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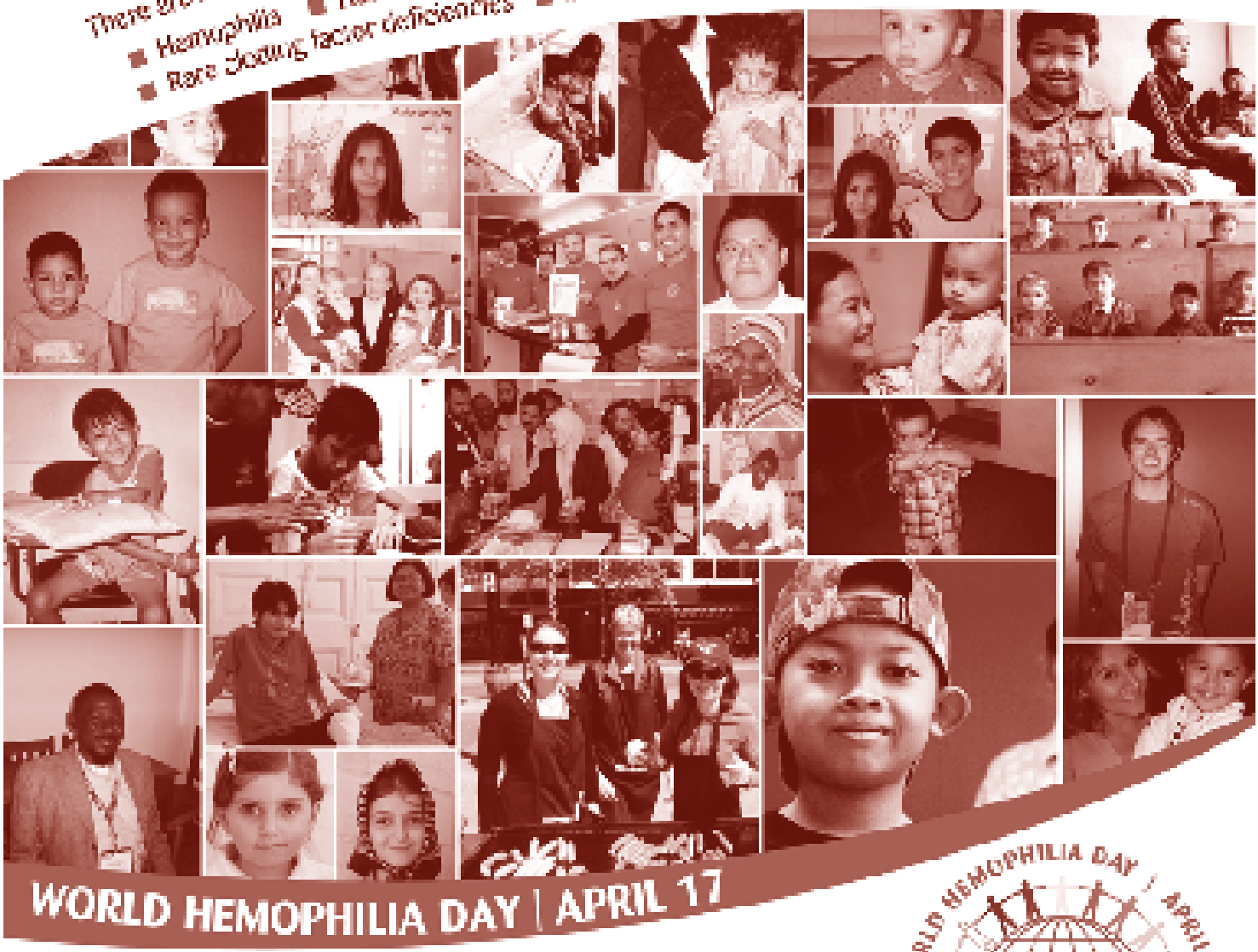
The Many Faces of Bleeding Disorders

WORLD FEDERATION OF HEMOPHILIA
Treatment for All

United to achieve Treatment for All

There are many different types of inherited bleeding disorders that affect both males and females.

- Haemophilia
- Haemophilia symptomatic carriers
- von Willebrand disease
- Rare clotting factor deficiencies
- Inherited platelet disorders



WORLD HEMOPHILIA DAY | APRIL 17

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For more information,
visit www.wfh.org/whd

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WORLD HAEMOPHILIA DAY 2010

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

This year's theme is "*The Many Faces of Bleeding Disorders: United through the WFH to achieve Treatment for All*". There are many different types of inherited bleeding disorders that affect both males and females:

- Haemophilia
- Haemophilia symptomatic carriers
- von Willebrand disorder
- Rare clotting factor deficiencies
- Inherited platelet disorders

An estimated 400,000 people worldwide are living with haemophilia. 75% of people with bleeding disorders throughout the world are undiagnosed and untreated.

On April 17, the WFH will launch "*The Many Faces of Bleeding Disorders*" video podcast. For more information, resources and the podcast launch visit WFH website www.wfh.org.

An estimated 400,000 people worldwide are living with haemophilia. 75% of people with bleeding disorders throughout the world are undiagnosed and untreated.

Sharon Caris is Executive Director, Haemophilia Foundation Australia

HEMOPHILIA 2010

Sharon Caris

Delegates from around the world will meet for the XXIX International Congress of the World Federation of Hemophilia in Buenos Aires, Argentina, from Saturday 10 July to Wednesday 14 July 2010.

It is exciting to hear that many Australians have submitted abstracts for the congress, and that others are busily making plans to attend. The Congress offers a broad program for people in the bleeding disorders community with different interests including people living with a bleeding disorder and their family members. Sessions will cover medical, multidisciplinary and laboratory science issues, with topics of special interest for people with bleeding disorders, members of national haemophilia organisations and health professionals. Have a look at the program World Congress website **www.hemophilia2010.org**.

