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The Word

Kia Ora everyone,

2013 has started with a hiss and a roar at HFNZ. We have an exciting year ahead with the WFH 50th Anniversary, World Haemophilia Day and national events – including the much anticipated Women’s Retreat, Youth Camp, PEP and the Adult’s Weekend. Plus we are looking forward to hearing about what’s happening in your community through the MRG’s. HFNZ hope that everyone, including new and old faces, takes the opportunity to attend the regional events to make friendly banter and receive support from their peers. Also to our Hepatitis C genotype 1 trial participants, HFNZ is here to support you throughout the duration of the trial. We will report on all these stories and more in our upcoming editions of Bloodline.

In this issue of Bloodline we feature the latest news from the Twinning Visit, information on how to safely workout at the gym to tone your muscles and provide information on participating in a drug trial in the 21st Century.

Don’t forget, if you have a story you think our readers would be interested to read, send it to us at HFNZ.

Kate Russell Editor / National Information Coordinator

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Cover photo: Master’s Workshop November 2012.

2012 Cambodia Twinning Visit

The World Federation of Hemophilia (WFH) Twinning Program is a collaboration of two haemophilia organisations or treatment centres from two different countries, one being from a developed country and another from a developing country. The objective of the WFH Twinning Program is to improve haemophilia care, by strengthening emerging haemophilia organisation’s or haemophilia treatment centres, through the transfer of knowledge, expertise, experience, skills, resources and information.

2012 was the second year of the 4 year WFH Hemophilia Organisation Twinning Partnership between CHA and HFNZ. In November the 6 day annual visit commenced with the arrival of HFNZ representatives Colleen McKay (Manager – Outreach Services) and Grant Hook (HFNZ Treasurer) in Siem Riep.

The agenda for this trip was prepared by CHA who took responsibility for organising the Twinning Visit from Robert Leung (WFH, Regional Program Manager – Asia and Western Pacific). This is an exciting step for CHA demonstrating their progress towards independence and development of leadership skills within their association.

The trip began with an outreach visit to Angkor Hospital for Children. This pediatric hospital is run by a non-government organisation (NGO) called Friends Without A Border which was established in 1995 to assist disadvantaged children in Asia. Despite the small turnout of approximately three families, the workshop included education, a question session and a discussion about living with hemophilia. The Cambodian families appreciated seeing Grant who is a 52 year old male with severe hemophilia A. In Cambodia the oldest known person diagnosed with hemophilia is in his mid-thirties.

Since the 2011 Twinning Visit the Angkor Hospital for Children now has the ability to manufacture plasma into cryoprecipitate on demand. This development is a reflection on the Cambodian Ministry of Health’s public blood drive campaign to increase the amount of blood donated in the country. CHA and HFNZ

were able to visit the laboratory to view the equipment for the manufacture of cryoprecipitate and the Blood Bank.

The CHA and HFNZ representatives took the Cambodian families with haemophilia on a boat trip for a Phnom Penh social networking event. During the boat trip the parents introduced themselves and discussed what it is like in Cambodia to raise a child with a bleeding disorder. Previously the Cambodian parents felt isolated believing they were the only ones in the world with haemophilia. The families have had the opportunity to meet together several times during 2012 so they had instant rapport. The bonding demonstrated the programme enabled parents to gain mutual support from each other, which is reflective of the support networks that families in the HFNZ community in New Zealand gain from participation in events and workshops. The children on the boat trip each received an activity gift pack of donated goodies from New Zealand. New Zealander’s really appreciate the opportunity to be able to donate goodies to the Cambodian children with haemophilia and their siblings.

As with the workshop in Siem Reap, there was a lower turnout of families this year which is indicative of one of the communication barriers that CHA face. Communication with members is one of CHA’s biggest hurdles to overcome because as a developing nation very few families can afford to have a telephone landline. Many people have a mobile phone number, however the numbers are changed frequently and are not passed onto CHA for updating. Another hindrance is many people do not have an address for postal mail.

The CHA and HFNZ representatives met with Dr Hok Kim Cheng, the Director of the Blood Bank. During the meeting they were able to thank the Blood Bank for their efforts to increase the number of voluntary blood donors. In 2011 the Prime Minister and the Cambodia Government promoted a policy for the recruitment of voluntary blood donations through public Blood Drives throughout Cambodia and raise awareness through advertising and the visit of the mobile Blood Unit.



Blood donation campaign billboard



Boat Trip in Phnom Penh with CHA members



CHA-HFNZ meeting during the Phnom Penh trip



CHA and HFNZ representatives at the Blood Bank

2012 Cambodia Twinning Visit

The Blood Bank is heavily supported by the Australia Red Cross; with the provision of technical assistance to run the National Blood Service. Currently 70% of blood is from this family replacement policy and 30% is from volunteer donation. The rate of paid donors has decreased since the public blood drives. In their National Strategic Plan it is intended to increase public blood donations by 10% each year. To cope with the increase in blood donations, the Blood Bank has plans to increase freezer space and move to a bigger building.



The Blood Bank at the Angkor Hospital for Children

The meeting with Dr Hok Kim Cheng also discussed how CHA could enhance blood donors and the blood donor service

including ways that the haemophilia community could promote blood donations to the public. CHA will look to assisting on World Blood Donor Day on 14th June in 2013 and beyond. At the conclusion of the meeting, Dr Hok Kim Cheng highlighted that the government understood the problems and the need to expand the National Blood Service; however he also explained that resources were limited and care must be exercised in order to ensure services were sustainable in the long term.

The CHA & HFNZ representatives were invited to the International Day celebration for Persons with Disabilities Day and the Opening of the National Conference on Disability Inclusive Development in Phnom Penh. 3,500 people were in attendance including many people with disabilities. After the official opening of the national conference the Prime Minister addressed the assembly demonstrating the high level of support that the Government has for people with disabilities in Cambodia. Law has been introduced on the rights of people with disabilities in Cambodia to reduce stigma and discrimination and to ensure that they are fully able to participate in society. During his address the Prime Minister also acknowledged that Employment and Disabled Person Welfare in particular are future challenges. The Cambodian Hemophilia Association (CHA) has ensured that haemophilia is officially registered as a disability. This is an important and strategic move because within Cambodian Law – any company or organisation that employed 2% of their staff who have a registered disability, that company or organisation receives a tax break. CHA hopes that when a person with haemophilia applies for a job alongside an able-bodied person with the same skills and qualifications that this will make it attractive for employers to employ the person with haemophilia in order to attract the tax break.

During the trip, Colleen and Grant met with Mr Sithan, Mr Rithy, and Mr Keo Aun from CHA for a Training and Planning Meeting. Colleen gave an informal training session on Leadership and Fundraising to the CHA Board. The Leadership presentation included information on record keeping, accounting and financial reporting, timely meetings, development of a diverse CHA board, maintaining a database, and the importance of developing a strategic plan. Following this was the Fundraising presentation which made the point that while the dedication of volunteers is very important to the success of haemophilia organisations, raising funds is also very important. Fundraising will be an important activity for CHA to undertake in the future for them



Celebration dinner

to be sustainable in the long term in order to meet the needs of their members after this Twinning Project has finished.

There was a lot of information for CHA to absorb about what is required for a successful Board, however they felt encouraged that they would undertake just one or two fundraising ventures in 2013.

On reflection of the 2012 CHA-HFZN Twinning Action Plan the following achievements were noted:

- CHA has increased Board Membership – which has allowed for further delegation of roles and tasks
- CHA has run its own events – Evening Boat Cruise, Day at Water Park, Mother's Lunch, Youth Lunch – all in Phnom Penh
- Sithan, the Chairperson of CHA, has represented CHA at the World Federation of Hemophilia National Member Organisation Training and the World Hemophilia Congress in Paris in July – available through a grant from WFH
- CHA has held regular meetings during the year
- CHA has a good relationship with Dr Chean Sophal and Dr Sing Heng – haematologists who deal with people with bleeding disorders in Phnom Penh and Siem Reap
- CHA has planned for this 2012 CHA HFZN Twinning Visit of the HFNZ Team to Cambodia

The 2013 Action Plan includes the following activities for CHA:

- Social activities in Phnom Penh in March & June to promote networking for families, youth and mothers
- Social activity in Siem Reap to promote networking for families
- Communication - development of a web-site, an independent permanent mail address (PO Box), a mobile phone to be used for contacting families for workshops / visits, development of a newsletter, development of a CHA brochure for Hospitals and Laboratories for distribution upon diagnosis
- A volunteer Social Worker to visit families to update contact details and to support families
- A three – four day Twinning Visit in August by one HFNZ representative which will include 1 day for a Workshop for families, 1 day for visits to the Ministry of Health, Blood Bank, and 1 day for Training for CHA, writing the Report and 2014 Action Plan

At the end of the trip everyone was exhausted but excited by the progress so far and by future possibilities. The HFNZ team departed Phnom Penh to return to New Zealand to share their experiences with the rest of New Zealand and get ready for another busy and worthwhile year of twinning.

