



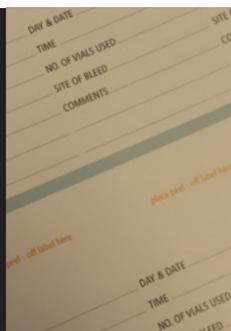
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Haemophilia Foundation of New Zealand Inc.

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The Word



Welcome to the December issue of Bloodline. As summer and the holidays approach, I always find myself reflecting on the year that was. The year has, as always, been a busy one for HFNZ with many regional and national programmes delivered, a highly motivating World Congress in Melbourne with record attendance from NZ and the appointment of a new Chief Executive.

We have a great network of volunteers around the country doing excellent work. Every now and then a particular act of kindness captures my attention and is a shining example of who makes up our wider community. Recently,

Izack Silva celebrated his 7th Birthday. On such an occasion, many 7 year olds would be making a Birthday wish list; and in this regard Izack is no different. What makes Izack's wish list unique is that he asked friends and family to donate to Cambodia instead of buying presents. The result was over \$170 donated towards the Cambodian Hemophilia Association (CHA). What a fantastic result – thanks Izack!

Why not follow Izack's example and think about making a donation to support our local or global bleeding disorders community. I make a modest donation every month to the World Federation of Haemophilia and I know of others who do the same, be it to WFH, HFNZ or our recent twinning country, Cambodia (through CHA). Just a few dollars can make the world of difference.

Wishing you all a safe and enjoyable summer.

Deon York

President, HFNZ

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Cover photo: Southern Region campers visit the Abel Tasman National Park in October 2014

57th Annual General Meeting

The 2014 Annual General Meeting (AGM) of the Haemophilia Foundation of New Zealand Inc., the organisation's 57th took place the 13th September 2014 at Holiday Inn Auckland Airport, in Auckland.

Having an AGM in September marked a change for HFNZ and reflected the change to a July-June financial year as was decided at the last AGM in March 2013. These means that the AGM and associated Annual Report covered the 18-month period from 1 January 2013 to 30 June 2014.

Apart from the usual business, the AGM provided a great opportunities to mark some significant changes to the organisation and celebrate some members of our communities. Members had the chance to farewell Belinda Burnett, who left the position of CEO in April, and welcome Richard Chambers to the role. A number of awards were also presented:

- **The McKay Trophy** for MRGS was awarded to Piri Toto for their excellent effort in organising their first marae Noho.
- The **Elizabeth Berry Exercise Cup** was presented by HFNZ Patron Elizabeth Berry to Tuatahi Pene for his initiative in starting up a hydrotherapy group for men with haemophilia at Olympic Pool.
- A **HFNZ Service Award** was presented to Leanne Pearce in recognition of her 10 years of working as the administrator for HFNZ.
- BJ Ramsay, Haemophilia Nurse Specialist at Wellington Hospital, was also awarded a special **Sir John Staveley Health Service Professional Award** to recognise all the work he does for and with people with bleeding disorders. BJ, who was surprised by the award, was also the guest speaker at the AGM.

With most members of Council continuing in their roles, the National Council for 2014/2015 will be able to continue to build on the positive work of the previous years.

- President: Deon York
- Vice-Presidents: Catriona Gordon, Richard Scott
- Treasurer: Grant Hook
- National Youth Delegate: Hemi Waretini
- Māori (Piritoto) Delegate: Patience Stirling
- Northern Delegate: Greg Jamieson
- Midland Delegate: Catriona Gordon
- Central Delegate: Stephanie Coulman
- Southern Delegate: James Poff

Co-opted members will be appointed at the next National Council Meeting in November.

Thank you to everyone who took the time to take part in the National AGM and at all the MRG AGMs held over the previous few months. HFNZ is built on the energy and drive of its members and it is you that keeps the Foundation running strong.



BJ Ramsey Recognized

BJ Ramsay, Haemophilia Nurse Specialist at Wellington Hospital, was surprised at the 2014 HFNZ Annual General Meeting to be presented with the John Staveley Health Service Professional Award. The award was created in honour of Sir John (Jock) Staveley, a pioneer in the field of blood transfusion, founder of the New Zealand Blood Service and HFNZ's first Patron. It recognises a Health Service Professional who has made a significant contribution towards improving quality of life for people with bleeding disorders through providing clinical care of the highest standard to people with bleeding disorders).

BJ came to New Zealand in 2008 and brought fresh invigoration to his role as a dedicated haemophilia nurse at Wellington Hospital. This was after a period of no-one in the role, or a nurse who we shared with other services and was not an expert in haemophilia care.

His enthusiasm and dedication to the role has improved the health of members in the Central region and has influenced the way other centres manage their patients with a bleeding disorder.



Among his successes

- BJ has been instrumental in introducing dedicated haemophilia physiotherapists into New Zealand and he continues to work on making physiotherapy available across all centres. Thanks to BJ, we know that 'treatment does not equal factor alone' and that patients can expect, and should have, physiotherapy after every bleed.
- BJ has been the driver behind many other improvements in haemophilia care in our region and has worked to make these a reality. He has strongly advocated for comprehensive care and followed this up by promoting dental care, rheumatology clinics and a specialist pain service in our region.
- BJ is the current chair of the Treater's Group and a member of NHMG. He is the first non-doctor to hold this position and has earned the respect and confidence of his medical colleagues who voted him into these positions.
- BJ has made the service child friendly from introducing the box of toys in clinic and iPad distraction, to playing with the children to make them feel comfortable, not to mention his great sense of humour, jokes and magic tricks!
- BJ runs outreach clinics in Kapiti and Wairarapa providing easier access for patients out of Wellington.
- BJ shares his knowledge and expertise by teaching hospital staff. His regional 'road shows' to outlying hospitals in the lower North Island as well as to community groups and schools are another way of sharing his expertise and knowledge.
- He attends the all-important educational camps and workshops run by HFNZ, which are usually on weekends. This is where grateful parents, children and youth gain their medical information in an accessible format.
- BJ helped design Tracker Factory - an online treatment diary for patients to record their treatments and incidents of bleeds.
- BJ is a 'constant' presence in haemophilia treatment in an environment where medical staff come and go. He knows all his patients and they feel he knows them and their individual situations and circumstances. The way he celebrates patient successes, such as first self-infusions, improves self-esteem and a sense of self-worth
- BJ has brought fresh ideas to the role, including the idea of 'bringing the hospital to the patient' when he visits patients at home. His support is at a practical level where it is most needed.

Upon being presented the award, BJ expressed his disbelief and said, "I feel I have gained much more from people with haemophilia than they from me." He noted that people with bleeding disorders have an amazing resilience and he enjoys working more in a partnership role.

HFNZ are proud to recognise BJ with the Sir John Staveley Award in 2014 for his significant contribution to haemophilia care. With him as a 'constant' presence, many people in the Central region can live their lives with haemophilia with confidence.

Elizabeth Berry Exercise Cup 2014 Awarded to Tuatahi Pene



Attending the 2014 WFH World Congress was an inspiration for many members. One member, however, was motivated into starting an exercise initiative that is providing a benefit to not only him but others in the community as well.

After returning from Melbourne, Tuatahi Pene, the Piritoto Northern Delegate, knew that he wanted to do something to have a positive impact on both his physical health and well-being, and also that of his peers.

The idea really hit home as he listened to Australian Andrew Selvaggi's story on how he turned his life around through physical exercise. Andrew, who has an inhibitor, spent most of his childhood in a wheelchair and struggled with his weight. After having ankle reconstruction surgery he recognised the detrimental effects of his lack of exercise, changed his attitude and turned his life around. Now in his mid-twenties he is a fit personal trainer and haemophilia advocate.

