# THE MISSING FACTOR

## THE CARRIER BARRIER

Women push for mild haemophilia diagnosis


## WHAT'S NEW IN TREATMENT FOR HEPATITIS C?

THE COUNT DOWN IS ON TO THE WFH 2014 CONGRESS

WFH 2014 WORLD CONGRESS
Melbourne, Australia • May 11-15

THERE IS STILL TIME TO REGISTER AND RECEIVE A SUBSIDY FROM HFV

DON'T MISS OUT — CALL HFV NOW!

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## our features



## hfv team




**Haemophilia Foundation Victoria Inc**

**ABN: 67 922 470 900**

**13 Keith Street, Hampton East, VIC 3188**

**Patron: The Honourable Alex Chernov, AC,QC**

**Governor of Victoria**

**P. (03) 9555 7595 F. (03) 9555 7375**

**E. info@hfv.org.au**

**www.hfv.org.au**

**Andrea McColl | Executive Assistant**

**andrea@hfv.org.au**

**Julia Broadbent | Communications Coordinator**

**julia@hfv.org.au**


## DIARY DATES

WFH Congress —11th to 15th May

Shepparton Regional Visit — 15th June

Horsham Regional Visit — 10th August

Grandparent's Luncheon — 24th August

Awareness Week — 12th to18th October

Ladies' Day Out — 19th October

# Committee of Management





# A message from *your* president, Ann Roberts

This is the last opportunity I will get to encourage you to attend the World Federation of Hemophilia Congress here in Melbourne this month. If you haven't already booked I urge you to check out their website (www.wfh.org/congress) and read through this magazine where you will find information on some of the sessions that will be running. This really will be a once in a lifetime opportunity on your doorstep. The majority of your haemophilia treatment specialists will not only be attending but many will be presenting. We will learn about new treatment developments, research and various haemophilia programs from around the world. We will hear from physios, haematologists, social workers, paediatric specialists, nurses – you name it, they will be there. And of course there will be many people from our bleeding disorders community – people like us.

HFV will have a presence at the congress. Our staff and committee will be wearing our red HFV polo tops so will be easily recognisable and we will have a designated meet up spot after sessions at the convention centre so we can all try and meet up and have a chat.

Shortly we will also be sending further information out to those who have received HFV subsidies to attend the congress containing some contact details and info on get-togethers that we have organised. It's not too late to register or apply for a subsidy so speak to our office staff ASAP.

Since our last edition of The Missing Factor we have been very busy with a number of member events. We kicked off with a Regional Visit to Torquay. We had over 20 members of all ages in attendance. It was a wonderful opportunity to reconnect with members, understand issues they are facing and offer peer support.

Zev Fishman led a Men's Retreat weekend away at the start of April. There was a good number of men in attendance who not only benefitted from the social aspects of the weekend but also the benefits of relaxation and massage sessions. A great weekend was had by all.

We have also just held our 3rd Blood Brothers Camp. This is a really important opportunity for our young guys to connect and develop strong bonds with their peers, enhance confidence and build resilience. Skills they will need for life.

I'd also like to take this opportunity to welcome two new members to our committee. Karen Donaldson and Donna Field have both enthusiastically put their hands up and joined our committee. Both Donna and Karen are based regionally in Victoria so will be instrumental in guiding us in linking in with our regional and rural members.

Finally, I would like to encourage all people with bleeding disorders to embrace MyABDR. There is information overleaf on the reasons why our community should be using this for recording treatment and the benefits it brings. There are some important points to note:

- MyABDR is a personal recording tool. It provides a history for you
- It makes managing your care quicker and easier
- It is not a pharmaceutical based app
- Stats help clinicians and researchers understand trends & patterns
- You can see when product will expire
- It's an integrated system
- It's a more efficient record keeping system for your treatment centre
- It was developed with help from our bleeding disorders community and your treatment centres
- Update your ABDR record at your treatment centres whenever you sync your app or save on the web site
- There is a paper based alternative!

So please, when you get a chance go to the web ite and get registered!

Ann Roberts

**What is the ABDR?**
The Australian Bleeding Disorders Registry (ABDR) is the system used by Haemophilia Centres around Australia for the clinical care of their patients.

The MyABDR app and web site link directly to the ABDR.

## What is MyABDR?

MyABDR is a secure app for smartphones and web site for people with bleeding disorders or parents/caregivers to record home treatments and bleeds.

It is an internet-based online system that gives you a quick, easy and reliable way to:

- Record treatments and bleeds
- Manage treatment product stock
- Share the information with your Haemophilia Centre
- Update your contact and personal details.


As an alternative, there is also a MyABDR paper-based treatment diary.

## Your choice

You do not have to use MyABDR to record your treatments. Talk to your Haemophilia Centre about options for recording that work best for you.

## MyABDR features

Features in MyABDR have been developed with the input of people with bleeding disorders:


- Quick, simple steps to record treatments
- Add bleed details to treatments
- Body map to help identify bleed location
- Areas for detailed notes
- View treatment plan details
- Reports of treatment and bleed histories on web site version
- Easy to use inventory section to manage stock at home
- Family logins to switch between multiple family members
- Updatable height and weight, contact and delivery address details.

## Why use MyABDR?

*MyABDR makes life easier for you, your family and your Haemophilia Centre.*

- It makes it quick and easy for you and your family to record treatments and bleeds, stocktake and update contact details
- Your recorded treatment information will be at your fingertips - on your smartphone or your home computer.
- It will make record-keeping more efficient - Haemophilia Centres won't need to re-enter or upload online patient diaries into the ABDR

*MyABDR helps you and your Haemophilia Centre to manage your care.*

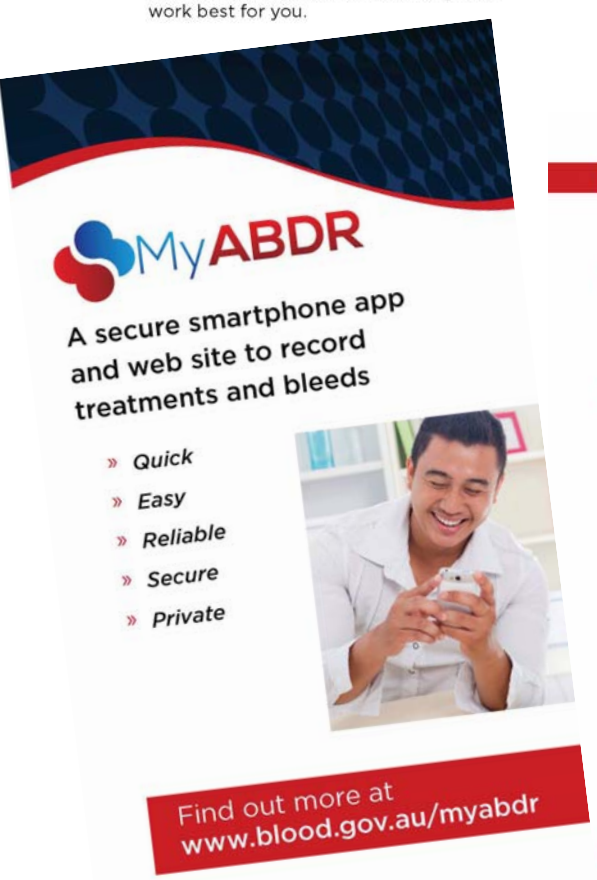
- Your Haemophilia Centre can keep track of what is happening for you or your family to see if there are any problems or if treatment plans need adjusting
- Statistics from the system can help specialist clinicians, researchers and advocates like Haemophilia Foundation Australia to study trends and patterns and work to improve treatment and care.

*MyABDR works in with the national system to supply treatment product.*

- You will be able to receive information about products or recalls
- Statistics about the amount of product being used can help the government to stocktake and plan for purchase of future supplies

*MyABDR will be around long-term.*

- MyABDR will be ongoing - it is part of the national ABDR system




## Privacy and Security

Security and protection of your privacy are priorities with MyABDR.

