Haemophilia New Zealand

Bloodline

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When the World Comes Together

Contents

OPENERS

H Word By Hemirau Waretini 2
Highlighting the happenings of HNZ in the past six months.

From the CE By Deon York 4
Introducing the latest issue of Bloodline.

IN DEPTH

Cover Story | When the World Comes Together: Special Report on the WFH 2026 World Congress

In a World of Contrasts By Deon York 7

Knowledge Is Power: My First Congress Experience By Amy Bollmann 11

It's Good to Be Back By Ashley Fowlie 16

Oral Health and Bleeding Disorders By Tineke Maoate 20

Bleeding Disorders and Psychosocial Care By Lynne Campbell 21

From AI to VWD By Darian Smith 27

Teen and Youth Camp: Cultivating the Next Generation 36
By Deon York

IN FRAME

When the World Comes Together: WFH 2026 World Congress 31
Photographs by Hugo Gong

Cultivating the Next Generation 38
Photographs by Deon York

IN BRIEF

Dr Elizabeth Berry Exercise Cup: Will You Be the Next Winner? 43
By Deon York

Paint the Town Ed! By Deon York 44

I See Red: **World Hemophilia Day 2026** By Deon York 45

IN THE END

Upcoming Events 46

Contacts 46

Cover photo by **Hugo Gong**

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With thanks to all contributors and the Hive Creative

H **Word**

Kia ora koutou,

It's been another full and energetic six months in the world of bleeding disorders, marked by connection, progress, and the ongoing commitment of our community. One of the real highlights has been seeing our local committees continue to bring people together. The Masters, Central, and Northern branches each wrapped up 2025 with end-of-year gatherings that gave members a chance to reconnect and strengthen the sense of community that sits at the heart of Haemophilia New Zealand (HNZ).

I also enjoyed running into so many of you at one of the Auckland Ed Sheeran concerts—a reminder of how vibrant and connected our community is. Thank you to Frontier Touring for providing the tickets and to everyone who donated; your generosity helps us keep delivering the programmes and support our members rely on.

Our national programmes started the year strongly with the Teen and Youth Camp at the beautiful Long Bay Marine Reserve. The camp gives young people with bleeding disorders the chance to learn more about managing their condition and to build confidence in taking charge of their own care. Even as treatment options evolve for some in our community, the skills, friendships, and leadership developed at these camps remain invaluable.

A huge thank you to the HNZ staff who delivered an outstanding programme, supported by dedicated volunteers and an inspiring group of young leaders. Many of these leaders are also part of the National Youth Committee, which continues to drive our Youth Twinning partnership with Hemophilia Foundation Pakistan. While travel isn't possible, planning is underway for a joint event later in the year.

Whether at local gatherings or national programmes, it's encouraging to see our community showing up for one another in so many ways.

In April more than 1,900 delegates from over 190 countries gathered in Kuala Lumpur for the 37th World Federation of Hemophilia (WFH) World Congress. The programme covered a wide range of issues: the challenges of providing ongoing care in a world experiencing some of the most significant levels of conflict and displacement in recent decades; the work being done to improve diagnosis, treatment, and care in low- and middle-income countries; and the rapid advancements in treatment globally.

The congress highlighted the importance of continuing to close gaps in treatment and care. A key theme was the continued focus on addressing the unmet needs of women and girls with bleeding disorders. While haemophilia has historically been viewed as a condition affecting men, we now understand far more about how bleeding disorders impact women, yet globally, around 70% remain undiagnosed. There were also several sessions on improving recognition, treatment, and care for people with von Willebrand disease and rare bleeding disorders. HNZ continues to be well represented at congress, with Lauren Philips, Deon York, and Darian Smith each presenting at various sessions.

Despite the difficult global environment, it was uplifting to hear about progress being made—from policy wins to innovative models of care, and the creative ways NGOs from around the world are supporting patients and families through education, advocacy, and community-building.

The insights shared at congress continue to shape our thinking here in Aotearoa, particularly as we look to strengthen equity of care across our own community.

International partnerships also remain an important part of our work. Although our official WFH Twinning with the Fiji Haemophilia Foundation has concluded, we were still able to discuss next steps with WFH colleagues and explore how we can continue supporting progress in Fiji. The work already achieved—including improved diagnosis and access to humanitarian aid—provides a strong foundation for future development across the Pacific.

Back home, World Hemophilia Day once again lit up the country, with 15 iconic sites—from Eden Park to New Brighton Pier—glowing red in support. We'd love to see even more landmarks involved next year, so if you have ideas for your local area, please get in touch.

Thank you also to everyone who completed the recent member survey. Your feedback gives us a clearer picture of what matters most to you and where we can strengthen our work. We're now reviewing the insights and weaving them into our planning for the year ahead.

Finally, I want to acknowledge our former communications manager, Phil Constable. Phil has been part of HNZ for more than a decade, leading our communications, keeping our systems running smoothly, and supporting staff and volunteers with unwavering dedication. Throughout his time with us, Phil has always kept the needs of our community at the centre of his work. Many of you will know him personally, and I'm sure you'll join me in thanking him for his tremendous contribution.

As we look ahead, I'm encouraged by the momentum across our community—locally, nationally, and globally. Enjoy this issue of Bloodline, and the reflections and learnings from the past six months.

Mauri ora,
Hemirau Waretini
Chair

From the **CE**

As we move through the wintry months of the year, we hope that this issue of Bloodline, hot off the press, will have enough content to warm you up.

We focus on the recent World Federation of Hemophilia (WFH) World Congress, bringing many pages of content directly to you from all over the world. Having read every word, I can say with confidence that the topics cover the breadth and depth of our membership and do focus on some 'home truths' of living with and managing a bleeding disorder. I hope, too, that you can see how the global perspective can help us closer to home.

This year's WFH World Congress was held in Kuala Lumpur, Malaysia from 19 to 22 April. Thanks to generous support from Roche and Sanofi, and invitations to speak from WFH, HNZ was able to support a contingent of physiotherapists, nurses, as well as HNZ staff and members to attend. Members who attended the congress underwent a contestable process.

In this issue we also reflect on the teen and youth camp held at the beginning of the year and remember the undeniable talent of Ed Sheeran. There's even a nod to the Dr Elizabeth Berry Exercise Cup. Can you be its winner this year?

As reported in the June Pānui, Phil Constable, the communications manager for Haemophilia New Zealand (HNZ) for a decade, quietly retired from his role in early March. Phil has been living with a cancer diagnosis and expressly told us 'not to make a fuss' about his departure, but that doesn't mean we shouldn't recognise his contribution to HNZ during his considerable tenure.

Phil began working with us following Chantal's departure about ten years ago as the national information coordinator, eventually becoming the communications manager. He has worked for every chief executive this organisation has had so far! While members know his communications role well, only a few of you are aware of much of the work he has done for us 'behind the scenes'; to name some, database administration, managing the back end of all our software licenses, and generally being 'Mr Fix-It' for HNZ board and staff for any IT need and concern. Those tasks are often thankless but incredibly essential to ensuring the business continuity of HNZ. Since receiving his health news, Phil was acutely concerned about what he is leaving behind for HNZ, for which we have enormous gratitude and respect. Phil, we are wholeheartedly appreciative of all the support you have given us over the years. We sincerely wish you well.

Some of the members attending Mike Mapperson's service, from left to right: Peta Hardley, Lynette Zink, Peter Zink, Dr Elizabeth Berry, Gabriel Larkin, Catriona Gordon, Nick Waters, Helen Spencer, TA Stirling, Dave and Gill Nelson, Hemi Waretini, Lynley Scott, Ian Hardley, Tony Goodwin, and John Cook

In the process of producing this issue, we sadly learnt of the passing of Mike Mapperson, former president of HNZ (1988-1996) and former vice president (1997-2002). His service took place in late June in Auckland with members in attendance to honour and celebrate Mike. While I was not able to attend the service in person, I watched the live stream. I always remember how much Mike gave to our community. He was vice president when I first started volunteering in the late nineties. I remember my first exposure to the global bleeding disorders community at a WFH World Congress in 1998. Mike was there representing us all. He, with another Mike—Mike Carnahan (also former president of HNZ)—and others, served us at a time when HIV and HCV were still a major concern and championed justice for everyone. To me, it was the 'two Mikes era'.

Mike has been one of those special people in our community. His legacy forms an unforgettable and indelible presence at our organisation. We are deeply indebted to Mike for his selfless and devoted service to our community. Thank you, Mike. And our condolences to his family.

Deon York
Chief Executive

Mike has been one of those special people in our community. His legacy forms an unforgettable and indelible presence at our organisation.

COVER STORY
When the World Comes Together: Special Report on the WFH 2026 World Congress

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Photograph by **Hugo Gong**

Illustration by **Caitlin Lovegrove**

In a World of Contrasts

By **Deon York** Photographs by **Hugo Gong**

Reuniting with friends, from left to right: Harshal Kale (WFH), Aris Hashim (former board member, WFH), and Hazri Aris (WFH)

This year's WFH World Congress was attended by a keen group of HNZ members, staff, and clinicians. For some, this was a new experience, while for others, comparisons could be made with other conferences and meetings hosted for our community. For me, this was far from my first attendance, which prompted me to ponder on such gatherings: Do we remain globally connected? Do these meetings still hold the same relevance they once did? Do they still reflect our shared aspirations and goals? In an increasingly polarised world, are the treatment- and care-related differences too stark to compare? The more I reflected, the more I thought about the contrasts we see globally, nationally, regionally, and even personally. What can we learn from these contrasts, and what actions can we take in response?

KUALA LUMPUR FINALLY WELCOMES THE WFH WORLD CONGRESS

It has been many years since a WFH Congress has been hosted in Asia, and this is where the contrasts begin. In a vast continent covering more than 60% of the global population, the social, cultural, geographic, and economic contrasts are evident. All such contrasts have an impact on treatment and care for bleeding disorders. Some of the most resource-rich countries occupy this region and are often right next door to places in desperate need of basic access to medication. This community is unified by living with bleeding disorders, but the contrasts could not be more apparent in how bleeding disorders manifest.

The host country this year, Malaysia, demonstrated the vibrant contrasts of its culture, influenced by the many peoples who call it home. The conference was originally scheduled to take place in the capital back in 2020 but was postponed due to the sudden COVID-19 pandemic. As President Edwin Goh of the Malaysian Haemophilia Society noted in the opening ceremony, it took a full cycle of the Chinese zodiac—12 years!—to see the congress finally arrive in the country, from the moment the decision was made to finally reaching the 2026 opening ceremony. A video played during Goh's opening address showed the passage of time as the children appearing in a conference promotion video were welcomed on stage now as young adults! Time truly flies!

My reflections on this year's congress centre on the many contrasts we see in an evolving world. Conflict, climate change, and the global economy were all front of mind among speakers and participants alike. New Zealand is not immune to any disruption to the global supply chain, and there are multiple opportunities for disruption. Understanding the realities for different countries helps us better plan for our own needs.

EVOLVING DEVELOPMENTS AND NEEDS

With the benefit of hindsight, the distinct changes in educational content over time have continued to accelerate. One only has to go back about a decade to see this change. The contrast is remarkable, when considering the short space of time in which this has happened. How have topics changed over time, and what does that tell us about care? More important, how does it reflect the ever-changing needs of the community we serve?

With the changing treatment landscape, increased access to humanitarian aid, and new markets for pharmaceutical development, more innovation has arisen as well as space for wider recognition of the many faces and forms of bleeding disorders.

Conference content once focused primarily on severe haemophilia and emphasised product safety, including the safety of the blood supply when blood components were directly involved in manufacturing. HIV and hepatitis C featured prominently, as did topics about orthopaedic surgery, and complications of severe haemophilia. Limited humanitarian aid was offered to countries with limited access to treatment and care. Topics of the past represented the 'pointy end' of treatment. Most of the treatment development also took place in the United States.

