From the President

Hi everyone,

Thanks to Australian government policy it's simply great news for those who have now been cured of Hepatitis C, many who have had the virus for more than 20 years. Today's modern treatments cure the majority of people which provides significant health benefits. So now that your cured, is it time to party like you did in your youth, I don't think so as the virus may have taken a toll on the liver – you may still have liver disease – remember it typically takes about 10 to 20 years for damage to accumulate so you may not have the liver you had in your youth. For those with advanced cirrhosis or fibrosis you will still need to have medical reviews – so don't forget your doctor - keep in touch and follow their recommendations, talk to them about your lifestyle and aim to live long.

To another health topic – men and general health behaviour. At a recent get together it was interesting to test how many people go for an annual GP checkup – hands up I asked who has been for their annual checkup this year – the only person to put their hand up was me. Picking up early warning signs of disease or illness - blood pressure, weight, skin , dental, testicle, heart, prostate, bone density … the list goes on. Did you know men are half as

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Inside this issue:

Presidents Message *Continued...*

likely to go to the doctor than women and men were more than twice as likely to say they never had contact with their GP as an adult – busyness, fear, shame and discomfort seem to be the reasons many keep away. So guy's do yourself and your loved ones a favour – 'man up' and go to the GP.

David Stephenson

President HFQ

Haemophilia Foundation Queensland Inc.
Health promotion, Education, Support, Representation

Staying Healthy

Regular exercise and nutritious food are necessary for anyone to withstand stress. Taking preventative action on your health and regular breaks and ensuring adequate rest are also vital. Plan your day with time for you to attend to your own health and ask for help if you need it.

Exercise doesn't have to be done at the gym, walking, swimming, yoga, gardening or dancing are good ways to get some gentle exercise. Learning to relax, listening to pleasant music, meditation or doing specific relaxation exercises can help you sleep better.

Nutrition isn't about fad diets. In fact, when it comes to 'fast foods', your mum was probably right; everything in moderation! However, don't hold back on the good stuff. Trying new vegetables or fruit, eating at regular times and looking for new recipes are good ways to make eating healthy easier.

Don't wait until health symptoms are present – practice preventative health. Preventive healthcare should be considered an investment in your future. Every positive change is a step towards better and longer lasting health and happiness.

Try to relax and enjoy yourself by maintaining an identity of your own, not as dictated by facebook etc nor by your bleeding disorder. A sense of humour can really help you get through the stresses of life as laughter can help relieve some of the stress.

Keep up or make your own friendships You need to keep your links to the world outside bleeding disorders. Absorbing interests, having fun and relaxation are all good for your physical and mental health.

HFQ also supports you in maintaining some items that keep you well. Don't forget we offer subsidies and discounts on supportive footwear, medic alert bracelets etc. Also; keep an eye out for a seminar on men's preventative health that we are planning for the end of the year. This will consist of a couple of presentations and a nice lunch to help you understand what actions you should be taking to keep yourself in tip-top shape.

Finally, Brett and I are always looking out for stories about what you are doing to look after yourself. We are happy to interview you or you can submit a story in your own words about living with a bleeding disorder inn the family.

Graham & Brett

ABOUT HFQ

The Haemophilia Foundation of Queensland (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation employs a part time manager and 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

Members of HFQ are entitled to benefits, including subsidies on:

- **Medic Alert bracelets (50% discount)**
- **Electric Shavers (up to $75 off)**
- **Supportive footwear (75% off)**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Adam Lish
Secretary	... ...	Ms Lauren Albert
Treasurer	... ...	Mr Peter David
Members	... ...	Mr David Bratby
		Mr Erl Roberts
		Dr John Rowell
		Mrs Leanne Stephenson
		Mr Robert Weatherall

HFQ Delegates to HFA

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

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

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr John Rowell - Haematologist	3646-8067
Dr Jane Mason - Haemophilia Fellow	3646-8111
(request to be put through to mobile)	
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
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

As of April, at the Royal Brisbane & Women's Hospital (Joyce Tweddell Building) checking in to the clinics and treatment area has changed.

The front reception desk has moved around the corner into the centre of the clinic waiting area. For the time being, there is still a receptionist at the desk in the front of level 4 but they only take phone calls and can be used to page Haemophilia Centre staff (this does not replace checking in for appointments).

It is very important that you check in at the new reception desk around the corner. If you have a clinic appointment, the administrative staff will attend to you - when they are busy, you will be given a "buzzer" and be asked to take a seat until they are able to see you.

If you have an active bleed and need treatment promptly, or need treatment that is specifically timed pre surgery, please go straight to the nurse (also at the same desk as the administrative staff) to ensure you are triaged appropriately. Please inform the nurse that you have a bleeding disorder and need to be treated in a timely manner. If you have not been brought around to the treatment area within 30 minutes please check in with the nurse to ensure you haven't been missed\or not checked in. The sooner you let the nurses know, the sooner this can be rectified and treatment given. The nurse will guide you where to sit, so that you can hear your name being called.

On occasions dependent on the type of appointment you have scheduled, the Oncology Day Therapy Unit and Oncology Procedure Unit staff will be doing your treatments. This will be due to the Haemophilia Nurses other workloads, sick leave, or rostered days off. At times when there are staff absences, the Haemophilia Centre phone (36465727) voicemail or switch will direct outside calls to these nurses.

For Wednesday afternoon, and Thursday morning clinics, our clinic room has also changed, and for these appointments it is better to wait in the area closest to the coffee cart / lifts.

Berryl & Alex

Paediatric Team Update

Physiotherapy the changing of the guard

We would like to farewell Wendy Poulsen as she steps away from her role as physiotherapist in Haemophilia. We thank Wendy for her dedication and her many years of care for the families and for her continuing support and advice as she hands over the reins to Hayley Coulsen.

Congratulations and welcome to Hayley who was recently appointed to the 0.5 permanent haemophilia role. The other half of Hayley's role is caring for the oncology children (children with cancer).

Clinical Nurse Amy Finlayson is staying with the haematology and haemophilia service so she will be assisting Joanna from Monday to Wednesday each week, as well as caring for patients with other haematological conditions.

Salena Griffin is back from maternity leave and has much experience caring for haemophilia; she is working Thursday and Fridays.

Upcoming Leave and other things

Dr Simon Brown is on leave October 9th – 22nd

The Haemophilia Foundation Australia conference is on 12th – 14th October in Melbourne and Moana and Hayley will be attending the conference and therefore away from the 11th to the 14th October.

