



PATRON

Dr Richard Pembrey AM,
MB BS, MD, FRACP, FRCPA

March 2020
Newsletter
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President's Report

After a summer of disaster, fire and smoke, damaging winds and hail, it's a welcome relief to get some milder weather, and some rain (which my garden really needed).

COVID-19 & Blood Donations

2020 is shaping up to be a busy year, and an interesting one both politically and economically. The onset and spread of the Coronavirus (COVID-19) has been concerning, and in response to a question about the safety of clotting factor treatments made from human blood plasma in the context of Coronavirus, HFA released a statement on its website on 27 February.

It notes that "Lifeblood (formerly the Australian Red Cross Blood Service) has confirmed that

donor screening procedures in Australia to prevent individuals who show disease symptoms typical of a coronavirus infection, including COVID-19, are routinely in place, and will continue to be reviewed. There is no current evidence suggesting coronavirus is transmissible by blood transfusion and other similar respiratory viruses are not known to be transmitted by blood. Virus detection in the blood has only been detected in a relatively small proportion of unwell patients who would not be eligible to donate blood. Further, dry heat treatment, solvent detergent and other steps used in the fractionation process inactivate and remove viruses".

The full statement is on the HFA website:

haemophilia.org.au/publications/news/coronavirus

can-do attitude and efficient manner are welcome.

...As Life is Hectic

On another personal matter, the birth of our fifth child (and fourth boy) for Julia and I in November, Giovanni Federico Damiani, brought another new member to not only our household, but to the HFACT community as well. Tests taken at birth from a small blood sample taken from Giovanni confirmed he has haemophilia A, with levels indicating moderate severity, just like his three older brothers. Four boys with haemophilia! Life in the Damiani household is hectic.

Claude Damiani

President, HFACT

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Learning to Treat at Home...

Personally, I've been going through prophylaxis training at the Canberra Hospital, under the watchful eye of Jayne Treagust, the new HTC haemophilia nurse. Jayne has been very patient with me as I've sought to "get it right", learning about the safety steps and importance of proper preparation, as well as technique, with an aim to soon graduate to practice injecting on myself and another guinea pig (the wife), before I'm in a position to ease the burden of prophylaxis undertaken by Julia on our second eldest boy Emiliano. I've been very impressed with Jayne, as her

Breaking News

Readers of the Canberra Times may have noticed an article on Sunday March 1st, announcing the February 29th birth of a third baby boy for Rebecca Minty and Jim Leitch, Julia's sister and brother-in-law. Mother and baby are doing well.

A photograph, by Canberra Times photographer Elesa Kurtz, of the whole family, including doting brothers Zachary and Elliott can be found using this shortened link:

bit.do/ct-leap-year-births

Counselling Services 2020

Services at No Charge

I am employed for 13 hours a week by the Haemophilia Foundation ACT and my role is funded by an ACT Health Directorate grant, so I do not charge clients for appointments.

I work across a variety of issues for example: discussions about child behaviour, access to NDIS, liaison with health professionals, health implications for people affected by bleeding disorders, discussions with school and child care centres about managing a

bleed of a student, managing grief, maintaining healthy relationships and more. I am available to anyone in the ACT and near region affected by a heritable bleeding disorder, and their families.

I have 15 years experience in counselling and am a former registered nurse. Clients can self refer.

Availability and Locations

My availability is Monday, Tuesday and Thursday. I can meet

clients in their lunch break or after work, at a local coffee shop or in their private homes. I visit the Canberra Hospital every Thursday for 4 hours if anyone wants to meet me at the hospital.

Most appointments are pre arranged by text, phone or email. My contact details are:

E: counsellor@hfact.org.au or
M: 0409 830 472.

Kathryn Body

Counsellor, HFACT

World Haemophilia Day 2020

GET+INVOLVED



World Haemophilia Day

Every April 17 World Haemophilia Day is recognised worldwide to increase awareness of haemophilia 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.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) which chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

HFACT WHD Family Picnic

To celebrate the 30th anniversary

of World Haemophilia Day, join us for a family picnic at 12.30 on Sunday the 19th of April at Nara Peace Park, Yarralumla.

"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."

