

# National



# Haemophilia

Haemophilia Foundation Australia

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

No. 173, March 2011

## Be inspired, get involved in Treatment for All



### Engaging Individuals, Empowering Communities

We all have a role in improving and protecting treatment for people with bleeding disorders. You can help by:

- Inspiring others by sharing your story
- Educating people about living with a bleeding disorder
- Getting involved with the bleeding disorders community at a local, national, or global level



**WORLD HEMOPHILIA DAY | APRIL 17**

To share your story visit [www.wfh.org/whd](http://www.wfh.org/whd)

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## BE INSPIRED.... GET INVOLVED... TREATMENT FOR ALL



World Haemophilia Day is celebrated on 17 April every year. This year, why don't you join us to celebrate some of our achievements and get involved to improve treatment and care around the world.

In Australia, treatment and care is of a high quality, and there are sufficient supplies of safe clotting factor for everyone who needs it. Most people have their treatment at home, and for many their clotting factor is delivered to their home. Visits to haemophilia centres are generally for reviews and unless there is a complication, most Australians with a bleeding disorder do not need to be admitted to hospital.

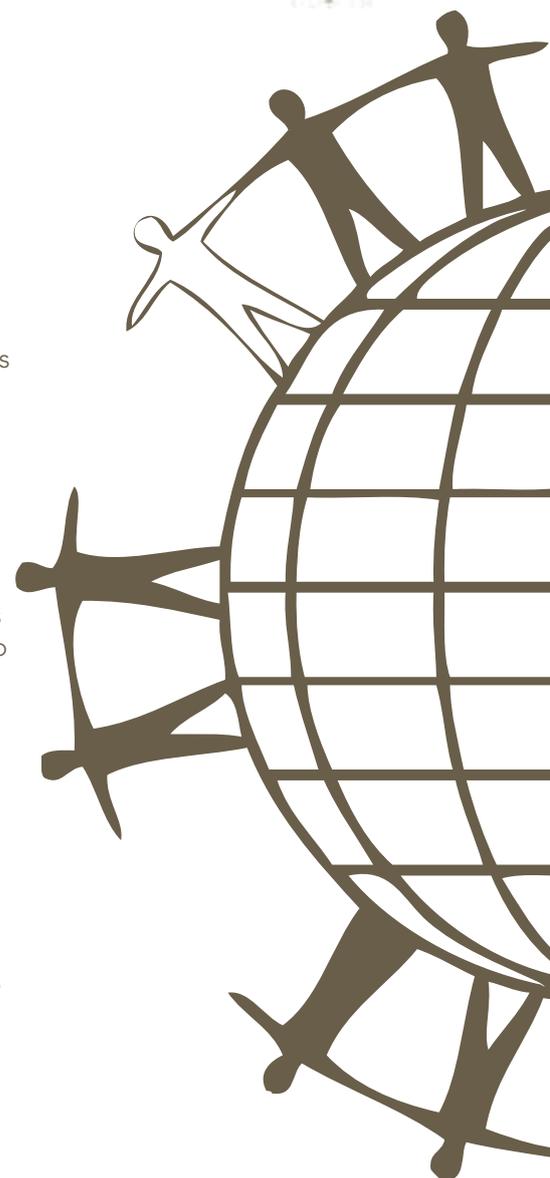
On World Haemophilia Day we ask you to think about the challenges faced by people in different countries and to be inspired by their stories. Join together with the international community to raise public awareness to improve the quality of care and accessibility for all people with bleeding disorders around the world.

Mark Skinner, President of World Federation of Hemophilia (WFH) says "When I was born with haemophilia, treatment didn't exist. My parents were told that it was doubtful that I would live into adulthood. Today, someone born with haemophilia can lead a relatively normal life if they have

access to proper treatment. Access to treatment is perhaps the biggest challenge facing the majority of people with haemophilia throughout the world. Only 25 per cent of those living with hemophilia are receiving adequate care. The WFH's vision is that one day treatment for all people with bleeding disorders will be available."

HFA President Gavin Finkelstein hopes some of the stories told for World Haemophilia Day 2011 will inspire Australians with bleeding disorders and their families to learn more about treatment and care for people around the world. In the lead up to World Haemophilia Day he said "I hope some of the successes and challenges around the world will inspire people to get involved so that Treatment for All becomes a reality".

The World Federation of Hemophilia is an international not-for-profit organization dedicated to improving the lives of people with hemophilia and other inherited bleeding disorders. Established in 1963, it is a global network of patient organizations in 118 countries and has official recognition from the World Health Organization. Visit WFH online at [www.wfh.org](http://www.wfh.org) or contact HFA if you want to get more involved. ■



# FROM THE PRESIDENT

Gavin Finkelstein

At the October 2010 Haemophilia Foundation Australia (HFA) Council Meeting, HFA commenced a new strategic planning process to build on work done by Council Delegates earlier in the year. The participants were Delegates from each State/Territory Foundation and HFA staff. Although HFA's members are each of the member Foundations around Australia, our stakeholders are a much broader group of individuals and organisations, and we work with each in different ways to achieve our goals and objectives. An important aspect of the strategic planning process was to take the needs and interests of the broader group of stakeholders into account.

HFA's primary objective is to improve the lives of people of all ages with bleeding disorders and ensure they have access to the world's best practice care and treatment and all necessary supports to lead active and fulfilling lives. We do this through activities which fall under the broad banners of education, advocacy and research. Only some of this work is represented in *National Haemophilia*. The feedback of our newsletter readers is important, just as the feedback of our donors is very important to us. Thank you for participating in our recent surveys and for your thoughtful feedback.

Our work at HFA is generated from the grass roots level – that is, from our member Foundations, and we also try to connect directly with people affected by bleeding disorders in different ways so people can contribute their experiences and views. This in turn helps HFA to develop its policy approaches and shapes advocacy that might be needed for parts or all of our community. For example, we have recently asked people with hepatitis C to provide more details about their experiences of the health system and barriers to accessing treatment and other necessary services and care. This process is an example of how we gather and use the experiences of many of our members to make a case for our community on a particular issue.

It is also helpful for us to know how people like to get their information and the sorts of information they need. You may have noticed our increased use of Facebook, and e-news to keep in touch with members of our community who like to receive information and communicate with us in that way. We are keen to find better ways to communicate with groups in our community and many of the questions in the HFA National Survey were directed at understanding this. In particular we are working on how best to engage with youth in our community and over the next year we hope to do some strategic work in this area. But this is not the only area that needs our specific attention. Other areas such as parents and siblings of newly diagnosed

children, women, the needs of men and women who are ageing with complex health issues due to a combination of their bleeding disorder and other health complications all present specific issues. In our planning, we are now talking about whole of life issues which means we really need to understand our community, and our responses need to be evidence based, and accountable to all our members. We have a resource development plan which includes the roll out of several new education materials – many of you will have seen and used the new haemophilia and von Willebrand disorder booklets. You will see more of these education materials over the next year.

From an individual patient point of view, I have written before that as individuals we also need to be responsible for our bleeding disorder and how it is managed. It is everyone with a bleeding disorder's right to have high quality treatment and care, but we must also ensure as individuals that we work well with our Haemophilia Centres to make sure our treatment and care is appropriate and that our treatment plan is regularly reviewed. Some people get worried when HFA talks about patient accountability and thinks that a decision maker somewhere will doubt our need for treatment product or will think that we might be using too much clotting factor. HFA knows the total amount used and cost of clotting factor is increasing greatly each year and this is a challenge for government budgets. On an individual basis we need to be confident we are treating ourselves most effectively, and that we are involved in the decisions about our treatment with our Haemophilia Centre health professionals. HFA needs to be confident that we are providing accurate and informed information about the needs of our community to governments and funding bodies and makes every effort to ensure that occurs.

As part of our future work, HFA will be working hard to ensure there is a commitment of all stakeholders to the comprehensive care approach to the treatment of people with bleeding disorders and that we have a sustainable system of providing care and treatment in Australia.

HFA can only be successful if we have strong partnerships – with our community, with health professionals and special interest groups, community organisations and governments because of the complexity of the bleeding disorders community.



The 16th Australian & New Zealand Haemophilia Conference will be held at the Novotel, Sydney Olympic Park, 20 - 22 October 2011. The theme for the Conference is "health and wellbeing – the decade ahead".

