

Factor Matters

Haemophilia
Foundation
NSW



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HFNSW ANNUAL
GENERAL MEETING 2021

MENTAL HEALTH DURING
COVID-19 LOCKDOWN

YOUR ONGOING SUPPORT
MATTERS!

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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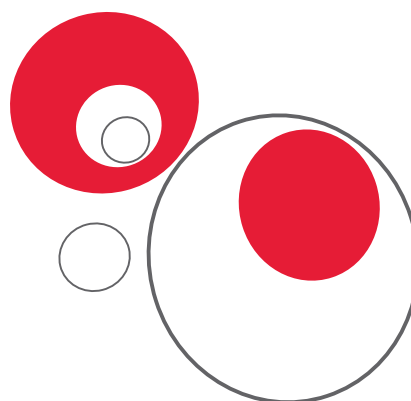
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Coping in lockdown

Things change so quickly, just enough time to adapt and things change again. People deal with change in different ways and at different paces. And there's always someone worse off, just have to watch the news to realise that.

Building on simple pleasures, weather permitting, we've made sure to go for a walk every morning and evening with the dogs. Celebrating small things has become a fun habit. Like, who gets to go to Woollies for click n collect, or who gets to pickup the takeaway. We're so fortunate to have great neighbours. We discovered that Lila makes the finest strawberry preserves in Sydney, and our pub trivia team has pivoted from our weekly Local to a fun Zoom night. Admittedly, while I've gotten into a bit more DIY around the house during this lockdown, done a 1,000-piece puzzle, loved the Olympics and binged the bingable, I've heard of some truly admirable lockdown activities.

Our friend from the dog park, Lois, recently digitized all 16 huge boxes of her family photos. Steph Devine, HFNSW Committee Member, has become proficient at hosting virtual birthday parties - arranging the same internationally themed food and decorations sent to five houses all on Zoom.

At the HFNSW, we're pivoted to holding more online sessions, the next of which is our AGM in October. We're also planning more regional in person functions for next year and will publish dates in this newsletter and on the website when that becomes possible. The most important event on our calendar is the 20th Australian Conference on Hemophilia & Bleeding Disorders, an easy to attend event with the most up to date information available from the experts. That's on October 8 & 9, registration fee assistance is available.

*Stay Safe,
Dan*



World Hepatitis Day is marked globally on 28 July.

In 2021 the theme is hep can't wait, reminding us that we need to be proactive and act on viral hepatitis. For people with bleeding disorders, this includes knowing your hep C status, having treatment to cure hep C, where possible, and following up on liver health after treatment.

On World Hepatitis Day we work towards the worldwide goal of eliminating viral hepatitis by 2030.

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.

A NOHEP FUTURE

Imagine a future without hepatitis C. Can we achieve this in the Australian bleeding disorders community?

New revolutionary hepatitis C treatments are widely available in Australia.

- Very high cure rates
- Tablets not injections
- Few if any side effects.



PERSONAL STORIES

Australians with bleeding disorders have been cured of hep C. Hear what they have to say about their experience.

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.'

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.'

Reprinted with permission from
National Haemophilia, No 215, September 2021

Lockdowns make people lonely!

Here are 3 steps we can take now to help each other

Michelle H Lim

*Senior Lecturer and Clinical Psychologist,
Swinburne University of Technology*



Millions of Australians are currently living under lockdowns in an effort to curb the rapid spread of the Delta variant of COVID-19. While lockdowns and other social distancing restrictions are important strategies to protect Australians' physical health during the pandemic, it's no secret they take a significant toll on mental health.

As well as financial stressors, including the loss of work, prolonged or frequent lockdowns can affect mental health by disrupting social routines. This puts people in lockdown at risk of loneliness.

So with lockdowns and social restrictions likely to be a part of life in Australia until a significant majority of us are fully vaccinated, it's timely to think about what we can do to look out for people who may be vulnerable.

Lockdowns and loneliness

Lockdowns reduce our opportunities to connect with loved ones in person, and slow our ability to develop or foster new connections. Many families are also divided across borders — both domestic and international — with little certainty as to when they'll be able to reunite.

Data were from the United Kingdom, the United States and Australia, examining loneliness levels in relation to the severity of social restrictions during the first six months of the pandemic. It was found, somewhat unsurprisingly, that as social restrictions eased, loneliness levels also dropped significantly.

While it's normal to feel lonely from time to time, some people are at higher risk of problematic levels of loneliness. We found being aged 18-25, being unemployed, and living alone were among the factors that predicted higher levels of loneliness.

Why should we care about loneliness?

For some people, experiencing persistent or distressing levels of loneliness can lead to poor health. In part, this may be because loneliness creates a physiological stress response.

Researchers from Denmark found loneliness increases a person's chance of developing heart disease by 20%, and type 2 diabetes by 90% within a five-year period.

