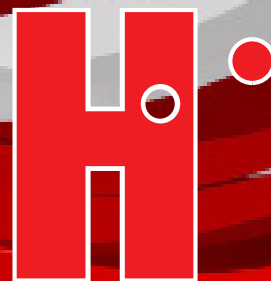


# Factor Matters

Haemophilia  
Foundation  
NSW



Published by HFNSW

Summer 2022

Volume 52



*Annual Family Camp & AGM 2022  
Photo Album*

*BDAM & Red Cake Day 2022*

*World AIDS Day 2022*

## About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, we provide complimentary services beyond the Treatment Centres such as continuous education, lifetime connections and community events, peer-to-peer counselling, and help with identifying solutions to improve the quality of life for people living with an inherited bleeding disorder.

## HFNSW Patron

Prof Kevin Rickard, AM, RFD

## HFNSW Committee

Dan Credazzi - President  
Dr Garry Lynch - Vice-president  
Paul Bedbrook - Treasurer  
Dr Liane Khoo - Member  
Nicoletta Crollini - Member  
Sam Linnenbank - Member  
Stephanie Devine - Member  
Dr Susan Russell - Member

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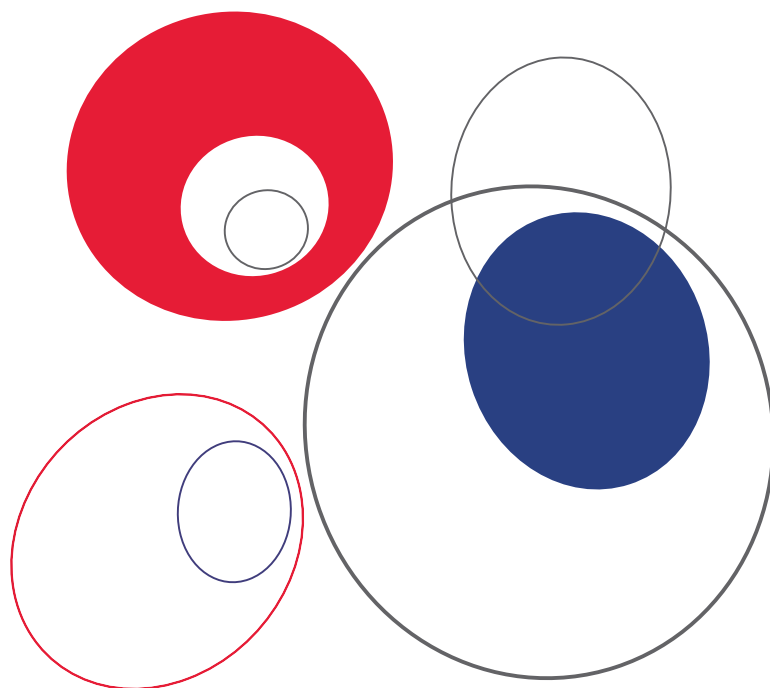
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## Factor Matters Vol 52, Summer 2022

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Editor In Chief: Shiva Tabari  
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Dan Credazzi

President,  
Haemophilia  
Foundation  
NSW

## A Word from the President

After a two-year break, we got our groove back and held Family Camp at the Academy of Sport & Rec in Narrabeen. It was fun to catch up with old friends and welcome new families into our community. The first camp I attended was in 2004, two months after our son was born. It's been 18 years since, and over that time, our families have continued to connect on this great occasion. It's heartwarming to spend time with people who know 'exactly what you mean' when you talk about things that normal mortals can't comprehend. It's also fun to see babies who have grown up coming to camp every year who are now young adults, some even sporting mo's. Everyone I spoke with agreed that camp is something we've got to keep up. However, post covid, the price has risen past what we can afford in a normal year. So while we are looking at other options, the Narrabeen facility has just worked out so well over the years that the Management Committee is drafting a petition to the Minister for Sport to give us a break on future camp costs. We'll let you know the result.