- **Security** - you will need to login on your smartphone or computer with a personal password. Both MyABDR and the ABDR are protected with the highest level of security.
- **Privacy** - information that could identify you will only be accessible in the ABDR by your Haemophilia Centre and specially selected National Blood Authority technical support staff authorised by the ABDR Steering Committee for the purposes of supporting and maintaining the ABDR.

MyABDR and the ABDR are overseen carefully by the ABDR Steering Committee. Its membership includes the Australian Haemophilia Centre Directors' Organisation, the National Blood Authority, Haemophilia Foundation Australia and a federal and state government representative. It deals with issues such as privacy, ethics, data accuracy and system development.

More details on how MyABDR works and the controls to protect your privacy and security are available on the MyABDR web site at www.blood.gov.au/myabdr.

**Important note**
MyABDR is a personal recording tool. Always contact your Haemophilia Centre directly for advice on treatments and bleeds.

## How to access MyABDR

Download the app from Apple App store or Google Play or go to www.blood.gov.au/myabdr.

MyABDR can be accessed through an iPhone, android-based smartphone or through a standard internet connected computer using a login and a password.

## How to register

MyABDR registration can be done online at www.blood.gov.au/myabdr or by creating an account when you open the MyABDR app. After you register your Haemophilia Centre staff will process your access to MyABDR.

## More information and support

W: www.blood.gov.au/myabdr

**HELPDESK**

T: 13 000 BLOOD (13 000 25663)

E: myabdr@blood.gov.au

Or contact HFA at 1800 807 173, email hfaust@haemophilia.org.au, www.haemophilia.org.au/myabdr

MyABDR is a collaboration between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of all Australian governments.


On the 30th March, HFV headed to Torquay as the first location for our regional visits program for 2014. Where are all the people you may ask? Well, I became so caught up in many interesting conversions about treatment, programs we offer, issues our members are facing — and issues we face as an organisation, that I forgot to take any photos!

Here are some comments from the day...

- *Extremely valuable. Got to know more families in the area and learnt about different hospital experiences.*
- *It allowed the opportunity for families in the region to congregate together and relate with each other regarding treatment of boys/men and haemophilia*
- *We were able to reacquaint with a few people that we have met over the years*
- *It provides more opportunities for wider community to benefit from this equity*
- *It is always good to catch up with other people who are facing similar challenges*
- *It was very interesting and helpful to talk with others affected by haemophilia*

If you live in the Shepparton region why not join us for lunch at The Parklake on the 15th June. Just call our office on 9555 7595 as bookings are essential! Hope to see you there.

Julia Broadbent

## Karen Donaldson — New HFV Committee Member

I wish to introduce myself as a new committee member and tell you a little about myself. I am the proud mother of two young boys, Will who is six and has severe Haemophilia A, and Archie who is a cheeky 2 year old and does not have Haemophilia.

I am also a musculoskeletal Physiotherapist, working in the Women's health sector in private practise. My purpose in becoming a committee member is to learn more about HFV and to be the best advocate for Will I possibly can.

In the long term, I wish to learn how I can give my time and skills to the Haemophilia community locally and internationally.

# THE CARRIER BARRIER
## Women push for mild haemophilia diagnosis

By Sarah Aldridge

They experience similar bleeds and bruises as men with mild haemophilia, yet they're called "symptomatic carriers." For women, that label is confining and confounding. It also places their health at risk.

"Using the term 'symptomatic carrier' doesn't validate us," says Tammy Davenport, 38, of Kingwood, Texas, a regional coordinator for Matrix Health. "We have very different issues than men, but they're no less severe." Davenport's father had haemophilia A and had her tested for it when she was 5. Her factor VIII (FVIII) assay was 23%. The doctor told her parents, "She has mild haemophilia. If she ever has any surgeries or accidents, she may need factor."

However, that news did no good when Davenport went into labour with her son in 1994. "I went into the hospital explaining that I had haemophilia, and they needed to be aware of that," she says. The doctors told her, "That's impossible. Women can't have it." Consequently, they ordered no factor product. Davenport developed a large haematoma with a golf ball-sized knot on her spine from the epidural. It took a year to heal.

The burden for women whose concerns are discounted is both physical and emotional. When their bleeding symptoms are under treated, they experience health complications. When their concerns are brushed aside, they feel frustrated and angry, losing confidence in the medical community.

But women are finding ways to get around the carrier barrier. Through advocacy and education, patients and providers are pushing for recognition of mild haemophilia.

### *"Carrier" Confusion*

In genetics, a carrier is typically defined as a person who has a genetic mutation for a disease that can be passed on to a child, but who doesn't have symptoms. But for haemophilia, the label "symptomatic carrier" describes a woman who not only has the mutation but also has symptoms.

"I want to clarify this terminology because people get this confused all the time," says Marion A. Koerper, MD, medical adviser of the National Hemophilia Foundation (US). She is also director emerita of the HTC at the University of California, San Francisco, where she practices paediatric haematology. "Being a carrier is a genetic designation, not a diagnosis. It says nothing about how you are clinically."

Clinical information is partially provided by measuring the factor level. "Regardless of whether you're male or female, if your factor FVIII (FVIII) or factor IX (FIX) level is below 49%, you can have bleeding symptoms," Koerper says. "You have mild haemophilia."

The haemophilia diagnosis can be confirmed by genetic studies. "As genetic testing is becoming more available, particularly gene mutation analysis, it's becoming increasingly helpful," says Steven W. Pipe, MD, medical director of the Pediatric Haemophilia and Coagulation Disorders Program at the University of Michigan, Ann Arbor. For a woman with no family history of haemophilia, the lab can analyse her DNA for the most common FVIII mutation, the intron 22 inversion, a reversal of a section of DNA. It accounts for 40%–50% of cases of severe haemophilia A. "We've identified some women from that second-step testing," Pipe says.

The concept that women can't have haemophilia needs to be corrected. "That's a misconception that we probably have to devote some more attention to for education and outreach purposes," Pipe says. "If they have bleeding symptoms that can be managed with the interventions we have available, then they should be considered as having a mild bleeding disorder."

According to NHF, the normal plasma levels of FVIII range from 50% to 150%. Mild haemophilia is defined as having a FVIII level of 6%–49%. Because women have two X chromosomes, the level of FVIII they produce depends on the balance between the normal X chromosome and the abnormal one carrying the haemophilia gene. If the balance is equal, the FVIII level would not typically be lower than 50%.

"If the greater proportion of their FVIII level is dependent on the mutant FVIII gene, their factor levels can clearly be in the low range," Pipe says. Additionally, some carrier women with FVIII levels as high as 50%–60% may still experience bleeds.

### *Symptoms: Missed and Dismissed*

Mild haemophilia's trademark symptoms—bruising, nosebleeds, heavy menstrual periods (menorrhagia), and prolonged bleeding after trauma or dental or surgical procedures—can be missed or dismissed in girls and women. Danielle and Heather Schwager, 25, twins from Strongsville, Ohio, had symptoms during childhood. "We were kids who grew up playing outside all the time, and we were always bruised," says Danielle. The twins' mother, Vickie, a neonatal nurse practitioner,

periodically questioned the paediatrician, wondering if her daughters had haemophilia B, like her father. "He kept telling me, 'No, females don't have haemophilia,'" Vickie says.

Five years later, Danielle bled for 10 days after having four teeth pulled. Her oral surgeon and orthodontist sensed something amiss and referred the family to the haemophilia treatment centre (HTC) in Cleveland. Factor level testing confirmed Vickie's hunch. "My factor level was about 8% or 9% when I was diagnosed with mild haemophilia B," says Danielle. Heather's was about 40%. Those diagnoses took more than a decade.

During NHF's Annual Meeting in Chicago in November 2011, Koerper and Vickie conducted an educational session for women with mild haemophilia. Many women recounted similar experiences. "These women know they're bleeding too much," Koerper says. But their doctors disregarded their concerns, saying: "You got a big bruise because you banged your leg." Problems result when a surgery is performed without a treatment plan. "They'll have their gallbladder out, and then they have bleeding complications," says Koerper.