On the Saturday before the Congress opening ceremony, delegates can participate in the very popular free Pre-Congress workshops and sessions, including sessions for specialist nurses, physiotherapists and social workers. These offer delegates valuable skills and knowledge to integrate into their own work and communities once they return home. Pre-registration is recommended.

Each Congress day includes plenary sessions led by some of the world's most distinguished researchers, physicians, and community leaders. Topics are always diverse and there will be many things to interest you personally or the people you represent.

Sharon Caris is Executive Director, Haemophilia Foundation Australia

STRENGTHENING COMMUNITIES AND SUPPORT THROUGH CAMPS

Sharon Caris

Haemophilia Foundation Australia (HFA) gratefully accepted the offer by Wyeth to support an HFA representative to attend the annual North American Camping Conference of Hemophilia Organisations (NACCHO) in February this year. Natashia Coco, Development Manager, HFA had attended NACCHO in 2007 and HFA was aware of the benefits of learning about other peer support and camp models for people affected by bleeding disorders. There is a strong camp culture in the USA where most children attend haemophilia camps regularly throughout their childhood and adolescence. Further, young people who have attended camps regularly are encouraged to become camp leaders. This is also recognised as one of the strongest ways to recruit volunteers for the various haemophilia advocacy organisations .

David Taylor, who is the President of Haemophilia Foundation New South Wales (HFNSW) and one of the HFNSW Delegates to the HFA Council, accepted our invitation to attend NACCHO. The following is an extract of his report to the HFA Board.

NACCHO *David Taylor*

The goal of the conference was to improve the camping experience for people with bleeding disorders in North America. It was attended by a number of people who operate camp facilities designed for children with chronic illnesses and those who operate specialised haemophilia camps in the United States. It is based on the idea of normalisation as the majority of American children attend a camp of some description during the June-August summer break.

Understanding this background, I was concerned that much of the information would be quite specific and indeed it was. However, I tried to

David Taylor

attend the sessions that I felt would most benefit HFNSW and HFA interests.

The camp training manual that was made available to NACCHO participants could be of great benefit to the HFA Youth Committee members for national activities and in their State Foundation work.

It is very simply set out and includes a paper based resource and then a short video (2-3 minutes) to reinforce the paper based material. Each year this organisation updates the information and has some of the leading minds in America working on it. It is pitched at 18-25 years old, but not exclusively. It would be interesting to see how the information presented can be used at the Australian camps and youth activities, and also for the training of new youth leaders. I think it will be of great benefit.

I had the HFNSW camp experience in my mind when I spoke with a number of people who operated camps out of a specified location using the location's counsellors which is a very similar model to ours. However, the major difference was that each year the location had different counsellors and different activities, so that children could attend over several years and enjoy a different camp experience each time. In Australia, we may have more limited venues available; however we should consider this model in our planning nevertheless!

An important principle was that children who attend the camps should be involved in the planning process. Yes, they do survey parents and children from the previous year's camp, but they also get some of the children in to assist in the planning stages of what activities they want to do, and to "buy in" (current buzzword) to the following year's camp. This way they are more likely to attend the camp without complaint about the activities because they have helped to plan them. The NACCHO people also advocated this as a great way to build numbers because the kids talk to each other about it.

The planning process is much tighter in the US compared to my local experience and there are specific camp planning committee meetings throughout the year to plan for the camp the next year. This group of people is responsible for one thing, and that is the delivery of a unique camp experience each year. Imagine what we could achieve if there were three people whose sole job was to create the family camp and report back to the committee with their results! We don't have the manpower at HFNSW for this yet, but let me know if you are interested!

Whilst there were a number of "camp traditions" in the American experience that are somewhat different to the Australia camp experience - campfires on the final night, plenty of singing and chants, and a focus on one person who is seen to be 'leading' the week and weekend – several can be adapted with an Aussie flavor.

There was also a big focus on the role of social media and websites. HFA have already moved in this direction with the creation of the Facebook page and embracing the Livewire site. The whole Twitter thing has gained traction in America in a big way and there is a site called Linked In which I had not heard of which I believe is a way to keep track of contacts.

Websites of course can be valuable, for information, fundraising etc, but they require people onto the website regularly changing and updating information to keep the site interesting and to keep the traffic flowing to it.

I attended a session that advocated for children to be divided into age groups, which is how most camps operate in America. Children are broken into 7-9 (children), 10-12 (the 'tweens), 13-16 (the teens). Obviously we need to cater for the tiny tots and pre schoolers as well. At 17 the kids become Junior Counsellors in training and then Camp Counsellors after that. Many of the activities for the 13-16 year olds are conducted off site – ten pin bowling, waterpark, theme park, laserzone etc.

I think it would be good if HFA considers the possibility of a boys only camp during one week of the school holidays each year, in addition to state camps for families. My idea is that it could rotate between the states. This would need an HFA-led group that organised such a camp each year and guaranteed funding. Something like this would be a fantastic event for the kids, and would also be an opportunity for many of the teenagers to take an active leadership role.

The US haemophilia camps have catchy names like 'Camp Hemotion' and 'Camp I-Vy'. Camp I-Vy specializes in teaching boys self infusion. They take boys from age 7-10 and spend the week focusing on self infusion in a non threatening way and after two years at Camp I-Vy all the boys can self infuse. They have exciting activities at camp and so the boys like to come back again and again, because they get to show off their self infusion skills once they have mastered the art. There is also a close partnership with haemophilia centre nurses and doctors at the camps. Some of the nurses attend camp as part of their paid activities, or donate their time.

Sharon Caris is Executive Director, Haemophilia Foundation Australia
Suzanne O'Callaghan is Policy Officer, Haemophilia Foundation Australia

TALKING WITH GOVERNMENT – HAEMOPHILIA FOUNDATION AUSTRALIA REPRESENTATION AT WORK

Sharon Caris and Suzanne O'Callaghan

The last six months have been a busy period for Haemophilia Foundation Australia (HFA) at a national representation level, with several opportunities for HFA to give formal feedback to the Australian government on issues that are important for the bleeding disorders community.

