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National Haemophilia

www.haemophilia.org.au

2023 Conference

Read the reports!

Bleeding Disorders Awareness Month

Celebrating in red around Australia

World AIDS Day

Reflecting on HIV today

HAEMOPHILIA FOUNDATION AUSTRALIA

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Haemophilia Foundation Australia
Registered No.: A0012245M
ABN: 89 443 537 189
Street address:
7 Dene Avenue Malvern East,
Victoria, Australia 3145
Postal address:
PO Box 1208, Darling,
Victoria, Australia 3145
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan
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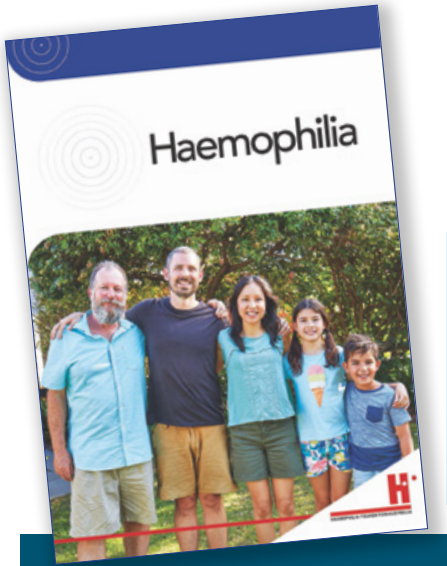
New haemophilia booklet



The new HFA Haemophilia booklet is now available. The 2023 edition has been revised completely to cover new treatments.

It is a great introductory resource about haemophilia that is very useful for new families and educating others new to haemophilia.

It covers:

- what causes haemophilia
- diagrams showing genetic inheritance and how bleeding occurs in haemophilia
- diagnosis
- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

Accessing *Haemophilia* 2023

- download it from the HFA website - https://tinyurl.com/HFA-haemophilia
- ask HFA to post you a free print copy - hfaust@haemophilia.org.au

Thank you to all of the community members and health professional experts who contributed to and reviewed this booklet.

Gavin Finkelstein

President, Haemophilia Foundation Australia

From the President

AUSTRALIAN CONFERENCE

It was great to see a lot of our community – new and old faces – in Melbourne at the Conference in August 2023. Our conferences are a forum that bring together people with bleeding disorders and their families and carers with health professionals, policy makers and industry. We were very pleased to have Dr Glenn Pierce, WFH Vice President, as a keynote speaker sharing his considerable expertise and an international perspective on new and emerging therapies. We thank all the speakers for a very insightful and interesting conference program and of course our sponsors, without whom the Conference cannot proceed.

In this issue of *National Haemophilia* you can read a few of the personal stories that were highlighted at the Conference. We thank everyone who shared their experiences of living with a bleeding disorder or being a parent. The patient voice is a valuable part of our program and many delegates have commented that hearing from patients gives them a very different perspective on clinical management.

I was honoured to receive the Life Governor Award at the Conference dinner. Thank you – it has been a privilege to serve on HFA Council for the past 17 years and as HFWA President.

GOODBYE TO SHARON

The time has come to say goodbye to Sharon Caris, who has been our Executive Director at HFA for 22 years. Appointed in March 2001, Sharon's background in social work, health administration and advocacy has enabled her to support HFA and the bleeding disorders community through many changes over the years. It was my pleasure to deliver the Jennifer Ross Award to Sharon Caris at the Conference dinner in recognition of her dedication and leadership.

We will miss you, Sharon! But we wish you all the best in your well-earned retirement. Thank you for your tireless efforts, knowledge, and wisdom.

We are pleased that Natashia Coco has been appointed as the new Executive Director (Acting). Many of you might know Natashia, who has been with HFA for 20 years. She is very excited to take on the role and to continue to strive for best treatment and care for the Australian community.

Message from Sharon

It has been an honour to work with HFA for 22 years.

I have loved every minute; and the 'job' has been a real privilege for me – the community is wonderful.

I very quickly learned that people living with a bleeding disorder and their families are courageous and resilient and their health professionals are devoted, expert and caring.

To all the people I have met along the way, and friendships made, thank you for sharing your stories and welcoming me to be part of your family and community.

Sharon Caris

Postcards for Sharon

After 22 years of service, it is time to say farewell to our Executive Director, Sharon Caris.

Since Sharon took on the role in 2001, she has touched many of us, being instrumental in welcoming, informing and educating, and advocating for the Australian bleeding disorders community.

Sharon, we will miss you so much! But we feel so blessed to have had your support these past two decades. Thank you.

You'll find a pre-addressed postcard enclosed in this issue of *National Haemophilia*. Please feel free to use this postcard to write to Sharon – perhaps share a memory, or your thanks, or simply wish her well in her retirement. We will make sure that Sharon receives all of the messages.

To write to Sharon, complete the postcard included with your copy of *National Haemophilia*. Alternatively, visit: www.haemophilia.org.au/postcards-for-Sharon to submit a message digitally (you may remain anonymous if you wish).

2023 HFA Awards

The HFA Awards are an important opportunity to acknowledge the exceptional service and commitment of individuals in our community.

Our congratulations to the 2023 HFA Award recipients, most of whose awards were presented at the Conference Dinner. We were delighted to present Tony Ciottariello with his award at the Government House event in Brisbane during Bleeding Disorders Awareness Month.

LIFE GOVERNOR AWARD

Gavin Finkelstein

In recognition of dedicated leadership to the Haemophilia Foundation Australia Council and long-term commitment to HFA objectives and goals.

JENNIFER ROSS AWARD

Sharon Caris

In recognition of dedication to the Australian and international bleeding disorders community and leading Haemophilia Foundation Australia for 22 years.

HFA VOLUNTEER AWARD

Antonio Ciottariello

In recognition of dedicated voluntary service to the Queensland bleeding disorders community over many years.

Ben Inglis

In recognition of dedicated voluntary service to the Victorian bleeding disorders community over many years.

Bleeding Disorders Awareness Month

OCTOBER 2023

Bleeding Disorders Awareness Month spanned the entirety of October 2023, and saw individuals, families, Haemophilia Treatment Centres, Haemophilia Foundations and other organisations all helping to raise awareness about haemophilia, von Willebrand disease and other bleeding disorders around Australia.

The theme, ***Working together***, was embraced fully as everyone came together in support of our bleeding disorders community.

PERSONAL STORY SHOWCASE

Throughout the month we featured different personal stories from our community members.
Read them here - www.haemophilia.org.au/storyshowcase



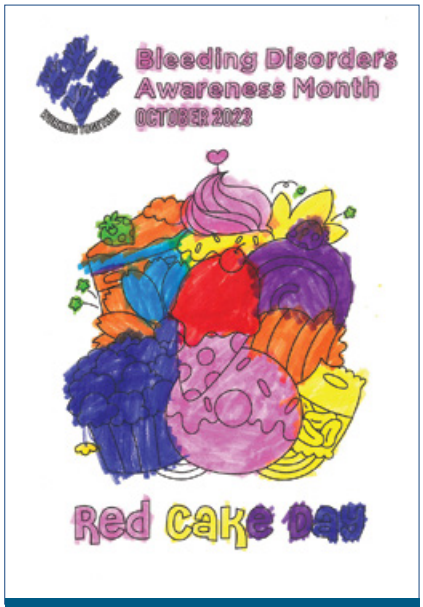

COMMUNITY INVOLVEMENT

It was so great seeing everyone in the community getting together to help raise awareness. Information desks at HTCs, red dress days, walks, trivia nights and even a spooky halloween-themed bake sale! A big thank you to the state and territory Haemophilia Foundations for running events throughout the month. It was a wonderful opportunity for members to catch up and have a fun time out.

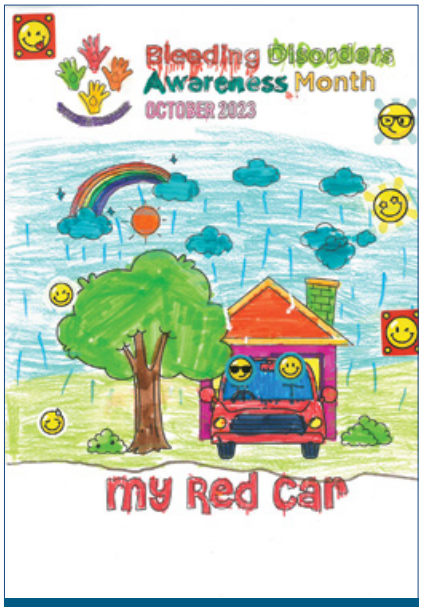
COLOURING IN COMPETITION

Thank you to all the children who participated in this year's **Working together colouring in competition**.

The winners are:



Category 1
children aged under 4 years
Indianna QLD



Category 2
children aged 5 to 8 years
Prisha NSW

Category 3
children aged 9 to 11 years
Poory NSW

BLEEDING DISORDERS AWARENESS MONTH IN PICTURES

HFNSW Family Day

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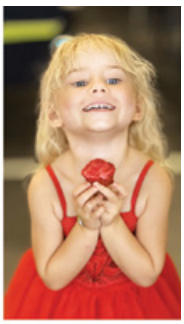
HTC team at The Children's Hospital at Westmead, NSW

HFV Walk

Dolphins Aquatic and Fitness Centre, Redcliffe, QLD



Lincoln and friends

HTC, Royal Adelaide Hospital

Freddie and friends

HFQ at Government House

Lucas giving his first school talk about VWD

...and they got cupcakes!

World AIDS Day is marked globally on 1 December. In 2023 the national theme for World AIDS Day is

Inclusion. Respect. Equity.

In Australia, it is a day for the community to:

- show their support for people living with HIV
- raise awareness about prevention, treatment and care
- eliminate stigma and discrimination around HIV
- remember people who have died of AIDS-related illnesses.

Much has changed since HIV was first identified in the mid-1980s. Today in Australia:

- People living with HIV can get medication that allows them to live a healthy, long life.
- People living with HIV who take antiretroviral treatment can supress their viral load and have no risk of transmitting the infection to a sexual partner.
- People can take preventive medication that removes the risk of getting HIV through sexual activity.
- People can quickly access medications that prevents HIV infection if exposed to the virus.
- We have safer-sex initiatives and programs to reduce the risk of harm from injecting drugs.

Wearing a red ribbon, the international symbol of HIV awareness and support, is one way of showing your support for people living with HIV and honouring lives lost over the past 40 years.

HIV IN THE BLEEDING DISORDERS COMMUNITY

Part of our everyday life as a community is being mindful of our community members living with HIV, of demonstrating our support for them and commemorating those with HIV who have passed away.

