

THE MISSING FACTOR

**CRUTCHES
FOR VIETNAM**
A life changing gift

**AGEING
GRACEFULLY**
...while letting charm do its work



BLOOD, SWEAT AND GEARS

Randall's Really Big Bike Ride
for Haemophilia is coming to an end!

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DIARY DATES

2015 Men's Retreat — 13th to 15th March

2015 Family Camp — 27 to 29th March

World Haemophilia Day — 17th April

2015 Blood Brothers Camp — TBC

Committee of Management

President

Leonie Demos

Vice President

Sharron Inglis

Treasurer

Zev Fishman

Executive Member

Ann Roberts

General Committee

Matthew Blogg

Karen Donaldson

Carol Ebert

Donna Field

Jodie Caris

A new year at HFV and a new journey begins

A happy new year to all in our community on behalf of the Committee of Management. As we start 2015 we also start the 61st year at HFV after our AGM in November and a newly elected committee.

I would like to start my new journey as President to acknowledge the hard work of many that goes behind the scenes at HFV all year. After many hours of volunteer support the Committee has farewelled two of our members as Michelle and Damian take a very well earned break. Both have contributed in many ways especially Michelle as a previous President. Michelle's dedication to HFV has value added in so many ways. From stakeholder engagement at a National level and also at a very personal level for many families as she has offered her shoulder many times to support others in difficult times. Both Michelle and Damian have left a significant 'footprint' at HFV that the current committee will continue to 'walk in' and we wish them well with their break and thank them most sincerely. We look forward to both of them continuing their support to our community in a different capacity as they take a different path beyond their role as members on the Committee.

Ann Roberts, our former President, has very kindly agreed to remain on the Executive and her very many years of experience will be valued by all, especially me, as I lead for the first time in very big footsteps from my predecessors as President.

Sharron has stepped up as Vice President to support our Executive and Zev has very kindly agreed to continue to monitor our finances as Treasurer. Fortunately others on the committee have stayed and we are all very committed and keen to take on all the challenges 2015 will bring.

A word from *our* president, Leonie Demos

There are many exciting projects on the horizon at HFV and we hope you will join in to support us as we build a stronger community for the future. In an ever changing landscape of reduced funding and changes at both Federal and State level in the health and allied sector HFV need to be united and strong as we work with our partners at HFA, other state associations, our treatment centres and other agencies beyond.

HFV are very blessed to have dedicated staff with both Julia and Andrea that always go above and beyond their role to provide the best possible service to our community. Like the COM, Julia and Andrea are dedicated in their time as they plan and develop programs and camps to enrich and support our community.

However HFV isn't just a name on a banner or the letterhead of this newsletter. HFV isn't just our staff, the COM and a handful of volunteers. HFV is you, your family and your community. As President, I invite you to be part of this journey and walk alongside us. Contact me, or any of the COM or our very welcoming staff for a chat and tell us what you want HFV to be. We are waiting to listen....

Looking forward to continuing our journey together and hope to see you next time at one of upcoming exciting events!

"So be sure when we step, Step with care and great tact. And remember that life's A Great Balancing Act. And will we succeed? Yes! We will, indeed! (98 and ¾ percent guaranteed) We can move mountains... We are off to great places. Today is our day. Our mountain is waiting.. So...let's get on our way!"

Dr. Seuss, Oh, The Places You'll Go!

Leonie Demos

Opinions expressed in the HFV Magazine do not necessarily reflect those of the foundation, HFA or the Haemophilia Treatment Centres.

All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control.

AGEING GRACEFULLY...

while letting charm do its work

The following article was featured in Hemophilia Today - the Canadian Hemophilia Society magazine. It highlights the experiences of three men with haemophilia and their experiences with ageing...gracefully.



Rick Waines, Vancouver, British Columbia

It was at the third set of rapids on day two, with so much turbulence in front of my mask that I couldn't see what was coming (and I knew it was) that the voice inside my head said, what on earth were you thinking! That voice was a little more pointed than the day before when, at the first set of rapids, it said something like, this might not have been a very good idea! Two weeks later as I type this, my ribs would agree. They're still yelling at me.

My ankles are shot. I am waiting for a fusion (it will be a two-year wait by the time I have it) which hopefully will relieve the pain that keeps me up at night. I can't walk for more than a block or two without having a lot of discomfort the next day. As a result I rely on my love of water to keep my body feeling alive. Swimming laps is great exercise but not very much fun. So I became a freediver. Freediving is like scuba diving without the tanks. It is also like snorkelling but with the intention of finding out how deep underwater you can go. It is a non-weight-bearing activity that in order to do well I must stay in shape (this being a relative term), go to the pool, do my breathing exercises, and get in the ocean regularly to train. I love it so much but it isn't without its own risks. But they

are risks I assess and manage. I'd say I certainly show much better judgment in my freediving decision-making than when I routinely get into a car or on my bike and travel any distance on our roadways. Being in a car as passenger or driver is clearly the riskiest thing we do. It is good to keep that in mind.

As a 48-year-old I am not ready to retire from physical adventure but sometimes I bite off more than I can chew, and on a weekend in September what I could chew turned out to be the boulders in Campbell River. The idea was to jump in at the outflow of the John Hart generating station, swim around in some pools with tens of thousands of sockeye salmon with 23 other like-minded and then float down river to the mouth. It was amazing fun. Being surrounded and jostled by countless salmon while swimming amongst them is an experience of a lifetime. The problem was that between these pools were sections of very fast water which by their very nature are filled with boulders that you may or may not be able to see, and if you can see them you may not be able to avoid them given that you are being hurtled along by an avalanche of water. No one was seriously injured on either day but I wonder whether or not that was due mostly to chance.

