

# Factor Matters

Haemophilia  
Foundation  
NSW



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Volume 43

Bleeding Disorders Awareness Week 2020

Annual Family Camp Postponed

HFNSW's Annual General Meeting 2020

What does quality of life mean to you?

What a fun online game evening!



## 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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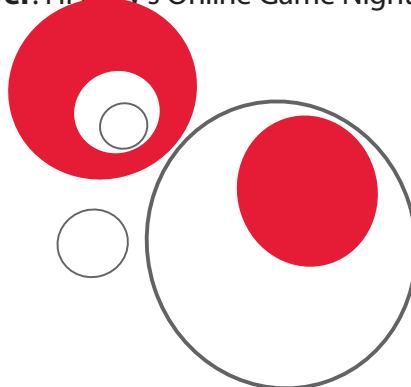
## Factor Matters, Vol 43, September 2020

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**On the cover:** HFNSW's Online Game Night



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Dear Members,

Our first online games night was a good time and since my teenage daughter actually enjoyed it, it scored highly at our house.

Going with the flow of moving events online this year, your committee has decided to hold our AGM via Zoom this year. All paid up members will be invited to attend. In addition to the traditional AGM reports, we'll have experts speaking about trials, treatments and research. As we have three-year voting cycles, there are no nominations this year, but there will be at next year's AGM.

And sadly, we've had to cancel our family camp this year. It's not logistically possible to hold a safe event this year given all the risks and requirements. We do intend to spend some of the camp funds on the online gaming nights, so please give those a try as they get advertised over the rest of this year.

On the treatment front, we'll have to wait for the outcome of the Jurisdictional Blood Committee negotiations with the States and Territory Health Ministries. In the past two months, HFNSW has traded letters on this topic with the Hon. Brad Hazzard MP and Mark Taylor MP voicing our collective support for all of our treatments to be managed by one supply chain as opposed to two or more.

In my opinion, the newer treatments are so novel, that our existing medicine supply apparatus struggles with their introduction and management. Nevertheless, HFA and HFNSW continue to campaign for broader access to all the safe modern medicines that are becoming available in other countries. Good things do take time.

*Safe wishes,*  
*Dan*



## What a fun evening!



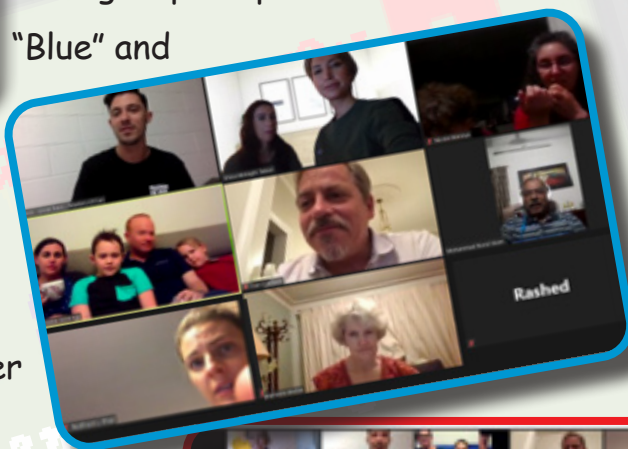
HFNSW organised an exciting and fun filled Online Game Show hosted by the Great Race Team. The show included a collection of challenges inspired by some of the most iconic television Game Shows. The participants were grouped up into teams of "Blue" and

"Red" and then competed in a series of challenges from Game Shows like Family Feud, The Chase and more.

Some challenges required one team member to perform on behalf of the team while other challenges saw teams unite in breakout rooms to discuss a challenge. Once finished we all reconvened back in the main meeting room to go through the answers.

Thank you those who joined the night!

**Missed this event?** Don't worry! There are more to come soon! Stay tuned for event updates via our website or just keep an eye on emails coming into your inbox from [coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au).





## ONLINE GAME SHOW (CONT.)



Always one to give something a chance and meet other families from the HFNSW community, I jumped at the chance of joining this online get together.

I thought I'm quite good at Trivia nights and with a house full of teenagers, how could I lose!! Of course, it was on Thursday night when my helpers all have soccer or netball training while it was being held.

It was so much fun; a trip through everyone's favourite TV game shows from Wheel of Fortune, the Chase, the Great Race and even a chance to run around the house to get objects or clothing of your team colour. Who knew that our fantastic President Dan was such a trivia buff? It was great family fun for all ages with everyone unmuting to shout their answers.