Twinning Visit to Cambodia - A Member's Perspective

By Grant Hook

Grant Hook, the HFNZ Treasurer, journeyed to Cambodia to represent the HFNZ with Colleen McKay. He describes his experience as a man with haemophilia.

On Monday 26th of November Colleen and I left Christchurch to commence the Twinning Visit for 2012. We travelled via Sydney, Bangkok then to Phnom Penh where we met up with the Cambodian Haemophilia Association (CHA) committee before travelling onto Siem Reap. After 30 hours travelling I enjoyed a much needed rest before meeting with the CHA committee over dinner that evening.

From reading the reports of the two previous twinning visits I understood that haemophilia care in Cambodia was at a very low level compared to New Zealand and that CHA had a big job ahead of them.

The CHA committee had grown in the past twelve months and has some very promising new members with great skills who are keen to take on responsibly in the roles we discussed during our planning session for 2013. I felt they were clearly progressing from the initial establishment stage to the next level and are ready to move forward with the job in hand. I could see big strides have been made by CHA since the initial twinning visit 2 years ago and the benefits of the programme to a country such as Cambodia are immense.

Although it is difficult to understand coming from New Zealand, one of their most important jobs is to identify people with haemophilia and create and maintain a register so that they

can quantify and get treatment for them. Because of their infrastructure people outside of the main cities do not have mailing addresses and cell phone numbers change often making keeping in touch difficult. To assist with this CHA is establishing a website with a permanent mailing address and contact cell phone number that will be manned 24/7 by one of the volunteers. Patients will be able to access the website by visiting a local health provider or chemist who has internet access.

With treatment only becoming available in recent years the level of joint damage among their younger generation is much greater than in New Zealand. Gaining access to treatment is very limited especially outside of the main centres, this will be improved with education for both patients and the medical profession although this will take time. There appears to be a level of mistrust between patients and people in authority which may have stemmed from Cambodia's recent history. CHA and medical professionals are overcoming this through education and shared experiences of the good results that are being achieved.

From my arrival in Cambodia I was impressed by the people's cheerful nature, people were very helpful with many working in tourist related jobs speaking English. I think we need to travel to appreciate everything we have in New Zealand, in saying that it was obvious that you do not need a lot of money to enjoy life, family especially children are very important to Cambodian people and they seemed to make time to spend with family. I couldn't get over how a family of 2 adults and up to 3 children were able to travel on a small motorbike with such ease and apparent safety, all with smiles on their faces!



Motorcycling in Cambodia

How to Safely Exercise in a Gym and Get Results

By Abi Polus and Ian d'Young

Introduction

Exercise is not just important when you are recovering from a bleed. A sedentary lifestyle (i.e. people who sit around a lot) is linked to decreased strength, balance and coordination, and this may increase the risk of injury and bleeding in people with haemophilia (PWH). 'Couch potatoes' are thought to be at a much greater risk of having a joint or muscle bleed when exercising or playing sport than people who are fitter.



Imagemajestic

Being fit, having strong muscles, good balance and a good pattern of movement is therefore considered to be protective for your joints: in other words you are less at risk of having a bleed in the first place. We all know about Factor prophylaxis, but we call exercising to protect your body and reduce your risk of problems before they start 'prophylactic exercise'. It is very important for all PWH, regardless of whether you have had a joint bleed before or not.

Having exercise as part of your lifestyle keeps you fit and looking good, but also keeps your joints and muscles in their best possible condition, even if you already have joint damage from bleeding when you were younger. This means that by exercising regularly you do as much as you can to reduce the risk of having a bleed by keeping fit and strong, as well as helping your body recover fully after a bleeding episode.

Building muscle power and fitness

The muscles in your body respond to the demands that you place on them. If you spend all day in front of a computer screen, you will have a body and muscles that are perfectly equipped for sitting. If you cycle for 30 minutes everyday, your body will adapt to this. In order to get bigger, stronger, more powerful muscles, and increase your endurance, you need to increase the demands you put on them. This can be done in a variety of ways; using weights (own body weight, free weights, or machines), or repetitive use, for example the recurring muscle actions used in walking, running, cycling, or using the cross trainer. If you want to lose weight then the energy you expend must be more than the amount you consume (the amount of energy provided by what you eat; calories and kilojoules are a measure of this energy). If you want to 'bulk up' then you need to increase the demand on your muscles in a way that is safe and will not increase your risk of bleeding.

The results you get from the gym depend not only on what you do, but how you do it. The speed and intensity of the exercise will influence which type of muscle fibres are recruited and the results that you get.

So what actually happens when you work out? In order to build muscle you need to load them to the point of hypertrophy (this

is when the muscle mass (the size) will increase). What actually occurs is micro-trauma; small tears occur within the muscle tissue. These increase muscle growth as the tears give rise to an activation of a complex process of cells being activated, multiplying and travelling to the site of the damage and helping regeneration. This also results in inflammation to help contain and repair damage and 'mop up' the waste products. At the same time, hormones and cytokines, including growth hormone and growth factors are released, which help the muscles increase. Muscle hypertrophy occurs when the muscle goes through the processes of healing itself, not when you are actually working out. For this reason, rest between exercise sessions is essential.

If the demands on a muscle are too great, for example building up your exercises or weights or distance too fast or too lifting too much too soon, this will cause the muscle fibres to be overused and to tear too much. This can cause bleeding in the muscles.

In a nutshell; in order to increase your muscles you have to subject them to micro-trauma. If you subject them to too much you may cause a bleed or other muscle damage.

Impact on joints

Another thing to consider is the state that your body is currently in. Joints may be vulnerable to repeated impacting stresses that are above their ability to cope. This is even more of an issue if the muscles are not working correctly to support the joint or if the joint already has damage. Again this may cause a bleed or worsen joint damage.

What type of exercise should people with haemophilia NOT do?

The type of exercises prescribed should be considered; in building muscle if the aim is to break down or tear fibres in order to get hypertrophy, this may cause a bleed, especially if done too fast or with weights that are too heavy or with incorrect technique.

Additionally, overstretching a muscle may cause stress and potential bleeding to a muscle. If a joint is contracted or fixed it should NOT be stretched beyond its usual limit or into pain. This will cause a bleed and potentially further damage the joint.

Contact sport is usually discouraged due to the increased potential for injury, although this is not always an absolute. Contact the local haemophilia treatment centre physiotherapist for advice on contact sports. Boxing training can be of great cardiovascular benefit but a blow should NOT contact you. Any sport where the aim is to land a blow on a client's body should NOT be done by people with haemophilia.

If you are recovering from orthopaedic surgery, post-surgical exercise regimes are encouraged, but be aware that rehabilitation may be slower than the non-haemophilia population for joint surgery.

It is recommended an assessment with a physio is performed prior to the gym programme

It is important to keep the muscles that surround joints with existing damage strong. It is also important to select exercises that are appropriate for the level of existing dysfunction that may be present. Ignoring previous injuries that have not been correctly rehabilitated or where damage is already established may make the joint vulnerable to further damage or bleeding. After an injury or bleed either in the muscle or joints, the surrounding muscles weaken rapidly due to immobility, as a response to pain, and inflammation. If these are not properly rehabilitated with physiotherapy and an exercise programme they are unlikely to correct themselves. This is why it is important to make contact with your physiotherapist after any bleed and make sure that you rehabilitate back to the level where you can safely exercise. Pre-assessment should involve identification and specific strengthening of weak muscles, identification and a stretching programme for tight structures, correct timing of muscle activity, proprioception and balance.

If you have had a bleed or injury recently, your exercise programme will be different when you are recovering from a bleed compared to when you are getting fit or playing sport. It is very important that you talk to your physiotherapist and rehabilitate the bleed properly before starting a new sport or exercise. Remember, doing too much too early can lead to another bleed.

You will need to start at a gentle level of exercise and gradually increase this as your body recovers after a bleeding episode. Exercise is very important, but it needs to be the right sort of exercise. Forget the idea 'no pain no gain!' It's 'NO GAIN WITH PAIN', so remember to tell your physiotherapist if an exercise is painful or if you are becoming tired or sore.

It is also important that when you start a new sport or exercise programme you choose your day wisely. If you take regular prophylaxis, it is sensible to start a new exercise programme on the days that you have your factor. Generally it is a good idea to administer factor an hour before you start your new programme. Remember that taking factor the night before you exercise does not give you any protection!



Stockimages

If you have mild or moderate haemophilia and take factor 'on-demand' (i.e. only when you need it), then you may not need to take factor beforehand because your exercises will be gentle to start with and should not lead to any bleeding. Check with your HTC.

Your physiotherapist can help to develop a sensible exercise programme that is safe and suits you. It is important that you start gently, with the supervision of your therapist who can make sure that you are doing the exercises correctly.