Tuatahi knew it was time to also make some changes. First he researched what activities could help people suffering from weak joints; ankles in particular since these are often target joints for people with haemophilia. He also wanted an activity that could prolong healthy bodies through low impact activities and exercises. He soon found hydrotherapy ticked all the boxes needed to help maintain or improve function for people living with weak joints.

So with that decided, Tuatahi set up weekly hydrotherapy classes for him and his friends with haemophilia at the Olympic Pool in Newmarket. Classes run weekly every Thursday night from 7 pm

to 8 pm. The cost of the pool sessions are now being covered through the HFNZ Swimming and Exercise Programme.

Hydrotherapy has not just benefited Tuatahi personally. "Creating a group such as this has shown great benefits in motivating people living with weak joints to get off the couch and be more proactive about how to manage life as a person with haemophilia," reflects Tuatahi.

At the moment up to 10 people attend the sessions, but as life can be busy there is usually an average of around five in attendance each week. Each session starts with a 5-10 minute warm up and 15 minutes of stretching, followed by a light crossfit like exercise that involves jumping and walking / running from one end of the pool to the other for another 15 minutes.

Tuatahi would like to see the Hydrotherapy sessions open up to the wider Haemophilia community. "It would be great to show them the benefits of what Hydrotherapy can do for people living with haemophilia. Knowing that there can be more to life than treatments and hospitals."

Congratulations Tuatahi for taking your inspiration to the next level, encouraging healthy physical activity and making a real difference in our community.

If you would like to know more about the Hydrotherapy sessions contact Tuatahi on 027 371 0403 or at tuatahi.night@gmail.com



Piritoto take home McKay Trophy for 2014

The 2014 winners of the McKay Trophy for Member Representative Groups, Piritoto, were recognised at the Annual General Meeting. Piritoto took home the award for best MRG event for their Marae Noho held in February 2013.

The Marae Noho was chosen because it represented how far Piritoto have developed as a group to organise the event and the process helped form the Tikanga of Piritoto – in fact the new name was adopted at the event.

Below is a summary of the event adapted from the application written by Carol Reddie:

As an attendee at the inaugural Noho of the Roopu held 15th – 17th February 2013 I wanted other HFNZ groups to get a picture of what was involved. We had waited 3 long years for this type of event to be realized. We knew it would take a lot of communication and hard work to get a core group who were committed to the

kaupapa (plan) to lead the way. I for one, am proud of to have been a part of it and also proud of our achievements to date and can credit Joe Wrathall for insisting that we keep striving to make it happen.

From our last Takawaenga Hui and also the last HFNZ AGM the topic of conversation was for the Roopu to get together for a Noho (sleep over) get some interest and invest some time in recruiting members who were in the area to come onboard to kind of 'have a look' at what we could or might do.

The venue was Omaha Marae, Leigh. The 3 days and 2 nights we spent there were sun filled and well received by all. Meals were catered leaving time for all to participate in all activities each and every day. We were able to bring together whanau (Families) from Invercargill, Gisborne, Wellington, Morrinsville, Rotorua, Auckland and Mangawhai.

We arranged for suitable activities that would encourage Hauora (health and wellbeing), such as kayaking and snorkeling. A resource that was sourced and given to all participants were Māori Language packs to take home. As Māori, the Reo is one of our taonga (treasures) which helps us to reconnect with each other and can assist with our Hauora (health and wellbeing). Night time activities were filled with fun and laughter with Te Reo focused Trivial Pursuits and Charades. Lots of waiata (songs) and mihi (greetings).

Other activities included: Nga wahine (the women) had Raranga (weaving) and Nga tane (the men) had Haka Practice. The boys had a Hui to come up with a new name for the Roopu but nothing was decided. Lots of whakawhanaungatanga (getting to know each other) sharing stories and experiences.

We hope that this is just the start of more to come and that we can share with our regional groups in the future. There is a lot of work putting these things together but if communication is there you can rock n roll. My personal thanks to Kahu, Hemi, Patience and their whanau (families) for all the effort they put in to get to the final stage. Nga mihi. (greetings)



HFNZ would also like to recognize the fantastic efforts of the other McKay Trophy applicants. Northern Branch's Women's High Tea provided an opportunity for women to get together in a positive low key forum to maintain and create social links. The Midland Branch Annual General Meeting at Hobbiton showed how selecting a great venue can maximise attendance at an AGM and how a social component can linked to committee 'business'.

Well done to all the MRG committees for all the fantastic events you organise throughout the year!

Home Therapy and Treatment Records

Mary Brassler, Haemophilia Nurse Specialist, Auckland City Hospital

Keeping a track of your infusion information is a very important step in treating haemophilia. Documenting each time you infuse can provide a better outcome to your health care.

Treatment records provide valuable information about your bleeding pattern. It helps your haemophilia team to make adjustments to your treatment plan to prevent bleeds and make better decisions about your care. It helps to get better picture of how your factor is working for you.

Recognising the important of complete treatment records, some Treatment Centres, such as the Auckland Haemophilia Treatment Centre, have recently put in place new protocols around submitting records for patients on home therapy. HFNZ recently wrote to the Treaters Group asking for clarification in regard these new procedures as they had received calls from anxious members. Some members did not understand the changes and felt concerned that their factor supply was being limited.

Treatment for haemophilia, like all medications, comes with responsibilities. In particular, haemophilia treatment comes with the need to keep and submit treatment records. This has been the case for many years but has not always been compulsory. Not only are treatment records important for providing a clearer picture of your health but as healthcare budgets get tighter there is an increasing need for accountability. As such, Treatment Centres are having to put practises in place to ensure that treatment records are received by all patients.

Factor has never and will never be refused.

Speaking from an Auckland perspective, we are asking patients for records monthly. If records are not submitted, we have been explaining that their factor supply will be limited and that they may need to come to the hospital for their treatment so WE can record it. That way continuing to keep a supply of factor and being able to treat at home becomes an incentive for patients or families to do their records.

The intention of this new requirement is not to threaten. It is possible that the change was just not well explained in some cases as the need for treatment records has always been important. It can be disappointing to find there are patients who are reluctant to submit treatment records and need a lot of follow-up to get them. However, there are other patients who have engaged with the new protocols and are regularly sending in their records. I thank them for it because we don't like having to ask every month.

Recording treatments is nothing new and has always been an expectation for people with haemophilia (PWH) who have been treating at home for the last 40 years.

In the past, patients had a restricted supply of clotting factor as there was limited amounts available and it was mainly used on demand. Patients were diligent in letting their Treaters know what they used and when they used it. This became very important when dealing with HIV and Hepatitis C infections as the recorded Batch Numbers proved who had used contaminated factor.

When more clotting factor became available, the amount patients had at home crept up and a 3-month supply became the norm.

Keeping records is now more important than ever. Many patients have their factor delivered to their home directly by the drug company as a convenience so the Centre has no record of the batch numbers or even if the right amount has been delivered.

Ensuring you are getting the right treatment

Home treatment has certainly changed people's lives for the better. It's convenient for the patient, and when a bleed does occur, the sooner the factor can be administered, the sooner the bleed stops. Hopefully there will be less pain and less long term damage. There are fewer hospital admissions and surveys show an improvement in Quality of Life.

Prophylaxis has enabled PWH to live near normal lives with the expectation they will reach old age. As the factor has a short half-life, prophylaxis is ideally given in the morning before daily activities to get the most benefit from it.

Unfortunately prophylaxis dosing and frequency can have 'The Creeping Effect'. PWH often decide themselves how often they should have their treatment and how much. Prophylaxis isn't designed to normalise levels and it's not a cure. It's supposed to stop those 'spontaneous bleeds' that severe PWH have by giving a little-and-often factor cover. We have many patients with clotting factor under 5% who we rarely see.

