



President's  
Report for  
2012

page 1



Elizabeth Berry  
Exercise Cup  
Competition  
2013

page 12



Mindfulness

page 15





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# The Word

The WFH World Congress is the largest international meeting for the global bleeding disorders community and in 2014 it is going to be held just a short flight away from New Zealand. As I write, I am at the Melbourne Convention and Event Centre on a sparkling Melbourne Day. As part of the Congress Organizing Committee, we have just received a tour of the convention centre. The facilities are world-class and very accessible. It is exciting to be here to see where this significant event will be hosted.

Registrations are now open for Congress and we all have a unique opportunity to attend in greater numbers than ever before. The knowledge gained and insights gathered from attending these congresses are invaluable.

Jump on board and take advantage of this rare opportunity to attend a WFH World Congress so close to home! New Zealanders who register early for the Congress are eligible to enter the draw to win their registration, return economy airfare, accommodation, airport transfers and Gala Dinner ticket.

For more information, visit [www.wfh2014congress.org](http://www.wfh2014congress.org)

See you there!  
**Deon York**  
HFNZ President

## Contents

Special Feature from the 2012 Annual Report .....	1
56th National AGM Weekend .....	3
Governance and Management of the HFNZ .....	4
Inaugural McKay Trophy .....	5
McKay Trophy Winners 2012.....	5
Learning the Ropes at Youth Camp 2013.....	6
Elbows – A Problematic Little Joint.....	10
New Generation HCV Drugs: What's On The Horizon?.....	11
Elizabeth Berry Exercise Cup Competition 2013 .....	12
Outreach Report on the Sport and Exercise Conference .....	14
In Memoriam.....	14
Mindfulness.....	15
1st International Parents Empowering Parents International Conference .....	16
Caroline Davis Raises Awareness on Rare Disease Day .....	17
MRG Reports.....	18
Youth Abel Tasman Tramp .....	20
News in Brief .....	22
Council Corner.....	23
MRG E-newsletter - Update Your Email Address.....	23
Melbourne Congress 2014 Applications .....	24
HFNZ News .....	24
Dates to Note .....	26



**Cover photo:**  
Raft building teamwork session at Youth Camp, April 2013.



## Special Feature from the 2012 Annual Report

### President's Report for 2012



*This report covers the period January to December 2012.*

*2012 was both a productive and enjoyable year for the Haemophilia Foundation of New Zealand (HFNZ). I personally enjoyed attending the national events as well as regional meetings, where I gained a sense that our membership is in positive spirits overall. There is also a clear sense of the work ahead to ensure that all people in New Zealand have equal access to a high standard of care and education for their bleeding disorder, irrespective of their geography.*

#### Membership

As at 31st December 2012, HFNZ represents approximately 1051 individuals with a bleeding disorder. The membership comprises 420 (40%) people with haemophilia A or B, 414 (39%) carriers, 187 with von Willebrand's Disease (18%) and 30 (3%) with a rare bleeding disorder.

#### Funding

To deliver services to our members and promote excellence in care, education, advocacy and support for all New Zealanders affected by a bleeding disorder, we are indebted to the members of the public who generously contribute the bulk of our funding. Our core fundraising drive is implemented by KiwiFirst Limited whom we are fortunate to have on board as our chief fundraiser.

We acknowledge the support from the following pharmaceutical companies: Baxter Healthcare Ltd, Bayer Healthcare, CSL Behring Ltd, Novo Nordisk Pharmaceuticals Ltd and Pfizer Ltd. We also acknowledge the funding received from the Ministry of Health that supports our members with Hepatitis C and the District Health Boards who part-fund our Outreach service.

We also appreciate the many charitable organisations and trusts that have provided part-funding towards a range of our programmes.

#### Men's Workshop Weekend.



## Representation

The National Council is elected by and represents the HFNZ membership. In 2012, the following people served on the National Council:

Vice-President:	Catriona Gordon (Midland)
Vice-President:	Richard Scott (Northern)
Treasurer:	Grant Hook (Central)
Youth Delegate:	Karl Archibald (Southern)
Māori Delegate:	Patience Stirling (Northern)
Northern Delegate:	Greg Jamieson
Midland Delegate:	Deborah Weir-Honor
Central Delegate:	Stephanie Coulman
Southern Delegate:	Rochelle Stott

Belinda Burnett (CEO, HFNZ) and Steve Waring (Managing Director, Kiwifirst) served as co-opted members.

## Affiliated Organisations

Catriona Gordon continued to represent the HFNZ on the National Haemophilia Management Group. This group is responsible for the management of haemophilia services and brings together clinicians, funders, key stakeholders and the HFNZ as the consumer organisation. We thank Catriona for her representation and the management group for their stewardship of services for people with bleeding disorders in New Zealand.

My role on the World Federation of Hemophilia Executive Committee continues until May 2014. I will chair the Funding and Resource Development Committee as well as be a committee member of the National Member Organization Capacity Building, Congress Organising, Educational Materials, Public Relations and Research committees. I look forward to working with these groups in 2013.

## National Programmes

In addition to our important Outreach service, the HFNZ provides a number of beneficial programmes to promote the health and wellbeing of our members. The Swimming and Exercise programme supports swimming lessons, therapeutic swimming and access to fitness equipment for people with moderate and severe bleeding disorders.

Every year, the HFNZ runs a range of national programmes to target the needs of our members and deliver our core mission: to support people with bleeding disorders.

### • World Haemophilia Day – Children's Education Workshops

17 April, Auckland

In 2012, the World Haemophilia Day was the ideal opportunity to hold the ever popular Children's Education Workshop. This event is targeted towards children aged 6 to 10 years old with a severe bleeding disorder. It was a great day for children to learn the basics of managing a bleeding disorder.

### • National Men's Workshop

22-24 June, Auckland

The Men's Workshop brought together men aged 25 plus with bleeding disorders for a weekend retreat of education and recreation. The aim is to relax, spend time together and to develop a sense of community while taking part in a number of activities and educational sessions. There is the chance to discuss strategies on living with haemophilia and learn from one another. In 2012, the weekend also featured a special 'Masters' focus meeting for men aged over 45 years to discuss the unique needs they may have as they age with a bleeding disorder, how the HFNZ can help them and what level of representation would best suit them.

The result of the Masters focus meeting was a subsequent gathering in November to further the goals of the group. This group will continue to work together to discuss and share solutions for our aging haemophilia population.

### • National New Families Camp

6-9 October – Forest Lakes, Otaki

Held biennially the New Families Camp brings together young families affected by bleeding disorders from all over New Zealand. Parents gain strength through knowledge and understanding, and look to each other for friendship and support. For many children, the camp is the first time that they have been around other children and adults with haemophilia or von Willebrands. This camaraderie provides campers with a sense of togetherness that they are not the only ones with haemophilia and an opportunity to share with others. Children learn about their disorder with fun being core to this learning.

Every year is full of activity for the HFNZ and 2012 has been no exception. I would like to extend my heartfelt thanks to the National Council for their dedication to their voluntary roles in 2012 and, on behalf of the National Council; I wish to thank the staff for their dedication. We all work together for the common cause of sustaining and improving the lives of people with bleeding disorder's and their families in New Zealand.



**Deon York**  
HFNZ President

# 56th National AGM Weekend

*The 56th National AGM was held on the 9th March in Wellington with a good attendance and mix of HFNZ members, life members, committee representatives, pharmaceuticals representatives and staff. Deon York, HFNZ President, opened the meeting followed by the new National Youth Delegate, Hemi Waretini, giving a Karakia (prayer) to draw participants together and ensure a favourable outcome to the event. Deon lit the Memorial Candle and recited a poem in remembrance of members and friends who passed away in 2012.*

The 55th Annual General Meeting minutes were adopted and were followed by the adoption of the President's, CEO's, Financial, Allan Coster Educational Endowment Trust (ACEET), and Member Representative Group reports.

The election of National committee officers also took place.

The HFNZ National Council for 2013 is:

President	Deon York
Vice President	Catriona Gordon
Vice President	Richard Scott
Treasurer	Grant Hook
Maori Delegate	Patience Stirling
Youth Delegate	Hemi Waretini
Northern Delegate	Greg Jamieson
Midland Delegate	Deborah Weir-Honor
Central Delegate	Stephanie Coulman
Southern Delegate	Rochelle Stott

A special resolution was passed to update to the HFNZ Constitution. Some of the changes to the constitution included: all regional branches, Roopu and Youth were to be referred to



HFNZ National Council 2013: Hemi Waretini, Stephanie Coulman, Belinda Burnett (CEO), Rochelle Stott, Grant Hook, Deon York, Deborah Weir-Honor, Catriona Gordon and Richard Scott.



HFNZ staff, National Council and MRG committee members.

as Member Representative Group's (MRG's); the instrument containing or appointing proxy shall be lodged with the Returning Officer at National office instead of with the MRG Secretary and Annual Financial Statements of the HFNZ would be for the period ending 30th June instead of 31st December.

A motion was passed accepting the membership fees being set at \$25 for a single membership and \$35 for a family membership. The fees would cover an 18 month period due to the change in the financial year period.

After the AGM concluded, guest speaker Sandra Kirby, CEO from Arthritis New Zealand, delivered an insightful presentation on how they developed their organisation into a sustainable charity as one of the 25,000 charities fighting for recognition and funding in New Zealand whilst maintaining their proud tradition of passionate and caring people. Arthritis New Zealand considers HFNZ a sister charity working with our members who suffer from the debilitating effects of arthritis caused by bleeding disorders.

Before the meeting adjourned the inaugural McKay Trophy was presented to Northern for their Rainbows End Christmas event.

Day two of the weekend was a MRG committee training day. The training day reviewed the organisational structure of the HFNZ and included brief introductions by all the attendees. The MRGs then broke away into groups for team building exercises and were later divided into their roles as President, Secretary, or Treasurer to receive training and guidelines on how to be successful in their role during their time on the committee. The weekend drew to a close with everyone departing home in the early afternoon.

The HFNZ 2012 Annual Report which includes the Patron's, President's, CEO's and Member Representative Group's reports are available from National Office or online at [www.haemophilia.org.nz](http://www.haemophilia.org.nz).



Deon York (HFNZ President) and life members Lyn Steele, Carl McKay, Anne Waring, Graham Waring and Steve Waring.



