

National



Haemophilia

Haemophilia Foundation Australia

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

No. 204, December 2018

# Red Cake Day &

BLEEDING DISORDERS  
AWARENESS WEEK



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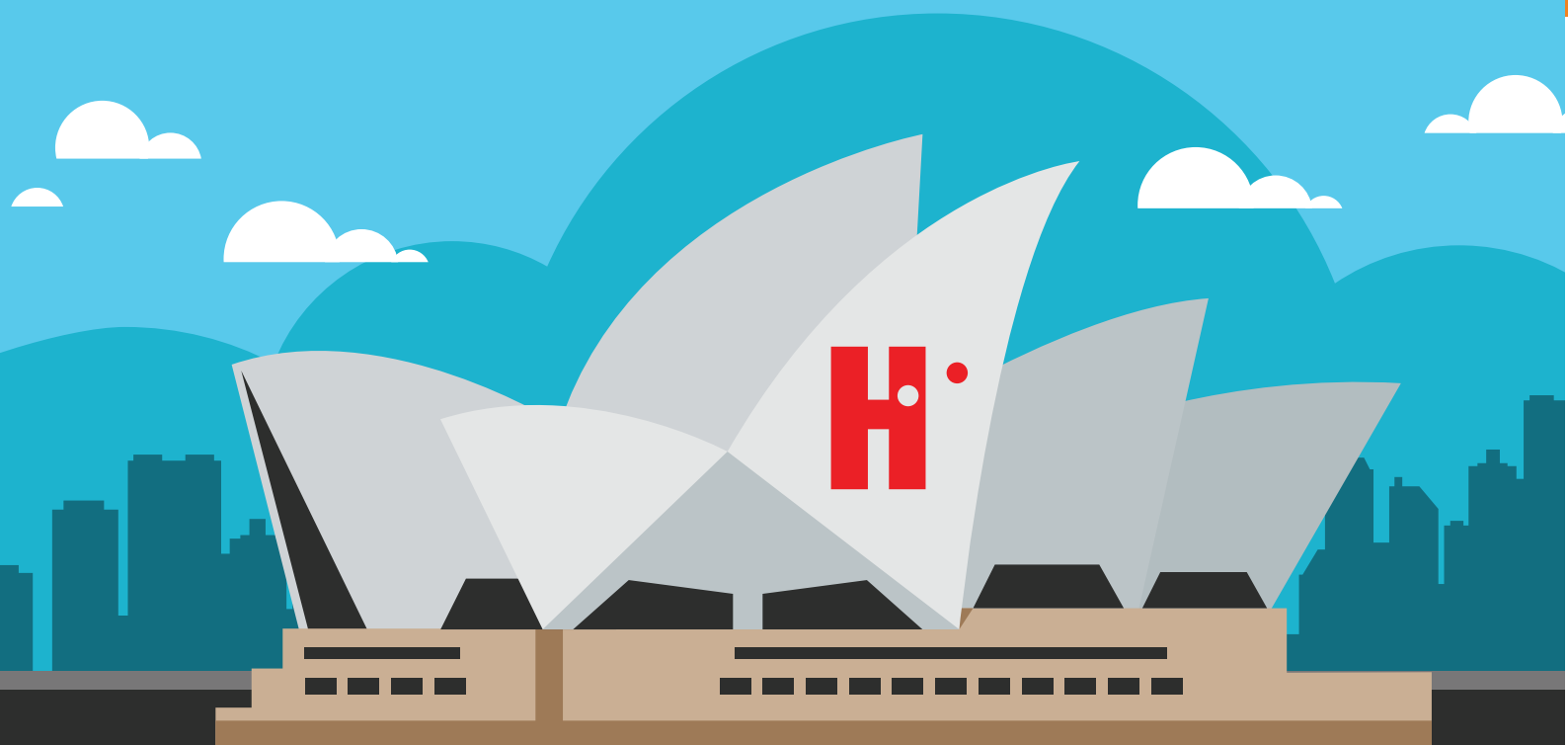
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# SAVE THE DATE

## 19th Australian Conference on haemophilia, VWD & rare bleeding disorders



~ 10-12 October 2019 ~

# FROM THE PRESIDENT



*Gavin Finkelstein*

**Haemophilia Foundation Australia** (HFA) held its Annual General Meeting (AGM) and Council meeting on 6 October 2018. We had no need for elections, as our Constitution requires elections for office bearers at the AGM every two years unless a vacancy occurs sooner. The HFA Annual Report, which includes highlights of the year and the financial report, can be downloaded from the HFA website - [www.haemophilia.org.au/publications/annual-report](http://www.haemophilia.org.au/publications/annual-report).

## UNDERSTANDING THE ISSUES

State/Territory Foundations are represented on Council by their President or Vice President, and our intention is that this would lead to timely and relevant discussion about the issues of concern to our communities around the country. It's always good to share local information and solutions, even when they are as simple as a strategy that helps local offices run more smoothly, or a successful activity at a family camp, for example. We spend time making sure our work is focused on our strategic plan; this often means tackling complex issues, such as the Foundation's approach to new and emerging challenges for people living with a bleeding disorder, advocacy about new treatment products, or setting priorities for the development of our education resources, for example. Key challenges for all relate to ageing, youth engagement, meeting the needs of different sectors of our community, reviewing and updating policies, ensuring future financial stability and working with the fast and ever changing social media environment and communications.

HFA works hard to ensure the voices of our members are heard in all that we do, so not only do we ask member Foundations to contribute their views on issues, but HFA staff also put calls out for comment to the members of each of the Foundations, to specialist health professionals who treat and care for our community, to other health consumer organisations and similar bodies, as well as talking to people with bleeding

disorders who generously share their experiences. It is these personal experiences that help us shape our policy recommendations to governments and expert committees, and shape the content for our education resources and peer support for our community. Our volunteers and staff have built up a long history of consulting expertise and we do gather and distil the needs and views of our community, and we work hard to find solutions for some of the problem areas.

## AGEING

We were delighted and grateful that the Australian Government Department of Health agreed to our special request recently for additional funding to address the growing needs of people with bleeding disorders who are ageing. This will involve extensive community consultation and I encourage people with personal experiences to contribute to this work.

As we will come to the end of a government funding cycle for our two government grants in mid-2019, we look forward to discussions with the Federal Health Minister, the Hon. Greg Hunt MP, and his Department in upcoming months about our work as the national peak body for bleeding disorders, and for our ongoing input to blood and blood product policy.

Best wishes to all for the Festive Season and wishing everyone a Happy and Healthy New Year. ■

# BLEEDING DISORDERS AWARENESS WEEK AND RED CAKE DAY 2018



**Bleeding Disorders  
Awareness Week**  
7-13 October 2018

**Red Cake Day**

**Bleeding Disorders Awareness Week** and **Red Cake Day** was held this year from 7-13 October 2018. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about bleeding disorders.

