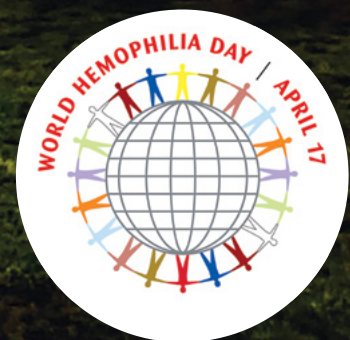


National Haemophilia

www.haemophilia.org.au



Lighting It Up Red

Raising awareness around the world

2021 Conference sessions

Watch them on the HFA website

Why you need a GP

In the 21st century

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Haemophilia Foundation Australia Research Fund New Funding Round Open!



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

Funding is for research projects to commence in the 2022- 2023 financial year. The Research Committee may decide to award one grant or two or more smaller grants depending on the strength of the applications received.

Closing Date 30 August 2022

For further details, guidelines and or an application form
visit www.haemophilia.org.au or request by phone 03 9885 7800 or email hfaust@haemophilia.org.au



Gavin
Finkelstein

President,
Haemophilia
Foundation
Australia

From the President

NATIONAL CONFERENCE VIDEOS

We are pleased that you can now view most of the sessions from the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders on our website. It was HFA's first virtual national conference, held over 8-9 October 2021, and we were grateful for the work put in by the Conference Program Committee to develop such an interesting program. When you watch the sessions, if you haven't already done so, you will see the invited speakers made a concerted effort to give lively and challenging presentations.

WFH WORLD CONGRESS

It is always exciting that no sooner has the HFA Conference taken place than we are looking forward to the WFH Congress. WFH held a hybrid congress this year during 8 -11 May 2022, making it possible to attend face-to-face in Montreal or virtually. You may have joined the Congress and associated meetings virtually as I did.

I was grateful that Shauna Adams from HFACT attended the Congress in person, and that she agreed to be the face-to-face presence for HFA, joining me as HFA representatives at the WFH General Assembly on 7 May 2022. This is the WFH Annual General Meeting and it is important to HFA that we participate. Shauna had been awarded a Youth Fellowship for the Congress which was to be held in Kuala Lumpur, Malaysia in 2020. Fortunately, this was carried over for the Montreal meeting and Shauna was able to attend.

You will hear from Shauna about her reflections on the Congress in the September issue of *National Haemophilia*, along with other reports of Congress sessions attended virtually by Australian community members and specialist health professionals.

AND FOR THE FUTURE

We finished the national Conference on a high. There is so much to look forward to and there is now considerable knowledge about the impact of some of the new treatments already available and others around the corner.

But significantly, the HFA Treatment Policy was affirmed. We learned how important it is that our community continues to have access to a range of treatment products, even the older ones which are effective and necessary for some people in our community. We will continue to advocate in support of the national framework established under the National Blood Agreement that means all Australian governments, federal and state/territory, share the cost of our treatments and that these are managed and supplied at no cost to patients by the National Blood Authority. We do not take this system for granted as we know how many of our global bleeding disorders friends do not have the surety of supply and ongoing treatment. As new therapies for bleeding disorders, including gene therapy for haemophilia, come to market we will be advocating to our governments for early access.

It is a critical time in our health system. The government policies for evaluation and assessing new treatments are being reviewed and HFA looks forward to participating in the National Medicines Review and the review of Health Technology Assessment. These reviews are both fundamental to access to medicines in Australia and the bleeding disorders community has considerable experience with this. We know the consequences of delays in access to available new treatments. We can also share in a constructive way the importance and value of new therapies to both individuals in our community and the Australian community generally, with case examples showing the benefits of new treatments. We look forward to early opportunities to meet with the new government to share some of these experiences. >>

<< REPRESENTING OUR WHOLE COMMUNITY

We are particularly mindful that there are no formal community organisations for bleeding disorders in either South Australia or Northern Territory, but there are informal connections and representation nevertheless.

Community members in South Australia should watch out for news about the next information evening to be arranged by the Haemophilia Treatment Centres in Adelaide.

We are very keen to make sure our community members have a say in HFA activities regardless of where they live and I invite you to contact HFA if you have ideas or concerns about your treatment or the work that HFA does. Feel free to phone HFA on 03 9885 7800 or email hfaust@haemophilia.org.au.

Damon Courtenay Memorial Endowment Fund Funding Round Open

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established by Haemophilia Foundation Australia in 1994 with financial support from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

Small grants are available to individuals or patient support organisations for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

WHO CAN APPLY?

- Anyone with a bleeding disorder or affected by a bleeding disorder who resides in Australia may apply for a grant
- Patient support organisations in Australia, however preference will be given to the needs of individuals with high needs

WHAT CAN THE GRANTS BE USED FOR?

An amount of \$20,000 is available for distribution. Applications will be considered on merit by a panel.

There is no limit on the amount that you may apply for, however activities up to the amount of \$2,000 are more likely to be successful.

Funding may be used for projects, services and/or care, or an activity aimed at improving the physical and emotional wellbeing and independence of recipient/s such as:

- medical appliances and equipment to help people live more independently
- career development
- training, education and coaching
- personal development
- conferences or workshops
- peer support activities/camps

HOW TO APPLY

The relevant application form must be used. Application form and guidelines available:

- HFA website www.haemophilia.org.au
- Request by email hfaust@haemophilia.org.au
- Telephone HFA on 1800 807 173

Applications close 30 August 2022

New HFA education resource

Explaining genetic testing and factor level testing

the **female** factors

Haemophilia testing in women and girls *Your questions answered*

Genetic testing • Factor level testing



Haemophilia Foundation Australia has published a new education resource, ***Haemophilia testing in women and girls: your questions answered***. It's a comprehensive booklet about genetic testing and factor level testing in haemophilia for women, girls and parents of girls.

