

PATRON
Dr Richard Pembrey AM,
MB BS, MD, FRACP, FRCPAAugust 2020
Newsletter
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President's Report

What a torrid few months it's been with COVID19. It's been a really difficult period for many individuals in our bleeding disorders community, just as it has been for the wider community. Just when it looked like we were coming out the other side of lockdown cases re-emerge. I can only hope the ACT does not experience a large upsurge in cases. For those individuals struggling with the impacts of self-isolation or social distancing, please don't hesitate to contact our counsellor and social worker, Kathryn Body.

I would like to acknowledge the support the ACT Government has provided HFACT during this COVID19 period. ACT Health has done a wonderful job keeping me and the community informed on a wide range of matters. It has also provided additional funding in support of our mission and for that I and the community are grateful.

On a more positive front, the National Blood Authority (NBA) announced funding for extended half-life clotting factor products on 30 June. This provides for extended half-life factor VIII for people with haemophilia A and an extended half-life factor IX for people with haemophilia B. Consideration of whether to move onto extended half-life should be undertaken as part of consultation with your treating doctor.

The new arrangements stemming from a prolonged tender process for the supply of standard half-life and extended half-life products commenced on 1 July 2020. Interestingly, the NBA announcement also noted that "Governments are still considering advice from the NBA in relation to whether a further product, for treatment of haemophilia A patients, should be made available under the national blood arrangements".

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Looking forward, I anticipate that the half-yearly clinic will proceed as planned, but things are so fluid at the moment that I expect that a firm decision on this wouldn't be made until closer to the date. I hope that by the time of the clinic that COVID19 is in our rear vision mirror. Should this be the case and social distancing requirements have eased then I'm hoping that HFACT can arrange some form of social gathering to bring the community back together, although this would only happen if it is sensible to do so, and within whatever social gathering requirements in force at the time.

Claudio Damiani
President

Did you know....

July 28 was **WORLD HEPATITIS DAY**



On World Hepatitis Day in 2020 by talking to our friends, family or a doctor we can work towards the [worldwide goal of hepatitis elimination by 2030](#).

New revolutionary hepatitis C treatments are widely available in Australia. They have very high cure rates, are tablets not injections and have few if any side effects. Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C. So, finding out your hep C status if you don't know it is a key message of World Hepatitis Day this year.

You can find out more on the Haemophilia Foundation Australia website: <https://www.haemophilia.org.au/> or the world hepatitis day website <http://www.worldhepatitisday.org.au/>

HFACT Counsellor Kathryn Body

HFACT's Counsellor Kathryn Body is available Monday to Friday, for phone contact and appointments, by Zoom and face to face. Kathryn is a very flexible counsellor, providing a listening non-judgmental ear to any family member affected physically or familiarly by a bleeding disorder.

Kathryn can assist with a wide range of matters, for example, sourcing haemophilia related information, providing support by attending difficult appointments with you, educating your child's school or pre-school about care of your child, assisting your older child with transition from paediatric to adult medical care and supporting parents with child behavioural concerns.

Kathryn can assist with patients and their families in dealing with physical and mental health issues. Take advantage of this free resource especially if you have more time to yourself working from home.

Kathryn can be contacted via email on: Counsellor@hfact.org.au or by phone / sms on 0409830472.

From the Treasurer

Membership Renewal

It is membership renewal time again. Haemophilia Foundation ACT membership fees for 2020/21 are now due.

The membership fee is just \$20 per annum, although donations are always welcome. Payment of membership fees can be made in either of the following ways:

Via direct bank deposit to:

Westpac Bank

BSB Number: 032-778

Account Number: 440919

Account Name: Haemophilia Foundation ACT Incorporated

Please include your full name in the reference or payee field.

Send a cheque to:

HFACT Inc

PO Box 331

Mawson ACT 2607

Membership renewal time is a good opportunity to review whether any of your contact details have changed. If so you can inform us either by using the change of details page on our website (www.hfact.org.au/update) or by completing a membership form, also available on the website (www.hfact.org.au/join), or from our counsellor Kathryn Body.

A copy of the membership application / renewal form has been included with this newsletter. Please note that HFACT does not have access to hospital records, so informing the hospital does not update HFACT.

