

# National Haemophilia

[www.haemophilia.org.au](http://www.haemophilia.org.au)



## Embracing a changing world

Managing the challenges of change over your lifetime.

## Bleeding Disorders Awareness Week

Go red for bleeding disorders!

## 2021 Australian Conference

Register now!

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## News from South Australia

### CAFÉ MORNING CATCH UPS

A group of people from the South Australian bleeding disorders community were able to meet for an informal catch up at a café in July, and have made plans for another catch up in due course.

### INFORMATION EVENING

The information evening planned jointly by the Women's & Children's Hospital and the Royal Adelaide Hospital was interrupted yet again by COVID-19, but it will be rescheduled, so please keep your eye out for the new date.

### LET US KNOW YOUR CONTACT DETAILS

If your contact details are not on the HFA database and you would like to receive *National Haemophilia*, e-news and invitations to events please make sure you contact us by email to [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) and we will make sure you are not overlooked.



**Gavin  
Finkelstein**

President,  
Haemophilia  
Foundation  
Australia

## From the President

### COVID-19 AND LOCKDOWNS

People in different parts of Australia have experienced various states of lockdown and hardships because of the pandemic. I talk to our members around Australia, and also overseas, and while it is harder for some than others, the implications of COVID-19 and, more recently, the Delta variant have been confronting and scary for everyone. In WA we have felt somewhat shielded from the eastern states, but we all know what it's like to have snap lockdowns and restrictions and to have to quickly adjust the way we live and work, and how we communicate and support our loved ones.

People with kids talk of home-schooling nightmares, and I know personally how difficult it is to support older members of my family. I know you may be supporting and caring for someone at the moment and this can become tiring and frustrating, but we need to do the hard yards and keep going. We know living with lifelong conditions like having a bleeding disorder often helps develop resilience and strengths some people might not even know they have until tested, but there will also be times when people need to reach out for support. Please let us know if HFA can help in any way.

We know some people have not been able to keep as well connected with their HTC as before, while others have been able to use telehealth and other services to connect more often. We thank our HTC staff for their work over this very difficult time. It may have been hard for some of our members to explore new treatments for haemophilia that are now available, because they haven't been able to get to their HTC. We urge you to stay connected with your HTC and make plans if you do need information about what new treatments might mean for you.

The HFA office staff still work from home, as the Melbourne office is temporarily closed, and the HFA Council continues to meet virtually. Although meetings via videoconferences are not as good as face-to-face, it has been helpful for some of us not to

have had as much travel. Unfortunately we have been pushed to a virtual national conference this year, but the advantage of this is that people can participate from the comfort of their own home! So please do register to attend the Conference!

### HEPATITIS C

An important issue for the HFA Council is to address the consequences of hep C for the bleeding disorders community. The World Hepatitis Day campaign you will read about in this publication is part of this. You might see postcards about hep C at local peer support meetings which are to remind people of the risks and to check their hep C and liver health test results. The *Double Whammy* report highlighted that a cure was a priority for our community. In Australia we have been fortunate to have highly effective hep C treatments available to everyone through the public health system and it is important to take advantage of that and make sure everyone with a bleeding disorder and hep C has treatment and opportunity for cure where this is possible. So we are trying to find people who might not realise they are at risk – or may have wondered, but not got around to following up.

We have also been discussing the ongoing issues with the hepatitis experts - that for some people with cirrhosis or advanced liver disease, keeping an eye on liver health into the future is crucial, even with a cure. Checking your liver test results with your hepatitis specialist after cure to know whether your liver has recovered is another important step, as you may need ongoing follow-up. Sadly, we know that some of our community members have very advanced liver disease from hepatitis C. This is a reminder of the consequences that can arise from hep C and I have shared my personal story to encourage others to please act on their hepatitis C health, if they haven't already.

*Continued on page 4*

# Dealing with challenges and change

Sharon Caris

In our June 2021 issue of *National Haemophilia* you may have read about some of the challenges and changes faced by people with bleeding disorders and their carers, and how they have addressed this.

Change can have a big impact on our lives and being able to recognise and adapt to it is a really important tool for our wellbeing.

HFA has adopted the **Embracing our changing world** theme for our upcoming national conference, and there will be sessions on change and coping with change that are practical for everyone.

The COVID-19 pandemic has raised so many issues and concerns for people, especially during lockdowns. Our way of life may have changed because we can't get out and about as much, we may not be able to see family, friends and our other support people as often as before, including our health professionals who have provided support and care.

At our April 2021 webinar on adapting to change for World Haemophilia Day, Nicoletta Crollini (Haemophilia Social Worker at RPAH, NSW) and Jane Portnoy (Haemophilia Social Worker at the

Alfred, Victoria) talked about the importance of resilience, self-care and seeking support. You can also read a report of this webinar in the June edition of *National Haemophilia*.

## ADAPTING TO CHANGE WEBINAR

Watch the video and read the report of the Adults adapting to change webinar at <https://tinyurl.com/HFA-adapting-to-change>

Jane noted the importance of seeking help if you are concerned about your mental health; and suggested talking to trusted people in your social network or your health professionals such as at your Haemophilia Treatment Centre (HTC) or your general practitioner or other trusted health professional. Some community services also offer online chat and telephone services when you have concerns and feel you would like some support. There is also online support available for mental health.

.....  
**Sharon Caris** is Executive Director, Haemophilia Foundation Australia  
 .....

<b>ONLINE</b> <b>MENTAL</b> <b>HEALTH</b> <b>SUPPORT</b>	Organisation	Telephone	Website
	Beyond Blue	1300 22 4636	<a href="http://beyondblue.org.au">beyondblue.org.au</a>
Lifeline	13 11 14	<a href="http://lifeline.org.au">lifeline.org.au</a>	
MensLine Australia	1300 789 978	<a href="http://mensline.org.au">mensline.org.au</a>	
Headspace	1800 650 890	<a href="http://headspace.org.au">headspace.org.au</a>	
Kids Helpline	1800 55 1800	<a href="http://kidshelpline.com.au">kidshelpline.com.au</a>	

**From the President** continued .....

The Getting Older Report has also identified the need for services and financial support and advocacy around insurance discrimination. This work is ongoing. Don't forget the **Getting Older Info Hub**

where you will find information on a range of issues that arise for those of us who are aging – [www.haemophilia.org.au/getting-older](http://www.haemophilia.org.au/getting-older).



8 | 9 October 2021

Virtual

# 20<sup>TH</sup> AUSTRALIAN CONFERENCE

ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

**EMBRACING A CHANGING WORLD**

The virtual **20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders**, 8-9 October 2021 is shaping up well, with a diverse program, great speakers, and an opportunity for you to catch up with friends, old and new!

## THEME AND SPEAKERS

Our theme is **Embracing a Changing World** and we have confirmed exciting speakers. You can find more information in the Program inserted in this issue of *National Haemophilia*.

