the H FACTOR

Haemophilia Foundation Queensland

AUTUMN EDITION

Issue 74

MARCH 2023

HFQ MEMBER MAGAZINE

FROM THE PRESIDENT

Hello everyone,

I hope you are all well. This edition I wanted to bring to your attention the topic of **'medical grade footwear'** and how this can have significant benefit for those with damaged joints.

Everyone's bleeding journey is different for many reasons but for those with damaged joints I generally see standard footwear used – where people put up with the pain from bleeds or arthritis, and accept the mobility limitations this imposes. There is a much better way to approach this situation – where the lower limbs are all considered in a holistic way to design modern medical grade footwear that can allow you to stand longer, walk further, reduce pain, bleeds and arthritis.

Regardless of the damage, the odd angles feet or knees etc. can end up with …. utilising pedorthic clinical services to assess your individual situation can really deliver amazing results. My journey in this picture has seen me using private, public and hospital pedorthic services over many years - where they have provided basic orthotics and shoe build ups to cater for ankles that hardly move. However most of these services have not approached this from an innovative, or whole body perspective, where other joints are also involved in mobility. For me it was really about finding a specialist in the area that really understands the 'medical technical practical mechanics' of how individuals mobilise and can then apply innovative design to deliver a solution which improves mobility – hence improving quality of life, independence and so on.

Adam from 'Technical Orthotics' who I met mid 2022 impressed me with his experience, understanding and innovative approach that no one else over the many years had done. I now have shoes that have reduced bleeds, allow me to stand longer, reduced arthritic pain … simply amazing, and he takes the time and effort to make them look as normal / modern as possible. So if this is you – someone who just has accepted and put up with limitations for years – check him out.

As a rule I don't recommend individual services but I know this could be of significant benefit to many in the bleeding community (http://technicalorthotics.com/)

Until next time…

Dave

David Stephenson
President HFQ

Inside this Issue:

ABOUT HFQ

Haemophilia Foundation Queensland Inc. (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation receives a grant from Qld Health and employs a part time manager and an administration officer. It is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via email (info@hfq.org.au) or post at PO Box 122 Fortitude Valley, Qld 4006

HFQ provides financial members with support and benefits, including subsidies on:

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

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Robert Weatherall
Secretary	... ...	Mr Tony Ciottariello
Treasurer	... ...	Mr Adam Lish
Members	... ...	Mrs Belinda Waddell
		Mr Charles Eddy
		Dr Jodie Caris
		Mrs Leanne Stephenson
		Ms Shannon Gracey
		Mr Shannon Wandmaker

HFQ Delegate to HFA

Acknowledgements

HFQ is grateful for the support of our patron: Her Excellency the Honourable Dr Jeannette Young AC PSM Governor of Queensland.

HFQ programs and services are funded by the Queensland Government.

HFQ is also grateful for the support it has received from the Prescott Family Foundation.

Internet

Find us on the web at *www.hfq.org.au* or at our Facebook page at *www.facebook.com/HFQLD*

QLD HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist
Dr Nathan Morgan – Haemophilia Fellow
Joanna McCosker – Nurse Practitioner
Tamara Shannen / Salena Griffin – Clinical Nurse
Claire Bennett (Mon, Tues, Wed) - Physiotherapist
Elise Mosey (Thur, Fri) – Physiotherapist
Tiara Tan - Psychologist (Mon 1/2 day, Wed, Thurs)
Lara Nicholson—Social Worker (Mon, Tues, Wed)

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

For all non-clinical/non-urgent enquires please email QCH-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 QCH-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 3c outpatients Level 3, Thursday afternoons 1.00 – 3.30pm

Haemophilia Carrier Clinic – as needed Thursdays 1pm – 3.30pm

ADULT CLINIC

ADULT CLINIC STAFF (RBWH)

Switch: 07-3646 8111

Dr Jane Mason - Haematologist	*On Maternity Leave*
Dr Sally Campbell - Haematologist	3646-8111
	(Page Dr's through switch)
Haemophilia Registrar	3646-8111
	(ask to page Haemophilia Registrar on 42177)
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Liam Ball - Physiotherapist	3646-8135
Vacant - Senior Social Worker	

Contacting the Clinic Please telephone in the first instance. Appointments 3646-7752 or 3646-7751

For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

Haemophilia and Genetic Clinic — Dr Jane Mason — Wednesdays 1.30pm New Patients Thursdays 8 - 9.30am

Haemophilia/Orthopaedic Clinic — Dr Jane Mason and Dr Brett Halliday — 9am every four weeks

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base Hospital & Townsville Hospitals: For queries email *CHQ-Haemaphilia@health.qld.gov.au* at QCH

What's On?

MAKE IT YOUR EVENT

April - June 2023

Some of the HFQ programs and activities already planned

Please call the office for other events, more information or to RSVP

APRIL

OBE's Monthly Lunch
Wednesday 5th April
Breakfast Creek Hotel

Youth Adventure Day
Sunday 15th April
Riverlife Kangaroo Point

HFQ Board Meeting
Tuesday 18th April

World Haemophilia Day
Monday 17th April
Light It Up Red, Various locations

MAY

OBE's Monthly Lunch
Wednesday 3rd May
Old Fernvale Bakery

Women's Day Spa
Saturday 6th May
Austhetics Skin & Beauty

HFQ Board Meeting
Tuesday 16th May

JUNE

OBE's Monthly Lunch
Sunday 4 June
Fox & Hound Country Inn,
Wongawallen

Men's Health Week
12th—18th June

HFQ Board Meeting
Tuesday 20th June

COMMUNITY FUNDING

To assist members to attend the HFQ board will be making a determination of levels of support available for members to get to Melbourne for the conference. HFA has also allocated funding to assist community members with expenses to attend the Conference. So check back with us in the next issue for what financial support will be available. For details and an application form for part HFA funding go to www.haemophilia.org.au/conferences or call HFA on 1800 807 173 for a form to be emailed or posted.

