

# FACTOR MATTERS

Haemophilia Foundation New South Wales



Published by HFNSW

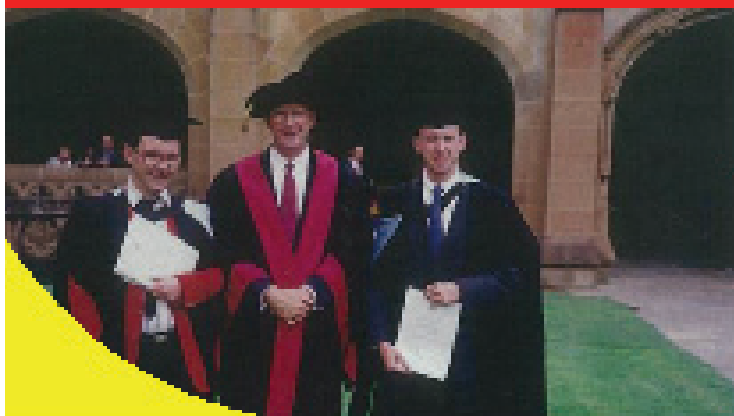
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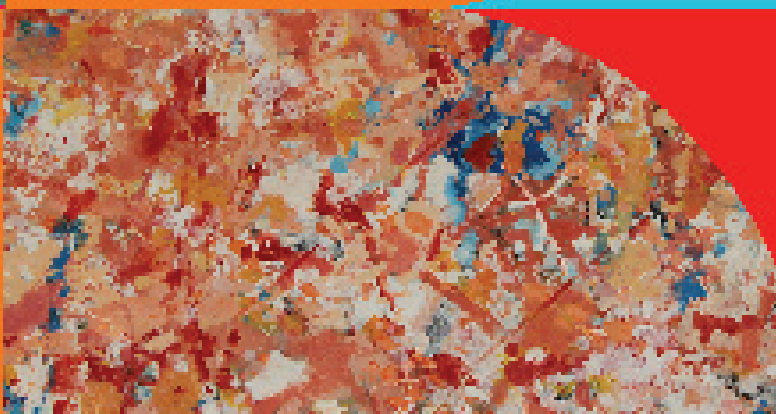
## HAEMOPHILIA FAMILY CAMP



## CELEBRATION OF THE LIFE OF LEO BELCHER



## MEET THE ARTIST!



## HAEMOPHILIA AWARENESS WEEK



## About Us

HFNSW is a 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/Treasurer  
Leonie Mudge - RPA Haemophilia Social Worker  
Craig Haran -  
Paul Bedbrook -  
Stacey Rohan -

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## Factor Matters, Vol 32: 2015, Sept Issue

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## In this issue

- p3 - Haemophilia Family Camp 2015
- p5 - PBAC Decision on New Hep C Drugs
- p6 - Celebrating the life of Leo Belcher
- p10 - Annual General Meeting 2015
- p11 - Personal Story: Blood transfusions keeps Austin alive
- p12 - World Hepatitis Day
- p14 - Haemophilia Awareness Week - The Red Trail
- p15 - Meet the Artist
- p15 - Haemophilia Foundation ACT Coastal Camp - Call for expression of interest!
- p16 - My ABDR Update
- p17 - Thank you to all our supporters and fundraisers
- p17 - Just Post It
- P18 - One last word from the president
- p20 - Haemophilia Awareness Week - "facing the future together"



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.



# HAEMOPHILIA Family Camp 2015



HFNSW will be holding its annual Family Camp on  
13, 14, 15 November 2015 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 October 23, 2015.**

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 0292802607 or email [coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au)

## Simple ways to help

Send us your gifts and other  
items to help for our camp  
silent auction

*Please contact the office if you wish  
to donate an item*

# Haemophilia Foundation New South Wales Inc.

ABN: 602 454 70729

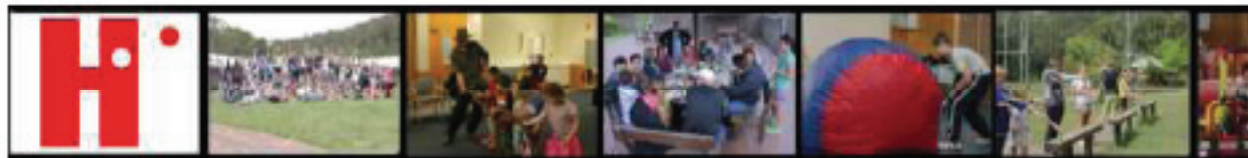
Member of Haemophilia Foundation Australia

Patron: Prof. Kevin A. Rickard AM MFD



## FAMILY CAMP 2015 Application Form

13<sup>TH</sup> to 15<sup>TH</sup> NOVEMBER 2015



### FAMILY MEMBERS

### AGE OF CHILDREN



ADDRESS: \_\_\_\_\_

Email: \_\_\_\_\_

CONTACT PHONE NO: \_\_\_\_\_

### ACCOMMODATION (TICK ONE ONLY)

- ☐ FRIDAY NIGHT ONLY
- ☐ FRIDAY AND SATURDAY NIGHT
- ☐ SATURDAY NIGHT ONLY
- ☐ DAY STAY ONLY (SATURDAY)

ANY SPECIAL ACCOMMODATION REQUIREMENTS \_\_\_\_\_


### MEALS — PLEASE INDICATE HOW MANY ADULTS & CHILDREN FOR EACH MEAL (CHILD — UNDER 15YR)

\_\_\_ 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 send printed form before Friday 23 October 2015 to HFNSW, PO Box 631, Broadway NSW 2007, or email to [admin@hfnsw.org.au](mailto:admin@hfnsw.org.au)

Haemophilia Foundation New South Wales Inc., Suite 5, 115 Mountain Street, Ultimo NSW 2007  
P O Box 631 Broadway NSW 2007 - Phone: 02 9202 8017 Mobile: 04 7063 7528 Web: [www.hfnsw.org.au](http://www.hfnsw.org.au)  
Email: [admin@hfnsw.org.au](mailto:admin@hfnsw.org.au) **DONATIONS ARE TAX DEDUCTIBLE**

Powered by New South Wales Health through SLHD





*Update from HFA*

In August 2015 the Pharmaceutical Benefits Advisory Committee (PBAC) recommended adding Viekira PAK® to the Pharmaceutical Benefits Scheme (PBS) for the treatment of chronic hepatitis C genotype 1. HFA welcomes this decision.