In the spirit of getting involved we will be hosting a range of activities, from outdoor games and sports to fishing, or simply sit back and catch up with your fellow community members.

Bring along a picnic lunch, something to sit on, and look out for the red tablecloths. Please RSVP to secretary@hfact.org.au or 0434 903 463 by April 13th.

Shauna Adams

Secretary, HFACT

Light It Up Red!

Landmarks and monuments in Australia and around the world will support World Haemophilia Day by changing their lighting red on April 17.

In Canberra, HFA has negotiated with Telstra Tower and the Royal Australian Mint to participate in Light It Up Red on Friday April 17, 2020.

Show your support on the night, and post photos on HFA's Facebook or Twitter pages of you and your friends at the landmark. #WHD2020

HFA on Facebook
[facebook.com/HaemophiliaFoundationAustralia](https://www.facebook.com/HaemophiliaFoundationAustralia).

HFA on Twitter
twitter.com/Haemophilia_Au

WFH on Facebook
[facebook.com/wfhemophilia](https://www.facebook.com/wfhemophilia)

Women's Wisdom High Tea

What is Women's Wisdom?

The HFACT women's group is there to provide support to women living with a bleeding disorder or supporting someone with a bleeding disorder. We aim to provide the opportunity for people to meet with others who may have the same challenges. All are welcome – women with a bleeding disorder, carriers, partners, sisters, daughters, carers, grandmothers.

We generally get together around food or drink, sometimes with a guest speaker or theme and sometimes just for a relaxed chat.

High Tea

The first function for 2020 is High Tea at the Hyatt Hotel, Canberra at 2.30pm on Saturday 28th March. This will be subsidised by HFACT for financial members (\$68 for non-members or members who are not financial) *. This special afternoon tea will provide an excellent opportunity to meet and mix with women in the bleeding disorders community in Canberra and surrounds.

Numbers are limited, so please RSVP to Jenny (0410 543 086 or treasurer@hfact.org.au) or Kathryn (0409 830 472 or counsellor@hfact.org.au) as soon as possible but by March 20th at the latest. Due to the cost of the High Tea we are asking for a deposit of \$10 to secure your seat and as your contribution to the cost. (See below for banking details)

Jenny Lees

Direct deposit details

WESTPAC

BSB number: 032-778

Account number: 440919

Account name: Haemophilia Foundation ACT Incorporated

Please include your surname and the words 'HighTea' in the reference or payee field.

* annual membership is \$20.00

Join at hfact.org.au/join



Introduction from Canberra HTC Nurse

Firstly, I would like to acknowledge the wonderful welcome and support that I have received from the haemophilia community here in Canberra. I feel very honoured to be working with such an awesome group of people. The haemophilia nurses working in other states throughout Australia have also been very welcoming. I was fortunate enough to have been given the opportunity to spend two days with Robyn Shoemark, the CNC at The Children's Hospital in Westmead on Monday 24th and Tuesday 25th February.

I come from a 40 year background of Haematology/Oncology nursing; having trained in Adelaide, extended my knowledge at The Royal Marsden Hospital in England and

consolidated that knowledge in Alice Springs (it is **COLD** in Canberra 😊). I have also worked in Toowoomba and Geraldton as a breast care nurse and chemotherapy nurse. I am enjoying the challenge of working with people who have a chronic condition that is non-malignant and will endeavour to help and answer all questions as best as I can. If I don't know the answer I can always find out!

On a personal note – I am married and have three children. My eldest child is Tom, he lives in Perth and will be 30 in April (where did the time go!!). Emily is living in Darwin and Claire is in Townsville – they both tell me how lovely and warm they are when we are freezing here in

Canberra. My husband is Steve and he is the reason we have moved to Canberra; you guessed it – for his job.

I hope to have a long relationship with you all and look forward to meeting everyone. Once again thank you for your warm welcome.

Jayne Treagust

Advanced Practice Nurse,
Haemophilia and Bleeding Disorders,
Haematology Department,
Canberra Hospital.

Men's Business - Breakfast in February

A perfect late summer morning on 22 February greeted a small group of HFACT community members enjoying breakfast and each other's company.

It was certainly fortunate that a booking was made as Double Shot café in Deakin was packed to the rafters as the saying goes. A steady stream of customers came and went and getting a table for breakfast without a booking meant long wait times, and understandably why.

