National Haemophilia
Haemophilia Foundation Australia
www.haemophilia.org.au
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YOUR SAY!

HFA NATIONAL SURVEY

CONTENTS

Haemophilia Foundation Australia

Registered No.: A0012245M
ABN: 89 443 537 189
1624 High Street Glen Iris,
Victoria, Australia 3146
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan

Paul Bonner is President, Haemophilia Foundation South Australia, and a member of the Haemophilia Foundation Australia Executive Board

HAEMOPHILIA FOUNDATION SOUTH AUSTRALIA (HFSA) UPDATE

Paul Bonner

In recent years HFSA has struggled to get sufficient numbers of members willing to take on committee and other tasks necessary to keep the foundation running properly. It has been difficult to prevent burnout for the same few volunteers who have tried to maintain the governance responsibilities of the foundation and run activities. We have struggled to get quorums at Annual General Meetings. After much consideration, the current committee decided to hold a Special General Meeting in February this year to vote on the dissolution of HFSA. This was a sad, but necessary step for our volunteers, but there was recognition that the foundation could not continue as it was.

Unfortunately, the Office of Consumer and Business Affairs requires HFSA to have another Special General Meeting to vote on the dissolution of HFSA and the distribution of HFSA assets. At this stage a date has not been set for this, however existing members will be notified of the date in due course. In the meantime HFSA still exists as a legal entity although it is not actively operating, but it is envisaged that it will be dissolved following the upcoming Special General Meeting.

Although people with bleeding disorders may not have wanted to participate in formal foundation activities we are aware there are individuals with bleeding disorders and their families who may want support or advocacy from time to time. I will be discussing options for such ongoing support and assistance to South Australians with bleeding disorders with Haemophilia Foundation Australia (HFA), and how we can keep them informed about issues and developments. I also hope it will be possible for us to have informal social events and activities from time to time if people want these. I will also ensure that haemophilia treatment centre staff are aware of developments.

South Australians with bleeding disorders will be encouraged to keep connected with issues affecting the Australia wide bleeding disorders community via connection with HFA through this newsletter, and HFA's website, e-news and Facebook. If you know people who might wish to join the HFA mailing lists so they can keep in touch please encourage them to contact HFA on 1800 807 173.

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

Responses to the HFA National Survey highlighted how important it is for HFA to remain proactive in representing the needs of the bleeding disorders community at a national level. Survey respondents spoke of the need to remain vigilant; that while HFA's work on treatment and care has enabled great improvements for individuals' quality of life, the health policy environment is constantly changing and we need to ensure that priority areas remain on the agenda. For the respondents, this included areas such as treatment and care, safety and supply of treatment product, living with co-morbidities and inhibitors, living with von Willebrand disorder and rare factor deficiencies, ageing, and mental health.

The Australian Government actively and continuously undertakes work to review and restructure the health and social services systems and HFA takes very seriously its role in monitoring this work and ensuring that bleeding disorder interests are represented. Over the past few months HFA has been involved in responding to several Government proposals and has also continued to raise other priority issues that remain unaddressed.

DISABILITY

One area of interest for the Productivity Commission has been the availability and accessibility of care and support for people with significant disabilities. In February 2011 the Productivity Commission circulated its report and recommendations for a National Disability Long-term Care and Support Scheme and a National Disability Insurance Scheme for public comment. The proposed Schemes aimed to create an integrated national support system that ensures that people in need of its services have improved access to the scheme and do not 'fall between the cracks' of support service schemes or schemes across sectors. The Schemes would tailor support and care to individual needs and focused on enabling people with disability and their carers to have an improved quality of life, more control over decision-making related to care and support and greater opportunities for independence, participating in their community and living a rewarding life.

From HFA's perspective, the Schemes may offer some people with bleeding disorders considerable benefit, but it is uncertain at this stage who would be eligible for the Schemes. HFA's response included an outline of the types of experiences of people with bleeding disorders and their carers and the community's ongoing difficulties with 'falling between the cracks' with complex co-morbidities, particularly with financial insurance, which was not addressed in the proposal. HFA will continue to follow the progress of this proposal and the outcomes for affected members.

COMPREHENSIVE CARE

The Australian Government's proposed National Health and Hospital Network Reforms have created considerable discussion about how to manage statewide or regional services such as comprehensive care provided by Haemophilia Centres under the proposed Local Hospital Networks and Medicare Locals. One initiative under discussion is the development of national and local Lead Clinicians Groups to complement the Reforms. These are specialist clinical advisory groups to provide advice and information to government to ensure that best practice patient-centred care is available across the health sector. In rare health conditions such as bleeding disorders where patient numbers are small, data to develop best practice care is collected internationally and nationally and the work of national organizations, such as the Australian Haemophilia Centre Directors' Organisation or HFA, to work with the collected data and the collected experience of their members to develop guidelines and responses is crucial. It would be important that the appropriate national bleeding disorder organizations were represented in Lead Clinicians Groups and involved in consultation processes and HFA has raised this to ensure it is the case.

BLOOD-BORNE VIRUSES

Financial issues for people with bleeding disorders affected by hepatitis C remains a priority for HFA. In April this year HFA had further correspondence with the federal government about this issue, particularly the out-of-pocket costs that are not covered by existing government schemes and other financial safety nets. We expect to have further meetings with governments about this and the HFA proposal for a financial assistance scheme over the coming months.

Usually patient safety is the main focus in an HFA response to consultation about guidelines for clinical practice and blood borne viruses. However, a recent request for feedback on the Medical Board of Australia guidelines for medical practitioners and medical students with blood borne viruses highlighted that people with bleeding disorders affected by HIV and/or hepatitis C might also themselves be health care practitioners and it is important that any such guidelines support them to maintain their health and wellbeing and protect their privacy.

And in a time when HFA reflects on its advocacy and representation work through the National Survey and considers where we must remain vigilant, it is also a time of hope and a time to appreciate how far we have come; that we are now in a position to consolidate national information and draw on our collected experience to make sure the bleeding disorders community interests remain on the agenda.

Suzanne O'Callaghan is Policy Officer,
Haemophilia Foundation Australia

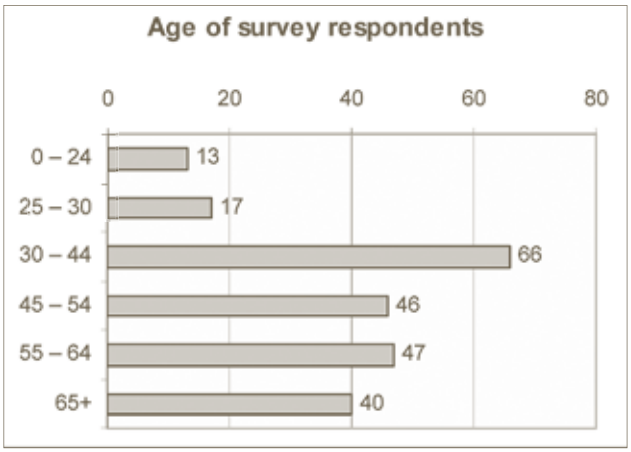
HFA NATIONAL SURVEY

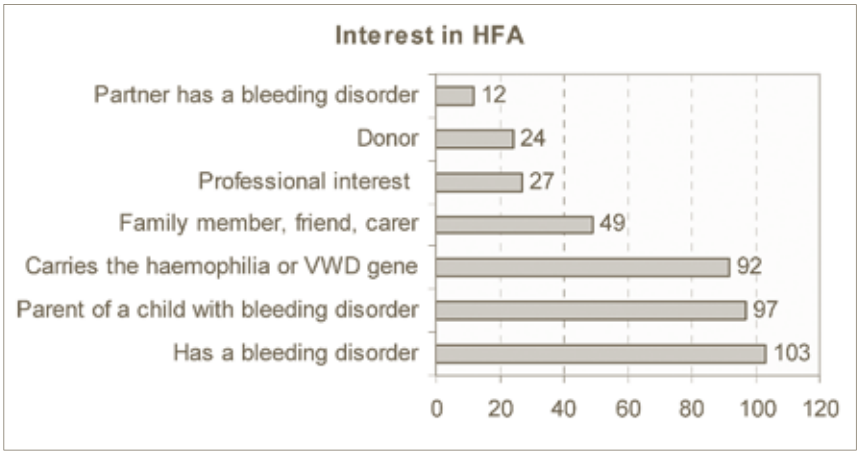
Suzanne O'Callaghan

What do community members and *National Haemophilia* readers want or expect from HFA? And how would you prefer information about HFA activities and educational material delivered to you?

Communication in the digital and wireless age has changed rapidly over the last few years and it has revolutionised the way people prefer to receive information and the type of information they need. HFA has been very aware of these changes and we have been working with different technologies – print, web site, email and social media, such as Facebook – to meet the needs of different members of the community.

However, it is important for HFA to have a clear sense of priorities for the bleeding disorders community and the range of individual preferences for information and education. In late 2010 HFA used a National Survey to ask the community these questions. The survey was available online and a print version was also mailed out to *National Haemophilia* readers in Australia and made available to state/territory Haemophilia Foundations. It was accompanied by a prize draw to encourage people to complete the survey.





WHO COMPLETED THE SURVEY?

In total 229 people from all states and territories completed the survey, 27% (62) online and 73% (167) returning the print survey.

66% (147) lived in a capital city and 34% (77) lived in a regional centre or rural area. More than half were female – 60% (137) compared to 40% (92) males. The older age groups were well represented, with youth less so.

WHAT DID PEOPLE SAY?

Priorities

In general people who completed the survey had confidence in HFA's direction in priority areas and its work in representation and advocacy, and felt that HFA 'does a great job with limited resources'. Treatment and care, safety and supply of treatment products and education and research rated very highly for most people. Other areas needing support include youth, von Willebrand disorder and rare factor deficiencies, siblings, genetic testing and family planning, rural and regional areas and peer support. They felt that while the bleeding disorders community had come a long way because of HFA's work, it was important to remain active and vigilant.

"Treatment and care is very good and remain paramount priorities. However, HFA should be vigilant to government and communities thinking that the 'job is done' and relaxing on other health-related issues such as: living with co-morbidities and inhibitors;

emerging issues such as ageing; and, of course, the 'next big thing' around the corner."

"There needs to be more support of teenage males in particular who may say they are coping but in fact may not be."

