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National Haemophilia

www.haemophilia.org.au

Lighting up red around Australia

World Haemophilia Day and raising awareness

Taking care of your ABDR data

How you and the Data Managers are involved

2023 Conference

What's on the agenda?

HAEMOPHILIA FOUNDATION AUSTRALIA

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Front cover picture of Tasman Bridge courtesy of the Department of State Growth, Tasmania

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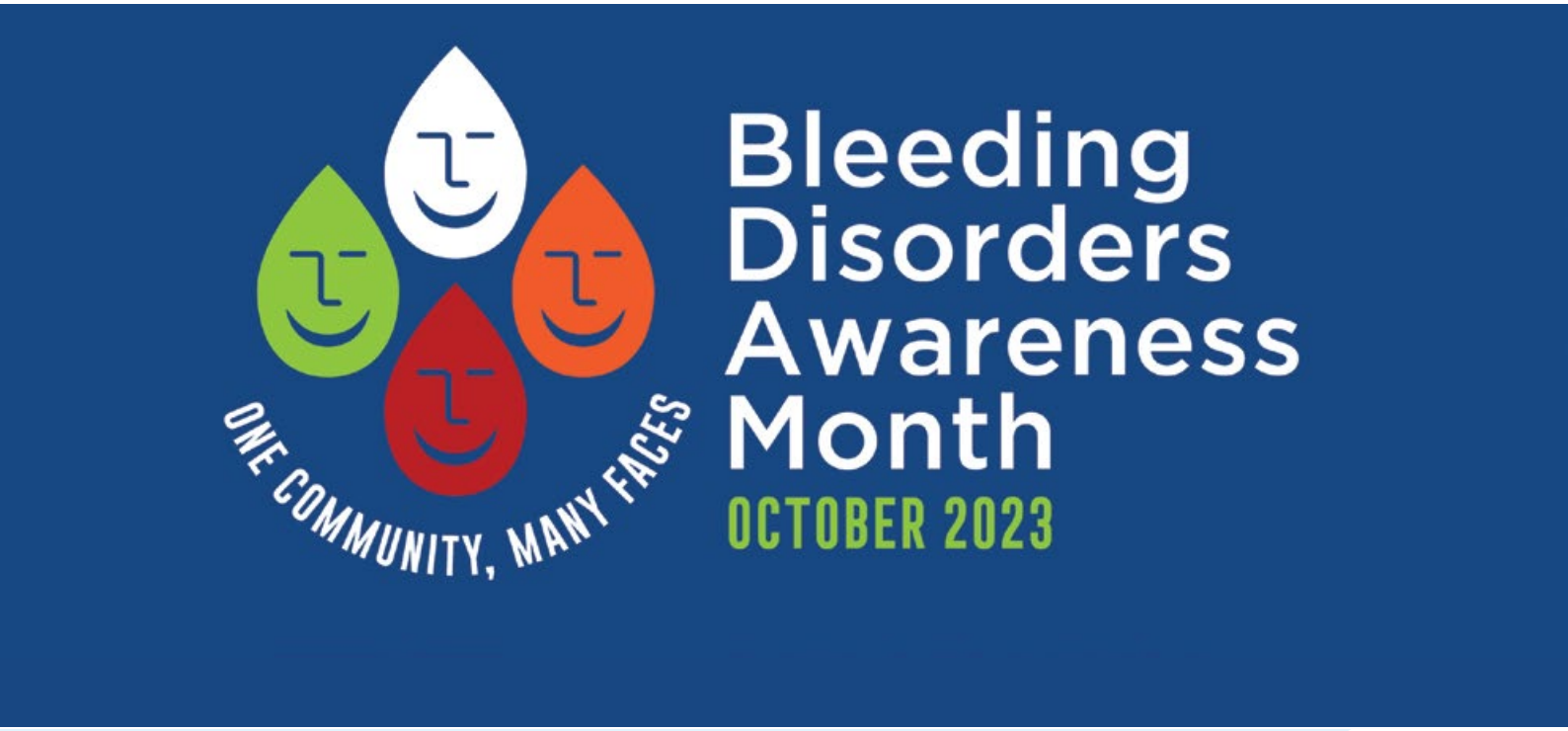

We have lots planned, including a dedicated **Red Week**, and events happening across Australia.

FIND OUT MORE
www.haemophilia.org.au/BDAM

Gavin Finkelstein

President, Haemophilia Foundation Australia

From the President

As I write my update for *National Haemophilia*, I can't help but think about where things will be at for HFA and our community next year at this time or the following years. Our community should be excited about the future, with new treatment options coming to the global market. Some of these will bring less onerous treatment, better health outcomes and improve quality of life and productivity for people who use them.

TREATMENT ADVOCACY

We encourage treatment product sponsors to work hard to bring their innovative treatments to Australia. The products need to be registered and funded by governments before they are available for our use, but I assure our community that HFA wants to play its part to ensure the treatments people need are available to them in the future. Our treatments represent a high cost for governments. Our engagement with our community is important so that we understand treatment preferences and can advocate for the treatments and care our community needs. We want to be able to work with governments to make sure the right treatment products are available at the right time for our community and that they are provided as cost effectively as possible.

The Federal government is undertaking a review of the government's health technology assessment process, which is the evaluation process used to assess the quality, safety, efficacy, effectiveness, and cost-effectiveness of health technologies – this includes our treatment products. We can contribute community expectations and preferences, based on the lived experience of people living with a bleeding disorder to these processes, so when treatment products are evaluated, the process is more 'patient' focused, and relevant questions are asked about how the treatment will impact or benefit from the point of view of patients.

HFA FUNDING

Some of you are aware that HFA faces a challenging financial situation. HFA has always relied on different sources of income: we have fundraising campaigns throughout the year, that you may generously contribute to by making donations, and we seek sponsorship from the corporate sector and charitable grants for some activities, and government grants. Our fundraising is transparent, ethical, and accountable.

We have taken significant steps over the last 5 years to strengthen our financial situation and establish a reliable source of income so that we can operate self-sufficiently and continue to respond to the needs of the community. But we are a small community, and many in our community have complex needs. Further, it has become more complex to operate, and to keep up with community expectations for digital communications and our website capabilities. HFA has always received Commonwealth government funding grants to enable it to operate as the national peak body, and so we can connect with our community, and provide advice about the treatment and care needs of our community to governments, and for the cost of some of our education and digital communications activities. HFA is an information provider to HealthDirect, which is funded by Australian governments to provide a national health information service to all Australians.

