Bloodline

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Haemophilia Foundation of New Zealand Inc. HFNZ

Bloodline

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THE H WORD

All too often we are so focused on the plans ahead that we don't take the time to look back, reflect on our achievements, and celebrate how far we have come. Our upcoming 60th anniversary celebrations are the time to do just that.

Keepers of our history will know that HFNZ was officially formed on 13 May 1958 at the Lower Hutt town hall. This year's celebrations are looking back on the past 60 years. The celebrations will span two days: on Friday 8 November from 5.30 p.m. to 7.00 p.m., a welcome reception will be held at the Grand Hall in Parliament, and on Saturday 9 November from 6.30 p.m. to midnight, we will host a gala dinner at Te Papa Tongarewa Museum of New Zealand. International guests attending the celebrations include the president of the WFH and the regional manager for the Western Pacific region. There are also related events happening around the same time. A youth workshop is planned from 6 November (also in Wellington), and there will be a von Willebrand's get together on Saturday 9 November, prior to the gala dinner.

We have already had a positive response to registrations, but there's still time! Email rsvp@haemophilia.org.nz for more information. These celebrations are for you, the members of HFNZ.

Let's all celebrate, together!

Deon York
HFNZ President

From the CEO

BY SUE ELLIS

It has been seven months since I started in this role back in November last year as CEO for the HFNZ.

I want to share with you my impressions, my aha moments, and the challenges of a new job as I have come to know the Foundation and its people.

The first month or so as I began to get an understanding of the systems and structures, and purchasing the required technology was a huge challenge. I have worked from home under my own business for many years so I felt comfortable in this space. However, getting on board with HFNZ's systems, getting all the right technological tools to make my life smoother took time. However, there were aha moments when it all seemed to come together!

It has been a joy getting to know the team and to realise what a great bunch of very professional people they are who care so much about what they do. My best moment in those early days was getting "Lovely Leanne" back on board! Thank you Leanne who has made my life so much easier.

I have done a lot of travelling around the country meeting with staff and getting to know their work space and their regions, chairing staff meetings in Wellington, undertaking staff performance reviews, attending meetings, including Council meetings, Piritoto Hui and attendance to the National Family Camp which was awesome!

I was also very fortunate, after only two months in the role, to attend the Annual Global Haemophilia Advocacy Leadership Summit in Brussels, courtesy of the Bayer pharmaceutical company. This was a very informative meeting, which gave me so many insights to bleeding disorders and the many challenges of getting access to the right evidence-based treatment. Something I am so very familiar with in my previous roles.

Now as I look towards the next six months it's about making sure we have the best-planned celebrations for the 60th anniversary of the Haemophilia Foundation of New Zealand in November 2019.

National Family Camp 2019

BY PHIL CONSTABLE

The biggest and most popular event of the HFNZ calendar is the national Family Camp. In April HFNZ headed back to Camp Keswick in Rotorua for this excellent camp. This was a great opportunity for our young families to connect with others from around NZ, to participate in some fun social activities, and to learn new skills and information in the educational sessions. By all reports, it was another raging success.

Image: making a splash at rainbow Springs

NFC 2019

On April 16 2019, families from around New Zealand came together in Rotorua for the 2019 HFNZ National Family Camp.

This event is perhaps the most important in our calendar. At the National Family Camp parents get to connect with other parents in the same situation as them, new families get to see the levels of support available to them, children get to mix with other kids with bleeding disorders, while staff and clinicians are able to mix and mingle with members on a less formal level. It is an essential starting point for many conversations and a lifetime of belonging and acceptance.

This year's version was no different in many respects. The children were able to participate in a variety of new experiences, and the parents were able to make new contacts, reinforce old ones, and learn new things.

This was also the first Family Camp AC (after Colleen). Colleen McKay had run our camps for over 20 years. This time Nicky Hollings took the reins, and she did a fantastic job! We had plenty of really positive feedback, particularly around the relaxed atmosphere, and Nicky's ability to adjust the programme to suit the needs of the participants. Awesome work Nicky!

It was great to be able to get the children off-site to enjoy some activities. Operating in three groups, the crèche, 4-7 year-olds, and 8+, Outreach staff and our amazing youth leaders were able to take the children to visit Rainbow Springs, and the Redwoods Treewalk. Also, a small group went out at night to see the Rotorua town centre lit up red for World Haemophilia Day. These were all very successful outings, and a great opportunity for our children to try something new.

Images top to bottom:
Fun at Rainbow Springs; Sue, Julia Phillips, and the Pharmac reps; Checking out the wildlife; Connecting with other parents.

NFC 2019

The children were also involved with on-site activities, including a movie night, newspaper fashion design, outdoor games, and arts and crafts.

While the kids were otherwise engaged, the parents were able to forge new connections, support one another, and learn new things. Over the course of the weekend we had a number of sessions covering everything from managing life changes, to a Mum's afternoon tea. A big thank you goes out to the following for the sessions they presented, and the time they spent supporting our people:

- Lynne Campbell – Parent introductions
- Cat Pollard – Physiotherapy
- Julia Phillips – New treatments
- BJ Ramsay – Haemophilia
- Maureen Campbell – vWD and rare bleeding disorders
- Pharmac – The latest treatment-funding round
- Ross Paterson – Managing life changes
- Deon York, Catriona Gordon, and Karl Archibald – All about HFNZ
- Andrew Scott, Zac Porter, Karl Archibald, Catriona Gordon, and Benedict Larkin - Our Ask the Experts panel

Also to Amber, who wrangled the youth leaders, making sure they were in the right place at the right time, fed, and watered.