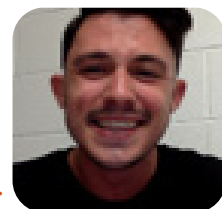
While we were working out the answers, we had the opportunity to chat about our families and where we are on our Haemophilia journey. This sharing is always one way to help support each other.

So next time- join in, have fun and meet some others who make up the community to which we all belong.

Stephanie Devine - mild haemophiliac, Mum to Cameron Brown 22 with severe Haemophilia A (who's just starting a new long-life drug trial)



- "This group were super adorable!
- There were families on this call and the kids were so cute!! They loved the game and yelling out the answers.
- When it got to the chase Dan who represented team Red said that we had made his year cause he watches the chase every night hahaha so cute!"
- Jared - Great Race Team Member



We mark World Hepatitis Day globally on 28 July. In 2020 we asked our community to help with the worldwide goal of hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New revolutionary hepatitis C treatments are widely available in Australia. They have very high cure rates. Treatment is simple - tablets not injections, few if any side effects.

## WHAT ARE THE ISSUES FOR THE BLEEDING DISORDERS COMMUNITY?

**Many Australians with bleeding disorders and hep C have now had treatment and been cured.** See their stories on the World Hepatitis Day page on the HFA website - <https://tinyurl.com/BD-WHepD2020>.

**Have you been cured of hep C? How is your liver going?** Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need ongoing care of your liver.

**Some people with bleeding disorders or who carry the gene may not realise they have hep C.** You could be at risk if you ever had a blood product before 1993. Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to talk to your doctor about a hepatitis test - and have treatment to be cured, if you do have hep C!

**Thousands of Australians are now living free of hep C, but many have not yet had treatment.** Treatment is simple and nearly all are cured – start the conversation.

**There is a small number of people with bleeding disorders and hep C whose treatment has not yet been successful.** Close liaison between their hepatitis specialists and their Haemophilia Treatment Centre is very important for their care. Research into new and improved hep C treatments continues.

**WORLD HEPATITIS DAY  
28 JULY**

**Let's Talk Hep**

Hepatitis B and C are viruses that can damage your liver and lead to liver cancer...

**You've been cured of hep C! How is your liver going?**

**Ask your doctor if you still need regular liver checks.**

hepatitis australia

[worldhepatitisday.org.au/quiz](https://worldhepatitisday.org.au/quiz)  
**#LetsTalkHep | 1800 437 222**

Images used are stock photos and the associated messaging may not represent the personal situation, views or beliefs of the people in the images.

## FOR MORE INFORMATION VISIT

- [www.world.hepatitisday.org.au](http://www.world.hepatitisday.org.au)
- The HFA World Hepatitis Day page - <https://tinyurl.com/BD-WHepD2020>



## What does quality of life mean to you?

Living with (an inherited) bleeding disorder in a changing world

CONNECTING  
THE GLOBAL  
BLEEDING  
DISORDERS  
COMMUNITY

[www.wfh.org/virtual-summit](http://www.wfh.org/virtual-summit)



by Nicoletta Collini  
Haemophilia Social Worker at Royal Prince Alfred Hospital



I thought I would take this opportunity to recap a session I listened to from the recent World Federation of Haemophilia Virtual Summit.

For those who missed out, do not fret as you are still able to view a majority of the sessions 'on-demand' for the next year via the World Federation of Haemophilia website.

### ***What does quality of life mean to you?***

***Living with (an inherited) bleeding disorder in a changing world***

#### **Deon York (President, Haemophilia Foundation of New Zealand)**

Deon was the session chair and asked those listening to the session to consider what quality of life means to you, particularly in the changing world we live in. Therefore, I too invite you to consider this question as you read over my recap of this session.

#### **Nathalie Roussel (Assistant Professor at the Faculty of Medicine and Health Sciences, University of Antwerp)**

Nathalie presented on mental health and how it correlates with chronic conditions. Nathalie stated quality of life is often described as a personal multidimensional concept that provides a standard for physical, emotional, material and social wellbeing. Quality of life is considered to be complex and unique to the individual, with our mental health only being one part of quality of life. Our mental health, being our beliefs, emotions and behaviour, plays a significant role in our understanding of quality of life.

