the FACTOR

Issue 65

Summer 2020 - 21

Newsletter of Haemophilia Foundation Queensland

From the President

Hello Everyone.

Can you believe it – Xmas is just about to land and it has been an early Xmas present from our great state and national health departments with the health minister (Hon Greg Hunt MP) advising that all Australian governments have now agreed to fund new treatments – life changing treatments which we now see rolling out – simply brilliant!

This is in stark comparison with our friends in Fiji where they are still relying on donated factor which is never sufficient for the needs of their bleeding disorders community, and where engaging their health department is difficult. However I did receive a lovely letter from the president of the Fiji Haemophilia Foundation thanking me for the advocacy we have done for them over the last year.

2020 has seen another year where our partnership with Queensland Health and the Haemophilia Treatment Centres played a key role in empowering and connecting people, representing them when required, bringing health promotion and personal health responsibility, together with education and support services.

Our partnership with Queensland Health is realistic, synergistic and outcome focused – I am sure I can speak for all of the Queensland Bleeding Disorders Community and thank the Treatment Centre Staff, Graham our HFQ manager, Sam our admin expert, the HFQ board who donate their time and

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Inside this issue:

From the President *continued*

judgment, as well as Tony who volunteers with our social media, and all our other volunteers – great work – good Job!

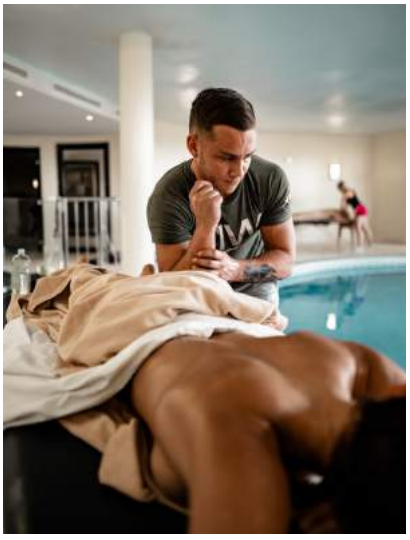
Until next time, take care of each other and stay away from the emergency departments unless you really have to.

Merry Xmas / Happy New Year ….

David Stephenson
President HFQ
president@hfq.org.au

Three Questions for Your physiotherapist

The QHC physiotherapist plays an integral part on the treatment team for anyone who has a bleeding disorder. While doctors and nurses help manage bleeds and make sure individuals get the factor and other medications they need, PTs address joint health, weight management and overall physical fitness.



Physiotherapists work to preserve joints and range of motion, to relieve pain and to improve quality of life. They keep people functional as possible for social activities, for school or for work.

Physiotherapists typically see people with bleeding disorders once a year for a check-up. View your annual appointment with your physical therapist as a time to discuss the coming year. Here are some sample questions to help you have the best year possible:

How can I prepare for my leisure activities or vacations?
A trip to the beach or to the mountains for hiking, for example, requires the right shoes. Your Physiotherapist can help you pick the proper pair and HFQ members can get a subsidy for supported footwear. Discuss precautions or special equipment associated with your bleeding disorder that you may need to consider.

What sports can I play with my friends or co-workers?
Before you join your company's softball team or your neighbourhood's soccer league, consult your physical therapist. Ask how to strengthen the muscles and connective tissue you'll use in your new sport so you can minimize your risk of a bleed. The same goes for parents of children with bleeding disorders: If your child wants to try a new sport, call your Physiotherapist and ask for advice, and download a copy of 'On the move with haemophilia', The HFA and HFNZ book on sport and exercise in young people with haemophilia. (https://invivoacademy.org/on-the-move-with-haemophilia-toolkit/)

How can I prevent or reduce pain at work?
Often, you can rearrange your workspace to make it more comfortable. Your PT can help determine the best setup for you.

"Before you come in, think about what you want from us so that we can prepare you for what it is you are planning to do," says Bailey. Think of your PT as a partner who can help you boost your quality of life and keep you doing the things you want to do, no matter your age.

Edited from '3 Questions for Your Physical Therapist (PT)', by Matt McMillen, *https://hemaware.org/mind-body/3-questions-your-physical-therapist-pt*

ABOUT HFQ

Haemophilia Foundation Queensland Inc. (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation receives a grant from Qld Health and employs a part time manager and an administration assistant. It is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via email (info@hfq.org.au) or post at PO Box 122 Fortitude Valley, Qld 4006

HFQ provides financial members with support and benefits, including subsidies on:

- **Medic Alert bracelets (50% discount)**
- **Electric Shavers (up to $75 off)**
- **Supportive footwear (75% off)**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Robert Weatherall
Secretary	... ...	Ms Lauren Albert
Treasurer	... ...	Mr Adam Lish
Members	... ...	Mrs Belinda Waddell
		Mr Charles Eddy
		Dr Jodie Caris
		Mrs Leanne Stephenson
		Mr Mike O'Reilly
		Mr Mike Holloway
		Ms Shannon Gracey

HFQ Delegate to HFA

Mr Adam Lish

Acknowledgements

HFQ is grateful for the support of our patron: His Excellency the Honourable Paul de Jersey AC.

HFQ programs and services are funded by the Queensland Government.

HFQ is also grateful for the support it has received from the Prescott Family Foundation.

Internet

Find us on the web at *www.hfq.org.au* or at our Facebook page at *www.facebook.com/HFQLD*

QUEENSLAND HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist

Haemophilia Fellow –- Dr Antoinette Runge

Haemophilia Registrar – Dr Chintaki (Chinthi) Jayasekera

Joanna McCosker – Nurse Practitioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Elise Mosey (M,T) - Physiotherapist

Hayley Coulson (W,Th, F) – Physiotherapist

Dr Moana Harlen - Senior Psychologist

Contacting the Clinic - Please call the Haemophilia mobile for urgent enquiries on 0438 792 063 (office hours 8 – 4pm).
For all non-clinical/non-urgent enquires please email QCH-Haemophilia@health.qld.gov.au

After hours—call switch and ask to speak with on-call haematology consultant or present to the emergency department

Appointments — Outpatient Bookings Office on 1300 762 831 or email QCH-Outpatients@health.qld.gov.au
Your health care team does not make these bookings or any changes to your appointments. Referrals can be sent to the Referral Centre Fax Number 1300 407 281

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 3c outpatients Level 3, Thursday afternoons 1.00 – 3.30pm

Haemophilia Carrier Clinic – as needed Thursdays 1pm – 3.30pm

ADULT CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - Haematologist	3646-8111
(Page through switch)	
Haemophilia Registrar	3646-8111
(ask to page Haemophilia Registrar on 59716)	
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Scott Russell - Physiotherapist	3646-8135
Loretta Riley - Advanced Social Worker	3646-8769

Contacting the Clinic ***Please telephone in the first instance.***
Appointments 3646-7752 or 3646-7751
For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

Haemophilia and Genetic Clinic — Dr Jane Mason — Wednesdays 1.30pm New Patients Thursdays 8-9.30

Haemophilia/Orthopaedic Clinic — Dr Jane Mason and Dr Brett Halliday — 9am every four weeks

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base Hospital & Townsville Hospitals: For queries email *CHQ-Haemaphilia@health.qld.gov.au* at QCH or *RBWH-Haemophilia@health.qld.gov.au* at RBWH.

