

Factor Matters

Haemophilia
Foundation
NSW



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Spring 2023

Volume 55

21st Australian Conference Report

Hep C Can't Wait!

HFNSW 2023 Family Camp

BDAM 2023 HFNSW Walk

Your Support Matters!



About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, 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.

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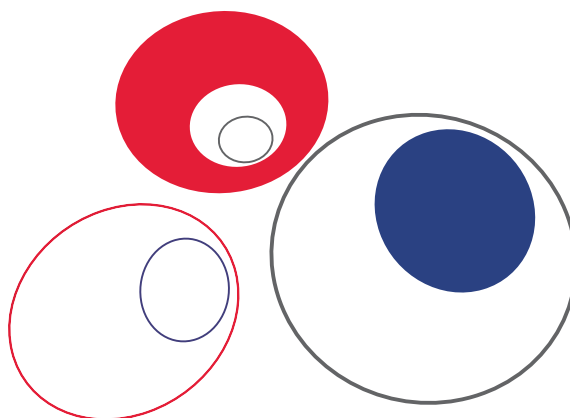
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A Word from the President



Dan Credazzi

President,
Haemophilia
Foundation
NSW



Since our last issue, the major event was the 21st Australian Conference on Haemophilia, VWD, and Rare Bleeding Disorders that took place in Melbourne in August. Seeing so many old friends, in person, in one place, was the consistent highlight for me. As it happens, I've developed some really great mates over the nineteen or so years that our family has been part of the Australian and NSW Foundations. You know how it is with old mates, no matter how many years, it's just great to pick up right where we left off.

Then there's the new things I learned, from the sessions held over the course of the two and a half days showcasing results from long term research, new treatments and new insights. If you weren't able to join in person, you should spend some time updating yourself on the latest advice and developments. Please visit the HFA website to access the content.

Back here in NSW, our new HQ is almost complete. This cost savings and excellent space will launch us into a sustainable orbit. It will enable us to improve our service delivery and it will give us a physical 'house' where we can all pop in, feel safe and get good, proper advice and support. We have also launched our campaign to find additional, permanent, non-government funding.

Our AGM in October is our next opportunity to gather as a community and discuss our future. For example, One interesting thing we were contemplating post-conference at the national HFA Council meeting, is a name change. To something more inclusive than just Haemophilia. This is something the other states are also contemplating, so we'll survey the NSW community in due course with some options.

I hope to see you at the AGM or at the upcoming community events. Please remember to use the myABDR app to record your treatments and keep in touch with your HTC.

*Best wishes,
Dan*



Conference Report

The **21st Australian Conference on haemophilia, VWD & rare bleeding disorders** was held face-to-face at the Pullman on the Park, **Melbourne, 24-26 August 2023.**

HFA conferences brought together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It was a great opportunity to learn, discuss key issues and plan for the future.

HFNSW's committee member, **Stephanie Devine** reports:



I was lucky to attend this conference and learnt a lot about current and future treatments and preparing for these changes. It was fabulous to be able to meet face to face again after the virtual conference in 2021. It's a chance to see all the members of our community in person and to actually ask a question to the researcher or expert.

I'm a member of the HFNSW committee, a mild Haemophiliac, Neurological Physiotherapist and Mum to 4 kids.

I have attended most of the conferences, beginning with combined HFNZ and HFA conference in Christchurch in 2001.

2023 is the first conference without my son Cameron, who attended his first conference at age 13 in 2011. We have made attending conference as "Mum and Son" time where we both learnt about the condition we share.

What I learnt..

There were many amazing presentations and I will describe only some of these. The slide presentations of the lectures are available on the HFA website.

This conference was going to be special as finally after hearing about it, since my son was diagnosed 25 years ago, gene therapy is available in Europe and USA.

My son was offered a spot in gene therapy research in 2018, but it just didn't fit with his life at that time and a lot was still unknown. I was surprised he didn't do it but proud that he felt he was able to manage his bleeds, that being haemophiliac was part of him and he didn't need to be "cured".

Lots of information regarding Gene Therapy was presented including all the valuable research carried out in Australia. This included multiple presentations by Dr Glenn Pierce.



