the FACTOR

Issue 47
Winter 2016
Newsletter of Haemophilia Foundation Queensland

From the President

Addressing the needs of those with bleeding disorders in the Qld community is in the DNA of HFQ.

Hi everyone, hope you and your family are well, HFQ with one paid employee (Graham Norton) & a volunteer board continues to work with Queensland Haemophilia Centre to target health needs for Queensland bleeding disorders community. Focusing Qld Health funding to deliver outcomes that deliver improved health outcomes across all our demographics. Our community is diverse and wide spread thought Qld including women with bleeding conditions.

Some quick facts that may surprise you:

- Did you know that from some studies it is estimated that up to 1% of the world's population has VWD - do the maths. Because most people are mild, few people are diagnosed.
- It's not all about the boys - Women with bleeding disorders in our community can suffer additional symptoms because of menstruation, childbirth etc. Which can result in anaemia – weakness, fatigue & other significant issues. In addition to this are the stories I hear where women are challenged with the uninformed view that women cannot have a bleeding disorder – go girls,

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part of the journey is educating others.

- Did you know that some people have multiple bleeding disorders – yes Haemophilia A + B. In 2012/13 there were 139 people in Australia in this category, as well as a few with three different bleeding disorders (<5).
- MyABDR is providing valuable information to support you and your family – I encourage you to register and use the system as it facilitates improved clinical care. In a busy life is it worth investing the time – yes it is, register now.
- Plasma collected in Australia 2014/15 was a staggering 571.9 tons
- 1542 patients receiving product for bleeding disorders in Australia (2014/15)
- 5385 people registered with NBA (2013/14), 2181 Haemophilia A, 530 Haemophilia B, 1912 VWD

We have to thank and appreciate the myriad of people and organisations involved in delivering product and services across the country – from haematologists, nurses, psychosocial professionals, physiotherapists, the national blood authority, blood bank, hospitals, scientists and drug companies etc. (apologies for missing anyone / org) – well done.

This month saw the departure of our adult physiotherapist Rebecca Dalzell at the RBW&H. Her position will be filled and we hope that the person who gets the job can fill the position as fully as she did. Rebecca you will be missed as the 'go to' person when it comes to bleeding conditions and physiotherapy.

David Stephenson

President HFQ .....Advocacy, Education, Health promotion, Support

Shoo, Flu

To avoid the knock-down, drag-out symptoms and complications of influenza (flu), take preventive steps now.

Get yourself and your family vaccinated. But check first with the team at the Queensland Haemophilia Center to see if you need to infuse beforehand. That's because most vaccines are given intramuscularly, in a muscle, which can trigger bleeding.

Queensland has been hit hard by flu's already and flu vaccinations are recommended for 6-month-olds, all the way up to seniors. Populations at higher risk include: pregnant women, children ages 6 months to 4 years, people who are immunosuppressed, adults over 50, caregivers and nursing home residents.

It takes two weeks for antibodies to develop once you've been vaccinated, so if you haven't done it already, do it as soon as possible.

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)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Adam Lish
Secretary	... ...	Mrs Leanne Stephenson
Treasurer	... ...	Mr Peter David
Members	... ...	Mr Robert Weatherall
		Mrs Sarah Hartley
		Dr John Rowell
		Mr Erl Roberts

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 Registrar Dr Melanie Jackson

Joanna McCosker – Clinical Nurse Consultant

Wendy Poulsen — Physiotherapist

Moana Harlen — Senior Psychologist

Contacting the Clinic ***Please call the mobile for urgent enquiries (during office hours only).*** *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 — Contact the Administration Officer for Haematology or 2e outpatients for queries regarding clinic appointments

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 2e outpatients Level 2, Thursday afternoons 1.30 – 3.30pm

Contact the Administration Officer for Haematology Department

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr John Rowell — Haematologist	3646-8067
Beryl Zeissink — Clinical Nurse Consultant	3646-5727
Alex Connolly – Clinical Nurse (Part time)	3646-5727
After Hours — Page Haematologist	3646-8111
Rebecca Dalzell — Physiotherapist	3646-8135
Michael Hockey — Physiotherapist	3646-8135
Loretta Riley — Advanced Social Worker	3646-7937
Desdemona (Mona) Chong – Advanced Psychologist (Fridays)	3646-8769

Contacting the Clinic ***Please telephone in the first instance.***

Appointments 3646-7752 or 3646-7751 or speak to Beryl

Haemophilia and Genetic Clinic — Dr 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.

Getting ready for hep C treatment.

It is indeed an exciting and hopeful time for many who can now access new treatments for hepatitis C under the Pharmaceutical Benefits Scheme. The new treatment regimens promise a higher cure rate with minimal side-effects and short treatment durations - taking away many barriers for our community. It is important to be ready to take advantage of this opportunity.

What is the process like?

Hopefully you have already booked an appointment to see your hepatitis clinic! Talk to your Haemophilia Treatment Centre about a referral if you don't know where to start. They might recommend that you get a 12-month referral from a GP to cover all of the visits for your treatment.

Moving forward with treatment, you will need to make time to attend appointments at the hepatitis clinic and pathology services to prepare for treatment, and monitor your progress and response. The number of visits you will need to make will depend on your individual health. People with no complicating factors won't need many visits. Others will need to have more intensive monitoring and follow-up.

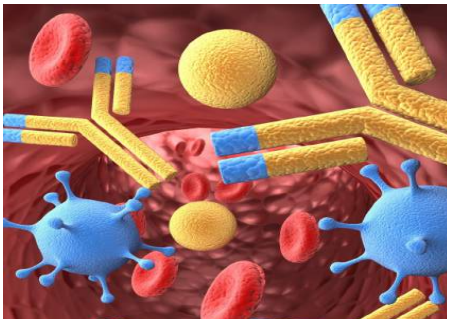
Overall, the feedback from people who are having treatment is that it is a reasonably straightforward and easy process.

How does this new treatment compare to previous interferon -based treatments?

The number of tests and appointments will depend on your liver health and other complications. Side effects, if any, are usually minor.
This means that compared to the previous interferon-based treatments, the length of treatment is shorter, there are fewer appointments and you are likely to be able to continue a normal life while on treatment.

How long is the course of treatment?

The new treatment courses are shorter – 8, 12, or 24 weeks. It depends on factors like your genotype, your liver health, whether you have had unsuccessful treatment in the past and other existing complications.



What does the treatment involve?

Medication for people with genotypes 1, 2 and 3 is now in tablet form. There are no injections. A small number of people with other genotypes may still need to have a combination treatment with interferon for a successful result.

Your treating doctor will also need to assess any other treatments you are on to see if they are compatible with the new hepatitis C treatments.

What about side effects?

There are few side effects and they are usually minor. They can include headache, nausea, diarrhoea, insomnia (sleeplessness), fatigue and, with ribavirin, anaemia. If you have any side effects – and many people don't – remember to talk to your treatment team to get some help with managing them.

People on treatment have reported little psychological impact. If anything, you may just require some practical support, e.g. to get to appointments or to be reminded to take your medication.

What if I have some problems, e.g. difficulty getting to appointments?

Speak with your Haemophilia Treatment Centre to see if they can provide support or help to problem-solve any barriers preventing you from seeking treatment.

