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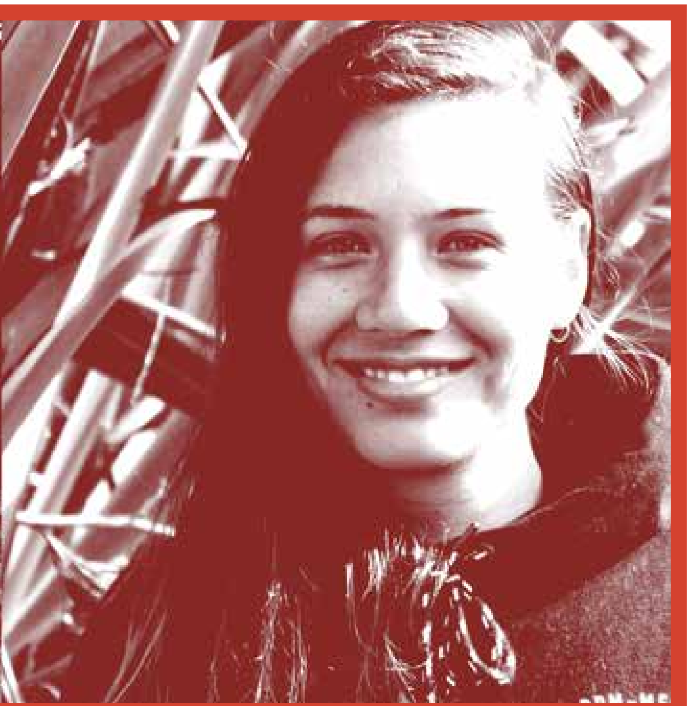
Magazine of the Haemophilia Foundation of New Zealand. Volume 46 Number 1

Bloodline



HFNZ's Next Generation

Haemophilia Foundation of New Zealand Inc.
HFNZ

HFNZ Menstruation Survey Results «

2017 HCV Report «

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.

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The H Word

Kia ora koutou,

I hope everyone has had a nice and relaxing summer and enjoyed the chance to get out in the good weather and spend some time with friends and family. With three months of 2018 already gone, it has already been an eventful year for HFNZ.

This year started the way last year finished, with many involved in a variety of events in NZ and around the world. Piritoto grew its connection to the community at the first summer noho since 2013, staff and members attended various training and education events, and there has been an emphasis on gathering and analysing information to help us to better support members.

In January, CEO Richard Chambers and I attend a global advocacy forum (in a very cold and wintery Budapest) and Courtney Stevens headed to Phoenix Arizona for NACCHO, the North American Camping Conference for Haemophilia Organisations. Events like these give us the opportunity to mix with others around the world, to learn, bring home the latest information on the treatment product pipeline, and inject new life into our programme of events.

The office has been focusing on increasing our understanding of the support members are looking for. This happened in a couple of different ways last year, with the annual hepatitis C survey, and the member-driven Women's Experiences of Menstruation survey. This issue of Bloodline has some very interesting data that has come from these surveys, and also introduces the 2018 members' survey. It's important that as many of you as possible complete the members' survey this year. Your feedback is crucial to designing programmes and services that you want.

Speaking of programmes, there are some important events planned for 2018. Over the April and July school holidays we have regional children's workshops in a town near you, in September there's the women's wellness weekend in Wellington (or, perhaps W3 for short?), and in October we have the AGM as well as a day of governance workshops. I hope that as many of you as possible can be involved in these events.

All the best for a successful 2018!

Deon York
HFNZ President

From left to right: *Zac Porter, Courtney Stevens, Ashley Taylor-Fowlie and Mahia Nightingale-Pene*

Our People: HFNZ’s Next Generation

As with many organisations, HFNZ’s strength is in its members. We’re blessed with strong dedicated leadership, and have worked to grow that into the future. We now have an emerging group of young people who have participated in our youth leadership development programmes, and who are starting to move into more prominent roles within the foundation. **Phil Constable** collected a snapshot of some of these young leaders.

Zac Porter

1. So, tell me about what brought you to the foundation.

Diagnosis of Von Willebrands type 3 when I was a little person.

2. And, what's your role in the foundation, what do you do in HFNZ?

Currently on the National Youth Committee and Southern Committee.

3. I know HFNZ isn't your whole life, so what do you do outside of HFNZ?

I am a keen biker and spend my free time out riding my bike. I am also currently studying towards my Masters at Canterbury University in psychology. I have just got back from doing a summer programme through UC at Peking University in China too.

4. What HFNZ stuff have you been up to recently?

Recently went to the Australia & New Zealand Haemophilia conference at the end of last year in Melbourne. Learnt lots about up and coming treatments and met heaps of other bleeders from across the ditch, which was awesome.

5. What interesting stuff do you have coming up, inside or outside HFNZ?

Hopefully do some more fun youth events in the Southern region soon. Other than that, I have a hectic year of study ahead.

6. What do you think about youth in HFNZ, now and into the future?

The HFNZ youth are an awesome social bunch who get a lot done. It sounds cheesy but the youth are the future of HFNZ. Eventually we won't be the youth anymore so it will be on us to step up and take HFNZ from here onwards.

Courtney Stevens

1. So, tell me about what brought you to the foundation.

Haemophilia is in my family; my older brother has Severe Haemophilia A and my mum and I are both carriers.

2. And, what's your role in the foundation, what do you do in HFNZ?

I have been going to family camps as a youth leader for the last ten years or so, I am on our National Youth Committee, and am also the Youth Delegate for National Council, have held positions previously in my region (Southern) as well.

3. I know HFNZ isn't your whole life, so what do you do outside of HFNZ?

Outside of HFNZ I work at the head office for a chain of convenience stores, called Night 'n Day. I also enjoy spending time with friends & family whenever possible!

4. What HFNZ stuff have you been up to recently?

Of recent times, I was lucky enough to travel to Nepal in October last year on the assessment visit for our Youth Twinning project. I also attended NACCHO (Camp planning conference in America) in January 2018. I have previously attended World Congress as well.

I also attended the last Family Camp and Advanced Youth Leadership weekend.

Myself and a couple of others helped Colleen plan the Young Women's Weekend that was held in 2016 as well (after pitching the idea at our first Youth Leadership Weekend).

5. What interesting stuff do you have coming up, inside or outside HFNZ?

More work to be done with our Youth Twinning Project, the Youth Committee is also keen to host an event soon.

6. What do you think about youth in HFNZ, now and into the future?

I think it is super important to keep engaging youth & to make sure we keep them interested. The next generation are going to be crucial to the success of the foundation, so we need to be teaching them as much as we can while we can.

Ashley Taylor-Fowlie

1. So, tell me about what brought you to the foundation.

I have von Willebrand's (VWD) as well as a family connection.

2. And, what's your role in the foundation, what do you do in HFNZ?

I am the secretary of the Central Region committee, and also active within the Youth Group. Recently I was invited to be a member of the WFH Youth Leadership Advisory Committee.