Karl Archibald presenting at the AGM.

# Governance and Management of the HFNZ

The HFNZ National Council is elected by its members to govern the organisation. So what is its role and how is it incorporated into the Foundation?

## The Difference Between Governance and Management

The HFNZ is overseen by the National Council who is the governing body of the organisation. The purpose of the governing body is to set a strategic plan and provide direction, leadership and control from a holistic point of view to ensure the Foundation achieves its purpose and vision and has a long term, sustainable future.

By having a holistic view of the HFNZ, the council views the overall picture of the organisation but does not get involved with the detail of the day-to-day operations. For this reason the council employs and oversees the Chief Executive Officer, Belinda Burnett. The CEO's role within the HFNZ is to deliver the HFNZ's strategic plan through management of the day-to-day functions including delivery of the programmes and activities, in accordance with policy and resources. Belinda is responsible for the employment of all staff (paid and voluntary) and all the work they do.

Effective governance reduces the risk of organisational failure, financial and legal problems and ensures the organisation does not lose sight of its purpose or the Foundation's responsibility to the people for whom the service benefits.

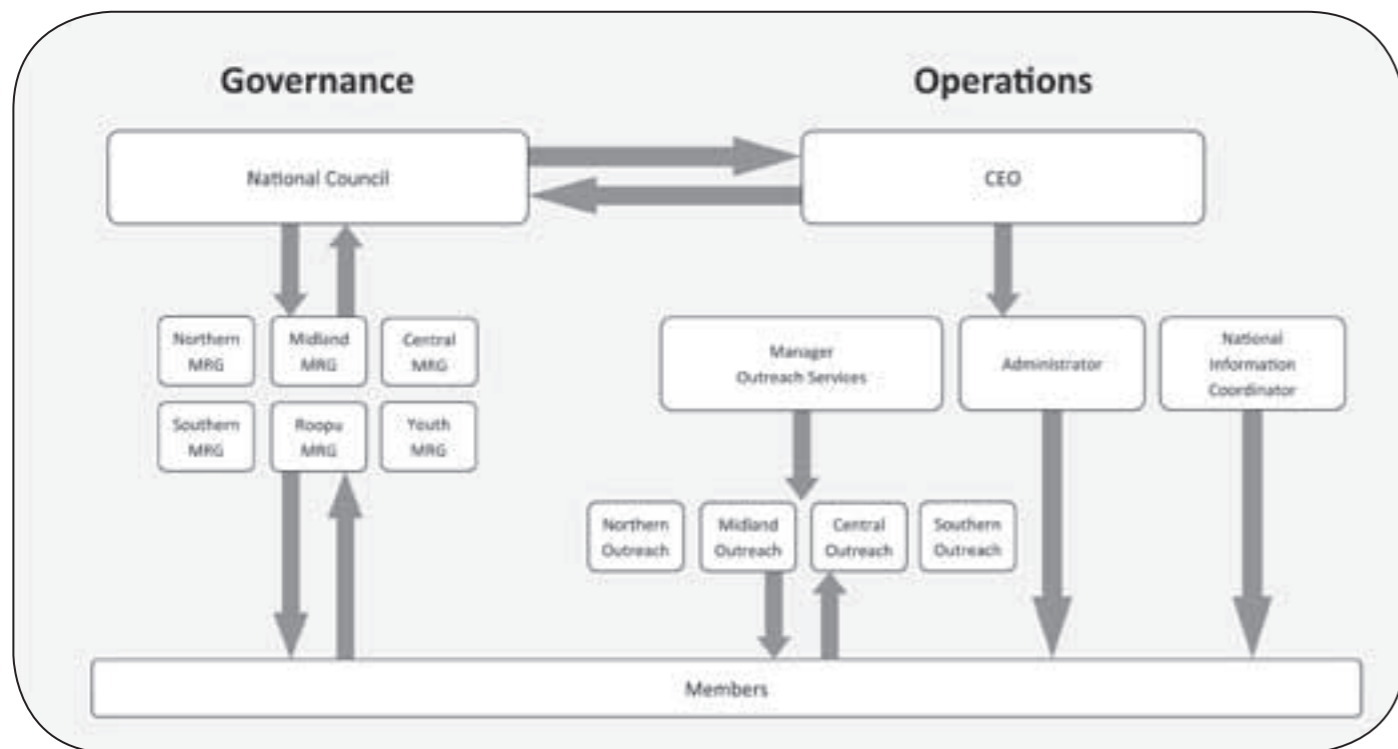
When governance and management are working well:-

### The National Council will:

- Set the values, mission and priorities of HFNZ
- Support the President
- Review and assess its own performance
- Set the strategic plan and plan strategically
- Ensure there are adequate resources
- Maintain accountability for all their decisions
- Monitor the services of HFNZ
- Increase the profile/image of HFNZ

### The Chief Executive Officer will:

- Work with clear accountability and delegation of authority
- Deliver the strategic plan
- Allocate resources
- Make decisions within guidelines
- Communication clearly to the council
- Implements policies



# Inaugural McKay Trophy

The inaugural McKay Trophy was presented to Northern MRG for their Rainbows End Christmas gathering at the AGM in March. Colleen and Carl McKay sponsored the trophy to commemorate their journey with haemophilia. Carl and Colleen both started at the Southern branch 30 years ago on 22nd February 1983, and today Carl is a HFNZ Life Member of the Foundation and Colleen is the Manager – Outreach Services.

During their time with Southern branch they gained a lot of support from their peers who were in a similar situation to them with a child with haemophilia, as well as having lots of fun. They also saw the HFNZ employ outreach workers, develop staff delivered camps and workshops to meet education needs, and see the member representative group's (MRG's) expand from the regional branches to now include roopu and youth committees.

The McKay's goal from sponsoring the trophy was to encourage the MRG's to stay strong and for the trophy to represent the support and connectedness in the bleeding disorder community. In the event that the HFNZ could no longer provide educational camps and workshops or outreach services – what would remain would be the MRG's.

Each year the National Council will decide what the criteria for the trophy is for. In 2012 the trophy was for the Best Event Run by an MRG. The MRG's were invited to submit an entry for an event they held in 2012 in which they had to describe how they planned and implemented the event, what they did for the event itself and the outcomes the event provided.

Three entries were submitted:

- A Northern and Midland joint event at Waitomo Caves that demonstrated the successful collaboration of two MRG's.
- A Central Christmas event where three events were held simultaneously including a dinner for Wellington and Palmerston North members, a family get-together at New Plymouth and a youth event to watch a Wellington Phoenix soccer match.

- Plus the winning entry from Northern for their Christmas family event at Rainbows End.

Northern were selected as the winners for demonstrating forward planning of their event, which they had decided upon in advance in their annual event calendar. They also had a division of labour to share the tasks involved with the preparation and organisation of the event meaning there was shared responsibility and one person was not left with the burden of planning the event by themselves. Plus during the year Northern promoted their Christmas event at other events they held and their outreach worker helped to spread the word.

The event also appealed to many people including families. Rainbows End catered well for the event as it had fun park rides for the youth and adrenalin junkies, as well as a central gathering place called The Barn (a room with picnic tables) where the group could sit, chat and have their BBQ and Subway lunch. They also had face painting for the littlies, a lolly scramble and Santa. Northern's event met the social needs of its members, plus they gained two new committee members as a result.

Ultimately, all the McKay Trophy entries provided well for the social needs of their groups and making the final decision was a close and difficult call. Both Colleen and Carl look forward to receiving the 2013 entries knowing that the MRG's are developing great skills to fulfil the needs in their community that will be passed onto future generations.



# McKay Trophy Winners 2012

By Richard Scott, Chairman Northern MRG

It was an honour for the Northern MRG to be awarded the inaugural McKay Trophy for best event in 2012. The regional Christmas party has a long tradition within HFNZ and our Rainbows End Christmas party was a highlight of 2012. There were many people involved in the organisation and different aspects of the day and many people turned up in support.

The Northern MRG over the last few years has had a large and committed committee which enables us to share the load amongst people making it less of a burden. It wasn't that long

ago that we would have only 3 - 4 people turn up to meetings. We have planned events that only committee members turned up to and have had the usual ups and downs that running any group may face. I would like to encourage other committees to just keep going organising events and asking people to get involved. It seems that over time momentum has built and as people get to know each other more and more people come to events to catch-up with their haemophilia whanau. The events organised by the Youth and Roopu over the summer will provide strong competition for the 2013 trophy.

# Learning the Ropes at Youth Camp 2013

By Commander Colleen McKay, HMS ClotKnot

## Commander's Log: 20-23 April 2013

On Saturday 20th April, 42 young cadets with bleeding disorders, together with 14 staff (Commander, Medics, Leading Hands and Marines) boarded the HMS ClotKnot for four days of education, recreation, challenging activities and fun. People flew into Auckland Airport from all over New Zealand – from Kerikeri in the north to Dunedin in the south and gathered together at the Sir Peter Blake Marine Education and Recreation Centre (MERC), located on the beach at Long Bay on the North Shore.

Youth Camp opened with a Mihi Whakatau, a Maori welcome, performed by Tama Pene from the Roopu.

As always each day of Youth Camp provided a mix of education, team building activities and fun specifically targeted for boys aged 10-18 years with bleeding disorders. The cadets were split into four teams – Te Kaha, Manawanui, Endeavour and Hawea – to allow them to get to know each better and promote healthy competition.

## Education

After being split into groups according to their personal bleeding disorders to learn more about them, the cadets were asked to teach the rest of the campers about severe, moderate and mild haemophilia, genetics, von Willebrand Disorder, signs and symptoms of a bleed, P.R.I.C.E., the importance of medical protocols and Medic Alerts. The cadets employed some creative

Every Youth Camp includes special self-infusion workshops. Each morning the Treatment Room was a hive of activity as the Haemophilia Medics took care of treatments, taught self-infusion or helped cadets brush up on infusion technique. At the end of camp Special Awards were given out for the cadets who successfully self-infused for the first time – 'First Stick Award' and a 'Self Infusion Proficiency Award' for those who have learned self-infusion since their last camp and could demonstrate proficiency to the Haemophilia Medics.

