Number 221 MARCH 2023

National Haemophilia

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Being a teenager with a bleeding disorder

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Being rare

HAEMOPHILIA FOUNDATION AUSTRALIA

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Gavin Finkelstein

President, Haemophilia Foundation Australia

From the President

I focused on new therapies, starting school and the national conference in *National Haemophilia* in December. Each of these are seriously big things!

UPCOMING NATIONAL CONFERENCE

You will hear more about the upcoming conference in this issue. We hope you can come to Melbourne for the Conference. We are supported by a great team to develop the program – with multidisciplinary health professionals and community representatives coming together to select topics of interest to people across all ages. There will be some financial assistance available, so please watch out for details on the HFA website or contact us for further information.

STARTING SCHOOL

By now, many of our younger families with a child with a bleeding disorder who started school this year may well be feeling more settled and getting into a routine.

It takes time for everyone in the family to adapt to changes like starting school or going to a new school or university. It can also be challenging for the kindergarten or school if they have not come across another student with a bleed disorder. But we know families know how to provide the right balance of information about their child so everyone can get on with the job of settling in.

Treatment with longer acting clotting factor or other types of products have made a great difference to the child from a bleed point of view, and for planning and organising for the whole family. We hear so many stories about the ways some of the new therapies now available make such a difference, with fewer bleeds, or no bleeds at all, and better quality of life for everyone in the family.

PARLIAMENT HOUSE CANBERRA

HFA representatives were in Canberra in February 2023 to promote awareness of new and emerging therapies at an education event for Federal Members of Parliament under the banner of the Parliamentary Friends of Children and Adolescent Health.

We were delighted this had been suggested by Dr Mike Freelander, Federal Member for Macarthur in New South Wales in the current Albanese government who is one of the Co-chairs of this Group with Dr David Gillespie, Member for Lyne and member of The Nationals in the House of Representatives and Dr Monique Ryan, an Independent Member of Parliament representing Kooyong, Victoria in the House of Representatives.

Our thanks to Dr Liane Khoo, Director of the Haemophilia Treatment Centre at the Royal Prince Alfred Hospital in Sydney, who gave a presentation on current and emerging haemophilia therapies.

Dr Liane Khoo presenting on new therapies

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Dan Credazzi speaking about his experiences as a parent

A special thank you to Dan Credazzi, HFA Vice President and President of HFNSW who attended the event and spoke about his role at HFA and HFNSW and also as a parent of a young man with haemophilia.

Dan told how he and his wife Dao had the opportunity to attend an HFNSW family camp when Jay was just one month old. They had been devastated for their son, that he had haemophilia, but this changed at the camp as they watched the children playing, doing rock climbing and the older kids supporting them, and the parents sharing their experiences about how they coped. Dan said we left the camp saying, “we can do this”.

Jay generously shared his experience of severe haemophilia – the thousands of infusions into his veins during his life, and how this has recently changed since he has used a new treatment, that is so silent in his life that he sometimes feels he must remind himself that he has haemophilia. Jay has started university this year, and haemophilia will not define him or the way he lives.

Haemophilia treatments survey

Suzanne O'Callaghan

What information does our community want about new haemophilia treatments? And for those who are affected, what would you like haemophilia treatment to achieve for you, or your child or partner, now and in the future?

In December 2022 and January 2023 Haemophilia Foundation Australia (HFA) conducted a community survey to find this out.

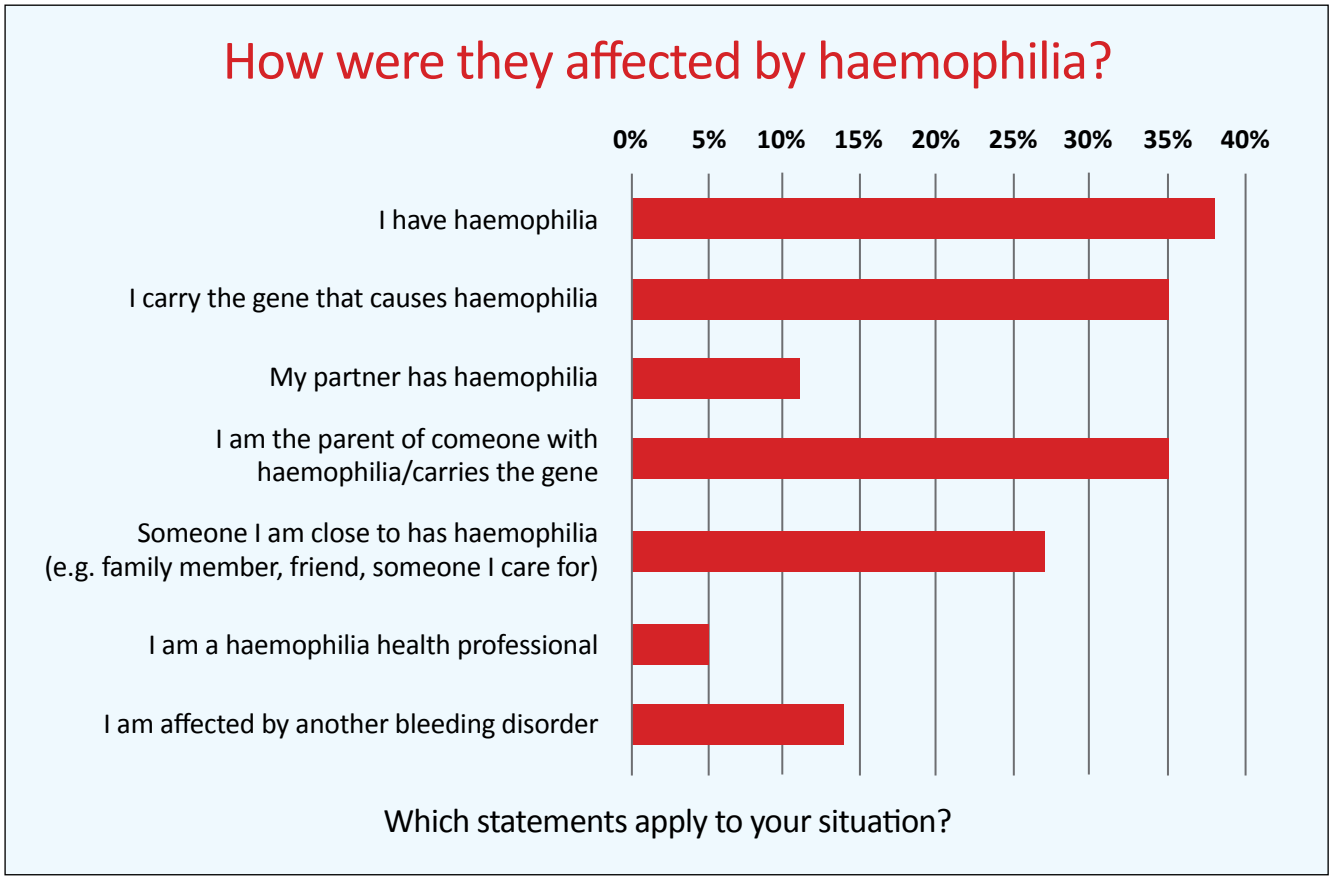
We are developing fact sheets on new haemophilia treatments and the answers to these questions will be very valuable to help us to know what to cover. They will also assist us with our other work – for example, contributing to the ideas when putting together sessions for the upcoming Australian Conference and adding to our sources of information to understand what is important to our community when we undertake advocacy around haemophilia treatment.

