Factor Matters

Haemophilia Foundation NSW

Published by HFNSW November 2016 Volume 34

HAMISH WONDERS ABOUT MYABDR DATA?
MORE NEW MEMBERS, HEAR FROM ONE...
THOUSANDS ATTEND WFH ORLANDO 2016
INCLUDING SAM LINNENBANK & HFA PRESIDENT,
WHO REPRESENTED AUSTRALIA AT WFH CONGRESS

ALL OF THE ABOVE **PLUS A MAJOR FEATURE OUR PATRON ON PROFESSOR BLACKBURN...** *& MORE!*

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About Us

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

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Factor Matters, Vol 34: 2016, Nov Issue

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Design: Steve Williams, Red Inc.

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Prof Blackburn. This portrait was commissioned by former students and colleagues from RPA & Sydney University. It hangs in the entrance hall of RPA.

Funded by New South Wales Health through SLHD

A Word from the President...

Dan Credazzi President Haemophilia Foundation New South Wales

Another packed edition, and so much important to our community….

It was my pleasure to recently personally welcome a new member, Nimal Kankanamala (see pic). *New members* are a great indication of HFNSW's continuing health & relevance. Another, Saravana Prasath, has generously penned the story of his journey for us.

Sadly Prof Blackburn has passed. Our Patron, Prof Kevin Rickard who joined the celebration of 'Blackie's' life at a packed Memorial in Sydney University's Great Hall has written about this important figure.

It's great to hear some positive anecdotes about the responses to the **amazing Hep C treatments** that really do offer a cure!

Using **MyABDR** remains an important (and convenient!) innovation, but how does it work?

Hamish, a MyABDR convert, asks ABDR data manager, Alvin what goes on behind the scenes...

And there's so much more,

HFA have produced '***thefemalefactors***', up-to-date Australian information, especially for women within our bleeding disorder mcommunity (your copy included).

'**Factored In**', the young member (mediated) web site has been even further developed.

Sam Linnenbank, and many others are back form **Orlando, WFH 2016 World Congress**.

Thanks to all associated with **our recent AGM…** a great attendance and interest in our guest speakers. We are trying to promote the availability and uptake of physiotherapy, so were delighted to have Bec Dalzell, experienced adult haemophilia physiotherapist speak, along with our patron, Prof Rickard and Sam Linnenbank all speaking.

Thanks to all those who supported **Haemophilia Awareness Week, & Red Cake Day!**

And finally, if you haven't done so already, please renew your membership, on line or use the form included, p14.

Warm Regards,

Dan Credazzi

Welcoming one of many new members

HFNSW participates in a NSW Health NGO Consultation

'LEST WE FORGET'

PROFESSOR C. RUTHVEN B. BLACKBURN AC. ED. MBBS, MD, BA, Mdhc, FRCP (LOND)

Thanks to Lloyd Williams for providing the Memorial Program

A MAN FOR ALL SEASONS

The Haemophilia community in NSW, in Australia and on the world scene, will note with sad regret the passing on April 12, 2016 of Emeritus Professor Ruthven Blackburn just short of his 103rd birthday. At this memorial service on May 30, 2016, in the Great Hall of Sydney University, he was compared to Sir (St) Thomas More. 'More (Blackburn) was a man of angels' wit and singular learning, a man of marvelous mirth and pastimes – a man for all seasons'. His son, Dr Simon Blackburn spoke of his father's ten careers! Accordingly, it is relevant to focus on one of these – Blackburn's influence in the world of haemophilia especially in Sydney.

Professor Blackburn was a giant of a man in medicine in Australia, in Sydney, at Sydney University and at the Royal Prince Alfred hospital. His impact extended to the Royal North Shore Hospital, Sydney Hospital and Concord hospitals, as well as at St. Vincent's before that hospital became affiliated with the University of NSW. He loved teaching medical students. Thus, he influenced academic medicine and the teaching of the science of medicine throughout much of Sydney during his 21-year tenure as Chairman of the Department of Medicine at Sydney University where he also served on the Senate.

THE BLACKBURNS

Like his father before him, Sir Charles Bickerton Blackburn, the longest serving Chancellor of the University of Sydney, Professor Blackburn also had a great influence on the deliberations and activities of the Royal Australian College of Physicians and Royal Prince Alfred Hospital (RPAH). He was awarded the Hamilton Fairley Medal of the RCP (Lond) and the RACP in 1975 and the John Sands Medal of the RACP in 1984. At RPAH he became Senior Physician, member of the Board of Directors, Chairman of the Division of Medicine and Chairman of the Project Planning Team, which led to the development of the Edinburgh Block. He published 190 articles in the scientific and educational literature and no less than 36 of his protégée's became professors of medicine and 16 Heads of clinical departments.