While these topics still hold relevance, with the changing treatment landscape, increased access to humanitarian aid, and new markets for pharmaceutical development, more innovation has arisen as well as space for wider recognition of the many faces and forms of bleeding disorders. The focus now is on all bleeding disorders by including different degrees of severity as well as women and girls with bleeding disorders, more sessions on ageing, and a broader promotion of higher intensity exercise.

This contrast signals many improvements for people with bleeding disorders.

This year I was invited to speak at a Roche symposium about how New Zealand gained access to optimal prophylaxis despite sitting at the bottom of the OECD when it comes to access to modern medicines. I presented alongside Dr Glenn Pierce (outgoing vice president medical of the WFH) and Dr Murina Borhany (consultant haematologist from Karachi, Pakistan). While the realities in New Zealand and Pakistan are vastly distinct in access to medications, some of the advocacy had a similar ring to it. With Executive Director Natasha Coco of Haemophilia Foundation Australia, we co-produced a conference poster on the changing needs of our respective communities. Trawling through member surveys, annual reports, and board minutes is not for the faint-hearted. The results demonstrated a few shifts in our community. Notably, there is a growing desire among members to have more local connections than larger national events, and to reach out to the organisation when the need is present rather than being proactively followed up. Moreover, members showed a strong interest in general education with targeted subsets instead of targeted educational programmes.

CONTRASTING TREATMENT OPTIONS

Treatment options continue to expand, and options for gene therapy for haemophilia B continue to progress. For instance, 47 out of 50 patients who were part of a gene therapy study have not required FIX prophylaxis after five years, and that was after a single infusion of etranacogene dezaparvovec (Hemgenix). Six

With some members of Hemophilia Foundation Pakistan, from left to right: Hassan Raza, Wajiha Javid, and Syed Shabistan

From left to right: With Salome Mekhuzla (WFH), Fatima Sahra Ben Fouila (Morocco), and Rana Saifi (WFH)

BELOW: Presenting at the Roche symposium

RIGHT: With Dr Glenn Pierce and Dr Murina Borhany

months of observation exhibited no evidence of oncogenicity–promoting formation of cancerous tumours, long-term toxic effect on the liver or any other substantial toxic effects. Trials continue for haemophilia A, but progress is slower, and many major companies have halted trials altogether due to complexity, uptake, and viability.

The introduction of emicizumab (Hemlibra) to the New Zealand market in late 2023 made a significant improvement for haemophilia A patients. Trials continue for an even longer-acting version (known as NXT007). Other trials are occurring in parallel such as Mim8 (Denecimig), for instance. There are trials for haemophilia B (or both A and B concurrently) and haemophilia B products, which are administered in the same way as Hemlibra. These were also reported at the global forum last November in Montreal–further details can be found in the December 2025 issue of Bloodline.

The landscape for therapies has clearly advanced well beyond traditional factor replacement, although for some this is still an important treatment option. The newer non-factor replacement therapies such as emicizumab, concizumab, marstacimab and fitusiran present opportunities for enhanced treatment. This also needs to be balanced with new considerations for bleed management, surgery, making product switches, and a closer examination of the management of thrombotic risk. Inhibitors have become less frequent with the introduction of these new therapies, but remain a consideration, particularly when branching out to gene therapy. For instance, if using an adeno associated virus (AAV) as a delivery method for gene therapy, while the delivery method may be low risk, it is still a foreign object to which the body could have a reaction.

A WORLD OF CONTRASTS

I can't help but see these meetings as a giant family reunion. At this reunion, there is never any awkward silence as the topic du jour is always just at hand. Among the many friends and colleagues, I was fervently approached by one of the participants who reminded me that we had known each other for more than 25 years, which is further back than the age of many of our members! The congress was also a major platform to meet many young and motivated people with bleeding disorders from all corners of the world. I was struck by the talent and diversity of the recipients of the Susan Skinner Memorial Fund. Yujie (Ruby) Zuo, a young woman with a bleeding disorder from China explained to me the acceleration of gene therapy and other therapies in her home country. Her enthusiasm for her family and community was palpable and could be felt throughout the congress among many of the young participants. Naturally, if treatment is available then younger people should be able to be more active, but this is not always the case.

While treatment outcomes in New Zealand have continued to improve, the many people I have met over the years still live in challenging circumstances when it comes to managing bleeding disorders. They have continued to work or volunteer for their community, facing far greater obstacles to achieve access to treatment and care. Coming face-to-face with these individuals once more, many of whom are now leaders in their community, is really a powerful inspiration. They have been able to achieve against insurmountable odds, remain positive, and keep their humanity. This is in part due to their exposure to the stark contrasts with and without access to treatment and care.

CONTRASTS CLOSER TO HOME

It was observed that I had the most problematic joints among the New Zealand attendees with bleeding disorders. I couldn't help but wonder how much has changed over time. I know plenty of our members who have various challenges with joints, so it was interesting to reflect that within this particular group I had relatively worse joints. I take this as a positive despite how that sounds. It speaks to how far treatment and care has come. When I was the one with relatively better joints (some years ago), the contrast was significant. It included contrasts such as the donning of casts, pushing of wheelchairs, being aided by crutches, and resting pseudotumours, just to name a few of the many 'joys' bleeding disorders can bring. In 2026 contrasts persist but the gap has narrowed considerably, at least in a New Zealand context. This is by no means to suggest that we should be complacent.

As the pace continues to speed up, no one should be left behind, and complacency is simply not an option. The more we leave behind, the wider the gaps will grow, and the contrasts will only be more pronounced. That is why it is imperative we all work together to ensure that everyone can receive diagnosis, treatment, and care.

CAN WE EVER RECONCILE THE CONTRASTS?

The way we connect has changed significantly over time, and it is not always necessary to leave your desk to reach anyone from around the world. That said, the WFH World Congress still holds relevance and significance. Despite the many stark contrasts, the participants are all striving to make improvements for people with bleeding disorders, even if the starting lines may vary. We can continue to appreciate these contrasts as they speak to how far we have come, but they also prompt us to act when needed.

While conferences necessarily focus on what is new and innovative, joining with the community is also a pertinent reminder of how our past impacts our present. In New Zealand we are fortunate but still do not have access to the entire suite of novel therapies available. As the pace continues to speed up, no one should be left behind, and complacency is simply not an option. The more we leave behind, the wider the gaps will grow, and the contrasts will only be more pronounced. That is why it is imperative we all work together to ensure that everyone can receive diagnosis, treatment, and care. Around the world, many do not live with a bleeding disorder, they sadly die too soon of a bleeding disorder. It was not in the distant past that the same happened here. We have a duty to honour those who have gone before us. We have lost too many and come too far. While it is important to focus on the future, being together with my many friends and colleagues in this globally connected community, those voices we lost too soon still resonate in my mind.

LEFT: Connecting in person with Vicky Hernández, a keynote speaker at HNZ's wellness weekend 2025

RIGHT: With Yujie (Ruby) Zuo, a recipient of this year's Susan Skinner Memorial Fund

LEFT: With Executive Director Natasha Coco of Haemophilia Foundation Australia

RIGHT: This year HNZ presented a poster jointly with Haemophilia Foundation Australia.

Knowledge Is Power: My First Congress Experience

By **Amy Bollmann** Photographs: **Supplied**

I don't remember a time before bleeding disorders; they have always been a part of my life in some form. Through my family or personally, I have been affected in some way by haemophilia or von Willebrand disease.

Over 20 years ago, at the age of 16, I had my first real experience of volunteering for what was then known as 'HFNZ' by joining the Northern committee, when the only other members were my extended family. Fortunately, that blip didn't last long. Over the years I have volunteered for HNZ in many ways: I have fundraised, cared for early learners at camps, been a youth leader at camps, held committee holder roles and helped arrange and run regional events. As a bonus, I often volunteer Jono, too (my obliging husband). With this experience of HNZ and our community, I wondered what new perspective I would gain from attending a WFH World Congress for the first time.

I strongly believe that knowledge is power; I attended the sessions with an open mind, knowing that you can always gain something new. The more we know about our conditions at different stages of our lives, their impact on us both physically and mentally, and the available treatments, the more prepared we can be to improve our quality of life.

GLOBAL NATIONAL MEMBER ORGANIZATION TRAINING (GNMOT)

Walking into the training was both exciting and intimidating. I felt honoured to be there and eager to learn how I can contribute to making HNZ stronger.

GNMOT is about building stronger organisations that collaboratively help their communities with the challenges they may face. WFH funds the training for one member of each associated National Member Organization (NMO). I was fortunate to be New Zealand's representative.

Walking into the training was both exciting and intimidating. I felt honoured to be there and eager to learn how I could contribute to making HNZ stronger. The tone of the training was set with an opening plenary where we were empowered by WFH leaders who shared a bit about what they had been doing and the importance of each NMO's leadership, community engagement, and advocacy. It was all very inspiring and left you feeling ready to move mountains.

The training was two full days, scheduled from 8 a.m. to 8 p.m. During this time there was a mix of plenaries, workshops, and networking events. We heard about the treatment landscape, strategic advocacy and youth engagement. I participated in small group activities, developed effective advocacy strategies, good governance, leadership, and organisation health as well as how to engage and retain volunteers. I heard from other NMOs and had the opportunity share what was important to me and ask questions about their experiences.

Being a part of our bleeding community for so long, I thought I had a relatively good grasp on things that affect, and have affected, our lives. I was surprised by how much I still have to learn. My life is just one experience which will be different to yours and dissimilar to those in other countries. Fortunately, it is these varied experiences that make the workshops so valuable. You have a subject matter expert in a room full of highly motivated individuals with a range of perspectives ready to think about current challenges, share experiences, and discuss possible resolutions.

GENERAL ASSEMBLY AND CONGRESS

My first insight into WFH 2026 was the Annual Meeting of the General Assembly. Each full NMO nominates two representatives who attend the three-hour-long meeting. They hear from the WFH board and vote on behalf of their NMO. Under the guidance of the HNZ CEO and board, Ashley and I were privileged to represent HNZ. It truly was an honour to be there.

Before attending, I knew there was a benefit to sharing experiences with people from a range of cultures and—now I have experienced it myself—I can bring new information of ways of working to strengthen our local community.

Due to my family and personal history, I am genuinely interested in a range of bleeding disorders and how they affect our wellbeing at different stages of our lives. I expected congress to give concrete answers, almost like an instruction manual, to best live your life with your bleeding disorder. I think I might have been dreaming there! Instead, what I found was a lot of different paths and options, which makes a lot more sense because we are all different people going through various challenges. Something I really enjoyed about the congress sessions was that each session had a panel of speakers, and they had a mix of backgrounds so you might hear from a couple of subject experts as well as someone with lived experience in the same session.

I expected congress to give concrete answers, almost like an instruction manual, to best live your life with your bleeding disorder. I think I might have been dreaming there! Instead, what I found was a lot of different paths and options.

Although I got a lot out of the sessions at congress, I did find some of the sessions more challenging to understand than I had anticipated. Some sessions had an expected background knowledge or used acronyms and terminology that I wasn't familiar with. It wasn't so unfamiliar that I couldn't overcome the challenge, but it was a lot of new information, so it did take time to digest. I found it helpful to take photos of the slides and ask my peers questions.

Throughout congress there was an exhibition hall set up where attendees could view posters, visit exhibitors and listen to pod talks. This is where I went if there was time between sessions such as the lunch break. There were a couple of highlights here. While looking at the posters that different NMOs had submitted, Ashley and I came across one that stood out about creating a children's book as a tool for education and support. It was fantastic. After reading it, we noticed that it was written by our very own outreach worker Darian Smith! My other highlight was connecting with the Pakistan exhibit as they are our twinning partner. I met a couple of the ladies at the NMO training and was fortunate to be grouped with President Dr Abira Maheen of Hemophilia Foundation Pakistan for the effective advocacy strategies workshop. They were surprised that HNZ had females actively involved and wanted to extend the female collaboration between our countries; I was so happy to show that New Zealand is inclusive and keen to engage.