WHO COMPLETED THE SURVEY?

37 people **(17 female/20 male)** completed the survey.

All age groups from 18 years and over were represented. 38% were 31-44 years old.

68% lived in a capital city; 16% in the rural/urban fringe of a capital city; 8% from a regional/rural remote area; 8% were from overseas.



EHLS AND NON-FACTOR THERAPIES

Asked about fact sheets on extend half-life (EHL) and non-factor therapies (eg, emicizumab/Hemlibra®), survey respondents thought they should answer questions about:

- What are they; how do they work
- Benefits/outcomes (short and long-term)
- Risks/side effects/safety
- How administered/dosing schedules
- Eligibility (who is it for?)/access to treatment/ costs?
- How to work out - is this treatment for me?
- Difference to standard therapy
- Transitioning experiences
- What needs to be managed differently (eg bleeds, surgery)
- Understanding a personalised treatment plan
- Storing the treatment product.

Some also had other questions, including information on treatments in the pipeline and the policy on treating babies with prophylaxis before their first bleed.

GENE THERAPY

HFA has already published information on gene therapy for haemophilia, but we asked what questions they would like covered in a short fact sheet. Their responses included:

- What the terms mean; how it works
- Types of gene therapy for haemophilia
- Benefits/outcomes
- Risks/Side-effects/safety
- Gene therapy procedure
- Availability/eligibility (who is it for?)
- How long does the effect last?
- AAV immunity and other options
- Options if it is not successful
- Other treatments needed for bleeding, surgery?
- What follow-up is required
- What has changed since the HFA booklet was published in 2019?
- Case studies/personal stories about experience
- Having children after gene therapy.

Some were also interested in the potential for gene therapies for other bleeding disorders.

PREFERRED TREATMENT OUTCOMES NOW AND IN THE FUTURE

With new and innovative haemophilia treatments becoming available, it's important to understand what people with haemophilia and their parents and partners would like to see as outcomes of the treatment. What would result in a better quality of life for them?

When asked what they would like haemophilia treatment to achieve for them NOW, people completing the survey gave simple and practical responses. Their answers related closely to the types of benefits they could expect from current new therapies:

- Reducing symptoms, preventing bleeds, stable factor level
- Normal life, participating in activities, travel, sport
- Easy administration
- Fewer doses
- No or minimal side-effects
- Safe - no viruses
- Healthy joints
- Not so many hospital visits/stays
- Less pain
- Access to new treatments, including gene therapy.

One person was also hoping for a cure now.

> 'Stop the bleeding into joints so my kids can enjoy a NORMAL life.'
>
> 'Easy, non-intensive delivery. Treatment that reduces all symptoms and prevents bleeds. Low frequency dosing.'

PREFERRED TREATMENT OUTCOMES IN THE FUTURE

When asked what they would like their treatment to achieve IN THE FUTURE, people responding to the survey had an opportunity to give their wish list and some of their answers were quite different:

- Cure
- Prevent passing haemophilia on to children
- Normal healthy life, travel
- No needles/injections/infusions
- Oral treatment
- No bleeds
- Normal factor levels
- No viruses or side-effects, including inhibitors
- Access to gene therapy
- Store at room temperature, longer shelf life
- Longer effect in the body
- Reduce treatment costs.

> 'A cure would be incredible!'
>
> 'Find a measure that can prevent carriers from transferring to their offspring.'
>
> 'No needles. No bleeds.'

HFA's vision is for active, independent and fulfilling lives for people in our bleeding disorders community. For many years our community members have had low expectations of their haemophilia treatments and it is exciting to see their vision of the future now that they can see the potential with new treatments.

WHERE TO NEXT?

We are currently working on fact sheets about new haemophilia treatments that will be available on our website. We have also included the survey results in our discussions about the 2023 Conference program. More about the fact sheets and Conference soon!

Our thanks to everyone who completed the survey.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

2023 Conference

The **21st Australian Conference on haemophilia, VWD & rare bleeding disorders** will be held face to face at the Pullman on the Park, **Melbourne, 24-26 August 2023**.

After a few years communicating and running our events virtually and online it will be wonderful to see everyone come together again and at a different time of year to our previous conferences.

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.

The program committee is developing a multidisciplinary program which will interest everyone.

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

VENUE ACCESSIBILITY

The venue has good access in and around the hotel and on the conference floor, with direct lift access. The hotel is suitable to people who use wheelchairs.

PROGRAM TOPICS WILL COVER

- new developments in care and treatment
- inhibitors
- new treatments
- gene therapy
- living with a bleeding disorder
- getting older with a bleeding disorder
- women/girls with bleeding disorders
- family planning and genetics
- von Willebrand disease
- rarer bleeding disorders
- managing pain
- bloodborne viruses
- new diagnosis
- youth
- sport and healthy activities
- and……what's on the horizon?