Our Patron, Professor Rickard AM and Elaine came to camp on Saturday. We're very fortunate to have Professor Rickards' unwavering support for all these years, his knowledge is our collective history. After lunch, the Prof told us about the history of haemophilia, from Queen Victoria to the Royal Prince Alfred and leading up to the present day.

This was followed by a discussion about new therapies available now and on the horizon led by Dr Liane and CNC Steve from the RPA.

We're all grateful to Shiva, Sam, Hamish, Big Sam & Wei for making the camp magic happen. Thanks also to everyone who attended for making it such a safe, special place for our families to learn and develop.

A note about home delivery and old stock. If you're reading this, you're aware of the cost of the medicines we receive. If, like us, you're on prophylaxis & receiving home delivery, then good inventory management is our responsibility. So, if you have old stock, or stock about to go out of date, please use that first. And if you've transitioned to a new treatment, please return any residuals you have to the HTC on your next visit.

We have sealed the deal with the Sydney Local Health District for permanent accommodation (utilities included!) on Carillion Avenue, five minutes walk from the RPA front door. We will be sharing these two, renovated side by side offices with the Thalassaemia Society, another SLHD NGO. The most important thing is to mark your calendar now for the grand opening party date, World haemophilia day, 17 April 2023!

Wishing you a merry Christmas season & happiness and good health in the new year.

*Dan*



# WORLD AIDS DAY

— 1 DECEMBER —

## World AIDS Day 2022

World AIDS Day is marked globally on 1 December. In 2022 the national theme for World AIDS Day is **Boldly Positive.**

World AIDS Day aims to encourage Australians:

- to educate themselves and others about HIV
- to take action to reduce the transmission of HIV by promoting prevention strategies
- and to ensure that people living with HIV can participate fully in the life of the community, free from stigma and discrimination

On World AIDS Day you can show your support for people with HIV by wearing a red ribbon, the international symbol of HIV awareness and support.

### HIV IN THE BLEEDING DISORDERS COMMUNITY

This is a time when we are mindful of our community members living with HIV and commemorate those with HIV who have passed away. It is also a reminder to bring this awareness to our everyday life as a community.

HIV is an important part of our community's history. In the mid-1980s some people with bleeding disorders acquired HIV from their clotting factor treatment products. Treatment product safety is now greatly improved and the risk of bloodborne infection products manufactured from blood is extremely low. However, the impact of HIV has been profound - on the people who acquired HIV, their partner, family and friends, the health professionals who have cared for them, and the bleeding disorders community generally.

The HIV experience drew on the resilience that was already a strong element among people with bleeding disorders and led to a resolve to respond as a community, taking on effective advocacy around safer treatments and providing support

Living with a bleeding disorder can have its challenges and peer support is valued by many. Our bleeding disorders community is diverse but comes together with an aim of valuing everyone for their mutual support, inspiring stories, and shared lived experience. When our affected community was asked about what they would like to see in peer support, they said that acknowledging and hearing their experiences is immensely important. Creating an environment where our members with HIV can thrive also involves recognising and respecting individual preferences. Every person or family affected by HIV has their own story or way of dealing with it. Some have spoken openly about having HIV or their experiences while others are very private; some prefer not to dwell on the past; others find it very difficult to think about the future. It can be important for some to commemorate those they have lost.

Our Foundations are committed to making sure their community activities provide a supportive and inclusive environment, which takes all of this into account.

#### Read more

**40 years of HIV – where to next?** for reflections from our affected community about their experiences and thoughts about the future - <https://tinyurl.com/HFA-40-years-HIV>

For more information about World AIDS Day, visit [www.worldaidsday.org.au](http://www.worldaidsday.org.au)

This article was written by Haemophilia Foundation Australia and printed with permission.



# FAMILY CAMP 2022

After two years of cancellations and postponements due to the pandemic, we finally got our Family Camp this year. During the weekend of the 11th-13th of November, our members and families from all over NSW gathered at the Sydney Academy of Sports and Recreation at Narrabeen NSW. For decades our Family Camp was known far and wide across NSW and it was great to be able to get families together again after two years of missing out. It was nice to see old families and meet some new ones.

