



## *Red Run Classic*

**Sunday 25 May 2008, New Farm Park, Brisbane**

The **Red Run Classic** is a fundraising run/walk for Haemophilia Foundation Australia and Haemophilia Foundation Queensland.

Join other women, men, teenagers and children 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 just come to walk with your family and friends for a great activity and fun on this lovely 5 km route.

### **Registration**

Register online [www.haemophilia.org.au/events](http://www.haemophilia.org.au/events) or call HFA on 1800 807 173 for a registration form.

### **Corporate Teams**

Get a team of colleagues and enter as a "Corporate Team" (up to four people)

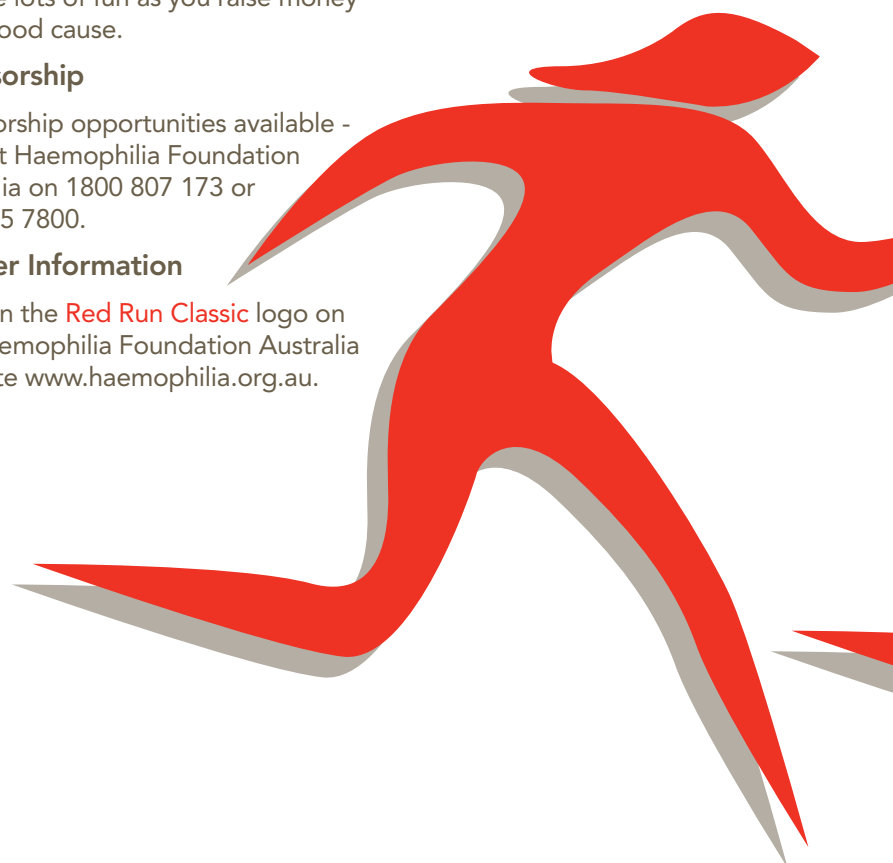
and join hundreds of other participants to have lots of fun as you raise money for a good cause.

### **Sponsorship**

Sponsorship opportunities available - contact Haemophilia Foundation Australia on 1800 807 173 or 03 9885 7800.

### **Further Information**

Click on the **Red Run Classic** logo on the Haemophilia Foundation Australia web site [www.haemophilia.org.au](http://www.haemophilia.org.au).



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# WFH CONGRESS, ISTANBUL, TURKEY 1-5 JUNE 2008

The Congress in Istanbul will be held 1-5 June 2008 and Haemophilia Foundation Australia (HFA) is currently making arrangements for the people who are attending with the support of HFA and State/Territory Foundation funding. Gavin Finkelstein, HFA President, will represent HFA at the pre-Congress National Member Organisation (NMO) Training on 29-31 May 2008, and at the WFH General Assembly on 6 June. Sharon Caris, Executive Director, has also been invited to facilitate a workshop with A/Prof Alison Street, The Alfred Hospital,

Melbourne, on ageing and other health issues facing the haemophilia community at the NMO Training.

Many health professionals and haemophilia community volunteers will also be attending the Congress. HFA, with a co-contribution from State/Territory Foundations is pleased to support the following delegates to the Congress who will report to the community upon their return:

**Debbie Kermod**  
 Australian & NZ Physiotherapy  
 Haemophilia Group  
 (Women's & Children's Hospital, SA)

**Kelly Brady**  
 Australia/NZ Haemophilia Social  
 Workers' & Counsellors' Group  
 (Queensland Haemophilia Centre)

**Salena Griffin**  
 Australian Haemophilia Nurses' Group  
 (Queensland Haemophilia Centre)

**Robert McCabe**  
 Community member  
 (Haemophilia Foundation Western  
 Australia) 



# WORLD 08 HAEMOPHILIA DAY

World Haemophilia Day is officially celebrated on the 17th of 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 the theme of World Haemophilia Day is **Count Me In** which focuses on identifying and registering people with bleeding disorders.

Because haemophilia and other inherited bleeding disorders are rare it is important to have accurate statistics on the number of people who are affected by these disorders. This information is needed to increase understanding of treatment needs and to ensure access to the care needed for people to achieve and maintain quality of life. It is important in countries where there is no treatment available or where treatment and services are limited that registries are established to record the number of people requiring treatment. This helps patient communities and treaters to justify to governments the need for funding and health services. This is also true in countries where treatment and care has been developed over many years, for governments, health professionals and

this year the theme is *Count Me In* which focuses on identifying and registering people with bleeding disorders

haemophilia organisations to maintain and improve treatment services and care. It is important to have comparative data available for national member organisations seeking to improve care and treatment in their countries.

WFH collects data from national haemophilia organisations around the world and publishes this data. The 2006 WFH Global Survey which was published in January 2008, identifies 205,472 people with bleeding disorders in 100 countries (source: WFH). Statistics for the 2007 survey are now being collected by WFH and Haemophilia Foundation Australia (HFA) is currently working with Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) to provide this data. **H**

# AUSTRALIAN BLEEDING DISORDERS REGISTRY REDEVELOPMENT PROJECT

*Sharon Caris*

The value of information in the treatment of people with bleeding disorders underpins some important work being undertaken currently in Australia which resonates with the 2008 theme for World Haemophilia Day, **Count Me In**. This work between stakeholders involved in the provision of care and treatment to people with bleeding disorders in Australia (including HFA) promises to deliver greater utility for health professionals in the understanding and management of treatment needs.

The Australian Bleeding Disorders Registry (ABDR) has been operated by Australian Haemophilia Centre Directors' Organisation (AHCDO) for more than 15 years since it was first funded by Haemophilia Foundation Australia (HFA). A major redevelopment project, funded by the National Blood Authority (NBA) on behalf of Federal and all State/Territory governments, has been underway for 12 months.

The ABDR is a collection of data sourced from Haemophilia Treatment Centres (HTC) around Australia. It has been used until now for quality assurance and improvement of clinical practice in the treatment of people with haemophilia, von Willebrand disorder and other platelet and coagulation deficiencies. It has also been used to report to governments on statistics of people with bleeding disorders and product use across the bleeding disorder population to assist with supply planning and demand forecasting.

The redeveloped registry will mean little change for people with bleeding disorders as their personal information will remain confidential and will only be available to health professionals at the haemophilia

centre where they receive treatment and arrange product supplies. However, de-personalised information will continue to be provided to stakeholders through various reports on the numbers of people affected by types of bleeding disorders and other related information as well as information relating to the supply and management of treatment products.

In conjunction with implementation of the redeveloped ABDR, governments will require a minimal set of data for all people with

by diagnosis, manage authorisation of product orders and enable governments to undertake supply planning and demand forecasting to secure ongoing funding for clotting factor product.

Delegates who attended the 14th Australian and New Zealand Conference in Canberra in October 2007 are aware of the strong interest, and support for the ABDR redevelopment amongst everyone involved in the bleeding disorders community, especially the patients.

...it has been used until now for quality reassurance and improvement of clinical practice in the treatment of people with haemophilia.

bleeding disorders who need access to clotting factor products. This information will help clinicians who treat people with bleeding disorders, as well as HFA in identification and planning for emerging needs in the community we represent, and for governments to have a better understanding of the demographic profile of those using treatment products to understand more about demand and supply needs.

