



From the President



Hi Everyone

I hope this finds you, your family and friends well. I am encouraged to see more people taking this pandemic seriously - keeping personal distance,

washing hands, not touching your face, coughing into your elbow etc - and not going out - flatten that curve.

I am not aware of any publications that indicate people with a bleeding disorder would be more likely to catch the virus than the general population, however it is sensible to keep your MYABDR card with you at all times and for those with a medic alert necklace or the like - make sure you wear it. People with the Covid19 virus have to be isolated so this may mean you won't have someone with you to explain your bleeding condition to any medical staff. For severe cases, where you are likely to be hospitalised it is essential the

medical staff are aware.

There is some discussion about changes in blood clotting for those who are sick - it appears from anecdotal reports that having haemophilia will not increase the risk. Contact your haemophilia treatment centre for advice or if you have any concerns - they will be best placed to advise if you become sick.

The government measures that have been taken to flatten the curve may have delivered significant stress to individuals and families - the worry of keeping everyone safe as well as financial issues can be overwhelming. Remember to

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Presidents Message *continues*

check the government website regularly to ensure you understand the situation and advice given, and how this can assist your situation.

Remember, if you have any concern about anything related to your bleeding disorder - call the haemophilia treatment centre. Also keep in touch with friends & family over the phone or on your PC / mobile device. HFQ can be contacted on the usual number if you just want to talk or raise a concern.

I am sure we all have sufficient toilet paper now, but if you have to go the supermarket keep a safe distance from others and be aware of what you touch and what to disinfect. I am still at work (essential service) and I see people going a bit stir crazy at home - to the point of wanting to go out or even come back to work - don't risk your life or those you come in contact with - this is serious - social isolation works.

In Australia we are lucky, less fortunate places like Fiji don't have the resources that we do, so the virus impact to them will be significantly worse. Where you have a family with one breadwinner on \$3/hr or less, and he or she gets sick, it's a really big deal - serious trouble for everyone.

Stay safe and ride this out at home.

David Stephenson
President HFQ
president@hfq.org.au

World Haemophilia Day - 17 April

It seems as if there is a day for everything: From the official World AIDS Day, Rare Disease Day, etc, to the lighter Love Your Pet Day, and even Talk Like a Pirate Day. From the serious to the funny, many people have a time to celebrate and observe according to their interest or cause.

17 April every year is Haemophilia Awareness Day. This day is an opportunity for the bleeding disorders community to band together and spread the word about the issues we live with as individuals and families with disorders including von Willebrand disease and the other bleeding disorders.

A bleeding disorder's invisible symptoms can cause it to be misunderstood. But we know that just because someone looks fine doesn't mean that people affected by bleeding disorders don't have struggles. A person with haemophilia can appear well on the outside while living with chronic pain or taking extra steps and precautions before doing what others can do without thinking.

We can't see someone pre-treating before a dental visit or struggling afterwards to stem a bleed. Nor can we see the inside of someone's muscle or joint, but we may notice a limp in the gait of someone with joint damage and we can notice the absence of someone while they deal with a pervasive bleed. They may need more time off school or work, they may have mobility issues that need a cane or a wheelchair. One of the hardest aspects of having a bleeding disorder is the judgment from others because the person doesn't look sick.

Few people understand the challenges of a bleeding disorder so it's up to us to tell others about our experience. Why not share your story this World Haemophilia Day?



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

The Haemophilia Foundation of 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 (Chinthei) Jayasekera

Joanna McCosker – Nurse Practitioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Stephanie Manning (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.

Improving Our Mental Health

Looking after our mental health is as important as looking after our physical health and yet most of us take our mental health for granted or do not talk about our mental health concerns due to the stigma that still exists.

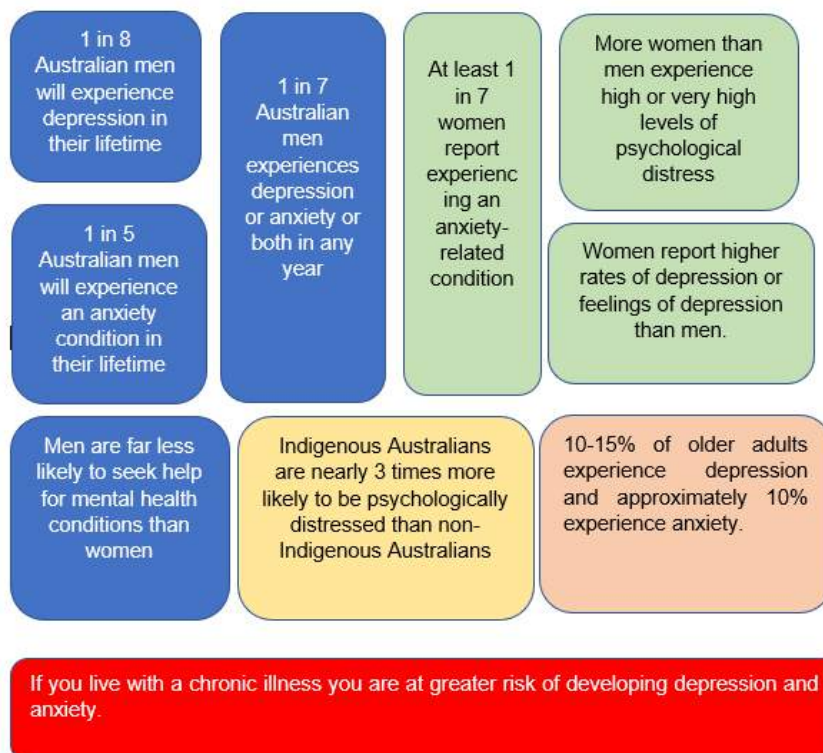
Some statistics from Beyond Blue's website (www.beyondblue.org.au) are presented in the infographic attached to this article

As many of you know, one of my roles is to assist people with their mental wellbeing and I want us as a community (people with inherited bleeding disorders, their families and staff working at HFQ and QHC) to enhance our mental well-being and live a productive and meaningful life. I would love to see if we can reduce the risk in the Haemophilia community of depression and anxiety.

So how do we do this at the Adult QLD Haemophilia Centre? It may involve a little bravery for you to call and ask for an appointment with Social Work, or undertake screening for mental health as part of your annual haemophilia review and/or attend workshops including the mental wellbeing workshop at RBWH scheduled for the 23rd May 2020. Please don't hesitate to call if I can be of help. I have lots of options and strategies and can make a cuppa if you want to come in and speak to me about how things are going.

The mental well-being workshop will be an interactive workshop filled with strategies you can use straight away and most importantly you don't need to have depression or anxiety to attend – the strategies can be used by anyone and

everyone. There is even a 'showbag' for every attendee to get you started on your journey to thriving. Please let Loretta (Phone 3646 8769 – or email loretta.riley@health.qld.gov.au) or Graham at HFQ (Mobile: 0419 706 056 – or email info@hfq.org.au) know if you would like to attend.



RBWH SOCIAL WORK -- BREAKING NEWS FOR MEN WITH SEVERE HAEMOPHILIA who have mental health concerns! 2020 has just become even busier for me, after I received some exciting news which I would like to share with you.

I have been successful in receiving a grant from Metro North Hospital and Health Service for a project that aims to improve the mental health of men with severe haemophilia. It will be a collaborative project between the QLD Haemophilia Centre and the RBWH Consultation Liaison Mental Health service. In short, the funding will be available from July 2020 and until mid-2021 and will enable the Adult Centre of the Haemophilia Treatment Centre to have a part time Psychiatrist (Doctor who specialises in Mental

Health) join our team to support the work I have been undertaking to improve the mental health and wellbeing of the haemophilia community. The Psychiatrist will be a valuable addition to our team and this may be an Australian first innovative model of care. I know many people may not have a regular GP, may not have funds to

access a Psychiatrist privately, don't meet the eligibility for ongoing support through the public mental health service and many of you have questions about medication which I am unable to answer. This project will fill those gaps around prescribing / recommending and reviewing medications and provide a comprehensive service to improve the

mental health of men with severe haemophilia. If successful, this project may be able to be expanded in the future to more people in the inherited bleeding disorders community. So, let's see if we can make it a success!

Although this project is currently in the planning stages, in order to access the Haemophilia Psychiatry service, interested individuals should contact me for an initial assessment and referral. If you would like to make an appointment for an assessment, have questions or would like to know more about this project, please do not hesitate to contact me on 3646 8769.

'Til next edition,

Loretta

Loretta Riley
Advanced Social Worker
3646-8769

Use of Injectable Drugs for Arthritis

A paper by Italian researchers published in a recent issue of *Haemophilia Journal* reviewed already published studies to evaluate the efficacy of 4 intra-articular drugs (injected into joints) used in patients with haemophilic arthropathy (HA). It is a form of joint degeneration that can lead to disability, chronic pain and impaired quality of life.

In haemophilic arthropathy, both inflammatory and degenerative components combine to determine articular cartilage degeneration. Intra-articular injections of hyaluronic acid and corticosteroids are commonly used in patients with painful knee osteoarthritis and provide some pain relief.

Studies from publications within the last 10 years, written in English, and published in peer-reviewed journals reporting clinical or preclinical results were reviewed.