My real problem was that after the bumps of day one I didn't use all this wisdom I have theoretically accumulated in these 48 years to avoid them on day two. There would have been smarter ways to approach the rapids but I was caught up in the moment and didn't want to miss a thing. It sure didn't feel like I was missing a thing that's for sure as I smacked knees, elbows and had one mighty collision with my rib cage as I attempted to navigate one of the trickier sections of the river drove home that feeling. Mostly I made out alright, thanks to prophylaxis before the swims and after when I felt I had really got a good thump or two, and now I just need to wait for my contused rib to smarten up. I guess what I can glean from this experience is that it is important to feel like a kid now and then and careening down Campbell River accomplished that, but it is also important to employ some of that hard-won wisdom that is supposed to be one of the benefits of our advancing decrepitude.

For more info on freediving and the risks for us bleeders you can reach me at rickwaines@gmail.com. For amusement, you can check out my mockumentary, Campbell River Salmon Swim, at <http://vimeo.com/105776888>.

Tim Ireland, Langley, British Columbia

For me, practically any topic or event seems to trigger a song in my mind. So what about an article titled Ageing gracefully with haemophilia? Surely you can hear a song, can't you? It's Barbara Streisand singing in the movie *The Way We Were*: "Memories may be beautiful, and yet, what's too painful to remember, we simply choose to forget." I think that with those lyrics, the incomparable Ms. Streisand was revealing a dimension of true grace. That is, the act of forgetting the hurts and the pains encountered in life. So, in my attempt to live a gracious life, I remember no more. Nevertheless, for the sake of

this article, let me dig up a few aches from the corners of my mind. For any severe factor VIII haemophiliac of my age group – I'm just about to turn 60 – this shouldn't be too hard.

The sixties were the pivotal years of my life, covering Grades 1 to 10. For the first seven years, factor replacement therapy was limited to what two pints of plasma could bring. Immobilization was an additional medical strategy that attempted to limit the joint damage produced by the inadequacy of plasma. Consequently, I endured lengthy periods of hospitalization, two years of going to school in a wheelchair, on crutches and in a knee brace. Unfortunately, medical treatments of the day did little to prevent the many sleepless nights of tossing and turning from the pain of a grotesquely swollen, bleeding joint. I recall that the cruelest part of those nights was when I would finally find a comfortable position for the affected joint, start to fall asleep, and then have a dreaded pre-sleep "body jerk" shatter my peace. The pain and the tossing-and-turning cycle would start all over again.

During this time period, I can vaguely remember the dread of a shortened lifespan. My nine-year-old haemocousin Tommy had died from a bleeding septum from complications arising after a surgical procedure to aspirate his badly swollen knee. Yet, if I did have a fear of dying, it was relatively small and temporary.

Cryoprecipitate's arrival on the scene in 1967 was great news for bleeds; however, lengthy waits at hospital emergency wards still deepened something that is surely the biggest pain in any teenager's life: the horrible state of being different. My wheelchair days were bad enough, but at least they came during my preteens. For me, the typically slow delivery of cryoprecipitate at the emergency ward still meant a knee brace and crutches, and a prohibition from high school physical education. My complete assimilation into my peer group did not happen until the advent of home care in 1972. Taking full advantage of the opportunity to treat bleeds promptly ushered in my happy golden years of the 1970s, which ended with my attaining a physical education degree at the University of British Columbia.

In stark contrast to the '70s, the '80s were the darkest of times for all haemophiliacs. I can barely remember a fear of death when Tommy died in 1965, but it is rather easy to recall the choking anxiety of having to inject vials of factor VIII concentrate from 1983 to 1985. Surely each vial was tainted with HIV and surely I was going to contract AIDS – or so I thought. But I had no option other than to infuse.

Well, that's enough of digging through my cerebral archives. I did not get HIV and I am still here. But what does recounting painful incidents have to do with grow-



ing old gracefully? Well, let me take the liberty of rejecting a proposition asserted by a portion of Ms. Streisand's lyrics: "What's too painful to remember, we simply choose to forget." I do not think I've chosen to forget a thing. I believe that, for the most part, forgetting painful incidents is a normal and passive act. Except for severe traumas, forgetting pain just seems to happen, at least for most of us. To me, this is a type of "God thing" – an expression of our divinely created beings. I think we are built to forget, naturally.

On the other hand, choosing to remember pain requires constant effort and serves to bring anguish, not relief. For me, growing old gracefully is enabled by having vision unblurred by bitterness. Do I hurt now? You bet. Every time I get up off the couch, I move more like a crustacean than a human – at least until my right ankle decides to quit complaining. But, in context, I can see clearly the multitude of benefits in my life. I can envision the grief of the families of the haemophiliacs who did not make it through the '80s. I can see fellow haemophiliacs who are much more crippled than I am. Goodness. With the help of a few good anti-inflammatory pills, plus the wonderful effects of low-dose, daily factor VIII infusions, I can enjoy competitive games of doubles tennis three to four times per week. Certainly, I'm an object of great grace. Ageing gracefully is therefore the only reasonable way to live.

