

the

FACTOR



Issue 55
Winter 2018
Newsletter of Haemophilia Foundation Queensland

From the President



Hi everyone.

I hope you are all well with no bleeds - this month I include my impressions from the world congress meeting where

scientists, clinicians, patient representatives, government health & regulatory officials (as well as drug companies) met to share and learn. There were so many attendees that some rooms could not cater for the numbers.

There were varied topics presented on just about everything in the arena of a bleeding condition, however gene therapy was the most significant part of the congress for me.

I was so impressed at the continued work around the world on different treatment possibilities for those with bleeding conditions and how

collaboration on issues, advances, even different perspectives on the same problem can allow the different labs to collectively build an expanding understanding of the very complicated biomechanics involved at a cellular level.

The outcomes refine treatment possibilities that I think we will all benefit from in the long term. It is clearly still early days for gene therapy, but the data so far is compelling – we are indeed on the precipice of a therapeutic revolution in treatment for bleeding conditions.

David Stephenson
President HFQ
president@hfq.org.au

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Governors Function

On World Haemophilia Day this year (17 April) our patron, the Governor of Queensland, His Excellency the Honourable Paul de Jersey AC, and Mrs Kaye de Jersey, hosted a function at Government House to mark the occasion and to acknowledge the contribution of three significant contributors to HFQ in Queensland who have worked very hard to raise awareness and ensure that our programs complement the treatment and care offered by the state haemophilia clinics.

The principle award recipient was Dr John Rowell. Given for his lifetime of care and support of people with bleeding disorders in Queensland. We were extremely grateful that current and past

presented John with his award. A second award was presented to Erl Roberts for the lifetime of work he and his wife June have contributed to HFQ and to all people with bleeding disorders across Australia.

The final award recipient was Rebekah Jensen who's mum has factor 10 deficiency. Bec has and continues to raise funds and

awareness for people with bleeding disorders in Queensland.

Over 70 people attended the late afternoon event and it was lovely to have our patron and his wife work with us and make their lovely official residence available to us for this event, they were truly wonderful hosts.

On behalf of the management committee at Haemophilia Foundation Queensland, I want to publicly express our thanks to His



Excellency and Mrs de Jersey for hosting the afternoon reception and acknowledging some of the key people who contribute to our work.

We are grateful for their continued patronage because haemophilia is still a problem for those people experiencing unexpected bleeds. They can still cause mobility and other disability issues and it's still a shock for families when a bleeding disorder is diagnosed. The function brought many of our supporters together for a very special occasion.

With our patrons generosity in hosting the event, everyone who attended felt themselves very special indeed and I was told by many attendees that they were appreciative of the chance to meet others like themselves and renew strong and enduring relationships with other people experiencing or passionate about the bleeding disorders in Queensland.

Graham



QHC team members as well as RBWH administrators were able to join us as the governor

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. 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	Mr Erl Roberts
			Dr John Rowell
			Mrs Leanne Stephenson
			Mr Mike O'Reilly

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.

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 (LCCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist

Haemophilia Fellow - Dr Jonathon Holzmann

Haemophilia Registrar – Dr Terence Lim

Joanna McCosker . Clinical Nurse Consultant

Amy Finlayson / Salena Griffen – Clinical Nurse

Hayley Coulsen - Physiotherapist

Moana Harlen - Senior Psychologist Thur, Fri & alt. Weds.

Cheryl Kadinsky - Psychologist Mon, Tue & alt. Weds.

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

Desdemona (Mona) Chong - Advanced Psychologist (On Leave) 3646-7937

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: Book through Joanna at LCCH and Beryl at RBWH.

NDIS & Inherited Bleeding Disorders

NDIS and inherited bleeding disorders: a brief overview

On the 22nd July, a very enthusiastic group spent the morning (in person and by videoconference) at our first "NDIS and Inherited Bleeding Disorders" presentation. It is believed that this may be the first presentation in Australia specifically for people with inherited bleeding disorders. It is also our first videoconferenced presentation using the Queensland Health telehealth portal, which allowed people to link in to the discussion from home and from regional hospitals.

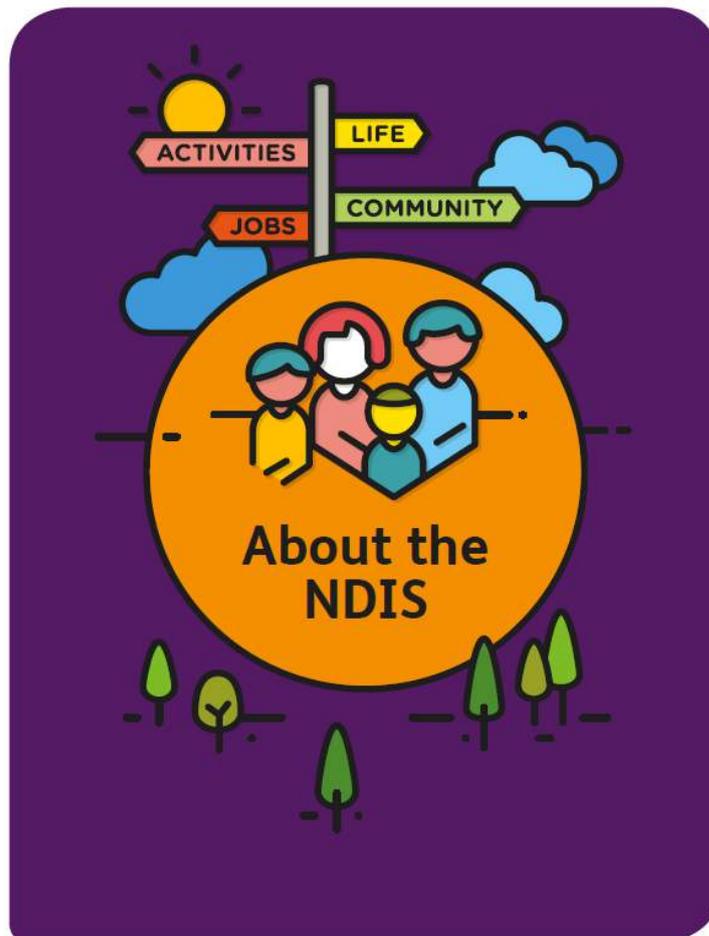
Joining myself as the 'tour guide' was the Metro North Hospital and Health Service NDIS implementation team (Shannon Dawson and Louise Lynch) and Jen Albright (Acting Stakeholder Engagement Director QLD Central – National Disability Insurance Agency). The National Disability Insurance Scheme (NDIS) was launched in Australia in July 2013 and has been steadily rolling out since this time.