This whole experience has opened my eyes to how people manage or don't manage with bleeding disorders around the world. It's reiterated how far we have come with our access to safe treatment. I am very grateful to those who fought for safe treatment, you have ensured many people have lives today. It also highlighted that our fight isn't over, we are just fighting for different things, so it looks different.

LEFT: Receiving a certificate of completion at the GNMOT

RIGHT: Participants of GNMOT 2026, photo courtesy of WFH

With President Dr Abira Maheen of Hemophilia Foundation Pakistan

AM I SELFISH FOR WANTING A FAMILY? FAMILY PLANNING FOR PEOPLE WITH BLEEDING DISORDERS

I requested to cover this topic as I know from personal experience that family planning can be an emotional rollercoaster. Throughout the years I have heard so many different opinions on what I should or shouldn't do, and sometimes other people's opinions can be overwhelming, especially when your own perspective changes over time. I wanted to hear from the experts and hopefully make someone else's journey a little easier.

Behind Every Gene Is a Story: Genetic Counseling and Informed Decisions

Presenter: Diana Salinas Chaparro (genetic counsellor, Spain)

Diana was very understanding about how complicated and emotional family planning can be as she works as a genetic counsellor in a children's hospital in Barcelona and helps families come to terms with the genetics alongside treating specialists. Genetic counselling can support families make informed decisions by educating, providing genetic testing, giving management options and resources, providing research and counselling.

At the appointments, genetic counsellors meet with the patients and families, set expectations, hear their concerns, gather medical and family history, perform risk assessments, provide psychological support, explain conditions and discuss family planning options.

It is all done with empathy and respect. Open dialogue is essential, it is fully patient centred with cultural, social, and religious factors often influencing genetic counselling. They are not there to make the family planning decision for you but to provide you with what you need to feel confident making your decision. There are no right or wrong choices.

Throughout the years I have heard so many different opinions on what I should or shouldn't do, and sometimes other people's opinions can be overwhelming, especially when your own perspective changes over time.

Beyond the Biology: Psychosocial Dimensions of Family Planning

Presenter: Richa Mohan (clinical psychologist, India)

Family planning brings the potential of medical risk and financial strain, which can affect people with bleeding and genetic disorders psychologically. They may be impacted by fear, guilt, stigma, and social expectations. To provide holistic care and support autonomy in family planning, it is important to understand how carriers and affected individuals experience conflict when considering family planning.

Both men and women can experience fear of passing on the gene or being perceived as 'less than', leading to anxiety about even the discussion of family planning. In some cultures, there is little communication about genetic conditions with stigma and shame attached making it challenging to reveal a condition to a partner or family members. This affects their reproductive outcomes. Assisted reproductive technology could help reduce the chance of passing on the condition; however, for some this raises moral, religious or psychological concerns as it conflicts with their cultural or personal beliefs.

Women who carry the gene often feel responsible, guilty and afraid of being judged. Men can be concerned about how they are perceived by others, their fertility and their potential burden on their families. There are often expectations from families that couples will have families. The expectations of others can make those with genetic conditions feel like failures when they do not live up to what is expected of them. Depression can occur when a person needs more support.

Communication is a real challenge. Partners need to discuss family planning openly with each other without the fear or rejection. To facilitate this, best practice would be a multidisciplinary approach, including haematologists, genetic counsellors, psychologists and social workers. These professionals should provide accurate information, address cultural and emotional factors, and offer support.

Not Just in the Passenger Seat: Dads Driving the Family Planning Conversation

Presenter: Taqrir Akramin Bin Khalib (father with severe haemophilia B, Malaysia)

Taqrir is married with three sons and a daughter

and a grandson. He grew up in Malaysia, a developing country where it used to be taboo to talk about haemophilia. It has taken an emotional toll; there are feelings of guilt, fear and doubts of masculinity. No one wants to pass on a hereditary condition to their children and grandchildren. In Muslim countries there is added pressure of societal expectations such as male circumcision– it brings about questions like 'Am I man enough for society?'.

Dads should be driving the family planning conversation. They too play an important role as they also desire children and grandchildren with their life partners like other families. These were emotional conversations for Taqrir that involved extended families and communities. He had to ensure his future wife was ready to marry someone with the challenges of a bleeding disorder. To prepare her, he invited her to activities organised by the Hemophilia Society of Malaysia, and at a time when they were still using potentially contaminated blood products. She accompanied him to the hospital for treatment. He showed her that other than some extra challenges that he faced, he was like any other man.

Family planning will be impacted by culture, religion, the law, the background of the people involved, and the availability of treatment and care. Now as a future grandfather, Taqrir is still part of the family planning conversation. He wants his daughter to be happy and his grandchildren to be happy and healthy. Taqrir also expects his future son-in-law to understand and accept the possibility of children with haemophilia and is planning for the best treatment and care for haemophilia in the future.

Becoming a Mother with a Bleeding Disorder: One Woman's Story and the Options We Have

Presenter: Soledad Rivero Haedo (mother who carries severe haemophilia A, Argentina)

About 20 years ago Soledad and her husband were deeply concerned by the number and size of bruises their baby Bruce had. At six months old he was diagnosed with severe haemophilia A (severe). There was no family history. The dreams they had for their son were replaced with fears, anxieties and over-protection.

Having already planned a much larger family they were now faced with the questions 'how can we expand our family responsibly? and how can we avoid passing on this disease?' They talked to doctors, psychologists, obstetricians, paediatricians, geneticists, and haematologists. As a Roman Catholic Soledad sought the perspective of her church on their family planning decisions. Intervention was not something well accepted. Although Soledad's husband is also Catholic, he took a more pragmatic approach to faith and wasn't ready to rule out IVF (in vitro fertilisation).

After confirming that Soledad was in fact a carrier, the first mutation of the haemophilia gene and many months of consultations, reflections, emotional conversations, they decided to proceed with IVF with sex selection. At the time (2005) it was not possible to select embryos free of the affected gene, so this was considered ethically acceptable. The process was long and emotionally draining, there were months of uncertainty. Ten eggs were collected, eight fertilised but only one female embryo was viable. That embryo was successfully implanted and became Soledad's daughter.

THE AGE-OLD QUESTION: HOW CAN WE BETTER ENGAGE OLDER PEOPLE WITH BLEEDING DISORDERS?

It's no secret that there are certain age groups that could benefit from increased engagement. I was really interested to hear how others had found meaningful ways to engage and was hopeful that we could implement new initiatives in our community.

Engagement Without the Labels?

Presenter: Suzanne O'Callaghan (policy research and education manager, Australia)

Suzanne worked on a 'Getting older with a bleeding disorder' needs assessment for Haemophilia Foundation Australia (HFA). She quickly learnt that language matters. Words and phrases such as 'aging' and 'early aging' are seen as negative and discriminatory. People don't see themselves as old, they don't want to be put in a box, and they want to be seen as an individual. She started asking how old the older guys were; answers showed that the older guys were the ones that didn't receive prophylaxis as a child, but there are currently men with haemophilia living into their nineties.

The World Health Organization only loosely associates chronological age with an older person's experience, as some people are very active throughout their 60s, 70s and 80s while some are not. What usually changes as people get older are their priorities and goals. The needs assessment identified maintaining quality of life, keeping healthy and remaining independent were the most common aspirations. Other common goals were maintaining mobility, reducing stiffness and pain, being able to participate in family life, travel, pursue interest and be useful.

An outcome from the needs assessment was the 'Getting Older Hub' on the HFA website. It consists of various topics such as health and wellbeing, services for getting older, work and finance, recreation and travel, planning for the future, and connecting to others. It has been tweaked since it was first created; it now has more topics that show strength and resilience when dealing with challenges, and images that reflect what getting older looks like for HFA.

Older people in the community have now highlighted the need for more opportunities to meet face to face and establish friendships. Once

these bonds have been formed, they could be maintained through technology such as Zoom and WhatsApp.

Old on Paper, Young at Heart: How I Want to Be Engaged

Presenter: Pamela Wilton (symptomatic carrier of factor VIII deficiency, Canada)

Pamela was raised to give back to her community, so volunteering has always been a significant part of her life. It has been a learning experience that taught her to overcome her fear of public speaking and has also given her an appreciation of what she has and a sense of purpose.

Pamela has always believed it's not about what's on your resume, but how you use it.
As a volunteer she found the following important to her when volunteering:

- Utilisation of professional skills as a respiratory nurse educator.
- Personal experience. The lived experience as a carrier, mother, wife, colleague, and friend of those with bleeding disorders.
- Meaningful work. There needs to be a purpose, the work should make a difference and be challenging in some way.
- Role clarity. She needs to understand exactly what is expected of her, and who she reports to.
- Respect. Understand time is valuable, volunteers do other things. Do not waste their time.

She takes responsibility for getting what she needs when volunteering. She offers to help and works to find the right fit. She appreciates other volunteers and mentors the next generation. Pamela is committed to working with others to make the world better for her granddaughter even though she may be considered old.

Building Bridges: Engaging Older People with Respect and Purpose–A Personal and Community Perspective

Presenter: Masoabi Clerment Sefojane (severe haemophilia A, chairperson, South Africa)

At 32 Clerment was first asked to speak on ageing, which he found quizzical. Now at 36 he has been asked again and understands he was asked at the right time as the decisions made then are affecting him into the future.

He surveyed his community and identified three main concerns from individuals aged from 25-85 years. They were worried about pain, mobility and the long-term impact. Ageing is physical, mental, and emotional. It affects how people move, work, and live, which flows into their friendships, relationships, and financial stability.

People getting older with bleeding disorders have something to offer and are willing to mentor the next generation but aren't being given the chance. So many people are focused on the younger generation discounting the lived experience. Clerment encourages those working in patient organisations and advocacy groups to bring in the people getting older with bleeding disorders to help design programmes because they have more experience and skills to share.

Research shows that many older people are comfortable with digital tools, but we design programmes to which they cannot relate. Clerment encourages future programmes to be designed with those getting older not just for them and include a space to share lived experiences beyond physical health.

Communication needs to be adapted to engage and empower all generations. Empowered to be independent, empowered to give to the community, and empowered to share what they are feeling.

Job Done? Not Yet!

Presenter: Tatjana Marković (carrier, vice president of the European Haemophilia Consortium and the Serbian Haemophilia Society, Serbia)

Tatjana has spent the last 26 years as a volunteer for her bleeding disorder community in Serbia. In 1995 her son was diagnosed with severe haemophilia A, and she found out there was better treatment in neighbouring countries. She tried to get him better treatment, but a mother on her own wasn't getting anywhere. In 2000 she helped establish the Serbian Haemophilia Society, and she attended every training she could. A few years later she became the vice president, which she remains today.

The power of parents is enormous. From meetings, workshops and projects, the Serbian Haemophilia Society has become part of more committees and influenced healthcare policies. They now have access to prophylaxis. Tatjana was also the founder of a parent's group. When she felt she no longer needed to be there, she ensured they had the training to run it themselves.

Although she wasn't a bleeder herself, she helped establish a women's bleeding disorder group and learnt about the different challenges they faced such as delayed diagnosis, inadequate treatment and stigmatisation.

Tatjana has also joined the women's bleeding disorder committee of the European Haemophilia Consortium (EHC). She shared with the audience an important project to her. EHC's 'living well, aging well', which brings together experts, patients, and caregivers to support fulfilling lives during ageing through webinars, virtual café talks, and peer pioneer podcasts. Keeping EHC's concept of 'living well, aging well' on World Hemophilia Day 2026, a time capsule letter addressed to the bleeding disorder community was sealed describing the community as it is now, their current journey, and their hopes for the future. The capsule will be opened in 2039.

Tatjana will tell you with conviction she is still here volunteering after 26 years because the job is not yet done.