We are grateful for the Federal government funding that has enabled HFA to do its work, and we cannot operate without this funding. We have never taken this funding for granted, but in return for these grants over many years we have delivered. The Australian government has been able to rely on HFA to work as the national peak body, to produce high quality education resources and represent its community through submissions and balanced advice about treatment and care. We can only do this because

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our connection with our community is strong and what you tell us about your experience of living with a bleeding disorder, your needs and the needs of your families and carers informs everything we do.

HFA is part of a broad 'blood sector' stakeholder framework that comes together so all Australians living with a bleeding disorder have the care and treatment they need to live full and active lives. This occurs with the support of different levels of government. HFA's national work is only possible because of the network of community members and health professionals who contribute in a voluntary capacity to work with our staff to make sure governments get value for their investment in our treatment products.

HFA's federal government grants have reduced significantly and without reinstated funding, HFA will not be viable going forward. We want government to recognise the value of the HFA input. I can assure you that HFA remains solvent as a business now, but our continued input into the national blood sector about our treatment and care needs will require a commitment from the Federal government to the costs of HFA's peak body and education activities.

Our pre-budget submission before the recent Federal budget was unsuccessful, but we will continue to discuss the needs of the bleeding disorders community with the Federal Health Minister, the Hon. Mark Butler, and Department of Health officials. We know many of our members will share my concerns and may wish to approach their local Federal Member of Parliament to explain why they believe our community representation and participation is important. Please feel free to contact me or Sharon and the team at the HFA office for further information.

In the meantime, HFA has been operating in line with our workplans and while we have needed to curtail some planned future activities, we have very important work to keep going so we continue to meet current grant deliverables and other activities not funded by grants, including our committee work and collaborations with other organisations. Our education work includes new information on the HFA website www.haemophilia.org.au and the youth website www.factoredin.org.au and a very shiny new education resource to add to our suite of resources for women and girls, A **Guide to haemophilia testing in women and girls** which was published in April. We also have new information on the Getting Older Hub - please take a look at it.

NATIONAL CONFERENCE

The **21st Australian Conference on Haemophilia, VWD and rare bleeding disorders** in August 2023 is our most important and valuable meeting. It is held every two years and we hope you are making plans to attend.

The Conference is unique; it brings together all stakeholders in the blood sector - patient and families, their treating health professionals, industry and policy makers together to discuss treatment and care from the perspective of the experts including from people who live with a bleeding disorder and their carers as experts. The focus is on improving the health and quality of life of people living with a bleeding disorder. It is always a vibrant meeting where every delegate learns more.

We urge you to come to Melbourne for the Conference in August. This is our first conference since we moved to a virtual conference during the COVID-19 pandemic and we know how valuable it is for our community to come together and share their experiences face-to-face.

It is also a great opportunity for us to time to show our solidarity and actively demonstrate our contribution to the blood sector.

The Conference is supported by corporate sponsorship specifically for the conference, and we have no doubt it will be a great meeting. Please contact HFA or your local Foundation if you require financial assistance to attend. We look forward to seeing you in August.

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

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

REGISTER NOW
https://tinyurl.com/HFAConf

PROGRAM

The Program committee is working to put together a program that is interactive, educational and covers current and emerging issues and topics.

Topics include:

- New therapies in bleeding disorders – including gene therapy
- VWD
- Rare bleeding disorders
- Women and girls with bleeding disorders
- MSK (musculoskeletal) and ankle arthropathy
- Mild haemophilia
- Children and families
- Inheritance, genetics and family planning
- Making career choices
- Fitness and sport
- Pain
- Getting older
- Good health and wellbeing

KEYNOTE SPEAKER

We are privileged to have Dr Glenn Pierce as our keynote speaker.

Dr Pierce currently serves on the World Federation of Hemophilia (WFH) as Vice-President Medical and WFH USA Board of Directors and NHF (US) Medical and Scientific Advisory Council. He is an Entrepreneur-in-residence at Third Rock Ventures USA, and a biotech consultant in the gene therapy and haematological areas. He has over 35 years' experience in developing new therapeutic medicines and led development of the first extended half-life FVIII and FIX products. Dr. Pierce lived with severe hemophilia A until 2008.

COMMUNITY FUNDING

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

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

ACCOMMODATION SUBSIDIES

HFA has negotiated a special rate bed and breakfast rate for all delegates. To assist with the cost, HFA will be making subsidies of $40 per night per room on Thursday and Friday evening. A limited number of subsidies will be available for rooms so get in quick. >>

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SPONSORS

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WHAT HAVE DELEGATES SAID ABOUT PAST CONFERENCES?

'The conference has made me reconsider the way that I approach exercise and active living.'

'Was a fantastic three days, especially learning and meeting the new faces. Highly recommend to anyone thinking about coming to future conferences.'

'As a health care professional, I found hearing the patient stories very motivating but also inspiring that we still need to do better. Opportunity to network is always invaluable professionally.'

'It is making me feel more connected to people with bleeding disorders. It has also helped me build on my confidence to advocate for my son.'

FIND OUT MORE

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

Register now!

MELBOURNE 24 - 26 AUGUST 2023

21ST AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS

FREE Mythbusting Animation Workshop at ACMI

Perfect for creative kids! Have fun meeting others, help us bust myths about bleeding disorders and learn how to animate.

This workshop will coincide with the HFA Conference. If their parent/guardian is attending the conference, kids are welcome to come for the day - we will have an activity in the morning.

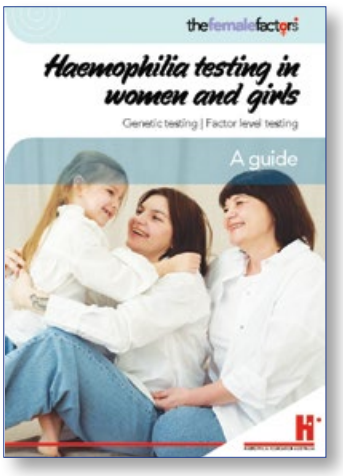
To express interest or find out more contact Natashia Coco: **ncoco@haemophilia.org.au**

- **12pm onwards, Saturday 25 August 2023**
- **ACMI Federation Square, Melbourne**
- **10-16 year olds**
- **Run by ACMI staff with HFA staff in attandance.** (Parents and Guardians welcome too!)