While people with a mental health disorder are more likely to report being lonely, it goes the other way too. Loneliness predicts more severe depression, social anxiety and paranoia.

There's increasing recognition that feeling lonely also costs businesses. The adoption of remote working practices beyond the immediate crisis of the COVID-19 pandemic will further limit our ability to form or keep those small, informal but important moments to connect with colleagues.

How can we help those who may be at risk?

Loneliness is a personal and distressing experience that can be complex to resolve.

But for people who are lonely, feeling meaningfully connected to others can help. Here are three steps we can all take to help people who may be experiencing loneliness.

1. Listen out

People who are lonely may not readily or explicitly complain about their loneliness due to fear of judgement or stigma.

If they do reach out, a person who is lonely may ask to connect in an indirect or non-urgent way. This can be because people who feel lonely don't want to burden others. For example, "when you have time, let's catch up" may appear non-urgent, but it's important to respond to these requests.

2. Check in and share

Living in a lockdown is stressful, but it's a shared experience. It presents us with opportunities to show kindness to people we may not know well. A simple "hello" can go a long way for many.

Asking others how they are can become part and parcel of our conversations with each other. Indeed, checking in — even with people who we may not know well, such as co-workers, neighbours, or the barista at the local coffee shop — is becoming the new normal.

Where appropriate, more often than not, sharing our lockdown experiences can create an opportunity to bond with and support each other.

3. Ask the right questions

If someone shares they are feeling lonely, asking "is there anything I can do to help?" facilitates the conversation and lets others know you are there without judgement.

Don't assume what works for you will work for someone else. Ask them "what do you think could help you?"

Being proactive

Since the pandemic began, many Australians have discovered different ways to keep in touch beyond the zoom call. These include things like writing stories and letters, leaving care packages, and exercising with a friend (while socially distanced and with masks).

Millions of Australians are living with multiple sources of stress right now. But it's not impossible to show emotional support and care to people around us while still sticking to social distancing rules.

Employers must also take proactive steps to keep workers engaged with each other and to the organisation.

So long as lockdowns are used as a strategy against the virus, there will be a social cost to our well-being. But that only makes it more important than ever that we make the effort to stay meaningfully connected to others.

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LOOKING AFTER YOUR MENTAL WELLBEING DURING LOCKDOWN

Nicoletta Crollini - Haemophilia Social Worker at Royal Prince Alfred Hospital



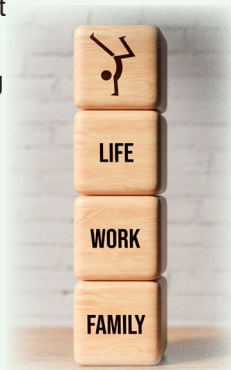
It has been several months since Greater Sydney and the state of New South Wales have been in lockdown. With the ongoing updates, changes and various restrictions, I feel an article on mental wellbeing is essential.

Living through COVID-19, particularly during lockdown, will be some of the most prolonged experiences of stress that most of us will ever endure in our lifetime. Therefore, how we cope with COVID-19 related stress will significantly impact our mental wellbeing.

Dr Murry Wright (Chief Psychiatrist for NSW Health) has provided tips for managing our mental wellbeing during lockdown. Below are some of the beneficial practices we can implement on a daily basis to support our mental wellbeing, reduce our stress during lockdown, and access help if needed.

Firstly, we should all consider having a stress management plan. Even if you're feeling ok day to day, it can be important to give your life some structure during lockdown.

A stress management plan can include things like:



• Creating structure and routine in our life

The lockdown has removed our everyday routines and practices, therefore, we need to adapt and create new ones. These practices can include doing regular daily exercise of some kind, maintaining contact with the people we care about in our life, including talking about how we are all coping.



• Monitoring our diet and lifestyle

Keep an eye out for the amount of junk food we might be eating or alcohol we are consuming. Also, monitor our sleeping habits or lack of sleep.

• Setting achievable daily goals and review them regularly.

Remember the stress management plan needs to be monitored and reviewed regularly.

The signs of a stress management plan not working are:



- Difficulties with sleep
- Difficulties with concentration
- Feeling fatigued
- Feeling overwhelmed
- Consuming too much alcohol

If you are experiencing any of the above, start to think about what you can do to change how you are approaching the day or consider seeking professional support if needed.

Things to keep in mind

We need to remind ourselves that others might also be struggling and not be afraid to ask if they are ok. It never does any harm asking someone if they are ok and often, it is an excellent help for that person to talk about what is happening for them.

Remember that most of the people you come into contact with will also be impacted by the stress of COVID-19 and may not be responding to things in the usual way.

It is crucial and beneficial for us all to make talking about mental wellbeing a recurring topic of discussion with our family, friends and loved ones.

