

# Bloodline

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Haemophilia Foundation  
of New Zealand Inc.  
**HFNZ**



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### CONTACTS

<b>Website</b> www.haemophilia.org.nz	<b>Lynne Campbell</b> Central Outreach Worker PO Box 24014 Manners Street Central Wellington 6142 04 382 8442 lynne@haemophilia.org.nz
<b>National Office</b> PO Box 7647 Sydenham Christchurch 8240 03 371 7477 info@haemophilia.org.nz	<b>Nicky Hollings</b> Midland Outreach Worker PO Box 357 Taupo 3330 07 856 4442 nicky@haemophilia.org.nz
<b>President</b> Deon York president@haemophilia.org.nz	<b>Amber Maihi</b> Northern Outreach Worker PO Box 41-062 St Lukes, Mt Albert Auckland 1346 09 845 4658 amber@haemophilia.org.nz
<b>Chief Executive</b> Sue Ellis sue@haemophilia.org.nz	
<b>Editor &amp; Communications Manager</b> Phil Constable phil@haemophilia.org.nz	
<b>Administrator</b> Leanne Pearce admin@haemophilia.org.nz 03 371 7477	
<b>Ross Paterson</b> Southern Outreach Worker PO Box 7647, Sydenham Christchurch 8240 03 371 7485 ross@haemophilia.org.nz	

 <b>Haemophilia Foundation of New Zealand Inc.</b> <b>HFNZ</b>	<b>OUTREACH FREEPHONE</b> <b>0508 322 867</b> <b>f HAEMOPHILIANZ</b>
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<b>Bank Details</b>	
Acct Name:	Haemophilia Foundation of New Zealand
Acct Number:	02 0828 0102656 000

Deon York  
HFNZ President

It is certainly true that we live in a new world. Looking back over the past year for our members, we connected and socialised, both regionally and nationally, and went about our day-to-day life as usual for the most part. The COVID-19 pandemic has changed that. In an instant we have had to become familiar with physical distancing, queuing up at the supermarket, and staying in our bubble, just to name a few changes. Although essential to control the spread of COVID-19, the impact of a nationwide lock down on many of our members' lives will be felt for years to come.

At a time like this, it is important that HFNZ remains strong and connected to you. My first priority has been seeking assurances that the supply of our much-needed factor replacement therapies remains constant, and that members can access care if it is needed, as well as knowing how to access it under new arrangements. The national executive also took the decision some time ago to cancel or postpone national events, and advise regions that events would not be taking place for some months. This was well before we moved to complete lock down. The same has occurred for all patient organisations around the world supporting people with bleeding disorders.

HFNZ staff have been thrown in to looking at new ways of working. Without an office having yet been purchased, and with outreach workers already working from home, some aspects have required little to no adjustment. The key is staying connected so we know what support our members need at this time.

The formation of our bubbles has brought our loved ones in to focus. I hope that many of you have been able to use this lock down to spend quality time with the ones you love. That being said, bubbles can come with challenges, so always remember we are here to support you too.

Noho tawhiti, tu kotahi

Sit at a distance, stand as one



# Covid -19

Well done New Zealand!

As of publication date, we're on alert level three. That means we're beginning to see the rewards of all the hard work we've all been doing to help stop Covid-19 in its tracks. However, we're not finished yet!

As the Covid-19 pandemic continues around the world, the health and safety of HFNZ members is our top priority. The HFNZ executive, CEO, and council has been meeting regularly and would like to assure you that we are taking our response to the pandemic very seriously.

We know that the health and safety of you, your family, and others around you is the most important concern for you right now. It is important to remember that people with inherited bleeding disorders are generally not immune-compromised or at greater risk of viral infections such as Covid-19.

Even though the daily numbers are looking better and better, it's still important that we continue to follow the rules around alert level three. You can find out more about what alert level three means here: <https://covid19.govt.nz/alert-system/alert-level-3/>

It might help to remember the Prime Minister's seven principles for level three:

1. Stay home. If you are not at work, school, exercising, or getting essentials, then you must be at home, the same as at level four.
2. Work and learn from home if you can. We still want the vast majority of people working from home, and

children and young people learning from home. At-risk students and staff should also stay at home, and they will be supported to do so. Early learning centres and schools will physically be open for up to Year 10 for families that need them.

3. Make your business Covid-19 safe. Covid-19 has spread in workplaces, so the quid pro quo of being able to open is doing it in a way that doesn't spread the virus. Important industries like construction, manufacturing, and forestry will be able to open, as will retail so long as it is contactless retail.

4. Stay regional. You can exercise at parks or beaches within your region, but the closer to home the better. Activities must be safe – keep two metres away from anybody not in your bubble. Make minimal trips.

5. Keep your bubble as small as possible. If you need to, you can expand your bubble a small amount to bring in close family, isolated people, or caregivers.

6. Wash your hands often with soap. Then dry them. Cough into your elbow.

7. If you're sick, stay at home and seek advice from your GP or Healthline about getting a test. There is no stigma to Covid-19. We will only be successful if everyone is willing to play their part in finding it wherever it is.

Let's all stick to them, because we're stronger together.

Earlier in April, the WFH hosted a webinar, Bleeding disorders and Covid-19. This was very interesting, and largely confirmed the information we already have. The

first section dealt with facts and risks, the second looked at the clinical frontline in Italy, and the third looked at how it was being dealt with in Egypt. This was followed by a Q & A session. [You can watch the whole webinar here.](#)

The key points from the webinar are:

- Bleeding disorder treatment products are not at risk of contamination or reduced supply
- People should continue to get and use their treatment products as normal
- People with bleeding disorders are not at greater risk than the general population
- There is currently no evidence of thrombotic complications with non-factor replacement therapies like emicizumab.

Remember, all HFNZ communication channels remain open, so follow us on Facebook, and look out for our emails. Also, the Outreach team continue to work to connect personally with our community while we're in lockdown. If you haven't heard from them yet, you can expect to soon.

We encourage you all to keep talking to one another. Keep an eye on the social media channels you favour, email and call your friends and family, learn how to use the technology to see and hear those that you're close to, and above all, be kind to one another.

Remember to keep yourself safe, be kind, and be patient.

