

Factor Matters

Haemophilia
Foundation
NSW



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Volume 45

HFNSW FAMILY PICNIC
2021

HEALTH & WELLBEING
BEING PRESENT

WORLD HAEMOPHILIA
DAY 2021

ANNUAL FAMILY CAMP
NOVEMBER 2021

WE NEED YOUR SUPPORT!
SUPPORTERS' LETTER INSIDE

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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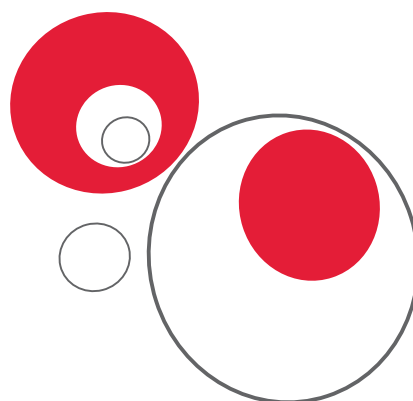
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As Minister Greg Hunt predicted last year, we are starting to hear the life changing stories emerge from our community because of the rollout of new longer-acting medicines. In every case, the stories are about relief. Parents are relieved to both be able return to work and relieved that the school doesn't call anymore. Patients return to work, have no more bleeds, are relieved that they don't have to explain to strangers anymore. These are the stories I've been hearing, and your committee members have been relaying at our meetings and webinars over the past six months. This is a new plateau in the treatment of severe haemophilia and if not already done, we encourage you to attend your clinic and discuss options with your Haematologist.

On other horizons, one specific problem we have is...how to connect to people with mild bleeding disorders?

As the committee president, we are invited to attend a portion of the quarterly NSW Health/ Haematology (HACC) meetings. Although infrequent in volume, one of the most persistent issues discussed over the years is the random presentation to a non-HTC hospital, of a patient

with a mild bleeding disorder.

As you can imagine, in an emergency, this could create delays in treatment caused by the need to conduct tests, check records, call family, etc to put the puzzle together. To solve this problem, HACC have cleverly created a state-wide network protocol wherein every NSW/ACT emergency department can connect and provide coordinated care for the patient. This takes care of such emergency situations. But from the foundation's perspective, this shows we've failed to connect with

an entire cohort of people with bleeding disorders in NSW. Based on population percentage, we are talking about over 1,000 people in NSW who could be in the category. We're looking for ideas, please send yours.

Last year's family camp was replaced with a series of afternoon events around NSW. Our first at Sydney Olympic Park is reported in this edition. Newcastle is the next community event and we are open to suggestions for the third. Please call Shiva or send an email with your ideas.

Covid vaccines are now available to our community members as part of the normal national rollout. My first reaction was to start worrying about how these novel vaccines would mix with bleeding disorders & clotting factors. Fortunately, the science to date indicates it's not a problem. If you want to learn more, please see the HFA FAQs on the subject [included in this newsletter](#) or visit

<https://www.haemophilia.org.au/publications/news/covid-19-vaccine-faqs>.

*Stay Safe,
Dan*



RARE DISEASE DAY®

28 FEBRUARY 2021

[RAREDISEASEDAY.ORG](https://rarediseaseday.org)

#RAREDISEASEDAY



What is a Rare Disease?

- The most widely accepted definition is that a rare disease is one that affects less than five in 10,000 people.
- It is prominently cited that there are more than 7,000 different rare diseases.
- While individual diseases may be rare, the total number of Australians living with a rare disease is not. Approximately eight per cent of Australians live with a rare disease. Extrapolated to an Australian population of over 25 million people, this equates to around two million Australians.
- Approximately 80 per cent of rare diseases are of genetic origin.
- While there is large variation among rare diseases, people living with a rare disease face common challenges including timely and accurate diagnosis, limited care and support options and lack of research.

Rare Disease Day

First launched in 2008 by EURORDIS – Rare Diseases Europe, Rare Disease Day 2021 (28 February) has marked the fourteenth time that rare diseases have been recognised globally. It has been the twelfth year the event will be commemorated in Australia.

The main objective of Rare Disease Day is to raise awareness among the general public and decisionmakers about rare diseases and their impact on people's lives. Australia first participated in Rare Disease Day in 2009 and have since hosted many exciting events to raise awareness among the general public.

These have taken place all over the country from Perth to Canberra and Sydney. Among them include an Indian dancing event, an online silent art auction, fun runs, public seminars, bake sales and a high tea event.

Rare Disease Day 2020 in Australia saw the launch of a National Strategic Action plan for Rare Diseases, a milestone event for Australia's Minister for Health. Across the country a vast number of events took place for all members of the rare disease community.