Supports available

Please note there are plenty of services available, most do not require you to leave your home. Please reach out for help if you need it!

These services are listed below:

- **Beyond Blue** (For everyone)

1300 224 636

www.beyondblue.org.au

- **Headspace** (For young people and parents)

Find local centre online

www.headspace.org.au

- **Kids Helpline** (For kids, young people and parents)

1800 551 800

www.kidshelpline.com.au

- **Lifeline** (For everyone)

13 11 14

www.lifeline.org.au

- **Mental Health Line** (For everyone)

1800 011 511

The NSW Government also has a range of information about maintaining your health and wellbeing during COVID-19. You can find this information via this website

<https://www.nsw.gov.au/covid-19/health-and-wellbeing>.

Finally, please feel free to give me a call – always happy to talk, provide support and, if needed, link you in with the services that can help out longer term. My contact number is 02 9515 8385

Wishing everyone all the very best during this challenging time, and keep safe!

Nicoletta Crollini





THE 20TH AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS WILL TAKE PLACE THIS YEAR FROM 8-9 OCTOBER 2021 **virtually**.

We have decided to hold a virtual conference this year due to the uncertainty of the pandemic and we are very excited about the opportunities this provides. Bringing together the different parts of our community with health professionals and other stakeholders has always been stimulating and rewarding for the bleeding disorders community and other stakeholders. Without the requirement to travel so many more people will be able to participate and contribute to the discussions. We expect our virtual conference will attract more delegates than usual and create innovative learning opportunities and discussion for everyone. We are confident that nothing will be missing - in fact it will be enhanced.

PROGRAM

We are on the road for a great program with topics across a range of areas and current issues:

- New and emerging treatments
- Managing complications of bleeding disorders
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over a lifetime
- Women and girls
- Getting Older
- Staying fit and well
- Participating in clinical trials

The program will include presentations from people living with bleeding disorders as experts, as well as specialist health professionals and others speaking on important matters that affect people living with a bleeding disorder and their families and carers. There will be plenty of opportunities ask questions and find out more.

The program will go over Friday and Saturday between 9am – 5pm. There will be keynote presentations for everyone, followed by concurrent sessions for you to choose from, and there will be breaks in between so you can plan your days. If you miss a session, you can playback later that day and all sessions will be as part of your registration for 6 months, you can log in anytime.

For up-to-date information about the conference and current program visit: www.haemophilia.org.au/conferences.

BOOKINGS NOW AVAILABLE

<https://www.haemophilia.org.au/conferences/2021-conference>

Why are you attending the virtual Australian Conference on Haemophilia, VWD & Rare Bleeding Disorders this year?

With the National Conference being held online as a virtual conference it makes it much more accessible to everyone. If you have never been able to attend a conference before due to travel challenges, work or family commitments this is an opportunity you should embrace.

As HFA and the conference committee work hard behind the scenes we can be assured that the range of topics on offer will be relevant to us all. At previous conferences there were always 3 concurrent sessions. This conference will have just two concurrent sessions, meaning there will be less opportunity to miss out. A huge benefit of this conference is that all sessions will be recorded so if you have registered your attendance you will be able to access all the recorded sessions after the conference. The beauty of this is that if there are two concurrent sessions that interest you, you'll not miss out! If you cannot attend a live session due to work commitments or childcare needs you can watch at a later date or time. The benefits of being able to log into the live sessions is that you will be able to interact, ask questions and really be involved.

As much as we have all adapted to the online space, please don't underestimate the amount of work behind the scenes that has already gone into providing this conference for our community. To ensure we continue to be able to access conferences like this in the future we need your support in attending.

The bleeding disorders community is unique and the conference really highlights this uniqueness with the drawing together of health professionals alongside community members. It is a union that brings together an array of benefits to both the community and our healthcare providers.

Show your support by REGISTERING NOW at www.haemophilia.org.au/conferences/2021-conference. Registration is \$50 per person.

If the fee is a barrier to you registering, please just email coordinator@hfnsw.org.au and we will assist you confidentially. We do not want any members to miss out on the opportunity to attend and benefit from all on offer.



"Being virtual, I can attend at my own convenience, multi-task around work/family commitments yet get brilliant insights into new treatments, research and hearing other people's stories in the community - all for the price of a family takeaway dinner!" - Bernard

"It will be great to attend the online conference because I want to hear the latest updates on new treatments and gene therapies, it is easy to listen to the recorded sessions during my own time". - Claire

<https://www.haemophilia.org.au/conferences/2021-conference>

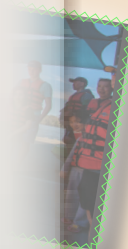
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**2021 FAMILY CAMP
CANCELLED**



Family Camp 2021



It is with much disappointment that we have to announce that our 2021 Family Camp has been cancelled. The decision to cancel the event has not been made lightly, but given the COVID-19 trends, it is apparent that we cannot hold a safe camp this year.