HAEMOPHILIA EMAIL

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

Haematology Fellow

Dr Olivia Starowicz remains in the Fellow (super senior Dr) position and will continue in this role until the end of January. Dr Rahul Joshi has slotted straight into the team in the Registrar position bringing his wealth of experience and knowledge. We will welcome a new Registrar in the coming months as the Doctors rotate through the different specialties at LCCH.

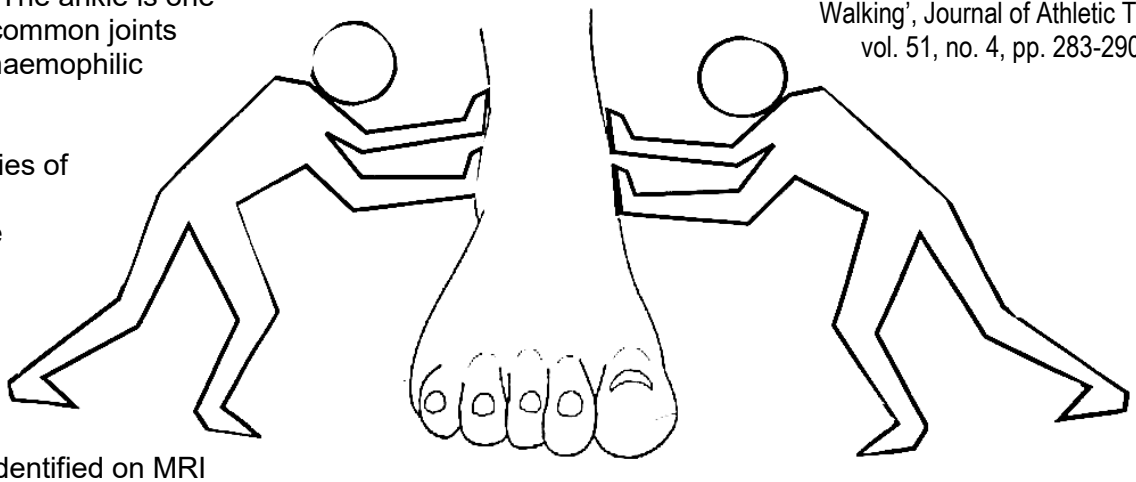
Ankle Support

The ankle is one of the most important joints of the human lower limb and plays an integral role in our locomotion. Injury to the ankle joint can result in significant functional impairment and decreased quality of life. Unfortunately, patients with haemophilia are at an increased risk of ankle joint injury due to haemarthrosis (joint bleed), resulting in haemophilic arthropathy. The ankle is one of the most common joints affected by haemophilic arthropathy.

Several studies of haemophilia cohorts have shown that joint destruction identified on MRI is evident before physical signs of ankle joint destruction, such as reduced range of motion and pain (1,2). This highlights the importance of preventative measures in reducing the incidence of ankle joint injuries.

Experts have long recommended the use of ankle braces for people with Haemophilia who are physically active, have a target joint or are prone to ankle injuries (3). Ankle supports such as bracing and taping have proven to be cost-effective additions in both the prevention and rehabilitation of ankle joint injuries (4). While taping the ankle does provide effective support the long -term durability of tape is poor and impacts the skin. The brace, however, provides greater protective mechanisms and reduces the risk of ankle injury (5).

Using ankle support during physical activities, combined with correct management of bleeds, will decrease the risk of further joint damage. If you have been having problems with ankle injuries whilst participating in activities, then this may be a solution to your problem. We are not recommending that all children should wear an ankle brace, only if you have been having issues. Your Physiotherapist can fully assess and identify any weakness in your ankle joint, and prescribe the use of an ankle brace if needed.



Hayley Coulson
in consultation with Wendy Poulsen
(Physiotherapists Lady Cilento Children's Hospital)

References:

(1) Kilcoyne R, Nuss, R, 2003, 'Radiological assessment of haemophilic arthropathy with emphasis on MRI findings' Haemophiilia, Vol.9, no. s1, pp. 57-64

(2) Dobon, M, Lucia, J, Mayayo, E, Roca, M, Solano, V, Pena, A, Giralt, M, Ferrandez, A, 2003, 'Value of magnetic resonance imaging for the diagnosis and follow-up of haemophilic arthropathy' Haemophilia

(3) Mulder.K, Llinas, A 2004, 'The Target Joint', Haemophilia, vol. 10, no.4, pp. 152-156

(4) Dizon, J, Reyes, J, 2010, 'A systematic review on the effectiveness of external ankle supports in the prevention of inversion ankle sprains among elite and recreational player', Journal of Science and Medicine in Sport, Vol.13, pp. 309-317

(5) Hall, E, Simon, J, Docherty C 2016, 'Using Ankle Bracing and Taping to Decrease Range of Motion and Velocity During Inversion Perturbation While Walking', Journal of Athletic Training, vol. 51, no. 4, pp. 283-290.

RBWH Hydrotherapy

Supervised Hydrotherapy and Gym-based exercise available at RBWH for Haemophilia Patients.

The RBWH now has allocated times for patients with Haemophilia to utilise the hydrotherapy pool or gym. This can be useful for rehab following a bleeding episode, orthopaedic surgery or for general exercise. All sessions are supervised by the Haemophilia Physiotherapist and tailored to each patient's ability and goals. The times are as follows:

Gym: Thursdays 8:00-9:00am
Hydrotherapy: Thursdays 2:00-3:00pm

For more information or to book into these sessions please contact:

Scott Russell – Haemophilia Physiotherapist
Ph: (07) 3646 8135
Email: scott.russell@health.qld.gov.au

Bridge 2 Brisbane - Come walk run or wheel

Bridge to Brisbane Day is a day when runners and walkers give back to the Queensland community.

At this years event they raised over $670,000 for charity and I posed the question to our facebook page; "Why weren't we there?".

This years big (over $20,000) fundraising organisations were: Crohn's & Colitis Australia; Guide Dogs Queensland; Wesley Medical Research; Redkite; and Brainchild Foundation. But smaller orgainisations did well as well. Did you know that Muscular Dystrophy Queensland; Alzheimer's Australia (Qld); Haematology & Oncology Clinics of Australia Research Centre; Stroke Foundation and Epilepsy Queensland Inc all generated over $5000 from the day?

So, my thanks to the 7 people who immediately nominated to give it a go next year. Seriously people; seven is great but if we got a big team together for next year, it would be a great fund / awareness raising opportunity for people with Bleeding Disorders in Queensland.

While I'm not exactly agile, if anyone else is interested in joining me to dress up and run (walk, crawl, push a wheelchair, etc) the event, please let me know.

Talk to your friends and family and get them on board to help us get fit and fundraise for HFQ.

Join me and I promise to put some effort into training for next year and see if I can keep up with you across the entire 10km (or perhaps the shorter 5km) run.

