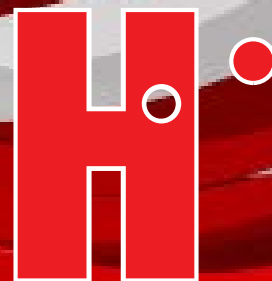


Factor Matters

Haemophilia
Foundation
NSW



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Spring 2022

Volume 51



Annual Family Camp & AGM 2022

Bleeding Disorders Awareness Month

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, we provide complimentary services beyond the Treatment Centres such as continuous education, lifetime connections and community events, peer-to-peer counselling, and help with identifying solutions to improve the quality of life for people living with an inherited bleeding disorder.

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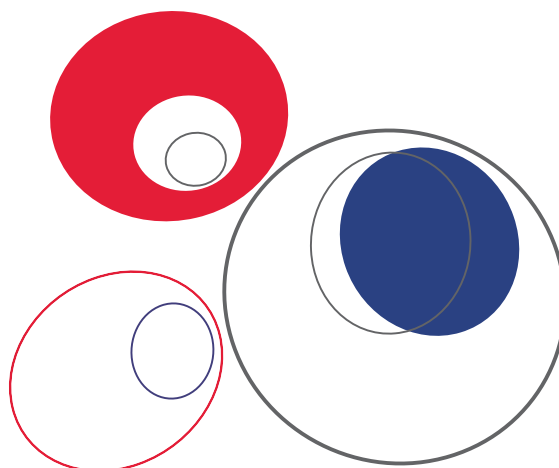
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Dan Credazzi

President,
Haemophilia
Foundation
NSW

A Word from the President

Milestones

This is a season of milestones. The Grand Finals are on, year 12 formals & graduations and most notably, the closing of the second Elizabethan era. Milestones are actually markers on a journey. Markers on a path already laid out. That's how milestones have been setup since Rome's Appian Way. You get to one, you can just make out where the next one is. But when the road you're on is a new one, then you have to create your own milestones along the way so that others can follow and more importantly, you can find your way back.



Roman Milestone

Photo: S.Júlio Reis

Source: [Wikipedia](#)

This month, the Royal Prince Alfred hospital saw it's 140th year. Opened in 1882 and named after the previous, previous Duke of Edinburgh, the RPA clinicians & scientists have pioneered new treatments and continue to be leaders in clinical innovation. The first liver transplant, the first coronary angiography, and the first haemophilia treatment centre in Australia, all at the RPA.

If you're reading this, your story is also woven into the history of the RPA. The story continues to unfold, in the latest chapter, the RPA is leading the way in gene therapy treatments, specifically for thalassaemia & haemophilia.

We're lucky to have such a campus with its legacy of brilliant, dedicated people in our great state. Happy Birthday RPA.

Take care & keep in touch!

Dan

World Hepatitis Day 2022

World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to eliminate viral hepatitis by 2030. In 2022 the theme is **hep can't wait**, reminding us that we need to be proactive in our efforts.



Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

TAKING ACTION

Highly effective hep C treatments are available in Australia. They are easy to take – one tablet a day, not injections - with cure rates above 95% and few if any side effects.

Who is at risk?

If you had clotting factor or a blood transfusion before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. You may have had very few treatments in your lifetime and never thought you would be at risk for hep C. If this is you, don't wait. Talk to your doctor about being tested – find out if you have hep C. Testing and treatment is simple. Hep C can be cured.

WERE YOU CURED OF HEP C?

Did you have liver damage or cirrhosis? Has your liver recovered from hep C? Don't wait to find out. Call your hepatitis doctor or your GP to check your liver test results. Find out whether you need ongoing follow-up with a liver specialist.

REMEMBER

If you had cirrhosis or extensive scarring before being treated and cured of hep C, you still need to have a liver ultrasound scan every 6 months long-term.

KEEP YOUR LIVER HEALTHY

Have a balanced diet, maintain a healthy weight, and avoid or minimise alcohol intake.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

For more information, visit

www.world.hepatitisday.org.au

or the HFA World Hepatitis Day page – www.haemophilia.org.au/world-hep-day



Clearing hep C as a child

John's story

** John is not his real name*

For most people who were exposed to hepatitis C through their treatment products, the diagnosis experience was more than 30 years ago. If they were diagnosed as a child, it might have been their parents who received the test results and they might not have been certain whether they still had hepatitis C until they were older.

John had hepatitis C as a child and cleared the virus naturally. He talked about his experience.

