

Factor Matters

Haemophilia
Foundation
NSW



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Volume 44

RESILIENCE – BOUNCING BACK
AND MANAGING LIFE!

HFNSW INFO EVENING
A NOTE FROM SHARON CARIS

WORLD AIDS
DAY 2020

ANNUAL FAMILY CAMP
MARCH 2021

2020
2021

About Us

HFNSW is a member driven not for profit organisation that provides support programs and advocacy for the NSW bleeding disorders community, their families and carers. While specialist doctors and nurses provide world class medical and social care for our members, our mandate is to support the full range of other important things for the bleeding disorder community such as: community participation, physical & emotional support, advocacy, education and financial assistance to members, their families and carers.

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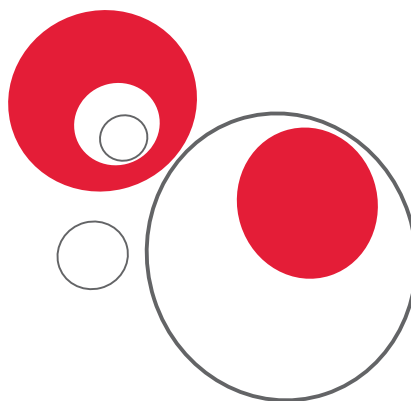
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Dear Members,

During this extra complicated year, your Foundation has managed to keep pace and adjust operations to keep going during 2020. As many businesses and not for profits have been shuttered due to the pandemic, the fact that we are still providing valuable services and strong advocacy, reflects the resilience of our community advisory members, dedicated staff and Clinicians. With the close of this strange year, we enter a new chapter in the Australian Haemophilia story. In our world, the seasons are synchronized with the National Blood Authority (NBA) purchasing cycles.

And with the benefit of one of the world's best healthcare systems, we now have access to the latest most advanced medicines. But nothing good comes without a cost and we can't forget the costs involved here. Some of these new treatments cost more than a house, per person per year. This is one of the reasons tracking your receipt and usage of your home deliveries with the MyABDR app is so important. Honestly, the lack of data from the receiving end (us) will eventually create a problem we don't want. Rights come with responsibilities. So please, try to always use MyABDR.

Given the events of the past year, the insane pace of change in our lives and the crazy news, it can be easy to fall into a doom scrolling, dark corner of life. I've personally experienced this dance with depression in 2020 and so have many of my friends and colleagues. If you feel unconnected, please contact us now. We can help you reconnect.

The last time the Christmas star became visible in the Western sky was 800 years ago, like it did on December 21st. I know that it's really Jupiter & Saturn, but still that's bound to mean something. So while we wait to find out (alien landing?!), I think we all have a lot to be grateful for in Oz, so count your blessings and keep looking up!

Stay Safe & Happy Hol's
Dan

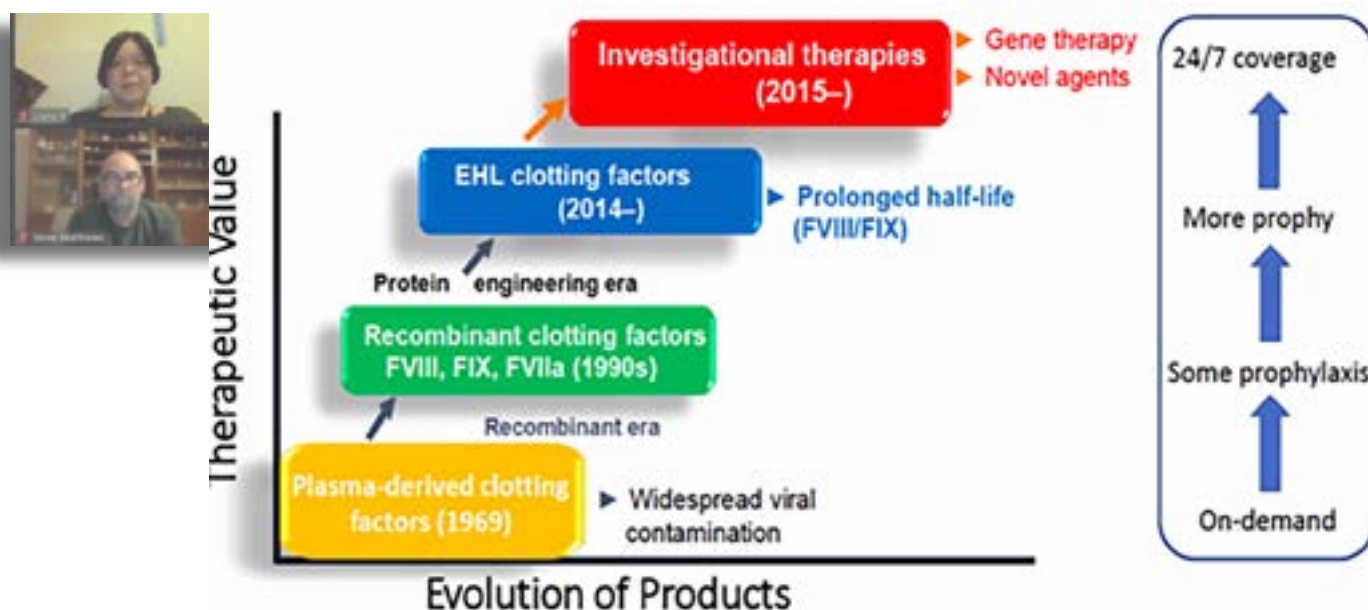
HAPPY
holidays

On 17 November, HFNSW in partnership with Royal Prince Alfred Hospital (RPAH) Haemophilia Treatment Centre (HTC) held an information night about the new treatment products available for haemophilia A and B.