Through his earlier leadership of the Clinical Research ward at RPAH and later as Head of the Division of Medicine at RPAH he had enormous influence for good on the welfare and care of people with haemophilia at RPAH. This influence extended over a period of 35 years. It continued for many more years after his retirement in 1978 from the Bosch Chair of Medicine at Sydney University.

PROFESSOR OF MEDICINE

When appointed to the Chair of Medicine Prof. Blackburn had already experienced a remarkable career. He graduated top of his year in 1936 with First Class Honours, the University Medal and took all the prizes. He completed his MD thesis in 1939 on Multiple Myeloma, trained in London and New York and had had a proud career in the Australian Army from 1940-1945. As NX12614, he served as physician with the 2-5th. Australian General Hospital in Palestine, Greece, Eritrea and New Guinea. Subsequently he was the Commanding Officer Senior Physician as Lieut. Col. Of the Malaria Research Unit working in the Atherton Tablelands out of Cairns with Sir Neil Hamilton Fairley. Their work under the auspices of General Blamey, with the support of General MacArthur, on the Chemotherapeutic Suppression and Prophylaxis of Malaria offered enormous medical support to the Australian Army campaign in New Guinea and particularly on the health of troops on the Kokoda Track.

When Prof. Blackburn was appointed to the Chair in 1957 he followed the great Scottish teacher from Edinburgh, Prof. Charles Lambie, MC MD. Dr Blackburn had also collaborated closely with Sir Harold Dew, MB (Melb), DSc (Cantab), FRCS when the latter was Foundation Prof. of Surgery in their combined care for people with haemophilia. Dew, himself, had an illustrious career in the WW1 Military, and at the Hall Institute in Melbourne. He subsequently became Dean of the Faculty of Medicine at Sydney. He was well known for his studies and writings on hydatid disease. Dew also found empathy and understanding for the welfare of people with haemophilia where he foresaw the need for a more organized approach to haemophilia care at RPAH and looked to the younger Dr. Blackburn for support.

HAEMOPHILIA AT RPAH

Perhaps it was predetermined that an abiding interest in Haemophilia developed at RPAH since it could be said there is a 'family history' of the condition in the hospital. HRH Prince Alfred, the Duke of Edinburgh, after whom the hospital was named following the attempt on his life at Clontarf, in Sydney in 1868 had a strong connection with Haemophilia. Alfred's brother, Prince Leopold, the Duke of Albany, the eighth of Queen Victoria's nine children had severe Haemophilia. Two of his sisters, Princess Alice and Princess Beatrice, were carriers of the gene. Prince Alfred's mother, Queen Victoria, had ten male descendants with Haemophilia and seven female descendants were carriers.

Mitochondrial DNA mutation analysis results published in 2009 on the 91 year old remains of the Romanovs found in the Ural Mountains of Russia, relate to Haemophilia. The granddaughter of Queen Victoria, the Tzarina Alexandra and her son, the Tsarivitch Nicholas, great grandson of Queen Victoria, were carrying the gene for Christmas disease. This bleeding disorder was first described by the group at Oxford in 1953. In relation to the British Royal family and consequently the Romanovs, the Factor 9 gene mutation probably arose spontaneously in Queen Victoria herself.

In the clinical research ward, (CRW) the new Professor Blackburn became interested in many complicated medical conditions, which came to him from a wide Sydney referral basis including the likes of Dr Alan Maginniss from Sydney Hospital. In the CRW, Blackburn became involved with haemophilia care, where people with haemophilia made direct contact. "It was not something a Prof. of Medicine could do as a sideline", he said but in the CRW he had a valuable stable medical staff. So a continuing line of physicians appeared who took a great interest in haemophilia such as Prof. Charles Kerr, Prof. Barry Firkin, Dr Marc Playoust, S.J., Dr Peter Harvey, Prof. Peter Harey, Prof. Peter Castaldi and Prof. Kevin Rickard. From 1957 much of the laboratory diagnostic work was based on a Haematology unit established at RPAH with significant input from Prof. Blackburn. In 1958, Dr Harry Kronenberg, a pioneer of laboratory Haematology in Australia, was appointed Haematologist and assumed the role as Head of the new Dept.of Haematology. He led the Dept. through amazing developments over the next 45 years. All these early appointments happened when Dr Edgar Thompson was General Medical Superintendent of RPAH. Thompson, a microbiologist of note, later became the Foundation President of the Royal College of Pathologists of Australia and President of the AMA.