There was great interest in the week and we had many supporters to help us fundraise and raise awareness over the week. Bendigo Bank branches in regional Victoria joined in partnership once again to raise awareness and funds; and schools, hospitals, libraries, families and local

communities around the country received promotional materials to help them run their own activities.

## THANK YOU NEWSLETTER

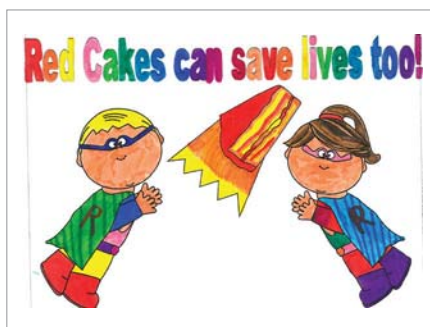
A newsletter highlighting all the events held during the week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy please email Natasha at [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)

Thank you to everyone who participated in Bleeding Disorders Awareness Week and Red Cake Day activities! 🍰

## COLOURING-IN COMPETITION 2018



**Category 1:** children aged under 4 years - Edie, VIC



**Category 2:** children aged 5 to 8 years – Maya, NSW



**Category 3:** children aged 9 to 11 years – Payton, NSW



# Bleeding Disorders Awareness Week around Australia

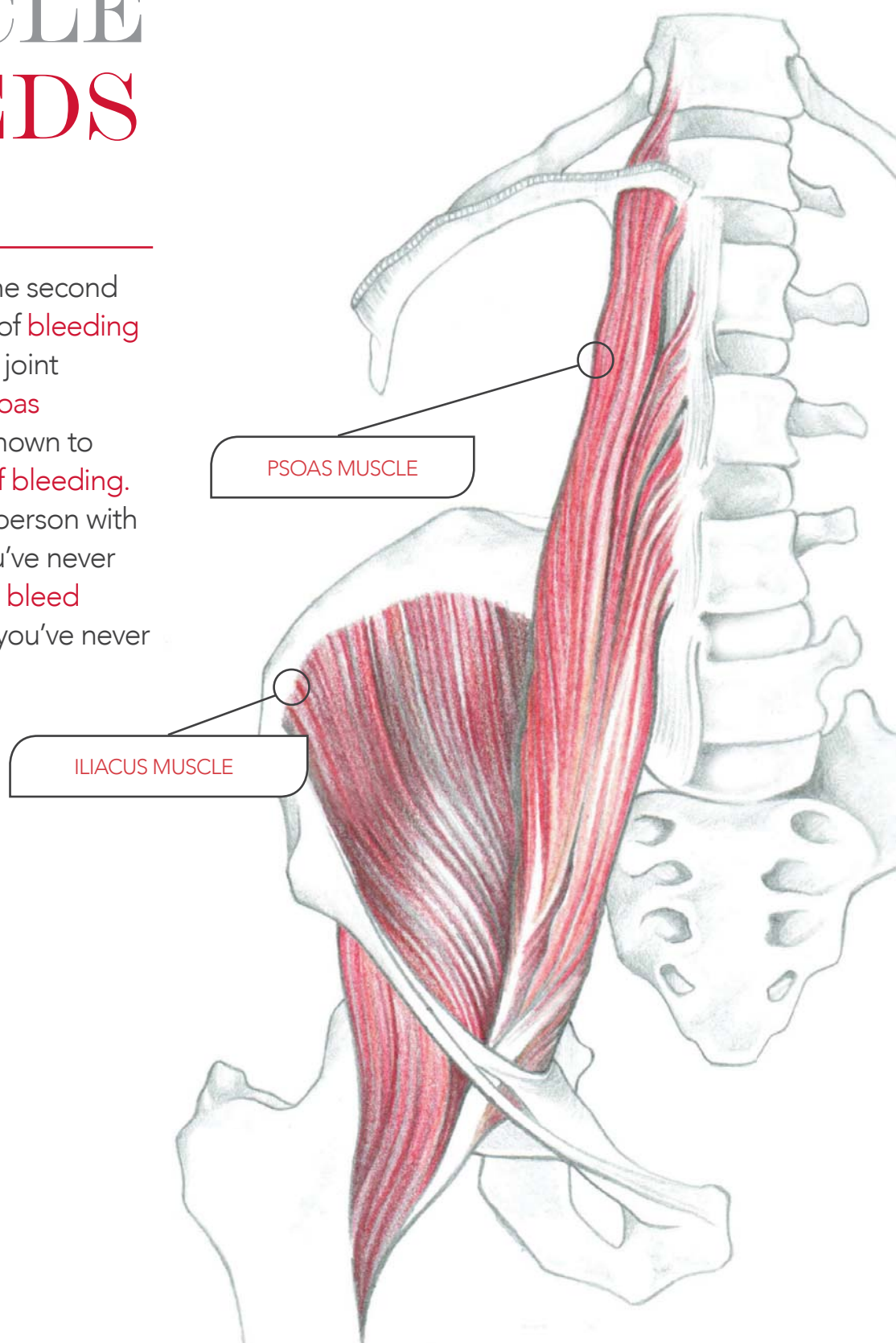




# ILIOPSOAS MUSCLE BLEEDS

Andrew Atkins

Muscle bleeds are the second most common sites of bleeding in haemophilia (after joint bleeding), and iliopsoas muscle bleeds are known to be a muscle at risk of bleeding. However, if you're a person with haemophilia and you've never suffered an iliopsoas bleed before, chances are you've never heard of this muscle.



The iliopsoas muscle is made up of the iliacus and psoas muscles combined. It is a large muscle attaching to your spine, pelvis and femur. The iliopsoas muscle is the only muscle that connects the spine to the leg. The muscle allows you to bend from the hip (i.e., to walk up stairs or pick something up from the floor), to sit up, and to move the leg forward to walk or run. It stabilises the spine and helps with posture. Structurally it is the deepest muscle in the body.

A bleed into the iliopsoas muscle may not be easily recognisable if you have not had one before or don't know what to look out for. Because the muscle is large, a lot of blood can be lost into it, which can obviously be serious – but this also means initially it may not appear serious because the pain from bleeding may not be as intense as a joint bleed feels. There are also a number of nerves in the region of this muscle, notably the femoral nerve. If this nerve is compressed, it causes loss of sensation and may take months to resolve, with long-term or even permanent disability if the bleed is not treated in time or adequately.

### SIGNS AND SYMPTOMS OF AN ILIOPSOAS BLEED

You may experience some or all of these.

