

# Factor Matters

Haemophilia  
Foundation  
NSW



Published by HFNSW

Autumn 2017

Volume 35



HFNSW High Achievers • Camp 2016 • Youth Lead Connect  
Our Oral Health • Joint Care: A Big Day at Westmead • **& MORE...**

## 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 Committee

Prof Kevin Rickard, AM, RFD - PATRON  
Dan Credazzi - President  
Dr Garry Lynch - Vice-president  
Paul Bedbrook - Treasurer  
Craig Haran - Member  
Hamish Robinson - Member

## Clinical Consultant to HFNSW Committee

Leonie Mudge - RPA Haemophilia Social Worker

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## Factor Matters, Vol 35: Autumn 2017

Editor in Chief: Tony Wilkinson  
Editorial Board: Dan Credazzi, Dr. Garry Lynch,  
Leonie Mudge.  
Design: Steve Williams, Red Inc.

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**On the cover:** Family camp 2016 sees our young members shine with support from family and staff. HFNSW congratulates our four young men selected for leadership & mentoring under Youth Lead Connect.

HAEMOPHILIA FOUNDATION AUSTRALIA  
**RED TIE CHALLENGE**  
how do you wear a red tie?  
[haemophilia.org.au/redtie](http://haemophilia.org.au/redtie)

The RED TIE CHALLENGE was created by the National Hemophilia Foundation (NHF) in the United States. NHF selected a Red Tie to symbolize the blood ties that bind our community. Based on the success of NHF, and with their agreement HFA will launch its own Red Tie Challenge to run during April 2017.

**HOW DO I PARTICIPATE?**

- 1 Wear a Red Tie or Red Scarf (you can download one online from [www.haemophilia.org.au/redtie](http://www.haemophilia.org.au/redtie))
- 2 Get your friends, colleagues and social friends on board
- 3 Record your look on HFA Facebook or Twitter with hashtag #RedTieChallengeAUS
- 4 Change your profile picture and/or page banner on Facebook in support of the Red Tie Challenge.
- 5 Make a donation at [www.haemophilia.org.au](http://www.haemophilia.org.au)
- 6 Be creative and have fun!

**For resources and more information visit [www.haemophilia.org.au/redtie](http://www.haemophilia.org.au/redtie)**

Opinions expressed in Factor Matters do not necessarily reflect those of the Foundation or NSW Health. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFNSW reserves the right to edit articles as it sees necessary. Materials supplied are for information purposes only and are not to be used for diagnosis or treatment.





Dan Credazzi  
President Haemophilia Foundation  
New South Wales

**Back in 2012 when we created our first strategic plan, we had a lot to consider and didn't know where to start. Through an introduction by our NSW Health program manager, we got to know the people from the Thalassaemia**

**Society of NSW. They invited us to their AGM and community gatherings and helped us understand the importance of KPI reporting, setting up a member database and keeping track of our 'total output hours'. We owe credit to their society coordinator, Nancy, for teaching us the ropes. Now, as they have had a change in staffing and board membership, we are helping them out too, in exactly the same way. This type of collaboration is more and more important in this time of tighter government spending. The fact that we are primarily funded by NSW Health is a real benefit to our sustainability as an organization...so that we can continue and even increase our services to members without end.**

Through just such a connection with NSW Health, we were invited to the recent inaugural Equity Festival in Ashfield opened by the CEO of the Sydney Local Health district, Dr Teresa Anderson. It was a full day of collaboration and idea sharing with other organizations like ours, i.e., for Purpose as opposed to for Profit. There were many volunteers and both your VP Dr Garry Lynch and I were impressed by the heroic people we met on the day. With such a sour news cycle on tv all the time, it's great to see community action at the grass roots and hangout with the passionate people who are on the front line. It was definitely a newsworthy day, but surprisingly, there was no media there. Well we are now part of that collective group of For Purpose

organizations and this new connection only makes your HFNSW stronger.

As you're probably tracking, the longer acting factor trials continue to have good results. The National Blood Authority requested submissions in support of adding longer acting factor to the basket of clotting factor they purchase for us. Along with HFA and the other State Foundations, we held focus groups and got our NSW member's accounts about their trial experiences and made our collective, formal submission. We are keen to add this and other new therapies to our clinician's range of treatment options. And we will keep you updated on this topic as it develops.

