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National Haemophilia

www.haemophilia.org.au

Heavy menstrual bleeding

Managing teens

Bleeding Disorders Awareness Month

What's on in October

Travel

Jack's latest adventures and tips

HAEMOPHILIA FOUNDATION AUSTRALIA

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Cover: Skiing in Canada Photo: Jack (with permission)

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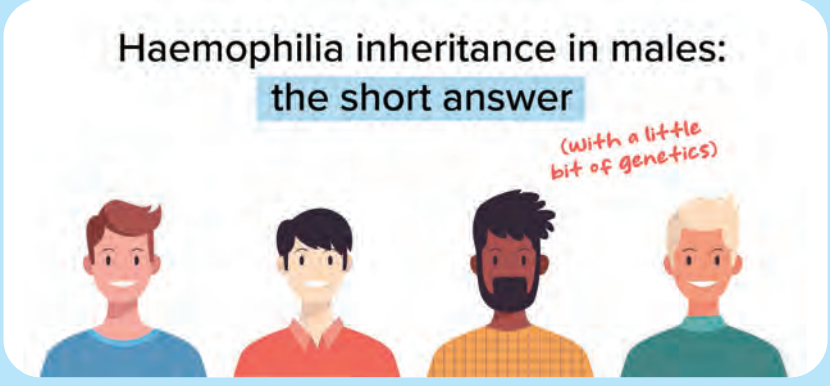
Haemophilia inheritance video

If you were born male and have haemophilia, will your children have haemophilia too?

This is a burning question for a lot of young men with haemophilia but the answer and explanation of why this occurs can be difficult to grasp.

We have created a 2-minute video for teenage males with haemophilia who have questions about how haemophilia is passed on in a family. It covers:

- inheritance patterns for males with haemophilia
- a short and simple explanation of the genetics involved.



Watch the video

- on the HFA website: https://tinyurl.com/haem-inherit-male-video
- on the HFA YouTube channel: https://tinyurl.com/YT-haem-male-inherit-video

We are very grateful to the young people with haemophilia and their parents and the health professional experts who reviewed the video – particularly the Haemophilia Foundation Victoria youth leaders who gave valuable feedback and advice to help with its development.

Gavin Finkelstein

President, Haemophilia Foundation Australia

From the President

As we head towards the end of the year, it's an important reminder to stay connected with your Haemophilia Treatment Centre - and if you have an annual review, have you been booked in for 2024? We as people change all the time, and sometimes your treatment also needs change and adjustment.

BLEEDING DISORDERS AWARENESS MONTH

Bleeding Disorders Awareness Month is coming up in October. This is a time for our community to raise awareness about bleeding disorders – it might be about your experience or sharing the stories of others. I'm always impressed to see the work of kids and their families in these activities – holding stalls or speaking to their class at school about their bleeding disorder and what it means. It's a really effective way to increase understanding in the wider community. With the theme NEW POSSIBILITIES over the month, we will share stories and a lot of information and facts. It's not too late to order promotional materials.

GENE AND EMERGING THERAPIES

We continue to monitor updates about gene therapy in haemophilia and watch the space overseas. Over the coming months we will be producing information and resources on gene and emerging therapies. Gene therapy for haemophilia is currently being evaluated by government, with gene therapy for haemophilia B being the most advanced in the process. Visit our website for information about gene therapy and listen to the webinar recorded in May 2024 with Dr Michiel Coppens.

HFA is working with a highly respected research company CaPPRe on a study about patient treatment preferences in haemophilia. This is important research for our future directions in treatment and we would like to hear what you have to say. We have chosen to undertake this research independently and it has been funded by the Haemophilia Foundation Research Fund. The survey will be launched soon. Keep an eye on your e-news if you wish to participate.

REVIEWING THE YEAR

HFA Council will hold our Annual General Meeting in October and look out for our Annual Report at the end of November, which will show our work and its impact over the last financial year. Most local Foundations will also host their AGMs around this time. If you would like to know dates and get involved, visit your local Foundation website.

Bleeding Disorders Awareness Month

OCTOBER 2024

NEW POSSIBILITIES

Bleeding Disorders Awareness Month is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about bleeding disorders.

Visit the web page!

www.haemophilia.org.au/BDAM

The 2024 theme for Bleeding Disorders Awareness Month is **NEW POSSIBILITIES**.

Throughout the month we'll share personal stories, fast facts and bust some myths about bleeding disorders. There will also be activities and giveaways for kids such as little red cars and nail stickers, colouring in sheets and word finds, events across the country, information sessions, competitions, and more.

The last week of October will be **Red Week**. During the week organise an activity with your family or friends around something red – wear red to school, bake red cupcakes, red hair day – the ideas are endless!!

We will launch our calendar at the end of September. To be advised about events, register for our E-news www.haemophilia.org.au/enews or keep an eye on our website and social media platforms.

PROMOTIONAL ITEMS

Orders for promotional items are now open. These items are free of charge. Order them to use for your school, workplace or family/friend event. We have little red cars, nail stickers, tattoos, balloons, pens, colouring-in sheets, information posters and lots more.

Put your order in at:

www.haemophilia.org.au/BDAMorder

HOW CAN YOU BE PART OF RED WEEK?

- Order promotional items for your event, information stalls and your child's school/childcare
- Run a fundraising event
- Host a Red event, e.g. Red Cake Day, Red Dress Up Day
- Share information on your social platforms
- Hold an information stall in your classroom or at school
- Children and their friends can take part in the colouring-in competition or a Scavenger Hunt
- Take part in HFA and Foundation activities (Calendar coming soon)

For more information

Contact:
T: 03 9885 7800
E: hfaust@haemophilia.org.au

ISTH 2024 Congress: novel therapies

Ashley Fletcher

Ashley Fletcher attending the Congress

At the **ISTH 2024 Congress** in Bangkok, Thailand, some exciting new treatments for haemophilia were highlighted. The treatments use a range of innovative new technologies that target different proteins in the body to prevent bleeding in haemophilia.

One important new treatment is called **Inno8**, a novel VHH-based FVIIIa-mimetic molecule, a new type of medicine for people with severe haemophilia A. It works very well, lasts a long time in the body, and can be taken as a pill once a day. This means people wouldn't need to get injections anymore, making it easier for them to take their medicine. However, it is currently at a very early stage and being tested in Beagle dogs rather than humans, so it may be quite a way off from being available.

But what about treatments that are almost ready? There are several that have finished phase 3 trials, which means they are very close to being available to be evaluated for government funding.

These include:

- **Mim8**: Works like emicizumab but lasts longer and could be available in 2026.
- **Fitusiran:** An RNA interference (RNAi) therapy targeting antithrombin, expected to be ready in 2026.
- **Concizumab**: A monoclonal antibody designed to inhibit tissue factor pathway inhibitor (TFPI), improving clot formation, expected in 2025.
- **Efanesoctocog alpha**: A new recombinant factor VIII with an extended half-life, also expected in 2025.

These treatments are showing promise and could soon help people with haemophilia manage their condition better.

Some other treatments are still being tested in phase 2 or 3 trials, meaning they are not yet ready but look promising for the future. These include:

- **NXT007**: Could be available by 2030. A bispecific antibody that mimics the cofactor function of activated FVIII.
- **SerpinPC**: Might be ready by 2028 and has shown promise in reducing bleeding episodes as it is a protein C inhibitor.
- **Marstacimab**: Another promising treatment, an antibody that blocks a protein called tissue factor pathway inhibitor (TFPI), could be available in 2027.

There was also talk about **SS315**, a novel FVIIIa-mimetic bispecific antibody, as another new medicine that might be available in the future.

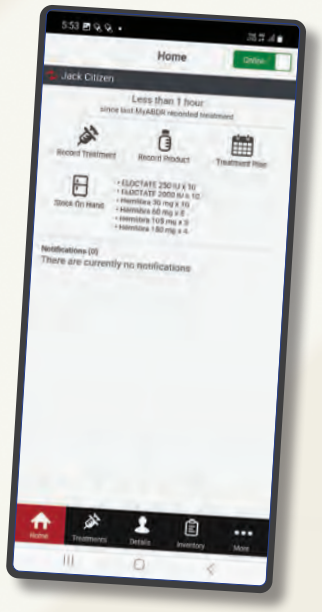
All these new treatments show that haemophilia care is getting better, with more options that might have fewer side effects and make life easier for patients.