Youth Camp 2013 Honours Board	
First Stick Award	Self-Infusion Proficiency Award
Riley Barnes	Zac Porter
Gabriel Bishop	Daniel Alexander
Luke Eliffe	Benedict Larkin
Nicholas Coulman	Ihimaera Ogle

The cadets also learned more about World Haemophilia Day and haemophilia around the world. Colleen McKay discussed who HFNZ and the World Federation of Hemophilia are and what their roles are. Together she and some of the youth leaders illustrated how fortunate people with bleeding disorders are in New Zealand, in terms of care and support compared to people in many other countries – only one in four people with a bleeding disorder around the world has access to treatment. They also



teaching methods – a television quiz show, a game of hangman, the von Willie's Rap, and a very realistic 'Mr' and 'Mrs' Haemophilia and 'Mr' and 'Mrs' von Willebrands gave a lesson on genetics. Haematologist Nicola Eaddy from Auckland Hospital joined us for the Sunday education sessions and answered additional questions.

BJ Ramsay, haemophilia nurse from Wellington, shared some important points about travelling when you have a bleeding disorder. The key to travelling is to plan ahead and consider the six W's – **When**, **What** to take, **Where**, **With**, **hoW**, and **What's** there. By considering each of these points and making the right preparations, (including informing your haemophilia centre with plenty of notice and getting the right paperwork for customs) having a bleeding disorder should not limit your travelling. Former Step Up Reach Out (SURO) graduates Hemi, Kyle, and Raukura, and Asia-Pacific campers, Andrew and Connor, also shared tales of their overseas adventures.

discussed the recent World Haemophilia Day and why it is important to celebrate this day each year.

Education sessions were not limited to bleeding disorders, and the cadets also learned about bullying and keeping safe in cyberspace. Social Worker student David Betts lead the teams in creating a definition of bullying, and then asked them to role play some scenarios of positive ways to deal with the types of bullying that could arise in their lives.

SURO graduate Jordan Young also led a session on the benefits of sports and exercise. In their groups, the cadets had to allocate various sports to one of three zones – the Red Zone, the Grey Zone and the Green Zone to classify them as suitable, not suitable or recommended for consultation with a physiotherapist for people with a bleeding disorders. Teams then had to negotiate with each other to come up with a consensus as to which zone various sports should ultimately be classified as.

## Team Building & Challenges

MERC staff led four teams in a variety of team building activities. The Adventure Based Learning activities (or ABLs) were fun and made the newly formed groups work together as a team. For example, in the orientation boat building challenge teams had to first earn 'money' in an orienteering challenge in order to 'purchase' their choice of equipment to build their boat. In another team challenge teams built a slingshot and later played a game of slingshot baseball.

Other challenges were more focused on the individual. Stack'em involved participants building a tower of crates by balancing them on top of each other. John Leslie set the Haemophilia Youth Camp Stack'em Record by stacking 14 crates before they all toppled. Cadets also pushed themselves by taking on extra challenges while abseiling, such as abseiling blindfolded or with no hands.

## Fun

On Monday morning the cadets were treated to a once in a lifetime experience. Following breakfast at '0-6-30' and a bus journey across the city to the NZ Sailing Trust based at Auckland's Viaduct Basin, the cadets boarded Sir Peter Blake's yacht Lion New Zealand and headed out into Auckland Harbour. The NZ Sailing Trust was originally established as a charity to preserve the asset of Lion New Zealand and make her available to as many young New Zealanders as possible. Lion New Zealand is an iconic vessel representing the start of Sir Peter Blake's dream of competing on the world yachting stage; since her adoption into the Trust, over 7000 young Kiwis have set foot on board and been

of strategy, sneaking around in the dark to get the opponents while protecting members of their own team.

After everything was put ship shape during the big camp clean-up on Tuesday morning, the cadets once again hopped on a bus over to Devonport for a visit to the Torpedo Bay Navy Museum and to explore the World War II Gun Emplacement Tunnels at North Head. Each team was equipped with a disposable camera to gather reconnaissance and provide photographic evidence on a range of fun clues.

## All Sewn Up

The final assembly was held at North Head. Each cadet was presented with their own special attendance certificate and an information pack for them to take home to discuss various aspects of camp with their parents.

During the camp a Point Board was maintained by Marine Sarah Preston to provide some healthy competition between the four teams and provide a positive camp culture. Points were awarded for qualities such as leadership, helpfulness, duties, timeliness, achievement in the challenges, bunk room cleanliness and tidiness and generally doing good. In the end the Red Team – Te Kaha lead by Leading Hands Hemi Waretini and Leighton Mabey were awarded the Gold Medal Prize.

The rain arrived at the same time as the final assembly ended. Despite this, the cadets were buoyed up as they boarded the bus back to the airport and home.



inspired by her unique story. On board, the cadets learned more about Sir Peter Blake, his life and achievements, and were able to participate in the sailing of the yacht from helming, to navigating, and grinding.

The cadets also enjoyed themselves the previous evening as they battled to save Camp. First Julian Bartram from Body FX, New Zealand's largest special effects make-up company, came along for a session called 'War & Wounds'. Cadets got to choose to be made up with a variety of different wounds. Once the VERY realistic wounds were in place, the teams headed outside into the dark for a Laser Skirmish Battle. Risk minimisation techniques were in place in order to reduce the possibility of injury, such as having a very clear boundary and running was outlawed. This made the game even more fun because it became a team game

## Commendations

Very special and big thank you to the following people:

- Medics (Haemophilia Nurses): Mary Brassler, Daryl Pollock, BJ Ramsay, Karen Slavina
- Marines (Outreach Workers): Sarah Preston, Joy Barrett, Linda Dockrill and David Betts,
- Leading Hands (Group Leaders): Hemi Waretini, Leighton Mabey, Kyle Cunningham, Garry Honor, Jordan Young, Mick Burnett, Dylan Christensen, Raukura Riwaka, Kelvin Elliffe.
- Parent Helpers: Richard Scott & Donna MacGregor

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## Learning the Ropes at Youth Camp 2013

- HFNZ Office Staff – Belinda, Leanne and Kate for helping with everything from booking activities, airfares, buses, writing documents, making name tags, and a whole range of tasks necessary for a huge Youth Camp such as this.
- Tama Pene from the Roopu for coming to camp to especially to perform the Mihi Whakatau.
- Thanks to Bayer for funding the Youth Camp and to Christie Murzello for always being a champion for HFNZ Youth and the benefits of HFNZ Camps.

Embarking on the journey was also overseas visitor Su Ngoh Lee (Sung) from Singapore, who joined us to immerse herself in Youth

Camp – Kiwi style. Sung is the Co-ordinator of the Asia – Pacific Youth Camp that was held last year in Korea and will be taking place in China later this year. The boys left a great impression and she wrote to comment “I would like to thank you for inviting me to have the opportunity to immerse in a very well-organised Kiwi style youth camp. It’s interesting to see how energetic and full of life the kids were, despite their bleeding disorders. There are certainly a lot of positive experiences that I could bring back to share with our Asian kids. I think the boys really enjoyed the slingshot, building a battleship, laser skirmish type of activities and I particularly liked the bleeding disorders 101 and bullying discussions and being out in the sea on board the Lion NZ Yacht.”

## Cadets and Parents Reflect on Youth Camp 2013

Where do I start.....  
First sole plane flights  
First time away from mum and dad for more than one night  
First time I have done all my own treatments without help

What made it great.....  
Laser Strike  
Making a raft  
Invisible chair with Mick  
John being a great friend to share a room with  
Too many things to write about as I have got to go to bed.

Thank you to all the great leaders and the people who gave money to help pay for the camp I will be back to the next one.

**Jack Uren**

“I had an awesome experience at youth camp. It was really cool developing more leadership skills and catching up with everyone. I am looking forward to the next one.”

**Connor McCone**

“I thought youth camp was awesome I really enjoyed all of the activities we did, especially the ride on the Lion New Zealand yacht.

Youth camp really helped me understand my bleeding condition, so now when someone asks me about it I can tell them what it actually is instead of saying I just have a bleeding disorder.

Thank you so much for organising the youth camp and I think MERC was the best place to have it.

For me there were no bad things about it. It was a very enjoyable camp. I have no suggestions of what we could do for the next youth camp but whatever it is I CANNOT WAIT.”

Yours sincerely  
**Eythn Charleston**

“I had a fantastic time at Youth Camp. Since it was the first Youth Camp I had been to for kids like me who had a bleeding disorder, I didn’t know anybody there other than my nurses and some of the Outreach Workers. The best thing about the camp for me was meeting other kids with a bleeding disorders and sharing our experiences with our condition. I met some great guys such as; Matthew Walls, Connor McCone and Zac Porter and really enjoyed spending time with them. Meeting the adult leaders was also very interesting and fun as I enjoyed talking to them and learning about how they managed their disorder as an adult. I especially learned a lot from the leadership talk we had and how we can embrace ourselves as role models to the younger kids at camp. I am very much looking forward to the next Youth Camp in 2015.”

**Brendan Lee**

“While initially a little apprehensive about sending Eythn on camp by himself I would have no hesitation in recommending to other parents to be brave and allow their youngsters to go. Eythn made friends and took part in activities that are just not available to us where we live.

The biggest gain for us is that up until now I have always managed Eythn’s condition (as a parent that’s just what we do) and now thanks to what he has learnt at camp he is taking a more active role in managing himself.

Thank you again for allowing Eythn the opportunity to attend..

Kind regards  
**Leanne Charleston**

“...Well I don’t know what you guys did with my baby but he left a reluctant & apprehensive 10 year old and returned a confident, knowledgeable, proud and happy young man. Everyone has commented on the difference in him. He had an amazing time and is looking forward to next time. The things he learnt about himself and about his haemophilia has given him a feeling of empowerment....”

**Kim McQueen  
and Gabriel Bishop**



“I enjoyed my time at MERC - it was a great experience. The activities I enjoyed on camp were 10 Pin Bowling which was a great social activity for all ages. The stage makeup artists combined with the outdoor laser strike was amazing!! It was man heaven for all of us, outside in the dark in the rain playing laser tag covered in gashes. The opportunity to sail on the Lion New Zealand boat that Sir Peter Blake sailed around the world was a great experience and a memory I will never forget.

I have been reunited with my friends that come from all over New Zealand that I haven’t seen for the past two years and have also met some awesome new

people on camp that I will remain in contact with.

