Haemophilia Foundation of New Zealand Inc.
HFNZ

bloodline

Newsletter of the Haemophilia Foundation of New Zealand Inc

March 2015
Volume 43 / Number 1

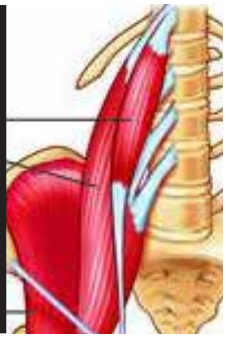
2015 Family Camp was a blast!

Siblings: Best of friends and rivals

Page 4

Psoas Bleeds

Page 8



Twinning Connection Wrap-up

Page 11

March 2015
Volume 43 / Number 1

Haemophilia Foundation of New Zealand Inc.
HFNZ

CONTACT DETAILS
Website
www.haemophilia.org.nz

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

President
Deon York
deon@haemophilia.org.nz

Chief Executive
Richard Chambers
richard@haemophilia.org.nz
Ph: 03 371 7477

Editor
Chantal Lauzon
chantal@haemophilia.org.nz

Manager Outreach Services
Colleen McKay
colleen@haemophilia.org.nz
Ph: 03 421 8452

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

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

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

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

The H Word

Another new year has arrived and with it many new resolutions and plans. HFNZ is as busy as ever working on events for members, such as the recent National Family Camp, and many other initiatives in the coming year.

Following on from the last Annual General Meeting, National Council has adopted a new Strategic Plan to help guide us through the next 5 years. It reflects the Foundation's values of Respect, Integrity, Inclusiveness and Strength, and organises our goals around our core tasks of building (Te Hanga) and growing (Whakatupu):

- Capacity, capability and knowledge of PWBD
- Ability of PWBD to self-advocate
- Support networks
- Quality, nationwide, equitable, comprehensive health care as well as ensuring security, safety and supply of treatment

The Strategic Plan is a living document and will be regularly reviewed by National Council to gauge how we are progressing towards our goals.

Thanks,

Deon York
President, HFNZ

Contents

Find us on Facebook
www.facebook.com/haemophiliaNZ
Masters Group (request to join)
www.facebook.com/groups/hfnzmasters

HFNZ Bank Details:
Account Name: Haemophilia Foundation of New Zealand
Number: 02 0828 0102656 000

Cover photo: *Family Camp 2015*

Family Camp 2015 was Out of This World!

What a fabulous time we all had at National Family Camp 2015! Or more accurately at HFNZ Space Camp.

With beautiful weather, fantastic families, wonderful volunteers, helpers, staff and nurses, the camp could only have been a success. The children showed their creativity with the many space-themed activities and the parents learned so much. Held 23-26 January at Camp Keswick in Rotorua family camp is usually a great place for parents to practice their venous access skills, but this year we had a record number of the young boys accessing their veins for the first time by themselves. So exciting!

The camp blasted off on Friday afternoon with a chance to all get acquainted and in the evening the children created alien-inspired masks and showed them off in a galactic parade.

As with previous Family Camps, the programme is split in several streams to help everyone get the most of the experience. The parents took part in an education programme that focused on topics related to bleeding disorders and parenting and the children had their very own programmes. This year there were three Kids Clubs – the Pocket Rockets for 0-3 year olds, the Space Heads for 4-7 year olds and the Cosmic Clusters for children over 8 years old. All were run by fantastic staff and volunteers to make sure everyone really got the most of the experience and had a lot of fun along the way.

Saturday kicked off with the (compulsory as Colleen liked to remind us) morning meeting and then the campers spilt into their respective groups for a full day of activities. The parents heard from treaters such as BJ Ramsay, Mary Brasser, Siobhan Cross and Lee Townsend as well as HFNZ Outreach Workers Lynne Campbell and Linda Dockrill on a variety of topics. The Pocket Rockets spent the day in the park, playing in their well-equipped crèche and having their faces painted by one of the volunteers, the very talented Anah Turner. The Space Heads, by far the largest group, created fabulous balloon aliens and an amazing 3D space mural, played games and conquered the obstacle course. The Cosmic Clusters created amazing space-inspired creations which they used to decorate the dining room for dinner that night and went offsite to play some ten-pin bowling. A lively space-inspired family quiz was held in the evening followed by a thought-provoking display by a local astronomy-enthusiast who showed some of the older kids and parents an amazing programme for tracking stars and close-ups of the moon through some impressive telescopes. Unfortunately after crystal-clear skies all day, cloud cover once the sun set meant they didn't get a chance to explore the rest of the sky.

Sunday was another hot and beautiful day. The morning was spent with each group doing their own thing. Parents talked about siblings (see next article), HFNZ's strategic direction and heard from an expert panel of youth leaders about growing up with haemophilia in their family. The panel session was particularly valuable with parents asking all sorts of questions from the impact on school and career plans, to parenting to dating. The children were very busy as well with the Space Heads creating rocket ships and the Cosmic Clusters talking about bullying and trying their hand at archery and the air rifles.

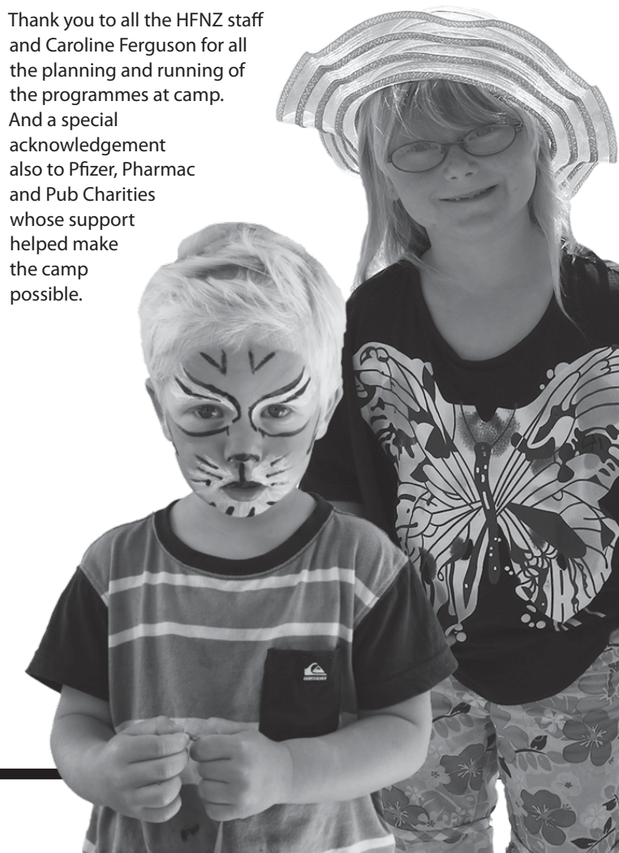
For the afternoon the whole camp drove out to the beautiful Paradise Valley where we saw the lions being fed and wandered over the shady boardwalks visiting the other animals and sampling the waters of the spring.

Many families took a chance to refresh themselves with a dip in Lake Rotorua when we returned before getting into character for that evening's Cosmic Disco. There were so many great costumes and campers really got into the spirit of the fun dancing the night away.