Nathalie outlined studies show patients with severe haemophilia report a poorer quality of life in comparison to those with moderate haemophilia. Additionally, studies show the presence of target joints have a negative impact on quality of life. Nathalie went on to explain, the main predictors of positive treatment outcomes when dealing with chronic pain, are as follows:

**Physical activity:** maintaining physical activity influences the brain to reduce pain. Nathalie suggested you speak with your HTC physiotherapist about the correlation between pain reduction and physical therapy. Reduce pain catastrophising/fear of movement – Similar to the above. Physical therapy is your ally to stop fearing movement or catastrophising pain.

**Self-efficacy:** It is essential to believe in yourself as this inner belief is what helps you to change. Nathalie finished off her session, encouraging people to seek psychological support to target their mental health as this will aid in improving their quality of life.

### **Cathy Harrison (Advanced Nurse Practitioner in Haemophilia, Sheffield Teaching Hospitals NHS Foundation Trust)**

Cathy provided a nurse's perspective on quality of life during COVID-19. Cathy explained that both on a personal and professional level COVID-19 caused her to experience a range of feelings. Cathy stated she endured heightened levels of apprehension, depression and anxiety, which she had to overcome, while still supporting the bleeding disorder community.

### **Lauren Phillips (Youth Delegate, Haemophilia Foundation of New Zealand)**

Lauren provided a fascinating recount of her patient experience, as a woman with a bleeding disorder and how it has impacted her quality of life. Lauren commenced her presentation by emphasising that she was presenting just one patient's experience regarding quality of life, which is her own. Lauren outlined quality of life means a reliable diagnosis, trust in your medical team and being empowered from a young age to manage your bleeding disorder. Quality of life should include high quality medical care that does not come at a cost, as this is fundamental to the life experience for people with bleeding disorders. Lauren acknowledged that unfortunately, not everyone with a bleeding disorder can access free healthcare. Lauren stated quality of life is being seen beyond just having a bleeding disorder. Holistic care is needed and not just pigeonholing symptoms as something a person with a bleeding disorder experiences. A person with a bleeding disorder can experience other health related matters that aren't connected to their bleeding disorder.

Lauren expressed autonomy is crucial in the quality of life for a person with a bleeding disorder. Autonomy is being heard by your treating doctor and the HTC team, relying on them and also challenging them. Disclosure of illness also impacts quality of life, therefore surrounding yourself with supportive people who accept you is key. Accepting yourself is part of quality of life, accessing social and mental health support when needed is important in achieving this.



Lauren concluded her presentation, stating our quality of life is constantly evolving. Lauren encouraged practitioners to listen to their patients to determine what quality of life means to them.

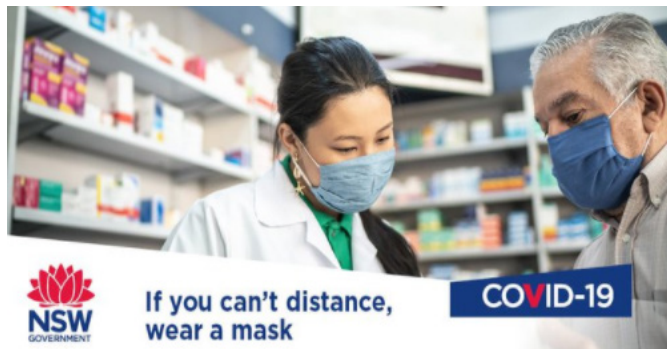
### **Randall Curtis (Project Manager, Hematology Utilization Group Study)**

Randall provided insights into the age disparity on quality of life measures. Randall outlined the quality of life scores in haemophiliacs tends to be higher than other chronic illnesses. Randall outlined that to understand this high score, one needs to change their frame of reference. Meaning, people compare another individual's quality of life based on their own; this is frame of reference. In other words, do not compare yourself to others when determining your quality of life, focus on yourself.

*I hope you have found this recap of the session to be helpful and informative. It certainly provided with plenty of ways to think about what quality of life means to me. I hope it has provided you too with this opportunity to reflect and consider what quality of life means to you.*

*Nicoletta Crollini  
Haemophilia Social Worker at RPAH*





## Situations to Wear a Mask

With community transmission occurring in the state, the NSW Government strongly recommends to take extra precautions to protect others. It is really important that you carry a clean face mask with you at all times and wear it:

- if it is hard to maintain 1.5 metres of physical distance from others
- when in high-risk indoor areas such as public transport, ride share, taxis, supermarkets, shops, places of worship and entertainment venues
- if symptoms develop while you are out of home
- if you are out of home and notified by NSW Health that you are a close contact of a confirmed COVID-19 case (including if you have visited a location with a reported case and must self-isolate immediately)
- when caring for or serving vulnerable people
- if working in a cafe, restaurant, pub, club or other high-risk indoor areas.