## WHAT WE ARE DOING

HFNZ are maintaining regular contact with all relevant groups including clinicians and pharmaceutical companies and taking advice from the World Federation of Hemophilia and the NZ Ministry of Health.

All upcoming national and regional events have been postponed. The executive will review this decision on 1 July 2020.

All staff and volunteer international and domestic air travel has been stopped until further notice.

All staff will be working from home and not physically meeting with members until further notice. Our Outreach team are always available if you need to reach out for support. Just call 0508 FACTOR. Outreach Workers will be in closer contact over the coming weeks, and are always at the end of the phone or email.

## WHAT YOU CAN DO

- Keep your treatments up to date, with a two-week

supply on hand

- Regularly wash your hands with soap and water for at least 20 seconds
- Avoid touching your eyes, nose, and mouth with unwashed hands
- Observe strict cough etiquette by coughing or sneezing into your elbow or a tissue. Discard the tissue



immediately into a closed bin

- Implement social distancing measures by avoiding shaking hands and kissing, crowded transportation, and unnecessary mass-gatherings
- Consider proactive workplace and school/day-care measures such as working from home etc.
- Take extra precautions for elderly or immune-compromised groups.

One way to fill a few minutes during lockdown is to complete the 2020 HFNZ member survey. This is a great way to help the HFNZ team do their work, and you can go in the draw for one of two \$50 Prezzy cards: <https://www.surveymonkey.com/r/2020HFNZsurvey>.

## BLEEDING DISORDER TREATMENT PRODUCTS

The companies that supply our treatment products have advised us that there is no concern over supply. In its agreements with the pharmaceutical companies, Pharmac has clauses that require that there are 3-6 months stock in the country at any time. That means patients should carry on as normal as far as their treatment goes. Please do not stockpile treatment products, as this may affect availability for others.

The World Federation of Hemophilia advises that there is currently no known risk to blood, blood treatment products, or plasma-derived products.

## HAEMOPHILIA TREATMENT CENTRES

As essential services, all haemophilia treatment centres remain available. However, at the moment all contact is by phone or online. If you have a bleeding disorder, you may be contacted by your treatment centre prior to any appointment. If you have concerns about an appointment, contact your HTC directly.

# Unite against COVID-19

Here's how you can connect with your local HTC:

**Auckland** - Contact Karen or Vanessa at [akhaem@adhb.govt.nz](mailto:akhaem@adhb.govt.nz) or on 09 307 4949 ext. 25285.

**Waikato** - Contact Maureen Campbell at [Maureen.Campbell@waikatodhb.health.nz](mailto:Maureen.Campbell@waikatodhb.health.nz) or on 021 846 920 or 07 839 8899 ext. 23638.

**Palmerston North** - Contact Darryl at [Darryl.Pollock@midcentral.co.nz](mailto:Darryl.Pollock@midcentral.co.nz) or on her cell 0272408254 as she is working from home.

**Wellington** - Contact the haemophilia CNS BJ Ramsay as normal at [Brian.Ramsay@ccdhb.org.nz](mailto:Brian.Ramsay@ccdhb.org.nz) or via the haemophilia phone on 0273345081.

**Canterbury** - Contact Kathy at [kathryn.fawcett@cdhb.health.nz](mailto:kathryn.fawcett@cdhb.health.nz) or 027 526 1574 during office hours.

**Southern** - Contact Val Waugh at [Val.waugh@southernadhb.govt.nz](mailto:Val.waugh@southernadhb.govt.nz) or on 027 269 9383, or the haematologist on call via main operator Dunedin Hospital at 03 474 0999 for any urgent problem.

#### HOW YOU CAN ACCESS SUPPORT

For some people the whole Covid-19 situation has been very difficult. Many have lost their livelihood, and everyday life has become even more of a challenge. There are a number of places you can turn to if you and your whānau are struggling for support and advice:

- If your work has been impacted by the Covid-19 outbreak and your income is affected you may be able to get financial support from the government. To find out more about your options check out the dedicated Work and Income Covid-19 page: <https://workandincome.govt.nz/eligibility/emergencies/2020/coronavirus.html>.
- For in-home childcare for essential workers try <http://education.govt.nz/covid-19/home-based-care-options-for-children-aged-0-14-of-essential-workers/>
- If you're unable to access essential supplies go to <https://www.civildefence.govt.nz/resources/news-and-events/news/cdem-group-0800-numbers-for-supporting-communities/>
- For advice for students and people studying during lockdown including links for distance learning and video conference classrooms try <http://www.education.govt.nz/covid-19/>
- The Salvation Army is offering assistance for food, clothing, and other needs <https://www.salvationarmy.org>.

[nz/get-help/food-clothing-and-furniture](https://www.aucklandcouncil.govt.nz/get-help/food-clothing-and-furniture)

• Auckland council are set to send out welfare packages to anyone struggling in the region <https://our.aucklandcouncil.govt.nz/media/34192/auckland-council-emergency-packs-easy-read-3-4-2020.pdf>

• The New Zealand Red Cross are offering their Meals on Wheels initiative <https://www.redcross.org.nz/stories/new-zealand/looking-after-our-older-generation/>

• For counselling and mental health support service numbers and contact info go to <https://www.mentalhealth.org.nz/get-help/covid-19/getting-through-together/>

Remember, we're all in this together, and it's ok to ask for help.

Where you can find out more

There are several useful sources of NZ-based information about the Covid-19 outbreak:

<https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus>

<https://covid19.govt.nz/>

<https://news.wfh.org/world-federation-of-hemophilia-statement-update-to-covid-19/>

The World Health Organisation (WHO) also has a wealth of information and resources:

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/infection-prevention-and-control>

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports>

If you have any questions, please contact HFNZ via the 0508 FACTOR number or via [info@haemophilia.org.nz](mailto:info@haemophilia.org.nz)



# WFH Virtual Summit



The World Federation of Hemophilia (WFH) is committed to bringing the bleeding disorders community together in the name of Treatment for All. This commitment is especially important during the COVID-19 crisis. In June 2020, we will be bringing our community together virtually.