- Pain in thigh, hip, groin, abdomen or lower back
- Unable to stand straight, or lie flat
- Hip remains flexed
- Inability to walk
- Unable to sit up without pain
- Numbness/tingling sensation along thigh.


Iliopsoas bleeds may occur due to an injury, or in severe haemophilia can occur spontaneously without an apparent cause. A scan (either ultrasound, CT or MRI) is usually required to confirm the diagnosis.

If you suspect you have an iliopsoas bleed, and you have home treatment, then treat immediately using the treatment plan previously given to you by your Haemophilia Treatment Centre (HTC) for a muscle bleed. Whether you self-treat or not, you should attend your nearest hospital's Emergency Department, preferably at your HTC hospital. This is especially important if you have any numbness or tingling sensation down your leg. Rest as much as possible in the meantime, and use crutches or a walking aid. Get someone to drive you rather than driving yourself.

### ATTENDING EMERGENCY DEPARTMENT (ED)

- Don't be hesitant to call the ambulance if you are unable to walk unaided and you are on your own – (make sure your ambulance cover is up to date)
- Have your ABDR patient card with you
- Know your factor baseline level, especially if you have 'discrepant mild' haemophilia – make sure your treating doctor knows your lowest level
- Treat before you attend (if possible)
- If you haven't self-treated, know when you had your last dose of factor and the amount (if you use MyABDR, this information will be at hand)
- Don't be afraid to speak up for yourself if you don't think you are being treated quickly enough (it's a good idea to have discussed this scenario with your HTC haematologist or nurse beforehand).

Treatment of an iliopsoas muscle bleed will be prolonged. Factor levels will need to remain raised to a high level for an extended number of days, along with strict bed rest. Blood tests for monitoring levels may be needed. For these reasons often a hospital admission is required, so that progress can be monitored closely. A physiotherapist should be involved with your care to provide advice during the acute stage of the bleed, and then to provide ongoing instruction and an exercise regime as improvement is made. Expect progress to a full recovery to be slow.

It is important to avoid re-bleeding into the muscle – if it occurs it will be more severe and will definitely delay your return to full capacity for everyday activities. Follow the advice of your HTC team, and particularly the physiotherapist. It is also important to establish the cause for the bleed, if at all possible, and it may help to have a frank discussion with someone from your HTC team to look at ways to prevent it happening again. 

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# PROBE STUDY PHASE 2 RESULTS



**How** can HFA have access to good quality data about the treatment and health experiences of Australians with bleeding disorders? This is crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

**PROBE (Patient Reported Outcomes Burdens and Experiences)** is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data. Each country will have access to statistical information collected from study participants in their own country and will be able to compare this data to the rest of their region or other regions around the world. The research will support efforts to improve treatment and comprehensive care programs in Australia and other countries around the world.

Phase 1 and 2 of the PROBE study tested a survey in people with haemophilia. The survey allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life.

## PHASE 2

Phase 2 of the PROBE study tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia conducted two rounds of the survey between 20 September 2016 and 22 February 2017.

Survey participants were welcome to complete both rounds. Participants lived in Australia, and were:

- Adults (18 years or over) and had haemophilia or carried the gene
- Or were the partner, family member or caregiver of someone with a bleeding disorder, but did not have a bleeding disorder themselves (controls).

Australian survey participants for phase 2:

People with haemophilia/carry the gene – 51 (required = 50)

People without a bleeding disorder – 52 (required = 50)

TOTAL – 103 (required = 100)

21 countries participated.

## RESULTS

An important learning from this phase was that larger numbers of survey participants will be needed at a

country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, eg mild/moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region and included countries such as Japan, Vietnam, Australia and New Zealand.

The results validating the PROBE study at a regional level were presented at the International Society on Thrombosis & Haemophilia (ISTH) Scientific and Standardization Committee (SSC) meeting in 2018 and are available on the PROBE study website – [www.probestudy.org](http://www.probestudy.org).<sup>1</sup>

Feedback about the online survey and its stability has been used to fix bugs and make enhancements for the phase 3 version.

## DASHBOARD

The international team have set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them in a meaningful way to funding bodies and decision-makers.

## PHASE 3

Phase 3 is planned to begin at the end of 2018. It is the final stage of implementing the study around the world, and will be collecting real world data to measure the impact of haemophilia and treatment.

This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - [www.haemophilia.org.au/research/probe-study](http://www.haemophilia.org.au/research/probe-study).

Or contact Suzanne O'Callaghan at HFA:

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# TELLING OTHERS

How do you tell a **new partner** about your **bleeding disorder**? Or your **daughter** that she may have a **bleeding disorder** or carry the gene? **When** are you required to tell someone about your **bleeding disorder**?

**Telling others about bleeding disorders** is the latest resource in HFA's The Female Factors project.

The booklet is intended for women, girls and their parents to consider some of the issues about telling others (disclosure). It may also be useful for men with a bleeding disorder when females in their family are affected: sometimes they may be the best informed family member to take the lead in talking to daughters, sisters, and others about what this may mean to them.

The booklet looks at the pros and cons of telling others and presents a range of situations where disclosure might come up. There are suggestions on how to prepare and personal stories and tips from other Australian women and parents.

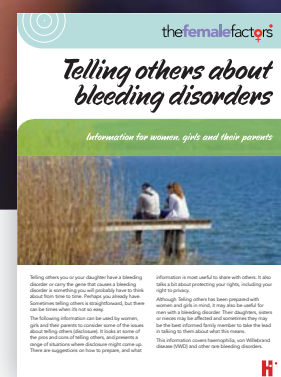
There is also a section on disclosure and the law, developed in consultation with legal experts. This is very important information and a generic version relevant to both women and men is available on the HFA website ([www.haemophilia.org.au](http://www.haemophilia.org.au)) under ABOUT BLEEDING DISORDERS.

You can find the *Telling others* booklet:

- On the HFA website ([www.haemophilia.org.au](http://www.haemophilia.org.au)) under PUBLICATIONS > WOMEN WITH BLEEDING DISORDERS
- Print copies will also be available from HFA, local Foundations and Haemophilia Treatment Centres.

Our thanks to the many people who contributed to the development of *Telling others*: Marg Sutherland, health educator, who wrote it; the women, parents, health professionals and legal experts who reviewed it; and the women and parents who very generously shared their experiences and tips in personal stories and quotes.

For more information or to order copies contact HFA:  
**E:** [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) | **T:** 1800 807 173



# THE ONGOING HEPATITIS C CAMPAIGN

## *A comment from HFA*

Dr Sumit Parikh's report is a welcome confirmation that Australians with bleeding disorders and hepatitis C have been able to access the new DAA treatments and be cured of their hepatitis C. We have heard from Haemophilia Treatment Centres that most of their patients have now had treatment and been cured and we look forward to an update from AHCDO with data from 2018 to confirm this.