HFA development activities

While 80% (168) were aware of HFA's youth development and mentoring activities, there was a 50/50 split between those who knew about the personal development awards for people with bleeding disorders, such as the Vision and Leadership awards and the Damon Courtney Memorial Endowment Fund, or the HFA partnership with Livewire, an online community for young people with health conditions, their parents and siblings. Nevertheless, most felt that these activities were valuable and could be promoted more.

"Getting youth involved can only lead to a better future. It is not only beneficial to the youth involved, but for the greater haemophilia community."

Education and information

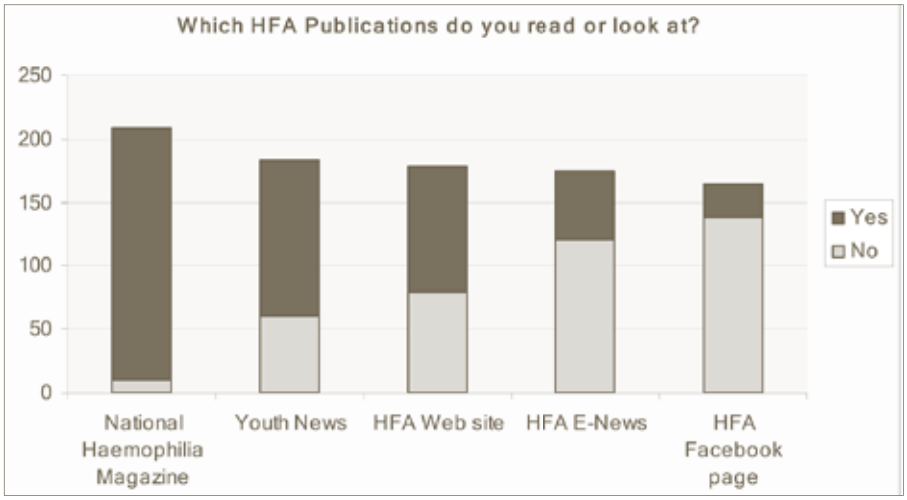
Many of those who completed the survey had looked for some information relating to bleeding disorders in the last two years, some with more success than others. They were more likely to find information on bleeding disorders and treatment and care, than travel, sport and exercise, parenting, growing older and family planning, genetics and childbirth. Interestingly, although HFA had assumed that "growing older" applied to older members of the community, youth were also keen to find information on this.

Most successful sources of information were: the internet (65%), *National Haemophilia* magazine (43%), Haemophilia Centres (42%), HFA web site (23%), state and territory Foundations (27%) and HFA *Youth News* (16%).

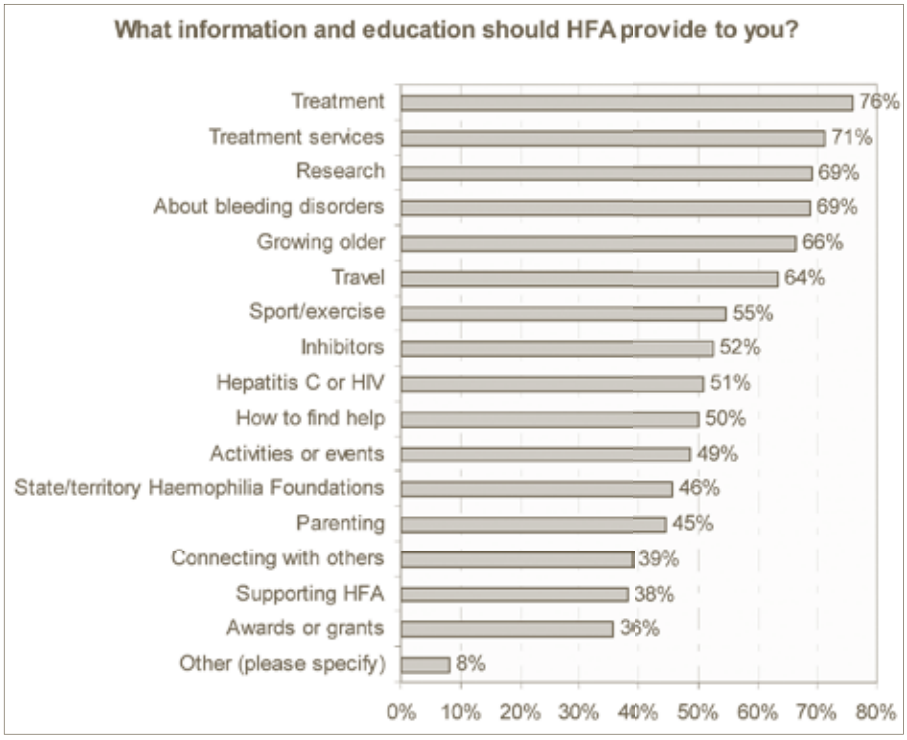
HFA publications such as *National Haemophilia*, *Youth News*, HFA information booklets and the web site rated most highly as useful sources of information. Some people had not been aware that HFA provided an e-news service or a Facebook page and were not sure how to connect to it.

The table below shows how people currently source their information from HFA. Many from all age groups preferred print publications. If they did not read or look at particular publications, their main reasons were that they did not have access to the internet, they did not use Facebook, *Youth News* was not relevant as they weren't a youth, they did not have time or that they did not know about the publication until now – some noted that they were now going to register for e-news or the HFA Facebook page.

HFA should be vigilant to government and communities thinking that the "job is done"



The most popular topics for education and information are outlined in the table below.



It is crucial to inform teenagers with bleeding issues...

Other suggested topics included:

- Personal stories about living with a bleeding disorder and quality of life, personal development
- Managing ageing and mobility, arthritis, joint replacements
- Women and girls and bleeding symptoms, carrying the gene
- Genetics and genetic testing, family planning, pregnancy and babies with haemophilia
- Von Willebrand disorder and rare factor deficiencies
- Research, new treatment products
- Youth and youth stories, music, sport, exercise
- Parenting and siblings.

The highest rating ways that people would prefer the information were:

National Haemophilia magazine	76%
Printed fact sheets/booklets	46%
Email newsletter	44%
HFA web site	40%
Education workshops	30%
Haemophilia Conference	27.2%
Phone or email	21%
HFA Facebook page	14%

"As a mild haemophiliac, my contact with the bleeding disorders community is small to non-existent. Receiving the email newsletters keeps me in touch with bleeding issues which have not affected me yet, but may in the future as I get older. I run a lot, so the sport issues news is interesting to me. I would have loved to receive these newsletters when I was a teenager in the 1970s - 1980s, when there was really nothing around in the way of information and I was quite ignorant about haemophilia. It is crucial to inform teenagers with bleeding issues about them. I have only ever met one other haemophiliac in my life - my brother!"

HOW HAS HFA RESPONDED?

When HFA distributed the Survey, a prize entry form was also included which gave people the opportunity to register for HFA e-news and to receive other publications and more than 45 people took the opportunity to do this.

Since survey results were collated HFA has also:

- Made a direct link from the HFA web site home page to the HFA Facebook page
- Actively sourced articles for HFA publications on popular topics
- Promoted personal development awards across all HFA publications
- Explained HFA's advocacy work in more detail in National Haemophilia.

The Survey results are an important source of information for HFA's strategic planning and will be used to assist with future planning and directions.

Thank you to all who took the time to complete the HFA National Survey.

WORLD HEPATITIS DAY

From 2011 World Hepatitis Day will be celebrated globally on 28 July. World Hepatitis Day is an opportunity for interested groups around the world to raise awareness and influence real change in disease prevention and access to testing and treatment.

World Hepatitis Day was endorsed as an international event by the World Health Organisation in May 2010. The date was chosen to recognise and honour the 1976 Nobel Laureate, Professor Baruch Blumberg, who celebrates his birthday on 28 July. Professor Blumberg is a leading figure in the research which led to the discovery of the Australian antigen; the hepatitis B virus, and ultimately the development of a hepatitis B vaccine.

This year in Australia the national campaign will focus on raising awareness about viral hepatitis in the context of good liver health. This campaign aims to support people with viral hepatitis by creating an environment in Australia where viral hepatitis is portrayed as a health condition without attaching value judgements and as a result there is less stigma in the community.

The national campaign will focus on World Hepatitis Day itself. The campaign will include:

- Redeveloped Love Your Liver Lunch web site with new and dynamic information on good liver health
- Community page for Lover Your Liver Lunch on Facebook
- O'Liver mascot for public events, the web site and Facebook
- National launch and webinar on World Hepatitis Day
- Poster, lapel pins, t-shirts, temporary tattoos and balloons

LOVE YOUR LIVER

State and territory hepatitis councils will be organising local events and lunches. Some are also holding a Hepatitis Awareness Week around World Hepatitis Day. For more information, contact your local hepatitis council.

For more information about the Love Your Liver Lunch campaign, go to the web site - **www.loveyourliver.com.au.**

HAEMOPHILIA FOUNDATION AUSTRALIA RESEARCH GRANTS

A funding round for grants for medical, scientific or social research which will improve outcomes for people with haemophilia, von Willebrand disorder or related inherited bleeding disorders, and/or medically acquired blood borne viruses is now open.

A total amount of $20,000 is available for one or more projects to be undertaken over the next year.

Application form and conditions of funding may be downloaded from Haemophilia Foundation Australia website at www.haemophilia.org.au or for a hardcopy contact:

Haemophilia Foundation Australia 1624 High St Glen Iris VIC 3146
Phone: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au

Closing date for applications: 19 August 2011

16th Australian & New Zealand Haemophilia Conference

Novotel Sydney Olympic Park 20 - 22 October 2011

Health and wellbeing – the decade ahead

The 16th Australian & New Zealand Haemophilia Conference will be held in Sydney, 20 - 22 October 2011. The theme for the conference is ***"Health and wellbeing – the decade ahead".***

The Conference is at the Novotel Sydney Olympic Park, Olympic Boulevard, Sydney. There is good access in and around the venue and on the conference floor and it is suitable for wheelchairs.

Registration brochures are available - for a hardcopy contact HFA or you can download online at **www.haemophilia.org.au/conferences**. Conference registrations can be made online at **https://www.haemophilia.org.au/registration** and accommodation bookings can be made at **www.haemophilia.org.au/accommodation**. Remember earlybird registrations end **31 July, 2011**.