Graham

Coping as a Carer

All people respond to the demands of a health condition within the family in their own way. When someone has a bleeding disorder, the people closest to them often step-up to help and support them as they deal with their bleeding disorder on a daily basis.

While the person helping may not call themselves a carer, helping a loved one can impact on you and the feelings you experience. It can be rewarding but you should regard any difficult feelings as signposts. They will tell you when it might be time to re-focus on yourself and the things impacting on you that need your attention.

Difficult feelings

Stress is a part of modern living, but too much stress can lead to physical and emotional exhaustion. Helping and caring for someone with a bleeding disorder can mean interruptions to your own routines and life choices, and it may see you being cut off from others and facing high stress over a very long period of time. Helping another person with a health condition can make you vulnerable to stress because of the demands of caring.

Helping someone with a bleeding disorder on your own can sometimes make you feel stressed, especially if others in the family don't seem to be doing their fair share, if there is no one else to help. This can cause you to become frustrated or resentful with the person you are trying to help. So reach out to your old friends and try to encourage them to stay in contact with you, or contact HFQ or our member families for support.

You may experience feelings of loss or grief due to a change in circumstances, or your dreams and hopes for the future are not as you imagined it would be or the changes that have occurred in your role from being a parent/ partner/sibling to also now being a carer. Talking to someone about how you are feeling can help. If feelings of sadness persist for a long time, or affect your life to a great extent, contact your GP or the QHC Psychologists or Social Workers.

Sometimes caring for someone can feel like an endless grind. Over time, you can stop feeling angry or sad about your situation and instead you just feel numb and the simplest tasks seem to take too much energy. If you find you are sleeping too much, or waking early or during the night, if happy times don't seem to lift you, or you experience feelings of worthlessness, agitation, or choosing to withdraw from people these could be signs that you are suffering from depression. Please talk to a doctor you trust because this is both common and treatable. Your doctor will be able to help you find the best treatment options for you.

Managing difficult feelings.

As a carer difficult feelings can sometimes become overwhelming but there is a way to deal with difficult feelings that many carers say is helpful – talking to others in a similar position.

Sharing ideas, feelings, worries, information or problems can help you feel less isolated. Giving yourself permission to have a break and get some information and support from others who know what your situation is like may help to reduce some of your distress, or provide you some examples of strategies which may be of assistance especially if family and friends don't understand the impact the bleeding disorder has on you.

Being a carer also has been shown to have positive aspects and benefits, with studies showing that carer's have reported enhanced relationships, providing love and support, personal development and growth, feeling a sense of purpose and achievement, with care-givers often being more resourceful. *(Savage and Bailey 2004).*

At HFQ we try to provide support opportunities to bring together people affected by bleeding disorders in SE Qld and other areas, where you can be heard and supported by others who understand. We are holding a carers day on 11 December to thank and support those of you in this situation. if you think this might be good for you, please have a talk to Loretta or myself for more information.

The psychologists and social work team members at the QHCs are a valuable support, not only for people with an inherited bleeding disorder, but also their family members and carers. They can work with you to discuss your experience and offer strategies to assist and support you or refer you to someone who can. Professional support like this can be a good way to assist with the many changes in your relationships and roles, as well as dealing with any strong feelings associated with your caring role.

Graham

If the Shoe Fits: support for your feet

Orthotics can relieve foot pain
Horses and humans have one thing in common: they're only as good as their feet. When your feet hurt, it can feel like everything hurts. Foot and ankle pain can prevent you from getting up and out, enjoying life, exercising and working. And the pain can radiate to other parts of your body, such as your knees and hips.

If you ask four people if their feet hurt, chances are one of them will say yes, according to the Arthritis Foundation. That's because foot problems run the gamut from painful bunions and hammer toes to rheumatoid arthritis, fallen arches and poor circulation from diabetes.

Those over-the-counter (OTC) slip-in shoe inserts can look like a solution and many sports shoes offer good ankle support. There are times when you may need an expert's guidance on the right orthotic for your feet, especially if you have a bleeding disorder.

Orthotic options

Shoe orthotics are devices that support and comfort your feet. They can provide cushioning that helps redistribute your weight, taking the pressure off sensitive parts of your foot. Shoe orthotics can also align and support your foot and ankle, improve overall function and correct deformities. They also can help fix your gait, if you roll your foot inward, called pronating, or outward, called supinating, when you walk.

You've probably noticed displays at your local pharmacy or favourite sporting goods store showcasing several different types of shoe inserts available without a prescription. OTC inserts save you money, but in the long run, there may be better alternatives to save your feet. Research showing that custom-made inserts can produce changes in the biomechanics of your feet, slowing or preventing arthritis. These inserts actually alter muscle activity in your foot, fixing your gait and decreasing stress. People who wear them report fewer incidences of foot pain and take fewer pain relievers.

Customised care

In the bleeding disorders community, foot and ankle problems develop as a result of chronic bleeds in the ankle, which

can become target joints. When your ankle bleeds, you feel pain and you may lose some range of motion (ROM) after a period of immobilization from the bleed. This can cause you to change your gait to compensate, but this can squeeze the tissues in the ankle causing further pain in the ankle. You need to stop the cycle at the point of loss of motion—that's where orthotics come in.

Help is at hand via your physiotherapist at the QHC. The HTC staff know you, your body and your bleeding disorder. The physio at the QHC is skilled in gait analysis which looks at how you walk or run. They can also look at postural analysis; how the foot aligns with the knee, hip and back and help create a shoe orthotic that works for you. You'll also have much more interaction with the QHC physios during the follow-up when you're getting used to your orthotic.

Some podiatrists use hard orthotics, which are not always beneficial to people with bleeding disorders because it holds your foot in a fixed position, not allowing for normal pronation / supination while walking. When you pivot on it, it puts undue stress on your knee.

If you see your child with a bleeding disorder walking funny to avoid ankle pain, orthotic help may be called for. So if your child reaches the age of 7 or so and has foot and ankle issues, consult the QHC physiotherapist who can prescribe a custom orthotic to help resolve the issue.

Adjustment period

Custom shoes or orthotics may not feel instantly comfortable. Because they help you walk correctly, you may have to gradually increase the number of hours you can wear them. Following a home exercise plan to stretch and strengthen the foot and ankle can help. Eventually, you should be able to wear orthotics for a longer period, and feel more comfortable when walking.

All orthotics come down to what is needed vs. what is practical. If you won't wear an ugly boot or can't perform the exercises recommended by your physio, work with them to find middle ground. They will be realistic in terms of what can be accomplished to help ensure your ankle stays sound.

