The Third Red Run Classic was held on Sunday 31 May at New Farm Park in Brisbane.

650 runners and walkers got together to raise money for people with haemophilia and inherited bleeding disorders. Our third Red Run Classic was a most successful event with many more participants than in previous years and promises of even more in 2010. HFA thanks all participants, volunteers and our sponsors.
CONGRATULATIONS TO THE FOLLOWING WINNERS:

Men – 5km
1st - Stuart Bowden (#50) 17:17
2nd - Oscar McPhee (#876) 17:56
3rd - Mark Tasney (#313) 18:22

Men – 10km
1st - Jackson Elliot (#495) 32:01
2nd - Geoff Heydon (#854) 33:20
3rd - Hayden Pickering (#902) 34:58

Women – 5km
1st - Michelle Woodhouse (289) 21:33
2nd - Tyra Evans (#62) 22:30
3rd - Allison Cresswell (#339)

Women – 10km
1st - Roxie Schmidt (#435) 35:56
2nd - Emily Donker (#929)
3rd - Annette O’Shea (493)

Children
1st Boy – Angus Douglas (#13)
1st Girl – Caitlin Large (#946)

SPONSORS
WFH MUSCULOSKELETAL
CONGRESS

Matthew Stewart

In April I had the privilege of travelling to Cartagena, Colombia, South America, for the 11th International Musculoskeletal Congress of the World Federation of Hemophilia, thanks to a generous grant from Haemophilia Foundation Australia and support from Queensland Health. After 36 hours of travelling, I arrived at Hilton Cartagena where the Congress was held.

This Congress had the largest number of attendees of any Musculoskeletal Congress ever held. Attendees numbered almost 300 health professionals representing every continent of the world and included orthopaedic surgeons, physiotherapists, haematologists, physiatrists, podiatrists, researchers and one physical education teacher from Brazil. As the only representative from Australia, I had plenty of opportunities to meet many leading clinicians and researchers from many countries, which afforded me the opportunity to develop relationships for professional support and potential involvement in international work in the future.

Approximately 100 presentations were made over the four days of the Congress by clinicians and researchers. Topics included the historical developments in musculoskeletal management of people with inherited bleeding disorders, current practices in musculoskeletal management of various body areas, current research initiatives and implications for clinical practice, case presentations on interesting and complex cases and provocative presentations on future formidable tasks and directions.

I only began working in the Queensland Haemophilia Centre at the beginning of 2008 and hearing these presentations and talking to overseas professionals was great in developing my understanding of historical developments and expanded my knowledge in day-to-day clinical care. I was also graphically exposed to some of the challenges in the developing world, which makes me grateful for the health infrastructure in Australia and helps me appreciate the responsibility we have to help where we can overseas. There is also much we can learn as physiotherapists from our colleagues overseas who deal with significant acute and chronic musculoskeletal problems.

Despite our ‘infrastructure,’ we have a way to go to improve the musculoskeletal care of people with inherited bleeding disorders in Australia. The Congress reinforced to me the importance of timely specialised physiotherapy assessment and intervention in the prevention and management of joint and muscle damage. It is challenging to see the number of physiotherapists with dedicated time to care for people with inherited bleeding disorders in other developed nations. In Australia, physiotherapy does not necessarily have such a significant profile and we might well improve the musculoskeletal outcomes of people with inherited bleeding disorders if they had access to more specialised musculoskeletal input.

A whole session of the Congress was dedicated to the psoas muscle which can be very painful and debilitating and may have significant long term consequences. The presentations covered the anatomy and function of the psoas, cause of bleeds and the subsequent diagnosis, management and rehabilitation. Sexual health was discussed in this context and we were challenged to view this important area of life as equal to other domains in the framework of comprehensive care.

“There is also much we can learn as physiotherapists from our colleagues overseas who deal with significant acute and chronic musculoskeletal problems.”
1960s: 
BEGINNINGS

The World Federation of Hemophilia (WFH) was established in 1963 by Frank Schnabel, a Montreal businessman born with severe haemophilia A. His vision was to improve treatment and care for “the hundreds of thousands of haemophiliacs” worldwide through a new international organisation. From a base of six national haemophilia societies, the Federation grew rapidly. It held world congresses every two years and created a global network of healthcare providers, national haemophilia associations, people with haemophilia and their families. At the 1964 WFH congress in Amsterdam, the structure of the new organisation was defined with a constitution and an executive board. The WFH reached a turning point in 1969 when the World Health Organization acknowledged the Federation’s growing international reputation and established official relations. The two bodies began working on joint projects.

1970s: 
THE WFH EXPANDS ITS ACTIVITIES

The WFH introduced the International Haemophilia Training Centre program in the 1970s, offering numerous fellowships and workshops to medical professionals from the developing world. Thailand was one target country; the WFH worked with Professor Partraporn Isarangkura to promote progress in national haemophilia care. Under her direction the Bangkok centre became a major venue for training on how to provide maximum treatment benefits with limited resources.

