

# THE MISSING FACTOR

*GROWTH PATTERNS  
A personal perspective  
on living with  
Haemophilia & Hep C*

**DIANA HARTE:**  
*Clinical Psychology  
at the Ronald Sawers  
Haemophilia Centre*

## STRETCHING & BLEEDING DISORDERS

Understanding the importance of stretching



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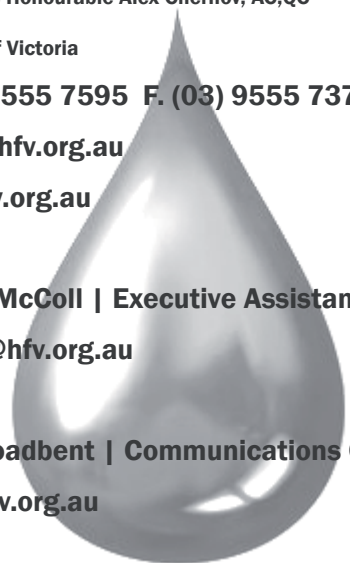
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## DIARY DATES

Grandparent's & Friend's Lunch —  
Sun 2nd Aug

Peer Training —  
Sat 29th to Sun 30th Aug

Ballarat (Creswick) Regional Visit—  
Sun 30th Aug

National Haemophilia Conference —  
Thurs 1st to Sat 3rd Oct

Haemophilia Awareness Week —  
Sun 11th to Sat 17th Oct

Ladies Day —  
Sun 18th Oct

2015 Blood Brothers Camp —  
Fri 20th to Sun 22nd Nov

HFV Remembrance Service —  
Sun 29th Nov

Family Picnic & AGM —  
Sun 29th Nov

## Committee of Management

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### Treasurer

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Karen Donaldson

Carol Ebert

Donna Field

Jodie Caris

## A word from *our* president, Leonie Demos

Winter has hit us with cold snaps and snow for some. However the days are getting a bit longer and a few spring bulbs are peeking out of the soil so not long until warmer weather and all the beauty Spring brings.

It might be cold outside but the team at HFV have continued to be very busy. The Strategic Plan is taking shape and the Committee are excited about the focused direction the service is heading. The constitution has been updated and the committee look forward to presenting the new constitution to our members at our AGM in November. I know there are not many of us that get excited about the paperwork such as constitutions etc but they are both crucial documents to help us plan for the direction of HFV and ensure our funders and stakeholders have confidence in us to grow and reach challenges as they may arise for our community.

Both Julia and Andrea have had a well deserved break. Planning is in full swing for the Peer Support training next month. HFV are really trying to connect and support to our members in regional areas. For this reason this training will be in Creswick and we are hoping as a result we will be able to develop a network of peer support members across Victoria. This will allow HFV opportunity to hear the issues and for HFV to be able to conduct regional visits

and know there are trained peers on the ground to assist.

There are other exciting projects being discussed also. As an example...drama workshops, improving employment outcomes and a fishing excursion of the ocean sort... Hopefully I have wet your appetite to read the newsletter and to get in touch with HFV to hear more about the upcoming plans.

In the meantime stay well and warm and most importantly stay in touch!

Leonie Demos

## HAEMOPHILIA AWARENESS WEEK

11th -17th Oct 2015

Help raise awareness of haemophilia and related bleeding disorders by holding a Red Cake Day event.

Contact HFA on  
1800 807 173  
for promotional items such as balloons and posters etc  
or go to

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

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.

# STRETCHING & BLEEDING DISORDERS

We listen to people telling us that stretching is essential before and after exercise, but have you thought about why it is significant and how stretching can help. Importantly for us: does stretching further assist people with bleeding disorders?



[www.stretchify.com](http://www.stretchify.com)

An article in the Journal of Haemophilia in 2010 highlights the importance of exercise programs for people with Haemophilia. The programs are usually designed and implemented to help manage the recovery after a haemarthrosis or a muscle bleed. The importance of an exercise program is also used as a tool to help prevent bleeding episodes from occurring.

Stretching is an important and individual component of exercise and conditioning. It is also only one of many elements of exercise: others being strength, kinesthetic sense (informs the body of its position in space), balance, overall function and flexibility. These elements, when combined, form what is required for optimal impact. (1)

### What happens to muscles when they are stretched?

When a muscle belly is stretched, some of its fibers lengthen, but other fibers may remain at rest. The length of the entire muscle at any given time, depends upon the number of stretched fibers. The more fibers that are stretched, the greater the length developed by the stretched muscle. (3)

The ability to comfortably lengthen muscles during sport or activity, combined with a thorough warm up and stretch prior to activity is important. It will result in less over stretching and trauma to the muscles when they are dynamically (or statically) contracted or stretched in movement.

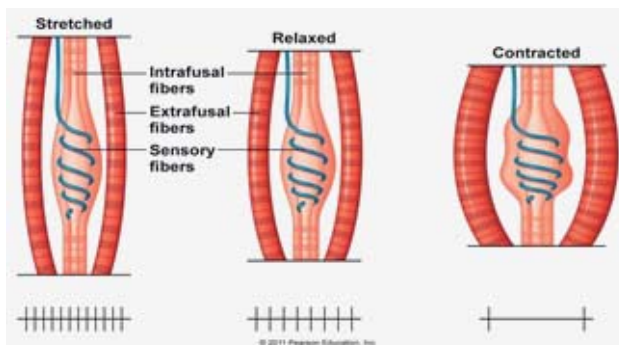


Diagram of a muscle belly stretched, relaxed and contracted.

<http://www.stretchify.com>

For example, playing a game of soccer and the action of kicking the ball.

The contraction of hip flexor muscles and quadriceps muscle group will occur during the initial phase of kicking a soccer ball (also named the agonists). It is a quick dynamic action. Simultaneously the muscles at the back of the leg, the hamstrings, gluteals and calf muscles will be dynamically stretched (antagonists) to allow for the kicking action. This is a simplified example of why it is important to have the flexibility in certain muscle groups to decrease the chance of muscle tears and joint trauma.

This is important not just in sports but also in every day life. Think about the dynamic and functional movements achieved during each day- walking up and down stairs, vacuuming (well, sometimes), lifting heavy objects, reaching overhead to hang the washing, running around during recess at school to let off some steam.



<http://www.footballmedicine.net>

### Benefits of stretch training

Stretching skeletal muscles and joints will have intrinsic benefits by:

- Increasing blood flow to the suitable muscle groups
- Relaxing stretched muscles
- Removing metabolic waste- improving circulation and blood flow to the targeted muscles help removal of waste products such as lactic acid in muscles post exercise. This is useful for relieving post-exercise soreness.

Stretch training extrinsic benefits include:

- Improving performance (of sport/exercise)
- Warming up prior to sports or activity to reduce or prevent injury
- Decreasing muscle soreness
- Gaining range of motion (1)

### Types of stretching

**Static stretching:** slow or passive stretching, allowing stress-relaxation to occur with a gradual reduction in tension as a stretch is held at a constant length over time

**Ballistic stretching:** bouncing motions or swinging a limb with momentum to stretch a muscle group. This causes the facilitation of the stretch reflex, and could injure the muscle fibres.

**PNF (proprioceptive neuromuscular facilitation) stretching:** also called a contract/relax stretch, uses a combination of a hold contraction (isometric) and a static stretch. PNF stretching follows the theory of reciprocal inhibition: the process of muscles on one side of a joint relaxing to accommodate contraction on the other side of that joint.

### How much is too much – can we injure ourselves stretching?

As previously mentioned, proprioception (kinesthetic sense) is one of the important elements of exercise and movement. It informs the body of its position in space. Information is sent from the muscles, tendons, ligaments and joints back up to the spinal cord and the brain to work out the degree of length, tension or pressure in these tissues. The brain then responds and causes appropriate muscular contractions to control our position in space and prevent injury.

