the H FACTOR

Issue 53
Summer 2017
Newsletter of Haemophilia Foundation Queensland

From the President

Dear Santa, I know your busy sorting millions of letters and I know you have put on extra elves to help. I was wondering if you're on social media and can help spread the word about bleeding disorders? - you may even have some elves with haemophilia as it occurs once in every 10,000 births. We need to let people know to record their treatment in the MyABDR so doctors can ensure their treatment plan is effective - as well as helping provide data that can justify better treatments- some of us have been a bit naughty but we promise to be better.

Hi All, hope you and your loved ones are well, on a more serious note there is good news to share … the recent haemophilia conference in Melbourne was informative and interesting covering a range of topics from NDIS, superannuation facts, gene therapy, women's issues and much, much more.

It was well attended with people from the bleeding community, drug companies, the NBA (National Blood Authority), medical practitioners and others. It was reassuring to see the continued interest for all concerned as it reaffirms the importance of needs of people in the bleeding community – your needs and your treatment. The great news was from the NBA where they are looking at extended half-life products.....

One of the conference presentations was about

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Presidents Message *Continued...*

employment with a bleeding condition and whether to disclose your bleeding condition - or not. There are different views - some people are very open, some don't disclose, and some consider disclosing later. It's an important decision and your haemophilia treatment centre psycho/social staff have professional experience and skill to assist - I would recommend everyone ring and make an appointment. You have everything to gain and nothing to lose!

The NBA told conference delegates they have undertaken extensive consultations to inform future procurement arrangements for clotting factor products. The consultation process prompted a substantial amount of information in relation to new generation Extended Half Life (EHL) clotting factor products as well as other new monoclonal products that offer substitute therapies for haemophilia treatment.

There has been a decision to commence a health technology assessment for the potential supply of EHL clotting factor products and the implementation of interim and limited managed access arrangements for rFVIII and rFIX products for some (but not all) patients while that assessment is being completed.

The limited access programs are expected to provide some immediate benefit to some (but not all) haemophilia patients while the evidence-based detailed assessment of EHLs is undertaken.

For those involved there is a requirement that data on usage and relevant outcomes are recorded with the MyABDR application. Without this data there will be no evidence to justify these better treatments – this is an exciting time but it is reliant on patients recording in the MyABDR application.

The limited access arrangements are expected to be implemented by the end of 2017. Refer https://www.blood.gov.au/closed-public-consultations

Have a happy and safe Christmas and see you all in the new year - Merry Christmas to one and all.

David Stephenson

President HFQ

president@hfq.org.au
www.hfq.org.au

Another year over

In this last year there has been many reports on new and improved treatments. Although most people living with bleeding disorders in Queensland now live with less pain and with less joint damage from chronic bleeding, some people still develop inhibitors, and target joints are still being identified which means that some people are still faceing mobility and disability issues as real as those our members faced fifty years ago.

This year we completed our first tri-annual Queensland Health funding grant not tied to HIV and HepC issues. This is an important change as it acknowledges the real needs of people with bleeding disorders need funded support from a group like HFQ. We also implemented the new HFQ website and I thank HFA for instigating and guiding the process. While it is still a work in progress, members can be assured that all health information is now vetted by HFA and will have cohesion and uniformity across all the state and territory foundation websites.

At the AGM we farewelled our treasurer Peter David and I want to thank him for his work and support in this role. As Manager, I see how many people, contribute to the work of the foundation and I would like to thank all of them, especially the board and our volunteers. I also want to extend my thanks to the QHC team members who support our events, review articles or provide advice to us.

And while making tributes I need to thank Liz Fistonich our previous manager, who started the process of organisational change fir us, before she took ill with cancer. It is with sadness that I wish to inform members that her cancer came back this year and Liz died on 21 August. Our condolences go to her husband John and daughter Alicia.

Graham

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 OReilly

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 Olivia Starowicz
Haemophilia Registrar – Dr Rahul Joshi
Joanna McCosker - Clinical Nurse Consultant
Amy Finlayson / Salena Griffen – Clinical Nurse
Hayley Coulsen - Physiotherapist
Moana Harlen - Senior Psychologist

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 John Rowell - Haematologist	3646-8067
Dr Jane Mason - Haemophilia Fellow *(request to be put through to mobile)*	3646-8111
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 (Fridays)	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 John Rowell — Wednesdays 1.30pm New Patients Thursdays 8-9;30

Haemophilia/Orthopaedic Clinic — Dr John Rowell 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.

Changes at RBWH

A letter for Dr John Rowell…

I shall be taking long service leave from my clinical role in the Haemophilia Treatment Centre at Royal Brisbane and Women's Hospital form early February 2018.

This role will be taken over by Dr Jane Mason who is an enthusiastic Clinical and Laboratory Haematologist with a special interest in Haemophilia and other bleeding disorders. Her background is in Paediatrics but she has been working as a Fellow at the Haemophilia Treatment Centre in 2017.

She will be taking this role over in early February of 2018.

The other staff at the Haemophilia Treatment Centre are unchanged. I will continue in my role at the Hospital as Director of Haematology of Pathology Queensland for the foreseeable future.

I have greatly appreciated the opportunity to be involved in your care and know that Dr Mason will provide excellent care for you in the future.

Regards

John Rowell
Qld Haemophilia Clinic
RBWH

Editors Note: the board and staff of HFQ greatly appreciate the work done by all the team at the Queensland Haemophilia Clinic (QHC), John has headed the QHC for a long time now and the number of staff and their speciality's that our members can access from the multidisciplinary teams that are at RBWH and LCCH has increased under his stewardship.

These are the best services available for all people with bleeding disorders in Queensland and we thank John for his past work and wish him an enjoyable time-off from his usual work load. We also welcome Jane (who many members have already met) and we are confidant that she will provide you all with the continuity of services that you need.

Australia Day Pool Party

We are writing this before Christmas, but 2018 is fast approaching and while your children and grandchildren may not believe you, the long days of the school holidays will be over before they know it.

In the last few years we have held a summer event for our families and last year this was at the Chermside Aquatic Centre.

Some families have asked that we look at alternatives and we are in the middle of negotiating a deal with a water park on the south side. It will be a more expensive proposition for us, but should be fun for all the family.

Please put the date aside for a great day out meeting other members and having a good time out with a variety of amusements and supports.

As part of the changed venue we still hope to offer some sort of lunch meal (burger & chips with a drink etc.), but we will need people to commit to a higher co-payment (depending on their financial status) as we have to pay for all people booked.

What's happening in Social Work?

Each newsletter, I have been sharing some information which has been about topics which I hope are of interest or as in the last issue, workshops which have already occurred. For this issue, I have decided to look forward and share my plans for the next year or so. I know there have been previous articles in H Factor written about goal setting – that is that they should be specific, measurable/meaningful, achievable, realistic and time-based, so I won't revisit this today, but instead share with you my goals/plans for the next year, which I hope meet the SMART goal criteria.

Telehealth: The adult service at RBWH will soon be offering appointments via telehealth, for people living in rural, regional and remote communities. Telehealth allows you to stay in your own community and talk with the Queensland Haemophilia Centre via a Queensland Health videoconference system at your nearest hospital or through the telehealth portal where we can link with you in your home (or GP clinic or community agency for example) via your computer, laptop, smartphone or a similar device using a secure connection. Telehealth in other areas has reduced travelling costs and time away from home. It is not intended to replace face to face appointments, but rather increase your access to the team. If you are interested in a telehealth appointment or to find out more information about it, please contact me on 3646 8769.

I have also been considering and have had community members suggest that we provide an option for our workshops to be held through the same system as telehealth. This is definitely possible and I will be looking at some of the workshops occurring in this format in the future. Instead of a one day workshop, we may break them into 30-60 minute sessions, for example to enable access to the workshop across the State.

Workshops: Over the next year, I will continue to work with Graham at HFQ to provide workshops. Unfortunately, Graham and I had to postpone a workshop for the partners and parents of adults who have a diagnosis of haemophilia, which hopefully will be one of a series of workshops. We have a new date in mind, and will send out invitations in 2018.