We have a population of pre-prophylaxis patients who have arthritic pains that are similar to joint bleeds. Until recently, some people were treating this joint pain with Factor - which was not effective or appropriate. Having a suspected bleed assessed to determine the source of pain and working with a specialist Haemophilia Physiotherapist to reduce chronic arthritic pain is far more effective in these cases than clotting factor.

We also have a population of young boys on prophylaxis who have never had a joint or muscle bleed so wouldn't know what a bleed was and should be assessed if there is 'any doubt' so the appropriate treatment can be recommended.

Other benefits of record keeping.

To be involved in clinical trials, there needs to be evidence of at least 50 infusions, and we rely on home records for this.

To be referred to Orthopaedics or to consider an increase in prophylaxis, there needs to be evidence of recorded bleeds.

While there are obvious advantages of treating at home, there are responsibilities.

- It is a prescribed medication. Adhere to the Treatment plan and only adjust doses and frequency following consultation with your Treater.
- Store clotting factor as advised.
- Do not let factor expire, rotate stock.
- Maintain and present your Home Treatment records monthly.
- Attend clinics so dose and frequency can be managed.

Keeping Treatment Records

Treatment Records can be presented several different ways. The most popular are an electronic record either on TRACKER FACTORY website or iPhone app, scanned notes on an email or a spreadsheet. Some patients prefer to stick the labels on a form and fax or post it.

Home Records should record the following:

- The Batch number and Product:

This is essential to be able to trace a product in case of a recall.

- The date:

We can look at the frequency and intervals of treatments to see if the prescribed treatment plan is being adhered to. If not, we can check why not.

- The Time:

Factor has its maximum effect in the first 8-12 hours, we can see that it is being administered at the appropriate time to get the most benefit.

- The Dose:

Several issues are considered when determining the dose including bleeding history, target joints, weight, age and IV access. The dose is prescribed by the Treater at reviews. Records indicate adherence and if necessary a review. By doing Recovery studies, we

can ensure that the correct dose is given and the bleed is treated adequately.

- Reason for Treating:

If on Prophylaxis, we can see if there is breakthrough bleeding. If on demand, a developing target joint can be identified early from the records. Treatment plans can be changed by the Treater if needed. An Inhibitor may be developing so early intervention essential.

- Any adverse reactions experienced or comments

These may be anything you think is relevant for the treaters to know such as pain, swelling, restriction in mobility, and other medications or interventions uses.

You can contribute to your haemophilia health by keeping good records even if you are on regular prophylaxis. We know that people who keep good records usually have good control over their haemophilia and bleeds.

In Auckland we ask that records be presented monthly. With 55 patients on home therapy in Auckland, we can more easily monitor that patients are using treatment to get the best benefit from it and change plans or refer to other relevant departments. We can also keep track of stock. We have to submit a report to the Management group monthly, so getting the records helps us do this.

Remember...

- Records assist us with planning for the future.
- 'Home treatment is a privilege, not a right.'

If you have feedback on this subject with ways of how we can make it easier for you to keep treatment records please contact me at AKHaem@adhb.govt.nz.

Editor's Note: *If you are outside Auckland, talk with your haemophilia nurse or haematologist how often you need to send in your treatment records and the best way to do this.*

Decision Number 2: Whose opinions will matter?

Everyone cares what people think about them – all human beings want the approval of others. During the first 10 years of life the approval of parents and family matters more than anything to a child. This changes as children get older.

Teens are generally for more concerned about gaining the approval of their peers, than of their parents. This is commonly known as peer pressure.

Wanting the approval of peers can lead to bad behaviour – sneaking out, driving alcohol, stealing, drugs, cheating, etc.

It is important to encourage teens to think long and hard about approval and the potential consequences of making poor decisions just for the sake of 'being cool' to their friends.

A critical point in growing up is when you decide whose opinion is going to matter to you. This can change everything. When teens reach the point where they realise that a certain person's opinion doesn't matter to them, then they can be at peace with their own decisions.

Decision 3: Whose advice will they follow?

Because of they often lack life experience; young adults don't always seek out the right sources for advice. They find it easier to listen to the most convenient, popular or loudest voices nearby – even if those sources are short-sighted or suffer from tunnel vision.

Teens need to make a decision about whose advice they will believe or follow.

It is important to listen to somebody who is more experienced, who has been down the road, and will help you to grow more confident, to be more successful. A common mistake for teens (and adults too for that matter) is to seek out people who will tell them what they 'want' to hear instead of what they 'need' to hear. Unfortunately the best advice sometimes contains things that they don't want to hear.

It is also important to accept that sometimes good advice is not easy to follow.

Key Advice Messages:

- Don't take relationship advice from someone who has never had a healthy relationship. Talk to someone who has been in a strong relationship for years.
- Don't take career advice from someone who lacks expertise in that particular career or field of work. Find people who actually work in the field and excel in it; talk to them, and take their opinions seriously.

Decision 4: What role will drugs, alcohol and sex play in your life?

It is much easier for today's teens to access and use drugs. There is also far more to choose from. Alcohol use and abuse has long been popular with teens. Many teens also have casual attitudes to sex without intimacy, making them far more likely to do it, and at a younger age.

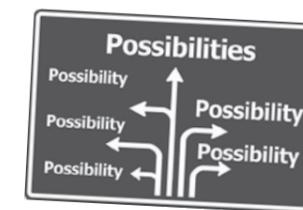
It is inevitable that all teens will have to deal with issues around sex, drugs and alcohol. These decisions are easier to make if they have been considered ahead of time. It is crucial for teens to think about in advance what they will or won't do, and under what conditions. If they don't consciously make a decision about these things beforehand, then they are likely to take an easy option by default when they are faced with a situation.

It is almost impossible to make a good choice about sex, alcohol or drugs in the heat of the moment. How often do we hear about decisions made by default, on the spur of the moment that end in an unexpected pregnancy, an alcohol-related vehicle accident, or experimentation with drugs and alcohol?

It is important for parents / families to discuss these issues openly. Have conversations with your children about drugs, sex and alcohol and discuss techniques that can be used in particular situations. Discussions such as these will ensure that teenagers have the confidence to stand up to peer pressure when confronted with a situation and know how what action they want to take.

Decision 5: What career direction will you choose?

Few people start out knowing exactly what they are going to end up doing for a living. It doesn't make sense to ask a teen to decide on a specific career. However, it does make sense to advise a teen to choose the right direction.



Rather than focus on a specific destination, focus on a career direction. Once on the road and gaining experience you'll eventually figure out where you want the road to take you.

It is important to ask children what direction they feel drawn towards and what are they interested in – rather than what they are passionate about. Parents and others can help teenagers to identify their strengths and interests, as well as their personal values/morals and principles so that they can follow that direction which will lead to their career.

If teens know from a young age which direction they want to take, it makes easy for them to make decisions about schooling; i.e., about their attendance, about their effort, about whether they complete their homework, and about their subjects at school.

Decision 6: How are you going to handle disappointments and set-backs in your life?

Disappointment and set-backs are inherent in life, not everything is going to go your way. Learning how to handle disappointments and set-backs is an essential life skill.

Parents can help teach their children how to handle set-backs, for example to step up and get on with it anyway, or just whinge and whine and blame others.

Teaching them to think about their attitude and to consider: What is my responsibility in what went wrong? What could I have done differently? Where are my options from here?