National Hepatitis C and HIV Strategies

In September and October 2009 the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections (MACBBVS) asked for community feedback on the draft National Hepatitis C and HIV Strategies. Government priorities and funding for hepatitis C and HIV are tied to the National Strategies and the feedback process is an important way of having needs of the bleeding disorders community recognised and incorporated into national strategy documents.

HFA responded to the call for feedback, noting with disappointment the lack of acknowledgement of bleeding disorders community needs in relation to hepatitis C.

In response, the most recent draft of the National Hepatitis C Strategy now includes a new priority population, *People with hepatitis C with co-morbidities*, which lists people with bleeding disorders as a specific sub-population in this group. The priority needs are described as:

> People with hepatitis C with co-morbid health conditions need to have access to education about hepatitis C disease progression and prevention, and the knowledge and skills to access hepatitis C treatment and care services.

The revised draft of the National HIV Strategy included a section on "People living with HIV with high support needs". This section mentioned people with co-morbidities, but no longer explicitly included people with bleeding disorders. It recommended resourcing a comprehensive approach to the complex needs of this group.

In its feedback on the revised drafts, HFA welcomed the inclusion of people with hepatitis C with co-morbidities (including people with bleeding disorders) as a priority population in the National Hepatitis C Strategy and made suggestions for priority actions, including education, support and care. HFA also commented on the need to include people with bleeding disorders as a specific group with high support needs in the National HIV Strategy. In both cases, we referred to the HFA hepatitis C needs assessment reports (*A Double Whammy* and *Getting it right*), and their sections on HIV/hepatitis C co-infection, and attached the reports to the response.

Hepatitis C financial issues

Financial issues remain a high priority and HFA has continued its work to address the financial support needs of people with bleeding disorders affected by hepatitis C, and has raised these issues with government. In January 2010, the Treasurer asked for community feedback on what should be considered in the Australian Government 2010 budget. HFA drew the Treasurer's attention to the financial needs outlined in the HFA hepatitis C needs assessment reports.

A preliminary meeting has also been held with Mark Butler, the Parliamentary Secretary for Health on HFA's proposal for a government funded no fault financial assistance scheme and since that meeting additional materials have been provided. There are many complex aspects of this proposal and HFA anticipates further discussions soon. More details about these discussions will be available in the June edition of *National Haemophilia*.

Migration

When people apply to visit or migrate to Australia, their access to a visa is conditional on them satisfying the health requirement specified in the Migration Regulations. As part of the health test, applicants with a 'disease or condition' are assessed on the potential cost and impact on Australian health and community services. They can be excluded if they potentially require medical treatment and/or health and community services which would "result in a significant cost to the Australian community". This is regardless of whether the health care or community services would actually be used by the applicant. For people with bleeding disorders, this can be a major stumbling block for immigrating to or visiting Australia, particularly as treatment for bleeding disorders may be considered to be high cost medicines. People with mild or moderate haemophilia can be excluded as well as those with severe haemophilia.

In October 2009 the Australian Parliament's Joint Standing Committee on Migration called for community comment for an inquiry into how health and community costs associated with a disability are assessed as part of visa processing in Australia. HFA responded with a submission to the Committee stating the HFA view that to exclude

...the feedback process is an important way of having needs of the bleeding disorders community recognised and incorporated into national strategy documents.

individuals from migrating to or visiting Australia on the basis of their bleeding disorder alone is neither ethical nor just; that as a basic human right, people with bleeding disorders in Australia should have access to the treatments they require and that everyone should be valued for their contribution to the Australian community regardless of health needs or their level of disability.

In February 2010 Sharon Caris was invited to give evidence on behalf of HFA at a Public Hearing for the inquiry into the Migration Regulations. This was an opportunity to reiterate HFA's views and ask that the Migration Regulations be reviewed and that there be more transparency in the criteria used for processing visas and migration applications to Australia. We hope the inquiry will result in some positive changes to the Migration Regulations and will keep members updated on the outcome.

National Drug Strategy

The day-to-day realities of living with a bleeding disorder and managing specialised treatment and care needs can become more complex if the person with a bleeding disorder also has alcohol and/or drug problems. The Ministerial Council on Drug Strategy is currently seeking input from expert stakeholders and the broader community on emerging issues and directions for the 2010-2015 phase of the National Drug Strategy. As an organisational member of the Australasian Society for HIV Medicine (ASHM), HFA had given feedback on and endorsed the ASHM submission to the Drug Strategy consultation – but in the process had identified a number of issues that are specific to people with bleeding disorders and made a separate additional submission to outline these issues.

The aim of making a submission to the National Drug Strategy was to highlight strategies that would improve the health and wellbeing of people with bleeding disorders who also have alcohol and/or drug problems. To make some targeted and pragmatic recommendations, we discussed with members of the haemophilia health professional groups the issues and solutions that might work well with health services. We discussed various scenarios, such as the person attending a GP in a local community health service or being referred to drug and alcohol services from the Haemophilia Centre – what works, what issues have come up. As a result, HFA recommendations included:

- Increasing public resources to ensure that stable living environments and ongoing case management are accessible to people with bleeding disorders who also have alcohol and/or drug problems
- Ensuring that GPs are aware of the need to include the specialist Haemophilia Centre team in the care of people with bleeding disorders, particularly if the GP is managing injuries, dental care, other bleeding problems and general health problems that require procedures or investigations
- Trialling positive and realistic health promotion messages for people with chronic conditions, such as bleeding disorders
- To consider other responses at a governmental level to risk factors such as inadequate pain management, psychological crises related to the HIV and hepatitis C epidemics, and pressures within the family of managing bleeding disorders, as well as other social and economic problems
- More education for parents, carers and health professionals on identifying risks for alcohol or drug use and how best to manage any issues that result.