In cases of genuine financial hardship, the committee is prepared to waive or reduce the membership fee. Requests will be handled with discretion and should be directed in the first instance to the Treasurer.

I encourage you all to complete the membership form as that will enable us to:

- Update our records
- Make sure you get communications in the appropriate format
- Tailor our activities to our membership
- Provide evidence to ACT Health on the size of our community to justify ongoing receipt of the grant that covers Kathryn's services

It will also save HFACT the cost and effort involved in mailing out renewal invoices.

Access to the services of our counsellor is not dependent on being a member as Kathryn Body is there to support anyone with a bleeding disorder in the ACT and region. However, being a financial member entitles you to other benefits, listed on our website, and in having a say in the running of the organisation. You also support HFACT financially in the work that we do.

Jenny Lees
Treasurer

Haemophilia Treatment Centre update

The COVID-19 situation has had a huge impact on society as a whole and I feel that it has also impacted the haemophilia community who, according to my own observations and chats with other haemophilia nurses, have had less people presenting with bleeds. If you look hard enough you can always find a positive out of a negative!

A quick update on 2 research projects that are being undertaken by the Australian Haemophilia Centre Directors' Organisation (AHCDO). AHCDO is the national medical body for haemophilia in Australia.

1. Extended Half-life Factor (EHL) Practice Research Proposal: A comprehensive evaluation of treatment and outcome for patients with haemophilia A and B on EHL: a 12 month data analysis. This research project will hopefully show that EHL products are effective, help with compliance and potentially influence policy making on their wider use.
2. HJHS Research Proposal: Reviewing haemophilia Joint Health Score (HJHS) as a tool to assess outcome measures in patients with haemophilia A and B. By understanding current patterns of HJHS tool usage, insights will be provided into its usefulness in the real world setting and potentially help identify barriers to its implementation in clinical practice.

I have now been in this role for 6 months and have been welcomed by all. I'm feeling like an old piece of furniture – I have settled in and feeling comfortable! One of the roles within this role that I have particularly enjoyed is the ability to be able to teach. Not only teaching practical components to members of the haemophilia community but also being able to reach out to other staff and provide them with information around haemophilia; they are all very interested.

At this stage we are hoping for a face to face clinic and it has been scheduled for November 27th, but it will depend on the current situation with COVID19. I will keep you posted.

My husband and I have just purchased an apartment so it looks like I'll be here for a while!

Stay safe and be well.

Jayne Treagust

Advance Practice Nurse - Haemophilia Treatment Centre

Getting Older with a Bleeding Disorder

In previous issues of ACTivated we have covered the research Haemophilia Foundation Australia (HFA) was doing into ageing. I am happy to report that the report from this research, 'Getting Older with a Bleeding Disorder: Needs Assessment Report – May 2020' has now been published and is available from the HFA website here: <https://www.haemophilia.org.au/publications/getting-older/reports>

As well as the report, an information hub 'Getting Older Hub' has been launched on the HFA website. The hub, for people who are ageing, families, carers and health professionals, covers subjects such as:

- Health and wellbeing
- Services for getting older
- Work & finances
- Support
- Recreation and travel
- Planning for the future
- Connect to others
- And a section for Health Professionals.



The hub is a combination of information snippets, documents, and links to appropriate websites for detailed information or application forms. For example, under the 'Services for Getting Older' you will find links to Commonwealth Seniors Health Card; My Aged Care and NDIS as well as fact sheets for staff and health professionals.

The hub is evolving. Please visit it and provide feedback so that it can be a useful resource.

<https://www.haemophilia.org.au/support-services/getting-older-hub>

Jenny Lees

Resource: Staying active = Better physical and mental health for everyone



Text and images from the Heart Foundation

A few tips to help you manage working from home and staying active

Media Release - 20 March 2020

<https://www.heartfoundation.org.au/media-releases/tips-for-staying-active-in-isolation>

As more and more Australians find themselves isolated at home due to COVID-19, the Heart Foundation is offering tips and tricks for staying active when alone and in confined spaces.

“COVID-19 is disrupting almost every aspect of Australians’ lives, including our physical activity routines – like going to the gym, playing team sports or even walking with a group of friends,” said Heart Foundation Director of Active Living, Adjunct Professor Trevor Shilton.

