

Factor Matters

Haemophilia
Foundation
NSW

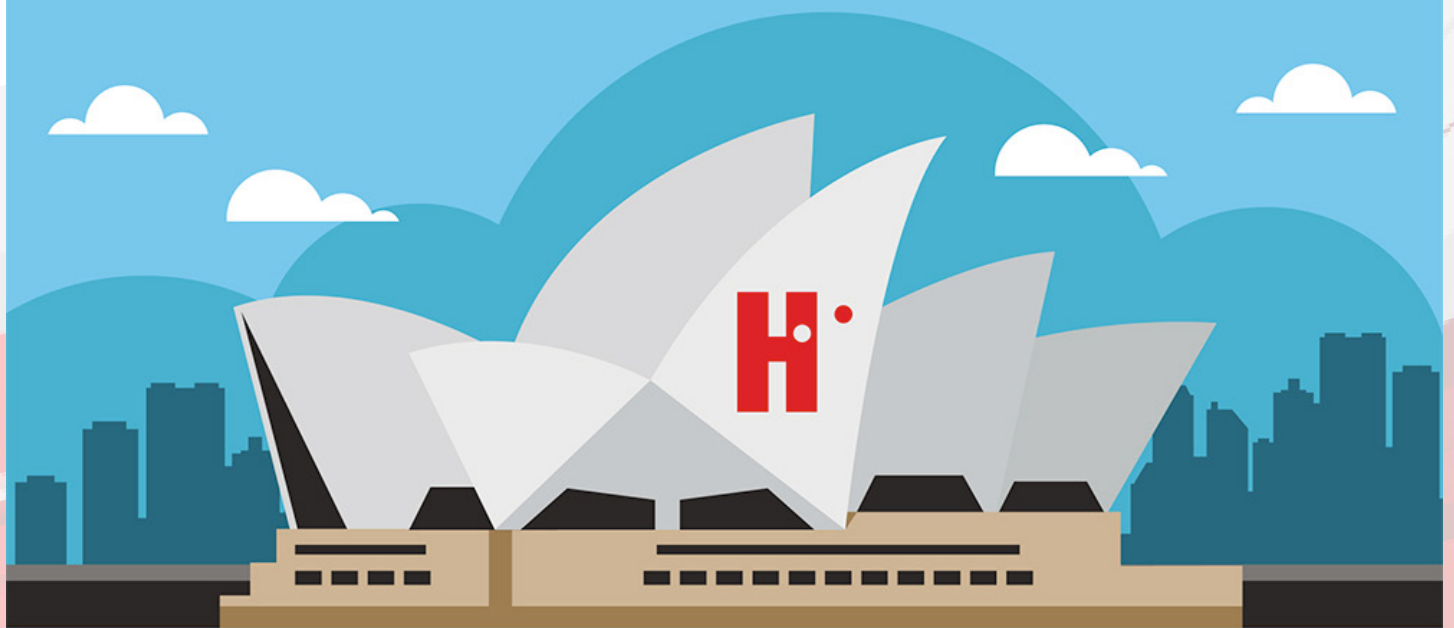


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Winter 2019

Volume 40

19th Australian Conference on haemophilia, VWD & rare bleeding disorders *Challenging the Status Quo*



~ Sydney 10-12 October 2019 ~

HFNSW is offering limited funding to assist members attend

Conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

About Us

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

HFNSW Patron

Prof Kevin Rickard, AM, RFD

HFNSW Committee

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

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Factor Matters, Vol 40: Winter 2019

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On the cover: Conference



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Dan Credazzi – President Haemophilia Foundation New South Wales

Since our last newsletter, more fascinating developments on the treatment front. The NSW Ministry of Health is conducting a review of a sub-cutaneous factor bypass medicine for prophylaxis

with findings due out in early August. Extended half-life (EHLs) factors 8 & 9 are also now on the next National Blood Authority (NBA) purchase cycle. Soon, your clinicians will have access to more options. Something we've been helping to accomplish under the leadership of Sharon & Gavin at HFA.

Whether you choose to remain on your current treatment or try a new one, there are some things that you need to do in order to make the whole system work properly. If you're using the MyABDR app, that's great! But only 1 in 4 people with a bleeding disorder in Australia actually record treatments using the app. This isn't good enough. Your usage data is both clinically valuable and necessary to control waste, stock and expiration. Also, if you're considering trying a new treatment in the near future, having accurate and accessible treatment records are necessary. It's a two-way street.