The Congress highlighted the need to choose the right treatment based on how safe it is, how often it needs to be taken, and how much it costs. The new oral treatments presented at ISTH 2024 give hope for a better future for people with haemophilia, aiming to make their lives easier and healthier.

Ashley Fletcher is the AHCDO Australian Bleeding Disorders Registry (ABDR) Research Fellow.

MyABDR and recording your treatment

Suzanne O'Callaghan



With new haemophilia treatments now available and more in the pipeline, recording treatment and bleeds in MyABDR is more important than ever. Although people's treatment experience has improved remarkably, the treatments have had unexpected results - ironically being more challenging for remembering to treat and record and managing treatment delivery.

WHAT HAS CHANGED?

For people with haemophilia, the effect of the new treatments generally lasts longer so they don't need treatment infusions as often and are experiencing fewer bleeds. You will have seen recent Congress reports that Haemophilia Treatment Centres (HTCs) are seeing how this impacts on adherence to treatment, for example, patients forgetting when to have their prophylaxis or to record.

HTCs also have to keep track of treatment product orders. Their patients don't require as many vials and in some cases treatment delivery methods have changed, for example, with emicizumab (Hemlibra®), from home delivery to picking it up at the community pharmacy.

WHAT'S THE VALUE OF MYABDR?

The MyABDR app was developed as a tool for patients and parents to enable people with bleeding disorders and their (HTC) to monitor and review their treatment and bleeds. It links directly to the Australian Bleeding Disorders Registry (ABDR), the system used nationally by HTCs for the clinical care of their patients. There is an app for mobile devices and a website version, with graphs and other reports on treatments and bleeds.

What can you do with MyABDR?

- Record treatments and bleeds as they occur – and add notes or upload photos
- Manage stock of treatment product (at your fingertips when you get the call asking what stock you need)
- Share and discuss the information with your HTC
- Have accurate records of your treatments and bleeds to look over anytime and discuss at your review – rather than trying to remember what happened
- Update your contact and personal details.

HTCs use the ABDR to monitor treatment outcomes for their individual patients but at a broader level they are also collecting 'real-world' data to measure the impact of the new treatments across their patient population. The ABDR and MyABDR have highlighted these issues with the new treatments.

HTCs are very aware of the challenges facing their patients.

Julia Ekert, Haemophilia Data/Product Manager at the Royal Children's Hospital Melbourne, suggested that people **use MyABDR functions as a memory prompt.**

'MyABDR works as a really good recording tool to remind you when you need to do your next dose. These days, when you're giving yourself or your child treatment less frequently, it can be hard to remember.

And it helps the HTC to know when your next script is due, if we know what you have at home and where you are up to.'

Participating in research studies is an important way to be part of the development of new treatments. If you are interested in clinical trials, having **a proven track record of treatment recording can work in your favour**, commented Megan Walsh, Clinical Nurse Consultant at the HTC at The Alfred in Melbourne.

'Clinical trials all require accurate record keeping and they usually check the past usage records as well.'

RECORDING TIPS

Everyone has their own preferences for ways of remembering to record stock or treatments in MyABDR – but sometimes it can help to find out what other people do. We asked our HFA MyABDR Focus Group for their tips.

Recording treatments

Many make a practice of **recording their treatment in MyABDR when they have it.**

'The only way I am sure to record the receipt of Hemlibra® or factor and infusions is if I do it on the day.'

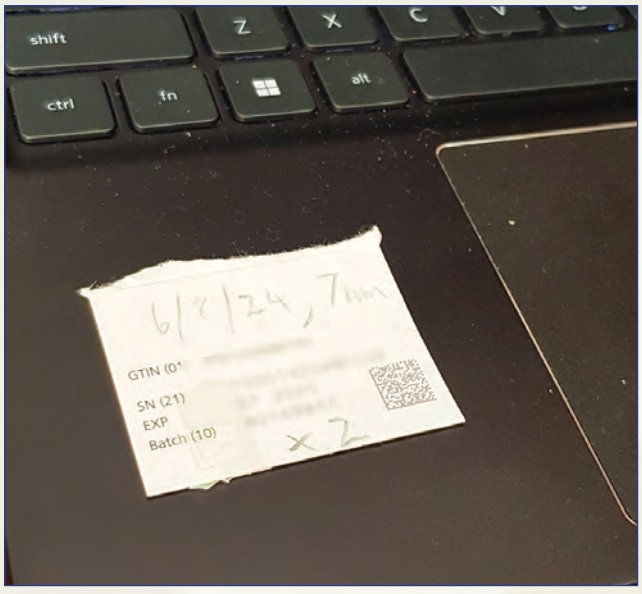
'Get into the habit of bringing your device with you when injecting so it's right there and you don't forget.'

'If I log in to the MyABDR app towards the end of having a routine prophylactic treatment, then the date and time are autofilled. And all other details are clear in my mind.'

'Put the app on your device's front screen so it's always in sight. Even subconsciously you will see it and this helps to remind you to use it.'

'I have my electronic calendar set up with a weekly recurring Hemlibra event on my designated treatment day. Email reminders work better for me than phone notifications.'

What if you are **too busy to record at the time** or it's not convenient?



'I rip the top off one of the boxes, attach a sticker from a vial and write the date on it. Then when I have entered it into MyABDR, I put a line through it. Easiest way to tell if I've put it in the system.'

'I sometimes tear off the panel of the cardboard box that has the batch and expiry. I scribble the 'time and date of use' on it, so that I can make the MyABDR entry later, when I'm not in a rush. I leave it in a prominent place, near my computer or on the bench where I can't miss it.'

'I have old treatment recording sheets onto which I place the stickers from my product vials. I keep the paper record with my treatment kit and fill it out before packing up. Then when I come to enter data into MyABDR, it's all in one place.'

'I use the web version of MyABDR to record my doses and update my inventory. I do this when I am sitting at my laptop catching up on emails. Sometimes I 'snooze' the reminder email, so that it returns to the top of my inbox.'

What about tricks for recording your treatment stock?

'After I collect my Hemlibra from the pharmacy, I take a picture of the whole lot, batch/expiry panels face-up, on my phone. It uploads to the cloud automatically, so the info is available on my laptop when needed. The date is automatically recorded.'

With more long-acting and highly effective treatments in the pipeline, remembering to treat and record is going to be an ongoing issue. Developing easy strategies to manage it will be crucial. Do you have strategies to share? Email Suzanne at HFA with your tips – socallaghan@haemophilia.org.au.

FIND OUT MORE ABOUT MYABDR

including MyABDR support contact details:

www.haemophilia.org.au/myabdr

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Haemophilia gene therapy snapshot survey

Suzanne O'Callaghan

In May-June 2024 HFA conducted a short community survey to ask people affected by haemophilia about what they want from their treatment and their thoughts on gene therapy in particular.

With a range of new and innovative haemophilia treatments becoming available, it is important to understand what people with haemophilia and their parents, partners and family would like to see as outcomes of the treatment. What would result in a better quality of life for them?

