Bloodline

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Haemophilia Foundation
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HFNZ

Bloodline

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Disclaimer: The information contained in this magazine is not intended to take the place of medical advice from your GP, haematologist, or specialist. Opinions expressed are not necessarily those of HFNZ.

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.

THE H WORD

Looking back on 2020, we have experienced everything from operating as usual, to rapidly adapting to new ways of working and connecting. In the last year's annual report I characterised the year as heading towards transformation. That now seems like an understatement. In 2020 our core purpose has not changed, but the way of connecting with our members has needed to adapt. Perhaps the theme of this year is 'gratitude'.

A special thank you to every member and volunteer of HFNZ. Thank you to our executive of Catriona Gordon, Karl Archibald and Hemi Waretini for your many volunteer hours and support. Thank you to Tineke Moate, Hemi Waretini, James Poff, and Stephanie Coulman for bringing the views of the region to the national council. Our central delegate decided to step down from the national council this year, so a special thanks must be paid to Stephanie for her many years of service to the National Council. Thank you also to everyone in the regions who were part of regional committees, with a particular shout out to Central for making a face-to-face camp possible!

Thank you also to Te Whainoa Te Wiata and Lauren Phillips for bringing the perspectives of Piritoto and Youth to the National Council table. Finally, many thanks to all regional chairs and groups for injecting some much-needed life into the regions.

I would like to express my appreciation to all the staff of HFNZ for their contributions. Thank you to the team of Sue, Phil, Leanne, Lynne, Nicky, Ross and Amber and your willingness to adapt during uncertain times.

In terms of HFNZ activities, there were several events planned for 2020, which had to be delayed due to the COVID-19 pandemic. Our priority has been to keep people safe and ensure that support networks were still in place for our members. Throughout the year, the National Council has continued to pay close attention to the financial health of the organisation, for now and the future.

We are so fortunate to have the continued support of the New Zealand public via Kiwifirst, generous benefactors, donors, companies, trusts and other organisations willing to support us financially. Times are tough out there for many, and I cannot emphasis enough our gratitude for this support. It really does make a difference to our community.

This year saw access to longer-acting factor replacement therapies. Overall, this has been a positive step forward for our members with haemophilia A or B, but as with all therapies, some experiences have been variable. We will continue to advocate for access to other novel therapies. The latter part of this year saw the decision that Hemlibra would be funded for those with inhibitors. This is a good start, but HFNZ's position is this therapy should be an option for all people with severe haemophilia A and this is what we will continue to advocate for. This is going to take a meeting in the middle of funders and suppliers alike.

Although there were fewer face-to-face events around the regions, and around the world, this year, there have still been opportunities to connect, with many virtual events being offered. This included the opportunity to continue the bond with our global community despite the challenges of a global pandemic, with the World Federation of Hemophilia (WFH) holding its first virtual summit this year, along with many other virtual events. My role on the board of directors of the WFH was extended slightly into 2020/21, however that role has now concluded.

As we approached the end of 2020, we managed to hold a national adult weekend, which I know was enjoyed by all who attended (myself included).

No doubt 2021 will bring new challenges and opportunities. We will be ready to take them on together.

Wishing you all peaceful and fun times with friends and family over summer.

Noho tawhiti, tū kotahi.

Sit at a distance, stand as one.

Deon York
HFNZ President

From the CEO

BY SUE ELLIS

Tēna koutou, Tēna koutou, Tēna tatau katou. Greetings, greetings, greetings to you all.

As we move towards the end of 2020, now is a good time to reflect on the year that has been. This year marked the introduction of the COVID-19 virus. New Zealand, and indeed the rest of the world, continues to reel from the impact of this deadly virus. It's hard to keep calm and carry on when the world is no longer the one we all know. However, we've been blessed by the quick response from the Government of "Go hard and go fast", to keep the restrictions tight, and the numbers of people infected under control.

New language, conversations, and behaviour emerged from the pandemic including new meanings for bubble, meetings in zoom, alert levels, community transmission, isolation, border restrictions, clusters, and lining up at supermarkets. COVID-19 has been a pivotal moment in our lives and has affected how we as an organisation manage and continue to support our members.

With the impact from COVID-19 including a potential drop in donations and funding, the Council made the decision to not replace Midland Outreach Worker Nicky Hollings when she left in April until we are on firmer footing financially. Since then our Central and Northern Outreach Workers have been covering the Midland region between them. I want to thank them for coming forward and offering their time and support under very trying conditions. Now, with the resignation of Southern Outreach Worker Ross Paterson, we are beginning the process of recruitment for both the Midland and Southern roles.

COVID-19 lockdown also removed the ability of Outreach Workers to travel and see people face-to-face for several weeks. However, they kept communicating with members via zoom, email and phone calls. It was a relief when the alert levels were reduced to allow travel once again.