Edited for size from an article by Sarah M. Aldridge that was published in Hemaware Jan 2016. https://hemaware.org/story/if-shoe-fits

Changes to MyABDR

Change to MyABDR Remember Me function

From the National Blood Authority and HFA MyABDR teams

From **Tuesday 22 August 2017** if you want to use the **REMEMBER ME function** on the MyABDR app, **you will need to set a 4-digit pin.**

To set the PIN, at the login screen tap the **REMEMBER MY DETAILS** button NOT **LOGIN.**

WHY HAS THIS CHANGE OCCURRED?

You may be aware of the current concerns at a national level about the protection of personal information.

Protecting ABDR / MyABDR users' personal information on mobile devices and computers, while preserving favourite functionality has been a subject of considerable discussion between the National Blood Authority and HFA.

Against this background the NBA has implemented a simple solution of a four digit pin lock to access MyABDR on your mobile device.

This solution is only required when accessing and using MyABDR and does not impact on the use of your mobile device. The pin lock is very similar to other applications such as online banking.

The enhancement to the 'Remember my details' functionality means that you can continue to use this option knowing that your access to the ABDR / MyABDR system is now more secure.

HOW WILL THIS WORK?

- When you tap the REMEMBER MY DETAILS button at the LOGIN screen, you will be invited to set a 4-digit PIN.
- Whenever REMEMBER MY DETAILS is activated, you will need to use your 4-digit PIN to login if you have not used MyABDR in the last 30 seconds.
- However, when you are logged out and need to login again, you will still need to enter your email and password **– BUT!!**
- If you want to use the 'remember me' functionality, you should tap on the REMEMBER MY DETAILS button rather than LOGIN to login, and then set or reset your PIN.

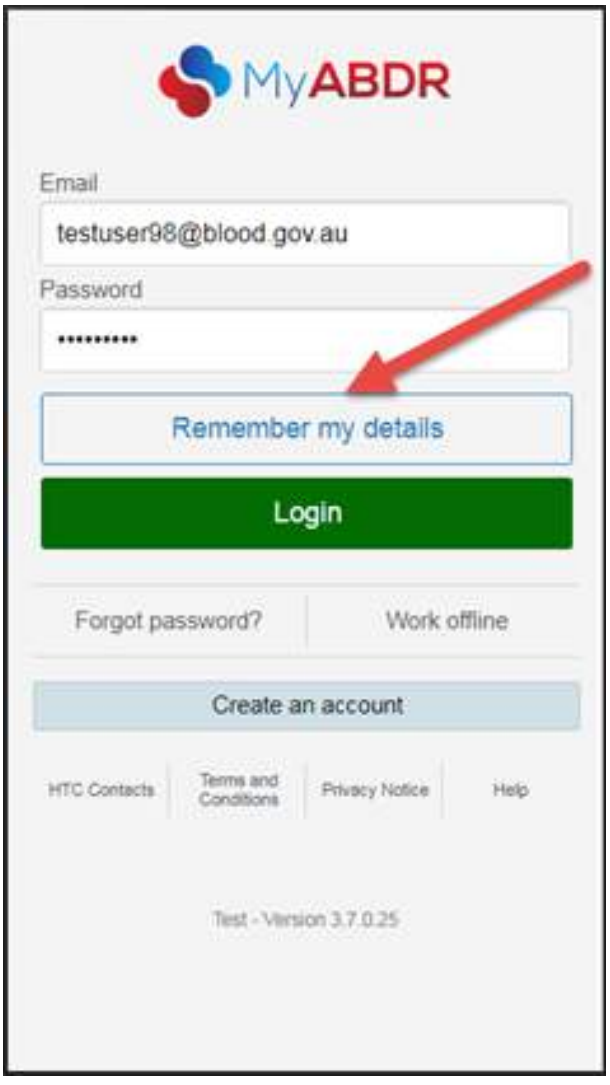
OTHER SECURITY IMPROVEMENTS

The National Blood Authority rolled out the new PIN functionality with other security improvements in the MyABDR release on 22 August 2017:

- Security improvements to the website version
- New messages on the mobile app where the device is insecure
- MyABDR will no longer be accessible from 'rooted' or 'jailbroken' devices.

ANY QUESTIONS OR NEED HELP?

Contact the MyABDR Support team (24 hrs, 7



Raising Awareness Can Really Help

A couple of years ago a video challenge spread across Facebook. People's feeds were suddenly filled with videos of people being doused by buckets of icy water. The people had got messages from their Facebook friends that said something like; "I'm doing this for ALS awareness. I challenge you to do the ice bucket too. Haha."

Oh, OK. It was for ALS. Except, wait - how many people in Australia even knew what ALS was? (ALS stands for amyotrophic lateral sclerosis; motor neurone disease). And how was it going to raise awareness?

The posts weren't that clear. It was often just a video. Maybe people asked their friends why they were doing it and then they had a meaningful conversation about motor neurone disease, but I'd guess that didn't happen much at all.

Many days, weeks, and months are dedicated to the awareness of different health issues. In fact there seem to be more awareness days than ever.

We have seen results from Haemophilia Awareness events. More than $35,000 was has raised in Australia during Haemophilia Awareness Week last year and over 100 red cake events were held. HFQ saw an increase in people registered on our FaceBook page and liking our awareness posts

In Queensland, we had 4 public structures lit red out of the 18 structures across Australia illuminated red as part of World Haemophilia Day (WHD) on 17 April. "Light it Up Red" was a trending topic on Facebook and Twitter in April. The money is something concrete that came out of our awareness month, but what about the rest?

Bleeding disorders are rare and the awareness generated through a red-light campaign like WHD is better than we can achieve via our members alone. On World Haemophilia Day the red -lit structures represent the collective voice of the bleeding disorders community, but only if people know why they are lit up! For us "awareness" should be about sending a message, gaining attention, and getting people to talk about bleeding disorders, at the very least on social media.

During HAW we get the most engagement and more new followers than from the rest of the year but social-media activism is sometimes called slacktivism. It's an easy way to reach a lot of people. But if it's just changing your FB profile and not backed up by money or deed, it's little more than lip service. Although lip service can help - if enough people on Facebook make their opinions on the issue immediately, graphically, demonstrably obvious, it could help us access improved treatments or additional clinical services etc. but they have to know what to do!

The first thing is that anyone who takes the time to ask for a building to be lit up or post a picture of it will feel invested, like they're part of something. It's a way to participate and it creates a sense of a community. Look at the motor neurone ice-bucket challenge. They wanted to be part of something that was bigger than themselves. It was free, it made you happy and it probably makes them feel like you're doing something.

