

bloodline

December 2013
Volume 41 / Number 4

Newsletter of the Haemophilia Foundation of New Zealand Inc



HFNZ
NEWSLETTER
4TH
ANNIVERSARY



CONTACT DETAILS

Website

www.haemophilia.org.nz

National Office

4 Washington Way,
Sydenham, Christchurch
PO Box 7647, Sydenham,
Christchurch 8240
Ph: 03 371 7477
Fax: 03 371 7479
info@haemophilia.org.nz

President

Deon York
deon@haemophilia.org.nz

Chief Executive Officer

Belinda Burnett
belinda@haemophilia.org.nz

Editor

Chantal Lauzon
chantal@haemophilia.org.nz

Manager Outreach Services

Colleen McKay
colleen@haemophilia.org.nz
Ph: 03 371 7479

Linda Dockrill

Southern Outreach Worker
PO Box 7647, Sydenham
Christchurch 8240
Ph: 03 371 7485
linda@haemophilia.org.nz

Lynne Campbell

Central Outreach Worker
PO Box 24014
Manners Street
Central Wellington 6142
Ph: 04 382 8442
lynne@haemophilia.org.nz

Joy Barrett

Midland Outreach Worker
PO Box 4357
Hamilton East
Hamilton 3247
Ph: 07 856 4442
joy@haemophilia.org.nz

Sarah Preston

Northern Outreach Worker
PO Box 41-062
St Lukes, Mt Albert
Auckland 1346
Ph: 09 845 4658
Fax: 09 846 8174
sarah@haemophilia.org.nz

The Word



Congratulations Southern!

It was my pleasure to attend the recent 30th celebrations of the Southern Branch of HFNZ. Did you know that Southern was the first branch of HFNZ to hold a National Family Camp outside of Auckland? With all the events that HFNZ runs all over the country, it almost seems unimaginable today. Southern has been involved with a lot of other "firsts" over the years including hosting the first ever Australasian Haemophilia Conference outside of Australia.

In this issue of Bloodline it's all about Birthdays, see more about Southern's 30th and this very newsletter's 40th Birthday!

Enjoy your summer edition of Bloodline.

Deon York
HFNZ President

Contents	Over 40 years of the HFNZ Newsletter.....	1
	Adult Weekend – Come to Casablanca.....	4
	Twinning Connection	6
	2013 Twinning Visit to Cambodia	6
	5th Asia-Pacific Hemophilia Camp	8
	Southern Celebrate 30th Anniversary	9
	Bruise Protection – Safety tips for infants and toddlers.....	11
	“What’s your Dream” Colouring-in Competition.....	12
	Getting a good night’s sleep.....	13
	So you’ve finished treatment... now what?	14
	AFFIRM goes Global.....	16
	Masters Group Update.....	16
	MRG Reports.....	17
	News in Brief	20
	Upcoming Events.....	22

Over 40 years of the HFNZ Newsletter

The first volume of the official newsletter of the then New Zealand Haemophilia Society consisted of six issues spanning 1972 and 1973. The newsletter, now known as Bloodline, has reported 40 years of excellent events, amazing advances in treatment, heart-breaking consequences from viral infections of the blood supply and many personal challenges and triumphs faced by members of our bleeding disorders community.

To better understand how the newsletter has evolved over the decades, here we present some of the history of the newsletter, its editors and the stories that have touched us all.

1970s



Although the New Zealand Haemophilia Society (NZHS), as our organisation was once known, got off to a strong start in 1958, the passing away of some of the key founding figures meant that by 1971, the future of the NZHS hung in a delicate balance; unless a new committee was willing to take on the leadership, the Society might cease to function altogether.

Up until this point the Society had been centred in Wellington, but in July 1971 John Davy called together many of the families in Auckland known to be affected by a bleeding disorder and the result was that Auckland enthusiastically agreed to take over the reins of the Society.

Recognising that because people with bleeding disorders were spread around the country, there was lack of communication and, for many, a sense of isolation, they decided to put a concerted effort into reaching out to as many people as possible. Bob White, the original chairperson had sent out the occasional letter to people with haemophilia he knew but there was no formal newsletter for the Society.

On a trip to Ireland Nicholas Gordon bought a portable typewriter – the Society's first asset. The NZHS newsletter was then revived in a much more professional and comprehensive format far exceeding the humble letters that had made up the sporadic correspondence of previous years. The intention was for the newsletter to ease the problem of distance by providing a means of regular communication; and, through that, the Society hoped to build a strong membership and encourage a "better feeling of, for want of a better word, togetherness". Initially compiled by Davy and Pat Sheary, the newsletter was put together and printed at the Auckland School of Medicine. Volume 1, Number 1 in June 1972 details the vision of the new committee and the results of the second Auckland AGM.

Readers should not think that it is the wish of the committee that the Society should develop into an organisation of "bleeders" whose only purpose is to bemoan their lot in life. That there is pain and hardship associated with the disease is a fact of life well known to those who suffer from, or are close to it. We hope that with a strong and vital Society we can assist members with problems, both social and economic.

From the Editor". NZHS Newsletter. Vol. 1(1); October 1972: p.1.

Although at the time there was only 38 member families of the Society, 150 copies of the quarterly newsletter were printed and distributed to contacts across the country. By 1975, the NZHS had 132 members and, by the end of the decade, more than 200 copies of the newsletters were being distributed.

It was in the newsletter that the notices of the first ever camp were advertised. The idea was to get as many people as possible together to reduce their sense of isolation and right from the beginning included a mix of education and fun. By all the accounts they first camp in 1976 was a huge success.

Our lasting impression is of putting faces to names, of marvellous food (and not having to cook it) and feeling that there is a much closer bond between us because of having been to the camp. As far as our family is concerned, it was the best holiday they have ever had, in spite of the weather!

Impressions of the First Haemophilia Camp, NZHS Newsletter Vol. 4(1); March 1976.



John Milne, Camp Chef 1976

1980s

Camp news, family conferences, advances in treatment products, and the setting up of new branches of the Society around the country all featured on front page of the newsletter during the 1980s.

It was not all good news however. The newsletter was also pivotal in informing the community about the tragedy of HIV and AIDS. The headline of the June 1983 issue of the NZHS newsletter reads simply "A.I.D.S. (Acquired Immune Deficiency Syndrome)". Those four little letters contained the unimaginable amount of pain, hurt, anger, anxiety, fear and loss that was about to befall the worldwide haemophilia community. In the early 1980s there was no internet, no Google, and with widely varying stories and hysteria circulating about HIV in the media, members turned to the NZHS newsletter to provide them with the facts of the situation for people with haemophilia in New Zealand and overseas.

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

It was the newsletter that later announced the appointment of Stephanie Forde, a nurse at the Haemophilia Centre at Auckland Hospital, as part-time field officer in 1989 – the Society’s first employee and outreach worker. Operating out of an office at Auckland Hospital, her mandate was “to enhance care and services to all haemophiliacs and their families”.²



1990s

The NZHS newsletter continued to be produced quarterly, bringing important updates and useful advice to all members and associates. After 10 years, Jock Church decided to step down as editor in 1995. He had done a wonderful job of ensuring there was a little something for everyone in the newsletter and maintaining a clear record of NZHS events over a very troublesome decade. In his time as editor, the newsletter had expanded from an A5 to A4 format, and he produced a very professional layout with the support of Copybook. His editorials often gave one pause for thought, and he had a knack for catching the problems or feelings of the time in just a few lines. Under his dedicated eye, the newsletter grew in stature and drew compliments from other haemophilia societies around the world.



To say that Jock has done us proud in his production of the newsletter is an understatement... I have been full of admiration for the dedication and care which Jock has poured into the editor's job. He has been a careful and compassionate mouthpiece for the Society in its many and varied communication tasks.

From the President. NZHS Newsletter. Vol. 23(3); September 1995.

The role of editor was taken over by Dr Peter Zink, who did a great job collating and editing the newsletter for 2 years, putting in considerable time and effort.

A new energetic and creative editor, Nikki Cunningham, was appointed at the 1997 AGM. A new era of the NZHS newsletter thus began: her editorials provided a personal touch to the newsletters, reminding readers that although a political force, the Society was made up of caring members with real families who all had to live with haemophilia as part of their daily lives. She saw the NZHS newsletter as a means to help disseminate knowledge to the people who needed it most and to empower them.

It was during the 1990s that the Hepatitis C scandal, or Bad Blood Affair, reared its head. Again, members turned to NZHS newsletter as a reliable source of information on both the disease and actions the Society was taking to try preventing further infections and seeking answers on how this second disaster had been allowed to occur. With so many members affected, articles related to hepatitis C continue to feature in Bloodline to this day.