Hyaluronic Acid

Hyaluronic acid (HyA) is a typical drug used to treat osteoarthritis. The researchers looked at four articles that studied its efficacy. One was a long-term follow-up study of patients treated in different joints (elbow, knee and ankle) with 2 cycles of HyA.

The outcomes, at 6-months, showed better joint function and improvements were also seen in pain relief as well as quality of life. The study authors say that the current literature confirms the efficacy of the use of HyA in the treatment of HA, but the effect of the therapy usually lasts between 6 months and 1 year. They found the level of evidence was low, and there is an absence of randomized control trials.

Corticosteroids

Intra-articular corticosteroids were mostly discontinued probably because of the increasing availability of safe clotting factor preparations that limited inflammatory reactions.

They found two studies: one on the effectiveness of intra-articular

Corticosteroid injection in the knees of patients with chronic synovitis. The other evaluated the efficacy and safety of ultrasound-guided corticosteroid injections for pain relief in patients with HA.

The first study showed mixed results with 40% good but 30% fair or poor outcomes one year after the injection. The other study reported a significant reduction in the median pain scores following injection.

The researchers called for better quality studies and Randomised Control Trials. In particular, taking into account clinical and imaging findings that include vascularity changes in association with bleeding states.

Association of Hyaluronic Acid with other drugs or treatments

Three of the reports studied reviewed combination treatment approaches. One study assessed the efficacy of joint lavage followed by either an injection of corticosteroid and/or Hylan G-F 20 (on its own or with triamcinolone and local anaesthetic for immediate pain relief following anaesthesia).

The studies found that most patients had some degree of improvement, and bleeding episodes decreased in frequency. The mental health of patients also improved. The studies of joint lavage followed by injections of triamcinolone and Hylan G-F 20 showed improvement in balance, function and bleeding events.

The study authors say that their results and the current literature with other drugs (in particular, corticosteroids) highlights the importance of this kind of treatment to improve the functional abilities of haemophilic patients. However, the researchers said that some data added controversy regarding the efficacy of corticosteroids added to intra-articular treatments.

Platelet-rich Plasma

Platelet-rich plasma (PRP) is a concentration of platelets derived

from peripheral blood. It contains a great concentration of growth factors (GFs) normally present inside the platelets. These GFs can lead to a regeneration of tissues including cell proliferation, matrix remodelling and angiogenesis. Two studies analysed the use of platelet-rich plasma in patients affected by haemophilia. All patients had a good improvement in pain scores, and one showed a statistically significant decrease in the joint score and in joint bleeding episodes.

However, the authors concluded that it is not possible to recommend or discourage the use of PRP in patients with HA. Therefore, more studies are necessary to understand the efficacy and safety of PRP in HA.

Mesenchymal Stem Cells

MSCs are multipotent cells that can transform into various connective tissue cells including the cartilage. Two experimental studies reported a good improvement in animals with HA.

The main outcome was the inhibition of joint bleeding that persisted for 8 weeks after treatment and an improvement in cartilage and less friction of the joint. Although the results appear promising; at the moment it is not possible to prove the efficacy of MSC in human beings.

This review study tried to provide a complete overview of the literature of all possible different intra-articular drugs that could be used to treat Haemophilic arthropathy (HA). It found that intra-articular injections of hyaluronic acid can relieve joint pain for months and can be repeated every 6-12 months, which is why they can be recommended. Corticosteroid injections seem to relieve joint pain for a few weeks, but their routine use is not recommended in haemophilia.

HFQ subscribes to Haemophilia Journal so if you would like a copy of the original paper which appeared in the October 2019 issue, or for access to the journals, please contact the office.

Natashia spends 5 Minutes With Brett

I caught up with Natashia at last year's haemophilia, Von Willebrand disorder & other bleeding disorders conference at Manly Sydney October 2019.

If you don't know Natashia, she's the one that's running around like a headless chook going from conference room to conference room checking if everything is going like clockwork.

I asked Natashia if she would be willing to be my next interviewee for five minutes with Brett, she said that she could but it had to be five minutes or less!

Natashia Coco works at Haemophilia Foundation Australia as the Director of Development based in Melbourne where she's been for the past 16 years.

Natashia has always worked in the not-for-profit sector and specialises in fundraising to events such as Red Cake Day, organising Conferences and other projects such as digital storytelling and websites.

Natashia has 2 kids, Rafa 11 and Giselle 9 who keep her busy outside work, and both of them and her husband Damian are often at haemophilia events – it has become a family affair.

What are your dreams/goals?

My goal and drive for HFA is "what can I do to better people's lives?". Our community is such a sharing and honest one, and anything I can do to help I do! I love working at HFA and with our community.



How long does take it to get things ready for a conference?

Conference in total takes about 2 years to organise, but the year leading into conference is where most of the work takes place.

We start off by choosing a destination – then the venue. The Program Committee, headed by a Program Chair, works hard for many months to put together an informative program.

As soon as one conference

ends, the next one starts to take shape.

How does/where do HFA get it's guest speakers?

With the 2019 Conference the Program Committee was headed by Dr Lianne Khoo. The

committee designed the program and sessions and chooses appropriate speakers in consultation with other health professionals.

How does HFA come up with a location for a conference?

We have to typically stay on the east coast and rotate it around.

* * * *

I tried my hardest to get out of Natashia to where the next

conference will

be, I even tried to give her \$100, but as much as I tried she told me that mum's the word.

I just like to thank Natashia for sitting down with me and it took exactly 5 minutes.

Have A Nice Day.

Brett Williams

Using Crutches After a Bleed

Why we go on and on about you **USING CRUTCHES AFTER A BLEED** ...even if it is a minor one

Why we go on and on about you using crutches after a bleed is because the advice we give is based on the most current and available research that we are able to access. Behind the scenes we are keeping up to date by reading journal articles on human and lab-based findings of studies, extrapolating principals from similar fields (for example healing principals in sports medicine), collaborating with our colleagues world-wide, and drawing from our extensive experience. We encourage dialogue and questioning of why we make our decisions and are happy to share our knowledge with you.

We recommend NO weight-bearing on a bleeding joint. The following aims to give some insight into why we make this recommendation. The literature demonstrates that we should not weight-bear on a bleeding joint. AT ALL. When it is bleeding (which may be longer than you realise). That means not "it's just 5m to the bathroom", or "I'll rest it after I just do X". There are two reasons for this.

Protection of the joint or muscle from re-bleeding.

We want to protect the bleeding area from a) more pain and from increase in bleeding (and swelling) and b) to prevent a re-bleed. We know that putting a muscle on stretch or in full contraction when it has blood present, hurts. We know that it hurts to put a joint that is bleeding in the 'closed-pack position' where the bone ends of the joint are in the closest proximity to each other, and it similarly hurts at the ends of its range of movement (fully bent or fully straight). In order to weight-bear it is usually put into this position. So,

we protect the joint or muscle in a position of comfort, usually around the middle of its range to reduce pain.

At this time of bleeding the lining of the joint (synovial tissue) increases to try and absorb the blood quickly and more effectively. It is able to do this but in this state it occupies more space than it usually would in the joint and if you walk on it there is more risk of 'pinching' it between the bone ends or other structures



within the joint. This will cause more bleeding. Additionally, we know that the clot is forming but may be tenuous (that is what the majority of bleeding disorder medication aims to do as an end result- to keep the clot stable and not breakdown). Weight-bearing on an 'immature' or not yet stable clot may similarly break it down and result in more or 're-bleeding'.

Ensuring no forced-load occurs when there is blood in the joint

Research in cells and in animal models has demonstrated that putting a forced load (eg weight-

bearing) on cartilage in joints in the presence of blood increases damage to the cartilage more than when it is unloaded (not-weight-bearing). Damage to the cartilage effects the incidence and rate of osteoarthritis.

How-long do I rest for?

The million dollar question! It is essential for weight-bearing to be gradually reinstated, as of course the benefits of movement and weight-bearing are vital for healthy joints and muscles. In general we aim to optimally load the joint when the risks have been negated. In very general terms we allow some partial weight-bearing once the joint can go through its full range of movement completely pain free. Once some weight on the limb is painlessly tolerated the load can be increased.

Every person and every bleed is different however and we recommend for each bleed, even though medical treatment may be at home, a full and individualised assessment and return to function with a physiotherapy consult; please call the HTC physio-therapist for this, it may be able to be advised over the telephone or you may best benefit from a physio-therapy appointment.

On a final note, the same principals apply for bleeds in the upper limb. Whilst gait aids are not needed for the arms (although if you use an aid for the legs this may need to be temporarily ceased), a temporary disuse of the affected arm is prescribed for all the same reasons. We use our arms constantly and do put pressure and essentially do weight-bear on them (consider getting up from the ground or a low chair).

Abi Polus

Musculoskeletal Physiotherapist
Bleeding Disorders
Alfred Hospital

First published by Haemophilia Foundation Victoria, used with permission.