Warming Up

Before you start your exercise programme it is very important that you prepare your muscles and joints. This helps to reduce the risk of injuries and will help you to perform your exercises better. Start by warming up your muscles and joints with a little 'cardio'. If you are exercising in a gym, use the treadmill, cross trainer, bike or rowing machine for around ten minutes. Alternatively, you can mix things up a bit and try a little time on each machine. Start gently, and slowly increase the intensity.

You will know that you are warmed up if you are starting to sweat and puff a little bit. If you are going swimming or plan to work on your arms in the gym, make sure you use your arms in the warm-up too! A cross-trainer, rowing machine or simply swinging your arms when you walk will get your arms as well as your legs ready for exercise.



Daniilo Rizutti

Stretching

Once you start to get warm and puff a little bit, you are ready for part two of your warm-up: stretching. Muscle is a little bit like chewing gum. If you stretch the gum when it is cold, it can snap. In the same way, if you stretch a muscle when it is cold, it is much easier to have an injury. This is why making sure you have warmed up well before stretching is so important in order to lessen your risk of a muscle injury.

Don't let yourself cool down too much when you are stretching. Many people feel like taking off layers of clothing after spending time on the treadmill or bike. Try to avoid this – peel off layers after stretching, not before.

When you perform a stretch, remember that you should feel a gentle pull in the muscle, but it should not hurt. If your stretches hurt you are doing them too hard and you will need to check with your physiotherapist that you are doing them correctly.

When you first start your programme, hold each stretch for 10 seconds but don't overdo it - stretches as part of a warm up shouldn't take too long and in most cases three stretches for each muscle group on each side is all you need to do. Eventually you will aim to hold your stretches for 20 seconds, however you may not get to this point for some time. Remember, do not push to pain – if it hurts, ease off!

Remember that as every person is different, every exercise programme will be different and will need to be tailored to your needs.

Warming Down

Once you have finished your programme, it is important that you warm down to prevent stiffness in your muscles. When you start a new exercise plan, it is very common to feel a little muscle stiffness the next day. Physiotherapists often call this

How To Safely Exercise In A Gym And Get Results

'DOMS' or 'delayed-onset muscle soreness'. In most cases, this feeling of soreness the day after exercise only lasts for a short time and generally only in the first week or so of starting a new programme.

By warming up and down sensibly, you can help to minimise this stiffness. Warming down simply involves repeating what you did in your warm-up, but this time, because you are already warm from your exercises you can start with the stretches and then finish with around ten minutes of 'cardio' – i.e. a brisk walk, riding your bike, or using the cross trainer or treadmill in the gym (or a little of each for variety!).

How often should I exercise?

When you are recovering from a bleeding episode you will notice that your exercise programme will be different compared to when you are exercising to move better or become fitter and stronger. This may be because you will need to rest certain parts of your body while keeping up with exercises to the unaffected parts of your body. In this situation your physiotherapist will tell you how often to exercise when you are recovering from a bleed or injury.

Generally young people should be active for around 60 minutes of daily activity in order to gain the health benefits of exercise, however this can be a mix of both low and high-intensity exercise. For example, swimming or a gym programme might be considered 'high intensity exercise', while a brisk walk around the park might be considered 'low intensity'. It is a good idea to have a variety of these types of exercise in your programme, which will also help to keep things from getting boring.

If you are starting a new exercise programme to improve strength, flexibility, balance or your cardiovascular fitness when you have not had a recent bleed or injury, then aim to repeat the programme three times per week initially. Try riding a bike, having a swim or going for a brisk walk on the alternate days to add a little variety.

If you take regular prophylaxis, then do your exercises around an hour after you had had your factor initially. As you get fitter and stronger, you can gradually increase the number of times you do your programme from three to five times per week and from there to every day. This doesn't mean you need to go to the gym every day, but repeating your exercise programme 'little and often' can be a very useful way of making sure your body is in top shape.

What about repetitions?

The number of 'reps' you do for each exercise will depend on your own situation. Often this number will be determined by what is felt to be safe by your physiotherapist and by listening to your body. If you start to feel discomfort this is normally a sign that you have done enough for the moment. Remember, when you are recovering from a bleed you may only be able to do a small number of reps.

Start slowly and gradually build up your program – it is much safer to build up an exercise programme over two or three



months than to start too hard and find you've had a muscle strain or another joint bleed.

One of the best ways to start is to use gravity or the resistance of your own body weight in very simple, practical exercises. You do not need to use expensive equipment, and generally the simple exercises are the safest. Don't be fooled though – simple exercises can also be very effective, as well as being easy to do at home.

Listen to your body

Be sensible and listen to your body. If your body is telling you that an exercise is hurting you or starting a bleed, listen! Never keep exercising through the pain – remember it's NO GAIN WITH PAIN!

Every person is different and every person may react differently to a type of sport or exercise, so it is important that you listen to your body. If you notice a bleed or sustain an injury every time you ride your bike or go for a run, your body is telling you that this is not the right type of exercise for you. Talk to your physiotherapist about alternative sports or activities.

Abi Polus is the Senior Clinical Physiotherapist in Haemophilia at the Alfred Haemophilia Centre in Melbourne, Australia. Abi is the co-chair of the Australia-New Zealand Haemophilia Physiotherapy Group (ANZHPG). Ian d'Young is the National Clinical Lead for Haemophilia Physiotherapy in New Zealand and is co-chair of the ANZHPG. Ian is also the co-vice president of Physiotherapy New Zealand.

Men's Masters Support Group

In light of the successful Master's focus group at Men's Workshop weekend in June, the Men's Masters group was established to support the needs of men aged over 45 years.

The group held their first workshop meeting in November last year with Greg Millan, Men's Health Consultant, facilitating the event. With Greg's leadership the group worked together to determine the new and emerging needs of their peers with bleeding disorders as they age.

After an initial icebreaker session, the men worked in small groups to brainstorm what needs they had that were not currently being provided for. They next prioritised the needs by importance and planned a potential solution so that need could be met.

Some of the highlights on the men's list included:

First Priority

- Form a Masters Steering Committee with a goal to have a delegate on HFNZ Council
- Develop a Masters only social internet site to increase contact between members
- The HFNZ to develop stronger links with men's health organisations
- The steering committee to prepare a paper on treatment and care protocols for older men
- The HFNZ to advocate to ACC for guidelines for assistance



Second Priority

- To have Outreach Workers increase knowledge of older men's needs and attend clinic reviews

Third Priority

- The Masters Steering Committee are to prepare a research brief on the difference between the quality of life between men with bleeding disorder and other men in the community to increase resources
- Implementation of regional education meetings for men

A key part of the Men's Masters group and top priority on their list, has been the formation of the steering committee by Paul Long, Willy TeKira and John Wrathall. They encourage anyone who is interested in helping build the foundations of this group to contact the HFNZ for further information.

Leave a Lasting Legacy

The HFNZ was established to serve the needs of people with haemophilia and other bleeding disorders. By making a bequest you will help the HFNZ continue to provide excellence in care, education, advocacy, and support to members. Whether your donation is to honour the memory of a loved one or to recognise the unique bond formed with the Foundation, your gift would be a special way to make a difference to the quality of life of people with bleeding disorders.

A bequest can enable the HFNZ to continue supporting people with a genetically inherited bleeding disorder across the country through helping to fund a wide range of services. Your bequest could help support:

- National Camps and Educational Workshops
- The Supportive Footwear Programme

- The Exercise Programme
- Bloodline Magazine
- HFNZ Website
- Outreach Services
- Administration

If you have already decided on leaving a bequest, making a will is the only way to ensure your wishes will be met in relation to the distribution of your assets. A will also helps to avoid confusion over your intentions and gives you peace of mind.

For further information on the type of legacy you can leave and what information your solicitor needs, please refer to our website www.haemophilia.org.nz or contact the HFNZ.

WFH 50th Anniversary

The World Federation of Hemophilia (WFH) celebrates its 50th Anniversary in 2013. For the past 50 years the WFH has been working globally to close the gap in care and to achieve treatment for all people, both men and women, with haemophilia and other inherited bleeding disorders, regardless of where they live. To mark the anniversary the WFH are reflecting on their accomplishments, milestones, and lessons learned. They have activities planned up until the 2014 World Congress in Melbourne, Australia.



As part of their anniversary the WFH is releasing a series of anniversary videos and commemorative articles. They have also launched the Close the Gap campaign. The Close the Gap campaign is seeking to accelerate the WFH's goal to close the gap in care for people with bleeding disorders internationally. They have developed a new project called the *Cornerstone Initiative* which targets the needs of people with bleeding disorders in the most disadvantaged regions of the world. Their aim is introduce, improve and develop sustainable care for people in these regions and further develop the care based on that foundation.

