Haemophilia Foundation NSW



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Winter 2022

Volume 50

## HFNSW FAMILY CAMP 2022

## MENTAL HEALTH MATTERS!

MAINTAINING MENTAL HEALTH DURING WINTER

WORLD HEPATITIS DAY 2022

YOUR CONTINUTED SUPPORT MATTERS!

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#### **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 Dr Liane Khoo - Member Nicoletta Crollini - Member Sam Linnenbank – Member Stephanie Devine - Member Dr Susan Russell - Member

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#### Factor Matters Vol 50, June 2022

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Tabari

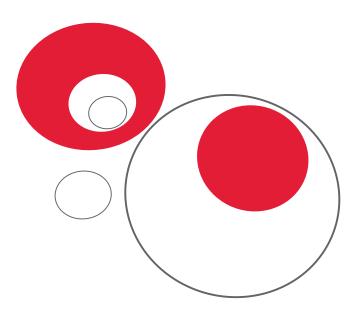
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Opinions expressed in Factor Matters do not necessarily reflect those of the Foundation or NSW Health. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. 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.

## A Word From The President...

Our family discovered haemophilia almost 18 years ago, just after our son was born. Once past the HSC exams, aside from all the other considerations, he's approaching the point of 'transition' to the adult HTC. Transitions in life, we all know about. Add the dimension of a bleeding disorder to those otherwise standard transitions and you get all sorts of exciting possibilities. From home care to preschool, primary to high school, these are just the early transitions our family has experienced.

Based on the conversations we've had over the years with many of you and your treatment centres, we've observed among our different cohorts in the NSW BD community that each phase in life has a different set of needs. And meeting these needs, or at least assisting our members to DIY, forms the basis of a new strategy we are developing. This HFNSW transition program would ideally see us remain connected to our members for a long time, via email, mobile or in-person occasions. Here is a snapshot:

Member Age	Individualized, programmed services & connections
0 to 5	Connecting mothers with advice and support, advice on home infusion & care
	Connections to government services Ensuring access to the right education resources
6 to 12	School visits, self-infusion demos, camps, friends
13 to 18	Empowering education, connections, challenge camps, menstruation, tattoos, shaving, grants, friends, disclosure, mental health grant
adult	Genetic education, dental, insurance, workplace disclosure, navigating government services (e.g., connecting members to free dental care only after receiving the mobility allowance)
senior	Grandparent brunches, mobility aids, transport assistance, Connections to government services
palliative	4G ipad, connections to government services

Based on our world-class health care system and some fine advocacy by our colleagues at HFA, we are really fortunate to have so many clinical treatment alternatives. As these and newer treatments become available, our members' needs change downstream. There's bound to be more amazing developments as there are some incredible trials underway now. So, we'll have to keep up with these changes and adjust the Foundation's services & assistance network accordingly.

This program is designed to ensure the HFNSW remains helpful and relevant into this changing future. We at the HFNSW keep in touch with you all as best we can. Your support via annual membership and keeping in touch with us is all we need in return. If you've got any ideas to add to this list, we need them. Please give Shiva a call or email.

Warm wishes for cold days.

Dan



On Saturday, 15 May 2022, HFNSW organised a family fun day at Dullboy's Social Co in Warners Bay, NSW. It coincided with the start of National Families week (15-21 May), and it was fantastic to see many families get together!

The day was a great opportunity for families to come along and catch up with one another while enjoying fun activities, including bowling and archade games.

There were about 40 attendees, including parents/carers and kids. Dan Credazzi, HFNSW's president and Jaime Chase, Haematology Clinical Nurse Specialist at John Hunter Children's Hospital, were also among us.

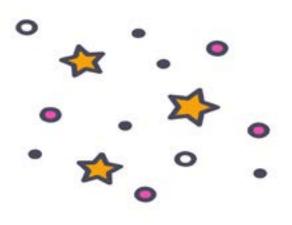
HFNSW takes pride in having been able to once again look after its members and their families and provide them with the opportunity to meet and connect with others who are living similar life experiences.