Celebrating 30 years of service...

Ask anyone who has been through the peadiatric haemophilia services in the last 30 years, and I can guarantee the name Jo McCosker not only rings a bell, but brings back fond memories of a nurse who made the often traumatic and upsetting hospital stays just that little bit better.

This year marks thirty years of service as a nurse, most of that spent within the haemophilia service so we thought it only fitting that we pay tribute to the woman who has spent the majority of her adult life caring for the children of our community.

There isn't a time in her life when Jo can remember wanting to be anything other than a nurse. Even as a young child, she was always caring for things whether they be animal, people or her dolls.

Born and raised in Brisbane, she used to call it the 'Tomato Hospital' until she was in her twenties when someone finally corrected her and explained it was, in fact, the 'Mater Hospital'. This is just one of many funny stories Jo shared with us, which she said will come of no surprise to anyone who knows her.

Outside of work, she loves swimming, bush walking, yoga and meditation. She spends her time with her two children and granddaughter as well as her 6 year old staffy. When she's not holidaying in Bali of course!

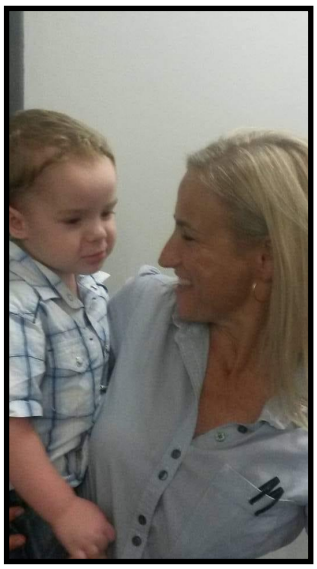
When asked what the highlights of her nursing career so far had been, it was hard to narrow it down, but the two that stood out are pretty impressive, to say the least.

Jo completed her Nurse Practitioner in 2017 and said walking across the stage with her Masters and her hat on was an absolute highlight and one of her proudest achievements.

She loves being independent so being able to complete a episode of care from admission to the ED or clinic, the assessment and the diagnosis to the treatment plan and the prescribing of treatment all the way to the letter to your doctor and any additional referrals, means she is able to be there through every step of the journey.

The start of the haemophilia service back in 2001 was a career defining moment for all involved and Jo was right there at the forefront.

" I was there in the beginning in 2001 when they were created and it has grown. I was reflecting on that this morning and we used to have a couple of patients and I would pack their supplies for them out of the old Banksia Ward at the Royal Children's Hospital and now we have this massive community and the whole hospital to deal with and it's changed dramatically. But I am very proud of the haemophilia service we have. " She said when asked about stand out points in her career.



Nurse Practitioner Jo McCosker

As you can imagine, after thirty years in the industry, Jo has seen some huge changes in the haemophilia space. When asked what the biggest changes were, she said;

"Wow! So many!

From the start of the Haemophilia Treatment Centre to prophylaxis for everybody, home delivery [of treatment], specialised clinics.

Hemlibra, that has been one of the single most defining moments in my career working in haemophilia. We've had 3-4 new diagnoses in the last few weeks. Prior to that, it would have been ports and admissions and lengthy stays and lots of training. And now, I don't feel so stressed about a diagnosis and I hope the families don't as well because, for Haemophilia A, you can just get them onto Hemlibra as early as you can. Watching the children and the families that I don't have that kind of relationship with because you don't see them all the time. These kids get to be kids and the parents get to have less worry, or I hope less worry. That has just changed the landscape and as a nurse who has to deal with that stress and trauma [of a child admitted for a bleed] it is amazing. "

Jo has been the pillar of strength, and a constant support for many families facing down a new haemophilia diagnosis.
So what advice would she give to parents of a newly diagnosed child?

"That haemophilia is manageable. It has treatment. Their children will grow up to be old and grey like any other child. ***It's going to be okay.*** *You are surrounded by a team who are here to support you, you just have to pick the phone up. "*

You might be wondering how Jo ended up in the haemophilia field and she credits that to one of her biggest influences in her career to date; Dr Linda Ewing. She was working in Oncology when Dr Ewing started a Graduate Diploma in Haematology/Oncology, which Jo completed and discovered haemophilia and knew, from that point forward, that was where she was meant to be.

She credits many of the doctors she has worked with over the years for helping to shape and mould her into the Nurse Practitioner she is today, such as Dr Simon Brown and Dr Bill McWhirter.

Jo has been passionate about helping young girls and women who are carriers and this is something that she was focussed on during her NP studies. She felt they didn't have enough of a voice so the carrier clinics were born and became a bit of a pet project for her. These have been growing steadily over the last few years and she is passionate about getting young girls who are potential carriers to not only get their factor levels tested but to be educated around what a diagnosis of carrier means for them and their futures.

