Haemophilia
New Zealand

Bloodline

JUNE 2025
VOLUME 53 | NUMBER 1

There's no place like home

Contents

The purpose of this magazine is to provide a wide range of accurate and timely information on all aspects of haemophilia and related disorders. Haemophilia is a dynamic specialty and therefore opinion may change or be varied from time to time.

Cover photo by **Deon York**

H **Word**

The ties that bind: Community, collaboration, and care

Welcome to our latest edition of Bloodline. As we look back on the last few months, it's clear we've been part of something special—both here in Aotearoa and across the globe. This issue is all about the power of connection, whether it's through international partnerships, local events, or simply sharing space with people who understand your journey.

This issue takes you from the global stage of the World Federation of Hemophilia's Comprehensive Care Summit to the heart of New Zealand's own family-focused initiatives, to an inspiring twinning partnership, strengthening bleeding disorder treatment and care in Pakistan. And at the centre of it all, a long-anticipated milestone: the opening of our new office, a physical space that symbolises not just an organisation's growth, but the strengthening of a community's voice and vision.

Let's take a look at what's been happening, and what lies ahead.

STRENGTH IN WHĀNAU: WAITANGI WEEKEND FAMILY CAMP IN NGĀRUAWĀHIA

Closer to home, our family camp over Waitangi Weekend in Ngāruawāhia was a real highlight. It had been a long time since many of our families were able to come together like this, and the joy was obvious from the moment everyone arrived.

There were practical workshops—like introductions to bleeding disorders, the importance of oral health, experiences of parents with older children and an opportunity to meet and talk to clinicians—but also plenty of fun. Games, activities and shared meals helped build friendships and community.

A HOME OF OUR OWN

After over 20 years of planning, fundraising, and dreaming, we are thrilled to announce the official opening of Haemophilia New Zealand's new office in Lower Hutt. It's taken many years and the hard work of many, many people to see this become a reality. This development marks more than a physical relocation—it is a symbol of consolidation, stability, and new possibilities.

Located in a central and accessible area, the office will serve as a hub for advocacy, support, education, and outreach. It will house a small but dedicated team and

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provide a welcoming space for community gatherings, workshops, meetings and events. Already, it has become a place where stories are shared, where challenges are met with solutions, and where ideas for the future are born.

This achievement belongs to every member, donor, volunteer, and partner who believed in the value of a home base for our mahi. We extend our heartfelt gratitude to those who made it possible—and invite all of you to come visit, whether for a kōrero, a cuppa, or to dream with us about what comes next.

BUILDING GLOBAL MOMENTUM: THE WFH COMPREHENSIVE CARE SUMMIT

The World Federation of Hemophilia's Comprehensive Care Summit brought together clinicians, patient advocates, researchers, and policymakers from across the globe. The summit reinforced the foundational principle that comprehensive care is the gold standard for people living with bleeding disorders.

New Zealand was well represented, with voices from our community contributing to important discussions on equity, accessibility, and innovation in care. As gene therapies edge closer to broader implementation and new models of care delivery emerge, the summit reminded us that while scientific progress is critical, it must always be matched by an unwavering commitment to patient-centred approaches.

TWINNING ACROSS BORDERS

In this issue, we share updates from the youth twinning with Pakistan. The Pakistan twinning story is just beginning, but it's already full of promise. We've been working closely with HFP's youth to identify the biggest challenges they face and have already facilitated virtual educational sessions with experts from New Zealand.

This partnership underscores that twinning is not a one-way transfer of knowledge or aid. Instead, they are mutual journeys where all parties grow through exchange.

IN CLOSING

As you move through the pages of this issue, we hope you feel the momentum that's building. From the global to the local, from policy to the personal, each story reflects a piece of the vibrant tapestry that makes up our bleeding disorders community.

Whether it's the courage of families navigating daily challenges, the dedication of healthcare professionals innovating in their fields, or the solidarity shown across borders through twinning, one thing is clear: our strength lies in our connections.

In 2025 and beyond, Haemophilia New Zealand is committed to continuing the work that binds us—strengthening care, supporting families, and standing in solidarity with the global bleeding disorders community. Together, we move forward.

Ngā manaakitanga,
Hemirau Waretini
Chair

CE **update**

Just a few pages into this edition of Bloodline, it is clear that this has been a very eventful six months, and we are galloping ahead. Not only do we have a new home, but we are also excited to share with you our new-look Bloodline! Since our December issue, two national events have been successfully held, regions have been connecting, and the office fit-out has finally been completed, not to mention the momentous occasion of recognising this by officially blessing and opening our permanent home for Haemophilia New Zealand.

This has been the culmination of years of fundraising, dedication, and determination to achieve this long-held vision for our organisation. Our national activities are also set until 2027, giving you plenty of time to register!