Reaching Out

Today is day one back from holidays for me. Well, I say holidays, but every week I had off, I actually engaged in some professional development, which has relevance to my work with the inherited bleeding disorders community.

Week one I stayed up late and attended my first virtual meeting with the World Federation of Hemophilia (WFH) Psychosocial Committee. I will be having some late nights throughout the rest of 2020 and into 2021 collaborating with some inspiring Social Workers and Psychologists from across the world. Even from an introductory meeting, I felt excited to be a Social Worker with such an opportunity to make a difference and contribute to psychosocial care across the world.

Week two had me suffering from sleep deprivation as I attended (virtually) the Happiness and its Causes Conference and workshops during the day and for 2 nights attended (virtually) the WFH Global Summit on Women and Girls with an inherited bleeding disorder. It is with sadness that I heard the stories from women and girls regarding their challenges with living with an inherited bleeding disorder but also with excitement about the positive action occurring across the world in bringing about change. Each change happens with one small step – which is sometimes hard to remember when you are in the situation or trying to help others.

Unfortunately we had to postpone our Women's workshop in 2020, but I am hoping that together with HFQ we are able to hold a forum in 2021 to enable women's voices to be heard and so that we can look at what we can do together to meet your needs.

The Happiness and its Causes conference identified for me the small things we can do everyday to help with our own well-being. Just like physical health, maintaining mental wellbeing is not just something that happens. It is something that we all need to work on… every day. I am planning on running some bite sized workshops in 2021 to look at some practical ways to enhance well-being – more on that another time. It also fits in well with other study I have been doing this year – so 2021 (COVID permitting) will have a focus on preventative mental

health/enhancing well-being from me. I will also be living what I am teaching after being inspired by Shannon Harvey who presented her documentary at the Conference on her year of living mindfully and I will be doing my own well-being toolkit experiment on myself.

My final week of leave ended with a webinar from the Queensland Mental Health Commission on the Productivity Commission report into Mental Health. It reiterated for me that there are groups of people (including within the inherited bleeding disorders community) who are slipping through the systems and are not able to access mental health support easily. I hope that the work that I do will assist some people, but also by working proactively and working on well-being we are able to address concerns early.

I also want to acknowledge that sometimes the steps or strategies and general information in my articles do not improve things. Sometimes the issues might mean that the person experiencing them needs more support or a different strategy. Fortunately, we are all individuals which means what works for one person, does not necessarily work for another. That is why there are numerous options and strategies to try. One thing that was highlighted in the Happiness and its Causes conference was that resilient people ask for help. Please, if my general suggestions in the articles don't help – reach out via phone or email to make an appointment with me. If I am not your cup of tea, please speak with your GP for a referral to a psychologist or social worker in the community. I will not be offended if you are seeking support from somewhere else – because at the end of the day, what I want for you is for you to access support that can be tailored to you and to your situation.

We are also coming up to a time of year which may be challenging for some people in the community. Christmas, the Wet Season, Cyclone season and intense heat of summer all bring about their challenges. Having grown up in North Queensland, being prepared for cyclone season was one thing we did every year (and to be honest, I still do it in South East QLD and

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What's On?

January to April 2021

Some of the HFQ programs and activities already planned

Please call the office for other events, more information or to RSVP

JAN

- **OBE's Monthly meeting** 6 January Old Fernvale Bakery Cafe
- **HFQ Board Meeting** 19 January 298 Gilchrist Ave, Herston
- **Australia Day Event** Sunday 24 January TBA
- Bubble Wrap Appreciation Day

FEB

- **OBE's Monthly meeting** 3 February
- **Women's Lunch** Sunday 7 February 11.30am to 1.00pm Everton Park Hotel
- **HFQ Board Meeting** 16 February May 298 Gilchrist Ave, Herston
- **Art Workshops** TBA
- **Rare Diseases Day** 28 February

MAR

- **OBE's Monthly meeting** 3 March
- **Art Workshops** TBA
- **HFQ Board Meeting** 16 March 298 Gilchrist Ave, Herston
- **Harmony Day** 21 March

APR

- **OBE's Monthly meeting** 7 April
- **Art Exhibition and WHD Display** RBWH Art Space
- **HFQ Board Meeting** 21 April 298 Gilchrist Ave, Herston
- **World Haemophilia Day** TBC

Reaching Out *continued*

have to eat baked beans and tinned spaghetti throughout winter!!) I think that we can also prepare in advance for times when we know it may be difficult. Having our toolkit of strategies available if we are going through a hard time is helpful. It may mean:

a) having a list of people to call when you are having a difficult day;

b) having a play list of songs that motivate you or you enjoy;

c) having some physical activity to do or creative activities to do;

d) having some strategies that you find relaxing, or that bring you into the present moment;

e) giving yourself some self-compassion;

f) the list is endless and it is about finding what works for you (and does not cause you harm) and doing that.

COVID permitting, 2021 will see an emphasis on creating change -- from the RBWH Haemophilia Centre Social Work service. This cannot be done alone (I cannot do it for you) and I will be reaching out for help so that we can collaborate together so that we can all thrive in 2021.

Plans for 2021:

- Art Exhibition in April 2021
- Well-being workshops
- Women's forum and subsequent activities
- Getting older activities for those over 65
- Pain workshops
- Self advocacy workshops

Loretta

QHC – RBWH Social Worker
3646 8769

Paediatric Team Update

It's that time of year again so Merry Christmas to everyone and Happy New Year. See you later 2020 and 2021 needs to put its best foot forward. In the Haemophilia space we have had many changes this year and not just COVID-19. New haemophilia treatments became available: the improved extended half-life factors (ELOCTATE and ALPROLIX) and the new subcutaneous monoclonal antibody (the mimic of factor 8) HEMLIBRA was finally funded and made available in Australia

EHL SWAP - The swap from Advate®/Xyntha® (recombinant factor 8) and BeneFIX® (recombinant factor 9) began end of July and I am pleased to say that we have almost swapped all the children with severe haemophilia over to the longer acting factors. For those children who are not on regular factor treatment we will slowly but surely catch you in clinic / on the phone / or in the emergency department and at this time we will update your Australian Bleeding Disorder Registry (ABDR) treatment plan and send you new treatment cards.

