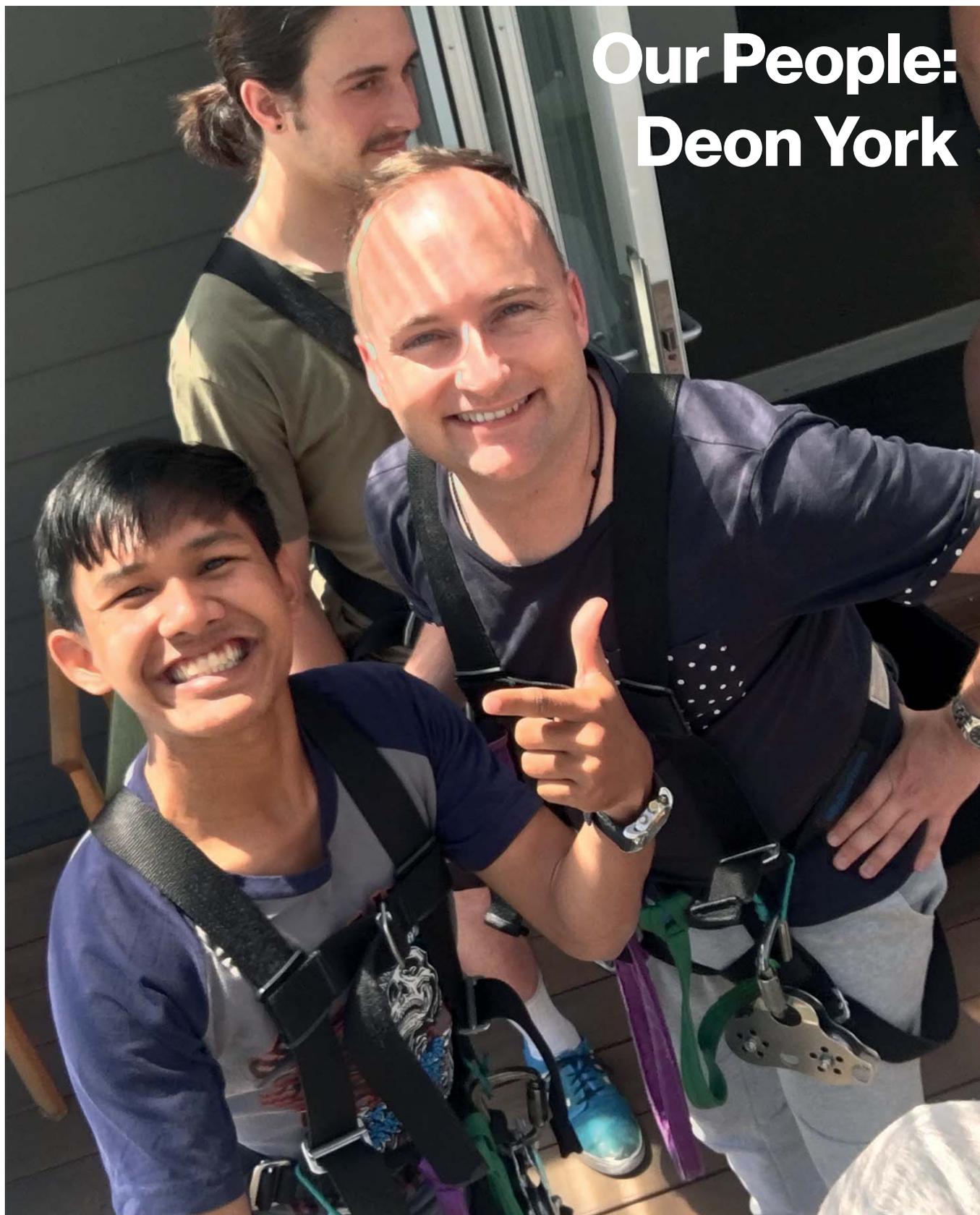


# Bloodline

Our People:  
Deon York



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Magazine of the Haemophilia Foundation of New Zealand. **Volume 45 Number 1**

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Acct Number: 02 0828 0102656 000

**Disclaimer:** The information contained in this magazine is not intended to take the place of medical advice from your GP, haematologist, or specialist. Opinions expressed are not necessarily those of HFNZ. The purpose of this magazine is to provide a wide range of accurate and timely information on all aspects of haemophilia and related disorders. Haemophilia is a dynamic specialty and therefore opinion may change or be varied from time to time.

# The **H** Word

We are now well into 2017 and HFNZ has plenty of interesting events lined up for our members. One that has just been is the Advanced Leadership Training weekend.

Karl Archibald facilitated the weekend and did a great job. Catriona and I attended and ran some of the sessions, along with Lauren Nyhan, and Ashley Taylor-Fowlie. Zac Porter did an awesome job of teaching the group to safely mountain bike, and we welcomed Rithy to New Zealand from Cambodia. Our bubbly Northern Outreach Worker Nicky has now well-and-truly received a baptism by fire. You can read more about this event on page 8.

I would like to take this opportunity to farewell one of our most beloved and experienced people at HFNZ. Our long-serving administrator Leanne has moved on to a new role. Leanne has been the glue of the national office for more than 12 years, and I for one have really appreciated all her hard work, dedication, and tenacity! I know you will all join me in wishing Leanne well in all her future endeavours, and in welcoming our new administrator Karen Melville.

All the best for 2017.

Deon York

HFNZ President.





## **Our People: Deon York**

HFNZ President Deon York is modest to a fault. He's been President for nearly 10 years, and is an elected director of the World Federation of Haemophilia, yet when you ask him about his accomplishments he's far more comfortable talking about those organisations and the work there is still to do. That is a testament to a man who works hard to make sure that HFNZ and its members punch above their weight on the world stage.

**Phil Constable** talked to Deon about where he's come from, and how the future looks to him

Many of you will know Deon York as the energetic young President of HFNZ. However, his apparent youth is belied by the many years of experience he has as a member and leader in the HFNZ community. Not only has he been HFNZ President for nearly 10 years, it is his second term as an elected director of the board of the World Federation of Haemophilia. He is the first New Zealander to serve on this board. This reflects his breadth and depth of experience, as well as the specific skills and talents he can bring to the global bleeding disorder community, and the esteem in which he is held internationally.

Locally, Deon has been instrumental in broadening the Foundation's focus on carriers and other bleeding disorders and promoting young leaders in HFNZ. He continues to advocate for a comprehensive care model for all people with bleeding disorders, regardless of region. He has supported, spoken at, and run many workshops for our members over the years, including the Advanced Leadership Training weekend this year. He is also a strong advocate for our members accessing the best possible treatment, and getting all the support needed to live life to the full. That includes promoting educational initiatives, and making sure that those who are more vulnerable, or who have more complex needs, are also well supported.

Although he is modest to a fault, we caught up with Deon for this issue of Bloodline and were able to dig a little deeper and learn a bit more about him...

## **Tell me about your early days with Haemophilia...**

There was no history of haemophilia in my family until I was born in 1980. I was diagnosed at 18 months. One morning my parents came into my room; I was nestled in a pool of blood. I had split the frenulum of my tongue while chewing on a child's toy. This resulted in a diagnosis of severe haemophilia A.

I have seen many changes to treatment in my life so far. In the beginning I was treated with cryoprecipitate on-demand. Around the age of 7, I was treated with blood-derived factor replacement therapy. I managed to escape contracting HIV between 1980 and 1984 when products had potential contaminants. This period from the early eighties sadly reduced the number of people with haemophilia of my generation. I was diagnosed with hepatitis C in the early nineties. I underwent pegylated interferon and ribavirin therapy in the early 2000s. This was a success and I am now free of hepatitis C. I have essentially been on prophylaxis since 1998, and have been on various generations of recombinant factor replacement therapy ever since.

So, you could say I am the 'middle generation' – I've benefited greatly from advances in treatment, but I've also been on quite a range of treatment regimens!

## **You got involved in HFNZ at a young age. How did you first get into the administrative side of things?**

I got involved with HFNZ mainly thanks to Mike Carnahan. He encouraged me to be involved with the National Council – and this was back when we had meetings that lasted up to three days! It may sound excessive, but remember, there were less staff in the late

90s and more responsibilities fell on volunteers. While the overall financial and reputational responsibility still sits with the council, there are more hands on deck to make the work lighter for volunteers. I am very thankful to Mike and many others, who mentored and encouraged me to take ownership of a community I'll always be a part of regardless.

