visits planned for 2009, on 19 February. The trip to Wagga coincided with a clinic visit to the area from Dr Sue Russell, Haematologist from Sydney Children's Hospital, who regularly visits families with bleeding disorders in the Riverina district.

Peter and I met with Michael Bolton, NSW Health, to discuss local plans for hepatitis C treatment. We then caught up with members of HFNSW who live locally, Geoff and Pam Frost and Darlene Cave. In the afternoon we were kindly hosted by staff at the Riverina Medical & Dental Aboriginal Corporation, organised by Mandy Atkinson from RivMed. HFNSW is working closely with RivMed staff to encourage all their patients with bleeding disorders to wear a MedicAlert.

Top
L-R Leonie Mudge, Pam and Geoff Frost, Darlene Cave

Above
L-R Mandy Atkinson and Leonie Mudge

Red Run Classic

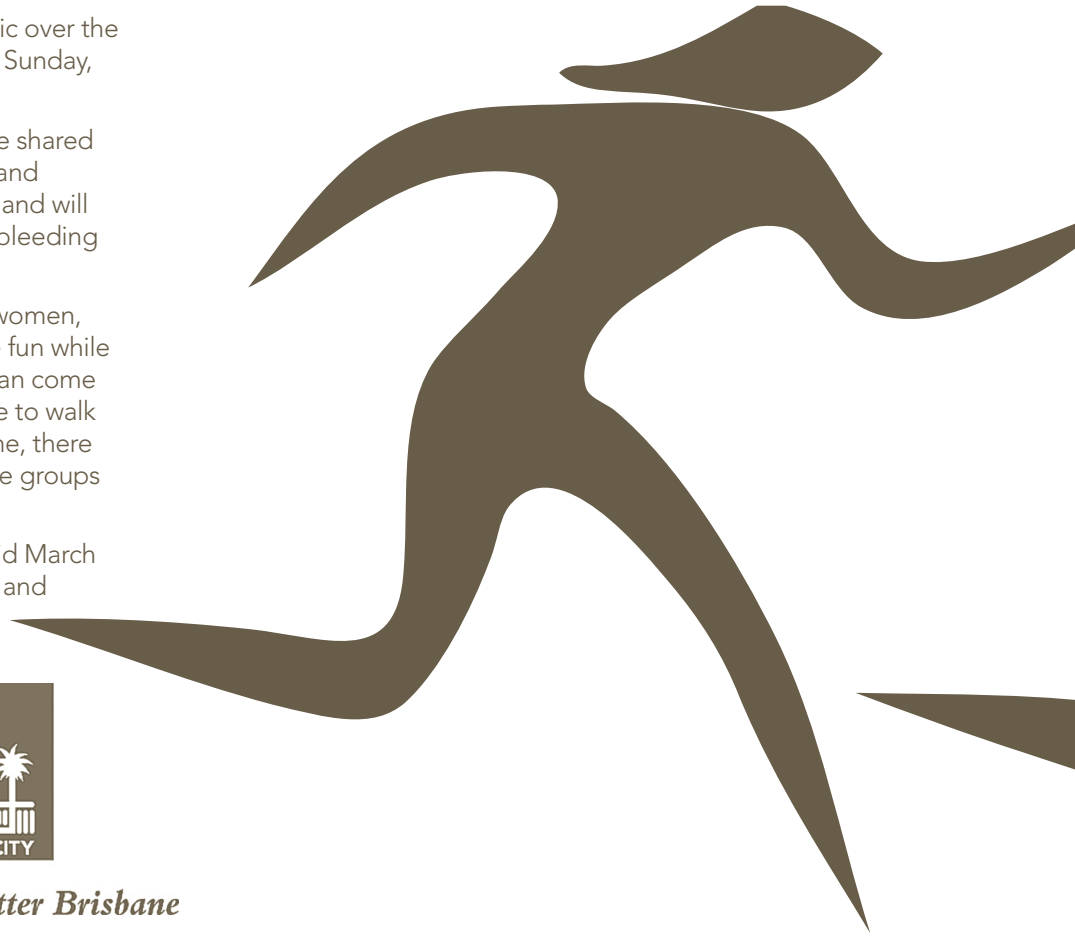
Sunday 31 May 2009, New Farm Park, Brisbane

After the success of the Red Run Classic over the past two years, it will be held again on Sunday, 31 May 2009.

All money raised from this event will be shared by Haemophilia Foundation Australia and Haemophilia Foundation Queensland and will be used services and activities for the bleeding disorders community.

Join hundreds of other participants – women, men, teenagers and children – to have fun while raising money for a good cause. You can come as a serious competitor or just be there to walk with family and friends. For the first time, there will be two distances to cater for all age groups and interests - 5km and 10km.

Online registration is available from mid March or call 1800 807 173 for an information and registration brochure to be sent.



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CALENDAR

15TH Australian & New Zealand HAEMOPHILIA CONFERENCE Life Challenges
Brisbane, 8-10 October 2009 www.haemophilia.org.au

15TH Australian & New Zealand Haemophilia Conference

Brisbane 8-11 October 2009
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au
www.haemophilia.org.au

WFH 11th International Musculoskeletal Congress

Cartagena, Colombia 26-29 April 2009
ph +1 514 394 2837
fax +1 514 875 8916
email msalas@wfh.org
www.wfh.org

Haemophilia Awareness Week

11-17 October 2009
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au
www.haemophilia.org.au

Hemophilia 2010 World Congress

Buenos Aires, Argentina 10-14 July 2010
ph +1 514 394 2834
fax +1 514 875 8916
email hemophilia2010@wfh.org

National Haemophilia - Electronic Version

Would you prefer to receive *National Haemophilia* electronically? You would be helping Haemophilia Foundation Australia save on production and postage costs - not to mention the environment. All you need to do is email your details to HFA at hfaust@haemophilia.org.au and we will set it up.

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WFH MUSCULOSKELETAL CONGRESS

Haemophilia Foundation Australia is pleased to have made part funding available to an Australian member of the Australian and New Zealand Physiotherapy Haemophilia Group to attend the upcoming 11th International Musculoskeletal Congress of the World Federation of Hemophilia, to be held in Cartagena, Colombia, 26-29 April 2009.

Matthew Stewart of the Royal Brisbane and Women's Hospital in Queensland has been selected by HFA to attend as a representative of his peers at this meeting. HFA looks forward to Matthew's reports and recommendations for the Australian community upon his return.

Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.