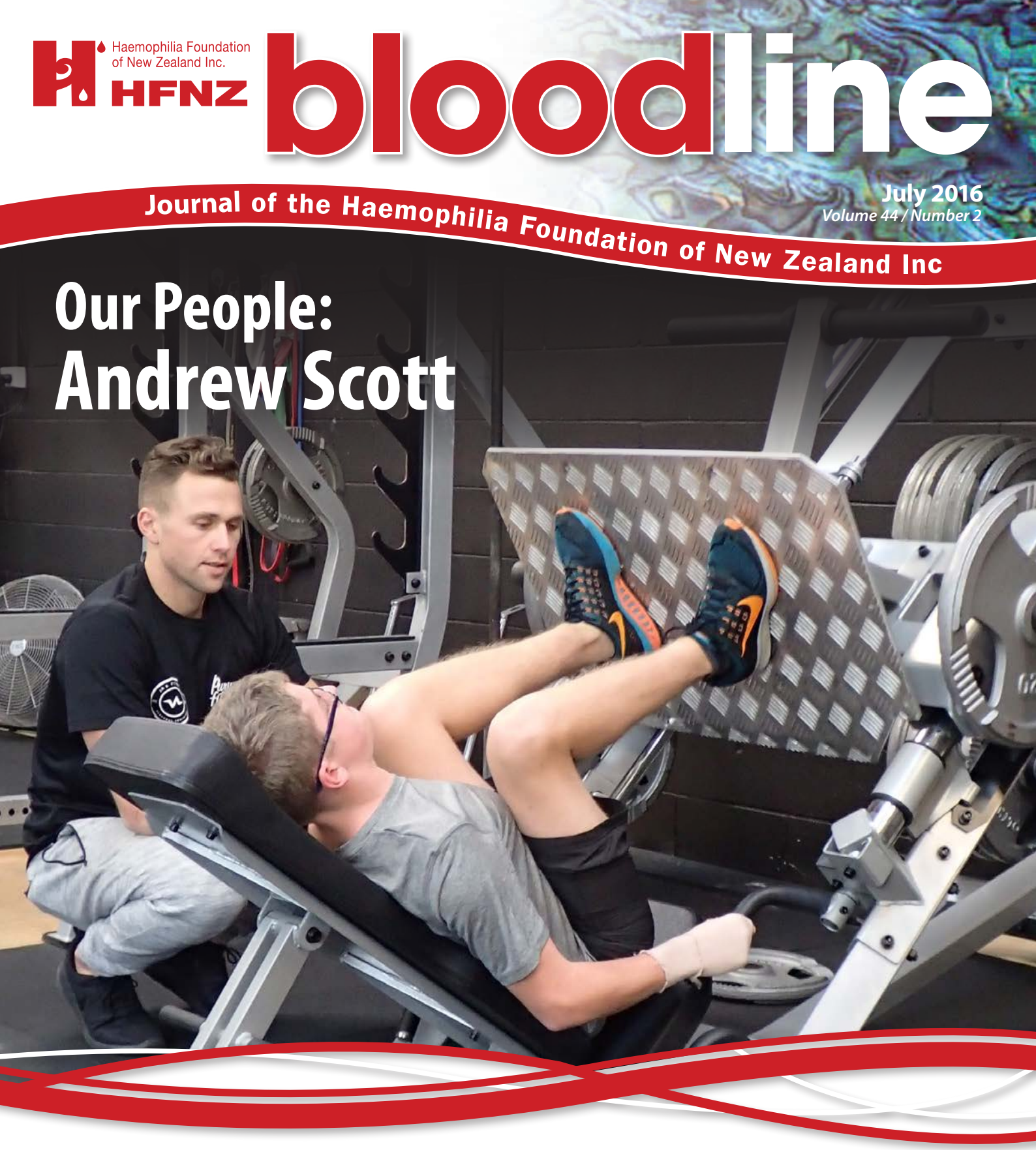
Haemophilia Foundation of New Zealand Inc.
HFNZ
bloodline
Journal of the Haemophilia Foundation of New Zealand Inc
July 2016
Volume 44 / Number 2

Our People: Andrew Scott



July 2016
Volume 44 / Number 2

Haemophilia Foundation of New Zealand Inc.
HFNZ

CONTACT DETAILS
Website
www.haemophilia.org.nz

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

President
Deon York
deon@haemophilia.org.nz

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

Editor
Phil Constable
phil@haemophilia.org.nz

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

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

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

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

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

The Word

With the shortest day of the year behind us, we're now on the downhill run to longer warmer days. That gives us all something to look forward to when it's pretty bleak outside. For HFNZ, the end of the financial year, and the slow roll into summer, means plenty of other things to look forward to.

It's July, and this month is the WFH World Congress, where representatives of bleeding disorder groups from around the world gather to learn new things to bring back to their members. We have a couple of members and staff attending, so we all look forward to hearing the latest news.

We are fortunate to have some wonderful members representing us. For example, this year Ashley Taylor-Fowlie was named as one of the International Susan Skinner Memorial Fund Scholarship winners, and received a 2016 WFH Youth Fellowship. These awards mean that she can attend National Member Organization (NMO) training before Congress, and has also been selected to present at the NMO Training. We are very lucky to have strong young leaders like this coming through.

Closer to home is the HFNZ AGM in Christchurch. This is a very important event for our organisation, because it's where our members get to have their say about how the foundation is run, and who is going to run it. I can't emphasise enough how much we all value our volunteers' time and energy to serve on the National Council, and the regional committees. Without their efforts we would not be the strong effective advocates for our members that we are today.

Finally, I would like to acknowledge all of this year's HFNZ Buddy Award winners. We recognise those who have made others' lives a little easier. Thanks to: Merv Hancock, Joy Barrett, Linda Mellsop-Anderson & Nigel Anderson, Julia Butcher, NZ Blood Service – Waikato Donors, Tom Syme, Robyn Coleman, Kathy Fawcett, Lorraine Porter-Bishop, and Lee Townsend.

Ngā mihi nui / Regards,

Dean York
President

Contents

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

HFNZ Bank Details:
Account Name: Haemophilia Foundation of New Zealand
Number: 02 0828 0102656 000
Cover photo: *Andrew Scott*

Our People: Andrew Scott

*Andrew Scott is 16 years old and has severe haemophilia A with inhibitors. In an effort to improve his health and fitness, and to reduce his bleeds, he has been attending personal training for the past year with Jaxon at Jax Fitness in East Tamaki. During this time **Andrew** and **Jaxon** have built a strong relationship based on trust, respect, and care. Here Andrew, Jaxon, and Andrew's Parents **Lynley** and **Richard** write about how training has worked for them.*

Before starting training with Jaxon, Andrew was having frequent bleeds, and finding it increasingly difficult to manage his day to day life. His training has helped to develop his independence and strengthened his self-belief. He has learned that even a small amount of targeted exercise is better than nothing, and that he is strong enough to keep up with the once a week commitment. Perhaps most importantly, he's learned how to be accountable for his own health and wellbeing.

Since starting his training Andrew has gone from 12 bleeds a month to three bleeds in five months, has been able to decrease his rehab time, and his pain medication has reduced significantly.

Andrew, his parents Lynley and Richard, and his trainer Jaxon have all learned a lot from his experiences with personal training. They now all have a far better understanding of the benefits of a focus on fitness to long-term health and wellbeing for people with bleeding disorders.

They share some of their experiences and learnings here.

Andrew

Before I started training at Jax Fitness I was in a very bad condition. I had a knee bleed every couple of weeks, and my knees were never strong enough to support me. Unfortunately, physio was proving to be increasingly difficult to manage and maintain, and I never had the opportunity to fully rehabilitate. Mum and Dad suggested I try personal training. Before then, the only images I had of training had come from TV and the media. All scary big men yelling at you and saying you were not good enough. I was cautious about going to a gym because I knew that I would be doing considerably less work than others. However, this was not the case with Jaxon.

During my first few sessions with Jaxon one thing he did, that stood out to me in particular, was that he consistently reminded me that it was about MY achievement, not anyone else's. In the first couple sessions we mostly did body weight movements, to get used to the movement. One example of this was squats, in my original state I could barely manage 10, and even then I would be in considerable pain afterwards. Jaxon showed me how to use the correct stance, and we did various exercises around squats that focused on correct knee position. Fast forward 5 weeks and I was doing squats with a 10kg weight on my back. Now I can squat 35kgs for 10 reps properly. At first I didn't think I was achieving much, but when I look back I see I have come so far. I couldn't imagine these achievements without Jaxon, he always encouraged me.

Since beginning training, my physical condition has improved drastically. Now that my muscles have developed my knees and joints have the support they need to perform without bleeds. This has enabled me to become so much more active. I now bike to and from school every day, and I bike to work in the evenings. Because my muscles are supported, when I have a bleed the rehabilitation process is much quicker. Jaxon also helped in this area, as I would often come into gym with a bleed (sometimes even 2!) and he would just work around it. If I was on crutches we would do upper body and back exercises. and if I had an arm bleed we would do legs. The improvement in my health has also made me so much more confident as a teenager with a bleeding disorder. The fact that, despite my disability, I have been able to push my body and train myself and become so much stronger is of huge significance. I feel so much better about myself and I have achieved more than I thought possible. I can't see myself giving PT up, and can't imagine where I'd be, or what I'd be like, without it.

I am so incredibly thankful for Jaxon and all the work he has put in. I am so much fitter and confident now than I was. Also thanks to HFNZ who have supported this through the Physical Activity Programme.

Andrew's Parents, Lynley and Richard

Initially we were hesitant about sending Andrew off to a gym, as we were concerned that the number of bleeds would increase. But then we figured that they couldn't increase any more than he was having already.

Jaxon initially attended a physio session at hospital with us to see what Andrew could and couldn't do, and to be educated about haemophilia. This information on haemophilia, and Jaxon's skill, has been combined to maximise what Andrew has been able to achieve. While physio is essential, having somewhere near home, with free parking, made Andrew's training a much easier experience than visiting the hospital.

Working in a private gym empowered Andrew to focus on what he was achieving, rather than compare himself with others, and has cemented good habits in terms of positioning and stance when exercising.

We have noticed the number of bleeds reduce but, more importantly, the time to fully recover after a bleed has significantly reduced for Andrew. His confidence in his body and his fitness has improved dramatically, and we can visibly see the strength and muscles that he has developed.

There have been times of resistance, when Andrew has not been looking forward to going to PT, especially when he has a bleed. However, on completion, realising that he could do it even with a bleed has encouraged and noticeably buoyed him. He comes home happy that he has achieved something even with a bleed.