At the recent office opening, our Patron, Dr Elizabeth Berry, inspired us all with her recollections and reflection of the organisation, both past and present. We have included a full transcript of her speech in this issue. Dr Berry also announced this as her last engagement as Patron. This was bittersweet, and I am very interested in who could possibly fill such big shoes. In fact, I think this is an impossible task. Elizabeth, thank you for your ongoing dedication to us all, and I look forward to catching up with you to discuss a future Patron.

April saw several landmarks across the country light up red for World Hemophilia Day 2025, provoking a focus and conversations pertaining to women and girls with bleeding disorders both among our members, and across the world.

I recently presented a strategic plan for Haemophilia New Zealand to the board for the coming years. Our constitution dictates our purpose, but how we deliver our mission adapts to the changing environment. We are in the context of reduced funding sources, proposed tax reform for charities and not-for-profits, a reforming health system, and the changing needs of our members.

As with any vision, we must all be both creative and pragmatic. I am keen to hear from our younger members, our 'masters', Piritoto, and the regions. What do you see for our future, and how can we best serve our members? What do we think will make the biggest positive impact?

The staff, board, and regions are planning for an eventful year with a focus on best serving the members of this special community. We look forward to seeing you at one of the many planned events.

Deon York
Chief Executive

National Family Camp 2025 offers something to everyone

Our youth leaders ensured that everything ran smoothly.

Around 100 campers descended on Ngāruawāhia in February, eager to connect with their bleeding disorder family. The experience was everything you would expect from a big family reunion, but it might have been a bit challenging to work out the family tree.

By **Deon York**

This year's camp, held across Waitangi Weekend, was a success from both the fun and education perspectives. Following the success of the family camp in 2023, we decided to return to the same venue and run a similar educational format with various activities. We covered 'haemophilia 101', exercise and nutrition, impacts of a bleeding disorder, and a 'meet the experts' panel. The panel was the most valued among all the educational sessions.

MEMBER FEEDBACK IS ALWAYS VALUED AND BENEFICIAL TO PLANNING THE NEXT EVENT. BELOW ARE SOME HIGHLIGHTS:

'Honestly! I enjoyed every single part about this CAMP!'

'Everything was the best! No doubt'

'We are super grateful for the opportunities, activities and education that was provided for us. Thank you for all the time and effort you put in!'

'We really appreciated how seamless and smooth it all went. Everything seemed very well thought-out'

'We really appreciate all the effort put into making camp a great experience for all of us'

'Keep doing what you're doing!'

'ME AND MY FAMILY WILL MOST DEFINITELY SEE YOU ALL AGAIN ON OUR NEXT CAMP!!'

'You guys do a fantastic job organising and planning for us and I really appreciate and am glad I could somewhat take part to help give back'

'Great teamwork, they looked out for each other's safety and that of the members and their families'

Wrangling an almost complete group photo was no mean feat.

For the parents of people with severe and moderate haemophilia A, being able to discuss the experience of using emicizumab together was invaluable. Families also appreciated understanding the pipeline of therapies available for other factor deficiencies.

Alongside activities such as kayaking, flying fox, quiz night, and tearing up the dance floor on disco night, a visit to the Hamilton pools, zoo, and gardens was also an option, which led to a very eventful few days.

Suggestions for the future included more information on von Willebrand Disease, making sure the adults stay out of mischief (rather than the kids!), and convening with the weather gods to turn down the heat!

Thank you to the staff for making this possible. A special thank you to the unstoppable Tineke (and her family) who worked tirelessly to make this event a success. Finally, we would like to express our heartfelt gratitude to Roche for its support of family camp 2025.

The flying fox (above) and Hamilton gardens (below) were a hit.

The staff team smiled all the way through camp.

Painting the town red for World **Hemophilia Day 2025**

Did you paint the town red on 17 April? We did! Several landmarks across both the North and South Islands lit up red to support World Hemophilia Day 2025, shining a spotlight to raise awareness.

The World Federation of Hemophilia (WFH) chose Access for All: Women and Girls Bleed Too as this year's theme. Women and girls with bleeding disorders remain underdiagnosed around the world. Through increased recognition, diagnosis, treatment, and care, the quality of life of women and girls will improve, and the entire community will be better for it.

While a red landmark may be obvious, bleeding disorders, particularly among women and girls, can remain invisible either through lack of diagnosis or recognition. The work continues to ensure equitable access to treatment and care for all people with bleeding disorders. Our heartfelt gratitude to Christchurch City Council, Palmerston North City Council, Wellington City Council, and Eden Park for your kind support; it means a lot! Last, but not least, many thanks to Bayley, Darian, and Ashley for the stunning images.

Palmerston North Clock Tower.
PHOTO BY ASHLEY TAYLOR-FOWLIE.

BELOW: Eden Park, Auckland.
PHOTO BY DARIAN SMITH.

Christchurch Cathedral.
PHOTO BY BAYLEY CORFIELD

LEFT: Armstrong Lawn, Christchurch.
RIGHT: Vaka 'a Hina, Christchurch.
PHOTOS BY BAYLEY CORFIELD.

