the FACTOR

Issue 64

Spring 2020

Newsletter of Haemophilia Foundation Queensland

From the President

Hi folks, I hope you are all well, so far we have not had any reports of our community experiencing COVID-19 issues and we want to keep it that way - so keep up those safe practices everyone!

This month I wanted to raise the discussion of GP's and what can occur when you're away from home and have to see a new GP where internal bleeding is involved. It can be a difficult situation if the GP has no experience with haemophilia - you have a very short time to tell your story and misunderstandings can easily occur, doctors are not mind readers, so you have to get your point across describing your symptoms and the normal medical treatment.

One tip is to always carry a letter from your treatment center along with a list of the medications you take to make it easy for the GP. You can also take someone along with you as an advocate to assist if required. But sometimes all of this does not work and the GP wants to do a battery of tests with x-rays etc., to confirm the bleed before any treatment. If the discussion gets to this point and there is still little understanding, (this was my experience recently when I just needed pain medication for a bad bleed), then it's perhaps time to thank the GP and find another. With better patient focused training these days we can expect to see less of these issues in future.
Until next issue, take care and stay safe!

David Stephenson
President HFQ
president@hfq.org.au

Inside this issue:

Cover photo: Owen Wilson Photography https://owenwilson.net.au

HFQ Library and Member Resources

HFQ maintains a small library of books and resources related to inherited bleeding disorders for people with a bleeding disorder and their support people, including parents and carers, clinicians and students. These cover topics such as: von willebrand disease, haemophilia, pain relief, diet, exercise, blood borne viruses, alternative therapies and children's books.

We also receive newsletters and magazines from allied foundations as well as subscribing to Haemophilia, the official journal of the World Federation of Haemophilia (published by Wiley-Blackwell).

HFQ also stocks the full range of published resources by Haemophilia Foundation Australia such as the information kit for newly diagnosed families, as well as general information booklets for parents.

At HFQ we are dedicated to the sharing and exchange of information and education materials on inherited bleeding disorders among our members, and we will continue to access and share local and overseas literature on behalf of members. So all our books, magazines and audio -visual material are available for loan to members.

The collection can be accessed in person at our Brisbane office next to RBWH in Herston or across Queensland through our mail delivery service provided you are a financial member.

A large range of publications are also available for download through the publication tabs on Haemophilia Foundation Queensland's website at www.hfq.org.au. We will also get in materials at the request of members if they are deemed suitable by the HFQ board.

The list on this page includes only some of the books, DVDs and educational resources currently available for people with a bleeding disorder. Please contact the HFQ Office on 0419 706 056 or email info@hfq.org.au for information about other resources.

- First Factor illustrated series of books for kids published by LA Kelly. (2008)
- Haemophilia - The official Journal of the WFH. A quarterly scientific publication
- Inspire DVD on Tai Chi and Yoga for adults with bleeding disorders
- Female factors, a booklet for young women with bleeding disorders (2018)
- Raising a child with haemophilia - a practical guide (2016)
- Managing your child's inhibitor (2010)
- Injection of Life an autobiography by Robert Weatherall (2014)
- Success as a Haemophilia leader (2008)

Disclaimer: All articles, advice and information included herein are written by various individuals who volunteer their input. While the 'H' Factor magazine puts every effort into providing honest and accurate information and where possible, reference to research articles are made to validate content, it cannot be held liable for any errors or inaccuracies in published articles. The views expressed in this newsletter are not necessarily the opinions of the Editor, their associates or supporters. Publication of contributions will be at the discretion of the Editor. Any articles containing racist, sexist, homophobic or defamatory remarks will not be published. Other original contributions and letters are welcomed and encouraged. Articles in the 'H' Factor cannot be reproduced without permission.

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 LCCH-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 LCCH-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 2e outpatients Level 2, Thursday afternoons 1.00 – 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

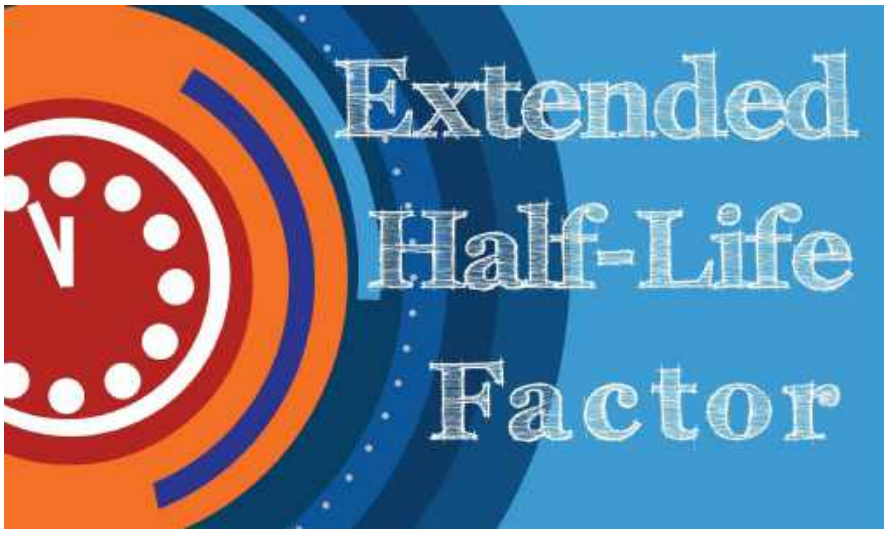
OUTREACH CLINICS

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

Transition to Extended Half Life Products

A message from the Adult and Paediatric haemophilia teams.

Finally the National tender was announced 2 months ago which now allows us access to the extended half life products.



There are many of you that will require transition to the new factor 8 (Eloctate or Adynovate) and factor 9 (Alprolix).

The transition process has many layers involved which are unfortunately quite time consuming but we hope to have transition completed within the next 4 - 6 months. In the last 8 weeks we have swapped 6 paediatric patients with preparation of 4 more swaps currently underway.

A sneek peek into what is involved:

- Planning meetings to make decisions regarding what stock will be held in QLD hospitals to maximise safety and minimise product wastage
- Patients prioritised due to high clinical need in the first instance e.g. those on every 2nd day & difficult venous access
- Otherwise we will talk with you about the products and treatment at your next clinic review
- Depleting stock across QLD pharmacy's and hospital emergency departments of Advate, Xyntha, BeneFIX
- Depleting your stock at home
- Preparing new home delivery forms/ scripts and cancelling your old orders.
- Replacing Eloctate & Alprolix into all QLD hospital and pharmacy's
- Preparing new treatment plans and ordering new ABDR treatment cards

We thank you all, for your patience as we work as fast as we can to transition all of QLD & NNSW onto extended half-life products.

Regards the Haem teams

Make Us Your FaceBook Fundraiser

Please consider nominating HFQ as your FaceBook charity fundraiser. A big thank-you to everyone who has previously nominated HFQ as their Birthday Fundraiser. Every dollar counts and you have raised as much as a Bunning BBQ for us, without the need to do the hard work!

P.S. Once your fundraiser has ended, please let us know the details of the people who donated to your birthday fundraiser, as FB only tells you that information. If we know the donors name and amount, HFQ will then be able to personally thank each individual donor and provide tax receipts.

Struggling?

It's Monday morning (in mid September) and to be perfectly honest with you, I have been struggling to write an article for this edition of The H Factor. I am in fact surprised that Graham hasn't sent me a reminder email/ phone message to tell me my article is well overdue. I haven't been able to put any ideas together for the topic I had semi-planned to write about – to paraphrase Marie Kondo "It has not sparked joy", so I will leave that idea on the sideline and re-consider it for a future edition.