With **Dr Ritam Prasad**, Haematology Treatment Centre Director, Calvary Mater Newcastle, NSW and **Suzanne O'Callaghan**, HFA Policy Research and Education Manager as co-chairs, the program committee has been developing a multidisciplinary program which will interest everyone.

**David Stephensen**, Haemophilia Physiotherapist from the UK, has more than 20 years' clinical and research experience working with children and adults with haemophilia. He will talk about his research on exercise for children with haemophilia and about the role of physiotherapy in the age of new treatments.

**Professor David Lillicrap** from the Department of Pathology and Molecular Medicine at Queen's University, Kingston, Canada is an expert on blood clotting and innovations in the treatment of bleeding disorders and novel therapies and will lead us through what the future holds.

**Professor Mike Makris** is Honorary Consultant Haematologist at Sheffield Teaching Hospitals, NHS Trust, UK and will challenge our thinking about where treatment and care is heading over the next few years.

**Paul McLaughlin** from the UK is the current chairman of the Haemophilia Chartered Physiotherapists Association (HCPA), a UK group of specialist physiotherapists working in haemophilia. He is going to speak on pain in haemophilia and managing chronic pain.

**Dr Christian Barton** works in both research and private practice treating sports and musculoskeletal patients in Melbourne. He will talk about research on exercise and the GLA:D®, Good Life with osteoarthritis Program.

Program sessions on advances in treatment and care, managing bleeds, diagnosing and treating VWD, specific issues for women and girls and young people, understanding and managing pain, sport and exercise, getting older, managing hepatitis C and HIV, mental health, managing change and optimising peer support will be among the sessions running over the two days of our virtual conference.

## CONNECTING WITH THE COMMUNITY

Connect with one another and share your experiences! This has always been a key part of our national conferences. There will still be plenty of opportunities for you to connect, share and have fun - we will be doing things very differently at our first ever virtual national conference!

### Hosted Social Activities

Look out for the hosted social activities over the two days and join us for the social function on the Friday evening.

### Remembrance Service

The Remembrance Service is an important part of our conference and all delegates will be able to reflect on the past and how it has affected each of us.

## REGISTRATION

Our aim is to make the Conference accessible and affordable for everyone. If the travel and cost has stopped you in the past, you can attend this conference from the convenience of your home or office.

### Registration includes:

- Access to all plenary and concurrent program sessions
- Access to all extra activities
- Access to Gold Sponsors' private rooms for health care professionals or for community delegates.
- Hosted opportunities to connect with other delegates
- Remembrance Service
- Social function on the Friday evening
- A conference satchel with abstract book and information can be either posted to you or sent digitally.

### Costs

#### Category 1 - \$50 per user access

Person with a bleeding disorder,  
family and carers  
Haemophilia Foundation staff

#### Category 2 - \$75 per user access

Health professionals, government officials,  
pharmaceutical company representatives  
and other regular delegates

#### Register online at -

[www.haemophilia.org.au/  
conference21registration](http://www.haemophilia.org.au/conference21registration)

Online registration only. If you require any assistance let us know. Your local foundation maybe offering funding or subsidies. Please contact them directly for further information.

## FAQs

### What do you need to participate successfully?

- Computer with sound card, tablet or smartphone
- WIFI or data, with enough data for a 2-day stream

### Do I need to sit in front of a screen for the entire 2 days?

No, there will be breaks, live sessions and pre-recorded sessions. To get the most out of conference, we recommend you attend the live sessions that are of most interest to you so you can ask questions and participate in conversations.

### Will sessions be available for playback on demand afterwards?

All live sessions will also be recorded and you will be able to access the recordings straight after the session.

With your registration you will also be able to access all the recordings on demand after the conference.

### Will I be able to meet others in the community during the conference? I enjoyed the face-to-face part of past conferences.

Yes, you will have the opportunity to meet others virtually in scheduled social activities. We will have allocated times for this.

# CONFERENCE PROGRAM 2021

## FRIDAY 8 OCTOBER 2021

0855	<b>Official Conference Welcome and Acknowledgement of Country</b> Gavin Finkelstein, President, HFA and Dr Ritam Prasad, Conference Co-Chair	
0900-1015	Plenary 1 – The changing world of bleeding disorders	
1015-1045	MORNING TEA	
1045-1215	Concurrent 1 - Managing bleeds under current new treatments	Concurrent 2 - VWD
1215-1325	LUNCH	
1325-1455	Concurrent 3 – Sex, sexuality and intimacy	Concurrent 4 - Women and girls
1455-1535	AFTERNOON TEA	
1535-1700	Plenary 2 – Dealing with change	
1800-1830	Remembrance Service	
1900-2000	Battle of the Trivia – Evening social activity free to all delegates	

## SATURDAY 9 OCTOBER 2021

0900-1015	Plenary 3 - Pain	
1015-1045	MORNING TEA	
1045-1215	Concurrent 5 - Making the most of your health virtually	Concurrent 6 – Exercise and resistance training
1215-1325	LUNCH	
1325-1455	Concurrent 7 - Youth – challenges, taboos	Concurrent 8 - Getting older
1455-1535	AFTERNOON TEA	
1535-1700	Plenary 4 – Where to from here?	

### SOCIAL ACTIVITIES

During break times join our community room to meet and chat with others or attend our sponsors' virtual exhibition rooms. We have a fun activity being planned for Friday night, which is free with your registration.

### THANK YOU TO OUR SPONSORS

All delegates will be able to meet our Gold Sponsors in their specially dedicated private rooms for health care professionals or community delegates.

### NO MORE SESSION CLASHES!

Most sessions will be recorded (depending on permission from speaker) and this will be clear on the online program. With your registration you will be able to access recorded sessions during and after the conference.

### FOR MORE INFORMATION

Visit the conference website at [www.haemophilia.org.au/conference21](http://www.haemophilia.org.au/conference21)  
Or contact HFA at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

### Thank you to our sponsors

#### Gold Sponsors

**CSL Behring**



**SANOFI GENZYME**



#### Silver Sponsors

**BIOMARIN**

**Pfizer Haemophilia**





# Bleeding Disorders AWARENESS WEEK

10-16 OCTOBER 2021

Bleeding Disorders Awareness Week 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 haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of **10-16 October 2021**.

The theme of the week is **Embracing a Changing World** to follow on from our conference theme days before.

## GO RED FOR BLEEDING DISORDERS

Looking for something to do during Bleeding Disorders Awareness Week either face-to-face or virtual? Host a red-themed event and **Go Red For Bleeding Disorders!**

Some quick ideas are:

- Host a red-themed morning tea
- Host a Red Cake Day
- Dress red for a cocktail night
- Host a red themed crafternoon
- Wear red in support of the day.

More information and ideas will be on our website.



## FUN ACTIVITIES

We have fun downloads on our website for you to take part in the week such as a colouring-in competition, trivia and a word find.

HFA has a limited supply of promotional items:

- **Red Cake Day Packs** for children, which include cake packet mix, cupcakes cases and some Red Cake Day toppers.
- Pens, pencils and stickers.

Check the HFA website for current updates, how to order and the free downloads and activities.