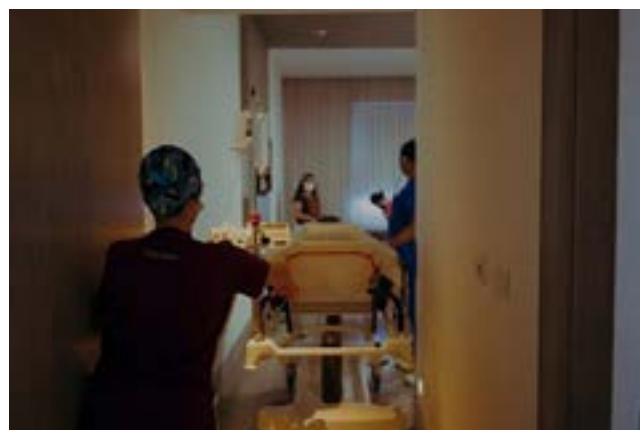
BEING DIAGNOSED

'It was in the early 1980s and not much was known about hep C at the time. I was a kid, around 9 or 10 years old, and when I was passing dark brown urine like tea. My parents thought that wasn't right and sent me off to hospital. They ran tests and diagnosed that I had what was called non-A non-B hepatitis.'

'I lost heaps of weight during that time and was very jaundiced and yellow. I can't remember how long I was crook for, but I was in hospital for two or three weeks. After that I had to get back up to strength and put weight back on and try to get back to normal.'

Although John and his parents didn't speak much about it over the years, he found out later that his time in hospital was traumatic for all of them.

'I recall it being a bit like COVID times. I was in isolation in my own room and wasn't really allowed visitors. My room had a glass window and my parents could only wave to me or speak to me from the outside of the window. The nurses and doctors were masked up as well.'



'It was very daunting and scary as a kid. I was so young and didn't know if I was going to survive the whole ordeal. And I still have mixed emotions when I think about how I obtained the virus through my blood products. You take a certain treatment for an illness that you think is going to save your life and then you end up with another life-threatening virus or condition because of it. But I am probably one of the lucky ones. Other people got HIV. I cleared hep C naturally and I didn't get HIV as well.'

Many years later, when John was celebrating a personal milestone, his normally stoic father was overwhelmed by the contrast between the happy occasion and the memory of John's hepatitis C scare and broke down.

'He said he wasn't sure I was going to survive,' said John.

CLEARING THE VIRUS

Although John isn't sure when he cleared the virus, he has had several occasions where his HCV RNA tests have confirmed that he no longer has the virus in his bloodstream.

'I had to obtain a few doctor's reports for one reason or another and they specified that I was diagnosed with hep C in my childhood but had cleared the virus spontaneously and this was verified in blood tests.'



Among the tests for hep C was preparation for IVF, when John and his wife were undertaking pre-genetic diagnosis for haemophilia before becoming pregnant. John commented that the IVF doctors identified that he had been exposed to hepatitis C but could also see that he had cleared the virus.

WHAT DO THE TESTS MEAN?

There are two types of blood tests to diagnose hep C.

Hep C antibody test

Positive result - shows you have had a hepatitis C infection at some stage in your life but not whether you still have hep C.

Negative result - shows you have never been exposed to hep C.

Hep C RNA test

This test is carried out if you have a positive hep C antibody test.

Positive result - shows you still have hepatitis C.

Negative result - shows you no longer have hepatitis C.

For more information, visit Testing for hep C (Hepatitis Australia)

www.hepatitisaustralia.com/testing-for-hepatitis-c

STIGMA

Stigma relating to hep C remains an issue for many affected people with bleeding disorders. For John, there is often no good reason to tell other people that he had hep C as a child:

'I cleared it naturally. it's a thing in the past and doesn't affect my day-to-day life anymore.'

However, he is conscious that he has told very few people in his life – only personal relationships and very close family and family friends - because of the stigma. This was influenced greatly by his experiences as a child.



'I was in primary school when it all came out in the news that haemophiliacs had been infected with HIV or hep C through blood products. Obviously, my classmates knew I had haemophilia and there was the stigma of them thinking do I have HIV or hep C. I didn't disclose having hep C at the time to my classmates. It was a bit daunting and I was worried whether I would be treated as an outcast, and by their parents as well. So that wasn't a very pleasant time. I kept it to myself. My parents probably told a few close friends but that was it. It was never spoken about outside that circle. And I thought their friends were a bit stand-offish towards me after that. The stigma is a big thing, even in this day and age.'

LIVER HEALTH CHECKS

Keeping on top of his liver health is something that John takes seriously. There are several factors that contribute to liver health, not just hepatitis C – for example, being overweight or drinking a lot of alcohol or other health conditions. And even those who have cleared hep C will need ongoing liver health monitoring if they have already developed more severe liver scarring like cirrhosis.

John encouraged others to have any tests that are recommended for them individually and to have hep C treatment if they haven't already.

“ Liaise with your treating doctor and see if you need more tests. Because there are treatments now that can cure hep C in a short time if you still have the virus. Treatment has definitely come a long way from the early days.”

“ Keep an eye on your liver. Even though you might have been exposed to hep C 30 or 40 years ago and you might have cleared the virus, it can still have some ramifications later in life - because there are occasions where it can lead to cirrhosis or liver cancer. So it's good to keep an eye on your liver and get any tests that you need, just to make sure there are no long-term consequences.”