Although there were many tired looking faces at breakfast after all the fun of the night before Monday morning meant it was time to pack up and clean up before the big final send-off. At the Final Assembly we had the chance to thank all the great volunteers and nurses, congratulate the boys who had learned to infuse their own treatment and all share our thoughts about the camp. Last, but not least, we recognised the Family Camp graduates – those boys who are turning 10 years old and so will be heading off to Youth Camp without their parents later in the year. It was a perfect way to conclude the experience.

Thanks so much to all the fantastic group leaders who did such great jobs in the children programmes, how you got involved and set great examples for the children was noticed by all. Thank you also to Richard and Lynley Scott and Barry for taking care of the details in the kitchen and being a great resource for the families. A special thank you to our nurses Maureen Hayes, Mary Brasser and BJ Ramsay for the great job they did in the treatment room, we could not have such a big successful camp without you. Also thank you for Siobhan Cross and Lee Townsend who gave up their Saturday and travelled from Christchurch to join us.

Thank you to all the HFNZ staff and Caroline Ferguson for all the planning and running of the programmes at camp. And a special acknowledgement also to Pfizer, Pharmac and Pub Charities whose support helped make the camp possible.










National Family Camp 2015 was really out of this world, but don't take our word for it; here is what some of the participants had to say:

Family camps for us have always been a lot of fun but also so valuable. Each time we make new friends and reconnect with old ones from previous camps. The education sessions are always so informative (and not always just about Haemophilia).

But the biggest benefit we have found is mixing with other people in the Haemophilia community and sharing stories, ideas and tips - which no medical person or book can ever give you. We have always come away from camp feeling so empowered and inspired. Seeing how the younger kids look up to the youth leaders and watch them doing their self-infusions and leading "normal lives" gives them the inspiration and determination that they can be like that too.

We are sad that we will not be attending any more family camps with Sam graduating to Youth Camp. But we have had a great time and feel very fortunate that the Foundation is able to do this for us. A big thank you to Colleen and your team - you are amazing!!!!!!! - Tracy and Steve

---

Hi my name is Tarquin and I am 12 years old. I was diagnosed last year with a rare bleeding disorder. My little sister has it too.

My life has had to change to accommodate my condition. My family was invited to the Space Camp in Rotorua. I was a little nervous about going, because I hadn't meet anyone else with this condition. We drove down there, which is an 8 hour drive. We were meet by all the HNZF family with a great big smile and an amazing pack of goodies and shown to our cabin. That afternoon we all meet to introduce ourselves. That was the beginning of a lifetime of friendships. I finally found some people that could relate to me. I felt so normal again. I made some really great friends and can't wait to go to youth camp in July. My mum said "It's so nice to know that you can live in such a remote area, but know that you have all these great people who are only a text, email or a phone call away". Thank you so much HNZF for all your support and kindness for me and my sister and family. - Tarquin

---

A fantastic time to connect with other families with a good mixture of fun and educational activities. - Bo

---

Excellent opportunity to meet parents going through similar experiences. Great access to personnel that we don't have the ability to see as we are in a remote location. Very educational and rewarding. - Scott

---

Thanks for an amazing Camp. It was our first one. We were surprised (pleasantly) at how informative it was, and very well run with the kids being well looked after and occupied. We loved connecting with old and new friends, and particularly the connections our son Henry made with older boys whom he looks up to immensely. We WILL be back!!! - Neil & Trinette

---

I liked all the activities and had lots of fun at the family camp. I'm really looking forward to moving up to youth camp and I'm excited about going to camp on a plane. – Sam

---

These Camps are invaluable not only to myself but also my children. I find nothing better than being amongst a group of people who are going through the same things as I do in everyday life. Also the fact that they are made as easy as possible to come to. - Krystell

---

This was a very worthwhile Camp, run by excellent staff who constantly went beyond their job. It seems to me that this is their calling, not just their job. - Trevor

---

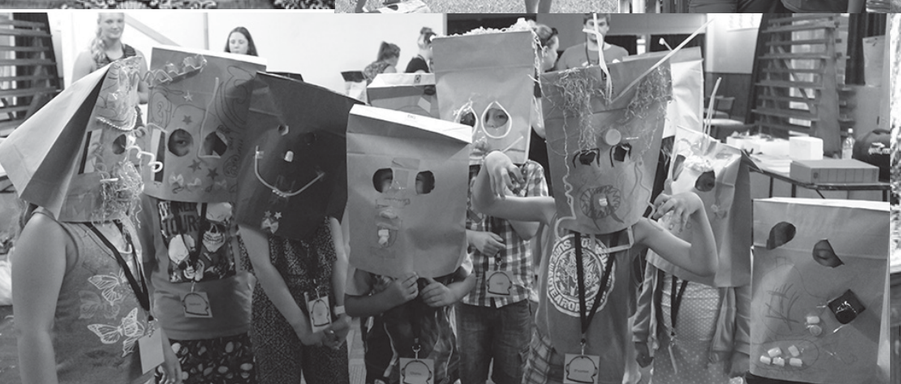
Everything was awesome – as I felt like part of a Team. It has been a wonderful experience, and it has been important to be able to participate as a volunteer now that my children have grown up. It has been a privilege to be part of a supportive and nurturing community here at Camp, and hopefully in the future. – Frances (Group Leader)

Wow I cannot believe how time has flown and Rorie is now able to go to Youth Camps!!! He started his first Family Camp at Rotorua and finished his last one there also. Rorie and his sisters Maisie and Maggie have fantastic memories of Family Camps and the girls still imagine they can attend. They now know they can't but could go in the future as youth helpers. Family camp for us has been firstly about learning, secondly about connecting with other families and reconnecting with those we have meet along the way. Rorie has learnt to play, interact and be a normal boy within a safe and familiar family of people. As a mum I don't know if I am ready for him to go to Youth Camp on his own, but he is and is so excited. Huge thanks to those that worked hard on this camp and on all the other Family Camps. A new challenge and new independence for Rorie! - Sandra

Check out the HFNZ Facebook page for lots more camp pictures!






Siblings – best of friends and rivals

by Colleen McKay, Manager Outreach Services, Haemophilia Foundation of New Zealand Inc.

If you have children, you know that maintaining peace in your household can be difficult. One minute your children are getting along and the next minute they're enemies. Knowing when and how to intervene can make a difference in how well your children relate to each other.

In families each child is an individual and their needs differ. If there is one or more members in a family with a bleeding disorder such as haemophilia or von Willebrand Disease (vWD), the entire family is affected in some way or another. This is why open communication with each and every member of the family, as well as listening to how each person feels about what is going on with the bleeding disorder, should be a high priority.

The first part of this article focuses on the common feelings and behaviours of sibling with bleeding disorders and tips for the parent to deal with them. The second part is more general and deals with strategies for understanding and dealing withsibling rivalry.

When a sibling has a bleeding disorder

In families each child is an individual and their needs differ. The child with a bleeding disorder can often require greater time and attention from their parents. Other children in the family can come to resent the time and attention that is given to the child with the bleeding disorder. If the bleeding disorder becomes the focus of your family, siblings may feel left out and even guilty that they are healthy.

Two things are certain. Firstly, the child with the bleeding disorder must have his / her needs met, and secondly, the other children are entitled to your love and attention also.