Images top to bottom:
Infusion practice; Games night ;Rotorua lit up red for World Haemophilia day; The leaders kept the kids entertained.

Piritoto Noho Marae

BY IAN REDDIE

2019 marked the 10th birthday of HFNZ's Piritoto group. From a small beginning, Piritoto has become a strong advocate for Māori in HFNZ, and a guide for the foundation. It is to their credit that they remain the only indigenous bleeding disorder group in the world. Piritoto marked their anniversary with a noho at Te Tahawai marae in Auckland.

Image Waiata practice

Ko Ian Reddie tōku ingoa. I have made it to level 46 in life, and have a 10 year old son, Nate, who also attended the Noho with me. I have severe Haemophilia A, and in the 80s I got a couple of special presents from treatment in the UK, as a lovely double cherry on top. I was very lucky to come under the care of Dr Ed Gane and his amazing team in the early 2000s and with their help and treatment cleared Hep C after 18 months' hard slog on Ribavirin and Pegylated Interferon. I haven't been engaged too much with HFNZ lately, but as I have enrolled at Victoria and begun studying Te Reo Māori, I figured it was time to get back and reconnect and share my experiences and learn from other people and what they have been through as well.

On 6 July and 7 July, I attended the Piritoto marae noho for the first time. This wasn't my first time on a marae, and I am embarrassed to say that, as my son and I travelled up a day earlier and stayed with whānau, we were late and missed the Pōwhiri! Not a great start. However, although we were late, everyone was incredibly welcoming, and I immediately felt comfortable and at ease.

We started with an introduction where we had to choose to be a bird and tree, which got the brain engaged immediately. I went with the Tui and the Harakeke.

The programme was varied, well structured, and engaging. Everyone participated and came up with some really cool ideas that I hope to see implemented in some way shape or form in the not too distant future. There were many common and shared experiences across a varied mix of attendees, and I definitely came away from this noho filled with empathy, passion, and a drive to continue all the work that has been laid down over last 10 years, to create a meaningful partnership with HFNZ to empower and support all its members.

A real highlight for me, apart from the amazing food over the weekend (shot Hemi and Amber!), was a live theatre show that we attended as a group, called Aroha is a Māori. The subject matter was very fitting and relatable, but mostly massively entertaining! Nate loved it as well, first time he has been to a live show that didn't involve music, so I was very happy he enjoyed it too!

I also really enjoyed meeting new people, and reconnecting with Te Whainoa. We had a long catch-up that got me buzzing about reconnecting with HFNZ, Piritoto, and being of service in any way that I can.

I want to thank Rosalie, Tuatahi and Hemi for the great job they did running the Noho without a hitch. Thanks to Amber (or mangōpare) too! I am busing learning the waiata for the next Noho, which I can't wait for!

Ngā mihi,

Ian.

Images top to bottom:
Hemi and Sue
Very happy about birthday cake
Work time

HFNZ 60th Anniversary

BY PHIL CONSTABLE

WE'RE ALL LOOKING FORWARD TO THE HFNZ 60TH ANNIVERSARY CELEBRATIONS,COMING UP IN LESS THAN THREE MONTHS!

Plans are starting to come together for the HFNZ 60th anniversary celebrations in Wellington in November.

This is an important opportunity for us to celebrate the outstanding work done by members, staff, and supporters over the last 60 years. Without the courage and commitment of those men and women, we wouldn't be where we are today, with a strong voice, and world-leading comprehensive care.

It is also a chance for us to look to the future. To consider what the next 60 years might be like, for our people, and for HFNZ as a whole.

Here's what we're looking at so far:

On Friday 8 November, we will have a welcome reception at parliament, and we are very lucky to have member of parliament Chris Hipkins hosting this event. There will be local and international guests speaking, and we'll all get a chance to reconnect.

If you plan to attend this event, please be aware that, as it's happening in the parliament buildings, there will be security procedures to go through before you enter the event.

The main event of the weekend is the Gala Dinner on Saturday 9 November. This will be held at Te Papa Tongarewa, and will include members, past and present staff, and special guests. Here you'll have the opportunity to mix and mingle with HFNZ people, past and present, and we promise we'll keep the speeches to a minimum. The band will be playing, so you can dance the night away.

As well as these two events, the youth committee are also running an event on Saturday afternoon as part of our youth twinning with Nepal.

This is to be an 18 years and over event, and there will be a small fee attached to attendance. For those that don't require flights and accommodation the fee will be $50 per person, $100 per person for those who do.

Everyone was sent an invitation, either via the post or by email. RSVPs were due by August 5 at the latest, so that we could organise flights, accommodation, catering, and seating. However, if you haven't managed to reply yet, it might not be too late. Contact leanne@haemophilia.org.nz to check where things are at.

The HFNZ team looks forward to meeting and greeting you at this wonderful event.

HFNZ 60th Anniversary

Wellington
November 8 - 10, 2019

Register Today

hfnz60.lilregie.com

Haemophilia Foundation of New Zealand Inc.
HFNZ

New Treatment for Kiwis with Haemophilia

BY PHIL CONSTABLE

This year Pharmac announced the preferred suppliers for haemophilia treatment medication for the latest funding round. For people with haemophilia, that supplier is Takeda. They'll be offering an extended half-life product, as well as a standard half-life product, and one or two special features.

As most of you will know, Pharmac recently announced the preferred suppliers for haemophilia A and B from the latest funding round. Takeda will be supplying long-acting Adynovate and standard half-life Advate to the majority of those with haemophilia A, and standard half-life Rixubis for Haemophilia B. The extended half-life product Alprolix from Sanofi-Aventis will be supplied for haemophilia B. Most of our members will change to one of these new treatments, unless there's a sound clinical reason not to.