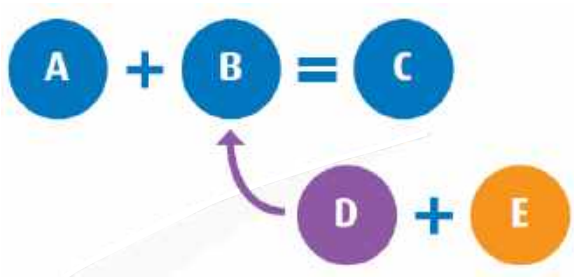
As some of you know, I am in the midst of making 2020 as a year to really engage in my learning– I have just completed a Certificate in Creating Positive Change and am in the middle of a Diploma in Positive Psychology and Wellbeing. Both courses have begun to lead me down a new path of how I practice Social Work – watch this space for some new opportunities!

The challenge with change is, that implementing the strategies involved in bringing about change in this space is not something that just happens to you – it is an active process – that sometimes feels uncomfortable, but when you put in the effort and the work, amazing and magical things can happen.

In my 'virtual class' last week, we discussed Martin Seligman's research on learned helplessness and learned optimism and were provided with an equation – (please don't freak out if maths isn't your strong point –stick with me for a bit longer).

A= Adversity
B= belief
C= Consequences

If this looks familiar, this is based on work by Dr Albert Ellis and Cognitive Behaviour Therapy. So, during the course of the class the equation changed a bit to



D= Distraction or Dispute (what is the evidence, the alternatives, the implications or the usefulness)

E= Engage or Energise – positive feelings, behaviours and actions that can follow.

What does this all mean and why am I sharing equations with you all? I believe that following these steps may help us all when we are struggling with a challenging situation. So, let's use writing this article as an example, to see what it looks like in reality.

The **adverse event** could be:- I haven't written my article on time for the Spring edition of H Factor.

My **belief and thoughts** could be – I am hopeless, I never get these articles in on time, Graham must be very angry with me. I am in so much trouble. My month is ruined.

Consequences – I might not do the article, I might avoid taking calls from Graham and ignore his emails, I might feel very down and have self talk that is not at all helpful around my actions and myself which will then bring my mood down.
So, adding in D – I might

Distract myself – going away and doing a quick walk before coming back to work on the article (as long as I don't use it to further the procrastination);
or more usefully in this case I may **Dispute** the thoughts and beliefs – am I really hopeless? (hopefully I am saying no as are all of you!) What is the evidence to support me being hopeless? Is it true that I never get any articles in on time? What is the evidence to support that? Where is the evidence that Graham is angry with me? Is this thought useful if I continue to think in this way? What are the alternatives? I can then add in the 3 P's also described by Martin Seligman to help me with disputing my thoughts and beliefs.

Is this issue **permanen**t? In this case, no – it is only temporary and will improve once I finish the article.

How **pervasive** is it? This situation is not impacting on all areas of my life, it is very specific to this issue. It is only one element (which is in reality a

To next page ⟶

Vale Michele Albert 25/6/65 to 7/8/20

It is with much sadness that we note the passing of Michele Albert who died in her sleep on 7 August 2020.

Michele was a long-time member of Haemophilia Foundation Queensland, past board member, wife, mother, grandmother and friend to many. Her son Sam was about 4 when Michele and her husband David joined the HFQ board in the early 2000's, with Michele eventually becoming president during her time of the board.

Michele was active in this roll until about 2010 and remained an active participant in HFQ activities. We are pleased that this legacy continues with her daughter Lauren who is currently on the board as HFQ secretary.

Our thoughts and prayers are with her husband David; daughter Lauren; son Sam and granddaughters Ruby and Layla.

Michele & David at the Banyo Picnic in the Park event 2018 ⟶

Struggling? *Continued from previous page*

small part) of my working day.

Personalisation – I must admit – I did have control over when I wrote the article and what I wrote, but there have been some outside factors, external to my role in the delay, which have impacted on my ability to complete it in a timely fashion. The 3 P's run on a continuum and they will change depending on where you are in the issue and what the issue is.

I have marked on the continuums where I feel I am for each of the 3 Ps today:

Permanent ——X—— Temporary

Pervasive ——X—— Specific

Internal ——X—— External
(personalisation)

There is no right or wrong answer to where you mark the continuum, but it helps put things in perspective. Sometimes when you are caught in the middle of an issue it can feel like it is taking over every part of your life and will never change, but when you look at it from a different view point, ask yourself some challenging questions, write it down or draw it up – it may help to assist your perspective to change, give you an alternative viewpoint, flip your perception and can help you to have some new ideas and solutions.

Energise or Engage – so, I am sitting down, taking action and writing the article, before I do any of the other items on my 'to do list' and before I have lunch. Just starting it has made me feel energised and more positive about having begun. My other follow up action could be that I start writing the next article whilst I am on a roll and get that finished early too (ok, that is being very, very optimistic and perhaps not too realistic).

You can see that by adding in D (Dispute) +E (Engage), I have changed C (the consequence). My article is now written, I don't have to avoid Graham's calls, my self talk is positive (although you will have to take my word on that one) and I am feeling able to tackle the other jobs on my to do list.

I hope that this may offer you another strategy to put in your toolkit to manage challenges when they occur. Please feel free to contact me if you want to discuss this strategy more, ask some questions and/or have a practice at trying out the process.

Loretta

Advanced Social Worker
RBWH
Ph: 07 3646 8769

(Ref: Thanks to Langley Group Institute for the graphics and the class)

Bleeding Disorders Awareness Week 2020

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of 11 - 17 October 2020.

With HFA, we are also rolling out a virtual campaign during the week which this year is themed "One Community, Many Faces". We will showcase our community and highlight the many different bleeding disorders and experiences.

These days we need not only members affected by bleeding disorders, but also continued awareness of the general community to keep generating funds and maintain their interest and support for the work we do.

How about you? One Community, Many Faces is a wide theme and you could use it in many ways to raise awareness of bleeding disorders and the impact it has on people in our community. HFQ has some pens and balloons, as well as pamphlets and other resources that we can make available as well as the HFA materials that are downloadable online.

Have a look at some of the ideas in the box at the end of this article or come up with your own way of informing your local group or community about the reality of life with a bleeding disorder.

Raising Funds

As a not-for-profit charity we need money to keep going, so why not help us by raising funds as well as awareness? As the list shows, you can organise a cake day and other events. But you could also try a garage sale, mini concert, or start a crowdfunding campaign. There are so many options for raising funds these days, our list is just a few suggestions. All you need is the right motivation and a little creativity.

Bleeding Disorders AWARENESS WEEK

Donate

Don't think that donations are limited to cash – you can donate goods for our eBay store, or stocks and bonds if you have them.

Volunteer and Participate

If you have the time, volunteer for us in your area or participate in our events to support other members.

Talk About It

Social media is a powerful tool for spreading awareness and nothing can be more believable than people who are campaigning and supporting a cause that they have experienced first-hand or through a loved one.

Share your story online, accept speaking engagements should you be invited, or speak out during meetings. You will lend credibility and strength to our cause.

Research

A well-informed advocate is the best kind. You can answer questions from interested parties, debunk myths, and further educate your local community.

Recruit Supporters

The more people who know about and support our cause, the more we can advocate and further our mission.

Approach your local member of parliament and ask if they can be part of your advocacy. If they understand why it's worth supporting, then they can aid us in getting additional funding.