But from a bleeding disorder perspective that isn't quite enough. You've got to follow it up with something else. Holding a Red Cake Day event is great, but what happens the week after Haemophilia Awareness Week and the week after that? And even if you get people to know what haemophilia is, how do you get them to do more than just post a status update? Unfortunately, being knowledgeable about a health issue does not equal taking action to address it.

So in addition to awareness-raising, as part of Haemophilia Awareness Week we are fundraising and asking people to talk to their neighbours and (even better) influential people to give them an insight into what a someone living with a bleeding disorder is going through. We need your story because our goal is for people to see the face of someone with a bleeding disorder, so that they carry that with them over the next week and the week after that.

If someone is aware of our health issue, it's a good step, and it might even be sufficient to address some health issues, but it doesn't address the complexity of the various forces that influence the health and wellbeing of a person with a bleeding disorder.

Those forces include things that can't be fixed with knowledge alone. Awareness days are not a bad thing. Awareness can be a first step toward taking action, but in my opinion it can and should be a first step to positively address the circumstances people with bleeding disorders live under and if we can tell them our stories and identify our needs, it could even reduce some of the stress and isolation many of our members live under.

Graham

Are You Taking Part?

Red Cake Day

2017

A PART OF

Bleeding Disorders
Awareness Week

8-14 OCTOBER

Red Cake Day

Help raise awareness and funds for people living with bleeding disorders in Australia by participating in Red Cake Day during Bleeding Disorders Awareness Week.

Red Cake Day is an opportunity for individuals, families, schools and workplaces to take part in a special fundraising event to raise funds and awareness about Bleeding Disorders.

To get involved visit
www.haemophilia.org.au
or call HFA on 1800 807 173

HAEMOPHILIA FOUNDATION AUSTRALIA

Monthly HIV Shot under Development

A daily regimen of pills for those living with HIV may soon be a thing of the past. A recent report published in the Lancet about a clinical trial showed that a new injectable antiretroviral therapy (ART) could given every four or eight weeks and may be just as effective as the daily oral medications that are currently used to keep the virus under control.

Maintaining the strict lifelong regimen of daily dosing with oral medication is crucial but it can be a struggle for some people, and low compliance can cause treatment failure and a rise in drug-resistant mutations.

The long-acting injectable ART could revolutionise HIV treatment and provide some patients with a more convenient treatment approach that avoids daily oral dosing, and the need to keep, store, and transport medications as they go about their daily lives

How the trial was conducted

The trial took place at 50 sites in the United States, Canada, Germany, Spain, and France. During the study, 309 participants were first put on daily oral medication for 20 weeks.

Once they had achieved viral suppression, some of the study participants were then given the injectable ART as a form of maintenance therapy either every four weeks or every eight weeks for nearly two years.

At the end of the trial, viral suppression was maintained in 94 percent of participants who were given the injectable ART every eight weeks (87 percent in the four-week group). These results are very promising and compare well with the 84 percent of patients who maintained viral suppression on oral medication throughout the 96-week period,

The introduction of single-tablet, once a day, medications represented a leap forward in ART therapies but the study researchers say that long-acting antiretroviral injections may represent the next revolution in HIV therapy by providing an option that circumvents the burden of daily dosing.

The results through to 96 weeks with this two-drug regimen are promising encouraging, and the study authors now need further research, including the ongoing phase 3 trial, to confirm these findings.

The importance of adherence

Treatment for HIV started with AZT and then progressed to multiple agents that sometimes needed to be taken every four hours and had bad side effects. It has evolved now with the development of single pills that can be taken once daily,

Even at once a day, life time treatment can lead to a pill burden that contributes to low adherence which can have severe consequences. Failing to adhere to the regimen of medication can make someone with HIV more susceptible to other infections. It can also allow the virus in their system to mutate and become resistant to the drugs they're prescribed.

The current simplified regimens like once-daily pills have little or no side effects, can help many people stick to their treatment better. That means better health for them, and when the HIV in their system becomes undetectable it means they can't pass on HIV to their sexual partners.

The development of injectables that might only need to be administered every four or eight weeks (and perhaps even longer with further developments), represents another evolution in treatment that aims to make taking antiretroviral therapy more convenient and therefore more dependable.

However while a long-lasting injectable ART may assist in improving compliance for some people. Most healthy people living with HIV in Australia get up to six months of their medication from a local pharmacy on one script meaning if HIV is controlled they only have to see their doctor every six months.

As such, a monthly or two monthly injection may actually require more visits to their doctor than one of the current oral medicines would, but having more options is always helpful and a positive step forward. A periodic injection will work well for some people and not for others.

From Progress Reported on Monthly HIV Shot. Written by Elizabeth Pratt and published in and article in HEALTHLINE NEWS on August 17, 2017

http://www.healthline.com/health-news/hiv-aids-monthly-shot#1

How Inhibitors Affects You

Some Haemophilia patients may, over time, develop inhibitors which restrict the efficacy of treatment making bleeding episodes more difficult to stop.

According to the Centres for Disease Control and Prevention (CDC), although the majority of people living with Haemophilia will be able to enjoy a long and healthy life thanks to treatments such as clotting factors, a small percentage of Haemophilia patients will develop antibodies known as inhibitors which will block the treatments.

Approximately 20 percent of people with Haemophilia A and 3 percent of people with Haemophilia B will develop inhibitors — a costly and dangerous complication. If a person develops an inhibitor, the body rejects the clotting factor they infuse which prevents the treatment from working, potentially leading to a dangerous bleed.

Haemophilia patients who develop inhibitors will need special treatment if they have a bleeding episode which can be both expensive and life-threatening. People living with Haemophilia who have inhibitors are two times more likely to be hospitalized for a bleeding episode.

Inhibitors tend to develop within the first 50 clotting factor infusions, although it can happen at any time. Haemophilia patients with certain gene mutations are more likely to develop inhibitors, other risks include a family history of inhibitors, race (black and Hispanic people are more at risk), increased frequency of clotting factor treatment, increased dosage of clotting factor treatment, and the number of lifetime exposures a person has to clotting factor.

Diagnosis of inhibitors is done via a simple blood test and it's recommended that Haemophilia patients are tested once a year for the presence of inhibitors. Treatment can be complicated and often involves giving higher dosages or more frequent sessions of clotting factor, using bypassing agents to bypass the inhibitors, and immune tolerance therapy (ITT) which aims to stop the inhibitor from blocking the clotting factor and trick the body into thinking the clotting factor is a normal part of their blood.

From: How the Development of Inhibitors Affects Haemophilia Patients www.Haemophilianewstoday.com/2017/08/10/Haemophilia-and-inhibitors/

What Would You Like to Know?