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

To register, go to:
www.haemophilia.org.au/conferences

POSTERS

We are calling for abstracts for our Poster Exhibition at the Conference.

We encourage posters on clinical practice and care, laboratory science, research, policy, community programs or living with bleeding disorders or treatment complications.

See www.haemophilia.org.au/conferences for the abstract submission form and more information. There will be prizes for the Best Poster.

Submit your abstract by 30 April 2023

OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

The annual meetings of **specialist health professionals' groups** will be held on Thursday 24 August 2023:

- Australian Haemophilia Nurses Group
- Australian Haemophilia Social Workers' and Counsellors' Group
- Australian & New Zealand Physiotherapy Haemophilia 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.

Young people

Young people from ages 16-30 are encouraged to attend. 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 25 August 2023 before the Conference Dinner.

Conference dinner

Join us for a relaxed dinner with other delegates onsite on Friday 25 August 2023.

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 help community members with 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 or call HFA on 1800 807 173 for a form to be emailed or posted.

ACCOMMODATION SUBSIDIES

HFA has negotiated a special rate bed and breakfast rate for all delegates. To assist with the cost, HFA will be making subsidies of $39 per night per room on Thursday and Friday evening. A limited amount of subsidies will only be available per night so get in quick.

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FIND OUT MORE

For more information and details visit:
www.haemophilia.org.au/conferences.

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

World Haemophilia Day 2023

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.

This year the international theme is **"Access for All: Prevention of bleeds as the global standard of care"**. The aim is to improve access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. This means making home-based treatment available as well as prophylaxis treatment to help people with bleeding disorders to have a better quality of life.

Did you know, WFH estimates that over **65%** of people living with haemophilia worldwide have not yet been identified and diagnosed.

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care and support for people with bleeding disorders in less well-resourced countries with their GAP and Twinning Programs and the Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that work to achieve the objectives of WFH.

In Australia, our community is fortunate to have access to a range of treatments, care and services. During recent times, some new haemophilia therapies available in Australia have led to fewer or no bleeds and greatly improved the quality of life of those who have been able to use them. We look forward to more novel therapies in the future for everyone.

LIGHT IT UP RED

We have many locations and landmarks all over Australia **Lighting up Red** in support of World Haemophilia Day. Updated locations will be listed on our website. Keep an eye out and share photos on our social media platforms.

LIGHT IT UP RED LOCATIONS

ACT
Telstra Tower
The Carillion
The Australian Mint, Deakin

NSW
Newcastle City Hall Clock Tower
Port Macquarie Town Square

NT
TBC

QLD
Brisbane
Breakfast Creek Bridge, Newstead
Brisbane City Town Hall
Gateway Bridge
Ipswich Civic Centre
King George Square
Kurilpa Bridge
Parliament House, Brisbane
Reddacliff Place sculptures
Sandgate Town Hall
Story Bridge
Treasury Casino, Brisbane
Victoria Bridge
Water Towers
Wickham Terrace Car Park architectural wall
Cairns
Court House Gallery
Maranoa
CBD Tree Lights, Maranoa
Rockhampton
Heritage Façade Council building
Stanthorpe
Stanthorpe Administration Building
Toowoomba
Victoria Bridge
Townsville
Central Park Boardwalk
George Roberts Bridge
Little Fletcher Bridge
Old Magistrates Court House
Townsville Sign
Victoria Bridge
Wharton Reef Lighthouse
Warwick
Town Hall Warwick Clock Face
Warwick Town Hall roof lights

SA
Adelaide Oval
The new Riverbank lighting feature

TAS
West Point Tower
Tasman Bridge
Festive Lights, Hobart

VIC
Ballarat Town Hall
Bolte Bridge
Drum Theatre Building, Dandenong
Geelong intersection Moorabool and Malop Street Geelong

WA
Council House
Trafalgar Bridge

More information

For more information and locations, visit the World Haemophilia Day page on the HFA website - www.haemophilia.org.au/WHD

Have your say about public transport

Do you want to help improve public transport accessibility for people with disability?

The Disability Standards for Accessible Public Transport 2002 (Transport Standards) seek to remove discrimination for people with disability accessing public transport services in order to provide equality and independence.

You can have your say as part of the government's **2022 Review of the Transport Standards**.

The Australian Government would like to hear from you, whether you are a person with disability, a family member, carer or friend, and encourage you to share your experiences using public transport. Let the government know if you have equal access to public transport and what needs to be changed.

You might have participated in the government's consultations in early 2022 to help modernise the Transport Standards. The 2022 Review is separate from these reforms, so it is crucial we provide our feedback for this as well.

Have your say

- by uploading a response to the 2022 Review discussion paper on the **Have Your Say** webpage – https://tinyurl.com/transport-mysay
- in writing, by video or by sending an audio recording to DisabilityTransport@infrastructure.gov.au
- by calling 1800 621 372
- by participating in an online public consultation event in early 2023.

Read the full 2022 Review discussion paper at https://tinyurl.com/2022-transport-review.

Find out more at: infrastructure.gov.au/transport-standards-review or by calling 1800 621 372.

Public consultation is open until **30 June 2023**.

Rare Disease Day 2023

Rare Disease Day is celebrated worldwide on 28 February to raise awareness about the experience of people with rare diseases. It is also an effort to work globally towards equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease.

The 2023 theme of **Rare is many. Rare is strong. Rare is proud** reminds us how important it is to come together and connect as a community. This is an opportunity to share personal stories and acknowledge the challenges for our community members who live with a rare disorder.

>>

WHAT IS A RARE DISEASE?

In Australia, a disease is considered rare if it affects less than 5 in 10,000 people.

Around 8% of Australians (2 million people) live with a rare disease.

About 80% of rare diseases are genetic.[1]

Haemophilia is considered rare. Approximately:

- 1 in 6,000 males has haemophilia A
- 1 in 30,000 males has haemophilia B

Researchers are still gathering data on how many females are affected by haemophilia.

Some bleeding disorders are very rare.

For example, factor X (10) deficiency only affects 1 in a million people.

