

Factor Matters

Haemophilia
Foundation
NSW



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Volume 48

HFNSW ANNUAL
GENERAL MEETING 2021

WORLD AIDS DAY

MENTAL WELLBEING
POST LOCKDOWN

YOUR OPINION MATTERS TO US!

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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Prof Kevin Rickard, AM, RFD

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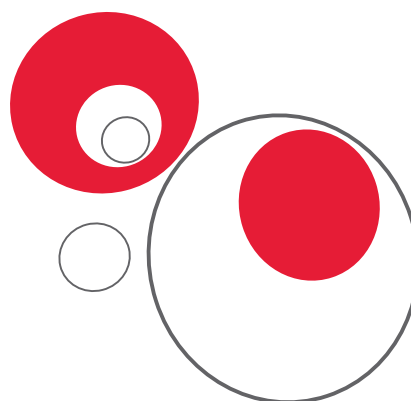
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Dear Members,

As the world becomes more complex and chaotic, it's comforting to know there are certain things we can count on. Most of the predictable things that tie us together don't take any effort at all. Things like sunrise, ocean waves and Murphy's Law. The predictable things that take effort, now those are special.



Your Foundation management committee is a group of volunteers who serve a three year term. The team was refreshed and renewed at this year's AGM and together, this team will work to keep the HFNSW sustainable and adaptive.

This past week, Sam and I visited the team at the RPA Virtual hospital. This is a remote patient monitoring and care service which really took off during the pandemic for patients undergoing treatment for cystic fibrosis with compromised immunity who needed to stay away from the hospital. Since then, over 20 months, the service has expanded, helping broaden the reach and cadence of follow-up consultations across a range of patient groups. We're looking into what sort of services might be applicable to our community using tele-health and the RPA Virtual Hospital. Services such as social work, physio and mental health follow up consultations for example. Ask your HTC clinician about a telehealth follow-up consultation, a lot can be accomplished, efficiently and safely, without having to go into the hospital. This style of follow ups may help you in your treatment journey and are becoming more widely available and convenient for both patient and clinician. If you haven't tried yet, give it a go in the new year.

Wishing You and Yours a safe and happy holiday season,

Dan Credazzi





WORLD AIDS DAY 2021

World AIDS Day is marked globally on 1 December.

This is a day to raise awareness about HIV. It is a day when we are mindful of our community members living with HIV, of demonstrating our support for them and commemorating those with HIV who have passed away. One simple way of showing this is to wear a red ribbon on World AIDS Day.

**world
AIDS
day**
DECEMBER 1
**where
to next?**

In 2021 the Australian national theme for World AIDS Day is **40 years of HIV – where to next?**

For the bleeding disorders community this is deeply significant. This year it is an opportunity to take stock of the last 40 years and consider the future.

As a special commemoration, HFA has created the 2021 World AIDS Day web page - <https://tinyurl.com/HFA-WAD2021>. This has reflections from our community about the past and the future, and a short video of the 4 Candles poem in tribute to the memory of those we have lost.

HIV IN THE BLEEDING DISORDERS COMMUNITY

Today it can be hard to imagine the devastation for the bleeding disorders community in the mid-1980s, when many people with bleeding disorders in Australia and internationally were diagnosed with AIDS after acquiring HIV through their plasma-derived clotting factor treatment products.

The experience with HIV has had an ongoing impact on our community: the trauma and health challenges for those who live with HIV, and the grief and sadness experienced by those who lost loved ones and friends to HIV. There is also the emotional impact on the health professionals at the Haemophilia Treatment Centres, with their close connection to their patients with HIV over their lifetime.

In Australia HIV infection is now usually well-managed with treatment. Some people with bleeding disorders and HIV are going well, but others have more complex needs. HFA continues to look at ways to address this in the Getting Older project.

Our community members have told us that recognising and hearing their experiences is immensely important. Foundations are committed to acknowledging and supporting community members affected by HIV.

Join us in supporting our community affected by HIV.

For more information on World AIDS Day, visit www.worldaidsday.org.au.



On Tuesday 19th October 2021, Haemophilia Foundation NSW held its 2021 Annual General Meeting online through ZOOM. HFNSW's honorary president, Dan Credazzi, officially started the AGM by introducing and welcoming the attendees to the event. The president then went ahead and presented a recap of 'what we do' at Haemophilia Foundation NSW and depicted a picture of the current situation and the future plans and the challenges and obstacles that need to be addressed. At the end, the president expressed his appreciation for the work and support of Sydney Local Health District (SLHD) NGO team, represented at the AGM by Kim Armstrong, Sharon Caris and the team at Haemophilia Foundation of Australia (HFA), the Hon Alister Henskens SC MP, Minister for Families, Communities and Disability Services, the Social Sector Transformation Fund, Haemophilia Treatment Centres (HTCs) clinical and allied health teams on the frontline in a pandemic, HFNSW's professional management team, Shiva Tabari and Sam Deylami, HFNSW's volunteers on the Committee, HFNSW's auditor, John Shute, and HFNSW's treasurer, Paul Bedbrook. He also appreciated the presence of the HFNSW Patron, Prof Kevin Rickard, AM, RFD at the virtual AGM.