And what a weekend! An opportunity to get away from everyday life to jump into a fully catered, all-inclusive two nights and three days of great food, awesome activities, information and knowledge sharing and quality time together. Thanks to Haemophilia Foundation NSW for organising and hosting it! The children and adults enjoyed the activities such as swimming, canoeing, archery, and team challenge games. Kids also had a blast with balloon twisting, face-painting, and the Disco Party with their favourite Claudia!

The Trivia night on Saturday was also a highlight for many of the adults.

The camp was a great opportunity to catch up with old friends and make new friendships. Everyone had plenty of time to share knowledge and experience with each other and to hear from experts. The self-infusion demonstration session led by Robyn Shoemark was well received by the children and the parents and carers.

John Salter, a member, also shared his travel experiences and some tips. John had recently been travelling overseas and his talk was so interesting and helpful and led to some questions and answers.

We were also lucky enough to have an information and Q&A session on different treatments, travelling tips, etc led by Dr Liane Khoo and Stephen Matthews from Royal Prince Alfred Hospital Haemophilia Treatment Centre.





Also, for the first time, HFNSW's Annual General Meeting (AGM) took place during the camp, on Saturday 12th November. In fact, the camp and the opportunity to have as many members in an in-person meeting was too wonderful to pass up. Fifty-five members participated at the AGM, including members and supporters. Thanks to Prof Kevin Rickard, HFNSW's Patron, for attending and the fascinating speech.

Thank you to everyone that attended the annual Family Camp and made it another success. And thank you to our volunteers, photographers and everyone who helped us with the smooth running of the camp, capturing the moments and making it more fun and safe.



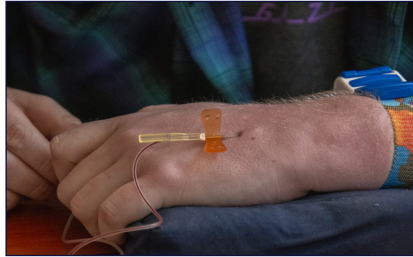
And last but not least, HFNSW would like to extend special thanks to Pauline Glea, an HFNSW member, and the team of beautiful women who took the time to sew and donate cute shopping bags for the kids and beautiful art quilts for our silent auction! The kids loved their bags and the adults loved the quilts!

Thank you again everyone for making another memorable camp! We're all done for 2022...but we'll be back with great events in 2023!

Enjoy the camp photo album in this issue!



















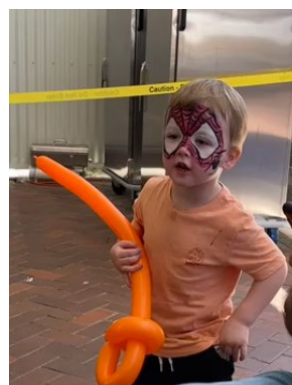




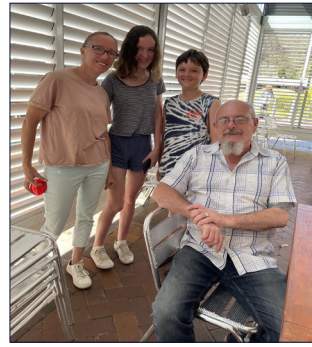
















# Planning a holiday?

## *“Travel Tips”*

Heading away on a trip, whether it's interstate or overseas, can be a great adventure, but planning is essential.

Your travel to do list:

1. Contact your HTC early
2. Research HTCs along your route
3. Organise (extra) Treatment and supplies
4. Travelling with & storage of treatment
5. Are you travelling by plane/boat? Do you need travel letters?
6. Do you need travel insurance?

## INTERSTATE TRAVEL

### Haemophilia Treatment Centres

It is a good idea if you intend to travel interstate to let your Haemophilia Treatment Centre (HTC) know you are travelling. It may be helpful for your HTC to advise the HTC in the state or territory where you will be travelling of your presence, just in case you run into problems.