It is important not to lose sight of the Australians with bleeding disorders who have not yet had testing and treatment for hepatitis C. This includes people who had blood products to treat their bleeding disorder before 1993 but are not registered in the ABDR – often people with mild bleeding disorders, who are not in contact with their Haemophilia Treatment Centre. It also includes people who have lost touch with their HTC for various reasons.

Our strategies to reach this group have targeted community doctors such as general practitioners who may see people with mild bleeding disorders in their practice, and also family and friends who are in contact with people with bleeding disorders not actively involved with an HTC:

- After feedback from HFA and AHCDO, the national clinical management consensus guidelines on who to test for hepatitis C virus now include 'people with coagulation disorders who received blood products or plasma-derived clotting factor treatment products before 1993'.
- AHCDO and HFA collaborated with hepatitis experts to produce a fact sheet for general practitioners on people with bleeding disorders and hepatitis C. This has been promoted through the viral hepatitis networks and to GP organisations.
- HFA's World Hepatitis Day campaign has included messages for family and friends to pass on to those affected, with compelling personal stories about treatment and cure.
- HFA continues to work with Hepatitis Australia and other hepatitis research organisations on wider community strategies to promote testing and treatment to people with hepatitis C.

It would be a great tragedy for someone with undiagnosed hepatitis C to go on to develop advanced liver disease or liver cancer when they could have had the opportunity for testing, treatment and cure, and HFA is committed to doing our very best to reach everyone affected in the bleeding disorders community.

Dr Sumit Parikh is the AHCDO  
ABDR Senior Research Fellow

## UPTAKE OF HEPATITIS C DIRECT ACTING ANTIVIRAL (DAA) TREATMENT

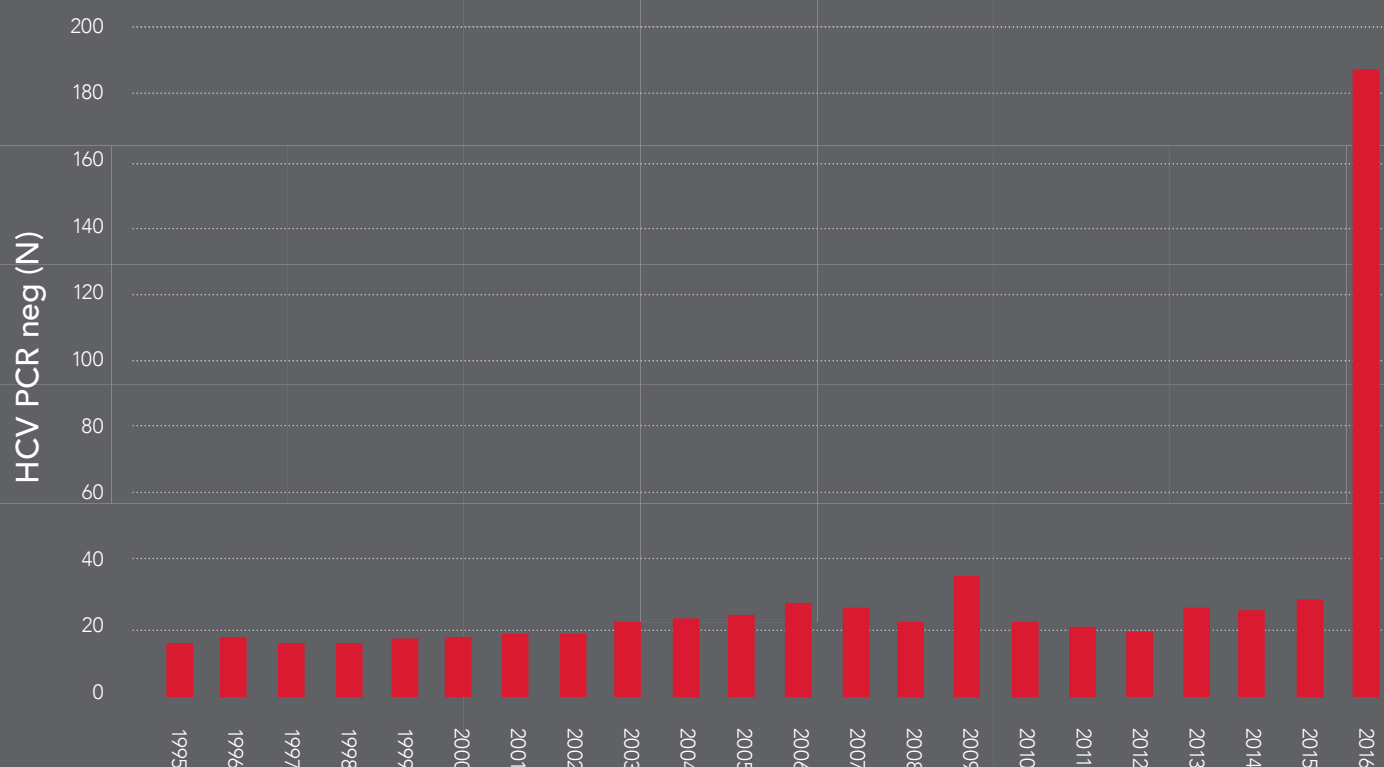
*Sumit Parikh*

Routine screening of blood donations for the presence of hepatitis C virus (HCV) commenced in Australia in 1990. Super-heat treatment and other HCV viral inactivation manufacturing processes were also introduced for plasma-derived clotting factor concentrates used to treat bleeding disorders, and HCV-inactivated factor VIII (8) concentrate became available in Australia in 1990 and HCV-inactivated Prothrombinex® concentrate for factor IX (9) deficiency became available in 1993. Many patients with bleeding disorders in Australia were exposed to plasma-derived clotting factor concentrate contaminated with HCV prior to that time.<sup>1</sup> These patients have been living with HCV for more than 25 years and it has become a leading cause of morbidity and mortality in this group.<sup>2</sup>

Epidemiological studies suggest that living with HCV without achieving a Sustained Virological Response (SVR) to treatment is a higher risk for advanced liver disease, and that disease progression accelerates the longer the patient has been infected and as they age.<sup>3</sup> The current incidence and prevalence of HCV among patients with bleeding disorders in Australia is unknown, including treatment uptake and outcome. This raises a grave concern about the number of patients who may be undiagnosed with HCV, including those who are not undergoing any treatment or follow-up.