The Seven Critical Decisions that Teens need to make

Report from NACCHO, written by Colleen McKay

For over 25 years, Jeffrey Leiken has used his mentoring and training programmes to empower teens and young adults with the critical skills and tools they need to lead thriving lives. At NACCHO (North American Camping Conference for Haemophilia Organisations) earlier this year, I participated in a session outlining the basis for Jeff's programmes which helps teenagers to find direction in life, and follow the path of their own personal adventure; helps them to overcome the obstacles and fully take advantage of the opportunities. Here I review his seven

Raising teens into responsible, productive, happy adults is a tricky task for even the most devoted parent. Teenagers will make 10,000,001 decisions in their formative years. However, there are just seven critical decisions made during teenage years that really matter; these seven will impact on their life for years to come. Understanding these decisions are and how important they are will help young adults be more aware and enable them to make smart decisions that impact their long-term future.

Decision Number 1: Who will your friends be?

"Show me who a man's friends are, I will tell you who he is."
- Ralph Waldo Emerson.

In other words, "You are the company you keep."

Who we associate in our life has a huge impact on our lives. Teenagers spend five-times as much time with their peers as with adults. This has a tremendous impact on their activities and decisions.

Values, interests and beliefs change dramatically during adolescence. As such it is important to choose people who have similar values to you. Someone who was a great friend at age 11 may no longer be a good match at 17 years.

Great friendships, which can last a lifetime, are born when are attracted to each other because of their own self-generated interests and qualities. True friendships can be priceless.

Who we spend time with, especially as teens, will shape who we are in our lives. Although these relationships are so important, no one gets any training for how to grow great friendships and relationships. Teaching teens how to find deep, loyal, lasting friendships and relationships is very important.

The consequences of spending time with the wrong crowd can be dire. And the opposite is also true – the results of choosing the right people to be with are particularly positive.

The Seven Critical Decisions that Teens need to make continued

Three strategies for dealing with set-backs:

1. Learn what can be learned.
2. Do what you can to move forward anyway.
3. Let go of anything that you can't change.

How do truly incredible people handle disappointments and set-backs? They reorganise themselves and start putting their attention on possibilities in order to move forward.

Decision 7: WHEN? WHEN? WHEN? When are you going to take these decisions seriously?

Making each of the critical decisions wisely and effectively requires deep soul searching. It involves deciding what sort of person you want to be and what sorts of things they want to accomplish in life.

This is an important question for parents as well. You need to ask yourself when are you going to make these decisions for

your parenting and when are you going to start having these conversations with your children? Remember they will always be your son or daughter but they won't always be your child. Parents cannot make their teenager's life decisions for them, but parents can help them learn how to make the right decisions for themselves.

Helping teenagers to identify when one of these critical moments comes up for them, knowing how to handle those situations and make excellent decisions for themselves that remain true to themselves and their belief system is one of the most valuable things you can do as a parent.

If we teach teenagers about these critical decisions, to notice when things don't feel right, to identify these decision points and equip them with the confidence to make smart decisions for themselves – then we can give teenagers a huge advantage in life.

You can download a free copy of Jeffrey Leiken's 7 Critical Decisions report at www.7criticaldecisions.com

Buddy Awards

Do you know someone who is a good buddy to a person living with a bleeding disorder? Do you think they deserve recognition? Then nominate them for a buddy award today!

We announced in the July issue of Bloodline that the Buddy Awards would be coming to Australia and New Zealand following the launch at the 2014 WFH World Congress. Well the Buddy Awards have now arrived in New Zealand!

To increase awareness of the challenges faced by people living with bleeding disorders, Haemophilia Foundation New Zealand have got on board with the Buddy Awards, sponsored by Novo Nordisk.

The Buddy Awards recognise the significant medical, emotional and practical support provided by family, friends, healthcare professionals, teachers and others, to people with bleeding disorders.

Families and friends take on a great deal of responsibility for their sibling/friend and this often goes unnoticed. The Buddy Awards celebrate the invaluable contribution they make.

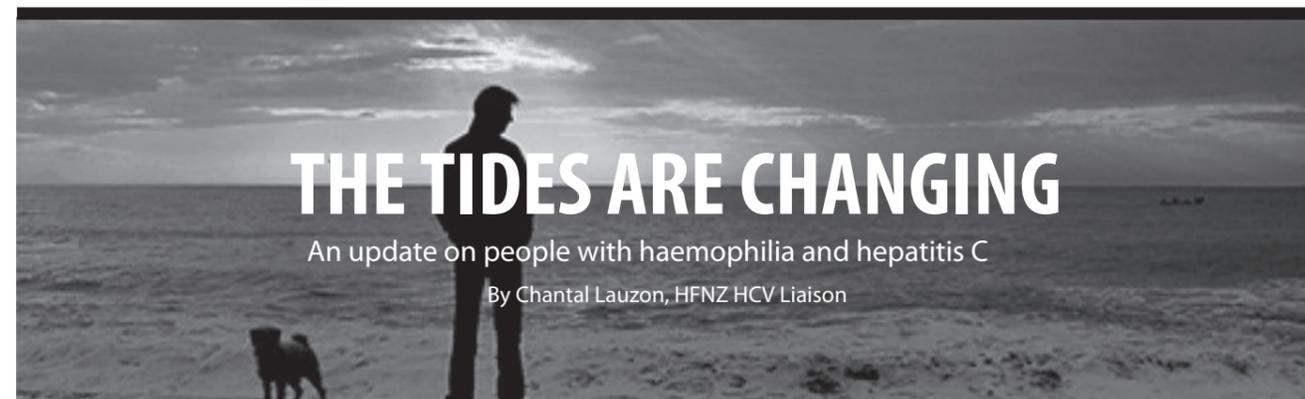
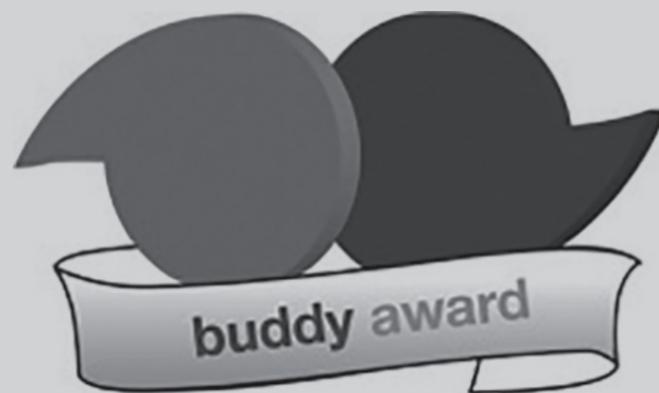
This is your chance to recognise those people in your life that make a huge difference to you.

How to nominate a Buddy

Application forms will be available on the HFNZ website, from National Office, your regional MRG committee or from your Outreach Worker. Simply complete the application form and return to HFNZ (buddy@haemophilia.org.nz) or by mail by 20 March 2015.

There will be four regional presentation ceremonies either on or near World Haemophilia Day on 17 April 2014.

Nominations close 20 March 2015 so be sure to nominate your Buddy today!



Prior to 1993, 189 people with bleeding disorders (PWBD) contracted hepatitis C (HCV) in New Zealand through infected blood products. Until recently, a third of these people continued to live with a chronic hepatitis C infection.

For the past 5 years HFNZ has sent out an annual survey to better understand the needs of people affected by HCV and the impact HCV has on our community.^{1,2,3} These surveys are also very important for our reporting requirements to the Ministry of Health. The results of the last few years have shown a real shift in the number of people living with chronic hepatitis C, largely due to the ability to participate in clinical trials for new Direct Acting Antiviral (DAA) treatments.

The surveys

A survey was sent to PWBD and chronic HCV in New Zealand each spring from 2010 to 2014. HFNZ also collects data on how many people start or finish treatment and people who pass away.

Members are asked about demographic information, employment, treatment for hepatitis C, symptoms, liver health, HCV education, their general health, activities and psycho-social functioning.

