



## From the President



Hi Everyone, this month I wanted to bring to your attention something that has been a bit of a surprise and disappointment to some patients in the bleeding community, and one that everyone should be aware of.

We all want the best possible treatment options, especially as new treatments develop through various trials, such as gene therapy and others. It is important to understand there are many strict rules surrounding who is eligible for clinical trials, particularly for gene therapy trials. One of the entry criteria for many of these exciting trials is having complete records of all your injections given over the last (at least) 12 months and any bleeds experienced. It is important to understand that these study entry requirements are set internationally and are outside the control of the QLD haemophilia centre. It would be a disappointment to miss out on being considered for current and future studies because of

missing MYABDR records.

Looking to your possible future where you may not have to inject as regularly - if at all, where you don't have to think as much as you do now about your physical limitations, having the freedom and benefit of less bleeds affecting work & school etc ... redefining your current boundaries to a less stressful / less anxious life experience. How good does that sound! So why wouldn't you use MYABDR. Call your treatment centre now and get the ball rolling.

**David Stephenson**  
President HFQ  
[president@hfq.org.au](mailto:president@hfq.org.au)

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## MedicAlert: When Seconds Count

Even if you keep great records of your bleeding condition and always have them with you, in an emergency this information may not be helpful if it doesn't reach the right people.

Many of our young members typically didn't wear emergency medical identification, such as MedicAlert, yet this type of identification, often worn as a necklace or bracelet, will alert paramedics and emergency-room staff that the wearer has a bleeding disorder because if there's an accident, the patient or parents might be injured or unable to speak.

Safety seems to be the main issue for infants not wearing them, as parents you may worry that your child could choke on the bracelet or be injured by the necklace. And older kids (and adults) may not like the identification because they don't want to look different.

But medical jewellery allows your family, friends, work colleagues and others to quickly recognise the medical requirements you may have in the case of an emergency. MedicAlert jewellery can mean the difference between life and death. The day you don't wear it could be the day you need it most.

HFQ sees them as a valuable tool and if cost and difficulty getting them to fit correctly are an issue please talk to Moana or Loretta as HFQ offers a 50% subsidy to all members on basic models and may be able to assist further if your psycho social team member thinks it important.



First responders are trained to look for MedicAlert jewellery and use them to gain access to vital medical information in emergencies. This lifesaving service can ensure that you'll receive fast and effective treatment when seconds count. While most practitioners, in the face of an emergency, will accept any and

all input they can get. Having a MedicAlert ID is much more valuable and will save a lot more time than having handwritten information from the patient.

Emergency medical providers usually only look for medical identification on the patients

themselves—not in their surroundings. Having a description of you or your child's bleeding disorder in your purse or wallet is a great idea, but it's no substitute for an easier-to-find MedicAlert ID on a necklace or bracelet.

Even if your child or teen objects, this information is too important to not display prominently. If you have an infant, have him wear a wrist band (or ankle band), and they'll

grow up understanding the importance of keeping this information handy.



**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](mailto: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](http://www.hfq.org.au) or at our Facebook page at [www.facebook.com/HFQLD](https://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

Elise Mosey (M,T) - Physiotherapist

Hayley Coulson (W,Th, F) – Physiotherapist

Dr Moana Harlen - Senior Psychologist

**Contacting the Clinic - Please call the Haemophilia mobile for urgent enquiries on 0438 792 063 (office hours 8 – 4pm).**

*For all non-clinical/non-urgent enquires please email [LCCH-Haemophilia@health.qld.gov.au](mailto: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](mailto: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](mailto: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](mailto:CHQ_Haematology@health.qld.gov.au) at QCH and [RBWH-Haemophilia@health.qld.gov.au](mailto:RBWH-Haemophilia@health.qld.gov.au) at RBWH.

## Returning to a 'new normal'

As I write this, Queensland is slowly lifting the restrictions that were put in place to keep us safe around the COVID 19 pandemic, with new guidelines about the numbers of people who can be in cafes, shops, etc. I wonder if this is an opportunity for each of us to think about a possible 'new normal' in our own lives. Has the pandemic brought about changes in your own lives that you would like to continue into the future, new routines, new experiences or a return to activities our parents or grandparents were involved in?

For some, they have been able to invest time in gardening – growing their own food, sewing and making their own clothes, baking bread and other items that they would normally run down to the shops to buy.

Perhaps it has given you time to think about what you prioritise in your days and weeks or what you have missed – meals out with friends and extended family, seeing grandchildren, nieces or nephews or just spending time with people who don't live in the same household as you. Maybe you have valued your time on your own and with your family, away from the hustle and bustle of shopping centres (or is that just me?).

On the other hand, maybe the restrictions have led to increased snacking, decreased exercise, poor sleep, increased alcohol consumption – things that you may not want to take into the 'new normal'.

The timing might just be right, if you want to take this opportunity to look at what you value, to make small changes which could make a big difference in your life. A suggestion is to start small and to start with one change first. Make it a routine and look for changes that are helpful for you. I am currently finishing a Certificate in Creating Positive Change and have been introduced to the work of BJ Fogg

who writes about tiny habits. From his research he recommends 3 simple steps to creating changes you want in your life.

1. **Make it tiny** – consider the changes you want to make and scale it down to something really small. So, BJ Fogg wanted to improve his fitness.



He now can do 50, 60, 70 + push ups a day, but he didn't start there. He scaled it back to 2 push ups.

2. **Find an anchor** - link your tiny habit to a specific routine you already do in your life, to trigger a reminder. It helps to use statements such as 'After I \_\_\_\_\_, I will \_\_\_\_\_'. So, for BJ Fogg he cemented his habit 'After I go to the bathroom, I will do 2 push ups'.
3. **Celebrate your successes** – this is linked to understanding that emotions create habits. If, when you do something, you have a strong positive emotion immediately, the next time you won't have to decide, your brain will lead you to seeking that strong positive emotion and you will do it automatically. BJ Fogg says "awesome" out loud once he has done his push ups. You might do a celebration dance, or something similar, it just needs to be immediate. Even tiny successes can loom large in your minds, so when you feel successful, you keep doing stuff.

Once you have this cemented, you can then increase the tiny step. Using BJ Fogg's example, he started with 2 push ups, but then increased to 5, then 10. In his TED talk, he says he now might do more than his planned number for 'extra credit'.

Celebrating your success is very important in these steps. Put simply, BJ Fogg says emotions create habits. If you have to decide and deliberate whether to do your activity, like doing push ups, going for a walk, eating healthier food it isn't a habit. But if you celebrate this success, like celebrating 2 push ups, you are really celebrating that you are changing your behaviour and learning how to change.