We've just described above how some people with haemophilia on recombinant factor concentrates, experience their immune system producing antibodies (inhibitors) which block the effects of the treatment.

Every year we have several approaches for more information on living and dealing with inhibitors so we'd like to know what we can do for you?

It might be you want the chance to meet with other families or individuals dealing with this issue. Perhaps you want to meet people who have successfully beaten their inhibitor and learn how the experience was for them. Or you might like a mix of educational and practical interactive sessions on dealing with inhibitors. Also what length of time can you spare? Will a half day do? Or perhaps only and hour or two, or an entire day?

HFQ is committed to educational meetings and social support in Queensland (SE Queensland works best to get medical team involved) to address members with specific needs and issues. So if you Do you, or a member of your family, have a current diagnosis of having an inhibitor – regardless of titre, please get in touch with the Foundation office and let us know if an event specifically targeting inhibitors would be of interest to you.

This request also applies if you have another topic you'd like us to cover, but we know there is an interest in inhibitors and your indication of interest will help us ensure that we can provide you or your family member with the most up to date information, support and education meeting possible that meets you immediate needs.

So, if you had an inhibitor in the past and it is successfully been treated please let us know so that we can update our records. Please call the office mobile on 0419 706 056 or email us on info@hfq.org.au

Graham

Toowoomba & Darling Downs

By time this magazine goes to press the OBE outing to Toowoomba will probably have occurred. OBE's is for the adult members who are living and thriving despite their bleeding disorder, but we know this is true of other members in the Toowoomba area, especially those with younger family members or partners they'd like to bring along too.

So please consider coming to our next event which is a family day on 5 November and everyone is welcome. We'll start the day off with a BBQ at Laurel Bank Park (HFQ will bring cold drinks, sausages and bread, but if you want other food items please bring you own or let us known if we can help.

After lunch we've booked the fully supervised laser tag area at the Bazanga centre and we have the option of 10 pin bowling as well so there are activities for the more active members.

We have also booked a table at Urban Grounds Café (ex-Angelos) just across the road for those who'd lie to retire to more comfortable surrounds to continue the conversations and friendships.

Please RSVP to the HFQ office so we can let the venues know numbers and organise catering. Phone us on (07) 3017 1778 or mobile 0419 706 056. Or email; info@hfq.org.au

Roger Ailes' Journey With Hemophilia

On May 18, Roger Ailes, the former CEO of Fox News passed away at his home in Florida after suffering a fall. The 77-year-old was diagnosed with haemophilia at the age of two, after he fell, bit his tongue and couldn't stop bleeding.

Despite his parents best efforts to keep him safe from injury, the future media mogul spent much of his childhood in the hospital, often after falling or suffering other minor incidents that resulted in heavy bleeding.

When Ailes was diagnosed, the life expectancy of a boy with haemophilia was just 11 years. As Ailes noted in his biography, The Loudest Voice in the Room, his family was told that he would die young and he was "told many times I wasn't going to make it."

Ailes rebelled against his illness often to his detriment. He once jumped off the roof of his house and ended up in the hospital following heavy bleeding — an incident which led to receiving a blood transfusion from his father's work colleague and being suspended upside down to prevent his blood from pooling.

Throughout adulthood, Ailes suffered terribly from joint pain brought on from childhood bleeds but would work through the pain. According to heavy.com, he predicted his own death in an interview with Vanity Fair in 2013, saying he believed he only had between six and 10 years left to live. Sadly for Ailes, he didn't make it that long. MORE: Prognosis and life expectancy for people living with hemophilia.

From Roger Ailes' Journey With Hemophilia by Wendy Henderson https://hemophilianewstoday.com/2017/06/06/roger-ailes-journey-with-hemophilia/

OBE's

Some say OBE's stands for Other Blokes Efforts, others say Old is one of the words used, or even Odd but none of it is true. It was originally named after the award granted by the Queen, before we have Orders of Australia. An OBE was a knighthood for great service or good works. Members of OBE's are men united by the commonality of living with a bleeding disorder. The Brisbane OBE group is men with various forms of haemophilia, ageing, from about 40 upwards but don't let age give you a reason why you don't come.

The modern OBE's is an updated alcohol-free version of the beer after work that has long been a part of Australian culture. Only it's coffee and a chat followed by a light lunch. You can come for the coffee, or the lunch, or all the day, whatever suites your timetable. OBE's happens all across South East Queensland and not just Brisbane. It also happens anywhere in Queensland that members express the desire to meet together socially

We get together every month. The Brisbane group usually meet on the 1st Wednesday, starting with morning tea if you can make it and concluding with a low cost of free lunch (OBE's is fully funded by HFQ but contributions from members are welcome). They meet at a different location each month, be it a restaurant, tavern or services club. If you don't drive and let Graham know, we can usually help with transport, especially if one of us lives near-by, we'll do our best to help you attend.

Not all OBE meeting are the same- if you came to one you might see a number of men talking about the changes in factor that will hopefully be becoming available soon, perhaps quizzing a speaker about possible help through Centrelink or planning a fundraising BBQ. You will see them accepting newcomers without questions (unless they want to share their story), sharing a comfortable chat over a coffee. Showing family photos, or swapping notes on how to get the most out of their computer, or other problem-solving discussion.

Sometimes we hire a bus to travel further afield (Toowoomba etc). We also try to make a regularly meeting closer to the Gold and Sunshine Coasts so that people living in these areas can join with us, which means that everyone who lives in SE Qld a chance to attend.

Not all meetings have a speaker, it can be enough to just spend time over coffee yarning together but when we do have a special guest it might be Dr John Rowell, Loretta (haemophilia social worker), Scott (haemophilia physiotherapist), or another staff member from the QHC. Or it might be a speaker another group like Arthritis Qld etc., to see what they have to offer or interest our members. The most important thing is that it's regularly, welcoming and affordable opportunity to gather without pressure to share anything because we know that many men have learned that in Aussie society, you don't talk about feelings and emotions.

So while some men at OBE's might be struggling with their own health and well-being, they do not want to make it a focus. They are living with their condition, not defined by it. The men at OBE's are willing to talk in their own way, amongst themselves, about almost anything from feelings of isolation, to early retirement, loss of children or relationship difficulties. Only it's not a support group. There is no gossip here, but there's also no Kum-Ba-Yah either, just quite conversations when the trust levels are right and a feeling that you are not alone.

Good health is based on many factors including feeling good about yourself, being productive, contributing to your community, connecting with friends and maintaining an active body and mind. Becoming a member of OBE's provides a safe and supportive environment where men can find many of these things in an atmosphere of old-fashioned mateship. And, importantly, there is no pressure. Men can just come and have a yarn and a cuppa if that is all they're looking for.