For more information visit Living with cirrhosis (Hepatitis Australia)
www.hepatitisaustralia.com/living-with-cirrhosis

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HFNSW-HFACT Trivia Night

online

According to HFA's website, approximately how many Australians have been diagnosed with a bleeding disorder?

- a) 4000 b) 6500 c) 9500 d) 14000

Would you have known the answer to this question?

If you picked b) 6500 you would have been off to a great start in correctly answering the first question in HFACT & HFNSW's inaugural virtual trivia event.

It was held online in the evening of Saturday 10th September and attended by eight teams: six from the ACT and 3 from NSW, with a further three NSW teams keen but unable to join on the night.

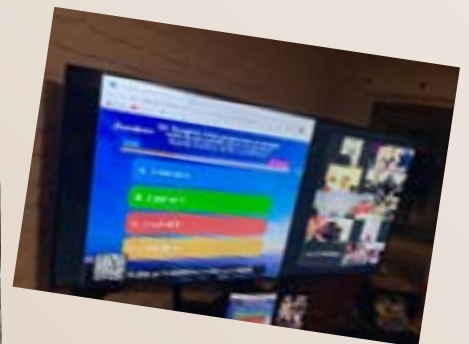
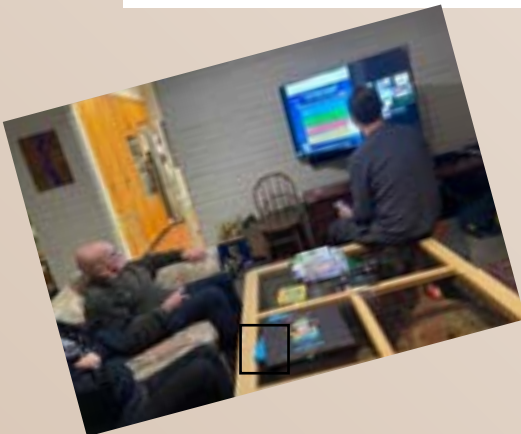
The event was hosted by HFACT's President, Claudio Damiani. It was great to meet people on camera before the trivia started and to hear a little about each other's experiences with haemophilia, and where we were from.

The first round was on bleeding disorders which really tested how much we all knew about some very specific (though certainly not trivial) information and a condition that's in our blood (excuse the pun).

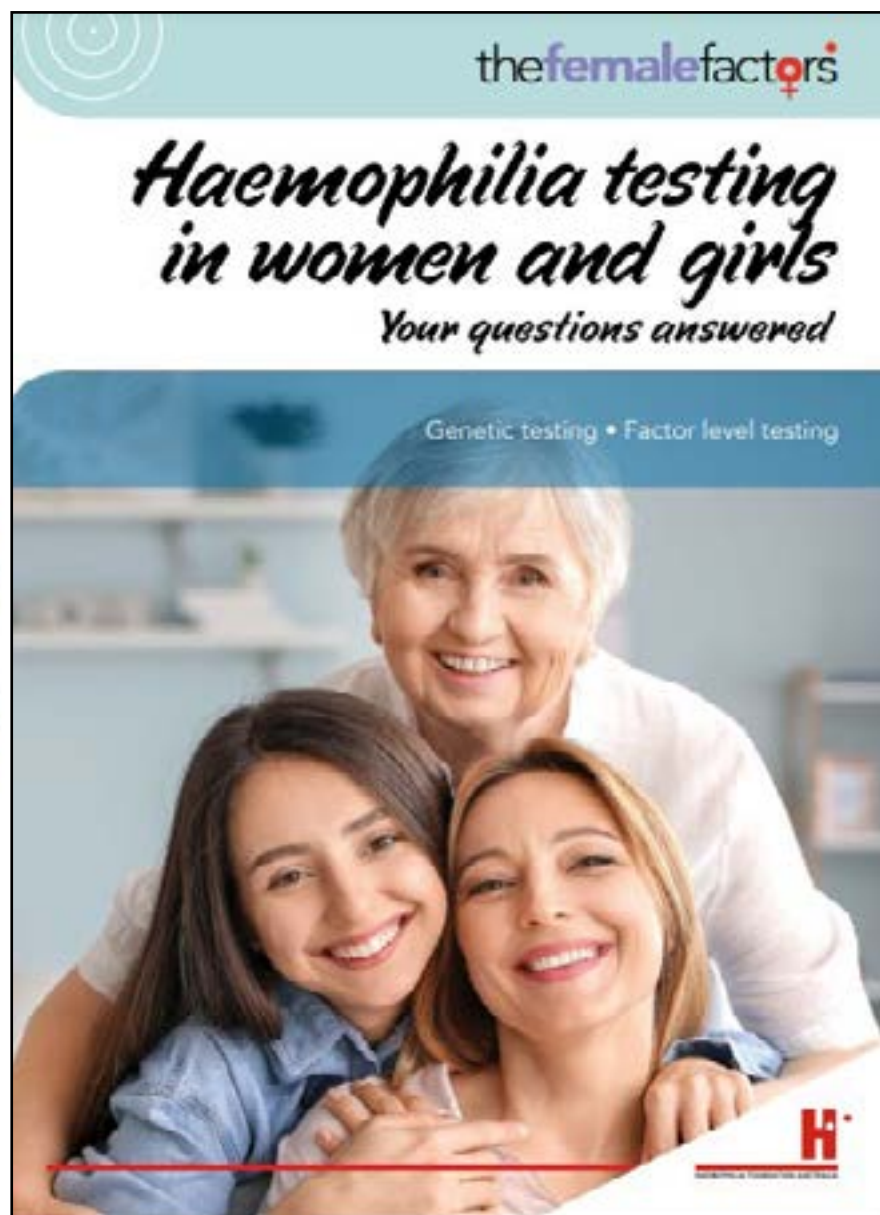
The second round was trivia specific to places in NSW / ACT with an even balance between geographic localities. We now know, for example, that the city that refers to itself as the 'city of good sports' because so many Australian sporting greats grew up there is.... [Mudgee, Lithgow, Goulburn, Wagga Wagga]... yes it is Wagga Wagga. And many Canberrans would know that their city was designed by Walter Burley Griffin, but did they know which other town was NOT designed by Burley Griffin [out of Canberra, Orange, Griffith, Leeton] – if you said Orange, you'd have been correct!