What can I do to maximise success?

Besides keeping to your medication schedule and attending all your appointments, it is also a good idea to reduce alcohol intake to get the best out of the treatment. Talk to your Haemophilia Treatment Centre if you have other concerns.

HELPING THE SYSTEM TO WORK

Because of the ease of treatment and the higher success rate, there are a lot of people waiting for treatment. It is important to be proactive about your appointments and keep them.

If you are unable to attend an appointment, let the clinic know in advance so that you can be rescheduled. Otherwise you run the risk of being removed from the system.
If you have not heard from the clinic for a couple of weeks, it is best to follow up with a phone call and check when your next appointment is.

It's by everyone working together that we can make this a success for all.

Mona Chong
Haemophilia Psychologist at the RBWH

Thanks to Dr Joe Sasadeusz, Infectious Diseases Specialist, and Megan Walsh, Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, from the Alfred hospital in Melbourne; and community members currently on treatment, for their helpful comments on this article.

Farewell to Bec

It's true! Rebecca (Bec) Delzell, our haemophilia physiotherapist at RBWH is leaving us!

Many of you have found Bec both helpful and healthful. She has always given 110% to our members, so the board of HFQ invited anyone who had utilised Bec's services over the past few years to join us and help us send her off with a fond farewell.

We held a small morning tea in June at Cafe Tara (The Gap) to say good bye and present her with a spa package that we hope she can use once she's a full time farmers wife in Port Maquarie.

The ultimate objective in physical therapy and haemophilia care is to restore everyone to their highest level of musculoskeletal performance and activity after a bleeding episode.

Bec did this through helping her patients incorporate regular exercise or sports into their everyday life. She instigated the Strong Bloody Men program and many other initiatives to introduce men withy bleeding disorders to specific sports and activities that have helped them maintain mobility, muscle mass, core stability and cardiovascular fitness.

We wish her well with her families future endeavours and I'm pleased to report that she is going to maintain her interest in haemophilia specific physiotherapy issues and will make herself available to us as we identify programs and activities she can come back to Queensland to run.

After all, Bec has never waivered from her belief that a healthier body is linked to a healthier mind and this improves your quality of life.

Rebecca you will be missed as the 'go to' person when it comes to bleeding conditions and physiotherapy.

A Marathon Effort

7 August is the 25th anniversary of the annual Brisbane Marathon Festival. It will attract thousands of competitors who are ready to run through the streets of Queensland's Capital City and one of the runners is Melanie Jackson.

Mel was the Haematology Registrar at Lady Cilento last year and she is coming back to the same role shortly (after a stint in Cairns). She has been training hard and will be entering into the half marathon as a personal challenge. Not only is Mel challenging herself on course, but she is also challenging her friends and family to raise funds for HFQ as part of the marathon process.

So she's set herself a worthy goal of running her best time on 7 August and fundraising for us so we can continue to support people with bleeding disorders.

The race starts and finishes at the City Botanic Gardens and it runs both sides of the river including past LCCH and the SouthBank precinct. We wish her well and are behind her 100% You can too, by coming along on Sunday morning to cheer her on or sponsoring her on this marathon effort (every pun intended).

Brisbane MARATHON Festival

Contacting the Paediatric Team

You should all have a copy of the Haemophilia Contact Plan Sheet by now, if not please email *LCCH-Haemophilia@health.qld.gov.au* and ask for one to be emailed to you.

A handy hint is to take a photo of the contact sheet for your phone for those times when you are not in front of the fridge and accidents happen.

HAEMOPHILIA MOBILE – THINGS TO KNOW

Nursing staff generally hold the mobile phone. Joanna (CNC/NPC) generally has the phone but when she is unavailable other nursing staff and even medical staff may be holding the phone.

The phone is normally attended from 8am until 4pm, after this time you should use the after-hours number to contact the on-call haematologists for medical advice.

If the phone goes straight to message bank then we are already on a call. So please try again in a few minutes time or sent a text as well to notify nursing staff you require some advice.. Always remember a phone call is the most effective way to communicate with the paediatric & children's QHC when you have an urgent medical issue

If the phone rings out then please wait for a few minutes and try one more time. If you are unsuccessful a second time and you have an URGENT medical issue then please use the contact sheet. The nurse may be away but more than likely is attending to other patient and family needs.

Haematology Resident

The Residents are with the Haematology and Haemophilia Service for a short time (approx. 12 weeks) so it is highly likely they will be unfamiliar with your child. So we will need your help to provide them with a quick summary of who, what, why and where…. . To decrease any anxiety you may be having about this the resident will contact the other members of the HTC for further advice or will know if the nurse is available.

Haematology Fellow

Dr Melanie Jackson is returning for another 6 months mid-August as we say good bye to Dr Maliaka Perchard. Thank you Malaika for your wonderful care and enthusiasm and good luck at the Gold Coast next year.

Upcoming Leave

Dr Moana Harlen (Psychologist) will be away end of July to attend the World Federation of Haemophilia Congress where she will be presenting on family functioning. Well done Moana!

Wendy Poulsen (Physiotherapist) will also be attending Congress! Hayley Coulson will be available during this time

Dr Simon Brown will be taking annual leave end August to early September

Joanna McCosker (CNC) will be taking leave in the month of December. Updates will be provided in the next newsletter.

Bunning's BBQ Fundraiser

Graham continues in his role as HFQ 'rain god', as the latest Bunning's BBQ fundraiser experienced a torrential downpour in the middle of the day!

Our sincere thanks to the Weatherall family who helped organised this event and to the many volunteers who helped out on the day. We especially thank Mona Harlan from the LCCH Haemophilia Team who brought her husband along with her and helped us raise these much needed funds.

Despite the rain storm we think we've raised over $700.00 on the day and this is money that we can use for the things our state government grant does not cover.

Experiencing loss

With a number of long term Queensland Haemophilia Centre staff leaving over the past 6 months, new staff starting, and also the inevitable occurrence that a number of people will have experienced changes in their lives, I thought an article on loss and grief may be timely.

Grief is an expected (normal) reaction to a significant change or loss. There is no 'normal' way to grieve; everyone will grieve in their own way and in their own timeline. Some people will have support from family or friends, or seek help from a professional.

Loss and grief do not have to be associated with the death of someone close, it can be (for example) the loss of a relationship, loss of independence, loss of functioning, loss of a dream (what could have been), changing roles, loss of work and change of circumstances in general. The list is endless. Often one loss (primary loss) will have other losses associated with them (secondary losses). For example: in keeping with the initial theme, if the primary loss is a staff member leaving the QLD Haemophilia Centre, secondary losses could include:

- Loss of a relationship built up over many years
- Loss of a shared experience and knowledge
- Changes associated with getting to know new staff and the way that they work

Grief can be expressed in many ways. Some people feel sad, may cry or experience an inability to cry or feel numb; others may feel angry or express feelings of guilt. Some may have changes in their sleep patterns or appetite; have difficulties with concentrating or making decisions and may lose interest in normal activities.
If you are experiencing a grief reaction, the following may help:

- Please be kind to yourself – there will be good days and bad days, your feelings are an expected reaction to the situation.
- Try to continue your usual routines, ie doing the things you enjoy doing
- Talk to a family member or friend; they may also offer to help with everyday tasks which can be of assistance
- Writing your thoughts and feelings: eg Keeping a diary or journal, writing a poem, drawing
- Utilising spiritual practices and beliefs
- Meditation, mindfulness and relaxation practices may help
- Exercise, gardening, walking, swimming
- Listening to music
- Finding something for you that you find relaxing and soothing.