In recent times there have been significant improvements in medical technology to diagnose HCV and major advancements in hepatitis C treatment,

# HCV clearance rate over last 20 years



including the availability of government-subsidised new direct acting antiviral (DAA) treatments, which have high cure rates and few if any side-effects. In 2017 Australian Haemophilia Centre Directors' Organisation (AHCDO) conducted a nationwide study looking at the current health status of patients with HCV in the bleeding disorders population and evaluating the impact of subsidised DAA HCV medications on treatment uptake and outcome. Data was drawn from the Australian Bleeding Disorders Registry (ABDR), which was established in 1988, and includes some people who are now deceased. The results of this study were presented at the World Federation of Haemophilia (WFH) 2018 World Congress in Glasgow, UK.<sup>4</sup>

In summary, a total of 2166 patients with bleeding disorders in the ABDR who received plasma products prior to 1993 have been tested for HCV, with 894 patients HCV antibody positive (i.e., showing evidence of exposure to HCV). The majority of patients who are HCV antibody positive have haemophilia A (68%), haemophilia B (18%) or von Willebrand disease (11%). Almost half of the patients who are currently HCV antibody positive belong to the 41–60 years age group.

By 2017 around 60% of these patients had cleared the virus with or without treatment and are now PCR negative (i.e., show no evidence of ongoing infection with HCV in their blood), including a significant number of patients with mild or moderate bleeding disorders. Almost one-third of the patients who had cleared the

virus had received subsidised DAA treatment in 2016, compared to the remainder who were treated with interferon-based therapy in the 18 years prior. This demonstrates a major advancement in the effectiveness and uptake of HCV treatment. A substantial number of remaining patients with HCV infection were undergoing treatment in 2017-18 which is a clear indication of the tremendous impact that the latest direct antiviral treatment have on the uptake and clearance rate of HCV.

A considerable number of patients who have received blood and/or blood products prior to 1993, however, have not yet been tested for HCV. The ongoing challenge is to identify all potential patients at risk of HCV infection and maximising this opportunity to eradicate HCV. ■

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# LIVING WELL WITH HIV: IT'S IN YOUR CONTROL

Trish Thompson

Trish Thompson has more than 22 years of experience in counselling and psychotherapy and is a guest presenter at the Phoenix workshop for newly diagnosed at Living Positive Victoria.

In this article Trish Thompson highlights the value of social connection. Both local haemophilia foundations and HIV organisations such as Living Positive Victoria work hard to provide peer support activities to their members and to offer environments for them to connect with each other. Anth McCarthy, peer support worker at Living Positive Victoria and a man living with HIV and haemophilia, talked to HFA about what this has meant to him:

*'In recent years I've had the great pleasure of connecting with other men with haemophilia who, like me, acquired HIV in the 1980s. Thank you Haemophilia Foundation Victoria for enabling that to happen. I got to hear how they have managed the same challenges and overcome the same hurdles I faced. Gaining an appreciation for their many different successes beyond simply surviving has deepened my own sense of worth and accomplishment and given me a sense of belonging to a very unique and special community.'*

*Living with HIV in 2018 tends to mean being as physically healthy as the general population.*

*But it can still feel like a daunting prospect to have to manage a health condition in such an on-going way, especially when there are parts of the community - including some health professionals—that still lack an understanding of HIV. Stress and encountering stigma can contribute to a number of health problems.*

*So what can be done to stay on top of things?*

## TAKING CARE OF MIND AND BODY

We now know more about the mind-body connection, or that our minds and bodies work in partnership and influence one another to help us live well. Remember the last time you had a bad cold or flu? Everything seems so much worse when we feel sick! And when we recover it's like the sun has come out again. The good news is that there are lots of strategies that we can put in place that can keep the sun shining. Having a balanced diet and exercising regularly are brilliant ways to take care of both mind and body alike. But there are some things we can do that particularly target our mental health.

## SOCIAL CONNECTION

How we experience human contact 'in the real world' has a big impact on our health and wellbeing. While researching this article, I came across a TED talk in which psychologist Susan Pinker presents research listing factors that predict living a long life. She visited a village in Sardinia, which has the highest rate of people who live to over 100 years.



“I’m thinking about allowing our minds to have some free time. To daydream, or meditate or notice what is going on in the here and now”

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Surprisingly, breathing clean air, having high blood pressure treated or being lean as opposed to overweight are quite low on the list.

The predictive factor that topped the list was social connectedness.

This is about talking to our neighbours, to the person who makes our coffee or smiling at the other person walking their dog. It is about being in a book club or showing up to the local primary school fete. It’s catching up with friends in person, not just on Facebook. Pinker explains that simply making eye contact with somebody is enough to release oxytocin and lower your cortisol levels. This means a boost to mood and a decrease in stress.

And what about the Sardinians referred to in the TED talk? They lived in tight-knit communities, never going a day without human contact.

## DECLUTTERING OUR MINDS

With the ubiquitous smart phone in all of our pockets, our minds don’t get much of a break.


We can be engaged by thousands of bits of information every day. Sounds great, but increasingly my clients are saying that they think their minds need a rest. The thing we might use to ‘have some down time’ can also actually over stimulate our brains. Our minds can get loaded up, not only by lots of external information but also by our reactions to this information. For example, we might see something on social media and then we can start thinking about how everyone else is having more fun.

So when I think about looking after our mental health, I’m not just thinking about things like getting help for issues like anxiety and depression. Of course this is also very important. I’m thinking about allowing our minds to have some free time. To daydream, or meditate or notice what is going on in the here and now. To go to the park with the dog and actually see the grass and trees. To hop on the train and notice the expressions on the faces of fellow travelers. To feel the sunshine on our faces or hear the birds call out to one another in the morning. In other words, to be more present. You might have heard about this thing called ‘mindfulness’. It is mostly about living our lives in real time, to be connected to what is happening around us. Being mindful more often creates space in our brain. And it is OK not to fill that space.

## BRINGING IT ALL TOGETHER

Given we all can’t move to the Mediterranean, what is the take home message? It is that isolation is not good for us. I have heard many of my clients living with HIV say that at times they feel that the stigma that still exists (but less so thanks to the tireless educational work of many) forces them to retreat. And so we talk about venturing back into the world, and finding those connections, whether they are at work, with family or maybe through a community-based organisation such as Living Positive Victoria.

So consider finding some opportunities to be present to the world you live in, and connect with others in person, not just online. Your mental and physical health will thank you for it.

*Susan Pinker’s TED talk ‘The secret to living longer may be your social life’ can be found at [www.ted.com](http://www.ted.com). *

# WORLD AIDS DAY

World AIDS Day is marked internationally on 1 December.

In 2018 the World AIDS Day national theme is  
**Everybody counts.**

This is a time to raise awareness in the wider community about the issues surrounding HIV and AIDS. It is a day to demonstrate support for people living with HIV and to commemorate those who have died. Wearing a red ribbon is a way that you can show solidarity and raise awareness of HIV.

