Factor Matters

Haemophilia Foundation NSW

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2018 Camp Group - "one of our largest"

What a fun family camp!

Contents

About Us

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

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HFNSW Staff

Tony Wilkinson - Program Coordinator
coordinator@hfnsw.org.au
Sam Deylami - Administrator/Accountant
admin@hfnsw.org.au

Contact Details

HFNSW Office
Room 1, Suite 5 - Level 1
88 Mountain St, Ultimo NSW 2007
P: (02) 9280 2607
M: 0470 637 928
Web: www.hfnsw.org.au
Mailing Address:
HFNSW PO Box 631 Broadway NSW 2007

Factor Matters, Vol 38: Summer 2018

Guest Editor: Natashia Coco
Assistant Editor: Tony Wilkinson
Editorial Board: Dan Credazzi, Dr. Garry Lynch Craig Haran.
Design: Steve Williams, Red Inc.

In This Issue

On the cover: HFNSW Family Camp 2018

NSW members, committee and HFA staff and council celebrating Red Cake Day

Part funded by New South Wales Health through SLHD

A Word From The President...

Dan Credazzi – President Haemophilia Foundation New South Wales

The last quarter of the calendar year is always a busy time for HFNSW, because it includes Bleeding Disorders Awareness Week and Red Cake Day, the HFNSW AGM & Info Evening, as well as our regular Family Camp in November. And, this year we also had a wonderful Christmas event in Newcastle, Hunter New England Local Health District (HNELHD) for people with bleeding disorders from around the Hunter.

In this edition of *Factor Matters* we will keep you up to date with what has been happening, and what we have planned for 2019.

Our 'AGM & Information Evening', Thursday 11th October was a good opportunity to catch up. Special thanks to our Guest Speakers, Dr Rob Russo, on Joint Care, and Dr Jenny Curnow, on Women and Bleeding Disorders.

The Family Camp went well. We had 125 people at the camp – including our live in campers, as well as families who came for a day, as well as health professionals and speakers. It was great to meet many new families and first time campers, and be able to share experiences. We appreciate your feedback sheets as we want to take into account your views about how we can make the camp even better in the future.

As I moved around I was struck by how many of you are talking about new treatments. From the show of hands during my *Report to Members*, Tony and I estimated that about 60% of you were currently or about to have treatment reviews, and about 40 % were on, or about to start a new treatment plan. It is certainly a time of change, with several new treatment opportunities, some through clinical trials. HFNSW works with Haemophilia Foundation Australia (HFA) to make sure we have funded access to the treatments everyone needs to live full and productive lives.

The Camp program runs with input from of our wonderful health professionals who were able to join us on their weekend, in particular Steve Matthews, Robyn Shoemark, Alvin Hoii and Jaime Chase.

In other news from around the state, we are pleased to hear there is progress with the vacant Social Work position at the Haemophilia Treatment Centre at RPAH. It is great that Jaime Chase has been formally appointed into the position of CNS at the John Hunter Children's Hospital. Jaime and Natashia Coco, HFA Director of Development, worked with us on our Christmas get together at Newcastle on Sunday 2nd December. It was terrific to meet families from the Hunter Region, and we look forward to having more activities in the area.
It was my pleasure to attend with our Co-ordinator Tony Wilkinson, along with Sharon Caris, HFA Executive Director, as well as local clinicians, Haematologist Dr Janis Chamberlain, and Jaimie Chase, CNS.

Finally, an important 'heads-up' re another great opportunity – the 19th Australian Conference on Haemophilia, VWD & Rare Bleeding Disorders will be held 10 -12 October 2019 in Manly NSW.. This is a great opportunity for us to hear from the experts about a wide range of topics relevant to our community. Conferences provide such a good chance to learn more, to hear about the HOT topics in bleeding disorders, but also for people to meet and share their experiences and concerns and for us to make changes to benefit everyone with a bleeding disorder in our community. So please come and have your say.

And there's more, so don't forget to check out our news on pg12.

Best wishes for a safe and happy Christmas, and holiday period.