Your unique way of supporting Bleeding Disorders Awareness Week can have a positive impact if you're consistent and honest.

Do something today and start building awareness so that it can be turned into action in the near future.

For downloads and information visit www.haemophilia.org.au or contact the HFQ office by email at info@hfq.org.au or call us on the mobile 0419 706 056

GO RED FOR BLEEDING DISORDERS

Looking for something to do during Bleeding Disorders Awareness Week either face to face or virtual? Host a red-themed event and **Go Red For Bleeding Disorders**! Some quick ideas are:

- Host a red-themed morning tea
- Host a Red Cake Day
- Dress red for a cocktail night
- Host a red themed crafternoon
- Wear red in support of the day

More information and ideas will be on *www.haemophilia.org.au/BDAW*

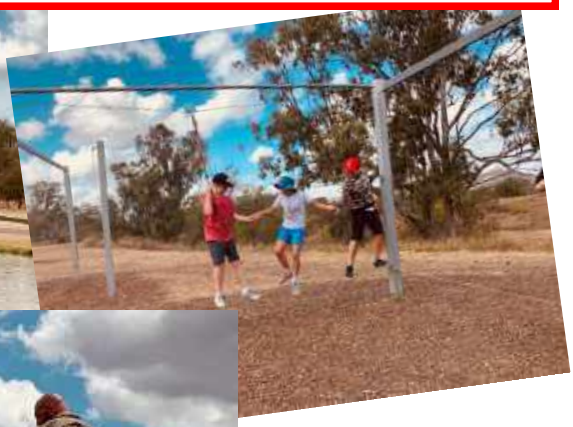
Youth Camp 2020

This years HFQ youth camp saw fifteen younger members attended camp at Emu Gully. Craig, Adam & the youth mentors offered our young men and women a great camp experience and the opportunity to make new friends or re-connect with old ones.

The weekend was enjoyed by everyone as they were safely challenged to explore and participate in a number of physical activities and challenges designed to promote independence, and self -confidence.

Emu Gully uses ANZAC themes as a way of building resilience and comradery among the campers. It gives our young people the opportunity to interact and forge friendships with other people experiencing similar challenges and concerns of life with a bleeding disorder.

A fuller report should be in the next issue.



Hemlibra Considerations

In 2018, emicizumab (Hemlibra) was approved in the USA for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with haemophilia A. In Australia we are hopeful that it will be approved before the end of the year, but it will probably have tighter restrictions on its use because of cost.

In the two years since its US approval, Hemlibra has demonstrated its efficacy in the inhibitor population. The immediate effects are clear in terms of the cessation of bleeding and the resolution of target joints and improvement in joint function, but we don't know if we'll see the same long term benefits to joints and muscles that were seen with the introduction of replacement therapy.

One of the most challenging areas with Hemlibra is treating very young babies. Intravenous therapy is almost impossible with babies. You can't put in a port because they are too small and central venous catheters are notorious for getting infected.

But emicizumab can be given subcutaneously. So we could have an option to start treatment right out of the womb because giving subcutaneous medication to a baby is not a problem. Really sick babies in neonatal intensive care get subcutaneous injections all the time.

So the question with Hemlibra is although we could give it at a very young age ...should we? And if we want to, what would be the reason? There is no data on babies that young, so it opens a Pandora's box of questions and the discussion with parents of newborns *[in the USA]* is very different now than it was two years ago, because we have to include that as an option.

Another big issue is intracranial haemorrhage. Bleeding in the brain only occurs about five percent of the time, but when it does occur, 90% of those occur before the child is nine months old.

Before emicizumab we'd just say; 'If it happens we'll deal with it.' But now there's an opportunity to give a medication that should be effective at improving the coagulation status of that baby. And therefore, in theory it could be effective to prevent intracranial haemorrhage.

I have one baby who already had an intracranial haemorrhage right after birth, he started on emicizumab at one week of age. We did factor for a week and then we bit the bullet and stopped the factor because we'd got enough factor to stop the bleeding, and then we relied on emicizumab from that point. So, there's really different discussions to be had because of that.

Inhibitors is another discussion you can't avoid even if you use Hemlibra. Before emicizumab the natural history of inhibitors was to start prophylaxis when the baby was nine to fifteen months old. It doesn't take a long time till you hit the fifty exposure days that inhibiters pretty much happen in. So before two years old, we know if you have an inhibitor or if you don't. If you don't, you'll probably never get one.

The issue with starting Hemlibra before you hit fifty exposure days is; what are you going to do if you have to use factor, because inhibitors are problematic. They are still a big deal.

One option is to say, I'm not going to use any factor. Now, the problem is the time it would take to get to 20 exposure days based on how effective emicizumab is. On average, it takes 13 years until you get to 20 exposure days, which means that instead of knowing if you have an inhibitor by the time you're two, you're going to have to wait for 10 to 15 or more years and so the inhibitor could show up at a really bad time.

A teenager out playing sports falls over, hits his head, gets an injury and is going to get some factor, needs some surgery. And now the inhibitors rearing up and you're giving factor and this kid is bleeding and the surgery's not going well. It becomes a potential nightmare scenario.

The other two options are; 1. Go ahead and start on Hemlibra, but at some point when it's reasonable (with or without a port) to add factor, you can add it every other week to several times a week. The problem with every other week is that it takes two years to get to 50 exposure days. So once a week makes sense. After a year you reach 50 exposure days and, you'll know whether you have an inhibitor or not.

The second option is to start prophylaxis early, without a port. Use an extended half-life product twice a week for about five months to get to 50 exposure days. There may be some issues with vein access, but at the end the chances of getting inhibitor is now pretty close to zero, and you'll know if he has or doesn't have an inhibitor and then go to emicizumab without that concern if you don't do it.

All of these things are real life scenarios that need to be considered and for which we don't yet have data and we're figuring it out as we go.

Written from interviews on the Bloodstream Poscast of 21 August 21 2020 with Dr. Leonard Valentino CEO of the National Hemophilia Foundation (NHF) and Dr. Guy Young. Professor of Paediatrics, University of Southern California
https://www.bloodstreammedia.com/episodes/gene-therapy-for-hemophilia-must-wait-for-now

World Hepatitis Day 2020

Every year we mark World Hepatitis Day globally on 28 July.

In 2020 we asked our community to help with the worldwide goal of hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New revolutionary hepatitis C treatments are widely available in Australia. They have very high cure rates. Treatment is simple - tablets not injections, few if any side effects.

WHAT ARE THE ISSUES FOR THE BLEEDING DISORDERS COMMUNITY?

Many Australians with bleeding disorders and hep C have now had treatment and been cured. See their stories on the World Hepatitis Day page on the HFA website - *https://tinyurl.com/BD-WHepD2020.*

Have you been cured of hep C? How is your liver going? Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need ongoing care of your liver.

