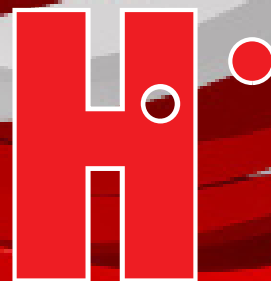


Factor Matters

Haemophilia
Foundation
NSW



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Volume 42

STAY COVID19 FREE

HFNSW FAMILY CAMP 2020

YOUR STORY MATTERS! 

WORLD HEPATITIS DAY

HEALTHY LIVING 

MAKE A DIFFERENCE & SAVE!

MEMBERS' CONTACT DETAILS UPDATE



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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Hamish Robinson - Member
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In This Issue

- p. 3** A Word from the President...
- p. 4** Greetings from HFNSW's New Program Coordinator
- p. 5** HFA Getting Older Report
- p. 6-7** Family Camp 2020
- p. 8-9** WFH Journal New Release
- p. 10** National Blood Donor Week: 14-20 June 2020
- p. 11** WFH Virtual Summit: 14-19 June 2020
- P. 12** World Hepatitis Day
- p. 13-14** Hepatitis C - Healthy Living
- P. 15** International Nurses Day
- p. 16** Easing of COVID-19 restrictions
- p. 17** Make a Difference & Save - Entertainment Digital Membership
- p. 18** World Haemophilia Day
- p. 19** Share Your Story!
Update Your Contact Details!
- P. 20** Hydrotherapy Research at RPAH
- P. 21** Save the Date!
- p. 22** Thank you!
Just Post-it
- p. 23** HFNSW Membership Registration/Renewal Form
- p. 24** Family Camp 2020 Application Form
- p. 25** Haemophilia Centres & HFNSW Member Service

Opinions expressed in Factor Matters do not necessarily reflect those of the Foundation or NSW Health. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFNSW reserves the right to edit articles as it sees necessary. Materials supplied are for information purposes only and are not to be used for diagnosis or treatment.



Dan Credazzi - HFNSW President

The pandemic has caused a lot of strain on people and society. It has been a hard time for many people during this period. Especially toilet roll hoarders and maskaphobiacs!

What the great pause did clear up for me is what is essential and what's not. All our health professionals deserve endless thanks for keeping things going for us in very difficult circumstances. And if life were just, they and teachers and cleaners and chefs and truckies would all be on rockstar salaries.

In these interesting times, I can hear the wheels of history grinding as they make that fourth turn (Strauss-Howe). And HFNSW is approaching 60 years of its own history! In a significant historical turn of our own, HFNSW's Tony Wilkinson has recently retired from the Coordinator role which he held for the past five years. We're grateful for Tony's front-line support to our members and his many years beyond that of coaching at camps and events across the country. Many of us have had our lives changed in a positive way by Tony and his impact is forever woven into the fabric of the HFNSW community. Shiva Tabari is our new interim coordinator and she has not dropped a beat in the transition. Reach out if you've got questions. As always, contact your HTC for all things clinical.

Scientific developments in treatments for bleeding disorders have advanced quickly in the past decade. Faster than I thought possible when we discovered haemophilia in our family fifteen years ago. At the time of writing this, NBA tender results have not been announced but will be in a few weeks. We are looking forward to a wider range of treatment options that will meet the needs of everyone in our community. This is what our advocacy has been focused on for the past three years. We'll see if it's paid off – keep an eye out for this news release via HFA.

In the last couple of years, we've also seen many new therapies in clinical trials here in Sydney. As trials, they won't be readily available to our community for another few years. However, that's clearly the next horizon. It's now evident to me that we can look forward to having even further treatment options in Australia in the future, including gene therapy for those who prefer it. Amazing. Thank a scientist next time you see one.

Like all organizations, HFNSW has not had face to face events for most of this year. We've been having Zoom Committee meetings instead which is very effective and saves heaps of travel time for Committee members. Our office is still open but, if you haven't visited, it's small enough such that only one person can be in there at a time given the current distancing rules. If you'd like to join the committee, don't forget to nominate yourself and join our AGM in October. At this point, it's likely going to be an online event, but we'll keep you posted.

We are also planning for our annual Family Camp to be held in November as usual if the restrictions allow. Otherwise, if we have to postpone it due to the pandemic and NSW Health guidelines, we'll keep you updated via emails, our website and newsletters as things develop. So remember to submit your interest online or by filling out the application form included in this newsletter.

Internationally, we are really proud of the work Sam Duffield is doing to help support the WFH Twinning partnership between national member organisations - Australia and Myanmar. Of course, this work has been interrupted by COVID, but Sam and Leonie Demos (HFV) have been working with the Myanmar Patients team to progress some work that can be done remotely as travel is just not happening. Sam and Leonie are teaching their counterparts in Myanmar how to setup and run a patient support organization.

If you didn't hear, the 2020 WFH Congress planned for Kuala Lumpur had to be cancelled. WFH is holding a Virtual Summit from 14 to 19 June instead. If you missed the sessions don't worry, they will be available online so you can catch up easily.

Thanks again to our HFNSW members who participated in the HFA Getting Older Project. That report will soon be published, and we know it will be a milestone document which will inform the services and care that will be required by our community members into the future.

Take care and stay connected,
Dan

GREETINGS FROM HFNSW's NEW PROGRAM COORDINATOR

Many of us in the community have had the pleasure of working with Tony Wilkinson in his previous coordinator role at HFNSW for about 5 years. His wonderful work has had an immense impact on our community in many positive ways; and, his years of dedication and efforts particularly in relation to our Youth Affairs will be forever remembered and appreciated.



