

Factor Matters

Haemophilia
Foundation
NSW



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August-September 2017

Volume 36

Are you coming?



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

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October 2017

THE **BLEEDING DISORDERS COMMUNITY** LED BY **HFA**
GOES TO **CANBERRA**, **PHYSIOS REPORT ON WFH**
MUSCULOSKELETAL CONGRESS, SEOUL, DETAILS ON
HFNSW FAMILY CAMP 2017, HEP C & MyABDR



ALL OF THE ABOVE **PLUS ANOTHER FEATURE FROM
OUR PATRON ON SIR PETER LAWLER & 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 Patron

Prof Kevin Rickard, AM, RFD

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On the cover: ANZ Conference.



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Dan Credazzi – President Haemophilia Foundation New South Wales

As part of our continuing advocacy on behalf of members, we recently went to Canberra to speak with the Assistant Health Minister Hon. Dr David Gillespie and other MPs and their staff about the

importance of longer acting factor medicines. Under the leadership of HFA, an event was hosted at Parliament House on the evening of 31 May 2017. Our host was MP Stuart Robert from Queensland and the evening topic was the case(s) for including Extended Half Life factors (EHLs or Longer Acting Factor) as new options for our haematologists.



Two of us from HFA, myself and Mr Zev Fishman, accompanied by his partner, Judith, all gave personal accounts of life without and the plausible result of life with EHLs. Especially for certain situations. Dr Simon McRae, Consultant Haematologist at the Royal Adelaide hospital also presented the scientific evidence of the efficacy of EHLs to the audience. As an interesting connection, we learned that the Hon. Dr David Gillespie, Assistant Federal Health Minister, did a haematology rotation at the RPA under our own Foundation Patron, Professor Kevin Rickard.

In terms of getting our message across, the evening was a success. We all received consistent, supportive feedback from the Ministers present about including EHLs as an option for our community members. Our factor is funded by both Federal and State budgets, and again, with the help of HFA, we are continuing our direct advocacy at the State and Territory levels. I'll report on the outcomes at our NSW level in the next edition.



IT in action! Sam with Joicy and Wei

Since our last newsletter, the not for profit news headlines in Australia have all been about limited budgets and the introduction of a sort of tendering or petitioning system for government grants to Non-Government Organizations (NGOs) such as our Haemophilia Foundation of NSW. On this front, our advocacy has been successful in that we avoided having to compete with other similar NGOs or not for profits in the new tendering system. And for the first time in many many years, we have achieved a rare, three year funding commitment from NSW Health Sydney Local Health District. It's a terrific team outcome, where our focussed committee combines with our staff – Sam, managing administration along with finances, plus our Coordinator Tony doing outstanding direct community work and advocacy here in NSW.

Another bit of news, we are updating our member database as our current version is no longer supported. Led by our Committee member, Hamish - who himself is an IT professional - we now have an ad hoc IT team to help us securely update our member database to a more useful and reliable platform. One of our community members, YiJU Wei visiting from Xian, China, happens to be an IT professional as well. And through a relationship we established with UTS, where we access a skilled volunteer pool for specific projects from the UTS Shopfront team, Joicy George, a UTS Masters student will also help us through July on this IT project.

Dan Credazzi

President Haemophilia Foundation New South Wales



Prof Kevin Rickard, HFNSW Patron, who worked with Sir Peter Lawler, on the Australian Government Plasma Fractionation Review Committee, has written in recognition of Sir Peter's contributions...

A GREAT AUSTRALIAN PUBLIC SERVANT – A FRIEND TO THE HAEMOPHILIA COMMUNITY

Although many in the haemophilia community may not have known him, in his later years Sir Peter was their friend at court. Accordingly, people with haemophilia in Australia may feel a sense of loss at the passing of their quiet but effective advocate, Sir Peter Lawler.

