Factor Matters

Haemophilia Foundation NSW

Published by HFNSW Spring 2018 Volume 37

Haem B Gene Therapy Trial, Successful Results Announced

Camp 2017

'Newly Diagnosed' resources launched, ANZ Conference, Melb. – some highlights, MyABDR update, HepC Treatment, Youth Canoe Adventure, RED CLASSIC *& MORE...*

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About Us

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

HFNSW Patron

Prof Kevin Rickard AM RFD

HFNSW Committee

Dan Credazzi - President
Dr Garry Lynch - Vice-president
Paul Bedbrook - Treasurer
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 37: Spring 2018

Editor in Chief: Tony Wilkinson
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In This Issue

On the cover: Making International News.
Successful Haem B Trial Results Announced.

HFNSW's Family Camp 2017 Join us in 2018?
Details inside.

SLHD Chief Executive Dr Teresa Anderson AM with Dan as Haem B gene therapy trial results announced'

Part funded by New South Wales Health through SLHD

A Word From The President...

Dan Credazzi – President Haemophilia Foundation New South Wales

Our Foundation's 59 year history is punctuated by some significant milestones in treatment. At our last AGM, Prof John Rasco presented the fantastic results with a Haem B gene therapy trial right here in Australia. There's plenty of news about longer acting factors as well. These are exciting, but not right around the corner. Good things take time. Discuss with your HTC team.

Another milestone on the horizon is the revelation that there are potentially unidentified females with bleeding disorders in the broader community. On this front, it's wonderful to see our HTC teams and members from NSW contributing to the support material developed and recently released by HFA for that subset of our community. Thank you for your priceless personal stories.

Following on from our Canberra trip, (last edition FM), while we haven't yet achieved universal roll-out of new longer acting factors, we have been advised of expansion of trials in the larger states. Check out the latest news at the National Blood Authority's website.

And some advice if you are thinking about pursuing a trial, I've heard from reliable sources that record keeping is very important with trials and expensive new therapies, so that's incentive enough to keep up with your MyABDR recording; it can only help. While headlines are compelling, nothing replaces mastering your own current care plan.

More recently, we've been busy up-dating the HFNSW constitution and aligning ourselves with recent ACNC and NSW Fair Trading requirements (as an organisation 'advancing health') making all better fit-for-purpose. This new constitution was ratified by a unanimous vote of members present at our EGM on the 27th of March. One interesting modernisation is that we have dropped the 'of' in our name and are now 'Haemophilia Foundation NSW'. Thanks to all those who supported this year long process, particularly our Project Leader, current Treasurer and former Foundation President, Paul Bedbrook.

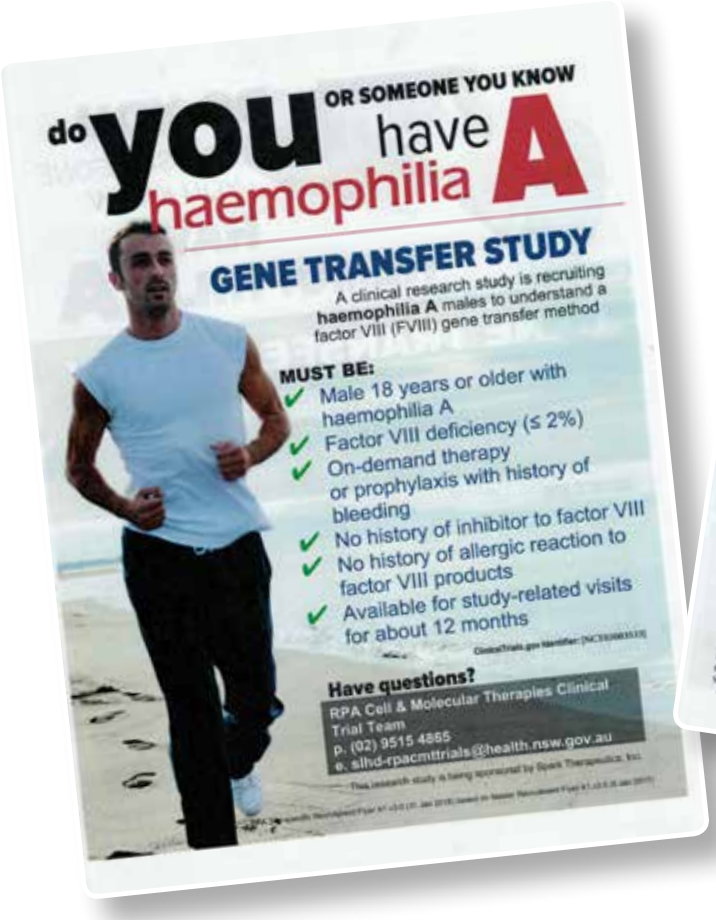
At this significant milestone in our history, our special thanks go to Lyn Bearlin at NSW Health for her steady guidance and sound advice over many years, and to Professor Kevin Rickard for his knowledge and generosity as our Foundation Patron for many decades.

