the FACTOR

Issue 60
Spring 2019
Newsletter of Haemophilia Foundation Queensland

From the President

Hi everyone,

I imagine for all of us, that we have not won the lotto and life remains much the same. For me I have returned from my uncle's 100th birthday ....and he is still going strong, as I imagine all of you are.

This edition I wanted to bring you hope for an improved bleeding treatment future next year - as some of you will be aware the National Blood Authority tender closed on the 16 July, and it will be interesting to see the outcome as tender responses are evaluated and any improvements then slowly implemented in the new calendar year (over a 6 month period).

I can only reassure everyone that there is genuine concern from the NBA about treatment outcomes for you & me - I really believe that after discussions with their CEI & 2IC. I know some will be concerned about possible treatment changes but I firmly believe we are in good hands. As usual, HFQ will bring you the latest info as it unfolds.

In the global picture it's good news; for example Canada has just approved Hemlibra (under the skin injection for haemophilia A) for all that need it (those with inhibitors, non inhibitors - and it covers all ages, just brilliant!) ...let's see what happens in Australia.

Wherever you are in the bleeding picture there are more international options slowly blooming through the evolution of science - an exciting time

Inside this issue:

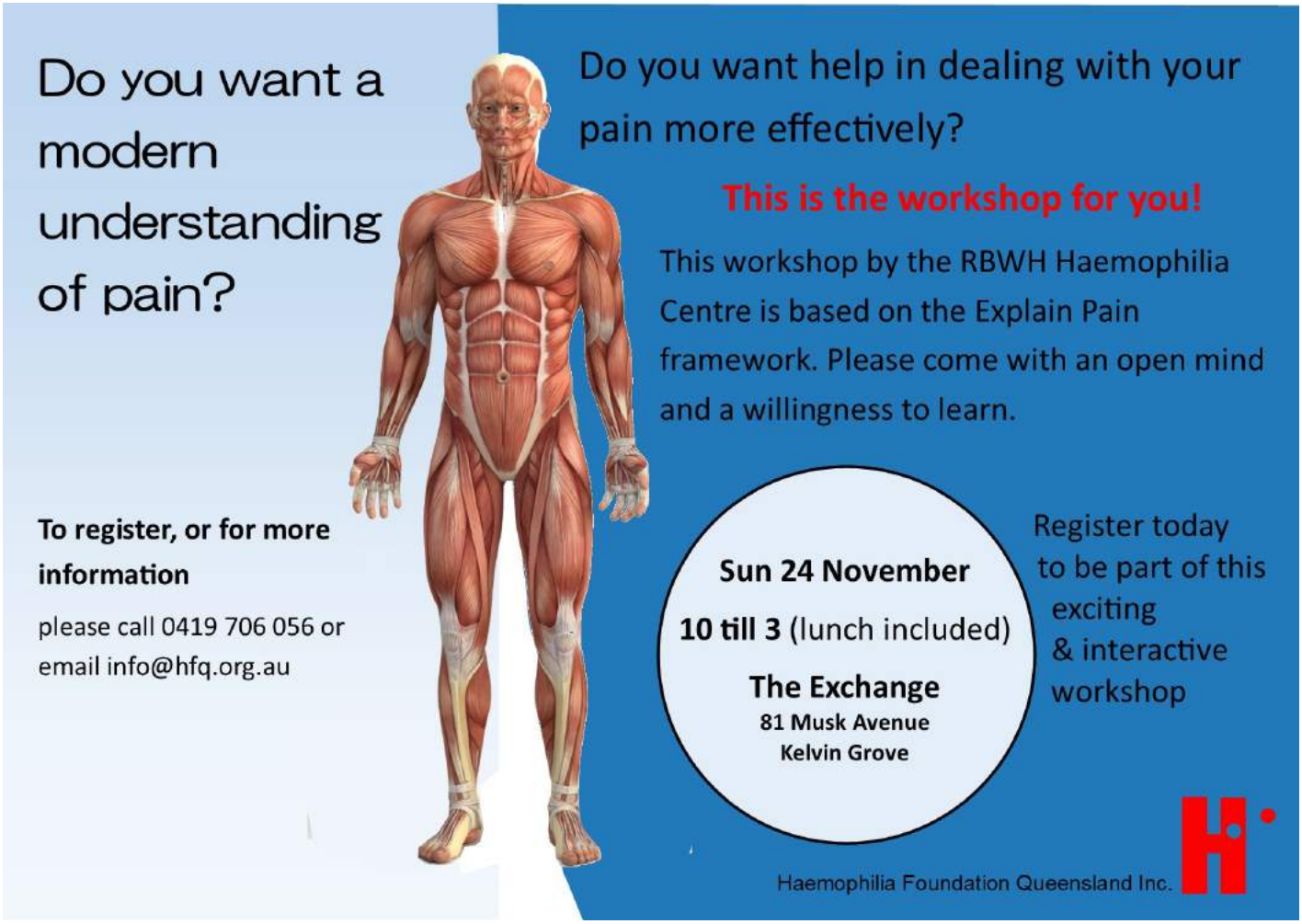
Presidents Message continues

indeed, and I aim to bring you more of the 'good news possibilities' from our national conference in October (Sydney later this year). I hope one day that HFQ will not be needed, that science will have curative therapies - perhaps a real possibility for the young, but not for those with damaged joints & associated issues due to bleeding.

Take care until next time

David Stephenson
President HFQ
president@hfq.org.au

Pain Workshop coming soon...



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)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	Mr David Stephenson
Vice President ...	Mr Robert Weatherall
Secretary	Ms Lauren Albert
Treasurer	Mr Adam Lish
Members	Dr John Rowell
	Mrs Leanne Stephenson
	Mr Mike O'Reilly
	Mr Mike Holloway

HFQ Delegates to HFA

Mr Adam Lish & Mr David Stephenson

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 Julia Wells

Joanna McCosker – Nurse Practitioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Stephanie Manning – 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

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - Haematologist	3646-8111 *(Mobile 0452 055 025)*
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 or speak to Beryl

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 LCCH-Haemophilia at QCH and Beryl at RBWH.

Services to maintain your independence

After attending the Future Proofing event, facilitated by Preetha (Ageing Project Officer from Haemophilia Foundation Australia) a few people reported that they were not aware of the community services and supports that are available as we age. To ensure this opportunity is not missed, my article this week is really a summary of some of the overarching (mostly subsidised) services that are available.

This is by no means an exhaustive list, but rather one that gives you an idea of where to start if you are looking for specific support. I have identified the ones which are only available for Queenslanders, and have added ones I know about in NSW, for our Northern NSW members. I am more than happy to talk to anyone individually about your specific circumstances to ensure you are linked with the most appropriate resources. This information does not cover the fee for service/non-subsidised services and is intended as general information only.

Aged Under 65

The National Disability Insurance Scheme (NDIS) provides funding for supports and services for Australians aged under 65 (who have a permanent and significant disability. Its aim is to provide assistance or products/equipment that help a person in their daily life and which helps them participate in the community and reach their goals.

Eligibility: Aged between 7 and 65; live in Australia and are an Australian Citizen or have a permanent or special category visa; have an impairment or condition that is likely to be permanent and stops you from doing everyday things by yourself.

Call NDIA (National Disability Insurance Agency) on 1800 800 110 to discuss your eligibility and to organise to be sent an Access Request Form.

More information can be found at www.ndis.gov.au

Queensland Community Support Scheme (QCSS)

QCSS is a new scheme to provide support to people under 65 (or for Aboriginal and Torres Strait Islander people aged under 50), who have a disability, chronic illness, mental health or other condition or circumstances that impact on your ability to live independently and who are not eligible for the National Disability Insurance Scheme.