Thanks to everyone who participated and made the day memorable as captured by photos and for all your positive feedback!





















































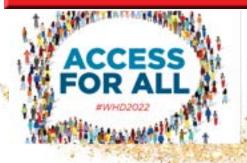








## WHD - HFNSW FAMILY LUNCH 10TH APRIL 2022



APRIL 17 2022

## WORLD HEMOPHILIA DAY





gathered together to celebrate
World Haemophilia Day 2022. The
event was organised and hosted by
Haemophilia Foundation NSW at
Castle Hill Tavern which was a nice
venue and the food was delightful
as well.
Thank you those who took time

On Sunday, 10th April 2022, we

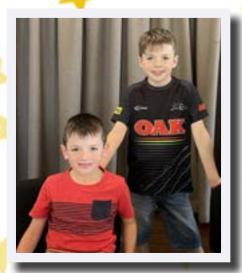


out of your busy life to attend and make it another memorable event. Your company was appreciated and enjoyed. Hope you enjoyed yourself as well.

We look forward to seeing more members, clinicians, supporters and families in our upcoming gatherings.



## HFNSW Family Lunch 10th April 2022













































# Haemophilia Foundation NSW Family Camp & AGM 2022

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

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.

Also, don't forget that HFNSW's 2022 Annual General Meeting (AGM) will be held at the camp this year.

When: Friday 11 November 5pm to

Sunday 13 November 2022.

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

This is a free event for members and their families.

Spaces are limited and booking is essential.

Please RSVP asap, no later than SUNDAY 9TH OCTOBER

Please send your completed form (included in this issue) to

coordinator@hfnsw.org.au

or, complete and submit the form online at

https://bit.ly/3yGL3dX

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



## **HFNSW Family Camp**

Despite our hopes and best efforts, the Covid-19 and the restrictions stood in the way of us holding our 2020 and 2021 annual family camps. 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 11th to 13th November 2022 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 9<sup>th</sup> October 2022**, as we must 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 Annual Family Camp Application



#### FAMILY CAMP 2021-22 Application Form

Friday 11 - Sunday 13 November 2022

FAMILY MEMBERS	AGE OF CHILDREN	
	<del></del>	
ADDRESS:		
Email:		
CONTACT PHONE NO:		
ACCOMMODATION (TICK ONE ONLY)		
<del></del>	ANY SPECIAL ACCOMMODATION REQUIREMENTS:	
FRIDAY AND SATURDAY NIGHT SATURDAY NIGHT ONLY		
DAY STAY ONLY (SATURDAY)		
MEALS – PLEASE INDICATE HOW MANY ADULTS 'A' & CHILDRE	N 'C' FOR EACH MEAL (CHILD – UNDER 16Y0	
AC DINNER FRIDAYAC BREAKFAST S.	ATURDAYAC LUNCH SATURDAY	
AC DINNER SATURDAYAC BREAKFAST S	UNDAYAC 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 <u>Sunday 9<sup>th</sup> October 2022</u> to:

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

Mail: HFNSW, PO Box 631, Broadway NSW 2007

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



#### **WORLD HEPATITIS DAY**

#### Held annually on 28 July World

World Hepatitis Day will be marked internationally on 28 July 2022 and is one of the World Health Organization's seven official global public health days.

It is an opportunity to come together to step up national and international efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. The global and Australian theme for World Hepatitis Day 2022 is Hepatitis Can't Wait.

Many people don't know that they have hep C – you could be at risk if you have a bleeding disorder and ever had had a blood product before 1993.

Or some people have been cured but still need follow-up for their liver health, especially if they have cirrhosis.

Do you think this might be you? Or someone you know?

By talking to our friends, family or a doctor about testing, treatment and liver health checks we can work towards the goal of viral hepatitis elimination by 2030.

On World Hepatitis Day we are reminded not to wait – know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

Keep an eye out on our website and social media for more information and activities in the week leading up to 28 July.



#### **FIND OUT MORE**

Australian World Hepatitis Day website - www.worldhepatitisday.org.au HFA World Hepatitis Day page - www.haemophilia.org.au/world-hep-day



## 7 WAYS TO BEAT THE WINTER BLUES AND THRIVE THIS SEASON

Flordis holistic health expert Michelle Boyd reveals seven ways to beat the winter blues and thrive this chilly season.

If you've ever felt like your mood or stress levels have been impacted by changes in the weather, you're not alone. While some of us thrive during the colder months, research shows that up to 20 per cent of the population are likely to face "winter blues", which are emotional challenges people experience as the season changes, including low mood, sleeplessness and lethargy, decreased motivation and concentration, or just general lack of energy.