Wearing a mask in NSW is not mandatory in the situations above. However, NSW Health strongly recommends people wear a mask when unable to physically distance, particularly in indoor settings, to keep everyone safe.

You should also wear a mask if you:

- have any symptoms and are seeking medical care
- are going to get tested
- are in the same room as another person when you have symptoms or have been asked to self-isolate.

(Source: <https://www.nsw.gov.au>)

## Masks help reduce community transmission

Wearing a mask helps to reduce community transmission. One way COVID-19 is spread is when an infected person coughs, sneezes or speaks near another person. The person infected with COVID-19 can be:

- asymptomatic (doesn't show symptoms at all)
- pre symptomatic (not yet showing symptoms)
- minimally symptomatic (showing mild symptoms).

If a person is infected with COVID-19, a face mask helps to stop them spreading COVID-19 when they cough, sneeze or speak.

But just remember:

A mask is not a substitute for good hand hygiene and physical distancing. The use of a mask and only a mask will not prevent infection. Remember, the best ways to protect yourself and others against COVID-19 remain:

- practicing physical distancing and avoid crowds
- washing your hands for at least 20 seconds with soap, or an alcohol- based hand-rub
- coughing or sneezing into your elbow or tissue
- staying home if unwell.



## Masks protect other people

The main value of wearing a mask is to protect other people. If used correctly, masks may prevent sick people from infecting others. If you are unknowingly infected, wearing a mask will reduce the chance that you pass COVID-19 on to others. Even if you are wearing a mask, stay 1.5 metres away from others, if possible.

## DEALING WITH STRESS AND ANXIETY DURING COVID-19

The outbreak of the novel coronavirus (COVID-19) may lead to stress and anxiety for some of us. Feeling overwhelmed by strong emotions during times like these is totally understandable. Coping with distress and fear in a healthy way will help ensure that you, your loved ones and everyone in our communities stay strong and resilient during this time.

Start a group chat, hang out through video conferencing, share pictures of your outfits or something positive that happened to you recently. Social distancing does not mean social isolation. Think of it as physical distancing instead.



Take a break from your news-feed and focus on something else. Replace the time you spend on social media or watching the news with an activity that'll nourish and entertain your heart and mind: read a book, indulge in your favourite TV show, bake some goodies or play a game on your phone.



A creative project will help focus the mind. Dust off your painting kit or reorganise your décor. Do an online language course or download a yoga app. There are thousands of tutorials on YouTube on just about any hobby – so why not learn how to knit, draw, dance? The digital world is your oyster.



Happiness is helping others and it is also good for your mental health. Look out for those in your own personal networks who may need support. Look in on your mates to see if you can help with essential supplies, or send an order of goodies to someone who may be doing it tough.



Check in with family, friends, neighbours, colleagues and loved ones. Do it by phone, SMS or online. It always helps to talk. Acknowledging your own feelings of distress and discussing this can also help you manage anxiety and stress.



While the places we hang out are temporarily unavailable, we can still keep in touch with our communities. Follow your favourite event/bar/club on social media, listen to a queer podcast. Fostering a sense of community is important at this time



If you're self-isolating, in quarantine or working from home, set and maintain routines. Make time for exercise using YouTube or a fitness app, cooking your favourite meals, getting in touch with friends. If you're working remotely, allocate specific work hours and take regular breaks.



It's natural to be affected by the outbreak of any new disease. Just remember that, for most people, the symptoms of COVID-19 are mild and similar to a flu. Australia has one of the world's best healthcare systems. Everything is being done to ensure communities are safe and protected.

(Source: Acon.org.au)

## WHAT HAVE WE LEARNED FROM PROBE?

Suzanne O'Callaghan - HFA Policy Research and Education Manager

If you saw the PROBE data about ageing and haemophilia in the HFA Getting Older report, you may have wondered if similar results are found internationally.