We look forward to 2022 and hosting the event. Thank you everyone for your understanding and patience!

Come along to
Narrabeen

You may enjoy
activities, and
love to see

When: From
Sunday 21

Where:
Wakehurst

This is a free

Booking is essential for this event.

Please RSVP latest by SUNDAY 10th OCTOBER by
sending the completed form included in this issue to
coordinator@hfnsw.org.au
or, submitting the form online at

<https://www.hfnsw.org.au/get-involved/events/family-camp-2021>

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

Seven Positive Outcomes of COVID-19

From recovering ecosystems to new ways of learning, there are silver linings to the global pandemic, writes Professor Debbie Haski-Leventhal of Macquarie Business School.

Professor Debbie Haski-Leventhal
Macquarie Business School

COVID-19 has had undeniable and horrific consequences on people's lives and the economy. With sickness, death and unemployment rates soaring almost everywhere on our planet, it is easy to despair.



Notwithstanding the gruesomeness of this situation, there are some outcomes that could have a long-term positive impact on the planet and humanity.

1. The Environment

Lockdowns reduce our opportunities to connect with loved ones. The first positive aspect of COVID-19 is the effect on the environment. Carbon emissions are down globally and with manufacturing and air travel grinding to a halt, the planet has had a chance to rejuvenate.

China recorded an 85 per cent increase in days with good air quality in 337 cities between January and March. With tourists gone from Italy, the long-polluted canals of Venice now appear clear as fish and other wildlife start returning. Elsewhere, wildlife is also reappearing in other major cities and the biodiversity is slowly starting to return in various parts of the world.

2. Peace

The coronavirus is also raising hopes of fewer battles and less conflict, resulting in increased levels of peace. The United Nations called to end all wars in the face of COVID-19 as the world confronts a common enemy: "It's time to put armed conflict on lockdown," stated Secretary-General António Guterres.

And according to the ABC, a ceasefire was declared by the Saudis fighting Houthi rebels in Yemen. Although there are many places in the Middle East where war persists, a stronger lockdown could lead to less violence in these countries too.

3. Connectedness

A third positive outcome is a rejuvenated sense of community and social cohesion. Self-isolation challenges us as social animals who desire relationships, contact and



interaction with other humans.

However, people all around the world are finding new ways to address the need for interconnectedness. In Italy, one of the worst-hit countries, people are joining their instruments and voices to create music from their balconies. People are leading street dance parties while maintaining social distancing.

People are using social media platforms to connect, such as the Facebook group The Kindness Pandemic, with hundreds of daily posts. There is a huge wave of formal and informal volunteering where people use their skills and abilities to help.

4. Innovation

COVID-19 is a major market disruptor that has led to unprecedented levels of innovation. Due to the lockdown, so many businesses have had to reinvent themselves with a new 'business as unusual' philosophy.



This includes cafes turning into takeaway venues (some of which also now sell milk or face masks) and gin distilleries now making hand sanitisers.

Many businesses have had to undergo rapid digitalisation and offer their services online. Some could use this wave of innovation to reimagine their business model and change or grow their market.

5. Corporate Responsibility

Coronavirus is driving a new wave of corporate social responsibility (CSR). The global pandemic has become a litmus test for how seriously companies are taking their CSR and their work with key stakeholders: the community, employees, consumers and the environment.

Companies are donating money, food and medical equipment to support people affected by the coronavirus. Others are giving to healthcare workers, including free coffee at McDonald's Australia and millions of masks from Johnson & Johnson.

Many are supporting their customers, from Woolworths introducing an exclusive shopping hour for seniors and people with disabilities to Optus giving free mobile data so its subscribers can continue to connect.

6. Reimagined Education

The sixth positive outcome is massive transformation in education. True, most of it was not by choice. With schools closing down all around the world, many teachers are digitalising the classroom, offering online education, educational games and tasks and self-led learning.



We are globally involved in one of the largest-scale experiments in changing education at all levels. Home-schooling is becoming the new way of learning, exposing many parents to what their children know and do.

Similarly, universities are leading remote learning and use state-of-the-art solutions to keep students engaged. Some universities are using augmented and virtual reality to provide near real-life experiences for galvanising students' curiosity, engagement and commitment and for preparing students for the workplace.

7. Gratitude

Finally, the seventh gift that COVID-19 is giving us is a new sense of appreciation and gratefulness.

It has offered us a new perspective on everything we have taken for granted for so long – our freedoms, leisure, connections, work, family and friends. We have never questioned how life as we know it could be suddenly taken away from us.



Hopefully, when this crisis is over, we will exhibit new levels of gratitude. We have also learned to value and thank health workers who are at the frontline of this crisis, risking their lives everyday by just showing up to their vital work. This sense of gratefulness can also help us develop our resilience and overcome the crisis in the long-term.