As well as testing our trivia, the night also tested our tech skills and yes, our patience with a few technology teething issues. Thank you to all participants for your good humour.

Congratulations to the winning team which was the Lees family: Jenny, Ron and Kieron. There was a three way tie for second, between Stephanie Devine, the Appleby family and the Damiani family (others in the family, not Claude!).



New HFA Education Resource



Haemophilia Foundation Australia has published a new education resource, Haemophilia testing in women and girls: your questions answered. It's a comprehensive booklet about genetic testing and factor level testing in haemophilia for women, girls and parents of girls.

There are often many questions and things to think about when checking to see if a woman or girl is affected by haemophilia.

- What is involved in genetic and factor level tests?
- Who should have them, and at what stage in their life?
- How is haemophilia passed on in a family – and what if there is no family history?
- And why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the booklet to answer these and other questions in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. It includes infographics, tables and personal stories.

HOW CAN YOU ACCESS THE BOOKLET?

Download the booklet from the HFA website-

<https://tinyurl.com/haemophilia-testing-WG>

You can also download specific sections if you are interested in a particular topic, for example, genetic testing and counselling.

If you would like a print copy, email HFA at hfaust@haemophilia.org.au or call 0398857800 to ask us to post you a copy.

Thanks to everyone who contributed to the development of this resource, and a special mention of Jane, Sharri and Michelle for sharing their personal stories.

We invite you to take a look at the resource and pass it onto anyone you think would find it helpful.

And look out for the short and simple version which is coming soon!

FACTOR FUN DAY



Team haem JHCH

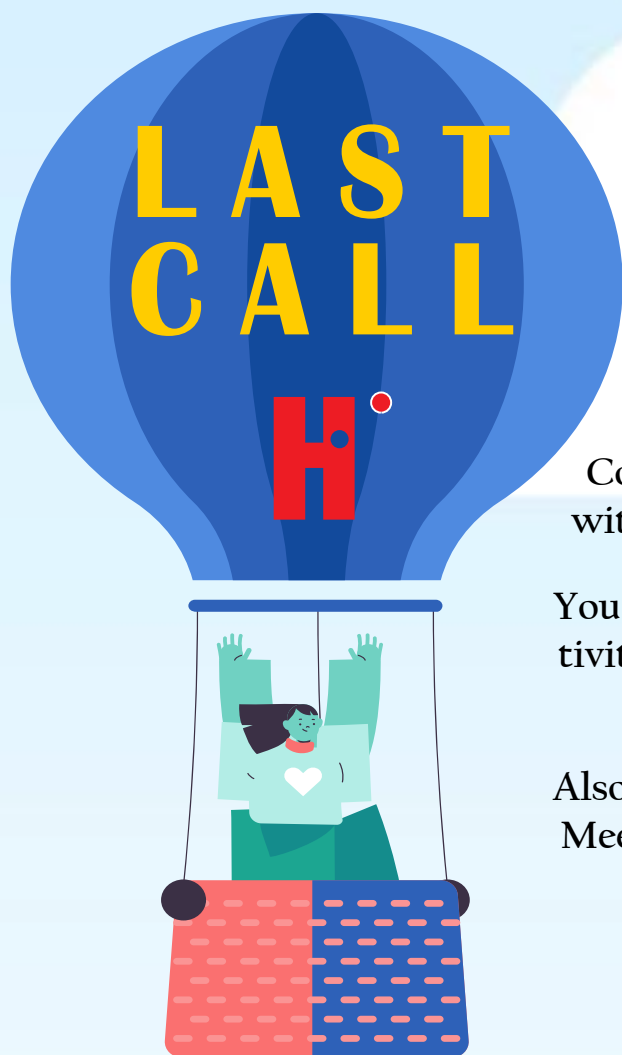
Veronica Oakley (Child Life Therapist), Jaime Chase (Haem CNS), Bianca Da Silva (Haem Physio), Dr Janis Chamberlain (HTC Director), Cathy Morrison (Haem Social work), Dr Emma Prowse (Haem Psychology), Dr Angela Dunford (Adolescent Gynaecology)

