Haemophilia Foundation of New Zealand Inc.
HFNZ
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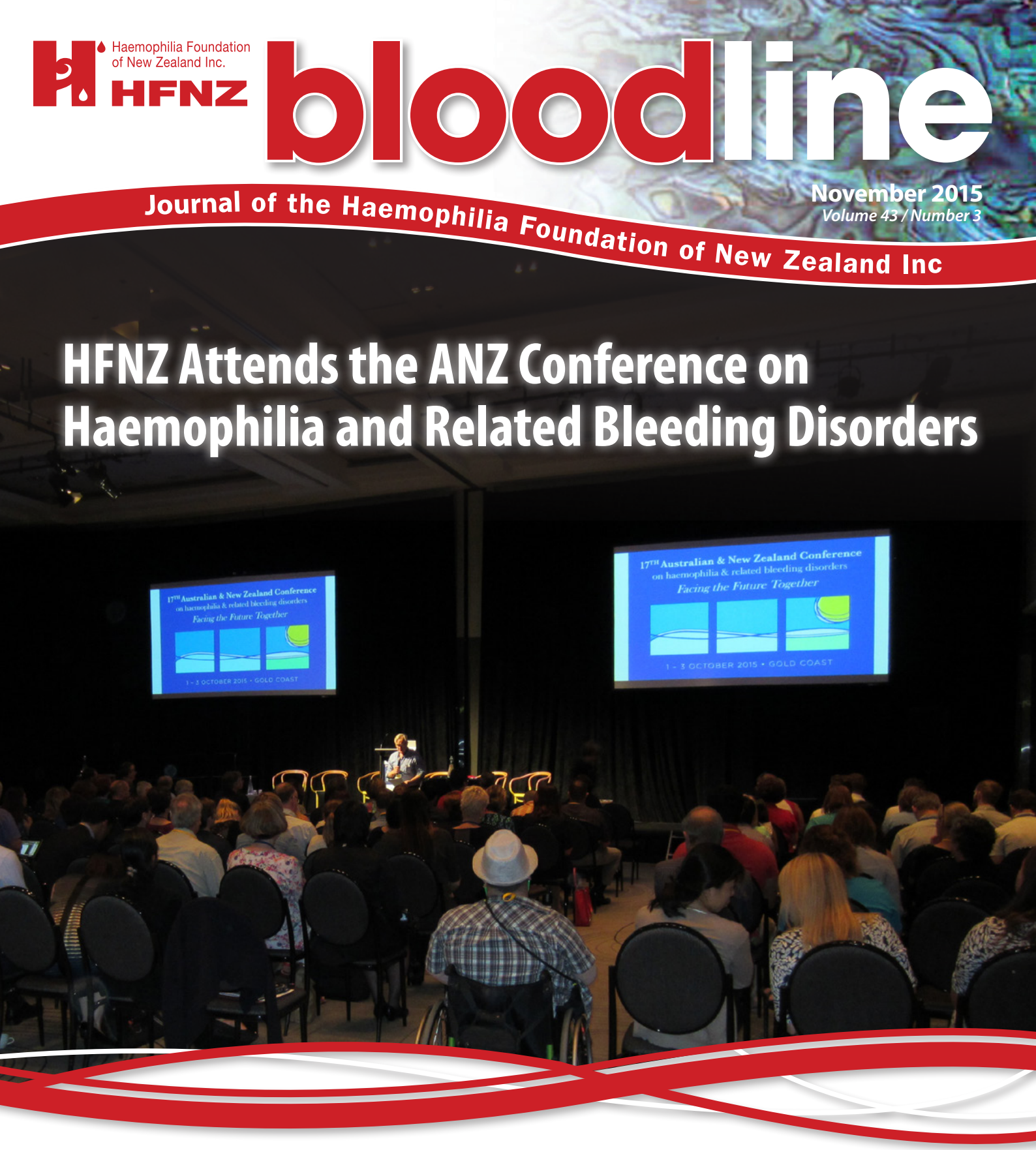
HFNZ Attends the ANZ Conference on Haemophilia and Related Bleeding Disorders



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The Word

Another year flies by! Catriona Gordon and I have just returned from the World Federation of Hemophilia's Ninth Global forum on research and treatment products for bleeding disorders. This two-day forum is packed with information about the latest research and products in the pipeline for treating inherited bleeding disorders. In brief, longer acting FVIII and FIX products are here and will be rolled out incrementally in the US, Canada and Europe. It is likely that New Zealand will have the opportunity to have these products next time there is a tender in a few years' time.

As relatively new products, there is little in the way of post-marketing surveillance – meaning that being first cab off the rank, so to speak, is not necessarily an issue. However, with the prospect of fewer infusions (particularly for FIX) leading to fewer needles, greater convenience and a longer half-life, this is indeed an exciting development.

Gene therapy was seriously discussed at the latest forum with many participants seeing it as about a decade away. Of course, many of you have heard this all before. It would appear that we are closer to a 'cure' than ever before. It all depends on how you define cure: if someone with severe haemophilia, for example, was to have factor levels increased from <1% to >5% would this be seen as a cure? It would certainly be an improvement to quality of life.

These are just a couple of the many developments in the bleeding disorders world. It is heartening that there are so many individuals devoted to research that will ultimately improve our communities' lives.

I wish you and your family a wonderful summer and an even better 2016!

Ngā mihi nui / Regards,

Dean York
President

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Cover photo: *From the floor at the ANZ Conference on Haemophilia.*

ANZ CONFERENCE 2015

From the 1st to the 3rd of October 2015 HFNZ staff attended the Australia & New Zealand Conference on haemophilia and related bleeding disorders, on Australia's Gold Coast. This is always a stimulating and educational event, and this year Colleen McKay (Outreach manager), Sarah Elliott (Northern), and Linda Dockrill (Southern) were all invited to run sessions, and Lynne Campbell (Central) was elected co-chair or the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group (ANZHSWCG); a testament to the high regard they, and by extension HFNZ, are held in. The staff attending the conference all wrote summaries of the sessions they attended, which are included here.

Improving Outlooks for Pain in Haemophilia: *Prof Lorimer Mosely & Associate Prof Carolyn Arnold*

By Colleen McKay

Everyone has different bleeding patterns and different experiences of pain; whether it's acute pain from bleeds into muscles and joints, or chronic arthritic pain from long-term muscle and joint damage.

Professor Mosely explained that pain is an output of the brain, not an input. It is the warning the brain gives when it determines that an injury is sufficiently bad, or causing enough potential danger, to warrant one. Furthermore, it is now known that the brain responds to more than just the signals being sent to it by the 'danger receptors' around the damaged area.

A simple experiment has transformed our understanding of how brains react to potential threats and injuries. In the experiment, participants' hands were touched with a very cold piece of metal while being shown either a red light or a pale blue light. Almost without fail, those who saw the red light described the experience as significantly more painful, some even pulling their hands away and talking about it being 'burning hot'. "That was a powerful study because it showed clearly that pain is not just a direct response to what's happening to the body" Prof Moseley says.

Pain is a protective function, and scientists now agree that pain occurs when the credible evidence of DANGER to your body is greater than the credible evidence of SAFETY for your body. Using this knowledge, the Protectometer has been developed. The Protectometer is an easy to use tool that helps to understand and deal with pain. The body will seek to protect if there is more evidence of Danger in Me (DIMS), than there is of Safety in Me (SIMS).

Early intervention is critical to prevent acute pain from turning into chronic pain. Chronic pain involves significant neurological changes, both in the nerves themselves and in the way pain is processed in the brain. Once these changes occur, recovery is much more difficult. Persistent pain should not be ignored. Deal with it sooner, rather than later.

The brain cells that produce pain get better and better at producing pain. They become more and more sensitive.

What factors influence Pain perception?

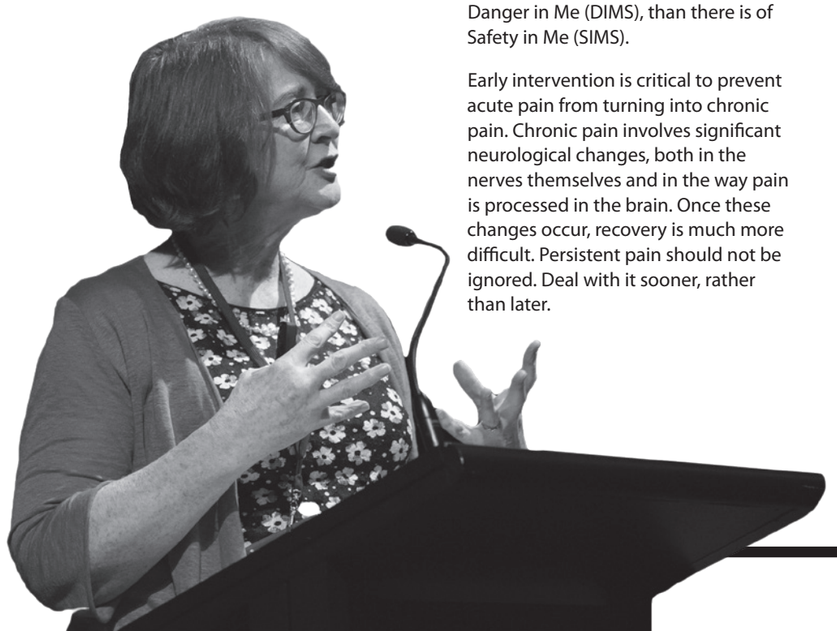
Psychological factors modulate pain intensity to a high variable degree. Prior experiences of pain, stress, anxiety, mood, constantly thinking about pain, fatigue, thoughts and emotions, cultural and social factors, biological factors, and visual stimuli have all have a role in the perception of pain. Many people with chronic pain also have psychological distress, especially depression and anxiety.

What can help with pain?

1. Chronic pain is real, not 'imagined'. Firmly reject the self-hating idea that pain is "just" psychological or psychosomatic. Even though pain is strongly regulated by the Central Nervous System, it is certainly not "all in your head."

2. Medication isn't the only way to manage chronic pain. Medical treatments and interventions have limited outcomes and substantial risks of harm. Generally they are recommended only for short term use. It is important to remember that medications are only part of a good management plan, and all medications should be reviewed regularly.

3. Like other chronic diseases/conditions, the successful management of chronic pain requires a collaborative approach between patient and healthcare providers; particularly the GP. Successful management of chronic pain can be facilitated via a range of



active strategies, like sleep and mood management, as well as via the promotion of a healthy lifestyle.

4. Seek effective management of your Joint Disease. Attend a thorough review from your Comprehensive Care Team – Haematologist, Haemophilia Nurse Specialist, Physiotherapist, Orthopaedic Surgeon, Social Worker, and others as needed.

5. Learn to determine the difference between the pain from an acute bleed and the pain from chronic arthropathic pain.

6. Undertake a programme of aerobic exercise, resistance exercise, swimming or hydrotherapy, Tai Chi, personalised Gym Programme, and/or walking (if tolerated). This will enhance endorphin production and cardiovascular function.

7. Seek effective management for Mental Health issues, particularly depression & anxiety. Depression is one of the most common psychological issues facing people who suffer from chronic pain, and it often complicates the patient's conditions and treatment.

8. Be kind to your nervous system. Create pleasant, safe sensory experiences and positive inputs. Seek comfort. If your brain thinks you're safe, pain goes down; and pleasure feels safe.

9. Fix the fixable in life, and be honest about what is fixable. These problems are usually the source of most stress, anxiety and depression: a bad marriage, toxic friendships, an unenjoyable job, a house or city or climate, an addiction, insomnia, and many more. Finally taking action to resolve such problems is the most direct route to easing a brain's interpretations of pain.

10. Change something, almost anything, about how a painful area feels. Make it as feel different as you (cheaply) can. Sensation is one of the factors the brain uses to set pain levels. If you can make a body part feel significantly different in any way, it may help, especially if it feels safe, protected, and stabilized. Classic examples include: taping, bracing, strapping, splinting, salving, vibrating, heating, or icing. Regardless of how they work, and there are many overly complex explanations, these methods mostly just change how a body part feels.

Chronic pain is always complex. Pain management must be holistic. Learn to think about pain differently, and be aware of the influence that we have over our brains.

Family Matters: Tips, Tools & Strategies to support your child

By Linda Dockrill

The section of the conference relating to paediatric mental health was presented by HFNZ Outreach staff, Sarah Elliott, Colleen McKay, and Linda Dockrill.

Sarah Elliott, social worker, presented a session entitled "Back off Bully". She described bullying as when someone, or a group of people, say or do something that hurts, embarrasses, frightens, or upsets somebody else on purpose. It is aggressive and intentional behaviour that involves an imbalance of power. Sarah noted that an important point about bullying is that it involves repeated behaviour, over time, and is deliberate. Parents and other adults in a child's life need to take it seriously if a child is telling them about, or showing signs of, being bullied. They need your help and support to get through this.

Sarah's investigation had revealed that very little research has been conducted specifically on bleeding disorders and bullying, although there are some thoughts on disabilities/health issues and bullying. Sarah said that it is important to acknowledge that children may be bullied whether or not they have a bleeding disorder, and that their bleeding disorder may or may not be the cause of bullying.

However, for people with bleeding disorders body image can be a big issue. Aside from changes in voice, weight, and height as puberty approaches, it is also a time when children grow rapidly. These growth spurts include changes in joints and muscles and could consequently cause more bleeds. It is also a time in life for testing boundaries, keeping up with friends, and making independent decisions, all of which could lead to increased bleeds. With more bleeds come more physical or functional limitations, such as: using crutches or wheelchairs, not being able to join in PE class, or having days of school, and these things may also lead to bullying.

The Haemophilia American Resource Centre and www.stopbullying.gov report that students with bleeding disorders are at a higher risk of being bullied. While there have only been 10 studies conducted in America on disabilities and bullying, it was found that children with disabilities were two to three times more likely to be bullied than their nondisabled peers. One study showed that 60 percent of students with disabilities reported being bullied regularly compared with 25 percent of all students. There is also discussion about people with disabilities becoming the bully.

Sarah noted that, because bullying is often without reason, it is best to focus on what to do about it and how to overcome it. Sarah shared the outcomes of two workshops that she ran on bullying for HFNZ with session participants. She found that in most cases children said that bullying was NOT necessarily because of their bleeding disorder.

Sarah suggested that families and parents create a toolbox of options for dealing with bullying that includes lots of different tactics. She highlighted the need to educate your child about bullying and bullies so they understand it better, know what it looks like, and know what to do if they come across it or it starts happening to them. Let them know bullying is never OK. She also emphasized the importance of keeping communication lines open with your child.