It's fantastic that our people are now able to access treatment with an extended half-life. It means fewer infusions, and a better quality of life. A win we can all celebrate.

Most treatment centres are transitioning members to the new product at their regular haematology clinic appointment. What this change means is that we're all going to have to adjust to using a new medication.

Many of you will remember using products from Baxter or Shire, that used a similar delivery method to the new Takeda haemophilia A treatments. Takeda are working extra hard to get people up to speed, distributing info on the products and the way they're used.

Both the new haemophilia A treatments use versions of the Baxject II reconstitution device. Regular for Advate, and high-flow for Adynovate. These are really easy to use, as long as you follow the instructions. There's not much that can go wrong with these devices, and there are very good troubleshooting guides that accompany each device.

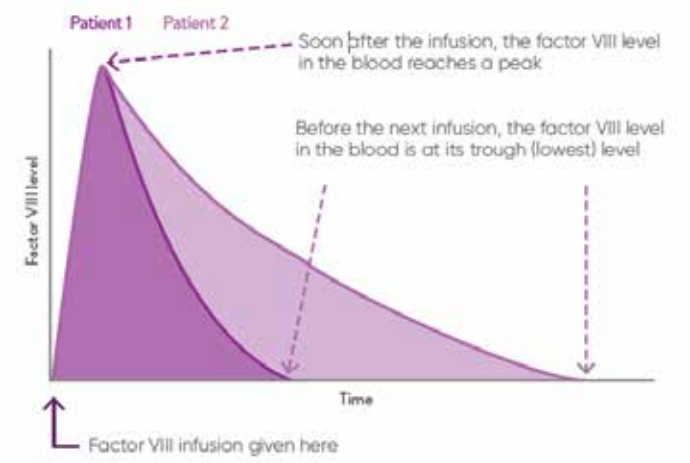
BAXJECT 11 Hi-Flow Device

Takeda have all sorts of fantastic documentation to support the roll out of these new treatment products. If you're being transitioned to one of them, you'll be given all the info you need to make it easy, and set your mind at ease. If you'd like to get the info sooner, or if you haven't received it for some reason, feel free to reach out to us at info@haemophilia.org.nz, and we'll make sure you get what you need.

As well as the new treatment, Takeda also have a couple of other interesting and useful things up their sleeve.

The first is myPKFiT.

You may know the term pharmacokinetics or PK for short. PK is the way in which a medicine moves into, through, and out of your body. After an infusion, the level of factor in your blood rises rapidly, and then falls more gradually. Also known as your PK profile, this rate of rise and fall is unique to you.

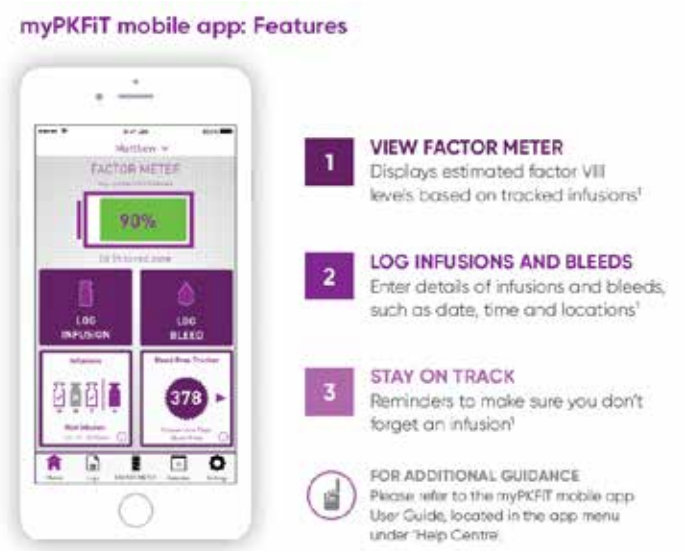


Hypothetical PK profiles for illustrative purposes.

Estimating your PK profile can help your haematologist's understanding of how long factor will stay in your body after an infusion, and when your peak and trough levels will occur. Using this information, your haematologist can set your factor-dosing schedule to suit you.

myPKFiT is software used by haematologists. It works by looking at personal characteristics that your haematologist inputs, as well as your personal factor levels measured from as few as two blood tests, to estimate your individual PK profile. The haematologist can then personalise your factor-dosing schedule.

That brings me to the second useful thing.



Using Takeda's myPKFiT mobile app, you can track your estimated factor levels in real time by recording your infusions and any bleeding events, and it will remind you when you have an infusion due. Using the app, parents will be able to keep track of their children's treatment, and young people will have a path to greater treatment independence.

The roll out of the new treatment products, and the associated software and app are underway now. If you have any questions about the new products, reach out to your clinician.

Piritoto - Pōwhiri Tikanga Māori

BY TUATAHI NIGHTINGALE-PENE

In New Zealand, official events and gatherings are often started with a powhiri, a Māori ceremonial process where the hosts welcome the visitors, and establish their intentions. There will be a powhiri at the HFNZ 60th anniversary celebrations. Here, Tuatahi Nightingale-Pene lets you know what to expect.

Image: At Te Tahawai marae

E rau rangatira mā, nei rā te mihi kau atu ki te hunga kai-panui

Hello, Bloodline readers!

In the next few issues of Pānui, Piritoto will be explaining the segments of Pōwhiri – Formal Welcome process. This will be in the form of a 'how to guide' to help whanau who might find themselves being a part of the Pōwhiri process.