It's Good to Be Back

By **Ashley Fowlie** Photographs: **Supplied**

In 2016 I was awarded the International Susan Skinner Scholarship through WFH at Congress in Orlando. Since then, I have remained a mentor for new Susan Skinner recipients. This year I was asked to be partnered with two women with bleeding disorders from Kenya and the United States. Prior to congress there were Zoom calls arranged between countries.

It was amazing to hear the personal journeys of these women that they shared throughout congress, and the insight they have offered into their organisation.

LEFT: With Sylvia Kathurima, Susan Skinner Memorial Fund recipient from Kenya

RIGHT: With Noemy E. Diaz-Burgos, Susan Skinner Memorial Fund recipient from the United States

Amy and I represented New Zealand at the General Assembly. This was an amazing opportunity to see the member countries and to hear some future insights. The next congress in 2028 will be in Chicago; however, the 2030 congress was not yet voted due to the reframing of the congress planning model. It was discussed that there has been a 25% increase in diagnosis of both haemophilia and von Willebrand disease worldwide, but the future will also focus on tracking women being diagnosed with bleeding disorders.

I was able to connect with the women from Pakistan. A past mentee of mine under the Susan Skinner Scholarship is now supporting the youth twinning programme between Pakistan and New Zealand. It was amazing to hear the personal journeys of these women that they shared throughout congress, and the insight they have offered into their organisation.

WELLNESS IN PWBD: HEALTHIER HABITS LEADING TO BETTER HEALTH OUTCOMES

Presenters: Tim Demos, Australia; Mohd Helmi Hashim, Malaysia; Maria Victoria Hernandez, Argentina; Ekawat Suwantaroj, Thailand; Michael Wilson, Australia

This session focused on wellness, lifestyle, support, and their influences on our long-term health outcomes.

The session speakers involved a person living with haemophilia, physiotherapist, psychologist, and a dietician. The main themes of the session were how to improve joint health, pain reduction and improve overall quality of life through improving physical activity, nutrition, weight management and mental health.

The National Hemophilia Foundation of Thailand identified that their members were skipping exercise due to the fear and limited knowledge of being able to safely exercise and lack of access to the correct equipment, impacting the exercise they can do. They also identified two barriers of exercise, namely fear of bleeding, and painful joints and muscles. Pain management involved addressing the chronic pain from past joint bleeds and reducing the gap in knowledge for exercises that are safe for joint conditions. Resource limitations such as gym, pools and equipment were identified. The Thailand group used smart watches to monitor physical fitness and encourage their members to be more physically active. Initial tests involved a 6-minute walk, wall squat test and monitoring resting heart rate. This made me think about setting up a monthly step challenge for our community!

Five ways to exercise safely with a bleeding disorder:

- PRICE is the first line of defence, which means protect, rest, ice, compress, and elevate.
- Isometric exercises (static strength training) as a starting point, which involves being able to build muscle strength without moving your joints. This is ideal for individuals with active joint bleeds or limited mobility.
- Flexibility and balance involve using simple stretching and single leg standing exercises to improve stability and reduce falls risk.
- Functional movement involves using our daily tasks such as gardening and cleaning as strengthening opportunities. These exercises can help increase your overall wellness through implementing them into your daily routines.
- Low-impact aerobics involves walking, cycling and hydrotherapy to improve cardiovascular health without requiring much equipment.

INTEGRATED APPROACH TO HEMOSTASIS, JOINT HEALTH, AND PELVIC FLOOR FOR WGBD

Presenters: Carla Daffunchio, Argentina; Abira Maheen, Pakistan; Robert Sidonio, United States; Lena Volland, United States

This session provided an integrated approach to managing haemostasis, musculoskeletal health and pelvic floor function for women and girls with bleeding disorders. By addressing these topics, the speakers reported a positive impact on the overall health and wellbeing for women and girls with bleeding disorders. The session highlighted the shift from the term 'carrier' to women with a bleeding disorder due to the stigma and previous use of the title.

The session discussed other areas to consider such as platelet function disorders, and other factor deficiencies, fibrinolytic disorders, connective tissue and hyper-mobility disorders. The needs of women with bleeding disorders have been overlooked, leading to limited research on how bleeding disorders in women affect their long-term musculoskeletal health. There was a call for more research to understand joint health for women with haemophilia and carriers. One of the approaches is routine musculoskeletal assessments and monitoring.

Chronic pelvic pain lasts longer than six months and involves persistent pain that affects emotional and behavioural wellbeing and can lead to sexual challenges. It can also affect urinary and bowel function. Chronic pelvic pain impacts 26% of the female population worldwide. Impacts of prolonged chronic pelvic pain can lead to:

- muscle hypertonicity
- dyspareunia
- peripheral nerve entrapment
- neuropathic sensation
- altered movement patterns
- altered diaphragm and core synergy
- reduced hip and trunk stability
- functional limitations, such as urination, defecation and sexual activity.

Two recommendations for those experiencing chronic pelvic pain:

- routine screening for pelvic health, incontinence, pelvic pain, and perinatal issues
- engagement with pelvic health physical therapists.

Red flags or warning signs:

- severe pain
- groin or perineal numbness
- bowel or bladder retention, or incontinence
- weight loss, fever, night sweats, or nocturnal pain
- infection
- postmenopausal bleeding, vaginal discharge, rectal bleeding
- a palpable mass.

WFH PROGRAMS ADVANCING CARE FOR PWBD: WHAT WE CAN LEARN FROM PAKISTAN

Presenters: Munira Borhany, Pakistan; Assad Haffar, Canada; Masood Fareed Malik, Pakistan; Tahira Zafar, Pakistan; Donna Coffin, Canada; Cesar Garrido, President of WFH, Venezuela; Rana Saifi, Canada

This session highlighted the relationship between WFH and the Hemophilia Foundation Pakistan (HFP) to improve care. The session discussed the progress throughout the year, and the barriers that they have overcome with diagnosis, access to treatment, and comprehensive care for people living with bleeding disorders in Pakistan.

The population of Pakistan is approximately 251 million. There is limited public funding for bleeding disorders, few licensed treatment products, high cost to individuals, only three government-run HTCs, few specialised HTCs and many run by the patient organisation. In 1995 haemophilia care was organised solely by HFP. From 1999, collaboration had begun with WFH, which led to official recognition of the HFP in 2000. 2021 saw the Path to Access to Care and Treatment (PACT) Program launch, offering more access to care and treatment, and this project continues. 2025 saw the start of youth twinning with New Zealand, following an assessment visit in late 2024.

Factors for success included the development of guidelines, a strong patient registry, implementation of WFH programmes, increasing government engagement, and increasing diagnostic facilities. Access to treatment remains the biggest barrier.

Priorities for the future include education and awareness for reducing the stigma and barriers of inclusion for women and girls with bleeding disorders.

HFP had a booth at congress. Amy and I were welcomed in, and we spoke to them about our journeys, particularly involving women and girls with bleeding disorders. The Pakistan team hopes to learn more about how we involve women and girls, especially young women.

DON'T LEAVE ANYONE BEHIND

Presenters: Cyrus Njuguma, Kenya; Marlène Beijlevelt, Netherlands; Anne Jackson, Australia; Sylvia Kathuima, Kenya

This session addressed the overlooked aspects of care in people with mild and moderate haemophilia, and women with bleeding disorders. It emphasised proactive management and early recognition of complications and strategies that can be incorporated to ensure comprehensive and equitable care is being provided to all patients living with a bleeding disorder.

The first part looked at using prophylaxis treatment for mild and moderate haemophilia. Considerations involved cost and production of factor. This session identified that there is a need for more awareness on prophylactic care for mild and moderate haemophilia.

A case study of a 14-year-old with FVIII levels of 21% was discussed. Although there was a family history of mild haemophilia, there was no previous history of inhibitors. Following discharge after an ankle bleed, there was a recurrent presentation of bleeds, resulting in severe bleeds. Rituximab was used to supress the inhibitors. The impact resulted in long-term rehabilitation being required, and the 14-year-old was described as presenting as an 80-year-old. There was an impact on school, work, finances, emotions, and there was the cost to the health system as well. A treatment plan was made in collaboration with other health professionals and the teenager. From this, the importance of identifying genetic mutation at diagnosis and education to prevent and recognise bleeds early was identified.

Another case study was presented where a young male presenting with mild haemophilia had been doing competitive handball. FVIII was 7%, with a poor response to DDAVP. He was initially treating on demand and had no joint damage. Unfortunately, recurrent muscle bleeds occurred while doing handball training and competitions. Delayed response in seeking treatment for the bleeds led to long-term physiotherapy support, immobilisation, and frequent periods of six weeks with no sports—this all had an impact on the recovery. It was later discussed in a multidisciplinary setting collaboratively to have twice weekly prophylaxis, which was life-changing for the young man and had a positive impact on his future in competitive handball.

The last speaker shared her lived experience of being a woman with a bleeding disorder. The woman was Initially labelled with abnormal uterine bleeding, abnormal menses, and having a postpartum haemorrhage, which she considered as the new normal. It wasn't until she had her first son that she was able to get the answers. When her son had his first vaccinations, the bruising, swelling, and bleeding led to her diagnosis—her son was able to give her condition a name.

LEFT: The alphabet always brings the Netherlands and New Zealand together at the General Assembly.

RIGHT: Ashley and Amy visit the Hemophilia Foundation Pakistan booth.

Ashley and Amy together at Congress 2026

OBSTETRICS & GYNECOLOGY

Presenters: Rezan Abdul-Kadir, United Kingdom; Nathan Connell, United States; Zane Kaplan, Australia

This session focused on the journey of women with bleeding disorders looking at reproductive health, fertility, and ageing. Approaches and evidence-based research is considered when identifying screening and treatment options and the importance of personalised care for women with bleeding disorders.

Women with bleeding disorders have reported difficulty conceiving and maintaining a viable pregnancy, spotting throughout pregnancy, and postpartum bleeding.

The health and wellbeing of women and girls with bleeding disorders can be enhanced by improving awareness and education, better collaboration with treatment centres, developing a clearer diagnostic pathway, development and implementation of standards and guidelines, and encouraging self-advocacy.

WOMEN AND GIRLS WITH BLEEDING DISORDERS

Presenters: Kara Cordiner, Australia; Jennifer Maahs, United States; Rhian Parry, United Kingdom; Kelly Tickle, United States

This session identified the importance of care when challenges arise for both women and girls with a bleeding disorder. The session looked at menstrual management, maternal and pregnancy care and support for women with a bleeding disorder.

Key themes identified were fear, anxiety and worry when women were diagnosed with a bleeding disorder, a delay or misdiagnosis of a bleeding disorder led to a loss of confidence in medical providers as well as the stigma that remains around menstrual bleeding.

Heavy menstrual bleeding was discussed, as blood loss that impacts the women's physical, social or emotional quality of life. Menstruation lasting longer than seven days, pads or tampons being changed every two hours.

The importance of planning with your treatment provider was stressed, and having a plan for delivery such as forceps and C-section were recommended to be avoidable where possible. Following up on levels after birth was discussed as FVIII and von Willebrand levels can rise during pregnancy. It was also recommended to monitor iron levels.

The session discussed the importance of early collaboration with your healthcare provider for pregnancy. Factors to consider are wound complications from a C-section, and episiotomy.

An individualised birth plan involves working in collaboration with all treatment providers, discussing mode of delivery, anaesthetic options, postpartum management, neonatal care, and treatment options.

Approximately one-third of women experiencing abnormal bleeding are affected by the gene.

Overall, this session highlighted the importance of advocating for yourself and the importance of having access to the right treatment plan for your period.

TACKLING DELAYED DIAGNOSIS OF VON WILLEBRAND DISEASE IN WOMEN AND GIRLS

Presenters: Ferdows Atiq, Netherlands; Nathan Connell, United States; Paula James, Canada

This session highlighted the challenges that arise in delayed diagnosis of women with von Willebrand disease. Due to the complexities of diagnosing von Willebrand, bleeding disorders in women can often be overlooked, therefore, collaboration in diagnosis and care with treating health professionals is key.

