

# National



# Haemophilia

Haemophilia Foundation Australia

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

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## 16TH AUSTRALIAN & NEW ZEALAND HAEMOPHILIA CONFERENCE

20-22 OCTOBER 2011



HEALTH AND WELLBEING INTO THE FUTURE -  
THE DECADE AHEAD

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## WFH 2012 WORLD CONGRESS, PARIS

The World Federation of Hemophilia (WFH) World Congress is the single largest event in the WFH calendar, and is very important to the global bleeding disorders community. Every second year doctors, scientists, healthcare workers, people with bleeding disorders and haemophilia organisations gather to learn about the latest developments in bleeding disorders treatment, to discuss, to debate and to contribute to a strong global organisation and community.

Taking place from 8-12 July 2012, the Congress will feature presentations, workshops, and exhibits on cutting-edge trends in research and treatment for haemophilia and other inherited bleeding disorders and also launch WFH's 50th anniversary commemorative activities.

For more information visit [www.wfhcongress2012.org](http://www.wfhcongress2012.org)

**PARIS**  
 World Federation of Hemophilia  
 2012 World Congress  
 PARIS, FRANCE  
 July 8-12

Fédération Mondiale de l'Hémophilie  
 2012 Congrès Mondial  
 8-12 juillet

Federación Mundial de la Hemofilia  
 2012 Congreso Mundial  
 8-12 de julio

[www.wfhcongress2012.org](http://www.wfhcongress2012.org)

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**WFH 2012  
 WORLD CONGRESS**

PARIS, FRANCE  
 Sunday, July 8 - Thursday, July 12

50 Years of Advancing  
 Treatment for All

# NOTES FROM THE PRESIDENT

*Gavin Finkelstein*

## **Conference in Sydney**

In this issue we present some impressions and outcomes from the recent 16th Australian & New Zealand Haemophilia Conference held in Sydney. The conference was vibrant, the program included challenging issues and there was active participation from delegates.

## **Congress 2014**

Usually we have no sooner finished one conference before we are planning the next. But it will be very different between now and when we would usually be running the 17th national conference! By then we will be well and truly geared up for the World Congress in Melbourne in 2014.

The 2014 Congress is a rare and great opportunity for us to gather as many Australians with bleeding disorders, as well as their families and carers, health professionals, government officials, industry and others together in Melbourne as possible to join with the rest of the world in this incredible Congress experience. It's such an opportunity - right on the doorstep of every Australian as well as our New Zealand neighbours, and easily accessible by others in the region!

We will be putting all our effort into working with WFH to make 2014 the best ever Congress and we want you all to be a part of that. Many people have already volunteered to play a part or indicated they have already started a savings plan so they can attend as a delegate. State/Territory Foundations are developing fundraising plans to help subsidise as many members as possible to attend. HFA will also develop plans to encourage and support attendance. For Congress to be successful we

need strong local attendance and will do all we can to encourage you to attend.

Although the Congress is the overall responsibility of WFH, HFA will play a part in several different planning committees. Health professionals and community volunteers will soon become a part of these committees and before we know it the Congress will be upon us. Sharon Caris has already been working with WFH staff on some of this preparatory Congress work. Next month WFH President Mark Skinner and Director of Congresses & Meetings Craig McEwen will visit Melbourne for further discussions and to sign a contract which sets out obligations between the two organisations in respect of the Congress.

## **Paris 2012**

HFA will have a small delegation at the WFH Congress in 2012. See further details about the Paris meeting in this publication.

## **HFA Council Meeting and Annual General Meeting 22-23 October**

Immediately after the closing session of the conference, the Delegates from each of our member foundations assembled for our AGM and the Council meeting. I am pleased that the energy remained and several issues under discussion at the Conference were raised for further discussion and action at the Council meeting.

There was considerable discussion about the importance of patient participation in their care and treatment and especially in relation to the need for people with bleeding disorders to keep connected with

their Haemophilia Centre, the importance of multidisciplinary health care and the likely impact of cost pressures on the governments which pay for and supply clotting factor products. During the conference we had discussed a range of issues related to these things and some of the ways potential problems could be addressed, and have been addressed in the UK and other countries, for example. Council recognised the need for the patients to take a responsible approach to their treatment and care and the importance of being able to measure the benefits of the treatments provided. We all know that clotting factor stops bleeds, but are we all good at recording our clotting factor use and working with our health professionals to understand what's going on with bleeds, working out ways to better manage them, as well as taking other steps to improve our general health? As our community ages these issues are even more important and we need to make sure we have the services required to meet everyone's needs. I am pleased that one of the significant resolutions of Council was to seek a collaborative partnership with stakeholders to develop a national system for patients to record clotting factor use in a way that enhances care and treatment and improves clinical outcomes.

Another important discussion of Council was about the difficulties for people living with hepatitis C and an ongoing commitment was made to ensure people have access to up-to-date and relevant information and education and access to treatment. Many people have been living with hepatitis C for more than 20 years and it has become clear that serious health

# HFA STAFF

problems are increasing and the need for action is urgent. All Council delegates emphasised the need for HFA to continue our campaign to governments for financial assistance to support people living with hepatitis C and their families. We are certainly doing this, and will continue with our work to raise the issues with governments and seek the services and support needed by this group of people in our community.

## **New Delegates and new Executive Board members on HFA Council**

We welcomed several new Delegates to Council. These volunteers will continue to represent their local Foundations at a national level and in many ways will provide the most important links between HFA and their Foundations.

Executive Board elections were held at the AGM and I was delighted to welcome Maria Wensing (HFACT delegate) and Dan Credazzi (HFNSW delegate) to the Executive Board. I wish to acknowledge the contributions of Paul Bonner (HFSA delegate) and Peter Fogarty (former HFQ delegate) for their contribution to the Executive Board over several years.

Regardless of which State/Territory they come from Executive Board members represent the whole community at a national level. The newly elected Executive Board is as follows:

President- Gavin Finkelstein  
Vice President- Jonathan Spencer  
Treasurer- Ann Roberts  
Executive Members-  
Dan Credazzi and Maria Wensing  
Best wishes for the festive season! ❏



Back L-R:  
Suzanne  
O'Callaghan,  
Sharon Caris,  
Joanne Luciani

Front L-R: Kate  
Walton, Natasha  
Coco, Trish  
Godden

As there have been some changes at the HFA office recently we wanted to make sure everyone is up to date. In July this year we farewelled Janine Staunton who had been in the part time Development Manager role while Natasha Coco was on maternity leave, and we have since welcomed Natasha back. Since this time we have also built on some of our plans and in August we appointed Trish Godden to a new part time Direct Marketing Manager role at HFA. Kate Walton joined HFA in August to work on our new and exciting youth project. Many of you will interact with Joanne Luciani more now, as she is now working in both the fundraising area and general admin at HFA and is likely to be the first point of contact when you call HFA. We are always happy to speak with you about any issues that arise for you that you think we might be able to help with.

## **Executive Director, Sharon Caris (Full-time)**

e: [scaris@haemophilia.org.au](mailto:scaris@haemophilia.org.au)

Sharon has worked at HFA since 2001 and has a background in social work, health administration and advocacy over 29 years. Sharon leads the staff team and works with the HFA Council, government and other stakeholders to implement the HFA objectives.

## **Policy and Education Manager, Suzanne O'Callaghan (Full-time)**

e: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)

Suzanne joined HFA in 2006 and helps HFA develop policy and education resources for the bleeding disorders community. Suzanne has a background in consumer health information and education, and has worked for many years in the blood borne virus sector.

## **Development Manager, Natasha Coco (Part-time, Tues, Wed, Thurs and every 2nd Monday)**

e: [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)

Natasha joined the HFA team in 2003 and looks after trust and foundations, planned giving, corporate fundraising, community awareness, events, particularly National Conference and 2014 World Congress. She has undertaken fundraising roles in not for profit organisations for over 12 years.

## **Direct Marketing Manager, Trish Godden (Part-time, Mon, Tue, Wed)**

e: [tgodden@haemophilia.org.au](mailto:tgodden@haemophilia.org.au)

Trish joined the HFA team in 2011 and looks after our fundraising direct mail campaigns and our donors. Trish has worked for several years in fundraising roles in the not for profit sector.

# MEET TRISH GODDEN



## **Youth Project Officer, Kate Walton (Part-time, Mon, Tue, Thurs, Fri)**

e: [kwalton@haemophilia.org.au](mailto:kwalton@haemophilia.org.au)

Kate joined the HFA team in August 2011 as the Youth Project Officer for a year. Kate is consulting with people with bleeding disorders and their families and carers, health professionals and other stakeholders about the needs of young people with bleeding disorders in our exciting project Beyond Prophylaxis. This work will result in a communication tool and education strategy for young people. Kate has worked for several years as a youth worker.

## **Accountant, Kevin Lai (Part-time, 1 day per week)**

Kevin has worked with HFA as a part-time accountant since 1995. His role is to prepare financial accounts and assist with financial management processes.

## **Administration Assistant, Joanne Luciani (Part-time, Tue, Wed, Fri)**

e: [jluciani@haemophilia.org.au](mailto:jluciani@haemophilia.org.au)

Joanne was appointed in 2007 to assist with fundraising, special events and general administration. Joanne has a background in fundraising and managing databases in the not for profit sector. #

The newest recruit to the HFA team, Trish Godden has joined HFA as Direct Marketing Manager and brings a wealth of experience and enthusiasm to this new position. HFA's programs and support for local Foundation activities such as camps, workshops and support groups rely heavily on donations and other forms of fundraising and Trish will be concentrating on growing financial support for these initiatives.

"A lot of people in the wider community have some knowledge about haemophilia, but they don't understand that there is a real need for support to manage the challenges of living with a bleeding disorder and living a fulfilling life. And that this support often comes in the shape of Foundation programs and activities - that need to be funded," says Trish.

In this endeavour Trish has a great deal of expertise to call on. She has marketing experience across a number of sectors, and has worked with organisations such as Western Bulldogs Football Club and large corporations such as Telstra. Her focus has been on understanding community needs and encouraging increased support. Most recently she worked in a similar role as Donor Development Manager at Make- A-Wish Australia, where individual donations contributed to over 5000 children's wishes being granted.