In the June /July School Holidays, John Hunter Children's Hospital HTC was thrilled to be able to offer a return to our Factor Fun Day annual experience.

This day is aimed at school aged children to form friendships and continue their education about their bleeding disorder. This day had fun, interactive presentations by our amazing coagulation scientists and hands on experiences of ultrasounds. The children also learnt about emergency situations and how and when to ask for help.

JHCH's Factor Fun days are hotly awaited by the children of the service and it is a fun way to strengthen healthcare alliance with the HTC team.

JHCH HTC is incredibly grateful to HFNSW for the sponsorship of the event - the children loved their show bags and the pizza lunch. The children have requested a Disco dance theme for 2023- so watch this space.



HFNSW Family Camp & AGM 2022

Come along and join us for HFNSW'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, on Saturday 12th November at 5 pm.

When:

Friday 11 November 5pm to

Sunday 13 November 12pm.

Where:

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

Only limited spaces are left! Please RSVP asap! Bookings will be confirmed subject to availability of the rooms.

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.



FAMILY CAMP 2021-22 Application Form

Friday 11 - Sunday 13 November 2022

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 9th October 2022 to:

Email (preferred): coordinator@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>





Bleeding Disorders Awareness Month

OCTOBER 2022

As you may know, this year in October we will have a whole month to raise awareness about bleeding disorders.

The 2022 theme for Bleeding Disorders Awareness Month is **ONE COMMUNITY, MANY FACES**. Each week we have different topics and will meet community members from all ages and stages of life to hear their stories.

ACTIVITIES AND EVENTS – BOTH VIRTUAL AND FACE 2 FACE

We will launch our calendar at the end of September. To be advised about events, register for our E-news www.haemophilia.org.au/enews or keep an eye on our website and social media platforms.

PROMOTIONAL ITEMS

Promotional items orders are now open. Order the free goods to use for your school, workplace or family/friend event. We have balloons, pens, Fling Things (like a frisbee), colouring-in sheets, information posters and lots more.

Put your order in at

www.haemophilia.org.au/BDAMorder



HOW CAN YOU BE PART OF THE WEEK?

- Order promotional items for your event, information stalls and your child's school/child care
- Run a virtual or face-to-face fundraising event
- Host a red cake day
- Share information on your social networks
- Share your story - <https://tinyurl.com/HFA-story>
- Children and their friends can take part in the colouring-in competition or a Scavenger Hunt
- Take part in HFA and Foundation activities (Calendar coming soon)

For more information, contact

Natashia Coco

MB: 0403 538 109

E: ncoco@haemophilia.org.au

How to brush your teeth properly, according to a dentist

Arosha Weerakoon
*Lecturer, General Dentist & PhD Candidate,
The University of Queensland*

Most of us brush our teeth on autopilot. So let's stop and ask: are you doing it properly? For a full two minutes? Do you use the correct type of brush and toothpaste?

Did you know you're supposed to spit, not rinse after brushing?

And brushing soon after eating acidic foods, like citrus, can damage your teeth?



Here, I answer five questions commonly asked at the dentist.

1. Am I brushing correctly?

For starters, make sure you're brushing both teeth and gums at least twice a day.

Brushing removes dental plaque, the grey-white bacterial mass that sticks to the tooth and gum surface. If left undisturbed for at least a day, plaque bacteria multiply and begin to mature.

Mature plaque forms an architecturally complex mass with its own sewerage system.

Plaque feeds on the food we eat, particularly carbohydrates (sweet and savoury) to reinforce and build a complex structure that releases acids and gassy, smelly by-products (plaque sewage).

Mature plaque on your teeth and gum surfaces can lead to cavities (holes in our teeth) and gum disease.

Cavities form in our teeth when the mineral in our enamel and eventually, dentine, dissolves to neutralise plaque acids. Over time, the tooth softens and caves in.

Every time you brush, you stop plaque bacteria from feeding on your food, multiplying and maturing.

Mature plaque mixed with mineral in your saliva forms calculus or tartar.

Calculus can only be removed completely by a dentist or hygienist using special tools.

Not brushing before bed is especially risky; saliva flow reduces and food stuck between your teeth ferments, creating a perfect petri dish for plaque growth. This is where flossing or using tapered interdental cleaners can help.