Type 3 VWD is the rarest form of von Willebrand disease, occurring in 1 in 500,000 people in countries like Europe and the USA.[2]

PERSONAL STORIES

In this issue of *National Haemophilia*, Adam tells his story of living with Type 3 VWD. He explains what it was like to grow up with a severe and rare form of VWD and what he has learned about becoming independent, participating and being active.

Sharing personal stories is an important way to help people with rare diseases feel connected. It can also help the wider community to understand better what it is like to live with a rare disease.

You may have seen some other personal stories about living with very rare bleeding disorders on our social media platforms in the lead up to Rare Disease Day, for example:

- Belinda's story (factor X deficiency) - https://tinyurl.com/FI-Belinda

Our thanks to Adam, Belinda and our other community members with rare bleeding disorders for sharing their personal stories.

Many people with rare diseases speak of feeling isolated. They may never have met another person with their condition. If they are the first in their family with the condition, it may have taken a long time for them to be diagnosed. Women and girls with haemophilia also talk of not being believed because of the common assumption that only males have haemophilia.

TREATMENTS

Treatment development is another issue. When rare diseases are very rare and numbers are small, this can mean that the development of new and highly effective treatments is slow. There may even be no treatment that specifically targets that condition. For example, while there has been great excitement around the world about the novel therapies developed for haemophilia and the difference they make to reducing bleeds and quality of life, there is not yet a specific clotting factor concentrate that is suitable to treat factor V (5) deficiency and fresh frozen plasma may be used for treatment instead.

HOW CAN YOU HELP?

You can help to raise awareness by sharing the stories of people with bleeding disorders through your personal networks.

Do you have a story you would like to share yourself? Visit the SHARE YOUR STORY section on the HFA website to tell us more - www.haemophilia.org.au/shareyourstory .

For more information on Rare Disease Day, visit www.rarediseasedayaustralia.com.au.

REFERENCES

1. Australian Government. Department of Health. What we're doing about rare diseases. https://www.health.gov.au/health-topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-rare-diseases Accessed 21 February 2023
2. Orphanet: the portal for rare diseases and orphan drugs. https://www.orpha.net/ Accessed 21 February 2023

Living life actively with VWD

Adam's story

Adam is in his late 40s and has Type 3 von Willebrand disease (VWD), which is a severe form. He has almost no von Willebrand factor in his blood and his factor VIII (8) levels are also low.

BEING DIAGNOSED

Adam showed bleeding symptoms from birth but it took some time before he was diagnosed with VWD.

'I was a caesarean birth. When they clamped the umbilical cord, my mother recalls I bled from that. Then they gave me a vitamin K shot in the heel, which was standard back then, and I bled quite a bit from that. And they knew something wasn't quite right, but ruled out haemophilia. It wasn't until quite some time later that I was formally diagnosed with VWD.'

For his parents it was quite a shock. They were both VWD carriers but were unaware of it. When his brother and sister were tested, they were unaffected.

Having a small child with Type 3 VWD could be challenging.

'It was quite concerning for them in the early days because I didn't have a treatment regimen yet. I would be learning to crawl and doing things and I would bleed. I had spontaneous bleeds. My recollection is of lots of trips to the Emergency Department.'

GROWING UP WITH VWD

Once he started school, Adam was keen not to have his bleeding disorder disrupt his life.

'I was worried I would miss out on things because of my treatment. I have very vivid memories of my mum driving me to Emergency with my head over a bowl and blood coming out of my nose because we couldn't stop it. And then I would turn around and try to go to school the next morning.'

It was important to him not to be different and he tried not to draw attention to his bleeding disorder.

'I went to a school where it was expected that you play a contact sport in winter, either rugby or soccer. Of course, I couldn't do either. So I took up rugby union refereeing as a way of fitting in, which was certainly a positive thing, something I did until I was in my mid-twenties.'

Adam was active physically, playing basketball and rock climbing. He was also involved in scouts and still has a role as a scout leader. Now that he is more involved in the bleeding disorders community, Adam can see the similarities between scouts and activities at community camps.

'Scouts is all about responsible risk-taking and it was an environment where I could do it quite easily. I know that the voluntary scout leaders at the time were certainly worried about my bleeding but I was able to participate in those activities to the fullest extent. That's why I think the Haemophilia Foundation camps for kids with bleeding disorders are really good.'

TRAVELLING AND WORKING

When he was younger Adam treated his VWD on demand when he had a bleeding episode. Adam learned to self-infuse from his late teens and found that it gave him a lot of independence.