3. I know HFNZ isn't your whole life, so what do you do outside of HFNZ?

I have previously studied social work and nursing, and am planning to finish of my registration within the next year or two. I have worked within dementia care for the last five years, and, deciding I was ready for a change last year, I accepted a role in a boarding school as a Matron. (I know, old fashion right) It's definitely different going from working in aged care, right down to primary school age children, but so far I am loving the new challenge and responsibility.

I have also had a big involvement in St John's over the years.

4. What HFNZ stuff have you been up to recently?

Central committee are planning our camp so keep a look out for your invite! Also, Youth Committee have a meeting coming up, there are conference calls for the WFH youth leadership advisory committee, and I am planning on self-funding to attend Congress this year.

5. What interesting stuff do you have coming up, inside or outside HFNZ?

I have decided to attend Congress, which is in Glasgow this year. This will give me a great opportunity to go and stay with my family in Aberdeen.

6. What do you think about youth in HFNZ, now and into the future?

Over the years the youth within HFNZ has remained strong, the training, events, and workshops we have been offered have allowed for this. It's great to see those children who were at the camps that I have volunteered at over the years have grown up to become fantastic leaders and becoming more active within the youth.

7. Anything to add?

I was the 2016 SSMF Scholarship recipient. The Susan Skinner Memorial Fund (SSMF) endowment was established in 2007 by the World Federation of Hemophilia (WFH) USA to support the training, education, and leadership development of young women with bleeding disorders.

Mahia Nightingale-Pene

1. So, tell me about what brought you to the foundation.

When I was a youngster I grew up going to the Family Camps with my whānau, so have been a part of the foundation through my family.

2. And, what's your role in the foundation, what do you do in HFNZ?

I am proudly a member of the Piritoto group and I am the Midland rep for Piritoto.

3. I know HFNZ isn't your whole life, so what do you do outside of HFNZ?

I work at Sport Waikato as an Energizer, with the goal of creating a healthier community in Waikato. I also love to do Kapa Haka with my group Ngā Tumanako.

4. What HFNZ stuff have you been up to recently?

In October, I was lucky enough to go the ANZ conference in Melbourne.

5. What interesting stuff do you have coming up, inside or outside HFNZ?

In February I am attending the Piritoto Noho in Raglan and in May I will be going to Glasgow for the 2018 World Congress. I am absolutely grateful I am going and am looking forward to it.

6. What do you think about youth in HFNZ, now and into the future?

Not sure as I have always had other commitments during youth get togethers, but am keen on getting more involved and join in more in the future.

> *Over the years the youth within HFNZ has remained strong, the training, events, and workshops we have been offered have allowed for this. It's great to see those children who were at the camps that I have volunteered at over the years have grown up to become fantastic leaders and becoming more active within the youth.*

2018 HFNZ Member Survey

It's that time of year again when the HFNZ team look for feedback on how well the Foundation is performing for its members. This is a really important time because the information we collect now helps set the direction for the coming year. Over recent years we've used the results from our annual member survey to streamline Outreach services, so that our members can get the support that they're looking for, and to improve the way we communicate with our members. The information we collect allows us to make good decisions about our priorities, so that we can give you the services that you want.

This year the HFNZ Members Survey is being administered predominantly online. That means that all members who have an email address registered with us will be sent a link, which takes them directly to the online survey. Those that don't use email have been sent paper copies of the survey. When the paper copies are returned to us, we'll manually insert the responses into the online survey, so that the results can all be collated together.

As you can imagine, manually entering the data from paper copies is very time consuming, filling in the survey online is our preferred option. You can complete the survey here:

https://www.surveymonkey.com/r/2018HFNZMemberSurvey

The HFNZ Member Survey is open now, and runs until Sunday May 13.

HFNZ Women's Experiences of Menstruation

In mid-2017 one of our members asked us whether there was any support available to help women pay the additional costs of sanitary items, like tampons and pads, borne by women who are carriers, or who have diagnosed bleeding disorders. This reflected an international movement to stop seeing these items as 'luxuries', and start recognising them as basic needs. This initial enquiry led to a plan to make a submission to Pharmac, and a survey of the experiences of HFNZ women. **Phil Constable** reports on the survey results.

For women who experience excessive or prolonged menstrual bleeding, the costs associated with sanitary products can be many times that borne by women with a cycle that falls more within the normal range. However, it can be difficult to determine how close to 'normal' individual women's bleeding actually is. There is stigma around discussing menstrual issues, and women with bleeding disorders, or who are carriers, often have no idea that they are anything other than normal.

In response to our member's query, HFNZ determined to find out more about our women's experiences of menstruation, with a view to submitting our recommendations to Pharmac. The first step was to design a survey that collected the information we needed. We used a survey designed for a 2013 international research project entitled The Effects of Menorrhagia on Women's Quality of Life: A case-control study (Gokyildiz et al) as our starting point. We then formed an advisory group comprised of HFNZ women, who helped shape the final survey into one that gathered the information required to inform our Pharmac submission, and that reflected the experiences of HFNZ women accurately. The questions gathered statistical information, as well as quality of life information. There were 16 questions in all.

The survey was emailed to 218 HFNZ women over the age of 16, with the instruction that young women under 16 were welcome to complete the survey with parental support (if required), or that adults may complete the survey on their behalf (with their permission).

We had a very good response rate, with 71 women (33%) submitting their survey. Of those, 97% had a diagnosed bleeding disorder or carried the haemophilia gene. Of the 71 women, 62 (87%) self-reported excessive bleeding, menorrhagia, during their period. Fifty-one of 67 (76%) reported they had been affected by menorrhagia for at least a year, with 43 (64%) saying they had been affected for more than 3 years. Surprisingly, 23% of women had never sought or undertaken treatment for their menorrhagia, with only 49% consulting their GP about it. The most common treatments were tranexamic acid (49%), and the oral contraceptive pill (43%).

As you might imagine, a significant proportion (75%) of the women categorized their bleeding as severe or very severe. This included experiencing flooding and the passing of heavy clots for 70% of women. On top of that, the majority of women experienced leaving blood on clothing (77%), on bedding (87%) and on underwear (93%).

The women shared that they generally used tampons and pads, although one used a moon cup. However, the number and frequency of change varied greatly. There were a very high number of women who used more than one sanitary item at a time, with 41 (58%) using a tampon and a pad, 10 (14%) using two pads at a time, and seven (10%) using a tampon and two pads.

As if using that number of sanitary items isn't expensive enough, 42 (60%) of these women reported needing to change their sanitary items at least every 2 hours at peak times. For some of these women that means in excess of 24 pads and 12 tampons every 24 hours. Furthermore, 44 women (62%) reported that their periods usually lasted longer than eight days each month. That makes for a lot of pads and tampons.