Scientifically speaking, as the days are shorter in winter and daylight hours are limited, this impacts your body's circadian rhythm (or body clock), leading to imbalanced serotonin and melatonin levels — both of which are essential for maintaining healthy emotional wellbeing and sleep. In addition, the rainy weather also means you are isolating indoors, avoiding social settings and reducing outdoor exercise, all of which can also contribute to decreased mood and motivation in the cooler months.

However, while I'm sure we've all faced a bout of winter blues at one point in our lives, the reality is that you don't need to just "put up" with symptoms and instead can make simple changes in your day-to-day routine that will help you achieve balance and contentment — even if the weather is doing the opposite.



So, here are my top seven ways to beat the winter blues and any niggly winter blues symptoms to thrive to your fullest capacity during these next few months!

#### 1. Get physical

In the words of Aussie icon Olivia Newton John, getting physical should be your go-to solution for combatting any signs of low mood or motivation.

Countless studies link regular exercise to improved mental health and emotional wellbeing in individuals, not to mention it also helps reduce the risk of developing more serious illnesses. And just because it's winter doesn't mean you need to put your joggers in the closet. Even if the weather isn't suitable to go outdoors, you can still hit the gym, try some indoor sports, or even if you don't want to leave the comfort of your house, try an easy at-home workout plan or YouTube fitness videos. Just stay physical.

#### 2. Try not to overindulge

I'm sure I'm not the only one who uses winter as an excuse to become a couch potato and indulge in a bit more food and alcohol; no one's going to see your beach body for another six months, right? Well, while it can be tempting to indulge more during winter, unhealthy foods and excessive alcohol can impact your emotional wellbeing and really heighten those winter blues. Instead of trying to cut foods out or make things incredibly hard for yourself, simply keep your diet as balanced as possible and limit your indulgences such as alcohol, sugars, unhealthy fats and unhealthy carbohydrates.

#### 3. Goal setting is for everyone

Goal setting is an essential part of teeing yourself up for success and, no, you don't need to be a business or a high-flying entrepreneur to set goals. Your cognitive abilities are strengthened as you set and maintain goals, no matter how big or small they are. On chilly mornings, it can be hard to even get yourself out of bed. So, start small and work your way up to

## MENTAL HEALTH MATTERS - MAINTAINING MENTAL HEALTH DURING WINTER (CONT.)



bigger goals. These will help keep you centred, give you motivation for each task and help you stay more focused. If you are finding it challenging to stay focused in order to complete your goals, you may wish to speak to your healthcare professional regarding complementary medicines you can add to your routine.



#### 4. Sleep, but don't hibernate!

There's a reason many animals hibernate for winter. It's cold, going outdoors is a difficult feat and it requires moreenergy to get up each day.

In Australia, as there is no daylight savings in winter, the days are shorter and the sun goes down earlier, this can totally offset your body clock and lead to disjointed sleep patterns.

A natural response is to oversleep; however, this can actually be worse for your health. The best thing to help yourself get back into good sleep patterns it to maintain your routine (preferred hours of sleep per night), avoid over-sleeping and try to minimise screen time before bed. Even standing outside in the darkness for a few minutes will tell your body it's time to get some rest. If you're still struggling with sleep quality, though, it is recommended you speak to a healthcare professional to explore potential complementary options.

## 5. Beware the opposite of self-care

People are always telling me they don't have time for self-care.



I gently like to remind them that the opposite of self-care isn't doing nothing, it's actually self-sabotage. Every time you put your health and wellbeing in the "too-hard basket", you are putting yourself at risk. While it is hard to make time and effort for yourself and do good things for your body during winter, it's one of the best ways you can set yourself up for success.

During winter, make sure you still do things that make you happy and fuel positive emotions in you, such as maintaining your social life, Pnding time to relax and practising mindfulness, reading, switching off from work etc. All these small ways you can look after yourself will make a world of difference.

## 6. Don't make excuses for your mood

The first and most obvious sign of winter blues will be your mood. If you're Pnding yourself getting snappy, feeling lethargic or just generally low, this is a good indication that the weather might be getting you down — and you don't need to feel pressure to make excuses for it. But, thankfully, you don't need to wait it out, either.