Queensland Haemophilia Centre -

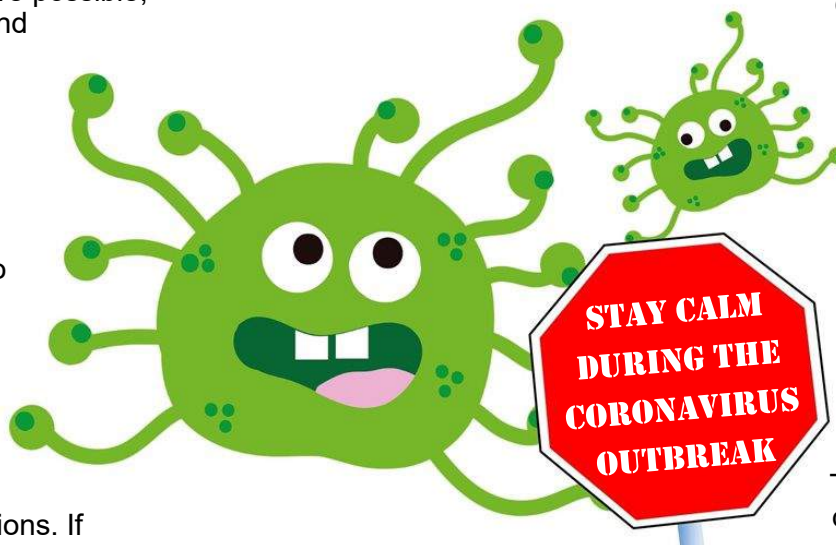
The QHC are working hard to ensure the ongoing appropriate care and safety of our bleeding disorder patient group during the COVID-19 pandemic. We wanted to take the opportunity to reach out to you and reinforce the stability of our service whilst outlining some necessary changes due to this unprecedented global health crisis.

QHC staff are, where possible, working remotely and when at work are practicing social distancing as per expert medical advice.

It is very important for us to continue to provide Haemophilia/ Bleeding disorder care to both prevent bleeds and manage bleeds promptly to minimise complications. If you are prescribed regular prophylaxis (preventative doses) of factor concentrates for home during this time it is particularly imperative that you adhere to your prescribed treatment regimen and don't miss any doses. For those on prophylaxis, preventing serious bleeds that may require hospital interaction / inpatient stay is of upmost importance in the current climate. Treating injuries early is also key to avoid a more significant bleed that may have serious consequences.

We have carefully reviewed our list of upcoming appointments and converted the vast majority to telehealth or phone consultations or deferred appointments to a later time where safe to do so. For some of our patients, attendance at the centre (ie for maintenance of critical central lines) is necessary and we are individually reaching

out to these patients to discuss options. There are strict infection control pathways within the hospital that have been instituted in response to this crisis. All hospital areas and waiting rooms adhere to social distancing requirements. The COVID-19 patient ward is located in a separate location to the QHC clinic and patients with respiratory symptoms are **NOT** allowed to interact with patients



presenting to the Haematology/ Oncology outpatients.

We are in close and regular contact with our product suppliers as well as Haemophilia Foundation Queensland, Haemophilia Foundation Australia, the National Blood Authority and the Australian Haemophilia Centre Directors Organisation. There is currently no indication of any interruption to factor supply or home delivery services for those on regular treatment. There is no need to stockpile factor. We remain confident in the safety of blood derived products (eg Biostate). We direct you to the following sources of reputable information:

 HFA website:
<https://www.haemophilia.org.au/publications/news/coronavirus-update>

 Australian Government Department of Health:
<https://www.health.gov.au>

 Australian Red Cross:
www.redcross.org.au

Regarding your personal health, it is important to observe social distancing measures designed to flatten the curve. Handwashing, covering coughs and observing a 1.5m distance is imperative.

Older individuals and vulnerable (eg compromised immune system or existing respiratory conditions) in the community in particular should be minimising any trips outside the house to fresh air and obtaining necessities (eg groceries) only.

This would be a time to draw on any family support to minimise trips outside the home. It is important to be proactive in obtaining scripts for your regular medications (eg HIV medications if this is relevant to you). Don't wait until you have run out before seeking an updated script.

It is understandable that many people are feeling anxious, worried or overwhelmed at present. If you are experiencing anxiety or stress about the pandemic, Loretta Riley (Haemophilia Centre Social Worker) will be available on 0428 756 071 (during working hours Monday to Friday).

A virtual group is planned for all members of the inherited bleeding disorder community called COVID Calm which will be run at least weekly, starting on

COVID-19 update and planning

Friday 17th April at 11am. This group is an opportunity to remain connected, share ideas and strategies to help all of us during this time.

This group will be run via either videoconferencing (similar to FaceTime or Skype, using a secure portal) or telephone conferencing. Please contact Loretta (via 0428756 071 or Loretta.riley@health.qld.gov.au) to register your interest and to get instructions on connecting to this group. If there is sufficient interest, additional days/times are able to be added.

The first point of contact for clinical enquiries is the Haemophilia nursing staff (Beryl or Alex) phone on (07) 3646 5727. If the office is unattended there will be a message directing you to further assistance. Non-urgent messages can be left as well. The Haemophilia Registrar or Haemophilia Director (Dr Jane Mason) can be contacted if nursing staff are unavailable (Phone (07) 3646 8111 and request via switchboard).

For urgent enquiries (acute bleed advice) out of hours contact (07) 3646 8111 and ask to speak to the Haematologist on call for advice or present to your Emergency Department and show your ABDR treatment card.

All non-urgent enquiries (requests for scripts, advice for upcoming non-urgent surgery, home delivery questions) should be directed to our Team email at **RBWH-Haemophilia@health.qld.gov.au**

During this difficult time, we may experience some clinical staff having to perform additional frontline duties to assist with managing COVID-19 patients and it is likely that there will be increased staff absences due to illness. We ask for your

understanding in any delay in responding to non-urgent enquiries. Note that it is very important that non-haemophilia related enquiries around general health issues be directed to your primary health provider (General Practitioner). If you do develop flu-like symptoms and are seeking GP review it is important to phone ahead to advise this – GP practices will have arrangements in place about patients to prevent spread of infection in waiting rooms.

Physiotherapy and physical activity

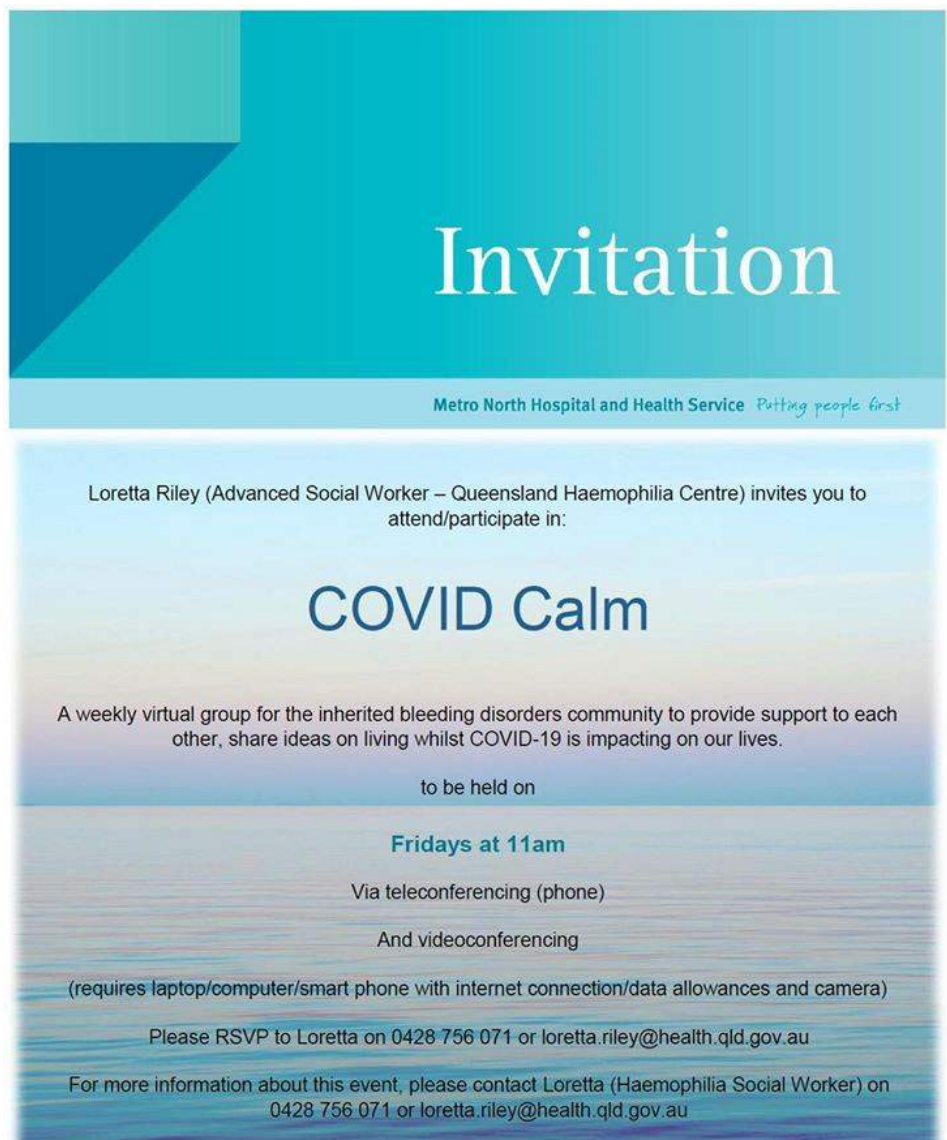
Being restricted in your ability to move around the community may affect your levels of

important physical activity. Should you need advice on maintaining physical activity during this time please e-mail our physiotherapist Scott (scott.russell@health.qld.gov.au). As well as providing advice on general exercise, he will still be available to conduct assessment via phone or webcam regarding injuries, bleeds and rehabilitation.