The scheme aims to enable you to gain or maintain your independence to live safely in your home and actively participate in the community, with a little assistance. It can provide assistance for example with cleaning, meal preparation, showering and dressing, support to go shopping, basic home maintenance (like mowing). You don't need a referral, you can call them on 1800 600 300, email QCSSacesspoint@ozcare.org.au or complete the online client registration www.serviceavailabilityregister.com.au. Further information can be found online at https://www.qld.gov.au/community/getting-support-health-social-issue/community-home-care-services/queensland-community-support-scheme.

Aged Over 65

My Aged Care is the starting point for accessing services to help you around the home or when you are beginning to look into residential aged care homes (nursing home care). Depending on your care needs, services which help you remain at home can be accessed through the Commonwealth Home Support Programme (if you need help with a few tasks) or a Home Care Package (if you require a number of services or have more complex care needs). An assessment process determines what program is more suitable for you. To find out more information or to apply:
Phone 1800 200 422
https://www.myagedcare.gov.au/
My Aged Care is also the access point for Respite Care (short term care), Transition Care (after you have been admitted to hospital and need some additional time to recuperate) and Long term care in an aged care facility.

Subsidised funding for Aids and Equipment

Medical Aids Subsidy Scheme (MASS) "provides access to subsidy funding for the provision of MASS endorsed aids and equipment to eligible QLD residents with permanent and stabilised conditions or disabilities.

To be eligible for MASS, you need to be a permanent

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Paediatric Team Update Aug 2019

Senior Medical Staff Rotation
We would like to farewell Nathan Morgan and Nikki Brennan.

We have a new registrar; her name is Julia Wills and she will be with the team until the beginning of November.

Upcoming Leave and other things
Amy will be on leave for 3 weeks in September and Tamara Shannen will cover for two of these weeks.

Simon Brown is on leave in early October.

Moana will now work Monday to Thursday's only.

Just a reminder that Gold Coast, Sunshine Coast and Toowoomba outreach clinics are upcoming.

HAEMOPHILIA MOBILE
A reminder to families that the Haemophilia mobile is not manned on weekends or public holidays.

You can speak to the Haemophilia nurse Monday to Friday between 8am and 4pm.

HAEMOPHILIA EMAIL
A huge thank you to all the families who are using the haemophilia email to communicate non-urgent requests to the team; we really appreciate it and it has helped manage the requests more efficiently.

HAEMATOLOGY FELLOW
Antoinette Runge is the current doctor in the fellow position (super senior Doctor) and will continue in this role until the end of January 2020.

Services to maintain independence *cont...*

Queensland Resident. Have a permanent or stable condition/disability, have a pensioner concession card, health care card or QLD Government Seniors card. The different aids and equipment also have a clinical eligibility which you need to meet.

Some medical aids and equipment that MASS subsidises include:

- communication aids
- daily living and mobility aids
- medical grade footwear
- Spectacles
- continence aids
- home oxygen
- orthoses
- artificial limbs"

There have been some changes with MASS since NDIS began, so it is best to phone them directly for some guidance before beginning the assessment process – which will be different depending on what you apply for.
Phone: 1300 443 570
https://www.qld.gov.au/health/support/equipment/subsidies

EnableNSW provides equipment and services to people in NSW (must be a permanent resident of NSW) with chronic health conditions or disability (lasting longer than 12 months) to assist them with mobility, communication and self-care. The aim of the equipment and services is to remain independent at home. Like MASS, there is an application and assessment process, which is required for the different equipment and services.
You can get further information by phoning 1800 362 253 or looking at their website http://www.enable.health.nsw.gov.au/

Carers QLD/Carers NSW
Are the peak bodies representing unpaid carers' and provide support through advocacy, counselling and advice (for example). They have a Carer Advisory Service, providing information and advice about carer supports and services, counselling and support groups. Carers QLD also has a no Interest Loan Scheme. Carers QLD and NSW can both be contacted Monday to Friday 9am-5pm on 1800 242 636. Further information can be found on their websites: https://carersqld.com.au/; https://www.carersnsw.org.au/

Please don't hesitate to call me at the QLD Haemophilia Centre, Royal Brisbane and Women's Hospital to discuss your specific needs on 36468769

Kind regards
Loretta

Gene Therapies Only Work For Some!

Gene therapies could offer a long-term fix for haemophilia and a host of conditions – except that many people's immune systems react to them. So researchers are looking for ways to help the treatments sneak past our antibodies.

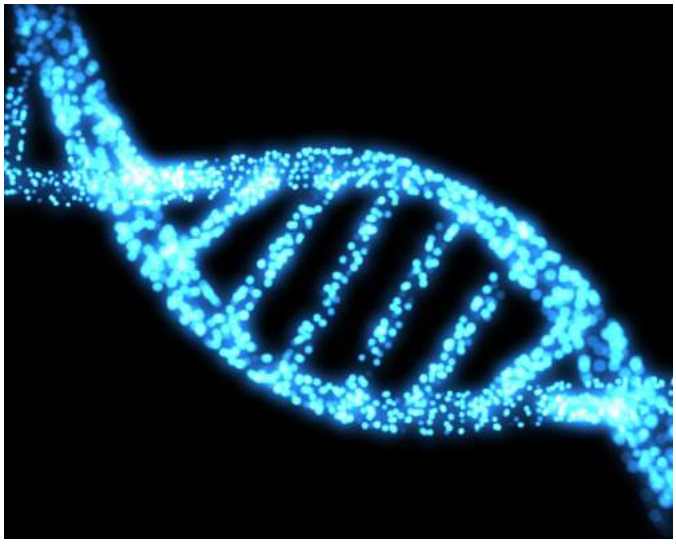
Growing up in Queensland in the 1970s, brothers Matt* and Mark* had to be careful with their antics – a cut or bruise could land them in hospital because of their haemophilia. As an adult Matt had to have a liver transplant and that provided an effective cure for his haemophilia as the new liver produced it's own factor. So when Mark heard about a clinical trial for an experimental gene therapy being run in NSW by Prof John Rasko, he was intrigued and excited, this could be the chance for him to have an effective cure too.

Gene therapy is a simple idea: if you inherit a faulty gene, then putting a working copy into the body's cells should fix things. For people like Mark these new treatments could be life changing. There's just one problem. For many of us, they won't work.

With severe haemophilia, patients have to boost their factor every three to four days, but gene therapy would instead give their bodies a working gene for them to make their own factor. But transferring a gene into a person is no easy feat. Genes are long strings of DNA that don't readily get inside cells. So therapies typically rely on a virus, modified so that it doesn't cause disease, and with the healthy human factor gene added to its DNA, injected into the body. It then enters the body's cells to deposit its cargo, leaving it as a separate piece of DNA in the nucleus next to the host cell's genome. The cells then start using the implanted gene to create factor.

So after years of regular treatment and being careful of which activities he did, Mark decided to sign up for the clinical trial. It was a small study, and part of a world-wide trial, but when he went down for some pre-trial tests, one of those tests revealed Mark had antibodies for the adeno-associated virus, or AAV, that the trial was using as the therapy's carrier. An infection earlier in life had rendered him immune to the treatment.

Mark is not alone. Across the population, it's thought that immunity to AAV, the type of virus used in this study, could be as high as 50 to 70 per cent. But estimates vary and we don't really know the scale of the issue. What we do know is that several Queensland members have started this trial process only to be rejected because of their pre-existing immunity and that it will severely restrict who gets to be treated if and when these therapies become widely available.



Immunity to AAV is gene therapy's Achilles heel. These are incredibly potent therapies, but they are only going to be relevant to a sliver of the population. So why, then, transport genes with such a common family of viruses that so many people have been exposed to? The truth is that AAV wasn't originally the leading candidate for gene delivery.