This is important when we put these tissues under stretch, dynamically or statically.

We have a wonderful system called a “stretch reflex” which prevents over-stretching and tearing of muscle fibres. When a muscle is stretched, especially stretched quickly like a strong hamstring stretch at the end phase of kicking a ball, a message is sent to the spinal cord and brain. This initiates muscular contraction and decreases the (over) stretch of the muscle.

Having these systems in place and the knowledge of these reflexes help us establish proper and safe stretching techniques.

**Keep stretching controlled and slow,  
hold for a longer period of time  
Limit fast paced less-controlled  
(ballistic) stretching**

### Recommended stretching routine for bleeding disorders

- According to Haemophilia Health in the UK, a recommended warm up and cool down (5-10mins) and stretching session (5-10mins) should be done pre and post all exercise or sport and should concentrate on the muscle groups that will be used during the activity. (2)
- Static stretching and PNF contract/relax techniques are best for increasing range of movement.
- Static stretching: holding each stretch is recommended for 15-30 seconds with 3-4 repetitions. Programs may be performed daily or at least 2-3 times per week for sustained increases in range of movement.
- PNF stretching can be performed 1-2 sessions weekly, and even one rep can acutely increase ROM from 3 to 9 degrees, dependent on the joint (5)

Overall conditioning, including stretching exercises are a valuable tool for keeping us as healthy as possible, and assisting in reducing the risk of an injury. It is an important routine to establish, a vital component for management of bleeding disorders in everyday activity and sport.

For further information, contact your local Haemophilia treatment centre who will direct you to the appropriate Haemophilia Health Professional for assessment and management.

### Karen Donaldson Physiotherapist & HFV Committee Member

#### References

- (1) Blamey, G. et al (2010), Comprehensive elements of a physiotherapy exercise program in haemophilia – a global perspective. Haemophilia The Official Journal of the World Federation of Hemophilia, 16: 136-145. Doi:10.1111/j.1365-2516.2010.02312.x
- (2) Haemophilia Health. Tips for starting a new exercise regime. www.haemophiliacare.co.uk
- (3) Rassier, D.E. (2007), Stretching Human Muscles Makes them Stronger. Journal of Applied Physiology
- (4) Knudson, D. The Biomechanics of Stretching. Department of Kinesiology, California State University, Chico.
- (5) Sharman MJ, Cresswell AG, Riek S. Proprioceptive neuromuscular facilitation stretching: mechanisms and clinical implications. Sports Med 2006;36: 929-39.

## CLINICAL PSYCHOLOGY at the Ronald Sawers Haemophilia Centre

Diana Harte, Senior Clinical Psychologist, has recently started working every second Tuesday at the Ronald Sawers Haemophilia Centre, at the Alfred

Diana has extensive experience working with people across the age span. She has worked in various settings including the Royal Children's Hospital, youth drug and alcohol, public mental health, cystic fibrosis, HIV/AIDS and with older adults who have chronic diseases. Currently she divides her time between the Alfred and private practice.

Aside from seeing people at the Alfred, Diana is also available by phone and email to consider if and how psychology may be of benefit. She can also try to assist people to consider what local community options may be available to them to access psychology, mental health, and counselling services.

As almost half of all Australians will experience a mental illness at some point in their lives but less than half of those will receive treatment, Diana is keen to implement a mental health screening as part of the annual review process. The goals of screening are to increase understanding of the mental health of individuals who have Haemophilia as well as facilitate timely and appropriate treatment. Additionally the information gained through a screening program could potentially assist in advocating for increased psychosocial services (psychology, psychiatry, social work, occupational therapy).

Diana is always interested to hear from people and welcomes your thoughts as to what you would like from a Haemophilia Clinical Psychology Service.

Diana can be contacted on alternate Tuesday's on 9076 2179 or D.Harte@alfred.org.au.

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### Who are Clinical Psychologists?

Clinical Psychologists work collaboratively with people on a range of issues ranging from everyday problems to serious episodes of mental illness.

Psychologists can help you build on your personal and unique strengths, as well as supporting you in learning new skills.

### Why would I see the Haemophilia Clinical Psychologist?

To gain assistance with:

- Adjustment to Haemophilia
- Thinking about if you need to, and how to tell people (friends, partners, employers) that you have Haemophilia
- Difficulty in committing to treatment recommendations
- Needle phobia
- Stress
- Worry about starting a family

People also talk to psychologists about:

- Dealing with emotions like anger, depression and anxiety
- Grief and loss
- Sleep
- Loneliness and social isolation
- Trauma
- Goal setting and taking action
- Troublesome habits

### What does seeing a Clinical Psychologist involve?

Contact with a Psychologist will have an assessment phase and may be followed by a treatment phase.

The assessment phase involves gaining a detailed understanding of your concerns and difficulties as well as your goals and expectations. As part of the assessment questions will also be asked about your family background. Consideration will also be given to linking you into community based services.

In the treatment phase you may be asked to complete tasks and try out strategies between appointments, to help you achieve your goals.

### What happens about the information I tell the Haemophilia Clinical Psychologist?

As with all health professionals Clinical Psychologists are legally required to keep records of their contact with you. At Alfred Health the information that is obtained about you is kept as an electronic medical record. The recording and access to your records is in keeping with relevant government legislation, and also to ensure the continuity of your treatment.

With your consent your Clinical Psychology Assessment and Discharge Summary will be forwarded to

your GP and other relevant health care professionals.

For further information about your privacy and confidentiality please refer to the relevant Alfred Health information brochures.

### **Where do I see the Haemophilia Clinical Psychologist?**

The Haemophilia Clinical Psychologist is based in the Ronald Sawers Haemophilia Centre at The Alfred. The hours are currently limited to every second Tuesday between 8.30 am and 5pm. Work is underway to consider how to expand access to clinical psychology including considering Skype/internet sessions.

### **How many times can I see the Clinical Psychologist?**

The frequency and length of contact is negotiated with the Clinical Psychologist as part of the assessment phase. At times, contact will not continue once the assessment has been completed.

### **Do psychological treatments work?**

“Research shows psychological treatments are effective in managing many common mental health disorders” [www.psychology.org.au](http://www.psychology.org.au)

Psychological treatments certainly do work, but not always. There are many people whose lives have been improved beyond recognition as a result of seeing a psychologist. Others know that they have, at least, experienced some benefit. The good periods may last longer and the bad times may be more manageable.

Your own attitude will make a difference. If you go along to each psychology appointment determined to make the most of it and are honest about yourself it is more likely to help.

### **Does it cost anything?**

No, if you are registered Alfred Haemophilia patient the clinical psychology service is free and voluntary.

### **I'd like to speak with the Haemophilia Clinical Psychologist AKA Diana**

If you would like to speak to the Haemophilia Clinical Psychologist you can:

- Let another member of the Haemophilia team know and they will arrange for the psychologist (Diana) to contact you.
- Ring the Ronald Sawers Haemophilia Centre on a Tuesday (remember though only every second one) on 9076 2179 and ask to speak with the psy-

chologist (Diana)

- Email Diana directly on [D.Harte@alfred.org.au](mailto:D.Harte@alfred.org.au) BUT remember depending on when you email there will be a delay in receiving a response.

### **Are there other community options?**

Yes. There are many psychologists working in the community. You may also be eligible to access a psychologist through your GP with a Medicare rebate. Another option is internet based psychological treatment.