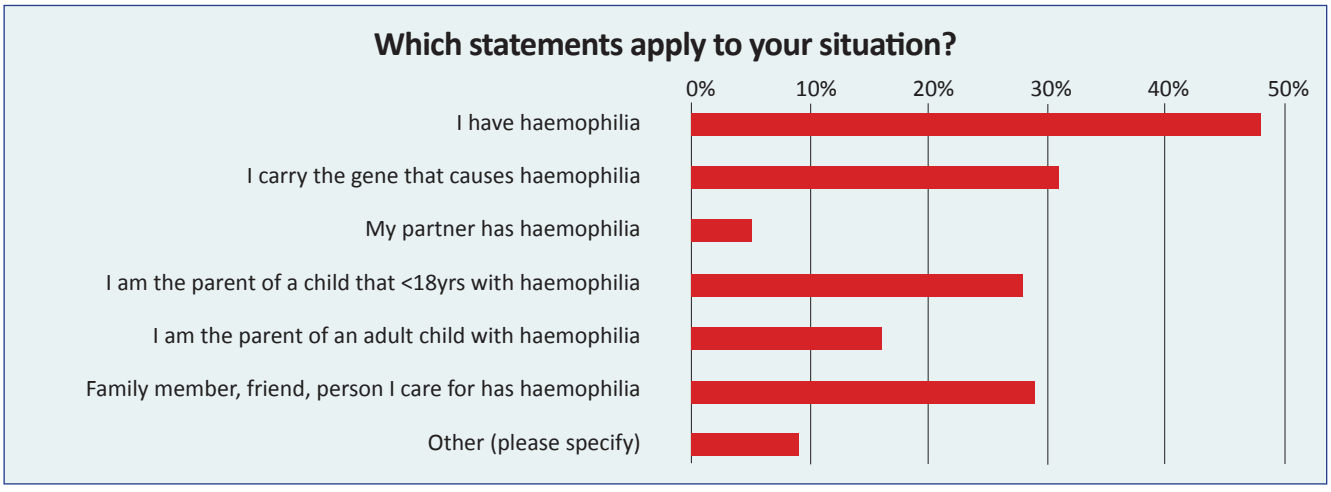
Our thanks to all who participated.

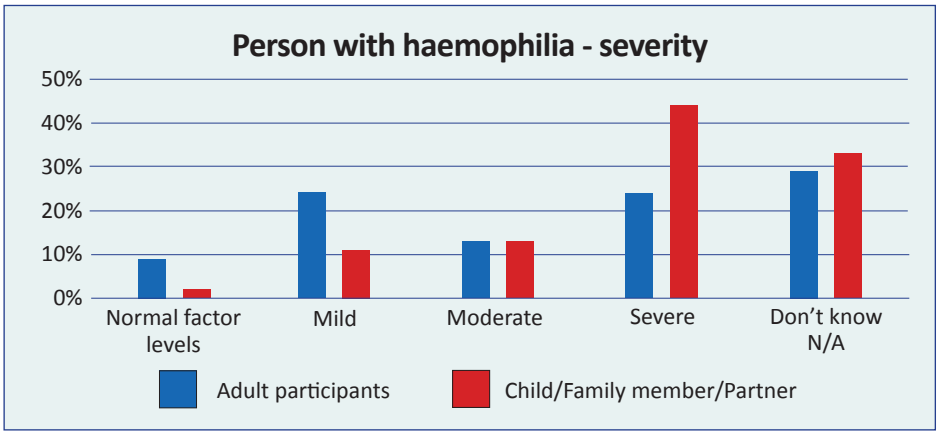
WHO COMPLETED THE SURVEY?

- **45** people (**19** female/**24** male/**2** preferred not to say) completed the survey.
- All age groups from 18 years and over were represented. 53% were 31-54 years old.
- 69% lived in a capital city; 4% in the rural/urban fringe of a capital city; 24% from a regional/rural remote area.

How were they affected by haemophilia?

In many cases both they and their child/family member were affected by haemophilia.





PREFERRED TREATMENT OUTCOMES **NOW**

When asked what they would like haemophilia treatment to achieve for them **NOW**, people completing the survey described both impacts on their quality of life and the way this would be achieved – with treatment and how treatment is delivered and supported.

The most common preferred outcomes were preventing bleeds, avoiding injections/infusions and living a normal life. They often had a realistic appreciation of current gene therapies and their limitations – that gene therapy may not work for all or result in normal factor levels or have an effect that is sustained permanently. Some women and parents of children who are both currently ineligible for gene therapy were hoping for access. Some respondents talked generally about 'better quality of life'.

Treatment outcomes

- Reducing symptoms, preventing bleeds, stable normal factor level
- Easier and less painful administration; no needles/ injections/infusions; oral/tablets
- Longer effect in the body
- Normal life, participating in activities, travel, sport
- Improves impact of complications - arthritis, HIV, work, education, pain
- Not so many hospital visits/stays; quicker recovery
- Cure
- Safety, no inhibitors, no other side effects, eg liver
- Better quality of life
- Happy with current treatment outcomes.

Treatment delivery

- Access to new treatments, including gene therapy
- Easy access to medical advice, testing, multidisciplinary care with bleeds.

'No more needles every two weeks. No more bruising. Less hospital visits'

'As someone with Moderate that only has factor from trauma, approx 1-2 times a year, the ability to not have to go to the hospital for treatment, allowing me to travel and not feel tied down.'

'To fix the gene responsible so my son can undertake normal activities like sport.'

PREFERRED TREATMENT OUTCOMES **IN THE FUTURE**

When asked what they would like their treatment to achieve **IN THE FUTURE**, people responding to the survey had an opportunity to give their wish list and their hope that future gene therapies would be an effective and safe cure. Some were looking for a germline gene therapy that would mean the gene alteration and haemophilia would not be passed onto future children.

Treatment outcomes

- Cure
- No bleeds, normal factor levels, prevent joint damage
- Easier much less frequent administration; no needles/injections/infusions; oral/pills
- Normal healthy longer life, participating in activities, sport
- Safe, no side-effects
- Long-term effectiveness
- Recovery from joint and muscle damage
- Having children safely; not passing haemophilia on to children.

Treatment delivery

- Better resourcing for HTC multidisciplinary care, support, referral, home testing
- Access to gene therapy
- Affordable genetics services to support family planning.

'Longer acting factor replacement. Pill form rather than injection. A gene therapy cure that lasts.'

'To CRISPR it out of my and my children's genetic structure.'

'To be able to play sport like other kids. No more needles. No need to worry about bleeds.'

'Repairing existing joint damage for patients with a history of bleeds. Research into some truly novel approaches (other than joint replacement/fusion) to heal or regenerate.'

'Informed treatment options. Holistic support. Continuity of specialist care.'

Photo: PEXELS/Gustavo

GENE THERAPY – BENEFITS AND CONCERNS

Participants were asked what they thought the main benefits of current gene therapies would be for them or their child/partner/family member. Their focus was on avoiding the frequency of painful treatments and the better quality of life that could result from no bleeds – perhaps being able to live a 'normal' life like people without haemophilia. Some hoped for a cure that would mean permanent normal factor levels and no longer having haemophilia. However, for others this was tempered with the understanding that it may not work for an individual or be a complete cure.

Perceived benefits

- No need for prophylaxis, frequent treatment
- Living a normal life, better quality of life, easier travel, no bleeds
- Cure: no longer having haemophilia
- Single long-acting treatment
- Potentially normal factor levels
- Beneficial if it works
- Preventing joint/muscle damage
- Less anxiety about periods, childbirth

'Single injection/infusion. Get rids of the burden on further injection/infusion.'

'Being "healed" from haemophilia for life.'

'A life without needles and treatment. A more normal way of living.'

'Better outcome for joints and muscles with longer, higher factor level. No more use of medication for a long time hopefully (regeneration for the injection places), no medication on vacations, no problems with these on custom controls and security checks.'

Their most common concerns by far were with safety and efficacy.

Concerns

- Safety, side-effects - known and unknown
- How long the effect will last
- Failure/might not work
- Can't have it again
- Eligibility
- Waiting for more advanced gene therapy
- Cost
- Requirements: no alcohol, contraception
- Requirements: appointments, travel
- Not a complete cure
- Not reversible
- Effect on future children
- Access: regional, rural, remote

'Triggering other health issues by manipulating genes.'

'Will it be difficult to qualify, will it last and what are the side effects.'