I also would like to extend my thanks to Tony for ensuring a smooth hand-over process. As the new Program Coordinator I realise that I have big shoes to fill!

I am grateful to HFNSW's committee members for putting their trust in me and giving me the opportunity to contribute to the work in the organisation.

I also would like to acknowledge the delightful welcome and support that I have received from the haemophilia community here in the New South Wales and other states and territories. I feel blessed to be a part of this awesome community and honoured to work with such an amazing team.

To give you a little bit of a background about myself, I have come from an academic and teaching background with a commitment to make a difference to the community in which I live and work. I have been a HFNSW member since 2013 and I am excited to continue making nice memories and to make helpful contributions to the organisation.

Please feel free to reach out for any questions or even just to simply say hi. The email address, coordinator@hfnsw.org.au, and the phone numbers will remain the same.

Stay Safe & Warmest Regards, Shiva





GETTING OLDER WITH A BLEEDING DISORDER: NEEDS ASSESSMENT REPORT

The HFA Getting Older with a bleeding disorder report is now available! The report presents findings on the needs of older people with bleeding disorders into the future, with recommendations about what will help. This is the result of extensive consultation with community, health professionals and other experts and agencies. It also includes the results from the HFA Getting Older Community Survey and the PROBE Australia Study.

Here's a summary of the conclusions and how to move forward with them:

A common goal of all community and health professional stakeholders consulted was to enable older people with bleeding disorders to maintain the healthiest life possible. The intention was to assist them to maintain or even improve their quality of life and to remain independent for as long as they could. Another important objective was to support the aspiration of many older people to contribute and be productive members of society.

Systemic barriers

In 2017 the Australian Productivity Commission identified factors and influences that may affect Australia's future economic performance and priorities to enhance national welfare. The Shifting the Dial report points to chronic ill health problems and systemic barriers in the health system that impact on the health of Australians. The Getting Older needs assessment confirms that many older people with a bleeding disorder are also deeply affected by comorbidities with other chronic health conditions. Some experienced poorly integrated health services, lack of case management, concerns about access to care, treatment and referral, particularly in the community and regional areas, inadequate or inconsistent funding models across jurisdictions, the tyranny of distance where living in rural and regional locations or marginalisation by disability or mobility issues. There is potential to address and prevent some of these complications now and introduce prevention strategies at an earlier stage of the lives of others as they grow older.

Reporting health outcomes

The bleeding disorders treatment environment is fast moving with innovative therapies including gene therapy on the horizon that can improve health outcomes. The outcomes of these treatments should be measured using patient-oriented outcome measurement tools already validated and available and the data should be reported and built upon. An important step will be to explore whether the PROBE Australia data can be combined with ABDR data to generate a more comprehensive dataset and subsequently incorporated into clinical guidelines.

Achieving bleeding disorder community goals and aspirations

For older people with bleeding disorders, HFA's vision of 'active, independent and fulfilling lives for people in our bleeding disorders community' has been translated to goals of living the healthiest life possible, maintaining or improving quality of life, prolonging independence and contributing to society.

A range of factors will be involved in achieving this:

- Innovations in comprehensive care to provide easier access to targeted services and programs and coordinated care with relevant medical specialties
- Treatment plans, including access to newer and emerging therapies, to improve quality of life and reduce the burden of treatment
- Further research to better understand specific issues of ageing, including in mild conditions, in the rarer bleeding disorders, and in women
- Targeted patient education to assist with their understanding of growing older with a bleeding disorder and effective self-management
- Education about growing older with a bleeding disorder for health care professionals and carers
- Continuing to address the complications of bloodborne viruses, such as HIV and hepatitis C, including the need for financial support
- Support for an active approach to life: exercise, travel, personal interests
- Support to continue working, where appropriate, and other ways of contributing their skills and experience
- Assistance with future planning
- Building on the resilience and existing support networks of older people with bleeding disorders
- Addressing the needs of their partners and carers
- Increased information about and access to community support and home care services
- Advocacy around financial issues
- Developing social connection and peer support for both the person and their partner/carers
- Investigating digital solutions for community information and communication needs related to getting older

Read the full report on the HFNSW or HFA websites, or, for a print copy (black & white version) contact HFA
T: 1800 807 173 | E: hfaust@haemophilia.org.au

Our thanks to everyone involved!



HAEMOPHILIA FAMILY CAMP

2020



Haemophilia Foundation NSW
will be holding its
Annual Family Camp
on
20, 21, 22 November
at the
Narrabeen Academy of Sport
(if COVID-19 restrictions allow)

Camp Application Form now available Online!

You can fill out and submit
Camp Application form online
on our Website: www.hfnsw.org.au
Submit your form today!



HFNSW 2020 Family Camp

HFNSW will be holding its annual Family Camp on **20, 21, 22 November 2020** at the Narrabeen Academy of Sport, *if the Covid-19 restrictions allow*. We'll keep you updated via emails, our website and newsletters as things develop.

Camp is a great opportunity to connect and catch up with other people living with Haemophilia, Von Willebrand Disease and other related bleeding disorders, their parents and siblings. It is designed for the whole family and is free of charge for our members.

Plus, a special invite to first timers - new and existing members yet to come to their first camp. We say 'camp', but it's comfy motel style accommodation (ie a private room with en-suite per family) with a great range of recreational opportunities at hand, all in beautiful surrounds.

The program includes indoors and outdoors activities aiming to form new friendships, have fun and develop resilience. It also includes educational information sessions like the self-infusion workshops led by Haemophilia Treatment Centre health professionals and our youth mentors.