Another suggestion he has is "After my feet touch the floor in the morning, I will say, 'It's going to be a great day'".

He also reports that if it isn't working for you, consider scaling it back even more. So, if your tiny habit is to walk 15 mins a day and you aren't finding this is happening, your first tiny habit may simply be, for example, 'when I get up in the morning, I will put on my walking shoes'. Celebrate that success, 'well done!'. Once this has become a habit/routine, you can then add your next tiny habit to 'when I put on my walking shoes I will walk for 5 mins' and celebrate that habit.

To learn more, check out BJ Fogg's TEDx Talk 'Forget big change, start with a tiny habit'

Ref: "Making positive psychology work #67 – BJ Fogg Cheat Sheet."  
[www.michellemcquaid.com](http://www.michellemcquaid.com)

*Loretta*

Advanced Social Worker  
RBWH  
Ph: 07 3646 8769

# Promoting Body Positivity in Teens

## Parents play a key role in helping their kids feel comfortable in their own skin

Almost all teenagers and young adults wrestle at some point with the pressure to conform to an “ideal” body type, a concern that social media often exacerbates. For kids with bleeding disorders, insecurity about their appearance may be further complicated by a sense that their bodies are already different.

For parents, the challenge is to encourage their children to make healthy choices without conveying the message that they should strive for a certain body type, so the messages they give are critical to their children’s self-image.

To foster a healthy self-image in your children, follow these tips:

### Educate them.

Get to know what diet culture, appearance ideal and weight stigma mean (see “Terms you should know,” at the end of this article) and the effects they can have, and talk about them with your children. It’s also important to explain the role of genetics in body type, because kids need to accept their particular body and size and think in terms of what it needs to be healthy and thriving.

### Focus on what they can do, not what they can’t.

It’s hard for teenagers to have restrictions on the activities and

sports they can participate in—such as football or cricket, which can lead to injuries. As a result, some kids are prone to spending too much time sitting around watching TV and playing video games. Encourage your teenagers to seek out a physical activity that they would enjoy but that would not compromise their safety.

People tend to stop engaging in

rather than push. Many teens go through phases where they will only eat certain foods, encourage them to try to eat balanced meals and eat things like cookies and candy in moderation.

It’s important to let your children have autonomy and convey that you believe in them to make good choices. Remember, the way we treat our bodies now is the gift we give to ourselves for the future.



physical activity when it changes from something fun to something necessary. “The key is to find a way for your child to move in a way that is joyful.

Let them make their own choices. As tempting as it can be to monitor your children’s eating and exercise habits, a better strategy is to gently encourage

## Terms you should know

### Diet culture

The term for a system of beliefs that worships thinness, equating it with health and moral virtue, and promotes weight loss as a means of attaining an “ideal” body.

### Appearance ideal

The idealisation of specific body types.

For women, this may mean being tall and skinny with long legs, and for men appearing tall, lean and muscular. (Keep in mind that idealized body types vary by culture.)

### Weight stigma

Discrimination or stereotyping based on a person’s weight. Weight stigma can increase body dissatisfaction and self-consciousness about being “overweight.”

*Edited for size from an article of the same name by Christina Frank that first appeared in hemaware*  
<https://hemaware.org/life/promoting-body-positivity-teens>



## Tranexamic Acid

Tranexamic (tran-ex-amic) acid (TxA) is also known as "Cyklokapron"(CY-klo-capron).

TxA is used in haemophilia and some other bleeding disorders to help stabilise a clot and stop the breakdown of this clot by the body's natural processes.

Fibrinolysis is the process that prevents blood clots from growing excessively in your body and is the body's way of breaking down clots once they have done their job in stopping the bleeding.

Blood clots are made up of fibrin, a protein that forms a mesh across the site of injury which stops the bleeding; this is what we call a fibrin clot.

A blood clot is formed when factor VIII (8) and IX (9) do their job in the coagulation (clotting) cascade so it is important to seek advice about appropriate factor replacement before starting tranexamic acid.

Tranexamic acid slows the breakdown of blood clots, so bleeding does not restart. TxA comes in 500 milligrams (mgs) tablets, these are white and easily crushed and dissolved in water, juice or milk.

One dose is not enough! TxA needs to be taken three times a day for up to 5 –7 days. It is particularly useful in mouth bleeding, post dental procedures and for heavy periods. Your

health professional may sometimes prescribe TxA for longer than 7 days.

Important:

1) If you or your child has renal (kidney) problems please let your treating health professional know as TxA is excreted by the kidneys.

2) If you have blood in the urine do not take TxA unless you have been directed to do so by your health professional, as clots may form that block your kidneys.

*Joanna McCosker*

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Haemophilia & Bleeding Disorders  
Qld Children's Hospital  
M: 0438 792 063

## Flu Time

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.



## HFQ Equipment Loan Program

Many people with bleeding disorders still experience down time because of bleeds and some have joint problems and/or poor mobility. This can lead to lower levels of financial security because of a broken work history through looking after their child's health or their own.

At the same time their health can necessitate immobilisation of limbs and clinic visits that can require painful trips to the Brisbane based clinics and/or a regional hospital for an outreach clinic. Or sessions via tele-health that uses up valuable data and band-width.

Access to wheelchairs and good IT and data for video conferencing and telehealth can help address these situations, but they can cost money that some of our members just can't afford from within their own resources.

HFQ has been fortunate to receive funding to purchase both wheelchairs and IT equipment such as LapTops and 4G data services under its Haemophilia Equipment Loan Program (HELP).

The prime audience for this equipment is seen in the first instance as Brisbane members for the wheelchairs (unless the PWBD or hospital can find a way of getting the equipment to them and have it returned after the loan period), and regional members for IT resources.

However the program is open to everyone, and all users of HELP need to be endorsed by the psycho-social work staff at the QHC's as needing assistance from the program.

Where possible members will be asked to contribute to the cost of the loan based on their ability to pay so that the equipment can be maintained and added to, over

**Haemophilia Equipment Loan Program**

**HELP**

HELP has wheelchairs and laptops available for loan to help people with bleeding disorders with their health access and mobility equipment needs.

Please phone or email the HFQ office for more information.  
e: [info@hfq.org.au](mailto:info@hfq.org.au)  
m: 0419 706 056

Haemophilia Foundation Queensland Inc.

time for sustainability of the program, but this requirement can be waived.

At this stage HELP has a minimal number of wheelchairs in stock as we are increasing these on an 'as needs' basis. This is also true for LapTops as only one or two will be held as 'core' stock, to avoid early obsolescence, so if you are wanting to access equipment through the HELP scheme there may be a slight delay in getting equipment to you.