### **Some helpful resources**

Lifeline T: 13 11 14  
[www.lifeline.org.au](http://www.lifeline.org.au)

Men's Line Australia T: 1300 78 99 78  
[www.mensline.org.au](http://www.mensline.org.au)

Beyond Blue T: 1300 22 4636  
[www.beyondblue.org.au](http://www.beyondblue.org.au)

BlackDog Institute  
<http://www.blackdoginstitute.org.au/>

Australian Psychological Society  
T: 1800 333 497  
[www.psychology.org.au](http://www.psychology.org.au)

Medicare and Psychology  
[www.psychology.org.au/medicare](http://www.psychology.org.au/medicare)

ACPA Find a Clinical Psychologist  
[www.findapsychologist.com.au](http://www.findapsychologist.com.au)

### **Free Internet Based Psychology Treatment**

[www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au)

[www.ecouch.anu.edu.au](http://www.ecouch.anu.edu.au)

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

<https://www.mycompass.org.au>

<http://mindspot.org.au/>

# Growth Patterns by Randall Stephens

*a hammer  
looking for something to nail  
didn't know what to do  
or what to say to you*

*took me a long time  
to grow into my own mouth  
open up this chest  
to fill my shoes*

*empty when I first found them  
skin so thin couldn't conceal  
the heart on my sleeve  
chip on my shoulder  
the bruises all over my ego*

*took years of awkward  
exchanges on aching knees  
to figure out where I stood  
waiting for a place in this world  
to find me*

*saw red  
while watching this space  
burnt bridges  
just to keep this spot warm*

*when I grew up  
I wanted to be  
the best thing  
that ever happened to you*

*and then that never happened*

*...and the story gets confused*

*'round the time they told me*

*I couldn't ever touch you*

*transfused blood virus  
before we'd ever figured out  
what exactly touch was for*

*life on hold  
a hammer  
looking for something  
a blunt instrument  
missing the mark  
missing the right questions to ask  
there was a hole to fill in my mouth*

*and I couldn't grow up fast enough  
to catch it*

*I caught Hepatitis C*

*had it by the tail  
-end of my fourteenth year  
and wasn't going to live past thirty  
had it so I couldn't have sex  
had it and that became  
everything that I couldn't get  
women a thing I couldn't get  
you became only  
what I could get mad at*

*couldn't reach out to you  
you couldn't touch this  
infectious adolescence  
I hated you for that*

*indulged my fat anger  
when I couldn't  
satisfy my starving affection*

*threw out so much  
over-muscled rage  
trying to shake*

*it was raw  
it was big and loud  
hard down there  
it had no handles  
no sides to hold on to  
to get over*

*said screw the world  
really just wanted  
to make out with it*

*until one day  
a cure came for me  
out of nowhere  
injected six months of  
interferon into my life*

*medication  
for whatever doesn't kill you  
makes you  
a prick of a needle  
in the belly  
by twenty six  
of the longest weeks suffered*

*it worked  
the poison out my blood  
success*

*that was nine years ago  
and I have been negative  
ever since  
so to speak*

*escaped that fate of a failed liver  
I got to live without expiry dates  
or a best before label, again*

*so where now  
needle looking for a cure  
hammer looking for a nail  
growing into touch  
learning how to feel it  
how to express*

*it took me  
a long time  
an awful-long time in the getting  
to grow into my own mouth  
to open up this chest  
to fill my shoes*

*I got through Interferon  
got over the Hepatitis C  
that I got from being a Haemophiliac  
and in all of that  
I got older  
faster than I should*

*acting like such a tool  
or a prick from that needle  
you haven't felt  
the needles the nails  
the medicine the waste  
the policy of no refunds  
on the years spent angry*

*can't change the past  
but can unmask scars  
here  
medication taken  
health restored  
liver forgiven  
more life left to me  
than I quite know what  
to do with*



*to heal this  
ridiculous long list  
of everything left unfixed  
given another chance  
I survived long enough  
to tell you this story  
how it is  
that I'm not dead yet*

*very much alive  
and plan on staying that way  
to keep growing  
but beyond  
the small feat  
of filling my own shoes  
beyond just surviving  
or learning to live with  
still have no idea  
how it is*

*I'm supposed to  
actually be living this*

*- Randall Stephens*

For more poetry by HFV Member  
Randall Stephens, please go to:

[www.randallstephenspoetry.com](http://www.randallstephenspoetry.com)

**COMMUNITY PHARMACY  
DISPENSING FOR  
HIV MEDICINES**

As of 1st July, people living with HIV will be able to access their HIV medications from community pharmacies (chemists) providing greater flexibility and convenience.

This is in addition to being able to obtain your medicine from your existing hospital pharmacy.

For further information contact  
Pharmaceutical Society of  
Australia (PSA)  
1800 303 270

## HIV FUTURES 8 An Australian survey of people with HIV

Please fill in the survey online now at  
[www.hivfutures.org.au](http://www.hivfutures.org.au)

HIV Futures 8 is a survey about the health and well-being of people with HIV. We are keen to hear from people all over Australia. All genders (men, women, trans) and sexualities (heterosexual, gay, bisexual).

HIV Futures is an important project. It provides information to help governments, clinical services and community groups such as Living Positive Victoria and VAC to plan relevant and appropriate programs and policy.

**The survey will be online until 14th March 2016.**

For more information or to request a copy of the survey booklet to fill in contact us:

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

You can also download a copy of the previous HIV Futures (HIV Futures 7) Report at:

[http://www.latrobe.edu.au/\\_\\_data/assets/pdf\\_file/0007/546037/HIV-Futures-Seven-Report.pdf](http://www.latrobe.edu.au/__data/assets/pdf_file/0007/546037/HIV-Futures-Seven-Report.pdf)

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University.

For more information contact Jennifer Power (03) 9479 8700 or [Jennifer.power@latrobe.edu.au](mailto:Jennifer.power@latrobe.edu.au). If you have any concerns contact the Senior Human Ethics Officer, La Trobe University (03) 9479 1443 or [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) (SHE CHESC s15/100).

## Haemophilia Humour: National Hemophilia Foundation (USA) spokesperson Alex Borstein found success, levity in comedy

If the name Alex Borstein doesn't sound familiar, maybe these do—Ms. Swan from FOX's *MADtv* and Lois Griffin from FOX's *Family Guy*. If you know those characters, then you know Alex Borstein.

Borstein played Ms. Swan starting in 1997, shaping the character into a cross between her grandmother and the eclectic Icelandic rock musician Björk. A year later, she starred on the animated sitcom *Family Guy*. Borstein is the voice behind Lois Griffin's nasal Long Island accent. She plays the patient homemaker to a husband who takes slothfulness to another level, the mother of an infant with a perfect IQ and the owner of a dog who has a crush on her. Borstein gave the character the ability to seamlessly flip from passive-aggressive back to perfection. And no, she doesn't really talk like that.

Borstein's sassy and sometimes lewd humour stems, in part, from her experience growing up in a family affected by haemophilia. Now, she can add another role to her résumé: the National Hemophilia Foundation's (NHF's) new spokesperson for genetic testing. "So much of raising a child is out of your control," says Borstein, who lives in California. "I want to encourage families to be prepared."

Before having children, Borstein's mother didn't know she was a carrier for haemophilia. Her brother, Borstein's uncle, had unexplained bruising and swollen ankles when the siblings were growing up in Budapest, Hungary, in the 1940s.

Doctors didn't know the cause of Borstein's uncle's injuries. "They said he had 'some kind of bleeding disorder,'" Borstein says. "He was in pain all the time."

Borstein's mother and her family left Budapest for the United States during the Hungarian Revolution in the late 1950s. She married Borstein's father in 1964 and settled down in Chicago to start a family. The couple's first son showed no signs of a bleeding disorder.