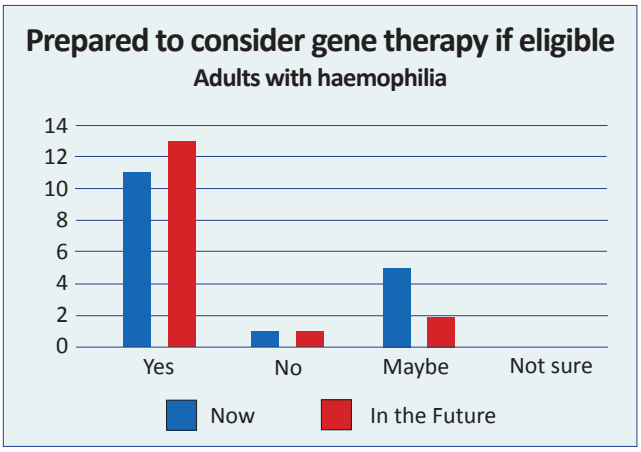
'Seems problematic, potential steroid reliance, no alcohol use, may not work.'

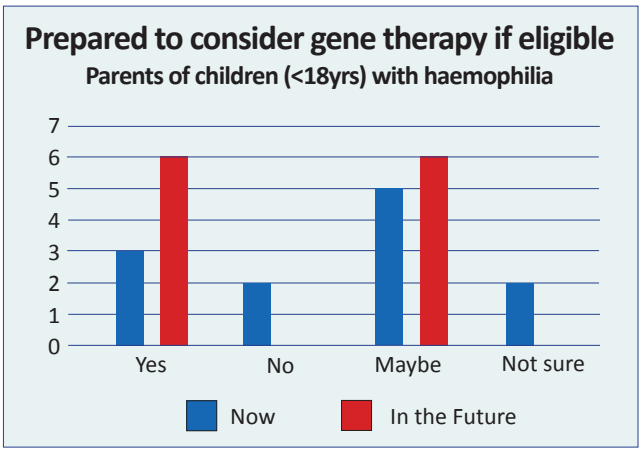
'The first year during treatment with multiple visits to the hospital and potential increased travel costs. Long term data. We are a young couple who would hopefully like to start a family and hence we are navigating when to have children vs when gene therapy becomes available.'

ATTITUDE TO GENE THERAPY

Would they consider having gene therapy now or in the future if they were eligible?

Parents of children were more doubtful than adults with haemophilia, but both assumed that treatment efficacy and safety would have improved in the future.





Adults with haemophilia	Parents of children
GENE THERAPY NOW	
'Having a single treatment is great and Hemlibra does not bring my factor 8 levels to normal.' *'Needs perfecting.'* *'Even a small improvement is better than none.'*	*'Until it's proven to be safe, would not be comfortable with him receiving this therapy.'* *'Not enough research yet and Hemlibra works fine for us atm.'* *'Need to know that it has been tested long term, and has proof of being safe and beneficial to the patient.'*
GENE THERAPY IN THE FUTURE	
'Because it hopefully would increase quality of life as long as the risk to benefit ratio was acceptable.' *'I'd prefer not to have haemophilia.'* *'Once it's reliable, I'd jump at it.'*	*'To cure him.'* *'Hopefully by then it's robust and thoroughly tested.'* *'I think it's a viable treatment at any age to improve outcomes.'*

ACCESS

Final comments from participants underlined their concerns about access and eligibility: making gene therapy available free-of-charge to the patient and enabling access for females and people with lesser severity.

'Access for mild to moderate patients - often with significant morbidity.'

'We need gene therapy to be available to females as well. I have a daughter with severe haemophilia B who is a sufferer just like the males. She has intravenous factor 9 injections just like the boys and has done her entire life. She normally doesn't get offered the same treatment options like gene therapy just because she is female.'

'I think gene therapy will be a wonderful thing. I really hope we are able to get funding for people with haemophilia to be able to access it.'

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Parenting a teenager with a rare bleeding disorder

How is parenting different if your child has a rare bleeding disorder? Elizabeth's daughter Grace has Glanzmann thrombasthenia, a rare hereditary platelet function disorder. Elizabeth spoke to HFA about the strategies her family has developed to manage the risks for a teenage daughter who has unusual bleeding problems.*

Grace has Glanzmann thrombasthenia. *'She has platelets but they don't function properly, so she has a treatment plan of "don't get hurt"!'* explained Elizabeth. While risk management is very important, Grace has a medical treatment plan for her bleeds with a variety of treatment products and a specific treatment plan for her periods that has been worked out with her gynaecologist.

THE CHALLENGES OF RISKS

Grace's diagnosis as a baby was very unexpected and Elizabeth and her husband have developed strategies to manage Grace's bleeding risks over time as she has grown up. Initially it was very challenging: *'we were first time parents and it felt like it was one long learning curve.'*

Now that Grace is a teenager, both she and her parents have a wealth of childhood experiences to draw on and her parents feel it is important to support her in developing independence and taking responsibility for herself – but also to enjoy her life.

'Grace just goes about life and has fun and always assesses her risk for injury.

'Grace is our only daughter. She is a typical teenager. She loves life, she loves fishing and camping and loves being outdoors.'

'So she can go for a run and be careful about it, but she is not going to play footy or even basketball or netball. She goes and finds things that she can do. When she wants to try new things, we try to make it happen.

'But Grace makes all her own decisions now. She covers academic and I cover bleeding until she feels comfortable taking over that. I help her with her appointments and I remind her if I feel some of her decisions about what she's doing is a risk for her health, but she understands what she can do. She has just learned it along the way.'

MANAGING SCHOOL

What is a 'contact sport' for Grace? With a new year starting, Elizabeth thought about what the letter to Grace's new teacher should say and decided to be very direct:

'I said, Grace will let you know if she is able to participate in what you may or may not consider contact sports. But you need to know that when she is sitting out, she needs to be safe too because she always gets hit in the face with a ball, whatever sport she is playing.'

It has been important to work with the school to align what everyone thinks is acceptable. For Grace, this approach has resulted in some strategies that work well for her – to streamline her treatment so she doesn't feel like she is missing out on her classes or feeling like *'the odd kid who is sitting there with an icepack'*.

For example:

- A red flag on her file and emergency plans and strategies in place
- An ice pack in the staff freezer with her name on it
- Quiet places she can go to ice or treat her bleed or injury
- A first aid kit in Grace's bag and a first aid kit for her in the office.

A SUPPORTIVE FRIENDSHIP NETWORK

Accidental injury when children are growing up is inevitable. But having a bleeding disorder can be challenging at school, where there can be children who think it is fun to hurt other children. With Grace they could see a result straight away:

'If they push her over and she skins her knee, she bleeds like a sieve and has an egg.'

'She has amazing friends now who rally around her. When she fell over and she couldn't really walk, they got an ice pack for her and went and got a teacher.'

Being careful extends to playing sport and socialising as well.

'When she does sports or when she goes out with her friends, she has to be out with more than 2 friends in case she falls over and hurts herself.'

MANAGING AT HOME

At home there is a balance.

'What's important is finding what works for you in a routine and inside and outside the house.

'We're relaxed about some things and strict on others. And we have rules – like she needs to be safe about what she's doing.

'I do notice that we do things differently. She is only allowed to cook when we are at home in case she gets a burn or cuts herself by accident. She loves to cook and she is a good little chef.'

Keeping fun in her life has also been important.

'If you have a bad day and you have something fun to do, you can just go and do it.

'Grace always wanted a pond and she now has one. So she can go out there every day and feed her fish and play with her fish, because they love coming up to eat off her hand.'

OPEN COMMUNICATION

With a bleeding disorder open communication is crucial. Some bleeding episodes can have very serious consequences and recovery can take weeks longer if the bleed is not treated quickly.

'When she does have a bleed she really needs to tell me so we can fix it. We nearly missed a head injury because she was trying to protect her friend – and lied and said "I fell over because I walked into a pole" but really she had fallen over and hit her head on cement when her friend was angry and pushed her.'

They have also been fortunate to have a good family friend whom Grace trusts.

'If your child is having a bad day and they just don't want to talk to you, it's important they have someone that both you and they are comfortable with.

'Grace is a teenager – I think she always talks to me, but she might not. But she has a friend of mine that she adores and my friend absolutely adores her. And if there's anything she can't tell me or her dad, she can tell her.

