

Bloodline

Our People:
Grant Hook



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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

In this issue of Bloodline, we farewell Colleen McKay as she retires from her role at the Foundation. Of course, as you all know, Colleen is also a member of our community – so it’s not really goodbye! Colleen’s association with HFNZ began after the birth of her son a mere 37 years ago. As a volunteer, outreach worker, and outreach manager, she has dedicated many years to this community and seen many of us grow up (and grow old!) The National Council presented Colleen with a gift as a token of our appreciation for her many years of service, but we won’t be stopping there. We will also be acknowledging her impact on our community at the next HFNZ national event in Auckland in late September.

Thank you Colleen for your service and commitment over many years. Goodbyes can be challenging, but I know for sure that Colleen only wants to see the Foundation grow from strength to strength and we all have a role in making that happen.

To keep HFNZ strong, we cannot be idle. At the last National Council meeting, an important decision was reached to ensure this. A property search for the national office has been initiated to be relocated to Wellington and make use of the property fund formed by the four branches over ten years ago. There have been a number of discussions and some action taken from successive national councils about using this fund according to the wishes of the membership. It has now been more than 10 years since the creation of the fund and a move is timely.

To provide some background to the fund, in 2007, because of requirements of the Charities Act 2005, we amalgamated the bank accounts of the four branches’ of the Foundation. Without the amalgamation, we would have not



been considered as one organisation. At an Annual General Meeting, the membership agreed that the funds were to be put aside for purchasing a property. This resolution was reached after a long discussion about how to fairly use funds raised in different regions for a national purpose. The fund has been left earmarked for property purchase ever since. Any borrowing in addition to the property fund will require a resolution at a special general or annual general meeting according to our constitution.

A property purchase and move for the national office will require work and you will all be kept updated. As your representatives, the National Council are unanimous in their commitment to this decision with the ultimate motivation being to continue to improve the lives of people with bleeding disorders and keeping us moving in the right direction.

Deon York
HFNZ President



With Michael at ANZ Conference Canberra 2007

Our People: Grant Hook

Grant Hook is the type of person you want to be part of your organisation. He is committed and enthusiastic, and he isn't shy about expressing his opinions on how to make things work better. Grant has filled many roles for HFNZ, and worked very hard. From being Vice President and Treasurer of the National Council, to running camps in the Central Region, to working with the Cambodian Hemophilia Association to improve their outcomes, Grant has always given of his best to benefit people with bleeding disorders. **Phil Constable** talked to Grant about his life and times with HFNZ.

Like many HFNZ members, Grant Hook grew up in a time when there was very little information about living with haemophilia, and few options when it came to treatment. For the Hook family, it wasn't until big brother Peter was four, and Grant was two, that they were finally able to get a diagnosis. Grant imagines that it was a relief for his parents to know what was actually going on with their boys. Grant says that, from his perspective, his parents always seemed to cope well with having children with bleeding disorders, and all the associated difficulties, "if not, they didn't show it!" He found out after his parents passed away that doctors warned them their boys probably wouldn't see 20 years of age, which must have been very hard.

There's nothing about his childhood and upbringing that really stands out for Grant as being particularly unusual, other than having to take lots of time off school due to bleeds. One thing he does remember, though, is that he and Peter received no medicine-based treatment until he was around 12. That meant that he just had to rest and wait every time he had a bleed, and that, consequently, his joints have deteriorated as he's aged.

Although he had a brother who shared his bleeding disorder, Grant didn't really think about having haemophilia too much. They grew up just like most kiwi kids, mixing with the locals, and didn't have any contact with other people with haemophilia until Grant was in his 30s; when former HFNZ Outreach Worker, Helen Spencer, tracked him down.

In those days, most camps were advertised as family camps, and, because Grant didn't have a family, he figured that he wasn't meant to attend. Luckily, things have changed a whole lot since then, and we now cater for all our members at HFNZ events and workshops.

The first camp Grant attended was a youth camp, he says, "it was great to meet so many people with their own unique stories, and many I could directly relate to, which helped normalise haemophilia for me."

Since starting out with that first Youth Camp, Grant has gone on to attend three World Congresses and five Australasian Conferences, but he thinks his first Congress, in Istanbul, made the biggest impression. "Meeting people from around the world and seeing where they were for treatment took me back to my childhood, when there was no treatment, a big wakeup call, and it made me appreciate our level of care". For Grant, this conference highlighted that we have an ageing

haemophilia population, and how great that is, but also that we are now facing new issues providing different levels of support to older people.

Grant remembers that there was a great team representing HFNZ at the Istanbul conference, and that he enjoyed mixing with the other council members on a social level, "Michael and I have many fond memories of winding down at the end of the day over a few drinks".

Grant is from a generation of HFNZ members directly impacted by HCV and HIV, because of infected blood products. He recalls, "I was married when HIV came along, so it was pretty scary to think I may have infected my wife. I remember being tested, and then waiting for 6 weeks as the tests were processed in Australia". Grant was lucky that time, and avoided HIV infection.

Unfortunately, he wasn't so lucky when it came to hepatitis C. He was tested and, because his haematologist never gave him any results, assumed he was all clear. However, it turned out he was mistaken. Grant didn't know he was positive until 2 years later, when, at an annual review, a new haematologist mentioned he was still positive, "much to my surprise!" Grant went back to the haematologist who had received his initial positive result to find out more about his lack of disclosure. Shockingly, the haematologist said that, because HCV was untreatable at that time, he didn't see any reason to tell Grant about it. We're fortunate to have moved on from those dark days, and communication is now far more open.

Grant has been involved in the administrative side of HFNZ for quite a while, and in various capacities. His first foray came when he attended the HCV conference in Wellington in 2005. The Central Region held their AGM as part of the conference, so he thought he would attend. As Grant frames it, "I must have looked in the wrong direction, and came away as the Central Chairperson."

Being new to the Foundation, and to the role of Chairperson, and with little in the way of history or meeting minutes to learn from, Grant just went ahead and did things his way. He must have been doing something right though, because, by the time it came to running his third annual regional camp he had 86 attendees, the largest number of campers ever to attend a Central regional camp.

After serving three years as Central Chair, Grant moved on to become the Central Delegate to National Council. At the 2008 AGM the members elected him

Vice President, and then he moved over to become Treasurer in 2011; a position he held until retiring from the National Council in 2016.

As you can see, Grant has served HFNZ with distinction for many years.

Grant nominates the move to centralised funding as the biggest change nationally since he first became involved in the governance of HFNZ. However, this has largely been a positive change. He says, “This made it easier all round, less responsibility for the regions so they could concentrate on regional events, and better management for the office and council.”

One of the most rewarding things that Grant has been involved with is the WFH Twinning programme with the Cambodian Hemophilia Association (CHA). This initiative pairs an established organisation with one in a developing nation. The goal is to enable the new organisation to be self-determining, and to empower them to become supporters and advocates for their people. Grant was instrumental in a very successful partnership between HFNZ and CHA.

Here’s what Grant has to say about his experience of twinning:

There are many issues for Cambodia to work through apart from supply of products, which I thought would be their major issue. There is a group of very able and committed people working to improve the lives of people with bleeding disorders in Cambodia, and there have been significant improvements for people who are able to get to medical facilities for education and treatment. This work will be ongoing, just as it is in New Zealand.

