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ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

I'm looking forward to the end of winter. Even though I've been in Canberra for 18 years, the cold Canberra winter mornings and evenings are one thing about Canberra I don't like. It's also been a winter of sickness. Within my family, friends, work colleagues, acquaintances, so many people seem to have picked up colds, flu, COVID, and other ailments over the recent months. It certainly has compounded the pressures across the local health network, but I admire the resilience and perseverance to good health care our nurses and doctors continue to uphold. That goes for the staff at the Haemophilia Treatment Centre.

The last few months have been a sad one for the local bleeding disorder community. A much loved youth member and my nephew, Zachary Minty, passed away after a nearly three year battle with cancer. It was a sad time for many who knew Zachary, or Zac as he was known to his family and friends, but a lovely service and life celebration helped many to express their emotions and show their appreciation of having been blessed with knowing Zac.

Zac's passing prompted the rescheduling of planned community activities which are being scheduled to go ahead over the coming months, starting with a trivia night in early September followed by a breakfast, and then a coastal camp in October. Details of each are provided in this newsletter. We acknowledge that these activities are made possible through an ACT Health COVID grant, the bulk of which we have not been able to utilise to date due to limitations on in person social activities, as well as from fundraising, membership fees, and prudent management of HFACT's limited financial resources.

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President's Report contd...

There has been some recent exciting news on gene therapy treatment for people with haemophilia. For years, the hope of gene therapy always seemed to be around the corner, although year after year would pass and the same message would be heard. We are nearly there... Well, based on recent media reports, we may well be there, although if, when, how such treatment may, and I emphasize may, become available within Australia is a big unknown to me at this stage. Nevertheless, more information on these recent press releases I'm referring to are also included in this newsletter.



Lastly, I've been contacted recently to discuss certain incidents or to assist address particular issues. I encourage all of you to reach out to either myself or HFACT's counsellor, Kathryn Body, if there are issues of concern with respect to your bleeding disorder, treatment, personal health or any other matter you wish to discuss. That's what we are here for.

See you soon

Claude Damiani

President

HFACT Breakfast

To herald the coming of spring, HFACT is inviting you to a breakfast at A Bite to Eat (at Chifley shops) on **Saturday 8 October** at **8.30am.**

This will be an opportunity to relax, enjoy good company and have breakfast and a drink. Open to all members of the bleeding disorders community, and financial members will be reimbursed for the cost of their breakfast. We hope to see you there.

Please RSVP to Claude on 0412 839 135 by 1 October



Ankle Fusion

Len Minty

Fusion is the uniting of two entities to produce a single entity quite different from the components from which it came. So saith the web authority consulted.

And how true it is. Over many years - possibly from the age of fourteen, I had bleeds in the ankle joints which were not treated as they would be today: no factor replacement, no pressure bandages, only occasional ice application and not enough joint elevation. (And aspirin for the pain!!!)

The consequences were inevitable. Residues of iron deposits that built up over the years to result in haemarthropathy in the joint. It was like sand mixed with very little oil being ground between the tibia and its ankle socket. Critically painful. An 8 (at least) on the pain scale with every step. Rather "unpleasant"!

Enter stage right: 'ankle fusion' played by Dr. Joe Lau. Result: A fixed joint. Pain level: about 1 (inconvenience factor) out of 10. A miracle.

But unlike miracles (which some people still believe in !) which are usually instant, the whole process took time. Consultation with doctors, with HFACT Counsellor, Kathryn Body, with family and friends.

And then there's the recovery phase: six weeks in a cast followed by six weeks in a 'moon boot'.



Dependent on the forbearance of my wife Mary Lou and family. Unable to weight-bear. To cook, to clean, to garden, to drive a car.

But the end result. Pain-free walking. Was it all worth it? I'll leave that as a rhetorical question.

Thanks Joe Lau, Mary Lou, families of Julia and Rebecca, and Kathryn Body.

If I might venture to offer some advice to all you young folk who have haemophilia. Don't hesitate to treat a joint bleed (or any bleed) with IMMEDIATE attention.

Twenty minutes of immediate attention today will ensure that you won't have years of painful joint movement (or sand and oil being ground in your joints)!