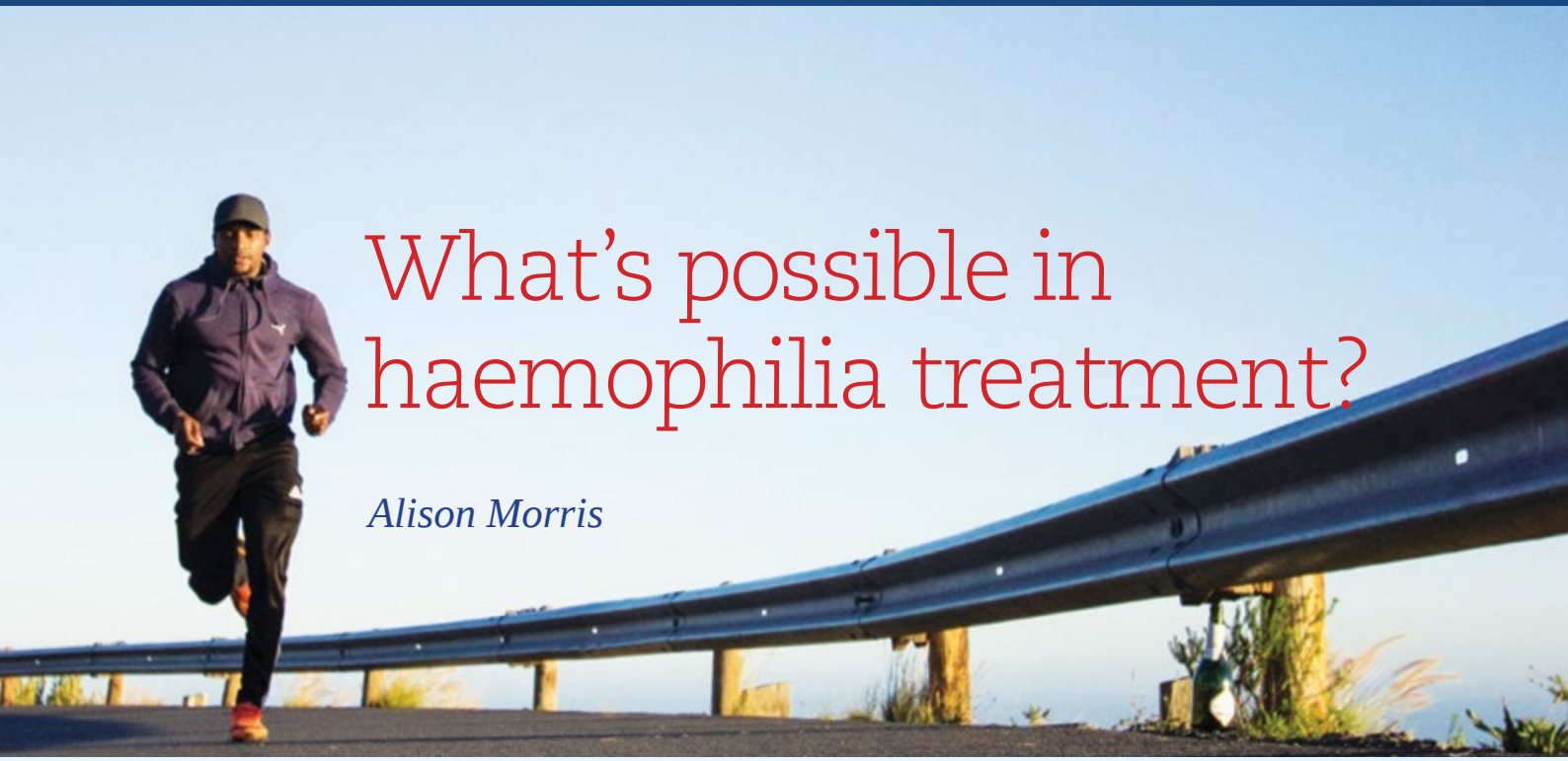
'That meant I could do things like go bushwalking and go overseas and take my treatment with me. And if there was an issue, I would be able to do my own injections.'

Adam has recently started treating himself by prophylaxis, preventive treatment with a clotting factor concentrate, three times a week. He started prophylaxis after some gastrointestinal bleeding during the COVID-19 epidemic when he was working from home – a great way to have the flexibility to try a new treatment regimen.

'It just means I plan my prophylaxis around my work and leisure activities. Getting into the routine of prophylaxis means I am not having to think twice about what I am doing and how I am doing it. I have some 'target' joints that bleed more often and the prophylaxis has stopped them from getting any worse.

As an adult Adam's VWD doesn't change a lot of what he does in his everyday life, including his work. He reflected that over his lifetime he has learned a lot about living with a bleeding disorder – and an important part of this is about understanding VWD and awareness to reduce bleeds, so as to enable an active, independent and fulfilling life.

'While VWD is rare, it need not be debilitating and it doesn't mean you can't participate. There's some things I can't and shouldn't do – contact sports! – but I am still quite active.'



What's possible in haemophilia treatment?

Alison Morris

The 16th Annual Congress of the **European Association for Haemophilia and Allied Disorders (EAHAD)** was held in Manchester, UK between 7 and 10 February 2023. Taking as its focus *'Knowledge and treatment advances require us all to re-examine what's possible'*, the Congress explored the implications for both people with bleeding disorders and the Haemophilia Treatment Centre teams who manage their treatment and care.

The Congress was run in a hybrid format, allowing the European haemophilia community the opportunity to reconnect in person after two years of online meetings while at the same time promoting attendance from a broader global community through a virtual option. The Congress included a separate Allied Health Professionals Day with concurrent streams for nurses, physiotherapists and psychosocial professionals.

NEW THERAPIES AND PHYSIOTHERAPY

One of the overarching themes of the Congress related to the rapid advancement in new therapies for those with haemophilia, including improved extended half-life (EHL) products, non-factor therapies and gene therapy. There is optimism that this will result in a reduction in joint and muscle bleeds with a subsequent reduction in haemophiliac arthropathy raising the question of whether physiotherapy will still be a necessary part of the multidisciplinary care team into the future. Many of the presentations demonstrated that the physiotherapy profession will continue to form an integral part of the care team in a multitude of roles including:

- Developing new outcome measures that are more sensitive to subtle change
- Advocating for people with haemophilia to participate in a wider range of sporting and recreational activities and
- Ongoing education and support of people with haemophilia in both bleed and sport injury management and prevention.

HAEMOPHILIA PHYSICAL FUNCTION OUTCOMES

During the Allied Health Professionals day, renowned UK based physiotherapist David Stephensen gave a presentation on *Consensus on outcomes of physical function and activities for persons with haemophilia: results from the 'IPOP' Study*.

At their Annual Meeting in 2021, the Australia and New Zealand Haemophilia Physiotherapy Group (ANZHPG) were lucky to have David present the initial work in developing Performance Based Outcome Measures of Physical Function in patients with haemophilia. The aim was to determine a battery of physical function tests that would complement the current Haemophilia Joint Health Score (HJHS) and joint examination in future assessments. Using domains from the International Classification of Function (ICF), 11 activities were identified by persons with haemophilia as those they had the most difficulty with, of which the four most important were **walking long distances, running, hopping and undertaking a complex lower limb task.**

At EAHAD, David provided a project update and the team have now identified **seven clinical tests** that could potentially be used to measure performance in these activities. These tests have been considered meaningful to physiotherapists and importantly, practical and feasible to perform in clinical practice as they are quick and do not require specialist equipment.