The purpose of the redeveloped ABDR is to facilitate the collection of information which will be used to: build an accurate demographic profile of bleeding disorders in Australia; keep clinical information that observes the pattern of care such as treatment, bleed frequency, joint health, pathology, radiology, genetic mutation and others to provide information for assessment of treatment outcomes to improve care; and to understand product use

A brochure explaining the ABDR and its purpose is currently being developed and will be made available to people with bleeding disorders and their families in the coming months through haemophilia centres. Confidentiality and privacy continues to be critical to the success of the ABDR and the data collection process, in addition to robust security measures, has been developed from the outset to ensure individuals and their health information remains secure and confidential. Data collected at haemophilia centres is de-identified when consolidated in the ABDR for reporting purposes.

HFA supports the redevelopment of the ABDR and has worked with the NBA and AHCDO to establish objectives for the new registry. **H**

# DELEGATE FOR A SMALL STATE

Jonathan Spencer



For me, one of the most humbling experiences in being actively involved in the bleeding disorders community is that I'm now hearing

from ordinary people who are coping extraordinarily well with problems that I had selfishly thought were more or less unique to me. Humbling because residing in the smallest state of the Commonwealth had isolated me from sharing other people's experiences as I spent many years trying to understand my life and the medical system of that time.

More than 40 years ago, as a child with a rare bleeding disorder, it was pretty cool to receive heaps of attention from medical staff and precociously refer to factor assays and base clotting levels, even whilst my mother was proving to others that my condition actually existed. Eventually, my condition was medically accepted, but less so by me. Overwhelmingly, I wanted to fit in and not be different. I certainly didn't want my friends knowing about it. These were the days before prophylaxis, counselling and treatment centres. It was a great day at school when my teachers decided that I couldn't be physically disciplined, but I then had to explain to the other kids why I wasn't punished in the same way as them, even though I was just as guilty.

I suspect that it is not so unusual that my denial continued as an adolescent with pretty average decision-making and poor self-management leading to still recurring knee problems after a skiing weekend.

Later, in the early 1990s and after several months of difficult interferon monotherapy, I remain clear of the active hepatitis C virus. Nonetheless, I wish someone could explain why I feel so tired and tell me if abstinence is the only cure for the effect of drinking even the tiniest amount of alcohol.

It took maybe 30 years for me to accept my condition. Two years ago, inspired by the tireless work of haematologist Dr David Jupe (now retired) and his colleagues, I decided that I wanted to give something to the small community of persons affected by haemophilia and related bleeding disorders in Tasmania. I attended an AGM for Haemophilia Foundation Tasmania (HFT) and almost immediately became a committee member and Treasurer; hopefully, more for my accounting skills rather than my insolvency experience.

Today, perhaps unsurprisingly, I'm still moved by the circumstances of families affected by bleeding disorders willing to share their experiences. A powerful and unique legitimacy is provided to member foundations by these stories. These stories and their issues are more clearly heard across the country by the dedication of foundation workers across the country.

As ethics and economics in health care are debated in the community, I am certain more than ever that those directly affected by bleeding disorders need a strong united voice in such debates or submissions to government in determining health care values.

A strong voice comes from an active organisation effectively engaged with its members through a strong foundation network.

For HFT, we are currently undertaking a process of renewal as members of the small management committee resign or are replaced. HFT is a 'bare-bones' community group and, like all the rest, we're always on the lookout for active members to become involved.

For committees, renewal of the representative members is important. New members bring fresh energy and perspective to a committee allowing retiring members to recharge and possibly return. However, committees should evolve rather than revolve, building on the legacy of past committees. Otherwise, history is doomed to be repeated.

For foundation members, a partnership exists with their

foundation. Infrequent or irregular contact with your foundation is not necessarily a bad thing, particularly as we need to acknowledge that a bleeding disorder may not always be a priority issue. We all have lives to live. However, members and foundations need to check, at least from time to time, that both are serving each other well and covering issues that are relevant to both sides.

If there is an art to sustaining foundations, it may be more readily discernible in smaller committees and foundations. My recent experience with HFT indicates that we must attract and manage volunteers in a sustainable way recognising that volunteer work often creates a tension with paid employment and personal relationships. Also, it's a good idea not to swamp any prospective committee members with opportunities.

Working on a committee brings many personal rewards. New relationships are created, knowledge and skills are shared, and selected challenges build expertise and self-confidence. For me, one of my most rewarding recent experiences was to bring together and share the stories of member families across Tasmania for a ZooDoo Family Day. **H**



Two young HFT members enjoy a day at ZooDoo.

**Postscript from Jonathan for Tasmanian readers:** HFT is keen to make more regular contact with Tasmanian readers. Committee meetings are usually held bi-monthly in Hobart and all members are welcome to attend. Also, members are advised of upcoming events. If you wish to contact HFT, make comment or assist with any work or activities in Tasmania, please feel free to contact HFA (free call 1800 807 173) to get in touch.



# WOMEN'S ISSUES

Kate McKenzie

I was delighted to hear that the haemophilia conference was to be held in Canberra last year. It was 10 years since I had attended a haemophilia conference in Melbourne, when I was pregnant with my son, Allan. At the time, it was an interesting experience to learn about the treatments, services, and meet some of the haemophilia community in Australia.

A little background regarding my family history: I immigrated in 1970 with my parents and sister. My mother (an undiagnosed carrier at the time) has a brother with severe haemophilia. I also have three cousins of varying ages with haemophilia living in Finland. I have always been close to my relatives in Finland, so I have always been aware of my potential haemophilia carrier status. After I was married, we decided that I should have my carrier status checked, before we decided to have children. My carrier status was confirmed in 1995. Allan was born in 1998 and he does not have haemophilia. We have chosen not to have any further children, even though we are aware of the huge changes in haemophilia treatment regimes and services.

The main reason I attended the conference was to learn more about new information regarding carrier's health and wellbeing. I was delighted to see the conference sessions divided to provide information on various themes. I attended the conference on the Saturday.

The morning plenary session covered the "Individualisation of prophylactic treatment of severe haemophilia: when to start and when to stop" by Dr Kathelijin Fischer, who spoke about prophylactic treatment regimes in patients in Denmark and the Netherlands. Then, Dr Penelope Foster from the Melbourne IVF spoke about the "Pre-genetic diagnosis/reproductive technologies" available in Australia and provided an insightful overview of the options of sex-selection or specific gene detection. Dr Foster also mentioned some of the negative aspects (pitfalls) of the

procedures. At least now, there are other options for couples to consider when choosing to have a family, who are living with haemophilia.

The first concurrent session titled "Women's Wisdom" covered:

- "Mothers, partners, carers, people with bleeding disorders and carriers of the haemophilia gene" by Belinda Burnett. She spoke about her experiences with her daughter with haemophilia, which raised many interesting questions about her daughter, as she is now entering her teens.
- "Menorrhagia: best care and practice" by Dr Julia Phillips. This session highlighted that we as carriers (with lower than normal clotting factor) may need to be aware of our options if you are suffering with heavy menstrual bleeding. It is a major health problem for women in general, which may be unrecognised by patients or doctors. The surgical approach of endometrial ablation and hysterectomy should be used only as the last option. Collaboration between family doctors, gynaecologists and haematologists is important to ensure all options have been assessed, depending on your own medical needs.
- "Management of delivery in carriers and management of the newborn" by Dr Susan Russell. I found this talk interesting, because the speaker spoke about the monitoring regimes of the mother of known carrier status and of the (unborn) baby; during the birth and post management of the newborn. I noted that considerable changes have been made since I had Allan.

The second concurrent session, titled "Planning and Managing Best Practice Care and Treatment", covered various topics which I was not familiar with and it was nice to be enlightened in areas such as the Australian Bleeding Disorders Registry, the National Blood Authority, government priorities and the safety of haemophilia products. It is very important to be familiar with the current issues with haemophilia

treatment, even as a carrier, because there is always the potential of major surgery and possibly requiring treatment with factor if our clotting factor is too low, to avoid or reduce haemorrhage.