The next presentation was from Colleen McKay, Manager of Outreach Services for HFNZ. The session was titled "Siblings – best of friends and rivals". Colleen presented international research that has been done on this issue, which showed that serious sibling rivalry happens less often in families where:

- Violence is not acceptable behaviour
- Children are role modelled good anger management and problem solving skills by parents
- Family members have time and fun together.

Colleen noted that there are many good things about sibling rivalry as it teaches skills such as respect, compromise, negotiation, and problem solving.

Our sibling relationship is the longest relationship we have in our life time and a bleeding disorder can impact on the function of this important connection. Parents and caregivers set the tone and are vital in helping this relationship be a positive one for all children in the family. If you would like to read more about this topic Colleen had an article in Bloodline in March 2015: http://www.haemophilia.org.nz/community/bloodline/bloodline-march-2015/

Linda Dockrill, social worker, gave a presentation entitled "Bouncing back: Increasing resilience in children with a bleeding disorder", which was a natural follow on topic from the other presentations. Resilience is a key part of dealing with bullying and is learnt in our families, alongside relationships with siblings.

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, or significant sources of stress — such as family and relationship problems or serious health problems. Linda explained that research has shown that resilience is ordinary, not extraordinary behaviour. Studies show is that resilience is not a trait that people either have or do not have. It involves behaviours, thoughts, and actions that can be learned and developed by anyone.

Linda observed that for a child with a bleeding disorder resilience is vitally important. They may have to learn to contend with medical procedures, being poked and prodded with sharp instruments, how their parents deal with learning infusion, missing out on being in the school rugby team, bleeds that see them on bed rest for a few days, crutches, wheelchairs and …. just being different to others without a bleeding disorder. How parents respond to their fears, anxiety, and the hurdles they encounter will set the tone.

Some signs that a child may be needing support were identified by Linda and included:

- Feeling low, sad, or depressed,
- Sleep problems
- Changes in appetite
- Irritability
- Resentment
- Excessive anger
- Jumpiness
- Indecisiveness.

Linda offered a model developed by Dr Kenneth Ginsburg, a paediatrician specialising in adolescent medicine at The Children's Hospital of Philadelphia and the American Academy of Paediatrics, detailing the Seven C's of resilience:

Each of the Seven C's were addressed by Linda and details of how to achieve these were explained in detail. Briefly these are:

- Competence – The feeling of knowing you can handle a situation effectively. Identify a child's individual strengths and traits, help them learn from their mistakes and learn to make decisions. Recognise each child individually and avoid comparisons.

- Confidence – A child's belief in his own abilities, is derived from Competence. Focus on the best in each child so that he or she can see those strengths as well. Clearly express how you value qualities such as fairness, integrity, persistence, and kindness. Offer authentic praise. Learning venous access is a great example of persistence.

- Connection – Developing close ties to family and community. Build a sense of safety at home and allow your child to express emotions. Address family issues openly, a family meeting is a great way to do this. Spend time together.

- Character - Morals and values to determine right from wrong and to demonstrate a caring attitude toward others. To strengthen your child's character, demonstrate how our behaviour affects others, the importance of community, and encourage the development of some form of spirituality.

- Contribution - Teach your children how to contribute by communicating the importance of serving others, and by modelling generosity. Children need to know that the world is a better place because they are in it. Look for opportunities to volunteer for HFNZ or with other community groups you are involved in.

- Coping - Learning to cope effectively with stress will help your child be better prepared to overcome life's challenges. Model positive and effective coping strategies and guide your child on a consistent basis. Realise that telling him or her to stop the negative behaviour will not be effective, the most powerful thing you can do is to be a good example

The final part of Linda's presentation related to how to increase resilience at each age and stage of a child's development. With pre-schoolers it is important to use play to help a child express their fears and parents can encourage them to use art or pretend games to express what they may not be able to put into words. Linda encouraged parents to utilise camps run by the foundation to let children see older boys managing their infusion confidently. She also stressed the importance of routines and predictability for this age group, and the value of a parent or caregivers time to a young child.

The ongoing development of resilience for primary school children can be enhanced by talking to your children using clear and simple statements. Answer their questions honestly. Provide reassurance that you will take care of them. Parents need to recognise that added stress may trigger bad behaviour.

Helping your child to keep perspective is the key to further developing resilience in the 10 -13-year-old age group. Adults need to share their feelings and role model how to deal with them. It is important to create a family team environment for this age group.

Finally, Linda talked about the teenage years. She encouraged adults to keep talking to their teens, ask their opinions and engage them in family life as much as possible. It is important to recognise the many physical and hormonal changes they are experiencing and to know when it is time to seek help from someone else such as a school counsellor or social worker. The value of developing a tool box of ideas to help a child increase resilience through connection with family members and community, acknowledging a child's feelings, and role modelling resilience was very evident in this presentation.

Hepatitis C: Medical Issues for PWBD and treatment, including direct acting antivirals

By Lynne Campbell

A/Prof Simone Strasser is Senior Staff Specialist in the AW Morrow Gastroenterology and Liver Centre, and the Australian National Liver Transplant Unit at Royal Prince Alfred Hospital and the University of Sydney.

She has a major clinical and research interest in a broad spectrum of liver diseases including viral hepatitis, advanced liver disease, liver cancer, and liver transplantation.

Simone Strasser provided a broad overview and many statistics relating to those who had contracted Hepatitis C (HCV) worldwide and in Australia:

- Most of those currently living with hepatitis C are aged between 35 years and 60 years of age.
- 55-85% will go onto develop chronic infection
- 20-30% will develop cirrhosis
- 2-4% will develop Hepato Cellular Carcinoma (HCC)
- There are 7 genotypes represented in HCV with a slight predomination of 1A over 1B. G3 is the most common genotype.
- One in four people in the general population don't know they have HCV and only 2% per year are being treated. There has been a noticeable increase in complications from cirrhosis.

Treatment of Hepatitis C is currently undergoing a major revolution.

Two case studies were presented to illustrate the spectacular success of the new Interferon-free treatments such as Harvoni (which is now available in New Zealand), even in the presence of cirrhosis and some other comorbidities such as HIV.

Case Study 1

A 52 year old man who had done 48 months of Interferon based treatment for HCV and failed to cure after immense negative physical and psychosocial impact.

The importance of monitoring liver status with Fibroscans to differentiate between cirrhosis and normal tissue was emphasised.

Because of the insidious nature of HCV, the 52 year old man felt well, even though his Fibroscan indicated significant cirrhosis.

Case Study 2

In her second case study Simone described a patient who had contracted HCV genotype 1 at a young age and had liver failure by age 27 years. He had a liver transplant in 2013. HCV is not cured in a transplant and when it attacks the replacement liver HCV progresses very quickly through its stages.

Her patient went on a trial for an Interferon-free drug and was cured of HCV.

Survival with a transplanted liver is excellent and the new Interferon-free drugs such as Harvoni are effective for those who have undergone liver transplant.

Lifestyle Management and Risk Factors

Prof. Strasser stressed the importance of (with respect to lifestyle management) the need to cease smoking, cease alcohol, reduce weight, and increase exercise; and with respect to management of cardiovascular risk factors - to undergo lipid lowering therapy, control Blood Pressure and control diabetes.

SVR = Sustained Viral Response.

Essentially the new anti-viral interferon-free medications now available target a range of genotypes and are suitable for those with cirrhosis and some co-morbidities. There are huge advantages to having treatment. After treatment the level of scaring in the liver will reduce and overall survival returns to that within the normal population (provided there are no unrelated medical factors).

Prof. Strasser went through the historic range of HCV treatments between 1991 and 2013. Their success rates fell well short of the new interferon free treatments which are curing 95% of patients, even those with cirrhosis.

Barriers: Treat now or treat later.

Prof. Strasser's message was strongly to "Treat Now".

She discussed a range of barriers to patients having IFN based treatment. Although there can be medical barriers to treatment, patient barriers such as lack of awareness of a potential cure, lack of confidence in therapy, feeling well at present, fear of side effects, and competing priorities were all significant contributors to delaying treatment.

Interferon-Free Treatments:

For the first time these treatments target the life cycle of the virus and are specifically designed to disrupt the replication assembly of the virus (through protease, polymerase and NS5A inhibitors). These treatments are still genotype specific regimes but work across a broad spectrum of genotypes.

The real advantages in Interferon free treatments are that they have very few side effects, have an exceptionally high response rate, can be given to patients before and after liver transplant, can treat patients with chronic kidney disease and are equally effective in patients with HIV co-infection.

For patients with cirrhosis the treatment regime is longer at just one pill per day for 24 weeks instead of 12 weeks.

To be able to eradicate the virus reduces the chance of liver cancer forming. Ultrasound (safe non-invasive monitoring) continues after treatment if a patient already has cirrhosis.

Genotype 3 appears to be the most difficult form of HCV to treat as genotype 3 produces more fat in the liver and disease progresses more rapidly through fatty liver tissue.

In conclusion:

- Hepatitis C can be cured! SVR = cure
- Interferon-free treatments offer a high chance of cure with excellent tolerability
- Eradication of HCV markedly reduces the chance of developing liver failure or liver cancer

PWBD and HCV should

- Have their liver disease status checked
- Have the new interferon free anti-viral treatment
- Be considered for liver transplantation if indicated

The remainder of this session was a panel discussion of three Australians (two Nurses and one patient) about getting into treatment in Australia (which is different to here in NZ) and some specifics about undergoing new HCV treatment.

The importance of adherence in all medical regimes was the main take home message.

In general HCV is more of a risk factor than HIV for those who are co-infected.

It was also noted that there is a high risk of Cardio vascular disease for those with HCV.

It is possible to have HCV treatment before and after a liver transplant. After treatment, ultrasound should be carried out every six months to see if any lumps or changes that weren't there previously show up. Early cancers are readily treated.

The new Interferon free treatments do contain Ribovirin so participants need to practise contraception to avoid conception for a period of six months.

Past experience is the main barrier to PWBD undergoing new HCV treatment regimes.

Managing your headspace for adults

By Sarah Elliott

Sarah Elliott, the Northern OR worker for HFNZ presented an outline of her Master's thesis which involved both a focus group and national questionnaire to investigate the impact of the unique issues and challenges facing men aged 45 years and over who are living with haemophilia, including their perceptions of supports and services available to them in Aotearoa, New Zealand.

Some initial psychosocial findings, and recommendations based on these were included (but will be presented to HFNZ much more fully at a later date):

- Family is the biggest support system identified, so service providers need to keep family involved where and how possible
- Connectedness to other men with bleeding disorders is also very important to this group, such as sharing, comradery and knowing they are not alone. Service providers need to find multiple opportunities to connect older men with bleeding disorders with one another in appropriate and relevant ways
- These men value social participation in communities; they enjoy being involved with groups, clubs and teams. Services need to encourage and support men with haemophilia to connect with different social groups, and plan around these where possible
- This group holds a lot of very real fears, and there are many unknowns for them. Therapeutic support may be needed to help work through their fears, and practical planning and preparing for the future is important to try to prolong and increase their independence
- More exploration and research is needed around spirituality, religion and connectedness to culture, as these could be used as a support mechanism for those who are open to it.

This group had positive mental and emotional health, and depression was extremely low. Perhaps there are other factors in New Zealand that may be contributing to this group's wellbeing and lack of overriding depressive factors, such as a positive outlook to life, a variety of learned coping strategies, or ways of maintaining wellness (or decreasing stress) and resilience. However, it is imperative there are standardized tools and clear processes to deal with those with emotional concerns.

Dr Ira Van der Steenstraten is a psychiatrist, psychotherapist, and family therapist and presented to the conference about mindfulness and why it is an effective strategy to use.

Current research shows that training your attention and doing selected mindfulness and meditative exercises can reduce stress, anxiety, and depression, boost the immune system, and strengthen your ability to focus your attention where you want it to be. It has even been shown to change the architecture of your brain

Evidence has shown that meditation no longer just for "hippies" and its benefits are now widely accepted by scientists and the general public both young and old. Mindfulness training programs have been implemented in schools, hospitals, sports, corporate business, and the military.

There are many verified benefits to mindfulness training:

- Training your body to be non-judgemental creates space to allow new opportunities to arise
- If your mind or body is in discomfort and you try to ignore it or resist it then it will only increase stress
- Mindfulness can help you accept situations
- It teaches that your thoughts are something you have but not what you are. You cannot stop your thoughts but you can gain control by learning not to listen to them
- Mindfulness techniques can be particularly effective for people suffering a chronic condition.

Making informed family planning decisions

By Colleen McKay

Speakers:

Peter Field – Pre-natal / PGD Testing

Pauline McCarthy – A Journey through Genetic Counselling & Prenatal Diagnosis

Robyn Shoemark – Role of Haemophilia Centres in genetic Counselling

Each individual has different needs for their own journey through genetic counselling and/or pre-natal diagnosis. Individuals, couples, and families require information and support to make their own decisions about whether genetic testing is right for them. The decision to use this information can be based on their personal and family experience of haemophilia, the severity of the haemophilia within the family, along with individual beliefs, values, morals, as well as cultural and religious beliefs.

The decision to have carrier testing, and the use of prenatal technologies, presents challenges. Today many people may seek counselling prior to a pregnancy because of concerns about implications for their family. Genetic counselling with regard to pre-natal diagnosis can be complex and filled with powerful emotional responses.

The role of the genetic counsellor is to ensure that those seeking genetic counselling, genetic testing, pre-natal diagnosis, or preimplantation genetic diagnosis have all the facts to enable them to make their own decisions. However, within this there remains the burden of decision making, which includes the emotional strains and worries associated with the possibility of an affected new-born, and what the future may hold.