There are often many questions and things to think about when checking to see if a woman or girl is affected by haemophilia.

- What is involved in genetic and factor level tests?
- Who should have them, and at what stage in their life?
- How is haemophilia passed on in a family – and what if there is no family history?
- And why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the booklet to answer these and other questions in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. It includes infographics, tables and personal stories.

HOW CAN YOU ACCESS THE BOOKLET?

Download the booklet from the HFA website - <https://tinyurl.com/haemophilia-testing-WG>

You can also download specific sections if you are interested in a particular topic, for example, genetic testing and counselling.

If you would like a print copy, email HFA at hfaust@haemophilia.org.au or call 0398857800 to ask us to post you a copy.

Thanks to everyone who contributed to the development of this resource, and a special mention of Jane, Sharri and Michelle for sharing their personal stories.

We invite you to take a look at the resource and pass it onto anyone you think would find it helpful.

And look out for the short and simple version which is coming soon!



World Haemophilia Day 2022

Thank you so much to everyone who participated in World Haemophilia Day and Light It Up Red in 2022. It was wonderful seeing people out and about visiting the landmarks. It wasn't just Australia turning on the lights – the entire world joined in to help show support for the bleeding disorders community.

World Haemophilia Day is celebrated worldwide on 17 April to raise awareness about haemophilia, von Willebrand disease and other inherited bleeding disorders. **Light It Up Red** is a way of raising awareness about bleeding disorders by lighting up local landmarks red on World Haemophilia Day and sharing photos with the wider community through communication channels such as social media.

This year the theme was **Access for All** - an important reminder that around 75% of people living with haemophilia worldwide have not yet been diagnosed, let alone have access to treatment and care.

COMMUNITY STORIES

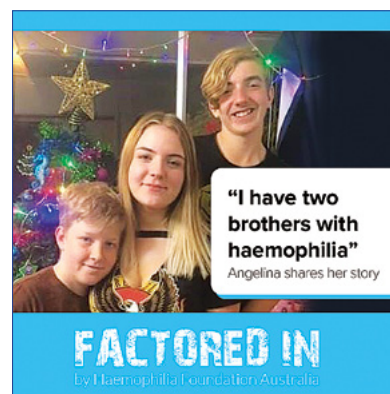
"The more people that raise awareness, the more it helps get the message out." - Adam's story.

Why is **Access for All** important to the Australian bleeding disorders community? How can we support the cause of sustainable and equitable access to care and treatment globally? Personal stories are a valuable way of making this real for the wider community.

In Australia people with bleeding disorders, mothers, siblings and haemophilia physiotherapists shared their experiences and highlighted the difference access for all can make.



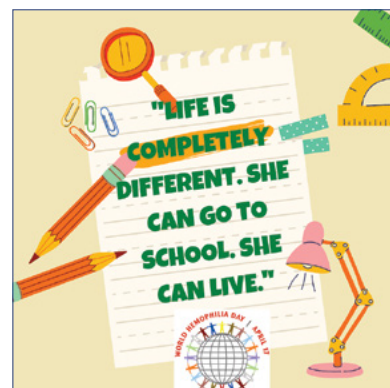
Adam's Story:
<https://tinyurl.com/FI-Adam>



Angelina's Story:
<https://tinyurl.com/FI-siblingbros>



Twinning Stories:
<https://tinyurl.com/Twinning-WHD>



Leah's Story -
<https://tinyurl.com/Leah-treatment>

LIGHTING IT UP RED AROUND AUSTRALIA



The Rocks for Sick Kids initiative sees thousands of rocks being hand-painted by Michelle each year and donated to children's hospital wards and outpatient clinics around Australia. She discovered that the endless hours spent in Emergency Departments, hospital wards and outpatient clinics pass more quickly when she is mindfully painting a bit of joy onto a rock.

New South Wales



The Kidz Factor Zone, The Children's Hospital at Westmead, Sydney

Australian Capital Territory (ACT)



Royal Australian Mint

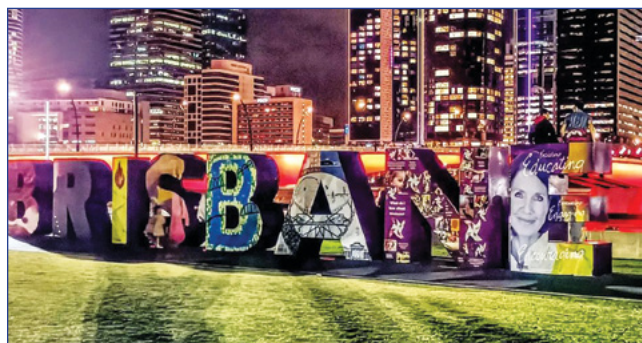


The Shine Dome, Australian Academy of Science

Queensland



Townsville



Victoria Bridge, Brisbane

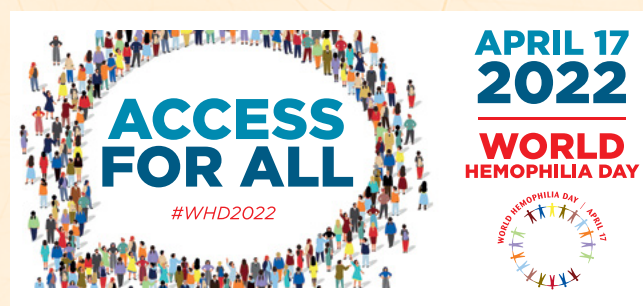
Twinning and Access for All

‘As a mother of a son with haemophilia it has always been a double-edged sword for me. On one side it feels unfair and unjust that we as a family have had to watch him with his challenges in life and the times that pain has been his enemy. However, like most of us I have always been so grateful for the medical care and the support we have in Australia.’