Andrew's Trainer, Jaxon

When I was first given the opportunity to work with Andrew I wasn't sure what to expect. I had no real knowledge of Haemophilia and the details of Andrew's condition. Prior to Andrew I had never trained anyone with any similar conditions, so naturally I was a little concerned about how much we could actually do inside the gym.

Once I had gotten over the fact that Andrew was not a fragile piece of glass, and wasn't going to break when we began loading his joints, we were able to make quality progress.

Our aim with Andrew's workouts was to increase the strength and stability of his joints in order for him to be as mobile and active as any child his age. To do this we needed to first learn the movement patterns of certain exercises – squats, presses, pulling exercises etc. Stability and control during these movements is paramount.

Using a combination of machines and free weights, with correct form, we were able to learn these skills quickly and move on to overloading the muscle. A stronger and larger muscle provides much more stability and strength around the joint. Especially around the knee, ankle, and shoulder.

It was impressive to see his mobility and ability to move improve as we progressed through the weeks and months.

This was not without its challenges though, as Andrew would frequently show up to our weekly trainings at the studio with a new bleed and a story of how he had managed to hurt himself the third week in a row!

Working around these challenges kept me on my toes, with adaptations of exercises to ensure we still had a great workout.

It's a testament to Andrew's character that he continued to show up, even when sometimes the only thing that we could train was an arm or just his legs.

Andrew has gained strength on every exercise and developed a foundation of lean muscle. He now squats with a loaded barbell on his back, can bench press around half his body weight for more than 10 repetitions, and has the ability to take himself through his own workout programme. This has allowed him to take part in many more physical activities, inside and outside of school, without the worry of bleeds.

With proper programming and a focus on progressive overload of the muscles we have continually increased Andrew's strength over the past 2 years. It is incredible to see not only an improvement in his situation, with bleeds now few and far between, but also to see his confidence, personality, and character grow.

It's such a pleasure to work alongside Andrew and have him as a valued member of Jax Fitness. I look forward to seeing the adventures and achievements that await him as he progresses through high school and into young adult life.

Buddy Awards 2016

One of the big events on the calendar for bleeding disorder groups around the world is World Haemophilia Day, which is celebrated every year on April 17th. One of the ways HFNZ celebrate this special day is for our people to recognise their best supporters by nominating them for a Buddy Award. Each region holds an event where the winners are presented, and everyone has a bit of fun. ***Phil Constable*** *looks at who was recognised in 2016, and what went on around the regions.*

This year the theme for World Haemophilia Day was "Treatment for all is the vision of all", which lines up with the World Federation of Hemophilia's vision of "Treatment for All". That means looking towards a future where everyone with rare and inherited bleeding disorders gets the treatment and support they need, when they need it.

In that spirit, as part of World Haemophilia Day 2016, HFNZ ran their second annual Buddy Awards. The Buddy Awards give our members the opportunity to recognise those in their community who have made their lives easier, or have really gone the extra mile for them. So many of the people and organisations that provide material and emotional support to our members do it for love, for the knowledge that they're doing a good deed. They certainly don't expect reward.

The Buddy Awards are a way of returning the favour in some small way.

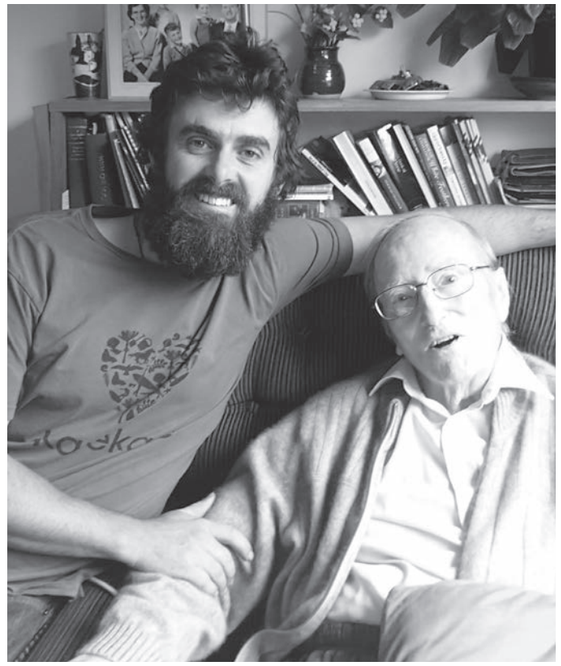
HFNZ members are asked to nominate people, inside or outside the organisation, who have gone above and beyond to make life a little better for them. Then, at regional events, the award winners are presented with special certificates, and have nice things said about them in a public forum. It can make them a little shy, but it's really nice to let them know how much we all value them.

The winners are a diverse bunch. In 2016 they ranged from an Outreach worker, to a community organisation, to a seven-year-old best friend. All, however, have given the person who nominated them something really special: their time, their attention, and their understanding.

Each MRG held an event for World Haemophilia Day at which the Buddy Awards for their region were presented. The Northern MRG held an event at Rocket Ropes, on a very wet day; the Midland crew had a family day at the zoo; Central held an event that combined the Buddy Awards with a farewell to departing haemotologist Julia Phillips; and Southern spent an afternoon bowling.

In some cases, the person nominated was not able to be present, but they were still celebrated. In others, there was a special event just for one person. In all cases the person receiving the award knew that they were special and valued.

This year's winners were:



Mervyn Hancock

While his home MRG is Central, Merv Hancock was nominated for a Buddy Award by a Northern member, his grandson Jack Finn, who said of him:

"A role mode to me in many ways, a tall totara of a person, enormous positive attitude on tackling life head on. Never shows his 89 years as a hindrance to living with haemophilia. Has battled many decades without treatment before blood products came along. Merv is a true buddy to me and has shown this by being my blood brother, hero, and grandad all the way."

Merv Hancock died earlier this year. He was an amazing man who is recognised as the pioneer of social work in NZ, and an HFNZ leader. His grandson, Jack Finn, has written an obituary, which features later in Bloodline.

Joy Barrett

Joy is the Midland Outreach Worker. She loves her job and is always enthusiastic about supporting and advocating for her members. We could say a lot of nice stuff about Joy, as we could about all our Outreach Workers, but we'll leave it to the person who nominated her, Jeff Litchfield:

Words cannot adequately convey just how helpful Joy has been in my battle with ACC for treatment of my Hep C. Thanks in a very large degree to Joy's efforts, and her persuasive manner with Management and others at ACC, I am now on Harvoni at last and have been taking the pills for 5 weeks. So far my liver is already showing signs of improvement. All down to Joy's sterling efforts.

She has also demonstrated an excellent working knowledge of both the Hep C and Von Willebrands conditions.

It's always such a pleasure when I get an email from her - checking to see it I'm okay, and checking also to see if there's anything I need or anything that she can do to help. What more can one possibly hope for from a support person?

Joy has told me on several occasions how much she just loves her job and this is reflected in the effort she goes to help and assist others. In this respect I could picture by the tone of her emails just how absolutely thrilled she was when, between us, we had overcome our battle with ACC and I received the 'Okay' to commence Harvoni.

I do honestly consider that Joy is the 'Crowning Jewel' in your organization and that we, as her clients, are indeed so very fortunate to have her on 'our side'.

Linda Mellsop-Anderson & Nigel Anderson

Linda has been involved in HFNZ for many years, in a variety of capacities. She's currently the Midland delegate to National Council, while her husband Nigel is also active at MRG level, as well as at camps and workshops. They are both strongly involved in their local community, and that's where this nomination, from John & Tineke Moate, comes from:

I nominate Linda for a Buddy Award as she has been there for my family and myself since we moved to Kawhia. Having a complicated Bleeding Disorder as we do, it has been wonderful to have someone that understands it.

I have felt confident in being able to go and do the things I need to do as a mother and living in an isolated area because I know Linda is there for my kids if anything were to happen to them while I was gone.

She has never complained if I have rung her for advice. She has been a real support with our doctor, educating him with treatments and advice. Linda has also taken the time out to support and educate the school in understanding the children's Bleeding Disorders.

Nigel has also been great, helping out with our son Tarquin who has been getting bullied at school and in the community because of his disorder.

With us having 6 children with this disorder it is comforting that Linda and Nigel have taken time to be there for us. Nothing is too much trouble.

New Zealand Blood Service – Waikato Donors

It's not usual for a Buddy Award to go to an organisation, they generally go to individuals, but in this instance it's well deserved. The New Zealand Blood Service is responsible for collecting donations of blood products via donation from across New Zealand. For nominator Linda Mellsop-Anderson the Waikato Service is particularly special:

Without the selfless voluntary blood donations, I would not have received lifesaving treatments on occasions where the outlook was bleak.

Blood donors willingly give their "gift of life" regularly – often making a life time commitment. Those donating plasma spend no less than two hours on the plasamatherisis machine. They need thanks as do employers supporting them.

Without the donors my life would have been significantly shorter and I wouldn't be playing with grandchildren.

Julia Butcher

Now, it's always tough to move away from your friends and family. When you have chronic medical issues, like a bleeding disorder, the support of your nearest and dearest is essential. That's why Lisa Power nominated Julia. When Lisa moved to Tauranga she moved away from her family and close friends, but Julia stepped up to be her rock:

I have no family in Tauranga, Julia always ensures I am well taken care of if I ever need assistance.

Julia is great as my buddy, I can always rely on her, she understands my Haemophilia well, but does not wrap me up in cotton wool !!! which can be common with people who are not familiar with Haemophilia.

She has attended appointments with me to gain a better understanding and is only a phone call away in an emergency!! Thankfully not needed as yet.

It is reassuring to have someone close, as all my family are out of town and overseas, Julia has taken on the role with gusto and never complains, I am very lucky to have her in my life.

Tom Syme

This is a really cute one. Leo McCarthy is seven and attends St Joseph's in Fielding. Leo's haemophilia means that he sometimes has to be in a wheelchair, and other times he can't attend school at all. He's nominated his mate Tom, who is also seven, because of all the help and support Tom gives him. Leo gave Tom his award at a special assembly at school, which was a great way to show his appreciation, while educating the rest of the school about haemophilia. Here's what Leo has to say about Tom:

Tom is always there for me; he pushes me around when I need to be in a wheelchair. He rings me to see how I am if I haven't been at school. He keeps me company at home when I'm really bored.

Mum and Dad say he's such a good mate, so caring and willing to be there for me whenever I need him.