The Australian Centre for Grief and Bereavement recommends that "if you are finding it difficult to manage on a day-to-day basis, it may be helpful to see a counsellor or other health professional. It's okay to admit you are struggling with your grief. No-one will think any less of you if you ask for help along the way". (Ref: *http://www.grief.org.au*)

Loretta Riley

Advanced Social Worker RBWH

Some services which may be of assistance:
Lifeline—phone 13 11 14 for free counselling and support (24 hours a day, 7 days a week).

Parentline—phone 1300 301 300 for counselling and support for parents (8am–10pm, 7 days a week).
Kids Help Line—if you are aged 5–25, call 1800 551 800 for free counselling (24 hours a day, 7 days a week).
MensLine Australia—call 1300 789 978 for professional support and advice for men (24 hours a day, 7 days a week).

Australian Centre for Grief and Bereavement has a number of fact sheets on grief and loss which may be of assistance *www.grief.org.au*

If you would like more information or support, the psychosocial staff at LCCH and RBWH can be of assistance, please call Moana (30684180), Mona (36467937) or Loretta (36468769).

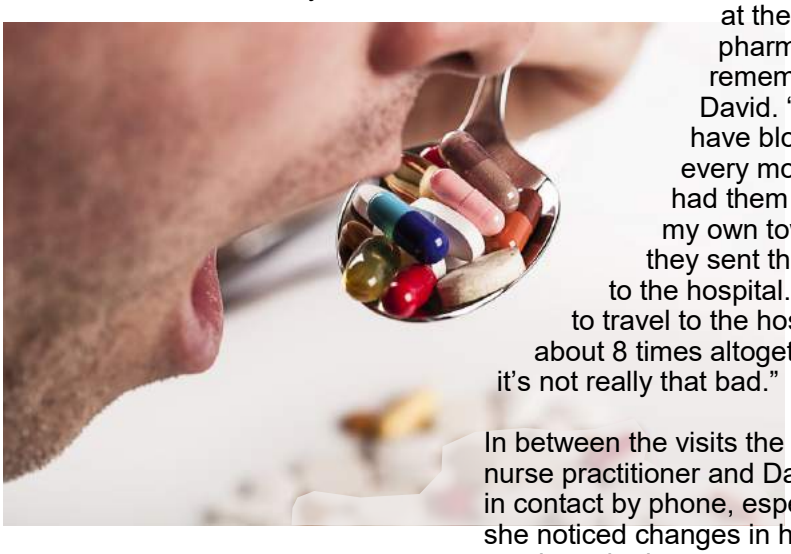
References: "Grief counselling and support" (last updated 9.5.16) https://www.qld.gov.au/health/support/loss/coping/;
"About grief" information sheet (2014) http://www.grief.org.au

Hepatitis C treatment – a personal story

David has von Willebrand disorder. Like many people with mild bleeding disorders who have only had the occasional blood product treatment, he never really thought that he might have been at risk of infection with hepatitis C virus from his treatment. New safety precautions for blood products were introduced in the early 1990s and after a few years the issue of hepatitis C for people who used blood products before 1990 no longer made news in the media. For David, it was off the radar.

David was feeling fine. He didn't even know he had hepatitis C. By co-incidence he underwent a series of tests for another health problem and it was then that his doctors found that he had hepatitis C. On reflection, David realised that he probably acquired hepatitis C in the early 1980s.

"I went for about 20, 30 years without even knowing," he said.



His Haemophilia Centre made a referral for him to visit the hepatitis specialist at the liver clinic. They wanted to check how his liver health was going with his hepatitis C.

"They looked at my liver by ultrasound and they saw I had a bumpy looking liver, like cirrhosis of the liver," said David. "The specialist wanted me to go on treatment, but this was the 12 month treatment with a lot of side-effects. So I told her that it wouldn't be for me."

GOING ON TREATMENT

Fortunately for David, the liver clinic was able to organise access to Viekira Pak ®, one of the new direct acting antiviral (DAA) treatments, which was not yet available on the Pharmaceutical Benefits Scheme but provided by the pharmaceutical company under an early access scheme.

The treatment program worked out for him that took his cirrhosis into account meant he would need to take about 12 tablets a day for 24 weeks - 6 months. David lives in a regional town, a few hours away from the hospital.

"I had to go down and see the hepatitis nurse practitioner and the hepatitis specialist every month, and I had to collect the medication at the hospital pharmacy," remembered David. "I had to have blood tests every month, but I had them done in my own town and they sent the results to the hospital. So I had to travel to the hospital about 8 times altogether – and it's not really that bad."

In between the visits the hepatitis nurse practitioner and David kept in contact by phone, especially if she noticed changes in his blood results or he became aware of side-effects.

"For a little while the haemoglobin wasn't exactly what the nurse practitioner wanted, so she monitored it very closely and I had to have blood tests every two weeks just for a bit, and sometimes had to adjust the dose of one of my tablets. I was worried that the treatment wouldn't work but she reassured me that I could afford to reduce the dose for a little while without risking a cure," he commented.

"For 4 months I went straight through with no problems at all, but then I started turning a yellowish colour, which they had to sort out. I didn't want to say anything about it, in case they stopped the treatment, but my wife knew better! That was the only side-effect I had over the whole treatment."

Twelve weeks after treatment, David had another blood test (a Hepatitis C RNA Viral Load) and visited the hepatitis specialist, who told him he had successfully cleared the virus.

"I feel a lot better knowing I don't have hepatitis C anymore," David said. "I'm going to be around a bit longer!"

AND FOR THE FUTURE?

Because he had already developed cirrhosis, David will need to have liver health checks regularly for the rest of his life to monitor his liver health and keep an eye out for signs of advancing liver disease or complications which can be managed.

His tips for other people with bleeding disorders and hepatitis C?

"Just do treatment. They are so much better now. Don't even hesitate.

"And if you don't know if you have hep C, get tested. It was just a fluke thing that I found out. But if I had known earlier that I had hep C, I probably wouldn't have cirrhosis of the liver because I could have had it treated back years ago.

"So if you have hep C, take care of it. Don't wait!"

David is an Queensland community member. He spoke with Suzanne O'Callaghan from HFA about his experience of treatment with one of the new hepatitis C direct acting antiviral (DAA) regimes

Rising Above

Joshua Williams is definitely not scared of heights. As a flight nurse who also has haemophilia, Josh who is 28 has learned to save others while managing the

personal challenges life with a bleeding disorder can present. His hard work and perseverance in overcoming these obstacles have literally allowed him to reach new and impressive heights.

Inspired by his time in and out of hospitals Josh thought he might want a career in the medical field. As a person with haemophilia he had to think hard about his future - he knew he might do damage to his joints if he took a job with lots of physical labor, so medicine was a good option for him.

He started in a small hospital emergency department and he thrived so much in that setting that he soon moved into a trauma facility which saw 170 patients each day. He recalls "it had everything I wanted, the fast pace, different people most of the time and work shifts consisting of what I consider “organised chaos". Though he loved it, he knew he wanted to become a flight nurse.

