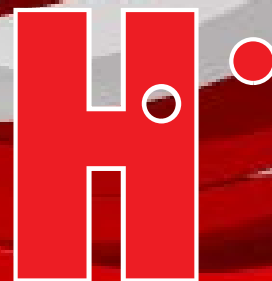


Factor Matters

Haemophilia
Foundation
NSW



Published by HFNSW

March 2022

Volume 49

WORLD HAEMOPHILIA DAY
2022

MENTAL HEALTH MATTERS!
HFNSW NEW FINANCIAL SUPPORT

HFNSW LUNCHEON
JANUARY 2022

INTERNATIONAL
WOMEN'S DAY 2022



About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, our mandate is to support the full range of other important things for the bleeding disorder community such as: community participation, physical & emotional support, advocacy, education and financial assistance to members, their families and carers.

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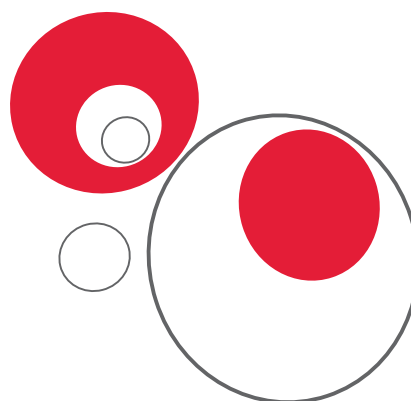
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Factor Matters Vol 49, March 2022

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Hello all. I am writing this on a day of rare sunny skies here in Sydney and hoping you all go as well as you can in these eventful times. Hang in there!

Having two thirty-something sons with severe Haemophilia A I have a life-long interest and involvement in all-things haemophilia. I enjoy and feel fortunate to be still involved, including being a director on the National Blood Authority (NBA) advisory board.

One of the reasons I became involved with the HFNSW in the early 1990s was when as a father of boys with haemophilia I really realised how fortunate I was to be in Australia health-wise. We have a medical system that is available to every citizen and permanent resident of this country and as a nation we can afford to treat most known diseases and disorders at no personal cost (or very low cost) to all patients. None of us parents could have personally funded our children's haemophilia treatments for life! And I think of third world countries (and the USA for that matter) and shudder.

Being on the NBA board I am conscious that the Federal health budgets in Australia continue to rise, and that haemophilia's necessary treatments continue to be expensive per patient. Yet at the NBA I see full commitment from Federal and State governments, the CEO and the dedicated staff to continuing to

fund and purchase the best blood related products available, including the best haemophilia treatment products the world can manufacture.

But all of this is not guaranteed forever of course. Times change, as we are seeing now. We need to be vigilant, engaged and strong advocates. There are treatments for other rare diseases and disorders that are also as expensive as those for haemophilia, but they are not blood related (which means they are not free, whereas all blood products are free), and nor are they on the Pharmaceutical Benefits Scheme (PBS). Some new treatments are simply not yet approved here, such that patients sometimes go untreated and suffer, or they are forced overseas. Australia doesn't buy everything. It has a budget.

It matters that we are a strong, connected haemophilia community here in NSW, as well as at the Federal level and all other States and Territories. This is so that government health officers/ executives and politicians see that we are organised and helping each other, as well as being part of the processes of government that ensure the future of Australia's supply of world class treatments for haemophilia.

I urge you to stay engaged, as the strength of the HFNSW is not a given. The strength of certain other State Haemophilia Foundations has struggled or floundered in the past decade or earlier, and even HFNSW has only rebuilt itself to be stronger and more sustainable over the last five years or so. We are currently fortunate to have a full committee, a great co-ordinator (thank you Shiva) and a hardworking, totally reliable Finance/Admin Officer (thank you Sam), as well as some spare funds to sustain us.

So, please, stay connected and great if you can contribute in some way.

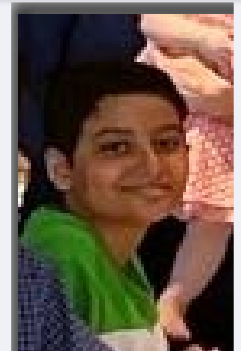
Paul

On Sunday 30th January 2022, Haemophilia Foundation NSW hosted a lunch gathering at Rashays Restaurant in Top Ryde Shopping Centre. There's nothing like a catch-up over a nice meal to loosen up and get our stories and ideas flowing.



Thank you those who took time out of your busy life to attend and make the day memorable. Your company was appreciated and enjoyed. I hope you enjoyed yourself as well.

We look forward to seeing more members, clinicians, supporters and families in our upcoming gatherings.





28 February was Rare Disease Day! Rare Disease Day is dedicated to raising awareness for the 300 million people living with a rare disease around the world including an estimated two million Australians, and their families and carers! On Rare Disease Day, many activities took place throughout Australia and over 60 landmarks around the country were illuminated to highlight people living with a rare disease. The rare disease is an opportunity for the community and its supporters to come together to share their colours and call for equity of social opportunity, treatment and care.