Tooth Structure



Make sure you clean the teeth at the back of your mouth, and don't rush. The Australian Dental Association recommends brushing for two minutes morning and night.

2. How do I look after my gums and prevent bad breath?

Bad breath can be caused by gum disease.

After two to three weeks of poor brushing, the mature plaque causes the gums to swell, redden and bleed easily.

This is because the gum's blood vessels leak immune fighting cells to try and destroy the plaque.

But the plaque's defence system repels the attack. Everything your body throws at it bounces off and starts to break down the bone that holds your teeth in your head.

This process is known as advanced gum disease or periodontal disease. It happens slowly and painlessly. As the gums recede, teeth appear elongated.

Untreated, your teeth may become painful, loosen and even fall out.

This is why it's important to have a regular dental check-up and to brush and floss frequently.

3. What kind of toothbrush should I use?

The Australian Dental Association recommends using a toothbrush with a small head and soft bristles.

Some of us are magnificent manual tooth brushers, but many would benefit by using an electric toothbrush.

Why? The same reason we ditched the broom for a vacuum cleaner.

It's faster, efficient and does a better job – as long as you hover over the surfaces you need to clean.

Aim for teeth as well as gums.

Electric toothbrushes come with various features to suit different budgets and needs.

For instance, some have an in-built warning signal to prevent you from brushing so hard you abrade (wear away) your teeth and gums.

4. When should I delay brushing?

Generally, wait at least 30 minutes after vomiting or consuming acidic foods and beverages.

If in doubt, check the food label as there are many different acids in our diet.

Acids soften the enamel and dentine like soaking dirty saucepans in the sink.





And if we don't give our saliva enough time to mop up the acids, the softened tooth surface scratches away when we brush.

5. What kind of toothpaste should I use?

Keep it simple. Select a toothpaste that contains fluoride.

Fluoride fills and reinforces the microscopic gaps in our teeth to create an acid-resistant barrier.

It also forms a non-stick surface to prevent plaque from attaching and maturing.

Do spit and not rinse at the end; avoiding rinsing means you get a fluoride treatment each time you brush.

What about whitening toothpastes? Whitening toothpastes can have strong abrasives that wear the tooth surface to cause sensitivity.

Most stain particles in our natural teeth hide in microscopic gaps in enamel.

The most efficient and least destructive way of removing these stains is by using peroxide-based whitening products.

Talk to your dentist about options and be wary of home remedies or gimmicks. And remember,

whitening will not change the colour of dentures, crowns, veneers or fillings.

This year for **Dental Health Week (1-7 August)**, the Australian Dental Association is asking Aussies to love their teeth! Here are five ways you can do this.

1) Take your teeth on a date to the dentist

You may not have been for a little while or it may be time for your regular check-up, take this as your reminder to take your teeth on a date and see your dentist! Your teeth will thank you.

2) Care for your teeth by brushing every day

Show your teeth you care by brushing two times every day. Brush once in the morning and once at night. At night, brushing is best done last thing before bed and no food or drinks to be had after.

3) Spoil your teeth by cleaning between them every day

Cleaning between your teeth helps to remove bacteria and food that build up during the day. Not cleaning these spaces can cause gums to become inflamed and sometimes tooth decay can develop.

4) Treat your teeth to healthy foods and drinks

The World Health Organization recommends adults have 6 or less teaspoons (24 grams) of sugar each day. Sticking to this recommendation can decrease the risk of tooth decay developing. Choose to drink water during the day and if having a sweet treat, do so together with a main meal instead of snacking on the treat between meals.

5) Show your teeth love by using them for their intended purpose

Teeth are made to chew and smile. They are not made for opening bottles, or packets. These habits can increase the risk of breaking or cracking teeth. Love your teeth by only using them for their intended purpose.



The WFH 2022 World Congress was held by the World Federation of Hemophilia in Montreal, Canada on 8-9 May 2022 as a hybrid event, both in person and virtually.

It was an opportunity for the international bleeding disorders community - including people with bleeding disorders, health professionals, national member organisations and industry - to come together to discuss current issues, share knowledge with colleagues, and problem-solve with delegates from diverse backgrounds.

So much has changed recently: radically different haemophilia treatments and the COVID-19 epidemic have impacted enormously on the community. There continue to be great strides ahead in managing women and girls with bleeding disorders and there is new research into VWD and the very rare bleeding disorders.

*In this issue of Factor Matters, we have included a summary of one of the sessions on “Living in the new world of novel haemophilia therapies” provided by Robyn Shoemark, CNC at Westmead Children’s Hospital. You can hear more from some other Australians who attended in person or virtually in the recent issue of HFA’s **National Haemophilia No. 219.***

Living in the new world of novel haemophilia therapies

Robyn Shoemark

Discussion about the impact of novel therapies for haemophilia was a highlight at the WFH Congress. This included non-factor therapies such as emicizumab (Hemlibra®) and fitusiran and gene therapies for haemophilia A and B.