Len Minty



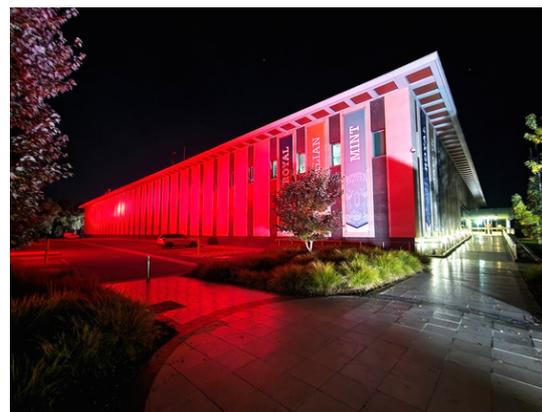
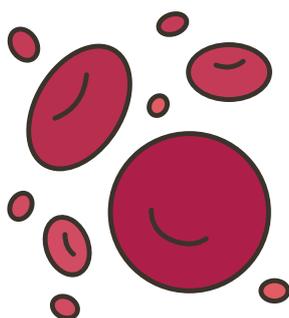
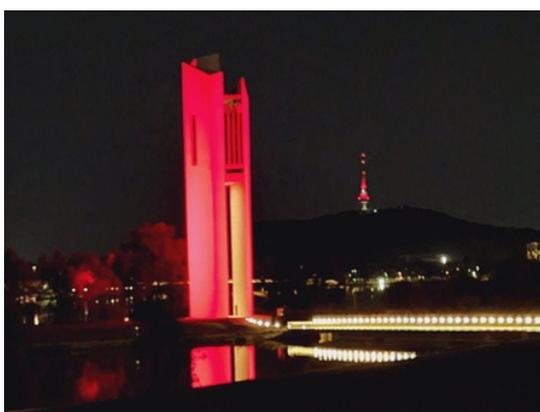
Light it up

RED

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders.

Canberra celebrated World Haemophilia Day in style with some key landmarks lit up red. Thanks to Ron Lees for capturing the images.

Clockwise from top: Shine Dome, Shine Dome, Royal Australian Mint, the Carillon, National Film and Sound Archives.



From the Treasurer

HFACT is fortunate to finish the 2021-22 financial year in a healthy financial position. This will enable us to fund a range of activities, COVID permitting, in the coming year. The financial statements will be tabled at the AGM in October (see notice below) and will be made available to attendees prior to the meeting.

We were recently notified by ACT Health Directorate that our grant to fund our counsellor, Kathryn Body, has been renewed for the next three years. During this period the next round of community grants, including ours, will be put out to tender requiring a more rigorous application process. A condition of the current three-year extension is that we work to improve the range and type of statistical information provided to the Directorate. You will hear more on this later in the year as the committee works through the request and our response to it.

We thank the ACT Health Directorate for this funding.

While our grant is small in the scheme of things it does enable us to provide a unique service to the ACT and region bleeding disorders community. Have you noticed that:

- Kathryn is able to meet with you outside the hospital (at home, office, local café, school)?
- all members of the family can access her services, not just the person / people with a bleeding disorder?
- there's not a long wait to get an appointment?
- there's plenty of time to discuss things?

This is not generally the case in other states where such services are strictly hospital-based.

To retain the valuable services of our counsellor it is essential that HFACT maintains a viable committee and a financial membership base. I urge you to read the AGM notice below and to attend if possible. Please consider standing for the committee. The more people we have the smaller the workload is for everyone. Committee meetings are 10-11 times per year for 1.5-2 hours and currently all online.

Jenny Lees

Treasurer



Advanced Notice

HFACT AGM
Saturday 15 October
6:30pm
All welcome!
More details to come

Membership renewal time



It is membership renewal time again. Haemophilia Foundation ACT membership fees for 2022-23 are now due.

The membership fee has remained unchanged and is just \$20 per annum. Donations are always welcome and are tax deductible.

Membership fees can be paid by direct bank deposit to:

Bank name: **Westpac Bank**
BSB Number: **032-778**
Account Number: **440919**
Account Name:
Haemophilia Foundation ACT Incorporated

Please include your name in the reference or payee field.

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).

A copy of the membership application / renewal form has been included with this newsletter.

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

Member Benefits include:

- Subsidies for medical bands or bracelets such as Medic Alert
- Conference subsidies
- Peer support groups such as Men's Business and Women's Wisdom
- Family camps and kids functions
- Free or discounted attendance at HFACT Social functions
- 3 newsletters per year, providing information about local services and events; posted or emailed to you and available on our website
- Membership of the peak national body, HFA
- Representation and advocacy at the local and national level
- Entitlement to vote at the HFACT AGM.