Measuring menstrual blood loss is an important factor. This is done through weighing menstrual fluid loss, pad counts, and duration of period. Heavy periods, bruising, and nosebleeds are often labelled as normal, and the symptoms are sometimes reported as similar among family members. It therefore becomes the new 'normal'.

Testing for von Willebrand disease in females can be inconsistent during illness, anaemia, pregnancy, or active bleeding. By incorporating a multidisciplinary care approach, treatment and care can be improved.

Overall, this session looked at identified and discussed ways to improve the diagnostic pathway for women with von Willebrand's to reduce the complexities that arise with delayed diagnosis and undiagnosed bleeding disorders.

Oral Health and Bleeding Disorders

By Tineke Maoate

Among the many sessions I attended, two were about oral health, including oral health in bleeding disorders, and oral health for women and girls with bleeding disorders.

The common message, which is worldwide, is that people with bleeding disorders must have a good relationship with their dentist. Research has found that some dentists do shy away from treating people with bleeding disorders, but this can be amended by having a good connection with your haemophilia treatment centre (HTC) and through having a treatment plan in place.

Research has found that some dentists do shy away from treating people with bleeding disorders, but this can be amended by having a good connection with your haemophilia treatment centre (HTC) and through having a treatment plan in place.

Many of us have had unpleasant dentist experiences, which can put many off from going back again. This can lead to a bigger problem with lots of people leaving it to the very last minute to get help with serious issues. That can be prevented by approaching dental care with a positive approach and starting as early as possible. Your HTC is an important part of this relationship.

The early years are easy with just monitoring the teeth coming through and practising good brushing technique. Once children start school, it helps to have a discussion with the school. HNZ outreach workers are available to support you with this.

At primary school, a dental bus comes to many schools, and the children are called in one at a time. This is where it's important that you are informed that this is happening so you can either be available to go with your child or talk to the dental hygienist before they call your child in. It's really important we make these visits safe, friendly and productive, as these visits early on will affect how your child sees the dentist in the future.

Once children go to college or high school, you may need to find a private dentist, and in some areas a hospital dentist is available. This, once again, is where you will have to alert the dental clinic about the bleeding disorder and make sure there is a connection with your HTC. (Please reach out to your HTC if you are having concerns with your teeth, as they can also refer you to the hospital dentist.)

There is also a charitable trust called ‘Wish for a Smile’, which you can apply to for help if your child is requiring dental care over and above the normal government-funded services. There are conditions for this service. Please reach out to your dentist, be open and honest, and never be afraid to ask questions. You are always able to say, ‘Before we do anything I would like to speak to my HTC.’ It would be great to be able to avoid preventable operations on our teeth just by having positive interactions with our dental teams. And don’t forget, we all should be using a soft bristle toothbrush, too.

Bleeding Disorders and Psychosocial Care

By Lynne Campbell

PSYCHOSOCIAL STRATEGIES IN MANAGING BLEEDING DISORDERS

This day-long interactive series of workshop sessions preceded congress. The WFH Psychosocial Committee had developed the programme for an international audience.

The increasing relevance for the need to consider the psychosocial impact and perspective of those with inherited bleeding disorders goes back to 2002, when the first unofficial meeting took place in Sevilla, Spain. In 2004, Bangkok, Thailand, the WFH Psychosocial Committee was formed and has continued ever since.

Today, there are resource booklets on a wide range of topics, including psychosocial issues. These are all freely available on the website of the WFH. Resource examples consist of overcoming challenges in hemophilia care, psychosocial support for families at the child's diagnosis stage and space to talk, room to listen.

The 2026 psychosocial day was well structured with most of the day involving situational issues, problem-solving, and group case-study discussions to consider psychosocial strategies in managing bleeding disorders.

The morning programme was comprised of 25-minute sessions encompassing education and schooling, support groups, adherence, coping strategies, complications, such as gene therapy, in general.

The afternoon session was made up of a series of 15-minute panel sessions on the topics of setting up psychological services (both NMO and HTC), parenting skills in haemophilia, and understanding psychological health, followed by Q and A.

The emotional anatomy of diagnosis parallels a reaction cycle to that of grief: i.e. shock, disbelief, anger, grief, fear, guilt, and relief. It is not linear and is unpredictable and culturally shaped.

MENTAL HEALTH AND COMMUNITY

Receiving a Diagnosis: Supporting Emotional First Steps

Presenter: Kathleen Schnur (clinical social worker, USA)

Kathleen's presentation began by describing the earth-shattering moments impacting mental health for those identified as having severe haemophilia from the diagnosis of a newborn and a mother, then getting a name for the symptoms she may have experienced for years.

The meta-analysis of approximately 3,000 patients indicated 74.4% of adults with haemophilia screen positive for significant anxiety, and 24.4% meet the criteria for significant depression vs the general population. 58% of European countries surveyed offer no psychosocial support in haemophilia care.

In von Willebrand disease (VWD) patients, the median timeline between the first bleeding event followed by years of symptoms to diagnosis is 14.2 years. 40% of women with VWD experienced 3+ bleeding events before diagnosis, and delayed diagnosis in VWD was associated with 2.7x increased risk of hysterectomy.

Delayed diagnosis often resulted in medical trauma and stigma around iron deficiency. The emotional anatomy of diagnosis parallels a reaction cycle to that of grief: i.e. shock, disbelief, anger, grief, fear, guilt, and relief. It is not linear and is unpredictable and culturally shaped.

Emotional responses vary wildly; they are not uniform and do not follow a predictable sequence. The patient needs time to process the diagnosis.

It is not just the person with the diagnosis affected, the family system is impacted, and psychosocial support is essential. The caregiver's burden shapes the child's outcomes. The early years after diagnosis shape future emotional outcome.

WFH guidelines state that the core members of the comprehensive care team must include a psychosocial specialist.

Stronger Together: The Power of Community

Presenter: Mariana Battazza (founder and president of ABRAPHEM (Brazilian Association of People with Hemophilia), mother of a young person with severe haemophilia A, Brazil)

Rare bleeding disorders are lived in a family and in the community. In chronic conditions, emotional suffering comes not only from the diagnosis but from continuous stress, unpredictability and the responsibility of constant care. Emotional silence is expressed in the body, behaviour, and mental health. Many families learn to endure everything and appear strong. Silenced emotions can manifest in the body, in behaviour and in mental health.

The speaker underlined the importance of relationships, specifically:

- The family is the first community of care. Many families carry everything alone, and this comes at a very high emotional cost.
- Emotional regulation is built in relationships. People cope better with stress in a safe environment that offers listening, predictability, and support.
- Community provides a sense of belonging that reduces the emotional burden, and connection buffers stress and functions as a collective emotional regulator.
- Patient associations strengthen care networks. They work beyond access to treatment through education, active listening, strengthening support networks, and advocacy. They improve the quality of the experience of living with haemophilia. Education: reliable information promotes safety and reduces overall stress. It reduces anxiety, creates predictability, and strengthens autonomy. Caregivers: sustainable care is not possible without consideration of the caregivers. Given their emotional burden, supporting caregivers means supporting the entire system. We are stronger together: community does not replace treatment but makes collective emotional care possible over time.

Support Groups as Safe Spaces

Presenter: Verónica Cerutti (clinical psychologist, Spain)

In her presentation, Verónica spoke of the calming effect of the Catalan Foundation of Hemophilia on the anxiety experienced by many people 'who have lived their illness alone, often encountering family, social or work environments that were not always supportive'.

Her focus was on the psychosocial aspects of haemophilia. Suffering extended beyond the treatment of the body. This led to a psychological service within the organisation in Catalan which gave space to each person's individual voice. Support groups were established to strengthen connection, and psychological implications were recognised. Over time, the urgency of difficulties in families managing the condition gave way to reflection.

AI in Psychosocial Support

Presenter: Shwetha Subramani (psychologist, India)

According to the presenter, the WHO estimates that one in seven was living with a mental disorder in 2021, yet there were fewer than 1 psychologist per 100,000 people in most low-income countries. She strongly believes in the role of artificial intelligence (AI) in addressing this situation given that psychosocial care is under-resourced.

Haemophilia brings the invisible burdens of anxiety, grief, identity struggles, and family stress. Patients with haemophilia often mask their emotional pain. Caregivers and parents are likely to get little support at all.

AI is available 24 hours a day and can bridge the time between professional sessions; it is therefore a useful discussion to have about what the role of AI might be in the future to support people with bleeding disorders.

Shwetha described a range of prompts to get more specific answers and examples where a person could ask age-appropriate questions and get constructive AI responses across a range of life stages and scenarios. She described the situation in Bangalore where a clinical psychologist who saw 12 patients per day now used AI to prepare for each consultation. This resulted in deeper sessions in less preparation time.

She cautioned that AI output is a starting point and should never be used to replace a final clinical document.

When it comes to AI, what you get out is related to what you put in, so input cannot be vague. Precision is required so that AI does not run with undetected inaccuracies in producing a report.

The AI SOAP format was recommended:

- subjective (S): patient's reported symptoms, history, and feelings
- objective (O): measurable, observable data such as vital signs and physical exam findings
- assessment (A): the clinician's professional diagnosis and clinical reasoning
- plan (P): future-care steps, including medication, referrals, and follow-up.

Shwetha advises patients on which AI to use in certain circumstances and noted the importance of not giving your name or the patient's naming when using AI.

She also uses the SAFE framework for AI use in psychosocial care:

- Supplement (S): AI supplements human care, it never replaces it.
- Anonymise (A): Never enter patient names or IDs.
- Filter (F): Run AI through your clinical judgement before acting, as AI can be wrong.
- Escalate (E): If any response triggers crisis language or clinical concern, escalate to a human immediately.

The presenter promotes teaching AI to her patients, caregivers and parents according to their specific needs. AI can provide information, offer non-judgemental listening and reflection, generate coping strategies and exercises, translate and simplify medical language, help with self-reflection strategies, and support professionals in document preparation.

It is important to note that AI cannot diagnose a mental health condition, provide clinical treatment, detect non-verbal cues and body language, escalate a crisis or call for help on its own. It cannot replace a human therapist. In addition, AI is an equaliser. It is available no matter what continent you live on. Moreover, AI can respond in more than 95 languages. It democratises access to psychosocial knowledge, regardless of geography or income.

IDENTITY AND LIFE STAGES IN BLEEDING DISORDERS

Bleeding and Being Heard: Women and Girls with Bleeding Disorders

Presenter: Amanda Stahl (clinical social worker, United States)

Women and girls with bleeding disorders are typically underdiagnosed. Inherited bleeding disorders affect approximately 1 in 100 people, yet women face disproportionately longer delays to diagnosis. Historically, women have been overlooked, underdiagnosed and undertreated. Consequently, there have been fewer studies on bleeding implications for women.

Bleeding symptoms in women are frequently not recognised as abnormal and are therefore dismissed. This situation is gradually improving. There has been a progressive rise in the numbers of identified women and girls in the WFH annual global survey data, reflecting growing awareness.

US data reflected dismissal across diagnoses in both von Willebrand disease and haemophilia. Repeated reporting of bleeding symptoms preceded diagnosis, which for some resulted in a diagnostic delay of up to 16 years.

The language shift for women with the haemophilia gene was formalised in 2021. This nomenclature removed the term 'carrier' in recognition that women can have a bleeding risk and hence haemophilia. For some women, the term 'carrier' did not reflect a potentially significant medical issue, shaping their identity and downplaying the significance for them and for females in the wider family with the haemophilia gene.

The language shift for women with the haemophilia gene was formalised in 2021. This nomenclature removed the term 'carrier' in recognition that women can have a bleeding risk and hence haemophilia.

Globally, there is huge disparity in delay in diagnosis between women and men. Women are deeply underrepresented.

Approximately 3-5% of haemophilia registrants globally are female, despite an estimate that one in three cases of women with the gene for haemophilia will have significant bleeding issues. High-income populations are well catered for. Regionally, those in low-income regions continue to remain undiagnosed. This impacts maternal mortality, especially in women with VWD.

