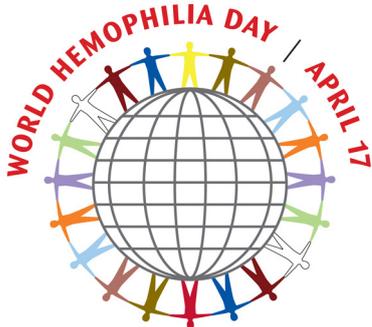




Our People: Rodney Phillips Wins Top Chef Award

World
Haemophilia
Day



Page 8

Young
Women's
Weekend



Page 11

Julia
Phillips



Page 14



CONTACT DETAILS

Website

www.haemophilia.org.nz

National Office

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

President

Deon York
deon@haemophilia.org.nz

Chief Executive

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

Editor

Phil Constable
phil@haemophilia.org.nz

Manager Outreach Services

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

Linda Dockrill

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

Lynne Campbell

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

Joy Barrett

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

Nicky Hollings

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

The Word



HFNZ says good bye (for now, we hope) to Julia Phillips

When I turned 18, I found out that I would be under the care of a new haematologist. Her name was Julia. It's always an adjustment going from one doctor to the next but it is the reality of having a lifelong condition. Now I cannot imagine a haemophilia clinic without her, yet unfortunately I will need to as the Wellington region says goodbye to Dr Julia Phillips.

My adept maths skills tell me that Julia has been my doctor for nearly half my life. When I put it in those terms, it is no wonder that I was so saddened to hear of her departure. Although I only occasionally go to my local GP, thanks to Julia's comprehensive letters he seems to know me better than I know myself. With Julia as my doctor, I have always felt part of the decision making about my care. I know that I am not alone in missing Julia in our region.

We wish you all the best Julia, and hope that in time you are able to make your way back to our community again. Your care of us, and with us, was second to none.

You can read more about Julia on page 14 of this edition of Bloodline.

Ngā mihi nui / Regards,

**Dean York
President**

Contents

Our People: Rodney Phillips	1
NZ Health Strategy Update	3
World Haemophilia Day & the HFNZ Buddy Awards	8
Your NFNZ Outreach Team	10
2016 Young Women's Weekend	11
NACCHO	13
A big HFNZ thanks to Julia Phillips	14
MRG Reports	15
Communication is the Key:	
Educating the school about you child's bleeding disorder	19
Walking Analysis and Haemophilia	21
News from Around the World...	22
The Year Ahead	28



Find us on
Facebook

www.facebook.com/haemophiliaNZ
Masters Group (request to join)
www.facebook.com/groups/hfnzmasters



HFNZ Bank Details:

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

Cover photo: HFNZ member Rodney Phillips wins Senior Lifestyles Cuisine Competition at the National Chef's Salon

Our People: Rodney Phillips, Top Chef



*We all know that life isn't always easy when you have a bleeding disorder. But Rodney Phillips is one of those people who is able to rise above it all and really succeed in his chosen field. **Phil Constable** spoke to Rodney about his life with haemophilia, and winning a prestigious award.*

Rodney Phillips is another HFNZ success story. Executive Chef at Elderslea Lodge in Upper Hutt, Rodney recently won the inaugural Senior Lifestyle Cuisines Competition at the NZChefs National Salon 2015. His winning dish was a spiced and crumbed chicken thigh with potato croquette, pureed carrot, buttered broccoli, and a thyme-infused gravy.

His 15 years as a chef has included stints at Chow in Wellington and Cafe Reka, by the Dowse art museum. But Phillips says that he's really enjoying his time at Elderslea, because the hours aren't as long and it's not so intensely

competitive. The best part is that the residents at Elderslea are so appreciative. "We get such good feedback. The meal is a highlight of their day; we get people waiting to get into the dining room."

Chefing is a very physically demanding occupation, and to be able to put in the hours and effort necessary to succeed when you have severe Haemophilia and a knee replacement is testament to Rodney's ability, tenacity, and sheer will-power. Winning this competition goes to show that having a bleeding disorder need not be a barrier to success.

After his big win Bloodline talked to Rodney about his work, where he's come from, and his plans for the future:

Bloodline: Hi Rodney, congratulations on your win. When were you first diagnosed with a bleeding disorder?

Rodney: Thanks. I don't know the fine details of how it all happened, but I do know that I was abandoned in hospital by my birth mother when I was born, and about 5-6 month later I was adopted. It wasn't until I started to use a baby walker that I began to get these bruises all over my stomach. At first the GP thought that I was being physically abused, but after meeting with a specialist, and a few tests later, they worked out that I was a Severe Haemophiliac. So, I think I was about 1 or 2 years old.

BL: How did your bleeding disorder impact on your childhood/growing up?

RP: Greatly! Like all kids you want to

play and run around and hang out with friends. But the treatment and medical expertise wasn't great in the 70s, so any bleeding episode could put me in hospital for two weeks, or, if I was lucky, 5-6 hours in A & E waiting for treatment, followed by having to tell the doctor what to do. Unfortunately, the long delays in treatment resulted in the need for some major surgery.

BL: Are there special people who helped you along?

RP: My Mum (adopted), of course. Without out her support and love I don't think I would be the man I am today. Dr De Zoysa, who took over my treatment when I was about 11 or 12 and really moved things forward. Also Dr John Carter and Dr Bart Baker who I had not meet either of until I was 16 or 17. They sorted a protocol for my treatment and made sure that I had regular visits at their clinics in Wellington and Palmerston North.

BL: So, what was your pathway into cheffing?

RP: Well, with all this time in hospital I found a talent for art, which led to me wanting to be a sign writer. I loved doing the job, but it was too hard on me physically, and I had to give it up and get a knee replacement, among other things. The long road to recovery meant that I needed a career change. I always had an interest in cooking, so I enrolled in a two year course to become a chef. I worked in local restaurants and cafes in Wanganui and made some great friends, including a beautiful American waitress. One thing led to another and we moved to Wellington, bought a house in Stokes Valley, and now have two beautiful daughters.

BL: What jobs/challenges have you had?

RP: A chef's life is not as glamorous as what you see on TV. It's tough hard work. The longest day I have worked was 14.5 hours: we got cleaned out, got to bed at 1am, and back at work at 7am to prep for the next day's service. Your feet are ringing, muscles ache, and espresso coffee is your best friend! Speak to most chefs and they will agree that Mother's Day would be one of the busiest day/nights to work. One café I was at for 5 years. On a Sunday we would average 140-180 meals for the day but on Mother's Day you could double that! But in saying all that, it can be a lot of fun, the

people you meet, after work drinks, job satisfaction.

BL: Did you do much training?

RP: Yeah, I did two year's chef training. The first year was laying all the foundations, doing the basics, and the second was a lot harder with more practical assessments. The whole time I was training I worked as a kitchen hand too, and then as a chef as my skills improved. I averaged about 35 hours per week at tech, and 35 hours at work. There was more than one occasion that a few of us would doze off during a theory class!

BL: I'm sure. So, what was the hardest part of your training?

RP: The theory was never a good time for me. But with hard work I managed to get good grades that set me up with the skills I still use today.

BL: And did your haemophilia impact on your choices?

RP: Strangely, long hours standing didn't bother me as much as you would think. But when you do get a bad bleed, and have to take time off to recover, you feel like you're letting the team down. Outside of work, I would have loved to have played more sports. I did use to be quite a fast runner, and would get picked last when playing bull-rush at school so they would have more chance of catching me. But if I got ankle tapped I was out for two weeks to recover. You soon learn what your limitations are and adjust.

BL: As far as cheffing goes, who were your role-models or inspirations?

RP: A few celeb chefs maybe; Jamie Oliver, Al Brown, Peter Gordon. But really more my tutors at tech; Joe Powers, Claude, chefs who I respect and consider friends. Various head chefs that I have worked with who have shown me the right (and sometime the wrong) way to handle certain situations.

BL: How did you end up at Elderslea?

RP: After a rough year and a half of switching jobs, because I was sick of working nights and weekends and not spending enough time with my family, I came across the position advertised on trade me. It sounded like the change I was looking for, and I applied and got the job.

BL: Nice one. So, what are the challenges



in terms of cooking for the elderly?

RP: Ensuring that meat is cooked until spoon tender, the food is tasty, constant temperature checks, and that dietary plans are kept to. Also that the menu that's designed by our dietician is adhered to. Our parent company are now starting to put fully-trained chefs into kitchens in other facilities around the country. So things are looking good for aged care cuisine.

BL: Tell me about the inspiration for your dish.

RP: I wasn't inspired as such, because there were guidelines that we had to stick to and ingredients that we had to use. I had to use:

Chicken (no bone)
Instant Mash (Maggi Product one of the



major sponsors)
 Light Gravy Mix (Maggi Product)
 Two NZ grown Vegetables

BL: Ok. What were the judging criteria?

- RP:**
- Degree of cooking and skill involved
 - Sponsored product used
 - Wastage
 - Correct hygiene protocol
 - Clean work area
 - Presentation of dish
 - 3 plates Main
 - 3 plates Soft Diet (same components but pureed and shaped)

BL: So, what next for Rodney Phillips?

RP: I have a few projects on the go at the moment. One is a café called Mint Café that I've set up in the facility, in an unused area by reception, that is going really well. The idea behind it was to get the residents

out of their rooms, tempt them with good coffee & tea, tasty sweets, and savoury dishes. It's free for the residents but any staff, family, or friends pay a small charge which goes towards the activities budget. Also, I'm working with our Dietician to fine-tune the recipes for the winter menu rotation. I also came up with the idea of setting up a pop-up shop in a vacant space in Upper Hutt to promote what we do here. It's going to look like a resident's room, and have a TV scrolling through all the cool things we get up to.

BL: Sounds great. Are there other competitions you'll enter?

RP: I will try and defend my title in August, but I do think the competition will be tougher. The other Chefs will know what to expect now, and will have all guns blazing!

BL: Anything new on the horizon?

RP: Maybe expanding the kitchen and doing out-catering, who knows...

The New Zealand Health Strategy is Set for Change

The government is currently reviewing and updating their health strategy. They're looking at how and why things are done, and deciding whether there's a better way. While there are many highly skilled and dedicated people working in the health system, it doesn't always service the needs of the community effectively, and it can be difficult to ensure fair access to limited resources. **Phil Constable** discovered that the challenge is to ensure that the right services can be delivered appropriately.

The current Health Strategy was developed in 2000. Since then a lot has changed, so it's time to re-evaluate, and look to the future. To that end the government has released two documents addressing what they believe needs to be done, and how they're going to do it.

Part One, Future Directions, looks at some of the key challenges and opportunities facing the current system. It describes the future they want, including looking at culture and values, and introduces 5 strategic themes for the changes that will take us into the future.

Part Two, Roadmap of Actions, identifies specific areas of work for the next five years that will allow the Strategy to be put in place.

1. Future Directions

In general, Ministry data suggests that NZ's health system does fairly well. 90% of New Zealanders report that they are in good health or better, 80% say they are happy with the care they get. 95% of people are enrolled with a primary health provider, and it is reported that we are more likely to get a doctor's appointment within 48 hours than people in the UK or Australia. Our current health system supports over 12 million daytime GP visits per year, dispenses over 64 million pharmaceutical items, and completes in excess of 24 million lab tests.

However, there are challenges too.

New Zealanders are living longer, which is great for individuals, but tough on resources and affordability. Keeping older people healthy and independent generally takes considerably more health and social services than younger people. Long-term chronic conditions, like haemophilia, are particularly challenging in aging populations.