PROGRAM

The multidisciplinary program has been developed to interest people with bleeding disorders and their families, health professionals and others involved in providing health care services. A range of topics will be featured in the program, including best practice treatment and new clotting factor products, comprehensive care, development and treatment of inhibitors, better joint care and management and physiotherapy, sexuality and body image, child and adolescent transition to adult services, youth issues, ageing, women's bleeding issues, reproductive health, and hepatitis C and HIV care and treatment updates. Each topic will be presented with patients and their families and their treating health professionals in mind.

POSTERS

There will be a Poster Exhibition during the Conference. We encourage Poster Abstracts relevant to clinical practice and care, laboratory science, research, policy or living with bleeding disorders or treatment complications.

OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

Health Professionals Meetings

Annual meetings of the Meetings of Australian Haemophilia Centre Directors' Organisation, Australian Haemophilia Nurses' Group, Australian Haemophilia Social Workers' and Counsellors' Group, Australian & New Zealand Physiotherapy Haemophilia Group and the ABDR Data Managers Group will be held on Thursday 20 October 2011 - members of the groups will receive details soon.

The theme for the Conference is *"health and wellbeing – the decade ahead"*

1st Australian & New Zealand Inhibitor Workshop 22-24 October 2011

This is our first specialised inhibitors workshop. Inhibitor development and treatment will included in the Conference program as a session topic, but the workshop will be more focused to the needs of individuals living with inhibitors and their carers. HFA is working with Haemophilia Foundation of New Zealand (HFNZ) to develop this workshop. There will be a limited number of subsidised places to attend the workshop, including travel expenses. You must be attending the Conference to also attend the workshop. The inhibitors workshop will run after the Conference from Saturday night until Monday. Participants will be nominated by local Haemophilia Foundations on the recommendation of haemophilia counsellors or social workers. For more information and registrations contact HFA on 1800 807 173 or HFNZ on 03 371 7477.

Youth Social Function

After the Welcome & Exhibition Opening on Thursday 20 October, youth are invited to a "meet and greet" social function. This will be onsite and will be free of charge. This will be a chance for youth to meet others and connect before the Conference program starts. Topics of interest to youth will be integrated throughout the Conference program. Further details for youth will be available to registered delegates later.

Remembrance Service

The Remembrance Service is a very special time held during our Conferences to remember friends and family and the people we have cared for in our community who have died. The service will be non-religious and everyone is welcome. It will be held on Friday 21 October before the Conference Dinner.

Conference Dinner ~ Novotel Sydney Olympic Park

Join your fellow delegates for the Conference Dinner onsite on the Friday evening. There will be no speeches or presentations, it will simply be a dinner where you can talk, share and meet with others at the Conference.

A Men's Breakfast and Women's Breakfast will be held on Saturday 22 October.

Come along to hear an interesting speaker and share your ideas and experiences with other men or women!

For more information, check the HFA conference website - **www.haemophilia.org.au/conferences**

Peter Fogarty is Vice-President, Haemophilia Foundation Australia

WORLD HAEMOPHILIA DAY

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Life-saving injection

Disorder stings brothers

Carly Hennessy

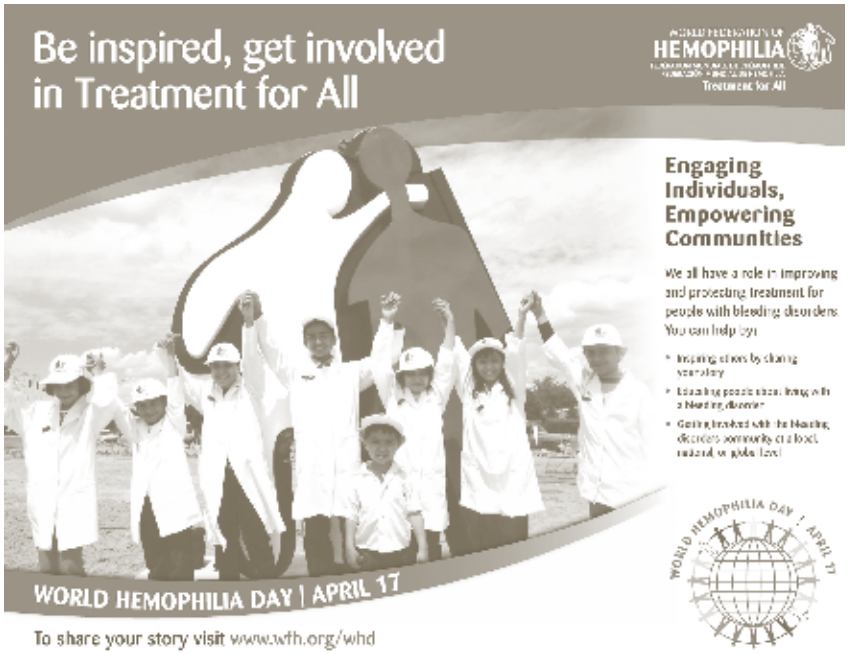
On World Haemophilia Day 2011, Peter Fogarty from Brisbane and his family shared their story of living with haemophilia as part of the World Federation of Hemophilia's ***Be inspired, get involved in Treatment for All!*** campaign.

Peter and his family appeared on the Channel 10 News program *In Their Own Words* to tell the story of discovering that his two young sons, Felix and Clancy, have haemophilia and Felix's journey growing up with severe haemophilia A – his brave and determined path from having treatment through a port to learning to treat himself, with a smile.

When Felix was 5 months old his parents discovered two giant bruises on his chest under where the buckles of his overalls would have been. However, when they found more unexplained bruises they were very concerned and knew that something was not right. After a series of traumatic blood tests on their baby it was finally confirmed that Felix actually had haemophilia. From that point on their family's life changed forever. Felix and his little brother Clancy both have severe haemophilia A. They both require prophylactic treatment with clotting factor three times a week to prevent bleeding episodes. When he was young, Felix was treated through injecting factor into a port in his chest. However, now that he is older his treatment is injected into his arm. Nine-year old Felix now actively takes part in learning how to treat himself and is becoming an excellent role model for his younger brother.

Stories just like this one, describing the struggles and successes of a person with a bleeding disorder, were shared around the world on World Haemophilia Day, April 17. During April 2011, people with haemophilia and other inherited bleeding disorders shared their stories on the World Federation of Hemophilia (WFH) website **www.wfh.org/whd** . This is an important part of the WFH campaign for ***Treatment For All.***

World Haemophilia Day was an opportunity to raise awareness around the world about the impact of haemophilia on the person and their family and the need to make adequate treatment available to all.



Haemophilia Foundation Australia took this message to the Australian community with a media release and highlighted the Fogarty family story on the HFA web site, e-news and Facebook page.

"About 40 years ago haemophilia treatment didn't exist. Most people with haemophilia at this time were not expected to live into adulthood," said Gavin Finkelstein, President, Haemophilia Foundation Australia. "Today, someone born with haemophilia can lead a relatively normal life if they have access to proper treatment. While treatment is available to people living with haemophilia and other bleeding disorders in Australia, access to treatment is perhaps the biggest challenge facing many people with bleeding disorders throughout the world who still do not have adequate treatment."

Sharon Caris, Executive Director, HFA, explained more about how the ***Be inspired, get involved in Treatment for All!*** campaign worked: "On World Haemophilia Day we wanted to inspire people to learn about haemophilia, von Willebrand disorder and other bleeding disorders and get involved in improving access and quality of care so that around the world ***Treatment for All*** becomes a reality. The WFH vision is that one day treatment for all people with bleeding disorders will be available".

Around Australia state and territory Foundations raised awareness for World Haemophilia Day with personal stories in their newsletters, stalls at the local hospital and fundraising activities.

To see the stories posted by the global haemophilia community for World Haemophilia Day, visit the World Federation of Hemophilia "Share Your Story" web site: **www.wfh.org/whd**

The video of the Fogarty family story is available at **http://www.youtube.com/watch?v=gBr_DkPlgqk**

Thanks to Channel 10, Brisbane, for permission to provide access to this video.

The Fogarty family story was also published in the Brisbane *Sunday Mail* on April 17, World Haemophilia Day.

IN HIS OWN WORDS:

Nine-year-old Felix Fogarty talks about what it was like to share his story for World Haemophilia Day

Q. Felix, why did you think it was important to share your story for World Haemophilia Day?

Felix: I think that I should let people know what it's like to have haemophilia and so people who don't have a condition like me can see that they are actually quite lucky that they don't have to have lots of needles and treatments.

Q. A few years ago you had some visitors from Thailand whose sons have haemophilia. Do you remember their visit? Did they tell you anything about life in Thailand for boys of your age with haemophilia? Is it different to your life?

Felix: I don't remember that much about them coming except that they were really nice and friendly. But when my dad went to Thailand he told me how the boys don't have treatments and have a lot of joint problems and can't play sport. I felt really sorry for them and lucky that I live in Australia.

Q. What was it like being filmed for the television news show?

Felix: I think it was a good experience for me because not everyone gets to go on TV and be in the newspaper.

Q. Did anyone from school or other people you know tell you that they saw it? What did they say?

Felix: A few kids did but they weren't so sure it was me and they asked me if it was me on TV.

Dr Desdemona Chong is a senior clinical psychologist (locum) in the Queensland Haemophilia Centre at the Royal Children's Hospital/ Royal Women's and Brisbane Hospital

ADOLESCENCE

Desdemona Chong

Adolescence is a transition period between a child and being an adult that is characterised by simultaneous physical, psychological, social and sexual changes. Many of the behaviours that cause so much anguish for parents are actually normal and healthy adolescent behaviours. Yet, parenting a teenager with haemophilia can have its added challenges as you grapple to fit your teenager's medical needs along with his developmental changes. This article looks at some of the issues that you and your teenager might face, and how you can help to make adolescence a smoother and more pleasant experience.

ISSUES YOU AND YOUR TEENAGER MAY FACE

Dealing with bodily changes

Puberty often marks the start of adolescence. Your teenager would start to become more self-conscious or private about his body and become more aware of his sexuality. This is also a time when he may want to conceal his haemophilia-related injuries and strive to mask any abnormality.

Increased sense of invincibility

Related to physical maturity, young people have an increased sense of invincibility. Those who are on prophylaxis tend to reap the intended benefits of fewer bleeding episodes and less damage to their joints and hence, become less familiar with long-term joint damage. This means that your teenager might start to question the need for regular treatment, develop his own ideas of what his treatment regime should be and start to compromise on the treatment regime.

