

# National Haemophilia

Haemophilia Foundation Australia

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

No. 205, March 2019



# REACHING OUT

**CONNECT TO  
YOUR COMMUNITY**

# CONTENTS

- |    |                             |    |                                 |    |                                     |
|----|-----------------------------|----|---------------------------------|----|-------------------------------------|
| 2  | Dawn Thorp AO               | 14 | New staff – Ageing Project      | 25 | HFA Research Fund                   |
| 3  | From the President          | 15 | Residential care guidelines     | 26 | Youth News – telling others at work |
| 4  | 2019 Conference             | 16 | Play therapy                    | 28 | Calendar                            |
| 6  | World Haemophilia Day       | 19 | Women and peer support          |    |                                     |
| 7  | Mental health options       | 22 | Team.Factor 2019                |    |                                     |
| 12 | Hydrotherapy in haemophilia | 23 | Competing in the sport you love |    |                                     |


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## DAWN THORP ORDER OF AUSTRALIA

Congratulations to Dawn Thorp AO who was awarded an Order of Australia on Australia Day in recognition of her outstanding contributions as a mentor and clinician to nursing and haematology.

Dawn is well known in haemophilia nursing both in Australia and internationally, and has been very generous over her career and now in retirement supporting both other health professionals and the community.

She was the haemophilia nurse for many years in the Haemophilia Treatment Centre at the Royal Adelaide Hospital and was instrumental in setting up the Australian Haemophilia Nurses' Group. She also served on the Haemophilia Foundation Australia (HFA) Council. 

Dawn before she retired in 2001  
Photo: Dawn Thorp





# FROM THE PRESIDENT

*Gavin Finkelstein*


Our conferences seem to come around quickly these days.

However, looking back, it is interesting that some seemingly significant issues have loomed large then settle, while others continue to challenge our stakeholder community over many years.

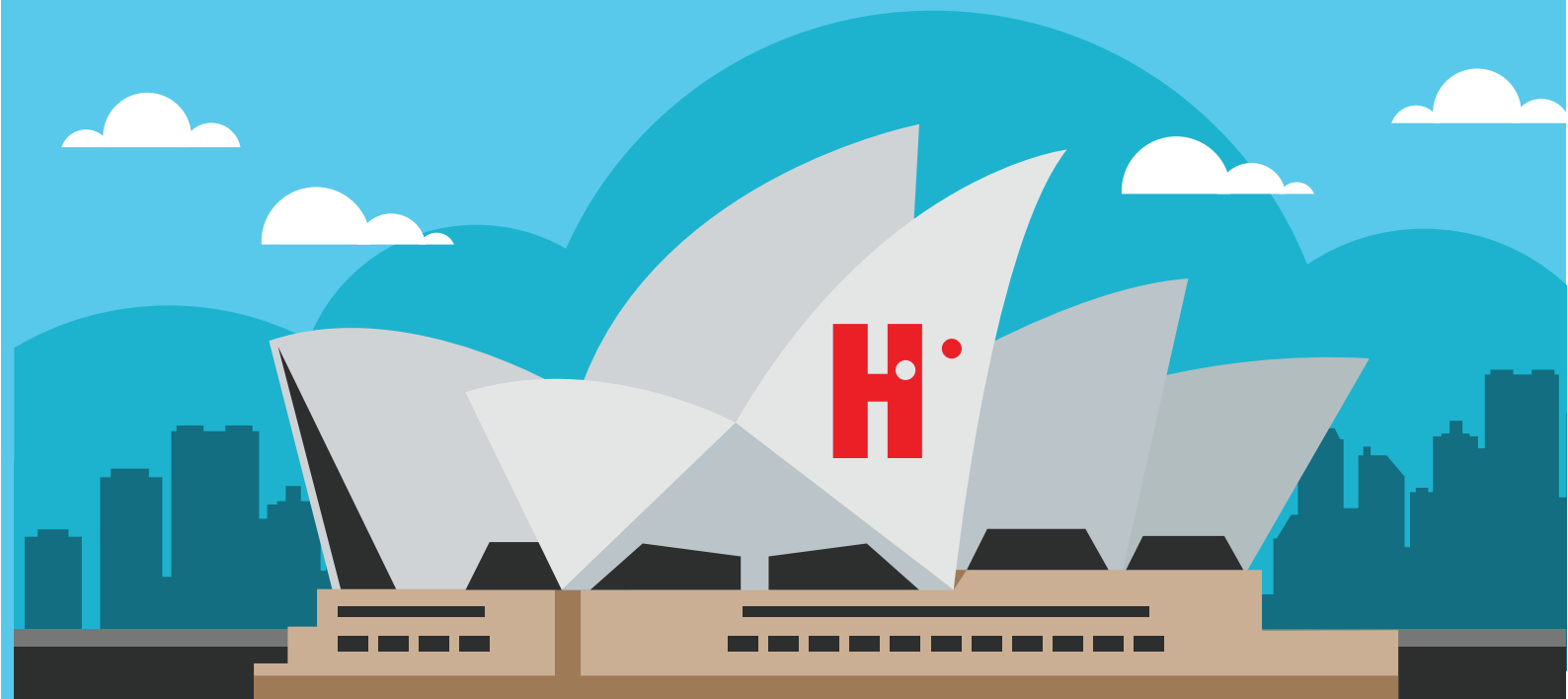
You can expect most of the challenges will be represented in some way at the upcoming Australian Conference in Sydney in October: from access to new and emerging treatment products, to best practice guidelines for the treatment and care of bleeding disorders; and how best to measure the outcomes of treatments through to the tools we want and need to live well with a bleeding disorder.

How we live well with a bleeding disorder depends on the treatment and care that is available, and our approach to our bleeding disorder. This also includes how we are feeling, coping with the issues that come up and managing our mental health.

The new and emerging therapies for haemophilia will likely challenge the way services are set up and provided in the future. This may differ from what we are used to – on one hand, we may think we don't need to attend an HTC as often as before, yet we may need specialist haemophilia health professionals even more to work to help us with our damaged joints, and new complications!

I look forward to discussion at the Conference with our members and other stakeholders about what treatment and care might look like heading into the future. 

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



~ 10-12 October 2019 ~

## 2019 CONFERENCE

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

Chaired by Dr Liane Khoo, Director, Royal Prince Alfred Hospital in Sydney, NSW, the program committee is developing a multidisciplinary program which will interest everyone. We are soon to confirm some of our local and international speakers.