Obesity is another condition that is becoming more common, and carries a host of long-term health impacts. Currently 10% of New Zealand children are identified as being obese, with the rate rising to 25% among Pacific children.

Also, some of New Zealand's population groups get unequal benefits from our health system. This is obvious in our life expectancy statistics, where, as a group we are living longer, but Māori and Pacific people still have a lower life expectancy.

At the moment NZ's total health spend is only just over the OECD average at around \$9.5 billion. That's about 7% of GDP, and is largely funded by taxpayers. However, treasury estimates that this figure will rise to around 11% by 2060, unless some changes are made.

There are also challenges from within the health workforce:

- It is aging – 39% of doctors and 46% of nurses are over 50
- It has a large number of care and support workers (about 63,000) with limited access to training
- Many of the workforce have trained overseas – 46% of doctors, 34% of midwives, and 26% of nurses – and are not permanent residents

In general, the needs and expectations of our health system are changing as our population ages, and as a result of increased ethnic diversity.

The opportunities identified include a focus on prevention and making healthy choices easy in order to stop or slow the occurrence of some health conditions. This includes early intervention, taking advantage of advances in technology and related infrastructure, the automation of routine tasks to free-up skilled staff, and the sharing of information across organisations to ensure everyone is getting the right treatment at the right time.

What government is aiming for is a system that reduces disparities, is fair and responsive to the needs of all people, and ensures a quality of life that maximises years of wellness.

To get there the 7 guiding principles from the 2000 strategy have been retained, and one more added:

1. The best health and wellbeing possible for all NZers throughout their lives
2. An improvement in health status of those currently disadvantaged
3. Collaborative health promotion and disease and injury prevention by all sectors
4. Acknowledging the special relationship between Māori and the Crown under the Treaty of Waitangi
5. Timely and equitable access for all NZers to a comprehensive range of health and disability services, regardless of ability to pay
6. A high performing system in which people have confidence
7. Active partnership with people and communities at all levels
8. Thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing

As a result of a focus on these guiding principles government hopes to see a behaviour shift at a system level:

- From treatment to prevention and support for independence
- From service-centred delivery to people-centred services

- From competition to trust, cohesion, and collaboration
- From fragmented health sector silos to integrated social response

Building on the guiding principles, the Draft Strategy has 5 themes, which are interconnected, and reflect the balance between what's best for people's health and well-being, and what is affordable and possible. The aim is a more cohesive system that works in the best interests of all New Zealanders.

1. People Powered

This theme is all about understanding what people need and want, and partnering with them to design suitable services. The key is to empower people to be more involved with their health by engaging with them and helping them make healthy choices. This theme focuses on communication, and includes supporting people's navigation of the system, building health literacy, and encouraging the use of technology.

The Government would like to move towards a more customer-focused approach that provides pathways to care that meet their immediate needs, as well as catering for their future needs across all stages of their lives. A people-centred approach seeks to understand how health fits into people's lives, and how it relates to their common needs, interests, and priorities. This can involve the development of tailored services that better cater for specific populations.

Here's what the Health Strategy sees People-Powered health looking like in 10 years' time:

- People have control of their own health, they make informed choices, and can access relevant information when they need it. E.g. through patient portals
- People charged with providing health and well-being services understand the specific needs and goals of the individual they're supporting, their family, whānau, and community, and are focused on the needs of the patient at all times.
- People can access practical information that supports them to make healthy choices and stay well. Technology tools are options for everyone.
- New Zealand has a reputation for innovative and effective patient-centred health services.
- People receive high-quality, timely, and appropriate services in the most convenient way.
- Health and injury services provide a more consistent experience for people.

2. Closer to home

This theme is all about more integrated health services; investment early in life and a focus on children, young people, and families and whanau; care closer to where people live, work, learn, and play; and a focus on wellness and prevention of long-term conditions through population-based and targeted initiatives.

This is important because good health begins in the home, and in communities. So, it makes sense to locate support services

as close to these places as possible; and that services are as coordinated as possible. Māori organisations are particularly well-placed, and can teach us all a lot. They are historically geared towards their population base, and the communities they serve, and are inherently people centred. This is doubly important as Māori and Pacifica adults are often the most likely to feel unable to access primary health care.

As well as developing new services, the goal here is to sustain already successful services, and to make better use of the opportunities they provide to work with families, and to promote healthy choices. This will require a social-investment approach and coordination across agencies.

This is what the Health Strategy sees Closer to Home looking like in 10 years' time:

- People are safe, healthy, and well in their own homes and communities.
- We have well-designed and integrated pathways for the common journeys people take through our health and disability system, starting and finishing in their homes.
- We have workforce capability and capacity in primary and community services that provide high-quality care as close to home as possible.
- We have adapted our service configuration so that we can leverage scale where we need to and take advantage of cross government partnerships, as well as public and private partnerships.
- Māori and Pacific health models, such as Whānau Ora and the Pacific Fonofale model, are used to provide effective and accessible care responsive to their communities.
- Our health system contributes to lifelong health through its support for parents, children, families, and whanau.
- We are good at identifying key health problems, preventing them or slowing their deterioration, and keeping people well. We provide coordinated care and rehabilitation for people with complex conditions, injuries, or disabilities, as well as for frail older people, and for children and families with unmet needs.
- The health system works effectively with other agencies, to improve outcomes for all children and young people, and particularly those at risk, through strong community links with early childhood centres, schools, marae, churches, local authorities, and other social service agencies; for example, in the areas of housing, social development, and corrections.

3. Value and high performance

This theme focuses on outcomes. This includes people's experiences of care, health and equity of health outcomes, and best value use of resources. Through transparent use of information to drive learning and decision making, strong performance measurement, and a culture of improvement, the new strategy strives for equity of health outcomes for all. This theme promotes an integrated operating model that makes people's responsibilities clear, and the use of investment approaches to address complex issues.

Because our current system needs to do better for groups whose

health outcomes are below national averages, the focus needs to be on removing barriers to delivery within the health sector, and between sectors. There needs to be clarity around who is responsible for what, and new ideas and evidence needs to be shared and put into practice more efficiently throughout the system. By being more integrated in our approach to healthcare across providers and stakeholders, adopting a more holistic approach, we can get better value for money, and better outcomes for all.

Here's what the Health Strategy sees Value and High Performance looking like in 10 years' time:

- The health system provides high-quality, accessible health services, that best help people live well, stay well, get well, at the lowest cost it can and within the income it has.
- The system deploys its resources skilfully to ensure services effectively reach people who need them. As a result, the system is more socially, financially, and clinically sustainable.
- Clinical and support systems are clearly understood. All involved in delivering and supporting services strive for excellence and improvement, and engage in analysis and modelling.
- All New Zealanders enjoy good health, and there has been a clear lift in health outcomes experienced by population groups previously disadvantaged, such as Māori, Pacific peoples, and people with disabilities.
- The health system minimises harm to people, by ensuring that it honestly and openly tracks harm when it occurs, and learns from mistakes, so that the system as a whole can improve.
- The health system has an operating model that clarifies relevant policies, legislation, regulations, guidelines, standards, roles and responsibilities, funding arrangements, systems and processes, and strategic direction. The model allows all parts of the system to play their roles effectively and efficiently.
- Funding approaches consider multiple 'bottom lines' as part of a commitment to a social investment approach.
- The health system constantly monitors its performance and scans the environment to ensure it is functioning well, maintaining its strategic direction and detecting changes. It learns and shares knowledge and innovation rapidly throughout.

4. One Team

This theme is concerned with operating as a team in a high trust system. The goal is to make the best possible use of the health and disability workforce, to develop leadership and to grow skills throughout the system, and to strengthen the role of families, whānau, and communities as carers. This involves system leadership by the Ministry of Health, and collaboration with researchers.

To achieve a high performing system, it is important to foster a more cohesive team approach across the health and disability sector, and to be able to work beyond organisation boundaries. Reducing the fragmentation of the system and increasing trust and collaboration will help to improve the service, and reduce doubling up of resources.

It's also important to make sure that the size and skills of the health and disability care workforce matches New Zealand's needs. This includes strengthening the capabilities of the NGO providers.

This is how the Health System sees One Team looking in 10 years' time:

- The health system is more than the sum of its parts, with each part clear on its role and working to achieve the aims of the system as a whole.
- The system has competent leaders who have an unwavering focus on the system's goals, and a culture of listening carefully and working together in the interests of people's ongoing wellbeing.
- New Zealand offers coherent pathways for leadership and talent development that inspire and motivate people already working in the health system, and those considering health work as a career.
- We invest in the capability and capacity of our workforce, including that in NGOs and the volunteer sector, and make sure that it fosters leadership, flexibility, and sustainability.
- The Ministry of Health is a competent system leader, playing its role effectively as part of the wider health and disability system, and partnering with other sectors.
- There is a culture of enquiry and improvement throughout the health system, and seamless links to the New Zealand and international science communities.
- New Zealand and international research, best practice, and local innovations are shared freely and used to roll out improvements nationally.

5. Smart System

To be a smart system, information must be reliable, accurate, and available at the point of care. That means having individual online health records that people can access and contribute to, information systems that improve evidence-based decision making and management, and standardised technology that works for the majority of users. It is also important to be able to take advantage of new technologies as they emerge.

The new system needs to include smart data collection systems, and well-organised data that helps to target specific population groups. The system must include ways to continuously monitor, evaluate, and learn, so that approaches can be standardised where possible.

This is what the Health System expects a Smart System to look like in 10 years' time:

- New Zealanders make regular and effective use of a patient portal to access their health information and improve their interactions with their doctor and other healthcare providers.
- When people first attend a health service, the provider already knows their details. Their journey and scheduling are integrated.
- People at risk of various conditions have easier access to follow-up tests and services and benefit from more individually tailored treatment and management plans.

- The quality of health care is high as health workers spend quality time with people, errors are reduced and better decisions are made.
- The data we collect is more specific, so that management can be more proactive.
- Data is used consistently and reliably, with appropriate

2. Roadmap of actions

The Roadmap of Actions lays out in detail 20 key steps to undertake over the next 5 years in order to grow an effective new Health System, based on the 5 themes identified in the Future Direction document.

People-Powered	1. Improve coordination and expand delivery of information to support self-management in health through digital solutions.
	2. Promote people-led service design including for high-need priority populations.
Closer to Home	3. Ensure the right services are delivered at the right location in an equitable and clinically and financially sustainable way.
	4. Enable all people working in the health system to add the greatest value by providing the right care at the earliest time, fully utilising their skills and training.
	5. Increase the effort on prevention, early intervention, rehabilitation, and wellbeing for long-term conditions and for obesity.
	6. Collaborate across government agencies, using social investment approaches, to improve the health outcomes and the equity of health and social outcomes for children, families, and whānau, particularly those at risk.
Value and High Performance	7. Implement service user experience measures.
	8. Implement a health outcome-focused framework to better reflect links between people, their needs, and outcomes of services.
	9. Work with the system to develop a performance management approach with reporting that enhances public transparency.
	10. Align funding across the system to get the best value from health investment, starting with better access to those most in need, improved delivery of major capital expenditure, and more effective commissioning by contracting for outcomes.
	11. Develop and use a health investment approach with DHBs and consider using this to target high-need priority populations to improve overall outcomes while developing and spreading better practices.
	12. Continuously improve system quality and safety.
One Team	13. Improve governance and decision-making processes across the system, through a focus on capability, innovation, and best practice, in order to improve overall outcomes.
	14. Clarify roles and responsibilities and accountabilities across the system as part of the implementation of the Strategy.
	15. Establish a simplified and integrated health advisory structure.
	16. Implement a system leadership and talent management programme and workforce development initiatives to enhance capacity, capability, diversity, and succession planning and build workforce flexibility.
	17. Create a 'one team' approach for health through an annual whole of system forum, sharing best practice and contributing to a culture of trust and partnership.
Smart System	18. Increase New Zealand's national data quality and analytical capability to improve transparency across the health system.
	19. Establish a national electronic health record that is accessed via certified systems including patient portals, health provider portals, and mobile applications.
	20. Develop capability for effective identification, development, prioritisation, regulation, and uptake of knowledge and technologies.