Health Technology Assessment

The Australian government published the Review of Health Technology Assessment in Australia in December 2009. Of particular note is recommendation 16, that *AHMC [Australian Health Ministers' Conference] be asked to consider the need for a national approach to HTA processes, including processes required to evaluate blood and blood products.*

HFA welcomes the recommendation and has written to the National Blood Authority (NBA) which administers the National Blood Agreement noting HFA's commitment to evidence based decision making around the safety and supply of treatment products for people with bleeding disorders. HFA supports a national approach which takes into account the potential changes to patient treatment requirements, and ensures access to emerging technologies. HFA also recognises the importance of a framework which is cost effective and sustainable and the important role people who use treatment products play in this.

This article is abridged and updated from the Hepatitis Australia article *Transient elastography (FibroScan)*, published as an "Article of the Month" on the Hepatitis Australia website, **www.hepatitisaustralia.com** on 16 April 2009.

FIBROSCAN – MEASURING LIVER HEALTH WITHOUT BIOPSY

If you have hepatitis C, it is important to monitor the underlying level of liver fibrosis (scarring) over time during the course of your infection. This can tell you whether there have been any changes in your liver health and can help in making decisions about the need for treatment.

Liver biopsy has long been considered the "gold standard" test to measure fibrosis. However, liver biopsy is a costly invasive procedure which can be painful, and carries the risk of bleeding complications. Because the amount of liver taken for a biopsy is very small, it can also sometimes result in sampling errors which under or over-estimate the amount of liver scarring. For people with bleeding disorders, a liver biopsy needs to be overseen by their Haemophilia Centre to minimise bleeding problems. Other less or non-invasive procedures have often been used in preference, such as blood tests, ultrasounds and magnetic resonance imaging (MRI), but these are generally not as accurate as a biopsy.

FibroScan® is an innovative new medical device that uses transient elastography to measure the elasticity or stiffness of the liver - the stiffer the liver, the more severe the hepatic fibrosis (scarring).

A relatively new technology, there are currently only nine sites with Fibroscans in Australia:

- *Melbourne: Alfred Hospital, Austin Hospital, St Vincent's Hospital, Monash Medical Centre*
- *Sydney: Concord Hospital, Liverpool Hospital, St Vincent's Hospital*
- *Brisbane: Greenslopes Hospital*
- *Fremantle, WA: Fremantle Hospital*

A number of other hospitals have also expressed interest in the Fibroscan.

"FibroScan is an ultrasound-like device that assesses the degree of liver damage, in particular scar tissue - or, as clinicians call it, fibrosis - through a measurement of liver stiffness," said Associate Professor Roberts.

Associate Professor Stuart Roberts of the Alfred Hospital in Victoria believes that the FibroScan will become a standard monitoring tool for hep C and that it may be very useful to monitor people with haemophilia.

Hepatitis Australia, the Australian peak body for Hepatitis, spoke to Associate Professor Roberts about the FibroScan: what it is, how to access it in Australia, how it works and how accurate it is.

"It is very likely that FibroScan is going to become fairly standard for patient assessment in most liver clinics and probably many private clinics. Given the interest we have had in Victoria amongst specialists and GPs, I think demand is only going to grow, and grow quite quickly," Associate Professor Stuart Roberts said.

A series of FibroScans can show whether a person's liver fibrosis is increasing, decreasing or stable, not

FibroScan is non-invasive and, for patients, that means a pain-free experience when clinicians are assessing their liver disease.

unlike an ultrasound.

"FibroScan is an ultrasound-like device that assesses the degree of liver damage, in particular scar tissue - or, as clinicians call it, fibrosis - through a measurement of liver stiffness," said Associate Professor Roberts.

"It does this by sending a mechanical vibration wave through the liver. The speed at which that wave travels through the liver is measured via ultrasound as it detects the sound wave reflection. This is then computed into a reading that measures the elasticity of the liver - or, conversely, the stiffness of the liver. The more scarred or fibrotic the liver is, the stiffer it is, hence the higher the reading."

While FibroScan is unable to accurately detect fibrosis in 100% of cases, Professor Roberts said there are a number of advantages of FibroScan in comparison to liver biopsy.

"Firstly, FibroScan is non-invasive and, for patients, that means a pain-free experience when clinicians are assessing their liver disease. It is a simple procedure that can be done in an outpatient setting relatively quickly - a typical test would take no more than ten minutes, 15 minutes in more difficult cases such as those who are overweight."

"There is also no need for preparation, as patients can have a FibroScan done while fasting or non-fasting," he said.

"FibroScan can also be performed over time, allowing numerous readings to be done on a yearly basis, for example, in order to track their liver disease and determine whether scarring is increasing. Liver biopsy on the other hand, is not a suitable test in the same sense – it involves a lot of anxiety for patients."

Although there are real benefits to patients undergoing FibroScan, there is also some limitation to its abilities.

"What we can confidently say with FibroScan is that it's a very good tool for assessing the severity of liver disease at both ends of the spectrum; that is, it's extremely good at picking up mild or minimal disease, and very good at diagnosing cirrhosis, with 90-95% accurate positive predictive value," said Professor Roberts.

"For those with more moderate disease, that being patients who have got stage 2 or stage 3 disease, or possibly even late stage 1, it is not as good at differentiating between the stages in these situations."

Some limitations to the current Fibroscan probe include its inability to get an effective reading in people who are markedly overweight, in those who have a pacemaker or in those who have very significant liver inflammation. If the liver inflammation is related to a liver disease flare, it is recommended that these patients come back at a later date for another reading when their inflammation settles down.

In conclusion, Professor Roberts states that FibroScans should be thought of as a complementary tool, to be used by clinicians to assess their patients, and not as a replacement for liver biopsies.