The pōwhiri (or pōhiri) is a process whereby the host party will welcome visitors on the marae. Understanding the Pōwhiri process, we first must understand why the Pōwhiri exists. The fundamental aspect can be broken down mainly in two parts. 1. a process where the two parties, (i.e. the host & visitors) come together as one, acknowledging people's ancestors. 2. finding out the intentions of the two parties whether they are friend or foe.

Every marae has their own kawa (protocols) and tikanga (rules). 'Kawa' is seen as a set of protocols that outline certain processes. Tikanga is a Māori concept with a wide range of meanings — culture, custom, ethic, etiquette, fashion, formality, lore, manner, meaning, mechanism, method, protocol, style.

Tikanga is generally taken to mean rules, it is derived from the Māori word tika meaning 'right' or 'correct.'

Pōwhiri can be outlined with the following steps:

1. Karanga - You will hear the karanga (welcome call) from a woman of the hau kainga (local people). The manuwhiri (guest/visitors)begins to advance and return the karanga.
2. Wero - The wero (challenge) may be issued by a male warrior from the hau kainga. This determines the intentions of the visitors.
3. Haka Pōwhiri.
4. Karakia - A person from the Hau Kainga will perform a karakia to begin the proceedings.
5. Whaikōrero - Once the Manuwhiri are seated (men in the front, women seated behind), the whaikōrero (speeches) take place.
6. After each whaikōrero, a waiata (song) is sung to show support for the speaker.
7. Koha - Sometimes a koha (a monetary gift) is given by the visitors.
8. Hāriru / Hongi - Once whaikōrero and waiata are completed, the Hau Kainga and manuhiri come together to hariru (shake hands) and hongi (press noses).
9. Kai - A hākari (meal) is then shared. This signifies the end of the Pōwhiri and lifts the tapu of the sacred part of the ceremony.

The Pōwhiri is about reciprocation, about validating relationships, and honouring visitors and hosts. It is a formal welcome carried out on the marae by the hau kainga (local people) to welcome manuwhiri (visitors) who are meeting for the first time. The lifting of tapu (sacred spiritual restrictions) and uncovering the intentions behind the manuhiri's visit were always brought to light during pōwhiri.

HFNZ Policy: Complaints

BY PHIL CONSTABLE

Our CEO, Sue Ellis, has begun the process of updating HFNZ's policies. One of the first to be updated is our complaints policy.

If you have a complaint about anyone associated with HFNZ, the first step is always to address your complaint to the person concerned. We think that it's only fair that the person being complained about gets a chance to clear up any misunderstandings, and an opportunity to sort things out personally. That means either get beside the person you have an issue with and discuss it personally, give them a call, or send an email outlining what you think the problem is.

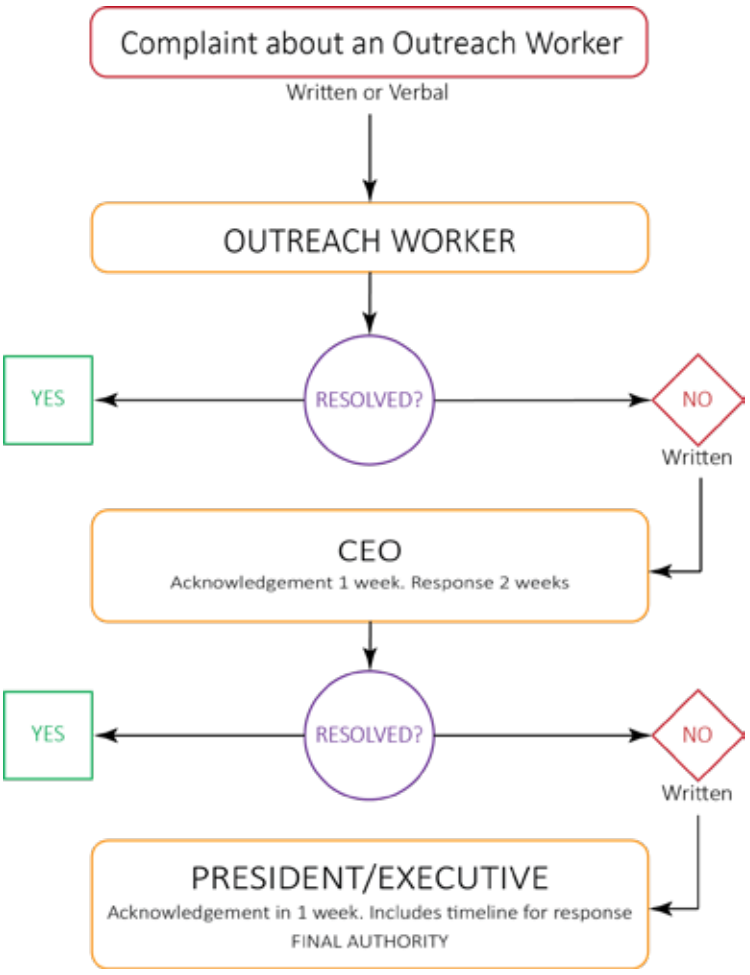
We believe that good open communication is the best way to sort out most issues.

Of course, sometimes the nature of the problem means that it's not appropriate to discuss your complaint with the person concerned. In that case, move on to the next step in the process.