Coming Soon: World Haemophilia Day and the HFNZ Buddy Awards

April 17th is World Haemophilia Day, a day to highlight all the hard work that goes into living life with a bleeding disorder, as a sufferer or a supporter. It's also a day to raise awareness of haemophilia and other bleeding disorders with the general public. It's an opportunity for us to talk to our family and whānau, friends and neighbours, about what it means to have a bleeding disorder, how they can help, and how much we appreciate their support.

This year the World Federation of Haemophilia are again encouraging their community to come together and show their support for World Haemophilia Day by lighting it up red. Each year new landmarks and monuments have been added to the list of WFH partners who support World Haemophilia Day by making their external lighting red on April 17. So, here's a World Haemophilia Day challenge... If there is a landmark near you, a special building, statue, or monument, contact them to see if it can be lit up in red on April 17. If not, why not pull out those red holiday lights and participate at home.

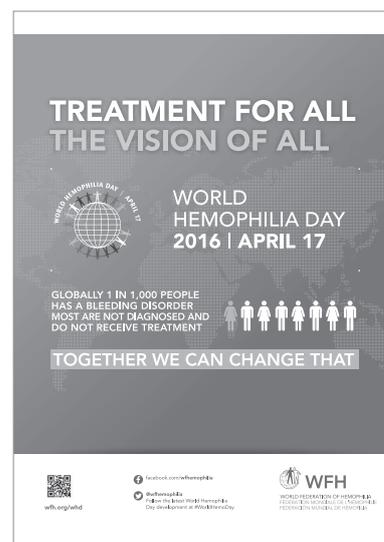
This April 17, join the WFH community in lighting it up red!

That's not all that's happening on April 17th. HFNZ are also running their annual Buddy Awards, recognising all the special people that go above and beyond to make life easier for someone close to them that has a bleeding disorder. In fact, it's not just those that are near and dear. Some of those receiving awards last year were HFNZ staff, who walked the extra mile to be there for HFNZ members.

The Buddy Awards is a great way to show your appreciation for those people that support you, or people you know. And it's so easy to nominate them. Just contact your Outreach Worker, or drop Leanne at Head Office a line (leanne@haemophilia.org.nz) asap, no later than April 8th, and they can get a nomination form to you. Then, on World Haemophilia Day, each region will hold an event at which the 2016 Buddy Awards will be presented.

So, if you know a very special someone

who has made your life easier, or helped out a person you know, think about putting them up for an award. They get a nice certificate, and, even better, they get to know that the things they do are truly appreciated. We all know that good deeds are their own reward, but it's really nice to be recognised occasionally.



HFNZ Hepatitis C Survey: What we learned

*In order to fulfil our contract with the Ministry of Health, each year HFNZ are required to produce a comprehensive report on how our members are affected by HCV, and what we do to support them. The 2015 report was submitted in January 2016, and is summarised by **Phil Constable** below.*

Since 2009 HFNZ have been contracted by the Ministry of Health to provide support services to individuals with both a bleeding disorder and the HCV virus, and their families and whānau. A part of the contract is surveying our members, and producing a report for the MOH based on the feedback we get. The information we collect and supply to the MOH via the report paints a picture of change over time, and gives our members the opportunity to comment on their experiences of the virus and of the available treatment options.

At the time of the survey there were still 37 people who continued to suffer with chronic HCV, out of the original 197 who contracted it via contaminated blood products. Of those, 6 were currently undergoing treatment, 13 had their interferon treatment fail, and 20 are yet to be treated, of which 4 are

ineligible due to age or other health issues.

In 2015, HFNZ spent 671 hours specifically on HCV issues, including 79 hours of Outreach contact with people with bleeding disorders (PWBD) who are also infected with HCV. In particular, a lot of time was spent working with ACC and government to ensure HFNZ members get funded access to the latest direct acting antiviral treatment.

HFNZ also continues to develop and maintain relationships with a number of outside agencies, including the HCV Advisory Group, treatment centres and hospitals across the country, the HCV Community Clinic in Christchurch, the Needle Exchange programme, public health researchers at the University of Otago, and ACC.

One direct outcome of our relationship with ACC in 2015 was facilitating our members' access to the newly approved Harvoni interferon-free treatment. This treatment has been shown in trials to have a 90%+ success rate, and, under the provisions of the Treatment and Welfare Package for People with HCV, all affected HFNZ members with existing ACC claims are eligible, where clinically appropriate.

For the 2015 HCV survey 34 of the 37 existing sufferers of chronic HCV were invited to participate. The 3 remaining people were unable to participate due to ill health. Of those invited, 13 returned their completed surveys.

Of those who responded, 62% reported having ever had treatment, either interferon-based, as part of a DAA clinical trial, or via ACC funded interferon-free treatment. Of those, 38% were currently undergoing treatment, and the remainder had completed treatment longer than 12 months ago. Disappointingly, only one respondent had achieved a sustained viral response to treatment, and another was awaiting the final results post-treatment. Comments from respondents include:

- “Very hard”
- “Had a negative effect but I managed to cope”
- “It was without a doubt the worst 18 months of my life (extended treatment). I had lost ownership and control of my own bodily functions, and was still having to sustain my existence mostly alone.”

When all respondents were asked about their liver health 69% of respondents indicated that they had been diagnosed with fibrosis, 15% with cirrhosis, 7% with varices, 7% with fatty liver, and 7% with hepatic encephalopathy. 23% respondents reported not having of the listed conditions.

For the first time in an HCV survey, all participants were asked if they had agreed on a treatment/monitoring plan with their healthcare professionals with regards to their HCV/liver health. Over three quarters of respondents had agreed on a plan, while 23% had not. Examples of monitoring plans included regular ultrasounds, participating in follow-up monitoring after participation in the clinical trials, and waiting to try the new interferon-free treatment available via ACC.

When participants were asked about the biggest barrier they have faced with regard to their HCV responses included:

- “Tolerable treatment”
- “Initially it was a lack of understanding by myself and the general public. Now it’s really the symptoms particularly fatigue as it restricts what activities I can do.”
- “Getting access to treatment”
- “Doing things”
- “Uncertainty about the future.”

Overall, well over half of respondents felt their general health was good or better. In 2015, 69% reported their general health as good, very good, or excellent and 31% reported it as fair or poor. The proportion who reported their health as poor (8%) was lower than in 2014 (19%).

Many respondents reported having severe physical limitations, especially when relating to vigorous activity (46%); a similar proportion to 2014. Moderate activity was less impacted with 41% reporting significant limitations. Nearly half of the respondents also reported that their health affected their ability to undertake light activities.

While PWBD are often disabled physically, or have impaired mobility, many are still able to go about daily activity, such as

cleaning and dressing. The survey showed that nearly one third of respondents found these tasks harder to complete because of the pain associated with HCV.

HCV-related fatigue is also negatively affecting members in their regular activities. A very high proportion of respondents (77%) indicated they had stopped or at least partially reduced doing a hobby or activity due to fatigue. The impact was similar on social activities, where 69% of respondents indicated their HCV interfered at least partially with their social activities.

While nearly all respondents agreed that they have at least good social support systems, with 25% rating their support as excellent, over half of respondents (61%) worry about the effects of HCV.

There has been a trend towards an increase in reports of depression over the years of the survey with two-thirds of all respondents agreeing they felt depressed to some degree in 2014. However, this trend has reversed in 2015. While 58% report some level of depression, only one respondent reported feeling mostly or completely depressed. It is interesting to note that apathy was reported to affect 54% of respondents at least slightly in 2015, a rise from 2014.

The percentage of respondents who indicated that their level of anxiety has risen has dropped sharply compared to previous years with just 46% of 2015 respondents indicating their anxiety has risen at least slightly, compared to 86% in 2014. Just 8% indicated their anxiety had risen mostly or completely.

Although 73% of respondents agreed that exercise was important to them, 31% respondents reported never participating in moderate activity for more than 30 minutes. However, 62% reported exercising at least two to four times a week, with 15% exercising every day.

Almost all respondents (92%) indicated that they are aware of long term consequences of HCV. The level of knowledge of current treatment continues to be high with 77% of respondents

feeling well or fairly well informed. Most respondents (85%) had at least a good idea of transmission risks of HCV.

HFNZ’s major goal for 2016 is to enable as many of our members as are deemed clinically appropriate to undergo treatment with Harvoni under the terms of the MOH Treatment and Welfare Package for People with HCV.

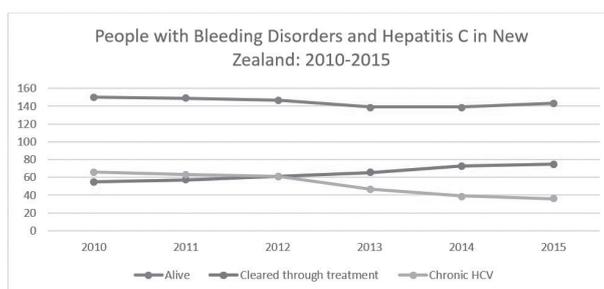


Figure 1. Recent trends in the numbers of people with bleeding disorders infected with hepatitis C through blood products.

To that end, the need for advocacy and support of PWBD and HCV is expected to increase in 2016. Encouraged by the success experiences by the first participants in the DAA treatment clinical trials, HFNZ will be working with all eligible participants to facilitate their access to a clinical trial. Supporting patients through the trial process can be time and resource intensive; however, the possible benefits of increased longevity and better quality of life are invaluable.

As always, Outreach Workers will continue to communicate directly with members, their families and associated organisations (employers, universities, private training establishments) regarding the sometimes debilitating effects of HCV and how it affects the individual as needed on a case by case basis.

Your HFNZ Outreach Team



Colleen McKay
Outreach Manager

HFNZ Outreach Workers offer support and services to members across New Zealand. Through our four regionally-based Outreach Workers, Linda, Lynne, Joy, and Nicky, HFNZ works to support and inform people affected by bleeding disorders, and their family members/ whānau.

HFNZ's Outreach Workers provide education, support, and advocacy. They understand bleeding disorders and the New Zealand health and social services sector. HFNZ's Outreach Service is provided free of charge to all people affected by bleeding disorders. The service is funded through donations, grants and government support.

Our Outreach Workers strive to work in partnership with people affected by bleeding disorders and their families/ whānau to identify their own needs and support them to achieve their potential.

HFNZ outreach workers help in all areas of a person's life providing education, support and advocacy. They provide information about your or your child's bleeding disorder, both when first diagnosed, and as you progress through different life stages. They also help explain information and how to apply it to your individual situation, work with regional Haemophilia Treatment Centres and other medical professionals, and help you understand health and support systems and how to access services. Your Outreach Worker can also provide information and education about your bleeding disorder to other organisations like schools, work, and other support organisations, and facilitate communication and co-operation between individuals and agencies.

Here's what one member has to say about his Outreach Worker:

"She is always helpful in every field. I always feel positive after meeting her and discussing things with her. She helps me to make decisions regarding my job, my health... And I feel that there is someone who is always there to help me".