My appointment as Haematologist to RPAH in 1969, where I spent the next 35 years, was due to the support of Dr Harry Kronenberg, Prof. Blackburn and the General Superintendent, Dr Donald Child. A prime duty of the appointment was to be responsible for the care of people with haemophilia and other bleeding disorders. In all of this Prof. Blackburn was a mentor and friend. In the 60s and 70s, people with haemophilia were admitted under his care in the professorial ward of BP2. The use of blood products was always an essential aspect of haemophilia care. Prof. Blackburn, himself, served for many years on the Blood Transfusion Committee of the NSW Red Cross where he influenced policy and collaborated with the Director, Dr Gordon Archer. Blackburn encouraged my active participation in the World Federation of Haemophilia, based in Montreal, Canada and was so pleased when the haemophilia centre at RPAH was designated an International Haemophilia Training Centre of WFH in 1979. It was the first of its kind in Australia and indeed in the southern hemisphere. Blackburn's influence was indeed far reaching in matters relating to haemophilia in this country.

My suggestion to the authorities at RPAH and the Director of Nursing in the early 70s, that nursing sisters, as I had seen in London, Oxford and Boston, be closely involved in interventive haemophilia care in the Professorial ward was supported by Prof. Blackburn and accordingly was approved. A long line of wonderful nursing sisters became active in the front line care


Health
Sydney
Local Health District

Emeritus Professor Charles Ruthven
Bickerton Blackburn AC ED MBBS MD BA MDHc FRACP
(1913 - 2016)

of people with haemophilia in Blackburn's ward but later in the newly designated Haemophilia Centre. Then Premier of NSW, the Honourable Mr Barrie Unsworth, officially opened the new Haemophilia Centre in 1987. Monies from a fund connected to my wife, the Godsil Family Foundation, established this centre. All these nursing sisters extended the kindest of care to the boys and young men with haemophilia and their families.

In the last decade, the medical care of people with haemophilia at RPAH has rested with Dr Scott Dunkley and more latterly with Dr Liane Khoo. Critical in haemophilia management as always has been the skilled laboratory services for clotting Factor assays, in diagnosis, quality control and inhibitor detection provided by the Haematology department until recently directly directed by Prof. D. Joshua. Rapid advances in genetics now see more frequent patient and family genetic analyses and carrier detection especially for the FVIII Intron 22 Inversion. These are provided by Prof. Ron Trent's genetics laboratory at RPAH.

The role of the nursing sisters developed and extended to provide the kindest of care to the boys and young men with haemophilia and their families. These nurses included among others, Pat Dorrity, Jean Campbell, Wendy Fischer, Denise Colbert, Fiona Rennison, Stephen Matthews and Clare Waite. The haemophilia nurses were trailblazers for the further active 'hands on' role of nursing officers in the continuing management of many patients in specialty areas of medicine at RPAH.

ORIGINS OF THE HAEMOPHILIA SOCIETY OF NSW (NOW YOUR HFNSW)

Prof. Blackburn's influence played a big part in the formation of the then Haematologist Society of NSW. At a meeting of the NSW Red Cross Blood Transfusion Service in York St. on Sept. 22, 1959, Dr Roger Vanderfield, Deputy Medical Superintendent at RNSH and father of a boy with haemophilia was appointed as the Foundation President of the Society. Certainly Blackburn was a catalyst for all of this when he, Sir Lorimer Dods, Prof. of Child Health at Sydney University, Prof. Robert Walsh of the Blood Transfusion Service as did Dr Ron Sawers, from Victoria, wrote encouraging letters to Dr Vanderfield. The first specialized clinic for haemophilia care in NSW had already been commenced at RPAH. Dr Colin Croker of the Dental Hospital, Earl Williams, a pharmacist, A.R. Green, W. Nicholas, K. Hatton and F. Shaw were all members of that first Haemophilia Society Committee.

The first international meeting on haemophilia was conducted during the Congress of the International Society of Haematology (ISH) held at the University of Sydney in August 1966. Such luminaries as Drs Rosemary Biggs, (U.K.), J.P. Soulier (France), Margareta Blomback (Sweden), Ken Brinkhouse (USA), C.E. Harris (Canada) as well as Dr Peter Castaldi and Dr Bob Walsh from Sydney participated. The meeting had some opposition with the concurrent screening at the Congress of a film on the birth of a kangaroo! This attracted a strong audience of overseas visitors.