The challenges have never really gone away, but the nature of the challenges have changed over time. After the Treatment and Welfare Package was signed in 2006 to ensure that all people who received hepatitis C through contaminated blood products received the care they needed, this was a turning point for the Foundation in recent history. Looking after people affected by hepatitis C has not ended there, and there are still members who live with the aftermath every day. What we have seen since that time is a generation unaffected by blood-borne viruses, and families that thankfully have only ever known products free of viral contaminants.

What emerged from the post-virus era was the ability for the Foundation to broaden its focus to further understand the needs of carriers, who are now also recognised as people with a bleeding disorder, and also focus on other bleeding deficiencies. Severe haemophilia, however, still remains the sharp end of the business. Now people with haemophilia are living longer than ever before, and experiencing the same aging process as the general population - just with a dash of haemophilia thrown in. It makes day-to-day life all the more exciting when balance is ailing, vision isn't what it was, and you are living with a condition that doesn't fit too well with falling, bumping, or scraping.

The ability to focus on our broader community has resulted in the continuation of a youth committee and Piritoto, and more targeted programmes. I see a very connected community who now have many more opportunities to get together. We should not forget those who remain isolated, however, and find ways to reach them (should they wish to be reached, that is!).

We have also broadened our focus beyond New Zealand. Several years ago we decided to support twinning with Cambodia (a WFH programme), and I know it was an enriching experience for the volunteers who represented us. In fact, both countries learnt just as much from each other. These relationships continue beyond the conclusion of this programme, and with that in mind we are now looking at our responsibilities in the South Pacific.

## **You must have some good stories to tell about camps and workshops back in the day. Anything that stands out?**

I've been to many a camp, workshop, conference, event, patient-initiated-therapy-session, and general catch up with this community over the years. I have always left any HFNZ event feeling like this is really what we are all about. We exist to connect people together who understand the reality of living with a bleeding disorder. I have lots of great memories, and I know there will be many more to come.

Camps were a lot larger, as there tended to be one big annual event. If you had survived by the end of the weekend, then you could survive anything. As for anything standing out, all I can say is 'what goes on tour stays on tour'.

## **How can other young members step up into leadership roles within the HFNZ community?**

Leadership is critically important and there are many leadership development opportunities for people in this community, through international programmes targeted at young people. From the Foundation's perspective, the number of individuals that go on to volunteer for the Foundation is low. I do not see this as a failing, as long as the leadership programmes are also of broader benefit for our community. The many opportunities that young people can take are positive.

The term 'leadership' can have a number of meanings. To me, leadership is not about position; it's about how to encourage everyone to work together towards a common goal, and about recognising the value of different perspectives in order to achieve a common good. My advice to anyone who is interested in a voluntary role within the Foundation is to act: volunteer for your local branch, find out what they are up to, learn more about the work of the Foundation, and seek advice from any of us about how you can help.

## **There have been changes in the funding landscape over the last few years. What do you see as the keys to maintaining and growing HFNZ's services into the future?**

Ensuring that the Foundation continues to be funded for the programmes it provides, or will provide, is an ever-present challenge. We must always ensure that our limited financial resources continue to be used for those who most need support. Despite the challenges, we should not let financial constraints prevent us from striving to deliver excellent services, or from expanding our thinking. The key for us to continue to be able to fundraise is to demonstrate to our donors the value we place on every dollar, and the care we continue to take in using these greatly appreciated donations.

The National Haemophilia Management Group has been running for about 10 years, and I will continue to advocate for its continuation, as it has demonstrated benefits in terms of the creation of physiotherapy and nursing positions, management of costs, and made useful connections with key decision-makers. There have been (at least) a few policy changes in my time as President that have impacted on this group's management of funds. As a patient organisation, we can demonstrate the value a group such as this has made to the lives of our community, and tend to bring a longer-term view to any policy decisions.

## **What's your role with WFH, and how does that impact on the stuff you do for HFNZ?**

Any disability brings its challenges, and there have been a few. However, without haemophilia, I would have never met some of the wonderful people that I have, both in New Zealand, and around the world. As well as my work with HFNZ, I've been a Director of the Board of the World Federation of Haemophilia since 2010. This is an elected position, where votes are cast at the General Assembly of the World Federation of Haemophilia every two years.

All member countries - that is patient organisations like ours - cast their vote. My term ends in 2020. I remain motivated to serve the global community, knowing that there continues to be a pervasive gap in care and treatment of people with haemophilia and related bleeding disorders.

I have found that this role has only complemented how I can assist our HFNZ community. The connections formed internationally are invaluable for our local community. For example, being able to pick up the phone and talk with the very scientists working on a novel treatment for bleeding disorders, or having access to early results of trials as well as the latest product information, ensures we are a very well informed patient organisation.

## **What are the big changes you see coming for bleeding disorder treatment and management nationally and internationally over the next few years?**

Treatment options for bleeding disorders are about to explode globally. There has never been a better time to have a bleeding disorder! We will continue to work with our clinicians to demonstrate the value of these therapies to funders, and show the long term gains that can be realised by some smart short-term decisions to continuously provide the best available therapies to our population.

## **Can you tell me a bit about what you do outside of HFNZ and WFH?**

Outside of what I do with HFNZ and WFH, I work at the Health Quality & Safety Commission. I manage a programme focusing on consumer engagement. The principle of the programme is that consumers should be actively involved in decision-making about health and disability services at all levels, including governance, planning, and policy development. Of course, the HFNZ and WFH work is voluntary, so it's a case of fitting it all in. I live in central Wellington, so there's no shortage of things to do when I'm not working!





*Opposite page...  
Running for HFNZ  
President 2007*

*Top to bottom...  
Leading from the front  
right from the start*

*At the Australasian Youth  
Convention 2001*

*Hangin' with the young  
leaders at ALT 2017*





## Advanced Leadership Training Weekend 2017

HFNZ has a history of strong leaders and advocates, working hard to achieve the best results for our members. We're very interested in continuing this tradition, which is why we've run our youth leadership workshops in the past. The most recent of these occurred over Waitangi weekend, when an invitation only-group of young people took to the roads of the North Island, and did some learning about what it really means to be an HFNZ leader...

Earlier this year a group of specially selected young people from around New Zealand were invited to participate in the first HFNZ Advanced Leadership Training weekend. Over Waitangi weekend, our members were joined by Rithy from the Cambodian Hemophilia Association (CHA) for a weekend full of learning, challenges, and fun.

Other than Rithy, these young people had already been through the 2014 Youth Leadership Workshop in Christchurch, and had continued to demonstrate their leadership abilities in support of HFNZ. Many of these young people have taken on committee roles at regional and national level. This was an opportunity to really stretch these young people, to educate them in some of the history of HFNZ, and to ensure that the future leadership of the Foundation is in safe hands.

The weekend started out in Auckland, with the young participants having no idea what was in store for them. The first of many surprises was a road trip, leaving right now, to points unknown. The young leaders were divided into two teams and sent away in vans with a list of clues and tasks to complete. The Auckland traffic was a bit of a shock to some of our young leaders. As one of them said, *"If this was Dunedin, we'd already be at Waitomo by now..."* And one level-headed young future HFNZ Treasurer, with their eye on the bottom line, reminded their team: *"If we get a speeding ticket just remember to ask for a GST receipt"*.

After visiting the Clotworthys, the ugliest town in NZ, and the kiwiana capital of the world, among other notable destinations, they all ended up at the home of *arachnocampa luminosa* (the glow worm) for their first bout of learning. That afternoon's sessions included sharing a bit about themselves, and finding out about the future of not-for-profit leadership from Karl Archibald. The day finished with a visit to the glow worm caves at Waitomo, and an early night. Because who knew what was on the programme for tomorrow...

The next day dawned with another secret road trip, which included dams, forests, and statues, before finding the next night's accommodation (a bit early for the cleaners...). The afternoon included some learning sessions with HFNZ Executive members Deon York & Catriona Gordon, and a chance for some 'Real-Time Risk Management' (Mountain Biking...) before settling in to their new home in Rotorua for dinner, and some more learning about bleeding disorders.