The Outreach Workers are a great source of information - about HFNZ programmes or events, health concerns, or assistance. Your regional Outreach Workers can help you with:

- Opportunities to meet other HFNZ members for mutual support
- Attendance at HFNZ Workshops Camps and Events

Outreach Workers have many clients, so it is important that you contact them when you need them. They are never too busy for you. They have

the flexibility to support individuals and families in different ways based on specific needs. Your regional Outreach Worker is available by phone, text, email, Facebook, and in person. All Outreach Workers work part-time and will respond as soon as they are available. Members are always welcome to leave messages or emails after hours for the Outreach worker to follow up.

It's also important to remember that HFNZ and our Outreach Workers do not provide medical care or an emergency service. For medical emergencies please contact your closest hospital or Haemophilia Treatment Centre.

Feel free to contact us with any questions or concerns you may have regarding your or your child's bleeding disorder. We are here to help.

To be put in touch with your regional HFNZ Outreach Worker call toll-free: 0508 FACTOR (322867)

Introducing Nicky, our newest Outreach Worker



As many of you will already know, at the end of 2015 HFNZ were happy to welcome Nicky Hollings to the team, to follow in Sarah Elliott's footsteps as the Northern Outreach Worker. After a very thorough selection and interview process Nicky Hollings emerged from the pack as the ideal candidate to support our Northern members.

Nicky has a background in counselling, with an emphasis on drugs and alcohol. She is very experienced at working with families, in supporting people to make good healthy choices, and in helping her people to access the right resources. As we've found out during the last three months, Nicky is bubbly and upbeat, and we're sure she'll be a great asset to the Northern group, and to HFNZ as a whole.

If you come across Nicky be sure to give her a warm HFNZ welcome!



Linda Dockrill
Southern Outreach Worker



Lynne Campbell
Central Outreach Worker



Joy Barrett
Midland Outreach Worker

2016 Young Women's Weekend

Arising from the Youth Leadership Weekend in 2014, Young Women's Weekend was an opportunity for young HFNZ women from around NZ to get together, share, learn, and have fun. From February 26th to 28th the women gathered at beautiful Hanmer Springs for the first of what we hope will be a regular event. **Colleen McKay** reports on the great time had by all.



The notion of a weekend dedicated to education, support, and fun for young women with bleeding disorders came out of the 2014 Youth Leadership Training Weekend, where Lauren Nyhan and Courtney Stevens developed the concept and a plan for such an event.

Courtney, Lauren, and Ashley Taylor-Fowlie put the leadership skills they'd learned at that weekend into practice, and joined Colleen on the planning team. They also took up the challenge to present and participate in a variety of sessions over the course of the weekend.

On February 26th 15 young women flew in from throughout New Zealand, to be met by Outreach Workers Nicky and Lynne. A couple of late flights caused a small delay, but eventually everyone was on the bus bound for Hanmer Springs,

with a short stop at Waikuku Beach Park for lunch: Subway, Sushi, and fruit, delicious!

The weekend all happened at the Hanmer Springs Forest Camp, a former forestry camp surrounded by the beauty of the forest, just outside Hanmer Springs Village. We discovered on our arrival that the Camp was also home for what seemed like a million bees. While the bees generally kept to themselves, two of our young women got to experience bee stings first hand.

The theme for the weekend was Reality TV, so every session was named after a reality television show. First up was 'The Amazing Race', where three teams competed for points in a range of challenges designed for teamwork and group thinking skills. Friday evening's activities began with

getting to know each other a little better, and a panel discussion 'Meet the Experts' where Laura Rutten posed questions to Courtney Stevens, Lauren Nyhan, and Ashley Taylor-Fowlie. Then we enjoyed a 'Reality Television' Quiz Night, which gave us an opportunity for more teamwork, and some fun and friendly competition.

On Saturday morning the young women participated in educational activities presented by the haematologist, haemophilia nurse, outreach workers, and each other. The morning started with interactive games designed to teach about blood and haemostasis (how blood clots), which demonstrated the interaction between platelets, von Willebrand Factor, and Factor VIII and IX in the formation of a blood clot. This was followed by Outreach Worker Nicky's

'Fear Factor' Session where the young women learned some assertiveness skills, and practiced the valuable practice of making 'I' statements.

We were very lucky with our next educational activity. Haematologist Laura Young flew in from Auckland for a comprehensive session entitled 'Women & Bleeding – everything you always wanted to know', then Kathy Fawcett and Laura Young answered all the questions that the young women had in the 'Question and Answer Workshop'.

After all that hard brain work, Saturday afternoon was dedicated to rest and relaxation at the Hanmer Springs Hot Pools. This provided a welcome opportunity for the young women to get off-site, to try out the Hot Pools, and to stroll through Hanmer Village.

Saturday evening was the big 'Master Chef Mystery Food Box Challenge'. Three Teams had 5 minutes for planning the challenge to produce a three plates of food for the judges – two main courses, one for vegetarians and one for carnivores, and a dessert. They then got just 60 minutes to cook a masterpiece for the judges, Kathy, Nicky, and Lynne. This was great fun, and the teamwork and creativity were superb.

After cooking up a storm, it was time for a relaxing evening of entertainment with 'Hanmer's Got Talent'. The evening started with Courtney, Lauren and Ashley demonstrating a range of activities that can be undertaken 'in your activewear', continued with two very brave solo performers, showcased the talents of the 'Pink Fairy' and the 'White Fairy', and concluded with 'chaos on the dance floor' as everyone got up to learn the line dance 'Mama Maria'. Let's just say that there were many interesting and creative moves!

Sunday was our last day, and the programme started with a quick look at 'What is health?', before settling in to take a closer look at Taha Wairua - Mental Health, and learning some tips and tricks for looking after yourself, based on the Mental Health Foundation's Five Ways to Wellbeing – Connect, Give, Take Notice, Keep Learning, and Be Active.

Following that, Courtney turned the Meeting Room into



something that resembled a Beauty Clinic with Face Masks followed by cooling and soothing Wheatie Eye Masks. Everyone had a chance to try Mindfulness Colouring, reflecting and taking notice while occupied with colouring in as a method of reducing stress. There was also a presentation about Giving Back to HFNZ, where a range of ideas and opportunities were discussed among the Regional Groups.

It was fantastic to see these young women supporting each other throughout the weekend - friendships were formed that will last a lifetime. As well as the valuable learning opportunities, we had fun, enjoyed some recreation time, and pampered ourselves. Perfect!

A huge HFNZ thanks goes out to:

Attendee - Stacey Booth

"It has been a fabulous way to meet amazing, strong women with bleeding disorders, and begin making my 'bleeding disorder' network"

- Haematologist, Laura Young - For flying in from Auckland to be with us for the day
- Haemophilia Nurse Kathy Fawcett - For giving up her whole weekend to be with us.
- The HFNZ Outreach Team, both those on Staff at the Weekend and those back at Home Base - For everything that you did to support the Weekend
- The HFNZ Administrative Team: Leanne, Phil and Richard - For everything that you have done for the Weekend
- And finally very big thanks to Novo Nordisk for funding the 2016 Young Women's Workshop Weekend, and for making a difference in the lives of young women with bleeding disorders. The knowledge and support that they have gained will benefit them now and well into the future.

NACCHO

Earlier this year two members of the outreach team, Colleen and Nicky, attended NACCHO, the North American Camping Conference for Haemophilia Organisations. This annual event is a fantastic place to develop the skills and creativity to put on amazing camps that benefit the children and young people who attend them. **Colleen McKay** reports on the great things that happened at NACCHO 2016.

Theme: - Tomorrowland

'The best preparation for tomorrow is to do today's work superbly well' – William Osler

From the 28th to the 31st of January Colleen McKay, Manager of Outreach Services, and Nicky Hollings, Northern Outreach Worker, attended the 2016 NACCHO conference. NACCHO is an annual coming together of the creative minds of those who share a passion for running camps to educate, extend, and nurture children and young people with bleeding disorders.

We were among a small team of international participants from around the world, including Nigeria, Romania, the Netherlands, and the Czech Republic. On the first evening of the Director's pre-conference, the international team were responsible for the pre-dinner reception session, where we introduced each other, and each talked about haemophilia camps in our own countries.

In the very first session at NACCHO, entitled 'Futurecasting', we were challenged to look forwards into 'Campland' and think about what bleeding disorder camps might look like in the future. Things to consider included:

- Medical advances: On the horizon are long-acting factors for haemophilia A & B, gene therapy for haemophilia B, sub-cutaneous factor replacement, and advances in laboratory technologies resulting in increases in the new diagnosis of rare bleeding disorders internationally.
- Demographics: Given the advances in bleeding disorder diagnosis and treatment, how will this change our camp demographic? Will there be a decrease in need for camp? Will there be an increase in activity? Do we need to be more inclusive, with the decrease in normalcy gap?
- Economic factors: Will there be an increase/decrease in the number of pharmaceutical companies involved? Or a change in funding structures? Or a more

difficult fundraising climate? Will camp costs increase? Maybe bleeding disorder camps could combine with another chronic disorder?

- The camp community: How will the camp community change? How will the need for camp change? Which groups in the bleeding disorder community will have greater need? What about inhibitors, and Women, and tweens – those bridging history (between old & new treatments)? Will camp become more important for developing countries?

Given all of these variables, we were challenged to think about where our bleeding disorder camp community would be in ten years' time, and how can we navigate the formative forces. There is much to consider, and there are exciting times ahead. However, one thing is clear – we must celebrate the advances in care, think about the future, plan for it, and move forward.

The NACCHO Conference has five Tracks for participants covering all aspects of camp organization and camp life:

The Administration Track: This involves all of the nuts and bolts of how to budget, promote, insure and manage camps including facility management, registration, policies, and much more.

The Staff Training Track: Information within this category falls into two areas:

1. That relating to staff hiring, training, and management
2. That related to camp leadership theory and practice, cultivation and training, vision, ethics, community building, and establishing and maintaining Camp Culture.

The ultimate challenge for the camp director is to create and maintain an environment in which elite and talented camp staff can sparkle.

The Camper Life Track: This relates to child & youth development in theory and

in practice. Sessions cover contemporary parenting issues, working with children with behavioural challenges, issues related to bleeding disorders, as well as related to working with parents, building partnerships, setting limits, and enforcing camp rules. One important take home message... 'Kids need challenges to give them the resiliency skills to cope with life events'. That means giving kids real life struggles so they can develop the skills necessary to cope with struggle in life.

The Programming Track: This track is critical, as it relates to the ways in which the camp programme is executed, and the activities within the camp programme. We were challenged to think about 'What is the why?' in intentional Camp Programming. It's inspiring to have a why? Why do we do this? FTK - For The Kids! Why?

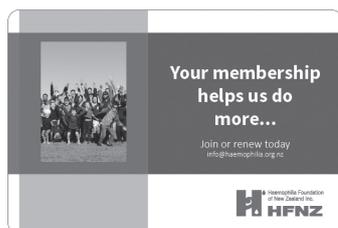
- To challenge,
- To develop self-reliance
- To meet individual's needs
- To want more for each camper
- To create a culture of 'yes you can'
- To build friendships
- To have FUN!

Being well prepared with a strong, well thought out, well-structured intentional programme together with a back-up plan pays off in the long run, or, as the session was named... 'If you wear your belt and your suspenders, you'll have less chance to get caught with your pants down!'

The Medical Track: Information in this track related to camper information, camper bleeding disorder education as well as camp emergency preparedness.