Stigma for women has a cultural bias in many parts of the world. Menstruation is often treated as private or shameful so is not openly discussed. Heavy bleeding runs in families, so symptoms may appear normal within the context of the family. Health literacy can be low, meaning many women don't know that heavy menstrual bleeding is a medical condition that can be treated.

Even with a diagnosis, receiving treatment can be difficult-especially globally. Unfamiliarity with rare disease, under-representation in research and sexism all delay diagnosis and result in provider bias. Medical consequences of delayed diagnosis are:

- iron deficiency resulting in chronic fatigue and reduced quality of life
- severe bleeding events especially during surgery, childbirth, or trauma
- gynaecological complications such as haemorrhagic ovarian cysts and unnecessary procedures including hysterectomy
- compounding disease burden: missed diagnoses resulting in cumulative harm and worse long-term outcomes.

Through psychosocial input, women can experience emotional support and validation for

the range of feelings, such as anger, grief, relief, that accompany a long-awaited diagnosis.

Trust in the medical system can be rebuilt, and women can become equipped with the language and confidence to discuss their symptoms and self-advocate.

Aging with Hemophilia: Redefining Wellbeing and Independence

Presenter: Jane Portnoy (social worker, Australia)

In her presentation, Jane looked at what makes the difference to maintain a good quality of life. Attitude is paramount—it is important to have meaning and purpose as well as a positive outlook in your life, regardless of your age. Ageing is a natural component of getting old. This can be more pronounced in those with bleeding disorders.

Good life choices are determined by having a positive mindset; working on relationships and connection; committing to self-care; fitness; focusing on mental health, general health; and, for those with bleeding disorders, having regular treatment. To be independent does not mean you have to do everything yourself. Ageing brings learning.

When the Future Is Now: Psychosocial Impact of Gene Therapy and Innovation

Presenter: Sarah Whitaker (clinical psychologist, United Kingdom)

In the UK clinical trials for gene therapy proceeded from 2012 to 2020. There was no psychologist involvement during the trials and minimal assessment of mental health. Gene therapy has been available on NHS for haemophilia B since 2024.

Research has informed three main themes, namely safety and efficacy, identity, and expectations.

Significant unmet psychosocial need became apparent to address the impact of gene therapy on the haemophilia patient community and their families. The need for wide-ranging psychosocial support throughout the entire gene therapy journey was identified. Every stage had its potential complications from pre-therapy assessment and preparedness, along with managing expectations as well as a range of mental health considerations, uncertainty of the outcome and impact on identity post-therapy. A comprehensive approach was developed to address additional considerations.

Various patient examples were cited. Some patients experienced a decline in factor levels post-gene therapy. Gene therapy is a 'once and done' treatment. There is not a second chance if it doesn't work long term. Some patients were ineligible. There was potential for a perception of failure as an individual. For families, there were wider identity considerations relating to unmet expectations from treatment, and uncertainty about the future. Gene therapy families with daughters too required input and consideration as those girls still had the gene or haemophilia. It is now recognised that psychosocial input is relevant to all stages of gene therapy. Longitudinal research is required to track the psychology demand of gene therapy over time.

Different Worlds, Same Diagnosis: Cultural Competence in Psychosocial Care

Presenter: Mohsena Olath (operations manager, Mauritius)

Mohsena cited a range of circumstances where for the person with a bleeding disorder there could be cultural and family consequences. For example, where a couple may be related (e.g. cousins) or where the implications of disclosing an existing bleeding disorder prior to marriage may present a perceived risk to proceeding.

Essentially, she reinforced the reality that two people can have the same diagnosis or condition, but their experiences may be completely different. Her point was that diagnosis identifies the condition, but not a person's experience. Culture, language, family roles, belief systems and stigma shape the psychosocial impact. Psychosocial care needs to be sensitive, responsive to the individual, not simply copied from one setting to another.

Mohsena's closing message emphasised that psychosocial care must be respectful and culturally competent so that people feel understood, safe and included. The result of such an approach means that identity, dignity and wellbeing are supported across the lifespan.

THE HIDDEN PATIENTS: RECOGNIZING AND SUPPORTING CAREGIVERS

Parenting Through Diagnosis: Emotional Journey

Presenter: Alice Oliver Rosa Sacramento (clinical psychologist, Brazil)

Caregivers are the hidden patients. They may experience a range of psychosocial demands related to fear, pressure, stigma, guilt, secrecy, and isolation.

Caregivers are the hidden patients. They may experience a range of psychosocial demands related to fear, pressure, stigma, guilt, secrecy, and isolation.

Alice noted that a new diagnosis is dual diagnosis: the child with the bleeding disorder as well as the parents of a child with bleeding disorders. She discussed the emotional journey of the parents from:

- fear of the child experiencing bleeding

- guilt, especially in families with a history of genetic inheritance
- grief: given idealised plans and perceptions of motherhood or fatherhood that may no longer align
- emotional overload relating to new routines and precautions
- anxiety over processing new information and ultimately hope, given the therapeutic advances which allow the child to live safely.

Changes in the whole family and for the couple were identified. These included parenting challenges such as balancing parental roles and communication, the impact on social life and routines, emotional reactions from siblings and their need for attention as well. For many caregivers, their availability to work and financial issues could also change. For some, the balance between becoming overprotective vs the child's need for independent living became a challenge, at times along with social stigma, or being misunderstood as well as navigating an unfamiliar healthcare system.

Parents often became the educators of others, sharing their information with schools and others to reduce stigma and misunderstanding and to promote safety. Three coping strategies for parents were offered:
- connecting with other parents with shared experiences to gain emotional support and help
- joining patient organisations to gain reliable information, gain a sense of belonging and an avenue for advocacy
- accessing support from the multidisciplinary team.

Psychosocial support for parents changes over time. Ongoing emotional support, education and shared decision-making helps families to adapt, gain autonomy and confidence. With the right support, families can achieve balance, confidence, and quality of life.

Masculinity and Fatherhood in Hemophilia

Presenter: Anthony Roberts (psychologist, South Africa)

Anthony described the main types of masculinity identified by Reinicke, Sogaard, and Mentler in 2019:
- Hegemonic: In Hegemonic, dominance/ power over women and other men prevails. Characteristics such as self-reliance, aggression, competitiveness, autonomy, stoicism, toughness, provider, protector, controller all fit into this realm.
- Complicit sustains a gender hierarchy where benefit is derived from patriarchal dominance. (Most men consider themselves to be in this category rather than Hegemonic.)
- Subordinate is a less powerful position where low socioeconomic status and/or stigma exclude some men from mainstream society.
- Marginalised is where ethnicity and culture may limit participation.
- Protest: in Protest, men embrace risk and destructive behaviour to prove their masculinity. The presenter identified this category as being applicable to men with haemophilia who want to have fun now and worry about the bleed later.

Historically, men have been encouraged to hide vulnerability and to not show emotion, so typically lack the emotional tools to cope with a crisis. Over time changes to gender norms, through education and modelling have, to an extent redressed this imbalance. There can be a hidden imbalance in the father-son relationship where the son has a bleeding disorder. Where hegemonic masculinity is pervasive, the father needs to reimagine his own sense of masculinity. For the father, his acquired notions of masculinity need to be balanced in order to be most helpful to his son as a man. For the man with severe haemophilia, the masculinity challenges can possibly be influenced by stigma if he feels he cannot live up to the hegemonic ideals of masculinity. There may be a sense that their bleeding disorder often prevents them from living up to social expectations as fathers, e.g. to not be able to play high impact sports such as rugby. Other risk-taking activities may also compromise the father's sense of masculinity and magnify his perceived inability to live up to hegemonic masculinity. This can lead to depression.

The rigid hegemonic benchmarking was then followed by a dissipation about a reconstructed sense of masculinity. In this, the father promoted the image where the child was presented with the good done by the father. Their image of their father as an adult then appeared relatively free of any past failures.

In conclusion, the presenter identified three challenges for psychosocial workers:
- working for persons with bleeding disorders, both males and females
- working with young men in a world inundated by hegemonic masculinities
- working with fathers who struggle to express their vulnerabilities.

Who Cares for the Caregiver?

Presenter: Shewetha Subramani (psychologist, India)

Shewetha identified the following challenges for the carer:
- the condition being invisible until too late
- life-long management with no cure
- unpredictability in daily life
- deep psychosocial impact
- significant financial strain
- the carer in the family may be the mother, or father, grandparent, sibling, or spouse.

The speaker talked of the vigilance of the carer, and how their care is not invisible. In haemophilia, the carer is fundamental to the care of persons

with bleeding disorders (PWBD). The caregiver was described as the 'second patient' who filled in where the health system did not. Sleep deprivation and social isolation were reported by more than 50% of those surveyed. The unmet needs of the caregiver included likelihood of clinical anxiety and depression, symptoms of post-traumatic stress, sleep deprivation, and burnout.

Recommended psychosocial support strategies included normalising therapy, peer groups, self-care plans (e.g. 10-minute walk, journalling, music) to rebuild inner strength as well as education to empower the carer and remove fear through building knowledge.

The role of the healthcare system was also discussed. This includes, ideally, screening caregivers for distress, offering pathways to mental health professionals and including caregivers in decision-making. In closing, it was noted that 'Behind every bleed is an unseen burden—let this be the moment we finally acknowledge and support the caregiver.'

Grief, Guilt, and Genetics

Presenter: Gráinne O'Brien (senior clinical psychologist, United Kingdom)

The presentation focused on carers where the identified inheritable bleeding disorders included:

- X-linked recessive (mother must have the relevant variant), e.g. haemophilia A and B
- autosomal recessive (both parents must have the relevant variant), e.g. Glanzmann thrombasthenia, Bernard Soullier syndrome, FXIII, VWD type 3
- autosomal dominant (one parent must have the relevant variant), e.g. VWD type 1 and 2, and dysfibrinogenemia.

The parent's guilt tends to be manifested in their psychological reaction to the diagnosis, e.g. shock, fear, anxiety, and uncertainty. This is followed by feelings of guilt and perception of responsibility (self-blame). Changes in daily life and family dynamics follow, such as changes within the family, adapting to limitations, concerns about education and the child's future. To cope with the condition, carers ideally have access to support mechanisms (individual coping mechanisms given the need for psychological and social support).

Guilt is likely to be experienced by all members of the family to a greater or lesser degree with intergenerational, inherited bleeding disorders. The person with the bleeding disorder can also develop deep feelings of guilt for not having a 'perfect child'. Guilt can build in three layers:

- Anticipatory grief/guilt occurs during pregnancy or on receiving the diagnosis. It is characterised by fear for the child's future and a sense of what aspects of life may be lost to the PWBD.
- Situational grief/guilt is triggered by bleed, hospital visits, and other challenges, which infiltrate day-to-day life. These may be perceived as a 'loss of normal life'.
- Existential grief questions why me and confronts long-term implications for inheritance.

What helps Individuals?

- good information from medical professionals
- ongoing learning about their condition
- peer support: sometimes the most effective support
- doing what works for you as a family.

Psychosocial support encourages open communication, acknowledges and normalises the condition. The aim is to walk alongside each individual and family to understand that person's experience and find out what matters to them. Psychotherapy may enhance resilience and build on strengths.

Overall, there are four key takeaways from the presentation:

- Acknowledge and validate the person's situation through recognition of grief, guilt, and cultural influences as normal and valid responses.
- Educate and understand an individual's perception and experience of genetic situation.
- Seek and offer support by prioritising connections and support systems.
- Empower and advocate to encourage individuals to live fully while respecting their personal needs and circumstances.

From AI to VWD

By **Darian Smith**

Presenting on resilience and recovery, photo courtesy of Amy Bollmann

With other presenters of the Mental Health and Community track, photograph: supplied

AI AND DIGITAL HEALTH

The use of digital and AI technology in healthcare was a theme that came up many times at the WFH Congress in Kuala Lumpur, and it's going to be more of a part of life as we go forward.