The WFH is pleased to announce the launch of the WFH Virtual Summit: Connecting the Global Bleeding Disorders Community. This series of live and recorded sessions will take place from Monday June 15 to Friday June 19, 2020 and will allow you to connect with the community and increase your knowledge from the comfort of your home. The approximate time slot will be 9 a.m. to 1 p.m. Eastern Daylight Time (EDT), 1 p.m. to 5 p.m. GMT-4. More details to follow.

We are also working on potential pre and post Virtual Summit sessions that will take place the week before and/or after that we will be announcing soon.

The WFH is pleased to offer this inaugural WFH Virtual Summit free of charge to the entire bleeding disorders community. In order for the WFH to plan the logistics of this important event, please register your interest in participating here. We will send you more information as it becomes available.

The WFH 2020 Virtual Summit program features many important events: plenaries, medical and multidisciplinary sessions, an e-poster session and free paper presentations, and the WFH State-of-the-art book. The WFH Virtual Summit scientific program will provide an innovative and comprehensive overview of the latest developments in our field, current patient healthcare issues and the challenges ahead in the management and treatment for people with hemophilia, von Willebrand disease and other rare factor deficiencies worldwide.

Our program will include the following topics:

- Redefining prophylaxis in the modern era
- Inhibitors-think differently
- Gene therapy
- Substitution

therapy

- Women and girls with hemophilia
- VWD
- Women ageing gracefully
- Is there a gain to pain
- Mental health and quality of life
- Late-breaking sessions
- WFH workshops

We look forward to welcoming you online this June. Should you have any questions, please email us at [registration@wfh.org](mailto:registration@wfh.org).

## SAVE THE DATE

SOURCE: <https://www.wfh.org/en/emailviewonwebpage.aspx?erid=2252624&trid=588a5d4a-0759-44d1-b285-272e670c1824>

# The 8th Annual Global Haemophilia Leadership Advocacy Summit

Lisbon, Portugal. 19 – 21 January 2020

By Sue Ellis

Along with President Deon York, I recently attended the 8th Global Haemophilia Advocacy Leadership Summit in Lisbon, Portugal.

This is my second attendance to these annual summits, and this one provided even more interesting presentations and workshops over the two days. It is always a privilege to be invited to attend these annual summits, hosted by the Haemophilia Advocacy Advisors Board, Bayer, and Biomarin. Although it was a long way to travel, it was kindly funded by Bayer and co-sponsored by Biomarin.

The theme for this summit was Advocacy in Action: Pushing the Access Boundary, and focused on how we as advocates can work to improve access to innovation and treatment advances.

There were panel discussions, workshops, and presentations from a number of experts. These included from industry, from academia, from other national and international haemophilia groups, including the European Haemophilia Consortium, the Australian Haemophilia Foundation, and the WFH, as well as from people with bleeding disorders.

Senior Medical Officer of the European Medicines Agency Hans-Georg Eichler gave an interesting keynote address looking at identifying decision-maker requirements from patients, and discussed what he called, “The evolution of the concept of ‘drug’”. He talked about the ‘advanced therapy medicinal products’, or ATMPs - from chemicals to biologicals to ATMPs and noted that for regulators, the problem is predictability. He believes that in the mid to long-term future 25% of all new approved drugs will be ATMPs. Currently the drivers of change are ethical concerns, and personalised treatment combinations. Change enablers include the availability of patient-level randomised controlled trials (RCT), and the availability of real-world data (RWD). An OECD report has recently been produced on this called “Readiness of electronic health record system” to contribute to national health information and research.

I particularly liked Dr Eichler’s discussion on interaction between decision-makers. Historically the flow of interactions between decision-makers goes from left to right - industry to regulators to HTAs to payers to clinicians to patients, which he believes are silos of collaboration. If the regulator fast tracks a product, the payer says ‘no not enough evidence’, therefore the patient misses out, which appears dysfunctional. The evolution of information needs to move from right to left. That is, start with the patient. Patient reported outcomes must be validated and methodology needs to be done to make it valid – that is: is this fit for purpose?

There was an interesting presentation on Barriers to Access: Patient-Payer Dialogue. Of importance, when we are looking at providing a submission, we must think about what do we need, what is important to us, what are our trade-offs? The submission must be quantifiable, reproducible, and transferable, not anecdotal. However, patients should stay out of the price debate, while insisting on what is important to them and what are the relevant risk/benefits.

Discussions on patient outcomes led well into an update on PROBE by Mark Skinner, President/CEO of the Institute for Policy Advancement. PROBE stands for Patient Reported Outcomes Burdens and Experiences, the global research project to enhance the direct patient voice in healthcare decision-making. PROBE is an online survey that patients with Haemophilia A and B and carriers can access through their smart phone or tablet. The PROBE study provides a way for people with haemophilia to report data on their health status and quality of life. This evidence can then be used as evidence to advocate for better care and treatment. The survey can also be completed by people who don’t have a bleeding disorder – they serve as a control group.

The App can be downloaded for free from the Apple Store for IOS and Google Play for Android - search for myPROBE - or you can complete the survey at <https://plus.macmaster.ca/PROBE>. The questionnaire measures key outcomes such