As a result of this award, these two were featured in a story in their local paper, which you can read here:
http://www.stuff.co.nz/manawatu-standard/news/79976396/haemophiliac-boy-thanks-friend-for-helping-with-his-disorder

Robyn Coleman

Robyn is just the sort of person we love to have as part of the HFNZ family. She is always busy helping out and giving of herself, to benefit others. Nominated by the Poff family, they highlight the wide range of roles and activities that Robyn gets herself involved in:

Robyn epitomises the type of person who is always willing to help with any task given. She has had a huge involvement with the Southern MRG for a number of years.

She provides advice and support to other families and still manages her own busy household. She supports events by being on the committee, and also by attending and supporting the activities organised.

Robyn is always cheerful and knowledgeable, and provides us all, within Southern, with the essence of a true volunteer and supporter for the bleeding disorder community.

My son Rorie is truly benefiting from all the years of hard work that Robyn has put into HFNZ.

Lorraine Porter-Bishop

Another nomination from the Poff family, Lorraine Porter-Bishop is also one of southern's dedicated community members. She can be relied on to get involved in whatever's going, from fundraising to knowledge sharing. It's volunteers like Lorraine, and Robyn, that make HFNZ the strong organisation we are:

Lorraine has always been a strong force within HFNZ and the Haemophilia community.

She has supported, and played an active part in, activities and fundraising. She has shared her knowledge and her experiences raising a child with a bleeding disorder, and provided information around the different types of disorders.

She is an excellent role model and provides a strong advocacy role within the community. She embodies the essence of a true volunteer to the cause and HFNZ committee.

My son Rorie now has an excellent role model in Lorraine's son, and Rorie's journey is made easier due in part to the good work of Lorraine.

Kathy Fawcett

Kathy is a haemophilia Nurse working out of the Christchurch Haemophilia Treatment Centre. Neville Findlay nominated her not only for the skills she brings to the role, but also for her willingness to go the extra distance for him, and other HFNZ members:

Kathy is a fantastic Haemophilia Nurse who is always there for me. Not only does she go above and beyond her call of duty, but she is a very pleasant person to deal with.

Her thoughtful and kind approach to her work makes her an awesome Haemophilia Nurse.

Lee Townsend

Lee is a Physiotherapist at Christchurch Hospital. She was nominated by Izack Silva, who is just a young chap of eight, for all her help with Izack's mobility issues. Izack has severe haemophilia as well as a foot and ankle issue that sometimes makes getting about pretty challenging. Thanks to Lee, Izack and his family know a whole lot more about how to deal with his issues, and have more confidence in the future:

Lee makes living with my bleeding disorder a lot easier. She helps my ankle get better and stronger by giving me exercises to do. She also gives me good advice about my body and looking after myself.

2016 Children's Workshop – Pirate for a Day

April 2016 saw young pirates from around New Zealand gather in Auckland for the 2016 National Children's Workshop. The boys and girls were aged just 6 – 10 years, and have severe and moderate bleeding disorders including Haemophilia A & B, von Willebrand Disorder, and Platelet Function Disorders. The kids flew or drove in from all over the country and arrived bright and early at the Wiri Community Centre for a day of learning and laughter. ***Colleen McKay*** *was there for all the fun and learning.*

The National Children's Workshop is carefully designed so that our young people learn as much about their conditions as possible, while having a great time. Upon arrival each pirate made themselves all of the essential gear necessary to be a successful HFNZ pirate; a specially named loot bag to hold all the goodies, a pirate hat, an eyepatch, and a sword.

Then they assisted in making a 'Bag of Blood' complete with:

- Red Blood Cells - for carrying oxygen around the body
- White Blood Cells - necessary to fight infection
- Platelets - sticky star shaped cells that clump together in order to make a Platelet Plug
- Plasma - containing Factor VIII, Factor IX, and von Willebrand
- Factors – all necessary to form a clot

Once the pirates had completed their blood work, Haemophilia Nurse Specialist, Karen Slavin, turned up in all her pirate finery and set about increasing their knowledge of the various bleeding disorders, the signs and symptoms of a bleed, as well as many other tips for being a healthy pirate.

Next, Cat Pollard, a Haemophilia Physiotherapist reminded our little pirates of the importance of having strong and healthy joints and muscles. Treating bleeds with factor replacement and PRICE (Protect, Rest, Ice, Compression, Elevation) as well as physiotherapy rehabilitation was the major message from the Cat. She reminded us all that it takes more than just Factor to treat a bleed.

In order to keep the pirates switched on, the educational sessions were interspersed with fun 'Pirate Activities', like Swab the Decks, Walk the Plank, Captain Hook Toss, and the Cannonball Throw. Even though water was involved in the Cannonball Throw, our young Pirates did not get drenched, and many budding buccaneers commented that Walk the Plank was their favourite game of the day. Three teams competed in the games for points to allow first pick at the Pirate Prize Table.

After a hearty lunch of Subway, Sushi and Fruit, Pirates were able to explore the personal qualities necessary to be a successful pirate in control of his own Pirate Ship.

Southern Outreach Worker Linda Dockrill, helped the pirates to discover that it takes more than good luck to navigate the perilous waters of bleeding disorders. They found that they needed a compass, to help navigate life with a bleeding disorder; the correct equipment and tools, to look after themselves and do the things they want to do; and a good crew, support to help them when they need it. Our HFNZ pirates also learned that leadership on land and sea means having discipline, knowing when to ask for help, taking responsibility, showing courage and resilience and being a role model. An ancient treasure chest provided the group with valuable lessons.

A visit to 'Treasure Island' Mini Golf concluded the day, after which a shipload of very tired pirates headed home with a few extra pirate friends, heads full of knowledge, and wonderful, fun memories.

Each pirate was sent home with a specially designed Pirate Workbook in order to reinforce and continue the learning at home with their parents.

HFNZ Pirate Day couldn't have happened without the support and input of all sorts of helpers and contributors. So a huge thanks goes out to…

Karen Slavin – Haemophilia Nurse Specialist and Cat Pollard – Haemophilia Physiotherapist for the preparation and delivery of education Sessions for the children. Thank you both for also donning a costume and getting into the spirit of the day.

Group Leaders Zac Porter, Chloe McCormick, and Andrew Scott for assisting with the children, ensuring that learning was enhanced, and making sure that fun was had.

Neville-James Reedy for coming along for the day as photographer providing photographic evidence of the fun and the day, as well as services as Van Driver of a Van full of children back to Hamilton.

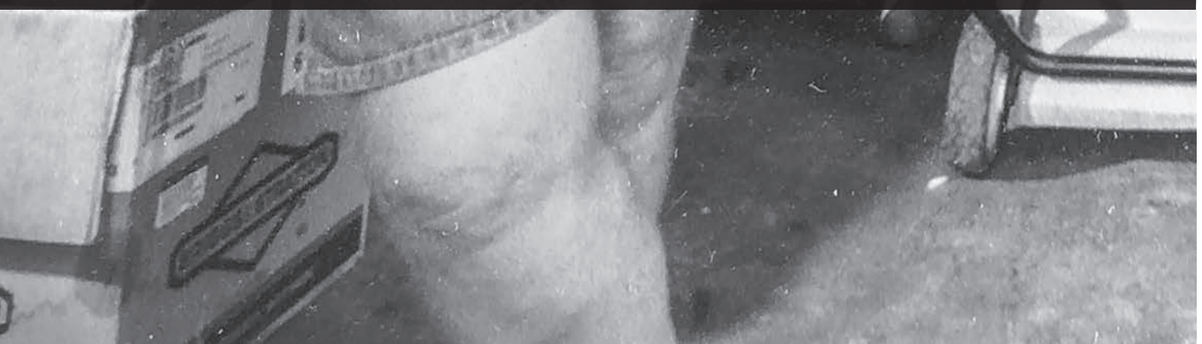
Outreach Workers Nicky, Joy, Lynne, and Linda for the early start, accompanying the young Pirates, ensuring that they had a fantastic day, as well as delivering education sessions and games.

Leanne Pearce for her competent assistance in the kitchen with lunches as well as morning & afternoon teas.

Pfizer Inc. for their Education Grant which allowed the delivery a successful Educational Workshop.

Our People:
Roger Manson

For years Roger Manson suffered with HCV. At first he didn't even know he had it, but once he was diagnosed it explained a lot about his poor health, low mood, and lack of energy. Even then he thought he was just too old to bother with any new-fangled treatment, 'leave it to the young ones' he thought. Luckily, his Outreach Worker, Joy Barrett, convinced him to join the sofosbuvir trial, and now he's never felt better. ***Phil Constable*** *talked to Roger about his HCV journey.*



Hepatitis C (HCV) is a silent killer that can lurk in your system for years before beginning to manifest symptoms. These can include extreme tiredness, nausea, and liver damage, even liver cancer. For years the best way of treating HCV has been with interferon, which works in about 50% of cases, but is a long and physically demanding road. The side effects of interferon can be as bad, or worse, as the HCV itself, and there's certainly no guarantee of clearing successfully. Many people have chosen to forgo treatment, just because it's so tough on them.

The recent rise of treatments like Harvoni has changed all that. These treatments are easy to take, are short duration treatments, have very few side effects, and are proven to be effective in over 90% of cases. People who have taken the Harvoni treatment have marvelled at how easy it was, and how quickly they started to feel better. One of the key components of many of these treaments is the direct acting anti-viral agent (DAA) sofosbuvir. The first sofosbuvir trials took place in NZ in 2013. Thanks to the people involved in the trials sofosbuvir was proven to be effective and safe, and the commercial treatment Harvoni was approved for use.

One of those early trialists was Roger Manson.

Roger is one of those old-school types of Kiwi bloke. He was getting on to forty before he was diagnosed with HCV, even though he'd been having symptoms for a while, and they reckoned he'd had it for a good 13 -14 years. Being supplied with tainted blood products back in the 80s, to treat his haemophilia, is the most likely cause of Roger's HCV, and he counts himself lucky that he didn't get HIV into the bargain. He rightly notes that "we lost too many guys" at that time.

As far as his HCV went, Roger didn't really want to cause a fuss, he just wanted to get on with his life. By the time the sofosbuvir trials came along he figured he may as well leave the fancy new treatment to the young people, folks who would benefit more than an old guy like him. He was asked more than once to get on board with the trial, but he wasn't interested. "Not for me", he said. However, his symptoms were getting worse, his health wasn't great, he was constantly feeling low and sad, and he'd developed mild fibrosis of the liver too. Still, he was happy enough soldiering on without treatment. From what he'd heard about the interferon days the treatment was worse that the cure anyway.