The WFH was founded in 1963 by Frank Schnabel, who brought together national patient societies and treaters to form the society. Schnabel, born with severe hemophilia A, had a vision to improve care and treatment for "the hundreds of thousands of hemophiliacs" worldwide. The inaugural WFH meeting took place in Copenhagen, Denmark with representatives from 12 countries in attendance. Today, the organisation has members from 122 countries.

The effort of the WFH over the past 50 years is reflected by these results:

- 240,000 patients have been identified with a bleeding disorder
- 5 per cent increase in the number of children with bleeding disorders surviving into adulthood in developing countries in six years (from 2002 to 2008)
- Over 225 per cent increase in the availability of treatment products since 2001
- National care programmes established in 16 countries through the Global Alliance for Progress (GAP) Program, 13 of these with official memoranda of understanding signed between the WFH and the national government
- WFH mission is carried out in more than 100 countries globally

Source: www.wfh.org, www.hemaware.org

Outreach Bring Home the NACCHO Cup for 5th Place

Outreach Workers Sarah Preston and Joy Barrett attended NACCHO (North American Camping Conference of Hemophilia Organisations) in January and brought back some wonderful new ideas for HFNZ events. They also brought home the NACCHO Cup for 5th place in the 'Blueprint for success' competition.

The conference weekend is organised by the Arizona Hemophilia Association and is facilitated by well-known presenters and leaders from the American bleeding disorder community. The weekend focused on the work of bleeding disorder summer camps and provided an environment to share useful information on camp resources and techniques, development of best practices and new ideas.

The 2013 conference theme of 'building today for tomorrow' flowed on from last year's theme about camp culture and values with the emphasis on how to plan camps today to shape and influence the camps of the future. Topics covered at the conference included how to develop the building blocks for the camp culture you want, intentional and unintentional culture, camp evaluations,

the rites of passage for young people and taking a step towards independence, bullying, education and more.

Joy and Sarah also each entered the NACCHO Cup competition where the entrants presented to their peers a 'Blueprint for success' describing a camp, its goals, programmes, activities and outcomes. Sarah presented on the Youth Boot Camp and Joy presented on the Boys Day Camp (Children's Workshop) which won the NACCHO Cup for 5th place and US\$250 to go towards a camp programme.



Winning this award is a great opportunity to recognise and acknowledge the planning and organisational efforts that go into HFNZ events, the expertise of our bleeding disorder specialists who make presentations and work in the treatments rooms at camps, and last but not least the events would not be possible without the efforts of our volunteer leaders and helpers.

Thanks to Pfizer for sponsoring NACCHO, and Sarah and Joy to attend the conference.

WFH 2014
WORLD
CONGRESS
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WFH 2014 WORLD CONGRESS

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY MELBOURNE, AUSTRALIA • MAY 11-15

FEDERACIÓN MUNDIAL DE LA HEMOFILIA
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www.wfh2014congress.org



Travelling to Australia - Be Prepared!



New Zealand and Australia have a reciprocal Health Care Agreement, but this does not mean you will qualify to receive your regular treatment during your stay or the same benefits as a permanent resident – so don't leave the country without careful planning!

Before you travel across the ditch to Australia for a holiday or to live take the time to thoroughly consider what medical treatment and benefits you will qualify for while you are there. Most importantly – talk to your haemophilia treatment centre (HTC) well in advance about your plans for departure.

If a New Zealander moved to Australia prior to February 2001 they qualified for a 'protected special category visa'. This means they are entitled to receive the same benefits as an Australian resident. However, New Zealanders who have moved or intend to move to Australia after this date have 'non-protected special category visa' status. Whilst you will be eligible to receive some benefits, you will not receive the full benefits available to residents.

Centrelink is Australia's equivalent to Work and Income. People with a protected special category visa qualify for all Centrelink payments that an Australian resident would receive. However non-protected special category visa holders only receive some benefits after they have lived in Australia for 10 years. After that period they are eligible to receive the Newstart Allowance, Youth Allowance or a Sickness Allowance for up to 6 months. Both protected and non-protected special category visa holders are entitled to receive Family Tax Benefit, Health Care Card, and Child Care Benefit. If you are on a New Zealand aged Pension, Disability Support Pension or Carer payment and remain eligible you can continue to receive these.

The reciprocal Health Care Agreement covers treatment whilst in Australia that is medically necessary and caused by an unpredictable incident such as a bleed, accident or surgery in an emergency. As a bleeding disorder is a pre-diagnosed condition, you cannot show up to the local HTC and expect to be given your regular prophylaxis treatment. Free treatment is only given in an emergency as an inpatient or outpatient at a public hospital or for subsidised pharmaceuticals under PBS (Pharmaceutical Benefits Scheme). Haemophilia treatment products, including plasma derived and recombinant products are not on PBS as they are funded through the National Blood Authority. It is important to check the rules of each state as they may

differ. People visiting Australia should take their own treatment to last the duration of their trip.

Any New Zealand citizen intending to live in Australia should get a Medicare card ASAP. To qualify for Medicare you need to show proof that you are intending to live in Australia. This proof would include documentation showing the sale of your property or termination of your employment in New Zealand, plus documentation that shows proof of purchase of property, a rental agreement, opening of a bank account and evidence of employment in Australia. Medicare does not cover medicine subsidised under PBS, treatment arranged before your visit, private hospital admissions or non-hospital medical care e.g. GP visit.

Medicare application forms are available online at the Australian Government Department of Human Services website. There is a special information page 'Medicare enrolment for New Zealand citizens' you should refer to. It includes forms as well as a list of the documentation you need to provide including: Medicare enrolment application form, Statutory Declaration form, used passport pages and documents to confirm residency. Please note to avoid delays in the processing of a Medicare application, it is important all the documentation prepared and completed correctly and that if original documents cannot be supplied, certified copies are prepared in advance – they will not be certified by the processing office.

What to do before leaving New Zealand

Get prepared for your move or trip to Australia well in advance by:

1. Contact your Haemophilia Treatment Centre in New Zealand

Your HTC will help you to organise:

- A supply of product to cover you for the duration of your holiday or if you are relocating enough product to last for 2-3 months.
- A doctor's referral, which is required for new patients in Australia
- Find the location of an Australian HTC. It is recommended you register with an HTC ASAP. A Global Treatment Centre Directory is also listed on the World Federation of Hemophilia's website. It lists the HTC's name, location, organisation type, contact people and phone numbers.

2. Get Travel Insurance

When you travel overseas it is recommended you don't leave home without travel insurance. Southern Cross Travel Care can be booked online and you can declare and apply for cover under pre-existing medical conditions for your bleeding disorder. You will be prompted to answer questions about your bleeding disorder such as Are you on recombinant factor?, Have you had any joint replacements? A surcharge for haemophilia is normally around \$50.

3. Travel Documentation and Factor

When travelling overseas it is important to:

- a) Take two letters with you:
 - i) Customs and Immigration Letter – Carry this letter in your hand luggage. The letter needs to outline that the person has a bleeding disorder and requires injections for the treatment of it. It is also important to list any prescription medicine, what factor they use, together with the needles and syringes needed to administer it.
 - ii) Letter of Introduction to a Haemophilia Treatment Centre or Hospital. This letter needs to state the person's name, date of birth, NHI number, bleeding disorder diagnosis, details of treatment regimen, and information about any recent problems related to their bleeding disorder. It needs to be signed with the name and contact details of a Clinician.
 - iii) Template examples of the letters are available on the World Federation of Hemophilia website under Tips for Travellers.
- b) Keep your factor in your carry-on bag in case your checked-in luggage goes missing during transit.

If you have any further questions regarding overseas travel or emigration please contact your Outreach Worker and HTC.

Source:
<http://www.humanservices.gov.au>

Clinical Trials in the 21st Century

By Carolyn Lauren. Haemostasis Research Coordinator, Christchurch Hospital.

Being involved in a clinical trial can often sound like a daunting experience. Some people might believe they will be used as a guinea pig, but gone are the days when scientists can randomly try new things out without scrutiny. Today there are many regulatory authorities and ethics committees involved in every stage of the process of drug development to ensure participant safety and well-being. Researchers are also bound by rules and guidelines ensuring that the protection and health of the participant is the most important priority.

Clinical trials are developed to find the best way to prevent, diagnose or treat a disease by providing scientific evidence behind the treatments used. In haemophilia research we seek to find better treatments in various aspects like to make products safer or last longer (have a longer half-life), or find improved ways of administering the product. Over the years, many thoughts and ideas have been examined, including the PEGylation of the FVIII molecule, the idea that treatment could be a subcutaneous injection rather than an intravenous one and the use of transgenic pigs to produce functional human FVIII in milk. Research work in 2005 into the haemophilia A gene therapy found FVIII was expressed long-term in platelets (megakaryocytes). Although none of these ideas have come to fruition yet, it shows that there are many interested people with lots of wonderful ideas examining different ways to make haemophilia treatment better. If early investigations show that these ideas do not work, it will not make it into human trials.