Among his many Federal Government related achievements, Sir Peter served as a most distinguished member of the Australian Government Plasma Fractionation Review Committee, chaired by

Phillip Flood, AO, which published its report in December 2006. Key recommendations were for the Commonwealth to a) provide the highest standards of safety, quality and efficacy in respect of plasma products, fractionated for use in Australia, b) assure security and supply, c) offer the best possible value for money for Australia. In all of this Sir Peter was very aware and most sympathetic to the therapeutic needs of the person with haemophilia and their reliance on blood transfusion services. In accord with this notion and although at the time in his early 80's he was a hard working and regular participant and contributor at the committee meetings in Canberra and other locations in Australia. With other Committee members, he visited the Blood Transfusion Services in the capital cities where his charm, integrity and honest enquiries made many friends among the staff.

Sir Peter was one of Australia's most distinguished public servants, advising nine Prime Ministers across his career from John Curtin to Bob Hawke. He died in Canberra on 1st of April 2017, just a few days after his 96th. Birthday. His son, John described him as "a colossus of his time". Former High Court Judge, Justice Michael Kirby, said of him "a very good person to have at your elbow if you were a politician - he would just remind them that everyone was temporary -you have just a relatively short time to do the best for the people of Australia."

SATURDAY, MAY 6, 2017 THE AGE

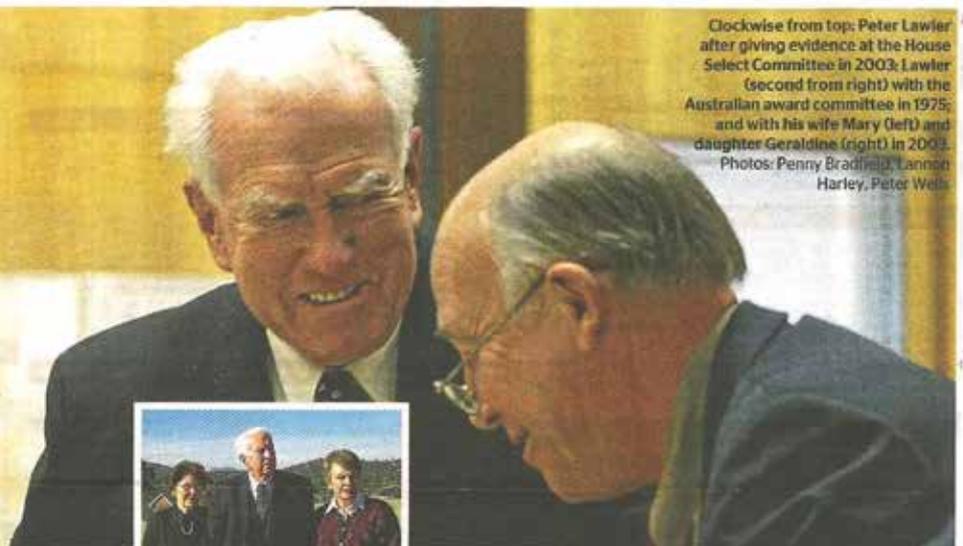
Readers are invited to submit obituaries of 700 to 1250 words, including dates of birth and death, and photos with a resolution of at least 150 dpi, to lifeandtimes@theage.com.au. There is no charge for obituaries. Preference is given to those whose death notices have appeared in The Age.

OBITUARIES 31

Peter Lawler 1921-2017

A giant among men

Despite a challenging childhood, Sir Peter Lawler was a leader in Australian public office, serving under 11 prime ministers.



Clockwise from top: Peter Lawler after giving evidence at the House Select Committee in 2003; Lawler (second from right) with the Australian award committee in 1975; and with his wife Mary (left) and daughter Geraldine (right) in 2003. Photos: Penny Bradfield, Lannon Harley, Peter Wells

VALE SIR PETER LAWLER, KT., GCPO, OBE



"A very good man to have at your elbow", Peter Lawler (second from right), in 1975 with then governor-general John Kerr (far left) and chief justice Sir Garfield Barwick (centre). Photo: Peter Wells

He wrote the 1966 cabinet submission that led to the abolition of the White Australia policy. After the Sydney Hilton bombing, he headed a task force whose recommendation led to the creation of the Australian Federal Police Force. AFP motorcyclists escorted his cortege from St. Christopher's Cathedral in Manuka to the Woden cemetery in the ACT where he was laid to rest.