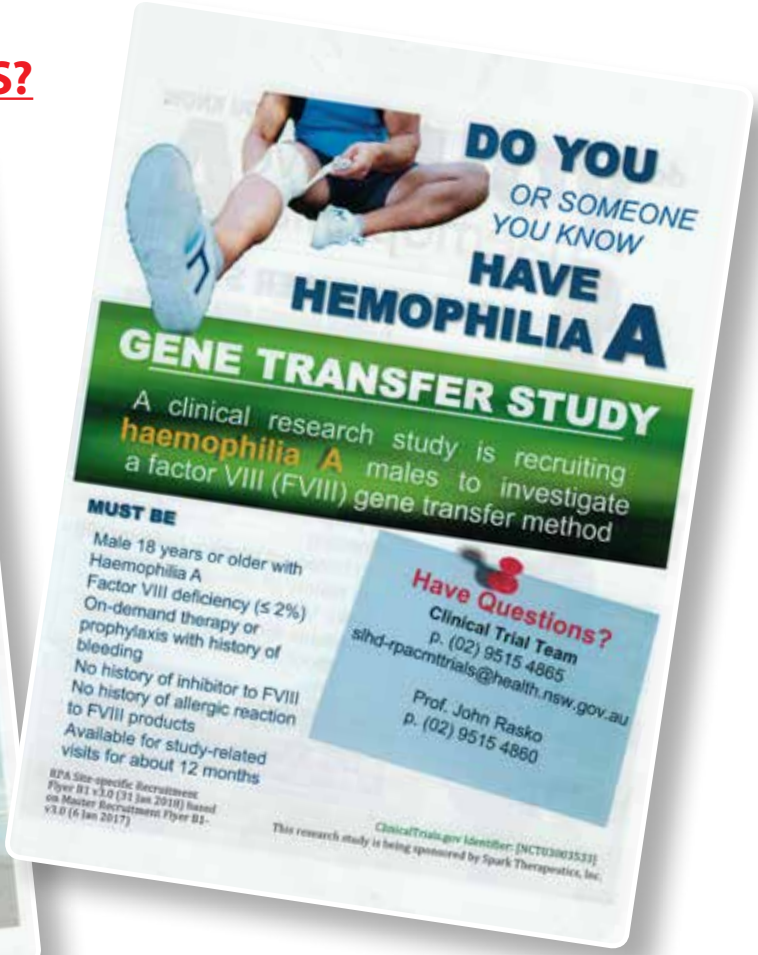
Lyn Bearlin NGO Director with Sam Linnenbank, SLHD EquityFest 2018

Dan Credazzi

President Haemophilia Foundation New South Wales

HAVE YOU SEEN THESE POSTERS?