A HUGE thank you to Pfizer for funding the NACCHO Conference, and for making it possible for Nicky and Colleen to attend. We have come back with so many new ideas that will be incorporated into HFNZ programmes including National Children's Workshop, National Family Camp, and Young Women's Weekend, with the aim of making good Camps GREAT!

Here's why it's great to be an HFNZ member



Becoming a financial member of HFNZ is a great way to support all sufferers of bleeding disorders across NZ, and a great way to make sure you have all the tools and information you need.

Having a bleeding disorder can be a real challenge at the best of times, and what can make it even worse is dealing with

it all alone. That's why HFNZ came into being over 50 years ago. A number of families and individual sufferers decided that they would do better, learn more, and have more clout if they joined forces. And it's that same sentiment that powers HFNZ membership to this day.

Becoming a financial member is very affordable, just \$25 for an individual or \$35 for a family, and gives you access to the resources of a national organisation. Our members get to travel to camps and workshops across the country, are entitled to footwear subsidies have HFNZ working hard for them in a whole variety of different ways.

Paying your membership fee allows you to play a part in supporting other members just like you; it gives you a voice, and the power to be heard when it counts; and lets you join in with events where you'll learn plenty and make friends for life. Best of all, paying your membership fee allows HFNZ to reach out and support all the other people with bleeding disorders around NZ.

So, join up, pay your fee, and enjoy all the benefits of being a full HFNZ members.

Contact info@haemophilia.org.nz to find out how.

Support HFNZ Next Time You Travel...

Do you travel for business or leisure?

Here is a great way you can help support our work at HFNZ, simply by doing what you were going to do anyway.

Next time you travel, please consider booking your accommodation through www.kiwikarma.co.nz

On Kiwi Karma it's easy to find, compare, and book accommodation at over 3,200 providers nationwide – from backpackers to luxury lodges. The room rates on Kiwi Karma are comparable to all other travel sites. The big difference is that 5-8% of the room rate goes to HFNZ.

CEO Richard Chambers says, "Other revenue streams are essential to our organisation, so booking your accommodation through Kiwi Karma is an easy way to help. Your stay will be even more enjoyable knowing you helped us provide improve the lives of those with haemophilia and related bleeding disorders."

Check out kiwikarma.co.nz/competition and enter their latest competition, where you could win a night at a brand new hotel in Christchurch.

kiwi karma
Book your stay and reward your favourite charity

A big HFNZ thanks to Julia Phillips

There are many people who contribute to the success of HFNZ's programmes, and the wellbeing of our people. Haematologist Julia Phillips has played a huge part in both. Through her work at the Wellington Haemophilia Centre, and as a guest at various HFNZ events, Julia has made a fantastic contribution New Zealand's bleeding disorder community.

At the end of 2015 Dr Julia Phillips announced that she was stepping away from her role at the Wellington Haemophilia Centre. Julia was an amazing friend to HFNZ, the sort of friend that supports you through thick and thin, and will wade into battle for you whenever you need them. She will be a great loss to our community, to the members she worked directly with, and to the people she worked alongside.

Helen Dixon, physiotherapist with Capital Coast Health says:

"Julia has been a tireless advocate for people with haemophilia in the Wellington region and all over New Zealand for well over a decade. Many of our teenagers in the community will have been born and grown up with Julia looking after their Haemophilia care. She was also a great supporter and helped to

secure the funding, through the NHMG, for Clinical Nurse specialist and Physiotherapy roles. These roles have proved to be an invaluable resource for the New Zealand Haemophilia Community."

Here's a little of what Julia herself had to say about moving on when she addressed us at an HFNZ event:



"It has been a huge privilege and a great pleasure to have been involved in providing care for people with bleeding disorders and their families and whanau over the past 16 years," says Julia. "I have learnt so much from the people that I have met and I am humbled by the awesome lives that you

lead in the context of the challenges that you face. My life has been much richer for getting to know you all.

"I would like to say a big thank you to

HFNZ for involving me from time to time in some of the inspirational social and educational events, that you excel at and for all the great work that you have done in supporting the activities of the haemophilia centre at Wellington.

"I will miss seeing all the familiar faces at the hospital and wish everyone that I have met all the best for the future.

"My sadness at leaving the role is tempered by knowing that I leave the centre in good hands and look forward to seeing it go from strength to strength."

Julia has been a great haemophilia educator, not only locally to the community here in New Zealand but also internationally as an invited expert.

We will all miss Julia very much and wish her all the very best with her new adventure. Goodbye Julia from all of us at HFNZ –we're very sad to see you go too.

MRG Reports

HFNZ's Member Representative Groups (MRGs) are the backbone of the foundation, and the reason we are able to support the interests of such a broad population base. Every year the regional committees organize and run a variety of events and activities. 2016 is no different.

Northern

Northern Branch ended 2015 with a splash at Parakai Springs, for our annual Christmas Party. There was a great turn out, with the sun shining for us while we enjoyed the pools. It was great to see some new families, and some old friends that we hadn't seen in a while.



2016 began with our regional camp at Marsden Bay, on the 12th to the 14th of February. We really enjoyed the new campsite (once we found it!) at Marsden cove, and the trip to Waipu caves was a highlight for all who went. We saw lots of glow worms, and quite a few people waded out of the cave in the stream. Some more than once. We had a smaller turn out than last year, but the competition for the Sing-Star Trophy was as fierce as ever with this year's winner, Hemirau Waretini, the creator of the trophy.

Upcoming events for the year include World Haemophilia Day in April at Rocket Ropes, where we celebrate and acknowledge the Buddy Awards. There's also the Ladies high tea in May, and a Men's fishing trip (date still to be confirmed). We are also planning to have a combined event with Piritoto for Matariki. Keep an eye out for your invites.

Lynley Scott

Midland

Midland Region held a Glitz and Glamour evening at Skycity Hamilton 14th November for our adult members. We had Julie-Ann Bell as a guest speaking and it was nice to have both Julie-Ann and Maureen attending the evening. The night started with taking a photo of each couple as they arrived which we used to choose our King and Queen of the evening, a lovely dinner followed by a DJ to dance the evening away.

We also had an end of year event planned at the end of November in Taupo. However, we had to postpone the day due to wet weather. The event was held on the 27th February instead at Action World Taupo. It was a great day out for our families with plenty of exercise involved. We started with a bbq lunch, followed by a safety briefing from the staff, then we broke into two groups and made a start. There was plenty of fun with climbing through tunnels, up and down stairs, lots of jumping off different levels, the good old slides, and the Flying Trapeze. It was nice to see whole families getting involved, and lots of encouragement from the youth towards younger children when they were outside their comfort zone, and plenty of cheers when they did it. We would like to say a big thank you to Action World for a fun afternoon for everyone.

Wendy Christensen



Central

Our Christmas event at Nga Manu Nature Reserve, Waikanae, last November was blessed with perfect weather. The reserve is lovely and we saw many species of birds, some wild and others in enclosures. Our BBQ lunch was cooked by the McCarthy duo and Judith Dudson did a grand job organising all the food. We had a good turnout with some fresh faces in attendance.

The educational talk about kiwi and tuatara lifecycles, finished with a hands-on experience with a tuatara - not as prickly as he looks. After lunch we fed the eels.

Our region is planning a family picnic at Levin Park, Sunday 17 April to celebrate World Haemophilia Day and our buddy awards.

Congratulations to our former youth delegate Lauren Nyhan, who has recently graduated with a law degree and a BA in Criminology and wasted no time getting a job at the Environment Court. Well done Lauren!

Stephanie Coulman

Southern

Hello and welcome to all our members for the coming year. Happenings from Southern over the past few months have included:

- A Farewell High tea for Lyn Steele who resigned after three decades of serving on our committee. Lyn along with her husband Tony were active committee members and were made life members in 1999. The morning tea was well attended and enjoyed by all. Lyn was presented with a beautiful handmade quilt as a token of thanks. We will miss you Lyn!
 - During November a get together/celebration was held at the home of the Waswo family this too was greatly enjoyed by all who attended. Huge thanks to the Waswo family for their generosity in hosting this event.
 - A 'bike for bleeders' is being co organised by Karl and Zac, this is yet to be finalised after a disappointing first run at the beginning of February.
- A busy year is planned in 2016 too, so mark your diary...
- Brick Road Production play - Tickets will soon be on sale for the May 7th play. Get a group of friends together for a great night out. Tickets \$20 per person
 - Next committee meeting being held June 10th 2016
 - Super rugby games!!

Finally, a big thank you to all our members who assist with all that is required to enable our Southern branch to run efficiently.

Theresa Stevens

Piritoto

Tena ra e nga kai-panui

Piritoto is progressing strongly, with the on-going support of our whānau and HFNZ, through the completion of set goals and creating new goals to be accomplished in this New Year. Since our last MRG meeting we have seen Te Whainoa stepping into a new role as National Council delegate on behalf of Piritoto, which left room for someone (i.e. myself) to be promoted to chairperson of the group. So, I thought this would be a great opportunity to introduce myself to you the readers of Bloodline and inform you all on who I am.

My name is Tuatahi Pene and I hail from the mighty Waikato. *He piko he taniwha, he piko he taniwha, Waikato taniwharau.* This Māori proverb illustrates my home region as a place plentiful of chiefs.

As a severe haemophiliac myself I understand how hard it can be living with this disorder, but if I could give a few words to the younger generation, who are in the process of coming to terms with what life can be like living with a bleeding disorder, it is this: Survival can be summed up in three words – Never. Give. Up. You are all survivors.

In 2016 we will hold our annual Marae noho, where we can congregate in a like-minded environment to strengthen our bonds and build new connections with those living with Haemophilia who identify as Māori, or who have close relationships to Māori. The Marae noho is a great way to put into practice Māori ideas and traditions in a safe learning environment, to help those who may need nurturing guidance in living with Haemophilia in their local community.

If you are interested in learning more about Piritoto and the activities we are currently engaged in, please don't be shy. Get in contact with us at info@haemophilia.org.nz or talk to your Outreach Worker for more information.

Mauri Ora.

Tuatahi Pene

Youth

The National Youth Committee has some exciting National and Local plans for the year ahead.

In Southern Region, Zac Porter and Karl Archibald have planned a bleeding fun day out for all in Christchurch called Bikes for bleeders. This includes a mountain bike ride, children's bike course, and bbq, and is scheduled for April. This event is going to be held at the Halswell Quarry park in Christchurch for local families. Zac and Karl believe this is a great way to get outdoors, hit the hills and trails, have some fun, and challenge each other. If other areas think that they would like to participate in something like this don't hesitate to get in contact with either the NYC or your local MRG or youth delegate.

Our young women spent a weekend in Hanmer Springs recently, looking at living with a bleeding disorder from a range of new angles and sharing stories that were both inspiring, heart-breaking, and just downright odd! A huge takeaway from this weekend was the need to put our own health first, and the importance of our connections with one another as women who carry or have a bleeding disorder. From this weekend the ladies from the Wellington region have floated the idea of having an informal coffee group or regional event, so watch this space for more details!

The NYC is also looking to a national event similar in scale to the Abel Tasman tramp that was held in 2014. Such an event requires some serious planning and commitment from the committee, but we are always on the lookout for new members to help New Zealand youth continue to lead the way in our engagement with our foundation.

Much aroha to all for the year ahead and keep in touch with your local MRG and youth rep to stay in the loop.

Lauren Nyhan & Karl Archibald

Away We Go!



TRAVEL TIPS FOR THE BLEEDING DISORDERS COMMUNITY

Sure, travel can pose some extra challenges for individuals and families who manage a chronic illness like hemophilia, vonWillebrands, and other rare bleeding disorders. But with a little planning there's no reason you can't set off on adventures near and far... relax and have a great time!