Possible feelings and behaviours of siblings of children with bleeding disorders:

- Jealous about the attention that they sibling gets
- Angry that no-one pays any attention to them
- Feel neglected and left out
- Feel guilty because of the feelings of resentment, jealousy, and anger
- Resort to bad behaviour in order to get attention, negative attention can feel better than no attention at all
- Worried about their sibling and scared that they might lose their sibling
- Feel isolated and alone, and unable to express their own feelings
- Minimise their own needs, because they do not wish to bother the parents
- Feels empathy towards their sibling, is caring and concerned
- Over-protective and looks after their sibling

Helpful Tips for parents to help siblings deal with these feelings and behaviours, and to manage the conflicting demands:

- Be open and honest with siblings about the bleeding disorder and any complications.
- Provide age-appropriate information about their sibling's bleeding disorder.
- Encourage siblings to be involved in treatment.
- Set aside time for talking about their feelings can help siblings to build coping skills and know that their feelings are acceptable.
- Recognise the needs of all of your children, including those who do not have a bleeding disorder.
- Value each child and spend individual, special time with each of your children.
- Accept that you might not be able to be completely even-handed – one child might need more of your time.
- Expectations regarding abilities, interests, and aptitude should be consistent for all of your children. Feelings and accomplishments of siblings should be respected and praised.
- Discipline must be safe and appropriate for all of your children. Avoid the temptation to treat the child with a bleeding disorder differently than you treat your other children.

Remember to take care of yourself too so that you don't become too exhausted. For example, plan with your partner to take some time out for yourself. Sole parents need to ensure they have support from parents, other family, friends and neighbours to enable this to occur.

Sibling Rivalry

Because brothers and sisters live closely together within the family and affect each other's lives, they often get angry and frustrated with each other. They sometimes compare with each other and can become jealous, bossy, resentful or competitive. They often test out their strengths and weaknesses on each other. These tensions are called sibling rivalry.

The biggest problem faced by young siblings is that they have to share the most important person / s in their lives: their parents.

International research shows that serious sibling rivalry happens less often in families where:

- Physical aggression and violence are not acceptable behaviour,
- Children are shown good anger management and problem-solving skills by adults,
- Family members have good times and fun together.

Sibling rivalry is very common, but it can still be very tiring and difficult to put up with for the parents and the rest of the family. As a parent there are a number of things that you can do to at least minimise the conflict.

The most important one is to accept that it is a perfectly healthy process during which both children are learning a lot of important skills about getting along with other people. Everything you do should be aimed at supporting and enhancing that process.

There are good things about sibling rivalry

As the children in a family discover how to get along together and grow up together they will learn very important and helpful life skills. Skills such as:

- How to understand, respect and consider another person's needs and ideas
- Ways to compromise, negotiate and problem-solve with others
- Ways to express and safely manage angry feelings
- How to forgive and patch things up after anger

These are great skills to have. It is important that children have the opportunity to learn them and have opportunities to practice them in a safe environment.

Tips for parents to deal with sibling rivalry:

- Try not to get involved – as far as possible encourage them to sort out their own differences and get along together. Mediate between them only of its really necessary.
- If you do have to step in, separate them until things have calmed down. Don't focus on who is to blame. Work with the children on ways of resolving the dispute; try to find a win/win solution.
- Acknowledge the resentment or anger, e.g., "I know that you feel very angry with Anne, but you can't hit her with a stick."
- Help them to learn not to expect everyone to always do or see things the way they do. Teach them to respect others. Everyone is different.
- Let them express angry feelings in safe ways. Teach them that it's OK to feel anger but hurting others or things when you are angry is never OK.
- Manage your own anger well. If anger management is a problem for you, seek help so that you can role model good anger management strategies.
- Teach forgiveness. Learning to patch things up and forgive is a life skill.
- Set ground rules for acceptable behaviour. Get the children involved on working out the ground rules. Keep them simple. Write them down and stick them on the fridge door or family notice board.
- Praise good behaviour. Let them know that it's great when they get along well together and enjoy each other's company.
- Don't make comparisons – each child is unique and resents being compared to another. Never show one child special treatment.
- Make time to have fun together as a family. Find things to do that everyone enjoys, even just simple things. Making memories is something special that siblings can share again together in the future. Celebrate special events.

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!

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.

The Buddy Awards have been run in Australia and in the United Kingdom. People have used the opportunity to acknowledge the support from siblings, nurses, friends and many others. Show your appreciation by sending your nomination today.

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

HOW TO NOMINATE A BUDDY

Application forms will be available on the HFNZ website (see Events listing), 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.

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

Profile: Sebastian Vivian

Sebastian Vivian is 12 years old and 6 foot 1 inch tall. He dreams of playing professional basketball in the States and seems to be well on the way to trying to achieve this.

Sebastian has mild/moderate haemophilia A and a second genetic mutation which affects the binding between his von Willebrands Factor and Factor VIII. This means he also has symptoms similar to people with von Willebrands Disease Type 2N.

"When I was little I had antibodies attacking my von Willebrands Factor and I had a few joint bleeds but I haven't had them in years. I had a kidney bleed when I was 6 but now I just get muscle bleeds in my legs and bloody noses and large haematomas if I collide with things or other players," explains Sebastian.

A Year 8 student at Birkdale Intermediate School, Sebastian lives on the North Shore with his mum Kelly and his little dog Pebbles. His favourite subjects are Maths and PE, and he enjoys travelling, hanging out with his friends and playing PS3 in his down time or when he is recovering.

Sebastian began playing basketball in March 2014 and found that it was a great way to keep fit and strong as well as make a heap of friends. He played cricket and soccer when he was younger but eventually found soccer to be too rough. Initially his mum was reluctant for him to play basketball because of his haemophilia but eventually they decided to let Sebastian try and see if he experienced a lot of bleeding. Happily he has had very few bleeds despite all the training and games he has played over the last year. Does he worry about how having haemophilia affects his ability to play?

"Honestly, I don't even think about it. Mum worries about it more than I do. I had a couple of meniscus bleeds in my knee and two calf muscle bleeds last year from Basketball though," says Sebastian.

As Sebastian learned to play he found that the fitter and stronger he has become the more his body can cope and the less bleeds he has. Wearing the right supportive footwear and learning how to correctly land and pivot to protect his joints has also been important.

Sebastian is clearly a natural baller and in his first year of playing he was part of the first North Harbour Basketball C Team to ever make it to the U13 Nationals and the only C Team player to ever be selected to play in Australia as part of the U14 Basketball NZ Koru Development Tour in the Australia Country Cup. Excitingly he was awarded the 2014 U13 Most Improved Player Award.

Playing basketball takes good hand-eye coordination, strength, fitness, high stamina, speed, quick learning ability, and the ability to dribble and shoot with both hands. Although some of these have come naturally to Sebastian, most he learned through hours and hours of training with his coach.

As well as working on his playing skills, having a mentor has really had a positive effect on Sebastians gamesmanship. "My mentor is my Hoopzcity coach Carl Buck Jr. He is an American ex-college basketballer who has trained in the NBA summer league. He has taught me all the physical skills of the game but he also teaches me how to deal with the mental side of basketball; like when things don't go right, how to deal with the frustration and anger I can feel sometimes. He teaches about attitude and presenting myself as a brand and maintaining my reputation as a player coaches will want to play for them. He's awesome," Sebastian explains.