"It's not perfect. It certainly does not replace the need for liver biopsy, but it's a very useful assessment tool that provides important input into a clinician's assessment of patients with liver disorders. FibroScans can be used to supplement decision making as to whether a biopsy is helpful or not," he said. "They are also a tool which can certainly assist greatly in identifying patients with undiagnosed liver disease. We have had a number of cases where we have diagnosed cirrhosis where cirrhosis wasn't expected by the treating doctor."

Note from the Editor: Fibroscan is the registered name of the product. HFA is providing this information for education purposes and has no relationship with the supplier, and its only interest is for its potential as a medical technology that might benefit some of its readers. HFA does not provide medical advice and recommends that individuals discuss with their treating medical specialists whether the use of such medical technologies would be of benefit to them before taking action or relying on published information.

Suzanne O'Callaghan is Policy Officer, Haemophilia Foundation Australia.
Peter Hull is Research Officer, Dr Max Hopwood is Research Fellow and Associate Professor Carla Treloar is Head of the Hepatitis C Program at the National Centre for HIV Social Research, University of NSW.

HEPATITIS C TREATMENT – DECISIONS, DECISIONS

Suzanne O'Callaghan, Peter Hull, Max Hopwood and Carla Treloar

What makes people decide to have hepatitis C treatment? We've heard some community members say they were inspired by another's story of their successful treatment to think about treatment again – or that a Haemophilia Conference presentation on the latest treatment results made them think that maybe now was the time. What other factors come into play? And what can prevent people from having treatment?

HFA's hepatitis C needs assessment (*A Double Whammy*) highlighted some concerns about treatment – health professional concerns that not enough people with bleeding disorders and hepatitis C were discussing treatment with them or were leaving it too late – and individual community member concerns about success rates, side-effects, managing financially during treatment, and perhaps a lack of knowledge about the changes in treatment over the last 12 years and what their options were. It was a surprise for some to hear that others had had successful treatment and a common theme was "we should hear more about this".

What are other common factors affecting treatment decision-making among people with bleeding disorders? When the Hepatitis C Project team from the National Centre for HIV Social Research (NCHSR) approached HFA about their hepatitis C treatment survey, it was an opportunity to build a solid evidence base of data.

State and territory Haemophilia Foundations were very supportive of the Project and mailed out surveys to their members. Overall 731 people with hepatitis C took part in the NCSHR survey; 98 of those who returned the surveys were people with bleeding disorders. The results from these surveys are summarised below.

NCHSR (Uni of NSW) Hepatitis C Survey Results

People with bleeding disorders and hepatitis C

Total number – 98

Male – 86 (88%), female – 12 (12%)

Average age was nearly 50 years – youngest was 20; oldest was 89 years of age

Co-infected with hepatitis C and HIV – 17 (17%)

How did they contract hepatitis C?

92 (94%) from blood products or transfusions

4 (4%) from non-sterile equipment used to inject drugs

When were they diagnosed with hepatitis C?

1978 – 1988	21
1989 – 1991	22
1992 – 1994	28
1995 – 2003	22
Missing	5

What was their genotype?

Genotype 1	31 (32%)
Genotype 2	6 (6%)
Genotype 3	13 (13%)
Don't know	42 (43%)
No answer	6 (6%)

How was hepatitis C affecting them?

15 (41%) said HCV has a greater impact on daily life than bleeding disorder

14 (38%) did not think HCV has a greater impact on daily life than bleeding disorder

Previous or current hepatitis C treatment?

3 (3%) currently on treatment

57 (58%) had previously been on treatment

38 (39%) had not had treatment

Of the 57 who had previously had treatment

21 (37%) had treatment in the last 4 years

13 (23%) had treatment in the last 4-6 years

20 (35%) had treatment more than 6 years ago

Did they complete treatment?

45 (79%) completed treatment

9 (16%) stopped before the end

Was treatment successful?

26 (46%) had successful treatment

28 (49%) had unsuccessful treatment

Of the 38 who had never had treatment, were any intending to have treatment?

3 (8%) in the next 12 months

6 (16%) in the next 1-5 years

14 (37%) never

10 (26%) didn't answer

What had their treating doctor advised?

4 (11%) on waiting list for treatment

18 (47%) told to have treatment

11 (29%) told not eligible for treatment

Why weren't they eligible for treatment?

2 (18%) – liver too damaged

4 (36%) – not enough liver damage/LFT normal

3 (27%) – other reasons

2 (18%) – didn't answer

What else influenced their decisions about treatment?

The NCHSR team looked more closely at some of the factors that might have influenced people's

decision-making and found that there were few differences between any of the groups. The severity of people's symptoms, the support of family, friends and partners, and being male or female did not seem to be related to decisions to take up treatment. Those who were older were more likely to never consider treatment and those who had hepatitis C longer were more likely to decide against treatment. Most people in the survey group who were co-infected with HIV had decided for treatment.

It was hard to gauge people's knowledge about hepatitis C and treatment. People who had decided to take up treatment had higher knowledge scores than others, but this isn't surprising as anyone who has had treatment or is being prepared for treatment would have received education about it from the clinic. However, it was a concern that nearly half of the group did not know what their genotype was, particularly as genotype is strongly linked to treatment success rates.

Resilience and coping during treatment

What other factors can help people to manage hepatitis C treatment? The NCHSR team has also conducted research on resilience during treatment in spite of difficult side-effects.

Resilience is fostered by:

- Connections to competent and caring adults in your family and the community
- Using resources and services available in the community to support you
- Skills in altering or managing thoughts, feelings, and behaviours (eg, doing something else when in pain to take your mind off it) and in taking control of yourself and your health
- Self-confidence
- Maintaining good relationships

The team interviewed 20 people who had recently had hepatitis C treatment and found that some had called on skills they had developed to manage other health experiences to cope with treatment side-effects.