A while ago when the opportunity presented Josh jumped (or flew) into a new job. After a very intensive three week program he earned his first set of wings. The intense training program continues for another five months and though intense, it has already paid off as Josh recalls, "My first flight was nerve wracking to say the least. We received a call that a patient needed to be transferred from a regional hospital into the city. It was such a great feeling helping to transfer this person to a higher level of care."

On a daily basis Josh is working hard with his team members to save lives. At the same time, he has had to learn to successfully care for himself and his haemophilia in order to best serve others. Josh learned to strike a special balance between managing his bleeding disorder and meeting the demands of the job. "I stay as fit as I can because I've noticed the healthier and more physically active I am, the less bleeds I have".

Fortunately Josh's managers have also been very understanding when modifications have been necessary. Recalling one experience Josh shares, "My target joints are my shoulders. One day I experienced a dislocation and was unable to do any lifting. My manager put me in a role where I was not required to perform any heavy lifting. My fellow team members have always been helpful when I need to infuse on the job. Given the flexibility in nursing, most of the time I can continue to work even while having a bleed, though I do all I can to avoid that from happening. In nearly six years, I have been fortunate to have missed only one shift because of my haemophilia." This can certainly be attributed to Josh's commitment to health and taking steps to manage his bleeding disorder to the best of his ability.

"I'll never forget the skyline over the city as I returned from my first flight," Josh reflects. The sun was rising and it was as though I had never seen a sunrise before. When you are 500 metres above the ground and lives are in your hands, everything changes. Thinking of the patient we transported, and knowing I did something that really mattered is a feeling and a rush not soon forgotten.

As Josh and others in our community have demonstrated, having a bleeding disorder should never stop us from pursuing great and lofty heights.

We must learn to manage our condition the best we can, taking consideration of our limitations and making modifications when necessary. We must learn that in order to do good for others, we must first learn to care for ourselves. There are always circumstances beyond our control, but by managing what we can to the best of our ability, the sky is the limit.

Written by Justin Lindhurst, Matrix Health Group
www.matrixhealthgroup.com

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Hey Sport!

Losing can be hard, especially when you've been trying real hard to win. Whether its chess or soccer; crumping or cheerleading, we can't win all the time. But being a good sport makes taking part more fun! Here are some ways to become a better sport, no matter what the event.

Playing fair

Good sportsmanship is about respect, self-control and playing by the rules. Good sports play because they love the game. They don't focus on the final score. They enjoy practicing their skills and spending time with their teammates.
When playing any sport or game, remember the golden rule: Treat others the way you want to be treated. So if you win, don't boast or pick on the other team. When you lose, try to lose gracefully. Congratulate the other team on their victory.

Here are five other tips for being a good sport:

1. Offer encouragement to your teammates, even when they make mistakes.
2. Lose without moping or pouting.
3. Win without bragging or rubbing it in.
4. Always play fair.
5. Don't blame others for losing the game.

Being a good sport means respecting yourself, your teammates, your coaches, the referees and the other team. Being respectful makes for better teamwork. And you'll have more fun during the game, too.

What if I can't play?

Games and sports teams are made up of different people who are all important. There are players, coaches and scorekeepers, for example. Sometimes, you may not be able to participate in certain games. Sports can be physically rough, and the risk of a bleed might be too high. This doesn't mean that you can't take part, though. Talk to the coach about helping out as a coach's assistant, or an equipment manager. You can still be part of the team even if you're not playing in the game.

Beyond the game

Life is a lot like a sporting event. It can be tough and sometimes the outcome may not seem fair or right, especially for kids with bleeding disorders. Good sportsmanship teaches us to focus on the good things, like having fun with your friends. That's a good habit to get into, on and off the court.

Written by Joe Rizzo and originally Published in Hemaware http://www.hemaware.org/story/how-be-good-sport#node-1504

What to do if you're bullied

Oh, no! Here comes that mean, angry kid at school. He always bothers me. Some kids say he's a bully. All I know is that when I see him, I get scared and wish I could hide. What's a kid like me supposed to do?

What is a bully?

A bully tries to hurt people with words or by hitting, punching or kicking. A bully wants to feel powerful and popular. He wants to prove to the other kids that he gets what he wants. He is sometimes bigger than the kids he picks on. A bully can be a boy or a girl. Sometimes girls who bully say mean things, whisper or tell lies about you that you might not even hear.

Bullies get mad quickly. They get frustrated when things don't go their way. Lots of times they blame everyone else for their problems. Sometimes they don't have happy homes. Many bullies have been bullied at home.

"I diet all year, and —BOOM!— one hemophiliac and it's back to square one!"

Why me?

Bullies pick on people who they think are:

- smaller or weaker
- not popular and don't have a lot of friends
- quiet and won't report it
- Different

A bully may pick on you if you are smarter than they are. Or if you wear glasses, speak another language or have a bleeding disorder. A bully will use anything that makes you different to tease you and put you down.

What to do?

Most schools have rules to protect kids from bullies. Nobody wants to be a tattletale, but a bully can hurt you, especially if you have a bleeding disorder. Being hit could cause a bruise or a bleed.

If you have to face a bully:

- Use words. Tell the bully to stop, but don't show anger or fear.
- Act brave. Stand tall with your head up and walk away to show you're not weak.
- Find friends. Keep them with you in the hall or playground, on the bus, or on your walk to and from school.
- Don't fight back. Stay calm so things don't get worse.
- Tell an adult. Reporting a bully will help stop him from hurting you and other kids, too.

Standing up for yourself in the right way can help you to say: Bullies, be gone!

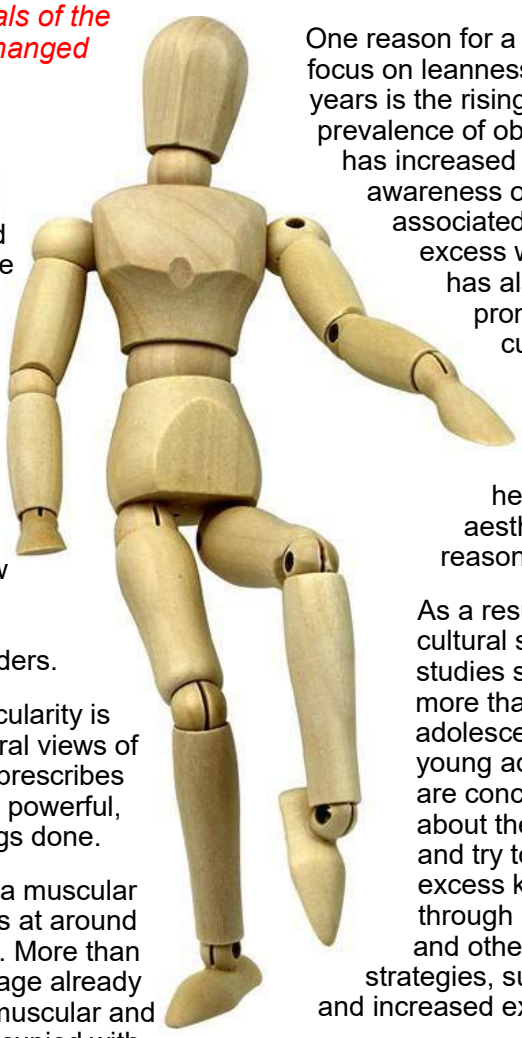
Originally Published in Hemaware by Sarah M. Aldridge, August 2015. http://www.hemaware.org/story/bullies-be-gone

Boys and Body Image Pressure

Boys aren't immune to body image pressures – *and never have been*

Male beauty and body image may receive less attention in the media than the female body. Yet buff, lean and muscular male bodies are the popular male image of blockbuster films, magazines and popular culture.