Multiple landmarks and buildings were lit up in rare disease day colours to mark the occasion. These include: The Story Bridge, The Victoria Bridge, Adelaide Oval, Perth's Parliament House, Perth's Yahan Square Digital Tower, Perth's Council House, Tasmania's Town Hall, Canberra's Telstra Tower, Brisbane's City Hall and Sydney's Town Hall.

On 28 February, hundreds of patient organisations from countries and regions all over the world held awareness-raising activities. The rare disease community united across borders to show that

Rare is **MANY**. Rare is **STRONG**. Rare is **PROUD**!

Resource:

www.rarevoices.org.au

www.rarediseaseday.org

www.rarediseasedayaustralia.com.au

RARE IS **MANY** RARE IS **STRONG** RARE IS **PROUD**

Rare Disease Day is organised by EURORDIS-Rare Diseases Europe and 62 National alliances of patient organisations for rare diseases.

On Sunday 28 March 2021, HFNSW organised a family picnic in a private area in the centre of Bicentennial Park at Sydney Olympic Park. What a beautiful Sunday! We couldn't have asked for a better day to go on a picnic! The sun was shining after days of cloud and heavy rains and everyone looked cheerful and happy, which was a testament to a day of fun and joy that would remain forever captured by a photo.



There were about 50 attendees and among them were Dan Credazzi, HFNSW's president, Robyn Shoemark, CNC at Children's Hospital at Westmead, and Nicoletta Crollini, Social Worker at RPAH.

The kids seemed to have a lot of fun. A highlight of the day for them was definitely the Jumping Castle, and the Fairy who did an amazing job with face/arm painting and balloon twisting.

In the afternoon Sam Linnenbank led a session of self-infusion demonstration and the children looked keen to learn all about it.



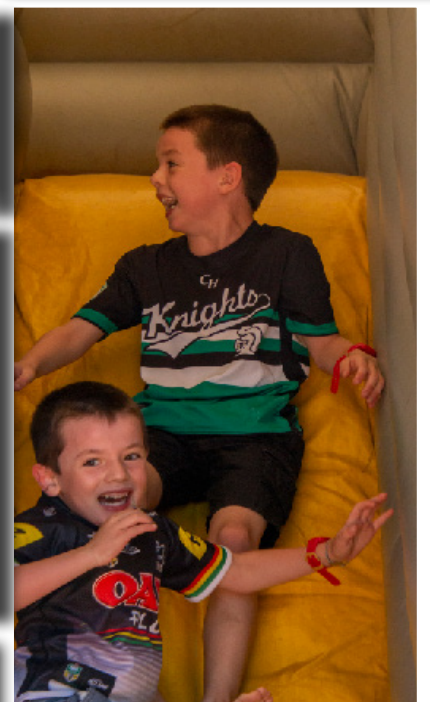
Overall, the event was a success and we received positive feedback particularly for bringing a group of members and their families together. The day out gave some momentary relief from hectic routines, and provided the opportunity to meet and catch up with one another and share experiences and insights with those who are walking through a similar life path.



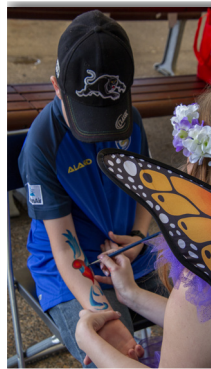
"This was a great afternoon and Liam and I were really grateful to be able to connect with other families. We would love to attend more of these."

Cara, mum of 22month old Finley

HFNSW's FAMILY PICNIC - 28 MARCH 2021



HFNSW's FAMILY PICNIC - 28 MARCH 2021



Being present

Nicoletta Crollini - Haemophilia Social Worker at Royal Prince Alfred Hospital

Focusing on the 'here and now' can sometimes be a challenging or overwhelming task, made a touch more difficult these days with the ever-evolving COVID-19 pandemic as part of our lives.



I thought focusing on techniques to help facilitate being present might help us become more mindful of the 'here and now', as opposed to worrying about moments that have past us and those that are yet to occur.

However, I acknowledge that thinking about the past or future in small doses can be helpful. For example, thinking about the past to relive a pleasant experience, identify where you went wrong, figuring out the key to a past success, and thinking about the future just long enough to prepare/plan for something.

Some of the benefits of being present are:

- Boosting our working memory.
- Improving our ability to focus.
- Reducing our levels of emotional reactivity.
- Being more flexible in our thinking.
- Improving our relationship satisfaction.



So, how can we live in the moment? We can engage in activities such as mindfulness practices or present moment meditation.