BEFORE YOU GO

1. QUESTIONS FOR YOUR TREATMENT TEAM

- Should you take a dose of factor before you leave?
- Should you change your prophylaxis schedule or temporarily adopt a prophylaxis regime?
- How many doses of factor should you bring with you?
Ask about other medications that are part of your treatment plan (Amicar, DDAVP)
- How should you pack and store medications?
- Do you need to carry prescriptions for your medications?

2. CARRYING PROPER IDENTIFICATION/ DOCUMENTATION

- Medical identification jewelry - it is always important to wear some kind of medical identification, but never more so than when you're traveling. Paper documentation can get lost or destroyed - this could save your life.
- Travel letter - provided by your Hemophilia Treatment Center (HTC) or Hematologist, this letter should describe your diagnosis, how you treat, what kind of medication and supplies you are traveling with, why it's important that your factor bag stay with you at all times, and contact information for your treatment team in case of an emergency. This letter should be dated within the last 12 months. Find a sample Travel Letter in HFA's Be Prepared Tool Kit at www.hemophilia.org
- Carry several copies of emergency contact info - if you can't speak up for yourself, make sure medical providers know how to contact your HTC or Hematologist and a designated friend or family member back home. Also leave important contact info with that person at home so they can help in an emergency.

3. PACKING YOUR FACTOR

- Most factor products can be stored at room temperature, but each product has different requirements so check the package insert or the manufacturer's website under "Prescribing Information."
- NEVER pack factor in checked baggage. Pack factor and supplies in their own carry-on bag to simplify the inspection process.
- Don't forget a small Sharps disposal container - you should be able to get one from your factor provider.
- While not always required, it is recommended that factor boxes have a prescription label including provider's name and contact info.

4. DO YOUR HOMEWORK

- Insurance coverage on the road - ask your health insurer about benefits outside of your area and what their definition of an emergency is. Some policies require that you seek care at the closest ER - what happens if you want to go a further distance to a recognized Hemophilia Treatment Center? This is even more important if you have Medicare or Medicaid as there are very specific rules for out-of-state coverage.
- Know where to find hemophilia specialists - research which HTC's are near your destination and along the way. A U.S. Hemophilia Treatment Center Directory can be found at www.cdc.gov/ncbddd/hemophilia/HTC.html. You may want to call ahead and tell them you'll be in the area; ask if they carry your brand of factor, and whether they'll let you bring in your own factor if you go to their ER. If you don't self-infuse, ask what support might be

Away We Go!



TRAVEL TIPS FOR THE BLEEDING DISORDERS COMMUNITY

available for infusions. The World Federation of Hemophilia (www.wfh.org) provides a list of HTC's in over 100 countries.

- Find out if your factor provider will ship to your destination – if you're going to be away for an extended period of time it might be easier to travel with a small amount of factor and supplies and have the rest shipped to your destination (be prepared to ship home or travel with whatever's left.) Knowing that you can get more factor in a pinch can also reduce stress while traveling.
- Don't be caught by surprise at the airport – check out The Transportation Security Administration (TSA) website: <http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>. The guidelines for persons with diabetes also apply to people with bleeding disorders.

- Mobility assistance – if you expect to need assistance at any airport on your itinerary, contact your airline at least 24 hours in advance. You may be able to request special seating on the plane by contacting your airline's Customer Service or Disability Service Dept. Be prepared for varying levels of service and accommodations.
- Hotel rooms – consider asking for a room on a lower level in case there's an emergency, power failure or maintenance issue that takes elevators out of service. Make sure your room has a refrigerator if cold storage is required for factor.

DURING YOUR TRIP

1. Airport Security – while you should be prepared for all possibilities, most people with bleeding disorders will tell you that they have no problems carrying factor and supplies through security.

- At the screening checkpoint, notify the Security Officer that you have a bleeding disorder and are carrying your medication and supplies with you.
- You can request that TSA officers visually inspect your medication and supplies instead of putting them through the x-ray.
- The limit of one carry-on and one personal item (purse, briefcase, computer case) does not apply to medical supplies.
- Let them know if you have any implants (i.e., port-a-cath, joint replacement) that might set off security alarms.

2. NEVER leave factor in a hot or freezing car!

3. Keep infusion records while traveling

4. International Travel

- If you're traveling to a country in which English is not commonly spoken, try to bring a Travel Letter written in a second language.
- Most private health insurance policies provide some coverage for emergencies abroad, but the only way to know for sure is to ask. Be prepared to pay upfront; get itemized receipts from all medical providers so you can submit a claim when you get home.
- Medicare or Medicaid pays only for services in the 50 states, Washington DC, and U.S. Territories such as Puerto Rico.

Communication is the Key:

Educating the school about you child's bleeding disorder

*Starting school for the very first time, changing schools, or even just moving from one year to the next can be a stressful time. Not just for children, but for parents and teachers too. This is doubly so when you throw a bleeding disorder into the mix. **Lynne Campbell** has some tips to help make the start of the school year a little easier.*

Ideally your child/young person will thrive in their school setting, and interact with confidence. Parents can help ensure their student will receive support appropriate for their particular inherited bleeding disorder by being proactive. Ensure that the teachers working with your child or teenager at school are fully informed of your young person's bleeding disorder, that the school staff know how to respond if your son or daughter experiences a bleeding incident at school, and know (based on an agreed plan of action) when to call you.

There are a variety of support people, including your Outreach Worker and/or Haemophilia Nurse, who are happy to help you with this process and can help you talk with key personnel at your child's school. These support people can provide information specific to your young person's particular bleeding condition for your school to keep as a reference. They are also happy to attend school meetings with you, or as your representative.

Talking with others can provide emotional support but it is entirely up to your young person who, if any, of their peers they choose to disclose their bleeding disorder to.

Although signs and symptoms of an inherited bleeding disorder are well

documented, the manifestations experienced by your child are individual.

A key message to school staff however, is that your child should not be singled out as "different" or be wrapped in cotton wool. Over time your child will learn what can be done safely and they will also learn how to manage their limitations. It is important not to overprotect as your child will become resentful, frustrated, and angry. Participation in a wide range of activities at school is encouraged with only high impact activities such as BMX, boxing, hockey, or rugby being actively discouraged.

Exercise and physical activity are beneficial not only for joint health, but also for general wellbeing, and engendering a sense of belonging in all those with an inherited bleeding disorder. It is well documented that, if your child has prophylactic infusions two or three times per week, treatment is best given in the morning to maximize the amount of circulating factor in the blood at times when the child is most active. The efficacy of treatment reduces over time, so managing the timing and administration of factor, or other treatment therapy, is an important consideration – even though mornings are very busy times in most households.

For those with severe Haemophilia joint pain is very real. School staff need to understand that there will be times when your child needs to sit out some activities in order to protect a joint from further damage following a bleed. It may be worthwhile for your child to have treatment stored in the school medical room for emergency situations. Please discuss with your Haematologist or Haemophilia Nurse whether this would be appropriate for your child. Also, making sure the school is educated about the P.R.I.C.E first aid protocol, and that your child has access to ice and compression bandages if required, are both very important.

Von Willebrand disorder can create complications for all those with this most prevalent of the inherited bleeding disorders. Excessive bleeding from the nose or gums, spectacular bruising, and sometimes in females, menorrhagia during menstruation, are all challenges that need to be managed with minimum stress and embarrassment within the school environment.

The following article from the HFNZ website discusses treatment for those with vWD:

<http://www.haemophilia.org.nz/bleeding-disorders/von-willebrand-disorder/vwd-diagnosis-and-treatment/>

For female students with low clotting factor levels, rare platelet disorders, or who carry the gene for Haemophilia, the management of bleeding symptoms needs to be acknowledged and addressed within the school setting so that they are



not prevented from participating fully. Low energy levels due to anaemia, and choosing to withdraw from participation in school-based sport and recreational activities, can result in significant misunderstanding if key personnel are not informed of the significance of low clotting levels.

It is essential, too, that Mild Haemophilia be understood and considered by staff at your child's school. A bleed in a child with Mild Haemophilia needs to be treated by way of P.R.I.C.E. Any single bleed should be managed correctly in order to avoid long-term problems. Resting the site of the bleed is important, your child may need to sit out an activity, or be encouraged by their teacher to do so for a prolonged period of time.

The following is a helpful Australian reference for students with Mild Haemophilia:

<http://www.haemophilia.org.au/publications/mild-haemophilia>

Here are a range of back-to-school kits from the Hemophilia Foundation of America:

<http://www.hemophiliafed.org/resource-library/toolkits/back-to-school-toolkit/>

This article is targeted at school staff:

<https://stepsforliving.hemophilia.org/next-step/for-school-personnel/tips-and-recommendations>

Here is an American YouTube clip aimed at parents of girls with a bleeding disorder. The information here applies to boys as well:

https://www.youtube.com/watch?v=53aNFKjXW_8

This article looks at some back-to-school basics:

<http://www.hemaware.org/story/back-school-basics>

This next article looks at ensuring that new staff are fully informed of your child's bleeding disorder when they move from one school to another school:

<https://stepsforliving.hemophilia.org/next-step/school/transition-to-a-new-school>

Your Outreach Worker has a school kit to give to school teachers/carers at your child's school visit. In it is a laminated page for the school to keep (in an accessible location such as on the wall in the school office) about the signs and symptoms of bleeds and early treatment via PRICE (Protection, Rest, Ice, Compression and Elevation). If you'd like a school kit, just ask your Outreach Worker.

Walking Analysis and Haemophilia

By Catherine Pollard

*Advanced Physiotherapy Clinician for Haemophilia
Auckland / Northland Region*

Research has shown that after bleeding episodes there are subtle joint changes that cause alterations in patterns of walking. This can occur even in young children with haemophilia. Increasing our awareness of this and ensuring proper assessment and rehabilitation following a joint bleed may minimise these changes and reduce the risk of further bleeding episodes and damage.

When a joint bleed occurs, blood starts to leak into the joint space. Blood is not normally present inside the joint and the presence of even a small amount can produce lasting damage to the joint. When the bleed has stopped and the blood is removed from the joint; the pain eases and range of motion returns. Once this has occurred it is easy to presume that the joint is back to normal. However, research of walking patterns in haemophilia has demonstrated that even in young children, bleeding episodes early in life can produce subtle changes in how the joints and muscles work to produce movement (Manco-Johnson et al., 2007). For example, when comparing boys with haemophilia to boys the same age but with no health concerns, there were differences noted in how the muscles surrounding the ankle and knee are activated. Boys with haemophilia also had less movement in their hips, knees and ankles and tended to walk with their knees slightly bent (Cayir et al., 2014; Lobet, Detrembleur, Francq, & Hermans, 2010; Lobet et al., 2013; Stephensen et al., 2009). These small changes in how the joints move can increase strain on muscles, ligaments and cartilage and increase the loading pressures through the joint. Ultimately this may leave the joint more vulnerable to structural overloading and synovial pinching, with the increased risk of further bleeding episodes and damage (Seuser, Böhm, & Wermes, 2014).

The development of three-dimensional gait analysis, which utilises multiple video cameras pointed at different angles to record a person walking, has made it possible to identify these changes. Providing information to clinical staff that would be undetectable just by watching the child during normal functional activities (Bladen et al., 2007). This could prove to be very useful as it may take years before the resulting damage shows up on x-ray or through clinical examination. Unfortunately three-dimensional gait analysis is not widely available in New Zealand or Australia and is expensive to perform.