I'm sure many patients, past and present, share the view that Nurse Jo is already basically a superhero to all of us, but if she could possess one super power it would have to be her 'magic wand'. She often remarks that she can't do everything at once, or work everything in the hospital, so it would be very handy to be able to pull out her magic wand.

HOLEY MOLEY - WHAT A DAY!

On Sunday 22nd January 2023, HFQ hosted it's annual Summer Member Function.

This year we decided to try out Holey Moley mini golf at Chermside. Around 30 members of all ages attended and everyone had a blast trying to score a hole-in-one (of which there were a few!), followed by some delicious lunch and great conversations.

An *Update* on Gene Therapy

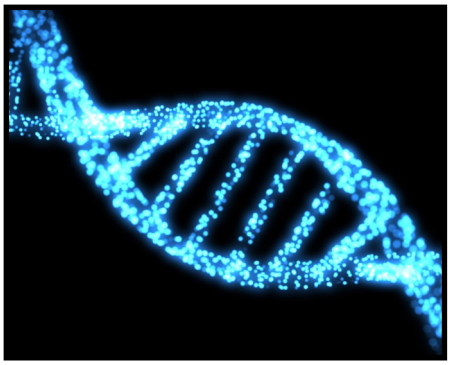
Long-term Data Reinforces SPK-8011 Gene Therapy's Potential for Hem A

One-time treatment with the investigational gene therapy SPK-8011 led to sustained low bleed rates for people with haemophilia A in a Phase 1/2 clinical trial.

That's according to data of up to 5 years of follow-up presented by the therapy's developer, Spark Therapeutics, at the annual meeting of the American Society of Hematology (ASH), which was held in New Orleans last December.

"For many individuals living with haemophilia A, current factor replacement therapies present limitations including the need for regular injections or infusions and unpredictable breakthrough bleeds," Stacey Croteau, MD, study investigator and medical director at Boston Haemophilia Center, said in a press release.

"We are encouraged by these data and the potential for investigational SPK-8011 to further improve on current standards of care by providing a one-time, durable treatment option, and we will continue with participant follow-ups," Croteau said.



SPK-8011 uses viral vector to deliver healthy copy of *F8* gene

Haemophilia A is caused by mutations in the *F8* gene that provides instructions for making the clotting protein factor VIII (FVIII). SPK-8011 is designed to use a viral vector to deliver a healthy copy of this gene to cells in the liver, to trigger the production of functional FVIII.
Data showed that 21 of the 23 patients had an increase in FVIII activity that was sustained as of the latest follow-up, with "no apparent decrease in FVIII activity over time," the researchers reported. The two patients who were the exceptions had experienced an immune reaction against the viral vector used in the gene therapy, as reported previously."

No new safety issues identified

Among the 21 patients with sustained FVIII activity, there was a 92% decrease in the average annual rate of bleeds, which dropped from 11.62 bleeds per year before treatment to 0.98 bleeds per year after gene therapy. Most (76%) of the patients had less than one bleed requiring treatment per year, on average, and 90% had less than one yearly spontaneous bleed requiring treatment.

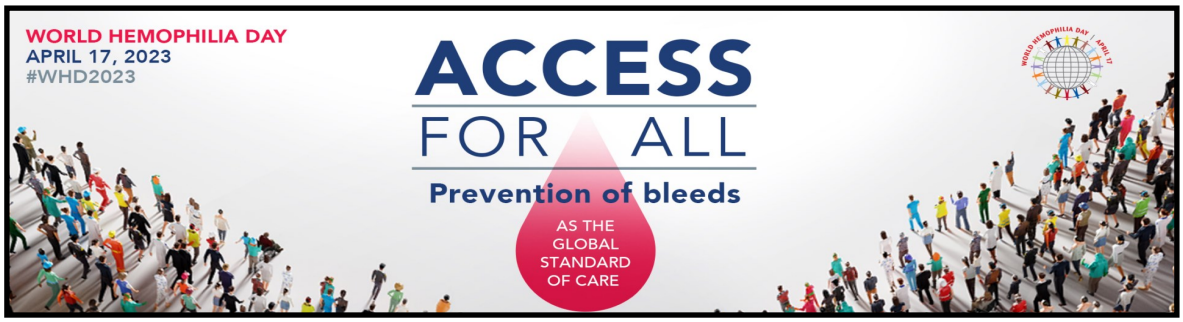
Decreases in bleeding rates were seen regardless of treatment patterns prior to gene therapy. Moreover, after gene therapy, there was a substantial decrease in the use of standard replacement therapies.

An updated safety analysis did not reveal any noteworthy new findings. So far, the only serious side effect related to the therapy was one case of increased liver enzymes, which had been reported previously.

"At Spark, we are focused on developing a gene therapy for people with haemophilia A that demonstrates safety, predictability, efficacy, and durability at the lowest effective dose with an optimal immunomodulatory regimen," Levy said. "This latest readout reinforces the potential for investigational SPK-8011 to deliver on our commitment, and we look forward to its continued evaluation."