Dan Credazzi

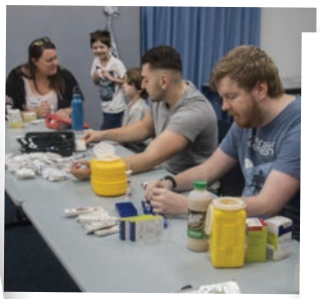
President, Haemophilia Foundation NSW

HFNSW *Family Camp*

Once again HFNSW hosted an exciting and fun filled family camp. The camp was held at Sydney Academy of Sport & Recreation in Narrabeen, it is a great location and has hosted us for many years. We had 125 people attend the weekend with lots of smiling faces. Activities included canoeing, rock climbing, archery and swimming. The kids had a fun crazy disco sports party on Saturday night while the parents had some trivia fun.

A big thank you to the health professionals that attended for the workshops.

The camp will be held on 8-10 November 2019 so mark your diaries.



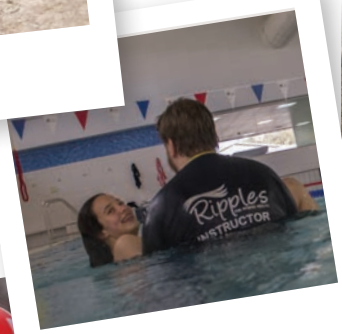
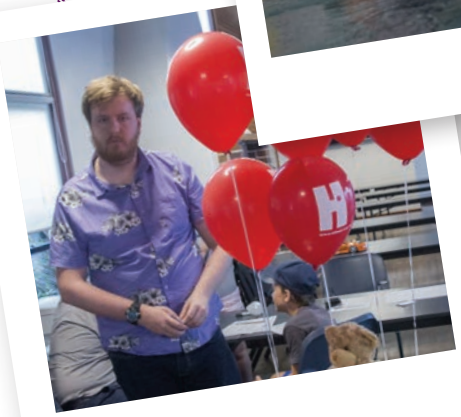










Suzanne O'Callaghan is HFA Policy Research and Education Manager

For a long time gene therapy has been hailed as a potential 'cure' for haemophilia, but the expectation has been that viable treatment is many years away in the future. In December 2017 two international experimental gene therapy studies published successful results, creating a great deal of publicity and excitement that a cure for haemophilia might finally be within reach.

ABOUT GENE THERAPY

Dr Glenn Pierce, Medical Member of the World Federation of Hemophilia Board of Directors, spoke with HFA about the background to these current gene therapy studies and what it means for people with haemophilia.

HFA: What is gene therapy?

Glenn Pierce: Gene therapy means a drug therapy that delivers a gene, made of DNA, to treat a disease, instead of a protein or small molecule. In the past, proteins such as factor VIII and factor IX, have been used to treat haemophilia. In work over the last 30 years, scientists have investigated using the DNA for factor VIII or factor IX to treat haemophilia in animals and humans.

HFA: How does gene therapy work?

Glenn Pierce: DNA can't be delivered orally, and when delivered intravenously, needs to be protected or it will be destroyed in the bloodstream. Viruses have evolved over hundreds of millions of years to deliver their genes into our cells. They are very efficient, which is why so many viruses cause so many infections in us. Scientists have harnessed several viruses and removed their genes to insert the factor VIII or factor IX genes. One virus in particular, adeno-associated virus (AAV), has proved to be very effective in delivering new genes to animals and humans. Thousands of mice have been cured of their haemophilia, and several trials are underway in humans.

HFA: What will the outcomes be for people with haemophilia?

Glenn Pierce: Early clinical trials in haemophilia were not successful but addressed many technical problems that needed to be overcome. More recent clinical trials using AAV-Factor IX have produced factor IX levels averaging 30% in persons with haemophilia B for at least one year. Likewise, a different biotech company has used AAV-factor VIII to produce on average 100% factor VIII circulating levels for at least one year. Many questions remain, including how long it will last and to monitor for long term safety.

HFA: What are some examples of gene therapy trials internationally now?

Glenn Pierce: Three companies are in advanced clinical trials and can be followed for clinical progress: Spark Therapeutics, BioMarin, and UniQure.

Dr Glenn Pierce, MD PhD, is Medical Member, USA, of the World Federation of Hemophilia Board of Directors and is on the Medical and Scientific Advisory Council of the National Hemophilia Foundation (NHF), the medical body which makes policy for the American bleeding disorders community.

A 'CURE'?

Media stories about the two gene therapy trials spoke of them as "a breakthrough" and "a giant leap forward" in the search for a cure for haemophilia. But what is meant by a 'cure' for haemophilia?