In January this year, before COVID-19 hit the world, the President and I were invited to attend the Eighth Annual Global Haemophilia Advocacy Leadership Summit in Lisbon, Portugal, sponsored by Bayer and Biomarin including support for travel and accommodation. It was so good to meet up again with fellow advocates from the haemophilia community around the world. All of us were there to engage with leading advocates, key stakeholders and industry experts, working together to learn new ways of doing things, to cement those and previous learnings that will benefit our haemophilia community.

Despite COVID-19, we have been busy reviewing and developing policies, getting our long-standing database issues fixed with a kind offer from Salesforce through their pro bono programme. A user manual has also been developed. The Foundation website refresh and renewal, which was long overdue, is also well underway.

There was a great response from our annual member survey "How are we doing?" Of the 537 surveys distributed to members by email and post, 182 responded, a response rate of 34%. The findings suggest members are interested in what the Foundation provides and relevance it has to their lives. Most people felt connected and supported. However, whilst largely positive, there is still work to do to improve the digital space, the need to engage younger members, and specific events for seniors. We also need to have a greater focus to support those with von Willebrand Disease and women with bleeding disorders. Check out the survey report on our website.

In March, just before lockdown, we held an Inhibitors Weekend workshop in Auckland, sponsored by Roche. It was a great weekend and people appeared to enjoy themselves. It was the first time those whose family member needed Hemlibra, and those who were already receiving it, were together. A huge thank you to Dr Christine Olsson from Roche who gave an interesting presentation and facilitated the sponsorship from Roche.

In light of the ongoing global pandemic, we were pleased to be able to go ahead with our Adult Weekend workshop in Christchurch, "Life is a Highway, Route 66". Although initially we had misgivings around safety, and holding an event in 'covidian' times was a challenge, by following the safety measures we have all become familiar with we were able to host a successful event.

I want to thank the staff for their patience and ongoing support to members during very trying times. They have continued to ensure the support and care continues, despite the restrictions. A huge thank you too to the amazing people who have given generous donations and to the clinical teams for their support ensuring people got their treatment products throughout the lockdown.

Despite the looming economic crisis and the need to keep a watchful eye on our financial management, I believe we can emerge from COVID-19 stronger than before.

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly: If you bow your head, let it be to a lofty mountain

This Whakataukī is about aiming high or for what is truly valuable, but the real meaning is to be persistent and don't let obstacles stop you from reaching your goal. Given the continued uncertainty, we need to ensure we keep striving for what matters: care, support, education and advocacy.

Sue Ellis

Chief Executive

Adult Weekend 2020

BY ROSS PATERSON

The first national event on the calendar for HFNZ since March, was held in Christchurch over the weekend of 6 - 8 November. I think that for some of us, both staff and attendees, there was a degree of trepidation in the months leading up to the event about whether COVID-19 would intervene and force a postponement. Fortunately, this was not the case and we able to get together and enjoy one another's company.

On the Friday evening after a briefing and welcome, we headed out to a Vietnamese restaurant. We enjoyed a multi course meal but the restaurant had grossly underestimated the time it would take to serve a large group when the restaurant was already busy. This meant a rearrangement of the programme, but the meal itself was both delicious and substantial.

Saturday morning commenced with an hour-long session entitled **Personal Journeys**, in which Central Outreach Worker Lynne Campbell facilitated a five-member panel in responding to five pre-determined questions about their own personal journey with their particular Bleeding disorder.

Dr Sharon Green, Clinical Psychologist then spoke to the theme of **"The impact of bleeding disorders over a lifetime"**. Sharon's presentation adopted a holistic view of these impacts and then viewed them through the lens of the various life stages of individuals. She was able to outline the psychosocial effects that can affect all of us, and ensured that we understood the differences between the normal emotional responses we can all experience, and clinical depression and other psychological problems. Dr Green encouraged all of us to express our emotions fully, offered strategies to cope with pressure, and suggested where to seek help if we need it.

The final morning session involved two workshops. Lynne Campbell facilitated a **Self-Advocacy workshop for Men**, while Amber Maihi ran a session entitled **The HFNZ Café**.

In her session, Lynne lead a conversation for men about how to advocate for themselves.

Participants were separated into groups of four or five. Most participants were men with a bleeding disorder, while others were the partner of a woman with a bleeding disorder.

Time for some work on self-advocacy.

Participants were encouraged to share their experiences and note their thoughts in relation to: What makes self-advocacy difficult?

Then, after thinking about when self-advocacy worked for them, they were asked to identify what skills they used to advocate for themselves, and how barriers or difficulties could be overcome.

Lynne would like to thank all participants in this workshop for so generously and candidly sharing aspects of their personal circumstances.

Amber's HFNZ Café session ran concurrently with Lynne's. In this session members were seated at one of four tables. They were given seven minutes at each table to answer and give feedback to a question relating to self-advocacy. At the end of each round they would each move to a new table indicated by a colour sticker in front of them. This way the groups were mixed up and new perspectives were heard.