There is no longer any Advate®/ Xyntha® and very little BeneFIX® in the Queensland Children's Hospital. There is no Advate®/ Xyntha® or BeneFIX® in any of the Queensland Health hospitals around the State. If you present to an emergency department you will receive Eloctate® or Alprolix® (even if your card still says Advate® or BeneFIX®)

HEMLIBRA® – We have started 9 children /babies with severe / moderate Haemophilia A on Hemlibra® over the last 6 weeks, some at QCH and others in regional cities. It has been very rewarding to see the changes for these families who were in urgent need of another option to manage their haemophilia. These families have come to their local hospital to have their first 5 doses of Hemlibra, this is so we can monitor post the injection and for the parents or young child / teenager to learn how to give the Hemlibra via subcutaneous injection. There are 4 weekly loading doses to achieve a steady state of Hemlibra in the bloodstream followed by the first maintenance dose on week 5. After week 5 the dosing schedule is generally every 2 weeks which can be done at home. New treatment cards will be done, and you can record your Hemlibra use in the MyABDR.

Hemlibra is ordered and supplied by a prescription written by the Haemophilia treatment centre (QCH). There is no home delivery available with Hemlibra and you can collect your 3 – 6-month supply from your nearest QH pharmacy. Convenience kits which are ordered from Roche (dosing supplies) will be supplied by your local nursing staff every 3 – 6 months. Stock of ELOCTATE or ALPROLIX will be reduced and depending on your circumstances you may have 1 or 2 doses at home in case of a bleed. **REMEMBER Hemlibra is for prophylaxis only, it is NOT used to treat any bleeding!**

Now for the boring bits…..

Senior Medical Staff Rotation
We would like to farewell Dr Antoinette Runge who has been with us for almost 2 years as the Haematology Fellow. She has gained valuable experience working with our team and all the families she has met over her time.

We currently have a new registrar; her name is Kristen O'Connell and she will be part of our team until 29th January 2021.

February 1st we will welcome Dr Annette Swift back to the team as the Fellow for the first 6 months and then Dr Jordan Staunton for the last 6 months.

Upcoming Leave – Christmas Break
Joanna and Amy will be off for the public holidays Xmas Day, Boxing Day and Tuesday the 29th December. Joanna will be around the Wednesday and Thursday before New Years if there are burning clinical issues

Moana is on leave from the 21st December for 3 weeks. Returning to work on the 11th January

The physio team is available for urgent clinical issues except on Dec 24th , 28th , 29th and the 31st December.

Simon Brown is on leave in January from the 12th – 24th

If there is no answer on the Haemophilia Mobile
Over the Xmas and New Year break the haemophilia mobile will be manned by the nurses or if required one of the doctors. In case of mass sick leave (preparing for the worst-case scenario) if you are unable to contact anyone via the mobile please call the switchboard at QCH on 3068 1111 and ask to speak to the on-call consultant for haematology/ haemophilia.

Please remember the Haemophilia mobile is not manned on weekends or public holidays.

HAEMOPHILIA EMAIL
Please continue to send you requests for school resources, script requests and any other non-urgent and non-bleed related requests to the haemophilia email.

Thank you for all your support in 2020
From *Joanna* and the haemophilia team

Notes from a long term Hemlibra user

Kyle is a 20 year old man who started on Hemlibra four years ago.

Before Hemlibra my life was pretty abysmal. I was having bleeds once or twice a week and that meant using product every day, to the point where we were having it up to three times a day the maximum amount possible.

I had a brain bleed when I was about five years old and developed tics from that. I was waking mum up in the middle of the night and it was just not a very good time. I was in hospital a lot.

Dr Simon had tried to get me on what was then called Ace910 but they wouldn't accept me on the trial, and then it comes to 2016 when I just come out of hospital for Psoas muscle bleed and which was like three litres of blood internally.

I almost died. And I said to Simon, "I can't keep living like this. Is there anything else you can do for me?" And he put my case to Roche and due to the trauma I sustained they put me on compassionate use.

Using Hemlibra

I had no fears starting on the drug, then called Emicizumab but now known as Hemlibra. I had always said, even when I was very young, that I would do anything it took to kill my haemophilia. I knew that there could possibly be side effects because it was still a trial drug, but I wasn't scared.

I think it took a series of four or five mandatory hospital injections and then my body was saturated with levels of the Hemlibra. It was about then I thought I saw a difference in my health and the clinic staff felt comfortable giving it to me to go home with. Yeah.

They did lots of blood tests to measure the clotting level and one day they came back and said, you clot better than some average normal people. So, I understand I am now considered a mild haemophiliac and I barely get any bleeds now.

> *my Mum was infusing the factor for me... I couldn't have done it as my hands were too shaky. But with Hemlibra... Mum has never had to do it since.*

There's still a risk of bleeding, but that would require a lot of trauma to the area or some actual surgery, but it's quite controlled and if a bleed pops up it's like gone by the next day and I've got factor seven if it doesn't, but I've never had to use it!

Before Hemlibra, my Mum was infusing the factor for me and occasionally my dad. I couldn't have done it as my hands were too shaky. But with Hemlibra, the nurses did the initial dosing just to get me going, but then I did it and Mum has never had to do it since.

There was redness in the area to begin with and there's been a bit of itching in the side, but that can just be chalked up to the needle injection.

Noticing Changes

The biggest change for me was just not having to have bleeds, I'm not a very active person anyway by not having to endure the pain of an individual bleed once or twice a week, and sometimes three times a week just by doing nothing, because of how severe my haemophilia was.

It's been fantastic for me. I'd gone to school up until 2015 [but with lots of breaks when] I was admitted to hospital and thanks to Hemlibra, I was able to get back to school in the middle of 2016, and [finish off my schooling].

Advice to others

If someone is thinking about starting on Hemlibra I'd say go for it. I wouldn't worry about the downside if there would be any, because anything that would be happening should have been found out by now. Because of the length of the trials any longer term side effects have hopefully been sorted.

Kyle

Kyle in the buggy at this years Youth camp

Women And Haemophilia

Many physicians would say that this title doesn't make any sense—women don't get haemophilia. Today we know that women can have Haemophilia, and in fact, the number of women with haemophilia is significant. Unfortunately, this "news" hasn't reached many physicians, especially those who do not specialize in haemophilia treatment. This is in spite of the fact that since the 1950s the medical literature has contained reports of haemophilia carriers with factor VIII or IX deficiency and bleeding problems.

Because the idea that women don't get haemophilia has been so ingrained, early researchers tried to imagine all kinds of other explanations for these reports. The genetics seemed so simple that there had to be an alternate reason. Now we know that the genetics are actually much more complex, and it is obvious that women can and do have haemophilia.

The lack of recognition of an obvious condition can make it difficult for women with haemophilia to be taken seriously about their disease. This is not a small issue. It is estimated that there are up to five times as many carriers as there are men with haemophilia and at least one -third of carriers have factor levels below the normal range [making them not just a carrier but a women with a haemophilia diagnoses. Although not all of them have bleeding problems, a significant number of them do.

The Genetics Explained

Carriers have a defective factor VII or IX gene on one of their X chromosomes, which they can pass on to their offspring. All of the daughters of a man with haemophilia are carriers. On average, half of the daughters of a female carrier will also be carriers and half of her sons will have haemophilia. Women have two X chromosomes. Men inherit their X chromosome from their mother and their Y chromosome from their father. Women inherit one X from each. The factor genes are located on the X chromosome, so men have only one factor gene but women have two.