## GREAT NEED FOR EFFECTIVE NEW TREATMENTS

The PBAC evaluated the treatment thoroughly and stated that all the approved new treatments for hepatitis C are very effective - both Viekira PAK and the other hepatitis C treatments approved in March 2015. They recognised that these all-oral interferon-free hepatitis C treatments are greatly needed as a treatment option on the PBS.

Viekira PAK® (paritaprevir with ritonavir, ombitasvir, and dasabuvir, with or without ribavirin) would be another option for treating genotype 1 – as effective as treatment with Harvoni® (Ledipasvir with sofosbuvir).

## ACCESS DELAYS

However, once again the PBAC did not accept the proposed treatment prices.

There are now four new hepatitis C treatment combinations that have been approved by the PBAC and none are available yet on the PBS. These treatments are already available in many other countries.

“Access to these treatments is critical for Australians with hepatitis C. My community members with bleeding disorders and hepatitis C have been waiting for these treatments for too long. Every delay puts their health and their lives more at risk,” said Gavin Finkelstein, HFA President, in a recent media statement. “Government funding is needed urgently to list these medicines on the PBS. These treatments can cure hepatitis C – and if they are not on the PBS, these treatments are just not affordable for most Australians with hepatitis C.”

The next step in the process is for the Australian government to consider the PBAC recommendations and make decisions about funding. We hope the cost of these drugs can be negotiated success-



fully with the pharmaceutical companies without delay.

HFA is continuing to make representation to government about access to these treatments for people with bleeding disorders.

## AND IF YOU HAVE HEP C?

In the meantime - if you have hepatitis C and a bleeding disorder, remember that you would need to have your liver health assessed before you could be considered for treatment:

- Make sure you have your liver health checked regularly
- If you don't know where to start, ask your Haemophilia Centre for a referral
- Stay in touch with your hepatitis clinic about what's new
- Don't forget to go to your appointment with the hepatitis clinic after your liver health check, even if the fibroscan shows your liver health is stable at the moment
- And for comprehensive care, let your Haemophilia Centre know about your liver test results or how your treatment is going to make sure they stay in the loop.

# CELEBRATING THE LIFE OF

## *Leo Belcher*

Hello, my name is Garry Smith and I am Leo's cousin and friend.

One day when visiting Leo in hospital, he said: "Garry, remember this word..... Eulogy." Leo had such a way with words and asking you to do things!

What should I say about Leo? Well, for one thing, we all know he hated hospitals and unfortunately, this is where he spent a large part of his life.

Leo was diagnosed with haemophilia following his birth in 1958. This disease and associated complications restricted his life and was the source of much pain which Leo had to endure for most of his life. Complications from this ugly disease, eventually took him away from us.

Leo was a very brave person, accepting his illness and despite the very restricted limitations that he had, he always tried to get the maximum out of life.

I will never forget how courageous Leo was and the positive spirit that he possessed in combating the many painful challenges that became part of his life. I don't think I will ever forget his spirit and his bravery; he should be an inspiration to all of us.

Leo was in ill health for so long, it's hard to remember a time when he wasn't – but we mustn't forget what an amazing person Leo was, and how much he achieved and contributed to us in his life.

Leo was born in Gloucester, the eldest of 3 children to Les and Marie Belcher.

Leo's younger brother Graham, also passed away from complications associated with this disease. Leo often thought about Graham, or "Freddie" as the family called him, and he spoke about their love/hate relationship that they had while growing up. Leo would talk about Freddie's love of the Flintstones and of how he was possessed by cricket.

My earliest memory of Leo, Graham and Margaret was when I was about 12 years old and I was holi-

daying at Auntie Thelma's – the Connolly's – Kenny and Rods place at Waukivory and we came to visit Les and Marie at their family home in Gloucester. I was given strict orders not to punch, push or wrestle with the boys. I asked why and they told me that Leo and Graham had a blood disorder and were bleeders. I did not understand this and I was terrified, especially of Leo who kept on pinching me.

Leo had many memories about growing up. He especially liked the fishing outings. He enjoyed going out on the fishing trawler, "The Irene 3" and beach fishing with his family. A very funny day occurred once when they were fishing. Graham had his line out, but wasn't paying attention, so Leo walked down to the water's edge and gave Graham's line a good pull. Well, Graham pulled on his line, as if he had caught a marlin. They were great memories.

I asked Leo earlier this year if he had any regrets in his life. He thought for a while and said, "I would have liked to have gone fishing more with dad.... and the family".

Leo attended Gloucester Primary and Secondary schools and took on many extra curriculum activities. Under the encouragement and guidance of his parents, Leo learnt to play the violin, piano and the electric organ. It was with the organ that Leo found an outlet, an interest and passion. He played in several eisteddfods and won at State level....on two separate occasions. He gave organ lessons and for many years was the organist at this Church and for some time at St Joseph's Church as well. Leo also played at weddings, but his best memories were of the concerts that his mother arranged for him in their family home. Leo would play the organ and take requests from invited guests, while his mother would provide supper and transport some of the guests' home.