Yours sincerely

Dr Jane Mason
Provider No. 2971806B
**Acting Director of Haemophilia
QLD Haemophilia Centre**

Telephone (07) 3646 8111
Email: **RBWH-Haemophilia@health.qld.gov.au**



Invitation

Metro North Hospital and Health Service *Putting people first*

Loretta Riley (Advanced Social Worker – Queensland Haemophilia Centre) invites you to attend/participate in:

COVID Calm

A weekly virtual group for the inherited bleeding disorders community to provide support to each other, share ideas on living whilst COVID-19 is impacting on our lives.

to be held on

Fridays at 11am

Via teleconferencing (phone)

And videoconferencing

(requires laptop/computer/smart phone with internet connection/data allowances and camera)

Please RSVP to Loretta on 0428 756 071 or loretta.riley@health.qld.gov.au

For more information about this event, please contact Loretta (Haemophilia Social Worker) on 0428 756 071 or loretta.riley@health.qld.gov.au

Whats On?



MAKE IT YOUR EVENT

April to July 2020

Some of the HFQ programs and activities are planned
Please call the office for other events or more information. SVP

APR	OBE's Monthly meeting 1 April Old Fernvale Bakery Cafe	HFQ Community Camp 3 - 5 April 2020 Noosa North Shore	World Congress 10-12 April Vespene
MAY	OBE's Monthly meeting 6 May	Women's Being Workshop 23 May Venue TBC	
JUNE	HFQ Board Meeting 16 June Toombul Library	Women's Brunch 21 June at 10:30 Café 63	
JULY	?Pain Workshop TBC	HFQ Board Meeting 21 July Toombul Library	Report back from World Congress TBC

Impact of COVID-19 On HFQ Activities

Please note – As of 25th March 2020, all our events and support groups are cancelled at this present time for our members and public safety due to COVID-19. We will notify you via our Facebook page and website when our support groups and events recommence.

If you wish to contact us for information and support please do so by email (info@hfq.org.au) and phone (0419 706 056) as Graham and Sam are still working, but from their respective homes.

If you haven't checked out our Facebook Page (<https://www.facebook.com/HFQLD>), please do so, as this is the fastest way to find out what is happening and we hope to keep you involved with what's happening including updates on the impact of COVID-19 and any special issues for

members of the Queensland bleeding disorders community. One of the fun things we are doing is posting selfies from members showing what they are doing while staying safe and sane at home.

If you find yourself in need of support during this time of social distancing please call us as HFQ continues to be available for the support of members and that can include helping you find additional support and services that may be more difficult to find at this time.

HFQ continues to offer limited welfare support to members in financial distress. This needs to be supported by one of the psycho-social workers from the two QHC clinics, but if you're concerned please call Graham directly on 0419 706 056 or email; info@hfq.org.au.

Fearing the Unknown

I Understand What It's Like to Fear the Unknown

There is a lot for our world to fear due to the outbreak of COVID-19. But there is one fear I have encountered in my life that surpasses anything this virus can bring to me: my son's haemophilia diagnosis.

In the early stages it was easy to be fearful as I couldn't understand what was happening. The questions ran through my mind constantly, but little by little, I began to seek answers. I spoke to people who were raising children with haemophilia and realised that I was not alone. Finally, fear had begun to lose its hold over me.

The fear of the unknown can be debilitating. With all the issues surrounding the new coronavirus, I can't help remembering the early days of my sons diagnoses and that eventually our fears subsided and we set our sights on the possibilities that lay ahead of us.

We took away from our experience several valuable lessons that serve us well during this time of uncertainty. First, this too shall pass. We will not live in a state of change forever.

During the early days, anxiety ruled my life, and the more I tried to deny my feelings, the worse I felt. This led me to the second lesson I learned: It is OK to feel off balance. Healing occurs when I stop pushing my feelings aside and embrace them. By doing so, I find a sense of quietness, and from there, peace is possible.

Another lesson we learned concerned rediscovering hobbies that bring us joy. I love to work and solve jigsaw puzzles. When everything appears to be in chaos, I have something to fix; I restore order. I also process different events throughout my day.

The act of puzzling centres me and quietens the loud voices in my head. As I arrange the physical clutter, I discover ways to approach the areas that bring me the most stress. I leave a session filled with

more strength and hope.

Another important lesson that we learned involved a personal commitment to remain connected to one another. My youngest son and I love to build Lego sets. We have a great time together by talking as we attach the parts.

This health crisis the world faces will eventually end. Stores will open, and social distancing will leave our vocabulary. Fear will cease to hold its awful grip on us.

Routine will be a welcomed guest.

For now, let us remember to keep the first thing at the top of our list: the love we have for one another.

May we all have hope for better days to come sooner rather than later.

Edited for size from an article by Cazandra Campos-MacDonald that first appeared in Hemophilia News Today <https://hemophilianewstoday.com/2020/04/09/crisis-hope-covid-19-anxiety/>


World Health Organization

Coping with stress during the 2019-nCoV outbreak



It is normal to feel sad, stressed, confused, scared or angry during a crisis.

Talking to people you trust can help. Contact your friends and family.

If you must stay at home, maintain a healthy lifestyle - including proper diet, sleep, exercise and social contacts with loved ones at home and by email and phone with other family and friends.





Don't use smoking, alcohol or other drugs to deal with your emotions.

If you feel overwhelmed, talk to a health worker or counsellor. Have a plan, where to go to and how to seek help for physical and mental health needs if required.

Get the facts. Gather information that will help you accurately determine your risk so that you can take reasonable precautions. Find a credible source you can trust such as WHO website or, a local or state public health agency.





Limit worry and agitation by lessening the time you and your family spend watching or listening to media coverage that you perceive as upsetting.

Draw on skills you have used in the past that have helped you to manage previous life's adversities and use those skills to help you manage your emotions during the challenging time of this outbreak.



Staying Healthy During The Lockdown

With gyms and pools closed and fitness classes suspended under Australia's social distancing measures, some of us are struggling to stay fit. If this is you, do yourself a favour. Ditch the idea of getting in your best shape ever and focus on meeting the absolute minimum exercise requirements for staying healthy.

Exercising can boost your immune system and improve mental health and at this time you just need to aim at putting in some effort, trying to maintain fitness and going for good enough.

For those who may be sitting much more, most notably because they have 'lost' the activity around their daily commute, it is even more important to be physically active. Here's what the bare minimum exercise looks like under our current lifestyle and social restrictions.

You'll need at least 2-3 hours a week

Australia's national exercise guidelines suggest a bare minimum of two and a half hours of moderate intensity activity, or one and a half hours of high-intensity activity, per week to stay healthy. (Ideally, you'd be doing double that — but maybe don't worry about that until you regularly have the minimum under your belt.)

On top of that, the guidelines also recommend doing muscle-strengthening activities at least two days each week and minimising the amount of time spent sitting.

For high-intensity exercise, think beyond a jog around the block

If you used to rely on swimming, Zumba classes, or another recently banned or restricted form of exercise as your "vigorous-intensity" workout, now's the time to try something new.

Plan for more moderate-intensity exercise than before

If you are missing out on the incidental exercise you used to get from walking or cycling to work or as part of your job, you'll probably need to do at least 10 minutes more each day of this moderate-intensity activity than you used to plan for.



Moderate-intensity exercise is any physical activity that requires some effort, but where conversation is still possible — such as brisk walking, cycling at moderate speeds, or dancing around the living room with your kids. Even a brisk half-hour window-washing session or equivalent is a viable option under the coronavirus restrictions.

If you're just getting out of bed and setting yourself up at

the kitchen table every day to work, and only going to the supermarket, it's easy to only do a few hundred steps a day, instead of the recommended 10,000 steps. Now is the time to pay attention to that pedometer, fitness tracker or smartwatch you got years ago.

Stay strong

The national exercise guidelines don't say exactly how long your muscle-strengthening workouts should last but a 15 to 20-minute routine twice a week should do it.

If you're used to going to the gym and using equipment there, it might be worth investing in some at-home equipment like dumbbells, kettlebells and resistance bands, or wear a backpack filled with books while

There are plenty of free ways to get puffing and panting. Jogging or riding a bike (fast) are both great for cardiorespiratory health if you are not in quarantine, and they also have the added benefit of getting you outside.

If you want to add an extra challenge and a bit of variety to a run, you can add in some interval training. You could use your phone as a stopwatch and do two minutes on, two minutes off, and do six rounds of that. Or have your run but break it up into a five-minute jog, then six to eight rounds of two minutes on, one minute off, then finish with a five-minute jog. You can also make a simple run harder by running up and down a hill or some stairs for 10 or 15 minutes.