The session was well attended with the presence of HFNSW members and supporters, including HFNSW Patron Prof Kevin Rickard, Sharon Caris, Executive Director HFA, Dan Credazzi, president HFNSW, and health professionals from NSW Ministry of Health.

Dr Liane Khoo and Mr Stephen Matthews from Haemophilia Treatment Centre at Royal Prince Alfred Hospital were the speakers.

Dr Liane Khoo started her presentation by providing an engaging historical background about Haemophilia treatments.



With a focus on new treatment products, Dr Khoo continued to explain about Extended Half-Life Concentrates (EHLs) for Haemophilia A and B and the non-factor replacement, Emicizumab (Hemlibra®) for Haemophilia A.



Hemlibra®, as Dr Khoo puts it, is “a novel recombinant, humanized, bispecific antibody that mimics the action of FVIII by binding to activated clotting factors (FIXa and FX) to form a clot and stop bleeding”.

Some of the advantages of this new product over other products is that it is injected under the skin (subcutaneously) and provides consistent protection without peaks and troughs.

With all the advantages, however, Hemlibra is not recommended for treatment of acute bleeding on its own. Hemlibra is a potent activator of the clotting system, but not able to form the blood clot very quickly, so there is a risk of going overboard. This can result in formation of too many blood clots and trauma to small blood vessels, causing possible harm to kidneys, brain, and other organs. This is particularly a safety warning for patients who are using FEIBA®.



Dr Khoo then wrapped up her speech by providing updates on haemophilia clinical trials at RPAH including

- **“Ultra” Extended Half-Life Concentrates**
BIVV001 - IV once a week dosing, Haemophilia A
- **Non-Factor Therapies**
Fitusiran - under the skin treatment for Haemophilia A & B
- **Gene therapy (open)**
Haemophilia A and B

The speech then was followed by questions and answers session where participants had the opportunity to ask their questions and receive updates and information on Haemophilia treatment products.

In response to some of the questions, Sharon Caris has also provided us with some helpful information in the form of a ‘fact sheet’ which is included in this newsletter ([see pages 6-7](#)).
Thank you, Sharon!

HFSNW would also like to thank Dr Liane Khoo and Mr Stephen Matthews for the informative session, and all of you that attended and made it such an interactive session. For those who missed out, we will host another next year. Please stay tuned for updates on [our website](#) and keep an eye on emails coming into your inbox from your Foundation.



Information about new treatments are available on HFA Website *Haemophilia.org.au*. If you have any questions about your treatment or treatment products, it is recommended that you discuss them with your doctor and clinicians at your Haemophilia Treatment Centre.



A note from Sharon to HFNSW members at the Zoom Info Evening on 10 December 2020



It was lovely to see you all at the information evening last night. As a couple of questions came up about the supply and cost of treatment products, I thought you might be interested in a few “fast facts” about this.

HFA and HFNSW are committed to advocacy for our members to make sure they have the treatment they need so they can get on and live full and independent lives. The information below is mainly about how treatments for bleeding disorders are supplied and funded in Australia, and the cost for governments. We don't want our families to worry about their treatment, but it is important to understand the basics – especially how to play your part to make sure the system is as cost-effective as possible for governments, so that the system is managed well, affordable and sustainable, and so that everyone in our community has access to appropriate treatment when they need it. We encourage everyone to work with their Haemophilia Treatment Centre team to make sure they have the information they need about their treatment options and the best way to manage their bleeding disorder. Part of this involves using MyABDR – please do, because it provides important information for you and your treating team.

Here are a few facts for your info!

- we are extremely fortunate in Australia that all Australian governments share the cost of treatment products and they are provided free to the people who need them. In some countries people must pay for their treatment themselves and for many this is unaffordable. In the US, most people must use private health insurance for this, and some “max out” of their insurance each year and are forced to go without the product they need until they are eligible for treatment under their insurance the next year.
- 70% of people with a bleeding disorder around the world receive inadequate or no treatment at all because it is unavailable and unaffordable.
- the National Blood Authority in Canberra purchases blood and blood related products on behalf of all Australian governments (this includes plasma derived factor VIII such as Biostate as well as standard and extended half-life recombinant clotting factors VIII and IX (EHLs) and the new non clotting factor treatment, Hemlibra)
- the Federal government pays 63% and state/territory governments pay 37% of the cost of treatment products for bleeding disorders, so treatment is not only important to each patient and families, but also to your federal and state members of parliament. Remember that for advocacy!
- In addition to the cost of treatment products governments also pay for hospital services (HTCs), pathology and other medical services required (some of these services are provided through public hospitals; some are provided via Medicare)
- HFNSW and HFA advocate on your behalf for best practice treatments for bleeding disorders and are already in discussion with governments about access to some of the new treatments expected to become available over the next few years.