HIV is a very important part of our community's history. In the mid-1980s some adults and children with bleeding disorders acquired HIV from their clotting factor treatment products. Some lost their lives to HIV while others live with HIV today. Treatment product safety is now greatly improved and the risk of bloodborne infection from products derived from blood is extremely low. Nevertheless, the impact of HIV has been profound. It affected not only the people who acquired HIV, but also their partner, family and friends, the health professionals who have cared for them, and the bleeding disorders community generally.

The HIV experience drew on the resilience that was already a strong element among people with bleeding disorders and led to a resolve to respond as a community, taking on effective advocacy around safer treatments and providing support.

INCLUSION. RESPECT. EQUITY

This year's theme is a timely invitation to consider what **Inclusion. Respect. Equity**. means to us.

We are grateful to some of our community members living with HIV who generously shared their thoughts.

Neil

I've been very open about my HIV status for years now and I've been humbled by the respect shown to me by everyone I've told. Being free to answer questions and break down any fears has only helped my inclusion in social circles.

Mike

When I see the word 'inclusion', I think of how the bleeding disorders community and the HTCs have come together to deal with HIV.

Haemophilia when I was growing up in the 1950s, 60s and 70s was life threatening and I required many treatments.

The 1980s was a catastrophic period. HIV caused a lot of devastation and worry to me and my wife personally. It also brought a lot of families together, and it was this support that helped us to survive this period in our lives where so much was unknown.

We were very fortunate to have great team of doctors, nurses and a psychologist who were very understanding and supportive, and we would not have survived this time without the tireless work from HFA.

Anth

For me, this year's World AIDS Day themes provide a checklist of game-changing ideals in global efforts to a) eliminate HIV transmission, and b) care for people living with HIV. Without a sharp uptick in inclusion, respect and equity, the world's poorest and least powerful communities will continue to be disproportionately affected.

But what do these words mean to our bleeding disorders community in Australia? Those of us who have lived with HIV for over 40 years, and those of us who have seen loved ones succumb? I often feel like our part in the story of HIV/AIDS gets forgotten. While the increasing dissociation of HIV/AIDS and bleeding disorders creates safety for us, it denies our truths and remarkable achievements too. Whether you mark World AIDS Day privately or publicly, or not at all, please know that you remain part of a community that is extraordinary for its resilience and dignity in the face of bloodborne viruses.

READ MORE

Read **40 years of HIV – where to next?** for reflections from our affected community about their experiences and thoughts about the future - https://tinyurl.com/HFA-40-years-HIV

Visit www.worldaidsday.org.au for more information about World AIDS Day in Australia.

The **21st Australian Conference on haemophilia, VWD and rare bleeding disorders** was held on 24 to 26 August 2023 in Melbourne and saw over 210 delegates come together - people with bleeding disorders and their families and carers, health professionals, policy makers and industry. It was wonderful to be face-to-face again.

The theme was **Working together – improving outcomes**. Over 50 speakers contributed to a vibrant and diverse educational program, covering new and emerging therapies, including gene therapy, women with bleeding disorders, mild haemophilia, VWD, rare bleeding disorders, family planning, pregnancy and newborns, making career choices, getting older, pain, and musculoskeletal issues.

In the final plenary Sharon Caris facilitated a discussion with a panel of health professional and community experts, reviewing the discussions over the two days and answering the questions: what are the challenges we are facing moving forward; and how do we keep connected? It was a lively conclusion to the Conference and the final take-home message was:

'There is a lot of challenging work to do, but we are in exciting times. There is reason to be optimistic.'

Most of the presentations are now available online at: https://www.haemophilia.org.au/Presentations23

ACKNOWLEDGEMENT OF COUNTRY

We respectfully acknowledge the Traditional Owners of the land on which we met for this Conference, the Wurundjeri Woi-wurrung people, and pay respect to their Elders past, present and emerging.

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Conference reflections

A FOUNDATION PERSPECTIVE

Haemophilia Foundation Australia President Gavin Finkelstein spoke with HFA about the Conference and its impact from his perspective.

What were your overall impressions of the Conference?

Considering we haven't had a face-to-face Conference in quite a few years, it was noticeable how excited people were just to get together with fellow members of the community and spend time discussing things - but also having the education and catching up with what the advances are when it comes to treatment for bleeding disorders. Having these twofold education and interpersonal aspects that we have missed out on over the last few years made it a brilliant conference.

It's so important to have the time to sit down and talk with each other about these things. You don't discuss your haemophilia or your bleeding disorder issues with your friends, but you can speak about them freely with the community because there is empathy and understanding and everyone goes through similar experiences together. Having this kind of environment to discuss your issues with your peers – between sessions or over a meal break – I find it quite invigorating. You build up friendships over time and it's great to catch up.

The education is just so important too, because things are moving very quickly and we need to keep up with what's happening and where it might go.

Were there any sessions that stood out for you?

The gene therapy session really stood out for me because there is such an emphasis on gene therapy.

Dr Glenn Pierce was an amazing speaker. He makes complicated science easy to understand and he is meticulous in working through the information and the messages. Gene therapy is incredibly complex, but he explains it so that everyone has a realistic understanding of the situation.

I thought it was important that there was a reality check that gene therapy, exciting as it is, is not the answer for everyone. For example, not everyone is eligible for the current gene therapy because some people have antibodies to the vectors that are used. Gene therapy isn't the only emerging therapy that is out there. There are other products that are fantastic compared to treatments used in the past. It's about using a suite of products that are available and for patients to work with doctors to get the best treatment outcome.

What was your take home message from the conference?

It reinforced the need to have the Conference. It's a really worthwhile exercise to bring the doctors and the other health professionals together as well as the community. The health professionals have their own meetings the day before the Conference and this builds strong national groups among the disciplines. And individuals in the community inspire you – it's a great opportunity to get together with them and catch up. We have done so much online but meeting face-to-face is very valuable.

We need to know what's happening and to think about the services that are provided and what we might need in the future. The holistic aspect of the Conference is very important. We hear about what's new, share our experiences and ideas and have an opportunity to think outside the box. It makes such a difference to comprehensive care and innovation going forward.

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THE HTC PERSPECTIVE

Haemophilia health professionals reflected on their experience at the conference.

This was the first time that the Conference was back to the in-person format since the outbreak of the COVID pandemic back in 2019. And what a joy it was to be able to see each other and have some great conversations and reflections at the various sessions and plenaries.

***Alex Klever**, Clinical Nurse Consultant, Queensland Haemophilia Centre*

The Conference ran over two days. This was the first Haemophilia Conference to be held in person in Australia within the past four years, encouraging members in the haemophilia community to reconnect. It also displayed a great level of multi-disciplinary team inclusion, with a separate day of meetings for health professional groups, which included sessions for nurses, physiotherapists, and psychosocial professionals.

As a new physiotherapist to this space, it was wonderful to see the passion from the health care professionals and members of the community as they advocated to embrace the future of treatments and improve outcomes for all people affected by bleeding disorders.

It was a wonderful opportunity to meet and learn from physiotherapists who have years of expertise within this area. Similarly, it was inspiring to see fellow physiotherapists presenting throughout the conference, sharing their experiences and knowledge in this rapidly changing space.

***Natalie Karlovic**, Physiotherapist - Oncology, Haemophilia and Palliative Care, Children's Health, Queensland Hospital and Health Service*

WHAT DID THE DELEGATES SAY?

'Marvellous to catch up with everyone - and to be able to discuss the sessions afterwards.'

'We have come back from the conference feeling validated, more confident and connected. We wish that we had been attending previously.'

'Being newer to this community personally I feel the importance of the community and can see the benefit for everyone. Professionally to have the privilege to listen to patients' experience is very humbling and I am grateful for this opportunity. It inspires me to do more professionally to make a difference.'

'Where to start?! It was such a fantastic experience. I am so grateful that we were offered the opportunity to share our experiences and to help perhaps encourage health professionals to re-evaluate needs and treatment for this group. I have come away feeling that I am part of an incredibly strong and educated community and am now in a much better position to be able to advocate for my boys. I feel so much more hopeful and better informed, especially regarding treatment options for bleeds, management of pain and arthritis. I would like to remain more connected and contribute more to our community in any way I can.'

'It has given me some concrete ways to develop my work further and ideas on what is a priority.'

'Hearing from patients helps me understand the importance of their voice and involvement to make my work truly successful. Provided good opportunities for professional networking.'

Hopes for the future - reflections from a parent

Claire shared her personal story as a parent of young boys with haemophilia at the 21st Australian Conference on haemophilia, VWD and rare bleeding disorders. This is transcript of her presentation.

DIAGNOSIS

'His blood is not clotting.'

I can vividly remember these words when I heard them for the first time.

Good morning, my name is Claire and I am the mother of 2 young boys who have severe haemophilia A.

There is no family history. It was the shock of our life for my husband Ben and I when we found out that our firstborn Louis was diagnosed at 6 months old.

It was a Saturday night. We took Louis to the ED at our local hospital as he had developed some pretty bad bruises at the back of his knees; he just started sitting in his high chair, banging his feet against it and had developed some pretty nasty black bruises.

'What do you mean his blood is not clotting?' was my first question to the doctor at the Emergency Department.

As a first-time mum, there is a constant worry.

But as a first-time mum of a child who has a severe medical condition, that worry is exacerbated: we just entered a whole new world, where all of a sudden nothing much mattered but the health of our little boy.

I quickly expanded my everyday vocabulary with words I never heard before.

I am always welcoming new words being a non-native speaker of the English language, but I guess I didn't have these ones in mind:

Clotting

Bleeds

Factor VIII

Long lasting

Ports

The list goes on…

Fast forward 6 months later: Louis had to have a port put in place to allow us parents to treat him intravenously with long lasting factor VIII.

As parents, we had to learn to infuse Louis.

While we had our fair share of scares with the port and numerous hospitalisations, the port did allow us to travel overseas and live a life as 'normally' as possible.

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NEW THERAPIES

Another 3 years later, Louis had the opportunity to start on an non-factor treatment product.

What a game changer it has been!

From intravenous port access 3 times a week to a monthly subcutaneous jab, it has revolutionised Louis's and our life.

We noticed a significant reduction of bleeds, improving Louis's physical and mental health therefore impacting our family's quality of life.

It has brought different challenges though for our family, refusal to do treatment at times which has been bringing some angst for everyone.

And then, 2020 happened, confinement and perhaps some would say a baby boom in 2021…

Téo, who is now 2, was born. He was diagnosed at birth and it was not a huge surprise or shock for us.

His journey has been a very different one, if we had to compare it to his older brother - as he started treatment much earlier.

We are part of a clinical trial and for us, it has meant no bleeds in two years.

There haven't been any hospitalisations, any port, any intravenous access…just few blood samples and his monthly needle.