In gene therapy this varies between studies. Around the world there are a number of gene therapy studies at different stages of development, and each study has its own measurements of success. The two gene therapy studies that published results in December are some of the most advanced: one trial in the UK studying haemophilia A and the other in the USA, Canada and Australia studying haemophilia B. Both of these studies were able to demonstrate that:

- For most, factor levels could be increased and sustained at the mild haemophilia range or higher for at least one year
- Prophylaxis treatment could be discontinued for all participants
- Nearly all participants had no further bleeding episodes. [1,2]

HAEMOPHILIA A STUDY

The haemophilia A gene therapy study took place across multiple centres in the UK and was sponsored by BioMarin Pharmaceutical. 9 men with severe haemophilia received a single infusion of AAV5 to deliver an altered human factor VIII gene into their body. One received a low dose, one an intermediate dose and 7 received a high dose. They were followed for a year.

The 2 men who received low or intermediate doses had factor levels that remained at 3% or lower (moderate haemophilia). Of the 7 men who received high doses, 6 gradually increased to normal factor levels and had maintained this a year after treatment. Prior to the gene therapy treatment, all 7 had been on prophylaxis treatment. By 22 weeks after treatment, all 7 participants no longer needed to use factor VIII treatment.[1]

'When we started out, we thought it would be a huge achievement to show a 5 per cent improvement, so to actually be seeing normal or near-normal factor levels with dramatic reduction in bleeding is quite simply amazing,' said Prof. K. John Pasi, Director of the Haemophilia Centre at Barts Health NHS Trust and one of the trial investigators.[3]

HAEMOPHILIA B STUDY

The haemophilia B gene therapy trial was a collaboration between the team led by Prof. John Rasko at the Royal Prince Alfred Hospital in Sydney and multiple centres in the USA and Canada, and was sponsored by Spark Therapeutics.

In the study 10 men with haemophilia B and factor levels below 2% were treated with a single infusion of AAV with an altered factor IX gene. After treatment all had a substantial increase in their clotting factor IX (9) levels, which were sustained at a mean of approximately 30%, ranging from 14% (mild haemophilia) to 81% (normal range). As a result of this treatment nearly all had no further bleeding episodes. 8 out of 10 have not used clotting factor replacement therapy since then. Only one participant needed to use factor replacement therapy for bleeds after treatment, but used 91% less factor than before. There were no serious side effects.[2]

Although this was a small study and has not yet had long-term follow-up, Professor Rasko sees this as a major step in haemophilia treatment. 'We now know how to beat the immune response to achieve what may be a permanent cure,' he said.

Professor Rasko explained that the success of this small clinical trial can now pave the way for a larger study in haemophilia B with long-term monitoring. His team at RPA and their collaborators in the USA and Canada will also be commencing a similar small experimental clinical trial in haemophilia A in 2018.

'LIFE-CHANGING'

Before receiving the experimental gene therapy treatment, Australian clinical trial participant Mark Lee, 38, had severe haemophilia and clotting factor infusions up to three times a week since birth. Since the gene therapy injection his factor levels are in the normal range and he has not had any bleeds.

'This is life-changing for me. I spent my childhood wrapped up in cotton wool, unable to play football or do any of the things my mates could. I would always remind myself that there were people worse off than me, but it was still disappointing," said Mark Lee. "I have two daughters who are carriers for haemophilia, but now I know that if they have affected children, it could be one injection and they could live normal lives. This goes beyond our little family currently. It will have a positive impact on all generations to come.'

Mark commented that it is sometimes the little things that show how much difference this has made to his quality of life. He travelled by plane to the Sydney press conference to present the results. 'I always used to wait for other people to get off the plane,' he said, 'but this time, I stood up, gave my knee a little wriggle and walked straight off with all the other passengers.'

LIMITATIONS

There is still a long way to travel with both of these gene therapy trials. Both studies were very small – just 9 to 10 people with haemophilia – and before these treatments can be made widely available, there will need to be studies of much larger groups of people with haemophilia who, along with these participants, will need to be monitored for at least 15 years to confirm the results and check for other complications.