You can find more information and **apply online** at: <https://www.hfnsw.org.au> or complete the application included in this newsletter and return by email or post:

Email (preferred): admin@hfnsw.org.au ,

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Please return completed applications by **Friday 25th September**.

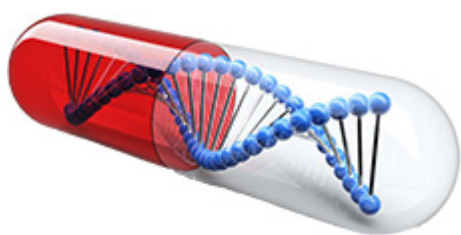
Need more info or have questions...please contact us.

Email: Shiva coordinator@hfnsw.org.au | Sam admin@hfnsw.org.au

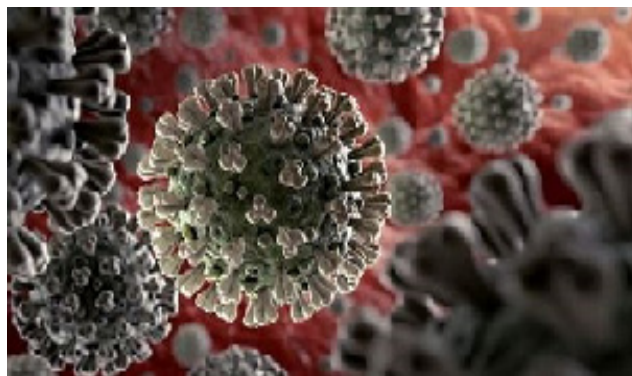
Phone: Office (02) 9280 2607 | mob 0470 637 928

The COVID-19 pandemic: New global challenges for the haemophilia community

A new article providing additional information on how people with hemophilia (PwH) may be impacted by the COVID-19 pandemic has been published in *Haemophilia*, the official journal of the World Federation of Hemophilia (WFH). "The COVID-19 pandemic: New global challenges for the haemophilia community" was written by Cedric Hermans, Medical member, WFH Board of Directors, Alain Weill, WFH President, and Glenn Pierce, MD, PhD, WFH Vice President, Medical. In their article, the authors begin by giving an overview of the fact that whilst viruses have long been considered true enemies of haemophilia patients, some of these viruses have now become partners in haemophilia gene therapy.



Clinical research has shown that it is possible to use viruses deprived of most of their content and infectivity, as vectors to transport genetic material and permit long-term, endogenous production of factor VIII or factor IX. However, despite the successes of gene therapy clinical trials, the emergence of new infectious viruses is a constant concern for the haemophilia community. For this reason, the last few decades have been devoted to the safety of the plasma-derived products and to the development of laboratory-produced clotting factor concentrates.



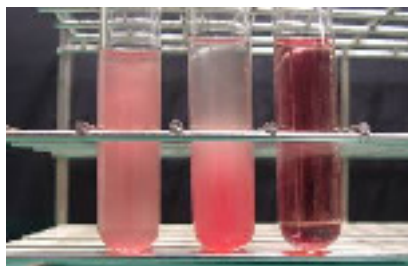
A new disease (COVID-19) caused by a coronavirus (SARS-CoV-2) that appeared in China at the end of 2019 spread all over the world. This emerging virus, spreads from person to person through respiratory droplets that may cause respiratory tract infections, and even fatal pneumonia in more vulnerable patients.

The pandemic is not short term. The current containment measures aim at decreasing the rate of new infections. At this stage it is not possible to estimate the number of patients with haemophilia who may become infected and whether their factor deficiency and their treatment could influence the manifestations of the infection, its natural course, treatment and consequences. However, it seems clear that the pandemic will have definite consequences, direct or indirect, immediate or delayed, on the management of haemophilia worldwide. Here are some of the likely consequences that the authors identify to best manage the challenges and anticipate major difficulties in the longer term.

The major concern and priority are to ensure access to haemophilia treatment. Haemophilia treatment centres are working hard to avoid any problems.

The authors maintain that the production of recombinant DNA produced replacement products (ie FVIII, FIX, FVIIa, emicizumab) will not be affected by the pandemic unless production plants run out of components of production process, which is unlikely.

However, the situation may be quite different for plasma-derived clotting factors if plasma donations are reduced, due to the deferral of infected donors and fear of donating blood and plasma and the mistaken understanding that donors may be at increased risk of COVID-19. Viral inactivation during the production process of plasma-derived clotting factors eliminates SARS-CoV-2, a lipid-enveloped virus like HIV.



Also clinical research programs may be negatively impacted by the pandemic. There are currently restrictions to initiate new studies or to recruit new patients, for both logistical and health reasons. Haemophilia centres are taking steps to adapt the monitoring of patients currently included in clinical studies by ensuring access to treatment and appropriate follow-up. Overall, some experimental therapies may be evaluated with delays, and some clinical trials may be interrupted or stopped, and the introduction of many new treatments will likely be delayed.

The pandemic also has resulted in the cancellation of many educational or research activities planned for the year 2020. These are all lost opportunities that will have to be reactivated. Although communication technologies has made it possible to maintain interactions, they do not replace the richness of direct human-to-human contacts.

However, effort should still move toward optimizing virtual meetings since this pandemic may not disappear soon.

The economic and social consequence of the pandemic also will be major. It is difficult to evaluate how the funding of haemophilia worldwide is affected, and it is expected that the entire community should prepare for a difficult financial situation.