For best management at the present time a specialist haemophilia physiotherapist can provide advice and support to recover from a bleeding episode quickly and rehabilitate the muscles and joint back to optimal function. Physiotherapists are trained to observe walking patterns and joint movements and can identify factors which may leave a joint more vulnerable to future bleeding episodes, as well as teach you how to help reduce these risks. If you are unsure who your local haemophilia physiotherapist is please contact your haemophilia centre for advice.

Bladen, M., Alderson, L., Khair, K., Liesner, R., Green, J., & Main, E. (2007). Can early subclinical gait changes in children with haemophilia be identified using the GAITRite walkway. *Haemophilia*, 13(5), 542. doi:10.1111/j.1365-2516.2007.01429.x

Cayir, A., Yavuzer, G., Sayli, R. T., Gurcay, E., Culha, V., & Bozkurt, M. (2014). Evaluation of joint findings with gait analysis in children with hemophilia. *Journal of Back and Musculoskeletal Rehabilitation*, 27(3), 307.

Lobet, S., Detrembleur, C., Francq, B., & Hermans, C. (2010). Natural progression of blood-induced joint damage in patients with haemophilia: Clinical relevance and reproducibility of three-dimensional gait analysis. *Haemophilia*, 16(5), 813. doi:10.1111/j.1365-2516.2010.02245.x

Lobet, S., Detrembleur, C., Massaad, F., & Hermans, C. (2013). Three-dimensional gait analysis can shed new light on walking in patients with haemophilia. *The Scientific World Journal*, 2013(Journal Article), 1-7. doi:10.1155/2013/284358

Manco-Johnson, M. J., Manco-Johnson, M. L., Jacobson, L., Valentino, L. A., Hoots, W. K., Buchanan, G. R., ... Funk, S. (2007). Prophylaxis versus episodic treatment to prevent joint disease in boys with severe hemophilia. *The New England Journal of Medicine*, 357(6), 535-544. doi:10.1056/NEJMoa067659

Roosendaal, G., Van Der Berg, H. M., Lafeber, F. P. J. G., & Bijlsma, J. W. J. (2000). Blood-induced joint damage: An overview of musculoskeletal research in haemophilia. In E. C. Rodriguez-Merchan, N. J. Goddard, & C. A. Lee (Eds.), *Musculoskeletal Aspects of Haemophilia*. Oxford: Blackwell Science.

Seuser, A., Böhm, P., & Wermes, C. (2014). Early orthopaedic challenges in haemophilia patients and therapeutic approach. *Thrombosis Research*, 134 Suppl 1(Journal Article), S61-S67. doi:10.1016/j.thromres.2013.10.022

Stephensen, D., Drechsler, W., Winter, M., & Scott, O. (2009). Comparison of biomechanical gait parameters of young children with haemophilia and those of age-matched peers. *Haemophilia*, 15(2), 509-518. doi:10.1111/j.1365-2516.2008.01934.x

Stephensen, D., Drechsler, W. I., & Scott, O. M. (2012). Biomechanics of lower limb haemophilic arthropathy. *Blood Reviews*, 26(5), 213. doi:10.1016/j.blre.2012.06.003



News from Around the World...

A Potential Cure for Hemophilia

By Rebecca Walker Comba

The first in vivo genome editing compound is cleared for human trials, a major milestone in the rejuvenated field of gene therapy.

On Dec 1, 2015, Sangamo BioSciences, Inc. received FDA clearance for the first clinical application of an in vivo genome editing therapeutic, SB-FIX, a potentially curative, single treatment therapy for hemophilia B. This is history in the making. While conventional gene therapy approaches have the potential to wash-out over time, necessitating repeated administration, the proprietary In Vivo Protein Replacement Platform™ (IVPRP™) from Sangamo is expected to result in therapeutic levels of human Factor IX (hFIX) for the lifetime of patients with hemophilia B, with only a single treatment with SB-FIX.

Truly efficacious therapies for genetic disease will treat the disease at the source, the genome. Sangamo's IVPRP™ technology takes advantage of zinc finger proteins (ZFPs), the most abundant DNA binding proteins in the body. An individual ZFP recognizes and binds to 3 base pairs of DNA. Several ZFPs can be strung together to recognize and bind to longer target DNA sequences. ZFPs are designed with "exquisite specificity" toward a unique site in the genome and strongly bind only that targeted site. These DNA binding domains are then coupled to a nuclease domain to create a zinc-finger nuclease (ZFN) that binds to and cleaves DNA at a specific spot to allow for the insertion of a gene. Sangamo's modular design of SB-FIX incorporates two ZFNs that are targeted to bind 6 base pairs of DNA in a specific location in the albumin gene of human liver cells. In this case, a correct copy of hFIX is inserted where the DNA is cleaved by the ZFN so that it can produce functional Factor IX protein.

In SB-FIX, adeno-associated virus (AAV) vectors encoding the engineered ZFNs and hFIX, were created to deliver both the nuclease and the correct copy of the Factor IX gene in liver cells. AAV was selected because it is preferentially taken up by the liver when given intravenously and has a history of safe and efficacious use in humans. The manufacturing of AAVs are also well understood. Only a small percentage of the liver cells actually will incorporate and express the hFIX gene after injection of SB-FIX. However, these liver cells, and more importantly their progeny, should express Factor IX for the lifetime of the patient. Because the promoter for the albumin gene is so powerful, the incorporation of the hFIX gene should produce stable, therapeutic levels of Factor IX from this small percentage of liver cells and permanently treat hemophilia B in patients.

Charles River's role

At Charles River, we feel privileged to have participated in these advancements by completing toxicology studies that supported the safety and efficacy of SB-FIX to win IND clearance for commencing clinical trials. These studies demonstrated that Sangamo's SB-FIX could precisely insert a copy of the hFIX gene into a specific location within the albumin gene of liver cells leading to the stable production of therapeutic levels of Factor IX. We look forward to watching the development of SB-FIX and other therapies incorporating ZFP Therapeutics® strategies. Beyond systemic application for liver-related diseases such as hemophilia and lysosomal storage diseases, there are potential direct tissue applications for treating several other diseases caused by protein deficiencies that could revolutionize treatment for patients.

Eureka blog. Feb 3, 2016. Available: <http://www.criver.com/about-us/eureka/blog/february-2016/a-potential-cure-for-hemophilia>

Hepatitis C tied to increased risk of Parkinson's

Immunohistochemistry for alpha-synuclein showing positive staining (brown) of an intraneural Lewy-body in the Substantia nigra in Parkinson's disease. Credit: Wikipedia

The hepatitis C virus may be associated with an increased risk of developing Parkinson's disease, according to a study published in the December 23, 2015, online issue of *Neurology*, the medical journal of the American Academy of Neurology. Parkinson's disease is considered the second most common degenerative brain disorder after Alzheimer's disease. Hepatitis C is a liver infection caused by a virus.

"Many factors clearly play a role in the development of Parkinson's disease, including environmental factors," said study author Chia-Hung Kao, MD, China Medical University in Taichung, Taiwan.

"This nation-wide study, using the National Health Insurance Research Database of Taiwan, suggests that hepatitis caused specifically by the hepatitis C virus may increase the risk of developing the disease. More research is needed to investigate this link."

The World Health Organization estimates that 130 to 150 million people have hepatitis C worldwide. While hepatitis C can lead to serious illness, many people have few symptoms and do not realize they have the virus, especially at first.

The virus is transmitted through sharing needles, needle stick injuries in health care providers and passed on at birth from infected mothers. In Taiwan during the time of the study, blood transfusions were the most common cause of the virus. In the United States, all donated blood has been screened for the virus since 1992.

The study involved 49,967 people with hepatitis and 199,868 people without hepatitis. Participants with hepatitis were

placed into three groups: those infected with the hepatitis B virus (71 percent), those with hepatitis C (21 percent), and those who had both viruses (8 percent).

The participants were followed for an average of 12 years to see who developed Parkinson's disease. Of those with hepatitis, 270 developed Parkinson's disease, including 120 people with hepatitis C. Among those who did not have hepatitis, 1,060 developed Parkinson's disease.

Once researchers controlled for factors such as age, sex, diabetes and cirrhosis, they found that people with hepatitis C were nearly 30 percent more likely to develop Parkinson's disease than the people who did not have hepatitis.

People with hepatitis B and those with both viruses were not more or less likely to develop Parkinson's than those who did not have hepatitis.

<http://medicalxpress.com/news/2015-12-hepatitis-tied-parkinson.html>

ZIKA Virus/NHF

Feb 5, 2016: UPDATE:

The Plasma Protein Therapeutics Association (PPTA) has released a statement regarding the Zika virus and plasma protein therapies.

The American Association of Blood Banks (AABB) has released a statement regarding the Zika virus and blood donations.

The National Hemophilia Foundation (NHF) has been working closely with the Centers for Disease Control and Prevention (CDC), the World Federation of Hemophilia (WFH) and numerous industry and healthcare organizations to monitor the Zika virus outbreak, which has been declared a public health emergency by the World Health Organization (WHO).

The Zika virus is spread from one person to another via the bite of an infected mosquito. Symptoms include fever, rash, joint pain and conjunctivitis, an inflammation of the eye. The symptoms are usually mild and can last a few days or up to a week. The CDC states that in rare cases, the Zika virus can be spread from a pregnant mother to her newborn at birth if the mother is infected close to the

time of her delivery. Cases of transmission have also been reported through blood transfusions and sexual contact.

Because Zika is a flavivirus, which is a lipid-enveloped virus, there is a high probability that it will be successfully inactivated by current viral inactivation techniques (heat, solvent/detergent, nanofiltration) used in the manufacture of plasma-derived medicinal products including plasma-derived FVIII and FIX and vWD concentrates.

Transmission via blood or non-virally inactivated blood components is a potentially greater issue. Transmission is possible through blood donated by infected residents or travellers returning from affected areas, many of whom may be asymptomatic at the time of donation.

Currently, transmission had been identified in at least 21 countries or territories in the Americas, including Puerto Rico. Zika virus infections have been reported in travelers returning to the US. With the recent outbreaks in the Americas, the number of Zika virus disease cases among travelers visiting or returning to the US likely will increase. These imported cases may result in local spread of the virus in some areas of the continental US, meaning these

imported cases may result in human-to-mosquito-to-human spread of the virus.

In response the CDC has issued the following healthcare advisory.

NHF is monitoring this situation and will issue updates as more information becomes available. Follow us on Facebook: @NationalHemophiliaFoundation and on Twitter: @NHF_hemophilia for updates.

For more information on the Zika virus:

- Centers for Disease Control and Prevention
- World Health Organization
- US Dept. of Health and Human Services Zika 101
- FDA website.

<https://www.hemophilia.org/Newsroom/Blood-Safety-News/ZIKA-Virus-NHF>

Data integrity issues with Japanese drug company

By Tim Sandle

Tokyo - A manufacturer of blood products and vaccines in Japan has been accused of adding undeclared ingredients and of trying to obfuscate the facts, leading to concerns about drug data integrity.

A discovery was made in late 2015, and now recently reported, concerning a Japanese company called the Chemo-Sero-Therapeutic Research Institute (Kaketsuken), based in Kumamoto. The company is a manufacturer of blood (plasma) products and vaccines. The product portfolio includes factor VIII, a drug product used for the treatment of the bleeding disorder haemophilia.

Investigators discovered the company had been adding unauthorized ingredients to its products and allegedly falsifying data in order to hide this fact. Worryingly, an

investigative panel discovered that the institute had been doing so for more than 40 years.

The main charges are:

Kaketsuken has been producing blood products using improper production processes.