The 1970s were also the decade of new products and opportunities, enabling home treatment and the use of prophylaxis to prevent bleeding – for those who could afford it. Then tragedy struck.

1980s: 
AIDS HITS THE HAEMOPHILIA COMMUNITY

The AIDS crisis struck in 1982 and the following year. Dr Bruce Evatt presented data to the World Congress in Stockholm connecting HIV infection in haemophilia patients and plasma-derived treatment concentrates. The WFH set up the World Haemophilia AIDS Centre with the Los Angeles Orthopedic Hospital to provide rapid access to vital...
information about the disease. AIDS contracted from HIV-contaminated treatment products swept through the haemophilia community. Among the victims was Frank Schnabel, who died in 1987. Until the end, he reaffirmed his vision with the words: “We are going to emerge victorious.”

To prevent any recurrence of the AIDS tragedy, the WFH set up a system of international groups and activities to monitor the safety and supply of haemophilia treatment products.

1990S:

A DECADE OF CHANGE

Many changes followed the death of the WFH’s founder. Business professional Charles Carman was elected President in 1988 and introduced important management structures. A 10-year plan was launched in 1992 and the funding base was broadened with new sponsors.

Brian O’Mahony, an Irish medical laboratory scientist with severe haemophilia, took over in 1994. He brought together the WFH’s Executive Committee and Council as one body composed equally of doctors and people with haemophilia. A modified constitution was adopted in 1996.

Greater access to improved products, self-treatment, and prophylaxis showed up the stark differences between the developed and developing countries. Under O’Mahony, the WFH focused its efforts more on the developing world, with programs that would help countries to help themselves.

One major step was the introduction of twinning programs in 1994-95 to link haemophilia organisations and treatment centres in developed and developing countries. By 2003, the WFH was helping more than 40 twins arrange training, workshops and other skills transfer activities.

Also during the mid-1990s, healthcare development programs and publications were expanded to include public affairs, data and demographics, and humanitarian aid. Twinning, humanitarian aid, medical training, data collection and other programs continue to grow.

A project in Chile represented the WFH’s first major success in achieving rapid and significant improvement in haemophilia. The WFH brought together what came to be called the “winning coalition.” Industry donated products; the Ministry of Health established a national haemophilia program, a key treater co-ordinated the program’s implementation; others received specialised training; and the patient organisation carried out an educational and advocacy role. The WFH served as a catalyst and adviser.

The lives of Chilean haemophilia patients changed dramatically in five years and the “winning coalition” model has been adapted successfully to other countries.

2000S:

CLOSING THE GAP

On World Haemophilia Day, 17 April 2003, the WFH launched the Global Alliance for Progress (GAP) in haemophilia. The 10-year health development initiative aims to greatly increase the diagnosis and treatment of people with haemophilia in about 20 developing countries. GAP is building on existing WFH haemophilia care projects in 60 developing countries and initiating new programs in many more places.

Brian O’Mahony ended his term in 2004 and Washington attorney, Mark Skinner, was elected the new WFH President. Skinner has had extensive involvement with the bleeding disorders community, fundraising, and advocacy for improved safety and supply of blood products. “The WFH enjoyed tremendous growth under Brian O’Mahony’s leadership,” says Skinner. “The organisation is now at a new stage and I’m confident that my experience will complement his work.”

“A project in Chile represented the WFH’s first major success in achieving rapid and significant improvement in haemophilia. The WFH brought together what came to be called the ‘winning coalition.’”
AN HISTORICAL NOTE FROM THE PRESIDENT

Gavin Finkelstein

The need for patient support and advocacy has been a feature of the development of Haemophilia Foundation Australia. State/Territory based organisations were formed more than 50 years ago by parents of children with haemophilia to support each other. At that time, services were limited and there were few treatment options. In 1979 the Haemophilia Societies of Victoria, New South Wales and South Australia came together to form the Australian Federation of Haemophilia Societies (AFH).

When HIV was identified in USA in people with haemophilia in 1983, patient organisations around the world soon realised the impact this would have on their community. In Australia this led to government lobbying for financial support for people with medically acquired HIV and for improved haemophilia services and support in all States/ Territories. By 1985 the haemophilia community was keeping in touch with issues via a monthly newsletter and it was understood there was a clear need for solidarity and collaboration. In 1986 AFH became incorporated as HFA has operated for 30 years with a broad program of advocacy, education and research activities.....

Haemophilia Foundation of Australia and the organisation was joined by Haemophilia Society of Queensland, soon followed by societies in ACT, Western Australia and some time later by Tasmania and the Hunter Valley in NSW.

HFA has operated for 30 years with a broad program of advocacy, education and research activities to improve care and treatment for people with haemophilia, von Willebrand disorder and other related bleeding disorders and their families. This work involves collaboration with individuals affected by bleeding disorders and their families who are usually, but not always, members of State/Territory foundations and a network of volunteers. Our work with our members and specialist health professionals and our relationships with a range of service providers and funding bodies in the government and not for profit sector is critical to improving care and treatment for our community.