The Conference theme is **Challenging the status quo** and it will cover a range of areas that are part of the discussion around this theme, such as:

- New and emerging treatments
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over the lifetime
- Participating in clinical trials
- Women and girls

The program will include presentations from people living with bleeding disorders as experts as well as health professionals and other specialist speakers

## Who should attend?

- People with haemophilia, von Willebrand disease or other bleeding disorders and their families - parents, siblings, partners – all ages welcome, from young adults to seniors!
- Health professionals – doctors, nurses, physiotherapists, psychosocial workers and other health care providers
- Treatment product producers, suppliers and service providers
- Policy makers and government officials
- Haemophilia Foundation volunteers and staff

**EARLYBIRD REGISTRATIONS  
CLOSE 31 JULY 2019**

## ABSTRACTS AND POSTERS

We are calling for abstracts. Abstracts may be accepted for a presentation in the main conference program or will be presented as a Poster in the Poster Exhibition.

We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy or living with bleeding disorders or treatment complications.

See [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) for the abstract submission form and more information. There will be prizes for the Best Abstract, and the Best Poster.

**Submit your abstract by Friday 31 May 2019**

## OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

The annual meetings of specialist health professionals' groups will be held on Thursday 10 October 2019:

- Australian Haemophilia Centre Directors' Organisation
- Australian Haemophilia Nurses Group
- Australian Haemophilia Social Workers' and Counsellors' Group
- Australian & New Zealand Physiotherapy Haemophilia Group
- ABDR Data Managers Group.

## Welcome and Exhibition Opening

Join us on Thursday evening at the official opening of the exhibition and welcome to the Conference. This is complimentary to all registered delegates.

## Youth

Youth activities will be organised throughout the Conference and the program will have sessions of interest to young people integrated throughout the program over the Friday and Saturday. Additional activities for young people will be organised and we will advise youth who have registered once the final program is confirmed.

## Remembrance Service

A Remembrance Service is a very special time during our Conference to remember friends and family, and the people we have cared for in our community who have died. The service is non-religious and everyone is welcome. It will be held on Friday 11 October 2019 before the Conference Dinner.

## Conference Dinner

Join us for a relaxed dinner with other delegates onsite on Friday 11 October 2019.

## COMMUNITY FUNDING

The conference is an amazing opportunity for the Bleeding Disorders community to attend, participate, gather information and knowledge, meet others and connect. To assist, HFA has allocated funding to assist community members with some of their expenses to attend the Conference. Haemophilia Foundations may also provide funding - contact your local foundation for more information.

For details and an application form for HFA funding go to [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) or call HFA on 1800 807 173 for a form to be emailed or posted. ■

## FIND OUT MORE

For more information and details visit [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences).

The registration and Information brochure is included in this issue of *National Haemophilia*, March 2019.



# WORLD HEMOPHILIA DAY

## 2019 | APRIL 17



**WFH**

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# REACHING OUT

CONNECT TO  
YOUR  
COMMUNITY

# LIGHT IT UP RED!

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

## LIGHT IT UP RED!

Landmarks and monuments in Australia and around the world will support World Haemophilia Day by changing their lighting red on 17 April 2019.

Show your support on the night, and post photos on our Facebook page of you and your friends at the landmark. [#WHD2019](#)

**Keep an eye on our website and Facebook page for a list of locations that will be supporting the day. We have some new and old places, and a location in every state/territory. We would love you to share your photos and pictures on the day.**

### Reach out and connect to your community!

Reach out to others in the bleeding disorders community. Take opportunities to meet others with similar experiences and share your stories and tips. No matter your age or stage, connection throughout life is vital.

Connect with your local foundation  
[www.haemophilia.org.au/foundations](http://www.haemophilia.org.au/foundations)

### Haemophilia Foundation Australia

HFA Website –

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

HFA's Facebook page –

[www.facebook.com/  
HaemophiliaFoundationAustralia](https://www.facebook.com/HaemophiliaFoundationAustralia).

### World Federation of Hemophilia

WFH World Hemophilia Day page –

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

WFH Facebook page –

[www.facebook.com/wfhemophilia](https://www.facebook.com/wfhemophilia)

Diana Harte is Senior Clinical Psychologist at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne

# MENTAL HEALTH OPTIONS

*Diana Harte*

Life is challenging and can be more so when living with a bleeding disorder. Research tells us that one in five Australian's between 16 and 85 years of age will experience a mental illness in any year.<sup>1</sup> People with a chronic physical condition are more likely to experience mental illness such as anxiety, depression and substance abuse.<sup>2</sup> Yet over half the people who experience a mental illness do not access treatment.<sup>3</sup> Now, everyone has times when they feel anxious, sad, 'not quite right' which can make it difficult to know when to seek help. That first step is often the hardest...

>>

## WHEN TO SEEK HELP

It is important to seek help urgently:

- When you are having suicidal thoughts (wanting to die) or are worried you might hurt yourself or someone else – services available are under **More immediate options** below.
- If you are concerned that you or someone you know is at immediate risk of suicide or self-harm - dial triple zero (000).

Some signs that you may benefit from more specialist mental health support include:

- If you have been feeling anxious, worried, sad, and/or "not quite right" and these feelings are not going away after several weeks
- If you have noticed changes in your sleep and appetite/weight
- If you are not doing the things you would normally do because you cannot be bothered or do not have the energy to do them including getting out of bed, having a shower, talking with friends
- If you have been having emotional outbursts including anger
- Friends and family have noticed that you are 'different'
- When your use of alcohol or other drugs is interfering with your health, relationships, school, and work. Also, when you notice that you are needing use alcohol or other drugs to help you cope with your emotions or behaviour. For example, you can only feel relaxed after several alcoholic drinks
- Hearing or seeing things that no-one else can
- Spending more money, being more outlandish, making impulsive decisions
- Believing that there are special connections between events

If you want to check whether you may have been affected by depression or anxiety in the last month visit the **Anxiety and Depression Checklist** on the **Beyond Blue** website:

<https://www.beyondblue.org.au/the-facts/anxiety-and-depression-checklist-k10>

Your GP is an excellent starting point to seek help. I would always encourage you to book a double or long consultation with your GP if you are wanting to raise concerns about your mental health. If you are at school or university there are student health services. If you are working, particularly for a large organisation, many now have employee assistance programs (EAP) that provide access to counselling. And, of course, there is your Haemophilia Treatment Centre (HTC). The majority offer social work and some have psychologists on staff, and they will all also be able to refer you to other psychological support services.

## TYPES OF HELP

There are however many forms of mental health support and treatment options; however, at times, particularly if you are struggling, it can be hard to know what is available. A few are outlined below.

### More immediate options

**Lifeline** – is for anyone having a personal crisis.

**T:** 13 11 14 operates 24/7

Or at night between 7pm and midnight you can chat online.

**W:** [www.lifeline.org.au](http://www.lifeline.org.au)

**Kids Helpline** – is for young people aged between 5 and 25 for any reason.

**T:** 1800 55 1800

Or webchat

**W:** [www.kidshelpline.com.au](http://www.kidshelpline.com.au)

Both are available 24/7.

**Suicide Call Back Service** – if you are thinking about suicide, wishing you were dead, thinking how about you could end your life.