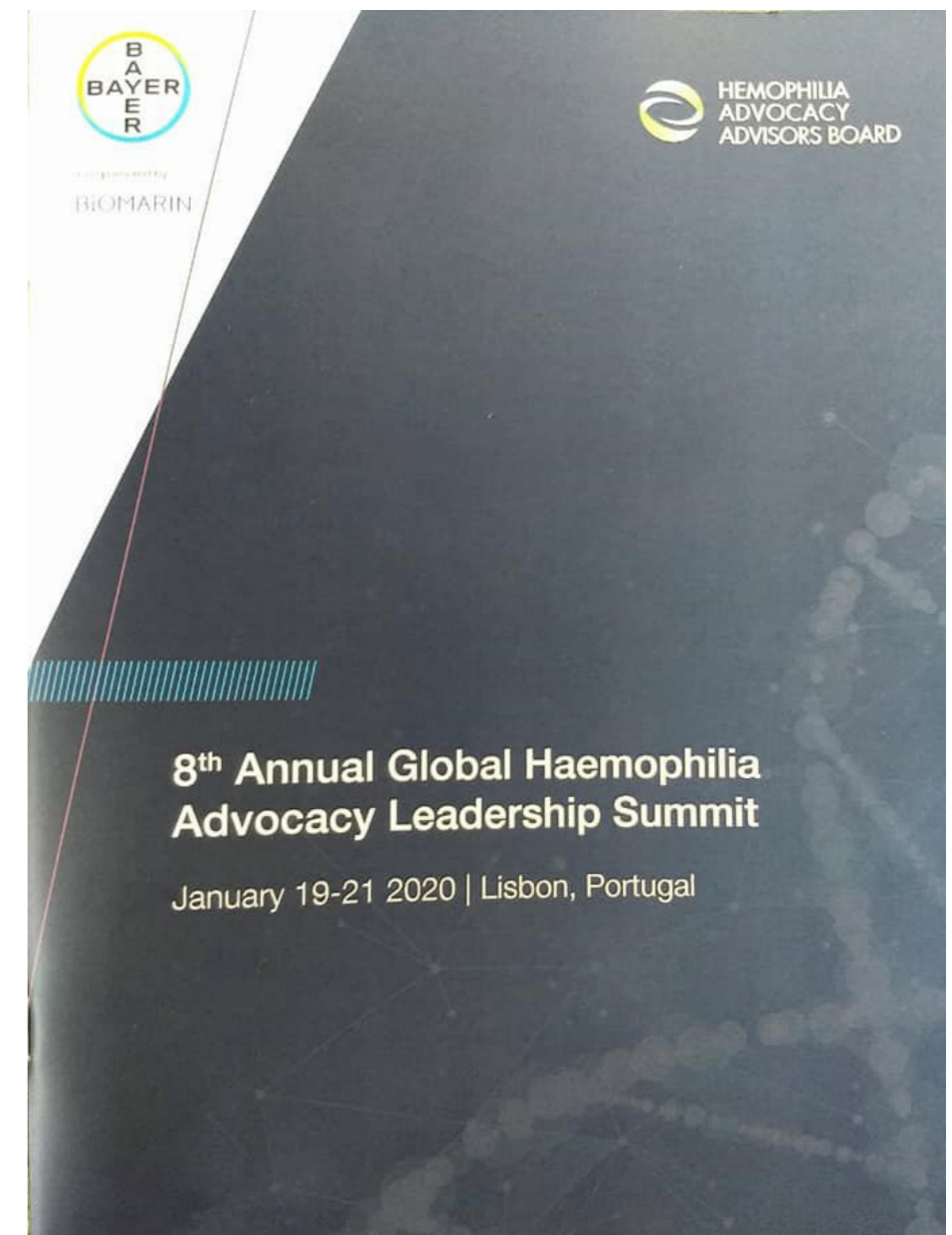
as pain, mobility, health impact on work and education, ability to conduct activities of daily living and quality of life. It takes less than 15 minutes to complete.

The Australian Haemophilia Foundation has been working towards getting all their members with haemophilia A and B to complete the survey, working through the laborious process of ethics approval.

Another presentation given by Amanda Bok, CEO of the European Haemophilia Consortium, was about working with key decision makers, taking a systems approach perspective. In this, Amanda noted there are different types of personalities. As she noted with a quote from Churchman, 1968, “A systems approach begins when you first see the world through the eyes of another”, keeping in mind the different personality types we may encounter in our advocacy work. These include the ‘Analytical,’ the ‘Driver,’ the ‘Expressive,’ and the ‘Amiable.’ We spent 3 hours in a workshop looking at how we can navigate our approach with these different types of personalities and what works best for each. This was an interesting exercise and lots of fun.

We also spent some time in another workshop planning an advocacy strategy to help a health organisation that was undergoing change, with workforce and resource issues, along with education and information requirements. It looked at organisational change and how we as advocates deal with those issues to ensure our voices and needs continue to be heard.

It was so good to meet up again with fellow advocates from the haemophilia community around the world and to meet new ones. All of us were there to engage with leading advocates, key stakeholders and industry experts, working together to learn new ways of doing things, to cement those and previous learnings that will benefit our haemophilia community.



# Inhibitors Workshop: March 13-15, 2020

By Nicky Hollings

Thank you to the Quality Inn Parnell, for all their support.

When I began my journey with the Haemophilia Foundation, I found it all rather overwhelming. Coming from a non-medical background, I had no understanding of the impact of living with a bleeding disorder, and I certainly couldn't get my head around what an inhibitor is and how that affects a person and their family. So, a big thank-you to Colleen and Lynne for explaining it to me as 'severe haemophilia on steroids'. In addition, special thanks to all of those that live or have lived with an inhibitor who have been kind enough to share with me and other staff how much of an impact having an inhibitor has. The knowledge and experience that you hold is priceless.

The Inhibitors Workshop is a space for love, support, connection, and education. At this year's workshop we had a great mix of our community; from people with haemophilia with inhibitors, to somebody who no longer has an inhibitor, the newly diagnosed, those taking Hemlibra, and those without.

The workshop offered a number of speakers and activities for adult attendees and for their children. While the adults were attending education sessions, the children were given fun things to do, or were taken out. There was also a crèche for the very young.

The power of people sharing their stories, the honesty and integrity of our members, led to a weekend of connection, empowerment, and growth. Lynley and Andrew Scott opened their hearts to the group, discussing their hardships living with inhibitors, and how living with no bleeds has changed the way that they live. They can now live without planning for a bleed, live with hope, and are able to plan for a year ahead. This led to an open heartfelt discussion on people's journeys living with inhibitors, with many a tear

and a laugh.

On the first morning of the Inhibitor's workshop, Zaheeda Patel and Ross Paterson took a group of eight children on an outing to the Auckland Zoo. A couple of the older children feigned boredom initially, because this was not a new experience for them. However, as time went on it was noticeable that everyone enjoyed the experience, in part due to them encountering new additions to the animal species housed at the zoo, as well as observing the funny antics of some of the animals.

The children particularly liked watching the otters being fed, and viewing red pandas, tamarins, baboons, and the aptly named pygmy marmosets. After two and a half hours at the zoo we walked next door to the Western Springs Lakeside Park and enjoyed a packed lunch and some time in the playground.