Intrigued by the early results from Australia, the international PROBE investigators analysed the PROBE data at a global level and found some strong correlations. Their conclusions? Aging is associated with a steeper decrease in health status and health related quality of life in people with haemophilia than in people who do not have a bleeding disorder. In people with haemophilia, this decrease is large enough to be identified and measured every 10 years from the age of 18 years. The results were published in a poster at the ISTH 2020 Virtual Congress.<sup>1</sup>

PROBE (Patient Reported Outcomes Burdens and Experiences) is a multinational validated study where Australians can give evidence about the impact of living with haemophilia and of different sorts of treatment on their bleeds, pain, activities of daily living and quality of life. There is also a comparison group of people who do not have a bleeding disorder. The PROBE questionnaire includes different sets of questions to measure health-related quality of life: specific haemophilia-related questions (the PROBE score), the EQ-5D-5L utility index, and the EuroQol visual analog scale (EQ-VAS) of global health. Interestingly, the international study also found that the PROBE score is more sensitive than the EQ-5D in measuring the association of ageing on the specific domains (eg, physical, psychological, social) that were measured in both people with haemophilia and people who do not have a bleeding disorder.

### HOW CAN YOU BE PART OF PROBE?

As you can see from the Getting Older report, the PROBE study is a very important source of data to help HFA to better understand current issues - and this data will be crucial for our treatment advocacy.

Have you already completed the PROBE questionnaire? If not, please take a moment to consider making your contribution to the data. The more responses we have, the more robust our data will be and the more questions we will be able to answer. At the moment, we still need more people on prophylaxis to complete the survey for solid data on the different types of treatment. But we would be keen to hear from everyone!



You are invited to complete the survey if:

- you are an adult with haemophilia or carry the gene
- or you are an adult and DON'T have a bleeding disorder (as a comparison group)

The survey is available at

<https://tinyurl.com/PROBE-Australia>

Or ask HFA or your Foundation for a print copy

### ANY QUESTIONS?

For more information about PROBE in Australia, visit [www.haemophilia.org.au/research/probe-study](http://www.haemophilia.org.au/research/probe-study)

Or contact Suzanne at HFA:

E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)

T: 1800 807 173

### REFERENCE

1. Germini F, O'Callaghan S, Chai-Adisaksopha C, Curtis R, Frick N, Nichol M, Noone D, O'Mahony B, Page D, Stonebraker J, Skinner M, Iorio A, PROBE

investigators. Association between aging and health status in persons leaving [living] with hemophilia and controls without a bleeding disorder – Insights from the PROBE Study. [abstract] Research and Practice in Thrombosis and

Haemostasis. 2020; 4 (Suppl 1). < <https://abstracts.isth.org/abstract/association-between-aging-and-health-status-in-persons-leaving-with-hemophilia-and-controls-without-a-bleeding-disorder-insights-from-the-probe-study/>>.

Source: <https://www.haemophilia.org.au/publications/national-haemophilia/2020/no-211-september-2020/what-have-we-learned-from-probe>





We are proud to announce that HFNSW has partnered with LIVEWIRE, powered by Starlight Children's Foundation, to deliver a fun, informative online space for teens with bleeding disorders and their siblings.

Livewire is a free online community for young people aged 12 - 20 (and siblings too) living with a chronic health condition.

Livewire is a safe, supportive and fun space that hosts a fully moderated chatroom (open 12pm-12am AEST, 7 days a week), competitions, live streaming, an active newsfeed, special events and regular visits from celebrity guests.

To find out more or to create an account visit [www.livewire.org.au](http://www.livewire.org.au) or check out their Instagram: @starlight\_livewire

After you have made an account, teens anywhere in Australia are able to join our Livewire group by searching for **Haemophilia Foundation NSW** and hitting the follow button.

Please share this invitation with any teens or families you think may be interested in connecting on this fun platform!

Thank you for your support, and please email through [coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au) any questions or ideas on how to support this important initiative.



### Bleeding Disorders Awareness Week 2020

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of **11-17 October 2020**.



What a different year it is going to be – with COVID-19 restrictions in place we are going to roll out a virtual campaign. This will involve many fun things that all ages can get involved in.

The theme of the week is **One Community, Many Faces**. We will showcase our community and highlight the many different bleeding disorders and experiences.