Taking part in a clinical trial is entirely voluntary. It is important to remember that before a clinical trial is offered to humans, it has already gone through many years of extensive laboratory testing to discover whether or not the treatment can be used and is safe. The results of that lab work needs to be reviewed and approved by regulatory authorities and ethical bodies before being allowed to start the first of four phases of human testing. Each phase involves a greater number of people and aims to answer questions on products safety and effectiveness. If you consider taking part in a clinical trial, an information sheet will be given to you which will outline the benefits, risks and possible side-effects of the trial. Research staff are there to help give you the necessary information on what will be expected of you during your time in the

trial. They are happy to answer any questions you or your significant others may have, before you decide whether to participate or not. You will be under no pressure to enter the trial, and if you decline, your health care will continue on as usual. Each clinical trial has inclusion and exclusion criteria, meaning that not everyone is eligible for a trial and this can be for many different reasons. These criteria ensure that all trial participants are similar to start with and in that way any differences in outcome are more likely to be the result of treatment and not some other factor.

Clinical trials provide the opportunity to have access to the latest treatments that may otherwise be unavailable in New Zealand. This is because once approved, drugs can be imported for clinical trial use even when they are not licensed for doctors to prescribe. Before a trial is started at any site, there is a strict selection and multiple set-up process, which involves legal, ethical and cultural consideration and review of what will happen, to whom and when. This can take approximately 6 months before all the boxes are ticked and that location can start recruiting patients.

The latest trial in haemophilia research involves three New Zealand sites with one patient per site. This new product is a long-lasting recombinant Factor VIII Fc fusion protein product, which makes use of a natural pathway to recycle this product in circulation, and enable it to remain in the body longer. Hence, the product used in this study aims to reduce the amount of prophylactic treatments required per week. It is also being developed for use in haemophilia B with a recombinant Factor IX Fc product. Fc fusion technology is already being used in seven FDA-approved products for the long-term treatment of other chronic diseases. The initial trial (called the A-Long study) started in New Zealand back in August 2011 and all essential data was completed by October 2012. Because in haemophilia it is discouraged to frequently swap products, the patients involved in that trial have now moved into an extension study. This means the product can be imported and provided to the patients involved free of charge until it gets licensed by Pharmac to use in New Zealand. It is at this stage that the sponsors biostatisticians and medical monitors spend months compiling the data and factually assembling all the necessary information to prove to the FDA and other international licensing boards that their product is an improvement to other treatments currently licensed.

Throughout New Zealand the opportunity to be involved in a clinical trial in haemophilia can be sporadic. As the opportunity comes up for us to be involved with a potential new therapy, we assess what criteria the trial requires, look to see if we are aware of anyone eligible, and then discuss this with you at either a clinic visit or on the phone. Please do not be afraid to ask as many questions as you need, as an informed decision and a willing participant leads to the high-quality data that companies have enjoyed receiving from New Zealand.



Phases of a Clinical Trial on Humans

If you are considering participation in a clinical trial it is important to acknowledge that before a drug trial on humans can commence in New Zealand it has to have been through approved laboratory and animal testing to test for toxicity, and be approved by the Medsafe Director - General of Health.

The approval process involves an application to conduct the trial being submitted to Medsafe (Medicines and Medical Devices Safety Authority) for consideration. Medsafe receive advice from the Health Research Council, Standing Committee on Therapeutic Trials (SCOTT), who undertake a scientific assessment of the application, as well as advice from an accredited ethics committee.

When health and disability research is undertaken in New Zealand, researchers need to meet the established ethical standards guidelines from the National Ethics Advisory Committee. Medsafe also have 'Interim Guidelines for Good Clinical Research Practice' which endeavours to have clinical studies in human participants designed and conducted to the highest scientific and ethical standards.

Once approval of the study is given, the trial will go through four phases where data on the new drug is collected and analysed. A guideline to what is involved in each phase is given below.

Phase I

Phase 1 trials involve the first tests on healthy humans and normally include a small number of patients (up to 30 people). The first phase enables the researchers to gather information of how the drug is tolerated, absorbed, broken down and eliminated by the body. The dosage of the drug is increased to develop the criteria for a dosage range, drug combination (2 or more drugs taken at once) and the frequency of administration to identify side effects and to establish the safety of a new drug.

Phase II

Phase 2 of a clinical trial tests a larger group of people (between 100 to 300 people) on the effectiveness of the drug to treat someone with an illness or medical condition. The participants have been identified by clinics, hospitals or research centres. The tests determine if the drug actually treats the condition being targeted and the effective dosage, drug combination and the best method to administer the drug and gathers information on safety, side effects and risks. At this stage the drug has a 60% of being approved and getting onto the market.

Phase III

In phase 3 of a trial, participants are randomised to the treatment they receive in order to test the effectiveness of a new drug as it would be administered if it were in the market, without bias. This means the participant can be randomly selected (e.g. by a computer) to:

- be treated with the "comparator" drug such as the standard therapy drug which is already being used on the market,
- be treated with the experimental drug or a combination of drugs, or
- be given a placebo drug (a sugar pill that has no medicinal value), if clinically appropriate.

In these studies often the investigator and participant are "double-blinded" so neither of them knows who is receiving the experimental drug. The data gathered from this study helps to collate information to indicate if the drug is better than the existing treatment on the market and helps to define what information, for example side effects, is described on the labelling for the new medicine.

The research can be conducted on between 300 – 3000 participants internationally and may take between 2 - 4 years to complete. By testing the drug on a greater number of people it will develop a better understanding of the benefits and risks of the drug. A drug in phase 3 of the clinical trial has a 70% chance of being approved and getting onto the market.

Phase IV

The fourth phase of a clinical trial is a post-market study which occurs after the new drug has been approved by e.g. Medsafe and has become available by prescription or as an over-the-counter medicine. Both the regulatory authorities and the pharmaceutical company gather information on the long-term side effects, benefits or optimal use of the drug which may only become obvious after continued usage of it. Phase 4 of the study can include gathering data on people in different patient populations, stages of the disease, drug doses and schedules of administration. The study can continue for a number of years.

Sources: <http://www.medicinesnz.co.nz>, <http://www.hrc.govt.nz>, <http://www.pfizer.com>, <http://www.drugtrial.co.uk>, <http://www.wellesley.edu>



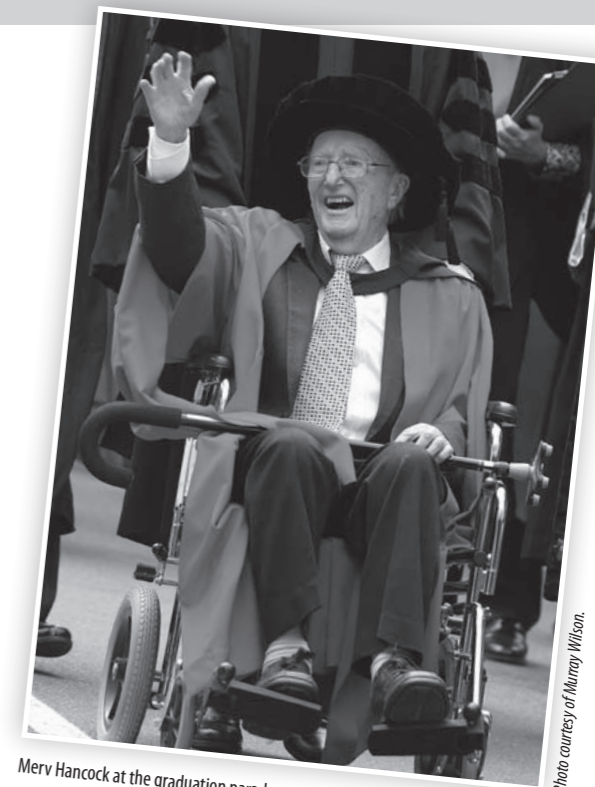
Profile: Merv Hancock Conferred with a Honorary Doctorate

Merv Hancock, 86, from Palmerston North was recognised last November for his pioneering work in social work with an honorary Doctorate in Literature from Massey University.

Merv has mild haemophilia A, however it has not held him back from achieving a life full of milestones. His interest in people was always very strong and he sought a professional life working with people. He started his career in social work with a solid tertiary education including a Bachelor of History at Auckland University, followed by a Master's Degree at Victoria University. After completing his studies Merv began a role at the head office of the Child Welfare Service in the early 1950's. The role offered him both professional experience and a training year which saw him enrolled as a student in the first intake for the Diploma in Social Sciences.

After being promoted to several senior roles in the Child Welfare Service located around New Zealand, Merv's career eventually took him back to Palmerston North where he was the District Child Welfare Manager. He later started a private practice which led him onto training people working in the social services sector and making connections in the education sector.