HFA's proven and strong national role in advocacy and education was

a great attraction for Trish. She has been impressed by the commitment of individuals in the bleeding disorders community to improving the future for their fellow community members and their openness and honesty in sharing their story.

"It's important to put a human face to the cause - it helps the wider community to understand what it means to live with a bleeding disorder," says Trish.

Her first project has picked up from an earlier area of work: she liaised with Chris Gordon, a young man with haemophilia who has become an Australian Football League umpire, to tell his story. Chris has become an inspiring role model for many young boys growing up with haemophilia.

Trish would love to hear from community members and welcomes your feedback, ideas and any stories you would like to share about making a difference.

Trish works Monday, Tuesday and Wednesday.

She can be contacted at:

T: **03 9885 7800** or toll-free  
**1800 807 173**

E: [tgodden@haemophilia.org.au](mailto:tgodden@haemophilia.org.au) #

# THE COTTON CLUB

Natashia Coco

One of the most important parts of HFA's work is its fundraising programs as the funds raised are used for the various programs undertaken at a national level or for local Foundation activities such as camps and workshops. Many of our *National Haemophilia* readers might also be donors to HFA, but if not we certainly encourage participation in our fundraising programs.

HFA has some inspiring volunteers who do amazing work to help us raise funds. Recently Miffy, Sally-Anne, and Holly organized another fantastic fundraiser for HFA and raised \$12,260 at "The Cotton Club" event they fully planned and hosted. This is their second fundraiser like this. Holly's son and Miffy's nephew, Jack, is 4 years old and has severe haemophilia. Their motivation is to raise funds that will support the future of Jack and other young children with haemophilia like him. Holly and Miffy's father also had haemophilia and they know about some of the challenges ahead for Jack and how the work of the Foundation will help address some of these so his journey is not so hard.

Tom and Grace heard about how their parents went to "The Cotton Club" and decided that they would also raise money for the Foundation. Their story (below) was written by Tom's mother:

*On Sat 30th July, Tom (8) and Grace (10) in conjunction with other family and friends who offered their services, held a cake stall to raise money for HFA. Both being incredibly empathetic children with a strong sense of social responsibility, they discussed what they could do to contribute to their community. Grace loves to cook and would one day love to be on MasterChef and although Tom doesn't do a lot of baking, he is great on the ideas and also very good at convincing others to get on board! Within a day, Grace and Tom had put together their marketing plan to make this fundraiser the biggest and best. Between the two of them, their hard efforts paid off.*

*Despite the cold rainy day, the cake stall that was planned to run for 2 hours had to be cut short due to a sell out! The children delivered over 200 pamphlets through the neighbourhood and also used their classes*

*from both Malvern Primary and Korowa to drum up support for attendance. Due to the generosity of other family and friends and Chef Momo who operates a wholesale cake business in Station Street, the stall had an abundance of quantity and variety. We had cookie monster cupcakes which looked professionally made, but baked and decorated by Grace and her friends. There were chocolate crackles and honey joys... yoghurt muffins and anzac cookies. We had small cakes and large cakes and sizes in between. The sense of community support was overwhelming as everyone popped by to make a purchase or two.*

*Grace and Tom were very proud of their efforts and very pleased with the fact that they raised over \$400 for such a good cause. They realise they are fortunate to be healthy and happy and they now understand what haemophilia is and how it impacts those who have the condition. They hope that their little contribution will assist. And they look forward to watching their mate, Jack who visited on the day, grow into a strong and healthy young lad! ❧*



Grace, Tom and their friends and their cake stall fundraiser

Do you want to organize a fundraiser?  
Do you want to donate to support programs  
and services and research?

If so contact HFA today on 1800 807 173  
or email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)



## Health and wellbeing into the future – the decade ahead

Haemophilia Awareness Week • 9-15 October 2011

# HAEMOPHILIA AWARENESS WEEK 2011

For Haemophilia Awareness Week 2011 we built on the theme “*Health and wellbeing into the future – the decade ahead*”. In Queensland, the Brisbane Bridge turned red for the week and in Victoria, Neerim South once again “*Painted the Town Red*”.

This year we received over 140 colouring-in competition entries. The standard was very high and we appreciate the pre-schools and schools from around Australia that participated.

The final winners are:

- Ruby, NSW 5 and under age group
- Jack, VIC 6-9 age group
- Nikolas, NSW 10 and over age group

Next year Haemophilia Awareness Week will be from 7-13 October 2012. 

Thank you to  
Donna Field in  
Neerim South for  
organising a great  
event and raising  
over \$450.

The winning entries



# HAEMOPHILIA CONFERENCE



The 16th Australian & New Zealand Haemophilia Conference was a great success. It was attended by 250 delegates, including people with bleeding disorders, their families and carers, health professionals, policy makers, industry representatives and many other stakeholders who came together to meet, share information and learn from each other.

The diverse program was developed by a multidisciplinary committee chaired by Dr Julie Curtin, and covered a range of interesting and challenging topics. We thank all the speakers and session chairs who contributed to our meeting.

Presentations and the abstract book are available to download from our website [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)

Thank you to our conference sponsors and supporters—

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#### Evaluation comments

*"Thought the topics were very interesting and varied, would have liked to have attended all concurrent sessions – but obviously not possible"*

*"The sessions that were relevant to me I found really interesting and informative. The intro session with Anna Louise was a great way to kick off the conference too"*

*"Overall I was totally in awe of the whole conference experience. This was my first conference and I was extremely impressed by the organization of the conference and the amount of work contributed in providing a professional and informative media. I was equally impressed with the amount of research that is being carried out regarding bleeding disorders and the dedication of those involved within the bleeding disorder community. The support I received and the opportunity to discuss my issues and concerns was of great benefit to me. I felt reassured with this support and have been encouraged to speak up for my family even when there is opposition. The conference experience has strengthened me as a carer..."*

*"One of the best conferences I have been too. Staff, speakers and attendees were amazing."*



# REFLECTIONS ON THE HAEMOPHILIA CONFERENCE –

## AN INTERVIEW WITH GAVIN FINKELSTEIN

The 16th Australian and New Zealand Haemophilia Conference brought together community members, health professionals and other stakeholders to discuss the latest advances in bleeding disorders. Gavin Finkelstein, President of Haemophilia Foundation Australia (HFA) spoke with Suzanne O’Callaghan, HFA Policy and Education Manager, about the Conference and its significance for health and wellbeing into the next decade.

### **Suzanne: What were your general impressions of the Conference?**

**Gavin:** What stood out most for me was the energy. The venue was particularly good and brought everyone together. The Conference had a practical, interactive and up-to-date program with a positive take on the future and encouraged youth involvement. People were very engaged and asking questions, which highlights how well the Conference was working.

I noticed that community members who were attending the Conference for the first time were very enthusiastic. It has inspired some of them to attend the World Congress in Paris and later Melbourne, which is a great result.

### **Suzanne: You mentioned that some sessions in particular came to your attention. What were your thoughts about the “Staying on your feet” session?**

**Gavin:** This session gave food for thought. As someone who would normally be reluctant to consider

invasive procedures or cortisone injections to treat joint problems, I was interested to see Associate Professor Prue Manners’ approach. She pointed out that joint damage can start quite early after only a few joint bleeds. It made me realise that you need to consider the benefits of the techniques she described, such as stepping in quickly with a joint bleed to wash blood and iron out of the joint and using corticosteroid injections. It might not be an appropriate course of action in all cases, but it was valuable to raise the question whether an early intervention like this would be an effective way to prevent long term damage in some situations. It also highlighted that a rheumatologist is an important member of the Haemophilia Centre team, especially with an ageing population, and was a reminder of the work to make sure rheumatologists are consistently involved and accessible as part of comprehensive care across Australia.

### **Suzanne: What were your reflections on the “Transitions” session?**

**Gavin:** From my position, as an adult with haemophilia who has been mentoring young people for some time, it was very valuable to see the differing perspectives of young patients compared to health professionals. The young guys had grown up with prophylaxis treatment. Their view on career and sport was that you test your boundaries, make decisions from your experiences and learn from mistakes. For example, you might start with a great desire to play

football but find that you can’t play it any more, so would have to change the sport that you play. Or with a career, try out bricklaying for a few weeks and then find out this isn’t for me and I need to find something that is kinder to my body. On the other hand some health professionals were saying this is too much of a risk and they shouldn’t even be considering it.

I wonder if there needs to be some middle ground? I think it is important not to feel that you are being told you can’t do something – that road leads to resentment and it might even lead to non compliance - but perhaps when you are walking the path to find out yourself if you can do some sport or career, to plan for it with Haemophilia Centre support and be aware that it might not work for you. This way young people can have the opportunity to come to a more realistic decision by finding out what their own limits are and have other options that they are prepared to consider if their first choice doesn’t work for them. The younger guys have an advantage over the older guys as they are testing this out at a younger age when it has less impact on their career development and they can make better decisions for the long term. They also don’t experience the frustration of always wondering what it would have been like to play a particular sport or try a specific career.

### **Suzanne: You also attended the “Living with hepatitis C and/or HIV co-infection” session. What messages came from that?**

**Gavin:** This was a very positive session with presentations describing new hepatitis C treatments and highlighting the message that a cure is now possible for more people. It is exciting to hear that new treatments with antivirals are more successful and offer a shorter length of treatment and that there is now the possibility of treatment for those with more advanced disease. If they have hep C, members of our community will have had it for more than 20 years and are now starting to be more affected by liver disease. They are looking more closely at their options for treatment; and with the effect of hep C on their liver and their lifestyle, they are being forced to take whatever action they can.

It was also useful to hear about the new approaches to monitoring hepatitis C and the importance of being responsible for managing your lifestyle – limiting alcohol and smoking, having a careful diet, keeping your weight down.