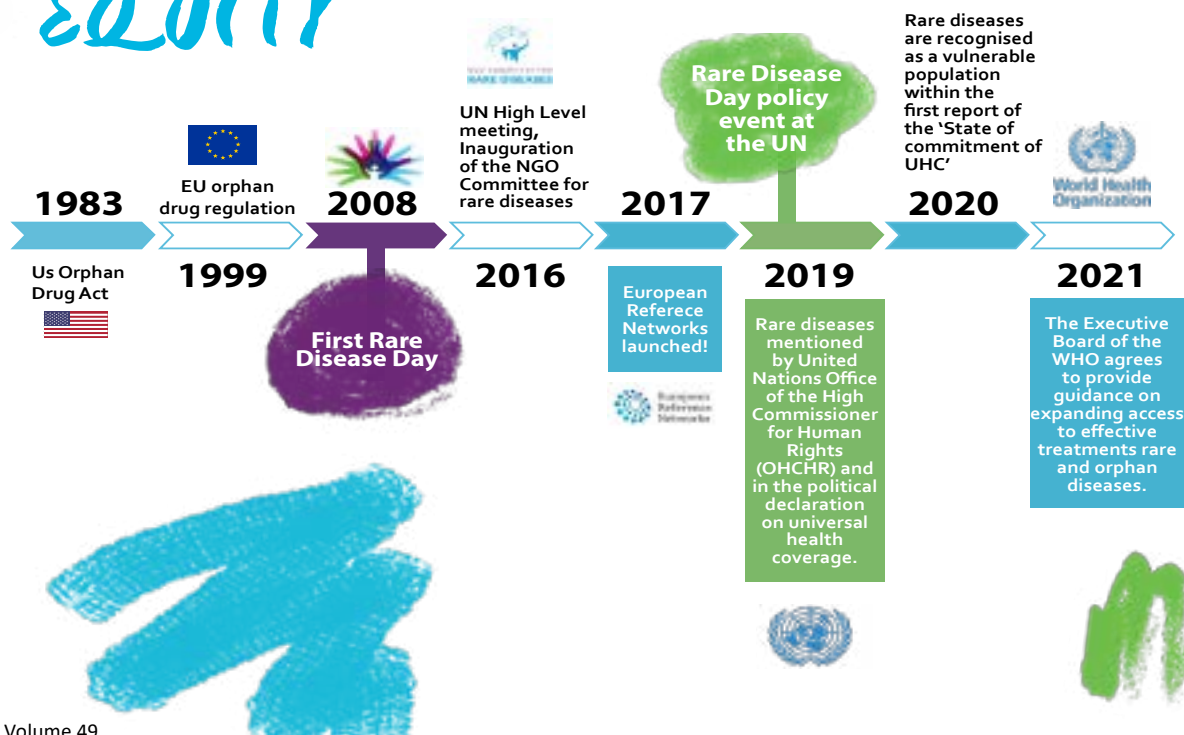
What does equity mean for people living with a rare disease?

Equity in practice means meeting people's specific needs and eliminating barriers preventing their full participation in society. For people living with a rare disease equity means social opportunity, non-discrimination in education and work, and equitable access to health, social care, diagnosis and treatment. On Rare Disease Day there is a call for action for people living with a rare disease to have equal opportunities to realise their full participation in family, work and social life. The long-term goal of Rare Disease Day over the next decade is increased equity for people living with a rare disease and their families.

JUSTICE
ACCESS TO SUPPORT
PARTICIPATION
SOCIAL INCLUSION
STANDARDS OF CARE
TREATMENT OPTIONS

VISIBILITY
DIAGNOSIS
ACCESS TO SUPPORT

MILESTONES IN ACHIEVING EQUITY





MANAGING YOUR MENTAL HEALTH AND ACCESSING SUPPORTS

Nicoletta Crollini - Haemophilia Social Worker at Royal Prince Alfred Hospital

The COVID-19 pandemic has ensured that mental health is at the forefront of the healthcare agenda. Over the past year, both NSW and Federal Governments have dedicated a significant chunk of funding to improve access and availability to mental health services.

This targeted funding boost was very much needed considering:

- 1 in 5 Australians have experienced some form of mental health disorder in the past 12 months.
- 1 in 2 Australians will experience a mental disorder in their lifetime.
- Younger males aged 16 to 24 experience the highest rates of mental disorders.

It is important to acknowledge that the haemophilia and inherited bleeding disorder community is not exempt from dealing with mental health issues, with an estimated 2 out of every 5 people with haemophilia dealing with depression and/or anxiety.

With these statistics and the funding boost, I thought it would be useful to raise awareness of the various mental health supports and services that anyone can access.

How to seek support?

There are plenty of services that are available to provide instant support to anyone dealing with a mental health issue or crisis. Below is a list of services that can be contacted to talk through what is happening in your life as well as link you in with long term supports.

Contact your Haemophilia Treatment Centre

You can contact your local HTC and connect with the

psychosocial worker at the centre to talk through what is happening, and if needed, the psychosocial worker can connect you with long term support.

Talk with your GP

You can also visit your GP who can complete a Mental Health Treatment Plan with you, which is a tailored plan that links you in with specific mental health support services. A Mental Health Treatment Plan will allow you to initially access 6 individual psychological appointments that are subsidised through Medicare. If more sessions are needed you can discuss this with your GP to access more Medicare subsidised psychological appointments. Through a Mental Health Treatment Plan, you will be able to access a range of psychological support specialists such as psychologists, social workers and occupational therapists to assist with your mental health care needs.

HFNSW financial support

If financial challenges are a barrier to you accessing support and dealing with mental health issues, please note that **HFNSW is now able to provide support to members. Financial assistance will be offered to HFNSW members dealing with mental health issues through bill rebates for mental health services, including consultation fees. Each year HFNSW members will be able to access up to \$100 of financial support to assist with their mental health care needs.**

References

Australian Institute of Health and Welfare (2020) Mental health, AIHW, Australian Government, accessed 24 February 2022.