Without minimising Téo's journey, it has been a much smoother sail for Téo and for all of us as a family.

THE FUTURE

We are very aware and very grateful that in the past 6 years, treatment for haemophilia has drastically changed and a utopic future would be a cure for haemophilia…

Gene therapy is allowing us to grab a glimpse of what a world without haemophilia could be.

One of my first hope would be a treatment that would not involve a needle.

I haven't met anyone who loves needles, I mean, do you? The reality of a needle on a young child is not a pretty one, and can be pretty traumatic for all parties involved.

Another hope, as my boys are growing and one day will be teenagers, is to avoid bleeds at any cost – and the current treatment is providing us with that hope.

We know that with past treatments, bleeds still happened regularly for some families.

We know what it does to them to miss out on school, birthdays, camps, sleepovers, everyday life activities because they have had a bleed.

We know as parents the negative impact it has on their physical and mental health.

We want to look after them as much as possible and we don't want them to experience early arthritis because they have had numerous bleeds during their teenager years.

We want them to avoid pain.

In 15 years, my boys will be young adults and will perhaps have the choice and opportunity to have gene therapy. I want them to make that decision the most informed possible.

Gene therapy might be the future for haemophiliacs, but what about the next generation? What about their daughters?

Gene therapy does not cure the carriers. Could it one day though?

The real hope for the future is an eradication of haemophilia for the next generations –

I want Louis and Téo to live their best life possible.

I want them to become confident and articulate advocates for themselves.

I want them to travel and see the world.

I don't want haemophilia to stop them from doing anything they want to do.

When we first met our haematologist 6 years ago, we were told that everything will be OK and from that day I still believe that everything is going to be OK.

So right now, the future for us is looking pretty optimistic.

Photos supplied by Claire and reproduced with permission. Stock image: Pixabay for Pexels.com

New haemophilia therapies

Alex Klever

Plenary -
Treatment landscape into the future

Chair ~ David Fagan

From then to now *~ Gavin Finkelstein*

What is precision or personalized medicine? New and emerging treatments for all bleeding disorders
~ Dr Glenn Pierce

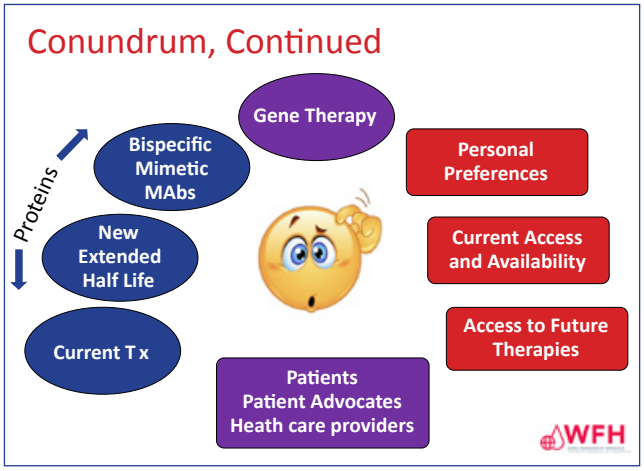
Australian experience and challenges with new and emerging haemophilia therapies
~ Dr Liane Khoo

Access to new therapies – policy and regulation
~ Jo Cameron

Hopes for the future: reflections from a parent
~ Claire

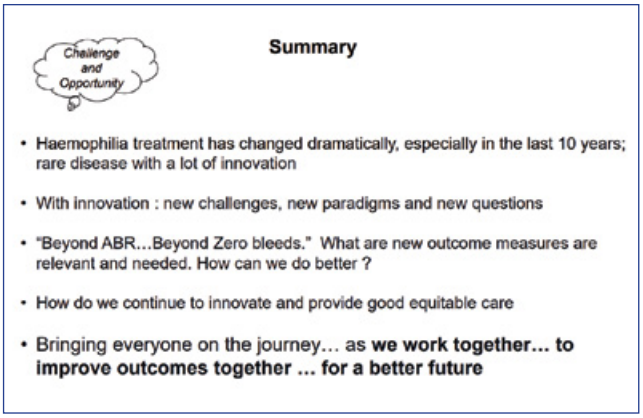
It was such a pleasure to have Dr Glenn Pierce giving the opening plenary at the Conference. He spoke about personalized medicine and emerging treatments, touching on the progression of treatment options for people with haemophilia over the years.

Dr Pierce discussed patient-orientated algorithms for personalised treatment choices in the current treatment landscape, which led to the development of the WFH Shared Decision-Making Tool, now available at sdm.wfh.org. This tool enables patients and their families to work together with their healthcare professionals to make the best informed choice about their treatment options.



One issue highlighted by Dr Pierce was the ongoing health inequity for people with haemophilia in countries with limited resources and how this could be addressed by providing gene therapy. Even though currently this is a costly treatment, it has the potential to be 'one shot and you're done' which may well be a more sustainable option in the long term for countries that have limited or no access to other haemophilia treatments.

Dr Liane Khoo then spoke about the Australian experience and challenges with new and emerging haemophilia therapies. She spoke about the whole team approach with patients and their families at the centre. The evolution of the treatments for haemophilia patients was very interesting and it was amazing to see how far we have come. What's even more exciting is that Australia thus far has participated in 64 clinical trials!



Dr Khoo then walked through the newer therapies that are on the market now and what is coming soon and the challenges these bring to patients and clinicians. Needs of the patients will be changing as well as the needs of the Treatment Centres and their models of care. As a closing note she mentioned as we work together to improve outcomes together for a better future, which was a very appropriate statement for this year's Conference.

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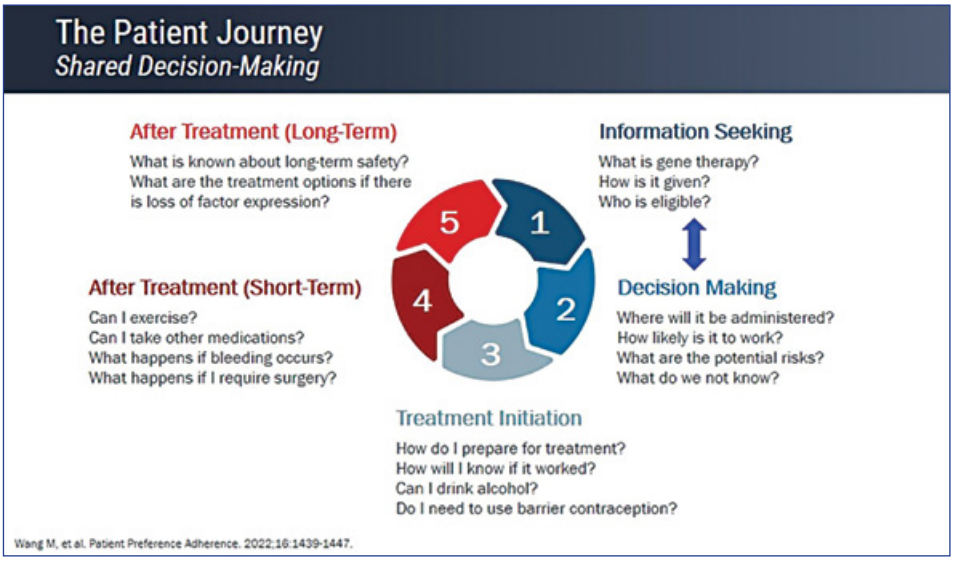
Natalie Karlovic



Plenary - Gene therapy

Chair ~ *Prof Huyen Tran*

Overview ~ *Dr Glenn Pierce*

Psychological overview ~ *Jane Portnoy*

Overview into AHCDO Gene therapy roadmap ~ *Prof Huyen Tran*

One of the hot topics at the Conference was Australia's foray into gene therapy. Already a few Haemophilia Treatment Centres around Australia have supported clinical trials with gene therapy for their patients. Whilst these presentations were predominantly focused on the medical complexities and further implementation strategies for Australia, the early evidence is showing good results.

Dr Glenn Pierce, one of the pioneers in gene therapy and currently the World Federation of Hemophilia Vice President Medical, was among the speakers sharing emerging evidence gathered from other countries and how this is applicable to Australia.

The impact of new treatments on children and families

Chair ~ *Anne Jackson*

The impact of new treatments on children and families ~ *Anne Jackson*

Impact on practice in the paediatric setting - a paediatric nurse's view ~ *Janine Furmedge*

Physical activity in children ~ *Nicola Hamilton*

Young adult and his mother's perspective ~ *Catherine and Lachlan*

While gene therapy is not currently available for patients under the age of 18 years, an insightful and valuable perspective was offered from a young adult patient and his family on the impact of extended half-life therapies. The change from daily prophylaxis dosing to less frequent infusions has had a large impact on their treatment burden and ultimately their quality of life.

The presentation from Nicola Hamilton, a physiotherapist from the Royal Children's Hospital in Melbourne, highlighted the importance of the role of physiotherapy within this space - in particular, helping children with haemophilia to identify what a joint/muscle bleed appears like when on these new therapies. Her presentation also encompassed the importance of physical activity and limiting increased screen time within all children - not only children affected by haemophilia or other bleeding disorders.

Alex Klever is Clinical Nurse Consultant – Haemophilia at the Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital.

Natalie Karlovic is Physiotherapist - Oncology, Haemophilia and Palliative Care, Children's Health, Queensland Hospital and Health Service.

Women and girls with bleeding disorders

Plenary - Women and girls with bleeding disorders

Chair ~ *Dr Meredith Wiggins*

Personal perspectives on the challenges and issues of living with a bleeding disorder

~ *Shauna*
~ *Cheryl*

Medical perspectives on diagnosis, assessment, treatment and care

~ *Gynaecologist: Prof Sonia Grover*
~ *Haematologist: Dr Briony Cutts*

Suzanne O'Callaghan

The challenges and issues for women and girls with bleeding disorders were highlighted in the plenary, which explored both the personal experience and the complexities of clinical management.

Shauna and Cheryl gave compelling accounts of what it has been like for them to live with a bleeding disorder, the complications they have had to deal with and what they hope for in the future. Shauna's story is published in this issue of *National Haemophilia*.