That's when Roger's HFNZ Outreach Worker Joy Barrett stepped in. Roger credits her with being the driving force behind him finally agreeing to take part in the trials of the new DAA, sofosbuvir. She recognised his low mood and declining health and wanted to give Roger the quality of life he deserved. Now, reading and writing aren't Roger's strong suits. So Joy had a lot to do in deciphering all the information and getting all the documentation together with Roger. Between them they managed to get it done and Roger was accepted into the trial.

The next big issue was actually getting Roger to his appointments. Roger had no problem with the driving, he used to drive bulldozers for a living, until his HCV saw him falling asleep at the controls. During treatment he drove trucks part-time. But Roger lived three hours away from Auckland, where his appointments were, and he had to attend appointments weekly initially, then fortnightly. That meant a lot of extra expense. Expense he just couldn't cover. HFNZ came to the party to help with Roger's travel costs, issuing Needs Grants to make sure he made it to his appointments. Roger says "Joy and HFNZ were fantastic, I wouldn't have been able to do it without them".

In March 2014 Roger was informed that he, along with the other 48 trial members, were totally clear of the hepatitis C virus.

Roger is amazed at just how much his life has been changed by taking part in the trial, and getting his HCV sorted out. He says that, while he was always one of those who was reluctant to try treatment, knowing what he knows now he wishes he'd tried it sooner. He is astonished by how much energy he now has, and how much better he feels in himself. "It's a marvellous thing that these people have found" he says, "the energy I've got now is unbelievable". Roger reports that his energy levels are three times what they were before the treatment, and that his depression has all but disappeared.

Roger's doctor told him that without the treatment he may not have lived another six months.

While he is quick to push Joy and HFNZ forward for supporting him in his treatment, the real credit has to go to Roger himself. At the age of 66, after a lifetime of just putting up with his symptoms, he made the choice to jump in with both feet and give himself a chance at a better life. Not only that, he volunteered for a trial that led to thousands of other Kiwis lives being made better too. He wouldn't like it, but that makes him a little bit of a hero.

Roger's reward is a better quality of life, the opportunity to experience the world without chronic fatigue and depression. He reckons that's a great deal, and he's quick to encourage all HFNZ members to step up and take the chance at a life free of HCV.

Feeling Down or Depressed?

It could be more than the mid-winter blues

Depression, stress, and anxiety seem to be common symptoms of living in today's world. But it doesn't have to be that way. If you're having mental health issues, there are ways for you to deal with them; you don't have to let depression rule your life. ***Joy Barrett*** *looks at how to recognise the symptoms of depression, and what you can do about it.*

Did you know that one in six people in New Zealand will experience a major depressive disorder at some time in their life? This can affect people of any age, from children to the elderly. I even have to watch out for my own mental health when I am feeling overwhelmed by life and events.

Most people feel miserable now and then, often when something upsetting or stressful is happening, like a relationship break-up, or losing a job. Feeling down in response to difficult situations is pretty normal, and usually the feelings fade over time and you get on with your life. But when your feelings of unhappiness are intense and persistent, and they don't go away even when things improve, you could be suffering from depression. The medical term for this is major depressive disorder.

Within our bleeding disorder community depression is not unusual, because, with a genetic disorder like this, there's nothing you can do to change it. There is no cure. When you add to this the constant pain; the loss of mobility; the disruption to routines; the difficulty in maintaining, or even gaining, meaningful employment; as well as the risk, or reality, of Hepatitis C or HIV; grief for the many losses in life for you, your family, and your extended whanau; a sense of guilt for being such a burden; the potential for needing significant surgery; and more, then it is little wonder that our people are at risk of depression on top of everything else.

During my years working in the counselling field I found that one of the significant feelings underlying depression was a real sense of powerlessness, a feeling that nothing is going to change. Being depressed can be a really dark lonely place; it can seem like no-one understands, and it's just too much of a risk to speak to someone about how it feels. However, the risk is part of the answer.

There just isn't enough room here to address this issue in the depth it needs but let's not ignore, dismiss, or minimize feelings that may be increasing with winter approaching. The cold wet weather, and a fear of slipping on wet icy surfaces, may make it more difficult for you to maintain essential exercise. Perhaps it takes too long to get up and out and about, so you just stay home instead. Then there's the risk of not getting enough Vitamin D from the sunshine, leading to seasonal affect disorder, a known contributor to depression. Little things like this, repeated over time, become habits that are hard to break without support.

There are a variety of known symptoms that are associated with depression, including:

- **Feeling sad, down, or miserable most of the time**
- **Loss of interest or pleasure in most of usual activities**
- **Tearfulness**
- **Sleep problems – too much or not enough**
- **Loss of energy and feeling tired**
- **Looking for escape in excessive spending, alcohol, gambling, recreational or prescribed drugs**
- **Irritability and grumpiness**
- **Changes in appetite in weight – losing or gaining weight**
- **Blaming yourself and feeling worthless**
- **Problems with concentration and making decisions**
- **Loss of interest in sexual activity**
- **Feelings of emptiness or loneliness, (even when with those you care about)**
- **Thinking about death**
- **Sense of disconnection from your "Higher Power"**

If you are experiencing some of these symptoms, or someone close to you is, and the symptoms seem to have worsened in the past few weeks, then please take action, because help and support is available. Find someone to talk to that you trust, this could be whānau, your employer, your doctor, HTC staff, your Outreach Worker, a trusted friend, kaumatua, pastor, or alternative religious leader. Take the risk, and get the help you need.

Remember depression isn't your fault, it's a chemical change happening within your brain. If you could just shake it off, snap out of it, you certainly would.

If you think that you need some support with feelings of depression, and you're not sure where to turn, here are some really useful places to start:

Depression Helpline
www.depression.org.nz
0800 111 757

The Low Down
www.thelowdown.co.nz
free text 5626

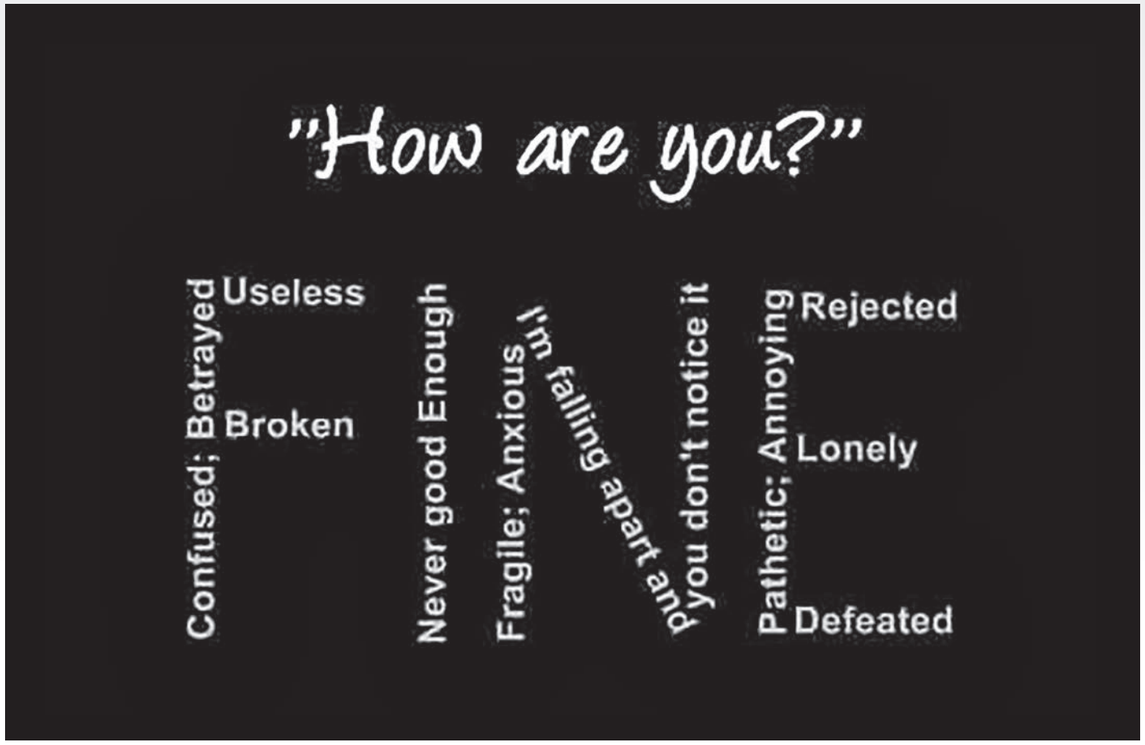
Lifeline
www.lifeline.org.nz
0800 543 354

Youthline
www.youthline.co.nz
0800 376 633 or free text 234

Suicide Crisis Helpline
www.lifeline.org.nz/Suicide-Intervention
0508 828 865 (0508 TAUTOKO)

What's Up (for 5–18yrs)
www.whatsup.co.nz
0800 942 8787

Kidsline(up to 14yrs)
www.kidsline.org.nz
0800 54 37 54 (0800 kidsline)
4pm to 6pm weekdays



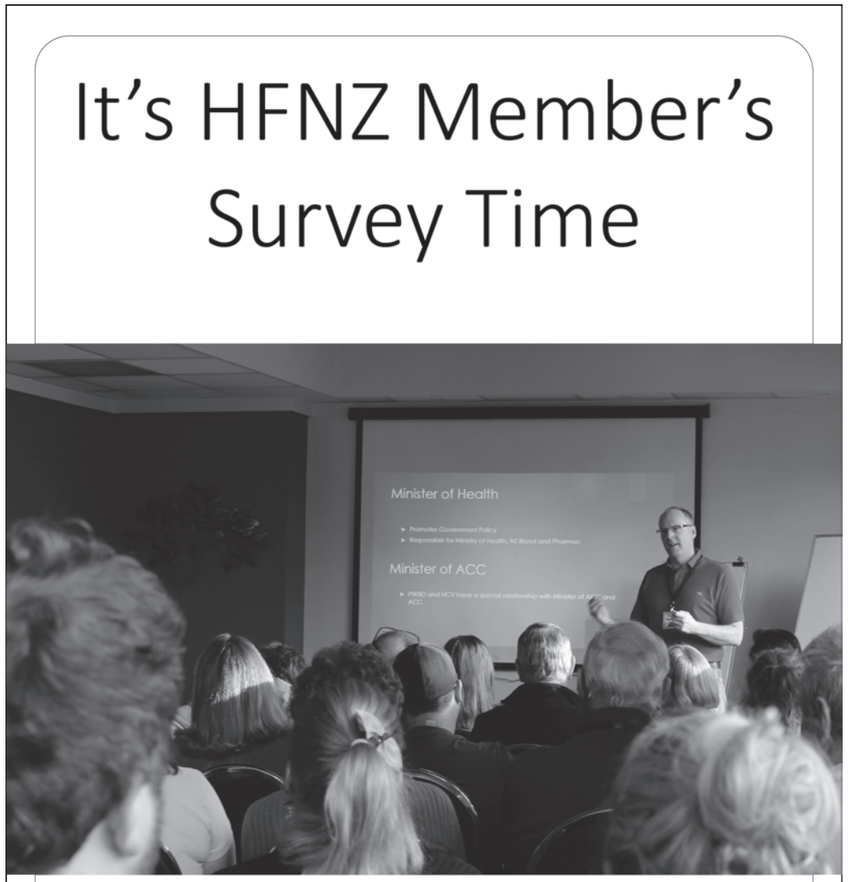
HFNZ Member Survey

It's that time of year again when HFNZ National Council look for feedback on how well the foundation is performing for its members. This is a really important time because the information we collect now helps set the direction for the coming year. Over recent years we've used the results from our annual member survey to streamline Outreach services, so that our members can get the support that they're looking for, and to improve the way we communicate with our members. The information we collect allows us to make good decisions about our priorities, so that we can give you the services that you want.