The food was delicious, but the company even better. For those who haven't been to a men's business event before, I encourage you to come along next time as it's a great opportunity to meet others in the community, share stories and enjoy yourself.



HFACT members gathered at Double Shot Café

Claude

Have you been PROBEd yet?

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 HFACT 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



ANU Medical School Teaching Sessions

The ANU Medical School conducts regular teaching sessions every year during which patients talk about living with a medical condition with a small group of 2nd year medical students. Each session takes place over an afternoon.

The sessions cover a wide range of medical conditions over the course of the year, including conditions relevant to our group - bleeding disorders, blood borne viral diseases and paediatric conditions. ANU is seeking HFACT members who might be interested in volunteering for one or more of these sessions in 2020.

The Medical School can book and pay for taxi transport to and from the sessions and offers all volunteer participants a \$30 gift voucher as a token of appreciation.

As ANU Semester 1 has only just started, the relevant dates for 2020 are still to be confirmed. HFACT will post the dates on our website when known. Meanwhile, if you are interested in volunteering for one or more of these topics, please contact:

Alastair Walters

Volunteer and Patient Recruitment Officer
ANU Medical School,
Canberra Hospital Campus
ANU College of Health and Medicine
The Australian National University
Building 4, Canberra Hospital
Garran ACT 2605

T: +61 2 5124 3389

F: +61 2 5124 4960

E: alastair.walters@anu.edu.au

Multidisciplinary Review Clinic Dates, First Half 2020

HTC Nurse Jayne Treagust has given advance notice that due to some unforeseen circumstances there will be two bleeding disorders multidisciplinary review clinic for the first half of 2020.

The first clinic, for patients of Dr Nalini Pati, has been sched-

uled for Friday 24 April 2020.

The second clinic, for patients of Dr Michael Pidcock, will be on Friday 15 May .

Save the date that is appropriate for you. You will be contacted closer to the clinic day with an appointment time if you are on the list.

If you are unsure which date applies to you please contact Jayne Treagust on 0481 013 323 or haemophilia@act.gov.au to discuss your circumstances with her.

Getting Older Project - an Update

The HFA Getting Older project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they grow older, and help find appropriate solutions for them and their partner/family or friends/carers. I have been participating as a community member on the Project Advisory Group since May 2019.

My role is interesting, and I have participated in a number of discussions with the advisory group covering such things as current and emerging issues in bleeding disorders and getting older, survey content and results, and, how to provide information to the community.

In November a group of community members from across Australia, including myself and Len Minty from Canberra, participated in a workshop to consider digital solutions for peer support and education. The day was interesting and productive; the mix of participants ensured that many different ideas were canvassed.



Getting Older Project workshop in Melbourne , November 2019

We worked in three small groups. The groups consisted of a group of men with haemophilia, a mixed group of men and women with a bleeding disorder (including von Willebrand Disease) and a group of spouses. It was interesting that, for the various exercises, each group approached the questions from a different perspective but when results were presented and combined it resulted in a complete picture. Thanks to Suzanne and Preetha for running the day so well. The out-

puts from this session feed into an online information hub that will be available as part of the HFA website.

The initial needs assessment project is drawing to a close and the report will be available later in 2020. Keep an eye out for an update in the next issue of *National Haemophilia*.

Jenny Lees

THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY

ORGANIZED BY: WORLD FEDERATION OF HEMOPHILIA
HOSTED BY: HEMOPHILIA SOCIETY OF MALAYSIA

SUPPORTED BY:



WFH 2020 World Congress – HFACT Grant available

Overview

The World Federation of Hemophilia World Congress is the largest international meeting for the global bleeding disorders community and it is hosted in a different country every two years.

The WFH World Congress is a key event for the WFH and for the global inherited bleeding disorders community. Every second year, doctors, scientists, healthcare workers, people with bleeding disorders and haemophilia organisations gather to learn about the latest developments in bleeding disorders treatment and care. It is during this important meeting that the discussions and debates that will shape our global organization and community take place.