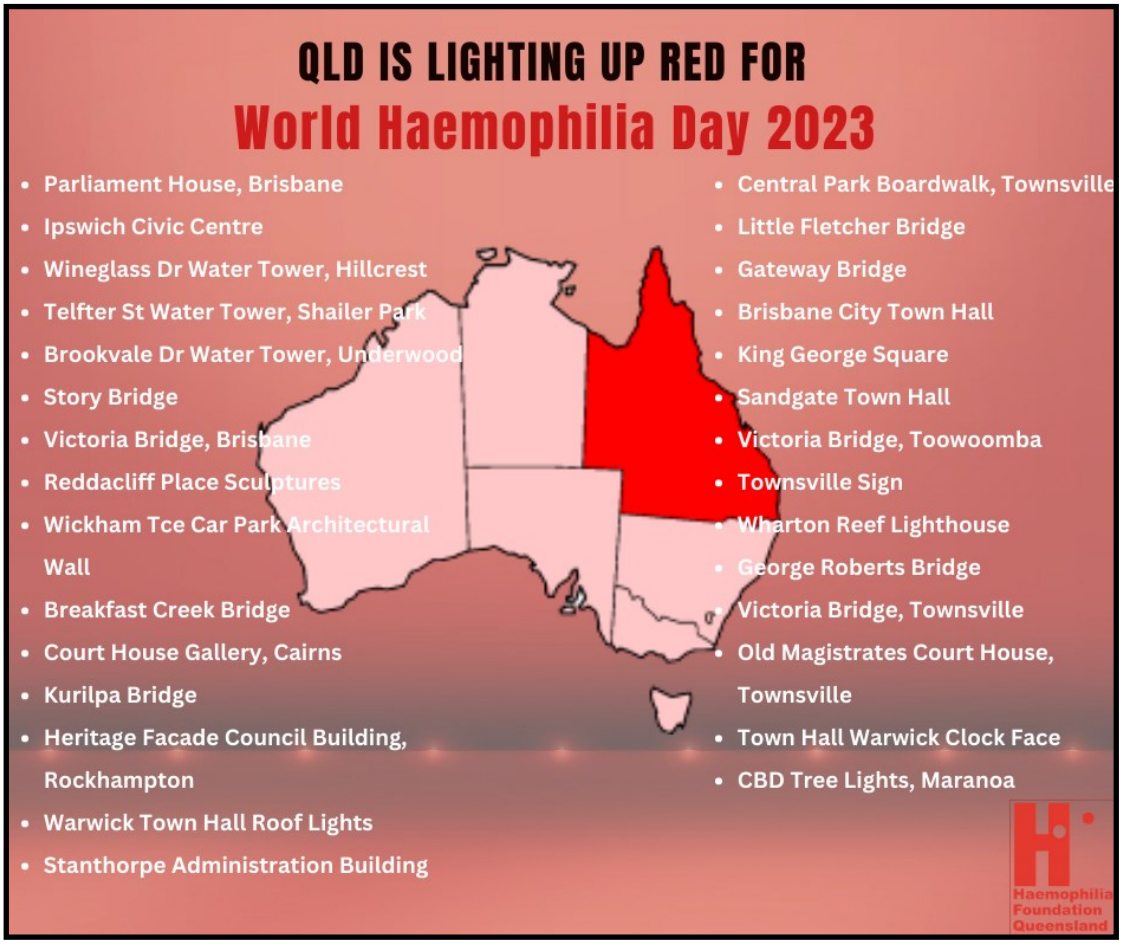
Edited for size from: Long-term Data Reinforce SPK-8011 Gene Therapy's Potential for Hem A | SPK-8011 Gene Therapy for Hem A Leads to Lower Long-term Bleed Rates | Haemophilia News Today

World Haemophilia Day



The theme of the event this year is **"Access for All: Prevention of bleeds as the global standard of care".**

Building on last year's theme, the call to action for the community in 2023 is to come together and advocate with local policy makers and governments for improved access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders (PWBD). This means the implementation of home-based treatment as well as prophylactic treatment to help. Those individuals have a better quality of life.



WHAT CAN YOU DO?

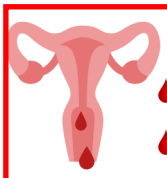
Why not consider hosting a free dress day at your school, a 'red cake' event at your workplace, or even just share your story on social media to help raise awareness of haemophilia and other bleeding disorders. Make sure to tag **#WHD2023**

Women do it differently

One of the most common issues raised by women in our community is the lack of education and awareness around the way carrying the haemophilia gene can affect women. Over the next few issues of H Factor, we will be addressing a few of these to shed some light on this often unspoken area.

Many haemophilia carriers are unaware of their status as there is still a misunderstanding in the community that **' haemophilia only happens to men'.**

However, many women who carry the gene can be affected. This is not always picked up by health care providers as women often present with very different symptoms to their male counterparts. One of the biggest issues women with a bleeding disorder face is menstrual bleeding, however this isn't the only one. *https://www.letstalkperiod.ca* has a fantastic resource that includes the main issues women with a bleeding disorder may encounter.



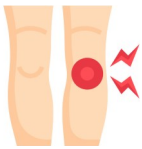
Heavy Menstrual Bleeding

- **Longer than 7 days**
- **Changing protection every 1 –2 hours**
- **Clots larger than a 10c piece**
- **Using 1+ pad/tampon at a time**

Nose bleeds that last longer than 15 minutes.

Prolonged bleeding after dental and surgical procedures

Postpartum haemorrhage



Joint bleeding

Easy bruising

Different women bleed differently

Knowing your factor level is an important step in determining your bleeding risk, but even carriers with *normal factor levels* can have *abnormal symptoms.*

If this sounds like you, you can take the **Self-Administered Bleeding Assessment Tool** (Self-BAT) and see if your bleeding is normal at ***https://letstalkperiod.ca***

As always, seek medical advice from your doctor if you feel your bleeding is abnormal and needs treatment.