The National Disability Insurance Scheme is designed to provide Australians under the age of 65, who live with a permanent and significant disability, with the reasonable and necessary supports they require, which will assist them to participate in the community, with education and employment. Reasonable and necessary supports are supports that are "related to a person's disability and are required for them to live an ordinary life and

achieve their goals".

For people who are eligible, the NDIS provides support in three ways:

Core Supports: enables a participant to complete activities of daily living and enables them to work towards their goal and meet their objectives: eg shower assistance, transport assistance.



Capital supports: an investment in for example assistive technology, equipment and home or vehicle modifications (eg wheelchair, roho cushion, ramps) - not flexible – will need quotes for these items.

Capacity building supports: enables a participant to build their independence and skills eg: increased social/community participation, support to attend education or workplace. NDIS assists people to link in with

mainstream supports, access activities, groups etc in the community and maintain their existing informal supports (it is not intended to replace the support you receive from family and friends). If you do not meet the access requirements for the NDIS, the NDIS is able to connect you to disability and mainstream supports in the community.

The NDIS is based on three pillars.

1. It is an insurance approach, meaning that all people in Australia are at risk of having a period of disability, so we all share the cost and can utilise the NDIS as we need it.
2. Choice and control, which shows a significant change from previous disability supports. The scheme helps people achieve their goals, foster greater independence, social and economic participation and value for money. The participant also has choice and control over how the funds are spent. Exercising choice and control in the pursuit of their goals and in the delivery of supports is a fundamental right of a person with a disability.
3. Community and mainstream is the third pillar. NDIS supports are not there to take over from other community and mainstream supports that are already in place.

We were able to hear about the key criteria, and the process of requesting access and the role of Local Area Coordinators and Early Childhood Early

NDIS continued...

Intervention.

Key take home messages:

- To start the application process, you call the NDIS on 1800 800 110 – they will start the Access Request Form (ARF) with you over the phone and send the partially completed form for you (and your health professionals) to complete.
- NDIS is around provision of reasonable and necessary supports needed due to a permanent disability which significantly impacts on your ability to do daily activities, not your diagnosis.
- To be eligible, when you apply you must be aged under 65
- Implementing your plan is just as important as making your plan. There are workshops being held in the community around implementing your plan. Please ask about this when you have your planning meeting (after your access request is approved).
- Your first plan may not be perfect. The plan will be reviewed in 12 months and if your circumstances change significantly, you can have the plan reviewed earlier.
- Use plain language when completing the form (for example no medical terminology)
- The NDIS will not cover

everything in a person's life.

- There will still be other supports that you will need to receive that aren't funded by the NDIS – your health needs, the support your family and friends provide, usual household bills that everyone needs to pay.
- You can appoint someone to act on your behalf
- There is an appeals process if you aren't happy with the decision.

Loretta (Social Worker) at the Royal Brisbane and Women's Hospital and Moana and Cheryl (Psychologists) at Lady Cilento Children's Hospital can help you with the NDIS. For example- assisting you to have the health information section of the Access Request Form (part F) completed. They can go help with preparing your goals and thinking about what you may need to ask for if you go on to making a NDIS plan. Please don't hesitate to call us.

For more information National Disability Insurance Scheme: <https://www.ndis.gov.au/> Early Childhood Early Intervention: <https://www.ndis.gov.au/ecei> Phone: 1800 800 110 Email: enquiries@ndis.gov.au

The Queensland Haemophilia Social Worker (RBWH) and Psychologists (LCCH) also have information which can be sent out to you.

Forum Observations from Graham

HFQ was pleased to support this important forum and after the forum I spoke to some of our members who attended. The following is just some of my thoughts and reflections on NDIS.

Several members have expressed to me the hope that they (or their child) would qualify for NDIS. Haemophilia and other bleeding disorders are NOT included in the named conditions that NDIS would automatically cover.

Some people were also concerned that receiving NDIS might impact on CentreLink career payments. The forum made very clear that CentreLink payments are separate to what the NDIS may offer and are unlikely to impact on any benefit you or a carer is receiving.

If you are interested in applying for NDIS, it is therefore very important to talk about the ways your condition impacts negatively on your social participation. This can be from getting work to participating in your local community.

Also don't forget to include the costs of doing things that family and other supports might be currently doing for you. What would happen if they weren't there to help?

Although you need a doctor to completed a form, they are not reviewed by medical people so neither you nor your doctor should say things like 'because of haemophilia', but talk instead about how you can not do things you think would make life better. Say things like 'I have haemo-arthritis in my left ankle that means I can't put my shoes on.'

Correction & Apology. Autumn 2018 (Issue 54)

In the welcome article to Dr Jane Mason on page 6 of our previous issue, the headline inadvertently spelt her name as Jayne. This is incorrect and we offer our sincere apologies to Dr Mason who spells her name as shown in the article (Jane). Please make sure that if you've recorded her details, that you use her correct spelling and not the version we incorrectly used in our title.

Bright Future for Treatment Options

Report World Haemophilia Congress – 2018

The recent international meeting on bleeding conditions in Glasgow brought together scientists, clinicians, patient representatives, government health & regulatory officials as well as drug companies. There were so many attendees that some rooms could not cater for the numbers.

There are many people talking about treatment options for haemophilia (and other bleeding conditions) being at the precipice of a therapeutic revolution. In many parts of the world extended $\frac{1}{2}$ life products have proven their worth along with a range of standard treatments, but recent advances in research is pushing therapeutic boundaries forward - new innovative therapies looking to deliver curative outcomes which may change the lives of those with bleeding conditions. It's unclear which drug companies (and there are many) will deliver the best solutions - scientific trial outcomes will eventually tell. The world market in bleeding treatments is expected to be approx. AU\$24Billion by 2024, this motivates developments, but more importantly will deliver safe superior treatments.

After several scientific presentations it was clear to me that the very fine detail of the how cells biology works in relation to factor generation is not fully understood. While much is known, I was astounded at the complexity of current understandings at a cellular level.