Unsurprisingly, 32 women (46%) reported that their higher than average use of sanitary products has contributed to financial stress or hardship in their family/whānau. This is particularly difficult for families with a lower than average household income. One woman commented, "When I was a student I would have no money to spend $30 on sanitary items per month. I would either use toilet paper or eat bread and rice for a week, meaning, I could not afford food and sanitary items at the same time." While another said, "When we were a young family this cost for products prevented us from buying other essential items"

For these women, it's not just the financial aspect that impacts on the lives of them and their families. Experiencing menorrhagia can also affect quality of life mentally, emotionally, and physically. The women report feeling tired, drained, and depressed. They felt anxious about their period affecting their schooling and work-life. They felt stress about doing regular everyday things, like going out, or even going to sleep, in case they flood the bed. One woman said, "I don't like to leave my house. It is embarrassing in front of my boyfriend when I bleed the bed. When I am in public, I have panic attacks if I have bled through my clothing. I get very stressed." While another said, "You sometimes feel you are living half a life. Iron deficiency following heavy bleeding leaves you feeling tired, grumpy, and unable to cope."

Following the survey the information gathered will be used in a couple of different ways. The primary use will be to inform an HFNZ submission to Pharmac. This submission will advocate for more affordable access to sanitary products for women with diagnosed bleeding disorders, or who carry the haemophilia gene. We'll also be using the information to design a poster for presentation at the WFH World Congress in Glasgow. This poster will be seen by attendees from around the world, and will highlight the good work being done for women by HFNZ.

The information gathered will also form the basis of discussions at the 2018 Women's Wellness Weekend. This event is for women aged 18+ who have a diagnosed bleeding disorder, or who carry the haemophilia gene. The weekend is scheduled for Wellington, at the Copthorne Oriental Bay, on the weekend of September 14 – 16. Registration will open in mid-April.

Dr Paula James

Let's Talk Period: An Interview with Dr Paula James

As the World Federation of Hemophilia (WFH) geared up for World Haemophilia Day 2017 - and its theme of women and girls affected by bleeding disorders – Christine Herr of WFH had the pleasure of sitting down with Dr Paula James, an academic hematologist based in Kingston, Canada, for a question and answer interview.

This article appeared previously (March 27, 2017) on the World Federation of Hemophilia's site Hemophilia World.

Dr Paula James is the Medical Director of the Inherited Bleeding Disorders Clinic of Southeastern Ontario, and the Women and Bleeding Disorders Clinic at the Kingston General Hospital. She is also a clinician scientist with a major focus on bleeding, von Willebrand Disease (VWD), and issues related to carrier bleeding. The WFH is very proud to have her on its von Willebrand Disease and Rare Bleeding Disorders Committee. We are also very proud that James is one of the first grant recipients of the WFH Clinical Research Grant Program.

Dr James is now working on a project called Let's Talk Period, which has the objective of increasing awareness of the signs and symptoms of bleeding disorders. The Let's Talk Period website offers a self-administered bleeding assessment tool (Self-BAT) that helps give people more information and advice about their bleeding and guides them toward the support they need.

During the interview, Dr James was able to provide us with rich insight into the issues facing women and girls with bleeding disorders. The reality, she explained, is that many women go undiagnosed and are not getting the treatment they need. Especially, when it comes to menstrual bleeding, it is difficult to make the distinction between what is normal—and what is abnormal and requires additional attention. The social stigma surrounding women and girls talking about their period is another barrier in proper diagnosis.

The following is an excerpt from our interview with Dr James where she shares her experiences regarding Let's Talk Period, and the positive impact it's having on the bleeding disorder community.

Why did you decide to study women and bleeding disorders? What interests and motivates you about this subject?

My interest in women and bleeding disorders started with patient interaction. It became blatantly obvious to me very early on in my career that women were struggling. In some instances, women were being cared for properly, but in many instances, they weren't. I realized the frustration around the lack of recognition of the issues affecting women and I wanted to be part of the movement, to make people more aware of the issues at hand and to provide better diagnosis and care for these women.

> *The reality, she explained, is that many women go undiagnosed and are not getting the treatment they need. Especially, when it comes to menstrual bleeding, it is difficult to make the distinction between what is normal—and what is abnormal and requires additional attention.*

It's not hard to treat women with bleeding disorders—in fact, it's actually quite easy. It's not complicated medicine; we have a whole list of effective treatments we can use. What's important is that we make sure we are identifying the right patients and getting them to the right clinics so they can be cared for properly.

Can you tell us more about the Let's Talk Period Project?

I had the general idea for Let's Talk Period five years ago. I was involved in developing bleeding assessment tools—also known as bleeding scores—which quantify the kind of bleeding that patients are experiencing. A lot of work went into validating an expert-administered bleeding assessment tool in primary care offices in Kingston, Ontario, with the goal of increasing referrals for bleeding disorders. Unfortunately, the referrals didn't happen. We still don't recognize how often—when a woman says that she's having problem with her period—that the underlying problem is a bleeding disorder. We decided to go to the general public and put knowledge in the hands of people who might be suffering with symptoms. We took the expert bleeding assessment tool and turned it into something that could be self-administered. This was an evolved optimization process, which included many rounds of revisions using feedback gathered from focus groups and from the way patients filled out the tool. We wanted to ensure that the bleeding score from the Self-BAT would be the same as with an expert administered tool. We are now able to provide people who complete the Self-BAT with a printable version of their results. If they find out that their bleeding is abnormal, there is a recommendation to speak with their physician about any concerns they may have.

We decided that we would use the internet—and especially social media—as a platform to get the word out. The website launched in May 2016 and the Facebook and Instagram pages launched in September 2016.

What has been the response from the public? When the WFH shared your site on our social media channels, the community reacted strongly with comments and shares.

I've been blown away by the response. I never fully understood the power of social media, especially as a knowledge translation and research tool. I knew it was an important topic, but didn't realize that there would be such an appetite for it.

There has been a steady growth on the website and on social media. As at March 2017, there have been over 9,124 hits on the website, 1,154 people have taken the Self-BAT, and 515 have an abnormal or positive score. Our Facebook account has 587 followers with a reach of 80,344 people. Our Instagram account has 82 followers.

I would never have anticipated the global reach of doing this project—the hits on the website are from 83 countries.

What do you hope for the future of the Let's Talk Period project?

I really would like to close the loop with the site. Right now, I don't know anything about what happens to people who take the test and have an abnormal score. Locally we would like to pilot a project where individuals in my catchment area would be invited to participate in a study that they would have to consent to and this would fast track them to our clinic for assessment and diagnostic testing. At the end of the test, we would like to build in a link to local clinics as much as we can, so people can have an idea of where they can get specialized care. We would also like to create links with practitioners who are willing to see patients and make the diagnosis.

Do you have a message that you would like to share with the global community?

The message that I would like to share with the global community would be the following:

To our community and colleagues, I would say this: Let's Talk period has been a far more powerful tool than I ever imagined. It is a reasonable way to reach individuals who are suffering with bleeding and don't know it.

To the general public, I would say this: pay attention to your bleeding symptoms and seek help if you are concerned. Your symptoms can be easy to treat and there are many great options for treatment.