Please talk to your clinic psycho-social work staff member or call the office on 0419 706 056 and have a chat with us if this is something that might help you or your family.

The project is willing to look at all requests from people affected by bleeding disorders in Queensland or our feeder areas of NSW, but priority will be made based on need and preference will be given to financial members in the first instance.



## Track yourself

Many parents put their kids in charge of preparing and recording their self-infusions to manage their haemophilia treatment and what type of bleed they are treating. Keeping good medical records is not just your treatment centre's responsibility. Maintaining up-to-date records can help you better manage your own, or your child's, bleeding disorder and may even be life-saving.

With our busy lives and dealing with your regular prophylaxis treatment or treating a bleed it can feel like enough of an intrusion into your life, let alone recording it as well. So why are we still going on about the need to record bleeds and treatments?

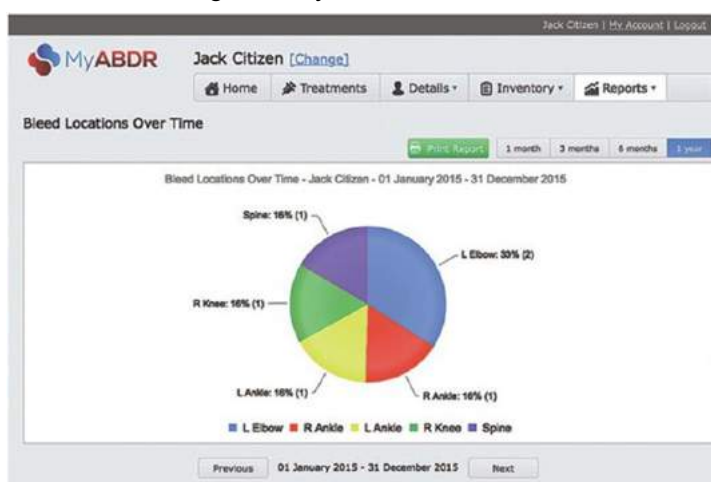
Recording them is helpful to the team at the Queensland haemophilia centre (QHC), but they don't have a lot of time to examine huge amounts of paperwork during your appointment. So if these records are recorded on MyABDR the QHC staff can look at it before your appointment and that way they know how well you are doing and you can also see if your treatment is preventing bleeds, or how often you do bleed and where. This way, by maintaining your own records, you're being a more active participant in your own healthcare.

Recording the treatment stock you use can also be immensely helpful in other ways. The NBA will receive statistics from the ABDR system so they can see the use of products and plan for the purchase of future supplies. Treatment products are a precious (and expensive) commodity. Having your treatment product inventory in MyABDR means that you can have your stock records at your fingertips and you don't have to look in the fridge to see how much you have left.

MyABDR is a user-friendly application to use on any electronic device that lets people log their factor infusions, bleeds and keep

track of other important treatment details. With this information in hand, you can help the QHC staff tailor your treatments to your individual needs. If someone can say, 'My child had four right knee bleeds and two left knee bleeds,' then the QHC team can say, 'Maybe we're not using enough factor, or maybe you need an orthotic for your shoes.'

Keeping such records keeps you engaged with your health care and is a good way to introduce children



to managing their own care. As a child gets older, by recording their bleeds and factor infusions it will help them to differentiate between a minor and major bleed, for instance and will give them the tools they need to manage their own care as they grow up.

MyABDR is your way of feeding into the ABDR which is the computerised system that holds your bleeding disorder records for the Australian HTC network. You control your full ABDR records and it's designed to help you track your history of bleeds and infusions and people with haemophilia and other bleeding disorders can record their bleeds and infusions with pen and paper in a MyABDR booklet, or, use the more high-tech tool. MyABDR app to upload your records so you can easily access them wherever you have a computer.

There was enormous excitement when MyABDR came out in 2014. MyABDR is a collaboration

between HFA, the Australian Haemophilia Centre Director's Organisation (AHCDO) and the National Blood Authority (NBA) – all the key players in your treatment and care, and recording with MyABDR helps maintain the best practice treatment and care. It's also a great way of showing what products work. The treatments and bleeds that each individual records can become part of the national de-identified statistics.

Any day now we will have access to extended half-life (longer acting) factor treatments and a subcutaneous treatment for haemophilia A called Hemlibra that just needs to be injected under the skin. These new treatments (and any treatments being trialed) need to be compared with current treatments. With bleeding disorders being rare we need as many patients as possible recording their treatments and bleeds to get meaningful data.

While there are more than 200 registered MyABDR users in Queensland, we are aware that a few of those users do not record regularly. We want to know why this is an issue and look at ways to increase recording and ease of use. If you have any thoughts or experiences relating to this, don't hesitate to tell someone involved about it! You can give your feedback to the MyABDR support team ([myabdr@blood.gov.au](mailto:myabdr@blood.gov.au) or 13 000 25664) or to HFA, or us and we will pass it on. You can email or phone any of us, or use the online MyABDR feedback form on the HFA website ([www.haemophilia.org.au](http://www.haemophilia.org.au)).

*[For more reading check out 'MyABDR – why record' by Suzanne O'Callaghan in National Haemophilia No 196 at <https://www.haemophilia.org.au/publications/national-haemophilia/2016/no-196-december-2016/myabdr-why-record/>]*



## Membership Renewal Time

HFQ annual membership subscriptions are now due for renewal. The side of this page can be torn off and used as your 2020-2021 Haemophilia Foundation Queensland (HFQ) membership form.

HFQ is not like life insurance. It is not a union, nor a church or a school; but we are a community of people dealing with the issue of living with a bleeding disorder. We are a registered incorporated society that because of our financial members can prove that we represent people with bleeding disorders in Queensland.

Through the HFQ board and subcommittees we advocate for improved services and programs on your behalf and we provide direct programs and activities where you have made the need for these apparent to us.

We only have two part time staff members, so your fees are important to us. Over the past 12 months HFQ has continued to provide services to the bleeding disorders community in Queensland despite Covid-19 and we rely on your support in the form of membership to maintain these services.

Limited funding from Qld Health provides financial support which goes a long way in allowing us to deliver outcomes for our community. Although we are excited that our current grant has been renewed for another three years, there are a number of the activities that we do, that require us to raise money elsewhere and independently of Qld Health.

Community Camp, regional support activities, youth camp & mentoring activities, health & wellbeing seminars, welfare support for those in need, and a range of targeted services in partnership with the Queensland haemophilia centre addressing community needs could not be

achieved on Qld Health money alone.

Having a membership base allows us to demonstrate we represent the bleeding disorders community and the fees you pay help make up the shortfall in the programs we currently provide.