**For downloads and information**

visit [www.haemophilia.org.au/bdaw](http://www.haemophilia.org.au/bdaw)

or contact **Natasha** on [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)

or **MB 0403 538 109**



# REDCLASSIC

*Supporting the Bleeding Disorders Community*

## REGISTER TODAY

[www.haemophilia.org.au/BDAWRC](http://www.haemophilia.org.au/BDAWRC)

For Bleeding Disorders Awareness Week we invite the community, family and friends to participate in the Red Classic.

Walk, run, get into your wheelchair, onto your scooter or get on your bike during the week, dress in red, and send in your km and your pics!

\*Stick within covid restrictions in your area\*

What do I need to do? Register at [www.haemophilia.org.au/BDAWRC](http://www.haemophilia.org.au/BDAWRC) and all the information will be sent to you.

## What is the date?

The classic will run from:

**Sunday 10 October – Saturday 16 October 2021.**

### Can we do anything?

Yes, think outside the square – roller-skate, skateboard, cycle, horseride – anything that keeps you moving.

**REGISTER TODAY!**



## EVERYONE HAS A STORY TO TELL

Would you like to share your story for Bleeding Disorders Awareness Week?

[www.haemophilia.org.au/shareyourstory](http://www.haemophilia.org.au/shareyourstory)

### DURING BLEEDING DISORDERS AWARENESS WEEK

Don't forget to follow us on our social media networks for links to virtual events and current up to date information:



Like HFA on Facebook



Like HFA on Instagram



Follow HFA @Haemophilia\_Au

# World Hepatitis Day 2021

*World Hepatitis Day is marked globally on 28 July. In 2021 we joined the global community in the message of **Hep can't wait!**, reminding us that we need to be proactive and act on viral hepatitis.*

Hepatitis C has had a profound effect on our community. 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.

## WHAT ARE THE KEY ISSUES IN 2021?

Revolutionary new hep C treatments are now available in Australia. They are easy to take – tablets not injections - with very high cure rates and few side effects.

### Who is at risk?

**If you had a blood product or a plasma-derived clotting factor concentrate before 1993, you could be at risk for hepatitis C.**

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. This could be the case for some women and men with mild bleeding disorders who may have had very few treatments in their lifetime and never thought of themselves as at risk for hep C. If this is you, don't wait to be tested – find out if you have hep C. Treatment is simple and hep C can be cured.

### You have been cured – has your liver recovered?

If you don't know the answer to that question, don't wait to find out. Take the time to **contact your hepatitis specialist and check your liver test results.**



It's very important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and State and Territory Foundations on the annual Australian awareness campaign and is committed to making a difference on hepatitis C in Australia.

## PERSONAL STORIES

We thank Gavin Finkelstein, HFA President, and Mary Jane for sharing their personal stories about living with hep C, treatment and being cured. Read their stories in this issue of *National Haemophilia*.

### FOR MORE INFORMATION

Visit:

- [www.world.hepatitisday.org.au](http://www.world.hepatitisday.org.au)
- The HFA World Hepatitis Day page – [www.haemophilia.org.au/world-hep-day](http://www.haemophilia.org.au/world-hep-day)



# Finally cured of hep C

*Gavin's story*

*Gavin Finkelstein is President of Haemophilia Foundation Australia (HFA) and Haemophilia Foundation Western Australia (HFWA). He has severe haemophilia A. He talked to HFA about living with hepatitis C, treatment and being cured. Our thanks to Gavin for sharing his personal story.*

For Gavin, growing up with severe haemophilia had meant living with joint bleeds. His generation became adults before the arrival of prophylaxis treatment to prevent bleeds and Gavin had relied on plasma-derived clotting factor concentrates to manage his bleeding episodes whenever they occurred. The regular bleeds resulted in arthritis and other joint and muscle damage.

*'As they say, pain was my constant companion, but not my friend.'*

What he didn't realise at the time was that another unfriendly traveller had also hitched a ride on his treatment products – hepatitis C virus, which had infected blood products like clotting factor concentrates through blood donations. By 1993 Australia had introduced new safety measures to prevent transmission of hepatitis C in blood products, but in the years before then Gavin had already been exposed to hepatitis C through his treatments many times.

Some years earlier Gavin had been told he had non-A non-B hepatitis – the name for hepatitis C before there was a test - but little was known about it at that stage. When his diagnosis with hepatitis C was confirmed in 1993, it had a very different impact on him.

*'At first I freaked out,' he said. 'After living through the HIV epidemic, I thought I was going to die. I was very worried about transmission and passing it on to others. I broke off my relationship and was fearful about going into other relationships. It had a very negative effect on my motivation and my career.'*

## EARLY TREATMENTS

Early hepatitis C treatment with interferon injections and ribavirin tablets was prolonged and arduous, with difficult side-effects.

*'I had 72 weeks of treatment in 2001-2, which was horrific. I was working the whole time, but it turned my mind to mush. I was forgetful, I was grumpy, I had no energy. It affected my home life as well as my work. Then I relapsed 6 weeks after the treatment finished, which was pretty demoralising.'*

*Continued on page 12*

With the ongoing impact of hepatitis C symptoms – fatigue, brain fog, lack of energy and motivation – and his increasing arthritis and joint problems with haemophilia, Gavin took early retirement from his job in the public service but continued his volunteer roles with HFWA and HFA.

In 2009 he tried the pegylated interferon and ribavirin treatment again, but his treatment was stopped after 6 weeks when tests showed it wasn't working.

## TREATMENT AND CURE

In 2016 the new direct acting antiviral (DAA) treatments for hepatitis C became available in Australia. They were described as 'revolutionary' – and in Gavin's opinion, lived up to their promise.

*'I had one of the new treatments, Harvoni, and it was a doddle. One tablet a day for 12 weeks and minimal side-effects. And I was cured – it was fantastic. It was the best thing I ever did. Now I feel fine and my liver test results are good too.'*

Checking liver test results to make sure his liver had recovered was an important step. This testing took place as a standard requirement when Gavin joined a

clinical trial for a new haemophilia treatment, but he encouraged others to ask about testing if they didn't know what their liver test results were after being cured.

'Don't wait' was the message he had for others considering treatment for hepatitis C.