- Clinical trials for new treatment products and gene therapy may be available to some Australians from time to time – discuss this with your HTC if you are interested to know more.
- New treatment products must first be evaluated as safe and effective by the Therapeutic Goods Administration (TGA) before they can be registered for use in Australia; this process may take one year or more after clinical trials which may also have run for a few years. Before they can be funded, treatment products usually need to be considered by a government committee which will evaluate whether they will be cost-effective and/or better in some way than current products – HFA and individuals can usually have input into this process by explaining the benefits of a new product – for example, in our submission in support of funding for EHLs we explained how EHLs benefit patients - fewer infusions, better vein health, factor stays longer in the body, better adherence to prophylaxis, less joint damage due to fewer bleeds, improved quality of life, less burden on families etc. HFA is concerned these evaluation processes sometimes take too long and we have recently made submissions to governments about speeding this up so access to new treatment is not delayed unnecessarily.
- Information about the cost of treatment products can be found in the National Blood Authority Annual Report – <https://www.blood.gov.au/document/nba-annual-report-2019-20>. The NBA reported that it spent \$656.08 million for fresh blood products and plasma collection and \$614.47 million for plasma and recombinant products in 2019-2020. Clotting factors comprised 13.9 percent of total blood and blood product expenditure. In recent years governments have had some savings because pharmaceutical companies have supplied treatment products for use in clinical trials and for compassionate access programs.

- Australian Bleeding Disorders Registry (ABDR) and MyABDR are critical for ensuring the NBA has the information it needs to purchase appropriate supplies of treatment products for our community. It is also important for health professionals to see how your treatment is going.
- For demographic and other information about bleeding disorders in Australia see the Australian Bleeding Disorders Registry Annual Report for 2018-2019 <https://www.blood.gov.au/system/files/ABDR-Annual-Report-2018-19-FINAL.pdf>

Data from the ABDR Report 2018-19:

- 6,355 patients
- 5,151 with hereditary Haemophilia A, Haemophilia B or von Willebrand disease
- 111 with acquired Haemophilia A, Haemophilia B or von Willebrand disease
- 1,093 with other bleeding disorders
- 1,804 received product

We are truly grateful for those who participate in clinical trials and pave the way for others. We always welcome your feedback if you have participated or have experience you wish to share with us. Our strong partnerships with the specialist doctors and other health professionals at our Haemophilia Treatment Centres around the country, with the pharmaceutical industry and with the World Federation of Hemophilia and other organisations around the world, help keep us informed about new treatment developments.

At any time if you have concerns feel free to contact HFA – you are welcome to call me direct – 0410419914 - but most importantly always talk with your HTC to make sure you are up to date about what the best treatment is for you or your family member.

Sharon Caris
HFA Executive Director
11 December 2020

Resilience – bouncing back and managing life!

Nicoletta Crollini - Haemophilia Social Worker at Royal Prince Alfred Hospital

Considering we are coming to the end of 2020 and about to start a new year, I thought it would be helpful to focus on resilience, so we can bounce back in 2021!



So, what is resilience?

Resilience is recovering or bouncing back from the misfortunes or challenges life throws at us, which are inevitable. These life set-backs come in many forms, with a few examples being relationship break-ups, being made redundant, a bleed or even a global pandemic and all the impacts that come along with it. Resilience is building up our mental and emotional strength after something challenging occurs in our life.

How we demonstrate resilience?

We demonstrate resilience in our everyday lives all the time, some examples are:

- Developing achievable plans and taking appropriate steps to succeed in completing those plans.
- Having a positive view in ourselves as well as confidence in our strengths and abilities, this is our self-esteem.
- Our skills in communicating, problem-solving and being adaptable to various situations.
- The ability to self-regulate or manage strong feelings, emotions and impulses.
- Caring about or helping other people in need who are going through their own challenges.
- Maintaining a balanced life of studies or employment, engaging in hobbies, social and cultural activities.

How to develop resilience?

Resilience is not something available only to a few, we are all capable of it and it is something we can build upon in preparation for the next challenge life throws at us. Here are some ways how:

- Build positive beliefs in yourself – This can be through achievable goals such as going for daily walks, or finding something that motivates you such as cooking new recipes. Resilient people are careful where to focus their attention, so focus on the good in your life and not the negative.

- Other people matter! Nobody navigates life challenges on their own - Identify your social support network, these are the people you feel comfortable confiding in and who can support you during challenging times.
- Get some perspective, step back and assess your situation as objectively as possible, is it really as bad as you think? Ask yourself, “is the way I am thinking or acting helping or harming me?”
- Take action in solving a problem instead of waiting for the problem to solve itself.
- Be gentle to yourself and practice self-compassion, which is being there for yourself like you would when a friend is going through a rough time. You won't always get things right all the time, failure is part of life but being hard on yourself does not need to be.



- Practice self-care. Self-care is doing things like exercise, taking time out to relax, ensuring you eat well and get a good night sleep.

How to raise resilient children?



