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Newsletter of Haemophilia Foundation Australian Capital Territory



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From the President

Welcome to 2022. As we emerge from COVID-19 restrictions and some semblance of normality returns, so does HFACT's ambitions to return to pre-COVID operations, including hosting social functions and get togethers for people with bleeding disorders and their family and friends. We plan on holding a range of functions and events this year so look out for notifications/invitations, including within this newsletter for a trivia night invitation at a local venue which has been hosting trivia nights for many years.

On the hospital front, some of you may be aware that Jayne Treugust has been elevated into an acting CNC Haematology role at the Canberra Hospital for 12 months. Congratulations Jayne. From my experience dealing with Jayne I'm not at all surprised, she is a very considered, friendly and competent nurse who strikes a good balance between maintaining a professional relationship and building good rapport with her patients. While acting arrangements were in place for a short period, I have been advised that Lauren O'Connell will be taking up the role of acting APN Haemophilia and Bleeding Disorder Nurse at the Canberra Hospital.

While a change of nurse can sometimes bring with it some concern from members of the community about the nurses' awareness of bleeding disorders, it is reassuring to know that Ms O'Connell has experience in both oncology and haematology nursing and, according to Jayne's correspondence to me, showed great interest in the role for quite some time. Lauren O'Connell formally commenced in the role on 17 March. Additionally reassuring is the fact that Jayne will also still be around the Haematology Department, so it's good to know she could possibly be called on if required.

I hope the start of 2022 has been a good one for you and look forward to seeing you through the year.

Claude Damiani

Meet the 2022 HFACT Committee

At the Annual General Meeting on 19 October 2021, the following HFACT office bearers were elected.



Claude Damiani
President



Jenny Lees
Treasurer



Rebecca Minty
Vice-President



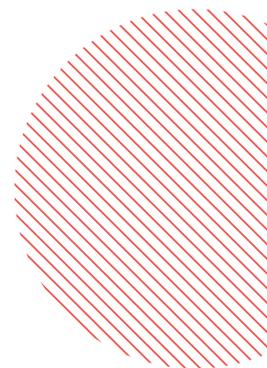
Shauna Adams
Secretary



Ron Lees
Committee Member



Len Minty
Committee Member

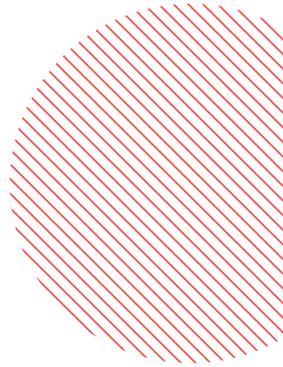


Vale Dr James D'Rozario



Some members of the bleeding disorder community may remember Associate Professor D'Rozario MBBS, FRACP, FRCPA who passed away at the age of 56 on Thursday, 27th January 2022. Although he specialised in blood cancers, he came into contact with some members of our community when he was completing advanced haematology training at Canberra Hospital and was directly involved in the care of patients with bleeding disorders. He went on to be Director of Haematology at Canberra Hospital in 2013 and from there to numerous other positions at Canberra Hospital, Calvary Hospital, and the Australian National University.

An obituary by the Haematology Society of Australia and New Zealand can be found on their website here:
<https://hsanz.org.au/news/12324651>



Back to school?



If you have children returning to school, and don't already have a haemophilia action plan in place, it might be worthwhile to consider having one. A plan can clearly explain your child's condition and what to do in case of injury or suspected bleed. It can set out communication protocols and also dispel any myths or misconceptions about bleeding disorders.

HFACT's counsellor, Kathryn Body, can assist in the process, including providing helpful templates. Kathryn can also conduct information sessions with school teachers and support staff.

If you'd like to find out more, please contact Kathryn Body on counsellor@hfact.org.au or 0409 830 472.

Haemophilia Treatment Centre Update

Hello everyone, my name is Lauren. I will be taking over from the wonderful Jayne in the haemophilia nurse role for the next 12 or so months. I'm really looking forward to supporting you all throughout this time.