Each HTC has different hours of operation. It is a good idea to check in advance with the HTC in the state or territory where you are travelling so you know when health professionals are available and how to access treatment if you need assistance, or where to attend if the HTC is too far away. Haemophilia and other bleeding disorders are rare and not all hospitals have the expertise or treatment you find in your HTC.

Contact details of HTCs around Australia are on the HFA website:

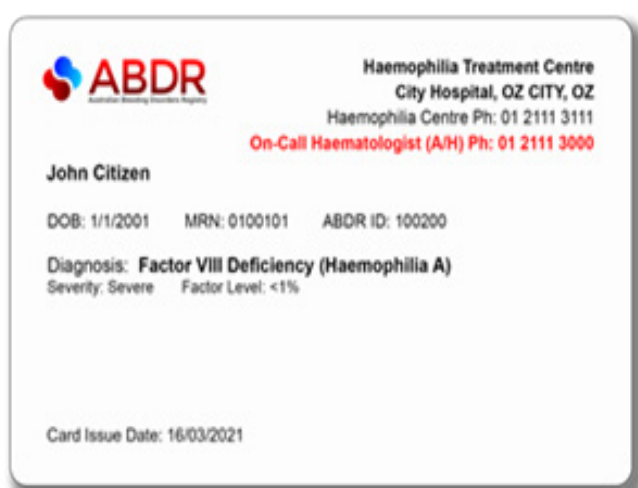
[www.haemophilia.org.au/support-services/treatment-services](http://www.haemophilia.org.au/support-services/treatment-services)



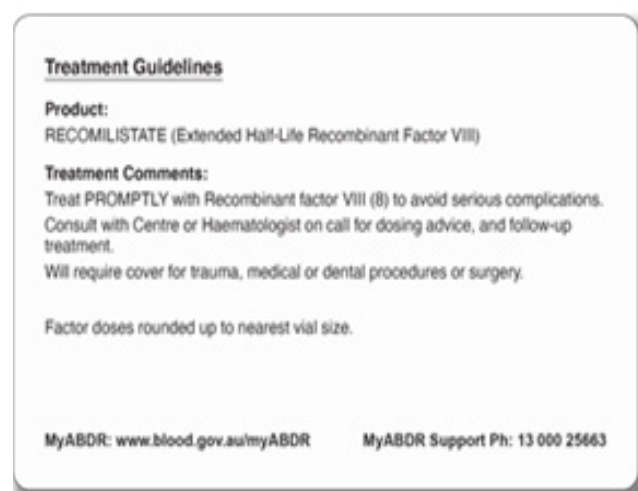
## Emergency treatment card

Carry your ABDR patient card as this is enough information to initiate emergency treatment in Australia if needed.

Your ABDR patient card explains your diagnosis, what treatment you should be given and who should be contacted for further advice. If you don't have an ABDR patient card, ask your HTC to request one for you.



The image shows a sample ABDR patient card. At the top left is the ABDR logo. To the right, it says 'Haemophilia Treatment Centre City Hospital, OZ CITY, OZ' and 'Haemophilia Centre Ph: 01 2111 3111'. Below that is 'On-Call Haematologist (A/H) Ph: 01 2111 3000'. The patient's name is 'John Citizen'. Below that are 'DOB: 1/1/2001', 'MRN: 0100101', and 'ABDR ID: 100200'. The diagnosis is 'Factor VIII Deficiency (Haemophilia A)' with 'Severity: Severe' and 'Factor Level: <1%'. At the bottom left, it says 'Card Issue Date: 16/03/2021'.



The image shows the 'Treatment Guidelines' section of the patient card. It lists the 'Product' as 'RECOMILISTATE (Extended Half-Life Recombinant Factor VIII)'. Under 'Treatment Comments', it says: 'Treat PROMPTLY with Recombinant factor VIII (8) to avoid serious complications. Consult with Centre or Haematologist on call for dosing advice, and follow-up treatment. Will require cover for trauma, medical or dental procedures or surgery.' Below that, it says 'Factor doses rounded up to nearest vial size.' At the bottom, it provides 'MyABDR: www.blood.gov.au/myABDR' and 'MyABDR Support Ph: 13 000 25663'.

