

Factor Matters

Haemophilia
Foundation
NSW



Published by HFNSW

June 2021

Volume 46

**HFNSW ANNUAL FAMILY CAMP
NOVEMBER 2021**

**HFNSW FAMILY FUN DAY
HUNTER REGION NSW**

**HEALTH & WELLBEING
SOCIAL SUPPORT**

**YOUR ONGOING 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, 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.

HFNSW Patron

Prof Kevin Rickard, AM, RFD

HFNSW Committee

Dan Credazzi - President
Dr Garry Lynch - Vice-president
Paul Bedbrook - Treasurer
Craig Haran - Member
Hamish Robinson - Member
Dr Liane Khoo - Member & Clinical
Consultant to HFNSW
Stephanie Devine - Member
Sam Linnenbank - Member

HFNSW Staff

Shiva Tabari - Program Coordinator
coordinator@hfnsw.org.au
Sam Deylami - Administrator/Finance Officer
admin@hfnsw.org.au

Contact Details

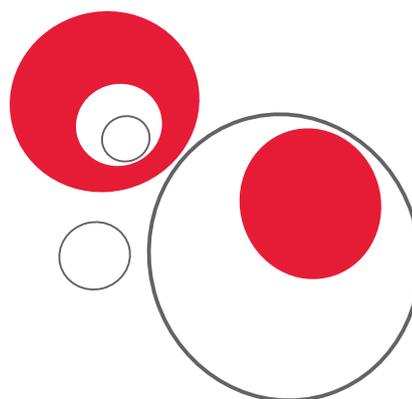
HFNSW Office
Room 1, Suite 5 - Level 1
88 Mountain St, Ultimo NSW 2007
P: (02) 9280 2607
M: 0470 637 928
Web: www.hfnsw.org.au
Mailing Address:
HFNSW PO Box 631 Broadway NSW 2007

Factor Matters Vol 46, June 2021

Content, Artistic and Layout Director: Shiva Tabari
Editor In Chief: Shiva Tabari
Editorial Board: Shiva Tabari, Dan Credazzi, Paul Bedbrook

In This Issue

- p. 3** A Word from the President...
- p. 4-7** Hunter Region Family Fun Day - 17 April 2021
- p. 8** World Hepatitis Day - 28 July
- p. 9-10** Health and Wellbeing
- P. 11-12** HFNSW Annual Family Camp and Form
- p. 13** Teens' Mental Health
- p. 14-15** Creativity for School Holidays and Beyond
- p. 16** Women and Girls with Bleeding Disorders
- p. 17** The 20th Australian Conference - 8-9 October 2021
- p. 18** Fundraising with Entertainment
Share Your Story
- P. 19** What's new: WFH Treatment Guidelines (TG) Resource Hub
HFNSW AGM 2021 - Advance Notice
- p. 20** A Thank You Note from HFNSW's Treasurer
- P. 21-22** HFNSW Membership Info and Form
- p. 23** Haemophilia Centres & HFNSW Member Service



Opinions expressed in Factor Matters do not necessarily reflect those of the Foundation or NSW Health. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFNSW reserves the right to edit articles as it sees necessary. Materials supplied are for information purposes only and are not to be used for diagnosis or treatment.



According to the latest Australian Bleeding Disorders Registry annual report, there are 6,355 people in Australia with a bleeding disorder of some sort. With 32% of the population located in NSW, that's just over 2,000 people in our State.

From our records, it seems that HFNSW had its first formal meeting after an informal peer support session in 1959 in the Hunter Valley. And we know that our Patron, Professor Kevin Rickard AM, started the first Haemophilia Treatment Centre at the Royal Prince Alfred in Camperdown in 1970.

When our family was introduced to the world of bleeding disorders, we had no idea how lucky we were to be in Australia. Here, the Federal government pays 63% and State/Territory 37% of the cost of treatment products for bleeding disorders. In addition to the cost of treatment products, governments also pay for hospital services (HTCs), pathology and associated medical services. To compare, in the US where I was born, most people use private health insurance to pay for treatment products until some 'max out' each year and are

forced to go without product until they're eligible again the next year. And according to the WFH, 70% of people with bleeding disorders get little or no treatment at all because it's unavailable or unaffordable. If you're transitioning to a new medication soon, be careful with your ordering. Any unused stock allocated to you can be reallocated to others by the supply chain, so please coordinate well with your HTC.

Your HFNSW Committee members are changing and at the next AGM, we are set to welcome the new Social Worker at the RPA, Nicoletta Crollini onto the Advisory Committee. Also, Craig Haran will be retiring from the Committee after nearly a decade of volunteer service to HFNSW. Craig's wise counsel and Heather's fundraising energy will be missed on Committee, so we're looking for new members and this year's AGM is the time to officially join. We have in person meetings which are more often held over lunch when possible and our meetings on zoom have been as productive as they can get. If you've been thinking of a way to join the legions of people who do something for nothing, and you've got some skills or perspective to contribute, then please consider joining the HFNSW Committee and contact Shiva at HQ.