HFA needs to keep on top of the changing needs of our community, and be aware of the developments around the world to ensure our members have access to best practice care and treatment and the services to meet their needs. HFA will soon embark on a strategic planning process to map these needs and how we can best contribute to the community in Australia and overseas.
Protecting the security of individuals using the internet has become a significant issue as people in the community increasingly use the internet for socialising, paying for products and services and managing their finances.

The Department of Broadband, Communications & the Digital Economy has launched the Government’s e-security website www.staysmartonline.gov.au with the aim of educating and changing the behaviours of internet users by raising awareness of e-security issues.

The website is designed to assist all online users to “stay smart” or understand their vulnerabilities and protect themselves when online. It includes easy-to-understand, step-by-step guides covering:

• Computer security issues such as hacking, scams and financial protection

• Games and safety programs to raise the security awareness of children and young people and with advice on making friends on the Net

• Information for parents.

For some time Haemophilia Foundation Australia has had an interest in providing a safe online community for children and young people with bleeding disorders but has not had the resources to develop an online forum. This has led to the establishment of a partnership and Memorandum of Understanding (MOU) with Livewire, which is the online community for children and young people living with a serious illness, chronic condition or disability developed by Starlight Foundation. The Livewire site is open to those aged between 10 and 21 years. Registration to join the community is carefully vetted, the chat forums are moderated by trained chat hosts and blogs are overseen by Livewire staff. Information and blogs on bleeding disorders will be managed through HFA.

The aim of the MOU is to support the potential of Livewire for young people with bleeding disorders. HFA and Livewire are currently planning promotion to children and young people with bleeding disorders between 10 and 21 years. Ultimately, if enough young people with bleeding disorders become Livewire users, there would be regular bleeding-disorder specific chat room sessions and other activities aimed at young people with bleeding disorders. HFA’s Youth Committee has contributed to the development work with Livewire and will continue to be involved in the future. A siblings’ and parents’ site is planned for later in 2009.

Suzanne O’Callaghan is HFA Policy Officer
The 15th Australian & New Zealand Haemophilia Conference will be held at The Sebel, King George Square, Brisbane from 8-10 October 2009.

Planning for the conference is well under way. The program will interest people with bleeding disorders and their families and those providing care, treatment and services to the bleeding disorders community.

Built around a theme of “Life Challenges”, the exciting multidisciplinary program will feature presentations on current and future issues affecting people with haemophilia, von Willebrand disorder and related inherited bleeding disorders:

- Family Factors: Challenges & Solutions
- von Willebrand Disorder
- Considerations for Couples
- Women’s Health
- Treatment and Management of Inhibitors
- Ageing
- Practical Living (Older Adults)
- Good Joints for a Better Life
- Good Dental Care for People of All Ages
- The Importance of Comprehensive Care for People with Bleeding Disorders
- Product Safety
- Living with Hepatitis C and Options for Treatment and Wellbeing
- Living with HIV
- New therapies, new opportunities and new challenges for the bleeding disorders community
- Gene therapy
- Treatment product supply and safety

There is already a list of excellent speakers from Australia, New Zealand, Canada, United Kingdom and USA and there will be more:

- Dr Tony Allworth, Royal Brisbane & Women’s Hospital, Qld
- Jann Anderssen, Arthritis Queensland, Qld
- Dr Chris Barnes, Royal Children’s Hospital Melbourne, Vic
- John Berrill, Maurice Blackburn Cashman, Vic
- Lorraine Bishop, bleeding disorders community member, New Zealand
- Dr Paula Bolton-Maggs, Manchester Haemophilia Comprehensive Care Centre United Kingdom
- Kelly Brady, Royal Brisbane & Women’s Hospital, Qld
- Dr Simon Brown, Royal Children’s Hospital, Qld
- Dr Michael Carr-Gregg, high profile psychologist, Melbourne Vic
- Dr James Daly, Royal Hobart Hospital, Tas
- Dr Greg Dore, National Centre in HIV Epidemiology & Clinical Research, NSW
- Prof Albert Farrugia, Plasma Protein Therapeutics Association, USA
- Helen Fogarty, bleeding disorders community member, Queensland
- Dr Penelope Foster, Melbourne IVF, Vic
- Janine Furmedge, Royal Children’s Hospital Melbourne, Vic
- Dr Kerrod Hallett, Royal Brisbane & Women’s Hospital Qld
- Sharon Hawkins, Royal Perth Hospital WA
- Dr Ian Hewson, The Alfred Melbourne, Vic
- Anne Jackson, Women’s & Children’s Hospital SA
- Dr David Kandiah, Royal Brisbane & Women’s Hospital Qld
- Penny McCarthy, The Alfred Melbourne, Vic
- Leonie Mudge, Royal Prince Alfred Hospital Sydney, NSW
- Kathy Mulder, Children’s Hospital, Winnipeg, Canada
- Mike O’Reilly, bleeding disorders community member, Qld
- Dr Paul Pun, Princess Alexandra Hospital, Qld
• Margie Rae, Royal Children’s Hospital, Qld
• Dr John Rasko, Centenary Institute New South Wales
• Dr Jeremy Robertson, Royal Children’s Hospital Qld
• Katherine Rose, Monash Medical Centre Melbourne
• Dr John Rowell, Royal Brisbane & Women’s Hospital Qld
• A/Prof Jane Smith, Bond University Queensland
• Maureen Spilsbury, Royal Brisbane & Women’s Hospital Qld
• Dr Huyen Tran, The Alfred Melbourne
• A/Prof Carla Treloar, University of New South Wales, NSW
• Dr Alison Turner, National Blood Authority Canberra, ACT
• Deon York, President HFNZ
• Gavin Finkelstein President HFA, WA