Dealing with relationships

Friendships become more important and intense for adolescents. They may start to pull away from parents and gravitate towards their friends. Teenagers with haemophilia need to figure out who they would tell and what they would say. They may also be concerned about how others (especially romantic partners) might see them should they disclose.

Changing relationships with parents

When your children were small, they turned to you for comfort in times of need. As teenagers, they tend to want to deal with these emotions themselves or with their friends. While it can be hard being shut out, it is important to recognise that strong family bonds are still important for young people. Your teenager also starts to form his own ideas and opinions, which may differ from you. He may start to express his thoughts and feelings more openly and challenge your views but this is part of normal adolescent development.

Cognitive changes

Unlike a child, your teenager can now consider the abstract and the unseen (eg, he can consider a hypothesis and imagine many possible outcomes). In terms of understanding illness, he can understand body parts and entire systems of the body and how they interact. At the same time, he tends to focus on the present and may not perceive the prevention of potential future joint disease as a high priority. Thought processes during puberty may include denial of the disease, while emotional responses may include fear.

Increased travel and mobility

Increased sense of independence may mean that your teenager would want to travel interstate or internationally with his mates and without you. Until now, you have probably looked after all his factor supplies and organised his treatment needs. Though it may be nerve-wrecking, it is important that you allow your teenager the same opportunities as his non-haemophilic peers with respect to social activities, and other lifestyle choices.

WHAT YOU CAN DO TO SUPPORT YOUR TEENAGER

Modify your parenting approach

Your approach to parenting needs to change as your child matures. To help your teenager move towards greater independence and take up more responsibility, you need to take time to listen to their views, understand the feelings that are driving their behaviours and if need be, direct them to achieve their personal goals using a safe route. Help them to make informed decisions by pointing out the consequences of the different options and raise your concerns for any risky behaviours.

Maintain strong family support

In spite of everything, strong family bonds are still important for young

people and it has been shown that good family relationships and support are protective factors against risky behaviours. You can help to build strong ties within the family and the extended family. Continue to assure your teenager that you love and cherish him and that you would be available to provide advice if he is stuck. The family acts as a secure base for the teenager to venture into the unknown.

Set clear boundaries

As with other important issues, it is imperative that you set clear boundaries for your teenager, and stand firm on what you will permit and what you will not. This is extremely important in terms of setting a good foundation for your teenager to take full responsibility for his treatment when he reaches adulthood.

Start young

As early as possible, get your teenager to be involved in his treatment. This could be as simple as mixing his factor, writing in his treatment diary or if relevant, getting him skilled in self-infusion. Education, encouragement, positive feedback and active participation in treatment by your teenager can support the perception that treatment is a normal way of life for him.

Initiate discussion about haemophilia

This would be a good time to start initiating discussion about sexual health and the inheritance of haemophilia. It is also important to help your teenager express his feelings and concerns about having haemophilia. There may be a need to assess and reinforce your teenager's understanding the treatment regimen. If your teenager wants to travel, get him involved in the planning. Contact your local Haemophilia Treatment Centre and discuss his proposed travel plans with them. Help your teenager to organise the necessary supplies, information and paperwork.

Emphasis importance of treatment adherence

The tendency of teenagers to focus primarily on short-term goals increases the likelihood that regular prophylactic replacement therapy receives low priority in the light of other competing demands. Research shows that the most important factor that influences adherence is support from parents, peers and caregivers, who provide encouragement and support active participation in health care management. As a parent, you are in a good position to implement personalised treatment strategies that suit your teenager and his lifestyle (eg, schedule prophylactic treatment prior to planned physical or social activities).

Encourage physical activity

Physical activity is important for everyone and can contribute to better coordination, endurance, flexibility and strength. In terms of haemophilia, it also contributes to healthier joints and reduces the risk of bleeding episodes. However, an orthopaedic examination, fitness check and motion analysis may be necessary in order to choose an appropriate sport that minimises risk of injury and matches your teenager's skills, interests and needs. Normal body weight also contributes to a healthy self-esteem and social adaptation.

Seek help

If you are having problems with your teenager over a prolonged period of time, you may need to get extra support from family, friends or seek professional help. For haemophilia-related concerns, approach your local Haemophilia Treatment Centre. The Haemophilia Treatment Centre team is there to support you and your family.

Information for this article was taken from the following sources:

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This article has been adapted from an article published in *Bloodline*, Volume 39, Number 2, June 2011, the magazine of Haemophilia Foundation New Zealand, and is reprinted with permission

Ian d'Young is the Haemophilia Physiotherapy Practitioner at the Auckland District Health Board and is the national clinical lead for haemophilia physiotherapy. He is co-chair of the Australia-New Zealand Haemophilia Physiotherapy Group (ANZHPG)

Kerry McIlroy is a Charge Dietician at the Auckland District Health Board and is the president of the Australasian Society for Parenteral and Enteral Nutrition

WEIGHT MANAGEMENT

Ian d'Young with Kerry McIlroy

Weight gain is a growing problem!

The number of people who are overweight or obese is a growing worldwide problem, particularly in developed countries. Being overweight or obese is strongly associated with many serious health problems, such as heart disease, some common cancers, diabetes, respiratory diseases, stroke and osteoarthritis, and greatly reduces quality of life [1-5].

Australia has one of the highest levels of people who are overweight or obese among developed countries[1]. In 2007-8 the Australian National Health Survey found that the number of people who were overweight or obese had grown to 68% of men and 55% of women. Among children and adolescents, 26% of boys and 24% of girls were classified as overweight or obese[3].

'Obesity' and 'Overweight' are calculated using the Body Mass Index (BMI). While not a perfect measure of obesity, it is considered to be a useful measure for the general population. The BMI is a simple calculation of height vs weight. For adults, a BMI of between 25-29.9 kg m^{-2} (weight divided by height squared) is considered to be overweight, while a BMI over 30 kg m^{-2} is considered obese[4].

WEIGHT AND HAEMOPHILIA

Since the introduction of effective factor replacement therapy, recombinant products and prophylaxis, the life expectancy of people with haemophilia (PWH) has increased dramatically. In 1939, the life expectancy of PWH in industrialised countries was just 7.8 years, compared to over 70 years by 2001[5]. Unfortunately, the down-side of this increased longevity is the increased incidence of overweight and obesity and associated conditions such as high blood pressure, high cholesterol, type II diabetes and osteoporosis, as well as the arthritic changes in joints that characterise a history of haemophilic bleeding.

Rates of overweight and obesity have therefore grown hugely over recent decades in PWH. In the Netherlands, in the ten years between 1991 and 2001 the prevalence of overweight PWH increased from 27% to 35%, while the prevalence of obesity in men with haemophilia doubled from 4% to 8%[6].

By 2010 in the state of Mississippi in the United States alone, 51% of PWH were classed as being overweight or obese. In adults above the age of 20 years, 36% were obese, while a further 32% were classed as overweight. In adolescents between 5 and 19 years of age, these figures were 21% and 16% respectively[4].

Impact of obesity: the joints

As we all know, bleeding into joints causes arthritic damage, known as a 'haemophilic arthropathy'. Joints do not normally contain blood, and the exposure of the joint surfaces to blood and the iron it contains mediates a rapid destructive process, resulting in arthritis. Haemophilic arthropathy is therefore often referred to as 'blood-induced joint damage'.

Joint damage in haemophilia is directly proportional to the number of bleeds that have affected the joint. Any issue that increases the risk of a joint bleed, or aggravates joint damage present due to previous bleeding is therefore a major problem. The heavier a PWH is, the more load is placed on the joints, and the more the joints are subject to bleeding episodes[7,8]. Arthritic joint damage related to previous bleeding episodes is also further aggravated by obesity[8]. The joints of overweight or obese PWH must cope with greater loads, muscles tend to be weaker, and balance and coordination are poorer relative to more active PWH, therefore leading to a higher risk of joint bleeds and accelerated arthritis[7,8,9].

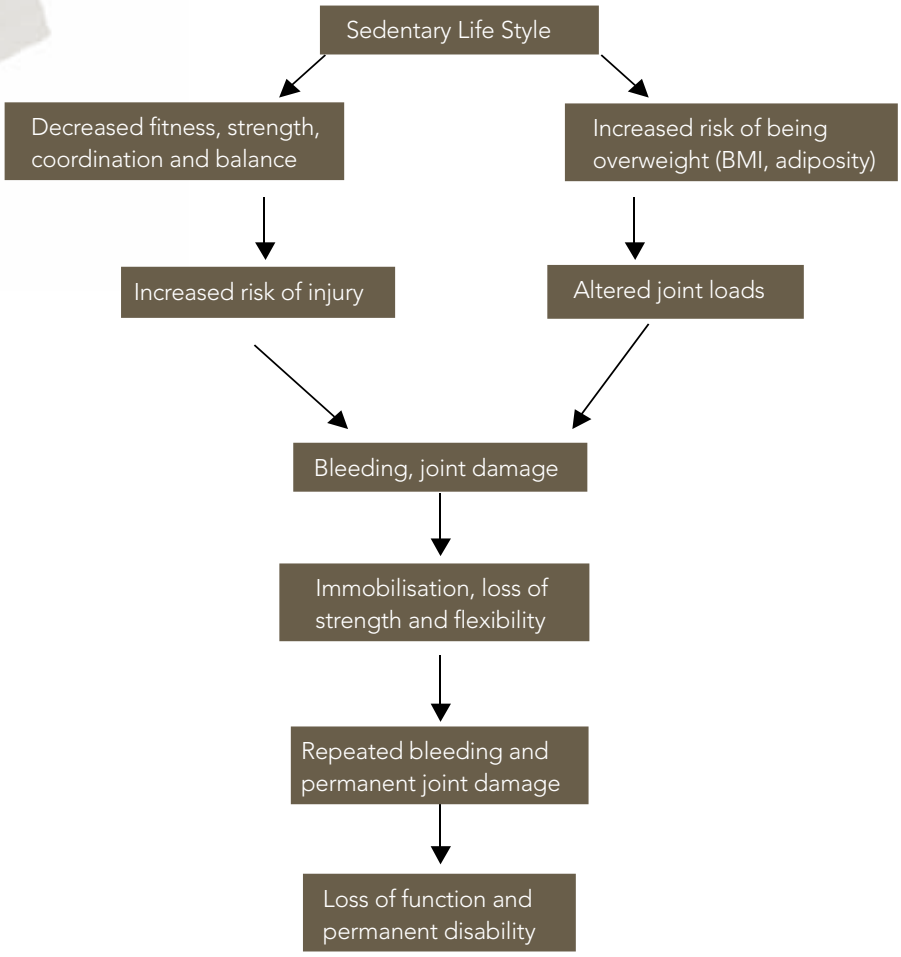
The prevalence of arthritis or haemophilic arthropathy also appears to be greater in obese PWH. A recent Dutch study indicated that up to one third of obese PWH had significant arthritis, compared to just one fifth of PWH with a relatively normal weight[8].