Leonie Demos, Reflections on Twinning with Myanmar

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 year the theme for World Haemophilia Day is **Access for All**. Here, in Australia we are grateful that our community has access to high quality treatment, but we recognise that many parts of the world do not have access to diagnosis, treatment and care. Working with the World Federation of Hemophilia (WFH), HFA and many Australian volunteers have joined WFH GAP and Twinning programs, where established and emerging haemophilia organisations and haemophilia treatment centres around the world share their knowledge and help to improve treatment and care.



‘Our friends in Myanmar share a genetic disorder like us. They share a heart and passion to work together to support each other and provide support for the rough times they face. But they have great challenges every day in living with a bleeding disorder and much to do to achieve the level of diagnosis, hospital services and treatment they need to live well.’

Leonie Demos, 'Reflections on Twinning with Myanmar'

Established more than 15 years ago, the **WFH Twinning Program** aims to improve haemophilia care in emerging countries through a formal, two-way partnership between two haemophilia organisations or treatment centres for a period of four years. Twinned organisations or haemophilia treatment centres work together and share information, resulting in a mutually beneficial partnership. It is a great way to transfer expertise, experience, skills, and resources.

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. Recently HFA and Myanmar have been WFH twinning partners and we look forward to further work together.

The importance of Twinning and GAP programs can't be understated, and in recent years with COVID and political unrest they are even more crucial to help raise awareness and bring assistance to these hard working but under resourced communities.

'There might not be a lot of us, but we all share a lot of the same experiences and can help each other and continue to improve the situation locally within Australia and globally.'

Sam Duffield, Myanmar Twinning Visit

Here is a snapshot of some Australian Twinning and GAP experiences over the years.

GAP VISIT WITH VIETNAM (2018)



'What could I bring to a country I don't know, with resource needs that I can't meet? I also wanted to think about how this trip could contribute to the service that I provide to my work here in Melbourne.'

Jane Portnoy, a Haemophilia Social Worker at the Ronald Sawers Haemophilia Centre, Alfred Health, in Melbourne, travelled to Vietnam with the Haemophilia Treatment Centre team from the Alfred.

'The hospitals in Vietnam seem familiar yet also really different. There was no privacy, but there was a warmth in the rooms that I was lucky enough to visit. The team knew all about their patients and the treatment that they needed. Laughter and support were common and there was a lot of sharing of experiences.'

Jane wanted to better understand how social workers operated in Vietnam, and how this differed to Australia.

She found social work to be an emerging concept in Vietnam, with few social workers trained to the role.

'The Social Workers were keen to hear about psychological interventions, and are starting to realize that this work is valuable, and enables patients to recover faster, use less resources and feel better in themselves. They are also becoming aware of the particular impact of having haemophilia.'



'One of the most powerful aspects of my time in Vietnam was seeing the collaboration, and strong bonds between patients and their hospital teams.'

To learn more about Jane's experience in Vietnam, read *GAPing with Vietnam*, originally featured in *National Haemophilia*, December 2018
<https://tinyurl.com/NH-GAP-vietnam>

TWINNING IN VIETNAM (2012-13)

In 2012, the Ronald Sawers Haemophilia Centre at The Alfred hospital, Victoria, was twinned with the National Institute of Haematology and Blood Transfusion Centre in Hanoi, Vietnam. Abi Polus is Senior Clinical Physiotherapist – Haemophilia at The Alfred and visited to deliver a program on the importance of physiotherapy in haemophilia. She gave lectures on the role of physiotherapy and the need to be active and exercise, as well as running practical workshops.



Abi found many patients had not had the opportunity to learn why haemophilia affects joints and muscles, and the connection between bleeds and musculoskeletal issues. A highlight of the trip was delivering a talk to patients where they asked question after question,

demonstrating that they had understood her immediately and wanted to know more.

'I found it immensely humbling and rewarding to be able to pass on my experiences in setting up a service and the knowledge I have acquired.'



'I asked one child if he had crutches? "I do", he told me proudly. "Big ones. I am just waiting until I grow into them!"'

Abi's story about her experience of Twinning in Vietnam, and how she was inspired by just how resourceful and hard working the Vietnamese doctors, physiotherapists and other members of the haemophilia team can be, was originally published in *National Haemophilia*, March 2015. Read Abi's story here:

<https://tinyurl.com/NH-Twin-Vietnam>

Treatment and care in Vietnam has continued to progress.

For example, you may be interested to watch the 2021 WFH Humanitarian Aid Program video, **Changing lives in Vietnam** - <https://www.youtube.com/watch?v=V1N51QUjY4A>



TWINNING WITH MYANMAR (2019)

'Sam and I felt our privilege in every way during our time in Myanmar. We also felt the hope and passion of a group of very special people who want to work together to improve treatment, care and peer support in their country. We have skills and experience to share and together we will work to do what we can knowing all our extended community is behind us.'