No Influence On Factor Levels

A recent study shows that neither Blood Type, nor Von Willebrand Factor play any role in FVIII Levels in people with non-severe Haemophilia A. This European study was published in the February issue of the Journal of Thrombosis and Haemostasis

Researchers at the University of Vienna conducted a study that included 89 adults, at a median age of 51, with non-severe haemophilia A. As controls, the team recruited 82 healthy men.

The lowest FVIII level in a patient's history was used for diagnosis and assessment of disease severity. Researchers assessed FVIII and VWF activity, and measured antigens (proteins) against FVIII and VWF. In addition, they examined links to mutations in the F8 gene, which provides instructions for making FVIII.

Results showed no significant differences in FVIII activity across

the blood type groups in haemophilia A patients. Neither was a correlation found between FVIII activity and VWF activity or levels in patients.

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

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

The researchers concluded that neither blood group, VWF levels, nor age were significantly associated with FVIII activity in patients with non-severe

Haemophilia A. However, in healthy individuals, the combination of blood group, VWF levels, and age explained 61.3% of the variation in FVIII activity.

These findings indicate that genetic mutations are likely the main drivers mediating this protein's levels in non-severe haemophilia A.

The researchers concluded that for patients with mild or moderate haemophilia A neither the blood type, nor the VWF level, need to be taken into account when assessing FVIII levels. Age can be considered a minor modification factor, as there is a consistent, but weak, increase in FVIII levels with age.

From "Influence of blood group, von Willebrand factor levels, and age on factor VIII levels in non-severe haemophilia A," published at: <https://onlinelibrary.wiley.com/doi/full/10.1111/jth.14770>

Staying Healthy *continued*

you work out; try weighted crunches holding a big bottle of water; or do some lunges holding a strong bag filled with cans.

If you have a small child, you might even try (safely) holding them in front of you, in a bear hug, while doing some lunges or squats. Use whatever you've got, as long as it's safe and you feel the benefits.

You can also easily increase the intensity of your strength session by playing with the speed of the exercises. Ten push-ups might be really easy if you do them quite quickly. But if you actually slow them down, it can feel like you've actually done 20 push-ups.

You can also search online for a routine involving body weight exercises such as squats, lunges, push-ups, planks and

hip extensions. You can find some great personal trainers and just follow their at-home body workouts.

Try short, sharp bursts throughout the day

If the idea of a 60-minute run or indoor workout seems daunting, it's totally fine to meet the minimum physical activity requirements by adding short bursts of exercise together.

Rather than waiting until the end of the day to try to do 45 or 50 minutes of exercise, when it's the last thing you want to do and your eyes are hurting, get up every hour" and do a few yoga stretches.

Stay accountable

If you're used to meeting up with a buddy or group to stay fit, you might have to find a new accountability system.

Setting up a routine for your days and weeks will help or get involved in a fitness challenge groups on WhatsApp and Facebook or start one with friends. And don't be afraid to include your children or partner as an option to increasing adherence. Depending on your level of fitness and the age of the children, this may take the format of the children cycling while you are speed walking or running/jogging.

Reduced for size from an article on ABC Life by Grace Jennings-Edquist. <https://www.abc.net.au/life/getting-the-bare-minimum-amount-of-exercise-during-a-lockdown/12125342>

This is general information only. For detailed personal advice, you should see a qualified medical practitioner who knows your medical history.

Maintaining mental well-being during a

We are currently living in a new, uncharted world, with the COVID-19 (or Coronavirus) pandemic possibly causing feelings of anxiety, worry, uneasiness, sadness or feelings of overwhelm with all the news, recommended changes to our lives (social or physical distancing, staying home, going out for essential tasks only, etc), temporary closure of businesses, reduced or changed services and having to change the way we interact with each other. To quote Michelle McQuaid "change is a messy and magical process". OK, so granted it's not feeling very magical at the moment, but it probably is feeling very messy for many of us.

For many people living with an inherited bleeding disorder, you have lived significant parts of your life dealing with uncertainty and learning that there are things that you cannot control.

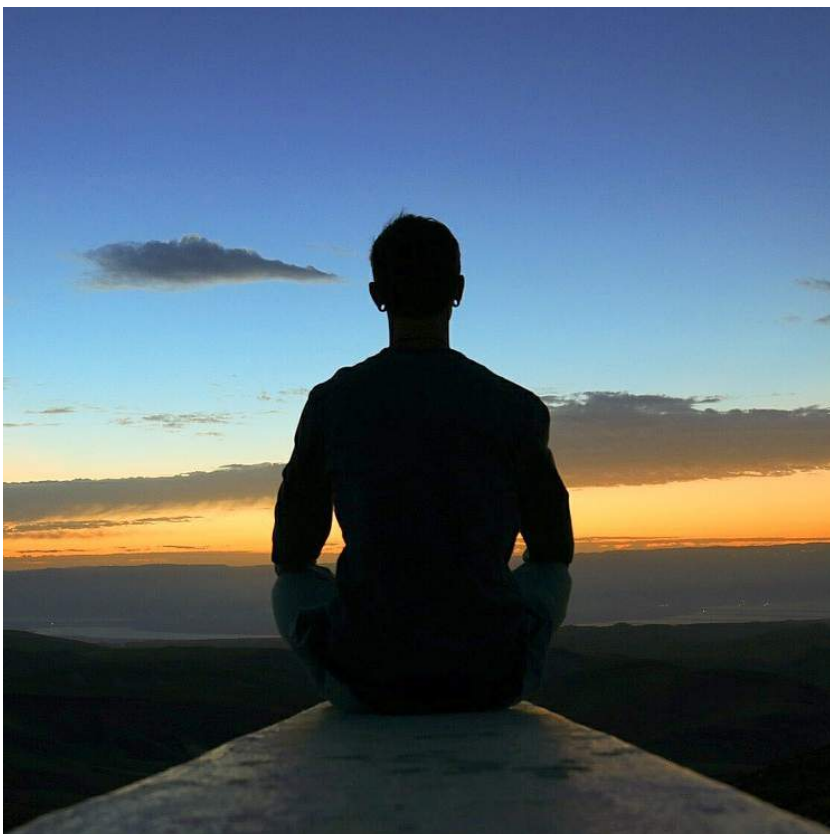
This previous experience will be of great help to you.

Some other strategies that will help:

1. Limit your exposure to media coverage, including social media, print (newspapers) and TV / radio if you are feeling overwhelmed or anxious.
2. Access information from good quality sources – Australian Government coronavirus (COVID-19) alerts <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>

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

Haemophilia Foundation Australia
www.haemophilia.org.au and
Haaemophilia Foundation Queensland www.hfq.org.au



3. Follow directives that are issued by Queensland Health, the Chief Health Officer, Queensland Government and Australian Government (for example – social (physical) distancing, good hand hygiene, staying home and leaving only for essential tasks like grocery shopping). Lifeline suggests a 'calm yet cautious approach'.
4. Showing kindness and compassion – to others, and most importantly to yourself. It is OK to feel anxious and overwhelmed at times, and at other times to feel calm. This is new for all of us and the situation is rapidly changing

(even to the point where some of the information in this article may no longer reflect the current situation as the Government works to keep us safe). Kristen Neff who researches and practices self compassion recommends that you speak to yourself like you would speak to a dear friend.

5. Utilise active strategies to manage your wellbeing – eg phoning friends and family, perhaps this is a good time to learn to Skype or FaceTime (or use another similar tool/app), send emails, SMS.

Remember, connecting with people does not need to be in person. Consider your language/or mindset – Dr Lindsay Jernigan (a clinical psychologist

from USA) suggests seeing social distancing as 'acts of mass cooperation intended to protect the collective as a whole'.

Or you can change your perspective of being 'stuck at home' to being 'safe at home'. Although none of us can change what is happening around us (ie the pandemic), we can control our own actions – doing breathwork, mindfulness or meditation, connecting with friends and family in new ways, getting enough sleep, washing our hands and not touching our faces (I must admit this last one is very, very hard) and our own

Continued on next page →

Pandemic

thoughts.

🔴 Keeping a routine – if you are self-isolating at home or working from home, having things to do – gardening, reading books, starting a new indoor hobby, getting up at the same time and getting dressed for the day and showering are all important things to do.

🔴 Be creative – there are new virtual groups starting up – gratitude posts, kindness posts, COVID Calm – starts Friday 17th April at 11am (unashamed plug). Singing a song for 20 seconds as you wash your hands or practicing mindfulness (especially around not touching your face!). This strategy may lead us forward into where the magic starts as we find activities and ways of connecting that we can use into the future. The pandemic may push you out of your comfort zone, which is scary, but may open up other opportunities which you never thought possible.

The current strategies to 'flatten the curve' have meant that many people may be facing temporary unemployment (hopefully), which will undoubtedly create additional stress. If you are unable to work during the pandemic, are in isolation or hospitalised or caring for children– please contact Centrelink to discuss your options as there are arrangements in place which may allow you to access some benefits until you are able to return to work. <https://www.servicesaustralia.gov.au/> and click on the banner on the top of the page which states "there's information if you're affected by coronavirus (COVID-19)" which will direct you to the specific information about the response to the coronavirus pandemic.