If you'd like to talk to an OBE member or to Erl Roberts OBE's coordinator, please call or Graham at the Office (3017 1778) and we'll connect you to OBE's

Brett

Gene Therapy Progress for Haemophilia B

We all know that Haemophilia is a rare blood disorder caused by a deficiency in one of a group of clotting proteins and that prolonged bleeding causes health problems. Most people inherit the genetic deficiency, though about 1/3rd have no family history of the disorder. In these cases, Haemophilia is caused by a genetic change referred to as spontaneous mutation.

HFA estimates that 2,700 in Australia are living with Haemophilia, and most diagnosed at a very young age. The median age at diagnosis in the USA is 36 months for people with mild Haemophilia, 8 months for those with moderate Haemophilia and 1 month for those with severe Haemophilia.

We recently posted a link to a video on our facebook page which offers a good explanation for a general audience on how AAV Gene Transfer Works.

Please check it out at: https://youtu.be/SUOskEqLpyY

Owing to the genetic nature of haemophilia many companies are working on gene therapy treatments, especially for Haemophilia B (whose patients are deficient in, or have defective, clotting factor IX) in the first instance, and some other genetic diseases. The common platform used in genetic therapy is adeno-associated virus (AAV) vectors who deliver the therapeutic gene treatment to the affected regions in the body.

One company in the race for a gene therapy is uniQure who made headlines - both good and bad - back in 2012 when they received the first ever marketing approval for a gene therapy. The company's therapy was approved for the treatment of familial lipoprotein lipase deficiency (LPLD), a rare genetic disorder that disrupts the body's normal process of breaking down fats. It was infamously priced at $1 million per patient in Europe. Five years later uniQuire announced that it wasn't going to renew of its marketing authorisation and ended that program because they couldn't sell enough product. Despite the commercial failure, this first therapy has established a proof of concept, expensive though it may be, for gene therapys for other conditions such as haemophilia.

Haemophilia B Results

uniQure's AMT-060 gene therapy for Haemophilia B is the most advanced of their pipeline products. They have received permission to expedite the development and review of this treatment, based on preliminary clinical evidence.

The evidence was presented in July when uniQure released updated, long-term clinical data from its Phase I/II trial of severe Haemophilia B patients. All 10 patients in the study demonstrated improvements in their disease state as measured by reduced clotting factor IX replacement therapy and bleeding frequency. Across both low-dose and high-dose cohorts, cumulative annualised factor IX consumption decreased by 79%, and in the higher-dose cohort, no spontaneous bleeds were reported in the last six months of follow-up. The data also showed a reduction in the annualised spontaneous bleed rate of 84% compared to the one-year period prior to gene transfer.

The company also presented new clinical data showing the efficacy of AAV5 gene therapy in the presence of pre-existing neutralizing antibodies (NABs). All three patients with detected anti-AAV5 NABs presented increases in factor IX expression. To date, 18 patients across two clinical studies have received intravenous, systemic administration of AAV5-based gene therapies without any observed T-cell activation. The data suggest AAV5 may have a superior immunogenicity and safety profile compared to other AAV vectors.

Only Haemophilia B is at this Phase 1/11 level but uniQure is also working on therapies for Haemophilia A, Huntingtons Disease, Congestive heart failure and several other research targets but these are all pre-clinical levels and will take longer to bring to human trials

Edited for size from a press release published at: https://www.equities.com/news/uniqure-qure-gene-therapy-progress-in-Haemophilia-b

Health Updates

Report Lists Latest Efforts to Combat Haemophilia

A recent study analysed that there are now 53 drug candidates in the pipeline in different stages of development for the treatment of haemophilia.

Some of the key players developing drugs for the treatment of hemophilia include Sangamo BioSciences, Inc., Caisson Biotech, Inc., XL-protein GmbH, and others.

Many drug candidates received USFDA designations namely Orphan, Fast Track or Breakthrough designations in their clinical stages for the treatment of haemophilia.

Explore Report Sample at: http://bit.ly/2xAQ3kS

Patient Surveys Can Help Doctors Better Treat Haemophilia

Information from patient surveys can help doctors do a better job of managing haemophilia and improving patients' outcomes, an American study which appeared in the journal Patient Preference and Adherence, reports.

Doctors need tools that help them assess and manage comorbidities, or diseases that accompany haemophilia.

The 381 men in the study filled out three surveys — two dealing with their general health and one with their haemophilia. The researchers measured patients' pain level on the day they completed the survey, and also determined their pain over the previous week.

There was a high correlation in measures of pain, functional impairment, and anxiety or depression, the team said. Importantly, each survey provided different details on haemophilia's effect on patients' health.

This means that choosing a survey may depend on individual symptoms, treatment planning goals.

For more information please go to: http://sumo.ly/EoLi

New Digital Innovations

Pfizer Inc. announced the launch of two fun and educational tools that can be integrated into everyday routines so that people with a bleeding disorder, and their friends and family can better understand the concept of factor levels in being able to stay active.

Hemocraft™ was created to help younger individuals with haemophilia learn the importance of integrating treatment into their routine in an educational and fun gaming environment. Players go on a quest and learn how to stick to their treatment plan, stay prepared, and understand how treatment works. Throughout the game, players are challenged to self-infuse to help control bleeding, if needed.

The HemMobile® Striiv® wearable device can be worn on the wrist, it has several useful features including tracking daily activity levels and monitoring heart rate to measure intensity.

The data captured generate personalised reports to provide insights that can help guide the discussion between a physician and their patient.

For more information please go to: http://bit.ly/2iu3ahT

FDA Grants Priority Review to Emicizumab

The US Food and Drug Administration (FDA) has granted priority review for Roche/ Genentech's once-weekly subcutaneous prophylaxis treatment Emicizumab, for haemophilia A with factor VIII inhibitors.

The priority review for emicizumab is based on results from the phase III HAVEN 1 study in adults and adolescents, as well as interim results from the phase III HAVEN 2 study in children.

Which showed that emicizumab has significant potential to help people with haemophilia A with inhibitors.

A decision from the FDA regarding an approval is expected early next year.

For more information please go to: http://bit.ly/2xYuIDe

Ap to Help People with Inhibitors

MicroHealth, a digital health start-up has developed an ap to improve outcomes in patients with haemophilia by enabling them to set reminders and record, store and share their health data. The ap drew on the experience of its co-founder, haemophilia A patient Aaron Craig, in designing the ap to help streamline haemophilia care to produce stronger adherence

For more information please go to: http://bit.ly/2iDcSPp

Prophylaxis Improves Function

For adults with severe haemophilia and pre-existing joint disease, prophylaxis is associated with improved function, quality of life, activity, and reduced pain, according to a study published last month in the Journal of Thrombosis and Haemostasis.