## A TIME TO REMEMBER

This is also a time when we remember the members of the bleeding disorder community who were affected by HIV when in the mid-1980s HIV was transmitted through some batches of plasma-derived clotting factor treatment product.

In 2018 HIV continues to be a part of our community's experience. For the family, friends, and carers of people who were lost to HIV/AIDS, we need to acknowledge the pain and grief that endures. We know from the family members we connect with that this remains a part of their life and it highlights how vital it is to create a supportive and inclusive environment for our community. The losses over the years have also affected our community leaders and the teams in our Haemophilia Treatment Centres deeply, for these were children and adults they knew well. This came to the fore in recent interviews for our digital history project, where Jennifer Ross AO, former HFA Executive Director, and Prof Kevin Rickard, former Haemophilia Treatment Centre Director at the Royal Prince Alfred in Sydney, reflected on their experiences during the HIV epidemic in the 1980s and 1990s and the sadness that remains for them. These digital stories will be available on the HFA website in 2019 and are a powerful account of the hardships as well as the successes in treatment and care for bleeding disorders over the last 50 years.

And what of the people with bleeding disorders who live on with the challenges of HIV? Anth McCarthy, one of our HIV positive community members, commented that for him, *'World AIDS Day is about celebrating our survival through the dark years to this era of treatment, thriving, treatment as prevention, partners, children and grandchildren. We are not unscathed but we are still here and that is totally amazing and testament to our hard work, resilience and the love and support of our family, friends and community. And the hard work and dedication of the HIV and bloodborne virus sector locally, nationally, internationally.'*




## EVERYBODY COUNTS

This year's theme also reminds us about the difficulties for the people with HIV in some resource-poor settings around the world. In their goals for World AIDS Day in 2018, UNAIDS reports that we still have miles to go to ensure that all people living with HIV can lead healthy and productive lives. There are many people who do not have access to high quality treatment and care services, and who may not have HIV testing until they are ill and symptomatic because of stigma and discrimination and lack of access to confidential testing and counselling.

## WHAT CAN YOU DO?

- Learn more about HIV in your community and share this knowledge with others
- Take action to reduce transmission of HIV by promoting prevention practices
- Support and understand people in your community living with or affected by HIV
- Uphold the right of people living with HIV to participate in the community free from stigma and discrimination
- Visit the UNAIDS ([www.unaids.org](http://www.unaids.org)) and International AIDS Society ([www.iasociety.org](http://www.iasociety.org)) websites for more information about the global efforts to end the AIDS epidemic by 2030.

## MORE INFORMATION

For more information about World AIDS Day, visit [www.worldaidsday.org.au](http://www.worldaidsday.org.au). 



# NEW YOUNG WOMEN'S RESOURCE

We are very pleased to announce the release of **Female Factors**, HFA's new resource for young women and teenage girls.

HFA worked with haemophilia and gynaecology experts to answer the questions of young Australian women about how bleeding disorders affect females.

The booklet has explanations about heavy periods and other bleeding symptoms in females. It looks at haemophilia - and why girls with haemophilia have different bleeding patterns to their father or brothers - von Willebrand disease (VWD), rare clotting factor deficiencies and inherited platelet disorders. It also covers other key issues for young women, including inheritance, diagnosis/testing, treatment and support, and tips for self-advocacy from other Australian women. And it includes FAQs such as what's 'normal' and what's not normal, and gives frank but reassuring answers to some of the questions that young women worry about.

The information is presented in a magazine style – colourful and easy to read. There are personal stories, quotes and tips.

## HOW TO ACCESS IT

Female Factors is available in multiple formats

- On the HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au) under PUBLICATIONS
- On Factored In [www.factoredin.org.au](http://www.factoredin.org.au) under INFO > GIRLS
- You can read the entire booklet online as a magazine in ISSUU, download it, or download specific sections

- Print copies are also available from HFA, local Foundations and your Haemophilia Treatment Centre.

## OUR THANKS

Many people were involved in developing **Female Factors**. Young women and their parents gave thoughts on the content and reviewed the text. Marg Sutherland, health educator, rewrote the text for a young female audience. Haemophilia health professionals and other experts suggested what topics to cover and reviewed it thoroughly. We would like to particularly acknowledge Prof Sonia Grover, Head of Gynaecology at the Royal Children's Hospital, Melbourne and Dr Jane Mason, Director of the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital, who did a substantial initial review and wrote new content for the booklet.

And many thanks to the young Australian women affected by bleeding disorders who contributed their personal stories and tips and focus-tested the design!

## FOR MORE INFORMATION

To find out more about Female Factors or order copies, contact HFA:

**E:** [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) | **T:** 1800 807 173. 





Scenes from the GAP visit to Vietnam | Photos: Jane Portnoy

Jane Portnoy is Social Worker – Haemophilia at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

## GAPPING WITH VIETNAM

*Jane Portnoy*

This August I was lucky enough to go to Vietnam with the Haemophilia Treatment Centre (HTC) team from the Alfred. There has been a relationship between the Alfred HTC and haemophilia services in Vietnam for nearly 20 years. The World Federation of Hemophilia has supported the Vietnamese services in their GAP and Twinning programs. When reflecting on this trip, my question to myself was what could I bring to a country I don't know, with resource needs that I can't meet. I also wanted to think about how this trip could contribute to the service that I provide to my work here in Melbourne.

### HAEMOPHILIA SERVICES

The hospitals in Vietnam seem familiar yet also really different. The teams looking after the patients consisted of doctors, nurses, and to a small extent, allied health, comprising social workers and physios. I was struck by the closeness and lack of space. In one hospital visitors were limited to only one per patient. There was no privacy, but there was a warmth in the rooms that I was lucky enough to visit. The team knew all about their patients and the treatment that they needed. Laughter and support were common and there was a lot of sharing of experiences.

My frustration was that I couldn't talk to the patients unless there was an interpreter as most patients didn't speak any English. Learning to say 'Xin Chào', 'hello' in Vietnamese, was a great ice breaker, and even the small kids were helping me with my pronunciation.

Hand gestures, and games were another way that the barriers were broken down. Activities during our visit included challenges to solve in teams, involving toys and a parachute, and one of the most powerful aspects of my time in Vietnam was seeing the collaboration, and strong bonds between patients and their hospital teams.