Over the last 5 years the total number of PWBD affected by HCV living has reduced from 157 to 139. In that same time the number of PWBD and chronic hepatitis C has reduced from 66 to 40 people; 12 having died and 14 having achieved a sustained viral response (SVR) to treatment. Another five are in treatment or awaiting their final results following recent treatment.

An average of half of the surveys were completed and returned each year. Each year the biggest group of survey respondents were aged over 61 years (35 - 53%), with only two people aged under 30 years. A little over half (52-66%) of those aged under 61 years are in full-time employment.

As shown in Figure 1, there has been a meaningful swing in the make-up of the PWBD and HCV population in New Zealand since 2010. In 2013, the number of PWBD who had cleared HCV through treatment topped the number of PWBD with chronic hepatitis C for the first time.

Another change has been the number of PWBD and HCV who had not yet tried treatment has halved from 42 to 21. Until recently only around half of the respondents reported ever having attempted treatment, with an average of two undergoing treatment each year. In 2013, however, 14 people responded they had undergone treatment in the last 12 months. The reason

for the large uptake of treatment was due to the participation of several members in a clinical trial for HCV therapy, all of whom successfully attained an SVR.4 Since then several more members have been able to participate in similar clinical trials.

The liver health of PWBD affected by HCV is being better monitored over time. The percentage of respondents having undergone a FibroScan® has increased each year from 53% in 2010 to 79% in 2013. The percentage of respondents who indicated they had been diagnosed with fibrosis has increased from 34% in 2010 to 55% in 2014, perhaps due to the increased access to a FibroScan. The percentage indicating they had cirrhosis has, however, remained consistent around 20%. An average of two respondents per year reported having or have had liver cancer.

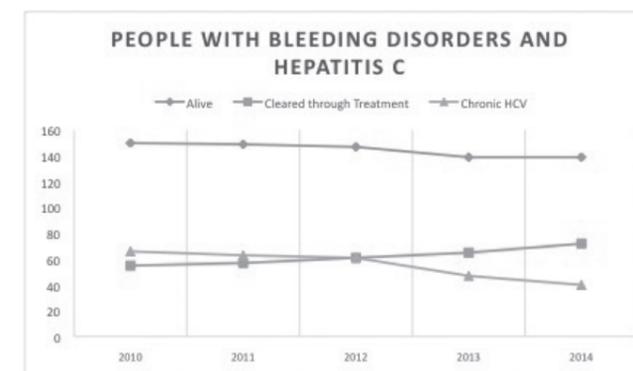


Figure 1. Recent trends in the numbers of people with bleeding disorders infected with hepatitis C through blood products.

Trends in well-being are shown in Table 1. Fatigue was reported to affect people the most and was the symptom that most impacted on their lives. Trouble sleeping was the second most commonly reported HCV symptom. Of concern is that reported feelings of depression have risen significantly over the time period from 3% in 2010 to 46% in 2013. There is increasing evidence of a correlation between HCV and depression, not only related to interferon treatment but having the virus itself. The various factors contributing to depressive disorders makes it difficult to establish a clear connection; however, the origins of depression with hepatitis C are most likely to be a combination of features related to how the virus affects the body, the emotional and physical health of the individual, the extent of a person's social support network, and available treatment options.

The tides are changing continued

Most respondents reported making beneficial lifestyle choices that support liver health. In 2014, 60% of people said they made at least one positive lifestyle change because of their hepatitis C. On average, 79% do not smoke, and 81% felt they had a healthy or very healthy diet. Despite recommendations that people with chronic hepatitis C avoid alcohol only half (52%) reported that they do not drink alcohol. Between 2010 and 2013, there has been a significant increase in the percentage of respondents reporting exercising at least once a week from 75% to 86% (p=0.013). This increase may have been partially due to the increased availability of specialised physiotherapy services for haemophilia in New Zealand. Unfortunately the number of respondents who exercise regularly has dropped in the latest survey, perhaps due to their advancing age or health, or this could reflect that the specialised physiotherapy service in the Northern region has been absent during this last year.

Current numbers

Of the 189 PWBD infected with HCV in New Zealand, regrettably 50 people have died. Of those 15 (30%) have died from causes related to their HCV infection.

As at the end of October 2014, 72 people have cleared the virus through treatment and 29 people cleared the virus naturally (meaning they are HCV antibody positive, but viral RNA negative). Of the remaining 40 people, there are five people either currently in treatment or who are awaiting their final results, 13 people who tried HCV treatment unsuccessfully and one where the outcome of their treatment is unknown. This leaves another 21 people who have yet to try to treat their HCV. Some of the people who have yet to try treatment are currently overseas or are and will remain ineligible for treatment due to their age or other health conditions.

Summary

There has been a noticeable shift in the numbers of PWBD and chronic HCV in New Zealand, especially over the last 2 years. While sadly some of the reductions have been through deaths, the opportunity to trial new direct acting antiviral therapies has had a positive impact on the HCV status and overall wellbeing of a number of PWBD.

Table 1. Trends in the well-being of survey respondents with bleeding disorders infected with hepatitis C through blood products in New Zealand, 2010-2013.

Year of Survey	2010		2011		2012		2013		2014	
	n	%	n	%	n	%	n	%	n	%
Returned surveys	32	52%	31	58%	32	52%	28	62%	20	53%
Experienced Fatigue			26	84%	19	59%	16	57%	13	76%
Experienced Trouble sleeping			20	65%	12	38%	9	32%	6	35%
Pain - Interferes with normal some activities/all activities	14	44%	15	48%	13	41%	14	50%	5	25%
Stop activity due to fatigue mostly/completely	10	31%	11	35%	13	41%	13	46%	6	30%
Depression mostly/completely	1	3%	6	19%	13	41%	13	46%	5	25%
Healthy diet good or very good	26	81%	26	84%	24	75%	22	79%	17	85%
Do not drink alcohol	16	50%	14	45%	19	59%	14	50%	11	55%
Moderate exercise at least once a week	24	75%	23	74%	24	75%	24	86%	11	55%
Do not smoke	26	81%	21	68%	28	88%	20	71%	17	85%

A major reason for this shift is the additional support that HFNZ Haemophilia Outreach Workers (HOW) have been able to provide for these people to undertake treatment since an increase in funding specifically for these services through the Ministry of Health was initiated in 2009. Those that continue to live with chronic HCV do, however, continue to be negatively affected by a variety of related symptoms, especially fatigue.

It is hoped that the new treatments that have proved to treat HCV so successfully in our population in clinical trials will soon be funded in New Zealand and allow more people with HCV to access them, giving them a real chance of clearing the virus with few side effects and improve their liver health, quality of life and long-term health outlook. Currently the best way to access new treatments is through a clinical trial.

If you are living with chronic hepatitis C seek help from your gastroenterologist to get access to new or upcoming trials. The experience of PWBD who have been on recent trials is that they are much shorter than traditional treatment, involve no injections and have limited side effects – and can give you a very high probability of clearing the virus for good.

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4. Steadman C, Hyland RH, Ding X, et al. Once Daily Sofosbuvir/Ledipasvir Fixed-Dose Combination with Ribavirin in Patients With Inherited Bleeding Disorders and HCV Infection. Presented at the Asian Pacific Association for the Study of the Liver (APASL), Brisbane, Australia. March 12-15, 2014.



In Remembrance Elizabeth (Ibby) Wheeler [29.10.1925 – 14.10.2014]

Many members from the Auckland area who were involved with the then named New Zealand Haemophilia Society (NZHS) throughout the 1960s to the 1980s will have very fond memories of Christmas parties and picnics at the beautiful Wainamu farm at Bethells Beach. This was the home of the Wheeler family, who sadly lost Elizabeth, known as Ibby, in October.