Bridge of Remembrance, Christchurch.
PHOTO BY BAYLEY CORFIELD.

There’s no place like home: Our permanent space officially opens

A home is often thought of as a place you live permanently, a place where you can be yourself, a place where you feel connected, secure, and surrounded by the people and belongings that matter to you, hence the saying ‘there’s no place like home’.

By **Deon York** Photos by **Caitlin Lovegrove**

We describe our new permanent space as a home because it represents so much more than merely a national office – it is a place where all of us belong, and where all of us can connect, reminisce, and plan for the future. Finding a permanent home has been many years in the making. We were poised to purchase property in Christchurch just prior to the first major earthquake. The property of interest at that time was flattened. However, the quest continued until we found the ideal property in late 2023, completed a fit-out and finally opened its door to welcome our members this year.

It was a crisp and blue-skyed late morning in Alicetown, Lower Hutt on 10 May. Around 20 members along with staff gathered in the office car park to await local iwi

LEFT: Erica Burke with Hemi under our shiny new logo.
RIGHT: Deon talking about the past, present, and future of HNZ.

LEFT: Patron, Dr Elizabeth Berry, cut the ribbon to officially open our offices.

RIGHT: Elizabeth and Karl Archibald enjoying a lighter moment.

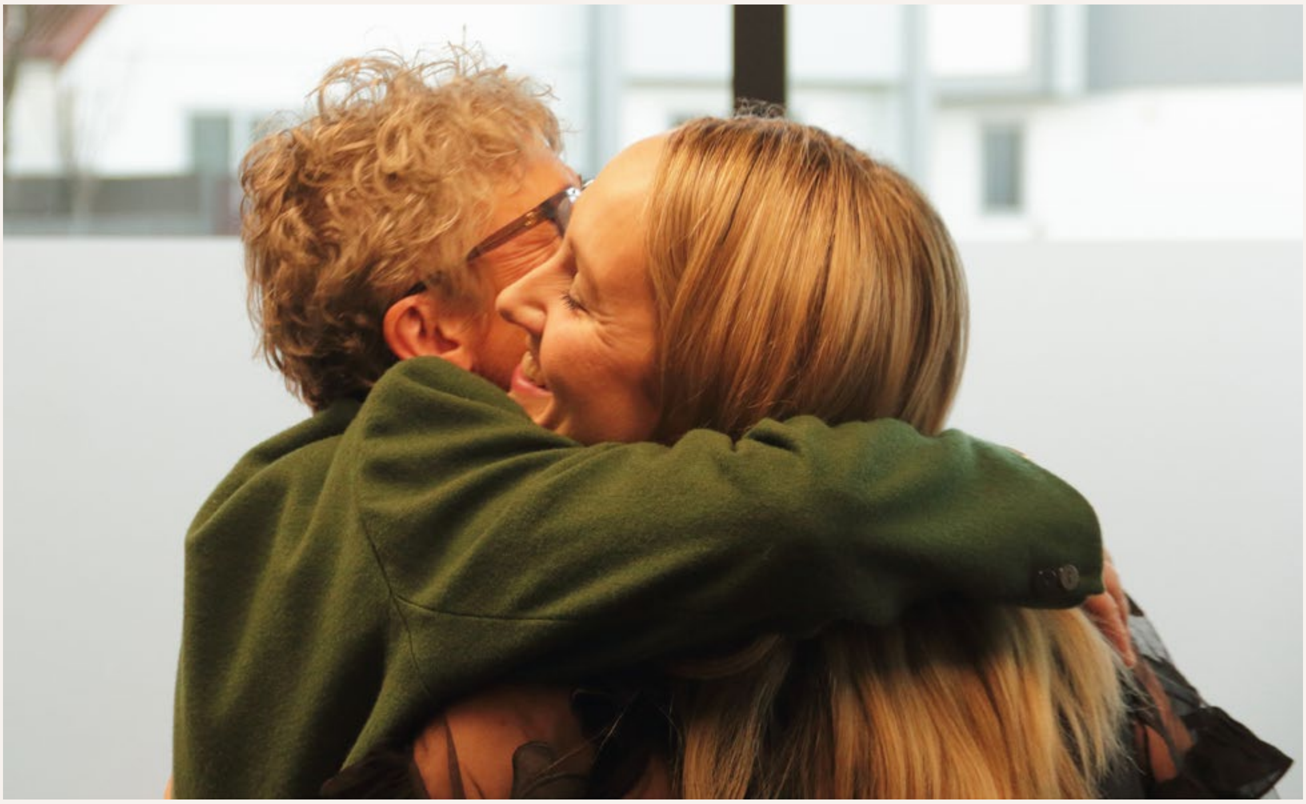
representative Tame Ngaheke (Te Ātiawa) from Waiwhetū Marae. As he arrived, a circle naturally formed as the blessing of the office was explained. Next, following Tame and our whaea and Patron, Dr Elizabeth Berry, we entered the office, single file. We were encouraged to touch the walls as we circled around all the spaces of the office and karakia were delivered. With the blessing of the office concluded and prior to kai together, members recounted their stories of our organisation, particularly the impact of Dr Elizabeth Berry on their life. This was incredibly moving and was an apt start to officially opening a permanent place to call home for Haemophilia New Zealand.