Just when we were starting to breathe a sigh of relief that blood products were clean and safe, now we are faced with the spectre of Hepatitis C contamination and infection... blood products seem to be the most important problem to be addressed in the coming year.

President's Report. NZHS Newsletter. Vol. 19(2); June 1991.

In terms of treatment advances, the June 1992 issue of the NZHS newsletter carried an article on recombinant factor VIII. Using recombinant DNA technology, recombinant pure versions of clotting factor proteins were now being manufactured in the laboratory instead of being extracted from blood.

During the 1990s, more recognition of the bleeding problems of women was beginning to take place and, with it, awareness of vWD. Articles on vWD began to appear regularly in the NZHS newsletter. People with vWD were encouraged to become members of the Society and those who already were, were persuaded to share their stories so that others could better understand the differences and similarities between the two bleeding disorders.

2000s

After much deliberation and numerous suggestions, the HFNZ newsletter was officially renamed Bloodline from August 1999. The name had been suggested both by Judy Stapleton and Christine Ingram. With the new name came a move to a new printer. Copybook Centre had been printing the newsletter for longer than most people could remember. Mac and Greg, along with their co-workers, dragged the newsletter into the 21st century; they were patient with HFNZ members as they grappled with the finer details of publishing, and their expertise



was appreciated by all the editors over the years. The production of Bloodline was moved to Clutha Print, in Balclutha, to make it easier for editor Nikki Cunningham, who lived in the area.

During Cunningham's stewardship, the newsletter grew into its new name and became available electronically on the web. Comprehensive conference supplements began to appear each year, with coverage of the Australasian Haemophilia Conference or the WFH World Congress. All HFNZ delegates had to contribute reports as part of HFNZ sponsorship of their attendance - so each supplement had a unique perspective carrying the messages that stuck most with attendees. The supplements allowed the entire haemophilia community in New Zealand to benefit from the knowledge shared at conferences.

Other big stories from this era was the continuing battle for hepatitis C compensation and Jack Finn's bike and kayak across New Zealand to raise awareness. Bloodline also reported on the transition from one big national family camp to targeted workshops for young families, youth, women and men's weekends.

Early in 2005 another staff member was added to the HFNZ team when Nova Guerin took up the new position of national information co-ordinator. The position was created to further ease the burden on volunteers on the national council by having a person dedicated to HFNZ communications. Part of this was taking charge of Bloodline when Cunningham stepped down from the position.

In 2006, Chantal Lauzon took over the role and the production of the newsletter. Printing was moved from Balclutha to Jeff Oliver Print in Whangarei and the current glossier look was introduced with a colour cover. The newsletter also became available on the Foundation's website so it could easily be shared with the world. Chantal has recently returned to the position of editor after entrusting the newsletter to the capable Kate Russell while she was on maternity leave.

The newsletter continues to contain stories of interest for all types of HFNZ members, from young families, to older men, to women with bleeding disorders, to people with hepatitis C. It features the many camps and education workshops run by HFNZ, the social activities organised by the regional branches and updates on treatment and well-being from various experts in their field.



Although it's difficult to predict what format the newsletter might take in another 40 years, looking forward HFNZ is committed to providing timely and relevant information on our members and events, as well news from the worldwide bleeding disorders community. We always welcome contributions or story ideas from you so please contact Chantal (chantal@haemophilia.org.nz) if you would like to share.

1. "From the Editor". NZHS Newsletter. Vol. 1(1); October 1972: p.1.
2. "Appointment of National Haemophilia Field Officer". NZHS Newsletter. Vol. 17(3); August 1989.

Jeff Oliver Print Ltd

Creative Design / Quality Print

T: 09 438 8313 / F: 09 430 8474 / info@jeffoliverprint.co.nz
24 Walton Street • Whangarei / www.jeffoliverprint.co.nz

Adult Weekend – Come to Casablanca

During the last weekend of September HFNZ hosted 'Come to Casablanca' an Adult Wellness Weekend in Christchurch. It was a great, relaxed weekend with a range of education topics and gave the 38 participants plenty of time to catch up with one another.

Adults with bleeding disorders, some with their partners, travelled from all over New Zealand to the Elms Hotel in Christchurch on Friday the 27th of September. After Mihi Whakatau delivered by Neville-James Reedy of Invercargill, and a welcome and an activity to get to know each other better the two winners from Baxter's Advance Your Passion Competition told us of their personal experiences in advancing their passion after being declared winners in the competition. First we heard from Jack Finn about his journey to Greenland, the home of kayaking. Jack showed fantastic slideshow of the rugged yet beautiful scenery and wildlife he experienced kayaking in the fjords. Nev Reedy then shared a little about the making of his Film 'Blood Land Journey' which features his cousin Te Ahuriri (TA) Stirling and his cycle journey, a tribute to whakapapa, around the East Cape of New Zealand. Without giving too much away he managed to whet our appetites for the feature film to be released next year.

After dinner Colleen McKay (HFNZ) and Lee Townsend (Haemophilia Physiotherapist) gave a reminder of the stark reality for 75 per cent of people with bleeding disorders around the world – no treatment! They gave an update of the World Federation of Hemophilia Twinning Partnership between HFNZ and the Cambodian Hemophilia Association (CHA) and the progress that has been made in assisting CHA to develop into an organisation that can plan and meet the needs of its' members. See the 'Twinning Connection' article in this issue of Bloodline for more detail of their 2013 Twinning Visit to Cambodia.

After a healthy breakfast, Saturday morning kicked off with the Haemophilia Outreach Workers Sarah, Joy, Linda and Lynne giving an overview of the Outreach Services, including what an Outreach Worker does, where they can help and explaining the importance of contacting them if you have any questions or need ideas or assistance.

Haemophilia Specialist Physiotherapists Ian d'Young and Lee Townsend then gave a Physiotherapy Master Class. Thanks to the two very brave volunteers who stripped down to demonstrate a Physiotherapy Assessment and get a Rehabilitation Plan. In the first assessment, Ian and Lee were able to concentrate on assessing Sam Bradley's knees and ankles and were able to suggest exercises that could help Sam pre surgery. For Grant Hook, the second volunteer, Ian was able to concentrate on assessing a recent shoulder injury.

Ian also talked about his Bleed Reporting Project which clearly demonstrates that the early reporting of bleeds, and engagement in a Physiotherapy Rehabilitation Schedule soon after a bleed leads to better rehabilitation, less likelihood of re-bleeding and reduced use of factor – a better outcome all round.

Saturday afternoon was the highlight for many participants. They were able to take part in a flight in a DC3 over Christchurch City and south Canterbury. It was a rare opportunity to ride in the

beautiful and historic old 'bird' as this the last season that the DC3 will be flying. Afterwards many participants took the opportunity to be dropped into town to view the sights of the 'broken city' and the Re-Start Mall.

That evening celebrity chef and author Richard Till entertained the group with his 'take' on food and food preparation urging people to cook for themselves, to keep it simple and to try new twists on recipes.

The Sunday programme started with Kathy Fawcett, Haemophilia Nurse Specialist at Christchurch Hospital, presenting an Overview of the Ageing Process and a reminder about the importance of taking action to seek help when experiencing a serious bleed rather than leaving it in the hopes that things might 'get better'.

Later during the Expert Panel, more brave participants presented their personal experiences from their lives:

- **'Keeping the Beat'** - 70 year old Reg Fuller spoke about his experiences having a triple by-pass after being diagnosed with a heart problem. Reg paid enormous tribute to his wife Sue and their friends and family for their support during this time.
- **'Dealing to the Sleeping Dragon'** - John Wrathall spoke of his experiences on the recent Hepatitis C Trial, which involved many trips to the trial centre Christchurch to attend appointments, sometimes weekly. John thanked HFNZ staff for their support of him over this time and urged others to make contact with their Outreach Worker should they need support.
- **'Taking care of the Think Tank'** - John Tuck spoke of his extremely serious brain bleed while holidaying in Australia. John reminded participants and their partners of the importance of seeking help if things don't 'feel right' or if your loved one is behaving in an uncharacteristic manner.

After lunch the men with bleeding disorders and the rest of the participants parted company so that Paul Long and John Wrathall from the Masters' Steering Committee could hold a Masters' Focus Group Meeting to report on their progress and seek clarification of 'where to from here?' Although the meeting did not follow a strict structure the Masters Steering Group took a great deal away from the meeting. The other participants took part in 'Living with a Bleeding Disorder – the Good, the Bad and the Ugly' where they were divided into two groups people with bleeding disorders and partners where they discussed the good things, the bad things and the ugly things about having/living with someone who has a bleeding disorders. Interestingly the list of the 'ugly' things was much shorter than the list of the 'good' points; the 'ugly' things included supporting your partner through pain, and the bleeds at 2am. Hannah Airey from Lotus Health gave participants a taste of Laughter Yoga which was a 'scream' and enjoyed by all.