## If you treat at home

- Take your treatment product with you.
- Carry enough of your treatment product with you for your stay. This is particularly important if you have changed to one of the newer products as some HTC's may not stock the full range of products or carry the full range of vial sizes.
- If you run out of factor while away, most HTC's would require you to visit the HTC and see a doctor for any product to be issued to you, even if you wanted to top up your prophylaxis stock. This is because factor is a prescribed medication.
- If you have an extended trip planned and your scheduled home delivery date is in that time, you may be able to have your delivery redirected to your holiday accommodation. This does require some advance planning and needs to be discussed with your HTC.

## Product transport and storage

If you are flying, ask your HTC to provide a letter stating that the factor and needles and syringes must be carried on board in the cabin section, as the baggage hold in a plane is exposed to extreme temperatures which may affect the factor.

If your child has an implantable port-a-cath device, please ask your HTC to provide a letter stating that factor and port-a-cath consumables must be carried on board in hand luggage. You may not be asked to show the letter but better to be safe than sorry! And there is nothing worse than you arriving in Tasmania and your luggage arriving in Darwin!!

- The factor can be put through the scanner in airport security without harm.
- For all travel, carry your product in a cooler bag. Even though most products can be stored at room temperature, it is very easy for them to overheat in hot weather particularly in cars or when camping. Do your best to keep it cool
- Always ensure you use the remaining product first when you return home



## OVERSEAS TRAVEL

### Planning

Planning is essential!

[www.Smartraveller.gov.au](http://www.Smartraveller.gov.au) has all the general information you need, but having a bleeding disorder requires extra planning.

With notice your HTC can provide a travel letter suitable to for customs that will allow you to take factor out of Australia and bring any remaining vials home. You will also require a medical letter from your haematologist in the unlikely event you need medical attention while away.

### Travel insurance

No matter how fit and healthy you are, you can't afford to travel overseas without travel insurance.

You must have travel/medical insurance and the level of cover should include a medical evacuation/repatriation in the case of emergency, particularly if you are travelling to countries where there is limited or no access to haemophilia care. In many countries, even if you are able to get a similar level of care to what you would expect in Australia, you would be paying full price for all costs for your treatment and care, which could end up being over \$100,000 for a single hospital stay.

The Australian government has reciprocal healthcare arrangements with several countries, including the United Kingdom, Republic of Ireland, Slovenia, Malta, Italy, Belgium, Norway, Sweden, Finland, the Netherlands and New Zealand. Australian travellers will be treated free of charge in these countries for emergencies. See [Reciprocal Health Care Agreements](#) on the [Medicare Australia website](#) for further information about access to health care in these countries, especially if you have other medical requirements in addition to your bleeding disorder.

Check your travel insurance fine print to make sure that it will cover everything you will need, including your bleeding disorder.

To have cover for haemophilia you must declare it as a pre-existing condition. You may be required to pay an additional premium for this level of cover. If you do not declare your bleeding disorder, your insurance may be deemed void if medical care is required.

It is worth considering having all your documentation letters translated if you are travelling to non-English speaking countries.

### Cruises

Cruise cover should include medical expenses, as there is no Medicare when you're on a cruise ship. This means you could be facing exorbitantly expensive international medical rates for something as simple as asking the doctor for some anti-nausea medication.

Hospitalisation costs on board can cost as much as \$5,000 a day – and all consultations, treatments and medications are charged at private rates. Repatriation costs to get you home from an overseas port can run up to the tens of thousands.

### Immunisations

Immunisations are necessary for some destinations and you should check well ahead of time (approx. 8 weeks). Discuss this with your general practitioner (GP) and HTC.

### For people who treat at home

Ideally you would carry all the treatment required for the trip with you, but if you are planning to be away for a long time, arrangements can be made to access factor overseas. You will need to plan well ahead for this. Organising this part of your trip will involve a lot of work and it will take at least three months.