'But Grace is such a good kid. Most days the worst thing she does is roll her eyes at me. When you're a parent and you complain that your daughter rolled her eyes at you, you're pretty lucky!'

Ultimately for Grace and her parents it's about living life and finding the positives – 'the things to look forward to.'

'We just feel normal. It's one of those things in life. And for Grace, it's just being careful.'

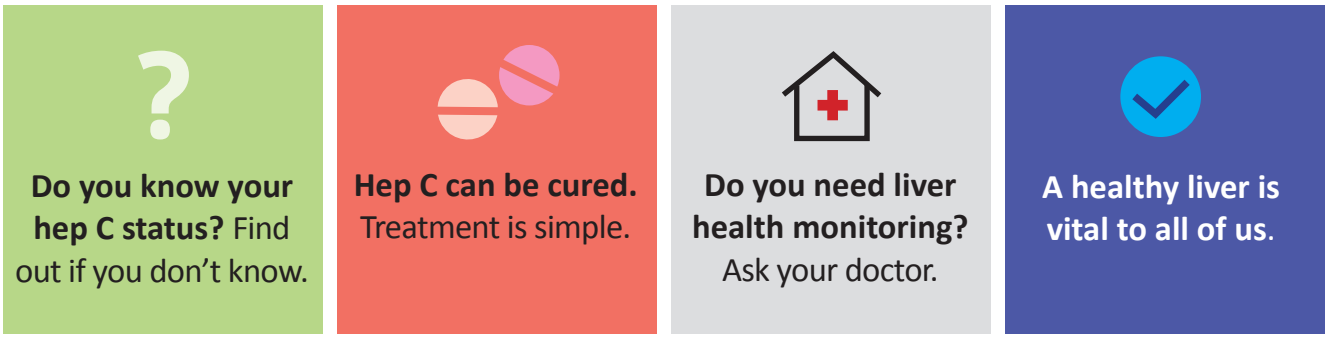
**Elizabeth and Grace are not their real names*

Stock photo: Karolina Grabowska for Pexels.com

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to see an end to viral hepatitis. In 2024 the national theme is *It's time for action*, reminding us that that hepatitis C and liver health remains an important issue for our community and that acting now is vital. This year landmarks around Australia glowed green on World Hepatitis Day to raise awareness about the campaign.

World Hepatitis Day 28 July

DON'T PUT IT OFF - TAKE ACTION NOW



HEP C AND BLEEDING DISORDERS

In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

WHO IS AT RISK?

It's estimated that 1 in 5 Australians do not know they have hep C.

For some people with bleeding disorders, it has been a surprise to find out they were exposed to hepatitis C, especially if they only had one or two treatments over their lifetime.

This includes:

- women who carry the gene
- women and men with mild haemophilia or VWD

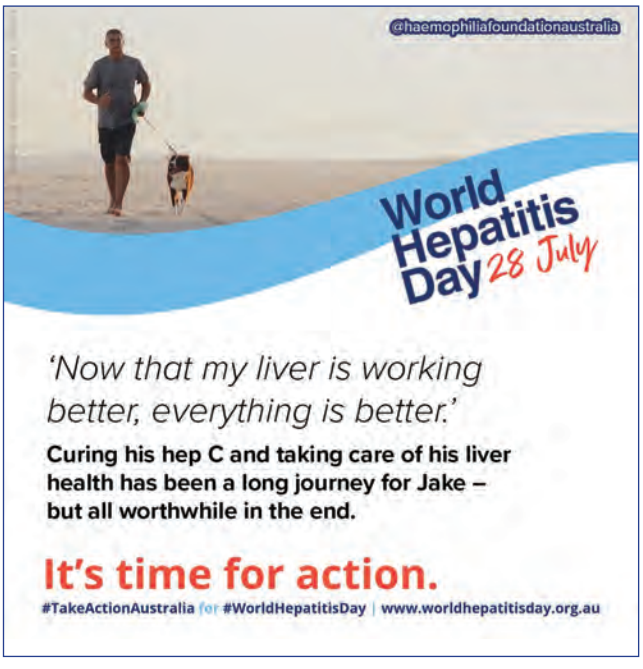
If you ever had a blood product before 1993, including blood transfusions and plasma-derived clotting factor concentrates, **you could be at risk of hepatitis C.**

Is this you or someone you know? Now is the time to talk to your doctor about a hep C test - and have treatment to be cured, if you do have hep C!
Hep C tests are simple blood tests.

TAKING ACTION

Hep C treatments now are radically different to the early interferon treatments - a once-daily tablet, few if any side-effects and very high cure rates.

Most Australians with bleeding disorders and hep C have now been cured – but some need ongoing care of their liver health.



POST CURE LIVER HEALTH

Were you cured of hep C? Has your liver recovered?

You might think it's all OK, but it's easy to miss symptoms of liver disease. Ignoring your liver health can have serious consequences.

If you don't know the state of your liver health when you were cured, contact your hepatitis doctor or your GP to check your liver test results. **Find out if you need ongoing follow-up with a liver specialist.**

REMEMBER

If you had **cirrhosis or extensive scarring** before being cured of hep C, you will still need to have a **liver ultrasound scan every 6 months** long-term.

Sadly, some people with bleeding disorders have very advanced liver disease due to long term hep C infection. Close liaison between liver specialists and Haemophilia Treatment Centres is important for treatment and care. Research into management of advanced liver disease is ongoing.

Q: Can I have gene therapy if I've had hep C?

A: Yes

...as long as you have been cured or you are HCV PCR negative (no active virus in your blood) and your liver is showing signs that it is functioning normally. Talk to your doctor about this and they may refer you to a liver specialist for a liver assessment with an ultrasound, and blood tests to show that your liver is healthy.

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How can you keep your liver in good shape?

A healthy liver is important to us all. Some tips from our hepatitis specialists:

1. Have a balanced diet
2. Stay active and maintain a healthy weight
3. Avoid or minimise alcohol intake
4. Take care of your mental health and wellbeing
5. Ask your doctor if you need liver health monitoring.

FIND OUT MORE AT:
www.haemophilia.org.au/healthy-liver.

PERSONAL STORIES

We are grateful to our community members for sharing their experiences with hep C.

You can read their stories on the HFA website at: https://tinyurl.com/HFA-hepc-stories.

FOR MORE INFORMATION

Visit:

- www.worldhepatitisday.org.au
- The HFA World Hepatitis Day page: www.haemophilia.org.au/world-hep-day

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and the state and territory Haemophilia Foundations on our awareness campaign and is committed to making a difference on hepatitis C in Australia.

Heavy menstrual bleeding in teenagers

Jaime Chase

When a period isn't 'just' a period… When to seek help.

Meet Marlie

Marlie is 14 years old, identifies as female (she/her) and has von Willebrand disease (VWD). She loves horse riding, ballet and swimming. She has lots of friends and could be described as an outgoing social teen.

Marlie started her period 6 months ago and describes it as tricky and heavy. Her menstrual cycle is erratic and lasts longer than what her friends experience. She has flooding at school and at night - soaking through her menstrual products and clothing. On occasions she has leaked onto her seat at school. She has issues accessing the toilet during class time - needing a pass from the teacher, which causes her anxiety.

She starts to not want to wear jodhpurs anymore and doesn't compete in as many horse riding competitions. She no longer attends dance classes and is refusing to swim due to the fact she can't trust wearing swimmers or leotards anymore. Her social circle is decreasing, and she is spending large amounts of time at home and in her room. Marlie also starts to refuse to attend to school when she has her period as she is so anxious.

Her parents are becoming increasingly concerned about her behaviours and periods and decide to book an appointment with Marlie's Haemophilia Treatment Centre (HTC).

Women with bleeding disorders often begin to experience bleeding concerns at puberty, which can potentially impair their activities as an adolescent. If a person with a bleeding disorder menstruates, bleeding problems can be a very regular occurrence from their adolescence and into adulthood. **Heavy menstrual bleeding** (HMB), also known as *menorrhagia*, can significantly impact a person's physical, social, or emotional quality of life. These effects can include physical and emotional effects and influence daily life such as work, school, and overall wellbeing.

