

Factor Matters

Haemophilia
Foundation
NSW



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Summer/Autumn 2020

Volume 41



Family Camp ~ what a fun weekend!

It's **World Haemophilia Day** on **April 17**
Get+involved (pg13)

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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Hamish Robinson - Member
Dr Liane Khoo - Member & Clinical
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Stephanie Devine - Member
Sam Linnenbank - Member

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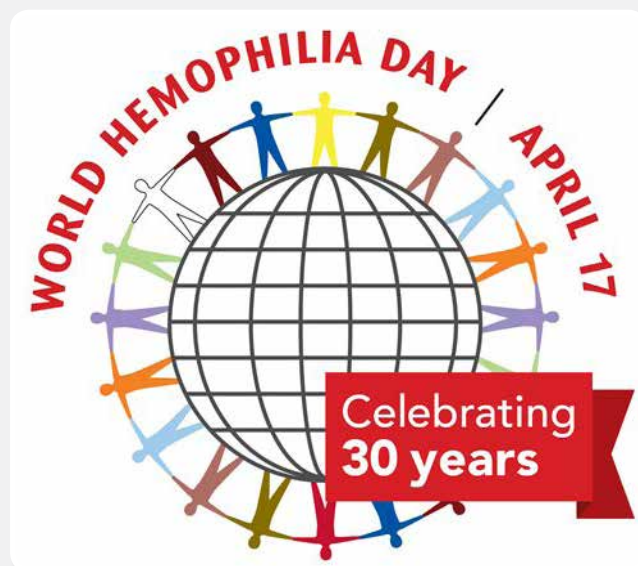
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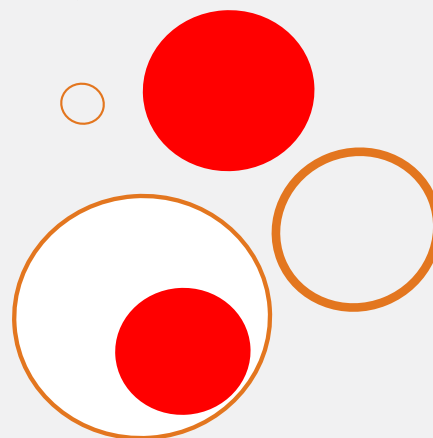
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On the cover: Family Camp



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Tony Wilkinson

It feels like we've all journeyed from bushfires to COVID-19! We hope you and your family are all staying well and safe in the current situation.

HFNSW has been very busy the past few months.

What a delight for me to join John Hunter HTC's 'Treasure Hunt'. The children had so much fun, a big thank you to the staff. Later when attending Dr Harry Kronenberg's memorial, I recalled HFNSW Patron Prof Rickard's high praise for all that unseen lab work that puts our HTCs on such solid clinical foundations. I wondered how Dr Kronenberg would have felt seeing the kids from Newcastle (complying with all protocols) so in awe, engaged and in amongst it in the lab.

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders held in Manly in October was a very informative and great conference. It was great to see many members come along.

Also in October was the HFNSW AGM & Info Evening. HFNSW activity for 2018-19 was summarised, and our ongoing Committee confirmed. We heard about Personal Treatment Journey's from Sam Linnenbank & Hamish Robinson, as well as Sam Duffield reporting his participation on an HFA & WFH auspiced Twinning Project trip to Myanmar.

Our annual Family Camp followed in November. Have you checked out this issue's picture gallery? Human FOOSBALL was a new and popular activity. Apart from the Infusion Workshop it was great to welcome Nicoletta Crollini, Haemophilia Social Worker (RPAH) and Ron Fleischer, Genetic Counsellor, who not only attended but ran great Info Sessions.

For the 2nd Year HFNSW joined a Rare Diseases Day event.

HFNSW continues to support research and we are asking for our members who haven't already to fill out the PROBE survey (more info in this newsletter) and thanks to everyone that completed the 'Getting Older' survey.