This was a wonderful experience and made me appreciate how lucky we are in New Zealand.

HFNZ has a lot to offer the Twinning programme, we will always be there to offer support to Cambodia and if WFH see that we can help another country I would like to see us get involved again.

Looking to the future, Grant believes that HFNZ’s future leaders will need energy and commitment to continue to build on the foundation HFNZ has already established. He notes that the bleeding disorder landscape is constantly changing, in both funding and medical advances, alongside changes to our members’ needs.

He emphasises that a sign of a healthy organisation is that new people regularly become involved in the running of the place, bringing new ideas, and the energy to see those ideas through to completion. Bringing

new people into leadership roles also ensures that we maintain strong links between the council and members, so we are able to meet our members’ needs.

Putting his former Treasurer’s hat on, Grant notes that diversifying our income, being innovative in funding applications, and looking at new sponsors are keys to maintaining HFNZ’s services into the future. “Our level of government funding is very low, and I believe with more data collection on the work we do, and on volunteer hours, there are opportunities to apply for funding in other areas”. This work is ongoing and new avenues are always welcome, including corporate sponsorship, regular gifting from wages, and regional charities & trusts. Grant firmly believes that we all have a role to play by being aware of what may be on offer in our communities, but he worries that failure to maintain, or increase, our income will mean that we are not able to continue supporting our community in the manner we have been able to do over the past 50+ years.

Grant has given a lot to HFNZ. He’s offered his skills and experience at the highest level, represented us internationally at Congress, and through the WFH twinning programme, and has worked hard to make sure that we can offer the best services possible to our members. His retirement from the National Council left a big hole to fill, but is consistent with his belief in constant rejuvenation, in changing in order to grow. His legacy is one we could all aspire to; he left the organisation in a better state that he found it.

Grant’s final piece of advice: “Get involved! Volunteering is a very positive experience and plays a big part in New Zealand’s success and way of life”.



Top to bottom:
1. With Belinda Burnett at Central Family Camp
2. With Steve Waring at 2011 AGM
3. With Michael at World Congress Istanbul 2008
4. With Catriona Gordon at 2011 AGM



Connor Kimble learning self-infusion

Home Treatment and Bleed Reporting

One of the greatest improvements in the treatment of people with bleeding disorders is the ability for them to administer treatment at home. A big part of the WFH principles of care is that treatment should be given as soon as possible, and what better way to do that than at home yourself. Haemophilia Nurse, **B.J. Ramsay**, explains some of the responsibilities and best practices around treating bleeds at home.

One of the greatest improvements in treating haemophilia over the last half century has been the increasing ability for patients and their families to treat themselves at home. This has allowed access to treatment far more quickly and efficiently than was available through emergency departments, or haemophilia centres alone. WFH Guidelines for the Management of Haemophilia recognises in its principles of care that “patients usually recognize early symptoms of bleeding even before the manifestation of physical signs”, and that “acute bleeds should be treated as quickly as possible, preferably within two hours.”

Within New Zealand, we hope to maintain a standard of care that meets WFH Guidelines and our own Service Specifications for Haemophilia and Related Bleeding Disorders in New Zealand. Throughout all 6 Haemophilia Treatment Centres (HTC) in New Zealand patients will have access to clotting factors, either via your HTC or a local hospital (if you live a distance from your HTC). For those who can treat themselves or have a family member who treats them home therapy is actively encouraged. There are however some responsibilities for both the person receiving treatment and for the HTC providing the home treatment products.

HTC responsibilities include:

- Continue to supply/stock appropriate treatments at the HTC to cover hospital/emergency treatments.
- Supporting and maintaining your treatment in the home environment, often this is managed by your haemophilia nurse and includes things like arranging further supplies of factor etc.
- Ensuring that all parties involved in the home delivery service treat your personal details confidentially.
- Regularly reviewing your home treatment service to ensure its safety and efficacy.
- Providing accurate and current data on product use to the New Zealand Haemophilia Management Group (NHMG).

The person or family on home therapy’s responsibilities include:

- Ensuring safe storage and rotation of stock, to prevent waste.
- Using treatment according to the prescription guidelines worked out with your HTC. If you feel you need to change it in any way discuss this with HTC staff.

- Complete and return accurate home treatment records on a regular basis (ideally monthly if on prophylaxis, at least each time you request further supplies of factor) so that the HTC staff can accurately assess and monitor your response to treatment.
- Attend your pre-arranged appointments so that you can work with your HTC staff to make informed care decisions. If you are unable to make your scheduled appointment contact the HTC staff to rearrange it.
- If you have any issues/concerns about the home treatment service, to discuss these with the HTC staff.

The aim of these responsibilities is to ensure that the home treatment service organised between you and your centre will run smoothly and meet all needs for safe and effective home therapy for you, and that there is a well-managed and transparent system for the centre.

Treatment Diaries/Reports

If you treat yourself at home then your Haemophilia Centre will ask you to keep a record of when you use products and why. Recently Pharmac has taken over the funding of most haemophilia products and they require that the HTC provide correct information on the usage of these products. To enable your HTC staff to provide correct information we are asking you to keep record of your treatment usage. There are many ways of recording treatments. Some people use paper based methods, like a treatment sheet that they can attach the stickers from the factor vials to, some prefer to use an electronic method such as a spreadsheet, or a programme specifically designed for haemophilia records such as TRACKER FACTORY. No matter which method you choose the information on them is essentially the same. It should include:

- Product name and batch number
- Dose taken
- Date and time of treatment
- Reason for treatment (prophylaxis/bleed etc.)
- Any adverse reactions to the treatment