Having completed our last Foundation Strategic Plan in 2015, your Committee members have drafted up a revision of the 2012-2015 plan. We've had input from NSW Health and the broader NSW haematology clinical community. From this plan, all required Foundation activities are contained in six job descriptions covering our Volunteer Committee, Office Holders, Members, and two part-time Staff.

Our updated vision is:

Connecting and Empowering the NSW bleeding disorders community, their families and carers

These are the five categories of activities under the new plan:

1. Facilitate support for people within the NSW bleeding disorders and BBV (Blood Borne Virus) community, their families and carers.
2. Ensure the financial viability and organizational sustainability of HFNSW Inc with appropriate governance and in line with the Australian Charities and Not-For-Profit Commission & NSW Health requirements.
3. Increase awareness of HFNSW and other programs and services available to the NSW BD & BBV community.
4. Maximize member empowerment and feedback.
5. Develop a sustainable organizational management, network & succession plan.

If you want the best update possible, you should make it to the October Conference in Manly. The latest treatment developments will be on display, the latest science will be revealed. This is truly a once in a generation opportunity. HFNSW can provide assistance towards registration costs (via reimbursement) for members upon application. HFA is also offering financial assistance, visit their website www.haemophilia.org.au for an application.

I look forward to seeing many HFNSW members there.

Thanks to Tony, Sam and Natasha from HFA, for pulling together this latest newsletter.

Dan Credazzi

President, Haemophilia Foundation NSW

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, Sydney, 10-12 October 2019.



Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

PROGRAM

Chaired by Dr Liane Khoo, Director, Royal Prince Alfred Hospital in Sydney, NSW, the program committee is developing a multidisciplinary program which will interest everyone.

Keynote speakers

International expert on pharmacokinetics (PK) and measuring treatment outcomes in haemophilia, Prof Alfonso Iorio from the Department of Health Research Methods at McMaster University in Canada, will be presenting on his work and contributing to the discussion about where treatments are going in Australia. We will also have a plenary session with Dr Tim Sharp, AKA Dr Happy. Dr Sharp is an expert in human behaviour, in what makes people tick; but his focus is mostly on the promotion of positive psychology principles. His passion lies in helping individuals, teams and organisations to really thrive and flourish.

SHOULD I ATTEND?

The Conference is a great opportunity for the bleeding disorders community and people working in the sector to hear the latest information and discuss current and emerging issues together. It is a niche conference, focused on the specific questions relevant to bleeding disorders, and caters for all delegates. We invite the following people to attend:

- People with haemophilia, von Willebrand disease or other bleeding disorders and their families - parents, siblings, partners – all ages welcome from young adults to seniors!
- Health professionals – doctors, nurses, physiotherapists, psychosocial workers and other health care providers
- Treatment product producers, suppliers and service providers

- Policy makers and government officials
- Haemophilia Foundation volunteers and staff.

COMMUNITY FUNDING

HFA has allocated funding to assist people living with a bleeding disorder, relatives/partners or carers to attend the Conference for expenses such as flight, registration, accommodation. Part funding applications are encouraged so we increase access and you will generally be expected to contribute towards your costs. Applications will be assessed on their merit – it is in your interests to provide full responses to the questions on the application form.

HFNSW is also offering limited funding to its members, contact coordinator@hfnsw.org.au for more information.

For an application form visit <https://tinyurl.com/HFA-conf-funding> or call HFA on 1800 807 173.

MORE INFORMATION AND DETAILS

- Visit www.haemophilia.org.au/conferences and download the registration and Information brochure
- Or email hfaust@haemophilia.org.au.

Q&A with Alan and Hamish about their conference experiences

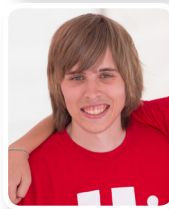
Alan is 22 from NSW and attended the last National Conference in Melbourne 2017

Hamish is 26 and on the HFNSW Committee. He has attended several conferences.



How did you hear about the conference?

Alan: I heard about it from my Mother and from other guys from Youth Lead Connect. I thought it was a good idea to get together and to meet other people with haemophilia, to share our different experiences and raise awareness.