Be sure to talk to your housemates or close friends/colleagues about how you're feeling, journal things out if you need to and, in some instances, seek out a healthcare professional if you feel you need more in-depth support.

#### 7. Seek professional support

In today's day and age, it is no longer taboo to seek the support of a qualified healthcare practitioner or psychologist to discuss your mental and cognitive wellbeing. If you notice any significant chang-



es to your health during winter, or you recognise it in any friends or family, it is recommended you speak to a professional about your symptoms so they can help you get on the right track. Feeling a bit down during winter is normal, but it doesn't have to become the norm.

Source: www.wellbeing.com.au

#### **HFNSW FINANCIAL SUPPORT**

If financial challenges are a barrier to you accessing support and dealing with mental health issues, please note that HFNSW is now able to provide support to members. Financial assistance will be offered to HFNSW members dealing with mental health issues through bill rebates for mental health services. including consultation fees. Each year HFNSW members will be able to access up to \$100 of financial support to assist with their mental health care needs.

## Which flu shot should I choose?

## And what are cell-based and 'adjuvanted' vaccines?

Tin Fei Sim

Senior Lecturer, Curtin Medical School, Curtin University

With Australians learning to live with COVID and resuming international travel, cases of influenza are steadily rising.

Getting a flu shot reduces your chance of catching the flu caused by four flu virus strains covered by the vaccine, and reduces the risk of severe complications and hospitalisations.

An annual flu vaccine is recommended for adults and children six months and older – unless you have a history of anaphylactic reactions to the vaccine or your doctor advises against it.



There are different brands and types of flu vaccines. So when booking in for your shot, your health provider will discuss the best option for you.

#### What are the options?

If you're over 65, you're likely to be offered an "adjuvanted" (Fluad Quad) vaccine. Those aged over 60 can also access the high-dose vaccine (Fluzone High-Dose Quad).

If you want to avoid vaccines made with eggs, you can ask for a cell-based vaccine (Flucelvax Quad). But for most other Australians, there isn't much of a difference between brands – Vaxigrip Tetra, Fluarix Tetra, Afluria Quad, FluQuadri, Influvac Tetra – aside from their suitability for different age groups.

GPs and pharmacists will generally stock one or two of these brands or whichever their state or territory governments supplies. Unlike in previous years, all eight flu vaccines available this year are "quadrivalent", meaning each vaccine protects against four strains of flu viruses.

The strains are predicted to be the most commonly circulating strains, based on trends observed in the Northern Hemisphere winter.

Flu vaccines are "inactivated", which means they don't contain live viruses and can never give anyone the flu.

#### Over 65s

For people 65 years and older, "adjuvanted" or immune-boosting (Fluad Quad®) or high-dose vaccines (Fluzone High-Dose Quad®) are recommended, as older people tend to have weaker immune systems.

Vaccines work by activating a person's own immune system. The "adjuvanted" vaccine activates a stronger immune response and is therefore more effective at preventing the flu in older age groups than the standard vaccines.

High-dose vaccines deliver a higher dose than standard flu vaccines and are also more effective than the standard vaccines at reducing transmission and preventing severe disease in older age groups.

Adjuvanted vaccines are free for over-65s under the National Immunisation Program.

If you're 60 or over, you can choose a high-dose vaccine, although you may have to pay for it, depending on local government programs.

## Cell-based vaccines don't use eggs

The flu vaccines are either egg-based or cell-based. Traditionally, flu vaccines were egg-based, meaning the flu viruses were grown in fertilised hens' eggs.

### FLU SEASON AND FLU SHOTS (CONT.)

But people with egg allergies can safely get the egg-based flu vaccine. The amount of egg protein left in each vaccine at the end of the production process is less than 1 microgram, much less than the estimated amount of 130 micrograms required to cause an allergic reaction.

In recent years, newer medical technology has led to the production of cell-based flu vaccines. Here, the virus is grown in host cells. So people who wish to avoid egg products may choose a cell-based vaccine instead.

Currently, Flucelvax Quad is the only cell-based flu vaccine approved for use in Australia and is also suitable for children from two years of age.