The amount of body fat (or 'adiposity') is also associated with decreased joint mobility. Recent research from the United States indicates that excess body adiposity accelerates the loss of movement in the weight-bearing joints of the lower limbs such as the knees and ankles[10]. PWH with higher adiposity also tend to lose joint flexibility at a much faster rate than their healthy-weight peers. The authors of this American study concluded that this was due to greater mechanical stress being

placed on the joints, resulting in both damage to the connective tissue surrounding the joint and structural damage to the joint itself[10].

Consider this example: When you walk on level ground, you take up to 4x your body weight in loading through your knee joint in a normal situation. When you walk downhill, you take at least 8x your body weight through your knee joints normally. If you are 10kg overweight, that is an extra 80kg load through the knee joints with every downhill step[11,12]. That is a lot of extra load! Joints tend to wear out faster if they have to carry a lot of extra load.

A theoretical framework for the impact of an inactive, sedentary lifestyle and obesity has been proposed by two leading Canadian Haemophilia clinicians[7]:



Adapted from: Wittmeier K, Mulder K. Enhancing lifestyle for individuals with haemophilia through physical activity and exercise: the role of physiotherapy. Haemophilia. 2007; 13 (suppl. 2): 31-37

Inactivity and poor diet leads to weight gain

Obesity is caused, in part, by a poor diet and an inactive lifestyle[7]. A sedentary, inactive lifestyle (ie, people who sit around a lot) is linked to decreased strength, balance and coordination, and this increases the risk of injury and bleeding in PWH. 'Couch potatoes' are thought to be at a much greater risk of having a joint or muscle bleed than their healthy-weight peers[7].

What is interesting from the recent Mississippi study is that no PWH under the age of 5 were obese, even though a significant proportion were by late adolescence. This suggests that an increasingly sedentary lifestyle during the adolescent period is associated with excess weight gain, and this weight gain tends to be independent of the severity of haemophilia[4]. Coinciding with this excessive weight gain is the fact that a significant proportion of school-aged PWH spend most of their leisure time engaged in watching TV or playing video games[13], rather than engaging in physical activity.

Cost impact of overweight and obesity

Overweight and obesity is not just a problem that influences joint bleeding and arthritis. Because the dosage recommendation of factor VIII or IX for PWH is calculated by weight in kilograms, the greater the prevalence of overweight or obese PWH, the higher the costs involved with treatment[14].

In the United States, a recent study examined the projected yearly costs of prophylactic and on-demand factor replacement therapy based on a person's ideal body weight, and compared this to the costs involved with the patient's actual body weight. Not surprisingly, the greater the weight difference between 'ideal' and 'actual' body weights, the higher the cost difference[14].

For the 20 children and adolescents in the study, in one year only, if each overweight or obese subject was at their ideal body weight, their cost of treatment would be reduced by around US$2 million. While the cost of treating obese children on average was more than US$1.3 million, this fell to US$325,000 for neither overweight nor obese children[14]. That is a huge difference! Other studies have shown similar results. In the Netherlands, for the years 2008 and 2009, the mean FVIII usage for obese PWH was more than double that of their healthy weight peers[8].

Physical activity is essential

Prior to the advent of effective prophylaxis and factor replacement therapy, most children were actively discouraged from physical activity due to the perceived risk of bleeding[15,16]. What is now clear is that exercise and physical activity are very important for PWH. Physical activity is an essential element of weight control, alongside a sensible diet, and helps to improve muscle strength, coordination, flexibility and balance, therefore minimising the risk of muscle and joint bleeding episodes[17,18].

Exercise and physical activity also improve fitness (or 'aerobic capacity'), increase circulating clotting factor and, especially when commenced before the onset of puberty, decreases fat mass[7]. Adults who are overweight who increase their level of physical activity have reduced rates of mortality and increased longevity relative to inactive adults[7].

What is also important to note is that in order to get and then maintain the benefits of exercise, physical activity needs to be regular and consistent[7]. Young people should participate in at least 60 minutes of daily activity and adults for at least 30 minutes per day in order to accrue the health benefits of exercise. Activity can be accumulated in periods of 5-10 minutes or as continuous sessions[7], and can comprise of a variety of activities – a brisk walk here, a swim there. Every little bit counts.

Maintaining fitness after a bleed

Maintaining appropriate levels of daily activity when there has been a bleed can be a big challenge for physiotherapists as well as PWH. During periods of inactivity, for example when recovering from a bleed, the physiotherapist must take into account the need to rest the affected joint or muscle, while maintaining fitness, strength and flexibility in other parts of the body.

If this does not happen, a vicious cycle of inactivity, loss of aerobic capacity (fitness), and muscle weakness occurs and this may lead to further injury and bleeding episodes[7]. So exercise is very important, even when you are recovering from a bleed, but it needs to be the right sort of exercise and appropriate to each person's specific needs.

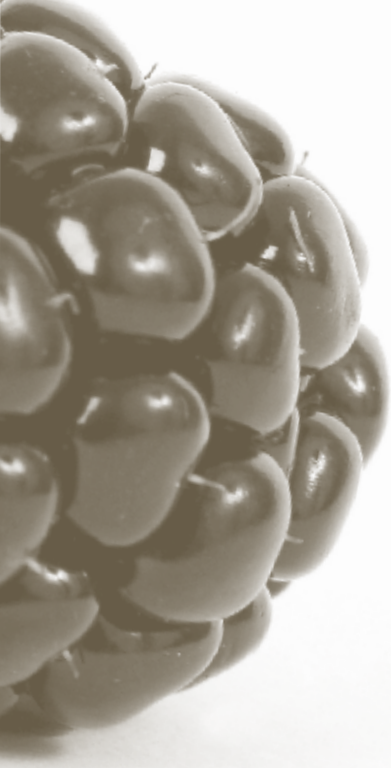
If you have had a bleed or injury recently, it is important that you see your physiotherapist to make sure that you are ready to get started on a new exercise or activity. Remember your exercise program will be different when you are recovering from a bleed compared to when you are getting fit or playing sport. It is very important that you talk to your physiotherapist and rehabilitate the bleed properly before starting a new sport or exercise. Remember, doing too much too early can lead to another bleed. You will need to start at a gentle level of exercise and gradually increase this as your body recovers after a bleeding episode. Forget the idea 'no pain no gain'! It's 'NO GAIN WITH PAIN'[7], so remember to tell your physiotherapist if an exercise is painful or if you are becoming tired or sore.

If you have some pre-existing joint damage related to a prior history of bleeding, your exercise program will need to be gentle on the joints that are affected. Your exercise program will therefore ideally be 'low impact' and 'low resistance'. This means that while you will get fitter, strengthen the muscles and improve the balance around a joint, you will not be placing too much extra load on the arthritic joint surfaces themselves. For example, when you are looking to improve your general fitness, your physiotherapist might suggest swimming, the cross trainer and the bike as good ways to improve your stamina, rather than running on a treadmill or pounding the pavements.

Remember, every person is different and every person may react differently to a type of sport or exercise, so it is important that you listen to your body. If you notice a bleed every time you ride your bike or go for a run, your body is telling you that this is not the right type of exercise for you. Listen! Talk to your physiotherapist about alternative sports or activities.

Type of Activity	*Calories used in 30 mins	Food eqivalent
Brisk Walking	120	1 banana
Cycling	140	4 pieces of sushi
Swimming	200	1 small pizza slice
Running	400	1 large cookie

*Approximate amount of calories used depends on body size.
* One calorie =4.25kilojoules



WEIGHT CONTROL

If you have a weight problem, it is best tackled by changing your eating patterns and choosing healthier foods that are life long choices, rather than seeing weight loss as a short term fix. To lose weight, the energy (as calories) consumed as food has to be lower than the energy expended as exercise – the concept is very much like a car and fuel usage. As with a car, the bigger the person, the more fuel (energy) they need to maintain their weight. They will also expend more energy when exercising.

Ideally it is advisable to reduce both energy intake and increase energy output in the form of exercise to manage weight loss. Energy intake is determined by:

- Number of calories or kilojoules in our daily intake of food and fluids
- Portion or serve size of foods and fluids we consume
- How often these are eaten

When looking to lose weight

- Aim to lose 0.5 - 1.0kg per week. Weigh yourself once a week to view your progress
- Don't diet but make lifestyle choices about exercise and eating that are long lasting.
- Aim for at least 30 minutes of exercise a day

Top tips for sensible weight control

- Choose an exercise you enjoy, otherwise it will be a chore you will give up.
- Keep a food diary and write down all you eat and drink. This makes you very aware of what you are eating and the quantities consumed.
- Eating breakfast kick-starts your metabolism.
- Sit at a table to have your meals.
- Reduce your portion sizes, for example 2 small midloin chops rather than 3 or 4.
- Be careful with sweet drinks and alcohol. These add calories without filling you up.
- Water has no calories so foods with high water content have a lower calorie value.
- Fat has double the energy of protein or carbohydrate – foods with a high fat content have more calories.
- Keep your intake of fats/oils at a minimum and avoid fatty foods such as fish and chips
- Remove fat from meat and skin from chicken before cooking.
- Use lower fat varieties of dairy products such as trim milk, low fat yoghurt or cottage cheese.

HAEMOPHILIA AWARENESS WEEK 2011

Haemophilia Awareness Week (HAW) is an opportunity for haemophilia foundations and other organisations, as well as individuals and families to take part in a campaign and activities to raise awareness about haemophilia and related inherited bleeding disorders throughout Australia. This year, the week of 9 – 15 October has been set aside and we encourage all our supporters to participate.

The Awareness Week theme is based on the Sydney Conference theme– *Health and wellbeing into the future– the decade ahead*.