The authors wrap up their article by indicating that they do not intend to be pessimistic but realistic. They stress that the current situation requires everyone to be vigilant, to be proactive in monitoring the situation on a daily basis, to anticipate for a long duration a 'new-normal', to work closely together, and to be innovative. The bleeding disorders' global community has experienced more than one crisis. This one is as different as it is unexpected. **Together we can all face it and learn the necessary lessons from it.**



Updates from the Australian Government Media Release published on 14 June 2020



Every day across the nation, someone, somewhere, needs blood. There are around 500,000 blood donors in Australia, who have made 1.5 million donations in the last year. Transfusions of blood and blood products save millions of lives every year across Australia and the world.

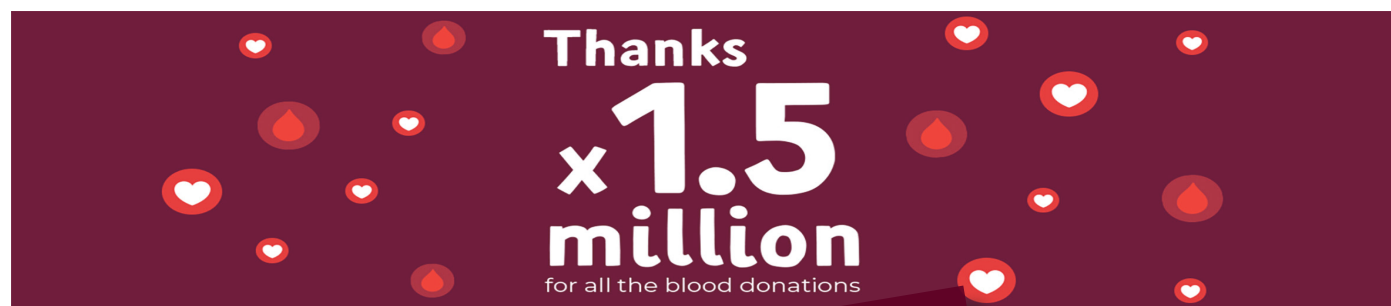
A safe, regular blood supply also helps people with blood and bone marrow disorders, inherited disorders of haemoglobin and immune deficiency conditions.

It can also provide critical support for people with traumatic injuries in emergencies, disasters and accidents, and patients undergoing advanced medical and surgical procedures.

Australia's blood supplies remain strong and have not been impacted by the COVID-19 health emergency. This is a great outcome.

Blood donations are a critical part of Australia's world class health system. The generosity of the donors ensures individuals and communities have access to safe and quality-assured blood and blood products in both normal and emergency situations.

For further information about the week or making a blood donation call 13 14 95 or visit www.donateblood.com.au



CONNECTING
THE GLOBAL
BLEEDING
DISORDERS
COMMUNITY

www.wfh.org/virtual-summit



The World Federation of Hemophilia (WFH) Virtual Summit has commenced on Sunday 14 June 2020.

As the WFH 2020 World Congress Kuala Lumpur had to be cancelled, WFH is bringing the global community together by holding a Virtual Summit from 14 to 19 June 2020. The Virtual Summit includes a series of FREE live and recorded education sessions.

The WFH is committed to bringing the bleeding disorders community together in the name of Treatment for All. This commitment is especially important during the COVID-19 crisis. The WFH Virtual summit allows you to connect with the global bleeding disorders community and increase your knowledge from the comfort of your home or office. All sessions are recorded and available for viewing online. So if you missed the sessions don't worry... for access register at <https://www.wfh.org/virtual-summit>

It is great to see the iPoster “Effectiveness of using SMS to improve the accuracy of recording Haemophilia patients’ bleeding history” by the team from Children’s Hospital at Westmead and Australian Haemophilia Centre Directors’ Organisation among the iPosters presented at WFH Virtual Summit.

Well done Alvin Hooi, Yvonne Brennan, Robyn Shoemark and Julie Curtin!

To read more about this research visit the iPosters section on <https://www.wfh.org/virtual-summit>



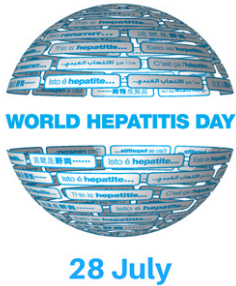
Effectiveness of using SMS to improve the accuracy of recording Haemophilia patients’ bleeding history

Alvin Hooi, Yvonne Brennan, Robyn Shoemark and Julie Curtin



<p>Introduction</p> <ul style="list-style-type: none"> • Capturing accurate bleed data is an essential component of comprehensive haemophilia care. • Reliance on bleed data reporting by patients to their Haemophilia Treatment Centre (HTC) has historically been <p>OPEN</p>	<p>Results</p> <p>Patient demographics</p> <ul style="list-style-type: none"> • The study started with 7 patients and increased to 26 patients enrolled to date. • Haemophilia A n=23, Haemophilia B n=2, Type 3 von Willebrand disease n=1. • The duration of this study for this analysis was 52 weeks. <p>Bleed outcomes</p> <ul style="list-style-type: none"> • Bleeds were reported in 41 SMS responses from 26 patients. <p>Fig 1. Bleeds notified on SMS only</p> <p>OPEN</p>	<p>Future directions</p> <ul style="list-style-type: none"> • We will continue to roll out our SMS bleed capture program across all our patients on prophylaxis. • Accurate bleeding data will help improve patient care and provides a more reliable base to assess the efficacy of new treatments. <p>OPEN</p>
<p>Aim and Method</p> <ul style="list-style-type: none"> • To review incorporation of an SMS program to improve capturing of bleed data in a tertiary HTC. <p>Method</p> <p>1st SMS Sundays 4pm</p> <p>OPEN</p>		<p>Conclusions</p> <ul style="list-style-type: none"> • In patients with inherited bleeding disorders who are on regular prophylactic therapy, a weekly SMS program improved the accuracy of the bleeding history. • 59% of bleeds were identified via SMS only (i.e. not recorded in MyABDR app or otherwise communicated to haemophilia team). • SMS response rates were very high <p>OPEN</p>

Update from Hepatitis Australia



World Hepatitis Day is one of only a handful of ‘World Health Days’ that are officially recognised by the World Health Organization. In May 2016, the World Health Assembly adopted the first ever Global Strategy for viral hepatitis which commits all countries to working towards the goal of eliminating viral hepatitis as a public health threat by 2030.