Alas, it is with much disappointment that due to COVID-19 we have postponed the Sydney Family Day and HUNTER VALLEY Day Out! We hope to run these later in the year.

On COVID-19 it's important to stay informed. Haemophilia Foundation Australia will provide relevant information when necessary, keep an eye on their website www.haemophilia.org.au or like their Facebook page <https://www.facebook.com/HaemophiliaFoundationAustralia>.

If you have general health or coronavirus concerns you are advised to contact your General Practitioner for advice. Do not change medications you are currently taking or begin new medications without consulting with your doctor.

If you have concerns about treatment for your bleeding disorder or your treatment product contact your HTC team in your usual way. It is recommended that you phone the HTC before presenting at the HTC.

In relation to ongoing supply of treatment products in Australia, the National Blood Authority has contracts with suppliers in place to ensure adequate supplies of local and imported clotting factors, including national reserves and advises there is no reason to expect any threats to supply at this time.

Take care and warm regards,

Tony Wilkinson

HFNSW Coordinator



R-L, Dr Tatjana Kilo Haematologist, Hamish Robinson HFNSW, Robyn Shoemark CNC, Adi Woods CNC, Sam Deylami HFNSW, Tony Wilkinson HFNSW

Thank you to everyone that attend the annual Family Camp. It was great to see old families attend and meet some new ones. The Camp is an important event on our calendar and so much fun for all. Over the weekend everyone got to participate in canoeing, human foosball, swimming and kids had fun at the Children's Party Disco, while parents had the opportunity to meet others. We were lucky enough to have 2 great workshops on Genetics & the latest on Testing, Ron Fleischer, Genetic Counsellor, RPAH, SLHD and The Female Factors' Experience, facilitated by Nicoletta Crollini, Social Worker, RHAP HTC, SLHD. We look forward to seeing you all later in the year.





TREASURE HUNT AT JOHN HUNTER HOSPITAL

The John Hunter Children's Hospital held a Treasure Hunt in the hospital for the children. They got VIP backstage access to so many parts of the hospital.



After meeting, each child was given a showbag which would then be filled with prizes they would select from a large pool, one prize for every question correctly answered on the treasure hunt. Our wonderful tour of hospital departments most relevant to the boys bleeding disorders began.



First step: The labs



While waiting in our lab coats Max noticed product with his name on it, in a row of fridges.



Once in with our lab guide, it was into gloves and lab coats.



As the tour advanced there were many highlights. One was the activation of plasma demonstration.



The kids were riveted by the equipment and detail. The lab staff were also intrigued by our presence. Remember these technicians in highly controlled lab conditions rarely meet those who benefit from their highly skilled work.

TREASURE HUNT AT JOHN HUNTER HOSPITAL



Before we left the lab there was a quiz on what we had seen and the relevance to the boys treatment and more prizes!

Onto the emergency department.

Then onto Medical Imaging. Social Worker Kristy "Why would you go here?"

And onto the haematology ward where the boys would come if an admission was required.

Jamie asks another question 'What would be required if you came here?' Answer: 'An admission band'.

The tour finished back at the Treatment Centre.

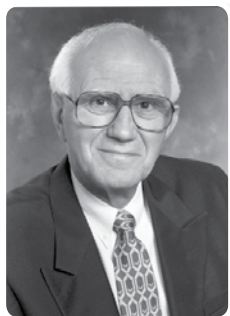


With all their correct answers the boys went on to select and collect their prizes from the pool.

The kids were made welcome wherever we went and we thank all the staff, particularly Jaime and the team for such a fun and educational afternoon.