This year the HFNZ Members Survey is being administered predominantly online. That means that all members who have an email address registered with us will have already been sent a link, which takes them directly to the online survey. Those that don't use email have been sent paper copies of the survey. When the paper copies are returned to us we'll manually insert the responses into the online survey, so that the results can all be collated together.

As you can imagine, manually entering the data from paper copies is very time consuming, filling in the survey online is our preferred option.

Don't worry, the survey is anonymous whether you do it on paper, or online.



You can complete the survey here:

https://www.surveymonkey.com/r/HFNZ_2016

The HFNZ Member Survey is open now, and runs until Friday August 19th.

Obituary: Merv Hancock

By Jack Finn

It is with much sadness that we acknowledge a great man's passing. Palmerston North born and bred Merv Hancock, my Grandad, was a tall Totara, a humble leader, an inspiration to many, but more than anything he was a good man. He lived a full life with his dear wife Alison Hancock and three children, Mary, Michael, and Brent, grandchildren, and great-grandchildren. Merv was a pioneer in social work, an historian for Manawatu, a local councillor and stood for the Labour party.

He commenced his career as a child welfare officer. He was the first president of the New Zealand Association of Social Workers and in 1975 he was appointed to run the first New Zealand undergraduate degree in Social Work at Massey University. He contributed much to Palmerston North by which he was honoured in 2012 with the naming of the Hancock Community House, which houses around 15 voluntary agencies. In the same year Merv received an honorary doctorate from Massey University. Other achievements include a QSO in 1989, the Massey Medal in 1999, and a civic award in 2008.

Merv lived to an incredible age considering many of the health issues he faced. For a large portion of his life both he and his brother Frank Hancock went without any factor treatment, but he just battled on. He was always positive in everything he did and found good qualities in all people he associated with. My Granddad's vision for an equal and fair world will live on in those that loved him.

MRG Reports

HFNZ's Member Representative Groups (MRGs) enable all our members to be involved in the running of the foundation, and to connect with and support one another. Each group runs a number of events through the year, to help educate their local members, to make sure that support goes where it's needed, and to have a little bit of fun. Here's what they've been up to recently.

Central Region By Stephanie Coulman

In May three of our boys helped out at an Ultrasound Training Meeting sponsored by Pfizer in Wellington, for haemophilia treaters around the country. Five of the six haemophilia treatment centres were represented at the session, which aimed to improve the skills of our treaters in interpreting ultra sound images.

Nicholas, Liam and Mohammed were very patient as they had their ankles, elbows and knees repeatedly scanned by nine physios, haemophilia nurses and haematologists. The boys were pretty pleased to get out of school early to attend.

Physiotherapist Helen Dixon says, "Haemophilic arthritis can severely affect the quality of life for people with a bleeding disorder and early detection of joint disease is the key to optimising therapy." A non-invasive method of characterising and monitoring joints is through imaging techniques such as x-ray, ultrasound, and MRI.

Helen says x-rays are currently the standard for diagnosing haemophilic arthopathy, but are unable to detect early changes or synovitis. MRI can visualise these early changes and synovitis, but is limited because of its high cost and lack of accessibility.

Ultrasound can be performed quickly at the bedside and at low cost.

Carlos Martinoli a radiologist from Italy has devised an imaging and scoring system to grade and monitor the elbows, knees and ankles of people with haemophilia.

This course was the second that has been run for the haemophilia treaters group. "We were concentrating on improving our skills of interpreting what we were seeing and scoring the images," says Helen.

David Stephenson a research Physiotherapist from the UK ran the course. "It was very helpful for us to have his expertise; he uses the ultrasound as part of the annual Joint Health Score that he completes with all his patients."

Helen says the knowledge gained from the day is a step towards being able to offer ultrasound scanning in all haemophilia clinics.

We haven't held a Wellington café evening for a while but have one planned in July in Petone at the Working Men's Club. They offer a very reasonably priced buffet meal.

Taranaki members attended a café evening at Marbles Buffet at the Devon Hotel in New Plymouth, arranged by Lynne as part of her Taranaki outreach visit. It was a good occasion for them catch up over a meal.

Planning is underway for our annual camp in August. This year we are going to El Rancho in Waikanae. They have a lot of fun activities for all ages as well as well-priced accommodation and catering. Look out for invitations in July.

Midland By Tineke Maoate & Linda Mellsop-Anderson

The two main events in the Midland region recently were both connected with World Haemophilia Day and the Buddy Awards.

We had the privilege of visiting the NZ Blood Service in Waikato to present them with a Buddy Award. We also had a group visit to the Hamilton Zoo to enjoy a day out and present the remaining awards.

The NZ Blood Service's certificate was accepted by a gentleman making his 205th donation of plasma, which in itself is staggering when you consider the process can take two to three hours. We learned that there are donors who have made over four hundred donations!

We had a guided tour and were shown the different stages and production of other products from the donation, and how it is all separated, stored, and sent to CSL in Melbourne.

Miss five was fascinated to learn that the platelets she received had previously been stored in a warm cabinet and gently rocked. Now she will always remember that you treat platelets like a baby. Then there was the chiller at minus 30°C. We decided it was better suited to penguins after feeling the chill on our feet!

The donors present were humbled by being thanked, and loved learning directly from recipients about the genuine lifesaving impact their donations have. The blood service recognises their contribution, but they seldom see or hear from the people they're helping.

Our visit grew awareness of HFNZ, and of World Haemophilia Day.

We chose a beautiful day to meet up at the Hamilton Zoo, and had a great turn out of our Midland members. We had new members show up, as well as existing members that we hadn't seen for a while. After gathering to go over the house rules and greet each other we went on through to see all the amazing animals. After we had done a loop around the zoo we met up at the playground to have lunch together. The Midlands committee had organised subway for everyone. Talk about feeding time at the zoo!

We then went on to present our Buddy Awards to our fantastic recipients: Linda Mellsop-Anderson & Nigel Anderson, Joy Barrett, and Julia Butcher. It was really great to have these nominations and to be able to recognise all their hard work and support. Thank you to all who came and made it a special day for everyone.

By the time you read this we will have had our AGM, scheduled for the 2nd of July at Off Road NZ in Rotorua. Any changes to the current committee will be shared as soon as possible. Once again thank you to everyone on the committee and to all our members for making our branch what it is.

Northern By Lynley Scott

Since the last issue of Bloodline Northern have had a couple of really good events, and have a couple more lined up. Our female members enjoyed the Ladies High Tea, and the Matariki event at Stardome, combined with Piritoto, also went well. Coming up we have our Movie night, and camp is on the horizon.

While the Ladies High Tea always has a smaller turnout, it's a great event for busy HFNZ women to be able to put their week aside, break away from work, the children, and the housework, and be treated to a lovely high tea. It was fantastic to see a couple of new faces there, along with the regulars. We encourage all HFNZ women to join us for the next high tea, it really is a great way to connect.

For the first time this year Northern teamed up with Piritoto to run a combined event for Matariki. Working this way was very successful. It gave our Northern members an insight into some of the culture and traditions around the Matariki celebrations, while empowering the Piritoto MRG to be more visible, and to share their tikanga. This was a really informative event, with some excellent games that taught us some Te Reo, including 5 different ways to say hello. The Stardome did a good job of explaining the significance of Matariki and the stories that explain the various stars and even the dark patches on the Moon.

Sadly, this month we also farewelled Ashley Fowlie-Taylor, who has moved south to Palmerston North. Ashley has been

a wonderful and committed member of our committee both in a youth role and also as secretary. Always willing to help out and put her hand to whatever is needed, she will be sorely missed.

On that note we welcome Neil Smith as the new secretary of the Northern MRG. Neil has been active in a number of ways for Northern over the years, and we know he'll do a great job filling Ashley's not inconsiderable shoes.

Looking forward, we have a whole-group trip to the movies planned for the school holidays. We're all heading into Hoyts Sylvia Park to see Finding Dory. Sounds like a fun time in store. We've also been busy as a committee looking at alternative camp venues for summer camp. We'll keep you all posted about how that plan is coming together.

Piritoto By Patience Stirling

On Saturday the 4th of June 2016, to celebrate Matariki, an historical HFNZ event took place, the first Piritoto/Northern get together at the Auckland Stardome in the One Tree Hill domain. We started by mixing and mingling with a little lesson in Māori greetings, and then we gathered for lunch. Straight after lunch it was time for our movie, which had awesome stories about the separation of Ranginui (the sky father) and Papatuanuku (the earth mother), Rona and how she was taken by the moon, the lunar cycles and stories of the Matariki constellation from a Māori world-view. Since this is Matariki, straight after the movie we gathered again for one more activity in goal setting, which was followed by a closing karakia and afternoon tea.

Matariki is a time of coming together and preparing for the year ahead, as well as acknowledging and remembering the past and those who have passed, which is what we managed to do. The event was very successful, it ran without out a hitch and it looked like everyone enjoyed themselves. It is the hope that this is just the beginning of this type of event to help celebrate Matariki in its true form and that this event may be taken on in the future by others over the Matariki New Year period. Thank you to those of Piritoto and the Northern MRG who contributed towards putting this together, and lastly to those of HFNZ who attended.