How have portrayals of the ideal male body changed over time?



The perceived attractiveness of muscular men has grown since around the 1950s, when the body size of male models gradually increased in muscle and lean body mass rather than body fat. The same trend can be seen in action figure heroes such as GI Joe, who now has a physique comparable to advanced bodybuilders.

The pursuit of muscularity is closely tied to cultural views of masculinity, which prescribes that men should be powerful, strong and get things done.

The preference for a muscular male body develops at around seven years of age. More than half of boys at this age already desire to be more muscular and may become preoccupied with exercise to build muscles.

Muscle mania

The muscular ideal is not a modern notion. Muscularity has been admired throughout history, where well-proportioned males have been idealised for their defined muscles and often low body fat. This can be seen in Michelangelo's statue of David, who is youthful, lean and symmetrical, yet muscular.

Leanness

Modern men don't just have to be muscular. Studies show women perceive lean men with body mass indices toward the lower end of the normal weight range as more attractive.

Researchers have found that men also select figures that represent low to moderately-low body fat as desirable roll models.

One reason for a greater focus on leanness in recent years is the rising prevalence of obesity. This has increased our awareness of the risks associated with excess weight and has also promoted a culture which values leanness for both health and aesthetic reasons.

As a result of these cultural shifts, studies show that more than 30% of adolescent and young adult men are concerned about their weight and try to shed excess kilos through purging and other strategies, such as diet and increased exercise.

Metrosexuals

The modern metrosexual is a prime example of the image-conscious man for whom leanness and youthfulness have become important standards of male beauty.

The metrosexual man is often considered the man we should desire to be and as with women, the media are guilty of promoting these images. But men who are persuaded to adopt these ideals can become trapped in a vicious cycle pf attempting to improve their attractiveness.

Studies have shown that almost two thirds of young adult men from the USA and Australia have removed their body hair (below the neck) at least once.

But the metrosexual is not a modern invention. Early Egyptian men and women valued both leanness and youthfulness and regularly used oils and creams to keep their skin soft and supple, and to prevent cracked dry skin.

They carefully watched their weight and tended to eat more fruits and vegetables than meats. They also valued hairlessness.

On the whole, men usually had a thin moustache or goatee, and tended to be relatively thin and even frail-looking with their faces and chests shaven, as they considered an abundance of hair a sign of uncleanness.

Modern pressures

The pursuit of muscularity, leanness and youthfulness are not new aspirations for men. But what has emerged in the past two decades is an ever increasing range of media (magazines, films, television, and the Internet) that promote a profoundly image-conscious society.

With increasingly sophisticated technologies and marketing strategies, the male body is becoming more exploited and commodified, and this is giving rise to higher levels of body image and appearance concerns among young men.

Men should be discouraged from adopting or internalising these unrealistic standards as the "yardstick" by which their own body image should be measured.

Edited for size from an article by Professor Lina Ricciardelli. Associate Professor of Psychology, Deakin University
First published in The Conversation on 8 February 2012

HFQ Women's Brunch 2016

On Sunday 26th June 2016, HFQ hosted a Women's Brunch for women affected by a bleeding disorder. Previously known as the 'Mother's Morning Tea', we decided to expand the invitation to women who carry the gene, women who suffer from a bleeding disorder, siblings, mothers and partners.

This event was held at Café 63 in East Brisbane, and was a fantastic success. We ended up having to be kicked out as the booking after us had arrived and we were all still chatting away! The women all talked about their experiences with bleeding disorders as well as the upcoming HFA Women's & Girls Project.

If anyone is interested in taking part in the next Women's Brunch, or the HFA project, please contact Graham for ways to get involved. A huge thank you to all the women who were able to come, and those who expressed interest but were unable to make it. We hope to see you at the next one on 16 October (to coincide with Haemophilia Awareness Day).

The Female Factors - and update from HFA

What are the experiences of women and girls affected by bleeding disorders? HFA's consultation has found that many have been treated in the community, for example, by a GP rather than a Haemophilia Centre. However, most doctors have not received training about managing bleeding disorders.

As a result many women have had problems with diagnosis and referral, and had bleeding problems with surgery, medical and dental procedures, with menstruation (periods) and after childbirth. Many women also spoke about difficulties in being 'taken seriously' as some of their treating doctors held the belief that women cannot have a bleeding disorder.

This is a similar experience to women with bleeding disorders in other developed countries like Canada. For these women, feelings of isolation are common.

The Female Factors is the HFA women and girls project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- **Increase understanding** of their bleeding disorder, treatments and care
- **Help them to feel more connected** with each other by sharing personal stories and tips with others in similar situations
- **Develop high quality, evidence-based information** that they can show to other doctors, nurses, etc who provide their care.

The first The Female Factors resource is now available – an introductory booklet called ***A snapshot of bleeding disorders in females***. Ask your Foundation or HFA for a copy, or download it from the HFA website – *www.haemophilia.org.au.*

Next, there will be a series of more detailed information resources on specific topics. They will include personal stories and tips. One suite is targeted at adult women and the other is for young women and teenage girls. The resources cover:

- Haemophilia: carrying the gene. and
- Living with a bleeding disorder from a female perspective

WANT TO BE INVOLVED?

You can contribute to the project by joining the HFA women and girls review groups: tell your story, and/or comment on the draft resources. Contact Suzanne at HFA on *socallaghan@haemophilia.org.au* (women) or Hannah on *hopeskin@haemophilia.org.au* (young women and teenage girls); or phone 1800 807 173.

MORE INFORMATION

Contact HFA **T:** 1800 807 173
E: *hfaust@haemophilia.org.au*
W: *www.haemophilia.org.au*

Dad's helping each other

All of us look for ways to cope with our problems and the demands of life. Some ways that we cope are helpful. Others do more harm than good. You may not have the same feelings or do the same things as the other dads that come to the HFQ Sunday brunch, but everyone there has a bleeding disorder in their family and chances are someone there will have a similar experience to you and you won't be alone in your response, whatever it may be.

When you first heard your child had a bleeding disorder, you may have been shocked. Perhaps you didn't find out about it until they were a teenager. You may have been angry that you missed the warning signs, or wanted someone to blame. As you wondered what kind of life your child would have, you were possibly afraid.

You may have pictured all of the things you had hoped they would do and now fear a life full of problems and things they will never be able to do. You may have grieved, both over the loss of the perfect baby you had in your mind and over the very real medical problems your child could face.

We'd like to know what helped, or what you'd have liked to know but didn't learn at the time, so we can remember these things when we meet another dad with a child who has been diagnosed with a bleeding disorder.