Three years later, a second son was born. As a Jewish family, the Borsteins held a ritual circumcision ceremony for him. But the bleeding wouldn't stop. That's when doctors diagnosed Borstein's brother with moderate haemophilia A. Borstein was born two years later.

"Aside from that circumcision, I don't think my parents knew what life was like raising a child with haemophilia until he was older," says Borstein.



Borstein's brother's injuries were so frequent that they seemed to occur monthly, she says. "My grandmother used to say that the world was such a messed-up place because God was too busy taking care of my brother."

The family's stress was multiplied by the fact that Borstein's brother wanted to keep his bleeding disorder a secret. "He was afraid that if anyone knew, he'd be a pariah," Borstein says. To fit in with his peers, Borstein's brother engaged in the same activities as other kids, which led to even more injuries.

The mood in the Borstein household was regularly filled with angst, as the family circle dealt with the cycle of Borstein's brother getting a new injury or recovering from one. After the family moved from Chicago to Los Angeles when Borstein was about 10 years old, she put herself in charge of breaking the tension—with jokes. During her brother's infusions, Borstein poked fun that he was "shooting up." Then, she'd take the syringe, fill it with water and squirt it at him. When her brother was in a wheelchair in the hospital, Borstein would grab another wheelchair and race him down the halls.

In another stunt, Borstein and her oldest brother tied the frame of her other brother's wheelchair to the garage door handle. They cracked up laughing as they watched him roll down the driveway until the rope was taut.

Around age 13, when Borstein started experiencing menorrhagia (long, heavy periods), a blood test revealed her

factor level was low and that she was a carrier for haemophilia A.

But Borstein's struggles were minor compared to her brother's. After a fall, Borstein's brother had a head injury so bad that doctors told the family he might not make it. "My job was to make him feel like everything was OK and not take everything so heavily," Borstein says.

That's when Borstein noticed humour could ease even the thickest tension. In high school, she decided comedy would be not only her coping mechanism, but also potentially her career.

The rigid structure of high school stifled Borstein's creative side. So, she entertained herself and her classmates with one-liners. Then, a teacher challenged her to take the antics to a real stage, like the school's drama club. After she joined the club, Borstein used the lunchtime performances to entertain people with her own written material.

Eventually Borstein got bold enough to pursue her first stand-up gig at a local bar. To help maintain her brother's privacy, her stand-up act never included her own or her family's experiences with haemophilia.

### **Facing carrier status**

After majoring in rhetoric at San Francisco State University and working as a copywriter at an ad agency, Borstein joined ACME Comedy Hollywood in 1994. There, she wrote and performed sketch comedy each week. She also met her husband, Jackson Douglas, now known for his role as Jackson Belleville in the WB television show *Gilmore Girls*.

Borstein and Douglas waited 10 years before starting a family. Part of the reason was that their careers had taken off. The other reason was Borstein's apprehension that the baby would have haemophilia. "In my industry, who knows when I'll have health insurance," Borstein says. "I knew firsthand how often we could end up in the ER."

But the medical costs were not Borstein's main concern. Her real worries were her ability to take care of a son with haemophilia and her own guilt. "I was scared to deal with the guilt of it, the anger that my son might have toward me later," Borstein says.

As Borstein and Douglas discussed having children, they decided to explore what life was like for other families with children who had haemophilia. They visited summer camps for children with bleeding disorders and attended conferences, where they interviewed families on camera. In hopes of one day producing a documentary, Borstein has kept the archive of more than 100 interviews. Borstein talked with many mothers who struggled with

feelings of guilt about passing haemophilia onto their sons. Some families talked about how the condition had brought them closer together. Certain children were angry about having haemophilia; others said it made them stronger, even special.

When Borstein got pregnant, she and Douglas opted to have the fetus tested for gender and chromosomal abnormalities. That way, they could arm themselves with the facts before their child was born. Doctors did a chorionic villus sampling (CVS) test at 11 weeks' gestation. CVS involves taking a cell sample from the placenta, which has the same DNA as the fetus.

A few days later, the nurse called with the first result: It was a boy. Their reaction: "Oh, no," Borstein says. "The nurse probably thought we were evil, heartless jerks who just wanted a girl."

The next step was to wait for results to confirm if Borstein's baby had haemophilia. "The results took so long, I started researching how we would raise a child with haemophilia," Borstein says. That's when she found NHF's website, accessing the information online and poring over the pages. Borstein reached out to other mothers in the First Steps chat room and began preparing herself.

When the results came back, Borstein and Douglas were relieved—their child would not have haemophilia. Their son was born September 8, 2008.

### **Championing genetic testing**

Earlier this year, NHF announced its involvement in the new genotyping initiative, *My Life, Our Future*. Its purpose is to educate people with haemophilia on the benefits of genetic testing, offering them free or low-cost genetic testing services.

"Through funding and partnerships we've created, this opportunity has been opened at little to no cost to members of our community," says Val D. Bias, NHF CEO.

This fall, Borstein will assume her new role as NHF's spokesperson for the genetic testing initiative. Previously, she was NHF's Victory for Women spokesperson, championing the needs of women affected by bleeding disorders. "Alex Borstein has a deep passion about genetic testing for bleeding disorders," says Bias. Unlike other celebrities who need crash courses on the health conditions they advocate for, Borstein is familiar with the community's issues, he says. "She already has a complete understanding of what life is like with a bleeding disorder.

"That understanding—plus the humour she brings—helps make the issues that come with having an intense, severe

chronic disease more palatable for people to hear and understand.”

Borstein began raising her voice about genetic testing the day she learned she would become a mother. “What I like about NHF’s genotyping initiative is that it’s being pushed for the bleeding disorders community by the community, not some outside entity,” she says. “We’re taking hold of our own power over this disease.” Borstein will speak at NHF’s Annual Meeting, October 3–5, in Anaheim, California, and at a Halloween comedy fund-raiser for NHF on October 30 in New York City.

Borstein lives by the adage that knowledge is power. “If you can arm and prepare yourself, those are the responsible things to do,” she says. She still has to deal with bleeding disorders in her family. Her 1 year old daughter is a carrier. “I hope and pray that when she has a child, there are even more options because research has advanced,” says Borstein. “And a cure would be fantastic.”

### By Kadesha Thomas Smith

Article courtesy of HemAware, the National Hemophilia Foundation (USA), copyright 2013



The My Aged Care website has been established by the Australian Government to help you navigate the aged care system. My Aged Care is part of the Australian Government’s changes to the aged care system which have been designed to give people more choice, more control and easier access to a full range of aged care services.

My Aged Care is made up of a website and a contact centre. Together they can provide you with information on aged care for yourself, a family member, friend or someone you’re caring for. You can call the My Aged Care contact centre on 1800 200 422 between 8am and 8pm on weekdays and between 10am and 2pm on Saturdays. The My Aged Care contact centre is closed on Sundays and national public holidays.

You can expect our staff to be polite, helpful and knowledgeable and to provide:

- Prompt, reliable and confidential services
- Clear information, which can be made available:
  - in languages other than English if you speak another language and need an interpreter
  - in other formats if you have hearing difficulties or a vision impairment
- Help to find Government-funded aged care services
- Prompt resolution of any complaint or concern you have with My Aged Care.

For most people, growing older means there are times you find it difficult to manage day-to-day living activities. You may need help, or you may be caring for a family member or a friend who needs help, but you just don’t know where to start or what help you can get.

There are different types of aged care services to support you, whatever your needs. When you call My Aged Care, our contact centre staff will ask you questions to help us understand your needs.