Remember, the Piritoto annual Marae Noho is in Rotorua on the first weekend of August. We came together last year around the same time, and the winter season made no difference to a warm and relaxing weekend for all the whānau who attended.

So, if it's not too late, contact the office today to make enquiries.

Lastly, Piritoto would like to congratulate Holden Stirling and his band 'Lies Within' for making it through the heats and the semis to now be in the Auckland 'Battle of the Bands' finals. If they do well they will go through to the 2016 National finals in August.

Southern By Theresa Stevens

Hello and welcome to all our members. Well, winter is upon us, the mornings are dark, and the temperatures are cooler. But that doesn't mean there aren't still things happening down here in the South.

We provided staff for Armageddon in Dunedin, which was held on March 19 and 20. As usual this was a busy weekend and the event was well represented by our community. It was a tough day's work at times, but it was exciting to meet some new faces. For me Star Trek Counsellor Troy was amazing, she is not only a Coronation Street Fan but a football fan too!

April saw World Haemophilia Day and the Buddy Awards. Southern held an event at Garden City Bowl. Those who attended enjoyed a bit of 10 Pin Bowling, and spot of afternoon tea, and the presentation of Buddy awards to Robyn Coleman, Lorraine Porter-Bishop, Kathy Fawcett, and Lee Townsend. Great to see the people who help our people being recognised.

In May Southern MRG in held their annual play night. We were able to fundraise from ticket sales, a raffle, and bar sales from one night of the run of *Anyone for a Threesome?*, three one act comedies from Brick Road Productions. This was a roaring success, with over $1800 raised in total! A big thanks to Sandra for your guidance and support for this great fundraiser, to director Heather Giles, and to the Southern team who ran the night like a well-oiled machine.

Our committee meeting on 10 June was cancelled, and will be rescheduled. Special thanks for all of your support at that time, as I had my mum in the ICU at Dunedin hospital. She is doing much better and was finally discharged on Friday 24 June to home.

We were very fortunate to be selected for a $250 donation from Gilmour Motors here in Dunedin. Thanks to Jacqui Woodford for the nomination and to Emma Gilmour and her team for the donation. Also, congratulations to Emma for her history making win at the NZRC Rally of Canterbury.

Coming up, Zac Porter has organised a youth dinner in Christchurch on Wednesday 29 June. It sounds like fun, and I hope that is well attended and that everyone enjoys the meal. The next committee meeting date is to be confirmed, but will be before the AGM in September. Another 'bikes for bleeders' is being co-organised by Karl Archibald and Zac Porter, this is yet to be finalised after a disappointing first run at the beginning of February. Not to mention the Super rugby games (go the Highlanders!!) and the Netball (wow! Go the Southern Steel!!)

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

Youth By Lauren Nyhan

Reflection seemed to be the focus of the National Youth Committee's (NYC) last meeting held recently in Christchurch.

We spent the morning acknowledging and discussing those who had created the solid ground on which HFNZ stands today - reaffirming not only the challenges that the foundation and individuals have faced, but also highlighting the importance of our continued work. The need for succession planning within the foundation was discussed. Such a plan is fundamental to the durability of the foundation to ensure that, as new social and medical challenges and needs arise, our members continue to receive support, advocacy, and education.

With this firmly in mind, we launched into our meeting. The NYC is looking to hold a youth winter getaway in 2017, with a focus on an holistic approach to health & wellbeing when you have a bleeding disorder as a young person. Physical activities, hot pools, hydrotherapy, and personal development will all be thrown in to the mix, along with a cooking challenge or two, so watch this space.

We also took time to reflect on the beginnings of the NYC, back in 2011 in a hotel in Rotorua. At times, as a committee, we have felt that we have not met the needs of our membership. Looking back, however, we realise that there were a number of achievements and actions to be proud of. The Abel Tasman walk, our weekend in Waiwera, our utilisation of technology, and a number of national events planned by our fairy godmother, Colleen, that we have played a hand in shaping and organising, such as the recent Young Women's Weekend in Hanmer Springs.

As is part of the NYC constitution, committee members are required to change roles every four years, a milestone which we have now reached. I want to thank the outgoing Chairperson, Karl Archibald, for his hard work and determination to get the NYC started, and increasing engagement in an age bracket which typically falls away from the foundation. I am excited to step into the role of Chairperson, and welcome Zac Porter on to the committee as our treasurer. Hemi Waretini steps into the role of secretary and, as his term as the National Youth Delegate comes to an end, the NYC is beginning to consider its own succession planning.

Opening Doors to Better Care

By Leslie Quander Wooldridge

Managing a bleeding disorder can be hard for anyone, but women face unique challenges, from getting a diagnosis to receiving treatment. To change that, the National Hemophilia Foundation (NHF) and providers across the country are raising awareness and working to improve the medical care offered to women.

"One way we can provide support for these women is through educational programs for them and their providers," says Kate Nammacher, MPH, NHF's director of education. "We also have active advisory groups working on solutions for broader systemic changes in the care and support of women with bleeding symptoms." Groups include the Victory for Women Working Group and the Centers for Disease Control and Prevention's Women with Bleeding Disorders Working Group (CDC WWBD). Both are made up of consumers and healthcare providers.

The Hurdles

The first step to improving care is recognizing the issues girls and women with bleeding disorders face. "The bleeding symptom that contributes the most to poor quality of life is heavy menstrual bleeding, called menorrhagia," says Robert F. Sidonio Jr., MD, MSc, associate director of hemostasis and thrombosis at Emory University/Children's Healthcare of Atlanta. Adolescent girls and young women may miss school or work due to heavy periods, adds Sidonio. He is a member of the CDC WWBD.

Women face several obstacles to getting a bleeding disorder diagnosis. One of the first is that they may not recognize the problem. Chris Guelcher, MS, APRN, PPCNP-BC, a member of the CDC WWBD and a pediatric nurse practitioner, says family history may keep women from seeking medical care. "Family members may have similar bleeding issues, so symptoms aren't recognized as abnormal."

When they do seek help, women may discover that bleeding disorders can be difficult to diagnose, even with testing. For example, anxiety in a patient can cause a falsely high factor level during testing for von Willebrand disease (VWD), notes Guelcher. She works at the Center for Cancer and Blood Disorders at Children's National Health System in Washington, DC. Because of this, it may take repeated testing to reach a conclusive diagnosis. But without an accurate diagnosis, it's hard for healthcare providers to tailor their treatment approach, or for patients' insurance to cover them.

Women may also encounter healthcare providers who view hemophilia as a male-only disorder. In addition, some healthcare providers may not understand or recognize unique bleeding issues in women.

A 2004 CDC survey of women with VWD found an average of 16 years between the onset of bleeding symptoms and diagnosis of a bleeding disorder. A 2015 needs assessment survey by NHF and its working group showed that the average gap was about 8 years.

Any delay in diagnosis can have serious health consequences for women. These include problems during pregnancy and childbirth, surgeries and joint issues due to microbleeds (bleeding from microscopic injuries in the joint).

Women may also face insurance hurdles to receiving treatment for a bleeding disorder. Without an accurate diagnosis, it can be hard for women to get appropriate insurance coverage for treatments. For instance, if an insurance company doesn't have a diagnosis on file for VWD or mild hemophilia, it may not cover drugs that a doctor prescribes to help—even if a patient has symptoms. In addition, some providers who treat women with bleeding disorders may be considered "out of network" for some patients. This makes access difficult and expensive.

The Clinics

Earlier recognition, diagnosis and care can result in better health outcomes for female patients and even family members. "Sometimes we will diagnose a child, and then recommend evaluation of an adult for a possible bleeding disorder," says Guelcher.

At Guelcher's center, the thrombosis and hemostasis program coordinates with the menorrhagia clinic. There, a hematologist and gynecologist participate in the twice-monthly clinic for girls and women up to age 21.

Sidonio's clinic also offers OB/GYN services that focus on managing heavy menstrual bleeding and pregnancy planning for all ages. This work is partially funded by an NHF Capacity Building Grant, which helps HTCs better fulfill their commitment to patients and collaborate with local chapters. Sidonio applied for the grant to create a women's bleeding disorders clinic with a wider range of services.

The Kansas City Regional HTC at Children's Mercy Hospital Kansas City holds a quarterly clinic where young women see a hematologist and a gynecologist. "The benefit for patients is the clinic is comprehensive: It helps with communication between these two disciplines," says Melissa Armanees, RN, MSN, CPNP, a pediatric nurse practitioner at the center. With early education, women can better prepare for future health concerns.

The Online Community

When HemAware went to press, NHF anticipated unveiling a refreshed Victory for Women website in April or May. This site will provide a place where women in the bleeding disorders community can connect. NHF surveys and discussions with women guided content. "Women can feel alone in what they are going through," says Corinne Koenig, MA, NHF manager of education and training. To remedy that, the site lets visitors share stories, art and podcasts, and access educational materials.

"NHF creates resources and workshops so that local chapters can better provide for women with bleeding disorders," says Koenig. "Everyone's voice matters."

Source:
Republished, with permission, from the US National Hemophilia Foundation's Hemaware magazine:
http://www.hemaware.org/story/opening-doors-better-care

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

WFH STATEMENT ON SIPPET STUDY RESULTS

The results of the SIPPET (Survey of Inhibitors in Plasma-Products Exposed Toddlers) study were published May 26, 2016 in the New England Journal of Medicine. The paper suggests that, in previously untreated patients (PUPs), the risk of developing an inhibitor when using recombinant factor VIII products is significantly higher than when using plasma-derived factor VIII concentrates that contain von Willebrand factor.

The WFH has reviewed the SIPPET study results and consulted with clinicians, regulators, medical advisory boards and other experts. The WFH has also requested comment from the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA). What follows is a description of the SIPPET study and a discussion of its findings.

The SIPPET study

The study was a prospective, randomized, multicenter open-label trial conducted in 14 countries. It compared PUPs treated with recombinant factor VIII (rFVIII) produced from hamster cell cultures to those treated with plasma-derived factor VIII concentrate containing von Willebrand factor (pdFVIII/VWF). The results showed a significantly higher rate of inhibitor (neutralizing antibody) development in the rFVIII-treated subjects compared to pdFVIII/VWF-treated subjects.

The cumulative incidence of all inhibitors was 26.8% (95% confidence interval [CI], 18.4 to 35.2) with pdFVIII/VWF and 44.5% (95% CI, 34.7 to 54.3) with rFVIII. This represents an 87% higher rate. The cumulative incidence of high-titer inhibitors was 18.6% (95% CI, 11.2 to 26.0) with pdFVIII/VWF and 28.4% (95% CI, 19.6 to 37.2), with rFVIII, a 69% higher rate. These data were obtained from 125 PUPs using recombinant and 126 using plasma-derived products.