After Final Assembly, Poroporoake where participants paid tribute to the Weekend, and a hearty afternoon tea everyone was whisked off to Christchurch Airport for their journey home.

A very special thank you to Novo Nordisk for their financial support for the workshop, all the speakers, Outreach Workers and Leanne and Belinda for all their work behind the scenes.



Twinning Connection

2013 Twinning Visit to Cambodia

Another very successful Twinning Visit took place when HFNZ Manager of Outreach Services Colleen McKay and Haemophilia Specialist Physiotherapist Lee Townsend (Christchurch Hospital) travelled from New Zealand to Cambodia from 30th August to the 2nd September 2013.

The annual Twinning Visits are a really important part of the Twinning relationship. They provide a chance to get together in person to review how things are progressing, an occasion for further training and activities and an opportunity to make plans for further development.

Workshop for families

One of the main objectives of the Twinning Visit was to deliver a 1-day workshop for families in Phnom Penh, the capital of Cambodia.

The workshop, "Physiotherapy for Hemophilia Patients" was held on Saturday 31st August at the Cambodiana Hotel in Phnom Penh. It was well attended, with 57 participants, including families with children with haemophilia.

Mr Rithy and Ms Tev Linat, volunteer Social Worker with CHA were in charge of communication with members to promote the event. The fantastic attendance and media coverage received was evidence of their success, including coverage on television and in newspapers

After opening speeches from Mr Kong Sithan and Mrs Colleen McKay, HFNZ, his High Excellency Ung Sambath, Deputy Secretary of the Disability Action Council, a physiotherapist by training, gave an overview of disability in Cambodia and the law that protects the rights of people with disabilities. This was followed by Mr Song Sit, Chairman of Physiotherapy Association in Cambodia on the Cambodian Physiotherapy Association.

Lee Townsend, Haemophilia Specialist Physiotherapist from Christchurch also travelled with HFNZ to Cambodia to help educate families and health professionals about bleeding disorders. She discussed what happens inside a bleeding joint,



how to recognise and treat a bleed, P.R.I.C.E. and the damage that can occur such as synovitis and arthropathy. She also discussed the importance of exercise and how it can help, especially when little product replacement is available. Lee was also able to assist with individual consultations for those with haemophilia alongside the local physiotherapists and recommend appropriate exercises in order to strengthen muscles and improve joint function.

After her presentation one patient commented that he now understood what had happened to his knee for the first time and why he is unable to bend his knee as much as he used to. He said he also understood that he would still be able to build up the muscles around the joint in order to keep his legs strong.

During the workshop CHA volunteers kept the children amused with drawing and a skeleton project brought from New Zealand. The children proudly displayed their skeletons on the wall and ensured that they took them home to show others.

Training and planning day with CHA committee

On Sunday 1st September Colleen spent the day with the CHA Committee to give further training on empowering them to succeed as an NMO and plan for the year to come.

Topics discussed included fundraising, running social activities for members and networking. The CHA website (www.chacambodia.org) and Facebook page are now up and running is now complete.

Together they reviewed their 2013 Twinning Action Plan and set goals for 2014. Activities and objectives for the HFNZ-CHA Twinning in 2014 include:

- Registering CHA with the Cambodian Disabled Person Organization
- Continue with home visits especially to newly diagnosed families
- Raising awareness of haemophilia
- Twinning Visit in August 2014
- Social events to promote networking support for members
- Continue to advocate with the Blood Bank and the Ministry of Health for people with haemophilia in Cambodia

Meetings with government and medical organisations

On Monday 2nd September, HFNZ and CHA representatives met with a number of stakeholder organisations and institutions including the National Blood Transfusion Center and Disability Action Council.

CHA and HFNZ congratulated the National Blood Transfusion Center on the success of their public blood drives. Due to these they now have a supply of regular donors and an excess stock of Fresh Frozen Plasma. Although the Center has sufficient plasma to manufacture cryoprecipitate, they currently lack the necessary equipment, trained staff and the room needed to begin. Presently, the National Pediatric Hospital in Phnom Penh has a very limited stock of donated Factor VIII from the World Federation of Hemophilia (WFH). With the increasing number of new diagnoses of haemophilia there is a desire for Cambodia to manufacture cryoprecipitate in order to become self-sufficient in the treatment of those with haemophilia. The manufacture of locally made cryoprecipitate would ensure that it was more likely that people with haemophilia in Cambodia would be able to have treatment for their bleeds. A plan was made to try to help source the necessary equipment and training for staff.

During their meeting with the Disability Action Council they discussed the important steps that had been achieved for those

with haemophilia and the importance of access to physiotherapy. For example, haemophilia had been recognised and listed as a disability which gives people with haemophilia in Cambodia rights under the Law on the Protection and the Promotion of the Rights of Person with Disabilities.

The visit also included visits to two physiotherapy clinics – one at the National Pediatric Hospital and one at an NGO-run clinic, the Kien Khleang Rehabilitation Clinic which is run by Veterans International Cambodia. In contrast to the Physiotherapy Department at the National Pediatric Hospital which had very little equipment, the Rehabilitation was full of physiotherapy equipment and mobility aids. They were also well staffed with physiotherapists, orthotists and prosthetists. They established that this Center is where people with haemophilia requiring mobility aids such as crutches, wheelchairs, and walking frames should come to be fitted with when appropriate. The NGO provides this service and the aids free of charge.

Farewell

On the Monday evening a Celebration Dinner was held at a local buffet restaurant where all were able to enjoy local fare at the many stations. The dinner was held to celebrate a wonderful Twinning Visit, especially the very successful Physiotherapy Workshop for families. High Excellency Dr Neth Un, Deputy-Director of DAC – Secretariat General, Dr Chean Sophal, Mr Sithan and his wife, Ms Linat, Mr Rithy, Mr Pahna, Mrs Mala and four CHA volunteers were in attendance along with Colleen and Lee from New Zealand.

Mr Rithy kindly collected Mrs Colleen and Ms Lee and drove them safely to the Phnom Penh International Airport the next morning for their 26 hour journey back to Christchurch, New Zealand.

Colleen and Lee would like to extend a big THANK YOU to everyone at CHA who looked after them while in Phnom Penh. We appreciated your kindness and felt heartened by the efforts they are making.

Check out more pictures on the CHA Facebook page (search for *Cambodian Hemophilia Association*). Don't forget to 'Like' the page while you are there. You might also want to check out the recently completed CHA website www.chacambodia.org.



5th Asia-Pacific Hemophilia Camp



For the second time, two young members of HFNZ had the opportunity to attend the Asia Pacific Hemophilia Camp. Zac Porter (16 years old) and Sam Bentham (12 years old) attended this year's camp along with their mothers Lorraine and Jo. The camp took place from 16-18 August 2013 in Qingdao, China, and included 33 other youth with bleeding disorders and their caregivers from Korea, China, Brunei, Malaysia, Taiwan.

Bloodline interviewed Zac and Sam about their experiences at the camp

• **How did you find travelling to China?**

ZAC: It was my first trip to Asia. I was looking forward to visiting someplace completely new and didn't really know what to expect. We flew to China for only two nights. It's strange to think we travelled 15 hours to spend only the weekend in China! I would definitely like to visit China again. I feel like it's such a big country that I only very briefly scratched the surface as to what they have on offer and would love to go back and explore it more.

SAM: It involved over 15 hours of flying time, but when you include travel to and from airports, wait time at the airport and a stopover, the travel time balloons to a marathon 21 hours – one way! We stayed 2 nights and then did it all over again! For the most part I enjoyed this time. It gave me a chance to watch movies, read a book, sleep and chill out. Also, as it was the first time I had travelled overseas everything felt pretty exciting. Everyone we came across was really nice, but the airport police in Hong Kong and China looked a bit serious with their guns.

• **Where did the camp take place?**

ZAC: We stayed at the Doubletree by Hilton hotel. This had to be the biggest most exquisite place I have ever stayed at. It was decked out with everything you could ask for, from an indoor swimming pool, man-made lake to a driving range.

It was around 45 minutes outside of Qingdao so it wasn't extremely busy in the area. It was only several minutes' walk from an enormous shopping centre which was convenient.

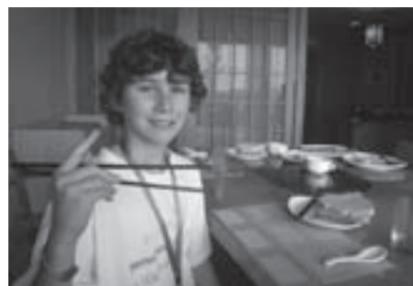
• **What kind of activities did you do at the camp?**

ZAC: At the camp we did a range of activities such as soccer games, obstacle courses, indoor swimming relays as well as some trivia, Taiji Quan exercise and even dumpling making.