**Suzanne: What other comments do you have about the Conference?**

**Gavin:** I was impressed by the very high level of audience engagement – lots of questions from community members during the sessions and discussion afterwards. It is also an opportunity for health professionals and community members to develop different relationships from the clinic visit. At the Conference, they mix socially and chat about the sessions together at the breaks. With people who have chronic health problems, this is very important and can make for more open discussions in the clinical setting. The health professional – patient relationship is a long term relationship and this is a way of breaking down barriers to make for a stronger connection. ■

# TREATMENT AND CARE – NOW AND THE FUTURE

Geoff Simon

## WHAT ARE SOME OF THE ISSUES?

*Geoff Simon introduced the final conference plenary, "Treatment and care – now and the future", with a summary of topics and concepts raised over the previous two days. Asking the question "What are some of the issues?", he grouped the issues under five headings and used his extensive experience and understanding of blood product management to give a clear description of the main points. The "mind map" he used to outline the issues is included with this article and HFA appreciates his generosity in making it available for publication.*

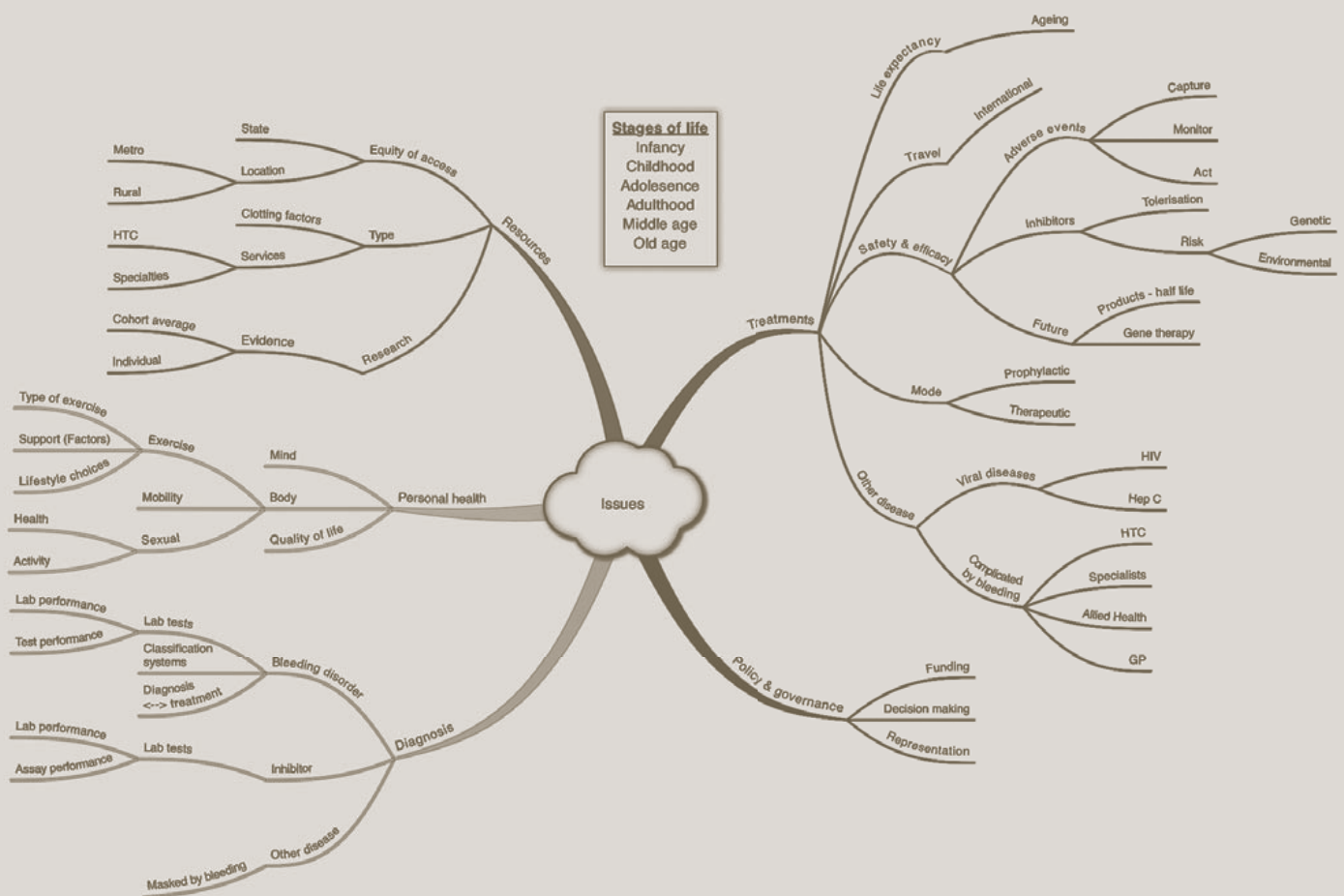
## Diagnosis

Discussions during sessions touched on the diagnosis of bleeding disorders, investigation of inhibitors, and the diagnosis of other diseases which may be masked or complicated by a bleeding disorder. In the case of the first two elements, the performance of individual laboratories and the performance of different assays (diagnostic tests) can be factors in achieving a satisfactory diagnosis and guidance for treatment. Other discussion included the complexity of classification systems, particularly for Von Willebrand Disease, and the importance of correct classification so that treatments will be most effective.

## Treatments

A broad range of discussion topics relating to treatment included:

- Life expectancy – issues associated with ageing are being faced by members of the community, with bleeding disorders sometimes complicating or exacerbating the effects of ageing
- Travel – support from Australia, either with clotting factor products or clinical advice, for those with bleeding disorders who are traveling internationally
- Safety and efficacy of treatments – including capturing, monitoring and acting on adverse events, dealing with inhibitors and approaches to tolerisation, studies of the contribution of environmental factors and genetic factors in the development of inhibitors, future clotting factor products with longer half lives, and the potential for gene therapy
- Modes of treatment – studies and discussion of prophylactic versus therapeutic approaches to treatment
- Treatments and progress with other viral diseases - particularly HIV and hepatitis C
- Treatments for other diseases – including the role of the Haemophilia Treatment Centre (HTC) versus the role of other specialists when being treated for non-related conditions or going for surgery, the roles and relationships of general practitioners with the HTC, and access to allied health professionals.



## Personal Health

Personal health was a significant focus of some sessions of the conference, including the importance of looking after mental health and agility to have the best outcomes for the health of the body. The importance of exercise and different types of exercise were discussed, along with the need for clotting factor support related to increased periods of activity, and the extent to which a desire to pursue 'extreme' or highly physical sports should be supported with clotting factors. Sexual health and activity and overall quality of life issues were discussed from a number of viewpoints.

## Resources

Equity of access to resources, both between different states and between living in major metropolitan areas versus living in more rural or remote areas promoted discussion in a number of sessions. There were interesting observations by Dr Mike Makris from the UK regarding access to products and services, with Australia generally faring well in the comparisons. While access to clotting factor products is pretty much equivalent across Australia, there are differences in access to HTCs and in the range of services available within them. In many sessions there were comments about the lack of evidence or adequate research to support

decision making and the desire expressed for additional resources for research.

## Policy and governance

Discussions regarding policy and governance included issues related to funding, decision making and representation, both in Australia and New Zealand, and in comparison with the UK.

Across all of the topic areas, themes emerged across the stages of life, from birth through infancy and childhood, adolescence, adulthood and middle age to old age, sometimes giving answers and sometimes raising more questions. ❧

# THE FUTURE OF HAEMOPHILIA CARE

*Suzanne O'Callaghan*

With a focus on treatment and care into the future, the final plenary of the Conference took a pragmatic look at what was likely to come and the decisions that might need to be made. In a personal view on the future of haemophilia care, Mike Makris brought a valuable perspective to the discussion with his considerable knowledge of the European haemophilia treatment experience. Dr Mike Makris is director of the Sheffield Haemophilia and Thrombosis Centre and leads the European Haemophilia Safety Surveillance (EUHASS) Project.

Makris highlighted the new treatment products in the pipeline – new recombinant products and products for rare factor deficiencies such as factor V, X and XIII, and longer acting recombinant factor VIII and IX products allowing once weekly dosing for prophylaxis. In an exciting new development, a UK-USA collaborative gene therapy clinical trial for haemophilia B has started to produce some sustained results in humans. A haemophilia A trial will probably start in the UK in 2013.

The European experience has been that as factor usage and costs have increased, there have been higher levels of scrutiny by funding agencies and requirements for higher quality data on outcomes for patients. This has meant that patients and health care providers are now agreeing to join as partners to provide data on bleeds and treatment, along with outcomes of treatment such as joint scores, quality of life questionnaires, and information on the number

of days off school or work.

There is also more work on efficiencies of scale, with a European database to share data, multicentre trials and efforts to centralise haemophilia care in regional centres to gain the benefit of concentrated expertise and services. Telemedicine and haemophilia nurse consultants are also potential additions to a Haemophilia Centre service. Efficiency and effectiveness of treatment is also a question. Makris raised the issue of pharmacokinetic assisted dosing and why it was not yet being introduced when it is currently available. This process involves assessing how long a treatment dose continues to work in each person with haemophilia and would enable prophylactic dosing to be tailored to the individual's needs, so that only the lowest effective prophylactic dose would need to be prescribed.

In summary, Makris saw a bright future ahead for bleeding disorder treatment and care. He pointed out that current treatments are safe and effective, longer acting treatments are on their way, there is potential for minimal joint disease and no infections and a life expectancy higher than the normal population. For clinicians, the main issues will be to manage inhibitors and the cost and delivery of care in an effective way. ■

# HEALTH AND WELLBEING INTO THE FUTURE

*Jonathan Spencer*

## **HAPPY BODIES, HAPPY MINDS**

– Anna-Louise Bouvier

The opening plenary session presented by Anna-Louise Bouvier, Sydney-based physiotherapist and author, challenged the traditional approach to keep the mind separate from the body. In fact, she noted, increasing scientific evidence indicates that the mind and the body are related with each affecting the other. Particularly relevant to persons with chronic disorders is the message that we need to look after our mind as well as our bodies. Stress arises when we can't control a situation – for example, stress might arise when a bleed occurs or when we're not able to perform a task that others do more easily. Stress can affect the body. Common responses to unwelcome stress are habits of 'self-medication' that provide temporary relief and help us feel better – such as common stimulants (eg nicotine, caffeine, alcohol) and poor diet choices – that may become cyclical and harmful to our bodies in the long-term.

Bouvier pointed out that purely focussing on immediate physical issues neglects personal wellbeing. Moreover, a happy mind can lead to a happy body; and a happy body helps create a happy mind.