Small promotional items will be available for distribution and HFA will publish the HAW newsletter which was introduced in 2010 and was successful in sharing information about bleeding disorders with the community. The newsletter will explore the Awareness Week theme and will be suitable for the bleeding disorders community as well as other interested to learn more about living with bleeding disorders.

For further information about Haemophilia Awareness Week or to order promotional items, please contact the HFA office 03 9885 7800 or email hfaust@haemophilia.org.au

9-15 Oct

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- Eat slowly, have three meals a day and use fruit and vegetables as snacks. One apple is the equivalent of 60 calories but one chocolate caramel bar [70gms] equates to 410 calories, with a small packet of potato crisps [50gms] 260 calories
- Add vegetables and fruit to dishes to make filling, lower calorie meals. Add canned tomatoes, corn, beans or other vegetables to mince and casserole dishes.
- Try stir-fries and use 3-4 times more vegetables than meat or chicken and use different herbs and spices to add favour.
- Keep a shopping list when you go to the supermarket so you are not tempted to buy 'non-healthy' foods.
- Remember treats are acceptable as long as they are not a regular part of the diet. Try including a dessert once a fortnight rather than daily.

Useful websites

Here are some useful websites where you can go to find out more about sensible weight loss:

Weight management - www.nlm.nih.gov/medlineplus/ency/article/001943.htm

The Australian guide to healthy eating - www.health.gov.au/internet/main/publishing.nsf/Content/health-pubhlth-publicat-document-fdcons-cnt.htm

SparkPeople
(free US-based weight loss program) - www.sparkpeople.com

Weight Watchers - www.weightwatchers.com.au

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NEW ONLINE HEMOACTION GAMES

Children around the world can now learn about haemophilia in the language they know best: play! The HemoAction games, developed by the World Federation of Hemophilia (WFH), have recently been launched on CD ROM and on their own interactive web site. Players embark on their very own "haemophilia adventure", and learn more about preventing bleeds and managing haemophilia while they test their knowledge about the clotting process, types of bleeds, factor infusions, and suitable physical activities. The focus, however, is on fun and the games are easy to understand and interactive.

The games can also be used by parents, nurses, and other healthcare providers to reinforce key concepts about the disease and its management. "As they learn more, players can challenge themselves with higher levels of difficulty in each of the games," says Elizabeth Myles, WFH Director of Communications and Public Policy. "Children learn not to be afraid of factor infusions and gain confidence and self-worth through educational play."

The CD-ROM of the HemoAction games can be ordered through WFH. To play online, visit www.hemoaction.org.

Dr Megan Sarson is Project Officer for Australian Haemophilia Centre Director's Organisation (AHCDO). AHCDO members are clinical directors at Haemophilia Centres around Australia.

HAEMOPHILIA CLINICAL TRIALS

Dr Megan Sarson

Recently HFA has developed a new on line resource which aims to facilitate consumer decisions about participating in clinical trials. The resource describes what 'research' is, looking individually at clinical research, social research and market research and explains what consumers should ask themselves before agreeing to participate in research studies and also how they can ask a question or make a complaint about a research study they are involved in.

AHCDO encourages its members to conduct clinical trials as one of our core objectives is to promote haemophilia research, and to disseminate the results of such research. Currently there are several clinical trials of particular interest to the haemophilia community; however their inclusion and description here should not be seen as an official endorsement by either AHCDO or HFA.

Some Australian patients are involved in the following clinical trials:

B-LONG: An Open-Label, Multicenter Evaluation of the Safety, Pharmacokinetics, and Efficacy of Recombinant, Long-acting Coagulation Factor IX Fc Fusion Protein (rFIXFc) in the Prevention and Treatment of Bleeding in Previously Treated Subjects With Haemophilia B

Study description: The current haemophilia standard of care for the prevention of bleeds and arthropathy is to maintain FIX activity level above 1%. Due to the short half-life of the current FIX products, prophylaxis therapy will require injection of 2-3 times per week. Treatment usually involves intravenous access, an invasive procedure, especially difficult in children. Episodic treatment will involve 1-3 injections to treat bleeding episodes, depending on the severity of the hemorrhage. In this trial severe haemophilia patients are treated prophylactically with the long-lasting recombinant factor IX Fc fusion protein (rFIXFc) in an interval to maintain FIX activity level for the prevention of bleeds. Any bleeding episodes are reported and the response to treatment is also recorded to access the effectiveness of the rFIXFc.

A-LONG: An Open-label, Multicenter Evaluation of the Safety, Pharmacokinetics, and Efficacy of Recombinant Factor VIII Fc Fusion (rFVIIIFc) in the Prevention and Treatment of Bleeding in Previously Treated Subjects With Severe Haemophilia A

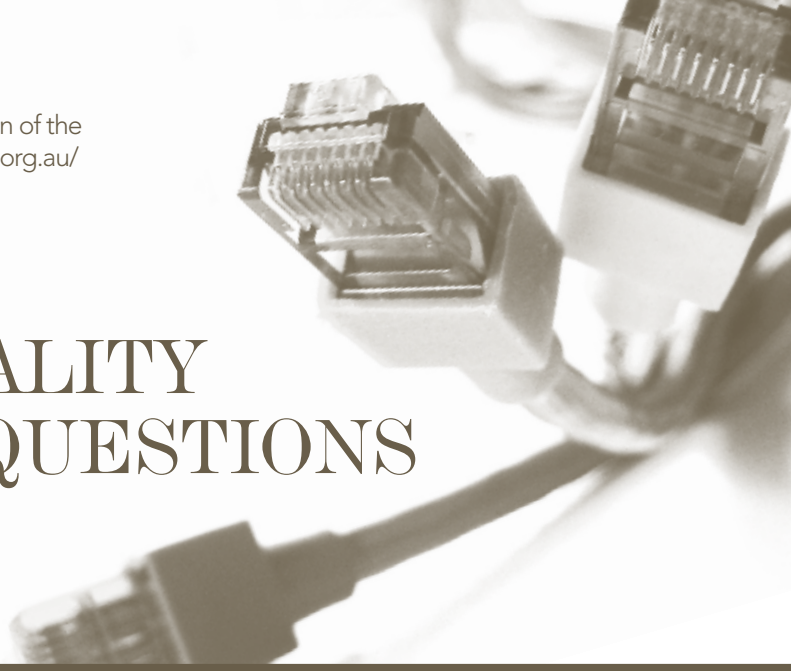
This study's objectives are to evaluate the safety and tolerability of rFVIIIFc, which will be measured by evaluating clinically notable changes from baseline in physical examinations, vital signs, lab values, and incidence of adverse events and inhibitor development.

The study will also assess the potential of rFVIIIFc to enable protection from bleeding by evaluating the number of both spontaneous and traumatic bleeding episodes in each treatment arm.

Females With Severe or Moderate Haemophilia A or B: an International Multi-center Study

The study involves two questionnaires: one on the diagnosis, symptoms, complications and treatment of each participant to be completed by a staff member; the other is a questionnaire to be completed by the participant on how the disease has affected her life. Finally, for those participants who have not previously had genetic testing, the third part of the study is an optional blood test to determine the genetic cause, what change in the factor VIII or factor IX gene, caused the haemophilia. The test results will be available to those participants who wish to learn their results. A data base will be compiled to examine the connection between the genetic cause of haemophilia and the course and symptoms of the disease.

This article was first published in the *Be Medicinewise* section of the National Prescribing Service (NPS) web site (http://www.nps.org.au/bemedicinewise/medicinewise_choices).



IS IT A GOOD-QUALITY WEBSITE? FIVE QUESTIONS TO ASK

In the recent HFA National Survey, 65% of people said when they had a question about bleeding disorders, they found the information on the internet. But a common problem we often experience is how to know whether the information on the internet is reliable or relevant to us. Is the information we are reading just someone's opinion? Or trying to sell us a product? Or is it from another country and not relevant to the Australian health system or our medicines?

The National Prescribing Service (NPS) has developed 5 questions to help you evaluate web sites.

Here are some questions to ask to help you decide if the medical or health information you find on the internet is what you need — accurate, unbiased and up-to-date.

1. Who is providing the information?

Is it clear who is providing the information? Also, who funds the website? If it is not clear, beware. If the website is run by a government authority, an independent body, a professional organisation or support body, the information is more likely to be reliable and of good quality.

Check to see if the website and the organisation linked with it is Australian. If not, some of the information provided might not be relevant to you.

2. Is the information biased?

Websites exist for a purpose — for example, to provide information, to sell a product or to tell the world about the theories of their contributors. Knowing the purpose of a website helps you judge the information it provides. Sites that provide information, without selling a product, will probably give you more balanced advice.

3. Does it promise too much?

The best information is based on evidence, not belief. The best information also acknowledges that all treatments have both positives and negatives, and that the outcome of treatments cannot be guaranteed. Warning signs to watch out for include:

- Promises that the medicine will be effective for everyone
- Promises of instant cures
- Promises of miracle recoveries
- Words like 'breakthrough', 'secret ingredient', 'scientific research' (without saying what that research showed) or 'side-effect free'
- Requests for payment.

4. Is the information up to date?

Look for dates on web pages. This is more important for some information than for others. General information about an illness and its causes may not change much in 2 or 3 years, but information about its treatment may well change within that time. Links are another clue: a lot of broken links suggest a website is out of date.

5. Are the links of good quality?

Most websites link to other sites. Have a look at some of these links. If a website you're interested in links to sites you assess to be good quality, then it reflects well. If its links are to websites that don't meet your quality standards, then this reflects badly.

For more tips on finding good quality information about medicines, visit the Medicinewise Choices section of the National Prescribing Service (NPS) web site **www.nps.org.au/medicinewisechoices**

Suzanne O'Callaghan is Policy Officer, Haemophilia Foundation Australia

HEPATITIS C TREATMENT NEWS

Suzanne O'Callaghan

"The good news is that the results of treatment continue to improve."

At the recent US and European liver diseases conferences there was great excitement at the release of data on two new triple combination treatments for hepatitis C genotype 1. The new treatments have added either telaprevir or boceprevir, hepatitis C protease inhibitors, to the combination: these are the most advanced of a new group of therapeutic agents known as "direct acting antivirals", oral medicines that are the first to be successful in targeting the hepatitis C virus (HCV) directly.