After attending the Happiness and its Causes Conference in June and seeing today on the Beyond Blue website that 3 million people in Australia are living with anxiety or depression (www.beyondblue.org.au) I am in the early stages of developing a series of workshops to provide practical information about skills and strategies to enhance mental well-being within the community. The workshops will be available and relevant to everyone as there is great benefit for all of us to look after our mental health.

Graham and I are also working on some other workshop ideas which have come from the community for example hearing from available community services and supports on various topics (for example services to assist us as we age, an update on HIV treatments, a World Café 'discussion', NDIS / MyAged care). Keep an eye out on the HFQ website / Facebook page and in your mailbox and email inbox for more information on the various workshops and events.

Transition: I have recently heard that I have been successful in receiving a grant from the RBWH Foundation and Cancer Care Services to develop approximately 50 sets of resources for young people who are transitioning to the RBWH. The first of these packs will be sent out in early 2018 to all young people when their care is transferred to the Adult Centre and will provide resources to assist young people navigating the new system and continuing to take on the responsibility for their own health care. This project will be an addition to the transition clinic and will build on the amazing work that LCCH staff (and parents) undertake over many years to prepare and support young people to manage their own health care.

Last but not least, please don't hesitate to contact me if you want to talk about any concerns or issues, or if you are interested in a workshop/group, etc., on a specific topic. I am available by phone (07 3646 8765), in person and now by telehealth.

Loretta

Advanced Haemophilia Social Worker
Royal Brisbane Woman's Hospital
Ph: (07) 3646 8765

Genetic Testing for Haemophilia

Readers may have heard about a free genetic testing (or genotyping) campaign in the USA offered to people affected by haemophilia including carriers and potential carriers.

Like all things to do with genetics, genetic testing has also changed dramatically over the past few years and in addition to testing for carrier status, genetic testing in haemophilia can now provide information that may be useful for making better treatment plans and avoiding inhibitors, as well as determining suitability for future gene therapies.

The USA program has two goals: to help families understand more about the disorder and to help researchers and clinicians better understand connections between the disorder's genetic cause and clinical outcomes.

Because of the changes in the types of genetic testing available, data acquired through genetic treating can also help researchers to explore long-unanswered questions about haemophilia, including why one person bleeds differently to another and why some people react differently to the same treatment.

A normal factor VIII or factor IX level test will not tell females if they carry the altered gene. Some women or girls may have normal factor levels, but still carry the gene. Carrier genetic testing is a relatively simple process that requires the patient having a discussion with a haemophilia specialist and/or genetic counsellor and understanding the impacts of the test result. The blood tests themselves can be organised through the Queensland Haemophilia Centre (QHC) after they have looked at the family tree to identify other family members who may carry the gene. The blood samples will go to a lab for genotyping and the QHC staff will share and discuss results once they have them.

Many people find that undertaking these tests gives them a lot to think about. The QHC can help with information and advice about genetic testing.

For more information about testing for haemophilia check out our section on bleeding disorders at: *https://www.hfq.org.au/about-bleeding-disorders/women-with-bleeding-disorders/carrying-the-haemophilia-gene/genetic-testing#MainContent*

Toowoomba Function

Haemophilia Foundation Queensland members live right across the state. Where there is local interest, we try to run events for members and in November we had a catch-up session with some of our Toowoomba and Darling Downs members.

Darian McCrindle and his dad came down from Nanango to help us run the day which started with a Bar-B-Que and concluded with a game of laser tag and 10-pin bowling for the younger ones and a quite coffee at the café next door, for the older members.

These meetings are an opportunity for local families to catch up with other families and individuals because living with bleeding disorders can be complex and meeting others doing the same can be helpful.

The people who came had a good time with everyone pitching in to cook the sausages and chat. We are also working with QHC staff to try and have them available to talk to members in an informal setting such as these meetings, so please look out for the next one or let me know at the HFQ office know if you'd like to host an event in your area.

Graham

New Treatments : Subcutaneous Injection

Jabbing your vein or that of a terrified toddler is not the ideal way to deliver factor product and using a 'port' isn't much better! Besides the needle phobia and the pain, there are other potential issues. There is the risk of infection, the inconvenience of regular infusions and then there's the reality that only half of adults keep to their prophylactic regimen.

If you've ever wondered if there's a better way to deliver factor, you're not alone. And the answer is yes. Researchers have found several novel ways to get medications into the body. From patches with micro needles to guns that fire micro particles, all are being investigated.

One way may be as close as your skin, and investigators are optimistic about the clinical trial results to date, involving humans.

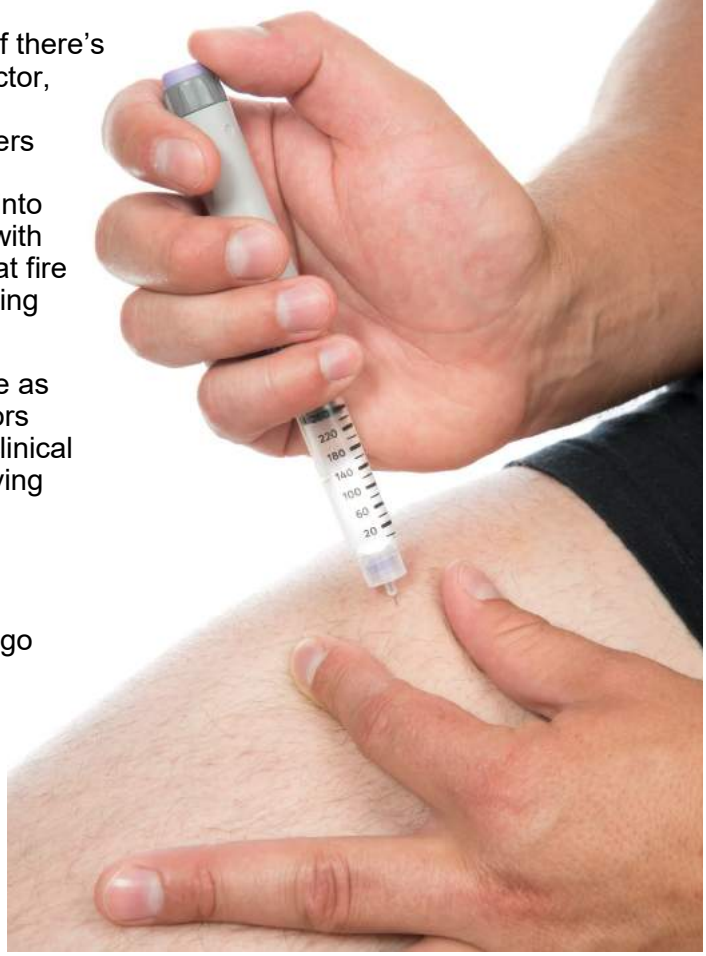
What is subcutaneous injection?

Subcutaneous injections go through the layer of the skin called the cutis, which comprises the epidermis and dermis. With few sensory receptors below the cutis, injections are nearly painless. Common sites include the upper arm and top of the thigh. Some vaccines and drugs, such as insulin, are already delivered in this manner.

So far, two pharmaceutical companies have trialled subcutaneous products and had promising results from phase 1 and 2 studies in treating haemophilia. Both companies presented their findings back in July 2016. And both use different strategies to achieve the goal of haemostasis, stopping bleeding after an injury and preventing bleeds. One product, (fitusiran) has had difficulties and in September announced it was halting dosing studies following the death of a patient participating in the trial. *Ed: See 'Health Updates'*

How they work

Fitusiran is an RNA-interfering (RNAi) molecule that turns off,



or silences a protein produced by the liver to prevent clotting. Using fitusiran helped increase levels of thrombin, which helps platelets rise and initiates the steps leading to clot formation.

Emicizumab uses a different mechanism. It is a bispecific antibody, an artificial protein combining two antibodies in one molecule. It binds to factors IXa and factor X (hence its alternative name ACE910), fulfilling the normal role of the missing factor VIII in the clotting process.

How they fared

In these early trials, emicizumab (also called ACE910) was given weekly to subjects with haemophilia A, with or without an inhibitor. It has been trialled by one of our members who has had good results and members were very excited to meet and talk to him and his parents at our recent community camp. The results can also be judged by his change in focus from surviving school to contemplating a much more active social life!