### **Her recommendations:**

*To keep your body happy* – move more (over two minutes at a time); sit less (if you're able; and if not, sit well with good posture); sleep better (practice relaxation and mindfulness techniques, before sleep); and, look happy (this actually sends good messages to the brain)!

*For a happy mind* – give more (being generous actually helps you live longer and increases mental wellbeing); be grateful (choose 3 good things that happened today); and, let go (try not to 'hold on' to unresolved issues for too long).

I came away from this entertaining, but informative, session recognising that treating both the mind and body is important for our long term health and wellbeing.

## **MEN'S BREAKFAST**

– Dr Kevin Rickard

At the Men's Breakfast session, Dr Rickard, a consulting haematologist with over 30 years experience as the clinical director of the Haemophilia Centre at Royal Prince Alfred Hospital until his retirement, and former Professor of Medicine at the University of Sydney, shared his wealth of experience in treating bleeding disorders. It was an opportunity for men with bleeding disorders to hear his personal observations and keen insights into the management of haemophilia and related bleeding disorders.

Dr Rickard engaged warmly with his audience and reminded us that, while we are fortunate with the level and standard of care achieved in Australia, we should not be complacent to emerging issues. It remains critically important that people with bleeding disorders understand their condition and work with their haemophilia treatment centres.

The advances in treatment and availability of products now mean that many persons diagnosed with haemophilia are able to undertake previously only dreamed of activities and opportunities. Nonetheless, questions on the appropriate use of factor should be considered and discussed in our community.

In Australia, the future for people affected by a bleeding disorder has never been better. It is important to remember our journey over the last decades and look forward to the new challenges that arise. ■

# CONFERENCE NOTES –

## THE PERSPECTIVE OF A FIRST-TIMER

*Donna Muszynski*

This was my first Haemophilia Conference experience and I greatly appreciated the opportunity to attend. I was in awe of the organisation of the conference and the amount of work contributed in providing a professional and informative forum. I was equally impressed with the amount of research that is being carried out regarding bleeding disorders and the dedication and commitment of those involved within the bleeding disorder community.

### **How a happier body can lead to a happier mind**

I was extremely impressed with the opening session on a happy mind in a happy body. What a fantastic, encouraging way to commence the conference. The session was applicable to everyone attending the conference as it related to every day life as it is now; whether you have a bleeding disorder, are a carer, health practitioner or just dealing with the every day. It was a great reminder on how important health and attitude is. Since attending the conference this presentation has often come into my mind and will be of great assistance to me in the future.

### **Von Willebrand disorder and the rarer bleeding disorders**

As a carer and not a health professional, I found the content of the von Willebrand disorder session extremely complex, particularly Dr Favaloro's discussion on the classification of Von Willebrand Disease (VWD). However whilst it was very technical, I was impressed with the amount of research and testing that is being conducted. I felt extremely privileged that VWD is not neglected and research is continuing. This will be extremely beneficial to my children and future generations.

Until attending the session on the rarer bleeding disorders, I was unaware that there were other bleeding disorders (apart from haemophilia and VWD). It is particularly helpful to hear personal accounts of other parents. Being informed strengthens the bond of the bleeding disorder community.

### **Women's health and reproduction**

I was not able to stay for the entire Women's health and reproduction session as I moved on to catch the panel

discussion in the Transitions session, but the discussions were very informative regarding genetic diagnosis and gave understanding as to why couples may choose this option. Dr McIntock's presentation on menorrhagia management was of particular interest, particularly with reference to reducing the need for hysterectomies.

### **Transitions: becoming an adult**

The panel discussion in the Transitions session involved two young people with bleeding disorders and two health care practitioners. The Youth Panel was a lively debate and raised lots of great issues regarding risk taking, treatment and lifestyle. As a carer it is often difficult to balance guidance regarding bleeding disorders – whether to dissuade from doing a particular activity or allow it. I found it very helpful to discuss my particular concerns with one of the health professionals on the panel after the session, and to have some very practical suggestions to discuss further with our Haemophilia Centre.

### **Treatment and care – now and the future**

The final plenary on treatment and care into the future was another very informative session. Of particular interest to me was the presentation of Stephanie Gunn on the role of the National Blood Authority in planning and procuring treatment products and the insight I gained into the acquiring and availability of treatment products. I had no idea of what takes place behind the scenes. My experience with treating products has been to just turn up and collect them. I am very appreciative now of the unseen work performed to ensure we have access to treatment products.

The support I received at the Conference and the opportunity to discuss my issues and concerns was of great benefit to me. I felt reassured with this support and have since been encouraged to speak up for my family even when there is opposition. The Conference experience has strengthened me as a carer.

I would encourage anyone who has an association with bleeding disorders, whether they are a person with a bleeding disorder, health professional or a carer, to attend future conferences and in particular the World Congress planned for Melbourne in 2014. #

Kate Walton is Haemophilia Foundation Australia Youth Project Officer

# FOCUS ON YOUTH



Kate Walton

Attending the 2011 Australian and New Zealand Haemophilia Conference was my first opportunity to meet a lot of the young people who represent the bleeding disorder community in Australia. At the youth meet and greet held on the Thursday night I met an abundance of intelligent and passionate young people who have aspiring dreams and goals.

To begin with we all sat around in a large circle and introduced ourselves, what states we are from, our ages and a little bit about ourselves. We then naturally broke off into smaller groups and this is when I got to really know some of the amazing young people I was surrounded by – the medical student, the film director, the AFL umpire and the aspiring haematologist, not to mention everyone else. The young people were keen to know about my background and how I ended up in the Youth Project Officer position. We shared stories, had a laugh and got to know each other. The meet and greet ended with new friends and contacts made by all. It was an incredibly motivating evening.

## Transitions: becoming an adult

On Friday I attended the 'Transitions: becoming an adult' session. Dr Desdemona Chong and Maureen Spilsbury from the Royal Children's Hospital (RCH) and Royal Brisbane and Women's Hospital presented "Transitioning in Queensland: from teddy bears to apprenticeships." This session discussed the key

differences between the adult and child services and the challenges for the young person, parents and the RCH Team. Sharon Hawkins, Senior Social Worker at the Haemophilia Centre of Western Australia, provided an overview of the Transition study completed in WA. Sharon discussed the background, method, implementation, findings and recommendations of the study. Of particular interest were the quotes that Sharon included in her presentation taken from the study, such as *"I felt very daunted having to leave (RCH) and feel it may not have been an appropriate time to move across, however maybe no time would have been a good time."* William Oversby, a young person man from Western Australia, then presented a patient perspective of transitioning which was honest and heart-warming. William included photos for his childhood and spoke openly and humorously about his experience of transition and life so far.

It was then my turn to host 'Can of Squirms,' as part of the Transition Session. There were four 'contestants' (two health care professionals and two young people) who were provided with the rules: contestants must be honest, there is to be no fence sitting, everybody gets to have their say and everybody's opinion is respected. The contestants were asked two questions: 'if you had a son with haemophilia are there any career choices, professions or vocations you would steer him away

from?' Secondly, 'should there be limits on people's life activities, such as the sports they play (if they have haemophilia)?' The answers provided were honest yet challenging as not everybody agreed with each other's responses. The professionals on the panel erred on the side of caution while the young people answered with their 'go for it' attitude. The audience members were then provided with the opportunity to ask questions. This was a thought provoking session that highlighted the need for the Beyond Prophylaxis Project to produce relevant and up to date information and resources for young people so that they have the knowledge to make informed and educated choices about their lifestyle and health.

## Communication and social media

I attended the Communication and social media session on Saturday. This was another interesting and riveting session. Suzanne O'Callaghan, the Policy Officer at Haemophilia Foundation Australia (HFA) presented 'Social networking: community perspectives and issues to consider for community organisations.' This session discussed why HFA has invested in social media, the value and benefits of this for the Foundation and community members and the risks associated for community organisations. Natasha Samy and Lyn Biviano from The Department of Social Work at The Children's Hospital at Westmead presented 'Maintaining the delicate balance of professional boundaries

in a new age.' This session focused on professional boundaries between staff and patients/families that are being complicated by new technology, for example friendship requests on Facebook. The session asked questions such as 'What guidelines does our organisation have about the use of social media?' and provided suggestions such as 'Before acting, consider the implications of your actions.' Melissa Sevil from the Australian Federal Police 'ThinkUKnow' program presented 'Privacy and reputation management in the digital space.' This presentation focused on cyber bullying, cyber safety, reporting any suspicious behaviour and protecting your personal and professional reputation on line when using social media.

Of particular interest was Melissa's comment that the things you post on line stay there for years and have the ability to come back and affect you in present time – food for thought. Melissa also shared her recommendations on how to safely and responsibly use social media technologies. The young people who attended this session participated at a high level, asking all panel members interesting questions to further their knowledge of social media. I have no doubt that everybody who attended this session learnt a thing or two about cyber safety.

The 2011 Australia and New Zealand Haemophilia Conference was a great learning experience for me. I enjoyed meeting all of the young people in attendance and hearing their stories. Returning from the Conference, I am more aware of the issues for young people affected by bleeding disorders and eager to work with them on the next step of the Beyond Prophylaxis Project.

*A reminder that any young people who are interested in working with Kate on the Beyond Prophylaxis project should contact her on [kwalton@haemophilia.org.au](mailto:kwalton@haemophilia.org.au) or phone 1800 807 173. #*

# WE WANT YOU!

Interested in the Beyond Prophylaxis Project?  
Aged between 13-30?

Also known as 'The Youth Project,' the Beyond Prophylaxis Project will address the information and resources you and other young people need about bleeding disorders. The aim of the Youth Project is to help make positive and informed choices about health and lifestyle.

The Youth Project will involve developing a user friendly place on the HFA website and you can play an active role in deciding what it will look like and what information it will provide. It will enable you to connect with other young people with bleeding disorders, share experiences and get information on issues such as your work, study, travel and health.

Want to tell us what is important to you?

Why not join the Youth Working Group for the project?