COMPREHENSIVE CARE

This portrait was commissioned by former students and colleagues from RPA & Sydney University. It hangs in the entrance hall of RPA.

In the continuing evolution of haemophilia care in the 70s, 80s and 90s, supported by Prof. Blackburn, the nursing sisters were valuable in the implementation of two major concepts in haemophilia care, namely the practice of *home therapy* and the coordination of *comprehensive care*. The latter involved the formation of a multi skilled team to optimize haemophilia care, such as the rheumatologist, Dr John York, orthopaedic surgeon, Dr Peter Holman, immunologist, Prof. Roger Garsia, general surgeons, dental surgeons, Ms Louise Martin, physiotherapists, blood bankers as well as experts in pathology diagnostics in Haematology, microbiology and biochemistry all coordinated and led by the Haematologist, ably assisted by the haemophilia Charge Sister. This collaboration all occurred in the designated haemophilia centre, which was the hub of a spoked wheel, optimizing haemophilia care. The nursing sisters were certainly crucial when it came to the aftercare for the person with haemophilia undergoing surgical intervention.

SUPPLY AND DEMAND

Prof. Blackburn was always interested in the development and use of increasingly effective products for the treatment of people with Factor VIII and Factor IX deficiency or von Willebrands disease. Such products ranged from Blomback Fraction 1-0, cryoprecipitate, CPG (Margolis) concentrate, heat inactivated Factor VIII concentrates to second and third generation recombinant products. For those with IX deficiency products ranged from plasma, the French concentrate PPSB, then Autoplex, Factor IX concentrates and subsequently recombinant products. All this to such an extent, that the Australian and State Governments together, spend $200 million on recombinant products and a total of $525 million on fresh blood and plasma products each year.

A TALE OF TWO CITIES - THE GOOD AND THE BAD

Blackburn, probably with his earlier Army background of 'supplies-procurement', was always interested in the 'supply and demand' situation for therapeutic products. In some ways this stimulated the development of the Haemophilia Therapy Review Group of NSW based at the Blood Bank. This group coordinated and ensured liaison between the various teaching hospitals in Sydney, for the rational supply and demand of Factor products, especially for elective surgery.

We witnessed the evolution of the Hepatitis c pathology from the early phases of acute infection in the 60s and 70s through cirrhosis to the now sinister appearance of hepatic cell carcinoma. When the HIV problem arose in the early 80s in Australia we were all totally shocked, perplexed and deeply saddened when some with haemophilia were affected and lost their precious lives to a ruthless virus at that time unrecognised. Here again, Prof. Blackburn was a great support, participated in discussions and offered his wisdom.

It is salutary to realise in the long and productive life of this man that in the year of his death giant strides are being made towards the correction of haemophilia by gene therapy. The latest approach uses the relatively common method of the intravenous injection of a super virus carrying the normal gene. The gene hones in on the liver cell to stimulate the production of the missing Factor.

So much can be said about Prof. Blackburn's contribution to medicine in such specialty areas as hepatology, gastroenterology, respiratory medicine and immunology and haemophilia care in Sydney. He was eternally vigilant. The haemophilia community owes him an enormous debt of gratitude. I think he would say he was doing 'his job' as a caring physician and a humane doctor!

The Haemophilia community in NSW may well rejoice in the centenarian life of our colleague, doctor and friend, Professor C.R.B. Blackburn, AC. We can be especially grateful to his trailblazing, longstanding and lasting contributions to the welfare and care of people with haemophilia and their families. We offer our sincere condolences to his caring family, his sons, Simon and Angus and to his daughter, Sandra. His first wife, Nell Freeman and his second wife, Prof. Ann Woolcock, AO predeceased him as has his daughter, Ann.

Perhaps our best act of gratitude to him is for the Haemophilia Foundation of NSW to continue its crucial commitment to the optimal care and safety of people and families with bleeding disorders in NSW.

Your Patron
Kevin A. Rickard

Prof. Kevin A, Rickard 6/6/16
AM, RFD, MBBS (Melb), FRACP, FRCP (Lond), FRCP (Ed.) FRCPA, FRCPath (Lond)

Prof. Blackburn Remembers
(Part I)
By Prof. C. R. B. Blackburn

ABOUT THE AUTHOR

Professor Charles Rulhven Blackburn retires from his position as Chairman of the Division of Medicine at Royal Prince Alfred Hospital and Chairman of the Department of Medicine at Sydney University on December 31. He has been Professor of Medicine since January, 1957.