Since this article first went to print in 2017, the Let's Talk Period site has continued to be very popular. Dr James wanted us to know that to date the site has had 23,742 Website hits from 123 countries, and there have been 3029 Self-BAT's completed, including 1715 that are abnormal (57%). On social media, the site has 1,003 FB followers, and a reach of nearly 200,000 people, as well as 157 Instagram followers. Add them to your list today!

To learn more about the Let's Talk Period project, please visit letstalkperiod.ca. We encourage you to share this site with your network, to help increase awareness of women with bleeding disorders.

The WFH and HFNZ would like to thank Dr James for taking the time to share her experience with us on this important project.

Since this article first went to print in 2017, the Let's Talk Period site has continued to be very popular. Dr James wanted us to know that to date the site has had 23,742 Website hits from 123 countries, and there have been 3029 Self-BAT's completed, including 1715 that are abnormal (57%).

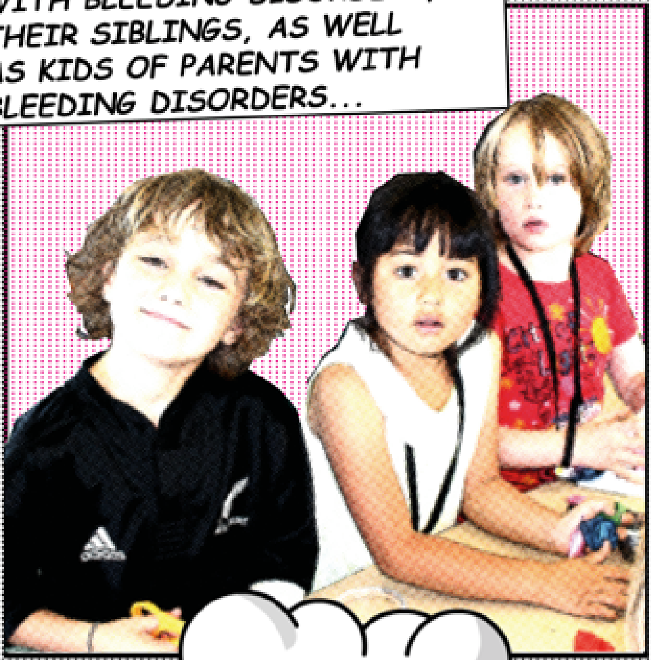
HFNZ WANTED A WAY TO GET KIDS AGED 6-10 TOGETHER FOR SOME FUN, LEARNING, AND SHARING. SO THEY CAME UP WITH...

The HFNZ Children's Superhero Workshop!

And Parents' Morning Tea...

COMING SOON!

BECAUSE BLEEDING DISORDERS IMPACT ON THE WHOLE FAMILY, HFNZ DECIDED TO INVITE KIDS WITH BLEEDING DISORDERS, THEIR SIBLINGS, AS WELL AS KIDS OF PARENTS WITH BLEEDING DISORDERS...



CONTACT YOUR OUTREACH WORKER TO FIND OUT MORE

MEANWHILE...

ALL SUPER-PARENTS ARE INVITED TO JOIN AN OUTREACH WORKER FOR A CUPPA AND A CHAT IN A LOCAL CAFE, AFTER THE KIDS HAVE BEEN DROPPED OFF...

Haemophilia Foundation of New Zealand Inc.
HFNZ

NACCHO

2018 North American Camping Conference for Haemophilia Organisations

NACCHO (North American Camping Conference for Haemophilia Organizations) is an international weekend conference, held in Phoenix Arizona, that focuses on the work of bleeding disorder summer camps. NACCHO is facilitated by presenters and leaders from the across bleeding disorder community who share useful camp resources and techniques. Participants exchange resource materials, meet with representatives from other organisations, pick up new ideas, and share their most successful endeavours with people from other camps. Our very own **Courtney Stevens** attended the most recent event.

This year, I was lucky enough to attend NACCHO (North American Camping Conference for Haemophilia Organisations) in Phoenix, Arizona. Every year the Arizona Haemophilia Association hosts approximately 200 people at NACCHO, where we learn different techniques and ideas for our camps, and network and share stories with other camp leaders. This was my first time attending NACCHO and I have returned feeling energized & full of ideas that I can't wait to help implement in New Zealand!

The theme for NACCHO this year was 'Pay it Forward'. This provided us with an opportunity to reflect on what we have given in the past and consider what we want to give in the future.

As an international guest, I was invited to attend the Pre-Conference as well (normally only reserved for Camp Directors) which started one day prior to the rest of NACCHO and had around 70 attendees. During this time, there was a great mix between facilitated sessions with everyone present, and smaller group activities, which allowed us to share ideas more freely. One of my highlights from the pre-conference was an activity known as '60 Second Seminars', where everyone got the chance to get up in front of the room and teach us all something about anything at all – the catch; you only had 60 seconds! This was a chance for us to get to know each other a little better, as people typically chose a topic they were interested in or passionate about. It was also valuable in the sense that it allowed people to realise that they are an expert in something, even if they don't think so.

> *The theme for NACCHO this year was 'Pay it Forward'. This provided us with an opportunity to reflect on what we have given in the past and consider what we want to give in the future.*

The pre-conference was centred on staff-training ideas and facilitation techniques, and was more integrated with group discussions rather than one person constantly talking to the group. This allowed people to share their own ideas, ask questions, and learn from each other.

The official conference period began on the Friday night, where we started-off with an 80's Dance Party! We were then split into groups and tasked with creating a fictional balloon animal. Once we had all created our animals, we went around all the groups where everyone had a chance to share their creation and provide some facts about the animal. During dinner, we had a presentation from Chris Bombardier about his work promoting awareness while climbing the seven summits and assisting 'Save One Life'. We were then tasked with a challenge – Play it Forward! The mission: to play as many games as possible to earn points, these points were then converted into actual dollars, with a goal of raising $1000 throughout the weekend to donate to Save One Life.

NACCHO included a mixture of keynote speakers and breakout sessions. The breakout sessions allowed us to choose which topic we were interested in attending, and they were repeated so we were able to see more than one session.

This year, the international guests were invited to give a presentation on what camp looks like in their countries during the conference. There were quite a few countries presenting this year: Romania, Nicaragua, India, Turkey, New Zealand, and Australia. The international presentation was a chance to share what we do in our countries in terms of our camps and other educational workshops. It was interesting to me that many of the chapters in America run only one camp every summer which is targeted at a specific age group rather than what we do here in New Zealand where we cater to all age groups.

The sessions I attended included tips for coming up with fun activities for kids on a budget, planning programming for younger children, and a first-time camp directors' panel. Each session allowed me to hear the experiences from the other attendees and provide my own insights. The smaller group environment created by the breakout sessions allowed for greater group discussions.

Overall, the entire experience was amazing. It was so enlightening to see what other countries are doing and how they make their situations work for them. One of my highlights was the dinner on Saturday night where we had a 'Camp Song Karaoke' – I have learnt so many new camp songs! I want to thank HFNZ for the opportunity to attend and cannot wait to share what I have learnt and get some new exciting camp activities underway!