Here are the Heart Foundation’s tips and tricks for staying active at this time:

Any physical activity is better than none. “Try to move in as many ways as you can throughout the day,” Professor Shilton said.

Build up over 30 minutes a day. The Australian guideline for adults is to build up over 150 minutes a week of moderate intensity physical activity.

This is about the equivalent of a brisk walk – enough to make you puff a little, but still be able to conduct a conversation,” he said. “Aim for 30 minutes a day or more.”

Moving about while at home

Ideas include:

- Catch up on gardening.
- If you’re lucky enough to have an exercise bike or swimming pool, use them!
- Develop your own short exercise routine and do it several times a day (adding up to at least 30 minutes).
- Use YouTube to find a home workout that best suits your fitness needs.
- Declutter and give away items to charity.
- Paint a room or restore a tired piece of furniture.
- Get the rusty bike/s from the shed and restore them
- Brush up on your golf-putting skills.
- Indoor bowls, if you have room.

If you can access an activity tracker, watch your steps. Aim for 10,000 a day and maybe introduce a challenge with friends and family members (most steps/active minutes).

Building strength

Muscle strengthening exercises are also recommended on at least two days each week. Try:

- Water bottle weight workout – filled water bottle or milk carton or similar with water and do some light weights with it.
- Do some resistance exercises against a wall or chair.
- Follow a simple program of yoga, step-ups using a makeshift step, modified push-ups or sit-ups, lifting weights, lunges, calf raises and half squats.

Sit less

More and more research is showing that it’s not good for your health to be sitting or lying down for long periods during waking hours.

- Avoid sitting for long periods; break it up by moving about the house.
- On the mobile phone? Stand, or walk around the house as you talk.
- Set timers/reminders to get up and move.
- Do some exercises (push-ups, sit-ups or half-squats) in the TV ad breaks.
- Try standing for activities for which you may usually sit (TV, folding washing, phone calls).



(contd.) What about the kids?

Children aged 5 to 17 need a minimum of one hour a day of moderate physical activity and more is better. We also need to limit their sedentary recreational screen time to no more than two hours per day. Break up the TV or movie with some fun activities with the kids. Keep them out of their bedrooms and off devices and be active together.

- Go outside and invent some lawn games, or just play catch or handball in the driveway.
- Try something new, like hula hoops, or juggling.
- Play the kids' favourite music and see how many "cool" moves you can do together.
- Backyard cricket (even in the tiniest space you can make your own rules).

- Dust off the Twister game or Wii Sports.
- Use a tennis ball to knock over plastic bottles filled with water (have a family competition)
- For strengthening muscles and bones, try skipping, yoga, jumping, push-ups, sit-ups, lifting weights, lunges and squats.
- Get adventurous, climbing trees or swinging on monkey bars.
- Build a cubby house together – even a makeshift one using re-purposed materials from around the house and yard.

World Federation of Hemophilia Virtual Summit



The World Federation of Hemophilia was due to have the 2020 World Congress in Kuala Lumpur, Malaysia from June 14-19, 2020. However, it was cancelled due to the outbreak of COVID-19 virus. In its stead the WFH Virtual Summit took place, which was a series of free live and recorded sessions that took place over the same period. All sessions were held in English. Below are summaries of a number of the sessions.

The sessions from the WFH 2020 Virtual Summit can be accessed by registering at <https://www.wfh.org/virtual-summit/home>. Click on the image of the globe to access the registration / login page.

Opening medical plenary – gene therapy

Gene therapy is a huge development for the treatment of haemophilia. It promises to be a one-off treatment, via an intravenous infusion of a vector that carries good copies of the haemophilia gene that target the liver which then produces good copies of cells with good copies of the gene. This leads to the body producing higher factor VIII or factor IX on an ongoing or steady state basis – ie, a "functional cure".

Dr Steve Pipe (Professor of Pediatrics and Pathology, University of Michigan) gave a presentation that focused on the preparation that different stakeholders (doctors,

patients, nurses, pharmacies etc etc) need to undertake to be ready for gene therapy.