Planning for the Conference is well underway. You will soon receive a registration brochure in the mail! Registration costs are very attractive – see the brochure when it arrives or visit the HFA website at [www.haemophilia.org.au](http://www.haemophilia.org.au)

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

### Program

The multidisciplinary program will interest everyone. A range of topics will be featured in the program, including best practice treatment and new clotting factor products, comprehensive care, treatment of inhibitors, better

joint care and physiotherapy, sexuality and body image, child and adolescent transition, youth issues, ageing, women's bleeding issues, reproductive health, and hepatitis C and HIV care and treatment updates. Each topic will be presented with patients and their families and their treating health professionals in mind.

### Who should attend?

- People with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners
- Health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers
- Treatment product producers, suppliers and service providers
- Policy makers and government officials
- Haemophilia Foundation volunteers and staff

### Posters

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

### Submit an abstract for our Poster Display by Friday 27 May 2011.

See the HFA website for the abstract submission form and more information – [www.haemophilia.org.au](http://www.haemophilia.org.au).

### OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

#### Health Professionals Meetings

Annual meetings of the Meetings of Australian Haemophilia Centre Directors' Organisation, Australian Haemophilia Nurses' Group, Australian Haemophilia Social Workers' and Counsellors' Group, Australian & New Zealand Physiotherapy Haemophilia Group

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



and the ABDR Data Managers Group will be held on Thursday 20 October 2011 - members of the groups will receive details soon.

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

This is our first specialised workshop for people affected by inhibitors. Although various aspects of the treatment and care of people who have develop an inhibitor to their clotting factor will be covered in the Conference program, HFA has also been working with Haemophilia Foundation of New Zealand (HFNZ) to run an additional workshop for people living with inhibitors, and their families and carers. This is a great opportunity to attend both the Conference and workshop. There will be a number of subsidised places to attend the workshop, including travel expenses, so people coming to the workshop will also be able to attend the Conference. The inhibitors workshop will run after the Conference from Saturday night until Monday.

**Youth Social Function**

After the Welcome & Exhibition Opening on Thursday 20 October, youth are invited to a social function. This will be onsite and will be free of charge. The purpose of the function is for youth to meet and connect before the Conference program starts. The Conference will have sessions of interest to youth integrated throughout the program over the Friday and Saturday. Further details for youth will be available to registered delegates later.

**Remembrance Service**

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

**Conference Dinner ~ Novotel Sydney Olympic Park**

Come and join your fellow delegates for dinner onsite on the Friday evening. This will be a social dinner giving people an opportunity to talk, share and meet others.

**A Men’s Breakfast and Women’s Breakfast will be held on Saturday 22 October**

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

**For more information, check the HFA web site - [www.haemophilia.org.au](http://www.haemophilia.org.au)**

# THAI- AUSTRALIA TWINNING PARTNERSHIP

Sharon Caris

A Training Workshop in Bangkok and regional outreach visit to Sakolnakorn Province in November 2010 that was attended by HFA representatives, Peter Fogarty (Haemophilia Foundation Queensland) and Jonathan Spencer (Haemophilia Foundation Tasmania) marked the next phase of the partnership between Haemophilia Foundation Australia (HFA), the National Hemophilia Foundation of Thailand and Thai Patient's Club.

The workshop at Ramathipodi Hospital was attended by 74 people – this included people with haemophilia and their parents, government officials, health professionals and some representatives of other patient organisations. It was a great honour that His Excellency, James Wise, Australian Ambassador in Thailand attended the opening session of the Workshop, and acknowledged the successes of the National Hemophilia Program in Thailand and the Twinning relationship between Australia and Thailand.

Ramathipodi is the hospital where people with bleeding disorders from around Thailand come for specialist care. A program of regional outreach has increased access to care and treatment far beyond Bangkok. Thailand is recognised as an excellent model of care and treatment, and offers clinical leadership in the region. It was the first country in the World Federation of Hemophilia (WFH) Global Alliance for Progress (GAP) program in 2004.

Over the years there has been much progress in Thailand with improved clinical outcomes, reduced patient hospitalization and raised quality of life for patients and families. With increased access to treatment and care, patients miss less work and school and feel more confident about dealing with haemophilia. The overall success of the national haemophilia care program in Thailand has resulted from government support, a good care delivery system, clinical and laboratory expertise, treatment product availability and a strong patient organization

This is supported by an active patient support program and a regular schedule of family camps which are enthusiastically attended by more than 100 people each time.

The twinning collaboration between the National Hemophilia Foundation of Thailand, Thai Patient's Club and Haemophilia Foundation Australia commenced in 2006. Workshops in Bangkok aimed at identifying, training and supporting volunteers, and visits to Australia by Thai parents of children with haemophilia have added to the



Building a strong Hemophilia Patient Organization in Bangkok and Sakolnakorn Province, Thailand

development of knowledge and increased confidence of the Thai Patient's Club to provide peer support to its members. Some of this work has also helped to identify larger numbers of people living with haemophilia in Thailand and ways of providing support to them and their families. The work has extended to regional areas of Thailand and has brought the haemophilia community closer together.

The twinning partnership has had benefits for both countries because it has enabled participants from each country to share ideas, learn from each other and take on leadership roles to help people meet the challenges of living with haemophilia. It has also built a meaningful cross cultural understanding and friendships between the Thai and Australian haemophilia patient communities.

Dr Monthon Suwannuraks, Chair of the Thai Patient's Club recently said one of the main goals of the HFA - TPC twinning has been to strengthen the TPC by working with HFA. He said the workshop in Bangkok was a good opportunity for the Australians and the Thais to "share and exchange knowledge on topics such as organization management, team building, internal communications etc".

He commented further that "the regional outreach visit in Sakolnakorn province increased the awareness and understanding of regional issues and the development in care and treatment".

From the perspective of HFA it is certainly a revitalizing experience to witness first-hand the work being done by the health professionals, the enthusiasm of the Thai Patient Club members and its increasing strength as a patient organization and HFA has learned much from the way this work is undertaken. ■

# HEPATITIS C FINANCIAL ISSUES UPDATE

*Gavin Finkelstein*

For affected members of the bleeding disorders community, the impact of hepatitis C is a reality that will not go away and HFA continues to pursue a means to address the health and financial needs of people with bleeding disorders who have acquired hepatitis C through their blood products.

Over the past 8 years, HFA has put together evidence about the impact of hepatitis C by consulting with members of the bleeding disorders community and HFA member foundations through surveys, focus groups, discussions and individual comments. HFA has also consulted with haemophilia health professionals. The results have been consistent: that people with bleeding disorders and hepatitis C experience complications requiring more complex care; this can impact on their ability to work full-time after the age of 35 years; their experience can lead to social and psychological problems; and they may also struggle with financial hardship, particularly as many are excluded from financial safety nets – sometimes, ironically, because they are still attempting to remain in the workforce or, with insurance, because of the fact that they have these health conditions.

Reports from both member foundations and health professionals have highlighted that, after more than 20 years of infection, there are increasing numbers of people whose health is deteriorating and that this can leave them in a desperate situation, concerned both for their own future and that of their family, if members of their family are dependent on them,

financially or for care and support.

In the December 2010 issue of *National Haemophilia* we reported that HFA had developed a proposal for a financial assistance scheme and had brought this to the attention of Federal and State and Territory governments. HFA has been encouraged by the response of State and Territory governments, as most have indicated that they are willing to discuss this at a national level. In early November 2010, HFA met with representatives from the Federal Health Minister's office and the ACT Health Minister and we expect to have further meetings with governments about the proposal.

In HFA's previous surveys and focus groups, many individuals told HFA that they were not eligible for various government schemes designed to help people with out-of-pocket medical expenses and with transport, services and housing or that these schemes did not cover their costs. These responses formed a part of our proposal to governments.

Over December and January we circulated a request to members for further information about their out-of-pocket costs, and particular schemes they had been unable to access and any barriers that prevented them from accessing financial support, services and care. Our thanks go to the community members who submitted details of their individual situations and costs. Some commented that this was difficult - to extract relevant information from the complexity of their health care costs, and psychologically, to acknowledge the day-to-day and long-term difficulties they face, and to actually complete

the task when living with fatigue.

We appreciate the personal effort that they made to contribute to this work for the benefit of the affected bleeding disorders community, some of whom are too seriously ill to do this.

If you are affected and would like to send HFA details of your out-of-pocket costs, your information would still be very valuable to help HFA to demonstrate the difficulties for our community to governments. You can download a form with more information on the types of costs from the HFA web site News section on the home page – [www.haemophilia.org.au](http://www.haemophilia.org.au). If you would like HFA to post or email you more information or a copy of the form, please contact HFA on 1800 807 173 or [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).