GO RED FOR  
Bleeding Disorders

Looking for something to do during Bleeding Disorders Awareness Week, either face-to-face or virtual? Host a red-themed event and **Go Red for Bleeding Disorders!**

- Host a red-themed morning tea
- Dress red for a cocktail night
- Wear red in support of the day
- Host a Red Cake Day
- Host a red-themed crafternoon
- Organise a red free dress day at school

There are some great links and ideas available on [www.haemophilia.org.au/BDAW](http://www.haemophilia.org.au/BDAW)

HFA will not be able to provide any promotional packs this year due to COVID-19 restrictions but we will have it all downloadable online.

For downloads and information visit [www.haemophilia.org.au](http://www.haemophilia.org.au)

or contact Natasha on [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) or MB 0403 538 109.



## Annual General Meeting & Information Evening

**Thursday, 22nd October 2020**  
**6:30 PM**

*AGM will be held via Zoom this Year. This means that  
you can attend from the comfort of your own home!*

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

### JOIN US

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

To access the Zoom link and the information,  
please click on the link below

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

or, send us an email to  
[coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au)

*We hope to see you soon! ☺*



### **Hemlibra to be publicly funded**

We are delighted that the Federal Minister for Health, The Hon. Greg Hunt MP, has announced today that emicizumab (Hemlibra®) will be publicly funded as a treatment for Australians with haemophilia.

Hemlibra® is a treatment that can reduce or stop bleeding in people with severe or moderate haemophilia A with and without inhibitors.

Gavin Finkelstein, HFA President, said, 'this is great news for our community. We are pleased all governments in Australia have agreed to fund their share of the costs of this treatment product for those in our community who need it'.

Minister Hunt said in his press release that regular supply of Hemlibra® is expected to be available by December 2020.

More information available at <https://www.hfnsw.org.au/get-involved/news>

### **NBA EHL Treatment Tender Announced**

The National Blood Authority (NBA) has announced the outcome of its recent tender process for extended half life clotting factor products today. You will see the relevant document on the NBA website - <https://www.blood.gov.au/plasma-and-recombinant-product-procurement>

This means that there is funded access to extended half-life factor VIII for all people with haemophilia A and an extended half-life factor IX for all people with haemophilia B where they and their treating doctor at their Haemophilia Treatment Centre consider it for their treatment. Due to COVID-19 and some other local reasons there may be some delays to access; however, those who have been waiting for this development should speak with their doctor at their Haemophilia Treatment Centre.

This announcement does not include a decision about government funding for Hemlibra (emicizumab) which is registered in Australia for the treatment of people with severe and moderate haemophilia A with and without inhibitors. Hemlibra is not on the National Product List. HFA will continue to advocate for Hemlibra to be funded as well as the products on this list for our community.

## Share *Your* story and *Win* Prizes



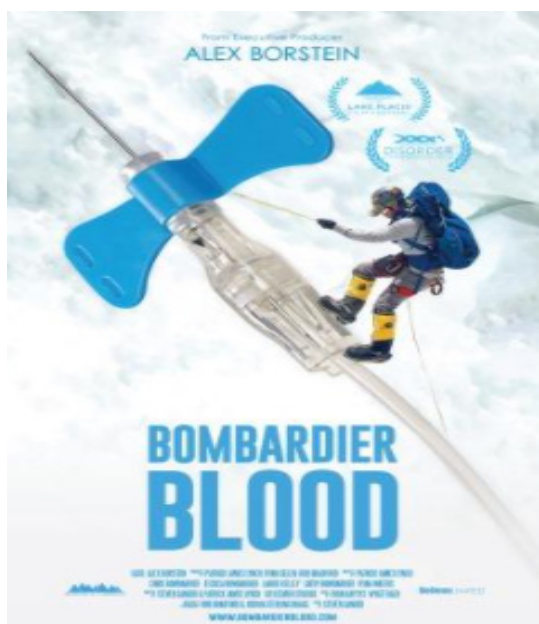
Sharing personal stories has benefits to the person telling the story, to those who share a similar experience, and to everyone who hears the story. Personal narratives have a great role in creating connections, raising awareness, and influencing policy that transforms lives. Now that Bleeding Disorders Awareness Week is around the corner, how about reaching out and share your experience of being diagnosed, or as a parent when your child was diagnosed with a bleeding disorder, what you'd like others to know about life with a bleeding disorder and some of the ups and downs, an inspiring personal

story about travel, achievements, sport, school, work etc. HFNSW will not publish your story without your permission (or parental/guardian if under 18) - and your story can be published anonymously.