Bleeding was well-controlled in the majority of subjects in both the fitusiran and emicizumab trials, with annualised bleeding rates falling and no inhibitor antibodies developed. Chugai the parent company for emicizumab is now testing its product using a monthly injection schedule.

These innovative therapies are quite different to the extended half-life products many members are talking about and waiting patiently for. Their success will have broad implications as doctors are going to be better understand the coagulation system thanks to these trials using the new pathway drugs. Hopefully this will lead to better treatments as they understand coagulation better.

Edited for size and local circumstances from an article by Sarah M. Aldridge "New Haemophilia Treatments: Subcutaneous Injection" that first appeared in hemaware https://hemaware.org/research-treatment/new-hemophilia-treatments-subcutaneous-injection

Living with Mild Haemophilia

58% of people living with haemophilia A and B in Australia have mild Haemophilia. While bleeds may be infrequent in this group of people, careful monitoring and prompt treatment are still essential if you want to be prepared and respond to the unexpected. There's a concern when they don't have a bleed often, that people with mild haemophilia may take their symptoms less seriously.

In fact many people with mild haemophilia are not diagnosed until an injury, surgery or tooth extraction results in prolonged bleeding. So, many people with mild haemophilia only start learning how to live with it later in life and some never receive a diagnoses.

Like all bleeding disorders, injuries or bleeds must be treated promptly, or they can lead to dangerous complications. Because they are not dealing with bleeds or infusions on a regular basis, sometimes it can be hard for people with mild haemophilia to wrap their minds around the fact that they have a chronic illness.

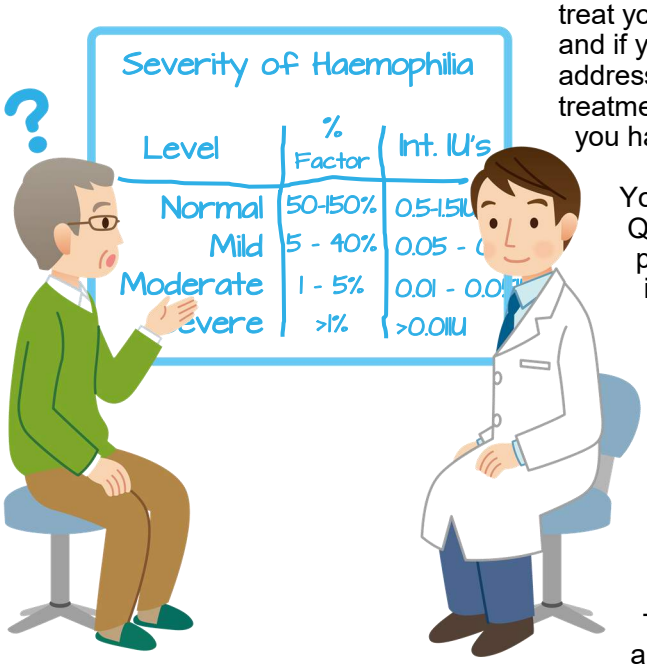
What is mild haemophilia?

Mild Haemophilia is defined as having 5 - 40% of normal factor VIII or IX (FVIII or FIX) concentrations in your blood. It is unusual for spontaneous bleeding to occur at this level, but bleeding with major trauma, surgery and invasive procedures is common.

Historically haemophilia has been thought of as a "man's disease," but some women who carry the haemophilia gene, have low enough levels of factor that they are diagnosed as having haemophilia and many women are classed as 'mild'.

Challenges of mild haemophilia

Mild haemophilia is not typically associated with the type of frequent bleeds and chronic pain often seen in more severe haemophilia and doesn't usually require the frequent factor replacement therapy that severs do. But men and women with mild haemophilia face their own set of challenges and those challenges include bleeding and pain, as well as developing inhibitors and difficulty getting care. About 5% to 8% of people with mild or moderate haemophilia A also develop inhibitors, which creates additional complications to managing the condition.



Another challenge for people with mild haemophilia is educating the people in their life so they get adequate care and understanding. Because their bleeds are infrequent, GP's are sometimes slow at diagnosing the condition. As people with mild haemophilia can go for long periods without a bleeding issue, it can also be hard to explain to an employer why you need longer time off work if the bleed cannot be controlled.

Preparation

Because mild haemophilia is unpredictable, it's important to remain vigilant about monitoring and treating the condition. As with all categories of haemophilia it only takes one bleed to set someone up for issues later in life. The big challenge with mild haemophilia is remembering to think 'bleed', when an injury occurs.

Even though bleeds occur rarely, a person with mild haemophilia should take time to get the right treatment plan for managing their complications when they arise. Your doctor may suggest keeping a treatment product (often Desmopressin, or DDAVP) close by, so put it in your first-aid kit. Also consider getting a medic alert bracelet printed with your health information so first responders can treat you in case of an emergency and if you travel, check out the address of the closest haemophilia treatment centre near you in case you have to get to them.

You should work with the QHC to develop a treatment plan that you can implement if you have a problem. And remember they are only a phone call away for you, or your GP. So if you think you may have a bleed starting or are feeling some unusual pain, call the QHC and run it by them. Prompt treatment is important for all people with haemophilia. Taking these precautions and being diligent will let you participate in your community and remain active. The key is knowing your limitations and being prepared should an injury occur.

Even when known, it can be hard to get the help you need, so stay in touch with the QHC especially if you do not keep a treatment product at home and always update them if you move house, as many of our members with mild haemophilia are lost to follow up and as treatments continue to change there may be good news that we can't share with you.

Edited for size from an article by Nancy Mann Jackson that was published in Hemaware called Managing Mild Hemophilia. https://hemaware.org/bleeding-disorders-z/managing-mild-hemophilia-be-prepared-unexpected

Different Pain Perceptions

A study published in the November issue of Haemophilia Journal assessed the perceptions of pain and pain management in adolescents and young adults between 13 and 25yo, with haemophilia or von Willebrand disease (VWD). It compared these with their caregivers and health care providers to determine agreement or disagreement.

The gold standard for identification of pain is the patient. Caregivers (ie parents) often are the primary source of pain assessment in children. Equally important to caregivers are the health care provider's perceptions of pain and the study looked at differences that exist between patients, caregivers and providers that may influence therapeutic decision-making and, subsequently, patient outcomes.

The study found that agreement between patients and their caregivers on pain ratings during acute bleeding pain episodes was fair; but there was poor agreement on chronic pain between patient and caregiver and also between the patient and their provider.

Pain Control

While ALL patients reported some chronic pain, nearly 30% of caregivers and more than 47% of providers believed patients had NO chronic pain. The average age at which patients began taking medications for chronic pain was 11.5 years and while 100% of patients reported acute pain, only 67% reported utilizing acute pain medication. Approximately two-thirds of patients, caregivers and providers felt the patient was in control of their pain, but approximately one-third did not feel the patient was in control of their pain.

The most common medications patients used for acute pain were factor and paracetamol, and for chronic pain it was factor and non-steroidal anti-inflammatory drugs. Besides RICE, patients also used other methods to address pain. The most frequently used non-RICE methods reported were diversional activities, such as: watching movies or television, deep breathing and exercise. Although not recommended by providers, marijuana (12.5%), alcohol (11.5%), and illegal drugs (2.5%) were used by patients for both chronic and acute pain.

Findings

The study found there was poor agreement between patients and caregivers across all levels of pain, perception of pain control and effectiveness of pain management especially between patient and both caregiver and provider on the level of chronic pain.

The study authors thought it was possible that patients may not self-report or display pain to their health care provider, as this may result in limitations to activity. The study also revealed patients are using more opioid medication than expected by providers and nearly one-third are receiving their pain medications from their GP or other sources.