On Sunday morning, Lynne and Ross facilitated sessions for the adults. Ross ran a meditation session before morning tea, then Lynne's session looked at support mechanisms.

Ross's meditation session started with a brief outline of the benefits of meditation followed by listening to two recordings. The first of these described how meditation can reduce pain and increase one's pain tolerance. The second explained how to meditate. We were taken through a guided meditation where we transported ourselves to another place by either lying on the floor or simply leaning back in our chairs with eyes closed.

In Lynne's session, the couples were separated into two groups. The women (mothers of children with Inhibitors or partners of a member with Inhibitors) were in one group and the men (fathers of a child with Inhibitors or a man with Inhibitors) were in the other group.

The two groups worked through a structured series of questions, focussed on support needs. They recorded their responses then reported back to the full group for further discussion.

This discussion took most of the morning given the diversity of the circumstances experienced by individuals present; in terms of residential geographic location, relationship with HTC's, and the very real impositions caused by having an inhibitor.

Those with Inhibitors in the bleeding disorders community face significant extra challenges that not only affect the individual, but the whole family. Those with access to Hemlibra remain in need of Outreach support. It was impressed on Outreach that those with inhibitors appreciate a friendly call from their Outreach Worker regularly.

Christine Olsen from Roche, delivered the data and progress of Hemlibra. Christine's in-depth knowledge of what people need to go through to get Hemlibra allowed members to know what the process is to meet the criteria for treatment, gave them hope, and strengthened their knowledge on how to self-advocate.

Dr Louise Malone talked about advocacy and what their group did to get the results needed. She discussed the importance of developing a support network, and about educating the people you have in your network about what your treatment needs are, so that they can be a voice for you.

Psychologist Gwendoline Smith talked about worry, and how to keep that to a minimum. She discussed interrupting thought processes using cognitive behaviour therapy (CBT), recognising that your thoughts can determine how you feel, and can influence your physical health and how you behave. CBT can be used to interrupt thought processes when living in fear, ruminating, etc.

HFNZ would like to thank all participants in this workshop for sharing so generously and candidly aspects of their personal circumstances. Those new to the world of Inhibitors gained advice and learned a lot from discussing their concerns and drawing on the experience of others. Also, thank you to Zaheeda Patel, Ethan Mathews, and Anna Ellis for giving of your time to help with members' children over the weekend.



*A beach outing for the kids...*



*Ross addresses the attendees*



*While the adults worked hard.*

# NACCHO 2020

By Nicky Hollings

Held in Phoenix, Arizona. Sponsored by Sanofi and Pfizer

Attending NACCHO is a must for anyone wanting to learn about running a camp for people with bleeding disorders. It is a four-day leadership conference within a lovely hotel, the days run from 7am until 11pm, full of high energy, and qualified, knowledgeable people giving of their time and experience.



Nicky Hollings and the crew at NACCHO 2020

Glasser's choice theory was the central theme of NACCHO this year. This theory suggests that humans have five basic needs: freedom, power, fun, love, and belonging/security. Glasser's theory is that how we behave is always our best attempt to meet these five needs, and therefore all behaviour is purposeful.

Over four days the facilitators used therapeutic games, building connections, giving people choices, and a safe environment to teach the theory.

When creating an inclusive camp that is a home away from home, the key questions are:

- How do we develop the programme so children and leaders feel welcome?
- How do you design a camp where children feel heard and understood?

This is where the importance of training for leaders and staff prior to camp is paramount. This includes having a leadership day prior to camp, making sure all the legal requirements are met before camp, and ensuring all staff have their first aid and legal checks prior to camp. One useful thing to try is designing a booklet outlining the rules, guidelines, and expectations. This can be done over email, in consultation with staff and leaders. This will help build a cohesive trust-based relationship with staff and leaders, and teaches leaders to be self-governing with clear boundaries. This is all important for good role-modelling when the campers arrive, as the leaders will know what they need to do to make sure that kids feel loved, safe, wanted, and that they

will be heard. This is all about giving children an amazing camp experience, from the beginning until the close of camp.

It is also important that parents are involved in pre-planning for camp. This is recommended as part of a

culture of growth and development by The American Camp Association (ACA). This document suggests the following tips for parents to help their child deal with homesickness at camp:

1. Encourage your child's independence throughout the year. Practice separations, such as sleepovers at a friend's house, can simulate the camp environment.
2. Involve your child in the process of deciding to go to camp. The more that the child owns the decision, the more comfortable the child will feel being at camp.
3. Discuss what camp will be like before your child leaves. Consider role-playing anticipated situations, such as using a flashlight to find the bathroom.
4. Prepare your child ahead of time that there will be no phone calls to set the expectations.
5. Send a note or care package ahead of time to arrive the first day of camp. Acknowledge, in a positive way, that you will miss your child. For example, you can say "I am going to miss you, but I know that you will have a good time at camp."
6. Don't bribe. Linking a successful stay at camp to a material object sends the wrong message. The reward should be your child's newfound confidence and independence.
7. Pack a personal item from home, such as a stuffed animal.
8. Talk candidly with your child before camp that he/she may miss home, that this is normal, and that they should let their counsellor know if they are having difficulties.
9. Don't feel guilty about encouraging your child to stay at camp. For many children, camp is a first step toward independence and plays an important role in their growth and development.

10. While most incidents of homesickness will pass in a day or two, approximately seven percent of the cases are severe. If your child is not eating or sleeping because of anxiety or depression, it is time to go home.



Camp staff in collaboration with you will determine if your child needs to come home. Don't make your child feel like a failure if their stay at camp is cut short. Focus on the positive and encourage your child to try camp again next time.

One of the most interesting workshops was on innovative themes and programmes, by a woman named Katie Hines from Canada. She and her team had built a large twister game, with king sized sheets sewn together so 20+ people can play. She is also developing a game of Haemopoly, as well as a bleeders edition of the game Cranium. This was a great workshop, which looked at novel ways to incorporate games with learning about bleeding disorders.

Parents, while we are in lock down these would be great games to teach kids about their bleeding disorder, as well as to revise your knowledge, because you and your kids are the experts.

My favourite session was Adventure Infusions for Teens. Heather Case and Tommy Russomano facilitated this session, both with years of experience in the camping world. The Adventure Infusions for Teens programme has a 3-year rotating curriculum, so that teens (ages 13-15) can increase their competence and self-confidence in managing their bleeding disorders in a more engaging way.