(Re-reading the last paragraph, can you hear Johnny Nash singing, "I can see clearly now, the rain is gone"? I can.)

François Laroche, Quebec City, Quebec

Growing old gracefully, even elegantly. Is this applicable to people with severe haemophilia? At first glance, it seems somewhat farfetched, however...

The fact is that as time advances, most people with severe haemophilia A of my generation tend to have their joints give out one after another. In my case, this was a process that saw its worst phase during my adolescent years, as a result of the many joint bleeds which afflicted me in my youth, when the treatments were less effective. I did not experience factor VIII concentrates until I was age 13; before that, fresh frozen plasma and then cryoprecipitate were my lot. Not to mention the knee joint aspirations for acute hemarthrosis. Ouch! If you've been lucky enough to avoid this type of indulgence, there's no need to chase after it... You're not missing out on anything, take my word! All this was followed by a long period of physical rehabilitation: leg immobilized for three or four days, sometimes in traction, and then, four or five days of physiotherapy awaited me before I could return home.

Nonetheless, this did not prevent me from living a fairly

active youth. I reckon this is due to the brain's selective memory. I played many sports – hockey, baseball, volleyball, golf, to name just a few – and got a better understanding of my limits, though not without the penalty of some visits to the hospital and all that comes with it. From these experiences, by circumstance and with the passage of time, I acquired a certain wisdom. I very quickly became aware that certain sports were more suitable to me than others.

Despite selective memory, the brain is not that masochistic. Golf, swimming and billiards have become my favourite activities, particularly in the last 15 years. In addition to travelling all over the world.

Over the past five years, however, despite prophylaxis with factor VIII concentrates every two days, my condition has gradually deteriorated. My right ankle and both my knees struggle more and more to support me. Long walks are synonymous with severe pain and climbing stairs has become a chore. I am no longer able to follow my children, ages 11 and 13. Not good.



So this year, I began a joint replacement process or fusion of my most affected joints. Total replacement of my right knee, implanted last July 11, has already started to change my life for the better. My left knee will in turn be replaced in November. After that, I will probably need to have arthrodesis of my right ankle.

After all these surgeries and operations, I'll let my charm do its work ... and it will work admirably, I'm sure. After all, unlike my knees, it's never let me down. That, perhaps, is ageing gracefully...

*Reprinted with permission from Hemophilia Today
www.hemophilia.ca*

Randall's really big bike ride for Haemophilia BLOOD, SWEAT & GEARS

Randall Stephens departed Melbourne in August last year on his epic adventure riding across Australia with the aim to raise money and to raise awareness of haemophilia. And that he has undoubtedly achieved.

As I write this Randall is currently just out of Adelaide with the home stretch in sight. What a mammoth achievement for anyone. And what a role model for all of us especially the young people in our community. Aim high and challenge yourself.

We look forward to hearing a full account of Randall's adventure on his return home.

You can support Randall by going to personalchallenge.gofundraise.com.au/page/Randall_Stephens

You can also access Randall's blog through his Facebook page.
www.facebook.com/randallsreallybigbikeride

Randall is a very talented poet. He's been published, broadcast and performed throughout Australia, and toured in New Zealand, Singapore, Malaysia and Borneo, and competed in slams in London as well as New York.

Together with filmmaker Alex Scott, Randall won the 2011 Queensland Poetry Festivals Filmmakers' Challenge, for their collaboration on an animated poetry film "I Statements".

Below is a poem titled 'Sometimes' recently written by Randall and taken from his facebook blog.



Sometimes

Sometimes you know you didn't deserve love in the first place. Almost as much as you didn't deserve the way it was taken away.

Sometimes you start paying for your mistakes before you even know what they are, and the not-knowing part becomes one of those same mistakes.

Sometimes it seems to make the most brutal, final and extreme sense to you. Causes, effects and all that cancelling-out here, as well-balanced as your bicycle. It's obvious, callous and reliable. Logic too perfect for anything as human as you.

Sometimes the world is too small, and the room you're in is too big. You've kept making space with all that ferocious creativity. You keep making it empty when you try and contain it.

Reaching out when you should be reaching in. Reaching in when you should be expressing the hurt away. Everything kept at arms length, yet held too tight to help.

Sometimes all you can do is mix this jazz off the radio with that sound of rain off the roof, and wind suffering the walls.

Sometimes all your clothes are wet the next day, the droughts never break right, and rest requires patience you can't find.

Sometimes you throw ugly nets out into the void and dredge up all that misplaced honesty, long thought lost to drowned sorrow. It's didn't go deep, it just wasn't buoyant enough to float.

Most of the time though, you're just lonely and doing the best you can about it.

Randall Stephens

ADVENTURE IN THE USA

Our family of four recently returned from a trip to Hawaii and Los Angeles. My husband and I travelled with our two sons, aged 9 years and 18 months. Our eldest son has severe haemophilia so we had to 'factor' in a few extra things like securing travel insurance for an existing medical condition, flying internationally carrying needles and clotting medication, refrigerating medication while staying in various hotels and infusing on the run.

We visited Waikiki Beach in Hawaii which was balmy and very festive, we swam at a waveless beach - we thought we'd leave the 60 foot waves to those fearless surfers! In Los Angeles we did some star spotting at the Hollywood Walk of Fame, played some air guitar at the Hollywood Hard Rock Cafe and strolled along Rodeo Drive in glamorous Beverly Hills. We cheered along at a baseball game at Dodgers Stadium. My husband and son scored a few touchdowns playing Grid Iron football together at Newport Beach. Disneyland really was the 'Happiest Place on Earth' for us and we all had a great time exploring the different 'lands' and experiencing some very high-tech and exciting rides.