Animations will be showcased during *Bleeding Disorders Awareness Month*

New simple haemophilia testing guide

Unsure about genetic testing and factor level testing in haemophilia and how it works in women and girls?



Haemophilia Foundation Australia has published a new education resource, **Haemophilia testing in women and girls: a guide** to answer these questions simply and clearly.

The resource is aimed at women, girls and parents of girls and uses relatable stories, infographics and diagrams to tackle some complex information in an accessible way.

How does a woman or girl know if she is affected by haemophilia?

- What are genetic and factor level tests?
- Who should have these tests and when?
- How is haemophilia passed on in a family – and what if there is no family history?
- Why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the education resource in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. We would like to thank everyone involved for their advice and creative ideas!

HOW CAN YOU ACCESS THE RESOURCE?

Visit the HFA website page:
https://tinyurl.com/haemophilia-testing-simple

- Download the entire resource
- Read it online magazine-style (ISSUU)
- Download specific sections, eg genetic testing and counselling.

Look out for the web page version – coming soon!

To request print copies (free)

- email HFA at: hfaust@haemophilia.org.au
- or call 0398857800.

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

World Haemophilia Day 2023

Every year on 17 April World Haemophilia Day the bleeding disorders community worldwide comes together to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders.

Joining other countries such as Austria, Canada, Colombia, Egypt, England, Ireland, Japan, Panama, Spain, Taiwan and US, building and landmarks were lit up in red across Australia in support of the day. We had over 60 landmarks across the country lit up red.

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care, and support for people with bleeding disorders.

DID YOU KNOW

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

CELEBRATING WORLD HAEMOPHILIA DAY

Thank you to everyone who participated in the day.

Performance Personal Training

The Haemophilia Treatment Centre team from the Children's Hospital at Westmead

LIGHTING IT UP RED AROUND AUSTRALIA

1. *Wrest Point Casino, Hobart TAS*
2. *Victoria Bridge and Treasury Casino, Brisbane QLD*
3. *Government House, Brisbane QLD*
4. *Sandgate Town Hall, Brisbane QLD*
5. *Story Bridge, Brisbane QLD*
6. *Victoria Bridge, Toowoomba QLD*
7. *Drum Theatre, Dandenong VIC*
8. *Bolte Bridge, Melbourne VIC*

Taking care of your ABDR data

Julia Ekert, Marina Goruppi, Linda Mason and Deirdre Tuck

Data Manager Julia Ekert at work

ABDR Data managers Julia, Marina, Linda and Deirdre spoke to HFA about their role with Australian Bleeding Disorders Registry (ABDR) data – and had a lot to say about why the ABDR and MyABDR are an important part of the life of the patient with a bleeding disorder.

'The ABDR tells the story of a patient, their bleeds and their treatment over their lifetime.'

Recording accurate and consistent information in the Australian Bleeding Disorders Registry is crucial to patient treatment care and Data Managers work as part of Haemophilia Treatment Centre (HTC) teams to ensure this takes place nationwide.

Where would you find a Data Manager? There are Data Managers in every Australian state and territory. Some work full-time, while others work part-time, depending on the number of patients in their HTC. Their workplace varies. Some are based in the clinic, others in the laboratory, some work from more than one hospital, and all can work from home in a hybrid model.

The Data Managers come from a range of backgrounds - nursing, laboratory scientists and administrative streams. Their positions are administered by Australian Haemophilia Centre Directors' Organisation (AHCDO) and supported by the National Blood Authority (NBA).

No matter where they are based, the Data Managers liaise closely and meet regularly with the Director of the HTC, Haemophilia Clinical Nurses, and other members of the multidisciplinary team.

'I work in a laboratory in an office with no windows but I share it with the HTC Director and it's a very collegial atmosphere in the laboratory.'

'I am in a laboratory as well, in an open office, and I work in the Haematology Department, very much part of the wider haematology team, not just the haemophilia team.'

'I work in an office within the HTC in both the adult and children's HTCs. I see some of the patients at the adult Centre and chat to them while I am doing other things, such as taking blood.'

WHAT IS THE ABDR?

The Australian Bleeding Disorders Registry (ABDR) is the system used by HTCs around Australia for the clinical care of their patients. It is much more than a simple registry of diagnosis, with data about a patient's bleeds, treatments and the treatment plan, results of tests and other measures, hospital admissions and related clinical interventions such as surgery, and information about treatment outcomes. It also includes details about ordering, supply and use of treatment products for each individual patient.

In these days of home treatment, it is important to know what is going on outside the hospital. Since 2014 people with bleeding disorders or parents/caregivers have been able to use the app MyABDR on their mobile device or their computer to contribute data about their or their child's bleeds and treatment, along with a record of treatment stock they are managing at home.

The ABDR has evolved enormously since it was first established in 1988. Originally it was an Access database funded by Haemophilia Foundation Australia which was updated using spreadsheets provided by each HTC. In 2008, funding was provided by the NBA, and the ABDR became a national and very complex internet-based database. The role of the Data Manager was developed to ensure that accurate ongoing information was recorded nationwide and to co-ordinate the protocols for entering data into the ABDR.

ENSURING ACCURATE DATA

'We are haemophilia detectives.'

Data Manager Deirdre Tuck at work

The goal is to ensure that all the relevant information about each patient enrolled in the ABDR and MyABDR is accurately recorded in a timely manner.

Adding data to the ABDR is a complex task. A Data Manager's work can be like being a detective, proactively investigating and building a record from pieces of information held in different hospital files to be an accurate picture of what has happened for a patient.

Each individual patient's record will follow their treatment and care history over their lifetime and it is important that the data is correct.

It is a legal requirement that each patient provides consent to being on ABDR/MyABDR. When they have consented, the Data Manager completes all sections of information within the ABDR database. This provides a very valuable Patient Summary display in the ABDR for the treating team: a concise snapshot with a comprehensive and current overview of each patient's diagnosis, genetic information, treatment, and health outcomes. This information can be also be discussed or shared with the patient, for example, in a clinical review, in MyABDR or an ABDR patient card.

Then ongoing information needs to be recorded: bleeds, treatment product use, relevant interactions with the health system, laboratory testing, radiology investigations - including inhibitor blood tests and adverse reactions. Hospital attendance such as Haemophilia Clinic Reviews, Emergency Department attendances, hospital admissions and surgical details at HTC or other hospitals are documented. >>

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As hardcopy documentation is being phased out in healthcare around Australia, the use of digital medical records makes the work of the Data Manager easier and less 'detective' work is required. When patients move interstate, permission for access to information is transferred via ABDR so that there is a seamless transition for patient care.