In the first trials to transfer genes into humans the preferred vectors were retroviruses and adenoviruses; but in 1999 a trial patient developed a fever and other reactions to the virus that could not be stopped. He slipped into a coma and died of multiple organ failure four days after receiving the treatment.

The trial was promptly stopped and the patients death cast a long shadow over the genetic treatment field. So, with heightened concern about patient safety, it was AAV's time to shine. It was known that AAV could safely shuttle genes into lab animals, and that the genes then worked and so AAV become a serious candidate for gene delivery.

But this isn't helping people like Mark. If you are fortunate and don't have pre-exposure to AAV, you can get treated; if you are not fortunate, you can't. So the researchers are trying to find ways to overcome the remaining challenges, such as pre-existing immunity. By creating new variants in the lab that are no longer recognised by antibodies. An alternative approach is to create many, many mutant variants, and then select those that slide past the immune system unnoticed.

The possibility of genetic treatments may cause friction in our community because of the current lottery pre-exposure and antibodies to AAV's causes and because of cost. Even for members who may be successful there may be guilt and sadness about getting the treatment and an effective cure when others don't. And no one knows how long current gene therapies will work, although earlier gene therapy trials for haemophilia offer a lot of hope: trial patients, including one from Australia are continuing to produce their own clotting factor eight years later.

If patients lose their modified cells

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Loretta Riley spends 5 minutes with Brett

What's your role within the Haemophilia and other bleeding disorders?
I am the Advanced Social Worker

What was your previous profession?
At the end of this year, I will have been a Social Worker for 25 years. I have worked in Mental Health teams, Hospitals (in Australia, the United Kingdom and Ireland) , rural Communities and child protection.

How long have you been in the role of social worker?
I started at the Queensland Haemophilia Centre in February 2016.

Before joining HTC, how much did you know about haemophilia?
I had done a lot of reading about Haemophilia when I saw the job advertised and spoke at length with Maureen (the previous social worker) before I applied. I had also read "April Fool's Day" by Bryce Courtenay. However, in all honesty, I didn't know that much. I have learnt a lot since working in this team.

Why the move to HTC?
I saw the job advertised at a time when I wanted a change from where I was working. I saw it as an opportunity to expand my knowledge and use the skills I had gained over my career. The way Maureen described it seemed like a good fit for me with my work in hospitals, rural communities and mental health.

Do you have any hobbies?
I have 3 main hobbies. One I have been doing a lot more of than the others, but they all tie in together. I really enjoy gardening. Although I don't have a big garden, I try to fit as much as I can into it and it is growing into my house, with an expanding indoor plant garden too. I mostly have edible plants outdoors – lots of herbs and started on edible flowers. Have some vegetables and fruit too. Thanks to a discussion with a member of the haemophilia community, I also have a native bee hive, which has been an invaluable addition to my garden, with more plants being pollinated. My other hobbies are baking and photography. I don't put nearly enough time into these two activities.

Are you liking your new role?
Yes.

I'm gathering that you are learning new things every day?
I think it is important to never stop learning. It is important for me to stay up to date with the new research and ways of 'doing social work'. If I don't, I am doing myself and more importantly, the community a dis-service.

This year my skills and knowledge have been expanded in coordinating the Art Exhibition (with the knowledge coming from within the inherited bleeding disorders community), I have learnt a lot about pain and ways to understand pain (please come to our workshop in November to find out more) and learning more about emotional well -being (happiness- find out more in September). I have also been on a steep learning curve about gene therapy and the other treatments that are on the way.

In actual fact, I learn something new every day, about what makes people resilient, what has helped them and how it impacts on the community.

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as they regenerate, they may not be able to repeat the treatment, because it's likely they will then be immune to it. However, in the future, we may not need viruses for gene therapy. Researchers are looking to develop other delivery methods, from liposomes – fluid-containing fatty molecules that can fuse with the cell's membrane – to synthetic nanoparticles that won't be seen by the immune system. Researchers are also investigating gene-editing methods to permanently embed the working gene into the recipient's genome.

There's a lot of funding going into gene therapy research, so problems will become easier to solve. It's only a matter of time.

* Some names have been changed.

This article is edited for size and local content from an article "Gene therapies only work for some people – so how do we fix this?" by Jovana Driniakovicthe, which first appeared on Mosaic and is republished here under a Creative Commons licence. For the full article please go to;*.https://mosaicscience.com/story/gene-therapy-treatment-clinical-trial-immunity-aav-haemophilia-genetic-disorder*

Getting Better Sleep

For people with bleeding disorders, a good night's rest is important. It can help with a more responsive immune system and better cardiovascular health. Sleep can also help in avoiding weight gain, which puts more pressure on joints, and in lessening the risk of anxiety and depression, so it pays to understand what to do and what not to do so you can protect your precious ZZZ's.

Do get regular exposure to sunlight during the day.
Getting at least 30 minutes of sunlight in the morning can help regulate the body's natural sleep-wake cycle.

Don't use smartphones, computers, tablets or watch TV for at least 30 minutes before bed.
The problem is that the light from screens stimulate the brain and leads to suppressed production of melatonin. Instead of looking at a screen, try reading an old-fashioned paper book or magazine before bed.

Do keep a sleep diary.
Use an apps or wearable devices to record you sleep cycle, or write down in a notebook what time you go to bed and what time you wake up. You'll quickly see how many hours sleep you're getting at night.

Don't drink caffeine late in the day.
It's a stimulant and it takes the body about four to six hours to metabolize half of it. Everyone is different so experiment to discover what timing works for you, but being conservative and cutting caffeine in the evening is a safe choice.

Don't rely on sleeping pills.
Sleeping pills should not be taken for too long. If you really need pills, talk to your GP about trying melatonin supplements to help you sleep better.

Talk to the QHC team.
CBT can help adults with chronic insomnia. Talk to your QHC psycho/social team member about this option. The QHC team can also help you find ways to manage chronic pain if it prevents you from falling sleep or is waking you up.

Community Camp 2020

HFQ Community Summer Camp

a great reinvergrating time away

Announcing our 2020 Summer Camp

Fri 3rd April to Sun 5th April

Noosa North Shore Retreat.
1 Beach Rd, Noosa North Shore

$75 per family
$50 per couple
$30 per individual

Camp is a space that allows everyone to be uniquely themselves and creates an atmosphere of support and inclusiveness

Online registration is now open

Noosa North Shore Retreat *3 - 5 April 2020*

https://www.hfq.org.au/get-involved/events/camp Mob 0419 706 056

Haemophilia Foundation Queensland Inc.

Wellbeing for Caregivers

If you have a child, partner or other family member with a bleeding disorder, you will know first-hand that supporting them can be emotionally and physically taxing. A parent or partner steps in out of love and does everything that's needed to help the person with the bleeding disorder. It can be like a second job. You always put in overtime and you're never off-duty.

In families with a history of bleeding disorders, the diagnoses of a child can still be a shock and raises fears if the parent has seen other family members struggle. Parents (especially mothers) days revolve around medications schedule and feeling a need to watch their child's every move. Decisions on health care and levels of activity that are safe for their child can mean many parents feel they have to be watching 24/7.

Being a full-time caregiver for someone with a medical condition or chronic illness can impact on your own physical and emotional health. The pressure of caring for another person releases hormones (such as cortisol and adrenaline) that can lead to irritability, headaches, poor digestion and even a weakened immune system.

If your foot is on the accelerator all day long providing support for the person in your life with a bleeding disorder, it can lead to physical, emotional and mental exhaustion. A recent study in *The Journal of Haemophilia Practice* found that parents of children with bleeding disorders who perceived their caregiving role as burdensome reported higher levels of physical pain and poorer social functioning.