The usefulness of AI and digital tech for education was raised in some sessions, with one speaker citing statistics from focus groups that showed only 80% of people with bleeding disorders could name the type and severity, and only 32% could accurately explain the genetic transmission involved. Digital technology could help fill in knowledge gaps and answer many of the standard questions people may have about their or their child's condition.

Digital literacy is important to tap into. A reported 80% of adults in the world own a smartphone, and this could be used to tap into health interventions but engagement with digital health tools is low, possibly because of inadequate local and cultural alignment of the content.

The use of AI chatbots is driving a paradigm shift for health education showing there could be a place for them to bridge gaps in knowledge about a condition. One example was an AI educational chatbot from Senegal that could talk about haemophilia in the local language and was trained to respond accordingly. It was developed in conjunction with local people, and users rated it highly.

Indonesia developed a digital self-screening tool to help identify those who might need further testing from the limited testing facilities available. Based on the answers to a series of questions, the app rates people as high risk or low risk of having a bleeding disorder and recommends further examination accordingly. Given that a person with haemophilia will fare best if they are diagnosed early, this screening tool can help streamline the path to diagnosis.

AI is good at pattern recognition, so there may be excellent uses for it in analysing data and using it to predict bleeds and create personalised plans from the result. Much of this will depend on the thoroughness of the data collected and inputted. AI is also being used to help sequence and recognise mutations in genes and proteins, design recombinant therapies, help management of bleeding around surgeries, and improve treatment adherence.

However, there are serious limitations to consider. There is a scarcity of data to provide the AI for analysis. AI can be unpredictable and results need to be validated by a trained professional to ensure things are correct. There are ethical considerations when inputting patient data into an AI system. The clotting cascade is very complex, and all factors may not be fully known or included in the AI system. Healthcare professionals need to be trained and familiar with an AI system to use it effectively.

The reality, though, is that AI is here to stay and is already part of the medical ecosystem. People

already ask ChatGPT questions about what treatment is appropriate, if a treatment is safe, which HTC they should visit and more.

AI avatars have the potential to support personalised learning with information tailored to the person's language, knowledge level, needs, and goals. They are accessible and flexible and simplify explanations. If they are set up with reliable sources of information, they could provide quality information without taxing the time constraints of clinic visits. This would require limiting the chatbot to approved sources of information. Poor questions or prompts however may produce poor answers, and medical educators would need to supervise.

AI has a lot of positives but also a lot of limitations and should never be considered a replacement for an actual clinician. Ultimately, the comparison given was that medicine should use AI as 'driver assistance, not autopilot', as it can be a tool to keep things on track but cannot be fully trusted to take over.

[Resilience] can also be described as a bucket of water if the water is our ability to deal with the challenges of life. Life's difficulties poke holes in the bucket so the water drains out, and we must find ways to patch the holes and/or refill the bucket fast enough not to run dry.

RESILIENCE AND COPING STRATEGIES

WFH brought me to the congress in Kuala Lumpur to be one of the presenters, and one of the topics I spoke about related to resilience and coping strategies, a topic I consider highly valuable for not just people with bleeding disorders but for all walks of life. It has come up throughout my career as a counsellor and working with people living with genetic disorders, so I thought I'd write up some of my presentation at congress.

Resilience can be described as a battery that stores the energy you have to deal with the challenges of life. The things we do can deplete or charge the battery. It can also be described as a bucket of water if the water is our ability to deal with the challenges of life. Life's difficulties poke holes in the bucket so the water drains out, and we must find ways to patch the holes and/or refill the bucket fast enough not to run dry. Resilience is also like a muscle in that it can be strengthened by successfully lifting a challenge or weakened by under or overuse.

The American Psychological Association defines that 'Resilience is the ability to mentally, emotionally, and behaviorally adapt to challenging life experiences, recovering from adversity, trauma, or stress. It involves flexibility in facing change, managing difficult emotions, and cultivating protective factors like social support, optimism, and self-care to "bounce back" stronger.'

One of the ways that we do this is through our coping strategies. But not all coping strategies are created equally. Unhelpful coping strategies can feel as if they work in the short term but cause more problems long term if you continue to use them. They're often based on distraction; examples include:

- alcohol/drugs
- unhealthy 'comfort food'
- compulsive behaviours such as 'retail therapy', sex, and risky activities
- denial.

Other, more helpful coping strategies can build up resilience and coping capacity with repeated use over time, like strengthening a muscle. Examples of these include:

- mindfulness and relaxation
- breathing exercises
- listening to music
- intentional sensory experiences, e.g. enjoying the feeling of sand beneath your toes and a cat's fur
- humour
- positive self-talk, such as finding ways to reframe a situation or having a helpful mantra
- exercise, good diet, and sleep
- creativity (which could include writing or painting, letting you 'zone out' and process).

An important thing to remember is that we already have many strengths and skills to help us get through challenges, so it's worth taking a moment to identify those and remind ourselves how capable we really are. What other challenges have you faced? How did you get through those? How can you use those skills to face this new challenge? Below are some good steps for coping:

- Get through the moment. Survival mode is okay.
- Identify what you need to be safe and do self-care.
- When it's safe to do so, feel emotions and find an appropriate way to express them.
- Take care of yourself.
- Identify what you want to do about the situation.
- Identify what support would be helpful with this plan and request them.
- Take action—small steps get you there.

EDUCATION AND SCHOOLING

Education and schooling was one of the topics discussed at the pre-congress psychosocial day in Kuala Lumpur. It was acknowledged that education for young people with bleeding disorders is essential. Education is a protective factor in life and a pathway to development. Being at school provides a sense of belonging, peer identity, autonomy, as well as helping

children develop self-management skills, self-esteem, and opens up opportunities for the future.

Unfortunately, a bleeding disorder can bring some challenges when it comes to schooling. Some of those can include:

- stigma, bullying, and isolation
- disclosure and privacy decisions
- absences due to bleeds
- pain
- fatigue
- mobility limits
- activity restrictions
- over-protection or excessive risk-taking.

And, of course, a child with haemophilia or a related bleeding disorder may have other issues not related to the bleeding disorder, for example, family dynamics, economic challenges, body image, and identity.

These complications can translate into development barriers, interrupted schooling due to missed classes, and more. Staff may have anxiety about how to deal with bleeding if they don't have adequate training or education. There may also be the question of the condition being used to avoid tasks.

Counteracting these difficulties may require some adjustments and planning ahead. Adapting physical activities to be more suitable is one way to ensure a child with a bleeding disorder can safely participate. Make a safe physical activity plan and have mobility supports available as needed. Reducing weight can help reduce pressure on joints. Having writing support can be useful. And planning for a graduated return to school after a bleed absence.

Communication is vital between family, child, school, healthcare team, and NGO associations. Approaching support in a holistic way helps ensure the child has the best outcome. A sound communication/information plan with the school should include:

- what must be disclosed vs what is private
- a school point person and backup
- written emergency action plan
- updated contacts
- established regular 'check-ins'.

Support can and should include:

- staff education on signs of bleeds (your outreach worker can help here)
- flexible learning during absences
- accommodations such as time or mobility
- individualised education plan
- psychological support
- NGO/association support, including educational materials and training.

Practical tools to guarantee safety in school are:

- school contact sheet with parents, HTC, and emergency numbers
- one-page action protocol that shows what to do, whom to call, and signs to watch for (keep it short and easy to follow)
- a medical ID card carried by the student.

Remember, your HNZ outreach worker can help you navigate this and educate school staff about your child's bleeding disorder. Don't hesitate to contact us to assist.

A big part of school is about preparing for life after school and a bleeding disorder shouldn't limit this. Starting career conversations early in adolescence helps planning. Focus on interests, strengths, and physical requirements. Support autonomy as much as possible, letting the child take responsibility for treatment adherence and self-management. Preventing school drop-out is important, so early engagement with support services is key.

Remember, your HNZ outreach worker can help you navigate this and educate school staff about your child's bleeding disorder. Don't hesitate to contact us to assist.

VWD

I attended the session on von Willebrand disease at the congress. It was interesting both in terms of learning about the history of this condition and the future. The speakers included Doctors David Lillicrap, Ferdows Atiq, Michelle Lavin, and Caterina Casari.

Dr Lillicrap told us VWD was first described 100 years ago by Dr Erik Adolf von Willebrand, but von Willebrand factor was present as far back as 500 million years ago in hagfish. They used it to make their slime! It would be a long time before it evolved into something used in blood by humans.

Dr von Willebrand's paper in 1926 described families who had several children die because of what would become known as VWD. One teen died after only her fourth menstrual period. Then, a paper in 1971 described the two different molecules involved: FVIII and von Willebrand factor (VWF).

The structure of the VWF has been known for over a decade, but there is still much more to learn. We still don't know everything about how it functions. Some of the major accomplishments in research and treatment of VWD include:

- Recognition that people who menstruate have the major burden of the disease. Over 80% of those enrolled in clinical studies are female. The intrauterine issues and those related to iron deficiency are well acknowledged now.
- Rediscovery and refinement of bleeding assessment tools. Efficient and effective

screening strategy, standardisation of clinical assessment, and justification of lab test ordering.
- VWF gene cloning. This allows better diagnostic refinements and pathophysiological associations. We now know there is a pseudo gene on a different chromosome.
- Improved laboratory assays for VWF function.

And some of the unresolved issues discussed included:
- Enhanced therapies are still in progress.
- Understanding the pathogenesis of type 1 VWD.
- Clinical significance of VWF's other functional roles—there is a role in angiogenesis, innate immunity, and wound healing.

The challenges of diagnosis were also discussed. Often, only those with very low VWF are diagnosed because they present with clear symptoms. Assessment tools need to consider symptoms, family history, age, sex, and other factors to make their assessment. Making diagnosis of VWD includes considering: why are they suspected of having it? What is the bleeding phenotype? Is there a positive family history? Were there any incidentally detected abnormal lab findings? The bleeding assessment tool helps assess risk factors of bleeding issues and VWD. Only some people with low VWF also have bleeding symptoms and are therefore diagnosed. Age impacts the likelihood of abnormal assessment test scores.

50-60% of type 1 patients will increase their levels as they age, so testing is a snapshot on a progression. But those increased levels don't necessarily ameliorate the bleeding. Even if a patient's levels become 'normal' with age, they may still be low for people of their age, so monitoring could still be required.

Naturally, the discussion of treatments is a part of any session about a bleeding disorder, and this one covered both current and future treatment options. The issue was raised that treatment options for VWD seem to lag behind those for haemophilia in both accessibility and research. Some of this is down to a lack of VWD visibility as many more people have it than are diagnosed or registered. There is still a lack of data on how many people are affected by it, and how they are affected by it. VWD needs more priority. Treatments are rarely donated through humanitarian aid, so parts of the world go without, and there's a risk of reliance on cryoprecipitate in lower-income settings.

Current treatments include:
- Desmopressin. If mild, it's suitable. It's not so good for other types; it can make it worse for type 2B. It's intravenous or a nasal spray; it can be used in a limited way only, as using it over multiple days causes issues.
- Clotting factor concentrates (Biostate and others).
- Sometimes administering FVIII as well as VWF is necessary, and there are important differences between getting FVIII and VWF vs just VWF, particularly for planned surgery.
- CFC prophylaxis:
    - o usually only for type 2 or severe type 1
    - o PK-based dosing used to be done for haemophilia but still not fully sorted for VWD
    - o hard to know what levels to aim for
    - o challenges for prophylaxis include:
        - patient burden
        - lack of familiarity and peer support
        - unclear what levels to target for FVIII or VWF
        - expect people 'bleed their way to the right dose' and adjust as we go
        - still seeing the discontinuation and reduction of prophylaxis for VW
- Gastrointestinal bleeding rates are 2.5x regular population and type 2A and B are especially vulnerable. Treatments for this are often difficult and involve infusions.
- Period bleeding treatments include contraceptive hormonal therapy, coil, and tranexamic acid instead of desmopressin.