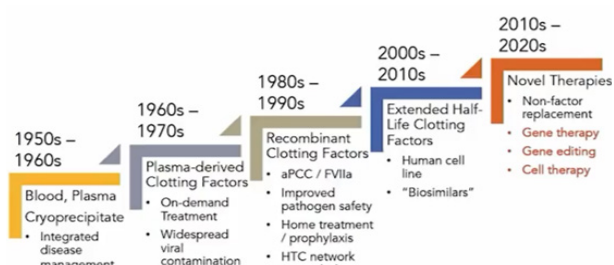
The AGM also included a summary of the annual accounts and a forward looking presentation by HFNSW's honorary treasurer, Paul Bedbrook.

At the AGM this year, we also had (re-)election of HFNSW's Committee for a three-year term from 2021 to 2024. Craig Haran and Hamish Robinson resigned from their position as a volunteer Committee member and the other Committee members were re-elected. Two new volunteers, Nicoletta Crollini and Dr Susan Russell also joined the Committee. Dr Russel expressed her appreciation for the opportunity to join the committee and pledged to work together to promote the interests of the Foundation.

Among the attendees was also the executive director of HFA, Sharon Caris. Sharon congratulated the team at HFNSW for another great year despite all the challenges. She appreciated the fact the HFNSW had been able to connect to so many people during the past difficult year. Sharon added that it is part of HFA's responsibility to make sure that everyone has access to the right sorts of treatment and care, and to make sure that the Government also understands the needs of the community. So she offered the support by HFA if anyone has got any issues to raise at a national level.

The meeting was concluded by Paul Bedbrook, HFNSW honorary treasurer, and Dr Garry Lynch, HFNSW honorary Vice-Chairman, who also thanked everyong and particularly HFNSW's management team, Shiva and Sam, for running the Foundation during the past year.

In addition to the usual AGM business, we were particularly excited about our Information Session that explored haemophilia treatments and therapies from the the past to present and the prospects for the future, which included



some crucial insight into the shifting from blood and plasma-derived clotting factor to non-factor replacements and therapies, by Dr Liane Khoo, Haematologist and Director of Haemophilia Treatment Centre at Royal Prince Alfred Hospital.

On a practical side, one of our community members, Jayden Credazzi, shared with us his experiences of using the new treatment, HEMLIBRA, and the positive impacts on his life. The evening ended with a final Question and Answers session.

On behalf of the committee at Haemophilia Foundation NSW, thank you all who attended the 2021 AGM and Information Evening and for your continued support and interest. With your attendance we feel this was a successful meeting, and we hope you also feel the same and have received some good information.

We look forward to seeing you at out next AGM in 2022!



MENTAL WELLBEING POST LOCKDOWN THROUGH SETTING BOUNDARIES

*Nicoletta Crollini - Haemophilia Social Worker
at Royal Prince Alfred Hospital*

On Tuesday 30 November, HFNSW organised a webinar on Mental Wellbeing post-lockdown. The presentation by Nicoletta Crollini from RPA Hospital HTC provided interesting and useful tips and information on how to maintain our mental wellbeing by setting boundaries. At the end of the presentation there was also an opportunity for questions and answers.

We appreciate the support and participation of our members from near and far, particularly Patrick who joined us from Ireland where he is doing a postgraduate course on Music Therapy. Patrick stressed the importance of mental wellbeing and the aspects that relate patients treatment not only for their medical condition but as a whole person.

Thank you once again to Nicoletta for running the session, and everyone who participated. For those who missed the session, please contact us at coordinator@hfnsw.org.au if you wish to receive a copy of the audio-recording.

Nicoletta has also provided the article below which is based on her presentation. Enjoy!



What are boundaries?

Boundaries are the physical, mental and emotional rules you set in place for yourself that guide what you are willing and not willing to do in all aspects of your life. A few areas where we can set boundaries in our life are our personal space, time, energy, emotions, relationships, and work.

Why are boundaries important to set?

It is important to implement boundaries in our lives to maintain our mental health and emotional wellbeing. Having boundaries in our life allows us to shape and develop who we are as we gain an understanding of what we are willing and not willing to accept in our life. Boundaries also help facilitate our independence as we move from childhood, into adolescents and then adulthood. The implementation of boundaries also helps reduce instances of professional and personal burnout in our lives. A bonus of setting boundaries in our own lives is that they can positively influence the behaviour of those around us.

How do we set them?

The boundaries we set in our lives range from those that are strict to those that seem like they don't exist. Keep in mind that having boundaries that are too strict can mean we keep people at a distance or avoid close relationships.

Having boundaries that are too loose can mean you find it difficult to say no to people, get involved in other people's problems, and seek to please others due to fear of rejection.

There are moments where you interact with people that leave you feeling angry, upset or find yourself complaining, this is probably an indication that you need to set a boundary. Listen to yourself, figure out what you feel like saying or doing and communicate this calmly but confidently.



Setting healthy boundaries in our life is a learning process that takes time. Listen to yourself and set your boundaries in a timeframe that works for you.

It is good to have a social support network of people that respect your boundaries, it might be challenging but this can sometimes mean eliminating toxic people from your life.