Unfortunately, caregivers often don't recognize that they are carers, much less take steps to lessen their load. Caregivers won't take time off for themselves. They take time off to go to doctor appointments, run errands or clean the house, but not to put their feet up and take a breath or go for a walk. However, if you can't take care of yourself, you really can't take care of someone else.

CAREGIVER CARE

How can you avoid (or recover from) caregiver burnout? These measures can help…

Take stock of yourself

Since burnout CAN go unnoticed, the first step is to do a self-check. It might be hard to take the time to self-reflect honestly and without judgment, but this step is crucial in starting to find some balance and get support. Be alert to signs like fatigue, sleeping problems, feeling overwhelmed or anxious, unexplained aches and pains, weight gain, frequent illness and social isolation.

Put on your oxygen mask first

Just like any role or job, you need occasional breaks. Give yourself permission to have a break, even if it's just taking a walk or having a cup of coffee by yourself for a half-hour. Then work up to a movie or a night out with friends. Once you're used to getting a babysitter or trusting your partner to look after themselves, taking a time out for you will become a little bit easier.

Allow all of your feelings

Sometimes people acting as the caregiver can feel anger and resentment about it …and then right after that, feel guilty for having those thoughts. It's normal to have a range of feelings, try not to beat yourself up over the negative ones.

Practice self-soothing

When you're stressed out and your breathing is shallow, stop and inhale deeply and exhale deeply. It really can help to de-stress in the moment. Regularly practicing meditation, guided imagery or other calming techniques can help in the long term.

Prioritise Exercise

A good way to counter the negative effects of stress in the body is to exercise. It doesn't have to be the gym, running or high-intensity workouts. Some caregivers do activities like yoga and tai chi, which do double duty, exercising the body and quieting the mind.

Seek the company of others

One of the best ways to prevent burnout is to enlist the support of others, particularly those facing the same challenges as you. Being around others like you can be a great feeling, and it builds that sense of community that makes it not seem as tough, think about coming to HFQ's women's brunch events or look out for our carer and wellbeing workshops.

Posting stories of how you manage parts of your care role on facebook groups can be a help. Check out groups like Haemophilia Families Australia and talk to us if you want links to other groups. It's a great way to stay connected and feel less alone.

Talk to a professional

Speaking with the psyc/social work team members at the QHC can help you strengthen your inner resources. It can be really helpful to talk to someone who can help you and with the right tools and the support of others, caregiving should get easier. Finding a new normal that balances caring for your child or partner and caring for yourself is going to help you to help them without feeling like a struggle.

Dating Struggles with a Chronic Illness

Looking at myself now, my younger self never would have expected me to be where I am. Recalling my younger years, I remember having anxiety about being alone when I grew up. I always thought I'd have a hard time finding a partner and that my dating life would be close to non-existent. But — surprise, surprise — here I am today, happy with my wife, Mary* and our baby, Ruth.

I remember school as a place where people bragged about having girlfriends and my juvenile self always felt left behind. Back then, my lack of finding a partner made me feel sad and lonely. I was afraid of being alone and I wanted a partner, even at the expense of not being truly happy.

Having haemophilia and epilepsy crippled me with fear because I thought no one would choose me. In a world with fully functional men and women, I saw myself as a broken toy. I didn't believe I would fit anyone's standard. I have shared these thoughts with some of my friends who also have haemophilia, and funnily enough, many have felt the same way.

The time I truly felt like a broken toy was when I experienced my second breakup during my second year in university. For the longest time, I had the support of my then-partner, so it devastated me and

filled me with fear when we broke up. It seemed as if I had lost one of the people who had filled me with confidence and happiness.

I sought comfort in my friends, hoping I would find the support I needed. But I also felt like a burden to others. Haemophilia had made me feel lonely, as if I were an outcast during the part of my life when I was supposed to be experimenting and having fun.

I also remember the rejection. My self-esteem would crash upon hearing the word "no" so often when asking people out. Dating is hard for many, but with chronic illnesses, I think it's significantly harder. In a world that focuses on high standards and finding the idyllic partner, it's hard not to succumb to a mild depression caused by fear and loneliness.

However, that situation won't always be the case. There are always people who are willing to accept others like me who have chronic illnesses. I'm extremely blessed to have someone like my wife Mary. I am truly grateful that people like her exist. With so much pain, suffering, and loneliness, people like Mary serve as beacons of positivity and hope and make us feel that we're accepted and loved.

* Names have been changed.

This article was written by Jared Formalejo and first published by Hemophilia News Today on 13 March 2019 (*hemophilianewstoday.com/2019/03/13/the-struggles-of-dating-with-a-chronic-illness*).

Emicizumab in Newborns and Infants

Safety and efficacy of emicizumab and other novel agents in newborns and infants

The evolution of a non‐clotting factor category of therapeutic agents presents a paradigm shift in decreasing the burden of therapy. Optimal protection of a newly diagnosed child with severe haemophilia from bleeding would ideally include starting treatment on the day of diagnosis. With the advent of long‐acting subcutaneous therapies such as hemlibra (emicizumab), this aspiration has become feasible.

The current standard of care using clotting factor concentrates is not amenable to immediate initiation of prophylaxis in a newborn given the need for frequent venous access. The subcutaneous route of administration of emicizumab and potentially several other novel agents in development make these attractive early interventions. However, infants less than one year of age are generally not included in drug trials and there are notable differences between a newborn's haemostatic system and those of older children.

However, the haemophilia community is keen to know if early initiation of emicizumab and other non‐factor agents might be safe in newborns and infants. Clinical studies, rather than anecdotal treatment reports, would permit answers to these questions. If found to be safe and effective when commenced at diagnosis and at very young ages, a policy change to expedite prophylaxis could be advocated.

From an editorial published in Haemophilia Journal 30 July 2019 by the Committee on Coagulation Products Safety Supply, Access (CPSSA) of the World Federation of Hemophilia (WFH) *https://doi.org/10.1111/hae.13822*

Bleeding Disorders Awareness Week

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 13-19 October 2019.

Have you thought about hosting a Red Cake Day during the week? It is a great way to involve family, friends and workplaces to take part in a special event to help raise funds during the week.

Some great ideas are:

- Organise a Red Cake Day at your school, hospital, workplace or local town
- Set up an information stand in your workplace, school, hospital or library
- Hand out promotional items in your local area
- Organise a casual clothes day at your workplace or school
- Organise a luncheon, sausage sizzle or morning/afternoon tea
- Set up a fundraising page – this way people who cannot attend your event can donate as well.

You could also run a virtual Red Cake Day and ask your family and friends for support

You can order promotional items for your event or awareness stand. It's easy to register. All you need to do is visit HFA's website *www.haemophilia.org.au/get-involved/events/bleeding-disorders-awareness-week* to place an order online.

Why do we do it?

The perception of life can change with the diagnoses of a bleeding disorder in the family.

Some members have gone through a lot. First there were no effective treatments, then just as treatments seemed to have started to improve, there was the bad blood epidemic and people became infected with HIV and HepC because of their bleeding disorder.

It's difficult to understand the depth of devastation that the bad blood epidemic had on families when it hasn't affected you directly. But we must remember the generation we lost so that we can avoid a reoccurrence of a tragedy like this.

Treatments are a lot better now and likely to get better still, so it's important to remind the general public that we are still here and that it's still a big deal for members of our community.

Here's what you can do throughout Bleeding Disorders Awareness Week to help raise awareness and advocate for the bleeding disorders community

- Get involved in the Red Cake Day Campaign. This began as a grassroots initiative to raise funds and awareness and to find better treatments and cures for bleeding disorders. Today it's a nationwide campaign that you can participate in at any time, but especially during Bleeding Disorders Awareness Week.
- Show your support by wearing red on social media. The red ribbon is the official symbol of the bleeding disorders community and wearing red reflects the fact that blood - embodied in the colour red - is what binds the community together.