One of the things I love the most about the Youth Camps is that the ones I have gone to have always been held in different locations, with different themes and guest speakers.

I loved this years camp at MERC and I’m looking forward to attending the next youth camp.

A big thanks to everyone who was involved with the organisation and running of the camp, you did an awesome job, thank you very much!!!”

**Luke Spencer**

“Sending Riley to youth camp on his own was the best thing that as parents we could have done for him... The benefits of him attending were huge; he went from leaving here being a boy to coming back a young man... He went from hating his haemophilia to embracing it; the education sessions were invaluable in helping him develop a better understanding to make sense of it all.”

**Sharon and Wayne Barnes**



# Elbows – A Problematic Little Joint

By Claire Bell

*Within Australia elbow arthropathy is becoming an increasing problem, affecting both young and older adults affected with severe haemophilia.*

The elbow is not only a hinge joint, like the knee, but rotation through the joint allows us to move our lower arm and hand into positions required to undertake daily activities. Unfortunately it is one of the joints that is prone to becoming a target joint for men affected with severe haemophilia.

Think about how we rely on using our arms during our day – you need to be able to bend it, extend it and move it around to so that our hands are facing up, down and all around. The elbow is a very complicated joint and surgeons around the world acknowledge this. At the recent World Hemophilia Congress it became the subject of a number of presentations.

## So Why Can't We Just Replace It?

Elbows are not like knees... Not only are elbow replacements extremely difficult to perform, they are not really suitable for men with haemophilia due to their weight bearing limitation. Elbow replacements have a weight capacity of only 5kg. 5kg may sound like a lot when you consider carrying a cup of coffee or the paper. What about picking up kids, grandkids, the dog... or when you have to use your arms for crutches because your knee or ankle has a bleed... or when you are simply using your arms to push up to stand from a sitting position. In these situations we place more than 5kg through the elbow, sometimes significantly more.

## So What Can We Do?

Firstly, it is important to state upfront that whatever is lost in the ability to extend or straighten the arm is lost forever. Therefore prevention and protection of the joint is critical to maintain normal function. If you have a target elbow joint maintaining regular prophylaxis or undertaking a course of secondary prophylaxis may be initiated to reduce the bleeding cycle within the elbow joint. Quick and correct factor replacement to manage a bleeding event is also very important.

But for some patients a surgical option may be considered when there is a significant reduction in the ability to rotate the lower arm and hand and/or when there is significant pain. The surgery offered is called a radial head dissection or resection.

## What is a Radial Head Dissection?

The radius is one of the bones in the lower arm. The other (larger) bone is called the ulna. Due to repeated bleeding events and developing arthritis, the radial head becomes bigger than normal. When it gets too big it sits right against the ulna bone. This loss of space between the two bones reduces the ability of the lower arm to rotate. The option then is to take off the end of the radial bone, thus allowing rotation to occur.

Everyone is a bit different, so while surgeons will make an effort to remove the bone above the ligaments which hold all the bones together, making it more stable in the long term, this is not always possible. Whilst it may seem odd that they would leave it "floating" around, the bones are well supported by muscles. Over time, however, this stability may reduce and there is then the risk of pain in the wrist. As with any surgery there are always risks, but this surgery offers the best chance to regain some function and maintain a quality of life for men with severe elbow joints.

## More Information

If you are concerned about the health of your elbows or would like more information please contact your local Haemophilia Centre.



*Source: This article was published in National Haemophilia, December 2012, the journal of Haemophilia Foundation Australia and is reprinted with permission. Claire Bell is Haemophilia Clinical Nurse Consultant at the Haemophilia Centre at the Royal Perth Hospital, Western Australia*

# New Generation HCV Drugs: What's On The Horizon?

By Professor Ed Gane

*Professor Ed Gane discusses the key findings presented at the 2012 AASLD meeting.*

The 2012 American Association for the Study of Liver Diseases (AASLD) was held in Boston in November 2012. The highlights this year included latest data on the effectiveness and safety of the new direct acting antiviral agents (DAAs) in patients with chronic hepatitis C infection.

In the 18 months since the FDA approved the use of the first generation protease inhibitors, as triple therapy, with pegylated interferon plus ribavirin, approximately 50,000 patients with HCV genotype 1 have been treated.

In the registration (phase III) studies, this triple therapy increased rate of cure from 45% to 75%, and although drug-specific toxicities were observed (anaemia and rash), less than 10% developed serious adverse events (SAEs) or had to discontinue treatment.

At AASLD, four separate studies of the "real world" experience of triple therapy in patients with advanced fibrosis or cirrhosis were presented. Only preliminary on-treatment data was available, however, all studies observed reduced tolerability of triple therapy - up to 45% of patients developed SAEs and more than 50% developed severe anaemia requiring either erythropoietin or transfusion. These studies therefore demonstrated that outside the strict exclusion criteria of clinical trials, triple therapy must be used with caution in patients with cirrhosis.

The biggest excitement at the meeting surrounded the new data from the phase II studies of interferon-free, all-oral DAA combinations. The three regimens, which are now entering Phase III and heading towards FDA submissions, are the Abbott, BMS and Gilead regimens (refer to table).

The Abbott regimen1 combines three DAAs for in genotype 1 patients for 12 weeks. This regimen was well tolerated other than raised bilirubin – a direct effect of ABT-333.

The BMS regimen2 was similar in design, with a combination of three DAAs for 12 weeks. Although not seen in this study, other studies have observed both ALT and bilirubin elevations with asunaprevir, suggesting possible hepatotoxicity of this agent.

The Gilead ELECTRON study3 has the advantage over the others in that it is also effective in patients infected with other HCV genotypes. This was proven by the previous collaboration between Pharmasset (now Gilead) and BMS, where the combination of sofosbuvir with daclatasvir for 12 or 24 weeks achieved 100% cure in genotype 1, 2 and 3 patients.

Both the current Gilead ELECTRON study and the previous Pharmasset/BMS collaboration demonstrated that the combination of a nucleotide with an NS5a inhibitor was an extremely effective and well tolerated regimen – neither agent has specific toxicity and both are given once daily, with no significant drug interactions, seen with a protease inhibitor of nonnucleoside NS5b inhibitor. This combination is likely to provide the first all-oral, pan-genotypic antiviral regimen.

Results from the Phase III studies from these interferon-free regimens should be available at AASLD 2013 and are likely to be followed by their rapid replacement of pegylated interferon and ribavirin as the new standard-of-care. The availability of well tolerated, highly effective, all-oral treatment is expected to markedly increase the demand for hepatitis C screening, referral and treatment.

	Abbott Regime	BMS Regime	Gilead Regime
<b>Drugs</b>	Three DAAs combination: NS5a inhibitor (ABT-267); Nonnucleoside NS5b inhibitor (ABT-333); and NS3 protease inhibitor (ABT-450).  Trial also included twice daily ribavirin.	Three DAAs combination: NS5a inhibitor (daclatasvir); Nonnucleoside NS5b inhibitor (asunaprevir); and NS3 protease inhibitor (BMS-791325).	Two DAAs combination with ribavirin: Nucleotide NS5b inhibitor (sofosbuvir); NS5a inhibitor (GS-6885); and Ribavirin.
<b>Cure Rate</b>	Achieved 87% cure (without ribavirin) and 98% cure (with ribavirin) in treatment-naive genotype 1 patients.  93% cure rate with null responder genotype 1 patients.	Achieved a cure in 94% of treatment-naive genotype 1 patients.	Achieved 100% cure in 25 treatment naive and one null responder genotype 1 patients.

References:

1. Kowdley et al. Hepatology 2012; 56: Abstract LB1
2. Everson GT, et al. Hepatology 2012, 56: LB3
3. Gane E, et al. Hepatology 2012; 56: 306A

*Source: This article was published in Hep C Quarterly, Autumn 2013, by the Hepatitis Foundation of New Zealand and was reprinted with permission. Professor Ed Gane is from the New Zealand Liver Transplant Unit, Auckland City Hospital.*

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# Elizabeth Berry Exercise Cup Competition 2013



The Elizabeth Berry Exercise Cup has not been awarded for several years, so it has been dusted off and polished up ready for the 2013 competition. Individuals, groups and MRG's can enter the competition with the cup being presented at the 2014 AGM. Whether you hold an MRG exercise event, start an individual exercise regime or enter your local fun run to raise funds for HFNZ - get out there, have fun and enjoy that feel good feeling exercise can bring. Information on the competition is available from your MRG.

**Walking Guide**

**Start your journey to better health**

Remember that your shoes should provide good support

	WEEK 1	WEEK 2	WEEK 3	WEEK 4	WEEK 5	WEEK 6
<b>Level ONE</b> <small>Start slow...</small>	5 mins out 5 mins back = 10 minutes	6 mins out 6 mins back = 12 minutes	7 mins out 8 mins back = 15 minutes	8 mins out 7 mins back = 15 minutes <small>walk faster back</small>	10 mins out 10 mins back = 20 minutes	10 mins out 10 mins back = 20 minutes <small>walk further each day</small>
<b>Level TWO</b>	10 mins out 10 mins back = 20 minutes	10 mins out 10 mins back = 20 minutes <small>walk further each day</small>	12 mins out 13 mins back = 25 minutes	13 mins out 12 mins back = 25 minutes <small>walk faster back</small>	15 mins out 15 mins back = 30 minutes	15 mins out 15 mins back = 30 minutes <small>walk further each day</small>
<b>Level THREE</b>	15 mins out 15 mins back = 30 minutes	15 mins out 15 mins back = 30 minutes <small>walk further each day</small>	17 mins out 18 mins back = 35 minutes	18 mins out 17 mins back = 35 minutes <small>walk faster back</small>	20 mins out 20 mins back = 40 minutes	20 mins out 20 mins back = 40 minutes <small>walk further each day</small>
<b>Level FOUR</b> <small>Build up...</small>	20 mins out 20 mins back = 40 minutes	20 mins out 20 mins back = 40 minutes <small>walk further each day</small>	21 mins out 19 mins back = 40 minutes <small>walk faster back</small>	22 mins out 23 mins back = 45 minutes	23 mins out 22 mins back = 45 minutes <small>walk faster back</small>	find a pleasant loop rather than an out and back path = 45 minutes

**Green Prescription – Practical activity for practical people**

Ph: 0800 ACTIVE (0800 22 84 83)    newzealand.govt.nz    www.moh.govt.nz/greenprescription    MEMBERS OF HEALTH

## Tips to fit exercise into your day

It is recommended that people do 30 minutes of activity on most days of the week, if not every day of the week and if it is moderate-intensity physical activity it is even better for you. Moderate-intensity activity is when an activity makes you breathe a little harder than normal and includes doing things like a brisk walk, cycling, gathering kai moana and gardening. Think of exercise as an opportunity, not an inconvenience. It can be done in 1 x 30 minutes block or can be split into 3 x 10 minutes sections throughout the day instead. If you think you don't have time to exercise, all it takes is to find a way. You can fit activity into your day like walking instead of driving to the shops or dropping your kids at school, parking further away, playing hide and seek or four square with your children, do an extra chore when doing housework, and walking around while you talk on the phone.