### SOCIAL WORK

There are similarities and differences between social workers across the two different countries. Social work in Australia is an established and respected career. In Vietnam it is an emerging concept. There are few social workers, and many are not trained in social work; they have come to work in their position through other pathways, such as nursing or administration. A key role of the social workers in Vietnam is dealing with funding for health care. Without their assistance many patients would not be able to receive the treatment that they need: sometimes it is the trip to the hospital itself that is unmanageable. By comparison, in Australia we are able to provide treatment to everyone in an emergency and all citizens receive home treatment if they need it. As a social worker I am able to help patients with psychological issues, emotions, family relationships, and all manner of practical challenges, as well as supporting them to manage financial barriers to treatment and care. I felt so fortunate to work in Australia, within a comparatively well-resourced service.





“Without their assistance many patients would not be able to receive the treatment that they need: sometimes it is the trip to the hospital itself that is unmanageable”

## EDUCATION SESSIONS

While we were there, the Alfred team gave many education sessions on treatment and care that we had tailored for the teams in Vietnam. I spoke about social work concepts and the way that we work with individuals and families in Australia. The Social Workers were keen to hear about psychological interventions, and are starting to realize that this work is valuable, and enables patients to recover faster, use less resources and feel better in themselves. They are also becoming aware of the particular impact of having haemophilia.

One of the most positive aspects of their program is the development of the Vietnam Hemophilia Association. I met a number of young men for whom this was very valuable. It enabled them to develop links and develop confidence, find career paths suitable to their health and make friends with others who have had similar experience through their life with haemophilia - for example, having mothers who were super protective, or missing out on activities at school.

I had a brief session with social workers in Hanoi looking at how they work and I was very impressed both with their knowledge of their patients, and the large numbers of patients that they work with.

I am looking forward to continuing my relationships and work with the Vietnamese haemophilia social workers. H



# Väntrum

## Koagulationsmottagning Barn & Vuxna

Anmäl er eller barnet  
i kassan eller i själv-  
registreringsapparaten  
på plan 3.

Sitt sedan ned och vänta  
tills ni blir uppropade.

Välkomna!

Patienter till mottagning och  
dagvård endokrina tumörer och  
sarkom fortsätt till A10:01

Välkomna!



Elias outside the HTC in Sweden  
Photo: Mindi Palm

Amanda (Mindi) Palm is a former  
Australian community member and  
blogger, now living in Sweden

## LIVING LIKE A SWEDE

Mindi Palm

We've had three years of haemophilia management at our Haemophilia Treatment Centre at Westmead Children's Hospital, NSW, working closely with our haemophilia nurse Robyn who has become a wonderful friend and support to our family.

Sadly, we said our final goodbyes in July 2018 before we embarked on a new journey and chapter to live in Stockholm, Sweden and learn to 'do as the Swedes do' with groovy ABBA music playing in the background.

Our son Elias was diagnosed with severe haemophilia A as an eight-month-old baby in 2015 and had received factor 'on demand' intermittently when we were living in Australia.

Upon our first visit to The Karolinska University Hospital here in Solna, Stockholm we learnt a few

things. Firstly, there is a panel of haemophilia doctors and nurses who regularly meet and make decisions for their patients based on group consensus. Children with haemophilia receive a dedicated carer at pre-school, funded wholly by the local government, hence why the taxes are so high!

Incidentally, we learnt that the longest word in all of medical history is: **Barnkoagulationsmottagningen**. Did you get that? It's the Swedish word for 'children's coagulation centre.' Now that's a mouthful!

Our family has started the process of learning how to give Elias factor intravenously, so not only is our Little Bleeder learning to get comfortable with needles, but he's also learning how to speak and act like a Swede!

Until the next update, hej då!

# Q&A

## MOVING TO SWEDEN

Mindi took the time to answer a few of HFA's questions about the move to Sweden.

**HFA:** What did you do with the Sydney and Stockholm Haemophilia Treatment Centres (HTCs) to prepare for the move?

**Mindi:** I consulted with our HTC Nurse, Robyn Shoemark, and haemophilia doctor, Dr Juliana Teo, at the Children's Hospital at Westmead who had a final consultation, blood test and wrote up a letter for us to give to our haematologist here in Sweden. Elias, our son, and Lucy, our daughter, both had bloods taken for final factor level testing and then (somehow) Robyn managed to find the clinic we attend now, 'Barnkoagulationsmottagningen' in Solna, Stockholm.

In the first few weeks we arrived, Elias had several incidents where he was bleeding through the nose, in the mouth and he had a swollen and bruised foot. So I commissioned my husband Tommy to go in for the first consult as it was considered an emergency and I was really in no state to handle it all - in Swedish! He gave them the letter from the HTC at Westmead and from there we started having regular consults. All children in Sweden – citizens, residents, and immigrants - are covered by the government for free access to healthcare, dentistry and medicine, so that was not an issue.

**HFA:** How did you manage the plane flights and international travel?

**Mindi:** Though not recommended, we opted to not have insurance as we had only one stop-over in Bangkok and straight onto Stockholm. So we just decided, it's a straight flight there and hopefully we wouldn't run into problems. Each time we travel overseas Robyn writes us a letter and we take that with us along with a supply of medication, which gets checked at every security gate. It's no problem taking it with us and, as we have the letter, there are no problems with international customs.

**HFA:** What is different for you and Elias in relation to haemophilia and care in Sweden?

**Mindi:** A marked difference is that our local government or 'kommun' issues a specific carer/aid person in Elias' pre-school to help watch him for any incidents. This is certainly new to us! 🇸🇪



Elias and Robyn at the HTC in Australia  
Photo: Mindi Palm



What's Happening in

# SOUTH AUSTRALIA



We hope to have an education and social event in early 2019, but in the meantime there is work going on behind the scenes to explore re-establishing a Foundation in South Australia for people with bleeding disorders.

Please get behind Team.Factor during the upcoming Challenge Tour in the Santos Tour Down Under. 🇦🇺



## Team.Factor 2019

For the seventh year a group of cyclists led by Dr Simon McRae and Andrew Atkins will ride as Team.Factor to take on the 2019 Challenge Tour in South Australia on Saturday 19 January 2019.

The 2019 Challenge Tour will be from Glenelg to Strathalbyn, just over 158.70kms. Challenge Tour riders will tackle the same route and on the same day as the professional riders in Stage 5 of the Santos Tour Down Under.

Team.Factor's chosen charity is Haemophilia Foundation Australia.

Last year after many months of training their ride was cancelled due to extreme weather conditions – so this year they are all ready to go again.

You can support Team.Factor on the day at the check points or you can make a donation at - <https://give.everydayhero.com/au/team-factor-2019-challenge-tour>.

If you would like to cheer the team on at key location points, let us know at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au). 🇦🇺



# Youth Update

Kassy Drummond



## CHANGES AHEAD

We are refreshing [Factored In](http://Factored In)!