It is well documented that children and adolescents with a bleeding disorder will already experience reduced quality of life due to the impact of their health condition. The negative psychological impacts of bleeding disorders escalate with the physical and hormonal changes of menstruation, and symptoms that indicate psychological distress can increase and become apparent over time.

There has been a lack of research into and education regarding bleeding disorders in females, which can lead to inappropriate clinical treatment and a healthcare experience that is fragmented. Research suggests that unsuitable treatment, or lack of treatment, may be avoided by increased disease awareness, accurate diagnosis, and a multidisciplinary approach to patient care.[1-3]

HOW DO YOU KNOW THAT YOU HAVE HEAVY MENSTRUAL BLEEDING?

Signs of excessive menstrual bleeding include:

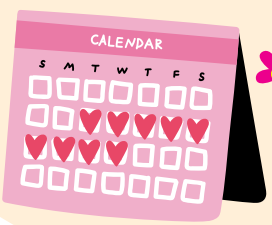
- Losing more than 5–6 tablespoons of blood (80mls)

- Bleeding through clothing

- On heavy days
  - Changing sanitary pads or tampons or other sanitary products every hour

- Having to get up at night to change sanitary pads/tampons/ products

- Passing blood clots larger than a 50 cent piece



- Prolonged bleeding – longer than 8 days.

(Heavy menstrual bleeding - RANZCOG definition[4])

HTC Appointment

Marlie attends her appointment at her HTC. The team there talk to her about her periods and how it feels to her when her periods are heavy. Marlie completes some diagnostic questionnaires with her HTC team - a bleed score and a menstrual bleeding assessment – and after discussing her answers, the team decide with Marlie and her parents that a referral to an adolescent gynaecologist is appropriate.

Marlie's HTC starts oral medication to help control her periods until her appointment with adolescent gynaecology. A blood test has shown that Marlie has anaemia as her iron stores are low due to her excessive bleeding, so she is also prescribed oral iron medication.

The HTC Nurse Coordinator contacts Marlie's school to discuss support for Marlie and access to the toilet during class times. Marlie is also referred to her social worker and psychology team to help with her feelings about her heavy menstrual bleeding that have influenced her quality of life.

THE PHYSICAL IMPACT OF HEAVY MENSTRUAL BLEEDING

The impact of heavy menstrual bleeding on a person can sometimes be hard to quantify.

People can experience one or more of the issues below:

- **Fatigue and weakness** – Significant menstrual bleeding resulting in excessive blood loss may lead to anaemia (decrease in red blood cells) which can make a person feel excessive tiredness, experience constant headaches and in severe cases, dizziness, and they may lose consciousness.
- **Pain** - Severe cramping and discomfort are very common which can be debilitating.
- **Sleep disturbance** – needing to change sanitary products frequently overnight can lead to a disruption in sleep patterns.

THE PSYCHOSOCIAL IMPACT OF HEAVY MENSTRUAL BLEEDING

Emotional and Psychological Impact

Stress and anxiety about heavy menstrual bleeding can play a large part in the life of a person with a bleeding disorder. The constant worry of needing to change protection regularly or the ability to access a toilet can create significant feelings of anxiety. This is especially apparent in school aged teenagers who may be denied access to toilets during class time.

Feelings of frustration, helplessness or isolation may arise if the person feels that their health concerns are not being taken seriously. If their heavy menstrual bleeding is not managed appropriately some people may feel depressed, which will increase the impact on their quality of life.

As they socialise less with others, there can also be a negative effect on their body image and self-esteem.

Social and professional impact

People with heavy menstrual bleeding may struggle attending school or work on their heavier days. This can be due to tiredness, anxiety, or the inability to access adequate protection or access to toilets. This can heavily impact the person's professional life due to missed and workdays as well as heavily impact schooling due to days missed.

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Management and Treatment

- **Medication** - medication is normally prescribed by your GP, HTC or gynaecologist. These can range in nature from medications to help clotting to oral medications to regulate hormones.
- **Surgical options/IUD (intrauterine device)** - many people with a bleeding disorder and heavy menstrual bleeding find having an IUD placed in their uterus is very successful in controlling their symptoms. Other options for people who have finished their family or for other reasons may include endometrial ablation (removing the lining of the uterus) and hysterectomy.
- **Psychological support** - if you have heavy menstrual bleeding and a bleeding disorder that is impacting your day-to-day functioning and socialising with others you may find it helpful to talk to a psychologist or counsellor about your experiences. It is very normal to be anxious about returning to activities that have caused you problems in past and a psychologist can help with these feelings.

So where is Marlie now?

Marlie is back at school full-time, has just started back at swimming and is loving the preparation for her end of year ballet concert. Her horse-riding competitions have restarted, and she is no longer scared to wear her white jodhpurs for competitions.

By working with her HTC she has been able to choose a treatment plan that suited her for her heavy menstrual bleeding.

Marlie chose to have an IUD placed in her uterus and had oral medication to deal with any spotting after the IUD was placed

She keeps in touch with her psychologist, social worker and the rest of her HTC team.

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Career and job pathways

Jane Portnoy

Finding the way towards your future

Decisions about careers and jobs cause significant worry for young people. There is pressure to make good choices and not miss an opportunity. However, there is just as much learning from the less obvious choices. Sometimes it is the unexpected experiences had along the way that bring new connections, offers, skills and interesting careers.

Research tells us that people with chronic illness and disability have a harder time finding work, progressing in work, and are often under-employed.[1] With this in mind, how can someone with a bleeding disorder have success in their journey and protect themselves?

FINDING YOUR DIRECTION

Finding one's own direction is not straightforward and young people have to identify their interests, find opportunities, and take their own steps toward their career.

Many successful people recommend being open to all opportunities as the key to finding their pathway. This can be as diverse as helping a teacher out with a project, taking on a part-time job, pursuing hobbies, talking to a broad range of people, or work experience.

The factors that are important in career and job selection are finding a balance between their interest for you, work available that pays enough and skill. The Japanese **Ikigai** model is a great graphic depiction of the various factors that impact on a positive work experience. (see diagram below[2]) The benefit is working with the big picture and expanding ideas, to support lateral thinking and identify priorities and values that will be important in career planning.

MAKING CHOICES

Parents, mentors, teachers and the Haemophilia Treatment Team are all interested in a young person's success and are often aware of the challenges. Nevertheless, it is ultimately up to the individual to forge their own way. We worry when that choice appears to be wrong. However, through 'bad choices' young people gain experience and develop insight. These experiences help them to develop maturity and motivation, which can lead to the development of skills and then new pathways emerge.

Some jobs are not as suitable as others, particularly with hard physical jobs. Age is another factor to consider with some jobs. Often as people age, they move into related areas that are gentler on the body, and use their acquired knowledge, skills, leadership while they take on more responsibility. These transitions require some planning, hard work and courage. Employers can assist workers to identify pathways, and help with the additional training in the workplace, supporting study and giving opportunities to take on new responsibilities.

Interestingly this generation is predicted to change careers 5 to 7 times over their working life and there are multiple pathways into chosen careers.

FACTORS TO CONSIDER

Physical issues

- Target joints
- Bleeding risk
- Find out the physical demands of a particular job you are interested in.

Work entitlements such as sick leave, disability support, safe workplace

Geographic factors

- How far from home
- What transport and parking options are there?
- How long will the commute be?

Your interests

- Passion
- Hobby
- Social aspect - do you work with other people?

Opportunities

- What study/courses are available? How long will it take? How much will it cost? Where?
- What jobs are available and are likely to be in demand when you finish studying?
- What skills do you already have?