"My coach has taught me that if I believe in myself and work hard, I can do anything! And it's true," says Sebastian, who hopes to be the first to be the first man with a bleeding disorder to play professional basketball internationally.

"I sometimes think that the scouts may not want to take a chance on me because of my bleeding disorder and their lack of knowledge about bleeding disorders, but I figure I will just prove myself to them and make them want me! Also DDAVP is a banned substance in professional sport, so I hope they will still let me use it for small bleeds."

For now Sebastian is looking forward to playing for North Harbour's U15 division, hopefully making it to Nationals again and hopefully being picked for the U16 Koru Development team (if he doesn't get offered to trial for the U16 NZ Team). He is also planning to travel to Florida to play as part of Hoopzcity's U16 Team, in the YBOA and UAA Tournaments over there.

To help fundraise for the Florida trip he has set up a Give-a-Little page. Visit http://givealittle.co.nz/project/sebastiansfloridadream2016# to help Sebastian take the next step towards achieving his dream.

Editor's Note: It's good for everyone to exercise. When you have a bleeding disorder, strong muscles are particularly important because they help to protect your joints from bleeds.

It is important, however, to find the right sport for you and the severity of your bleeding disorder. Some high-impact sports such as rugby and ice hockey are not recommended because the contact involved carries a high risk of causing a bleed.

The intensity of a game of basketball can vary a lot but at a highly competitive level basketball is considered to be a moderate to high contact activity for people with haemophilia. Protective equipment can be worn to protect eyes and joints, including high-top shoes or ankle supports.

Talk to your treatment team and family about what sports you are interested in and what would work best for you.

Psoas Bleeds in Haemophilia

By Lee Townsend, Physiotherapy Specialist Haemophilia, Christchurch Hospital and Ali Polus, Physiotherapist, The Alfred in Melbourne.

Around 25 per cent of bleeds in patients with haemophilia are into muscles. Muscle bleeds are occasionally not initially recognised as bleeds, and may be mistaken as muscle strains. In deep muscles there may not be visible signs. Around 11 per cent of muscle bleeds are into the psoas muscle. This often occurs around adolescence and in young adults in the 11-25 age group.

The psoas is a muscle that flexes the hip; it lifts the leg up relative to the body and bends the trunk forward when the legs are fixed. It is located deep in the pelvis and runs from the lower spine and back of the pelvis, sweeping forwards to the top, inside portion of the femur (thigh bone). If this muscle is tight, for example when filled with blood, it can cause the hip to flex upwards and the lower back to arch. The muscle runs together with another muscle called the iliacus. They are often grouped together and called the iliopsoas.

Located in the path of the muscles are the femoral nerve and artery, the main nerve and blood supply to the whole leg. If these are compressed by a haematoma (accumulation of blood in the muscle) this may have serious implications, such as weakening the quadriceps muscles that the nerve controls resulting in difficulty extending (straightening) the knee, which may affect walking. If this occurs and the bleed is not resolved quickly, these may become long term or even permanent issues

Diagnosis

If you suspect a psoas bleed you should call the haemophilia centre. If it is out of hours or at the weekend presentation to the emergency department is recommended. Psoas bleeds may present as back pain or hip pain and must be investigated further. A CT scan is usually needed to confirm or rule out the diagnosis.

Initial Treatment

If a psoas bleed is diagnosed, initial management includes factor replacement as soon as possible. Due to the potential size and seriousness of this type of bleed, this is often given in hospital. Remember that factor replacement helps blood clot, it does not heal the body. Resting the muscle completely until the bleeding has stopped allows the body to heal itself; this means complete bed rest, including not walking, even with crutches. Ice is advised over the groin, avoiding the genital area, during this time. Lying down with a straight leg may be too painful so the leg can be supported with pillows in a bent position if this is more comfortable. Often after the bleeding has stopped, temporary use of crutches can be utilised to decrease weight bearing on the affected side initially.

Rehabilitation

The psoas muscle will lose flexibility and strength during and after a bleed. If it is not rehabilitated correctly then there is an increased risk of re-bleeding or having long-term impaired function, which may impact daily activities and sporting ability.

A psoas muscle bleed is serious and may take weeks and even months to resolve. The risk of re-bleeding in the first 6 weeks is high, even if it appears to be recovering. Rehabilitation must be slow and supervised. If increasing pain or decreasing movement or any of the above indicators appear to be occurring, further bed rest and contacting the haemophilia centre is necessary.

SIGNS AND INDICATORS OF A PSOAS BLEED	
Pain in lower back, abdomen or groin.	This is the location of the psoas muscle; as blood accumulates in the psoas muscle it increases in volume and the associated pressure increase causes pain. If the bleed occurs on the right side the pain may mimic appendicitis.
Flexing (bending up) the leg and/or arching the back.	These positions relieve some of the pain as it limits muscle distension.
Inability to straighten the leg due to pain (common sign of a psoas bleed).	Having the hip straight or extended (straightened) stretches the psoas muscle, which is already engorged with blood, causing pain.
Tingling or numbness and loss of sensation at the front of the thigh (an important early warning sign of a bleed and also of nerve damage)	This is caused by pressure on the nerve; the haemophilia centre must be contacted immediately, or your doctor/health professional if you are already in hospital.

Rehabilitation of the muscle includes stretching back to a correct length and strengthening the muscle when the bleed in the muscle has sufficiently resolved, which will be determined by your physiotherapist or upon medical advice. If the muscle is stretched or strengthened too early there is a high propensity to re-bleed.

The leg should only be stretched to the point where the muscle begins to feel tight; over stretching and 'pushing it' may re-injure the muscle and/or cause pain. Stretches should be performed by the patient only, without help from another, and should feel comfortable. Stretches should be held in a sustained position without 'bouncing' the stretch.

Activities to avoid and modify

Walking with and without crutches

This will depend on your level of pain and will vary. It should be discussed with your physiotherapist. In general, when you can extend your leg without pain when lying on your front this is a sign that you are ready to return to walking unaided. Short distances should be undertaken initially, building up to longer over time.

Wheelchair Use

Pushing yourself along in a wheelchair using the other foot must be avoided, as again there will be a muscle contraction both in the side with the bleed and the other side. If a wheelchair must be used, propelling with the arms is preferable, but bending and straightening of the trunk (body) should be avoided as much as possible. Rest is recommended over early mobility in a wheelchair, as the psoas muscle is still used when propelling and transferring in and out.