Parents, teachers, caregivers and any important adults in children's lives can help children grow up with resilience. Here are a few ideas on how to encourage resilience in children:

- Encourage your child to make connections and build their own support network, remind them that you are there for them when experiencing the challenging moments in life. As previously mentioned, healthy social support networks encourage resilience.
- Allow your child to embrace failure as well as witnessing your own failings. Learning about failure and experiencing it is not a weakness, it is a part of life.
- Model positive self-care behaviour for your child to learn. This can be through the previously mentioned self-care activities such as: healthy eating, exercise, relaxing, engaging in hobbies and maintaining a good sleep routine.
- Encourage your child's self-efficacy skills in doing things for themselves, for example teaching and supporting them to self-infuse.
- Support your child in setting achievable goals, which can be accomplished in steps. Achieving goals in steps will allow your child to reflect on what they have accomplished and what they are yet to complete. Try not to reward your child for each step they accomplish but cheer them on.
- Encourage your child to develop 'grit' and persistence. Developing skills or achieving something in life can take time and practice is key.

- Remind your child how they have previously demonstrated resilience through overcoming past challenges, and link their past successes to future positive opportunities.
- Encourage keeping things in perspective and maintaining a long-term view, especially when your child is focusing on something negative.

Teach your child to embrace the inevitability of change in life. For example, goals which are no longer attainable, can be replaced with new or updated goals that are more relevant.



The take home message

Resilience is an important trait for us all to have. Hopefully I have helped you understand that resilience is developed overtime and a trait we can all acquire. With resilience, we work through our challenges, and rise up to carry on managing our lives.

To finish off, a poem written by Aija Mayrock which highlights the essence of resilience.

When you are knocked down, remember it's not what made you fall, it's what makes you get back up.

Reference:

<https://positivepsychology.com/what-is-resilience/>



Haemophilia Foundation NSW Annual Family Camp

26, 27, 28 March 2021

Narrabeen Academy of Sport

(if COVID-19 restrictions allow)

Camp Application Form
also available Online

at <https://bit.ly/3nAGbio>

Applications must be submitted
NO LATER THAN
Friday 5Th February 2021.
Complete and Submit your form
today!



FAMILY CAMP 2020-21 Application Form

Friday 26 - Sunday 28 March 2021

FAMILY MEMBERS

AGE OF CHILDREN

ADDRESS:

Email:

CONTACT PHONE NO:

ACCOMMODATION (TICK ONE ONLY)

- ☐ FRIDAY NIGHT ONLY
☐ FRIDAY AND SATURDAY NIGHT
☐ SATURDAY NIGHT ONLY
☐ DAY STAY ONLY (SATURDAY)

ANY SPECIAL ACCOMMODATION REQUIREMENTS:

MEALS – PLEASE INDICATE HOW MANY ADULTS 'A' & CHILDREN 'C' FOR EACH MEAL (CHILD – UNDER 16Y0)

A C DINNER FRIDAY A C BREAKFAST SATURDAY A C LUNCH SATURDAY
A C DINNER SATURDAY A C BREAKFAST SUNDAY A C LUNCH SUNDAY

ANY SPECIAL DIETARY REQUIREMENTS OR ALLERGIES:

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

Please complete and return latest by Friday 5th February 2021 to:

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

Mail: HFNSW, PO Box 631, Broadway NSW 2007

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



HFNSW Family Camp

HFNSW will be holding its annual Family Camp on **26, 27, 28 March 2021** at the Narrabeen Academy of Sport, *if Covid-19 restrictions allow*. Due to the uncertain times we are facing due to Covid-19, all bookings remain tentative until closer to the date. We'll keep you updated via emails, our website and newsletters as things develop.

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

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

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

You can find more information and **apply online** at: <https://www.hfnsw.org.au/support-services/family-camp>

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

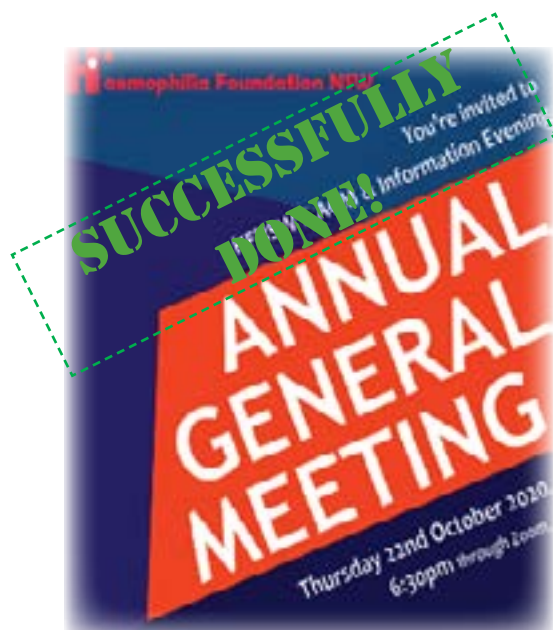
Email (preferred): admin@hfnsw.org.au ,

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Please return completed applications **NOT LATER THAN Friday 5th February 2021**, as due to current circumstances and restrictions we have to finalise the numbers by that date.

Need more info or have question.. please contact us at coordinator@hfnsw.org.au | admin@hfnsw.org.au

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



HFNSW 2020 'Virtual' AGM was successfully held on 22 October, featuring an Information Session with Dr Liane Khoo, Haematologist and Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital and Robyn Shoemark, Clinical Nurse Consultant, Haemophilia/Haematology of Children's Hospital at Westmead.

One of the benefits of having the event online was that it opened it up to everyone in our community from close and faraway.