Sam Duffield and Leonie Demos represented HFA at the National Member Organisation Twinning Meeting with the Myanmar Haemophilia Patient Association (MHPA) in March 2019. Over the course of five days, Sam and Leonie were inspired by the dedication and passion of the bleeding disorders community in Myanmar.

'The MHPA is working hard on behalf of those with haemophilia in order to provide improved

access to information, treatment, hydrotherapy and opportunities. The doctors have also developed their expertise through participation in training programs where they could visit HTC's in the UK and learn more about diagnosis, treatment and care.'



For Sam and Leonie, this was an opportunity to discover how the Myanmar group and HFA volunteers might work together to strengthen their advocacy skills so they can represent their needs to other organisations and the government to continue to improve the situation for people with haemophilia. It was also a reminder of how powerful the community can be to bring about change.

Sam Duffield is a Haemophilia Foundation Australia Youth Leader. Leonie Demos is a delegate on Haemophilia Foundation Australia Council and President, Haemophilia Foundation Victoria. To read their full story, originally published in *National Haemophilia* September 2019, visit: <https://tinyurl.com/NH-Myanmar>

MORE INFORMATION

Learn more about the WFH Twinning Program here:
<http://www.wfh.org/en/twins>

Find out more about World Haemophilia Day here:
<https://tinyurl.com/WHD-AUST-2022>



Bleeding Disorders AWARENESS MONTH

OCTOBER 2022

Bleeding Disorders awareness activities are a high priority on the HFA calendar. In the past the activities have taken place over a week, with the date linked to the first HFA Council meeting which was 13 October 1979. After consultation with our Haemophilia Treatment Centres and the community, for the first time we have moved our most important awareness campaign and spread it out over the month of October. This will make it a lot easier for everyone to schedule their events and awareness activities and enable us to raise more awareness across the country.

EVENTS

HFA and our state and territory foundations will aim to host events around the country. You can also host your own event. Some ideas:

- Organise a Red Cake Day
- Host a red-themed morning tea/afternoon tea either face-to-face or virtually
- Dress red for a cocktail night
- Host a red themed crafternoon – we have colouring-in sheets and other great ideas on our website
- Wear red in support of the day
- Organise a red dress day for your school classmates
- Set up an information stand in your workplace, school, hospital or library
- Hand out promotional items in your local area (check out our website to order)

PROMOTIONAL ITEMS

We will have free promotional items to hand out at your events and information stalls. Orders will open in August 2022. To have an alert from us about ordering, email your contact details to ncoco@haemophilia.org.au

GET INVOLVED

There are many ways you can get involved in the week – wear red, host an event, hand out information at school, get your children's class or day-care involved in the colouring-in competition and sharing social media messages to spread the word.

SHARE YOUR STORY

Do you want to share your experience with a bleeding disorder? We are looking for stories from all ages and from different perspectives – person with a bleeding disorder, carrier, parent, partner, carer, sibling.

Visit www.haemophilia.org.au/BDAMsharestory to tell us about your story and we will be in contact.

FOR MORE INFORMATION

Visit: www.haemophilia.org.au/BDAM

Contact: Natasha Coco 0403 538 109

Email: ncoco@haemophilia.org.au

2021 Conference available on HFA website

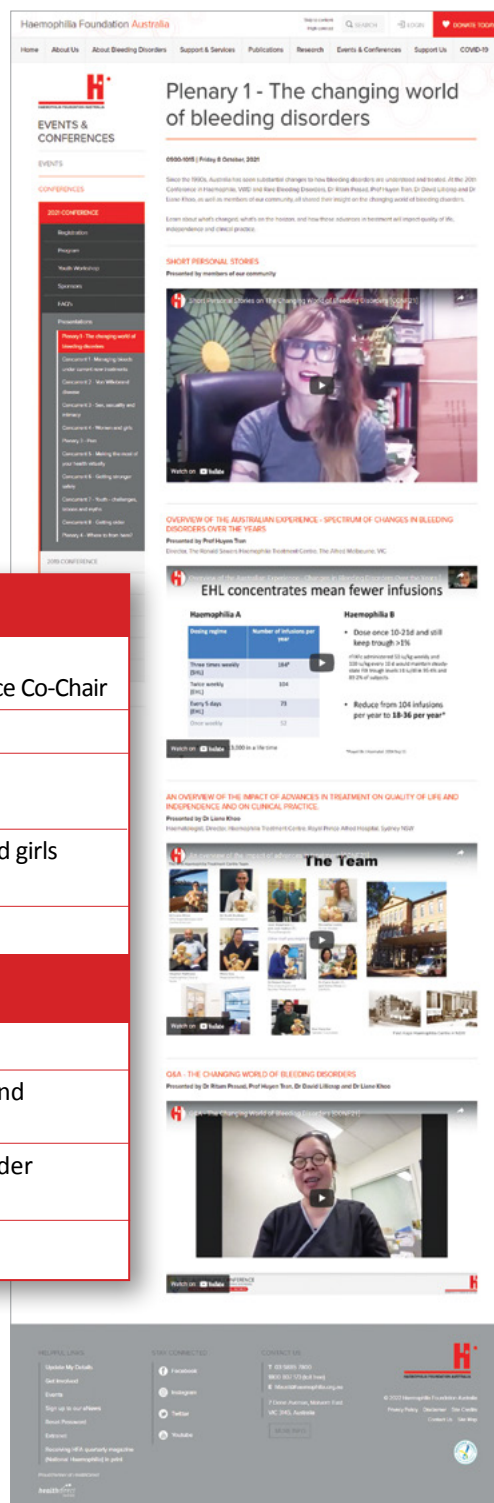
We have some great news! Most of the 2021 Conference presentations are now available to view on the HFA website. We thank the chairs and speakers for giving their permission and allowing such great content and information to be available free of charge.