The questions:

- Please describe a moment when self-advocacy worked well for you.
- What resources/ Skills do you use to advocate successfully for yourself?
- What has made self-advocacy difficult for you?
- How have you overcome difficulties with self-advocacy?

A recurring theme that came out of all four stations was the importance of education about bleeding disorders, rights to care and treatment, and what support is available to the person and their family. Overall the session worked well and all of the information gathered from participants will be used to help enhance self-advocacy.

The next educational session, an interactive one, was provided by Dr Julia Phillips. Dr Phillips stepped in at late notice after the sad passing of the late Dr Mark Smith, who was originally going to undertake this presentation. Dr Phillips provided us with an overview of how haemophilia works. She described the effects of long-acting treatments, and the efficacy of Hemlibra and its potential to impact on a wider population of our HFNZ community. Dr Christine Olsson from Roche was able to contribute to this conversation. Finally, Dr Phillips discussed the mechanics of gene therapy. Originally, the presentation had intended to include coverage of Von Willebrands disease but a considerable number of questions curtailed the workshop before this could be done.

The afternoon session consisted of two outings one of which encompassed a tram ride through the CBD. We were taken around and through the Christchurch city centre, looking at what was new, and remembering what was no longer there after the Christchurch earthquakes. Following the tram ride, some people chose to have a short walk in the botanic gardens, while others had a look around town, and the remainder returned to the hotel for a rest.

The second outing was a trip on the gondola above the Heathcote valley in the Port Hills. This provided for a wee adrenalin rush on the ride and some stunning views, especially from the top where to the north we could look out over Christchurch and the estuary, as well as over Lyttleton Harbour to the south. A café at the top provided sanctuary from the wind and refreshments while savouring the views. A time tunnel provided a three-dimensional experience, which sadly was culturally inappropriate in its depiction of the history of Banks Peninsula, and there were no staff to guide people on to the individual carriages. However, in the true HFNZ spirit we all got on and derived some fun from the experience.

The HFNZ Café.

A delicious buffet dinner was provided back at the Hotel during which a local singer, Mattie Smith provided background music. A quiz rounded the evening off with a tight finish seeing the winning team sneaking across the finish line by half a point. A few hardy types then watched a tense game of rugby in which the All Blacks on this occasion came second.

The next morning Karl Archibald introduced us to the Bombardier Blood documentary movie, in which Chris Bombardier, a U.S. citizen, demonstrated that with modern treatment and the correct preparation, it was possible to undertake some extreme physical challenges. The documentary revealed the impact that severe haemophilia had on his life and the worry his sporting activities caused to his mother and partner. Chris explained his fight against acceptance of his bleeding condition in his childhood and youth. However, his gradual understanding of the need to look after himself and of the best options for exploring physical challenges led him ultimately to conquer the highest peaks on each of the seven continents of the world. Chris Bombardier also used his documentary to expose the plight of third world haemophiliacs, citing Nepal as an example, whose access to treatment is extremely limited.

The HFNZ Annual General Meeting concluded the weekend's activities. Notably the Elizabeth Berry Exercise Cup was presented to Rorie Poff. Rorie's dogged determination on the Port Hills walks impressed all in attendance and he was one of the more regular attendees. Rorie is now pursuing another sporting interest – the field events in athletics and we wish him every success. In addition, Torin Smith accepted the Sir John Staveley Health Professional Award, posthumously awarded to his late father, Dr Mark Smith, for his outstanding commitment to supporting and advocating for people with bleeding disorders.

Sue seeing the sights from the tram.

On the tram.

Hemi, Kathryn, and Erica listening to the panel.

The panel.

Life is a Highway
ROUTE 66
2020 HFNZ Adult Weekend

The judges, Quiz night.

The winners!

Our People: My time with HFNZ

BY STEPHANIE COULMAN

As I come to the end of my time on the central regional committee and as a delegate on National Council I reflect back on my years.

What did I get out of my experiences, and what did I in turn give back to our HFNZ community?

My introduction to the Foundation was well before my son Nicholas was born with severe Haemophilia A in 2003. We have a fine pedigree of Haemophilia A in our family. My father had haemophilia and was involved in the society, as it was known, in earlier days. So the world was not unfamiliar to me but my perceptions of the quality of life and treatment for people with haemophilia were outdated and no longer applied.

In some ways it is better to know to expect it when you are having a family. When Nicholas was diagnosed there was no huge shock or traumatic adjustment. But having a history brings its own fears of the past. Fortunately my sister had paved the way ahead of me with her son with haemophilia, who was 5 months old when we had Nicholas, and she seemed to be coping, so I felt sure we would too. Anyway, I had more pressing concerns in the early days, as Nicholas and his twin sister Anna were born at 35 weeks and spent the first 3 weeks in the neonatal ward at Wellington Hospital.