Contact Kate on 1800 807 173 or

[kwalton@haemophilia.org.au](mailto:kwalton@haemophilia.org.au)

## ATTENTION PARENTS!

**Do you have a teenager in the house?  
Or a young adult up to the age of 25?  
If so, Kate wants to talk to you.**

Kate Walton is the Youth Project Officer at Haemophilia Foundation Australia, working on the 'Beyond Prophylaxis' project. This project is about understanding and addressing the needs of young people with bleeding disorders and will focus on the information and resources they need to make positive and informed choices.

Kate would like to hear your thoughts and concerns about your teenager/young adult by answering a few short questions about what issues they may be facing at the moment, what information you think they need and what resources you believe will be beneficial for them now and in the future.

If you are interested please contact Kate on 1800 807 173 or [kwalton@haemophilia.org.au](mailto:kwalton@haemophilia.org.au)



Wendy Poulsen is Co-Chair of the Australian and New Zealand Physiotherapy Haemophilia Group

## AUSTRALIAN AND NEW ZEALAND PHYSIOTHERAPY HAEMOPHILIA GROUP MEETING

Wendy Poulsen

Once a year Haemophilia Foundation Australia (HFA) provides the opportunity for all health workers in haemophilia centres to come together to plan, discuss and learn. In 2011 the Australia New Zealand Physiotherapy Haemophilia Group was twelve in number, with representatives coming from Western Australia, South Australia, Victoria, Queensland and New Zealand.

This year there were new members to the group: though their haemophilia experiences were minimal, in terms of the numbers of patients they can see, their musculoskeletal knowledge is extensive and it is very important to bring these skills to their individual haemophilia treatment centres as a part of the comprehensive care team.

Opportunities for participants to learn from each other, teach and share information is an important part of our meeting: time to share research being done; time to share challenging situations; time to educate those whose experiences are less than others.

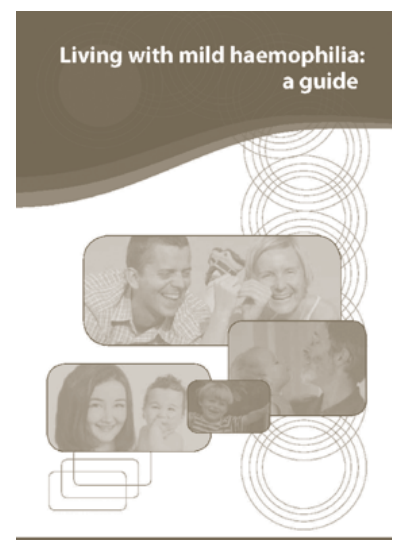
It is also a time to provide continued support to all those physiotherapists who are working in positions without haemophilia funding. It is our dream to have dedicated physiotherapists in funded positions in all haemophilia treatment centres.

Thanks to HFA for the opportunity that allows us to come together yearly so that we can be a united front in providing optimal treatments and management for people with haemophilia and their families. ■

# NEW MILD HAEMOPHILIA BOOKLET

Although people with mild haemophilia do not have bleeding problems as often as those who have moderate or severe haemophilia, this can often lead to challenges because bleeding problems are unfamiliar and people are not sure how to deal with them.

How do you know what a "bleed" looks or feels like? What do you do when you have an injury or bleeding? What does your GP or dentist or surgeon or obstetrics team need to know? And what about everyday living – travelling, playing sport, working, going to school, having babysitters, getting insurance, having relationships, planning a family? How does this work if you want to live well? What precautions do you need to take? What should you tell other people in your life?



HFA's comprehensive new booklet, *Living with mild haemophilia: a guide*, has been developed to answer these questions. Two volunteer groups, one a panel of people with mild haemophilia or women who carry the haemophilia gene, the other a panel of expert haematologists and haemophilia nurses, social workers and counsellors and physiotherapists, worked with HFA to put the booklet together. They listed Frequently Asked Questions, developed key messages and made sure the information was accurate, relevant to Australians and right up-to-date with the very latest research information.

Throughout the booklet there are also quotes and tips on managing mild haemophilia from people with mild haemophilia and women who carry the haemophilia gene.

Our thanks to the review panels, who were very generous with their time and made a major contribution to the development of the booklet. HFA is also planning a short fact sheet on mild haemophilia which will be available in the new year.

Print copies of the booklet can be ordered from HFA by emailing [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or calling **1800 807 173**. The booklet can also be downloaded from the HFA web site – [www.haemophilia.org.au](http://www.haemophilia.org.au) >Publications ■

# AUSTRALIA AND NEW ZEALAND INHIBITOR WORKSHOP

## AN ORGANISER'S PERSPECTIVE

Colleen McKay

On the evening following the close of the 16th Australian and New Zealand Haemophilia Conference, 25 people gathered for the official opening of the 1st Australia and New Zealand Inhibitor Workshop at the Novotel Sydney Olympic Park. Participants came from all around Australia and New Zealand and included parents of children with inhibitors, as well as men with inhibitors of all ages and their partners or a support person. Inhibitors are a serious medical problem that can occur when a person with haemophilia has an immune reaction to treatment with clotting factor concentrates and is considered one of the biggest challenges in haemophilia care today. This educational workshop was the first ever Trans-Tasman event focused specifically on the challenges faced by families with inhibitors.

After the workshop was opened with a Mihi Whakatau (a special prayer of welcome and introduction) and Waiata (song), Workshop Co-ordinator, Colleen McKay, welcomed everyone in anticipation of two days of learning, laughter and support. A little friendly competition with the challenges over dinner ensured that participants had the opportunity to mix, mingle and meet each other in a fun way.

In the 'Caring for ourselves' session, New Zealand social workers Sarah Preston and Linda Dockrill introduced the concept of Te Whare Tapa Wha as a model of health and wellness. Together the group discussed each of the four cornerstones of health (physical, mental, social and spiritual) and were reminded of the importance of seeking out help if you

need it with suggestions of where to turn. Ian D'Young, one of the Co Chairs of the Australia New Zealand Physiotherapy Haemophilia Group, then gave tips on managing chronic arthropathy for those with inhibitors. Participants were invited to 'have a go' at t'ai chi. While it appealed to some people and not others, the session was useful in demonstrating non-traditional forms of exercise.

On Monday morning Dr Scott Dunkley, Haematologist from the Royal Prince Alfred Hospital in Sydney, hosted an informal session which encouraged participants to ask their individual questions. The treatment of inhibitors is challenging and the message that came through was that the treatment of inhibitors is not an exact science; there is not one answer and treatment plans vary between individuals as what works for one person might not work for another. This session also illustrated the importance of monitoring and maintaining communication between all members of the comprehensive care team.

The haemophilia nurses involved in the Workshop - Mary Brasser (Auckland), Grainne Dunne (Sydney) and Beryl Zeissink (Brisbane) – then tested everyone with a quiz, helping everyone learn in a fun and competitive way. Messages such as using R.I.C.E. and tips for treating nose bleeds were reinforced with the quiz.

Katrina Smith from the Independent Living Centre in Sydney presented participants with a range of gizmos and gadgets designed to assist with getting through the day. She brought

along many examples for people to examine. Independent Living Centres do not sell products, but provide an information service which has examples of a wide range of aids for mobility and daily living. There are Independent Living Centres throughout Australia and Enable centres located in New Zealand.

The final Session 'Coping with Challenges – Finding Creative Solutions' gave everyone a chance to discuss their challenges, share their solutions, rate their top three strategies in small groups and report back to the whole group. Participants were split into four groups: adults with inhibitors, young adults with inhibitors, parents of children with inhibitors, and carers/partners. While some groups found it difficult to narrow it down to three tips, those common to most groups were:

1. Become informed or educated
2. Get connected to others with inhibitors.
3. Maintain a good support network.

The Inhibitors Workshop finished with Karakia from Patience Stirling and the Waiata 'Tutira Mai Ngi Iwi' which carries messages of unity and learning.

We believe that everyone left the workshop with more knowledge and a great feeling that they have connected with others with inhibitors. HFA and HFNZ are currently reviewing the evaluations of each of the participants and will prepare reports with recommendations about when further inhibitors workshops might be held in the future.

## A PARTICIPANT'S PERSPECTIVE

Michael Lucken

This was the first Australian and New Zealand Inhibitors Workshop ever so I was excited to be a part of the very first group and see what it all was about. At the same time I was a little hesitant as I was not sure what to expect or to learn as I have lived with inhibitors for 28 years.

The Inhibitor Workshop started Saturday evening with a meet and greet, introductions, ice breaker games, group activities and team brain teasing/problem solving, which was very active for our brains straight after the Haemophilia Conference had finished! It included a sit down dinner and a great chance to catch up and get to know the people around you before the next day started.

*"This Workshop is SO needed for the inhibitor community. Please don't wait too long for another one! Thank you! Thank you! Thank you! Thank you!"*

*"Gaining understanding, empathy, knowledge, and forming new relationships with carers, people with haemophilia, health professionals has given me better support."*

*"Well organized and catered to everyone's needs. A great way for people to meet and feel involved when they rarely meet people with similar issues."*

*"Thank you so much for all the organization that went into this Workshop. I loved meeting everyone and hearing their stories."*

Sunday started with a mix of personal journey stories and inhibitor life struggles told by parents, but one that was different and stood out the most to me was presented by Andrew Salvaggi from Victoria. Andrew was very well spoken, funny, had great visual aids and told of his journey in an upbeat, light-hearted and entertaining way. His story was the closest to mine and I could very much relate to it. He told us about his struggles with pain and pain relief, movement, mobility issues, treatment issues, even the "unhappy with yourself down days" and how he turned it all around by losing weight and getting fit. He is now a personal trainer working out 6 days a week and has halved the number of his bleeds. It was inspirational.

After morning tea two social workers spoke about wellbeing and how it is more than just looking after your physical body but also your spiritual, emotional, mental, family and social wellbeing. They explained it as being like the four walls of a house: if one aspect breaks down or is missing then the body becomes unbalanced or unwell.

Another speaker I enjoyed listening to and learning from was New Zealand physiotherapist Ian D'Young. He made a few very important points about joint bleeds and that you must rehabilitate joints properly after each bleed or you could have more joint damage and muscle problems. He described how arthritis can heat and swell and can make it hard to tell the difference between arthritis and bleed pain. He also explained that losing weight and having a little strength and fitness training is good for keeping the joints

moving and supported by muscle if done correctly, and can improve pain and the number of bleeds. Ian also gave some good information on joint replacement compared to joint fusion and noted that joint fusion is the more common practice for people with haemophilia and inhibitors. However, he focused on exercise and that even three 10 minute lots of exercise a day can make a big difference.