Sir Peter came from humble backgrounds, held a degree in Economics from Sydney University, joined the Public Service in the Department of Post War Reconstruction in 1944 and the Prime Minister's department in 1950. He undertook postgraduate training in several European cities while posted to the British Cabinet Office.

His later appointments included Deputy Secretary of the Prime Minister's Department, Secretary of the Department of the Special Minister of State and Secretary of the Department of Administrative Services. From 1983 - 1986, he was the Australian Ambassador to Ireland and the Holy See. For his services to the State, he was honoured by the Queen who appointed him as an Officer of The Order of the British Empire in 1965 and subsequently knighted him in 1981. For his services to the Church, he was appointed by St John Paul II, whose visit to Australia he helped to arrange, as a Knight Grand Cross of the Order of Pius IX. In 1986.

He had 8 children, six by his first wife, nee Patricia Thornton, who tragically died in childbirth. By his second wife, Lady Mary nee Robinson, he had two more children. He had 23 grandchildren and 19 great grand children. He jokingly called them 'his kibbutz'. His family was his bedrock. He and his wife, Mary, were shattered when they lost their home in Duffy ACT as well as all their treasured possessions in the Canberra firestorm of 2003. Thereafter he lobbied for much improved warning systems during bushfire conditions.

He was a truly great Australian. I was honoured to be able to call him 'my friend'. To extrapolate Sir Michael Kirby's words - for people with haemophilia in Australia, he was a very good person to have at their elbow in a time of near crisis for Australian Blood Transfusion Services following the HIV endemic in the early 2000s. As an Australian community, we are grateful for the life and work of Sir Peter Lawler.

May he rest in peace.

Your Patron

Kevin A. Rickard

Kevin A. Rickard,
AM, RFD, FRCP (Lond), FRACP. FRCP(Edin)
Honorary Consultant in Haematology, RPAH
Clinical Associate Professor of Medicine,
University of Sydney (Rtd.)

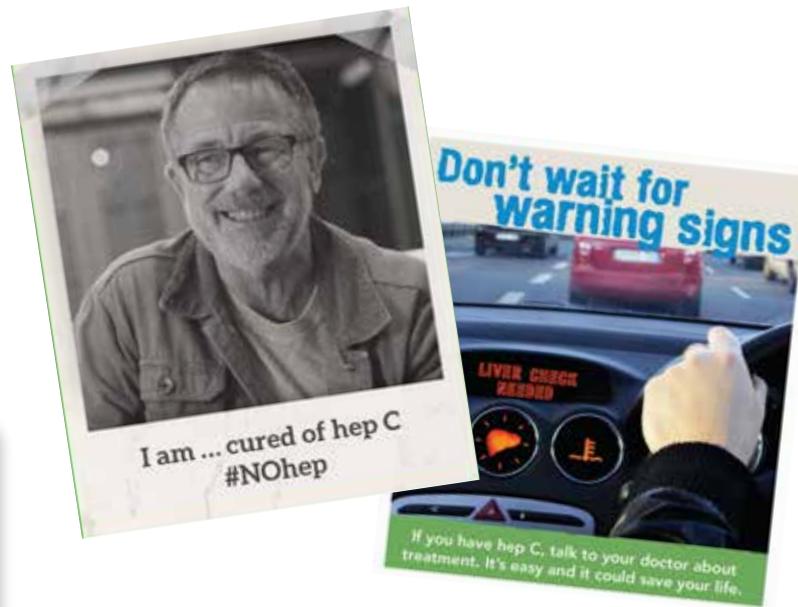


(L-R) Peter Lawler, Tony Abbott, Phillip Flood, & Kevin Rickard, at hand over of the Report to the then Federal Health Minister Tony Abbott.