Day three saw our young leaders heading into the treetops for a forest canopy tour and some zip-lining. The fun and games were again mixed with some great learning, including learning about higher level advocacy with Deon & Catriona, and some strategies to help manage group conflict with Lauren Nyhan.

The final day was the last chance for our young leaders to get some more learning under their belts, and plan for the future. Ashley Fowlie-Taylor shed some light on the world youth scene, before Karl Archibald led a session on SMART planning. Then it was off back to Auckland, and the plane ride home.

One of the big challenges of the weekend was for the young leaders to set themselves goals to achieve within HFNZ. They are now looking forward to touching base in a couple of months' time to assess their progress. This is a great

opportunity to really see how good planning and follow-through can lead to positive results.

This was a fantastic weekend. The young people learned a lot, and really stretched themselves, and HFNZ will benefit from the skills these future leaders have developed. The Canopy Zipline Tour, the mountain biking, and the travel challenges were all very popular activities, and the educational presentations by other leaders went down very well too. Here's a just a couple of the comments the participants made in their evaluations:

*"The ALT Weekend provided an amazing opportunity for experience, growth, and knowledge"*

*"The youth are the future! Thanks HFNZ for investing in us. With your help I feel more comfortable in my leadership skills to work towards a brighter future for those with bleeding disorders."*

Special mention must go to Karl Archibald, who stepped up and assumed responsibility for running the show when Colleen and Ed became unavailable. He truly showed that we produce great leaders here at HFNZ.

Thanks also to:

- Deon and Catriona for giving up their weekend to provide leadership and education to our young people
- Ed Kuebler for donating time and organising some funding from Global Blood Disorders to put towards the planning of the weekend
- CSL Behring for their contribution to funding the weekend.

# Ashley Taylor-Fowlie: Youth Leadership Workshop, Barcelona



One of the great things about HFNZ is that by becoming involved in our organisation, our people get some amazing opportunities to extend themselves, and to bring new ideas home to us. In December of 2016 one of our young leaders, **Ashley Taylor-Fowlie**, was invited to travel to Barcelona to participate in a Youth Leadership Workshop. Here's what she had to say about the experience. In December 2016, I was invited by the World Federation of Haemophilia to attend the Youth Leadership Workshop in Barcelona. This was a great opportunity to learn about other youth projects around the world and to share some of our own ideas!

Youth Engagement was a focus, and the session centred on it was my own personal highlight. The session discussed the importance of empowering youth by bringing them into the decision making process. There was discussion around ways to motivate youth by allowing them to be heard, appreciating their skills, raising their public image, and offering opportunities to be actively involved. To ensure youth engagement, it is important for youth to believe in the common issue that unites the group. This ensures that youth can continue what the previous members have achieved, and maintain or raise the standards of care in order to build a brighter future for people with Bleeding Disorders.

There was an opportunity for youth groups from around the world to share about their own organisations. Similar challenges were discussed, including ways to engage youth, establishing new youth leaders, geographic challenges, and fundraising. Where these countries see their youth group proceeding in the future was also discussed and involved advocacy - who will continue what others have started, fundraising to insure future youth events and workshops would be able to continue, leadership - encouraging and training the next generation, and connecting with other youth groups worldwide.

An open discussion on the challenges and cycle of youth engagement was facilitated by our own Deon York, who was there as a WFH board of directors member.

This was followed by some training on Social Media. We looked at some social media tools that other youth groups are using, as well as the challenges and success of these tools. Facebook, email, and what's app were the most popular.

The training concluded with a discussion on how to move forward with our own youth groups, so watch this space, because I have some great ideas to get our youth group involved with!

# Look What ACEET Can Do For You



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

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

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

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

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

Dustin's decision to make a change, coupled with an ACEET grant to get him started, has been a revelation. These days Dustin says, *"I love my job. I can't wait to get going each day"*. He's happy, and healthy, and hasn't had a bleed of any sort in over a year.

This is a great result, and just the sort of thing that the ACEET grants were designed to make happen. If you're interested in finding out how ACEET can help you, contact your Outreach Worker today.



# World Haemophilia Day and HFNZ Buddy Awards

April 17th is World Haemophilia Day, a chance for people around the world to learn more about the impacts of bleeding disorders on their communities. It's also an opportunity for local bleeding disorder organisations to be more visible, and to acknowledge the roles of different groups within their organisations.

With that in mind HFNZ will again be running their annual Buddy Awards.

The Buddy Awards give you the opportunity to recognise those that have gone the extra mile to help you, or to help others in your local BD community. From Outreach Workers, to friends, to school mates, these are the people that are there to support you when you need them most.

Around the regions events will be organised on or around April 17th to present the awards to the winners. Details of the events will be available closer to the time. In the

meantime, it's time to get your thinking caps on and nominate those who you think are really deserving of an award.

To nominate someone you think has gone above and beyond, just email Karen at head office for a nomination form at [karen@haemophilia.org.nz](mailto:karen@haemophilia.org.nz). She will either email you a form, or put one in the post for you. Fill out the form, along with why you think your buddy deserves an award, and return it to us ASAP!



## **NACCHO 2017: Phoenix, Arizona**

When many people think of HFNZ what comes to mind are the many awesome camps and workshops we run. From Family Camp to Youth Camp all the way to the Adult Weekend and everything in between, these events take a lot of planning, and a lot of inspiration to get going. One of the ways we get inspired is to attend the Annual North American Camping Conference of Hemophilia Organisations. This year **Nicky Hollings** travelled to Phoenix Arizona to get inspired at NACCHO.

NACCHO is the North American Camping Conference of Haemophilia Organisations. Every year the conference looks at what works and what's new in the world of haemophilia camps and workshops. HFNZ staff that participate always come back brimming with enthusiasm, and full of new ideas. This year NACCHO, was held in Phoenix, Arizona in January. It was themed around the movie *Zootopia* and the idea that camp works towards "making lifelong happiness more likely".

My first experience at NAACHO was last year. It was overwhelming, exciting, informative and engaging. Having a year under my belt with HFNZ has taught me more about the complexities for people living with a bleeding disorder, how a BD camp is run, and what the requirements are for this to happen.

This year I had to do a presentation on BD camps in New Zealand, where I got the chance to describe HFNZ camps and what they entail. There was lots of support for us running the Young Women's Weekend last year, and for running a mixed gender youth camp later this year. One bit of culture shock happened at a workshop on risk, where there was a discussion on children bringing food to camp. I suggested that if children know that they have to share what is the issue? The response was "then we have a problem with the bears", which led to great hilarity and a discussion of what our risk analysis is based around, as bears are certainly not an aspect of HFNZ risk management.

This conference focused on how important it is to develop leaders in our bleeding disorder communities, and to understand the importance of really seeing individual campers, of being aware of people using masks to hide overwhelming feelings of sadness, hurt, loneliness, fear, or anxiety. It is important to let campers know that they are seen, heard, and wanted, and that their feelings are valid.

## Developing Leaders

Having enthusiastic, committed, skilled leaders is central to the success of any camp or workshop. In the first instance a group of leaders has to be able to work well together. They need strong relationships built on trust, mutual understanding, and a shared goal. Some keys to camp leadership include:

- Strengthening relationships between leaders and their colleagues
- Recognising that activities are all about encouragement, support, working together, and healthy risk taking
- Focusing on creating joy for campers, taking it to the extra level
- Knowing their own boundaries and limitations, getting support when they need it, knowing when to reach out, and not leaving it too late
- Touching a campers heart

It is important that organisation staff validate volunteer leaders, by sharing their story, telling them what they do well, and being kind when giving feedback on what they need to see change.

At the conference there was a workshop on how to be the best you can be as a staff person and as a leader. Learning

how to know when a camper needs that extra support, as well as knowing your own limitations and boundaries. The workshop looked at team building with staff and leaders, teaching staff to let the leaders lead with support, how to transition from camper to leader, and what the challenges might be e.g. campers not listening to you, or being a role model.

This was described as getting your Beast Mode on:

- Do what you say you will
- Go to the extra limit
- Be present
- Be open, honest, and trustworthy
- Make connections
- Take responsibility
- Work from a place of kindness to others and self.

Beast mode is intentional, inspiring, and empowering!