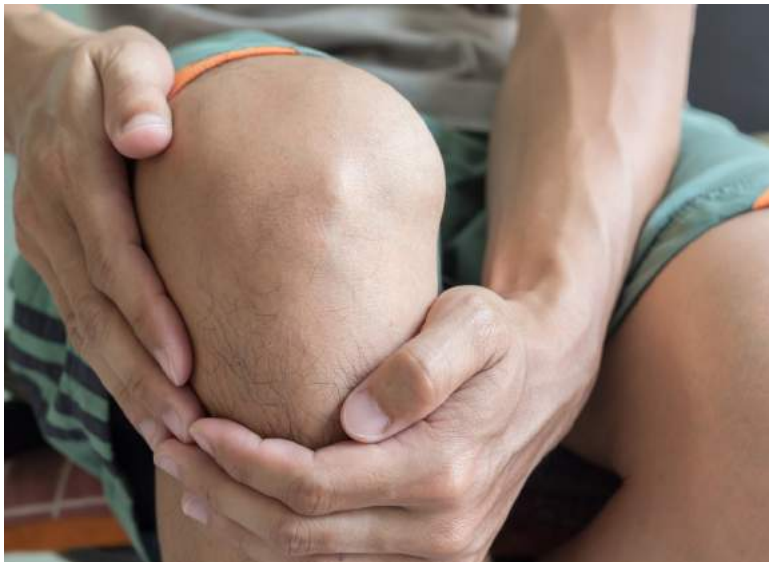
Given that this age group reported pain despite the use of ongoing factor replacement therapy, the authors suggested that prophylaxis to control bleeding events may be suboptimal or treatment adherence is lacking and there is a need for improved adherence to treatment regimens, with the goal to eliminate bleeding events that result in chronic pain.

This study suggests that pain is an early and common aspect of the bleeding disorder ensemble. Based on the observation that pain medication use reported by patients and providers differed, the authors suggested that doctors should listen to patients regarding their complaints of pain, explore optimal pain management options and optimise prophylaxis to minimize or eliminate bleeding events.

From previous studies we know that patients with bleeding disorders struggle to describe their pain differences between acute and persistent pain. Patient reporting on pain and education such as point-of - care ultrasound to distinguish between arthropathic pain and pain due to a bleeding event could also contribute to better pain management

The study recommended that health care providers should continue to make greater efforts to discuss patient pain levels, rather than assume an absence of pain if not articulated by the patient, who may accept pain as routine. And we would encourage patients to speak candidly with their caregivers and providers regarding their pain and the effectiveness of their pain management.

Edited for size from an article by Angela Lambing et al on Patient, caregiver, and provider perceptions of pain and pain management published in Haemophilia journal Nov 2017 page 852 - 860



Conference Report

I was lucky enough to attend the 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders in October this year.
During this conference, I was able to network with other women with bleeding disorders which, for me, was the highlight of the conference, as I had never met women who were officially diagnosed as having Haemophilia A or, even just a low factor 8 level, before. This, along with the focus on women's bleeding issues throughout the conference, for not just haemophilia A, but all bleeding disorders, gave me great hope for the future of women with bleeding symptoms and who carry the gene in Australia, something a lot of female bleeders have not had in their lifetime.

This year, I was able to take my partner along with me and, as he is new to the scary world of dating someone with a potential to pass on a genetic disorder to his child, I was both excited to introduce him to a community I'd been a part of almost my entire life, but also terrified it would scare him away. The absolute highlight for me, apart from networking with so many incredible women, was when a mother at the Newly Diagnosed session mentioned her son plays rugby, much to the dismay of many nurses and doctors, I'm sure, but something my partner had always wanted for his child and was concerned if they had Haemophilia, he may not be able to.

Being able to connect with other families with young children, people who are going through what there is a very good chance we will in the near future, and seeing that their children are not only well treated and active, but happy, was a huge turning point for both of us. I had always accepted haemophilia as a part of my life, and more than likely my children's lives, but my partner, prior to us getting together, had never experienced it, hell – he'd never even heard of it! So for him to be able to hear the stories of mothers and children who were, despite a few hurdles, living a full and healthy life, was a real reassurance for him and instilled a sense of hope in both of us that our child, if they were to inherit my crappy genes, would live a relatively normal life.

I found Dr James' seminar on Women with Bleeding Disorders to be incredible, and changed my view on many areas of my current bleeding issues. I was unable to attend the entire seminar due to some health issues, but was lucky enough to have a friend record it for me. To see so many, not only females, but male bleeders there, supporting the women of our community, eager to learn more, to know more, and to help more, truly summed up for me what our community is about. We are here to do what we can to educate, inspire and support, and that starts from within. I don't believe we should ever stop learning about our disorder, and those of the other people in our community, and looking for new ways to support one another.

Dr James' talk on what constitutes 'normal bleeding' in women and how to complete a Bleeding Assessment Test (BAT) was fantastic, and no doubt a huge help to a lot of women who carry the gene who have, for years, dismissed their symptoms as nothing more than 'annoying periods'. I truly believe that HFA did a massive service to the females of our community by inviting her to speak and I believe this will lead to many more women accessing the services they need to get help for their bleeding issues, as well as to educate our current medical professionals, and the general community, on the advances in the understanding of how X linked bleeding

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OBE's & Women's Brunch Meetings

HFQ provides social support groups for people who have a bleeding disorder or care for, or about, someone with a bleeding disorder. Out two regular group meetings are for men living with haemophilia and other bleeding disorders. The other is for women affected by bleeding disorders.

Our groups offer a low cost and supportive environment where people have the opportunity to talk about their feelings, help explore alternative ways of coping, offer support to other group members, or to simply listen and observe.

OBE's is usually a lunch meeting across Brisbane and this happens in the first week of each month. The women's brunch happens on a quarterly basis and the next meeting is scheduled for 4 February. If you'd like to know where the next meeting is for either of these groups please call the office on 0419 706 056.

Support groups can be a valuable means of informing and supporting subsets of members about an issue of concern to them. For example we are looking at offing a meeting for people impacted by inhibitors.

And if there was a number of people in a regional area who wanted to meet, we would consider this as well.

A support group is where people are able to talk with other people who are like themselves - people who truly understand what they're going through and can share the type of practical awareness that come from personal experience and they tend to be small in size, to give everyone a chance to talk.

Please email the office on info@hfq.org.au or phone Graham on 0419 706 056 if you'd like to be part of a support group.

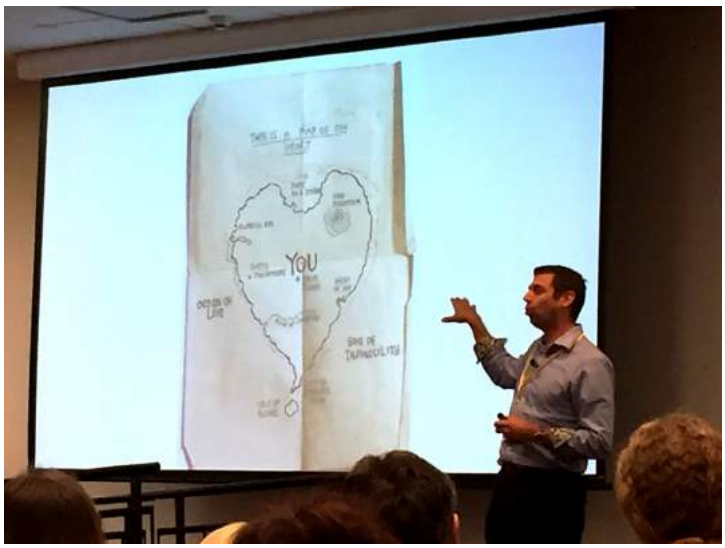
Conference Report *continued*

disorders affect women. Dr James' main message was one I think is vital to our community going forward and it is this; 'accurate diagnosis of women with bleeding disorders is critically important in order to ensure proper management. ' There are so many women living with a bleeding disorder, or living with bleeding complications who carry the gene who have never had access to proper testing or treatment, due to Haemophilia A especially being a bit of a 'boys club' and always being told 'only men get haemophilia', so this approach, if it is adopted by medical professionals within Australia, could very well revolutionise the way we approach, diagnose and treat, women who carry the gene.

I'm lucky enough to currently have treatment that significantly reduces my bleeding complications, however there are so very many women within our community who are only now learning that their decades of struggles had a reason, that they probably didn't need that hysterectomy or years of hormonal treatment, that there was a solution, we just weren't there yet. Well we're getting there and it's a very exciting time to be a woman who carries the gene. I am a woman who carries the Haemophilia gene, a woman who is very grateful to have access to treatment, a woman who is so blessed to have the support of so many people within our little community – both male and female and a mother who no longer fears for her daughter's bleeding issues as she hits puberty because I know she has a whole family of people behind her supporting adequate treatment for all women with bleeding complications.