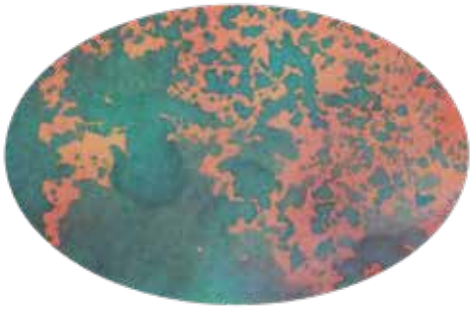
If you don't get the result you want after talking to the person concerned, the next step is to refer the complaint to the CEO. Sue will listen to your complaint, discuss it with the person concerned, and decide what, if anything, needs to be done to resolve the impasse. She'll work on getting the issues resolved as quickly as possible, to everyone's satisfaction. The expected time-frame for resolution at this stage is two weeks.

If, after you've tried discussing the matter with the person concerned, and the CEO has attempted to resolve the issue, you're still not happy with the outcome, the final step is take the matter to the HFNZ president. The president will look at the issue and what steps have been taken to resolve it, talk to the parties involved, and make a determination. Again, the expectation is that this will happen within two weeks.

Below is a handy flowchart illustrating the process. While this chart refers to complaints about Outreach, the process is the same for other groups.



New Haemophilia Book



EARLIER THIS YEAR A NEW BOOK ABOUT HAEMOPHILIA IN AOTEAROA HIT THE SHELVES

Earlier this year a new book about Haemophilia in Aotearoa hit the shelves.

This work, entitled *Haemophilia in Aotearoa New Zealand: More than a bleeding nuisance,* is the product of many years of work and research, and represents a fantastic perspective on living with haemophilia in New Zealand, and the wider haemophilia landscape.

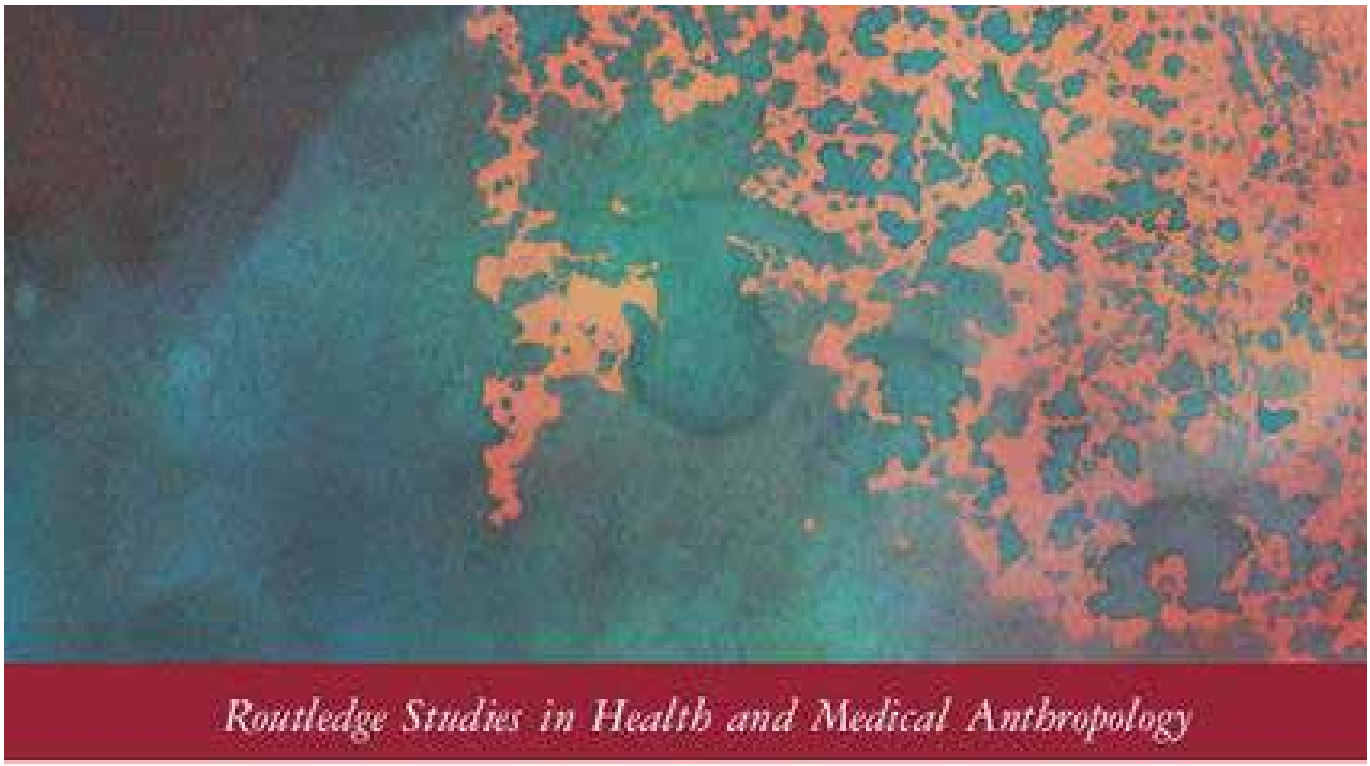
This book, whose authors include Prof Julie Park and Dr Kathryn M. Scott along with HFNZ President Deon York and former president Mike Carnahan, has been on the way for quite some time, and now it's finally available to purchase. You can order the book from most good booksellers.

To make it accessible to everyone, HFNZ President Deon York has suggested that members in each area go into our local libraries and request a copy. Our understanding is that if more than six people request it at each library, it will be added to the purchase list. Alternatively, for those libraries that support it, you can ask for an electronic version instead.

Your help with this would be much appreciated.