Because women have two X chromosomes, carriers usually have a second X chromosome that contains a normal factor IX gene. It is only the rare carrier who has defective factor VII or IX genes on both X chromosomes. These women unquestionably have haemophilia, even by old-school standards.

The More Common Situation

In the rest of this article, we'll focus on the more common situation of carriers with one normal and one defective factor gene.

The idea that women do not get haemophilia comes from the fact that most carriers still have one normal factor VII or IX gene. Reasoning that males with one normal factor gene do not have haemophilia, it was thought that most carriers should also not have haemophilia. However, this reasoning is faulty because it doesn't take into account that even though every cell in a carrier's body contains a normal factor VII or IX gene, those genes are not all active.

Having two copies of every gene on the X chromosome could cause problems, so the body can inactivate one of the two X chromosomes in women. Therefore, a carrier's cells will only contain one active factor gene; the other one on the inactivated X chromosome will not produce any factor VII or IX. This process is called ***X chromosome inactivation*** or "lyonization."

Lyonization is normally a random process, so each cell has a 50-50 chance of having the active factor gene be the normal one. Thus, a carrier will usually have approximately half of the amount of normal factor that a non-carrier woman has and just based on factor levels, carriers can have anything from severe haemophilia to no bleeding problems at all.

No one knows why one carrier might have a factor level of 25%, for instance, and another have a level of

150%. For persons without haemophilia, the actual level appears to depend on parameters such as blood type and body mass index, but those parameters do not seem to affect levels for men or women with haemophilia. One thing that does appear to cause the extremely low factor levels seen in some carriers is a phenomenon where the lyonization process may preferentially inactivate one of the X chromosomes. If the X chromosome that is inactivated in more cells is the one with the normal factor VII or IX gene, the carrier will primarily produce defective or no factor. She will

thus have a much lower level of normal factor in her blood than would be the case if the inactivation were 50-50.

Carriers with low factor levels bleed the same way and have the same kinds of problems as males who have haemophilia and similar factor levels. They are susceptible to easy bruising, joint damage, and bleeding problems after dental and surgical procedures, among other things.

They can also develop inhibitors and target joints. In addition, some of these women have excessive menstrual bleeding, a tendency toward miscarriages, and excessive bleeding after giving birth. These are all issues that can be managed once it is accepted that they have a bleeding problem.

Bleeding in carriers can also be due to other bleeding disorders. Just because a woman is a haemophilia carrier does not keep her from having other bleeding problems. Some carriers, for instance, might have von Willebrand Disease (vWD), which is much more prevalent in the general population than haemophilia. Many of the symptoms are similar between some types of vWD and haemophilia, so proper testing is important to establish the actual cause.

In the past, carriers who exhibit bleeding problems have often been called “symptomatic” carriers, as though they have bleeding symptoms but are somehow different from males with actual haemophilia. They have haemophilia as shown not only by their bleeding symptoms but also by their genetics and factor levels.

One recent study has shown that carriers tend to develop reduced range of motion (ROM) in their joints, just like males with haemophilia. This indicates that they have suffered joint damage, presumably from bleeding into the joints. The reduced ROM gets worse with age and in general is worse in proportion to the carrier’s factor level—the lower her factor level, the greater the reduction in ROM.

A couple of the carrier studies have noted that women with factor levels in the 40–60% range sometimes do have bleeding problems and joint damage. The reason for this is also unknown, but a similar occurrence can happen in men — the factor level does not always predict the severity of bleeding symptoms.

With the recognition that carriers can have significant bleeding problems and suffer joint damage, it becomes more important to identify them, assess their bleeding tendency and offer them treatment, if needed. Several studies have shown that women with bleeding problems are usually identified later in life than men, often not until their teens or later, depending on the severity of their condition.

Many HTCs offer carrier testing, but often not until a woman has reached adolescence. Since it is now known that joint damage can start to develop undetected at an early age, it would be beneficial to identify affected women early enough to help prevent those issues. Other reasons that it is beneficial for carriers to know their status include decisions about participation in sports, taking certain medications like aspirin, getting tattoos or piercings, and most of the other things that men with haemophilia need to consider. Iron deficiency anaemia also appears to occur more frequently in carriers.

More and Better Information Needed

The situation for women with haemophilia is slowly getting better, but there is still a lot of misinformation in the medical community. HFQ recognises that there are significant unmet needs among the women of the haemophilia community. A number of concerned medical professionals have also founded the Foundation for Women and Girls with Blood Disorders (FWGBD) *www.fwgbd.org*, which has a lot of useful information on its website. Hopefully, with continued advocacy, women will be able to receive the care they need.

Edited for size from an article by David Clark PhD called “Women with Haemophilia”. Published in Fall 2020 Factor Nine News https://www.hemob.org/factor-nine-news/2020/11/4/women-with-haemophilia

Fame on TikTok for VWD Nerf student

2.5 million Australians a month use the social media platform TikTok, which supplies users with an endless stream of videos. One of them is Sophie Jamison, or Sophie Lightning as she's known online. She uses TikTok almost every day to entertain her 1.4 million followers with creative 60 second videos about her passion; Nerf.

Nerf blasters may be marketed to preteen boys but they became a passion for Sophie after she was diagnosed with a blood disorder right as she was entering High School. She was a promising soccer goalie when she was diagnosed with Von Willebrand disease. Due to the contact involved in soccer she was advised not to pursue playing the sport.

Being diagnosed with von Willebrand Disease was definitely challenging because soccer was my whole life and all my friends were on the team. Unlike any normal kid, I have to take extra precautions and watch if I have a nose bleed or bruising. If a normal kid has that, then it's not a big deal, but for me it can definitely be serious.

Not one to stay idle for long she started playing more with the Nerf blasters around her house and the young teenager jumped on Instagram. She didn't like the idea of posting a selfie, so she opted to post pictures of Nerf blasters instead. What started more as a joke started to blossom into blaster reviews and serious knowledge of all things Nerf. Soon she reached 10,000 followers and her page caught the eye of the toy company Nerf who sent Sophie a package with a new blaster.

More exciting things continued to happen.

Sophie discovered the world of competitive nerf battles and started attending them. (She is very good.) She got invited to toy conventions and toy fairs. Sophie was also in a Nerf commercial and Nerf became her first official sponsor, meaning they would start paying her.

When Covid-19 hit, all of the events she was expected to attend cancelled. Bored she turned to TikTok in January this year and within a month started to have viral success. In 10 short months her followers grew, and along with it, her sponsorships.

But TikTok fame hasn't come without a price. Sophie said it was one thing for someone to say your hair looks stupid. But it's another thing when you're self-conscious about it, and then have people push that button 10 million times.

The hateful comments and trolls on TikTok got so intense, Sophie deleted the app from her phone and then she checked her private messages. There she found messages of hope from young fans. A boy told her he published a song on Spotify because of Sophie. Another fan said they wrote a book because of her. It was the light she needed so she returned to making videos.