They are:

- **Six minute walk test (6MWT)**
- **Timed up and down stairs**
- **30 second sit to stand**
- **Single leg balance**
- **Tandem stance**
- **Single hop for distance (children only)**
- **Timed up and go (adults only)**

The team are now undertaking the next stage of the project, which involves evaluating the psychometric properties of all these tests before proposing a core outcome set for the quantitative measure of physical function in people with haemophilia. David and his team were recipients of an EAHAD Research Grant at the conclusion of the conference to fund further work on this project.

SPORT AND HAEMOPHILIA

Another exciting session in the main congress was a multidisciplinary educational session on *Supporting sports in haemophilia*.

This session started with a presentation by German physician, Thomas Hilberg on *'tailored treatment for supporting sports in haemophilia.'* The opening message was the need for all people (including those with haemophilia) to be meeting the World Health Organisation (WHO) physical activity guidelines as this has proved to reduce risk factors for all-cause mortality.

He then went on to discuss the need for people with haemophilia to liaise with their Haemophilia Treatment Centre to ensure they choose sports and activities that are appropriate for them and that there is definitely no 'One Size fits All'. Consideration needs to balance risk of injury versus benefit but also allow for individual preference. This involves shared decision-making regarding choice and timing of prophylaxis, education regarding the most common injuries, differentiating these injuries from joint and muscle bleeds and implementing rehabilitation and prevention strategies.

This was followed by an inspiring presentation by Clive Smith – *'How running changed my life'*.
Of all the excellent presentations over the course of the congress this was probably the one that resonated most strongly with me. Clive is well known in the international bleeding disorder community and is currently a Board Member of The Haemophilia Society UK. He is also a passionate patient advocate who has severe haemophilia A.

'Limits like fear are often only an illusion'

Clive described growing up in the 1980s, the era before regular prophylaxis, and spending much of his youth on crutches or in a wheelchair due to frequent joint bleeds. Once on regular prophylaxis, he was finally able to participate in physical activity and sport. He started running, later adding swimming and cycling into his regime to limit the repetitive load on his ankles, and this led him to 'dare to dream' - to complete an Ironman Triathlon. For those of you who aren't in the sporting sphere this entails a 3.8km swim directly followed by a 180km cycle, finished off with a marathon distance 42km run. Definitely not an event for the faint-hearted.

He described his apprehension in asking his HTC physiotherapist whether he would support him in his 'crazy' endeavour but was aware that to be successful he would need the expert advice that only someone experienced in haemophilia care could provide. He reflected that his physiotherapist's response was not perhaps what he was expecting with him being given the support that he needed and in 2014, he became the first person with severe haemophilia to complete an Ironman Triathlon.

The advice to allow your physiotherapist to work with you in achieving your goal rather than trying to do it alone is one that I echo. Especially now, in the times of changing treatment regimens and less haemophilia arthropathy, all people involved in haemophilia care need to shift their expectations with regards to what can be achieved in the physical activity domain.

Anything (well, almost anything) is possible.

I look forward to exploring these topics further when reconnecting with our community at the upcoming 21st Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders in Melbourne in August. See you there.

Alison Morris is Senior Musculoskeletal Physiotherapist at the Haemophilia Treatment Centre at Perth Children's Hospital, WA

Choosing or changing your career path

Pauline Hill

Whether you're just starting to think about entering the workforce, or you're a long-term employee ready for a change, there is a lot to consider and prepare for – and adding a bleeding disorder to the mix doesn't make it any easier.

During Bleeding Disorders Awareness Month in 2022, we ran a series of webinars aimed at supporting people with haemophilia, von Willebrand disease (VWD) and other rare bleeding disorders. For the webinar **Choosing or changing your career path**, we were joined by Craig Eastwood from Jobs Victoria Career Counsellors Service and Penny McCarthy, Haemophilia Nurse from The Alfred hospital in Melbourne.

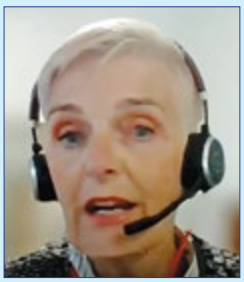
Choosing or changing your career path

HFA Zoom and Facebook Live webinar, 18 October 2022

Facilitator ~ Natashia Coco, Haemophilia Foundation Australia

Speakers

~ **Penny McCarthy**, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, The Alfred hospital, Melbourne



~ **Craig Eastwood**, Jobs Victoria Career Counsellors Service

Watch the webinar online - https://tinyurl.com/HFA-Changingcareers-webinar

WHY DO WE WORK?

Penny opened the presentation asking, 'Why do we work?' The simple answer might be - money. 'We all love money. We need money to look after ourselves, support our families, give us the financial freedom to do the things we want to do, like travel, and provide us with security.'

But it's so much more than just money.

'To go to work means you have a job, you learn new skills and you gain new experiences. You follow a set routine, which in turn makes good habits – you have to get up in the morning and go to work, have to plan ahead for when to have treatments, organise doctor's appointments, and so on.'

Working also gives us opportunities to be social and connect with our community.

Every job gives you new skills and experiences:

- We connect and socialise with people in the community.
- Having a job and somewhere to go is a really important aspect of our life.
- We can make a positive contribution to society
- We can look after ourselves and our families - and not have to rely on government support
- It helps us to maintain a level of mental and physical health.

FINDING A JOB

Sometimes finding work, or even knowing what career path you might want to take, can be a real challenge. Craig Eastwood explained how career guidance counsellors can help us to gain the tools and confidence to understand, develop and self-manage our career options.

'Career guidance counsellors work with people one-on-one to understand and develop their sense of purpose and provide direction. Whether it's a first job, a 'survival' job, or your dream job.'

'Our service looks at you, the person, and we go from there. Understanding all your obstacles, your challenges, your constraints, your frustrations – but also all your skills, your strengths, experience, your relationships with your peer group – and then we build out a plan for you.'

When to seek a career counsellor:

- Unsure of your work/career options and pathways
- Seeking employment but don't have a clear vocational pathway/plan
- Unemployed and struggling to secure work due to lack of work experience (e.g. recent graduates)
- Underemployed and seeking more secure and/or skilled work
- In need of support to plan a transition to a new occupation/career
- Wishing to pursue a professional career involving tertiary education pathways.