October of this year is the next ANZ bi-annual Haemophilia & Rare Bleeding Disorders conference in Melbourne. We hope that as many of you can attend as possible so to that end, we will again be helping out by offering to reimburse our active members for the conference registration fees. If you're going to attend, there's information in this newsletter (p.13), on the HFA website and you can always contact Sam at our office on [admin@hfnsw.org.au](mailto:admin@hfnsw.org.au).

Warm Regards,

*Dan Credazzi*

President Haemophilia Foundation New South Wales



Dan meets Nurul, more p.12



Bubble Soccer



Pool



Bubble Soccer

# HFNSW Family Camp 2016



HFNSW Family Camp 2016



Rock Climbing



Rock Climbing



Rock Climbing



Rock Climbing



Rock Climbing





Canoeing



Canoeing



Archery



Archery



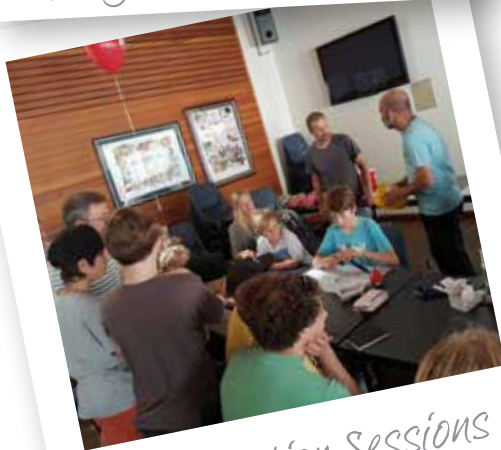
Crazy Claudia  
Young-uns in Fancy Dress



Crazy Claudia  
Young-uns in Fancy Dress



Crazy Claudia  
Young-uns in Fancy Dress



Information Sessions



Information Sessions



Information Sessions



Hanging Out



Fire Engine

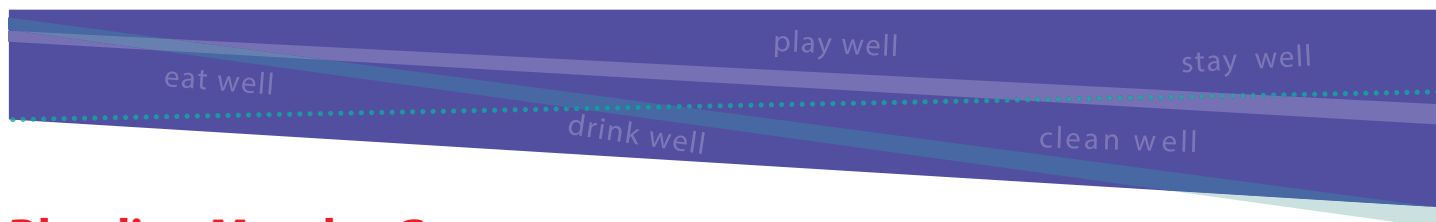


Craft Corner



Special thanks to Melissa  
& the Stever Family  
for capturing so many great  
photos & camp moments.





## Bleeding Mouths, Gums... Dental Care & Bleeding Disorders

**No doubt from a very young age most of us have had it drilled into us by our parents, minders and teachers to brush and look after our teeth. Many of us are clearly aware of the folly of not taking good care of our teeth and gums, namely tooth decay, infections, pain and very expensive trips to the dentist. Perhaps less well appreciated is that poor dental health and decay build up is highly associated with bleeding gums. Which for a person with a bleeding condition literally adds fuel to the fire of problems already.**

Within the many and various types of bleeding disorders, people with the most common bleeding condition, von Willebrand's Disease (i.e., vwd and occurs in the general population with a frequency of about 1 per 100)<sup>1</sup>, are particularly likely to have mouth and gum bleeds.

This is because people with vwd, depending on the severity, have a high risk and likelihood of mucosal bleeds, such as from lining of the mouth and gums. Because vwd in addition to possibly having a lack of clotting factor VIII (i.e., a blood coagulation problem, just as classic Haemophiliacs do), they also have an additional and different problem with their von Willebrand factor (vwf) (i.e., a blood platelet problem). This means that if there is a tear or rupture in a blood vessel, eg in the gums or lining of the mouth, they do not have the vwf which normally would act like glue to attach blood platelets to the edges of the broken blood vessel, and would normally literally plug up the blood vessel hole. For people with vwf such bleeds untreated can go on for hours, days or weeks of stops and restarts.