In the 1960's a Social Services Association was established by social service professionals throughout New Zealand and Merv was elected President. During this time the association pushed hard to improve the professionalism in the industry by encouraging tertiary education providers to add social work courses to their curriculum. The effort paid off and Canterbury University responded with a 2 year Diploma in Social Work and Massey University was the first university to offer a 4 year Bachelor of Social Work, with the first students graduating in 1978. Merv resigned as President of the Social Services Association and became involved as a supervisor at Massey



Merv Hancock at the graduation parade

Photo courtesy of Murray Wilson.

University from 1975 to 1982. During this time he helped the university set-up and develop the social work course standards and curriculum.

Dr Hancock's contribution to the community were also previously been recognised in 1989 when he was awarded the QSO for his work as a Palmerston North city councillor for setting up community social services and a Massey Medal in 1999 for his contribution to education at Massey University.

Council Corner

The National Council meeting on 24-25 November took place in Christchurch.

The National Council held a two day meeting in November with the first day consisting of a training, team building and updating day. Each council member lead a different activity which included: get to know each other better exercises, understand board responsibility, governance and management, what makes a good meeting, what makes a good not-for-profit organisation, and the history of the HFNZ.

Belinda spoke on her and Colleen's visit to the Irish Haemophilia Society (IHS) and the United Kingdom Haemophilia Society (UKHS) in June 2012 prior to the WFH Congress in France, which enabled them to see and hear the differences between their peers in Europe.

Colleen presented on the feedback from 2012 HFNZ programmes and gave a preview of 2013 & 2014 events.

The second day of the meeting included finalisation of HFNZ policy documents for the Youth Terms of Reference and establishment of a complaints procedure

for the outreach workers and other staff.

The budget for 2013 was discussed and priorities for expenditure were determined in light of the deficit.

An archive project of important and historic HFNZ documents was approved to ensure the documents are copied and stored to protect their longevity.

SURO Graduates - Where Are They Now?

The Step Up Reach Out (SURO) programme is an international leadership course designed to help build tomorrow's leaders in the bleeding disorders community. Applications for the next intake are due to open next month so we took a look back to see where some of our graduates are now and how their experiences at SURO have benefited their lives both socially, professionally and within the HFNZ community.

Applications for the 2013-2014 program are due to open on the 1st April with the first session 'Building the Foundation of Leadership' taking place during September (San Francisco, California). The second session occurs in March 2014 and covers 'Defining Your Leadership Role' (Edinburgh, Scotland).

More information on SURO and application details are available at www.stepupreachout.net. Applications open from the 1 April 2013 and close on 1 June 2013. Please contact your Outreach Worker if you think you would be a good ambassador for the HFNZ.

Graduate: Blair Wightman

Age: 26
Bleeding Disorder: Moderate Haemophilia A
Year(s) you attended SURO: 2007 - 2008
Favourite memory from a SURO trip:

I found the visit to Bayer's factor VIII factory in San Francisco interesting. It was great to see the processes followed to produce factor and also to see how interested management were in our views and feedback.

On a social note the baseball and basketball games we attended were a great insight into American culture and very enjoyable.

Why has SURO been important to you?:

SURO reinforces the value that youth can bring to HFNZ and has provided me with the confidence to participate in leadership roles. SURO was also important as I got to learn more about the history of haemophilia treatment and also the medical and scientific background to haemophilia.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

I have definitely been able to apply the skills I learnt at SURO in my life. SURO teaches general presentation skills but also skills in public relations and advocating for yourself and others, in particular - how to get your message across to others. These were very useful skills in life and I use them frequently at work.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

Through SURO you meet other people with bleeding disorders from around the world and the networking is valuable. You can understand what other youth are doing in their countries with their member organisations and also how fortunate we are with our haemophilia care in New Zealand.

Graduate: Karl Archibald

Age: 26
Bleeding Disorder: Severe Haemophilia A
Year(s) you attended SURO: 2007 - 2008, then as a mentor in 2010, 2011 and 2012.

Favourite memory from a SURO trip:

Meeting the diverse array of people that all have similar interests, goals, and seeing how peoples action plans came into fruition. The best trip would have had to be Dublin over St Paddys Weekend in 2012.

Why has SURO been important to you?:

SURO gave me my first opportunity in the international arena. It is not until you leave NZ that you appreciate how much time and effort people have put in over 2 or 3 generations to give you the quality of life that you have today.

SURO is also a great way to develop leadership skills and build confidence that you may not have had before.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

Yes, SURO looks great on your CV, it helped me secure a job, gave me confidence to stand up for what I believed in and fostered leadership capabilities which I was able to apply to HFNZ and the National Council as National Youth Delegate.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

You get to experience parts of the world in a way that you otherwise wouldn't. The first part of the program is in San Francisco where the Bayer Plant is located, then the second is in another part of the world.

You meet great people from all over the globe and learn heaps. HFNZ creates an environment that lets you apply the skills you have developed back home, and you have a great time while you are there.

Graduate: Stace Hardley

Age: 26
Bleeding Disorder: Severe Haemophilia B
Year(s) you attended SURO: 2007 - 2008

Favourite memory from a SURO trip:

In 2008 in Houston, Texas we went to a Houston Rockets basketball game, which was an awesome experience in its self, but just to add to it, we arrived in style in a Hummer limo!

Why has SURO been important to you?:

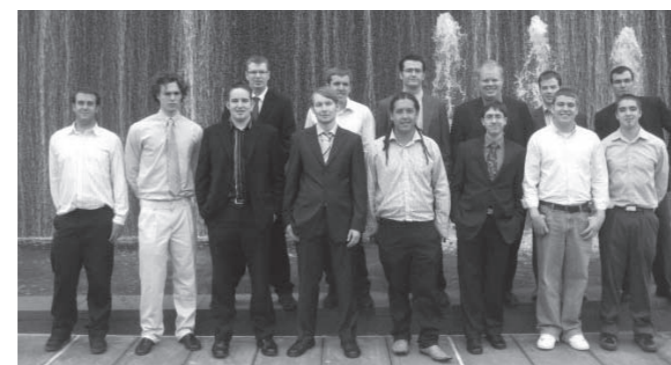
SURO allowed me the opportunity to meet some awesome people and to see how haemophilia affects people around the world.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

SURO taught me leadership and organisational skills and how I can help and support those people within my community, it inspired me to join the Northern committee and organise social events for youth members.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

It is a great chance to meet some cool people with bleeding disorders and learn from them. The tutors are helpful, funny, and thought provoking. The whole experience is a life changing experience.



Graduate: Raukura Riwaka

Age: 27
Bleeding Disorder: Severe Haemophilia A
Year(s) you attended SURO: 2008 - 2009

Favourite memory from a SURO trip:

On the final day at SURO we had to dress-up and present our project to the group. I won a prize for the best project which was a video about youth activities that were done for the Foundation.

Why has SURO been important to you?:

It has helped me to become more involved in the Foundation in areas that I'm interested in and I hope that one day it will benefit the Foundation.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

SURO teaches you leadership and how to apply yourself. You are able to apply the skills you learnt in all aspects of your life and those skills are gradually being given back to the Foundation.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

In general it makes you a better person when you attend. Naturally, you get on with the other boys because you have a bleeding disorder in common. It is a confidence booster.

Graduate: Sam Hawkins

Age: 22
Bleeding Disorder: Mild Hemophilia A
Year(s) you attended SURO: 2009 - 2010

Favourite memory from a SURO trip:

Meeting people from around the world with haemophilia and hearing their stories.

Why has SURO been important to you?:

The SURO experience opened my eyes to haemophilia and I learned how to be a leader within the community as well.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

I am the Southern Youth Delegate and attending SURO gave me confidence and the ability to communicate in different ways.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

To have the opportunity to meet other people with haemophilia from around the world and learn to be a leader in their community.

Graduate: Hemi Thomas

Age: 22
Bleeding Disorder: Moderate Haemophilia B
Year(s) you attended SURO: 2010 – 2011

Favourite memory from a SURO trip:

Cycling around San Francisco and getting to show the guys around my home town and the far north.

Why has SURO been important to you?:

I've met some great people from all over the world, made life long connections and been to some fantastic places. The course itself gave me invaluable communication skills. Public speaking doesn't come naturally to me so SURO helped enable me to get up in front of a room of people and talk.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

The skills that I learnt from SURO started to pay dividends immediately. It made me think more critically and was a huge help with me organising group projects and presentations at university.

Outside of university I am a member of the Executive Committee of Nga Kaitata Maori o Aotearoa (The National Maori Accountants Network), without the skills I learnt from SURO I wouldn't have put my hand up to be in this role or any of the roles that I have within the Haemophilia Foundation.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

Step Up Reach Out is a great opportunity for anyone and I would encourage every eligible person to apply for the programme. It is run by a group of genuine, committed and talented people who want to share their knowledge and experiences with you. I count myself lucky to have attended Step up Reach Out.

Graduate: Ethan Matthews

Age: 23
Bleeding Disorder: Severe Haemophilia A
Year(s) you attended SURO: 2011 San Francisco & 2012 Ireland

Favourite memory from a SURO trip:

In 2012 being in Dublin, Ireland for Saint Patrick's Day and the parade!