Overall, the conference was an opportunity to expand my knowledge, introduce my partner to all of it, and help to gain some reassurance for our future children, and network with some truly incredible and inspiring people. I am, as always, truly grateful for the opportunity to attend, with the help of HFQ, as the knowledge I have gained and the experiences I have had, will only help me go forward in my role as secretary of the board and a member of our community, in the best way possible.

Lauren Albert



Bleeding Disorders in Queensland

Back in January 2015, HFQ conducted a state survey to identify issues affecting people living with bleeding disorders. This survey is over three years old now and MyABDR was the new 'thing' we were dealing with. Most people are finding MyABDR easy to use and the QHC staff tell us it is very helpful in managing patients' treatment programs and identifying patterns of bleeds etc., at your clinic appointments. However some of the questions where not as well formulated as we would have liked and the data is 3 years old.

Last year we helped HFA focus test a new international survey called PROBE and we will get data on the lives and needs of our community at a national level from this survey. But we may not get that much information at a state level, so we still need to ask our readers and members about their needs and expectations so we can provide what you see as important.

We already know some of your thoughts and feedback from the previous survey, especially about dealing with social and geographic isolation as well as some of the non-clinical situations our respondents found themselves in. But it is important to check that these needs and interests are still important to you.

Knowing where people live and what their circumstances are will help us know if our current programs are those we should be offering.

With this in mind we will be again survey members this coming year especially things like on-going recording of health and treatment data in MyABDR and also looking at members' interest and needs with respect to the new treatments coming on-stream across the globe.

In the last survey people told us they had social, emotional or practical support needs beyond addressing the health aspect of their bleeding disorder and that the issues affecting people with bleeding disorders vary depending on the different stages of life you are at.

Our members like to live where they are but regional living with a bleeding disorder can have an impact on employment with several people reporting experiences of stigma and discrimination. Many people with a bleeding disorder in their family told us in the last survey that they were reliant on some form of government assistance.

But before we start on a new survey, I wanted to share some of the things we learnt from the last survey that we believe are still relevant based on feedback we have received:

- Most of our members have one or more severe bleeds every year and almost half have severe Haemophilia.
- People with less severe or infrequent bleeds said they felt unsure managing their condition.
- Members are keen for services that are specific to issues and demographics – such as young adults, children and families, older people and women.
- While many members will travel significant distances to access support services, there were requests for local events or assistance to travel for help.
- Most respondents knew about the importance of physical activity, however activity levels are low (there are well-known long-term health and potential social impacts that result from not being active).

At the time of the last survey My ABDR had just been introduced and new genetic treatments were still seen as a while away, so we only have anecdotal feedback on member interest in the new extended half-life products and genetic treatments for bleeding disorders. HFQ's support for members to access clinical help was seen as generally positive, and many people expressing satisfaction with the various programs and support offered by HFQ itself with participants highlighting as helpful HFQ's magazine, website and Facebook page.

At the time of the last survey people told us that the lived experience of having a bleeding disorder very much focused their attention on the uniqueness of bleeding disorders and that they still wished for scientists to find a cure but in the meantime they would really like to experience a reducing number of bleeds each year and get some help in educating GP's and healthcare workers who are not part of the Queensland Haemophilia Centres about their bleeding disorders.

If you have something you'd like to know about our community, or ideas for questions we should be asking, please contact the HFQ office via email: info@hfq.org.au or mobile: 0419 706 056

Inhibitor Invasion

Hark! Who goes there? If it's a nasty bug, your body is ready to attack. Your body is a fortress, and every day, a battle is going on inside. Your body fights to keep the good stuff healthy, like your organs and your blood, and keep out bad stuff, like bacteria and viruses that make you sick.

We all have special soldier proteins called antibodies patrolling our blood, looking for invaders. When they find them, these soldier proteins sneak up on the invaders and—hiyah!—they destroy them.

If you have an inhibitor, your soldier proteins are also trying to kill your haemophilia factor. To them, factor is just another alien invader that must be kicked out. The trouble is, when your soldier proteins attack the clotting factor, it can't work. So you might bleed more than other kids with haemophilia.

Scientists aren't sure why some kids have "soldiers" that cause inhibitors. But if you have inhibitors, you aren't the only one with this kind of overactive immune system. Kids with allergies to pollen, pets or peanuts also have immune systems that attack things they shouldn't.

And just like kids with allergies, some medications will work for you and some won't. There is a special kind of factor just for kids with inhibitors, but it doesn't work for everyone. And because your defence system is so strong and stops the factor from working, your bleeds might last longer, hurt more and cause more damage. Sometimes kids with inhibitors have to use wheelchairs or crutches.

The good news is that scientists are trying to stop your super-strong soldier proteins from overworking, or at least find a factor that works for all kids with inhibitors.

Remember, you're on your body's defence team, too. So gear up. Be careful playing with your friends and running around in the house. And look for signs that you could be bleeding, like areas on your body that feel warm, tight, tingly or bubbly. Let your parents or another grown-up know if you feel pain, even if it's just a headache. Being responsible is important, so you can get treated faster and feel better soon.

Come to your body's defence - and don't let an inhibitor get you down.

Edited or size from an article by Heather Boerner called Inhibitor Invasion that first appeared in Hemaware Junior *https://hemaware.org/life/inhibitor-invasion*

Art Response to Bleeding Disorders

Back in 1994 the National Gallery of Australia, hosted an exhibition called Art in the age of AIDS. At the time people with Haemophilia had also been affected through receiving infusions of factor made from infected blood.

The exhibition made many statements, some more and some less subtle. It sought to broaden its audience's understanding that HIV had reached into the lives and homes of many people in Australia with many art works that were poignant and often realistic.

Dark humour surfaced in many exhibits, evidence of the many different methods people call on to get them through the anger and grief. One example was a colourful T-shirt that said "It's my party and I'll die if I want to".

We know that many people affected by a bleeding disorder have also responded to their own devastating diagnoses through art, but are there enough works out there that we could use to host an exhibition during next years Haemophilia and other bleeding disorders Awareness Week in October?

If you have some art works for display during the week, please contact the office and let us know so we can plan for an event next year that marks the change in name from Haemophilia to be more inclusive of other bleeding disorders.

Eradicating HIV

How HIV Establishes Its Reservoirs

One of the major barriers to a cure for HIV is the latent reservoir of HIV that persists in infected individuals despite receiving antiretroviral therapy.

A study reported in the journal Immunity, that in untreated patients, HIV replicates continuously, avoiding immune responses through rapid evolution in a process known as viral escape.

The researchers argue that latency is simply an "unfortunate consequence" of CD4+ T cell infection within a narrow time frame after T cells are activated.

They report that during the natural process of T cell transition from one functional state to another (effector-to-memory transition or EMT) T cells temporarily increase the expression of CCR5, a critical receptor for HIV, and decrease the function of certain normal cell genes necessary for HIV growth. So the virus gets into the cells more easily via the abundant CCR5, but then is rendered dormant because of dampened gene activity.

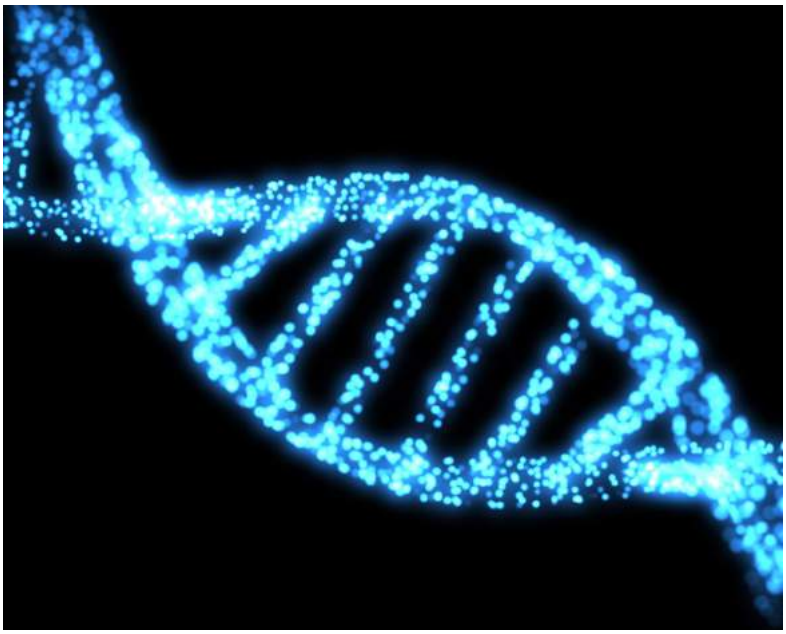
The study found that this process of viral latency could be interrupted by HIV-specific CD8+ killer T cells. So the findings have implications for elimination of latent HIV-1 infection by T cell-based vaccines.