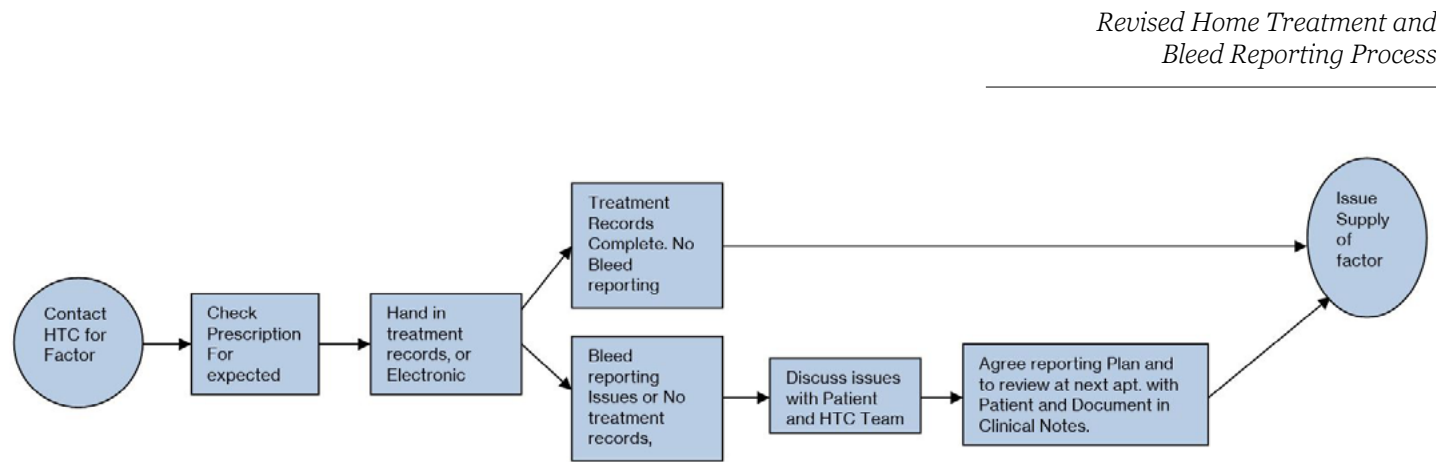
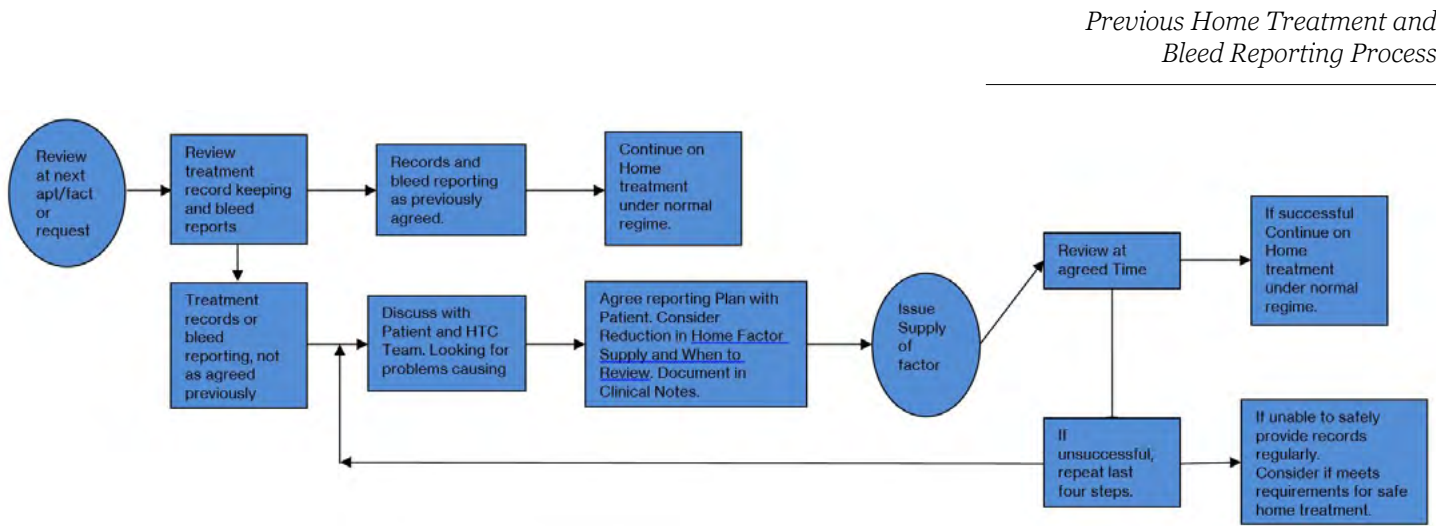
It is extremely important that these records are kept up to date and regularly returned to your Haemophilia Centre. Some people using the paper-based method photograph their records with their phone so they can easily bring the information with them to clinic.

The treatment record can be useful for lots of reasons:

1. Your HTC staff can note any unusual treatment patterns that might indicate a problem. They can then offer support, or refer you to another service.
2. In the unlikely event that there is a problem with a batch of treatment, your HTC will know exactly where all the affected batches are, and how many have been used.
3. When you come in for review the HTC staff know if you have had any problems/bleeds since you were last seen.
4. The HTC staff can make the appropriate usage reports to allow proper scrutiny of the service.
5. To ensure treatment is nationally consistent and equitable.

The Issuing of Factor and Home Treatment Records

HTC’s actively foster and support their patient’s home therapy where possible. However, patient safety is paramount within this and, as previously discussed, treatment records are an essential part of this safety. If there is not good quality record keeping, then an HTC may be required to reduce, curtail, or even stop home therapy for a patient. This is not done lightly, or to penalise, but to try to ensure patient safety. This will not mean that a patient cannot receive treatment, but that the treatment will be co-ordinated via the HTC and local hospital, so that the appropriate records, which are required for safe and accountable therapy, are kept for the patient. If this ever occurs, it is expected that the HTC and patient will have discussed it beforehand. Your HTC staff will always be available to make an appointment to review this with you.



2017 HFNZ Buddy Awards

PHIL CONSTABLE

Since the last issue of Bloodline HFNZ have celebrated World Haemophilia Day with the HFNZ Buddy Awards. The Buddy Awards are an opportunity for HFNZ members to recognise people in their community who have stepped up and really made a difference to their lives. In the past we’ve seen clinical staff, best friends, and community organisations nominated. This year we had fewer nominations, but they were all well-earned, and deserve to be celebrated by all.

This year’s winners included a Grandad, nominated by his grandson; a Camp Mother, nominated by a former camper; a nurse, nominated by a patient; and one community member nominated by another.

Rob Thorpe was nominated by his grandson, Izack Silva. In his nomination, Izack noted that Rob is always there for him, understands his bleeding disorder, and makes living with his bleeding disorder easier.



He goes on to say:
My Pop is a wonderful person. I have nominated him because he understands me and cares for me. My Pop always is overjoyed when I’m around him. I feel that when we are together I can tell him anything. If I have a problem his smile will make me feel happy straight away. He always encourages me in lots of ways. I love you Pop, you are the best friend someone could have.

Colleen McKay has been Camp Mother to a generation of young HFNZ members. She was nominated for a Buddy Award by Karl Archibald, who is now in his thirties, whom she remembers as an accident-prone camp



Top to bottom:
1. Izack & Rob
2. Colleen & Karl

kid surgically attached to his bicycle. In his nomination, Karl emphasises that Colleen has always gone above and beyond to understand, support, advocate for, and just be there for him, and other HFNZ members.

I nominate this buddy for being the warm friendly face to turn too, who provided information and consolidation when a parent’s world crashed down in the early stages after that initial diagnosis. For providing ongoing support, information and advocacy within the bleeding disorders community. For being camp mother, cuddles, for being the mother of the foundation, for countless hours of personal sacrifice, and behind the scenes work. For the supporting letters and recommendations for international programmes such as SURO and for providing the expert advice, planning skills and delivery systems that ensured a recent Advanced Leadership Training weekend went off without a hitch.

Kathy Fawcett was a Buddy Award winner last year too. It just goes to show how much work she does for the HFNZ community. This year she was nominated by Pablo de Figueiredo, who really appreciated all the help and support Kathy offered him when he had to undergo surgery recently.

I am certain this wonderful lady gives up more than her allocated working time to accommodate ‘out of business hours’ surgery related matters, not just for me but many other haemophilia patients. Kathy is immensely friendly, kind, and warm spirited, she brings out the best in people, and makes you feel at ease. Only a text or phone call away and always there for any day-to-day advice. I am truly grateful for her on-going advice and support.

Lynley Scott is one of those people who you know will always be there when you need them. She’s been a part of the HFNZ community for many years, in various capacities, and is a wealth of knowledge and support for all those who come into contact with her. She was nominated for a Buddy Award by Bo Silva, who is a parent of a child with a bleeding disorder, for understanding what life is like for her, and being there to support her when she needs it.

I would like to nominate Lynley as I feel she is a wonderful support person to me. If I ever have questions or issues regarding Izack or haemophilia, Lynley is always there to answer my questions & offer support. I really appreciate you always being there Lynley. Thank you so much.