To support the Global Strategy, the World Hepatitis Alliance launched NOhep on World Hepatitis Day 2016. NOhep is a global movement to eliminate viral hepatitis; it provides a platform for people to come together and take action to ensure global commitments are met and viral hepatitis is eliminated by 2030.

In Australia, World Hepatitis Day is coordinated nationally by Hepatitis Australia and rolled out at local level by Hepatitis Australia member and partner organisations. Australia is leading the way for a NOhep future. A big focus recently for World Hepatitis Day in Australia is treatment; an important step on the road to elimination of viral hepatitis.

Effective viral hepatitis treatments are available in Australia to cure hepatitis C and to help manage hepatitis B.

For further informatio go to: <https://www.hepatitisaustralia.com/world-hepatitis-day>



For further information about the global campaign go to <http://www.worldhepatitisday.org/>

HEPATITIS C

GUIDE TO HEALTHY LIVING



People's lives have changed dramatically in recent weeks due to the outbreak of COVID-19, however it is important not to ignore your general health, particularly if you have a chronic health condition. To help people living with hepatitis C during this time, the fact sheet released by Hepatitis Australia provides information on looking after yourself and protecting your liver.

Getting cured

Direct-acting antivirals (DAAs) are the latest treatment for hepatitis C (HCV) and they have been available on the Australian Pharmaceutical Benefits Scheme (PBS) since March 2016. These DAAs are very safe and effective and can cure hepatitis C more than 95% of the time with few side-effects.

The DAA treatments are tablets taken orally with most medicines only requiring one tablet a day for 8 to 12 weeks in most cases. You can now get hepatitis C medicines from most GPs in Australia. To find out more about hepatitis C treatment and medicines currently available in Australia, please visit: www.hepatitisaustralia.com/hepatitis-c-cures.

When to start treatment

Where possible, it is best to start hepatitis C treatment as soon as possible, especially if you have signs of liver damage or have developed cirrhosis. Getting treated for hep C means it can't keep damaging your liver and you cannot transmit it to anyone else.

However, if you are unable to seek treatment at this time, the following information is designed to assist until you start your hepatitis C treatment.

If you have already started treatment, you should continue to take it as directed by your doctor

How your liver works

The liver is a large organ in your upper right belly, usually protected by the ribs. Its functions include:

- producing bile to help digest fats
- making proteins for the blood
- turning excess glucose into glycogen for energy storage and later release
- regulating blood clotting
- working as part of the immune system
- breaking down toxins and drugs.

Over many years, the hepatitis C virus can cause irreversible damage to your liver. Other things like poor diet, alcohol and drugs can also damage your liver. This is why it is important to look after your health if you have hepatitis C.

Food that is good for your liver

In general, food that is good for your liver is a healthy and balanced diet.³ People with hepatitis C are more susceptible to liver disease and other diseases such as coronary heart disease and hypertension (high blood pressure). By eating healthy food, you will be giving your body the opportunity to function at its best; and enjoying a healthy diet can help to:

- relieve some of the symptoms related to hepatitis C infection and treatment, such as nausea
- boost your immune system
- give your body the nutrients necessary to maintain liver health.

HEPATITIS C

GUIDE TO HEALTHY LIVING



Consuming the right amount of kilojoules to maintain a healthy weight, having lots of fibre to keep your digestive tract healthy, reducing cholesterol levels and eating only a small amount of fat are all part of a healthy and balanced diet.⁴ To find out more about what food is good for your health, please visit <https://www.eatforhealth.gov.au/guidelines/australian-guide-healthy-eating>.

Food and medications to avoid for people with hepatitis C

One of your liver's many jobs is to filter or break down anything you take into your body, although it may not be able to work as well if you have hepatitis C. Food and/or medications may stay in your system too long and affect you more, which in turn can actually injure your liver. To avoid damaging your liver further, there are some food and medications that are best to avoid.

When to start treatment

Alcohol is a toxin. It is broken down by the liver, but it can cause build-up of fat in the liver that can eventually lead to cirrhosis (severe scarring of the liver). There is a significantly higher risk of developing cirrhosis if you have hepatitis C and drink alcohol, so it is wise to avoid alcohol altogether. However, if you do choose to drink, limit yourself to moderate amounts.

Alcohol and Hepatitis C

Alcohol is a toxin. It is broken down by the liver, but it can cause build-up of fat in the liver that can eventually lead to cirrhosis (severe scarring of the liver). There is a significantly higher risk of developing cirrhosis if you have hepatitis C and drink alcohol, so it is wise to avoid alcohol altogether. However, if you do choose to drink, limit yourself to moderate amounts.

Water

Water is important for maintaining a healthy liver. Australian Guidelines recommend that adults drink 8 to 10 glasses of water a day and more if engaging in physical activity and in hot weather.