Davenport warned her new haematologist, who was inexperienced in treating women with bleeding disorders, that her factor level might soar from the stress she was feeling before a hysterectomy, but then would plummet afterward. Because her factor level skyrocketed to 80%, the haematologist took no precautions. Davenport woke up in the recovery room hearing her doctor tell the staff, "I don't know what's causing her bleeding. She doesn't have haemophilia."

"When they call you a 'symptomatic carrier,' and that's your label, you tend not to be treated seriously," Davenport says. For her, that resulted in post-op bleeding. For others, it might mean joint damage and arthritis from untreated bleeds or serious complications following childbirth.

***Emotional and Behavioural Toll***


The emotional and behavioural consequences for women with mild haemophilia who perceived errors in their medical care were documented in a 2011 study in Haemophilia by Nisa Renault and researchers at Dalhousie University in Halifax, Nova Scotia, Canada. The 11 women interviewed cited 264 negative emotional responses, including anger, doubt and mistrust.

A doctor's disbelief can lead to a patient's disillusionment. "It is frustrating to try to explain this to physicians who I would expect to know something about bleeding disorders," says Vickie.

Davenport was devastated when her doctor denied that she had haemophilia after her hysterectomy. "It was very hard on me to doubt the fact that maybe I believed this for 35 years, and it just wasn't right," she says. The pain went deep, as Davenport lost a comforting family connection. "That took away my identity—all I had of my dad."

Perceived mistreatment by healthcare providers also produced negative behavioural responses in the Canadian study subjects. Some women minimized the importance of their symptoms. Others avoided conflict by finding a new doctor or treatment centre. Some were so desperate that they treated themselves with factor product they borrowed from a family member. However, this practice is not recommended and may even be dangerous. "The borrowed medication may be the wrong dosage or wrong medication entirely from what your physician would have prescribed," says Pipe.

***Advocacy in Action***

A positive behaviour that emerged among women in the Canadian study was to advocate for themselves or others. Some insisted on in-depth testing or better treatment, or seeking another opinion.

When Davenport needed emergency gallbladder surgery, she chose a smaller hospital closer to home. There she found an understanding haematologist. "He said, 'Okay, you seem to know what you're talking about,'" says Davenport. "He went with my history, not my labs." She brought in factor and saw the haematologist three times before the procedure. "I was on prophylaxis for a week out," Davenport says. "I had zero bleeding problems."

Vickie and Danielle are involved in local advocacy through the Northern Ohio Hemophilia Foundation in Cleveland. "Our local task force set up a program for dental professionals to make sure that they were educated on women's bleeding disorders," says Vickie. Further, the chapter has invited gynaecologists and obstetricians to evening meetings to educate them. Danielle put together a brochure for the chapter to raise awareness about women's bleeding disorders. Both are on NHF's Women's Task Force, broadening their advocacy reach.

***Critical Role of the HTC***

Building a relationship with your HTC is critical for women with bleeding disorders. “Primary care physicians don’t always understand the nuances of the testing,” says Koerper. “They may order the standard screening tests, see that the partial thromboplastin time [PTT, a measure of clotting time] is within normal range, and tell women they’re fine,” she says. “They don’t understand that they have to order the actual FVIII or FIX activity test.” The HTC can also order further tests to pinpoint the mutation. A 2011 study in Haemophilia showed that a woman’s mutation, not factor level per se, was a better predictor of bleeding. (See “Test Takers,” HemAware Fall 2011; “What’s Your Genotype?” HemAware Spring 2010.)

Once you receive a mild haemophilia diagnosis from your HTC, you can get the benefits of comprehensive care. “We can offer them the same things we do for men with mild haemophilia, guidance around procedures and haemostatic support if necessary,” Pipe says. “We can help them with their family planning.”

Prior to surgery or dental procedures, your HTC can create a treatment plan to prevent or stop bleeding, which the dentist or surgeon can follow. “They were very aggressive with my treatment when I had dental work,” says Davenport of the staff at her son’s HTC. “I was on prophy, and everything was taken care of.”

***Mild Haemophilia: Not for Men Only***

Mild haemophilia should no longer be a “for men only” diagnosis, says Davenport. “If you have the symptoms of a disease or disorder and you have the labs to prove it, then you have it. It doesn’t matter what your gender is.”

Danielle has fully accepted her diagnosis and identity. “When I identify myself, I say, ‘I am a woman with mild haemophilia. I am a woman with haemophilia B’.”

Article courtesy of HemAware, the National Haemophilia Foundation (US), copyright 2012

# 2014 MENS RETREAT

Six men shared the HFV Mens Retreat weekend at Kattemingga. The ages ranged from early 30s to 80s and a relaxed weekend was had by all.

It is a pity that this venue will not be available in the future as the property has been sold, I hope HFV can find a suitable venue for future small group retreats.

I would like to see these weekends continue, which would mean that they were supported by sufficient numbers of men with haemophilia. I enjoyed being engaged with other men who shared similar challenges in life, and comparing changes to treatment from prior to factor 8/9 to modern prophylactic treatment.

It is interesting to hear personal life stories of how the individuals overcame dealing with a potentially debilitating condition to make a meaningful life for themselves and their families.

I would like men of all ages to be involved to share what haemophilia means to them and how they learn to cope.

Haemophilia is a rare condition and being involved with these activities helps me be part of a community and not feel isolated.

Russell Williamson


"Volunteers **STILL** needed for WFH World Congress! Experience the excitement of an international event and make a valuable contribution to our bleeding disorders community"

**VOLUNTEER ROLES**

HFA & WFH **still** require a number of volunteers to

- Delegate badge verification in the Congress sessions
- Give general directions to participants
- Assist those with restricted mobility to get around

Volunteers will be provided with –

- Meals or refreshments during shifts
- Uniform top
- Reimbursement of public transport fare or parking costs on site at MCEC. (Please note that no reimbursement will be made for travel, accommodation or meals and refreshments purchased off site)

**Please note, there is flexibility to fit in volunteering around the session times you wish to attend.**

For more information please contact Natashia Coco on 9885 7800

**It's not too late...there is still time to book in!**
**HFV will subsidise HFV members for $125 of their registration cost and for their WFH membership cost so call HFV now!**

**Not a HFV member?**

**No problem - join today and enjoy free membership for your first year.**

**Please go to our website for all the forms you need or phone our office and speak to Andrea 03 9555 7595**
**www.hfv.org.au/resources**

# HEADING TO CONGRESS? Not sure what sessions to go to?

*The Alfred Treatment Centre team have suggested attending some multidisciplinary sessions, as listed below. HFV have picked out some particular multidisciplinary sessions (on the opposite page) that may be of particular interest to members.*
*For more info please go to www.wfh.org/congress/en/Multidisciplinary_sessions*