  Create your own wear red event and ask people to join you for a donation.
- Make a donation yourself. Your generous gift will support programs and activities that others can't engage with without subsidies. Advocacy and education is still important to our community, as is raising awareness of our conditions.

  Get involved with events HFQ has planned for Bleeding Disorders Awareness Week. Check out our sales on the eBay store or sign up for World Café.
- Support HFA's advocacy efforts for better treatments by taking to your local MP (state and federal) and tell them what a difference improved treatments would make in your life. Or post a comment on your facebook page
- Get involved in other advocacy and support efforts, particularly here in Queensland. Volunteer your time at HFQ or tell us how we can help you help us.

Cerebral Haemorrhage & Recovery

It was determination, strength and prayer that got me through the most dangerous time in my life. Not long after I left Montrose and started attending the local state school, I stayed over at a friend's place for a special sleepover. While I was there, I had a fall riding along on my scooter. When I fell, I hit my head on the concrete ground. A knock on the head like that for a person with Haemophilia is not to be taken lightly, as we were about to find out. And Oh boy did we ever!

I was feeling sore at the time as anyone would but throughout the night, I started to develop a headache that refused to ease up. So, Dad came and picked me up from my friend's house. We then went home but my headache was getting worse. So up to the hospital we went.

The knock to my head had caused a bad cerebral haemorrhage. I was bleeding into my brain. I was admitted to the Children's Hospital Brisbane and from there I went into a coma for about a week.

This was a scary and worrying time for my parents. Something had to be done. The doctors looking after me had an innovative blood product that gave me a 50/50 chance to survive the operation I needed. It was called A.H.F. Artificial Haemophilia Factor. They decided to go ahead with the operation and the risk paid off. It was all worth it. The AHF worked and stopped the bleeding. It saved my life.

My mother and father spent the next fourteen days or so, in the old Red Cross room at the General Hospital after my operation on my head. My father had to take days off from work and after my operation my Aunty May gave me a wristwatch with the date of the operation engraved on the back.

My neurosurgeon's name was Doctor Jamison and I clearly remember him saying to me in an amazed, illogical sense that I shouldn't be here in the condition I was in. Dr Jamison was impressed with me hanging in there. All the doctors too, were taken back by the fact that I had event lived through the operation. The medical doctor and student doctors were constantly studying me because I made medical history.

After the initial operation I couldn't talk or walk, and I had lost use of the left side of my body. It took months of hospital care to get me on my feet.

Things were achievable as we now had a ground-breaking clotting factor, and it was working! But it was still far from over and far from easy, because the injury had left me crippled on the left side of my body, like a stroke victim.

After many months in hospital, I went home with a Calliper on my left foot (like the ones on Forest Gump's legs). With Mum, Dad and Julie's help and patience, they continued with my rehabilitation.

So many times, I was defiant and wouldn't put the effort in to improve but they were determined to persevere. If it wasn't for their stubborn tough love, I would never have regained a near normal life.

During this time, I returned to school for a couple of months, when my calliper came out of my shoe. I fell over and hit my head again. Unfortunately, this fall caused another haemorrhage.

This put me back to square one all over again, commencing with the same remedial management and rehabilitation. This was when my school days were announced 'over', at only a fourth-grade level.

It took me months and even years to find my way back. All up, it took me about 10 years to recover, especially my balance. To assist with mobility through this time, I used crutches a lot too.

- Robbie's Story continues

My head injury was just one of so many trips, visits and stays to the Brisbane Chidlren's Hospital. And not once did my parents complain about anything. Not long after my head injury, I was transferred to the adult's section into the General Hospital, under Doctor Samson, the blood specialist from The Terrace in Brisbane.

They said I had to be sent over to the General Hospital because I got too tall for the beds. Back in those days the children beds were white metal, smaller framed beds with hessian mattresses. The changeover was a little daunting because the environment had a whole different atmosphere and only adult faces. It was all different staff who needed to get to know me and my quite rare condition. After being under Doctor Samson for many years, over at the 'General', he retired and I was put under another doctor, Doctor Knowles. From about then on I was treated under 'Haematology'.

I soon adjusted and found that life was, at times, more interesting amongst adult patients. It was the school of wisdom that I soaked up from these older patients that helped me become the person I am today. I think that's why I find it easy to start up a conversation these days.

And I often like to share my knowledge too, as they did to me all those years ago. Perhaps that's why I'm drawn to a passion of teaching and helping people. There were also funny random things that happened. Like the time when a professional roller skater with one busted ankle playfully skated around the Physio department on the one other skate and copped it big time from the head nurse.

My hospital stays and visits were a pretty jammed packed schedule back then, but the need for hospital stays greatly reduced with the introduction of clotting factor. Recovery time was more successful and quicker for a bleed to settle. Getting better was not just a waiting game anymore. And it was sometimes just a matter of having one Factor VIII does and going home. But sometimes an appointment visit can end up with a hospital stay. So, go prepared.

This is part 3 of Robbie's self-published story "Injection of Life" and we have edited the start of his book for this article. We hope to publish more extracts during the year but if you'd like to read the full story please contact the office on 0419 706 056 and we can lend you our copy of the book.

Protein could 'ZAP' HIV-related viruses

A newly identified protein might be the missing piece for an antiviral weapon to destroy viruses related to HIV.

In a paper published to eLife, researchers from King's College London announced they had identified a new protein called KHNYN that could be the missing piece of a new antiviral weapon in conjunction with another recently discovered protein.

Genetic information that makes up the genomes for many viruses comprises building blocks called RNA nucleotides. A previously discovered protein, ZAP, binds to a specific sequence of RNA nucleotide called CpG.

HIV usually evades being 'zapped' by ZAP because it has very few CpG's in its genome. By adding CpG's back into the virus, ZAP could become a tool of destruction, but the researchers hypothesised that ZAP needs to recruit other proteins to destroy the viral RNA.

This led to discovering the important role played by KHNYN, which was shown to reduce a typical HIV's ability to multiply about five-fold and decrease the ability of CpG-enriched HIV to multiply by about 400-fold.

The researchers then repeated the experiments and found KHNYN couldn't limit the CpG-enriched HIV from multiplying in cells without ZAP.

The researchers felt that a potential application of this work is to make new vaccines or treat cancer by developing CpG-enriched cancer-killing viruses that would not harm healthy cells.

But much more research is necessary to learn more about how ZAP and KHNYN recognise and destroy viral RNA before we can move on to explore such applications.

To read the full paper, please go to; https://elifesciences.org/articles/46767

The Importance of physical activity.

Children who have too many sedentary behaviours and not enough activity are at a greater risk of being overweight or obese. Encouraging children to be active every day establishes good habits that can stay with them throughout their lives.

As many parents will tell you, the key to getting your kids to live a long and healthy life is to get them from sitting on the sofa staring at a TV screen or tablet, to engaging with a favourite physical activity. Ensuring your children develop healthy habits early through eating well, regularly participating in exercise, and enjoying plenty of sleep will not only help your child's weight, but it will also reduce stress and arguments at home, making life more harmonious for everyone.

A report from the Australian Heart Foundation called "Active Healthy Kids Australia Report Card" found that 80% of Australian children are not meeting the recommended levels of daily physical activity. According to the report only 19% of children and young people aged between five and seventeen years old meet the national daily activity guidelines of accumulating at least 60 minutes of moderate to vigorous physical activity, every day of the week.

By making an effort to incorporate better health and fitness practices into your home, you are promoting healthy growth and development and helping ensure your children build strong bones, muscles and joints. This is something vital for all people with bleeding disorders.

The Department of Health says there are some activities such as reading, or doing school work, working on a computer that may require you to sit, but the key to finding a healthy balance is to stand up and look for opportunities to move whenever you can.