<https://www.aihw.gov.au/reports/australias-health/mental-health>

Al-Hunuti, A., Reyes Hernandez, M., Ten Eyck, P., & Staber, J. M. (2020). Mental health disorders in haemophilia: Systematic literature review and meta-analysis. *Haemophilia: the official journal of the World Federation of Hemophilia*, 26(3), 431–442. <https://doi.org/10.1111/hae.13960>

Beyond Blue	1300 224 636	www.beyondblue.org.au	For everyone
Headspace	Find local centre online	www.headspace.org.au	For young people and parents
Kids Helpline	1800 551 800	www.kidshelpline.com.au	For kids, young people and parents
Lifeline	13 11 14	www.lifeline.org.au	For everyone
Mental Health Line	1800 011 511		For everyone

How to look after your mental health if you're at home with COVID

Louise Stone

General practitioner; Associate Professor, ANU Medical School, Australian National University

For many of us, catching COVID and isolating at home can be a lonely, scary and distressing experience.

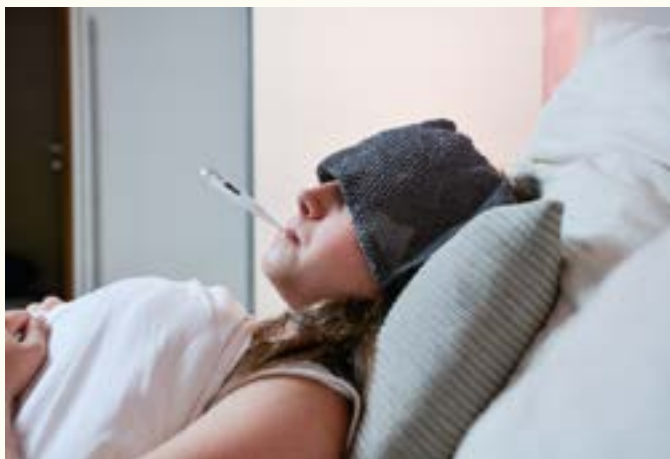
For those with a pre-existing mental illness, it can be even more difficult.

The following strategies are designed to help you look after your mental health if you get COVID and are isolating at home.

Remember the basics

When living in a time of great uncertainty and threat, it can be difficult to remember and practice simple strategies to maximise wellness.

If you're isolating at home with COVID, it's important to:



- manage fever and other symptoms like aches, pains and sore throat with paracetamol or ibuprofen
- maintain a healthy diet
- keep your fluid intake up, particularly if you have a fever
- stop exercise for at least 10 days, and depending on the severity of your symptoms, return to exercise slowly (if you have any questions about returning to exercise, ask your GP)
- deep breathing, which can help lung function and help you stay calm during isolation and recovery, but this should be done in consultation with your doctor



- practise mindfulness to help cope with the inevitable anxiety around illness and isolation
- find distractions like reading, watching movies or doing a creative activity, which can help keep your brain from fixating on worry (this is particularly important for children).
- and stay connected with friends and family, online or over the phone.

It's important to monitor your COVID symptoms. The Royal Australian College of General Practitioners has a useful symptom diary to assist with this. Or use the Healthdirect symptom checker to decide whether you need medical help.



If you live alone, you should arrange for someone to contact you regularly to make sure you are managing.

Some coping strategies to avoid

During times of anxiety and uncertainty, such as isolating at home with COVID, it's understandable people may turn to drugs and alcohol, unhealthy eating, gambling, or other addictions to manage psychological discomfort.

These strategies may temporarily alleviate stress. But they can cause more mental health issues in the longer term.

It's also important to avoid "doom scrolling", which is the tendency to continue to scroll through bad news on your mobile phone, even though the news is saddening, disheartening or depressing.

You might want to disengage from mainstream or social media if it has become harmful to your mental health.

It's been extra hard for those with mental illnesses

The COVID pandemic has made living with mental illness even more difficult. The last few years have been challenging and exhausting for many. People with mental illnesses, and other chronic conditions, have had to adapt their normal management strategies to cope, shifting care



and some forms of therapy online.

Recovery from, and management of, mental illness often involves activities like exercise, positive social engagement and therapy – all of which may be limited due to COVID restrictions, financial constraints and staff shortages.

Acute services, including hospitals and general practice, are struggling to meet demand.

Isolation can be particularly difficult for people who don't have a safe and secure home. People experiencing domestic violence have more difficulty accessing care as they may not be safe interacting with health professionals in their homes.



Children are at increased risk of harm if they live with domestic violence. They may have no safe places to go when schools or childcare facilities are closed, so family, friends and services like Kids Helpline play an important role in supporting children.

Seeking help

There are many resources available to assist you if you're isolating due to COVID.

Your GP can provide advice, help you navigate the health system and treat physical and mental health symptoms, via telehealth over the phone or online. Medicare rebates for telehealth are available if you have seen the GP face to face in the previous 12 months.

The National Coronavirus Helpline is a 24-hour service that provides free advice on how to seek medical help.

Beyond Blue offers a series of resources for adapting to the pandemic, including for Australians living overseas and people who speak languages other than English. The organisation also offers free counselling during the pandemic. Call 1800 512 348 to speak with a trained mental health professional, or chat online.

The federal government provides a free mental health service for people in Victoria, NSW and the ACT who've been affected by the pandemic. Call 1800 595 212 from Monday to Friday, 8:30am-5pm.