At the time of publication, fitusiran and gene therapy for haemophilia were not registered by the TGA in Australia as prescription medicines.

CLINICIAN PERSPECTIVE

Surgery in an era of novel therapies

Chair ~ BJ Ramsay, Clinical Nurse Specialist, Blood and Cancer Centre, Wellington Regional Hospital, New Zealand

I was fortunate to present in the nursing session on surgery when a patient is being treated with novel therapies, along with Jaime Chase from John Hunter Children's Hospital in Newcastle. In this session nurses from around the world discussed case studies of patients using new treatments and Jaime and I represented Australia with our patient case studies.

It was great to hear about the patients on emicizumab having surgery and the treatment regimens they used. When there is little information or limited use of the new treatments, seeing what someone else has tried can help clinicians make an informed decision when you are planning treatment or surgery for your patient.

Changing treatment, changes diagnosis

Chair ~ Kate Khair, Director of Research, Haemnet, London, UK

What PWH tell us about living in the new paradigm of hemophilia treatment

~ Simon Fletcher, Lead Haemophilia Research Nurse, Oxford Haemophilia And Thrombosis Centre, UK

Non-factor therapy in persons with acquired hemophilia A and von Willebrand disease

~ Ming Lim, Assoc Prof, Division of Hematology and Hematologic Malignancies, University of Utah Health, Salt Lake City, USA

Patient panel:

Life with hemophilia after gene therapy

~ Luke Pembroke, Creative Director, Haemnet, London, UK

Life with hemophilia with fitusiran

~ Louis Marlow, biotechnology researcher, University of Edinburgh, UK

Life with hemophilia on emicizumab

~ Andrew Selvaggi, haemophilia advocate, Haemophilia Foundation Australia, Melbourne, Australia

In the first session, Simon Fletcher presented his view on how changes in treatment have changed the lives of his patients. He was careful to start by saying that he did not have haemophilia and that he is a treater. His role was to undertake and review studies aiming to find out what it means to have haemophilia and then use that information to help patients.

He described current treatments available for patients as aiming to **Replace, Rebalance and Replicate**. He grouped the studies into two categories: one he called **Emi and Me** for patients on emicizumab and the other **Exigency** for patients undergoing/who have undergone gene therapy.

In these studies, people with haemophilia made the following comments about what changes/improvements in treatment meant to them:

Freedom – patients gained freedom and felt they and carers were liberated with new treatment options.

Control – patients and carers being able to plan for the future. In some cases, this was the first time they had ever felt able to plan for the future.

Reduction in pain – many patients were experiencing less bleeds so in turn, less pain.

Reduced burden – newer treatments being quicker and easier to administer allowed more time for life.

Side-effects – for example, in gene therapy known side-effects include needing to take steroids but this is still better than having to do prophylaxis.



Old Montreal

Photo: Shauna Adams

ACQUIRED HAEMOPHILIA

Ming Lim then presented on non-factor therapy in people with acquired haemophilia A.

Acquired haemophilia is a rare autoimmune disease predominantly diagnosed in the elderly, where immunoglobulin (IgG) antibodies, also known as inhibitors, attack factor VIII (8). It presents often with severe bleeding and has a high morbidity and mortality often associated with gastrointestinal bleeds.

Past treatment was to control and prevent bleeding using bypassing agents or recombinant porcine factor VIII. The goal is to control bleeding and eradicate the inhibitor. Therapy includes the use of steroids and/or immunosuppressive therapies.

There have been several reports of off-label use of emicizumab. Ming Lim reported on a review of 24 patients using emicizumab to help control bleeding. Dosing varied from the same as that recommended for people with haemophilia A to a modified version of dosing. The duration of treatment ranged from 20 days to 10 months with 100% of patients reporting no further bleeds after commencing emicizumab. Clinical trials are ongoing.

PATIENT PERSPECTIVE

In the patient panel, three men told us their story of their journey with changing treatment for their haemophilia.

Luke from London spoke to us from the jungle in Peru where he has been for the last month. He underwent gene therapy in February 2020. He now has factor levels around 20-25% and has not needed any factor in the past two years. He has taken emergency factor with him to Peru and the only time he touches it is when he changes out the ice packs to keep it cold.

The presentation made Luke reflect on the last two years and what it has meant for him. As he underwent the treatment one month prior to COVID lockdown in the UK, he not only had a change in his treatment but found himself moving to be close to the hospital so he could reduce his risk for getting COVID and continue his hospital visits as part of the trial he was on. This was difficult for both his physical and mental wellbeing. He felt unwell with the side-effects of the medications he needed to take post gene therapy. He thought his veins would get a rest but with all the blood tests, this was not an option for the first 12 months. Moving on, he now only has visits every 6 months and his veins are finally having a rest.