The evening started with President Dan Credazzi looking back at the highlights of the last 12 months and looking forward to the exciting plans for the future. The president also expressed

his appreciation for the work, support, and dedication of Sydney Local Health District (SLHD) and extended well wishes to Lyn Bearlin in retirement and welcomed Kerry O'Neill. He also expressed his gratitude to the HFA staff over the course of the year, as well as HFNSW Committee members for their interest in carrying on this community service.

There was then an engaging presentation by Dr Liane Khoo on "New Therapies for Haemophilia: Balancing Excitement with Expectations" with a focus on Extended Half-Life factor products, non-factor replacements and gene therapy clinical trials. The speech was then followed by a Question & Answer session where both Liane and Robyn shared their expertise with attendees.

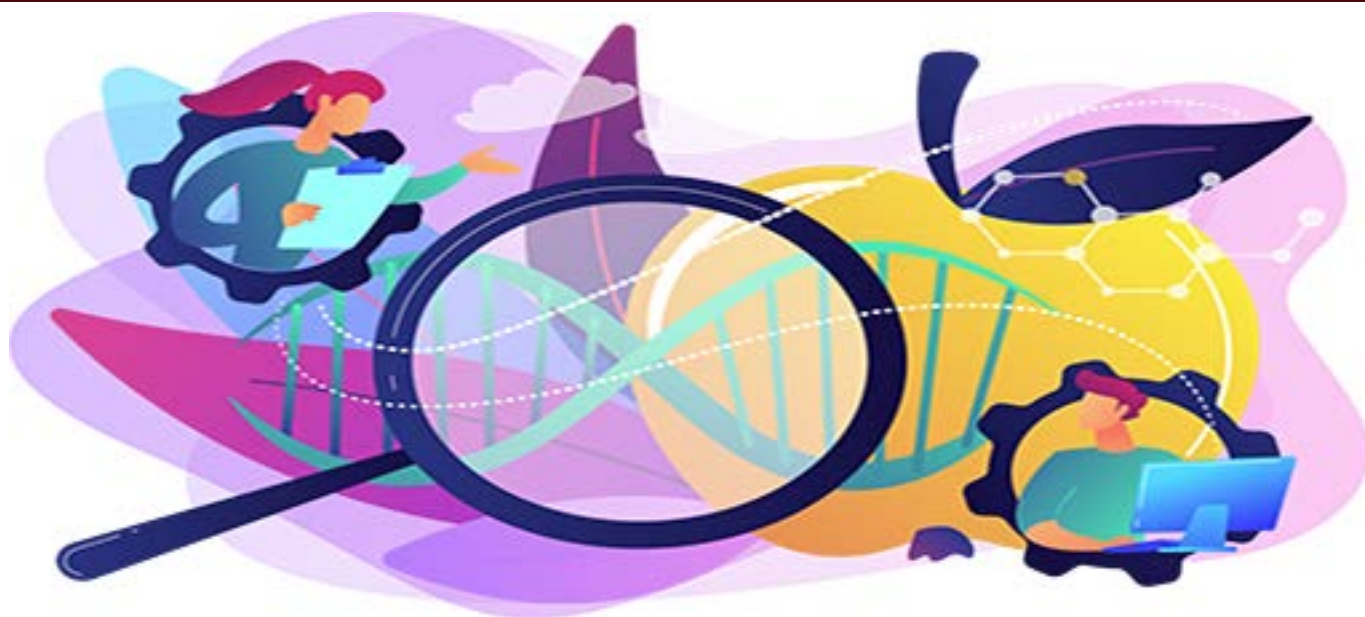
Members can access information about new therapies on HFA website and through their HTC.

HFNSW would like to thank all that attended HFNSW 2020 AGM and Information Session. We also appreciate the attendance of Prof Kevin Rickard, AM, RFD, HFNSW's

Patron. Also special thanks to Tony Wilkinson, HFNSW's former Program Coordinator, and Leonie mudge, a former social worker at RPAH for joining and supporting us from lockdown in Melbourne.

There were no nominations at the 2020 AGM as we have a three-year voting cycles. However, in our next AGM in 2021, HFNSW Committee shall be elected for another term of three years. General committee member positions will be open for all members throughout the year. If you wish to indicate an interest to be nominated please contact us at coordinator@hfnsw.org.au.





HFNSW alongside HFA and other state and territory Foundations have been advocating for the community to ensure a range of best practice treatment products are available and publicly funded for the bleeding disorders community. We are pleased that extended half-life clotting factor treatments have become available for Haemophilia A and B from July this year and more recently, Hemlibra® or emicizumab, a treatment that can reduce or prevent bleeding in people with severe or moderate haemophilia A with and without inhibitors.

It is not HFNSW's role to recommend specific treatment products as this must always be a careful decision made by the patient (or carer/s in the case of a child) with their treating doctor.

In light of the new treatments becoming available to patients it is important that you attend your clinic session to discuss options that may be available to you. There are many important aspects to new treatments that need to be considered and discussed, particularly with Hemlibra® as this is a subcutaneous based treatment and works in a different way to the more conventional prophylaxis treatments we are familiar with. These considerations may include what that process will look like to transition to a new treatment such as monitoring requirements, suitable dosing, possible side effects, etc.