The Raising Healthy Minds app has information, ideas and guidance for parents to help them support their child's mental health and well-being.

People who are experiencing domestic violence can access support through calling 1800RESPECT on 1800 737 732 or visiting the organisation's website.

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<https://theconversation.com/how-to-look-after-your-mental-health-if-youre-at-home-with-covid-174536>



World Haemophilia Day 2022

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the theme is Access for All. The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work with developing countries with their GAP and Twinning Programs and Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Did you know, WFH estimates that over 75% of people living with hemophilia worldwide have not yet been identified and diagnosed.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that work to achieve the objectives of WFH.

We are grateful that our community has access to high quality treatment but we recognise that many other parts of the world do not have access to diagnosis, treatment and care. Together as Australians, let's take this opportunity to recognise this special day and put our support behind the worldwide effort for Access for All.

Light It up Red

We have many locations and landmarks over Australia Lighting up Red in support of the day. These locations will be listed on HFA website. Keep an eye out and share photos on HFA social media platforms.



Like Haemophilia Foundation Australia on Facebook



Like Haemophilia Foundation Australia on Instagram



Follow HFA @Haemophilia_Au



Subscribe to Haemophilia Foundation Australia on YouTube

HFA will have some virtual activities available at <https://www.haemophilia.org.au/WHD>

For more information, virtual activities and **Light It Up Red** Landmarks visit <https://www.haemophilia.org.au/WHD>



Family Leisure Day-Out

--World Haemophilia Day--

Get your family and friends together and come along for a leisure day-out on the occasion of the **World Haemophilia Day***
You may wish to take a walk, scoot or jog on the Bay Run and show your support of the bleeding disorders community!

This is a free event, and participants will get a commemorative cap.

Meet our HTC's clinical experts and social workers as well as other families from the community and share stories over some drinks and food.

When: Sunday, 10th April 2022; 11:00 – 2:30pm

Where: Leichhardt Oval #3 located on the Bay Run, Maleny St, Lilyfield NSW 2040

Bookings are essential and should be made latest by Thursday 7th April 2022.

Please RSVP through the link below:

www.trybooking.com/BXYHJ

Or, RSVP by emailing us at coordinator@hfnsw.org.au

If you have made a booking, but cannot attend the event for any reason, please return your tickets through the link provided in your booking confirmation email; or, just let us know by email at coordinator@hfnsw.org.au

* Please note that due to the coincidence of the World Haemophilia Day and Easter Sunday on the 17th April, the event is organised a week before, on Sunday 10th April 2022.



About the Haemophilia Treatment Centre

The Kids Factor Zone (KFZ) is located on level 1, opposite sibling care. This is the Haemophilia Treatment Centre also used for review of other patients with Haematology disorders.



To get there from the main entrance, go past Starbucks and the Bandaged Bear Outpatient Clinic. Take the ramp or the lift down to level 1.

If taking the ramp, continue past the cafeteria. The KFZ is located on the right hand corner.

If taking the lift, exit at level 1 and turn right continuing past the cafeteria. The KFZ is located on the right hand corner.

Alternatively you can present to the Information Desk as you enter the hospital and they can page the nurse for you.



There is a phone located outside the entrance of the KFZ. If the room is not occupied when you arrive, use the phone and follow these instructions to call the nurse.

Pick up the handset and press *2. You will hear 'enter the pager number followed by the star (*) key'. Enter 7052* to contact Robyn Shoemark or 6273* to contact Ady Woods. You will then hear the message 'your page has been sent'. Hang up the phone and wait for a call back. If you don't receive a call back within 5 minutes, page again or try the other nurse's page number.

IMPORTANT – you must enter the star (*) to use the paging system.



To change any appointments please contact

- SCHN-CHW-Haematology@health.nsw.gov.au or 02 9845 3295
- Robyn Shoemark robyn.shoemark@health.nsw.gov.au or 02 9845 0000 page 7052
- Adrienne (Ady) Woods adrienne.woods@health.nsw.gov.au or 02 9845 0000 page 6273

The Kids Factor Zone at Westmead Children's Hospital

Map



HEAVY PERIODS? YOU MIGHT HAVE AN UNDIAGNOSED BLEEDING DISORDER

Paula James

Professor of Medicine, Queen's University, Ontario

Women with bleeding disorders can wait up to 15 years to get appropriate testing and treatment.



About 30 per cent of all women report heavy menstrual periods at some point during their reproductive years. Up to 15 per cent of these have an underlying bleeding disorder and yet most have never been diagnosed, leaving thousands of women to suffer from a treatable problem.

As a hematologist and clinician scientist at Queen's University who cares for patients with inherited bleeding disorders, it is a major source of frustration for me that women with bleeding disorders can wait up to 15 years to get appropriate testing and treatment.

I worry even more about what happens to those who never get diagnosed. These women are at risk of acute hemorrhages leading to blood transfusions and the need for hysterectomy.

Because April 17 is the annual World Hemophilia Day — a day focused on outreach and education about hemophilia — I would like to share some evidence-based information about heavy periods, what it means to be a female “carrier” of hemophilia and how you can easily test yourself for a bleeding disorder.

Iron deficiency and abnormal periods

Bleeding disorders that affect women include von Willebrand disease and hemophilia — both are inherited and are caused by low levels of “clotting factors” (proteins needed for normal blood clotting).