Around this time, Leo had a fond interest in astronomy and had his own telescope. He also had a good collection of books, magazines and articles on the topic and he used to share and discuss this interest with his teachers.

After he finished school and despite all obstacles,



*Sydney Uni Graduation Ceremony. From left : Leo Belcher, Prof Kevin Rickard and his son Justin*

Leo continued his studies and attended Newcastle University, receiving his Bachelor of Mathematics and his Diploma in Education.

In 1987 Leo became a Maths teacher at Dover Heights High School and later taught at Top Ryde High School.

The following year, he had to have bilateral knee surgery and left the class room to work at the Department of Education's Human Resources Department at Rozelle.

In 1990 his health deteriorated further and he was medically retired and moved back to Gloucester to live.

But his thirst for knowledge did not stop there; Leo continued his studies over the years, receiving:

- His Masters in Arts in Applied Mathematics in 1990 at Sydney University.
- His Masters in Arts in Pure Mathematics in 1993 at Sydney University
- His Bachelor of Science in Pure Mathematics at Armidale University 2006
- His Master of Letters at Armidale University 1997.
- And he also started a Forensic Science course and law and psychology.

While he continued his studies, Leo tutored many

students, assisting them with their studies and preparing them for exams.

Leo loved his Maths and as a Geography teacher, I could not understand this. For many years he would get his old teacher, Bob Clunes to give him copies of the HSC Maths papers, so he could do them. He would also ask Erin and Alex for their exam papers.

Leo wanted to be involved, up to date and he loved the challenges that Mathematics provided.

Leo gave presentations and spoke about his disease at community organisations and in 1997; he was awarded the Rotary Youth Leadership Award.

Leo also served the community and was a committee member of Gloucester Home Maintenance and was president of this committee from 2002 to 2011. This committee organised modifications to housing for those people with a disability or those with health problems enabling them to remain in their homes for as long as possible.

Leo was a keen card player and enjoyed playing with his family and friends and Margaret enjoyed being his partner. He was unpredictable at cards and had an uncanny ability to bamboozle his opponents... even his partner. I think Margaret was the only one who had the patience to be his partner.

Leo loved music and reading. He needed to broaden his knowledge and his library contained 15 tea chests of books on every possible subject. This quest for knowledge, wasn't just about him, he wanted to share his knowledge and encourage others to go further. It was Leo's constant encouragement the major reason behind Margaret becoming an RN.

I spoke to Leo about his knowledge once and how he should write a book or an article about living with haemophilia. He was interested at first and then after thinking about it, his response was "I don't think it will be a best seller!!"



Leo loved cooking and the family recalls when Leo learnt to make rock cakes in Year 7 Home Economics and how they had to eat nothing else but rock cakes for the next 3 months. He loved watching the reality TV cooking shows and on several occasions, he tried to share a recipe with me, but soon realised that apart from cooking BBQ's, I knew very little about cooking and he knew his efforts were in vain. Leo's love of cooking without doubt came from his mum, a passion that was shared with his sister.

Leo was very dependent on his mother for his health care. When she suddenly passed away in 2001, this had a huge impact on Leo and his life. He was lost and unsure. After living with Margaret and Hughie for a few months, he decided, with help from his father Les, to live independently in town.

Leo spent a lot of time visiting doctors and in hospitals. Apart from family, there are so many other people who helped him over the years, too many to mention all of them, but the family would like to thank a few. Les Potter, Leo's past Science teacher and friend, who transported Leo on so many trips. Dr Scott Dunkley and Dr Paul Stalley, Leo's Haematologist and surgeon at Sydney, Dan Credazzi, President Haemophilia Foundation NSW, Leonie Mudge, Haemophilia Social Worker and our local Doctor, Dr Garry Lyford, thank you for your time, effort and passion in the treatment of Leo.

Leo had a good relationship with all the medical staff who treated him, but he said: "they have left the best until last." Leo spoke very highly of Bishop Tyrrell Anglican Care, the facility and the staff. He didn't want to go to an Aged Care Home..... he wasn't old enough....but they made his stay pleasant.

Leo was a Christian and was very faithful to God and to his Church. For many years he was on the Parish Church Council and he enjoyed midnight mass. Because he was such a regular at Midnight mass, last Christmas, when he was unable to attend, they recorded Leo reciting verses and played them at the mass. This was very important to Leo. He also made some very good friends through the Church, particularly in Father Keith and Father John who he had the upmost respect and gratitude for.

God and the Church were a big part of Leo's life .... and he had made his peace with God.

Leo had many wonderful characteristics; he was a gentle person with a somewhat dry sense of humour. Later in life, his passion turned to family and friends. Leo became the family tree. He knew everyone, their birthdays, their phone numbers and when you visited him, it was never about him, but always about you and your family, where were they and what were they doing. He was always interested in you and your work and your trips. He had a great interest in family life and history. Family and friends were very important to Leo.

Leo looked forward to all his visitors and always thanked them for coming. The family would like to thank you all for your support and for caring so much about Leo and visiting him, especially in the past few weeks. A special thank you to the Connolly's, especially Rita Connolly and her family, in particular Magella and Greg. Thank you also to Robin Friend and Griselda Brown. ...You were all there, when Leo needed you the most.

Griselda you were always a good friend and had a deck of cards and a scrabble board in your car for whenever Leo wanted a game.

Recently, I was visiting Leo and during a quiet period I looked around his room and there were 3 photos on the shelves and I thought about the importance of those photos.

The first photo was of Leo in his academic gown receiving one of his degrees. He had that smile on his face and those big eyes.... An expression of pure pride....how hard was it for him to get those degrees and diplomas?... Leo always tried to convince me that he was an academic!