We are aware that for many members affected by hepatitis C this is an increasingly urgent issue and that it is essential to have agreement on a plan to provide support and relief to them in the near future. HFA will continue actively to seek progress on this. ■

This article is adapted from an article published in *Hemophilia World*, December 2010, the magazine of World Federation of Hemophilia, and is reprinted with permission.

Professor Alison Street is Head of the Haemostasis/Thrombosis Unit and Director of the Ronald Sawers Haemophilia Centre at Alfred Health, Melbourne, Australia and World Federation of Hemophilia Vice-President Medical.

Professor Street is based in Australia but wrote this article for young people with bleeding disorders and members of the World Federation of Hemophilia worldwide.

## PREPARING FOR LIFE AS AN ADULT WITH HAEMOPHILIA

*Alison Street*

As young boys with haemophilia grow up, not only do they experience the usual emotional and physical challenges of adolescence and early adulthood, but their relationships with family and caregivers also change when taking on more direct responsibility for their bleeding disorder. Haematologists who look after children will heavily involve parents as much as the young child in decision making. This is very different from the care given to adults, in which the person with haemophilia is encouraged to become independent and accept personal responsibility and 'ownership' of the disorder.

Transition between these two models is progressive over many years, emphasized particularly at the time of transfer from paediatric to adult care centres, where separate facilities exist. There may be a structured transition program to introduce you and your family to the new service.

Let us assume that you are a young man who is now cared for by an adult haemophilia centre, and that you are attending for the first time without your family. You are ready to move forward with the excitement of emerging adulthood. What are your expectations and what are those of your family, friends, and the new

clinicians who are ready to assume responsibility for your care? It is very natural to be apprehensive.

### **How do you best prepare for the challenges of life as an adult with haemophilia?**

The level of care to which you have access will critically determine your opportunities. Being involved in your local haemophilia foundation is a great support to the improvement and maintenance of your physical and psychological well-being.

Where possible, try to set your life and career goals to maximize your potential: you don't have to know exactly what you will be doing in ten years or even three, but embarking on a course of study or acquisition of life skills that gives as many opportunities as possible is important. Remember that many physically demanding occupations are difficult and time-limited for men without musculoskeletal disabilities, much more so for men with haemophilia. That's not to advise a totally sedentary job or lifestyle, far from it; both physical and emotional well-being is best preserved through regular exercise.

Read and learn about your disease to help you make informed

discussions with clinicians and family. Although the management of your haemophilia may have seemed to revolve around avoiding bleeds and using factor replacement during your childhood, it is more complex than that. As an adult you will now be responsible for reporting your joint and muscle bleeds and need to know about their common presentations, including some which you may not have experienced yet, for example, back, loin, or hip pain caused by bleeding into the large ileopsoas muscles, which may be associated with the onset of sexual activity.

It is very important that you and your healthcare team develop treatment plans for your bleeds; you may be away from home and have to attend an emergency department where you know more about your condition than any of the clinicians. It's not as scary if you recognize that you may have a bleed and to request doctors to immediately contact staff at your 'home' centre for advice.

Your life beyond the constraints of childhood, with increasing periods of time away from home, can be more chaotic and your bleeding experiences altered. If you are fortunate and receive prophylaxis,

What are your expectations and what are those of your family, friends, and the new clinicians who are ready to assume responsibility for your care? It is very natural to be apprehensive.

your product replacement routines may no longer be appropriate. Discuss your activity timetable openly with haemophilia centre staff - you may need to modify your treatment schedule or your plans to permit safe participation in these activities.

You will also need to think about disclosing your condition to friends and colleagues.

These can be complicated discussions and it is best to involve your family and clinicians in making decisions about whom, what, and when you will tell. Find out about the genetic inheritance of your disorder so that you have accurate knowledge to share with your family members and potential life partners.

Transition can be a very exciting time for the young man who is well prepared for the increased responsibility and independence of adulthood with haemophilia. Talk with your family and clinicians, ask them to share your goals, and get out and enjoy! ■

Maureen Spilsbury is Senior Social Worker and Beryl Zeissink is Clinical Nurse Consultant – Haemophilia at the Queensland Haemophilia Centre, Brisbane.

Helen Fogarty is the mother of two young boys with haemophilia and a daughter and lives in New Farm, Brisbane. David Stephenson has haemophilia and is HFQ Delegate to HFA Council.

# NATURAL DISASTERS - A QUEENSLAND EXPERIENCE

## FLOODS, CYCLONES AND THE HAEMOPHILIA EXPERIENCE IN QUEENSLAND *Maureen Spilsbury*

As the end of 2010 loomed and 2011 was still only just on the horizon, Queensland was hit by a series of floods which forced the evacuation of thousands of people from towns and cities. At least seventy towns and over 200,000 people were directly affected. Three-quarters of the state of Queensland was declared a disaster zone. The chilling image of a flash flood racing through the city of Toowoomba is burnt into our minds as is the potent wall of water, described by some as an inland tsunami, which went on to devastate communities in the Lockyer Valley west of Brisbane. A few days later thousands of houses in Ipswich and Brisbane were inundated as the Brisbane River rose menacingly, flooding homes within its path. Thirty-five people lost their lives in Queensland during this tragedy and a number of people are still missing.

The Queensland floods were followed shortly by floods in Victoria and bushfires in Western Australia. In addition, a number of other smaller cyclones menaced the coasts of Australia and brought heavy rainfall to already sodden areas. Crops, property, stock, the tools of people's livelihood and their hopes and dreams were literally washed away.

Just as Queensland began to assess the immense damage in the south east of the state, Tropical Cyclone Yasi, a storm of monster proportions, terrorised communities along the Northern Queensland coast as well as in areas further inland. The rest of Queensland watched with bated breath as the cyclone, said to be so large that it would almost cover the United States, most of Asia and large parts of Europe, crossed the coast of Queensland between the highly populated centres of Cairns and Townsville. Cyclone Yasi was the largest and most powerful cyclone to hit Queensland in living memory and while loss of human life was less than feared, devastation in the affected areas was crippling. For some the loss of power will continue for many more weeks as nearly 50% of power lines were flattened by the wind in those areas.

The damage bill from the January floods and Tropical Cyclone Yasi is expected to reach several billion dollars. Flood and cyclone victims left with nowhere to live have begun moving into caravans and demountables which might need to house them for up to a year. It has certainly been a Christmas and New Year season which many will remember for the sheer magnitude

of the disasters experienced across the country.

In this feature article Beryl Zeissink and I will try to give you a sense of the experience of the staff at the Queensland Haemophilia Centre in response to the impending weather catastrophes. Two community members were also generous enough to give their account of how they dealt with haemophilia in the midst of the craziness of the Brisbane flooding. ■



Scenes of devastation in Far North Queensland after Cyclone Yasi

# THE HAEMOPHILIA CENTRE EXPERIENCE – THE SOCIAL WORKER PERSPECTIVE

Maureen Spilsbury

The first calls made by staff of the Queensland Haemophilia Centre to check on the welfare of community members likely to be affected by the anticipated severe weather conditions began back in early December 2010. We have, however, had smaller but similar experiences during the summer months over preceding years. Since December, these phone calls have continued in a “rolling out” type pattern to those who live over much of the state. Initial calls were made to community members living on the Mid Coast and areas of Central Queensland. We didn’t ever expect that we would be making “check up” calls to flooded farming areas west of Brisbane. The district was just beginning to recover from a prolonged period of severe drought. But severe weather conditions don’t discriminate and soon we were making calls to those who live in metropolitan Brisbane, areas of the North Coast and Burdekin, northern New South Wales, checking on the welfare of haemophilia community members and offering support where we could. As a result of Cyclone Yasi, we found ourselves making subsequent calls to those living in the small towns and larger centres in Far North Queensland.

Calls were made by staff members to parents of children as well as to adults of the haemophilia community. Our first goal was to check on people’s general welfare. In the first instance we aimed to make contact with people who have regular factor replacement and those who were known to be currently having difficulties following injuries or surgery. We used the opportunity to ensure that community members had adequate access to and knowledge of how to store factor products should the anticipated problems with loss of electricity supply eventuate. We asked if people needed any additional forms of assistance and whether they had a plan about how they would stay safe

and how they might access medical treatment should that be necessary. It was music to my ears to hear over and over again, “we live on a hill” and “we just ordered a delivery of factor or we went to the pharmacy this week” and “yes we can get through to the hospital”! There were of course, some families who did have concerns about the product supply and our nurses did a sterling job of making sure that people got access to factor if it was possible. A number of families of the community were isolated by the floodwaters or the destructive winds of the cyclone and we know of a couple of families whose homes or property were inundated by the floods. No doubt we will learn of others who have been affected directly or indirectly as they make contact in clinics throughout the coming months.