Professor Blackburn's father, Sir Charles Rulhven Blackburn, was Chancellor of the University of Sydney from 1941 until 1964, and also Honorary Physician and Honorary Consultant Physician at R.P.A.H. for many years.

The following is part of an address given by Prof. Blackburn to a gathering in October. The remainder will be published in the next edition of the magazine.

Prof. C. R. B. Blackburn

THE pattern of this seminar is based on the premise that the future of academic medicine depends on the attitudes of academics and their settings rather than on external pressures and so I will present:

(1) a prejudiced and personal account of the acquisition of and changes in my attitudes to academic medicine;

(2) an account of the setting at Sydney in 1957;

(3) some references to changes in the medical school in the past 20 years, specially those involving me and the Department of Medicine and which affect the present setting; and

(4) some comments on some of our problems and how I look at some of the academic solutions.

What of my undergraduate medical course? What do I recall now that influenced my attitudes?

Being locked into Physiology and Biochemistry lectures; enjoying hours and months of dissection and remembering some anatomical irrelevancies;

standing, standing and standing on ward rounds, often while the H.M.O. examined the patient in detail;

learning three different classifications of nephritis to regurgitate to whichever examiner asked about it in the finals;

wonderful tutorials on Clinical Medicine from Bill Morrow in a 1 to 1 setting;

and many clinical cases in hospitals.

Mostly, I remember the men and women who taught me, not what they taught, but this does not mean the course was not good. On the contrary, it was excellent.

Two men who were major positive influences on my academic attitudes were Neil Hamilton Fairley and Robert F. Loeb.

In the latter 2½ years of my army career, Brigadier Neil Hamilton Fairley F.R.S. was my Director. I commanded the Army Malaria Research Unit at Cairns. He was a great man who accomplished a great deal by having an intensely loyal staff, which he worked very hard. In his research, he saw the central problems and attacked them getting what he needed — nothing was too hard — he was like a bulldog when he wanted something he regarded as necessary. He had a tremendous capacity for arousing enthusiasm and for presenting the practical application of research to laymen.

Our work was concerned with the administration of drugs to volunteers who were given

Fourth Year Lecture Notes with Professor Lambie's book on Clinical Diagnostic Methods in comparison with a modern textbook.

R.P.A.

SUMMER ISSUE, DECEMBER, 1978

Keen MyABDR user & advocate, Hamish Robinson wonders about all that data? Alvin Hooi explains, 'What Data Managers do?'

In simplistic term, we manage and coordinate the protocols for data entry/flows into the ABDR – Australian Bleeding Disorder Registry.

In Australia, every state or territory has at least a haemophilia treatment centre (HTC) with a designated data manager like me! We provide clinical support to clinicians (doctors, nurses and allied health) in maintaining the database registry, reporting and feedback.

Overview... the big picture

The ABDR provides health-care teams, support staff and users with a record that better enables them to monitor and manage treatment over time, thus improving quality of life.

This data, de-identified, is a valuable resource for researchers, seeking to better understand and improve the treatment of bleeding disorders. The release of any such information is considered against strict and specific criteria, designed to be highly protective of individual user privacy.

ABDR data also provides governments with information on total clotting factor product requirements, key to their supply planning for all Australians with a bleeding disorder.

More Locally... MyABDR practically applied

Clinicians require this comprehensive database registry that captures patient data and provides feedback on annual bleed rate, trend analysis and treatment regimen compliance for decision making purposes in healthcare.

We need patients to be compliant and take the initiative themselves in recording of personal usage of factor replacement for clinical monitoring. This data will enable clinicians to do forward planning and funding of factor concentrates on a national basis.

The famous boxer Muhammad Ali once quoted: "Your hands can't hit what you can't see".