To open, Dr Pipe contextualised gene therapy by looking at earlier approaches to haemophilia treatment and care. Initially there was no factor replacement therapy, then came on-demand plasma derived therapy, and then recombinant clotting factors. Initially treatment was just on demand, but many patients are now on prophylaxis, and there are extended half life products that reduce the frequency of infusions required, and non-replacement therapy (such as bispecific antibodies). We have come a long way in the last 50 years.

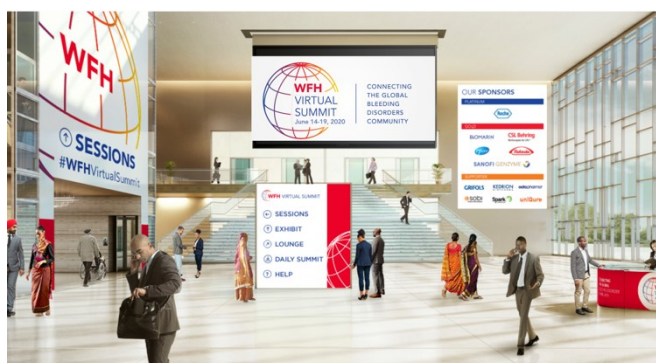
Dr Pipe noted that gene therapy is so different from the haemophilia treatments used by the bleeding disorder community to date. All stakeholders need to be prepared,

and the first step of this preparation is education and awareness raising, for example, what is informing all stakeholders about what gene therapy is, how it works, what are the risks and benefits, and how is it actually administered and followed up.

Survey data was presented to support Dr Pipe's position that there is much work to be done in raising awareness about gene therapy. He presented data from a survey of over 5000 healthcare professionals (the majority of whom had direct experience in caring for patients with haemophilia). More than 1/3 felt unable to explain gene therapy for haemophilia and lacked comfort in answering patient questions on the topic. In another survey, conducted by WFH, almost 70% of patients said they had 'only basic' understanding of gene therapy.

From my perspective (the carer of a child with haemophilia in the ACT), gene therapy is of limited immediate relevance to my son, as the current Phase 3 trials currently underway (including in Australia) exclude paediatric patients. However, following Dr Pipe's argument, we should actively educate ourselves for what is just over or appearing on the horizon.

Rebecca Minty



1 The WFH Virtual Summit moved presentations online

Multidisciplinary Plenary: Women Ageing Gracefully

Session Chair: Kate Khair, Director of Research, Haemnet

Presenter: Michelle Lavin, Clinical Research Fellow, Irish Centre for Vascular Biology at the Royal College of Surgeons in Ireland

Panel members:

Rezan Abdul-Kadir, Consultant Gynaecologist, Royal Free London NHS Foundation Trust

Latifa Lamhene, Association Algérienne des Hémophiles

Jameela Sathar, Senior Consultant - Haematology, Ampang Hospital

This session commenced with a presentation by Michelle Lavin providing an overview and setting the focus for the discussion panel.

All the usual ageing challenges of ageing apply to women with bleeding disorders (WBD) with the added complexity of a bleeding disorder.

Peri-menopause: The hormonal changes that occur may lead to the onset of heavy bleeding. This may need input from a gynaecologist; contraception is still required after periods end – intrauterine device suggested; Oral HRT (Hormone Replacement Therapy) is generally OK; it is a risk if the woman has a thrombotic condition, not a bleeding disorder.

Age-related medical conditions. (Joint, cardiac, gastrointestinal, and cancer) Ageing brings an increased need for surgery - orthopaedic, cardiac or cancer – which carries a higher bleeding risk. There is a need to balance bleeding and thrombotic risk which requires specialist management. (ie get the Haemophilia Treatment Centre (HTC) involved early).

Gastrointestinal (GI) bleeding is a new issue with age that affects both men and women. This is difficult to manage and unpredictable in onset. No specific preventative measures exist.

Access to age appropriate care. There is little research to call upon in this area. Are HTC's equipped to deal with the needs of an ageing population, including access to combined care? Maybe haematologists should be attending ageing clinics. Age-related increase in factor levels can lead to the 'removal' of the bleeding disorder, however the woman may still be at risk of bleeding. No studies have been done to show that the age-related increases in VWD level does remove the likelihood of bleeding.