It was however, very encouraging to learn that ideas / results / theories from different labs around the world are shared - effectively adding to a collective understanding which in turn, drives the science and the treatment products forward - the future is indeed very bright for treatment of haemophilia and other genetic diseases.



Gene Therapies

Gene therapy presentations played a significant part in the congress. Numerous trials were reported on with several reporting evidence of significantly reduced annual bleed rates which is simply brilliant, however it's important to remember that trials can have associated risks - immunity against vectors - or immunity against the foreign DNA sequence (toxicity and gene mutation when foreign DNA is inserted may be a risk).

My message to you if you are considering joining a clinical trial is to get informed from your medical professionals & understand the possible risks and issues. Remember gene therapy is still relatively new and continuing to develop - one of the presentations commented about the 'luck of the draw' where some patients end up with higher

factor levels than others ... scientists are trying to understand why this occurs, so they can deliver more predictable outcomes.

It was interesting to hear the experiences and decisions that some patients made after their gene therapy treatment - some patients who were effectively

moved from severe to mild or moderate (or even into the normal range - still not cured but experiencing a curative treatment). Many changed their lifestyle to a significantly over active one - unfortunately resulting in breakthrough bleeds and a wakeup call to pull back.

For a one-off injection you can understand how great these patients must have initially felt after decades of issues - to experience the sense of freedom where you're no longer tied to several injections a week, where you are no longer burdened with 'I cannot do that because it will cause a bleed' - it must have been brilliant.

The take home message for me was the need to completely change / reset your thinking as a patient.

Gene Therapy for those with Blood Borne Viruses

What was not discussed at any of the presentations that I attended was the implications of gene therapy for people who are HIV positive, so I made it my business to talk to several of the presenters to get their views. The presenters theorised the

Wold Congress Report continued...

vector will not be disrupted in its delivery of therapy to the cells – so that's great. However, with the Lentivirus solution where replication is required in the cell – one presenter said it may be an option to stop HIV meds and recommence after gene therapy – or start on another combination after the gene therapy had done its work. BUT this is all very much theoretical and any such situation would have to be thoroughly worked through with a range of specialist to see if this is even possible – again, any questions in your situation should go through your treating haematologist / HTC as these comments are purely theoretical and not based on validated facts.

Following on from the HIV question – I asked what the implications are theorised to be for people with some liver disease –but it is unclear what the treatment protocols will be in cases where the liver is compromised. This will eventually be worked out as gene therapy evolves so it's a wait and see. The scientists did not know at what point liver damage may impact gene therapy treatment. Time will tell, and, as always, your treating medical team will be the people to talk to about this.

Despite the progress in bypassing methods or extended ½ life products or gene therapy, there is no 'one size fits all' approach. These current possibilities do not bring factor levels to 100% normal – or replicate the bodies normal ability to ramp up clotting factor when needed beyond 100%, but these treatment options can significantly improve quality of life, reduce time in hospitals, reduce the number of infusions, have potential to shift people from

severe to mild haemophilia and that is simply one giant step forward.

Cost of Treatments

What is a fair price for treatment – data and evidence on therapeutic effectiveness is the first issue. One thing is clear to me – there will be a number of high cost therapies in years to come – and not just for bleeding conditions. For newer treatments it's currently unclear about long term safety and ongoing effectiveness. This all adds up to a significant challenge in how governments will handle this. One suggested option is a 'risk sharing' approach where leasing reimbursements or annuity strategies may be affordable to government budgets and at the same time allow access to patients. In my opinion, it's up to all of us – patients and medical professionals, to help define the value and outcomes of these new therapies and represent them where we can to decision makers – for us in Australia being diligent with entering MyABDR data is an easy way to help everyone.

Genetics and inhibitors are complicated, but very encouraging as different teams around the world shared outcomes and collectively advance understandings – hopefully this will bring a range of indicators together to try and somehow predict patients at greater or lesser inhibitor risk – allowing better treatment plans.

In conclusion I am so impressed at the continued work around the world on different treatment possibilities for those with bleeding conditions and how collaboration on issues, advances, even different perspectives on the same problem can allow the different labs to collectively build an expanding understanding of the very complicated biomechanics involved at a cellular level – the outcomes refine treatment possibilities that I think we will all benefit from.

Regards

David Stephenson, president
HFQ



Resources for Awareness

Raising Awareness: Learning, sharing and fundraising

At HFQ we have many sources of information that may be helpful to you, your family, health professionals, and the broader community. This magazine for Queensland members and the HFA National Haemophilia Journal are (or can be) delivered to all members and associates of HFQ, please let us know if you are not receiving both magazines via the post or email.

We also have information and resources on our website (www.hfq.org.au); and we post updates to our facebook page (www.facebook.com/HFQLD). We also have an Instagram account (HFQld) and twitter post.

But we have many more resources that you may not be aware of. Among the things we offer is access to the journal; Haemophilia. This is the official journal of the World Federation of Hemophilia and dedicated to the exchange of information regarding the comprehensive care of bleeding disorders. It has peer reviewed scientific papers and research articles you can access through us by joining the contents page distribution list or asking us to research topics of interest.

We also have a library of resources containing books & DVD's for you and your family to better explain aspects of living with a bleeding disorder. They range from cartoon explanations of bleeding disorders for children through to books on managing inhibitors and/or haemophilia as well as autobiographies from people living with bleeding disorders. We also maintain a list of website and on-line resources that can help you better understand or explain your own

circumstances. If you'd like to access any of these, please let the office know and we can post them out to you on a loan or keep basis depending on the resources required.

Of course, being informed is important to you if you are managing a bleeding disorder, but so to is getting the public on-side and helping them understand what living with a bleeding disorder is like and we



are very excited that HFA have released a brochure called 'About bleeding disorders', that can be given away to family and friends that explains in simple terms, what a bleeding disorder is. This is a great resource to use at any time when talking to people who don't understand, but it can be especially helpful at times when we are trying to raise public awareness such as World Haemophilia Day (17 April) and Bleeding disorders Awareness Week (7 – 13 October 2018 and every October in Australia).

Bleeding Disorders Awareness Week was previously called Haemophilia Awareness Week,

but it was rebadged because we want everyone living with a bleeding disorder to feel supported by Haemophilia Foundation Queensland and we recognise that we have many members with von Willebrand Disease and several other rarer bleeding disorders. It is vital that the voices of all our members are heard and that the general community know that haemophilia is just two of the disorders we represent and support.