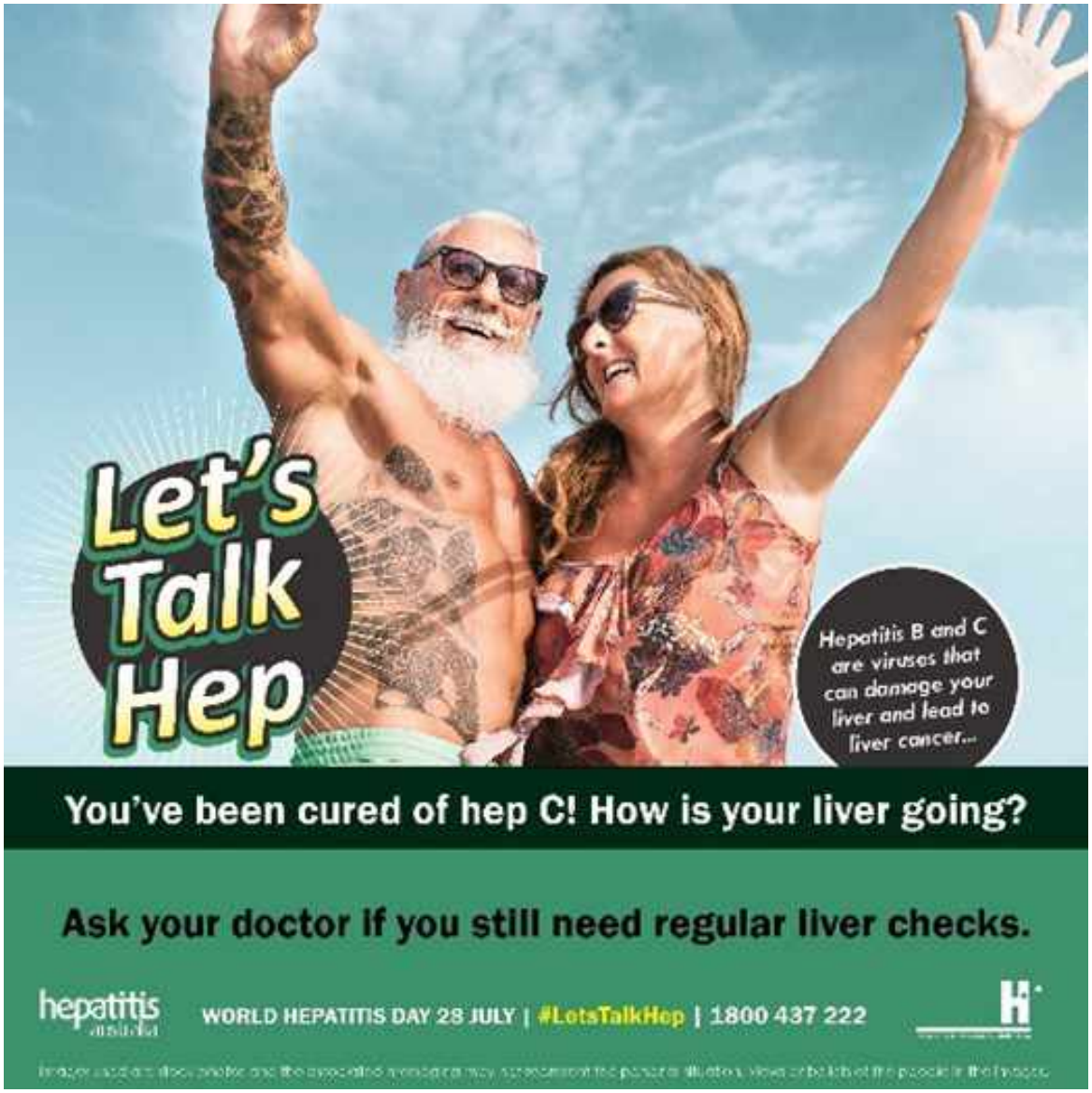
Some people with bleeding disorders or who carry the gene may not realise they have hep C. You could be at risk if you ever had a blood product before 1993. Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to talk to your doctor about a hepatitis test - and have treatment to be cured, if you do have hep C!

Thousands of Australians are now living free of hep C, but many have not yet had treatment. Treatment is simple and nearly all are cured – start the conversation.

There is a small number of people with bleeding disorders and hep C whose treatment has not yet been successful. Close liaison between their hepatitis specialists and their Haemophilia Treatment Centre is very important for their care. Research into new and improved hep C treatments continues.

FOR MORE INFORMATION

Visit *www.world.hepatitisday.org.au* The HFA World Hepatitis Day page - *https://tinyurl.com/BD-WHepD2020*



Beyond Diagnosis, We Found Community

I am the first person to insist that a diagnosis does not define my children. In my home we focus on the fact that they are human beings who have haemophilia. I never want my sons to think that their whole person is only a bleeding disorder.

My sons, whom I refer to as “MacDonald the Older” and “MacDonald the Younger,” are much more than their diagnoses. I previously wrote about this.

As a caregiver, I also realise that haemophilia is more than a diagnosis. While it is sometimes frustrating to treat bleeding episodes, I receive some incredible benefits as a member of my unique community. I found some of my best friends in the bleeding disorders family. We help one another along the way and provide encouragement when times get tough. I never would have met some of the greatest humans on earth had it not been for haemophilia. They are kind and help me move forward in my pursuits.

I learned a new vocabulary as part of the haemophilia population. I never knew what a factor level was, the nature of a half-life, the different products available in the community, or the careful attention one must pay to an inhibitor. All of these words did not affect me until the births of my amazing sons. We learned that understanding these new concepts proved to be a lifesaver. The more we learned, the more power we developed to protect our sons.

Equipped with knowledge, we discovered ways to get our message through to state, and national officials regarding quality healthcare. We learned that our voices counted, and that the more we empowered others by telling our stories, the more we could make our community a better, safer place for our children.

One of the most important lessons my boys learned is that they are not alone in their battle. A whole team of loved ones surrounds them and does everything they can to pave the way for a world of infinite possibilities. In return, we stood on the battle lines for their loved ones, demonstrating that the welfare of their sons, daughters, fathers, mothers, brothers, and sisters were equally as important to us as our children were to them. We stand together, sharing a special bond that will never die.

I hope that my sons see the valuable resources at their disposal and feel connected to the incredible community that stands in witness to their amazing lives. Haemophilia does not define my most magnificent works of art: my sons. It does, however, provide infinite resources in the strength of the community.

That brings me back to the topic that haemophilia is more than a diagnosis. It is a way of life, a part of our way of being in the world. We do not let the diagnosis control our concept of who we are, but we learn, finding productive ways to empower our children.

Today, I am grateful for a place to land, a space to find hope. May we all discover strength in numbers and remember that we are so much more than the name of a chronic illness.

Haemophilia will always be a part of our lives, but we know that we are grander than the name of a bleeding disorder. We are a community, trying to do the best we can for those we love with all our hearts.

From an article Beyond Diagnosis, We Found Community by Joe MacDonald And published in haemophilia news Today. *https://hemophilianewstoday.com/2020/07/23/beyond-diagnosis-community-bleeding-disorders?utm_source=BenchmarkEmail&utm_campaign=P%c4%81nui%3a_July_2020&utm_medium=email*
Used with permission.

Medicinal Cannabis, explained

What is medicinal cannabis?

Medicinal cannabis products are mostly made from chemicals found in the cannabis plant, called phytocannabinoids. There are more than 100 different types of cannabinoids in cannabis plants.

Some medicinal cannabis products are produced synthetically in a laboratory but synthetic cannabinoids can have more harmful side effects, and when used have resulted in a number of deaths.

How does medicinal cannabis work?

Cannabinoids are also found in the human body and they affect appetite, sleep, memory, pain and inflammation.

Cannabinoids act on receptors in the brain and other parts of the body by mimicking these naturally occurring endocannabinoids.