Make family activity part of everyday living

Healthy Kids, a NSW government website says if you'd like your screen obsessed child to be healthy, you have to start by looking at yourself and your family. While it will take some effort to maintain, visiting playgrounds, parks, beaches or home activities as a family can prove rewarding.

Frequently the biggest hurdle to family activity is finding the time, but you don't need to find new activities all the time. Instead Healthy Kids say you will be more successful if you incorporate a few key activities into your family's daily life in a balanced way.

These may include walking or riding a bike with your children to and from school, encouraging children to help with household chores such as walking the dog or mowing the lawn, going for a family walk after dinner or keeping a frisbee, skipping rope or scooters in your car at all times.

Organising is Key

Nothing good ever comes easy, so you'll need to put some effort in. The best way to do this is to plan ahead and schedule a regular time for physical activity that fits in with the whole family. You may also like to consider talking part in some organised sport or activities – such as kite flying in the park or fun runs. These tend to work best at weekends.

Healthy Kids says its easy to let your enthusiasm slip as it becomes more routine. To avoid this happening, they say you should consider choosing activities the whole family will enjoy.

Healthy Kids can be accessed at: *https://www.healthykids.nsw.gov.au/*

To read the full Heart Foundation report go to: *https://www.activehealthykidsaustralia.com.au/siteassets/documents/2018/ahka-report-card-long-form-2018-final-for-web.pdf*

PROBE study

Have you completed the PROBE (Patient Reported Outcomes Burdens and Experiences) questionnaire yet?

The survey is available at *https://plus.mcmaster.ca/PROBE*

HOW WILL PROBE HELP PEOPLE WITH HAEMOPHILIA?

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and it is crucial for our treatment advocacy!

WHO CAN HELP?

We need to hear from **more people with haemophilia**.

We also need around **200 people who DON'T have a bleeding disorder** – the survey will only take around 10 minutes if you don't have a bleeding disorder. Your experience is invaluable as a comparison. Pass it on to family and friends!

Consider being involved and help us with this important study!

And many thanks to those people who have already completed the questionnaire.

For more information visit *https://www.haemophilia.org.au/publications/news/probe-study*

Ride a Bike?

Last week, I did something I never dreamed I would do: I taught "MacDonald the Younger" how to ride a bike.

At 13, he is considered a senior statesman in our neighbourhood. Other children learn at age 5 or 6 how to balance on two wheels and head down the street. Unfortunately, while others were finding their way, my son lay in a hospital bed suffering through internal bleeding that proved painful and debilitating. It is hard to worry about balance when confined to a bed or a wheelchair. Independence must wait for another day.

My boy talked about riding a bike for many years. He kept asking me, "Dad, when are you going to teach me to ride a bike?" The fact that he asked the question in the middle of all his discomfort made me stand back and admire his willpower. Yes, the joint pain proved excruciating, but hope still sprang loud and clear in his voice. He garnered up his fantastic determination and iron grit. Haemophilia would not win.

I responded by saying to him, "We will start riding as soon as we can clear these nasty, stinky, no-good, rotten bleeds up." That seemed to encourage him to fight. He had a purpose.
When things looked their darkest, I concluded that he would be unable to participate in many activities that I enjoy, such as skiing and skating. We would find something for him to enjoy from the vantage point of sitting down or something that did not require pressure on his joints. For a while, he enjoyed swimming, but he always asked the question, "Dad, when are you going to teach me how to ride a bike?" I guess a boy needs his independence. I kept assuring him that one day he would learn.

In the twinkling of an eye, the constant bleeding episodes stopped. A new medical regimen worked, and with a season of good health came a desperate need to revisit the issue of hot-rodding down the streets of our tiny city. We took the proper precautions of learning excellent bike safety and establishing where and when MacDonald the Younger could travel.

I decided early on that I would not teach my son how to balance on two wheels the way my uncle had taught me. He stood behind me, pushed, and said, "Now balance yourself." After endless falls and struggles, I finally found my balance point. I looked like a war veteran, but I did it.

I made sure that my son could fully extend his legs to the ground, and I let him scoot down the street as he found his sense of balance. While he lost balance and steadied himself by placing a foot on concrete, he never fell off the bike. In just one day, he managed to balance himself for short spurts of time, then longer ones, until — voila! — he rode his bike. I could not believe that he learned so quickly. Now he is a riding fool, going to the post office, the store, and even to say hello to me at church. He knows the taste of freedom.

As I watched my son pedal down the street, I began to think about his struggles and realized that while I do not have haemophilia, I do have issues that keep me from attempting to do things or experience events. My fear or anxiety sometimes gets the best of me, and I choose to shy away from things that I've wanted (or needed) to do for a long time. Maybe it is time to get up on the bike, so to speak, and learn to balance. That is the only way to journey down the road.

This article was written by Joe MacDonald and first published by Hemophilia News Today on 18 July 2019 *https://hemophilianewstoday.com/2019/07/18/bike-riding-independence-overcome-obstacles/*

Health Updates

Immune Gene Variations May Help Predict Inhibitors

A study, published in the journal PLOS One, sought to identify genetic markers that could help predict which patients were prone to develop an immune response against external factor VIII.

They analysed data from 586 patients with severe haemophilia A from Bonn in Germany. 19% developed inhibitors and the analysis revealed that patients with a familial history of inhibitors had 5.94 times higher risk of developing them.

The team sought to understand how different genetic and clinical parameters could explain the development of inhibitors in some patients. Results showed that patients with a specific HLA haplotype (called HLA-DRB1*15), and with a particular SNP in the IL-10 gene, had higher risk for developing inhibitors. Of 30 patients in this group, 23 developed an immune response against factor VIII.

The team concluded that the results "show associations between genetic factors and the occurrence of FVIII inhibitor development in severe haemophilia A patients,"

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0218258

Hypertension in Swedish persons with haemophilia

A report in the September issue of Thrombosis Research by Swedish researchers showed that persons with haemophilia (PWH) had higher prevalence of hypertension than matched controls using a longitudinal study design.

They identified 19.7% diagnoses of hypertension in PWH born in 1978 or earlier compared with 11.2% among controls. The findings were similar in subgroup analyses of patients with non-severe and severe haemophilia with or without HIV and/or viral hepatitis.

https://www.thrombosisresearch.com/article/S0049-3848(19)30310-X/fulltext

BioMarin planning to launch world's first haemophilia A gene therapy

Biotech company BioMarin has make a leap for an accelerated approval of their gene therapy "Valrox". That decision was made despite a considerable backlash against the latest data, which showed worsening efficacy over time and a lower initial response in their pivotal trial — but excellent bleed rates, so far.

BioMarin says that they have good reason to believe they are on track to field the world's first gene therapy. The company is focused on getting Valrox to market as soon as possible by submitting their data based on their Phase 3 interim analysis to the FDA.

And BioMarin has outlined plans to charge in the range of $2 million to $3 million per treatment — with the capability of earning $10 billion to $15 billion a year

https://endpts.com/billions-on-the-line-biomarin-bustles-past-enthused-rival-planning-to-launch-worlds-first-hemophilia-a-gene-therapy/

'Mosaic' HIV vaccine to be tested in thousands of people across the world

A new experimental HIV vaccine that targets more strains of the virus than any other developed so far will start a late-stage clinical trial later this year. The 'mosaic' vaccine also seems to have the longest-lasting effects of any others tested in people.

Starting in September, scientists will test it in 3,800 participants across 8 countries to assess whether the vaccine provides any protection against HIV infection. Half of the participants will get four vaccine injections over the course of a year, and the other half will receive a placebo.