Research. There is limited data on age related issues. (Only 2 small studies on patients with BD, and the focus was not specifically on women.)

My takeaways from the panel discussion were:

Ageing in the bleeding disorders community is an issue across genders, not just for women.

Research. It appears to be a major challenge to collect any data on females with bleeding disorders – the issue is not limited to ageing. Studies that include WBD should include duration and flow as a base measurement – not an afterthought. There is even less research done on Factor XI than Factor VIII or VWD. Research into ageing for WBD should be encouraged and funded.

Over the world, there are identified barriers to treatment and research. These include: not a recognised female condition; assays are not accurate for women (anecdotally) and studies are needed to prove this; and the focus tends to be exclusively on males with bleeding disorders, the female family members should also be involved – in clinics & investigations.

Jenny Lees

Managing COVID-19 and bleeding disorders

This article summaries a General Plenary held during the 2020 WFH Virtual Summit. Although intended to be for general audiences, the plenary was primarily medical. For brevity, only those aspects relevant to people with bleeding disorders (PWBD) appear here.

Since the outbreak of the coronavirus disease 2019 (COVID-19) there has been an unprecedented global public health challenge. This session—developed as an educational response for the global bleeding disorders community - presented four main topics: pathophysiology of COVID-19; the clinical manifestations of COVID-19; practical advice on the management of COVID-19 for PWBD; and information on the safety and supply of plasma derived products during the pandemic.

Pathophysiology of COVID-19

Radoslaw Kaczmarek - WFH Coagulation Products Safety, Supply and Access (CPSSA) Committee Chair

The pathophysiology of COVID-19 is complex and multifaceted. However, there is one crucial aspect that is of importance with respect to PWBD – thrombosis.

The structure of SARS-CoV-2, the virus that causes COVID-19 disease, is such that it can infect multiple organs including the lungs, arteries, heart, kidney and intestines. Infection of the lungs can elicit a hyperinflammatory immune response which in turn compromises the epithelial-endothelial barrier (the inner and outer surfaces of blood vessels) in the alveoli, the smallest anatomical units of the lung. Activation of, or damage to, the endothelium stimulates release of procoagulant molecules such as clotting factor VIII (FVIII) and von Willebrand factor (VWF).

The release of FVIII and VWF can cause complications such as pulmonary thrombosis, endothelitis (inflammation of the endothelium) and angiogenesis (splitting or sprouting of blood vessels). A high incidence of venous thromboembolism (VTE) has also been seen in association with COVID-19 coagulopathy.

Clinical Manifestations of COVID-19

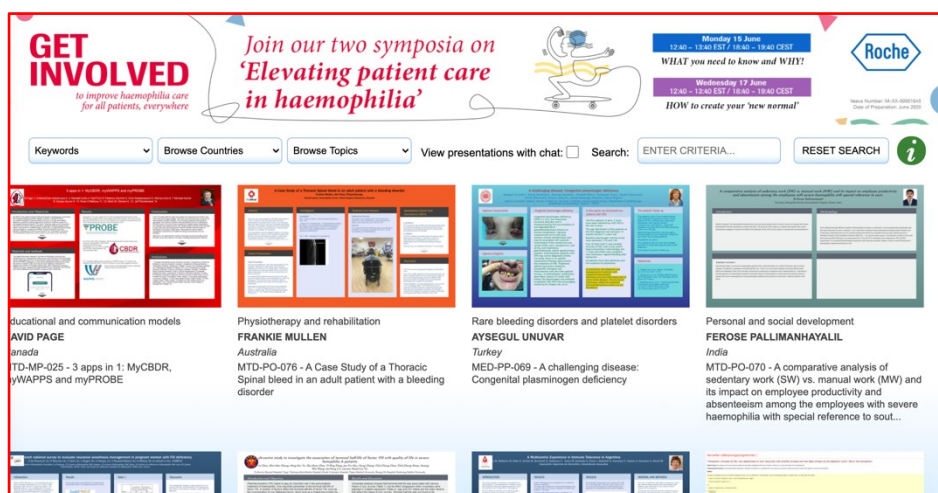
Flora Peyvandi MD, PhD, Angelo Bianchi Bonomi Hemophilia and Thrombosis Centre, IRCCS Policlinico, University of Milan, Italy

The clinical manifestation of COVID-19 in PWBD is not different to other patients. There are no specific clinical features, but instead a wide range of *possible* symptoms:

- Constitutional – fever (only 30-50% of patients at time of admission), myalgia, headache.
- Upper respiratory – runny or blocked nose, sore throat.
- Lower respiratory – difficulty breathing, chest tightness, cough, sputum, haemoptysis
- Gastrointestinal - 10-20% patients present initially with GI symptoms such as nausea, vomiting, diarrhoea.