Inclusion criteria were also very strict and limited the number of people who could participate and use the treatment. Both studies used an adeno-associated virus (AAV) to transport the corrected gene to the participant's liver. AAV is a small virus that is not currently known to cause disease, but many people with haemophilia may already have been exposed to AAV and their immune systems could reject it. To take part in these trials, participants needed to be AAV negative. There are a number of gene therapy studies around the world using variations on AAV to deliver the gene within the body. All these studies have similar exclusion criteria, including other requirements; for example, participants also have to be adult males with severe or moderate haemophilia, without active hepatitis and have no history of inhibitors.4,5 A next step for the haemophilia A AAV5 study is to trial a high dose in a small number of people who are AAV positive to see what the outcome is.[6]

FOR THE FUTURE

Apart from AAV, other types of gene therapy are also being studied, some with very promising results. Researchers are working on a range of methods to deliver the corrected gene within the body: lentiviruses have been used successfully in dogs with haemophilia; platelets derived from hematopoietic stem cells (which produce blood cells) are also being investigated to transport the corrected gene directly into the blood stream. Other forms of gene technology are also being researched, including gene editing and other novel approaches.[5]

Daniel Credazzi, Vice-President of Haemophilia Foundation Australia, who has a son with haemophilia, welcomed the breakthroughs, saying: 'The real potential of a cure with safe and effective gene therapy is very exciting for people living with this chronic condition, and for their families. My wife and I have been looking forward to this news since our son was diagnosed with haemophilia 13 years ago. We are grateful to all the courageous people who have participated in gene therapy trials.'

MORE INFORMATION

For people with haemophilia in Australia, these are exciting times, with a range of new ground-breaking haemophilia treatments coming on to the market as well as the first indications of success in these experimental gene therapy trials. If you have haemophilia and are interested in more information about experimental gene therapy or other new haemophilia treatments, talk to your Haemophilia Treatment Centre.

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5.George, LA. Hemophilia gene therapy comes of age. Blood Advances 2017;1(26)2591-2599.

6. BioMarin Provides 1.5 years of Clinical Data for Valoctocogene Roxaparvovec Gene Therapy for Severe Hemophilia A at 59th American Society of Hematology (ASH) Annual Meeting Concurrent with NEJM Publication. 9 December 2017 <http://investors.biomarin.com/press-releases>

Female Factors – New Young Women's Resource

HFA has released Female Factors, an innovative new resource for young women and teenage girls.

This was developed to answer the questions of young Australian women about how bleeding disorders affect females – but in a magazine style that is fresh and engaging. There are personal stories, quotes and tips.

HFA worked with haemophilia and gynaecology experts, who put together easy-to-read information for young women.

The booklet has explanations about heavy periods and other bleeding symptoms in females, covering all bleeding disorders. It answers FAQs - such as what's 'normal' and what's not normal, or why girls with haemophilia have different bleeding patterns to their father or brothers - and gives frank but reassuring answers to some of the questions young women worry about.

HOW TO ACCESS IT

Female Factors is available in multiple formats

- On the HFA website www.haemophilia.org.au under PUBLICATIONS
- On Factored In www.factoredin.org.au under INFO > GIRLS
- You can read the entire booklet online as a magazine in ISSUU, download it, or download specific sections
- Print copies are also available from HFA, local Foundations and your Haemophilia Treatment Centre.

Many people were involved in developing Female Factors. Both young women and their parents and health professional experts suggested what topics to cover, reviewed it thoroughly and wrote new content or gave personal experience to answer questions.
We would like to particularly acknowledge Prof Sonia Grover, Head of Gynaecology at the Royal Children's Hospital, Melbourne and Dr Jane Mason, Director of the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital, who did a substantial initial review and wrote new content for the booklet.

And special thanks go to the young Australian women affected by bleeding disorders who contributed their personal stories and tips and focus-tested the design!