A little bit about me. I was born and raised in Canberra and have lived here ever since. I love running and going on hikes, I'm currently training for a half marathon and to do the Overland Track in Tasmania. Favourite food is a tough one but I would have to say hot chips and I'm very eclectic in my music and movie tastes, I love everything from Star Wars to The Notebook.

I'm soon about to turn 29 and have been nursing for 8 of those years, my background is in oncology/haematology, mostly working in the chemotherapy day treatment wards. I'm very passionate about nursing and I'm lucky enough to have this wonderful career that I love!

I'm really looking forward to providing everyone with the support and care they need. Haemophilia and bleeding disorders is something I'm really interested in and I'm looking forward to learning some new things!

Lauren O'Connell

Haemophilia Treatment Centre Nurse

A colorful poster for the HFACT Community BBQ & Picnic. The background is light blue with white clouds. At the top right is the Haemophilia Foundation Australian Capital Territory logo, featuring a red 'H' with a white dot. The text 'COME AND JOIN US!' is in orange. The main title 'HFACT COMMUNITY BBQ & PICNIC' is in large, bold, dark blue letters. To the left, 'Games & Prizes!' is written in a pink, cursive font. Below the title is an illustration of a picnic scene with a blue BBQ, a red and yellow striped umbrella, a guitar, a director's chair, a red picnic basket, a water bottle, and a picnic basket. At the bottom, the event details are listed in orange and blue text: '19 MAR 2022 • NARA PARK, FLYNN DRIVE, YARRALUMLA • FROM 4PM', 'FOOD (INCL VEGETARIAN) AND DRINK PROVIDED - ALL WELCOME!', and 'RSVP TO CLAUDE - 0412 839 135'.

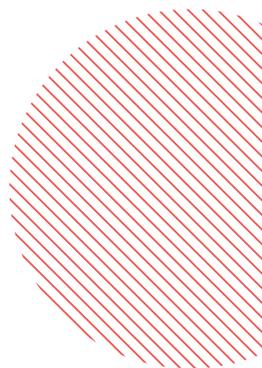
COME AND JOIN US!

HAEMOPHILIA FOUNDATION
AUSTRALIAN CAPITAL TERRITORY

HFACT COMMUNITY BBQ & PICNIC

Games & Prizes!

19 MAR 2022 • NARA PARK, FLYNN DRIVE, YARRALUMLA • FROM 4PM
FOOD (INCL VEGETARIAN) AND DRINK PROVIDED - ALL WELCOME!
RSVP TO CLAUDE - 0412 839 135



The Bleeding Obvious: It's trivia time again!

We are delighted to announce that HFACT will again field a trivia night team under the team name 'The Bleeding Obvious' at PJ O'Reilly's Monday Night Trivia, on 2 May 2022 (at PJs in the City: 52 Alinga Street, Canberra City). Come one, come all, and bring your expansive knowledge of things big and small! Come at 6pm for a 630pm trivia start.

HFACT will cover a meal and a drink for attendees. Please RSVP to president@hfact.org.au



Light It Up Red! - World Haemophilia Day

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.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday. This year the theme is Access for All. The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work with developing countries with their GAP and Twinning Programs and Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Canberra landmarks to be lit up include the Royal Australian Mint and the Carillion.

For more information, virtual activities and Light It Up Red Landmarks visit <https://www.haemophilia.org.au/WHD>

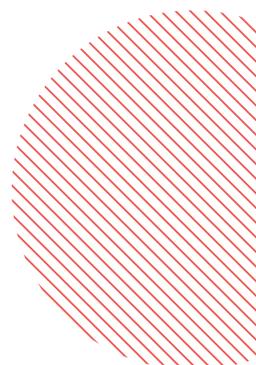


Royal Australian Mint, photo credit Bosco Lighting



DID YOU KNOW?

75% WFH estimates that over 75% of people living with haemophilia worldwide have not yet been identified and diagnosed.