Two of the most common cannabinoids used in medicinal cannabis products are THC, and CBD. CBD does not cause a 'high' generally associated with THC and recreational cannabis use. THC is used to reduce symptoms of nausea, vomiting, pain and muscle spasticity as well as improve sleep and appetite. In some people,

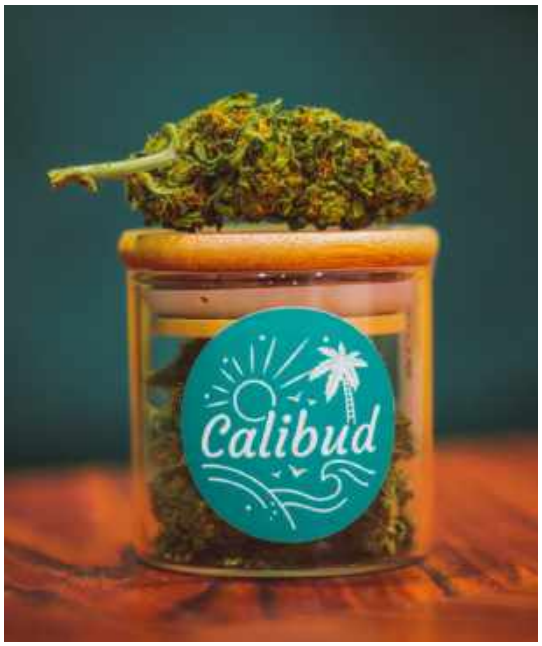
CBD and THC combined are thought to help manage seizures and pain and may also help to reduce anxiety.

Medicinal cannabis is not considered a 'first-line' treatment for any health condition. Treatment with medicinal cannabis should only be considered by a prescribing doctor once all other standard approved treatments have been unsuccessful.

Is medicinal cannabis the same as recreational cannabis?

No. Medicinal cannabis is a therapeutic good, which means it is regulated to ensure its safety.

- Medicinal cannabis producers must comply with Australian standards for producing pharmaceutical-grade medicines.
- Medicinal cannabis products must contain known quantities of the cannabinoids THC and CBD.



Who can prescribe medicinal cannabis and for what conditions?

Prescribing doctors must apply for approval to prescribe the product from the Australian government regulatory authorities.

In Australia, the Therapeutic Goods Administration (TGA) has approved applications for the use of medicinal cannabis to treat conditions including:

- nausea and vomiting due to chemotherapy
- epilepsy in children
- palliative care
- cancer pain
- neuropathic pain
- spasticity from conditions such as multiple sclerosis
- anorexia and wasting associated with chronic illness such as cancer.

How do I take medicinal cannabis?

Medicinal cannabis is not considered to be a 'first line' treatment for any health condition. It should only be considered as a treatment if the usual approved treatments have not worked effectively.

If you have been prescribed medicinal cannabis, always take the dose (amount) as directed.

Medicinal cannabis side effects are commonly dose-dependent, so it's important to follow the dosing recommendations.

Smoking cannabis products is not recommended. Smoking increases the risk of cancer, stroke, heart disease and other serious health conditions.

Medicinal cannabis products should only be taken under medical advice because they may interact with other medicines or cause side effects.

What are the risks of buying medicinal cannabis online?

Australia has a very good system for maintaining the safety and quality of medicines that are sold here. Medicinal cannabis is being regulated here to ensure the safety of the people for whom it is prescribed.

Even if they have an authorised prescription, it is illegal for an individual to personally order medicinal cannabis products online, or to import medicinal cannabis for personal use and any medicines that are not regulated by the TGA carry risks.

For more information, go to NPS MedicineWise medicinal cannabis information https://www.nps.org.au/professionals/medicinal-cannabis-what-you-need-to-know

Belinda's Haemophilia Story

Hi, my name is Belinda.

I was diagnosed with Mild Haemophilia A with a factor 8 level of 28% in August 2018 at the age of 45 years. I had no known family history of Haemophilia at the time. I had experienced many bruises and bleeds prior, and had never been tested previously.

I have been anaemic most of my life. I have always bruised very easily and often without any impact. I have complained of a heavy menstrual cycle which was incredibly embarrassing when I would bleed through onto my clothes. This did reduce slightly when I was introduced to Tranexamic acid during the diagnosis process. I have sore joints and signs of early degeneration, and was always told this was because of my hypermobility.

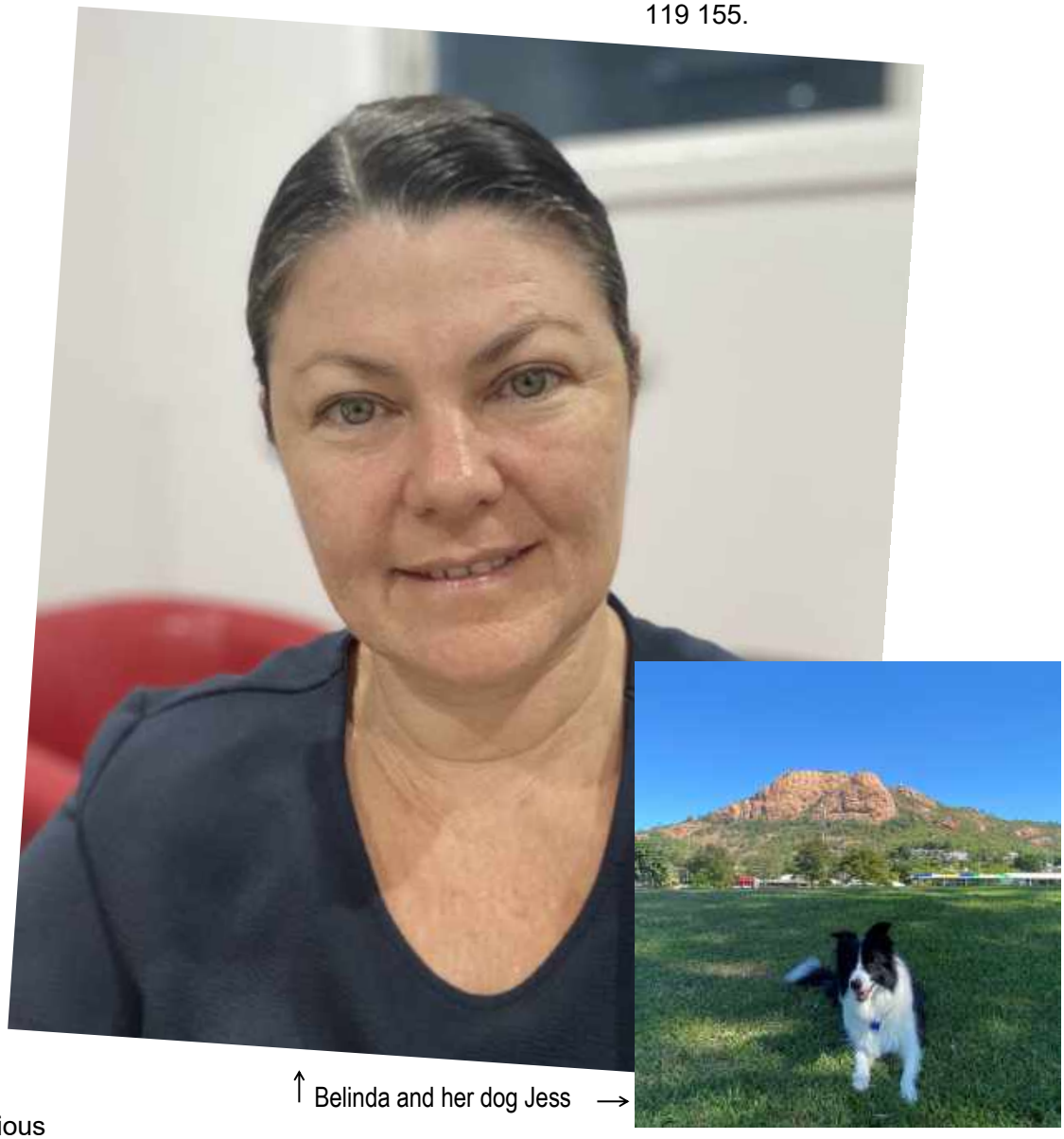
I vomited up a lot of blood after having my wisdom teeth removed. I haemorrhaged when I gave birth to my first child and was given 3 bags of blood and the vein tissued towards the end of the 3rd bag. This resulted in a very large bruise to my right arm and hand. I questioned why I bled so much and the Dr said it was because I was anaemic. With my 2nd pregnancy I had big bleeds from 30 weeks and had to stay in hospital for 24 hours after the bleeding stopped each time. Again I haemorrhaged when giving birth. This time I begged not to be given a transfusion after developing Kell antibodies from previous transfusions. I received iron injections instead.