FOR MORE INFORMATION

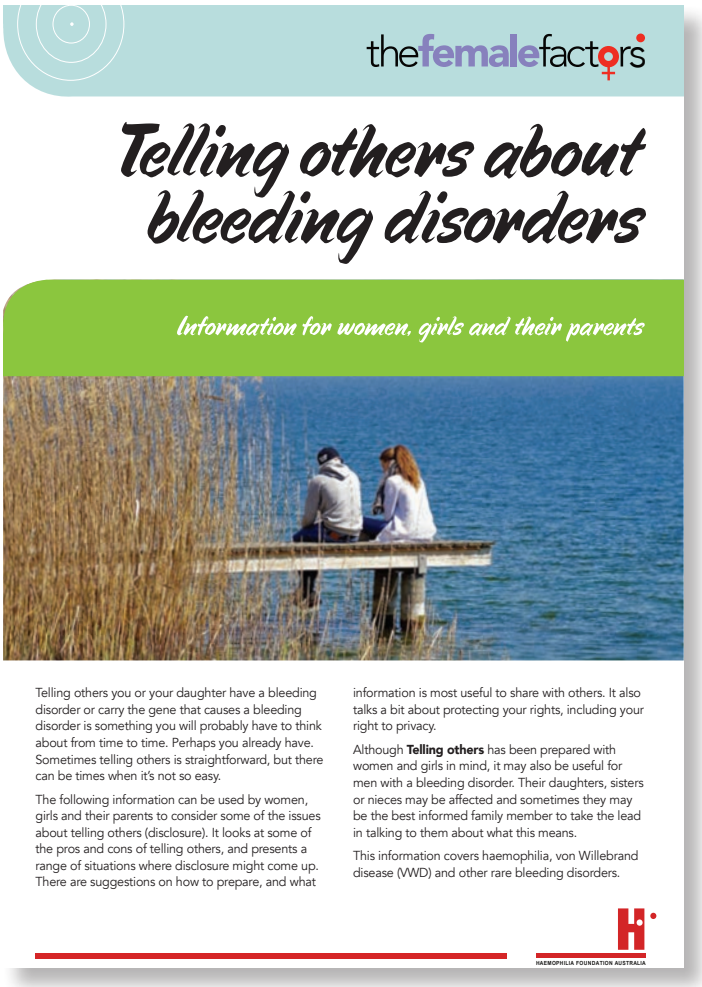
To find out more about Female Factors or order copies, contact HFA:

E: hfaust@haemophilia.org.au

T: 1800 807 173.

New Resource - Telling Others

How do you tell a new partner about your bleeding disorder? Or your daughter that she may have a bleeding disorder or carry the gene? When are you required to tell someone about your bleeding disorder?



Telling others about bleeding disorders: information for women, girls and their parents is the latest resource in HFA's The Female Factors project.

- Visit the www.hfnsw.org.au website under PUBLICATIONS > WOMEN WITH BLEEDING DISORDERS to view it online or download it.
- Contact HFA, www.hfnsw.org.au or your Haemophilia Treatment Centre for print copies.

Telling others includes:

- The pros and cons of telling others
- The range of situations where you might disclose
- Talking to your daughter about her bleeding disorder
- How to prepare to disclose
- When you are required to disclose
- Personal stories and tips from other Australian women and parents.

DISCLOSURE AND THE LAW

HFA has also developed information about disclosure and the law for both women and men in consultation with legal experts. This is available on the www.hfnsw.org.au website under ABOUT BLEEDING DISORDERS > DISCLOSURE.

Thanks to the many people who contributed to the development of Telling Others: Marg Sutherland, health educator, who wrote it; the women, parents, health professionals and legal experts who reviewed it; and the women and parents who very generously shared their experiences and tips in personal stories and quotes.

PROBE Study Update *from HFA*

Some of you have helped to test the print and online survey for the PROBE (Patient Reported Outcomes Burdens and Experiences) study. This is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data – crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

PROBE
Patient Reported Outcomes Burdens and Experiences Study

PHASE 2 RESULTS

21 countries participated in phase 2 of the PROBE study in 2016-17. This tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia contributed a total of 103 survey participants.

People with haemophilia/carry the gene
– 51 (required = 50)

People without a bleeding disorder (controls)
– 52 (required = 50)

An important learning from this phase was that larger numbers of survey participants will be needed at a country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, eg mild/moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region, including Japan, Vietnam, Australia and New Zealand.

The results validating the PROBE study at a regional level are available on the PROBE study website – www.probestudy.org. Feedback about the online survey has been used to fix bugs and make enhancements for the phase 3 version. The international team set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them to funding bodies and decision-makers. This questionnaire is about haemophilia, but a survey on VWD is also planned for the future.

NEXT STEPS

Phase 3 is planned to begin at the end of 2018. It is the final 'real world' stage of implementing the haemophilia survey around the world – where we invite the wider Australian bleeding disorders community to complete the questionnaire. This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

Our thanks to Dr Liz Bishop, Michael Kirby Centre for Public Health and Human Rights, Monash University who continues to provide oversight of the ethical process.