### All documentation and approvals by the National Blood Authority (NBA) need to be completed and approved before you leave Australia.

The NBA pays for your factor on behalf of Australian governments. The NBA currently has agreed to fund overseas delivery of factor for up to 12 months in a 2-year rolling period. However, factor can only be supplied overseas in countries where the product is registered and the pharmaceutical company is able to supply it. Each country has different rules and regulations around this so be prepared that there may be costs involved. Costs that you may incur could be doctors' appointments, travel to another country to collect the factor or import taxes. Unlike at home, delivery isn't to your front door!



## Product transport and storage

Some airlines have a medical allowance to carry a quantity of medication on board the aircraft, so it is a good idea to ring around to check their requirements, especially if you will be carrying enough vials to last 3 months.

- Treatment product must be carried on board the plane with you in a cooler bag in the cabin section as the baggage hold in a plane is exposed to extreme temperatures which may affect the factor.
- The National Blood Authority has stated that no lost or damaged product will be replaced other than in very exceptional circumstances. Product will not be replaced if it has been lost/damaged in checked luggage or has not been carried and managed with all proper precautions.
- Factor vials and needles and syringes in their original packaging can be put through the scanner in airport security without harm.
- Port-a-cath consumables (dressing packs, sterile gloves, etc) must be carried on board in hand luggage. It would ruin a holiday if they went missing in lost luggage!
- While most factor concentrates can be stored at room temperature, it is very easy for them to overheat in hot weather particularly in cars or backpacks. Do your best to keep it cool or at least room temperature.
- Always ensure you use the remaining product first when you return home.

## Aviation security requirements

Aviation security has restrictions, including rules for taking liquids, aerosols and gels.

Medical products and devices are exempt but you must carry appropriate documentation. Be aware that gel or ice packs are not exempt and you may not be able to take these through security. It is essential that you carry letters describing your product, the active ingredients, its presentation and how many vials you are carrying. The letters must state that the product is for your personal use and that the vials must not be opened when they are being checked by security officials.

The product must be carried in its original packaging. This means you should not unpack the vials from their packaging to save space. You may need to declare the product at some security points and customs, so keep the letters accessible if required.

If you have any medical devices aids or implants, e.g. a metal joint or port-a-cath, you must inform the screening officers prior to screening. It would be worthwhile having this mentioned in your medical letter.

## Plasma products

If you are travelling with plasma products produced in Australia (such as plasma-derived factor VIII - Biostate®, or plasma-derived factor IX - MonoFIX®) you will require an export permit to take the product out of the country. Your HTC can arrange this to ensure you have appropriate documents. Please give your HTC plenty of notice!

## First Aid

When travelling with factor away always take a bit more than you think you will need.

Remember, you will probably be more active than you normally are when travelling, especially as you may be dragging heavy cases, lifting things and putting your bag in the overhead locker. We have reports of people who have been bumped by a taxi, badly bruised by an out-of-control motorbike, walked into a tow ball on safari, tripped and fallen under a rickshaw, and had shoulder bleeds from retrieving heavy cases from the luggage belt. Accidents do happen and you should be well prepared.

Consider taking a first aid kit with you. Here are some items others have found useful.

- Instant ice packs or zip-lock bags for ice packs
- Scarf for a sling
- A simple analgesic such as paracetamol
- A styptic stick or pencil (shaving stick) for small cuts and abrasions
- Fess® nasal spray
- Tranexamic acid tablets for mouth and nose bleeds.



And not to forget Rest Ice Compression Elevation (RICE)! Talk to your HTC about the importance of using RICE while away.

### **Venous Access**

If you are on regular home treatment and are travelling to places with limited access to safe health care, it is a good idea if a partner or your travelling companion learns to access your veins and give your treatment in case of emergency.

If you cannot access your own veins and you are on regular treatment you will have to contact the overseas HTC to investigate whether you can access assistance with your infusions and whether there will be costs for this. Be aware that your travel insurance may not cover this.