Here is a range of present moment and mindfulness activities for you to try:

Mindful colouring – I imagine plenty of you have seen this by now. Newsagents, bookstores and a range of other retailers tend to sell these mindful colouring books, which are a highly effective way to relax and focus on one task in the present. A great thing about mindful colouring is that adults and children can do it.

Connect with nature – Step outside, breathe in the fresh air, listen to the sounds of birds chirping, feel the wind blowing and give yourself that moment



to connect with your surroundings. If you can't get outside, you can listen to nature's sounds through various audio Apps or on YouTube.

Meditation – Give it a go! There are plenty of free meditation guides online. Find a comfy place to sit down, shut your eyes (if you like), and focus on the present through a guided meditation. You can meditate for as little and as long as you want. Headspace has a range of great meditations for all situations. Here is a link to a free 5-minute meditation on the headspace website <https://www.headspace.com/mindfulness>

Mindful cooking – This is a great way to allow yourself to be fully present in the kitchen while cooking (something we all do). Mindful cooking allows you the opportunity to slow down, relax, focus on what you are cooking and eventually eating. If you are interested, please give the recipe I have included a try. I love to make this recipe in the cooler months, and I find it rather relaxing to make it on a Sunday afternoon.

The recipe is healthy, tasty and includes a range of simple tasks that hopefully keeps you relaxed yet focused. It is my mother's family recipe ☺

MINESTRA DI LENTICCHIE (Lentil soup) –

Serves 4 people generously ☺

Ingredients:

1.5 cups of dried brown or red lentils

Extra virgin olive oil, enough to cover the bottom of a large pot

1 medium brown onion

2 medium carrots

2 stalks of celery

1 - 2 ripe tomatoes or 2 tablespoons of passata

2 medium or 1 large potato (peeled and washed)

2 low salt chicken stock cubes

Salt and pepper to taste

1 cup of rice

Method:

1. Place the dried lentils in a bowl, cover them with plenty of cold water and put them aside while you carry on with the rest of the preparation.
2. Place the pot on the stove and cover its bottom with the oil.
3. Chop the onion, carrots, and celery into small pieces and add this mixture to the pot.
4. Dice the tomato (if using tomatoes).
5. Strain the lentils and give them a good rinse under-water.
6. At this point, turn the heat on high and sauté the onion mixture for 5 - 6 min.
7. Add the lentils, rice, diced tomato (or the 2 tablespoons of passata), the whole potato and plenty of cold water to cover all the ingredients in the pot.
8. Add the salt, pepper, stock cubes and bring the content to boiling point.
9. Then lower the heat to a slow simmer, with the lid on, for 45 minutes. Don't forget to stir from time to time.
10. After 45 minutes, remove and roughly mash the potato. Throw the mashed potato back into the pot of soup, give it a good stir and allow the soup to cook a further 15 minutes.
11. The minestra is now ready to serve. Enjoy! ☺



Reference:

Snyder CR, Lopez SJ, Edwards LM, Marques SC. Eds. The Oxford handbook of positive psychology. 3rd edn. Oxford: Oxford University Press, 2021.

<https://www.headspace.com/mindfulness>





We are pleased to announce that
Haemophilia Foundation NSW
will be holding its

Annual Family Camp

on

19, 20, 21 November 2021

at the

Narrabeen Academy of Sport

(Subject to COVID restrictions)

Camp Application Form included
in this issue also available On-
line at www.hfnsw.org.au

Applications must be submitted
NO LATER THAN SUNDAY 10TH
OCTOBER 2021.

Complete and Submit your form today
to secure your spot!



FAMILY CAMP 2020-21 Application Form

Friday 19 - Sunday 21 November 2021

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 'A' & CHILDREN 'C' FOR EACH MEAL (CHILD – UNDER 16Y0)

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 latest by Sunday 10th October 2021 to:

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

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Applicaton form also available to be filled online at <https://www.hfnsw.org.au/support-services/family-camp>



HFNSW Family Camp

Despite our hopes and best efforts, the Covid-19 and the restrictions stood in the way of us holding our 2020 annual family camp. With the current more stable circumstances, we are delighted to announce that we are organising our Family Camp for this year and we are hoping that the situation will allow us to run a full covid-safe camp from **19th to 21st November 2021** at the Narrabeen Academy of Sport.

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/support-services/family-camp>

or complete the application form included in this newsletter and return it by email or post:

Email: coordinator@hfnsw.org.au

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Please return completed applications **NOT LATER THAN Sunday 10th October 2021**, as due to current circumstances and restrictions we have to finalise the numbers by that date.