The phone number to try is 132

850 – however there are long delays and difficulties getting through. You can register your intent to claim through the MyGov website. Centrelink have waived a number of eligibility criteria, however your partner (or parent's) income may affect your eligibility to claim a payment and you will need to meet the residence rules and income tests.

Most importantly, please seek additional support if you require it, through HFQ and the Queensland Haemophilia Centre Social Worker (RBWH) and Psychologist (QCH).

Throughout the pandemic, Loretta at RBWH will be running

assist - 24 hours a day / 7 days a week -

🔴 Lifeline 13 1114,

🔴 Kids Helpline 1800 55 1800,

🔴 Beyond Blue 130022 4636 and Suicide call back service 1300 659 467

Loretta

Loretta Riley
Advanced Social Worker
3646-8769

References:

Centrelink: <https://www.servicesaustralia.gov.au/>

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



a virtual group Fridays at 11am called COVID Calm, where you can connect with other members of the inherited bleeding disorders community to discuss what is working for you, share new strategies and gain support. There is no shame in seeking and asking for support. The first step (of reaching out) is the hardest!

Given that we are not available 24 hours a day, there are a number of services who can

Australian Government: <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>

Lifeline: <https://www.lifeline.org.au/get-help/topics/mental-health-and-wellbeing-during-the-coronavirus-covid-19-outbreak>

Beyond Blue: <https://www.beyondblue.org.au/the-facts/looking-after-your-mental-health-during-the-coronavirus-outbreak>

Australian Psychological Society: www.psychology.org.au

How to stay connected

Social distancing can make you lonely. Here's how to stay connected when you're in lockdown

COVID-19, the disease caused by the novel coronavirus, is a challenge for everyone.

We know positive social support can improve our capacity to cope with stress. But right now we're being asked to keep our distance from others to minimise the spread of the virus.

Many people are facing periods of enforced isolation if they are believed to have COVID-19 or have been in contact with someone who has.

Even those of us who appear to be healthy are being directed to practise social distancing, a range of strategies designed to slow the spread of a disease and protect vulnerable groups from becoming infected.

Among other things, this means when we're around others, we shouldn't get too close, and should avoid things like kissing and shaking hands.

This advice has seen the cancellation of large events of more than 500 people, while smaller groups and organisations have also moved to cancel events and regular activities. Many workplaces with the capacity to do so have asked their staff to work from home.

While it's crucial to slowing the spread of COVID-19, practising social distancing will result in fewer face-to-face social interactions, potentially increasing the risk of loneliness.

Humans are social beings

Social distancing and self-isolation will be a challenge for many people. This is because humans are innately social. From history to the modern day we've lived in groups – in villages, communities and family units.

While we know social isolation has a negative impact on health, we don't really know much about what the effects of compulsory (and possibly prolonged) social isolation could be.

But we expect it could increase the risk of loneliness in the community. Loneliness is the feeling of being socially isolated.

Recent reports have indicated loneliness is already a significant issue for Australians, including young people.

Loneliness and social isolation are associated with a similar increased risk of earlier death: 26% and 29% respectively compared to someone who is not lonely or socially isolated. People who are socially vulnerable, such as older people, are likely to struggle more through this uncertain period.

If older adults are forced to self-isolate, we don't have contingency plans to help those who are lonely and/or have complex health problems.

While we can't replace the value of face-to-face interactions, we need to be flexible and think creatively in these circumstances.

Can we equip older people with technology if they don't already have access, or teach them how to use their devices if they are unsure? For those still living at home, can we engage a neighbour to check in on them? Can we show our support by finding the time to write letters, notes, or make phone calls?

Supporting each other

Research shows a period of uncertainty and a lack of control in our daily lives can lead to increased anxiety.

In times like this, it's essential we support one another and show compassion to those who need it. This is a shared experience that's stressful for everyone – and we don't know how long it's going to go on for.

Fortunately, positive social support can improve our resilience for coping with stress. So use the phone and if you can, and gather a group of people to stay in touch with.

Further, positive social interactions – even remotely – can help reduce loneliness. Showing genuine interest in others, sharing positive news, and bringing up old memories can enhance our relationships.

Staying connected

Here are some tips to remain connected when you're practising social distancing or in quarantine:

1. think about how you can interact with others without putting your health (or theirs) at risk. Can you speak to your neighbours from over a fence or across balconies? We've seen this in Italy
2. if you have access to it, use technology to stay in touch. If you have a smartphone, use the video capabilities (seeing someone's facial expressions can help increase connection)
3. check in with your friends, family, and neighbours regularly. Wherever you can, assist people in your life who may be more vulnerable (for example, those with no access to the internet or who cannot easily use the internet to shop online)
4. spend the time connecting with the people you are living with. If you are in a lockdown situation, use this time to improve your existing

Get Your Flu Shot

It's important to get you flu vaccination this year to reduce the risk of a dangerous double-up of influenza and COVID-19.

While the vaccine won't protect you against COVID-19, it will reduce your risk of getting influenza — which kills hundreds of people every year and leads to thousands more hospitalisations.

In 2017, a particularly bad season in Australia, the flu caused more than 1,200 deaths (3.9 per 100,000 people).

The National Immunisation Program (NIP) Schedule provides free flu vaccinations to the people who are most at risk of complications from the flu, including:

- pregnant women,
- Aboriginal and Torres Strait Islander people,
- people aged 65 years and older,
- people with certain health conditions (such as heart disease, diabetes and asthma), and
- all children aged between 6 months and 5 years

Free or not, everyone is encouraged to get a flu shot. If you're not eligible for an subsidised vaccination, you can get one for a small cost through your GP or local pharmacy.



- How to stay connected - continued

relationships

5. manage your stress levels.
Exercise, meditate, and keep to a daily routine as much as you can
6. it's not just family and friends who require support, but others in your community.
Showing kindness to others not only helps them but can also increase your sense of

purpose and value, improving your own well-being.

So get thinking, take considered action, and be creative to see how you can help to minimise not only the spread of COVID-19, but its social and psychological effects too.

Authors Michelle H Lim Senior Lecturer and Clinical Psychologist, Swinburne University of Technology & Johanna Badcock Adjunct Professor, School of Psychological Science, University of Western Australia

This article is re-published under creative commons. Originally published on The Conversation. <http://theconversation.com/social-distancing-can-make-you-lonely-heres-how-to-stay-connected-when-youre-in-lockdown-133693>

For years during the HIV epidemic I reported on developments in HIV treatments. For the first decade this was mainly undermining fake claims that may be dangerous or overhyped success stories. Then as treatments success began it became about promoting them and how to take them properly.

Given the improved pace of research, the level of research resources directed at covid-19 and the level of international cooperation and communication the time for a vaccine or effective treatments may be soon - but that's only if everything goes perfectly - but things rarely go perfectly and until vaccines are trialled we won't know.

It's really tempting for someone like me to write about a lot of the early vaccine development or early speculation about treatments which might have some role - there's a huge amount to write about but the problem with writing about very early speculation is that it has to be read in a particular way - it's publication can help change research priorities based on

However, at the moment it's too soon to write about covid-19 treatment or vaccine development. The best advice for consumers at the moment is that if a really effective treatment happens you will know about it - in the meantime take any early advice about potentially successful treatments with 99.9 out of 100 levels of scepticism.

[illegible]

Second patient cured of HIV?

A study of the second HIV patient to undergo successful stem cell transplantation from donors with a HIV-resistant gene, found that there was no active viral infection in the patient's blood 30 months after they stopped anti-retroviral therapy, according to a case report published in The Lancet HIV journal.

Although there was no active viral infection in the patient's body, remnants of integrated HIV-1 DNA remained in tissue samples, which were also found in the first patient to be cured of HIV. The authors suggest that these can be regarded as so-called 'fossils', as they are unlikely to be capable of reproducing the virus.

Professor Ravindra Kumar Gupta from the University of Cambridge, was the lead author. He said that the results represent the second ever case of a patient to be cured of HIV. Their findings show that the success of stem cell transplantation as a cure for HIV, first reported nine years ago in the Berlin patient, can be replicated.

However, this curative treatment is high-risk, and it is not a treatment that would be offered widely to patients with HIV who are on successful antiretroviral treatment.

In 2011, a patient known as the 'Berlin patient' was the first HIV patient to be reported cured of HIV after undergoing similar treatment. His treatment aimed to make the virus unable to replicate in the patient's body by replacing the patient's immune cells with those of the donors.

This kind of experimental research can provide insight into how a more widely applicable cure might

be developed in the future.

The patient reported in this study (the 'London patient'), underwent one stem-cell transplantation and a reduced-intensity chemotherapy drug regimen. This study reported that HIV had been in remission for 30 months.

The authors highlight that their case study represents a step towards a less intensive treatment approach than the Berlin patient, showing that the long-term remission of HIV can be achieved using reduced intensity drug regimens, with one stem cell transplant (rather than two) and without total body irradiation.