SAM: I enjoyed all the outdoor physical activities, but my favourite activity was the mini soccer game. It was on the last day of camp which meant I knew everyone in my team really well so I think all of us were more relaxed and able to enjoy it. I also know how to play soccer because I play for my school soccer team and I think when you know what to do it helps you to enjoy it.

• **What was your favourite part of the experience?**

SAM: The best thing about camp was all the activities that all us kids did together. I really liked all the kids in my team and it was good talking to them about haemophilia and we laughed a lot too. To meet and talk to other kids and their families with the same problems was really helpful. I learnt lots from them and they helped me to solve some problems. They understand how you feel and make talking about haemophilia interesting. Some will end up being lifelong friends. I also know



that there are people other than my family that really care about me which makes me feel good. I also think that the camp has motivated me to learn more about my haemophilia.

I also experienced my 5 minutes of fame in China. They obviously don't see a lot of people like me: curly hair and blue, round eyes. It felt like I was on show for EVERYONE AND ANYONE. So many photo shoots! People staring! I loved it!

ZAC: My favourite part was meeting lots of awesome and enthusiastic friends from all over Asia-Pacific who, after trying to break past the language barrier with lots of made up sign-language, share some common stories and were really great people.

• **What was the most important/memorable thing that you learned?**

ZAC: The most important thing I learnt on the trip was to be grateful.

Some of the children, depending where they live, have very little in terms of funding, treatment and support for their bleeding disorders compared to what we have here in New Zealand. They have to live a completely altered lifestyle based around their conditions and ensuring they don't get bleeds. Here we have fewer problems and can live a relatively straight forward lifestyle with treatment available should we need it.

We are given so many opportunities such as chances to attend camps put on by HFNZ and grants which some of these people need more than us. For example, one of the boys I was talking to from Brunei has to travel over an hour to attend swimming lessons which are easily triple what we would pay, but we here in New Zealand have swimming pools abundant and can even receive grants to assist payment of swimming. We are extremely lucky to have the support we do.

SAM: One of the main things I learnt at camp was that people with haemophilia in New Zealand are lucky because they get to participate in a lot more activities than our Asian counterparts. A boy told me that his classroom teacher wouldn't allow him to participate in any physical activities. He has mild haemophilia (the same as me) and had experienced one bleed. He said he didn't mind anyway because he was too scared he would hurt himself. Many of the other kids shared long lists of things they couldn't do. I don't have a list of things I can't do, I just focus on the list of things that I can do. Maybe we are more positive because we get more support than they do?

Thank you to Bayer for their support of the Asia-Pacific Hemophilia Camp and making it possible for participants from New Zealand to attend.

Southern Celebrate 30th Anniversary

Over Labour Weekend the Southern MRG held the celebrations for the 30th year of the Southern Branch.

On Saturday night was a formal dinner at the Blossom Lounge at Addington Raceway. Guests were greeted by Lynne and Lorraine and everyone was name tagged!

The evening opened with Jim Hopkins the Master of Ceremonies greeting people, blowing bubbles and blowing a trumpet.

Carol, Deon and Lynne lit the memorial candle and a lovely poem titled "Four Candles" was read by Theresa Stevens. James Poff read apologies out and spoke of the hard committed work put in by previous members. Deon spoke of what was happening in the world 30 years ago and also of the commitment by people within the Southern Branch. Graham and Anne Waring spoke of the earlier

years and of being asked by Dr Green to speak to other newly diagnosed families and of their families' journey starting in 1963. They spoke of the importance of the integrity of MRGs and of decisions that came out of the first meetings. They also spoke about the aims for the very first meeting which were streamlining treatment at Christchurch Hospital; gaining knowledge of treatment; instituting a programme of family support; employment prospects and education. The first national camp in the South Island, which they are extremely proud of, came 4 years after the first Southern Branch meeting.

A video was shown from Mike Carnahan, who spoke of working with Elizabeth Berry in 1994 on "Defining Standards of Care". He also talked about prophylaxis and inhibitors and the 'need for action' primarily around access and equity. His wish is that the MRGs continue to be

strong and the huge importance of HFNZ working at a regional level and a national level.

Karl Archibald spoke of his HFNZ journey and the haemophilia friends he has made across the world. He talked about the SURO (Step Up Reach Out) and other leadership programmes he is part of.



>>>

Southern Celebrate 30th Anniversary

Colleen McKay presented "Petrieved parent to Camp Mother", a wonderful insight into her journey with Rodney, Carolyn and Carl. As always she spoke from the heart and truly holds a lot of the oral journey of the Southern Branch close to her heart.

A wonderful slide show in the background provoked many memories of wonderful events, fun camps and missing comrades.

Jim Hopkins was hilarious, a bit risqué in parts but jolly funny! He had a good handle on the issues for the bleeding community. He was able to enjoy the jokes and hilarity from Table 5 (Jayden's table) and had Table 2 in convulsions about pregnant sand-flies and 'bugs'.

On Sunday a lunch was held at Cracraft Guiding Centre. The mini microclimate provided relief from the easterly wind and provided a great backdrop for a BBQ. People mixed and mingled, eating sausages, Subway, chips and cake. The girls team won the tug of war, children had a lolly scramble and enjoyed the face painting from Chanel and Dominique.

A big thanks to all who attended from parents, to members, to health professionals, to friends and family.



Bruise Protection – Safety tips for infants and toddlers

Avoiding trips to the emergency room with your toddler is an unspoken goal for every parent, but especially for parents of children with bleeding disorders. But how do you protect your child from the potential for injury that comes with the territory when your child is learning to walk?

Prevention versus Exploration

As the parent of a child with a bleeding disorder, you are left to consider the value of preventing injuries versus allowing exploration.

It's natural to want to protect your child as much as possible, especially when they are very little. It can be a very tricky line for parents to toe when children's natural tendencies are to get into trouble when they're newly mobile. On balance, it is considered much healthier, psychologically, for children to be able to interact with their environment the way all toddlers need for their growth. They instinctually want to get into things they shouldn't and run before they're completely balanced. They are going to fall down and potentially get bruised.

Most other parents will tell you that being overprotective will not pay in the long run. Placing a protective 'blanket' over your child will not stop bleeds.

Taking steps to protect a child with a bleeding disorder from typical bumps and lumps is still important but, at the same time, parents will not want to hamper the child's growth by being so protective that the child ends up fearful, frustrated or angry. It may also tire you out as well.

Options to reduce risks include padding furniture or using protective gear which enables the child to explore his environment and play and have fun. The severity of a child's bleeding disorder should factor into a parent's decision about whether protective equipment is necessary.

Most toddlers who get hurt and require a trip to the hospital have fallen off a bed or have run into a coffee table. Although joint bleeds to elbows, ankles and knees can happen, the main concern is to prevent head bleeds. The head is bigger and heavier and that's generally where kids hit when they fall. Parents should watch their child's gait for signs of discomfort if they suspect a joint bleed. Symptoms of a head bleed include repeated vomiting, irritability, drowsiness, headache and confusion.

Although it is impossible to protect your child 100 per cent of the time, there are some common-sense methods that can be used to minimise the chance of potentially dangerous accidents and head-on collisions.

Tips for Toddlers

Parents can be very creative, especially when it comes to protecting their children. Here are a variety of measures that other parents have taken to help reduce the chance of bleeds from injuries.

- If the cot is a source of injury, consider using a cot bumper pad when the child is old enough.
- Line hardwood floors or play area with interlocking foam playmats. They are

great shock absorbers and easy to keep clean. Available from The Warehouse and a variety of retailers.

- Tape or glue foam pads to the sharp edges of counters and coffee tables. Some parents remove coffee tables while their child is learning to walk. Foam padding on walkers will help protect elbows.
- Use baby gates to block stairs – a good way to prevent falls.
- Place nonskid strips on the floor of the shower or bathtub. Help your child in and out of the tub until the child is old enough to manage without falling.
- Sew padding into the knees and seat of your toddler's pants and overalls to reduce bruising.
- Make sure your toddler wears shoes to protect his feet. High-top sneakers provide good ankle support.
- Buy athletic elbow pads and kneepads to help protect against joint bleeds caused by falls.
- Soft cotton head gear, like rugby helmets, are an option for some parents.
- Make sure your child wears a helmet when scooting, bicycling, etc. – this includes balance bikes. This is the same for all children. One parent has her son keep his bike helmet on while playing on the climbing equipment at the park. This does not look out of place as many other children have helmets there.
- Discourage physical activity that involves rough body contact, such as rugby and wrestling.
- Enrol your child in the Medic-Alert system.
- Talk with other parents about safety measures they use.