Financial members may also apply to HFACT for financial assistance with quality of life expenses such as swimming lessons, gym memberships, orthotics and mobility aids.

I encourage you to complete the membership form as that enables 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 counsellor Kathryn Body's services.

Reconnecting with the community post COVID

I was fortunate to have the opportunity to attend the WFH world congress in Montreal in May. I was excited to attend my first congress, but it was also wonderful to meet and catch up with people face to face for the first time in some months. It was interesting to hear about how National Member Organisations (NMO)'s around the world stayed connected during the pandemic, and some of the challenges they faced. Everyone is now very fluent in Zoom, and it was great to see the positive spin on things experienced by a lot of the community.

Most local groups moved to a complete remote delivery of their gatherings and meetings for some time, slowly transitioning into mixed mode delivery as social distancing requirements allow. The congress itself was delivered in a mixed mode platform, and while this allowed people to attend who may have been impacted by COVID restrictions, it also meant that people who may have been financially restricted or not physically able to attend could also be involved in the congress.

WFH reported that they have been able to increase the delivery of training packages to NMO's around the world, which has been hugely beneficial to remote countries who are generally not able to attend on location training sessions. This has resulted in a review of the ongoing delivery methods used so that we can continue to reach the wider global community in future.



In the medical delivery space, several countries moved to telehealth for ongoing care of patients with bleeding disorders. NMO's in the US reported that patient satisfaction surveys indicated over 70% of patients were satisfied with this method of care. Surveys also indicated that telehealth was more readily adopted by the younger cohort of patients.

Where local groups have shown great success in moving to virtual activities,

some of the global initiatives saw a decline in attendance as time zone differences became a challenge. The affirm program found countries with time zones that were drastically different from the host country to have a higher dropout rate.

It was great to see the creative ways our community have kept in touch on a social level in the face of adversity. The Pakistan Haemophilia group conducted youth events as joint online gaming sessions in the absence of usual youth camps. A lot of NMO's reported zoom catch ups socially too. I look forward to transferring some of these ideas across to our upcoming events, like the trivia night coming up soon (see details on next page).

Shauna Adams



Haemophilia Treatment Centre Update

Just a quick one from me - It's been a busy first half of the year! I'd just like to say it has been lovely getting the chance to meet everyone over the last couple of months and thank you for everyone's patience at the haemophilia clinics, I know it can make for a long day.

A gentle reminder that if you require a plan for surgery or are travelling overseas could you please give me at least 2 weeks' notice and preferably more if possible.

The date for the November haemophilia clinic is now 4 November 2022 - apologies for any inconvenience caused by the change of date.

Lauren O'Connell

Haemophilia Treatment Centre Nurse



H HFACT AND HFNSW PRESENT
THE FIRST EVER JOINT
ONLINE TRIVIA NIGHT
Saturday 10th September - logon @ 6:30 for 7:00pm start

Uber Eats voucher for financial members to use on the night

Log on with your own device, in the comfort of your own home and compete with others online

win great prizes!

All you need is an internet connection and a sense of fun!
To RSVP/sign up, email newsletter@hfact.org.au.
Full information about how to participate will be emailed in advance.

The poster features a light orange background with a large white 'H' logo in the top left. Below the title, there are three cartoon characters sitting at red quiz stations with green screens. Each character has a speech bubble above them. The first character is a man in a blue shirt, the second is a woman in a green shirt, and the third is a man in a brown shirt. The text is arranged in a clear, readable layout with various font sizes and colors.

In loving memory of
Zac Minty



3rd April 2011 - 29th May 2022

We mourn the loss of HFACT member 11 year old Zac Minty, who passed away from cancer after an almost 3 year battle. He was passionate about his family and friends, soccer (in particular, Liverpool FC) and reading, and was in year 6 at Mawson Primary School.

Zac was brave, courageous and kind to everyone. He is deeply missed and will never be forgotten.



Zac was one of the HFACT community members behind the successful nomination of the then Haemophilia Treatment Centre nurse James Slade as 2017 ACT Nurse of the Year.

To the right is a photo that appeared in The Canberra Times about the award, and below it, Zac's illustration that formed part of the nomination.