After afternoon tea we went to a different room to do some t'ai chi with John Gough, t'ai chi Master. We did a few simple and easy to learn t'ai chi movements. John had explained that t'ai chi can reduce stress, lower blood pressure, improve muscle strength and flexibility and can even relieve some arthritis pain.

On Monday morning Dr Scott Dunkley, Haematologist, talked to us about the different types of factor and how they work and about tolerisation. Then Katrina Smith from the Independent Living Centre showed us lots of gadgets and gizmos for getting through the day: things like wide grip bottle openers, a back washing sponge, wide handles for cutlery, etc, were passed around the room, which was quite fun, and useful!

The workshop was very good and fun, informative and well planned out. This is the first workshop I have been to where I have gone away with food for thought and with motivation to actually improve my situation, even if it's only a little, and the thought that all hope is not lost with me yet. Thank you to HFA and HFNZ for a great workshop and for the opportunity to participate. ❏

# HELPING YOUR CHILD MANAGE ANXIETY

*Dr Desdemona Chong*

Anxiety is a normal part of childhood and every child goes through phases where he might develop anxiety over a variety of issues such as the dark, going to school and being separated from parents. In addition, children with haemophilia may also perceive invasive medical procedures, such as injections and venepuncture with fear and anxiety.

The difference between children and adults when confronted with anxiety and stress is that most adults have found ways to manage their anxiety while children need to be taught and guided to manage their emotions. This article provides an overview of what you can do as a parent to help your young one develop adaptive anxiety management skills that can be used in different difficult situations.

## BRIEF LOOK AT ANXIETY

First, let's look at what anxiety is. Put simply, anxiety is a normal response to a real or imagined threat. When we perceive something as dangerous, many rapid changes occur in the mind and body to help us deal with that threat. This reaction is known as the 'stress response' or 'fight or flight' reaction. This fight or flight response is automatic and causes a range of changes in your body.

These include:

- Breathing rate becomes heavy and quicker
- Heart rate increases
- Muscle tension
- Increased sweating

- Dizziness, numb or tingling hands and feet
- Mind becomes preoccupied with the threat, unable to reason, concentrate or process information as normally would

In children, other signs and symptoms may include constant crying, moodiness, trouble sleeping, unexplained gastrointestinal problems, headaches, and a need to repeat certain behaviours such as hair pulling, head banging or repeated blinking.

## WHAT CAN YOU DO?

1. **Have a discussion with your child**  
Children get anxious when they do not understand what is happening to or around them. For example, they may not understand that the bodily changes they are experiencing are signs of anxiety and thus, would benefit from being taught how to recognise anxiety. Let your child know that you understand he is afraid and allow him to express his feelings. Remind him that everyone gets frightened at times, even parents and tell him how you managed your anxieties. Let your child know that you are here to help him.
1. **Set a good example**  
Children are like little sponges. They learn from observing their environment. The child of a nervous, anxious parent will most likely be nervous and anxious. Hence, at all times, model positive coping behaviours and try to remain calm in stressful

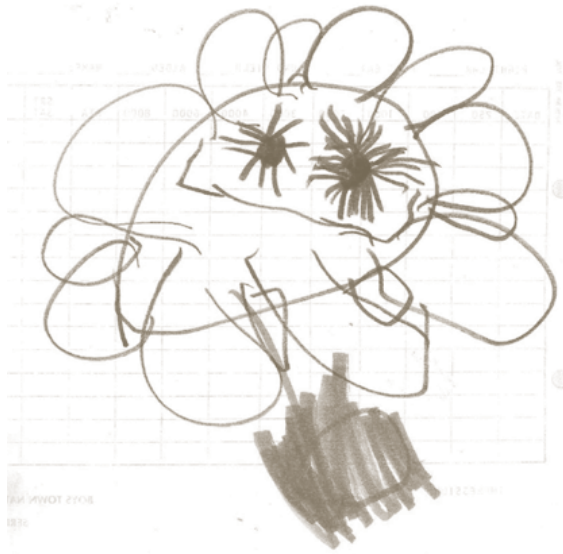
situations. This will help your child to learn to respond positively. For example, if you miss a vein during venepuncture, you could say "well, I missed it this time, but let's stay calm and try again". In addition, getting impatient with your child (e.g. telling him to "get over it and stop being a baby") serves to increase his anxiety and escalate the situation. Instead, praise your child when he attempts to face his fear and where appropriate, provide a small reward to reinforce the behaviour.

## 2. Teach your child coping strategies

Finally, teach your child relaxation strategies to manage his anxiety. A number of useful techniques are listed in this article. It is best to help him develop these skills during peaceful times where he is calm and has time to learn. Remember that relaxation is a skill that needs to be practised over time (just like learning to drive a car) and best integrated into your child's daily routine.

## RELAXATION STRATEGIES AND TECHNIQUES

The aim of teaching relaxation is to alleviate your child's anxiety and fear of situations (or in the case of haemophilia, an invasive procedure) so that he develops a good ability to cope, self-calm and self-soothe. The important thing to note is that techniques should be selected and adapted based on your child's age, level of understanding and interests.



Imagination is a special form of distraction that comes very easily to young children. The idea is that by concentrating on a pleasurable image, your child will no longer be preoccupied with the source of anxiety.

Also, you may wish to find out more about a particular technique before teaching your child as this article provides a brief overview only.

(For specific tips on how to manage fears surrounding needles, go to [www.hemaware.org/story/needle-know-how](http://www.hemaware.org/story/needle-know-how))

### CONTROLLED DEEP BREATHING

This is a highly effective method to help children relax and focus attention away from the anxiety-provoking stimulus. Deep breathing helps to bring about positive changes in blood pressure and heart rate, thus helping your child to regulate his breathing, prevent hyperventilation and reduce symptoms of anxiety. It is important that your child uses an abdominal breathing style (i.e. use the tummy to breathe in and out) rather than a chest breathing style. You can check this by getting him to place one hand on his stomach and one hand on his chest. The hand on his stomach (at the base of his rib cage) should rise when he breathes in.

The following steps can be read to your child.

1. Breathe in for three seconds
2. Hold your breath and count to three
3. Breathe out for three seconds
4. When you get to three, say the word 'relax' to yourself, in a calm and soothing voice.

There are some fun ways to help children master this skill:

- Have your child imagine 10 candles in a row and then blow them out one by one
- Have your child actually blow bubbles with a bubble solution and wand
- Use a straw to blow a cotton ball across a table or the floor
- Use an easy-to-turn windmill to teach breathing.

These visual exercises (seeing the bubbles and cotton ball move) can help reinforce children's efforts and provide a means for them to monitor their breathing. Once your young one has mastered the art of controlled breathing, you can get him to practice it in his daily life, or during anxiety-provoking situations like receiving a treatment. Note also that controlled deep breathing is often paired with progressive muscle relaxation and imagery (these techniques are explained below) to enhance relaxation.

### Progressive Muscle Relaxation

Progressive muscle relaxation (PMR) consists of systematically tensing and relaxing specific muscle groups twice before moving on to the next muscle group. It helps children become more aware of their bodily changes that take place when they tense and relax. You may do this relaxation technique in any comfortable, well-supported position, sitting or lying down. To get the most out of relaxation, prepare your child and his surrounding by

reducing potential distractions, such as from the telephone and television. A good time to practise is at night just before sleeping. There are many PMR scripts for children available online (e.g. [www.yourfamilyclinic.com/adhd/relax.htm](http://www.yourfamilyclinic.com/adhd/relax.htm) and [www.aboutkidshealth.ca/En/Documents/Progressive\\_Muscle\\_Relaxation\\_Script\\_EN.pdf](http://www.aboutkidshealth.ca/En/Documents/Progressive_Muscle_Relaxation_Script_EN.pdf)), in books and in audio formats which you can use with your child. Choose one that suits your child's developmental stage.

### Visual/Guided Imagery

Imagination is a special form of distraction that comes very easily to young children. The idea is that by concentrating on a pleasurable image, your child will no longer be preoccupied with the source of anxiety.

The important thing is to help your child select an image or scene that is meaningful or pleasant for him (some people call it a "safe place"). Once chosen, help your child to focus on his senses – the sights, sounds, smells, touches and tastes. So for example, if your child enjoys being in the playground, you can gently guide him (using a slow, calm and reassuring voice) by asking him about the sound and feel of the wind, smell and colour of the grass, and the taste of his favourite drink as he sits on the swing.

Finally, what good are skills if you forget to use them? You can supplement the above techniques with visual reminders such as:

# HIV FUTURES 7 REMINDER

## MAKE YOUR EXPERIENCE COUNT

A reminder that the HIV Futures Seven survey will run until 15th January 2012. This is the seventh national survey of people living with HIV (PLHIV) conducted by the Living with HIV program at the Australian Research Centre in Sex, Health and Society, LaTrobe University, Melbourne.

HIV Futures is an anonymous survey of PLHIV. It asks people about a range of issues including their health, treatments, work and financial situation.

The survey is an important opportunity for people with bleeding disorders and HIV to contribute data on their particular experience and be counted in a national evidence-based study. The evidence provided by HIV Futures is used by community organisations, service providers, doctors and government to understand the current needs of people living with HIV and help make decisions about future directions for services and programs.

The survey can also be filled out online by going to: [www.hivfutures.org.au](http://www.hivfutures.org.au). Print copies of surveys are available from local HIV organisations and in some Haemophilia Centres and from HFA.

For more information, or to request a copy of the survey booklet, contact:

### HIV Futures – Living With HIV Program

Freecall 1800 064 398 or email [hivfutures@latrobe.edu.au](mailto:hivfutures@latrobe.edu.au)

### Haemophilia Foundation Australia

Telephone 03 9885 7800 or call 1800 807 173 (toll free).

Or speak to your Haemophilia Social Worker or Counsellor.