- Year one: Infusions on kayaks or canoes
- Year two: Infusions on a moving school bus
- Year three: Infusions while hiking.

Initially both the parents and the teens thought infusing on a kayak was crazy. They had a lot of blowback in the first year. They are now entering year 5, and those same teens and parents are the biggest advocates for the programme. This would be an excellent camp to run in New Zealand, as we have amazing outdoor experiences, which make it specific to how we live.

Many teens point to their experience on an adventure infusion as the 'tipping point' in them becoming more independent and confident.

NACCHO is invaluable for staff who will be involved in planning camps and workshops. It helps with maintaining professional and legal requirements for camp, but also develops programming and activity skills that are required to make a camp successful. NACCHO has been one of my favourite professional development opportunities because of all of the above, but also for building relationships with others internationally. I have had contact with a number of camp directors in America, and several of them are still looking at going forward with a camp in June and July. I hold huge concerns about that choice, and I'm very pleased with the Council's decision to look at changing the date for Youth Camp, as the health and safety of our members, leaders, and staff should always be paramount when it comes to camp.



# The Waikato haemophilia space

By Maureen Campbell

After many years we finally have a place to call our own, this takes the form of an area that our patients and families can drop in to see the haemophilia nurse and be treated for minor injuries that do not require emergency department input.

- HFNZ CEO Sue Ellis
- NHMG (National Haemophilia Management Group) for their continued support.

This is a place where you can come to have your treatment before minor surgical and dental procedures.

Our HTC (Haemophilia Treatment Centre) is very modest but fit for purpose and we love it.

Members of our bleeding disorder family have already started to use it and as time goes on it we know it will be well used and become just the norm to pop and see us.

Our hours are between 8am and 4:30pm Monday to Friday.

Our centre is growing we now have two bleeding disorder specialist consultants, Dr Julie-Anne Bell and Dr Julia Phillips, plus the wonderful addition of a haemophilia specialist physiotherapist Abhi Tikki setty who has already made great improvements to those he has treated.

Of course there is also our awesome HFNZ outreach person Nicky Hollings, who is sadly moving on, and Maureen Campbell, Clinical Nurse Specialist - Haemophilia. Midland Region.

I would like to thank the people who made this possible for their continued support:

- Alex Gordon, Director – Cancer & Regional Medical Services.
- Gabby Reynolds, Clinical Nurse Director Ambulatory, Cancer and Regional Services.



*Julia Phillips, Maureen Campbell, Julie-Anne Bell, and Abhi Tikki setty*



# Regions and Groups

HFNZ's Regional and Group committees enable all our members to participate in the running of the Foundation, and to connect with and support one another. Each Region and 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.

## NORTHERN

We had a fun day out at Parakai in February. It was great to see the Davis family make the trek from Whangarei. The kids had a great time and showed the locals how to do a "manu".

Unfortunately, we had to cancel our movie event due to the lock down. We have put all events on hold until there is clarity around the virus.

We have had feedback that members are not receiving the invites to events. If you haven't received invites to the Christmas event at the grounds or Parakai please let Phil know at the national office by email or let Outreach Worker Amber Maihi know.

Please stay safe and look after yourself and your family during this crazy time

## MIDLAND

Hi to everyone and their bubble. Hope everyone remembered World Haemophilia Day on 17 April. Hopefully everyone is keeping safe and enjoying each other's company. Midland have been very lucky as our Outreach Worker Nicky Hollings decided to stay on during this important time. We all send her thanks for doing this for us. So please contact her if you require her help. She can be contacted through Facebook or cell phone and will do her best to help you. Once we are able to get around safely and be in contact with each other, Midland will plan an event to bring us all together again. Remember that all treatment centres are open through your DHB's. Look after each other and stay safe.

## CENTRAL

Here at Central we've had to postpone a few events, but these are all ready to be kicked off again once the COVID alert level relaxes.

Keep an eye out for:

- A dinner in Palmerston North
- The ever-postponed Men's fishing trip. Currently scheduled for May 9 departing Seaview Lower Hutt
- Regional Camp at El Rancho in Waikanae from 28 to 30 August 2020
- Screening of Bombardier Blood.

Stay safe everyone!

## SOUTHERN



Here at Southern we hope everyone is safe in their little bubbles. Such a trying time for everybody-especially those working on the frontlines.

Not a lot to report at this point as we have had to postpone our walking group until further notice.

The movie we had planned to show for World Haemophilia Day, Bombardier Blood, has also been postponed, but we have been assured that we can definitely screen it at a later date.

On a positive note, the HFNZ Women's High Tea held at Penny Black cafe at the Tannery was a wonderful excuse to dress up and enjoy some wonderful company. Approximately 10 ladies came to share a delicious afternoon tea. Definitely recommend the cafe when things go back to normal! We also raised \$165 to send to our sisters in Nepal to have a treat from us. Fantastic effort ladies-thank you.

## YOUTH

The National Youth Committee welcomed in the 2020 Committee (which has some new faces after our Youth Development Workshop in November last year) with their first official meeting in February. Like many of you, we had opted to take a break over Christmas / New Year to recharge our batteries.

We are thrilled to announce that our twinning with the Nepalese Haemophilia Society's Youth Committee was renewed for another year and are looking forward to supporting the Nepalese Youth to plan and host their own Youth Development Weekend in Nepal.

We have big plans to get some regional events going this year, with each of our Regional Youth Delegates working with Outreach Workers to put some cool events together.

Our intention is to get together and work on getting a strategic direction/goals document finalised, which we can use as a reference document to make sure the events and workshops we're hosting are getting the results we are looking for.

Unfortunately given current Covid-19 situation, these plans have been put on hold. We hope everyone is taking care and staying safe during the lockdown; once we have more certainty around the outbreak, we will look at getting some events in the calendar.

The Youth Committee can still be contacted on Facebook or via phone if anyone is having difficulties (Covid and general life) and would like some assistance, we are here to help!