My first regional camp was in Whanganui in 2005 organised by Grant Hook and the committee at the time. We enjoyed meeting other families and sharing experiences, this is the power of HFNZ camps. We were also thrilled to have a weekend away with our young twins, in a nice motel, at very little cost to us – what a wonderful organisation this was!

My real involvement with the committee came with a phone call from Lisa Habershon on behalf of the central region committee inviting me to apply to go to the Australasia Haemophilia Conference in Melbourne in 2005, in return for some time on the committee. Little did either of us know I would stay on so long; I was on the regional committee from February 2006-2020 and a regional delegate from 2012-2020.

My time has been nothing but positive and I have gained so much and had opportunities that I may not have had otherwise. Perhaps only Armageddon expos would count as experiences I could have done without, as well as the mail-out of 20,000 publicity flyers. We did these as a fundraiser for HFNZ so it was all for a good cause but I was glad when we didn't have to do those anymore.

I learnt as much as I could at family camps, these for me are the heart of the Foundation, equipping parents to cope and advocate and be knowledgeable. Once Nicholas graduated from family camp he started going to youth camps without us. At the last family camp he returned as a junior youth leader, so the tide has turned and he too is gaining new experiences and giving back to the Foundation.

I learnt so much from the two Australasian Haemophilia Conferences (Melbourne 2005 and Canberra 2007) and the World Federation Congress (Melbourne, 2014) that I was fortunate enough to attend.

A highlight for me was being a facilitator on the Parents Empowering Parents course. It was a privilege to share that experience with the parents and the other facilitators;

Rotorua Family Camp 2010

At Family Camp 2008

Outreach Worker Drew McKenzie, fellow parent facilitator Di Bell, and Palmerston North Nurse Daryl Pollock. We learnt so much about each other and I have kept all their stories close to my heart ever since.

One of the things you learn in PEP is about our own unique 'world view' – this blows your mind a bit. Looking back on how I was parented, I understand now why certain things are important to me, and why my values are my values. It is a worthwhile exercise to explore your own world view, if you ever get the chance.

I enjoyed organising camps and family outings for the region. I am proud of what I have achieved in bringing members together at regional camps, to network with each other and learn more about their condition from expert speakers and of course the fun activities we have shared together.

Central region camps over the years:

2005 Whanganui

2006 Kennedy Park, Napier

2007 Solway Park, Masterton

2008 Kennedy Park, Napier

2009 Kennedy Park, Napier

2010 Solway Park, Masterton

2011 El Rancho, Waikanae

2012 no camp

2013 Kennedy Park, Napier

2014 Anndion Lodge, Whanganui

2015 Suncourt Motel, Taupo

2016 El Rancho, Waikanae

2017 no camp

2018 Kennedy Park, Napier

2019 no camp

2020 El Rancho, Waikanae

Joining the National Council was a new experience again, seeing how the Foundation is run and being around the board table with reps from around the country, bringing their talents and perspectives to ensure the Foundation stays strong.

As a parent of a boy with haemophilia my motivation and enthusiasm is centred around ensuring the Foundation remains a vibrant support group for its members. This is not a group that you resign from, we'll always have a special connection with HFNZ. However, in moving aside from committee roles I allow others to gain the experiences and opportunities I have had.

Women's Weekend 2009

With Lynne at Women's Weekend 2009

HFNZ 60th - With Catriona at Parliament

HFNZ 60th Gala Dinner

Step towards your future with ACEET

The Allan Coster Educational Endowment Trust (ACEET) offers grants to help people with haemophilia and other rare bleeding disorders access vocational training and education. Over the years, ACEET has helped many people to change their lives, providing them with the financial support for their education that they may not otherwise have been able to access.

The ACEET grants are not just for university study. The ACEET trustees will consider applications for primary, secondary, undergraduate, postgraduate, trades, or vocational training. That means, if you have a bleeding disorder, a dream, and a course that will help you to get where you want to be, then an ACEET grant could be what you need.

Previous recipients have used their grant to complete courses from reading assistance, to business management, to graphic design. If it is going to improve your prospects, then it's worth getting an application in.

Grant applications are considered three times a year. To check the next application deadline, or apply for a grant, just contact your Outreach Worker.

Here's what ACEET has done to help HFNZ members like you:

DUSTIN TRAIL

Dustin Trail lives in Auckland with his partner and two kids. He's really pleased with how his Allan Coster Educational Endowment Trust (ACEET) grant changed his life for the better.

Several years ago Dustin was living in the Manawatu, and working in dispatch, loading and unloading bread trucks. This was hard work, and not great for his haemophilia. He was constantly getting bleeds, and having to soldier on just to make ends meet. Dustin has severe haemophilia A, which means hard physical labour is always going to be hard on his body. He often saw the truckies come in, happy and cheerful, and disappear off for a coffee while he loaded or unloaded their truck. It looked like a pretty good life to him.