This service is available 24/7 on

**T:** 1300 659 467

Or there is an online chat service as well as video chat

**W:** [www.suicidecallbackservice.org.au](http://www.suicidecallbackservice.org.au)

**Beyond Blue** – focuses on anxiety and depression.

**T:** 1300 22 4636 24/7

And between 3pm and 12 midnight you can chat online

**W:** [www.beyondblue.org.au](http://www.beyondblue.org.au)

At times people who have contacted telephone and internet support have told me that the wait has been too long so they hung up. If you do need support please try to remember that there is someone who will take your call as soon as they can.



## Public mental health services

Public mental health services are available in each state. In general, public mental health services tend to provide 'crisis' services and treatment for acute, significant and serious mental health concerns.

AUSTRALIAN CAPITAL TERRITORY	
<b>Mental Health Crisis Team</b> T: 1800 629 354 or (02) 6205 1065	24-hour/7-days a week service, for assessment and treatment of mentally ill people in crisis situations
Further information can be found at: <a href="https://health.act.gov.au/services/mental-health">https://health.act.gov.au/services/mental-health</a>	
NEW SOUTH WALES	
<b>Mental Health Line</b> T: 1800 011 511	24-hour telephone service, operating 7 days a week
NORTHERN TERRITORY	
<b>Mental Health Support</b> T: 1800 682 288	Free and confidential 24-hour hotline for mental health inquiries
QUEENSLAND	
1300 MH Call or 1300 642 255	Tele-triage service that delivers a single-point-of-access to public mental health services. 24-hour, 7-days-a-week service.
Further information can be found at: <a href="https://www.qld.gov.au/health/mental-health/help-lines/1300-mh-call">https://www.qld.gov.au/health/mental-health/help-lines/1300-mh-call</a>	
SOUTH AUSTRALIA	
<b>Mental Health Services</b> T: 13 14 65	24-hours/7-days a week advice and information in a mental health emergency
TASMANIA	
<b>Mental Health Helpline</b> T: 1800 332 388	Free statewide 24-hour/7-days a week service for mental health crisis reaching all regions
You can learn more about Tasmania's mental health services at <a href="http://www.dhhs.tas.gov.au/mentalhealth/mhs_tas">www.dhhs.tas.gov.au/mentalhealth/mhs_tas</a>	
VICTORIA	
You can find the contact details for your local service and learn more about the Victorian Public Mental Health Services at: <a href="http://www.health.vic.gov.au/mentalhealthservices">www.health.vic.gov.au/mentalhealthservices</a> .	
<b>Nurse On Call</b> T: 1300 60 60 24	For immediate, expert health advice from a nurse.
WESTERN AUSTRALIA	
<b>Mental Health Emergency Response Line</b> T: (08) 9224 888 1300 555 788 (Metro) 1800 676 822 (Peel)	Psychiatric emergency assessment and advice for mental health clients and their carers
<b>Rural Link</b> T: 1800 552 022	Specialist after-hours mental health telephone service for rural communities Mon-Fri: 4.30pm-8.30am, Saturday, Sunday, Public holidays: 24-hours. It is my understanding if you ring the number during business hours your call will go through to your local mental health service
Further information can be found at: <a href="http://www.mhc.wa.gov.au/getting-help/public-mental-health-services">www.mhc.wa.gov.au/getting-help/public-mental-health-services</a>	



## Structured internet-based treatment options

**Mental Health Online:** offers an online mental health assessment as well as a set of programs for specific anxiety disorders and depression.

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

**MoodGYM and e-couch:** these are free self-help programs designed for use by adolescents and adults respectively.

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

For adolescents – <https://ecouch.anu.edu.au>

**myCompass (Black Dog Institute):** a free self-help program for people experiencing mild to moderate stress, depression and anxiety.

**W:** [www.mycompass.org.au](http://www.mycompass.org.au)

**OnTrack:** offers several free self-help programs including one for problem drinking as well as support of family and friends who are supporting someone with a mental illness.

**W:** [www.ontrack.org.au](http://www.ontrack.org.au)

**THISWAYUP:** a set of self-help programs available in a desktop form or as an app with specific programs for particular disorders; there is even a chronic pain course. You can access these courses independently, or if you are seeing a mental health clinician or doctor that is registered with THISWAY UP they can supervise your progress through the program. Some of the courses do have a cost to access them.

**W:** <https://thiswayup.org.au>

## In person options

Your Haemophilia Treatment Centre (HTC) may be able to provide access to mental health assessment and treatment, as most have social workers and/or a

psychologist on staff, or can refer you to a counsellor or psychologist. Once again, your GP is always a good starting point as they tend to know the availability of local public and private services. Additionally, GPs can make a referral to a mental health clinician through Medicare. One of the most common Medicare programs under which GPs make referrals to private mental health professionals is **Better Access to Mental Health Care:** this offers a rebate for up to ten sessions individual and/or ten group sessions in a calendar year. To be eligible for Better Access to Mental Health Care you need to have a 'clinically diagnosable' mental illness. At times when you are experiencing difficulties, your symptoms may not be at the level that allows a referral under Medicare. However, it is always worth a discussion with your GP and it is recommended that you book a longer appointment with your GP for that conversation.

You can learn more about the various different Medicare programs for Mental Health at [www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services](http://www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services).

For those linking in rural and remote Australia there are now Medicare rebates for telehealth. Some HTCs also offer telehealth under certain circumstances.

You do not need a referral to access a psychologist or counsellor, but there will be a cost to you. Word-of-mouth is always a good guide as to the options in your local area. Internet searches such as 'mental health providers' or 'psychologist' are good general terms. There are also professional bodies that list potential providers such as:

**Australian Counselling Association**

**T:** 1300 784 333

**W:** [www.theaca.net.au/find-registered-counsellor.php](http://www.theaca.net.au/find-registered-counsellor.php)



### Australian Psychological Association

T: 1800 333 497

W: [www.psychology.org.au/Find-a-Psychologist](http://www.psychology.org.au/Find-a-Psychologist)

### Australian Association of Social Workers

W: <https://www.aasw.asn.au/find-a-social-worker/search/>

### Headspace

If you are aged 12 to 25 years, Headspace offers both face-to-face, online and telephone support with the majority of their services at no cost. You can find out more at

W: [www.headspace.org.au](http://www.headspace.org.au).

## Internet versus in-person treatment

One of the major benefits of internet-based treatments, like those listed above, is the convenience. You can do internet-based treatment anywhere you have an internet connection. Another factor is cost: there are no travel expenses and as you can see from the above list there are many free options. Self-help/structured internet programs however may miss information that can be very important in accurate diagnosis such as facial expressions and tone of voice. Also, at times it can be very difficult to maintain motivation to complete the program without someone to encourage you to do so. In-person treatment offers that human connection and ability to adapt treatment to your specific needs. Also, some very effective treatments are not suitable to be offered over the internet.