As the disease progresses there are a range of emerging clinical manifestations, including cutaneous and neurological manifestations, but also, thromboinflammation and hyper-coagulation.

- Infection causes formation of microthrombi and various forms of thrombosis
- Mainly venous thromboembolism
- Arterial events
- Bleeding in patients with a low platelet count
- It is now known that all patients with severe COVID-19 should be treated with heparin to prevent the formation of thrombi, and that may be the cause of the bleeding in some patients.



The virtual summit included a poster exhibition, which can be viewed online

Management of COVID-19:

Practical guidance

Professor Cedric Hermans - Haematologist, UCL Saint Luc and currently the Editor of Haemophilia journal.

Professor Hermans presented a paper recently published in *Haemophilia*, referenced below, which goes into greater detail than space permits here. In summary –

Home management of, and during, COVID-19 in PWBD:

- At home -
 - Regular treatment should be continued (ideally prophylaxis)
 - Patients should maintain physical activities (avoid joint stiffness, muscle loss) / self-physiotherapy, especially those with arthropathy
 - Patients and their HTC should avoid shortages of concentrates and maintain contact with pharmacy / pathology
 - Patients should maintain regular contacts with HTCs
 - Avoid the overuse of paracetamol
- Most PWH developing COVID-19 can be managed at home.
- Prophylaxis with FVIII/FIX should be continued, although medical staff know that this could be challenging in some settings.

COVID-19 in PWBD:

- Patients with haemophilia are **not at greater risk** of infection with SARS-CoV-2
- Compared to the general population, patients with haemophilia are **not likely to develop more severe** COVID-19
- Patients with haemophilia **should follow precautions** with respect to their disease management
Haemophilia could impact on the management of patients who need to be admitted to hospital

However, as COVID-19 causes thrombotic problems, treatment in PWBD can be more complicated while continuing to provide haemostasis for their bleeding disorder. There is a need to balance bleeding complications vs thrombotic complications.

How to control blood coagulation in PWBD and severe COVID-19?

- For bleeding complications, haemostatic treatment ideally with FVIII/FIX concentrates.

- For Thrombotic complications, need for antithrombotic treatment ideally with low molecular weight heparin (LMWH) or un-fractionated heparin (UFH).

The paper in *Haemophilia* goes into greater depth, including recommendations for managing PWBD if admission to ICU is required.

10 principles for the management of patients with inherited bleeding disorders and COVID-19:

1. Uninterrupted access to usual haemostatic treatment(s) (using home delivery)
2. Continuation of prophylaxis
3. Use of physical barriers (confinement, distancing, face mask)
4. Hospital admission criteria is not different
5. Upon admission, alert staff for the presence of a coagulopathy
6. Daily involvement of the haemophilia specialist in hospital care
7. Partial or complete correction of the coagulation deficiency depending on the setting and the risk of haemorrhagic/thrombotic complications
8. Same management (ICU, ventilation) as patients without coagulopathy
9. Prevention of thrombosis with LMWH/UFH (benefits >> risks)
10. End of Life Directive not different from patients without coagulopathy

Safety and Supply of Plasma Derived Products

Mark Skinner, President, Institute for Policy Advancement Ltd. Previous President of WFH 2004-2012.

Cryoprecipitate and fresh frozen plasma (FFP) products are still widely used in countries around the world where they are the only available or affordable treatment options.

WFH statement from 21 March 2020 regarding plasma products:

- Viral inactivation and elimination procedures employed are sufficient to destroy lipid-enveloped viruses like SARS-CoV-2.
- For PWBD treated with other blood-derived products which are not virally inactivated (e.g. cryoprecipitate, platelets), treatment decisions should be based on clinical risk/benefit analysis balancing the safety of not treating a bleeding event and any residual risk of acquiring another infection.