Sexual Activity

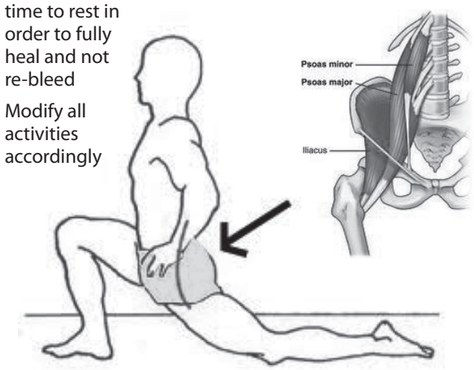
Sexual activity during and after a psoas bleed is generally discouraged. The pelvic thrust action is an isometric muscle contraction (that is, using the muscle without changing position), as a man's thighs are usually braced either against his partner or the furniture, is of concern with regard to re-injuring or re-contraction according to some studies. Abstinence from sexual activity during this period is considered the ideal for muscle inactivity however gentle masturbation or intercourse in a safe position without the forceful thrust action is advocated. Couples, or singles, should make positional choices given their specific physical limitations, and consider other methods, for example masturbation over intercourse, oral as opposed to penetrative, decreasing length of time and force, etc.

Sports

A return to sport and high level activity is only advised when the muscle is fully strengthened and able to be stretched. A return to sport should not be undertaken in the first six weeks, and is likely to be at least 3 months after a psoas bleed. Before resuming sporting activity an examination by your physiotherapist is recommended.

Take Home messages:

- Be aware of the signs and symptoms of a psoas bleed
- Contact your haemophilia centre immediately if signs appear
- Treat it early with factor replacement and rest
- Allow the muscle time to rest in order to fully heal and not re-bleed
- Modify all activities accordingly



Everyday tips for living with von Willebrands Disorder

Here are some tips shared in the Von Willebrands & U community (https://www.facebook.com/VonWillebrandandU).

Have you got tips for living with vWD? Send them to info@haemophilia.org.nz and we can put together our own list.

- If you or your child is diagnosed with von Willebrand disease, it's important to educate others in your family about the disorder. It will help them support you and your child, and may spur some family members to be tested for the disorder.
- Use care when taking pain medication. Some medicines can further aggravate your bleeding disorder. Avoid aspirin and all aspirin-containing products. If you have a question about any particular drug, check with your treatment centre or doctor.
- Swabbing our daughter's nose using a cotton bud dipped in olive oil each night and running the humidifier in her room has kept her nosebleeds from recurring so frequently.
- Teens reluctant to wear their Medic Alert bracelets? Try visiting a local jewellery store changing the chain so it is less clunky but still has all their vWD info on it.
- Ice blocks are handy to get cold ice to mouth or nose bleeds. It also works great for when children lose their teeth.
- Keep those gums and teeth healthy by using the right toothbrush. Choose one with soft, rounded bristles, and replace it with a new one at least every three months.
- A gentle dental floss really cuts down on gum bleeds.
- For summer activities, freeze a drink for each member of the family like water, juice, or tea. You then have a nice cold drink that slowly melts in the sun, an ice cube that water can be added to, and best of all you have ice available for those inevitable boo-boos that seem to happen far away from any treatment.
- When a woman with a bleeding disorder shaves her legs or underarms, a little nick may leave her oozing blood all day. Opt for electric or safety razors, or investigate whether a chemical powder for removing or destroying hair growth might work. As always, consult with your healthcare provider on this issue.
- Ouch! You may be able to stop a bruise by quickly moulding an inexpensive bag of frozen food around the body part. Then, refreeze the bag of food for future use (Just label the bag "DON'T EAT.")
- Common sense is an important key to managing vWD. Choose exercise activities carefully, and if one causes you to bleed, modify or omit it from your routine. Consult with the physical therapist at your haemophilia treatment centre on the sports and exercises that are best for you.
- Heavy or prolonged bleeding during menstruation is the most common gynaecological problem for women with vWD. If your period interferes with your daily activities, consult with your treatment centre's nurse or doctor about treatment options.
- People with vWD may experience bleeding during or after dental procedures. Always contact your bleeding disorder treatment team prior to dental treatments such as fillings, extractions, block anaesthesia and root canals. They will work with your dentist to determine what medications you should receive prior to and after the procedure.
- Planning to take a spin on your bicycle? It's good exercise! Just don't forget to wear a helmet and other protective gear. It's important to try to prevent head and other injuries if you should fall.

Leaving a lasting gift – make a bequest to HFNZ

HFNZ were grateful and touched to recently receive the generous bequest of Mr Albert Arthur Thomas of Christchurch. The $40,000 will be put to very good use supporting people with bleeding disorders in New Zealand.

A bequest is a simple act anyone can do by including a gift to a charity in their will. It's one of the easiest ways to give, however, approximately 60 per cent of people don't have a will.

You may think only the rich and famous leave money to charity when they die. The reality is that most bequests are made by ordinary, hardworking people who want to make a positive difference to their community and other people's lives after they've gone. Whoever you are, whatever your situation, you can help make a difference and help strengthen our community by including HFNZ in your Will.

Your bequest will make a difference

By supporting HFNZ through your bequest you will help to ensure our services continue to make a difference in the lives of people with bleeding disorders. You will be assured that you will be continuing to contribute to the well-being of the community well beyond your lifetime and that your financial contribution will be well managed. By leaving a bequest you are not impacting on your current financial situation - but making a real difference to the future.

How do I make a Will?

Your Will is a unique and clear record of your wishes. No matter what your financial situation, making a legal Will enables you to provide for the needs of family who depend on you, as well as the charities you choose to support. If you have not yet made a Will, the good news is that this is usually a very simple, inexpensive process.

A Will is a Legal Document, it is important to seek the right advice and wording of a Will. Your lawyer, the Public Trust Office or a Trustee Company, will be able to explain to you the various ways in which this can be done.

If you already have a Will and wish to change this, you can include a Codicil (amendment or addition) to incorporate your bequest to the Haemophilia Foundation of New Zealand Inc.

Your Will is a living document that continues beyond your lifetime. Advisors recommend that you review your Will every 5 years or so in case your circumstances and intentions change.

Your review is an ideal time to add an amendment to your Will to give a wonderful gift of support to people with bleeding disorders.

If you choose to leave a gift to HFNZ, some suggested wording for your Will might be:

"I give to the Haemophilia Foundation of New Zealand Inc. the sum of $..... .....or (% of estate, or the residue of my estate, or a description of assets or property) for the general purposes, for which the receipt of the Chief Executive or other proper officer, shall be full and sufficient discharge to my trustees."

For more information you may wish to visit includeacharity.org.nz. Include A Charity has been designed to raise awareness of the ease and effectiveness of leaving a gift in your Will.

Heartfelt Thanks

HFNZ extends its heartfelt thanks to those who decide to contribute to future generations through a gift in their Will. We ensure your money will be used to benefit and support people affected by bleeding disorders in New Zealand.

We would be very grateful if you would let us know that you had left a bequest to HFNZ. This way we can thank you in advance for your generosity. Please be assured that your bequest will be kept strictly confidential, unless you request otherwise.

Twinning Connection

The Haemophilia Foundation of New Zealand Inc (HFNZ) and the Cambodian Hemophilia Association (CHA) entered into a 4-year WFH Hemophilia Organization Twinning Project in 2011. Sadly, 2014 marked the fourth and final year of the Twinning Project.

We wanted to reflect on the fantastic strides CHA have made as an organisation over the last 4 years and share the many initiatives they are undertaking as they continue to grow.