The length and frequency of sessions required to address your mental health and emotional needs will depend on a broad range of factors including the severity of your symptoms, goals, and the type of treatment. You will find that the majority of publicly-funded programs offer a limited number of sessions and at times people will require more. The **Better Access to Mental Health Care** initiative program under Medicare only provides a rebate for ten sessions in a calendar year with an approved mental health clinician.

This can be incredibly concerning and frustrating for everyone; it is why using all available options such as internet-based programs and working with your mental health clinician prior to discharge on a wellness or relapse plan is so important.

## INSURANCE

An issue to be aware of, unfortunately, is that people who have or had a mental health diagnosis can have difficulties obtaining insurance. If you do not disclose on insurance forms, even when applying for mortgage insurance, that you have sought emotional or mental health support it can void any policy.

You can learn more about this on the Beyond Blue website at [www.beyondblue.org.au/about-us/about-our-work/discrimination-in-insurance](http://www.beyondblue.org.au/about-us/about-our-work/discrimination-in-insurance).

There are many reasons as to why people who experience mental illness do not seek help. At times it is not understanding that what is being experienced is an illness and that there are effective treatments. On other occasions it is not being aware of the many options that are available. It can be incredibly hard to take that first step, and sometimes in that first step you do not find the 'right' person or service to support you, so you need to take a second step. I do hope that this article makes taking a step to looking after your mental health a little easier. ■

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# HYDROTHERAPY IN HAEMOPHILIA

*Josh Wakefield*

Exercise is an essential part of a healthy life, which is well supported by research and promoted in national and international guidelines. The benefits of challenging the human body through exercise are well founded by research and extend well beyond the musculoskeletal. Of course, improvements to strength, endurance, flexibility, balance and proprioception (our awareness of where our body is in space) are of great importance, particularly as we age. This allows participation in valued activities and maintaining quality of life and independence throughout life. Often overshadowed, however, are benefits to neuro-immune function, psychological well-being and cardiovascular function which should also be considered as part of the wellbeing cocktail that physical activity can provide.

These benefits are of even greater importance to people with haemophilia. Several modalities (treatment methods) of land-based exercise such as resistance, flexibility and cardiovascular training have demonstrated reduced bleed frequency and severity, improved range of motion and strength during bleed rehabilitation and pain management. However, these land-based modalities often come with an inherent risk of injury and bleed, especially when first commenced. As a result, these exercise forms often require close and ongoing supervision from a healthcare professional with haemophilia experience such as a physiotherapist.

## BENEFITS

Hydrotherapy provides a non-land based, low impact exercise option that has many of the above benefits with a significant reduction in bleed risk. International and national guidelines also support the therapeutic benefits of hydrotherapy. Specific benefits demonstrated in the literature include benefits to:

- Elbow, knee and ankle range of motion (ROM)
- Knee flexion and extension strength
- Pain
- And cardiorespiratory function (oxygen uptake, relative



oxygen uptake, carbon dioxide production, heart rate, respiratory quotient, and distance run in Cooper's test - a 12 minute timed running test designed to measure aerobic/cardiovascular capacity).

Most of the programs in the literature consist of 12 x 1 hour sessions over 6 weeks, supervised by a physiotherapist.

The physiological improvements above are attributed to several properties of water.

- **Hydrostatic pressure** is the pressure exerted by a liquid depending on how deep it is, due to gravity. This pressure is about 88.9mmHg at 1.22m deep, which is slightly higher than normal diastolic blood pressure (80mmHg). The circulatory and lymphatic systems are both influenced by this external environmental change. Compression of the superficial vessels promotes lymphatic fluid and blood centrally towards the abdomen and thorax. Increases of central blood volume of up to 60% have been documented in literature as a result of hydrostatic pressure. These processes result in reduced peripheral oedema (swelling), improved cardiac output and improved muscle contraction. Hydrostatic pressure is most effective when in water at least at sternum (breastbone) level.
- **Buoyancy** occurs due to displacement of fluid and acts directly opposite to gravity. When the human body is immersed in water, pressure on joints can decrease by up to 60%. This decreased compressive load through weight-bearing joints enables people with haemophilia to complete activities that may be difficult on land including walking, squatting, jumping and hopping.





- **Water temperatures over 30 degrees Celsius** have been shown to improve muscle contractility, joint movement and can assist with reducing pain.

However, the current evidence is actually quite poor, as highlighted by Nicola Blum's 2015 literature review. This is primarily due to methodological pitfalls including small sample populations, lack of comparison to control populations, poor long-term follow-up and the wide variety of outcome measures used. Some studies also failed to outline their hydrotherapy program, making reproduction impossible. Nevertheless, it is still clinically worthwhile to identify common themes in the literature to guide hydrotherapy programs.

There are several useful resources available online that provide some useful ideas for exercising in water – the article on swimming and haemophilia in the National Hemophilia Federation (USA) magazine *Hemaware* provides a great introduction: <https://hemaware.org/bleeding-disorders-z/swimming-and-hemophilia>. As a general rule, most land-based exercises can be adapted to the hydrotherapy/pool environment with a little creativity. Exploring these movements may allow you to find new ways of completing land exercises. For instance, practicing a step up or squat in a pool provides a much safer environment than on land. The same could be said for practicing heel-toe walking for balance or leg kicks for lower limb strength.

To ensure you are using your time as efficiently and safely as possible, contact your local HTC Physiotherapist for guidance on an individualized hydrotherapy program. 🏊

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# NEW STAFF – AGEING PROJECT

Preetha Jayaram joined the HFA team in February 2019 to start work on HFA's new Ageing project.

HFA has received funding from the Australian Government Department of Health to investigate the needs of the bleeding disorders community around ageing and try out some solutions relating to education and peer support. Preetha is leading the project and will be in contact with community members, HTC's and other stakeholders to consult about the issues.

With her diverse set of skills and background, Preetha is looking forward to taking on the Ageing project with HFA.

She began her career as a social scientist and anthropologist conducting research into castes, tribes and rural development in Kerala State in India.

'After migrating to Australia in early 1990s, I continued my research career working with Melbourne's local government community services departments on ageing projects,' said Preetha. 'This involved visiting and talking with many older people in the community – in one project we interviewed around 500 older residents!'

Preetha then moved on to curatorial work and digitising the indigenous collection at Museum Victoria. She also had the opportunity to undertake research and community consultations for the Stolen Generations organisation in Melbourne.

More recently, Preetha has followed her interest in education and has gained qualifications and expertise in education program design and content development for the Vocational Education and Training (VET) sector. She currently also works part-time as the Training and Compliance Manager for a vocational education provider in Melbourne.

'I love interacting with people and listening to their stories. I have a strong belief in using personal stories to understand and empower the community.'