In families with a bleeding disorder, it is common for women to not realize their periods are heavy because other affected women in the family have similar problems. To them, heavy periods seem normal.

There are also social stigmas against an open discussion about periods that can be difficult to overcome. And there is a lack of accurate information about normal versus abnormal periods.

Key features of heavy and abnormal periods include having to change pads or tampons more than every hour, having iron deficiency anemia, frequently soaking through your sheets at night and bleeding that lasts longer than seven days.

Iron deficiency anemia is of particular concern because it leads to fatigue and shortness of breath as well as poor school and job performance.



Iron deficiency and heavy periods are too often ignored but can be signs of an underlying bleeding disorder. Both are easily treated once the diagnosis is made.

Women can also have hemophilia

Women who are carriers of hemophilia are very often considered to be “only carriers” — capable of passing on a mutant gene to their children. They may be told this by their doctor. Their bleeding then often goes untreated because of this misconception.

My own research has shown, however, that around 30 to 40 per cent of hemophilia carriers experience abnormal bleeding including heavy periods, post-partum hemorrhage and joint bleeds. Some, but not all, have low clotting factor levels.

Effective treatments for heavy periods in women with bleeding disorders are widely available. These include the oral contraceptive pill and medications like tranexamic acid (that prevent clot breakdown) and desmopressin (that increases clotting factor levels).

Gynecologic options such as the levonorgestrel intrauterine device (IUD) and endometrial ablation also exist.

In rare cases, women with bleeding disorders require clotting factor infusions to control heavy periods. If iron deficient, iron supplementation is a key component of treatment as it improves quality of life. Dietary iron intake alone is not enough to correct iron deficiency, particularly once it has caused anemia.

Historically, much of the focus of research and education for hemophilia was on improving treatment for boys and men with the disease. The mainstay is frequent intravenous infusions of the missing clotting factor. Significant advances have been made including the development of better treatments and the possibility of cure.

Are your bleeding symptoms normal?

Many organizations are now focused on increasing public knowledge about bleeding disorders. The recognition that women can also have hemophilia is increasing through the efforts of organizations like the World Federation of Hemophilia.



The role of novel therapies for women with hemophilia isn't clear, and additional research is required to understand exactly why these women bleed. One recent study from my lab showed that the blood clotting system of hemophilia carriers doesn't react to hemostatic stress (such as trauma) as well as it does in healthy controls. A rapid and sustained increase of blood clotting factors is required to halt bleeding following injury and this was significantly impaired in hemophilia carriers.

If you are wondering if you have a bleeding disorder, the Self-BAT (self administered bleeding assessment tool) is freely available and can tell you if your bleeding symptoms are normal or abnormal.

This tool analyzes information about your bleeding symptoms to generate a bleeding score. A high bleeding score is associated with an increased chance of having an underlying bleeding disorder and should be discussed with your doctor.

Significant advances have been made in understanding the problems faced by women with bleeding disorders. More research and education is needed so that all women are diagnosed and treated properly.

Bleeding disorders in women and girls is now a priority area in many countries worldwide as well as Australia.

This article is an example of the work being done internationally. There are other examples available in [HFA](#) and [HFNSW](#) websites. They include evidence-based information, tools for women and girls to monitor their periods (menstrual bleeding) and personal stories.



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WELLNESS IS NOT WOMEN'S FRIEND. IT'S A DISTRACTION FROM WHAT REALLY AILS US

Kate Seers & Rachel Hogg
Charles Sturt University

Wellness is mainly marketed to women. We're encouraged to eat clean, take personal responsibility for our well-being, happiness and life. These are the hallmarks of a strong, independent woman in 2022.

But on the eve of International Women's Day, let's look closer at this neoliberal feminist notion of wellness and personal responsibility – the idea women's health and well-being depends on our individual choices.

We argue wellness is not concerned with actual well-being, whatever wellness "guru" and businesswoman Gwyneth Paltrow suggests, or influencers say on Instagram.

Wellness is an industry. It's also a seductive distraction from what's really impacting women's lives. It glosses over the structural issues undermining women's well-being. These issues cannot be fixed by drinking a turmeric latte or #livingyourbestlife.

What is wellness?

Wellness is an unregulated US\$4.4 trillion global industry due to reach almost \$7 trillion by 2025. It promotes self-help, self-care, fitness, nutrition and spiritual practice. It encourages good choices, intentions and actions.

Wellness is alluring because it feels empowering. Women are left with a sense of control over their lives. It is particularly alluring in times of great uncertainty and limited personal control. These might be during a relationship break up, when facing financial instability, workplace discrimination or a global pandemic.

But wellness is not all it seems.

Wellness blames women

Wellness implies women are flawed and need to be fixed. It demands women resolve their psychological distress, improve their lives and bounce back from adversity, regardless of personal circumstances.

Self-responsibility, self-empowerment and self-optimisation underpin how women are expected to think and behave.

As such, wellness patronises women and micro-manages their daily schedules with journaling, skin care routines, 30-day challenges, meditations, burning candles, yoga and lemon water.

Wellness encourages women to improve their appearance through diet and exercise, manage their surroundings, performance at work and their capacity to juggle the elusive work-life balance as well as their emotional responses to these pressures. They do this with support from costly life coaches, psychotherapists and self-help guides.

Wellness demands women focus on their body, with one's body a measure of their commitment to the task of wellness. Yet this ignores how much these choices and actions cost.

Newsreader and journalist Tracey Spicer says she has spent more than A\$100,000 over the past 35 years for her hair to "look acceptable" at work.