Information edited for size and locality from https://letstalkperiod.ca

YOUTH ADVENTURE DAY

Come join us for a fun adventure day out on the Brisbane River.

HFQ is hosting a Youth Adventure Day on Saturday 15th April 2023 at Riverlife, Kangaroo Point.

It will include kayaking down the Brisbane River followed by a gourmet BBQ lunch by the water.

The day is open to all youth **13 to 20 years old**. Parents are welcome to come along and join us for a delicious lunch.

Minimum numbers are required for this event to proceed.

RSVPs are required for catering purposes by no later than 1st April 2023 to the HFQ office on *0419 706 056.*

Easter Competitions

Colouring In Competition

Enter to win a $25 Event Cinemas gift card and a HFQ teddy bear!

Complete the Easter colouring in page and enter by taking a photo and emailing to info@hfq.org.au.

Guess the number of eggs in the jar.

Correctly guess the number of easter eggs in the jar below to win a $25 voucher.

Your guess can be submitted via email to info@hfq.org.au, via our social media post or by texting your name and guess to the HFQ phone 0419 706 056.

Entries close Sunday 9th April

50 Years of Love

Robyn Holloway - wife and partner of long time HFQ board member Mike tells us about her experiences as a partner of someone living with haemophilia.

Interview by Charles Eddy

Tell us a little background about your experiences with bleeding disorders?

I met Mike in the early 70's. I knew there were people with bleeding disorder and even though I was in nursing, I didn't totally understand the full impact. It was all a big learning curve. As the years went on I learned more and more. I met Mike when I was about 19, and we have been together since!

What was your experience like dealing with Mike's bleeding disorder back then?

We were living in Sydney and I remember we used to trot into the Royal Prince Alfred all the time. In those days he used to have cryo-precipitate, and we used to have to wait for the registrar to come and put the needle in. Sometimes you might be there 4-5 hours, other times, you might be there for an hour. Some weeks this might have been every day, or 3-4 days in a row, but then sometimes it could only be once a week or so.

"I was learning everything as we went along, learning about what was needed for people dealing with haemophilia in those days."

How did that affect you? Was it hard to wrap your head around what living with a bleeding disorder was like?

I'm a pretty calm person. It didn't stress me, but I could see that the treatment needed to be done. I think I coped with it well. Having to wait for the treatments was more stressful than thinking that I can't cope with this. I've never ever had that feeling.

Obviously Mike knew a lot about it, but I was learning everything as we went along, learning about what was needed for people dealing with haemophilia in those days. I didn't go in all the time, but when I wasn't working I'd go in. I never felt negative about it.

What are the biggest changes since those experiences? How is life different from then?

Just being able to have the treatment at home and not having to rely on other people, that was a huge turnaround. Knowing that you could actually go away. I think the biggest stress was going away to another town or city because you were going somewhere where nobody understood what was needed to treat somebody with haemophilia.

Treatments are so much better as well, but as you mature, as you get older, you're more aware of what your limitations are and you're a lot more careful. Mike is on hemlibra, but even before, he didn't have as many treatments as some other people may have, just because of his lifestyle. He pushed the boundaries sometimes, but he's always been responsible for his own health, which is a big positive. If he needed treatment, he would do it rather than putting it off.

Knowing your limitations, knowing that Mike isn't silly enough to do something makes a big difference to managing and living in a relationship with someone with haemophilia.

Being a partner & a carer

A lot of people can experience fairly traumatic events living with a bleeding disorder, and these sorts of events can test a relationship. The carers and partners are also going through this traumatic experience, but we often don't think of how this may affect them.

I would never say I don't worry. You worry every day. You think 'I hope nothing traumatic happens'. Mike has had a few near misses. He had a huge issue with his gall bladder that was really traumatic. Even just in everyday living, you could fall, even just a gentle fall, but in the back of your mind you think all the time, 'what if this happens?' You can't continually think like that, you've got to be positive all the time. I don't get up every day and think what's going to happen today. A big worry is identifying what's haemophilia related, as it can mask a lot of other issues.

The biggest thing is we probably don't do a lot of out and about activities. If we go to the beach, Mike will just sit in the car. The biggest drawback is that you can't do everything together. I go and play golf, but Mike can't, so you do tend to do your own things sometimes.

What do you think the future looks like for bleeding disorders? Do you think things are going to continue to change at the rate they have in recent times?

I think the changes with the treatment are a massive positive. Going from having to go to the hospital, to home treatments, to having longer acting treatments, to Hemlibra that is not IV is a big change. I think for young people growing up with bleeding disorders today, they're not going to have to suffer the traumas that the older generation have. Their life is going to continue to improve, and I don't know whether there's a lot things they aren't going to be able to do.

I feel like this is also going to help parents, partners and carers feel more at ease. It's a massive positive for those living with bleeding disorders, but it really helps the whole community.

I think it will stop a lot of that feeling of living on tenterhooks thinking 'Oh what if this happens?' or 'I hope we don't have a bleed today'. I believe today's generation will be listened to more. I remember travelling to northern NSW and Mike had a massive thigh bleed. We went to the hospital in Lismore and the doctors there didn't want to listen to him about getting treatment.