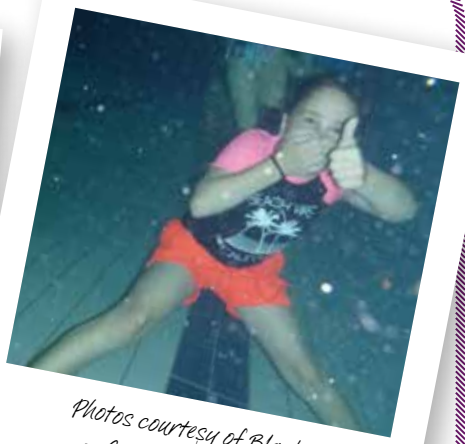




There is now a global haemophilia A Trial, targeting adults – further details above and from the Clinical Trial Team.

HFNSW suggests contacting your Haemophilia Treatment Centre (HTC) first, if interested. HTC staff are not only familiar with these and other developments, they have direct clinical knowledge of your condition and personal situation.

President's Report



Photos courtesy of Blayke – Camp Photographer.

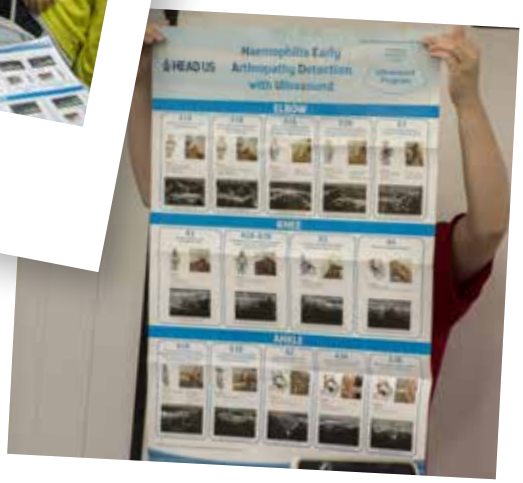
HFNSW Family Camp

2017

Dan welcomes Alvin Hooi & family

Join us in 2018
November 9, 10, 11

Applications, page 13



Thank you Sam,
our pool session supervisor

Thank you Blayke - Great photos!

Hep C Treatment – A Personal Experience*

Preparing this presentation began with me wondering what it was that I could bring to the Conference regarding my experience with hep C and its treatment. I mean, a guy in his mid-40s takes a pill with no side-effects for three months and is cured of a disease without any residual issues is hardly compelling listening. In conversation with Suzanne from HFA though, my jaw dropped when she told me that some people had not taken up treatment. I couldn't believe that anyone would refuse the opportunity to finally rid themselves of that bomb ticking away inside them.

So I thought, well then, this is going to be about me giving reasons and experiences that you can relate to patients you encounter. Patients that may have reasons for avoiding or delaying taking up this quite amazing treatment. So I thought I'd imagine what those could be.

1. For those who are perhaps suspicious

As I, or I should say my mother and I, were in the early 80s when all of a sudden treatment became dangerous. It was about 1984, a year or so after I had already contracted hep C from blood products taken for a couple of tooth extractions. Never mind the opportunity to contract HIV had probably already come and gone, the fact was that trust in treatment had evaporated.

So what to do? As a mild haemophiliac I had the option, for the most part, of just waiting out the slow healing of my joint trauma injuries. And my mum, keen to find some way to ease the pain and bleeding from injuries to my joints looked into alternative medicines. Safe medicines, and as it turned out quite useless ones.

I recall lying on my couch strapping cotton wool soaked in arnica to my knee, or ankle, or elbow – tinctures – for years of unnecessary pain and lost days suffered. It still makes me very angry to think someone, an adult, advised a haemophiliac child and their mother to undertake such nonsense.

So for those who are suspicious, I've tried things that don't work too, and I also had good reasons. This treatment we are talking about isn't that.

2. For those who have already lost time

I avoided any form of treatment for hep C following my ultimately unsuccessful interferon treatment in my early 20s. I had cleared the virus after the 6-month treatment. It was quite heartbreaking to discover it had returned in the 6th month following the end of treatment, and contributed to a period where I lost about a year of my studies – or of much of anything really – to that vague funk that accompanies interferon treatment, along with the distress of the unsuccessful aftermath that I had found hard to take and the source of quite crippling anxiety.