Why has SURO been important to you?:

SURO has been important to me mostly because of the motivation it gave me to re-involve myself and join in with the Foundation again. A presentation I saw and thoroughly enjoyed also gave me another perspective I had never thought about in depth – what the parents of children with haemophilia experience and go through.

Have you had the opportunity to apply the skills you learnt at SURO in your life or through your connection with HFNZ, and how?:

The main skills that have been applied through life would have to be organisation, mainly in regards to employment and I applied the leadership skills at the 2012 New Families camp with organising the "Ask the Experts" panel.

Why would you encourage other young people with haemophilia to apply to attend SURO?:

Step Up Reach Out opened my eyes, boosted my confidence as well as made me aware of how good we have it in New Zealand. I would encourage other young people to attend SURO because as well as providing you with invaluable life skills, you also establish worldwide connections.

SURO 2011 - 2012



HFNZ News

Congratulations on Your Qualification Linda!

HFNZ's Southern Outreach Worker, Linda Dockrill, has qualified for the Social Work Competence Certificate and completed her Social Work Registration. The process of recognising adherence to the Aotearoa New Zealand Association of Social Workers (ANZASW) and the Social Workers Registration Board's ten Competence Standards for Social Workers involved Linda demonstrating proficiency through the presentation of a portfolio that included social work case studies and references from her colleagues, manager, supervisor and a client.

Linda was also interviewed by an ANZASW Competency Panel of as part of this process. The Panel, impressed with her capability commented: "Linda's portfolio was very strong as was her interview. Her competence is supported by excellent references and illustrations of her practice. In her interview she demonstrated huge levels of enthusiasm, passion, skill in advocacy and teamwork. She has a powerful ability to challenge and advanced skills in professional reflection. We are pleased a social worker of her ability is taking a student this year and encourage her to be active in the branch (ANZASW)."

Well done, Linda.

David Betts Joins Our Southern Outreach Worker on Placement



On the 11th February Canterbury University student David Betts joined the HFNZ on practice placement to work alongside Southern Outreach worker Linda Dockrill. David is in his 4th year of a Bachelor of Social Work and working at the HFNZ is one of two workplace placements he will complete this year.

The experience David will gain during the 15 weeks he is at HFNZ will contribute to the ten core competence standards required by the Social Workers Registration Board to gain his Competence Certificate and Annual Practising Certificate. These include the competence to practise social work with Maori and other ethnic and cultural groups in New Zealand; promote the principles of human rights and social justice, social change, empowerment and liberation; practice approaches, human behaviour and social systems, problem-solving in human relationships, accountability and adherence to professional social work ethics.

David has chosen a career in social work as he considers it would be a satisfying and rewarding career path to help to improve people's lives. He hopes to gain from his time at the HFNZ practical experience working with people, learn about NGO's

and the medical nature of bleeding disorders. In the future David intends to complete a Masters in Social Work.

During David's time at the HFNZ, as well as assisting Linda, he will work with the Youth Committee and attend the National AGM, Youth Tramp and Youth Camp. We are pleased to have David join us and believe he will add value our team while he is here. We look forward to you to having the opportunity to meet him.

HFNZ Bank Account

If you need to make a deposit or internet banking transaction to the HFNZ for your membership, event registration fees or make a donation, the account number is 03-0207-0093558-00. Please include a reference description e.g. Membership, Youth Camp and email Leanne to let her know you have made the deposit.

Congratulations on Your Engagement

Sarah Preston, Northern Outreach Worker, is off the market after her partner Frazer proposed at Brick Bay Beach on Christmas Eve. Congratulations Sarah we wish you and Frazer a happy future together.

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

News in Brief

Hep C Drug Linked to Fatal Skin Reactions

A prominent boxed warning will be added to the oral hepatitis C drug Telaprevir (Incivek) after multiple deaths occurred in people who developed skin reactions while receiving an Incivek combination treatment.

The fatalities were reported during post-marketing surveillance of the drug in people who continued to take the combination treatment after the development of a progressive rash with systemic symptoms or progressive severe rashes.

The skin reactions affect less than 1% of patients and a warning was reported on the original labelling. During the clinical trials prior to approval, some people required hospitalisation for what was considered life-threatening reactions.

Anyone who develops a skin reaction to the Incivek combination treatment should seek immediate medical advice.

Source: http://www.medpagetoday.com/InfectiousDisease/Hepatitis/36528?utm_source=breaking-news&utm_medium=email&utm_campaign=breaking-new

New Xyntha Preloaded in Single Device

If you are using the factor VIII replacement XYNTHA® for your haemophilia A treatment please note this now comes with XYNTHA® and diluent preloaded in a single device.

If you have any questions or would like a demonstration to use this new preloaded device, please contact your Haemophilia Treatment Centre.



Inhibitor Rates Related to Treatment Product in Previously Untreated Patients (Pups)

A large international study of risk factors for inhibitors in children with severe haemophilia A appears to have identified a difference in inhibitor rates between different types of clotting factor concentrates. This study was published in the New England Journal of Medicine on January 17, 2013 (www.nejm.org/doi/full/10.1056/NEJMoa1208024).

The international RODIN study (Research of Determinants of Inhibitor development among previously untreated patients with hemophilia), which is based on the PedNet Registry (European Paediatric Network for Haemophilia Management), includes 29 hemophilia centres in 16 European countries, Canada, and Israel. By taking into account all known risk factors for inhibitor development, particularly the type of product being used or switching between products, the study aimed to investigate their impact on inhibitor development.

Of the 574 children, born between 2000 and 2010, who participated in this study, 177 (31%) developed inhibitors. The risk of developing inhibitors among these previously untreated patients (PUPs) was similar in those receiving plasma-derived or recombinant products. However, an increased risk of inhibitor development was observed in PUPs using the second generation recombinant product (Kogenate®-Bayer/FS, also called Helixate/FS) as compared to a third generation recombinant product.

This was an unexpected finding in the study and the investigators do not have any mechanistic explanation for it. The researchers have therefore stated that this needs further evaluation and confirmation in a second study. The study found no increased risk of inhibitor development linked to switching treatment products.

Regulatory authorities in Europe and North America are studying the data presented in this paper. The Kogenate®FS manufacturer, Bayer Healthcare, which partially funded the study, has responded that this finding needs to be interpreted with caution. Other studies have not found such high rates of inhibitor development in PUPs treated with their product nor are these data applicable to previously treated patients.

Much more debate and discussion regarding this finding are likely to occur. The WFH will provide updates as they become available.

Source: Statement from the World Federation of Hemophilia, <http://www.wfh.org/en/page.aspx?pid=769>

Gene Therapy for Hemophilia: Addressing the Coming Challenges of Affordability and Accessibility

Improvements in treatment product over the next few years could see advances in biosimilars ('generic' versions) of current therapies, longer lasting efficacy and the prospect that gene therapies could produce a cure for haemophilia. However along with the evolution of improved treatments comes the challenge of how to make the new treatments accessible and affordable in both developed and developing countries.

Currently prophylactic infusions two or three times a week for hemophilia reduces the risk of long term joint damage, related morbidities and early mortality however quality of life limitations still exist. This lifelong regimen could soon be replaced by a single gene transfer.

The cost of prophylactic and inhibitor treatment is already high but it is not yet known what the cost for gene therapy could be. The World Federation of Hemophilia has a vision to achieve treatment for all however access to care in developed countries is already a complex system. Developing countries have a less certain ability to access treatment, with 75% of people with haemophilia receiving inadequate care.

It is considered that emerging therapeutic advances should be brought to the market because they could offer improvements in treatment adherence, reductions in frequency of bleeding, better management of clotting factor toughs, and improved health outcomes instead of because they are more affordable.

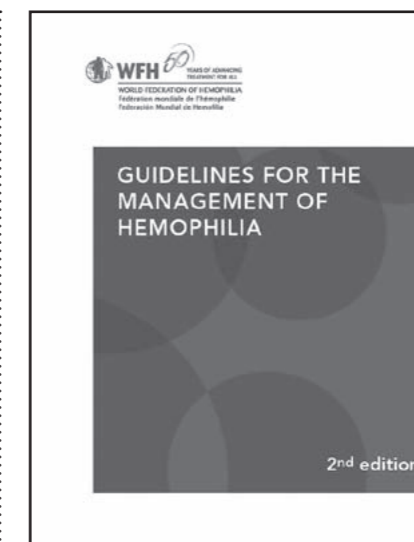
In order to make gene transfer accessible and affordable to all, the challenge for the next decade will be being prepared to advocate by developing policy arguments, economic justifications, outcomes scenarios, and global strategies.