*'Don't even think about it. Go for it – get it done. These new treatments have such positive results and there is hardly any impact on your life to undergo the course of treatment. There are several different treatments, so your doctor will be able to find one that suits your individual health and lifestyle.'*

*'If you are worried about having hep C treatment, ask your haemophilia team or your hepatitis clinic to put you in touch with someone who has had the new therapies so they can have a chat with you about what it's like. These days you don't need to think about the implications for your work or home life because it's so easy to take and there are hardly any side-effects. And when you are cured it puts you in good stead to deal with the rest of your life with haemophilia.'*

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# Women can have hep C too

## Mary Jane's story

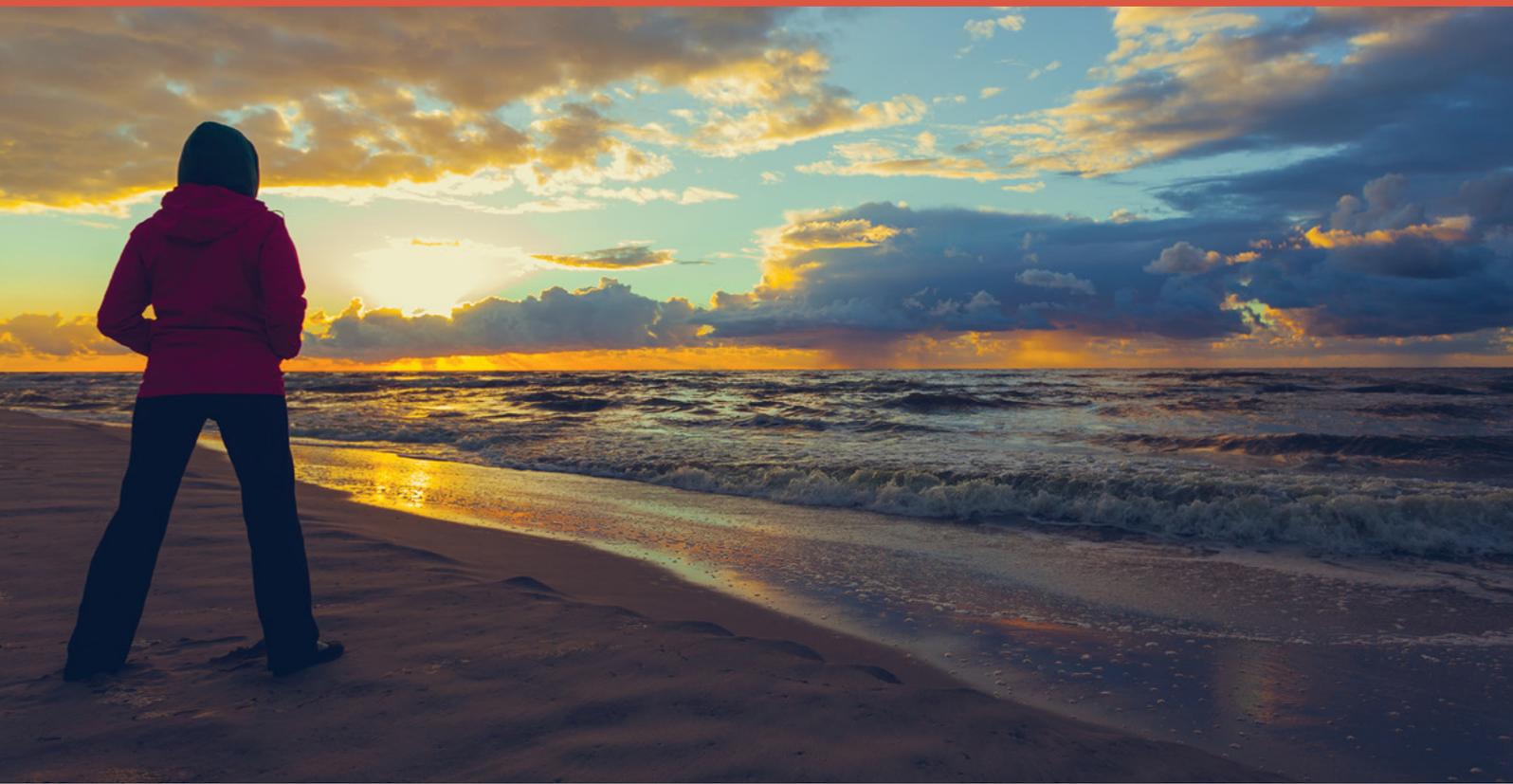
*Mary Jane\* is an Australian community member with von Willebrand disease (VWD). She spoke to HFA about her experiences with hepatitis C and being cured. Our thanks to Mary Jane for sharing her story.*

Women with bleeding disorders don't usually think of themselves as being at risk for hepatitis C. Mary Jane's story is a reminder that anyone who had blood products before 1993 might have been exposed to HCV, the virus that causes hepatitis C.

Mary Jane has von Willebrand disease (VWD) type 3, which is a severe form. Over the years she has experienced a range of bleeding problems, including

bruising, heavy periods, joint bleeds and gum bleeding. Growing up, she had the treatment product cryoprecipitate to control her bleeding. Cryoprecipitate is a clotting factor product manufactured from human plasma – the pale yellow fluid part of blood. Over the years she also had other gynaecological problems such as ovarian cysts and had a hysterectomy in the late 1980s, treated with whole blood products to manage bleeding.

In the past, human blood products – whole blood, cryoprecipitate and clotting factor concentrates - were a risk for bloodborne viruses such as HIV and hepatitis C. By 1985 Australia had introduced testing of blood donations and viral inactivation manufacturing



processes to prevent transmission of HIV through blood products. A test for hepatitis C virus became available in 1990, followed quickly by testing of blood donations. By 1993 there were similar safety measures to remove or inactivate HCV during the manufacture of blood products. They were important steps for blood product safety but too late for people like Mary Jane.

Mary Jane discovered she had hepatitis C after abnormal liver function tests just over 20 years ago.

*'I didn't really know much about hep C. We heard more about HIV at that time, because we knew that people with haemophilia in our community were affected by it.'*

*'I had probably had hepatitis C for about 20 years, but I wasn't aware that I had symptoms. I had some fatigue, but I thought that was just getting older and being tired from work. I didn't classify it as there is definitely something wrong with me.'*

Discovering she had hepatitis C impacted not only on Mary Jane but also made her worry about the people close to her.

*'I was pretty horrified to find out I might have had hep C for 20 years or more and not known the risk of transmitting it. I was concerned about my husband. He needed to have a hep C test as well – which was negative. I was much more conscious of what I was doing – for example, if I cut myself, I was careful to make sure my blood didn't go on anyone else, like the kids.'*

Her first round of hepatitis C treatment involved injections of interferon and ribavirin tablets and was not successful. In 2016 she had treatment again, this time with the new Direct Acting Antiviral (DAA) therapy.

*'It wasn't too traumatic - very easy to take, just tablets, and I didn't have any side-effects.'*

Mary Jane took the treatment for 6 months and her test results confirmed that she had been cured. Follow-up tests also showed that her liver was functioning normally.

*'I feel fine now. My joints still give me trouble, of course!'*

Her message for other women in her situation?

*'Just go and get tested. It's not difficult in any way. If it turns out you have hep C, treatment is very straightforward and simple and the specialists at the hepatitis clinic keep an eye on you all the time. If you have any questions, you can ring them or go to see them anytime. It's all very easy.'*

\*name changed for privacy reasons

# Social support and social connectedness

*Nicoletta Crollini*

*This article is adapted with permission from Social support and social connectedness – good for the soul. Factor Matters, vol. 46, June 2021, the newsletter of Haemophilia Foundation NSW ([www.hfnsw.org.au](http://www.hfnsw.org.au))*

## WHAT IS SOCIAL SUPPORT

Social supports are the network of friends, family and other people who you turn to in times of need or crisis. The help one can access through their social supports can be both practical and emotional support.