Checking and recording treatment product usage is an important responsibility of Data Managers. Home delivery information, Community Pharmacy dispensing of emicizumab (Hemlibra®) and other products, travel supplies and inpatient usage are all cross-checked and recorded. If you manage your inventory of treatment product at home, imagine monitoring a state-wide treatment product inventory! This careful work is essential to ensure treatment product is available, particularly for patients residing in rural areas, and to minimise wastage of precious supplies. It also enables accurate financial reconciliation for treatment products by the NBA.

Data Manager Marina Goruppi at work

Putting this information together and checking it involves paying close attention to the work of the HTC, accessing multiple systems and scrupulous attention to detail.

'As a Data Manager you have to work out how your system works and how you will get your information because it works differently in every hospital and in every state. You get the data in many and various ways. When there's a clinic on and when there is a surgery you know you will have data to enter.'

'You are part of the team. We are sitting in the office space and we can hear that there is a clinic on, or we attend the clinic, or there are various meetings for example, at my HTC we have a clinical huddle every morning.'

'I can login to the digital medical record to verify details, for example, when people have attended the Emergency Department, or follow up on admissions or discharges. Because I am in Pathology, I have access to all of the information of every product that has been dispensed that month. So at the beginning of a new month, I can go and call up all of the information on product that has been dispensed. And it has the name and the date, and then I can go into the digital medical record and find out why it was dispensed.'

'With home deliveries, the companies have an agreement with the NBA to send a monthly report of all the deliveries to the HTCs so that we can see what product was delivered. But at the same time the product orders are checked by the HTC, the company does an inventory with the patient and then the company sends an email with the requested amount to be approved by the HTC, so we can cross-check. With Hemlibra® we now get a monthly report of the community pharmacy delivered product from the company that delivers it – when it's delivered to the pharmacy and when it's picked up by the patient.'

This work is highly skilled and benefits from access to good technology.

'Sometimes you have two or even three systems open at once, which you can do from your desktop. But you also might need to be logged into the hospital system at the same time and interpreting the clinical information from there to add it to the ABDR.'

'Two screens make a big difference – sometimes three would be great!'

PRIVACY AND SECURITY

Health information systems require very high levels of privacy and security and this has always been at the forefront with the ABDR. The database is managed by the NBA and protected by world best practice security. Moreover, access to the database is restricted and governed by the ABDR Steering Committee. Access to the ABDR by hospital staff is limited to specific health professional roles, such as the HTC team and Data Managers, and must be approved by the HTC Director. Patient privacy is taken very seriously and guarded carefully.

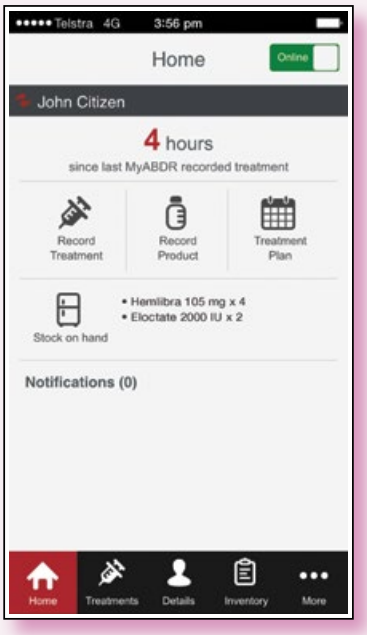
'We can look at hospital data but hospitals can't look at ABDR data. I always lock my ABDR screen when I am not near it, but one of the safeguards is that it closes down if you don't use it for 30 minutes. Also we don't discuss patients using names; we always use their ABDR ID number, including when we are asked to share information.'

WHY RECORD ON MYABDR?

The contributions patients and parents make in MyABDR are an essential part of the ABDR patient history. In these days of personalised treatment where people with haemophilia treat at home, the data on when and how much product they used in treatment and details of bleeding episodes play an important role in developing a treatment plan that works best for the individual.

With MyABDR the patient can record quickly on their phone and can keep a record not only of details of treatments but bleeds as well – including the part of the body, so that they can see patterns emerging.

'For patients the ABDR is such a good record of bleeding events and treatments but it needs to show an accurate summary of their progress. When they are reviewed by the doctor, the doctor can look at their record and the ABDR tells a story. And now with new treatments like Hemlibra®, being able to keep a record of the dose and weight are important clinically. It means the individual can get the right dose of the medication.'

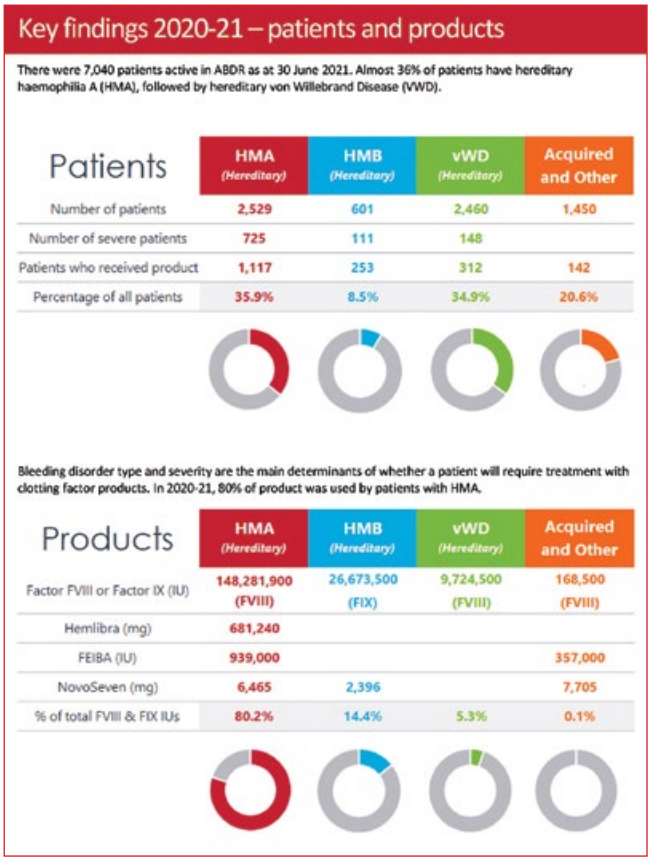


'Patients are a member of the HTC team in their home treatment. Haemophilia treatment is more of a home treatment than it ever was. In order to understand what's going on at home and whether people are having their doses as per their treatment plan, it's really important that the patients do their part and fill out their MyABDR records - so we know what's going on at home.'