Travel Insurance

I travelled to the USA with my son four years ago and ran into the problem of securing travel insurance for an existing medical condition like haemophilia. At that time we had success with Covermore who provided our son with medical cover for haemophilia-related issues for an additional fee. However, our application for cover with them this time was unsuccessful. We tried other companies such as Cuna Mutual and Medibank Private and got the same result.

We had success with Southern Cross Insurance who provided our son with unlimited medical cover for any haemophilia-related issues for an additional fee of approximately \$200. We thought this was a good deal for us considering the potential cost of admission to hospital in the USA. Fortunately our son had no bleeds overseas and did not need any hospital treatment.

Flying with factor

The Haemophilia Centre at the Children's Hospital provided us with a letter we could present to authorities if we had any trouble getting through airport security with our needles and clotting medication. The airlines like people to keep any medication nearby in case of a medical issue in flight, so we had to take the factor on board in hand luggage.

The airline had no space to refrigerate medication in

flight. We had the factor packed in with ice packs however by the end of the flight (9 to 10 hours later) the ice packs had melted so the medication was still cool, but not cold anymore.

Refrigeration of factor

Fortunately all the hotels we stayed at had small in-room refrigerators so the medication was kept cold. With the exception of the hotel in Los Angeles, where first the fridge had a meltdown and ceased to work, then I had a meltdown when I realised all the medication was no longer cold or even cool. My husband raced down to the reception desk and requested a replacement fridge and was told yes, he also asked if there was a fridge we could use in the meantime and he was told no. A construction worker who was renovating the bar area overheard our plight and said that while the bar was only half built, there was a perfectly working fridge there that we could use, so he saved our day in a big way.

Infusing on the run

My husband currently infuses my son with factor so on the trip they set up on the desk in the hotel room. We bought disinfectant to clean the desk surface and had our usual local anaesthetic cream, tourniquet, spare alcohol wipes, needles, cotton wool balls and band aids on hand.

We did a lot of walking on the trip, some days 2 or 3 hours and other days up to 6 hours, not to mention being thrown around a bit on roller coasters and white water rapids rides! So it was great to know that our son had factor on board when we went off on our daily adventures.

We travelled to a developed country, so it may be different for travellers to a developing country. But in our experience, our son's haemophilia didn't impact on us visiting any of the places we wanted to visit or doing any of the activities we wanted to do. For those of you thinking of travelling overseas with a child with haemophilia, I encourage you to go for it. It might mean a bit of extra planning and thinking on your feet while you're there, but hey that's something we in the bleeding disorders community are all used to!

Sarah Hartley - Haemophilia Foundation Queensland

This article was featured in HFQ's magazine 'The H Factor' and has been reprinted with permission.

2014 FAMILY CAMP

For those of you that attended our 2014 HFV Family Camp we very much hope you had an enjoyable, relaxing and rewarding experience.

We are very lucky to have such a dedicated team on our committee as this camp was organised by our newly formed camp sub-committee. They were very driven to rework the camp to have a more united HFV feel. There was much involvement from our committee, staff and youth leaders in all aspects of the camp - which in the previous few years many aspects of had been outsourced.

This was an opportunity for us to reconnect with our members and show our community that HFV is actually just the sum of the people involved - our members. The committee was very thoughtful in their process and decision making to provide an inclusive camp where all members in attendance felt supported and very much part of our unique community.

Of course we had a few issues - the sound system for one - and we learnt some lessons along the way but overall the committee really did an excellent job and we will be moving forward to the 2015 camp with enthusiasm, insight and a keen sense of community and look forward to seeing you there - and hopefully some new faces!

So thank you to our sub-committee and Andrea McColl for piecing together such a lovely weekend away for our families.



Crutches Drive a huge success THANK YOU!!!

Abi Polus

*Senior Clinical Physiotherapist - Haemophilia
Alfred Health*

I have just returned from our WFH haemophilia twinning visit to the National Institute for Haematology and Blood Transfusion (NIHBT) in Hanoi. This is the centre's 4th year of twinning and my 3rd visit to the centre.

Over the past years of the twinning program, the importance of physiotherapy in haemophilia and the assessment and management of physiotherapists working with people with haemophilia in Vietnam has been discussed. Additionally education of patients and their families regarding what they can do to help themselves to preserve their joints and their function has been an important topic. The use of crutches is a standard practise in the management of a bleed. There has been emerging evidence



that weight-bearing on a joint that has a bleed may accelerate the arthritis process, which is why we encourage gait aid use during a bleed, in addition to decreasing the risk of re-bleeding by walking on the bleeding joint and the pain.



One of the main issues that became apparent when we spoke with staff and patients was that the cost of crutches, which for many patients is prohibitive. This meant that during the acute pain period during a bleed (during which time the patient may or may not have been able to access a clotting factor or cryoprecipitate), they would have to walk on an exquisitely painful joint or else not move from their house, be carried by a family member or crawl. The functional and social aspects of this may be huge.

Similarly compression bandages, which can decrease the size and intensity of a bleed if applied early were also prohibitively expensive to many, despite being \$2 each.