I got my first over 50's covid jab last week and am looking forward to the next. As a possible cure for any vaccine hesitancy out there, particularly for AstraZeneca jab and its link with 'blood clotting' let me offer up this: According to Australian Health Department the chance of this side effect, is as low as around 4-6 people in every million (say, 1 in 200,000)! To put that in a comparative perspective based on a Google-fact, your chance of getting struck by lightning in Australia is 1 in 12,000. And that's why I always wear runners.

*Stay Safe,
Dan*

HUNTER REGION FAMILY FUN DAY - 17 APRIL 2021

On Saturday 17 April 2021, on the occasion of **World Haemophilia Day**, HFNSW organised a family fun day at Dullboy's Social Co in Warners Bay NSW. It was fantastic to see many families come along!



The day was a great opportunity for families to get together and catch up with one another while enjoying fun activities including bowling and arcade games.

There were about 30 attendees and among them were Dan Credazzi, HFNSW's president and Jaime Chase, Haematology Clinical Nurse Specialist at John Hunter Children's Hospital.



We also had a session of self-infusion demonstration led by Jayden Credazzi, which seemed to be really interesting to many of the children.

Indeed, the family fun day was a great way to celebrate **World Haemophilia Day**. HFNSW takes pride in having been able to once again look after its members and their families and provide them with the opportunity to meet and connect with others who are living similar life experiences.

Massive thanks to everyone who participated and made the day a memorable one as captured by photos, and for all your positive and constructive feedbacks!



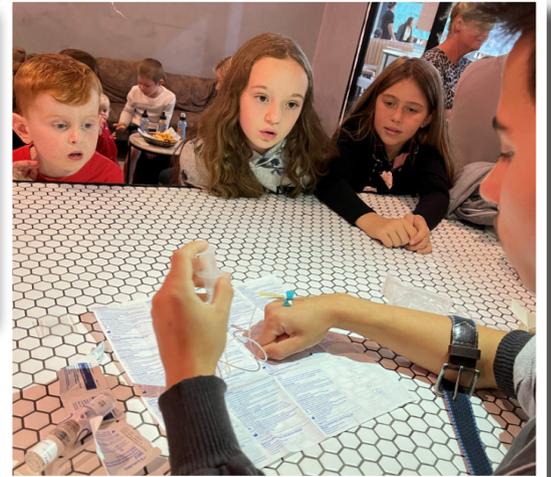
"We really enjoyed the day. The highlight being Linc watching Jayden do his factor. It is so important to keep doing these events and even organising social days to keep our community connected. We really noticed all of the small attention to detail and are so thankful. "

Jasmin, Ted, Linc and Hazel





HUNTER REGION FAMILY FUN DAY - 17 APRIL 2021





ABOUT

Hepatitis is the inflammation of liver cells caused by virus. Of all the types of hepatitis, the three most common viruses in Australia are hep A, hep B and hep C. While there exist vaccines for hep A and B, there is no vaccine yet for hep C. However, hep C which is caused by hepatitis C virus (HCV), is an easily-cured liver infection. Hep C is transmitted through blood-to-blood contact with someone with hep C. The virus is slow acting and symptoms may not appear for many years. Hep C can cause long-term liver health problems if left untreated.

Close to 42,000 people across NSW have hepatitis C (at Sept 2020), but many, including some people with bleeding disorders or who carry the gene, may not know they have it. If anyone ever had a blood product before 1993 or thinks they might be at risk of hep C, it's very important to get tested and know their status. This is because hep C is now easy to cure. In fact, the new cures are different to the previous treatments because they cure around 95%, or more, of people who take them (even if one has cirrhosis).

Many Australians with bleeding disorders and hep C have now had treatment and been cured. However, for those who have been cured of hep C, it is recommended to ask their hepatitis specialist or GP if they need follow-up for their liver health.

Also, 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 Held annually on 28 July World

On the 28 July each year, World Hepatitis Day brings the world together to raise awareness of the global burden of viral hepatitis and to encourage prevention, diagnosis and treatment. World Hepatitis Day is one of eight official global public health campaigns marked by the World Health Organization (WHO).

The date (28 July) celebrates the birthdate of Nobel Laureate Baruch Samuel Blumberg, discoverer of the hepatitis B virus.

The theme for World Hepatitis Day 2021 is 'Hep Can't Wait', that is

- People living with viral hepatitis unaware can't wait for testing
- People living with hepatitis can't wait for life saving treatments
- Expectant mothers can't wait for hepatitis screening and treatment

- Newborn babies can't wait for birth dose vaccination
- People affected by hepatitis can't wait to end stigma and discrimination
- Community organisations can't wait for greater investment
- Decision makers can't wait and must act now to make hepatitis elimination a reality through political will and funding.

In Australia, World Hepatitis Day is coordinated nationally by Hepatitis Australia and rolled out at local level by Hepatitis Australia member and partner organisations, including Haemophilia Foundation Australia and its member foundations such as HFNSW.

The aim of World Hepatitis Day in Australia is to mobilise national action on the elimination of viral hepatitis in Australia through a coordinated response.