They told him to go home, measure the bleed and if it got any bigger they would treat it. We had driven up from Sydney. Well, we just packed up and drove 8 hours back to Sydney so we could get treatment. If we had have been able to get the treatment 8 hours before that then the bleed wouldn't have lasted as long as it did. Going from there to what we have today it's like chalk and cheese. People are now being more educated about listening to patients. Measuring the bleed was normal procedure back then, but we knew that was not right.

I think moving forward the majority of people should have an amazing life as long as they listen to what needs to be treated at the right time. Even with Hemlibra, we know that if you have a trauma, you still need factor. It's about educating the community and understanding it really well to make it work well for you.

Robyn Holloway

How important are organisations like HFQ? Is our role still an essential one?

If you're someone new to the bleeding disorders community and not had it in your life before, communication with other people is essential. It's great knowing that there is someone there that you can contact in a crisis, or just someone to ring up and say hello to. I think now recognising more that females have bleeding disorders too, it's important for the foundations to be there, just to know you've got someone to talk to with similar issues to you.

I think it's also really important to know where haemophilia was many years ago compared to where it is today.

It hasn't always been as easy as it is today, even though it is still not easy, having a group behind your concerns and needs is essential.

I think it's a really important point you made about acknowledging the history and people's experiences. It's wonderful that we have got these amazing treatments, but it is important that we recognise and acknowledge that if not for the challenging experiences that huge numbers of our community have gone through, things wouldn't be the way they are today.

It's really easy to become complacent, but there could be a time where the treatment may not be as effective and all of a sudden you're dealing with a horrible situation, and you will think that this is what it would have been like. Thankfully you've got the treatment, and you don't want anybody to suffer the way some of these guys have suffered over the years. Mike didn't get proper treatment until he was a teenager, he had a horrible childhood.

We really do need that community. When we would go into the Royal Prince Alfred, it wouldn't just be Mike there, there'd be 4 or 5 other people around a table, all having a chat. It made him feel like he wasn't alone. Having that contact is so important.

Even for the kids now, they might be the only one at their school, but when they go to camp, or go to an event, all of a sudden there's another group of kids that understand their experiences

Any final thoughts, messages or experiences you'd like to share with the community?

I have to mention all the support from Mike's family. They have always been there for us. I am very grateful to them, and I believe it really makes a difference to know that they are they for you.

I have had an amazing life with Mike since the 70's. He's my rock, keeps me grounded and he's an amazing husband, partner and friend. That's life living with someone with a bleeding disorder.

HFQ would like to take this opportunity to thank Robyn for her ongoing support of the foundation, whether it be through awareness raising, attending events or volunteering.

Navigating the NDIS

The National Disability Insurance Scheme (NDIS) aims to give people living with a disability the funding and supports they need to live their best life. But navigating your way around the NDIS is no easy task!

1. Find out if you are eligible.

Eligible participants need to meet certain criteria before they can apply for the NDIS, including:

- You must be 65 years of age or younger
- You must be an Australian Resident
- You must have a permanent disability or require early intervention supports

Find out more about your eligibility by visiting NDIS Eligibility Checklist.

2. If you are eligible, find out more about the NDIS Participant Service Charter

This will help you to better understand what to expect when you deal with the NDIS

3. Be prepared for your initial NDIS meeting

Make a checklist of what you may need to take with you to your first NDIS meeting. This should include:

- Information about your/your child's individual needs
- Information about your/your child's current living arrangements
- Diagnosis reports and assessments
- Questions you may want to ask

4. Take a trusted friend, parent or partner with you to the NDIS meeting for support

If you think you may need help with interpreting or advocating for your needs, don't be shy to take a friend/partner/parent with you for additional support. HFQ also offers advocacy services if needed.

5. Be clear about your needs

When thinking about what support you need try thinking about what you can't do but would like to? Or make a list of where you need to go each week, how you get there, and the support you need in order to get ready to go and when you arrive at the destination. And plan for worst case scenario, not just when everything is running smoothly.

The NDIS asks participants to show that the support they need is both reasonable and necessary. An explanation of these terms is listed below, but it is worthwhile being clear with yourself around what a reasonable and necessary support looks like for you.

6. Understand what your NDIS entitlements/plan

NDIS Support Coordination is funded through your NDIS Plan and can assist you with understanding and implementing supports to assist you to with;

- Understanding your NDIS plan and budget
- How to best manage your plan
- Provide links to other NDIS supported services
- Help you to review your current plan; and
- Provide advice and assistance if your circumstances change

7. Work with a Support Coordinator to prepare for your annual plan review

Every 12 months the NDIS reviews your plan to see if it is still meeting your needs. The is an opportunity to make important changes to your plan if there have been changes in your life, or if there is something you are not happy with.

Understand key words used regularly by the NDIS and what they mean for you

8. Call for more information

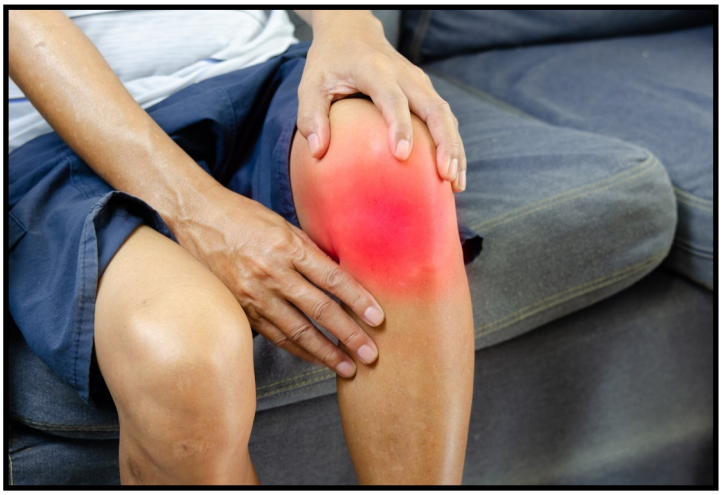
And finally, if you are not sure about anything that you are hearing or reading call the NDIS for more information on 1800 800 110 or talk to your Support Coordinator.