CBD with stunning views of Brisbane. Transport from The Sebel and return will be provided at advertised times, or you can arrange your own transport. There is plenty of parking available at Hillstone.

Dinner includes – canapés, 2 courses (main and dessert) soft drink, beer and wine @ $65 per adult and children under 12 years @ $30 per child.

Dinner tickets must be purchased in advance - no tickets will be available during the conference or at Hillstone St Lucia on the night. Free seating at the Dinner.

Remembrance Service ~ Hillstone St Lucia (offsite)

The Remembrance Service will be held at a lovely place at Hillstone before the Gala Dinner. This is a time to come together to think of friends and family, and the people we have cared for in our community who have died. The service is non-religious and everyone is welcome.

Welcome and Exhibition Opening

Join us on the Thursday evening at The Sebel for the Welcome and Exhibition Opening and to meet up with new and old friends.

Gala Dinner ~ Hillstone St Lucia (offsite)

The Gala Dinner will be held at Hillstone St Lucia on the Friday evening. Hillstone is a property of 100 acres located 6 km from Brisbane.
NEW DEVELOPMENTS IN RESEARCH

Dr Alok Srivastava

Two studies were published recently that highlight exciting new developments for treating haemophilia.

Longer Acting Concentrates

Dr Philip Fay and his group from Rochester, New York, USA, have been working on developing a more stable factor VIII protein. Factor proteins are present in the blood, but once activated, they gradually disappear. The time taken for the activity of a particular factor to halve is called its “half-life”. The half-life of factor VIII is 8-12 hours.

In 2008, Fay and his colleagues first reported their work (Blood, 2008; 112:2761-9), in which they showed that carefully designed molecular changes in factor VIII could increase the stability of both factor VIII and its activated form (cofactor VIIIa). The benefit of these new molecules would mean that factor VIII would survive longer in the blood, meaning less frequent infusions for patients. The initial results of in-vitro (in the test-tube) assessment of the function of these molecules are promising, showing a several-fold increase in their stability. However, more work needs to be done, including in-vivo (within a living being) studies in animal models to assess whether the use of modified molecules leads to the development of inhibitors and to determine their efficacy in controlling bleeding. This would be done before human studies can be undertaken. Although there is a long way to go, the prospect of having to use replacement therapy much less frequently is an extremely attractive option.

Platelet-Delivered Factor VIII

Another new development is the delivery of factor VIII specifically to the site of bleeding by platelets. Dr Robert Montgomery and his group from Milwaukee, Wisconsin, USA, have discovered a way to do this and described it in a recent paper (Blood 2008;112:2713-21).

The Milwaukee group first created mice that expressed factor VIII in their platelets by inserting the factor VIII gene into haematopoietic stem cells (the source of all blood cells) but with a promoter (a sequence of DNA required to switch on a gene) that is expressed only in platelets. These genetically modified stem cells were then transplanted into haemophilic mice with induced inhibitors. Recipient mice had to receive whole body irradiation as “conditioning”, a process required for these stem cells to engraft. These stem cells produced platelets that carried factor VIII in them. Haemophilic mice with these transplanted stem cells survived clipping of their tails, which is usually fatal in such animals.

This is a new approach to managing patients with inhibitors. The factor VIII in platelets is protected from being destroyed by circulating inhibitors. In addition, it is delivered to the exact site of bleeding by the platelets, which are part of the first response to any bleeding. It also offers a form of gene therapy for all patients with haemophilia. Much more work will need to be done, including studies in larger animals, to assess the safety and efficacy of this approach. However, this certainly is a significant development in the field.

Longer acting concentrates and platelet-delivered factor VIII for patients with inhibitors
The Australasian HIV/AIDS Conference 2009 (21st Annual ASHM Conference) will be held on Wednesday 9 September – Friday 11 September 2009 in Brisbane.

The conference brings together a range of Australian and international experts with presentations on the latest research findings across the spectrum of HIV management. It will include sessions on HIV and hepatitis co-infection.