GHA Forum - Budapest

Global Haemophilia Advocacy Leadership Summit

Organised by the Haemophilia Advocacy Advisors Board and Haemophilia Solutions by Bayer, the Global Haemophilia Advocacy Leadership Summit convenes global advocates to identify and discuss unmet needs in the haemophilia space. Held annually and now in its fourth year, the Summit provides a platform to discuss important issues affecting advocates and the training to implement change within their haemophilia communities. HFNZ CEO **Richard Chambers** reports on the summit.

HFNZ has had two representatives selected and sponsored to attend this forum for the past three years, by the Haemophilia Advocacy Advisors Board (HAAB) and the event sponsor, Bayer. The HAAB, Val Baas (USA), Carlos Galan (Mexico), Brian O'Mahony (Ireland), Yasuharu Nishida (Japan), Uwe Schienkrick (Germany), Mark Skinner (USA) and Pam Wilton (Canada) create and lead the programme.

Our representatives were Richard Chambers (CEO) and Deon York (President). They gave up the sizzling southern summer for a quick trip to Hungary with temperatures below 0° and more time travelling than actually in Budapest.

This year's theme was advocacy for access to innovation. The global haemophilia community is very aware of the innovative treatments that are now becoming available, or will be within the next five years. We need to consider carefully how we work with politicians, funders, and pharmaceutical companies to gain access to these new generation treatments for the right people at the right time.

Topics included:

Innovation Evaluation for Payers

Discussing what the payers consider when evaluating the benefits, risks, value, and costs of an innovation for a specific patient group. For example, there may be a strong case for making a new treatment available for a person with a severe condition, but not for a mild condition. How do we as patient advocacy groups respond to this?

How to advocate in 280 characters or less

Using current and new mass communication methods to share information and create interest

Expert Panels

Discussing the economics of health care from different perspectives.

Assessing Innovation as part of stakeholder communications

How do patient advocacy groups ensure that they are part of the assessment of new technologies and talk the language of the decision makers?

Global Innovation and Its impact in Advocacy for Rare Diseases

A challenging presentation from Carole Langson from the National Institute for Health and Care Excellence NICE (UK) about how the UK has created a model for evaluating the cost benefit of health innovation. Of note was that by NICE criteria Haemophilia as a whole is not a rare condition, but sub groups do or may fit the definition of a rare condition; e.g. Factor 13 deficiencies, inhibitor patients, or severe patients. This could result in some Haemophilia A people having access to a new treatment but some not as they would be in different funding categories, as well as having a different level of assessed need.

PROBE (Patient reported outcomes, burdens and experiences) international survey

HFNZ will be asking for your involvement in this project in the near future. We're also supporting the World Bleeding Disorder Registry project, and other advances in information collection, to support the bleeding disorder community to inform international and national decision makers.

Deon and Richard presented a poster, put together by Deon, Richard, and Phil Constable about the advocacy that lead to creation of the NZ National Haemophilia Management group 10 years ago, the ongoing advocacy process that has resulted in our current comprehensive care model, and the participation of HFNZ with the National Haemophilia Management Group. The poster was one of four selected for a verbal presentation at the main meeting.

> *This year's theme was advocacy for access to innovation. The global haemophilia community is very aware of the innovative treatments that are now becoming available, or will be within the next five years. We need to consider carefully how we work with politicians, funders, and pharmaceutical companies to gain access to these new generation treatments for the right people at the right time.*

Delivering the settlement proposal to MoH.

2017 HCV Survey Report

In order to fulfil our contract with the Ministry of Health, each year HFNZ is required to produce a comprehensive report on how our members are affected by HCV, and what we do to support them. The 2017 report was submitted in January 2018, and is summarised by **Phil Constable**.

Since 2009 HFNZ has been contracted by the Ministry of Health (MOH) to provide support services to individuals with both haemophilia and the HCV virus, and their families and whānau. A part of the contract is surveying our members, and producing a report for the MOH based on the feedback we get. The information we collect and supply to the MOH via the report paints a picture of change over time, and gives our members the opportunity to comment on their experiences of the virus and of the available treatment options.

At the time of the survey, of the original 197 people who contracted it via contaminated blood products there were still 22 who continued to suffer with chronic HCV. Of those, seven are currently undergoing treatment, five are unsuitable or unwilling to undergo treatment due to age or other health issues, and the remainder's status is unknown.

In 2017, HFNZ spent 243 hours specifically on HCV issues, including 47 hours of Outreach contact with people with bleeding disorders (PWBD) who are also infected with HCV. In particular, a lot of time was spent supporting members undergoing the latest direct acting antiviral treatment. Under the provisions of the Treatment and Welfare Package for People with HCV, all affected HFNZ members with existing ACC claims are eligible, where clinically appropriate.

HFNZ also continues to develop and maintain relationships with a number of outside agencies, including the HCV Advisory Group, treatment centres and hospitals across the country, the HCV Community Clinic in Christchurch, the Needle Exchange programme, public health researchers at the University of Otago, and ACC.

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HFNZ sent out 23 surveys in 2017, 14 via email and 9 by mail. Three other PWBD and chronic HCV were not included due to lack of current contact details. Outreach Workers followed-up by telephone or in person with all those surveyed, to assist with any queries they might have.

In total seven surveys were returned. The response rate was 30%, a 15% decrease on 2016.

Of those who responded, 83% reported having ever had treatment, either interferon-based, as part of a DAA clinical trial, or via ACC funded interferon-free treatment. Of those, none was currently undergoing treatment, and four had completed treatment in the last 12 months. Encouragingly, 60% had achieved a sustained viral response to treatment.

When all respondents were asked about their liver health four (67%) respondents indicated that they had been diagnosed with fibrosis, one (17%) with cirrhosis, and one (7.69%) with fatty liver. One (17%) respondents reported not having any of the listed conditions.

When participants were asked about the biggest barriers they have faced with regard to their HCV treatment, responses included:

"Took so long for me to get treatment due to not being able to take time off work (had to support my family)"

"Assumed to be an intravenous drug user by society, and initially by even some medical professionals"

Overall, half of respondents felt their general health was good or better. In 2017, 3 respondents (50%) reported their general health as good, very good or excellent, and three (50%) reported it as fair. The proportion who reported their health as poor (0%) was significantly lower than in 2016 (8%).