Preetha enjoys music, art and meditation and values its therapeutic effects.

Preetha works on Monday, Tuesday and Wednesday and can be contacted at HFA office:

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

T: 03 98857800



# RESIDENTIAL CARE GUIDELINES



## What does a nursing home or aged care hostel need to know if a person with a bleeding disorder moves in as a resident?

With improved treatments, many people with bleeding disorders now live into their senior years and may need to move into a residential care facility at some stage in their life. The staff at the facility may have a range of new situations to deal with, such as:

- What to do when the resident has an injury or a bleed
- How to work with their Haemophilia Treatment Centre
- Managing the resident's treatment and infusions
- Understanding their or their carer's expertise in managing their care after a lifetime of dealing with their bleeding disorder
- Managing their privacy, especially around bloodborne viruses.

The Australian Haemophilia Nurses' Group (AHNG) and the Australia/New Zealand Social Workers' and Counsellors' Group (ANZHSWCG) have developed an

information booklet and fact sheet for nurses, personal care assistants and other staff in residential care facilities that answer these and other common questions.

**Caring for people with inherited bleeding disorders: information for staff working in residential care facilities** fact sheets and booklets are available in print from your local HTC. Usually the HTC will provide these resources to the staff with some education when one of their patients enters a residential care facility.

They are also downloadable from the HFA website under PUBLICATIONS at <https://www.haemophilia.org.au/publications/ageing/for-health-professionals>. 

# PLAYING FOR A SUCCESSFUL HTC VISIT

## Teaching and supporting children with haemophilia

Jaime Chase and Veronica Oakley

*Tom is 5 years old and has mild haemophilia A. He has had a minimal number of injuries in the past that have required the intervention of factor. He is normally very happy to come in to his Haemophilia Treatment Centre (HTC) to see staff and looks curiously at staff if he does require treatment.*

*Tom was wrestling with his brother 3 days ago and has a swollen shin on his left leg. He presented to the hospital over the weekend and has had two doses of factor, each on consecutive days. On arrival to the HTC for review and a likely third dose of factor he is clingy to his caregiver and panicky about the possibility of more factor...*

A child with haemophilia passes through many stages of childhood, as does any child. Generally, a child's ability to understand their disorder will relate directly to the stage of childhood they are currently experiencing. Babies to adolescents all have different needs and requirements both for learning about their haemophilia and how to manage their treatment.

Child Life therapy or [play therapy](#) is therapy offered by specialist professionals across many children's hospitals across Australia. Child Life Specialists work with other health care staff to adequately prepare children and families in hospitals and other settings to cope with hospitalisation, procedures and understanding their condition. The Child Life Specialist has an extensive knowledge about the differing stages of child development and how each stage can affect treatment. At John Hunter Children's Hospital the Haematology Child Life Therapist has been working with the Haematology Clinical Nurse Specialist to develop specific activities to support children with haemophilia.

One way of supporting a child with haemophilia we have been exploring is the utilisation of a [busy bag](#). This play or activity bag is one that comes with the child to the HTC or hospital and is used at home for infusions. This bag of activities has specific play items in it only to be used for hospital or treatment days. Devices can have specific apps that are only used on these days. The bags described below are designed specifically for each developmental stage that children to adolescent's experience.



## BABIES (UP TO ONE YEAR)

Babies need comfort and support during their infusions and examinations. This may mean a [position of comfort](#) for the baby, where the parent holds the baby in a specific position to allow a hugging hold. This hold gives comfort and security while giving health care staff safe access to the child for infusions and examination of limbs. The upright position promotes a sense of control for the child. The utilisation of calming music and distractions such as bubbles can also be useful. The introduction of picture books about factor and infusions can be beneficial at this time.

### Busy Bag Contents

Pacifier (dummy, cuddly etc)

Bubbles

Special toys that are only used for HTC trips and infusions

Calming music





## TODDLERS (1 TO 3 YEARS OLD)

Toddlers of this age understand their world through touching, seeing and hearing. We know that toddlers do not understand cause and effect, so they are often very surprised that an adventure has ended up in their HTC.

Comfort for the toddler remains paramount at this time, so a position of comfort is very important, as is the nomination of [one voice](#) – nominating one person only to speak to the child. To enhance the child's sense of security, a parent who has been educated on what will happen prior to the intervention is ideal to talk during the procedure. This allows the child to feel secure and validated and gives positive reinforcement. The involvement of parents/caregivers is vital. Using numbing cream pre-infusion and distraction can be beneficial at this time.

As soon as the child is able, they should be involved in the procedure - holding band-aids® and helping staff set up (if appropriate). The use of medical kits to play with at home are encouraged as are the continued reading of board books about haemophilia.

Toddlers will also benefit (if able) from a trip to the HTC when nothing happens. The opportunity to come to a centre and have no infusions and play is very comforting to the toddler and may allay fear that the HTC is a place where you always get held and are given infusions.

### Busy Bag Contents

Cuddly toy (if wanted)  
Special busy toy  
Bubbles  
Specific App on IPAD/ phone that is only used for HTC trips/ infusions  
Calming music  
Making a small photo book of the child's trips to hospital can also be beneficial

## PRESCHOOL (3 TO 7 YEARS)

Children of this age group have what is called 'magical thinking'. This can be explained as the six-year-old who only draws from his own experiences to explain the world around him. When asked what is haemophilia, he may reply 'when I get hurt and need a needle'. Pre-schoolers are very egocentric - meaning that they understand that these things are happening to them but do not have the capacity to know that what happens to a doll might happen to them. Preparation toys at home and practicing factor administration are very successful for this age group.

Positions of comfort are still very important during this age group as is the involvement of the children in setting up for their procedure and asking them to hold band-aids etc. Numbing cream (if used) remains important as do distraction techniques.

Education involves the reading of books, making a social story about going to hospital and the use of colouring in pages. A medical kit at home and time spent acting out infusion scenarios can be beneficial, with play being directed and initiated by the child. Trips to the HTC that do not require treatment are also beneficial at this age.

### Busy Bag Contents

Cuddly toy  
Art and/ or craft activity  
Playdough  
Special app on device  
Using a photo book to document experiences

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## SCHOOL-AGED (7 TO 11 YEARS)

This age group is entering into the realm of logical thinking - meaning that they can start to think in a step-by-step process. This enables them to start to think about self-infusion. They are less egocentric in the way that they view the world - this is when demonstrating on a doll or arm makes sense to the child. School-aged children are able to read more and understand relevant teaching steps.

This age group is perfect for books and simplified teaching about their haemophilia. Encourage participation in the transfusion process - working towards self-infusion. Involve the child in decision-making regarding sports and activities that may be offered and ask for their input early about activities offered. This can mitigate the way that children approach sporting activities and perhaps making the wrong decisions about what lunchtime sport they should join in for.