Need more info or have question.. please contact us at:

coordinator@hfnsw.org.au | admin@hfnsw.org.au

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

Bleeding disorders and surgery: WHAT TO EXPECT

ALEX CONNOLLY

Alex Connolly is the Clinical Nurse – Haemophilia at the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital



Having surgery can be a daunting prospect at the best of times and people with a bleeding disorder might be more worried than others. However, just because you have a bleeding disorder that doesn't mean you can't undergo surgery. It does require a bit more planning and keeping your health care professionals in the loop on what is happening. Patients should be managed ideally at or in consultation with a comprehensive Haemophilia Treatment Centre. In an emergency situation this might not be possible but consultation with the staff at the Haemophilia Treatment Centre is a must.

Any person undergoing surgery will have a pre-operative health assessment and again people with a bleeding disorder are no different. They do, however, require a consultation with a haematologist to develop a surgical plan and to determine the need for replacement therapy and what type.

At the pre-operative assessment the doctor will determine if you need a blood test. An inhibitor screening test and or a factor level may be required to adequately determine a treatment plan. When you are having surgery, in most cases a bolus dose of factor replacement is given about 60-90 minutes before your procedure.

For people responsive to desmopressin (DDAVP) either an intravenous or subcutaneous dose is given. The bolus dose is to ensure a factor level peak while in surgery. This will limit bleeding during or immediately post-surgery. Patients with severe to moderate haemophilia may need a continuous infusion of factor replacement during and after surgery to keep their levels at optimum levels to decrease the risk of bleeding.

WHAT IS MINOR SURGERY AND WHAT IS MAJOR SURGERY?

Minor surgery is the type of surgery that can be often done as a day procedure and has minimal blood loss - procedures such as minor dental procedures, endoscopy/ colonoscopy, removal of skin lesions and arthroscopy.

Major surgery is surgery that has a significant risk of large volume blood loss or blood loss into a confined anatomical space. Procedures such as joint replacements, spinal, cardio vascular, abdominal and intracranial (brain) surgery are considered major procedures.

Both minor and major surgery requires factor replacement therapy.

In the case of minor surgery this may be one to five days of therapy and in major surgery can be at least five to fourteen days. Both depend on the type of surgery and the severity of the bleeding disorder.

When undergoing a dental procedure it is recommended that patients take some form of antifibrinolytic agents such as tranexamic acid as this will promote clot stability and ideally should be administered shortly before induction of anaesthesia. Alternatively, oral administration (1 g 3-4 times per day) may be commenced a day or two before surgery to ensure adequate blood levels are present at the time of operation.

POST-OPERATIVE MANAGEMENT

Depending on individual needs and type of surgery, a hospital stay may be necessary. This can be an overnight stay or several days or weeks. At times patients may be able to attend an outpatient or GP setting to receive factor replacement for a number of days post-surgery. Factor levels may be checked regularly to determine the adequacy of factor replacement. If you have mild haemophilia A, and have had intensive replacement therapy for the first time, an inhibitor test should be performed approximately four to twelve weeks after surgery.

Your surgeon might want to see you for a follow up appointment and it is important that you keep this appointment even if you feel okay. The haemophilia team might be able to see you then as well to see how you are progressing and if you need anything from the team, please ask!

THINGS TO KEEP IN MIND

- Inform your Haemophilia Treatment Centre (HTC) sooner rather than later when surgery is planned. It takes time to get factor organised particularly if the surgery is not at an HTC.
- Have your blood tests as required and let the HTC team know so results can be checked in a timely manner.
- Tell your specialist that you have a bleeding disorder. This may sound silly but you are the best advocate for yourself!
- The key to successful surgical management of the patient with a bleeding disorder is a multidisciplinary approach involving not only surgeons, anaesthetists and haematologists, but also laboratory scientists, specialist physiotherapists and haemophilia nurses. With careful planning, most surgical and invasive procedures can be carried out safely in persons with haemophilia and other bleeding disorders.
- A question not asked is a door not opened.

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1. Australian Haemophilia Centre Directors' Organisation (AHCDO). Guidelines for the management of haemophilia in Australia. Canberra: National Blood Authority, July 2016.
2. Mensah PK, Gooding R. Surgery in patients with inherited bleeding disorders. *Anaesthesia* 2015;70 (Suppl 1): 112-120.
3. Royal Brisbane and Women's Hospital Services District. Procedure Haemophilia and Von Willebrands Disease. Brisbane: RBWH, 2014.
4. Marilee Goldberg. The art of the question: a guide to short-term question-centered therapy. New York: Wiley, 1998.