He has Haemophilia A and was cured in 2008 (by early gene therapy research).

He wrote a recent article regarding the recent rush to commercialise gene therapy treatment, called “First Do No Harm”. He reinforced the concept that the current treatment for Factor 8 is the first generation and advised it is probably better to wait for the following generations.



Dr Pierce MD, PhD is an eminent researcher in gene therapy and has worked on the current extended half-life FVIII and FIX products which are either available or currently being researched. My son (severe haemophilia A) is currently part of this research and has access to once-a-week factor replacement therapy.

Dr Pierce currently serves on the World Federation of Hemophilia (WFH) as Medical Vice President, WFH USA Board of Directors, and National Hemophilia Foundation (NHF) U.S. Medical and Scientific Advisory Council. He spearheaded the donation of 1 billion international units (IUs) and initiation of the humanitarian aid collaboration with WFH. This is where factor is donated to those urgently needing it in countries who don't have access to recombinant therapy. This saves lives or allows surgery to be carried out.

Results for factor 8 were mixed with some patients requiring long term steroid treatment due to toxicity of the treatment. The initial expression of up to 24% factor was down to around 6% after 5 years.

Results for factor 9 were significantly better with stable expression of factor 9 at 40% after 5 years. Both forms of gene therapy results in the patient with factor levels equivalent to someone with mild haemophilia.

These treatments are cost effective paying for their initial extreme cost (approx. 3-3.5 million USD) after 7 years due to requiring none or minimal ongoing treatment for bleeds.

For this reason, Dr Pierce believes gene therapy will be the answer to equity of access to treatment for haemophilia, for the 85 % of the world who find factor costs prohibitive and WFH is working towards this goal.

The WFH has spent some time creating a “shared decision-making tool” to assist those keen to get gene therapy to decide if and when to do so. This is currently available on their website.

The Australian Haemophilia Centre Directors Organisation has spent time planning how we would roll out this new treatment throughout Australia to ensure even distribution to all in Australia, regardless of distance from haemophilia centres, in the future.





The National Blood Authority is the organisation that approves and pays for any blood products that the haemophilia community uses. The director of commercial blood products Jo Cameron explained the process to getting new treatments approved.

The minimum amount of time to go through all the stages in the approval process takes 43 weeks. This helps in understanding the timeframe from knowing of an available product overseas and approval of that product in Australia.

An entire session was held on Women and girls with bleeding disorders. This subject obviously is something I'm very interested.

I plan to participate in the upcoming virtual WHF 3rd World Global Summit on women & girls with bleeding disorders on 28th and 29th Sept.



Here women from around the world describe living with a bleeding disorder that many in medical profession believed does not happen in women. The WHF and local Haemophilia communities attempt to work together to make life easier for all these women and girls wherever they reside in the world.

Recently my own twin daughters aged 21 had genetic testing to determine their carrier status. This is important for their futures in regards to pregnancies, but also just in case they potentially could experience bleeding symptoms like their mother.

Genetic testing was arranged via attending the HTC at RPA and results were available after a few months.

Two women from our community described their lives in relation to their bleeding disorders.

Gynaecologists and haematologists are becoming aware that a history of heavy menstrual bleeding and diagnosis of endometriosis may be related to existence of a bleeding disorder. Factor levels need to be tested when in a non-stressful environment and are known to increase during pregnancy and as women age. Some women despite normal factor levels are seen to have bleeding symptoms and need to be alert to this fact.

Another area of interest was a presentation regarding mild haemophiliacs. Many knew they had an issue with their blood but weren't aware of their factor levels. As they have infrequent bleeds, they often are uncertain if it is simple muscle or joint injury, or a bleed into the joint and are unaware how to treat these bleeds.

These haemophiliacs may not be included in treatment trials or research and may not be diagnosed until later in life where they may discover an already damaged joint. They may also get inhibitors to treatment. They may not be linked to the HTC.

As we hopefully "cure" severe haemophiliacs with gene therapy, we will end up with more mild haemophiliacs within the community. HFA and HTC's will need to provide more services to these haemophiliacs in the future.