I attended the Women's breakfast on the Sunday morning, a last minute decision. I found Mary Lou's story inspiring. Len's haemophilia, raising children, working and travelling the world, and finally, fundraising. Travelling to Africa and teaching children, and continuing to support a teaching program and an orphanage; such an inspiring story. I thoroughly enjoyed speaking with other carriers, carers and health professionals. H

Since the conference, Kate McKenzie has worked with Clare Reeves, HFACT counsellor, to organise a Women's Wisdom High Tea in Canberra for carers of people with haemophilia and carriers of the haemophilia gene to have an opportunity to chat together about issues or inspiring ideas of interest and concern to them.

## SHARING INFORMATION

HFA seeks to meet the needs of the bleeding disorders community in different ways. National conferences are a great way for State/Territory Foundations and other stakeholders to showcase their work, and share their successes. It is also important if something has not worked as expected, to share understandings about this and provide guidance on how to avoid pitfalls, and make improvements.

Sharing and learning from others with similar experiences is one of the basic principles which underpins haemophilia foundations and similar organisations. HFA aims to provide opportunities for our members to share their experiences at national conferences and through newsletters etc, so that others learn more about living with bleeding disorders, the benefits of peer support and also to encourage people to try out some of the ideas in their local environment. Peer support for specific interest groups such as discussion groups for men, women, youth, parents of newly diagnosed children, and family camps, for example, are amongst the most popular activities run by our local haemophilia foundations.

Kate McKenzie's article in this edition of *National Haemophilia* shows the benefits of sharing with others and learning from the experiences of others. Congratulations to Kate and Clare Reeves, haemophilia counsellor at HFACT, for organising the Women's Wisdom High Tea in Canberra.

# FAMILY 2 FAMILY SUPPORT

Kelly Brady is Haemophilia Social Worker at the Queensland Haemophilia Centre, Royal Children's Hospital. She is Co-Chair of the Australia/NZ Haemophilia Social Workers' and Counsellors' Group.

*Kelly Brady*

'Support' is a word mentioned by both parents and professionals at some stage(s) during the family's involvement at a Haemophilia Centre. This can include, "What support is there for children and their families who have a bleeding disorder?" "How much support can I get?" "Where can I get it from?" "What will it cost?"

Obtaining support can be a number of things to different people.

Along with information and education about a bleeding disorder, families are also given information about what type of support is available to them and their child in their local area. In the early stages, some parents are eager to obtain some support, or as much support as possible, and some prefer to be left alone, and there are some who decline the offer of support, preferring to manage independently in their own time, in their own space. Whatever the family's choice, it should be accepted and respected. A family's need for support may change from time to time as their baby/child grows and develops, so support should be re-offered at different stages of the child and family's life.

In the Queensland Haemophilia Centre (QHC), I have been involved in my role as the (paediatric) Haemophilia Social Worker, developing and providing a number of different avenues for families and extended families to obtain support, particularly in the early stages when a family is told that their baby/child has a bleeding disorder. This can be a time fraught with grief; guilt; uncertainty about the future; confusion; and denial as the family begin to go through the process of coming to terms with their baby's/child's diagnosis, and to come to a stage of acceptance. During this

time, support from other parents/families is offered as a way of encouraging and assisting parents to make some sense of the situation by talking to another parent who has been in a similar, or sometimes the same situation as themselves. The feelings may be different, but often parents find they are very similar. While meeting or talking to another parent, parents can realise they are not alone in their thoughts and feelings, and do not have to feel isolated. This type of family to family support can also decrease feelings of uncertainty and encourage the family to 'see' that they can learn how to manage the bleeding disorder in their own daily lives and that their child can and will, have many positive experiences.

The following are examples of types of family to family support that is offered from QHC:

- offering a family a phone number or face-to-face contact with other parent(s) who also have a newly diagnosed baby/child;
- offering a family a phone number or face-to-face contact with other parent(s) who have a child who is older than the newly diagnosed child;
- family to family group support, ie Newly Diagnosed Families BBQ Picnic once a year; Young Families Support morning held in a child friendly venue so that children can play and adults can talk;
- community support (HFQ/HFA);
- invitation to education and information days/evenings; conferences etc.

From these opportunities and events, I have observed several situations where families sought and received positive support from other families. For example, a father of a new baby who was diagnosed with severe haemophilia was eager to talk

to another parent. I approached a father of another child, who also had severe haemophilia but was a few months older than the other baby. The father was only too happy to pass his phone number on to the new parent. The new parent contacted the other father, and later reported that the conversation was very helpful in terms of what to expect in the first few months of his baby's life. In another situation, at a Newly Diagnosed BBQ Picnic, a toddler attending the BBQ with his family was due to have a portacath (port) inserted the following week. Another child also attending the BBQ with his family had a port inserted a few months prior, so the two families talked, and the family whose child was about to have a port inserted had the opportunity to have a look at a 'real' port and ask questions to the other family about their experiences regarding port insertion. These are a few examples of how family to family support can be powerfully affirming and useful to both new parents and other families.


In addition to parents receiving support from other parents, there have also been instances where grandparents have sought and obtained support from other grandparents during New Diagnosis events. And let's not forget the children of course! Witnessing small children meeting other children their age, and learning that they also have haemophilia and perhaps a port too, is a touching, yet powerful event. I have been told by some parents that their child thinks that they are the only child to ever have haemophilia, but after meeting other children who also have haemophilia, they say it has positively changed their child's outlook on having haemophilia.

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However, not everyone wants to attend a support group for a range of reasons. Although children may have the same bleeding disorder as other children, it doesn't make them the same in terms of their experiences, how they react, and what their feelings, thoughts and emotions are. Parents of children who have a bleeding disorder also have different experiences and perspectives about the disorder. The key is, everybody is unique. The lives of families are busy and running at such a pace that some families are unable to attend support groups; or some choose not to attend as it reinforces something they don't wish to be constantly reinforced, ie they wish to focus on other aspects of their child's life. Whatever the case, each family has their own reasons for attending or not attending a support group, and this should be accepted and respected.

If you're thinking about attending a support group in your local area but are unsure what a support group can offer, here are a few things what you could expect:

- increased knowledge of a bleeding disorder, such as haemophilia or von Willebrand disorder;
- reduced feelings of isolation;
- opportunities to ask questions;
- to gain emotional/social support;
- a chance to share experiences – good and bad (remember, every child is different);
- to receive and offer advice, tips and strategies in managing your baby/child's bleeding disorder;
- to become empowered regarding treatment and management of your baby/child;
- to make friendships (children and parents);
- to learn how you could become involved in your local Haemophilia Foundation;
- and most importantly, to have fun and laugh!

Thank you to the families who agreed for their situations of family to family support to be printed. 

Dr Megan Sarson is Project Officer for Australian Haemophilia Centre Directors' Organisation (AHCDO).

# AUSTRALIAN HAEMOPHILIA CENTRE DIRECTORS' ORGANISATION UPDATE

*Dr Megan Sarson*

During the past few months there have been some important changes at AHCDO. In October we held our AGM in parallel with the HFA conference in Canberra. The Chairman of the previous four years, Dr John Rowell, stood down, having completed the maximum number of terms allowed by our Constitution and was replaced by Dr Scott Dunkley from the Royal Prince Alfred Hospital Haemophilia Treatment Centre (HTC) in Sydney. In addition to a new Chairman we also have Dr James Daly from the Royal Hobart Hospital HTC joining the Executive Committee for the first time.


Shortly after the AGM there was another change in AHCDO personnel with my return from 12 months' leave and Vicky Mrowinski, who had been filling in during my absence, departing to pursue other interests. There have also been several changes in HTC directors. A/Prof John Lloyd has gone into semi-retirement and his replacement at the SA adult centre is Dr Simon McRae. Dr Liane Lockwood at the Queensland paediatric centre has been replaced by Dr Simon Brown and finally Dr Ahti Lammi from The Children's Hospital at Westmead has handed over the reins to Dr Julie Curtin.

The redevelopment of the Australian Bleeding Disorders Registry has been a key issue for most of this year and will continue to be so until its official launch planned for later this year. Dr Rowell has been chairing the Redevelopment Steering Committee on AHCDO's behalf and other AHCDO members have contributed advice to both the Steering Committee and the Reference Group in collaboration with HFA and other stakeholders. Great efforts have been taken to

ensure patient confidentiality is maintained and we are confident that this will be achieved with the measures which have been designed and built into the registry. By the end of the year we will have a cutting edge registry which will facilitate clinical management of bleeding disorders!