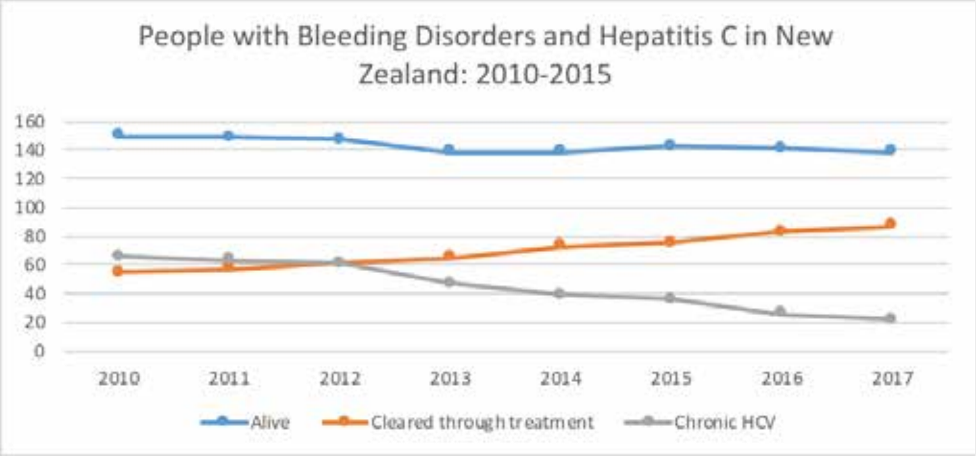
Many respondents reported having some level of physical limitation, especially when related to vigorous activity (50%). There was less impact on moderate activity, with two respondents (33%) reporting some level of limitation. It is common for older men with haemophilia to have some joint damage due to haemophilic bleeding over their lifetime, which could also be contributing to the limitation of their physical activity.

While PWBD are often physically disabled, or have impaired mobility, many are able to go about daily activity, such as cleaning and dressing. The survey showed that one third of respondents found these tasks harder to complete because of pain (n=2; 33%). Half of the respondents (n=3; 50%) agreed that it takes more effort and energy to complete daily tasks, which is not related to having a bleeding disorder.

HCV-related fatigue is negatively affecting members in their regular activities. Half of respondents indicated they had stopped or at least partially reduced doing a hobby or activity due to fatigue. The impact was even more pronounced on social activities, where 66% of respondents indicated their hepatitis C interfered at least partially with their social activities.

Half of respondents agreed that they have at least good social support systems. However, none rated their support as excellent. Significantly, despite a high clearance rate, half of respondents still worry at some level about the ongoing effects of HCV.

There has been a trend towards an increase in reports of depression over previous years of the survey, with all respondents agreeing they felt depressed to some degree in 2017. This represents a significant increase over previous



years, where 58% reported some level of depression in 2015, and 54% reported some level of depression in 2016. It is interesting to note that apathy levels have remained high during 2017, with 67% reportedly affected at least slightly in 2017.

The percentage of respondents who indicated that their level of anxiety has risen is significantly higher than 2016, with all 2017 respondents indicating their anxiety has risen at least. Only 33% indicated they slept mostly or completely well.

Although only 50% of respondents agreed that exercise was important to them, 66% (n=4) reported participating in moderate activity for more than 30 minutes at least 2-4 times per week, with two of these (33%) exercising almost every day.

Likewise, all respondents indicated that they are aware of long-term consequences of HCV. The level of knowledge of current treatment continues to be high with all but one respondents feeling well or fairly well informed. All respondents also had at least a good idea of transmission risks of HCV.

The major goal for 2017 is to continue to enable as many of our members as are deemed clinically appropriate to undergo treatment with DAAs under the terms of the agreement reached between Ministry of Health and HFNZ, the Treatment and Welfare Package for People with Hepatitis C, on 9 September 2005.

To that end, HFNZ expect the need for advocacy and support of PWBD and HCV to continue in 2017. Encouraged by the success experienced by the first members going through the DAA treatment process, HFNZ will be working with all eligible participants to facilitate their access to DAA products. Supporting patients through the treatment process can be time and resource intensive; however, the potential benefits of improved longevity and quality of life are invaluable.

Although the numbers of PWBD may be decreasing, those that continue to live with the disease are requiring ever more support from Haemophilia Outreach Workers (HOWs). In addition, many of those who have recently achieved a sustained viral response have already incurred liver disease, and their need for support and information will only increase with time.

As always, Outreach Workers will continue to communicate directly with members, their families and associated organisations (employers, universities, private training establishments) regarding the, sometimes debilitating, ongoing effects of HCV, even post-clearance, and how it affects the individual as needed on a case-by-case basis.

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News from around the world

Fiji Haemophilia Foundation Medical Symposium

The haemophiliac foundation in Fiji hosted its first-ever local medical two days symposium at Nadi Bay Resort.

Co-founder of the foundation and a board member, Roshika Deo said the objectives of the foundation was to create awareness, source services and medications, and advocate for people with haemophilia in Fiji.

“It is a general lack of awareness, stigma, discrimination, and major gaps in medical services for people living with this genetic condition,” she added.

Miss Deo believed the event was to hold the first-ever medical symposium on haemophilia, which is a genetic medical condition in which your blood doesn’t coagulate or you have spontaneous bleedings in your muscles and joints causing deformity.

“The second day was to set up Fiji Haemophilia Foundation – Fiji first and a much needed body to create awareness, source and provide factors (medication for haemophilia which is not available in Fiji) and increase the capacity of medical professionals to identify, treat and provide patient care including technical lab diagnostic capabilities,” she added.

She said over 50 medical professionals participated in the medical symposium on Saturday and over 30 patients and their family members participate on Sunday.

“Medical professionals have been able to gain technical knowledge on haemophilia during the medical symposium and we then had a panel with patients and their families who shared their experiences and difficulties,” she added.

“This would help improve the services that medical professionals provide on same note patients will benefit the most as they will finally have access to proper diagnostic services, medications to live a healthy life, a life free from pain and reach their fullest potential,” she added.

Meanwhile, the medical symposium is hosted by LA Kelly Communications (USA) who is an expert in haemophilia education as well the medical specialist from New Zealand not forgetting local medical practitioners, nurses, educators, people with haemophilia and families.

Source: http://www.thejetnewspaper.com/2018/02/19/fiji-haemophilia-foundation-medical-symposium/

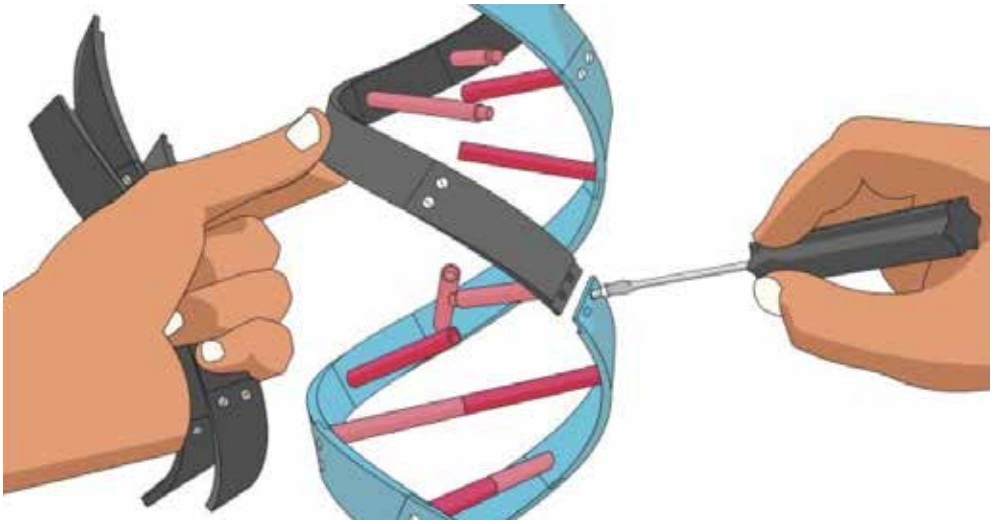
Gene therapy making strides in treating rare diseases

Research beginning to show results for conditions such as haemophilia and inherited blindness

BY CLAIRE O’CONNELL

The idea behind gene therapy sounds simple – a person is born with a version of a gene that causes a disease, so you deliver a new gene to resolve the issue.