In 2018 I developed a large bruise on my stomach with no impact to the area. After a couple of weeks I noticed a large lump underneath. This led to me go see my GP who sent me for further tests.

The pathologists comment on my bloodwork was that I needed to be referred to a Haemophilia Treatment Centre for genetic testing and counselling. The GP read this to me and said "we don't have one of those here and anyway females can't be Haemophiliacs, but you need to get your son tested". I looked up Haemophilia Treatment Centre in Brisbane (1,350km from Townsville) and gave them a call. They got the ball rolling with more blood tests and genetic testing of myself and my children.

After further testing I was told in June 2020 that I no longer meet the mild Haemophilia diagnoses. I felt dismissed, but I am working with HFQ to ensure I get the help I need before my upcoming surgery in case of a bleed. I also need to resolve why I still have issues yet I no longer have a diagnoses of mild Haemophilia.

If anyone in the bleeding community has any questions or would like to talk to me, please feel free to contact me on 0400 119 155.



↑ Belinda and her dog Jess →

HFA Getting Older Report

The HFA Getting Older with a bleeding disorder needs assessment report was published in May 2020.

The report describes the needs of older people with bleeding disorders and the needs of their partners, family and carers. It includes proposed solutions and recommendations for an HFA national strategy.

Many members of the community, health professionals and other experts contributed to the needs assessment through interviews, community forums, the HFA Getting Older Community Survey and the PROBE Australia Study. Our thanks to all involved for their valuable input.

There are two versions:

- The full report - with all the details of findings and recommendations
- A community report – a short summary of the findings and suggested solutions

These are available online on the HFA website *www.haemophilia.org.au* and in print. A copy of the community report is included with this issue of the H Factor newsletter. If you would like a print copy of the full report, please contact the HFQ office on info@hfq.org.au or phone 0419 706 056.

And check out the new **Getting Older Info Hub** on the HFA website - *www.haemophilia.org.au/getting-older*. This is a great go-to zone to find online information about getting older with a bleeding disorder!

History of Bleeding Disorders

As we approach Bleeding Disorders Awareness Week it is worth while reflecting how far we have come since 1803 when the first article was published recognising that a hemorrhagic bleeding disorder primarily affected men, and occurred in some families

100 years later in 1926 von Willebrand disease was first described. Factor I deficiency was described in 1920, then Factors II and V deficiency were identified in the 1940s. The 1950s saw an explosion of work on rare factor deficiencies, as deficiencies of FVII, X, XI & XII were recognized. In 1960, FXIII deficiency was described.

By the 1930s, there was evidence that patients responded readily to infusions of plasma when given promptly after they sustained spontaneous joint and muscle bleeding.

In 1937 it was shown that an anti-haemophilia globulin found in plasma could decrease clotting time in patients with haemophilia.

By the late 1950s and early 1960s fresh frozen plasma was being transfused in patients in hospital and in 1965, it was found that the precipitate left from thawing plasma was rich in factor VIII.

By the 1970s, freeze-dried powdered concentrates containing factor VIII and IX became available allowing patients to "self-infuse" factor products at home.

In a ten year period from the 1980's first HIV then HepC were passed onto people with bleeding disorders through contaminated factor products.

In an already small community of people affected and effected by bleeding disorders these blood borne infections decimated our community.

Factor products became safer in the 90's as tighter screening methods were implemented and advanced methods of viral inactivation were used.

In the 1990's synthetic factor products were manufactured using recombinant technologies.

By the end of the twentieth century, prophylaxis became more common. With the use of prophylaxis, most people with haemophilia in Australia live with less pain, without the orthopaedic damage associated with chronic bleeding.

In 2013, gene therapy trials began using viruses as vectors, or vehicles, to deliver factor genes into patients' livers, correcting their haemophilia.

In 2020 new longer-lasting products that decrease regular infusion rates from 2-3 times per week to once-weekly or even less were made available to Australians with haemophilia and as we go to press, a new subcutaneous drug called Hemlibra is awaiting federal approval for release in Australia.

Relationships & Intimacy

Can a person with the Haemophilia gene ever have a boyfriend or girlfriend just like anyone else?

Yes they can. It is part of life to feel interested in other people, to wish to be closer to them in some point of life, to date, and who knows, form a relationship and even get married. If you have Haemophilia or carry the haemophilia gene it is part of your life too, but it should not define whether or not someone can date or form relationships

Is there any danger or special consideration to be taken when you kiss someone because of your Haemophilia?

Kissing is fine, it's one of the big moments for two people when they feel attracted to each other that they want to explore each other through kissing. It is however important to consider oral health as part of your overall physical health and if you have teeth and gums that are prone to bleeding, it can affect our self-esteem, so having good oral health is something that's really important when it comes to thinking about kissing.

When should you tell someone about your Haemophilia? Do you need to tell them straight away or later on?

There's no right time to disclose personal health information, it's something that's different for everybody. It's the kind of thing that should happen when the relationship has struck the right balance so that they're both comfortable with that kind of information. If you think about the other perspective, from the side of the partner in the relationship, they should feel more confident in their love for you because they realised that you have trusted them with this information and with your struggles, and with his treatment experience.

If you feel the need to tell someone about your haemophilia because it's an important part of your life, one way to make things easier can be to start asking your partner a question about haemophilia. For example; “Do you know about haemophilia?” because we assume that people know a lot of things about haemophilia but there are a lot of misconceptions so this can become an opportunity to clarify doubts, to talk about your life, where haemophilia fits in your life and adherence to treatment. It's a very personal decision but if you know your relationship is getting serious, honesty and taking safe sex precautions like using condoms is very important.

What about sex, what do you need to look out for?

Before deciding to have sex, remember that like anything else, the more strenuous the activity the more likely it is that you may get a bleed. The signs and symptoms that appear are no different from any other ways you get hurt.

Remember you can get a bleed anywhere that blood flows including your penis. If you have pain or swelling; or if you develop signs or symptoms of a bleed and things don’t seem to improve talk to your doctor for advice. You don’t have to explain how you got the injury. All they need to know is the part of your body that is bleeding.

If you are considering having sex or have concerns about masturbation you may want to talk to your doctor or someone you trust.

Can someone with haemophilia get married? Can they have a family, and kids of their own?

Haemophilia shouldn't be an obstacle at all, when we love each other, health issues are part of the relationship and when we get married we never know what's going to happen in terms of health issues or any other aspects of life …mutual support is so important. I think that marriage is really a big adventure. When people get married one of the things they may have discussed is if they're going to have children, and that's also really good time to talk to the comprehensive care team about genetic counselling. It's really important that both of them understand the issues of inheritance around Haemophilia.