## LIST OF MULTIDISCIPLINARY SESSIONS:

MANAGEMENT WITH NO OR LIMITED CFCS – WHAT IS POSSIBLE?-
Monday, May 12, 8:45-10:15

AGEING GRACEFULLY WITH HEMOPHILIA-
Monday, May 12, 8:45-10:15

RECIPES FOR HEALTHY LIVING-
Monday, May 12, 14:00-15:30

WE SHOULD TALK: SHARING INFORMATION WITH CARRIERS AND THOSE WHO CARE FOR THEM-
Monday, May 12, 14:00-15:30

NON-ADHERENCE: EXPLANATIONS AND STRATEGIES TO OVERCOME IT-
Monday, May 12, 16:15-17:45

LEADERSHIP DEVELOPMENT STRATEGIES: AM I READY TO “CARRY THE FLAG”?-
Tuesday, May 13, 8:45-10:15

DIFFERENTIATING ARTHROPATHIC PAIN FROM PAIN RELATED TO ACUTE BLEEDING-
Tuesday, May 13, 8:45-10:15

DISCLOSURE: WHEN, HOW, AND WHO TO TELL ABOUT A BLEEDING DISORDER-
Tuesday, May 13, 14:00-15:30

EMBRACING WOMEN’S SEXUALITY-
Tuesday, May 13, 14:00-15:30

THE FUTURE OF HEMOPHILIA CARE – UNDERSTANDING GLOBAL DEMAND FOR TREATMENT-
Tuesday, May 13, 16:15-17:45

BEYOND REGISTRIES: INTEGRATED INFORMATION SYSTEMS-
Wednesday, May 14, 8:45-10:15

BUILDING A TEAM AND LEARNING HOW TO WORK TOGETHER: MULTI-PROFESSIONALS AND PATIENTS-
Wednesday, May 14, 8:45-10:15

APPROACHES TO INHIBITOR MANAGEMENT-
Wednesday, May 14, 14:00-15:30

STRONGER TOGETHER: MEDICAL AND LAY COLLABORATION-
Wednesday, May 14, 14:00-15:30

EDUCATION AND EMPLOYMENT ISSUES FOR PEOPLE LIVING WITH A BLEEDING DISORDER-
Wednesday, May 14, 16:15-17:45

MULTIDISCIPLINARY MANAGEMENT OF CHRONIC PAIN-
Wednesday, May 14, 16:15-17:45

**Monday, May 12, 8:45-10:15**
**AGEING GRACEFULLY WITH HEMOPHILIA**
Chair: Anne Duffy, Psychotherapist, Irish Haemophilia Society, Dublin, Ireland

The objective of the session is to explore some of the challenges of ageing with hemophilia while at the same time bringing to light coping skills which, developed over time, will benefit people with hemophilia as they age.

**Tuesday, May 13, 16:15-17:45**
**THE FUTURE OF HEMOPHILIA CARE – UNDERSTANDING GLOBAL DEMAND FOR TREATMENT**
Chair: Mark Skinner, President, World Federation of Hemophilia USA, Washington, DC, USA

Current treatment paradigms around the world are often dictated by scarcity of treatment products, rationing of care, limitation on reimbursement, and a lack of understanding of patient needs and desires. This short-sighted approach is a significant shortcoming of existing healthcare financing models. The challenges of answering government and payer demands for evidence-based medicine and cost justification for the introduction and further enhancement of treatment are ever-present and growing.
Achieving adequate and affordable supplies of treatment products includes developing a keen understanding of demand. The research challenges of past decades have evolved into the access challenges of the current decade. The best way to prepare for these challenges is to conduct the necessary research to understand patient and clinical expectations and desires for new therapies, coupled with an understanding of the existing and potential demand for the new product introductions. A number of recent research initiatives will provide greater understanding and knowledge about the needs of the global hemophilia community.

**Wednesday, May 14, 16:15-17:45**
**MULTIDISCIPLINARY MANAGEMENT OF CHRONIC PAIN**
Chair: Ian d'Young, ASB, BPhty, MSc, MPNZ, National Clinical Lead, Haemophilia Physiotherapy, Auckland DHB Haemophilia Centre, Auckland, New Zealand

There are many options for people with hemophilia who experience chronic pain, which can be more effective than simply taking pain medication or avoiding activity. Managing chronic arthropathic pain adequately can have a significant effect on perceived bleeding episodes and can greatly improve quality of life.
The objectives of this session are to understand the bio-psychosocial nature of chronic pain relative to acute pain and the different ways to treat them; to understand the negative effects of long-term opiate use and the more successful multidisciplinary models of care used by modern chronic pain management teams; and to provide concrete advice and options for people with hemophilia and families in managing chronic pain more effectively.

**Monday, May 12, 14:00-15:30**
**WE SHOULD TALK: SHARING INFORMATION WITH CARRIERS AND THOSE WHO CARE FOR THEM**
Chair: Pamela Wilton, RN, CRE, London, Canada

Carriers and healthcare providers should be aware of the potential risk factors and know when and where to get information, support, and care. The objective of this session is to share new information and science about issues related to carriers; to identify potential resources in the bleeding disorders community for carriers; to increase recognition of possible signs and symptoms of trouble for carriers; and to stimulate discussion amongst healthcare providers and carriers.

# *Be kind to yourself...*

Jenna shares her story of living with vWD on FACTORED IN - the Haemophilia Foundation Australia youth website. Factored In was created by young people, for young people. Thousands of young people in Australia have bleeding disorders or are close to someone who does. This site has been created to talk about life, being young and having a bleeding disorder.

*I was diagnosed with VWD when I was 16 years old. I went to get checked out after having almost two years of violently heavy, erratic and unpredictable periods.*

*My mum had suffered the same from her teens. It was a relief to know why I lost so much blood (not to mention the frequent bruising, never ending cuts and scratches, nose bleeds etc), why I was so tired and felt unwell all the time. It was also comforting to be told that there were a range of treatment options for my symptoms.*

*At the time, only four other people knew; a friend, my mother, my brother and a teacher at school who we had been keeping up to date with all my absences and medical problems. My brother wasn't too interested but my mum, friend and teacher were all supportive and helped me get through school with all of my absences and leave due to doctors' appointments.*

*In hindsight, I wish I hadn't been so hard on myself. It took a few years for it to finally click that I didn't have normal periods, and that it was ok to ask for extensions at school, to take time off, and to take care of myself. I sometimes still have to say to myself "its ok, you need time to rest so your body can recover". If I could talk to my 15 year old self, I'd let her know that asking for help is ok, and to trust what your body is telling you.*

*Now I'm a bit older, I'm looking forward to the future challenges of being a female with a bleeding disorder. I'm going to have to deal with coming off the pill to get pregnant, everything from those scary periods, to nose bleeds and bruising, not to mention the potential issues with delivering a child. And then the cycle will start again – as I have type 1 VWD, I have a one in two chance of passing the disorder onto any of my children. In a way, I'm excited by the prospect of getting to help a child through the challenges a bleeding disorder can bring.*

*If you are a girl who has just been diagnosed with VWD, or any other bleeding disorder my advice is firstly be kind to yourself. You are your own best friend, so don't beat yourself up for needing extra care, support or rest. Get to know your doctors (you'll have a GP, and will need a referral to a haemotologist, and a gynaecologist if you don't have one). They will provide extra knowledge and support and will be on your side if you can tell them not just the medical information, but how you're feeling, what you need to function in your world from your medication, and your opinion about the treatment they're recommending. And lastly, join your local Haemophilia Foundation. Your local branch should be able to connect you with other people who can provide you with the support and friendship only other people in the same situation can understand.*

*(I'm presenting at Congress in the Youth Engagement session and would love to see HFV members there!)*

*Jenna*

FACTORED IN

WWW.FACTOREDIN.ORG.AU

# HFA Women's Project

Our consultation with Australian women with bleeding disorders has highlighted how important it is for women to connect with each other by sharing their stories and realising that they are not alone in their experiences – and that having a bleeding disorder is something that can be talked about.

HFA is going ahead with its work on resources specifically for women, which will include personal stories and information answering women's questions.

There will be two new resources:

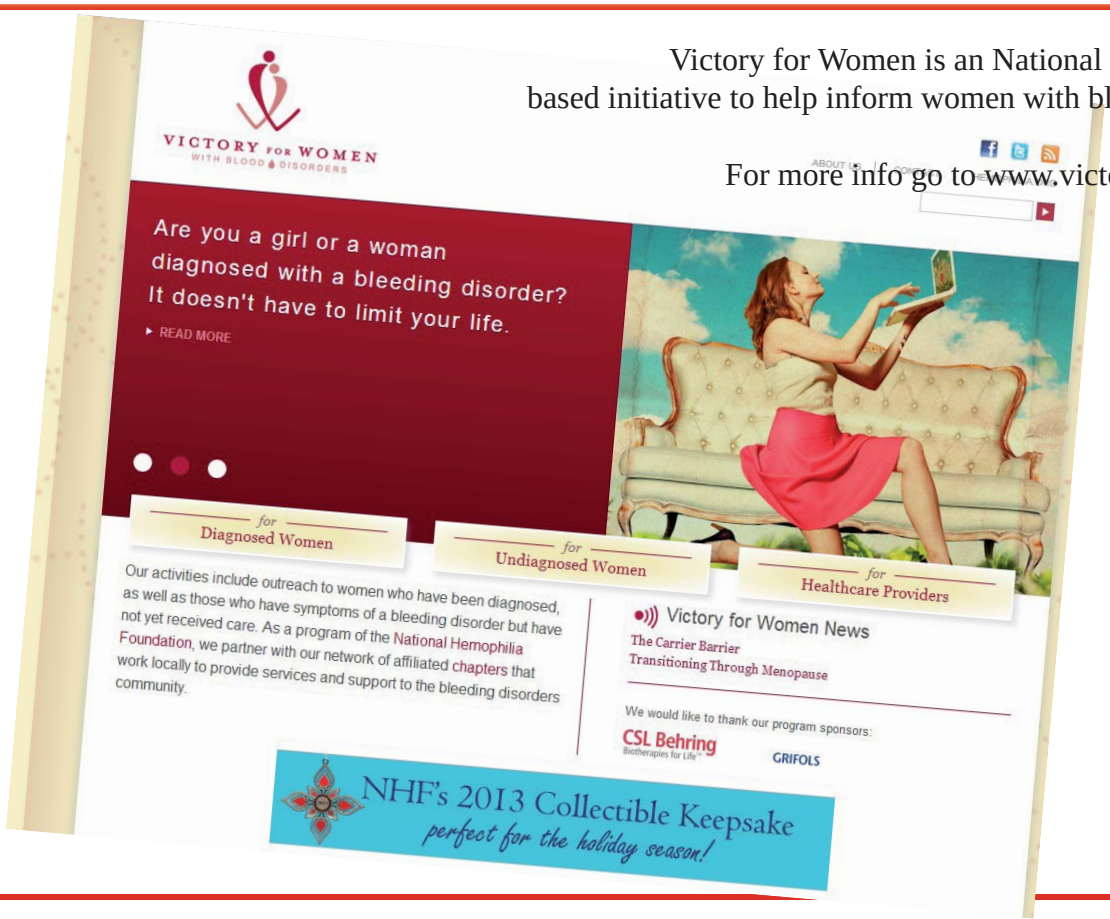
- Carrying the haemophilia gene
- Living with bleeding symptoms (haemophilia, VWD and other rare disorders)

How to be involved?
If you are an Australian woman and have VWD, carry the gene or have bleeding symptoms and are interested in being involved, you can:

- Participate in the HFA women's resources review group. This involves contributing ideas on what should go in the resources, reading over drafts of the resources and giving your comments
- Tell your story and have it included in the new resource (and National Haemophilia) – it can be anonymous if you prefer – and you can write your story yourself or be interviewed over the phone.

If you would like to be involved, please contact Suzanne O'Callaghan, Policy Research and Education Manager, Haemophilia Foundation Australia:

socallaghan@haemophilia.org.au
Phone 1800 807 173




Victory for Women is an National Hemophilia (US) based initiative to help inform women with bleeding disorders.

For more info go to www.victoryforwomen.org

# Helping your children's teachers to understand haemophilia

*I was delighted to again attend the Haemophilia Teachers Seminar at the Royal Children's Hospital at the end of February. HFV helps support this event by producing information booklets and by processing the registrations of teachers - the administration side of it. It is then a wonderful opportunity to go and see the benefits these teachers are getting from attending this seminar and knowing how that will impact positively on the children they teach.*

*Teachers had the opportunity to listen to some parents of children with haemophilia and the children themselves talk about their condition. This was a great opportunity for the teacher to ask questions and understand frustrations that the children themselves may come across and hopefully alleviate these for the children they are teaching.*

*The RCH team have shared a number of comments received from some of the teachers that attended such as, "I was amazed at how normal the boy's lives can be. I now feel more relaxed and aware of how to deal with this disorder ... Super helpful makes me feel much more confident with dealing with my student." Here are some other positive comments we received from the teachers that attended about what they had learnt.*

- *Bleeding is internal.*
- *The patient knows when it happens*
- *The child will not bleed to death*
- *They are very normal and can do normal things*
- *To listen to the student and keep talking with the parents*
- *There are always people to go to for questions and further info*
- *First aid as normal*
- *Importance of physical activities and to promote inclusion*
- *Gained an overall understanding of the disorder*
- *The child in my room may participate fully in the program without concern of an injury*
- *First aid and what to expect when a bleed happens*
- *Hearing from the Parents/Children*
- *The difficulties for adolescents and their families with transitioning*
- *That factor makes bleeds feel better so students can stop using crutches/splints too early*
- *Haemophilia is a big deal but not a big deal*
- *Each presentation gave something to take home*
- *Treat the child with respect and understand without stressing*
- *Look out for a limp etc.*
- *Treatment and myths*
- *That an action plan needs to be developed by the staff at my school in preparation for camp*
- *To have a clear understanding - know your child's treatment plan*
- *To be able to recognise signs and symptoms*
- *Open communication with student's parents*

*If your child's teacher was not able to attend this seminar they can still download the information booklets by going to the 'resources' section on our website or by contacting us directly and we can mail copies out.*

*Also, please encourage your school to become a HFV 'Friend of the Foundation' member. This type of membership is free but they would receive our magazine and other information about bleeding disorders — which may be interesting reading in the staff room!*

Andrea McColl
HFV Executive Assistant

# PROJECT RECOVERY

In what's being hailed as a world first, protein left over from the manufacture of plasma products from Canadian blood donors are being turned into life and limb saving treatments for thousands of people living with hemophilia in developing countries.

The World Federation of Hemophilia (WFH), in partnership with Canadian Blood Services (CBS) and two manufacturers of plasma products, BIOTEST AG and GRIFOLS, officially announced the launch of Project Recovery during the WFH Eighth Global Forum on the safety and supply of treatment products for bleeding disorders in Montreal, Canada, on September 26. This humanitarian aid project, first conceived by the Canadian Hemophilia Society (CHS), now becomes a reality after a dozen years of effort.

Project Recovery will transform previously discarded cryoprecipitate from Canadian blood donors into BIOTEST's factor VIII concentrate, called Haemoctin®, to treat people with hemophilia. It will be channelled through the WFH Humanitarian Aid Program, which focuses on providing for patients in developing countries who have little or no access to these life and limb saving medicines and would otherwise be at risk of death or severe disability.

"Project Recovery has the potential to improve the lives of thousands of people with hemophilia all over the world," said Alain Weill, WFH president. "It also allows the WFH to carefully plan where and when these essential medicines will be distributed thereby maximizing the benefits of this wonderful humanitarian endeavour."

It is estimated that in each year of the project at least five million International Units of factor VIII will be donated. This will allow the annual treatment of approximately 5,000 joint haemorrhages, the most common symptom of hemophilia, in children and adults. This is the first time anywhere in the world that such a partnership has been created to transform surplus cryoprecipitate into factor VIII for humanitarian use. Contracts for this international cooperation were signed in July of 2013 and the first production steps have begun. The WFH will receive the first deliveries of this factor VIII in 2014.

With Project Recovery, the cryoprecipitate will be harvested by GRIFOLS at its plant in the U.S., transported by BIOTEST to Germany for manufacturing. This finished pharmaceutical product will be manufactured and released under the BIOTEST license and trademarked Haemoctin, a high purity and double virus inactivated factor VIII product for the treatment of hemophilia A. A portion will be marketed by BIOTEST and the remainder allocated to CBS for donation to the WFH. BIOTEST will also support the WFH in distributing the donated Haemoctin to recipient countries. The partnership is cost neutral for all parties. This project will enable the WFH to expand its Humanitarian Aid Program as part of its comprehensive activities to achieve treatment for all people with bleeding disorders.

# What's new in treatment for Hepatitis C?

**These are promising times for people living with hepatitis C. On 1st April 2013, innovative new treatments for hepatitis C genotype 1 became available in Australia, and more are expected to follow for all genotypes as clinical trials continue over the next few years.**

This was the first step towards achieving an interferon-free treatment that will significantly reduce the side-effects of hepatitis C treatment, while making the whole process much quicker, simpler, more tolerable and far more effective in curing all hepatitis C genotypes.