A small but significant number of the HFNSW community, have been affected by 'blood borne viruses' (bbv) such as hepatitis C (HepC), mainly acquired prior to 1991. **New treatments offer Cure**, with incredibly high success rates! **Suzanne O'Callaghan**, from HFA, and Convenor, Hepatitis Campaign Working Group, updates us...

This year we celebrated World Hepatitis Day with the stories of people with haemophilia who have been cured of their hep C.



We are pleased to hear from Haemophilia Treatment Centres that most people with bleeding disorders have now been treated and cured of their hep C.

What is it like to have the new treatment and be cured?

Paul and Len tell their stories in our new video - Hep C - I am cured! – <https://tinyurl.com/hepc-cure>

WHAT CAN YOU DO TO HELP?

- Spread the word!
- Many people with bleeding disorders were exposed to hep C. Have you ever been tested? If you used factor before 1993 – even as a baby – you could be at risk. Act now – if you don't know whether you have hep C or not, get tested!
- If you have hep C, talk to your doctor about treatment that could cure your hep C.

A NOHEP FUTURE

In 2017 the global community has come together in support of the World Health Organisation's commitment to eliminate viral hepatitis by 2030.

Imagine a future without hepatitis C.

Can we achieve this in the Australian bleeding disorders community?

I AM CURED OF HEP C

The new direct acting antiviral (DAA) hepatitis C treatments are truly revolutionary. In Australia they are available on the PBS (Pharmaceutical Benefits Schedule), which means they only cost as much as any prescription medication. Hepatitis and haemophilia specialists are encouraging everyone with hepatitis C to come forward for treatment.

- High cure rates - 95% overall
- Few if any side effects
- Tablets – no injections
- Shorter treatment courses – 8-24 weeks.

WHAT'S STOPPING YOU FROM TREATMENT?

If you or someone you know with a bleeding disorder and hep C has something that is getting in the way of treatment, we invite you to speak to your Foundation or your Haemophilia Treatment Centre to find a solution together

MORE INFORMATION

- HFA Hep C treatments page - <https://tinyurl.com/new-hepc-treatment>
- World Hepatitis Day page - <http://www.worldhepatitisday.org.au>



Dr Rob Russo, in action, on Ultrasound and 'HEAD US' chart, at 'Kids Factor Zone' with Jo Newsom, Senior Physiotherapist Dr Julie Curtin (last *Factor Matters*, vol 35 p10-11).

From our 'Big Day Out at Kids Factor Zone, Westmead' 12th January, Dr Rob Russo, kindly follows on for us... concisely detailing how Joint Care & Imaging go hand in hand, to achieve optimal care, and concluding "the future is bright" with treatments already at hand.

Joint Imaging and Management in Haemophilia

Recurrent haemarthrosis is a destructive process that often results in debilitating joint disease and functional impairment, contributing most to the morbidity and cost associated with haemophilia. In that context plain radiographs have played the central role in documenting the site and severity of joint disease. However, they are limited in their ability to detect earlier stages of joint disease and as such modalities such as MRI scan and Ultrasound have been considered as alternative options.

Whilst MRI is considered the gold standard as it provides a comprehensive assessment of both soft tissue and articular changes, there are limitation in its

use such as the cost, accessibility and need for sedation in the paediatric population. Consequently Ultrasound presents itself as the ideal modality. There is a role for ultrasound both in the acute evaluation of a swollen joint, that is in being able to differentiate between a haemarthrosis and a flare of underlying chronic arthritis, as well as in the detection of synovitis and degenerative changes. The information provided can greatly assist the clinician in providing a tailored approach to the management of haemophilia associated joint disease.