Sophie doesn't read comments anymore but is always very aware of the influence she has and so she stays positive and kind along with having fun. Sophie says her biggest supporters have been her parents who have always encouraged her to be herself. "It's definitely not considered quote on quote cool to be playing with nerf blasters especially at my age," Sophie says with a smile. But that's the thing about Sophie, at 20 years old she is still loving being a "professional Nerfer" and she is not going to change for anyone.

What may look like child's play is something few other college students are able to do, turn their passion into a job they love. While not making a fortune, she's making enough to pay for her business degree, an apartment and "everything that that requires.

As for the future for Sophie Lightning, she is finishing up her degree, working on her podcast, 'Shooting the Foam' and has an internship lined up at Hasbro, Nerf's parent company. And she's still enjoying making TikTok videos everyday and connected with fans online.

Edited for size and local content from an article by Beth McEvoy of the Main News centre *https://www.newscentermaine.com/article/news/local/207/usm-student-sophie-lightning-attracts-fame-on-tiktok-for-all-things-nerf/97-b4b6c2ed-21a5-4f72-ba42-027e44a2bbcb*

Why Compliance Matters

Most children diagnosed with haemophilia learn to self-infuse factor at late primary school age. With the support of their parents, they usually do well with their treatment in childhood.

But when they get to high school, TAFE or university, time management can become an issue and sticking to prophylaxis can be difficult.

Just around half of nurses at haemophilia treatment centres (HTC) who were surveyed in a 2010 survey reported that adherence (taking prescribed doses on time) was highest among those younger than age 2 and lowest among those ages 18 to 24.

Staying on top of treatment regimens can prevent devastating consequences. Adherence is associated with fewer bleeding events—overall and in the joints—and a reduction in joint disease. What's more, it's linked to fewer sick days, decreased pain and a greater quality of life both now and into adulthood.

The goal is to prevent bleeding and the complications that come from it, and it's hard to do that if patients aren't infusing consistently, which leads to a world of difference in people with bleeding disorders who are compliant, compared with those who are not.

Getting Organised

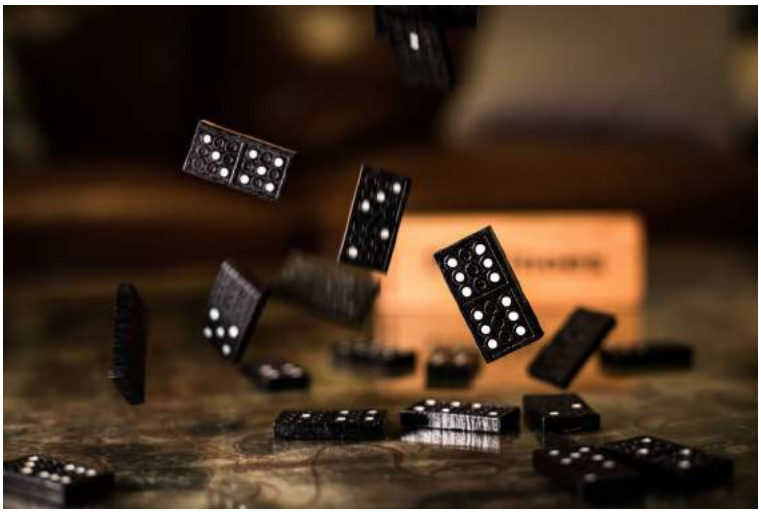
Haemophilia can be especially challenging. Patients need to know how to infuse factor, store it properly, discard medical waste and document infusions on MyABDR, while staying in close contact with members of their care teams.

Treatment logs like MyABDR are the foundation to proper care. Patients can use it to record bleeding episodes and treatments.

The logs are shared with your HTC and are important for developing the best treatment plan for yourself or your child.

Empowering Young Patients

Turning aspects of your child's care over to them is key to nurturing lifelong adherence habits and the transition can starts quite early. Every year your child can take on more responsibility, from learning how and when to infuse factor, to how to mix factor and so on.



Barriers to Adherence

The period of time that can be a real challenge for people to keep on the right track is adolescence. Early, proper treatment can be a victim of its own success. When you have somebody who's doing very well, they can forget what it's like to have problems. Then they might slack off on their treatment a bit because the last time they missed a dose, nothing happened. But it's the consistency that's important.

The overarching aim is for people with haemophilia (children and adults), to appreciate the importance and benefits of sticking with their treatment regimen. You want to feel that 'by doing this, you've helped yourself, not just because you have haemophilia.

How to Get the Most Out of a QHC Visit

Developing solid communication skills with providers can help them better manage you or your child's bleeding disorder.

Before your next appointment consider why you are going? It may be for your annual comprehensive visit, for evaluation of a bleed or for a follow-up after a bleeding episode.

Between appointments keep a running list of questions you have for your healthcare team and if you or your child has specific issues, write down when the problems occur, or if there is something that precipitates a problem. Clinic visits can be hectic and you will see a lot of providers. Remember to bring your notes with you!

Bring with You to the Appointment

A health history since your last visit. Bring any pictures you have taken documenting bleeding episodes, and don't forget your list of questions.

Names of prescription and non-prescription medications you or your child takes (Include vitamins, herbal remedies and pain medicines).

A notepad to jot down information.

If possible, bring a trusted family member or friend with you to the visit. This extra person will help you remember what was said, and he or she may ask questions you didn't think to ask.

Edited for size from and article by Beth Howard titled 'Why Compliance Matters When You Have a Bleeding Disorder' Published in Hemaware

https://hemaware.org/mind-body/why-compliance-matters-when-you-have-bleeding-disorder

Why Do I Bleed More?

One of the mysteries in haemophilia is that some people don't bleed as much as would be expected from their factor level. Studies have shown that 10 - 15% of people with severe haemophilia have a clinically mild disease with few bleeds and minor joint damage. Conversely, some people with mild or moderate haemophilia may bleed more like a severe patient. Even people in the same family, with the same defect, may bleed differently.

This is the difference between genotype and phenotype. Your genotype is your genetic makeup. If you have a mutated factor gene that only gives you an activity of less than 1%, we would expect you to have severe haemophilia and bleed a lot. Your phenotype is the set of observable characteristics of an individual. That is, our phenotype is what you actually are, no matter what your genotype says you should be (in our incomplete understanding).

Researchers are finally starting to understand why there is a difference. A big part of it apparently has to do with the variable levels of all the other clotting factors and anticoagulants in your clotting system.

Your clotting system is a large collection of proteins and other molecules that causes your blood to clot. The proteins include clotting factors that promote clotting and anticoagulants that inhibit clotting to provide control for the system. In a person without a bleeding disorder, everything is in balance, so the blood clots when it should and doesn't clot when it shouldn't.

We tend to assume that if we have haemophilia, we only have a defect in our factor level, but everything else is the same from person to person. It's not, in medicine everyone is different. This is where the phenotype versus genotype differences come from. For instance, we say that the normal range for factor IX is 50 - 150% of average. That's quite a big range, and it does make a difference. A person with a 150% level will clot much more rapidly than one with 50%, even though both clot quickly enough that we call them "normal."