These awards symbolise all that makes HFNZ such a fantastic community. We are always there for one another, with whatever it takes to help each other along. Well done to all winners. You make the world a better place!



Employment Issues

Finding a job can be really difficult, especially if you're young, just out of school, returning to the workforce after a long break, or have medical issues. HFNZ Southern Outreach Worker **Josiane McGregor** is very experienced in helping people from all walks of life find meaningful employment. She has a great range of tips and tricks to help you make the most of your skills and experience.

Whether you're looking for a job for now, or a 'forever' career, job search and career planning require thoughtful planning and consideration; not to mention an idea of what, why, when, how, and who.

Employment, whether 5 hours a week or 50, is well documented to have a positive impact on our psyche, and on our physical wellbeing. Being in work keeps us busy, challenges us, and helps us grow. It enables us to socialise and build contacts in our lives, provides us with money to support ourselves, and gives us a sense of identity and personal achievement.

"The expert in anything was once a beginner" **Helen Hays**

This is never truer than when looking at ways to choose, get, and keep work. While challenging and frustrating, work can be worthwhile and rewarding, so having some insight, tips, and tricks can help along the way. Talking to other people, and being able to ask for help, are also key contributors to success.

Your CV

Before you do anything else, it's important to put together a Curriculum Vitae, otherwise known as a CV. A CV is a document that job seekers use to tell a prospective employer about their previous employment and/or education. They're not always an easy piece of paper to produce, so knowing where to seek help is paramount in creating a document that you can show off proudly.

There are many ways to put together a CV, but the general layout should be as follows:

- Name and contact details
- Key skills and attributes – related to the job you're applying for
- Work history – most recent first
- Education - if applicable
- Any voluntary work or groups/clubs you belong to
- Hobbies – optional
- Telephone referees – may be included separately

Don't be shy to list and talk about your accomplishments in your CV - show off a little!

For examples and further guidance, you can go to Careers New Zealand's page [Parts of a CV¹](#), a great resource with many tips, not only for putting together a CV and a cover letter, but also for finding out information about jobs and careers, from

person specifications to salary and wage information.

Google™ is also your friend; make use of it to search out anything you want to know about a CV, even how to word your content.

A CV for a school student/leaver can be quite different and only cover education, and that's ok. It is also wise, to talk about your attributes in attending to school, your study, your commitment, and extra-curricular involvement.

So, what if you have no experience in employment, or have not worked in a while? This can be a frustrating and scary aspect of job searching, that many people experience, particularly if you have a medical condition or disability, or you're returning to work after having a family. The barriers associated with this can be daunting, and may feel impossible to overcome, but knowing who and where to seek support from will make your journey to work that much easier.

Voluntary Work

No work history, or no work history for some time, can be minimised or eliminated as a barrier by participating in some voluntary work.

Voluntary work can address a number of things for a job seeker all at once, and make your road to employment that much quicker by showing a recent work ethic, reliability, commitment to something, and by giving you a work related referee, which many people can struggle to find. Many agencies and charities offer the opportunity to volunteer. Even if you are not ready to go into formal employment just yet, and you want to test your capacity to attend to and commit to a role and workplace, this is an ideal environment to do so.

[Volunteering New Zealand](#)², the Salvation Army, Red Cross, St Vincent de Paul, and even [SEEK](#)³ are great places to start, as well as local food banks, marae, or second hand stores.

Voluntary work on your CV doesn't always have to be related to the paid work or industry you are interested in, because it still allows you to get out there, gain some skills, demonstrate a work ethic, and collect people who will vouch for you. However, volunteering in a job or industry that you want to go into is a valuable way to get relevant experience and referees.

It may also help you decide on a career or job by giving an insight to what it's like to work in the role or environment.

Preparation

“One important key to success is confidence; an important key to self-confidence is preparation”
Arthur Ashe

Being clear about the type of position you want is central to successfully landing an interview and getting a job. Preparing a CV and a cover letter are one thing, but having some idea about what sort of work you want to do will help make your job search more targeted and specific. This can be a difficult decision; many job seekers struggle to identify with any one specific job.

So, take a step back in your preparation. If you're unclear on exactly what job you want, think about other aspects relating to employment that are important to you. What do you want to do each day? Do you want to work inside, or outside? Do you want to work with your hands or in an office? Do you want to work in a large team or small? How many hours do you want to work? Day or night shift?

All these aspects of a job are important especially when someone may be factoring in a medical condition or disability. Can you work consecutive days, maybe you need alternate hours, or perhaps shifts that suit other aspects of your life?

These considerations are important when considering what sort of work you are looking for, especially if you're unclear about the actual role. Once you have a list, you may find that some points are non-negotiable while others are more flexible. Start thinking about where you might find the right working conditions for you. Begin by weighing up your list against the jobs advertised, and then start identifying which jobs look like they fit your criteria.

Job searching is daunting, and sometimes completely terrifying; being prepared will help build your confidence to get out there.

Where to Look

So, where and how can you find a job?

It used to be that the newspaper was the No.1 place people searched for employment. Nowadays, the internet and online job websites have the monopoly on the job seeking market. To be successful job searching online you need to be vigilant, and check daily so as not to miss that perfect job. Job seeking online requires you to have the computer skills to attach your CV and cover letter to your application. In some cases, this can be the first step in testing whether you're the right candidate.

While the newspaper and online job sites are important to your job search, your focus should be the 'hidden' job market. This is a term used to describe jobs that are not posted online or advertised. Many people do not recognise the hidden job market as being important, but it can account for up to 75% of the total jobs available.

You can tap into the hidden job market by networking with people you know, or by making cold calls to businesses that you would like to work for. You will need to commit time, energy, and focus, and have a positive and proactive approach. This approach requires you to have researched the organisation, finding out about what they do, and who the right person is to contact. Be prepared with questions you need to ask, what you want to say about yourself, and what you want from them. Practice beforehand, and do not be put off if there are no current vacancies. Offer to send or leave your CV for their files, and follow up with contact regularly to discuss any new opportunities.

Similarly, if you're registering your interest in working for a particular business online, remember that you still need to keep in touch with them.

What Employers Want

“Hire character, train skill”
Peter Schultz, former President and CEO Porsche.

What employers look for is not what you think.

It is important to understand that, in general, qualifications aren't everything. Employers place just as much importance on experience and personal qualities as they do on any qualification you may have.

Your ability to demonstrate that you're reliable and have a good attitude is often underestimated. According to one study, employers say that job seekers often overestimate the importance of work experience, citing it as the key criteria. Employers suggest that job seekers prioritise personal attributes, in conjunction with experience. Aside from skills and experience, employers indicate that reliability is a key quality they look for in candidates. Demonstrated reliability will raise one candidate over another, regardless of experience. Being positive is also a key quality, as is showing passion, and an ongoing desire for improvement.

In the absence of accumulated skills and experience, other things you've done in the past can indicate your ability to learn, develop, and succeed. This applies to first



time job seekers, as well as job seekers who have not worked for some time. Volunteer work is a great way to prove reliability and attitude.

As with all things, planning and preparation are key. Make sure you plan and prepare for [the job you want](#)⁴.

When was the last time you worked?

How do you explain a gap in employment to a prospective employer without compromising your appeal?