Boundary setting tips:

- Once a need to set a boundary has been identified do it in a clear, calm, direct and respectful manner with as few words as possible.
- You do not need to justify your boundary, get angry, or apologise about the boundary you have set for yourself.
- Remind yourself that you are not responsible for the reactions of other people regarding your boundary. If the boundary has upset another person that is for the other person to deal with, just remember to convey the boundary in a respectful manner.
- Your actions and behaviour need to match the boundaries you have set, you cannot establish a clear boundary if you send mixed messages by apologising for the boundary you have set.
- Remember that when you begin to set boundaries you might feel selfish, guilty or even embarrassed. Set the boundary anyway and just continue to remind yourself that you are entitled to self-care and maintaining your mental wellbeing.
- Do not let the anxiety, fear or guilt stop you from caring for yourself and setting healthy boundaries.

Teaching children about boundaries

Providing boundaries and consequences teaches children accountability, responsibility and independence, which is especially important as they get older and begin to enter more complex relationships.



Here are some tips on how to support children to set healthy boundaries:

- Explain to your child what boundaries are – I know this can be difficult for adults to understand, so explain it to your child in a simple way that you know they understand.

- Model setting healthy boundaries for your children – through showing your children how you set and maintain healthy boundaries, they will learn and do the same for themselves.
- Give your children the opportunity to make choices for themselves or include them in decision making – being involved in decision making gives children a sense of independence and accountability for themselves.
- Teach them if/when/how something has invaded their boundary – just like adults, if they are starting to feel uncomfortable or upset in any way, it most likely is an indication that their boundaries have been invaded.
- Explain that saying no is ok – this is something that is difficult for a lot of people, even adults.

Please remember...

Setting healthy boundaries is an important part of life and significant to maintaining our self-care. Setting boundaries helps maintain our mental health and well-being.



Remember to also respect the boundaries that others have set for themselves. Respect is a two-way street, and appreciating the boundaries others have set for themselves is as important as setting boundaries for oneself.

I hope you have found this article useful, particularly as we are all trying to resume our lives post COVID-19 lockdown.

Wishing you all the best for the final period of 2021 and into the New Year.

Nicoletta Crollini

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Email: nicoletta.crollini@health.nsw.gov.au

RARE DISEASE DAY 2022
28 FEBRUARY



Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse— but united in purpose.

Rare Disease Day is observed every year on 28 February (or 29 in leap years)—the rarest day of the year.

Rare Disease Day was set up and is coordinated by EURORDIS and 65+ national alliance patient organisation partners. Rare Disease Day provides an energy and focal point that enables rare diseases advocacy work to progress on the local, national and international levels. Though Rare Disease Day is patient-led, everyone, including individuals, families, caregivers, healthcare professionals, researchers, clinicians, policy makers, industry representatives and the general public, can participate in raising awareness and taking action today for this vulnerable population who require immediate and urgent attention.

By Sharing your colours via social media, events, illuminating buildings, monuments and homes, by sharing experiences online and with friends, by calling on policy makers and shining the light on people living with a rare disease, collectively we aim to change and improve lives of the 300 million people worldwide.

How can Rare Disease Day make a difference?

Rare Disease Day raises awareness for the 300 million people living with rare disease around the world, including an estimated two million Australians, and their families and carers.

The long-term cause of the Rare Disease Day campaign is to achieve equitable access to diagnosis, treatment, health and social care and social opportunity for people affected by a rare disease.

Important progress continues to be made with joint international advocacy efforts for universal health coverage (UHC), part the United Nation's Sustainable Development Goals (SDGs) to advocate for equitable health systems that meet the needs of people affected by rare diseases in order to leave no one behind.

Rare Disease Day is the opportunity advocate for rare diseases as a human rights priority at local, national and international level as we work towards a more inclusive society.

I SUPPORT
RARE DISEASE DAY
28 FEBRUARY 2022
#RAREDISEASEDAY RAREDISEASEDAY.ORG



Join the community. Help us build awareness. Share your photos, videos and experiences!

SHARE YOUR COLOURS

4 ways to get your kids off the couch these summer holidays

Come school holidays, your school-aged kids are more likely to spend longer on their screens than they do in term time. Here's how to get them outside and active, with a bit of planning.

Professor Tim Olds; Amanda Watson; Associate Prof Carol Maher
University of South Australia

The sun's shining and there's a trampoline in the backyard. Yet your kids want to spend their summer holidays lying on the couch playing computer games all day.

So what can you do to help your school-aged kids stay active and healthy this summer?

Kids put on weight over the holidays

In 2016, a US study found that all the increase in fatness of school-aged children occurred over the summer holidays. During term time, kids get leaner and leaner, only to put it all back on, and then some, during the holidays.



Their fitness also declines during holiday time. To make matters worse, changes are greater in kids from poorer, less educated backgrounds, and the gap between rich and poor widens over multiple summer holidays. The work of the school is undone at home.

What's going on, and what can parents do about it?

Holidays are different

Kids spend their time differently on holidays, as we showed in a study published earlier this year.

On holidays, Australian kids get 58 minutes a day more screen time than during term time, including spending 16 minutes a day more playing video games. They get 16 minutes less sport and vigorous exercise each day.

They also get 40 minutes more sleep, staying up about 40 minutes later, and sleeping in 80 minutes more.



All this adds up: their overall energy expenditure is more than 5% lower. Over six weeks of school holidays, that amounts to an extra half kilogram of fat in a typical 11-year old, and that's without counting changes in diet.

Kids eat differently on holidays, too.