As usual, a conference providing lots of information still raised lots of questions for now and in the future, and the need to work together to improve outcomes.

Don't hesitate to contact me if you wish to discuss any of these issues and look on the HFA website to read the presentations by these eminent speakers.



Stephanie Devine
0411548101

PROBE STUDY AUSTRALIA

*The 2023 round of
the PROBE Australia Study
has now commenced!*

WHAT IS PROBE?

*What is the impact of haemophilia on Australians?
What has changed since new treatments became
available? What about people with mild haemophilia
and women?*

HFA has joined with the international **PROBE (Patient Reported Outcomes Burdens and Experiences)** study team (www.probestudy.org) in a multi-national and well-respected research study to provide strong and credible data about this for our advocacy. The study compares the answers of people with haemophilia and who carry the gene to other people in their community who do not have a bleeding disorder.

**You may have done the PROBE survey in 2019.
This is a new round of the survey.**

The 2023 round will compare results now to 2019, which was before new treatments were widely available in Australia.

HOW CAN YOU HELP?

You are invited to complete the questionnaire if you are an adult (18 years+) who lives in Australia and:

- have haemophilia or carry the gene
- OR
- do NOT have a bleeding disorder.

HOW TO DO THE SURVEY

The questionnaire is available:

- Web version at myprobe.org
- Or download the myPROBE app from Apple Store or Google Play (Android)
- Or ask your local Foundation or HFA for a print survey pack

Choose Country-Australia and Language-English and CONTINUE. The web and app surveys automatically save answers as you go so you can come back later.

WHAT HAPPENS TO YOUR DATA?

The survey is voluntary. All responses are anonymous and confidential. They are combined for statistical data and will not identify individuals. You may have seen the 2019 data in the HFA Getting Older report.

MORE INFORMATION

For more information about the PROBE Australia study, visit

www.haemophilia.org.au/research

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173

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Navigating the different Aged Care services can be confusing.

In the new HFA Getting Older Hub section on Aged Care services and homes, we walk through types of services and care, special issues for people with bleeding disorders and link you to more information.

Find out more at <https://tinyurl.com/GOH-Aged-care>



HEP CAN'T WAIT!

WORLD HEPATITIS DAY 2023

28TH July 2023

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to see an end to viral hepatitis. In 2023 the theme is hep can't wait, reminding us that hepatitis C remains an important issue for our community and that acting now is vital.

In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and the state and territory Haemophilia Foundations on the annual Australian awareness campaign and is committed to making a difference on hepatitis C in Australia.

TAKING ACTION

Current hep C treatments are radically different to the early interferon treatments. They are now a once-daily tablet, with few if any side-effects and very high cure rates. Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some need ongoing care for their liver health.

Were you cured? Has your liver recovered?

It's a temptation to put your liver health out of your mind once you are cured. But if you don't know what your liver test results were when you were cured, don't wait to find out. Take the time to contact your hepatitis doctor or your GP and ask them.

REMEMBER

If you had cirrhosis or extensive scarring before being treated and cured of hep C, you will still need to have a liver ultrasound scan every 6 months long-term.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research into management of advanced liver disease is ongoing.

5 WAYS TO KEEP YOUR LIVER HEALTHY

A healthy liver is important to us all. Your liver has a lot of different jobs to do to keep your body working well.

These are some tips from our hepatitis specialists to keep your liver in good shape.

1. Have a balanced diet
2. Stay active and maintain a healthy weight
3. Avoid or minimise alcohol intake
4. Take care of your mental health and wellbeing
5. Ask your doctor if you need liver health monitoring.

PERSONAL STORIES

We are grateful to Alex and Jake for sharing their experiences with hep C – being cured and caring for their liver health. Read their stories on the HFA website at www.haemophilia.org.au/world-hep-day.

WHO IS AT RISK?

For some women and men with mild haemophilia and VWD, who perhaps only had one or two treatments in their lifetime, it has been a surprise to find out they were exposed to hepatitis C.