As the sun went down, the dim red lights grew brighter and around 50 members across the country arrived throughout the evening, passing along the red carpet and joining an evening celebration to officially open the office. As more people piled in, the murmur of conversation rose to a crescendo, and the evening passed in a flash.

Remarks were shared by chair, Hemirau Waretini, chief executive, Deon York, and our past-chair, Mike Carnahan, via a pre-recorded video message. Our Patron, Dr Elizabeth Berry shared a special message with guests. Members also recounted many stories, which have all contributed to shaping the organisation today.

LEFT: Deon and Karl rolling out the red carpet.

RIGHT: Nev Reedy and Ian Reddie.



Fond reunions dominated the evening's festivities.
Lisa Habershon and Lauren Phillips embrace.

As the night progressed, merriment ensued, photo albums were further strewn across the office, and voices echoed throughout the new space. Reaching this milestone for our organisation is significant for all members, be they present or not.

The decision to purchase a permanent space was not simply about having a national office once more, it was realising the long-held vision following the amalgamation of branch funds to one national account in 2005 when the Charities Act required one account for entities like ours. Members agreed that the only apt use of many years of dedicated fundraising would be to find a permanent home for the organisation. Twenty years later, we have finally achieved this vision. Thank you to everyone who made it possible.

Special mention to Caitlin Lovegrove for being a volunteer event photographer, capturing this special occasion and its precious moments.

Ian exploring the archives.

Amy Bollmann and Ashley Taylor-Fowlie from the Central Branch ready to celebrate.

Official office opening: **Mike Carnahan's reflections**

We share a transcript of Mike's reflections on the opening of the national office.

GREETINGS TO YOU ALL.

Apologies from Cheryl and myself with respect to our non-attendance. For Cheryl the Air New Zealand timetable would have given her but one hour at the event. For me now in a wheelchair, Air New Zealand travel out of Nelson, results in extreme difficulty and risk in loading and unloading.

We are both delighted to see a project identified early in this millennium as being necessary for Haemophilia NZ's future, has now been achieved.

Haemophilia NZ now represents a number of bleeding conditions, and we all recognise these conditions can be multi-generational. Therefore, a permanent base for the organization, on which we all depend, will be needed for some generations to come until our troublesome genetics can be resolved. For all of us in NZ, the primary reasons for progress in haemophilia medicine has been access to world's best clinical practice on a home-based care model. This model directly involves patients, clinicians, funders, and manufacturers in all practice and supply.

Mike Carnahan, former HNZ president.

This model, developed from our rocky past of HIV, HCV, precarious blood-based products, no prophylaxis, no national delivery system, and insufficient resources for a NZ wide oversight from clinicians.

This model must not be lost or hijacked and requires continuous oversight, and liaison. To facilitate this, I believe we will need a national meeting place where the organisations involved in our care model can be invited to visit and talk.

So, congratulations to the management committee on achieving the long-term plan.


Haemo
Office
10 May 2

Official office opening: Patron's remarks

We share a complete transcript of Dr Elizabeth Berry's remarks on reaching the milestone of opening a permanent space for the organisation.

Thank you for your kind introduction, Deon. It's wonderful to see so many old friends as well as new faces at this auspicious and exciting occasion, the opening of our very own building. As your patron I wish to give you a very warm welcome.

This has been a long-term ambition of Haemophilia NZ, and it was a pleasure to be here this morning at the blessing of this splendid new building. I am particularly pleased that there is now space to liberate and display all our taonga, precious archives so long in storage. They document all the many amazing and important achievements of this group since the NZ Haemophilia Society was first established in 1958.

This rich history came to mind when I was musing on what I might say today. I think the Māori proverb 'Ka Mua Ka Muri' or 'looking back in order to move forward' is particularly apt. That for me is a very long time, 55 years, actually. So, I'm going to begin by looking back at some of the events and accomplishments, which, I think, have been most important in the care of people with bleeding disorders, and to remember and celebrate some key people who have played a major role.

First, Sir John Staveley known as Jock who established the Blood Transfusion Service in NZ. Jock was still looking after in-patients scattered through medical wards when I came back in 1970. The only treatments available were plasma and cryoprecipitate and he used to encourage the donors to run around the domain to increase the factor 8 yield! Playboy magazines had a similar effect and there was stack of those available too! Jock maintained a life-long interest in the haemophilia community and was your first patron.

This rich history came to mind when I was musing on what I might say today. I think the Māori proverb 'Ka Mua Ka Muri' or 'looking back in order to move forward' is particularly apt.