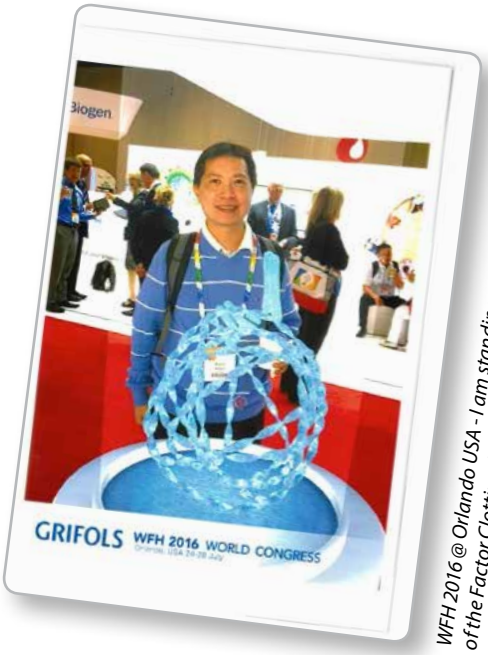
Hence, your collaboration, advocacy and feedback is important evidence to help clinicians to plan ahead and show patients' treatment regimens are effective to maintain government funding for treatment products. Please refer MyABDR app for more information.

For more info or need help?
Don't hesitate to contact the MyABDR Support Team with any queries. Meghan, Danny, Lachlan or Rebecca are always available & happy to assist you.

T: 13 000 BLOOD / 13 000 25663
E: myabdr@blood.gov.au
Available 24 hrs a day, 7 days a week.

Alvin

Alvin at Orlando WFH World Congress 2016



WFH 2016 @ Orlando USA - I am standing next to a 3D hologram of the Factor Clotting / Protein molecule.

Hi, my name is Alvin Hooi and I am the Bleeding Disorders data manager for Sydney Haemophilia Treatment Centres (HTCs). I was given this opportunity to attend the WFH 2016 @ Orlando USA and one topic that stands out was the Research Epidemiology Workshop. It gave us an insight into medical research and what are clinicians' needs in the study and analysis of a preventable disease in healthcare.

What is Epidemiology? The study and analysis of the patterns, causes, and effects of health and disease conditions in defined populations. It is the cornerstone of public health, and shapes policy decisions and evidence-based practice by identifying risk factors for disease and targets for preventive healthcare.

Basically, epidemiology is the study of how often diseases occur in different groups of people and why. Epidemiological information is used to plan and evaluate strategies.

Clinicians require a comprehensive database registry that captures patient data and provides feedback on annual usage rates, trend analysis and treatment regimen compliance for decision making purposes in healthcare.

We have to start getting this clinical data for clinicians to formulate a plan and strategies.

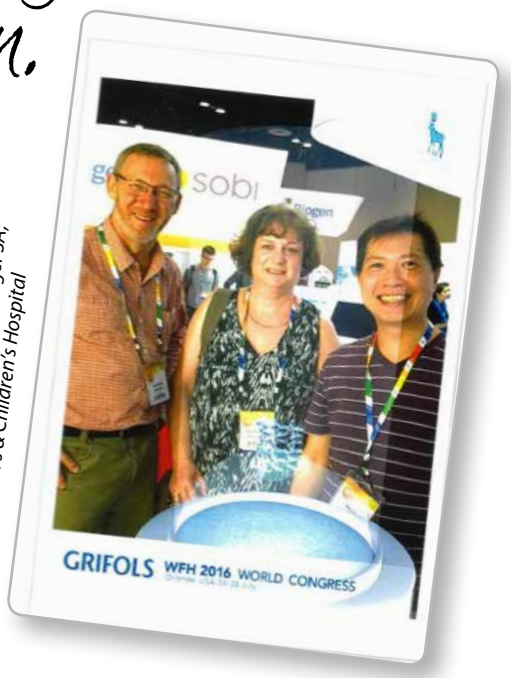
WFH plays a fundamental role in coordinating data being collected in the Annual Global Survey. This comprehensive survey includes selected demographic and other de-identified data on people with haemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders throughout the world. The reporting tools can be customised to fixed/real time, automated validation, customisable queries and 'view in graphs'.

"There is no one-size-fits all approach in data collection, but there is a credo: quality data needs to be trustworthy, appropriate, understandable and powerful" said Alfonso Iorio, McMaster University, Canada.

The type of health care system in a country can also influence data quality. In Australia, we are "lucky" to have a comprehensive health care system. We are more likely to identify patients with haemophilia even if they don't require treatment. This is in comparison to developing countries health care, where it is likely that patients with haemophilia who do require treatment may not be identified.

Hence, quality data is extremely useful in advocating for better care for people with bleeding disorders. It is important evidence to help clinicians to plan ahead and make appropriate decisions in health care. The data can be used to monitor trends in health, help decision makers to allocate and distribute medical resources.

Warm regards,
Alvin.