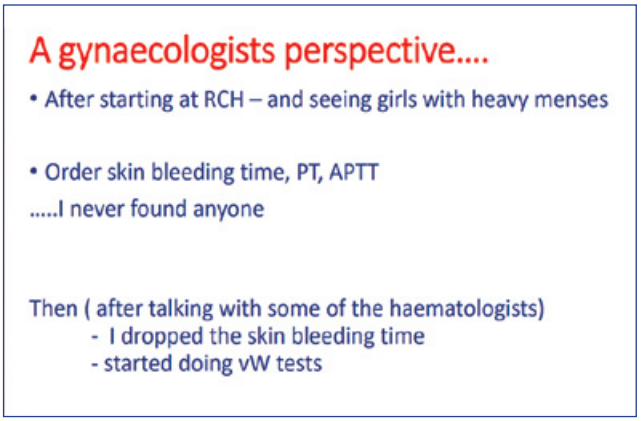
Although there have been advances in medical management in recent years, both Professor Sonia Grover and Dr Briony Cutts commented on the high level of under-diagnosis in women and girls and the value of Bleeding Assessment Tools (BATs) as a support to taking a bleeding history, along with checking the family history for abnormal bleeding. While a general practitioner could undertake initial laboratory testing, it was important that a specialist laboratory should process the testing and the woman or girl should be referred to a specialist to interpret the results.

Anaemia or iron deficiency is a common complication of a bleeding disorder in females and Briony Cutts noted that it is a significant outcome that can impact on cognitive as well as other physical functioning.

Individual data is vital to understanding the impact of bleeding disorders in women and girls as well as managing their bleeding disorder over their lifetime. Briony Cutts recommended that women and girls be registered with their Haemophilia Treatment Centre and with the Australian Bleeding Disorders Registry (ABDR).

Alex Klever

Professor Sonia Grover spoke about her experiences - suspecting that women and girls were being underdiagnosed and trying to find more effective ways to identify those who had bleeding disorders. Early in her career the basic teaching was to consider a bleeding disorder in teenagers with heavy menstrual bleeding but then no further questions were being asked. She herself started doing blood clotting time testing such as APPTT and PT but these tests did not find anyone with a bleeding disorder. But she changed tack and then started performing specific von Willebrand testing. She undertook some audits at her adult women's hospital and found that a lot more women with heavy menstrual bleeding qualified for bleeding disorder testing than were being tested and that a large number who were tested had abnormal results and some were even diagnosed with an inherited bleeding disorder.



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Sonia highlighted:

- gynaecologist and GPs should be asking more questions about heavy menstrual bleeding and ovulation pain
- consider the use of the Bleeding Assessment Tool www.letstalkperiods.ca
- not to test when women/girls are stressed as results are not accurate
- suppress periods and ovulation though the use of oral contraception
- use tranexamic acid
- Mirena IUDs (intrauterine devices) can be used even in young teenagers.

Dr Briony Cutts spoke as well about the use of the Bleeding Assessment Tool (BAT) developed by the International Society on Thrombosis and Haemostasis (ISTH) - https://tinyurl.com/ISTH-BAT This tool is easy to use and, with the combination of taking a clinical history, can be useful in diagnosing bleeding disorders or to establish if bleeding disorders are normal or abnormal.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Alex Klever is Clinical Nurse Consultant – Haemophilia at the Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital.

The challenges of living with VWD – Shauna's story

Shauna shared her personal story of managing quality of life issues while living with Type 3 VWD at the 21st Australian Conference on haemophilia, VWD and rare bleeding disorders. This is a transcript of her presentation.

My name is Shauna, I have type 3 von Willebrand disease (VWD). I'd like to take the next ten minutes or so to talk about my experiences living with a severe bleeding disorder and how this has presented at different stages of my life. I know there are a few friendly faces in the room who already know a bit about me – so no spoilers please!

I was diagnosed as an infant and have lived my whole life knowing I had a bleeding disorder. As a baby learning to walk, I was progressively becoming covered in bruises with no known reason why. Due to the rare nature of my bleeding disorder, and the lack of any family history, it took some time to achieve a diagnosis. It wasn't until a serious bleed from a cut lip that I was diagnosed with type 3 von Willebrand disease. My parents carefully navigated through my upbringing, figuring things out along the way under the guidance of my haematology team.

GROWING UP

The way my bleeding disorder presents itself and impacts my life has evolved a lot throughout my growth and development. As a child, we were mostly focused on preventing injury and bleeds. At this point in my life, I was in otherwise good health. My parents allowed me to stay active as much as possible engaging in activities like athletics, swimming, and ballet. During my childhood my main causes for concern were very severe nosebleeds that often-required hospitalisation, and careful watch during a couple of small dental procedures. At a young age,

my bleeding disorder didn't greatly impact my life. I would sometimes become frustrated that I couldn't join in on all the sports my peers were playing, but beyond that my symptoms just were. I didn't know any different and I was unbothered by any bleeds that occurred.

My paediatric HTC consisted of a very comprehensive team and the co-location of a women's hospital led to a relatively smooth transition into puberty – as much as anyone could expect having severe clotting issues! I experienced extremely heavy periods that would often last over two weeks, initially managed with tranexamic acid only. I then began experiencing ovarian cysts mid cycle, and due to the comorbidity of VWD these would bleed into themselves resulting in large orange sized cysts with significant clots. During these episodes I would be in a huge amount of pain and unable to stand upright. The combination of these two issues led to a prescription of an oral contraceptive in the hopes this may solve both – and thankfully this did get everything under control to an extent.

This allowed me to then focus on re-establishing my non-existent iron levels, which continued to be a problem into my early twenties. After years of attempting to manage anaemia with oral supplements, I was eventually moved on to iron infusions. Our society is not generally accepting of open conversations about periods, something that is amplified during teenage years. My bleeding disorder symptoms during this period of my life made me feel extremely isolated. My peers could never understand the level of medical trauma I was experiencing. The fatigue and pain I experienced also led to missing out on a lot of social development and many days away from school. While in the moment we just got on with it, I do reflect on this time with sadness regarding missed opportunities.

BECOMING AN ADULT

During my early twenties I tried to stay as active as possible, continuing ballet and working in a relatively physical job. I started to experience new symptoms, like joint bleeds and bladder bleeds. When asked if I identified these bleeds because there was blood in my urine, the only way to describe the severity is that it was more like I had urine in my blood. After the third recurrence of this testing suggested surgical intervention was required and I had a few small pre-malignant polyps removed from my bladder. This was one of the first instances where I started to realise that my bleeding disorder sometimes led to more severe symptoms in relation to other health issues. I was bleeding due to the polyps, but the bleeding symptoms were amplified significantly due to the von Willebrand's. Being extremely career driven at this point in time, I focused on work more than my health and I am proud of the milestones I achieved under the circumstances. I worked full time while completing an undergraduate degree and progressed to management level in the workplace before reaching my mid-twenties.

HEAVY MENSTRUAL BLEEDING

After almost a decade using oral contraceptives to manage heavy periods with only a few episodes of ovarian cysts, it was no longer effective, and I was experiencing extensive episodes of menorrhagia. While I was not bleeding as heavily as I was during my teenage years, I was bleeding consistently for weeks on end, with seemingly no links to my cycle. Concerned that there may have been something more suspicious going on due to the incident with my bladder, I became concerned about using further contraceptive methods to potentially mask a more suspicious issue. My haematologist suggested seeking out opinion from a gynaecologist. Unfortunately, my bleeding symptoms were prolonged due to wait times and then having to seek multiple opinions. The first specialist I met with insisted my symptoms were just bleeding disorder issues. When I expressed my concern about other problems, using the example of my experience with polyps, they again insisted that this was due to my bleeding disorder and that I should either learn to live with it or have a hysterectomy. I was 24.

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TREATMENT CHANGES

I eventually met with a new doctor who was completely understanding of my experience living with a chronic condition. They listened to all my concerns and proposed a plan of action that would address my concerns and attempt to resolve the issues. They suggested trying a Mirena for the bleeding symptoms while also conducting biopsies to ensure there were no other potential causes for the bleeding I was experiencing. I was assured that if this didn't work, we would immediately remove the Mirena, and we would continue exploring other options.

As a culmination of this, joint bleeds, and again becoming quite fatigued after prolonged blood loss, my HTC supported a transition onto prophylaxis. The combination of these two solutions has been successful for the past 5 years. After developing the confidence to advocate myself while leaning on a support system of other people with bleeding disorders, I became more involved with the community and found it empowering to continue sharing my story to help others. I have met multiple people who have sought out a diagnosis after hearing my stories. The strength I have found to continue living a normal life despite my ongoing bleeding disorder symptoms is owed in great part to my community of peers, as well as knowledgeable and supportive health professionals.

ADDITIONAL DIAGNOSES

Once I had stabilised after an extended period of bleeding episodes with the introduction of prophylactic care, I started to notice some other ongoing pain that had previously been secondary to bleeding symptoms. While seeing my rheumatologist for joint care as part of the multi-disciplinary clinic, I was diagnosed with hypermobile EDS (Ehlers-Danlos Syndrome). In hindsight, this has shed light on the reason why I always seemed to experience an increase in joint bleeds when I took breaks in my exercise routine. Having this diagnosis has meant that I can establish an exercise routine that will support my joints and reduce ongoing pain from the EDS while also reducing joint bleeds and the gradual damage this can cause. It was a relief to work through this diagnosis with health professionals who helped me understand the importance of maintaining physical health to keep everything under control. With their support I am able to continue doing things I enjoy – such as hiking and Pilates – in order to maintain an appropriate level of fitness.

While recently having a cystoscopy to ensure the polyps in my bladder have not returned, the surgeon noticed severe cystitis. I'm now undergoing the process of being diagnosed with endometriosis as a potential cause of this. Again, in hindsight this may have been the cause of a lot of the gynaecological issues I experienced growing up where the more immediate concern of bleeding was treated as a priority, as it should be, though further investigation may have prevented ongoing pain and trauma. I am now undertaking ongoing pelvic floor physiotherapy to rectify some of the ongoing pain symptoms I have, and with hopes to reduce the inflammation in my bladder. I do occasionally feel overwhelmed by all of the additional diagnoses, but at the end of the day these issues were always there and understanding how to manage symptoms has only had a positive impact on my overall health.

Managing my ongoing medical conditions and how they interact will continue to evolve as I age, and my medical health plans will accommodate these changes over time. While my bleeding disorder is usually the primary concern as the symptoms often have the most serious consequences, understanding how other health concerns may exacerbate my bleeding symptoms has been crucial in reducing the occurrence of serious and ongoing bleeding episodes. Finding health care specialists who treat my symptoms holistically and actively work against generating a band-aid fix has drastically improved my quality of life and I am thankful to have reached a point where I am able to feel in control of my own health and that I am working toward reducing occurrences of bleeding and pain.

Photo supplied by Shauna and used with permission. Stock images: Freepik; Pixabay and Burst for Pexels.com.