Edited for size from https://www.autismspectrum.org.au/blog/top-tips-for-navigating-the-ndis

Problem Joints Are Associated with Worse Quality of Life and Work-Productivity Loss in Adults with Haemophilia

Problem joints are associated with worse health-related quality of life (HRQoL) and work-productivity loss in adults with haemophilia, according to a study published in *Haemophilia*.

"Recurrent hemarthrosis causes irreversible joint damage in people with haemophilia," the researchers wrote in their report. "In order to address both patient-centric and research-oriented needs for more precision, the 'problem joint' concept was developed and defined as chronic joint pain and/or limited range of movement due to compromised joint integrity."



In the study, the investigators aimed to quantify the humanistic burden of problem joints in people with haemophilia to validate the problem joint outcome measure.

The CHESS II sample included 292 people with haemophilia. Of those, 39% reported >1 problem joints and 61% reported no problem joints. Work-productivity loss data was available for 134 of these individuals.

The CHESS US+ population included 345 people with haemophilia . Of those, 43% reported >1 problem joints, while 57% reported no problem joints. Work-productivity loss data was available for 239 of these individuals.

The researchers found the presence of problem joints was associated with worse HRQoL in both the CHESS II and CHESS US+ populations (*P* <.001 for both).

The team found upper body problem joints were significantly correlated with work -productivity loss in the CHESS II population and >1 problem joints or upper and lower body problem joints were significantly correlated with work-productivity loss in the CHESS US+ population.

"This study has shown that an increase in the number of [problem joints] was associated with an increasing humanistic burden, that is, worse HRQoL and larger work productivity loss, in [people with haemophilia] of all ages, types and severities across Europe and United States," concluded the researchers.

Edited for size from https://www.hematologyadvisor.com/home/topics/bleeding-disorders/haemophilia-problem-joints-worse-quality-life-health-treatment-risk/

The unspoken side of pain management ... Addiction

When talking about the problems of illicit drug use in Australia, conversations will tend to focus on ice, heroin, ecstasy and similar drugs.
But one class of drugs rarely gets a mention, despite the fact that it's now overtaking heroin as the cause of calls to drug treatment services.
Prescription pain-relieving opioids, such as morphine and oxycodone, are fast becoming the top drugs of misuse in Australia.

Prescription rates skyrocket

Opioid prescriptions have increased dramatically in the past two decades. The supply of oxycodone increased from 95.1kg in 1999 to 1270.7kg in 2008, and prescriptions increased 20.1 per cent from 2005-06 to 2006-07 alone.
The picture is the same for morphine. One study reported a 89 per cent increase in the rate of morphine prescription per person between 1995 and 2003.

Emergency medicine specialist Dr David Caldicott from Canberra's Calvary Hospital says there is a clear pattern of overprescribing, and inappropriate prescribing, of opioids in Australia, and some of that is being driven by patients themselves.
"I think there is perhaps an expectation or sense that pain from whatever painful condition can be obliterated, and that may be contributing to the over prescription of these drugs," Caldicott says.

Doctors are also under increasing pressure to dispense quick solutions.
"In an increasingly time-poor medical environment – where to get optimal pain relief you want to sit them down, tell people what exercises to go through, what other non-pharmaceutical tricks they could use to minimise their pain – it is very tempting just to give them a pack of pills and send them on their way," he says.

Edited for size from: https://www.abc.net.au/health/features/stories/2014/11/10/4125167.htm

More harm than good

However in many cases, this pack of pills is likely to do far more harm than good. One particular issue is that it's possible to become tolerant of the effects of these drugs, and therefore require higher and higher doses to achieve the same effects.

Prescription opioids are also featuring more prominently than ever before in the overdose figures, according to Professor Louisa Degenhardt, professor of epidemiology at the National Drug and Alcohol Research Centre at the University of New South Wales.

How useful are these medications?

There are also serious questions about whether opioids such as oxycodone and morphine do actually help in the case of long-term, chronic, non-cancer pain, says pain medicine specialist Professor Milton Cohen from Sydney's St Vincents Hospital.

Chronic pain generally – is still relatively poorly understood and is under-represented in medical education, largely because of its complexity.
"Chronic pain is not a reliable guide to a body disease, so it's hard for medicines to come to grips with."
"When somebody says 'my pain is getting worse', often what they mean is 'my life is getting worse'."
Addiction medicine physician Professor Yvonne Bonomo from St Vincent's Hospital in Melbourne says people may not even realise they are becoming addicted to their opioid pain relief.

"Some are on prescription opioids and don't realise they are becoming dependent, then suddenly their supply runs out and their doctor is not prepared to prescribe anymore, '

"There are guidelines around longer term use now … but really the bottom line is before you start the opioids you have a plan for what other aspects of pain management are going to take place."