Alvin with Andrew Atkin, CNC, Royal Adelaide Hospital & Voula Vournas, Data Manager SA, based at Women's & Children's Hospital

Personal reflections on having a bleeding disorder & his amazing journey

I would almost continuously keep asking myself... 'How will my bleeding disorder affect my life & prospects?'

And to be honest with you, reflecting now it's always never been difficult for me to lead a happy and normal life.

In fact, it's possibly this disorder that has substantially made me the person I am today! Surely, it evoked in me the attitudes and confidence I have.

Remember that Haemophilia is a disorder and not a disease. I believe there is a lot of difference between the two. In my view, we have to be a little cautious and take good care at the time of bleeding. Indeed, being precautious is good, but the bleeding disorder should not come to dominate or diminish our desire to peruse a normal life.

Yes, ofcourse!, we are as normal as others, though from time to time we may get a bleed.

We should have this motto in our mind always. "Yes!!! We are and We can".

My Journey... which I barely believe myself

I would like to share my life journey till now. Here it goes.

Now here I am in Sydney, working as a software professional. My journey, all the way from the Southern part of India to here, is almost unbelievable to me. Really I am happy and feel the way I was brought up (to face all challenges) was a most precious gift! It gave me confidence, and set me on a path to challenge and persist when I met any barrier in my life.

Having a son with 'a bleeding disorder', meant it was difficult for my parents to get admission for me to a school. No schools in our home town were ready for such a challenge. After a persistent struggle, one school (St. Joseph's) offered admission. This was not so straight forward as they had a condition (only one) - that my mother should accompany me daily. And not just to (& from) school, but stay the whole school day! From then on my Mother did accompany me to the school, spending her whole day sitting in the corridor. This continued until my 8th grade - by then I had grown, was trusted more and had many friends, we all shared the responsibility of 'looking out' for me. During my secondary examination, I suffered from a serious psoas muscle bleed. My family and I faced a dilemma, could I even make it to the exams? But I didn't give up, and my friends came to the fore. They would literally carry me to the exam hall everyday, where I managed to sit through the 2 hours of exams.

Result? I gained admission to a University! And with that a new challenge - it was 300km away from my home town. My mother required a lot of convincing, but eventually I gained her permission to take up the place. This was the first time I was going to be away from my parents. Lots to think about, not least the isolation from the familiar, family and friends? But I was strong in my decision. I wanted to get some exposure so I took the hard decision.

Now, from my heart I would say that this is best decision I have ever taken in my life. Since then, I've never looked back, so far the days have been golden! College is where I found myself and it's the reason why I am here. I had an opportunity to learn and experience this beautiful life more than academics. I got a chance to mould myself and develop a positive attitude towards life. Once again my friends played a vital role, and I now reflect... 'did I receive this wonderful support without realising it?... without much insight in real time? I was and am always truly special for them, not because I am a special child, but out of the real love and bonding.

And finally I got a job as a software engineer.

I started my career in the northern part of India and there I met my beloved life partner. She truly loved me for what I am and she continues doing that perfectly still. All went well and we are here now happily. Still I am restricted in a few things. And the reason is certainly not that I am haemophilic. The reason is mainly for my beloved ones surrounding me. I don't want to let them worry or go down because of me.

Attitude is everything!!! It's all in our hand and how we mould ourselves by being ourselves.

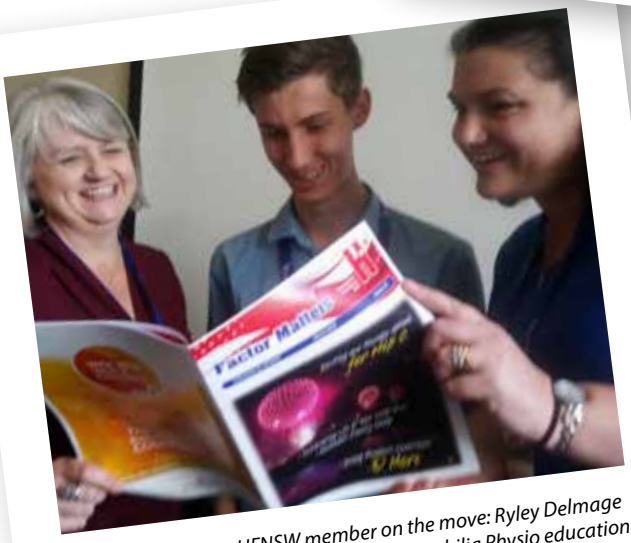
Don't ever give up!!!
Be happy and make others happy!

Cheers
SP (SaravanaPrasath)

HFNSW's Picture This... Including Our AGM!