This was a fabulous workshop that I found truly inspiring. Being a camp leader is about leading by example, being excited by the new day and being where you are, doing the best you can, and allowing others to be able to be the best that they can be.

## Really 'Seeing' Campers

There are many things that contribute to a child's experience of camp. How camp goes for them the first time will often determine whether they come back next year. You might have the best activities in the world, but if a child feels unhappy, or unimportant, they may rather stay home with their folks next time around.

These are powerful reasons why a child chooses to return to camp:

- A sense of belonging,
- Community
- Activities
- Friendship
- Fun
- Independence
- Role models
- Normalcy.

Why a child might not return to camp:

- Bullying
- Not feeling safe
- Life happens
- Not being understood
- Caregivers
- Pressure to self-infuse
- Missing home

- Rules and policies
- Economic disadvantage

Understanding these reasons helps us to challenge the way camps are run, and to take a reflective honest look at what can be changed and what can't. Camp isn't all about the activities and the education, it's about belonging, connection, care, kindness, fun, and purpose.

Camp should be a place where people can have transformational experiences. This can happen by doing your first infusion, by having someone notice how you are feeling, by being heard, or by being validated. It's all about growth through achievement, belonging, and relationships.

Good organisation is integral to a camp running well, and keeping parents in-the-know about what will be

happening when their children are at camp is a big part of this. It is important to recognise the concerns that parents may have when their children first go to camp without having them present. Keeping parents informed not only helps with parental anxiety, it also helps parents communicate with their children as they talk about their camp experiences, which is also great for the camper.

NACCHO reinforced to me that HFNZ run great camps. We truly go the extra mile to be inclusive and to inspire campers and leaders alike. Thank you Colleen for making this happen to such a high standard for so many years. A big thank you to Pfizer for their ongoing sponsorship of this event. With their investment, kids with bleeding disorders around the world are able to benefit from the camp experience.

## Farewell & Welcome



*Leanne Pearce*

There's been a bit of a changing of the guard here at HFNZ head office, as we farewell our long-serving administrator Leanne, and welcome her replacement Karen Melville.

Leanne has been with HFNZ for over twelve years, and in her time has seen a lot of change in the Foundation. Her last official day was Friday January 27th, however, she's been in more than once, including weekends, to help the head office team do some of the important tasks, and to do some training with Karen.

We miss Leanne already, and appreciate all the time and effort she's put in over the years. We also wish her all the best for whatever life brings her next. We'll always have the Onehunga WMC...

As a result of Leanne moving on we get to welcome the



*Karen Melville*

newest member of our team, Karen Melville, as our new Office Administrator. Karen's first day was February 24th, and so far she's slotted in admirably. There is a lot to learn when you first start out at any organisation, and HFNZ is no different. Karen is fitting in nicely, and quickly getting up to speed with what it is we do here.

Karen comes to us by way of school office administration at a couple of different schools, and an interesting career in media and journalism in South Africa. She is full of skills and talents that we look forward to making the most of as time goes on.

No doubt you'll be hearing from Karen at some point in the future, as she sends out invitations and information, or if you need to contact the office for any reason.



# Global Haemophilia Advocacy Leadership Summit

One of the core functions of HFNZ is to advocate for our members. In order for us to do this to the best of our ability it's important that we're able to learn best practice from others in similar circumstances. In January of this year our President **Deon York**, and our CEO **Richard Chambers**, travelled to Amsterdam for the Global Haemophilia Advocacy Leadership Summit, where they learned about some great ways to advocate for our people.

In January 2017 Richard Chambers and Deon York attended the fifth Annual Global Haemophilia Advocacy Leadership Summit. This is the second time that New Zealand has been invited to attend. The summit is sponsored by Bayer, and we are very appreciative of their support.

This year the summit was held in Amsterdam, and 24 countries were represented. The summit commenced shortly after arrival and we were back on a plane for the long trip home a couple of hours after it finished.

There were a number of interesting speakers and workshops, summarised below.

## **Speaker 1: Steven Pearson, from the Institute for Clinical and Economic Review**

*Assessing the "Value" of New Treatments: Does What Matters to Patients Count?*

Many countries have developed a Health Technology Assessment (HTA) approach to making decisions about the purchase of health care products. These organizations, including our own PHARMAC, tend to be evidence-based, clinically informed, but not expert driven.

Patient groups can 'assist' these organizations by helping to

- Determine what outcomes are important
- Provide opportunities for using or generating real-world evidence

Funders look at a number of factors when determining whether a treatment will be funded, including effectiveness, quality of life impacts, and cost. Often they have to compare treatments for the same condition. They have to decide whether the benefits outweigh any additional cost, and how to prioritise treatments if you can't afford both.

## **What does this mean for New Zealand?**

- Be aware of PHARMAC's process for patient engagement
- Be quantitative wherever possible when filling in the blanks of "what matters to patients" inside the Quality Adjusted Life Year (QALY) measure or outside of it
- Find credible clinical experts to support treatment recommendations
- Remember that people with bleeding disorders are special but not unique
- Fight hard for a fair decision while respecting the goals of Pharmac and the government
- Debrief with Pharmac afterwards – discuss how we can improve processes.

## **Speaker 2: Dr Gerry Dolan. Haemophilia Centre Director at St Thomas' Hospital, London**

*Progress in Haemophilia treatments: Physicians as Advocates*

<b>Value</b>	• The worth of a healthcare intervention in terms of money and clinical benefits
<b>Efficiency</b>	• Sharing healthcare resources in a way that maximizes the total benefit to patients
<b>Equity</b>	• Fairness when sharing healthcare resources
<b>Scarcity of resources</b>	• Lack of healthcare resources, which makes sharing them among patients even more challenging
<b>Health economic evaluation</b>	• A comparative analysis of two or more alternatives in terms of their costs and benefits

How do we improve quality of care, when treatment is expensive, and we have limited health budgets and numerous conditions all needing treatment?

How do you compare different therapeutic products in a tender?

As advocates we need to be able to make the case for extended half-life factor concentrates. But we need to know whether they are more effective, help ensure treatment compliance, are safer, and what a reduced number of infusions is actually worth in dollar terms?

There are more and more demands on health systems, and it is very difficult to introduce new therapies without major evidence for patient benefit or cost saving.

What is needed is

- Real quality measures
- Good clinical outcome measures
- High quality evidence
- A focus on Prophylaxis
- Effective inhibitor treatment

We also need an accurate and effective way to compare new therapies.

**What does this mean for New Zealand?**

- In New Zealand the development of treatment and centres was strongly influenced by physicians such as Dr Elizabeth Berry and Sir John Staveley, along with a strong patient advocacy group, now known as HFNZ.
- It is clear from international experience that a truly strong advocacy group includes Clinicians, Nurses, and the patient group. In New Zealand we have a history of working together. The National Haemophilia Management Group (NHMG) includes Haematologists, Specialist Nurses and physios, an accountant, and HFNZ. Together we can have more influence than if we work separately.

**Speaker 3: Dr. Sean Tunis from the Centre for Medical Technology Policy, USA**

*Better Evidence through Patient involvement*

The Health Technology Assessment (HTA) tries to assign value to a treatment by evaluating:

- Technical properties
- Safety

- Efficacy and Effectiveness
- Costs, budget impact
- Ethical, legal, social, political considerations

To measure effectiveness studies must include a broad range of patients; the treatments should be provided in real world settings by experienced clinicians; comparisons must be made to commonly used alternatives; the outcomes reported must be meaningful to patients; and efforts made to promote adherence.

The issue for bleeding disorders is that there are limited patients for clinical studies. There is also often more reliance on observational evidence than quantitative evidence.

The PROBE study is evidence the world bleeding disorder community is working hard to develop a validated, standardised way of collecting self-reported data about living with haemophilia.

Globally, the decision making process for HTAs needs to be more informed, transparent, and accountable. Decisions will then be more robust and comprehensive, and they will incorporate social values and ethics, as well as patients' problems, lived experiences, outcomes, and preferences.

**What does this mean for New Zealand?**

- PHARMAC needs HFNZ to contribute to its decision making. Pharmac is not an expert on bleeding disorder care, they need to be informed by the patients and the treaters
- HFNZ needs to proactively engage with PHARMAC and present evidence about the impact of treatment on quality of life
- It is important for HFNZ to work alongside treaters to ensure access to the best standard of comprehensive care and treatment
- The National Haemophilia Management Group can be a significant partner in improving care.