## Get help with motivation with a Green Prescription for you or your family

If you have been inactive for a while and need a little encouragement to start an exercise programme or perhaps you have trouble staying motivated then ask your GP or the GP practice nurse for a Green Prescription. A Green Prescription provides written advice for individuals, families and young people and is a cost effective way to increase your physical activity, loose weight, help prevent type 2 diabetes, reduce the impact of cardiovascular disease and improve your mental health. If you want on-going support your script is forwarded to a Patient Support Person who encourages you to become more active through monthly telephone calls over 3-4 months or; face to face meetings or; group support in a community setting for 3-6 months. Plus your progress is reported back to the referring health professional and you can receive an extra Green Prescription for on-going support.



Walking is a great way to ease into exercise. We've included the Green Prescription walking guide to help you get started. If you are an absolute beginner and not sure how to find time in your day to exercise, start out by walking 10 minutes every second week day and 10 minutes each weekend day. That is walk 5 minutes from your gate and 5 minutes back home, and gradually you can build up to 30 minutes or more.

## Don't get bored with your exercise routine – Keep it fresh with these tips on activities to do

If you are looking for inspiration for activities to do then visit the Department of Conservation website ([www.doc.govt.nz/parks-and-recreation/activity-finder/](http://www.doc.govt.nz/parks-and-recreation/activity-finder/)). The website has a useful activity finder resource to help you find a broad range of activities to do in your region. The ideas include child and family friendly activities, walks (including short walks around the city), dog walking, fishing, kayaking and more. Regional councils and libraries are also be a great resource listing local parks, botanic gardens, walkways and walking groups - your MRG could form its own walking group.

Individuals, families and groups could also sign-up for fun runs and walks that are held regularly throughout New Zealand. If you prefer indoor activities you can join a sports club, gym or try swimming or aqua jogging. Children may also consider entering the Weetbix TRYathlon. (Don't forget to consult your HTC physiotherapist first).

## Make exercise more enjoyable by wearing comfortable gear

You don't need to have fancy brands of clothing or equipment to enjoy exercise. In fact, whether you exercise on your own or

with a group, people will be inspired by you for getting out there and participating, spending quality time with your family and for enjoying life.

Here are a few tips to make exercise more enjoyable - rain or shine.

### What to wear during exercise:

- Wear supportive footwear.
- Wear comfortable clothing that is easy to move in and appropriate for the weather – sun, rain or cold.
- Layer your clothing instead of wearing one thick layer.
- Wear a hat in summer and for warmth during winter.
- Use appropriate safety gear e.g. wear a helmet for cycling.

### Other things you might like to take with you include:

- Take a water bottle and drink enough water.
- Carry a lightweight backpack or a "bum bag".
- Lunch and/or snacks – scroggin, bananas for sustained energy on a longer walk.
- Sunblock

Finally, create a goal and keep an exercise diary with your daily activity to monitor your progress, changes in mood and energy levels.

No matter what goal you set yourself – realise you don't have to be the next New Zealand gold medallist - just get involved and enjoy living in our beautiful country.

Source: [www.activecanterbury.org.nz](http://www.activecanterbury.org.nz), [www.doc.govt.nz](http://www.doc.govt.nz), [www.health.govt.nz](http://www.health.govt.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](http://www.givealittle.co.nz/org/haemophilia)



# Outreach Report on the Sport and Exercise Conference

By Joy Barrett

*The entire HFNZ outreach team was fortunate to have the opportunity to attend the Sports Participation in the Management of Bleeding Disorders meeting held in Melbourne during February. The meeting assessed the benefits and potential risks of participation in sport by patients with haemophilia and bleeding disorders.*

Historically and not so long ago people living with bleeding disorders were actively discouraged to take part in any sporting activity as the ability to treat or rehabilitate bleeds was not an option. Sadly this is still the case in many countries that do not have access to treatment products.

While there was a large range of opinions about what sport or exercise is suitable for the bleeding disorder community to participate in, there was a general agreement about many aspects. It is widely accepted that people with bleeding disorders should endeavour to live full and active lives, but participation in high impact sports brings significant risk to the individual. The degree of contact and risk in sports is important to consider when choosing a sport. It was recognised that there is also great social pressure to be involved in high impact activities in both New Zealand and Australia. Often younger people with bleeding disorders play these sports and bear the high consequences to fit into social norms.

Reduction of risk is very important and does need to be thought through for all participants of physical activity but even more important for the bleeding disorder community. Many activities have protective gear that does reduce the risks of harm such as mouth guards, helmets, gloves, shin pads, supportive footwear with ankle protection, knee or elbow pads, chest pads and many more. Self-monitoring is crucial in your ability to continue exercise or sporting activity at a safe level and being open to discussion about it with your HTC staff. Treatment on the days of participation is one such issue.

It is also essential to seek support from a physiotherapist who is familiar with both the bleeding disorders and the type of sport or exercise you want to participate in to confirm if it is a suitable activity to take part in. The physiotherapist may conduct a joint assessment during which your major joints are scored on their range of movement and they may consider the alignment of

joints as well. It could also be recommended to strengthen muscle groups, build resilience and increase some of the skills in your particular sport first before full participation.

With the availability of long acting treatment products and new ways to treat bleeds, our community of people with bleeding disorders will continue to see changes in exercise participation levels. These aspects of the workshop raised questions that will be discussed in the years to come including the ethics of participation in activities that require increased use of product and balancing this with the continuing rise in the cost of haemophilia treatment.

What we do know is that participation in physical activity brings a wide range of benefits, including:

- Improved outlook on life, natural “feel good” chemicals are released when we are active for at least half an hour
- Reduces stress, depression, anxiety as well as physical health risks of diabetes and heart disease
- Increases bone density
- Improved balance and mobility in general
- Improved self-esteem and confidence as competence grows
- Social network of feeling included
- Assists weight control (crucial in assisting joint maintenance)
- Access to veins is easier if excess weight is not carried.
- Can be targeted to strengthen muscle groups that support joints whether they are damaged or not.
- Younger people involved in sporting activities had a reduction in the other risk taking behaviour.

So overall, it is a matter of open communication with all those involved in your care, taking on board recommendations, assessing risks, modifying the way we play, wearing protective gear and having fun. Whether you participate in sport or exercise, if you are up and about and moving as part of a team activity and there is scoring, winning or losing; or you are involved in a less intensive or solo physical activity - it is good for you. Sport and exercise is about finding the right activity for you in consultation with your Haemophilia Treatment Centre.

## In Memoriam

The HFNZ notes with sadness the passing of member and friend Graeme (Memphis) Lampshire from the Central region.

# Mindfulness

By Desdemona Chong

## What is Mindfulness?

‘Mindfulness’ is currently a very popular concept in psychology in countries like Australia. It is simply becoming aware of your here-and-now experience in an attitude of openness, interest and receptiveness. Consistent use of mindfulness exercises has been shown to lead to positive outcomes such as reduction in stress, increased self-awareness and better emotional regulation. It has also been shown to reduce the impact and influence of stressful/painful thoughts and feelings on the individual.

For individuals living with an inherited bleeding disorder, this could be a very helpful tool for you to manage the added challenges that comes along with the condition.

## Why Mindfulness?

As an evidence-based tool, mindfulness training has shown benefits in common health issues like chronic pain, substance use, anxiety and depression. In fact, there is recent research showing that with as little as 20 minutes of daily mindfulness practice, the brain structure actually changes. Specifically, brain imaging studies indicate that the portion of the brain that sends messages of anxiety and distress slows down while the portion of the brain responsible for sending messages of calmness and comfort to the body actually becomes more active.

## How to do it?

Mindfulness exercises do not need to be done only in times of distress; they can be incorporated into your everyday routines, such as mindful walking or eating. By making a conscious decision to incorporate mindfulness in as many aspects of your everyday life as possible, you will begin to increase your ability to focus on everyday activities and increase your sense of control and choice over your life. There are countless mindfulness exercises available online and in audio formats. Check out a few today and see what suits you. Like any new skill, they need to be practiced and it is best to practice them BEFORE you really need them so that they are familiar to you.

## Breathing Mindfully

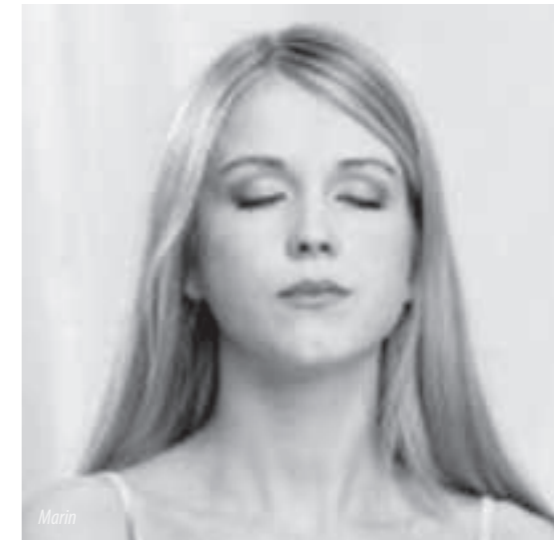
Background: The purpose of this exercise is to simply notice, accept and be aware of your breath – it is not about relaxation or stress reduction, although this may well occur. Breathing is something we all do – if you have a pulse then you breathe. Your body knows how to do this; it has done it since birth. This is simply about breathing mindfully. Breathing is something you carry with you everywhere; you are just not usually aware of it.