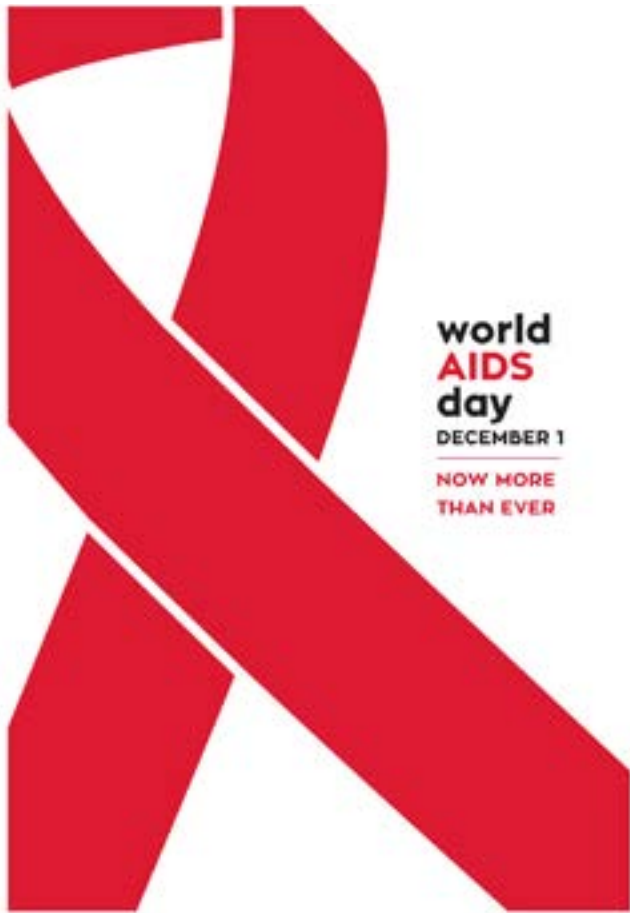
If you have any questions about new treatments contact your HTC team and they will be more than happy to answer your questions.

Below are some key points available on the National Blood Authority website regarding Hemlibra.

National supply arrangements for Hemlibra (emicizumab)

- Hemlibra will be available under national supply arrangements from 2 November 2020
- Hemlibra will be available to prevent or reduce the frequency of bleeding in severe or moderate haemophilia A patients without inhibitors, and in haemophilia A patients with inhibitors
- Hemlibra will be available through specialist clinicians at Haemophilia Treatment Centres
- Distribution arrangements will support local delivery for patients who can appropriately self-administer Hemlibra at home, with ongoing clinical oversight from a Haemophilia Treatment Centre. This will include distribution through a community pharmacy, or home delivery on an exception basis within a defined set of eligibility criteria.
- The timing of transition arrangements for Hemlibra will take account of the need for appropriate clinical oversight of transitioning patients, and the efficient use of stock of current products already held by Haemophilia Treatment Centres and patients, and stock required to be held in Australia under NBA contracts

www.blood.gov.au/national-supply-arrangements-hemlibra-emicizumab



WORLD AIDS DAY 2020

World AIDS Day is marked globally on 1 December.

The theme for World AIDS Day in 2020 is Now more than ever. For the bleeding disorders community this is a profoundly meaningful message.

1 December is a day when we are mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA's recent Getting Older report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The Getting Older report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the Getting Older consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

'There needs to be a concerned education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

TAKING ACTION

On World AIDS Day we are encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the Getting Older report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events. Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action – and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.



Highlights from the first-ever WFH Global Summit on WGBDs

Luisa Durante - December 8, 2020



Over a year ago, a seed was planted to organize a global summit for women and girls with bleeding disorders (WBGDs). That seed came to fruition this past November when the WFH held the first-ever Global Summit on women and girls with inherited bleeding disorders. Because of the COVID-19 pandemic the event was held virtually—but that didn't stop it from being dynamic, creative, and inspiring for all who attended in a global show of solidarity and empowerment. Nearly 1,400 participants from all corners of the world registered for the event—helping to make it a major success.

The Summit kicked off with an address from Cesar Garrido, WFH President, who emphasized the need for inclusion. Gina Schnabel—daughter of Frank Schnabel, founder of the WFH—then shared her story as a carrier. In her opening video, she declared, “You are your most powerful ally, never stop speaking up”, which set the tone for the next two days.

Dawn Rotellini, Chair of the WFH Women with Inherited Bleeding Disorders Committee, shared data from the 2019 WFH Annual Global Survey related to women; she also shared information on actions the WFH has taken to serve female patients. Other sessions from the Summit began with testimonials from women who discussed how living with a bleeding disorder has shaped their lives.

Quality of life and the impacts of a bleeding disorder on women and girls was discussed in the first session of the Summit. The session outlined the numerous challenges women and girls face due to heavy menstrual bleeding and the fact that their condition is often dismissed by physicians.

The diagnosis dilemma—and the challenges it poses in both developed and developing countries—was addressed by Robert Sidonio, MD. What is considered normal bleeding was

looked at by Michelle Lavin, MD, who mentioned the term, “menstrual blindness” which describes the fact that often, female patients do not recognize in themselves symptoms of having a bleeding disorder, such as excessive menstrual bleeding. Lavin went on to cover the importance of monitoring and tracking periods and other bleeding-disorders-related symptoms. Roshni Kulkarni, MD, an expert in telemedicine, illustrated opportunities for reaching and treating patients who live in remote areas far from treatment centres—thus giving patients hope and offering them counsel on care and treatment options and during today’s pandemic conditions.