When parents are told that their child has a serious medical problem, they go through a very emotional time. Common feelings are shock, not believing it is true, and anger. Some dads suffer fear and depression as well. These feelings may come up at different times. After you think you have gotten over it, you may find the emotion coming back.

When trying to deal with their feelings, sometimes parents get stuck. A dad may not be able to accept that his child has a bleeding disorder and many parents can't move on to coping with the problem. If this should happen HFQ wants to be able to help. Most families do come to accept that their child has a bleeding disorder. They also become determined to face problems one day at a time and to make the most of life.

Our dads brunch is for you, but also to help us help other families. As they begin to deal with their child's bleeding disorder, they may feel very alone. It can be hard to find someone who can answer questions and give support, so finding out what has worked, or could work is very important to us and to every new father.

You may feel that family members do not understand. Your friends may know too little and only feel sorry for you. It may seem that your doctor doesn't have time for you. Where do you turn?

HFQ want to help parents directly and by supporting the QHC staff team. They are already trained to help patients and their families understand and manage bleeding disorders. They know all about how to deal with the problems dad's face, but your experience is important and will help us make the next dad's experience better.

At the brunch you may find other men who have gone through the same or similar things. Brunch is a time to talk to other guys who has been where you are now (or to not have to explain anything because the men there already know what it's like). You and your family will probably make changes at each stage of your child's life. This brunch will help us identify what we can do to help.

After all it happens to all families, whether or not a child has a bleeding disorder. It is normal to worry about the future for your children and you can help us help new dad's.

Will You Need to Retire Early?

Some people with bleeding disorders fear they may not be able to work through to normal retirement age. In our mid life circumstances can change and we review what is important to us. Our parents may start to need our support and care. Our careers may have reached their zenith and our health not as good as it once was. Looking for new work opportunities can become harder once you pass into your 50's.

If you've been working all your life and have paid into superannuation, are now over 57, were working and now suffer from an injury or illness that has prevented you from working for 6 consecutive months; or if you are concerned about bleeds getting in the way of continuous on-going work, you may be able to get an early payout of your super funds. You may also have total and permanent disability (TPD) insurance with your superannuation that you can claim. Even if you don't have super or TPD, you might be entitled to the CentreLink Disability Support Pension (DSP) both are designed to provide support for people who have a permanent disability that prevents them from working. Both forms of payment can be difficult to access and require specific conditions to be met.

You can claim TPD insurance in the case of a partial or total permanent impairment or injury, ie. if you are unable to work due to any injury or illness. The general definition that entitles you to a superannuation lump sum benefit is “that you are partially and/or totally permanently disabled and unfit for your old job or any other suitable job that relates to your education training and experience”.

The Disability Support Pension (DSP), is granted after assessing the impact of medical conditions on work capacity and can be very complex. It is important that the Assessor has all the relevant information available to them (especially medical documentation) to make an informed decision and Centrelink looks at the person’s physical, intellectual or psychiatric impairment as well as their work ability.

The functional impact of a person’s impairment is assessed using prescribed Impairment Tables and you must also be unable to do any work of more than 15 hours a week at or above the relevant minimum wage, or be re-skilled for any work for at least the next two years.

The Impairment Tables are designed to focus on a person’s ability, not their disability and it has become increasingly hard to be accepted on initial application as the descriptors in the Impairment Tables do not list specific medical conditions; instead they assess the functional impact caused by the conditions.

At the moment of applying for a DSP you will need to provide medical assessment forms completed by your doctor, and you will be placed on 'New Start' while awaiting a decision. This can give you about $650 per fortnight including rent assistance, whereas the DSP is the same rate as the 'Aged Pension'. The department will then do a psychological and a medical assessment (which can be done over the phone), to determine your eligibility for the DSP.

We have heard that many people fail this initial assessment process because there is a 20-point ‘table’ system for determining a person’s medical condition. These tables are extremely rigorous and some people who have been rejected say it’s almost like its been compiled to prevent almost anyone from successfully qualifying for a DSP.

However, if your application is declined, you can appeal and you application will be reviewed by a CentreLink Review Officer and ultimately if you are not happy with the decision of the Review Officer you can appeal to the Social Security Appeals Tribunal (SSAT) which is an independent review process.

The message to anyone who may be considering early retirement and applying for these financial supports is to make sure:

- you understand the criteria
- you have the full support of your primary doctor
- your documentation is impeccable.

The application and appeals process for superannuation TPD and for CentreLink DSP can take over 6 months. Having a support worker to help you through the process is also a good idea. Talk to the psycho-social staff at the QHC or Graham at HFQ who may be able to help you find the support you need.

Do men with haemophilia consult their GP's?

Olivia (previous RN at the RBWH Haemophilia Centre) and Beryl our current CNC have recently had a letter published in the Haemophilia Journal about their study of Queensland men with haemophilia and their level of engagement with GP's for health checks.

In their letter they say that as the life expectancy of men with haemophilia increases, the challenges posed by ageing means that we need to work with our GP's for the prevention & management of age-related comorbidities. Olivia's study surveyed men in Qld with haemophilia to ask if they see a GP to discuss health promotion and illness prevention.

The study looked to see if there might be a negative impact on accessing GP's because of the lifelong and comprehensive clinical management offered by QHC, or any other barriers unique to people with bleeding disorders such as any concerns among men with haemophilia, that GP's may not understand the clinical complexities of their bleeding disorders.

106 men living in Queensland of differing ages, work status, residential location and severity of haemophilia did the survey. 66% had seen a GP in the last 6 months and only 10.4% did not have a GP or relied solely on the QHC. 72.6% always went to the same GP clinic and the majority saw the same doctor all or most of the time.

Awareness of preventative screening was reasonably high, with over 66% indicating they were aware of health checks for men. However, only one in three men in the survey went to their GP specifically for a recommended health check. Of those who did so; blood pressure was the most frequent health check, followed by blood tests for cholesterol level and skin checks for moles.

About half the respondents had a conversation about physical activity or the warning signs for prostate cancer and other health matters our members talked to their GP about included flu shots, mental health and relaxation or sleep patterns. Among the men surveyed who drank alcohol or smoked about half had discussed their drinking habits or strategies to quit smoking.

Most participants said they received the help they asked for and two thirds felt their GP usually understood their haemophilia. However one quarter of respondents were still concerned about their GPs' knowledge of haemophilia. Participants also described barriers associated with time and access on their part and also because of the time limited nature of the GP consultations.

Conversely those men who felt their GP expressed a genuine interest in them as a person; was mindful of haemophilia; and who communicated with staff at the HTC when needed, were much more likely to acknowledge the benefits of having a GP as part of their care services and this encouraged or helped them access their GP.

In summary; Olivia and Beryl's study found that men with haemophilia in Queensland are able to navigate between GP's and hospitals and don't need to rely solely on the QHC team. Many do visit a GP for health advice and treatment, and one in three accesses a GP specifically for men's health checks. However with only one in three men visiting their GP to access recommended health checks we could do better.

So, if next time you have a QHC appointment and one of the team has a general health discussion or encourages you to see a GP to meet your other health care needs, don't be dismissive. Consider how you can encourage your GP to improve their understanding of haemophilia and their communication with the QHC. By using a GP you can also help increase the knowledge of haemophilia among non-specialist clinical professionals in the Queensland health sector.