- Will a vaccine really solve our COVID-19 woes?
- How Sydney has coped with pandemics in the past

All of these positive aspects come at a great price of death, sickness and a depressed global economy. As heartbreaking and frightening as this crisis is, its positive outcomes can be gifts we should not overlook. If we ignore them, all of this becomes meaningless.

It will be up to us to change ourselves and our system to continue with the positive environmental impact, peace, connectedness, innovation, corporate responsibility, reimagined education and gratitude. This crisis will end. We will meet again. We can do so as better human beings.

Debbie Haski-Leventhal is a Professor of Management at the Macquarie Business School. She is a TED speaker and the author of Strategic Corporate Social Responsibility: Tools and Theories for Responsible Management and The Purpose-Driven University.

Republished from <https://lighthouse.mq.edu.au/article/april-2020/seven-positive-outcomes-of-covid-19>

Haemophilia Treatment Centre

Royal Prince Alfred Hospital

Patient information

About the Haemophilia Treatment Centre

Referral

Your GP should send through a referral letter. Once the referral is received, you will be contacted by the RPA Haemophilia Treatment Centre (HTC) to book in your first appointment.

First appointment

During your first appointment you will:

- Meet and get to know the HTC team
- Have blood tests taken by the haemophilia nurses in the HTC
- Have your joints X-rayed either at Royal Prince Alfred Hospital (RPA) Radiology department or Chris O'Brien Lifehouse
- Meet with the social worker who can provide you, your relatives and carers with emotional and social support, and practical assistance related to life changes, illness and treatment

You might also:

- Attend the Joint Clinic – which is a clinic that includes the entire HTC team, physiotherapist and Dr Robert Russo (Rheumatologist). The clinic will provide you with a detailed and up to date understanding of your joint health, as well as a treatment or joint care plan if needed
- Receive a referral to see the hospital dentist, if there are any specific oral health care needs identified
- Receive a referral to see the hospital genetic counsellor for genetic education and support, as well as access to genetic testing, resources and research

Please allow about half a day for your first clinic visit, especially if you are going to attend the Joint Clinic and have blood tests.



SLHD-89562
Last updated: August 2021



Location

The HTC is located on the ground floor (Level 5) of the main building at Royal Prince Alfred Hospital (Building 77 on the map).

The RPA Radiology department is also located on the ground floor (level 5) of the main hospital building (building 75 on the map) and is where you will have your X-rays taken. You might also be redirected to the Chris O'Brien Lifehouse Radiology Department (opposite RPA, located at the basement level, building 14 on the map) for X-rays.

The Joint Clinic takes place in the Institute of Rheumatology and Orthopaedics (IRO), also known as the Queen Elizabeth II (QE2) (Building 10 on the map), this is also where the RPA dentists are located.

Food options

Your first visit may be a long day, so you may wish to bring food with you.

RPA has a number of cafes located inside the hospital on Level 5 and Level 4.

There are a selection of cafes on Missenden Road where you can grab coffee and meals to eat-in or take-away. They are about a 5-10 minute walk from RPA. King Street, Newtown also has a selection of reasonably priced food and is only a 10-15 minute walk from RPA.

Internet

RPA has free guest WiFi for patients and their visitors.



Health
Sydney
Local Health District

Getting to RPA

Public Transport

Bus

There are a number of buses you can catch from the city to stops near RPA either on Parramatta Road or King Street, both about a 5-10 minute walk to RPA.

Buses that stop on Missenden Road outside RPA are the 412 and 422.

Train

The nearest train stations to RPA are Macdonaldtown and Newtown, both about a 10-15 minute walk.

Parking

The RPA car park is highlighted in pink on the map and concession rates are available. The car park is located directly behind the King George V Building (Building 13 on the map), entrance is via Susan Street.

Concession parking

To receive concession parking rates:

1. Park your car in the car park
2. Complete one of the concessional parking forms and ensure it has been authorised by staff
3. Proceed to the RPA Enquiries Desk on ground floor (Level 5) in the main foyer and collect a validated ticket. You will need to select the option of the first 3 hours free, a one day parking pass, a three day parking pass or a seven day parking pass. Please refer to the concessional parking form for further details
4. With your parking ticket, proceed to the parking pay station machines, located outside the King George V Building near Drug Health Services and pay for your parking
5. Once you have paid for your parking you will be able to exit from the car park using your ticket

Things to remember about hospital parking:

- Parking spaces are subject to availability and no refund will be issued for individuals with a 3 or 7 day parking pass
- Only a maximum of 2 parking cards can be issued per patient during the hospital admission
- Get in early as this car park fills up quick
- The parking pay station machines take coins, notes and credit cards (Visa and MasterCard)