… [H]aving lived with chronic pain for the whole of my adult life basically, I already had coping mechanisms to handle those things … I'm used to just not being able to get out of bed for two or three days in a row. That happens occasionally; I just live with it … [I] may be in a better position than some other people to cope with the [hepatitis C] treatment because I'm used to being in a debilitated state …that's not a good thing, but it's a fact. I guess the coping mechanisms were always there, from over a long period of time.

Gerry, 48

I don't sort of wear [haemophilia] like a badge. I generally have a haemorrhage once a week but I have intravenous injections. I self-treat and have done since I was about ten. I just self-manage, self-regulate it. I think, with haemophilia too, you tend to be a bit onwards and upwards in your approach to things. It's like okay, right, you started day one with haemophilia and it throws a whole lot of challenges and you sort of deal with those however you wish.

Sean, 35

A hepatitis nurse commented:

… [S]ome [clients] are more resilient because they say "I've been through everything in life" or "Life's thrown everything at me. Well, I'll be fine". But some are really resilient like that. And I suppose they tend to draw on services a lot more to help them through …

Where to next?

Clearly hepatitis C treatment can be challenging and people need to make their own informed decisions about whether treatment is right for them.

The NCHSR studies raised a few important points:

- How much do people with bleeding disorders and hepatitis C know about their current liver health status and the likelihood that treatment would be successful?
- Is it particularly important for those who are older or who have had hepatitis C longer to revisit their treatment options?
- Focussing on positive strategies to manage treatment can improve the treatment experience
- Skills you have learned to manage your bleeding disorder, your pain and other health problems can help with managing treatment side-effects. Asking services for support when you need help is an important part of dealing with treatment.

HFA wishes to thank the people who completed the NCHSR survey and state and territory Haemophilia Foundations for their support of this project. Thanks also to the Hepatitis C Project Team at the National Centre for HIV Social Research for its initiative to involve people with bleeding disorders and hepatitis C as a specific group in its research so as to contribute to the understanding of hepatitis C in the bleeding disorders community.

Further information on these research studies is available in Carla Treloar's presentation at the 2009 Haemophilia Conference – see the HFA web site www.haemophilia.org.au .

HEPATITIS AWARENESS WEEK

In 2010 National Hepatitis Awareness Week will run from 17-23 May, with World Hepatitis Day marked on 19 May 2010. The worldwide theme for World Hepatitis Day is "***This is hepatitis***…". It aims to increase understanding and awareness of hepatitis and generate action, and will focus on personal stories about people's lived experience of hepatitis B and C. The *Am I number 12*? logo – 1 in 12 people worldwide lives with hepatitis B or C – will now be the ongoing logo for World Hepatitis Day.

In Australia the focus will be on hepatitis testing and management. There will also be *Love Your Liver Lunches* with liver-friendly food - some will aim to raise funds for hepatitis C research and awareness. HFA is working with Hepatitis Australia to develop an approach that is specific to people with bleeding disorders affected by hepatitis C.

This year the national resources will include a bookmark aimed at young people, along with posters and stickers and Community Service Announcements on free-to-air television. Hepatitis Australia will release these resources closer to the date. Local Hepatitis Councils will also be running activities such as picnics, lunches, street stalls and concerts – contact them for more information.

If you would like more information about Hepatitis Awareness Week or the HFA approach this year, please contact Suzanne O'Callaghan on 03 9885 7800 or socallaghan@haemophilia.org.au

World Hepatitis Day web site – www.worldhepatitisday.org

THE RED RUN CLASSIC (RRC)

Red Run Classic

Sunday 16 May 2010, New Farm Park, Brisbane

Sunday 16 May 2010

5km & 10km Route

Meet and Finish at New Farm Park, Brisbane

Registrations from 6am (Pre-registration is encouraged as last year the event was sold out before the day and we had to turn people away)

All entrants will receive a free commemorative RRC cap OR RRC drink bottle (while stocks last)

Race Starts 7.30am

The Red Run Classic (RRC) will be staged again in May for the fourth consecutive year. This successful event has proven to be a must on the Brisbane Running Calendar.

RRC is a fundraising run/walk for Haemophilia Foundation Australia and Haemophilia Foundation Queensland. Funds raised will provide programs and services for the bleeding disorders community in Queensland and across the nation.

Join hundreds of other women, men, teenagers, children and families to have fun while raising money for a good cause. If you are a serious competitor make the Red Run Classic one of your big events, or walk with your family and friends for a fun social morning.

For more information or to register online visit www.haemophilia.org.au or call 1800 807 173.

Gavin Finkelstein is President, Haemophilia Foundation Australiaa

HEMOPHILIA 2014 FOR MELBOURNE, AUSTRALIA?

Gavin Finkelstein

International Congresses of World Federation of Hemophilia (WFH) are not only the most valuable multidisciplinary education meetings for the worldwide bleeding disorders community, they are also one of the most important ways for WFH to generate funds for programs and services around the world. This is especially important for revenue to support advocacy and development programs to increase access to care and treatment in the developing world.

WFH has developed a successful model for running congresses "inhouse" with its team of highly skilled and experienced congress organisers and the location of each Congress is decided by National Member Organisations (NMOs) at a vote at the WFH General Assembly several years before. The host NMO then works closely with WFH to develop the Congress program and associated activities.

The WFH Congress has never been held in Australia. HFA was greeted with enthusiastic support from member Foundations, health professionals, industry and government organisations around Australia when it explored the feasibility of bidding for the Congress in 2014.