In 1974 a Haemophilia Centre was established at Auckland Hospital. This was a major collaborative effort between the NZ Haemophilia Society, treaters, and the blood and transfusion service. With a nurse, haematologist, and other interested specialist staff we were able to offer a comprehensive care approach. Then, as small volume concentrates became available, self-therapy at home became practical. The emphasis shifted to quality of life!

NZ has also played an increasing role on the world scene through the World Federation of Hemophilia. For me, attending the 1976 Congress in Kyoto was a great joy and relief.

The centre served a wider function though – as a hub, a place to meet, a place of belonging. Over the years centres were established in other major cities.

The next milestone was the first haemophilia family camp held in Auckland in 1976. It was an initiative of Jan and Tony Goodwin in answer to the many requests for information and support, especially from geographically isolated families - 40 people attended. We self-catered; I still remember Elizabeth Wheeler's wonderful potatoes grown in the black sand of Bethell's Beach and John Milne with his long crutches presiding over the kitchen. There was a mix of fun, learning to self-inject, confidence building, and networking. It was also a great opportunity for staff to see families out of hospital enjoying themselves socially.

This format has worked well ever since and now there are many focused and smaller workshops and weekends for different groups. I am so pleased that there are sufficient older men about to warrant their own group and that girls and women with bleeding problems are recognised too. I still think this camp model is the most effective way to educate and support families. I certainly feel that it is one of the most important and enjoyable things I have been a part of. But you know all this already and share my enthusiasm, judging by the many happy reports and photos in Bloodline. Incidentally, NZ pioneered the family camp concept later adopted in many countries. A contribution we should be proud of. Thank you to the Goodwins.

Next is the Education Trust or ACEET established in 1979. It was named after dentist Alan Coster whose wry sense of humour and giant toothbrush at camps were always a favourite. Since then, about 80 grants have been given for a wide variety of purposes such as coaching for younger students, music courses, tertiary fees and job changes. For example, Leon traded IT for wine making, Stace swapped sport coaching to become an electrician and Dylan got a heavy truck licence to drive the truck rather than lifting heavy boxes.

NZ has also played an increasing role on the world scene through the World Federation of Hemophilia. For me, attending the 1976 Congress in Kyoto was a great joy and relief. I found experts in all aspects of haemophilia care including product suppliers as well as people with haemophilia and they were all in one place. Contacts were established – so important in pre-email days.

Being the sole representative and trying to cover all the different sessions was a major challenge though- I felt like a one-armed paper hanger!

The WFH became even more important to us during the AIDS crisis providing up to date information and support and later, help with political lobby. This unique and important organisation serves the whole world, and I am very proud of NZ's many contributions in recent years. Members have given papers chaired meetings, our nurses have run workshops, and we have taken part in twinning programmes. And as you know, Deon York's contribution as a Board member and on many committees has been major, resulting in his being given the 'volunteer award of the year' in 2024.

With such excellent products and coordination of care nationally through the National Management Group, haemophilia treatment has advanced substantially.

He has also held roles in HNZ for 25 years - a formidable record of service for which we are most grateful. Our heartfelt thanks, Deon.

Next come the disasters of viral infection in the blood supply, HIV in 1983, and hepatitis C finally identified in 1990. It was a devastating time for families and an enormously stressful, worrying and busy time for everyone including staff. Memories of the paperwork pile have faded but the people have not.

They were so courageous and resilient, often with wry humour. The one good thing to emerge is that blood and plasma products are now safer than ever for everyone.

I want to salute Mike Mapperson, Mike Carnahan, and Steve Waring for their persistence, immense work, and their willingness to be the public face of haemophilia then, and for achieving success in obtaining compensation for Hepatitis C. The Mikes have also been Presidents, and both have been ACEET trustees. Mike Carnahan was also responsible for the decade plan and the very successful first Australasian Congress. Steve is our long-time fundraiser supremo. A huge thanks to you all.

And now with the availability of recombinant therapy and drugs such as Hemlibra we are in an era of once fortnightly SC injections for many of you. With such excellent products and coordination of care nationally through the National Management Group, haemophilia treatment has advanced substantially. The collaborative involvement of key players – patients, government officials, and medical staff has proven to be highly effective and must remain.

Is HNZ still required? Definitely, 'yes'. I cannot overemphasise how crucial I believe it is to maintain the presence of a strong and active Haemophilia Foundation in the future. Education will be even more important as people need less contact with the Centres and will have less ability to recognise a bleed. New babies will continue to be born and families to need support. As well, there will always be a need to maintain a strong political visibility as bleeding disorders are resource intense.

The opening of a new building is the most wonderful way to finish my role as your Patron. The Haemophilia Foundation is in fine shape today thanks to the tireless work, resilience and dedication of your many volunteers and staff. You have all done a marvellous job.

My long journey with you has been fascinating, intense at times, rewarding and enjoyable. I look forward to following your further activities through the excellent Bloodline and Pānui publications. Thank you and enjoy your new building.