Sit quietly in a chair with both feet on the ground and your hands on your lap. Allow yourself to feel centred in the chair. Bring all of your attention to the physical act of breathing. Start to notice the breath as it enters your body through your nose and travels to your lungs. Notice with curiosity whether the inward and outward

breaths are cool or warm, and notice where the breath travels as it enters and departs.

Also notice the breath as your lungs relax and you inhale through your nose. Don't try to do anything with your breathing – simply notice it, pay attention to it and be aware of it. It doesn't matter if your breathing is slow or fast, deep or shallow; it just is what it is. Allow your body to do what it does naturally.

You will start to notice that each time you breathe in, your diaphragm or stomach will expand... and each time you breathe out your diaphragm or stomach will relax. Again, don't try to do anything – just be aware of the physical sensations of breathing in and breathing out. If you find that thoughts intrude, this is okay. Don't worry, just notice the thoughts, allow them to be, and gently bring your awareness back to your breath.



Start this exercise initially for 5 minutes, building up daily. You can also do this exercise lying down in bed if you have difficulty sleeping. It is simply a way of allowing you to have more mindful and conscious awareness of your body and its surroundings, its breathing and its capacity to relax. When our breathing relaxes our muscles relax.

## Finding out More

Information for this article was taken from the following web sites. Please also visit the web sites for more information about mindfulness and actual guided exercises to help you start on this journey.

**ABC1. Making Australia happy: Mindfulness**  
<http://makingaustraliahappy.abc.net.au/mindfulness.php>

**Harris, Russ. The happiness trap: Mindfulness**  
<http://thehappinesstrap.com/mindfulness>

**Living well. Tips for living well: What is mindfulness**  
<http://www.livingwell.org.au/Tipsforlivingwell/Whatismindfulness.aspx>

**Griffith University. Relaxation, focusing and mindfulness exercises [audiotapes]**  
<http://tinyurl.com/griffith-mindfulness>

*Source: This article was published in National Haemophilia, March 2013, the journal of Haemophilia Foundation Australia and is reprinted with permission. Desdemona Chong is Advanced Psychologist – Haemophilia at the Royal Brisbane & Women's Hospital.*

*Living Well. 5. Breathing mindfulness exercise reprinted with permission from Living Well, www.livingwell.org.au.*

# 1st International Parents Empowering Parents International Conference

By Linda Dockrill

In early April Linda attended the 1st International PEP Conference held in Houston, Texas. The conference was hosted by members of the International PEP team Ed Kuebler, Social Worker; Madeline Cantini, Haemophilia Nurse and Danna Merrit, Social Worker. They are all responsible for bringing the Parenting Empowering Parents programme to ten countries over the past five years.

The main objective of the conference was to:

- Bring together key coordinators for PEP internationally
- Share ideas of how to teach PEP based on culture, global differences and different environments i.e. developed vs. developing countries
- Highlight some of the changes to the new PEP Manuals
- Discuss challenges that countries face in sustaining the PEP programmes locally

Attendees at the conference were a global representation of Haemophilia, Social Work and the PEP programme from USA, Israel, Ireland, Canada (2), India, Panama, El Salvador, Peru, South Africa and New Zealand. Everyone delivers the PEP programme from the same manual and it was inspiring to hear the creative ways other countries are doing this. A memorable example was how Panama delivers the PEP programme.

In Panama PEP has only been running for a couple of years but in that time they have provided the programme for 61 families throughout different regions of the country. Luz Villalaz is a nurse working with the programme and told us that part of their success is that PEP is included as a part of the treatment plan and has the full support of clinical staff. The HTC supply a letter to employers, if required, to explain why a parent will be missing a day of work to attend. One of the challenges in Panama is a the low level of literacy so the programme is delivered in a group



work model with people sharing their stories verbally and with lots of fun and acting involved! Luz, Elsy (El Salvador) and Mary (Peru) are all Spanish speaking, so their stories were conveyed to us through a translator (Mary). This added to the richness of the experience and helped those of us who only spoke English to understand the challenges around bringing PEP to the world. In New Zealand the PEP programme is delivered through a PowerPoint presentation and learning through fun with group work and social activities.

The PEP manual is 10 years old and is in the process of being updated with current parenting practices and issues e.g. managing cyberspace. Danna Merrit, one of the original creators of the PEP programme, guided us through the draft of the revised programme and it was a great opportunity for the attendees to provide feedback about values and ideas from around the world that may be useful for inclusion.

The conference concluded with the making a worldwide plan and agreement that we all be part of a global taskforce to take PEP to other countries in our corner of the globe. It is very clear that while 75 percent of the world does not have factor there is a need for 100 percent of the parents to have this programme to help navigate life with a child with a bleeding disorder.



# Caroline Davis Raises Awareness on Rare Disease Day

The 28th February was Rare Disease Day and it was perfect time for Caroline Davis from Whangarei to spread the word on haemophilia as it coincided with her youngest son John starting pre-school. Caroline is a mother with plenty of verve and time for her family. She has four children Austin (7), Eden (5), Cormac (3) and John (2) and a baby due in July. Her two boys Austin and John have severe haemophilia.

On Rare Disease Day Caroline's day started early at 7.30am at a local primary school where along with friends Caroline runs a breakfast club. Caroline's big heart isn't limited to her own children but also to the welfare of disadvantaged children in the community. Caroline set up the breakfast club in 2012 for a low decile school where kids go to school with no lunch, shoes or coats. Through the breakfast club and donations of breakfast cereals, bread and milk from friends and a local church, Caroline is able to share god's love and also enable her children to see that despite having haemophilia and having to use needles and have bleeds you can still have the right attitude to life and shine a little light on someone else and make their day a little brighter. On Rare Disease Day the kids at breakfast club had fun wearing red clothes and having their faces painted.

Next on her agenda to raise awareness of haemophilia Caroline visited Austins and Edens school, Excellere College, where the kids supported Rare Disease Day by wearing red to school too. The previous night Caroline had given a presentation on haemophilia to the teachers. The school also placed an article on their website to help educate parents and students about haemophilia.



The next stop was Mainly Music at 10am. Mainly Music is where local parents get together for dancing and songs with their toddlers. At this class she gave another presentation on haemophilia using lollies to represent platelets and factor in blood. Once again the audience was all dressed in red and a friend baked delicious red cake!

Finally, at Smart Start Preschool Caroline gave a presentation to her last audience dressed in red for the day. This time the local newspaper visited to get a photo for an article in the Northern Advocate. Below is the article Tots in Red from that visit.

## Tots In Red

**Smart Start Preschoolers dressed up in red to support two young brothers who battle the rare blood disorder severe haemophilia A. Austin, 7, and John Davis, 2, suffer from the disorder which causes severe bleeding.**

Mother Caroline Davis said the general perception is that haemophilia is only an external bleeding problem. "When I'm going shopping and I lift the boys out of the car and his shirt rides up so you can see he is a lot more bruised than other kids people do give me funny looks.. Severe haemophilia A causes serious internal bleeding, often on joints which can lead to scar tissue building up around joints and arthritis. Anything from going down a slide or climbing over something can leave the boys covered in bruises.

There is no haemophilia centre in Whangarei, so the Davis family had to learn how to administer the medicine the boys need to maintain regular blood results at home. Austin has an injection directly into his vein every morning while John receives his once a week. "We need three people when we give John his injection. One person holds him, my husband finds the vein and puts the needle in, and I screw the medicine on and make sure it goes in smoothly," Mrs Davis said. Mrs Davis reached out to her friends, who have created a roster to make sure someone is available to help the Davis' give John his medicine each week. That had been a huge help for the family, she said.

Mrs Davis also praised the support the preschool showed their family. "The awareness here is amazing.. Mrs Davis said there is a 25 per cent chance that the boys will develop a resistance to the medicine in their lifetime.

February 28th is International Rare Disease Day - held to raise awareness of all rare diseases.



Every day is a challenge for Austin Davis, 7, and younger brother John, two boys who suffer from severe haemophilia A.

Source: This article and photo was published in the Northern Advocate, 1 March 2013 and is reprinted with permission.

# 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

As with every other year Northern kicked off the year with a great camp held at Campbell Park in Mangawhai Heads. While there were some of the faithful Northerners notably absent, we were joined with some awesome new families. Friday started with dinner then a few ice breaker games, Saturday we headed up to the local mini golf course for a round, then back for the flying fox and the well-loved 'caterpillar ride'. After lunch, nurse Mary Brasser, joined us for a question and answer session. This was a great way to learn and engage in conversation around issues we all face in our bleeding disorder journey. Then it was a trip to the beach. After dinner it was time to break out the Singstar, with a few managing to avoid the competition by claiming their children needed them! Nicky Jamieson claimed the winner's title but there was some tough competition leading up to the deciding round. Sunday saw us gather together to talk through events to plan for the year ahead and hold the AGM. After lunch it was time to bid a fond farewell to our friends and look forward to seeing them all again at Northern events during the year.

We have a great Northern Committee this year with the addition of a few new members:- Richard Scott (Chairman), Greg Jamieson (Northern Delegate), Lynley Scott (Secretary), Hemirau Waretini (Treasurer), Kylie Andrews, Tineil Casey, Mike Mapperson, Susanne Nio, Tahī Pene, TeAhuriri Stirling and Jordan Young. We have some great events planned throughout the year so keep a watch out for invitations. Like other MRG's we are moving towards using email to send out invitations, to save on cost and also time. Please ensure you check National Office has your current email address and also check your spam box from time to time just in case the invitations are delivered there.

April saw us celebrate World Haemophilia Day, two days late, with a dinner in Auckland and Whangarei. We had a whopping turnout of approximately 60 people across both events. It was the first time we have held simultaneous events and it seemed to work really well. It was great to see a wide age range at the dinner and was awesome to see a number of people who we haven't seen for a while.

We look forward to seeing you all throughout the year, and let's keep up the great attendance record we have for many of our events.



## Central

By Stephanie Coulman

Wellington members enjoyed a dessert evening to celebrate World Haemophilia Day on 17th April. A small group of 10 people got together and chatted over chocolatey, lemony and berry delights.

Some of our members attended the Youth Camp in Auckland during April, with one youngster attending for the first time. It was reported all his belongings came back with him and by all accounts they had a great time, and learnt a lot about their condition as well as some new big words, like 'self-infusion'.