HFA expressed interest to WFH and was advised in June 2009 that it had advanced in the process along with USA, Syria, Malaysia, Mexico and Vietnam. HFA commenced a national bid selection process to seek the most suitable venue and partners to work with HFA on the bid. We selected Melbourne which has a state of the art, recently opened convention centre which meets WFH criteria for a suitable venue. Our plan has been to put a choice to WFH which meets the most important elements of a congress to be inclusive, accessible and affordable for participants, and importantly a profitable congress for WFH. We believe our bid offers an option which will be great for the worldwide bleeding disorders community as well as the Asia Pacific region and the bleeding disorders community of Australia. The bid is backed up with guaranteed government support and expert advice and services.

The field has now been narrowed down to just two countries, and in July this year in Buenos Aires, all WFH National Member Organisations will vote for the 2014 Congress to be held in either Miami, USA or Melbourne, Australia. We know that each option will be considered carefully by NMOs over the next few months before they vote.

If our bid is successful it would follow the Congress to be held in Buenos Aires, Argentina in July 2010 and Paris, France in 2012.

We appreciate the efforts of individual members, health professionals and industry from around Australia who have supported our Australian bid and those who are helping with our lobbying efforts ahead of the decision is made by NMOs in July.

HIV FUTURES 6 SURVEY REPORT

The report from the HIV Futures 6 Survey is now available for downloading at: www.latrobe.edu.au/hiv-futures/

If you would like a print copy of the report, please contact

- HFA or your local Haemophilia Foundation
- Your Haemophilia Social Worker/Counsellor
- Phone HIV Futures on 1800 064 398
- Or email hivfutures@latrobe.edu.au

The HIV Futures 6 survey was completed by 1106 HIV positive Australians from all states and territories, including some people with bleeding disorders. It considered many aspects of people's lives, including their health and treatments, services they used, their social world, home, work and financial situation.

HIV Futures is an ongoing research study into all aspects of living with HIV in Australia. Results are an important means of highlighting the current needs of people living with HIV around Australia. The study is conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, Melbourne.

Thanks to those who completed the survey and state and territory Haemophilia Foundations and Haemophilia Social Workers and Counsellors who supported the survey process.

HAEMOPHILIA AWARENESS WEEK 2010

Haemophilia Awareness Week will be celebrated across the nation from 10-16 October. Promotional items will be available – if you would like to be placed on the mailing list to pre-order items contact Natashia Coco at ncoco@haemophilia.org.au or call 1800 8017 173.

Sharon Hawkins is Senior Social Worker – Haemophilia, Haemophilia Centre of Western Australia

SHARING WOMEN'S EXPERIENCES

Sharon Hawkins

In the course of my work as a Haemophilia Counsellor, I have met many women. Women with von Willebrand Disorder (vWD), women with other factor deficiencies, women who carry the haemophilia gene, sisters, wives, mothers of obligate carriers, grandmothers and aunts. Considering haemophilia "affects males almost exclusively" (quoted from many haemophilia resources) and haemophilia services have, historically, been concerned with males managing their condition, it's quite extraordinary that ALL of the peer support groups I facilitate on behalf of the Haemophilia Foundation Western Australia (HFWA) are attended by women. Even vWD Information Nights attract many more women that men. What does this say about the affect bleeding disorders have on all individuals in the family? It may be that women engage more in support services when they're offered, but it might also be that bleeding disorders have a significant affect on women's wellbeing whether that is their own health or as a nurturer or carer of someone with a bleeding disorder.

This is not to say that men in WA miss out altogether. The HFWA also hosts a Men's Breakfast meeting every six or so weeks, but of course, due to my gender, it is facilitated by male members of the HFWA committee. HFWA also hosts a couple of family BBQs a year, which attract a good smattering of men and boys. Still, overall many more women than men participate in Haemophilia Foundation peer support.

One of the peer support groups hosted in WA is a six weekly breakfast meeting for women with inherited bleeding disorders, including women with vWD, women who carry the haemophilia gene and women with other factor deficiencies. These breakfast meetings have grown immensely over time and average attendance is fifteen women.

There's no shortage of discussion at these breakfasts and subjects can range from genetic inheritance, children and pregnancy, treatment and surgery, relationships and any number of other interesting and sometimes totally irrelevant to bleeding disorders topics.

During the course of these breakfasts it's not uncommon to hear those women who are symptomatic talking about their very difficult experiences of menorrhagia. They relate stories of how menstrual "flooding" has kept them home from work or reduced them to tears and total humiliation in the middle of the breakfast cereal aisle in the supermarket. The taboos associated with talking about women's menstrual cycles may have diminished a little bit, perhaps due in some small way to tampon and sanitary pad advertisements on television. However, bleeding of any kind is often viewed with great apprehension and concern by most people and menstrual bleeding often appears to add a level of repugnance to that apprehension and concern. There is a whole discussion that could be had about the history of beliefs about women's menstrual

cycles, which I won't touch on here.

The women's breakfast meetings appear to have become a safe place to discuss these issues and also for these women to be able to laugh about how awkward the situation can be. The understanding and camaraderie that has developed through the sharing of their "most excruciatingly embarrassing bleeding experience" appears to have been empowering for many of these women. They find that they are not alone with their fear. They also find that other women know what it's like to have to stay at home in case you "flood" or at the least make sure you've got something to wrap around yourself while you're out and to never wear white skirts or pants at that time of the month! These tales are told, initially with some reservation and eventually with hilarity. Laughter is great therapy.

The breakfasts also provide an opportunity for information about attending the Haemophilia Treatment Centre (HTC) to be passed on. When new faces turn up to subsequent breakfasts there is a congenial sharing of information about different options that women have tried to manage their menorrhagia. Most women indicate that they leave the breakfast with a shared sense of validation that their difficulty with their bleeding disorder is believed, that they're not alone, that there are others they can talk to who don't treat the subject as unmentionable and a sense of hope that they may be able to access appropriate treatment.

While going out for breakfast sounds like a perk of my job, I have a very strong belief in the benefits of peer support. Peer support can lead to better health outcomes. It is a means of providing emotional support, informational support and increasing confidence. My presence at the breakfasts enables me to facilitate discussion amongst the women, act as a resource for information or guidance and also utilise the experiential knowledge of the women that attend.