But the path to getting gene therapies working in humans has required decades of research to understand the particular genes needed and how best to deliver the genes into the body, often using modified viruses as carriers or “vectors”. That research is



now starting to bear early fruit for some patients with rare conditions such as haemophilia and inherited blindness.

It's an exciting time for the field, according to US-based Dr John Murphy, who is vice-president, biology, at Pfizer's rare disease research unit.

US-based Dr John Murphy: "All the patients treated [in a gene therapy study] have responded, and most of them are not bleeding at all."

He was in Ireland last week to speak at the BioPharma Ambition event about gene therapy, where it's going and what we are learning along the way. "The technology, we feel, has reached a point where you can impact disease," he says.

Haemophilia success

One condition where gene therapy has made a recent splash is haemophilia B, a rare genetic disorder where the function of a clotting factor called Factor IX is disrupted. This means people with the condition can bleed for longer, and in severe cases that can cause internal damage.

Late last year, the results of a gene therapy study for haemophilia B delivered promising results: A group of 10 men with the condition received an infusion of a "new" Factor IX gene and most of the participants had no bleeding attacks in the space of a year or more.

The study, published in the New England Journal of Medicine, was supported by Pfizer and US company Spark Therapeutics. "All the patients treated [in the study] have responded, and most of them are not bleeding at all," says Murphy.

Haemophilia B gene therapy has been widely researched and getting the measure of it has taken some time, he notes, but advances in understanding how the immune system responds to the therapy and the ability to target the gene more specifically in the body have helped.

"We don't know how long the effects will last, but these treatments are durable and one injection lasts for as long as anyone has looked so far," says Murphy of the trial. "There is the potential for people who have a rare disease to live their life as if they don't have a rare disease, in terms of not having to think about taking medicine."

Eyeing-up gene therapy developments

Spark Therapeutics also has an interest in gene therapy for inherited forms of blindness, and in early 2016 the company acquired gene technology to target retinal disease that was developed at Trinity College Dublin.

That research in Trinity was started in the 1980s by the patient group Fighting Blindness Ireland, and led to the discovery of key genes involved in retinitis pigmentosa or RP, a rare inherited form of progressive blindness.

Prof Jane Farrar, Prof Pete Humphries and colleagues researched the genes and developed a system to "rescue" their function with gene therapy. The technology was acquired by Spark in the United States.

"Spark Therapeutics recently achieved a hugely significant milestone in the field – the company recently got FDA approval for a gene therapy, Luxturna, for another eye disease which is the first of its kind," says Farrar.

Overall, our understanding of gene therapy has grown in the last 10 to 15 years, says Farrar. "Because these gene therapies are rationally designed to target a specific inherited problem, they have the potential to have a powerful effect," she says. "And we have learned a lot about the best ways to design and manufacture gene therapies to optimise them, and about how the body responds to them."

New genes for stickier skin

For University College Dublin researcher Dr Lara Cutlar, the target is a rare condition called epidermolysis bullosa or EB, where the skin blisters and peels off easily.

EB hit the headlines recently when it was revealed that a boy with the condition had been successfully treated by genetically altering his skin cells in the lab and growing them up to be attached back onto him.

“I was at a conference in Austria when that work was presented to the top experts in EB, and everyone in the room went quiet, people were blown away,” recalls Cutlar.

Working with Prof Wenxin Wang in UCD, she is developing a more generic type of gene therapy for a form of EB called recessive dystrophic epidermolysis bullosa, where the body cannot make enough of a protein called collagen VII to anchor skin layers in place.

The research, which has been funded by Science Foundation Ireland and Debra Ireland, uses a specially designed molecule to carry genes into the skin and allow the body to make collagen VII to secure layers of skin.

“We are using a polymer-based gel that can hold on to the collagen genes and get them to where they are needed,” explains Cutlar. “We have done extensive laboratory studies and are now at the stage of looking at how to scale up the [molecule] and produce them in larger amounts for trials.”

Future impact

While some forms of gene therapy are closer to being available than others, for Cutlar, Farrar and Murphy, the ultimate drive of their research is to help patients. “This is really an exciting time,” says Murphy. “And it’s nice to work in something where you can see the obvious impact of what you are doing.”

Source: https://www.irishtimes.com/life-and-style/health-family/gene-therapy-making-strides-in-treating-rare-diseases-1.3400252

Roche haemophilia drug lowers costs despite high price: ICER

REPORTING BY DEENA BEASLEY; EDITING BY CYNTHIA OSTERMAN

(Reuters) - A costly new Roche Holding AG drug to treat the bleeding disorder haemophilia A could significantly reduce healthcare expenses for certain patients, a draft report from an independent U.S. nonprofit organization that evaluates clinical and cost effectiveness of new medicines said on Friday.

Logo of Swiss drugmaker Roche is seen beside the entrance of its research unit Roche Glycart AG in Schlieren, Switzerland December 18, 2017. REUTERS/Arnd Wiegmann

The drug, Hemlibra, or emicizumab, was approved by the Food and Drug Administration in November as a once-weekly injection for adults and pediatric patients with haemophilia A who have developed inhibitors, or resistance, to other treatments. Roche’s medicine is required to carry a black box warning, the most serious, about the risk of blood clots.

The Institute for Clinical and Economic Review (ICER) found that, for such patients aged 12 years and older, emicizumab at current wholesale prices would reduce spending by around $1.85 million per patient annually. In patients under 12 years of age, emicizumab would reduce costs by about $720,000 per patient annually.

Haemophilia is a rare bleeding disorder in which a clotting protein is missing or does not function normally. Roche plans to charge about $482,000 for the first year of treatment and $448,000 a year after that.

To avoid joint damage and other complications, patients with severe haemophilia need regular infusions of very expensive clotting factors. About 25 percent of people with severe haemophilia A develop factor antibodies, called inhibitors, at some point, making it difficult to control bleeding without very high doses of clotting factors or other expensive treatments known as bypassing agents.

Hemlibra is an antibody designed to activate the natural coagulation cascade and restore the blood clotting process for haemophilia A.

ICER noted in its analysis that haemophilia is a lifelong disease that creates substantial burdens for patients.