Edited for size from and article by Dr Jeffrey Laurence called How HIV Establishes Its Reservoirs. *http://www.curecountdown.org/research-index/2017/11/6/how-hiv-establishes-its-reservoirs*

Cancer drug may be able to eradicate HIV

Doctors in France have found the first evidence that a drug normally used to treat lung, kidney or skin cancer may be able to eradicate HIV-infected cells in people with the AIDS virus.

Nivolumab is designed to help the body's own immune system fend off cancer and in a case described as potentially exciting by French scientists, a 51-year old man given nivolumab - and



saw a "drastic and persistent decrease" in the reservoirs of cells where HIV normally hides away and evades standard treatments.

In this case, after the 51-year-old man had received his first injection, the man's HIV infection load, which had been low, increased progressively up until day 45, then fell back again. At the same time, the doctors explained - the activity of his immune system increased.

By day 120, the treatment had resulted in the drastic decrease in the HIV reservoir ... leading to a sustained reduction of the HIV reservoirs. However it needs more looking into as this is only one case and the same doctors also gave a case study of another patient treated with this drug who did not show any HIV benefit.

We must remain careful, especially because this is only one case," said Jean-Philippe Spano, a professor and head of the medical oncology department at the Paris hospital. "This is the first case of such a drastic decrease of the HIV reservoir (but) we have ... another case where there was no decrease."

Scientists have been trying to find a way of clearing HIV reservoirs for years, with a view to eradicating the virus completely and cure AIDS. These reservoirs of HIV-infected cells lie hidden and dormant, and can't be reached with standard anti-retroviral therapy HIV treatments. If treatment is stopped or interrupted, the virus starts to replicate from these sanctuary sites and infect the patient once again.

"Increasingly, researchers have been looking into the use of certain drugs that appear to re-activate the latent HIV-infected cells," Spano said. "This could have the effect of making them visible to the immune system, which could then attack them."

Edited for size from an article by Kate Kelland first published at: *http://www.smh.com.au/lifestyle/health-and-wellbeing/cancer-drug-prompts-drastic-hiv-decrease-in-lung-cancer-patient-20171201-gzxbcd*

Health Updates

Fitusiran trial suspended (Sept 2017)

Alnylam Pharmaceuticals, one of the new biotech companies using gene-silencing treatments to treat haemophilia. It has announced the suspension of its haemophilia drug trial (Fitusiran), following the death of a patient with haemophilia A on the study. The patient died from an acute clot in the brain (cerebral venous sinus thrombosis) rather than a bleed.

http:// investors.alnylam.com/releases.cfm

STOP PRESS

HFQ is saddened to learn of this patient's death, but we are optimistic about the potential of the new treatment options being developed for patients with haemophilia.

Fitusiran is NOT a factor replacement medication, it restores the balance between bleeding and clotting by inhibiting the production of antithrombin and a major concern with RNA therapeutics like this is that it can increase thrombin levels too much, so that clots form where they shouldn't.

In November Officials of the FDA & Alnylam Pharmaceuticals agreed on safety measures and a "risk mitigation strategy" to allow the resumption of clinical studies of fitusiran.

HFQ remains supportive of drug trials, but we remind members that all trials carry some degree of risk and if you are considering taking part in a trial you should always talk it through carefully with your QHC team.

FDA Updates Label of Bioverativ's Alprolix Upon Positive Trial Data

The U.S. Food and Drug Administration (FDA) has approved an update to the label of Alprolix, based on long-term efficacy and safety data from two Phase 3 studies.

This label update adds paediatric data and further supports the efficacy of Alprolix to treat adults and children with haemophilia B.

Alprolix is an extended half-life therapy using recombinant clotting factor IX engineered based on fusion protein technology, and in the three years since approval, there have been continued low overall bleed rates, as well as low spontaneous and joint bleeds with extended prophylactic dosing across all populations.

The addition of the paediatric annual bleed rates, and adult and adolescent joint bleed data, to the label reflects a growing body of evidence highlighting the clinical benefit of Alprolix

Based on this data, the FDA added obstructure uropathy, the inability to drain urine, to the label as a common adverse reaction, which was reported to be resolved with hydration. Other adverse reactions linked to Alprolix include headache and abnormal sensation in the mouth.

https:// hemophilianewstoday.com/2017/12/04/hemophilia-b-therapy-alprolix-gets-updated-label-following-fda-review-of-positive-interim-data/

Study Shows New Path to Stopping HIV in Its Tracks

Researchers have been asking if HIV-1 could be stopped before it makes it into a cell? A recent study suggests this could be done, and it starts with the microtubules tracks the virus uses to get to the nucleus, as well as a protein known as bicaudal D2. The findings were published in the Proceedings of the National Academy of Sciences.

If HIV-1 doesn't have that protein, it essentially becomes stranded and a sitting duck for cellular sensors. The study opens up the possibility of creating a drug that would leave HIV-1 stranded in the cytoplasm — an area within the immune cell that's thick with proteins and mitochondria.

The virus must navigate through the cytoplasm to reach the nucleus and interrupting that trajectory could play a key role in future HIV treatments, or a cure.

https://futurism.com/thanks-new-study-stop-hiv-tracks/

Spark Therapeutics shares slide more than 40% after haemophilia data disappoint

Shares of gene therapy biotech Spark Therapeutics tumbled more than 40% on the share market, after it reported data from trials of a haemophilia treatment that analysts said look less competitive than a rival product from BioMarin Pharmaceutical Inc.

The company presented early data from a trial of its SPK-8011 in haemophilia A involving five patients. "Although the enrolment size is small so far (n=5), early signs raise more caution than encouragement, on balance, and lead us to question whether there will be adequate dose-response for patients to reliably achieve normal Factor VIII expression levels.

Spark also unveiled longer-term data from a treatment for haemophilia B, that it is working on with Pfizer Inc. Shares are down 14.7% for 2017, while BioMarin shares rose 8.4%.

https://www.marketwatch.com/story/bluebird-bio-rallies-spark-therapeutics-craters-after-unveiling-data-at-ash-meeting-2017-12-11

No evidence for Rituximab use to treat inhibitors

Rituximab is often used off-label for people with haemophilia with inhibitors, so researchers searched a number of sources to find out how well rituximab works to treat inhibitors in people with severe haemophilia A and B.

They found the only evidence available was from case reports and case series. Well-designed controlled trials are needed to assess rituximab use in severe haemophilia.

Lu J, et al. Rituximab for treating inhibitors in people with severe hemophilia. Cochrane Database of Systematic Reviews, 2017. Issue 7. CD010810. DOI: 10.1002/14651858.CD010810.pub3

Pet Ownership Can be a Win-Win

Pets are an integral part of our lives as Australians but did you know that having a pet can positively affect your child? Overall, an estimated 4 in 10 children begin life in a family with domestic animals and about 80% of Australians have an animal companion at some time.

Pets are important in children's lives as they provide enjoyment and help children develop responsibilities transferable to adulthood. Experts say a child's physical, social, emotional and cognitive development can all be encouraged by interaction with the family pet and sometimes pet relationships are ranked higher than certain kinds of human relationships for comfort, esteem, support and confidence.

It's not just entertaining and giving kids warm feelings; the presence of animals in your house can also help foster emotional, cognitive, social, and physical development.