Types of pre-natal testing:

- **Chorionic Villus Sampling (CVS) –** Abdominal CVS tests are performed at 11 – 14 weeks' gestation. Under ultrasound guidance, a needle is introduced into the placenta. The procedure takes about 2-3 minutes to extract a small amount of chorionic villi which are then sent to be tested for the haemophilia gene. If the placenta is in a posterior position, it is inaccessible. In these situations, it might be necessary to perform a trans-cervical CVS procedure.
- **Ultrasound Scan –** Can be done on a pregnant woman at 12 to 18 weeks' gestation. The ultrasound gives a picture of the baby inside the womb, and sometimes you can see the sex of the baby. Some couples with a family history of haemophilia may use the knowledge of the baby's sex to prepare themselves for the child's potential health problem. It is now possible to have 3D and 4D Ultrasounds; these produce wonderful images of the foetus. However, these scans are not diagnostic.
- **Amnio-centesis –** This test is done during the 15th to 20th weeks of pregnancy. For this test, a thin needle is used to draw out a small sample of the fluid that surrounds the baby. Cells in the fluid can be checked to learn the baby's sex, and they can also tell if he has haemophilia. Amniocentesis is very accurate.
- **MaterniT21 –** The development of this test is advancing quickly and its application is on the horizon. MaterniT is a laboratory-developed test that is the most technologically advanced non-invasive pre-natal test of its kind. It is used for detecting foetal chromosomal abnormalities. This non-invasive test requires only a blood sample, and it can be performed as early as 10 weeks' gestation. The results take around 5 – 6 days.
- **Preimplantation Genetic Diagnosis [PGD] –** Available since 1992, this procedure involves the removal of one or two cells from an embryo and testing them for specific genetic conditions or chromosomal disorders. It is specifically related to IVF treatment, harvesting eggs, and fertilising each egg with a single sperm to produce embryos. Each embryo created can then be tested for serious genetic disorders using PGD. For single gene disorders, such as haemophilia a process called polymerase chain reaction [PCR] is used. There are a number of PGD methods including direct mutation detection, linkage analysis, and karyomapping to check for the haemophilia gene. Once the results are known, the fertility specialist and the couple decide which embryos to transfer to the woman in order to become pregnant. PGD is highly medicalised, invasive, and there is no guarantee of pregnancy. Generally, IVF has a 40 – 50% success rate over all women.

It must be noted that preparing for pregnancy is considered to be a valid reason for pre-natal testing. It is important to be aware that both CVS and Amniocentesis carry a small (0.5 – 1%) risk of miscarriage.

The role of the Haemophilia Treatment Centre is to inform and educate people about the inheritance of bleeding disorders, to arrange for genetic testing, and to arrange for referral for genetic counselling where appropriate for males with haemophilia, obligate carrier females, potential carrier females, and extended family members. 'Progeny' is software used to map the haemophilia gene in families; clearly mapping obligate carriers and potential carriers. Testing of a potential carrier can be undertaken when the young woman is able to give Informed Consent; usually at around the age of 16.

For female haemophilia carriers, the choice to add a child to their family goes far beyond the question, 'Should we or shouldn't we?' It is important that women and couples considering a family seek genetic counselling, ask lots of questions, be realistic about the process and the outcomes, decide what is a 'good fit' for them, and seek the support that they need throughout the process. Pre-natal Genetic Diagnosis is a valuable asset, but it is not for everyone. Having a child is a personal decision and every woman has the right to choose what's best for her and her family.

Inhibitors

By Linda Dockrill

This session covered information about inhibitors, the risk factors associated with developing an inhibitor, and the impact of product transition on the risk of inhibitor development in Australia; a very pertinent issue for NZ patients currently transitioning due to the latest Pharmac funding round.

Dr Alfonso Iorio, from Canada is the current chair of the WFH Data and Demographics committee. He went over the information we know about inhibitors:

- About of PUP's (Previously Untreated Patients) develop some sort of inhibitory response
- About ¾ of inhibitors disappear at some point
- The Quality of Life (QoL) of patients with persistent inhibitors is reduced.

The development of inhibitors is generally linked to either genetic risk factors or treatment related risks. The genetic factors are:

- Factor 8 deficiency
- A family history of inhibitors
- Ethnicity
- Immune genotype.

It is evident that some mutations are more high risk than others.

Prof Iorio went through various studies that showed factor use and inhibitor development and argued that they all, over time, ended in the same outcome – 30% development of inhibitors. He stated that reactions at this rate are not considered "rare" adverse events. He suggested that it is better to ask why 2/3rds of patients DO NOT develop inhibitors if we want to further understand this issue. Prof Iorio said that some testing has been done on mice around modulating the development of an inhibitor but there needs to be much more long-term research done on patients via longitudinal studies, something I have regularly heard said at Haemophilia conferences over the past 6 years.

The importance of data collection in such a small community is vital. Where capacity to collect data has increased enormously, Prof Iorio argued that the observational approach has not produced any actionable evidence. He stated we need to climb up one step in our capacity to produce trustable comparative data. His final words were that guidelines tell you what to test, not what to do.

The next speaker was Dr Ann Wilson, who had been involved with a study of Australian patients during and after the 2012 switch to a single provider. All the Australian HTC's participated and data was collected over 18 months from patients with all severities. They had a large group of subjects, 533 patients, of which they analysed 237 patients who had made the switch from Kogenate to Advate. There was also a control group of 100 patients who did not switch products. The outcome was that 1% of the product change group developed an inhibitor (3 people) and 4% of the control group (4 people) developed an inhibitor. So, there was no difference displayed overall. Interestingly, those that developed an inhibitor were all adult males but a difference was noted in the product change group as the median titre was lower than the median titre for the control group.

Ann concluded that genetic testing for a predisposition to inhibitor development is a good idea, and, most importantly for NZ patients currently, that switching products is not associated with inhibitor development.

The final speaker in this session was **Dr John Rowell,** Director of the Queensland Haemophilia Centre. He emphasized that inhibitors are the most significant cause of death for those with factor 8 deficiency. Less than one percent of those with factor 9 deficiency develop an inhibitor by comparison.

Inhibitors are the development of an antibody to one part of the factor 8 molecule. Approximately 50% of inhibitors are transient and will decrease or disappear. Most tolerisation occurs in the paediatric group, and he noted that tolerisation protocols work but take time. Dr Rowell also noted that there are predictors of success for tolerisation:

- Less than 8 years of age at start of tolerisation
- Initiated within five years of inhibitor developing
- No interruptions to ITI (immune tolerance induction therapy)

The other variables involved are – mutation, ethnicity, and factor 8 product. The genetic mutation in particular makes an impact on the ITI success.

As part of his presentation, Dr Rowell discussed the recommendations from the UK Haemophilia Centre of Directors Organisation (UKHCDO) guidelines. He noted that these guidelines stated the following:

- ITI is recommended for those with severe haemophilia A
- ITI is recommended for patients with a persistent inhibitor that interferes with prophylaxis or treatment of bleeds at standard doses
- ITI should be started as soon as possible
- If bleeding occurs while on tolerisation, dosing should be increased
- ITI should continue as long as there is a convincing downward trend.
- In patients with mild/moderate haemophilia with a family history of an inhibitor it is recommended that treatment is made with DDAVP to avoid factor 8 exposure – a DDAVP trial was recommended for this reason

Dr Rowell also noted that there are several alternative therapies available to treat inhibitors. He listed them as RNA Interference, Monoclonal Antibodies, Porcine Factor 8, and platelet derived therapeutics.

The consequences of inhibitors and the demands of treatment increase the burden on patients and their families, leading to reduced quality of life, financial stress, and strained relationships. Improved management of patients with haemophilia complicated by an inhibitor is a challenge for the health care community and for HFNZ in particular, as the main support system for these individuals and families.

Women Bleed Too

By Lynne Campbell

Haematologist Dr Stephanie P'Ng addressed the symptoms, significance, and extent of bleeding for symptomatic women who have an inherited bleeding disorder.

Menorrhagia is common in women with inherited bleeding disorders and can contribute to absenteeism form school or work, limit activities, and impact reproduction.

Menorrhagia is defined as menstrual bleeding lasting longer than 7 days resulting in the loss of more than 80mL/menstrual cycle. 10-57% of carriers of haemophilia, and up to 80% of women with vWD, will report menorrhagia. Approximately 50% of patients with severe platelet dysfunction and other rare bleeding disorders also reported experiencing menorrhagia. Gynaecological conditions such as fibroids, polyps, endometriosis, or endocrine dysfunction, as well as liver or kidney disease can also cause excessive bleeding.

Once recognised, menorrhagia is manageable for most women. Treatment can be continuous through the use of combined hormonal options, or intermittent using Tranexamic Acid (TAA) or Desmopressin (DDAVP). In some cases factor may be required and iron replacement therapy should be considered if a patient becomes anaemic. Surgical options such as endometrial ablation (D&C), endometrial resection, and hysterectomy also have their place.

Women with bleeding disorders may also present with other obstetric and gynaecological issues such as haemorrhagic ovarian cysts, endometriosis, hyperplasia, polyps, fibroids, miscarriage, and difficulties with child-birth.

During a normal pregnancy there is a rise in clotting factor levels for many bleeding disorders but not for women with factor IX deficiency. In general pregnancy is associated with improved bleeding control. Careful planning and good communication between patient and medical teams is the key to managing pregnancy and safe delivery. Epidural analgesia is controversial and the decision is made by the anaesthetist.

Genetic counselling should be offered to all patients as women need to know the risks of having an affected child, information about reproductive options, as well as prenatal testing, and management options during pregnancy and delivery.

Dr. P'Ng emphasised that any invasive procedure on the baby, such as circumcision, should be delayed until the status of the baby is known.

In the remainder of this session a young woman from Queensland described her personal situation and experience of excessive bleeding and its impact at different times in her life. She was ultimately diagnosed as being a symptomatic carrier of mild haemophilia plus she has vWD. With careful management from her multidisciplinary haematology team she is now leading a normal and active life.

Mild Haemophilia

By Sarah Elliott

This session had a number of high calibre speakers:

Penny McCarthy
- Clinical nurse consultant at The Alfred hospital

Dr Jamie Price
- Haematologist and Oncologist at Princess Margaret hospital

Dr Simon McRae
- Director of Royal Adelaide Haemophilia Centre

Nathan
- a young man who shared a personal story about life with mild haemophilia and inhibitors.

Illustrated by case studies and data collection, there were a number of key takeaways to come out of this session. All of the speakers emphasised that the complexity of managing bleeding in people with mild haemophilia is often underestimated.

There is often a lack of education and understanding in the sufferers themselves. Because people with mild haemophilia may rarely have bleeding episodes they often present late to HTCs, do not know their treatment products, do not know what to ask for or even say to GPs or ED staff, and do not understand how to manage a bleed or post-bleed. In one case study this lack of knowledge lead to a man developing compartment syndrome.

Not being aware of family trees and genetics can contribute to this lack of understanding. Obligate carriers often have no idea that they are carriers of mild haemophilia, even though it is a genetic certainty because their fathers have haemophilia. This may lead to the carriers having sons with haemophilia without realising or preparing for this.

In general, due to the low visibility of symptoms and this lack of knowledge and education, diagnoses of mild haemophilia are often made later in life.

This can be telling because the INSIGHT study shows that 4% of people with mild and moderate haemophilia get inhibitors. This typically occurs later in life (30-50 year old) and usually after a bad bleeding episode. Although inhibitors are uncommon they can convert a mild bleeding disorder into a severe bleeding condition, and therefore have serious consequences that someone with mild haemophilia is not used to managing.

The general consensus is that we need to uncover mutations and do genetic testing on all people with haemophilia to find out if they are at an increased risk of inhibitors, so they can be monitored and have treatment considered accordingly. For high risk inhibitor groups DDAVP should be considered where possible.

von Willebrand Disorder: Meet the Experts

By Colleen McKay

Bobby's Journey:

Bobby, is a successful, vibrant, creative, positive, delightful, and witty young woman from ACT (Australian Capital Territory). She inherited von Willebrand Disorder (vWD) from her father, and spoke at this session about the realities of living with this bleeding disorder – or as Bobby calls them; "the deeper joys of vWD".

Bobby explained that throughout her childhood she really didn't have too many problems with bleeding. That was until she hit puberty and the realities of menstruation set in. After consultations with Dr Alison Street at The Alfred in Melbourne, Bobby discovered Wonder Drug # 1 – The Oral Contraceptive Pill. The pill was a wonder Drug because it enabled Bobby to attend school and University, have a career, and to continue with her many interests and hobbies – everything a vibrant young woman should be doing!

While in Canberra working with a theatre group Bobby had an unfortunate accident and met Wonder Drug # 2 – Biostate. It was at this point that she discovered that the Hospitals all talked to each other; thus facilitating speedy treatment. Bobby considers Wonder Drug # 3 – Tranexamic Acid to be a 'Godsend', because it assists her to manage menstrual bleeding and nose bleeds.

After a tough time discovering that she also has Endometriosis, caused by reverse blood flow back through the reproductive system, and some early signs of endometrial changes, Bobby now able to claim to have found Wonder Drug # 4 – Love, Care, and Community through the Haemophilia Foundation of ACT. The care and support that she found via HFACT was just what she needed at this difficult time. Bobby is a regular attendee at HFACT's Women's Wisdoms breakfasts, and spoke highly of her HFACT Counsellor, Clare Reeves. Thank you Bobby for sharing your journey – you are one inspirational and amazing young woman!

Sally & Cassie's Journey:

Sally, who prefers to be known as Sal, is an amazingly awesome and positive young mum who lives in rural New South Wales, a two-hour drive north of the Regional Hospital of Newcastle. Sal shared her journey with her daughter – 11-year-old Cassie. After unusual and unexplained bruising at age 8 months, Cassie was diagnosed with von Willebrand Disorder Type 1. Given that there was no family history of vWD, it was thought to be a Genetic Mutation. Treatment was mostly Tranexamic Acid; Factor was not stocked at the local Hospital. Early issues were generally small, mostly slow mouth and nose bleeds, especially with colds. Because of prolonged bleeding, even though it was slow, Cassie often had issues with low iron levels. After one particularly serious bleeding experience, direct contact with the specialists was arranged, by-passing the Emergency Department, where much time can be wasted.

Sal and her husband continued with their family and went on to have two more children, both boys. At the age of 5 years Cassie was re-tested, and consequently re-diagnosed with vWD Type 3, and her Mum and Dad were both diagnosed with vWD Type 1. This diagnosis resulted in an expanded Team of Specialists for Cassie, and a supply of Factor at home.

Sal shared the challenges of living with a rare bleeding disorder in a rural town:

- Distance and the travel to the Regional Hospital is an issue in terms of time and the cost of travel
- Living in a small community – **EVERYBODY** knows! As Cassie approaches her teenage years, she has reached the point in her life where she wants her privacy
- The long term retention of GPs familiar with Cassie's vWD. GPs tend to come to remote areas to gain experience; once they have that experience they head off back to the city
- Isolation. There is no local Support Group for those with vWD; Sal and her husband know very few families to share experiences for mutual support
- Financial challenges; not just the travel, but employment too. Sal and her husband both work part-time in order to be there for Cassie's medical needs if necessary.

However, given the challenges, Sal and her husband remain positive. They have joined the Haemophilia Foundation of New South Wales for support and to offer support to others. They say that Family Camp is an important support for them as parents, as well as for Cassie.

The future for Cassie? It is well recognised that menstruation could pose problems for Cassie. In preparation Cassie has been learning to self-infuse in readiness for prophylaxis. For 2016, Cassie's parents have made the brave and commendable decision to support Cassie's choice to attend boarding school in Sydney, where she will be in a better place geographically, and also be able to maintain her privacy.

Cassie, we wish you all the very best for your future.