If you ever had a blood product before 1993, including blood transfusions and plasma-derived clotting factor concentrates, you could be at risk of hepatitis C.

You may have been wondering about testing and not got around to it yet. But now is the time to talk to your doctor about a hep C test - and have treatment to be cured, if you do have hep C! Hep C tests are simple blood tests.

FOR MORE INFORMATION

Visit

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page – www.haemophilia.org.au/world-hep-day

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Haemophilia Foundation NSW Family Camp 2023

Come along and join us for HFNSW's family camp, with lots of fun and activities for all family members.

You may wish to attend both nights and enjoy all activities or part of the camp. Either way, we would love to see you there.

When: Friday 17 November 5pm to Sunday 19 November 2023.

Where: Narrabeen Academy of Sport, Wakehurst Pkwy, North Narrabeen NSW 2101

This is a free event for members and their families.

Spaces are limited and booking is essential no later than **MONDAY 9TH OCTOBER.**

Please fill out HFNSW's registration form available on [HFNSW's website](#), also included in this newsletter, and RSVP through the links below

[ADULT REGISTRATION](#)

[CHILDREN'S REGISTRATION](#) (to be completed by parents/carers)

The links are all available on HFNSW's Website:
[www.hfnsw.org.au/support-services/family-camp]



FAMILY CAMP 2022-23 Application Form

Friday 17 - Sunday 19 November 2023

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 SATURDAY 30th September 2023 to:

Email (preferred): coordinator@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>



A Word with...

Parents with a Newly Diagnosed Bleeding Disorder: *Navigating the Path*

Shiva Tabari, PhD
Program Coordinator,
Haemophilia Foundation Australia (HFNSW)

Receiving a diagnosis of a bleeding disorder for your child can be overwhelming and challenging. As a parent, you may find yourself grappling with a multitude of emotions, questions, and concerns. In this article, we aim to provide support and guidance to parents who are facing the reality of a newly diagnosed bleeding disorder in their child. We will explore key aspects of the journey, from understanding the disorder to accessing resources and connecting with the bleeding disorder community.



Understanding the Diagnosis

What is a Bleeding Disorder?

A bleeding disorder is a medical condition characterised by a defect in the body's blood clotting process. In Australia, bleeding disorders are relatively rare but can have a profound impact on the lives of those affected. It's important to note that these conditions can vary in severity, and each may require a different approach to management.

- Haemophilia: Haemophilia is the most well-known bleeding disorder, characterised by a deficiency of clotting factors, usually factor VIII (haemophilia A) or factor IX (haemophilia B).

- **Von Willebrand Disease:** Von Willebrand disease is another common bleeding disorder, caused by a deficiency or dysfunction of von Willebrand factor, a protein crucial for clotting.
- **Rare Factor Deficiencies:** There are also other rare bleeding disorders, such as factor VII deficiency or factor XIII deficiency, which are less common but equally important.



The Importance of Accurate Diagnosis

Obtaining an accurate diagnosis is the crucial first step in managing a bleeding disorder for which, you can access specialised diagnostic services and expert haematologists. Stress the importance of thorough testing and consultation with healthcare professionals who specialise in bleeding disorders. These experts are typically associated with Haemophilia Treatment Centres (HTCs) across the country.

Coping with Emotions

Emotional Impact on Parents

Receiving a diagnosis of a bleeding disorder for your child can be emotionally overwhelming. Parents often experience a range of emotions, including guilt, anxiety, and fear for their child's future. Highlight the importance of acknowledging these feelings and seeking support from healthcare providers, psychologists, and support groups.

- **Support Groups:** In New South Wales, there are specific support groups and events organised by HTCs and Haemophilia Foundation NSW (HFNSW) where parents can connect with others facing similar challenges.



Connecting with Support Networks

It is of significant importance to connect with the Haemophilia Foundation in your State/Territory, such as HFNSW in NSW, and the national bleeding disorder organisation, Haemophilia Foundation Australia (HFA). These organisations can provide a wealth of information, resources, and a supportive community. Share personal stories from Australian parents who have found strength and guidance through these networks.