Exercising

Exercise has many benefits and is part of maintaining a healthy body, which is needed for good liver health. Although group exercising and most sports are not permitted under the governments COVID-19 social distancing rules, other exercising activities are still available (e.g., walking or jogging around your suburb or apartment block, gardening or yoga). Your local gym club may also be offering digital membership that grants you access to work-out programs available on their fitness app or social media platform, while their physical facilities are closed.

What to Avoid	Why
Raw or undercooked shellfish	A high risk of contamination from a variety of organisms that can cause gastroenteritis or hepatitis A
Eggs	Risk of contamination from a variety of organisms
Fats and Oils	An excessive intake can increase your risk of developing diet-related cardiovascular disease and becoming overweight
Medications and Supplements	Some medications have been found to cause harmful reactions and liver problems for people with hepatitis C. always check with your doctor before taking any medications or supplements.



On 12 May each year International Nurses Day is celebrated globally. This year, particularly, is special, as it has been named the International Year of the Nurse and Midwife for its coincidence with the 200th anniversary of the birth of Florence Nightingale, who is widely regarded as the founder of modern nursing.

This year's theme for International Nurses Day was even more relevant in our Covid-19 world

Nurses: A Voice to Lead - Nursing the World to Health

The theme illustrates how nurses are a critical part of meeting a wide range of health challenges across the globe in so many different settings.

In Australia, the importance of frontline and essential workers was highlighted, and their tireless work, particularly during the COVID-19 pandemic, was recognised by the greater public across the country.

This day is particularly an opportunity to celebrate and acknowledge the enormous contribution our nurses and other healthcare and social workers make to Haemophilia community each day and every day.

To all our nurses, THANK YOU for your dedication and kindness in caring for our community!





Easing of COVID-19 restrictions – what does this mean?

Nicoletta Crollini – Haemophilia Social Worker at Royal Prince Alfred Hospital

As news and circumstances regarding COVID-19 change daily, I thought it would be useful to explore how this situation impacts our bleeding community.




Up to date information about COVID-19 and all current restrictions can be found on

www.nsw.gov.au/covid-19

or you can contact the Coronavirus Hotline on **1800 020 080** for advice and guidance.

The current message from Government is:

“stay COVID-19 free and do the three” anytime you leave your house:

1. Wash your hands as often as possible 
2. Keep your distance where you can 
3. Download the COVIDSafe app 

Most importantly, if you're feeling sick, you need to get tested and stay at home.

Regarding your Haemophilia Treatment Centre (HTC), things are pretty much business as usual with drop-ins and treatment needs remaining the same. However, there may be a few changes:

- Medical reviews and clinics might be conducted via telehealth and pathology might be delayed until your next visit.
- When entering hospitals, you will be asked some screening questions and have your temperature checked.
- Appointments at the HTC are being scheduled to accommodate physical distancing requirements, so it is important to arrive at your appointment on time.
- Most hospitals have restricted patient visiting and are allowing one visitor per patient.

Entering a hospital during the COVID-19 pandemic might be concerning and worrying for some people. We encourage you to contact your HTC to discuss any concerns or inquiries regarding further advice or information you might need.

For now, community events are postponed, this does not mean you can't stay connected. There are virtual forums like videoconferencing and various social media platforms to keep in touch.

Look after yourselves and those around you during this challenging time and stay safe.

MAKE A DIFFERENCE & SAVE

ORDER YOUR

New

ENTERTAINMENT DIGITAL MEMBERSHIP



HELP SUPPORT HAEMOPHILIA FOUNDATION NSW BY ORDERING YOUR 2020 | 2021 ENTERTAINMENT DIGITAL MEMBERSHIP NOW!

20% of every membership sold through HFNSW is donated to your foundation.

The Entertainment Digital Membership is a guide with discount vouchers and special offers for the most popular restaurants, hotels, cafés, arts, attractions, shopping, travel, cinemas and more.

For \$69 you will receive over \$20,000 in valuable up to 50% off and 2 for 1 offers all into your iPhone or Android smartphone, that you can use until 1 June, 2021 + 2 months. By ordering your Entertainment Digital Membership you can Save and Make a Difference, as you will contribute \$14 to HFNSW's fundraising.



You can choose a membership right for you. Further Information available online on <https://www.entertainment.com.au/subscription>

Your entertainment subscription can be purchased and paid online on <https://www.entertainment.com.au/subscription> or visit our HFNSW website for a quick access: <https://www.hfnsw.org.au/get-involved/fundraising>

YOU CAN HELP US BY SHARING THIS WITH YOUR FAMILY AND FRIENDS.
THANK YOU FOR YOUR SUPPORT!

**When you buy through the Haemophilia Foundation of NSW
you contribute **\$14** to our Fundraising!**

WORLD HAEMOPHILIA DAY 2020

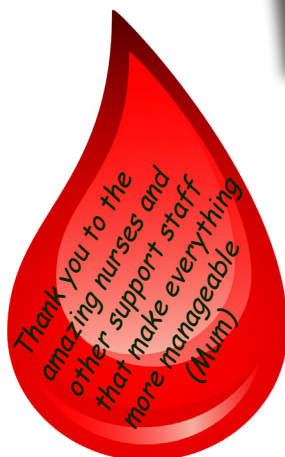
Thank you to all who supported World Haemophilia Day!

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. The theme for 2020 was is “Get+involved”! Celebrating with friends, colleagues and family has always been a big part of World Hemophilia Day, but this year, we had to stay home, use our internet-connected device to Get+involved virtually and stay safe! Although some of us had the opportunity to celebrate the day outside home.