AHCDO is planning to review several of its treatment guideline documents this year including the Guidelines for the Management of HIV and Hepatitis C Infection in People with Haemophilia and Guidelines for the Treatment of Inhibitors in Haemophilia A. The Guidelines for the Management of Pregnancy and Delivery in Women who are either Carriers or Patients with Bleeding Disorders were completed at the beginning of this year and have now been published on the AHCDO web site. We generally try to review the AHCDO guidelines every 2-3 years so that new treatment products and research can be incorporated into them.

The web site itself has also undergone rejuvenation and a new revitalised site has been launched recently - do take a look at [www.ahcdo.org.au](http://www.ahcdo.org.au). All AHCDO guidelines and publications are available on the site.

The AHCDO Executive Committee continues to examine a wide range of issues affecting the bleeding disorders community and has recently looked at eligibility of people with bleeding disorders for Medicare funded dental treatment, a review of the AHCDO Comprehensive Care policy and the latest developments in gene therapy research. 



# CLINICIAN RECOGNISED FOR SERVICE TO BLEEDING DISORDERS COMMUNITY



there are more than 900 people in Queensland with significant inherited bleeding disorders, including more than 110 with severe haemophilia

Dr John Rowell (left) receives his Award from Queensland's Minister for Health, Stephen Robertson

On 25 January, Dr John Rowell was recognised for his work at the Queensland Health annual Australia Day Awards.

Dr Rowell, Director of Haematology at Pathology Queensland, and Director of the Queensland Haemophilia Centre based at Royal Brisbane & Women's Hospital (RBWH), was recognised for 'service above and beyond the call of duty to the inherited bleeding disorder community throughout Queensland and northern New South Wales'.

Commencing at RBWH in 1984, Dr Rowell has dedicated his time here to haemophilia work, establishing a statewide service based at RBWH, which is also closely associated with the Royal Children's Hospital (RCH) service.

Dr Rowell said the formal establishment of centres at RBWH and RCH in 2000 ensured cooperation and an ability to provide a continuum of care from birth through to adulthood and old age.

"The cooperative services provide multidisciplinary care for those with haemophilia, von Willebrand's disorder and other inherited bleeding disorders," Dr Rowell said. "We also conduct outreach clinics at the Gold Coast, Toowoomba, Nambour, Townsville and Cairns providing local review for patients, maintenance of clinical and laboratory treatments, and ensuring there is a focus on haematology care in these areas."

Haemophilia and related blood disorders are uncommon but are highly resourced, due to the intensive treatment required by those suffering from these illnesses. Treatment requires replacement of factors missing in the blood, which are different depending on the disorder; for example those with haemophilia A have a factor VIII deficiency and people with haemophilia B have a factor IX deficiency. Treatment may be administered as a prophylaxis, which involves the infusion of clotting factor on a regular schedule to prevent spontaneous bleeding episodes, or on-demand treatment, which involves treating bleeding episodes as they arise. Some people with haemophilia develop antibodies (inhibitors) against the replacement factor which means the amount of the factor must be increased or alternative products must be given.

As well as being involved in direct clinical care, Dr Rowell works in the laboratory to ensure accurate and prompt diagnosis, monitoring of therapy and genetic testing providing carrier and antenatal diagnosis.

Caring for a haemophilia patient involves a multidisciplinary team including a nurse, social worker, physiotherapist and physicians specialising in infectious diseases, liver disorders, and orthopaedics.

"At present there are more than 900 people in Queensland with significant inherited bleeding disorders, including more than 110 with severe haemophilia A," Dr Rowell said.

"Over the past 30 years there has been a gradual change from hospital treatment to home treatment, with care of a person with haemophilia considered a partnership."

As well as monitoring treatment, Dr Rowell said it was also important to educate people about haemophilia. This includes parents, when a child was first diagnosed; their teachers and classmates, as they grew older; and their colleagues, as adults.

"Most people with haemophilia manage their treatment at home, so few require treatment at emergency rooms. To facilitate prompt treatment each person has a card outlining their specific diagnosis and treatment needs such as product used and dosing," he said.

"Although there is no cure for haemophilia at present, prophylactic factor replacement now means that those born with haemophilia can look forward to a near-normal life span and better quality of life."

Dr Rowell was recently Chairman of the Australian Haemophilia Centre Directors' Organisation. The Organisation's current major project is to develop a national register and database which can be used as a clinical and research tool for those involved in haemophilia treatments. **H**

# THE IMPACT ON PARENTS OF DEVELOPMENTS IN THE CARE OF CHILDREN WITH BLEEDING DISORDERS

*D Shaw and G A Riley*

## INTRODUCTION

Recent decades have seen important changes in the services provided for children with long-term medical conditions<sup>1</sup>. Whereas, previously many spent much of their childhood in hospital, now there is an emphasis on ensuring that they remain with their families, attend local schools and lead as normal a life as possible. There has also been a move away from a paternalistic doctor-patient relationship towards greater patient autonomy, in which the child and their parents are given responsibility for decisions about treatment and the day-to-day medical management of the condition.

Previous research has shown that the shift to home-based care, facilitated by prophylaxis, has led to significant improvement in the quality of life for children with bleeding disorders<sup>eg2</sup>. Nevertheless, the impact of these changes merits further attention. Current measures of quality of life are fairly blunt tools for assessing the complex impact of a medical condition on a child. When given the chance to air their views in open-ended questions, parents and children tend to highlight continuing areas of difficulty and concern<sup>3</sup>. Moreover, the impact of the changes on the wider family has less often been investigated.

To address these gaps, the present study explored the impact of these changes (ie the move to home-based treatments and greater parental responsibility) on the parents of children with bleeding disorders using open-ended questions and qualitative methods.

## METHOD

Participants were accessed through two Comprehensive Care Centres in the UK providing specialist care for people with bleeding disorders. Parents of children between the ages of eight and 12 were asked to take part. Twenty-seven families were approached and 24 of these agreed to be interviewed. The interviews involved open-ended questions designed to elicit information about the parents' perceptions of the advantages and challenges associated with home-based treatment and parental responsibility. In the case of nine of these families, the child was on home-based prophylaxis and their condition was classified as 'severe'; in eight cases (all but two of which were classified as 'severe'), the child

received on-demand treatment at home; and the remaining seven cases (only two of which were classified as 'severe') received on-demand treatment in hospital. Four of the children had von Willebrand Syndrome, and the rest haemophilia.

## RESULTS

### The benefits of home-based treatment and prophylaxis

Parents of children on home-based treatment viewed it as less disruptive of normal family life than hospital-based treatment, with less time taken off school and work. It was also valued because, by providing treatment without delay in a safe and familiar environment, it avoided the stress associated with emergency or quasi-emergency journeys to hospital for treatment. More generally, parents appreciated the normalising effect of home-based treatment. Dealing with the child's condition became part of the normal family routine, rather than a time-consuming and disruptive intrusion. Parents of children on prophylaxis were also enthusiastic about the additional benefits it brings. They felt able to relax some of the restrictions previously placed on the child's and the family's physical activities, and felt less need to monitor or worry about what the child was doing.

### The challenges of home-based treatment

Although most parents carried out the treatment without difficulty, a few struggled with the task of injecting their child. They felt squeamish about it, or lacked confidence in their ability to carry it out correctly and were fearful of doing something wrong or causing pain to their child. The task of delivering the treatment was occasionally made more difficult by resistance on the part of the child.

Some parents with experience of spending lengthy periods in hospital valued the opportunity that this had given them to make contact with other parents of children with bleeding disorders. Not having access to this mutual support was viewed as a potential disadvantage of home-based treatment.

### The challenges of greater parental responsibility

Parents in this study had less experience of a more paternalistic style of medical care, and so it was difficult for them to elaborate on the advantages of greater parental responsibility. This report accordingly focuses on its challenges.

The decision about what form of treatment to choose had proved difficult for some parents. The difficulty stemmed from the lack of guarantees about product safety. Anxiety about the contamination of blood products, often based on family history, was a major factor. There was also concern about the potential long-term side-effects of prophylaxis, and a desire to avoid any medication unless necessary. For some, the fear of being responsible for a treatment that harmed their child outweighed the advantages of home-based treatment and prophylaxis, and they had opted to remain with on-demand treatment in hospital even though they considered prophylaxis to be the rational choice.