Practical Steps for Parents

Learning about Treatment Options

We, in Australia, are so fortunate that the treatment options are advanced and accessible. It is important that parents become familiar with the various treatment approaches, including prophylactic treatments (preventative measures), factor replacement therapy (administering the missing clotting factor), and emerging therapies such as gene therapy.



You can access these treatments through health professionals at the HTC's. It is important for individuals with haemophilia and their caregivers to work closely with their healthcare team to develop a treatment plan and adhere to it diligently. Adherence to haemophilia treatment plans is crucial for several reasons:

- **Preventing Bleeding Episodes:** Regular adherence to prophylactic therapy helps maintain a stable level of clotting factor in the blood, reducing the risk of spontaneous bleeding episodes and joint damage.
- **Minimizing Complications:** Untreated or poorly managed haemophilia can lead to severe complications, including joint damage, chronic pain, and disability. Adherence to treatment helps minimise these risks.
- **Improving Quality of Life:** Effective treatment allows individuals with haemophilia to lead active and healthy lives. Adherence ensures that they can participate in various activities without constant fear of bleeding.
- **Reducing Healthcare Costs:** Consistent adherence to treatment plans can help reduce the overall healthcare costs associated with haemophilia by preventing emergency room visits and hospitalisations.
- **Enhancing Overall Health:** Adequate treatment supports overall health, as bleeding episodes can lead to anaemia and other health complications if not managed properly.

Open communication with healthcare providers and regular follow-up appointments are essential for monitoring progress and making necessary adjustments to the treatment plan. This comprehensive approach to care ensures the best possible outcomes for individuals living with haemophilia.



Education and Advocacy

Encourage parents to become informed advocates for their child's health and education. It is recommended that parents work closely with healthcare providers and schools to ensure that their child's bleeding disorder is well understood and accommodated. There are educational resources offered by HFNSW and HFA to help parents in this role.

Managing Bleeds and First Aid

Managing bleeds at home is an important aspect of caring for a child with a bleeding disorder. Having a first-aid plan in place can make a significant difference in handling bleeding episodes promptly and effectively. Here is practical guidance for parents:

1. Education and Training:

- Ensure that you and any caregivers are educated about haemophilia, including the type and severity of the condition your child has.
- Attend training sessions provided by your healthcare team on managing bleeds and administering factor replacement therapy at home.

2. Maintain an Emergency Contact List:

- Have a list of emergency contacts readily available. This should include your child's treating haematologist, the nearest haemophilia treatment centre, and local emergency services (dial 000).

3. Stock Necessary Supplies:

- Keep a well-stocked first-aid kit that includes sterile gauze, bandages, adhesive tape, scissors, and disposable gloves.
- Ensure you have a supply of your child's prescribed clotting factor concentrate, syringes, and any other medications or equipment needed for treatment.

4. Know the Signs of a Bleed:

- Familiarise yourself with the signs and symptoms of a bleed, which can include swelling, pain, warmth, and limited range of motion in the affected joint or muscle.

5. Prompt Treatment:

- If you suspect a bleed, act quickly. Contact your haemophilia treatment centre or haematologist for guidance.
- Administer factor replacement therapy as directed by your healthcare provider. This often involves infusing the clotting factor concentrate.
- Keep a record of the treatment, including the date, time, dosage, and location of the bleed.

6. R.I.C.E Method:

For joint or muscle bleeds, use the R.I.C.E method:

- **Rest:** Encourage your child to rest the affected limb or joint.
- **Ice:** Apply an ice pack (wrapped in a cloth) to the area for 20-30 minutes every 2-4 hours to reduce swelling.
- **Compression:** Use an elastic bandage (not too tight) to support the injured area.
- **Elevation:** Elevate the affected limb to help reduce swelling.



7. Seek Medical Attention:

- If the bleeding is severe, uncontrollable, or if you are unsure about its severity, seek immediate medical attention by calling 000 or going to the nearest emergency department.

8. Preventive Measures:

- Encourage your child to avoid high-risk activities that could lead to injury.
- Ensure they wear protective gear when participating in physical activities.
- Teach them about the importance of reporting any injuries promptly.