Source: <http://www.nature.com/mt/journal/v21/n1/full/mt2012272a.html>



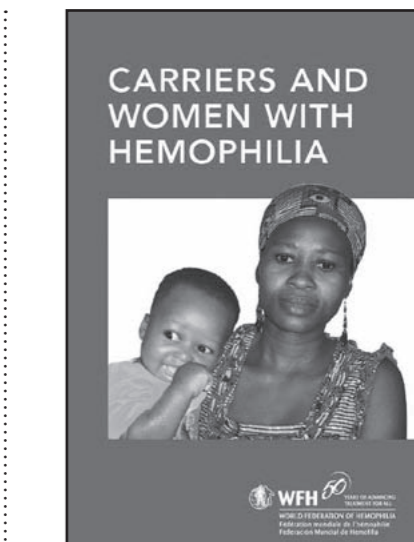
Revised WFH Guidelines for the Management of Hemophilia

The second edition of the WFH Guidelines for the Management of Hemophilia is available to download at www.wfh.org. The first edition was published in 2005. The contributors to the revised edition include eight international senior representatives from medical, nursing, dental and orthopaedic specialties.



New Approaches to the Management of Hepatitis C in Hemophilia

New Approaches to the Management of Hepatitis C in Hemophilia is a publication written by the Hepatology Department at the University of Lyon, France. It outlines the progress being made in the management of hepatitis C with the development of non-invasive tools such as the FibroScan to assess liver fibrosis stage, the evolution of antiviral therapy and triple therapy. The publication is available to download from the World Federation of Hemophilia website publications at www.wfh.org.



Carriers and Women with Hemophilia

The World Federation of Hemophilia has added a new website section for carriers and women with hemophilia. The page includes information on diagnosis, management, care, family planning and pregnancy.

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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 Roopu, which represents Māori members.

Northern Region

By Lynley Scott

Early December saw Northern's biggest event yet take place with about 110 members gathering at Rainbows End for the Northern Christmas Party. It was a beautiful day and there was great excitement when everyone arrived and started to enjoy the rides on offer. At lunch we all gathered in 'The Barn' for some lunch, a lolly scramble and face painting. The jolly man himself, Santa, paid a visit with presents for the children. This was a great opportunity to catch up with old and new faces. Then it was free time for everyone to again enjoy more of the rides on offer.

The Northern Camp to be held at Campbell Park in Mangawhai Heads 15-17 March. As always it'll be a great weekend to catch up and have fun with the Northern Members. At camp the AGM will also be held. This is an opportunity to review the year that's been and look towards the year that's coming.

There are some great events being planned for Northern, so keep an eye out for invitations and come along and join us.

Northern Christmas Party at The Barn, Rainbows End



Midland Region

By Deborah Weir-Honor

It's not often that members of the bleeding community are able to participate in adrenalin pumping activities, but this is exactly what Midland offered its members for an end of year get together, in November 2012. Adrenalin Forest, located half-way between Rotorua and Tauranga, is where we all gathered to challenge ourselves on the high ropes course. Six different levels, at varying heights from 3 - 16 metres off the ground, tested and challenged the members. After a quick lesson on safety and 'how to', we were off. Some of us managed 2 or 3 levels, whilst one brave boy managed all six! As usual, Midland get-togethers offer everyone a great chance to catch up with familiar and new people. It was fantastic to see old, regular and new faces for this activity. A lovely catered lunch gave all members the opportunity and plenty of time to mix and mingle after the adrenalin levels calmed down a bit!

Keep your calendars free for our next event.

Midland high wire adventures at Adrenalin Forest



Central

By Stephanie Coulman

The central region held simultaneous Christmas events on Sunday 9 December at Cobb & Co in Paraparaumu and at the Pioneer Village in Stratford, Taranaki. Thanks to Tracey Gregory for organising the Taranaki event.

Also on 9 December and thanks to our Westpac contacts, Lauren and Tracey Nyhan, members were invited to watch a Phoenix game at the Westpac Stadium.

The region held its AGM in Palmerston North at Te Manawa Rugby Museum on 10 February to elect its committee and office holders. Members enjoyed a lunch followed by a museum visit.

Having a dedicated haemophilia physio will mean a much better response time to bleeding episodes. Helen will aim to contact people within 24-48 hours of them reporting a bleed. Also because she is dedicated to haemophilia she will be the physio that patients will see when in hospital, in clinic and in the community so it means our patients can build a great rapport and relationship with one person.



Taranaki members enjoy a Christmas gathering at Pioneer Village

Southern Region

By James Poff

Teapot Valley Southern Family Camp 9-13 January 2013.

What a fantastic camp! The setting was amazing with great accommodation and even greater food! The facility was perfect with a lot of on-site activities such as archery, BB shooting, swimming, a maze, a huge waterslide, climbing wall, flying fox and wee petrol jeeps. The staff at Teapot Valley provided the safety instructions and support for a lot of the activities. The parents participation and help was freely given and played a vital part in the camp as did the older youth who did a wonderful job watching over the younger children.

A highlight of camp was Pottering About in Nelson where you can choose a plain piece of pottery and paint it any colour and design you liked and for those who went the stock cars wowed with mud, dust and noise! Some people ventured into the Nelson Markets for bargains and Founders Park was a great location for lunch. The disco was a big hit and thanks to the talented Luke Spencer who compiled, mixed and delivered the music.

Cathy and BJ provided their brilliant medical support and a lot of families benefited from their knowledge. A big thanks to Rochelle, Linda, Liz and Lyn and the children who played, had fun, learnt stuff, renewed old camp friendships and made new special camp friends.

Southern Camp at Teapot Valley



Southern at Pottering About in Nelson

Roopu

By Patience Stirling

Transpired as the very first inaugural Marae noho for HFNZ whanau, from the 15th to 17th of March 2013, members throughout Aotearoa gathered at Omaha Marae in Leigh, north of Auckland for an amazing weekend of whanaungatanga me te kotahitanga (being together as one whanau). With the age group from baby Levi Reedy through to our Nannies, we all enjoyed meeting new whanau and reconnecting our links amongst ourselves. The entire weekend was filled with korero, waiata, occasional dance and the highlight was a sunny afternoon of kayaking and snorkelling at the reserve beach at Goat Island and swimming and relaxing at the beach.

A huge 'Thank You' to Robyn Thompson for her teachings of the Harakeke (flax), followed with lessons on weaving putiputi (flower) and (tipare) headbands for our wahine Ataahua (beautiful women), while the men had their own discussion groups with various topics. The evening trivial games were also a delight with the trophies going to our nannies Nell Paenga and Helene Crown for their excited outbursts when knowing their group answers.

Omaha Marae is an exceptional Marae with its unique carvings and the whale bone overhanging at the entrance, with a brief history by the Kaumatua clarifying its beauty; it is located in an exquisite region with precious sea views, making our weekend so significant and relaxing.

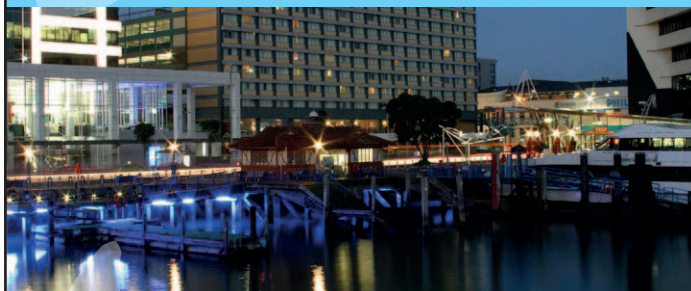
Lastly our appreciation and gratitude goes to Kahurangi Carter for her dedication while organising our noho, to ensure its planning worked towards an eventful weekend, 'Nga mihi nui kia koe'.

Roopu Marae Noho flax weaving



Roopu Marae Noho

Women's Retreat 2013



When:

19-21 July 2013

Where:

Copthorne Hotel HarbourCity
Auckland

For:

Women with bleeding disorders and women
who carry the H gene

About:

Celebrate being a woman with a bleeding disorder and join us for a mid-winter weekend of education, recreation and discussion at the Copthorne Hotel HarbourCity, Auckland. Women of all ages 16+, including international participants are invited to attend.

Registration forms will be sent out in March. Accommodation is share twin. A limited number of places are available for international participants.

For more information please contact:
Colleen McKay on 03 3717479 or
colleen@haemophilia.org.nz

Dates to Note

3 March

Midland AGM and Social
Totara Springs
Matamata

9 March

HFNZ AGM
West Plaza Hotel
Wellington

15-17 March

Northern Summer Camp
Campbell Park
Mangawhai Head

17 April

World Haemophilia Day

17 April

Southern World Haemophilia Day
Vanilla Bean Cafe
Christchurch

20-23 April

Youth Camp
MERC – Sir Peter Blake Marine Education and Recreation Centre
Auckland

17-19 May

Parents Empowering Parents
Jet Park Airport Hotel
Auckland

19-21 July

Women's Retreat
Copthorne Hotel
HarbourCity
Auckland



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