The committee met in Paekakariki on the 5th May and mainly discussed the upcoming regional camp being held in Napier on

6th - 8th September. This will be a shared camp with the Midland region as both regions have suffered from low attendance in the past and are going to try a collaborative approach instead this year.

The central region is getting involved in a bigger, better, longer Armageddon Expo over Queen's Birthday weekend at the Westpac Stadium. Carol Reddie is co-ordinating volunteers for this fundraiser event. Stephanie Coulman and Lisa Habershon made fast work of an Armageddon flyer mail-out to schools with 20,000 flyers delivered to about 140 schools in Wellington. It's always good to see the back of the mountain of boxes and regain one's living room.

## Southern Region

By James Poff

We have had a reasonably busy couple of months throughout the Southern Region. The AGM was held on 12th February 2013 and the following officers were elected:- Chair - James Poff, Treasurer - Susan Inwood, Secretary - Sandra Poff, Youth Representative - Sam Hawkins, National Delegate - Rochelle Stott. Our committee members also include:- Leanne Spencer, Kyle Cunningham, Jacque Hawkins, Liz Rutherford, Karl Archibald, Lorraine Porter-Bishop, Matthew Walls, Theresa Stevens, Lyn Steele and Ann Leslie. We have our next meetings planned for 7th May and 6th August.

Thursday 17th April 2013 was World Haemophilia Day. In conjunction with the head office team, the Southern MRG supported an evening event at Vanilla Bean Café. It was a very good event that included social and educational opportunities. The guest speakers covered topics ranged from current research trends, how research "happens", positive movement to access physio services, bleeding disorder management and the role of the Outreach worker. A successful raffle was also held in support of the HFNZ Cambodia Twinning project.

The Christchurch branch of the Southern MRG got together and held a successful fundraising event by organising and running a sausage sizzle at the local Bunning's. Saturday 20th dawned as a non-typical Canterbury autumn day, "wet & windy". After our stunning summer it was a shock to the system at the prospect of standing in the wintery weather selling sausages. But it turned out to be a stunning plan to run this event on such a miserable day as the sausages sold steadily throughout the day and over \$600 was raised. The funds will all go towards sending our members to the WFH 2014 World Congress. Well done and a big thanks to everyone who assisted to make this event a success, especially those who gave up their time to man (or women) the BBQ on the day.

Armageddon was held in Christchurch over the weekend of 9-10 March, which unfortunately clashed with the HFNZ AGM. As a result Sam and Jacque Hawkins found it difficult to round up enough volunteers to assist at this event. However Sam and Jacque persevered including the roping in of 3 family members and a friend to assist at the event. As a result \$504 was raised for the Foundation - well done to Sam, Jacque and Luke Spencer and to everyone who gave their support to this event.

Dunedin hosted the first Armageddon Expo in March, hosting over 6000 guests over the two day event. Teresa Stevens reported they were lucky to have great supporters, not just people with Haemophilia, but their family members and friends also. For Teresa's family it was known as a family outing as all four of them were at both days! They were lucky to have sufficient volunteers for each day and felt extremely fortunate to earn the Foundation \$2660. This fundraiser will be utilised towards the Melbourne Congress in 2014. It was a greater success than that originally hoped for by Bill and Adele so they will be returning next year and have already asked us to be involved. The days were long and tiring but also great fun to meet and mingle with the Hobbit guests and the other guests present. The costumes that die hard Armageddon fans turned up in were amazing! Look forward to next year with the willing volunteers to do it all again.

Other upcoming events in 2013 include 'The Secret Lives of Henry and Alice' - a fundraising play held on August 17th. Heather Giles (the director and organiser of the play) will be obtaining a liquor license, so HFNZ will be able to sell wine on the night and there will also be a fundraising raffle. A major event of the year is the Southern MRG 30th Anniversary that will be held at Labour Weekend. The venue and activities are to be confirmed but planning is underway for this event.

Any locals who are interested in helping out at either of these two events, please contact the Southern MRG.

## Youth

By Lauren Nyhan

In this edition of Bloodline we would like to take the opportunity to acknowledge some of the talent that has emerged from the National Youth Committee (NYC). From talking to members, both old and new and especially parents, we have come to understand that the success and hard work of our youth, both personally and within the Foundation, is of great importance to the membership base and succession.

Firstly the Youth Committee would like to congratulate Hemi Thomas on being appointed the new National Youth delegate for HFNZ. Hemi is capable of fulfilling any expectations that our members have of him and has proven himself both nationally on the Northern Committee, Roopu and NYC, as well as being a fantastic ambassador for HFNZ globally.

We would also like to acknowledge the huge amount of hard work and effort that Karl Archibald has committed to seeing the National Youth Committee (NYC) established as well as the time that he has given to the global bleeding disorders community. Karl has also been a great sounding board for many parents throughout the years. Thanks for playing an integral role in getting the NYC off the ground Karl and we look forward to having you continue as our Chairperson.

Raukura Riwaka is another emerging talent. With his innovative use of various media forms such as art and video Rau has really managed to capture some amazing sentiments and experiences that our members have shared. Many of you would have seen his work on the Facebook page. Rau has bought a new dimension to the NYC from which we can continue to build.

We would also like to welcome Tama Pene our new Maori Youth delegate on the NYC. We appreciate the commitment of his time and look forward to seeing what talents he can offer.

Kyle Cunningham and Jordan Young have also recently extended their experiences and skill set. Both have returned from SURO and we can't wait to hear about their experiences and the new ideas they have picked up. Congratulations to Jordan who is the new Northern Youth representative for the NYC.

The young men and women that make up the youth portion of our membership have a lot to offer and it is our intention to tap into that so that we can engage youth members as well as provide great mentors and role models for the younger members. We are incredibly proud of the vision that the NYC is striving to fulfil and what we have already achieved and have nothing but energy and excitement with which to meet the challenges and successes of the next year.

# Youth Abel Tasman Tramp

*After early morning flights arriving into Nelson and a trip to Marahau in a van, which didn't like going into second gear, or third, fourth or fifth for that matter; the youth made it to the start of Abel Tasman Coast Track to commence their first national event, a tramp.*

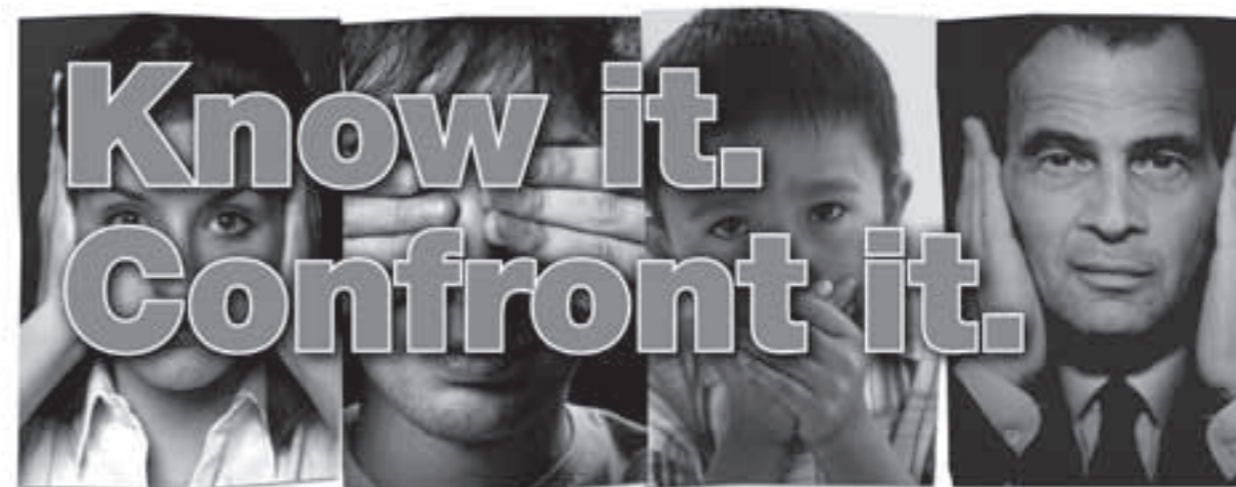
After sorting out equipment and the divvying up of food we were off. We initially walked along the side of the road, but we soon found ourselves walking through the bush, up and around headlands and every so often we would catch a glimpse of the stunning coastline between and over the trees. After a couple of hours we stopped for a quick lunch at one of the golden granite sand beaches, however before long we started the next hill climb, up and over the top and into slow decent to the Anchorage Hut where we stayed for the first night.

On arrival to the hut, we had a quick breather before most of us got straight into the water for a refreshing swim. Later that night we broke out the cards and got down to some serious card playing. Scum, also known as P's & A's and many other names, turned out to be the game of the trip. Cards continued throughout dinner, which was steak. One or two pieces even came served with gourmet hut floor crusting. To finish the night we ended up going down to the beach to make the most of the view and the fading light.

On the second day we had a couple of medivacs in the morning with a water taxi taking two of our members to the next hut to find something for dinner (and give their ankles a bit of a rest). The rest of us had a slow start while we waited for the low tide to cross the estuary and save ourselves a steep 2 hour up and down trek. This gave us an extra couple of hours to spend relaxing on the beach. Eventually the day started with a walk down the beach then across an estuary where the tide was further out in some parts than others. Some of us managed to get across without wet feet, not many though. On the other side of the estuary was Torrent Bay Village. There are "roads", paths and houses there but not too many cars. With no road access the only vehicles using the roads were tractors towing boat trailers to the beach. When we reached the next hut our team members who had gone on ahead in the water taxi had come through with dinner! While there, we fished off the rocks and the fishing line got caught... on mussels, the biggest mussels we had ever seen. We all got in and picked mussels off the rocks, proving that haemophiliacs really are ideal hunter gatherers. That evening there were more games of scum before bed.

The last day of walking started with a long steep climb which was a rude awakening after the relaxed morning we'd had the day before, but the view at the top was worth it! When we arrived at Awaroa Bay we found a hotel, complete with pizza bar in the garden. We made our way to the other end of the beach to the DOC hut to set up our beds, play some more cards and have some dinner. After 3 days of freeze dried dinners we had a second dinner with a few brews at the pizza bar. We played a few more rounds of cards before heading back along the beach to our more modest hut accommodation.

The next day we had a full breakfast at the lodge then took the water taxi back to Marahau and a freshen up in Nelson before departing for the airport and flying home.