**Workshop 1: Mark Skinner from the Institute for Policy Advancement and Brian O'Mahony of the Irish Haemophilia Society**

*Using Health Economics to Develop your Case:*

The PROBE (Patient Reported Outcomes Burdens and Experiences) study for people affected by haemophilia has almost completed its validation process. The purpose of this study is to collect regular information about the experience of people with haemophilia, that is validated and robust, and can be used by patient organisations to gain access to better treatment. It is expected that in future years study will be extended to include other bleeding disorders.

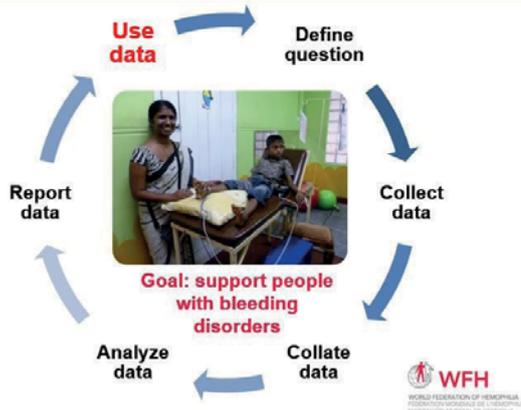
Countries are able to compare their results to other countries who, for example, might have different levels of prophylaxis and use it to support their advocacy work. Participants in the workshop had to use the data from PROBE to prepare for Workshop two which involved using the information in group role play.

### What does this mean for New Zealand?

- HFNZ will be asking members to participate in this study on a regular basis to help us to collect the information necessary to advocate to PHARMAC and government on your behalf.
- We will be closely monitoring the impact of the introduction of extended half-life products and other novel treatments across the world as we advocate for access in New Zealand.

### Speaker 4: Alain Weill and Antonio Almeida from the World Federation of Haemophilia

#### DATA MANAGEMENT CYCLE



#### Communicating your case using health economics

Organise your data to tell a story, it is important that real people are part of the picture you are communicating, not just data.

How to communicate your case

1. Understand the external environment
  - Health budgets are under threat or decreasing
  - There is a perception that unmet need in bleeding disorders is diminishing
  - The high costs of BD care & treatment are being examined more closely
  - CFCs are among the highest-cost medications
  - Competition for funding within speciality care is increasing
  - Healthcare environments change, things don't stay the same; change of Government priorities and officials
2. Make data-driven decisions
3. Develop and present your message and key arguments
4. Include ways that data can support and be used to advocate for PWBD

### What does this mean for New Zealand?

- We need to be well informed about new treatment options available, while also retaining a focus on the comprehensive care model that has been so successful in New Zealand: Haemophilia Treatment Centres with

specialist haematologist, nurses and Physiotherapist, supported by social/outreach workers employed by the Haemophilia Foundation.

- We need to be clear about what is needed and set clear realistic goals to achieve them
- Be prepared to deal with counter-arguments
- Work with our clinical teams
- Understand how our purchasing and decision making system works. In New Zealand it is rare that we know the actual purchase price that Pharmac gets for a product as there are often confidential bulk purchasing discounts involved. This makes comparing the monetary value of different products difficult
- All people with bleeding disorders must understand that the quality of their future care is dependent upon their participation in data collection programmes.
- New Zealand is a small market, with a population the size of a small international city

### Workshop 2: Communicating Your Case Using Health Economics

In small groups we were involved in role plays using the data from PROBE and suggestions about how to approach a Minister of Health or a Journalist

### Speaker 5: Andre Picard of The Globe and The Mail

*Lost in Translation? Communicating Complex Health issues in the Age of Twitter*

Andre was one of the international journalists who broke the tainted blood scandal. As an experienced journalist, Andre explained how the journalism landscape has changed. There are now fewer journalist and even fewer who specialise in health.

Journalists are looking for headlines and will have little or no existing knowledge about bleeding disorders. As advocate organisations we need to be clear about what we are saying, be accurate and be truthful and provide them with a quality media release that includes background information. Press releases need to find the balance between being short and succinct, and having enough information.

### What does this mean for New Zealand?

- Use the media at the right time for the right reason
- Prepare well before hand, making sure that we have all the information necessary
- Use simple language and real world examples to explain the issue, but be willing and able to provide research to support the message.



## Region and Group Reports

HFNZ's Regions and Groups enable all our members to be involved in the running of the foundation, and to connect with and support one another. Each group runs a number of events through the year, to connect their local members, to make sure that support goes where it's needed, and to have a little bit of fun. Here's what they've been up to recently.

# Central



The final event in 2016 was an afternoon of fun spent Ten Pin Bowling in Paraparaumu. The bowling was great fun, although the turnout was lower than expected.

The start to 2017 saw the Advanced Youth Leadership Weekend where the journey started in Auckland. Central was lucky enough to have four members to represent the region and attend the training. These four members have planned to hold a Youth Event (18-30) within the region in March.

Central region has planned to hold an event for World Haemophilia Day on Sunday 9th April at The Esplanade in Palmerston North. Here we will also be recognising some important people who help support those with bleeding disorders. So don't forget to nominate your buddy! For more information in the Buddy Awards contact head office at [info@haemophilia.org.nz](mailto:info@haemophilia.org.nz).

As the committee has decided not to run a regional camp this year Central Region will be holding their AGM at Owlcatraz in August.

Plans are also underway for a fishing charter on Saturday 20 May for men with a bleeding disorder - so keep an eye out for your invite.

# Midland



Last year the Midland Group finished a busy year off with a harbour cruise in Raglan aboard the Wahine Moe. This was a well-attended event and thoroughly enjoyed by those present.

We cruised the harbour sedately, visiting sights of significance. However, our journey was not without excitement. We came across a boat that had engine failure, so, as a responsible craft, our captain took the boat under tow and we returned it to the wharf then set off again. At the harbour entrance we watched with great

enthusiasm a kite surfer.

Lunch was gourmet hamburgers enjoyed at anchor in a tranquil bay. Many of the children took the opportunity to steer the boat and to introduce themselves over the onboard P.A. system.

In February we tried something different by inviting all men over forty to a trout fishing experience on Lake Taupo. The idea behind the event was to cater to a group that often don't participate for whatever reason, and to provide an opportunity for the men to talk freely.

Eight men enjoyed a trip on Lake Taupo, and there were even some fish caught! The men enjoyed a shared lunch in a relaxing environment out on the lake, and had the opportunity to share stories, meet each other in some cases for the first time, and relax.

Reminder from the Committee:

If your details change please let Joy, our Outreach Worker, know, or contact the office.

When you receive an invite for an event please just a quick text or call to say yes or no. That way we know the information is getting out to you all.

As a group we are endeavouring to have events that cater for individuals and families.

# Northern

Happy New Year everyone! If it's too late then at least happy Chinese New Year. The year of the rooster has got off to a cracker.

Speaking of crackers, since we last spoke we've had our wonderful end of year party at Rainbow's end. On a day where it was supposed to be pouring down with rain, our extended blood buddies family had an excellent time. The big man in red dished out some sought after presents and I hear there were some first timers on the roller coasters and even some (splash?) records broken (not bones!) on the log flume. Thank you to the people that pulled this together to make for another great event.

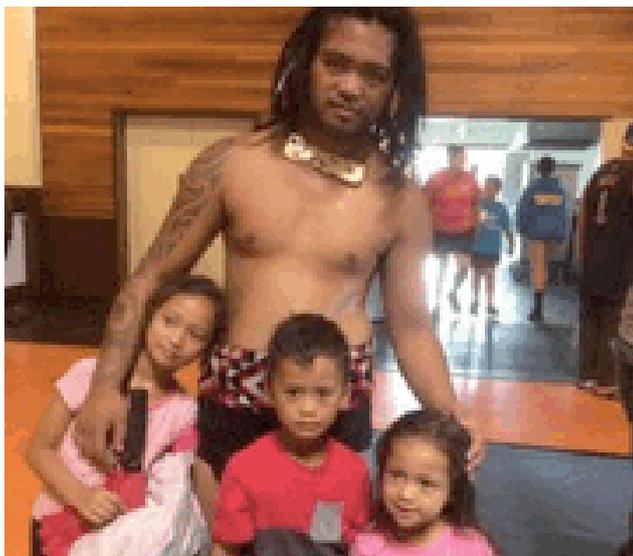
At the time of writing the Northern Committee are busily planning a fun filled family camp for March and lots more events for the year coming up, including a dinner for World Haemophilia Day. On that, start thinking about who you would like to nominate for a buddy award and surprise them with some deserved recognition at a celebratory dinner. Also if you'd like to get more involved in the bleeding community then drop us a line, as we'd love to get you involved, even just a little bit. It's not as scary as you think - honest.