Any description of the treatments I've been offered over the years since involved lengthy commitments of up to 12 months, the possibility of side effects and unsatisfying cure rates, particularly for my genotype. I had already lost time and was not keen to lose more, to give up time that could be spent on my post-grad studies, or later the projects I was working on such as Federation Square, later the time for my business I was building: it just didn't seem worth it. I was yet to have a result from biopsy or ultrasound that showed the disease was doing any damage, so I waited. **And I am now glad I did for the total time lost to this treatment, the one that worked, would be three trips to the pharmacy and two to the hepatitis clinic.**

3. For those who are avoiding it

That said, waiting was not so easy. It's a time spent wondering why I couldn't feel comfortable to tell people that I have this disease, and that's why I hide my toothbrushes away from accidental use by others. The awkward explanations to new partners, when you aren't exactly sure how much risk you are asking them to take. The mornings after too many drinks the night before when you wonder if this really was the time that you'd done it to yourself, that the next fibroscan would come with bad news.

And so, like most people faced with the fear of bad news, I tried avoiding it, missing scans and not chasing referrals, hoping my fears away. Finding out that I no longer have anything to avoid, no longer need to worry about some future where my luck runs out really was such a release.

4. The last reason I'll give is not really a specific argument against why a person might refuse to take treatment. It's really just to say that the moment when the specialist looked at my results and turned casually saying, yep, you're cured – there was a tone he had like there was never any possibility – that was one of the most incredible moments of my life. **Thirty-three years of carrying this disease with all the strange sense of shame, worry and wondering what might happen into the future evaporated like it never happened. And that's a feeling you really do want.**

On reflection it's the lack of drama in this story that's the real point. After so many years the end was so easy and ordinary.

**Simon presented at the 2017 Conference - this written version 1st appeared in HFA's National Haemophilia, (No 200, Dec 2017, p.14-15).*

A PSYCHOSOCIAL PERSPECTIVE

Jane Portnoy, Haemophilia Social Worker, The Alfred Hospital, Melbourne, reports on Youth Myth Busting, session chaired by Dr Moana Harlen, Snr Psychologist, QLD HTC.

Youth Myth Busting was the most exciting session that I attended. I really enjoyed the energy and involvement from the audience.

The session involved three teams: a youth team, an adult team, and a health professional team. There were a series of 'myths' and the question was posed whether each myth was true or false. The audience voted, true or false, and then the teams were given a chance to answer and support their response. Finally the audience was asked if they had changed their views. There was a chance for comments and more questions, and we were really lucky to hear from so many members of the community about their own experience.

We were lulled into a sense of false security with a couple of easy 'myths' where there was a general consensus; these included 'prophylaxis means that there are no more bleeding problems' and 'tattoos are perfectly safe for people with bleeding disorders'. However, the myths became more controversial, and there was a broad range of different views. The answers were rarely straightforward. Yes … but, or No … maybe, or perhaps! Or … but if you put it that way … seemed to be very common.

The most interesting thing for me was the stories that were told to support or to demonstrate a particular point. Talking about telling your boss about your bleeding disorder was one area where there were many examples on both sides. Generally it seems that being proactive and taking responsibility for yourself was a really positive and successful way of approaching this area. However, we did hear of one young woman who was fired after she informed her manager of her haemophilia. She went to the union and was supported to approach her employer. She got her job back and the offending manager was dismissed.

Another interesting debate was 'it is inappropriate to discuss sex and bleeds with your treating team'. Of course, this seemed obvious to me, but then one of the young people said it was really uncomfortable as he had known his treating team his whole life, and it felt a bit like talking to your auntie about sex … YUK! It seems that whilst the professionals are in agreement that it is appropriate and reasonable to talk sex and bleeds, usually they don't bring these things up. So it's left to the patients. One of the great strategies we heard about was the session at the 'blood brothers camp' where anonymous questions are able to be put to either one of the haematologists or the nurses. Usually a great conversation follows; of course everyone wants to know about the same things.

Thanks to Hannah, who worked hard to put this session together before she left HFA for a new job.