Haemophilia Foundation Victoria, along with funds raised by Donna Field through Haemophilia Foundation Australia's Red Cake Day Awareness Campaign donated a sum of \$1000 to take to Vietnam to purchase equipment, specifically for this purpose. It enabled the purchase in Hanoi, of 70 pairs of crutches, 5 walking frames, and 50 compression bandages. Along with education on how these may benefit patients and best practice of use, these were presented to the National Institute of Haematology and Blood Transfusion, for the use of haemophilia patients. This will vastly enable improved self-care and management of bleeds for patients who were prohibited by cost from accessing equipment.

Obtaining the equipment was an experience. We had worked out that it would be more cost effective to purchase equipment in Vietnam, but my haggling and my maths skills – in Vietnamese - leave a lot to be desired! I did have help through wonderful interpreters, but the process took hours, with people racing off on bikes and bring back crutches – 20 pairs strapped to the back of one motorbike, 5 frames to the back of another. And then trying to source bandages, and then even more bandages from elsewhere. It was hilarious. Luckily we had a van whose boot slowly filled up with crutches.

The joy on faces was humbling when we returned to the hospital with the booty. Patients were so grateful, walking patterns immediately changed and grimaces of pain on faces eased. The hospital and patients alike were effusive with thanks. This is a donation that will, very literally change lives. A heartfelt thank you to HFV, Donna Field and all involved in this wonderful donation.



2014 Melburnian of the Year: Professor Sharon Lewin

Professor Sharon Lewin is an infectious diseases physician and scientist and is internationally renowned as one of the leading research scientists on HIV and AIDS.

Professor Lewin is the inaugural Director, Doherty Institute for Infection and Immunity at the University of Melbourne and The Royal Melbourne Hospital. Prior to this, she was Head of the Department of Infectious Diseases at Alfred Health and Monash University; and Co-Head of the Centre for Biomedical Research, Burnet Institute in Melbourne.

The Doherty Institute has a major focus on diseases that pose serious public and global health threats such as HIV, viral hepatitis, influenza, tuberculosis, Ebola virus disease and drug resistant bacteria and hospital associated infections. Professor Lewin's research focuses on understanding how HIV persists in patients on antiviral therapy, strategies to cure HIV infection and biological determinants of immune recovery following antiviral therapy and the pathogenesis of HIV-HBV co-infection.

Professor Lewin was the Local Co-Chair for the AIDS 2014 Conference held in Melbourne in July 2014 – the largest health and development event ever held in Australia, with 13,600 delegates attending from over 200 countries, with Sir Bob Geldof and Bill Clinton as keynote speakers. It was the first time in 10 years since the International AIDS conference was held in the Asia-Pacific.

The highly-anticipated event put Melbourne firmly in the international spotlight. Many of the attendees at AIDS 2014 were there entirely due to Sharon's appointment as Co-Chair and her unrelenting drive to educate and advocate on behalf of the HIV/AIDS community. At the Conference, Sharon was hailed by the International AIDS Society as one of the



most influential campaigners and researchers in the world – not an appellation that comes lightly.

Professor Lewin is frequently asked to speak internationally and she is passionate about both her work and also Melbourne more broadly. She is an extraordinary advocate for the HIV community, research community and is always ready to promote Melbourne in terms of medical research.

www.melbourne.vic.gov.au/AboutMelbourne/MelbourneAwards/Pages/MelburnianoftheYear.aspx

IMPORTANT!!!

HEPATITIS C: HELP HFA WITH THE GOVERNMENT INQUIRY

Are you an Australian with Hep C and a bleeding disorder? Or a partner/family member?

Please help HFA to tell the Australian Government what impact hepatitis C has on you and your life – and what strategies would help to improve your situation.

The Australian Government House of Representatives Standing Committee on Health is conducting an inquiry into hepatitis C in Australia - www.aph.gov.au/hepatitisC. HFA will make a submission on the issues for the bleeding disorders community.

HOW CAN YOU HELP?

We need your help with real life examples for the HFA submission.

Please take 5 mins to complete the HFA hep C member survey and tell your story.

Please complete the survey by **Friday 13 February 2015**.

WHAT IS THE INQUIRY INVESTIGATING?

The Inquiry is looking at particular issues, including:

- How common hepatitis C is in Australia
- The costs associated with treating the short term and long term impacts of hepatitis C
- Methods to improve prevention of new hepatitis C infections
- And methods to reduce the stigma with a positive diagnosis through:
 - The public health system
 - Public health awareness and prevention campaigns
 - Non-government organisation health awareness and prevention programs.

You may also wish to make your own submission.

The deadline for submissions is Friday 27 February 2015.

For more information, go to www.aph.gov.au/hepatitisC.

www.surveymonkey.com/s/5D2PX3K

STEPPING UP: A Strong Youth Leadership at HFV

At the 2014 WFH World Congress we heard a great deal about the importance of a strong youth involvement for National and State Foundations. We had the opportunity to hear from various youth participants from all over the world about how they connected with their foundation, why they were involved and what they hoped to achieve.

It was at this point I felt a small sense of disappointment that we didn't have our HFV youth up there on the stage presenting. The congress was in our city - on our turf and we really do have a great group of youth leaders, who are inspiring others getting involved and taking ownership.

Many of our youth were at the same sessions I attended and the congress obviously made a huge impression on them as we have since seen the development of the Haemophilia Youth Network by Tim Demos and Natasha Ritchie and we had the pleasure of witnessing HFV youth led sessions at the 2014 Family Camp.