Genetic Counselling Workshop

By Lynne Campbell

Facilitated by Mona Chong and Maureen Spillsbury.

This was a small Workshop for invited women only. The purpose was to openly and in confidence discuss the dilemmas associated with choices made surrounding PGD.

Preimplantation Genetic Diagnosis (PGD) is a procedure involving the removal of one or two cells from an embryo and subsequent genetic testing of these cells for specific genetic conditions or chromosomal disorders.

Severe haemophilia is a condition which qualifies for PGD if a woman who carries the gene for severe haemophilia wishes to pursue it. In Australia this selective form of IVF treatment is not financially subsidised.

Two people shared their very different personal stories. Issues and solutions were viewed from a totally personal point of reference.

Not all women enter their reproductive years knowing they have the gene for haemophilia. Everyone who gives birth to a child with haemophilia responds differently and copes differently.

Mothers are not "just Mums". There are some women who know they carry the gene for haemophilia, may be symptomatic themselves and may suffer silently and alone.

Essentially with decisions surrounding PGD a candidate is provided with the full spectrum of information and the counselling required in order to make their decision. There is no right or wrong choice and the decision made by the potential mother is often based on personal experience and from witnessing extreme suffering resulting from haemophilia in their own family history.

Everyone's story and situation is valid, no matter what they ultimately decide.

PGD is not an easy process and there are no guarantees of a healthy baby after undergoing the PGD IVF process.

Other Sessions in Brief

By Joy Barrett

HIV

It was exciting to hear that the last 12 months have seen significant research findings returned, which form a basis for improved treatment options. Although, due to the complexity of the HIV virus, no cure is on the horizon, most people with HIV now have the same life expectancy of those without HIV. Treatment drugs are now more tolerated by patients, and significant benefit has been seen in starting a treatment regime as soon as the virus is detected, rather than wait for the viral load to increase further as was the historical treatment option.

Co-morbidities, other chronic illnesses suffered at the same time, are now a more common cause of death. These include diabetes and cardiovascular disease, as well as non-AIDs defining cancers.

Thankfully, if patients are having to be cautious of drug interactions there are now several medication options available.

Getting Older

It is essential that health issues other than your bleeding disorder are monitored by your GP, as your Haematology Clinic is a specialist provider that is dealing specifically with your Haematology.

Plan now for the next stage of life, with special focus on your living arrangements:

- How accessible is your home for you, as your joints may deteriorate?
- Do you need to consider a change in occupation before retirement?
- Do you need to re-examine the activities and interests that you're currently engaged in the long term?

Special note was made of the need to maintain physical activity at any level possible for your current condition. Balance and fall prevention is worth pursuing, because the impact of falls, whether in the home or in other areas, can have a serious impact. Balance can be easily tested by standing on one leg with eyes open looking straight ahead, if this can be sustained then try with your eyes closed. Practising this simple exercise can greatly increase balance in a short period of time.

The great news is that most people with a bleeding disorder are now living almost as long as others in their age group. One of the benefits of attending regular Haematology clinics, that has seen throughout Australia, is that issues like weight gain, dental work etc. are also discussed in clinic, so there is a heightened awareness of a range health issues in our population group.

Regular screening is still essential for cancers of the bowel, breast, and prostate.

Longer Acting Factors

A Family's Personal Experience. We were privileged to hear from a teenager who is currently on longer acting therapy. He spoke of the significant impact that this has had on his life. Since starting the trial his only bleeds have been trauma based. Currently he has two treatments a week instead of the three previously. This has freed up his time and his mind to allow room for more normal activities, without the pressure of thinking "only another day and then treatment again". It also has reduced his mild anxiety of needles, as he is having 52 less injections a year.

One of the issues associated with trialling these new treatments is an ethical one; what if the patient has to revert to the original treatment plan after the trail?

This session made significant reference to technology, such as work on modifying the structure of factor VIII into a single chain with the aim of making it more stable.

Another trial taking place in Australia is administering the Factor subcutaneously as opposed to venous access.

By Richard Chambers

Comprehensive Care: The Journey

Presenters: Dr Alison Street, Leigh McJames and a panel discussion

Alison led us through the history of treatment of bleeding disorders; from Rasputen through the development of replacement factor products, the 1980s HIV and and HCV infections and the ongoing impact that has had on individuals and the community, new safe products, and in the 1990s the first descriptions of what comprehensive care for bleeding disorders could look like. New Zealand is slightly ahead of Australia, having documented standards of care, but have yet to establish an audit process to see if we are meeting those standards of care. Alison made special mention of our own Deon York and Dr Elizabeth Berry and their contribution to the haemophilia community.

Leigh discussed the Australian system for funding product and their priorities, which are the same priorities as New Zealand: Treatment must be effective, appropriate, sustainable and affordable.

Youth

Presenters: A panel (including a Physio, Nurse, Psychologist a young man and a young woman)

A very interactive session with a lot of input from those present. The issues for youths/teens are the same on both sides of the Tasman. How and when to take full responsibility for your own life, treatment, and contact with the HTC. The answer is to have control, to know yourself and to know your treatment. HTC staff expect to be working directly with you, not your Mum, when you are an adult.

Make sure that you consider access to treatment when travelling or being involved in sport. Should you or shouldn't you inform a potential employer, or current employer, about your bleeding disorder? This is a very personal decision, people have had good and bad experiences as a result of informing employers, or in one case being informed on. At times employers were very supportive, in other cases employment ceased shortly after disclosure. It's clear that it is important to know your legal rights and responsibilities.

Being Active for children, teenagers and young adults

Presenters: Dr Chris Barnes, Tim Marchinton, Cameron Cramey

Chris reminded us about the importance of keeping good treatment records, that include the cause of a bleed, and talking with your HTC so that they can work with you to design a prophylaxis schedule that works most effectively for you or your child's activities. Clinicians have mixed views about what sports are appropriate, often the age of the individual, the physicality of the sport, and the timing of the activity all need to be considered before decisions are made, to ensure that our children get appropriate and regular physical activity and time with friends.

Tim talked about the Australia haemophilia 'camp' programme and how many activities can give the perception of challenge and risk while actual risk is minimised.

Cameron spoke about making good use of your physio in rehabilitation, strengthening, and activity planning.

New Therapies and future horizons

Simon spoke about the ongoing research in long acting factors and how this could change bleed management and prophylaxis. There is research underway looking at subcutaneous delivery systems.

Member Profile: Dylan Christensen

Sometimes HFNZ members do so well that their names appear in the media. This happened recently for one of our young men, Dylan Christensen. He was featured in the September issue of TRUCK Journal for his skill and dedication to the transport industry. Anyone that knows Dylan knows how much he loves truck and trucking. This article, reprinted by kind permission of Simon Vincent, has been edited slightly to fit in Bloodline. It shows just how well this HFNZ member has done, and illustrates the point that, with the right attitude, our members can do almost anything.

Passion and persistence equals results

This month we return to our younger generation series. Dylan Christensen has been super keen on trucks since anyone can remember. His family seems to have had a close association with transport with his father, uncle, grandfather and great grandfather all involved in transport at various times in their lives. Simon Vincent went to Rotorua to see how this young man is shaping up as one of the new generation.

Dylan Christensen has officially been involved in the transport industry for just over four years, since graduating from industry training at the Bay of Plenty Polytechnic. Today he drives a late model Western Star logger for the Holmes Group based out of their Rotorua depot. He shares the truck with shift partner Cedric, working a four day on four off roster, hauling logs around the central North Island.

But Dylan's story begins much, much earlier.

The Christensen family has a history in the transport industry that spans four generations.

Dylan's great grandfather was a grader driver for the local county council either in Levin or Gisborne.

His grandfather, Evan 'Denny' Christensen, a trained diesel mechanic, worked in the workshop at the Levin Dairy factory, and drove the firm's trucks. After the plant closed Denny moved on to Modern Freighters as head mechanic for another 2 or 3 years before joining Newman's Coach Lines as a driver. He drove buses for another 20-30 years.

Dylan's father Craig is a fitter welder by trade, however today he is the head driver with Alsco. Craig started driving during the hay seasons. He spent a couple of years market gardening and regularly drove to Turners and Growers in Wellington to deliver the produce. He was offered an adult apprenticeship at the Horowhenua Electric Power Board, where he remained for 15 years until the Power Board closed in 1993/94. After a spell at a service station in Levin, the family moved north to Rotorua looking for better job prospects.

Uncle Kevin started out in retail before he got behind the wheel of a truck. He became a store manager at The Warehouse before, looking for a change, Kevin arranged his own driver training in Rotorua. After a week of intensive training he came away with the necessary heavy vehicle licences, secured work with TransOtway, and remained there until the company closed 15 years later. Today he is driving for Route and Retail delivering from Auckland to Kaitaia in Northland 6 days a week.

It seems that Dylan was fated to be a driver right from the word go. Craig happily reported that Dylan's first truck show was one of the regular Mystery Creek transport shows, Transport 93, which he attended even before he was even born! His mother Wendy tells us that, "The first words out of Dylan's mouth were, he was going to be a truck driver." That's not all, his father Craig built some large scale wooden models of trucks and Dylan managed to cadge one of these as a toy.

As a truck mad kid, Dylan pursued his dream of one day driving the big rigs like his Dad and his Uncle. From an early age his interest in trucks saw him take up truck photography, which introduced him to a group of likeminded individuals and friends. He also spent as much time as possible with his uncle and family friends in the cabs of their trucks, or in the back helping to load and unload.

This all stood him in good stead for his future career behind the wheel.

Like so many young people who have grown up in the industry, Dylan learned the trade from the left hand seat of a truck.

Family friends John Matangi, Geoff Hurst, and Geoff O'Riley were early driving influences, who would take Dylan out on the road. He was also fortunate that his Uncle Kevin's employer was happy to allow the young Dylan to ride in the truck when it was fast becoming unfashionable for kids to do so.

It was Kevin who really took a keen interest in mentoring the young fella. He would take Dylan out on the road every school holidays and even after school on the days he was delivering to Rotorua. When Dylan was only about 10 years old he would be driven out to the Atiamuri sale yards to meet up with his uncle. The pair would set off for a holiday trucking adventure. At the end of the holidays it would be back out to Atiamuri to pick up Dylan and everything would return to normal.

Riding with his uncle wasn't just fun and games, Dylan was expected to 'pay his way' by helping with the loading and unloading. Dylan was also just the right size to send into the belly locker boxes to toss out the cardboard boxes stored there.

Dylan vividly remembers these trips as they crisscrossed the North Island. Deliveries would be made to McDonald's Palmerston North distribution centre before heading off to Wanganui. Store deliveries to the McDonalds outlets along the way were all part of the fun.

As a senior driver, Kevin would invariably be given the new trucks to shake them down. This was great for the truck mad Dylan who got to ride in the Mitsubishis, Kenworths, Macks, and Freightliners that found their way into the TransOtway fleet.

Dylan has been a keen truck photographer since he was about 10 years old and became an expert at taking shots of moving vehicles through the windscreen of the family car. Wendy light heartedly 'complained' that she was banished to the back seat so that Dylan could perfect his art.

It was at truck shows that Dylan started forming friendships with other photographers from around the country. Today he has a group of mates whom he regularly communicates with, online and at various truck shows and events throughout the year. The BP Truck Rodeos at Taupo, Mystery Creek Transport shows, and many of the regional shows became regular ports of call for the whole family.

During his last year at high school, Dylan undertook 10 weeks of work experience. One day a week he would head out on the road with Rotorua Mainfreight contractor Matt Thompson. This opportunity showed Dylan the ropes (well, strops and load restraints…) and proved to be a great building block for his next move, driver training.

As soon as Dylan could leave school he enrolled in the Certificate in Commercial Road Transport Level 3 course at the Bay of Plenty Polytechnic. The 16-week course covered safe driving skills, traffic law, a Class 2 drivers licence, and other essential knowledge including dealing with workplace stress and other health issues. It also included a compulsory 100-hour work placement with a transport company. Dylan was fortunate to be able to secure a work placement in Rotorua with Mansel Transport.

The decision to attend the BoP Polytech was made after Dylan and his parents visited the careers pavilion at The EXPO. After considering offers from all the providers on site, the family felt the BoP Polytech course was the most suitable. The ability to secure funding by way of a student loan was also an incentive to attend. Dylan proudly told us that his student loan has just been paid off.

At graduation Dylan was only a few months past 18, one of the youngest people to have completed the course. He was fortunate that he had held his car licence for long enough to gain a class 2 licence. He emphasises the importance of young people getting their car licence as soon as possible if they are keen to join the industry. This allows them to progress through the graduated licence system as efficiently as possible.

Dylan says he enjoyed the learning experience. He explained that out on the highway the driving experience bears little resemblance to sitting in the classroom being told what to expect. "It's a whole different story working than sitting in a class room and learning it," he noted. However, once he had experienced the situations described during his training, the examples came into perspective. He admitted to feeling a bit apprehensive in the early days behind the wheel, especially when he had some big loads on, but time and experience have increased his confidence.

With a licence in hand and having been told by the Polytech tutors to go out and gain some experience in the industry, Dylan began looking for work.

Dylan replied to an ad in the paper a short time later, looking for someone to help with a livestock operation, and soon an interview was arranged. He met with Ray Kerley of R J Kerley Ltd. Interestingly, Wendy had driven him out and had expected to wait in the car until the interview was over, but she was invited in to be part of the process. Things went well and Dylan soon had the job he so desperately wanted.

Dylan started straight into bobby calf season. After a few days training with one of the other drivers, Verna, he was sent out on his own.

Once the bobby calves had been collected, calf meal had to be delivered out to the farms. The truck could carry 2 or 3 tonne lots at a time, which Dylan would deliver as whole pallets or break down and hand ball as bags. These farm deliveries also taught Dylan how to drive tractors and how to change the implements on the front end loaders so he could lift off the pallets.

This lead on to picking up the cull cows for the freezing works, which would be consolidated back at the yard and loaded onto one of the bigger trucks. Slinks, prematurely born calves, were also collected and brought back to the yard for consolidation.

Dylan was clearly very proud of the trucks he was driving. He would bring them home and wash them on the front lawn at the family home. Wheels would be painted and silicon applied to the tyres. Craig recalls the lawn smelled like cow poo for a very long time.

Six months after getting his class 2 licence, Dylan returned to the Polytech to complete Strand one, his Class 4 licence. As he had done the paperwork once he had completed his Class 2 course, he only needed 2 days (one of training and one for the test) to gain his Class 4 licence. With a fresh new licence Dylan was allowed to help with the silage on the bigger eight wheeler truck.

With his first season coming to an end, it was time for Dylan to start looking for work again.