Something I learnt this week with Henry (7 years old with VWD Type II) who just lost his front teeth is the magic of gauze soaked in tranexamic acid powder in a little bit of water, bunged up against the "tooth hole". Magic! Thanks to our fantastic nurses at the treatment centre for the advice and shout out to the Tooth Fairy who cleaned the sheets and left \$2.

An impromptu event was held at Okahu bay Pizza on the Beach with Rithy from the Cambodian Hemophilia Association. It was the second time Rithy had tried Pizza and was clearly a highlight of his NZ experience. It was

great to be able to show Rithy Auckland city. Richard Scott took a couple of days off work and explored Mt Wellington, the Arataki visitors centre, Karekare falls and the black sand beach, and the Gannet colony at Muriwai. Despite his best efforts, Rithy couldn't manage a full pie and donut lunch. The next day was the Auckland Museum and Maori cultural show, the Sky Tower and the Auckland waterfront before winding up at Okahu Bay for pizza. It's always a great reminder that we are a global community and that we all share so much in common and that treatment for all is a great goal for WFH and HFNZ to be aiming for.

## Piritoto



Nga Mihi of te Tau hou ki runga I a tatou katoa.

A happy new year to us all.

After a successful year of assorted activities that had seen Piritoto reinforce our ideals of togetherness and promoting wellness with each other, we are striving to better ourselves again in this New Year.

Mid last year we proposed a joint event with the Northern Region in celebration of the Matariki Maori New Year at the Auckland observatory in Cornwall Park. The joint venture saw the coming together of the two MRGs, and a great chance to get to know one another better. The aim of this year's Matariki event is similar to the last. We are hoping to foster better relationships with other MRGs throughout the country, establish events in those areas, and invite more people to join in.

Our annual Noho Marae will follow the same intent as above. We are hoping to find a location that will better strengthen our ties not only with people in our Piritoto whānau, but others in the local area too. With that in mind there is a possibility of having two Noho annually rather than one.

This year will see our whānau fortifying our ties and stimulating a better understanding of what we do as an MRG, striving to express what it means to be Piritoto – 'the blood that binds us.'

An acknowledgement must be made to the whānau who participated in the Matariki National Kapa Haka competition, held in Hastings on the 26th of February. The competition is a significant cultural festival that promotes Māori performing arts and tests the boundary of physical limits

where Kapa Haka performers contest on stage to find out who will reign supreme.

Waru pictured with daughter - Te Whetumatarau - Haemophilia Carrier

## Youth



Several of us attended the Advanced Leadership Training weekend a couple of weeks ago in the North Island. Flying into Auckland and getting a series of clues to follow to our 'mystery destination', we successfully navigated ourselves over the island! The weekend consisted of some awesome activities and some workshop style education sessions. Highlights included mountain biking and an amazing zip-line tour through the forest canopy in Rotorua. Some of us were lucky enough to be a part of someone's treatment for the first time as well!

As part of the weekend's fun, we had the opportunity to get into our regional groups and discuss some ideas about what sort of events we could have in each region to engage some more youth members. Watch this space if you're keen to meet up with some others in your region. We're also looking at getting a Facebook page up and running, rather than a closed group, so people can find it more easily, learn about what we're up to, and get in touch with us.

The National Youth Committee are currently planning a winter getaway in June in Queenstown, comprising educational as well as fun elements, so we can connect and grow relationships within our bleeding disorder community. Keep an eye out for invitations and further information to follow soon!

On that note, if anyone is interested in being a part of the Youth Committee, or would like to know more about what's involved, please get in touch!

# Southern

Hi folks

I hope you all had an enjoyable and safe festive season... The nights are getting darker earlier now, and so we know winter will once again be upon us. I love winter, it is my favourite season!

Firstly I would like to say a huge thanks to Linda Dockrill, our former Outreach Worker, and wish her all the best in her new field of work. To Leanne Pearce, a huge thanks too from Southern for all the years of organisation, smooth air journeys, and a great attitude on the other end of the phone.

Welcome to Josiane, our new Outreach Worker. We hope your time with the Foundation will be long and prosperous. Josiane will be in touch with everyone as she ventures around the countryside on Outreach visits.

A big welcome and huge congratulations to Rodney and Jo McKay on the birth of their daughter Madeleine (and congratulations to Gran and Pop, Colleen and Carl!) Thank goodness Madeleine will not be a Crusader fan as she was born on the Gold Coast!!

2017 started off with our committee meeting in February which was poorly attended, still we managed to get underway with planning for our Southern Family Camp. Mark your diary for 6 May for the annual play, we will be seeking your support leading up to and on the night.

Armageddon. Sadly Dunedin are not involved this year, simply due to lack of interest from members. It is getting harder for our group to supply the number of volunteers over the two day period.

In June we are planning a get together at Burns Lodge in Mosgiel, I will inform you of the details as soon as the date has been confirmed.

Zac and Karl are organising the biking for bleeders so watch out for information in relation to this event.

## HFNZ Shout Out...



HFNZ would like to take the opportunity to shout out to Quality Hotel Parnell, who have been very generous supporters of our programmes. We have run events at the Quality Hotel Parnell, and they are always happy to go the extra mile to make things work for us.

If you're heading to Auckland, please consider Quality Hotel Parnell for your accommodation needs.

You can find out more about this great venue here:

<http://www.theparnell.co.nz/>

# Giving Factor to Children at Home

By Janine Furmedge

Janine Furmedge is the Haemophilia Nurse Coordinator at the Royal Children's Hospital, Melbourne

Prophylaxis with factor concentrates has been, without doubt, a great advance in the management of severe haemophilia and is well established in developed countries such as Australia. However starting regular factor infusions in infants and young children brings many challenges; finding veins is often difficult and upsetting for all involved and the thought of home treatment is a daunting prospect for most parents.

Ports, often called Port'a'caths in NZ, are temporary devices that are surgically implanted to allow easy access to a central vein. Ports have a reservoir that is inserted under the skin, usually on the chest. The reservoir connects to tubing (a catheter) that is tunneled under the skin and feeds into a large vein in the neck. A special needle is inserted through the skin and into the port reservoir and the injected factor travels along the catheter and into the bloodstream.

In cases where IV access has been difficult, establishing reliable vein access via a port makes home treatment feasible in small children. But while ports bring considerable benefits, they are not without risk. Infection is the most common complication and parents are provided with comprehensive education so they learn how to administer factor safely and with a technique that minimises the risk of infection. Parents make a decision with the staff at their Haemophilia Centre if and when a port is appropriate for their child. And for children who have a port, the next step is to transition to peripheral veins once the veins further develop.

The Haemophilia Centre at The Royal Children's Hospital Melbourne wanted to develop a formal port education package. As the first step in the process we carried out a study to explore the experiences and education needs of parents who had learnt to use a port to administer factor to their child.

So what is it like for families learning to use their child's port?

Firstly, most parents were learning to use the port at a time when they were still dealing with the distress of the diagnosis of haemophilia in their child as well as beginning to experience bleeds, trips to the emergency department and treatment. So a very difficult time!

There were four main themes that emerged from the study focus groups:

## 1. Dealing with Fear and Anxiety

Most parents told us they were very anxious when accessing their child's port for the first time. They described 'shaking', 'sweating' and feeling 'nervous'. Many felt very emotional about putting a needle into their child and fearful of hurting them. There was enormous anticipation leading up to the first time they accessed their child's port but once it was over there was great relief and the feeling that in fact it wasn't so bad and much easier

than expected.