Eight products were used in the study: the recombinant products were Recombinate and Advate (manufactured by Baxalta, now part of Shire), Kogenate FS/Helixate NexGen (Bayer AG), and ReFacto AF (Pfizer); and the plasma-derived products were Alphanate and Fanhdi (Grifols), Emoclot (Kedrion Biopharma), and Factane (LFB).

Other considerations

Because pdFVIII/VWF is made from pooled human plasma, it may carry a risk of transmitting infectious agents such as viruses. Stringent procedures designed to reduce the risk of viral transmission have been employed in the manufacture of these products, from the screening of plasma donors and the collection and

For further information please contact the World Federation of Hemophilia
Tel: +1 (514) 875-7944 • Fax: +1 (514) 875-8916 • E-mail: wfh@wfh.org • www.wfh.org

testing of plasma, through the application of viral elimination/reduction steps such as solvent detergent and heat treatment in the manufacturing process. Despite these measures, such products can still potentially transmit disease; therefore, the risk of infectious agents cannot be totally eliminated. The confirmed risk of inhibitor development must be weighed against the theoretical risk of a pathogenic infectious agent being transmitted by pdFVIII.

Decision-making process

Based on currently available evidence, there are different options depending on the status of the patient and the availability of specific treatment products.

1. In many countries only one FVIII product is available. That product should be used no matter what it is. **Not treating carries a much higher risk of much more serious outcomes.** Every FVIII product carries a risk of causing inhibitors but a majority of patients will never develop inhibitors, so the decision not to treat is not justified.
2. When the treatment products available are of the 2 "classes" in the SIPPET study (pdFVIII/VWF or rFVIII)

    a. In the case of newly diagnosed individuals (PUPs) with severe hemophilia A who are not yet treated, the new data from the SIPPET study should be considered in the choice of product classes with which to initiate therapy. The treatment options are:
        - Initiate therapy with a pdFVIII/VWF product, or,
        - Initiate therapy with rFVIII

    b. Individuals with more than zero and less than 50 exposure days to rFVIII should consider staying on their current recombinant FVIII product, since the differences between SIPPET and numerous other studies may not warrant switching patients who have already initiated a treatment regimen.

    c. **Individuals with greater than 50 exposure days to any FVIII product (i.e. Previously Treated Patients or PTPs) should remain on their current therapy**, since multiple clinical studies have shown that the risk for inhibitor development is very low.

3. High purity plasma-derived FVIII which does not contain VWF, newer rFVIII products and longer-acting rFVIII products were not used in the SIPPET study, so no conclusion can be made regarding their associated risks.

Finally, the risk for inhibitor formation in PUPs, regardless of class of treatment product, is today the most serious concern of patients and treaters. All efforts by governments, hemophilia treatment centers, patient advocates, and industry should be directed at reducing the risk of inhibitors. An international registry to monitor inhibitors in PUPs is essential in working towards this goal.

The WFH will continue to monitor the situation as it evolves and continue its own deliberations on the subject. We will report on any new developments in the thinking about the SIPPET study and on inhibitor risk in general.

The paper can be accessed here:
http://www.nejm.org/doi/full/10.1056/NEJMoa1516437?query=featured_home

For further information please contact the World Federation of Hemophilia
Tel: +1 (514) 875-7944 • Fax: +1 (514) 875-8916 • E-mail: wfh@wfh.org • www.wfh.org

News from Around the World...

2 New Findings Offer Hope for Those With Severe Hemophilia

By Amy Norton
HealthDay Reporter May 25, 2016

Two new studies could pave the way to major changes in how doctors treat severe cases of hemophilia -- a rare genetic disorder that can cause uncontrolled bleeding.

Both studies tackle a key challenge: Up to one-third of children with severe hemophilia develop antibodies against the standard therapy.

But one study highlights the value of an old therapy, while the other shows promising early results with an experimental drug.

Experts said both should stir discussion among doctors, patients and parents who deal with hemophilia. But they were especially hopeful about the new drug, known as emicizumab.

In the United States, about 20,000 people -- mostly boys and men -- are living with hemophilia, according to the U.S. Centers for Disease Control and Prevention.

The disorder is caused by a defect in one of the genes that controls proteins needed for normal blood clotting. Most people have hemophilia A, which means they lack a protein called factor VIII. In severe cases, they have little to no factor VIII in their blood.

The standard treatment is to replace the protein through intravenous infusions done at home.

Years ago, that replacement protein came exclusively from donor blood. "That worked well until the 1980s and the HIV epidemic," said Dr. Christopher Walsh, director of the hemophilia program at Mount Sinai Hospital, in New York City.

Between the late 1970s and mid-1980s, half of Americans with hemophilia became infected with HIV through contaminated blood products, according to the National Hemophilia Foundation.

That led to the development of genetically engineered "recombinant" factor VIII.

In the United States and other wealthy countries, most patients receive recombinant factor VIII, Walsh said.

In general, the therapy works well, he noted. But a major problem is that some children develop antibodies against the replacement factor VIII soon after they begin treatment.

One question has been whether the source of the factor VIII -- donor blood or DNA technology -- makes a difference, explained Dr. Donna DiMichele, of the U.S. National Heart, Lung, and Blood Institute.

One of the new studies was designed to answer that question, said DiMichele, who wrote an editorial published with the findings.

An international team of researchers randomly assigned 264 young children newly diagnosed with severe hemophilia to start replacement therapy with either blood-derived or recombinant factor VIII.

Overall, 37 percent of children on the recombinant therapy developed antibodies. That compared with 23 percent of kids on blood-based therapy.

Lead researcher Dr. Flora Peyvandi said the findings suggest blood-derived factor VIII is the "better choice" for children beginning therapy.

The findings do not apply to patients who've been on therapy for a while, according to Peyvandi, of the University of Milan, in Italy.

If a child is going to develop antibodies, that usually happens within the first 50 infusions, she explained.

But Walsh and DiMichele expressed doubts about whether blood-derived factor VIII is better for children just beginning therapy.

For one, DiMichele said, the risk of developing antibodies might be lower, but it's still significant.

Walsh agreed, and also pointed to safety concerns.

The blood supply is thoroughly tested, and considered very low-risk. "But," Walsh said, "anytime a 'new' virus comes out that could be spread through blood transfusions -- like the Zika virus -- patients worry. You're always looking over your shoulder."

He and DiMichele both predicted that doctors will vary in their opinions, and their advice to patients.

Meanwhile, the emicizumab study suggests an entirely different solution to the antibody problem, Walsh said.

The drug is a lab-generated antibody that "mimics" the form of factor VIII, which allows it to do the protein's job. It's designed, in part, to get around the problem of factor VIII antibodies.

DiMichele called the drug "ingenious."

"The fact that they could even do this is remarkable," she said.

The new trial tested the drug in just 18 patients with severe hemophilia. But over three months, 72 percent had no bleeding episodes. And it was just as effective in patients who'd developed antibodies to factor VIII as those who were antibody-free.

The study was sponsored by Japanese drug maker Chugai Pharmaceutical, one of the companies developing emicizumab. Larger trials are underway, according to the company.

Emicizumab is easier to take than factor VIII replacement. It requires one weekly injection, versus several IV infusions per week. Young children on factor VIII often need a catheter device implanted under the skin to allow the frequent infusions.

The new findings "should be very exciting for patients and parents," DiMichele said. "But we still need much more information."

Researchers need to show the drug is effective and safe in the longer term, she said. It's also unclear whether it not only prevents bleeding episodes, but treats them when they do happen -- as factor VIII replacement can.

"Does this represent a sea change?" Walsh said. "We'll see."

The ultimate hope, he noted, is to use gene therapy to potentially cure hemophilia. Researchers are already working on it, he added.

Both studies were published May 26 in the New England Journal of Medicine.

Source: http://www.pantagraph.com/lifestyles/health-med-fit/new-findings-offer-hope-for-those-with-severe-hemophilia/article_23c7a6bf-19ca-56fc-a368-72985908c7e8.html

Hemophilia 'cures' are proving gene therapy really is all it's cracked up to be

By Graham Templeton
June 15, 2016

Gene therapy is part of an increasingly large collection of research fields: those with a huge, useless backlog of innovations. Gene therapy researchers have spent decades developing amazing, world-changing therapies with absolutely no ability to use those therapies outside of a test tube, or at best a cloned rodent. Now, with the advent of advanced gene-editing tech, we can apply them, and dozens of genetically inherited diseases could soon be curable as the result. The latest example is hemophilia, and the incredible recent progress toward a cure (or cures) show just how much potential the field really has.

Hemophilia is a disease defined by insufficient clotting of the blood, and in extreme cases it can lead to excessive bleeding with as little as a small bruise. One of the two main types of the disease is called hemophilia B, caused by a deficiency in a particular clotting protein, called Factor IX. Injections that can currently provide a synthetic version to replace factor IX can be ruinously expensive — one patient told Technology Review his treatments cost three quarters of a million dollars per year.

One of the main centers making progress in this field is called Spark Therapeutics, which recently announced findings in four human patients: the patients given gene therapy treatment showed naturally produced ("endogenous") factor IX production to about 30% that of a healthy person. That's far from what we would call a healthy level, but it does provide a huge proportion of the most important therapeutic effects of the injections — namely, it stops bleeding from truly incidental trauma like bruises and sprains.

A simplified schematic of the CRISPR system. RNA guides Cas9 in cutting at the CRISPR sequences.

Though the treatment is in no way a pass to a totally normal life — at least, not yet — it does allow patients to forego their injections without taking on any unreasonable risk during the basic activities of life. That's the threshold of a cure; not a perfect cure, mind, but a cure nonetheless, and there's every reason to believe the effectiveness could improve in the future.

It's a breakthrough that has the potential to affect the lives of millions of men — men because, as a recessive, X chromosome-linked disease, hemophilia A and B are both found virtually entirely in the male population. Women, with their second X chromosome, have a second chance to get a healthy version of the gene and thus have a much smaller chance of getting the associated disease. About 1 in 5,000 males is born with Hemophilia A, which has to do with the function of the protein factor VIII, and 1 in 30,000 is born with hemophilia B, due to defective versions of factor IX.