Some studies have shown cell-based vaccines are better at triggering the body's immune response. This is because the viruses used to make cell-based vaccines are more similar to circulating wild flu viruses – and the closer it resembles the real thing, the more effective it is.

However, Flucelvax Quad isn't currently funded under the National Immunisation Program, so you'll need to pay yourself, even if you're eligible for a free vaccine under the national program.

## When is the best time to get vaccinated?

It takes seven to 14 days for our body to respond to a vaccine. Once you receive the vaccine, your body starts to recognise the four strains of flu viruses and starts to develop an immune response over the course of about two weeks.

Once this occurs, when you come into contact with one or more of these four strains of viruses, your body's own immune response will be able to protect and prevent you from getting sick.

The flu season typically peaks in Australia between July to September. The vaccine will provide the highest level of protection for three to four months. So late May to early June is generally the best time to get it.

For people travelling overseas, your doctor or pharmacist can advise you on what's best for you based on where and when you're travelling.

The flu vaccine can also be given at the same time as most other vaccines, including COVID vaccines.

It's also safe – and recommended – in pregnancy.

#### What are the side effects?

People may experience cold and flulike symptoms for up to 24–48 hours after getting the vaccine. This shows the body's immune response is kicking in and the vaccine is working.

You can take over-the-counter pain medications such as paracetamol or ibuprofen to relieve these symptoms.

Other common side effects may include local injection site reactions such as redness, mild swelling and tenderness. This should subside within 48 hours without any treatment. Applying ice or a cold pack can help.

Some people may develop more severe reactions, including anaphylaxis (a severe, life-threatening allergic reaction) in extremely rare circumstances. This is also why your doctor or pharmacist recommends waiting on-site for 15 minutes after vaccination for monitoring.

If you've had a severe reaction to any vaccine in the past, it's important to tell your doctor or pharmacist.

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### WHAT'S NEW: A HIGH-TECH SCANNER NOW AVALIBALE AT CHW

A new high-tech scanner is giving kids with bleeding disorders a glimpse into the future as a way to help them stay on track with treatment.



In my last visit from the Kids Factor Zone at the Children's Hospital at Westmead (CHW), Robyn Shoemark, Clinical Nurses Consultant in Haematology, demonstrated how this high-tech device works.

The CHW is the first hospital in the country to receive the scanner, donated by Sanofi, and so far, it's proving to be a great success. The Joint Scanner, uses augmented reality to show patients with haemophilia disorders what their joints will look like 10, 20, 30 years in the future both with and without treatment. The scanner aims to educate patients about the impact of haemophilic arthropathy (permanent and irreversible joint damage) over the course of a lifetime, as well as reinforcing the importance of therapy compliance.

The Scanner works by using a 'leap motion' 3D camera attached to a computer to scan and map a person's hand when placed under the device. A specially designed software then overlays imagery onto the user's hand to replicate normal ageing and the impact of joint disease.

While the Scanner uses only the user's hand as its reference point, it also has the ability to expand the replicated view on the screen beyond the hand to see what is happening elsewhere in the body, focusing on specific joints known to be impacted by haemophilia including the shoulder, knee, or ankle.

Treatment for haemophilia is often self-administered at home, with patients and parents being responsible for treatment compliance. If a treatment is missed, it can cause a "bleed" and lead to bruising and joint swelling. Short-term, the effect of this is minor but if treatments are continually missed over time, it can result in long-term, irreversible damage. The scanner



demonstrates the extent of this damage.

In an interview with 7News Sydnay, Robyn explained,

cc

"we can talk about the benefits of doing treatment and the consequences of not doing treatment, but what this scanner does is show our patients and their family what this looks like and how this will impact them throughout the life. It makes it much more real."

You can see the 7News report through the link

https://bit.ly/3N61aFJ

The full article is also available at

https://www.schn.health.nsw.gov.au/news/ articles/2022/05/new-scanner-helps-kids-stay-ontrack-with-treatment

> Shiva Tabari Source: https://bit.ly/3NbM01E

### NATIONAL BLOOD DONOR WEEK: 14-20 June 2022

National Blood Donor Week is a time for us to celebrate the dedication of thousands of people from all walks of life working together as one.

This National Blood Donor Week we celebrated our half a million active donors in Australia who gave **1,596,803** individual donations in the last year. The generosity of the doners ensures individuals and communities have access to safe and quality-assured blood and blood products in both normal and

emergency situations.