Thanks to HFA for Permission to re-print this article.

WORLD HAEMOPHILIA DAY 2021



Since 1989, patient groups worldwide have annually marked World Hemophilia Day on April 17 to raise the awareness and understanding of hemophilia and other bleeding disorders. The date was chosen in honor of WFH founder Frank Schnabel, who was born on that day.

World Hemophilia Day aims to:

- Promote the importance of taking coordinated and concerted actions to achieve the WFH vision of "Treatment for all"
- Draw attention to the key issues and put hemophilia and bleeding disorders in the spotlight

ADAPTING TO CHANGE
Sustaining care in a new world
WORLD HAEMOPHILIA DAY



The theme of the event this year is "Adapting to change: sustaining care in a new world". This important event is about bringing the global bleeding disorders community together. With the COVID-19 pandemic having a major impact on people with a bleeding disorder, that objective has never been more important. Our community is made up of a great diversity of people—from patients and their families, to carers, physicians and researchers—each of whom has been affected by the pandemic in a different way. We need to continue providing support to these people now, and in the future once the pandemic has passed. The world has changed greatly over the last year, but one thing hasn't: we are still in this together, and we will always be stronger together as a community in our shared vision of "Treatment for All".

GET SOCIAL BY

Using hashtags:
#WHD2021
#WorldHemophiliaDay
#LightItUpRed

Sharing pictures with us through Facebook, Twitter and LinkedIn



ACTIVITIES

HFA will be planning virtual events and activities – to keep up-to-date visit www.haemophilia.org.au/WHD and follow our social media networks.



Like Haemophilia Foundation Australia on Facebook



Like Haemophilia Foundation Australia on Instagram



Follow HFA @Haemophilia_Au

Some activity suggestions to raise awareness on social media:

Use the following hashtags on social media to join the conversation

#WorldHemophiliaDay

#WHD2021

#LightItUpRed



Change your profile picture and Light It Up Red

- Wear something red at home and share a selfie on social media

Show your support on Facebook and add the special World Hemophilia Day Frame

www.facebook.com/profilepicframes/?selected_overlay_id=280462933708433

- Challenge your coworkers or schoolmates to post a picture of themselves wearing red for the day—or post a picture collage of everyone in your organization wearing red!

Spread the word

- Share this year's World Hemophilia Day website worldhemophiliaday.org

- Like, share and retweet HFA's Hemophilia Day-related posts on social media

We will once again participate in Light it Up Red and showcase landmarks across the country.

The World Federation of Hemophilia is encouraging our community to write on their page worldhemophiliaday.org about how you or someone you know has adapted to change in the last year. This page will go live from 1 April 2021.

Special call out to the bleeding disorders
community and their families in the
HUNTER REGION

Come along and join

for a range of fun activities and enjoy food on

World Haemophilia Day

at

Dullboy's Social Co



You may wish to **wear RED** to raise awareness and
support **Haemophilia Community**.



When: Saturday 17 April 2021, from 11am to 3pm.

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



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



THIS IS A FREE EVENT

Booking is essential for this event.

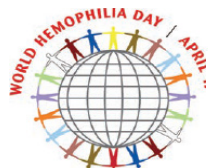
Please RSVP latest by Wednesday 14 April through

www.trybooking.com/BQCEN

or email coordinator@hfnsw.org.au.



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



Supported by HFNSW

HAEMOPHILIA FOUNDATION
NEW SOUTH WALES





With the rollout of the COVID-19 vaccine commencing in Australia, members of the community have asked us about how this will impact on people with bleeding disorders.

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has endorsed the joint COVID-19 vaccination guidance for people with bleeding disorders, produced by the World Federation of Hemophilia (WFH), European Association for Haemophilia and Allied Disorders (EAHAD), European Haemophilia Consortium (EHC), and U.S. National Hemophilia Foundation (NHF). This has detailed information and is available on the AHCDO website - <https://www.ahcdo.org.au/news>

AHCDO has advised HFA on some answers to some common questions.

These FAQs may be updated as more information becomes known.

To get regular updates from HFA, sign up up to the HFA E-News at <https://www.haemophilia.org.au>

1. Is the COVID-19 vaccination safe for people with bleeding disorders?

In general the COVID-19 vaccine is as safe and effective for people with bleeding disorders as for anybody else without a bleeding disorder. As with all immunisations, there are some steps you may need to take before being vaccinated. See Qs 4, 5 and 6 below.