With over 30 Australian and international speakers and a range of stimulating and informative sessions, there is so much for you to see.

2021 CONFERENCE PROGRAM

FRIDAY 8 OCTOBER 2021		
0855	Official Conference Welcome and Acknowledgement of Country Gavin Finkelstein, President, HFA and Dr Ritam Prasad, Conference Co-Chair	
0900-1015	Plenary 1 – The changing world of bleeding disorders	
1045-1215	Concurrent 1 - Managing bleeds under current new treatments	Concurrent 2 - VWD
1325-1455	Concurrent 3 – Sex, sexuality and intimacy	Concurrent 4 - Women and girls
1800-1830	Remembrance Service	
SATURDAY 9 OCTOBER 2021		
0900-1015	Plenary 3 - Pain	
1045-1215	Concurrent 5 - Making the most of your health virtually	Concurrent 6 - Exercise and resistance training
1325-1455	Concurrent 7 - Youth – challenges, taboos	Concurrent 8 - Getting older
1535-1700	Plenary 4 – Where to from here?	

Visit the HFA Conference page at
haemophilia.org.au/conference21



Pain and bleeding disorders

Suzanne O'Callaghan


Pain is a significant issue for many people with bleeding disorders. It can be pain related to a bleed or pain from complications, such as the haemophilic arthropathy or arthritis that results from repeated bleeding into a joint. Pain is not limited to older adults: people with bleeding disorders experience pain over their lifetime, from childhood through to old age.

The session on pain at the recent Australian Conference was a great opportunity for presenters to explore issues around pain from different perspectives.

This is a summary of the discussion, but if you are interested, some of the presentations are available online for you to watch in full. Visit www.haemophilia.org.au/conference21 for more information.

Plenary 3 – Pain

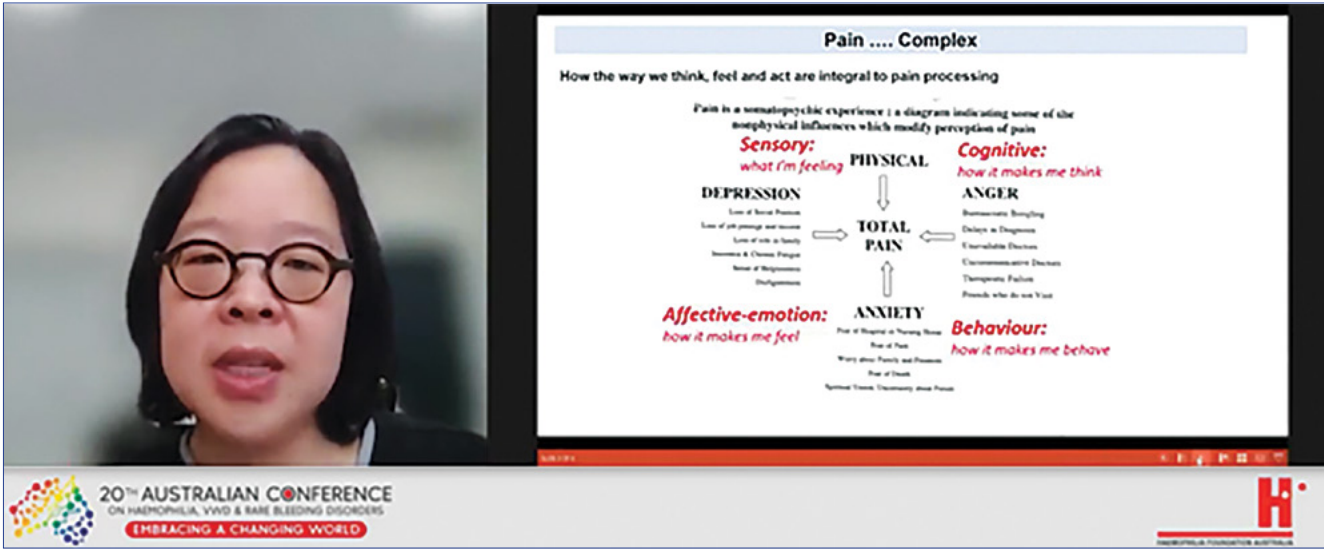
20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders

	<p>Chair ~ Dr Liane Khoo</p> <p>What's new in pain? Is it different now with new treatments? ~ Dr Liane Khoo</p> <p>Pain in haemophilia ~ Paul McLaughlin, UK</p> <p>A body and mind approach for pain management in people with bleeding disorders ~ A/Prof Carolyn Arnold</p> <p>Patient personal perspective on chronic pain ~ Jane Portnoy, social worker interviewing Dylan</p> <p>Osteoarthritis, exercise and pain: the GLA:D® program ~ Dr Christian Barton</p>
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Dr Liane Khoo, Haemophilia Treatment Centre Director at the Royal Prince Alfred Hospital, Sydney, introduced the session by commenting that pain management is an important part of treatment and care for haemophilia.

'It is a biopsychosocial experience. It is beyond the mere concept of nociception, or the brain processing pain,' she said.