The main aim of the CHA/HFNZ Twinning Project was to build a strong and effective Cambodian haemophilia organization. Over the course of the Twinning Project, CHA has made significant progress towards that goal. They have an active dedicated committee of four people based in Phnom Penh, a well-used Facebook page and are organising activities for their communities on an ongoing basis. In 2014, CHA established the Angkor Hospital for Children Support Team, which is available to support those with bleeding disorders from in and around the Siem Reap area.

Initially CHA was run by medical professionals and is now truly a patient-led organisation. The CHA committee is made up of Mr Sithan Kong (Chairperson), Mr Sem Sokpanha (Depute Chairperson), Mr Run Chanthearithy (Treasurer) and Mr Chaii Soksovanra (Administrator) and three volunteers (Mrs Ika Mala, Miss Tep Soriya and Mrs Tiv Linat). Dr Chean Sophal still also acts as a clinical advisor. They operate really effectively together and have been successfully organising both social events and educational workshops, as well as raising the profile of haemophilia in Cambodia.

They have learned so much and are coming up with lots of great ideas for their community. For example, one of their first fundraising efforts, printing greeting cards for sale here in New Zealand, has raised in $500 USD which HFNZ has transferred back to CHA.

Looking ahead

The next few years will be a very busy time for CHA as they have become involved in a number of programme and initiatives.

CHA have successfully applied for a grant from the NovoNordisk Hemophilia Foundation (NNHF), a non-profit organisation who support a number of programmes for people with bleeding disorders in developing countries. The grant focuses on three areas: improving diagnosis and care, and improving education and awareness. For example, in the medical area Dr Sophal plans to write treatment guidelines for Cambodia and hold workshops in the provinces to teach other

clinical staff about haemophilia. Over the next 2 years CHA will be organising several workshops aimed at helping people live with haemophilia to help meet their education goals. Some of these workshops have already taken place. Their first awareness effort has also already started with the production of a short video spot about haemophilia that is available on You Tube and will air on Cambodian Television. (See the CHA Facebook page for more information).

CHA have also signed up with Save One Life (www.saveonelife.net). Founded in 2000 by Laureen A Kelley, Save One Life is a non-profit organisation that offers sponsorships directly to individual children or adults with a bleeding disorder in developing countries. Unlike many other child sponsorship programs where sponsor funds are pooled, Save One Life beneficiaries receive money directly from their sponsors, with a small percentage given to the national or local haemophilia non-profit organisation that registers and cares for them. With the new addition of Cambodia, Save One Life now have over 1200 children enrolled in 11 counties in the programme. There are currently 11 children from Cambodia who are in need of sponsors, with others expected to enrol.

Sponsoring a child through Save One Life can all be done online. If you are interested you can visit their website (www.saveonelife.net), click become a sponsor and see the children sign-up as beneficiaries. To choose a child, click on his photograph and then click on "sponsor now" and you should soon receive an email with further instructions. A sponsorship is USD $264 (approximately NZD $335) per year. Typically sponsors pay with PayPal or a credit card.

HFNZ and CHA – friends for life

Although our formal Twinning relationship has finished, the bonds between HFNZ and CHA continue to be strong.

One small way HFNZ are keeping the ties alive is through the purchase of two wheelchairs, tubigrip and instant ice packs for the use of people with haemophilia in Cambodia from funds raised through donations and various initiatives.

Cambodia has also been recommended to be part of a WFH Cornerstone Initiative, which provides support, expertise, and training to countries with minimal levels of care, and help them improve and benefit later from WFH's full range of programs and activities. Through this initiative, the WFH hope to lay the foundation of basic care and build partnerships that lead to an integrated and sustainable structure of patient support and care delivery. Over a 2- to 4-year period, this initiative will aim to improve two or three aspects of care development, scaled to the skills and resource capacity in Cambodia, such as:

- Developing or improving diagnosis capacity. With the support of WFH medical and lay volunteer network, and in partnership with international organisations, improved diagnosis will lead to the identification and treatment of more people suffering, unbeknown to themselves, with a bleeding disorder.
- Providing basic training in the management of bleeding disorders, where treatment products are neither available nor accessible, the WFH will build capacity among healthcare professionals, patients and their families, previously identified thanks to our partners across the world, to better manage the illness; making life with bleeding disorders more tolerable.
- Strengthen patient organisations. These organisations will provide greater networks of support, knowledge and comfort to patients and their families; improved education for patients and parents, based on training programs; and assistance for people and families living with bleeding disorders, so they feel supported by a network.

HFNZ have been asked to support CHA as they embark on the Cornerstone Initiative, which is hoped to begin in late 2015. The form this support will take has not yet been confirmed, but will likely focus on further efforts to strengthen the patient organisation.

HFNZ are very proud of how far CHA have come and look forward to the chance to continue to work with CHA as they continue to grow and develop.

UPCOMING EVENTS IN 2015

HFNZ have many great national events planned for 2015! Mark your calendars and keep an eye out for invites to the following plus all the great social activities planned by your local branch. If you have any questions on any of the events or want to express your interest in attending please contact your local Outreach Worker.

World Haemophilia Day

17 April 2015

This year's World Haemophilia Day will focus on encouraging the global bleeding disorders community to Build a Family of Support.

Families come in many forms but they all share the ability to support and advocate. World Haemophilia Day provides an opportunity to talk to your extended family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder.

You can also go one step further and have light in your home or office, lit in red on 17 April to show your commitment to the bleeding disorder community.

This year connect the global bleeding disorder family on the World Federation of Hemophilia social media network and encourage your online community to join the global family. You can follow the World Federation of Hemophilia's (WFH) Facebook page and follow the latest global developments on Twitter #WorldHemoDay.

Keep an eye out for local events to celebrate to World Haemophilia Day.

Buddy Awards

April 2015

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.

This ties in well with this year's theme for World Haemophilia Day of Building a Family of Support and there will be four regional Buddy Awards presentation ceremonies either on or near World Haemophilia Day on 17 April 2014. For example, Northern will be celebrating with a trip to Rangitoto.

Show you appreciation by nominated a person that supports you in your life. Nominations close 20 March. See events listing on HFNZ website for more information.

Parents Empowering Parents (PEP) Programme

22-24 May 2015 – Auckland

PEP is an innovative, peer-to-peer skills programme that introduces parents to tools to better handle the realities of raising a child with a bleeding disorder. PEP programmes are led by an outreach worker, parents and a haemophilia nurse who use classroom discussions, role playing and hands-on experiences to educate parents about the types of skills needed for effective parenting. We have had rave reviews from parents who have participated in previous programmes.

National Adult Weekend

12-14 June 2015 – Wellington

This workshop weekend is aimed at adults with bleeding disorders. Partners are also invited in recognition of the huge support role they play. The atmosphere is relaxed, inviting and provides plenty of opportunities to get to know each other while sharing information to support living well with haemophilia or vWD. Come spend some time with others who know what it is like living with a bleeding disorder.

Youth Camp

10-12 July 2015 – Auckland

2015 Youth Camp will be taking place at Motu Moana Scout Camp & Outdoor Activity Centre, Blockhouse Bay, Auckland and will feature a Search and Rescue theme. The camp is for young men with a bleeding disorder aged 10 to 18, with a great mix of time together and time in smaller age groups - and lots of fun of course. Team leaders are older youth with bleeding disorders who all provide important mentorship. Boys who attend HFNZ Youth Camp often return home with an increased sense of self-confidence, a new-found sense of community, and for many, the ability to self-infuse. They also have the chance to make new friends and participate in a number of fun activities that entertain, amuse and challenge.