The Australian Government has a careful and thorough process to check that the COVID-19 vaccines in Australia are safe and effective before it makes them available to the community. You can find more information about this on HealthDirect, the Australian Government-funded health information website - www.healthdirect.gov.au/coronavirus

2. Am I in a priority population because of my bleeding disorder?

People with bleeding disorders are not at greater risk of contracting COVID-19 or developing a severe form of the disease, so they are not considered a priority group for vaccination.

The Australian Government will roll out the vaccine in phases, starting with priority populations. Some groups have been prioritised because they will be the most affected if they become infected with COVID-19. Information on the phases for the vaccine rollout is on the HealthDirect website - click on Who will get the COVID-19 vaccine first?

3. Where will I receive my vaccination?

The Australian Government has not yet announced specifically where Australians in the community will receive their vaccines and more will be known when this information becomes available. This may include hospital hubs, some general practitioners (GPs) and community pharmacies. Haemophilia Treatment Centres may not be accredited for vaccination. HTC's will update you about their position as they are advised of this information.

You can find more information about getting the vaccine on the HealthDirect website - click on Getting the COVID-19 vaccination

4. Do I need treatment for my bleeding disorder before I have the vaccine?

Both of the currently approved vaccines require 2 intramuscular injections over a number of weeks for full vaccination. They cannot be given sub-cutaneously (under the skin) like the Fluvax.

You may also need to have treatment beforehand to prevent bleeding from the injection. Please contact your HTC to discuss this.

If you have a moderate or severe bleeding disorder, such as haemophilia or VWD or a rare clotting factor deficiency:

- If you are on prophylaxis with clotting factor concentrate, time it to have it on the day of your vaccination before the injection

- If you do not routinely give yourself factor, please contact your HTC for advice

- If you are taking emicizumab (Hemlibra®), whether you have inhibitors or not, just follow your usual treatment plan - you do not need to take any extra treatments before the vaccine injection.

If you have mild haemophilia or Type 1 or Type 2 VWD:

- Usually you will not need any special treatment with factor concentrate or DDAVP before the vaccine. Please follow the general precautions for immunisations - see below.

- However, if you have ever had a problem with bleeding from an injection in the past, please contact your HTC or haematologist for advice before you have the vaccine.

5. How do I prevent bleeding with the vaccine injection?

As you would do with any immunisation, let the health care provider who is giving the vaccine know that you have a bleeding disorder.

- Ask them to use the smallest gauge needle that is available for the vaccine. Some COVID-19 vaccines must be administered with the needle and syringe package provided and a smaller gauge needle may not be possible.

- Apply pressure on the injection site for 10 minutes after the injection to reduce bleeding and swelling

- Check the injection site several minutes and 2-4 hours after the injection, both visually and by touching it, to make sure bleeding and swelling (haematoma) has not occurred

- You may have discomfort in the arm for 1-2 days afterwards. If it becomes worse and there is swelling, contact your Haemophilia Treatment Centre (HTC)

- Do not lift anything heavy with that arm for 24 hours, eg, shopping bags, gym weights, handbags.

6. Does my bleeding disorder mean I am more likely to have an allergic reaction?

No.

It is rare, but some of the vaccines are known to cause allergic reactions in people who have a history of severe allergic reaction.

If you have ever had an allergic reaction to any vaccine or drug (for example, a severe allergic reaction to PEG or other vaccines) or have had other severe allergic reactions, you should talk to your doctor before you have the vaccine.

If you experience an allergic reaction after the vaccine injection (fever, warmth, redness, itchy skin, rash, shortness of breath, or swelling of the face or tongue), contact your doctor immediately and go to the nearest hospital emergency department straight away as it can be life-threatening.

7. Do I need to have the Fluvax as well as the COVID-19 vaccine?

Current advice is that people should still have a Fluvax this season as well as the COVID vaccination.

Ask your doctor about having Fluvax and the timing of having it if you are also having the COVID vaccination.

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



Important Note: This information was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information.

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WFH Global
Summit on

women & girls

with **inherited
bleeding disorders**



WFH staged their first ever **Global summit on women and girls with inherited bleeding disorders** in November 2020.

The Summit was an exciting two-day virtual meeting for women with bleeding disorders, patient organisations, doctors, nurses and other healthcare professionals and other supporters from around the world to exchange information and experiences. It covered:

- diagnosis and management
- quality of life
- how women are advocating for better care
- the ways women are getting their voices heard.

Some highlights from the Summit are published in this issue of National Haemophilia.

One of the speakers in the Summit was Australia's Susie Couper, who presented on the international VWD

(von Willebrand disease) clinical guidelines and how to use them from the perspective of a patient

representative. Susie has put together her reflections on the session and her personal involvement in the development of the guidelines - see page 16.