### How My Aged Care helps you

My Aged Care helps you find the information you need about aged care services. This can be as simple as calling the My Aged Care contact centre on 1800 200 422 or reading this website. My Aged Care provides you with information about:

- Different types of aged care services
- Eligibility for services
- How we understand your aged care needs and help you find local services to meet your needs – you are able to select your own service provider
- Costs of your aged care services, including fee estimators.

To help you find the right services, the contact centre will ask for your consent to create a personalised client record. A client record holds up to date information on your needs and any services you receive. The client record will reduce the need for you to retell your story to the contact centre, assessors and service providers.

**1800 200 422 [www.myagedcare.gov.au](http://www.myagedcare.gov.au)**

## A look inside a carer's world... *When Counselling can help*

As a counsellor for a number of years at Carers Victoria I have regularly observed and heard about the external and internal pressures carers experience. Counselling offers an opportunity to understand these pressures and opens options for carers to manage them differently.

Externally a carer can seem to be 'coping'. Sometimes they are even congratulated by others for the very situation they struggle with, making it difficult for them to share their actual 'real' experience. This can further compound the emotional isolation and disconnection they often describe to me.

Carers may also experience many external pressures for example: hospital discharge, loss of services, family expectations and obligations to care. It's common for these obligations to provide the care to be fuelled by judgments from others such as "you're the sibling without children" or "you live the closest". Society can also place pressure on caring, for example, carers say "what would it look like if I didn't care for my sick wife?" or "It's just what you do, isn't it?"

Internally, caring can be a demanding, draining and confusing role. Internal pressures include our own core values and thoughts like "I should be able to do this", "I couldn't live with myself if something happened", "I couldn't bear the thought of putting him into a nursing home" and so on.

Carers have described to me that it can be a roller coaster of emotions –guilt, fear, worry and isolation.... The world of caring can be a very private one; behind closed doors, with nobody witnessing the sleepless nights and restless feelings.

Carers have often expressed feeling trapped, anxious and uncertain. These feelings aren't exclusively the experience of just carers; many other people can feel emotionally vulnerable and anxious through difficult situations and challenging relationships. It's worth remembering that not all these unpleasant feelings are experienced by every carer.

In my counselling work I have seen how these beliefs and expectations can be difficult for carers and can lead carers into a seemingly never – ending trap of guilt and emotional survival. After quietly managing these uncomfortable and often conflicting feelings carers can be left feeling like they have very limited options; either "suffer and lose myself" or "give up caring and live with the turmoil"... when really there is a spectrum of options and on

either end perhaps are these two extremes. This is where a counsellor who has worked with carers can help.

Research tells us that carers are more vulnerable to a significant lower level of wellbeing than any other cohort, measured via the Australian Unity/Deakin University Wellbeing of Australia Study. Caring for a loved one, a sister or brother, a partner, a parent, a child dealing with a significant health problem makes carers more vulnerable and indeed more exposed to significant trauma, loss and grief.

External and internal pressures work together – emotions are not had in isolation; there is always a bigger context, a connection to other experiences, thoughts, feelings, triggers and meanings. I have found it helpful to understand pressures facing carers in these terms. As a counsellor I help carers to unpack their external and internal worlds and navigate them. Counselling is an opportunity to widen the perspective: to be more aware and therefore open to more options than was once thought possible. Counsellors join with carers in this personal journey to new places where comfort and more peace are found.

Anna Tedesco, Carers Victoria

*The carer counselling program is subsidised for all carers. Six sessions of counselling are provided by professionally trained counsellors across the state. Group, telephone and video counselling are offered through this service.*

*To access the carer counselling program through Carers Victoria please call 1800 242 636.*

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### **HFV AGM 2015**

*Our AGM will commence at 12pm on  
Sunday 29th November at the  
Royal Botanic Gardens.*

*The AGM will be held in conjunction  
with our annual Christmas Picnic.*

# HEP C TREATMENT UPDATE - *from HFA*

## NEW TREATMENTS

Access to the new generation direct acting antiviral (DAA) hepatitis C drugs has been at the forefront of HFA's work on hepatitis C this year.

These new treatments have been described as "game changers". They are part of the new wave of far more effective hepatitis C treatments that many people with bleeding disorders have been waiting for.

In clinical trials they have had very high success rates – over 90% for most – with few side-effects, and shorter treatment courses. Most will be available in all-oral interferon-free combinations. Some will also be ribavirin-free regimens, which is good news for those who can't tolerate ribavirin. Some have had encouraging results even with people who previously had unsuccessful treatment or who have advanced liver disease, such as cirrhosis. Most of these treatments are already available in other countries.

## PBAC RECOMMENDATIONS

To speed up the approval process, the new treatments have been going before the Therapeutic Goods Administration (TGA) to be approved for use in Australia at the same time as the Pharmaceutical Benefits Advisory Committee (PBAC) for listing on the Pharmaceutical Benefits Scheme (PBS). Listing these new treatments on the PBS would mean they are subsidised by government and would allow Australians to access them at an affordable cost.

Several of the new treatments went before the PBAC in March 2015. HFA made a substantial submission to the PBAC including the comments of community members – thanks to the community members who completed the HFA survey on new hepatitis C treatments last year. Your responses were vital to the HFA submission.

We were very pleased that in March 2015 the PBAC recommended that these hepatitis C treatments should be added to the PBS for the treatment of chronic hepatitis C:

Daclatasvir (Daklinza®) in combination with Sofosbuvir (Sovaldi®)

Ledipasvir with sofosbuvir (Harvoni®)

Sofosbuvir (Sovaldi®)

In its decision, the PBAC explained that the "new treatments for HCV were very effective" and would offer

options for treating people with genotypes 1 to 6.

The PBAC also recommended that the new all oral treatments should be listed in the General Schedule, rather than the Section 100 Highly Specialised Drug Program. This would mean that prescribing these treatments would no longer be limited to specialist clinics.

However, clearly the PBAC was not satisfied with the proposed treatment prices and advised that the Australian Health Minister should negotiate lower prices for them to be cost-effective.

## NEXT STEPS

"Government funding is needed urgently for these medicines to be listed on the PBS so they are affordable to Australians with hepatitis C," said Gavin Finkelstein, HFA President.

The next step in the process is for the Australian government to consider the PBAC recommendations and make decisions about funding. We hope the cost of these drugs can be negotiated successfully with the pharmaceutical companies without delay. Access to these medicines is critical.

Disappointingly, the Health Minister did not include the new hepatitis C drugs in the pre-Budget announcement of \$1.3 billion to subsidise high-cost medicines. However, the pricing agreements for these hepatitis C drugs would need to be finalised with the pharmaceutical companies before they could be listed and this process is no doubt still underway.

"The good news is that the Minister confirmed that the Abbott Government is committed to listing approved drugs as fast as possible," commented Helen Tyrell, CEO of Hepatitis Australia in a recent press release. "Minister Ley made it clear that other high-cost medicines – which we assume means the hepatitis C therapies – are now being considered for a government subsidy."

HFA continues to follow up with further representation to government about access to these treatments.

## IMPACT OF DELAYED TREATMENT

It is very important that the current range of new DAAs be made available as quickly as possible to people with hepatitis C, particularly those with long-term infection who are at risk of advanced liver disease.

At the recent European Association for the Study of the Liver (EASL) Congress in Vienna, a large US study confirmed the detrimental effects of delaying treatment with the new DAAs until the person has advanced liver disease. “The benefits of treatment are diminished if treatment is delayed. If you treat too late it is not going to be as effective,” noted the researchers.<sup>1</sup>

This is particularly relevant in Australia, where access to the new treatments off clinical trial has been limited only to the sickest patients through special access schemes provided by the pharmaceutical companies. Australian hepatitis specialists have been very concerned about the potential impact of delaying access to treatment with DAAs. In a letter to the Medical Journal of Australia they used a modelling approach to demonstrate that if treatment access was delayed by 1 or 2 years, it would result in many new cases of liver cancer, advanced liver disease and liver-related deaths.<sup>2</sup>

People with bleeding disorders and hepatitis C in Australia have been living with hepatitis C infection for more than 20 years now – many for much longer. Treatment to cure their hepatitis C and prevent further liver damage is urgently needed. Many have waited a long time for a treatment that is likely to be successful and they can't wait any longer. HFA continues to pursue every avenue possible around access to these new treatments for affected members.