The Mosaico team hopes that their vaccine will help to protect at least 65% of the study participants. However some HIV researchers suspect that finding an effective vaccine will take longer than the Mosaico researchers think.

https://www.nature.com/articles/d41586-019-02319-8?utm_source=PL+full+mailing+list&utm_campaign=08abd7ff3a-EMAIL_CAMPAIGN_2019_08_01_10_19&utm_medium=email&utm_term=0_e4f77dc29a-08abd7ff3a-370434349

New Data Support Long-term Effectiveness of EHL Treatment

New data from clinical studies suggests that long-term preventive treatment of severe haemophilia A or B with extended half-life blood clotting factors (EHLs) , increased quality of life and reduced annual bleeding rates.

The data on Eloctate and Alprolix was presented at the 27th Congress of the International Society on Thrombosis and Haemostasis. It presented data from two Phase 3 clinical trials: ASPIRE (NCT01454739) and B-YOND (NCT01425723). These were open-label extension studies in patients of all ages.

In ASPIRE, 70 people with severe hemophilia A had switched from an on-demand treatment to prophylactic Eloctate. The median annual bleeding rate dropped from 30.0 to 1.5, and this was stable over time. Additionally, 29% of patients experienced decreased joint pain.

In B-YOND, the median annual bleeding rate among these participants decreased from 24.2 on on-demand treatment to 2.0 on prophylaxis.

In both studies, quality of life was improved, specifically "in relation to areas such as sports, leisure and physical health.

https://hemophilianewstoday.com/2019/07/17/effectiveness-of-preventive-ehls-treatment-in-hemophilia-a-and-b/

World Café

This Bleeding Disorders Awareness Week we are hosting a World Café event. World cafe is a simple, effective, and flexible format for hosting a group dialogue with people from the bleeding disorders community.

Our World Café event will be at Riverside Receptions, beside the river at New Farm on Saturday 19 October.

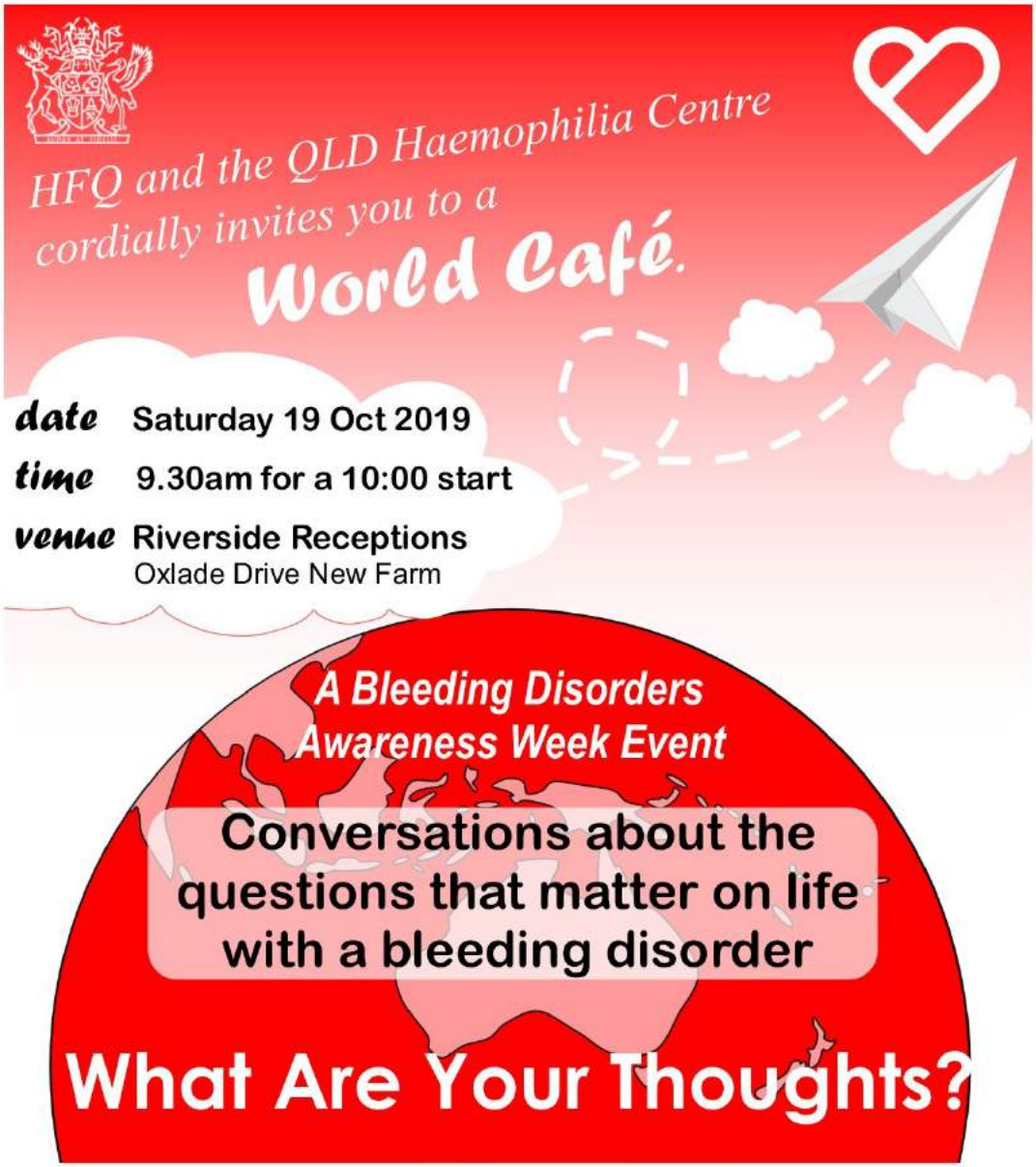
People already have within them the wisdom and creativity to confront even the most difficult challenges; the answers that we need for helping meet the needs of the Queensland Bleeding disorders community are available to us, through you! We are Wiser Together than we are alone.

We hope to create a "special" environment, conducive to having a good discussion with you all, i.e. small tables for group discussions, good food and nice (air conditioned) environment on the river bank.

Each table will be set-up for a small number of people to have a twenty minute conversation seated at the table. At the end of the conversation, each member of the group moves to a different new table. It's a bit like speed dating!

After the small group discussions we'll invite people to share their insights or other results from their conversations with the rest of the large group. This process will help us identify what you see as needs within the bleeding disorders community and also where the Queensland haemophilia Clinics and Haemophilia Foundation Queensland can support you better in addressing these needs as well as helping us plan Annual and Regional Meetings.

Your input is very important to us and we strongly encourage everyone in the Queensland bleeding disorders community to put the day aside to join with us at our World Café.



Keep Up With School

It's important to keep education an active part of your child's life during their treatment and clinic appointments. This way they will not fall too far behind. If you do not encourage your child to keep up with school work, you may be telling them that it is no longer important. This also sends an indirect message that there is no point in trying, which is both wrong and can be upsetting for your child.

School also plays an important role in the social development of all children. It is a place where they can relate to their peers, learn the norms of social behaviour, and interact with others. With the advice of the QHC team or HFQ, it may be possible to arrange a special training session for your child's class or teachers during the early stages at a new school, or if time off is needed.

If your child needs to stay home for a certain amount of time, educational instruction at home may be available for several hours a week. Your child's school will decide whether they qualify for this.

Many teachers may not have experience working with children with a bleeding disorder. Keep your teachers informed about your child's condition to help them understand and be supportive of your child's needs. This can help them approach your child's situation with the same positive outlook that you have for your child.

Time Off School

If you child has had time off school they will eventually be ready to start school again. Kids can feel anxious about returning to school after being absent for a long period of time. They may also feel uncomfortable about the changes in their circumstances and what restrictions they may have placed on activates they can do that make them seem les then 'normal'.