Contact

Haemophilia Treatment Centre: **02 9515 7013**
Social Worker (Nicoletta): **02 9515 8385**

slhd.nsw.gov.au/rpa

The RPA Haemophilia Treatment Centre Team



Dr Liane Khoo
RPA Haematologist and
Centre Director



Dr Scott Dunkley
RPA Haematologist



Stephen Matthews
Haemophilia Clinical
Nurse Consultant



Melly Gou
Registered Nurse



**Josh Wakefield (L)
and Josh Hutton (R)**
Physiotherapists

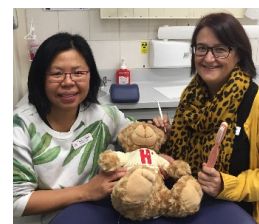


Nicoletta Crollini
Social Worker

Other staff you might meet



Dr Robert Russo
Rheumatologist and
Nuclear Medicine physician



**Dr Claire Scott (R)
and Emily Chow (L)**
Dentists



Ron Fleischer
Genetic Counsellor

Sydney, it's *your* local health district



invites you to join us for

2021 Annual General Meeting & Information Evening

When: Tuesday, 19th October 2021, at 6 PM

HFNSW 2021 AGM will be held online via Zoom.
This means that once again you can attend from the comfort of your own home!

President, Mr Dan Credazzi JP
to Welcome All and MC us through the meeting

The meeting will be an opportunity

- *to be in the know with what has been done and future plans*
- *to hear about recent innovative treatment developments and trials from our clinical consultants*
- *to participate in HFNSW Management Committee election for the next three years*
 - *to share your ideas*

HFNSW is now calling for **nominations for the election of the board committee** at the 2021 AGM.

Nomination forms are available on our website: hfnsw.org.au

*Please return the completed forms via email to coordinator@hfnsw.org.au **THE LATEST by 12th October 2021***

IS YOUR MEMBERSHIP UP TO DATE?

To nominate a candidate for election to the HFNSW Board, you must be a paid-up member.

If your membership is overdue, please renew your [membership for 2021-22](#).

To make a booking and access the Zoom link, please click on the link below

<https://www.trybooking.com/BUBJY>

or, send us an email to
coordinator@hfnsw.org.au

We hope to see you at the AGM! 😊

OVERCOMING PERSONAL CHALLENGES

Gavin's Story



As a Haemophiliac, it seems a challenging task to perfectly describe the intense undulations of my life's physical journey, but I will do my best. Let me start at the beginning.

I was a few months old in 2001 when my parents finally found out that I had Haemophilia. It was at the stage when I was using a walking ring to mischievously manoeuvre myself around the house. The walking ring was unfortunately made of plastic and was constantly pushing into my ribcage. That resulted in excessive bruising, which of course alarmed my parents, and shortly afterwards they found out about my disorder at the hospital.

Fortunately for me, and my parents, the first few years of my life seemed relatively trouble-free. Or at least I think so, I do not remember much of my early childhood. But even so, up until I was about 12, for someone who had little knowledge of the importance of exercise and as someone who did not get weekly treatment for my Haemophilia, I think I had a smooth run. Looking back, there are only three moments which I consider physically significant in my life as a Haemophiliac.

There was a moment in Grade 2 when I tripped on concrete and hit my knee quite badly. I still have the scar to prove it. But even that was not such a big deal, the skin healed quite quickly, and I moved on. What I consider to be the physically worst accident I have ever had occurred in 2011 when I went go karting with some friends.

I was not familiar with the power of the go kart and I went straight into the barriers at the first corner at full speed. Quite silly, I know. Thankfully, I did not break anything, but I did get severe internal bleeding and felt weak for several weeks after.



With much needed treatment, I healed back up in due time and was on the go again. I think the most life altering incident came earlier than that, when I tripped and hit my mouth on the corner of a large step in my back yard. That hit caused severe bleeding and altered the structure of my teeth. But again, I was OK. The real problems started in my teenage years.

Throughout the years of 2013 all the way to about 2017, I had repetitive problems with spontaneous injuries. These injuries always came in the form of pulled muscles and they were always in my legs. Needless to say, these spontaneous injuries significantly frustrated

me because I was immobilised on countless occasions. These injuries were not as physically bad as the injuries incurred during the iconic go kart crash or the fall in my back yard, but to me, mentally, they were the worst injuries because they just kept happening, through no fault of my own. My emotions were certainly being tested.

Finally, in 2016, I learnt how to inject the needed medication and I was fortunate enough to carry out such treatment every two days. This was a massive help and definitely reduced the number of spontaneous injuries I had. However, I still had spontaneous injuries from time and time, even spanning through to 2017. It was then I stopped and thought, "Hang on. Something is fundamentally wrong. I shouldn't be getting these injuries." It was then that I decided to do some research, and that deci-

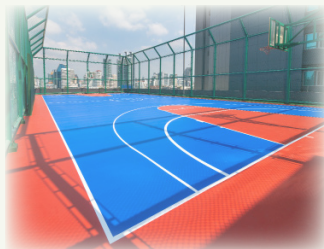


sion changed the course of my life.