We see this as a really important opportunity for our youth to not only connect with their peers but have the opportunity to build their skills in leadership, communication, collaboration, social awareness to name a few. It gives our youth a sense of ownership over the camp and other events they are involved in and it makes them feel more connected with us as a foundation. They are our future leaders.

If you or your child (youth aged) would like to step up and be involved in our new Youth Initiatives, including the youth led sessions at the 2015 family camp please either call or email me. Alternatively you can speak to our youth leaders directly at camp.

Hope to see you there.

Julia Broadbent



HAEMOPHILIA YOUTH NETWORK (HYN)

The Haemophilia Youth Network (HYN) is an exciting new initiative being developed by HFV youth to give youth an opportunity to develop their skills and make a meaningful contribution to the bleeding disorders community in Victoria. The HYN is an ongoing project with the first stage involving the formulation of the Haemophilia Youth Committee. The HY committee will be a recognised part of the HFV team and give youth greater responsibility in assisting HFV with various activities and events while also giving direct feedback to HFV about how to better engage young people. Potential committee members are in the process of being contacted so if you are a youth with a bleeding disorder or family member/friend of someone who has a bleeding disorder and are interested in becoming involved please contact me (Tim) via the HFV team on 9555 7595 or email info@hfv.org.au. Tim Demos



2015 HFV FAMILY CAMP



FEATURING:

- **YOUTH TRAINING WORKSHOPS**
- **YOUTH LED PROGRAMS**
- **THE NEERIM BOWER –**
INSPIRED BY BIRDS



WHERE: Forest Edge CYC
405 McKenzie Road, Neerim East

WHEN: 27th - 29th March 2015

WHY: Meet other families affected by bleeding disorders

WHO: All family members who would like to attend,
young and old! **ALL INVITED**

- Heaps of fun activities, meet new people, catch up with old friends, share stories
- Discover new ways to care for yourself and your family
- Relax and unwind... 'Time out' socialising sessions, plenty of games
- All meals supplied from Friday evening dinner to Sunday lunch
- Comfortable accommodation (private rooms with bunk beds) with shared bathroom facilities



SUBSIDISED CAMP FEES TO CURRENT HFV MEMBERS:

\$150 per family, \$80 per extra single adult over 18 yrs

Please complete the included form or contact HFV on 9555 7595 for more details.

HOPE TO SEE YOU THERE!

VAUGHN RIPLEY: MAN IN MOTION

When Vaughn Ripley heard about the Men's Health Ultimate Guy fitness competition he joked to his family that he should enter. As a devoted health advocate and trainer, it was not an absurd idea that he would be considered for the top prize and featured on the magazine's cover.



Vanessa Herrick
WFH COMMUNICATIONS MANAGER

What makes his story unique is that Ripley's motivation to enter was not to raise his personal profile in the health and fitness world but to raise awareness and advocate for two other communities to which he has a deep connection. The first being that he was born with mild haemophilia A and the other community he learned he belonged to during the tainted blood scandal that broke in the 1980s when doctors told him he had less than two years to live.

He was just 17 years old when he learned he had been infected with the HIV virus from a blood transfusion. "My doctor could not look at me when he told me. He stared at the floor," he remembers. "He finished with...and you have less than two years to live. It was devastating to hear, especially as a teenager."

Choosing a Positive Life

The impact of his HIV positive status had serious implications for Ripley and his family. "We were all in shock. Because of the stigma we were afraid to discuss it outside of the family. When neighbors did find out, we started receiving crank calls and even death threats. Someone even threatened to burn our

house down if we did not move out of the neighbourhood and our community swimming pool kicked me out. It was a tough time for sure."

The following years were a very dark time and Ripley credits his then girlfriend and now wife with helping him through it. When asked about having outlived his prognosis by nearly two decades and his approach to life, he recognizes that facing death opened his eyes to living "with more zing!"

"I am a born fighter and I see life as a battle at times. This excites me and motivates me to try even harder." His secret to healthy living and dealing with both his HIV and his haemophilia is what Ripley calls his survival pie. "It is my belief that you must do a combination of things to live through, survive and thrive despite a life-threatening illness. Survival is essentially a balance of family, work, fitness, good nutrition, meditation, spirituality, positive thinking, surrounding yourself with positive friends and daily gratitude."

Ripley has developed his health regimen over the past two decades and is often approached by others looking for health advice. "I constantly get questions from the bleeding disorder community, people looking for advice on training as it can really curb

bleeding episodes.” He started writing blog posts but it felt restrictive to try and “pack it all into one post.” He sees the value in blogging but realized that videos would be more efficient and instructional.

“It would give people a real visual sense of what I am talking about. My thought was a video would be more powerful and YouTube provides a perfect forum. You can upload videos for free and they are available to folks for free.”

Paid Forward and Back

The idea of access appeals to Ripley and while he is aware that he could have created DVDs that focus specifically on joint health and marketed them, it did not sit well to charge a fee when the motivation behind the project is to help others. He has developed outlines for 18 videos and will begin to shoot and upload them to YouTube soon.

Ripley may be feeling particularly indebted to the community these days after the extraordinary amount of support he was given after deciding to make the leap and enter the Men’s Health competition. “I had no idea that so many people in the haemophilia and bleeding disorders community would step up and vote for me.”