Dylan found temporary placements around the area, and was even offered full time work by one of the construction companies. However, the second stock season was approaching and, as Dylan had promised Ray he would return for another season with the Kerley family, he felt obliged to honour his commitment.

The second season was pretty much a repeat of the season before and a chance for Dylan to hone his stockman skills. During this time Dylan returned to the Polytech for the final time to complete Strand 2, the Class 5 licence. Three days later he was qualified.

With work winding down for the season, Dylan was again looking for work. At first he was unable to secure employment, then a promising opportunity fell through. Finally, Dylan was successful in securing a position. The following Monday he was in a truck with one of the firm's driver trainers, beginning the process of learning to drive a log truck.

One factor that helped him secure his new job was his previous experience driving livestock, and the associated experience he had gained working on gravel roads. Dylan said that initially he was scheduled to be given an older log deck unit to drive but, wisely, the Rotorua manager decided it would be safer for him if he was put on one of the new Western Star's which featured all the latest safety systems.

On logs Dylan has been to a huge variety of places, from the very back of Lochinver Station to Matakana Island and most places in between. He visits the regular skid sites in the forests of the central North Island as well as isolated wood lots dotted around farms.

Still, at the start of each bobby calf season, Ray asks Dylan to come in on his days off to help train up the new drivers for the bobby calf runs. Dylan admits, "I don't mind the stock, I quite enjoyed it and I wouldn't mind going back to it one day, to be perfectly honest".

Asked what it is that he likes about his job, Dylan replies, "I'm getting paid to see the countryside".

When asked if he would recommend the industry to young people, he indicated that, first of all, the industry needs to improve its perception with the general public. He doesn't believe the industry as a whole is doing enough to promote itself.

He also suggests that pay rates is another area which needs addressing if the industry wants to attract more young people. However, he is realistic enough to understand that you have to start somewhere, that young people have to accept that there is a cost with any career, and that new drivers will always start on lower pay rates.

Dylan has noticed that in a minority of workplaces the attitude of some older drivers can be discouraging. He believes that some older drivers, at or past retirement age, might see young drivers as a threat to their jobs. He also mentions that, while younger drivers are willing acceptors of new technology, a few of the older drivers have difficulty changing, preferring the status quo. He says young guys may have been shown different ways of doing jobs and at times can feel that they are not being given respect for adopting new methods.

On the other hand, Dylan respects the advice of the older drivers and points out that his former neighbour, Gary Cooper, advised him 'to sit back and relax in the cab and take in as much of the knowledge that the older drivers will tell you'.

Today Dylan and long-time partner Cassandra are putting down their roots in Ngongotaha. He is thriving working for the Holmes Group and driving his Western Star. He thoroughly enjoys the freedom that the 4 on 4 off schedule offers, but still finds the early morning starts a bit challenging, especially during the cooler weather.

Dylan has gone a long way towards realising his dreams, however there is still one more dream job he wouldn't mind attempting: driving one of the Australian super car racing transporters. Right now he is still enjoying the comfort of a new home, nearby family, a great job and good friends just a phone call away.

The benefits of HFNZ membership

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.

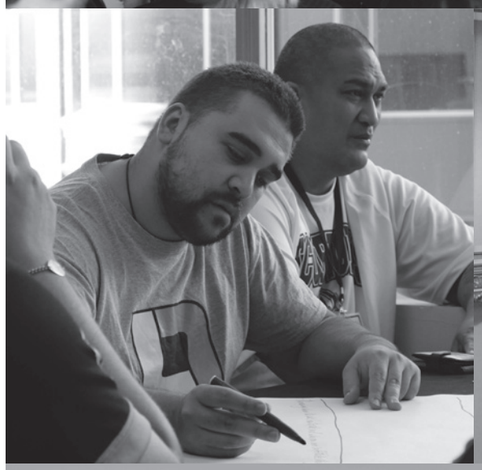
Becoming a financial member is very affordable, just $25 for an individual or $35 for a family, and gives you access to the resources of a national organisation. Our members get to travel to camps and workshops across the country, are entitled to footwear subsidies, and are party to all negotiations and advocacy between HFNZ and third parties.

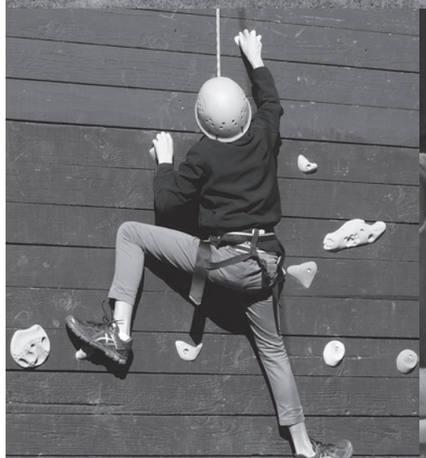
That means having HFNZ working hard for you in a whole variety of different ways. Just one example of this is this year's Pharmac funding round, where HFNZ were able to supply and receive information and opinions on behalf of all our members, ensuring that they got the best result possible, and that their concerns were heard.

Paying your membership fee allows you to be a part of 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 member.

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





Adult wellness weekend

By Sarah Elliott

Adults with bleeding disorders and their partners from around the country flew into Wellington on 12-14 June to share a weekend of learning about bleeding disorders, networking, and fun! In all there were 55 people plus staff in attendance.

To get the weekend underway Te Whainoa Te Wiata delivered a Mihi Whakatau, which was followed by an official welcome and an activity to everyone get to know each other better. After the opening, to set the scene and encourage an atmosphere of openness and trust throughout the weekend, some brave people with bleeding disorders or partners of people with bleeding disorders shared their personal journeys and experiences – the hard times, the good times, and everything in between. This was a very moving and emotional experience for some of the speakers and audience.

There were some very interesting educational sessions over the course of the weekend. Saturday was spent getting into the nitty gritty of bleeding disorder education and discussions. The day started with "There will be blood", in which HFNZ CEO Richard Chambers talked about bleeding disorder care in NZ and how all the different organisations and providers fit together.

Later that day Wellington haematologist Dr Julia Phillips presented a session about present and future perspectives of Haemophilia treatment for adults, while haemophilia nurse BJ Ramsay ran a concurrent session about von Willebrand disorder and platelet disorders. It was great to have so many people with vWD and other rare bleeding disorders along to the weekend, our most ever!

Because there were so many questions for these two very well-informed speakers, the next session was significantly reduced. Sarah Elliott gave a brief information overview of the current research and surveys happening in NZ at the moment, and their importance.

Sunday's education session was physiotherapist Helen Dixon, who came along to discuss using ultrasound equipment to diagnose early arthropathy. This was another very interesting session, which led to lots of time spent answering questions and furthering the discussion.

As the purely educational sessions, there were a number of workshops hosted by HFNZ staff and other professionals.

On Sunday morning there was a split session held by the Outreach Workers This saw people with bleeding disorders and their partners in separate rooms from each other. The workshops were based around participants sharing experiences, discussing support systems, and looking at ways to look after themselves from a holistic perspective.

By far the most heated session saw PHARMAC representatives come along to the workshop to discuss the proposed changes to treatment products and the tender process. A lot of emotion and debate was generated, and it was fantastic to see the levels of passion and fire in our members.

The workshop's final session was run by counsellor Rosemary Nourse, who got people to role play and practice a range of different communication techniques. This turned out to be a real hit, and a highlight of the whole weekend. Everyone headed home with some new tips and tools to help them to communicate with their loved ones more effectively.

Of course Adult Wellness Weekend isn't all about education and workshops; there was also time for some fun.

On our first night we had the "Slumdog Millionaire" Wellywood themed quiz night followed by a prize Steal-a-thon. This was great fun, and the winning team really benefited from BJ Ramsay's broad general knowledge…

Both Saturday and Sunday morning saw attendees given the opportunity to have a go at Tai Chi with Rosalie Reri, who is the partner of one of our members with a bleeding disorder. While these sessions weren't highly attended, those that did go really enjoyed them. Thanks Rosalie.

On Saturday afternoon participants got the choice of adventuring off to Weta Workshops for a full tour, which was a highlight for many, or to wandering around Te Papa Museum. It was great to get out of the hotel for the afternoon and into the fresh air for a bit. Saturday evening was the big Wellywood glitz and glamour dinner with a red carpet, Oscar trophies and all. Attendees went to great lengths to dress up to the nines and get into the spirit of the evening. It was a great night for one and all.

After the final assembly on Sunday afternoon everyone headed off home, full of new knowledge, and with some fantastic new experiences under their belts.

Adult Wellness Weekend was very successful this year, and thanks must go to Baxalta, who sponsored the event; to Barb Hodges, the Baxalta rep, for joining in with our quiz night and the glitz and glam dinner; and to Pharmac, who contributed towards the food. A special mention goes out to Leanne, our super-admin, who organised all the logistics, and to the Outreach Workers, Sarah, Lynne, Linda, and Joy, who really stepped up and ran the camp like clockwork in Colleen's absence. It's a real testament to their skill and professionalism, and to Colleen's experience as an event planner. Well done to all.

Youth Camp 2015

By Colleen McKay

In July this year a fantastic group of young people, leaders, nurses, and staff gathered at Motu Moana Scout Camp in Auckland for Youth Camp 2015.

All together 24 youth with bleeding disorders, 12 Youth Leaders, 3 Haemophilia Nurses, and 3 Outreach Workers joined together for a winter 'Search and Rescue' themed weekend escape. Even in balmy Auckland mid-winter actually means something, the days were sunny with blue skies, but the nights were very cold. We had to survive Auckland's coldest night in history in VERY basic scouting accommodation.

To begin the weekend the youths were divided into four Teams, the Youth Leaders taking their team through Team Building Games in order to get the groups to work well together and to have fun.

One of the first tasks was for each team to create a 'Haemo-man' mascot that had to safely undertake all activities in the programme, including rock climbing, the challenge valley obstacle course, and laser tag, alongside the group. Each team gave their mascot a name: X Man, Blue Barrymore, Viper, and Hugo. The twist was that each mascot had to have a raw egg securely packed inside his head. Much planning, strategy, and stuffing went into each mascot. On the last day of camp the much awaited official autopsy revealed that all four mascots survived Youth Camp with raw eggs intact. No brain bleeds!

The education session 'Developing specific Bleeding Disorder knowledge' saw participants designing and filming three training videos to educate Search and Rescue medics about bleeding disorders, how blood clots, the signs and symptoms of a bleed, and all about joint bleeds. These are awesome, and can be viewed on YouTube:

- Jurassic Clot - http://youtu.be/s48_vITk_iM
- The Flying Fox Accident - https://youtu.be/3Ojkman-inQ
- Bloody Joints - https://youtu.be/Bo3zHEO2lrY

They are well worth watching, and are a testament to the knowledge of bleeding disorders that was developed, the team work generated by the Youth Leaders, and the creativity of all the participants.

Other educational activities included ones the Outreach Workers designed to increase general health knowledge and increase Life Skills – 'Let's get InQUIZative', 'Health Search and Rescue', and 'Where am I?' Haematologist, Nicola Eady came for a 'Question and Answer' session, Physiotherapist, Lisa Weaver talked about the benefits of physiotherapy, and Liam Brodie came and talked to the older youths about issues related to employment.

Alongside the education there were also some fun and social activities. We made the most of the Motu Moana Scout Camp facilities by having a go at the rock climbing wall and the Challenge Valley obstacle course. Team building initiatives included a very fun pioneering activity as well as Queen Scout Peter Leslie leading a bivouac building activity accompanied by campfire building and marshmallows toasting.

The Mystery Food Box MasterChef Challenge saw teams cooking their own dinner from a surprise collection of ingredients, and the three Haemophilia Nurses bravely judging each dinner for taste and presentation.

Youth Camp wouldn't be complete without the traditional Laser Tag. Sunday evening saw everyone, complete with team mascots (well maybe one poor Mascot was left behind and missed the fun…) board a bus and head off to Megazone Laser Tag in Manukau for a very competitive and lively game of Laser Tag. No injuries sustained, back to Camp with a bus full of exhausted Campers.

By Monday afternoon it was time for all the very tired but happy campers and leaders to wing their way home, having learned new things, made new friends, and had a fabulous and FUN time.

Check out the Youth Camp Video on YouTube and see for yourself all the learning and fun that was had - http://youtu.be/YzZmkARlLzU

Many thanks to all those involved:

- The haemophilia nurses for their oversight of the Treatment Room: BJ Ramsay, Mary Brasser, and congratulations to Amy Suddaby for braving her very first Camp,
- Our guest speakers Nicola Eady, Lisa Weaver, and Liam Brodie, who all made the journey out to Motu Moana to share their knowledge and expertise,
- Our amazing youth leaders. Fantastic 'young' men from within our bleeding disorder community who all stepped up with enthusiasm and energy to give their young 'Blood Brothers' a fantastic and memorable camp experience. You all lead by example – Thank you very much.
- The hardworking HFNZ staff. CEO Richard for joining us for the day, the multi-talented Phil Constable who joined us to edit the educational movie clips – they are fantastic. A special big thanks goes to our great team of Outreach Workers, Sarah, Joy, and Linda, for EVERYTHING – presentations, enthusiasm, supervision, setting up, cleaning up, too many jobs to mention - as well as keeping a kindly, watchful eye on Campers to ensure their health and happiness.
- And to our Funders, Novo Nordisk. Thank for your belief that the camp experience builds community, knowledge, independence, and makes magical memories for our youth with bleeding disorders – memories that they NEVER forget.

Piritoto

Kia ora koutou te hunga pānui.

Piritoto is an HFNZ national member representative group. Our role is to offer a Māori perspective and to reinforce the role of tikanga, Māori cultural practices, for people living with Haemophilia in Aotearoa. We are slowly working on building new connections with any individual, or any family, who identifies as Māori, or has a close connection to Māori, and who lives with haemophilia personally or as a partner.

The Piritoto name was chosen specifically to highlight our top priority, to connect our people. Piri in Māori means to stick or to keep close, while toto refers to blood. Piritoto members have a unique double connection, our bleeding disorders and our culture. It makes no difference to us where you come from, how closely you may associate with your Māori side, or whether you speak te reo. In Piritoto all of this is secondary to growing our connections with each other. Every year we aim to have a Marae noho, a gathering to help build and strengthen these relationships and to create new ones, as well as introducing the Māori world to those who are yet to encounter it.

If there is a Piritoto activity in your area please feel free to come along and say hello. To find out more about Piritoto just drop us a line at info@haemophilia.org.nz or talk to your Outreach Worker.