On school days, kids can only eat during recess and lunch. Their options are limited by school-based healthy eating initiatives such as "fruit time", healthy canteen menus, and the curriculum about healthy lunchboxes.

All that goes out the window on holidays. Kids fall victim to the gravitational pull of the big white box in the kitchen.

On weekends and school holidays, kids have greater choice of how much, what and when they eat. Most (knowingly) choose less healthy options.

Later bedtimes mean more screen time and more snacking. Longer lie-ins often mean kids skip breakfast.

The importance of structure

US researchers coined the idea of "structured days". School days, they argue, are characterised by consistency and structure, which regulate how kids use their time, and when and what they eat.



On school days, for example, two-thirds of kids get up within an hour of each other (roughly between 6:30 and 7:30 am); on non-school days, it is over three hours (between 6:45 and 10:05 am).

Their review of 190 studies compared children's sleep, physical activity, sedentary behaviours and diet on school days and weekends. They found that in 80% of studies, weekends were associated with unfavourable activity and dietary patterns.

During school term, the unhealthy impacts of unstructured weekend days are diluted. In contrast, the school holidays, and particularly the summer holidays, involve a long string of unstructured days and unfavourable activity and dietary behaviours. This leads to a decline in fitness and accelerated weight gain.

The “filled-time perspective” describes the sensible idea that when children’s time is filled with favourable activities, the time cannot be filled with unfavourable ones.



This suggests it is helpful to fill children’s time with favourable activities, like physical activity and excursions, to reduce the time available for unfavourable activities, such as snacking and screen time.

So what can parents do to keep kids healthy and active on school holidays?

Here are four ways, with a proven track record

1. Get kids outside

Studies consistently show time spent outside is strongly associated with both physical and mental health. That effect is likely due to kids being more physically active outdoors.

2. Try summer camps

Summer camps are popular in Europe and North America, and also run in Australia.

An estimated 1.3 million French school children go off to their “colonies de vacances” each summer. In the US, over 14 million kids attend summer camps.

Children who spend more time in summer camp are more active than those who spend more time at home over the summer holiday.

Some 80% of boys and 73% of girls who attended a summer day camp met the daily physical activity recommendations of 60 minutes per day — about four times as many as those reaching that target during the year.



Some universities are using augmented and virtual reality to provide near real-life experiences for galvanising students’ curiosity, engagement and commitment and for preparing students for the workplace.

3. Activity before screen time

Only allow screen time when the kids have been physically active, even if that only means doing household chores. On holidays, kids spend 35 minutes more each day doing chores, so this may be your chance to get your kids to pitch in.

4. Plan the day



Organise time for physical activity with your child. Have a game of beach cricket or a mini-Olympics in the backyard. Take the dog for a walk. Organise excursions to the museum, or even shopping, where they get to walk around. Have regular times for meals and relaxation.

Good luck 😊

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Haemophilia Foundation NSW

Special call out

to the bleeding disorders community and their families in the Hunter Region!

All other members and their families across NSW, and all clinicians and supporters who can make it to the event are also most welcome!



*As the holiday season is approaching,
let us get together to celebrate and be merry!*

Come and join us this festive season and have some food and fun!

Please mark your calendar:

When: Sunday, 19th December 2021; 11:30am – 2:30pm

Where: Dullboy's Social Co, 326 Hillsborough Rd, Warners Bay, NSW 2282

The event is **free** for all members and their families.

Bookings are essential and should be made by **Wednesday 15th December 2021 at the latest.**

Please RSVP through the link below:

www.trybooking.com/BVSIY

Please note that we'll gather at 11:30am in a private room that HFNSW has booked for us at the back of the bar area. The staff members at Dullboy's centre can guide you to the room. Please make sure to be there at 11:30am so you won't miss the opportunity to meet and greet with other members and families over food and drinks, which will be followed by fun activities including bowling and arcade games.

If you have made a booking, but cannot attend the event for any reason, please return your tickets through the link provided in your booking confirmation email; or, just let us know by email at coordinator@hfnsw.org.au

We are so excited to see you and celebrate with you ☺

9 WAYS TO SUPPORT YOUR TEEN'S MENTAL HEALTH AS RESTRICTIONS EASE

Associate Professor Marie Yap, Psychology, Monash University;
Emeritus Professor Anthony Jorm, The University of Melbourne;
Mairead Cardamone-Breen, Research Fellow & Psychologist, Monash University



Headlines about the impact of the pandemic on youth mental health have left many parents worried about their children and unsure what they can do to help.

Now, as restrictions are eased – and school, home and social lives return to something resembling normal – young people are having to make significant adjustments as they face new pressures.

Parents need clear, evidence-based, practical strategies to support their teen's mental health. But this can be hard to find.

To fill this gap, our yet-to-be-published study asked 35 international experts (researchers, health professionals and parent advocates) what parents can do to support their teenager's mental health during the pandemic.

Here are their nine key tips:

1. Parents, look after yourselves

While parents' natural instincts are to be concerned about their children (and possibly ageing parents), looking after your own needs will put you in a better position to support those you care about.

2. Keep the conversation open

Constantly changing local regulations and restrictions, and rules around reopening, can make teens more anxious.

Help your teen feel more in control by providing them with clear, up-to-date and age-appropriate information about the pandemic and restrictions when the situation changes.