Protecting your child from harm becomes easier with experience and a better understanding of bleeds and their treatment. When in doubt err on the side of caution but remember that being overprotective will only make things difficult for you as the parent. No matter what you do, your child will still have bleeds. Treat your child as you would any other without a bleeding disorder and you will be doing your child, and yourself, a favour.



"What's your Dream" Colouring-in Competition

Haemophilia Foundation Australia (HFA) has launched an exciting colouring in competition "What's your Dream" to be judged at the 2014 WFH Congress in Melbourne. The competition is supported by the Octapharma Group.

This Colouring-in Competition is open to children from any country in the following three categories:

- **Category 1: children aged under 4 years**
- **Category 2: children aged 5 to 8 years**
- **Category 3: children aged 9 to 11 years**

Only one entry per child will be accepted.

The prizes for each age category are as follows –

Children aged under 4 years

- **1st prize** Toys R Us voucher or nominated toy shop voucher in your country to the value of A\$200
- **2nd prize** Toys R Us voucher or nominated toy shop voucher in your country to the value of A\$150
- **3rd prize** Toys R Us voucher or nominated toy shop voucher in your country to the value of A\$100

Category 2: children aged 5 to 8 years

- **1st prize** iPod Nano or Apple voucher for the equivalent value + \$50 itunes voucher. Total value \$219A
- **2nd prize** iPod Nano or Apple voucher for the equivalent value + \$20 itunes voucher. Total value \$189A
- **3rd prize** iPod Nano or Apple voucher for the equivalent value. Total value \$169A

Category 3: children aged 9 to 11 years

- **1st prize** iPod Nano or Apple voucher for the equivalent value + \$50 itunes voucher. Total value \$219A
- **2nd prize** iPod Nano or Apple voucher for the equivalent value + \$20 itunes voucher. Total value \$189A
- **3rd prize** iPod Nano or Apple voucher for the equivalent value. Total value \$169A

How to enter

The template colouring in sheet and registration form are inclosed in this issue of Bloodline or can be downloaded from the HFA website (<http://www.haemophilia.org.au>), under Events & Awards – Colouring In Competition 2013-2014.

The template colouring in sheet and registration form must be received by Monday 21 April 2014 to:

HFA

"What's your Dream" Colour In Competition
1624 High Street, GLEN IRIS VIC 3146 AUSTRALIA

Or scanned in colour and in a pdf document emailed to hfaust@haemophilia.org.au

HFA will not provide notification that the entry has been received. At the end of the competition HFA will issue a certificate to each child that participated.



Additional Terms and Conditions

Schedule of the competition

- 12 October 2013 - Competition Opens
- 17 April 2014 - Competition Ends
- 21 April 2014 - Last date for entries to be accepted
- 11-13 May 2014 - Exhibition of entries at 2014 WFH Congress and voting to take place
- 14 May 2014 - Votes to be counted, results announced and awards given to winners
- 14 May -30 May - certificates to be issued to each participant

Judging and competition results

Entries will be judged via a voting process to be held during the 2014 World Congress in Melbourne. All entries will be exhibited at the Octapharma booth at the 2014 WFH World Congress in Melbourne. All visitors to the booth will be invited to vote for the entry they think is best in each age category.

Voting process at the 2014 WFH World Congress

- Delegates may visit the Octapharma booth and vote for the entry they think best in each category
- Vote on the voting slip provided will be placed in the ballot box provided for this purpose.
- The votes will be counted at the close of voting.
- The entries which record the highest 3 number of votes in each category will be declared the winners of 1st, 2nd and 3rd prize.

Announcement of prize winners

After the votes have been counted, the results will be announced at the Octapharma booth on Wednesday, 14 May 2014. HFA representatives will contact each winner by telephone, email or by post within 24 hours. Prizes will be announced. The list of winners by category will be on the HFA website www.haemophilia.org.au and the Octapharma group www.octapharma.com from 14 May 2014.

Copyright and image rights

Entries will not be returned to entrant. Entries will be retained by HFA and Octapharma and may be used in promotion of the competition in the future.

Getting a good night's sleep

Sleep is one of those essential activities we simply have to do. In fact, we spend nearly one third of our life sleeping, however, for some people getting enough sleep is a major issue. Nearly everyone has difficulty getting to sleep from time to time, but when this is on-going, it can really interfere with day to day functioning and affect your health.

Each person is different and some people need more sleep than others. Kids and teenagers need more sleep than adults. Older adults tend to take longer to fall asleep and wake more often during the night than younger adults. Most adults and kids would sleep 10 to 12 hours a night without clocks or routines. You know that you're getting enough sleep when you don't feel tired or drowsy during the day.

Most of us, though, just don't get enough sleep.

Types of sleep problems

Everyone knows they feel better after a good night's sleep. But for some, sleep does not come easily.

Problems getting to sleep, staying asleep, or feeling rested after sleep are surprisingly common. One in four people experience regular sleep problems. You're more likely to have sleep difficulties when you experience stress, major life changes, health problems or substance use problems. Sleep difficulties can then make these problems even worse.

Common sleep issues:

- Trouble falling asleep: lying in bed for more than 30 minutes without being able to fall asleep
- Trouble staying asleep: waking up frequently during the night
- Early morning waking: waking in the early hours of the morning before you need to get up but not being able to fall back asleep
- Behaviours that interfere with sleep: such as snoring, teeth-grinding, restless legs, sleepwalking and breathing problems
- Sleeping too much or for too long
- Excessive sleepiness or urge to nap during the day
- Excessive fatigue or lack of energy

As we get older our normal sleep patterns change. Most people (but not all) find they wake earlier than they did when younger and get tired earlier in the evening. This can lead to unnecessary concerns, which may

result in seeking help to sleep, usually in the form of taking sleeping tablets.

Unfortunately, using sleeping tablets on a long-term basis produces problems, such as dependency, increased risk of falls, confusion and difficulties with driving. Research has shown that taking sleeping tablets for more than 10 nights in a row can make sleeping difficulties worse.

If you're taking sleeping tablets on a regular basis, ask your doctor about ways to help you stop taking them. It may be necessary to stop taking them gradually, taking several weeks to months to stop completely.

Tips for a restful night's sleep

Although sleep problems are common, there are some easy ways to improve the quality of your sleep. Many people find that their physical and mental well-being also improves when their sleep improves.

One of the most powerful ways to improve sleep is to make small changes in everyday behaviours that impact how fast you fall asleep and whether you stay asleep. The goal is to increase the behaviours that improve sleep while you reduce the behaviours that interfere with sleep.

The following tips may help you get into better sleeping habits:

• Set your body clock.

- Try to go bed and get up at the same time each day, including weekends, even if you have had a disturbed night's sleep.
- If you really need to catch up on sleep, it is better to go to bed earlier than normal and still get up at the same time as normal.
- Get out in bright light as soon as you wake up - light is the best regulator of your biological clock
- Avoid taking naps if you are experiencing sleep problems. If you do take a nap, try to keep them to 30 minutes or less.

• Wind down at bedtime

- Make your bedroom comfortable and only use it for sleeping
- Keep your bedroom dark, cool and quiet and make sure that your pillows, sleep surface and coverings are comfortable.
- Try milk or a light snack before retiring.
- Take a warm bath, but not right before bed.

• Keep your evenings stimulant free

- Don't smoke or have excessive alcohol or caffeine drinks late in the evening.
- Avoid using your computer, mobile phone and other electronic devices for at least 30 minutes before going to bed or in the bedroom.

• Go to bed when you're tired

- If you're awake after 20 minutes, get up and do something relaxing in another room.
- Try scheduling worry time during the day; write worries down, then let them go.
- Read a long boring legal document - bet you don't get to the end of it!

• Be active in the day

- Avoid strenuous exercise or a heavy meal just before going to bed.
- Regular exercise improves sleep, but not directly before bedtime.

If you do wake up in the night or can't sleep remember that you can function without a perfect night's sleep. When you can't sleep, it's normal to check the clock and worry about getting through the upcoming day. This increases anxiety and makes it even harder to fall back asleep. Turn the clock away from your view. Remind yourself that you can likely do your daily activities even when you feel tired (unless this would pose a danger to yourself or others).

To improve the quality of your sleep you need to be consistent in your use of the strategies and remember that it takes time to change sleep behaviours and see positive results.

Still having sleep problems?

Sleep problems can have a negative effect on your mental health by influencing your emotions, thoughts, behaviours and body sensations.

If you continue to experience difficulties with your sleeping patterns, talk to your doctor or mental health professional. Sometimes, sleep problems can be a sign of a sleep disorder, mental illness or substance use problem. Health problems like asthma and chronic pain can also affect the way you sleep. Quality of sleep often improves once these problems are identified and managed.