Decisions about the daily management of the condition could also be difficult. Some parents lacked confidence in their ability to make decisions about how best to respond to a bleed. In addition, most parents, even those who had opted for prophylaxis, struggled with the dilemma of balancing the desire for the child to have a normal active lifestyle and the desire to protect them from risk. There was considerable variation across families in terms of how this dilemma had been resolved, with some children having more restrictions placed on their physical activities even though their condition was not as severe.

Because of the uncertainty and difficulty surrounding these decisions, responsibility for managing the condition was experienced as stressful by some of the parents. Many parents also expressed a need for support and reassurance in making the decisions. In this context, the support provided by the staff at the Comprehensive Care Centres was highly valued. At times when staff at the Centre were not available, some parents had accessed local non-specialist medical staff for guidance and help, but in several cases this had proved unsatisfactory because of their perceived lack of expertise.

## DISCUSSION

Consistent with earlier research<sup>eg2</sup>, the study found that home-based treatment and prophylaxis have major advantages. However, it was evident that the change to home-based treatment and greater parental responsibility has also presented parents with some challenges.

There were problems around treatment administration. Some parents found it difficult because of their squeamishness or lack of confidence, and child resistance was also a factor. These difficulties surrounding treatment administration, as well as being distressing for those involved, may also have significant implications for choice of treatment and compliance. Hacker et al<sup>4</sup> reported that <60% of their sample of parents rated their compliance with prophylaxis as 'excellent' (defined as giving at least 76% of prescribed infusions). Lack of co-operation from the child and the difficulties of administration were cited by parents as major reasons for reduced compliance.

Child resistance was also cited by some of their sample as a reason for not starting prophylaxis. It is clearly important that support is made available to parents in addressing these difficulties surrounding treatment administration. Programs for teaching parents the practical skills of home treatment should also address how to deal with child resistance and the emotional aspects of treatment delivery. In more serious cases, access to specialist psychological support may be needed.

Making the decisions about treatment and daily management of the condition was also a challenge for most of the parents. Miller<sup>5</sup> highlighted the particular challenges raised by haemophilia in the move from the paternalistic model of care to greater parental responsibility and patient autonomy. Because of the lack of guarantees about treatment safety and the lack of an overriding consensus about the best form of treatment and management, these decisions are inevitably complex and uncertain. Services thus need to give particular attention to how they support parents in making these decisions. The provision of clear information is obviously important, but parents should also be encouraged to discuss the anxieties associated with the decisions. Some parents were aware that their decisions were driven by these anxieties rather than a rational appraisal of what was best for the child and the family. Support from staff at the Comprehensive Care Centres was highly valued, but problems had arisen when parents accessed local non-specialist services outside the normal working hours of the Centres. Extending hours of access to staff support at the Centres merits consideration. Parents also valued mutual support from other parents, and the loss of this was seen as a potential disadvantage of home-based treatment. Parents could be encouraged to access this support through alternative routes (eg telephone support networks and internet-based discussion forums).

For some parents, in the study, the shift to home-based treatment and greater parental responsibility was associated with a significant increase in stress – because of difficulties in treatment administration, worry about the child's physical activities and the challenge of making decisions about treatment and management in the face of uncertainty. Parental stress needs to be supported when they are not coping well with their situation. There should be access to specialist psychological support at these times.

## DISCLOSURES

The authors stated that they had no interests which might be perceived as posing a conflict or bias. **H**

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# STORIES FROM PEOPLE LIVING

Suzanne O'Callaghan

What is it like to live with a bleeding disorder and hepatitis C?

One of the biggest issues that came up in the HFA Hepatitis C Needs Assessment was that many people felt alone. They thought it was important to hear other people's stories about their experiences but did not have many opportunities to do this.

Some showed interest in being linked up with another person in their situation. The Haemophilia Social Workers and Counsellors have been working on confidential 'buddying' systems, where they help individuals with a bleeding disorder and hepatitis C to contact each other for mutual support, particularly during treatment. If you are interested in buddying, contact your local Haemophilia Social Worker or Counsellor.

In the feedback on the 'Double Whammy' Report so far, several people commented on the difference it made to them to read the stories in the Report and realise that other people shared their experiences. The Report includes many personal stories, both from the HFA member surveys that were returned in 2003 and from the focus groups in 2007. The summary of the Report sent out with the December 2007 *National Haemophilia* also included personal stories. Some people wanted to read more stories but found the Report too large to read all at once, so we have taken samples of quotes and personal stories from the Report to make a few articles on specific topics. These will be published over the next few issues of *National Haemophilia*.

## PART 1. LOOKING AFTER YOUR HEALTH

### Health and hepatitis C

What was the impact of hepatitis C on people's health?

- Some people did not have symptoms and felt that hepatitis C was not affecting them. This included some people who were HCV antibody positive but no longer had hepatitis C on their RNA PCR test and some who had completed treatment successfully.
- Most felt chronically unwell and described feeling "down", tired, lacking stamina, having liver pain, nausea and "brain fog". Many were experiencing depression.
- If they had moderate or severe haemophilia, hepatitis C was an added burden on top of joint pain and disability caused by haemophilia and sometimes HIV as well. Without successful treatment, this often made their level of disability unmanageable by the age of 35-40 years.

My son is the spitting image of good health at the moment. When you see him you wouldn't have a clue that he had any medical problem whatsoever. [parent]

Life had been pretty tough. Haemophilia, arthritis, HIV and hep C, and dealing with normal day-to-day pressures were getting pretty hard to deal with. I was constantly fatigued, in pain, suffering nausea and my mood was pretty flat.

I've had hep C for so long, I don't know what it's like to be healthy... Sometimes I have good days, some not so good.

What's good, what's bad? I feel I'm doing alright, and just carry on regardless... I'm not here for a long time, I'm here for a good time. That's pretty much the attitude that I've got.

[My husband] is quite lethargic... he always presents that he's fine but you know things aren't quite right. [partner]

If you were going to ask me how has hep C affected me, I can't tell you.... because if I go to work during the day I might get up at 10 o'clock because I'm too tired then, and I don't know whether that's hep C or because of my lifestyle.

I don't know whether it's because I'm just getting older, you have to use a little bit more energy walking around because of the problems that we have, or it's just the hep C.

You try to carry on just like anybody normal, but you can't say much because back in those days it was taboo to mention hepatitis C or haemophilia. You'd get a big frown from everybody if you said a word about it.

I'm not working full-time but the days when I work, come 2 o'clock I hit a wall. Want to just put my head forward and doze off. I guess that's my biggest problem.

...the daily nose bleeds and things like that, the tiredness, I guess the stress of his hep C which has progressed on to a [liver] cancer. [partner]

Over the years, because he's had it since [early 1980s], and as he gets older, it's impacting more... there's a constant foggy brain, there's a constant fatigue. But he can wake up one morning and be fine and charge around like a maniac... then you've got fatigue and mood swings and foggy brain the day after. [partner]

[my husband] mentioned to me last night that he possibly won't be able to take anti-inflammatories [because of liver disease] That's a big worry because he has an anti-inflammatory every day. He can't really get around without it; he's in a lot of pain without the anti-inflammatories.



# WITH HEPATITIS C

Often if I get a funny result – I take mine home, I analyse it and I'll get on the Internet and have a look on the Internet, and then if I can't pinpoint something down..., I'll go back to the nurse or the doctor and say, well what's this?

I only know what two of my tests are and that's my [haemophilia levels], so that's like two out of eight tests I get every six months. So other than that I have no idea what they're testing for. Just eight vials of blood.

I'd say go for treatment if you are given that option. I think we have regrets in that department... and we now since find out that he's got the good genotype and it's too late.

I know what a lot of them [test results] are, what the abbreviations are and all that sort of stuff. Only because it's been explained to me a few times. And I know the key ones to look for. And it's just a matter of taking the time to understand that because the staff are more than happy to help you with that kind of thing. And you've got to enquire, you've got to ask these sorts of things, I feel. Then once you do that then you can pretty much keep control on what's happening with yourself.