Dustin approached his HFNZ Outreach Worker and asked for support from the Haemophilia Foundation to change his life. His job was impacting too much on his body and on his state of mind. He was feeling negative all the time, and struggled even to pick up his son some days. Something had to change.

After his experiences at work, Dustin decided that he wanted to have a go at being a truck driver too. It was recommended he apply for an ACEET grant to get his licences underway. With the help of the grant Dustin was able to sit, and pass, his Class 2 licence, and get himself his first job driving trucks.

He has since sat and passed all his licences, which means that now he can drive any truck you point him at.

Dustin's decision to make a change, coupled with an ACEET grant to get him started, has been a revelation. These days Dustin says, "I love my job. I can't wait to get going each day".

This is a great result, and just the sort of thing that the ACEET grants were designed to make happen.

LAUREN PHILLIPS

Having a huge student loan was always going to be a reality for me; but I knew that the benefits outweighed this temporary setback. I had looked at various types of funding and scholarships to assist me throughout my study but never quite met the right criteria. I had heard of the Allan Coster Education Endowment Trust (ACEET) before, but it was my outreach worker who encouraged me to apply.

Studying law meant expensive books, expensive course fees and, being in Wellington, expensive coffees! ACCET couldn't help me with the last one but it did assist me with course materials - which when you're paying $160 for a 2 cm thick book is very handy! I was successful in obtaining a grant through the Trust to assist me but perhaps more important than the financial assistance, it felt like a vote of confidence from the trustees. They believed in the work that I was doing and wanted to support that.

I have now graduated from Victoria University of Wellington Law School and been admitted to the Bar. I hope that my legal skills can be used to benefit the Foundation going in to the future.

My one piece of advice to anyone studying and thinking of applying for ACEET is DO IT! Compared to other lengthy and convoluted scholarship processes the ACEET process is much more straightforward; and getting that vote of confidence from people in your community is a great feeling.

HANNA PATEL

Hi, my name is Hanna Patel and I am a severe haemophiliac with factor VII deficiency. I am currently in my final year of a Bachelor of Fine Arts majoring in fashion design at Whitecliffe.

The last year was a very trying year for me. Because of my condition, I have had to overcome a lot of medical issues while studying. My major issue last year was needing to have eye surgery, on top of my regular bleeding.

Despite support from my school, I still found myself having to work endless long nights to complete my assignments and deadlines. Despite my poor health, I still managed to produce several garments and showcase my work at the university's yearly fashion show last November.

As my health conditions already make university on its own difficult for me to manage, I am understandably unable to take on any part time work while in school, so receiving the ACEET grant was a major weight off of my shoulders, as it made me able to afford the materials and supplies I need for my course.

Farewell to Ross

We are sad to say that Southern Outreach Worker Ross Paterson is moving on. Ross has been a great addition to the HFNZ Outreach team. He has always been strongly community focused, and those of you lucky enough to have connected with him will know what a generous and supportive advocate Ross is.

Perhaps Ross's greatest legacy will be the Port Hills Walking Group. Ross saw an opportunity to get members out and about, and set about making it happen. Even the disruption of COVID-19 wasn't enough to derail this initiative.

Ross was also the driving force behind the recent Adult Weekend. His attention to detail ensured that this was a focused and enjoyable weekend.

Here's what Ross has to say:

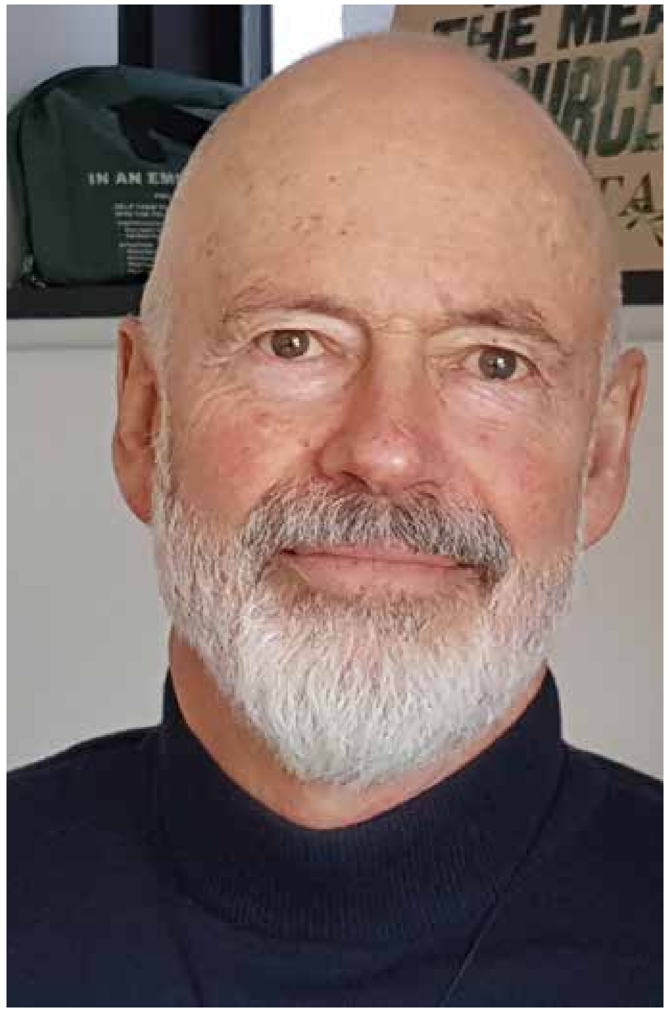
Kia ora koutou katoa,

As the time approaches for me to leave HFNZ, I am increasingly aware that I am going to miss "you lot". I have met some wonderful people in my time with the organisation, many of whom helped me in my learning and I am thankful that I have had the experience of working with you.

It is my intention to continue my involvement with the Port Hills walks – until people at least have decided they have had enough! or my body calls time.

E noho ra

Ross.



Southern Walks 2020

During 2020, despite the rude interruption of COVID-19, the Southern walking group continued to get out and about. It was pleasing to see the group consistently turn up to enjoy the magnificent Port Hills walking tracks. While the goal was always to improve our fitness, the best parts were the developing of friendships, and the wonderful views of plains, sea, and harbour.

Here are a selection of the best vistas of 2020.

Regions and Groups

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. Due to the COVID situation, events have been limited this year. Here's what's happened in 2020 in your area.

CENTRAL REPORT

BY STEPHANIE COULMAN

This year the central region has done its best to gather as a community despite the difficult times we are facing.

After postponing the planned April screening due to Covid, we have re-booked the Time Cinema in Lyall Bay, Wellington to screen Bombardier Blood, the inspiring documentary about haemophiliac Chris Bombardier who climbs Mt Everest. The new date is Saturday 28 November.

We have also attempted on several occasions over the past 2 years to run a second men's fishing trip, following a successful one in 2017. Each time our plans have been hampered, mostly by the weather, and more recently COVID-19.

A picnic at The Esplanade in Palmerston North at the end of November brought together about 20 members to enjoy each other's company and see out the year.

There have been changes to the Central committee at the 2020 AGM. Chair Blair Wightman, and delegate Stephanie Coulman both stepped down after years of great service. Chair Tracy Nyhan and delegate Ana Clulee have replaced them. We wish Blair and Stephanie well.

Just as life continually sets us challenges along the way, and those living with a bleeding disorder certainly experience this every day, we will persevere and meet these challenges head on!

NORTHERN REPORT

BY GREG JAMIESON

What a year...

We started strong with holding our Christmas catch up at the Grounds in Henderson. We had a solid turnout with close to 50 people. The kids got to enjoy the playground and the netted orb-shaped feature, while the adults were able to catch up over a meal.

Rosalie then hosted a great day out at Parakai hot springs for our summer catch up. We had the wonderful Davis family join us for the day all the way from Whangarei. Rosalie made sandwiches for lunch and the kids had a great time on the waterslides.

We then booked a movie theatre to host our region at the movies in April but this had to be cancelled due to COVID. The ongoing complexities with COVID meant that we had to put several events on hold. However, with NZ now seemingly very settled at level one, we are currently planning to head to the Auckland Zoo for a Christmas outing on 13 Dec. Keep an eye out for your invite.

On behalf of the Northern Committee, I hope everyone is safe and healthy and we look forward to catching up once COVID is behind us.

MIDLAND REPORT

BY TINEKE MAOATE

This is going to be a very brief report. Unfortunately, Midland haven't had much interaction recently. We had the pleasure of seeing most of you at the 60th celebrations, which was a successful event. However, COVID has swallowed up most of 2020, so it hasn't been possible for us to catch up. We had an amazing event planned for August but, unfortunately, COVID hit us once again.

We had an AGM at the recent Adult Weekend, and there were some changes to the committee. I stood down from the chairperson role, which was taken up by Wendy Christensen. I will stay on in the committee as delegate to the National Council, as I really enjoy it. I think it would be great to have some fresh people coming in to the committee and sharing their ideas.

If you want to contact the committee you can email us at midland@haemophilia.org.nz.

Speaking of Adult Weekend, it was great to finally get together with our HFNZ family from around the country. Thanks to COVID, it has been a long time since we could do that.

Take care of each other and I look forward to when we can all meet again.

PIRITOTO REPORT

BY TE WHAINOA TE WIATA

Piritoto, Piri tata, Piri tonu, Piri tonu ee..

Ko te mihi tuatahi ki te kaihanga o ngā mea katoa a ko Io tēnā,

Ko te mihi tuarua ki tō tātou kiingi a Tūheitia Pōtatau te Wherowhero te tuawhitu me te whare ariki, Paimaarire

Otirā, ki a rātou o te wā, o te tau kua huri atu ki tua o te ārai, haere, haere, haere atu rā.