So you've finished treatment... now what?

You've come to the end of your treatment - that is an accomplishment in itself. No more pills, no more injections: time for celebration! But why do you still feel like you do? Talking Hep C discusses what to expect post-treatment.

Written by Dr Frank Weiler
(Hepatologist at Waikato Hospital)

First of all - well done!

You have made it all the way through the never-ending treatment period. It is time to look ahead at what you can expect.

How do people feel after completing treatment?

You may still experience side-effects of the medications. This will usually get progressively better over the first four weeks. Most of the medications will be out of your system in one to two weeks. However, some of the after-effects may drag on a bit. You will find the immediate side-effects, such as headaches, nausea, loss of appetite, and skin rashes, will improve first. Following this, you can expect to see an improvement in fatigue, especially if the medication made you anaemic. Psychologically there will also be changes; but do not change your medication until at least four weeks after stopping anti-viral medication. This is especially true if you were on anti-depressants, as these should only be changed on instructions from your medical team.

As Dr Weiler wrote, completing hepatitis C treatment is an achievement. Take time to congratulate yourself. While many people expect completion of treatment to be the end of feeling unwell, this may not be the case. You could continue to feel ill for weeks or even months after treatment is completed.

An anecdotal study:

Dr Max Hopwood, a researcher at the National Centre in HIV Social Research (University of New South Wales), conducted an interview-based study, focussing on people's perspectives of post-treatment issues. Hopwood recruited 27 participants, stating that people who have had more extreme experiences often volunteer to be involved in this type of research.

How did participants feel after they had completed treatment?

He found some participants, who were cured of hepatitis C, felt an increase in renewed energy, improvements in mood, and relief from worrying about future health. However, other participants did not notice any improvements in their health after treatment, and some even felt new health issues had emerged.

What proportion of participants experienced symptoms?

Twenty five out of the 27 participants described physical and psychological symptoms after completing treatment. These symptoms included fatigue, 'brain-fog', muscle aches, and skin problems.

When do people find out if they have been cured?

There is an element of waiting and suspense as you will not know if you have cleared the virus until further testing. This is usually done at three and six months after finishing your treatment. I can imagine how difficult that is. Sometimes you get concerned as you get symptoms that remind you of your hepatitis C of the past. If that is the case, an early test can be done to see if you have relapsed. However, a negative test at three and six months means a permanent cure! Let this be a new beginning and make some plans for the future.

Once you have been given the all clear you will be released from the clinic. If you have cirrhosis you will need follow-up as there are still long-term risks, despite the virus being cured permanently. The clinic will still be responsible for organising ultrasound scans and blood tests. Remember to look ahead and share the message! Know it. Test it. Treat it... cure!

What did the specialists say?

In Dr Hopwood's report (2009), it was noted that specialist physicians rejected an association between treatment and some of the persistent symptoms. However, most participants felt these symptoms were directly linked to the hepatitis C treatment.

It is important to be aware that, after finishing treatment, you may take a while to feel 100 per cent again (if treatment is successful). Whether this is due to the treatment, difficulty adjusting to finishing treatment, underlying liver damage, or the return of hepatitis C (in those who did not clear the virus), it is difficult to attribute. Knowing you may feel unwell for a period of time after treatment may not affect your decision to start treatment, but it will help prepare you for the treatment journey.

If you have been released from the treatment centre and you are still feeling unwell speak to your doctor.

References: Hopwood, M. (2009). Recovery from hepatitis C treatments (Monograph 6/2009). Sydney: National Centre in HIV Social Research, The University of New South Wales.

Physical symptoms

Common physical symptoms participants faced after completing treatment were general aches, impotency, skin problems, and the inability to sleep (Hopwood, 2007). Other self-reported effects included fatigue, muscle aches and pains, migraines, hair loss/changes, and hearing and eyesight issues.

Psychological symptoms

On-going psychological symptoms the study participants faced ranged from depression to poor concentration and forgetfulness (Hopwood, 2009). The most commonly reported symptom was 'brain-fog', which affected 12 of the 27 participants.

Feeling of renewal

People who were successful in clearing the hepatitis C virus felt a sense of renewal (Hopwood, 2000). They felt their health was restored and they were free from physical and psychological constraints imposed by hepatitis C infection. Hopwood (pg. 6, 2009) reported: "The post-treatment period was a time when participants looked forward to overcoming isolation and, for some, overcoming a sense of shame."

However, Hopwood (2009) found not all participants who successfully cleared the hepatitis C infection felt renewed. Some still felt concerned about the consequences for their future health after having a chronic infection, while others had difficulty deciding if there had been an improvement in their life from clearing hepatitis C.

Coping with unsuccessful treatment

People responded differently to the disappointing news of failed treatment. Participants in this study who had not cleared the virus "usually expressed disappointment, anger, frustration, fear, and/or sadness at hearing the news of their non-response and realising that there was nothing they could do to change it" (Hopwood, pg. 7, 2009). As a coping mechanism, most of these participants reframed their thinking to make it more positive, such as hope for the new drugs which promise to be more tolerable and have higher cure rates; feeling like it was worthwhile as the treatment gave their liver a temporary break from the damage of high viral loads; or acknowledging there are others that are less fortunate than them.



AFFIRM goes Global

Second Generation of Affirm Goes Back to NYC

Karl Archibald, chair of the HFNZ National Youth Committee is a current member of AFFIRM and was able to share this article from the group about their recent training in New York City.

AFFIRM (Adult Fellowship for Integrating Responsible Mentors) is a group of 10 men from different parts of the world aged 25-35 who have something in common. It's our ability to listen, learn and teach others about bleeding disorders; to lead and drive change within the Bleeding Disorders community. The different meetings of the AFFIRM program have been focused on giving participants deep exposure to different stakeholders in the haemophilia community.

Recently, in early November 2013, members of the AFFIRM group participated in a meeting in New York City to learn about the organisations that support the haemophilia community. Members heard from Val Bias, the CEO of the National Hemophilia Foundation, as well as members of their senior staff, the Communications Director of Hemophilia Federation of America (Rich Pezzillo, a participant in a previous Affirm group) and David Page, the Canadian national director of the World Hemophilia Federation. The group came away impressed by the quality of these three organisations, and their dedication to the community.

The NYC Meeting was the third of five meetings in which the group will participate. The first was held in Boulder, Colorado and focused on history of the haemophilia community, HTCs and lab work. The group participated in a hands-on experience conducting some basic lab tests to assess clotting factor levels and inhibitor levels. The second meeting was in San Francisco, and involved a visit to the Bayer manufacturing plant to learn about how Factor is manufactured. Also at the second meeting,

Randy Curtis spoke on the history of the haemophilia community giving the group an invaluable perspective on the past leaders of the community.

The next meeting will be held in Chicago, and will focus on medical research. The AFFIRM group accepts new applicants every 3 years, and will be looking for new applicants in the Spring of 2015.

The current affirm group includes members from Serbia, the United States, New Zealand, Switzerland and the Netherlands. Facilitators of the group include Ed Kuebler, LCSW; Jim Munn, RN, MS; Madeline Cantini, RN; and Sharon Funk, PT.



Members of the current AFFIRM Group and Group Facilitators

Masters Group Update

By Paul Long

Since our last report we have been busy.

Two of the Committee attended a Dinner in Christchurch the night before the Wellness Weekend. We had a great turnout and spent the night discussing some of the issues within the Masters Community.

Then we spent the Weekend at the Wellness Weekend and a great time was had by all. On the Sunday the Masters Group held a session for our members. The Steering Group took a great deal away from the meeting and hope to have some great things for you our members in the New Year.



Before the meeting I was unsure if we could meet the deadline for getting things done next year but we are now confident that we will achieve all deadlines and report back to our members and the National Council on time.

The Masters Steering Committee is now working on the calendar for next year and also researching the list of problems identified in 2012.

We have a private Facebook group where we can post issues and news that all men with haemophilia in New Zealand are welcome to join. (www.facebook.com/groups/hfnzmasters/ or search for HFNZ Masters). Because it is a private group to become a member email me at paul.longz@me.com. If you are already on our Facebook group page then please feel free to post anything you want to share, the more the better. Remember since this is a private page only other members of the group will see your posts or comments. Once you are a member you

will be able to see posts in your newsfeed but any likes or comments will not show up in the newsfeed of your other friends.

Special Thank you to Rob McIntosh and his Family

At the Dinner in Christchurch Linda Dockrill presented a donation to the Masters Group from Rob's Estate on behalf of Rob and his family. We know that Rob would have been a very welcome voice within the Masters Group and we all mourn Rob's passing.