You are better off being there, because [my husband] just stopped going [to the hepatitis clinic]. I saw [haematologist] and he'd say, he hasn't had a blood test for a while or hasn't done this, and that's when we found out he was really badly ill and had to go back to clinic again. [partner]

## Keeping track of hepatitis C

How did people keep a check on their liver health? Some Haemophilia Centres performed hepatitis C and liver function tests themselves, while others referred their patients to the hepatitis clinic. Tests included:

- Hepatitis C RNA PCR test - testing for hepatitis C virus in the blood
- Hepatitis C genotype test - testing for the strain of hepatitis C
- Liver function tests (LFTs) – blood tests measuring the general condition of the liver
- Ultrasound – a scan of the outside of the liver and the blood flow through the liver
- Liver biopsy – a sample of a small amount of the liver to look for scarring or inflammation in the liver

## Treatment

Some people with bleeding disorders had already had successful hepatitis C antiviral treatment. Side-effects of treatment had varied from person to person.

Some people were considering treatment with pegylated interferon and ribavirin, which had higher success rates than earlier treatment courses. For many others, treatment had failed or they had relapsed after treatment, particularly if they had the less effective interferon monotherapy in the early 1990s.

## More information and support

HFA has produced a basic information booklet on hepatitis C for people with bleeding disorders. This is available from your local Haemophilia Centre or Haemophilia Foundation. It is also on the HFA web site: [www.haemophilia.org.au](http://www.haemophilia.org.au)

There is a lot of high quality information on hepatitis C available from Hepatitis Councils. HFA has developed a hepatitis C section of the HFA web site with links to selected information from the Councils and other sources. Haemophilia Centres and Haemophilia Foundations usually have a range of relevant resources as well.

For other information about services and support for people with bleeding disorders and hepatitis C near you, contact your Haemophilia Social Worker/Counsellor, your Haemophilia Centre, your state/territory Haemophilia Foundation or HFA. You will also be able to obtain valuable information from Hepatitis Councils.

I had the interferon when I was [a teenager]. Everyone said it was going to give me side effects and all this. And I felt nothing. I had it and felt healthy the whole time.

I'd read all the side effects and said, oh well, I might be lucky and get two or three of them and then I felt like I had all of them. It slowly got better, but it lasted the whole treatment.

My doctor said I should have treatment, but I am worried about whether I would cope. They say it's pretty bad and I live on my own. Besides I am not sure that I could cope with work as well – and I couldn't afford not to work. I already use most of my sick leave and recreation leave on time off because of bleeds.

I've been on two courses of treatment now and both times I've relapsed as well. So I'm at a loss now where to go.

I think I'll go [on treatment] again because it doesn't get rid of the virus but it gives it a hell of a hiding. I think that makes a difference.

But then you have to weigh up the options of what's going to happen in the future. Am I going to be for a year and a half or two years Depressed In the Corner Dad then maybe clear the virus, or am I going to be Thirty Years Dead Dad?

Antiviral combination therapy is what we went through... It was hell to live through but it had a positive outcome. [partner]

I had flu-like symptoms, particularly during the first 4 weeks, a lot of nausea, a lot of fatigue, needed to rest a lot to deal with those things. Certainly there were personality changes. Not just in the first 4 weeks but for the whole duration of the treatment and probably for several years afterwards. You become less tolerant, certainly harder to live with, moody. As I mentioned before there were certain fluctuations in sugar levels which affected the way I behaved and how much energy I had.

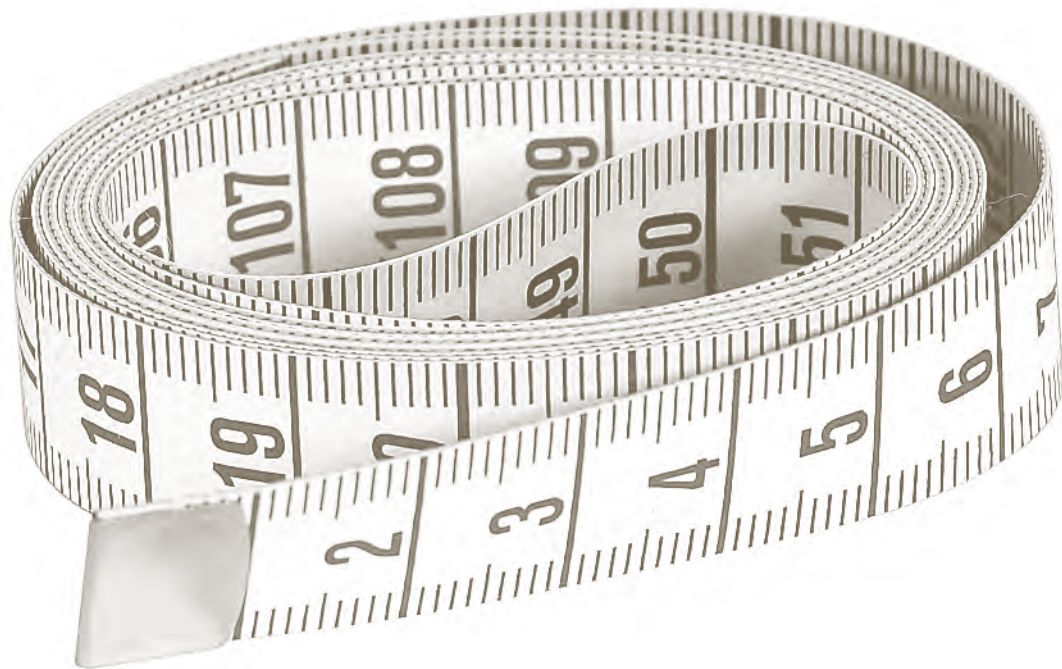
[The treatment] got stronger and stronger with the pegylated and the ribavirin... There were signs that the liver was actually improving... It might have been OK if I was in the situation where I was able to just do nothing, but at the time I was trying to earn a living and dealing with all life's little issues... It was just too overwhelming... I only got 8 weeks into it, so that was it. It was all over.

I was cared for 24/7 when I was on treatment years ago. I was living at home with mum and dad and mum was my carer. She did everything for me. Fed me, got me out of bed, sent me off – I continued to work, but it was a struggle.

I've had the hepatitis C treatment... for 6 months and it didn't affect me whatsoever. I just went straight through it.

# LOOK DOWN- the key to your health is your waist

Peter Lavelle



You might have heard the latest figures from the Australian Bureau of Statistics; overweight and obesity rates are up. In 2005 (the last year for which figures are available), 54% of Australian adults were overweight or obese. In 1995, that figure was 45%.

And you might have thought, 'yada yada yada, doesn't affect me, I'm not overweight'.

And if you're health conscious (and have a calculator) you might be able to prove it to all and sundry – by dividing your height by the square of your weight, and come up with a number that proves you're not overweight. This figure, known as the body mass index (BMI), is a convenient way of telling if someone is overweight. It's more reliable than simply weighing yourself on the scales, because weight varies with height. If you're tall, your weight might be normal even though it's greater than an average person's weight.

Body mass index is weight in kilograms divided by height in metres squared – just go to [www.mydr.com.au/tools/bodymass.asp](http://www.mydr.com.au/tools/bodymass.asp) for a BMI calculator. Over 25 means you're overweight, over 30 means you're obese.

But increasingly experts are coming to believe that the type of fat and its location may be more important than the BMI – and that your abdominal girth is really the figure that you ought to be worried about. Even if your BMI is normal, if you have a big gut – a 'beer gut', a 'pot belly', a middle aged spread – you're at risk of serious chronic disease, say researchers.

US researchers looked at 2,700 men and women in Dallas, Texas, aged 18-65, measuring their body weight, their height, their waist circumference, and waist-to-hip ratio; and then gave them a battery of medical tests, including MRI scans of their abdomen and scans of their coronary arteries to see if they had atherosclerosis, the disease of the arteries that causes heart attacks. They found that even a small increase in the waist-to-hip ratio increased the risk of heart disease

even if the person's BMI was normal. They published their findings in the *Journal of the American College of Cardiology*.

BMI is a rough measure of obesity – it doesn't tell you where the fat is located. But fat that's located in the abdomen seems to be much more dangerous than fat elsewhere, like the hips and buttocks. Fat in the abdomen is stored in and around the internal organs in the abdomen. It's also called visceral fat. The term 'viscera' means 'organ' and there are more organs in the abdomen than elsewhere, hence most of the fat ends up in the abdomen. Abdominal fat accelerates atherosclerosis. We don't really know how; perhaps it's by releasing fatty acids and inflammatory chemicals from fat cells that damage the arteries.

But fat in other areas doesn't put a person at increased risk of heart disease. So, in fact, waist circumference is a better indicator of risk for disease than total body weight as measured by BMI.