If you would like to hold a fundraising event or awareness stall during one of these awareness times (or at any other time) we also have posters, balloons colouring competitions, branded pens, shopping bags and USB sticks that can be given away for a suitable donation etc.

We also have polo shirts and t-shirts that you can wear to show your support. These are available in assorted sizes and are given away at cost of free depending on the activity.



Membership Renewal Time

HFQ membership subscriptions are due for renewal. The side of this page can be torn off and used as your 2018-2019 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 one part time staff member, 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 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, however government funding is not dependable and our current grant was offered only for two years and will run out in 2019. A number of the activities that we do 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 using the QR code below. 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

HFQ MEMBERSHIP

RENEWAL



Membership of HFQ for 2017/18 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: \$ _____

Tips for Disabled Parking

People with a disability parking permit can stay as long as they like at any Westfield's around Brisbane including; Carindale, Chermside, Garden City, Helensvale, Northlakes and soon to open in late 2018 Coomera. Many other shopping centres also offer longer free parking times for "registered mobility parkers"

All you need is to take a photo (or photocopy) of both sides of your disability parking permit with your mobile and the cars Rego details. You then take all the information to the customer service desk and they will process your information & keep it on file. After this is done, depending on the centre, you can stay as long as you need or you can get your parking ticket validated for the longer free parking

Even better once you sign up at a Westfield's like North Lakes your automatic signed up at all Westfield's. Normally you don't need to, but after speaking to management at a Westfield they inform me that it would be a good idea to take a photo of your permit and your Rego just in case you get stuck with the boom gate

Most shopping centres have a number of disabled parking bays located near each centre entrance.

Plan your journey to the Centre and park in the most convenient disabled parking bays to the stores you are visiting at the centre.

Many shopping centres also offer specific facilities for wheelchair users or visitors with a mobility restriction. Some have complimentary mobility scooters and others offer wheelchairs to use in their centre.

For complimentary use of a mobility scooter, you usually need proof of identification, which should be either a valid passport, driver's license or proof of age card. You'll then be asked to fill out a hire agreement form and you'll be ready to shop.

Visit the Concierge desks at your shopping centre to see what help they can offer. Don't forget to ask about Mobile Phone charging stations and if access to free WIFI is available.

Brett



My ABDR – what's coming up?

From the National Blood Authority and HFA MyABDR teams...

Why is there so much emphasis on using MyABDR to record your treatments and bleeds?

MyABDR was developed to support best practice clinical care and treatment of people with bleeding disorders.

It is a tool that can make it easier for both people with bleeding disorders and their Haemophilia Treatment Centre (HTC) to monitor and review treatment and care. It links directly to the Australian

Bleeding Disorders Registry (ABDR), the system used nationally by HTCs for the clinical care of their patients. So when you record treatment and bleeds and maintain your treatment product inventory on MyABDR, you have a copy of your records and you can also share them with your treating team.

You can also login to the website version of MyABDR to look at graphs and other reports on your records of your treatments and bleeds – a great way to keep an eye on target joints, or talk to your HTC about how your treatment plan is going. This kind of monitoring is very important if you are considering a change to a different treatment or are having bleeds.

What can you do with MyABDR?

- Record treatments and bleeds as they occur – and add notes or upload photos

- Manage stock of treatment product (at your fingertips when you get the call asking what stock you need)
- Share and discuss the information with your Haemophilia Treatment Centre
- Have accurate records of your treatments and bleeds to look over at home and discuss at your review – rather than trying to remember what happened
- Update your contact and personal details.

And there are other benefits!

UPCOMING ENHANCEMENTS

The NBA will soon be implementing new security enhancements to improve the security of MyABDR system. The changes will include:

- extending the mandatory password character length from 9 to 10 in line with government security standards
- the requirement for users to update their password regularly

More information will be emailed to MyABDR users ahead of the changes.

You will be pleased to hear that – with a lot of work behind the scenes to assess the current change requests – other improvements are also planned for MyABDR over the next 18 months.

The NBA has compiled a list of change requests and new functionality/

enhancements and will commence a project to update the MyABDR system in latter half of 2018 and 2019.

Stay tuned for more details!

ANY QUESTIONS OR NEED HELP?

Don't forget that the MyABDR Support team is always happy to help you with any problems, and can make a time to get back to you if that suits you.

They are available 24 hrs, 7 days a week.

T: 13 000 BLOOD / 13 000 25663
E: support@blood.gov.au.



Some people are coming back to using MyABDR after being on a clinical trial or starting to use MyABDR for the first time. What tips do regular MyABDR users have for new users? Michael, a MyABDR user from South Australia, had this to offer:

My favourite features are:

- 4-digit pin access code for log in
- Easy-to-track stock levels
- Simple user interface for recording bleeds

My tips for new users or people coming back to it are:

- Get into the habit of bringing your device with you when injecting so it's right there and you don't forget.
- Put the app on your device's front screen so it's always in sight. Even subconsciously you will see it and this helps to remind you to use it.

Another benefit of MyABDR - your records can contribute to health and treatment statistics. This helps with treatment supply planning. This also helps with developing evidence for best practice and for new innovative treatments.

The treatments and bleeds that you record can become part of national statistics to show how a particular treatment works, including in individualised treatment regimens, and its impact on bleeding patterns. This is an effective way to understand and improve current treatments, and it is also a very valuable resource for national advocacy for future treatments.

My Health Record opt-out date announced

Australians who do not want their medical records stored on a national electronic database can opt out of the scheme from July 16 to October 15 this year.

My Health Record is a computer-based system that has been taken up by over 5 million Australians already. It is designed to collate a patient's desired health records into one place, with the aim of making it easier to share this information with their various healthcare providers.

My Health Record should provide many benefits to patients, including reduced duplication of tests, better coordination of care for people with chronic and complex conditions, and better-informed treatment decisions.

Currently, Queensland Health sends discharge summaries to patients' My Health Records from most of its facilities and by mid-2018 Queensland Health will be uploading more documents to the

My Health Record system, including approved reports from pathology and diagnostic imaging tests.

Provided your GP or other health care professional is registered with the My Health Record system, they will be able to view any of your clinical information completed during a visit to Queensland health public facilities.