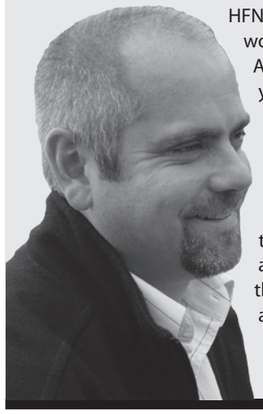
Ngā manaaki ki runga i a koutou.

Piri toto

HCV

By Richard Chambers

Sometimes people might wonder why the work of HFNZ includes Hepatitis C work. In the 1980s a number of our members received blood products that were infected with Hepatitis and HIV. In 2006 HFNZ and the government agreed to a treatment and welfare package for people who received infected blood products. The agreement included a government commitment to ensure ongoing access to current best practice treatment for all affected HFNZ members. Recently a new type of hepatitis treatment has become available, this treatment has few side effects, has a short treatment cycle, and an exceptionally high cure rate.



HFNZ has been working with ACC for a year to enable its members to gain access to the new treatments as soon as they were approved in New Zealand.

We are pleased to confirm that access to the new treatment is now available through ACC if it is recommended as clinically appropriate by your specialist. If you have an accepted ACC claim for HCV, contact our outreach team for advice, and then go to the specialist who treats your hepatitis. It is helpful for our outreach team to be aware that you are sending a request in to ACC for treatment. That way we can coordinate with the ACC team leader with responsibility for HCV, and ensure that the ACC process goes as smoothly as possible.

Recently HFNZ member Steve Waring completed treatment as part of a trial of Harvoni (Sofusbrivir), the same treatment that is now being made available to all our members via ACC:

I am as a person reluctant and a little nervous about "new" treatments etc. but after waiting more than 20 years for a non-interferon based cure I put those fears aside and grabbed the opportunity to clear my HCV in just 12 weeks, without all those horrible side effects, with both hands. It was the best decision I have ever made.

I didn't really know what change being cured would have on how I felt physically, as I had been under the HCV fog for so long it was hard to remember what normal felt like. But I knew that the mental relief of getting rid of that little voice my head that kept telling me that "HCV would catch up with me one day and take me out" would be immense, and it was.

It was like a huge weight had been removed from my shoulders, and, unlike haemophilia with its ongoing bleeds and bad joints, I knew this wouldn't be coming come back.

I felt better with every week that went by. I went into treatment determined to stay well. With "keeping well" in mind, I kept my water intake up and ate "healthy", and apart from some slight end of workday fatigue towards the end of the 12 weeks of treatment, I stayed very well and overall felt better with every week that went by. The fact that HCV was untraceable within my system after only 2 weeks of treatment probably explains the feeling better, with friends and family commenting on how well I was looking as the weeks went on.

This is life changing treatment and I can't wait to see all the guys clear of the virus and out of the HCV fog.

That's a fantastic result for Steve, and the prospect of the same for all our other affected members is exciting.

2015 AGM

By Phil Constable

The 2015 AGM took place in Hamilton on September 12th. This was an opportunity for the foundation to present all of its successes from the preceding year to its members, to elect new office holders for the year to come, and for all the people that contribute to the foundation to touch base.

The meeting was opened with a karakia from Te Whainoa Te Wiata, followed by a waiata, before President Deon York welcomed all attendees. Patron Elizabeth Berry was then invited to light a candle and say a few words to recognise the HFNZ members who passed away during the year. It is important for us to recognise that all members, past and present, are an ongoing part of the work we do.

The main business of the meeting was to ratify the reports from the President, the CEO, the Treasurer, and the Member Representative Groups, and to elect officers and group representatives to the National Council.

Representatives were given the opportunity to comment on their report as it was presented in the Annual Report, before a vote was held on whether to adopt them. All were carried.

There were no challenges to the existing office holders, so all were returned unopposed. The office holders for the 2015/16 year are:

- President – Deon York
- Vice President – Catriona Gordon
- Vice President – Richard Scott
- Treasurer – Grant Hook

The Piritoto and Youth delegates, along with the regional Member Representative Group delegates, were also announced at the meeting. These delegates are elected by members of each group, and represent them at National Council meetings. The delegates for 2015/16 are:

- Piritoto – Te Whainoa Te Wiata
- Youth – Hemi Waretini
- Northern – Greg Jamieson
- Midland – Linda Mellsop-Anderson
- Central – Stephanie Coulman
- Southern – James Poff

Another important part of the AGM was the awarding of the McKay Trophy and the Elizabeth Berry Exercise Cup.

The McKay Trophy is awarded to the MRG that hosts the best event during the year. This year the cup went to the Northern group for their World Haemophilia Day trip to Rangitoto. This outing was chosen because of the way it catered for people of a range of ages, stages, and abilities, and the fact that they also incorporated Buddy Day into their thinking. The feedback for this outing was fantastic. The trophy was accepted by Richard Scott, chair of the Northern MRG.

The Elizabeth Berry Exercise Cup is awarded for contributions to health, fitness, and wellbeing. This year the cup went to Willy TeKira. Willy is a member of our Masters group, older men with haemophilia. He has joint and mobility issues, but he's taken up exercise with a vengeance. Not only does he get himself out and about every day, be it the gym or swimming, he's also an inspiration to the rest of the group. In fact, on the day of the AGM Willy completed his 100th consecutive day of exercise! We called him from the conference venue to let him know he was the winner, and he was very pleased. Maybe even a quiet tear. Good on you Willy.

To wind up the meeting we had President Deon York put on his World Federation of Hemophilia hat and talk to us about how WFH works, and his role in it. This was a really interesting presentation full of enlightening information and some pretty startling statistics.

All in all, this was a successful meeting and those that attended were rewarded with good company and useful updates. We look forward to the next one.

2015 President's Report

By Deon York

I concluded my report last year by writing that change brings opportunity. Reflecting on the past year, change certainly has brought us opportunity but it has equally brought some uncertainty to our community.

As at June 2015 we were on the verge of announcements affecting the products available for use in New Zealand to treat bleeding disorders. While all proposed are safe and efficacious, the change is more than a new factor concentrate; it means adjustments to the routine, learning how to draw up a new product, and it can create anxieties. Exciting developments in hepatitis C treatment have heralded a new and highly effective treatment with a success rate of over 90%. Of the 186 members originally infected with hepatitis C through contaminated blood products, 37 remain affected. This reduction in members living with hepatitis C is bittersweet. For many this is a result of completing a successful course of treatment, but in some cases it has been a heart-breaking loss to a family and a community. This is why access to the most effective treatment for all 39 of these people remains a priority for us. The changes of 2014/15 have only emphasised the continuing importance of a strong national organisation dedicated to improving the lives of people with haemophilia and related bleeding disorders.

This past year has highlighted the remarkable commitment of our staff as they have supported our new CEO, as well as the dedication of our many volunteers as they support each other. A key challenge this year has been to ensure that we support our community as a whole, so that we are not contributing to widening inequities. While our core work is for relatively rare bleeding disorders, the needs of our community are varied. This year I have seen a very positive and resilient community emerge, despite the challenges that we all face together.

Membership

As at 30 June 2015, HFNZ represents approximately 1074 individuals with a bleeding disorder. The membership comprises 437 (41%) people with haemophilia A or B, 383 (36%) carriers, 211 with von Willebrand's Disease (19%) and 43 (4%) with a rare bleeding disorder.

Funding

We could not deliver many of our services without the donations fundraised with the help of KiwiFirst Limited. It is through them that the New Zealand public can donate to our cause. We are truly grateful for the support given by such a wide range of people. Without this, we would not be able to deliver the support that our members need.

HFNZ remain fortunate to have a group of outstanding supporters who have committed to making an investment in our programmes and educational workshops. We gratefully acknowledge the support of Baxalta, Bayer Healthcare, Novo Nordisk Pharmaceuticals Ltd, and Pfizer Ltd.

We are also contracted by the Ministry of Health to support our members with Hepatitis C, as well as by District Health Boards through the National Haemophilia Management Group which part-fund our Outreach services.

We appreciate the many charitable organisations and trusts that have contributed funding towards a range of our programmes and services. All contributors to our mission are detailed in the financial report.

Representation

The National Council, the governing body of HFNZ, represents and is comprised of people whose families are affected by bleeding disorders. In addition to the officer holders, who are elected nationally, our six Member Representative Groups each elect a delegate to National Council to represent them.

In 2014/2015, the following people served on the National Council:

- Vice-President: Catriona Gordon (Midland)
- Vice-President: Richard Scott (Northern)
- Treasurer: Grant Hook (Central)
- Youth Delegate: Hemi Waretini (Northern)
- Māori Delegate: Patience Stirling (Northern)
- Masters Group Representative: Willy Tekira
- Northern Delegate: Greg Jamieson
- Midland Delegate: Catriona Gordon
- Central Delegate: Stephanie Coulman
- Southern Delegate: James Poff

Richard Chambers (CEO, HFNZ) served as an ex officio member and Steve Waring (Managing Director, Kiwifirst) served as a co-opted member.

Affiliated Organisations

Catriona Gordon remained as the representative on the National Haemophilia Management Group. This group is responsible for the management of haemophilia services and brings together clinicians, funders, key stakeholders and the HFNZ as the consumer organisation. Once again, we thank Catriona for the time she has devoted on our behalf.

I continued on the World Federation of Hemophilia's (WFH) Board of Directors. I continue as Chair of the WFH Fundraising and Resource Development Committee and Co-Chair of the National Member Organization Capacity Building Committee and Youth Leadership Advisory Group. I also continue to remain involved in the areas of research and educational materials.

National Programmes

In addition to our important Outreach service, the HFNZ provides a number of beneficial programmes to promote the health and wellbeing of our members. The swimming and exercise programme supports swimming lessons, therapeutic swimming, and access to fitness equipment for people with moderate and severe bleeding disorders. HFNZ also provides vouchers for supportive footwear for those with severe bleeding disorders or joint damage as proper footwear is important in reducing the chance of ankle bleeds and long-term joint damage.

Every year, the HFNZ runs a range of national educational workshops to target the needs of our members and deliver our core mission: to support people with bleeding disorders. Over the last year, HFNZ have held several workshops, including:

- National Inhibitors Workshop, Auckland. July 2014
- Youth Leadership Weekend, Christchurch. August 2014
- National Family Camp, Rotorua. January 2015
- Parents Empowering Parents Weekend. May 2015
- Adult Wellness Weekend, Wellington. June 2015

You can read more about these activities in other sections of this report.

Other Activities

HFNZ's formal twinning relationship with the Cambodian Hemophilia Association (CHA) came to an end this year. While this has concluded, the relationship has only deepened and HFNZ will continue to work with the region as resources allow. We have learnt and gained so much from working alongside the CHA.

I would like to take this opportunity to personally thank all the dedicated members, volunteers, and staff for their efforts in making this year a successful one. We are all working together to make lives better for those with bleeding disorders and their families. With such a great network of support I am confident that we will have another great year ahead.

MRG REPORTS

Central

By Stephanie Coulman

We had our annual camp at the end of August in Taupo. Attended by 60 members, we had an enjoyable time with some fun outings, interesting talks, and time to mix and mingle.

On the Saturday morning, while the younger children were ably supervised by Michelle Guevara and Wadid Ballo (thank you to them!) we heard from Deon York about the World Federation of Hemophilia. Deon is a very knowledgeable source on the latest developments coming out of World Fed and we appreciated him giving up his weekend to share his expertise. He also acted as our after dinner speaker and gave a motivating talk on how haemophilia is actually the 'awesome gene' and proved it with all the positives having haemophilia has brought to his life.

We held our AGM at camp – a great way to get a good attendance! - and elected our office holders and committee members. There are not too many changes for the 2015/2016 committee apart from Ross McCarthy taking on the role of Secretary:

Chairperson/National Delegate: Stephanie Coulman

Treasurer: Blair Wightman

Secretary: Ross McCarthy

Maori delegate: Carol Reddie

Youth delegate: vacant.

Committee: Judith Dudson, Lisa and David Habershon, Grant Hook, Michael Ho, Lorraine Gordon, Lauren Nyhan.

We had a good discussion about funding and events and discussed the idea of having a camp every two years. In fact, in a survey which Ross McCarthy sent central region members, 55% of respondents indicated they would prefer a camp every two years. That said, we are not sure if these results are statistically reliable due to the low number of respondents.

After the AGM and lunch, we visited the Craters of the Moon geothermal park and walked amidst a mysterious atmosphere of swirling steam vapours.

On Sunday morning most of the group met at the deBretts hot pools for a soak and a chat before departing for home.

It was great to see some new faces at camp and also to see the teenagers getting to know each other and getting on well, even the ones who were resistant to coming to camp. If that was their last family camp, it looked like they ended it on a good note.

Midland

By Catriona Gordon

Midland held its AGM at Hobbiton, just out of Matamata in July 2014. It is a remarkable place to visit, and incredible to think that the set has been seen all round the world. Our members all enjoyed walking around and then finishing off with a beer at the Green Dragon Inn. As there was only one ring, we managed to get a committee elected without everyone disappearing on us. It was actually at the AGM that the new Adult Colouring-in craze started, with some committee members so engrossed in their drawings that they almost forgot to vote themselves on.

In December we organized a bus for an expedition to Rainbows End. It was a huge amount of fun, with stomachs being left behind left right and centre.

In March we held a blow karting event at Papamoa which was attended by several families.

Joy did a great job rallying our teen and youth following the National New Families Camp in January, resulting in Midland boys making up over half the attendees of the Teen and Youth Camp which was held in July.

We look forward to the coming year, meeting up with old friends and new families throughout our region.

A huge thanks to Joy, who does so much for our members.

Northern

By Richard Scott

The last year was a successful year for the Northern branch with some new members on the committee and many successful events.

With larger numbers turning up to events our costs have been higher and the year ahead may see slightly fewer events and some trimming of costs, but we have still got a great programme planned. The region is growing in diversity with many nationalities represented at events, which is great to see, and we hope that we can maintain this engagement across many cultures going forward.

The highlights of the year were the Christmas party at Rainbow's End, the Summer Camp (including the Karaoke competition), and the Buddy Awards and hike up Mt Rangitoto. We even got some press coverage in the NZ Herald.

Many people enjoyed the national events too and many northern members helped out at the New Families Camp and Teen and Youth camp. Thanks to everyone who turned up to events that were organised, it's great to see more people involved and meeting others.

It was good to finally get a new AHDHB physio with specialist skills dealing with Adult Haemophilia patients. Those who have had a break please get back into physio, as you will soon remember how much better you were health-wise.

Looking ahead, we have a new venue for summer camp. We have outgrown the Mangowhai heads camp and will be trying a larger venue. Upcoming events include our AGM, Genghis dinner, Armageddon volunteering, Rock climbing, the men's fishing trip, and a Christmas party (venue yet to be determined). Challenges for the next year will be changes in product for many members as the Pharmac tender takes effect.