Current therapies for hepatitis C depend on the type of hepatitis C you have. You may be offered a triple combination of Pegylated Interferon, Ribavirin and Boceprevir or Teleprevir if you have hepatitis C genotype 1 and you may need as little as 6 months therapy thanks to the introduction of these direct acting antiviral therapies.

For now, the therapy plan for Australians living with other hepatitis C genotypes remains the same as it has been for many years. This involves a combination of weekly Pegylated Interferon injections and daily Ribavirin tablets.

## The future is very promising

Two studies, both published in the January 16 issue of the New England Journal of Medicine, involved giving various combinations of direct acting antiviral drugs to patients with hepatitis C. Some had failed to respond to standard Interferon therapies, and some had not received therapy as yet. In the studies between 93 percent and 98 percent of patients cleared the virus.

These antiviral combinations are game-changers for the people living with hepatitis C who are considering therapy. Studies indicate that with these new direct-acting antivirals, almost everyone can appear to be cured with the right combinations of drugs.

With Interferon based therapies it is often a case of 'if I get cured' with these new antiviral therapies it's more a case 'when I get cured'.

## Very low or no side effects

In one of the studies two direct acting antiviral drugs, Daclatasvir and Sofosbuvir are taken for 12 or 24 weeks, with or without the addition of Ribavirin. Studies show that the experimental drugs were safe and effective, even those who'd had earlier failed standard Interferon therapy showed good results with minimal side effects.

Antiviral therapies in development pave the way forward for Interferon-free therapies; they are highly effective, safe and tolerable!

The U.S. Food and Drug Administration has approved Sofosbuvir for the treatment of hepatitis C and Daclatasvir is still in the approval process. These are only two drugs in long list of drugs in development and being studied for effectiveness, safety and side effect tolerability.

As these experimental drugs are approved and become available there will be a range of antiviral options for treatment specialist to consider depending on the situation of the patient. For instance it's likely that some combinations of antivirals will be more effective than others for treating past non-responders to Interferon therapies or for treating people with more advanced liver disease. So the hope of a cure is being considerably widened for many people living with hepatitis C.

The first wave of antiviral therapies were introduced in Australia in April 2013 when Tepaprevir or Boceprevir, (both direct acting antivirals) were added to the standard Interferon therapy for hepatitis genotype 1.

Whilst we are seeing significantly better outcomes, with up to 80% of people with genotype 1 now being cured, patients are also dealing with significant side effects, including, increased skin rash and anaemia, as well as the Interferon and Ribavirin side effects which can include flu-like symptoms, anaemia, nausea, fatigue, anxiety and depression.

Antiviral drugs still in the development or trial stages are proving to have very few side effects and the question of side effect tolerability may also become a thing of the past once these new therapies become available.

## Non Interferon therapies are on the way

The second study, headed up by researchers at Virginia Mason Medical Center in Seattle, involved more than eight medical centers in the United States and internationally. It included 571 patients with hepatitis C, some of whom had not received treatment previously and others who had previously received standard therapies with interferon injections and ribavirin, but had not responded to them.

The participants were given any of three combinations of

antiviral drugs, medications called ABT-450, ABT-267, and ABT-333 for 8, 12 or 24 weeks. Almost all of the patients (more than 93 percent in both groups) saw the virus cleared from within 24 weeks, *"Even patients with prior non-response to Interferon/Ribavirin therapy had good results in this study, this all-oral regimen for 12 weeks can achieve a cure in the vast majority of patients. It is safe and well-tolerated"* the study concluded.

## The importance of monitoring liver health as you wait for new therapies

The next step is to keep pushing for better hepatitis C and liver health screening for all people with hepatitis C, so that patients can receive therapy before they develop serious liver disease. This is very important as cirrhosis reduces the success rate of all hepatitis therapies and cirrhosis remains as a serious chronic illness even after hepatitis C has been cured.

Undertaking hepatitis C therapy before the onset of serious scarring or cirrhosis is very important for successful therapy and to reduce your chances of liver failure or liver cancer.

The future of hepatitis C therapies is very bright indeed with the end of Interferon in sight and with many specialists talking about the potential to eradicate hepatitis C from the community.

This may be the beginning of the end of hepatitis C!

Garry Sattell
Community Support Services Coordinator, Hepatitis Victoria
*Sources: New England Journal of Medicine and Hepatitis Australia information was used to inform this editorial*

*Reprinted with permission from Hepatitis Victoria*

** PLEASE NOTE: This article highlights the positive impacts of new treatments. However, these treatments may not be suitable for people with advanced hepatitis, hard-to-treat hepatitis or people with complex health conditions who may be taking one or more medications. The hope is that more and more combinations become available to treat all people with hepatitis C.*
*HFV advises regular liver health checks for anyone with hepatitis C.*

To find out more about new and emerging therapies for hepatitis C call the Hepatitis Infoline 1800 703 003

Or go to these websites to find out more:
http://www.hepatitisaustralia.com/treatment-for-hep-c/
www.hivandhepatitis.com http://hcvdrugs.com

If you are thinking about undertaking standard Interferon/Ribavirin therapy check out the Hepatitis C: Treatment Side Effect Management Guide http://www.hepvic.org.au/hepatitis_resources

Or talk to your treatment specialist and find out about your current liver health and what your treatment options are.

# Ladies' Day Out

*Celebrating*
*10 years of support!*

true thai MASSAGE

The "Ladies' Day Out" event is designed to provide a much appreciated yearly break from the routine and demands of women who are impacted in some way by Bleeding Disorders, either directly or as a caregiver or family member.

We offer peer support and an opportunity to try new, perhaps previously undiscovered, methods of relaxation and improved wellbeing.

New and renewed friendships are developed, and support is provided in a carefully selected, fun environment.

So come and join other HFV ladies for a special 10 year anniversary pampering treat!

**True Thai Massage**
**308 Chapel St**
**Prahran**

**Sunday 19th October 2014**
**11.00am**

**Followed by lunch at a local café (TBC) 1.00pm**

Bookings essential either on 9555 7595 or through our website. Numbers limited to 20 so book early to avoid disappointment.

A $5 contribution is required on the day.

# HFV Member Bursary Submissions

HFV have received a wonderful response from our members for bursaries this year. We have included 5 submissions in this edition of The Missing Factor, including Harrison's on the back cover. We will have more heartfelt, interesting and inspiring submissions featured in our August edition of The Missing Factor.

## It's Tom's Life!

My name is Thomas but most people call me Tom. I live in Bannockburn with my Dad Peter who is a Teacher at a Secondary School, my Mum Rebecca who is a teacher at my Primary School and my sister Ella who spends most of her time with her new rabbit Nellie. Ella is 9 years old and in grade four, she is a very kind sister to me. I am nearly 8 and in grade Two. My Teacher this year is Mr Simmons. He is a great Teacher except he barracks for the Brisbane Lions. My family barrack for the Richmond Tigers. My favourite player is Jack Riewoldt. I have a new baby cousin called Oliver.

Last week I got my very own pet turtle. His name is Timmy and he is a Macleay River Turtle. He has his own tank to live in and I have to feed him every morning. Right now he is only as big as a 50c piece. I like watching him swim up to breathe. I try to see him up on his turtle bank and snap a picture but he is very fast and usually jumps off when he sees me coming!

It is very annoying to me that I have Haemophilia but I have no choice. I am learning how to mix my Xyntha Factor V111 with my mum and I can nearly do it all by myself. I use to have a port on my right side that was put in when I was 8 months old. When I was a Prep my port stopped working and I had to get another one. Soon I am going to start to have my factor into my arm but I am not really looking forward to this.

Sometimes I get a bad bleed but not very often. Once I had a bad bleed in my knee and had to go to school in a wheelchair! My friends liked pushing me in my chair but I got sick of it pretty quickly. I always have lots of bruises but they don't worry me too much. Now I have my Factor every second day and that has helped a lot. I don't like The Royal Children's Hospital when I have to sleep there, but I do like to go and see Dr Chris, Janine and Tim. Dr Chris always teases me. He is very funny but he barracks for a bad football team and tries to make me wear a Swans jumper – never!!