Hamish: I have attended 4 conferences over the years and each time I get so much more out of it. I first heard of conferences from HFA when I was on

their Youth Program.

What did you get out of attending conference?

Alan: I got so much from attending– I met a lot of new people that I didn't even know were in the Sydney, or NSW region, and from other states. It was amazing

to hear about their different experiences and how different people react to having haemophilia and how they live their lives. I really enjoyed the reception where all the youth came and talked about different ideas and conflicting ideas in the community and hearing both sides - health care professionals and youth.

Normally when we hear from health care professionals, it's either getting told what to do or reading an article saying "this should be done", it was really good that we can discuss with them what they were saying.

Hamish: I get so much out of attending a conference – I enjoy meeting new people who I have spoken to online or heard of, and of course seeing old friends face to face. Attending sessions and learning something new and hearing your healthcare professional speak about haemophilia care in a different way.

What was your most memorable Conference moment?

Alan: The biggest one was the first night coming in and being able to sit down with some people I knew and some people I had never met and talk with no boundaries.

Hamish: The youth program is always so great – everyone gets involved, it's really fun and the people you meet are so nice. I enjoy hanging out and being able to talk about anything.

Conference-Why Everyone should go!



Stephanie Devine- mother of Cameron (mild haemophilia), Neurological Physiotherapist and HFNSW committee member

Conferences-I love them. As a Physio, you try and go to any conference you could afford to attend. You'd catch up on all the latest research and catch up with all your colleagues who you'd wanted to stay in touch but life got in the way. Any health professional would tell you, it is how to stay up to date with cutting edge research and current information over one massive weekend/week.

The National Conference is no different - but even better!

It's set up so everyone who's affected by a bleeding disorder - Doctor, researcher, health professional, carrier, person with a bleeding disorder and family members can get together to find out everything about that condition that impacts every aspect of your life.

I attended my first Haemophilia conference in

Christchurch in 2001. There I learnt about being a symptomatic carrier and attended the very few sessions regarding women. Today at conference you'll find women have lots of sessions and a lot of research is being carried out for this previously silent proportion of the haemophilia community.

My son Cameron reluctantly agreed to attend his first conference in Sydney in 2011 at the age of 13.

I think he was keen to have a few days off school and as I explained to him- it's YOUR condition, you need to be up to speed with it and how new research will impact your life. He had done his own prophylaxis since 11 and I felt he needed to take responsibility for what he had to manage for the rest of his life. It's hard as a carrier to pass on responsibility to your son. It's part of feeling responsible for the situation your child finds themselves in. His eyes were opened to seeing how many people spent their lives trying to improve his, met people who had been dealt a worse deal than him, and he caught up with his friends from camp.

I was proud of how he was able to chat with everyone and was made welcome to his 'conference' by everyone there. Yes some of the sessions went over his head but sessions are made so everyone in our community can understand, not just the medical professionals.

We've been to every conference since- World Congress in Melbourne in 2014, Gold Coast in 2015, Melbourne in 2017 and of course the one coming up this year in Manly. The trips away have been OUR time when I get one-on-one time with my only son away from our busy family of 6. World Congress made both of us realise we do truly live in the 'lucky country' with so many of our worldwide haemophilia community lacking access to treatment leading to death, deformity and discrimination. It made us appreciate what we receive at no cost to ourselves.

So this year, we expect to learn lots about every aspect of our condition from carriers, kids and the ageing process. The new treatments- longer half-lives, gene therapy and more!

It's amazing how much treatment for Cameron has changed even in his short 21 years and it's so different from what happened in the past. Can't wait to see what the future brings for us all and conference is where we go to find out! *Look forward to welcoming you to Manly in October.*

Myanmar, formerly known as Burma, is found between Bangladesh, China, Laos & Thailand, with a population of approximately 55 million. In March this year Leonie Demos (HFV President & HFA Council Member) and I represented HFA at a series of meetings in Yangon (formerly known as Rangoon) with the Myanmar Haemophilia Patient Association (MHPA) to discuss the possibility of establishing a World Federation of Hemophilia (WFH) twinning partnership between each of the organisations. We were accompanied by Marie Ann Fernandez who is the WFH Regional Manager for Asia/Western Pacific.