While the physical pathology at the site of an injury such as a joint bleed needs to be identified, this is not enough to explain 'the complex process by which pain is transformed into the physiological, cognitive, affective and behavioural responses labelled as pain. How we think, feel and act are integral to pain processing.'



Pain Complex

How the way we think, feel and act are integral to pain processing

Pain is a somatopsychic experience : a diagram indicating some of the nonphysical influences which modify perception of pain

Sensory:
what I'm feeling

Cognitive:
how it makes me think

Affective-emotion:
how it makes me feel

Behaviour:
how it makes me behave

PHYSICAL

DEPRESSION
Loss of Social Function
Loss of self-perception and identity
Loss of role in family
Insecurity & Chronic Fatigue
Sense of Helplessness
Isolation

ANGER
Biomechanical Struggling
Delays in Diagnosis
Unrealistic Expectations
Communication Difficulties
Therapeutic Failure
Painkillers which do not Work

ANXIETY
Fear of Worsening or Spreading Disease
Fear of Pain
Worry about Family and Others
Fear of Death
Optimism/Despair/ Uncertainty about Future

TOTAL PAIN

20TH AUSTRALIAN CONFERENCE
ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS
EMBRACING A CHANGING WORLD

H⁺

Paul McLaughlin followed with a fascinating discussion of pain and its complexities from the point of view of a haemophilia physiotherapist. You can read more on his presentation in the December 2021 issue of *National Haemophilia* - <https://tinyurl.com/PM-pain>.



A BODY AND MIND APPROACH

A/Prof Carolyn Arnold specialises in pain management at The Alfred hospital in Melbourne and walked through some of the recent changes to pain management.

She highlighted that a holistic approach to pain management is essential.

New and innovative haemophilia treatments have made a substantial difference to the experience of acute pain, reducing the number and severity of bleeding episodes. This will also impact on joint degeneration from bleeding into joints.

Knowing the cause of pain is important – if it is a bleed, synovitis, haemophilic arthropathy or sensitisation. However, what can be seen on an X-Ray or other imaging is only one part of understanding pain.

As people with haemophilia grow older, the experience of pain can be disproportionate to what can be seen clinically, with the pathology of a joint, for example. This can be due to ‘sensitisation’ within the sensory system and it is important to manage pain and have pain free intervals to minimise this sensitisation.

With repeated episodes of injury with pain, the person's ability to recover reduces and chronic pain can result, along with an inability to tolerate as much activity – known as the 'boom and bust cycle'. 'The art is to find the right amount of activity to function better on every day and maintain your strength and mobility.'

How to do this?

- Consulting with your physiotherapist about recovery exercises to restrengthen muscles
- Varied options for exercises, including personalised gym exercises, swimming, hydrotherapy, modified T'ai Chi, walking (if appropriate)
- Overcoming fear of movement (relearning)

While medications may be used, they need to be used wisely and other non-drug options will be very important, as part of a 'healthy, happy, resilient lifestyle approach'.

This consists of:

- Strong opioid medications used early for severe acute pain, but then reduced and ceased quickly
- Seeking pain management services/programs outside the HTC team
- Understanding pain and perception of pain
- Mind-based tricks to manage tricky pain
- Reduce the body's over-protective response to pain
- Changes to lifestyle, including exercise and weight loss.

She spoke about avoiding the hazards of chronic pain – its impact on reduced fitness, strength and balance, on mental health, relationships, work, social isolation and over-reliance on drugs.

She also drew attention to the information about pain on the website www.painrevolution.org, which is a program for regional and rural Australia, but has valuable information for everyone.





A PATIENT VIEW OF CHRONIC PAIN

When our understanding of pain is so subjective, hearing the patient experience is crucial. Jane Portnoy, Haemophilia Social Worker at The Alfred in Melbourne, interviewed Dylan, a young man with haemophilia A, about pain and how it has affected him. Dylan's articulate comments on his experiences gave great insight into the day-to-day impact of pain.

Dylan explained that it is often difficult to explain his pain to the Haemophilia Team – what he is feeling, how long he has had the pain, how he would describe the pain. 'It can be a really frustrating experience when people don't seem to understand what you are going through as a haemophilia patient,' he said.

Another significant aspect was the impact of pain on limiting his life: his career, his social life, his mental health, exercising. 'It's hard not to put some blame onto yourself because you are constantly worrying that the things that you are doing everyday are causing your pain,' Dylan remarked.

How does he manage his pain?

- Listening to his favourite music as a distraction
- Working on his strength and muscle resistance with the help of his physiotherapist and personal trainer. This not only reduced his bleeds, but also helped with his mental health
- Having a chat with the social worker and psychologist at the Haemophilia Treatment Centre, for support and strategies and also just to vent.

His biggest barrier?

- Not knowing what help to ask for.
- It would be really valuable to have education on this for both patients and doctors.

His suggestion to others?

- Don't wait to ask for help. There is a multidisciplinary team at the HTC who can help you.



OSTEOARTHRITIS, EXERCISE AND PAIN

Surprisingly, the recommended first line treatment for osteoarthritis in the knee and hip is exercise, education and weight control, no matter what the severity of pain.

Dr Christian Barton walked through the research and the international GLA:D® program that is led in Australia by his team at LaTrobe University, Melbourne.

His key messages:

- Combining patient education with exercise improves patient outcomes with pain and function
- Exercise therapy is consistently beneficial for pain
- There are better outcomes if the exercise is tailored to the individual
- Aquatic therapy is good for people who cannot do land-based therapies
- There needs to be a program – preferably twice a week for at least 6 weeks
- Overweight and obese people can achieve great health benefits with weight-bearing exercise.