## WHY HAVING A SOCIAL SUPPORT NETWORK IS IMPORTANT

Having a social support network is incredibly important to maintaining our physical and mental wellbeing. Research has shown that having high-quality social supports in our lives can improve our resilience skills and decrease the impacts of trauma-related mental health issues. Social supports help to enhance our quality of life, providing a buffer to manage and overcome adverse life events.

## HOW TO BROADEN YOUR SOCIAL SUPPORT NETWORK - IT IS NEVER TOO LATE

Most people already have an established social support network through their family and friends. As we progress through life, our circumstances may change and so may our social support networks. I thought it might be useful to list a few stages in life and the avenues in which we can explore meeting new people and potentially developing new social support networks.

**Please note that a majority of the organisations provided also tend to have online/virtual social groups and activities available.**

## Bleeding Disorders Community

**Your local Haemophilia Foundation** – find your state/territory Foundation contact details on the HFA website – [www.haemophilia.org.au](http://www.haemophilia.org.au)

This is your opportunity to connect with the bleeding disorders community and develop a support network that understands what it is like to have a bleeding disorder or be the parent, carer and loved one of a person with a bleeding disorder.

**General local council** - Either call or visit your local council's website to learn about the various social groups and events run by your local council that promote social connectedness and social support.

## New parents, carers and babies

Certainly, being a new parent is a different experience. It can be a challenging time for some to navigate and socially isolating at times. There are a range of groups and supports people can access as new parents or carers. Here are a couple:

**Your local playgroup** - access the Playgroups Australia website to find your nearest playgroup - [playgroupaustralia.org.au](http://playgroupaustralia.org.au)

Playgroups provide parents and carers the opportunity to get together with their young children for a couple of hours each week to connect, learn through play and have fun. Playgroup is one of the first social networks for children and families.

**Local parent support services** – visit the Raising Children website and look under GROWN UPS > SERVICES & SUPPORT > LOCAL SERVICES - [raisingchildren.net.au](http://raisingchildren.net.au)

You may have specific parenting networks in your state or territory, where you can access a parenting advice, support and connect with other parents through a range of groups. For example, in NSW there is Karitane - [www.karitane.com.au](http://www.karitane.com.au)

## Children and young people

For kids and young people, making new friends is very personal, due to their unique personalities, emotional skills and social skills. Preschool and school are environments where children and young people tend to develop most of their friendships. However, there certainly are a range of other avenues where children and teenagers can make new friends and develop their social support network.

Local community sports and activities – information regarding these can be accessed through schools and via your local council website.

**PCYC** – is an organisation that aims to support young people reach their potential through a range of activities and groups which are fun, safe and friendly. There are local PCYC clubs across Australia. You can find your local club and what activities they offer by searching for PCYC on the internet.

## Adults

Most adults tend to have their own established social support networks, but there are plenty of options available to make new friends. Funnily enough, most dating apps now have a friendship section, where you can match with new friends. There is also a specific app/website dedicated to making new friends and joining new social groups called MeetUp.

You can also join a local sporting team, a local club or a workout group like yoga. I joined both a local touch footy team and a yoga class recently. They both have certainly increased my feeling of social connectedness and physical activity levels.

## Older People

Maintaining social supports and social connectedness in our older age is extremely important. There is plenty of research outlining the many physical and mental health issues impacted by social isolation. Fortunately, the importance of maintaining social connectedness to reduce social isolation experienced by older people has been recognised as serious issue. There are a number of ways older people can develop social support networks.

**My Aged Care** - for access to formal social support services, for example the Community Visiting Scheme, which is a service matching socially isolated individuals with volunteer visitors - [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

My Aged Care can also link socially isolated older people to their local community transport services, which tend to run regular social group outings.

**University of the Third Age (U3A)** – there are many U3A networks across Australia. You can find your local U3A and the courses they offer through the U3A online website - [www.u3aonline.org.au](http://www.u3aonline.org.au)

U3A offers a range of stimulating courses for retired or semi-retired people who enjoy learning and meeting like-minded people. There are no previous learning requirements, no exams and no awards at the end of a course. U3A is an opportunity to keep stimulated and meet interesting people while you continue to learn.

## Carers

Carers are also at a higher risk of social isolation. Maintaining social connectedness and social support networks is very important for carers to reduce instances of social isolation.

**Your local Carers association** – find your state/territory Carers association on the Carers Australia website – [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

Carers associations are organisations that support all carers who are looking after individuals with support needs relating to ageing, disability, health and mental illness. Local Carers associations run a range of carer support groups and networks.

Do not to forget to reach out and maintain contact with your current social support networks. New jobs, study, raising a family, poor health and even a pandemic can slow down your ability to maintain connectedness with your close friends and family. Maintaining contact with your social support network is still really important and can be as simple as a text message, a phone call/video call, catching up for a walk or doing something a little more special like a lunch or dinner out.

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**Nicoletta Crollini** is Haemophilia Social Worker at the Royal Prince Alfred Hospital, Sydney, NSW  
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# Understanding disability and aged care services

Alex Coombs and Jane Portnoy

*This article is adapted with permission from Ask us: Q & As with Alex and Jane, Alfred Hospital HTC Team. The Missing Factor, September 2019, magazine of Haemophilia Foundation Victoria (www.hfv.org.au)*

Alex Coombs and Jane Portnoy are Social Workers – Haemophilia & Other Inherited Bleeding Disorders at the Ronald Sawers Haemophilia Centre at Alfred Health, Melbourne

Read this article online on the HFA website to click on the links:  
[www.tinyurl.com/GOIH-disability-aged-care](http://www.tinyurl.com/GOIH-disability-aged-care)

**Q: I'm a bit confused by the Disability Support Pension (DSP) which I get, the National Disability Insurance Scheme (NDIS) and My Aged Care. Does one affect the other? I live with my mum who is getting older and slower every day and we are both beginning to have problems and might need help.**

It can be daunting to unravel the government benefits schemes and services available to people with bleeding disorders and their family as they grow older. This question is common among our clients.

We are all growing older and some days it seems the acceleration is faster than others. Disability and aged care services can be a minefield of terminology, acronyms, official websites and guidelines. Waiting in the queue on the telephone for answers can seem endless and be very tiring. With that in mind, we have outlined answers to some of the issues raised in this question.

## DO I HAVE A DISABILITY?

If you have a bleeding disorder, it is important to understand the difference between a medical condition and a disability.

When you are applying for government benefits or services, the terms 'haemophilia', 'von Willebrand disease', 'inherited bleeding disorder', and 'genetic disorder' are considered to be medical conditions. When you give your medical history, you will disclose these if asked to ensure your records are accurate.

Having a medical condition is not deemed a 'disability' in itself, but you may develop a disability as a consequence of this medical condition, or your bleeding disorder can contribute to your disability.