The objectives of World Hepatitis Day 2021 in Australia are to:

- Mobilise the community, organisations, research institutes, media and governments to take action in support of the elimination of viral hepatitis as a public health threat by 2030
- Challenge stigma, discrimination and systemic barriers faced by people impacted by viral hepatitis
- Amplify the diverse voices of people impacted by viral hepatitis to influence public dialogue, decision making and health policy development
- Inform and educate the community, priority populations and health service providers on viral hepatitis
- Celebrate and reinforce achievements towards hepatitis elimination
- Coordinate a national agenda of activity and events
- Encourage national use of the World Hepatitis Day theme and national assets

Australia is leading the way for a **NOhep** future. Thanks to groundbreaking medications, elimination of hepatitis C is now an achievable goal, but one which requires the combined efforts of government, the health sector, and community to be fully realised.

For More Information Visit

- www.world.hepatitisday.org.au
- www.haemophilia.org.au



References:
www.hep.org.au
www.worldhepatitisday.org
www.haemophilia.org.au



Social Support and social connectedness – good for the soul

Nicoletta Crollini - Haemophilia Social Worker at Royal Prince Alfred Hospital

WHAT IS SOCIAL SUPPORT

Social supports are the network of friends, family and other people who you turn to in times of need or crisis. The help one can access through their social supports can be both practical and emotional support.



WHY HAVING A SOCIAL SUPPORT NETWORK IS IT IMPORTANT

Having a social support network is incredibly important to maintaining our physical and mental wellbeing. Research has shown that having high-quality social supports in our lives can improve our resilience skills and decrease the impacts of trauma related mental health issues.

Social supports help to enhance our quality of life, providing a buffer to manage and overcome adverse life events.

HOW TO BROADEN YOUR SOCIAL SUPPORT NETWORK - IT IS NEVER TOO LATE

Most people already have an established social support network through their family and friends. As we progress through life, our circumstances may change and so may our social support networks. I thought it might be useful to list a few stages in life and the avenues in which we can explore meeting new people and potentially developing new social support networks.

Please note that a majority of the organisations provided also tend to have online/virtual social groups and activities available.

Bleeding Disorder Community

Haemophilia Foundation NSW (HFNSW) - This is your opportunity to connect with the bleeding disorder community and develop a support network that understand what it is like to have a bleeding disorder or be the parent, carer and loved one of a person with a bleeding disorder.

www.hfnsw.org.au

General

Local Council - Either call or visit your local council's website to learn about the various social groups and events run by your local council that promote social connectedness and social support.

New parents, carers and babies

Certainly being a new parent is a new experience, it can be a challenging time for some to navigate and socially isolating at times. There are a range of groups and supports people can access as new parents or carers. Here are a couple:

- **Playgroups NSW** - you can access the Playgroups NSW website to find your nearest playgroup. Playgroups provide parents and carers the opportunity to get together with their young children for a couple of hours each week to connect, learn through play and have fun. Playgroup is one of the first social networks for children and families.

www.playgroupnsw.org.au

- **Karitane** - you can access a range of parenting advice, support and connect with other parents through a range of groups. For more information please access the Karitane website.

www.karitane.com.au

Children and young people

For kids and young people, making new friends is very personal, due to their unique personalities, emotional skills and social skills. Preschool and school are environments where children and young people tend to develop most of their friendships. However, there certainly are a range of other avenues where children and teenagers can make new friends and develop their social support network.

- Local community sports and activities – information regarding these can be accessed through schools and via your local council website.
- PCYC – is an organisation that aims to support young people reach their potential through a range of activities and groups which are fun, safe and friendly. There are 65 PCYC clubs across the state, you can find your local club and what activities they offer on the PCYC website.

www.pcywnsw.org.au

Adults

Most adults tend to have their social support networks established, however, there are plenty of options available to make new friends. Funnily enough, most dating apps now have a friendship section, where you can match with new friends. There is also a specific app/website dedicated to making new friends and joining new social groups called MeetUp.

You can also join a local sporting team, a local club or a workout group like yoga. I joined both a local touch footy team and a yoga class recently, they both have certainly increased my feeling of social connectedness and physical activity levels.

Older People – Maintaining social supports and social connectedness in our older age is extremely important. There is plenty of research outlining the many physical and mental health issues impacted by social isolation. Fortunately, the importance of maintaining social connectedness to reduce social isolation experienced by older people has been recognised as serious issue and therefore, there are a number of ways older people can develop social support networks.

- My Aged Care - for access to formal social support services, for example the Community Visiting Scheme, which is a service matching socially isolated individuals with volunteer visitors.

My Aged Care can also link socially isolated older people to their local community transport services, which tend to run regular social group outings.

www.myagedcare.gov.au



- University of the Third Age (U3A) – Offers a range of stimulating courses for retired or semi-retired people who enjoy learning and meeting like-minded people. There are no previous learning requirements, no exams and no awards at the end of a course. U3A is an opportunity to keep stimulated and meet interesting people while you continue to learn. There are many U3A networks across the state, you can find your local U3A and the courses they offer on their website.

www.nsw.u3anet.org.au

Carers

Carers are also at a higher risk of social isolation. Maintaining social connectedness and social support networks is very important for carers to reduce instances of social isolation.