For a man who has Haemophilia, if he has daughters, they will be carriers of the gene and if he has sons, they will be free of the disease. But if the woman has haemophilia or carries the haemophilia gene, they need to know that each of their sons or daughters would have a 50% chance of inheriting the gene too. It can be complicated and a genetic counsellor can help all of that make sense.

Inspired by a WFH video conversation on relationships and intimacy and haemophilia at: www.youtube.com/watch?v=YhgMnzSXmR0 and three videos on the same topic from the NHF at: www.youtube.com/watch?v=F_1_0diuouE

Annual General Meeting

This year's Member Information Night and Annual General Meeting (AGM) will be on Tuesday 20th October 2020, at 7:00pm. It will be held it the MIFQ Meeting Room, ground floor at 298 Gilchrist Avenue, Herston (below the HFQ office). There is free parking available at the front of the building, but because of Covid-19 social distancing rules RSVP's are required, or you can zoom in on-line for the meeting.

Ever popular and informative, this is your chance to hear from all areas of the foundation, from President David Stephenson and board members to manager Graham Norton delivering their review of the last year updating on progress and forecasting for the year ahead. As always, both the AGM and Members' Information Night offer you the chance to ask your questions of the foundation, feed in your opinions and be fully updated on the work we do.

The meeting will conclude with the presentation of reports for the 2019/20 year, an amendment to the constitution, and the election of board members. Financial members can also nominate to positions on the Board of the foundation. The total board membership can be eleven including 4 office holders and 7 ordinary members.

Nominations, declarations and proxies relating to the AGM closed on Tuesday 29th September 2020 but you can still attend the meeting (provided you RSVP for Covid-19 compliance)

To RSVP for the meeting, or if you want to renew your membership, or have any other questions please contact Graham Norton, our manager on mobile 0419 706 056; or email info@hfq.org.au

Covid-19 complications and VWF

Researchers at St Petersburg University have advanced a hypothesis that the severe course of COVID-19 may be associated with the von Willebrand factor. The replication of the virus stimulates the development of micro damage on blood vessel walls. In its response to this, the body releases von Willebrand factor into the blood, trying to 'patch' possible holes. As a result, the risk of thromboses increases. It is with this clotting that a significant part of the deaths from COVID-19 are associated.

While it is known that SARS-CoV-2 affects the lungs by binding with receptors on the surface of the lungs, today, it is also believed that something similar happens with endothelial cells—the internal surface of blood vessels. Apparently, it is capable of causing local inflammation of the walls of blood vessels and capillaries. This results in an increased release of VWF into the blood, which, in turn, provokes clotting.

The researchers hypothesise that the level and activity of VWF might be important predictors for COVID-19 morbidity and mortality. It might also itself be involved in the disease process but further large-scale and research into the level and activity of VWF in people infected with SARS-CoV-2 is required.

The attention of researchers from all over the world is now starting to focus on VWF, its role in COVID-19, and new treatment regimens that will take into account the individual characteristics of the human body associated with von Willebrand factor.

From a paper by Anna Yi. Aksenova, called "von Willebrand factor and endothelial damage: a possible association with COVID-19" published in Ecological Genetics (2020). *https://journals.eco-vector.com/ecolgenet/article/view/33973*

Health Updates

Resumption of Concizumab Trials soon.

Novo Nordisk has announced that clinical trials for their investigational subcutaneous therapy concizumab will resume after a pause in response to non-fatal thrombotic events in three enrolled patients.

Concizumab is developed using a synthetically produced (recombinant) antibody derived from a single cell clone, designed to be equally effective in individuals with haemophilia A and B, irrespective of inhibitor status.

The trials are part of an ongoing phase 3 program. The trials are set to resume "as soon as local procedures allow," with new safety measures and guidelines in place.

https://pipelinereview.com/index.php/2020081375564/Antibodies/Novo-Nordisk-resumes-the-phase-3-clinical-trials-investigating-concizumab-anti-TFPI-mAB-in-haemophilia-A-and-B-with-or-without-inhibitors.html

RNA in Nanoparticles Leads to Efficient FVIII Production in Mice

Tiny particles containing RNA led to successful delivery and production of factor VIII (FVIII) in a mouse model of the disease, according to a new study published in the journal Science Advances.

Using a mouse model of haemophilia A as well as healthy (or wild-type) animals, investigators at Ohio State University (OSU) found that administering the nanoparticles via intravenous (direct-to-the-vein) injection induced FVIII production in the liver that reached 90% of normal activity within 12 hours. No signs of organ damage were detected.

Investigators also explored the nanoparticles' potential applications by loading them with RNA carrying the genetic code for a DNA editor and a guide RNA to ensure that the edits occurred in the desired target. Results showed approximately 60% targeting efficiency at a low nanoparticle dose.

They demonstrated two applications for lipid-like nanomaterials that effectively deliver their cargo, appropriately biodegrade and are well-tolerated. With this work, they have lowered potential side effects and toxicity, and have broadened the therapeutic window.

https://advances.sciencemag.org/content/6/34/eabc2315

Poor Joint Health Linked to Lower Self-Esteem in Adolescents

A study in Turkey looked at self-esteem among adolescent haemophilia patients. Among 32 patients (28 As and 4 Bs; two-thirds with severe hemophilia; 81% on prophylaxis), the median Offer Self-Image Questionnaire (OSIQ) score was 212 compared to 250 for normal controls (35 healthy volunteers without hemophilia). Lower scores indicate less self-esteem.

Their patients' Haemophilia Joint Health Scores (HJHS) were also lower than the controls, suggesting a correlation between self esteem and joint condition.

https://journals.lww.com/jpho-online/Abstract/2020/04000/Assessment_of_Self_Image_With_the_Offer_Self_Image.25.aspx

Funding Secured for Portable Device to Monitor Coagulation

A $1.64 million investment has been secured to finalise the development of a handheld diagnostic device to monitor blood coagulation status in people with haemophilia, and to secure regulatory approval.

Named Enzypad, the device is to be a near-patient test (NPT), similar in function to the glucose monitors used by diabetics to manage their blood sugar.

Using a blood sampling device — called TAP a patient will collect a small sample of their blood which is then placed into a card which contains all the reagents necessary to perform up to 16 coagulation tests that measure up to 12 biomarkers of blood coagulation. The processor will then send the results to a patient's phone.