Thank you to everyone from Queensland and interstate who made enquiries about haemophilia community members and about the staff of the Haemophilia Centre over the past months. I am pleased to be able to tell you that staff members were largely unaffected by the floods as far as loss of property is concerned. I was effectively cut off from Brisbane for three days during the peak of the Brisbane flooding. I was thankful to be able to access other staff by phone and email and to be able to follow up on families by phone. As the staff settled into a pattern of contacting community members and sharing information with the other members of the team, I thought back to a session I attended at a World Federation of Hemophilia Congress. A Social Worker from New Orleans recounted her own despair and gave a moving account of the days, weeks and months following Hurricane Katrina. She described the difficulties faced by the local haemophilia team as they struggled to check on the welfare of community members. They had lost their office, all of their equipment and all data related to their work.

I was incredibly pleased that in Queensland the haemophilia team were able to access the Australian Bleeding Disorders Registry and follow up community members before and after the disastrous events which struck from one end of the state to the other. I cannot begin to imagine how difficult it might have been without such a valuable tool.

It was, however, frustrating and worrying to find on occasion that phone numbers were outdated. We were powerless to reach those people and unable to pass on information which they may have needed in dire circumstances.

In closing I would like to list a few wise words I came across on the Queensland Health web site about dealing with emotions following disaster situations.

I have noted a few but hope you never need to use them:

- Be aware that it is normal to experience some form of emotional distress as a result of being directly or indirectly affected by any form of natural disaster. You may experience some of the following symptoms, amongst others: nightmares or flashbacks; work or relationship difficulties; problems with memory and concentration; fearfulness; anxiety and depression. Seek help early if these symptoms persist or if you are concerned about yourself or others around you.
- Remember that children process traumatising events differently to adults. They need age appropriate information and opportunities to ask questions about the trauma. Children may temporarily exhibit regressive behaviour. Talk to them about the situation and provide opportunities for them work through the situation. Observe their behaviour closely. They may show signs of being

clingy, irritable and exhibit difficult behaviour.

- Teenagers may not show their distress openly. Provide them with opportunities to talk about the situation and to ask questions if they choose to, but some teenagers will be more open with their peers about their worries and concerns. Be observant of their behaviour and offer support and the opportunity to talk to a professional counsellor if there are continuing concerns about how they are dealing with the traumatic event.
- Be encouraged that times of extreme stress can be opportunities for families, friends and communities to grow closer together, to value others and choose new ways of doing things.
- There are a number of agencies which can provide support after a natural disaster including:
  - The Australian Red Cross - 1800 733 111
  - Lifeline - 13 11 14
  - Missing Persons Qld - 1800 017 744
  - SalvoCare Line - 1300 363622 (general counselling and support)
  - Centrelink Flood assistance scheme - 180 2333
  - Your General Practitioner or local Community Health Centre.
- Lastly, be wary of trying to salvage medicines, drugs and poisons stored at home, which have been damaged or contaminated by flood water. See your local pharmacist for advice if unsure. If disposing of medicines wrap them securely and ensure that sharps are disposed of safely.

Further detailed information can be found in detail on these fact sheets, produced by the Mental Health Branch, Queensland Health - [http://www.health.qld.gov.au/disaster/stress\\_well.asp](http://www.health.qld.gov.au/disaster/stress_well.asp) ■

## LESSONS LEARNED – A NURSING PERSPECTIVE

*Beryl Zeissink*

During the first week of January, floods had started to hit regional and remote areas of Queensland. Nursing staff at the Royal Brisbane and Women's Hospital called patients who perform home therapy to check that they had adequate supplies and treatment to cover them for periods when they may potentially be isolated.

In the evening of Monday 10th January we watched news that a tsunami type flood had hit Toowoomba and followed on down through to Grantham. By early Tuesday morning we were calling our Toowoomba home therapy patients to check on their individual situations, that they were safe and that they also had enough factor - not knowing what the situation was yet in the local Toowoomba Hospital, where these patients obtain their supplies.

However, then things changed rapidly in Brisbane and at midday I was called to an urgent nursing meeting, where it was announced that the hospital was calling a code brown – an external emergency. Staff who lived in areas at risk of flooding were sent home, and those who knew they would not be able to reach home were found accommodation within the hospital for the night. For me, the five minute ride home was a 45 minute ride, as people were busy on this route preparing sand bags.

On Wednesday we were busy again, this time calling Brisbane and Ipswich patients to check that they had factor and discuss how to store factor if there were power outages in their areas. At this stage it was becoming evident that we could not contact everyone directly and that not all people had updated their phone contact details, as these had changed. We hoped a way around this was to put some basic information up on the HFA website. Two updates were placed on this website during the flood period.

All appointments for elective surgery were cancelled for the week, as well as clinic and non urgent treatment appointments. This was necessary, as the hospital became inaccessible when the corner near Butterfield Street close to the Breakfast Creek was flooded. However, in the following week the cancellations had to be rebooked in a timely manner, as this required finding new times for a whole week of appointments in clinics and surgery lists that were already full.

After a week there were still king tides affecting Brisbane and some people were still flood bound. The clean up continues throughout the state.

### Points to remember

- Updating your contact details is not passed on automatically to all other groups and hospitals, as this may contravene privacy laws. You need to update your details at all the hospitals you attend, home delivery providers, HFA and HFQ.
- If electricity is off in your area, try and keep your factor in a cool place and store in an esky with ice if possible. Make contact with your Centre as early as possible so planning can commence to replace stock that has not been kept in the appropriate temperature range
- Never leave it until the last second to replace stores when running low on factor. Adequate factor supplies should always be on hand, not just when there is an emergency. ■



The aftermath of floods near Brisbane – the debris in the tree-top indicates the flood levels

## A PERSONAL FLOOD EXPERIENCE

*Helen Fogarty*

Like most Brisbanites, I'd always believed the throw-away line that Brisbane would never see another flood. So much so that we barely thought twice about buying a house right on the edge of a blue patch on the flood map. But as we've all learned, nature likes to occasionally dish out harsh lessons in complacency, just to show who's boss.

So, like many people in South East Queensland, we spent Tuesday 11 January preparing as best we could, with the tragic events of Toowoomba and Grantham rolling on the TV in the background, building a sense of dread but also reminding us of what really matters. With my husband Peter desperately trying to get a flight back from Singapore, I accepted help from all sides - people minding kids, carrying things upstairs, texting weather updates, relocating our chickens to higher ground and organising somewhere for us to stay.

Talking to people since then, I realise that our experiences over those few days - physically and emotionally - were very typical.

However, there were a few differences because of haemophilia. For instance, while others were filling their cars with food and valuables, we were filling the car with treatment supplies. At first I just packed enough for a few treatments, but by the end of the day, as the flood predictions worsened and there were rumours of flood waters staying for

weeks and whole suburbs being cut off, I shoved almost all our supplies in the car.

Of course, when the power went off, while others were concerned about losing food, all we really cared about was keeping the factor cool. Just by chance we had a camping fridge that we'd borrowed from friends for a trip a few weeks earlier. We'd plugged it in as soon as we heard the flood warnings but the battery only lasts for a few days. Luckily, while we were wallowing in what seemed like a disaster zone, we realised that most of New Farm was unaffected and people in houses just a few streets away had power and were living completely normal lives, so we moved the factor to another friend's house.

The other way that haemophilia made our flood experience a bit different was the need to continue with prophylaxis. Rather than letting the treatments slip because of all the other things going on, we treated almost as soon as we heard the flood warnings and made a concerted effort to keep up regular treatments. Which meant that on the morning of the main cleanup, while a wonderful team of gurney-wielding friends began the messy job of cleaning out our downstairs rooms and backyard, I was at a friend's house doing both the boys' treatments. It seemed odd to not be there for the start of the clean up, but we knew it was important insurance against bleeds (which at that stage would have been almost too much to handle),

particularly since the kids would be spending a lot of time being looked after by other people while we got on with the cleanup.

Although we fared quite lightly in the scheme of things, we were deeply touched by the generosity of friends, the community spirit and the stories of tragedy and kindness. I'm also grateful that the flood experience has given many of us a small glimpse into the feelings of fear, helplessness and loss that come with natural disasters, and the added difficulties for people with any sort of health issue. Increased empathy is surely a good thing.