DATES FOR THE DIARY

HFACT Community BBQ	19/3
World Haemophilia Day	17/4
Men's Business Trivia	2/5
@ PJ O'Reilly's, Civic (6pm)	



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: 0481013323
Email: haemophilia@act.gov.au
More details at:
www.hfact.org.au/treatment

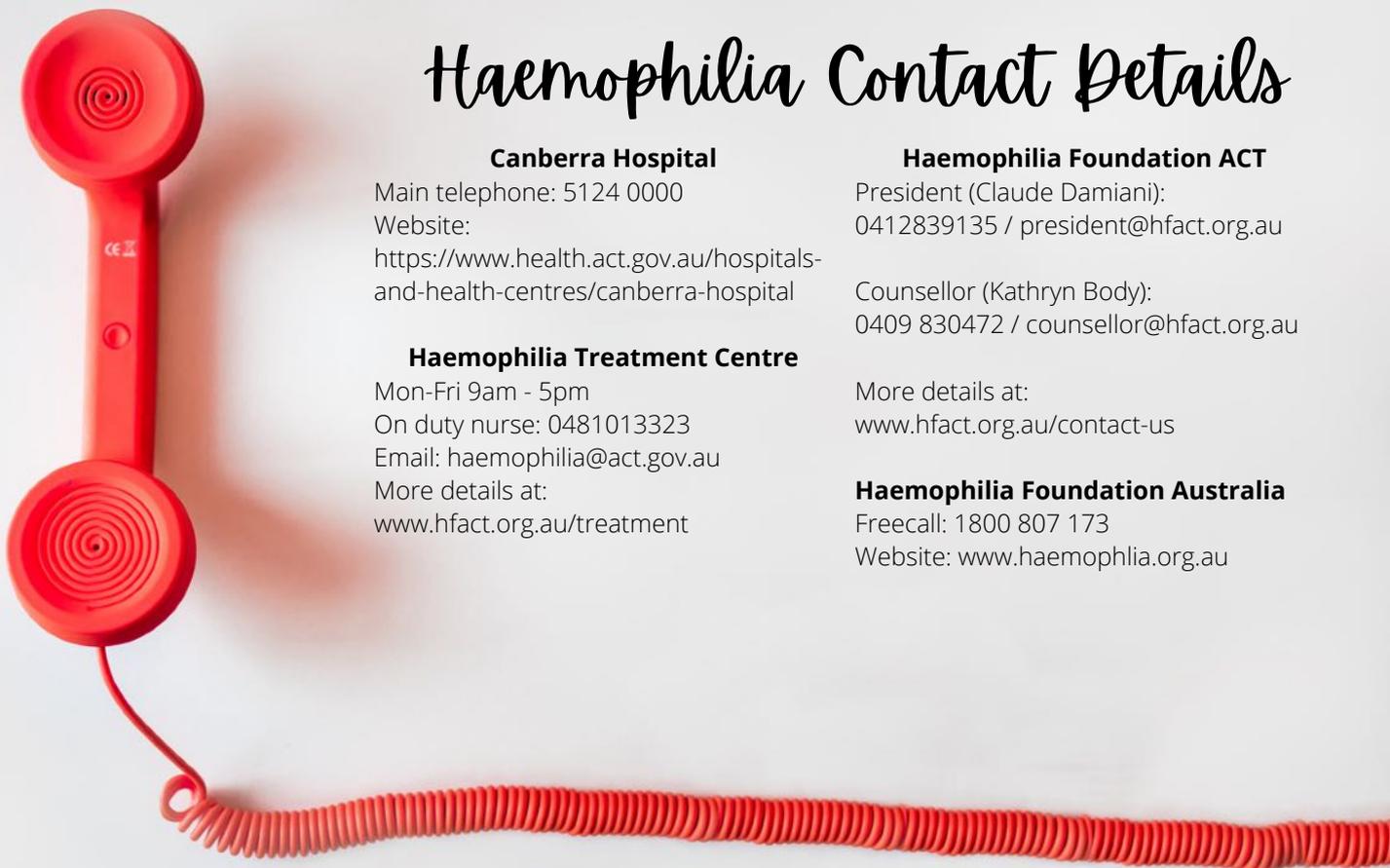
Haemophilia Foundation ACT

President (Claude Damiani):
0412839135 / president@hfact.org.au
Counsellor (Kathryn Body):
0409 830472 / counsellor@hfact.org.au

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

Haemophilia Foundation Australia

Freecall: 1800 807 173
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