The exchanges in the session on what women need and want were powerful, allowing both treaters and patients to dive deep into how to change the current situation and respond to the needs of WGBDs.

The WFH launched its new Initiative for Women and Girls in a fun, interview-style session led by Sharon Caris, and featuring special guests Cesar Garrido, WFH President; former WFH president Mark Skinner; Jameela Sathar, MD, from Malaysia; and Luisa Durante on behalf of the WFH. This endeavour will focus on key areas such as training for health care professionals so they can provide comprehensive care for WGBD patients. The initiative will also offer recommendations to national member organizations (NMOs) on how to conduct outreach and awareness campaigns on issues such as early diagnosis, inclusion and impacts on WGBDs. It will also encompass knowledge exchanges as well as the sharing of best practices between healthcare professionals (HCPs), patients and NMOs.

The second day started with a deep and insightful conversation on stigma, cultural norms, and taboos—all of which are barriers that often prevent women and girls from accessing adequate care and treatment.

There were exchanges on how to normalize talking about blood, and how to connect with other women and girls to break the marginalization that is often experienced by WGBDs.

Another session covered the concept that access to health care is a fundamental human right for everyone, and how one can advocate for adequate care and treatment. The International VWD guidelines were shown to be a great tool for health care professionals and patients alike for addressing this challenge. This session showed how patients were engaged in the development of the guidelines. It also offered attendees many tips—which can be applied in local contexts—to advocate for change for persons living with von Willebrand disease (VWD).

NMOs from Tunisia, Malaysia and Honduras shared the actions their organizations are taking for WGBDs to foster leadership, empowerment, and a sense of belonging.

The Summit also featured bleeding disorders trivia, which was offered as an amusing and interactive way to test knowledge and to identify areas where more work is needed.

Participants for the first-ever Global Summit on women and girls with inherited bleeding disorders came together as a global community to listen, to learn, to enhance empowerment and to encourage greater participation and inclusion of WGBDs in patient organizations. A shift has begun, where bleeding disorders are not automatically only associated with men, and where there is greater awareness that women bleed too.

Reprinted with permission from Hemophilia World online: “Highlights from the 1st-ever WFH Global Summit on WGBDs”

My Fiancé Liam and I welcomed our baby boy Finley, almost a year and a half ago. We were told of his Haemophilia A (moderate) diagnosis a day after he was born. He experienced trauma from a forceps delivery, and a routine heel prick oddly continued to bleed longer than normal. It was a complete shock to us as I am adopted and do not know any family medical history, yet despite this I never prepared myself for the possibility that we would face something like this. As first time parents this was devastating and so scary. It's hard to put into words how it felt, but the first few months were really tough for me as Finn's mother. I was so anxious and worried about everything, thinking so far ahead into the future about things that may or may not happen. We had only lived in Sydney for one year, with all our family and friends in Victoria and the UK, so I felt especially alone. Although we both have an amazingly supportive family, I felt extremely lonely as his mother and that no one else understood how it felt or what we were going through.

A year and a half later we have a very active, cheeky little boy that we just love watching grow up and change everyday. I'll admit that I still have days where I feel overwhelmed, heartbroken and consumed with grief, but most of the time I am too busy raising a crazy toddler that I don't get a chance to think about it too much. I also try to remember how lucky we are that we have so far experienced a very normal time as parents watching him grow. My heart still skips a beat when I see him fall, and I wish I could take him to the playground without feeling mountains of anxiety, but I am learning to trust him and his capabilities.

We are so thankful that we live in a time and place where we have access to treatment, amazing nurses and world class doctors and specialists. Although we are so new to this journey, we are hopeful that with more time and experience things will feel easier. Liam and I want Finley to grow up as a confident, courageous and resilient young man who knows that Haemaphilia doesn't define or limit him in the things he wants to do in life.

Cara Anderson
HFNSW Member



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

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



Personal narratives have a great role in creating connections, raising awareness, and influencing policy that transforms lives. Now with a fresh start to the New Year, let's reach out and talk about our experiences, whether as a person living with a bleeding disorder, as a clinician, or as a carer or a parent with a child being diagnosed with a bleeding disorder. Let's share what we'd like others to know about life with a bleeding disorder and some of the ups and downs, achievements, sport, school, work etc. HFNSW will not publish your story without your permission (or parental/guardian if under 18) - and your story can be published anonymously.

Submit Your Story through the link <https://www.hfnsw.org.au/get-involved/share-your-story>! Or, via email at coordinator@hfnsw.org.au

BOMBARDIER BLOOD LIVE CHAT REPORT NOW AVAILABLE

In October 2020 HFA hosted a Zoom and Facebook Live webinar for Bleeding Disorders Awareness Week



featuring US mountain climber Chris Bombardier who joined a panel of Australian rock climbers with haemophilia and HTC health professionals in a live chat with the Australian bleeding disorders community about taking on extreme sport with severe haemophilia. The panel of speakers includes:

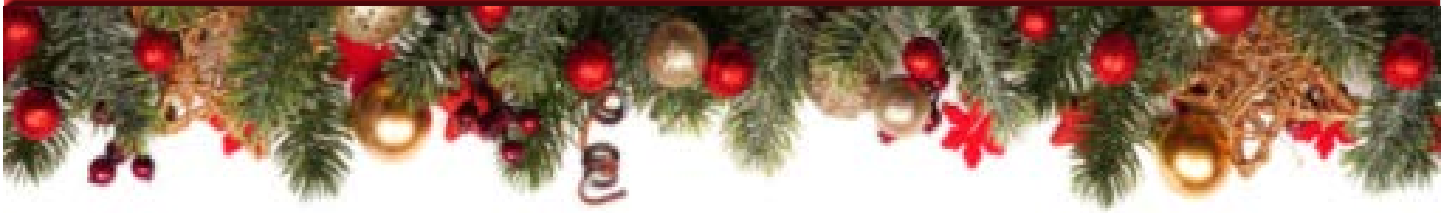
- Chris Bombardier, a mountain climber with severe haemophilia
- Andrew and Scott Godwin, Australian brothers, rock climbers with severe haemophilia
- Penny McCarthy, Clinical Nurse Consultant,

Ronald Sawers Haemophilia Centre, The Alfred, Melbourne

- Alison Morris, Senior Musculoskeletal Physiotherapist, Perth Children's Hospital

"This journey was the culmination of a lifetime of struggle to deal with his haemophilia and to achieve his goal of climbing the Seven Summits"

The full report and the video of the live chat are now available in [National Haemophilia HFA](#).



It's hard to believe that 2020 is almost over – what a year!

Looking back at each year that passes, we can see that there are always ups and downs and challenges and highlights. But I think we can all agree that 2020 has been unlike any other year we have ever gone through, from the wildfires to the pandemic. Millions of people have lost their lives worldwide and human beings have experienced new forms of social contact since the emergence of COVID-19.



Still amidst all these strange times, and as we get closer to the end of 2020, we are all encouraged to take a few minutes to count our blessings, to reflect on any highlights that can bring joy and contentment, and to see there's still so much to be grateful for including our families, friends, and our community, to name a few.

As a relatively new member of the Foundation, I keep reminding myself of how fortunate I am to have been surrounded by and working with amazing people in the community.

As the year is coming to a close, it is a good time for reflection and a rejuvenation of hope and new beginnings. Through these challenging times, may we stay connected together and keep the spirit of always supporting and caring for each other. I am particularly cognizant that HFNSW's success and effectiveness rest upon the continued involvement and support of its members and supporters, and the inspirational dedication of its committee who volunteer and generously give their time. So I'd like to take this opportunity to thank you all for your continued support, contributions and dedication.

Wishing you a safe and very happy holidays and a New Year filled with health, peace, and joy.

Safe wishes,

Shiva

Program Coordinator

SAVE THE DATE...

Virtual MSK Congress - May 2021

For the first time ever, the WFH International Musculoskeletal (MSK) Congress will follow a virtual format in 2021, featuring a mix of educational sessions and interactive workshops, where participants can engage with key researchers and inspiring speakers.

From May 3 to 7, 2021, specialists from all over the world will come together online to discuss the most

current knowledge on musculoskeletal approaches to bleeding disorders. The MSK Congress is being built with the needs of participants in mind. Two, to three sessions per day will be distributed over the course of 5-days and will feature diverse start times, allowing international attendees to participate in as many sessions as possible, regardless of time zone.

In 2021, the WFH MSK Committee's goal is to focus on collaborative research, promote training to the musculoskeletal community, and continue to educate and exchange best practices. The program for the MSK Congress will feature small-group clinical case discussions and instructional courses; new therapeutic options and outcomes with front line joint specialists; and discussions related to prevention, diagnosis, treatment and management of musculoskeletal complications related to bleeding disorders. Participants will also have the chance to network with experienced members of the MSK community, and to present their research to a global audience of peers.

Registration and call for abstracts open on January 20, 2021. Stay tuned—more information on the MSK Congress is coming soon! To find out more about the WFH International #MSKCongress, please click [here](#).



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

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

THANK YOU FOR SUPPORTING YOUR FOUNDATION

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

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

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

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

Thank you for your considered support.

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

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

Payment Details

Please make cheques/money orders payable to:
Haemophilia Foundation NSW Inc. and send to
Haemophilia Foundation NSW, PO Box 631, Broadway
NSW 2007

EFT Payment

BSB: 062 204

Account number: 00902590

Account Name: Haemophilia Foundation NSW

Please include your name in the comments field and email your receipt number to

admin@hfnsw.org.au

HAEMOPHILIA CENTRES

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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.

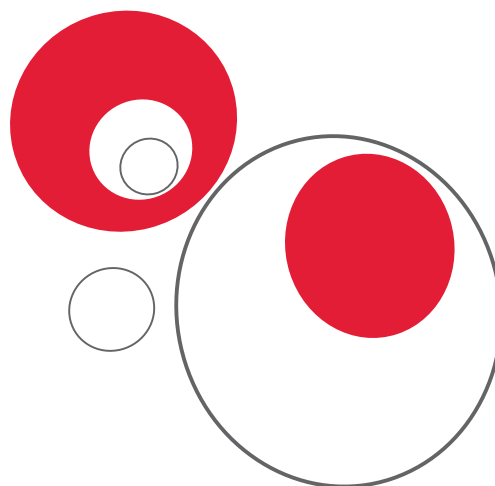
Financial Assistance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

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





Haemophilia Foundation NSW

would like to

wish

you all

happy and safe holidays!

Happy 2021