We rely on fundraising to ensure these services happen and I thank those who donate to us or volunteer their time at events like Bunning's BBQ's and the like.

A significant part of fundraising is membership subscriptions and this is one easy way you can help HFQ help those in need in the bleeding community.

Please complete the attached membership form or go to our website where you can renew and pay on-line (<https://www.hfq.org.au/get-involved/memberships>). HFQ looks forward to your continued support and thanks you for your subscription.

We recognise that the small annual fee can still be too much for some people, so we also have provision for accepting members in financial distress so that you still remain part of our organisation. Please talk to Graham if you are in this situation

Regards,



**David Stephenson**  
President HFQ ..... Advocacy,  
Health promotion, Education,  
Support



[www.hfq.org.au/get-involved/memberships](https://www.hfq.org.au/get-involved/memberships)

# HFQ MEMBERSHIP

# RENEWAL



Haemophilia Foundation Queensland Inc.

Please tear off this section & fill out the details on the reverse or renew your membership online at: <http://bit.ly/2s1XtYd>



Membership of HFQ for 2020/21 is \$20 per annum for each membership or \$100 for a lifetime membership. These fees are due at 1 July each year and membership is open to all people with a bleeding condition, their families and people wanting to support a person with a bleeding condition.

Please fill out this form, tear if off and return to HFQ at PO Box 122 Fortitude Valley Qld 4006

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone No: \_\_\_\_\_

Email: \_\_\_\_\_

☐

Membership: Annual (\$20) or one-off payment (\$100)

Donation : \$ \_\_\_\_\_

Total: \$ \_\_\_\_\_

## von Willebrand Disease

### A Global Concern

von Willebrand disease (VWD) is a bleeding disorder linked to a blood-clotting protein called von Willebrand factor that helps control bleeding. People with VWD do not have enough von Willebrand factor, or it does not work the way it should. As the most common bleeding disorder, VWD should be a well-known condition. In fact, the opposite is true. Haemophilia is much better known, and many people are not even aware that VWD exists.

Because of this lack of awareness, there are many misconceptions about the seriousness of the disease, often leaving people with VWD feeling alone and isolated. Fortunately, VWD awareness and education are improving. While the gap in knowledge is still great, the World Federation of Haemophilia (WFH) is helping to empower and educate both the community and healthcare professionals so they know how to recognize VWD and how to help manage it.

The VWD Initiative Program of the WFH addresses the unmet needs of people with VWD by focusing on outreach, building knowledge of the clinical management of the disease, and providing training and guidance on the integration of VWD into the work of national member organizations (NMOs) such as HFA. The Global VWD Call to Action is one example of how this awareness is building.

The impetus for the VWD Initiative Program came from a meeting in early 2017 in which patients and representatives of patient organisations discussed the crucial need to address the impact of VWD in the community. The attendees identified eight priority areas to help WFH NMOs place greater focus on the disease.

They are

- Improve diagnosis
- Address the misconception that VWD is not a serious disease
- Facilitate the availability of safe, effective and easy-to-use treatments everywhere
- Encourage greater leadership and advocacy in the medical community, the patient community
- Establish a consensus on Standards of Care (SOC) and global guidelines (GG)
- Request that organizations incorporate VWD into their work
- Destigmatize the discussion of women's health
- Empower patients everywhere

Lack of awareness and education around VWD, together with a difficult diagnosis process, has isolated people with the disease. We have to remember that both women and men are equally affected by VWD. The purpose of this Call to Action is to help NMOs be more inclusive, so that we become stronger as a bleeding disorder community.

Global Initiatives for Bettering Care of VWD covers ways to simplify diagnosis, making it more accessible and feasible and include special considerations for women with VWD; treatment guidelines and the genomic approach to diagnosis of VWD. How VWD is perceived and the psychosocial issues that patients face.





## Female Factors - a magazine for girls

**A great educational magazine from Haemophilia Foundation Australia (HFA) tackles everyday issues and helps Answer Girls' Questions on Puberty and Bleeding Disorders.**

The onset of adolescence can be sudden or slow, but regardless, it comes with a host of physical changes. And for girls who have bleeding disorders, there are extra considerations. Thankfully, there are some good resources that addresses these issues in an approachable and clear way.

The 48-page magazine, *Female Factors*, from Haemophilia Foundation Australia provides a comprehensive overview of bleeding disorders, how they are affected in puberty, treatment options, and tips and tricks. While it's important that girls with bleeding disorders have an open dialogue with their doctors, the magazine is a good place to start finding information before engaging in those face-to-face discussions.

### **What is the right age to talk about puberty?**

Talking about puberty with your daughter should start earlier than you may think—by age 8 or 9 is often thought best. The average age of a girl's first period is around 10 to 11 years of age, so it is important to provide some anticipatory guidance.

This HFA publication is particularly good because it's visually appealing—with a format and wording geared towards adolescents. There's a section on frequently asked questions that covers everyday problems tween and teenage girls with bleeding disorders face, such as just what is heavy bleeding and what

treatment options are there. Many of these questions are ones we hear in conversation with members, but some teenage girls may be afraid or feel uncomfortable asking their parents or providers about these issues.

It can be difficult for young women with bleeding disorders to know what is and is not normal. There may be other female family members who are affected but don't realise it,

because heavy bleeding is the 'norm' in their family. This magazine addresses these issues in an age-appropriate way.

The magazine helps girls understand that there are lots of ways to manage heavy menstrual bleeding and we have copies available at the HFQ office. Please call us on 0419 706 056, or email us on [info@hfq.org.au](mailto:info@hfq.org.au) if you'd like us to send one out to you.



## Tony spends 5 Minutes With Brett

Tony Ciottariello is in his late 40's and living with Severe Haemophilia A. He currently treats with Adynovate (an extended life product), by prophylaxis - 3000 units x 3 times a week.

### Age of diagnoses

Approximately 8 months of age (when I started crawling—my parents took me to the Doctor as I started bruising pretty bad).

### Spontaneous bleeds?

I occasionally get a spontaneous bleed into one of my elbows (Target joints), but nowhere near as many as I did prior to commencing Adynovate approximately 18 months ago. This extended life product has certainly reduced the number of bleeds I now have.