You can choose to accept your records becoming part of your My Health Record, you can opt out (provided you do it before 15 October) or you can and you can set multiple limits on who can see this data and at what level. If you stay in the system, you can also upload information yourself and share information like allergies and test reports with clinicians.

A national information roll out will be implemented shortly to inform all Australians of the benefits of digital health, and to explain the

opt-out process. The My Health Record system and opt out process has the full support of Queensland Health, the AMA and other medical and pharmaceutical guilds as well as the Consumers Health Forum.

The "My Health Record" is not linked to MyADBR in any way but like all data you need to be proactive in what you want done with your records.

There are already some protections in place to ensure your "My Health Record" data is protected. The Australian Government has developed a framework that defines how data on the My Health Record system can be used for research and public health purposes while preserving privacy and security of data in the system.

For more information see www.health.gov.au/internet/main/publishing.nsf/Content/eHealth-framework.

HFQ 2018 COMMUNITY CAMP NOOSA NORTH SHORE RETREAT

\$100 per family \$70 per couple \$40 for individuals \$25 day visitors
(subsidies available on request)

Nature, outdoor adventure, play, explore, share and interact



FRIDAY 9 TO SUNDAY 11 NOVEMBER

Contact the HFQ office on info@hfq.org.au or 0419 706 056
to register & for more information

Haemophilia Foundation Queensland Inc



Art Competition

“Bleeding Heart” is HFQ’s Art Competition running in parallel with Bleeding Disorders Awareness week in October. The theme is ‘A life affected by bleeding disorders’, so this could take you anywhere from your own experiences, to how you think other people see bleeding disorders, or you could even explore feelings deep inside you!

It’s open to all people affected by bleeding disorders. Young people up to the age of 26 are especially welcome to contribute and there are prizes for several age groups and category types.

You may like to enter any section of the competition or all of them! Think about your life with a bleeding disorder in the family... And have fun!

There are two main categories: 2D Art and Digital Photography. As

long as your artwork has some connection to bleeding disorders and what they mean to you or the impact they have on your life, you can enter the competition.



The complete rules are posted on our website but stay open to ideas that inspire you or messages you’d like others to know. You’ve got lots of time so your ideas can evolve, so go with it. There is a prize in each section and where possible all winning entries will be publicly displayed during Bleeding Disorders Awareness Week in October.

Start thinking about materials and how could you possibly create your concept. When you have an idea

or a couple of ideas talk to your parents if you need materials and start to think how you might create your bloody art work.

“Bleeding Heart” launched on World Haemophilia Day and is open to everyone. In addition to the open section, there special categories for young people up to 25 (the categories are: under 5, 5-11, 12–17 and 18-25 years who are formally diagnosed with a bleeding disorder or have a family member with a bleeding disorder.

For all entries, the judges will be looking for the overall look and impact, as well as the effort and execution/construction and the meaning you want it to convey. The competition will close on Friday 28th September and winners will be invited to attend the Awards Ceremony during Bleeding Disorders Awareness Week.

World Hepatitis Day - 28 July

Within the bleeding disorders community many people with hepatitis C have not yet pursued the new effective treatment's that are now available. This may be because they are unaware how effective and side effect free the new treatments are, they may not have time for a clinic visit, or they may be unaware they have hepC. Treatment can now be managed through your GP and anyone (even those with mild bleeding disorders) who has had a clotting factor treatment before 1993 could be affected.

The affected group would now be at least 24 years old and includes women who are “carriers”, who might have had bleeding after dentistry or surgery or a post-partum haemorrhage and had a treatment with clotting factor concentrate or a blood transfusion. So if you or anyone you know may have received a blood product before 1993, please use World Hepatitis Day to encourage them to test for hepatitis C and if they have it, to treat it and get rid of it!

If your GP is unsure how to proceed because of your bleeding disorder please talk to the QHC staff or access the factsheet for GP’s on the HFA website. And if you have already treated and cleared it, good for you - but please remember that if you have cirrhosis, you should still get liver health checks regularly to make sure everything is OK.



Looking after your Veins

Home treatment and prophylaxis have become a way of life for people with haemophilia. It is very important to look after veins as you will need to use them for a long time.

Veins have thinner walls than arteries; they lie closer to the surface and it is very important to look after them as you will need to use them for a long time. Learning how to look after veins is important and requires work.

Have you ever noticed how body builders and brick layers usually have big, strong veins? This is because of the upper arm exercises and work they do. You can make veins bigger in your arms by doing some simple exercises.

EXERCISES FOR VEINS

1. Squeeze a sponge ball in your hand. Start with ten squeezes daily and build up to 50 squeezes per hand daily. This exercise helps to develop the supporting muscles.
2. Place a tourniquet around your upper arm. It should be

tight enough so that your veins stand out in a few minutes, but not so tight that you can't feel a pulse at the inside elbow. Squeeze your fingers in and out with/without a sponge ball until your arm gets tired. Loosen the tourniquet and rest a little, then repeat this exercise again. If you do this frequently, at least twice a day, it will improve your veins.

How do these exercises improve your veins?

When you do these exercises, your muscles tighten, forcing the blood to return through surface veins. This causes veins to become larger and stronger, making them easier to find and use. These exercises will help with your infusions but like any exercise, it only works if you do it regularly.

VEIN ROTATION

When you put a needle in your skin, it leaves a small hole that needs to heal. Changing which veins you use can help

decrease irritation and scarring. You can keep your veins in good shape if you let them heal before you use them again. Rotating your vein is often recommended, where you let one spot heal while you use another. It is also useful to have a backup vein that is used to being injected in case you have issues with your regular vein.

TIPS FOR TREATMENT

Please see over for some tips you can do to make things go more smoothly when you need treatment.



This article and the one on the opposite page were originally published under the heading Looking after your veins. in National Haemophilia No.202 June 2018, the journal of Haemophilia Foundation Australia. By the authors; Robyn Shoemark and Helen Starosta.

Robyn Shoemark is Clinical Nurse Consultant, The Children's Hospital at Westmead

Helen Starosta is Clinical Nurse Consultant, Royal Hobart Hospital



Tips for Taking Treatment

What can you do to make things go more smoothly when you need treatment?