In the triple combination treatment studies either telaprevir or boceprevir was added to pegylated interferon and ribavirin, which is the current standard therapy for hepatitis C. However, some studies have now started testing combinations of direct acting antivirals without interferon. This is an important new stage of treatment development for hepatitis C therapy, especially for people who have not had success with interferon-based treatments or have found the interferon side-effects too hard to tolerate.

Some studies are also evaluating other types of direct acting antivirals such as polymerase inhibitors or NS5A inhibitors, which may be more successful for people with HCV genotypes 2 or 3 – protease inhibitors such as telaprevir or boceprevir have not been as effective for these genotypes. However, this research needs to progress carefully as there is potential for some direct acting antivirals, particularly protease inhibitors, to develop resistance.

Overall people with HCV genotype 1 have had less success with the current standard hepatitis C therapy than people with genotypes 2 or 3. The results of large international clinical trials presented at the conferences was good news for people with genotype 1. They showed that both people with genotype 1 who had previously had unsuccessful treatment and those who had never had treatment were significantly more likely to achieve a cure with the triple combination therapies that included telaprevir or boceprevir.

There were some cautions. Both telaprevir and boceprevir may cause additional side effects in some people, such as skin reactions, rash or anaemia. However, the study results also highlighted other benefits. If people have a very good initial response to treatment, they may be able to finish treatment at 24 weeks rather than completing the full 48 week course of treatment.

"The concern for people with hepatitis C 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," explained 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."

With convincing results from large-scale international studies, the US Food and Drug Administration (FDA) fast-tracked the approval of the new experimental treatments telaprevir and boceprevir in May 2011. Both treatments are currently undergoing evaluation for licensing in Europe and the UK. The Pharmaceutical Benefits Advisory Committee (PBAC) is considering whether to approve boceprevir for use in Australia at its July 2011 meeting and it is likely that the pharmaceutical company involved with telaprevir will also seek approval with PBAC.

A SAMPLE OF THE STUDY RESULTS

The REALIZE and the RESPOND-2 studies presented their treatment results at the 2011 Meeting of the European Association for the Study of the Liver (EASL). These are two major investigations into the safety and efficacy of the new treatments for people with genotype 1 who have previously had unsuccessful treatment.

REALIZE study – telaprevir combination therapy vs current standard treatment in people whose prior hepatitis C treatment was unsuccessful

Source: Zeuzem, S et al. REALIZE trial final results: telaprevir-based regimen for genotype 1 hepatitis c virus infection in patients with prior null response, partial response or relapse to peginterferon/ribavirin [abstract]. Journal of Hepatology 2011;54:S3

Sustained Viral Response in different treatment groups (SVR = cure)			
	Prior relapsers (previously had undetectable virus at end of treatment, but had detectable virus in follow-up)	**Prior partial responders** (previously had a treatment response at week 12, but virus was still detectable at week 24)	**Prior null responders** (previously did not have treatment response at week 24)
Telaprevir/ Peg interferon/ ribavirin	83%	59%	29%
Peg interferon/ ribavirin	24%	15%	5%

RESPOND-2 study – boceprevir combination therapy vs current standard treatment in people whose prior hepatitis C treatment was unsuccessful

Source: Bacon, BR et al. Boceprevir for previously treated chronic HCV genotype 1 infection. New England Journal of Medicine 2011; 364; 1207-17.

Sustained Viral Response in different treatment groups (SVR = cure)		
	Prior relapsers (previously had undetectable virus at end of treatment, but had detectable virus in follow-up)	Prior partial responders (previously had a treatment response at week 12, but virus was still detectable at week 24)
Boceprevir/ Peg interferon/ ribavirin	75%	52%
Peg interferon/ ribavirin	29%	7%

FURTHER READING

Hepatitis NSW. Hepatitis C factsheets: Emerging Treatments (March 2011) - www.hep.org.au/documents/factsheets/TreatmentsNew2011.pdf

The following article was published in *Positive Living*, September 2010, the magazine of the National Association of People Living with HIV/AIDS (NAPWA), and is reprinted with permission. Adrian Ogier is the Editor of *Positive Living*.

PREPARING OURSELVES FOR THE FUTURE

Adrian Ogier

In ten years time over half of Australia's positive population will be over the age of 55. What this means exactly for the community, ageing and health sectors is something 60 agency representatives from around the country came together to discuss at NAPWA's recent think tank on 'HIV & Ageing'.

David Menadue's personal reflections set a human tone for the day. As someone living with HIV into his fifties, David counted off the conditions he has collected in recent years – diabetes, risk of cardiovascular disease, early stage kidney disease, bone and joint problems, gout. These complications and their apparent cascading effect is something Edwina Wright, infectious diseases specialist from The Alfred, touched on in her clinical overview. Having HIV does put you at greater risk of contracting a range of non-AIDS related conditions as you get older. And having one increases the chances of you getting another.

In separate presentations, John Murray and James Jansson, both from the National Centre in HIV Epidemiology and Clinical Research, and Jeffrey Grierson, from the Australian Research Centre in Sex, Health and Society, provided a variety of comprehensive data on older PLHIV: the later in life someone is diagnosed the more likely they are to have lower CD4 counts; the older you get, the more likely you are to be living in regional centres rather than cities; more PLHIV have left New South Wales and Victoria and moved to Queensland; older PLHIV use fewer psychiatric drugs yet access more support than younger PLHIV; the older you are, the less sex you get.

It was good to hear how well many people with HIV are doing.

Wilo Muwadda alluded to this in his Welcome to Country when he talked about the glowing health of many of his positive Aboriginal peers. The truth is that many of us are taking better care of ourselves because of our condition. PLHIV tend to go to the doctor for regular health monitoring and this allows our clinicians to more efficiently screen us for and manage any conditions earlier – particularly the 'over-fifty' ones such as prostate and bowel cancer. As well, we are more prone to the reminders to stop smoking, eat less animal fats, exercise more and drink less alcohol. All of which do have a profound positive impact on life-expectancy regardless of serostatus. And the constant reminding does appear to have a positive compounding effect.

The fact that many positive people still smoke is a phenomenon that cannot be addressed simply, as Dr Wright pointed out. If the positive community is to tackle smoking as well as alcohol and diet issues, we need to take both a creative and a realistic approach, she says.

We must ask ourselves what is important, and if it is health, then we should embrace the changes we need to make. Also, if we are to expect our HIV doctor to manage our complexities then we must strive to be candid with them about what is going on in our lives. In short, we need to take firmer control of our health and work more closely with our health professionals.

But how well-equipped is our health system to cope with what sometimes seems like an endless list of possible complications? And are the community and ageing sectors prepared for an onslaught of older PLHIV? Clearly, cooperation between all three is needed. This kind of collaboration was described by the partnership in Queensland. Simon O'Connor (QPP), Paul Martin (QAHC) and Gary Boddy (Queensland Health) detailed efforts occurring there to better understand the nature and implications of their ageing positive population. This was particularly pertinent as John Murray had earlier provided compelling evidence of the migration to Queensland of many HIV positive people.

In the afternoon of the think tank, we broke into three discussion streams to examine various fictional case-studies focussing on the psycho-social issues, policy or clinical dimensions, respectively. Each group fed back discussions to a lead rapporteur and a final summary was provided that sorted the various themes into implications for services, people and what planning needs to occur in order to improve future options.

As we age, HIV may continue to confound and to complicate. Fortunately, as this day attested, we have a dedicated bunch of professionals working in the sector to help us face whatever may lie ahead.

This article is adapted from an article previously published in *Hemophilia News*, Wednesday 14 July 2010, the official newspaper of the 2010 WFH World Congress, and is reprinted with permission.

AGEING WITH BLEEDING DISORDERS

At Hemophilia 2010, the World Federation of Hemophilia World Congress, Dr Gerry Dolan of the UK's Nottingham Haemophilia Comprehensive Care Centre outlined some of the challenges ahead for people with bleeding disorders as they age and the Haemophilia Centres that provide their care.

The bleeding disorders community is beginning to face the same challenges as the general population, as improved treatments and longer life spans bring problems of ageing to the forefront of haemophilia care.

"The fact that we're having a debate in the first place is actually a major triumph," Gerry Dolan explained in a World Congress plenary. "In the past, many of our patients never made it to middle or older age."

But haemophilia practitioners "have to look at what we really mean by comprehensive care, to make sure our patients receive the standard of care afforded to the general population" in different countries.

He added that an ageing population with bleeding disorders will use substantially more factor concentrate, making it "relatively urgent that we do the economic modelling to prepare for this. Because one thing all providers in healthcare finance hate is a nasty surprise."

Although the limited available research has been plagued by methodological issues, Dr. Dolan gave an overview of the new health issues people with haemophilia will face as they age. Heart disease, cancer, kidney failure, and osteoporosis all increase with age, so that 77% of seniors over 65 have two or more chronic conditions, but "we have very little experience managing multiple medical conditions in our older patients with haemophilia."

One study of 1,805 patients with severe haemophilia A also pointed to a gradual increase in inhibitors as people age. The incidence of inhibitors peaks in the youngest age groups, falls off in early adulthood, then gradually increases from 1.67 per thousand cases in the 40-49 age group to 8.89 in people over 70. Dr. Dolan said the study raised the "intriguing question" of whether the risk of inhibitors increases with age, why that should be, and whether continuing prophylaxis can prevent the problem. At present, "we don't really know."

The limited epidemiological data on cardiovascular disease in people with haemophilia has yielded mixed results, but the markers and objective evidence seem to indicate minimal differences in atherosclerosis between test subjects with and without haemophilia. "My conclusion, and that of others, is that haemophilia does not protect the patient from the underlying mechanisms of atherosclerosis."

Hypertension may increase with haemophilia, possibly due to renal factors and probably as a result of obesity and smoking. "You add age to that equation, and you're immediately looking at significant cardiovascular risk."

Mature haemophilia patients are at particular risk during intensive replacement, suggesting that continuous infusions may be needed during surgeries to avoid peaks of factor VIII.

One question that still needs to be investigated, said Dr. Dolan, is whether older people with haemophilia are receiving the same prevention and health promotion services that are available to the general population. To help with advocacy for such services, more data needs to be collected on the magnitude of their age-related problems.