The 2020 Congress will take place in Kuala Lumpur, Malaysia June 14-17. For details go to www.wfh.org/congress

HFACT Congress Grant

The HFACT Committee has funds available to sponsor a community attendee to the 2020 World Congress in Kuala Lumpur. The amount of \$2,500 is available from HFACT fundraising activities and the donation from the Stever family (2018) for conference at-

tendance and education activities. This will not cover the full cost of attendance but should cover a large proportion.

To be eligible you must be a financial member of HFACT (check with the Treasurer – treasurer@hfact.org.au if you are unsure of your status).

Expressions of interest should be emailed to the Secretary secretary@hfact.org.au by 10th April 2020. You should include your reasons for wanting to attend, how it will benefit you and the HFACT community. It will strengthen your case if you show how you have (or will) participate with HFACT. The successful applicant will be expected to provide an article about their experience at the congress for the HFACT newsletter **ACTIVATED** and / or a presentation about the congress to HFACT members at a social event.

Congress Musings

I have attended two World Congresses – Paris in 2012 as an attendee and Melbourne in 2014 as a volunteer.

Both congresses were eye opening and great experiences. You get the chance to mix with people from all over the world and hear about experiences that are quite different from those in Aus-

tralia. It is an opportunity to learn about the latest research and advances in treatment, gain knowledge of how treatment is, and is not, delivered in other countries and how grass-roots organisations, like ours, are operating around the world. From each congress I went away with the knowledge that while the treatment available in Australia is good, there is still room for improvement and that the bleeding disorders community needs to keep putting their case forward.

We are also much better off than many countries in the world and World Federation of Hemophilia is working to improve diagnosis and treatment world-wide. I encourage anyone to attend a World Congress if they get a chance.

Jenny

Wanted - Newsletter Editor

The **ACTIVATED** newsletter editor is standing down after over 16 years in the role.

HFACT is reaching out to the community to find someone, or more than one, to take on the role.

ACTIVATED is produced three to four times per year and is distrib-

uted via mail, email and published to the HFACT website. Currently the editing, layout, printing, stuffing, mailing and website update is done by one person. This does not need to remain the case. A laptop and printer go with the role and, if required, training can be provided as part of the handover.

If you are interested or would like more information, please email newsletter@hfact.org.au or president@hfact.org.au

Production of the newsletter is one of the requirements of the funding that provides the services of our counsellor, Kathryn. It is important that this role be filled.

Reading the paper copy? Clicking on the underlined links with your index finger doesn't work? 😊 Switch to the electronic version to get interactive features. Join the approximately half of **ACTIVATED** subscribers who have already made the switch by contacting me at newsletter@hfact.org.au .

Dates For Your Diary

Saturday 28th March, 2.30pm	Women's Wisdom, Hyatt Hotel, Yarralumla - RSVP 20th March
Friday 10th April	Due date for World Congress grant expressions of interest
Sunday 19th April, 12.30pm	World Haemophilia Day Picnic at Nara Peace Park - RSVP 13th April
Friday 24th April	Multidisciplinary Review Clinic - Dr Pati's patients
Friday 15th May	Multidisciplinary Review Clinic - Dr Pidcock's patients
June 14 - 17 2020	WFH 2020 World Congress, Kuala Lumpur, Malaysia

Haemophilia Contact Details

Canberra Hospital

Main telephone: 5124 0000

Website: <https://health.act.gov.au/hospitals-and-health-centres/canberra-hospital>

Haemophilia Treatment Centre:

Mon to Fri 9am - 5pm

On duty nurse: 0481 013 323

Via email: haemophilia@act.gov.au

More details at: www.hfact.org.au/treatment

Haemophilia Foundation ACT

President: 0412 839 135
president@hfact.org.au

Counsellor: 0409 830 472
counsellor@hfact.org.au

More details at: www.hfact.org.au/contact-us

Haemophilia Foundation Australia

Free call: 1800 807 173

Website: www.haemophilia.org.au

Our Mission

"To improve the wellbeing of the haemophilia community through mutual support, networking, advocacy and striving for optimal health care."

Acknowledgement

The newsletter of Haemophilia Foundation ACT is supported by ACT Health Directorate.



**HAEMOPHILIA FOUNDATION
AUSTRALIAN CAPITAL
TERRITORY**

**PO Box 331
MAWSON ACT 2607**

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