The WFH Twinning Program aims to improve haemophilia care in emerging countries through a formal, two-way partnership between a patient organisation in an emerging country with a more experienced patient organisation. It has operated for more than 20 years and in that time there have been 215 partnerships across 113 countries. HFA had previously twinned with the Thai Patients' Club in Thailand from 2008-2011. WFH also has a program for HTC's to twin to help increase access where haemophilia diagnosis, treatment and care is limited because of economic and other circumstances.

Over the course of 5 Days, Leonie and I were introduced to the Council of driven young men and women who are working hard to improve the situation of those living with haemophilia in Myanmar. We also met with doctors at the hospital which has recently opened a haemophilia centre. We learned more about the difficulties for people living with haemophilia in Myanmar. Their only access to clotting factor is through the WFH Humanitarian Aid Program. Many of the young men cannot work because of their bleeds.

These challenges aside, the MHPA is working hard on behalf of those with haemophilia in order to provide improved access to information, treatment, hydrotherapy and opportunities. The doctors have also developed their expertise through participation in training programs where they could visit HTC's in the UK and learn more about diagnosis, treatment and care.

During our discussions we talked about how the Myanmar group and HFA volunteers might work together to strengthen their advocacy skills so they can represent their needs to other organisations and the government in order to continue to improve the situation for people with haemophilia.

As with any organisation, including our own HFNSW, it's all about having a strong governance structure

and leaders, and Myanmar has some very smart driven young leaders, who are looking to do more to help their community.

This is just a short snapshot of my recent trip to Myanmar, so please watch this space as the journey continues. The next step is for the two groups to apply to HFA to be formally recognised as twinning partners.

But this is also a small reminder to the community out there reading this to be involved whenever possible, because without your involvement, your foundation doesn't know how to help you. Be involved because you are not alone, there might not be a lot of us, but we all share a lot of the same experiences and can help each other and continue to improve the situation locally within Australia and globally.



World Hepatitis Day is marked globally on 28 July. The World Hepatitis Alliance has committed to eliminating viral hepatitis by 2030.

Imagine a future without hepatitis C. Can we achieve this in the Australian bleeding disorders community?

HAVE YOU BEEN CURED?

The new hepatitis C treatments can cure nearly everyone and have few, if any, side-effects.

Haemophilia Treatment Centres are currently collecting data to check which of their patients have been cured of their hep C and their current liver health. You can help this work by making sure your HTC has your results for:

- your hepatitis C treatment
- your most recent fibroscan.

Ask your hepatitis clinic if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need to have liver health checks regularly.

Many people with bleeding disorders have been treated and cured but some might not even know they have hep C.

You could be at risk

- If you ever had a blood product for treatment before 1993 – even as a baby
- If you shared equipment that allows blood from an infected person to enter your bloodstream. Wondering about this? Take the Hep C Risk Quiz - www.worldhepatitisday.org.au/quiz
- Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to be tested - and have treatment to be cured, if you do have hep C!

FOR MORE INFORMATION

Visit

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page - <https://tinyurl.com/HFAWHD19>

FUTURE PROOFING

Preetha Jayaram



I took up the position of Project Officer at HFA in February 2019 and, as a first step in the project, have been looking into the needs of people with bleeding disorders in the future. This has involved consulting with community

members, state and territory foundations, medical specialists, haemophilia nurses, psychosocial workers and physiotherapists to explore current issues and how to 'future proof' as people grow older.

Getting Older is a priority project of HFA. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they are getting older and help find appropriate solutions for them and their partner/family or friends/carers.

In the second stage of the project we will look at some solutions to enable people in the bleeding disorders community and their partner/family to manage their health and wellbeing into the future as they grow older. These will be taken from the recommendations

in the needs assessment. To reach the community in this digital age, this will include online options for community members to inform themselves and connect with each other. This may involve, for example, expert information about exercise with arthritis or travelling as you get older. It will be important to give a voice to men and women – both people with bleeding disorders and partners/family or carers - so that they can share thoughts about what is needed and the strategies and services they have found useful. It may also involve strengthening current peer support groups.

I am looking forward to speaking with bleeding disorders community members and their partners/family around Australia to hear the issues they see around 'future proofing' their lives.

STAY POSTED FOR THE COMMUNITY SURVEY!