**Dr Harry Kronenberg, AM MBBS DCP FRACP FRCPA
1926 – 2019**



**Dr. Harry
Kronenberg AM,
haematologist
at RPAH for over
40 years died,
peacefully at home**

**amongst those who loved and
cared for him on October 11,
2019. He was 93 years old. He
was deeply respected by his
peers as a clinician, Haematology
department head and medical
educator. An afternoon event
was held at RPAH in Nov 2019
to pay respect to his most
distinguished career.**



*Prof. Kevin Rickard
speaking at the service*

Dr Kronenberg was appointed haematologist at RPA in 1957 at the age of 31, and then served his patients and Department of Haematology with consistent loyalty for 50 years. He directed the Blood Transfusion Service at the hospital ensuring the safety and compatibility of blood transfusion practice in all those

years. In doing all this he provided a tremendous service to the people with haemophilia and their families, providing at all times an accurate, rapid and accredited diagnostic service.

He led the way to the introduction of increasingly sophisticated methodology for diagnosis and management at RPA. A full blood count could be done within a minute or two and sometimes up to 700 blood counts were done per day. Such a highly efficient level of testing was interfaced with the wards and outpatient services by rapid computer transmission of results to the clinician.

It was possible to quickly obtain accurate results necessary for the diagnosis of haemophilia and other bleeding disorders. Such precise testing enabled quality control of blood products used in treatment. The availability of a first-class haematology laboratory is essential for haemophilia treatment and care. Dr Kronenberg's laboratory was certainly one such entity.

More than 170 research papers were produced by his department. One author described Dr Kronenberg as "a well-balanced and competent haematologist... Aside from his laboratory managerial responsibility involving significant staff management, he carried a very heavy clinical load in the treatment of people with haematological malignancies." The latter involved considerable psychological challenges.

Born in Melbourne, Dr Kronenberg graduated in Medicine from Sydney University. He was a Foundation Member and Fellow of the Royal College of Pathologists of Australasia, Fellow of the Royal Australasian College of Physicians and of the Royal College of Pathologists of London. For a number of years, he was also Consultant in Haematology at both the Royal Alexandra Hospital for Children and Concord Hospital. He was Chairman of the Scientific Committee of NSW Red Cross Blood Transfusion Service. A member of the Joint Specialist Advisory Committee of the Australasian Colleges of Pathologists and Physicians. Harry was made a Distinguished Fellow of the Royal College of Pathologists of Australasia in 2001 and a Member of the Order of Australia in 2001 Australia Day Honours List for Services to Medicine, Blood Transfusion and Medical Education.

The haemophilia community in NSW owe much to the scientific endeavours of Dr Kronenberg over 50 years, for his continuing knowledge, skill and scholarship.

HFNSW extends its eternal gratitude to Dr Kronenberg and deepest sympathy to his family.