### **Port-a-caths**

Are you travelling with a child or grandchild with haemophilia? Families travelling to places with limited access to safe paediatric health care or paediatric emergency care will need to advocate that they access their child's port-a-cath device in the event of an emergency or to give factor treatment in a hospital setting. Please ask your HTC to provide a letter to support this.

If you need assistance to access the port-a-cath and require regular treatment, you will have to contact the HTC overseas to investigate whether you can access assistance with this and whether there will be costs involved. Be aware that your travel insurance may not cover this.

If your child or grandchild has a temperature of 38 degrees Celsius or above during your trip, you will need to attend the nearest emergency department for a medical assessment as this could be a sign that your child has a port-a-cath infection.

### **Finding an HTC overseas**

For contact details of HTCs around the world, see the World Federation of Hemophilia (WFH) Global

### **For people who don't normally have treatment at home**

Talk to your HTC team about what they would recommend for your individual circumstance.

If you do not usually make up your product, consider learning how to reconstitute it before you leave home! This can be helpful especially in places where the medical staff are unfamiliar with your treatment product

### **Keep your documents safe**

- Load all letters to your phone or email copies to yourself
- Take photos of your passport, Medicare card, letters and ABDR patient cards

## **FOR MORE INFORMATION**

**HTCs in Australia** - [www.haemophilia.org.au/support-services/treatment-services](http://www.haemophilia.org.au/support-services/treatment-services)

**HTCs worldwide – WFH Global Treatment Centre Directory** – [www.wfh.org](http://www.wfh.org)

**International travel advice** - [www.smartraveller.gov.au](http://www.smartraveller.gov.au)

**And speak to your Haemophilia Treatment Centre.**

**And last of all have a great holiday!**

**Bon voyage!!**

This article is reprinted with permission from Walsh M, McCarthy P, Finlayson A. Travel tips. <https://www.haemophilia.org.au/about-bleeding-disorders/living-with-a-bleeding-disorder/travel/travel-tips>

Date last reviewed: 18 November 2021





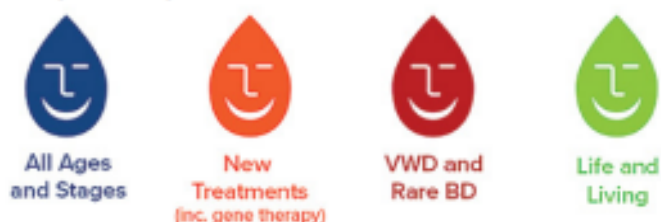
# Bleeding Disorders Awareness Month

OCTOBER 2022

For the first time, Bleeding Disorders Awareness was hosted over a month – and what a great month it was.

Bleeding Disorders Awareness Month is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders around Australia.

The theme of the month was **One community, many faces**. We showcased different topics for all ages and stages during the month.



## PERSONAL STORIES

Thank you to the individuals and families who shared their stories during the month. You can read some of their stories in this issue of *National Haemophilia*.

## WEBINARS

Over the month HFA hosted 4 webinars, covering very topical areas.

The webinars can be viewed at <https://tinyurl.com/BDAM22-webinars>

## RED CAKE DAY

Across the country our community hosted Red Cake Days, information stalls, children with a bleeding disorder did show-and-tell to their classmates.



Lincoln educated his peers in kindergarten at Heritage College Lake Macquarie about bleeding disorders and haemophilia B. Thank you Jasmin for the awesome photos.





# Save the Date

The 21st Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders will be held on 24-26 August, 2023 in Melbourne.

The conference will see expert health professionals and community members come together to share their knowledge and experiences with bleeding disorders. With topics ranging across a variety of areas and current issues, the 2023 conference will cater to everyone in our community. We hope to see you there!

Registration will open early in 2023.