HFNZ National Annual General Meeting

Saturday 12 September 2015 – Midland Region

This year's Annual General Meeting is taking place in the Midland Region, venue to be confirmed. Further details and a copy of the agenda will be available online before the meeting. See the listing on the Events webpage later in the year.

17th Australian and New Zealand Conference on haemophilia and related bleeding disorders

1-3 October 2015 – Gold Coast, Australia

Mark your calendars and consider planning your next holiday to coincide with the conference which will feature speakers on a range of related topics from around Australia, New Zealand and further abroad. Come hear the latest on bleeding disorders and meet lots of other community members

Snapshots of Northern's and Midland's trips to Rainbows End

Central's Harbour Cruise

MRG REPORTS

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

Northern *By Lynley Scott*

Well, yet again the Northern Christmas Party in late November was a big success with over 150 people turning up to a great day at Rainbows End, great to see some new faces, a number of old ones and some we haven't seen for a while. Subway and BBQ lunch was a great way to bring everyone together and then a visit from the jolly old man himself, Santa, with presents for the children. A huge thanks to all the committee who helped put together such a great day.

A number of Northern members had a fantastic time at Space Camp (aka National Family camp) in January. Northern was well represented with a number of outstanding teen/youth members who attended to assist in the children's programme – Ashley Taylor-Fowlie, Frances Taylor, Amy Waters, Jono Bollman, Francis Glynn, Olivia Glynn, Andrew Scott, Ethan Matthews, Brendan Lee, Ashley Morse, Ella Brown, Anahera Turner and Pare Turner-Graham. They did us proud and really were great role models!

By the time this goes to print we will have had our Northern Camp, another great event to mix and mingle and catch up with friends. The kids are all geared up to have surfing lessons again, and of course no doubt the SingStar competition will hit the stage on Saturday night. Who will get the coveted trophy this year?

The committee has some great events in the pipeline so keep an eye on your email inbox for invitations (or letterbox for those of you who aren't' connected with HFNZ via email).

Midland *By Wendy Christensen*

We tried something a little different this year for our Christmas party heading to Rainbows End for a fun-filled day of rides and lots of laughter. We provided a bus leaving Rotorua at 7 am and made another stop in Hamilton at 8:30 am before arriving at Rainbows End just after 10am. We had a full bus with another 25 people making their own way to Auckland.

There was a lot of talk going on heading to Auckland but very quiet on the return trip home with lots of very tired people. We had a room for the families to come and go from all day which was a great time to catch up with one another and reflect on who had done what ride and which one they were going to do next.

Joy took the lead and headed off to the roller coaster for the first ride of the day, while others headed to the gold rush. It was nice to see so many families with great smiles on their faces and the children all finding different rides to suit their age.

It was a little risk taking the region so far for an outing and so close to Christmas, but it was one that paid off for our region with the biggest turn out in sometime. Now it's time to put our thinking caps on to see what we can come up with next for our families to enjoy. If anyone has any ideas or places they would like us to visit in their area please let us know.

Piritoto *By Rosalie Reiri*

2015 The International Year of Light

Tēnā koutou katoa and belated seasons greetings to you all! How amazing is it that this year has already steamed ahead as we are into the second month of 2015. In a new year people generally make new goals, assess themselves against last year's goals to see how well (or not) they did. In this regard I make reference to Piritoto, we can be proud of our efforts of 2014, celebrate our achievements and learn from our experiences, as there is always room for improvement.

On Waitangi weekend we celebrated as a nation the coming together of people in remembrance of a rich Māori and European culture and heritage we share in New Zealand. It was delightful to observe on Waitangi day the different cultures participating in performances and events and just enjoying each other's company. In my opinion it truly fulfilled the whakatauāki (proverb) "He aha te mea nui o te ao? Māku e kī atu, he tangata, he tangata, he tangata". As an explanation the question is posed "What is the most important thing in this world? I would reply, it is people, it is people, it is people".

If I were to take this concept and apply it to Piritoto and haemophilia it is to embrace the culture and identity of those who have haemophilia and promote uniqueness of the blood that binds this group together. One of Piritoto's goals for this year is to strengthen our ties with one another, in Māori terms we use the word 'whakawhanautanga' which is building relationships. To achieve this Piritoto have welcomed Marcy Morris of Rotorua to the group and to support Marcy and her whānau we thought it would be a great idea to have a marae stay in her neck of the woods. We hope to build greater awareness of haemophilia in this community, support Marcy in her new role and the bigger idea is to have new whānau (families) on board.

In conclusion I wanted to enlighten you with a new thought for the new road ahead. Did you know this year is the international year of light? Even though it is likened to technologies, we can take from the theme 'light' many different concepts. Let me share a few examples: Lighten up, lighten your load, lighten the load of someone else, I can see the light, light the fire within and for those of you who may be religious, Do you have the light of Christ in your life?' It is my prayer and hope that you have a great year, be kind to yourself and be mindful of those around you.

Nāku iti noa

Central

Central celebrated Christmas with a dinner cruise in Wellington Harbour on the evening of Saturday 29th November 2014. It was a lovely evening, as shown in the lovely pictures above supplied by Stephanie Coulman.

NEWS IN BRIEF

First recombinant treatment for vWD filed with FDA

Baxter International Inc. recently filed a biologics license application with the U.S. Food and Drug Administration (FDA) for the approval of BAX 111 – an investigational drug for the treatment of patients with von Willebrand disease (vWD). If approved, BAX 111 will be the first recombinant treatment in clinical development for vWD.

The filing was based on the completion of a Phase III, multi-center clinical trial assessing the safety, efficacy and pharmacokinetics of BAX111. The study was initiated at trial sites in the U.S., Europe, Australia, Japan, Russia and India in October 2011.

In April 2014, Baxter reported that the study met its primary efficacy endpoint defined by the number of patients who received successful treatment for control of bleeding episodes. Baxter expects to publish additional data from the trial in the coming months.

BAX 111 was granted an orphan-drug designation by the FDA and the European Commission in Nov 2010. With a U.S. filing for this treatment, Baxter intends to further advance its pursuit of new treatment options and improved quality of care for people with a range of bleeding disorders around the world.

Source: www.Zacks.com, 23 December 2014

Third publication suggests recombinant FVIII product associated with higher risk of inhibitor development

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 will closely monitor this situation and will communicate again when further relevant information is available.

Source: www.wfh.org, November 2014

Professor Gane honoured for breakthrough in hepatitis C treatment

In November, Professor Edward Gane was one of more than a dozen researchers and scholars awarded medals by the Royal Society of New Zealand at a ceremony in Wellington.

Professor Gane, from Auckland City Hospital and the Auckland District Health Board, received the Liley Medal for his work on an improved treatment for hepatitis C, which is a major cause of liver failure in New Zealand. The Liley Medal recognises an individual whose recent research has made an outstanding contribution to the health and medical sciences.