### Busy Bag Contents

Special cuddly toy  
Craft/ building activities  
IPAD/device  
Music devices  
Knowledge of deep breathing and visualisations.

## ADOLESCENT (11 YEARS AND OVER)

Adolescence is an area of great growth and with this brings opportunities for learning, experiences and experimentation. Adolescents continue to be able to think logically (step-by-step) and to understand that there are consequences for their actions.

Talk openly and honestly with the adolescent about both their treatment and their plans for the future. This is the age where most adolescents are self-infusing and starting to take control of their own haemophilia.

### Busy Bag Contents

Personal devices  
Knowledge of deep breathing/visualisations  
Specific games activity - cards etc.

If we look back to the example of 'Tom' given in the first paragraph, we can see a child who is worried and nervous about the possibility of factor. Luckily, he didn't need any more factor that day and the experience was turned into a positive one with a trip to the Starlight room and spending time playing with nursing staff before leaving the Unit. This positive experience was very beneficial to Tom

The utilisation of play in the ongoing care of children and adolescents with haemophilia is important to promote trusting relationships with healthcare providers.


If you have any questions, please see your local HTC for further information.

## FURTHER READING

Association of Child Life Therapists Australia -  
[Childlife.org.au](http://Childlife.org.au)

Child Development:  
The Center for Parenting Education –  
[centerforparentingeducation.org](http://centerforparentingeducation.org) Child Development  
Institute -  
[childdevelopmentinfo.com](http://childdevelopmentinfo.com)





Julia Minty is a Committee Member of Haemophilia Foundation Australian Capital Territory and carries the gene for haemophilia

# WOMEN AND PEER SUPPORT

## PEER SUPPORT FOR WOMEN IN A LOCAL CONTEXT

How are local Foundations exploring peer support for women? What can we learn from their experiences?

The importance of peer support for women affected by bleeding disorders was a key finding in HFA's consultation for The Female Factors Project. Often feeling isolated and as though they are the only ones with their experiences, women have found connecting and sharing stories to be immensely valuable and empowering.

The local Foundation activities to connect and support women are a concrete way of making a difference for women. HFA also makes a point of including personal stories from Australian women with the evidence-based information in all The Female Factors education materials.

This report from Haemophilia Foundation Australian Capital Territory (HFACT) is the third in a series about local peer support for women from Australian State and Territory Foundations.

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*HFA spoke with Julia Minty from HFACT about the Foundation's peer support activities for women.*

## STARTING UP

How do you go from thinking a peer support group for women is a good idea to making it happen? Julia Minty was part of the push to set up the women's group in the ACT and recalled how it came about.

'Our Women's Wisdom group is our key activity supporting women,' said Julia. 'We started it in April 2008. It's already more than 10 years old, which is hard to believe! There was a sense that there was an unmet need in that area. I think a few of us thought, why don't we try getting women together on a semi-regular basis. It can be women with a bleeding disorder, carers, partners, friends of people with bleeding disorders – we took a very inclusive approach. I can't remember the exact details of the first event, but it was clearly successful because it has continued pretty consistently since then.'

Being personally affected by a bleeding disorder (her father has haemophilia as do her three sons), Julia was keen to help establish and benefit from the group, but could also see the bigger picture for the community. 'I've been connected with the community all my life,' commented Julia. 'My family has always been involved with the HFACT Committee in one way or another. So I was part of the conversation with other women about starting a support network for women. My husband and I wanted to start a family and I knew the group would be beneficial to us, but I could also see it would benefit others in the community. My whole family was on board, my sister, and my mother who was on the phone with us inviting women in our community to come along and participate.'

## WOMEN'S GROUP MEETINGS

The HFACT Women's Wisdom group has been very successful.

'The group meets about three to four times a year. We get a pretty good turnout, considering we are a fairly small community: 10 to 15 women, sometimes more,' reflected Julia. 'There are the women who come all the time, but there are also new people from time to time, which is always welcome. You feel like you are giving them some sense of connection, someone to talk to.'

'We have a range of activities. Some of the events we have done have been afternoon teas that someone will host, or we will go to a café. One of the most successful events recently was a women-only drinks on a weeknight after work. It was only intended to be an hour drop-in on your way home, but as it turned out, 15 or more women came, it went for 2 hours, some new women came and joined the Foundation, we exchanged phone numbers and email addresses, and discussed a whole range of interesting topics. For example, one woman with a bleeding disorder was pregnant with her first child, so there were experiences to share and ways to assist each other.'

'We also have other opportunities for women to connect, for example, at community camps, and the annual midwinter dinner. Sometimes there will be a special session at the HFACT community camp where women will meet separately to chat, but often women will just feel more confident about catching up with each other in general camp activities. You can really see the network fostered through the Women's Wisdom forum at work in these broader events because you can see the connections the women have built with each other and there is a natural ease and friendliness straight away.'

## STRATEGIES TO MAINTAIN ENGAGEMENT

'We are pretty flexible in our thinking about the kinds of activities or events the Women's Wisdom forum holds, and like to try different things out.'

'However, one thing we noticed was that when there was no particular focus for a gathering, interest would start slipping. We have found it is good to have a key point of discussion or key speaker to give a focus to the meeting and that tends to attract members to come along.'

'On one occasion we met at the [former] counsellor's house for afternoon tea and had invited a music therapist as a guest speaker. She played her harp and talked about her experiences as a therapist in medical settings, and that was thought-provoking and different. Often this kind of approach can work as an ice-breaker, something to start the discussion, so that people relax and open up.'

'On another occasion we went to one of the women's house for afternoon tea and had the genetic counsellor





from The Canberra Hospital speak to us. It was well attended and quite a few young women came along to that because of the subject matter.

‘The group waxes and wanes and sometimes we have had to contact women directly to invite them to attend. Women appreciate that personal touch, the extra step to make them feel included, especially in an area like haemophilia, which can be a bit male-dominated. We do promote the events in the newsletter, but you need to follow up with personal contact to keep people involved and keep the group alive.

‘The HFACT counsellor is very active in enabling women to get in touch with each other, bringing new members into the forum and facilitating the exchange of contact details. Bringing people into the fold can be a challenge - making them feel part of the group and letting them know that there are people there they can talk to and who will listen to them.’

## IMPACT OF PEER SUPPORT

Bleeding disorders are rare and treatments and services are specialised, which can be very daunting for women negotiating the health system for the first time for themselves and their family. Peer support can be invaluable.

Julia described her experience of using the women’s network to provide peer support to women with bleeding disorders in the ACT.

‘My sister Rebecca and I have personally set up one-on-one catch-ups with other women who were having particular issues and we were able to draw on our own experiences to share in our conversations with them. One example was with a woman who was new to Canberra and was trying to start a family but was having difficulties finding out what networks and services were available. We were able to put her in contact with the genetic counsellor; share our experiences of testing during pregnancy and post-birth. She found this very useful and then felt comfortable to join the after-work women’s drinks to talk to the other women.