9. Regular Follow-Up:

- Keep regular follow-up appointments with your child's haematologist to monitor their condition and adjust the treatment plan as needed.

10. Emotional Support:

- Offer emotional support to your child. Living with haemophilia can be challenging, and they may have concerns or fears. Open communication is key.

11. School and Caregiver Training:

- Inform your child's school about their condition and ensure that teachers and caregivers are trained in haemophilia management.

12. Emergency Plan:

- Develop an emergency plan that outlines what to do in case of severe bleeding, including specific instructions and contact information for healthcare providers.

Having a well-thought-out first-aid plan and being prepared for bleeds can help you manage your child's haemophilia effectively at home, minimise complications, and provide them with the best possible care and quality of life. Always consult with your child's healthcare team for personalised guidance and recommendations.

In this challenging journey, parents of children with newly diagnosed bleeding disorders are not alone. By understanding the disorder, seeking emotional support, and accessing valuable resources, parents can empower themselves to provide the best possible care for their children. Remember that organisations like Haemophilia Foundation NSW (HFNSW) are here to assist and connect you with a community of individuals who share similar experiences and can provide guidance on this unique path.



Empowering Hope: Australia's Bleeding Disorder Breakthroughs

In recent decades, the advancements in treatments and management strategies for bleeding disorders have been remarkable. Individuals in Australia living with a bleeding disorder are exceptionally fortunate to have access to some of the finest treatments available worldwide, often at minimal or no cost. This accessibility has significantly enhanced their prospects for a life filled with happiness and good health, marking a remarkable progress in the field of medical science.

References and Useful Links:

Haemophilia Foundation Australia
(www.haemophilia.org.au)

Haemophilia Foundation NSW
(www.hfnsw.org.au)

National Blood Authority Australia
(www.blood.gov.au)

Australian Bleeding Disorders Registry
(www.abdr.org.au)

(Further info about Haemophilia Treatment Centres in NSW available on P. 23)



Bleeding Disorders Awareness Month

OCTOBER 2023



Come and enjoy a day out with your loved ones at
HFNSW Walk

We will have plenty of food, snacks, and drinks for everyone to enjoy!

When: Sunday 29 October 2023, from 11:30am to 2:30pm,

Where: Osborn Park

Boomerang Street and Motley Avenue, Haberfield, NSW 2045.

Let's raise awareness for haemophilia and other bleeding disorders by participating in one or two laps of running around the park.

Don't worry, you can go at your own pace!

Booking is essential for this event. Please register through the link below

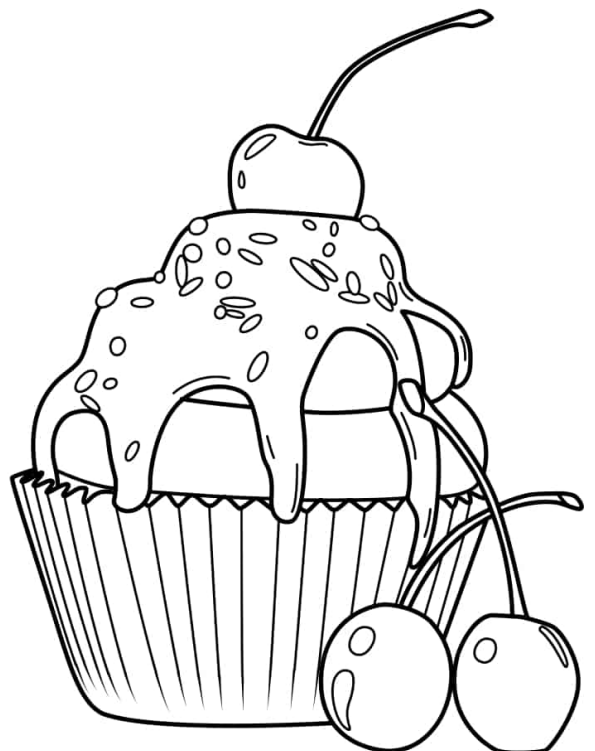
WWW.TRYBOOKING.COM/CIXTK

or email coordinator@hfnsw.org.au

Don't miss out on this great opportunity to connect with others in the bleeding disorders community, and raise awareness for an important cause.