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - https://www.haemophilia.org.au/research/probe-study.

Or contact Suzanne O'Callaghan at HFA:

E: socallaghan@haemophilia.org.au T: 1800 807 173

Hunter Valley Christmas Party

It was lovely to see many faces at the Hunter Valley Christmas Party held at Lambton Park on the first Sunday in December. Sharon Caris from Haemophilia Foundation Australia, our President Dan Credazzi and health professionals from the John Hunter Children's Hospital attended as well, it was great to have them there. Thank you to everyone that attend and for those that missed out we will host another next year.





Red Cake Day Morning Tea

To celebrate the start of Bleeding Disorders Awareness Week we hosted a morning tea. HFNSW members, committee, staff and HFA staff and council attended the morning. It was lovely to catch up and particularly the young people meeting old friends again.









News, Events and Dates For Your Diary

Mario Kart & Pizza Party – 12 January 2019

Hosted by John Hunter Children's Hospital

Calling all children and adolescents with a bleeding disorder and currently attending school. Come learn about taking control of YOUR bleeding disorder and take part in our first annual Mario Kart Challenge… plus eat lots and lots of pizza

Invite and details enclosed

For more information contact Jaime 0448511539

NSW family get together – 24 February 2019

Join us for a get together in Sydney. This is a great chance for children with a bleeding disorder, their siblings to meet others with similar experiences and for parents and carers to meet and chat.

Date: Sunday 24 February 2019

Where: Newington Armory train ride and picnic at Blaxland Riverside Park

Invite and details enclosed

For more information contact hfaust@haemophilia.org.au or 1800 807 173

Red Classic 2019 – 07 April 2019

Come and join us for the Red Classic on Sunday 7 April 2019

For details visit www.haemophilia.org.au/RC
e: hfaust@haemophilia.org.au p: 1800 807 173

World Haemophilia Day - 17 April 2019

www.wfh.org/whd

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

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

Is HFNSW meeting your needs?

Either way we would love to hear from you, feel free to email us on coordinator@hfnsw.org.au

We are looking at the 2019 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

HFACT Camp is extending an invitation to HFNSW members to their Family Camp.

HFACT Family Camp

When: Friday 5th April to the afternoon of Sunday 7th April

Where: Warrambui Retreat and Conference Centre, Murrumbateman NSW

Registartion and costs: for information visit https://www.hfact.org.au/support-services/community-camp. Forms are available for download. (Note: HFACT are offering early bird specials until 25/12/18).

NSW FAMILY GET TOGETHER SUNDAY 24 FEB 2019

Join us for a get together in Sydney. This is a great chance for children with a bleeding disorder, their siblings to meet others with similar experiences and for parents and carers to meet and chat.

Date: Sunday 24 Feb 2019

Where: Newington Armory train ride and picnic at Blaxland Riverside Park (HFNSW will pay for train rides)

Time: Meet at Blaxland Riverside Park (Jamieson St, Sydney Olympic Park) 11am onwards and we will co-ordinate train rides

What to bring: Pack a picnic lunch, chairs and rugs and look out for the red balloons (pack bathers and towel for kids as they have a water play facility)

RSVP: 18 Feb 2019 to hfaust@haemophilia.org.au or call 1800 807 173.

HAEMOPHILIA FOUNDATION NEW SOUTH WALES

JHCH's Haematology Service presents...

Mario Kart & Pizza Party!

Calling all children and adolescents with a bleeding disorder and currently attending school.

Come learn about taking control of YOUR bleeding disorder and take part in our first annual *Mario Kart Challenge*... plus eat lots and lots of pizza.

Date: Saturday 12 January 2019

Time: 11am - 1pm

Where: JHCH

Please meet staff outside The Children's Cancer and Haematology Unit

RSVP: Jaime 0448511539 by 6 Jan 2019

Psst- parents this is for kids and adolescents only ☺

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
RPA, Missenden Road
Camperdown NSW 2050
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
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 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

RED CLASSIC

Sydney, NSW • Sunday 7 April 2019

Supported by Bioverativ Australia

SAVE THE DATE

REGISTRATIONS OPEN SOON – Visit haemophilia.org.au/rc for more information & details or call 1800 807 173