But on a 'lighter' note, writing this has reminded me that, after the flood, I vowed to get some decent torches and prepare a proper emergency kit... so I'd best get organised now before complacency sets in again... ❧

# BRISBANE FLOOD 2011

David Stephenson

Working in Brisbane CBD with water rising at the beginning of the flood seemed quite safe until lunchtime when roads effectively turned into car parks with people trying to get home before it got worse. I took the risk of choosing to stay until the roads cleared. This increased my chance of being cut off but meant I wouldn't be stranded in a line of cars that possibly couldn't move forward or back. By late afternoon there were very few cars on the road, water was continuing to rise and some streets were already cut off by the murky, brown, silt-laden water. My first attempt to get home was blocked by police so then I faced the real possibility of not getting home for who knows how many days. In addition to this, all my medications were in a fridge at home with the possibility of power loss. I knew my particular clotting factor can be stored at room temperature below 30 degrees Celsius as long as it is used within 6 months, so loss of power at home was not such an issue - but not having access to it was a problem, so I went off to the hospital to pick up some supplies from pharmacy. The only thing I was missing was a tourniquet but a belt or sock would have done the trick if needed.

So then it was time to have another go at getting home, again blocked by police even though I had a 4WD this time. At this early stage mobile phones were still working so I called my son who hooked up the boat and came down the main road for the rescue/pickup. This worked well except there were many people on each side of the expanding water wanting a ride across, people pleading with us to take them. We took one lady over but it was not possible to become a ferry as there were more creek crossings to drive through and water was rising fast. As it was, the car stalled in the middle of the next crossing. Luckily it started again and we eventually got home.

Being on higher ground, we fared better than some, but others had real problems - one lady was ready to have her baby, another older man had run out of heart medication, another had only a day left of his medication for schizophrenia and so on. Luckily the army/state government had set up a centre that many people who were cut off could access where medications could be flown in and a doctor was on site.

The days passed with black hawk and media helicopters constantly overhead, some households with power and some without. We had little petrol left in the cars - not that we could travel far - but we knew getting fuel after the flood would be a problem and that was indeed the case. With all the difficulties, it was good to know that haemophilia services continued to operate and connect with people. The Haemophilia Centre was very active, ringing people who might be affected and organizing to have flood information put on the HFA website for those who could access it. HFA also offered any other assistance they could provide. ¶



Little remained of some buildings after flood waters had passed through

## Christchurch Earthquake

Since these articles were written, our colleagues at Haemophilia Foundation of New Zealand, which has its main office in Christchurch, have experienced a massive and devastating earthquake. Although the staff were safe, the office and office contents were damaged and HFNZ staff are currently assessing this, and trying as best as possible in the circumstances to prepare to move forward. We are unsure how many other members of the bleeding disorders community may have been affected. Our thoughts are with our friends and colleagues in New Zealand. HFA has offered to assist where possible, however the main difficulties are on the ground in Christchurch. We keep in touch with HFNZ staff and haemophilia health professionals to offer them our thoughts and pass on messages with good wishes from the many Australians who contact us to ask about the bleeding disorders community in Christchurch and New Zealand. ¶

This article is adapted from the "Ankle sprains" brochure published in November 2009 by the Women's and Children's Hospital, North Adelaide, South Australia, and is reprinted with permission.

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# ANKLE BLEEDS AND SPRAINS IN HAEMOPHILIA

*Auburn McIntyre and Abi Polus*

## WHAT DO I DO IF I HAVE A BLEED OR SPRAIN AND HOW DO I REDUCE THE RISK OF INJURY?

Ankle pain is one of the most common presentations in haemophilia, particularly in the second decade of life. It is important to distinguish the reason for the pain in the ankle.

The ankle joint is made up of the tibia and fibula (shin bones) and the talus and calcaneus (foot bones). Muscles and ligaments attach the bones together provide structural stability. The ligaments on the outside of the ankle are most commonly injured (torn or sprained). These structures all have a blood supply, and injury to them may cause bleeding into the joint.

## ANKLE BLEEDS

An ankle bleed is blood within the joint space of the ankle with any injury to the ankle, which may be very minor. You may even have trouble identifying how you did it. These are associated with the haemophilia population only.

## ANKLE SPRAINS

Ankle sprains are common in both the general and the haemophilia population. They can result in bruising, swelling and damage to the ligaments and joint surfaces. An ankle sprain may result in a joint bleed.

In most cases, a sudden loss of balance results in a roll outwards, known as a 'lateral inversion ankle sprain'.

## THERE ARE THREE GRADES OF ANKLE SPRAINS:

**Mild:** Minor tear and stretch of the ligaments. Mild swelling, locally tender and little loss of function.

**Moderate:** Moderate, partial tear with swelling, bruising and tenderness over a wide area.

**Severe:** Complete tear of the ligament. Substantial bruising and swelling up the leg and into the foot. There is marked loss of movement and function. Joint stability is compromised. A bony chip may become detached where the ligament attaches to the shin bone.

Physiotherapy is usually necessary with these injuries: examination, treatment and recovery are dependent on the type of injury, number of sprains and your bleeding history.

In people with haemophilia an ankle sprain must be treated very seriously. If it is not rehabilitated fully it may become more prone to reinjury and become a target joint, where there are repeated bleeds into the ankle, with little provocation or injury.

## INITIAL TREATMENT OF A SPRAIN

Immediate treatment ensures the ankle ligaments and soft tissues heal well and more quickly. It attempts to minimize swelling, reducing the time of exposure of the joint to blood and reduce joint damage.

## Initial treatment: (even at scene of injury)

### F actor

### R est

### I ce

### C ompression

### E levation

**FACTOR:** should be administered as soon as possible and injuries of this nature should be reported to the haemophilia treatment centre.

Seek additional medical advice if there is continued swelling OR you are unable to weight bear after 48 hours.

**REST:** Crutches and a splint are necessary for 48 hours for haemophilia patients. It would be usual to expect weight bearing through the leg after 48 hours within the limits of pain.

**ICE:** Cold in the form of crushed ice, frozen peas or cold packs should be applied to the ankle and lower calf immediately. To prevent ice burns the chosen product should be wrapped in a damp towel. Cold should be applied for between 10-20 minutes every two hours for 48 hours. Check the skin regularly for ice burns.

**COMPRESSION:** A supportive bandage should be applied from the toes up the leg to just below the knee in addition to using a splint. This should be worn continuously except when in bed at night.

The bandage and a 'U' shaped gutter foam under the ankle joint

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It is essential that you contact your physiotherapist at your local haemophilia treatment centre for assessment, advice and education. after any ankle injury or bleed.

may be needed for up to two weeks when the leg has reduced bruising and swelling. It may be removed when swelling has disappeared.

Frequently a physiotherapist will make a splint to keep the ankle joint and calf in a good position.

**ELEVATION:** The leg should be elevated above the level of the hip when sitting, and above the heart when lying. The knee should be straight not bent when lying; a bent knee leads to a tight calf and longer rehabilitation.

#### FURTHER TREATMENT

**PHYSIOTHERAPY:** Physiotherapy is likely to be prescribed depending on the severity of the injury.

**It is essential that full range of motion, muscle length and strength and extremely good balance reactions are restored to prevent reinjury and reduce the risk of the ankle becoming a target joint, where there are repeated bleeds into the ankle, with little provocation or injury.**

**EXERCISES:** Exercises may be commenced safely when bleeding has stopped and the ankle is able to move without pain. There should be no increased pain or swelling after exercise.

#### REDUCING THE RISK OF RECURRENT ANKLE SPRAINS

There is a risk of repeated ankle sprains within the first 12 months of

any ankle sprain. Muscles need to be rehabilitated to become strong, quick and efficient. It is essential to build up endurance to be pain free and protect from future sprains.

Semi rigid ankle supports, taping and bracing can be helpful for functional use but needs to be combined with specific functional exercises.

Prior to return to sport you/your child should have:

- No pain or swelling.
- Should be able to walk normally (without a limp) and balance on either single leg with the same degree of balance and stability.
- Should be able to rise up and down on your toes on the sprained leg side whilst displaying the same balance skills as on their good leg, and also hop and stop-still on either leg with the same skill level.
- Have equal muscle size (calf and thigh) on the affected and unaffected side, or the same as pre-injury.

**It is essential that you contact your physiotherapist at your local haemophilia treatment centre for assessment, advice and education. after any ankle injury or bleed. #**

Are you having a bleed...??