### Growing up with Haemophilia

Growing up with Haemophilia as a child was extremely difficult at times. There was no history of haemophilia in my family and being the child of Italian immigrants who had only moved to Australia a few years prior to my diagnosis, I guess the language barrier between my parents and treating Doctors was major issue at times. I also had a brother who was only 15 months older than myself who did not have Haemophilia. My brother and I were both sports crazy growing up and on most afternoons would be found in the back yard (or sometimes inside the house ☐) playing some kind of sport after school when I was physically able to, whether it be cricket, golf, tennis or passing/kicking the footy around. Of

course a lot of the time I would end up with a bleed of some sort in one of my joints later that night and have to be rushed to the RCH for treatment at all hours of the night which was extremely draining on my parents as well as my brother

cycle. I guess reflecting on my childhood, I or my parents for that matter were not aware of how all these joint bleeds and playing sports (whether it just be backyard fun with my brother) as a child would impact me later in life. There was no prophylactic

treatment in those days and only on-demand treatment was available.

I often think if there was a history of haemophilia in my family would I have done the things differently growing up? If I perhaps had a few older relatives with Haemophilia who were around in my life and I saw first hand how haemophilia can impact sufferers in later life I probably wouldn't have done half the things I did as a child. Would my parents have been a lot more stricter on me and tried harder to stop me from doing things I shouldn't have etc? Who knows what the answer to those questions would be, but no doubt there were a

lot of hard times growing up but I had a lot of fun growing up along the way also - Boys will be Boys as they say.

### Primary/High School

My schooling years were pretty difficult at times. I tried to keep having Haemophilia mainly to myself apart from a small close circle of friends and teachers. I obviously could not partake in any sports days/carnivals or go away on school camps. I often felt like an outsider during my schooling as I could not be involved in a lot of activities and could only sit on the sidelines and be a spectator. I recall being fairly envious of my brother at high school as he would be involved in



who would have to tag along to the hospital. As a result I would be out of action for a few days and often admitted to hospital for few days and missed a lot of my primary schooling growing up. At times the children's hospital felt like my second home. Home therapy treatment was definitely a game changer as my mother learnt to give me the infusions and hospital visits at all hours of the night were no longer as frequent.

Being a pretty stubborn child and much to my parents frustration (and Dr McWhirter's lol) once I felt better again my brother and I would be back at it in the backyard again and again and it was pretty much a vicious



all the school sporting teams such as cricket, athletics and Rugby Union.

My high school years were no doubt the most difficult as I went to an all boys school. During my schooling years my knees were the biggest issue with constant bleeds and I recall my left knee being permanently swollen to the size of a small rockmelon with all the fluid build up etc. I also constantly walked with a pretty bad limp so was a big target for the bullies and was called all sorts of names. I kind of went into me shell as a result and tried to fly under the radar throughout my latter school years to try and avoid the bullies and only kept to a small circle of 4 or so friends.

Bullying certainly did not get the attention that it currently gets in this day and age when I was growing up. I think people need to realize that constant bullying in childhood years or at any stage of life can most definitely have a long lasting impact on people's wellbeing many years down the track!

### **Current Friends**

All my current friends are aware of my condition. I feel as I have grown older, it is something that I am willing to share more freely with people as opposed to my childhood wherein I would try to hide my condition. My friends are understanding of my condition and accept that there may be occasions where I am unable to catch up with them as I have had a bleed or just not feeling up to it on the day due to pain etc.

### **Employment / Retirement**

Unfortunately, I was never really the academic type and university was not really an option. Office/sedentary type employment I felt would be most suitable as it would be a little easier on the joints etc. I joined the public service in 1990, a few months after completing year 12.

I worked in a large Qld Govt organization which enabled me to work in a variety of different areas of the company and various roles.

Unfortunately my elbows are severely damaged from all the bleeds over my lifetime and have extensive arthropathy. Over the last few years, they have deteriorated quite significantly and even office based work was triggering elbow bleeds constantly, up to 2 - 3 times a week. I often found myself having a treatment in the sick room at work, only to go back to me desk afterwards and continue working in pain and discomfort.

If I wasn't in pain from the elbow bleeds, I was in pain from the arthropathy. As a result, I wasn't the most pleasant guy to be around at work and this was having a negative impact on my day to day work and home life.

After much deliberation, I came to the realisation that continuing to push through and keep on working was doing me more harm than good, not only physically but also mentally.

With next to no real surgical options for my elbows at this stage of my life I realized that I had to preserve what little remaining function I have in them as long as possible. So after working just shy of 30 years, and with the support of Dr Mason and Loretta, I decided to pursue medical retirement in October 2019.

It has been quite an adjustment after nearly 30 years of working to ummm now what!? With Loretta's

guidance and help I have sought out some volunteering roles in a few different areas since October. Some areas have worked out and some haven't for one reason or another. I have even graced Graham at the HFQ office with my presence a few times and hope to make it a regular ongoing occurrence.

### **Family**

I have one daughter, Olivia, who is 15. Olivia, is a carrier of the Haemophilia gene and is aware of this. Whether she truly understands what this means for her later in life and with her own children, I am not truly sure. However, as she grows older obviously I will explain things further and have more in depth discussions regarding this.

Should I have any grandsons in the future who have Haemophilia, I am very optimistic that with the current/future treatment advancements in the not too distant future such a gene therapy etc they will be able to lead a relatively normal healthy life with Haemophilia or even a majority of their life without Haemophilia.



## A Pinch Of Salt – interpreting good news

Salts, if you believe some news reports, will save you from stroke or diabetes. If you believe others, it'll kill you. Always take a nice, healthy pinch of it when you're reading your next treatment breakthrough headline. Of course, as engaged patients you are probably very good at sorting the decent health news from the questionable. But for many of us, it's not always easy. There are so many stops on the journey between scientists doing important research and the everyday person getting the message.

There's the scientists themselves in how they design their experiments and then interpret their results. And that's why we have the peer review process. If something's been published in a peer reviewed journal, at least it's been checked by another scientist or two. But after that point, the researchers are trying to make their research exciting and appealing to the public.

It's easy to laugh at people who believe outrageous health claims. But sometimes these problematic messages actually come from the original press release itself which may be more hyped up than anything that appears in the actual research article.

Another link in this long chain from the research paper to us is social media and the power of the Internet for people to self publish. While research institutes have greater reach online, so do people doing questionably designed research as well as self-styled wellness experts with blogs spruiking their own brand of supplements. Any one of the links in this chain can result in us getting a garbled and potentially damaging message. Always read between the lines with health news, no matter where its come from.

A healthy scepticism is a good place to start. Firstly, we should ask who's put out this study and who's paid for it? Do they have vested interests as a

pharmaceutical company? Publishing a survey that they've run that's happens to put their research in a positive light?

Or are they a research institution with funding coming through a transparent process such as by the National Health and Medical Research Council? Where's the study been published? Is it just a press release? Or are we looking at something that's been published in a high quality academic journal after a peer review process? We can also ask if the study measures what the headline is claiming?