## 2. A Supportive Learning Environment

Many parents described the relationship with and the support received from the person teaching port access as one of the most important aspects during their learning. It was important that the teacher could foster confidence in parents during this difficult time and that both parent and child felt comfortable with and had trust in their teacher. Respecting the needs and wishes of the child was significant, as by 'making my child feel comfortable you [the parent] are automatically in a different place'.

## 3. Establishing a Ritual

Interestingly, many parents described the importance of having a routine or ritual around how the port was accessed. This helped both parent and child to feel comfortable and confident about the procedure. Children responded well to having some control and the ritual also assisted parents in their learning process. Parents described practices such as their child always sitting in the same place and position, always inserting the needle on the count of three and always setting out equipment in the same way.

## 4. Empowerment and Liberation

Parents described taking over their child's treatment as empowering. After a life dominated by the uncertainty of bleeding episodes and urgent visits to the Emergency Department for treatment parents could now take control; 'feeling in control after feeling so out of control ... I think that's the biggest stand out about ports'. Ports were seen as a 'blessing', allowing most children to participate in all kinds of activities including sports and school camp.

What information did parents want in an information package?

Parents asked that a teaching package incorporate photos, checklists and 'step by step' instructions. They also expressed the desire to hear the voices and experiences of other families and so we included stories, anecdotes and tips from other parents. In addition, consistency of teaching was identified as very important and so a checklist and information directed to nurse teachers was included as a mechanism to address this issue, especially for when several nurses are involved in the teaching process. The education package was developed with the help of parents who were experts in their child's port access as well as those who were learning for the first time.

The study helped us to have a greater understanding of what it is like for parents learning to give factor to their child via a port and to develop an education package that we hope will address parents' needs. The ability to give treatment at home was liberating for families but also meant less connection to the hospital and other families. Parents told us the enormous value they found in sharing their experiences and stories. This highlights the importance and great work of our Haemophilia Foundations in providing strong support and opportunity for children, families and adults with bleeding disorders to connect with each other.

*More information*

If you have any questions about your child and ports, please contact your Haemophilia Treatment Centre.

## Acknowledgements

A special thank you to the families who generously gave their time to share their experiences of learning how to use their child's port, to write their stories, to be photographed and to review and pilot the port guide. Development and publication of the port guide was supported by a Bayer Haemophilia Caregiver Award. Thank you also to the Educational Resource Centre at the Royal Children's Hospital, Melbourne for their expert photography and design.

# Men and early ageing

By Suzanne O'Callaghan

HFA Policy Research and Education Manager



A fairly common comment over the last few years has been that with prophylaxis and home therapy, people with bleeding disorders no longer need to spend so much time in hospital – but that, ironically, this means there are fewer opportunities for them to connect for peer education and support.

This makes local Foundation activities like community camps and retreats and the men and women's breakfasts and other peer support groups an immensely precious time together and HFA works hard to find funding to support them.

The needs of men around early ageing is a new and challenging area for HFA. Our intensive work on The Female Factors, the women and girls project, has given a real insight into the education and peer support needs of women and girls in our community and the education resources and activities evolving out of this are very exciting. However, HFA's long experience of working with men in the community has shown that a different approach is required for men, and we also know that there is much more work that needs to be done to understand and respond to the issues around early ageing.

## Growing older with haemophilia

Advances in haemophilia treatment and care over the last few decades have meant that there has been overall increase in life expectancy for people with haemophilia, and many are now living into their senior years.<sup>1</sup>

Jason, now 44 years old, has mild haemophilia and recalls

the very different story he was told when he was first diagnosed as a teenager:

*"The doctor said my life expectancy was 30. So when you've got a kid who's 13 and is told they might only live to 30, how daunting is that!"*

Growing older with haemophilia has raised another set of issues. Men with haemophilia who are now in their mid-20s or older lived through a time when prophylaxis was not yet available and there were treatment shortages at times. Most now have haemophilia-related arthritis from repeated bleeding into joints. They also experienced the hepatitis C and HIV epidemics in the bleeding disorders community in the 1980s, where many acquired bloodborne viruses from infected clotting factor concentrates.

As a result, issues of ageing, such as mobility and pain problems relating to arthritis, occur at a much earlier age in this generation of men with haemophilia – in general at around 35–40 years, although it can be at a younger age if they have had many bleeding episodes, particularly if they have had inhibitors and their treatment has not been effective.<sup>1,2,3</sup>

Even with mild haemophilia, and not having as many bleeding episodes as someone with moderate or severe haemophilia, Jason hasn't escaped without some complications.

*"Now at the age of 44, I have some osteoarthritis in my right knee. My condition has absolutely had an effect on my life, and I do have to take care of myself more than others. I still keep active, training with the local over 35s football team, riding my bike and running on nice soft grass to keep my joints in order."*

He also acquired hepatitis C, he suspects from a blood product he received when he was 13.

*"I was diagnosed with hepatitis C in 2005 after a routine medical check. In the 1980s, most people with bleeding disorders were exposed to hepatitis C virus before it had been 'discovered'. I underwent treatment and I am now hepatitis C free."*

## Resilience and fatigue

HFA's community consultations have highlighted that the Australian bleeding disorders community has a culture of stoicism and resilience. As one man with haemophilia said, "you learn to live with haemophilia. You're born with it, you grow up with it."

In spite of the good news that lifespans for many have increased, it is a community that remains aware of its vulnerability; that, for example, a head injury or a bloodborne virus like HIV or hepatitis C might tragically cut short a life.

The pain of bleeds and arthritis, the complications of bloodborne viruses if they have them, and limitations of their haemophilia can be challenging and make it hard to maintain a positive approach to their life.<sup>4,5</sup>

Jason comments,

*"I still train with the over 35s masters football, but it's really frustrating. I train really well on the track, and people ask why I don't play, but I know my limitations."*

*I still have to be careful what I do, and the difficult thing is the pain. People don't understand that if I get a bleed it will knock me around for a week or two."*

## Managing multiple health conditions

Apart from the mental fatigue of constantly fighting their physical problems, these men can become overwhelmed by the number of health conditions they have and the appointments and procedures required.

As one man with severe haemophilia in his 30s said to HFA,

*"If you ask about the perfect consultation, I think these haemophiliacs, they're like sports cars. They need to come into the pitt lane. We get the arthritis, we get the hep C, we get the HIV, and those when they combine, create a mental health issue. And also there's counselling you need if you are in work. You are going to need some support to stay there. You need someone to help you get out of bed in the morning sometimes. You need rails in your bathroom. Other times you need other things."*

As they grow older, they face the same other health conditions associated with ageing in the general population: cancer, heart disease, kidney disease, mental health problems and lifestyle issues such as weight control and muscle development. These are usually managed by a general practitioner and will create another set of medical appointments for this generation of men. How can this be made more manageable for them?

## Peer support and education

HFA is starting new work to better understand the issues of early ageing in men with haemophilia and potential benefits of a "men's health" approach.

What opportunities are there to help men with haemophilia to support each other and maintain a resilient and positive approach to life?

And what kind of information and resources would be helpful for these men about their health and wellbeing – and how would it be best to deliver it?

The very successful men's peer support groups in some local Foundations show how valuable it can be to have a face-to-face relaxed environment for men to chat together about ordinary things like sport and cars, while at the same time sharing strategies for managing their health and learning about relevant health issues and services. But with mobility and distance issues, travel and meeting can be difficult. What other potential is there for connecting and peer support? Are there other ways that would suit this generation of men to come together? For example, online forums, phone or video or email networking, a virtual "men's shed"?

These are just some of the questions we are aiming to answer.

In Australia Hannah Opeskin, HFA Health Promotion Officer, will be leading the work on this project. In NZ you can contact your HFNZ Outreach Worker to discuss issues related to aging with a bleeding disorder, or your Regional Group for opportunities for social support.

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# News From Around the World

## UT Austin Engineers Develop First-Ever Capsule to Treat Haemophilia

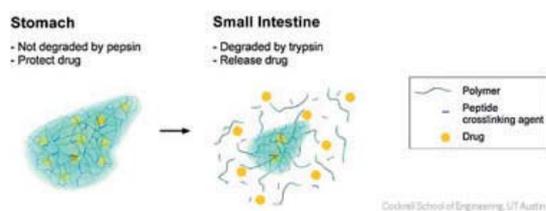
AUSTIN, Texas — In the near future, haemophiliacs could be able to treat their disease by simply swallowing a capsule.