Ko rātou ki a rātou, ko mātou ki a mātou, e te hunga tēnā tātou...

Kei ngōku rangatira o tēnei te whānau toto tepe kore,

Tēnā koutou katoa...

Well, what can I say, this year has gone from one challenge to another, yet we are still here to tell the story, which is always a good thing. However, due to these unfortunate circumstances we the whānau of Piritoto have been unable to touch-base properly with each other. Generally, for many of us, it is a juggle of work, whānau, iwi / hapū / marae obligations, and many other commitments. Then COVID-19 hit us all and everything amplified, which I think needs no explaining. We took the approach of not touching base until quite late into lockdown, because everyone was going online and emails were a little overwhelming, so a few texts here and there just to see if others were OK was how we did things. Lockdown #1 saw many positives and negatives and from my point of view, it brought about a whole new level of uncertainty, stress, and an overall lack of wellbeing. So, I am grateful to say that the general consensus thus far for those of us of the Piritoto whānau is that everyone is ok.

Aside from planning a date to touch base and catch up online we have nothing on the horizon for the next few months, but once we have met together we will be sure to inform the wider HFNZ whānau of what we have coming up.

We want to give a quick mihi to HFNZ for the way we were kept informed about COVID-19, you are amazing, the brief messages were digestible, in other words, they were short and sharp which was hugely appreciated considering the amount of time many of us were spending online for work and non-work commitments. Also, to the wider HFNZ whānau as a whole, well done for seeing it through and although the challenges never stop we are a resilient whānau and always push through.

Kāti i konei...

Paimaarire ki a tātou katoa

SOUTHERN REPORT

BY SUSAN INWOOD

It has been a very unusual year for all.

I was on my way to Canada again this year for four months work - and to see my youngest son Matthew and spend some overdue time with him - unfortunately that is postponed until 2021 - or later.

Our fundraiser at the central library in April had to be postponed due to the COVID outbreak and travel/lockdown restrictions.

However, we had a wonderful fishing trip in February to Moeraki. We had a fantastic turnout and each member went home with a few good feeds of fish. The next fishing trip is to Nelson, at the top of the South Island, in November.

We are lucky to have the walking trips start again with Kyle and Ross taking charge. By the looks of things, they have a good turn out as well. We are very sad that Ross has moved on. He was a great asset to the Southern community.

Thank you to all our committee who have helped me through this year as Chairperson - my first and last - and we shall just have to see how the next year unfolds.

I hope everyone is safe and happy and looking after themselves.

YOUTH

BY COURTNEY STEVENS

At the Youth Development Workshop we held at the end of last year, the Youth Committee decided that our focus should be on hosting regional events, and we tasked each of the regional youth delegates to brainstorm some potential event ideas, even something as simple as a dinner out. Some fantastic ideas came out of this brainstorming so watch this space!

The Youth Development Workshop was notable because we had four young leaders from Nepal in attendance. This was part of the ongoing WFH twinning programme with which the NYC is involved. We were pleased to hear that our twinning with the Nepalese Haemophilia Society's Youth Committee was extended for another year, albeit not a lot of our initial plans for the Twinning have eventuated given the Covid-19 situation but we are hopeful we should able to pick this up again next year.

There isn't much to report for the remainder of the year, given the lack of events and ability to plan too far in advance with the everchanging alert levels. We will aim to get some regional events on the calendar where possible in the coming months, so keep an eye out for events in your area!

As a result of the recent member survey, The Youth Committee have also asked HFNZ staff to consider how it can best meet the needs of teenagers and those in their early 20s. We are excited to hear their ideas.

Finally, the Youth Committee is contactable on Facebook or via phone if anyone needs some assistance. If you're keen to have a more active role in the committee we're always keen for newbies so please get in touch!

Central Camp 2020

New drug gives ‘normal life’ to haemophiliac who thought he would never study, surf or be on stage

BY BRIDIE WITTON

Andrew Scott has such severe haemophilia that he never thought he would be able to go to university.

Performing on stage, going to university and surfing are things Andrew Scott never thought he would be able to do.

But since taking Emicizumab, a cutting-edge preventative treatment for people with severe haemophilia, he can now live what he calls “a relatively normal life”.

“I thought it was too rare to be cured,” the 20-year-old said. “I was in a really helpless place.”

“Now I am actually able to function and produce an income.”

Come December 1, up to 15 other New Zealanders with severe haemophilia will also be able to access the drug, which Government drug-buying agency Pharmac says will improve both their quality of life and life expectancy.

Scott was diagnosed with haemophilia A when he was born. It is an inherited blood disorder that causes increased bleeding and usually affects males.

He spent the majority of his youth in and out of hospital with bleeding episodes, and even sat his NCEA exams in hospital. He has frequently used a wheelchair.