If you are interested in sharing your thoughts about 'future proofing' and getting older with a bleeding disorder, please contact Preetha Jayaram at HFA to talk about your availability.

Partners/family also welcome.

Phone: (03) 9885 7800 •

Email: PJayaram@haemophilia.org.au

The real-world PROBE study is now available!

What is the impact of haemophilia and treatment on Australians? How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

The **PROBE (Patient Reported Outcomes Burdens and Experiences) study** is a great opportunity for you and others in our community to give this evidence.

What is PROBE?

Australia has joined 60 other countries in the PROBE study (www.probestudy.org). This is a multi-national research study which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

You may have done the PROBE survey in past years. This was testing the survey.

In 2019 the PROBE study is collecting real-world evidence – statistics we can use in our advocacy and planning for the future.

How can you help?

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia** and:

- Have haemophilia or carry the gene
- OR
- Do NOT have a bleeding disorder.

You may also like to pass the survey on to your partner/ wife/husband or other members of your family or interested friends.

For good quality results we currently need about:

- 100 more people with haemophilia
- And 200 people without a bleeding disorder (to be a comparison group)

So, the more people who complete the survey, the better!

How to do the survey

The questionnaire is available:

- Online at <https://plus.mcmaster.ca/PROBE/>
- Or ask your local Foundation or HFA for a print survey pack

What happens to your data?

All responses are anonymous and confidential. They are combined as statistics and will not identify individuals. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

And our thanks to the many people who have already completed the survey. We are off to a great start!

More information

For more information about the PROBE study in Australia, visit

www.haemophilia.org.au/research

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173



HAPPY 70TH VANITA

Vanita has Von Willibrand's disease and celebrated her 70th birthday this month. She wanted to celebrate her milestone at the Royal Prince Alfred with the Haemophilia Treatment Centre (HTC) as she says that without RPA and the support from everyone here, she would not have been able to make it this far. We wish her a very Happy Birthday and many happy returns.



(L-R) Nobby Alcala (General Manager of RPA Hospital), Vanita Khakhar, Stephen Matthews, Dr Liane Khoo and Dr Teresa Anderson (Chief Executive of Sydney Local Health District).

MEET THE RPA TEAM

RPA has a long history of supporting patients, being Australia's first major Haemophilia Treatment Centre.

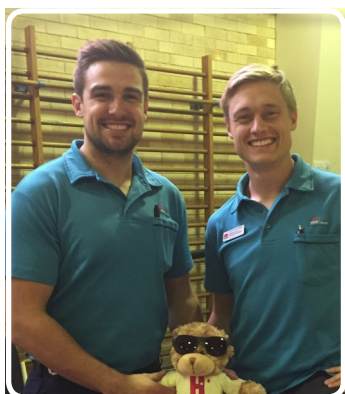


HTC Director - Dr Liane Khoo

Dr Khoo is RPA haematologist and Centre Director. She is very passionate about caring and advocating for patients with bleeding disorders. Dr Khoo is the Program Chair for the upcoming National

Conference in Sydney.

Crazy things she does at work: Likes to play practical jokes, especially on Head of Department



Physio's - Josh W (L) and Josh H (R)

Josh W is the Senior Rheumatology Physiotherapist. His interests include working with patients who want to participate in sport or return to sport after a bleed or injury and getting people moving in the hydrotherapy pool.

Secret talent: bass and guitar player, played in live rock bands since 15 years old

Josh H is a physiotherapist working in the Rheumatology department. He is involved in a research project with Josh W looking at the effect of hydrotherapy on the quality of life and function in people living with bleeding disorders.

Favourite food: Lamb roast with baked vegetables and gravy



Social Worker - Nicoletta

Nicoletta commenced working in the role of senior Haemophilia social worker in April this year. She is passionate about ensuring the people she works with feel supported, both in a practical sense (linking them in with

specific services they may need) and in an emotional sense (providing a safe space to talk and counselling).

Favourite food: Chicken Schnitzel



Nurse - Stephen Matthews

Stephen is the Haemophilia Clinical Nurse Consultant and has worked in haemophilia for over 15 years.

Favourite Marvel Character : Groot (I am Steve...)



Senior Dental Officers - Dr Claire (R) and Dr Emily (L)

Dr Emily Chow

Dr Emily has worked for 10 years in the dental department. She is passionate about managing patients with special needs or are medically compromised and enjoys being at work with her small team over at IRO.