The company began falsifying production records for national inspections around 1995.

To add to this, Pharmaceutical Manufacturing reports "According to allegations, the company went as far as to artificially age fake documents exposing them to ultraviolet radiation in order to produce the needed historical paper trail."

Following the discovery, Japan's Ministry of Health Labour and Welfare (MHLW) issued a demand to all manufacturers of biological products within its territory, requiring each company to confirm that the current actual manufacturing process complies with the

approved regulatory files held within Japan.

This requirement means all manufacturers of drug products, active pharmaceutical ingredients, and intermediates, must review all of their manufacturing batch records and interview their operators to confirm conformance. This needs to be carried out by an independent quality department within each company. The due date for domestically owned companies is by the end of February, with foreign owned firms needing to complete the activity by March 22, 2016.

The issue highlights the importance of data integrity in the pharmaceutical sector. Digital Journal recently reported on a different type of data integrity violation, relating to an Indian pharmaceutical company called Ipca Laboratories. The charges here related to the accuracy of laboratory records.

<http://www.digitaljournal.com/life/health/data-integrity-issues-with-japanese-drug-company/article/458376>

Donor-Derived Factor VIII More Effective than Synthetics:

Inhibiting antibodies seen more often with recombinant products

By Charles Bankhead, Staff Writer, MedPage Today

In patients under treatment for factor VIII deficiency, use of recombinant replacement products was associated with a greater risk for development of inhibiting antibodies than was plasma-derived factor VIII in a randomized trial.

Alloantibodies were seen in 35.4% of 251 randomized patients across both treatment types in the study, which was reported at the American Society of Hematology meeting. However, they developed more often in patients assigned to recombinant factor VIII, with a hazard ratio for inhibitor development of 1.87 compared with the group randomized to receive plasma-derived factor VIII.

Analysis of the subgroup of patients with high-titer inhibitors showed a 70% greater risk of inhibitor development with recombinant product, according to presenter Flora Peyvandi, MD, PhD, of the University of Milan.

A multivariate analysis that accounted for a dozen demographic and clinical factors showed a consistent pattern of increased risk of inhibitor formation in patients treated with recombinant factor VIII.

"Patients treated with recombinant factor VIII have an 87% higher risk to develop inhibitors than those treated with platelet-derived factor VIII containing von Willebrand factor," Peyvandi said in conclusion. "This difference remained even when second-generation full length recombinant factor VIII concentrate was excluded from the analyses.

"These findings are clinically important because the development of factor VIII alloantibodies is currently the major therapeutic complication in hemophilia A that causes a marked increase in morbidity, mortality, and treatment costs."

Conflicting Data

The findings conflict with those of a previous retrospective review that found recombinant and plasma-derived factor VIII resulted in similar rates of inhibitor development, said Margaret V. Ragni, MD, MPH, of the University of Pittsburgh Medical Center. Switching among products and von Willebrand factor in the products did not affect the results. However, second-generation recombinant products conferred a significantly greater risk of inhibitor development as compared with third-generation recombinant factor VIII products.

"The question is, should we be changing to using plasma-derived clotting factors," Ragni said. "At this point, there are some controversial findings, but really neither of the studies that have been published reduced the rate of inhibitor formation, and that's one of the biggest complications of hemophilia.

"We will be doing a study try to prevent inhibitor formation using some of the extended half-life products, which have tolerance to whatever they happen to be combined with. It may be that just using an extended half-life drug will reduce the inhibitor rate."

For reasons that remain incompletely understood, some patients who receive factor VIII develop circulating alloantibodies that neutralize and inactivate the procoagulant activity of factor VIII.

Patient-related factors associated with the development of inhibitors include severity of hemophilia, factor VIII gene mutations, family history of inhibitor development, ethnicity, and polymorphisms of immune-response genes. Treatment-related factors include number of exposure days to factor VIII product, intensity of treatment, age at first exposure to factor VIII products, the type of factor VIII concentrate, and current infection or inflammatory state.

Specific predictors for development of inhibitors have remained elusive, Peyvandi said. More than a dozen observational studies have shown a two-fold increased risk of inhibitor development in association with use of recombinant factor VIII. Of note, two consecutive multicenter observational studies involving almost 900 patients found no evidence of reduced immunogenicity with the use of plasma-derived factor VIII products.

A few meta-analyses demonstrated a higher risk of inhibitor development with recombinant factor VIII products, and the difference did not decrease after adjustment for confounders.

"Previous studies have had a number of limitations, including heterogeneous patient groups, assessment of several factor VIII concentrates, different study designs, and incompatibility of patient groups in observational studies," Peyvandi said.

SIPPET Study

To provide level 1 evidence to inform decision making about use of factor VIII products, investigators organized the SIPPET (Survey of Inhibitors in Plasma Product-Exposed Toddlers) study, the first-ever randomized trial to compare inhibitor development in patients treated with recombinant versus plasma-derived factor VIII agents.

The principal inclusion criteria were male patients younger than 6 years with severe hemophilia A (factor VIII:C <1%), negative inhibitor measurement at enrollment, and no or minimal exposure (fewer than 5 exposure days) to blood products. Patients were randomized to a single platelet-derived factor VIII containing von Willebrand factor or to recombinant factor VIII.

The specific treatment regimen was left to the discretion of the treating physician. Follow-up continued for 50 exposure days, 3 years, or until inhibitor development.

Confirmed inhibitor development was defined as a measurement ≥ 0.4 Bethesda unit and high-titer alloantibody formation as ≥ 5 Bethesda units. Inhibitors that spontaneously disappeared within 6 months were considered transient. Patients were evaluated for inhibitor development every 3 to 5 exposure days for the first 20 exposure days and then every 10 exposure days or 3 months thereafter, and every 2 weeks during prophylaxis.

The primary analysis included 251 patients who had a median age of 14 to 15 months. Baseline characteristics included a family history of hemophilia in 44% of patients, a family history of

inhibitor development in 10% to 11%, and a history of exposure to blood products in 43%. The most common treatment regimen was on demand (40%), followed by modified prophylaxis (32%) and standard prophylaxis (14%).

The study population had a 35.4% cumulative incidence of inhibitor formation and a 23.3% incidence of high-titer alloantibodies. The group randomized to recombinant factor VIII had 44.5% incidence of inhibitor development and a 28.4% incidence of high-titer inhibitors. Rates in the patients treated with plasma-derived products were 26.8% and 18.6%, respectively.

Adjusted estimates yielded hazard ratios for alloantibody development for recombinant versus plasma-derived treatment ranging from 1.55 to 1.97, depending on the variable assessed.

Given the evidence of increased immunogenicity of second- versus third-generation recombinant factor VIII, Peyvandi and colleagues analyzed their data after excluding patients treated with second-generation products. The analysis resulted in an HR of 1.98 for all inhibitors and 2.69 for high-titer inhibitors versus plasma-derived products.

The SIPPET trial's influence on choice of blood products for treating severe hemophilia remains to be seen, Donna DiMichele, MD, of the National Heart, Lung, and Blood Institute, said during a brief introduction to Peyvandi's presentation.

"Importantly, the study brings new data to bear on the enigma of factor VIII immunogenicity, hopefully, moving us closer to the knowledge that will reduce or prevent all antidrug antibodies in at-risk individuals with hemophilia A," DiMichele said.

The study was supported by the Angelo Bianchi Bonomi Foundation, Italian Ministry of Health, Grifols, Kedrion, and LFB.

Peyvandi disclosed relevant relationships with Novo Nordisk, Alexion, Bayer, Baxter, Roche, LFB, Kendrion, and CSL Behring.

Primary Source: American Society of Hematology

Source Reference: Peyvandi F, et al "Source of factor VIII replacement (plasmatic or recombinant) and incidence of inhibitory alloantibodies in previously untreated patients with severe hemophilia A: The multicenter randomized SIPPET study" ASH 2015; Abstract 5.

<http://www.medpagetoday.com/Cardiology/Prevention/55140>

New Human Virus Linked With Hepatitis C

Justine Alford

Each year, millions of people across the globe depend on life-saving blood transfusions. Needless to say, ensuring this limited supply is clean is imperative to ensure the safety of vulnerable recipients. This message has just been highlighted by a new study, which identified a novel human virus that seems to be transmissible by blood products. Furthermore, it appears to be strongly linked with the hepatitis C virus.

Though clearly blood-borne and infectious, at this stage scientists don't know whether the virus, provisionally called human pegivirus 2 (HPgV-2), can cause disease. But what is interesting is that back in September, a separate, independent study also identified this virus from a different sample of people. Though given a slightly different name, human hepegivirus 1 (HHpV-1), the authors of the present study are confident they are not distinct entities.

"Their virus is about 4 percent different across the genome compared to ours," one of the study's lead investigators John Hackett Jr., Ph.D., manager of Abbott's Virus Discovery Program, told IFLScience. "It's essentially the same virus, so the data is mutually supportive of this being a novel virus. A committee will resolve what the

final name is."

Described in the journal PLOS Pathogens, this is the second pegivirus to have been documented to date, the other being human pegivirus (HPgV). Both of these, alongside hepatitis C virus (HCV), belong to a family of viruses called Flaviviridae.

The investigation started off with an index case, a 70-year-old, HCV-infected woman who had a history of injecting drug use and multiple blood transfusions to treat the blood disorder sickle-cell anemia. She died shortly after being admitted to the University of Chicago Medical Center back in 2011 due to multi-organ failure following sepsis.

Using a technique called next-generation sequencing, which allows for millions of genetic sequences from a sample to be read in parallel, the team was able to establish the presence of this novel virus. The researchers then took this information and used it to come up with tools for the screening of further samples. These were both molecular, looking for viral genetic information, and serologic, searching for antibody responses that would be indicative of infection and not sample contamination.

After searching through an additional 2,400 samples, all of whom were considered high risk for viruses like HIV and HCV due to their circumstances or lifestyles, 11 further cases of this virus were identified. What was interesting was that all of these

12 patients were also infected with HCV; no cases were found in those infected solely with HIV or hepatitis B virus.

"We found this strong association with hepatitis C," said Hackett. "Whether this indicates something about the route of transmission, or whether the virus persists more when HCV is present, currently we have no idea. But I wouldn't rule out that we will find it in other settings."

While Hackett adds that currently they have no data to support that HPgV-2 is pathogenic, or capable of causing disease, studies like this are crucial to keep blood banks as safe as possible.

"HPgV-2 is a blood-borne virus we were unaware of before," Hackett said. "If you don't know it's there, you can't screen for it."

"We identify novel viruses, that's part of the effort. It's then establishing whether there is a link to human disease. By virtue of that answer you decide whether you manufacture an assay to screen blood."

But VDDC's work doesn't end at discovering new viruses: Scientists are also working on developing assays for use in the clinic that could improve disease diagnostics. For instance, if testing windows can be slashed, responses to outbreaks could be improved.

<http://www.iflscience.com/health-and-medicine/new-human-virus-linked-hepatitis-c>

The Year Ahead

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

April 17th

*World Haemophilia Day & HFNZ Buddy Awards
Regional events*

April 21st

*National Children's Workshop
Auckland*

July 24th – 28th

*World Federation of Hemophilia Congress.
Orlando, Florida*

September 17th

*HFNZ Annual General Meeting
Christchurch*

September 30th – October 3rd

*National Family Camp
Keswick Christian Camp, Rotorua*

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



Rather read Bloodline Online?

You can choose to receive your copy of Bloodline by email instead.

Just let us know...
info@haemophilia.org.nz

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

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



Give a little? Give a lot!

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