The research was influenced by some individual diagnosis – I concluded that I had significant muscle weaknesses in my legs.

So I researched not just how to strengthen my legs, but how to strengthen my whole body. Over the next few years I started working out, being very particular about type of exercise, rep counts, set counts, etc. It did not take long for me to build up a desirable amount of muscle (I'm not talking bodybuilder level; I'm just talking general fitness). I was incredibly proud of the muscle I was gaining, and why? Because with more muscle, came less injuries.

Back then (late 2017, early 2018), fitness was like a drug. I just kept wanting more. So, my life started to turn around for the better. But the positives did not end there. That was just the start.



A little earlier, I fell in love with the sport of Mixed Netball. But of course, my level of play was low due to my weakened muscles at the time. But once I started getting stronger from the results of working out, I started to train harder, not just because

I wanted to get stronger, but because I became obsessed with the idea of winning the Mixed Netball championship my school took part in. Of course, that could not be down to me alone because Netball is a team sport. So, when the time came, my team and I were put through vigorous training sessions in school breaks, and we undertook excessive tactic analyses whenever we could. In 2016, we only won a single match, and we were nowhere near our competitors. In 2017, when I was stronger and my team was more experienced, we made it to the semi-finals. Even though we did not win the championship, I was still very happy with that result as it was an astronomical improvement. And then came 2018, which happened to be the least year we got the play in that championship.

The first match of the season that year, we were placed up against a team who had won the championship the year before and were the favourites going into this season. Guess what – we beat them. 17-12. I still vividly remember that day and their shocked expressions. Let me tell you, we were unstoppable. We played our way through round after round without even being challenged. Before the final, our biggest challenge was playing a match in a heatwave with midday temperatures that never dipped below 35 degrees Celsius. But yet again, we still won that match with ease.

And then came the final, and who were we up against?

The same team we played against in the first round. And they were there for vengeance.



That final was incredibly intense, and they had obviously made some improvements since they were leading 11-9 at half-time. Just before the third quarter, we had a team discussion, and then resumed play in the third quarter, more determined than ever. We were simply playing perfectly and did not let them score a single goal more. Their defence was strong, but our offence was stronger. By the time the third quarter came to an end, the scoreboard read 11-11. Scoring only 2 goals during 12 minutes of play during Netball is rather unprecedented, but that is how high the intensity was between both teams. We only needed to score 1 more goal in the fourth quarter, and we knew it would be challenging.

To complicate things, it started to rain lightly. It was if the weather was starting to match the intensity of the game. Through sheer finesse, we managed to score 2 more goals and our defences held against their ruthless attacks. It was the most dramatic 12 minutes of my life. The final whistle blew with the scoreboard favouring us at 13-11. To this day, that was the happiest moment of my life and will stay with me forever.

I had never put my body through such physical extremities before, and throughout the whole championship, I never got injured. I was incredibly proud of myself because I did what seemed impossible just a couple years before. I became a winner. But beyond that, I pushed myself to get healthier and stronger.

Since then I have not taken part in any sporting championship as intense as that one, but I have continued to get stronger and fitter. I take pride in what I have done, and you know what, I am proud to be a Haemophiliac, because it has defined me in ways that I could have never imagined.



I went on to successfully finish high school and now I am studying development planning at Macquarie University. In 2020, I also took on the task of writing my first book, 'Jake Raven and the Heists of Opulence,' but that is another story.

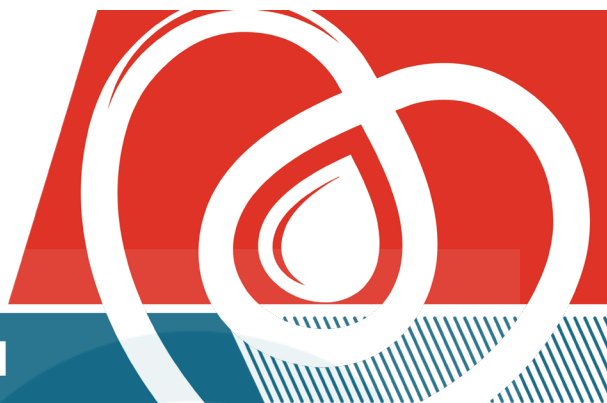
I intend to continuously get stronger and fitter. Haemophilia has taught me a lot of things, but one of them is to keep pushing the limits.

Yours truly,
Gavin Kerst



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**.

With COVID-19 restrictions in NSW once again a virtual campaign has been developed. This will involve many fun things that all ages can get involved in. Keep an eye on the HFA's events page and social networks.

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

Do you want to share your story?