Wellness keeps women focused on their appearance and keeps them spending.

It's also ableist, racist, sexist, ageist and classist. It's aimed at an ideal of young women, thin, white, middle-class and able-bodied.

But we can't live up to these ideals

Wellness assumes women have equal access to time, energy and money to meet these ideals. If you don't, "you're just not trying hard enough". Wellness also implores women to be "adaptable and positive".

If an individual's #positivevibes and wellness are seen as morally good, then it becomes morally necessary for women to engage in behaviours framed as "investments" or "self-care". For those who do not achieve self-optimisation (hint: most of us) this is a personal, shameful failing.

Wellness distracts us

When women believe they are to blame for their circumstances, it hides structural and cultural inequities. Rather than questioning the culture that marginalises women and produces feelings of doubt and inadequacy, wellness provides solutions in the form of superficial empowerment, confidence and resilience.

Women don't need wellness. They are unsafe. Women are more likely to be murdered by a current or former intimate partner, with reports of the pandemic increasing the risk and severity of domestic violence.

Women are more likely to be employed in unstable casualised labour, and experience economic hardship and poverty. Women are also bearing the brunt of the economic fallout from COVID.

Women are more likely to be juggling a career with unpaid domestic duties and more likely to be homeless as they near retirement age.

In their book *Confidence Culture* UK scholars Shani Orgad and Rosalind Gill argue hashtags such as #loveyourbody and #believeinyourself imply psychological blocks, rather than entrenched social injustices, are what hold women back.

What we should be doing instead

Wellness, with its self-help rhetoric, absolves the government of responsibility to provide transformative and effectual action that ensures women are safe, delivered justice, and treated with respect and dignity.

Structural inequity was not created by an individual, and it will not be solved by an individual.

So this International Women's Day, try to resist the neoliberal requirement to take personal responsibility for your wellness. Lobby governments to address structural inequities instead. Follow your anger, not your bliss, call out injustices when you can. And in the words of sexual assault survivor and advocate Grace Tame, "make some noise".



International Women's Day

International Women's Day (IWD) – 8 March – is a time to reflect on progress made, to call for change and to celebrate acts of courage and determination by ordinary women, who have played an extraordinary role in the history of their countries and communities.

In 2022 IWD is celebrated under the International Women's Day theme, **Changing Climates: Equality today for a sustainable tomorrow** – a theme that recognises the contribution of women and girls around the world, who are working to change the climate of gender equality and build a sustainable future.

CHANGING CLIMATES
Equality today for a sustainable tomorrow

HFNSW FINANCIAL SUPPORT FOR MENTAL HEALTH

HFNSW now provides financial assistance to members for Mental Health services and treatment!

We all deserve to live a life full of happiness and and wellbeing, and finances should not stand in the way of getting the mental health treatment that you need.



Mental wellbeing matters! Good mental health helps us cope with everyday stresses, work more efficiently, and contribute more to our community and personal relationships. While our Government provides mental health support and services in different ways, for many of us treating a mental health issue can still involve high out of pocket expenses. Therefore, HFNSW is now offering members additional financial assistance in the form of bill rebates up to \$100 per year for mental health services, including consultation fees.

For more information please call us on 0470637928 or email us at coordinator@hfnsw.org.au.

HFNSW MEMBERSHIP 2021-22

HFNSW's annual membership is available from 1 July each year, and all memberships expire on 30 June each year. Membership fees are \$20 per year (Incl. GST). Membership benefits include a range of support and services comprising subsidised annual Family Camp, assistance to members who are having extended stays in hospital, support groups and other social activities, representation to State and Federal Governments, quarterly newsletter, membership to our national body Haemophilia Foundation Australia, rural visits to outer-lying areas of New South Wales where there are no Specialist Haematologists, and financial support including **REBATES FOR SHOES AND MEDICALERT MEMBERSHIP AND PRODUCTS, AND NOW REBATES FOR MENTAL HEALTH SERVICES AND TREATMENT.**

Please make sure that your membership is up-to-date. The membership registration/renewal form is enclosed with this issue, also available at <https://bit.ly/3yYpRwC>.

For any further information contact us on coordinator@hfnsw.org.au or MB 0470 637 928..

Payment of the membership fees can be made through the following options:

- Visit the donation or membership pages on the Haemophilia Foundation NSW website : <http://hfnsw.org.au/> or use the QR code below
- cheques/money orders payable to:
Haemophilia Foundation NSW Inc. and send to
Haemophilia Foundation NSW, PO Box 631, Broadway NSW 2007
- EFT Payment
BSB: 062 204 Account number: 00902590
Account Name: Haemophilia Foundation NSW

Please include your name in the comments field and email your receipt number to admin@hfnsw.org.au



(Hardship Provision In cases of genuine financial hardship, the committee is prepared to waive or reduce the membership fee. Requests will be handled with discretion and should be directed to coordinator@hfnsw.org.au)

YOUR CONTINUED SUPPORT MATTERS!

After a months-long hiatus,
we are back with yet another event
in the HUNTER REGION!



Come join us
for a variety of fun activities
while enjoying food and drinks



at



Dullboy's Social Co



When: Sunday 15 May 2022, from 11:30am to 2:30pm.

Where: Dullboy's Social Co, 326 Hillsborough Rd, Warners Bay, NSW

Let's get together at 11:30am in a room at the back of the bar area that has been booked for us. The staff at Dullboys can direct you to the room. Please make sure to be there at 11:30am so you won't miss any activities that have been arranged.