## Calming-down Kits

Children can benefit from creating a portable calming-down kit that they can bring around to potentially stressful situations (e.g. planned surgery). This kit can take various forms and depends largely on your child's age and interests. You can get your child involved in the creation of such a kit. Things that are typically used include bubbles, colourful squeeze balls, small stuffed animals, candles, cotton balls and straws.

## Calming Cue Cards

Some children and teens may not be interested in completing an actual kit. A good alternative would be cue cards that are created, laminated and connected by punching a hole in the card and stringing the cards together. Examples may include pictures of a bottle of bubbles, a squeeze ball, calming images or picture and speech bubbles with self-talk statements (e.g. "take 5 deep breaths slowly").

## KNOWING WHEN IT'S TIME TO SEEK PROFESSIONAL HELP

Anxiety in children with chronic conditions is common and can be effectively managed using simple techniques. It is normal for children to experience anxiety and as a rule of thumb, you should be more concerned if your child's anxiety and fears are excessive and he is not able to cope in everyday living. If that happens, seek professional help for your child. ■

## Sources

[www.hemaware.org/story/needle-know-how](http://www.hemaware.org/story/needle-know-how)

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HIV futures seven  
[www.hivfutures.org.au](http://www.hivfutures.org.au)

futures seven  
Making positive lives count

Suzanne O'Callaghan is Haemophilia Foundation Australia Policy and Education Manager

Paul Bonner is the former President, Haemophilia Foundation South Australia and member of the Haemophilia Foundation Australia (HFA) Executive Board. He is currently a mentor to the HFA Youth Committee

# SPEAKING UP

Suzanne O'Callaghan

## **Paul Bonner talks about what motivates him to be involved**

*"I've seen younger kids leading full and active lives, and other people who have limited mobility. It's good to be able to pass on my experience so that other people might not have to go through the same things."*

At 35, Paul has personally faced many challenges since he was diagnosed with haemophilia when he was 5 years old.

Growing up with haemophilia exposed Paul to some of the hurdles he would continue to deal with as an adult.

*"I remember as a kid going into hospital, seeing the doctors and helping to mix up my own treatment. When I had bleeds it was quite painful. I missed so much school one year they held me back."*

Like many men with haemophilia, Paul has had to deal with long term joint damage and arthritis as a result of bleeds into joints and muscles at a young age.

*"I had to have a career change because of arthritis in my left ankle. I was a boat builder for 14 years, but because of the amount of bleeds in my left ankle and the pain they caused, it was hard to keep working in that field."*

Paul began working as a health and safety officer, but was still experiencing a lot of pain. He had an operation to have his ankle fused to improve his pain and ability to get around.

*"There were complications. They missed a blood vessel and it kept oozing causing swelling, so I went back to hospital. First, they thought it was infected but it wasn't. Then I was back 2 days later in extreme pain. I went back into surgery and they found the problem and fixed it."*

Paul's experience highlighted for him how much he has learned over his life and why it is important to share this. He has become involved as a community leader, both locally and nationally. As President of Haemophilia Foundation South Australia he worked to develop his local community and also represented national interests in the HFA Executive. This extended to an international role with his participation in the Australia-Thailand World Federation of Hemophilia member organisation twinning program.

*"It's about empowering people to manage themselves – to be strong enough to speak up if they think something's not right"*

Issues for young people with bleeding disorders continue to be one of his major interests. Paul has been involved with the HFA Youth Committee since it formed and now acts as a mentor.

*"I've seen the difference the Youth Committee makes to some people. They know themselves and their condition better and are more able to advocate for themselves. It's about empowering people to manage themselves – to be strong enough to speak up if they think something's not right and ask the health professionals to investigate further. Or if they don't understand a diagnosis, to give them the power to ask for an explanation." ❏*



Paul relaxes at the Youth Camp

# WORLD AIDS DAY

Every year World AIDS Day is celebrated on 1 December. For the bleeding disorders community in Australia it is a day to remember the people in the bleeding disorders community who were affected by HIV when HIV was transmitted through some batches of clotting factor treatment product in the mid 1980s. As a result of this tragic episode, some people lost partners, family members, children, patients, colleagues and friends. Some people continue to live with the challenges of HIV and some to inspire others with their positive attitude and determination to build a better future.

In 2011 the World AIDS Day theme is "HIV is still here". The aim is to encourage all Australians to be aware that HIV still exists in the community; to take action to reduce the transmission of HIV by promoting safe sex practices; and to accept and support individuals living with or affected by HIV.

World AIDS Day highlights the role of HIV positive people in strengthening community spirit. It shows how important it is for people living with HIV to feel included and to share their experiences and knowledge and educate others about HIV. It is a reminder that people living with HIV have the right to participate in the community free from stigma and discrimination.

In this issue of *National Haemophilia* Neil Boal gives a compelling account of his experience of HIV and hepatitis C co-infection and explains why he is committed to breaking down the barriers and stigma surrounding HIV and hepatitis C. ■



The following article is abridged from an article published in *Poslink*, No. 58 August 2011, the newsletter of People Living with HIV/AIDS Victoria Inc, and is reprinted with permission

Neil Boal is a community member with haemophilia and the former President of Haemophilia Foundation Victoria. He is also undertaking the speaker training program at the People Living with HIV/AIDS Victoria Positive Speakers Bureau

## LIVING WITH TWO BBVS

*Neil Boal*

*This article is drawn from a talk Neil Boal presented at an HIV Educators' workshop on living with HIV and HCV. HFA joins with the publishers of Poslink to thank Neil for telling his story in such an open and honest way and agreeing to have it published in Poslink and National Haemophilia to create greater awareness about haemophilia, HIV, HCV and the issues of living with co-infection.*

*Neil contracted HIV and hepatitis C through infected human plasma derived clotting factor concentrates he used for his haemophilia treatment before HIV and hepatitis C testing and viral inactivation procedures were introduced. In Australia these new safety measures commenced in 1985 for HIV and in the early 1990s for hepatitis C. The risk of new infections from using blood products made with*

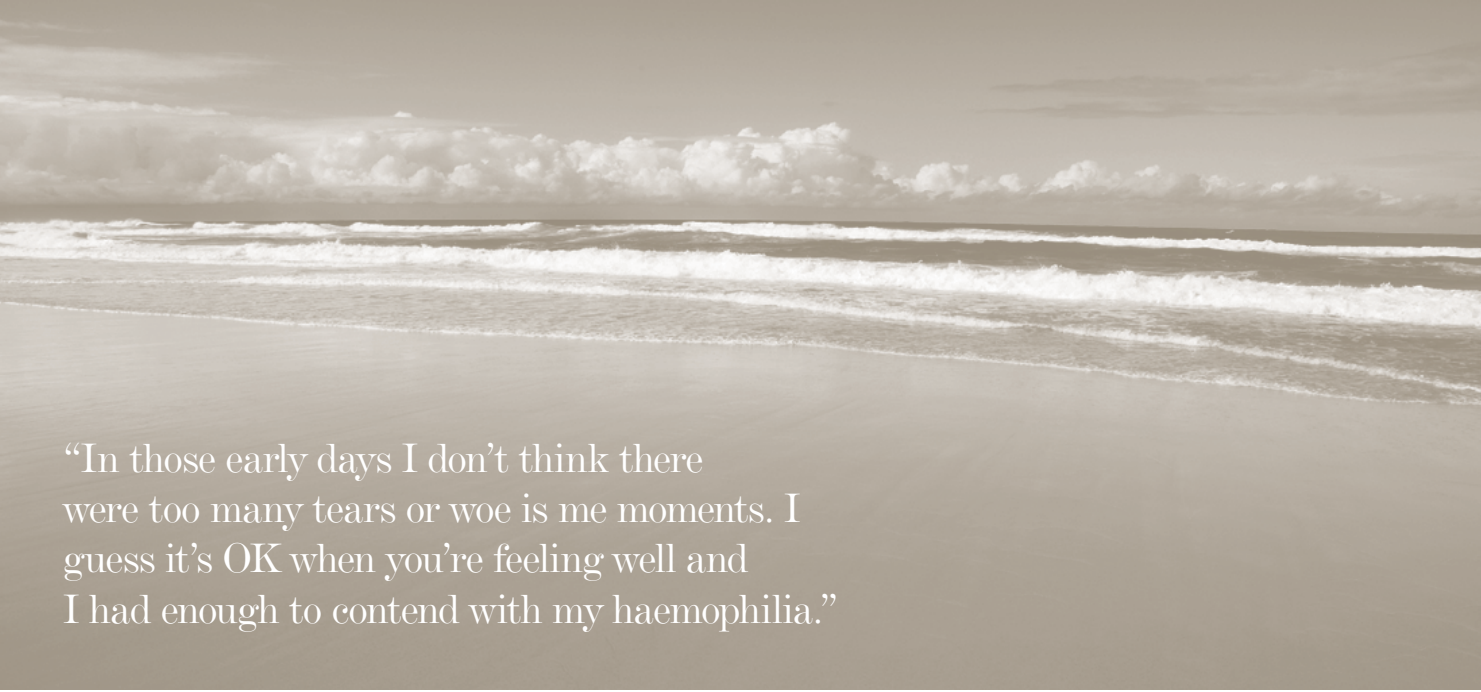
*human plasma is now thought to be extremely low.*

My experience with HIV began in 1985. I was 22 and unaware of the gravity surrounding HIV. I had recently started dating Julie, now my lovely wife, and was planning on moving interstate and embarking on an exciting future.

Our going-away present was a letter informing me I had been exposed to HIV but may not experience any problems. Julie and I read this as like being exposed to a cold but developing antibodies or something and didn't think more about it. Life continued on as normal.

By then we were enjoying our new idyllic life in Byron Bay; but we began reading all of the horror stories on the front pages of newspapers that now





“In those early days I don’t think there were too many tears or woe is me moments. I guess it’s OK when you’re feeling well and I had enough to contend with my haemophilia.”

included people with haemophilia among the groups who were likely to have AIDS as they called it back then. This is when our lives really changed.

We realised we might have misunderstood the letter and sought a GP’s advice. After being retested we became acutely aware of the situation. My first concern became Julie. We had been having unprotected sex for quite some time and I had this huge fear that she might have been exposed herself.