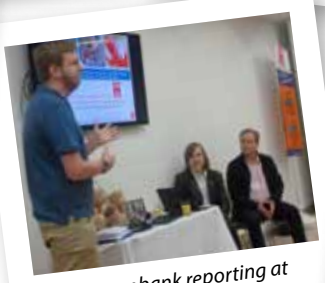
"Is that Sam at the UN?" No, but close – he is representing Australia at the WFH Congress with HFA President Gavin Finkelstein.

HFNSW at a NDIS talk via NSW Health SLHD.



And another young HFNSW member on the move: Ryley Delmage gave the consumerperspective at a Haemophilia Physio education day, with CNC Robyn Shoemark & Jo Newson, paediatric physio from Westmead Children's Hospital.

HFNSW's Picture This... Including Our AGM!



Sam Linnenbank reporting at Orlando.

Post AGM - the stayers.

Lyn Bearlyn & Nimal, one of many new members, with Steph Brown & Leonie Mudge.

Craig, Heather & Sam.

Thx Supporters! (pics p12)

Support Your Foundation!

Haemophilia Xplained (see back cover)

Launch of HFNSW's website

Probe Research continues for Haem A– phase II Thx participating members!

HFA's Factored In looking good!

thefemalefactors

A snapshot of bleeding disorders in females

Information for women

Haemophilia - carrying the gene

What does it mean to "carry the gene"?

Everyone has the genes responsible for making factor VIII (8) and factor IX (9). These factors are necessary for blood to clot.

Haemophilia is caused by a mutation in the factor VIII (haemophilia A) or IX gene (haemophilia B). This altered gene is commonly called the "haemophilia gene".

If you are a female who "carries the gene" or a male with haemophilia, you will have a genetic alteration in your factor VIII or IX gene and can pass this altered gene on to your children.

Haemophilia is inherited and occurs in families, where the altered gene is passed down from parent to child. However, about one third of all cases appear in families with no previous history of the disorder. This happens when a new genetic mutation occurs during reproduction. The child who is conceived will carry the altered gene or will have haemophilia.

If someone is diagnosed with haemophilia or as carrying the gene, it is likely that other members of their family also have haemophilia or carry the gene. Diagnosis will also include checking the family history for bleeding problems. Other family members, including females, may also need to be tested for haemophilia.

Your Copy Enclosed (if by mail).

Membership Renewal Form

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 Foundation New South Wales Inc., Suite 5,88 Mountain Street, Ultimo NSW 2007 P O Box 631 Broadway NSW 2007
Ph: 02 92802607 Web: www.hfnsw.org.au Email: coordinator@hfnsw.org.au; admin@hfnsw.org.au

HAEMOPHILIA CENTRES

Kids Factor Zone
The Children's Hospital at Westmead

General: (02) 9845 0000
Robyn Shoemark (Nurse)-- quote Pager no. 7052
robyn.shoemark@health.nsw.gov.au
Ady Woods (Nurse)-- quote Pager no. 6273
adrienne.woods@health.nsw.gov.au

Sydney Children's Hospital Randwick
Haematology

C2 North, Sydney Childrens Hospital
High St. Randwick NSW 2031
Direct: (02) 9382 1240
Gráinne Dunne (Nurse)
Grainne.Dunne@sesiahs.health.nsw.gov.au

Royal Prince Alfred Hospital
Haemophilia Treatment Centre

RPA, Missenden Road
Camperdown NSW 2050
Stephen Matthews (Nurse)
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Phone: (02) 9515 7013
Clare Waite (Nurse)
clare.waite@sswahs.nsw.gov.au
Leonie Mudge (Social Worker)
Direct: (02) 9515 8385
leonie.mudge@sswahs.nsw.gov.au

Calvary Mater Newcastle
Haemotology Department

Corner of Edith & Platt Streets
Waratah, NSW 2298
General: (02) 4921 1211
Dale Rodney (Nurse)
Dale.rodney@calvarymater.org.au
Melissa Walker (Bleeding Disorders Social Worker)
Melissa.walker@calvarymater.org.au

HFNSW MEMBER SERVICE

Membership $20 (inc. GST)

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

Newsletter: Your quarterly newsletters from HFNSW and HFA offers information and details of events, personal stories, education, treatment information, etc.

Financial Assisstance: MedicAlert Bracelets, Shoe rebates, Travel assistance, Education & Training, grants.

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

HFNSW COMMITTEE...

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

Committee meetings held monthly