Speculating on what their results might mean for future developments of HIV cures that utilise the CCR5 (HIV resistant) gene, Dr Dimitra Peppas, one of the co-authors said that these two patients are examples of using the CCR5 gene in curative therapies outside of gene editing. "There are still many ethical and technical barriers before any approach

At 29 months, the patients CD4 cell count (indicators of immune system health and stem cell transplantation success) was measured, and the results showed no active viral infection was detected in samples of the patient's blood, or in their cerebrospinal fluid, semen, intestinal tissue, and lymphoid tissue after stopping ART.

The patient had a healthy CD4 cell count, suggesting they have recovered well from the transplant, with their CD4 cells replaced by cells derived from the HIV-resistant transplanted stem cells.

Furthermore, 99% of the patient's immune cells were derived from the donor's stem cells, indicating the stem-cell transplant had been successful.

The authors predicted the probability of cure based on two possible scenarios. If 80% of patient's cells are derived from the transplant, the probability of cure is predicted at 98%; whereas if 90% were donor derived cells, there was a 99% probability of cure.

using CCR5 gene editing can be considered as a scalable cure strategy for HIV."

Writing in a linked comment, Professor Sharon R Lewin, University of Melbourne, Australia, (who was not involved in the study), wrote that the finding of no intact virus can be reassuring for a patient who might face significant anxiety and uncertainty about whether and when viral rebound off ART might occur, which in other settings has been completely unpredictable. The additional data provided in this follow up case report is certainly encouraging but unfortunately in the end, only time will tell if, in the absence of any intact virus, the London patient truly cured.

Edited for size from "Evidence for HIV-1 cure after CCR5Δ32/Δ32 allogeneic haemopoietic stem-cell transplantation 30 months post analytical treatment." By Ravindra Kumar Gupta, et al. published in The Lancet HIV, 2020.
[www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(20\)30069-2/fulltext](http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(20)30069-2/fulltext)

Opioids Underreported for Treating Pain

More opioids were prescribed to treat pain in adults and children with haemophilia than was reported in U.S. national datasets, a new study published in the journal *Haemophilia* shows.

The study researchers say that as such use carries a risk for opioid related complications, haemophilia treatment centres need to take a more active role in pain management and provide alternatives.

While previously opioids have been promoted as a safe treatment option for pain, it has now become clear that their use comes with substantial risks.

Long-term opioid use has been generating concern, with reports from the U.S. and now in Australia showing higher rates of overdose related to prescription opioids.

Although clinical trials support the short-term effectiveness of opioids to reduce pain, only a few studies have assessed the long-term benefits of these medications for chronic pain.

And, despite anecdotal reporting to the contrary from some of our members, the study says there is little evidence that opioids ease pain and improve function and quality of life in people with chronic pain.

In contrast to the increasing number of options available to us to prevent or treat bleeding, options to treat pain in people with bleeding disorders are still lacking.

In the study the US researchers set out to investigate opioid use in haemophilia patients, and compare their findings to a national haemophilia (ATHN dataset) registry and a Centres for Disease Control (CDC) general

population registry. In addition, they wanted to identify predictors of opioid exposure.

The team analysed medical records of 183 adults (mean age of 40.9 years) and 135 children (mean age 10.7 years) with haemophilia from two HTCs between January 2015 and June 2018.

Results indicated that 56% of adults and 21% of paediatric patients were prescribed opioids, which is substantially higher than reported in the ATHN dataset (6%). The researcher found that more men (38 – 49%) were prescribed opioids than the CDC's national population data between 2015 and 2017 (11 – 28%).



The most commonly prescribed opioids to treat chronic pain were oxycodone (37%), hydrocodone (13%), methadone (13%), morphine (11%), and codeine (11%). Among this group, 74% of patients had severe haemophilia.

Amongst the group treated for acute pain, oxycodone (62%), hydrocodone (17%) and codeine (17%) were the most frequent opioids used. As in the chronic pain group, most patients (56%) treated for acute pain had severe haemophilia.

In adults, but not children, severity of haemophilia was a significant predictor of opioid exposure. No

such link was found with different haemophilia types.

Interestingly, most opioid prescriptions were not written by the patients' HTC provider, as only 23% (children) and 34% (adults) of opioid prescriptions were provided by HTCs. This observation was particularly concerning in the paediatric group, as 59% of acute opioid prescriptions were associated with non-joint surgeries, which are not performed by HTC providers.

The researchers say this highlights the importance of HTCs taking a more active role in providing alternatives to opioids to manage pain in haemophilia patients.

They wrote that opioid exposure was more common than predicted in both adult and paediatric study populations and was most often prescribed for acute pain or procedures by non-HTC providers.

The researchers concluded that haemophilia treatment centres need to take the lead in assessing pain in haemophilia patients, guiding treatment promoting non-opioid

options, strengthen efforts to monitor opioid exposure and collect data on pain treatment in the haemophilia population.

This is an edited version of the paper "Opioid exposure in haemophilia patients is common and underreported". We encourage all members with pain issues to discuss them with the QHC team members as they have access to a variety of options that can help address this.

The Study was published in Haemophilia Journal Volume 26, Issue 2 [March 2020] (<https://onlinelibrary.wiley.com/doi/10.1111/hae.13950>) and is available from the HFQ office.

Health Updates

Phase 3 Trial of AMT-061 Gene Therapy for Hemophilia B Exceeds Target Dosing.

A Phase 3 clinical trial investigating gene therapy candidate AMT-061 (etranacogene dezaparvovec) has exceeded this initial goal of dosing 50 participants with moderate or severe haemophilia B.

54 patients have been given the one-time dose of AMT-061. The trial's main goal is to determine whether a single injection can improve FIX activity within 26 weeks. Secondary goals include measuring the number of yearly bleeding events, and how often patients have to use a FIX replacement therapy one year after dosing.

Recently released data from a Phase 2b trial (NCT03489291) showed that treatment with AMT-061 resulted in sustained FIX activity and no spontaneous bleeds one year after dosing in three patients with severe haemophilia B.

According to uniQure, treatment with AMT-061 did not cause an immune response against the viral vector in any trial so far, indicating the therapy's safety.

<https://www.globenewswire.com/news-release/2020/03/26/2006871/0/en/uniQure-Announces-Achievement-of-Target-Patient-Dosing-in-HOPE-B-Pivotal-Trial-of-AMT-061-Etranacogene-Dezaparvovec-in-Hemophilia-B.html>

Education Needed for Successful Weight Loss in Obese Haemophilia Patients.

Although obese people with haemophilia — as well as their spouses and caregivers — are aware of the risks of excessive weight, fewer than half are actively taking steps to lose weight, a new study shows.

The study, "Awareness, Care and Treatment In Obesity maNagement to inform Haemophilia Obesity Patient Empowerment (ACTION-TO-HOPE) was designed to identify insights on the specific challenges faced by these patients and barriers to successful weight management.

The study included 124 adults with haemophilia (median age 35) who self-identified as obese or overweight. Most (61%) had haemophilia A and the

remaining 39% had haemophilia B. Over the prior five years, only a minority said they were successful (9%) or somewhat successful (38%) in losing weight.

The majority of people with haemophilia anticipated that weight loss would reduce joint pain (62%), bleeding (58%), recombinant therapy use (52%), and also improve mobility (62%).

The researchers said that most patients desired more education on weight management and more details on specific actionable recommendations distributed through existing haemophilia channels.

https://hemophilianewstoday.com/2020/04/01/education-needed-for-successful-weight-loss-in-obese-hemophilia-patients-study-suggests/?utm_source=Hemophilia+News&utm_campaign=48ab80f37f-RSS_EMAIL_CAMPAIGN_NON-US&utm_medium=email&utm_term=0_ab10fdd11a-48ab80f37f-71884349

FDA OKs Rabbit-Derived Drug for Haemophilia.

The FDA has approved a recombinant coagulation factor VIIa (Sevenfact) for treatment and control of bleeding in haemophilia A or B with inhibitors in patients 12 years and older.

Sevenfact is the first product for haemophilia treatment that contains an active ingredient obtained from genetically engineered rabbits to produce a protein necessary for blood coagulation.

Sevenfact's active ingredient is expressed in the genetically engineered rabbit's mammary glands, secreted into their milk, and then converted into activated FVII (VIIa) during the milk's processing.

The recombinant DNA construct, which is inserted into the rabbit's genomic DNA, was found to be safe for the rabbits and humans handling them, and approved by the FDA's Centre for Veterinary Medicine.

<https://www.fda.gov/news-events/press-announcements/fda-approves-additional-treatment-adults-and-adolescents-hemophilia-or-b-and-inhibitors>

Catalyst Preparing to Launch Phase 3 Trial of MarzAA in Haemophilia.

Catalyst Biosciences is preparing to launch a Phase 3 clinical trial assessing marzeptacog alfa activated (MarzAA) for the treatment of bleeding episodes in people haemophilia A or B with inhibitors, but the exact timing depends upon the resolution of the COVID-19 pandemic.

The upcoming trial aims to recruit 75 patients worldwide to study the safety and efficacy of subcutaneous (under-the-skin) injections of MarzAA as an on-demand treatment. Patients may receive up to three injections for each bleeding episode.

In a prior Phase 2/3 trial, preventive treatment with MarzAA significantly reduced the number of bleeds per year and lowered the proportion of days with bleeding.