The second photo was a large photo of his mum ..... Marie. There was no doubt how much he loved his mother and how much he missed her.

The third photo was a photo of his two nieces, Erin and Alex. He told me once that they were his children ..... his girls too. He had watched them grow..... took an interest in their studies and in their careers. He was so proud of you and loved you both so much.

Leo's immediate family meant the world to him. He loved family get-togethers, birthdays and other events. He just enjoyed being with you.... especially at Christmas time. Leo loved Christmas; it was the highlight of the year. He would get the girls to come around to put the decorations up. According to Erin and Alex, he had boxes of decorations. They would empty one box and suddenly another full box would appear ..... and Leo



loved Christmas shopping. One year they went to K-mart and they had an electric scooter, he was a little reluctant to use it at first, but once he was on it, they could not get him off. He even got it stuck in one lane and they had to pull him back out.

He liked his electric wheel chair as well. I am sure he thought it was a 4 wheel drive, as he use to get it bogged while showing visitors the farm at Bishop Tyrrell. There is also a story about him driving his electric wheel chair down High Street, Taree, with Margaret in a panic and Dad offering encouragement to go faster, so he could jump a lip in a drive way.

Over the years, when visiting Leo, he would never complain about his condition or his pain, of course he would talk about it, but he never really complained. If you asked him how he was going, he would reply OK, or a little sore and switch the conversation to you and your family and what you have being doing.

But there was always a person that Leo would take time to talk about and that was his sister Margaret. When Leo's mother passed away, Margaret took on a lot of the responsibility that his mother was doing. Margaret became Leo's carer. When talking about Margaret, Leo said: "Do you know, she is not just my sister, she is my right hand, she is my best friend and I love her so dearly." Every time I heard Leo say goodbye to Margaret, whether it was on the phone or in person, the last thing I would hear him say, would be 3 little words ..... "I love you".

I picked up one of the articles Leo had beside his bed. It was about "knowing how the story ends ... how we are just passing through this world". Leo knew he was dying, but had accepted it and did not openly show whether he was worried about it, but I am sure he did think it was not fair, but I think he did believe he was passing through this world to somewhere else.

Leo and I went out to the cemetery once and we had a bit of a look around, visited some of those we knew and paid our respects, usually in silence and Leo said, "do you know, the older I get, the more people I seem to know in this place" .... Well Leo ... I will now be visiting you and we will have a silent conversation.

Leo, you will be sadly missed. We will remember you for the joy that you had in your life and what

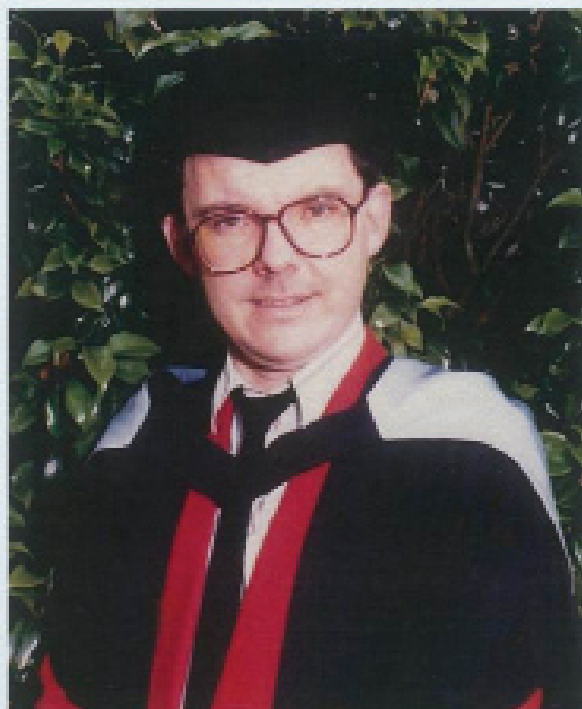
you meant to us.

We will all remember you for different things and these things we will keep in our hearts forever and every now again, we will smile as we think about you, for your love of family and friends will continue to be with us throughout our lives.

I have one last request from Leo ..... for his immediate family: Les, Val, Margaret, Hughie. Erin and Alex ... and for all other family members and friends .... and that is to say ..... I love you ..... and thank you.

See you mate!

Leo Charles Belcher  
Eulogy by Garry Smith, July 23, 2015



*Sydney University Graduation  
Ceremony, Leo Belcher.*



The Annual General Meeting 2015 of the Haemophilia Foundation of New South Wales took place on October 17, in Broadway. Thanks to our guest speakers, the Professor Kevin Rickard AM RFD, Patron of HFNSW, Dr Liane Khoo, Haematologist at the Royal Prince Alfred Hospital and Dan Credazzi, HFNSW president, this AGM provided a great insight into the past, present and future of Haemophilia treatment and care in Australia.

20 people attended the AGM: families, youth mentors, health professionals, committee members and our Manager for the NGO Program from the Sydney Local Health District.

We have been told some fascinating stories by our Patron, Professor Rickard. And this lead up to another captivating presentation from our expert Dr Liane Khoo about new treatment and therapies.

Our president Dan Credazzi also gave us a heads up on HFNSW achievements in 2014/2015 and financials.

This was followed by the election of next year's committee members. We are very thankful to all actual committee members who have agreed to stay involved for another year: Dan Credazzi was re-elected as HFNSW President, Garry Lynch as Vice-President, Leonie Mudge, Craig Haran and Paul Bedbrook as committee members.

Each year these meetings provide fantastic occasions to catch-up, connect and learn. We are very grateful and would like to thank again Professor Kevin Rickard, Dr Liane Khoo, our health professionals, Hamish Robinson, supporters and friends who have made it all possible.