Thanks to a breakthrough led by researchers in the Cockrell School of Engineering at The University of Texas at Austin, treatment for haemophilia can now be administered via a biodegradable system, a capsule, giving people affected by the hereditary bleeding disorder hope for a less expensive, less painful treatment option than conventional injections or infusions.

The researchers designed the oral delivery system, which contains micro- and nanoparticles, to carry a protein therapy that treats haemophilia B. There are approximately 400,000 people worldwide living with either haemophilia A or haemophilia B, both caused by a missing protein in their blood. Haemophilia B is caused by a missing or defective factor IX, a clotting protein. The researchers describe their system in the Nov. 30 issue of the International Journal of Pharmaceutics.

The bleeding disorder affects people throughout the world, but global accessibility to therapy is limited by cost, the need for trained medical personnel and possible complications associated with needle-based drug administration. Thousands of people endure multiple injections weekly to keep symptoms, such as excessive bleeding and pain in the joints, at bay and prevent future joint disease.

“While an oral delivery platform will be beneficial to all haemophilia B patients, patients in developing countries will benefit the most,” said Sarena Horava, the study’s lead author who is a recent Ph.D. graduate from the Cockrell School’s McKetta Department of Chemical Engineering and a National Science Foundation graduate research fellow. “In many developing countries, the median life expectancy for haemophilia patients is 11 years due to the lack of access to treatment, but our new oral delivery of factor IX can now overcome these issues and improve the worldwide use of this therapy.”



Horava, who now works at Triton Systems, collaborated with co-author and co-inventor Nicholas A. Peppas, the director of UT Austin’s Institute for Biomaterials, Drug Delivery and Regenerative Medicine and a Cockrell School professor who also holds appointments in the

Dell Medical School and School of Pharmacy. Katie J. Moy, an undergraduate student in the Cockrell School’s Department of Biomedical Engineering, is also a co-author on the study.

Peppas said that alleviating the burden of injections for children was the impetus for the research project, which started about nine years ago.

“My most pressing concern was the treatment of younger patients who suffer from haemophilia and who have to apply injections every two days,” Peppas said. “The original idea of the project was conceived when Dr. Lisa Brannon-Peppas, who at the time was a biomedical engineering faculty member, discussed with me the side effects of the disease and the psychological impact it has on mothers.”

Peppas and Horava’s work has been patented and builds upon their published and patented system for the oral delivery of human factor IX (hFIX), a prophylactic treatment for haemophilia B patients. That system was successful in transporting hFIX, and it was able to deliver adequate levels of the drug to the target site in the body. The biggest challenge in delivering hFIX is that it is extremely delicate and unstable in the body’s various pH environments. The researchers’ new and improved system is designed to capitalize on the body’s pH and changes in enzymes inside the gastrointestinal tract for a smooth delivery.

As it moves through the body, the particle-containing capsule resists the major gastric enzyme to remain intact while in the stomach, providing protection for the encapsulated drug. In the small intestine, the capsule begins to swell with the increase in pH and is then degraded by the major intestinal enzyme, slowly releasing the drug over time.

“Based on the current capabilities of this system, approximately two capsules would be equivalent to one injection,” Horava said. “However, we anticipate that we will make further improvements to the delivery capacity of the oral delivery system and therefore decrease the capsule amount.”

The researchers plan to further test this system before clinical trials. They are working with the UT Austin Office of Technology Commercialization to further advance the technology for clinical use. The researchers indicate that their ultimate goal is to position this technology for Food and Drug Administration approval.

This research received funding from the National Institutes of Health, the Fletcher S. Pratt Chair, the National Science Foundation Graduate Research Fellowship Program, the P.E.O. Scholar Award and the UT Austin Undergraduate Research Fellowship.

Source: <https://news.utexas.edu/2016/11/28/engineers-develop-first-ever-capsule-to-treat-hemophilia>

## World AIDS Day Events Focused on Toll Disease Took on Haemophilia Community

By Carolina Henriques

More than 1,300 people who have been affected by acquired immune deficiency syndrome (AIDS) gathered at the National AIDS Memorial in San Francisco on Dec. 1 to commemorate World AIDS Day. During two days of events, family and friends paid tributes to those lost to the disease, while inspiring remembrance and conveying a message of hope for the future.

This year, the event saw special emphasis placed on the tragic legacy AIDS has left on the haemophilia community.

In collaboration with the HIV Story Project, the memorial published a series of personal video stories capturing the diversity of this epidemic with testimonies of survivors, this year focusing on the plight of the haemophilia community and the loss of life caused by a tainted blood supply, which led to the death of 50% of those who received it between 1980 and 2010.

The World AIDS Day event included an unprecedented panel discussion, which brought together leaders in the national haemophilia community to debate the need for featuring those infected by the blood contamination crisis at the memorial.

Jeanne White-Ginder, AIDS activist and mother of the late Ryan White, a young boy who received tainted blood, accepted the Thom Weyand Usung Hero award, on behalf of the national haemophilia community.

“We have to honour and respect those who went through this horrible, horrible epidemic,” said White-Ginder. “Too many people we loved were lost and the haemophilia community needs to come together to share our stories and communicate with one another the sadness and the sorrow, but also the joy that maybe nobody has to live with this again,” she said.

In the early 1990s, a small group of San Francisco residents, representing a community severely affected by the AIDS epidemic, started gathering in an abandoned grove in Golden Gate Park, restoring the area and creating a serene place where people who sought healing could gather to express their collective grief.

The founders of “The Grove” wanted to create a living memorial for all those affected by HIV/AIDS. Their efforts built a movement, which led to new legislation five years after they began, proposed by U.S. Rep. Nancy Pelosi, D-Calif. President Bill Clinton later designated The Grove as the official national memorial for HIV/AIDS.

Now, 25 years later, about 25,000 volunteers have passed by the site, donating more than 150,000 hours of their time to help maintain the memorial, clear overgrowth, reintroduce native species and plant new trees, plants and shrubs.

“The Grove is a place of both remembrance and renewal with people coming from all over the world to remember those lost and look to the future,” Rep. Pelosi said in a press release. “Twenty-five years after this important designation, we still strive for a future in which we end

stigma and discrimination, ensure continued research, care and resources, and, at long last, find a cure,” she said.

This year, World AIDS Day events included a “Light in the Grove” session, which illuminated The Grove to honour those who have passed away, as well as a candlelight reflection at the “Circle of Friends.” Special artistic performances were included in the event.

“As we gather in this beautiful meadow, we pay tribute to the lives lost to this pandemic,” said John Cunningham, National AIDS Memorial’s executive director. “It was within their struggle and the grief and pain that followed that the Grove was born 25 years ago. Today, we join together to honour their legacy and recognize some of the leaders who have made lasting impacts in the fight against AIDS.”

During the event, college students wanting to pursue their education while staying actively committed to fighting AIDS also were awarded scholarships, as part of the National AIDS Memorial Pedro Zamora Young Leaders Scholarship Award Program.

Source: <https://hemophilianewstoday.com/news-posts/2016/12/09/world-aids-day-events-focused-hemophilia-community/>



# The Year Ahead...

More details on all events are available from your Outreach Worker

## April 17th

World Haemophilia Day & Buddy Awards

Keep an eye on Pānui for information on events in your region

## April 20th – 23rd

National Youth Camp

Waipara Adventure Centre, North Canterbury

## June 16th – 18th

PEP

Aotea Lodge, Wellington

## August 18th – 20th

National Inhibitor Workshop

Quality Hotel Parnell, Auckland

## September 29th – October 1st

Adult Weekend

Auckland

## October 1st

HFNZ Annual General Meeting

Auckland

Visit [www.haemophilia.org.nz](http://www.haemophilia.org.nz) for more information on bleeding disorders, HFNZ news, and past issues of Bloodline

Haemophilia Foundation of New Zealand Inc. **HFNZ** **bloodline**  
 December 2016  
 Volume 49 / Number 3  
 Journal of the Haemophilia Foundation of New Zealand Inc

**WFH 2016  
 WORLD  
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Orlando, USA · July 24-28

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National  
 Family Camp  
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