As the author who has type III vwd, and one of the most rare and severe types of bleeding conditions (i.e., with incidence of up to ~ 1 in 1 to 2 million)<sup>2</sup>, can attest when younger it was absolutely no fun going out on a first date or job interview with bleeding teeth and mouth full of blood.

Adding also that stress can also lead to more bleeds. So the reality is that when all put together folk with bleeding conditions have a number of particular and added incentives to make sure they look after their teeth and have regular dental check ups.

### References:

1. Centres for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/vwd/data.html>
2. Portal of Rare Diseases & Orphan Drugs: [www.orpha.net/consor/cgi-bin/OC\\_Exp.php](http://www.orpha.net/consor/cgi-bin/OC_Exp.php)

Added below are some contact details for some available Public Dental services.

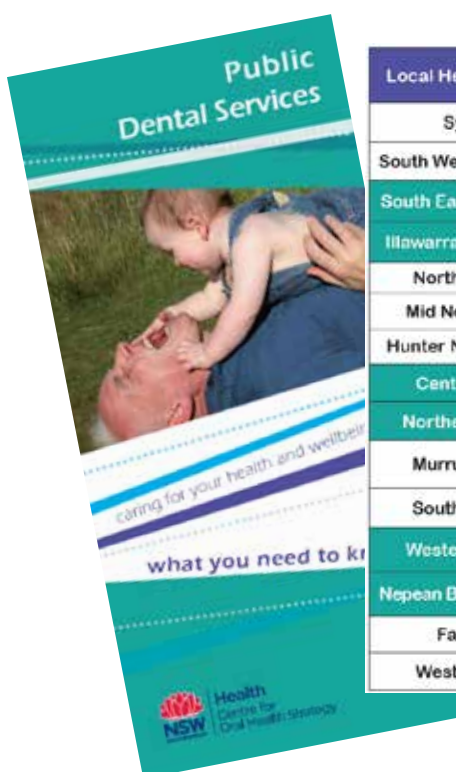
Planned for a forthcoming issue of Factor Matters is a more in depth article on Dentistry in Haemophiliac bleeding conditions.

If anyone has any related anecdotal stories or comments please send them along, and also include some basic information of age, M/F, bleeding condition and type; and whether mouth and or teeth/gum bleeding has or hasn't been a problem.

Warm regards,

*Dr. Garry Lynch* PhD.

Vice President, HFNSW



Local Health District	Phone Number
Sydney	(02) 9293 3333
South Western Sydney	
South Eastern Sydney	1300 134 226
Illawarra Shoalhaven	1300 369 651
Northern NSW	1300 651 625
Mid North Coast	
Hunter New England	
Central Coast	1300 789 404
Northern Sydney	1300 732 503
Murrumbidgee	1800 450 046
Southern NSW	
Western Sydney	(02) 9845 6766 or
Nepean Blue Mountains	1300 739 949 (Land line only)
Far West	1300 552 626
Western NSW	

*It's Important!*

## Q & A with RPAH Dental Clinic

1. 'I have always come to the Haemophilia treatment centre to organise my dental care, as I thought this was the safest. Has there been a change in thinking, policy or clinical practice that means I need to change the way I manage my haemophilia and dental care?

***If a patient has severe haemophilia or a type III von Willebrands they should be managed at the RPAH for any oral surgery or significant periodontal therapy: General checkups and restorations should be able to be carried out in the general practice setting. If the patient is unsure we are happy to arrange an appointment to assess them and advise accordingly, and we are also happy to consult with the patients dental GP.***

2. Do people with haemophilia have extra issues when needing false teeth?

***The only real issue with false teeth is the removal of the natural teeth prior to the construction of the dentures. Properly constructed full or partial dentures should not be a problem.***

3. How often should regular dental checks be performed and from what age should these begin?

***Beginning from age two I feel that patients should have two regular checkups a year. This allows for any problems to be diagnosed early and usually prevents significant dental disease such as gross carious destruction of teeth, infections from impacted wisdom teeth and periodontal disease. If the patient is very prone to dental decay or has periodontal issues more regular checks may be required, such as three or four times a year.***

4. Does your clinic provide dental care available for all people with bleeding disorders for a full range of dental procedures?