I don’t remember how long it took for her test results to come back - it was just all a blur - but I do know the anxiety was unbearable. What would I say to her? Have I given her a death sentence? Would she forgive me? Could I even look her in the eyes? Thankfully her results were negative; we had escaped a disaster. I gave Julie the offer to walk away and words can’t express how lucky I am to still have her. It really was such a brave choice, even more so back then.

We chose not to disclose my status to our families because we weren’t there to help them cope and it was huge burden to keep such a secret.

In those early days I don’t think there were too many tears or woe is me moments. I guess it’s OK when you’re feeling well and I had enough to contend with my haemophilia. The biggest impact was on our sex life. It became less frequent as I was so afraid to put Julie at risk and any

thoughts of planning a family seemed extinguished.

When we moved to Byron, I made a choice not to mention my haemophilia because it may affect my chances of getting work. It became even more important to hide because people might join the dots and conclude I had HIV or AIDS.

In social circles, talk of AIDS was a popular topic and we often heard the irrational hysteria that flowed out of people’s mouths. The usual drinking out of the same cups argument, to kissing and shaking hands all came up regularly. Julie and I had to hide our emotions and bite our lips and then vent once we were alone. Yet all of the time we felt we were being deceitful and guilty of not standing up and setting things straight.

Circumstances had us moving back to Victoria in 1989. I was a patient at the Alfred Hospital. We had a small room where we met with our specialists. Here we would sit and see fellow haemophiliacs, some I knew very well, in varying states of health.

It was so distressing to see family members in tears, their loved father, brother or son wasting away to a shadow, almost skeletal, and then never seeing them again. When was it going to be my turn?

In 1990 as an added bonus, the non A-non B hepatitis had been given a name, hep C. At the time not much concern was given about this

particularly if you had HIV as you were on limited time anyway. I can remember Julie and I just rolled our eyes and shrugged our shoulders.

1996 saw my first AIDS defining illness. After feeling quite breathless for a couple of weeks and losing weight alarmingly, I was diagnosed with pneumonia. I weighed only 45 kilos and, after seeing a friend pass away just weeks before, I believed my time was near.

Julie broke down. It wasn’t until I was alone that I could show my fear and break down too. It was terrifying, lying in a ward with five other patients, from all walks of life, all seemingly clinging to life. None of us talked much - perhaps even that seemed taboo.

It was then we thought we had to tell our family and close friends about everything. This was poor timing and we wish we had done it earlier. I don’t know when the right time is to disclose your status but I now know when the wrong time is.

I am so grateful that I have never had a bad response from anyone I have told. The only emotion I have felt from those close to me is that they thought we couldn’t trust them and that they could have helped us. But they have respected our decision.

Thankfully I responded well to antibiotics and was home in two weeks. In 1996 HIV combination therapy arrived. As a result, my health improved greatly and blood

counts started responding positively. Although some of these drugs had onerous regimes to follow, I found I was coping very well.

It was around the year 2000 I realised fatigue was becoming a real issue. My HIV specialist had always been keeping an eye on my liver function and the results were nothing untoward.

People often describe their brain as being in a thick fog and this is a great description of what I felt. However in the final two months I had to push on as I had come this far and I just had to give it everything.

Hep C was now well and truly recognised as being a severe chronic disease, even potentially fatal and, ironically, the longer I survived with HIV, the greater my chances of having liver related problems were. I was now becoming so tired I had to stop driving any distance. I lost all concentration and awareness; I was beginning to lose my independence.

I also had to give up my work as a mechanic. I hadn't told my work about my hep C or HIV. I had been reducing my hours gradually blaming it on my haemophilia, but it got to a point where I just couldn't get out of bed in the morning to do half a day's work. It was time to seek treatment for my liver.

All along my HIV specialist at the Alfred was keeping in touch with the hep C specialists and with my 3 monthly blood tests I also had annual liver ultrasounds.

In 2002 I was told of the exciting advances in treating hep C. Pegylated interferon, combined with ribavirin, had been showing really encouraging results.

Although this was exciting, Julie and I decided not to start treatment. We had found the chance to start having a family, something we thought was beyond our dreams. We were to become the first sero-discordant Victorian couple to have IVF using sperm washing. However, ribavirin causes severe birth defects and part of the stipulations of beginning combination therapy is you cannot risk a pregnancy during the treatment course and for some time after.

I'd love to tell you that we went on to have a successful IVF result but it was not the case. After a series of invasive, impersonal and devastating cycles, it was all for nothing. Though we will always be grateful for the chance, it remains one of the most painful and biggest regrets we have.

With support from both of my specialists, I began my 48 week hep C treatment campaign in 2005. Though we did not know if I had any cirrhosis, the fact that I'd had hep C for 30 years suggested I should start.

Although I was experienced in injecting into veins I had little to do with subcutaneous injections. I was given instructions on how and where to inject, to rotate injection sites as well as being made aware of all the possible side effects to expect. I had to be particularly careful about depression as I had already been diagnosed with it. I was already under

the watchful eye of my psychiatrist and was in good hands.

The regime of one injection a week was ok although I did experience some minor discomfort from the injections and a bit of redness at the injection site.

As far as the tablets go, an extra five tablets a day on top of the 20 odd meds I was already taking for HIV was not a problem. I now just had to watch what side effects might occur. This was a part of the psychological impact I had to wrestle with in the beginning. Would I be able to cope? Was I going to become suicidal? Will I become some angry ogre and snap at any given moment? I have never been an angry person and this really worried me. Would I even last the distance and give myself the best chance at getting rid of hep C?

Even though I knew I had support at the end of a phone line, the last thing I wanted was to hurt my marriage.

I can honestly say I coped really well, at least through the first seven months. I did have some minor flu symptoms and my hair was thinning, a bit alarming looking at the plug in the shower, even with the last bit of vanity I had left. However I had great test results that proved that things were going my way.

From the first month my ALT levels dropped enormously. I can't remember what all the tests were or said back then but I do remember that encouragement was all I needed to keep going. I did start to struggle with depression and extreme fatigue. People often describe their brain as being in a thick fog and this is a great description of what I felt. However in the final two months I had to push on as I had come this far and I just had to give it everything. I did not miss an injection or a tablet in that 48 weeks, it was just so important to me.

Drug compliance has shown to be vital in treating HIV so it was no different in this case. Finally, at the end, my blood tests showed all of my liver levels had returned to normal and the virus was gone. I had a real feeling of achievement and happiness

# HAEMOPHILIA AND YOU

but had to temper this with the knowledge that the virus could return within the next 12 months.

That following year turned out to be glorious. I felt so good I was jumping out of my skin. My energy levels seemed ridiculously high; I couldn't remember when I felt so good. Julie and I put it down to a false high due to finishing the treatment and perhaps the joy of the good result.

So how do I feel today? I unfortunately lost that euphoria I mentioned above, but my fatigue levels have improved. My HIV is undetectable too. I am still on anti-depressants but my mood is good and I have returned to driving but not to work. I am on a pension and struggling financially.

I have often found it very difficult to be sure which one of my health conditions is the cause of my problems. I still deal with varying degrees of nausea but is it from the HIV meds I consume each day? Fatigue is still a big issue but is that due to the constant pain from my haemophilia issues?

My haemophilia has really limited my activities more so than my viral issues however they have certainly taken their toll on me both physically and psychologically. Interestingly I have been discriminated more against because of haemophilia than BBVs but probably because I was more open about haemophilia.

However this disorder has opened up doors for me. I have fought for the rights for people with haemophilia and been on various committees over the years. I have always been passionate about BBV issues and in the last six years I have decided to speak up and help break down the barriers and stigma surrounding HIV and hep C. ■



## INVITATION TO PARTICIPATE

If you are aged 30 or over and have haemophilia you are invited to participate in a project being undertaken by the National Ageing Research Institute (NARI), in conjunction with the Ronald Sawers Haemophilia Centre at the Alfred Hospital.

This project aims to provide a profile of older people with haemophilia in Australia. This profile will assist in the development of a framework for planning health promotion approaches for people with haemophilia and assist in guiding management into their care for the future to support them in ageing well.

It would require you to complete a survey that explores the physical, psychological and social factors related to haemophilia and ageing well. The survey asks questions about your age, co-morbidities, health service use and medication use, severity and symptoms of haemophilia, pain coping, quality of life, physical activity level, falls and falls efficacy, nutritional health, depression, anxiety and social connectedness.

The survey will take approximately 30 minutes to complete and by completing the survey you will go into the draw to win one of 5 \$100 Coles Myer gift cards.

If you would like to participate in the project, there are two ways of completing the survey. You can either do it online using a secure website ([www.surveymonkey.com/s/haemophilia\\_NARI](http://www.surveymonkey.com/s/haemophilia_NARI)) or you can contact Marcia Fearn at NARI on (03) 8387 2567 or via email [m.fearn@nari.unimelb.edu.au](mailto:m.fearn@nari.unimelb.edu.au) to obtain a hard copy of the survey.

If you would like any further information about the project please contact Marcia Fearn at NARI on (03) 8387 2567 or via email [m.fearn@nari.unimelb.edu.au](mailto:m.fearn@nari.unimelb.edu.au)

PROJECT FUNDED BY THE NATIONAL AGEING RESEARCH INSTITUTE

# CALENDAR

## WFH Congress 2012

8-12 July 2012 – Paris, France  
World Federation of Hemophilia

Tel.: +1 (514) 875-7944  
Fax: +1 (514) 874-8916  
Email: [info2012@wfh.org](mailto:info2012@wfh.org)  
[www.wfhcongress2012.org](http://www.wfhcongress2012.org)

## World Haemophilia Day

17 April 2012  
[www.wfh.org](http://www.wfh.org)

## Haemophilia Awareness Week

7-13 October 2012

Tel: 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)

## XXXI International Congress of the World Federation of Hemophilia

Melbourne, Australia 2014  
[www.wfh.org](http://www.wfh.org)

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***The Council and Staff of Haemophilia Foundation Australia wish you a safe and happy festive season. Thank you for your support during the year and we look forward to working together again in 2012.***

The HFA office will be closed from Friday 23 December. The office will reopen fully on Monday 9 January 2011. During that time if you have any queries or need to contact HFA, please note that messages left on the answering machine will be monitored. If you have an urgent matter please contact Sharon Caris on 0410 419 914.



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