Professor Gane was the lead author on two very highly cited papers in the prestigious medical journal, New England Journal of Medicine, which showed that people could be cured of the hepatitis C virus in just 12 weeks using an antiviral treatment called sofosbuvir.

"Less than 1 per cent of New Zealanders infected with hepatitis C are treated each year because the current treatment, which uses interferon, is not very effective and is poorly tolerated," says Professor Gane.

Interferon occurs naturally in the human body. When extra quantities of it are injected into the body, the immune system is stimulated to fight off hepatitis C. Unfortunately, because interferon is given by weekly injections at a much higher dose than what the body produces naturally, it can cause many adverse side effects.

The antiviral treatment successfully developed and tested by Professor Gane has become the first interferon-free treatment for people with hepatitis C infection.

"Hepatitis C virus has become the global and silent epidemic of this century, affecting more than 180 million people. Here in New Zealand, almost 50 per cent of adult liver transplants are for hepatitis C virus-related liver failure," says Professor Gane.

The HRC's Acting Chief Executive, Dr Tania Pocock, says Professor Gane's studies have been instrumental in helping to develop safer, more effective and better tolerated therapies for hepatitis C virus that are of short duration. "The impact of this research is substantial due to the high prevalence of the disease worldwide and the relatively simple treatment developed and tested by Professor Gane."

Source: hrc.govt.nz, 27 November 2014

AbbVie's new hepatitis C treatment gets approval

AbbVie Inc.'s new, all-pill hepatitis C combo treatment has been approved for patients in the 28 European Union member countries. It's already approved in EU nonmembers Switzerland, Norway, Iceland and Liechtenstein, plus Canada and the U.S.

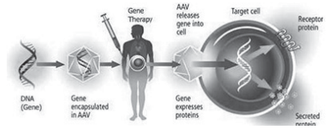
Marketing authorisation has been granted for the combination of Viekirax and Exviera. Viekirax itself is a combination pill containing antiviral drugs ombitasvir, paritaprevir and ritonavir; Exviera is a single pill containing dasabuvir. In some countries, Viekirax and Exviera are sold separately, while in others, including the U.S. they are packaged together under the name Viekira Pak.

These part of a new generation of hepatitis C treatments that are extremely expensive but don't require any injections, have fewer side effects and cure nearly all patients in as little as eight weeks. In patient studies, AbbVie's Viekirax and Exviera cured 95 percent to 100 percent of patients with the genotype 1 subset of hepatitis C, the most common in Europe and the U.S.

The EU and U.S. approval is for patients with genotype 1 and, for patients who have genotype 4, combining those pills with the drug ribavirin.

The newer generation of medicines, particularly sofosbuvir (Solvaldi) by Gilead Sciences, have become targets for critics because of the high prices drugmakers are demanding. In the U.S. Sovaldi's list price is $84,000 for a course of treatment, Harvoni's (sofosbuvir and ledipasvir combination) is about $94,000 and Viekira Pak's is $83,300.

Source: www.nzherald.com, 20 January 2015.



Gene therapy for haemophilia B: update on efficacy and safety

In a paper published in the New England Journal of Medicine in November 2014, researchers reported that their single-dose of gene therapy has resulted in long-term factor IX expression with clinical improvement.

In patients with severe haemophilia B, gene therapy that is mediated by a novel self-complementary adeno-associated virus serotype 8 (AAV8) vector has previously been shown to raise factor IX levels for periods of up to 16 months.

To determine the lasting effects of the gene therapy researchers evaluated the stability of transgene expression and long-term safety in 10 patients with severe haemophilia B: six patients who had been enrolled in an initial phase 1 dose-escalation trial, with two patients each receiving a low, intermediate, or high dose, and four additional patients who received the high dose (2×1012 vector genomes per kilogram of body weight). The patients subsequently underwent extensive clinical and laboratory monitoring.

A single intravenous infusion of vector in all 10 patients with severe haemophilia B resulted in a dose-dependent increase in circulating factor IX to a level that was 1 to 6% of the normal value over a median period of 3.2 years, with observation ongoing. In the high-dose group, a consistent increase in the factor IX level to a mean (±SD) of 5.1±1.7% was observed in all six patients, which resulted in a reduction of more than 90% in both bleeding episodes and the use of prophylactic factor IX concentrate.

With a follow-up period of up to 3 years, no late toxic effects from the therapy were reported.

Source: Nathwani et al. N Engl J Med 2014; 371:1994-2004.

Lettuce Pills May Help Treat Haemophilia

Investigators are looking at new ways to help stop inhibitors forming to Factor IX with the use of freeze-dried lettuce. Although more commonly seen in haemophilia A, inhibitors develop in approximately 5% of people with haemophilia B.

The oral treatment is a concentrate of freeze-dried lettuce-leaf cells, each containing around 10,000 chloroplasts—the organelles responsible for photosynthesis—that have been genetically engineered to produce factor IX. These proteins cannot themselves be used to prevent bleeding episodes, because the cellular machinery found in plants cannot package the human clotting factors into the biologically active form. What they can do, however, is prevent the immune system from mounting an attack against subsequent therapy.

The researchers have shown that inhibitor formation and severe allergic reactions can be prevented in mice by feeding the animals with a product based on these plants. The theory is now being tested in factor IX deficient dogs. If the strategy works in the dogs—and ultimately in humans—it could form the basis of the first product to protect against the immune responses associated with haemophilia treatment.

Other strategies being pursued to prevent the formation of inhibitors of clotting-factor therapy include immunosuppressants and drugs that deplete specific immune cells. However, these therapies have many side effects, including increased susceptibility to infection. There are also many other approaches under investigation which focus on using nanotechnology to engineer products that will help.

Source: E Dolgin, Nature, 26 November 2014.

New NHF Brochure on Prolonged Half-Life Factor Products

The National Hemophilia Foundation (NHF) have created a new brochure to give consumers a better understanding of prolonged half-life factor products recently approved by the US Food and Drug Administration (FDA) for individuals with haemophilia A and B. By prolonging the time that clotting factor circulates in the blood, these products offer longer protection from bleeding episodes and require less frequent infusions. These new treatments will no doubt prompt questions from patients. NHF hopes that this brochure will both provide baseline knowledge of these novel clotting factors and foster further discussion between patients, families and their healthcare providers.

"Role of New Prolonged Half-Life Clotting Factors in Hemophilia," includes a basic explanation of the differences between these newer products and traditional factor therapies, and the treatment choice implications for consumers. It also provides a description and helpful graphic representation of factor half-life. The brochure is now available through HANDI, NHF's information service, via email: handi@hemophilia.org (link sends e-mail) or contact your HFNZ Outreach Worker for a copy.

Upcoming Events

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

20 March 2015
Deadline for Buddy Award Nominations

17 April 2015
World Haemophilia Day

22-24 May 2015
Parents Empowering Parents (PEP) Programme Auckland

12-14 June 2015
National Adults Weekend Wellington

10-12 July 2015
Youth Camp, Auckland

12 September 2015
HFNZ National Annual General Meeting Midland Region

1-3 October 2015
17th Australia and New Zealand Conference on haemophilia and related bleeding disorders Gold Coast, Australia

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

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***

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