© Julián Rovagnati | Dreamstime.com

## OTHER NEW TREATMENTS

Other new DAAs are continuing to work their way through the treatments pipeline. In July 2015 another new combination treatment will go before PBAC for PBS listing:

Paritaprevir with ritonavir, ombitasvir and dasabuvir, with

or without ribavirin (Viekira Pak®) – for the treatment of chronic hepatitis C genotype 1

At the recent EASL Congress, researchers reported on the next generation of experimental hepatitis C drugs. The current range of interferon-free DAA treatment combinations can cure most people with hepatitis C genotype 1 in 12 weeks. Now researchers are trialling new drugs to work against multiple genotypes ('pan-genotypic') and that aim to cure patients with shorter treatment courses, eg 6 weeks. However, in the experimental treatments presented at EASL, people who had previously had unsuccessful treatment or had cirrhosis still needed longer treatment courses to achieve a cure and the next round of studies are investigating this.<sup>3</sup>

In comparison to previous studies, which took years to complete, clinicians expect that these clinical trials will produce results much more quickly as the treatment courses are quite short. With the current pace of hepatitis C research, we are likely to see a very different hepatitis C treatment landscape in the next few years.

## AND IF YOU HAVE HEP C?

In the meantime - if you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment:

- Make sure you have your liver health checked
- regularly
- If you don't know where to start, talk to your Haemophilia Centre about a referral.
- Stay in touch with your hepatitis clinic about what's new
- Don't forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

## REFERENCES

1 Highleyman, Liz. EASL 2015: Another study confirms detrimental effects of delaying hepatitis C treatment. <[www.hivandhepatitis.com](http://www.hivandhepatitis.com), 30 April 2015

2 Sievert, W, Razavi, H, Thompson, A et al. HCV-infected patients need access now to new direct-acting antiviral agents to avert liver-related deaths. Medical Journal of Australia 2015;202(9):479.

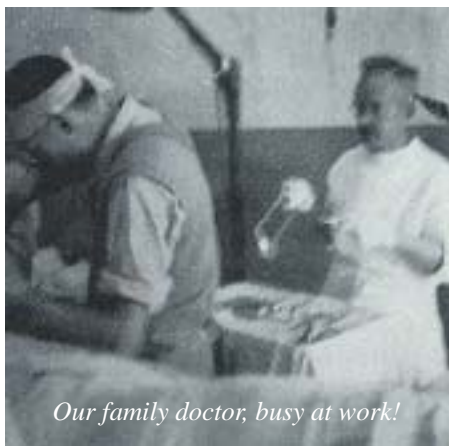
3 Highleyman, Liz. Gilead triple combination cures easy-to-treat hepatitis C patients in 6 weeks, but 4 weeks is not enough. <[www.aidsmap.com](http://www.aidsmap.com), 15 May 2015 - <http://tinyurl.com/easl-2015>>

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## AN INTERESTING JOURNEY

*Fellow HFV member, Carsten Johow, emigrated to Australia from Germany in 1976. He has a most interesting and colourful life, sailing the seas and travelling the world. Now in retirement, things haven't slowed down for Carsten as he spends time exploring the Australian outback. Here is an insight into his life.*

As a child I did not know that something was wrong with me and my mother did not treat me different to other children. As it was normal in the time I grew up my mother was in charge of us children and she took the main burden of my upbringing. I had the usual bruising and cuts any children have at that age. When I was 3 years old I cut myself and the wound was stitched up by an old army doctor on the kitchen table. No special treatment was given. Three years later I was bitten by a dog which also required stitching. When I was 10 years old another cut in my hand required hospitalisation, not so much due to bleeding as to an infection. Contaminated haemostatic cotton, which my mother used as treatment, was blamed for that. When I lost my milk teeth I had severe bleeding which was treated with haemostatic cotton and a foam which was made from rattlesnake venom!



*Our family doctor, busy at work!*

The family history of haemophilia was well known. My mother's brother had severe joint damage. He was not drafted into the German armed forces during the war. Sadly he died from internal bleeding in 1955 after treating pain in his knee joint with aspirin - aged 37. His daughter had three sons - two with haemophilia. Luckily their father is an orthopaedic surgeon and therefore a lot of potential joint damage was prevented.

When I was growing up the treatment for haemophilia was very different. The main form of treatment was haemostatic cotton, foam out of snake venom, stitching and pressure on wounds. When I had bleeding of the kidneys I was treated with vitamin K and tranexamic acid which led to the forming of blood clots in the kidneys and severe pain due to a blockage which was treated with pethidine. At the end of the winter of 1964 I experienced bleeding of the kidneys. I blamed it on school stress, as at that time I was sitting exams which determined if you passed the year and unfortunately I failed. The bleeding went away after a few days and I did not mention it to anybody (as

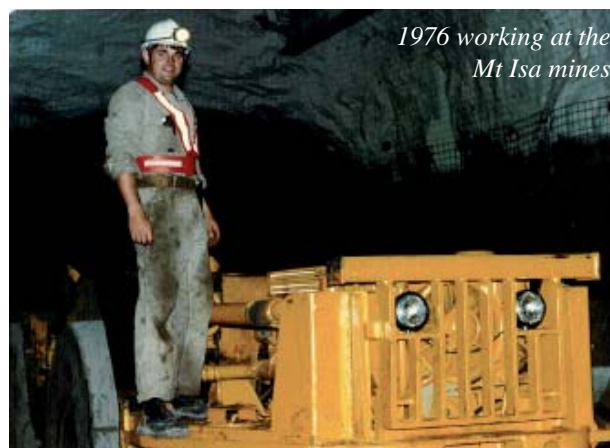
at the time I was educated the German boy had to be healthy!) However the following year the bleeding returned. I had double the stress, as I would have to leave school if I failed the year again. I passed so the stress was gone, but the bleeding continued. I mentioned it to my mother, who took me to the family doctor. Further specialists examinations revealed that my left kidney was bleeding. It was established that I had haemophilia A and the kidney bleeding in Spring and Autumn (with the change of the season) was a common occurrence for haemophiliacs.



*1971 - Working in the Philippines protecting ships from pirates!*

My father was very relaxed and matter of fact about my diagnosis in 1965. I remember him saying 'nothing serious has happened so far, why should anything happen now?' Funnily enough, at that time I had also been interested in chemistry and had been experimenting at home with chemicals such as nitro-glycerine and ammonium nitrate and I was afraid the nitro oxide gases, which develop in the production process, might have caused the problem!

On a school excursion later that year I stepped on a broken glass bottle on the beach. I treated the wound as usual with a pressure bandage in which I put a 5 DM coin (which was a lot of money for a schoolboy) to apply additional pressure on the spot. The bleeding stopped however the teacher insisted that I should see a doctor. The doctor did not stitch up the wound and replaced only the bandage which did not stop the bleeding. Not only did I lose



*1976 working at the Mt Isa mines*



my 5 DM coin, I also ended up in hospital and then my school knew about my haemophilia.