***We still like to see all the haemophilia patients for oral surgery and significant periodontal treatment as I feel we are in the best position to manage this and reduce any risk of post-operative bleeding to an absolute minimum. General dental care, restorations, cleaning etc can be managed away from the hospital setting.***

5. As a person with mild haemophilia I hope extractions will still be done at the dental clinic in conjunction with the HTC. Will this be the case?

***This will depend on the treatment needs of the individual. If someone with mild haemophilia or vWD type I or II is managed in the community, this should be with an oral surgeon who is experienced with managing someone with a bleeding disorder.***

6. Apparently the dental clinic has had successful outcomes reducing the need for Factor VIII using tranexamic solutions. Will Factor VIII still be available if needed?

***Factor is used for all extractions and is available should a patient have problems with a post-operative bleed. This is organised in conjunction with the Haemophilia Centre clinicians.***

### Who can get free dental care?

Free dental care is available at NSW public dental clinics for:

- all children under 18 years of age.
- adults who hold any of the following Centrelink concession cards



- anyone listed on your card is also eligible for free public oral health care.

**All patients must be eligible for Medicare and should have a valid Medicare card. For Medicare information call 13 32 54.**





Over 2016 two young men from NSW, Hamish & Sam, stepped up to the Youth Lead Connect challenge and participated in their local community.

Hamish joined the HFNSW Committee as a member with a special interest in Youth Affairs & IT. Sam, a trained Swim Instructor studying teaching, contributed his time at the Family Camp, particularly in assisting with our costs by supervising at the pool, where his teaching skills were evident. Both Sam & Hamish contributed mindfully at the self-infusion sessions (both the formal & informal) as well as in the general running (see photos of the Family Camp p 4-5).

In 2017 four young men from Sydney were successful in selection for HFA's YLC leadership program. Here are some pictures & quotes (below) from their initial weekend training program in Melbourne on 18th & 19th February.



*National Group.*

Facilitators included the education team from HFA and Dr Moana Harlen, Senior Haemophilia Psychologist from the Lady Cilento Children's Hospital, Brisbane, along with expert youth trainers, *The Frank Team* and *Reach*. Sessions covered authentic leadership, how to be an effective mentor, boundaries, leading without telling

people what to do and effective communications. Hamish was invited back to the weekend as a YLC graduate mentor.



*5 NSW participants, left to right, Robbie Bedbrook, Saravana Prasath (aka 'SP'), Hamish Robinson (kneeling), Sam Duffield, and Alan Dursun.*

**Sam** – 'Having a group who started the weekend not knowing what would happen, and who over just 2 short days have been able to look inside themselves and realise how much more potential they have. And now this group of young people will be able to give back to the community and hopefully inspire the next generation of leaders within the community'

**Alan** – 'The main highlight for me was the REACH program that was organised for us. This was the in-depth relaxation and deep thoughts about ourselves, the way we connect spiritually, emotionally and physically with not only ourselves but with the rest of the group. The whole weekend was spectacular, and I enjoyed the company of all the beautiful people that attended, but by far this experience was my highlight. The exercise really opened up to me and made me look back at the progress in my life that I have uncovered, achieved and made me think about how I have got to where I am today.'





**Sam** – ‘Anyone and everyone can be involved. You don’t have to think you’re a leader to be a leader. Just by leading by example you have a positive impact on others. And also, that we are never alone. There is a large mixed community of people who are all dealing with the same things, while trying to live their own lives, but who have valuable experiences which they can share.’

**Hamish** – ‘It doesn’t matter how you see yourself, someone else will see something awesome’



**SP** – ‘Sharing and caring is what I learned the most. It’s really important for us each to share our story and encourage younger people in the community to also share their story.’

**Robbie** – ‘The hardest part of working to help others is allowing them to see your vulnerability and authenticity which builds trust and confidence.’

**Alan** – ‘...how to be a mentor and what it takes to do it. The individual skills involved in being a mentor were taught all across the weekend and how to become better leaders. I thought of it as instead of being a boss, telling individuals what to do, it was a way in which we can show the path to the younger generation to become better members of the organisation. This is where we have boundaries, limitations, objectives and ways to connect with the youth. All in all the weekend was jam packed with knowledge, ideas, skills and means to go about being better leaders in our community.

Becoming a better leader and how to mentor the younger kids in our community was the one big thing I have learnt this weekend.’

All 4 participants are now inducted and on their way with personalised goals. They have worked with Hannah Opeskin, HFA Health Promotion Officer and



the HFNSW Coordinator, Tony Wilkinson to develop a Leadership Achievement Goal to be completed over the next 12 months.