Face it head on, and be prepared. Keep it simple, think about it in advance, and almost script it in your mind.

Boost your appeal, be bold about highlighting your strengths, dispel doubts before they arise and be mindful of the employer's point of view.

When disclosing to a prospective employer previous or current medical information think about it from their perspective, identify any possible concerns or questions before they arise.

Don't get bogged down in details that are too personal, stick to the facts. i.e. "I had a health issue, took care of it, and I am now ready to get back to work", "I have a medical issue that required some intervention, it is now manageable and I am ready to return to work".

Positive disclosure around health or disability requires you to deliver information to the employer in a way that

they can acknowledge it, and understand its impact, without minimising your ability to fulfil the role.

1. Be positive about your condition, illness, or disability. Show that it's just part of you and doesn't negatively define you. This is the fastest way to start working together with a shared understanding. Most negative attitude towards illness or disability arises from a lack of understanding.
2. Talk about how you manage your health. A developed awareness of potential barriers, and ways to overcome or minimise them, shows you have taken control of your life, can anticipate potential risks, and have planned ahead.
3. Talk about what you have already achieved in spite of it.

Underlying your disclosure is the planning you have done in preparation for working. You can confidently approach your job search and an employer already knowing you can do the job because you have carefully planned ahead to address any potential barriers by making choices like, where you work, when, what you do, how long for etc. Thus minimising the risk as much as you can to your health and your ability to meet the requirements of the job.

Getting Help

Job seeking can be soul destroying. Add to that, life, illness, the labour market, where you live, and it can be difficult to start, let alone maintain. However, the outcome far outweighs these difficulties, and knowing when to seek help, and who to ask, could make your journey much less overwhelming.

There are a number of people and agencies, New Zealand wide, who can help you to find employment; from Recruitment Agencies to Employment Support Services, local community groups, or networking with people in your life.

Understanding how these avenues work will enable you to make an informed choice about what or who might be right for you.

First, networking with all the people in your circle of friends, whanau, and contacts should be part of your daily framework, and is highly rated as a job-seeking tool. You can take a direct approach and ask for job leads or try a less formal approach and ask for information and advice. Contact everyone you know. The people they know may surprise you. Make yourself pick up the phone and call. It helps to assign yourself a quota of calls to make each day. The more phone calls you make the easier it will become. Remember to be very specific about what you’re looking for so you’re not dealing with well-meaning jobs offers and leads that are not realistic.

Recruitment Agencies can be an essential part of job seeking, depending on what type of role you’re looking for. It’s a good idea to research what agencies place candidates in the industry you might be looking at, and approach one or two in an effort to get your CV out there. Remember to be proactive. Stay in touch with them after your initial contact. They may not always communicate with you as much as you would like, so it’s best to instigate the contact yourself. Ring them weekly, or twice weekly, depending on your situation. Try to stay professional and not react with frustration or impatience, this can reflect on you as a candidate.

[Employment Support Agencies](#)⁵ are for people with an ongoing medical condition or disability. Support areas focus on pre placement support such as job/career development, CV preparation, job seeking assistance, and ongoing support once in work. These agencies are skilled at helping you to develop your job seeking profile, support you to make informed choices about work, profile you to employers, and support you in your job. This kind of assistance is aimed at highlighting your strengths and abilities.

Finally, be mindful of the amount of time you are putting into your job search. There is a saying, “getting a job is a job”, try and take this on board and work at it. What you put into it is what you will get out of it; 1 hours effort will get you 1 hours’ worth of results, one day’s effort, one day’s result, and so on.

Your activity will also help you to stay motivated and deal with the emotions around unsuccessful applications. Plan, prepare, keep at it, fight for it, and never be afraid to ask for help.

If you’re an HFNZ member, and you want to talk about issues related to finding a job, feel free to contact me at josiane@haemophilia.org.nz

Key links from the article:

- 1. www.careers.govt.nz/job-hunting
- 2. www.volunteeringnz.org.nz
- 3. www.seekvolunteer.co.nz
- 4. www.careers.govt.nz/plan-your-career
- 5. www.nzdsn.org.nz/providers

Other useful links:

Occupation Outlook 2017:
occupationoutlook.mbie.govt.nz

National Survey of Employers 2015/16: Snapshot of Key Trends:
www.mbie.govt.nz/info-services/employment-skills/labour-market-reports/national-survey-of-employers/2015-2016/snapshot.pdf



PEP: Parents Empowering Parents Workshop

JOSIANE MCGREGOR

On June 16th - 18th 2017 a group of 8 parents gathered at Aotea Lodge in Porirua for a weekend of full-immersion parenting skills development.

This was the fifth PEP weekend run in New Zealand, and was led by the PEP guru himself, Ed Kuebler. Ed is an International Coordinator and Facilitator for PEP and a long serving Social Worker in Haemophilia in the U.S. Of this weekend, Ed said, “I am always so impressed how parents of children with a bleeding disorders, when given the opportunity to attend a PEP Program, find a renewed excitement in how they parent their children.”

We were also lucky to have the PEP trained parent facilitators Richard and Lynley Scott, and the support of Outreach Workers Lynne Campbell (Central) and Josiane McGregor (Southern), and Haemophilia Nurse BJ Ramsey.

The PEP programme was first written in 1995, and has undergone a number of revisions as more information has become available, and advances in the care and treatment of bleeding disorders have occurred.

The PEP (Parents Empowering Parents) programme is designed to empower parents by teaching skills to improve quality of life when raising a child with a bleeding disorder. The topics covered over the course of the weekend include:

- Child Development
- Strengthening Skills for parenting
- Applying your Parenting Style
- You and Your World View
- How Thoughts and Feelings Affect Parenting
- The Role of Self-Esteem and Self-Confidence in Parenting

- Understanding the Process of Communication
- There were also Getting Started and Moving Forward sessions at the beginning and end of the weekend.

The focus of the PEP programme is to develop a “can do” approach to parenting a child with a bleeding disorder. By working through the nine sessions over the course of the weekend, each parent learned and built on the skills and experiences they already had, while working towards completing a new plan, a blueprint, for their family life into the future.

The goal was to use positive peer-to-peer education, grounded in evidence and strengths-based parenting strategies, to facilitate increased knowledge, nurture parents with similar struggles, and help them to become emotionally, behaviourally, and physically empowered to cope with parenting a child with a bleeding disorder. The PEP weekend certainly lived up to this, with parents, facilitators, and staff alike learning, sharing, and supporting each other.

Parent Iona Kahu shared her perspective on the weekend:

“As an initial sceptic of the PEP weekend I wasn’t sure what to expect. What I experienced though I don’t think I could have expected anyway. The small group of passionate parents that I met, who, like me, just want to be the best parents they can be for their kids whilst navigating their unique and ever changing journey with a bleeding disorder, is a group I will never forget. We shared, laughed, cried, ate lots, and had fun together whilst bettering ourselves for our children’s’ sake. I learnt lots thanks to the facilitators and host parents and have already started implementing things at home - as I most importantly learnt not to TRY but to DO. Thanks to HFNZ for providing this opportunity and thanks to those who attended for the life changing weekend.”

Connection is a key aspect in our lives, and feeling connected to others in a similar situation helps us to have a sense of focus, hope, and confidence as parents as we confront and manage the difficulties of life parenting a child with bleeding disorder.

Well done to all involved.