Sharon Caris is Executive Director, Haemophilia Foundation Australia

JOURNEY AROUND THE WORLD

Sharon Caris

This program was developed by the World Federation of Hemophilia USA (WFH USA) in 2010 to help raise awareness of the needs of people with bleeding disorders in different parts of the world. The activity is a suitable activity for people of all ages at family camps and will help them learn about the different care and treatment in a selection of developed and developing world countries. It is a great way for people to get to know one another and to participate in a low key, fun activity, while at the same time learning about how haemophilia is managed in countries with limited clotting factor and in countries where treatment and care is abundant. It is a great way for both children and adults to learn and to appreciate the situation in Australia whilst at the same time understanding more about countries where treatment is different, in short supply or unavailable at all.

Participants are formed into "travel groups" and armed with an itinerary and boarding passes they set off to visit several countries. On each visit they will learn about a country, how haemophilia is treated in that country and a little about what it is like to live in that country. They will participate in activities on each country visit and after their visit their Passport will be stamped before they move on to the next country on their itinerary.

It is an easy program to run as WFH (USA) has prepared the necessary materials which can be requested in advance or downloaded and instructions for the program are clear and easy to follow. Volunteers are required to represent each country visited and assist with activities, and can easily be recruited shortly beforehand if you are running the activity during a camp. Farewell and welcome home parties can be added before and after the flights to prepare and de-brief participants. Materials can be requested from WFH (USA) in advance. However, HFA has a full set of materials which we will share with you if you would like to try it out at an upcoming family camp or weekend workshop. We will happily send you a full kit of laminated instructions and the printed materials you will need along with some spare Passports to help you start your journey.

I recently facilitated the program at the HFQ Family Weekend, and although the activity was not formally evaluated, feedback was positive. Many people commented on how valuable it was to learn more about care and treatment in other countries and noted how much they appreciate living in a country where they have access to effective treatment, a specialist haemophilia centre, and a strong patient organization.

For further information about Journey Around the World go to http://www.wfhusa.org/Summer_camps_Journey_Around_World.asp.

Contact HFA if you would like to borrow the kit – we promise it will be fun, everyone will learn something new, and it really is suited to people with bleeding disorders and their families of all ages!

The Haemophilia Foundation Australia Vision and Leadership Awards 2011 funding round is now open.

Background

The Awards were developed by Haemophilia Foundation Australia (HFA) five years ago to enable people who are affected by a bleeding disorder to seek and achieve new goals in their lives. The Awards program is funded by an education grant from Pfizer Australia.

Who can apply?

People affected by haemophilia, von Willebrand disorder and other rare inherited bleeding disorders of all ages are eligible to apply. This is a chance for you to do something you have always wanted, but not had the financial capacity to achieve.

What is it for?

It might be for an education activity or special project to enhance your personal development or career, or to attend a conference or program to enhance or develop new skills for leadership and participation in the bleeding disorders community.

What would make a difference in your life?

5 Awards of $2,000 each are available for applicants who have a bleeding disorder or who are affected by bleeding disorders in one of these categories:

- Young men and women aged 15-25
- Men or women aged 26 yrs and over

Applications must be received by HFA by 8 August 2011.

For further details and the application form see the HFA web site www.haemophilia.org.au or contact the HFA Office on ph 03 98857800 or hfaust@haemophilia.org.au.

Erl Roberts is President, Haemophilia Foundation Queensland
Suzanne O'Callaghan is Policy Officer, Haemophilia Foundation Australia

GROWING OLDER IN STYLE – ESSENTIALLY!

Suzanne O'Callaghan

Erl Roberts talks about the challenges of growing up and growing older with severe haemophilia and about the importance of taking the time to appreciate the smaller pleasures of life.

Recovering from a bleed – Erl as a teenager

For the last several years the OBEs – the Old Boys Essentially – have been meeting monthly in Queensland to catch up, talk about what's happened in their life lately, get some tips from each other about how to manage common problems and try out new places and experiences. Erl Roberts started the group to give older men with haemophilia an environment that is friendly and accessible for people with mobility issues and provides an opportunity to be proactive about their life experiences in the company of others who share the same problems.

"We come from a different era," explained Erl. "A lot of us have experienced similar things like haemophilia without treatment, so we do have a broader understanding of what haemophilia is all about and how important it is to look after yourself as much as possible - because haemophilia certainly comes back and bites you, if you've grown up when there's no treatment around."

When Erl was born there were no transfusions available for haemophilia. His oldest brother also had haemophilia, but died because of a bleeding episode when he was five years old. By the time Erl was growing up whole blood and fresh frozen plasma became available for treatment, which helped people to survive bleeding episodes but did not stop the swelling and the pain.

"So with a knee bleed, you would have a knee that was the size of a football, as hard as a rock and unbelievably sensitive and painful. I put up with the pain as long as I could day and night at home, and then ended up being taken to hospital and would get some morphine for the pain. But you couldn't move your leg; you would be out of action for months. It would take many, many weeks before the swelling went down and before the movement returned. It was nothing to be in hospital for three months or six months at a time, waiting for this to settle down and trying to get back on your feet and get your muscle strength back. It would be six months from the beginning of a bleed in the knee before you could take weight or even begin to start walking again."

Repeated bleeds into his muscles and joints caused permanent problems for Erl – shortening of the tendons in the back of his leg meant walking on his toes. An operation (when treatment to stop bleeding became available) partly corrected his problem. However; arthritis in his joints, servere stiffness and difficulties moving have always been a part of life. Like many others of his generation, his education at school was also very intermittent as he spent so much time at home or in hospital dealing with bleeds.

However, the stoicism and determination that helped him to manage the pain and get on his feet again after every bleed has also given him the resilience to take on new challenges and succeed. When Erl was in his late twenties and with the arrival of the first product to treat bleeding episodes he decided to go to adult classes and commence his secondary education which lead to university study and the commencement of a course in speech pathology.

"I decided that what I wanted out of life I was not going to get if I stayed on the pension" said Erl.

He relearned how to study and made his way through his university course "going from one end of the campus to the other at times on crutches with a bag of books. I would arrive at the lectures late, because I just couldn't get there on time, getting up stairs, etc." With determination he succeeded with his study resulting in graduating with a degree in Speech Pathology and working for 27 years.

Erl's ability to think his way around problems has stood him in good stead with overcoming some of the mobility issues related to his haemophilia. Most of his joints have been affected by arthritis caused by haemophilia and he has a serious reduction in joint movement. He has had two knee replacements, a hip replacement and a shoulder replacement and has severe arthritis in his elbows; he has also suffered a heart attack and undergone bypass surgery. Because of this there

A hard won degree - Erl graduating from university

are many things he can't do that others would take for granted: gardening, mowing the lawn, bending down to get things out of a cupboard, getting up a ladder, changing a light bulb, putting his socks on, putting a jacket on or having a soak in a bath.

Often asking others for help with simple tasks can be one way around a problem. For example, if the weather changes and Erl needs some help getting in or out of his jacket, he will ask people in the street. "People don't mind. I will say, 'Look would you mind helping me out of this' and I have never had a problem with that."

Getting a motorised scooter has revolutionised his enjoyment of life. "The scooter has made a huge difference. It's allowed me to go with my wife when she takes the dog for a walk. We can walk down the footpath - it's very different walking down the footpath compared to driving. You can meet people, you can talk to people, you can hear the birds, you can see things. I can put the scooter in the car and then take the car to the city. I can hop on trains or the City Cat, the river ferries that we have in Brisbane - so it's allowed an awful lot of mobility for me."

Other modifications help with everyday life. Erl has special rubber shoes to allow him to stand in the shower. His car has been modified with a seat rail so that that the driver's seat will go back to the back seat as his knees are stiff and he has difficulty getting into the car. "So the seat goes right back and I can then swing around and pull the seat up to the driving position and away we go."

An important part of Erl's connection with life is his involvement with advocacy with Haemophilia Foundation Queensland (of which he is currently President) and ensuring support is available for other members of the community. Erl recognises how important it is to make sure that the new generation does not experience the same problems he has had; that access to adequate treatment product is essential for preventing joint damage and should not be taken for granted: "We are in a very lucky country from that point of view and let us not forget that now."

For Erl, seeing the results of supporting and promoting the social occasions provided by Haemophilia Foundations is a great pleasure. He points out that these social occasions are major ways of allowing people to connect and learn from each other and get support – whether it is a lunch for members in regional and remote areas, or a family camp where parents of newly diagnosed children can find out how others manage or where young women who carry the gene can watch young boys with severe haemophilia running, jumping and playing and see that life for their child if it was born now with haemophilia, would be very different from their father's life: "that social contact and interaction and networking is very, very valuable".

And the OBEs continue to meet, sharing a meal along with a few jokes. And they continue to make a difference to their and other people's wellbeing - whether that is to make an outreach visit, for example to the guys with haemophilia in Toowoomba, or to find solutions for managing their day-to-day challenges.

Taking on the world – Erl on his scooter

CALENDAR

World Hepatitis Day

28 July 2011
www.loveyourliver.com.au

Haemophilia Awareness Week

9 -15 October 2011
ph 03 9885 7800
fax 03 9885 1800
email: hfaust@haemophilia.org.au
www.haemophilia.org.au

16th Australian & New Zealand Haemophilia Conference

20 - 22 October 2011

Novotel, Sydney Olympic Park, Sydney NSW

ph 03 9885 7800
fax 03 9885 1800
email: hfaust@haemophilia.org.au
www.haemophilia.org.au

WFH Congress 2012

8-12 July 2012 – Paris, France
World Federation of Hemophilia
Tel.: +1 (514) 875-7944
Fax: +1 (514) 874-8916
email: info2012@wfh.org
www wfhcongress2012.org

XXXI International Congress of the World Federation of Hemophilia

Melbourne, Australia 2014
www.wfh.org

BEYOND PROPHYLAXIS PROJECT

The Beyond Prophylaxis Project is a new HFA initiative to understand the needs of young people with bleeding disorders and enable them to connect with each other and develop life skills for the future.

HFA has recently received funding for the Project from the Commonwealth Department of Health and Ageing and a philanthropic trust and will be employing a Youth Project Officer for 12 months to get the project underway.

The Youth Project Officer will bring together a national Working Group of young people affected by bleeding disorders. The Working Group will work with the Youth Project Officer using web-based technology to create a space for young people with bleeding disorders share experiences and provide each other with peer education and support.

If you think you or someone you know would be interested in taking part in the Youth Working Group, contact HFA on 1800 807 173 or hfaust@haemophilia.org.au or let your state or territory Foundation know. More information will be available after the Youth Project Officer commences the Project.

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