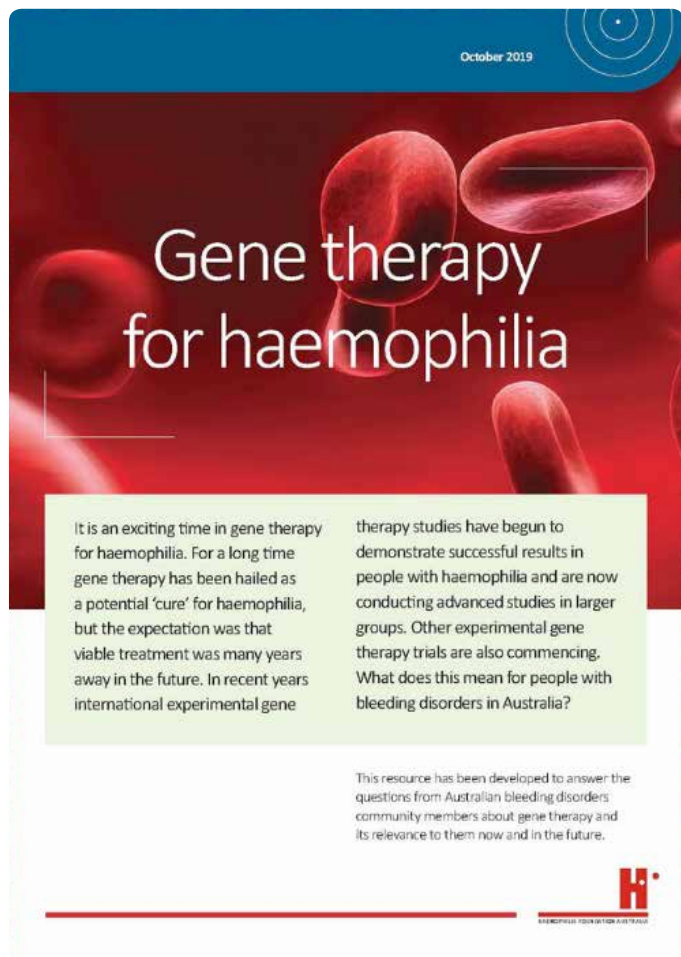
Your Patron,

Prof. Kevin Rickard, AM, FRACP, FRCP(Lond), FRCP(Edin), FRCPA, FRCPATH(Lond)



New gene therapy resource

Do you have questions about gene therapy for haemophilia?



HFA's new resource **Gene therapy for haemophilia** was developed to answer the questions from our community:

- What types of gene therapy are used in haemophilia?
- How does gene therapy work?
- Is it a cure?
- How safe is it?
- Who can have gene therapy?

The information includes diagrams to explain simply how genes and gene therapy work.

OUR THANKS

We would like to thank the bleeding disorders community members and expert reviewers who made valuable contributions to this resource, and to our designer, Ray Hehr, for his clear and thoughtful diagrams.

This resource was funded by an education grant from BioMarin.

HOW TO ACCESS IT

Gene therapy for haemophilia is available online on the HFNSW website (www.hfnsw.org.au), under ABOUT BLEEDING DISORDERS.

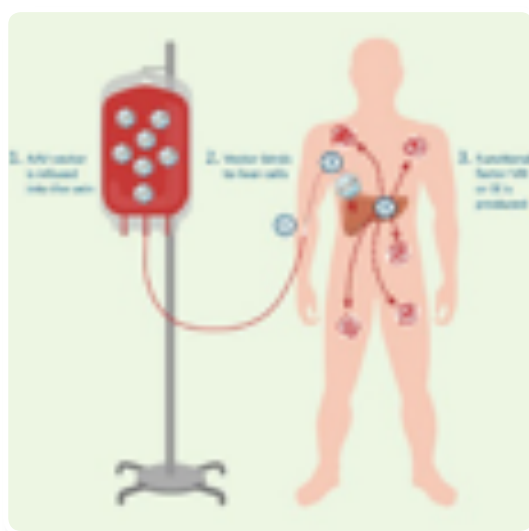
A print copy has been included in this issue of Factor Matters.

To find out more about **Gene therapy for haemophilia** or to order print copies, contact HFA:

E: hfaust@haemophilia.org.au

T: 1800 807 173

W: www.haemophilia.org.au



Thanks to all who supported Red Cake Day during Bleeding Disorders Awareness Week 13-19 October 2019

It kicked off as a morning tea at Manly Conference and included events at Kidz Factor Zone Westmead, Pfizer, and Calvary Mater Hospital Newcastle.



GETTING OLDER PROJECT UPDATE



Preetha Jayaram, HFA Getting Older Project Officer

LET'S TALK ABOUT GETTING OLDER

My thanks to those of you who took the time to participate in our Getting Older Community Survey. This survey was part of our needs assessment and was a way to hear from the wider bleeding disorders community members about what is needed and the strategies and services that would help with getting older. This survey was available online, and the print version was mailed out to community members. We had a good response and are looking forward to the insights that will come from analysing your answers.

FOCUS GROUP WORKSHOP

In late November 2019 we held a community focus group workshop to consider digital solutions, such as an online information hub on getting older with a bleeding disorder and digital peer support options. The group gave valuable contributions about what an online hub should look like. Thanks to the group for their hard work and inventiveness!