Pakistan youth twinning off to a **promising start**

The Pakistan and New Zealand Youth Twinning is off to a promising start. Our first online gathering via Zoom served as an icebreaker, allowing members from both countries to meet informally, share personal stories, and begin building the trust essential for a successful partnership.

By **Connor McCone**, youth delegate

The second session shifted to skills-building with an advocacy workshop led by our very own bleeding disorder advocacy champion, Deon York. Deon shared his vast knowledge in advocacy, and we were incredibly grateful for him taking the time out of his own life to join us!

I recently spoke with Wajiha Javaid, Pakistan's twinning coordinator, who reports that the Pakistani youth group has rated the experience extremely highly so far. Our next meeting will focus on psychosocial support details and a date to be confirmed shortly. We look forward to deepening the connection between our groups and equipping participants on both sides with the tools they need to thrive as future advocates.

If being involved with this twinning programme interests you, feel free to reach out to me!

> **I recently spoke with Wajiha Javaid, Pakistan's twinning coordinator, who reports that the Pakistani youth group has rated the experience extremely highly so far.**

Reflections from Dubai:

Growing the Next Generation of Bleeding-Disorder Advocates at the 2025 WFH Global Youth Leadership Training

Amongst Dubai's late April heat, myself and 19 other young leaders within the worldwide bleeding disorders community gathered for the 2025 WFH Global Youth Leadership Training. We had travelled from every corner of the globe, from Atlanta in the States, Amsterdam in the Netherlands, Freetown in Sierra Leone and the beautiful Kirikiriroa Hamilton. Fresh after attending the summit, we were motivated to unite to achieve a common goal.

By **Connor McCone**

Over two tightly packed days, the World Federation of Hemophilia (WFH) offered far more than a crash course in organisational skills. Day one opened with Hemophilia of Georgia's Deniece Chevannes and Alesha Wright, who treated "effective communication" not as a buzz-phrase but as a lifeline. Their session pushed participants to translate personal narratives into strategic messages, stories that resonate with donors, governments and, crucially, with newly diagnosed families searching for hope. Laptops snapped shut, phones were switched to silent, and we practised our advocacy pitches in real time, learning to pair clinical facts with the emotional clarity that moves policy - in the long and short, basically how to spin a good yarn using data and facts.

Their session pushed participants to translate personal narratives into strategic messages, stories that resonate with donors, governments and, crucially, with newly diagnosed families searching for hope.

Youth participants gathered from all over the world in Dubai for the 2025 WFH Global Youth Leadership Training

If the morning honed the message, the afternoon expanded its reach. Patrick James Lynch from Believe Limited, himself a filmmaker with haemophilia, delivered a masterclass on marketing for advocacy. Between anecdotes about shooting documentaries in hospital corridors, he demonstrated how a single TikTok clip, filmed with sincerity, can travel further than a white paper ever will. The subtext was unmistakable: in a short attention economy, authentic lived experience is irresistible currency.

Day Two shifted focus to project management. South Africa's Bradley Rayner and WFH's Salome Mekuzla walked attendees through the disciplined art of proposal writing, SMART goals, and monitoring-and-evaluation plans. Later, Clive Smith of the UK Haemophilia Society offered a sobering lesson from the Infected Blood Inquiry, underscoring why rigorous governance and fearless transparency must sit at the core of every patient organisation.

Overall, it was an absolute privilege to be selected for the WFH Global Youth Leadership Training. I'm deeply grateful to Hemophilia of Georgia and the WFH for making it possible.

To the youth of HNZ: if this programme interests you, get in touch with me at youth@haemoplilia.org.nz, you might find yourself at the next training in Malaysia!

News from **Paxton Mills**

Paxton Mills spent the first half of 2025 at the University of Otago studying abroad for one semester. Paxton shares her impressions of our community and her work with the National Bleeding Disorders Foundation in the United States.

My name is Paxton Mills, and I am a biochemistry and molecular biology student from the United States studying for the semester at the University of Otago in Dunedin. I am a volunteer and Youth Representative to the Board of Directors for the National Bleeding Disorders Foundation back in the US, as well as an active volunteer and committee member for my local chapter, the Virginia Hemophilia Foundation. I am also a lived experience expert (LEE) with a rare platelet disorder.

While I have been here in New Zealand, I have been very excited to get to know the wide variety of community members and employees who make Haemophilia New Zealand successful and to expand the lens through which I both view and approach the bleeding disorders community at an international scale. I have felt very much welcomed and have enjoyed the productive and engaging conversations I've had regarding the similarities and differences our countries face in bleeding disorders care, treatment, and diagnostic journeys. This has been supplemented by being able to observe the partnership between New Zealand and Pakistan through the World Federation of Hemophilia's twinning program, and I am excited about future opportunities to engage with, learn from, and contribute to our global bleeding disorders community. I am hopeful to see some of my New Zealand connections in Malaysia in 2026 for WFH's World Congress!

Paxton Mills at the National Bleeding Disorders Foundation Conference in the United States.