Source: https://www.reuters.com/article/us-roche-hemophilia-icer/roche-hemophilia-drug-lowers-costs-despite-high-price-icer-idUSKBN1FG00O

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. 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 over the summer.

Central

By Ashley Taylor-Fowlie

The Wellington fishing charter that had been planned for late 2017, and was postponed due to the weather, finally took place at the end of January 2018. Originally, this event was intended to be for men with a bleeding disorder. However, with low numbers, we extended this to any men and accepted some requests to bring children too.

This was a great day for those who did attend, even though the fish were not keen on being caught. The weather was fantastic and the conversation lively, and most of us were able to return home with fresh fish for dinner.

We had our first committee meeting of the year on Sunday 25 February to plan further events for the central region.

These include a quiz night for World Haemophilia Day. Planning is also underway for a youth event as well as a camp in Napier on 1-2 September. Our last camp was held in 2016 so we are due a winter escape together as a region. Keep an eye out for your invites in June. And if you have any suggestions for events you would like to see in our region please drop us an email at hfnzcentral@gmail.com

Midland

By Tineke Maoate

Hi to all our Midland members and a big welcome to all our new members. I hope you've all had a safe and enjoyable summer.

We have an eventful year ahead of us with lots going on.

First up, we have a Youth event planned for Sunday 15 April; ten-pin bowling at the Hamilton Sky City starting at 11am. This event is for Youth aged between 11-18 years with a bleeding disorder, so we would love to see youth in the above age group there. This will be a great event for all our youth to have a good catch up.

Next, on May 27 (To be confirmed) we have a planned family event at the Rocktopia indoor rock-climbing park in Mount Manganui. This will be a great way interact with your families and support others when trying something new.

We are also in the planning stages of a men's masters event, for those aged over 35 years with a bleeding disorder.

We are also planning a morning tea for women who have a bleeding disorder, or have partners or children with a bleeding disorder.

For these events to be special and productive, we need us all to participate. These events are really important ways for us to support each other and to help support the foundation.

Midland has vacant positions on the committee if anyone is interested in supporting us. We try to get together every second month and work together to share the load planning future events for our families.

Our AGM is scheduled between August and October this year, so if you're interested in joining the Midland Committee, then please make contact with me and asap or you can put forth your nomination at the AGM.

I look forward to seeing old faces and new faces at the up and coming events this year.

Please come along and support Midland we would love to meet up and catch up.

Feel free to contact me on 078710006 or 0274949991 if you have any queries.
Take care and be safe.

Northern

By Neil Smith

Happy New year all.

Our end of year get together out at Parakai pools was another great outing. It was an absolute scorcher of a day, so, though it was packed, we had a good little possie reserved just for us. The big red man made a guest appearance too, and it looked like his elves in Lynley and Jess did a great job with pressies judging from the smiles from the little ones.

We had a few first timers on the hydro-slides, young and old, which was great to see.

Our next event was to be our summer camp, out at Chosen Valley in Hunua. Unfortunately, not enough people expressed interest in this event, so we have had to cancel. This is a bit of a shame, as the Northern Summer getaway has traditionally been a great weekend, and fantastic way to farewell the last of the golden weather. There's always next year...

Instead, we changed the event into a day at The Grounds, where we had a mini tornado that took part of the neighbour's roof off. We then we had no power, so the kids started their dinners off with ice-cream (they were sooo sad!). The Grounds has a massive supervised playground, so, while the kids played, the adults sat and talked. A lovely, if not a crazy, evening out, with the fabulous families of HFNZ. We would love to have more people be part of our committee to help with new ideas. Remember to give me, or anyone in the Northern Committee, a yell if you have ideas on events.

Enjoy the summer and cheers.

Piritoto

By Tuatahi Pene

Tēnā koutou katoa,

A big aspiration of Piritoto is coming to fruition in this New Year. 2018 is the year where we are broadening our goals and aiming to strengthen ties with all who are living with bleeding disorders.

Left to right images:

1. Central Fishing

2. Northern kids at Parakai Springs

We have successfully finished our summer weekend Noho in Raglan, the first of its kind since 2013, and what a great time was had. Piritoto is aiming to have one winter Noho followed by a summer camp each year, in as many different areas of the motu (islands) as possible, to encourage as many participants to attend and join in on the fun. The sun and sea weren't the only exciting aspects of being in Raglan; another was an opportunity to experience the recycle and waste initiatives that make Raglan one of the leading towns in New Zealand in waste management.

An acknowledgement must be made to the hau kainga (local residents) who took it upon themselves to secure a venue for the Piritoto whānau, a community hall called the 'Kokiri Centre'. A place that holds a great deal of history in Raglan. Not only could it house the many, the amazing part was that it was no more than 50m walk to the beach. Having the water near the camp gave the feeling that we were all on holiday, leaving our worries behind to enjoy our time; the children along with their parents and grandparents took full advantage of the warm weather.

We were lucky to have our very own tour guide, Hakopa Pore, a resident and Piritoto member, lead a convoy around some historical spots, and give us a kōrero about the area and a lot of the rich history behind the important landmarks and people. We also learnt about the colourful past behind the Kokiri centre and the land it sits upon.

Saturday afternoon was a scheduled 'Xtreme Waste tour' of one of Raglan's waste management treatment centres. The Raglan Resource Recovery Centre consists of a reuse shop, a retail wood yard, a retail metal yard, a public recycling bay, a refuse transfer station and a green waste drop-off. Their objective is to continually increase the ability to reuse materials in the community.

Ongoing with the theme of recycling, a spoke person for 'Parakore', an initiative on zero waste, came to talk about different ways to think about how products and food source can be recycled. Jacqui Forbes talked on what can be reused, recycled, and composted, thereby helping to reduce the extraction of natural resources and raw materials from Papatūānuku. The presentation inspired all who watched to contemplate their own view on how waste is treated and really assess what it means to achieve zero waste, looking at our own lives to process a new way of thinking.

A weekend full of days in the sun with the black sand in between our toes. The success, as always, is shown by the people who attend the Noho. It is a time to re-connect, to meet new people, a time to have fun, a time for learning as well as a time to relax.

A great appreciation to all those who made the weekend experience special. Nei rā te mihi ki a koutou katoa.

Mā te wā whanau.

The Year Ahead...

April & July 2018

- **Regional Children's Workshops**
  - Central: April 17 @ Johnsonville Community Centre, Wellington
  - Midland: April 24 @ Discovery Christian Centre, Hamilton
  - Northern: July 9 @ Athol Syms Hall, Epsom
  - Southern: July 17 @ Bromley Community Centre, Christchurch

May 20 - 24, 2018

- **WFH World Congress**
  Glasgow, Scotland.

August 31 - September 2

- **Central Winter Escape**
  Kennedy Park, Napier

September 14 - 16, 2018

- **Women's Wellness Weekend**
  Copthorne Oriental Bay, Wellington

October 20 & 21, 2018

- **HFNZ AGM and Governance Workshops**
  Copthorne Oriental Bay, Wellington

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

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