‘Another example I have personally is of a mother wanting to know how she could put together

information packs and emergency plans to assist her child with haemophilia starting at childcare and then at school. She wanted to know how you go about this process – it can be quite challenging when you first let your child go out into the world and have other people take over their care. We talked with her about how we managed this and what we did. We ourselves have been on the receiving end of this kind of advice in the past: years ago when our children were starting childcare, we also went through the Women’s Wisdom network and spoke to a woman who had already gone through this important step with her son. She explained the process to us and shared the proformas she had developed for emergency plans and so on, and we then developed our own. This transfer of knowledge is incredibly important.

## EDUCATION MATERIALS

Education materials like **The Female Factors** booklets are an important tool to use with peer support. These kind of resources have been posted out with the HFACT newsletter, but are also valuable information to take to one-to-one meetings with new people. ‘The HFACT counsellor is well aware of the range of new resources and is proactive about making them available to community members and the hospital, which means they are there for people to access them when needed,’ said Julia.

## MAKING IT ATTRACTIVE

One of the most important lessons HFACT has learned from the Women’s Wisdom forum is to make sure an information night or a peer support meeting is tied into a good social experience. ‘The most successful events have been a good social catch-up but have also had a particular focus – a topic of interest or something else that draws people in. Once the women are there, the networks begin to get established and then the benefits really start to flow.’

Julia’s final reflections on establishing a women’s peer support group? ‘To get a group off the ground, you need a fairly committed and sustained push and to have some attractive events. The groups will ebb and flow, but just keep pushing them along – there are real benefits for the women in your community’. ■



# TEAM.FACTOR 2019

For the seventh year Team.Factor took on the 2019 Challenge Tour in South Australia on Saturday 19 January 2019. The ride was from Glenelg to Strathalbyn, just over 158.70kms. This was the same route and on the same day as the professional elite cyclists in Stage 5 of the Santos Tour Down Under.

The team who took on the challenge this year included Andrew Atkins, Uwe Hahn, Philip Shaw, Cameron Cramey, Dan Drake and Bradley Clausen. Some of Team.Factor you may know from the South Australia Haemophilia Treatment Centre or the Royal Adelaide Hospital, and they were all keen to support their cause with this challenging ride.

Team.Factor's chosen charity is Haemophilia Foundation Australia and they have raised just over \$600. We thank everyone who made a donation supporting the team. It's not too late to make donation - visit <https://give.everydayhero.com/au/team-factor-2019-challenge-tour>.

Andrew Atkins, Nurse Consultant at the SA HTC and the organiser of Team.Factor, wrote:

'The full Challenge Tour this year took the riders (including Uwe, Dan and Cameron) from Glenelg at 6 am south through the Fleurieu Peninsula to Sellicks Hill (King of the Mountain) and on to Willunga. From here the course tracked down to Yankalilla then inland through Inman Valley to Victor Harbor, then along the coast to Goolwa, and finishing 35 km later in Strathalbyn. A whopping total of 160 km but (apparently!) a less strenuous ride than previous years.

'Willunga was the second starting site for those smart enough to know they couldn't do the full journey (i.e., Brad, Phil and myself) - a much more realistic 100 km... We set off at 7 am and despite making an average speed of 25 km/hr were still overtaken by Dan and Uwe 15 km before the end (damn!).

'A great ride, with enjoyable scenery along winding hills and valley roads. Well worth the effort for those keen on cycling.

'Thanks to the Team and a special thanks to those who donated to HFA.' ❧







Alex with local SA community members and HTC and HFA staff in 2012  
Photo:HFA

## COMPETING IN THE SPORT YOU LOVE

Alex Dowsett's trip to Australia to compete in the Tour Down Under in South Australia and the Cadel Evans Great Ocean Road cycling races this January was a great opportunity for some young Australians to catch up with Alex and talk about haemophilia, sport and following your dreams.

Alex is a young man from the United Kingdom with severe haemophilia A who is an elite cyclist and is an ambassador for the haemophilia community internationally. In 2012 he appeared on the UK television program **Embarrassing bodies** talking about haemophilia and how he manages his cycling career (Series 5, Episode 3). He is now part of the Little Bleeders team, a UK charity that raises awareness about haemophilia, young people and sport. You can read Alex's story on the Little Bleeders website - <http://www.littlebleeders.com/alexs-story>

After his first ride in the Tour Down Under in 2012, Alex met with the local haemophilia community in South Australia and inspired the HTC team at the Royal Adelaide Hospital to set up Team.Factor for the Challenge Tour.

After competing in Race Melbourne at Albert Park, Alex took time out from his busy training schedule to meet up and have a chat with the Donaldson family from Victoria, particularly with their son Will, who has haemophilia and is a keen surfer. Reflecting on this experience, both the Donaldsons and Alex felt that there was much to learn from each other.

**Alex Dowsett** commented:

*'This today has made my whole trip, meeting young Will, an 11-year-old surfer from near Torquay, Victoria. Like me he's also got severe haemophilia A, and I guess also like me it's clearly not stopping him competing in the sport he loves.'*

*Haemophilia has come such a long way in such a small space of time. If I was born 5-10 years earlier it would've been a different story for me, and haemophiliacs born later and later have such bright prospects, which is incredible to see.*

*It's the stories and examples like Will that let others know their youngster with haemophilia won't be restricted in their life ahead and sends a message that they will grow up with the same opportunities to lead as normal lives as possible with a condition that was once hugely debilitating - and that's all any parent wants for their kid, equal opportunities.'*



**Karen Donaldson**, Will's mother, spoke afterwards about their meeting:


*'We have been very fortunate to meet this incredible human who has inspired many people including kids with haemophilia. To reach the top level of their sport with a condition we know is difficult to manage at the best of times is such an incredible achievement. Thank you, Alex Dowsett, for stealing some of your time and for encouraging Will to drive forward in sport and conquer to the best of his ability, despite having haemophilia. I hope you heard us cheering loudly at the Bell's Beach climb!'*

*'I enjoyed the connection and interest Alex had with Will when they met up.'*

*'They discussed the frequency of prophylaxis, the issues associated with self-infusions, target joints and how to combat rigorous training with the important timing of factor administration.'*

*It seems kids with haemophilia do tend to grow up quickly, as Alex suggested. It's not often you would have such mature discussions with an 11-year-old.*

*What a positive and humble person Alex is. To give up his time to have a meaningful discussion with a local 11-year-old boy is something pretty special.'*

Our thanks to the Donaldson Family and Alex Dowsett for permission to publish their story, photos and posts from Facebook. 



Will Donaldson and Alex Dowsett catching up along the Great Ocean Road  
Photos: Karen Donaldson



Alex (number 131) in Race Melbourne  
Photo: HFA





2019-2020 Funding Round Open!