'It can also show how effective treatments are. For example, one of our adult patients was constantly treating himself because he was always bleeding. He's in the third year of a new treatment now and since he's had the new treatment, he has not attended hospital. And that's very clear in the ABDR because his dosages and no admissions are all there.'

'People sometimes think we are "nagging" them about it, but it's more that we want to give them the right medication, with the right treatments and the right doses. Some have now gone from treating three times a week to once a week, once a fortnight, once a month. If a patient records what they are actually doing, it really does make a big difference, especially to the nursing staff who are trying to track all the medication and work out when their next prescription is due and how things are going with the treatment.'

DATA FOR RESEARCH AND PLANNING



Key findings 2020-21 – patients and products

There were 7,040 patients active in ABDR as at 30 June 2021. Almost 36% of patients have hereditary haemophilia A (HMA), followed by hereditary von Willebrand Disease (VWD).

Patients	HMA (Hereditary)	HMB (Hereditary)	vWD (Hereditary)	Acquired and Other
Number of patients	2,529	601	2,460	1,450
Number of severe patients	725	111	148	
Patients who received product	1,117	253	312	142
Percentage of all patients	35.9%	8.5%	34.9%	20.6%

Bleeding disorder type and severity are the main determinants of whether a patient will require treatment with clotting factor products. In 2020-21, 80% of product was used by patients with HMA.

Products	HMA (Hereditary)	HMB (Hereditary)	vWD (Hereditary)	Acquired and Other
Factor FVIII or Factor IX (IU)	148,281,900 (FVIII)	26,673,500 (FIX)	9,724,500 (FVIII)	168,500 (FVIII)
Hemlibra (mg)	681,240			
FEIBA (IU)	939,000			357,000
NovoSeven (mg)	6,465	2,396		7,705
% of total FVIII & FIX IUs	80.2%	14.4%	5.3%	0.1%

A sample of data reported in the ABDR Annual Report

The comprehensive information entered by the Data Managers enables deidentified data to be extracted from the ABDR to support research projects coordinated by AHCDO and the Annual ABDR Report, which can be seen on the NBA website. It can answer many specific questions, from how many patients have a fibrinogen disorder to what impact emicizumab/Hemlibra® has had on the factor levels of individuals with haemophilia. Research reports from the ABDR have been presented at national and international conferences and prepared for publication in peer reviewed journals.

This can provide important evidence to understand the impact of new treatments and compare them to existing treatments – what have been the outcomes for people's quality of life, their bleeding episodes and their hospitalisations? How is this impacting on their joints?

Data from the ABDR is also central to the work of the NBA in forecasting future treatment product requirements and budgeting, essential to the ongoing supply and availability of these treatment products to Australians.

Data managers belong to the national ABDR Data Managers Group. Group members meet regularly via teleconferences and once each year meet in person (online during COVID) for study days that also coincide with HFA conference dates. Data Managers are represented on several national committees – the Research Committee, Treatment Advisory Committee and the ABDR Stakeholder Group. It is because of these opportunities that collaborative relationships have developed between the Data Managers Group, the NBA and AHCDO members and staff, leading to a level of camaraderie that ensures the best outcomes for all.

'I work in a very cohesive environment with the HTC Director and the haemophilia nurse and the scientists. It's a pleasure to come to work with the group and all the latest developments are shared amongst us and we celebrate the improved quality of life of the patient.'

The Data Managers Group would like to dedicate this article to Debra Belleli (dec.), our beloved and dedicated colleague, who worked as a Data Manager at The Alfred hospital in Melbourne for many years. RIP 2022.

Julia Ekert is Haemophilia Data/Product Manager at the Department of Clinical Haematology, The Royal Children's Hospital, Melbourne, Victoria.

Marina Goruppi is Australian Bleeding Disorders Registry (ABDR) Data Manager at Fiona Stanley Hospital and Perth Children's Hospital in Perth, Western Australia.

Linda Mason is Transfusion Scientist/ABDR Data Manager Qld at the Blood Bank/Haemophilia Treatment Centre at the Royal Brisbane and Women's Hospital, Queensland.

Deirdre Tuck is Data Manager/Nurse at The Royal Hobart Hospital, Tasmania.

World Hepatitis Day

NOhep

In July 2023 Australian landmarks will be glowing green to raise awareness about eliminating viral hepatitis. World Hepatitis Day is marked internationally on 28 July and is one of the World Health Organization's nine official global public health days. Green is used by the global NOhep movement – the colour of life, vitality and progress.

World Hepatitis Day is an opportunity to come together to step up efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. Once again, the theme in 2023 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.

Look out for more information and activities on our website and social media 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

WFH 2023 Comprehensive Care Summit

Yu-hsuan Lin (Yoshi)

WFH 2023 Comprehensive Care Summit: New Developments in Bleeding Disorders and MSK

10-12 May 2023, Buenos Aires, Argentina

The World Federation of Haemophilia (WFH) 2023 Comprehensive Care Summit was an amazing event, full of vibrant energy and excitement, with fabulous talks and knowledgeable speakers from all over the world. I greatly appreciated the opportunity to hear and connect with the many nurse specialists who were involved in this conference and gave presentations about patient management from a nursing perspective.

For me the highlights were the sessions on ageing, informed patient consent and the current challenges in caring for patients with bleeding disorders, for example, where new haemophilia treatments essentially allow patients with severe haemophilia to become more like patients with mild haemophilia. Apart from all the great sessions, it was amazing to meet with nurses from many parts of the world. We even spent International Nurse's Day together!

Dr Liane Khoo and Yu-hsuan Lin (Yoshi) at the Congress

Plenary: Aging

Challenges and experiences of aging: I'm still here, now what?