Pregnancy and childbirth

Stephen Matthews

Pregnancy, childbirth and newborns

Chair ~ *Dr Jane Mason*

Nursing perspective – pregnancy and delivery management ~ *Robyn Shoemark*

Delivery and birth ~ *Dr Iniyaval Thevathasan*

Best practice management of Previously Untreated Patients ~ *Dr Simon Brown*

Personal Story ~ *Rebecca*

PREGNANCY AND DELIVERY MANAGEMENT

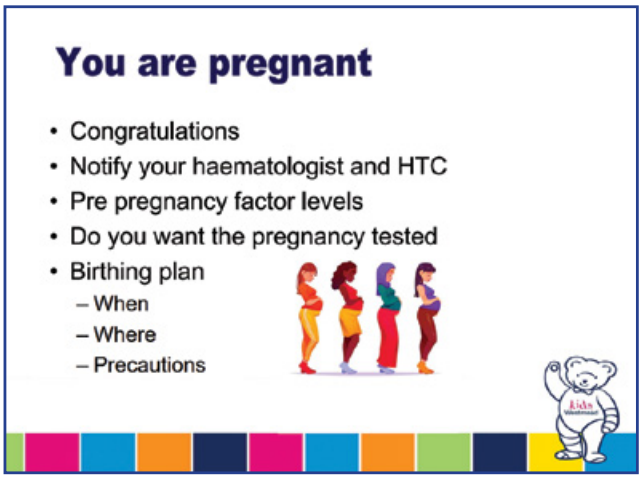
In her presentation on the nursing management of pregnancy and delivery, Robyn Shoemark highlighted the importance in keeping in touch with your Haemophilia Treatment Centre (HTC). Through discussions with the HTC, family planning can hopefully be streamlined to maximise the best outcomes with the pregnancy.

Optimally discussions should start prior to becoming pregnant as this will give the opportunity to establish baseline factor levels and refer to genetic counselling. This will also give your partner information on the bleeding disorder, how it is passed on, the chance of a child being affected and what to expect regarding treatment. Genetic counselling can also provide information on options such as natural conception and pre-implantation genetic diagnosis.

Once the pregnancy is confirmed, discussions can be had around:

- monitoring the mother's factor levels during pregnancy
- testing of the baby (whether to test for the condition or not)
- ultrasound to determine the sex of the baby to help with the birthing plan
- where to have the baby, referrals to obstetrics, type of hospital
- birthing plan for the mother (depending on levels) and baby (depending on what information is known).

The earlier plans can start to be formulated and put in place the better the process should be.



Stephen Matthews is Clinical Nurse Consultant Haemophilia at the Royal Prince Alfred Hospital, Sydney, NSW

Von Willebrand disease

Suzanne O'Callaghan

VWD

Chair ~ *Dr Chee Wee Tan*

Personal story ~ *Adam*

Personal story ~ *Susie*

VWD diagnosis ~ *Dr Geoffrey Kershaw*

VWD clinical management ~ *Dr Nalini Pati*

PERSONAL STORIES

The von Willebrand disease (VWD) session began with Adam's story of his personal journey with type 3 VWD. He has always been very physically active, but as he has grown older, he has become more aware of the impact of bleeds from injuries on his long-term health, as well as experiencing gastrointestinal bleeds, and is now looking at ways to manage this better into the future. He has learned to self-infuse and has considered employment options to support working from home to help manage bleeds. His advice to others with VWD:

- Don't ignore a bleed (as he has done, being male)
- Get a good GP and train them; and a good gastroenterologist
- Explore flexible employment options.

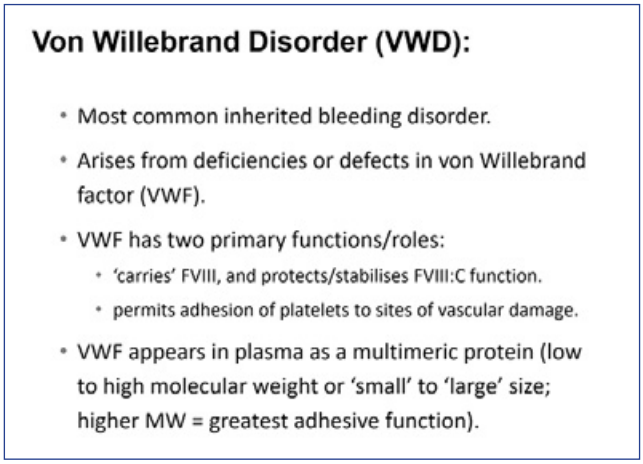
He finished with the comment that VWD is a disorder, not a disease – a view held by many in our community.

Susie followed with her experiences of living with type 1 VWD. Susie's story is published separately in this issue of *National Haemophilia*.

VWD DIAGNOSIS

Diagnosing VWD is complex and specialised. Dr Geoffrey Kershaw gave a remarkably accessible presentation on the key aspects of laboratory testing in an area that is very scientific. He explained that different regions of the von Willebrand factor (VWF) structure have different functions: binding to collagen or FVIII (factor 8) or platelets through glycoprotein 1b (Gp1b). These different functions relate to the laboratory tests available.

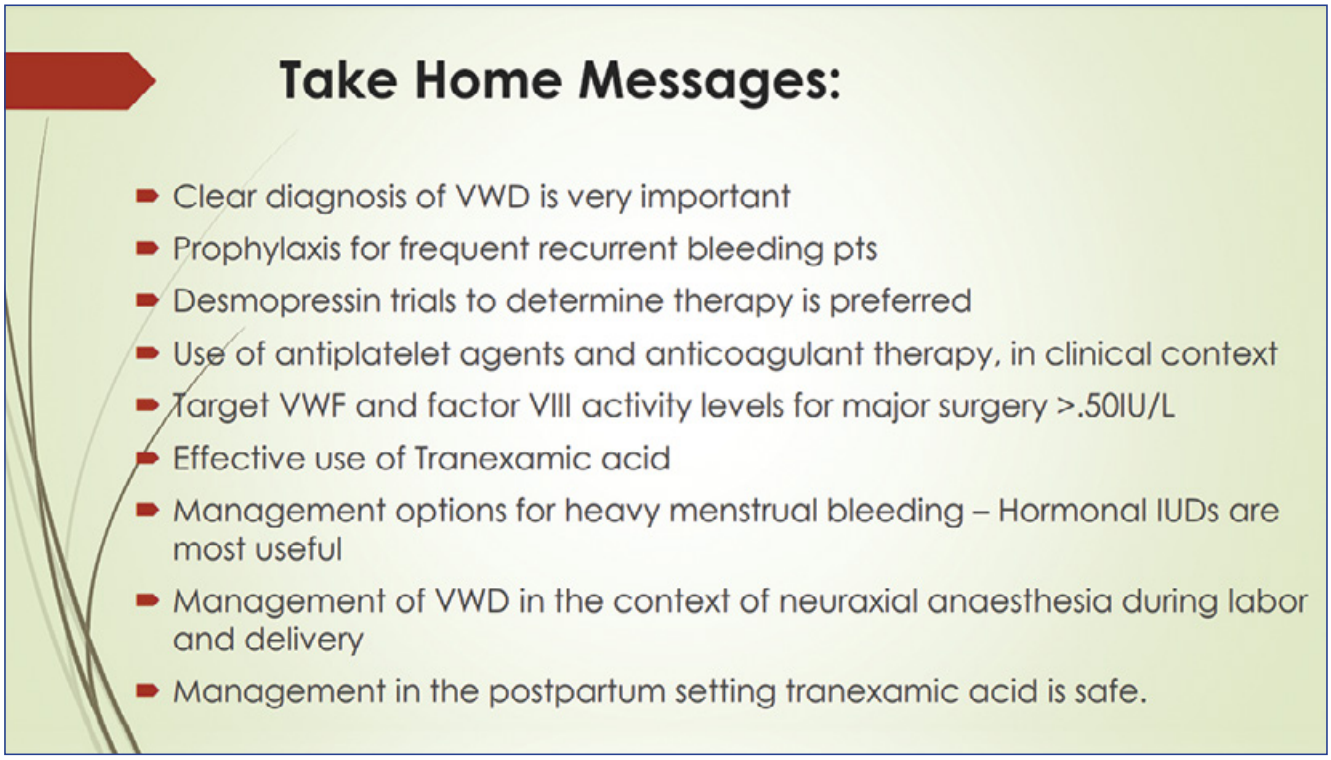
Testing and results can be affected by many variables. For example, an individual's VWF levels can increase because of stress, physical exertion and inflammatory illnesses and the sample must be kept at a specific temperature range for its quality to be maintained.



VWD CLINICAL MANAGEMENT

In a presentation on the medical issues, Dr Nalini Pati highlighted some of the factors affecting a patient's journey to appropriate diagnosis and treatment.

A lack of awareness among general practitioners and other health professionals in the wider community



and a wide variation in presentation means that VWD diagnosis often occurs late. He noted that treatment needs to be personalised but that treatment options in Australia are currently limited.

There was a consensus in the session that current challenges include:

- Need more data on Australian experience
- Need Australian VWD clinical guidelines
- May be multiple factors at play, not just VWF
- No recombinant product available in Australia
- Would be good to have a long-acting VWF product
- Better education for GPs, dentists, allied health to identify VWD and refer appropriately.

This was discussed in the final plenary, with a recommendation from Assoc Prof Chris Barnes that VWD needs to be included in the Australian Bleeding Disorders Registry (ABDR), along with education of health professionals in the wider community.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

WANT TO KNOW MORE?

Many of the Conference presentations are now available on the HFA website.

View the presentations:
haemophilia.org.au/conf23

Living with Type 1 VWD – Susie's story

Susie shared her personal story of living with Type 1 VWD at the 21st Australian Conference on haemophilia, VWD and rare bleeding disorders. This is a transcript of her presentation.

My name is Susie and I have type one von Willebrand Disease (VWD). I am a parent of a person with type three. My short bio is that I was an undiagnosed bleeder until after my second child was diagnosed when they had a minor surgery at age 6 weeks. The diagnosis at 27 was a shock but explained so much.

I actually have two bleeding disorder identities. They are the dual experiences of a person with a bleeding disorder and a parent of a child with a bleeding disorder. I will not speak here for their experience – I hope they will do that for themselves sometime.

I want to talk today about my lived experience. I'm going to be quite blunt and perhaps a little direct here but I'm not trying to be controversial. I have the fortune of being a type one with a mild bleeding tendency. I am not seeking to overstate this but to draw attention to the flow on effects and quality of life issues.

As for my lived experience, I could give you the run-down of all my symptoms pre-diagnosis but I wonder about the usefulness of that. I figure it would be most useful for the people who could come into contact with the undiagnosed - the GPs, the midwives, the dentists, allied health - there's quite a list. However, it is also useful here in thinking through the full experience of a type one. My VWD has absolutely had an impact on my life, my friendships, my relationships.