The following are tips and tricks which may help you:

- Clean – Always wash your hands before you start and have a clean area to make up and give your factor. To avoid infection, clean the skin area you are using and then wipe with an alcohol swab before infusion.
- Drink plenty of fluids – make sure you have enough to drink before you try to give your factor so that your veins are plump and bouncy.
- Keep warm –veins shrink in the cold, making them much more difficult to find. If you're cold have a warm shower or bath. A warm breakfast or hot drink will warm you from the inside. A heat pack over the vein you are using is another great way to help find your veins.
- Environment – makes sure you are relaxed. Being stressed or scared makes it more difficult to find your veins. Sit somewhere comfortable and if you need to be distracted, turn on music or the TV. Take a few deep breaths before you start if you need to calm yourself.
- Exercise –Just before you have your factor, doing a quick round of exercise such as running on the spot or star jumps will help get your blood pumping and make finding your veins easier.
- It is better to use a plump bouncy vein that you can feel than a vein you can only see. If a vein is plump and bouncy it will be easier to access than a vein that is visible but flat. Take your time to feel and get to know your veins and the direction they are running.
- Being in a well lit area will help you see the vein and help you get the butterfly in first time! But

remember it is not only seeing the vein but feeling the vein.

- Position – make sure you have your arm below the level of your heart. Dangling your arm over the edge of the bed/chair before you access your veins will allow gravity to increase blood flow to



the area and the vein. After applying the tourniquet squeeze a rubber ball or make a fist or flap your arms up and down to help increase blood flow.

- Use distraction for small children – TV, DVDs, iPad, toys, bubbles, Buzzy Bee, another person. Anything your child likes is helpful.
- Pain relief – if using anaesthetic 'numbing' creams. Remember to remove and clean the area well. Finding the veins is easier if the cream has been removed for around 10 mins before trying to use the vein.
- Avoid pressure on the needle insertion site during an infusion or when taking the needle out. Remember to release the tourniquet before you start infusing your factor.

- Apply pressure after the needle is removed to make sure the bleeding has stopped. If you do not apply adequate pressure for long enough then you may get a bruise over the vein making it difficult to feel when you next need to use it. Using a pressure band aid will help prevent bruising. If you do not have pressure band aids: use the palm of your other hand to apply firm pressure not just with your finger. If you only use your finger it may roll off the puncture site. Looking after your vein makes it much easier to find the next time you need treatment.

- Rotate vein sites as needed – you may not need to do this but if you are having problems with the vein, it is always good to have an alternative to use.

- If you need a blood test – ask the health professional if they could use a different vein to your regular vein or alternatively inform the phlebotomist (blood collector) that you have difficult veins & a more experienced collector may be able to collect the blood. This may involve some waiting, until that person is available.

- Ask for help – sometimes you will have problems despite your best efforts. Remember, it is ok to ask for help if you are having problems.

For more information about looking after your veins, talk to the haemophilia nurse at your Haemophilia Treatment Centre.

This article is adapted with permission of the authors from the article published by HFA in National Haemophilia No.202 June 2018.

It was adapted by Graham Norton, HFQ Manager, and Beryl Zeissink, CNC – Haemophilia, Queensland Haemophilia Centre

Bridge to Brisbane

Bridge to Brisbane Day last year celebrated the 21st running of this much loved Queensland event. If you didn't enter, please don't miss out for 2018! HFQ has several people participating this year and you are welcome to join with us as we walk or run. You will enjoy a course that takes in some of Brisbane's most iconic landmarks including running over the Story Bridge and finishing at the beautiful South Bank Parklands.

Choose to take on the 5k or 10k challenge and join with the Haemophilia Foundation Queensland Team and take on the challenge to raise vital funds for people in Queensland affected by bleeding disorders. Entries are open now and if you are thinking of taking part in 2018 for HFQ then please let us know.

Why not make your next fun run effort mean more and fundraise amongst your friends, colleagues

to Brisbane run in your preferred category and elect to fundraise for HFQ. Once you're signed up,



and acquaintances to support HFQ. As a member of our team you will be eligible for a number of rewards and incentives including HFQ T-Shirts.

let us know and we will be in touch.

If you have any questions, or for more information about Team HFQ please call the office on 0419 706 056 or email info@hfq.org.au

To join Team HFQ all you need to do to is register for the bridge

WFH 2018
 WORLD
 CONGRESS

**WFH Congress update
 Tues 7 August 10:00am
 Windsor International Hotel**

Health Updates

New HIV vaccine shows promise in human trials

An HIV vaccine produced an anti-HIV immune system response in tests on 393 people, a study published in the July Lancet found.

HIV vaccines have proved a challenge for scientists because there are many strains of the virus and because HIV is adept at mutating to elude attack from our immune systems.

For this "mosaic" vaccine, scientists have developed a treatment made up of pieces of different HIV viruses to offer better protection against the almost unlimited number of HIV strains found across the world.

Scientists tested various combinations of the mosaic vaccine and all of the combinations produced an anti-HIV immune system response and were found to be safe.

They also gave rhesus monkeys the vaccine to confirm protective levels from simian-human immunodeficiency virus - a virus similar to HIV that infects monkeys.

The mosaic vaccine combination that showed the most promise in humans was found to protect 67% of the 72 monkeys from getting the disease.

Although it is not clear if this would be enough to prevent infection, the promising results mean researchers will next test the treatment on 2,600 women in southern Africa who are at risk of getting the illness - one of only five vaccines to make it to this stage of so-called efficacy trials.

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)31364-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)31364-3/fulltext)

New Study on Cardiovascular Disease in Haemophilia Patients

The study published on June 12, 2018 in the journal Blood Advances suggests that screening and managing risk factors for cardiovascular disease is needed for men with haemophilia.

Haemophilia patients are generally thought to be better protected from cardiovascular disease (CVD) and

a team of investigators enrolled patients from 19 U.S. haemophilia treatment centres (HTCs) to determine whether data supports this assumption.

The purpose was to better understand the prevalence of CVD in these patients and 200 moderate and severe haemophilia patients, between 54 and 73 years of age, were enrolled in the study.

30 of the haemophilia patients met established CVD criteria, with the most common events being angina and Myocardial Infarction (MI). When compared with the unaffected group, the HTC patients did experience significantly less CVD events and procedures, with an overall rate of 15% vs. 25.8% in the comparison group.