I interviewed Ibby as part of the research for Still Standing and was moved by her peaceful manner, even when recounting the difficulties they faced raising a son with haemophilia in the 1950s. It was a time well before treatment beyond transfusions was available and their remote location meant they often dealt with bleeds on their own. The family made connections with other NZHS members and Ibby became involved in a number of initiatives from fundraising stalls to growing peanuts to be shared with other families for their reported help with clotting. The Wheelers were also the source of local legend as their son John had a rare form of haemophilia, haemophilia B Leyden, where factor levels start to rise after puberty so he essentially 'grew out' of his severe haemophilia, a story that was shared many times over among other haemophilia families.

We present a few words of tribute and remembrance to Ibby, who according to HFNZ Patron Elizabeth Berry was a "graceful, generous and caring lady whose door was always open, cake tins stocked and garden produce to be shared".

For many years Elizabeth served on the committee of the NZ Haemophilia Society. Travelling from Wainamu, Bethells Beach, she had no road access so had to drive down the stream bed and often returned in the dark. Despite this she was so faithful in attending meetings. Her lovely warm personality and calm demeanour was so inspirational to those of us who at times were on the edge of panic.

Her practical outlook on life was apparent with her help in running our first camps at The Scout Campsite, Motumoana, Green Bay. She also arranged for one of our early get together at her sister's home, where there was a pool, and where so many of us met for the first time outside of a hospital surrounding. We had wonderful times at her home at Wainamu where Elizabeth, her husband Hap, and the family made us so welcome. Here we could slide on the sand hills, visit the site where they filmed "Black Beauty" and "The Children of Fire Mountain", swim in the lake, and enjoy the company of others with Haemophilia.

On a personal level, I can't forget the times when the Wheelers allowed me to bring Timothy out to sleep in the barn and hunt non existing pigs in the hills above the farm. Some of the happiest times of his life were out there with his rifle.

Elizabeth leaves her six children, John, Sue, Sarah, Adair, Jim, Simon, and her extended family.

Tony Goodwin, Life Member HFNZ

Elizabeth was a wonderful woman with such grace. I'll always remember her gentle laugh and smile. She was so generous in sharing her beautiful home at Bethells. In fact it was there that Tony Goodwin hit me up to become involved in the NZHS, when Stace was just a few weeks old. That was over 27 years ago.

Peta Hardley, Life Member HFNZ

Twinning Connection

In October 2014, HFNZ Manager of Outreach Services Colleen McKay and HFNZ Treasurer Grant Hook travelled to Cambodia for the final HFNZ-CHA Twinning Visit. It is hard to believe that our 4-year Twinning Project is already nearing the end. Robert Leung from the World Federation of Hemophilia (WFH) also returned to Cambodia to take part in the visit.

The visit focused on a workshop for children and families in Phnom Penh and on recognising the progress CHA has made over the 4 years of the Twinning Programme and helping them plan for the future.

The workshop included 29 adults and 9 children with haemophilia from Cambodia. Messages were reinforced about the lack of cure for haemophilia, how it is a lifelong condition and tips for recognising and treating bleeds. After CHA Chair Mr Sithan Kong opened the Workshop, Robert Leung from WFH spoke. This was followed by an address from Grant Hook from HFNZ. After a break, Colleen McKay presented information for parents about raising a child with haemophilia. This comprised the nature of haemophilia and genetics and well as the management, including the signs and symptoms of a bleed and P.R.I.C.E. The open question time that followed was an important part of the workshop.

Michael Ho and Caroline Ferguson from New Zealand who self-funded their travel were also able to assist with the workshop. Caroline lead the children's programme where they worked through specially translated workbooks adapted from an HFNZ Children's Education Workshop with basic knowledge about haemophilia. Although language always creates some barriers, Mr Run Chanthearthy (Rithy) served as a very successful translator. The children had a great time and enjoyed the goodie packs donated from New Zealand. Together all the participants shared a special lunch before returning home. Spare gift packs were also given to CHA to be able to be distributed to children when they are visited at home or in hospital. The workshop received media coverage in the newspaper and on the national television news.

During the visit representatives of HFNZ and CHA met with the Director of the National Blood Transfusion Service in Phnom Penh. The US Embassy Department of Defence is supporting a new building for the National Blood Transfusion Service and as part of this project funding is secured for the equipment required to manufacture Cryoprecipitate – an important move forwards for Cambodia to be able to provide a treatment product for their patients. Production of Cryoprecipitate is expected to start by early 2015. Other meetings included the World Health Organisation and Dr Sophal to discuss plans for treating adults with haemophilia in Cambodia. Currently treatment is only

available through two paediatric hospitals – one in Phnom Penh and one in Siem Reap. Adults can receive treatment through the centres but plans are being discussed on how to provide treatment through an adult hospital.

HFNZ representatives also spent time with the CHA committee helping them structure their plans over the next two years. They have a very busy time planned and HFNZ encouraged them to expand the committee to increase representation of their population and to share the work load. Together they also discussed the ways that WFH can assist CHA move forward into this next stage of their development.

On the Tuesday evening a Celebration Dinner was held at Tonle Bassac Buffet Restaurant where all were able to enjoy local fare at the many buffet stations. The dinner was held to celebrate the conclusion of not only the Twinning Visit but the upcoming end to the Twinning Project between the two organisations.

It was an evening of celebration, fun and laughter as they marked how far CHA have developed as an organisation and their achievements. It was also a celebration of the bonds that have developed between HFNZ and CHA – people with haemophilia in Cambodia will always have a special place in the hearts of HFNZ members. In a thoughtful gesture, CHA members presented HFNZ Representatives and Robert Leung with a lovely gift to remember Cambodia.

HFNZ are so proud of how CHA have developed as an organisation over the course of the Twinning Programme. They have a strong core of committed volunteers and many plans for people with haemophilia in Cambodia. In the next issue we will feature a final wrap-up of the HFNZ-CHA Twinning Project and all the many plans CHA has going forward.

Supporting CHA

Generous gift

HFNZ want to recognise Izack Silva! Instead of presents for his 7th birthday Izack asked friends and family to make donations towards our friends at the Cambodian Hemophilia Association. He collected over \$170 in donations! On behalf of CHA, thank you for your generosity Izack!

Greeting Cards

HFNZ still have CHA Greetings Cards for sale. Contact our Administrator Leanne – Leanne@haemophilia.org.nz

8 Greeting Cards with envelopes,
4 of each design = \$10.00.

All proceeds go directly to CHA for their work with the families with bleeding disorders on Cambodia.



MRG Reports



Piritoto

By Rosalie Reiri

Piritoto is proud to have attended and supported this year's AGM with a variety of waiata, haka and a lovely poem from our elegant Helen Crown. Some describe the day as being very 'eventful' and somewhat different from other meetings.

Piritoto were awarded with two trophies, one was the McKay Trophy for the noho marae stay over we had at Omaha at the beginning of 2013. Many thanks to Kahurangi Carter and whānau and those who supported this event as it has turned out to be quite a significant activity in terms of new beginnings. A new chairperson and board were elected, Piritoto the name was given by Pete Pene for the rōpū (group), the boys wrote a haka, the rōpū created a charter, Tahī Pene also created a logo and most importantly new friendships were formed.

Tahī was also recognised at the AGM for his initiative for starting up hydrotherapy in Auckland. Well done Tahī for being pro-active and actually taking the opportunity to 'Step up and Reach out'. This idea was inspired from the Congress in Melbourne as a positive activity that focuses on health and wellbeing by doing stretches and exercises in the water followed by a relaxing hot spa. The invitation is open for HFNZ members who live in Auckland to attend, we meet up every Thursday night at New Market at the Olympic Pools from 7.00-8.30pm, nau mai, all welcome. For myself personally it has made the doom of winter pass by quicker but most importantly Te Whainoa always comments how good his legs feel the next day!