- Carers NSW – Is an organisation that supports all carers who are looking after individuals with support needs relating to ageing, disability, health and mental illness. Carers NSW runs a range of carer support groups and networks. For further information visit the Carers NSW website.

www.carersnsw.org.au

Do not forget to reach out and maintain contact with your current social support networks. New jobs, study, raising a family, poor health and even a pandemic can slow down your ability to maintain connectedness with your close friends and family. Maintaining contact with your social support network is still really important and can be as simple as a text message, a phone call/video call, catching up for a walk or doing something a little more special like a lunch or dinner out.

Wishing everyone all the best over the winter period.



HFNSW Family Camp

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

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

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

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

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

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

Email: coordinator@hfnsw.org.au

Mail: HFNSW, PO Box 631, Broadway NSW 2007

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

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

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

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



FAMILY CAMP 2020-21 Application Form

Friday 19 - Sunday 21 November 2021

FAMILY MEMBERS

AGE OF CHILDREN

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

ADDRESS: _____

Email: _____

CONTACT PHONE NO: _____

ACCOMMODATION (TICK ONE ONLY)

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

ANY SPECIAL ACCOMMODATION REQUIREMENTS:

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

___A___C DINNER FRIDAY ___A___C BREAKFAST SATURDAY ___A___C LUNCH SATURDAY
___A___C DINNER SATURDAY ___A___C BREAKFAST SUNDAY ___A___C LUNCH SUNDAY

ANY SPECIAL DIETARY REQUIREMENTS OR ALLERGIES: _____

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

Please complete and return latest by Sunday 10th October 2021 to:

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

Mail: HFNSW, PO Box 631, Broadway NSW 2007

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



Sleep loss plus social media bad combo for teens

RESEARCHER: Professor Ron Rapee

WRITER: Vanessa Walker

There are mental health problems that specifically begin in adolescence, says the researcher behind the high school Raw Project, which surveys more than 500 teens every year.



A study that aims to identify early indications of mental health issues in teenagers has found a correlation between teens' use of social media and the emergence of issues including social anxiety and poor body image.

It has also found links between a lack of sleep and depressive feelings in young adolescents.

Professor Ron Rapee of the Department of Psychology set up the Raw Project, a longitudinal study that conducts annual assessments on the emotional health of young people in a bid to discover the warning signs in children who may, in their teens and beyond, develop mental health issues.

"There are three mental health problems that specifically start in adolescence," Professor Rapee says. "Social anxiety disorder, which has an average onset age of 13; depression, which most dramatically emerges in 14-15 year-olds, and eating disorders, which experience an upswing in those aged 13-17."

Comparing appearances is destructive

The driving question behind the Raw Project, run out of the Centre for Emotional Health, is: what are the characteristics of adolescence that trigger these mental illnesses?

And now, after four years of tracking their participants, insights are emerging, including how social media affects young people's happiness.

"Early indicators are that kids who compare themselves on social media, thinking others are more attractive and have better lives are more likely to be socially anxious with difficult relationships, to be victimised, and have fewer friends," he says.

"They also have a slightly worse body image than those children who use don't use social media."

He also notes that of the 500-plus 11-year-old participants who began the study, more than 70 percent were social media users, despite 13 being the lawful age to use sites such as Facebook and Instagram. This increased to 90 percent by the time the children were 13. "We also found that kids who were more developed, pubertally, thought that others looked better than them on social media. They compared their appearance more negatively to others," says Professor Rapee.

The early findings also prove the value of sleep. At 11, the participants slept an average of just over nine hours per night (however, this dropped to 8.4 hours by age 13).

It emerged that less sleep was related to higher levels of anxiety and depression and more feelings of social isolation.

The Raw Project began in 2016 when Professor Rapee and his team of six postdoctoral fellows, a project manager and various students, recruited 528 Year Six students and one of their parents or caregivers.

Each participant agreed to an annual evaluation that involves a one-hour online questionnaire, a one-hour telephone interview, and, for the child only, a three-hour laboratory session at the university. Funding, primarily from the Australian Research Council and Macquarie University, guaranteed the study could be undertaken for four years, with another funding round soon aiming to ensure it can continue until the participants are 18.

The questionnaire asks the parent/caregiver and child questions about a variety of personality, emotional and social factors, including friendships, anxiety, mood, bullying, appearance concerns, sleep, coping styles, life satisfaction and resilience.

The telephone interview, conducted a week later, asks about the child's emotional functioning and includes questions about anxiety, low mood and body image/eating concerns.

In the laboratory session, participants complete games and activities; some on computers, some involving puzzles or problem solving, and others requiring verbal answers to questions posed by the clinicians.

- Gaming headsets to help tackle concussion in sport
- Why can you see the sun and the moon at the same time?

One example is an eye-tracking machine that evaluates the direction of the children's eye gaze in response to pictures of different people. "This serves to evaluate how quickly they learn to respond to particular images and how quickly they 'unlearn' that response, the results indicating how long they persist in the face of frustration," says Professor Rapee.

And because these are teenagers, the carrot dangling at the end is a \$100 gift voucher, and various competitions and games and prizes throughout the year. For the parents/caregivers, there is also a measure of reassurance, with any troubling indicators brought to their attention, and support offered.