INFO HUB

As a first step in our digital solutions, we have been working on an online information hub for the HFA

website with resources on getting older with a bleeding disorder and peer support options. The information hub will grow and develop over time as we explore the issues raised in the needs assessment. It is currently being designed with the assistance of the HFA Getting Older Focus Group and will be available soon – watch this space!

WHAT'S NEXT?

The Getting Older needs assessment report will include recommendations, including areas to explore further. The aim is to start a discussion both the community and health care providers about where to go next with the recommendations and to look at ways to achieve them. We would value your input and you will have opportunities to provide more comments and suggestions.

ANY QUESTIONS?

If you have any questions about the Getting Older Project or needs assessment report, please contact Suzanne at HFA.

Phone: (03) 9885 7800 Tollfree: 1800 807 713

Email: socallaghan@haemophilia.org.au



It's not too late to complete the PROBE (Patient Reported Outcomes Burdens and Experiences) questionnaire!

The survey is available at
tinyurl.com/PROBE-Australia

Or ask HFA or your Foundation for a print copy

HOW WILL PROBE HELP PEOPLE WITH HAEMOPHILIA?

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if:

- you are an adult with haemophilia or carry the gene
- or you are an adult and DON'T have a bleeding disorder (as a comparison group)

Consider being involved to help us with this important study!

ANY QUESTIONS?

For more information about PROBE in Australia, visit www.haemophilia.org.au/research/probe-study

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173



World Haemophilia Day 2020 – 17 April 2020

Get+involved

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

April 17, 2020 is the 30th anniversary of World Haemophilia Day! The longevity of this celebration is proof of the dedication and tight-knit nature of our community.

The theme of World Haemophilia Day in 2020 is “Get+involved”. Whether you are a patient, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world.



WORLD HAEMOPHILIA DAY
2020 | APRIL 17

GET+ INVOLVED




WORLD HEMOPHILIA DAY
2020 | APRIL 17

GET +IN VOL VED

 facebook.com/wfhemophilia

 Find important educational resources
and hear from top experts at
elearning.wfh.org

 [@wfhemophilia](https://twitter.com/wfhemophilia)
Comment, tweet, follow and hashtag
#WHD2020 to stay social!



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

It is with much disappointment that both the Hunter Valley Day Out and Sydney Get together have both been postponed. We will advise new date as soon as we can.

SYDNEY GET TOGETHER SATURDAY 18 APRIL 2020

Join us for a get together in Sydney to meet others and celebrate World Haemophilia Day (17 April).

This event is open to all ages, parents and carers.



Date: Saturday 18 April 2020

Where: Sydney Live Steam Locomotive Society

Cnr Anthony Rd & Betts St West Ryde
(next to West Ryde Marketplace carpark)

Time: 1.30pm onwards

RSVP: 14 April 2020 to hfaust@haemophilia.org.au or call 1800 807 173

Names of all attendees (plus ages of children) and Phone

HFNSW will pay for train rides and provide afternoon tea



HAEMOPHILIA FOUNDATION
NEW SOUTH WALES



For any support contact your HTC www.hfnsw.org.au/support-services/treatment-services

Keep up to date with current information on HFA website www.haemophilia.org.au and HFA social media pages -

Facebook <https://www.facebook.com/HaemophiliaFoundationAustralia>

Instagram <https://www.instagram.com/haemophiliafoundationaustralia/>

Twitter https://twitter.com/haemophilia_au

Join us for HUNTER VALLEY DAY OUT!

Special call out to the bleeding disorders community and their families in the Hunter Valley.
Come along all day for both activities, or part of the day, either way we would love to see you there. Suitable for all ages.