Speaker ~ Mark Skinner, President and CEO, Institute for Policy Advancement Ltd, USA

Plenary: Comprehensive care of aging

Chair ~ Mark Skinner

Speakers: physiotherapists: Felipe Contreras, Chile, Piet de Kleijn, Netherlands; social worker: Susan Cutter, USA; nurse: Niamh Larkin, Ireland; haemophilia organisation: William McKeown, UK (Access And Service Improvement Ambassador); dentist: Lochana Nanayakkara, UK

The session on ageing considered some of the challenges both for our older patients and the services and care we provide in our Haemophilia Treatment Centres (HTCs). Ageing is a fact that we are all facing from day to day, but until relatively recently it was a foreign concept for a lot of our older haemophilia patients. In earlier years, this group of patients were told that their life expectancy was short, with the result that some decided to not start a family or participate in the community.

So Mark Skinner's presentation asking 'I'm still here, now what?' struck me and made me reconsider what we can do as health professionals to help our older patients living with bleeding disorders. The speakers discussed the Multidisciplinary Team and asked the burning question: 'have we got the right or appropriate Multidisciplinary Team to help our ageing patients?'.

In the Adult Haemophilia Treatment Centre South Australia we currently have haematologists, a physiotherapist, a haemophilia nurse consultant, a social worker and a data manager as core members of our team. But as our patients get older, we need to involve more health professionals like psychologists, ENT (ear, nose, and throat) specialists, rheumatologists, cardiologists and geriatricians in the hospital setting, but we also need to connect with services in the community like GP services, local health centres, community nurses, local pharmacists and dentists.

People with bleeding disorders, like everyone, need social support from the community, family and health care providers, and may have even greater needs due to their fragility and mental health issues, accumulated over the years of negative and sometimes traumatic experiences. Studies reported in the session showed 88% of older haemophilia patients have unexpected longevity. Some now find themselves lonelier and more disconnected from society.

Assisting our patients to grow older with dignity and support them with what matters as they age is an ongoing issue for health professionals in HTCs. We also need to consider how early we should start this conversation about ageing with our patients, and how this translates into ongoing education materials for our patients, from younger age groups to older.

GETTING OLDER

HFA's Getting Older report explored the needs of older people with bleeding disorders and consulted both community members and HTCs about what would help. This is ongoing work which will be discussed further at the national Conference in August 2023.

The report resulted in the Getting Older Hub, a website updated regularly with online information for older people with bleeding disorders.

- Read the Getting Older report: https://tinyurl.com/HFA-GOR
- Visit the Getting Older Hub: www.haemophilia.org.au/getting-older

I was also very interested in the presentations on gene therapy from the perspectives of patients and nurses, especially those related to the processes involved: preparation, screening, education, consenting, post gene therapy monitoring and ongoing support.

Education and shared decision-making with our patients were the focus of these sessions.

Multidisciplinary session: Informed patient consent

Chair ~ Keith Gomez, consultant haematologist, UK
Nurse perspective
Speaker ~ Kat Molitor, haemophilia Clinical Nurse Specialist, USA

Kat Molitor, Clinical Nurse Specialist from the USA, spoke about nurse responsibilities and the important role of nurses in advocating, educating and access when it comes to implementing new treatments, gene therapy and post gene therapy management.

She also provided three models that could assist with partnering with patients:

- Shared-Decision Making (SDM)
- Person-Centred Care (PCC)
- Strengths-Based Nursing and Healthcare (SBNH).

She underlined that social psychological assessments are a crucial part of screening patients for gene therapy and presented the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) tool for this. The session raised the question about educating health professionals for the upcoming gene therapy – do they need more education to prepare adequately and would there be value in providing the Multidisciplinary Team with ongoing formal training on patient care models.

Plenary: Transitioning to mild hemophilia

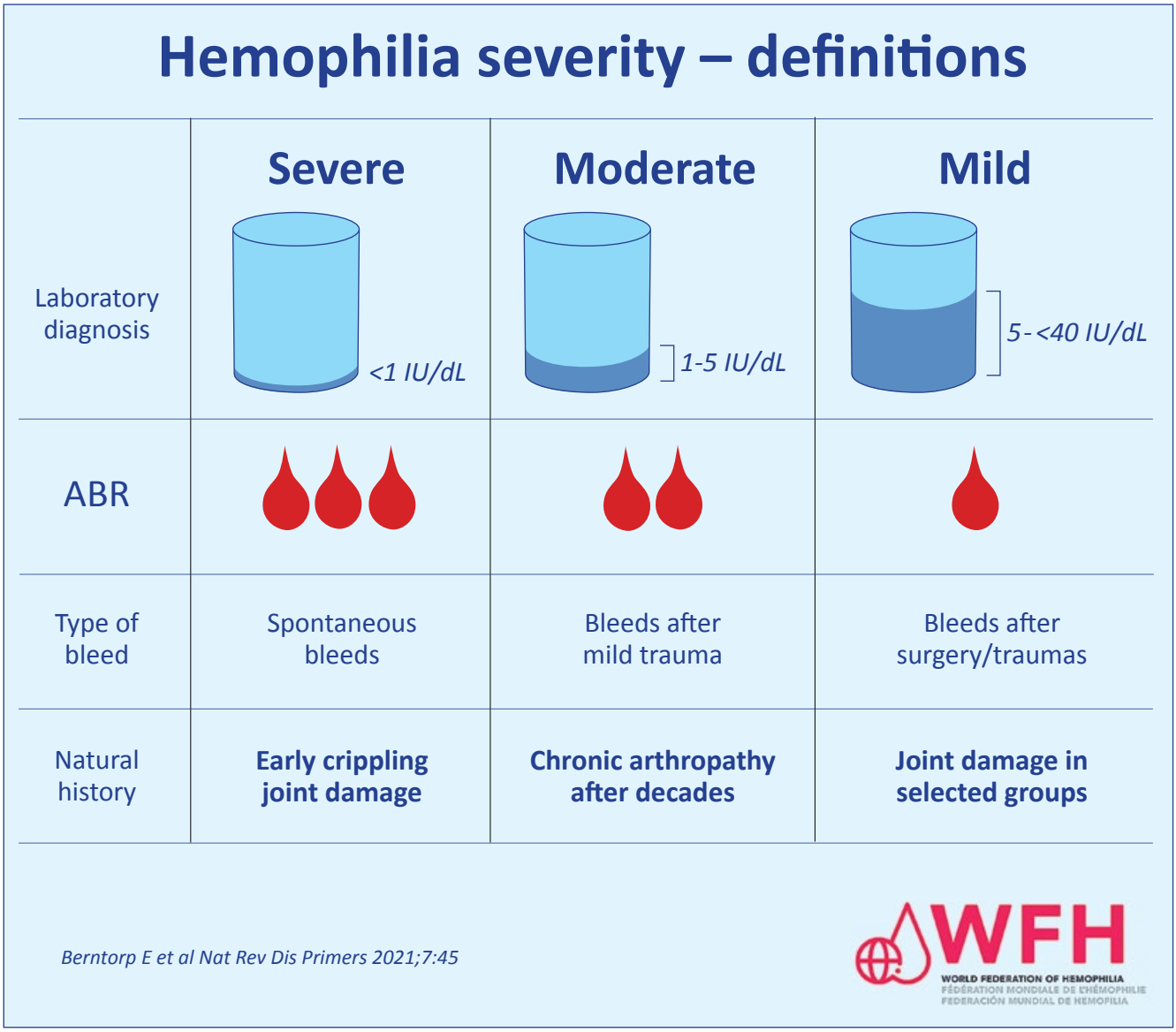
Speaker ~ Maria Elisa Mancuso, haematologist, Italy