THIS IS A FREE EVENT

Booking is essential for this event.
Please RSVP latest by Thursday 12 May through

WWW.trybooking.com/BXYHF

or email coordinator@hfnsww.org.au

Please mention Names of all attendees, ages of children, phone and any dietary requirements.

Supported by HFNSW

HAEMOPHILIA FOUNDATION
NEW SOUTH WALES



Your Opinion Matters!

Thank you those who have taken their precious time to complete HFNSW's survey. Congratulations to our winners! The prizes will be mailed out to you together with this Newsletter.



Those who haven't had a chance to take our survey yet, HFNSW would greatly appreciate it if you would spare a few minutes of your time to do so, as **Your Opinion Matters to Us!** Again we have included the survey in this newsletter.

In appreciation of your time, there will be a range of shopping gift cards up for grabs. Complete the survey and you will enter a draw to win a chance for a gift card.

Send the completed questionnaire via email at coordinator@hfnsw.org.au or by post to PO Box 631, Broadway NSW 2007.

Feel free to contact us if you have any questions and once again, many thanks for your support.

JUST POST-IT!

Your Opinion Matters!

Take HFNSW survey available in paper and online

<https://bit.ly/3INGctS>

and win prizes!

Hunter Region Family Fun Event

15 May 2022

Please RSVP latest by Thursday 12th May through www.trybooking.com/BXYHF

WHD 2022 Family Leisure Day-Out

10 April 2022

Please RSVP latest by Thursday 7th April through www.trybooking.com/BXYHJ

World Haemophilia Day

Save the date

17 April 2022

Your Mental Health Matters!

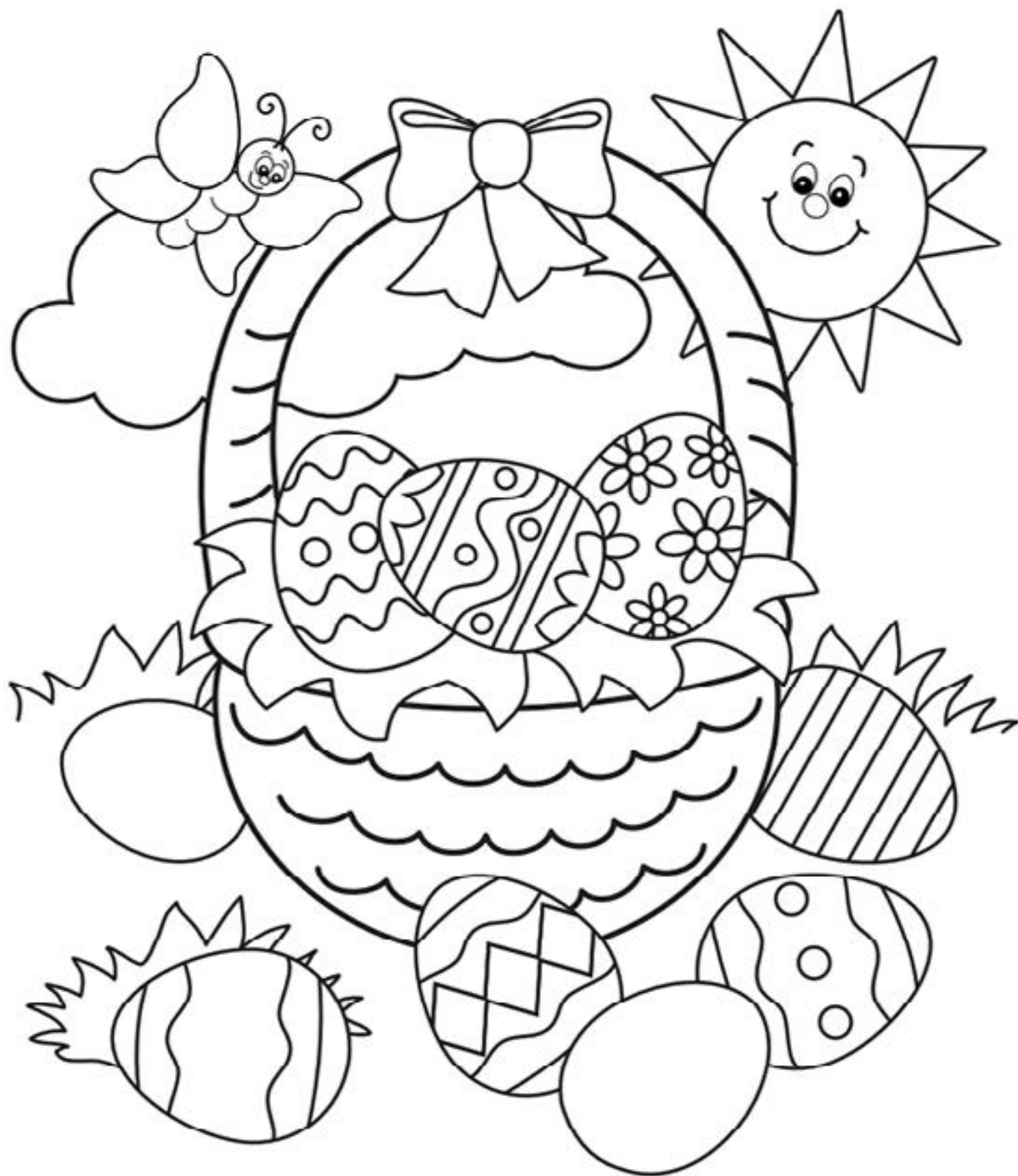
HFNSW now provides rebates on Mental Health Treatment!