## FIRST THINGS FIRST – GETTING STARTED

### MyGov Portal

**W:** <https://my.gov.au/>



MyGov is the online portal that allows you to access Centrelink, the ATO (Australian Tax Office), Medicare, and many other public services including your NDIS or MyAged Care account.

Using MyGov is almost mandatory if you want to interact with Centrelink.

- You will need to create an MyGov account with a reference number and password.
- Keep these details secure and handy whenever you make inquiries.



### Centrelink

**W:** <https://www.centrelink.gov.au>

**T: 13 2300**

Monday to Friday 8 am to 5 pm



Login to MyGov to access your Centrelink account.

Centrelink delivers Centrelink (Australian Government) social security payments and services to Australians.

To find more information about Centrelink payments and services, go to <https://www.servicesaustralia.gov.au/>

### Centrelink Indigenous Call Centre

**T: 1800 136 380**

Monday to Friday 8 am to 5 pm

## DISABILITY SUPPORT AND SERVICES

### Disability Support Pension (DSP)

**W:** <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension>

**T:** 13 2717

Monday to Friday 8 am to 5 pm



Australian Government

The Disability Support Pension is your income. It is means tested and based on your inability to work full-time or part-time.

You are eligible if you are aged between 16 and 64 years and experience a reduced participation capacity due to a physical, intellectual, or psychiatric condition.

To meet the medical criteria, individuals applying for the DSP must be manifestly medically eligible or have a disability or medical condition that is:

- fully diagnosed, treated and stabilised
- has a minimum impairment rating of 20 points under the Impairment Tables of the Social Security
- and have been assessed as unable to work or be retrained for any work of at least 15 hours a week in the next two years

The DSP allows you to work part-time/casually up to a certain level of gross pay (pre-tax amount). Centrelink will advise you of the allowable pay level or you can check on the Services Australia website. You must report any gross pay you have earned and the number of hours worked fortnightly to Centrelink, and then they will reduce the pension payment accordingly.

Your DSP amount received does not affect the NDIS funding.

Please note your local Centrelink office should have a social worker available to clarify any questions if you still feel confused after talking with the front counter staff. Make an appointment (if this is permissible under COVID restrictions) to sit down and raise your questions or concerns about your entitlements or your application. This can include an appeal against a decision to refuse your application, if this occurs.

### OTHER QUESTIONS?

#### Assessment of your claim

Centrelink will assess your impairment as part of the general medical rules for Disability Support Pension (DSP)

Go to: <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/how-we-assess-your-claim/impairment-rating>

#### Medical Evidence

Centrelink requires medical evidence if you claim the Disability Support Pension (DSP) or have a medical review. Follow this link to ensure you provide the evidence required.

Go to: <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/how-we-assess-your-claim/medical-evidence>

## The National Disability Insurance Scheme (NDIS) & National Disability Insurance Authority (NDIA)

**W:** <https://www.ndis.gov.au/>

**T:** 1800 800 110

Monday to Friday 8am to 8pm (local time)

The NDIS logo consists of the lowercase letters 'ndis' in a white, sans-serif font. A small green dot is positioned above the letter 'i'.

The NDIA is the agency that administers the NDIS.

The NDIS is the scheme that provides the funding for your services, support and equipment/modifications to the home/car etc. which will enable you to be as independent as possible.

Eligibility:

- As an applicant you must be under 65 years of age.
- If you are successful in accessing the NDIS and you later turn 65, you will be able to continue to have NDIS support

Having haemophilia as a **medical** condition in itself will not suffice. It is about the impairments associated with haemophilia and other inherited bleeding disorders that impact on your day-to-day functioning and capacity to be independent.

This must be impressed upon when you complete your **Access Request form**.

You need to identify your goals and needs and have a physiotherapist/occupational therapist/medical officer assessment to support your request.

To get started, you can go to the NDIS website to download an Access Request form or call the contact number to request a form to be sent to you.

Go to <https://www.ndis.gov.au/how-apply-ndis/what-access-request-form#access-request-form>

Complete this form in consultation with your GP initially or your specialist(s).



### OTHER QUESTIONS?

#### Am I eligible?

Go to <https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>

#### NDIS – What types of support are funded?

Go to <https://www.ndis.gov.au/understanding/what-ndis-responsible#what-types-of-supports-are-funded>

#### NDIS Goal Setting

Go to <https://www.ndis.gov.au/participants/creating-your-plan/setting-goals>

## Disability Gateway

**W:** <https://www.disabilitygateway.gov.au/>

**T:** 1800 643 787

Monday to Friday, 8am to 8pm AEST



The Disability Gateway has information and services to help people with disability, their family, friends and carers to find the support they need in Australia.

## THE TRANSITION FROM NDIS TO MY AGED CARE

Currently there is no automatic transition from NDIS to My Aged Care.

Upon turning 65 years old, if you have been on the NDIS funding, you have a choice to move to MyAged Care or remain on the NDIS.

These are two separate pools of funding initially dependent on the age of the applicant. Discussions with the Federal Government to open up the NDIS to those over 65 as well who have a disability are on-going.

In short, to be eligible for the NDIS you will need to apply before turning 65 years of age and have functional impairments brought on by a developmental, intellectual or mental health disability or an acquired disability such as from an accident or illness, which restricts your ability to lead an independent life. It provides funding for in-home supports such as support workers, equipment and home modifications. Once approved for a NDIS funding budget, it is for life.

Currently My Aged Care is for those 65 years and older (50 years or older for Aboriginal or Torres Strait Islander people) whose independence is impacted by the aging process and its effects and where it reduces their capacity to continue their self-care. You may need in-home services to continue to live in your existing home. Some may consider relocation to supported accommodation in either an aged care home providing different levels of support or in

a retirement village. If you acquire or develop a disability after 65 years of age you currently cannot apply to the NDIS for additional funding.

## TRANSITIONING TO THE AGE PENSION

On reaching Age Pension age (see under **Age Pension** below for your respective attainable date) and if you are in receipt of an eligible payment, you can apply for a transfer to the Age Pension, which is simpler and easier than completing a full Age Pension claim.

Centrelink will send you an invitation to transfer 13 weeks before you reach Age Pension age. Qualifying for the Age Pension depends on your circumstances and the payment you currently get. On contact with Centrelink's Age Pension staff, you will need to tell them if you:

- want to apply to transfer to Age Pension or not
- have superannuation, because any superannuation you have may affect your rate of payment.

Please ensure you complete the process to the end to ensure continuity of your benefits and entitlements.

Go to <https://www.servicesaustralia.gov.au/individuals/topics/transfer-age-pension/31161>

## AGED CARE SUPPORT AND SERVICES

### Age Pension

**W:** <https://www.dss.gov.au/seniors/benefits-payments/age-pension>

**T: 13 2300**

Monday to Friday 8am to 5pm



Australian Government

The Age Pension is the main income support payment for people who have reached the **Age Pension age**:

- On 1 July 2021, the Age Pension age increased to 66 years and 6 months for people born from 1 July 1955 to 31 December 1956, inclusive.
- If your birthdate is on or after 1 January 1957, you'll have to wait until you turn 67. This will be the Age Pension age from 1 July 2023.