## PIRITOTO

Over the last few weeks I, and I am sure everyone else, would have felt a sense of uncertainty about this pandemic. How can one not feel uneasy in the face of hourly updates of people falling ill and in extreme cases people passing away due to this ngangara/bug that we call COVID 19. This

feeling of unease can be identified only as 'the unknown'. If I step outside my doors will I contract the virus? What will my life be like when this is all over? What do we have to look forward to? What will the future hold?

I don't know what the future holds for this new world of tomorrow. "Whāia E Tātou Te Pae Tawhiti - Getting



Courtney & Hemi on a twinning visit to Nepal

Through Together," A whakataukī used by the Mental Health Foundation of NZ to express working together, as a nation, to pursue our future. We are facing unprecedented times whānau. I think that through it all we should remember to be kind, compassionate, patient, and respectful to others.

## 2020 HFNZ Member Survey

It's that time of year again when the HFNZ team look for feedback on how well the Foundation is performing for its members. This is an 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 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.

The HFNZ Members Survey is administered and collated online. So, the best and easiest

way to complete the survey is by going here:

<https://www.surveymonkey.com/r/2020HFNZsurvey>

If there are any other HFNZ members in your household, please get them to fill the survey out too. The more responses we get, the more representative your HFNZ can be. As an incentive, everyone who completes the survey can enter the draw to win one of two \$50 Prezzy cards. Details are on the survey.



The HFNZ Member Survey is open now, and runs until Monday 4 May, so get in there and have your say.

# Latest news

## BLOODTYPE, VON WILLEBRAND FACTOR PLAY NO ROLE IN FVIII LEVELS IN NON-SEVERE HEMOPHILIA A, STUDY SUGGESTS

APRIL 13, 2020 Patricia Inacio, PhD

In contrast to observations in the general population, blood type and levels of von Willebrand factor (VWF) don't appear to influence factor VIII (FVIII) levels in people with non-severe hemophilia A, a study reports.

Moreover, age was found to play only a minor role in FVIII levels in these patients.

The study, "Influence of blood group, von Willebrand factor levels, and age on factor VIII levels in non-severe haemophilia A," was published in the *Journal of Thrombosis and Haemostasis*.

Hemophilia A is caused by a lack of FVIII, a protein involved in blood clotting. FVIII binds to VWF, which protects and helps maintain FVIII in the circulation to help reduce hemorrhage.

Previous studies demonstrated that VWF, age, and ABO blood groups influence the levels of FVIII in the general population, but the relation between these factors and FVIII in non-severe hemophilia has not been extensively studied.

To address this, researchers at the University of Vienna and their colleagues conducted a study that included 89 adults, at a median age of 51, with non-severe hemophilia A from four hemophilia centers across Austria. As controls, the team recruited 82 healthy men.

The lowest FVIII level in a patient's history was used for diagnosis and assessment of disease severity. Mild and moderate hemophilia was determined according to guidelines established by the Scientific and Standardization Committee of the International Society on Thrombosis and Haemostasis.

Researchers assessed FVIII activity using a one-stage clotting assay and a chromogenic substrate assay. They also evaluated VWF activity, and measured antigens (proteins) against FVIII and VWF. In addition, they examined links

to mutations in the F8 gene, which provides instructions for making FVIII.

In the hemophilia A group, 47 patients (52.8%) belonged to the O blood group, and 42 (47.2%) to non-O groups. In the control group, 32 participants (39%) belonged to the O blood group and 50 (61%) had a different blood type. Eighty-five patients showed 46 different mutations in the F8 gene.

Results showed no significant differences in FVIII activity across the blood type groups in hemophilia A patients. Neither was a correlation found between FVIII activity and VWF activity or levels in patients.

In controls, those with a non-O blood type had higher levels of FVIII than those in the O group — 150% versus 109.5%. The activity of VWF was also higher in the non-O group than in the O group — 117% versus 71%.

Healthy individuals from the non-O groups also had higher levels of VWF (126%) than those in the O group (86%). In fact, the team estimated that a 1% increase in VWF levels or activity correlated with a 0.73–0.77% increase in FVIII activity.

Next, they analyzed the influence of age on FVIII and VWF levels in hemophilia patients. The association between age and FVIII activity was not significant, but there was a weak correlation between older age and higher FVIII levels. A similar association was also found between patients' age and VWF levels and activity.

Further analysis showed that neither blood group, VWF levels, nor age were significantly associated with FVIII activity in patients. However, in healthy individuals, the combination of blood group, VWF levels, and age explained 61.3% of the variation in FVIII activity.

These findings indicate that although factors such as age may influence FVIII levels in non-severe hemophilia A, genetic mutations are likely the main drivers mediating this protein's levels, the scientists said.

"We conclude that for the assessment of FVIII levels in patients with mild or moderate haemophilia A neither the ABO, nor the VWF level, have to be taken into account. Age

has to be considered a minor modification factor, as there is a consistent, but weak, increase in FVIII levels with age," they wrote.

"These aspects are important in daily practice, when a diagnosis of non-severe haemophilia A has to be made," they added.

SOURCE: <https://hemophilianewstoday.com/2020/04/13/blood-type-vwf-play-no-role-in-fviii-levels-in-non-severe-hemophilia-a/>

## SPECIFIC RISKS OF COVID-19 TO THE BLEEDING DISORDERS COMMUNITY

World Federation of Hemophilia - April 2, 2020

WFH COVID-19 Task Force: Assad Haffar, Cedric Hermans, Barbara Konkle, Brian O'Mahony, David Page, Flora Peyvandi, Steve Pipe, Mark Skinner and Radek Kaczmarek and Glenn Pierce, Co-chairs

### Risks of acquiring SARS-CoV-2 (the virus) and COVID-19 (the disease)

- No increased susceptibility to infection has been found in immunocompetent patients with bleeding disorders. SARS-CoV-2 is passed primarily through droplets in the air coming from infected persons. These droplets get into the upper respiratory tract where they establish an infection.
  - <https://www.who.int/news-room/commentaries/detail/modes-of-transmission-of-virus-causing-covid-19-implications-for-ipc-precaution-recommendations>
- There is no information about whether persons with HIV are at increased risk of acquiring the infection. However, if infected, immunocompromised people are at much higher risk for severe disease. For HIV, that includes:
  - People with a low CD4 T-cell count (e.g., <200)
  - People not on antiretroviral HIV treatment
  - If there are other underlying diseases associated with severe COVID-19
  - <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/hiv.html>

### Risks if you have COVID-19 infection and a bleeding disorder

- This is a potentially deadly infection that causes a spectrum of disease, from asymptomatic to severe pneumonia and lethal systemic sequelae. While older individuals and those with identified risk factors are at greater risk of serious and lethal disease, children and

young adults may also develop severe disease, although less frequently.