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# HAEMOPHILIA FOUNDATION AUSTRALIA RESEARCH FUND

\$20,000 is available for medical, scientific or social research to improve outcomes for people with haemophilia, von Willebrand disease or other related bleeding disorders, and/or those with medically acquired blood borne viruses.

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The funding round is for research projects to be commenced in the 2019 - 2020 financial year.

Closing Date - 19 July 2019

For further details and application form:


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

or

contact HFA

A: 7 Dene Ave Malvern East Vic 3145

T: 03 9885 7800

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

# YOUTH NEWS

*'An employer might be much more understanding and supportive if I am open from the beginning!'*

Starting work a new job is a stressful time for anyone, but bleeding disorders can carry with them a few extra challenges. We spoke with one of our youth leaders, Robbie, who has severe haemophilia. He shared with us his story about disclosure at work and the issues that came up for him.

*'When I start a new job there are millions of things running through my mind. How am I going to remember all these names, what day do I get paid, who am I working with, am I in over my head, where was the bathroom again?'*

*In a time that is already equal parts exciting and stressful it can seem overwhelming to throw another big question into the mix; do I need to tell my workplace that I have haemophilia?'*

## DO YOU NEED TO DISCLOSE?

It can be hard to know if you need to disclose your bleeding disorder at work, or if it would be helpful.

Usually you are not required to tell your employer about your bleeding disorder unless

- you are applying to join the Australian Defence Force or police force
- or your health condition means there may be a risk to occupational health and safety or you may not be able to perform the basic requirements of your job.

See the **Disclosure** section on the HFA website for more information - <https://www.haemophilia.org.au/about-bleeding-disorders/disclosure>

You may be wondering if your employer needs to know about your bleeding disorder so that they can make reasonable arrangements that would allow you to continue working without causing injuries, or so that they can be prepared in case any emergencies occur.

Robbie's approach to these questions was, *'I like to think about it in two ways; how my job can impact my health and my haemophilia and if I might need to take sick days off work. If a job is physically demanding and likely to place a strain on my health then I might consider telling my boss*

*Some questions I have asked myself to help make this decision are:*

*'What kind of activities does this job involve?', 'Will my target joints be used a lot in this job?', 'Am I going to be on my feet for extended periods of time?', 'Does this job involve heavy lifting?', 'Does this job involve a lot of walking or a large amount of stairs?'*

Robbie prefers to be realistic and to think about these kind of things before he begins a new job. *I think that it is important to be honest with myself when answering these questions. If the answer is an overwhelming yes and I think that there might be some impact on my health then that's fine, there's absolutely no shame in that!*

*No job is worth risking my health.'*

## WHY WOULD YOU DISCLOSE?

Another question is whether or not you would disclose your bleeding disorder to your new employer. This is a very individual decision and can often depend on the workplace as well as your personal situation. It might be that it's easier for everyone involved if you don't volunteer information unless asked, or you might decide that it's in your best interest to do so, particularly if you have frequent bleeds.

For Robbie, *'the other important consideration is taking sick days off work. If I know that I might have to regularly need to take days off because of an injury or a bleed, whether this has been at school or in previous jobs, then I think it might be time to think about talking to my boss.'*



# TELLING OTHERS AT WORK

*'An employer might be much more understanding and supportive if I am open from the beginning!'*

Robbie commented that, although he had more frequent sick days in high school, he is better now at managing his health, and this hasn't happened in his post-school life, so telling his employer has not been necessary for him.

## WHAT ABOUT COLLEAGUES?

What about telling work colleagues about your bleeding disorder?

Once again this is a personal decision and could be influenced by the workplace situation or your relationship with individual colleagues, as Robbie has experienced:

*'Even though I haven't told my employer about my haemophilia, it doesn't mean I haven't discussed it with anyone at work! There are days I have been at work when I'm in pain, having an arthritis flare-up or just need to vent about how I'm feeling and some of my colleagues have been a great support-system for me! We spend a lot of our lives at work and it's good to feel confident in those around us. I recently opened up to a colleague about my haemophilia and she then told me she had rheumatoid arthritis; we developed an instant, powerful connection and have become lunch-break buddies and true friends.'*

*There's no way to guarantee how people will react when you tell them about your bleeding disorder and over time Robbie has developed his own set of strategies. 'Of course, telling anyone that I have haemophilia has involved all sorts of reactions. Most often people have no idea what I'm talking about, sometimes they have heard of it and assume I will bleed to death from a paper-cut and sometimes they're as un-phased as if I had told them what I was having for lunch! What has worked well for me is having a simple, rehearsed way of explaining haemophilia to whoever I decide to tell. I treat it with importance but am very relaxed with my tone so that people don't have license*

*to worry for no reason or want to put me in bubble wrap! I'm also careful about who I tell. I am a fairly private person and I don't like discussing any part of my life with people who I don't have mutual trust with. But I know other people can be much more of an open book and will happily share and create instant connections that way.'*

## GETTING ADVICE

Who would Robbie go to for advice about disclosing haemophilia at work when he needs it?

*'Some great sources for advice on this are other people you know with haemophilia already in the workforce, our parents or relatives who may have had to have these discussions and/or the HFA and your Haemophilia Team. Even if someone doesn't have haemophilia, it doesn't mean they can't offer great advice; everyone has their struggles and some friends will really surprise you with their depth of insight.'*

Everyone is different and will have to take their own working environment and health situation into account. Robbie's message for other young people with bleeding disorders? *'Whatever you decide, make sure you're comfortable, confident and that your health is not at risk!'*

## MORE INFO

Check out the **Employment** section on Factored In for more information about disclosure in the workplace - <https://www.factoredin.org.au/info/employment>.

There is also a section on **disclosure and the law** on the HFA website - <https://www.haemophilia.org.au/about-bleeding-disorders/disclosure> 



# 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

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

## 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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We thank the individuals, philanthropic trusts and companies which have made donations to support HFA programs, and the following companies that sponsor education programs, conferences or peer support programs run by the Foundation for the bleeding disorders community:

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

# REDCLASSIC

Leichhardt Oval #3, NSW • Sunday 7 April 2019

Supported by Bioverativ Australia



HAEMOPHILIA FOUNDATION AUSTRALIA

## BOOK ONLINE AT

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## This is a FREE event



Join us for the Red Classic in Sydney on Sunday 7 April to show your support for the bleeding disorders community.

- ◆ Sunday 7 April 2019
- ◆ 4.5km route
- ◆ Start & finish at Leichhardt Oval #3
- ◆ Activities hosted after the classic
- ◆ All registrations receive a free cap
- ◆ Race starts at 9am

**Visit [haemophilia.org.au/rc](http://haemophilia.org.au/rc) or call 1800 807 173 for more information & details**

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