There has been, Professor Rapee says, an astronomical amount of data gathered, all of which needs to be coded, cleaned (of anomalous answers) and scored. It is, he says, a huge undertaking and that's why the preliminary findings primarily relate to 11-year-olds, although the participants are now aged 14-15 years.

The final results will be invaluable in helping teenagers emerge from the storm of adolescence mentally healthy. Once the study is completed, the team's first step will be to develop a theoretical model showing the causal links between behaviour and issues. They will then create processes that might predict the onset of mental health problems.

Eventually, this knowledge can inform programs for parents and high schools that help identify, and aid, teenagers who might be susceptible to mental illness at a time when those issues are emerging, rather than years down the track.

Source: <https://lighthouse.mq.edu.au/article/october2/sleep-loss-plus-social-media-bad-combo-for-at-risk-teens-study>



14 TIPS TO ENCOURAGE YOUR CHILD'S CREATIVITY THESE SCHOOL HOLIDAYS AND BEYOND

Frances Vidakovic

Creative kids...It's natural for children to be creative, but they also need a supportive environment to keep that spark alight.



But how can we do this well?

How can we encourage creativity in a child that isn't naturally creative?

As a parent, you can help your child to appreciate art and express themselves in ways they would not have alone discovered.

Each of us can be creative, and it's a skill that can be developed.

Yes, it is a skill that needs to be practiced.

It is not innate in all kids!

Innovation and originality extend beyond visits to galleries and museums (as much as these can be fun).

The bonus is that creativity is a skill and quality that can be applied throughout our personal and professional lives.

So, learn to share the joy of creativity with your family.



If you aren't naturally creative yourself, you can still learn more about how to help your child use their imagination.

Here are some benefits of Encouraging Your Child's Creativity:

TIP # 1 – Build confidence.

Is your child scared to try new things?

Fear of failure inhibits the artistic process.

Therefore, you need to CREATE opportunities for your child to take risks and learn from experience.

Show them that it's okay to be different and to make mistakes.

Help them to identify and use their personal strengths.

TIP # 2- Manage stress.

Crafts and hobbies are a healthy way for children to process difficult emotions.



They may not realise that this is even happening but being involved in a creative task is therapeutic and usually means your child is less likely to turn to riskier options like overeating or drugs in the future.

As they aren't holding in their negative emotions – they are instead releasing them through their creative endeavors.

TIP # 3 – Develop cognitive skills.

Creativity involves thinking as well as making things.

There are so many benefits to encouraging your child's creativity.

While they're finger painting or writing songs, they're also solving problems and innovating.

TIP # 4 – Enjoy life.

Creative children are likely to experience more happiness and success.

That's because they know how to entertain themselves, manage their emotions, relate to others, and contribute in the workplace.

TIP # 5 – Offer praise.

Children want to use their imagination but might hold back if they feel like they're being judged.

If it's the case, refrain from judging them!

Stay positive and recognize their efforts, even if they color outside the lines.

TIP # 6- Enable unstructured play.

Is your child overscheduled?

Leave some free time in between dance classes and organized sports, so they can explore on their own.

Buy open-ended toys like blocks or let them fool around with empty boxes and string.

Anything that allows their imagination to be free and run wild.

TIP # 7 – Actively engage.

Limit TV and computer time unless you want to risk your child becoming dependent on these things for entertainment.

Instead spend your days doing things together instead of just sitting and watching.

Go outdoors for a hike.

Play board games and talk about your day.

Actively engage with your kids rather than always ignoring them.



TIP # 8 – Dare to be messy.

Children love sticky stuff, so relax the rules during craft time.

I promise you, sometimes the activities that are the most fun involve the most mess!

If you're overly concerned about the cleaning, designate a special area in the basement or backyard where spills and smudges are allowed.

TIP # 9 – Provide prompts.

Even great artists sometimes need help getting started.

So if your child needs promptly from you there is nothing wrong with you giving them a slight push.

Complete the first few steps of a drawing, and then ask your child to help you.

Ask them questions about what they want to make and why.

TIP # 10 – Seek inspiration.

Stay on the lookout for stimulating ideas.

Visit art museums and watch nature documentaries.

Carry a journal around, so you and your kids can jot your thoughts down for later use.

The way to be inspiring to your kids is for you yourself to be inspired by life.



TIP # 11 – Stock up on supplies.

Be prepared for when your kids have sudden artistic urges or complain about being bored.

This is where it is so handy to have a craft corner or box at home.

Keep a variety of materials on hand, like crayons and clay so your kids can use them whenever they get the creative urge.

TIP # 12 – Pursue passions.

Choose activities based on your child's personal interests.

A soccer fan might want to assemble a collage with images from sports magazines and their own ticket stubs.

A music lover might try building their own instruments using household objects or record their own songs.

What do your kids love and how can you encourage them to be more creative in this area?

TIP # 13 – Make it social.

Invite other family members and friends to join you for playdates and outings with a creative theme.

Help your child upload images of their favorite works to share with their grandparents or classmates.

They deserve to get some positive recognition for their creative endeavors!

TIP # 14 – Teach by example.

Your children will be more likely to develop their creativity if they see you doing it too.

Work on your individual projects side by side and discuss your experiences.