## METABOLIC SYNDROME

Excess abdominal fat is one of a cluster of conditions collectively known as 'metabolic syndrome' which also includes high blood pressure, abnormal blood cholesterol and fats, and abnormal blood sugar metabolism. Metabolic syndrome – having all these conditions – greatly increases the chances of heart disease, diabetes and stroke.

As we get older, we tend to put on more abdominal fat than fat elsewhere. It's more common in men – especially men who drink a lot of alcohol, as the extra kilojoules from the alcohol are stored in the abdomen as fat. It's more common in people who have a diet high in fats and sugars, especially highly processed, energy-dense foods, which provide more energy than they need. And it's more common in people who don't exercise to burn the excess kilojoules off. It's also more common in people who smoke and who are stressed. Abdominal fat tends to be more common in Asians and Indians than in white Caucasians of the same BMI.

So how much abdominal fat is too much? In men, a waistline of greater than 94 cm carries a risk of heart disease, stroke and diabetes. For women, the figure is 80 cm or more. The risk is substantially increased over 102 cm (men) and 88 cm (women). These are World Health Organization figures. The waistline is measured by running a tape measure around the waist at the narrowest point between ribs and hips (usually just above the belly button) after breathing out. For Asians and Indians, the cut-offs are 10 cm lower.

Even more accurate, according to the Dallas researchers, is the waist-to-hip ratio (WHR). You get that by dividing the waist circumference by the hip circumference – which is measured by running the tape around the hips at their widest point (usually around the bony prominences). The ideal WHR is 0.9 or less for men and 0.8 or less for women.

## GETTING IT OFF

So even if your body mass index is in the comfortable range, if your waistline is outside of these figures, you're at risk, unfortunately. No more yada yada yada.

The good news, though, is that as well as being a type of fat that is quickly put on, abdominal fat is more quickly taken off than fat in other areas. The way to do it is to:

- Reduce your alcohol intake and don't smoke.
- Not eat foods rich in fats and sugars, like processed and take-away foods. Eat a low calorie diet, with plenty of fresh food and vegetables.
- Exercise regularly. People who diet and exercise are much more likely to lose abdominal fat than those who diet only.

If your waistline (and/or WHR) is over the recommended limits given above, see your doctor for a check up and possible blood tests. Commercial weight loss programs are also worth considering. **H**

But increasingly experts are coming to believe that the type of fat and its location may be more important than the BMI – and that your abdominal girth is really the figure that you ought to be worried about.

# WHAT IS HFA DOING ABOUT HEPATITIS C?

Suzanne O'Callaghan

## 'DOUBLE WHAMMY' REPORT FEEDBACK

What has the community had to say about the 'Double Whammy' Report? As you may recall, HFA included a 'Your Say' form in the last *National Haemophilia* to invite feedback and asked everyone to return their comments by 31 January 2008.

Due to popular demand, the return date for feedback has been extended to 18 April 2008. If you are thinking about sending back your comments, please take this opportunity to get them back to us – we'd love to hear from you!

You can also give feedback via the HFA web site. See 'Your Say' on the *Double Whammy* page – [www.haemophilia.org.au](http://www.haemophilia.org.au).

## HFA HEPATITIS C WORKING PARTY

The HFA Hepatitis C Working Party has met by teleconference four times now and is developing a strategic plan around the financial issues and the health and wellbeing recommendations in the Report. Results so far:

**Financial issues:** HFA is seeking advice about insurance, to see if there are ways of increasing access for people who may be excluded because of pre-existing medical conditions.

**Treatment access:** HFA is actively pursuing access to subsidised retreatment for hepatitis C for people whose doctors recommend it. The Pharmaceutical Benefits Scheme, which subsidises hepatitis C treatment, technically excludes people who have previously had hepatitis C treatment. In spite of this, there may be other ways for doctors to access subsidised retreatment for their patients, eg through compassionate access or clinical trials. While this can work well for some people who attend large hepatitis clinics, it can be a problem for those at smaller clinics or in rural and regional areas with limited access to treatments. It is also a greater administrative workload for the clinics. HFA sees this as a barrier to making hepatitis C care available equally across Australia for all people with bleeding disorders affected by hepatitis C.

If you are considering hepatitis treatment, speak to your hepatitis specialist who will look at the options for you including access to subsidised treatment.

**Education and health services:** my initial discussions with hepatitis health professional groups highlighted that they do not often consider the issues relating to people with bleeding disorders in their education programs or their guidelines for medical or nursing management, but that they are very happy to include them. Education for the bleeding disorders community on hepatitis C and health services for people with bleeding disorders affected by hepatitis C also came up in the Needs Assessment. I am currently discussing how best to follow all these issues up with the national haemophilia and hepatitis health professional groups.

## STAGE 3 HEP C FOCUS GROUPS

In Stage 3 of the Hepatitis C Needs Assessment, HFA is following up issues that were raised in the first set of focus groups and consultation. This stage involves feedback from the bleeding disorders community about the Report and recommendations, as well as gathering further information on some questions, such as ageing, young people, women, living in rural, regional and remote areas, and Aboriginal and Torres Strait Islander issues.

Stage 3 included a number of focus groups in Victoria and NSW in early March.

The focus groups were advertised by HFV and HFNSW and were supported by Sandy Breit, the Haemophilia Counsellor in Victoria and Leonie Mudge, the Haemophilia Social Worker in NSW.

The information HFA obtains from the focus groups and other consultation will be written up into a short report and used to fine-tune the HFA national hepatitis C strategy. We will summarise this in an article in *National Haemophilia*.

## HEPATITIS AWARENESS WEEK

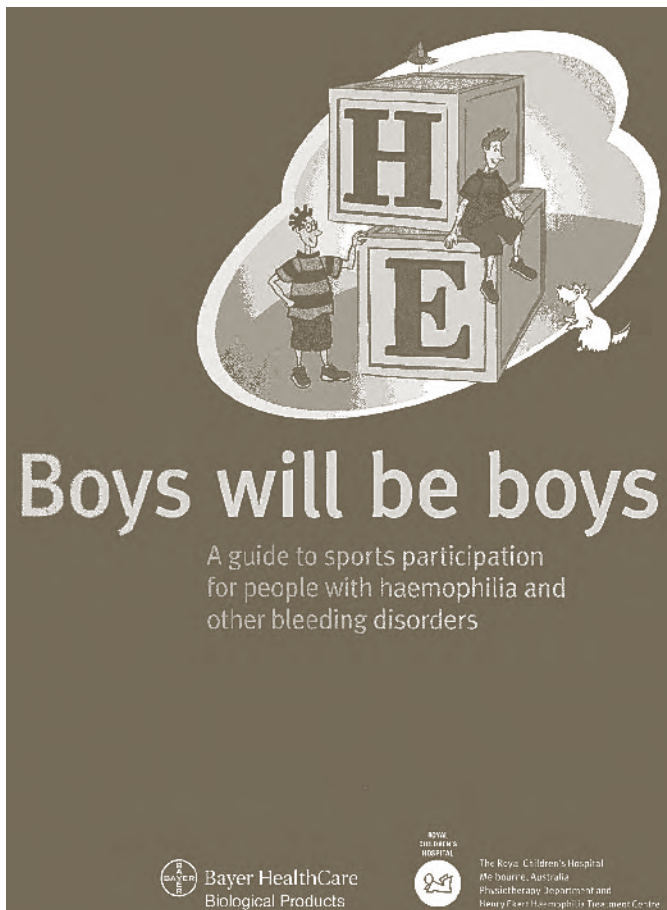
World Hepatitis Day is on 19 May 2008. Australia will be holding Hepatitis Awareness Week in the week 19-25 May 2008.

How can we make Hepatitis Awareness Week relevant to people with bleeding disorders? I am working with state and territory Haemophilia Foundations and Hepatitis Australia to look at ways we might be able to achieve this. So keep an eye out in your local newsletter or on the HFA web site to see what we come up with! **H**



# THE IMPORTANCE OF SPORT

Brendan Egan



For many years people with haemophilia and other related bleeding disorders were not actively encouraged to participate in sport or physical activity, to try to minimise the number of bleeding episodes they experienced. During the 1980's doctors in many developed countries, including Australia, began giving boys and men with haemophilia clotting factor concentrate on a preventative basis (called prophylaxis).