In simple terms I had bruising that was normalised in my family. It didn't seem problematic to me and so as a child, it wasn't an impact. Quite honestly, I had plenty of other health issues that were impacting me more significantly. I did, however, have weird oozing bleeds that just kept on going. Small injuries took so very long to clot. Gum bleeds, nose bleeds. In my teens I had chaotic, heavy and problematic menstrual cycles but lived in a family where we didn't talk about our periods properly. I had a catastrophic post-partum haemorrhage after my first caesarean preceded by a massive leg injury resulting from a fall when 36 weeks pregnant.

Throughout the years I have had in simple terms, abnormal menstrual bleeding. Hormonal treatment worked effectively but wasn't always appropriate for me. The other side effects and risks associated meant I chose not to be on it all my menstruating life. Also, if I wasn't trying to achieve contraception (as I wasn't

having sex with a fertile man) why do that to myself? Sometimes it was a matter of being heavy. Sometimes it was awful substantial clots that no tampon or pad would absorb. I had a few years with light on and off bleeding throughout the day in most days across the month. This was when I tracked I was having only about 10 bleed free days a month but I had no idea in advance which days they would be. The Gyno investigations ruled out other issues. Imagine trying to have a sex life with this going on, imagine starting new relationships with this going on…

The VWD diagnosis provided information to explain in part what had been happening in my body. It was quite literally life changing. My life went in a direction I did not ever expect. I had to learn skills to help my child that I was terrified by. I had to master the fear and navigate the complexity of a rare bleeding disorder. I received treatment that gave opportunities for improved health as well as safety when having procedures. I think of my first iron infusion at my HTC – it was like the afterburners kicking in on a rocket, I was absolutely 'on'. I have made friends with some truly kind and compassionate people. By volunteering and speaking up I've travelled to places I could only dream about.

My VWD diagnosis brought up some questions. Had my also undiagnosed coeliacs resulted in a compounding effect, doing more harm to my health? All those years what kind of gastrointestinal bleeds had been trickling in the background? Was this all the cause of the intractable iron deficiency that I just gave up on trying to treat for many years? Why did I have such a massive bleed after my first caesarean and not the second one? Why do I not bruise for some time and then randomly, back to it?

My family and I spent so very much time in hospital with plans cancelled at random over and over when we could not handle things at home. I took on the role of educator for my child's teachers, the parents of school friends, sporting clubs, all those contact points. There's also a whole other story about the impacts on my first child, as the 'other child', the coper, the hidden trauma they experienced as well.

COVID has been the great unknown. When I had COVID as well as some of my vaccinations, I had what I describe as super periods. They weren't super fun, they were super weird, heavy and gushing. I'm hearing some rumblings about not enough research into the menstrual irregularities with COVID both in normal population as well as bleeders.

And now, I'm getting older. I'm well peri menopause, counting down to November which is this anniversary of my last period. Huzzah. I have been retested and have near normal levels. But what will happen? I know phenotype doesn't change but some mild type ones don't sustain peak levels after trauma or surgery. My biggest fear is what if I need surgery after an injury like that fall nearly 24 years ago.

So what does this all mean? I think it means we have to keep talking, to keep listening. To hear the diversity of experience for people with bleeding disorders. Dismissing von Willebrands as a mild disorder does nothing to help people live a full and healthy life. I feel it can be a barrier to diagnosis – what's the point when they don't need anything? I hope a little of what I have said here today can shift that opinion. To enable us as a community to come together and to see that while we all need treatment that will look differently for each one of us as well at different times in our life.

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Mild haemophilia

Plenary - Managing mild haemophilia

Chair ~ Dr Heather Tapp

Personal perspective from a young adult and his dad *~ Louis and Tom*

Diagnosis and treatment *~ Dr Heather Tapp*

Mild haemophilia in adults: medical issues *~ Dr Stephanie P'ng*

Nursing management, including surgery in mild haemophilia *~ Alex Klever*

Physical activities and sport across the lifespan *~ Abi Polus*

Suzanne O'Callaghan

Dr Heather Tapp introduced the session on managing mild haemophilia by describing it as 'the new frontier' and there was consensus among the speakers that there is still much to be understood.

If there is no family history, diagnosis can be delayed until there is unexpected bleeding following an injury or medical procedure and there is some concern internationally that mild haemophilia may be underdiagnosed.

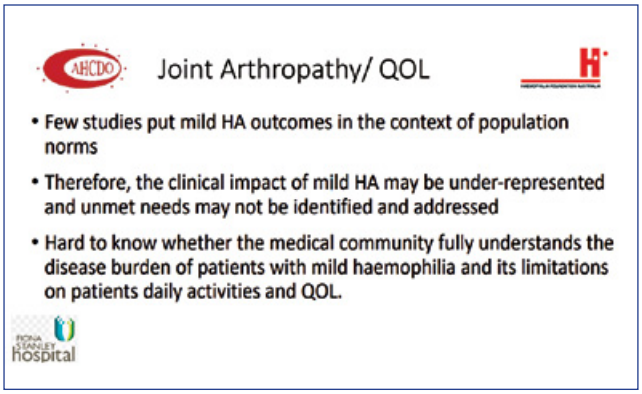
Another issue reported commonly internationally is that people with mild haemophilia may not recognise bleeds or access assessment and treatment by their Haemophilia Treatment Centre (HTC) in a timely way. An outcome of this has been that a substantial number of males with mild haemophilia experience joint problems, even those who are younger adults.

Heather Tapp highlighted that providing education and support to people with mild haemophilia is becoming an increasingly important aspect of the work of HTCs. She drew attention to an example of an innovative injury self-management app (**HIRT** – Hemophilia Injury Recognition Tool) developed in Canada specifically for young men with mild haemophilia. The app assists them to identify the signs and symptoms of a bleed and then steps them through the process of assessment, with reminders to check the injury and contact their HTC when appropriate.

Although many people with mild haemophilia experience significant morbidity and consequences of unrecognised bleeds, she pointed out that mild haemophilia is not currently an indication for novel haemophilia therapies. She called for consideration to be given to access to the pipeline of novel therapies that may help normalise the lives of people with mild haemophilia. While gene therapy seems to be aiming to convert people with moderate or severe haemophilia to mild haemophilia, having mild haemophilia creates its own set of challenges. She concluded with a question for the future: 'can we hope for a cure of mild haemophilia – the truly "haemophilia free mind"?'

Natalie Karlovic

During the **Managing mild haemophilia** session, we heard from medical professionals, nursing staff, physiotherapists, and a patient perspective. A young adult and his father offered their experience with the condition.



Some of the more surprising evidence highlighted that people who have mild haemophilia often have worse physical impairments as they get older in comparison to their peers with moderate or severe.

Mild haemophilia also has a large spectrum of severity, with Dr Stephanie P'ng posing the question, 'should we be classifying patients into severe-mild, moderate-mild and mild-mild?'.

Reflecting further on this, as gene therapy aims to transition patients from severe or moderate to mild, should physiotherapists play a larger role in the education aspect for this population to support them with identification and management of joint bleeds prior to permanent joint arthropathy?

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Natalie Karlovic is Physiotherapist - Oncology, Haemophilia and Palliative Care, Children's Health, Queensland Hospital and Health Service.

Rare bleeding disorders

Stephen Matthews

Rare bleeding disorders

Chair ~ Dr Jane Mason

Personal experience ~ *Chauntelle, FXIII deficiency*

Rare bleeding disorders ~ *Dr Sally Campbell*

Personal experience ~ *Jenny, acquired haemophilia A*

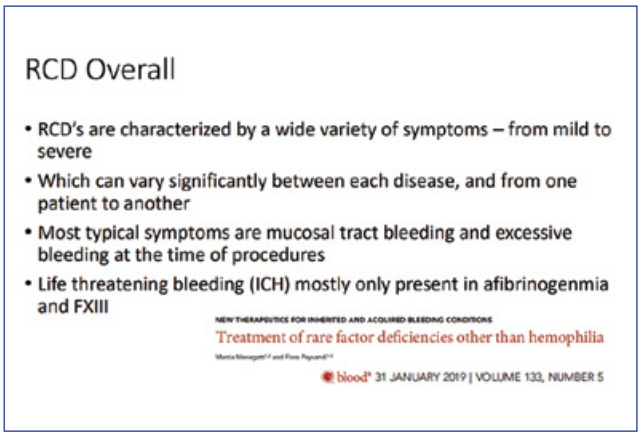
Acquired haemophilia ~ *Dr Jane Mason*

Hereditary Hemorrhagic Telangiectasia ~ *Alex Klever*

RARE BLEEDING DISORDERS

In her Rare Bleeding Disorders presentation, Dr Sally Campbell provided an overview of the rare coagulation disorders.

This incidence of these disorders ranges from 1 in 500,000 to 1 in 2,000,000, with one being extremely rare, and only reported in <30 families worldwide.



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For each of the conditions she covered:

- The mode of inheritance, ie whether both parents needed to have the gene or just one parent.
- What the standard coagulation test would show to prompt which specific coagulation factor to test for.
- The typical type of bleeds that occur and the available treatment in Australia. Recommended doses were also included for on-demand, prophylaxis, minor and major surgery.

As these are rare conditions, not all treatments have factor-specific concentrates available like haemophilia, so fresh frozen plasma is still a mainstay therapy for treatment.

Another important consideration in this group is that factor levels do not necessarily reflect the anticipated bleeding pattern. Therefore, factor levels plus bleeding history need to be taken into account to predict treatment.

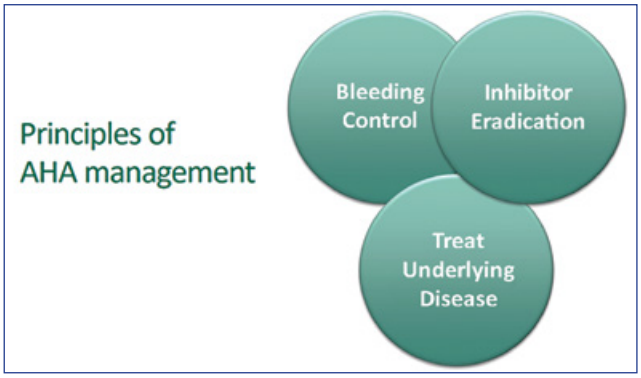
ACQUIRED HAEMOPHILIA

Dr Jane Mason gave a presentation on acquired haemophilia and noted that in approximately 50% of cases no cause for the development of acquired haemophilia A can be found.

The three most common causes, however, are underlying malignancy, autoimmune disease and pregnancy.

Typically, most cases are in the older age group (median age 74), with a fairly equal spread between male and females. The 20 to 40 age group is predominantly women and pregnancy related.