**STEPS**

- Factor Now
- Start R.I.C.E Regime
- Report Bleed

**FACTOR ALONE DOES NOT EQUAL TREATMENT**  
Physiotherapy is a specialty service & is safe from activities.

**TO RECOVER QUICKLY FROM bleed, OR JUST SPRAINS OR STRAINS**

**R.I.C.E**

- R**est
- I**ce
- C**ompression
- E**levation

✓ Factor in Physiotherapy  
✓ Factor in a PHONE CALL

WOMBLE FOUNDATION AUSTRALIA

# A DAY IN THE LIFE...WHEN YOU ARE A PARENT OF BOYS WITH BLEEDING DISORDERS

*Cheryl Ellis is interviewed by Suzanne O'Callaghan*

The day starts early when you have two boys who need to have their prophylaxis treatment before they go to school. Cheryl Ellis and her husband Darren are parents to two boys with severe haemophilia A – Taj, who is 10 and a half years old, and Ben, who is 9.

## **6.30am**

It's a treatment *and* a school day today, so Cheryl is up. The boys have their prophylaxis or preventative factor treatment on alternate days. When this day falls on a weekend, there is a bit of a sleep-in for everyone and treatment is done later in the morning. But not today! Between 6.30 and 7am Cheryl puts Ben's topical anaesthetic cream on the inside of his elbow – the boys don't like having the needles for their treatment in the back of the hand as it's too painful for them, so they use either arm. Taj is older, and he doesn't need the cream any more (his choice).

## **7am**

Cheryl is dressed and ready for the next steps. The boys are awake and about to make themselves breakfast. The TV is off – watching the TV in the morning is saved as a reward for when they have finished their morning routine – dressed, breakfast over, teeth cleaned, faces and hands washed, lunches in their bags.

## **8am**

Factor treatment is the last task before they all head out to school at about 8.20am. During treatment the boys are allowed to watch TV – it's relaxing and a distraction from the needles. Cheryl gives the infusion and Taj and Ben watch TV or read a book. Ben is a bit hands-on and has started to help with the preparations – mixing factor and swabbing. They're not quite ready to start needling themselves yet. Haemophilia Foundation Western Australia holds an afternoon annually with Princess Margaret Hospital Haemophilia Centre staff, where the children have the opportunity to try needling out on Arnie the Fake Arm. It's a good way to get some practice and see when they are ready to take on treating themselves.

## **9am**

School has started. Cheryl works from home, so she can go into school to follow up any concerns if necessary, but that doesn't happen often – it used to be about twice a term when they were younger, but she rarely needs to go up now - even though they are both normal boys, who love their outdoor activities. With prophylaxis every second day, the boys always have some factor coverage, and they both try to be careful.

The school has done a good job of working with the family to manage the boys' haemophilia and making sure problems are minimised. Two years ago Cheryl visited the school and talked to Taj's class about his haemophilia and explained his routine in the morning, and showed them what the treatments are and how they work. Sharon Hawkins, the Haemophilia Counsellor, has also met with the teachers at the school, who were very receptive. The teachers understand that management at school is mainly about first aid. If something hurts or feels tingly or swollen and they think they might have a bleed, the boys will go to the teacher straight away. If they fall over and have a graze on the knee, they will be sent to the administration staff member in the front office, who will clean them up and supervise them for a while. The boys are encouraged to try out all the different sports at school. The sports teachers understand about the risks, possible joint problems and bleeds. Fortunately the boys haven't wanted to play rugby or other serious contact sports!



Testing the needle on Arnie the Fake Arm

**10am**

There is a phone call from the pharmaceutical company that supplies the boys' factor to do a monthly stocktake of their treatment products and arrange the delivery for next week. The factor will be delivered to the door, but Cheryl needs to change the normal delivery time to earlier in the day as she will be out with the boys at swimming training when the factor arrives.

**1.30pm**

Cheryl gets a call from the staff member in the front office. Ben fell over at lunchtime and has had a small graze on his knee. She has cleaned it up and put a band-aid on it and is keeping an eye on it to make sure it stops bleeding. The staff member has become a good friend. She rings Cheryl regularly to let her know what has happened or if there are any queries or concerns and have a chat. She will watch the boys if they have had a minor injury, like a bump to the shin or a graze, and if it doesn't stop bleeding, she knows to ring Cheryl again who will then go up to the school. If there are problems that could be potentially serious, such as head injuries or a mouth bleed, Cheryl will go up straight away.

**3.30pm**

School is over and the boys come home. They do their homework straight away and as a treat can have a swim in the pool in the backyard. It has been very hot in Perth and like most boys, they love to play in the pool – whirlpools, fetching things from the bottom of the pool, wrestling, being "sharks". The boys have swimming lessons twice a week – the school swimming carnival is coming up. On swimming days it's a busy evening - they go to training, then come home to do homework, have a quick swim and then dinner.

It's Thursday today – the day when Ben has a half-hour drum lesson as well. Taj has drum lessons on Saturday morning. This is a great way to improve their upper body strength – and mute pads on the drum kit make it bearable for the neighbours!

**7pm**

After dinner, when it's cooler, it's time to take Harry the dog for a walk in the park. Fortunately there are lots of parks nearby, and the whole family can play with the ball thrower and the boys can have fun with the kite they got for Christmas.

**8.30pm**

The boys are in bed and Cheryl and Darren have some time to talk about what they might do on the weekend. Darren's work building swimming pools is very busy with long hours, but on the weekend he enjoys the opportunity to spend time with his family.

Saturday mornings are busy. Taj and Ben have tennis lessons from 9.30am to 10.30am. At 11am Taj will go off to his drum lesson. Then afterwards, if it is a treatment day, Darren gives the infusion when their blood is flowing well after all the exercise. Taj's veins are smaller and harder to access, but with the drum lessons they seem to have developed – certainly Darren has found it easier to infuse his factor.

Learning different sports has been important for the boys' development and for keeping them fit and flexible. Last year the boys learned karate as well – they have been too busy to continue it this year – but it taught them discipline, focus and organisation, and helped them to feel confident to deal with bullying, to defuse the situation or, if necessary, to defend themselves.

What's on the agenda for the weekend? A few weeks ago, it was the Weetbix Kids TRY-athlon. Taj and Ben and some of their friends had a fantastic time in their introduction to triathlons – for them a 100 metre swim, a 3 kilometre ride and a 500 metre run. This time it might be a visit to the beach. The Ellis family have a boat and often go fishing and squidding and the boys love to snorkel off the boat. If it finally cools down, they might all go for a ride on their bikes – Cheryl and Darren might take the boys on a training ride around the Perth bridges, getting them used to riding on bike paths and roads.

As a family they love being active and outside and Cheryl likes to encourage this – as compared to becoming "zombified" inside glued to the Playstation!

Haemophilia might not be curable, but it's definitely manageable! Taj and Ben are proof of that. They love to be active, and they need to be treated like boys and behave like boys. **H**



Taj and Ben taking life easy at Harvey Dam

Penny McCarthy and Megan Walsh are Clinical Nurse Consultants at the Ronald Sawers Haemophilia Centre at Alfred Health in Melbourne, Victoria.

# HOME TREATMENT DIARIES

*Penny McCarthy and Megan Walsh*

Patient home treatment diaries are a hot topic of conversation in Haemophilia Centres all over the developed world.

It is well recognised that without adequate treatment haemophilia is a painful disabling disease. Access to treatment early is essential; and where available prophylaxis from an early age to prevent spontaneous joint bleeding is the gold standard of care.

Home treatment was introduced over two decades ago to expedite access to factor treatment and be able to treat bleeds early, and to allow people with haemophilia to 'get on with life'. With the introduction of prophylaxis from a young age, people with haemophilia are reaching adult life with healthier joints and muscles and most are much closer to living 'near normal' lives.

These days contact with Haemophilia Centres is minimal, with some patients visiting only once a year for an annual review. Traditionally clotting factor concentrate was issued by hospital blood banks and blood banks would record the vials and batch numbers as the factor was dispensed. With treatment at home and the convenience of home delivery, recording clotting

factor infusions has become the responsibility of the person with haemophilia.

There are several important things to consider about recording clotting factor use.

## **Why keep a home treatment diary?**

Home treatment diaries are an essential part of haemophilia care. The diary is an important clinical tool that assists the Haemophilia Centre team in designing care and it is also the reconciliation between the clotting factor provided for the person with haemophilia and their clotting factor usage

Diaries can be in electronic form such as an excel spreadsheet, on paper, or in some cases on mobile phones or PDAs which transmit the data directly to the Haemophilia Centre.

In Australia, clotting factor is provided free to patients by Australian governments because individuals could not afford to pay for it. In some countries some government insurance schemes do not cover the clotting factor needs of patients and these patients live in fear of not being able to access sufficient product. For a 70kg man receiving 1500IU three times per week the cost of the factor VIII is around \$200,000 every year. As the

funding is paid for by both state and federal governments, the usage needs to be reported to be sure governments plan for enough factor to be purchased and budget accordingly. As part of this process, Haemophilia Centres are required to medically manage their patients and monitor the appropriate use of clotting factor.