HOW CAN YOU BE PART OF THE WEEK?

- Run a virtual fundraising event
- Share information on your social networks
- Change your Facebook profile pic in support of the week
- Register to take part in the virtual **Red Classic**
- Children and their friends can take part in the **colouring-in competition**. **The colouring-in sheet is included in this issue. Further details of the competition can be found on HFA's website at <https://bit.ly/3yYIYrQ>**
- Take part in activities

There are some great links and ideas available on www.haemophilia.org.au/BDAW

SHARE YOUR STORY

Share Your Story and Win a Prize



Thank you to our members who have shared their story and life experiences with us.

As a person living with a bleeding disorder or as a parent/carer, sibling or friend of a person with a bleeding disorder you have experiences that can teach, inspire, motivate, or challenge. So let's share what you'd like others to know about life with a bleeding disorder and some of the ups and downs, an inspiring personal story about travel, achievements, sport, school, work etc.

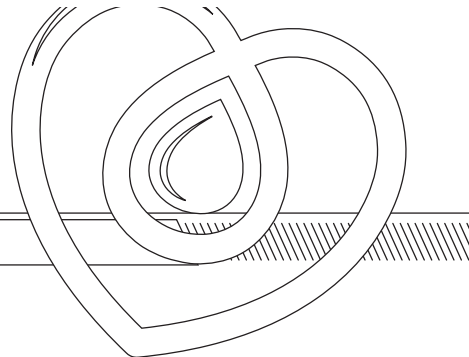
HFNSW will not publish your story without your permission (or parental/guardian if under 18) - and your story can be published anonymously.

Submit Your Story through the link <https://www.hfnsw.org.au/get-involved/share-your-story>! Or, via email at coordinator@hfnsw.org.au



Bleeding Disorders
AWARENESS WEEK

BLEEDING DISORDERS AWARENESS WEEK | 10-16 OCTOBER 2021



Embracing a Changing World



Entries Close Friday 5 November 2021

Please send to:

Haemophilia Foundation Australia

PO BOX 1208, Malvern East VIC 3145



WALK FOR BLEEDING DISORDER AWARENESS CHALLENGE

10-16 OCT 2021

Are you up to the challenge? This year we may not be able to walk together as group but we can still be unified in our goal of increasing awareness for bleeding disorders!

Join us and other community members from around NSW AND AUSTRALIA in walking, riding, running, hopping, skipping or jumping around your local area and let's see how many kilometres we can clock up during **Bleeding Disorders Awareness Week!**

SIMPLE RULES...

- walk, run or ride (hop, skip or jump!) within the government restrictions
- all participants kms are counted
- you can wear red (optional)
- you can dress up (optional)
- share photos on HFA social media (optional)
- remember to tally your kilometres
- share your suburb to be mapped nationally!
- most importantly...HAVE FUN!

To register please go to

www.haemophilia.org.au/BDAWRC

HFNSW is offering TWO \$50 prizes!

1 x \$50 visa gift card - Randomly selected

1 X \$50 visa gift card - Best awareness photo

(Please send the photos by email to coordinator@hfnsw.org.au or post it to PO Box 631 Broadway NSW 2007)



**Bleeding Disorders
AWARENESS WEEK**

10-16 OCTOBER 2021



HFNSW MEMBERSHIP 2021-22

IS YOUR MEMBERSHIP UP TO DATE?

Thank you to those members who have paid their 2021-22 membership fees. All memberships expire on 30 June each year. If you haven't renewed yet, it's not too late! The form is included in this newsletter and also available online at <https://bit.ly/3yYpRwC>.

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/>
- 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!



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.

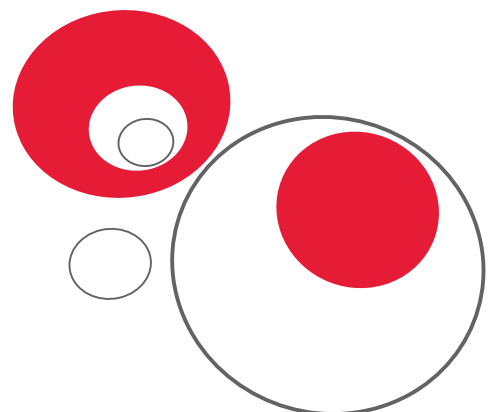
Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, travel assistance, education & training, grants.

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





YOU CAN'T WAIT

Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C.

You could be at risk for hepatitis C if you had a blood product before 1993.

**Don't wait! Know your status.
Get tested for hep C.**

**You've been cured of hep C!
Has your liver recovered?**

Don't wait to find out.

Call your hepatitis specialist to check your liver test results.

Know if you need ongoing follow-up for your liver health.

It's 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.



Find out more
www.haemophilia.org.au/world-hep-day

 **HEP
CAN'T
WAIT!**