These results are expected to have the same quality as if performed on the large instruments available in specialized laboratories, and such data may provide early warnings of changes in bleeding risk, preventing crises caused by sudden changes in coagulation state. Frequent, real-time data of this nature should make it possible for patients and their healthcare providers to work together to optimize individual treatment.

https://hemophilianewstoday.com/2020/07/29/enzyre-secures-1-4-million-advance-enzypad-portable-blood-coagulation-monitor/

Non-invasive Prenatal Diagnosis of Haemophilia

The presence of foetal cell-free DNA (fcfDNA, genes from the growing foetus in the mother's womb) in the mother's plasma was first reported in 1997. Now a group of Chinese researchers has reported that this fcfDNA can be used to determine whether the foetus carries mutations that would put it at risk for haemophilia and other disorders. Because the analysis is done on a simple blood sample taken from the mother, there is miniscule risk to either the mother or the child

So far, the test has only been used for two families at risk for haemophilia A but with good results, identifying one baby as not having haemophilia and one as being a carrier. The study needs to be repeated with a large patient group to finalise its validity.

https://www.future-science.com/doi/10.2144/btn-2019-0113

Action Calendar for Families

1 Go on a smile collecting mission, starting with a smile in the mirror	**2** Choose one song each and arrange family dance off	**3** Send someone a message to show you really appreciate them	**4** Take turns to notice 3 things around you that are beautiful	**5** Be kind to yourself and others	**6** Together make a list of things you are grateful for	**7** Think of a goal to work towards and do one thing to get started
8 Take a mindful walk together and notice what you see hear and smell	**9** Play Musical Statues	**10** Create a bedtime routine together to help with sleep	**11** Bake cupcakes and decorate them as gifts for each other	**12** Cross your arms and give yourself a hug	**13** Take turns to share a happy memory	**14** Find out about the values and traditions of another culture
15 Do something together to support a local charity	**16** Create a collage of things that make you feel happy	**17** Before bedtime, share what has gone well during the day	**18** Introduce a family 'Daily Pause' to be calm together	**19** Create a family wishes jar and take steps to make them happen	**20** Lean a new skill together as a family	**21** Create a kindness box to keep a record of kind actions
22 'Surprisercise' yourself. Find unexpected ways to move your body	**28** Make a rainbow salad	**24** Smile and say something positive every time you walk into a room	**25** Create a poster highlighting everybody's strengths	**26** Notice the shapes, colours and smells of a new family meal	**27** Make a list of things that have helped you cope with difficult times	**28** Tell someone you love how much they mean to you and why
29 Do something good for the environment	**30** Hold an awards ceremony to celebrate acts of kindness					

"A person's a person, no matter how small"
- Dr Seuss

ACTION FOR HAPPINESS

www.actionforhappiness.org

Find out more about the Ten Keys to Hap

Keep Calm · Stay Wise · Be Kind

How to handle fear about the future

Life as a student was probably stressful enough before COVID-19 added more uncertainty. You may be finding the resulting situation really hard to deal with and as a result, you're likely experiencing a range of different emotions, including stress, fear, uncertainty, depression, frustration, anger and disappointment.

These emotions are understandable, but they can be distracting and have negative impacts on our health and mood. Worrying about the future gets in the way of enjoying and making the most of the present. Luckily, there are some strategies for managing our worries about the future so that we are able to re-focus on and enjoy the present as much as possible.

Ways to cope

Feel prepared, come what may
It can be helpful to sit down and write yourself two plans: Plan A (what you would want to do if things were 'normal') and Plan B (your best choice of what to do if things aren't 'normal'). Plan B is an opportunity to work on some personal projects and goals while you pit Plan A on pause for a little while.

Be balanced and compassionate in your thinking

It's important to be kind to yourself and realistic in your thinking. Ask yourself: 'What's the best thing I can do right now to take care of myself and help me feel better?' Try to be as kind and supportive when speaking to yourself as you would be if you were talking with your best friend.

Improve the moment

If you find yourself getting bogged down in worries and negativity, try to improve the moment by doing something nice for yourself. Watch a funny video or favourite movie, play a game, or spend time on an hobby or craft.

Focus on your surroundings

Right now, the future can seem pretty overwhelming. It can be helpful to focus your attention on what's immediately around you and disconnect from the outside world for a bit. Just think about the task at hand (whether that's school work, caring for pets or plants, or working on a creative project).

Slow down to be in the 'now'

Spending a lot of time on screens can lead to a feeling of frenzy and stress. Slow down by practising some breathing exercises, or doing stretching, yoga or a mindfulness meditation. These reduce physical tension and can help to clear your mind.

Take control in your own world

Have a few things in your life that you are in control of. Examples include keeping your room or desk tidy, organising/cleaning out a space in the house, or making a plan that you stick to, such as messaging three friends each day, taking the dog for a walk, or completing a level on your game.

Practise gratitude

It's really easy right now to think that everything is pretty bad, but it's usually possible to find things, big and small, to be grateful for. Start by listing three things each day that you are grateful for on your phone or in a diary.

Engage in random acts of kindness

Engaging in random acts of kindness will enable you to bring something good or positive into the world, and give you some sense of control. Ideas include making a gift for someone, sending a kind/encouraging message, or helping out a family member, friend of local community with something they are working on.

Stay connected

Your friends are probably experiencing similar worries and it can really help to talk about it together and support each other. If you don't feel comfortable talking with friends about your concerns, you can get some support online via the ReachOut Forums at: *https://forums.au.reachout.com/*

Get support

You don't have to work everything out by yourself! Talk to someone 'in the know', such as a teacher, the school careers counsellor, and ask for their advice and suggestions. If you are feeling really overwhelmed, it could help to talk to a mental health professional online via sites such as eheadspace (*https://headspace.org.au/eheadspace*), beyondblue (*https://coronavirus.beyondblue.org.au/*) and Lifeline (www.lifeline.org.au)

It may be difficult to stay calm and focused when the world around you is in chaos, and it's challenging to accept that we can't predict the future right now. However, it can help to remember that although things may look a little different from how you imagined they would be, or how you had planned, by focusing on the things that you can control and trust, no matter what happens, you'll be able to cope.

This article was edited for size from an article written by Dr Amy Burton, Clinical Psychologist and published on ReachOut *https://au.reachout.com/articles/how-to-handle-fear-about-the-future-a-guide-for-year-12-students*

Important Dates for HFQ Members

It's been hard to meet during the physical distancing restrictions of Covid-19, but as we go to press the following activities have been booked or re-booked based on covid-19 restrictions...

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

Bleeding Disorders Awareness Week
10 - 17 October 2020

Patrons Afternoon Tea
15 October 2020
Government House (RSVP event)

Women's Brunch / Lunch
Sunday, 18 October
11.30am Tingalpa Hotel

AGM
20 October 2020
7.00pm
298 Gilchrist Ave, Herston

World AIDS Day
1 December 2020

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.

Hemlibra waiting for approval

HFQ is waiting for an announcement from the National Blood Authority (NBA) about the funding of a new treatment for patients with severe Haemophilia A called Hemlibra (emicizumab).

Hemlibra was released in the USA two years ago and has since been approved for use in the UK, Ireland and most developed countries. We have previously made representations to our state health minister, the Honourable Dr Steven Miles. He has assured us that Queensland is in favour of making this treatment available, but as it is funded via NBA all states and territory's have to agree for it to proceed. There was a meeting of the Joint Blood Committee to discuss this in September and we are hopeful that an announcement will be made shortly.

Until now this drug was only available to patients via clinical trail or compassionate access, but if funded it will mean that every individual with severe FVIII deficiency will have the option to switch to Hemlibra or remain on their current treatment.

While there are new extended half life products available for people with Haemophilia, and prospects of Gene Therapy continue to move closer, a favourable decision on funding hemlibra will mean greater choice for the community and we will continue to advocate for access to this and other new treatments as they become available.

Hemlibra is a bi-specific antibody which binds to both activated FIX and FX and allows the coagulation cascade to continue, and the blood to clot, in the absence of FVIII; mimicking the effect of the clotting factor VIII injections for patients with haemophilia A.

Hemlibra is manufactured and is not derived from blood products. It offers good protection against bleeding and rather than requiring vein access, it is injected subcutaneously (under the skin) once a week or once every two weeks. This will be a very significant step forward as it will provide as much protection for people with haemophilia A from the risk of bleeding as current treatments and it will be much easier to administer, without the need for regular intravenous injections. We also hope to see a similar product for haemophilia B in the near future.

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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