Another important consideration for clinical trials for new treatments for haemophilia is that evidence of at least 50 factor infusions is generally needed to meet the requirements to participate in the trial. Haemophilia Centres will be relying on the home treatment diary for this.

## **What is your role?**

Home treatment has great advantages for a person with haemophilia – but it also comes with responsibilities, as it is a prescribed medication:

- Treating according to your treatment plan and only adjust doses after consultation with health professionals at your Haemophilia Centre.
- Storing clotting factor correctly
- Rotating stock to prevent expiry
- Maintaining a home treatment diary.

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# Treating at home does come with responsibilities, such as providing accurate treatment diaries

## How does the home treatment diary work for you?

For the Haemophilia Centre team, the home diary is an important clinical tool. Clinical staff interpret and use a range of parts of the diary in their patient care. These are some examples:

### THE DATE

Haemophilia Centre staff look at the intervals between infusions and this is reconciled against the prescribed treatment plan, reports of breakthrough bleeding, or episodes of pain. Is the treatment plan being adhered to (eg, three times per week) or are extra or less doses being administered? Repeated bleeding into a joint can result in the development of a target joint.

A developing target can be identified early from the treatment diary if increased frequency of treatment for breakthrough bleeding or change in treatment dose is noted. The person with haemophilia will be contacted to come in for review and intervention by the doctor. Without this timely information the target joint may not be identified and further damage to the joint may occur.

### THE TIME

When factor VIII is being infused, it is at its maximum effect for the first 8-12 hours. Is it being administered at the appropriate time for the person with haemophilia to gain maximum effect from the treatment? For example, if a young apprentice starts work at 7am, but doesn't administer his prophylaxis until he gets home at night, the maximum cover from the clotting factor is when he is asleep and his level is low when he is at work.

### THE DOSE

Several issues are considered when the treating team determines the dose including a person's bleeding history, age, and weight. The dose and treatment plan is usually discussed at the annual review by the haematologist. The dose should not be adjusted without advice from the health professionals at the Haemophilia Centre. The diary can indicate adherence to the prescribed prophylaxis regime. It is well known that at some time most people with haemophilia choose to have a break from prophylaxis. In these cases, the staff rely on the diary entries to ensure the person with haemophilia is treating any bleeding adequately, avoiding under- or overdosing with factor.

### THE REASON FOR TREATING

The mantra of haemophilia has been "when in doubt treat". For a person with haemophilia who has had the benefit of prophylaxis does this still hold true? Particularly for people who can't remember having a bleed! For example, an older patient who delivers his records monthly reported multiple treatments for ankle pain. When Haemophilia Centre staff became aware of this, he was asked to come in for review and further investigation. His pain was diagnosed as arthritis and not bleeding. More appropriate and effective treatment was commenced.

### THE BATCH NUMBER

If there is ever an issue with the batch or a recall of product, the batch number would be essential to trace the product. Without home treatment diary records it would be very hard to

trace particular batches - the patient has the most accurate record of which batches they have used.

### How to keep your home treatment diary commitments

- Keeping treatment records needs to be part of your routine, just like brushing your teeth
- Record your doses when you infuse clotting factor
- Provide your records to the haemophilia centre at timely intervals, eg monthly, so that they can be useful for your care
- Even if you are on regular prophylaxis, keeping records isn't a waste of time. Our data shows that people who keep good records usually have good control over their haemophilia and bleeds - which makes for better health!

Treatment for people with haemophilia is constantly improving. Home treatment is an extension of the care provided by the Haemophilia Centre and is not intended to be independent of, or to replace the haemophilia treatment team, and it works best where the person with haemophilia works in collaboration with their treatment team.

Treating at home does come with responsibilities, such as providing accurate treatment diaries - but remember, next time your Haemophilia Centre requests your treatment diary, this is how you contribute to your medical records so that the Haemophilia Centre team can enhance your care. #

# FOOD FOR THOUGHT: HIV/HEPATITIS C CO-INFECTION AND NUTRITION *PART 2*

Lia Purnomo

## DIET AND HIV/HEPATITIS C CO-INFECTION

Although most people living with HIV/hepatitis C co-infection do not need a special diet, they are best advised to maintain a healthy diet. Healthy eating for people who are co-infected with HIV and hepatitis C is the same as recommended for the general population.<sup>1</sup> However, dietary choices should be based on individual circumstances and will depend on any symptoms being experienced at a particular time.

## WHAT IS A HEALTHY DIET?

A healthy diet contains the right balance foods from each of the five major food groups. Choosing a variety of foods within and across food groups is essential. Healthy eating also means following a regular meal plan which provides the body with a constant supply of protein, carbohydrate, fat, vitamins and minerals.

## Healthy eating for people co-infected with HIV and hepatitis C should generally be:

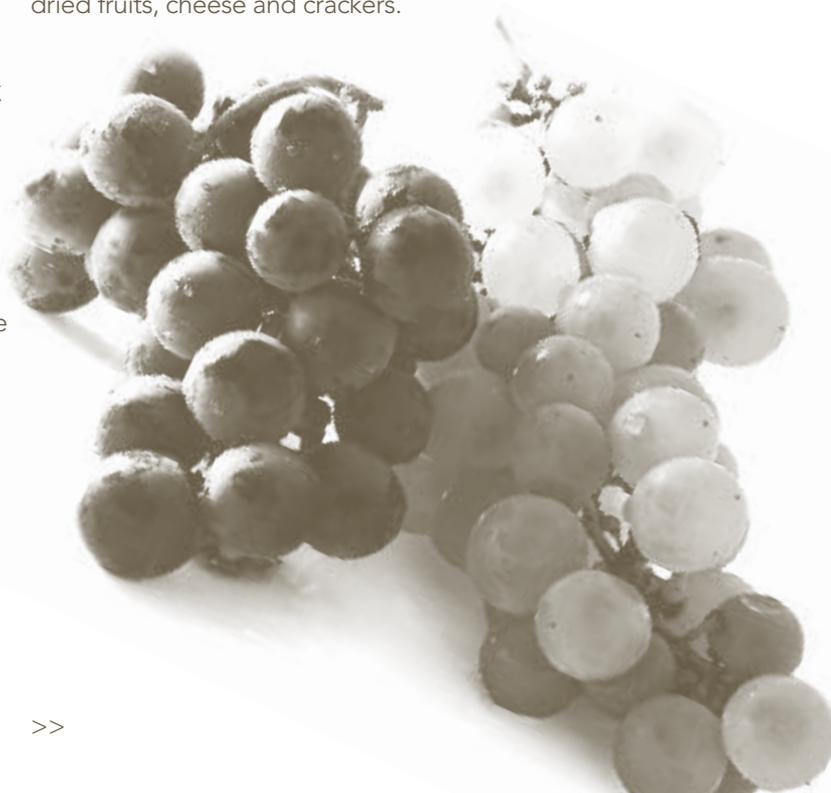
- high in fibre from wholegrain foods, vegetables (including legumes) and fruits
- high in unsaturated fats such as fish, nuts, avocados, canola, olive and sunflower oils
- low in saturated fats, which commonly come from animal fats, high fat dairy products and highly processed convenience foods
- low in added sugars, such as that which is found in soft drinks and lollies

- adequate in calcium – low fat dairy products are excellent source of calcium, and
- low in alcohol.

## LIVING WITH HIV AND HEPATITIS C CO-INFECTION: SYMPTOMS RELATED TO EATING AND NUTRITION

Symptoms experienced by co-infected individuals may impact on nutritional status by affecting the amount or range of foods eaten. Appetite may be reduced and the taste of foods can be altered, changing the types of foods consumed and affecting absorption and utilisation of nutrients.

There are many strategies to manage these symptoms, but in general the best way to meet nutritional needs is through eating regular small portions of food and drinks that are high in calorie and nutrient density, such as smoothies, yoghurt and milk drinks, and high energy snacks (nuts and dried fruits, cheese and crackers).



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## FATIGUE

Recent research suggests that fatigue is among the most common presenting symptoms associated with HIV and hepatitis C coinfection.<sup>2</sup> There is no nutritional 'quick fix' for fatigue, however, these suggestions may help manage fatigue:

- focus on adequate energy intake
- stock up the pantry when feeling well, cooking in bulk and freezing meals for use another time
- reduce highly processed foods
- incorporate light exercise into daily routine, and
- have support systems of family and friends to prepare meals.