Sessions involved personal stories from women with bleeding disorders around the world – including Sharri Brodie from Perth, Western Australia, who introduced the session on diagnosis and management. The personal stories were thoughtful and compelling and highlighted the reality of the issues for women.



WFH's **Women and Girls Initiative** was also launched at the Summit. HFA Executive Director, Sharon Caris, interviewed key international leaders about what the Initiative will involve. The Initiative will support more education and training, both for health professionals and the community. You can watch Sharon's interviews on the Summit website.

ACCESS THE SUMMIT ON DEMAND

Even though the summit is over, you can still register and watch recordings of the Women and Girls Global Summit sessions on demand at <https://na.eventscloud.com/VirtualWGBD/>

- click on VIEW RECORDED SESSIONS
- click on NEW REGISTRATION and register. WFH will send you a confirmation email
- On the website, use your email address and your last name to login
- Go to the AGENDA and click on RECORDINGS to watch the session.

MY STORY: "LIVING WITH HAEMOPHILIA IS A JOURNEY..."

This is an edited version of the story shared by Sarah Maguire, a parent of four children, including two boys with Haemophilia.

My story dates back to 17 years ago when I found out I was pregnant with Mitchell my first child. We had him naturally and did all the right measures to ensure there would be no complications. It was just a week after the arrival of our beautiful baby boy when we found out he had severe Haemophilia A. It was not easy at all! It was a real challenge when he started learning to walk, and was prone to incidents and injuries that were out of our control. And even more challenging was holding down a screaming baby while finding the veins and trying to get the factor injected. Overall, life was difficult then but we managed to get through it. We took lessons from what had gone wrong and learned from every experience.

With all that experience, we welcomed our second child, Mason. We were thrilled by the news that he did not have haemophilia. His arrival helped us emotionally to get through all the challenges and hard times we were facing at the time, from port infections to injuries and head traumas.

With our third baby boy, Tate, who was born with Haemophilia, it seemed like things were going more easily as you had walked through the same path before and you would know what was going on. Of course, this doesn't mean that there was no obstacles in the way, but I was a lot more experienced and so was able to prevent the occurrence of some of the dramas and problems. After all, with all that experience, you would know what to do. But the veins! they have always been a challenge causing a hard time absolutely out of our control.

Amidst all the busy crazy life, the arrival of my baby girl was a blessing. In fact, despite all the hard times throughout the years, I wouldn't wish to change a bit of it. My boys have been living fabulous lives. I have also gained knowledge with every experience, from port infections to broken bones and treatments. I have become a lot more assertive, and learned by experience the best ways to care for my children. I have always been over the top with treatments and so treated them as normal just like other parents do with their kids and let them do whatever they wish to do, from basketball to soccer, skatepark etc. It is amazing to witness the treatment developments over the years. We have gone from 2nd daily injections to long-life treatments, and now the new product Hemlibra, the subcutaneous injection every two weeks! A life changer for us! We are still in disbelief how the new treatment has changed our life into almost normal.

We have experienced many ups and downs but these all have taught me and my boys resilience and patience and to value and cherish life even more. With new treatments as my children go through their teenage years, we feel reassured that it's going to be ok. I write this to all those parents out there who have newly diagnosed children or those who have young children, things are getting better and easier! Let's be grateful for all these amazing new treatments. I feel blessed and grateful that after all these years we have gotten to this point in our lives.

I'd like to offer my support to any of you who might need to have a chat or advice, or just someone to be there to listen and tell you that it's going to be ok. Living with haemophilia is a journey and your children are so worth every second of it. I, Sarah Maguire, parent of four children have experienced it all, good times and hard times, and I can tell you that it's all worth it.

Sarah Maguire

HFNSW Member





New content is added to the HFA Getting Older Info Hub regularly.

Check it out at www.haemophilia.org.au/getting-older

WHAT'S NEW?

- HEALTH AND WELLBEING section – lots of great info on getting older and exercise and how to manage joint replacements and other surgery
- WORK AND FINANCES section – concession cards for older people
- CONNECT TO OTHERS section – videos of personal stories

Any feedback or ideas on more topics?

Contact Suzanne at HFA on socallaghan@haemophilia.org.au or phone 1800 807 173.

SHARE YOUR STORY

Share ^{Your} story and ^{Win} Prizes

We are so grateful to those of you who take the time to share your stories and help many of us who are walking a similar life-path. It is heartwarming and inspiring to hear about common ups and downs and to feel that we are not alone.