The researchers found that 94 percent of study participants had a reduction in total and joint bleeding events (BEs) despite severe pre-existing arthropathy. 35.7 percent were bleed-free and 76.2 percent had fewer than two BEs per year.

The researchers also found that prophylaxis led to decreased bleeding and improved joint health, activity, satisfaction, and Quality of Life scores. Prophylaxis also produced less chronic pain and It was also favoured in activity and satisfaction scores, but no reduction was found in structural arthropathy progression, suggesting pre-existing joint arthropathy may be irreversible.

For more info go to: http://bit.ly/2xuGTGh

Youth Camp

This years HFQ youth camp saw an increase in younger members attended camp at Emu Gully. James & Lauren acted as drivers for the people without transport and we are especially grateful to Zupps, Mt Gravatt for the free use of their cars to make this possible. I also want to thank Dr Melany Jackson who came out and worked with the young people on self-infusion practice.

This years camp offered our young men and women a great camp experience and the opportunity to make new friends or re-connect with old ones. We had a surprise birthday party for James as well as practicing infusion and participating in a number of physical activities and challenges designed to promote independence, and self-confidence.

Next Years camp is tentatively scheduled for 21st – 23rd September at the Helidon Campus so if your child is reaching year 5, please consider the HFQ youth camp for next year.

Quiz

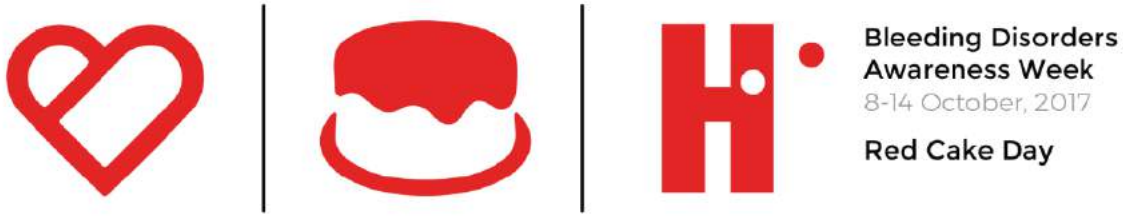
1. Who had an encounter with the three bears?
2. Who painted the Mona Lisa?
3. Who stole Christmas in the Dr Seuss book?
4. What is the name of Harry Potter's pet owl?
5. In which town do the Flintstones Live?
6. Wolverine is the leader of which band of superheros?

Answers

1. Goldilocks
2. Leonardo da Vinci
3. The Grinch
4. Hedwing
5. Bedrock
6. The X-Men

Bleeding Disorders Word Find

BLEEDING DISORDERS WORD FIND 2017



Q	M	F	N	I	N	F	U	S	I	O	N	S	W	M
P	R	O	P	H	Y	L	A	X	I	S	D	F	T	P
V	O	N	W	I	L	L	E	B	R	A	N	D	W	G
E	B	I	I	H	M	S	T	E	L	E	T	A	L	P
P	R	M	G	H	G	C	O	X	C	G	D	G	S	K
H	A	E	M	A	T	O	L	O	G	I	S	T	P	K
L	R	G	H	K	Y	G	J	K	J	F	H	I	O	Y
A	E	X	A	B	D	R	N	P	O	R	T	N	T	P
I	E	F	C	C	J	F	L	V	I	E	C	H	A	A
C	C	P	M	L	V	A	R	T	N	E	B	I	N	R
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S	C	O	N	C	E	N	T	R	A	T	E	Y	C	G
P	H	Y	S	I	O	T	H	E	R	A	P	I	S	T
C	H	R	O	M	O	S	O	M	E	E	G	E	N	E
H	A	E	M	O	P	H	I	L	I	A	W	B	N	U

ABDR	BLOODCLOT	CLOTTING
CHROMOSOME	CONCENTRATE	FACTORS
GENE	GENETHERAPY	HAEMOPHILIA
HAEMATOLOGIST	HTC	INFUSIONS
INHIBITORS	JOINTS	NURSE
PLATELETS	PHYSIOTHERAPIST	PLASMA
PORT	PROPHYLAXIS	PSYCHOSOCIAL
RARE	SPONTANEOUS	VONWILLEBRAND

Answer sheet available for download online at www.haemophilia.org.au

Important Dates for HFQ Members

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

2017 Aus & NZ Haemophilia Conference
12 - 14 October. Melbourne

Toowoomba Meetings
OBE's visit 5 October.
Family Fun Day Sunday 5 November.

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

Men's Health Forum
Nov 2017 day and venue TBA.

Carers Self-Help Day
11 December 2017 at Toowong Rowing Club.

Australia Day Event
26 January 2018 venue TBA

Women's Brunch
4 February 2018 venue TBA

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

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

Haemophilia Awareness

Haemophilia Awareness Week is our community's time to shine and to raise awareness amongst our neighbours and community about a group of rare bleeding disorders and the people affected by them (us)!

The HFA council has been discussing how we can make the week more inclusive of the bleeding disorders we represent, so this year it has been formally re-launched as Bleeding Disorders Awareness Week! This should help everyone living with or affected by a bleeding disorder to start a conversation about inheritable bleeding disorders and support October 2017 as the first Bleeding Disorders Awareness Week in Australia.

You can hold a red cake day event, set up a display, or run a wear red day in you workplace, school or local community. Even updating your Facebook and Twitter profile images with the new logo will help.

One idea we're keen on is having members tell their own story and what you'd like people to know about your condition. Write or record a short video to post on our Facebook page or here in H-factor.

Blood is one of the things all humans have in common and the problems it causes when it won't clot properly also binds our community together. The colour red that we use in our logo has been deliberately chosen to convey strength, courage and determination and the heart of the Bleeding Disorder Awareness Week speaks of empathy and love — qualities and emotions that define our bleeding disorders community here in Queensland.

By celebrating the first Bleeding Disorders Awareness Week, holding a red event or other fundraiser, you help show our other members that we are not alone in living with an inheritable bleeding disorder and you raise awareness and support from the larger community. By encouraging any of your friends or family to make a donation at *www.HFQ.org.au/get-involved/donate-now* you support the bleeding disorders community. All donations over $2.00 to HFQ will be receipted and are tax deductible. Making a donation helps advance the mission of HFQ and that enables us to support all people in Queensland living with a bleeding disorder.

About The H' Factor

The 'H" Factor is published four times each year by HFQ. 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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