Many of the other clotting factors and anticoagulants also have wide "normal" ranges from person to person. The clotting system can't correct for a complete lack of factor, but it can partially correct for the smaller decrease in factor activity in mild and moderate haemophilia. With a little outside help, it can even work adequately for severe haemophilia.

We are starting to see some restore haemostasis with the new nonfactor products being developed. In haemophilia the balance in the system is disturbed, leaving too much anticoagulant activity. By reducing the anticoagulant activity researchers are showing that they can tweak the clotting system to restore haemostasis achieve adequate, controlled clotting.

Several companies have shown that by inhibiting tissue factor pathway inhibitor (TFPI) they can restore haemostasis in haemophilia patients. What if a severe haemophilia patient naturally has a lower amount of TFPI in his blood? He might not bleed as much — he might have a milder bleeding phenotype. It appears that the many of the genotype/phenotype differences come from differences in the levels of all the clotting factors and anticoagulants in one's blood.

A group of researchers looked at the levels of various clotting factors and anticoagulants in 40 haemophilia A subjects, 32 haemophilia B subjects, and 40 subjects without bleeding disorders. They measured each person's bleeding tendency and found that the more thrombin generated, the more clot created. They also found that factors were positive influences on thrombin generation; and anticoagulants, were negative influences. TFPI (and anticoagulant) was the strongest inhibitor and had the largest person-to-person variation.

The difference between genotype and phenotype comes down to the differences in the amounts of all the clotting factors and anticoagulants in a patient's blood, not just factor. If we expanded our concept of the genotype to include some of those other genes, we could probably establish a measure that would give a more accurate picture of true severity. Until then, your phenotype is what you really are; your single-factor genotype is just an approximation.

Edited for size from an article by David Clark PhD called "We're Both Severe... Why Do I Bleed More? Published in Winter 2019 Factor Nine News https://www.hemob.org/newsletter-archive

Australia Day Fun Day

@ KINGPIN Westfield Chermside

in air-conditioned comfort
& our own party area
Free parking, free food,
TEN PIN BOWLING,
and Laser Tag.

$15 per person
(max of $50 per family)

11.00am on Sun 24 January

RSVP's essential
by 15 January
on 0419 706 056

HFQ Fun Day for all the Family

Carrier Clinics at QCH

Did you know that Joanna is holding carrier clinics? These clinics are for any of the young girls or young adolescents who have a brother with haemophilia, a mother who is a known carrier or have a father who has haemophilia and have not yet turned 16 years of age. The clinic is Thursday afternoon's at the same time as the regular haemophilia clinic.

The focus of this clinic is education about haemophilia and preparation for genetic testing to confirm or exclude carrier status. Joanna will discuss in an age friendly way current and future treatment, inheritance of haemophilia, chance of being a carrier, difference between factor levels and genetic testing and why it's important to have your factor levels checked.

If you are interested please see your GP for a referral to Joanna McCosker, Nurse Practitioner Carrier Clinic at Queensland Children's Hospital. You can also be seen via telehealth or potentially outreach if we can get available rooms.

Our summer social event is TenPin Bowling & Laser Tag at KingPin Chermside. HFQ's Fun Day is for everyone, whether you are on your own, or with the family.

KingPin have private lanes and a lounge area exclusively for us on the Sunday before Australia Day. There is free parking for the first couple of hours and it's air-conditioned They also have arcade games you can add to your experience for $8.00 extra.

We'll meet at 11:00 for food, drinks and a chat in our exclusive lounge, then we'll have a go at Bowling on our own lanes and laser tag, after which you can stay for as long as you want.

To register your place go to *www.hfq.org.au/get-involved/events/summer-social-event*
or call or email us on 0419 706 056 or *info@hfq.org.au*

Keeping Memory Sharp as You Age

Don't assume that as you age, so-called senior moments have to become a part of your future. Sure, everyone misplaces the keys occasionally. But by taking steps to maintain your brain health, you can keep your memory sharp, helping you to continue living independently and enjoying life to the fullest.

Having a bleeding disorder doesn't make you more or less likely to experience age-related memory issues, but no doubt you and your loved ones will feel more confident in your ability to manage your condition if you make brain health a priority.

If you're truly serious about it and you're ready to be proactive in taking care of yourself to decrease the odds of memory loss, there are lots of things you can do.

Eat right

Eat whole foods rich in brain-healthy nutrients. Berries, leafy greens, fish, nuts and seeds all contain vitamins, minerals and other compounds that studies show are associated with slower cognitive decline.

Don't try to take a shortcut to eating well by relying on claimed brain-health dietary supplements as most older adults don't benefit from such supplements. When thinking about food, change your view from 'oh, this is tasty and delicious' to thinking about how nutrition selections can benefit you.

Exercise

Regular physical activity can help keep you fit and mentally sharp by increasing blood flow to the brain, reducing inflammation and strengthening areas of the brain thought to be involved in memory.

Any type of blood-pumping activity is really good for your brain. Incorporate activity into your day and do something to help yourself be less sedentary.

Sleep enough

Most people need between 7.5 and nine hours of sleep. Sleep-deprived people have trouble concentrating and are more likely to make mistakes, especially behind the wheel or when handling machinery. Prioritising sleep helps boost your cognitive ability and stay neurologically healthy.

Avoid stress

Too much stress may hamper your cognitive abilities over time. When possible, pick ways that you can decrease your stress and anxiety and learn some coping mechanisms. Meditation, deep breathing—all of that helps.

Manage your health

If you're diagnosed with diabetes or another chronic condition, it's crucial to consider your bleeding disorder while managing that additional disease or complication. Talk to your haematologist or QHC team because some medications may cause cognitive side effects.

Stay engaged

Maintain social connections as you get older, because isolation may lead to depression or cognitive decline. And challenge yourself intellectually with games such as crossword and sudoku puzzles, which encourage your brain to function optimally.

Be a lifelong learner, and be curious and willing to be engaged. These things can stimulate and keep us challenged with our cognitive abilities.

Edited for size from 'Keeping Memory Sharp as You Age Helps You Manage Your Bleeding Disorder' by Lisa Fields *https://hemaware.org/life/keeping-memory-sharp-you-age-helps-you-manage-your-bleeding-disorder*

World AIDS Day 2020

World AIDS Day is marked globally on 1 December.

The theme for World AIDS Day in 2020 was Now more than ever. For the bleeding disorders community this is a profoundly meaningful message.

1 December is a day when we are especially mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA's recent Getting Older report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The Getting Older report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the Getting Older consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

'There needs to be a concerned education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

TAKING ACTION

On World AIDS Day we are encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the Getting Older report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events. Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action – and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.

Long-acting injectables for HIV treatment

The European Medicines Agency (EMA) last month recommended approval of cabotegravir (Vocabria) plus rilpivirine (Rekambys), a long-acting injectable regimen which must be administered by healthcare providers. every one or two months to treat HIV.