There are range of eligibility requirements associated with the Age Pension that are based on age, residency and means test qualifications.

### MyAged Care

**W:** <https://www.myagedcare.gov.au/>

**T: Ph 1800 200 422**



My Aged Care is a referral and information system for anyone aged 65 years and older (50 years or older for Aboriginal or Torres Strait Islander people).

This is not the Age Pension available from Centrelink.

This is where you or your family go to begin the process of seeking appropriate services, equipment, and specialist aged care assessments of your needs that will assist in keeping you or your aging family member at home and independent for as long as possible. It is also the point at which you can request

an in-home assessment for possible nursing home placement or what other supported residential options exist and including access to planned respite stay for the ageing person.

You can still seek out your family GP after accessing My Aged Care as well.

Once your register, it is important you keep the reference number you receive handy at all times to make further enquiries.

### WHERE TO GET MORE HELP

You may be wondering where you can go and who to talk to for more help.

Links and contact numbers have been provided above to help you to look further into your respective claim area.

#### If you need more help?

Haemophilia Treatment Centre (HTC) social workers and counsellors can support you with gathering information in making your application, referring you on to Centrelink helplines, Centrelink social workers and other community advocacy services.

# women & girls

with **bleeding disorders**  
July 8–10, 2021



## *Suzanne O’Callaghan*

WFH (World Federation of Hemophilia) staged the second **Global summit on women and girls with inherited bleeding disorders** in July 2021. This was a virtual meeting for women with bleeding disorders, patient organisations, healthcare professionals and other supporters from around the world to exchange information and experiences.

The Agenda covered topical issues in diagnosis and management, how women are advocating for better care, and the ways they are getting their voices heard. This included plenaries and education sessions on diagnosis, multi-disciplinary care and self-advocacy. There were ‘hot topic’ sessions: from oral health in sexual intimacy and what treatment products women would like to see available, to gynaecologists in comprehensive care and stigma in talking about bleeding.

There were also sessions about ‘toolkits’ – sharing the language and tools to describe, record and report bleeding disorders in women and girls. For effective treatment and care, understanding bleeding disorders in females is crucial, but it involves discussions between patients and health professionals where this information can be reported and assessed objectively – where everyone is speaking the same language. Joanna McCosker explores this further in her article **Talking about periods** with pre-adolescent girls in this issue of *National Haemophilia*.

The WFH summit has global representation in its presenters as well, and it was great to see Australian Susie Couper chairing the final toolkit discussion



on actions and ways to address the disparities in care, treatment and diagnosis. Susie is on the HFWA Committee and is a member of the WFH women with inherited bleeding disorders committee.

## HEALTH OUTCOMES

Advocacy around treatment and care relies heavily on data as evidence and if we are to improve the health and quality of life of women and girls with bleeding disorders, collecting consistent data on this will be essential.

One very topical plenary asked three questions:

- What are the desired health outcomes for women and girls with bleeding disorders?
- Are they the same as men?
- How can we advocate for women and girls with bleeding disorders when there is little data about them?

Dr Robert Sidonio is a leading US haematologist specialising in women and girls with bleeding disorders and discussed the importance of collecting data about women and girls into bleeding disorders registries. This is new work that involves defining what data about female bleeding needs to be collected and how to restructure the databases to measure relevant treatments and outcomes.

Dr Sidonio described some US-based projects that had attempted this and outlined some of the issues they raised – for example, the diversity of bleeding disorders and treatments in women and girls and inconsistent documentation of heavy menstrual bleeding, joint damage and post-partum haemorrhage. He thought the new VWD (von Willebrand disease) guidelines may improve this, as they take into account the different patterns of bleeding symptoms in females. Quality of life impacts are also more common in females with mild bleeding disorders than males due to heavy menstrual bleeding and complications such as iron deficiency. He highlighted the benefits of having an obstetrician/gynaecologist as part of the comprehensive care team.

Following Dr Sidonio's presentation, Declan Noone from the European Haemophilia Consortium looked at data and why it matters. He explained some of the issues with registries – that they have not been designed to collect information on 'minor' bleeds, eg, nose, gum, menstrual, sub-clinical, reported bleeding. Moreover, for advocacy, good statistical data is very important but aligning it with the personal story to explain the human experience of the statistics is very important, otherwise the data will be misunderstood. Another complicating factor is that there have not been consistent and objective ways to collect information on health outcomes for females – for example, a woman might not judge her bleeding as a problem if all the women in her family have very heavy periods, but in surveys will comment on being weary of the 'monthly bloodbath'. Finding effective ways to measure symptoms like heavy menstrual bleeding and its impact on quality of life will make a big difference to meaningful data collection.

This is very relevant to our work in the HFA The Female Factors project to understand and explain bleeding disorders in women and girls. We are looking forward to the conference session on women and girls in our 2021 national conference, where we will be exploring this further!



Australia's COVID-19 Vaccine Roadmap

COVID-19 VACCINE

COVID-19 VACCINATION

## With lockdowns around Australia due to COVID-19, getting vaccinated has become a high priority in all states and territories.

Do you have questions about the COVID-19 vaccine for people with bleeding disorders?

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has advised HFA on answers to some common questions relating to the vaccine and bleeding disorders.

The HFA **COVID-19 vaccine FAQs** also includes links to the Australian Government information about the vaccine.

Read the COVID-19 vaccine FAQs on the HFA website - [www.haemophilia.org.au](http://www.haemophilia.org.au)

There is also a PDF version online for you to print or download and take to your appointment.

The FAQs may be updated as more information becomes known. Please check the HFA website for updates.

If you have any questions about your bleeding disorder in relation to the COVID-19 vaccine, contact your Haemophilia Treatment Centre or your treating haematologist.

# How to talk about periods?

Joanna McCosker

## Prepare your daughter before menarche

A girl's first period is known as **menarche**.

Why is it important to see your health professional before your daughter's period starts?

It is important to prepare and equip your daughter with the knowledge and tools to manage her period.

Doing the groundwork **BEFORE** her period starts.



Firstly, it's important for your daughter, yourself and your health professional to build a relationship. You want to feel comfortable and have fun so it's not too embarrassing. It is also important to set an attitude early that periods are not taboo, and you don't have to be fearful of your period starting. Young girls need knowledge, so don't fear talking to your daughter: periods are a normal bodily function for all women.

In the first clinic visit we want to discuss what to expect and provide a perspective of what is normal versus what is heavy and abnormal. If you come from a family of heavy bleeders and your bleeding is also heavy, you will just think that your bleeding is normal.

## COMMUNICATING ABOUT PERIODS

Communication is important and we all need to be talking the same language as PERCEPTION matters and everyone will have a different idea or understanding. We need to explain and define all the terms we use, such as a blood clot and what is heavy blood loss compared to relative 'normal' blood loss. The words we use to describe menstrual flow and symptoms - including both slang and medical words - need clarification and we also need to think about culturally appropriate words. What words do you use to describe your period? Does your health care professional know what you're talking about – do you understand them?