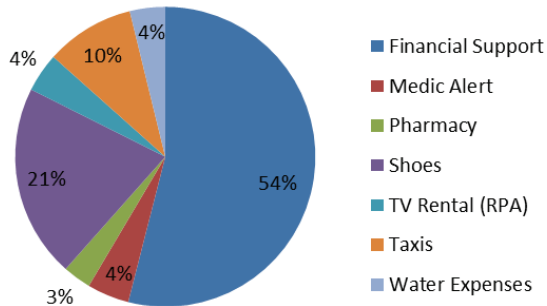
## HFNSW SERVICES IN NUMBERS

- **31** new families have joined the foundation and received assistance,
- **160** occasions of one on one support,
- **78** occasions of financial assistance for disorder-related costs,
- **30** families attended camp, **23%** of these families attended for the first time.
- **940** hours of support including health related activities during camp
- **5** health related information sessions and get together meetings inc. camp
- **4** newsletters
- **912** website visits

## FINANCIAL ASSISTANCE

During the year there were **78** occasions of financial assistance representing a total of **\$11,019**

Financial assistance spread  
% AUD per category - 2014/2015

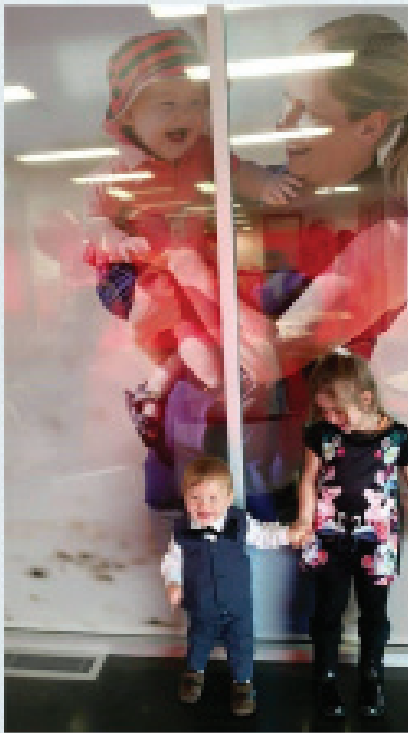


Total Assistance	\$11,019.33
Financial support (*)	\$5,948.32
Medic Alert	\$499.36
Pharmacy	\$335.45
Shoes	\$2,296.95
TV Rental (RPA)	\$462.72
Taxis	\$1,056.52
Water Expenses	\$420.01

**\*Financial support** : travel to camp, entertainment during long term hospitalisation, physio, medical trolley, RPA texting services, participation to SCHW ultrasound etc.

## Personal Story

### BLOOD TRANSFUSIONS *Keeps Austin* ALIVE



*Blood Bank Entrance  
with Austin, Francina  
and Amity*

*Austin is now one of the main faces at the entrance of the Newcastle Blood Bank. For the opening of the new centre, Austin and Francina were able to go to each person donating blood and thank them for their wonderful donations on behalf of all the fellow haemophiliacs.*

Without blood transfusions Austin Cummins would not have survived his first month of life.

Born with severe type A haemophilia, Austin, now fourteen-months-old, relies on weekly transfusions made from plasma. It is a sad truth that he will require many more for the rest of his life. Known as "liquid gold", the demand for blood plasma is rising nationally by 14per cent per year.

Newcastle is set to play a vital role in meeting Australia's increasing need, with a new donor centre opening at Broadmeadow.

The facility will replace the Watt Street Donor Centre and will allow 3000 additional appointments.

Red Cross Blood Service spokesman Steve Eldridge said the centre was geared to meet the rising demand, with an additional 700 plasma donations sought during the centre's first year of operation.

"Plasma is the golden coloured, nutrient rich part of blood used to make as many as 18 different life-saving products and new plasma therapies continue to be discovered," Mr Eldridge said. "It is used to help treat burns victims, haemophiliacs, trauma and cancer patients as well as those with blood and immunity disorders."

The new Lambton Road facility is one of the state's largest blood donor centres.

# World Hepatitis Day



- 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.
- It's time for action! If you don't know whether you have hep C or not, get tested now!

- If you have hep C and haven't had a liver health test in the past 2 years, it's time to get your liver checked now. Have your liver checked regularly.

- Did you know that if you need hep C treatment you need a liver health assessment first?
- Get a liver health check now.
- If you don't know where to start, talk to your Haemophilia Centre about a referral.

- If you have hep C, let your Haemophilia Centre know about your liver test results and treatment.

**Don't wait for warning signs**

If you're living with HEPATITIS B or C (or think you may be), talk to your doctor about a regular LIVER CHECK-UP. It's easy and it could save your life.

**WORLD HEPATITIS DAY**

hepatitis can't wait

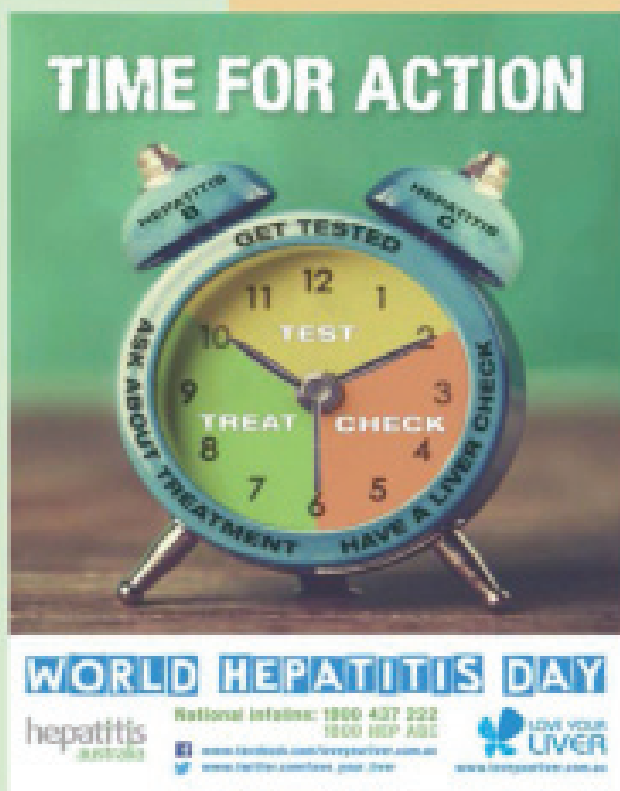
National helpline: 1300 437 222  
[www.hepatitis.com.au/hepatitis](http://www.hepatitis.com.au/hepatitis)  
[www.livercheckup.com.au](http://www.livercheckup.com.au)