The study authors drew important takeaways from the study. While haemophilia may offer some protection from CVD in certain moderate and severe patients, older patients are not completely immune from heart-related complications. Cardiovascular risk factors such as hypertension, are still common in haemophilia and measures directed at screening for and managing cardiovascular risk factors and optimizing management of CVD in this population are needed, the authors concluded .

[A https://www.hemophilia.org/Newsroom/Medical-News/New-Study-on-Cardiovascular-Disease-in-Hemophilia-Patients](https://www.hemophilia.org/Newsroom/Medical-News/New-Study-on-Cardiovascular-Disease-in-Hemophilia-Patients)

How Exercise can Improve Bone Health

Medibank Australia says 2.4% of Australians suffer from osteoporosis — a chronic disease which causes severe weakening of the bones. The condition becomes increasingly prevalent as people age, with over 50's being the worst affected age-group,.

So it's essential that we look after our bones throughout adult life and experts suggest exercise plays a key role in building and maintaining bone density.

Numerous studies have found that resistance training is the most

beneficial method of exercise to help strengthen bones — not only for people living with osteoporosis, but also for those looking to avoid the onset of any bone issues.

Similarly, a Pennsylvania State University study found bone mineral density had significantly increased in the arms, legs, pelvis and spine of people taking part in low resistance, high repetition training.

A mix of balance and mobility exercises are recommended by Osteoporosis Australia, as well as aerobic activities and progressive resistance training like lifting weights. But just remember, bones need to be challenged in order to gain strength, so exercises should be regular, varied in type, and the intensity should be slowly increased over time.

<https://www.osteoporosis.org.au/sites/default/files/files/Exercise%20Fact%20Sheet%202nd%20Edition.pdf>

Who Makes Bangor's Best Bloody Mary?

The Hemophilia Alliance of Maine held a "Bangor's Best Bloody Mary" event in May. This was an awareness event that pitted local bartenders against one another to see whose spicy concoction will be deemed Bangor's Best.

Competitors, were granted a table at the event where they created their bloody mary. All vendors were provided with vodka from the event partner, but had to bring their own mix, spices, and garnishes to make their own unique drink. The winner of the populous vote received a \$100 cash prize. Guest judges awarded a \$250 grand prize and the title of Bangor's Best Bloody Mary.

All proceeds from the event will benefit the Hemophilia Alliance of Maine, whose mission is to assist and enhance the quality of life for Maine's people and families who have a bleeding disorder.

<http://bangordailynews.com/bdn-maine/community/who-makes-bangors-best-bloody-mary-you-decide/>

Telling other Kids about Bleeding Disorders

You can choose how much to tell your friends about your haemophilia or VWD

If you're confused about whether to tell a new friend about your bleeding disorder, don't worry, you're not alone. It's normal to be concerned about what your friends may think. You might wonder: Will they treat me differently? Will they still like me? Will I feel like an oddball?

It's your decision whether you say anything about having a bleeding disorder. If you discuss it with your friends, you may be surprised at how well they respond to the news. Once they understand why you have to do certain things to stay as healthy as you can, they can encourage and support you.

Talking to friends about your bleeding disorder may make you nervous, but there are some things you can do to make it easier.

Pick a good time

A friend might have questions for you, so telling him as he's about to go up to bat at baseball is

probably not the best moment. Try talking when you have more time, like during lunch or while hanging out after school or on the weekend.

Explain that your friends don't have to worry about you

Upon learning that you have a bleeding disorder, friends may think that you're sick and that you shouldn't do activities you usually do together. You can tell them that you take special medication to stay healthy, and even though you have to be careful, you're the same friend you've always been.

Keep it simple

There's no need to explain how you infuse or what happens if you get a bleed. In the beginning, you can simply tell your friends that your bleeding disorder means your blood acts differently than theirs and that you need shots to stop your body from bleeding too much.

Get help from your team

If you're not sure what to say, you might try talking with your parents first. You can role-play with a sibling or a staff member at your haemophilia treatment centre to see how the conversation might

go. Other kids you know with bleeding disorders can provide good advice.

Be prepared for questions

Some friends may be curious. You might get questions like, "How did you get it?" and "Is it contagious?" They'll be looking to you as the expert on your bleeding disorder, but you can decide how much you want to answer.

Don't forget that nobody is perfect. You might sometimes feel that having a bleeding disorder makes you not "normal," but everyone has something they have to deal with. Some kids need to wear glasses. Some kids need to wear hearing aids. Some kids have food allergies and can't eat certain foods. You might find that when you tell your friends about your bleeding disorder, they share something you didn't know about them.

From an article by Ian Landau on HemAware Junior called How Kids Tell Kids They Have a Bleeding Disorder

<https://hemaware.org/life/how-kids-tell-kids-they-have-bleeding-disorder>

Go For It Grants

Have you ever wanted to be daring and take on a challenge but found it too scary or don't know where to start? Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you GO FOR IT!

The Haemophilia Foundation Australia's Go for it Grants program assists people living with bleeding disorders take the first step towards achieving their goals. The grants are open to anyone in Australia who has, or is affected by, a bleeding disorder.

There are 2 x \$2,500 Go for it Grants on offer to provide winners with the financial support to help pursue their dreams.

What do you want to try? From study to advance your career, increasing your confidence and leadership skills, or training to be the next sports star - the Go for it Grants can take you one step closer to realising your dream.



Check out the HFA website for more information at: <https://www.haemophilia.org.au/get-involved/awards/go-for-it-grants>

Youth Canoe Journey

The Youth Canoe Journey is an exciting extension to Youth Lead Connect to build education and life skills for young people. The program is designed to assist young people in their personal development and build connections with others living with a bleeding disorder. HFA have teamed up with adventure therapy company Purple Soup to bring you this exciting experience.

The plan for the trip will be to meet up in Melbourne on the Thursday night, before heading up to the Murray River, where we will be taught how to canoe by Purple Soup's experienced instructors. From there we will begin our journey along the river, stopping each night to set up camp until Sunday, when we'll head back to Melbourne.

This is not just a weekend away, participants will be challenged to work as a team, overcome obstacles, and develop initiative skills.

Why the change?

- So far Youth Lead Connect has been for youth leadership and mentoring training. This is a great program, but reaches a few of our youth members around Australia, those who have the time and resources to be current leaders in their community. The Youth Canoe trip needs those people as well, but it's also for those young people who maybe

aren't ready for the commitment that Youth Lead Connect requires, but are still looking for ways to challenge themselves and become more involved with others affected by a bleeding disorder.