All in all, there are plenty of things you can do to nurture your child's creativity and imagination.

And I promise you, you'll wind up with something more than cute drawings for your refrigerator door.

You'll be helping them to think independently and develop their emotional intelligence which will be so beneficial to them in the future.

Source: <https://www.inspiringlifedreams.com/>

Sport and Exercise for Girls

HFA has released a new fact sheet, Sport and exercise for girls and young women with bleeding disorders.

This was developed out of a survey of young women and their parents and answers their questions, such as:

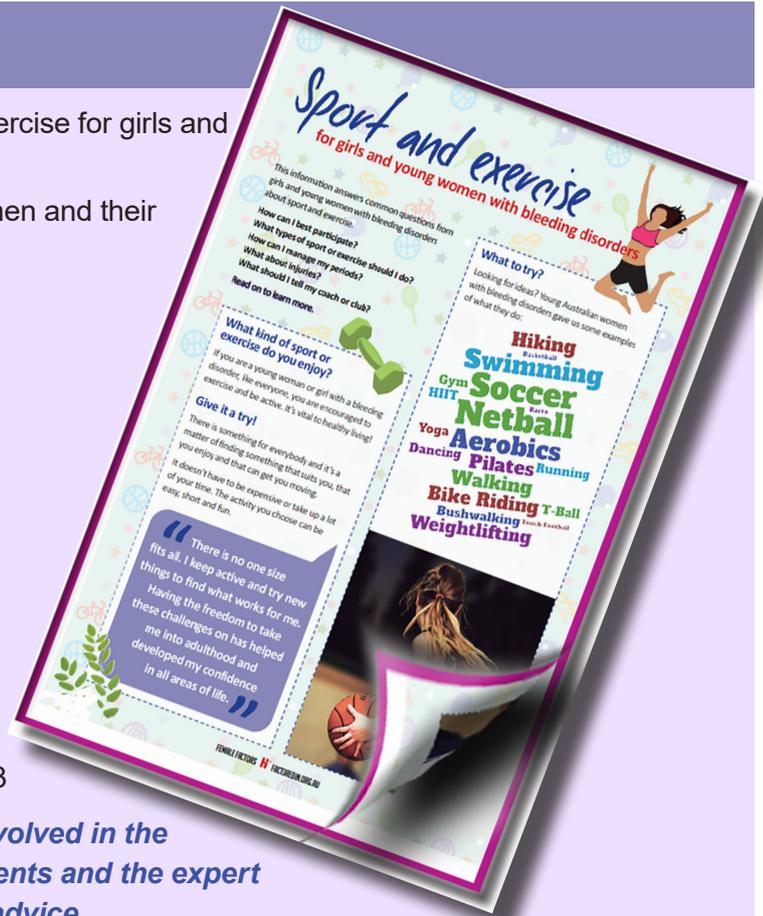
- How can I best participate?
- What types of sport or exercise should I do?
- How can I manage my periods?
- What about injuries?
- What should I tell my coach or club?

ACCESSING THE FACT SHEET

- Read it online or download it from Factored In <https://tinyurl.com/FI-sport-girls>
- Ask your HTC for a copy
- Contact HFA to send you copies

E: hfaust@haemophilia.org.au or T: 1800 807 173

HFA would like to pass on our thanks to all involved in the development: the young women and their parents and the expert health professionals for their comments and advice.



WFH Global Summit on

women & girls

with bleeding disorders July 8–10, 2021

This WFH Global summit on women and girls with bleeding disorders will bring together women with different bleeding disorders, patient representatives, supporters, and healthcare professionals from around the world to exchange on the realities of care and treatment around the world for these patients.

During this two and a half days virtual meeting from 8th to 10th July, the global bleeding disorder community will be able to learn and hear about women's experiences with diagnosis and management, how women are advocating for better care, and the ways they are getting their voices heard.

The online registration site for the Global Summit on women and girls with bleeding disorders, is <https://bit.ly/35tb1Cd>.



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

The 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders will take place this year from 8-9 October 2021 **virtually**.

We have decided to hold a virtual conference this year due to the uncertainty of the pandemic and we are very excited about the opportunities this provides. Bringing together the different parts of our community with health professionals and other stakeholders has always been stimulating and rewarding for the bleeding disorders community and other stakeholders.

Without the requirement to travel so many more people will be able to participate and contribute to the discussions. We expect our virtual conference will attract more delegates than usual and create innovative learning opportunities and discussion for everyone. We are confident that nothing will be missing - in fact it will be enhanced.

PROGRAM

We are on the road for a great program with topics across a range of areas and current issues:

- New and emerging treatments
- Managing complications of bleeding disorders
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over a lifetime
- Women and girls
- Getting Older
- Staying fit and well
- Participating in clinical trials

The program will include presentations from people living with bleeding disorders as experts, as well as specialist health professionals and others speaking on important matters that affect people living with a bleeding disorder and their families and carers. There will be plenty of opportunities ask questions and find out more.

The program will go over Friday and Saturday between 9am – 5pm. There will be keynote presentations for everyone, followed by concurrent sessions for you to choose from, and there will be breaks in between so you can plan your days. If you miss a session, you can playback later that day and all sessions will be as part of your registration for 6 months, you can log in anytime.