I like playing Skylanders Swap Force but sometimes I like Disney Infinity too. I have lots of Lego and I like to play with my Trash Wheels. At quiet time I play with my dinosaurs. I am really interested in Marine Animals and like watching Wildlife shows and reading books about animals and reptiles. I like to go on holidays with my family. We pack the Factor and all the transfusion supplies into a little case and Dad carries it onto the aeroplane so it does not get lost. My best thing on holidays is swimming in the pool and beach. When I was little I needed to watch TV when I had my factor but now I sit up on a big stool – Mum makes sure it is over very fast.

Sometimes I fall over at school and all of my friends come over and see if I am ok. They are very nice to me and they take me to the sick bay. They know what Haemophilia is and sometimes tell a Teacher on yard duty just in case they forget. Otherwise nobody really worries about me having Haemophilia – I play chasey, footy, cricket and lots of other stuff just like all the other kids at school.

If you have Haemophilia, don't worry because the numbing cream helps when the needle goes in so it doesn't sting. Also, even though I have haemophilia I have a really great life.

By Tom, with help from Mum.

# My Poppy – My Hero

My Poppy, Neville, was my hero. My Poppy passed away when I was 15 months of age. I do not remember much about my Poppy. But what I do remember is that Poppy and I always had fun together. Nanna has shown me photos of Poppy and me watching television together and yes we both fell asleep.

Nanna has a lovely photo of Poppy and me racing around Geelong Hospital in his wheelchair. I have that photo on my wall of photos of the most precious people in my life. I love it so much.

I would like to tell you a funny story. Nanna told me this story. One day when I was little I had a tea party in my room. I had set up my kinder table with all my cups and saucers. I then heard Nanna crying, I did not know what had happened. I had taken Poppy's photo from his special place and put it at my kinder table for the tea party. I showed Nanna where I had placed Poppy's photo. So, all three of us sat at my kinder table for a tea party. My Poppy means the world to me and I know that I mean the world to him.

Every time that Nana and I go the Haemophilia Family Camps, yes we have lots of fun – camp fires canoeing, games and giant swing. What a great way to meet new friends and catch up with old ones (Nanna knows a lot of people at camp). I like getting to learn more about haemophilia from everyone at camp. I have learnt that haemophilia is a bleeding disorder and you cannot catch it from anyone.

A lot of people throw the word hero around, and yes a lot of people are heroes. But to me the real heroes are those boys at camp that manage their haemophilia in such a fun way. They are so funny sometimes.

I am proud to be part of the haemophilia family and I would like to in the future somehow help, even in a small way.

I know that my Poppy is with me always, I love him so much. He is my hero.

By Elizabeth

## HAEMOHPILIA

## WHY I WOULDN'T CHANGE IT

By Ben

# The Realisation

It has been nearly 10 years since my brothers were diagnosed with Haemophilia, and it really is now just part of our life. But I can still remember vividly the day we found out about haemophilia and that shock that it gave to my family. I watched the devastation on both my brothers faces when they found out that this was a condition that they were going to have to live with for the rest of their lives. Although they both never displayed that negative attitude towards haemophilia I knew it was affecting them when it came to having to stand out of sporting events due to an injury, wearing a helmet in football or just having a bad bleed and being in excruciating pain.

I have just completed VCE and one of my subjects I studied was biology, this is where I really understood the rare sex-linked recessive condition that affected my family. I learned the background of the condition and what it is that determines whether someone carries or has the haemophilia gene which now enables me to finally comfortably explain what haemophilia actually is.

Being a carrier, this unit really got me thinking about my future and the future of my unborn children, will I be able to accommodate for a child with haemophilia? At the time I thought no!, I will just go through gender selection and choose to have girls but now I think that you know what, haemophilia is a part of my life, I have seen so many families with beautiful, energetic, talented outgoing boys who live a normal life and most are all happy and if nature decides that I do have a child with haemophilia, mild, moderate or severe it will make no difference to how much I love that child.

I have watched my brothers in the past 10 years grow to the acceptance of haemophilia, I have seen both my parents come to terms with it and most of all my mum, scared of needles, is now administering factor 8 to the boys as soon as they need it, showing how it is just another part of our life that is comfortably dealt with.

I have a strong belief that everything happens for a reason in this life, and God gave these mothers children with haemophilia because he knew that she and her family had the strength to look after them.

So, if in the future I am one of these mothers I am okay with that. It only makes you stronger.

By Andrea

## *GRANDPARENTS & FRIENDS LUNCH*

*You are invited to join our annual Grandparents and Friends Lunch at the beautiful 'Madeline's At Jells'.Weather permitting we may take a stroll around the park so please bring your walking shoes!*

This get together provides grandparents and friends of those with bleeding disorders the opportunity of valuable support and information.

Sunday 24th August 2014, 12.30pm — 2.30pm

Madeline's At Jells, Jells Park, Waverley Rd, Wheelers Hill

2 course lunch, a glass of wine & coffee — all provided courtesy of HFV

Bookings essential on 9555 7595

Madeline's at Jells

# SPECIFIC TIPS FOR OVERSEAS TRAVEL

Members often ask us for information about travel. Here are some tips from HFA:

- For overseas travel you will need documentation for customs and security – talk to your Haemophilia Centre about this at least 3 months before you travel so you have plenty of time to prepare
- When going through customs checks, your ice packs may need to be examined as they could be interpreted as contributing to the liquids limit for international flights. This is why you need the documentation mentioned above!
- In some cases, the National Blood Authority will need to approve taking factor products out of Australia
- Different counties require different documentation, so it's important to let your Haemophilia Centre know exactly where you're going
- You may also consider having the documentation translated into the language of the country you are travelling to
- Be patient with border control! Don't assume immigration officials are knowledgeable about bleeding disorders!
- If you require regular on demand treatment it is recommended that you take treatment product with you on your trip
- You should have enough treatment with you to give yourself 24-48 hours' cover to get to a country where you can access adequate medical treatment. If you are on prophylaxis, you should take all of your required treatment with you for longer trips or organise for more to be delivered to you overseas
- Your treatment product may not be available in the country you are travelling to. There may be a different range of plasma derived and recombinant factor products available
- Be aware that some countries don't have as much money as Australia. This means that their services may not be what you are used to receiving at home. For example, blood products may not be checked as thoroughly for blood borne viruses like HIV or hepatitis and you may only have access to reused needles and equipment. It is a good idea to carry your own treatment and injecting equipment
- Even if Australia has a Reciprocal Health Care Agreement with the country you are in, you will probably still need to pay for the treatment product and this can be very expensive. This is why travel insurance is very important!
- Take your Medicare Card so you can prove that you're eligible to receive health care treatment (if Australia has an agreement with the country you're in)
- You cannot give unused treatment products back to your Haemophilia Centre when you come back – they cannot be returned

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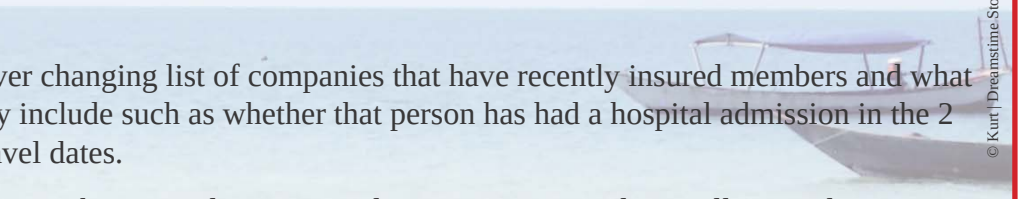
# TRAVEL INSURANCE

As stated above it is **very** important to have adequate and suitable travel insurance when travelling overseas. We often get calls from members asking who will insure them if they have haemophilia or other bleeding disorders. The reality is insurance companies are constantly changing and reviewing their policies with regards to bleeding disorders and other related and unrelated conditions.

We try and keep an ever changing list of companies that have recently insured members and what the terms of the policy include such as whether that person has had a hospital admission in the 2 years prior to their travel dates.