In regards to treatment, prophylaxis has clearly established itself as the cornerstone of modern treatment of haemophilia arthritis. There is convincing evidence of it reducing the incidence of bleeds and thereby retarding the progression of disease and hence improving long-term joint function and limiting disability. These benefits are further improved with physical synovectomy, provides an effective intervention to reduce the frequency of bleeds, and in those with chronic arthritis intermittent intra-articular steroid injections as well as the judicious use of NSAIDS can assist in symptom control.

The future looks bright with the current paradigms of treatment.

References: 1 & 2. Manco-Johnson MJ et al. *NEJM* 2007;357:535-544



Dr Russo first graduated in Physiotherapy before continuing on to complete broad medical studies. He is an acknowledged researcher, with a keen and active interest in haemophilia care. As well as private practise, Rob is the Director of Nuclear Medicine at Concord Hospital, Sydney.



Recently reviewed *Guidelines for the management of haemophilia in Australia (2016)* emphasise the **important role of physiotherapy** within **comprehensive care**. Whilst Governments State and Federal bear the substantial cost of product, facilities and staff, it is great that two of our NSW physiotherapists, **Jo Newsom & Josh Wakefield** were recently supported by HFA and donors, to attend the **WFH Musculoskeletal Conference**.



Here **Josh Wakefield** from the Royal Prince Alfred Hospital reports on being in the same room as world class musculoskeletal clinicians....

Joshua Wakefield, Physiotherapist, Royal Prince Alfred Hospital, Sydney, NSW

The 15th Musculoskeletal Congress of the World Federation of Haemophilia (WFH) was held recently in Seoul, Korea over three days. The Congress focuses on musculoskeletal approaches to Haemophilia and brings together members of the haemophilia multidisciplinary team with a particular interest in the management of joint and muscle complications. This year's agenda included sessions on skill acquisition techniques, synovitis prevention strategies, and the effects of training load on people with Haemophilia. It was a real pleasure to be able listen, in person, to some inspiring and thought provoking presentations.

Of particular interest was a presentation given by Sebastien Lobet, a physiotherapist and researcher from Belgium, on the global effect of joint deterioration. The functional deficits that arise from joint deterioration are well documented in literature and are well monitored clinically. In order to quantify these deficits, dynamic tools such as the **Functional Independence Score in Haemophilia (FISH)** and static tools such as the **Haemophilia Joint Health Score (HJHS)** have been

developed and validated. However, **the metabolic cost** of such static and dynamic deficits are not well known. Understanding the metabolic cost of compensatory gait patterns may allow clinicians to individualise training programs to target a specific compensation or deficit. **Improvements to energy conservation strategies could therefore provide a significant increase in function and quality of life.**

Sebastien's research used force platforms and gait analysis to measure such compensatory movement patterns in people with haemophilia (PWH). These compensations were measured against oxygen uptake (VO₂) using gas exchange data. In the healthy adult population, there is 3-4cm of vertical movement of centre of mass (CoM) as stance transitions to swing phase.

This is indicative of a kinetic chain that is not stiff nor over-compliant, allowing for maximal economy of locomotion. In PWH, the study identified compromised vertical displacement patterns which lead to CoM shifting greater than 5cm. **Interestingly, there was a direct and proportional relationship between joint arthropathy of the hip, knee and ankle and increased CoM displacement through gait.** Ankle arthropathy with a subsequent reduction in plantarflexion power was found to have the strongest correlation with CoM displacement and energy consumption.

Clearly, the lack of access to equipment would present the average clinician with a significant barrier to performing gait analysis and movement compensation assessment. However, discussion in the room did support the application of the study in a clinical setting. It was noted that the importance of identifying functional deficits via other forms of assessment including the HJHS, and applying modelling principles of metabolic cost against CoM displacement and

movement compensation, would be beneficial in guiding treatment strategies. The presentation also stimulated considerations of the metabolic cost locomotion of my own patients, an area that may be neglected at times.