The Campers

2017 HFNZ Youth Camp: Waipara

Youth Camp is a great opportunity for young people who have graduated from Family Camp to practice some independence and spread the wings, while learning about how to become more responsible for decisions around their health and wellbeing. This year's camp was extra-special, because young women were invited to participate for the first time. **Colleen McKay** looks at the highlights of another fantastically successful Youth Camp.

Over a chilly, but sunny weekend, HFNZ held another National Youth Camp – Hero Camp!

On Thursday April 20, 31 young HFNZ members, boys and girls with haemophilia, von Willebrands and Platelet Function Disorders, from as far afield as Hikurangi, flew in to Christchurch Airport. After arrival, everyone hopped on a bus and headed north to the Waipara Adventure Centre in North Canterbury.

The overall theme of the weekend was Heroes. With that in mind, Thursday's programme was devoted to discovering: What it Takes to be a Hero – the qualities, attributes, skills, and values that heroes possess.

After being put into teams, everyone introduced themselves, and the teams set about creating mascots from piles of junk. The mascots each had a uncooked egg in their chest cavity, in their heart, because heroes have big hearts! The teams were challenged to take care of their mascots while ensuring that the mascots were involved in all team activities within the programme.

In the evening, we were straight into bleeding disorder work. Six working groups were asked to learn about various aspects of bleeding disorders and devise a way to teach what they'd learned to the other groups later in the Camp. The topics included: What's in a blood drop? How does blood clot? Basics of haemophilia, Treating bleeds, Basics of Von Willebrands, Girls bleed too, and Genetics.

Friday morning was devoted to learning about: What do HFNZ Heroes (Heroes with Bleeding Disorders) Need? The sessions included a self-infusion workshop with Paediatric Haematologist Siobhan Cross; advice on staying fit, healthy, and strong from Physiotherapist Helen Dixon; as well as talk about managing risk to undertake a range of activities safely.

Friday and Saturday afternoons saw participants managing physical challenges without bleeds – Archery, Mountain Biking and BMX, Rifle Shooting, Flying Fox, and Kayaking. The Waipara Adventure Centre staff ensured that these activities were undertaken safely and that they were heaps of fun.

On Friday evening – the youth leaders planned and implemented a surprise party for 'Camp Mother' Colleen McKay, complete with balloons, streamers, party poppers, and a huge cake, to honour her last ever HFNZ camp. As befits her status, this included a royal chair for Camp Mother complete with a special hat and crown. Various campers and youth leaders paid tribute to 'Camp Mother' – a very humbling experience.

It has been a tremendous privilege to be part of the lives of such inspirational youngsters. It has been wonderful to have seen many of them grow from newly diagnosed children attending Family Camp with their parents, to seeking their own independence by attending Youth Camp, then stepping up into leadership and assisting at camp as Youth Leaders, before going on to take part in Youth Leadership Programmes and stepping up within HFNZ. It has been an honour indeed.

The theme for Saturday morning's programme was Skills for HFNZ Heroes. Throughout the morning, the campers enjoyed educational sessions on first aid with Ashley Taylor-Fowlie, employment with Josiane McGregor, and good nutrition with dietician Lea Stenning. After lunch, the groups were again involved in outdoor adventure activities under the supervision of the Waipara Adventure Centre team.

The first thing that happened on Sunday was a BIG Camp clean up, including bags packed, rooms cleaned etc. Then it was on to the final assembly. The first order of business was the Autopsy of the Mascots... well, what was left of them. They were a bit the worse for wear from having taken part in all of the activities. Three of the four egg hearts survived the Camp Activities, much to the excitement of team members. The assembly also included the awarding of camp certificates to all the participants and of special Hero Awards to those who had earned them by self-infusing for the first time, or something equally amazing.

After assembly, it was onto the bus and off to McLean's Island for a fantastic barbeque lunch and our traditional Youth Camp laser tag. This was a great way to finish off the weekend as a group, before heading to the airport and home for a well-deserved rest.

Over all this was an awesome camp, with the best-behaved group of campers ever.

A big HFNZ thank you must go to:

- The Waipara Adventure Centre staff
- The Haemophilia Nurses: BJ Ramsay, Kathy Fawcett, and Amy Sudderby
- Helen Dixon
- Lea Stenning
- Siobhan Cross
- The HFNZ admin team
- Youth Town



Keep calm and let Colleen handle it

Farewell to Camp Mother

Since the last issue of Bloodline, our beloved Camp Mother has had her last day as staff at HFNZ. Colleen McKay has been a part of the HFNZ family for nearly 40 years, and a staff member for over 20. That means a whole generation of HFNZ members have been able to look to her for support and advice. Not to mention all the awesome camps and workshops.

- Top to bottom:
1. At the Antarctic Centre
 2. With the kids
 3. In Cambodia

Friday May 5th 2017 was a significant day in the history of HFNZ. Colleen McKay, our own Camp Mother, wound up her career as a staff member that day. After more than 20 years working with our people, Colleen decided it was time to call it a day.

It was always going to happen sometime, but we'd been trying not to think about it.

Colleen has been an integral part of the Foundation right from when she started as a volunteer many moons ago. She started staff life as an Outreach Worker, before leading the Outreach team, and, ultimately, running all our camps and workshops, always bringing something new and exciting to the table. She's also been 2IC of the head office team for many years. We're just not sure how we'll cope without her. Colleen has been a fantastic supporter of, and advocate for, HFNZ members at all times. She has represented us with distinction on the world stage, and is highly regarded in the international bleeding disorder community. We all just love her to bits, and are sad to see her go.

Colleen was an HFNZ member before she became a staff member, and will continue as a member now she's stepped away, because she has haemophilia in her family. It's in her blood...

On Colleen's last day she was overjoyed to have a number of people she'd worked with and for over the years pop in to the office to reminisce about the good old days, give her cuddles, and say nice things about her. She was particularly touched by a visit from Grant Hook and Michael Ho, who travelled from Palmerston North just to surprise her.

Suffice it to say, that Colleen has played a huge role in the development of the Foundation, and leaves a huge hole with her departure...

There's a lot we could say about Colleen, and her contribution to HFNZ. But we'll leave that for another edition of Bloodline. Instead, we'll leave the last word to Colleen herself.

Camp Mother thanks you all very much! Thank you all very much for everything in my last days at HFNZ...

Thank you all for amazing messages on Facebook, emails, cards and gifts – it has been very humbling.

Thank you to all of the Southern members who popped in to say Good-bye – I appreciated each and every one, it was wonderful to see you all and to share precious memories.

Special thanks to Grant & Michael from Palmerston North and Theresa & Courtney from Dunedin who made the big journey

to be with me at my last day Party; I really appreciated that you were there.

Thank you to HFNZ Staff for all of your input into my last weeks at work, especially my wonderful last Youth Camp, my last day at work and the last Staff Meeting Dinner.

To all of the Youth – thank you for the wonderful surprise party at Youth Camp complete with balloons, streamers, gifts, a cake and wonderful words; it was wonderful.

Big thanks to Belinda, Chantal, Linda, and Leanne – former Christchurch HFNZ Staff for making my last day very, very special, and for my Book of Memories – it is so awesome.

To Te Whainoa, Rosalie, and everyone at Piritoto – thank you for the visit and koha – all colour coded in my favourite colour – lime green! You know me well. Piritoto will always have a very special place in my heart.