The unknowns of gene therapy, no effective new treatment options for VWD (von Willebrand disease) patients and the 'forgotten' group of patients with mild haemophilia are continuing to be challenges we are facing.

Dr Maria Elisa Mancuso discussed the impact of new haemophilia treatments on raising the bar of protection from bleeds in haemophilia and the transformation of the severe phenotype to mild.

She stated that patients with a trough factor VIII (8) level of 12% still have risk of bleeding spontaneously and a level of 6-7% is an even higher risk. Therefore, she suggested – based on her research findings - that prophylaxis treatment should maintain a certain high factor VIII (8) trough level at 40% or above to achieve zero bleeds and that prophylaxis treatment should also be available for mild haemophilia patients.

The new standard of prophylaxis treatment is to transition patients to mild haemophilia with a higher trough level. She noted that the challenges here are to improve current monoclonal antibody therapy and factor VIII replacement therapy with longer-acting and better recombinant products. She recommended that patients who wish to have an active lifestyle with sport and activities should also be supported with factor and on prophylaxis treatments regardless of their severity of haemophilia.



Overall, the WFH Comprehensive Care Summit experience was extraordinary and covered a wide range of issues. I found it very helpful for my role as a haemophilia nurse consultant who has only been in the role for 9 months.

I had the privilege to meet with nurses from around the world and listen to them share their experiences in their own countries. WFH is promoting treatment for all and the struggles and difficulties in getting adequate treatment for patients in some developing countries were described in this Summit. I felt greatly touched by the health professionals and patients who presented at the Summit and their contribution and dedication to the world of haemophilia.

Finally, I would like to thank our Australian Haemophilia Nurses Group, who nominated me and supported me to attend this Summit. I would also like to thank Sanofi who funded me to attend. Hopefully we can all participate in the 2024 WFH Congress in Madrid, Spain.

Nurses from around the world at the WFH Comprehensive Care Summit

Top row: *L to R: Marcela Ganella, Brazil; Camila Stephanes, Brazil; Janette Itaas Kemp, UK; Andrea De Almeida Sambo, Brazil; Mariana Takahasi Hosokawa, Brazil; Tayane Oliveira Reboucas, Brazil; Collette Pigden, UK*
Middle row: Josefina Santillan, Argentina
Bottom row: *L to R: Michelle Mackey-Newfoundland, Canada; Yu-Hsuan (Yoshi) Lin, Australia; Kat Molitor, US; Valeska Becker, Chile; Niamh Larkin, Ireland*

Your rights: superannuation and insurance

Suzanne O'Callaghan

What are your rights and responsibilities with superannuation and insurance if you have a bleeding disorder or carry the gene?

In a recent HFA webinar Laura Davies from Maurice Blackburn Lawyers explored the ins and outs of superannuation, travel, life and income protection insurance – applying, what do you have to disclose and what to do if you think you have been assessed unfairly.

She was joined by an expert panel of Haemophilia Treatment Centre health professionals to discuss some case studies and answer audience questions.

Your rights: superannuation and insurance

HFA Zoom and Facebook Live webinar, 27 October 2022

Facilitator ~ Suzanne O'Callaghan, Haemophilia Foundation Australia

Speakers

~ Laura Davies, Maurice Blackburn Lawyers, Melbourne

~ Dr Stephanie P'ng, haematologist and Fiona Stanley Hospital HTC Director, Perth

~ Jane Portnoy, haemophilia social worker, The Alfred HTC Melbourne

~ Megan Walsh, haemophilia nurse, The Alfred HTC Melbourne

Watch the webinar online: https://tinyurl.com/BD-insurance

PROTECTING YOUR FUTURE

Jane Portnoy commenced the webinar with a reminder that insurance and superannuation are an important part of planning for the future.

For people with bleeding disorders there can sometimes be barriers to acquiring insurance or drawing on their superannuation early. Some people have experienced high premiums or have initially been refused. Jane's advice: don't give up.

- Take the time to shop around and learn about opportunities for people with bleeding disorders
- Learn about the rules with superannuation and insurance
- Source help and documentation from your HTC if need be
- Sometimes you may need support from legal experts to deal with insurance companies
- Organise your life insurance and superannuation when you are well and younger – you will have more options
- There are also community financial counsellors who are independent and can help with advice.

AVOIDING PROBLEMS WITH INSURANCE

People with bleeding disorders can have problems with insurance and superannuation for a number of reasons.

Laura Davies outlined some common scenarios where insurance companies reject claims or avoid policies.

- A company may argue that an applicant did not disclose completely or misrepresented their health or circumstances in the application
- The reason for the claim being rejected may be unrelated to the alleged non-disclosure or misrepresentation.

She recommended seeking legal advice as soon as possible if you are advised that your claim will be rejected or avoided. Knowing what documentation to request from the company, a careful analysis of policy wording and familiarity with recent consumer legislation will key aspects of an insurance claim dispute.

Laura's tips to avoid problems:

- When applying for insurance, read and answer the questions carefully
- Look out for relevant questions, eg not only blood conditions but others such as family history
- When in doubt, always disclose – an insurer may still approve the application but with conditions or a higher premium
- Investigate the insurance through your superannuation or mortgage – default packages may not require you to disclose medical conditions
- Seek financial advice about what fund would be most suitable for you if you think there could be issues
- Be alert for wording or rules that might exclude you or your situation.