GETTING OUT THE MESSAGE

Ripley not only entered the Ultimate Guy competition, he held first place in the public voting for two months straight and even had other competitors contact him and tell him they were rooting for him. “It was humbling and awesome!” He accumulated over 15,000 online votes. While Ripley did not win the competition, the editor of Men’s Health felt his story was compelling enough for a profile article in their upcoming November edition. When asked what advice he would pass on to a young person with a bleeding disorder Ripley speaks from the heart as he has a young daughter with mild hemophilia A. “Break free of the chains that would have you believe that you are disabled or incapable of doing great things. The sky is the limit for people and you are no different.”

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World Federation Hemophilia www.wfh.org.au

BLOOD BROTHERS CAMP 2015

- **ARE YOU AGED 12-25?**
- **ARE YOU A GUY WITH A BLEEDING DISORDER?**

**COME AND JOIN OTHER
YOUTH FOR AN AWESOME
WEEKEND AWAY AT OUR
4TH BLOOD BROTHERS
CAMP.**

All accommodation and food is provided and transport is available from the HFV office.

Booking are essential through the office.

Not been before? You or your parents are welcome to speak to our office staff or our HFV Youth Leaders before you book. Please call 9555 7595.

LOCATION: To be confirmed

DATES: To be confirmed (before the end of June)

Please check our website for updates.www.hfv.org.au

SEXUALITY

Congress opens the door to talk about sexuality

The subject of sexuality might make some people uncomfortable yet it is a subject that is important to us all. For the bleeding disorders community, it is something that must be talked about in an open and straight forward manner. For many people though this is easier said than done.

At the WFH 2014 World Congress, the subject of sexuality and bleeding disorders was open for discussion during several sessions and poster presentations. Ed Kuebler and Declan Noone spoke during their session titled, Sexuality and Risk Reduction, Greig Blamey and Alfonso Iorio presented their free paper on Investigating attitudes and practices of Canadian physiotherapists on sexual health: A comparison to the HERO dataset; an entire session was devoted to the subject of Embracing Women's Sexuality with Claire McLintock, Jill Smith, Lisa Thomas all speaking on a variety of topics around women and sex, and several posters were displayed. (Addressing the sexual wellbeing needs of adolescents with haemophilia; Sex life and self esteem in adults with haemophilia; and Love, sexuality and communication in haemophilia: A psychosocial and patient perspective book developed for adolescents, adults, and carriers.)

These presentations and discussions were an important step in addressing a relevant issue for everyone in the bleeding disorders community.

For psychologist Frederica Cassis, WFH psychosocial committee member and longtime WFH contributor, sexuality is not only about the act of sex, it is about well-being, whether you are single or in a relationship, celibate or sexually active, a parent or without children. To be desired, cherished and loved is universal to the human experience and these feelings are no different for the young and not so young living with bleeding disorders. For Cassis it is vital to begin having this discussion with young people with bleeding disorders as soon as possible to remove the stigma attached to sex, because not talking about it with young people can lead to a whole host of issues for the one with the bleeding disorder and for their partners.

One of the most common feelings expressed by peo-

ple with bleeding disorders when it comes to sexual intimacy is insecurity; insecurity about one's physical appearance, insecurity about bleeds, and a general insecurity about the act of sex. This rings true in both men and women with bleeding disorders. Issues that can also affect wellbeing are brought about by limitations in movement due to fatigue, chronic pain, side effects from medications, as well as a lack of confidence in their appearance due to joint damage and the potential for a painful bleed. These may lead to a lack of desire and depression. These are things that go through the mind of every single person with bleeding disorders at some point in their lives but the hope is that through open discussion and education, the insecurities can (slowly) be cleared away.

These concerns people have are real and they need to be addressed so people have the tools to face their problems. Ignorance breeds fear, and not having proper information and counselling can lead people to feel isolated and alone. Psychologists like Cassis suggest that people with bleeding disorders should talk to a professional as early as possible to obtain information but also learn communication skills that would help improve the quality of relationships.

"Being able to mention these issues and others in a setting, either through counselling, with a parent, or with a doctor, can be very helpful because the person could learn to cope with these difficulties," said Cassis. "A lot of people's concerns are about how to communicate these issues related to health to a partner and still give off a positive self-image to others." The goal of having sessions and discussions like those at the recent Congress in Melbourne is to open up the discussion and break the stigma, starting with those on the front lines of care having the right information who in turn pass it down to the patient in all corners of the globe.

"It is not about telling people how to have sex, but

about giving the most useful information to someone with a specific issue, so he/she can have the right mind set (and information) to fully enjoy the heat of the moment,” said Cassis.

The good news for the community, as the data shows from the HERO (Haemophilia Experiences, Results and Opportunities) study, people with haemophilia in sexual relationships have an overall high rating of satisfaction in their sex lives and that with a little knowledge they don’t have to feel like they are not normal. From 675 PWH who answered in the HERO quantitative study;

- 384 PWH were in relationships;
- of these, 324 (85%) answered questions regarding sexuality and intimacy;
- 78% (236 of 303) responded they were extremely/moderately satisfied with the overall quality of their sex life.

Frederica Cassis, Irene Fuchs and Edward Kuebler have worked together to produce a booklet on the subject of sexuality and haemophilia that is currently only available in Spanish.

English and Portuguese editions will soon be available. The booklet’s name is Amor, Sexo y Comunicación en hemofilia or Love, Sexuality and communication in hemophilia.

Jay Poulton, WFH EDITOR/EDITORIAL SERVICES COORDINATOR

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www.wfh.org

SAVE THE DATE...!