Child Development

Kids with pets tend to be more capable of showing empathy to other people because they learn how to nurture their animal. It can also help them develop responsibility skills. Researchers are finding that all children can benefit from the presence of a nonjudgmental pal with paws. In one study, children were asked to read in front of a peer, an adult, and a dog.

Researchers found that kids were most relaxed around the animal, not the humans. Having a pet might also encourage a child to learn more about animals in general and in turn foster an appreciation for research and science.

Comfort

According to one study, kids who have pets have higher self-esteem. Children with low-self esteem may talk to, or confide in, an animal in ways they would not with people. They are often more confident in performing tasks they find difficult with an animal simply because the animal does not care if mistakes are made, nor will the child be afraid of looking silly in front of the animal.

Animals are also a great source of comfort. Whether a hamster or a horse, an animal gives a child something to talk about and a shared interest with other kids and more than 40 percent of kids spontaneously mentioned turning to their pets when they felt sad, angry, afraid, or when they had a secret to share.

Building Family Bonds

One of the biggest benefits of having pets is on family harmony. A pet is often the focus of activities that families do together. Everyone takes the dog for a walk, or shares in looking after them or getting down on the floor and playing with them. There are even benefits from simply watching a cat chase her tail or a fish swim in his tank.

Research shows that families with a pet spend a lot more time interacting and the pet can be the basis for fun activities and friendly conversation including the important topics of life.

Spending time with pets also offers the wonderful potential of slowing down the hectic pace of modern life. And in this era of overscheduled children and parents who are constantly on the go, "nothing" can be an important thing to do.

Health

There is reason to believe that animals can help protect kids from at least some illnesses. According to one study, having multiple pets actually decreases a child's risk of developing certain allergies. Researchers found that the children who were exposed to two or more dogs or cats as babies were less than half as likely to develop common allergies as kids who had no pets in the home. the studies have suggested that an early exposure to pets may decrease a child's risk of developing asthma.

The relaxation and relief from stress provided by animal companionship also yields health benefits for parents. In comparison with their pet-less counterparts, pet owners have a decreased risk of cardiovascular disease, visit their GP less often and have fewer minor illnesses and complaints

Having a pet helps kids increase their overall activity. A 2010 study showed that kids who had a dog exercised on average 11 minutes more a day than other children who didn't have a dog. But while owning a dog can be a delightful family experience and has enormous benefits for the child and the family, parents need to be aware of the risk of injury from dog bites.

Encouraging Your Children into Sports

We know that athletic participation helps in fighting childhood obesity, encourages social interaction and promotes self-confidence and independence in many children. But pushing children into sports can have adverse consequences. Besides the potential musculoskeletal complications, the competition can put too much pressure on the child to succeed, even in recreational athletes. Consider weighing up the pros and cons of involving your children in sports and if you need ideas or support contact your QHC to discuss further

Choosing a Sport

Forcing children to play sports can ruin their experience of participation. A child who is adamantly opposed to competing may rebel, and will probably hate the sport he was "pushed into." Encouraging a child to try his hand at a particular game is a much better strategy. Bear in mind the limitations of their bleeding disorder may impose on sports selection and talk to the QHC staff about what to look for and what to avoid. Consider his natural inclinations and match these to the type of sport he is most likely to enjoy. For example, if your child loves interacting with nature, encourage him to participate in cross country running, cycling, bush-walking, golf or climbing. Attune yourself to your child's interests, and don't sign him up for cricket if the only reason is that you played it as a child. Your kid is likely to enjoy a sport more if it suits his particular abilities. If your child is drawn to arts or music rather than sports, accept this and do not insist he participate in athletic competitions, rather provide alternatives such a scouts, music or art lessons that align with their interests

Benefits of Participating

There are multiple physical benefits to participating in sport. These include strengthening muscles, increasing flexibility, increase in the metabolism, improvement in circulation and promotion of good mental health. Organised activities also give children a chance to develop social skills. Your child learns how to participate and share, as well as how to cope with both victory and failure. Physical accomplishments yield confidence and assurance for growing children. Sports, in general and handled well by parents in particular, are incredibly beneficial for children in terms of body, mind and spirit.

Potential Problems

While sports provide excellent physical and mental growth opportunities for children, "pushing" a child too hard into athletics might result in very negative outcomes. Serious injuries can occur to growing bodies if a parent encourages his children to train too heavily. Children placed in strenuous activities at an early age can develop physical problems that could not only impact their coping, but their physical status such as their muscles and joints. The long-term complications could impact them in the later stages of their lives, which is why discussing their sports with your QHC is important. "Star" players might become arrogant and belligerent or falsely believe their accomplishments on the field outweigh every other aspect of their lives. Alternatively, children can become anxious, stressed or extremely bored with a sport if you place too much emphasis on success.

Modelling Good Sportsmanship Appropriate modelling by parents and coaching should also occur. Adults who react positively by applauding all children's efforts, encourage teamwork and friendship among competitors and keep their expectations realistic regarding a child's abilities and limitations are likely to have children who enjoy playing the sport and who are likely to enjoy all the benefits of participation.

Help with Costs

Sometimes the costs of club membership can get in the way, but did you know that the Queensland government recognises that kids need to be active and offers 'Get Started Vouchers' for families genuinely needing some help with club fees. The voucher covers the first $150 of membership or participation fees and there are limited numbers issued each time for children aged 5 to 17.
These are available each year and if you have a Centrelink Health Care Card or Centrelink Pensioner Concession Card you can apply directly via their website at *https://www.qld.gov.au/recreation/sports/funding/getinthegame/getstarted*

If you would like another child to be able to also have access to the Get Start program, Moana the haemophilia psychologist at LCCH is an approved Get Started referral agent and is able to refer any siblings to the programme where families are unable to afford the cost of involving the sibling in a sporting activity. Please email her for more details: Moana.Harlen@health.qlf.gov.au.

Youth Pages

Factor is given to improve clotting in people with haemophilia. The way we put factor into a vein is called infusion.

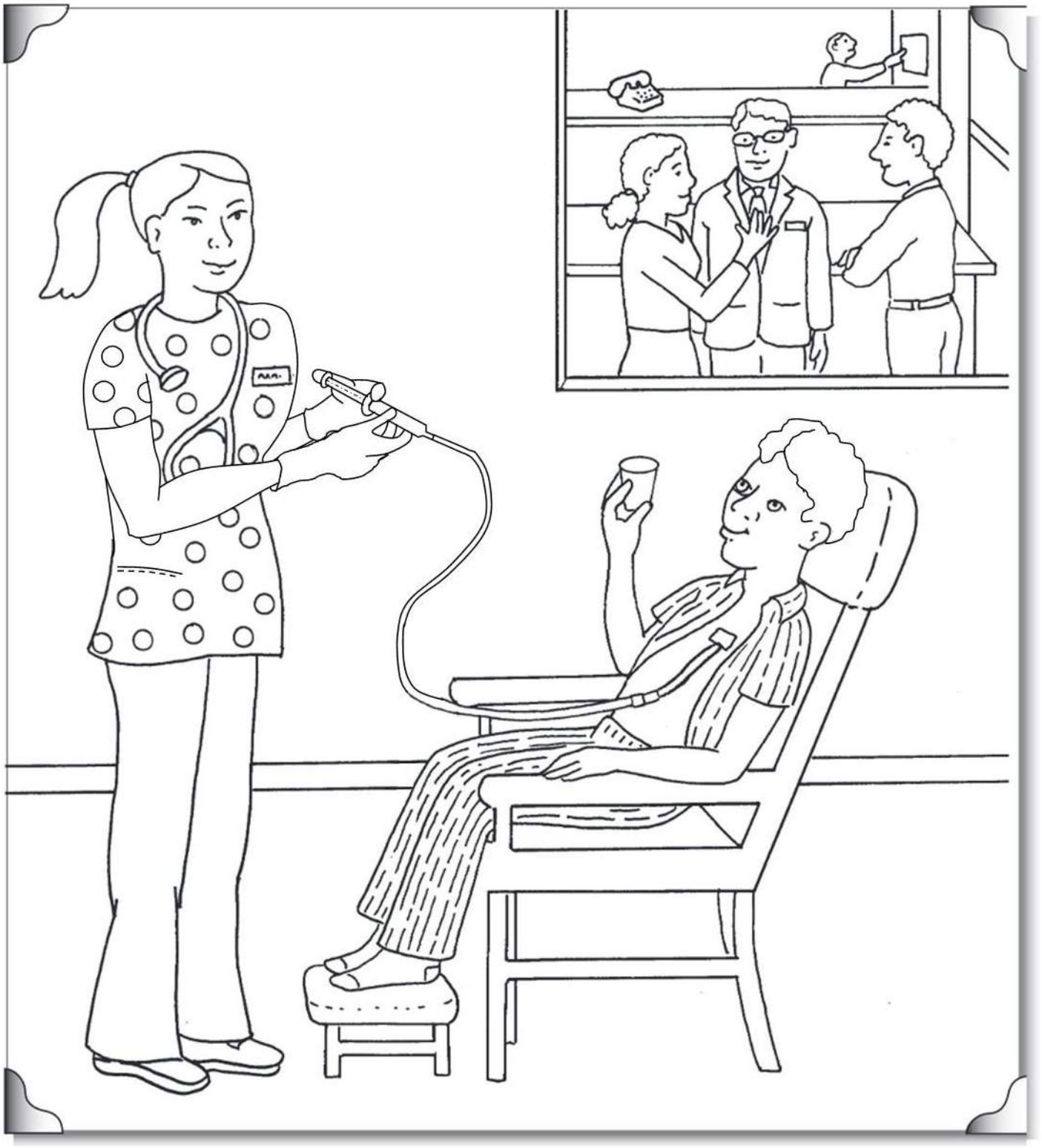
This is often done at the treatment centre or in the emergency room, through a central line such as a port-a-cath. Many children also do it at home.