Submit Your Story through the link <https://www.hfnsw.org.au/get-involved/share-your-story!>

Or, via email at [coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au)

## BOMBARDIER BLOOD MOVIE



Some great news! BOMBARDIER BLOOD will be available to purchase or rent via <https://www.bombardierblood.com/buy-or-rent> soon.

Bombardier Blood directed by Patrick James Lynch depicts an inspirational and emotional journey following a young mountaineer and activist's historic quest to become the first person with severe haemophilia to complete the Seven Summits, and to inspire an international community to help suffering "blood brothers and sisters" around the globe.

The movie is suitable for kids and teens! Stay tuned for updates to follow!

## ANNUAL FAMILY CAMP POSTPONED!



*It is with much disappointment that our Annual Family Camp this year has to be postponed! We are planning to hold it next year **26-28 March**, if circumstances allow. So please save the dates!*

*Thank you everyone for your understanding and patience!*

## ENTERTAINMENT DIGITAL MEMBERSHIP

### MAKE A DIFFERENCE & SAVE

STILL HAVEN'T GOTTEN YOUR ENTERTAINMENT MEMBERSHIP YET? NO WORRIES!

*There's still time to*

### ORDER YOUR

### ENTERTAINMENT DIGITAL MEMBERSHIP

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



20% of your Membership sale goes  
directly to Haemophilia Foundation NSW.

Your entertainment subscription can be purchased and paid online on

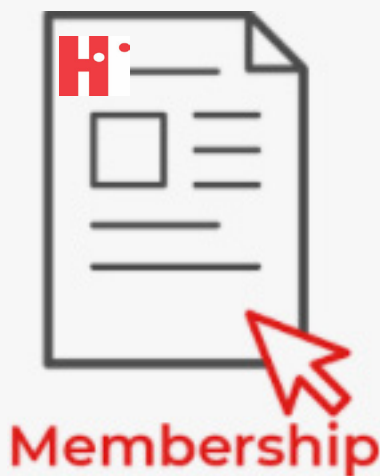
<https://www.entertainment.com.au/subscription>

or visit our HFNSW website for a quick access:

<https://www.hfnsw.org.au/get-involved/fundraising>



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 here, also available at <https://www.hfnsw.org.au/get-involved/memberships>.

For any further information contact us on [coordinator@hfnsw.org.au](mailto: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](mailto: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](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.matthews@sswahs.nsw.gov.au](mailto:stephen.matthews@sswahs.nsw.gov.au)

Phone: (02) 9515 7013

Nicoletta Crollini (Social Worker)

[nicoletta.crollini@health.nsw.gov.au](mailto:nicoletta.crollini@health.nsw.gov.au)

Phone: (02) 9515 8385

#### **Newcastle - Adult Services**

##### **Calvary Mater**

##### **Haematology Department**

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

Dale Rodney (Nurse)

[Dale.Rodney@calvarymater.org.au](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)

Fiona Keegan (Social Worker)

[Fiona.keegan@health.nsw.gov.au](mailto:Fiona.keegan@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.

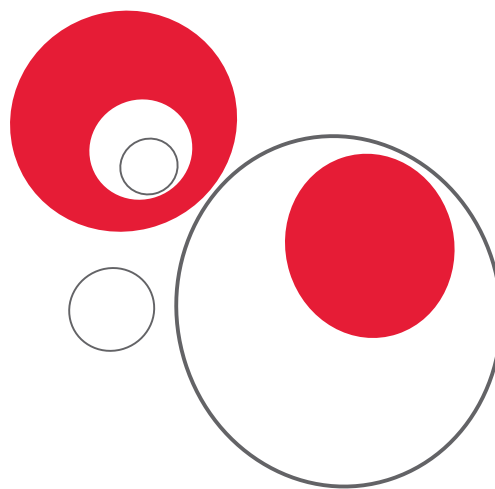
**Financial Assistance:** MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

### **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](mailto:coordinator@hfnsw.org.au)



You're invited to  
HFNSW'S AGM & Information Evening

# ANNUAL GENERAL MEETING

Thursday 22nd October 2020  
6:30pm through Zoom  
(Details inside)

Be there to:  
find out what has been done  
hear from guest speakers  
be in the know with important plans  
share your ideas