Primary school children are more likely to be accepting of your child's restrictions in physical activities. They may see it as something special and unique, and help find activities they can all do together. However, peer pressure to conform and "fit in" becomes increasingly important as children progress through high school.

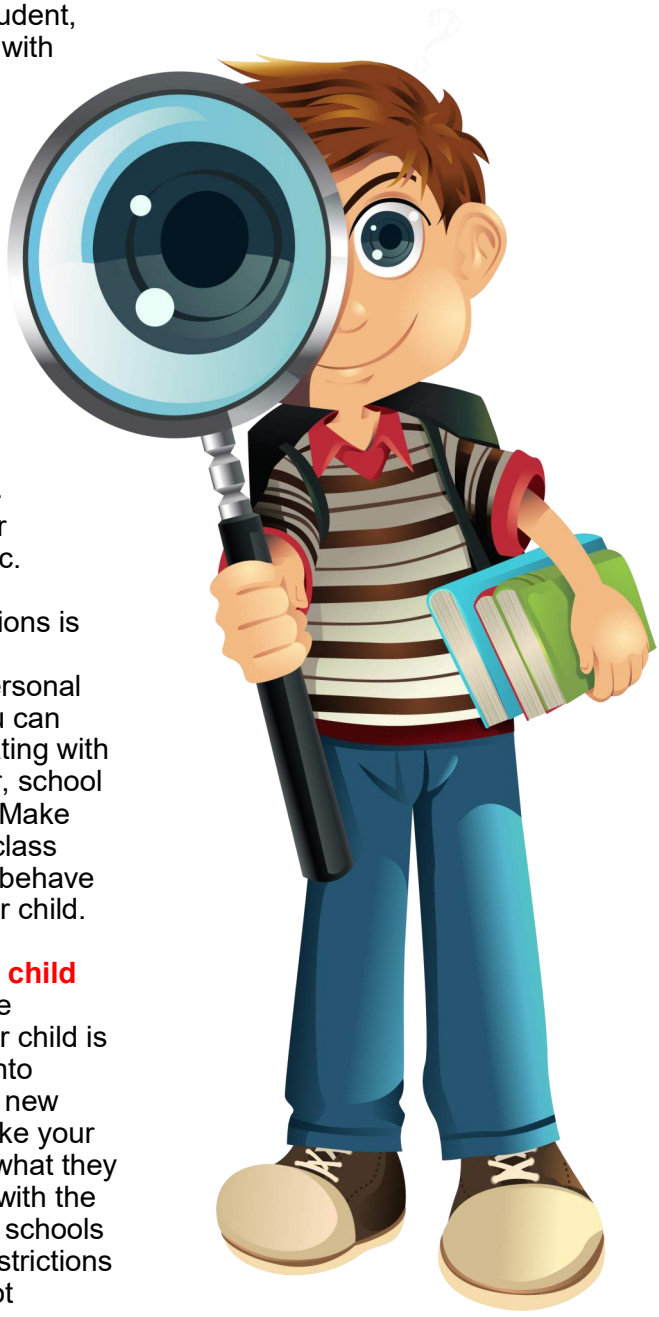
As a high school student, your child interacts with more teachers. They may be more concerned about the time missed from school. This feeling can be made more challenging if your child is preparing for university. It might mean that they will have to re-adjust plans for ther future work roles etc.

Managing expectations is part of helping kids understand their personal circumstances. You can help by communicating with your child's teacher, school nurse, or principal. Make sure they help the class understand how to behave and act around your child.

Advocate for your child

You may need to be assertive when your child is transitioning back into school or starting a new school. If you feel like your child is not getting what they need, get involved with the school. Sometimes schools go overboard on restrictions because they do not understand the implications of your child's bleeding disorder. On the other hand, schools can be too lenient and exert no oversight when it comes to sports and academic activities.

You may want to go to school to meet with teachers, and other personnel to make sure that your child is performing at their optimal level. You also want to make sure that your child is getting the special help and accommodations that they need.



Important Dates for HFQ Members

OBE Lunch Forum
Informal support group for men with a bleeding disorder. Usually meets first week of the month. Next meeting on; 2 October 2019.

Youth Camp
20 - 22 September 2019
Emu Gully, Hildon

Wellbeing Workshop
26 September Veue TBA

Haemophilia, VWD & Rare Bleeding Disorders Conference
10 - 12 October 2019 Manley NSW

Bleeding Disorders Awareness Week
13—19 October 2019
World Café Event 19 October
Riverside Receptions

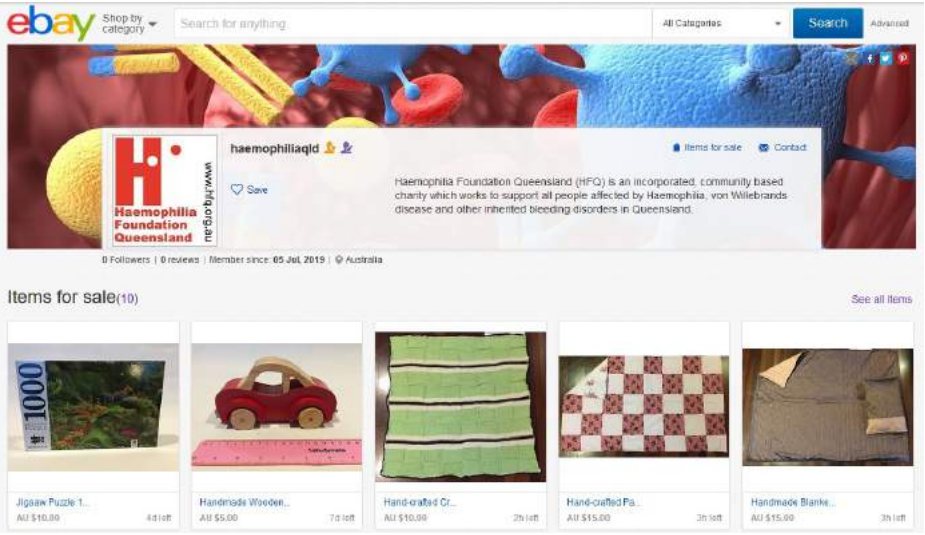
Women's Lunch
10 November 2019 at 11:30
New venue: Everton Park Hotel

Community Camp
3 - 5 April 2020
Noosa North Shore Retreat

Regional Meetings
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.

Donate to our eBay Store



Did you know that we can sell your unwanted goods online through our online eBay charity store www.ebay.com.au/usr/haemophiliaqld

We are not big enough to have an actual charity shop but every month millions of people go to eBay to shop. Last year more than 1,500 registered charities sold items on eBay, collectively raising over 32 million dollars. If everyone on our mailing list gave us one item a year that sold for $10 we would be raising over $4,000 PA without the need for other fundraising endeavours.

Just as retailers offer their customers on-line stores we can too. Selling via our eBay online auction is an easy way for you to help us raise funds. All you need to do is identify the unwanted goods you want us to sell via the store and let us know what you have.

Please think of items that will generate customers interest that you can donate to us. A typical on-line charity shops stock might include collectibles, branded merchandise and perhaps the occasional valuable or high-profile item such antiques, books and furniture. Modern Electronic items are another category we're keen to sell, however, any electrical item donated need to be thoroughly tested for functionality and safety before we can list them.

You can call the office on 0419 706 056 to arrange for handing over your donations or talk to us about listing your goods that you can keep at home until sold. All you have to do is make sure your items are photographed and described to the highest standards you can manage. The buyer pays postage as well so there is not cost to you.

And, if you're shopping for things, make sure you don't miss out on any bargains by visiting our eBay shop. You'll find all sorts of hidden gems at great prices, and all proceeds go to help us care for more people living with an inherited bleeding condition and their families.

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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