Of all I am reporting on here, I've saved possibly **the most thought provoking** to conclude on. A physiotherapist from the UK and co-developer of the HJHS, Paul McLaughlin's presentation was aptly named "**The elephant in the room...the things we don't always ask, but should**". It served as an excellent reminder that **a holistic assessment of PWH involves questioning beyond the conventional musculoskeletal paradigm.**

[Jo Newsom shares a couple of key points from her MSK Congress report and article to HFA, originally printed in National Haemophilia, June 2017.](#)

[Exercise and Training](#)

'Appropriate exercises and activities can be one of the most effective (and cheapest!) methods of managing haemophilia and minimising bleeds, pain and other problems. In this session, we heard about how to plan an exercise program safely, including the vital step of having a physio or other expert globally evaluate the entire musculoskeletal system (screening for previous injuries, damage and other issues with joints, or muscle weakness) before commencing a new activity. We discussed safe ways to progress activities and train harder to get fitter and stronger, and talked about how the muscles, joints and bones respond to training. We also heard about some scenarios where poor training techniques lead to injuries and problems – a good reminder to us all to take it easy and listen to our bodies (and the haemophilia team) when we decide to hit the gym!'

Want to know more? Why not check it out, in full via, *National Haemophilia, No. 198*, June 2017 p.10-11. And it's available on-line www.haemophilia.org.au

Consideration of self care, sexual behaviour, drinking and drug use comprise a patient centred assessment. Paul asked the question, "How many of us would comfortably investigate a conversation about how a PWH with significant elbow arthropathy goes to the toilet"? The conversation then turned to how this activity limitation would be assessed and the potential beginning points of an intervention. As Paul challenged us **'joint restriction and pain may only be the tip of the iceberg, what lies beneath may actually be more meaningful to the patient.'**



Jo reading Factor Matters



[Synovitis](#)

'There was a lot of debate around how to decide when synovitis becomes chronic synovitis, and what assessments we can use to help make that distinction – the Haemophilia Joint Health Score, a comprehensive clinical assessment, and imaging (like X-rays or MRIs) all seem to have their part to play...the take home message is that regular check-ups will help to identify any early changes in the joint lining, and the information gained from these assessments will help to tailor an individual treatment program for anyone who appears to have inflammation in their joints. So it is important to keep those clinic appointments!'

Johanna Newsom, Senior Physiotherapist, Children's Hospital at Westmead, Sydney

From the National Blood Authority and HFA MyABDR teams

From Tuesday 22 August 2017 if you want to use the REMEMBER ME function on the MyABDR app, you will need to set a 4-digit pin.

To set the PIN, at the login screen tap the REMEMBER MY DETAILS button NOT LOGIN.

WHY HAS THIS CHANGE OCCURRED?

You may be aware of the current concerns at a national level about the protection of personal information.

Protecting ABDR/MyABDR users' personal information on mobile devices and computers, while preserving favourite functionality has been a subject of considerable discussion between the National Blood Authority and HFA.

Against this background the NBA has implemented a simple solution of a four digit pin lock to access MyABDR on your mobile device.

This solution is only required when accessing and using MyABDR and does not impact on the use of your mobile device. The pin lock is very similar to other applications such as online banking.

The enhancement to the 'Remember my details' functionality means that you can continue to use this option knowing that your access to the ABDR/MyABDR system is now more secure.

HOW WILL THIS WORK?

- When you tap the REMEMBER MY DETAILS button at the LOGIN screen, you will be invited to set a 4-digit PIN.
- Whenever REMEMBER MY DETAILS is activated, you will need to use your 4-digit PIN to login if you have not used MyABDR in the last 30 seconds.
- However, when you are logged out and need to login again, you will still need to enter your email and password – BUT!!
- If you want to use the 'remember me' functionality, you should tap on the REMEMBER MY DETAILS button rather than LOGIN to login, and then set or reset your PIN.