By rolling up their sleeves to donate, they're providing a life-giving treatment that can help people with cancer and blood diseases, treat anaemia, or those who've recently undergone surgery, or given birth. That's just a few of the incredible things a blood donation can do.

Especially on 14th June, on World Blood Donor Day, we want to thank each and every one of the donors, who took the time to give life and continue to be the Lifeblood of Australia.

For further information about the week or making a blood donation call 13 14 95 or visit www. https://www.lifeblood.com.au

## National Volunteer Week: 16-22 May 2022



National Volunteer Week (NVW) is Australia's largest annual celebration of volunteering. It was held on 16-22 May 2022 with the theme "Better Together". Volunteering brings people together; it builds communities and creates a better society for everyone.

National Volunteer Week is a chance for all of us to celebrate and recognise volunteers' vital work and say thank you.

As one of the HFNSW's family members, I would like to take this opportunity and thank each of our foundation's committee members for their dedication to volunteering. We are, Better Together





## Your Continued Support Matters!



As the financial year 2021-22 has come to a close, we would like to thank our members for their ongoing support and engagemen with their Foundation throughouth last financial year. As we look forward to the financial year 2022-23, our focus will be on enhancing our services and this will not be possible without your ongoing support, membership fees and donations.

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

The membership registration/renewal form is enclosed with this issue, also available at https://bit.ly/3yYpRwC. For any further information contact us at coordinator@hfnsw.org.au or MB 0470 637 928..

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

Visit Haemophilia Foundation NSW website <a href="http://hfnsw.org.au/">http://hfnsw.org.au/</a>, the donation button at the top of the Home-Page of the website, or the membership page https://bit.ly/3QHhVdh or use the QR code below

cheques/money orders payable to:

Haemophilia Foundation NSW Inc. and send to Haemophilia Foundation NSW, PO Box 631, Broadway NSW 2007

**EFT Payment** 

BSB: 062 204 Account number: 00902590 Account Name: Haemophilia Foundation NSW

Please include your name in the comments field and email your receipt number to admin@hfnsw.org.au (Hardship Provision In cases of genuine financial hardship, the committee is prepared to waive or reduce the membership fee. Requests will be handled with discretion and should be directed to coordinator@hfnsw.org.au)

\*\*\*YOUR CONTINUED SUPPORT MATTERS!\*\*\*

## HFNSW AGM 2022 - Advance Notice

#### **HFNSW AGM – Advance Notice**

The HFNSW AGM will be held at HFNSW's Family Camp this year. A notice will be sent out separately. There will be a presentation of the year's activities, financial statements and information sessions by experts about treatments and research, followed by Q&As. We'd love to see you at our camp & AGM this year. Stay tuned for more details ©











## HAEMOPHILIA CENTRES & HFNSW MEMBER SERVICE



#### **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)

 ${\it Bryony.} Cooke@calvary mater.org. au$ 

(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.

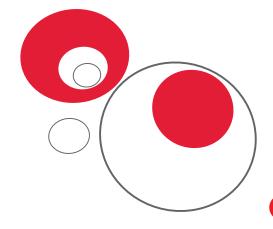
**Financial Assisstance:** HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

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

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

#### HFNSW COMMITTEE...

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





## YOU CAN'T WAIT

Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C.

You could be at risk for hepatitis C if you had a blood product before 1993.

Don't wait! Know your status. Get tested for hep C.

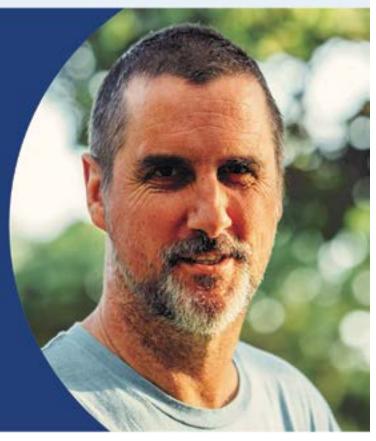
You've been cured of hep C! Has your liver recovered?

## Don't wait to find out.

Call your hepatitis specialist to check your liver test results.

Know if you need ongoing follow-up for your liver health.

It's important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.







Find out more www.haemophilia.org.au/world-hep-day