A few month later the summer holidays began. I had a job for the holidays to work as an apprentice on a cargo ship bound for the Senegal in West Africa. To make the ships departure I had to ask the school for a couple of extra days off. The headmistress of the school rang my mother and demanded that the shipping company and the captain of the ship had to be informed about my haemophilia (I had the required clear certificate of health from the doctor of the Maritime Board). My mother was adamant that what I could and couldn't do and who I needed to tell about my haemophilia was not her concern and my problems in school began! Luckily this was the only school problem due to haemophilia. I was also dyslexic, but that is another story. Eventually I finished school and studied mechanical engineering.

I was always a cautious and did not take unnecessary risk in regards to injuries. On my travels I carried the required medication such as dolantine, chirurgical needles and threads, clips, bandages etc. I also got information from medical sources such as newsletters from the German Haemophilia Society. During my technical training on a German shipyard (where there was a very high rate of fatal incidents) I develop a sense for dangerous situations and stayed away from them.

Probably due to my fathers positive and carefree attitude I was not very concerned about events which might happen and had a positive outlook on life. I did not let the fact that I have haemophilia rule my live. This could have been different if the internet had existed at that time and I would have found out that the average life span of a haemophiliac was 37 years in the 1960's.

I overcame the hurdles and challenges of life, including passing health checks for obtaining a visa to take residency in Australia, and various certificates to work on a variety of jobs throughout the world. The impact of haemophilia on my life is minimal . The effects are mainly on foot and knee joints, and luckily not more serious as with many other people in my age group. The pain is manageable by relevant treatment and medication. Now I reach an age where I can take life a bit easier and do not need to take any risks, which I may have taken before. I think I have sufficient knowledge to help myself and be prepared and for travelling into the outback I carry a satellite phone so help can be reached when required.

My advice for young people: Do not let haemophilia be a major part of your life. Learn to manage the condition, learn self-treatment, learn

your limits with haemophilia. Do not take unnecessary risk such as extreme sports and always evaluate the risk to you against the benefits for you.

Carsten Johow



Hi.

*My name is Jaden and I go to St Kevin's School. I am in Grade 6.*

*My dad has haemophilia. Although he has a bad knee he gives himself injections to make his blood clot so we can do stuff together. We can ride our motorbikes – he does it carefully and he is building me a jump at the farm for when I get better at riding because I only got my bike this year. We have to wear all the safety gear to make sure that we don't get hurt and so that he doesn't get a bleed somewhere.*

*Dad told me that people older than him didn't have the same things to treat themselves with and that they got lots of bad knees and ankles and spent lots of time in hospital.*

*He spent a lot of time in hospital when he was my age because his treatment didn't work, he had six months off school in one year. He had to have three needles a day at home for a few months to get it to work again, and it did so now he himself needles two times a week.*

*So it is good that people my age with haemophilia now get to have treatment a few times a week. At camp everyone was doing everything the same as me. They can play football like me...I love soccer – my uncle takes me to see it with my cousin.*

Jaden



# BLACK DOG SNAPSHOT

## Overview of Snapshot

The Black Dog Snapshot mobile phone app is designed to help you to keep track of your mental wellbeing.

Designed by researchers at the Black Dog Institute, Snapshot is a confidential, password-protected tool that enables you to measure and monitor your mental health and wellbeing. It is designed for use among Australian adults.

By assessing your general happiness, mood, and anxiety, as well as work stress, sleep, social support and alcohol intake, this app provides general feedback and options for online and offline help-seeking services in Australia.

Data inputs are not shared with any third parties and the Black Dog Institute regularly reviews and updates the app content. The feedback provided is based on comparisons with Australian population data including The Black Dog Index. Resources for help include evidence-based interventions where possible.

## Rationale

Every year, approximately one in five Australians will experience a mental illness. Anxiety and depression are common. Individuals experiencing mental illness

are much more likely to take time off work and have problems in other areas of their life.

Sadly, only one third of people seek professional help for their mental health problems, with men much less likely to seek help than women. Instead, many people prefer to seek help and information about mental health on the internet.

The use of the internet, and in particular, internet-enabled mobile phones, has surged in Australia. A growing number of Australians use their mobile phone to access the internet, with many accessing it more than once a day. Mobile phones apps are also commonly used. However, very few evidence-based apps for mental health are currently available.

## Project Aims

This project aims to develop an evidence-based application that would allow Australian adults to monitor their mental health and wellbeing using their mobile phone. By providing individuals with feedback and resources, we wished to increase users' knowledge of their mental health and encourage help-seeking behaviour.

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

## CONGRATULATIONS

to HFV member Adam Field!!!

*Adam won this amazing Aquayak Kayak as 3rd prize in the major prize draw at the Twin Rivers Bream Classic, held in July on the Gippsland Lakes.*



## HFV REMEMBRANCE SERVICE

10am Sunday 28th November  
Royal Botanic Gardens

Our HFV committee and staff would like to invite members, family and friends to attend a celebration of life service to be lead by our former HFV president Neil Boal. The service will run for approximately 15 minutes and will be an opportunity for us to celebrate the lives of all those we've lost in our community throughout the years and to share memories, in a beautiful and relaxed setting.

This is intended to be a low key informal service, as suggested by a number of HFV members. It will commence at 10am on Sunday 28th November at the Melbourne Botanical Gardens. The service will be followed by our annual Christmas Picnic and AGM and we invite all to stay and join us.

More information will be posted on our website soon and will also be included in the November edition of The Missing Factor.

## BLOOD BROTHERS CAMP 20-22ND NOV 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 IN PORTSEA!**

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

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

Bookings essential through the HFV office. Please call 9555 7595

## 17<sup>TH</sup> Australian & New Zealand Conference on haemophilia & related bleeding disorders



1 - 3 OCTOBER 2015 • GOLD COAST

# Who pays for clinically necessary patient transport in Victoria?

This document aims to provide information to the community about who is responsible for paying for clinically necessary patient transport in Victoria.

For more information please see the Patient transport charging guidelines for Victoria (the guidelines) at <http://www.health.vic.gov.au/ambulance/guidelines/index.htm>. The Guidelines were updated and published on 1 July 2014. They cover clinically necessary patient transport provided by Ambulance Victoria and licensed non-emergency patient transport providers in Victoria.

## What is clinically necessary patient transport?

In Victoria, free patient transport to concession card holders and members of Ambulance Victoria's membership scheme is only provided if it is clinically necessary.

For a patient transport to be considered clinically necessary, the patient must need clinical monitoring or assistance during the transport.

All clinically necessary patient transport must be medically authorised by an appropriate health professional, such as:

- a registered medical practitioner
- a registered nurse (division 1)
- an Ambulance Victoria paramedic or authorised staff of the Emergency Services Telecommunication Authority (ESTA)
- a registered mental health practitioner.

Clinically necessary patient transport includes emergency and non-emergency patient transport (NEPT).

Please note that a transport is not regarded as clinically necessary where it is initiated by the patient (refer What is a patient initiated transport? below).

Emergency transport is for patients who require a time-critical response. Most emergency transports occur from the community to hospitals (such as from a patient's home to the emergency department) and between hospitals (such as a rural hospital transferring a patient to a larger hospital for specialist care). Emergency patient transport can only be provided by Ambulance Victoria.

Non-emergency patient transport is for patients who do not require a time-critical response. This transport can be provided by Ambulance Victoria or licensed private NEPT providers.

## What if I have a concession card?

The following Victorians are eligible for free emergency and non-emergency ambulance transport to the nearest and most appropriate hospital. This transport must be clinically necessary and authorised by an appropriate health professional.