Back in the United States, I am wrapping up my last few months as part of the National Youth Leadership Institute (NYLI), a professional development program designed to help prepare passionate and engaged young adults for meaningful, long-term engagement within the bleeding disorders community. The NYLI program and my overall involvement with NBDF have equipped me with the tools to confidently move forward in my journey to become a hematologist helping to diagnose and treat bleeding disorders. NBDF has granted me several opportunities to speak publicly, whether at their annual Bleeding Disorders Conference (BDC) or through the virtual Wednesday Webinar program. As part of the NYLI program, I was able to partner with the research department on a project investigating the time to diagnosis in bleeding disorders patients on the basis of birth sex. I've had the opportunity to travel around the country for their events and hear stories from individuals, providers, families, researchers, and leaders that have resonated with me and confirmed my direction and pursuit of this career path.

It's no secret that youth engagement is often a tricky subject for our community. I would encourage all young adults to consider getting involved in the bleeding disorders community, whether at the local, national, or international level. Regardless of where your specific interests lie, the bleeding disorders community has something for you through a wide diversity of programming offered in education, advocacy, policymaking, research, medicine, and public outreach. By participating, you'll have the chance to make new connections, practice public speaking, and most importantly, share your story. You never know who you might meet or where that engagement might take you. Incredible opportunities wait for you if you choose to get involved!

Regardless of where your specific interests lie, the bleeding disorders community has something for you through a wide diversity of programming offered in education, advocacy, policymaking, research, medicine, and public outreach.

Building and nurturing resilience in children with hemophilia

RESILIENCE IS BUILT NOT BY LUCK BUT THROUGH INTENTIONAL PARENTING

by ***Jared Formalejo*** | June 25, 2025

Growing up, I was coddled – constantly protected from the world, from pain, and often, from myself. My parents loved me deeply, but understandably, fear sometimes ran the show. Decisions were made for me. I wasn't encouraged to speak up, take risks, or manage my condition.

They meant well. But I'm still wrestling with the impact of being so heavily guarded: difficulty with self-care, hesitation to assert myself, and the feeling that independence is something I have to earn, not something I deserve from the start.

Now, as a parent, I see that same instinct in myself. I have the urge to protect, to prevent, to do everything. But I also know how much that can cost. My goal isn't just to keep my child safe; it's to raise someone confident enough to live their own life, with hemophilia as part of the picture, not the whole frame.

RESILIENCE IS THE SKILL THAT MAKES THAT POSSIBLE.

Resilience is built, not given

Resilience isn't about "bouncing back." It's the ability to navigate difficulty, manage stress, and adapt over time. And it doesn't appear in a void. One way resilience is shaped is through repeated experiences guided by the adults closest to the child:

- with manageable challenges given at the child's pace
- in a safe environment where mistakes are allowed
- amid dialogue with the child about choices made.

That's a learning technique called scaffolding. When parents step in too fast or too often, kids miss the chance to learn they're capable.

BUILD CONFIDENCE THROUGH COMPETENCE

A child's belief that they can handle their condition, what psychologists call self-efficacy, strongly forms motivation to mental health. To build self-efficacy in hemophilia care:

- Teach them what's happening. Use clear, honest language about hemophilia. Don't oversimplify. Facts create clarity and reduce fear.
- Let them participate. Even small tasks like helping prep an infusion or tracking symptoms give them ownership.
- Guide, don't fix. When problems come up – "What if your ankle hurts at school?" – ask them what they think they can do. Help them brainstorm.
- Normalize trial and error. Learning doesn't look perfect. When something doesn't go well, walk through it together without shame.

The more control kids have over their own care, the more empowered they feel.

HELP THEM BUILD STRONG CONNECTIONS

Isolation is a real threat for children with chronic conditions. They may feel like the only one and that feeling of "otherness" can lead to withdrawal or shame. Parents can help counter that by providing empathetic social support as a buffer against stress and teaching them to process negative emotions rather than suppress them.

- Practice open communication. Talk about your emotions. Let them see how you manage stress or fear without pretending everything's fine.
- Validate their feelings. Let them express frustration or sadness without rushing to fix it. "That sounds really hard" goes a long way. The Gottman Institute provides advice on how to approach these conversations.
- Connect them with peers. Whether through camps, local groups, or online communities, being around others with hemophilia makes a difference.
- Teach them to advocate. Don't always speak on their behalf. Show them how to explain their needs to teachers or friends. Let them try, even if it's awkward at first.

These experiences build social confidence and a sense of belonging – two key ingredients for resilience.

NURTURE HOPE WITHOUT SUGARCOATING

Kids living with chronic conditions need honesty, but they also need hope. Not the empty kind, but the kind built through action and intention.

Here's how to cultivate that:

- Practice gratitude. Try simple routines like "What went well today?" at dinner or bedtime. These small habits of gratitude build a lasting resilience, research shows.
- Celebrate who they are, not just what they manage. Notice their creativity, kindness, or curiosity. Don't let their condition be their defining feature.
- Keep your language grounded. Don't catastrophize. Say, "Let's take care of this," instead of, "This is serious." Your tone shapes their internal voice.
- Recognize progress. This goes back to self-efficacy. Whether it's a self-infusion or speaking up at school, celebrate effort and growth, not only outcomes.