Finally, a HUGE thank you to HFNZ National Council for the wonderful heartfelt message and lovely gift; a beautiful piece of pottery from Master Potter Royce McGlashin. It is a beautiful colour and shape, has amazing detail and I LOVE it; it will always remind me of everyone at HFNZ and my twenty-one years employed at HFNZ.

HFNZ is a very special community that I feel very privileged to have been a part of. I wish HFNZ all the very best for the years ahead.

Arohanui ki a koe!





Regions and Groups Reports

HFNZ's Regional and Group committees enable all our members to be involved 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 as autumn rolled into winter.

Central

Ashley Taylor-Fowlie



Next on the calendar for Central Region is the AGM, which will be held at Owlcatraz in Shannon on Sunday 27th August. A short AGM meeting will begin at 11am, followed by lunch, and a visit to the owl sanctuary. Look out for your invitation in July.

The current Chairperson will be standing down from the position and we farewell some other hardworking committee members too. This means the committee is looking for a new Chairperson as well as some fresh faces to join the committee. If you are interested, please send your nomination forms into head office now, or speak to one of the committee members at the AGM for more information.

We welcome Blair Wightman back into the country, after being away for nearly four years! Blair still managed to keep track of our finances as Treasurer, it worked well for us but we have welcomed him and it is great to see Blair in person at the committee meetings now.

The long awaited Men's Fishing Charter in May had to be postponed, as the weather was not playing the game. The Fishing Charter has been rescheduled for January 2018 when we should have better weather conditions. We will be in touch once we have more details and look forward to putting in a line with you.

During March a group of Central Youth Members (aged 18-30) had a get together lunch in Lower Hutt. We had a great turn out and it was fantastic to see some new and old faces.

Our Christmas Event has already been booked. You can look forward to a Wellington Harbour dinner cruise on 25th November. This may sound familiar, as we last went in 2014 with great success.

Midland

Linda Mellsop-Anderson

Like many other community groups, it can sometimes be difficult to meet all the needs and desires of all members at any one time.

This is particularly true when, as is the case with the Midland committee, there are only a handful of members performing several key tasks.

Sadly, personal issues have meant that some of Midland's plans for the last few months have been affected.

It's been great to see our Midland Youth membership getting organised. They have planned a couple of awesome sounding events for some fun and mixing:

- Sunday August 13 - Ten Pin Bowling in Hamilton, featuring some tasty snacks.
- Sunday September 10 - Team problem solving at the Escape Complex in Rotorua, also with tasty treats.

Watch your emails and post box for more info

We do have one whole group event planned for Sunday August 20th.

Midlands members will be getting together to enjoy Steamfest in Otorohanga. There are lots of activities ranging from performances and displays, to food and market stalls, from near and far. The best bit is a trip on an old-fashioned steam train to Te Kuiti and back! A fantastic chance to enjoy the wonders of steam travel during a fun filled family outing with HFNZ Midlands.



Seats on the train trip will be limited due to having to book in advance, so rsvp to your invite as fast as you can!

Also, another get together for Masters is in the planning stage, as is our AGM.

Please keep an eye out for email or post confirmation of details.

Northern

Neil Smith

A lot has happened since the last Northern report.

Our very successful, chillaxing weekend getaway at Mangawhai Heads seems like a long time ago now. Watching the kids play (a lot of cricket) and time socialising over a cup of tea was the order of the weekend. Doing our own catering meant the kitchen

became the hub, and we ate very very well. We did surf lessons again this year and I loved seeing the give-it-a-go attitude. The chilled out theme continued with a dinner at Mangawhai Tavern, where bleeding disorders were put aside and we just got to be a group of mates around a couple of tables.



Following Chris Bombadier’s Everest climb in the media was inspirational, and an awesome reminder of what you can achieve with the right support and motivation. Interesting how we felt so connected to someone we hadn’t met. If platelets help with clotting, maybe that makes us matelets!

We also had a dinner out at Valentine’s on Dominion Rd. where it was great to see a few new faces. Meeting and talking to HFNZ Patron, Elizabeth Berry, was pretty cool, and made us appreciate how far treatment has come.

It can be scary to come along to events, and it’s not always easy to get there. We all have our lives going on, bleeding problems, or otherwise. I’d encourage people who haven’t come along to these things to give one a go. We’ll support you and are here to help. Just drop me a line if you aren’t sure at neilandtrinet@gmail.com. I can also add you to our Facebook group.

We’re also making an effort to get out to places outside of the Auckland city limits. We could do with a bit of support around that. Again, give me a yell if you can help, or if you’re feeling a bit left out in your area. Like me, the committee are all volunteers and we often need a hand. We’re a low-key, friendly bunch, and, if you feel like stepping up, we’re always interested in fresh blood...

The latest event my family attended was Piritoto’s Matariki event out at the Stardome, followed by a visit to Te Tahawai marae, Pakuranga. My whanau has no Māori links, but this was one of the best things I’ve done with HFNZ. To be welcomed onto the marae, immersed in the culture of my country, and surrounded by people I did not know, but had a binding commonality with, was something our family will not forget. It felt like home. From it, we’ve developed a desire for stronger ties with Piritoto. The blood that binds us. Thank you Piritoto and friends

for the hangi, waiata, the welcome, and the Matariki education.

We have things coming up with dates below and I really look forward to meeting more of you...

- Silverdale Adventure Park and Northern AGM, 2nd September
- Parakai BBQ, 2nd December
- Northern Family Camp, March 9 – 11 2018

Piritoto

Rosalie Reiri

Tēnā rā koutou katoa!

Piritoto has been busy meeting online and offline to organise our Māori New Year event, which I will talk about later but first off, we have some successes to share.

Haka with Standing Rock

Our very own Holden Stirling was responsible for organising a haka on the beachfront in Gisborne to support the indigenous peoples of Standing Rock. What is so amazing about this story is that Holden posted his intentions to Facebook, which caused an overwhelming response from the local community, where hundreds stood to haka with Standing Rock. The event was so phenomenal that to this day there has been 7,599,226 views. You can watch it here: <http://gisborneherald.co.nz/localnews/2542046-135/haka-supports-standing-rock> or google search haka-supports-standing-rock in Gisborne.



Whakamīharo ana! Kei tāwhiti koe Holden.

Congratulations Te Whainoa

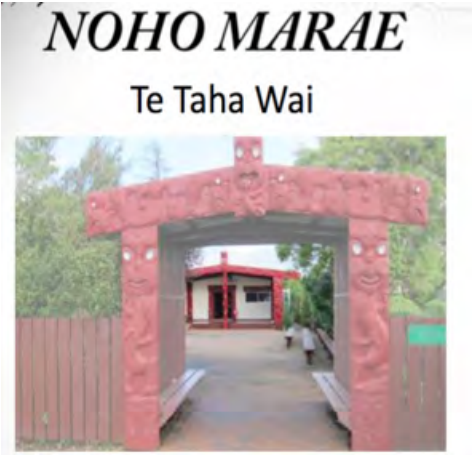
Recently Te Whainoa Te Wiata graduated with a Bachelor of Arts in Linguistics. Although I am a biased sideline supporter, I would like to acknowledge Whainoa for his dedication and persistence. I have witnessed the struggle behind the struggle on a daily basis. To look at Whainoa one would never know the hard trials he faces.