Also, we are always looking for new committee members and nominations will be needed two weeks before the AGM.

Southern

By James Poff

The Southern MRG have had some fantastic events over the 2014/2015 period.

Take a Kid to Footy in the winter months is a good chance for the hardy to get out and support the Crusaders.

August was the Southern AGM which was held at the amazing Antarctic Centre. There was a fantastic turn out and the opportunity to look through this wonderful attraction after the AGM and afternoon tea.

Another amazing Southern MRG camp was held at Tea Pot Valley in Nelson. The snow through the pass made a long day for those who didn't have chains, and had to back track around the long way via Kaikoura. Some battled through the snow, oblivious to those that had been turned around.

All an adventure for the families who attended!! The children and adults enjoyed the full range of activities at the camp, a trip to an animal farm and a market morning for mums. Everyone had a memorable trip from Kaiteriteri to Bark Bay! It was great to see the children have such a good time and again, for parents to meet, or to reconnect.

Also in October the Youth had a night out, to consolidate all their hard work, plans, and ideas on the back of the Leadership Weekend.

The Xmas event was again held at the Groynes with Santa in attendance.

A good representation from Southern went to the Families Camp in January 2015 in Rotorua, and fun was had by all that attended.

A Southern Men's dinner was held in February and more events for the wider group are planned.

Armageddon events were held in both Dunedin and Christchurch with HFNZ supporters using this as a great fundraising opportunity.

In April, to celebrate World Haemophilia Day, Buddy Awards were held at the Christchurch Gondola and some very special people were awarded certificates, nominated by people who they have helped on their journey. Big thanks to Robyn Coleman for the organisation.

In May another successful fundraising event was held. In conjunction with Heather Giles and Brick Road Productions, tickets to the play Shirley Valentine were sold, and a fair portion of the sales went to the HFNZ. Supporters bought a plate and Lorraine again supported with wonderful raffle prizes, and Karl was our trusty barman!

We also recently did a fundraising sausage sizzle at the Hornby Mitre10. This was a great success due mainly to all the donated supplies, and the help of a hardy few. A Big thanks goes to Susan Inwood, Rob Silva, Shane Steele, Abby Blackler, and Amy's Mum for all their hard work. As well as the Poff kids and Robyn Colman for their top-drawer onion slicing.

Big thanks to the Outreach Coordinator Linda, and all of the formal and informal supporters of the Southern MRG. Lyn Steele continues to support unconditionally so special acknowledgement for her contribution.

Everyone has busy lives and I truly appreciate the support that you have given over the last year.

Youth Report

By Courtney Stevens

As always, it's been a busy year for all youth involved in the National Youth Committee. We are always looking for new members for our Youth Committee and any ideas/contributions for events are welcome from everyone!

Whilst we haven't had any major events this year, we are constantly looking for ideas that push the boundaries of what people with bleeding disorders can do, but that also come within our budget. Our plan with future National Youth events is to keep the focus on activities that help us to keep active. The latest ideas involve the Queen Charlotte track in Nelson, Kayaking the Wanganui River and something in the Central Plateau – a region where there are plenty of things that would keep us busy! Our plan is to restrict National events to every two years due to budgeting but to fill in the gaps with some Regional events.

Our committee meeting in July was a chance for us to discuss the changes that are happening within the foundation, such as changes to our budget and the move to a 'preferred provider' system, as well as anything that is beneficial for youth with bleeding disorders in New Zealand. Each of the regional youth delegates provided a report about what has been happening in their regions, as well as discussing ideas for regionally focused youth events across all areas. We also worked on our 2-3 year plan and any regional and national events we can fit into this timeline in order to maximise and retain youth involvement. If anyone is keen to get involved and join our committee, make sure you let us know so we can get you on board!

Lastly, I would like to temporarily farewell Hemi on his adventure overseas and introduce myself as the Youth Delegate for National Council in his absence. I would also like to thank the efforts of everyone involved with the National Youth Committee over the last year and extend an invitation for any youth who are keen to join us!

Piritoto Report

By Patience Stirling

"He toto, he taimaha kia piri, tukua kia rere",

The blood, the burden that binds us, let it be free

Tena koutou katoa

Piritoto are continuing with one major event for the year. This year in June we gathered for a wonderful weekend Marae noho at Te Roro-o-Te Rangi Marae in Rotorua. Although quite makariri ki waho (cold outside) the Marae was heated by its natural thermal waters that kept everyone warm and happy. Another positive were the huge thermal baths at the Marae that were a great relief for those with joint pain and just a great time to chat with others while soaking away the day's events.

It was a pleasure to have our CEO Richard Chambers spend the weekend with us and involved himself really well with the Marae duties. Saturday morning was too wet to venture out, so when our manuhiri arrived for just the day's activities, we all participated in group discussions to chat over various topics with our CEO.

However, the highlight of the weekend was our afternoon spent at the tranquil Waikite Thermal pools, (yes I know, more chatting while relaxing in hot pools) and of course thoroughly appreciated by all those who attended.

A reminder to all HFNZ members that if we are participating in a Marae noho in your region, you are more than welcome to spend the weekend or even just a day with our Piritoto whanau, please don't hesitate to make enquiries with the outreach in your region.

I would like to acknowledge Tuatahi Pene for his commitment with the Hydrotherapy classes at Newmarket pools in Auckland. His kaupapa has been very timely while we have been without a Physiotherapist, his exercises combined with some Yoga sessions from Rosalie have been beneficial for all the attendees.

An acknowledgement also to Tama Pene for his stage performance at the 2015 Matatini with his roopu Te Iti Kahurangi from Hamilton, the hard work that's required for kapa haka at that level is so challenging, your commitment and wellness is impressive.

I would like to give a huge thanks to our roopu who continually volunteer their time to ensure our participation with HFNZ is a time for Whanaungatanga (connecting with each other) Awhi me te tautoko (embrace and support each other).

Therefore, my gratitude firstly to our Kaumatua/Kuia Pete Pene, Robyn Thomas and Helene Crown, who guide and maintain Tikanga and Kaupapa Maori for Piritoto.

And lastly to Piritoto Takawaenga - Te Whainoa Te Wiata, Rosalie Reiri, Hemirau Waretini, Tuatahi Pene, Tama Pene, Carol Reddy and Kahurangi Carter, your obligations to Piritoto is so commendable, nga mihi nui kia koutou.

He iti rā, he iti māpihi pounamu

Small things too, have their value

No reira e te whānau whānui

Tēna koutou Tēna koutou Tēna koutou Katoa

HFNZ Remembers John Ferguson

By Carolyn Ferguson

John Ferguson had a great life. He married Carolyn at 19, and they had five lovely children, four boys and a girl. He loved his family with all his heart.

John worked until he was 66 and lived life to the full, never letting his Haemophilia stop him from doing the things he loved, whether it was hunting with his dogs, fishing, or walking the hills for hours.

John was a great friend, he loved to make people laugh, and was always joking around.

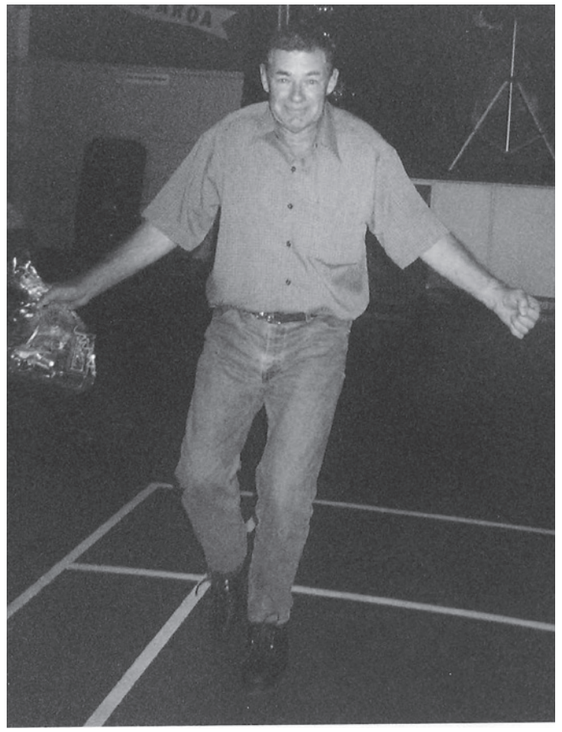
He and Carolyn travelled a lot, mostly cruises, they loved the lifestyle. They both enjoyed seeing new places, meeting new people, and they made friends everywhere they went, of course, you couldn't help but like John.

In June 2014 John got an inhibitor in his blood.

The hospital realized that the Factor 8 was no longer working to stop the bleeds, so John was moved onto Novo 7. He got to the point where he was getting impromptu bleeds while sitting in bed. They then decided to introduce chemotherapy, which took the inhibitor from the hundreds down to three. John spent 72 days in hospital, he was so fed up, it was the longest stay in his whole life. He couldn't walk without a crutch, and he couldn't get out and do any of the things he loved to do. Not even go on holiday. But John never stopped trying to keep up his happy ways around people, even though he was always in pain.

As well as the blessed family he built with Carolyn and his children, he also had eleven grandchildren and two great grandchildren, many nieces and nephews, and a close group of very caring friends who were always there to support them both.

The hospital staff in ward Five North were amazing, it was like a home away from home. Nothing was too much trouble. The intensive care unit staff were amazing as well, where John spent his last couple of days. Thanks to Julia Philips, and to BJ for his



ongoing care. BJ came to the house every day for 3 months to give John his Novo 7 and to check his levels, even Christmas Day and New Year's Day. We're grateful to BJ's family for us being able to borrow him. Thanks also go to Helen, his physio, for helping John as much as she could, and to Huib for his help and support.

John was admitted to hospital with a suspected stomach bleed. He was so positive, he thought he would be back home in a few days. But that wasn't to be. He got an infection, then pneumonia. He was such a brave man and put up a good fight during this time.

John Ferguson; husband, father, grandfather, and friend, passed away on April 13th 2015, just 3 weeks short of his 71st birthday.

He has left a huge hole in our hearts that will never heal.

AN HFNZ XMAS

This is the last issue of Bloodline before Xmas, so we'd like to take the opportunity to wish you and yours all the best for the holiday season, and lots of fun and excitement for the year ahead.

The HFNZ Head Office will close from midday on December 23rd, and reopen on January 11th. During this time, you'll still be able to access an Outreach Worker by calling the Freephone number 0508 FACTOR (322867).

We're looking forward to getting back to a new year full of new challenges and some fantastic national and local events, starting with the Northern Camp in Marsden Bay, and the Young Women's Weekend in Hanmer Springs. It will be great to catch up with you all as the year unfolds.

Merry Xmas and a Happy New Year to one and all!

From Around the World...

Differences between men and women with hepatitis C

The hepatitis C virus doesn't discriminate against gender – anyone can become infected. However, the virus does have a slightly different impact on women compared to men. There are also more men infected with hepatitis C. Approximately 60% of the estimated 50,000 New Zealanders living with hepatitis C are male. Men and women can have different experiences in many aspects of their health. Some of the ways hepatitis C affects men and women differently are described below.

Infection

Research has shown women are more likely to spontaneously clear the virus. When a person comes into contact with hepatitis C there is a 15 to 20 per cent chance that their body will clear it naturally in the first six months (acute stage). The 75 to 85 per cent of people who don't clear the virus will develop lifelong chronic hepatitis C. The percentage who clear the virus in the acute stage is higher in women. Although it is unknown why it is higher in women, it is thought that hormones may be partly responsible.

Some research has shown males are more likely that females to engage in at-risk behaviours, such as injecting drugs. While this is debatable, it means men are more likely to be exposed to the virus.

Alternatively, some women can be more at risk of hepatitis C exposure because of their job. Some predominantly female occupations may be more at risk of blood-to-blood contact, such as nursing, housecleaning, and working in the cosmetic industry.

Liver damage

Research has found men seem to be less protected against liver cirrhosis than women. This means liver damage occurs faster and more frequently in males. Men who have cirrhosis are five times more likely to develop liver cancer than women who have cirrhosis.

Some experts believe the female hormone estrogen protects women from liver damage, making them less susceptible to cirrhosis. However, this also means the protective effect decreases after menopause.

Another factor which influences liver damage is alcohol consumption. Men typically consume more alcohol than women. Alcohol is harmful to the liver and will speed up liver damage.

Treatment

Women have been found to respond better than men to combination treatment of pegylated interferon and ribavirin. This means women are more likely to clear the virus after treatment. However, women who have gone through menopause are also less responsive than younger women to pegylated interferon and ribavirin.

When on treatment for hepatitis C, women are more likely than men to develop anaemia. Anaemia is a condition when there is a deficiency of red cells or of haemoglobin in the blood. It is a common side-effect of ribavirin.

Pregnancy

Women with hepatitis C also have the added concern of passing the virus on to their children. However, there is a very low risk of transmitting hepatitis C to your baby while pregnant or during birth (less than 5 per cent chance). Hepatitis C infection is more likely to happen when a mother has a high hepatitis C viral load, so it is important the doctor is aware that you have hepatitis C in order to monitor your health and minimise the risk of infecting the baby. If the baby is born with hepatitis C, there is a 45 per cent chance they will clear the virus naturally within the first 12 months.

Breastfeeding is safe for women with hepatitis C. Although very low levels of the virus have been detected in breast milk, it is destroyed in the stomach and there is no indication that breastfeeding passes on the virus. You may need to temporarily stop breastfeeding if you have cracked or bleeding nipples.

Source: talkinghepC Spring 2015: Edition 14

Looking to rabbit milk for hemophilia cure

By Lisa Eckelbecker

Telegram & Gazette Staff

CHARLTON – The biotechnology company that turned goats into barnyard drug manufacturers is adding an animal to its production line – the rabbit.

LFB USA Inc. of Framingham has opened a new facility on its 383-acre Central Massachusetts farm and filled it with white, wiggly, genetically altered rabbits that produce milk containing Factor VII, a human protein used to treat the bleeding disorder hemophilia.

The expansion has been years in the making, and is part of LFB's preparations for a product that, if approved, would compete against hemophilia treatments made the old-fashioned way, from human blood; or the less old-fashioned way, from high-tech cell culture systems. LFB's French parent company, LFB SA, is already in the final stages of testing its Factor VII in humans, using material made in rabbits in France.

"We're getting ourselves positioned for launch and commercialization operations," said William G. Gavin, a veterinarian and president of LFB USA. "This is the time to get this facility up and running."

LFB has gone through a number of name and ownership changes since it was created in 1993 as a subsidiary of Cambridge-based Genzyme Corp., but its focus has always been on harnessing animals to make materials for human medical treatments.