OTHER SECURITY IMPROVEMENTS

The National Blood Authority rolled out the new PIN functionality with other security improvements in the MyABDR release on 22 August 2017:

- Security improvements to the website version
- New messages on the mobile app where the device is insecure
- MyABDR will no longer be accessible from 'rooted' or 'jailbroken' devices.

ANY QUESTIONS OR NEED HELP?

Contact the MyABDR Support team (24 hrs, 7 days a week)

T: 13 000 BLOOD / 13 000 25663

E: support@blood.gov.au.



HFNSW Family Camp 2017
17-19 November
(Applications now available,
see pages 12 & 13 ahead,
or our website).

Aust & NZ Conference



Save the date!
HFNSW AGM &
Information Evening
Thursday 26th October,
6:15pm onward

Considering Melbourne Conference
& you're a 'Paid Up' Member?
Why not talk to your Foundation
about assistance with the
Registration fee?
Sam D's got you covered..
admin@hfnsw.org.au

From RPA, L.Mudge, Social Worker

Recently I had contact with a widow of someone with Severe Haemophilia A and their 15 year old daughter. Her father had died when she was very young, and haemophilia had not been discussed with her. Then at 15 she wanted to know more about 'Carrying the Gene'. The Haemophilia Centre were able to direct her to genetic counselling through the excellent network available in NSW.

We were also able to provide her with access to the written material, 'Finding Out You Carry the Gene' (second in a series called 'thefemalefactors'), recently developed by HFA.

The information can be overwhelming for a teenager, so if your daughter is learning about her carrier status it is good to have access to clinical staff at the Haemophilia Treatment Centres, as well as Genetic Counsellors.

Written material such as this resource and others in the series 'thefemalefactors', can be taken up and looked at when your daughter is ready, wanting to know...



Your copy enclosed or attached



HFNSW Family Camp 2017

HFNSW will be holding its annual Family Camp on 17, 18, 19, November 2017 at the Narrabeen Academy of Sport

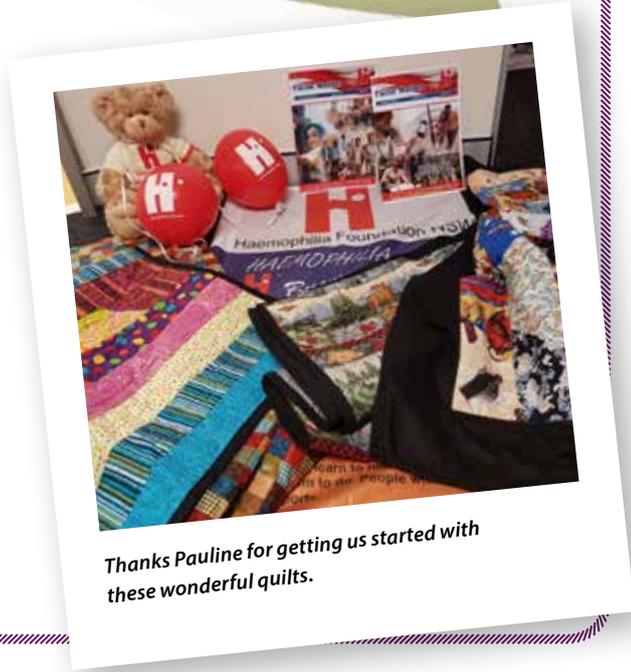
Camp is a great opportunity to connect and catch up with other young people living with Haemophilia, von Willebrand Disorder and other related bleeding disorders, their parents and siblings. It is designed to suit the whole family and is free of charge for our members.

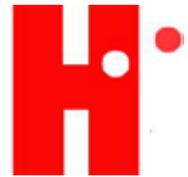
The programme includes indoors and outdoors activities aiming to gain self-confidence, form new friendships and develop resilience. The 3 days of camp also include educational sessions such as self-infusion workshops led by Haemophilia Treatment Centres health professionals and our youth mentors.