Certainly, in the world of haemophilia care, women's issues are being highlighted more. A whole session dedicated to Women's Issues at the 2009 Haemophilia Conference in Brisbane is notable. Claire Bell, one of our haemophilia nurses has been trying different means of encouraging women who carry the haemophilia gene to attend our Haemophilia Treatment Centre including running a Carriers Clinic. Claire will also attend one of the HFWA Women's Breakfasts to get some feedback from women about their needs and how best they can be assisted. This can be viewed in a very positive light.

One of the great benefits of involving women more widely, apart from treatment for their own bleeding issues, is to improve the flow of information in families regarding genetic inheritance. Women are often well known as the communicator in families. Information gleaned from a study conducted in 2008 on transition of patients from our paediatric HTC to adult HTC, revealed a lack of knowledge amongst young men about whether their children would be affected with a bleeding disorder. Perhaps through contact with females in the family, we can make some headway ensuring other members of the family get that information.

Haemophilia, vWD or other factor deficiencies affect entire families and it's encouraging to see this being recognised and reflected in the scope of support, information and resources offered through the Haemophilia Foundation and Haemophilia Treatment Centres.

If you're unsure about genetic inheritance or you would like further information about women's services, information and supports, contact your Haemophilia Social Worker/Counsellor, Haemophilia Treatment Centre or Haemophilia Foundation.

Peer support can lead to better health outcomes. It is a means of providing emotional support, informational support and increasing confidence.

WOMEN'S STORIES

During 2010 HFA will be developing some information resources for women with bleeding disorders. These will in a magazine style and will include the personal stories of women who have a bleeding disorder, including those who carry the haemophilia or VWD gene.

Sharon Hawkins' article on women's group meetings in this publication and Haemophilia Foundation Australia's 2003 Women and Bleeding Disorders survey and interviews all highlight how important it is for women to connect with each other by sharing their stories and realising that they are not alone in their experiences – and that having a bleeding disorder is something that can be talked about.

If you would be interested in telling your story and having it included in the new resource – it can be anonymous if you prefer – please contact Suzanne O'Callaghan, Policy Officer, Haemophilia Foundation Australia:

- socallaghan@haemophilia.org.au. or
- phone 1800 807 173

DO YOU NEED TO UPDATE YOUR E-NEWS EMAIL ADDRESS?

Haemophilia Foundation Australia (HFA) regularly sends a short email news update of topical items to people who have registered for the HFA email newsletter.

If you haven't received an E-News bulletin in 2010 and your email address has changed since you registered, you may need to update your email address.

How do you update your email address?

This is a very simple process.

EITHER

1. Go to the HFA web site www.haemophilia.org.au, click on the SIGN UP FOR NEWSLETTER button and fill in your name and email address and click in the box to ***Receive updates by email***.

No need to worry that you may already be listed – any duplicate entries are cleaned up.

OR

2. Email hfaust@haemophilia.org.au and ask HFA to register you or check your address.

And if you would like to join the E-News list?

Just register online or email HFA, following the steps above. Simple!

NATIONAL HAEMOPHILIA READER'S SURVEY

Watch out for the survey that will come with the June publication of National Haemophilia to seek your views about content, and the sort of information and services you would like to receive from Haemophilia Foundation Australia (HFA).

LIVEWIRE (LIVEWIRE.ORG.AU)

The Livewire team have attended several state and territory Haemophilia Foundation camps and picnics recently, helping young people and their parents understand how Livewire works and how they can join. Some recent visits:

- HFNSW Family Camp at Narrabeen Sport & Recreation Centre
- HFWA Camp at Point Walter
- HFV Christmas picnic at Werribee Zoo
- HFV Camp at Portsea

A number of young people with bleeding disorders, siblings and parents have already registered. Livewire is an initiative of the Starlight Foundation to provide safe, positive and entertaining online communities. It is now available to young people with bleeding disorders and their brothers and sisters, if they are between 10 and 21 years, and there is a third community for parents. HFA is a Livewire Affiliate Partner.

What does Livewire offer young people with bleeding disorders and their families?

- A fun and friendly community where you can touch base with other young people of your age with bleeding disorders, or siblings, or chat with the rest of the group, enter competitions with prizes such as a mobile phone, iPod touch or Notebook, play games, have chat sessions with celebrities, read and talk about news on all sorts of things, including the latest computer games, football, bands and animals – what's on depends on what the group is interested in - and the community is carefully moderated so that young people are safe online
- For parents, it is an opportunity to share information and experiences with others in similar situations.

How do you join?

- Collect a registration pack from the Livewire team, or
- Ask HFA or your Haemophilia Foundation for a registration pack, or
- Join online – check the Livewire page on the HFA web site www.haemophilia.org.au under *Kids and Youth – Fun Stuff,* or
- Contact the Livewire Support Team on (02) 8425 5971

Make sure you select "bleeding disorders" when you are creating your profile to connect with the bleeding disorders group.

Prize draws for new registrations

If you join before 30 May 2010, Livewire members have a chance to win a mobile phone, siblings a Nintendo Wii, and parents a $250 Caltex gift voucher.

CALENDAR

Red Rum Classic

On line registration available on
www.haemophilia.org.au

Hemophilia

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

7th Australasian Viral Hepatitis Conference

Melbourne 6 - 8 September 2010

ph 02 8204 0770
fax 02 9212 4670
email info@hepatitis.org.au
web www.hepatitis.org.au

22nd Annual ASHM Conference

Sydney 20 - 22 October 2010

Phone: 02 8204 0770
Fax: 02 9212 4670
email info@hivaidsconference.com.au
web www.hivaidsconference.com.au

16th Australian & New Zealand Hameophilia Conference

Sydney 20-22 October 2011

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

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