The staff at Kids Factor Zone, Westmead Hospital, decorated the area and dressed up in red to celebrate. Patients and families were asked what it means to them to have haemophilia/bleeding disorder or have haemophilia/bleeding disorder in their family, all written in blood drops displayed in frames outside the KFZ to help raise awareness in the community.



KIDS FACTOR ZONE
Blood Drops



What is *your* story?

Sharing personal stories has benefits to the person telling the story, to those who share a similar experience, and to everyone who hears the story. Personal narratives have a great role in creating connection, raising awareness, and influencing policy that transforms lives. You can share your story of living with a bleeding disorder or raising a child with a bleeding disorder by submitting it here. Once received, we will consider your story for publishing on our website, in our newsletter and across social media. **Also, you will be entered into a draw to win prizes.** You can submit your story easily through our website:

<https://www.hfnsw.org.au/get-involved/share-your-story>



UPDATE YOUR CONTACT DETAILS...

UPDATE YOUR CONTACT DETAILS

For a good start to the new financial year your foundation would like to make sure we have the right contact details to get in touch with you!

If you have recently changed postal address, email address and phone numbers please let us know. It's easy.....you only need to complete and submit a short form online on our website: <https://www.hfnsw.org.au/get-involved/memberships/member-details-update-form> or simply let us know by an email to admin@hfnsw.org.au

You can also renew your membership on our online membership form or download the form on <https://www.hfnsw.org.au/get-involved/memberships> to update your details as well as the Treatment Centre you attend.



ROYAL PRINCE
ALFRED HOSPITAL

Research Participants Needed!

Do **YOU** have:

➤ **HAEMOPHILIA A or B?**

OR

➤ **TYPE 3 Von Willebrand DISEASE?**

TIME to participate in a physiotherapist supervised 12-week hydrotherapy program (1 hour 2 x a week) at the Royal Prince Alfred Hospital in Sydney!

If this sounds like you, or someone you know:

- Please discuss participation with your treating doctor at the Royal Prince Alfred Hospital Haemophilia Treatment Centre in Sydney.
- Email: joshua.hutton@health.nsw.gov.au or Call: 0436646472 to register your interest.

This study has been approved by the Sydney Local Health District Ethics Committee (X19-0370).



The Haemophilia Treatment Centre at Royal Prince Alfred Hospital is conducting a study to investigate the impact of a Physiotherapy supervised 12 week hydrotherapy program on the quality of life and function of those living with bleeding disorders. We are recruiting adults with Haemophilia A or B and those with type 3 Von Willebrand Disease.

Eligible participants will be asked to attend Royal Prince Alfred Hospital for 2 x 1 hour hydrotherapy sessions per week for 12 consecutive weeks. The research team will conduct an assessment of Quality of Life and Function at the beginning, midway through and at the end of the hydrotherapy program. Assessments will take place at Royal Prince Alfred Hospital.

The study team is expecting that the hydrotherapy program will improve joint related pain and improve joint range of motion. We also expect to see a positive impact on Quality of Life and Function.

Hydrotherapy sessions will be run by a qualified Physiotherapist and will be comprised of warm up, strengthening, aerobic, flexibility and warm down components. Heart rate monitoring will be used to ensure participants are reaching the desired exercise intensities. All participants who complete the study will be given the equipment they used in the program so they can continue to exercise independently after the program has ceased. Participants will be reimbursed for parking at Royal Prince Alfred Hospital upon presentation of a valid parking ticket and receipt.

To register your interest, please speak to your treating Physician or Clinical Nurse Consultant at the Royal Prince Alfred Hospital Haemophilia Treatment Centre or contact the study's Principle Investigator Joshua Hutton on 0436646472 (Monday – Friday 8am – 4:30pm) or email joshua.hutton@health.nsw.gov.au

Family Camp 2020

HFNSW will be holding its annual Family Camp on **20, 21, 22 November 2020** at the Narrabeen Academy of Sport, if the Covid-19 restrictions allow. We'll keep you updated via emails, our website and newsletters as things develop.

Camp is a great opportunity to connect and catch up with other young people living with Haemophilia, von Willebrand disorder and other related bleeding disorders, their parents and siblings. It is designed to suit the whole family and is free of charge for our members.

The program includes indoors and outdoors activities aiming to gain self-confidence, form new friendships and develop resilience. The 3 days of camp also include educational sessions such as self-infusion workshops led by Haemophilia Treatment Centres health professionals and our youth mentors.

The camp application form is enclosed in this newsletter and will be available on our website to be completed and submitted online. We hope to see again all our known members and families as well as the ones we have recently met! For more information please call HFNSW on 0292802607 or email Shiva on coordinator@hfnsw.org.au



2020 Bleeding Disorders Awareness Week

Bleeding Disorders Awareness Week is an opportunity to raise awareness about Haemophilia, von Willebrand disorder and related inherited bleeding disorders during the week of **11 – 17 October 2020**.

HFA, HFNSW and State Foundations around Australia are calling on friends and supporters to help raise awareness and celebrate **Red Cake Day**. It's easy... all you have to do is bake some delicious red cakes or cupcakes, decorate them, and share them with your friends or work colleagues in exchange for a donation or a gold coin. You could take them to work, school, have a cake stall or simply host an afternoon tea with your nearest and dearest family and friends. Not only will you be having a delicious morning tea but you'll be helping raise funds and spread the word about haemophilia and other inherited bleeding disorders!

Then, simply send the donations to Haemophilia Foundation New South Wales. All funds raised will go to a range of programs and services all across the New

South Wales. Promotional items ordering system will be available on the HFA website at the end of July. For more information visit www.haemophilia.org.au/redcakeday or call HFA on 1800 807 173.