The impact on the older population has been good, assisting in reducing their bleeding frequency. However these men are still dealing with the impact of the physical consequences of years of muscle and joint bleeds, including arthritis, joint inflexibility and muscle weakness.

However for many boys with haemophilia, particularly those who have grown up only with prophylaxis, it has markedly reduced the number of bleeding episodes, therefore reducing the joint and muscle changes so common in the older haemophilia population. The joint does not get damaged if a bleed does not occur.

Receiving prophylaxis is not the only reason that bleeds have decreased. As prophylaxis has allowed more participation in physical activity, boys with haemophilia have stronger muscles and are more able to accommodate the stresses placed on their body.

Within the group of boys who have only known prophylaxis it is the boys who are active, fit and strong who have the least problems. Even with prophylaxis, boys who are not active, do not participate enthusiastically in sport and leisure activities and who are possibly overweight all seem to get into more trouble with their bleeds.

Physical activity has many benefits for everybody, but particularly for people with haemophilia, who often have reduced fitness levels compared to their peers without a bleeding disorder.

These include:

- Increased muscle strength and endurance
- Improved joint stability
- Improved confidence and self esteem
- Improved normal motor development and enhanced skill acquisition and co-ordination
- Greater opportunities for socialisation at school and during sport and leisure activity.
- Maintenance of appropriate body weight.

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This book came about to ensure that people with haemophilia are fully informed about their sporting choices and understand the risks of a particular sport.

Over the past ten years health professionals working in this area have been an increase in sports participation and also in the type of sport played. Every sport we have reviewed in this book has most probably been played by one of our boys in that time. Sometimes we have known about it, other times we have not. This book came about to ensure that people with haemophilia are fully informed about their sporting choices and understand the risks of a particular sport.

## THE RISK OF INJURY/BLEED

There are many factors that may influence how a person with haemophilia copes with physical activity.

There are factors that are related to the person's body:

1. How strong and fit they are and how well conditioned their body is to the sport or activity they are commencing or participating in.
2. What previous injuries they have experienced. For a person with haemophilia this will also take into account their previous bleeding history and the presence of joint damage or arthritis.
3. Full rehabilitation before returning to the sport.
4. A player's skill level.

There are also factors related to the inherent nature of the sport or environment in which the sport or activity is being played:

1. Playing surface
2. The nature of the contact (if any)
3. Use of appropriate protective equipment
4. Rules of the game (modified to reduce the risk of injury)
5. The position a player competes in.

This booklet will address these issues generally and specifically for each sport. Each sport profile will outline what the common injuries are for that particularly sport and then discuss injury prevention under three headings:

### 1. Warm-up

This section explains what is the most appropriate warm-up for the sport and includes the correct stretching routine.

### 2. Protective wear

- **Mandatory:** equipment that the governing body or laws of a game state must be worn by each competitor or participant.
- **Strongly recommended:** this is equipment that is not mandatory but we strongly believe should be worn at all times by people with bleeding disorders participating in the sport.
- **Optional:** this is equipment that might be appropriate for a person with haemophilia, but is not essential. This might include equipment or bracing/taping that is recommended to you by your physiotherapist because of your individual history and requirements.

### 3. Additional protective considerations

This section lists other issues that may assist in reducing the risk of injury. This might include issues relating to playing surface, skill level or player position.

## WHEN PREPARING FOR A SPORT

We strongly recommend that all people with haemophilia discuss sport participation on a regular basis with a haemophilia physiotherapist. This is of particular importance when choosing a sport not played before, or if there has been a history of a target joint or pain. A physiotherapist will be able to assess a person's physical condition. They will prescribe exercises to improve strength, flexibility and give advice regarding the use of additional protective equipment, taping or bracing and the use of orthotics (arch supports).

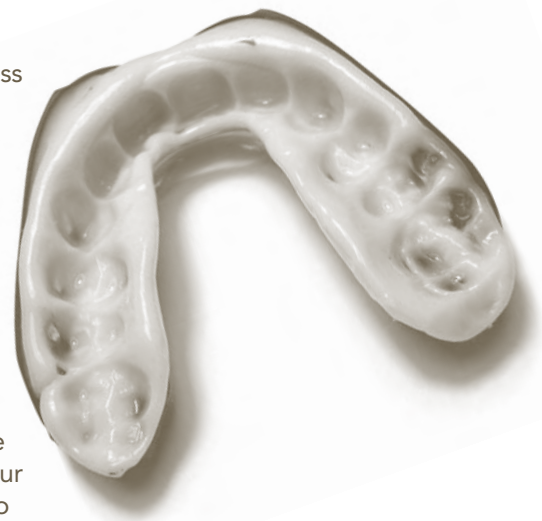
It is also important to discuss prophylaxis with a haemophilia consultant when commencing a sport. It may be possible to change the days of factor treatment to occur just prior to or on the day of play to ensure that there is the maximum factor level whilst playing sport.

It must be remembered that people with bleeding disorders generally

have lower levels of fitness than their peers. Other factors that may improve a person with a bleeding disorder's readiness to play sport include:

1. A gradual increase in activity. This might include training for a few weeks before competition or having shorter and less intensive sessions before embarking on longer and more intensive sessions.
2. Training, specific to the sport to be played.
3. Appropriate muscle strength and flexibility. It is particularly important to fully rehabilitate after a bleed/injury.
4. A good standard of coaching and supervision.
5. An appropriate level of skill.


Children and adults with a bleeding disorder and their families must have an understanding of the risks involved with each sport and weight them up with the benefits that will be gained from their participation. This is best done in consultation with the physiotherapist and other health professionals at the Haemophilia Treatment Centre. **H**



# TWINNING WITH THAILAND

World Federation of Hemophilia (WFH) has advised Haemophilia Foundation Australia (HFA) that the WFH Hemophilia Organisation Twinning Committee has granted funds to support the next stage of the Thailand-Australia twinning project. This will enable HFA and the Thai Hemophilia Patients Club to progress the work commenced in 2007.


We are delighted that Robert McCabe, Co-Chair of the HFA Youth Committee, and Thakul Vechpanich, an active youth leader in the Thai Hemophilia Patients Club, will both be attending the WFH National Member Organisation training in Istanbul on Youth Fellowships.

Representatives from the National Hemophilia Foundation of Thailand, Thai Hemophilia Patients Club and HFA will meet to make plans for the next steps in May during the WFH Congress. 

# HAEMOPHILIA FOUNDATION RESEARCH FUND

The Haemophilia Foundation Research Fund was established in 1990 to fund Australian based research in the area of haemophilia and related bleeding disorders. Since then, a range of medical, scientific and social research projects have been funded throughout Australia, amounting to \$467,592. Many of these projects have resulted in positive outcomes including improved treatment, care and services for people with haemophilia and von Willebrand disorder, including those with blood borne viruses, and other related issues for the bleeding disorders community.

## NEW FUNDING ROUND

A new funding round will be announced shortly. See the next edition of *National Haemophilia* for further details. If you wish to be advised by email when the funding round is announced, please contact [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or freecall 1800 807 173. 

# CALENDAR



## Red Run Classic

Brisbane 25 May 2008

ph 03 9885 7800

fax 03 9885 1800

email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au](http://www.haemophilia.org.au)



## XXVIII International Congress of the World Federation of Hemophilia

Istanbul, Turkey, 1-5 June 2008

[www.wfh.org](http://www.wfh.org)

## 20th Annual ASHM Conference

Perth 17-20 September 2008

ph 02 8204 0770

fax 02 9212 4670

email [conferenceinfo@ashm.org.au](mailto:conferenceinfo@ashm.org.au)

[www.ashm.org.au/conference](http://www.ashm.org.au/conference)

## 6th Australasian Viral Hepatitis Conference

Brisbane 20-22 October 2008

ph 02 8204 0770

fax 02 9212 4670

email

[conferenceinfo@hepatitis.org.au](mailto:conferenceinfo@hepatitis.org.au)

[www.hepatitis.org.au](http://www.hepatitis.org.au)

## Haemophilia Conference 2009

Brisbane 8-11 October 2009

ph 03 9885 7800

fax 03 9885 1800

email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au](http://www.haemophilia.org.au)

## Corporate Partners

Haemophilia Foundation Australia (HFA) values the individuals, Trusts and Corporations which donate funds to support our objectives.

Among our valued donors are our Corporate Partners who provide unrestricted grants to HFA to support our programs:

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