Congratulations to HFNSW Members Sam (middle of upper pic) and Heidi Linnenbank (right of lower pic) experienced discussion leaders on this lively panel.

From the National Blood Authority and HFA MyABDR teams

MYABDR TIPS

Some people are coming back to using MyABDR after being on a clinical trial or starting to use MyABDR for the first time. What tips do regular MyABDR users have for new users? Michael, a MyABDR user from South Australia, had this to offer:

My favourite features are:

- 4-digit pin access code for log in
- Easy-to-track stock levels
- Simple user interface for recording bleeds

My tips for new users or people coming back to it are:

- Get into the habit of bringing your device with you when injecting so it's right there and you don't forget.
- Put the app on your device's front screen so it's always in sight. Even subconsciously you will see it and this helps to remind you to use it.

UPCOMING ENHANCEMENTS

The NBA will soon be implementing new security enhancements to improve the security of MyABDR system. The changes will include:

- extending the mandatory password character length from 9 to 10 in line with government security standards
- the requirement for users to update their password regularly

More information will be emailed to MyABDR users ahead of the changes.

You will be pleased to hear that – with a lot of work behind the scenes to assess the current change requests – other improvements are also planned for MyABDR over the next 18 months.

The NBA has compiled a list of change requests and new functionality/enhancements and will commence a project to update the MyABDR system in latter half of 2018 and 2019.

Stay tuned for more details!

HFNSW Bear first to check the latest hot Tips on MyABDR

ANY QUESTIONS OR NEED HELP?

Don't forget that the MyABDR Support team is always happy to help you with any problems, and can make a time to get back to you if that suits you.

They are available 24 hrs, 7 days a week.

T: 13 000 BLOOD / 13 000 25663

E: support@blood.gov.au.

Alvin Hooi, NSW Data Manger leads a well attended MyABDR info session, Family Camp Nov 2017

Launch of the 'Newly Diagnosed' Folder

It's out with the old and in with the new!with the new!

The folder was launched on 26th October 2017 at the colourful Kidz Factor Zone, The Children's Hospital at Westmead, Sydney by Suzanne O'Callaghan Policy Research & Education Manager and HFA's Executive Director Sharon Caris.

Suzanne O'Callaghan, Sharon Caris join Dr Julie Curtin

Dr Julie Curtin, the Haemophilia Treatment Centre Director, was one of the expert reviewers of the folder and presented it to a group of parents and health professionals at the launch.

Westmead Team including Dr Julie Curtin, Ady Woods CN S2, Jo Newsom Snr Physio, et al.

The Guide explains haemophilia and how it is managed in plain language for parents who are new to haemophilia, with diagrams and personal stories, tips and photos from other Australian parents. It also includes two quick reference cards:

'An emergency checklist for when a parent suspects a bleed'

'Information on how to recognise a bleeding episode in a small child'

The folder will be distributed to parents and caregivers through Haemophilia Treatment Centres and is also available for downloading from the HFA website-

www.haemophilia.org.au/newly-diagnosed.

Even critics are engrossed!

Just Post-It... News, Events & Dates for your Diary

Youth Canoe Adventure,
see back cover plus insert,
applications closing,
extended to end of August

Go for It! grants,
see below,
closing end of August

REDCLASSIC run,
see p. 4 plus insert,
Sunday 7th October
A National event, hosted in Sydney,
launching Bleeding Disorders
Awareness Week in Australia

HFNSW AGM,
venue & date agreed,
St Barnabas', Ultimo,
Thursday
11th October, 6pm

** Remember you can check the latest 'News', 'Dates', information and much more, any time, just visit our website* ***www.hfnsw.org.au*** *or HFA* ***www.haemophilia.org.au***

HFNSW members have successfully applied for 'Go for It!' grants over the last few years.

HFNSW staff are familiar with the guidelines and available if you would like to talk through an idea. Act or pickup the phone soon though – they need to be in by end of August.

Have you ever wanted to be daring and take on a challenge?

Or do something that's a bit scary?

Or try something new?

Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you GO FOR IT!