Enjoys: loves hiking, spending time with her young children and "Marvel" adventures.

Dr Claire Scott

Dr Claire has been taking care of patients with haemophilia and bleeding disorders for 18 years. She has a special interest in hospital based Special Needs Dentistry.

Secret talent – mum to 3 little boys



Head Scientist (Coagulation laboratory) - Geoffrey Kershaw

Geoffrey and his team do all the testing for haemophilia and other bleeding disorders at RPA. He is a mentor

in the scientific community to young scientists and to haematology registrars. He is currently working on improving the testing of the new haemophilia treatment products in Australian laboratories.

Best attribute: Loves puns and dad jokes



Haematologist - Dr Scott Dunkley

Dr Dunkley is a haematologist with a keen interest in bleeding disorders and is the former chair of the Australian Haemophilia Centre Director's Organisation.

Something that people don't know about you: Loves to garden ; which has proven to be hazardous



Rheumatologist - Dr Robert Russo

Dr Russo was previously a physiotherapist, but now works as a rheumatologist and is head of nuclear medicine at Concord Hospital. Rob is a strong advocate and a leader in the use of

ultrasound in patients with inherited bleeding disorders in Australia.

Secret talent: Can recite the NRL grand final winners back to 1979 and can recite soccer world cup winners since 1934



Head of Rheumatology - Dr Bethan Richards

Dr Richards is the head of Rheumatology at Royal Prince Alfred Hospital, Deputy Director of the institute for Musculoskeletal Health and the first

Chief Medical Wellness officer in Australia.

Secret talent: ability to clear a room if I start singing. Also very good at making up the words to songs as I can never remember them.

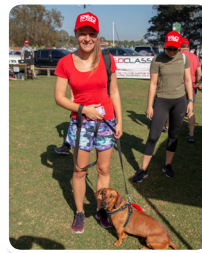
The Red Classic was a fun and free event hosted in Sydney on Sunday 7 April 2019 – it was a chance for people to walk, ride, scoot, or run the 4.5km around the bay surrounding Leichhardt to show support for the bleeding disorders community.

Thank you to all the HFNSW members that came out on the day. It was a great opportunity to meet others and wonderful for our committee to meet some new faces. The games and activities afterwards proved to be a hit with young and old.

Thank you to Sanofi Genzyme for sponsoring the event and to all those who attended.

REDCLASSIC

Leichhardt Oval #3, NSW • Sunday 7 April 2019
Supported by Bioverativ Australia



NEWS, EVENTS AND DATES FOR YOUR DIARY

19th Australian Conference on haemophilia, VWD & rare bleeding disorders

Novotel Manly, Sydney
10-12 October 2019

www.haemophilia.org.au/conferences

Bleeding Disorders Awareness Week - 13-19 October 2019

www.haemophilia.org.au/bdaw

HFNSW Camp - 8-10 November 2019

www.hfnsw.org.au

Details and booking form included in this newsletter

Remember you can check the news and dates on our website www.hfnsw.org.au

www.hfnsw.org.au



Is HFNSW meeting your needs? We would love to hear from you, feel free to email us on coordinator@hfnsw.org.au. We are looking at the 2020 calendar and trying to meet all the needs of our vast community. Are you interested in:

- Young mums group
- Men's Group
- Women's Group (for parents, carers and womens with bleeding disorders)
- Youth group
- Family catch up's

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

Lauren Fehlberg (Social Worker)

Lauren.Fehlberg@health.nsw.gov.au

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Grainne Dunne (Nurse)

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Nicoletta Crollini (Social Worker)

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Waratah, NSW 2298

General: (02) 4921 1211

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

Simon Cavaliere (Social Worker)

simon.cavaliere@hnehealth.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

HFNSW Annual Family Camp: free of charge for people with bleeding disorders and their families

Newsletter: Your newsletters from HFNSW and HFA offer information and details of events, personal stories, education, treatment information, etc.

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

Information and Support:

-Education and assistance to members with bleeding disorders and those who also have HIV

-Provide tutors and entertainment to members who might require extended hospitalisation

-Information and social activities for members and their families

-Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

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

Committee meetings held monthly

HFNSW Committee Group



Craig Haran,
HFNSW Committee Member