## Your continued support matters!

As we are turning another year, HFNSW committee and staff would like to thank you all for your support during 2022. HFNSW was able to hold online and in-person activities and events and could wrap up the year with our popular family camp after two years of cancellation due to COVID. HFNSW looks forward to organising and hosting events and gatherings in 2023, and for that to happen, **your continued support matters!**

The membership registration/renewal form is included in this issue. Payment of donations and the membership fees can be made through the following options:

- Visit Haemophilia Foundation NSW website <http://hfnsw.org.au/>, the donation button at the top of the Home-Page of the website, or the membership page <https://bit.ly/3QHhVdh> or use the QR code below
- cheques/money orders payable to:  
**Haemophilia Foundation NSW Inc.** and send to  
Haemophilia Foundation NSW, PO Box 631, Broadway NSW 2007
- EFT Payment  
BSB: 062 204    Account number: 00902590  
Account Name: Haemophilia Foundation NSW



Please include your name in the comments field and email your receipt number to [admin@hfnsw.org.au](mailto:admin@hfnsw.org.au)

We would like to wish you all a merry Christmas and happy holidays, and a safe festive time, and look forward to working with you again in 2023.





## MEMBERSHIP FORM 2022-2023

### PERSONAL DETAILS

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

(Member details below only required if changed)

Mailing Address: -----

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

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

Email: -----

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

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

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

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

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

Treatment Centre Attended: -----

### PRIVACY

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

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

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

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

Donation\* \$ -----

TOTAL \$ -----

### PAYMENT DETAILS

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

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

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

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

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

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





## HAEMOPHILIA CENTRES

### **Kids Factor Zone**

#### **The Children's Hospital at Westmead**

General: (02) 9845 0000

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

[robyn.shoemark@health.nsw.gov.au](mailto:robyn.shoemark@health.nsw.gov.au)

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

[adrienne.woods@health.nsw.gov.au](mailto:adrienne.woods@health.nsw.gov.au)

Social Work Department:

[Schn-chw-socialwork@health.nsw.gov.au](mailto:Schn-chw-socialwork@health.nsw.gov.au)

### **Sydney Children's Hospital Randwick Haematology**

C2 North, Sydney Children's Hospital

High St. Randwick NSW 2031

General: (02) 9382 1111

Grainne Dunne (Nurse)

Direct: (02) 9382 1240

[Grainne.Dunne@health.nsw.gov.au](mailto:Grainne.Dunne@health.nsw.gov.au)

### **Royal Prince Alfred Hospital Haemophilia Treatment Centre**

RPA, Missenden Road

Camperdown NSW 2050

Stephen Matthews (Nurse)

[stephen.matthews1@health.nsw.gov.au](mailto:stephen.matthews1@health.nsw.gov.au)

Phone: (02) 9515 7013

### **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](mailto:Dale.Rodney@calvarymater.org.au)

Bryony Cooke (Social Worker)

[Bryony.Cooke@calvarymater.org.au](mailto: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](mailto:jaime.chase@hnehealth.nsw.gov.au)

Cathy Morrison (Social Worker)

[cathy.morrison@health.nsw.gov.au](mailto:cathy.morrison@health.nsw.gov.au)

## HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

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

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

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

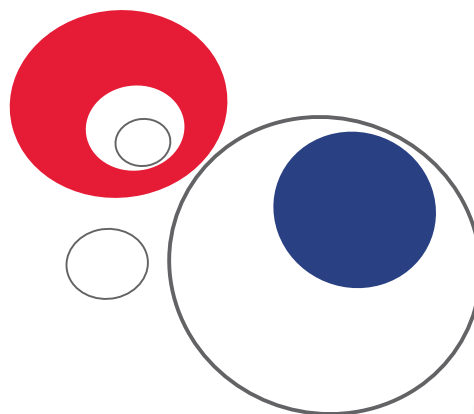
**Financial Assistance:** HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

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

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

## HFNSW COMMITTEE...

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







# *Season's Greetings*

*The Haemophilia Foundation NSW  
Committee and staff members  
wish you  
a happy and safe festive seasons.*

*Thank you  
for your support during 2022  
and we look forward to  
working with you again in 2023.*