The Haemophilia Foundation Australia's Go for it Grants program assists people living with bleeding disorders take the first step towards achieving their goals.

WHO CAN APPLY?

The grants are open to anyone who has, or is affected by, a bleeding disorder.

There are 2 x $2,500 Go for it Grants on offer to provide winners with the financial support to help pursue their dreams.

What do you want to try? From study to advance your career, increasing your confidence and leadership skills with a public speaking course, or training to be the next sports star - the Go for it Grants can take you one step closer to realising your dream.

2018 Camp Application Form

Haemophilia Foundation New South Wales Inc.

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

FAMILY CAMP 2018 Application Form

9, 10, 11 NOVEMBER 2018

Sydney Academy of Sport & Recreation, Narrabeen, NSW

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 & CHILDREN 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 to:
Email (preferred): admin@hfnsw.org.au *OR* Mail: HFNSW, PO Box 631, Broadway NSW 2007
PS: Don't forget visitors welcome Saturday and Sunday up to & including lunch – just let us know.

Haemophilia Foundation New South Wales Inc., Room 1, Suite 5 88 Mountain St, Broadway NSW 2007
P O Box 631 Broadway NSW 2007
Phone: 02 9280 2607 Web: www.hfnsw.org.au Email: admin@hfnsw.org.au

Membership Renewal

Haemophilia Foundation New South Wales Inc.

ABN: 60245470729
Patron: Prof. Kevin A. Rickard AM RFD

2018-19

Personal Details

Mr/Mrs/Ms/Other:_____ Name:_____(Required)

(Members details below only required if changed...)

Mailing Address:_____

_____Postcode:_____

Ph: (H)_____ (Mobile)_____

Email: _____

Family Details (if completing this as a parent/carer indicate with * for person with bleeding disorder)

Mothers Name: _____ Fathers Name:_____

Child's Name: _____DOB: _____ BD: ☐

Child's Name: _____DOB: _____ BD: ☐

Treatment Centre attended:_____

_____

TAX INVOICE ABN: 60 245 470 729

ANNUAL MEMBERSHIP RENEWAL $20 PER APPLICATION (INCLUDES GST) SINGLE OR FAMILY MEMBERSHIP

Membership Renewal $20.00 (Inc. GST)	$_____
Donation*	$_____
TOTAL	$_____

*All donations to Haemophilia Foundation NSW are tax deductible.

Payment details

- Please make cheques/money orders payable to: **Haemophilia Foundation NSW Inc.**
  Mail to: **HFNSW,**
  PO Box 631,
  Broadway NSW 2007

- EFT payment to: **Commonwealth Bank**
  BSB: Account number: **062 204 00902590**
  Account Name: **Haemophilia Foundation NSW**

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 Foundation New South Wales Inc., Suite 5,88 Mountain Street, Ultimo NSW 2007 PO Box 631 Broadway NSW 2007
Ph: (02) 9280 2607 Web: www.hfnsw.org.au Email: coordinator@hfnsw.org.au; admin@hfnsw.org.au

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

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
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Stephen Matthews (Nurse)
stephen.matthews@sswahs.nsw.gov.au
Phone: (02) 9515 7013

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
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Carol Doherty (Nurse)
carol.doherty@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 Assisstance: 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