WAYS TO FIND OUT WHAT DIRECTION A YOUNG PERSON SHOULD TAKE

Talk to

- Teachers,
- People working in fields you may be thinking about
- Career counsellor at school or in the community

Work experience and experience working

- Get a job
- Take an opportunity to go in for a short time to learn about a job

Take a look at

- The classic book *What Color is Your Parachute* by Richard Bolles
- Guidance about how to find your direction
- Japanese IKIGAI – see diagram above
- Working out what the balance you need for a fulfilling and satisfying career
- Take some of the careers and personality quizzes and questionnaires that are available
- Myers Briggs

There are no regrets, only lessons.

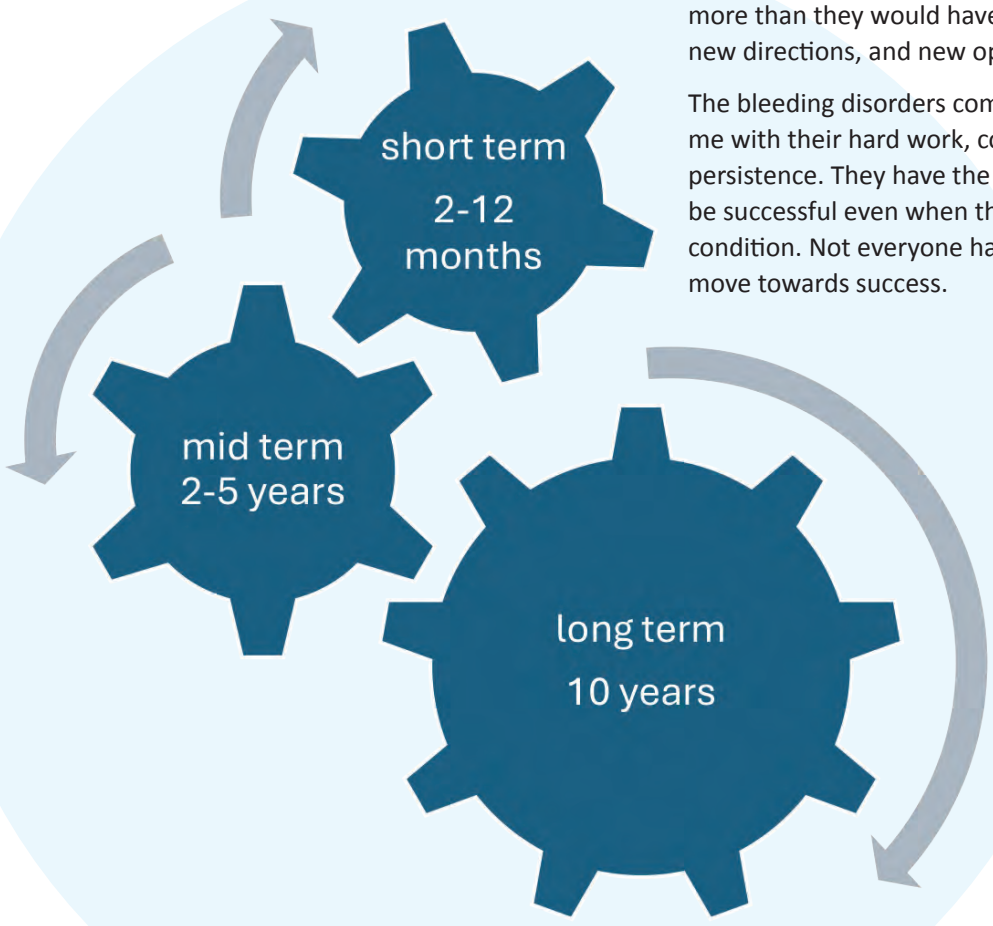
GOAL SETTING

Making long term plans is one of my favourite ways to start planning. It can often encourage some unconsidered priorities or wishes.

A useful way to think about goals is to break them down by time span into:

- Short-term
- Mid-term
- Long-term goals.

Of course there can be an intersection between these, but they are often powerful as standalone goals.



Working towards **short term goals** is more achievable and doesn't have all the pressure of big goals. It can be something relatively small, yet make a significant impact on day to day life.

The **mid-term goals** provide a space for some planning and usually require courage to take steps towards them.

Long-term goals go alongside dreams and hopes for the future, but inherently require thought and preparation, as well as hard work.

In thinking about setting goals the individual has to consider multiple factors, and often comes up with more than they would have expected - different goals, new directions, and new opportunities.

The bleeding disorders community continue to amaze me with their hard work, commitment, creativity and persistence. They have the skills and determination to be successful even when they live with a chronic health condition. Not everyone has it easy, but it is possible to move towards success.

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FACTORED IN
FOR YOUNG PEOPLE

Jack's latest travel adventures

Hi, my name's Jack. I am 23 years old and I have severe haemophilia A

HFA interviewed Jack about his recent trip to the USA and Canada and what was different for him. In the past Jack has also travelled to southeast Asia and Europe – see his story here:

https://tinyurl.com/NH223-Jacks-story

Where did you go on this trip?

On my most recent trip, I went over to North America and to Canada. So, places like Vancouver, Whistler, Banff, Calgary, which was awesome, very cold. And then we went down to America, to Las Vegas, Arizona and San Francisco.

In the Rockies it got down to -40 degrees.

Jack's story

What were the highlights for you?

The highlight of my trip was probably in British Columbia in Canada. We spent a lot of time snowboarding in the Rockies. It got down to -40 degrees at one point, which was an interesting experience. But I spent lots of days on the slopes and saw some cool wildlife and had some awesome snow.

I loved the Grand Canyon in America. It was much bigger than I expected. We went to the Western Ridge and I did a skywalk. You walk out and it has a glass bottom - and I really hate heights so that wasn't my favourite thing. But I walked around a bunch of different spots along the edge and looked out.

And Las Vegas? Oh, you know what they say - what happens in Vegas stays in Vegas! But I saw Fisher at Caesars Palace, who is a big Australian DJ. That was pretty cool.

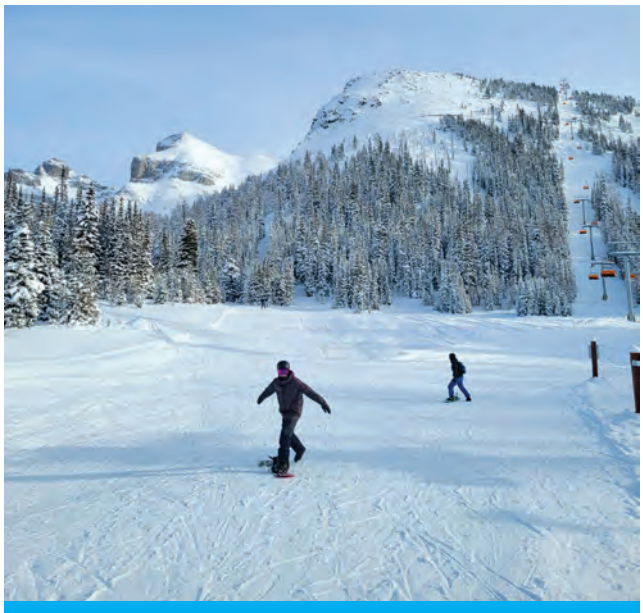
I also got to go to the Sphere, which was unreal. Obviously, it's a massive sphere - fully immersive 360 degrees, screens that go all the way around you and when you sit in it, it feels like you're flying. They have videos and robots in there as well. I think it holds 40,000 people. It's crazy. They have a screen on the outside, so as you walk through Vegas, there's a smiley face looking down at you, or basketballs, all different sorts of things.

How did you manage your haemophilia? What was different this time?

My treatment schedule with my subcutaneous product is once every fortnight. On this trip I had 3 treatments in 5 weeks - a massive change compared to when I went to Asia on factor treatment. I was doing factor treatment 5 times a week at that stage, so it was more like 30 treatments.

This time round, the biggest challenge for me was doing a lot more high-risk activities. We did about 7 or 8 days of snowboarding.

So, it was important to have a good treatment plan to manage the high risk of bleeding, and make sure I had a factor product with me to treat any bleed in case I got injured, not just my regular subcutaneous non-factor product. And it did happen - my ankle blew up on the second last day of snowboarding.



This was a different trip for me with the snowboarding.

What did you need to plan for?