In fact, the challenge at this point may be as much to modulate the effect down as up, with national regulators beginning to worry that increasing the natural factor IX output could lead to accidental over-compensation, and the production of potentially fatal blood clots. Just a few years ago, the whole idea of increasing this sort of protein output through gene therapy was considered at least a bit idealistic; today, there are genuine concerns about how to keep from increasing those protein levels too far.

An adeno-associated virus much like Spark's custom-engineered one affecting these diseased liver cells.

One big reason is that gene therapy technologies for inserting genetic material into the cells of interest are still very primitive in an objective sense; only a minority actually reach their targets, and only a minority of these actually manage to get their genetic payload into the cells. As a result, these early therapies must usually find a way to augment the baseline infection rate of their therapeutic virus. Most commonly, they infect a small proportion of cells and allow those cells to out-compete non-infected ones, simply because they're healthier. In this case, without such an evolutionary mechanism to help them, the scientists had to go for a more extreme version of the factor IX protein.

That's why the worry about over-clotting: the version of factor IX that is being used by the therapy was in fact found and copied from a real patient suffering from overly common blood clots. Despite the low number of cells "fixed" through insertion of the super-factor IX, its incredible level of activity, almost eight times that of the natural version, allows it to make up for its low concentration. And the team has already increased the infection rate by making their custom virus head more directly for the liver, where its therapeutic genes are actually needed. Only time will tell whether it turns out to be safer and more effective to increase the virus' infection rate for the target cell type, or the protein's clotting strength, or both.

Unlike real viruses, these therapeutic ones have been neutered of their replication mechanisms, meaning that the low infection rate can't become a high one without another deliberate infusion of the virus from doctors — so it's not likely the protein levels will run away unexpectedly. Still, it's worth being cautious with anything derived from a quasi-living entity evolved very specifically to do things to our cells that our cells want to stop them from doing. Putting such microscopic beasts to work is a very powerful approach, but it's one that requires great care as well.

Source: http://www.extremetech.com/extreme/230215-hemophilia-cures-are-proving-gene-therapy-really-is-all-its-cracked-up-to-be

News from Around the World...

Refined dosing strategies may improve perioperative treatment of patients with hemophilia A

Hazendonk HCAM, et al. J Thromb Haemost. 2016; doi:10.1111/jth.13242.
May 27, 2016

Efforts to refine perioperative Factor VIII dosing for patients with hemophilia A based on blood group, age and other individual characteristics may improve quality of care and cost-effectiveness, according to results of a retrospective observational study.

Hemophilia A — a genetic bleeding disorder caused by a deficiency of coagulation Factor VIII (FVIII) — is treated with IV-administered factor replacement therapy. In severe and some moderate cases, prophylactic treatment is administered to prevent spontaneous and frequent bleeding.

Although prior studies showed FVIII concentrate replacement therapy to be effective, overdoses remain common, according to study background.

In addition, the extent, timing and associated risk factors of overdosing and under-dosing have not been established, Hendrika C.A.M. Hazendonk, MD, MSc, of Erasmus University Medical Center-Sophia Children's Hospital, and colleagues wrote.

"We believe that both under-dosing and overdosing can be reduced by alternative dosing strategies that take into account individual patient characteristics, leading to optimization of care and a greater efficacy of consumption of costly factor concentrate," Hazendonk and colleagues wrote.

Hazendonk and colleagues evaluated 119 males with severe or moderate-severe hemophilia A, defined as FVIII levels less than .05 IU mL^{-1}, who underwent surgery between 2000 and 2013.

The study population included 75 adults (median age, 48 years; median body weight, 80 kg) who underwent a combined 140 surgical procedures, as well as 44 children (median age, 4 years; median body weight, 19 kg) who underwent a combined 58 surgical procedures.

All patients received perioperative FVIII concentrate.

The majority (70%) of patients had severe hemophilia A and received prophylactic treatment. About half (51%) of patients were in blood group O. Most adults (61%) underwent major surgery, whereas most children (81%) underwent minor surgery.

On the first day after surgery, 283 of 308 samples (77.3%) revealed FVIII levels outside the target range. Of these, 101 (32.7%) were above the target range (median deviation, 0.23; interquartile range [IQR], 0.1-0.4) and 137 (44.5%) were below the target range (median deviation, 0.17; IQR, .08-.33).

Between 2 and 5 days after surgery, 339 of 510 (66.5%) samples revealed FVIII levels outside the target range. Of these, 303 (59.4%) were above the target range (median deviation, 0.23; IQR, 0.12-0.41) and 36 (7.1%) were below the target range (median deviation, 0.17; IQR, 0.07-0.24).

By 6 or more days after surgery, 383 of 471 (81.3%) samples showed FVIII levels outside the target range. Of these, 343 (74.7%) were above the target range (median deviation, 0.31; IQR, 0.15-0.45) and 40 (8.7%) were below the target range (median deviation, 0.11; IQR, 0.05-0.16).

Researchers reported total FVIII concentration consumption of 6.8 million IU during the perioperative period.

"If target ranges had been adequately maintained, an impressive overall reduction of FVIII consumption of 44% would have been possible," Hazendonk and colleagues wrote.

Logistic regression analyses showed blood group O (OR = 6.3; 95% CI, 2.7-14.9) and major surgery (OR = 3.3; 95% CI, 1.4-7.9) were predictive of under-dosing. In addition, increasing age (OR per year = 1.02; 95% CI, 1.01-1.02) and replacement therapy via bolus infusion (OR = 1.92; 95% CI, 1.45-2.54) were predictive of excessive overdosing.

Patients in blood group non-O also demonstrated a higher risk for overdosing (OR = 1.5; 95% CI, 1.1–1.9).

Results showed 32% of adult surgical procedures and 5% of children's surgical procedures were complicated by perioperative bleeding.

Patients in blood group O demonstrated more complications than patients with blood group non-O (OR = 2.02; 95% CI, 1–4.09). A higher percentage of blood group O patients than non-blood group O patients experienced severe bleeding complications (33% vs. 18%).

Researchers observed no association between bleeding complications and FVIII plasma level at the time of bleeding in adults or children.

The researchers acknowledged the study was limited by the retrospective nature of the data, the potential overrepresentation of major surgical procedures, and the possibility that use of one-stage laboratory assays to measure FVIII plasma levels led to biased results.

"These data underline that quality of care and cost-effectiveness can be improved by future refining of dosing strategies based on individual patient characteristics, such as ... blood group and mode of infusion," Hazendonk and colleagues wrote. "However, we also believe that not all variables of influence on dosing and clearance of FVIII concentrate have yet been defined." – by Kristie L. Kahl

Disclosure: The researchers report no relevant financial disclosures.

Source: http://www.healio.com/hematology-oncology/hematology/news/online/%7B2ff70871-dc6b-4625-9b91-1279ac90fb6d%7D/refined-dosing-strategies-may-improve-perioperative-treatment-of-patients-with-hemophilia-a

Hepatitis C now the deadliest infectious disease in America – as man shares story

WRBL Staff
May 12, 2016

KENANSVILLE, N.C. (WNCT) – A potentially deadly disease and heroin use go hand-in-hand. One North Carolina man is sharing his story about how his former drug abuse cost him his dreams, even after he got clean.

Dylan Smith, a recovering addict, is dealing with a disease that set him back on his dream to become a law enforcement officer and help in the fight against drugs.

Hepatitis C is the deadliest infectious disease in the United States. Both Smith and local doctors don't want anyone to become a statistic

Nausea and headaches are just a few of the many symptoms Smith deals with while suffering from hepatitis C.

Dylan Smith said, "I wouldn't wish this on no one."

For years, Smith was addicted to heroin, something he's now paying the price for, despite being sober for two years.

"I purchased some heroin off of someone and days later they told me they had Hepatitis C and I had used their needle," said Smith.

More people die from it than the number of those who die from HIV and tuberculosis combined.

"There's just been a lot of people infected who don't know about, so there's been an increasing number of people who have died from it," said Dr. Alicia Lagasca, an ECU physician.

ECU doctor, Alicia Lagasca, credits the recent spike in part to the rise in heroin use. Baby boomers are also learning they have it because blood transfusions weren't always safe.

Dr. Lagasca says symptoms can take years to show up and people don't know they have hepatitis C until it's too late.

"It can go asymptotic for so long in order to develop liver damage and symptoms it actually takes 20,30,40 years," added Dr. Lagasca.

Smith says he wouldn't wish his struggles on anyone.

"If someone can just see this, and they can think about what they're doing with themselves, and it would make them stop or realize what they're doing then I've accomplished my goal," said Smith.

Dr. Lagasca encourages all baby boomers and drug users to get tested. You can get Hep C from blood transfusions, intercourse, or like Dylan, dirty needles.

As for Dylan, he's expected to make a full recovery and will start his treatment for Hep C in a couple of days.

Source: http://wrbl.com/2016/05/12/hepatitis-c-now-the-deadliest-infectious-disease-in-america-as-man-shares-story/

The Year Ahead

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

July 24th – 28th

World Federation of Hemophilia World Congress
Orlando Florida

September 17th

HFNZ Annual General Meeting
Christchurch

September 30th – October 3rd

National Family Camp
Keswick Christian Camp, Rotorua

April 19th – 23rd, 2017

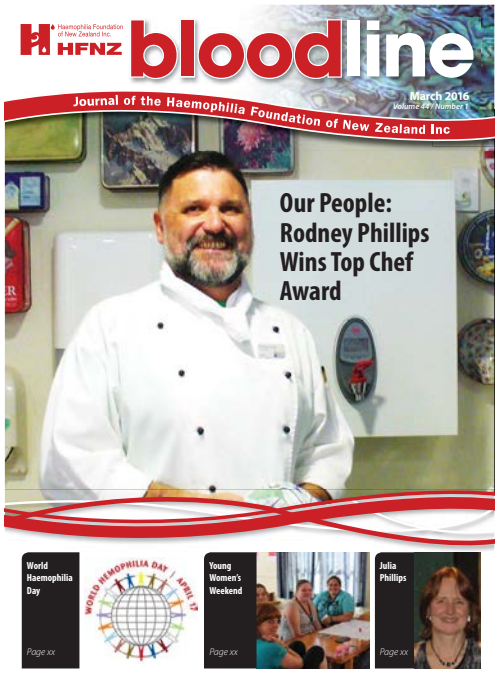
National Youth Camp
Waipara Adventure Centre

July 7th – 9th, 2017

National Inhibitor Workshop
Auckland

Also, keep your calendar clear for the Advanced Leadership Training weekend on Waitangi Weekend, and Adult Weekend in September 2017!

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



Rather read Bloodline Online?

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

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

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

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

give a little

Give a little? Give a lot!

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