17TH Australian & New Zealand Conference on haemophilia & related bleeding disorders



1 - 3 OCTOBER 2015 • GOLD COAST

THE GENETIC SUPPORT NETWORK OF VICTORIA (GSNV)

Invites its community to get involved and raise awareness for genetic support.

The GSNV will be facilitating our annual Genetic Support Awareness Week (GSAW) from February 23-27 2015. GSAW strives to raise awareness about living with a genetic condition and to support people affected by genetic conditions through activities which are held throughout the week. As an activity in the GSAW 2015, we are seeking to visually display the human face of genetic conditions. Your visual interpretations of life with a genetic condition will assist the GSNV in developing a tapestry of the genetics community.

Support is an important component in understanding and managing genetic conditions. However, public awareness and the value of support services are lacking and the people affected and those providing support are often faceless.

The aims of the “Facing Forward” campaign are to give the public a visual insight into the ‘people’ affected by genetic conditions and to raise awareness of the importance of support services in genetic health. Over Genetic Support Awareness Week, the GSNV will be using social media as a wide reaching platform to showcase the people behind genetic labels.

The GSNV invites you to ‘Face Forward’ and submit a photo that represents your experience.

HOW TO SUBMIT YOUR PHOTO:

Please submit your photo along with a caption of 25 words that reflects your journey. You can submit your entries via email to info@gsnv.org.au with the subject line “Facing Forward”. By submitting a photo you are consenting to the GSNV reproducing the photo and caption during GSAW on our website, Facebook, Twitter and electronic communications.

World Hemophilia Day APRIL 17, 2015

Building a family of support

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate. World Hemophilia Day provides an opportunity to talk to your extended family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder.

You can also go one step further and have a local landmark, a light in your home or office, or your front porch light lit in red on April 17 to show your commitment to the bleeding disorder community.

This year connect the global bleeding disorder family on the World Federation of Hemophilia social media network and encourage your online community to join the global family.

HFV encourages you to get involved and email your ‘red light’ photos to info@hfv.org.au. We will then publish the photos in the May edition of The Missing Factor.





HAEMOPHILIA FOUNDATION VICTORIA



2015 Royal Children's Hospital HAEMOPHILIA TEACHER'S SEMINAR

TEACHERS - you are invited to attend the 12th Haemophilia Teacher's Seminar presented by the Haemophilia Treatment Centre Team at the RCH. Supported by Haemophilia Foundation Victoria.

When: 9am to 12pm on Friday 27th February 2015
Where: Vernon Collins Theatre, 1st Floor, Royal Children's Hospital

PURPOSE...to educate, inform and reassure

Comments from teachers that attended last year...

- Haemophilia is not something to be scared of!
- I feel assurance that promoting physical activities is the right thing to do
- Listen to the child, he knows his own body
- I now have the confidence to know what to do
- Not to treat kids with haemophilia any differently
- I now know what I need to have in place as my role as his teacher
- The boys were incredible and their stories really highlighted everything spoken about
- I am now comfortable with myself and the idea that I will have to assist our little boy
- I feel much better about dealing with my student in a "non over anxious way"

Speakers:

Dr Chris Barnes -
Director of Haemophilia Treatment Centre

Janine Furmedge -
Haemophilia Clinical Nurse Coordinator

Nicola Hamilton - Physiotherapist

Special Guest Speakers:

A primary and secondary school child
with Haemophilia



Contact HFV on 9555 7595 for more information

HFV BURSARY 2015

Applications for HFV education bursaries have now opened. Please refer to the enclosed application form and guidelines for more information. Copies are also available on our website at www.hfv.org.au

HFV committee of management are currently reviewing policies with respect to applications for bursary and living well grants. Any change to process for future applications will be announced in the next newsletter.

Bursary Categories for 2015:

School year Kindergarten	up to \$400 per award
School years Prep-9	up to \$500 per award
School years 10-tertiary	up to \$600 per award
Adult education	up to \$600 per award

our community

2015 HFV Men's Retreat

When: 13th -15th March

Where: Lochinver Farm Homestead and Cottages,
Carisbrook

If you have a bleeding disorder and you are over the age of 25 why not join Zev Fishman from our committee and other members of HFV for a long weekend of relaxation.

Recharge your batteries in a comfortable environment and have the opportunity to enjoy the company of other guys from our community.

Bookings essential, either through the HFV office on 03 9555 7595 or contact Zev for more information on 0419 552 695.



All food and accommodation costs covered for all current HFV members - new members welcome! Free membership for the 1st year!



quickbeds

Grassroots Fundraising Program
Supporting local sport & community groups

BRANDSPOT FOR SALE BY THE
**FLIGHT
CENTRE**
TRAVEL GROUP

Haemophilia Foundation Victoria is now part of the Quickbeds Grassroots Fundraising Program. This is a great opportunity for our organisation to raise funds.

IT'S VERY SIMPLE!

Next time you are booking accommodation, go to Quickbeds, use our unique Grassroots Code: **1215** and you'll be helping our organisation.

Thank you.

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 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



WORLD HEMOPHILIA DAY | APRIL 17

BUILDING A FAMILY OF SUPPORT

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate.

WORLD HEMOPHILIA DAY 2015 | APRIL 17



wfh.org/whd



facebook.com/wfhemophilia



@wfhemophilia

Follow the latest World Hemophilia Day development at #WorldHemoDay



WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia



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