Practically we need show the girls the 'tools' we will use, such as pads and tampons, including the many and varied types and their levels of absorbency. This discussion should also now include the new revolution of period underwear that has become mainstream. It is essential to describe and show 'spotting' looks like versus a relative normal amount of blood loss compared to a soaked and saturated pad or tampon. What on earth does your healthcare professional mean when she/he says do you flood, or do you pass clots? Furthermore, is pain normal, what about cramping? What medications can be used? When should you talk with your doctor/general practitioner/Haemophilia Treatment Centre?

We need to empower our young women by learning together and explaining these types of terms to our young girls before they start their period. There are many resources available to assist our young women to learn but it is most important to be matter of fact and honest. We also need to encourage them to track their periods in whatever manner they wish. Managing your period is like any other bleeding symptom that you need to report and that may need intervention!!!

## AFTER MENARCHE

When your daughter has started her periods, it is helpful for her to be prepared for her clinic review. She should gather and document information including:

- Tracking her periods, menstrual flow (heavy, moderate, light)
- How long her menstrual cycle last for, what type of sanitary products she uses and what level of absorbency.

- The frequency of changes – spotting, soaked/saturated, leaks, flooding overnight.
- Pain and what medications she may take and whether they are effective or do they have side effects.
- She should also consider the emotional and physical impact her periods are having on her life including work, school and sport.

Encourage her to make notes and have questions ready for her health care professional.

Please remember it is not complaining – it is symptom reporting just like any other bleeding issue.

.....  
**Joanna McCosker** is Haemophilia Nurse Practitioner at Queensland Children’s Hospital  
 .....

## PERIODS – WHAT’S NORMAL?

### Period pain is considered ‘normal’ if:



The pain is manageable or goes away if you take simple period pain medication



It is only there for a few days before and on the first one or two days of your period



It goes away if you use the contraceptive pill (particularly if you use the pill continuously and skip your periods)



You are able to do all of your normal daily activities such as going to school or work, or playing sport.

### Here are some signs that suggest that a period is ‘heavier’ than average.



Soaking through a super tampon or pad every two hours or less, or needing to change protection or put a towel under you or flooding the bed during the night



Periods that last for longer than 8 days



Bleeding with clots bigger than a 50 cent piece



Cramping and pain in the lower abdomen (tummy)

Constant tiredness.

If your period pain does not fit the description of ‘normal’ and is so bad that it stops you doing what you would normally do on a daily basis, such as going to school or work, it is important to talk to your health care professional or gynaecologist.

### Heavy periods

Heavy periods are also called ‘heavy menstrual bleeding’. Health care professionals may also use the terms ‘abnormal uterine bleeding’ or ‘menorrhagia’. It can be difficult to define what heavy periods are because what different girls and women call ‘heavy’ can vary. It partly depends on what you or your family are used to, and how much your period interferes with your everyday life.

**Source:** Women’s bleeding explained in *Female Factors: information for young women with bleeding disorders* (Melbourne: HFA, 2018) - <https://tinyurl.com/Femalefactors>

### LOOKING FOR IDEAS ON PERIOD DIARIES?

Talk to your Haemophilia Treatment Centre about pictorial charts and smartphone apps that you can use to record menstrual cycles. Some have been designed specifically for girls and women with bleeding disorders.

There is also more information about period diaries on Factored In under GIRLS - [www.factoredin.org.au/info/girls](http://www.factoredin.org.au/info/girls)

# YOUTH NEWS

## Facing my fear of needles



My name is Bailey. I am 16 years old and I have moderate haemophilia A.

### Bailey explains how he dealt with the challenge of infusing his treatment when he had a fear of needles

My name is Bailey. I am 16 years old and I have moderate haemophilia A.

For most of my younger years, the only person I knew who had the same condition as me was my mum, who also has mild haemophilia A. It wasn't until we attended our first haemophilia family camp that I met other kids my own age with haemophilia.

It was a really nice feeling to be around other kids who had similar challenges to myself as a result of being born with a rare bleeding condition. I found watching the other boys self-infuse very confronting as the only time I receive factor is at the children's hospital and up until recently I have had a fear of needles. Most of the boys I know have severe haemophilia and I have always admired how brave they are self-infusing factor from such a young age.



I have always admired how brave they are self-infusing factor from such a young age.



## What's happening?

### Living with moderate haemophilia means...

I am very grateful to have only moderate haemophilia as it means I do not need to worry about spontaneous bleeding however I think I am a lot more cautious in my everyday actions than my friends with severe haemophilia as my factor VIII (8) levels are low every day and it's a really big deal to go to the hospital whenever I get injured.

### Overcoming my fear of needles

Now that I am a teenager and I want to be more independent, I have been able to overcome my fear of needles. The haemophilia nurse at the children's hospital has now trained me up to be able to give myself my desmopressin medication subcutaneously (under the skin) by injection. This means that when I am on camp or staying at friends' houses, I know I can help myself if I get injured. This has made me relax a lot more.



Now that I am a teenager and I want to be more independent, I have been able to overcome my fear of needles.

### What's the best thing?

The best thing about having haemophilia is the community. I have made so many friends in the haemophilia community and the family camps are so much fun.



It was a really nice feeling to be around other kids who had similar challenges to myself.

### Read more

Visit Factored In to read other young people's personal stories about living with a bleeding disorder – [www.factoredin.org.au](http://www.factoredin.org.au)

This article was originally published in *The Missing Factor, Winter 2021*, the magazine of Haemophilia Foundation Victoria ([www.hfv.org.au](http://www.hfv.org.au)), and is reprinted with permission.

Photos supplied by Bailey and his parents and HFV and used with permission.

# CALENDAR

## 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders (virtual meeting)

8-9 October 2021

Tel: 03 9885 7800

Email: [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)

[www.haemophilia.org.au/conference21](http://www.haemophilia.org.au/conference21)

## Bleeding Disorders Awareness Week

10 -16 October 2021

Tel: 03 9885 7800

Email: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

[www.haemophilia.org.au/BDAW](http://www.haemophilia.org.au/BDAW)

## World Haemophilia Day

17 April 2022

[www.wfh.org/whd](http://www.wfh.org/whd)

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BIOMARIN | CSL BEHRING | NOVO NORDISK  
PFIZER AUSTRALIA | ROCHE | SANOFI GENZYME  
TAKEDA

# Have you changed your address?

## Make sure you stay connected!

If you have changed your contact details, like your postal or email address, let us know so that we can update our database.

That way you will keep receiving *National Haemophilia* or the HFA e-news if you have subscribed.

## How to change your details?

- Complete the Update my details form under HELPFUL LINKS at the bottom left of the HFA website – [www.haemophilia.org.au](http://www.haemophilia.org.au)
- Or email us at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)
- Or call us on 03 9885 7800



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