The four concurrent streams include:

- Understanding and identifying HIV: Basic Science, Biology and Pathogenesis
- Managing HIV: Clinical management and the lived experience of HIV
- Preventing HIV
- HIV in populations.

Registration is now open. Earlybird registration closes Friday 3 July. Registration deadline is 27 August 2009. Special rates apply for PLWHA or people with hepatitis C.

Further information regarding the conference and program can be found at www.hivaidsconference.com.au or contact +61 2 8204 0770.
World Hepatitis Day is celebrated globally on 19 May. Once again, the theme this year was “Am I number 12? 1 in 12 people worldwide live with hepatitis B or hepatitis C.”

How is this relevant to people with bleeding disorders affected by hepatitis C? Haemophilia Foundation Australia (HFA)’s Hepatitis Awareness Week Working Group, in collaboration with Hepatitis Australia, developed a local theme specifically for the bleeding disorders community:

“I am number 12: I am part of a worldwide community with hepatitis C, but this is my story.”

This is about telling the particular stories of those people with bleeding disorders who have been affected by hepatitis C.

**HFA resources**

For Hepatitis Awareness Week 2009 HFA released:

- Personal stories about living with a bleeding disorder and hepatitis C
- Fact sheets on telling people you have hepatitis C and a bleeding disorder – at work, and to family, friends and new partners

These resources were launched via the HFA E-News on 19 May and can be found in the Hepatitis C section of the HFA web site – www.haemophilia.org.au. A print copy of each of the fact sheets has been included in this copy of National Haemophilia and more are available from your local Haemophilia Centre or Haemophilia Foundation.

**How did we decide what resources to develop?**

Feedback from the community and health professionals in the HFA hepatitis C strategy evaluation (Getting It Right Report) highlighted several priority issues:

- Importance of personal stories to feel connected to other people with bleeding disorders and hepatitis C
- Need for the general community in Australia to understand the particular story of people with bleeding disorders and hepatitis C
- Need for fact sheets with tips on how to disclose hepatitis C at work and to family/friends/new partners.

Information for a health care setting would also be useful.

State and Territory Foundations asked for volunteers to write up their experiences of living with hepatitis C for the HFA web site. In response, “Ben” and “Les” (not their real names) produced candid accounts of their lives and the impact of hepatitis C.

HFA sought and received funding from a philanthropic trust to publish the stories and the fact sheets to its web site and to print the fact sheets. Priority was given to the fact sheets for the workplace and for family/friends/partners; the fact sheet on the health care setting is next on the agenda.

Many thanks to all involved:

- “Ben” and “Les” for their personal stories
- The HFA Hepatitis Awareness Week Working Group – Dave Bell (HFWA), Robert Lambeth (HFQ), Pamela Punch (HFV), Erin James (HFA Youth Committee) – for their input, advice, support and their feedback on the fact sheets
- HFA hepatitis C needs assessment focus group participants, who gave permission for their personal stories to be quoted in the fact sheets
- Sharon Hawkins and Leonie Mudge (Australia/New Zealand Haemophilia Social Workers’ and Counsellors’ Group) and Penny McCarthy and Megan Walsh (Ronald Sayers Haemophilia Centre, The Alfred, Melbourne) who put considerable work into reviewing the fact sheets.

**Your feedback**

What do you think about the personal stories and the fact sheets? Your feedback is very important to us and helps us when we are developing new resources. If you have any comments, please:

- Let us know directly (phone 1800 807 173 or email hfaust@haemophilia.org.au)
- Or tell your local Haemophilia Foundation or haemophilia health professional and ask them to pass your comments on
- Or go to the personal stories/fact sheets pages on the HFA web site (www.haemophilia.org.au) and fill in the online survey.

For more information on the national Hepatitis Awareness Week campaign, see the Hepatitis Australia web site - www.hepatitisaustralia.com
Hepatitis Awareness Week (18-24 May 2009) provided Haemophilia Foundation Australia (HFA) with an ideal opportunity to raise awareness about treatments for people with bleeding disorders who also have hepatitis C.

HFA distributed a media release on 15 May (see page 14). The aim was to serve two purposes:

- Update people with bleeding disorders and hepatitis C who have lost touch with information about new hepatitis C treatments
- Educate the general community about the health and treatment issues for people living with a bleeding disorder and hepatitis C

HFA’s hepatitis C needs assessment, the Double Whammy Report, identified a clear need to reach people with bleeding disorders and hepatitis C who do not visit their Haemophilia Centre regularly and may miss out on the latest news about hepatitis C treatments and the message that they need to review their liver health regularly. The Report also highlighted how little people in the general community know or understand about the experiences of people with bleeding disorders and hepatitis C – which adds to problems with stigma and discrimination and can leave people with bleeding disorders feeling unsupported and isolated.