To give you a flavour of what is in the book, here's an excerpt from the opening chapter:

Through our stories of the experience of haemophilia in Aotearoa New Zealand we explore key issues of our time. These include questions such as 'How should we respond to the new and developing issues associated with treatment of genetic disorders; issues such as gene therapy and selective reproductive technologies?'. Some issues are situated at the level of the state, such as, 'How should the government's health budget be allocated and health services be organised to care for or cure those with expensive or rare disorders?' and, 'How can patient groups make a difference to health systems?' or, 'What are the state's responsibilities to its citizens when things go badly wrong in its health provision?'. And some are deeply personal: 'How and when do I tell my becoming-partner that I have a genetic condition, or hepatitis C?' or, 'Should I have a baby, knowing that it may have a serious genetic condition?'. Some questions are specific to Aotearoa New Zealand, such as, 'What has Rugby got to do with haemophilia?', and 'What does this genetic condition reveal about this society and culture?'.



HAEMOPHILIA IN AOTEAROA NEW ZEALAND

MORE THAN A BLEEDING NUISANCE

Julie Park, Kathryn M. Scott, Deon York and Michael Carnahan

Walking in the Port Hills

BY ROSS PATERSON

Kia ora. Ross here, your Southern Outreach Worker. In the last edition of Pānui, I spoke of the fun that Kyle Cunnningham and I get from taking a stroll in the Port Hills. Many in Christchurch are unaware of how readily available a great morning or afternoon hike is, with the Port Hills just a quick drive or bike ride away.

A number of people indicated that they would like to join Kyle Cunningham and myself for the first walk in the Port Hills. So, a decision was made, and the first walk took place on the last Sunday in July. Kyle got out in advance a couple of weekends earlier and walked the track, just to make sure it was suitable. We consulted with Lee Townsend and Kathy Fawcett, to make sure we weren't biting off more than we could chew, and that our members would be ok. And we were good to go!

This was a great opportunity to get some fresh air, snap some lovely views, and keep the physio happy all in one! The smiling faces you see here are the first participants of HFNZ's inaugural "Bloody Big Walk"!

Righto, so where did we go? The walk started from the Huntsbury Ave car park, took us along the edge of the Summit Road above Bowenvale Park, skirted around Sugarloaf, and ended up at the Sign of the Kiwi, where we indulged ourselves with a cuppa and a treat. A big thank you to the local Lions club, who offered to transport us back down to the car park.

This really was a fantastic outing, and one that we're looking at repeating on the last Sunday of each month. The walk is relatively low-impact, the company is sparkling, and the health benefits are manifest.

Check out the glorious images we captured along the way...

If you're looking for a bit of exercise, and you're in Christchurch for the last Sunday of the month, feel free to join us. The next walk is set down for 25 August. You can find out more by emailing me, ross@haemophilia.org.nz, or Kyle, mrcunninghawk@gmail.com or by keeping an eye on Pānui each month.

We'd love to see you there.

Ngā mihi,

Ross

Region group reports

HFNZ's Regional and Group committees enable all our members to participate in the running of the Foundation, and to connect with and support one another. Each Region and Group runs a number of events through the year, to help educate their local members, to make sure that support goes where it's needed, and to have a little bit of fun. Here's what they've been up to recently.

CENTRAL REPORT

By Stephanie Coulman

The central region held a concurrent dinner in Wellington and Palmerston North to celebrate World Haemophilia Day. A concurrent dinner is two dinners happening at the same time in different places (as aptly described by our Communications Manager, Phil Constable).

We had a great turnout at both venues, and it was wonderful to meet some members attending their very first events. This tied in well with the theme for this year – 'identifying new members of the bleeding disorder community'.

We chose to host the event at restaurants serving Nepalese-style cuisine to align with the Foundation's youth twinning event in Nepal.

We've also almost held our Men's fishing charter on three occasions. As our readers will understand, Wellington is not known for consistent fine weather. We've had high winds or storms on our three attempts to hold the charter and had to postpone. However, Central men are a resilient bunch and we're not letting this get us down. We have a core group of fisher/men who are looking forward to the trip. The charter is rebooked. We hope the Wellington weather will be more predictable.

We had our AGM at the Carter Observatory in Wellington on ii August. We are always keen for new members to join our regional committee so if you're interested – please reach out.

MIDLAND REPORT

By Tineke Maoate

Hope everyone is keeping well and warm this winter.

It's been a very quiet time in the Midland region this year. We are planning an event at Tauranga Ten Pin bowling on Sunday 1 September. This will be a family event, so hopefully you can all show up. A good friendly competition between us all, followed by with a good lunch.

With the 60th celebrations in November we won't be having a Christmas event this year, but are planning a January/ February summer event.

I look forward to catching up with you all either in Tauranga or in Wellington. Look after each other and keep warm.

SOUTHERN REPORT

By Zac Porter

Kia ora HFNZ whānau,

The Southern region has had a very busy past few months, which has culminated with our annual fundraising play and a youth event to Scared Scriptless.

The annual fundraising play was entitled Original Sin, and was again produced by Brick Road productions. The play was based on an unsettled marriage and provided many laughs. We had an excellent turnout and it was wonderful to see all of our HFNZ community supporting the region. We raised a total of $1946.90 which was a great effort, and the committee would like to thank everyone who supported this evening.

The Southern region also held a youth event where we had a pizza dinner and attended Scared Scriptless, an improvised comedy show put on by The Court Theatre. The evening was great for getting the Southern youth together, the pizza was top notch, and the show was hilarious too.

We look forward to putting on more events for you in the not too distant future!