When it comes to future treatments, the speaker pointed out that research lags behind haemophilia at a rate of 12 studies to 54 in a recent year. VWF has multiple functions and partners, so it may be difficult to find a molecule that covers all these functions. And because bleeding types vary greatly throughout patients with VWD, clinical trials can be challenging.

But some developing options for treatment include emicizumab. Because one of the VWF functions is to carry FVIII, it appears this may be useful for patients with VWD. Ten severe VWD patients received emicizumab off label and resulted in lower bleeding and improved quality of life. Studies are underway to investigate this. There is the suggestion that other FVIII mimetics could work as well for the same reasons.

There are molecules in development, designed to specifically treat VWD. Some of those are:
- KB-V13A12: roughly twofold increase in VWF for ten days after one dose.
- HMB-002: subcutaneous prophylactic. Used for type 1 and type 2 who respond to DDAVP. It would increase the half-life of recombinant VWF and therefore reduce the frequency of injections.
- BT200: developed for stroke. It decreases clearance of VWF.
- VGA039: a rebalancing agent.

Overall, the session was a good snapshot of where we are with VWD, with both exciting developments and disappointing challenges, but there is still work being done.

When the World Comes Together: WFH 2026 World Congress

Photographs by **Hugo Gong**


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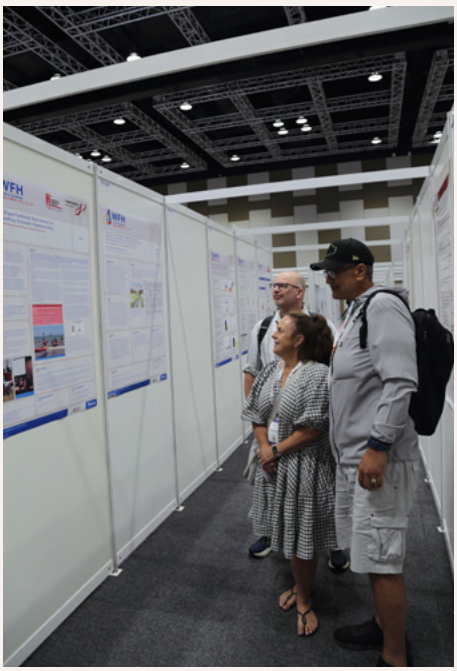
WFH
Haemophilia New Zealand
Creating a Children's Book as a Tool for Education and Support

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Diagnosis
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of von Willebrand Disease
A POCKET GUIDE FOR THE CLINICIAN


What is
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What are
rare clotting factor
deficiencies?


What are
Inherited Platelet
Function Disorders?


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Women and Girls
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Aadyamaatra Artisukma


Datuk Dr. Mahathar Abd Wahab
Director General of Health
Ministry of Health Malaysia


International Lifetime Achievement Award
Winner: Ampaiwan Chuansumrit, MD


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Ask the Experts
MONDAY, APRIL 20 | 15:40-16:10
POD A
WGBD - Low Resource Settings: Accessing WGBD in Rural Areas
POD B
LAB - Bispecific FVIIIa-Mimetics: Essential Knowledge for Laboratories
POD C
PWBD - Sexuality and Intimacy
POD D
MEDICAL - Management of Cardiovascular Complications in Bleeding Disorders
WFH

Teen and Youth Camp: Cultivating the Next Generation

By **Deon York** Photographs by **David Coulson**

Earlier this year, from 30 January to 1 February, around 40 of our members attended the teen and youth camp. We returned to the Sir Peter Blake Marine Education Centre, as it had proved to be a popular choice last time. Much like the adult wellness weekend held in November last year, the sun shone once more for another of our national events, with Auckland's Long Bay glistening in both the sunlight and the moonlight over the entire weekend. Attending the camp gave me a valuable opportunity to hear directly about both the successes and challenges faced by our younger members. Here are some of my highlights from the weekend.

As the name suggests, these weekends are centred on our young members. The weekend was packed with activities to develop skills to live well with bleeding disorders, collaborate, connect, and create bonds that can last a lifetime. Participants were the eclectic mix that you have all come to know as HNZ with onlookers probably wondering how we could all possibly be connected. Little did those on the outside realise that not only is blood thicker than water, but blood can also bind us in other ways, too.

Along with outdoor activities such as kayaking and paddle boarding, participants also learnt about treatment and care, including physiotherapy and exercise. At times, the programme was anything but regular. You may

The weekend was packed with activities to develop skills to live well with bleeding disorders, collaborate, connect, and create bonds that can last a lifetime.

have had to look after a family member or a friend before, but have you ever looked after an egg? I mean that literally. Camp-goers were divided into teams and tasked with looking after an uncooked egg for the entire weekend. What followed was an explosion of confetti, cardboard, random egg repositories, and a whole plethora of inventions designed to protect said egg. The lessons learnt went far beyond appreciating the value of duct tape, and extended to building a team, thinking creatively, and bringing a healthy dose of competition.

The paddle boarding was a very popular activity and was another confidence builder for many. As someone with a respect for the sea, it can be hard to convince me to dip my toes in the water. An activity I did take part in which arguably required a similar level of courage was the taste-testing as part of a 'bake off' held in the evening. Trickery and bribery were rife, ingredients were questionable at times, and I suspect we have several members who may go into marketing when they are older. The judges' (Vanessa, Shamus and I) stomachs must have

The biggest change I can see in these activities is that they were once almost exclusively the domain of boys and young men with severe haemophilia or severe von Willebrand disease. Our activities now see a broader spectrum of participants, including all severities of haemophilia and von Willebrand disease, more girls and young women with bleeding disorders, and greater participation from siblings and parents.

been fortified, as we all emerged from this activity unscathed. It was probably worse for those who cleaned up, with flour, sugar, lollies, and all manner of items strewn throughout the venue.

While Tineke and I did about the tenth run to the supermarket on the final day, I returned to see children and adults hauling themselves up a wall on the last day, enjoying the opportunity to fit in one more activity before being piled on a bus and sent back to everyday life.

The opportunity for others to observe treatment and how it is given is always an educational mainstay of camp events. It builds confidence in treating bleeding disorders. Vanessa and Kaushik from the Auckland Haemophilia Centre talked about care and treatment, and Vanessa stayed for the weekend to look after camp-goers. We truly appreciate both of you devoting your weekend to support us.

If you are new to HNZ, this may be the first time you are reading about teen and youth camp. Others will recognise that this event occurs roughly every two years, and reading about it may seem quite familiar. While there are some familiar activities, topics, and even the venue itself, there are gradual differences.

The biggest change I can see in these activities is that they were once almost exclusively the domain of boys and young men with severe haemophilia or severe von Willebrand disease. Our activities now see a broader spectrum of participants, including all severities of haemophilia and von Willebrand disease, more girls and young women with bleeding disorders, and greater participation from siblings and parents. This demonstrates not only the evolving needs of our members, but also the family team it takes to raise and support a person living with a bleeding disorder.

A review of post-event feedback was positive and, without any exaggeration, many of the participants did not want to go home! Thank you to all the volunteers who contributed to the success of this weekend, particularly our youth leaders. Thank you to Tineke and John for expert volunteering in the kitchen. Appreciation must also go to Roche for its grant contribution to this year's camp.

I used to be an attendee at these camps in my younger days. I cherished many memories as well as close friends I can call my brothers. Now I come in as an adult leader, hoping the younger generation get to experience the same and be someone they can look up to and ask for guidance. I have also noticed, from past to present, there are a lot more women coming into these camps, which is great, as it is not just men that share these blood conditions. I find that these camps have deep meaning to us with these conditions, as we find comfort in knowing people already understand the difficulties we face on a day-to-day basis. This allows us to grow together as people and create wonderful relationships with wonderful people. I hope we can carry on these youth camps, and I'll give it my all to be around as a leader. -Shamus Cross

Teen and youth camp was a fantastic experience this year, I felt that working as part of the 'uncs' was a deeply satisfactory experience. Was such a blessing to give back to the HNZ community, and to be part of a larger team seeing new leaders develop and grow. It's a fantastic opportunity. -Andrew Scott

Cultivating the Next Generation

Photographs by **Deon York**


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93

Dr Elizabeth Berry Exercise Cup: Will You Be the Next Winner?

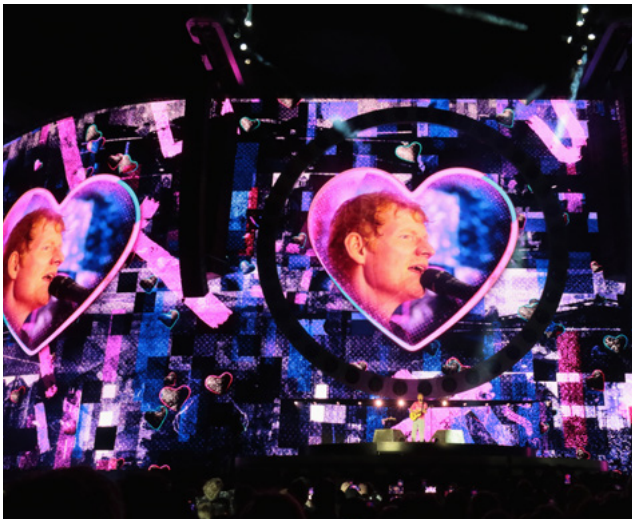
By **Deon York** Photographs by **Hugo Gong**

Steve Waring was the triumphant recipient of the cup at our last Annual General Meeting. Do you know someone who has been keeping up with exercise? Nominate that person today by contacting your outreach worker!

Paint the Town Ed!

By **Deon York** Photographs by **Hugo Gong**

Did you paint the town Ed in January? Once again, we would like to offer heartfelt thanks to Frontier Touring and beaut! for its very generous donation of tickets to the Ed Sheeran Loop Tour in Auckland, Wellington, and Christchurch to our community. Our gratitude also goes to Neil and Trinette Gibborees-Smith for making the connection for us. Our administrator Leanne deserves special mention for tirelessly processing the unsurprisingly high volume of ticket demand from our members and supporters at short notice! Many of our volunteers and members enjoyed the spectacular Auckland, Wellington, and Christchurch concerts.



I See Red:

World Hemophilia Day 2026

By **Deon York** Photographs by **Mike Tame, Michael Ho, and Caitlin Lovegrove**

World Hemophilia Day 2026 did not disappoint with landmarks being lit up red all over the country. The theme of our special day this year was ‘Diagnosis: First step to care'. It underlined diagnosis as the essential first step in treatment and care. While this is no longer a major concern in New Zealand, accurate diagnosis remains critical.

Special thanks to Michael Ho, Grant Hook, Ashley Fowlie, Mike Tame, and Caitlin Lovegrove for capturing some of the red icons this year and sharing them with us.

HOPWOOD CLOCK TOWER
PALMERSTON NORTH

Photograph by Mike Tame

Photograph by Michael Ho

EDEN PARK
AUCKLAND

Photographs by Caitlin Lovegrove

Upcoming Events

2-4 October 2026
Auckland
Strong Women, Strong Bloodlines:
Women's Wellness Weekend

28 November 2026
Wellington
Annual General Meeting

16-18 July 2027
Christchurch
National family camp

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4 WAYS

you can support Haemophilia NZ

Our work on behalf of all kiwis with a bleeding disorder is only made possible with your generous support.

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1. Your **membership** helps us do more

You can join or renew your membership at **haemophilia.org.nz**

2. Leave a **lasting legacy**

Honour the memory of a loved one, or recognise the special bond you have with HNZ by leaving a bequest on your will.

Find out about leaving a bequest at **haemophilia.org.nz**

3. **Make a donation**

We are always very grateful to receive your kind donations at any time. You will find a “Donate Now” button on our home page at **haemophilia.org.nz**

4. Read Bloodline online at any time

Reading Bloodline online saves trees and us money!

You will find the latest issue at **haemophilia.org.nz**

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