For up-to-date information about the conference and current program visit: www.haemophilia.org.au/conferences

VIRTUAL POSTER DISPLAY

Posters are an integral part of the conference, and we are calling for poster abstracts for our virtual poster display.

We encourage abstracts relevant to clinical practice and care, laboratory science, research, policy, living with bleeding disorders or treatment complications, peer support programs and special projects. This is a great opportunity to share ideas and experience.

See www.haemophilia.org.au/conferences for the submission form and more information. There will be prizes for the Best Abstract, and the Best Poster. Submit your abstract by Friday 30 June 2021.

FOR MORE INFORMATION VISIT www.haemophilia.org.au/conference21

Entertainment

Fundraising with Entertainment - Give. Get. Share.

20% of every Membership purchase, goes directly to your fundraising.

Help Support **Haemophilia Foundation NSW** by ordering your Entertainment membership now!

There are always more ways to enjoy your every day, and Entertainment does just that. From dining, to shopping, to travel and more, joining our community means getting more of what you need and love, giving back to the causes you care about and sharing in the moments with those around you. Savings right at your fingertips. Get endless offers across dining, shopping and experiences while supporting **Haemophilia Foundation NSW** and the community. .

SAVINGS near and far!

Get a **FREE UPGRADE** to Multi City and go into the draw to WIN a holiday! Enjoy incredible offers over the **school holidays** and beyond.



When ordering your membership, don't forget to choose **Haemophilia Foundation NSW** as your fundraising cause.

For more information and purchasing your membership visit

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

or HFNSW website for a quick access:

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

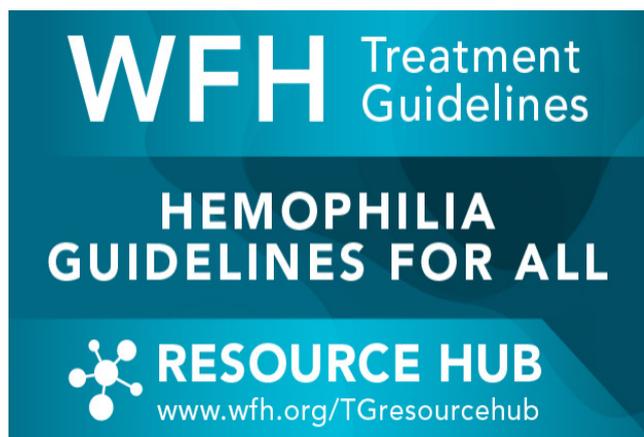
SHARE YOUR STORY

Share Your Story and Win a Prize

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. Sharing our story makes us reflect on what happened, how it made us feel, what we did, and the way this experience(s) influenced our present life. When we share our stories, it opens up our hearts and invites others to share their own. It creates a ripple effect and it gives others and ourselves the sense that we are not alone in this journey, that there are other people who also have been in similar predicaments and made it out alive. Sometimes, that is all someone needs to hear to get through a tough time. By sharing our experiences we may help even more by ideas and solutions that worked for you and may also work for others who are walking a similar life path.

As a person living with a bleeding disorder or as a parent/carer, sibling or friend of a person with a bleeding disorder you have experiences that can teach, inspire, motivate, or challenge. So let's open up and share 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



The WFH Guidelines for the Management of Hemophilia offers up-to-date guidance and practical recommendations on the diagnosis and management of hemophilia, including the management of musculoskeletal complications and inhibitors, updates to laboratory diagnosis and genetic assessments, and new recommendations on outcome assessments. Now, for the first time, all this information has been gathered together in the new WFH Treatment Guidelines (TG) Resource Hub. With the click of a mouse, you can get easy access to critical information such as key messages, short narrated videos, slides and easy-to-

read documents.

Cutting edge science, easy to use training tools

Find key information in our chapter snapshots for healthcare providers (HCPs), which are informed by the best available evidence and supplemented with expert opinions and patient preferences.

Key messages for people with hemophilia

The TG recommendations for people with hemophilia (PWH) are easy to understand and allow everyone to learn more about their disease, take ownership of their care, and advocate for themselves and other PWH. These condensed chapter snapshots offer highlights of the most important information for PWH.

Expert-guided content made easy

The WFH Treatment Guidelines (TG) Resource Hub offers expert-guided content to help you more easily understand the content and how it relates to real-life situations.

- Listen to expert narration for each chapter that bring real world practices to the TGs
- Learn about actionable recommendations explained through clinical cases
- Read condensed TG chapter recommendations

To access the WFH Treatment Guidelines (TG) Resource Hub, visit <https://guidelines.wfh.org/>.

HFNSW AGM 2021 - ADVANCE NOTICE

HFNSW AGM – Advance Notice

The HFNSW AGM will be held later this year, by the end of October at the latest. A notice will be sent out separately. Hopefully we can gather together depending on the COVID-19 situation. There will be a presentation of the year's activities, financial statements and presentations by experts about treatments and reserach. Also there will be nominations and an election for board members. All paid members are encouraged to attend. Stay tuned as we'd love to see you there 😊



Haemophilia Foundation New South Wales Inc.