## POOR APPETITE

Lack of appetite may cause insufficient dietary intake, making it difficult to maintain adequate supply of nutrients.

### Dietary strategies include:

- eat small amounts often, rather than relying on appetite to prompt eating
- eat most when feeling the best
- separate consumption of liquids from meal times
- eat meals with family or friends
- make meals as tempting as possible by varying tastes, colour and texture
- eat in well-ventilated room
- rinse the mouth before meals, and
- light exercise before meal-time may stimulate appetite.

## NAUSEA AND VOMITING

Nausea can occur as a result of skipping meals, feeling hungry or having gastrointestinal disease. Prolonged cases of vomiting can lead to symptoms of dehydration.

### Dietary strategies include:

- avoid having an empty stomach
- avoid fatty foods (eg, fried foods, pastries)
- rest after eating
- nibbling on salty foods(eg, crackers) or dry toast

- sip on ginger ale, and
- try small, frequent sips of nourishing fluids after the vomiting is controlled and gradually introduce small amounts of solid foods.

## WEIGHT LOSS

Unintentional weight loss occurs because the body is using up more nutrients than it is absorbing from food. There can be many causes of weight loss in people co-infected with HIV and hepatitis C. Some causes include increased metabolism and malabsorption associated with HIV; symptoms associated with each condition; and drug treatments that affect appetite.

### Dietary strategies include:

- never skip meals
- increase healthy fats (eg. add extra olive oil, avocado, nuts and seeds to salads), and
- avoid eating 'junk food', as this is not the best way to gain weight. Instead, increase intake of nutrient dense foods such as starchy vegetables and dense wholegrain breads and cereals.

## DIARRHOEA

Diarrhoea is the passage of three or more loose or liquid stools per day, or more frequently than is normal for the individual.<sup>3</sup> A variety of bacterial, viral and parasitic organisms, HIV itself, side effects of HAART (and some other medicines, such antibiotics) can cause diarrhoea in HIV positive people who are co-infected with hepatitis C.<sup>4</sup>

### Dietary strategies include:

- drink plenty of fluids
- limit consumption of highly spiced, fatty foods, and of alcohol, caffeine, and carbonated drinks
- limit food with insoluble fibre such as wholegrain cereals, brown rice, raw vegetables, nuts and seeds
- increase soluble fibre intake, such as oats, bananas, apples, fibre supplement (psyllium husk)
- reduce high fructose foods such as fruit juice, and
- try soymilk or lactose free milk until diarrhoea ceases as

diarrhoea can cause temporary lactose intolerance (yoghurt and cheese in small amounts are usually tolerated).

Once bowel function returns to normal, it is important that the diet returns to a balanced diet which includes fresh fruit and vegetables and wholegrain cereals.

It is recommended that people with HIV / hepatitis C co-infection consult a HIV/HCV specialist dietitian to ensure all dietary requirements are met and obtain advice on suitable dietary changes. ■

## REFERENCES

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# IL28B GENE TESTING AND TREATMENT OVERVIEW

Toby Armstrong

*Genetic testing for people with hep C is one of the biggest developments in years. Toby Armstrong explores this new treatment-related blood test.*

There's been a lot of buzz about a genetic "signpost" which shows how likely hep C treatment is to be successful. That variation is usually found in the IL28B region of our genetic material, and is usually just referred to as IL28B. You might have heard about the new test and the influence it might have over treatment decisions and hep C research. Here's a more detailed rundown of what it is and what it might mean for you.

Discussion of IL28B has been circulating in academic journals since late 2009, but the news has only just hit the mainstream. It's all about a "genetic polymorphism", which just means there's a natural variation in genetic material between people, and some people have a variation which has a positive influence on treatment success. That variation is in people's DNA: it's not a characteristic of the virus. "IL28B" describes the location of that variation in our genetic material. By testing for that variation, we can now get a better idea of how likely a person is to respond to treatment.

Having the favourable variation means your chances of SVR (Sustained Virological Response, also called cure) are twice what they would be without it. In one study, around 40% of Caucasian people without that favourable variation had an SVR, whilst 80% of people with the variation had an SVR. That doesn't mean that if you have genotype 1

and the right genetics, you'll have a 100% chance of curing your hep C. It just explains the variation in treatment response that already exists. This genetic variation doesn't account for all the variations in response, and of course it's still possible to have an SVR without it.

IL28B testing may lead to more personalised (possibly shorter) treatment regimes after more study, and at the very least will help people to make better treatment decisions. For example, if you find that you have the responder genotype, you might be swayed towards treatment. If you find that you have the non-responder genotype, you might wait for more effective treatments to become available. If you have severe liver disease that's progressing quickly and you don't have the favourable characteristic, you might be considered for a transplant earlier.

The favourable characteristic that's being testing for is a "CC genotype". There are two other possibilities: "TT" and "TC". People with those genotypes have significantly less chance of clearing. "TT" is the least favourable (just over 30% of Caucasian people) and "TC" slightly better (around 40%).

We already know that treatment response varied with ethnicity and IL28B goes some way to explaining why. The favourable variation is found more frequently in East Asian people, followed by Caucasian and Hispanic people and less commonly in people with African ancestry. According to the articles available, the genetic variation accounts for 50% of the difference in

treatment response (they don't talk about other factors).

These results seem to hold for treatments other than the current interferon and ribavirin combination: it's been studied with telaprevir too. It's not clear how the variation might influence a treatment that didn't include interferon (which we might start to see more of down the track). The differences in treatment success are independent of other pre-treatment variables, like gender, fibrosis stage and viral load. That could mean that we'll see a whole new approach to how people are assessed for treatment, and that research into treatment is significantly different in the future.

So what does this mean for you if you're considering treatment? Well firstly it might mean that having an IL28B test is a good idea if you have genotype 1. Knowing if your chance of a cure is around 50% or around 80% might be one of the key factors when making your choice. If you have genotype 2 or 3, these tests won't mean much for you: your chances of cure are probably around 80% already.

This information might help you decide if current treatments are for you. If they're not, remember to check back in a year or two if you're still interested, because new treatments are being developed all the time. ■

If you want more information about the IL28B test, talk to your hepatitis clinic or your Haemophilia Centre, if they manage your hepatitis C. If you are interested in having the test, there may be a cost involved.

# CALENDAR

## World Haemophilia Day

17 April 2011

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

## Haemophilia Awareness Week

9 -15 October 2011

Phone: 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)

## 16th Australian & New Zealand Haemophilia Conference

20 - 22 October 2011

Novotel, Sydney Olympic Park,  
Sydney NSW

Phone: 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)

## XXX International Congress of the World Federation of Hemophilia

Paris, France 2012

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

## XXXI International Congress of the World Federation of Hemophilia

Melbourne, Australia 2014

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

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# ADVANCE YOUR PASSION AWARDS

The Advance Your Passion Awards are development grants to help young Australians with bleeding disorders to pursue a specific dream or talent.

The program is open to people with haemophilia, von Willebrand disorder or other related inherited bleeding disorders in the following age groups:

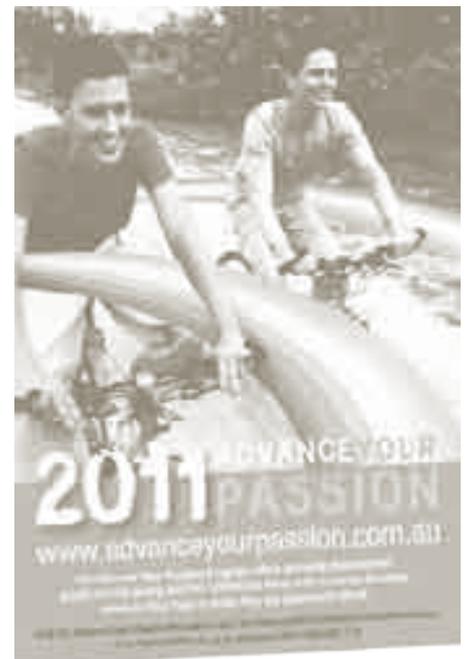
- 14-17 year olds. Grants of up to \$2500 are available
- 18-24 year olds. Grants of up to \$5000 are available

A total amount of \$15,000 is available.

For more information on the Awards and how to apply:

- visit the web site: [www.advanceyourpassion.com.au](http://www.advanceyourpassion.com.au)
- or contact HFA on 1800 807 173 or [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

Application forms must be submitted by midnight 30 April 2011.



The Advance Your Passion Awards are managed by Haemophilia Foundation Australia and sponsored by Baxter Healthcare. ■



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