THANK YOU!

Support *Your* Foundation!

We know there are many worthy charities out in the world, but if you're reading this, that means that ours is special to you and yours.

Our funding from NSW Health doesn't cover everything we do at your Foundation. It's always covered about 70% of our annual activity. So we've always depended on donations from members, HFA and fundraising events such as BBQ's, walks and rides.

So if you haven't already made a donation this year, or haven't paid your membership fee of \$20, please consider it. This will help.

As a tax deduction, your donation can offset your own tax liability, reducing the actual cost to you, but passing on full value to HFNSW. We'll send you a receipt. Try the secure online donation feature on our website. It's via the Commonwealth Bank, and we can track and receipt from that system too. Be sure to fill out all the information fields.

Thank you for your considered support.

Visit the donation or membership pages on the Haemophilia Foundation NSW website :

<http://hfnsw.org.au/>

Payment Details

Please make 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

JUST POST-IT!

Your Story Matters!

Submit your story online
<https://www.hfnsw.org.au/get-involved/share-your-story>

and win prizes!

FAMILY CAMP 2020
Save the date

20 - 22 November 2020
Registration also available on our website

Bleeding Disorders
Awarenessseek 2020

Save the date

11 - 17 October 2020

World
Hepatitis Day

Save the date

28 July 2020

We are tidying up our data base!

Please fill the form online
<https://www.hfnsw.org.au/get-involved/memberships/member-details-update-form>
or send your new contact details to Sam on:
admin@hfnsw.org.au

HFNSW Staff

Shiva Tabari
has joined HFNSW as
a new interim coordinator
coordinator@hfnsw.org.au



Haemophilia Foundation New South Wales Inc.

ABN: 60245470729

Patron: Prof. Kevin A. Rickard AM RFD

2020-2021

Personal Details

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

(Member details below only required if changed)

Mailing Address: _____
Postcode: _____

Ph: (H) _____ (Mobile) _____

Email: _____

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

Mothers Name: _____ Fathers Name: _____

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* \$ _____ Donations over \$2 are tax deductible

TOTAL \$ _____

Payment details

Please make 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 Foundation New South Wales Inc.

ABN: 602 454 70729

Member of Haemophilia Foundation Australia

Patron: Prof. Kevin A. Rickard AM RFD



FAMILY CAMP 2020 Application Form

Friday 20 - Sunday 22 NOVEMBER 2020



FAMILY MEMBERS

AGE OF CHILDREN

ADDRESS: _____

Email: _____

CONTACT PHONE NO: _____

ACCOMMODATION (TICK ONE ONLY)

FRIDAY NIGHT ONLY

FRIDAY AND SATURDAY NIGHT

SATURDAY NIGHT ONLY

DAY STAY ONLY (SATURDAY)

ANY SPECIAL ACCOMMODATION REQUIREMENTS _____

MEALS – PLEASE INDICATE HOW MANY ADULTS & CHILDREN FOR EACH MEAL (CHILD – UNDER 16YO)

___A___C DINNER FRIDAY ___A___C BREAKFAST SATURDAY ___A___C LUNCH SATURDAY

___A___C DINNER SATURDAY ___A___C BREAKFAST SUNDAY ___A___C LUNCH SUNDAY

ANY SPECIAL DIETARY REQUIREMENTS OR ALLERGIES: _____

Dinner on Friday is served between 6 -7pm. Lunch on Sunday is served after 12.00pm

Please complete and return by Friday 25th September 2020 to:

Email (preferred): admin@hfnsw.org.au

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Or simply complete and submit your application online at www.hfnsw.org.au



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

Lauren Fehlberg (Social Worker)

Lauren.Fehlberg@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.matthews@sswahs.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

Simon Cavaliere (Social Worker)

simon.cavaliere@hnehealth.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

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

Newsletter: Your newsletters from HFNSW and HFA offer information and details of events, personal stories, education, treatment information, etc.

Financial Assistance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

Information and Support:

-Education and assistance to members with bleeding disorders and those who also have HIV

-Provide tutors and entertainment to members who might require extended hospitalisation

-Information and social activities for members and their families

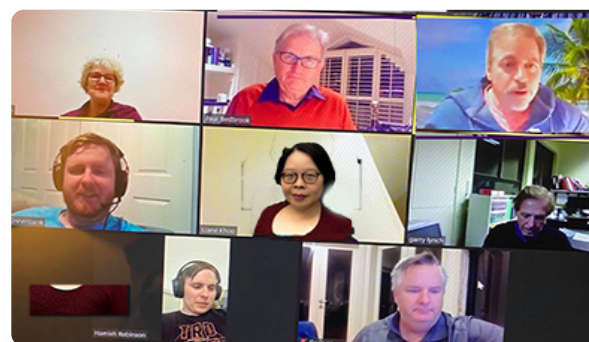
-Rural visits to areas of NSW where there are no specialists

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

Committee meetings held monthly

HFNSW Committee Group



Left to right: Stephanie Devine, Paul Bedbrook, Dan Credazzi, Sam Linnenbank, Dr Liane Khoo, Dr Garry Lynch, Hamish Robinson, Craig Haran

Haemophilia Foundation New South Wales

NATIONAL 18-24 MAY 2020
VOLUNTEER
WEEK
CHANGING COMMUNITIES.
CHANGING LIVES.



VOLUNTEERS

do not necessarily

have the time

They just

HAVE THE HEART

Volunteers
THANK YOU