ABN: 602 454 70729
Member of Haemophilia Foundation Australia
Patron: Prof. Kevin A. Rickard AM RFD

Dear Supporters,

YOUR ONGOING SUPPORT MATTERS!

As the financial year 2020-21 is coming to an end, we would like to THANK YOU for financially supporting your Foundation as evidenced by your donations during the past financial year. For people living with a bleeding disorder and their families and carers, your support means to get the best practice treatments available and to receive the needed support and services.

As many of you are aware, Haemophilia Foundation NSW (HFNSW), a not-for-profit organisation, has represented the bleeding disorders community of New South Wales for over thirty years. HFNSW is committed to offer support and services to cater the needs of its members and their families and carers and is devoted to provide advocacy for them to make sure they have the treatment they need so they can live full and independent lives.

HFNSW as a volunteer-based organisation takes pride in thriving in its efforts and operations although much of the time with minimal financial resources and staff, and it owes a big part of its achievements to its donors and supporters. Your generosity and ongoing support makes it possible for HFNSW to survive and fulfill its commitment to make a difference in the community. That is why **Your Ongoing Support Matters!**

We once again thank you for your generosity and call for your continued financial contributions, no matter how small, to help us reach our target of a modest \$25,000 per annum. **ALL DONATIONS TO HFNSW ARE 100% TAX-DEDUCTIBLE!**

You can send your donations via cheque, bank transfer (details below) or PayPal (link available on our website www.hfnsw.org.au).

For any questions or more information, please contact us on (02) 92802607 or email coordinator@hfnsw.org.au, or visit our website at www.hfnsw.org.au.

Thank you once again for your continued support in sustaining HFNSW on its mission.

Sincerely,

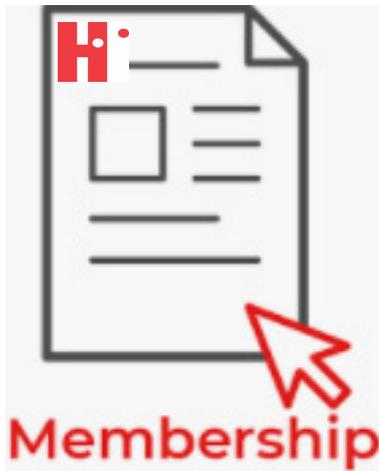
Paul Bedbrook
Treasurer, HFNSW

EFT Payment to:
Bank: Commonwealth
Account Name: Haemophilia Foundation
NSW
BSB: 062204
Account Number: 00902590

Cheques/money orders payable to:
Haemophilia Foundation NSW Inc.
Mail to:
HFNSW, PO Box 631, Broadway NSW
2007



HFNSW's MEMBERSHIP FEES FOR 2021-22 FINANCIAL YEAR ARE NOW DUE!



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.**

Thank you to those members who have already paid their 2021-22 annual membership fees.

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

- Visit the donation or membership pages on the Haemophilia Foundation NSW website : <http://hfnsw.org.au/>
- 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)

Are Your Details Up to Date?

Membership renewal time is a good time to review whether you have recently changed any of your contact details. If so, you can inform us either by:

- Completing a membership form included in this issue and sending by post or email coordinator@hfnsw.org.au.

The form is also available on our website: <https://www.hfnsw.org.au/get-involved/memberships>

Or

- Using the [CONTACT DETAILS UPDATES](https://www.hfnsw.org.au/get-involved/memberships) page on our web site: <https://www.hfnsw.org.au/get-involved/memberships>

Please note that HFNSW does not have access to hospital records, or vice versa, so informing the hospital does not update HFNSW's records. Please make sure that your membership is up-to-date.

Thank you for supporting HFNSW in the work that it does!



MEMBERSHIP FORM 2021-2022

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
 Nicoletta Crollini (Social Worker)
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
 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.

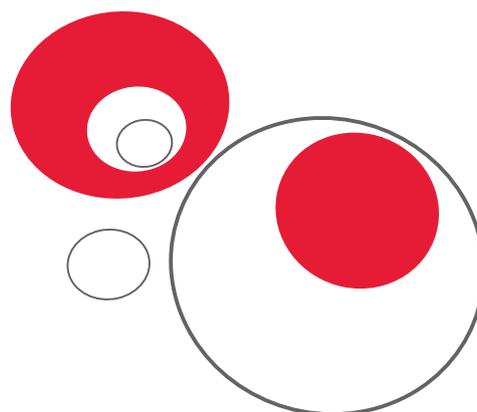
Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, travel assistance, education & training, grants.

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





Haemophilia Foundation NSW Family Camp 2021



Come along and join for HFSNW's family camp at Narrabeen Academy of Sport.

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

When: From Friday 19 November 2021 5pm to Sunday 21 November 2021 2pm.

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

This is a free event for members and their families.

Booking is essential for this event.

Please RSVP latest by **SUNDAY 10th OCTOBER** by sending the completed form included in this issue to coordinator@hfnsw.org.au or, submitting the form online at

<https://www.hfnsw.org.au/get-involved/events/family-camp-2021>

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

Camp Application Form included in this issue, Also available Online at <https://www.hfnsw.org.au/>

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

Complete and Submit your form today to secure your spot!