He talked about how gene therapy has changed his life for the better. He is able to plan things for the future. He felt he was unable to do that prior to gene therapy as he never knew when he might bleed and need to be near the hospital. He no longer thinks about haemophilia every day. Going to Peru has been a road test for his therapy. He does still have ankle pain from previous joint bleeds, but he knows the difference between pain and bleeding and is able to rest, take his pain medication and keep going the next day.

In the Q & A, when asked if he would do it again, he replied absolutely yes. He felt the trial process outlined the risks versus benefits and he had a very good consenting process so he would strongly advocate for trials and collection of long-term data associated with trials. He is very positive and has no regrets but did say he would be very disappointed if the effects wore off and he had to return to having factor again.

Louis from Scotland talked about life with haemophilia on fitusiran. Louis was diagnosed with severe haemophilia B at 18 months and then went on to develop an inhibitor. He was then treated with the bypassing agent NovoSeven® (recombinant factor VIIa). When tolerisation was attempted, he had an anaphylactic reaction. He has undergone radiosynovectomies for his target joints.

In 2019 he joined a trial using fitusiran for his prophylaxis. Other than developing asthma, which is a known possible side-effect of the medication, Louis is very pleased with his new treatment. He has gone from having approximately 9 bleeds per year down to 1 bleed per year. He has been able to increase his activity levels and finds that his bleeds are now injury/trauma related rather than spontaneous. He has gone from regularly needing to use a wheelchair to now the wheelchair is taking up space in the garden shed. He is very happy to be on a new therapy.

Andrew from Australia talked about life with haemophilia on emicizumab. Andrew was diagnosed with severe haemophilia A at 15 months and by the age of 2 years had developed an inhibitor. By 2007 at age 20 years, he had had over 700 joint/muscle bleeds, had developed 7 target joints and was wheelchair bound from 5-18 years of age. He underwent a personal transformation and lost 30kg.

In 2016, he participated in the Haven clinical trial and had his first dose of emicizumab. The life changes for him have been immense. Since starting on the trial, he has not had any muscle or joint bleeds. Since commencing emicizumab

he has undergone orthopaedic surgery again. In past surgeries, it had been difficult, 'full of bleeding' but this time it was controlled with less bleeding.

His described the challenges as both mental and psychosocial and that he needed to reset his expectations after starting the trial. He found he needed to build confidence and start trusting his body, something he had not been able to do pre-trial.

He did mention that while he strives to do his treatment as recommended, sometimes he forgets, likening it to putting out the bins. We all forget regular things sometimes. He is, after all, only human like the rest of us!



CURRENT RESEARCH

Late-breaking Clinical Research

Chair ~ Glenn Pierce, Vice President Medical, World Federation of Hemophilia, USA

A phase 1 sequential pharmacokinetic (PK) evaluation of octocog alfa, ruriocog alfa pegol, and efanesoctocog alfa in severe hemophilia A

~ Annemieke Willemze, Senior Clinical Research Director, Sanofi Genzyme, Amsterdam, Netherlands

I attended the Late Breaking Clinical Research session where Annemieke Willemze discussed the BIVV001 (efanesoctocog alfa) trial results. These are very promising for people with haemophilia A, with a 3-4-fold half-life increase to an average of 43.3 hrs and requiring a weekly treatment injection.

Robyn Shoemark is Clinical Nurse Consultant Haemophilia/Haematology at the Kids Factor Zone, The Children's Hospital at Westmead, Sydney, NSW

Source: This article was published in National Haemophilia No. 219 September 2022, the journal of Haemophilia Foundation Australia, and is reprinted with permission.

Support your Foundation!

HFNSW Membership

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





MEMBERSHIP FORM 2022-2023

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

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Royal Prince Alfred Hospital Haemophilia Treatment Centre

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Phone: (02) 9515 7013

Newcastle - Adult Services Calvary Mater

Haematology Department

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Dale Rodney (Nurse)

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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.

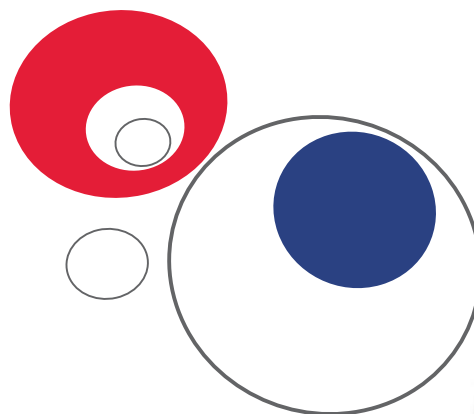
Financial Assistance: HFNSW offers MedicAlert subsidies, shoes rebates, Mental Health Consultation rebates, travel assistance, education & training, grants.

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





Bleeding Disorders Awareness Month

OCTOBER 2022

Your Continued Support Matters!

HFNSW AGM 2022

The HFNSW AGM will be held on Saturday evening, 12th November 2022 at HFNSW's Family Camp. 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 AGM.