Health Updates

Hemlibra Helps Keeps Bleeding Under Control in Babies in HAVEN 7

Preventive treatment with Hemlibra (emicizumab) appears to be safe and helps keep bleeding under control in babies who have severe haemophilia A.

The number of bleeds was "zeroed out" in nearly half of the babies, and most had zero bleeds requiring treatment.

That's according to interim results from HAVEN 7 (NCT04431726), a Phase 3 clinical study testing the benefit of preventive treatment with Hemlibra in infants whose ages ranged from newborn to 1 year.

"These initial results support the benefit of starting Hemlibra from birth given that early preventative treatment is essential in infants," Levi Garraway, MD, PhD, Roche's chief medical officer and head of global product development, said in a press release. Roche owns Genentech, the company that markets Hemlibra.

Hemlibra Safely Keeps Bleeding Under Control in Babies in HAVEN 7 Trial | Interim Data Support Benefit of Starting Hemlibra From Birth for Hem A | Haemophilia News Today

Pfizer announces positive phase 3 results for haemophilia B gene therapy

Pfizer's investigational haemophilia B gene therapy candidate, fidanacogene elaparvovec, has shown promising top-line results in a phase 3 trial of adult male patients with moderately severe to severe haemophilia B.

The BENEGENE-2 study met its primary endpoint of non-inferiority and superiority in the annualised bleeding rate (ABR) of total bleeds after a single intravenous (IV) infusion of fidanacogene elaparvovec versus prophylaxis regimen with factor IX, administered as part of usual care.

The results showed superiority, with a mean ABR for all bleeds of 1.3 for the 12 months from week 12 to month 15 compared to an ABR of 4.43 during the lead-in pre-treatment period of at least six months, demonstrating a 71% reduction in ABR.

https://www.pmlive.com/pharma_news/pfizer_announces_positive_phase_3_results_for_haemophilia_b_gene_therapy_1484893

Misfolding proteins bring caution for gene therapies for haemophilia

US researchers have discovered a link between protein misfolding and liver cancer, that could help improve gene therapy for haemophilia.

Researchers from Sanford Burnham Prebys, US, led by Dr Randal Kaufman, have found misfolded proteins in liver cells contribute to the development of liver cancer also link to haemophilia.

The findings, published in the journal Molecular Therapy, could also help improve the safety of certain gene therapies for haemophilia. Factor VIII is normally manufactured by endothelial cells in the liver. Protein replacement therapy is currently the standard of care for haemophilia A, which works by giving patients FVIII that is produced in the lab using cultured mammalian cells.

https:www.drugtargetreview.com/news/107235/misfolding-profeins-bring-caution-for-gene-therapies-for-haemophilia

Ascension Healthcare Announces Positive Data from Phase 2 Study of SelectAte in Severe Haemophilia A Patients with inhibitors

Results from the study demonstrated that the clotting improvements conferred by PEGLip co-injection with standard half-life FVIII led to an extended dosing interval of, on average, once every 5.2 days for a 30IU/kg dose, compared to the normal prophylactic dosing interval for this FVIII (and similar standard half-life FVIII products), at this dose, of once every other day or 2-4 times a week for long-term prophylaxis. Current extended half-life FVIII products approved by the FDA recommend dosing between 2-3 times weekly or every four to five days but at a higher dose of 45IU/kg (average). These results were achieved in both non-inhibitor patients and also those that were both inhibitor prone and presenting with low levels of inhibitors. Despite the lower dose rate, the number of bleeding episodes was significantly reduced in all three patient groups (non-inhibitor, inhibitor-prone and inhibitor-presenting) over the six-week trial period, compared to the 6 month history preceding the study.

https://www.yahoo.com./entertainment/ascension-healthcare-announces-positive-data

Factor VIII Concentrate With an Extended Half-Life for Patients With Haemophilia A

In a study of patients with haemophilia A (HA) in Thailand, researchers identified improvements in clinical outcomes after patients were switched from a factor VIII (FVIII) concentrate product with a standard half-life (SHL) to a product with an extended half-life (EHL). These and other study findings were recently published in a report in the journal Haemophilia.

Use of EHL FVIII concentrates having a median of 1.3- to 1.6-fold longer half-life, compared with SHL FVIII concentrates, potentially may reduce prophylactic dosing from 3 to 2 times per week, the researchers explained in their report. However, there may be variation among patients in the dose of EHL FVIII concentrate that is needed.

https://www.hematologyadvisor.com/home/topics/bleeding-disorders/treatments-factor-viii-concentrate-extended-half-life-patients-thailand

Important Dates for HFQ Members

OBE's Monthly Lunch
Wednesday 5th April
Breakfast Creek Hotel

Youth Adventure Day
Sunday 15th April
Riverlife Kangaroo Point

World Haemophilia Day
Monday 17th April

OBE's Monthly Lunch
Wednesday 3rd May
Old Fernvale Bakery

Women's Day Spa
Saturday 6th May
Austhetics Skin & Beauty

OBE's Monthly Lunch
Sunday 4th June
Fox & Hound Country Inn, Wongawallen

Want to be featured in our magazine?

We want to make the H Factor more about our wonderful members.

Do you write poetry? Create beautiful artwork? Recently travelled somewhere amazing? Have a fabulous recipe? We would love to celebrate our members in our magazine.

Send it to us at info@hfq.org.au with the subject line 'Magazine Contribution'

About The H' Factor

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