Teenagers are likely to seek answers from their peers, online, and from social media. Help your teen get in-



formation from reliable and credible sources, such as government websites or the World Health Organization.

Talking about the pandemic and easing of restrictions can help them understand and cope with what they're hearing.

3. Support teens to follow the local rules and restrictions

Be a good role model by following the local regulations and restrictions yourself.

Model flexibility and problem-solving by showing your teen how you adjust your daily life in response to changing regulations and restrictions.

4. Accept your teen's emotions

It's normal for teens to feel a wide range of strong emotions at different points during the pandemic: angry, scared, sad, frustrated, grief, worried, bored, confused, isolated, concerned.



You can help your teen cope with these by:

Asking and listening. Ask how they're feeling and coping, especially as the situation changes. When they open up, focus on listening – what they need most is empathy, compassion and comfort.

Showing them how you do it. Teens look to their parents to see how to respond and how worried they should be. Try to set a good example by appearing as calm as you can, and using healthy coping strategies yourself.

Being patient, perhaps more than usual.

Being reassuring but realistic. Despite negative news they may be hearing, teens need their parents' reassurance their family will get through the pandemic together and things will improve over time. But be careful not to make unrealistic promises.

Monitoring. Keep an eye on your teen's stress levels – look for changes in their behaviour, health and how they're thinking and feeling. Encourage them to do things that have helped them cope with stressful times in the past.

5. Help your teen work out what they can and can't control

Encourage them to focus on what they can control. For example, young people can control their own COVID-safe behaviours (such as wearing masks and following local restrictions), but need to accept they can't control the behaviour of others.

Model helpful ways of dealing with uncertainty by showing them how you accept what is outside your control and focus your effort on things you can control.

Show appreciation for their efforts to adjust to pandemic challenges, big or small.

6. Provide support as needed

The ongoing uncertainties during the pandemic can affect teens many months after local restrictions have eased.

So be prepared to provide ongoing emotional support as needed, rather than assume all will be well because life is "back to normal".

7. Establish routines

Routines help teens feel more organised, in control, safe and secure and less stressed – this can help protect their mental health.



Ensure your teen's routine includes set times for homework, meals and snacks, physical activity, free time for fun and relaxation, and time for socialising.

Regular sleep routines are also important. This means having a regular bed time and wake time, and minimising

the use of electronic devices before bed. Review and adjust this routine with your teen as needed, such as when local restrictions change.

8. Adjust your expectations

With the changes and uncertainty caused by the pandemic, you may need to adjust some expectations of your teenager and of yourself. Focus on emotional and physical well-being rather than perfection or high productivity.

Try to practice self-compassion and forgiveness towards your teen and yourself if either of you don't meet your expectations.

9. Look for silver linings

Try to convey a sense of confidence to your teen that things will improve over time. Encourage any optimism or hope your teen shows.



Showing compassion, empathy and kindness to others can also benefit your teen. It can help them gain perspective, give a sense of achievement and pride, and give opportunities for social interaction. Encourage your teen to take up opportunities to help others when they can.

When to get help

Seek professional mental health support if your teen has major difficulties adjusting to challenges of the pandemic or reopening, or you are struggling with your own mental health.

Some signs you or your teen might need professional support include changes in mood or behaviour that impact school, work or relationships, withdrawal from friends or family, intense distress, and problems that don't seem to be improving with time.

Remember, by seeking support for yourself when needed, you are also setting a good example for your teen.

For more helpful tips, see the Parenting Strategies website. Parents across Australia can also access the evidence-based Partners in Parenting online program for free.

If this article has raised issues for you, or if you're concerned about someone you know, call Lifeline on 13 11

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Haemophilia Treatment Centre Service Sydney Children's Hospital

A guide for families and carers with bleeding disorders

About the Haemophilia Treatment Centre

Sydney Children's Hospital Haemophilia Treatment Centre focuses on comprehensive care. We provide a wide range of services to children with bleeding disorders and offer support to their families.

The centre provides a regional and rural service with outreach clinics in Campbelltown, Canberra, Wagga Wagga and Coffs Harbour. We liaise with regional centres providing advice and support to health professionals regarding the management of bleeding disorders.

For new appointments to outreach clinics please contact (02) 93821690, with a GP referral.

Location

Sydney Children's Hospital is located in the Eastern Suburbs of Sydney on High Street, Randwick.

The haemophilia clinic and haemophilia treating centre is situated on level 2 of Sydney Children's Hospital, on ward C2North and is a part of the KCC [Kids Cancer Centre].



This centre is open Monday – Friday: 08:00 – 16:30.

Outside of these hours patients will be seen and treated at the Sydney Children's Hospital Emergency Department.



Services provided by our centre

In providing comprehensive services the centre concentrates on a wide range of care including factor replacement therapy, musculoskeletal and orthopaedic assessment, genetic counselling and psychosocial support.

A dedicated team of medical, nursing and allied health professionals provide care for children with conditions such as Haemophilia, von Willebrand Disease, platelet disorders and other less common bleeding disorders.

Medical Services

- Diagnosis and management of children with bleeding disorders.
- Pregnant mothers (known to be haemophilia carriers) have access to the Royal Hospital for Women which is located on the same hospital campus. They can safely deliver their babies close to our Haemophilia Centre.
- Expert management of children with bleeding disorders undergoing all types of surgical procedures.
- Other medical services at the hospital include genetic counselling, physiotherapy, neurological assessment and dentistry.