The company's scientists used a combination of microscopic skills and veterinary know-how to build a herd of more than 1,000 genetically engineered, or transgenic, goats, capable of producing the human clot-busting protein antithrombin III in their milk.

The protein is sold under the name ATryn by another LFB subsidiary, rEVO Biologics, to prevent clotting problems before surgery or childbirth in patients who lack antithrombin. Sales totaled about $7.7 million in 2013, and rEVO is aiming to expand its use by testing the protein as a treatment for the pregnancy ailment pre-eclampsia.

When LFB decided to pursue a Factor VII product, however, it concluded that goats wouldn't work.

The pattern of carbohydrates that animals deposit on proteins in their milk, something like a decoration, impacts the biological activity of those proteins. The pattern on molecules made by goats just wasn't right for Factor VII, Mr. Gavin said.

"The rabbit milk did the best job of the carbohydrate pattern and the decoration on that molecule," he said.

LFB is not the only company tapping rabbits for pharmaceuticals. Dutch company Pharming NV uses rabbits to make Ruconest, a recently approved treatment for the skin-swelling disorder hereditary angioedema. Pharming posted about $1.1 million in Ruconest sales during the first quarter of 2015.

Rabbits present certain advantages as dairy animals. Females, or does, can begin reproducing at about five to six months old. The New Zealand white rabbits used by LFB also have big litters of about 10 kits.

Once they've given birth, does can produce milk for about three weeks. Although LFB declined to say how much milk it's getting from its rabbits, animal researchers have estimated the average output of a rabbit is about 200 milliliters per day.

Then there's the cost.

"Breeding rabbits is relatively simple, and they are then cheap to house and maintain," researchers for investment bank Stifel wrote in an August report on Pharming.

At LFB's farm in Charlton, the company houses 410 rabbits in a new 12,000-square-foot facility built off an unmarked road. About eight to 10 workers tend the animals.

It's a milking operation very different from LFB's goat farm. The company's goats live together in open barns, stroll and play on rocks in outdoor corrals and line up for milking in a facility that looks like any modern cow dairy.

LFB keeps its rabbits indoors to avoid exposure to disease. Milking them is unique, said Sharoll L'Italien, rabbit operations manager, who has 20 years' experience working with lab animals.

"Rabbits are more particular than a lot of other species," she said.

In a secure room visible through a window, workers clothed head to toe in sterile garb milk rabbits at two stations. One worker lifts a rabbit into a hammock-like contraption that sits on a table top and secures the animal in place with a flap and straps that look like a coat a dog might wear for winter walks. Another worker attaches mechanical pumping tubes to the doe's teats.

During a recent visit to the center, one worker lightly stroked a rabbit's head and pink ears while it was milked.

Milking takes about six minutes. From there, does go to rolling carts with open containers, then travel back to metal cages in another room.

The cages contain perches, where the rabbits can climb, and balls to occupy the animals.

It's the kind of life that concerns the U.S. Humane Society. Animals might get milked and handled more than they should, and they might suffer stress or pain, said Pascaline Clerc, senior director of policy and advocacy for society's animal research issues department.

"We don't support the use of transgenic animals, especially in that field, because there are other alternatives those companies could use" for production, she said.

Animal health and welfare is paramount to LFB, Mr. Gavin said. The company does not hide what it does, he said, which is producing life-saving drugs in dairy animals.

"I may be running a company," he said. "I'm still a veterinarian."

The LFB rabbits are the result of years of work. The company's U.S. scientists generated the first Factor VII rabbit, or founder animal, took its offspring to France to build up a colony and brought the resulting animals back to Charlton only in June.

LFB is aiming to breed the rabbits, and have about 1,000 animals on site by 2017. The company already knows where it could construct additional buildings.

It's all in an effort to address a disease that is a ripe target for drug developers.

An estimated 20,000 people in the United States have hemophilia, in which blood fails to clot properly. No cure exists.

The most common treatments are intravenous infusions of clotting factors grown in modern biomanufacturing facilities, or drawn from human blood plasma.

Some patients, though, develop antibodies, or inhibitors, to manufactured versions of the most often used proteins, Factors VIII and IX. That's where LFB wants to come in.

The company's rabbit-made Factor VII would compete against Novo Nordisk's NovoSeven, a cell-cultured product with about $1.4 billion in sales worldwide during 2014, as well as plasma-derived Feiba from Baxalta Inc.

It's a competitive market with disruptive threats on the horizon, wrote Karen Andersen, senior equity analyst for the financial research and ratings firm Morningstar, in an email. Feiba is taking business from NovoSeven because it works longer in the body, Baxalta is testing a recombinant Factor VII, and Roche Holding AG is developing a treatment called ACE910.

"In the long run, I expect there could be dramatic improvements — most notably, Roche's ACE910 — that would make all of these therapies a lot less desirable for inhibitor patients," Ms. Andersen said.

For LFB's parent company, which also sells plasma-derived treatments, hopes are high for the rabbits and their Factor VII, Mr. Gavin said.

"Do they see this as a significant component within their portfolio? Absolutely," he said.

Source: http://www.telegram.com/article/20150913/NEWS/150919640

SBM* - A Pilot Pilates Program

SBM is a newly designed program that we have been running since the beginning of August. It was developed by Rebecca Dalzell, the physiotherapist at the Old Haemophilia Centre, and Monique Kurki, a Musculoskeletal Physiotherapist and Pilates instructor.

It combines evidence based physiotherapy and Pilates principles to specifically address the unique needs of the men attending who are all living with a bleeding disorder and have either; joint problems, osteoporosis, or poor mobility and increased falls risk.

Research has shown that weight bearing exercises such as these improve bone density, falls risk, strength, core stability, function, and general well-being. These in turn impact on people's ability to participate in community activities.

This program is a 10-week trial we are running because there were no specific exercise class available for this group of men and they found it difficult to access general community programs due to their complex musculoskeletal needs.

They signed up because they wanted to enhance their bone and muscle strength, prevent further bone loss, reduce their falls risk, and enhance their overall function, condition, mobility, and quality of life.

So far it's been a great experience and the men attending SBM tell me they have enjoyed the instructions from Monique, doing the exercises with other men, and that they have also enjoyed the social connections made. They are enjoying the opportunity to meet with other men with bleeding disorders to share stories, learn from each other, and encourage one another, motivating each other to pursue greater health benefits. But it's the change in thinking about posture and balance that they will take away with them after the program ends that's just as important.

Monique has applied similar principles in osteoporosis patients previously, and saw significant improvements in the same areas as our men have identified. At the start of SBM Bec and Monique asked the men to do a Balance/Falls Risk and Quality of Life measure so they can evaluate the program when it ends.

Monique and Bec hope to present the preliminary findings at the Haemophilia Conference on the Gold Coast at the end of this month (October).

The outcomes achieved through SBM so far have been an improvement in the participants' confidence greater well-being, and enhanced strength, endurance, and general function. This means that we can expect to see our participants getting outdoors a bit more and perhaps pursuing more activities than previously.

*SBM = 'Strong Bloody Men'

Source: The H Factor: Newsletter of the Haemophilia Foundation Queensland. Spring 2015: Issue 44

Researchers find way to reverse clotting factor deficiency that triggers hemophilia A

For the first time chromosomal defects responsible for hemophilia have been corrected in patient-specific iPSCs using CRISPR-Cas9 nucleases

Sufferers of hemophilia live in a perpetual state of stress and anxiety: their joints wear down prematurely and they have bleeding episodes that feel like they will never end. Their bodies lack the ability to make the clotting factor responsible for the coagulation of blood so any cut or bruise can turn into an emergency without immediate treatment.

Hemophilia A occurs in about 1 in 5,000 male births and almost half of severe cases are caused by identified "chromosomal inversions". In a chromosomal inversion, the order of the base pairs on the chromosome are reversed so the gene doesn't express properly and the sufferer lacks the blood coagulation factor VIII (F8) gene, which causes blood to clot in healthy people.

A Korean team led by Director of the Center for Genome Engineering Jin-Soo Kim, Institute for Basic Science (IBS) and Professor Dong-Wook Kim at Yonsei University has experimented with hemoplia A-derived induced pluripotent stem cells (iPSCs) and hemoplia mice and found a way to correct this inversion and reverse the clotting factor deficiency that causes hemophilia A.

This was the first time a type of stem cell called iPSCs--which possess the ability to change into any cell type in the body--was used in a procedure like this. The urinary cells were collected from patients with the chromosomal inversions causing hemophilia to make iPSCs, the team applied CRISPR-Cas9 nucleases (Clustered Regularly Interspaced Short Palindromic Repeats-CRISPR associated protein 9) to them.

The CRISPR-Cas9 reverted the F8 genes which enabled them to function correctly. Corrected-iPSCs were induced to differentiate into mature endothelial cells which expressed the F8 gene. These new endothelial cells were able to reverse the F8 deficiency. To verify that the process worked, the endothelial cells with the inversion-corrected genes were transplanted into F8 deficient mice (mice with hemophilia A) and the mice started producing the F8 clotting factor on their own, which essentially cured them of hemophilia A.

According to Director Jin-Soo Kim, "We used CRISPR RGENs [RNA-guided engineered nucleases] to repair two recurrent, large chromosomal inversions responsible for almost half of all severe hemophilia A cases." Professor Dong-Wook Kim added, "To the best of our knowledge, this report is the first demonstration that chromosomal inversions or other large rearrangements can be corrected using RGENs or any other programmable nuclease in patient iPSCs."

What may be equally as important to the ability to reverse the chromosomal inversion is the fact that there was no evidence of off-target mutations resulting from the correction. This was a precision procedure: only the parts of genome that the team wanted to change were affected.

These findings open the door for further testing and if the results are anything like the mice trials, the future of this treatment looks promising.

Source: http://www.news-medical.net/news/20150724/Researchers-find-way-to-reverse-clotting-factor-deficiency-that-triggers-hemophilia-A.aspx

Bon Voyage Sarah

Our wonderful Northern Outreach worker has decided to move on after 6.5 years in the role. As of November 5th Sarah is off to take on a leadership role at IDEA Services.

We love Sarah, she's a smart, enthusiastic advocate for our people, and for the values we hold dear at HFNZ. We will miss her and all the hard work she puts into everything she does. We know she will do exceptionally well at anything she chooses, as she has done here at HFNZ.

From all of us, staff and members, we wish Sarah happy trails and many exciting adventures. We'll leave the last word to her:

To the wonderful haemophilia community, near and far….

As I move on to my new role with IDEA Services in Gisborne, I am sad to say good bye to an organisation that has always been so supportive of me, and where I have had so many fantastic opportunities. The last 7 years have truly been amazing for my growth, both personally and professionally. What I have learned and gained through my time at HFNZ is immeasurable.

When I first came into the OR role in Hamilton I remember thinking "what have I got myself into?!?!" And a quick read of Bryce Courtenay's book, April Fool's Day, did nothing to sooth my fears (It's about a child contracting HIV from bad blood…). That's one book I won't recommend as an induction into the BD world. Things were a little tricky in my initial phases in both the Midland and Northern regions, as I moved into an area where there hadn't been a solid OR for a while, and where some 'bad blood' had been shed with the foundation and my predecessor. There were some rocky paths to walk and some rocky relationships to mend.

But fear not, then came congress, and camps, and conferences, and more camps, and workshops, and a TV appearance, and articles, and speaking engagements… This job has given me countless opportunities to travel, to grow, to learn, and to further my passion for the work I do and for the BD community.

On top of the fabulous opportunities and experiences I have been able to enjoy, comes the most important thing, the thing that has always been the main pillar of this organisation, and the reason I could not turn my back even when other jobs and opportunities were beckoning me: the people. I have had many successes with individuals and families in terms of my case work, and can leave knowing that I have really helped some people in overcoming some big challenges in their lives.

Firstly, my amazing colleagues, we are such a tight knit team where much has been shared between us over the last years. It is a truly special team that I have been privileged to have been a part of – I thank them all for their guidance, wisdom, support, and aroha. I have learned so much from them, and I hope all the members see and know, like I do, their absolute commitment and dedication to their jobs and to people with BD.

Most importantly the membership, I know you always hear the words of how inspirational and resilient you all are. But, I honestly think you are all beautiful people, people I truly admire, and respect, people I take strength from every day. You get through whatever life has to offer you and you strive to make the best of the situations you come across. It has been an absolute honour to serve for you, get to know you, and be a part of your journeys.

There have been hard times with deaths of members – people I had built close relationships with; specifically acknowledging Jeff Oliver, DJ and Cecelia Eliza, and Maurice Wymer, and seeing other people face some really dark, hard and challenging times in their lives.

I think many other organisations need to take a leaf from HFNZs book. To realise the community is all about people. People binding together, comradery, taking strength from one another and truly caring for one another. I hope I can take what I have learned from you and HFNZ and try to infuse some of that into other organisations.

I knew I was somewhere special and with very special people when I would openly say how much I loved this job, when I was excited to go to work, and felt like I was in a place where I was really making a difference. In fact, I think you have ruined me for all other work I do – I think what I have experienced is rare - To have so much love and respect for an organisation, the staff, and the members. I know I will likely never get something quite like this again in my working life. But I look forward to new adventures and challenges in my work, and I am excited to move to tranquil Gisborne and embrace what the future holds for both me and Frazer.

The hardest thing is leaving and letting go of a place that has been much of my adult life. I have been in the HFNZ world for 6.5 years. I really feel so connected to this organisation, and to the people, and letting go is going to be hard, and is something I have had to think about a lot. I want to hold on and see people grow and develop, I want to know where you all go with your life and see and hear your successes, I want to watch as the organisation further blossoms and continues to make the lives of people with BD easier, I want to know what the future holds in terms of treatment and next steps, and I will be keeping an eye and ear out for all of these things… But, I also know I have to let Nicky, the new outreach worker, come in and spread her own wings, to do things her way, to really have the opportunity to develop connections like I have been blessed to do, and to have the space to grow and become part of this wonderful community. I hope you embrace her and teach her and help her to find her feet, as I know she will do a wonderful job…

And to do that, I must say farewell and go well and thank you and arohanui x

Sarah.

Upcoming Events

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

23 December 2015 - 11 January 2016
HFNZ Office Closed

26 - 28 February 2016
Young Women's Camp
Hanmer Springs Fortest Camp

18 March 2016
Deadline for Buddy Awards nominations

17 April 2016
World Haemophilia Day & Buddy Awards

20 April 2016 (tentative)
Children's Workshop
Venue TBD

24 - 28 July 2016
WFH Congress
Orlando, Florida

30 September - 3 October 2016
Families Camp
Keswick Christian Camp, Rotorua

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

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

give a little

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