She included a table that compared acquired haemophilia with congenital haemophilia and pictures of bleeds typical of acquired haemophilia, which was very useful to show how different the two conditions are.



There was then a discussion on two papers relating to the off-label use of emicizumab (Hemlibra®) in treating acquired haemophilia and Jane's personal experience in seven patients. With the introduction of emicizumab in the treatment schedule, there was a dramatic reduction in the number of bleeding episodes and use of bypassing agents needed to treat bleeds. The length of hospital admission was also reduced.

HEREDITARY HAEMORRHAGIC TELANGIECTASIA

In the presentation on hereditary haemorrhagic telangiectasia (HHT), Alex Klever discussed the clinical features of HHT, how it is diagnosed and symptoms. The major symptoms are nose and gastrointestinal bleeding which can lead to anaemia.

The Epistaxis Severity Score is an online tool that evaluates nosebleed severity after answering six questions. This can be used to initiate treatment and then monitor how effective the treatment is. As it is easily available and simple to use, it is a great tool for continued monitoring.

Monitoring of HHT can be time-consuming and invasive. Monitoring can involve blood tests, CT scans, MRI, ultrasound, endoscopy, gastroscopy and capsule endoscopy. Treatment of anaemia can also be time-consuming, especially if blood transfusions are required.

Alex finished her presentation with a discussion of the InHIBIT-Bleed study, which retrospectively reported on the off-label use of bevacizumab (a monoclonal antibody used to treat some cancers) in people with HHT. The report only included 140 patients, but the results are promising. It showed that with bevacizumab therapy haemoglobin levels increased and the epistaxis severity score, blood transfusions and iron infusions all decreased. This has the potential to lead to clinical trials in the future.

Stephen Matthews is Clinical Nurse Consultant Haemophilia at the Royal Prince Alfred Hospital, Sydney, NSW

Identifying bleeds

Stephen Matthews

Is it a bleed? MSK recovery

Chair ~ Jo Newsom

Conditions that can mimic a bleed *~ Dr Rob Russo*

Joint bleed recovery – how long does it really take? *~ Ali Morris*

Muscle bleed recovery *~ Jarrad King*

CONDITIONS THAT CAN MIMIC A BLEED

Dr Rob Russo began his presentation by going through the examination of a swollen joint and not surprisingly most observations are what we would expect from a bleed into the joint. He then went on to discuss the conditions resulting in a swollen joint, the most common being mechanical injuries.

Mechanical injuries include ligament tears, trauma to the cartilage, meniscal and tendon injuries, and osteoarthritis. These injuries are most commonly seen in the knees and ankles.

Other processes resulting in swollen joints include a variety of arthritic conditions caused by the activation of the immune system, eg rheumatoid arthritis, and metabolic conditions such as gout. Another cause to rule out is infection of the joint.

To establish the cause of a swollen joint a combination of techniques must be used:

- Clinical history
- Physical examination
- Blood and urine tests looking for metabolic, immune or inflammatory causes
- Aspiration of fluid from the joint for testing especially infection.
- Imaging

Stephen Matthews is Clinical Nurse Consultant Haemophilia at the Royal Prince Alfred Hospital, Sydney, NSW

Pain

Emma Wells

Pain

Chair ~ Jonathan Spencer

Better pain management for haemophilia in the future ~ *Dr Carolyn Arnold*

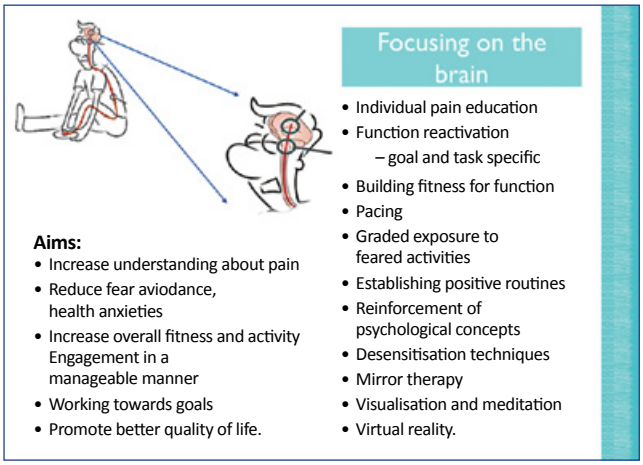
Physiotherapy approaches to pain management in haemophilia care ~ *Cat Pollard*

Strategies to manage procedural and acute pain in children ~ *Michelle Perrin*

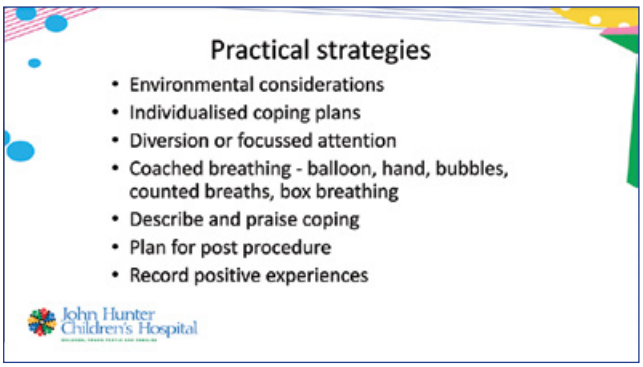
This highly anticipated session included three presenters who shared their expertise and knowledge regarding the topic of pain. I found these speakers to be inspiring, informative and educational.

Chronic pain is more common in people with haemophilia, commented Dr Arnold, a Pain Medicine Specialist. Dr Arnold stated that this pain is mostly from haemophilic arthropathy in joints, so the aim is to reduce bleeding joint episodes. Dr Arnold mentioned the benefits of MDT (multidisciplinary team) clinics, based on an interdisciplinary approach, which can provide a range of pain management strategies.

Pain Specialist Physiotherapist, Cat Pollard outlined that musculoskeletal bleeding is the most common complication of haemophilia. Ms Pollard discussed the complex interactions of how pain is experienced and processed and said that targeting all areas can improve the ability to manage pain more effectively.



The final speaker, Michelle Perrin, Child Life Therapist, outlined strategies to manage procedural and acute pain in children and emphasised the long-term negative impacts on children and young people if medical procedures are not well managed. The importance of building strong relationships with the treating team to ensure patients feel informed, safe and empowered was acknowledged as an essential part of engagement.



Emma Wells is Paediatric Social Worker – Haematology, John Hunter Children's Hospital, Newcastle NSW

Getting older

Nicoletta Crollini

Getting older

Chair ~ Suzanne O'Callaghan

Personal story ~ *Mike*

Medical issues ~ *Dr Liane Khoo*

Hep C and liver health ~ *Dr David Iser*

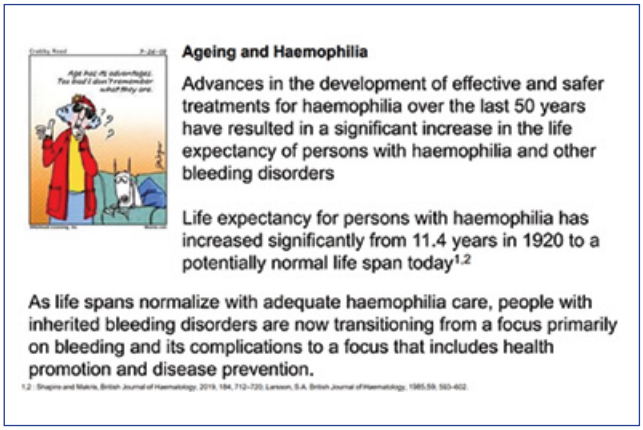
Social connection ~ *Marcia Fearn*

Panel discussion and Q&A ~
Speakers; and nurse: Jayne Treagust; physiotherapist: Cathy Haley; psychosocial worker: Kathryn Body

I was eager to attend the Getting Older session as, thanks to advancements in treatment, people with inherited bleeding disorders are living longer and longer. This session was highly informative, and included stories from those with a lived experience and a panel of experts who are supporting the inherited bleeding disorder community as they get older.

The session began with Mike, who spoke about the challenges of growing up with severe haemophilia, how developments in treatment have allowed him to be more active and how his hope is for this to continue. Mike explained that he leads a very social life, which he enjoys and has found this to be a meaningful aspect of ageing.

The session continued with Dr Liane Khoo outlining medical aspects of getting older with an inherited bleeding disorder. Dr Khoo stressed the importance of health promotion, as good health and quality of life is a major goal for patients, their families and carers. Dr Khoo explained that upskilling general practitioners and educating other specialists are important for dealing with the complications of ageing associated with inherited bleeding disorders.



Dr David Iser discussed the Australian experience of treating hepatitis C, which has been positive, particularly for those with inherited bleeding disorders, who were some of the earliest cured of the disease. Dr Iser explained that if a person is reinfected with hepatitis C, they can be re-treated and that treatment is still covered by the PBS. Dr Iser outlined the importance of testing and monitoring liver cirrhosis even after cure of hepatitis C, stressing that testing and monitoring is non-invasive.