Nursing Services

- Specialist haemophilia nursing care.
- Co-ordination of care in the hospital, home and community setting.
- Education & support for management and prevention of bleeds.
- Education and support for home venepuncture, central venous access devices, product preparation and administration.

Emergency Department (ED)

ED is for all emergency presentations requiring urgent treatment. This includes a suspected bleed or concerns around central venous access devices.

ED Location: Level 0, High Street. The ED entrance is slightly up the hill from the general entrance for Sydney Children's Hospital.

If living outside the Sydney area, you should discuss with your treating haematologist which Emergency Department is best suited to your child's needs in an emergency.



On arrival to ED, your child will see the emergency triage nurse, who will assess the urgency of your child's presentation. It is very important to present your Medical Emergency Care Plan letter to the triage nurse so that ED understands your child's diagnosis and plan of care.

The ED team may need to contact your haematology team [or on call haematologist] for treatment advice relating to your specific presentation.

Where possible topical numbing cream (LMX or Emla cream) should be applied in advance of your arrival to ED, to your child's inner aspect of the elbows, back of hands or if relevant over the 'port a cath' site in preparation for intravenous factor administration.

Medical Day Unit (MDU)

In providing comprehensive services the centre concentrates on 'planned' presentations outside C2 North ward opening hours eg planned review of a bleed or planned factor administration over weekends/public holidays. Location: Level 2, north end of corridor "C2 North".

Getting to Sydney Children's Hospital

Public Bus service to Randwick

370 Leichhardt to Coogee.

M50 Drummoyne to Coogee

348 Bondi Junction to Wolli Creek

400/410 Burwood to Bondi Junction (via airport).

372 Railway Square to Coogee.

373 Circular Quay to Coogee.

374 Circular Quay to Coogee.

376 Railway Square to Maroubra Beach.

377 Circular Quay to Maroubra Beach.

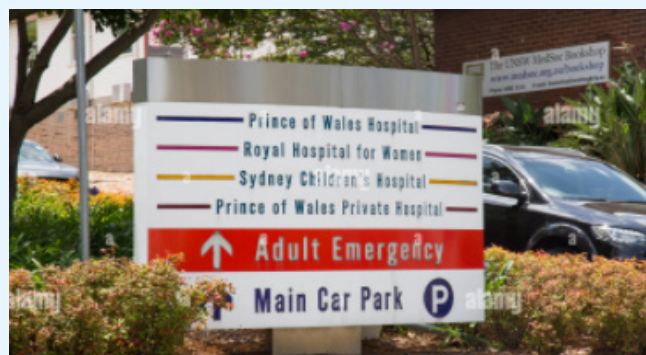
314 Bondi Junction to Coogee.

316 Bondi Junction to Pagewood.

418 Bondi Junction to Burwood

Parking - Patient & Visitors

The car park is privately operated by Metro Parking 24 hours a day. Concessional parking rates are available for patients/carers. For more details, please speak with the admission clerks within the ward or clinic area.



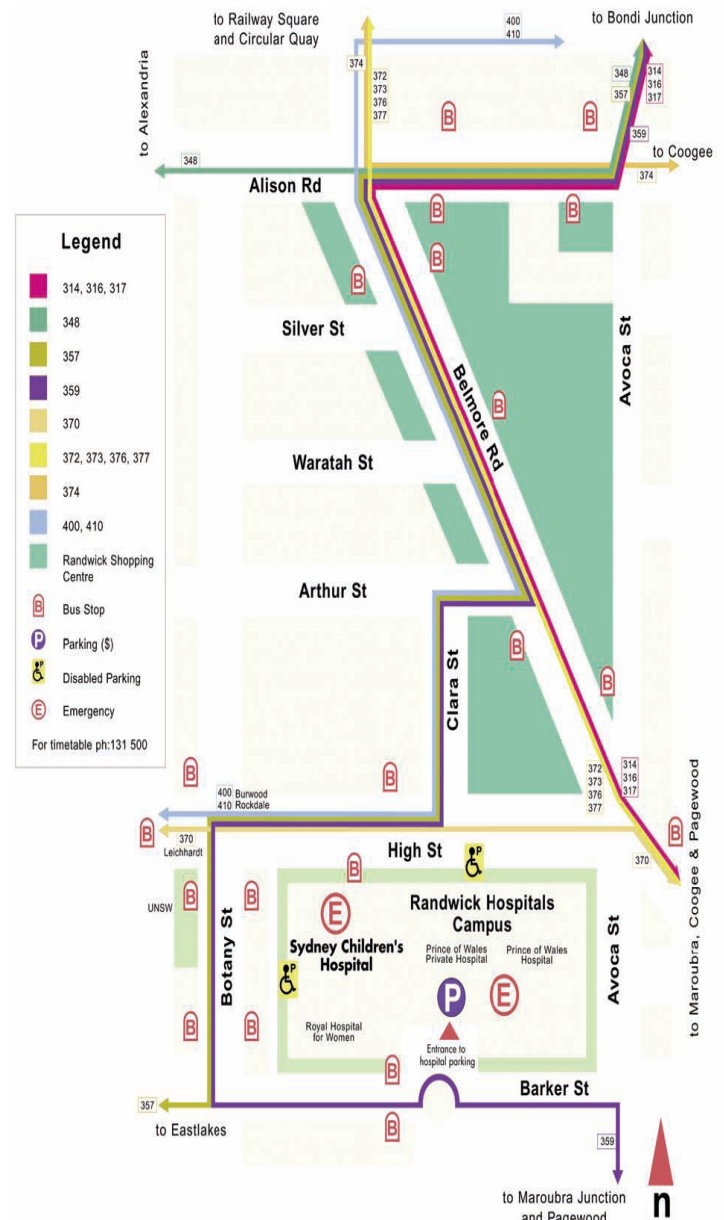
Enter via the roundabout on Barker Street, Randwick. Take the lifts at the back of the car park to Level 0. Enter the main doors of Prince of Wales Campus Centre. Signs will direct you through to the Sydney Children's Hospital. Disabled parking spaces are found on Level B1 of the car park - in front of the lifts. Enquiries: (02) 9382 3400 or email SCHN-SCHCarParking@health.nsw.gov.au