At the end of April, the major European hepatitis conference released new data on hepatitis C treatments that was very relevant to the bleeding disorders community. The CHARIOT study, led by Associate Professor Stuart Roberts, Director - Gastroenterology and Hepatology, The Alfred hospital in Melbourne, gave a strong message to people with hepatitis C genotype (virus strain) 1 to consider treatment before liver damage develops. Hepatitis C genotype 1 is the most common strain among people with bleeding disorders, but has generally had lower success rates for treatment than genotype 3 – so it is very exciting to find success rates for people with genotype 1 and lower levels of liver disease that are equivalent to those with genotype 3.

Retreatment with the current standard therapy (pegylated interferon/ribavirin) has shown successful results for some people who had earlier less effective treatments, such as interferon monotherapy. For those with genotype 1 who have had unsuccessful treatment with the current standard therapy, there was the welcome news that new treatments in the pipeline are considerably more successful. Clinical trials studying a triple therapy combination of telaprevir/ribavirin/pegylated interferon are the most advanced of these.

HFA’s media release focussed on this news, with expert advice from Assoc Prof Roberts and input on the background issues from Gavin Finkelstein, HFA President. Kevin Fisher, a member from Victoria, generously offered to tell the story of his recent treatment experiences and the impact hepatitis C has had on his life.

The message is an important one: as Gavin Finkelstein says, for those who haven’t been fortunate enough to have cleared hepatitis C already, “We encourage them to come forward, have their liver health reviewed and talk to their hepatitis specialist about their options for hep C treatment - we know it won’t help everyone, but it’s worth knowing where you stand. Life is tough enough with haemophilia without having to battle with hep C as well.”

“At the end of April, the major European hepatitis conference released new data on hepatitis C treatments that was very relevant to the bleeding disorders community.”
Good news about hep C treatment for people with haemophilia

Results presented at an international conference have given hope of a cure for those people in Australia with bleeding disorders who also live with hepatitis C.

For people living with long-term infection with hepatitis C, the results of clinical trials of hepatitis C treatment presented at the European Association for the Study of the Liver (EASL) Congress in Copenhagen at the end of April 2009 give welcome news of higher cure rates. This is even for those with genotype 1, the commonest strain of hepatitis C among people with bleeding disorders in Australia, but also the hardest to treat.

“Many people with haemophilia in Australia acquired hepatitis C from the blood products they used for treatment in the days before testing was available for the virus,” explains Gavin Finkelstein, Haemophilia Foundation Australia President. “That means they’ve been living with hepatitis C for 20-30 years, with symptoms such as fatigue, nausea and liver pain – and that’s on top of the joint damage and other effects of repeated bleeds from the haemophilia itself.”

“We think I was actually infected way back in 1978, when I started treatment with a plasma concentrate pooled from many donors,” says Kevin Fisher, who has haemophilia, “but I didn’t find out until 1990 after hepatitis C testing became available. Back then I was told by a specialist that I probably only had 20 years ahead of me because there was no treatment at that stage. I had a responsible job in a major Australian company and the hep C symptoms made it hard to do my work – I had to give up my social life and looking after things at home and slept all weekend, just so that I could go back into work on Monday.”

“The concern for those who have this liver infection is the possibility of serious liver damage or liver failure over time – including those with bleeding disorders who have long-term infection, which can increase the risk of liver damage,” explains Associate Professor Stuart Roberts, Director, Gastroenterology and Hepatology at The Alfred hospital in Melbourne. “The good news is that the results of treatment continue to improve – and successful treatment can prevent liver failure.”

“You know, I’d got used to the idea that I was only going to live a short life, which was confirmed for me when I tried hepatitis C treatment in the early 90s. It had some difficult side effects and didn’t help,” says Kevin Fisher. “But last year I decided to have the latest therapy and although it had side effects too, it’s been successful and I’ve cleared the hepatitis C virus. I’d given up hope but now I feel better than I have for years. My wife and I have just had our first real holiday in several years and it’s been great.”

According to the results of the large Australian led, international CHARIOT clinical trial presented at the European Association for the Study of the Liver Congress in Copenhagen at the end of April 2009, people with genotype 1 hepatitis C who receive treatment when they have minimal, or no liver damage, have double the chance of a cure, compared to those treated in the later stages of liver disease. The study included more than 700 Australians with hepatitis C and 33 Australian hospitals.

“These cure rates are a lot higher than we thought – up to 7 out of 10 people with genotype 1 may be cured if treatment starts before liver scarring or damage has occurred,” says Stuart Roberts, who was the lead investigator. And it’s far from hopeless for people who already have some liver damage or who previously relapsed after treatment. Some, like Kevin, have recently had successful treatment or retreatment with the current standard treatment.

The same international conference also reported on the new hepatitis C treatments in the pipeline. A combination treatment of a new drug telaprevir with pegylated interferon and ribavirin is currently being trialled in Australia. At the conference, researchers presented data on the US/European arm studying people with genotype 1 hepatitis C treated with this triple therapy. The study found that up to 76% people who had previously relapsed achieved a cure with this treatment.