A lot of the work behind travel in this trip hadn't changed in terms of planning and insurance and carrying enough treatment.

I started conversations with my Treatment Centre about my travel plans about 4 months before I went so we had time to sort the documents and get them printed out and on my phone.

We also discussed treatment, mainly that I had enough factor and I knew where hospitals or help was on my travels if I needed it. I did use all of my additional factor VIII (8) whilst I was over there, which hasn't happened to me on a trip before, just from being really banged up with lots of bruising.

I made sure I had an Esky and cooler bag to keep my treatment cold whilst traveling and had the right documents with me, all in my carry-on.

Did you have any treatment adventures?

America was the first country that has actually pulled me up at customs. That's never happened to me before, so it was a bit freaky.

They stopped me and I was pulled aside with the Border Patrol officers. They ripped apart my bag, going through everything - they're like, why do you have needles and all this sort of stuff in your bag? They took my treatment out of the boxes and swabbed down all my stuff and tested it to make sure it wasn't some illicit drug.

I had my treatment letters and they just looked at them. Then I pretty much got waved through, once they checked it was all good. But it definitely highlighted the importance of having letters!

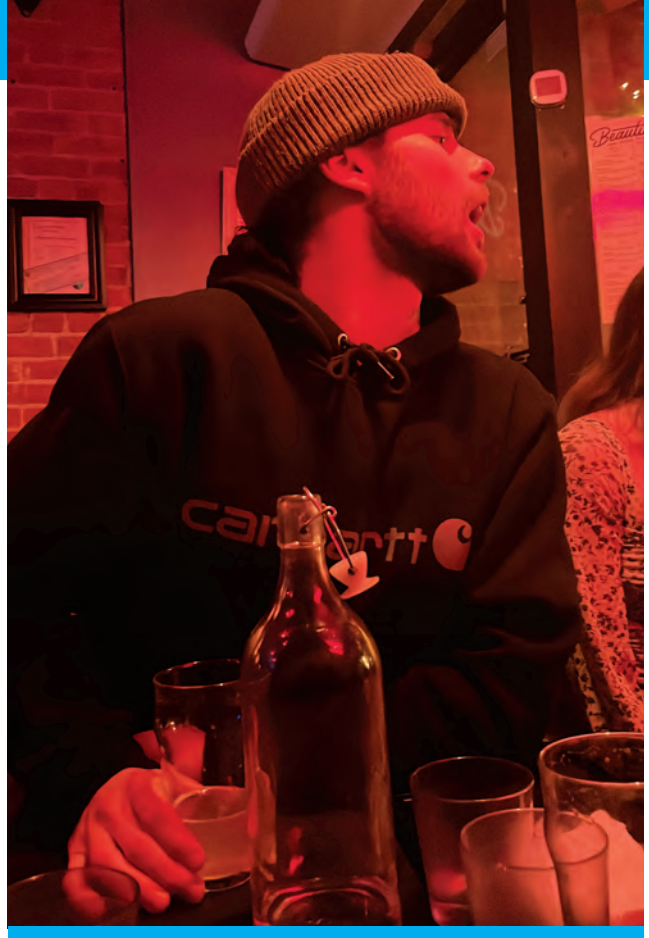
Who did you tell about your haemophilia while you were travelling and why?

I travelled with the same mate who went to Southeast Asia with me, so he was already across my treatment and haemophilia in general, which was really handy.

But it was certainly a different experience for him, because last time, I wasn't on my non-factor product, whereas now I am. He was amazed by how much less treatment I had to bring this time, compared to when we went to Asia.

And I think having other people aware that you're travelling or of your condition when you're travelling is massively important, especially in countries that don't have the same sort of healthcare system. America is very different to Australia. Having people who know your condition and can talk to doctors is super important, especially if something bad was to happen, to make sure that they can get what's needed across in those situations.

I travelled with my mate, so he was already across my haemophilia



Another thing is staying super vigilant when you are drinking or partying.

What travel tips do you have for other young people with haemophilia?

One tip is being aware of the risks you're taking and staying within your limits. Don't push yourself when you're a long way from home.

This was a different trip for me with the snowboarding. But when I was sore, I would not go out and looked after myself. I was with some friends who are much more experienced than me and don't have this sort of injury risk. They would be doing big jumps but I would just do stuff that I'm comfortable with.

Drinking overseas is part of growing up. But another thing is staying super vigilant when you are drinking or partying because it's at times when you're not as rational about what's going on that you can get hurt if you're not careful.

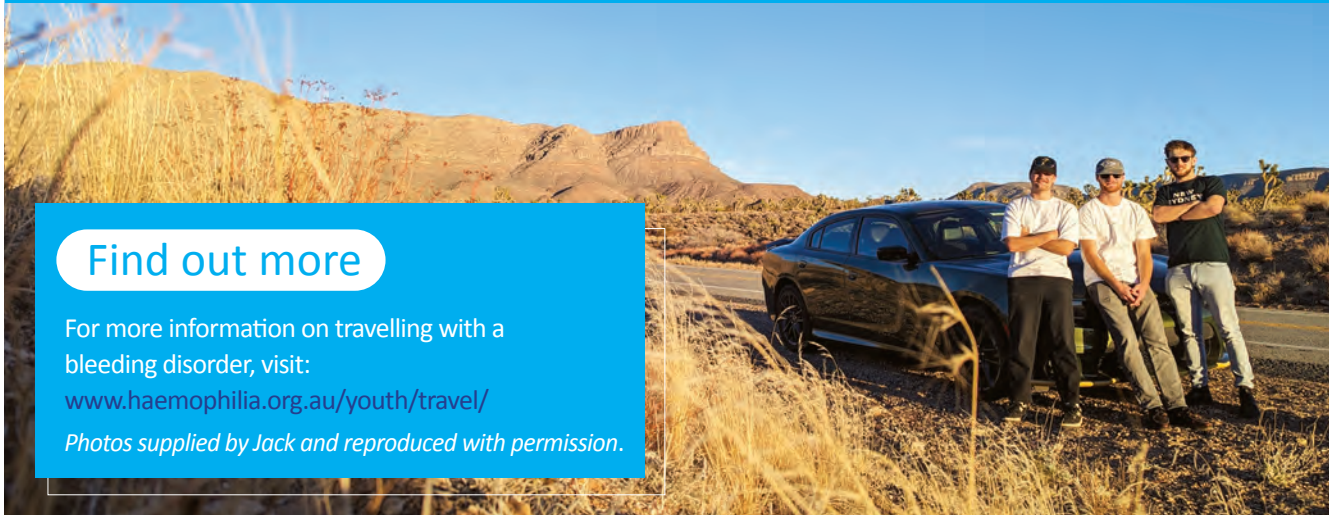
As far as general travel tips for young people with haemophilia - the number one thing is make sure you plan – a plan for your treatment, a plan of where you'd go if you were injured, your insurance.

As long as you've got everything ticked off before you go, you can travel just like any normal person.

Jack's top travel tips

- Plan ahead!
- Organise a treatment plan and treatment, documents for customs or healthcare
- Know where the local HTCs and hospitals are
- Have travel insurance
- Make sure someone you are travelling with knows about your bleeding disorder and what to do in emergencies
- Know the risks you are taking and your limits
- Take extra care of yourself when you are drinking or partying.

Make sure you plan – and you can travel just like any normal person.



Find out more

For more information on travelling with a bleeding disorder, visit:
www.haemophilia.org.au/youth/travel/

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CALENDAR

Bleeding Disorders Awareness Month
October 2024
www.haemophilia.org.au/BDAM

World Haemophilia Day
17 April 2025
www.haemophilia.org.au/WHD

22nd Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders, Brisbane
16-18 October 2025
www.haemophilia.org.au/conferences

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or: email hfaust@haemophilia.org.au

Haemophilia Foundation Australia acknowledges the Traditional Owners and Custodians of Country throughout Australia, the land, waters and community where we walk, live, meet and work. We pay our respects to Elders past, present and emerging and extend that respect to all Aboriginal and Torres Strait Islander peoples.