Is SARS-CoV-2 transfusion transmitted? Recent papers report there is no precedent for transmission of any respiratory virus by the parenteral route, including this century's two serious emergent coronaviruses (SARS and MERS). The US FDA supports this position. While a theoretical risk remains, the current evidence is that the risk of transfusion-transmitted of SAS-CoV-2 is very low.

Product supply considerations:

- The production of recombinant DNA produced replacement products is not expected to be affected.
- The situation may be quite different for plasma-derived clotting factors if donations are reduced due to the deferral of infected donors and fear of donating blood and plasma.
- Already, US donations are down due to the misunderstanding that donors may be at increased risk of COVID-19.
- WFH and other patient organisations have been lobbying to ensure that plasma collection is deemed an essential critical infrastructure and national (US) strategic priority

Key references:

Papers appearing in *Haemophilia* journal and available online:

The COVID-19 pandemic: New global challenges for the haemophilia community

Hermans C, et al. *Haemophilia* 2020 May; 26(3):371-372 doi: 10.1111/hae.14001.

<https://onlinelibrary.wiley.com/doi/10.1111/hae.14001>

In-hospital management of persons with haemophilia and COVID-19: Practical guidance

Hermans C, et al. *Haemophilia* 2020; May 8, doi: 10.1111/hae.14045. [Epub ahead of print]

<https://onlinelibrary.wiley.com/doi/10.1111/hae.14001>

Ron Lees



We are all in this together! - picture from the 2019 HFACT Family Camp

News: extended half life products funded

As noted in the President's report, in June 2020, the National Blood Authority (NBA) announced the outcome of its tender process for extended half life clotting factor products.

The new arrangements are outlined in the table below:

	Previous Arrangements Product name (Supplier)	New Arrangements Product name (Supplier)
Standard half-life rFVIII	Advate (Shire)	Advate (Shire)
	Xyntha (Pfizer)	Xyntha (Pfizer)
Standard half-life rFIX	BeneFIX (Pfizer)	BeneFIX (Pfizer)
	Rixubis (Shire)	Not available after a transition period
Extended half-life rFVIII	Adynovate (Shire)*	Adynovate (Shire)
	Eloctate (Sanofi)*	Eloctate (Sanofi)
Extended half-life rFIX	Alprolix (Sanofi)*	Alprolix (Sanofi)

* Previously available under limited interim arrangements for EHL products.

Source: National Blood Authority blood.gov.au

More information can be found on the NBA website, including product names.

- <https://www.blood.gov.au/plasma-and-recombinant-product-procurement>

As noted by Haemophilia Foundation Australia "This means that there is funded access to extended half life factor VIII for all people with haemophilia A and an extended half life factor IX for all people with haemophilia B where they and their treating doctor at their Haemophilia Treatment Centre consider it for their treatment. Due to COVID-19 and some other local reasons there may be some delays to access; however, those who have been waiting for this development should speak with their doctor at their Haemophilia Treatment Centre." (source: haemophilia.org.au).

Women's Wisdom

2020 has not been a good year for social gatherings. It was disappointing that we could not have our 'High Tea' at the Hyatt as scheduled. We will keep that on the back burner until things are more 'normal' and we feel comfortable socialising in groups again.

I am thinking of scheduling a virtual Women's Wisdom meeting if there is enough interest. Please drop me a line (treasurer@hfact.org.au) or text (0410543086) if you think this is something that you would participate in.

There could be a theme, even a guest speaker or we could schedule around afternoon tea or evening drinks for a relaxed chat.

I think it is important that we continue to support each other, especially through the current situation and am open to other suggestions on how we can connect – in smaller or larger numbers.

Jenny Lees

AGM – Advanced notice

The HFACT AGM will be held later this year – by the end of November at the latest. A notice will be sent out separately. Hopefully we can gather together depending on the COVID-19 situation. Stay tuned, as we'd love to see you there!

Dates for the diary

November	27	Multidisciplinary Review Clinic (subject to confirmation in light of COVID-19)
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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 Australian Capital Territory
PO Box 331, MAWSON ACT 2607

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

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