Do you, a sibling or someone you know have to infuse factor through a port?

Do you help? This could be something you could learn to do to.

Any person who does the infusion needs to understand when to do it, the factor type, dose, how to do it, and how to keep the equipment clean.

Here's a drawing for you to colour in of the nurse doing an infusion at the hospital.



Nine Summer Stats (a short quiz)

What do you know about some of the common things that nature brings our way each summer? See how many answers you know to these summer science questions.

How many cyclones typically cross the coast of Australia each year?

a. 1
b. 4
c. 8

Which mosquito bites you?

a. Male
b. Female
c. Both males and females

How long is summer in Australia?

a. A few days shorter than the north hemisphere
b. A few days longer than the north hemisphere
c. The same length of time

The bush is noisy with cicadas, but how loud are Green grocer cicadas? The sound level of:

a. A food processor (88dB)
b. A lawn mower (100dB)
c. A chainsaw (120dB)

Where is the highest temperature recorded in Australia to date?

a. Marble Bar, Western Australia
b. Oodnadatta, South Australia
c. Birdsville, Queensland

Which of the following stars are not visible before midnight from some parts of Australia?

a. The Southern Cross
b. Andromeda
c. Orion *aka 'The Saucepan'*

Which venomous snake has the longest fangs?

a. Eastern brown snake
b. Red belled black snake
c. Coastal taipan

The latest sunset of summer falls on the longest day of the year. True or false?

A True
B False

What are bush flies after when they land on you?

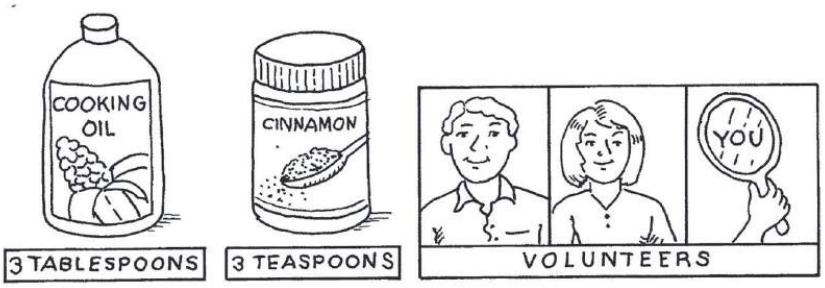
A Your blood
B Your sweat
C Just somewhere to sit

Answers: b, b, a, c, b, a, c, b, b

Hand Washing Experiment

Here is a hand-washing experiment to find out the best way to wash away germs. See if your mum and dad will help you with this experiment. Or you can do it at school with your teacher and class.

You will need: 3 tablespoons of cooking oil, 3 teaspoons of cinnamon and you and 2 other volunteers.



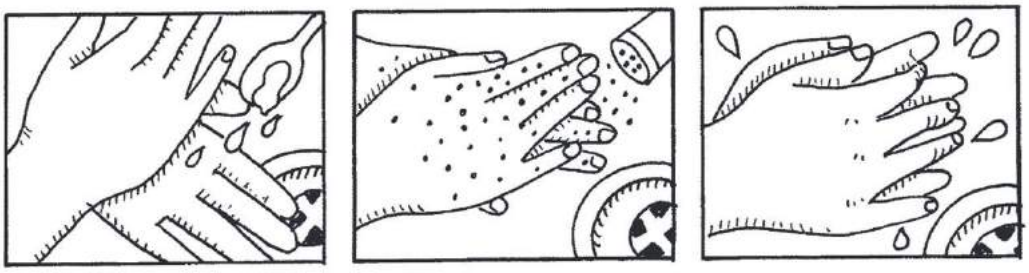
First: Each volunteer hand washer: Rub 1 tablespoon of cooking oil all over your hands until completely covered. Sprinkle 1 teaspoon of cinnamon on your hands and rub it all around. The cinnamon is the make-believe germs. It's all over unless you can removes them, and this is what washing your hands does!

Now: Everyone washes their hands by rubbing them briskly for 20 seconds.

Hand Washer 1: Use cold water and no soap.

Hand Washer 2: Use warm water and no soap.

Hand Washer 3: Use warm water and soap



Whose hands are clean?
Whose hands still have "germs" on them?

I'm sure you already know the answer - ***The best way to wash your hands is with warm water and soap.***

Important Dates for HFQ Members

OBE Lunch Forum
informal support group for men with a bleeding disorder. Usually meets first Wed of the month.

Australia Day Event
HFQ Pool Party 26 January 2018 venue TBA

Women's Brunch
4 February 2018 venue TBA

HFQ Youth Event
Supa Golf. Mt Cotton. 24 February 2018

World Haemophilia Day
17 April. Family Fun Day.

Regional Meeting *Please ask if one is happening in your area.*

Camps

- **Youth Camp**
  12—14 October 2018 at Toowong Rowing Club.
- **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.

New Youth Activities

Youth camp is only once a year and our community camp is only every other year. But are you looking for events that young members of our community can get together to do (with adult supervision)?

In 2018 HFQ has set up some extra events for our young people. Our first planned event is on 24 February. And it's SUPA GOLF!

Supa Golf is a modified form of golf that is easier, quicker and safer to play; with bigger clubs, bigger golf balls and bigger putting holes. Suitable for all ages, it makes an ideal pastime for everyone.

Situated at Sirromet Winery, the 9-hole Supa Golf course is the only one of its kind in Queensland, and one of just two in Australia (the other is located in WA) offering a fun nine-hole course that anyone can play, from frustrated golfers to families.

All equipment - including specially designed over-sized clubs, brightly coloured balls, scorecard and pencil – is provided.

Only four clubs are needed: the driva, strika, lofta and putta. Based on conventional clubs, they're made of lightweight polycarbonate and swing the same as standard golf clubs.

The golf balls, brightly coloured and 2-3 times bigger than regular golf balls, are more difficult to lose (bonus). They're also safer being made of soft polyurethane.

Likewise, the putting holes are two and a half times bigger than those on a traditional golf course. Another bonus is that there are no bunkers or water hazards on this picturesque course. Nine holes should take about one hour to play. Afterwards, enjoy a glass of award-winning wine at the winery on top of the hill.
Need to know - No bookings are required. No BYO food or drink.

We have scheduled another event for 17 June. And we're looking for ideas. We have Go-Karts, Escape Hunt's, laser tag and 10-pin bowling on our list, but if you have ideas of things your kids would like to do please let the office know. By calling 0419 706 056

About The H' Factor

The 'H" Factor is published four times each year by HFQ by the HFQ manager and assisted by Brett Williams, our communications volunteer. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

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