The injectables have been under study for several years, in both phase 2 and phase 3 studies.

Of the 274 original participants, 34% were still receiving monthly injections and 49% were still receiving injections every other month five years later.

Over the five years of the phase 2 trial, 96% were given within the allowable seven-day window of the scheduled dosing date. Results were similar for the monthly and every-other-month schedules.

In the two studies combined, 313 of the 354 injection visits that had not taken place within the seven-day window ended up being done within the week that followed. None of the 41 injections that occurred more than 14 days after the scheduled date resulted in a case of confirmed virologic failure.

Eighteen participants in the two studies 31 people missed injection visits that were foreseen in advance. All but one were covered by substituting daily oral doses. All those who did so still had an undetectable viral load when they resumed injections and at the end of the study period.

One person used oral drugs to cover planned missed injection visits on seven times due to frequent work travel.

"The use of oral cabotegravir plus rilpivirine to bridge planned missed injection visits provided an effective strategy to maintain virologic suppression during short period of long-acting treatment interruption," the researchers concluded.

Many people on stable HIV treatment only need to see a clinician once every three to six months, so injections that must be administered by a provider every month or two (in the buttocks, which requires a degree of privacy) could strain health care resources.

In a study of health care worker attitudes to providing the treatment, researchers conducted qualitative interviews before clinics started offering the injections and again after patients had received their fourth jab.

At the outset, a majority of providers expected the injectable regimen would meet patients' needs. Perceived advantages included reduced stigma related to pill bottles (38%), ability to live or travel without worrying about carrying or losing pills (31%) and removing the daily reminder of having HIV (20%).

However, some providers and administrators had initial concerns about implementation, including staffing, scheduling and space allocation. At the four-month analysis, most providers said these concerns were surmountable. A majority of staff (71%) reported no changes in official clinic hours, but some noted the need to adjust hours to accommodate injection visits before the clinic opened or at lunchtime.

The respondents recommended identifying designated rooms for injections, identifying a person to track appointment schedules and creating a system for rescheduling and reminders. They found it was helpful to schedule visits during the early part of the monthly treatment window to allow time for rescheduling if needed. About one in five clinics needed to purchase a suitable refrigerator to store the injectable drugs. The participants favoured face-to-face, rather than virtual, injection training, especially given that many HIV providers do not routinely give injections.

Nearly half of the staff members cited the high rate of patient acceptance of the injectables, and they said that such positive attitudes on the part of patients heightened their desire to offer the treatment and facilitated successful implementation at their clinics.

"Overall, study participants viewed operationalising long-acting cabotegravir plus rilpivirine as an important and achievable goal that will facilitate patient preferences and treatment adherence," the researchers concluded. "Staff members are optimistic that monthly long-acting cabotegravir plus rilpivirine is manageable with minimal disruption to routine HIV care in US settings."

ViiV plans to do another round of surveys after a year of providing injections, which will include any impacts related to COVID-19. A similar study called CARISEL, which is evaluating implementation of the long-acting regimen in European healthcare settings, started in September and initial results are expected in 2021.

Edited for size from an article by Liz Highleyman
https://www.aidsmap.com/news/nov-2020/long-acting-injectables-appear-feasible-long-term-hiv-treatment

Health Updates

von Willebrand Disease False Levels, Misdiagnosis Still an Issue

Significant discrepancies between onsite and off-site processing were found in von Willebrand Factor (VWF) samples from women who were tested for VWD according to recent study.

The retrospective study assessed the number of post-menarchal women with inconsistent VWF testing results between off-site and onsite processing.

A total of 263 women were included in the analysis. 72% of women were referred for testing by a physician because of heavy menstrual bleeding, followed by easy bruising (37%), and nose bleeds (30%). GP's and obstetricians/gynaecologists were the most frequent referrers (63% and 24%, respectively).

Low VWF antigen was reported in 38% of samples processed off-site and 22% of those processed onsite. Similarly, FVIII levels were confirmed lower in off-site processing compared with onsite processing (29% vs 13%, respectively).

The investigators noted that heavy menstrual bleeding has been recognized as a symptom of an underlying bleeding disorder, which has led to an increase in evaluation, diagnosis, and treatment of bleeding disorders in this population.

The authors concluded that these results highlight the need for VWF testing to ideally be both drawn and processed with little delay at laboratories with onsite processing under the guidance of a haematologist.

Jaffray J, Staber JM, Malvar J, et al. Laboratory misdiagnosis of von Willebrand Disease in post-menarchal females: a multi-center study [published online May 17, 2020]. Am J Hematol. doi: 10.1002/ajh.25869

Global Dosing Hold in Fitusiran Trials Initiated by Sanofi Genzyme to Investigate New Adverse Events November 5, 2020

Sanofi Genzyme has initiated a voluntary global dosing hold on its full clinical development program for fitusiran due to the identification of new adverse events. It is not the first time that studies of fitusiran have been halted due to thrombotic events. In September 2017, ongoing trials of fitusiran were halted following the death of a 78-year-old man with hemophilia A in the mid-stage open label extension. The U.S. Food and Drug Administration lifted the hold a few months later after reaching agreement on new clinical risk mitigation measures.

Fitusiran is a once-monthly, subcutaneously administered investigational non-factor-replacement therapy that uses an interference mechanism known as small interfering RNA (siRNA) – sometimes known as silencing RNA – to target and reduce antithrombin, thereby promoting sufficient thrombin generation to restore hemostasis and prevent bleeding in patients with hemophilia A or B, with or without inhibitors.

https://endpts.com/sanofi-hits-the-brakes-on-a-top-pivotal-program-following-new-adverse-events/

Scientists find potential new way to improve treatment for Von Willebrand Disease

Patients with Von Willebrand Disease have a deficiency or dysfunction in a protein that plays a key role in clotting blood. The current treatment for the disease is to frequently inject patients with a drug that promotes the production of this protein or with concentrations of the protein itself.

The study, published in the Journal of Thrombosis and Haemostasis tested a modified molecule that extends the life of the clotting protein within the body's circulation. Their study found that administering this modified molecule significantly increased the half-life fivefold compared to the unmodified protein in laboratory models.

RCSI University of Medicine and Health Sciences
Journal reference:
Fazavana, J., et al. (2020) Investigating the clearance of VWF A-domains using site-directed PEGylation and novel N-linked glycosylation. Journal of Thrombosis and Haemostasis. doi.org/10.1111/jth.14785.

Hemlibra Safely Treats Children

Prophylactic (preventive) treatment with Hemlibra safely and effectively lowers bleeding rates in children and adolescents with severe haemophilia A, according to a recent study The study published in the British Journal of Haematology.

These findings support Hemlibra's use in the haemophilia A paediatric population, regardless of inhibitor status.

Researchers evaluated the safety, effectiveness, and monitoring of Hemlibra prophylaxis in children with a median age of 5.5 years (range: 1 month to 18.5 years). Nine were less than 1 year old. Who has severe haemophilia A, regardless of inhibitor status.