TRAVEL INSURANCE

Travel insurance is a hot topic for many people with bleeding disorders. The case studies considered some common issues:

- Disclosing a bleeding disorder, even if it is a mild form
- Expecting the unexpected when travelling
- Being aware of legislation in different countries that might impact on a claim, eg legal age of drinking alcohol, having an appropriate vehicle licence
- Ensuring medical bills can be paid and having medical evacuation included in insurance
- Checking the fine print of an insurance policy
- What do insurers mean by a 'pre-existing condition'?
- Shopping around; checking travel insurance with credit cards and health insurance as well
- Knowing what will be covered medically in the countries where you are travelling – by the country's health system and by the insurance policy.

EARLY RETIREMENT

In another case study the panel addressed the issues that might arise when a person retires early due to complications with their bleeding disorder. What happens if their application is refused by their insurer?

Laura outlined some typical approaches:

- Getting advice from legal experts
- Clarifying what is reasonable in relation to the person's ability to continue working
- Supplying medical documentation.

INCOME PROTECTION INSURANCE

With new haemophilia treatments, many younger people with haemophilia are likely to have a different experience of working over a lifetime compared to older generations. The panel discussed the implications for income protection insurance – how actuarial data is put together, what people can do to manage income protection insurers and other options to consider.

Laura also discussed the importance of revisiting life insurance if it has been refused in the past and getting expert advice on the best options for the individual situation.

Our thanks to Laura, Stephanie, Jane and Megan for volunteering to share their expertise in this webinar.

Please note: Any advice or comments during this webinar were general principles. You should always seek individual professional advice about your personal situation before you make any decisions.

FIND OUT MORE

- Visit the Disclosure section on the HFA website - https://tinyurl.com/HFA-disclosure
- Visit the Financial planning and management section of the Getting Older Hub: https://tinyurl.com/GOIH-finance
- Watch the webinar at: https://tinyurl.com/BD-insurance

Suzanne O'Callaghan is HFA Policy Research and Education Manager

YOUTH NEWS

A message to your younger self

If you could go back in time, what would you say to your younger self?

Growing up with a bleeding disorder can be challenging.

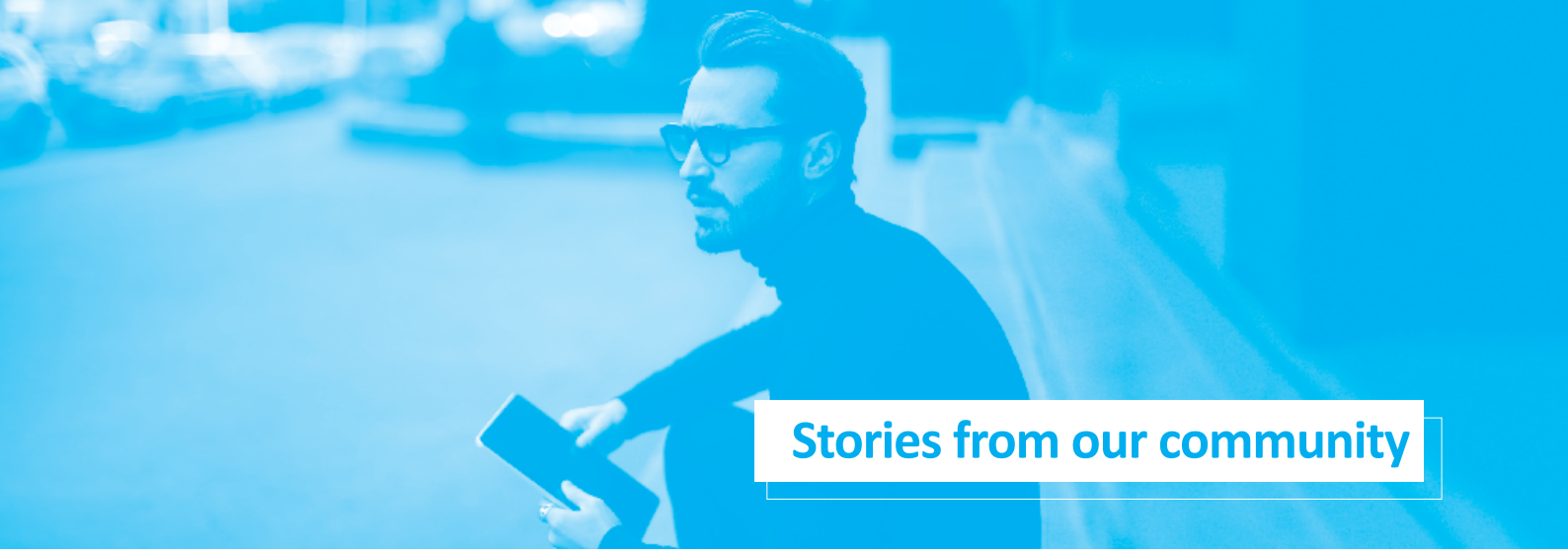
We asked some of our community members with bleeding disorders what they would tell their younger self. They reflected on what was most important to them when they were young and had some thoughtful and encouraging messages from what they have learned as they became adults.

Cheryl

You can handle a bleeding disorder. Learn as much as you can. You are your own advocate, but don't be afraid to ask for help when you need it. And pay that help forward when you are able to.

Tim

Be more open and trust that people aren't going to judge you for your condition. Most importantly, be patient and kind to yourself and cut yourself some slack for the times when you have no control over bleeds or your condition.



Stories from our community

Chris

Learn to look after yourself. I was always scared of going to hospital so I would hide being in pain and treat my bleed at home so mum and dad wouldn't take me there. Inevitably, I ended up in hospital anyway because I hadn't treated my bleed with a dose of factor from the onset.

Sharron

Don't worry. The treatment options will be much better when you are older and there will be many more options.

Dale

Don't skip treatments, always ask about new technologies.

Look after your joints because they only get worse the older you get.

Always keep an open mind with regards to treatments and others' opinions.

Respect the older generation of bleeders, they limp so we can run.

Share your story; you'd be surprised who would benefit from hearing what you've been through.

Do what you can to give back to the community that's advocated and looked after you.

Read more

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

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

Thanks to Cheryl, Tim, Chris, Sharron and Dale for their contributions.

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CALENDAR

World Hepatitis Day
28 July 2023
www.haemophilia.org.au/world-hep-day

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

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

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

Face to face once again
Register now!

www.haemophilia.org.au/conferences