“This new treatment combination shows great promise for people with bleeding disorders who relapsed following previous treatment,” says Stuart Roberts.

If the clinical trials continue to show successful results the treatment should be available in Australian clinics some time after 2010.

“There could be over a thousand people with bleeding disorders in Australia who acquired hepatitis C via blood products contaminated with hepatitis C,” claims Gavin Finkelstein. “Some of them have already cleared hepatitis C naturally or through treatment. But for the many others who haven’t been so fortunate, we encourage them to come forward, have their liver health reviewed and talk to their hepatitis specialist about their options for hep C treatment - we know it won’t help everyone, but it’s worth knowing where you stand. Life is tough enough with haemophilia without having to battle with hep C as well.”

HFA Media Release - Hepatitis Awareness Week (18-24 May 2009)
NEW DIRECTIONS IN HEP C THERAPY

Professor Greg Dore

The development of new therapeutic agents such as protease and polymerase inhibitors provides hope that treatment responses will be improved over shorter treatment durations.

Treatment of chronic hep C has improved in recent years, particularly since the advent of pegylated interferon (PEG-IFN) and ribavirin (RBV) combination therapy. Depending on HCV genotype, 50-80% of people achieve a sustained virological response following 24-48 weeks therapy. However, treatment numbers remain low, in part due to treatment side effects and length of therapy.

The development of new therapeutic agents such as protease and polymerase inhibitors provides hope that treatment responses will be improved over shorter treatment durations. This is particularly important for people with genotype 1 infection. Studies have revealed several important features.

1. At least initially, these individual oral therapy agents will be combined with PEG-IFN and RBV.
2. Triple therapy is likely to provide additional side effects.
3. Early HCV resistance is an important issue, particularly for protease inhibitors.
4. Treatment responses should be improved by at least 15-20%, with shortened treatment durations.

Two agents, telaprevir and boceprevir (protease inhibitors) have recently finished enrolment into large-scale international phase III trials, with separate studies in genotype 1 patients with, and without, previous treatment. Results from these trials should be available by early 2011. Assuming enhanced treatment outcomes and an adequate safety profile, these initial protease inhibitors should be licensed by 2012 with potential access through Medicare (if demonstrated to be cost-effective) in 2013.

Although some agents have been withdrawn from development due to significant side effects, several other protease and polymerase inhibitors are in clinical development, including agents that require single daily dosing (telaprevir and boceprevir are dosed three-times daily).

International phase II studies with MK 7009 and BI 201335 (protease inhibitors) are currently enrolling and will include several Australian hospitals (including St Vincent’s Hospital, Sydney). These trials involve patients with HCV genotype 1, including those with, and without, treatment experience.

Requirements for study entry for these and other protease and polymerase inhibitor trials generally include:

- chronic hep C
- liver biopsy within the previous 1-2 years, although some studies are now allowing Fibroscan assessment of disease stage
- no active illicit drug use or alcohol dependence
- no active psychiatric disorder
- no evidence of major chronic medical conditions
- for treatment-experienced participants, generally a non-response at week 12 or relapse following combination PEG-IFN and RBV is required to be documented.

Patients and doctors are “blinded” to the group to which patients are randomised, which means that they are unaware of whether they are receiving triple therapy, or the standard combination therapy (generally between one third and one fifth of people receive standard combination therapy only).
“GRASS ROOTS TO NATIONAL ACTION”: NATIONAL HEPATITIS HEALTH PROMOTION CONFERENCE

Hobart, 29-30 October 2009

Hepatitis Australia is hosting a two day conference for health and community workers with an interest in viral hepatitis prevention and support.

The conference will feature plenary addresses from health promotion experts, health promotion skills workshops and presentations on viral hepatitis prevention, education, health maintenance and support projects.

It will showcase hepatitis health promotion projects and strategies used across Australia to engage various populations and will explore issues in working collaboratively to achieve change. Conference streams will include: using new technologies and social networking sites; the role of peers; building partnerships; health promotion in prisons, Aboriginal and Torres Strait Islander communities, with youth, CALD communities and people living with hepatitis.

Visit the Hepatitis Australia web site for more information on abstract submission and registration – www.hepatitisaustralia.com

Dr Megan Sarson is Project Officer for the Australian Haemophilia Centre Directors’ Organisation

NEWS FROM AHCD0

Dr Megan Sarson

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There is now an ABDR data manager at each of the 16 HTCs. In order to bring all the data managers together to facilitate professional networking, Australian Haemophilia Centre Directors’ Organisation (AHCD0) has auspiced the establishment of a Data Managers’ Group (DMG). This will operate in a similar way to the already existing nurses’ group, physios’ group and social workers’ group. The first teleconference was held in April and AHCD0 congratulates Julia Ekert (Royal Children’s Hospital, Vic) and Katheryn van Dieman (Royal Adelaide and Women’s and Children’s Hospitals, SA) who were elected as co-chairs of the Data Managers’ Group. DMG members will now work on developing their Terms of Reference and some data entry guidelines which will ensure that data is being entered in the same way at every HTC.