The GLA:D® (Good Life with osteoArthritis: Denmark) program is an education and exercise program developed by Danish researchers for people with hip or knee osteoarthritis symptoms. It is now available across Australia, delivered by physiotherapists who are trained and led by the LaTrobe team. The focus of this program is to change the way people think about their joints and pain, and the many factors that can affect and improve their pain and mobility, using exercise and education as strategies. Dr Barton explained there are a range of

exercises aimed at building confidence – you can find examples online at the free open-source website <https://nemex.trekeeducation.org/>.

An important take-home message from his session was that exercise therapy needs to address the commonly held myth that exercise is detrimental to arthritis and deal with the barriers to participating in exercise.

Q&A

The session finished with questions from the audience.

What can you recommend for family and carers who feel so helpless when our loved ones are in pain?

A/Prof Carolyn Arnold answered:

- It is valuable for the family and carers to understand the process of pain as well
- Then you can give positive guidance and support when the family member experiences pain
- Be aware of the impact of pain on their social relationships and emotional health, and support them.
- Sometimes you need to let young people learn, try things out and make their own mistakes.

This was a rewarding and enlightening session about an issue of concern to most people with bleeding disorders and the full presentations are well worth watching.

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Suzanne O'Callaghan is HFA Policy Research and Education Manager

WORLD HEPATITIS DAY

28TH JULY 2022

#HepCantWait

#WorldHepatitisDay

Hepatitis Info line: 1800 437 222

worldhepatitisday.org.au



**HEP
CAN'T
WAIT!**

World Hepatitis Day will be marked internationally on 28 July 2022 and is one of the World Health Organization's seven official global public health days.

It is an opportunity to come together to step up national and international efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. The global and Australian theme for World Hepatitis Day 2022 is **Hepatitis Can't Wait**.

Many people don't know that they have hep C. For example, you could be at risk if you have a bleeding disorder and ever had a blood product before 1993.

Or some people have been cured but still need follow-up for their liver health, especially if they have cirrhosis.

Do you think this might be you? Or someone you know?

By talking to our friends, family or a doctor about testing, treatment and liver health checks we can work towards the goal of viral hepatitis elimination by 2030.

On World Hepatitis Day we are reminded not to wait – know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

Keep an eye out on our website and social media for more information and activities in the week leading up to 28 July.

FIND OUT MORE

Australian World Hepatitis Day website -

www.worldhepatitisday.org.au

HFA World Hepatitis Day page -

www.haemophilia.org.au/world-hep-day

Why do we need a GP in the 21st century?

Alex Coombs



Those with long memories will recall the days of your Haemophilia Treatment Centre (or HTC) being a ‘one stop shop’ for a variety of health problems. However, this wasn’t sustainable and hasn’t been the practice for many years.

What has been increasingly obvious is that health issues of all sorts continue for everyone as we all age. This is where having a General Practitioner (GP) comes in.

Building a relationship with a local GP who is kept informed about your medical history is the recommended primary contact point for your general health matters and to help you apply for and complete the variety of medical documentation required for your government assistance, community services or employers.

This enables your HTC to provide specialist care and focus on the care, coordination, education, and treatment that relates to your bleeding disorder.

WHAT CAN A GP DO FOR ME?

You are always encouraged to contact your HTC for advice, and particularly when you think that it is related to your bleeding disorder.

However, there are many times when your GP should be your first point of contact for non-emergency and preventative medical care.

GPs are trained in medicine and are qualified to treat people for general health problems, such as illnesses or injuries that cannot be treated by over-the-counter medication. Some GPs also specialise in particular areas, such as children’s health, mental health or aged care for example.

Better Health Channel - Seeing a doctor or general practitioner (GP)¹

Throughout your lifespan you will experience a range of health problems that are not related to your bleeding disorder.

You may also find routine medical check-ups with your GP will benefit you by keeping you up-to-date on your overall health status and may prevent some health conditions or detect them early enough to treat them more effectively. This includes health screening, such as skin checks, blood pressure checks or cervical screening.

Your GP can support you by co-ordinating the variety of government or workplace application forms which require medical summaries for services, including the Disability Support Pension, Unemployed (now known as Jobseeker) temporary sick leave, Disability Parking Permits, Office of Housing Medical Priority Forms and National Disability Insurance Scheme (NDIS). This may involve requesting specialist reports from your HTC on specific questions, but your GP can help complete the overall application. Your GP can also help with referral to other local community services.

GPs are experts in managing your general health. Your chosen GP is encouraged to call the HTC for advice if they have any doubts or questions regarding your bleeding disorder or they suspect the presenting issue may be related to your bleeding disorder.

It is essential that you select a GP whom you feel comfortable to talk with about the difficult or complex parts of your health. You may base your choice on recommendations from others, the GP's gender (if you feel that they will be more sympathetic or empathetic towards you), or from your ethnic/cultural/language group. Alternatively, you may visit multiple GPs in your local area until you have chosen one who you are comfortable with, maybe even one medical centre with several GPs to choose from, until you find the best person to coordinate your overall healthcare.

Once you have the name of your preferred GP and their medical centre, make sure you inform your HTC and update the HTC when you change GPs. Your HTC can ensure your GP is kept informed with summaries from each clinic or admission you have at your HTC hospital.