Please complete the camp application form enclosed in this newsletter (also available on our website) and return to HFNSW office before Friday 27th October.

We hope to see again all our known members and families as well as the ones we have recently met! For more information please call HFNSW on (02) 9280 2607 or email coordinator@hfnsw.org.au.

*Simple ways to help.
Send us your gifts and other items to help our camp silent auction.
Please contact office to donate*





FAMILY CAMP 2017 Application Form

17th - 19th NOVEMBER 2017

Sydney Academy of Sport & Recreation, Narrabeen, NSW



FAMILY MEMBERS

AGE OF CHILDREN

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

ADDRESS: _____

Email: _____

CONTACT PHONE NO: _____

ACCOMMODATION (TICK ONE ONLY)

<input type="checkbox"/>	FRIDAY NIGHT ONLY	ANY SPECIAL ACCOMMODATION REQUIREMENTS _____
<input type="checkbox"/>	FRIDAY AND SATURDAY NIGHT	_____
<input type="checkbox"/>	SATURDAY NIGHT ONLY	_____
<input type="checkbox"/>	DAY STAY ONLY (SATURDAY)	_____

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 **ASAP** to:

Email (preferred): admin@hfnsw.org.au

or

Mail: HFNSW, PO Box 631, Broadway NSW 2007

Ps Don't forget visitors welcome Saturday & Sunday up to & including lunch - Just let us know.



Haemophilia Foundation New South Wales Inc.

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

2017-18

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 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

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Lauren Fehlberg (Social Worker)

Lauren.Fehlberg@health.nsw.gov.au

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C2 North, Sydney Children's Hospital

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Grainne Dunne (Nurse)

Direct: (02) 9382 1240

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Haematology Department

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John Hunter Children's Hospital

Lookout Rd

New Lambton Heights NSW 2305

General: (02) 4921 3000

Carol Doherty (Nurse)

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Simon Cavaliere (Social Worker)

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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:

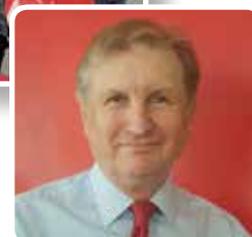
- Education and assistance to members with bleeding disorders and those who also have HIV
- Provide tutors and entertainment to members who might require extended hospitalisation
- Information and social activities for members and their families
- Rural visits to areas of NSW where there are no specialists

HFNSW COMMITTEE...

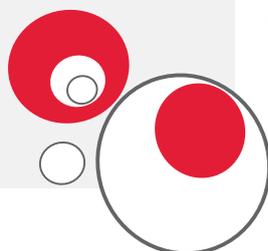
Being a member driven organisation, the committee is always interested in hearing from its members, community, friends and family. If you want to have a say in how the Foundation delivers its service and shapes its future, please contact the office at coordinator@hfnsw.org.au

Committee meetings held monthly

HFNSW Committee Group



Paul Bedbrook, Treasurer



Are you coming?
See you there!



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 HFA have been running conferences that provide current information and resources, discussion on topical issues and that look 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.

Chaired by Dr Huyen Tran, the program committee is developing a multidisciplinary program which will interest everyone. We are soon to confirm some of our local and international speakers.

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 welcome from young adults to seniors!
- 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

For HFNSW Members:

HFNSW strongly recommends the program, plus it is a great opportunity to catch up with others from the broad bleeding disorders community. And, as an HFNSW member, up to 100% of your conference registration is covered.

Please contact admin@hfnsw.org.au if you wish to attend.

For more information, registration and details visit

www.haemophilia.org.au/conferences

PROGRAM TOPICS

- New treatments
- Women/girls with bleeding disorders
- Carrying the gene
- von Willebrand disease
- Rarer bleeding disorders
- Using data to improve treatment and care
- Managing pain
- Blood borne viruses
- Ageing
- New diagnosis
- Youth
- Sport and physical healthy activities
- And...the future?