**Hepatitis affects over 500 million people.  
It could affect you.**



**This is hepatitis...**

**World Hepatitis Day: 28 July**  
[www.worldhepatitisday.info](http://www.worldhepatitisday.info)



# News in Brief

## Bond University Seeks Participants for the Hepatitis C Treatment Outcome Study

Bond University in Queensland, Australia is seeking survey participants for The Hepatitis C Treatment Outcome Study. The study is investigating the physical, psychological and social factors associated with Hepatitis C treatment outcomes. Previous research has indicated that certain physical and psychological profiles predict better treatment outcomes across a range of medical conditions. The aim of the study is to gain a greater understanding of individual's profiles that are associated with better Hepatitis C treatment outcomes.

Individuals aged 18 or over, who have internet and a current email address, and are preparing for Hepatitis C treatment are being asked to complete two confidential online surveys. One survey is to be completed prior to the commencement of treatment and the second during treatment.

Further information is available by contacting Mr Simon Langston at [slandto@bond.edu.au](mailto:slandto@bond.edu.au) or at <http://hepcstudy.hsstechnology.bond.edu.au/>.

## Factor VIII Products and Inhibitors in Severe Hemophilia A

Gouw et al has reported on the findings of a study on inhibitor development in the New England Journal of Medicine. The study has provided a comparison of the risk of inhibitor development associated with different factor VIII molecules in previously untreated children with severe haemophilia A. The findings indicated there is a higher rate of inhibitor development for second generation recombinant factor VIII. Recombinant and plasma-derived factor VIII products conferred similar risks of inhibitor development. The content of von Willebrand factor in the products and switching among products were not associated with the risk of inhibitor development. Second-generation full-length recombinant products were associated with an increased risk, as compared with third-generation products.

The generation effect was questioned by peers who suggested that a sensitivity analysis be undertaken to compare first and second half patients and determine if the trends were temporal and influenced by recombinant concentrate use. They suggested comparing the recombinant concentrate produced in baby-hamster-kidney cells and Chinese-hamster ovary cells would test a more plausible hypothesis than the generation effect. The researchers felt that with respect to cell lines only one company produced recombinant factor VIII products that were derived from baby-hamster-kidney (BHK) cells which concludes that cell-line based analysis would not have developed different results.

Source: [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)

## Obesity in Haemophilia Patients: Effect on Bleeding Frequency, Clotting Factor Concentrate Usage, and Haemostatic and Fibrinolytic Parameters

With the rate of obesity in patients with haemophilia on the increase, it was investigated how weight affected bleeding frequency and clotting factor concentrate. The research studied whether prothrombotic changes were different in controls and obese people with haemophilia.

The number of bleeds and clotting factor concentrate usage were compared between obese and non-obese haemophilia A patients. Markers of haemostasis (stopping of bleeding) and fibrinolysis (normal breakdown of blood clots) were compared between people with haemophilia and gender, age and body mass index and matched non-haemophilia controls. The median number of bleeds per patient per month was comparable between obese and non-obese patients. Obese patients used with severe haemophilia used 1.4 times more clotting factor concentrate per patient per month than non-obese patients. However, when adjusted for weight this difference disappeared. von Willebrand factor plasma concentration, factor VIII activity and endogenous thrombin potential were higher in obese than in non-obese controls. Obesity did not influence these markers in people with haemophilia.

Plasminogen activator inhibitor type 1 levels were higher in obese vs. non-obese whereas levels were comparable between people with haemophilia and controls. Plasmin- $\alpha$ 2-antiplasmin complex levels appeared to be lower in obese vs. non-obese subjects, both within controls and people with haemophilia. However, in people with haemophilia Plasmin- $\alpha$ 2- antiplasmin complex levels were higher than in controls. Obesity is associated with an increase in net clotting factor concentrate usage in people with haemophilia, but has no effect on bleeding frequency. In addition, obesity attenuates hyperfibrinolysis in people with haemophilia.

Future research investigating whether obese people with haemophilia need clotting factor concentrate treatment dosed on weight or whether a lower dosage would suffice to prevent and treat bleeding is needed.

Source: <http://onlinelibrary.wiley.com>

## New Data From In Vivo Protein Replacement Platform for Development of ZFP Therapeutics For Monogenic Diseases

Sangamo BioSciences has presented new data demonstrating the successful application of the In Vivo Protein Replacement Platform (IVPRP) to produce therapeutically relevant levels of factor VIII in a mouse model.

"Our IVPRP provides a potentially curative therapeutic solution for hemophilia A – a monogenic disease caused by the absence

of the coagulation protein, factor VIII," said Philip Gregory, D. Phil., Sangamo's vice president of research and CSO. "These data provide further proof-of-concept for the broad application of our IVPRP strategy for monogenic diseases currently treated using protein replacement. Our data demonstrate that a single systemic treatment results in the stable production of therapeutically relevant levels of functional Factor VIII."

The IVPRP method enables the replacement factor VIII gene to be inserted directly into the albumin gene. This ensures that factor VIII is highly expressed at stable levels entirely in the liver. With Sangamo's zinc finger DNZ-binding protein (ZFP) genome-editing technology the IVPRP enables the permanent production of therapeutic proteins from the liver with a single systemic treatment, potentially providing curative treatments for a range of monogenic diseases including haemophilia.

Source: [www.sacbee.com](http://www.sacbee.com)

## Council Corner

### The National Council meeting on 2 February took place in Wellington.

During the meeting the council approved the HFNZ National budget for 2013, including a revised MRG budget of \$8,500 per group that better reflects the actual expenditure within the MRG's.

The Council pre-set membership fees for 2013 at \$25 for a single membership and \$35 for a family. It was also suggested that the End of Financial Year dates be revised to 1 July – 30 June to align with other key governmental organisations and to reduce the workload at HFNZ

during a busy time for large events such as the New Families Camp. The HFNZ AGM would therefore need to be held in August or September and the MRG AGMs held around May. Committee members would initially need to be on the committee for 18 months until HFNZ started the next 12 month cycle. These changes were later voted on and passed at the National AGM.

Colleen McKay (Manager - Outreach Services) presented on the November Twinning Visit to Cambodia that Grant Hook (National Treasurer) also attended, as well as an update on Outreach delivery.

A RAMS (Risk Assessment Management System) document template has been developed to evaluate any potential risks that may occur at all national and MRG events, excluding low risk activities like dinner. This is to reduce the incidence of injury and manage the HFNZ's potential exposure to loss and liability. The RAMS document is to be used from February 2013. Additionally, Outreach Workers will now have First Aid Kits kept in their vehicle during visits and at regional activities, and gain or update their First Aid Certificate.



Leave a Lasting Legacy

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

Information on making a bequest in your will to the HFNZ can be found at [www.haemophilia.org.nz](http://www.haemophilia.org.nz)

## MRG E-newsletter - Update Your Email Address

The MRG's are moving toward using email to send members news and invitations to events. Emails are not only a quicker form of communication, they are also cost and time effective. If you wish, you can still receive mail via the post, however if you prefer to receive information via email, please ensure that Leanne (HFNZ Administrator) has your current email address. Please contact her at [leanne@haemophilia.org.nz](mailto:leanne@haemophilia.org.nz) to update your details.



# Melbourne Congress 2014 Applications

Applications to apply for funding to attend the World Federation Haemophilia Congress, held in Melbourne in 2014, are now being accepted. Congress is a wonderful opportunity to learn about the advances in haemophilia care, and to meet international people with bleeding disorders and members from the comprehensive care teams.

To apply for funding to attend Congress you must:

- Be available to travel to Melbourne from 11-14 May 2014
- Hold a valid passport – must be valid for at least six months from the time of travel (and a current visa if applicable)
- Not have any criminal convictions that would stop you from entering Australia
- Have a strong command of the English language and be able to write reports on the sessions you attend for Bloodline

Please note - Child care is not available at Congress and children are not allowed to attend sessions.

The deadline for applications is set at Monday 14th October 2013. Recipients will be notified on or before Friday 1st November 2013.

Information and application forms are available at [www.haemophilia.org.nz](http://www.haemophilia.org.nz), from your MRG or Outreach Worker. Completed Forms must be received by email or POSTMARKED on or before 14 October 2013 to HFNZ, as stated on the application form.

## HFNZ News



### World Haemophilia Day

World Haemophilia Day was celebrated around the country in April. Southern celebrated with an evening of guest speakers from the bleeding disorder community. The speakers included (Left to right in photo) Belinda Burnett, HFNZ CEO; Dr Mark Smith, Haematologist/Clinical Director; Siobhan Cross, Paediatric Haematologist; Linda Dockrill, Southern Outreach Worker; Carolyn Lauren, Research Nurse; Kathy Fawcett, Haemophilia Nurse and Amie Myers, Physiotherapist. Each speaker gave an overview of their role within the Comprehensive Care Team and there was the opportunity for the audience to ask questions. This event was kindly sponsored by Baxter Healthcare Ltd.

A raffle for the Cambodian Twinning Project was also held and raised \$138. Other MRG events included a Northern dinner held simultaneously in Auckland and Northland, and a dessert evening at Strawberry Fare for Central members.

### Kyle Cunningham on CTV

Christchurch member Kyle Cunningham was interviewed about his journey with haemophilia on Canterbury Television's – Canterbury Life on World Haemophilia Day. The video is available to view at [www.haemophilia.org.nz](http://www.haemophilia.org.nz).



### Farewell David

In May we farewelled David Betts, who was at the HFNZ on practice placement for his Bachelor of Social Work. David was an active participant at the National office and at events including the Youth Tramp, AGM and Youth Camp. We wish him well for the future.

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Christchurch**

**Singles & Partners Welcome**  
**Watch in the mail for your invite**

## Dates to Note

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

### **19 - 21 July**

Womens Retreat  
Cophorne Hotel HarbourCity  
Auckland

### **27 July**

Northern Waitomo Caves  
Waitomo Caves  
Otorohanga

### **28 July**

World Hepatitis Day

### **17 August**

Southern 'The Secret Lives of Henry and Alice'  
Christchurch

### **25 August**

Northern Stardome  
Stardome  
Auckland

### **27 - 29 September**

Come to Casablanca - Adults Weekend  
The Elms Hotel  
Christchurch

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