If you require information about travel insurance please contact us and we will certainly give you the latest info we have. Also, we ask that if you have obtained travel insurance recently to let us know so we can share it with the rest of our HFV members and community.



## our community

# REGIONAL VISITS 2014

## Shepparton 15th June
12pm @ The Parklake (book by 2nd June)

## Horsham 10th August
12pm @ RSL

## YOUR REGION NEXT?
CALL US IF YOU WOULD LIKE HFV TO VISIT YOUR REGION IN THE FUTURE

*Lunch will be provided by HFV.*
*Check our website for more details.*

VIC FOR IA

**CARRIER INFORMATION SESSION**

HFV is looking at running a carrier information session in September or October. We are currently reviewing issues and topics that we should be covering.

Your input is valuable so please contact our office on 9555 7595 or email julia@hfv.org.au if you have any suggestions on what you would like addressed.

More details will be in our August edition of The Missing Factor.

## HAEMOPHILIA CENTRES

### Henry Ekert Haemophilia Treatment Centre

Royal Children's Hospital
Flemington Road, Parkville
P. (03) 9345 5099
E. he.htc@rch.org.au

Dr Chris Barnes | Director Henry Ekert HTC
Janine Furmedge | Clinical Nurse Consultant
Julia Ekert | Office Data & Product Manager
Melinda Cumming | Social Worker

### Ronald Sawers Haemophilia Centre

The Alfred
1st Floor, Sth Block -William Buckland Centre
Commercial Road, Melbourne 3004
P. (03) 9076 2178
E. (03) haemophilia@alfred.org.au

Dr Huyen Tran | Director of RSHC
Penny McCarthy | Clinical Nurse Consultant
Megan Walsh | Clinical Nurse Consultant
Susan Findlay | Secretary
Alex Coombs | Haemophilia Social Worker
Daniel Bostelman | Hepatitis C & Haemophilia Social Worker
Abi Polus | Physiotherapist

## HFV Membership Renewal Subscriptions

Renewal subscriptions for 2014/15 will be mailed out at the beginning of June to all members.

We are hoping that renewals will be able to be processed through our website. This will be confirmed in writing closer to the time.

Payment is due by the 30th June 2014

## HFV MEMBER SERVICES

Membership Fees:

| | |
|---|---|
| Standard family membership | $33.00 |
| Concession member | $16.50 |
| Allied Member | $16.50 |
| Organisational member | $55.00 |

* No joining fee for new members joining at the Standard Family Membership rate.

Ambulance Subscription Subsidy:
To ensure all people with haemophilia have ambulance cover, the Foundation will subsidise Ambulance Subscription Fees to the value of half the family fee. (Members who have Health Care Cards which also cover their dependants, are automatically entitled to free Ambulance transport for themselves and their families.)

To obtain an Ambulance Subsidy:
Forward subscription receipt (or a copy) to the HFV Office with your contact details. Subsidies will be paid on a reimbursement basis.

Other Subsidies:
SOS Talismans are available for purchase for $15.00 from the office.
MedicAlerts: A subsidy of 50% of the first purchase price of any MedicAlert, (with the subsidy payment being up to $30 in value and not including the annual fee) is now available. To obtain a subsidy, forward a cover letter and receipt to the HFV Office.

Care and Counselling:
This is available through your treatment centre.

Magazine:
Your quarterly magazine offers information and details of upcoming events.

Website - www.hfv.org.au
The new HFV website is now online. It provides information, details of upcoming events and more. The site is updated weekly.

The HFV Office:
The office is usually open from 8.30 am to 4.30 pm Monday to Thursday. If you plan to come to the office, we suggest you ring ahead to check if the office is staffed.

We are located at:
13 Keith Street,
Hampton East, Victoria, 3188.

| | |
|---|---|
| Phone: | (03) 9555 7595 |
| Fax: | (03) 9555 7375 |
| Website: | www.hfv.org.au |
| Email: | info@hfv.org.au |

## ATTENDING THE CONGRESS?

HFV will have a notice board displayed by the HFA stand with a list of HFV events or get-togethers for HFV members such as where we will be meeting for lunch.

HFV committee and staff will be attending the HFA meet and greet at Plus 5 Bar, 37 South Wharf Promenade from 3.30pm on Sunday 11th May, and encourage those attending the congress to join us. We will then attend the opening ceremony together followed by light refreshments in the Melbourne Convention and Exhibition Centre.

We will meet HFV members outside door 9 to the auditorium directly after the opening ceremony and we will have this as our designated HFV meeting point at break times. This way we hope all HFV members will get the opportunity to meet with other HFV members and have a chat. Of course, we would also encourage other people with bleeding disorders from around the globe to join us!

# BLOOD BROTHERS YOUTH CAMP

Our HFV Blood Brothers have just returned from their 3rd annual camp. We had 13 guys head to Portsea to spend the Anzac weekend together.

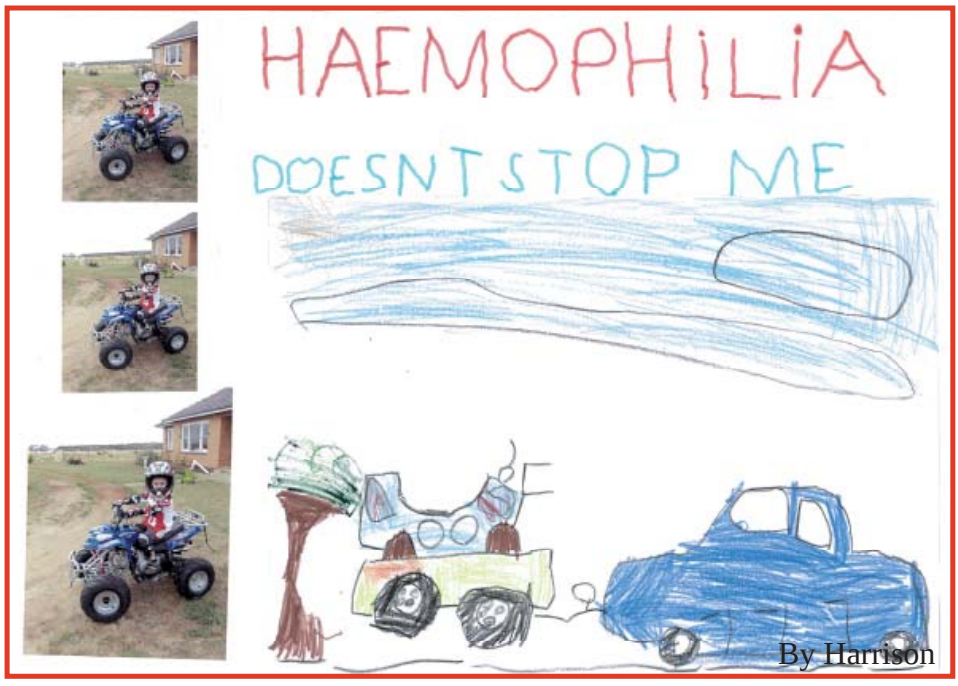
Purple Soup had many activities set for this important weekend. The benefits of this camp for our youth involved are immense. Networks are established amongst the youth and also peer support connections are made creating lifelong emotional support — and HFV benefits from the guys becoming more involved with our foundation.

The young guys also benefitted from the participation of key medical professionals from both HTC at Alfred Health and the RCH. Dr Chris Barnes from RCH and Penny McCarthy from The Alfred both came on Saturday and ran health promotion sessions. This really helps develop open lines of communication between the guys and their care givers and creates pathways to their care givers out of a clinical setting.

There is also a strong component of mentoring at the camp which helps to develop self awareness and helps the younger guys to build on their strengths and seek assistance in areas of greater need. Mentoring also helps with the process of transitioning from the RCH to The Alfred.

We hope these guys come back from this camp feeling more resilient, more connected with their peers and with a greater capacity to manage their condition.

More on the Blood Brothers Camp in the next edition of The Missing Factor!




By Harrison

Haemophilia Foundation Victoria Inc acknowledges the support of the Victorian Government.

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