**KEEP YOUR LIVER**  
[www.livercheckup.com.au](http://www.livercheckup.com.au)



- If you have hep C, stay in touch with your Hepatitis clinic for latest news and updates
- Does someone in your family have hep C? Talk to them about looking after their liver!
- Visit the Love Your Liver website for easy recipes for a happier healthier liver!

It's time for action! Know if you were exposed to hep C; Get tested; Have a liver check; Ask about treatment.



Love Your Liver

<http://loveyourliver.com.au/>

Love Your Liver health check

<http://loveyourliver.com.au/liver-check-ups>

Love Your Liver recipes

<http://loveyourliver.com.au/entrees-and-light-meals/>

HFA Hep C news

<http://www.haemophilia.org.au/news/id/565>

## New Hep C Personal Stories Book

29 Australians have come together to tell their story of living with Hep C. Among the individual accounts are the personal stories of two authors who have bleeding disorders: Ian Pengelly, from Queensland who has Von Willebrand disease, and Malcolm Cockrum from NSW who has Haemophilia.

Every story in the book gives a different perspective and includes comments from friends and relatives.

You can download or read the book online at  
<http://www.hepatitisaustralia.com/together-we-can/>



## The RED Trail

Supporting Haemophilia Foundation NSW

A family-friendly charity event raising awareness and vital funds for people with bleeding disorders during

Haemophilia Awareness Week



Walk it! Ride it! Roll it!  
Sunday 11th October 2015  
10am - 2pm



Leichhardt Oval no3  
Maliyawul St,  
Lilyfield



Scan QR code  
to view website

Attend our FREE EVENT and WEAR RED to show your support.

We welcome everyone, young and old,  
to come participate all for a great cause.



Scan QR code  
to donate

Pack a picnic, hat & sunscreen and join 'Our Heroes' on the inspirational 7km Challenge!

Haemophilia Awareness Week is an opportunity to raise awareness about Haemophilia, von Willebrand disorder and related inherited bleeding disorders during the week of 11 – 17 October 2015.

The RED Trail is a great opportunity for the bleeding disorder community to meet up with other families, share your stories, and make new connections. Invite your friends and your neighbours to join us to help bring awareness about Haemophilia and related inherited bleeding disorders in the community. We welcome everyone, young & old, no matter what fitness level to come participate all for a great cause.

Pack a picnic, hat & sunscreen and join 'Our Heroes' on the inspirational 7km Challenge - a walk to honour past and present Heroes, whilst also raising vital funds to support HFNSW. Finish the

day enjoying delicious cakes by CakedOut-3D and refreshing drinks at our Red Cake Stall.

In support of Haemophilia Awareness Week, here's your chance to help raise awareness by sharing your story. We would love to feature the various bleeding disorders in our community. Whether you have Haemophilia, von Willebrand Disorder (vWD), or you are a symptomatic carrier, feel free to email us your 'Hero Story', attach some pictures and we will add you to 'Our Heroes' page.

Read the Hero Stories shared by other families and to find out more about The RED Trail, visit our website at: [haemophiliaevents.wix.com/theredtrail](http://haemophiliaevents.wix.com/theredtrail)

Together we can all make a difference !

Lyn & Jayden Wong



# MEET *The* ARTIST

In July 2015, HFNSW met with Thomas, a young artist from the Central Coast passionate about painting.

We heard from Clare Waite (RPA Nurse) that a young man at the Royal Prince Alfred Hospital had a talent and a story we should really hear about! So off we went to meet Thomas who shared with us aspects of his life, guided by passion and dedication to art.

Thomas got his inspiration from growing up in Sweden where he visited a lot of art galleries and discovered many different styles. Back in Australia he had a big project to work on for school and started painting with a particular style, inspired from waves. It made a big impression on his school teachers who encouraged him to keep on painting.

With orange as a favourite colour, when he was younger Thomas painted a lot of sunsets inspired by the views

he had from a beach house. Later his style progressed towards abstract painting and when he paints or finds a good style, Thomas can just keep on painting throughout the night!

Painting makes Thomas feel happy, relieved, and proud too when a painting is finished! He also gets advice, support and feedback from his brother Hamish. It is a passion unrestricted by his condition and Thomas would like to make it his profession. A lot of work has been done and his big dream is to open an exhibition.

We heard that the Haematology Clinic at The Royal Prince Alfred Hospital has received two wonderful original pieces: one in the treatment room and one in the patient area... so next time you visit, be on the lookout for the artwork!

Thank you Thomas.



## HAEMOPHILIA FOUNDATION ACT COASTAL CAMP *Call for Expression of Interest*

HFACT is calling for anyone interested in attending a camp and has extended its invitation to HFNSW members.

Date: Friday 8th April - Sunday 10th April 2016. Note this is the first week end of ACT and NSW holidays.

Venue: Camp Longbeach, just north of Batemans Bay.