News from around the world

STRUGGLING WITH SELF-INFUSION

By Shellye Horowitz

I have a confession: I hate to self-infuse. I am really bad at it. Well, at least most of the time I am. The multitude of blown and missed veins over the past few years have synthesized to wholly deflate my confidence with this critical skill. ¬

Rural hemophilia

I live in a rural area. My nearest hemophilia treatment center is over six hours away. No hospital in my county stocks my factor; I must have my own supply.

I moved here almost four years ago. A few months after I moved, I tripped and fell at 3 a.m. on the way to the bathroom (a whole 20 steps away from my bed). I landed hard. The hard landing was a wake-up call. What was I to do if I hurt myself at night or on a weekend and needed factor VIII replacement? I wrote to my hematologist the next day, and she set me up with a specialty pharmacy. The pharmacy would provide infusion training and factor VIII doses for my home.

Infusion lessons

In May 2016 I received my first lessons in self-infusion. I was 43. On the first day, I spent hours practicing on a fake arm with a vein (I am sure there is a proper term for that, which I do not know). I was pretty good at hitting that vein! Next, I hit an actual vein in the person training me. Then, I had to hit my own vein using one hand. With excellent coaching, I hit my vein on the first try! I then proceeded to blow the next two veins, along with my ego.

For the past three years, I have had ups and downs with infusing. In October 2016 I had to infuse for a real bleed — my hip was injured. With the nurse from the specialty pharmacy on FaceTime, giving me moral support, I infused on the first try. I was so happy! The next few times, I was not successful, and I felt horrible on evenings when I had to toss factor after too many attempts and blown veins.

Factor needs

In March 2017 I had a bad fall. I slipped down a flight of stairs, hitting three metal steps and then the ground on my rear end. The end (no pun intended) result was a buckle fracture of my sacrum. I knew immediately that I had broken a bone because of the pain. There was a swollen strip across my rear end where the stair had hit it; I needed factor and I attempted infusing ... 12 times with no success. Two days after the accident, I finally got the factor VIII I needed when my local infusion center inserted a peripheral IV line so I could more easily administer it on my own.

I started to get dependent on IV lines because my infusion attempts did not play out well. For the next year or so, every time I had a bleed, I went to the infusion center and asked for a line to be placed. My confidence had tanked, and I did not want to waste factor VIII or any time with failed infusion attempts. Once in that time frame, after a major surgery, I did self-infuse successfully before heading to the emergency room due to significant post-surgery hemorrhaging. To this day, I am grateful for my success that night. For the subsequent three weeks, I had IV lines in my arm to continue to infuse.

Many men with hemophilia learned how to infuse at camp as children. Many women I know are struggling to learn how to infuse now. When I do infuse successfully, there is a great sense of empowerment and accomplishment. When I blow multiple veins in an infusion attempt, it can be incredibly frustrating.

Continued practice

I do not need to infuse on a daily basis, so I treat "on demand" when I have a bleed. When I am lucky, I can go weeks or even months without infusing. As a result, I do not get as much practice as people on prophylactic treatment. I need to practice more, and it is hard to be motivated to stick myself with needles when I feel fine. This summer, I am going to challenge myself to practice multiple times a week to become more independent with my own care. It is a critical skill to have when you're far away from a hemophilia treatment center.

I believe in the value of being able to self-administer factor, as needed. I highly encourage my female peers to talk to their care providers about learning to infuse. One day, the skill might save their life.

Source: https://hemophilianewstoday.com/2019/06/11/struggling-with-self-infusion-factor-viii/

News from around the world

HEAVY MENSTRUAL BLEEDING CAN BE A SYMPTOM OF UNDIAGNOSED HEMOPHILIA

By Anubhuti Matta

About 30% of women, worldwide, report heavy menstrual periods. Of these, 15% have an underlying bleeding disorder. However, most of these women go undiagnosed, which leaves them with a problem that is actually treatable, Paula James, a hematologist at Queen's University in Canada, writes for The Conversation.

These disorders, writes James, can be classified as von Willebrand disease or hemophilia, but women often wait up to 15 years before getting appropriate testing, diagnosis, and treatment, mainly because they don't know what constitutes an unusually heavy period. This delay increases their risk of acute hemorrhages that ultimately end up in blood transfusions, and in some cases, hysterectomies.

Both von Willebrand disease and hemophilia are inherited and are caused by low levels of blood-clotting factors. Thus, the diseases primarily affect the body's soft tissues, and patients can suffer complications including frequent and severe nose bleeds, extremely heavy menstrual periods and bleeding gums.

Although the incidence of von Willebrand disease is low in India, compared to in the West, hemophilia is more common. Estimates suggest up to 80% of people who have hemophilia live in developing countries; in India, experts believe roughly one in 5,000 people have the condition. Yet, according to the most recent survey published by the World Federation of Haemophilia, with data provided by the Haemophilia Federation of India, only 13,448 patients are registered, acknowledging that there is a lack of diagnosis.

So far, James writes, hemophilia was thought to affect only men, while women were thought to be carriers of the genetic mutation that causes the condition.

"Women who are carriers of hemophilia are very often considered to be 'only carriers' — capable of passing on the mutant genes to their children. They may be told this by their doctor. Their bleeding often then goes untreated because of this misconception," James writes.

However, she adds, "My own research has shown that around 30 to 40% of hemophilia carriers experience abnormal bleeding including heavy periods, post-partum hemorrhage and joint bleeds. Some, but not all, have low clotting factor levels."

Therefore, many organizations like the World Federation of Hemophilia are now focused on increasing public knowledge about bleeding disorders and awareness that women can also have hemophilia.