One participant with support from the others, has a plan for a get together of youth in the western Sydney area:

## ATTENTION YOUTH OF NSW!

The NSW Youth Lead Connect group are looking for expressions of interest from young people aged 16-30 who are affected by Bleeding Disorders, whether with a bleeding disorder, a sibling or carrier who would like to attend an evening of fun and games, to catch up with other members of the bleeding disorder community.

We are currently looking at organising a bowling night.

At this stage a final date hasn’t been set. However it will likely be a Friday night within the next 2 months, but further information will follow.

If this is something you would be interested in attending, to meet and catch up with other young people in the community or if you may be interested in attending any future events being organised please email us and let us know.

Don’t be afraid to be involved.

*We look forward to hearing from you:*

**Email:** [info@hfnsw.org.au](mailto:info@hfnsw.org.au)

*Alan, Sam & Hamish*

## The Importance of Joint Health for Haemophilia Patients

**An Exciting Big Day at Westmead ! SCH Factor Zone. What a great start to our year... Thursday 12th January**



Jo Newsom, Physio, Dr Rob Russo, Monica Collins (Pfizer), Paul Whiteley (Whiteley Diagnostic).

Paul was thrilled with the quality and power of such a compact user friendly Ultrasound, donated exclusively to Factor Zone via Pfizer lease...



..and Dr Julie Curtin, Haematologist Westmead.



Dr Russo identifies the joint on the chart, 'Haemophilia Early Arthropathy Detection with Ultrasound' (HEAD US).

Innovatively, this is all taking place in the HTC, initially without the need for an imaging referral!



Robyn Shoemark CNC & Monica Collins with some of the support material.

So while a new machine is always welcome, the important part of this story is it's roll out in combination with conveniently packaged and validated materials i.e.; the 'HEAD US' chart, manual and training.

Monica commented..'the start of this project goes back at least 18 months...and you have to remember that the Supporting Materials & that summary chart have all been validated, globally.'





## A YOUNG ARTIST IN OUR MIDST

### Congratulations Tom !

**You might remember Tom from Factor Matters vol 32 2015 - 'Meet the Artist'.**

Generously two major pieces have enhanced RPA HTC since then.

We were thrilled to be invited to the opening of his public exhibition 11th February at Sydney's MW Maunsell Wickes gallery!

Congratulations Tom, on so many new substantial works (with many selling on the day!).



### A Proud Grandfather & Father, Visiting Sydney Surprise, Surprise, is President, Hemophilia Society of Bangladesh (HSB) And a Co-Winner of WFH Twin of the Year

**Mohammed 'Nurul' Islam: 'Nurul' is a father who beams with pride when he talks about his son, Sydney-based daughter AND Australian grandson!**



During the recent WFH Congress in Orlando, the HSB shared the '2015 Twins of the Year' Award following their successful twinning with the Canadian Hemophilia Society. The Twinning Program's objective is to improve haemophilia care in emerging countries through a formal, four year, two way partnership. The award at the Congress was followed by a panel discussion led by WFH Hemophilia Organization Twinning Committee Chair, Sharon Caris, CEO of HFA.



**This article courtesy of WFH from Hemophilia World Aug 2015**

Jay Poulton, EDITOR/EDITORIAL SERVICES COORDINATOR

Even though Bangladesh has made great strides in the last few decades in terms of social, political and economic improvement, when Islam first found out his son had a bleeding disorder there was nowhere for him to turn to for care, let alone information. As hemophilia is rare, those that have it in Bangladesh often choose to keep their diagnosis a secret for fear of becoming social outcasts. Instead of remaining quiet, Islam decided to stand up and take an active role in the community.

"At that time there was no diagnostics facilities in Dhaka. At that time there was no factor, there was no cryo (cryoprecipitate), only fresh frozen plasma. This is why I founded the Hemophilia Society of Bangladesh. We started with six hemophilia patients," said Islam.



In March 1994, Islam established this patient organization in order to get his son the help he needed and to ensure that other parents like him had a place to turn when their child became diagnosed. He has made it his life's goal to raise awareness about bleeding disorders to change the government's attitude toward funding treatment for people. He also

sought to establish the society in order to help educate the public on bleeding disorders so that those living with it do not have to hide for fear of being ostracized.