Joy and confidence aren't naive. They're protective.

Model what you want them to learn

Resilient kids often come from homes where resilience is visible. That doesn't mean being unbreakable. It means being honest, regulated, and willing to take care of yourself, even when it's hard.

Parents need support, too. Chronic illness in the family is draining. And if you're constantly depleted, your child will feel that, even if you think you're hiding it.

Take breaks. Ask for help. Talk to someone. Let your child see that self-care isn't selfish. It's responsible. And when they watch you manage hard days with compassion and structure, they're learning how to do the same.

REMINDER: STRENGTH ISN'T JUST ABOUT PROTECTION

Keeping a child safe is part of the job. But helping them become strong, capable, confident, and in control is just as important.

I didn't grow up feeling empowered. But that gap showed me exactly what I want to give my child: tools, not just protection. Independence, not just oversight. The ability to say, "I've got this" and mean it. That's the heart of resilient parenting. Not doing everything for them, but teaching them how to do things for themselves – and reminding them, over and over, that they can.

Source: https://hemophilianewstoday.com/for-the-caregiver/research-backed-tips-teaching-resilience-children-hemophilia/

Clinical trial's 13 years of follow-up: gene therapy is effective, safe for hemophilia B

By ***Ulrike Reiss, MD, Andrew Davidoff, MD, Andrew Moreno*** - Last Updated: July 1, 2025

The follow-up data from a 13-year clinical trial evaluating a gene-transfer-based gene therapy approach for treating hemophilia B were recently published in *The New England Journal of Medicine.*

Watch on YouTube: https://youtu.be/hbJRKZRxcEw

Heme Today spoke with two members of the investigative team who conducted the trial; principal investigator **Ulrike Reiss, MD,** the director of the Hemophilia Treatment Center at St. Jude Children's Research Hospital, Memphis, Tennessee, and **Andrew Davidoff, MD**, chair of the Surgery Department and the director for Surgical Research at St. Jude.

The treatment agent assessed in the clinical trial was scAAV2/8-LP1-hFIXco, an adeno-associated virus (AAV)-mediated gene therapy. The vector was administered as a one-time intravenous (IV) infusion to ten men who had severe hemophilia B. The study team then monitored this cohort over 13 years.

In terms of circulating clotting factor IX expression in patients, the results the team observed from the gene therapy, over the long-term monitoring of the cohort, were encouraging. Dr. Reiss and Dr. Davidoff described how the clinical benefit associated with the single infusion persisted over the 13-year follow-up period.

"The significant finding was [that] the activity of the replaced clotting factor lasted for the duration of the study without really declining over time. That's the first time that long-term successful gene therapy has been achieved," Dr. Davidoff summarized.

Illustrative of these positive long-term factor IX effects was that several patients in the cohort with severe disease, who required once or twice weekly IV factor IX infusions, were able to discontinue such infusions and remain off them over the 13-year follow-up period. Another positive development was the clinically meaningful, sustained decrease in bleeding rates that the patients experienced.

"This treatment has taken off a lot of burden of the disease for all these patients, all 10 participants, even the patients who still continue prophylaxis have had significant benefit with reduction in their bleeding rate and reduction in having to treat with additional factor any bleed events during that time," Dr. Reiss elaborated.

The investigators each highlighted that the results demonstrated the safety of the gene therapy vector treatment, with no significant toxicities or side effects observed over 13 years of follow-up.
Source: https://www.docwirenews.com/post/clinical-trials-13-years-of-follow-up-gene-therapy-is-effective-safe-for-hemophilia-b

Upcoming events

31 October-2 November 2025
Wellington
Wellness weekend

30 Jan-1 Feb 2026
Auckland
Teen and youth camp

Late 2026
Women's wellness weekend

21-24 January 2027
Christchurch
National family camp

CONTACTS

National office

44 Victoria Street
Alicetown
Lower Hutt 5010

info@haemophilia.org.nz
www.haemophilia.org.nz
Free phone: 0508 FACTOR (322867)

Chair:
Hemirau Waretini
hemi@haemophilia.org.nz

Chief Executive:
Deon York
ceo@haemophilia.org.nz

Communications Manager:
Phil Constable
comms@haemophilia.org.nz

Administrator:
Leanne Pearce
03 371 7477
admin@haemophilia.org.nz

Southern Outreach:
Vic Turner
03 371 7485
vic@haemophilia.org.nz

Central Outreach:
Lynne Campbell
04 382 8442
lynne@haemophilia.org.nz

Midland Outreach:
Loren Silva
07 856 4442
loren@haemophilia.org.nz

Northern Outreach:
Darian Smith
09 845 4658
darian@haemophilia.org.nz

4 WAYS

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