Personal narratives have a great role in creating connections, raising awareness, and influencing policy that transforms lives. Whether as a person living with a bleeding disorder, as a clinician, or as a carer or a parent with a child being diagnosed with a bleeding disorder, let's share what we'd like others to know about life with a bleeding disorder and some of the ups and downs, 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



20TH AUSTRALIAN CONFERENCE



20TH AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

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 the conference virtually this year due to the uncertainty of the pandemic. We are very excited to go down this path. Bringing together the different parts of our community with health professionals and stakeholders has always been stimulating and rewarding. This year we expect our virtual conference will attract more delegates and create innovative learning opportunities and discussion for everyone. We are confident that nothing will be missing - in fact it will be enhanced.

Registrations will be available soon.

TO BE KEPT UP-TO-DATE

Register for our

Enews www.haemophilia.org.au/Signup

Or visit the conference page

www.haemophilia.org.au/conference21

For any enquiries contact:

Natashia Coco

Director of Development and Relationships

ncoco@haemophilia.org.au



17th WFH
International
Musculoskeletal
Congress

MAY 3-7
2021

NEW interactive workshops—reserve your spot today!

The first ever virtual edition of the 17th WFH International MSK Congress will be held from May 3 to 7, 2021.

INTERACTIVE WORKSHOPS

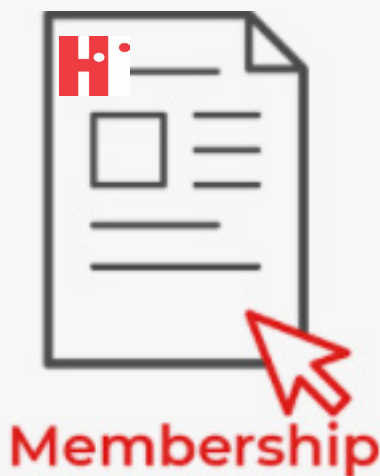
In virtual format for the first time, the MSK Congress will include four interactive workshops designed to inspire collaborative learning. With a maximum size of 30 people per group, these workshops will offer participants a unique opportunity to interact closely with experts and peers, share and explore ideas and uncover alternative approaches to current issues.

Workshops are 75 minutes, and will follow the general format below:

- Presentation or demonstration from a leading expert – 10 minutes
- Discussion – 60 minutes
- Review and closing remarks – 5 minutes

To read more about the learning outcomes for each workshop—and to stay tuned for announcements from our experts—be sure to visit www.wfh.org/msk regularly.

HFNSW's annual membership is available from 1 July each year, and all memberships expire on 30 June each



year. Membership fees are \$20 per year (Incl. GST). Membership benefits include a range of support and services comprising subsidised annual Family Camp, assistance to members who are having extended stays in hospital, support groups and other social activities, representation to State and Federal Governments, quarterly newsletter, membership to our national body Haemophilia Foundation Australia, rural visits to outer-lying areas of New South Wales where there are no Specialist Haematologists, and financial support including **Rebates for shoes and MedicAlert membership and products.**

Please make sure that your membership is up-to-date. The membership registration/renewal form is enclosed with this issue, also available at <https://www.hfnsw.org.au/get-involved/memberships>.

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

THANK YOU FOR SUPPORTING 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

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

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Grainne Dunne (Nurse)

Direct: (02) 9382 1240

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Nicoletta Crollini (Social Worker)

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Phone: (02) 9515 8385

Newcastle - Adult Services Calvary Mater

Haematology Department

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Bryony Cooke (Social Worker)

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(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

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Cathy Morrison (Social Worker)

cathy.morrison@health.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.

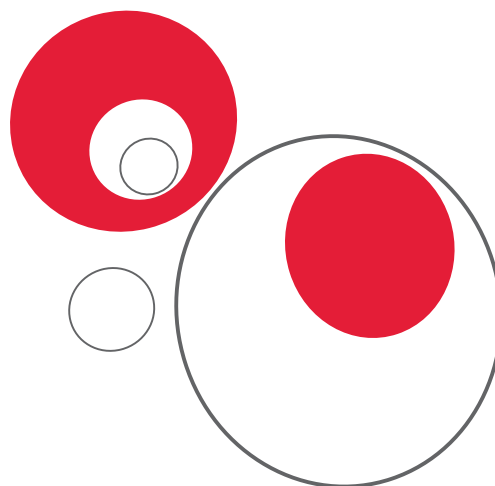
Financial Assistance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

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



ADAPTING TO CHANGE

Sustaining care in a new world



www.facebook.com/HaemophiliaFoundationAustralia

www.instagram.com/haemophiliafoundationaustralia

https://twitter.com/Haemophilia_Au

www.youtube.com/channel/UCFF5AAxKdbzD7QhfWS71KfA