The QHC staff may be able to help you address any concerns you may have in accessing a suitable GP as many of these concerns are not unique to haemophilia and the hospital system has processes in place to help you find a GP who can then look after those non bleeding disorder health matters we all face across our lifetime.

The article discussed here; "Haemophilia and age-related comorbidities: do men with haemophilia consult a general practitioner for men's preventative health checks?" will be published in the next issue of Haemophilia Journal as a Letter to the Editor.

Making It At Work

Whether just starting the job hunt, or having worked a while, young adults with bleeding disorders need to know their rights in the workplace and consider how they might disclose their condition, if at all, to their employer.

Workplace accommodations

As part of Australian legislation (Fair Work Act), all people are entitled to reasonable adjustments in the work place or their job role so you can work.

Common modifications include physical changes, such as installing a ramp or modifying a workspace or restroom, and being given time off for treatment.

Your employer is required by law to do the relevant modifications and changes to a job role for you; but not all will; and when do you tell them you need this help; and might it loose you a job even if the law says it can't?

Different needs for different workplaces

Some of our members who are now in their late 20's or 30's have had different experiences and responses to requests for help. These have been across jobs ranging from office work to more physically demanding tasks.

You may not consider your haemophilia diagnosis relevant if you are applying for jobs that are office based. In contrast to the sedentary nature of that type of work, if you have a passion for jobs that require physical labour (even delivering pizza), it may impact on your health and on your employer.

Understanding the additional stress on your joints that any job can have is important. This can also occur in sedentary jobs so if you are putting your body under stress that could cause bleeds you need to consider disclosing your condition to your employer and adjusting your work place to avoid it happening.
You also need to diligently follow your treatment regimen and takes breaks to rest or self-infuse if you need to. James, one of our members says that if he starts feeling pain or has reached his limit, he tries not to do anything too strenuous.

With one job he's even infused himself in the car between appointments. James schedule at the time allowed him to head home or self-infuse at the start of a bleed, but some jobs simply don't allow for that flexibility.

Mike worked at a restaurant that was on two levels & he asked if it was possible to work on one level to avoid multiple trips up and down a set of stairs. His boss ignored his request and one day, after working a shift in the upstairs section, he experienced back and stomach pain so severe that he admitted herself to the hospital emergency department, where he was then hospitalised for three days because of a spontaneous stomach bleed.

Sometimes not taking a job is better for your health and wellbeing. At work it is important to prioritise your personal and medical needs first. If your employer can't understand that your bleeding disorder is a hidden health issue that needs to be addressed so you can successfully work, you may need to decide if the job is right for you!

Investing time in educating somebody is a lot to take on and sometimes it can be unnerving to share this information at work. If you already have a job it is sometimes best to find one person at who is high enough up in the company to make decisions that can help you and your health needs.

Negotiating workplace conditions

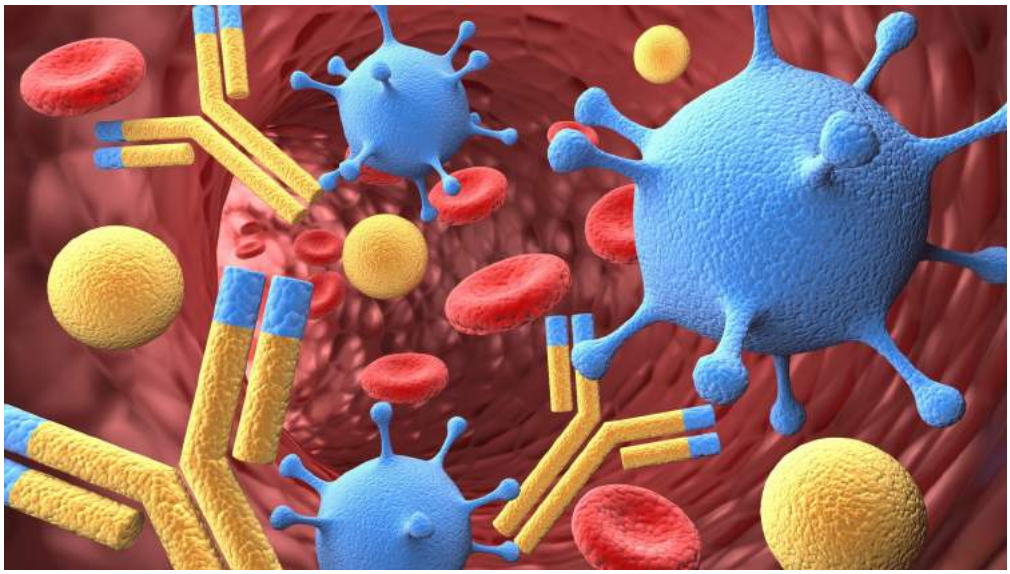
To be eligible for suitable workplace adjustments you will need to disclose your condition or disorder to your employer.

They are not allowed to discriminate against you because of your condition, but choosing when to tell is very important if you want to maximise the chance of getting that dream job.

One way to approach the issue is to wait till you're offered the job and then raise it with your new employer, but from their perspective. If you are effectively managing your condition, tell them it's impact will be small. You can show them that you want to make their business work and that any changes you negotiate will help you to help them by performing at your best. Approaching people the right way will encourage them to be accommodating of your needs.

Although these conversations may feel awkward and uncomfortable at first, they're critical. It can be hard to identify yourself as having a so-called "disability' if you are effectively managing your condition, but if you have a bleeding disorder, you will always need to advocate for yourself, so why not do it from the start of your employment.

Inhibitor Concerns continue



which products a person should be treated with - and in this case, what is best practice treatment for babies and children having their first and ongoing treatments.

The best practice is to talk to your treating haematologist at the Qld Haemophilia Centre for a discussion about how the current evidence is playing out, what else is known about inhibitor development, and therefore what treatment the doctor thinks is best for the child.

There is a bit of activity on the web (including reporting on the world federation site) about the SIPPET study results which been discussed in previous editions of the H Factor. While we are waiting to get an official reaction / comment, some members continue to expressed their concerns.

The first caveat you need to know is that the 'T' in the Sippet study is very specific, it refers to 'Toddlers'. So unfortunately it's too late if you a already on treatments or are no longer a child. The second is that in Queensland the haemophilia centre looks at each new baby individually and determines the best treatment options based on that child's needs and genetic history.

So while some members have said that if it was their previously untreated child they would be wanting blood derived product initially, we have to be very careful of study results and approach results with a critical eye to ensure the study is not misleading. The best person to help you with this is your haematologist.

The SIPPET study (Peyvandi et al, 26 May NEJM) suggests the risk for previously untreated patients (PUPS) – babies/ children developing an inhibitor is higher with recombinant FVIII (rFVIII) than with plasma derived FVIII (pdFVIII) containing von Willebrand Factor (vWF).

In a 2014 publication (Collins et al in Blood 2014-07-580498) of a UK study, Kogenate FS was associated with a higher inhibitor incidence than Advate in PUPs with severe haemophilia A.

These followed the 2013 RODIN study results which suggested there was no difference in inhibitor development whether patients were treated with pdFVIII or full length rFVIII (Kogenate FS); that the content of vWF in the pdFVIII did not influence inhibitor development; nor did switching from a pdVIII to full length rFVIII. Some experts had thought these issues came into play with inhibitor development.