The challenges include the distances to walk to lectures, where to park, how to carry books, food, and a computer all in one bag. The catch 22, using crutches to alleviate the bleeding knee when his arm is too weak and using the crutches creates a bleed in his arm. These are just some examples. I would like to thank HFNZ for the financial assistance that supported local transport when Whainoa didn’t have any. I would like to thank the physio workers and the nurses at the Auckland hospital that have helped also. Mei kore koutou ka kore ia e tutuki pai i ana wawatā.

- You can watch Te Karere: <https://www.youtube.com/watch?v=gzKix2N7UOg>,
- read the Auckland University paper: <http://www.arts.auckland.ac.nz/en/about/news/2017/05/maori-representative-on-haemophilia-foundation-graduates.html>
- or listen to national radio station interview here: <http://www.radionz.co.nz/national/programmes/sunday/audio/201850425/language-music-and-battling-the-pain-whai-te-wiata>

Noho Marae and Piritoto AGM



It is the belief of the Piritoto whānau that connecting bloodlines and blood ties is of the utmost importance; on the 23rd-25th of June this rang true. We had our fifth consecutive noho marae at Te Tahawai marae, Pakuranga. It was a weekend of reconnection and invigoration not only with ourselves but also with a few of those from the Northern Region. The Piritoto Matariki event coincided with our noho and the invite went out to our Northern HFNZ whānau to join us at the Auckland Stardome and then back to the Marae for Hangi to celebrate Matariki. It was a great weekend, which we hope to have more of in the future.

Piritoto would like to acknowledge Te Tahawai Marae and their wonderful kaimahi, as they offered Piritoto to stay at no cost for the weekend, plus they have offered the marae at no cost again for another noho in the future. Ngā mihi ki a rātou e kaha manaaki nei i a mātou o Piritoto, nei rā te mihi maioha ki Te Wai o Paoa.



News from around the world

Coloradan with hemophilia summits Mount Everest

KASSANDRA LAU, KUSA

KUSA - Many Coloradans have reached the top of Mount Everest, but Chris Bombardier may very well be the first climber to do so with severe hemophilia.

Bombardier summited Mount Everest on Sunday. His wife Jessica tells 9NEWS every two to three days he had to take medication intravenously to replace the clotting protein missing in his blood.

After reaching the top of the mountain, a post on Bombardier’s Facebook dedicated the climb to others with bleeding disorders. It read in part, “For every child who has been told ‘no’ due to their bleeding disorder... For every hemophiliac athlete who waits in quiet hesitation out of fear of injury... This mountain is for you.”

Bombardier’s trip to the top of the world’s tallest mountain put members of his family back in Colorado on cloud nine.

“There was a huge risk in all of this, and somehow he managed to get through it all,” Bombardier’s mother Cathy said. “It just blows me away.”

Bombardier’s climb also raised more than \$10,000 for the nonprofit Save One Life, which helps people with bleeding disorders in developing countries. Bombardier plans to donate the money to hemophilia relief efforts in Nepal, which experienced a devastating earthquake in 2015.

“Chris’s whole reason behind all of this is to bring awareness to those poor kids in third-world countries that have no access to the medical care that Chris does,” Cathy Bombardier said.

Bombardier’s family says he plans to return to Colorado on June 3. His adventures are far from over. He plans to conquer the seven summits – the highest peak on every continent. After Mount Everest, he’s down to one last climb in Antarctica – which he hopes to begin in December.

Source: <http://www.9news.com/sports/outdoors/coloradan-with-hemophilia-summits-mount-everest/442064183>

Doc develops one-shot treatment for inherited bleeding disorder

BY TOM AVRIL TRIBUNE NEWS

At a Home Depot not long ago, Jay Konduros was hefting a 40-pound box of shelving into his cart when it suddenly slipped -- and bam! The blood welled up from a gash in his shin, and his mind flashed back to a lifetime of caution and pain. Konduros was born with hemophilia, the blood clotting disorder.

Any time he banged a limb, and sometimes even without apparent injury, he could develop the swelling and pain that are the hallmarks of dangerous internal bleeding. Each time it happened, he had to infuse himself with costly synthetic clotting factor -- a lifetime tab that had run into the millions.

Then last year, the 52-year-old was among the first in the world to receive a one-time, experimental treatment: a dose of genetically engineered particles that would enable his liver to make enough clotting factor on its own.

The Home Depot accident, near his home outside Toronto, represented an unplanned test of the treatment. In the hours and days after, Konduros waited and watched. There was no bruising. No swelling. No debilitating pain. “You kind of smile and think, ‘Ok, that’s abnormal,’” he said.

A new hope

Dr. Katherine High’s first extended experience treating patients with hemophilia came during an especially dark period for the disease.

The advent of donated clotting factors had revolutionized treatment for a condition that once meant a shortened, painful life. But in the 1980s, scientists learned that HIV could be transmitted through these donated blood proteins. As many as half of the patients in the U.S. would become infected with HIV. Some also contracted hepatitis C, another serious blood-borne illness. High wondered if the answer lay in genetics.

In the 1990s, then at Children’s Hospital of Philadelphia, High pursued the idea of treating hemophilia with gene therapy -- infusing patients with “vector” particles that carried the genetic recipe for clotting factors they could not make on their own.

High and her colleagues got the treatment to work first in mice, then in dogs. Then in 2006, they announced

it had worked in humans, but only temporarily.

That was because the vectors carrying the recipe were made from viruses, which had provoked a response from the patients’ immune system. Within weeks of treatment, the patients’ bodies destroyed the cells, and the benefits of the treatment wore off.

In 2013, High decided the best pathway to success was through the private sector. With Children’s Hospital investing \$50 million, High co-founded a biotech startup called Spark Therapeutics.

To the test

In November 2015, Konduros’ doctor told him about High and the gene therapy.

Konduros came to Philadelphia in June. Lindsey George, a hematologist at Children’s Hospital, administered the infusion, known as SPK-9001. Trillions of the special particles traveled through a tube into his arm, destined for his liver.

Konduros is one of 10 patients to get the treatment so far. Spark has announced results for nine, all of whose ability to make clotting factor has soared. As of Nov. 30, the patients had all but eliminated the use of synthetic clotting factor.

So far, physicians not involved with the study are impressed.

“It’s pretty exciting news,” said Jason Taylor, associate director of the Hemophilia Center at Oregon Health & Science University. “We’re still not exactly sure what’s going to happen in the long term.” High is optimistic.

“For all of these people, it’s a little bit like they come in, they get the infusion, they walk out, and they leave their hemophilia behind,” she said. “How long will it last? I don’t know. Were they very brave to volunteer? Absolutely.”

Source: http://www.chieftain.com/life/health/study-shows-broccoli-has-positive-impact-on-type-ii-diabetes/article_d594621c-cacc-5588-a8d7-4b03e5eb5943.html#tncms-source=article-nav-prev



The Year Ahead...

More details on all events are available from your Outreach Worker

August 18 - 20

- National Inhibitor Workshop
- Quality Hotel Parnell, Auckland

September 29 - October 1

- Adult Weekend, Auckland

October 1

- HFNZ Annual General Meeting, Auckland

October 12 - 14

- Australia & New Zealand Conference on Haemophilia & Rare Bleeding Disorders, Melbourne

May 20 - 24, 2018

- WFH World Congress, Glasgow

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

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