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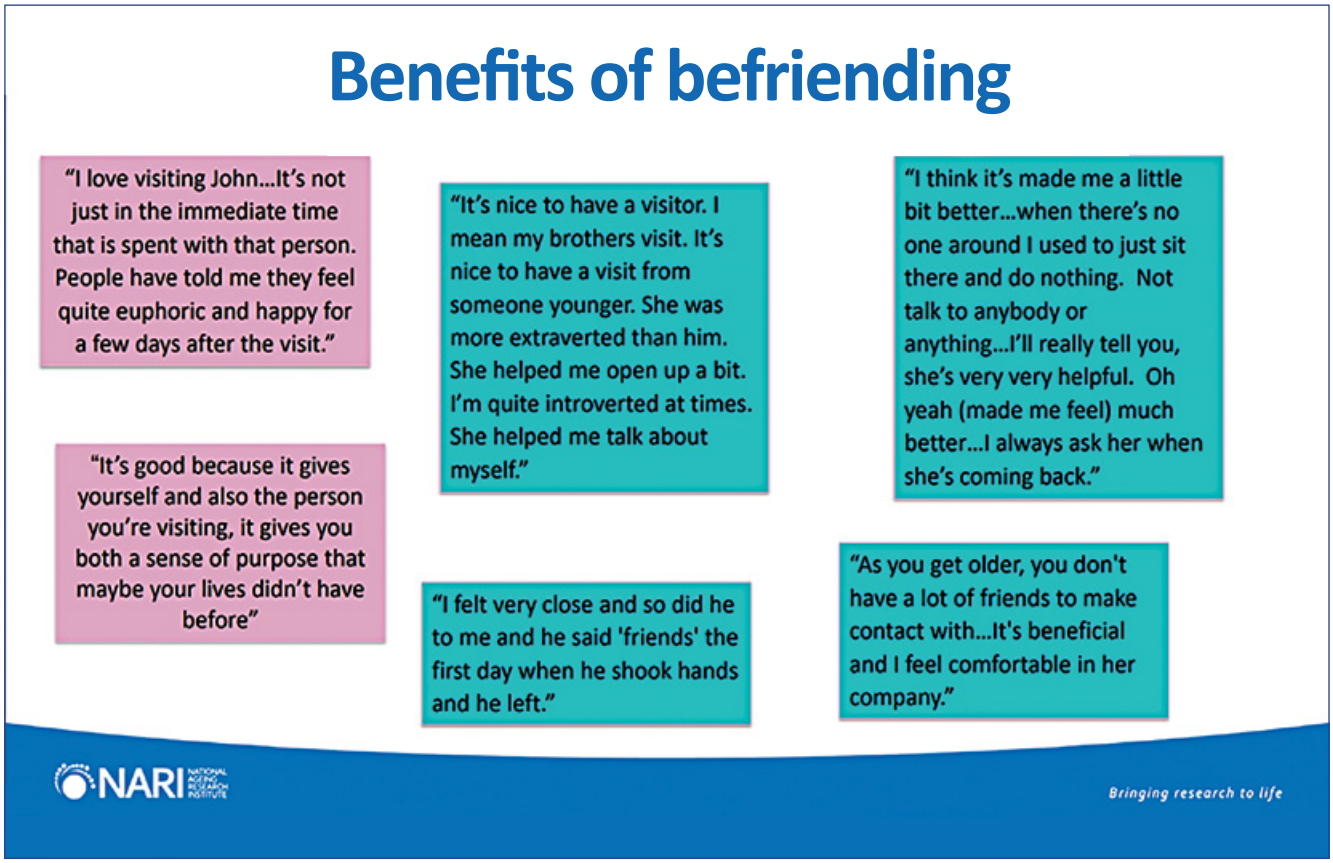

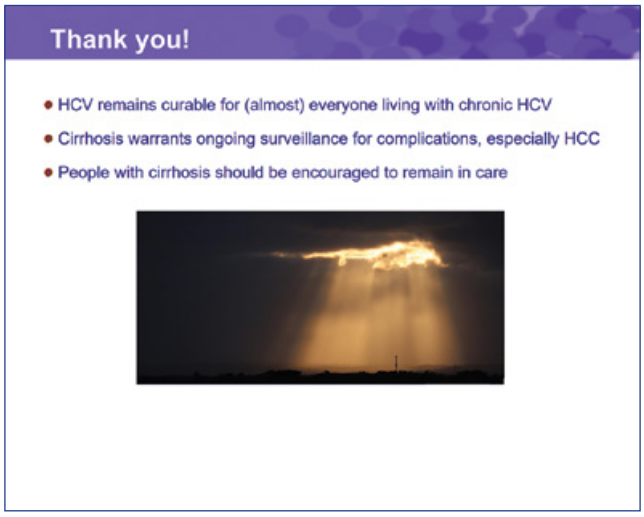

Marcia Fearn discussed the importance of social connection as loneliness has been identified as contributing to several physical and mental health issues. Supporting and maintaining existing connections, engaging in new social connections (such as joining a social group or volunteering) and supporting one's mental wellbeing were all identified as measures to help prevent loneliness.

The session concluded with a robust discussion amongst panel members: Mike, Dr Liane Khoo, Dr David Iser, Marcia Fearn, Jayne Treagust (Nurse), Cathy Haley (Physiotherapist) and Kathryn Body (Psychosocial worker).

Nicoletta Crollini is Haemophilia Social Worker at the Royal Prince Alfred Hospital, Sydney, NSW.

Making career choices

Jane Portnoy

Making career choices

Chair ~ Penny McCarthy

Career choices over a lifetime. Do they change with new treatments? *~ Penny McCarthy*

Personal stories video

How to make career choices *~ Jon Hazelton*

Employment: discrimination, disclosure and the law *~ Mark Waters*

Personal story *~ Dale*

Panel discussion and Q&A *~ speakers and nurse: Kara Cordiner; physiotherapist: Abi Polus; social worker: Nicoletta Crollini*

We were very lucky to have such a skilled and interesting group of presenters to the session on making career choices. They provided some legal perspective, career advisor wisdom, lived experience, and the various MDT (multidisciplinary team) perspectives. However, it is no surprise that the best part of the presentation was the discussion with the audience at the end. Hearing how various people managed their own employment challenges was thought-provoking and useful. Everyone agreed that the direct approach, ie talking to your employer was usually a great place to start.

The experience of the Careers Advisor, Jon Hazelton from Bravo Careers, was to get familiar with yourself, your learning style, what you want and then set yourself up to take action towards what your goals. 'If it's to be, it's up to me' (William Johnsen 20th century painter), was Jon's slogan to encourage those looking to change their career to have a 'bias towards action' alongside goal-setting, and planning.

Mark Waters from CIE Legal spoke about some of the legal issues that workers face. Discrimination and disclosure are the challenges that are sometimes encountered by people with chronic illness. He also spoke about a worker's options when they have experienced discrimination. Being well informed and understanding the relevant Act of Parliament is a starting point in understanding if there is discrimination. Other advice was to work out what outcome you would want and to weigh up the costs: time, emotional and financial. It is really important to do this analysis as even when you win and are clearly in the right; a legal pathway is not easy. Getting good legal advice is essential in these situations.

Relevant Acts include:

- The Equal Opportunity Act (Vic)
- Commonwealth Disability Discrimination Act 1992
- Workplace Injury Rehabilitation and Compensation Act 2013
- Fair Work Act 2009: https://www.legislation.gov.au/Series C2009A00028
- The Anti-Discrimination and Human Rights Legislation Amendment (Respect at Work) Bill 2022

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

FACTORED IN
FOR YOUNG PEOPLE

Youth at the conference

Hi, we are Adam, Alan and Cassie and these are our thoughts about the Conference

The Melbourne Conference in August 2023 was the first time the national Conference had been held in person since the COVID-19 epidemic began. It was a great opportunity for young people with bleeding disorders to catch up with each other and hear the very latest information from the experts.

Adam, Alan and Cassie talked to HFA about their experiences.

The best part was meeting new people who have similar experiences to me

Our experiences

The gene therapy session gave me information on what patients need to know before doing gene therapy

What did you enjoy most about the conference?

Adam
I enjoyed seeing familiar faces, meeting new people outside of my state who have a bleeding disorder. Going to the Casino to celebrate a peer's birthday, meeting the 'old timers' and learning about their journey. Being able to go off on my own and do my own thing in the Conference without a parent. I liked the coffee van with unlimited good coffee especially for the early morning sessions. Experiencing the hand simulator in the trade stands.

Alan
The best part of the Conference was meeting the new faces and learning more about the future treatments and technologies.

Cassie
I enjoyed meeting other people who have had similar experiences to me.

What sessions did you find the most interesting and why?

Adam
The Gene Therapy session. It explained what gene therapy is and how testing in people with haemophilia has occurred in many countries around the world. Gave me information on what patients need to know before doing gene therapy. Key takeaways were the level of clinical trial follow-up required is a big commitment. Variability of results means success is not guaranteed. Possible risks some are major ones. The next wave of gene therapy will be non-viral, less toxic and gene therapy is rapidly evolving.

Alan
The majority of sessions in the last few conferences were centred around the males but this time I found the women's bleeding disorders sessions quite fascinating especially when thinking of family planning and having a chance of a daughter being a carrier.

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Cassie

I enjoyed both the VWD and Girls with Bleeding Disorders sessions the most. I found it helpful hearing from other people who have lived through similar experiences to me and who had insights into potential issues I may have in the future. Also hearing doctors talking about possible solutions.

What message would you give to other young people about the Conference?

Adam

You have to experience at least one Conference as they really open your eyes to what is happening with bleeding disorders, and you get to listen to the medical specialists. You get to see the bigger picture. Not only that but you get to meet new people from all states who have a bleeding disorder and make new friends as well as catch up with peers you may not have seen for some time. Final message is you're not alone and have a lot to look forward to. Your bleeding disorder doesn't define you, you define it.

Alan

It is such a great opportunity to meet others with haemophilia, educate yourself and really bond/learn with/about others in the haemophilia community.

Cassie

Go! It's definitely been worthwhile for me going to the conference, and hearing from and connecting with other people. The bleeding disorder community is great to be part of.

Go! Conferences really open your eyes to what is happening with bleeding disorders.

Read more

You can read reports from the Conference in this issue of *National Haemophilia*.

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

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

PROBE AUSTRALIA STUDY

PROBE
Patient Reported Outcomes Burdens and Experiences Study

Have you done the PROBE survey yet?

The 2023 round of the PROBE Australia Study has now commenced!

You can contribute to our evidence on the different experiences of living with haemophilia.

What is the impact of haemophilia on Australians?

What has changed since new treatments became available?

How does haemophilia impact on different people over their lifetime? For example, women, people with mild haemophilia or inhibitors, younger people, getting older with haemophilia.

HFA uses statistics from Australian PROBE survey responses in our advocacy and planning for the future.

Please complete the survey by Wednesday 31 January 2024.

WHO CAN DO THE SURVEY

You are invited to complete the questionnaire if you are an adult (18 years+) who lives in Australia and:

have haemophilia or carry the gene
OR
do NOT have a bleeding disorder.

HOW TO DO THE SURVEY

The questionnaire is available:

Web version at myprobe.org

Or download the ***myPROBE app*** from Apple Store or Google Play (Android)

Or ask your local Foundation or HFA for a ***print survey pack***

MORE INFORMATION

For more information about the PROBE Australia study, visit:

www.haemophilia.org.au/probe-study

Or contact Suzanne at HFA:
E: socallaghan@haemophilia.org.au

T: 1800 807 173

CALENDAR

World AIDS Day
1 December 2023
www.worldaidsday.org.au

World Haemophilia Day
17 April 2024
wfh.org/world-hemophilia-day

WFH 2024 World Congress
Madrid, Spain
21 – 24 April 2024
wfh.org/congress

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

Season's Greetings

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

Thank you for your support during 2023 and we look forward to working with you again in 2024.

The HFA office will be closed from noon on Friday 22 December 2023 and reopen on Monday 8 January 2024.

During that time if you have any urgent queries phone 03 9885 7800 or email hfaust@haemophilia.org.au. Messages will be monitored, and we will respond as soon as possible.

Haemophilia Foundation Australia acknowledges the Traditional Owners and Custodians of Country throughout Australia, the land, waters and community where we walk, live, meet and work. We pay our respects to Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.