📷 Nurse of the Year: James Slade, with Rebecca Minty, who is the secretary of the Haemophilia Foundation ACT and nominated him for the award, and her six-year-old son Zach, who has Haemophilia A. Photo: Sitthixay Dittavong





IN THE NEWS

Bleeding disorder treatment updates

Gene therapy trial markedly cuts bleeding risk in haemophilia B patients

A new gene therapy has dramatically cut the risk of bleeding in people with the rare condition haemophilia B. Researchers found that a single injection of the gene therapy, called FLT180 α , removed the need for people to inject themselves weekly with clotting factors. In the 26-week trial, published in the *New England Journal of Medicine*, experts found that a single treatment with FLT180 α led to sustained production of the protein from the liver in nine out of 10 patients with

severe or moderately severe haemophilia. Patients on the trial had to take immune-suppressing drugs over several weeks to several months to prevent their immune systems from rejecting the therapy. While the treatment was generally well tolerated, all patients experienced some form of side-effects, with an abnormal blood clot in one who received the highest FLT180 α dose and had the highest levels of the protein.

Excerpt from an article published in the *Guardian* newspaper on 22 July 2022

<https://www.theguardian.com/science/2022/jul/21/gene-therapy-trial-markedly-cuts-bleeding-risk-in-haemophilia-b-patients>

First gene therapy to treat severe haemophilia A

The European Medicines Agency (EMA) has recommended granting a conditional marketing authorisation in the European Union (EU) for Roctavian (valoctocogene roxaparvec) for the treatment of severe haemophilia A in adults who do not have factor VIII inhibitors and no antibodies to adeno-associated virus serotype 5 (AAV5). Roctavian is the first gene therapy to treat haemophilia A. The active substance in Roctavian, valoctocogene roxaparvec, is based on a virus (adeno-associated virus or AAV) which has been modified to not cause disease in humans.

The virus contains the gene for factor VIII; once given to a patient as a one-off infusion, it is expected to carry the factor-VIII gene into the liver cells, enabling them to produce the missing factor VIII. This helps the blood to clot more easily and prevents bleeding or reduces bleeding episodes. It is yet known how long the treatment effect from this single infusion will last in an individual patient. A sustained positive treatment effect of up to two years following a single infusion has been reported in approximately one hundred patients in the main study and up...

...contd. on next page

First gene therapy to treat severe haemophilia A (contd)

to five years in a few patients in a supportive trial conducted by the applicant. Longer-term follow-up tests may be required to verify a continued safe and effective response to the medicine.

EMA's recommendation is based on the results of a Phase 3 study. Two years after the administration, efficacy data showed that the therapy significantly increased factor VIII activity levels in the majority of patients. Bleeding rates were reduced by 85% and most patients no longer needed factor VIII replacement therapy.

Patients treated with Roctavian will be monitored for 15 years, to ensure the long-term efficacy and safety of this gene therapy.

In its overall assessment of the available data, the Committee for Advanced Therapies (CAT), EMA's expert committee for cell- and gene-based medicines, found that the benefits of Roctavian outweighed the possible risks in patients with haemophilia A.

The CHMP, EMA's human medicines committee, agreed with the CAT's assessment and positive opinion, and recommended approval of the medicine.

CHMP recommendation will now be sent to the European Commission for the adoption of a decision on an EU-wide marketing authorisation.

Excerpt from a media release published on the European Medicines Agency website on 24 June 2022

<https://www.ema.europa.eu/en/news/first-gene-therapy-treat-severe-haemophilia>

HFACT's

*Coastal
Getaway*

Bateman's Bay, 14-16 October 2022

Cabin-style accommodation

Costs for HFACT financial members heavily subsidised

Express your interest to attend HFACT's coastal getaway by **9 September** by contacting Kathryn Body - counsellor@hfact.org.au or 0409 830 472

DATES FOR THE DIARY

Express interest for coastal camp	9/9
Online Trivia Night	10/9
HFACT Community Breakfast	8/10
HFACT Coastal Getaway	14-16/10
HFACT AGM and gathering	15/10
Bleeding Disorders Clinic	4/11



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

Haemophilia Contact Details

Canberra Hospital

Main telephone: 5124 0000
Website:
<https://www.health.act.gov.au/hospitals-and-health-centres/canberra-hospital>