Useful Resources & Websites

- Haemophilia Foundation of Australia (HFA) www.haemophilia.org.au
- Haemophilia Foundation of NSW (HFNSW) www.hfnsw.org.au
- World Federation of Haemophilia www.wfh.org
- Canadian Hemophilia Society www.hemophilia.ca/en/
- Sydney Children's Hospital website www.schn.health.nsw.gov.au/

CONTACT DETAILS	SYDNEY CHILDREN'S HOSPITAL
Sydney Children's Hospital switch board	(02) 93821111
Haemophilia Treatment Centre Mon – Fri: 08:00 – 16:30 Clinic bookings	(02) 93821007 (02) 93821006 (02) 93820048 (02) 93821009
Haemophilia Nurse Mon – Fri: 0800 – 1630	0436601238 grainne.dunne@health.nsw.gov.au
Haematology Consultants: Dr Susan Russell Dr Meredith Wiggins Dr Paul Monagle Haematology Fellow	(02) 93821690 Or after hours: (02) 938 21111 0459290827
Social Worker	(02) 93821021
After hours in case of emergency	Call switch and ask for "Haematologist on call."

Sydney Children's Hospital Map



HFNSW

Lunch Invitation

We begin in 2022 with a sense of optimism as we look forward to the return of full-fledged physical events!

So let's get together and catch up over lunch at the beginning of 2022!

The Bleeding Disorder community members and their families across NSW, clinicians and supporters are welcome!



Please mark your calendar:

When: Sunday, 30th January 2022; 12:00 – 2:00pm

Where: Rashays Restaurant, Top Ryde City Shopping Centre Level 1, Shop MM14 Devlin Street &, Blaxland Rd, Top Ryde NSW 2112

The event is **free** for the Bleeding Disorders Community.

Bookings are essential and should be made by Thursday 27th January 2022 at the latest.

Please RSVP through the link below:

www.trybooking.com/BWCSE

Or, RSVP by emailing us at coordinator@hfnsw.org.au

If you have made a booking, but cannot attend the event for any reason, please return your tickets through the link provided in your booking confirmation email; or, just let us know by email at coordinator@hfnsw.org.au

Happy New Year! We are so excited to see you there ☺

As we are approaching the end of the year, it's time to say goodbye to 2021 and hello to the New Year 2022! 2021, following its previous year, has certainly been another challenge. In the past two years, there has been a real threat to our health, both physical and mental, grief and loss, and financial problems for many of us, but as well as collective unity, things to celebrate, love and hope. And throughout all this mixture of happy and sad moments, we have grown and learned along the way.

Now, once again, we are looking towards another year and all that it will bring for us. It's time to let go of the feelings of loss and anxiety and move on as we are turning the page. Even though the fallout from the past couple of years may remain for some time, we all know that "this too shall pass" and there is always hope for a brighter future on the horizon. So at this time of the year, let's reflect on what we have lived through. We may have had plans that we put on hold, and the resolutions that remained unfulfilled, still we are standing! And this is testament to our strength, resilience and health. The challenges of the pandemic may have taught us that happiness is not necessarily bound by being overly concerned about objects, plans and resolutions, but it is a state of being, of living our best life in the present, being satisfied with ourselves as we are, our relationships, sharing and caring, and how we come to each other's aide when needed.

So with all the challenges, we are grateful for what they have taught us and charge us into 2022 with a renewed sense of purpose. And we are of course grateful for the countless blessings surrounding us including our loved ones, family and freinds and the community we have been connected with, even virtually.

With that, I would like to thank you all for having been in touch and connected with us and supporting us during 2021. Let us continue with this way of working together, and supporting each other. We need your support and we would love to hear from you to provide you with more tailored and efficient service. Please follow our newsletter and our website, participate in our events, and take our surveys to let us know how we can improve our service. Your Foundation, through its volunteer committee members and its staff will continue to serve you with all the hope of healing and returning to real human interaction 2022 brings.

Happy New Year!