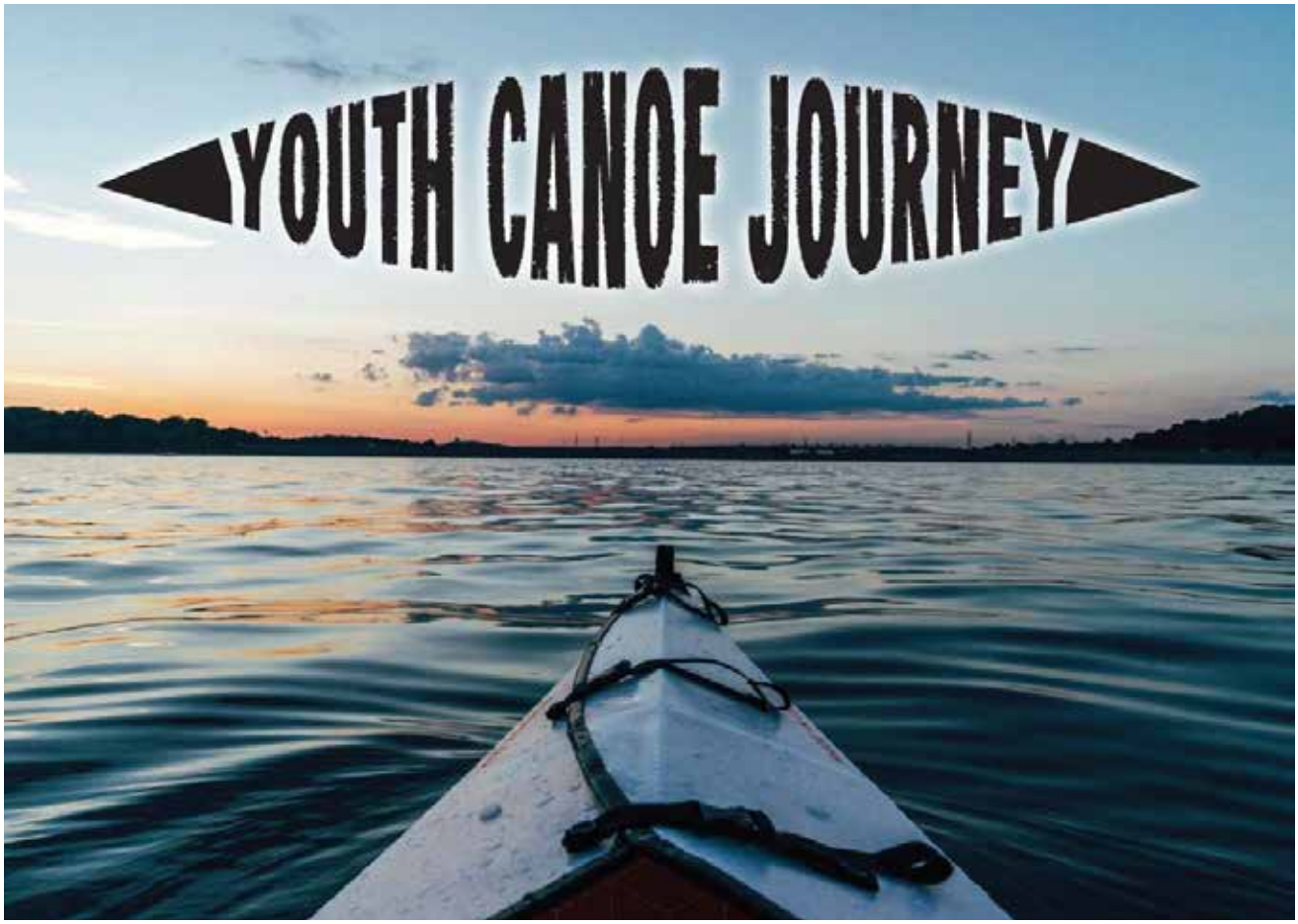
HFNSW COMMITTEE...

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



If you are *even considering* - ACT & CONTACT US NOW!

YOUTH CANOE JOURNEY

DO YOU NEED A **NEW CHALLENGE**?
ARE YOU LOOKING FOR **ADVENTURE**?
JOIN US ON THE **YOUTH CANOE JOURNEY**!

We've teamed up with adventure therapy group Purple Soup to bring you this exciting experience.

This program is designed to build education and life skills for young people.
We hope to empower them to work on their personal development and build connections with others living with a bleeding disorder.

Participants will be challenged to work as a team, overcome obstacles, and develop initiative skills.

The Youth Canoe Journey is open to anyone aged between 18-25 years, and has a bleeding disorder, carries the gene or has a sibling with a bleeding disorder.

The event will be held mid-November: Dates to be confirmed.

For more information, and to apply, head to www.factoredin.org.au

purple soup

HAEMOPHILIA FOUNDATION AUSTRALIA