Supported by
Haemophilia Foundation Australia and Haemophilia Foundation NSW





It's Bleeding Disorders Awareness Month!

Young Ones Are Invited!

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

Please send by 10 November 2023 to:

Haemophilia Foundation NSW

PO BOX 631, Broadway NSW 2007



invites you to join us for
2023 Annual General Meeting & Information Evening

When: Thursday, 19th October 2023, at 6 PM

**Where: Embassy Conference Centre (ECC)
826 George St, Chippendale, NSW 2008**

President, Mr Dan Credazzi JP

to Welcome All and MC us through the meeting

The meeting will be an opportunity

- *to be in the know with what has been done and future plans*
- *to hear about recent innovative treatment developments from our clinical consultants*
 - *to share your ideas*

LIGHT REFRESHMENTS WILL BE PROVIDED.

Booking is essential for this event. Please click on the link below:

www.trybooking.com/CJMJT

or, send us an email to

coordinator@hfnsw.org.au

We hope to see you at the AGM! 😊

Support your Foundation!

HFNSW Membership

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

The membership registration/renewal form is enclosed with this issue, also available at <https://bit.ly/3yYpRwC>.

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

Payment of 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

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

YOUR CONTINUED SUPPORT MATTERS!





MEMBERSHIP FORM 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

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

adrienne.woods@health.nsw.gov.au

Social Work Department:

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

Sydney Children's Hospital Randwick

Haematology

C2 North, Sydney Children's Hospital

High St. Randwick NSW 2031

General: (02) 9382 1111

Grainne Dunne (Nurse)

Direct: (02) 9382 1240

Grainne.Dunne@health.nsw.gov.au

Royal Prince Alfred Hospital

Haemophilia Treatment Centre

RPA, Missenden Road

Camperdown NSW 2050

Stephen Matthews (Nurse)

stephen.matthews1@health.nsw.gov.au

Phone: (02) 9515 7013

Newcastle - Adult Services

Calvary Mater

Haematology Department

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

Dale Rodney (Nurse)

Dale.Rodney@calvarymater.org.au

Bryony Cooke (Social Worker)

Bryony.Cooke@calvarymater.org.au

(02) 4014 4811

Newcastle - Paediatric Services

John Hunter Children's Hospital

Lookout Rd

New Lambton Heights NSW 2305

General: (02) 4921 3000

Jaime Chase CNS

0448 511 539

jaime.chase@hnehealth.nsw.gov.au

Cathy Morrison (Social Worker)

cathy.morrison@health.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

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

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

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

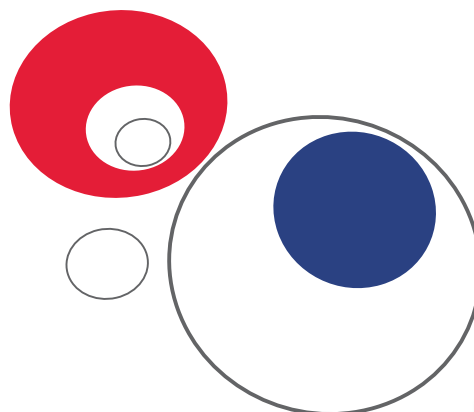
Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

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

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

HFNSW COMMITTEE...

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



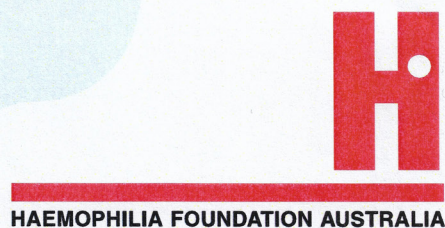


Bleeding Disorders Awareness Month

OCTOBER 2023

Help raise awareness for bleeding disorders

Posters, postcards, balloons, pens, children's activity packs and more available. Order your promotional items today. Scan the QR code below or visit tinyurl.com/bdam-orderform



HAEMOPHILIA FOUNDATION AUSTRALIA