Piritoto wishes to acknowledge our new CEO Richard, we wish him all the best for an exciting road ahead, we also would like to welcome Marcia Morris from Rotorua to the Piritoto whānau.

Southern

By Sandra Poff

Well finally we can say goodbye to the winter and hello to the spring / summer period, let's all hope for a great summer period – weather wise anyway.

The biggest thing to happen for the Southern MRG was the holding of our bi-annual Family camp, for a second time the camp was held at the Tea Pot Christian camp in Nelson at the beginning of October. Although the weather was not perfect a great time was had by all with many activities for young and old undertaken. Nine families attended made up of 17 adults and 17 children.

These activities ranged from arts & crafts to visits to a local Farm park through to a great day spent in the Abel Tasman National Park. The day started early with all participants travelling by bus to Kaiteriteri and then onto the launch for a 1 hour cruise to Bark Bay where we all spent the day enjoying this wonderful part of the NZ country.

Beach cricket, exploring the rock pools, walking part of the Abel Tasman track were some of the activities that were undertaken and even a few brave people were tempted to go for a swim – enough to say the water temperature was "stimulating"!!

Back at the camp, all the adventure based activities were given a good work-out, the shooting range and archery proved popular but like our last visit the Flying –Fox and Go-Kart also proved to be hugely popular!!

Thanks to everyone's hard work in making this event a huge success for our members and a big thanks to Kathy & Sophie for giving up their time to attend this camp.



A Nautical day ahead for the Southern MRG Campers

A great day had by all at the Beach

Upcoming Events:

Southern MRG Christmas Party on the 14th December from 11-4pm, The Groynes, Christchurch.

Central

By Stephanie Coulman

As another year wraps up the Central region was pleased to nominate BJ Ramsay for the John Stavely Health Professional Award which was awarded to BJ at the AGM in Auckland. The award was somewhat of a surprise to BJ as he thought he was invited to talk about new haemophilia treatment. Unknown to him that was just an excuse to get him there so he could receive the award and be recognised for his commitment and dedicated to his patients, by the assembled audience.

Unfortunately a ten pin bowling youth event for 13-18 year olds was cancelled when only one person responded. It would be great if people could RSVP to invitations before the due date – even if you can't attend. It's nice to get some response rather than silence – especially for our keen new youth delegate who tried her hand at organising her first event. Better luck next time Laura!

By contrast, numbers were limited to 50 for a dinner cruise on the Wellington Harbour on Saturday 29 November. For the sake of comfort aboard the ferry we could only accept 50 members on a cruise around the harbour. Delicious hors d'oeuvres were served as we set sail and a buffet meal was served once we had anchored in a sheltered spot. It was a treat to see Wellington from a different perspective. Happy holidays to everyone.

Northern

By Lynley Scott

Northern AGM had a great turnout this year. After a quick and to the point AGM, afternoon tea followed and then we all had a chance to look around Butterfly Creek. It was great to have such a wide range of Northern members there and also a great opportunity to meet Richard Chambers, our new HFNZ CEO.

The Northern Committee was voted in at the AGM: Richard Scott, Chairperson; Hemirau Waretini, Treasurer; Lynley Scott, Secretary; Greg Jamieson, Northern Delegate; Committee Members – Jess Hirst, Jo Brodie, Liam Brodie, Ken MacGregor, Ashlie Fowlie. We have already had a meeting and have some great events planned for next year.

Labour weekend saw a group of volunteers head to Armageddon Expo to help out and raise funds for HFNZ. This year was particularly interesting as our members were 'minders' to the stars who were visiting. Huge thanks to all who volunteered and helped out this year – Liam Brodie, Tim Lowe, Richard Scott, Jo Brodie, Ethan Matthews, Amy Waters, Amy's partner Jono, Ashlie Fowlie, Amie Taylor, Frances Taylor, Phil Salmon, Jeanette Salmon, Ken MacGregor, and James Mimilo.

In November 12 Northern men had a great day on the Hauraki gulf for a day of fishing. The men were a mix of men with haemophilia and fathers and sons. Everyone caught something and went home with fish for dinner.

The catch of the day went to Te Ahuriri Stirling with the largest snapper and Mark Allat was the shark hunter catching two Lemon sharks. Phil Salmon even caught a fish without using a hook, the snapper wrapped itself in the line. The weather was great and the sea relatively calm so no sea sickness. It was a great time to talk



Central region members at camp in Whanganui in September.

Midland

By Wendy Christensen

Although we have been pretty quiet over the last 3 months, we have been working on an extra special Christmas outing for this year. It is one not to be missed. So if you live the Midland region be sure to keep the 13th of December free. We will be heading to Rainbow's End in Auckland. A bus will be departing Rotorua at 7am and stop in Hamilton along the way to pick up members if you want to travel together. Contact Wendy for more information.



and fish and just enjoy being out on the sea. We all went home smelling of fish and enjoyed the day.

At the end of November, our Christmas party heads back to Rainbows End. This seemed to be a popular choice a couple of years back so it will be great to see the changes and new rides at the park. We have great numbers attending so it will be great to see so many Northern members together.

Planning is underway for the Northern Camp at the end of February, this year heading back to Campbell Park in Mangawhai Heads. As our regional camps grow, rooms are getting limited so hopefully people who have tents can bring along their tents and enjoy the camp too. Keep an eye out for the invite which will be out early January.

Wishing you all a wonderful Christmas and a New Year full of fun, excitement, rest and relaxation. See you in 2015!

News in Brief

Study suggests higher risk of inhibitors with some recombinant FVIII products

In October, the World Federation of Hemophilia (WFH) issued a communique regarding a study published by a group in France that demonstrated a higher than expected incidence of inhibitor development in previously untreated patients (PUPs) with severe hemophilia A treated with Kogenate FS/Bayer/Helixate NexGen compared to other recombinant factor VIII (rFVIII) products. Since then, a study published by a group from the UK has reported similar findings.



These results follow on from the unexpected results in the RODIN study, published in January 2013. That study was reviewed by regulators and in December 2013 the European Medicines Agency's (EMA) Committee on Human Medicinal Products (CHMP) endorsed recommendations which concluded that the benefits of Kogenate FS/Bayer/Helixate NexGen continue to outweigh their risks in PUPs with hemophilia A. The EMA stated that the product information for this product should be amended to reflect the results of the RODIN study and clarify that there is no different risk between products.

Inhibitor development is caused by many risk factors, which makes it difficult to draw conclusions in a small patient population. At the moment, no firm conclusion can be made.

The WFH has requested that the US Food and Drug Administration (FDA) and the European Medicine Agency (EMA) examine all the relevant data and come to a conclusion as soon as possible. Both the FDA and the EMA have confirmed that they will be re-examining the data but they will not have the results ready before early 2015. It is the view of the WFH that all of the available data should be pooled

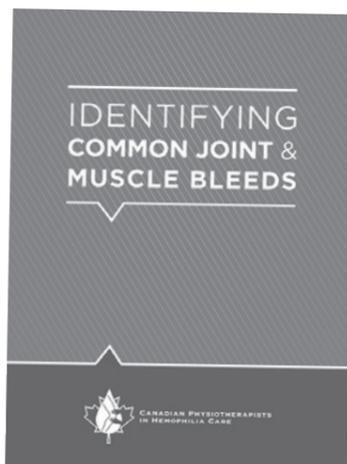
in order to give a clearer answer about the relative risk for individual products.