Was it really in a human population, or just in a petri dish, or in animals like mice? In vitro studies and animal studies, are important and informative. But we need to make sure we're not overstating the evidence. So looking at sample size is also important. Looking at sampling methods is important and perhaps most important of all for readers is looking for those hedging words linked to could cause it's rare that a single study ever proves something definitively.

There are so many factors at play. It's virtually impossible to say for sure that one thing causes the

other. And just because it looks like there's a link between two things doesn't necessarily mean one causes the other. As that weary science chant goes, correlation does not imply causation. I can show you a chart with very strong correlation between US per capita cheese consumption and the number of people who died from being entangled in their bedsheets. It might be a pretty chart, but does it prove that one of these things causes the other?

Now, if there are double-blind, randomised controlled trial that gave one big group of people all the cheese and the other big group of people no cheese, and the cheese eaters all died, then maybe we could draw that conclusion. That would be a really interesting story.

Here's some more questions... What's the dose? Too much fluoride will kill you, but just enough will keep your pearly whites pearly and white. What's the delivery method? And when we talk about risk, what does that mean? In real terms?

Equipping yourself to ask the right questions so you can understand health research is important. People make health decisions based on what they're gleaned from stories in the news.

You still see news about vaccines causing autism. Years after that research was debunked and those things that captured the public imagination are often drivers for policy change, as we're seeing now around calls for shark attacks. So getting the right messages out can be powerful to do this. We need good science communicators at the institute level, good specialist reporters in the media and more conversations like these. That way we can help empower everyone to be more curious, sceptical and science literate readers.

*From notes taken at a talk by Tiguan Taylor at the World Science Festival in Brisbane 2019*



# We need to care for people

How many of us have organised or joined a local Facebook group so we can help each other out through this crisis? Before Covid-19 we may not have bothered to do much more than nod and smile to our neighbours, usually too “busy” for strangers. Yet Covid-19 seems to have brought about a need for us to make connections. To reach out to others, answering some human need to embrace more than our immediate circle.

We know a Facebook group isn't going to help. But with all norms disappearing, what is most important becomes clear. At the very moment we must isolate ourselves, to keep distance from each other, it has never been more obvious how connected we are. Connected to the street we live in and connected to a larger group of acquaintances, family and friends that we have.

We stayed home not just to protect ourselves – but to protect the group.

And as confusing and frightening as this crisis is, a powerful message has been that we must make sacrifices to protect the vulnerable among us – the elderly, those with heart conditions, hypertension and cancer. We must care for the people we do not know. After this, perhaps we will focus on what is meaningful about all our human interactions, to make each of them count

The alternative is “Lord of the Flies” – a collapse of the moral

code, each of us living only for ourselves. We saw it with the stripping from supermarket shelves of toilet paper and essentials. The fear is understandable, because this is like no other natural disaster we have faced (at least in my lifetime), but somehow most of us realise that to truly help ourselves, we have to look after

because we couldn't be bothered going have now disappeared. Some of them were tiresome. Many of those work meetings seemed pointless. Yet after this, perhaps we will focus on what is meaningful about our human interactions, to make each of them count.

We need our celebrations – weddings, kids' birthdays, our grandparents' anniversaries, and the backyard barbecues. Yes, it will still be a risk until we have a vaccine, but we need something, just one thing, to distract ourselves and to share with others. One silly thing. And we can find a way because we are adaptive creatures. Before Covid-19, many of us worried that the online world was cutting us off, as we watched Netflix rather than going to the movies, and ordered uber eats rather than dining in groups. Now we have Zoom meetings and Skype birthday parties so we still find a way to gather.

There's no one to blame for Covid-19, yet it has brought everything into sharp relief. If we do not care for people we do not know, what is society for? What are we protecting? If most of us can agree that we are responsible for the vulnerable, that the virus is not their fault, then the virus will still be health crisis, and an economic crisis, but it need no longer be a moral crisis as well, for any of us.



others. Something many of us seem to have lost, or forgotten.

What's now so obvious is how social we really are. Touching and hugging others is not just something nice; it's a human need. Solitary confinement is a form of torture and the loss of contact, especially for the already lonely and vulnerable makes this a “social recession” as well as an economic recession.

All those social events we used to cancel at the last minute

## Poor outcomes linked to detectable HIV

New research has underlined the importance of having an undetectable HIV viral load while taking antiretroviral therapy (ART). The study shows that individuals with a persistent low-level viral load (50-999) have a higher risk of all-mortality compared to people with an undetectable viral load. They also had more serious illnesses such as heart disease and some cancers.

The research involved a retrospective analysis of the medical records of 7000 individuals who received ART since 1996. The researchers compared the risk of mortality, developing an AIDS-defining illness or a serious health event (such as heart, liver, and kidney disease) according to their level of viral suppression.

Improvements in treatment and care mean that people living with HIV who are treated with ART can have a life expectancy that is close to that observed in the general population. However, up to 10% of people taking ART have a persistent detectable viral load.

The study aimed to compare the risk of death from any cause (all-cause mortality) between individuals with an undetectable viral load and those with a low-level viral load, and also to determine if a low viral load was associated with the development of AIDS or another serious condition such as cardiovascular disease, stroke, cancer, liver disease or kidney failure.

The researchers grouped individuals into three categories according to their viral load:  
1) Undetectable viral load below 50;  
2) low-level viral load (50-999); and  
3) persistent viral load over 1000.

The first set of results showed that, when compared to people who were undetectable, those with a low-level viral load had a more than two-fold increase in mortality risk.

Only individuals with a persistent viral load above 1000 were at risk of developing an AIDS-defining illness. This was also associated with an almost threefold increase in the risk of a serious non-AIDS

event, while a viral load between 200-999 was associated with a doubling of the risk, with no association seen for viral loads between 500-199.

The investigators suggest that the poorer outcomes seen in individuals with low-level viral loads were linked to immune activation and inflammation.

The researchers say they observed increased mortality for participants with low level viraemia (50-999 copies), which was also found in a subset of persons with low level viraemia (50-199 copies). In addition, individuals with 200-999 copies/ml had an elevated risk of serious non-AIDS events compared with those with virologic suppression. This research adds to mounting evidence that shows that anything above undetectable is associated with worse clinical outcomes.

Edited for size from a report published in *Clinical Infectious Diseases* <https://pubmed.ncbi.nlm.nih.gov/32271361>

## Does fatigue improve after HepC cure?

Patient-reported outcomes such as fatigue, vitality and mental health improve substantially in the two years following a hepatitis C cure for people with cirrhosis, but people with cirrhosis are less likely than others to experience rapid resolution of severe fatigue after successful hepatitis C treatment, according to two recent studies the Centre for Outcomes Research in Liver Diseases.