Haemophilia Treatment Centre

Mon-Fri 9am - 5pm
On duty nurse: 0481 013 323
Email: haemophilia@act.gov.au
More details at:
www.hfact.org.au/treatment

Haemophilia Foundation ACT

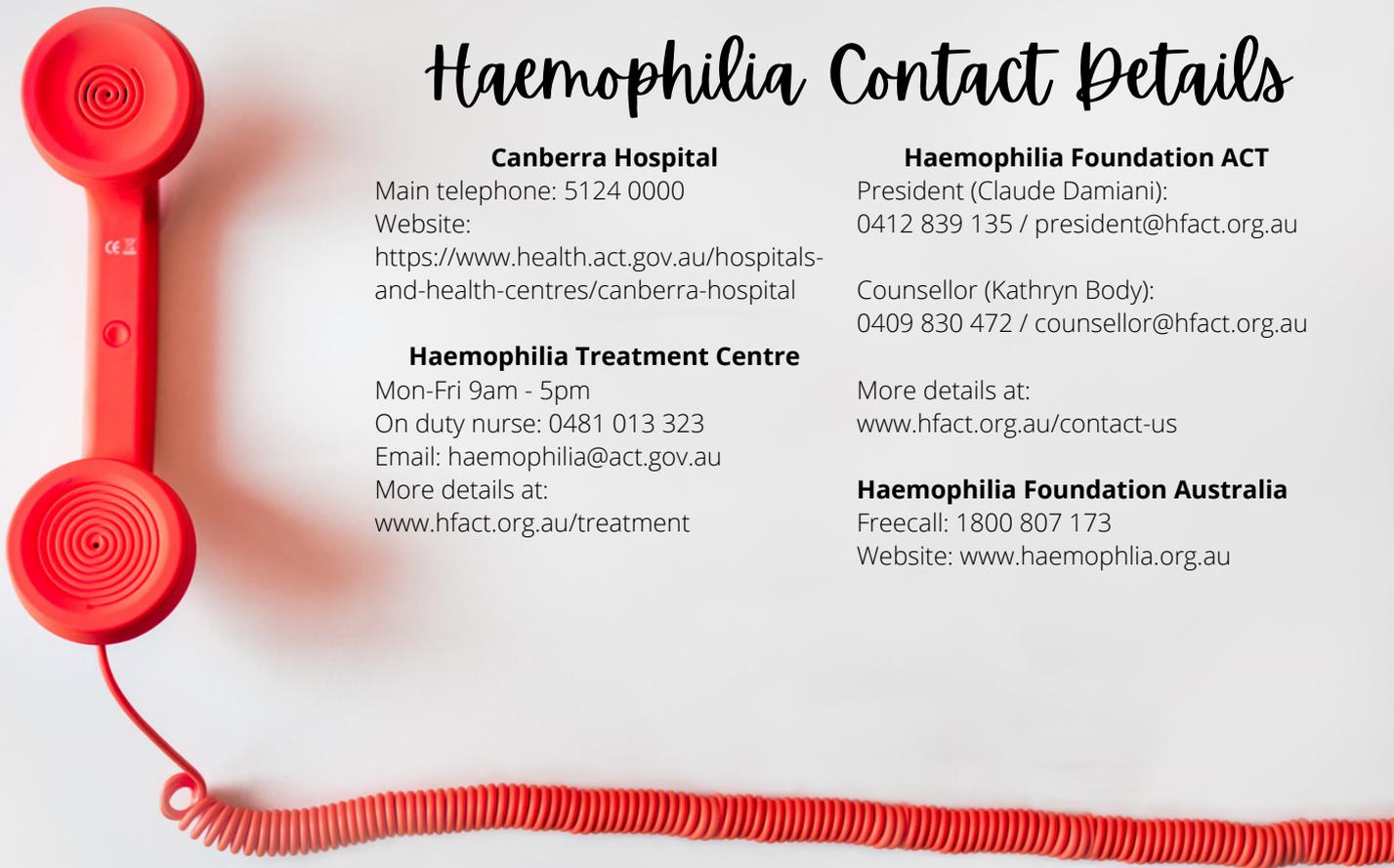
President (Claude Damiani):
0412 839 135 / president@hfact.org.au

Counsellor (Kathryn Body):
0409 830 472 / counsellor@hfact.org.au

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

Haemophilia Foundation Australia

Freecall: 1800 807 173
Website: www.haemophilia.org.au



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