Based on the currently available published data, it remains the position of the WFH that it may be prudent to consider not using Kogenate FS/Bayer/Helixate NexGen for newly diagnosed PUPs with severe hemophilia A where other safe clotting factor concentrates are available. There is no known increased risk for any other patients using these products.

The WFH has also stated: "There is no evidence of a higher risk of inhibitors with this product in previously treated patients." See the WFH website (www.wfh.org) for future updates.

Identifying common joint and muscle bleeds

The Canadian Physiotherapists in Hemophilia Care (CPHC) have developed an information booklet designed to help people living with bleeding disorders identify common joint and muscle bleeds in their earliest stages, so that proper treatment can begin as soon as possible. It is written to help people of all ages perform a self-assessment and to help parents assess their children.



The booklet is available for download on the CHS website: <http://www.hemophilia.ca/files/Identifying%20bleeds.pdf>

New study findings on young women and bleeding disorders

It is estimated that approximately 1% of U.S. women may have an undiagnosed bleeding disorder, which can diminish quality of life and lead to life-threatening complications during menstruation, childbirth, and surgery. Information about bleeding disorders is vital for young women. It can help them recognise symptoms sooner and prompt them to seek medical care faster so that they get an earlier diagnosis and treatment.

To better understand the issues, together a division from the Center for Disease Control (CDC) along with the National Hemophilia Foundation (NHF) initiated a national internet survey of 1,243 young women.

Participants knew that a bleeding disorder is a condition in which bleeding takes a long time to stop (77%) or blood does not clot (66%). Of the women, 57% incorrectly thought that a bleeding disorder is characterised by thin blood; many were unsure if bleeding disorders involve blood types, not getting a period, or mother and foetus having a different blood type. Women at risk for a bleeding disorder were significantly more likely to report that menstruation interfered with daily activities (36% vs 9%); physical or sports activities (46% vs 21%); social activities (29% vs 7%); and school or work activities (20% vs 9%) than women not at risk. Findings suggest that the most influential messages focus on knowing effective treatment is available (86% gain-framed vs 77% loss-framed); preventing pregnancy complications (79% gain- vs 71% loss-framed); and maintaining typical daily activities during menstrual periods.

Researchers concluded that lack of information about bleeding disorders is a serious public health concern. Health communications focused on gain-framed statements might encourage symptomatic young women to seek diagnosis and treatment. These findings and corresponding recommendations align with Healthy People 2020 and with CDC's goal of working to promote the health, safety, and quality of life of women at every life stage.

Source: www.hemophiliafed.org

FDA approves first combination pill to treat hepatitis C

In October, the U.S. Food and Drug Administration (FDA) approved Harvoni (ledipasvir and sofosbuvir) to treat chronic hepatitis C virus (HCV) genotype 1 infection.

Harvoni is the first combination pill approved to treat chronic HCV genotype 1 infection. It is also the first approved regimen that does not require administration with interferon or ribavirin.

Both drugs in Harvoni interfere with the enzymes needed by HCV to multiply. Sofosbuvir is a previously approved HCV drug marketed under the brand name Sovaldi. Harvoni also contains a new drug called ledipasvir.

Harvoni is the third drug approved by the FDA in the past year to treat chronic HCV infection. The FDA approved Olysio (simeprevir) in November 2013 and Sovaldi in December 2013.

Harvoni's efficacy was evaluated in three clinical trials enrolling 1,518 participants who had not previously received treatment for their infection (treatment-naive) or had not responded to previous

treatment (treatment-experienced), including participants with cirrhosis. Participants were randomly assigned to receive Harvoni with or without ribavirin. The trials were designed to measure whether the hepatitis C virus was no longer detected in the blood at least 12 weeks after finishing treatment (sustained virologic response, or SVR), indicating that a participant's HCV infection has been cured.

In the first trial, comprised of treatment-naive participants, 94 percent of those who received Harvoni for eight weeks and 96 percent of those who received Harvoni for 12 weeks achieved SVR. The second trial showed 99 percent of such participants with and without cirrhosis achieved SVR after 12 weeks. And in the third trial, which examined Harvoni's efficacy in treatment-experienced participants with and without cirrhosis, 94 percent of those who received Harvoni for 12 weeks and 99 percent of those who received Harvoni for 24 weeks achieved SVR. In all trials, ribavirin did not increase response rates in the participants.

The most common side effects reported in clinical trial participants were fatigue and headache.

Although shown to be very effective, the high cost of the new treatments for HCV (over US\$1000 a pill) has received much criticism overseas. Harvoni has not yet been approved by Medsafe for use in New Zealand.

What's Up Now Online

The 0800 What's Up crew are now online! To connect with a counsellor just visit their website: <http://www.whatsup.co.nz/>

Whatsup.co.nz provides a safe place for children and young people to talk about anything at all. Children and young people can also get tips on dealing with the most commonly called about issues through the 'most talked about' sections of the kids and teens sections of the website.

Counsellors will be online from 7-11pm every night. Carefully selected and trained, the counsellors help young callers to find their own solutions to the challenges and issues they face, equipping them with strategies to deal with issues now and in the future. A child can ask to speak to either a male or female counsellor, and they can have ongoing counselling with the same counsellor. Counsellors also encourage callers to talk with the trusted adults in their lives about what's going on for them.

Honour the memory of a loved one or recognise the unique bond you have formed with 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

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

This magazine designed and printed by:

Jeff Oliver Print Ltd

Design • Print • Marketing • Websites • Distribution

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Upcoming Events

**23 December 2014
– 4 January 2015**

HFNZ Office closed for the holidays
Contact HFNZ Office on 03 371 7477
for on call Outreach information

23-26 January 2015

National Families Camp
Camp Keswick, Rotorua

17 April 2015

World Haemophilia Day
& Buddy Awards NZ

10-13 July 2015

Youth Camp
Blockhouse Bay, Auckland

8-11 October 2015

17th Australia and New Zealand
Conference on haemophilia and
related bleeding disorders
Gold Coast, Australia

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



Looking for a unique way to give this Christmas?

HELP SEND A FAMILY TO SPACE (CAMP)



Help families with young children with bleeding disorders join together for education and support

Although they aren't really heading into outer space, having a child diagnosed with a rare bleeding disorders can be like a taking huge leap into the unknown.

HFNZ National Family Camp is a 4-day camp that brings together families with young children affected by a bleeding disorder from all over New Zealand. For some 'campers' it is the first time they have met other families with bleeding disorders. All meals, accommodation, activity and transport costs are covered by HFNZ apart from a small registration fee. Held every other year, the theme for the 2015 camp is Space!

Do you have special memories from one our camps? This is a chance to help another family create some of their own.

Your support will not only allow us to assist a family get to camp but will also help with the purchasing of camp supplies and food. Donations over \$5 are tax deductible.

Shoot for the stars and Donate Now!

\$20 Donation – Thank you!

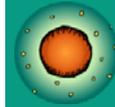


\$50 Donation – Send a child to camp!

A donation at this level helps sponsor a child to attend camp. Receive a personal thank you card from the child you help.

\$200 Donation – Send a family to camp!

Your donation will cover the registration fee for a whole family. Receive a personal thank you package from HFNZ and the family you help.



Donate at:

www.givealittle.co.nz/cause/HFNZSpaceCamp
Or contact HFNZ at:
care@haemophilia.org.nz

Be sure to provide your contact details

Get Ready to Blast Off to...

NATIONAL FAMILIES CAMP

23-26 January 2015
Camp Keswick, Rotorua

Held every other year, HFNZ National Families Camps bring together young families with a child with a bleeding disorder under 10 years old from all over New Zealand. The whole family including siblings are welcome to join in the fun!

At Camp, parents gain strength through knowledge and understanding. Children enjoy having fun whilst being "just like everyone else".

Registrations Closing Soon!!