They reported that quality of life can be severely impaired in people with chronic hepatitis C, especially in people with cirrhosis because the damaged liver begins to lose its capacity to remove ammonia and other toxins from the blood. This may lead to poor concentration, insomnia, anxiety, fatigue, slow movement and depression.

People with late stage cirrhosis (or decompensated cirrhosis) - where the liver cannot perform some vital functions and complications occur; rated their physical health, vitality and activity levels especially low prior to treatment, but improvements were reported after treatment. People with cirrhosis were approximately 35% less likely to experience rapid recovery from severe fatigue whereas people with compensated cirrhosis had more comprehensive improvement in patient-reported outcomes.

By the time of the analysis 45% of people who had been cured of hepatitis C had experienced some improvement in fatigue and 12% had improved so much that they reported minimal or no fatigue. Depression, anxiety and insomnia were especially associated with a lack of improvement, as were type 2 diabetes, cirrhosis and co-infection with HIV.

The investigators commented that management of fatigue after hepatitis C cure should focus on co-morbidities that contribute to fatigue such as depression, insomnia and type 2 diabetes. The findings also suggest that fatigue in people with hepatitis C is a liver-related phenomenon.

Edited for size from an article in *AIDSmap*. <http://www.aidsmap.com/news/may-2018/do-fatigue-and-quality-life-improve-after-hepatitis-c-cured>

# Health Updates

## HIV Found in Old Tissue Sample

A tissue sample dating back to the 1960s harbors a near-complete sample of HIV. This appears to be the oldest known nearly full-length sample of the virus.

The researchers sifted through 1,645 formalin-fixed paraffin-embedded tissue specimens that were collected in Central Africa between 1958 and 1966. As they report in the Proceedings of the National Academy of Sciences, their RT-PCR assay detected HIV-1 within a sample that was collected in Kinshasa in 1966. While this is the oldest near-complete HIV genome, there are older, but less complete HIV genomes from 1959 and 1960.

Previously, scientists estimated that HIV arose in the early 1900s in Central Africa, and when the researchers added their new sample into a molecular clock analysis, it further confirmed that HIV likely emerged between 1881 and 1918. The authors say that "This is nice to know, because it means that our evolutionary models that we are always applying to our virus sequence work well, we didn't have big surprises."

<https://www.iflscience.com/health-and-medicine/oldest-near-full-length-hiv1-genome-found-from-1966/>

## Nonviral Transfer of the Gene Encoding Coagulation Factor VIII in Patients With Severe Hemophilia A

Researchers have conducted a phase 1 open-label trial on the safety of a nonviral somatic-cell gene-therapy system in patients with severe haemophilia A.

Dermal fibroblasts obtained from each patient by skin biopsy were grown in culture and transfected with a plasmid containing sequences of the gene that encodes factor VIII.

Cells that produced factor VIII were selected, cloned, and propagated in vitro and administered back to the patients by laparoscopic injection into the omentum. The patients were followed for 12

months after the implantation of the genetically altered cells.

Analysis showed that there were no serious adverse events related to the use of factor VIII-producing fibroblasts or the implantation procedure. No long-term complications developed, and no inhibitors were detected. In 4 of the 6 patients, plasma levels of factor VIII activity rose above the levels observed before the procedure. The increase in factor VIII activity coincided with a decrease in bleeding, a reduction in the use of exogenous factor VIII, or both, which suggests that this form of gene therapy is feasible in patients with severe Haemophilia A.

<https://pubmed.ncbi.nlm.nih.gov/11396439/>

## Health Canada approves GSK monthly HIV injection

Health Canada has given the green light to GlaxoSmithKline's HIV treatment Cabenuva, a long-acting monthly injection designed as an alternative to daily pills.

The Canadian approval is the first for the regimen (the U.S. FDA had declined approval in December, questioning its chemistry and manufacturing controls process, but not its safety). GSK says the company is continuing to work with FDA to address their concerns. and bolsters GSK's push to using fewer drugs in HIV treatments, with fewer potentially toxic side effects.

The Cabenuva injection contains only two active ingredients - cabotegravir and rilpivirine - and has proven as effective as standard daily pills with three active ingredients when given monthly and also once every two months.

<https://www.jnj.com/janssen-announces-health-canada-approval-of-cabenuva-the-first-long-acting-regimen-for-the-treatment-of-hiv>

## Early treatment linked to reduced joint damage.

Children with severe haemophilia A who receive early prophylaxis are less likely to have joint damage in young adulthood than those who begin treatment later, according to a study in Blood Advances.

A previous trial found that administering prophylactic FVIII, rather than episodic treatment, resulted in better joint health for haemophilia A patients by age 6 years. In the current study, researchers followed these same patients until age 18 to evaluate their long-term joint health.

One-third of those who received early treatment (mean age 1.3 years) experienced joint damage, or injury to the cartilage of a joint and/or the bone underneath, compared to more than three-quarters of those whose prophylaxis was delayed until age 7.5 on average. Bleeding rates were also higher with delayed prophylaxis.

Only a small number of study participants reached adolescence without any joint damage at all, suggesting that early prophylaxis does not offer full protection and underscoring the need for additional therapies for use in treating severe haemophilia A.

<https://ashpublications.org/bloodadvances/article/4/11/2451/460607/Young-adult-outcomes-of-childhood-prophylaxis-for>

## Long-term Rebinyn Can Safely Prevent Bleeds in Children With Severe Hemophilia B.

Rebinyn, is a FIX replacement therapy developed by Novo Nordisk for adults and children with haemophilia B.

The trial assessed the safety and efficacy of Rebinyn in previously treated boys, 12 or younger, with severe haemophilia B. The medication was given intravenously (directly into the bloodstream) once-a-week at a dose of 40 international units/kg.

This study reported on the safety and efficacy results after five years. None of the patients developed inhibitors and no other safety concerns were observed. Analyses showed that the median annualised bleeding rates decreased to 0.66 at five years.

<https://www.thieme-connect.com/products/ejournals/html/10.1055/s-0040-1709521>



# School Holidays ...On The Road Again

## Travel advice to make your trip with your family safe and fun!

Planes, trains, cars and vans—there are lots of ways to travel these days! And all the things that keep you healthy and stop bleeds fast at home can come with you on your trip.

Here are some travel tips for making your next trip safe and fun:

### Pre-Trip Check-up

Your friendly neighbourhood nurse, doctor or physical therapist at your haemophilia treatment centre (HTC) may want to see you before you go.

If you like to hop, skip, run and play, a physical therapist might ask a few questions about what kind of exercises you like. They can help you come up with active things to do while you're away.