During the treatment period, yearly bleeding episodes dropped from 20 to 1.6, and the proportion of days troubled by bleeding dropped from 12% to only 0.8%.

The treatment was safe and well tolerated, with only two patients experiencing reactions at the injection site. Notably, no inhibitors were detected.

Recent studies have suggested that MarzAA can not only prevent bleeds in haemophilia patients, but also treat acute bleeding episodes when they happen.

An additional study also suggested that MarzAA may safely be used to treat breakthrough bleeds in people on preventive treatment with Genentech's Hemlibra (emicizumab). It also provides a more convenient method for treating bleeds, since current treatments used in combination with Hemlibra require intravenous (into-the-vein) injections.

<http://www.globenewswire.com/news-release/2020/04/06/2012086/0/en/Catalyst-Biosciences-Announces-Pivotal-Phase-3-Study-Design-for-MarzAA-in-Individuals-with-Hemophilia-A-or-B-with-Inhibitors.html>

Bullying Goes High-Tech

How parents can help kids cope in the age of cyberbullying

Bullying has moved beyond the schoolyard to the digital playground. Cyberbullying, the use of technology to threaten, intimidate, harass, embarrass or target another person, has been a growing problem.

About 21% of children aged 12 to 18 report being the victims of cyberbullying through a combination of text messages, social media apps and online gaming platforms.

The consequences for victims can be both immediate and long-term, including decreased self-esteem, increased anxiety, depression, difficulty in school, self-harm and even suicide.

Unfortunately, most children who are cyberbullied do not tell their parents. According to recent research, just 1 in 10 children tell an adult if they're being cyberbullied.

Magnifying the situation is that many kids, bullies and victims alike, operate anonymously, using apps or accounts that mask their identities.

Instead of expending a ton of energy trying to stay ahead of the technology curve, parents should consider the following when educating their children about cyberbullying.

1. Talk with your kids early about cyberbullying, and keep the conversation going.

Cyberbullying can start with simple texting. So before your child gets their first mobile phone, discuss digital safety with them and establish how you will monitor your child's online safety. Explain privacy issues, and address cyberbullying

directly.

It's important for kids to know that they have a right to be safe on their mobile just like they have a right to be safe in school. They are entitled to a good experience.



2. Consider a "prevention through education" approach.

When kids don't understand someone else's differences, they're more likely to react to it, and sometimes in inappropriate ways. If your child is being targeted based on their bleeding disorder or any other medical condition, a little education can go a long way.

Most kids want to do the right thing and it's up to each child and their entire family to decide what they feel comfortable sharing. As a family you can help them know what the right thing is to do and peer education from friends and siblings can be a positive approach to developing empathy in other children.

3. Don't dismiss it. Listen closely and be supportive.

Cyberbullying is an imbalance of power. It's not something your child can simply ignore. The wrong thing to say is words like: "Just stay off your mobile or computer." Because so much of life is now online, including schoolwork, that's just not realistic.

What is often heard from children who are bullied is the statement 'I feel so alone.'

So have the conversation. Find out the details. You want to make sure your child feels supported. You want to make sure that they know you're there for them."

4. Involve your child in the solution.

It's so important to listen to your child, because they know the social nuances within their culture. You're giving them some of the power back in this situation, and you're not going to do anything that makes them uncomfortable.

To help families address school based cyberbullying incidents, The Queensland government has a website <https://www.qld.gov.au/education/schools/health/cybersafety>

Legal Aid Qld has an excellent resource on cyberbullying and the law at <http://www.legalaid.qld.gov.au/Find-legal-information/Factsheets-and-guides/Legal-information-guides/Cyber-bullying-sexting-and-Facebook-guide.-Know-the-law-know-your-rights>

Adapted and edited for size from an article by Rita Colorito originally published on Hemaware <https://hemaware.org/life/bullying-goes-high-tech> used with permission

Dealing with Unhelpful Friends & Family

Not everyone you encounter will handle your child's bleeding disorder appropriately. Here's some things you can do.

In a perfect world, everyone would be knowledgeable, understanding and supportive about your child's bleeding disorder.

In the real world, unfortunately, that isn't always the case. Maybe there's an uncle who continually roughhouses with your child. Perhaps a friend or relative routinely gives you unsolicited parenting advice that's off the mark - and potentially dangerous. Or maybe it's a neighbour who treats your child with pity and tells their own children that they should feel sorry for your child because of their bleeding disorder.

Dealing with these unhelpful or difficult people can try your patience and cause friction in your relationships. What's the best way to cope?

1. Don't assume your family knows the drill

Sometimes we take it for granted that members of our family will always know what they should and shouldn't do if a child has a bleeding disorder, but that's not always the case.

So if a family member is being reckless or otherwise doing something that could be harmful to a child with a bleeding disorder, the solution is to educate them the same way you'd talk to someone who was meeting your child for the first time.

It might be best to not address the issue right after you see your relative playing rough with your child, as the adult might be more open to the conversation during a separate time and space. It's often better to wait to talk to them, either over the phone or in person at a time when you think they would be most receptive to having the conversation.

Your child's haemophilia treatment team can also be a resource. Talk

to the team at the QCH Haemophilia Centre who will have resources and helpful ideas to help you talk to your family members and answer questions.

2. Start on a positive note

Whether you're talking to someone who's not being safe or who's walking on eggshells and pitying your child, it's best to begin by emphasising something positive. So, if one of your in-law's is playing too rough, you could start out by saying you're grateful that they like to play with your child, and you know your child enjoys playing with them too. From there, you can explain why playing rough can be dangerous and provide examples of other activities that your child could do with his relatives.

In the case of a neighbour who feels sorry for your child and treats them with pity, you could start by telling them you appreciate how thoughtful and careful they are. Then, you could remind the neighbour that even though your child has a bleeding disorder, it doesn't define them and they're living a normal life.

3. Use "I" instead of "You"

When talking to friends and relatives, using "I" statements instead of "you" statements can make a conversation more positive and less tinged with blame.

Starting a sentence with 'I feel' or 'I need or want' can really help two people in a conversation relate to each other more and ultimately lead to a shared perspective.

For example, if a close friend or relative is in the habit of sharing incorrect information about bleeding disorders on social media, you could say, "I understand that you would like more people to understand my child's bleeding disorder, but not all of the information that you are sharing is the same as what my

child's haemophilia treatment centre has given us about their diagnosis and treatment. Would you mind if I emailed you some information?"

4. Validate the other person's feelings

If people are giving you unsolicited advice, hear them out and acknowledge where they are coming from, even though you don't agree with what they are saying. You can say, 'I can see why you think that or why you would recommend that.' You can then gently remind them that you are working with your child's medical team to provide them with the best care for their bleeding disorder and that you prefer to stick with the team's recommendations.

No matter who you're dealing with, if you assume the person has good intentions, it can help you handle the situation better.

Try to remind yourself that most people, like you, want the best for your child - they want them to grow and thrive and be as normal as they are able to be.



Edited for size from an article by Donna Behen first published the Hemaware <https://hemaware.org/life/4-ways-deal-unhelpful-friends-and-family> used with permission

Important Dates for HFQ Members

It's obvious that in these days of social distancing it's very hard to meet and offer support in person. If you're feeling isolated please call the office mobile (0419 706 056) as Graham will be happy to have a chat and also see if HFQ can help in any way.

There are still some dates and events we hope will happen, even if later in the year...

World Haemophilia Day
17 April 2020

OBE Men's Forum
Going on-line for now
Call for details

Women's Lunch
Going on-line for now
Call for details

Community Camp
Postponed
New Dates TBC

Youth Camp
Usually held in October so may still run
TBC

Please ask for events and activities happening in your area.

Please call Graham at the office on **07 3017 1778** for more info on any of these events and activities.

COVID Calm

Invitation

Metro North Hospital and Health Service *Putting people first*

Loretta Riley (Advanced Social Worker – Queensland Haemophilia Centre) invites you to attend/participate in:

COVID Calm

A weekly virtual group for the inherited bleeding disorders community to provide support to each other, share ideas on living whilst COVID-19 is impacting on our lives.

to be held on

Fridays at 11am

Via teleconferencing (phone)

And videoconferencing

(requires laptop/computer/smart phone with internet connection/data allowances and camera)

Please RSVP to Loretta on 0428 756 071 or loretta.riley@health.qld.gov.au

For more information about this event, please contact Loretta (Haemophilia Social Worker) on 0428 756 071 or loretta.riley@health.qld.gov.au

Throughout the pandemic, Loretta at RBWH will be running a virtual group at 11am on Fridays called COVID Calm, where you can connect with other members of the inherited bleeding disorders community to discuss what is working for you, share new strategies and gain support.

This group will run via either videoconferencing (similar to FaceTime or Skype, using a secure portal) or telephone conferencing. Please contact Loretta (0428 756 071 or Loretta.riley@health.qld.gov.au) to get instructions on connecting to this group. Additional days and times can be added if there is enough interest.

There is no shame in seeking and asking for support. The first step (of reaching out) is the hardest!



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.

Graham Norton
HFQ Manager & The 'H' Factor editor
Ph: (07) 3017 1778 E: info@hfq.org.au