- <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-at-higher-risk.html>
- Risk factors include other systemic diseases including hypertension, diabetes, cardiovascular disease, and immunosuppression.
- Individuals with hypertension should not discontinue their medication. Current evidence does not support changes in the management of hypertension.
- As COVID-19 progresses, coagulation pathways are activated as part of the host inflammatory response to limit the viral infection. Specifically, D-dimers, products of fibrin as it is degraded within clots, are elevated in many cases of hospitalized COVID-19 patients. D-dimers are an indicator of clot (thrombus) formation and breakdown.
- More severe COVID-19 disease may lead to overt disseminated intravascular coagulation (DIC), associated with high mortality. DIC is a coagulopathy that may arise from the systemic inflammatory response to the virus and damaged tissue caused by the infection. In DIC, decreased platelets, prolonged screening tests (PT and aPTT), and decreased fibrinogen are
  - Close monitoring for bleeding and thrombosis is recommended for all individuals who progress with signs or symptoms of DIC.
  - Anticoagulants (e.g., low molecular weight heparin, LMWH) are being recommended as part of treatment protocols for patients with elevated D-dimers and severe infection. Use of anticoagulants should be accompanied by factor replacement therapy.
  - Should a thrombotic event occur in a hemophilia patient, detailed reporting is important (including COVID-status, laboratory assessments, imaging, replacement therapy).
- If COVID-19 is diagnosed, prophylaxis with factor replacement therapy should be continued, and if hospitalized for severe infection, higher trough levels may need to be considered as if treating major trauma.
- The risk of thrombotic complications for hemophilia patients who are currently treated with non-factor replacement therapies including emicizumab or other investigational agents (e.g. fitusiran, anti-TFPI) is unknown in the presence of COVID-19 infection.
  - In individuals with hemophilia A receiving emicizumab, it is unknown how the drug may interact with coagulopathy caused by infection and close monitoring for thrombosis is recommended.

- Prophylaxis should be continued, and in the event of missed doses, the long half-life (~30 days) of emicizumab should be taken into consideration, since it will be present and active for a prolonged period of time.
- Patients should be assessed to determine if they need additional clotting factor replacement therapy.
- Anticoagulants may be considered as per recommended treatment protocols.
- In patients with FVIII inhibitors receiving emicizumab, extra precautions should be taken if a patient requires aPCC due to the known drug-drug interaction between emicizumab and aPCC.
- [https://www.hemlibra.com/hcp/safety.html?c=health65155ea50d&gclid=EA1aIQobChMI7sT20bvG6AIVlddkCh3lFAG0EAAAYASACEgI-2vD\\_BwE&gclidsrc=aw.ds](https://www.hemlibra.com/hcp/safety.html?c=health65155ea50d&gclid=EA1aIQobChMI7sT20bvG6AIVlddkCh3lFAG0EAAAYASACEgI-2vD_BwE&gclidsrc=aw.ds)
- Be aware that some one-stage coagulation assays, such as aPTT which is often used to diagnose and monitor patients in DIC, overestimate coagulation in patients on emicizumab and thus may mask coagulopathy.
- Investigators are advised to seek guidance from the

study sponsors and medical monitors for subjects within clinical trial programs for these agents. Patients should inform health care providers they are on a clinical study and reference back to their hematologist is recommended.

- For patients participating in a clinical trial of gene therapy, in addition to caution regarding infection risk when immunosuppressed, as outlined in Practical Recommendations for People with Hemophilia <https://news.wfh.org/covid-19-coronavirus-disease-2019-pandemic-caused-by-sars-cov-2-practical-recommendations-for-hemophilia-patients/>, supplementation to higher coagulation factor levels (e.g. as if treating major trauma) could be considered in those who have had a suboptimal response to the gene therapy.
- Patients with bleeding disorders of all severities and COVID-19 should be eligible for all available therapies that would be required depending on their condition (e.g., ventilation support, ECMO, hemofiltration).
  - Having hemophilia should not exclude individuals from invasive management of COVID-19.

SOURCE: <https://news.wfh.org/specific-risks-of-covid-19-to-the-bleeding-disorders-community/>



Outing to the Auckland Zoo during Inhibitors Workshop 2020

## THE YEAR AHEAD

As we've mentioned in our weekly email updates, all HFNZ events and workshops have been postponed until further notice as a result of the Covid-19 situation. The HFNZ National Council executive will revisit the scheduling of events and workshops after 1 July 2020.

Here are the national events that are currently affected.

- **Premiere of the Bombardier Blood Movie**  
*Christchurch.*
- **Youth Camp**  
*Auckland.*
- **Adult Weekened**  
*Christchurch.*
- **National Family Camp**  
*Kaiapoi, Blue Skies*

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

## vWD Guidelines Submissions

Submissions are open for comments on the proposed guidelines for the diagnosis and management of vWD.

The American Society of Hematology (ASH), the International Society on Thrombosis and Haemostasis (ISTH), National Hemophilia Foundation (NHF), and the World Federation of Hemophilia (WFH) have joined forces on this very important project.

You are invited to comment on the DRAFT recommendations by visiting: <https://hematology.org/education/clinicians/guidelines-and-quality-care/public-comment-guidelines/public-comment-on-guidelines-on-the-diagnosis-and-management-of-von-willebrand-disease>.

Submissions close 15 May.





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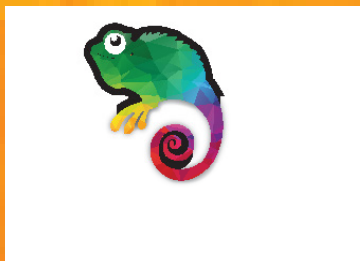
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<https://haemophilia.donatenow.co.nz/>

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# Bloodline

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