And if there's a pool in your hotel or motel, great! Swimming is great for joints. So listen close and remember your physical therapist's tips, even when you're daydreaming about your trip.

### Power Packing

To keep boredom away, traveling long distances means packing things to keep you entertained, like your favourite toys, books, games, music and movies. It also means packing supplies that keep your body strong and help you heal from bleeds.

You can help your parents round up your usual supplies, putting the important stuff in your carry-on bag and extra supplies in your suitcase. Mum and Dad might have to make sure they have enough of these supplies before the trip, so remind them, and know where in the carry-on bag your factor and supplies are stored.



### Alert! Alert!

Travel can be tricky. That's why it's important to be prepared. If you have a medical alert bracelet, be sure to wear it before leaving home.

Make sure Mum and Dad have your travel letter. It's written by your doctor, and describes your bleeding disorder and the treatment you need to keep you healthy. Your parents will probably present this to the airport or other security staff, so all your factor and supplies can come with you on the plane.

Now that you're packed, prepared and prepped... Have Fun!

*by Heather Boerner. First published in Hemaware Junior on 19 Sept 2013  
<https://hemaware.org/life/road-again>*

## Fun Quiz

1. What is a Blue Whale's heart the same size as?
2. Of all the months in a year which month has 28 days or more?
3. Who was the first Twitter user to reach 20 million followers?
4. What is middle of Paris?
5. Which word is spelt wrong in every dictionary?
6. On a menu what is Bombay Duck?
7. Which fruit is the most popular and most consumed in the world?
8. Which singing voice is the highest pitch? Soprano, tenor or baritone?

Answers on page 20

## Notes to Teenagers with Bleeding Disorders

Your teenage years are an in-between stage of your life. They can be a confusing and sometimes painful part of growing up. You are no longer a child but not yet an adult. In truth, you may not be sure which you want to be. Although you want your independence, sometimes you wish your parents could still make decisions and work things out for you. At one time or another, all teenagers feel this conflict between growing up and staying a child.

Having a bleeding disorder may make you even more concerned at times about being like your friends. Perhaps you feel left out if you cannot compete in the sports your friends choose. Some boys with bleeding disorders feel less masculine than others their own age. Some girls feel hampered by heavy periods and visible bruises. Some teens even feel "defective" at times. It may help to know that all teenagers are very lonely sometimes and feel they have problems no one else has.

body in good shape is one way. The physical therapist at the HTC can help you plan a program that is right for you.

Another way to feel better about yourself is to work on an interesting hobby or skill. Every person has special talents. Maybe yours is a creative skill such as writing or drawing. If you make an effort to improve yourself or grow in some way, you will become more satisfied with yourself. This is a good time to begin planning for a future career.

Planning for a future job can help you find out your interests and abilities. You can learn what skills are needed in the jobs you would like to do.

Sometimes, young people with bleeding disorders are so eager to be just like everyone else they begin "denying" that they have a bleeding disorder. They ignore the signs of bleeding as long as they can and delay taking medication. They may do dangerous things and take foolish, unnecessary chances. They may not realize that they are doing

this to prove to themselves and to others that they are no different from anyone else.

This does not mean that you should never take a chance on anything. All of life involves some risk-taking. The only way to be independent is to try new things on your own. However, when you take foolish and unnecessary risks just to prove something, you are only setting yourself up for injury. Growing up includes accepting yourself as you are, both your strengths and your limitations. It means making mature decisions about which risks are the right ones to take.

*From Hemophilia of Georgia  
The Hemophilia, von Willebrand disease  
and Platelet disorders Handbook [https://  
www.hog.org/handbook/](https://www.hog.org/handbook/)*



Because you have a bleeding disorder and depend on adults for medical care, you may feel even more confused at times about growing up and being independent. One way to ease this problem is to take charge of taking your medication. As you learn to treat your disorder yourself, you will gain a sense of control over your life. Being in tune with your body and being able to respond to your medical needs can make you feel very good about yourself.

During their teens, most young people feel a great deal of concern about their looks and body build. It may be very important to you that others your same age (your peers) accept you as being part of the group. Most teenagers want to fit in and not be different in any way.

Since you have a bleeding disorder, you do have concerns not faced by everyone. It may be helpful to meet other young people your age who also have bleeding disorders. A great place to do this is at the HFQ Youth camp or Community Camp. Teens who have the same experiences as you have can suggest ways to handle common problems. If you share your feelings and worries with people who care, you may find that others have felt the same way. You will feel better yourself. If you ever feel that your troubles are just too much for you, talk to your doctor, nurse, or social worker.

When you feel down about yourself, look for ways to boost your self-confidence. Starting an exercise program to keep your



## Important Dates for HFQ Members

It's been hard to meet during the physical distancing restrictions of Covid-19, but as we go to press the following activities have been re-booked for later in the year...

### OBE Men's Forum

First week of the Month  
Call for details

### Women's Lunch

Sunday, 19 July 2020  
Everton Park Hotel  
11:30am to 1:00pm

### Youth Camp

18– 20 September 2020  
Emu Gully

### Bleeding Disorders Awareness Week

10 - 17 October 2020

### Community Camp

9 - 11 October 2020  
Noosa North Shore Retreat

*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.

Our youth and community camps are on again. We will be reviewing both camps to ensure we provide the best possible safety for all participants, but the camps (as always) will provide a stress free environment where people affected by haemophilia and other bleeding disorders can meet to share experiences, create networks amongst members and develop ongoing peer support networks. There will also be opportunities for problems to be discussed and answers sought in a relaxed and supervised environment.

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## ANSWERS TO THE QUIZ ON PAGE 18

1. A small car 2. All months in a year have 28 days and more 3. The singer Lady Gaga, who recently won an Academy award 4. R
5. Wrong (what else could it be?) 6. A fish 7. Bananas – more than 40 tons of bananas are consumed annually. 8. Soprano

## Camps Are On Again



READY.SET.HFQ

YOUTH  
CAMP



EMU GULLY, HELIDON SPA

18-20 SEPTEMBER 2020

PHONE 0419 706 056 OR EMAIL [INFO@HFQ.ORG.AU](mailto:info@hfq.org.au) FOR MORE INFORMATION

## IT'S BACK ON!

New Dates for

### HFQ COMMUNITY CAMP

Following the lifting of the Covid-19 Restrictions.

Fri 9th to Sun 11th October

Noosa North Shore Retreat

\$75 per family

\$50 per couple

\$30 per individual



For more information please call the office

Mob: 0419 706 056

Email: [info@hfq.org.au](mailto:info@hfq.org.au)



Haemophilia Foundation Queensland Inc.

## 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](mailto:info@hfq.org.au). You can be removed from the list at anytime.

### Graham Norton

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