"In my case I am open to all. I am the founder of the society so everyone knows me," he said. "But there is a social barrier. Those rich people don't like to disclose that they have hemophilia and they treat outside. They don't even go to doctors of our country because of marriage or other social reasons; it is really a big problem in Bangladesh."

However, with each passing day, Islam can see things are getting better for people in the community. Bangladesh has a long way to go to offering people proper basic care but treatment is getting to many who need it most and they are getting some social acceptance where before there was none.





## 18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS

**LOOKING FORWARD TO CHANGE**

**Melbourne • 12-14 October 2017**

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017.

The theme for the conference is ***“Looking Forward to Change”***.

Over the past 37 years, we have been running conferences that provide current information and resources, discussion on topical issues and looks into the future.

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 to plan for the future.

The program covers current topics and issues to interest everyone including:

- new treatments for haemophilia
- using data to improve treatment and care
- women with bleeding disorders
- genetic testing
- living with von Willebrand disease
- new approaches to managing pain
- HIV and hepatitis C
- living with a bleeding disorder at different life stages - newly diagnosed, children, adult life, ageing
- issues for families and siblings
- youth matters
- sport and healthy activities
- what is the future like?

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

### WHO SHOULD ATTEND?

- people with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners – all ages
- health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers
- treatment product producers, suppliers and service providers
- policy makers and government officials
- haemophilia Foundation volunteers and staff

**EARLYBIRD REGISTRATIONS CLOSE 31 JULY 2017**

For more information, registration and details visit [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)



## Haemophilia Foundation New South Wales Inc.

ABN: 60245470729

Patron: Prof. Kevin A. Rickard AM RFD

### MEMBERSHIP RENEWAL 2016-17

#### Personal Details

Mr/Mrs/Ms/Other: \_\_\_\_\_ Name: \_\_\_\_\_ (Required)

Members Details Below, Required Only 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 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](mailto:robyn.shoemark@health.nsw.gov.au)

Ady Woods (Nurse)-- quote Pager no. 6273

[adrienne.woods@health.nsw.gov.au](mailto:adrienne.woods@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](mailto:Grainne.Dunne@health.nsw.gov.au)

Georgette Sukkar (Social Worker)

[Georgette.Sukkar@health.nsw.gov.au](mailto:Georgette.Sukkar@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](mailto:stephen.matthews@sswahs.nsw.gov.au)

Phone: (02) 9515 7013

Clare Waite (Nurse)

[clare.waite@sswahs.nsw.gov.au](mailto:clare.waite@sswahs.nsw.gov.au)

Leonie Mudge (Social Worker)

Direct: (02) 9515 8385

[leonie.mudge@sswahs.nsw.gov.au](mailto:leonie.mudge@sswahs.nsw.gov.au)

### **Calvary Mater Newcastle**

#### **Haematology Department**

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

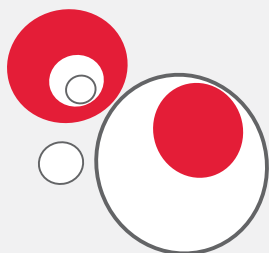
Dale Rodney (Nurse)

[Dale.Rodney@calvarymater.org.au](mailto:Dale.Rodney@calvarymater.org.au)

Bryony Cooke (Social Worker)

[Bryony.Cooke@calvarymater.org.au](mailto:Bryony.Cooke@calvarymater.org.au)

(02) 4014 4811



## HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

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

**Newsletter:** Your quarterly newsletters from HFNSW and HFA offers 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](mailto:coordinator@hfnsw.org.au)

### **Committee meetings held monthly**

*HFNSW Committee Group*

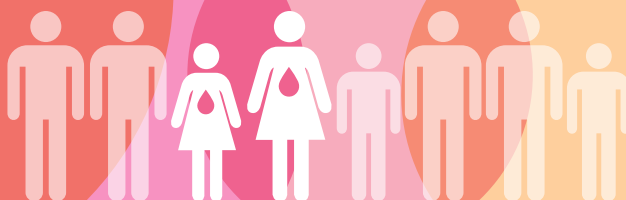


*Paul Bedbrook, Treasurer*


# WORLD HEMOPHILIA DAY 2017 | APRIL 17

## HEAR THEIR VOICES

On World Hemophilia Day let's come together to show our support for the millions of women and girls affected by bleeding disorders.



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# WFH

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