(see page 23)

For more information contact us via email coordinator@hfnsw.org.au or phone 0470637928

HFNSW Membership

forms available online <https://bit.ly/3Ko26Eo> and included in this issue



Young Ones Are Invited!

Colour in this page and win prizes such as movie tickets.

Please send by 15 May 2022 to:

Haemophilia Foundation NSW

PO BOX 631, Broadway NSW 2007



MEMBERSHIP FORM 2021-2022

PERSONAL DETAILS

Mr/Mrs/Ms/Other: ----- Name:----- (Required)

(Member details below only required if changed)

Mailing Address: -----

----- Post Code: -----

Ph: (H) ----- (Mobile) -----

Email: -----

Family Details (if completing this as a parent/carer indicate with * for person with bleeding disorder)

Mother's Name: ----- Father's Name: -----

Child's Name: ----- DOB: ----- BD: -----

Child's Name: ----- DOB: ----- BD: -----

Child's Name: ----- DOB: ----- BD: -----

Treatment Centre Attended: -----

PRIVACY

We respect your privacy. Your details will NOT be provided to other organisations or individuals without your permission. Your membership details will assist HFNSW in planning for activities to meet your needs; however, you are not required to provide all details including health information on this form if you do not wish to. Haemophilia Foundation New South Wales (HFNSW) was founded to provide support and education to individuals and families affected by haemophilia, von Willebrand disorder and other related bleeding disorders. HFNSW is a member organisation of Haemophilia Foundation Australia (HFA) which is the national peak advocacy body for the bleeding disorders community.

HFNSW membership automatically entitles you to have access to HFA services and programs, including receiving their quarterly newsletter National Haemophilia. Mark this box if you do **NOT** ☐ want your name and address recorded on the HFA database.

ANNUAL MEMBERSHIP \$20 PER APPLICATION (INCLUDES GST) SINGLE OR FAMILY MEMBERSHIP

Membership \$20.00 (Inc. GST) \$ -----

Donation* \$ -----

TOTAL \$ -----

PAYMENT DETAILS

Payment of the membership fees can be made through the following options:

- Cheques/money orders payable to: Haemophilia Foundation NSW Inc.

Mail to: HFNSW, PO Box 631, Broadway NSW 2007

- EFT payment to: Haemophilia Foundation NSW CBA BSB: 062204 Account number: 00902590

WHEN PAYING ONLINE PLEASE USE YOUR FULL NAME IN THE DESCRIPTION FIELD & FORWARD YOUR RECEIPT NUMBER WITH YOUR MEMBERSHIP RENEWAL.

Please retain a copy of this form for tax purposes if desired. A receipt will be posted to you.



HAEMOPHILIA CENTRES

Kids Factor Zone

The Children's Hospital at Westmead

General: (02) 9845 0000

Robyn Shoemark (Nurse)-- quote Pager no. 7052

robyn.shoemark@health.nsw.gov.au

Ady Woods (Nurse)-- quote Pager no. 6273

adrienne.woods@health.nsw.gov.au

Social Work Department:

Schn-chw-socialwork@health.nsw.gov.au

Sydney Children's Hospital Randwick Haematology

C2 North, Sydney Children's Hospital

High St. Randwick NSW 2031

General: (02) 9382 1111

Grainne Dunne (Nurse)

Direct: (02) 9382 1240

Grainne.Dunne@health.nsw.gov.au

Royal Prince Alfred Hospital Haemophilia Treatment Centre

RPA, Missenden Road

Camperdown NSW 2050

Stephen Matthews (Nurse)

stephen.matthews1@health.nsw.gov.au

Phone: (02) 9515 7013

Nicoletta Crollini (Social Worker)

nicoletta.crollini@health.nsw.gov.au

Phone: (02) 9515 8385

Newcastle - Adult Services Calvary Mater

Haematology Department

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

Dale Rodney (Nurse)

Dale.Rodney@calvarymater.org.au

Bryony Cooke (Social Worker)

Bryony.Cooke@calvarymater.org.au

(02) 4014 4811

Newcastle - Paediatric Services

John Hunter Children's Hospital

Lookout Rd

New Lambton Heights NSW 2305

General: (02) 4921 3000

Jaime Chase CNS

0448 511 539

jaime.chase@hnehealth.nsw.gov.au

Cathy Morrison (Social Worker)

cathy.morrison@health.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

HFNSW Annual Family Camp: HFNSW offers free of charge family camp for people with bleeding disorders and their families

NSW Community & Educational events: HFNSW offers fun community and educational events for members and their families/carers across NSW for different purposes including raising awareness, building community, and updating, training and educating.

Newsletter: HFNSW provides quarterly newsletters that offer information and details of events, personal stories, education, treatment information, etc.

Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

Information and Support: HFNSW provides information and support in the form of:

- Education and assistance to members with bleeding disorders and those who also have HIV
- Tutors and entertainment to members who might require extended hospitalisation
- Information and social activities for members and their families
- Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

Being a member driven organisation, the committee is always interested in hearing from its members, community, friends and family. If you want to have a say in how the Foundation delivers its service and shapes its future, please contact the office at coordinator@hfnsw.org.au



ACCESS FOR ALL

#WHD2022

**APRIL 17
2022**

**WORLD
HEMOPHILIA DAY**