We've created a Youth Working Group to lead these changes, and direct us towards the future of Factored In. The group will be discussing what they like about the site, what they think needs refreshing, and what new stuff they'd like to see. We've had a fair bit of excitement from the group so far, with some of them having already sent us in their ideas and suggestions. It's really great to see young people being so engaged and actively working towards improving the website that they, and some of their predecessors originally built.

The group will have their first meeting in early December and from there we'll decide a plan for any future meetings. They'll be meeting via skype in order to enable everybody to attend. If you'd still like to be involved in the group, or if you have any suggestions for new content, send us an email at [factoredin@haemophilia.org.au](mailto:factoredin@haemophilia.org.au).

We anticipate that layout of the site will stay the same, but in the coming months you may notice some new content being added, as well as some of the images being refreshed.

## NEW INFO AND STORIES

We also have new content on Factored In! During Bleeding Disorders Awareness week we released some

new personal stories videos about building communities, featuring some of our young people! We have also released a 'Girls' information section, based on the information that can be found in the new HFA young women's resource, Female Factors.

Check it out at [www.factoredin.org.au](http://www.factoredin.org.au)!



Unfortunately we have had to postpone Youth Canoe Journey, due to a number of reasons. This will be disappointing for the participants who have already applied, but we want the event to be the best experience possible and right now that means postponing the event.

However, we still have plans for the Youth Canoe Journey to go ahead in the future! If you were thinking about applying and never got around to it, or were unable to attend on the previous dates, send us an email on [factoredin@haemophilia.org.au](mailto:factoredin@haemophilia.org.au) and express your interest. Feel free to let us know what it is that you'd like to see happen on the trip, and any dates that you think would work well for you and other applicants! #

# YOUTH NEWS

## GOING FOR IT



Pat warming up wearing his new shoes

The Haemophilia Foundation Australia's **Go for it Grants** program assists people living with bleeding disorders take the first step towards achieving their goals. The Grant judges have reviewed the applications for the 2018 program and we should hear who has been successful soon.

Some young people in our community have applied for and received this award in the past. In this issue of **Youth News** we have another look at the stories and experiences Pat, Jayden and Sam shared on **Factored In**.

### PAT'S STORY

Last year, Pat received a grant to enable him to play cricket in Darwin. He said *'The Go For it Grant financially assisted me in my journey from Adelaide to play cricket this year in Darwin. It really helped in the first two weeks when my only cricket shoes broke and required immediate replacing.'*

Pat explained that he was also grateful for the support of the Northern Territory haemophilia specialist, which has allowed him to play the sport he loves: *'Other than [my cricket shoes breaking], the season has been relatively hassle free and thanks to the help from the haemophilia specialist up here, I have only missed the 1 game because of an injury.'*

*'Currently we are on mid-season break where the 8 teams are split into 4 for a premier competition called "Strike League". Fortunately I have been lucky enough to be selected to join one of the teams, so my break period will be filled with cricket. This competition appeals to many first class cricketers around Australia, thus giving me the chance to bowl to and stand alongside some of the best young cricketers Australia has to offer. I played my first game on the weekend for them which sadly we lost, but it was a class above any grade I have participated in before.'*

*Without the assistance from the Go For It Grant, I would have either been struck down with injury or had to work instead of playing.'*



Jayden and his clubs getting ready for a round of golf

## JAYDEN'S STORY

Another sporting enthusiast, Jayden used his Grant to assist him with his study at West Virginia University Institute of Technology where he had already received a Golf scholarship for his Tuition. Jayden heard about the Go For It Grant when visiting the Alfred Hospital in Victoria at an orientation day. Upon explaining that he had been offered a scholarship to go to the USA, the Haemophilia Treatment Centre staff proposed that he apply for the Go For It Grant to help him with his flights and college fees in West Virginia.

When asked about his 4 year Aerospace engineering course, he explained *'I wanted to be an engineer before I got the offer to go overseas and I still wanted to do something in aviation'*. It seemed like this scholarship would be the perfect opportunity for Jayden to do both.

His advice to others is: *'Take every opportunity and get everything organised as quickly as possible and as efficiently as you can. Yeah just try and make it happen – if you're suffering with a blood condition – it doesn't mean that you can't do the things you want to do.'*

## SAM'S STORY

Sam took a different path with his Go For It Grant, and used it to travel to the WFH Congress in Orlando. Of the Congress he said *'it was inspiring. The first and most eye-catching thing that you see is a gigantic red banner that had the message "Treatment for All" which was the message for this year's Congress.'*

*'The first and most humbling experience was meeting the sheer amount of people from around the whole world*



Sam takes selfies with the Factored In poster, and represents Australia with HFA President Gavin at the WFH Congress and General Assembly

*that are all here for the same reason - whether they are people with a bleeding disorder looking to see what advancements are happening and how other people are treating, to the doctors and nurses that are looking to other countries as to how they are treating people and the different procedures.*

*That's thousands of people, all experiencing the same thoughts and problems that you are. Haemophilia can sometimes be a really personal disorder to suffer through sometimes, and knowing that there are so many other people just like you is eye-opening, and really helped to set me at ease in this large crowd of so many people.'*

## ACHIEVING YOUR GOALS

The main message from all of these participants is that the Go For It grant really allowed them to achieve things that they might not have been able to without it.

The Go For It Grants program is about enabling people to reach their goals. If there's something you want to get involved with but think you might need extra resources or support, maybe consider applying for a grant in 2019.

Look out for the 2018 Grant recipients soon on the HFA website ([www.haemophilia.org.au](http://www.haemophilia.org.au)), and keep checking the HFA website later in 2019 for information on how to apply for the next Go For It grants.

**Read Pat, Jayden and Sam's full stories on [www.factoredin.org.au](http://www.factoredin.org.au).**

The HFA Go For It Grants are supported by Pfizer. 



# CALENDAR

## **World Haemophilia Day**

17 April 2019

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

## **19th Australian Conference on haemophilia, VWD & rare bleeding disorders**

Novotel Manly, Sydney

10-12 October 2019

## **Bleeding Disorders**

### **Awareness Week**

13-19 October 2019

Tel: 03 9885 7800

Fax: 03 9885 1800

Email: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

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

## **WFH World Congress**

Kuala Lumpur, Malaysia

14-17 June 2020

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

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BIOMARIN | BIOVERATIV | CSL BEHRING  
NOVO NORDISK | PFIZER | ROCHE | SHIRE



## SEASON'S GREETINGS

**The HFA Council and Staff wish you a happy  
and safe festive season.**

**Thank you for your support during 2018 and  
we look forward to working with you again  
in 2019.**

The HFA office will close on Monday 24 December 2018 and reopen on Monday 7 January 2019. During that time if you have any queries or need to contact HFA call 0398857800. Messages during that time will be monitored.

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