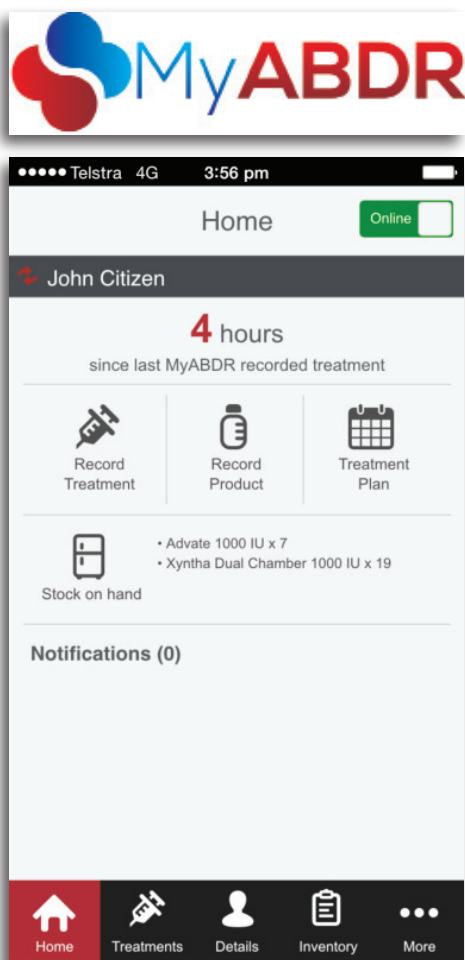
- A quiet bush setting by the beach not far from Canberra.
- Accommodation options include cabin and camping.
- A range of facilities for gentle and sporting activities.
- HFACT needs your expression of interest before

they can finalise the venue and make bookings.

HFACT camp will offer a mixed program of fun leisure activities and informative sessions, an occasion to catch up with old friends and make new ones, supervised fun stuff for children during sessions, plenty of time for the adults to relax and have fun too. A small contribution to the cost will be required.

If you or your family members are interested in attending the family camp please contact Haemophilia Foundation ACT at: [secretary@hfact.org.au](mailto:secretary@hfact.org.au)

Update from the HFA and the National Blood Authority My ABDR Team



## WHAT'S NEW?

A new version of the MyABDR app was released in August 2015, bringing you more improvements and features:

- Faster synchronisation
  - Access to your HTC contacts and Help pages without needing a data connection
  - Bug fixes to prevent any duplicate stock and treatment entries, and to tweak the time 'since last MyABDR recorded treatment' timer and the default treatment day.
- These changes are all in response to user feedback over the last few months.

Make sure you update your MyABDR app to take advantage of these new enhancements and fixes!

## NEED HELP?

Don't hesitate to contact the MyABDR Support team with any queries. Meghan, Danny, Lachlan or Rebecca are available 24/7 and will be happy to assist you.

T: 13 000 BLOOD / 13 000 25663

E: [myabdr@blood.gov.au](mailto:myabdr@blood.gov.au)

Available 24 hrs a day, 7 days a week.

## MYABDR AT THE CONFERENCE

Look out for the National Blood Authority booth in the exhibition at the 2015 Gold Coast Conference in October.

The team will be keen to catch up with you about MyABDR to fill you in on the latest developments and what is planned, get your feedback and suggestions, and to help you with any queries.

## MYABDR SURVEY

Thank you to all those who replied to the MyABDR user survey held in July 2015. We had a wonderful response rate and will use all your feedback and comments to develop future enhancements for MyABDR. We are analysing the data and will provide a summary feedback and what we are actioning from the feedback in coming weeks.

## MYABDR FUTURE PLANS

The next release of MyABDR will be available in mid-October, and will include the ability for users to request their own updated emergency card and whether they would like it sent to their Haemophilia Treatment Centre or direct to their nominated delivery address.

This update in October will also further streamline the treatment recording process to make it even easier to add in treatments.



# Thank you

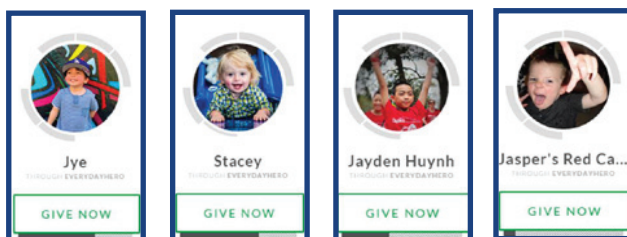
## THANK YOU TO ALL OUR SUPPORTERS AND FUNDRAISERS

Many friends and members are showing their support by planning a Red Cake Day event between 11-17 October at their workplace, school, Treatment Centre or at home.

Others have created fundraising pages for Haemophilia Awareness Week, The Red Trail, Red cake day events or the Blackmores Sydney Running Festival.

Your support through awareness or fundraising is vital for your foundation, so we would like to thank you once again and wish you all the best for your events!