Haemophilia Foundations do not have the expertise to provide technical advice about the content of treatment products, how they work in a person's body or whether they cause inhibitors. We cannot provide clinical advice or advice about

FYI, due to the most recent NBA tenders Kogenate FS is no longer available in Australia. This decision was made for commercial reasons , rather than safety or efficacy – Kogenate FS has generally been known to have a long history of safe use in Australia and globally.

The pdVIII available in Australia , Biostate, contains vWF.

The two available rFVIII products in Australia are Advate (full length – Baxalta/now Shire), and XYNTHA (B domain deleted, Pfizer).

For those that want to do their own research the link to the WFH statement on the SIPPET study is:

http://www.hemophiliaworld.org/2016/06/wfh-statement-on-sippet-study-results/

Other useful links are;
https://www.allaboutbleeding.com/documents/Kessler_Iorio_Haemophilia_2013.pdf

and;
http://www.wfh.org/en/our-work/treatment-safety/recombinant-fviii-risk-of-inhibitor-dev

Health Updates

Patients Warned About Risk From Antacids With Aspirin

The US Food and Drug Administration (FDA) is warning patients about the risk for serious bleeding that comes with over-the-counter (OTC), aspirin-containing antacids for heartburn, acid indigestion, and sour or upset stomach.

It's not new as in 2009, the FDA added the risk for serious bleeding to the labels of all OTC products, including antacids, that contain aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs). However, the agency says that it has received reports of eight serious bleeding events associated with aspirin-containing antacids since 2009. In each case, the patient landed in the hospital.

Serious bleeding is more likely for patients who

- Are older than 60 years of age;
- Have a history of stomach ulcers or bleeding problems;
- Take an anticoagulant or steroid medicine;
- Take another drug containing an NSAID; or
- Drink three or more alcoholic beverages each day.

Consumers considering an OTC antacid should study the label to see whether it contains aspirin. There are OTC products without aspirin that also can relieve their stomach problems, the agency noted.
http://www.medscape.com/viewarticle/864351?nlid=106338_1842&src=WNL_mdplsfeat_160614_mscpedit_wir&uac=246920ER&spon=17&impID=1127094&faf=1

Subcutaneous Factor Therapy

Treatment for severe haemophilia is by way of regular prophylactic and episodic intravenous infusion of factor done intraveniously. However, these treatments are burdensome, especially for children, and may lead to the formation of inhibitors.

A recent Japanese study trailed Emicizumab (ACE910), a humanized bispecific antibody mimicking the cofactor function of factor VIII, to abate these problems.

18 patients with severe haemophilia A received subcutaneous (into the skin) injections weekly for 12 weeks. There were no serious adverse events, nor clinically relevant coagulation abnormalities. Plasma concentrations of emicizumab increased in a dose-dependent manner. The median annualized bleeding rates decreased from between 15 and 32 to between none and 5. There was no bleeding in 73% (8) of patients with inhibitors and in 71% of patients without inhibitors. Episodic use of clotting factors to control bleeding was reduced. Inhibitors did not develop.

Once-weekly subcutaneous administration of emicizumab markedly decreased the bleeding rate in patients who had haemophilia A with or without factor VIII inhibitors.
ORIGINAL ARTICLE: Factor VIII–Mimetic Function of Humanized Bispecific Antibody in Hemophilia A. May 26, 2016
N Engl J Med 2016; 374:2044-2053

A Recombinant VWD Product

In December 2015, the US Food and Drug Administration (FDA) approved a recombinant von Willebrand factor (VWF) product for patients with VWD. The drug company Baxalta won the honour with it's debut product Vonvendi®

Prior to Vonvendi's approval, patients with VWD had basically two treatment choices: a nasal spray or a plasma-derived factor product -combining VWF and factor VIII (FVIII). Now they will have the option of treating with this VWF only product when necessary. Vonvendi is approved for on-demand treatment and control of bleeding episodes in adults 18 and older.

In the phase III clinical trial of Vonvendi, 81.8% of bleeds were resolved with one infusion. The therapy's mean half-life was 21.9 hours. There were no serious adverse effects, but 2% of the subjects experienced itching. None of the participants developed an inhibitor. Baxalta expects Vonvendi to be available in the US later in 2016.
http://www.hemaware.org/story/first-recombinant-vwd-product-two-other-drugs-approved

Haemophilia B gene therapy data keeps coming

Netherlands-based uniQure has released preliminary data from phase 1 of a trial of its haemophilia B gene therapy AMT-060. A single low dose infusion of AMT-060 improved the haemophilia phenotype of all five study patients.

After six months, the haemophilia phenotypes of the patients, which were classed as "severe" or "moderate-severe", had all improved. Three of the participants had a mild phenotype, while the other two were classed as moderate.

While AMT-060 delivered across-the-board improvements in phenotype and FIX activity, and freed all but one of the patients from the burden of prophylactic infusions, the question of whether it will be good enough for the product to succeed is unanswered.

We just don't know which of the handful of haemophilia gene therapy and editing programs will win out. In theory, higher FIX activity levels could reduce spontaneous bleeds and the need for on-demand FIX use.

Data from the second part of the Phase I/II trial will be released later this year, in which it administered a dose four times higher than that given in the first stage of the study to five patients, raising the possibility that data on it will eradicate the efficacy questions that cropped up with this initial data.
http://www.fiercebiotech.com/biotech/uniqure-slides-toward-historic-lows-after-its-hemb-gene-therapy-goes-up-against-spark

Important Dates for HFQ Members

OBE Lunch Forum An informal support group for men living with a bleeding disorder. Meets in SE Queensland on the first Wednesday of each month.

Youth Event 24 July Treasure Hunt & 10 Pin Bowling. Murarrie Recreational Ground

Dad's Brunch 28 August at Cafe 63. Stanley Street, South Brisbane

Regional Meetings HFQ host local meetings as required, please ask if one is happening during the next centre visit.

Haemophilia Awareness Week & Red Cake Day 11 – 17 October 2016

Youth Camp 28 - 30 October Emu Gully, Hildon Spa

Community Camp Easter Weekend 14 - 16 April 2017

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

Youth Events

Our October HFQ youth camp sometimes leaves other family members behind, so this event is for everyone!

If you're not a teenager yet, you can join us for the treasure hunt in the morning at Murarrie Recreation Ground. The treasure hunt will meander it's way through the park and along the river, eventually ending up at the AMF Bowling centre for lunch.

If you can't make 11 O'Clock for the treasure hunt, you could start with lunch (about 12.30pm) at AFM Bowling and then stay on for a couple of games in the afternoon (starting at 1.30pm).

If your really time poor, just come for lunch (or you can do any other part of the days activities that works for you)!

Please let us know if your coming and for what part of the day as we have to organise prizes for the two activities and we need to let the AMF people know numbers for lunch and for people staying on to go 10 pin bowling in the afternoon.

The day is $10.00 per person up to a maximum of $30 for each family grouping although donations to cover the total costs are also welcome as we can put that towards people who need support in attending.

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.

Graham Norton
HFQ Manager & The 'H' Factor editor
Ph: (07) 3017 1778 E: info@hfq.org.au