See your GP for:

- minor injuries and illnesses (if you have a serious injury or illness, call an ambulance on triple zero (000) or go to your nearest hospital emergency department)
- health advice
- prescriptions for medicines
- ongoing care if you have a chronic condition
- health screening, such as cervical screening, or blood pressure checks
- vaccinations
- general care during pregnancy
- general care for children
- care if you're feeling overwhelmed or depressed
- a medical certificate, certified document or report about an injury.

HealthDirect – The role of a GP ²

Ask your GP to liaise with your HTC around care for your bleeding disorder.

FOR MORE INFORMATION

Contact the Royal Australian College of General Practitioners (RACGP)

T: 1800 472 247

E: racgp@racgp.org.au

Useful links:

1. Better Health Channel (Vic Govt Dept of Health) - Seeing a doctor or general practitioner (GP) - <https://tinyurl.com/BHV-Seeing-GP>
2. HealthDirect (Australian virtual public health information service) – The role of a GP - <https://tinyurl.com/HD-GP-role>

This article is adapted with permission from 'Why do we need a GP in the twenty-first century', The Missing Factor, the newsletter of Haemophilia Foundation Victoria (www.hfv.org.au), Autumn 2022, pages 10-12.

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Alex Coombs is Social Worker – Haemophilia & Other Inherited Bleeding Disorders at the Ronald Sawers Haemophilia Centre at Alfred Health, Melbourne

YOUTH NEWS

Growing stronger



Gavin spoke to HFA about growing up with haemophilia and what he has learned about developing his strength and resilience. And his career plans for the future!

My name's Gavin. I am 21 years old and I have severe haemophilia A

How did you and your parents find out you had haemophilia?

There is no recorded history of haemophilia in my family – I supposedly got haemophilia due to a spontaneous mutation.

As a baby/toddler I was using a walking ring to get around the house, and the plastic from the walking ring bruised my ribcage. My parents were concerned so they took me to the hospital, where it was eventually confirmed that I have haemophilia.

What is your treatment like?

I have prophylaxis twice a week and I inject into a vein. The process of learning to self-infuse involved practising on a plastic model, followed by practising on myself, whereby I got into the vein the very first time.

Did haemophilia impact on your time at school?

Before prophylaxis I was very injury prone and had lots of spontaneous bleeds. I either went to school in pain or

had to take a lot of time off, which probably affected my grades although I didn't realise that at the time.

My friends and teachers knew of my haemophilia. It was important for them to know in case I happened to get injured at school. However, they still treated me normally just like they treated everybody else in the school, which is exactly what I wanted, and I am grateful for that.



Learning to self-infuse involved practising on a plastic model, followed by practising on myself



Gavin's story

Do you have a favourite sport?

I love playing tennis from time to time and in high school I loved playing mixed netball with friends.

What have you learned about managing your haemophilia to play sport?

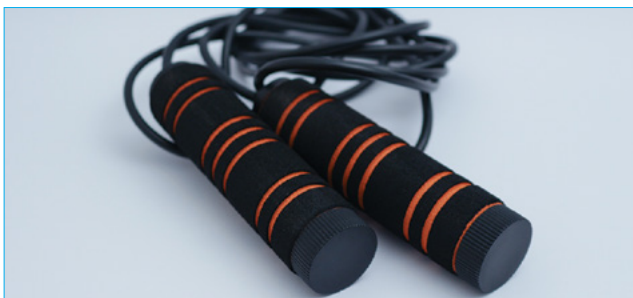
Of course, I am fortunate enough to have prophylaxis, which eliminates the spontaneous bleeds. Beyond that, it's incredibly important to do strength training, specifically in the legs, and really utilising compound movements in general. With the build-up of strength and muscle, the risk of playing sport is very much decreased. Nowadays it takes a lot for me to get injured in comparison to before.

What else has haemophilia taught you?

Haemophilia has taught me to be resilient, as the physical (and mental) pain is only temporary for me, as long as I implement sufficient recovery management. That being said, haemophilia has taught me to stay disciplined, especially with something like working out. Nowadays I'm much stronger than what I was and it's easy to skip workouts and lose sight of why working out is important, but the discipline I've developed as a part of having haemophilia helps me stay on the right track.



My friends and teachers treated me normally just like they treated everybody else in the school, which is exactly what I wanted



Haemophilia has taught me to stay disciplined, especially with something like working out

What are you up to now?

I am currently studying city planning at university. Using my degree, I hope to encourage positive decision making in the face of sustainability, albeit through the avenue of city planning.

In 2020 I self-published a book called *Jake Raven and the heists of opulence*. At the time I just did it for fun, but I discovered that I have a huge passion for writing, so I hope to make a career out of it (alongside city planning of course). I am currently working on the sequel which I aim to finish by the end of 2023.

Read more

Do you have questions about building your physical strength? Speak to your HTC team to find out more and for an individualised plan. And check out:

- The Factored In sports info – www.factoredin.org.au/info/sports
- **On the move with haemophilia** toolkit and videos - <https://tinyurl.com/HFA-OTMWH>

Want to read other young people's personal stories about living with a bleeding disorder? Visit Factored In, the HFA youth website - www.factoredin.org.au

CALENDAR

Bleeding Disorders Awareness Month

October 2022

www.haemophilia.org.au/BDAM

World Haemophilia Day

17 April 2023

www.wfh.org/whd

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

Don't forget to add it to your diary!

www.haemophilia.au/BDAM

Register for alerts
by emailing

ncoco@haemophilia.org.au



Bleeding Disorders
AWARENESS MONTH

OCTOBER 2022

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