His disease was unpredictable and made it difficult to socialise. Plans often included ensuring a family member was on stand-by in case something went wrong.

“Even when I wasn’t bleeding, I had very weak knees.”

Scott was able to get Emicizumab through Pharmac as a special case in 2018, when his haemophilia ramped up and he was having two to three bleeds a week.

Haemophiliacs face a risk of permanent damage from bleeding into the joints or death from severe internal bleeding.

But the drug reduces the frequency of bleeding episodes and hospital visits, improving people’s quality of life, Pharmac deputy medical director Dr Pete Murray said.

The drug would cost patients $600,000 a year without Pharmac funding, he said.

Pharmac already funds haemophilia medicine, including two long-acting treatments.

Andrew Scott is now able to fulfil his lifelong dream of performing on stage.

Now Scott is working part-time in retail while studying a Bachelor of Arts degree at the University of Auckland, majoring in English and drama.

He took part in his first theatre show in September, something he thought was an “unfeasible dream”.

He is also able to go surfing: which his is dad taught him when he was a child, but which he hadn’t been able to do in a number of years.

He hopes to be a teacher.

Source: https://www.stuff.co.nz/national/health/123386475/new-drug-gives-normal-life-to-haemophiliac-who-thought-he-would-never-study-surf-or-be-on-stage

Women and girls face greater difficulties accessing treatment, diagnosis and referral for bleeding disorders

BY DAME DIANA JOHNSON MP

The APPG on Haemophilia and Contaminated Blood's inquiry into bleeding disorders found the UK has fallen behind in outcomes for people with bleeding disorders.

Despite major steps forward in the treatments available to people with bleeding disorders, most still see their lives held back by their condition. This is the conclusion of the new report by the All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood.

This week we published the final report of a detailed review of the standards of care and access to treatment for people with bleeding disorders in the UK. It found that the vast majority of people with bleeding disorders were not very involved in decision-making about their treatment; good multi-disciplinary care was rare; and women and girls found it harder to get diagnosed and access care.

The APPG on Haemophilia and Contaminated Blood campaigns in Parliament with and on behalf of people with bleeding disorders. In recent years, we led the successful Parliamentary campaign for the Infected Blood Inquiry to be established.

In April 2019, the APPG launched an inquiry to understand to what extent people with bleeding disorders get the best care and what barriers there are to improving outcomes. The final report made nineteen recommendations to government and the NHS under three main themes.

There is a lack of informed and collaborative decision-making between patients and clinicians

Firstly, while the report looked in detail at drug treatments, it is clear that proper access to treatment goes beyond just drugs provision. It includes proper care from a multi-disciplinary team of professionals. Due to a lack of resources, wider holistic needs are not being met by treaters across the UK.

Many patients are not seeing genuine comprehensive care. A peer review of haemophilia centres published earlier this year confirmed the scale of this problem. Only half of centres have sufficient physiotherapy provision and less than a third provide dedicated psychological or social worker support. As a result, the UK has fallen behind other comparator countries, such as France and Germany, in outcomes for people with bleeding disorders.

Secondly, there is an inequity in access to treatment for many people. Women and girls have greater difficulties in accessing treatment and face disproportionate delays in diagnosis and referral to care.

At the report launch this week, APPG members heard how on average it takes seven years for women to be diagnosed with a bleeding disorder. Many others spend years navigating primary care and it is thought that as many as 50,000 UK women may never receive a diagnosis at all. The report also notes that rarer bleeding disorders, such as FX deficiency and Factor XIII deficiency, have had or continue to see delays in approval for newer treatments.

Finally, there is a lack of informed and collaborative decision-making between patients and clinicians. Most people with bleeding disorders did not feel particularly involved in decisions about their treatment, with fewer than half feeling able to influence their choice on treatment. The inquiry instead observed a system where commissioners' desire to drive down costs are unduly influencing proscribing decisions at the cost of patient choice and holding back innovation in treatment.

We will now work with the government and the NHS to ensure that our report's recommendations are fully considered and implemented so that people with bleeding disorders no longer see their lives held back by their condition.

Dame Diana Johnson is the Labour MP for Kingston upon Hull North and co-chair of the APPG on Haemophilia and Contaminated Blood.

Source: https://www.politicshome.com/thehouse/article/women-and-girls-face-greater-difficulties-accessing-treatment-diagnosis-and-referral-for-bleeding-disorders

The Panel - Adult Weekend 2020

THE YEAR AHEAD

13 December, 2020

- Northern Xmas outing
  Auckland Zoo

29 April– 2 May, 2021

- Youth Camp
  Kaiapoi

Late 2021

- Women's Weekend
  Date and venue to be determined

Early 2022

- National Family Camp
  Date and venue to be determined

Visit www.haemophilia.org.nz for more information on bleeding disorders, HFNZ News, and past issues of Bloodline

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