Date: Sunday 29 March

Day out Plan:

10am – 12pm Indoor Rock Climbing @ Pulse Rock Climbing, Adamstown

Minimum climbing age: 5 years
(You can pre-sign up here at <https://trello.com/toc717>)

Lead by Andrew Goodwin, a professional climber and works in Newcastle. He has severe haemophilia A. Last year with his brother Scott they climbed El-Capitan, Yosemite in California.



12pm – 4pm @ Henry Park Hall

Lunch followed by Premiere of Bombardier Blood and an afternoon of casual chat.



Bombardier Blood is a powerful documentary about Colorado-based Mountaineer Chris Bombardier, who has never let haemophilia stop him from climbing some of the world's tallest mountains. In 2017, Chris partnered with filmmaker Patrick James Lynch, who also has haemophilia, to film his journey through Nepal to summit the world's tallest peak, Mount Everest.

THIS IS A FREE EVENT

Come and meet people from HFA and HFNSW. Let us know what sort of activities and services you would like from the Foundation

RSVP by 22 March to hfaust@haemophilia.org.au or call 1800 807 173

Names of all attendees (plus ages of children) and Phone

Final information and details will be emailed a few days before the event

Supported by HFNSW

HAEMOPHILIA FOUNDATION
NEW SOUTH WALES



HAEMOPHILIA CENTRES

Kids Factor Zone

The Children's Hospital at Westmead

General: (02) 9845 0000

Robyn Shoemark (CNC) - quote Pager no. 7052

robyn.shoemark@health.nsw.gov.au

Ady Woods (CNC) - quote Pager no. 6273

adrienne.woods@health.nsw.gov.au

Jaime von Drehnen - quote Pager no. 6119

Jaime.VonDrehnen@health.nsw.gov.au

Sydney Children's Hospital Randwick Haematology

C2 North, Sydney Children's Hospital

High St. Randwick NSW 2031

General: (02) 9382 1111

Grainne Dunne (CNC)

Direct: (02) 9382 1240

Grainne.Dunne@health.nsw.gov.au

Royal Prince Alfred Hospital Haemophilia Treatment Centre

RPA, Missenden Road

Camperdown NSW 2050

Stephen Matthews (CNC)

stephen.matthews@sswahs.nsw.gov.au

Phone: (02) 9515 7013

Nicoletta Crollini (Social Worker)

nicoletta.crollini@health.nsw.gov.au

Phone: (02) 9515 8385

Newcastle - Adult Services

Calvary Mater

Haematology Department

Corner of Edith & Platt Streets

Waratah, NSW 2298

General: (02) 4921 1211

Dale Rodney (CNC)

Dale.Rodney@calvarymater.org.au

Bryony Cooke (Social Worker)

Bryony.Cooke@calvarymater.org.au

(02) 4014 4811

Newcastle - Paediatric Services

John Hunter Children's Hospital

Lookout Rd

New Lambton Heights NSW 2305

General: (02) 4921 3000

Jaime Chase CNS

0448 511 539

jaime.chase@hnehealth.nsw.gov.au

Fiona Keegan (Social Worker)

fiona.keegan@health.nsw.gov.au

HFNSW MEMBER SERVICE

Membership \$20 (inc. GST)

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

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

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

Information and Support:

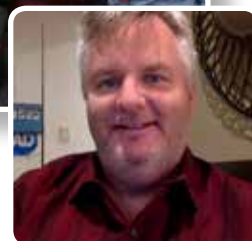
- Education and assistance to members with bleeding disorders and those who also have blood borne viruses
- Provide tutors and entertainment to members who might require extended hospitalisation
- Information and social activities for members and their families
- Rural visits to areas of NSW where there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

HFNSW COMMITTEE...

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

Committee meetings held monthly

HFNSW Committee Group



Craig Haran,
HFNSW Committee Member



Haemophilia Foundation New South Wales Inc.

ABN: 60245470729

Patron: Prof. Kevin A. Rickard AM RFD

2019-20

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.