- Don't worry! The original Youth Lead Connect training will be returning in 2019

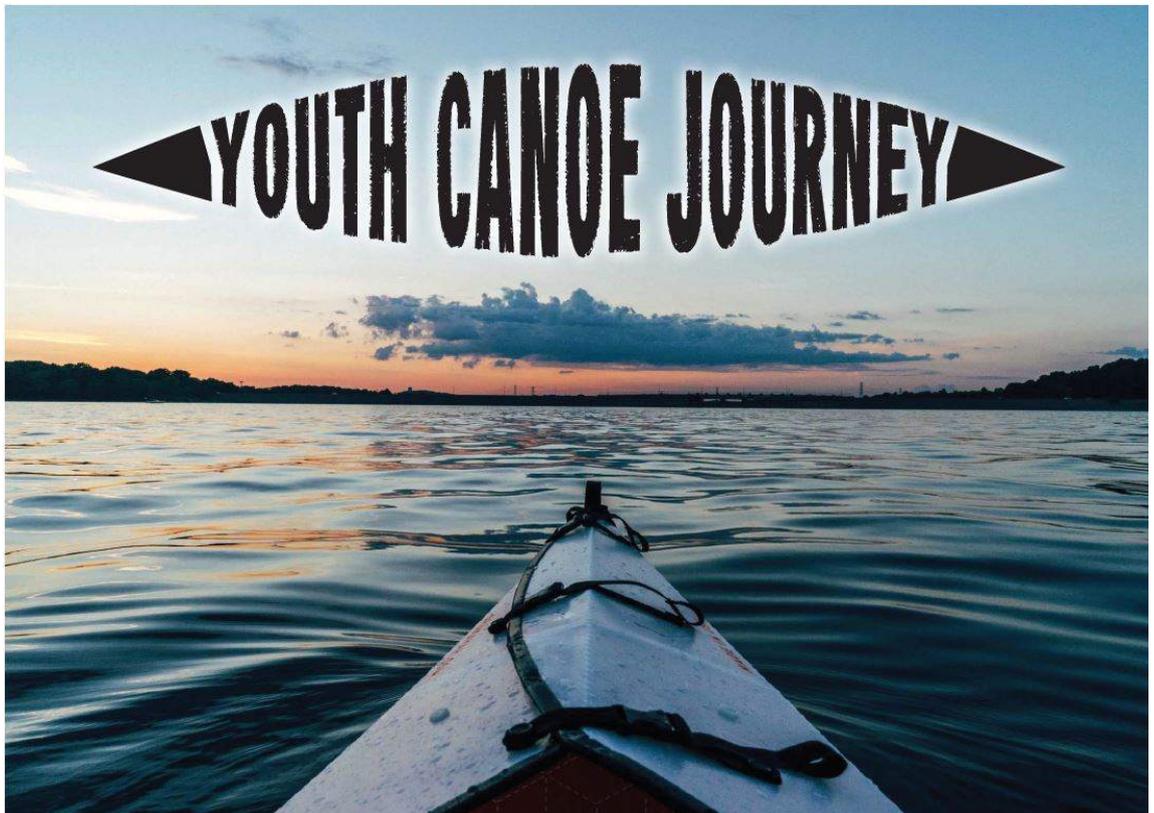
The Youth Canoe Journey will be held mid-November: Dates to be confirmed

interviews will also be held (via skype if not located in Melbourne).

We'd love to take everyone but space is limited! We'll be selecting participants based on their application, with feedback provided to everyone who applies.

How to apply?

Head to www.factoredin.org.au for more information and the application form. Note that the



Who can apply?

Anyone aged between 18-25 years, and has a bleeding disorder, carries the gene or has a sibling with a bleeding disorder. The application process is a little different to how the Youth Lead Connect program has worked in the past. Applicants will be required to submit a CV and letter explaining why they want to join the Youth Canoe Journey. Applicants will also be required to provide references, and

application form requires a recommendation or referee from your Haemophilia Foundation or Haemophilia Treatment Centre.

Applications close 31 July 2018

Questions?

Contact Kassy Drummond, Health Promotion Officer at HFA
Kdrummond@haemophilia.org.au
 or 0429 988 264

Important Dates for HFQ Members

- 🔥 OBE Lunch Forum**
 Informal support group for men with a bleeding disorder. Usually meets first Wed of the month.
- 🔥 WHF World Congress Update session**
 7 August. A report back from congress at the Brisbane International Hotel Windsor.
- 🔥 Dad & Son Kayak Day**
 26 August 2018 at Enoggera Reservoir. RSVP's essential
- 🔥 Bridge to Brisbane fun run.** 26 August 2018
- 🔥 Women's Brunch**
 The next event is scheduled for October 2018 venue TBA
- 🔥 HFA Youth Canoe Trip**
 Mid November. See HFA website for further details
- 🔥 Regional Meeting** *Please ask if one is happening in your area.*

Camps

- 🔥 Youth Camp**
 12—14 October 2018 at Emu Gulley
- 🔥 Community Camp**
 9-11 Nov 2017 Noosa North Shore Retreat

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



The HFQ Kayak Day is a Dad & Son (or Parent and Sibling) Event at Enoggera Reservoir.

Come and join us on Sunday 19th August at 10:30am followed by BYO lunch. It's for all young people from 6 to 16 and their parent/carer.

Craig is leading this leisurely trip as we paddle around Enoggera reservoir in our double kayaks supplied by Walkabout Creek Adventures.

The day offers a great way to connect with nature (and each other), enjoy the fabulous lake scenery, and wildlife... all while having fun!

Kayaks, paddles, lifejackets, & basic instruction are provided by

Walkabout Creek Adventures so reservations are essential.

Cost per person: \$15.00

The HFQ Kayak day is a health paddle around Reservoir, that's not so active to exhaust you, but it will leave you with the deep appreciation of our local recreation spaces and ready for youth camp later in the year! If your dad wont come, bring your mum.

Subsidies are available so everyone can attend!

Please contact the HFQ office for more info and to book your place on our kayaking tour now!

Phone: 0419 706 056
 Email: info@hfq.org.au

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 editor at-large. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

Graham Norton

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