MRG Reports

HFNZ operates six groups that represent our members, four regional branches (Northern, Midland, Central and Southern), the National Youth Committee (NYC) and the Piri Toto, which represents Māori members.

National Youth Committee

By Lauren Nyhan

On the weekend of the 4th – 6th of October HFNZ youth members headed up to Waiwera for our "spring break" event. The focus of the weekend was to plan the events for the coming year as well as to discuss engagement of youth and teenagers within the Foundation. We also managed to find some time to visit the Waiwera hot pools and to go clay pigeon shooting.

One of the key topics discussed was the implementation of a mentoring programme where youth members would act as mentors to teenagers within the Foundation. It was great to have a variety of different perspectives from Laura who works for Riding for the Disabled to Ashley who is soon to be a social work graduate.

We also discussed our big summer event for next year and the idea of attempting to cycle the rail trail through Central Otago seemed popular. We are hoping to be able to do this over Waitangi day and the weekend that follows. When planning our events we aim to push the envelope a bit with regards to the physical aspect of events yet we also give heed to the needs and requirements of those who want to participate. For example the Abel Tasman tramp had a support boat and similarly we intend to have a support vehicle for the cycle. Our intention is to show that bleeding disorders are not a barrier and that given the right planning and situations many physical feats are achievable.

Central region youth are planning to have a ferry ride to Somes/ Matiu Island in Wellington over the summer and to do the Island walk then return to shore for lunch (though planning for this has been delayed due to my exams, wish me luck!). Northern are



Lauren, Angela, Edie, Hemi, Laura, Sarah, Ashley and Jordan

quite keen to head back the clay pigeon shooting and hold a BBQ as everyone had a fantastic time and I'm sure that Midland and Southern have some events that they would like to get up and running.

All in all the Youth Committee has had a good year and we have managed to hold two national events. Our goals heading into the next year are to get more Youth involved, to help nationally with planning regarding teenagers and to work on building connections within our regions.

We hope everyone has a great summer and Christmas/New Year break and we look forward to seeing lots of people at next year's AGM were we will report back on our cycling adventure.

Southern

By James Poff

Hi and welcome to the December Southern MRG report. It has been a busy (behind the scenes) couple of months for the branch.

The big event was celebrating the 30th Anniversary of the branch over Labour weekend.

The Saturday evening celebration meal / event went extremely well at the Blossom Lounge at Addington Raceway. Jim Hopkins did a really good job as MC for the night. He had clearly done his research and showed a great sense of humour. There were speeches from past and present office holders, including poignant moments reinforcing the amount of work and battles that have been fought by those who came before us.

It was great to see such a wide range of branch members attending the event. All the stories and laughs shared left us all with a determination to keep on keeping on with the great work being achieved by the Southern MRG.

Sunday dawned to be yet another glorious spring/summer Canterbury day and several families attended the BBQ held at Cracroft House Guides HQ. The location was perfect, well shielded from the easterly winds and with the sun shining it was a great afternoon. Again it was so good to see many southern members, both old and new enjoy the day. I believe the girls won the tug of war, however, there are some very reliable reports that they had a couple of "female" ring ins??

HFNZ National President Deon York also attended the evening as well as the family picnic; thank you Deon for taking the time to travel south.

As with any event recognition must be given to those members and staff who gave up their time to make these celebrations an immense success – thanks to you all.

Upcoming events:

Christmas Party
8th December
Venue: The Groynes, Area 2D
TIME: 12-5pm
BBQ/ Magician/ Bouncy Castle

Once again thanks to everyone's hard work, without these combined efforts these events would not be the success they are.

Central

By Stephanie Coulman

The first combined Central/Midland regional camp took place in Napier in September; a successful weekend marked by great weather, informative speakers, fun activities

for the children and entertaining outings for families. Lauren Nyhan did a wonderful job of entertaining about 20 children for two hours while the parents attended two educational sessions. Haemophilia Nurse BJ Ramsay gave a presentation on haemophilia and travelling followed by Haemophilia Physiotherapist Helen Dixon who gave an inspiring talk on physiotherapy, joints, muscles, supportive shoes and exercise. We all came away with something to think about.

Once the education was done we headed out to Napier, firstly to the National Aquarium where we observed the shark feeding and wandered around the facility absorbing all things marine. Then we soaked away our cares in the Ocean Spa hotpools picturesquely situated on the waterfront.

On Sunday morning we heard from Catriona Gordon about the WFH Global Forum on the safety and supply of treatment products for bleeding disorders, which she attends on our behalf prior to her visit to Montreal to attend a two-day meeting later in September. The Forum addresses issues related to the safety and supply of treatment and brings together patient groups, regulators, representatives from industry.

The rest of the morning was led by Lynne Campbell where we split into teams and had to design, create and one person had to model a garment made entirely of newspaper. It was very entertaining and a chance to see everyone's strengths in a group; some of us are leaders, some have the ideas and some are attentive to detail while others are team players who do what needs to be done. It was a fun team building activity which involved everyone. An independent adjudicator in the name of Eugene Larkin chose the winning team, modeled by BJ, a kilt of course.



Group photo of central and midland members.



(L-R) Rohan Manley, BJ Ramsay, Amy David and Rosie Lynch model their teams' creations.



Steve Gregory and Amy Davis with their children at the Aquarium

CCDHB has begun a joint clinic with a rheumatologist at Wellington Hospital. "We are now planning to run haemophilia-specific rheumatology clinics twice a year (as we already do with orthopaedics). The aim is that by promoting rheumatology we may be able to have a bigger impact on improving joint health and hopefully be able to reduce or slow the need for orthopaedic input to our patients," says BJ.

The Christmas event for the central region is a day at Zealandia on 1 December. We will have a tour of this wonderful predator-free wildlife sanctuary, on Wellington's back doorstep, followed by a Christmas-theme lunch on the balcony of the Rata café.

Also in December Central region youth have planned a visit to Somes Island, situated in the middle of Wellington harbour. The island has an interesting history as an enemy alien internment camp during the war and as a quarantine station.

A youth planning event in Waiwera had four Central region attendees out of nine which was great to create some engagement in our region and get some ideas about how to do this.

Midland

By Wendy Christensen

Family Duck Tour

On the 10th of November turned out to be an excellent day for HFNZ Midland Branch to put on a great event in Rotorua, the highlight of which was the infamous Rotorua Duck Tour. Fifty-four people came out to support the event where they boarded the 'duck' that can be driven on road and transforms into a boat!! Each person was given a 'quacker' so all could be heard from far and wide. The families got to discover Rotorua on a unique 90-minute sightseeing tour. The tour began in town taking riders through Rotorua's rich history and landmarks including Lake Rotorua, Mokoia Island, Geothermal Sulphur Point, Government, Gardens, The Museum, Blue Baths and much more...

The adventures continued when the duck headed out to the lake for 'Splashdown' (entry) into Lakes Tikitapu (Blue Lake) and Okareka. Families also got the chance to visit a small lakeside community where



they got fantastic views of Mt Tarawera. The duck tour was fun and educational for all who got to experience it.

When it came to lunch where everyone had the challenge of all you can eat pizza. There was a slight hiccup during lunch when we learned that Santa was double booked, however, the day was saved when John took Santa's place and handed out the gifts to all the children. A big thank you to John and also to Sam Bentham and his mum for talking to everyone about their exciting trip to China. It reaffirmed for families how advanced we are in New Zealand in regards to haemophilia care.

After a busy morning and big lunch it was time to have some team building and fun games to finish the afternoon off. Games included egg and spoon race, water passed over and under, and one where groups held hands tangling themselves up and then working together to untangle themselves again without letting go.

We would like to say thank you to all of those who attended the day and made it such a great success. We hope to see you all again at future events and hope those whose attended an HFNZ Midland Branch event for the first time thoroughly enjoyed yourselves and got as much out of it as current members do. We hope to see you at future events.

Northern

By Lynley Scott

The end of the year always seems a bit quieter with events in the Northern MRG.

But that didn't stop about 20 people joining together for a Cambodian banquet at Sopheara Restaurant. This was held in September and as always attracted a wide range of members to enjoy great company and fantastic food. It was a chance for us to raise some funds for our Cambodian Twinning partnership and the WFH Close the Gap programme.

Well, they say "many hands make light work" and that is definitely true of Northern members when it came to helping out at to Armageddon this year. We were so grateful to the amazing number of people who responded to our request for volunteers to help out. So many helps in half day shifts, some even doing a full day, and many bringing along whanau and friends to help out. A big thank you to Phil, Jeanette, Garrett, Rosalie, Tahi, Frances, Barry, Lucy, Oscar,

Keep your eyes and ears open for more upcoming events in the near future.