Career guidance sessions help you to develop a career plan, identify skills and strengths, identify labour market trends, assist with resumes, and provide interview coaching.

PREPARING FOR WORK

Both Penny and Craig spoke in detail about preparing for work.

Depending on the type of work, you may need to get 'work fit'. Penny explained, 'Work fit is getting in the best physical shape you can be for the job you want to do. If you wanted to run a marathon you'd have to exercise first. It's the same for a job – whether it's a physical job with ladders, or a desk job and you need to look after your back.'

Craig suggested, 'For people with a disability, you might need to identify how your workplace can better accommodate you. You have a lot of power and agency in the workplace and there are a lot of organisations out there that are really driven to assist persons with a disability.'

One of the key difficulties identified for people with bleeding disorders was simply talking about their health condition and explaining it to a current or prospective employer. Both Craig and Penny were quick to recommend looking to your support network for assistance. Craig suggested role playing a conversation first in a comfortable environment and bringing any questions or notes with you to the interview or meeting.

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Penny noted that people with bleeding disorders may sometimes have trouble articulating what their health condition is, 'and then they might freeze or get really anxious when someone asks about it.

'This is where your HTC or Foundation can come in to help give you the words to use to explain to others in such a way that prevents misunderstandings.'

Disclosure

If you are unsure whether you need to disclose your bleeding disorder it may be helpful to speak with your Haemophilia Treatment Centre (HTC). You can also find out more at:

- **Disclosure (HFA) -** www.haemophilia.org.au/disclosure
- **Disability disclosure chart (CRS Australia) -** https://tinyurl.com/CRSdisabilitydisclosurechart

MANAGING UNCERTAINTY

The webinar concluded with a lively Q&A session during which Penny and Craig fielded questions from the audience.

One of the key questions that came up asked, 'How do I take into account my intermittent issues? Most of the time I'm fine – I don't have a disability as such – but sometimes I might have a bleed and be restricted for a couple of weeks. How do I explain that might happen?'

Penny described this as being similar to a chronic migraine, epilepsy, or diabetes.

'You are fine most of the time. But when it happens, it takes you out for a while.'

She recommended speaking with your HTC or Foundation to develop the words needed to explain this and provide a work certificate or letter of support for work.

Craig commented, 'In the world of flexible work arrangements, where working virtually is the norm, or only working a specific roster, it is possible for your employer to develop contingencies around that if you can inform them in advance that it's a possibility and develop a plan.'

Penny concluded, 'People can't bear surprises. It's surprises that hurt the employer. But if you are a good employee and look for alternatives – perhaps working from home for that six-week period, or seeing what other options are available – it works.'

Thank you so much to Penny and Craig for taking the time to share their thoughts and knowledge during this webinar.

Find out more

Visit the webinar page on the HFA website to

- watch the webinar
- find links to career counselling services in your state or territory and other support organisations

https://tinyurl.com/HFA-Changingcareers-webinar

Pauline Hill is HFA Digital Communications Consultant

Being a teenager with a bleeding disorder

Jaime Chase

Adolescence is a time of great growth, development and also a time of great insecurity. As a young person you are trying to find your way in the world and where you fit - especially with your friends. Adolescence is often filled with trials, mistakes and lots of learning experiences and this is ok – when we make mistakes we learn, become more knowledgeable and understand more about our life and where we stand in the world.

Having a bleeding disorder when you are developing as a young person adds another layer or complexity to experiences that are already sometimes difficult, anxiety-provoking or important to you and your sense of self.

As you continue to grow as a person you will start to move away from your parent or caregiver and start to assume some independence around choices for you and your body. This is where a close and supportive relationship with a key person and your Haemophilia Treatment Centre (HTC) will help as you continue to grow and develop into an adult.

KNOW YOUR BLEEDING DISORDER

As a young person, it's important that you have a clear understanding of your bleeding disorder and what it means to you. Your family and your HTC can work together with you to learn over time – including your bleeding disorder's 'proper' name, cause, what it will mean for you, inheritance and treatment.

As you become older, it's time to begin taking charge of your bleeding disorder care - make your own appointments, move towards giving your own treatments and monitoring injuries. Every young person needs a key person in their friendship group who knows they have a bleeding disorder. Think about who of your friends know you have a bleeding disorder- especially as you start to be more independent and spend more time away from family and caregivers.

Do you have your HTC's contact numbers on your own phone? Do you know who to call and when? Do you know when to carry treatments with you in case of trauma? Do you know how to store them? These are all questions as a young person you need to be confident in answering. If you don't know the answers, chat to your HTC and your parents/ caregivers about them.

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COMMON EXPERIENCES

There are a lot of questions around experiences that you may have as a young person that have an extra layer when you have a bleeding disorder. Some of these are addressed below. If you ever find yourself wondering what to do in some of these examples, it's a great idea to chat with your HTC about the issues before they happen. Then you are prepared and know what steps you may need to take - just in case.

Alcohol - As you grow into an adult you may start to experiment with drinking alcohol. Alcohol is known for its ability to lower inhibitions and take risks that you might not normally take. It is always a great idea to have a friend who is aware of your bleeding disorder in case of an injury/trauma situation - just in case you are unable to speak up for yourself. Great ways to keep safe are wearing a medic alert, ensuring the lock screen on your phone is set to say you have a bleeding disorder, ICE information completed on your phone and carrying your ABDR card.

Drugs - If you do decide to experiment with drugs, be it vaping, smoking, marijuana use or other, be aware about what is safe for you. You need to have a safety net plan just like when you have alcohol, and you need to have a clear understanding of the effects of the drugs you are taking.

Piercings - Piercings include those to your ears, nose and other areas such as the nipple, face areas and genitals. Before you have a piercing, talk to your HTC and have a treatment plan in place pre-procedure. This will reduce your risk of the procedure not being successful or the proceduralist not proceeding due to increased bleeding.

Tattoos - Discuss tattooing with your HTC before the procedure as tattoos may not be as successful with increased bleeding. A treatment plan pre- and post-procedure will ensure the best quality tattoo is achieved.