Still, in most cases, the disorder gets missed because in families with a bleeding disorder, women don't realize that their period is unusually heavy because other women in the previous generations may have always bled heavily.

"Other issues that make it difficult to identify the problem include social stigma against discussing periods openly and also lack of awareness about what constitutes normal and abnormal periods," says Dr. Vidya Shah, a gynecologist with Mumbai's Motherhood Maternity Clinic.

To identify an unusually heavy period, both James and Shah say that some signs include changing pads or tampons every hour, suffering from an iron deficiency, frequently soaking the sheets at nights and bleeding that lasts longer than a week.

To identify a bleeding disorder, iron deficiency or unusually heavy periods are the first giveaways, but they are the ones often ignored.

Other symptoms in women could include bruising easily, experiencing prolonged bleeding after surgery and trauma or heavier postpartum bleeding.

A bleeding disorder is easily treatable, says Dr. Shah. Doctors may prescribe contraceptive pills that thin the uterine lining, or endometrium, and thus lighten bleeding. Additionally, they may also give medications like tranexamic acid and desmopressin, which aid clotting. James also adds that hormonal intrauterine devices (IUDs), which like contraceptive pills reduce the thickness of the endometrium and lighten period flow, may also be prescribed.

Many carriers of the genetic mutation that causes hemophilia do experience symptoms of the condition, but some women live with their symptoms for years without ever being diagnosed, or even suspecting a bleeding disorder. "Education and awareness-raising is the only way we can close the gap in this care," says Dr. Shah.

Source: https://theswaddle.com/heavy-menstrual-bleeding-can-be-a-symptom-of-undiagnosed-hemophilia/

News from around the world

WOMEN WITH MILD HEMOPHILIA DESERVE PROPHYLACTIC TREATMENT

By Shellye Horowitz

When someone has a hemophilia diagnosis, they receive treatment in one of two ways: on demand, in which they are given products to help their blood clot after an injury or before a scheduled medical procedure; or prophylaxis, which is regular, preventive treatment. The latter is often used in those with severe or moderate hemophilia, and as most of these are men, few women are treated prophylactically.

Prophylactic treatment for mild hemophilia

Studies of those with severe hemophilia show that the number of bleeds is reduced when trough levels increase. However, many people with mild hemophilia — factor levels below 40 percent, and even as low as 5 percent — may not receive prophylactic treatment. I wonder if individuals with severe hemophilia on prophylaxis are more protected than those with mild hemophilia who are treated on-demand?

In a Phase 3 trial, published in 2018, participants with severe hemophilia A without inhibitors given regular doses of the medication Hemlibra (emicizumab-kxwh) reported a 96 to 97 percent reduction in bleeds.

Meanwhile, those with mild hemophilia, both male and female, are still getting multiple bleeds a year. I average six to 12 bleeds a year as a woman with mild hemophilia.

Treatment improves lifestyle choices

I know of teens with severe hemophilia A who are on prophylactic treatment to optimize their factor levels. One young man plays basketball and is far more active than I could ever dream of being. He can play a contact sport because he is protected. His factor levels are increased before a game for safety.

My factor levels are continually low as I am not on prophylactic treatment. I ride a bike 14 to 16 miles a day and struggle with mobility issues from joint microbleeds. I love to run on the beach with my dog, but can't risk sustaining an ankle or knee bleed that would take weeks to heal.

Recently, I had an elbow bleed that required factor. The bleed did not limit my leg mobility, so the day that I infused I ran with my dog on the beach as I was protected. It was a wonderful, freeing moment. My companion asked me, "Why are you able to run today?" I answered, "I have factor in me. I am safe."

It felt so good to let loose and feel "normal." Afterward, my knees and ankles felt better than on the days I ride my bike because I was protected. Why do we have a system in which someone with severe hemophilia is supported and another with mild hemophilia has low protection? This potentially limits the activity of the person with mild hemophilia more than the person with severe disease.

Women want treatment

I know that many women with mild hemophilia question why they are denied access to prophylactic treatment. They want it for many reasons: to be physically active, to prevent injuries, and to mitigate the effects of heavy prolonged monthly bleeding. They struggle with being intimate with their partners. They want prophylactic options to protect them so they can have an active, safe sexual life with their significant others.

Early treatment options

As new treatments enter the market, the standard of care for hemophilia is rapidly changing. Many infants with severe or moderate hemophilia are being placed on prophylactic regimens prior to any injury with the aim of preventing long-term joint damage and increasing overall health and mobility.

Studies are showing that women carriers of hemophilia, even those with higher levels of factor, have joint damage as they age. They are less likely to have access to treatment for bleeds, and may not realize when they are bleeding — possibly due to years without treatment and having learned to live with the pain of bleeds.

Women deserve to be free from fear

Women with mild hemophilia are asking about prophylactic treatment. They want to live their lives without pain, to protect their joints, and to not worry about injuries while being active. While we are not demanding a weekly infusion routine, we want options to infuse before activities that may cause bleeding. We want to be active without fear. Women with mild hemophilia deserve to be just as protected as someone with severe hemophilia.

Shouldn't we all be able to run on the beach or be intimate with a partner without fear of bleeds?

Source: https://hemophilianewstoday.com/2019/07/02/women-mild-hemophilia-deserve-prophylactic-treatment/

National family Camp -Rainbows End

THE YEAR AHEAD

October 19, 2019

- HFNZ AGM
  Rotorua

November 8 - 10, 2019

- HFNZ 60th Anniversary Celebrations
  Wellington

March 13 & 14, 2020

- Inhibitors Workshop
  Auckland

July 9 - 12, 2020

- Youth Camp
  Auckland

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