Teen Day

The day started with laser tag. All who attended were split into teams; each team had to run around on the hunt for body parts, in the mean time defending themselves and trying not to get hit by other competitors from different teams. To make the challenge even harder the teams had to also battle the appalling wet weather that the day brought. The day was planned for only one round however due to popular demand the teams went back for round two.

In between the groups playing Laser Tag each person got to indulge in a yummy BBQ lunch. A special thanks to Craig Christensen for cooking the BBQ providing everyone a hot lunch to keep warm during the horrible weather.

All participants who were under the age of 16 got to head off indoors for a fun afternoon of Tenpin Bowling at Strike Zone while all those who were over the age of 16 got to spend their afternoon with some adrenalin rushing, drift kart racing. The racers got broken into teams of four where each group got to race against each other with the winner from each group going through to the finals, until one final group got to go head to head and fight out to be the overall

champion and winner of the Drift Karts T-Shirt. Big congratulations to Dylan Christensen on taking out this title and being the overall drift karts winner for this event.



Andrew, Jay, Antonio, Christina, Oliver, Hemi, Jake, Kylie, Patience, Henry, Briar, Reagan, and Rose; you guys are all stars and we are grateful for the time you gave up to assist with this event. Also a huge thanks to Richard who has faithfully organised the volunteers for this over the past few years. A total of \$1392 was raised and this goes directly to Northern members to attend WFH Congress in Melbourne in May 2014.

We continue to be incredibly grateful for the fantastic care that we receive from the whole haemophilia team in Auckland. And most of all, the fantastic support our Northern members receive from Sarah Preston our Outreach Worker.

Plans are well underway for next year's camp, Northern Escape 28-30 March 2014 at the popular Campbell Park in Mangawhai Heads. Please mark it on your calendar and look out for more details early next year. There are a number of other events in the pipeline for next year too.

Our change to sending event invitations

out by email seems to be working well, although I am sure there are people that we may miss so please let Leanne know of your email address so that we can continue to save on postage. Alternatively, if you prefer to receive it by post, please let us know.

Wishing you and your whanau a fabulous Christmas and New Year. I hope you all get a chance to have a break, put your feet up, relax and enjoy the company of those you love.



Invitation to participate in international research study

Prof. Eduardo Remor from the School of Psychology at the Autonomous University of Madrid, Spain is conducting an international research study on the perception of well-being in haemophilia patients. This is a brief online survey that takes

less than 10 minutes to complete. The survey is available in three language options English, Spanish or Portuguese. The researchers would really appreciate your contribution to this international effort!

After the research is finished, all Haemophilia Societies will receive a copy of the research report and HFNZ will make it available online. To answer the survey in English click visit <https://es.surveymonkey.com/s/hemophiliawellbeingenglish> or look for the link in the News section of the HFNZ website (www.haemophilia.org.nz).



Haemophilia carriers 'at lower risk of heart disease'

Women who carry the haemophilia gene appear to be protected against fatal ischaemic heart disease, according to research from the Netherlands. Their mildly reduced blood clotting ability seems to protect them from the disease, says the team from Leiden University Medical Centre.

Researchers looked at the 1,002 mothers of all known people with haemophilia in the Netherlands, from birth to death or the end-of-study date. These women were heterozygous carriers of the disease, and had one unaffected allele. This means their

concentrations of clotting factor VIII or IX were about 50 per cent of what is considered normal.

The researchers compared overall and cause-specific mortality in these women with those in the general Dutch female population. The study discovered that the women had a 36 per cent lower risk of ischaemic heart disease than would be expected for the general female population. In addition, the percentage of overall deaths was 22 per cent less than predicted.

Researchers speculate that the haemophilia carriers have a mild decrease in blood coagulation that lowers the risk of heart attacks. They add, 'This finding re-emphasises the role of clotting and changes in clotting, in the development of myocardial infarction, which may in the future have implications for prevention of this disease.'

Source: <http://www.tele-management.ca/2013/08/haemophilia-carriers-at-lower-risk-of-heart-disease/>

New haemophilia products begin to reach market overseas

A number of pharmaceutical companies have been hard at work developing new haemophilia products.

NovoEight, a recombinant Factor VIII product from NovoNordisk has been granted marketing authorisation in the European Union and the United States. They have also submitted the product for regulatory approval in Japan, Australia and Switzerland.

Biogen Idec is awaiting approval for its new haemophilia A drug Eloctate by regulators in the USA and Europe.

Earlier in 2013, Baxter announced that Rixubis, recombinant factor IX, was approved and introduced in the US and Puerto Rico for treatment in adult patients with haemophilia B. Baxter has submitted a marketing authorisation application to the European Medicines Agency for approval of Rixubis for the treatment and prophylaxis of bleeding in patients of all ages with haemophilia B. Baxter have also recently completed enrolment of a Phase III clinical trial of BAX 855, an extended half-life recombinant FVIII for haemophilia A. The BAX 855 molecule was modified with PEGylation technology designed to extend its duration of activity in the body. The ongoing trial is aimed at assessing the efficacy of the compound in reducing the number of bleeds experienced during a year in both prophylaxis and on-demand treatment schedules, and will also evaluate its safety and pharmacokinetic profile.

When and if these products will be available in New Zealand is not yet known.



Certain F8 mutations increase inhibitor formation in haemophilia A

Nineteen specific mutations in the Factor VIII gene were associated with inhibitor development in patients with nonsevere haemophilia A, according to the results of a retrospective cohort study.

The inhibitor incidence in nonsevere haemophilia A patients with certain F8 mutations approaches the inhibitor incidence in severe patients. Researchers in the Netherlands conducted the multicenter INSIGHT study to analyse risk for inhibitor development after treatment with Factor VIII concentrates in 1,112 patients with nonsevere haemophilia A who received treatment between 1980 and 2011. Researchers identified the F8 genotype in 895 (81%) patients.

Prior studies have demonstrated that the risk for inhibitor development in patients with severe haemophilia A is less than 1% after 50 days of exposure to Factor VIII concentrates. However, most adults with nonsevere haemophilia A haven't been exposed for this length of time, and thus are still at risk for inhibitor development and resulting complications, researchers wrote.

Fifty-nine patients (median age, 46 years; median exposure days, 28) developed inhibitors, equating to a cumulative incidence of 5.3%. The researchers found no association between inhibitor development and ethnicity or disease severity. Fifty-one (86%) of patients who developed inhibitors had the F8 genotype. They found that specifically 19 out of 214 F8 mutations, each located in the same parts of the gene, were associated with inhibitor development.

The study highlights that the substantial risk of inhibitor development in nonsevere haemophilia A patients has been previously underestimated and the potential at genotyping to identify patients at risk of inhibitor formation.

Source: *Eckhardt CL. Blood. 2013;10.1182/blood-2013-02-483263.*

Panel recommends FDA approval of sofosbuvir for hepatitis C

The FDA's Antiviral Drugs Advisory Committee has recommended the approval of sofosbuvir, a first-in-class, once-daily oral nucleotide inhibitor from Gilead Sciences, for treatment of chronic hepatitis C. The panel voted unanimously in support of approving sofosbuvir in combination with ribavirin for treatment of HCV genotypes 2 and 3 in adult patients. They also mirrored the vote in support of sofosbuvir in combination with pegylated interferon and ribavirin for treatment of HCV genotype 1 and 4 in treatment-naïve patients.

Source: www.healio.com



The gift of love, the gift of peace
the gift of happiness...
May these be yours at Christmas
and throughout the New Year



Leave a Lasting Legacy

Honour the memory of a loved one or recognise the unique bond you have formed with the HFNZ to make a difference to the quality of life of people with bleeding disorders.

Information on making a bequest in your will to the HFNZ can be found at www.haemophilia.org.nz

give
a little

Give a little?
Give a lot!

Charitable donations to HFNZ can now be made online at:
www.givealittle.co.nz/org/haemophilia



Children's Education Workshops 2014

Join HFNZ for this magical opportunity for children aged 6 to 10 with bleeding disorders, their siblings and those with a parent with haemophilia to come learn some "Tips and Tricks".

HFNZ will be conjuring up 4 regional Children's Education Workshops

- Northern - 14 January 2014, Auckland
- Midland - 16 January 2014, Tauranga
- Southern - 21 January 2014, Christchurch
- Central - Date to be Confirmed
All 10am to 4 pm



Send your Registration Now
Look out for your invitation in the mail in early December or talk to your Outreach Worker

Upcoming Events

8 December 2013

Southern Christmas Picnic
The Groynes, Christchurch

January 2014

HFNZ Regional Children's Workshops
See above for more information

11-15 May 2014

WFH World Congress
Melbourne, Australia
www.wfh.org

More details on all events are available from your local Outreach Worker.

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