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STAFF CHANGES

Heather is well known for her friendly and helpful approach. She has very often been the first point of contact when people call HFA and with her knowledge and sensible approach she has helped many people to access the information or education materials they require, or to make connection with others.

Heather is also well known and respected by many of HFA’s stakeholders, including other community organisations and government officials who HFA works with to meet its objectives.

Heather’s loyal service to HFA was recognised in 2001 when she received the HFA Jennifer Ross Award which was established to recognise outstanding service to people with haemophilia and their families.

After 20 years working at HFA, Heather will retire from the organisation on 16 July. At an informal presentation during a meeting of the Executive Board in Melbourne on 13 June, HFA President, Gavin Finkelstein, presented a small gift in appreciation of Heather’s valued contribution and acknowledged her long service and commitment.

Heather is planning to take a well earned break, but is unlikely to be idle in her retirement. She said her “immediate plans are to look forward to some travel, joining the mid-week walking group, and increasing my volunteer work, including working with the preps at the local primary school”. We have no doubt Heather will continue with her many social activities and interests with her wide circle of friends and we thank her for her wonderful work at HFA and wish her a very happy retirement.

Heather Lauder started working at Haemophilia Foundation Australia in 1989 when the office was based in Hartwell. She came to HFA as an Executive Secretary to the Executive Director, Jenny Ross. Since that time Heather has become well known to people with bleeding disorders and their families around Australia and overseas.

“Heather is well known for her friendly and helpful approach. She has very often been the first point of contact when people call HFA.”

Sharon Caris
THAILAND - AUSTRALIA TWINNING

Sharon Caris

Haemophilia Foundation Australia (HFA), the Thai Patient’s Club (TPC) and National Hemophilia Foundation of Thailand (NHFT) are working together to plan and organise a workshop in Bangkok in September for Thai patients and volunteers.

Since an earlier workshop in April 2007 a team of volunteers in several regions of Thailand have been working hard to identify patients and families affected by bleeding disorders and to provide support and information to improve access to treatment and care.

The upcoming September workshop will be attended by patient leaders from around Thailand and will provide an opportunity for these volunteers to share their experiences and learn new skills in advocacy, lobbying and fundraising. After the workshop Australian representatives will join with Thai colleagues on a regional outreach visit.

HFA was delighted to host the visit of Mr Nawin Pajakgo and Mr Narong Yamnual in September 2008. They are both members of TPC, and each have a child with haemophilia. This visit enabled volunteers and health professionals in South Australia, Queensland and Victoria to learn more about haemophilia care in Thailand and the needs of the bleeding disorders community, and to learn from their experiences of running family and youth camps for their members.

The twinning between the organisations is supported by grants from the World Federation of Hemophilia (WFH).

For more information about WFH Twinning visit the WFH web site at www.wfh.org.

“The upcoming September workshop will be attended by patient leaders from around Thailand and will provide an opportunity for these volunteers to share their experiences and learn new skills in advocacy.”
Would you like to participate in 2009 Global Feast?

Global Feast is a fundraising opportunity for Australians to raise funds which will be used for people with bleeding disorders around the world who need our help.

Without proper treatment for their bleeding disorder, most children with severe haemophilia will die when they are very young. An estimated 400,000 people worldwide are living with haemophilia. 75% of people with bleeding disorders throughout the world are undiagnosed and untreated, particularly in countries where health care is not well resourced. WFH is striving to close this gap. Australia is one of the fortunate countries where people with bleeding disorders receive high quality care and treatment. We can all make a difference by working with World Federation of Hemophilia (WFH).

Invite your family, friends and work colleagues to a meal and ask them to bring a donation instead of flowers, wine or a gift. If a dinner isn’t your “cup of tea”, any type of festive event will do - a pancake breakfast, pizza party, backyard barbeque, afternoon tea or picnic lunch. Do it at home, or meet in the park! Be creative and have fun! We can help you run your own Global Feast event at any time during the year!

All monies will be donated directly to WFH. WFH will use these funds to provide safe and effective blood treatment products free of charge to people in urgent need. WFH works in more than 50 developing countries providing programs, services, educating families and training doctors and nurses in some of the poorest regions of the world.

For more information and promotional items, contact Natashia at HFA on 1800 807 173 or ncoco@haemophilia.org.au.
CALENDAR

WFH Global Forum 2009
Montreal, Canada 24-25 September 2009
email mbrooker@wfh.org
www.wfh.org

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

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

Corporate Partners
Haemophilia Foundation Australia (HFA) values the individuals, Trusts and Corporations which donate funds to support our objectives.
Among our valued donors are our Corporate Partners who provide unrestricted grants to HFA to support our programs:

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.