Periods - A young woman with a bleeding disorder is quite often at risk of developing heavy menstrual bleeding or heavy periods. This may be debilitating for her. If your periods are longer than 8 days, you change sanitary protection every 1 to 2 hours and often pass clots it may be worth discussing with your HTC. There are plenty of options to help manage heavy periods and your HTC is a good place to start the conversation.

Taking risks - Being a young person is a time of great experimentation and finding out your limits. Having a bleeding disorder means that you do have to take extra precautions and perhaps plan your adventures/ experiences accordingly. Being aware of your limitations and what to do in case of an emergency are all things where you need to have a clear understanding and a plan. Talk to your HTC and trouble shoot issues for you, know what to do in case of an emergency and who to contact. Going to concerts, festivals and overnight trips with friends all may need some extra thought. Plan ahead so you have an awesome time!

Sex - Having sex for the first time can make young people very anxious, even more so if they have a bleeding disorder and worry what effect that might have. Your HTC will talk openly and honestly with you about these issues and what you might be anxious about. You can put a plan in place in case of issues and know who to call (believe it or not your HTC has heard it all before and can manage anything that comes up, promise).

Feeling different - No one likes to be different when they are navigating their way through adolescence. If you have a bleeding disorder, sometimes you can feel different, especially when you have to plan a little bit more than your friends. If you are struggling with how you are feeling, there are a number of people who can help. Your HTC may have a social worker or psychologist for you to see or be able to refer you to one for further support.

Alternatively your GP can create a mental health plan for accessing support. Needing to talk about how you feel about having a bleeding disorder is OK. Lots of young people feel the need for this extra support and find it helpful - and accessing help is an important way to take care of your wellbeing and develop a positive mindset.

Adolescence and growing into young adulthood is an amazing time of self-development and self-discovery. Having a bleeding disorder does not mean that you can't try different experiences - it's just that some may need some more planning and troubleshooting.

Having a good relationship with your HTC and a thorough knowledge of your bleeding disorder is important as you move to the next exciting stage of growing up into a young adult. You and your HTC can make sure that the experiences you have are planned for as much as possible so you don't need to feel like you are missing out during your journey to become an adult.

Find out more

Factored In (www.factoredin.org.au) is an HFA online resource with hot-topic information and stories for and by young Australians with bleeding disorders, both in their teen years and moving into young adulthood. There are also Q&A, answering questions submitted by young people, and you can submit your own questions if there are things you would like to know that aren't already covered.

Where to get help

- **Kids Helpline** (www.kidshelp.com.au) - call 1800 55 1800. Telephone and online counselling for ages 5-25
- **Lifeline** (www.lifeline.org.au) - call 13 11 14
- Call **Parentline** (www.parentline.org.au/parent-line-in-other-states) in your state or territory for counselling and support for parents and carers
- **eheadspace** (headspace.org.au/online-and-phone-support) to chat online
- **SANE Australia** (www.sane.org) – for people living with a mental illness and their carers — call 1800 18 7263
- **ReachOut.com** (au.reachout.com) – a youth mental health service. Visit the website for info or use the online forum
- **Raising Healthy Minds app** (raisingchildren.net.au/guides/raising-healthy-minds) is a free app with evidence-based information to help parents or carers with the wellbeing of their child
- **Beyond Blue** (www.beyondblue.org.au) – call 1300 22 4636 or chat online with a trained mental health professional
- **Head to Health** (www.headtohealth.gov.au) - for advice, assessment and referral into local mental health services - call 1800 595 212 from 8:30am to 5pm on weekdays (public holidays excluded)

Source: HealthDirect. Kids and mental health - www.healthdirect.gov.au/kids-mental-health

Jaime Chase is Haematology Clinical Nurse Specialist, Children's Cancer & Haematology Service, Haemophilia Treatment Centre, John Hunter Children's Hospital, Newcastle NSW

YOUTH NEWS

Haemophilia – the spice of life

My name's Willem. I am 20 years old and I have severe haemophilia A.

Willem talked to HFA about being part of his local community, making friends and trying out new skills.

Have you been involved in any local foundation activities?

I have been to camps in my youth and more recently to some of the men's breakfasts and Christmas parties. It's been good to participate in the community.

The camps were great – an introduction to haemophilia, meeting other kids my age and learning from them and older people.

What were the camps like?

The camps were great – an introduction to haemophilia, meeting other kids my age and learning from them and older people. It's a good place to make friends and I still keep up with them.

Willem's story

It's a good place to make friends and I still keep up with them.

I have also done the Bunnings sausage sizzle events. A good hands-on experience.

What other Foundation activities are you involved in?

At the men's breakfast we have a good social time but we also talk about new treatments, how they are progressing and hear how the new treatments are going for the people who are on them.

I have also done the Bunnings sausage sizzle events. It's a good confidence booster for a young person to know you are capable of doing these events – a good hands-on experience to talk to people and answer their questions. It's also a great way to educate the community so that they understand the experience of living with haemophilia today and know how to treat people with haemophilia that they meet.

Read more

Check out the personal stories from other young people with bleeding disorders on:

- Factored In, the HFA youth website - www.factoredin.org.au
- The HFA YouTube channel - https://tinyurl.com/HFAYouTube

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CALENDAR

World Haemophilia Day
17 April 2023
www.wfh.org/whd

21st Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders
Melbourne
24-26 August 2023
www.haemophilia.org.au/conferences

Bleeding Disorders Awareness Month
October 2023
www.haemophilia.org.au/BDAM

ACKNOWLEDGEMENTS

Haemophilia Foundation Australia (HFA) acknowledges funding grants received from the Australian Government.

We thank the individuals, philanthropic trusts and companies which have made donations to HFA, and the following companies for sponsorship of education programs, conferences or disease awareness programs run by the Foundation for the bleeding disorders community.

HFA acknowledges the grants and/or conference sponsorship from the following pharmaceutical companies:

BIOMARIN | CSL BEHRING | NOVO NORDISK
PFIZER AUSTRALIA | ROCHE | SANOFI GENZYME

Face to face once again! Registrations now open

www.haemophilia.org.au/conferences