Visit their everyday hero page:



Support Sarah for Sydney Running Festival  
on GoFundraise



## Support Foundation!

Visit the donation or membership pages on the Haemophilia Foundation NSW website :

<http://hfnsw.org.au/>

### Payment Details

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

### EFT Payment

BSB: 062 204

Account number: 00902590

Account Name: Haemophilia Foundation NSW

Please include your name in the comments field  
and email your receipt number to

[admin@hfnsw.org.au](mailto:admin@hfnsw.org.au)

## Just Post-it

FAMILY CAMP 2015

Save the date

13 - 15 November 2015

Haemophilia  
Awareness Week  
2015

Save the date

11 - 17 October 2015

THE RED TRAIL

Come and visit us  
on the Leichhardt  
Oval no3 from  
10am to 2pm

11 OCTOBER 2015

Family Planning  
Discussion Session  
Newcastle

CALVARY MATER

To be announced shortly  
on HFNSW Website

HFNSW Staff  
Delphine Schwartzmann

Will be on maternity leave for  
6 months starting on  
October 16, 2015

Tony Wilkinson

will be covering the position  
[coordinator@hfnsw.org.au](mailto:coordinator@hfnsw.org.au)



*Dan Credazzi -*

On September 17th, we held our Annual General Meeting and were treated to a couple of fascinating presentations. Our Patron, Professor Kevin Rickard AM, reminded us of the rich history that Australia has had in the care and development of treatment for people with bleeding disorders. We learned that Queen Victoria had originally dispatched her son Leopold to Australia in the late 19th century with hopes that the warm climate might help his mysterious condition. As it turned out, he couldn't make the voyage and so she sent her second son and fourth child, Prince Alfred. Alfred had a grand time in Oz, touring the colony and getting along with the natives. That is until 1868 when one bad seed named O'Farrell visiting Sydney from Ballarat decided to shoot the Prince in the back. The Sydney siders were aghast and immediately set upon the assailant, and just about hung him on the spot. As you can imagine, the colonists were so ashamed and worried that such a thing should happen to one of the Queen's sons, that the elders got together and decided to build and name the largest hospital in Australia after Prince Alfred – who by the way recovered from the assassination attempt and lived a full life.

And this is how the RPA became the RPA. Which went on to become the first haemophilia treatment centre in Australia and also one of the original centres which formed the World Federation of Haemophilia, i.e., a true, global centre of excellence. (Prince Alfred is also the name of the Haemophilia Treatment Centre in Victoria, Melbourne - The Alfred Hospital, known these days as The Alfred).

And this brought us up to the present day at our AGM, ready for our next speaker, Dr Liane Khoo, Haematologist at the RPA and one of the world's

leading researchers into new treatments and therapies. Did you know that at the RPA, at our own central treatment centre, trials are currently underway with longer acting factors, sub-cutaneous factory therapy and even gene therapy for Haemophilia B was trialled successfully at the RPA a few years back. So the thread of history which started in 1868 - when the NSW Legislative Assembly decided "to raise a permanent and substantial monument in testimony of the heartfelt gratitude of the community at the recovery of HRH" – runs right through our HFNSW and into the future. And because of our home-grown heroes like Professor Rickard and Dr Khoo, we are front and centre.

It was a truly great evening that night at our AGM (in the shadow of the RPA) seeing old friends and meeting new ones. We hope you can attend the next one, or one of our evening information sessions.

We also took the opportunity to thank Delphine – who is going on maternity leave – for her tireless work and expert management of our Foundation and its programmes. And then introduced Tony Wilkinson as your Foundation Coordinator while Delphine's away. And that was another page turned in our history book. So here we are – now in our 56th year - in the business of helping you to write your page.



## 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 Childrens Hospital  
High St. Randwick NSW 2031

Phone: (02) 93821240

Gráinne Dunne (Nurse)

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

Kate Lenthén (Children's Social Worker)

[Kate.Lenthén@sesiahs.health.nsw.gov.au](mailto:Kate.Lenthén@sesiahs.health.nsw.gov.au)

### Royal Prince Alfred Hospital Haemophilia Treatment Centre

RPA, Missenden Road

Camperdown NSW 2050

Leonie Mudge (Social Worker)--(02)9515 8385

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

Clare Waite (Nurse)

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

Stephen Matthews (Nurse)

[stephen.matthews@sawahs.nsw.gov.au](mailto:stephen.matthews@sawahs.nsw.gov.au)

Phone: (02) 9515 7013

### Calvary Mater Newcastle Haematology Department

Corner of Edith & Platt Streets  
Waratah, NSW 2298

Phone: (02) 4921 1211

William Whitbread-Brown (Nurse)

[William.whitbread-brown@calvarymater.org.au](mailto:William.whitbread-brown@calvarymater.org.au)

Melissa Walker (Bleeding Disorders Social Worker)

[Melissa.walker@calvarymater.org.au](mailto:Melissa.walker@calvarymater.org.au)

Dale Rodney (Nurse)

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



## HFNSW MEMBER SERVICE

Membership \$11 (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

## JOIN THE COMMITTEE

HFNSW is looking for new talent to join our Management Committee. Free training and induction is available to all new Committee members. 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

All committee meetings are on a Tuesday evening and commence at 6.00pm

November 17, 2015  
December 15, 2015  
February 16, 2016  
March 15, 2016  
April 19, 2016  
May 17, 2016

June 21, 2016  
July 19, 2016  
August 16, 2016  
September 20, 2016  
October 18, 2016  
November 22, 2016

***All are welcome to attend!***



# Haemophilia Awareness Week

## *"Facing the future together"*

11-17 October 2015

P: 1800 807 173 W: [www.haemophilia.org.au](http://www.haemophilia.org.au)

### Haemophilia

- A rare inherited genetic bleeding disorder where blood doesn't clot properly as there is not enough of a protein in the blood (called factor VIII or IX) that controls bleeding
- It's incurable and can be life threatening without treatment
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems
- Most people with haemophilia are male
- Women and men can have the haemophilia gene and pass it on to their children
- Some women who carry the gene also have bleeding problems

### Von Willebrand disorder (VWD)

- A bleeding disorder where there is not enough of an essential blood clotting protein (called von Willebrand factor) for blood to clot properly
- Both men and women have VWD

### Affected Australians

In Australia there are more than 5,300 people with haemophilia, von Willebrand disorder or other related inherited bleeding disorders.



**Haemophilia Awareness Week • 11-17 October 2015**  
**[www.haemophilia.org.au](http://www.haemophilia.org.au)**