*Stay safe, and best wishes,
Shiva*

HAPPY

Holidays



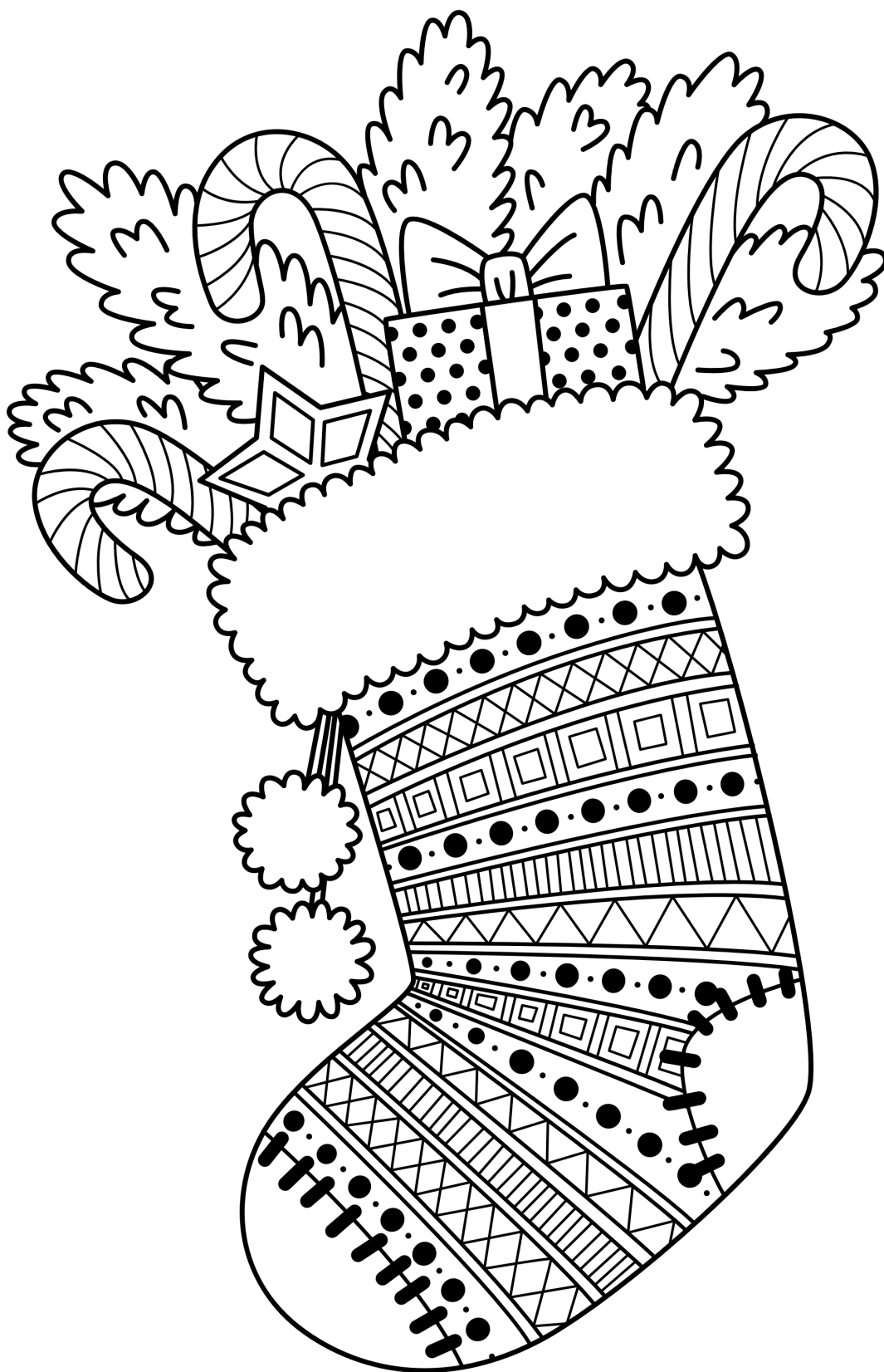
Young Ones Are Invited!

Colour in this page or the back page, or both, and win a prize.

Please send by 10 January 2022 to:

Haemophilia Foundation NSW

PO BOX 631, Broadway NSW 2007



Homemade
GIFTS MADE EASY

Young Ones Are Invited!

Colour in this page or the back page, or both, and win a prize.

Please send by 10 January 2022 to:

Haemophilia Foundation NSW

PO BOX 631, Broadway NSW 2007

Take the Survey for the chance to win a prize!



To get the New Year off to a positive start, HFNSW would greatly appreciate it if you would spare a few minutes of your time to complete the questionnaire which is included in this newsletter.

We appreciate you are busy but this is an important piece of work as **Your Opinion Matters to Us!** In appreciation of your time, there is a range of shopping gift cards up for grabs. Complete the survey by 30th January 2022 and you will enter a draw to win a chance for a gift card.

Send the completed questionnaire via email at coordinator@hfnsw.org.au or by post to PO Box 631, Broadway NSW 2007.

Feel free to contact us if you have any questions and once again, many thanks for your support.

HFNSW MEMBERSHIP 2021-22

IS YOUR MEMBERSHIP UP TO DATE?

Thank you to those members who have paid their 2021-22 membership fees. All memberships expire on 30 June each year. If you haven't renewed yet, it's not too late! The form is included in this newsletter and also available online at <https://bit.ly/3yYpRwC>.

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)

YOUR CONTINUED SUPPORT MATTERS!



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

would like to
wish you all

Happy and Safe Holidays!

HAPPY NEW YEAR

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