Results showed that 50% of patients had trauma-related bleedings during the study period, with no reports of spontaneous bleedings. Most bleeding episodes were treated with a single dose of factor

https://onlinelibrary.wiley.com/doi/epdf/10.1111/bjh.16964

Packing for an Emergency

With the emergencies we have all faced in 2020, the need to be prepared is again highlighted. Bushfires, Floods and a Pandemic. In the event you need to evacuate in a hurry, or you may be without power and clean water, a little planning now will spare you precious time.

Where do you begin to prepare for an emergency?
For starters, it is good to have a minimum of three days of supplies at the ready.

A "go bag" is an emergency bag you pack in advance, but hope you never need. Ready packed, you can just "go go go".

Find a bag that is sturdy enough to carry essentials, with a little spare room. A plastic storage tub can also be useful to readily store some of the supplies listed below. Some may already be in your camping equipment. Place reflective tape on watertight containers or bags to easily find them in the dark.

Consider that electricity and drinking water may not be available.

The Car
Keep your car fuelled topped up so you can leave without delays at petrol stations.

It's a great idea to have a first aid kit in the car, and sun protection and insect protection. Water and snacks in case you are stopped on route. A Hi-Visibility vest is also a useful item to have on hand. In your first aid kit, make sure you have facemasks, zip lock bags for soiled masks, steriliser and disinfectant. (Take care how you store the steriliser and disinfectant, particularly in hot weather). Consider a small bag you keep with your keys or the toiletry pack which is packed and ready to go, but stored at your home, and kept out of the heat).

Medicine and medical supplies
Don't forget your medications. Try to keep at least a few days supply on hand in case you have to leave in a hurry. Pack extra amounts of medicine and supplies in the event that your return home is delayed.

Label all medicine and medical supplies and pack them separately in a carry bag or small esky. That way you will have your items with you and you will be able to use your items at any time.

Essentials - Items to pack
For a good packing List go to *https://www.ideas.org.au/images/*

Christmas Closure

The HFQ Office will be closed over the Christmas / New Year period, commencing Thursday, 24th December 2020 at 12:00pm, and reopening on Monday, 4th January 2021.

We wish all our readers heartfelt and warm wishes for the summer holidays and the new year to come. Merry Christmas from Graham, Sam and the board and we look forward to seeing you at one of our events in 2021.

If you have anything urgent, please leave a message on the office mobile and we will endeavour to get back to you as soon as we can.

5 Minutes goes to Youth Camp

Youth Camp was held over a weekend during the September school holidays this year. Adam was one of the participants at Youth Camp and we asked him a few questions...

What was your favourite activity at camp?
I loved the Mud run – the very first time I went (I was only 8 years old) I hated the mud.. now I love it.

What were the meals like at camp?
really good for camp food.

Did you do anything you've never tried before?
No, don't think so, cannot remember

Tell us about your fellow campers?
There were only a few boys and two girls. Most of them came from around the Brisbane area, they were between the ages of mid to late teens. As well as a couple of older boys – Kyle, Darrian, Craig and the other Adam

Tell us about the staff at Emu Gully?
The staff were very nice. Nothing fun or wacky.

What did it feel like to be around other people with a bleeding disorder?
I liked it. It was nice not being the only one. It was good listening to their stories, particularly about their bleeds because I don't get them even though I have severe haemophilia. I asked Adam about what it was like to experience a joint bleed – dumb question…. I'll have to ask someone else.

Amongst the fun activities, what was the coolest activity you did?
I've been going to Youth Camp for years. At first I thought it would be boring doing the same thing over and over again… but you know what to expect and it's fun. Now that I am older I can drive the buggy …but the coolest activity was Laser Tag

Adam helping his fellow campers during the mud run.

What did you do outside of the activities - was there time to talk about infusion or other things related to your bleeding disorder?
We chatted to each other and we played games and we talked about the basic things, injections and we learnt about Hemlibria

Did something or someone change how you think/feel about having haemophilia? In what ways?
Kyle – I didn't realise you could get so many bleeds and problems with your joints. He has been through a lot because of Haemophilia. I didn't realise how lucky I really am.

Did anything happen at camp that felt life-shaping – or even life-changing – for you?
I'm growing up… I'd like to be a youth leader when I get older… I would like to help the younger children, talk to them about haemophilia and how it 'just is' something we have to live with but it doesn't define who we are.

What challenged you?
All the activities gave me a good challenge even though I had done most of them before. I still liked them.

What do you think will stick with you?
The friendships that I made on this camp and previous ones. Going from youth camp and then a couple of weeks later going to family camp… that was good.

What did you enjoy this year more than past years?
Being with my friends again as we only get together once or twice a year at haemophilia camps.

What do you love now that perhaps you didn't as a younger camper?
More confident in going, remember the people and activities.. I look forward to it… cannot wait till next year.

What have you now found about yourself?
I'm no longer the youngest…. I can help the others

What would you say to someone considering coming to youth camp?
Youth camp is really fun, you get to socialise with other people that have haemophilia and you can try different things to challenge yourself and make some great friends.

Important Dates for HFQ Members

Covid-19 is still a concern and all HFQ activities are subject to social distancing and other covid-19 restrictions that may apply at the tome of the activity.

OBE Men's Forum
First week of the Month
Call for details

Australia Day Social Event
24 January 2021

Women's Brunch / Lunch
Sunday, 7 February 2021
Everton Park Hotel

Rare Diseases Day
28 February 2021

Paint it Red Art Workshops
February & March 2021

ArtExhibition
5 - 30 April 2021

World Haemophilia Day
17 April 2021

Please ask for events and activities happening in your area.

Please call Graham at the office on **0419 706 056** for more info on any of these events and activities.

Art Workshops

Are you a budding artist or someone with years of experience in your art?

We are planning several introduction classes in different modalities of 'art' from Flow Art and Fluid Painting, to origami or photography. These workshops will help you convey your own ideas and energy into your art work. All art materials included. All you need to do is book in, rock up and enjoy the creative experience!

We'd also like to hear from you if you are an experienced artist we'd also like to hear from you if you would like to co-facilitate a workshop session.

You can then enter your creative work in our World Haemophilia Day Art Exhibition during April in the Art Space at RBWH. We have limited space for ceramics/woodwork/other items which are unable to be hung, but plenty of wall space for art to be hung using the theme "RED".

All visual artists (whether they have taken part in a workshop or not) are welcome to submit work for this display in the RBWH Art Space (limited space for items that can not be hung)

All art work must be submitted by the 29th March 2021. Please contact Loretta at the Queensland Haemophilia Centre – Phone 3646 8769 or Email loretta.riley@health.qld.gov.au (or via RBWH-haemophilia@health.qld.gov.au with Attention Loretta in the subject line) if you would like to exhibit work.

Please RSVP to info@hfq.org.au or call 0419 706 056 for information or to register your interest.

About The H' Factor

The 'H' Factor is published four times each year by HFQ by the HFQ manager and assisted by Brett Williams, our communications volunteer. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

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