- A person holding a current Pensioner Concession Card

(including dependant children as listed on the card but excluding spouses)

- A person holding a current Health Care Card (excluding holders of a Health Care Card for Carer Allowance and Foster Care issued in the name of the child) and their dependants, including spouses as listed on the card (in circumstances where the dependant is the patient)
- A child holding a current Child Disability Health Care Card (payment type CD) or Foster Care Health Care Card (payment type FO), but not their guardians/families as listed on the card
- A child under a Custody to Secretary Order
- A child under a Guardianship to Secretary Order

For an eligible person listed above, where the individual is being transported from a private healthcare facility (such as a private hospital or a private day procedure centre), the private healthcare facility is responsible for paying.

Please note that to access these entitlements a valid card number must be provided at the time of transport or when an invoice is received from Ambulance Victoria. Failure to provide a valid card number will result in the account remaining the responsibility of the relevant person, hospital or other party as detailed in the guidelines.

Concession benefits for free clinically necessary transport do not apply to:

- a patient who only holds a Commonwealth Seniors Health Card; and
- transports that are requested by the patient and are not authorised by an appropriate health professional as clinically necessary. For example, this could be when a patient requests to be moved to a preferred hospital (such as from a public hospital to a private hospital) or to be treated by a preferred physician in another location. This also includes when a patient requests to move hospitals to be closer to home or relatives. In these instances, the patient is responsible for the payment of the invoice.

## Have there been any changes for concession card holders?

Yes, there has been a change but it only impacts pensioners and healthcare card holders being treated in a private healthcare facility and require clinically necessary transport from that facility.

From 1 July 2014, the private healthcare facility where you are being treated is now responsible for paying for this transport as it is considered part of your private care and treatment. For example, if you are being discharged home and require clinically necessary patient transport to get you home, the private healthcare facility is responsible for payment.

A private healthcare facility is a registered private hospital or a registered private day procedure centre.

Whether or not the private healthcare facility passes this

cost onto you, is a matter for the private healthcare facility. If you have concerns about how this might impact directly on you, you should discuss this with the private healthcare facility where you are receiving treatment and/or your private health insurer.

### What is a patient initiated transport?

A patient initiated transport is where the transport is requested by the patient and is not authorised by an appropriate health professional as clinically necessary.

For example, this could be when a patient requests:

- to be moved to a preferred hospital (such as from the public hospital where they are currently being treated to a private hospital of their choice; please note this also includes when a patient is at public Emergency Department and requests to be moved to a private hospital);
- to be moved to another hospital to be treated by a preferred physician; and/or
- to be moved to another hospital to be closer to home or relatives.

In these instances, the patient is responsible for the payment of the invoice. A patient's concession card or Ambulance Victoria membership does not cover these transports.

If you are unsure, please call Ambulance Victoria on 1800 64 84 84.

### I am a pensioner or healthcare card holder and I need an emergency ambulance, will I be covered?

Yes, you will be covered.

However, if an emergency ambulance is taking you from a private healthcare facility to another setting, such as a public hospital's Emergency Department, then the private healthcare facility will be responsible for the cost of this transport.

### Does my private health insurance cover patient transport?

Each private health insurance policy is different and you should contact your private health insurer direct to discuss what your policy covers you for.

If your current private health insurance policy does not provide the type of coverage for clinically necessary patient transport that you need, you could consider changing to a policy that does or join the Ambulance Victoria Membership Scheme.

### Should I join Ambulance Victoria's Membership Scheme?

Yes, all Victorians are encouraged to join Ambulance Victoria's membership scheme.

Please note that the Victorian Government halved the cost of joining on 1 July 2011.

To join simply call Ambulance Victoria on 1800 64 84 84 between Mon-Fri 8am to 8pm or Saturday 9am-5pm.

You can also join through the website at <http://www.ambulance.vic.gov.au/Membership/Join.html>.

### If I join Ambulance Victoria's Membership Scheme, will I receive free transport?

The Membership Scheme benefits cover transports that are clinically necessary – as authorised by an appropriate health professional.

The Membership Scheme does not cover non-emergency transports that have been requested by the patient and are not authorised by an appropriate health professional as clinically necessary.

If you are unsure, please call Ambulance Victoria on 1800 64 84 84. Please note that membership benefits commence 5pm the day after joining.

### What do the Transport Accident Commission, the Victorian WorkCover Authority and the Department of Veterans' Affairs pay for?

For patients who are eligible under TAC or VWA entitlements, transport costs may be covered under these schemes.

An eligible DVA patient includes:

- Persons holding a Repatriation Health Card – For All Conditions (Gold Card)
- Some holders of a Repatriation Health Card – For Specific Conditions (White Card).

Eligibility for free transport is subject to the conditions of the card.

For further information regarding these schemes, contact the respective agencies:

- TAC: 1300 654 329
- VWA: 1800 136 089
- DVA: 1800 555 254

### What if I need to use an ambulance when out of Victoria?

Victorian residents are liable for fees payable in other states unless they are either a member of the Ambulance Victoria Membership Subscription Scheme, eligible for concessions in the other state, or covered by TAC, VWA or DVA subject to the details of each of these schemes.

### I am visiting Victoria – will I be responsible for patient transport fees?

Visitors to Victoria are responsible for patient transport unless they:

- have an eligible concession card (see above for relevant inclusions/exclusions).
- are Australian residents who are covered through their own state or territory arrangements
- are covered by TAC, VWA or DVA.

In general, a non-Victorian resident is not eligible to join the Ambulance Victoria Membership Subscription Scheme. For details refer to <http://www.ambulance.vic.gov.au/Membership/FAQs/I-dont-live-in-Victoria-can-I-buy-membership-.html>

*Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne*

## our community

### LADIES DAY OUT 2015

This year we are participating in a fun group dance session, where we will first watch a beautiful Bollywood dancer and then learn a short routine ourselves & then enjoy lunch together

**Sunday 18th October 2015**  
**Studio Doors will open at 10.45**  
**11am start 1 hour class.**

**Followed by LUNCH @ THE AEGEAN**

**Dance Baladi Studio**  
**at The Aegean (above Aegean Restaurant)**  
**19 Brunswick St, Fitzroy, 3065**

It is suitable for all ages and abilities. Dance can be a fun way to de-stress and unwind and could be something our ladies had not considered as a relaxation option.

Everyone takes part in the **entire day** as a group. The activity part of the day is an important element in what makes this group work and a lot of effort goes in to making sure it's suitable for all!

Numbers are limited. \$5 per person - bookings essential. through the HFV office 9555 7595.



### RITCHIES COMMUNITY BENEFIT CARD

*An easy way to support HFV!*

Here's how it works!

- Ask for your free Ritchies Community Benefit Card at your nearest Ritchies super-market or liquor store.
- Enter Haemophilia Foundation Victoria as the community group that you would like to be the recipient of a donation from Ritchies.
- Your card will be scanned at the register, which will automatically allocate 0.5% of the money you spend\*\* to your nominated organization, as long as they are achieving the minimum of \$2,000 spent each month.



# quickbeds

**Grassroots Fundraising Program**  
 Supporting local sport & community groups

BROUGHT TO YOU 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  
Diana Harte | Senior Clinical Psychologist

## 2015/16 HFV Membership Renewals

### ARE NOW OVERDUE

Payments can be made via

- cheque
- credit card
- online by direct deposit to:

BSB# 033063  
ACC #116909

Thank you.

## 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](http://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](http://www.hfv.org.au)

Email: [info@hfv.org.au](mailto:info@hfv.org.au)



# TIME FOR ACTION



## WORLD HEPATITIS DAY



National Infoline: 1800 437 222  
1800 HEP ABC

[www.facebook.com/loveyourliver.com.au](http://www.facebook.com/loveyourliver.com.au)  
[www.twitter.com/love\\_your\\_liver](http://www.twitter.com/love_your_liver)



[www.loveyourliver.com.au](http://www.loveyourliver.com.au)



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