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ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

New counsellor & HTC nurse

The HFACT committee would like to welcome Laura Bardell to HFACT. Laura is our new counsellor and commenced work on 5 August 2024.

After two rounds of advertising the job, and subsequent interviews, the committee is pleased to have found a successor to Kathryn, in Laura. Laura is currently completing her Masters of Counselling at the University of Canberra after a career as a midwife.

Over the next month or so, Laura will be contacting all HFACT members. Please take the opportunity to organise a chat with Laura. Everyone has a different story and experience of bleeding disorders and talking to Laura about your experiences will help ensure she has a holistic view of the various bleeding disorders experienced by our community.

Laura is currently working Mon/Tues/Wed and can be contacted on those days by phone (0409 830 472) or email (counsellor@hfact.org.au). We are currently talking to the hospital about access to a counselling room. We will let you know how that progresses.

We are also pleased to welcome the new bleeding disorders nurse, Rosamma Varghese, who has taken over the role following the recent retirement of Jayne Treagust. Rosamma has substantial experience working at the Canberra Hospital, including with people with bleeding disorders.

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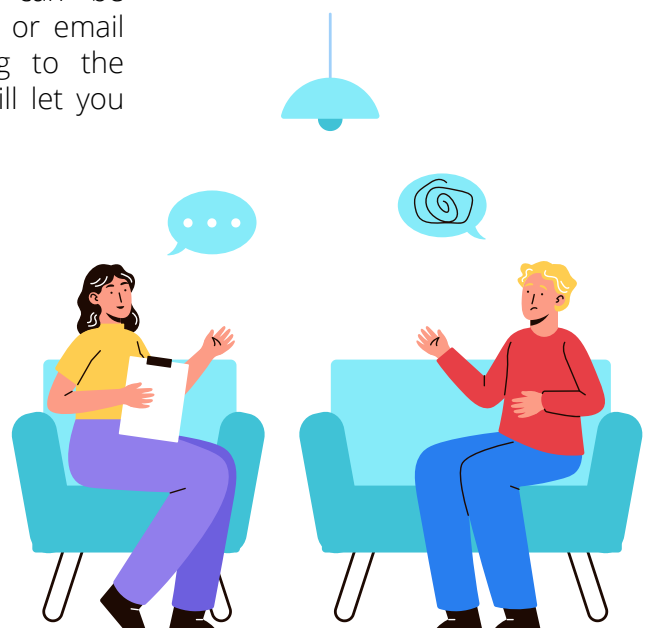
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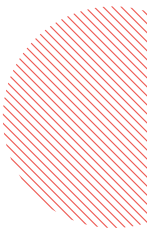


Introductions



**ROSAMMA
VARGHESE**
Registered Nurse

I am a registered nurse who has been working in The Canberra Hospital, Haematology department since 2009. I work as an Apheresis nurse, Chemotherapy nurse and currently I work as a Haemophilia Special nurse. I have also previously worked in India, UAE, and the UK. Nursing has provided me with the opportunity to develop my interpersonal skills, allowing me to effectively communicate and build rapport with patients, their families, and my colleagues. I take pride in my ability to provide compassionate care, support patients emotionally, and guide them through their treatment.



Hello, my name is Laura and I am the new HFACT Counsellor who has very big shoes to fill as I take over from the wonderful Kathryn! I'm really grateful and appreciative of the opportunity to work with you all and I look forward to meeting you and getting to know you in the coming months.



I thought I'd share a little bit about myself. Though I am originally from Melbourne, I moved to Canberra in 2013. Now that it's been over ten years, and having adopted the Raiders as my favourite NRL team, I feel I can officially call myself a proud Canberran (even though I technically live over the border in NSW)!

Prior to being a counsellor, I was a midwife at Canberra Hospital but after having my own children have felt the pull to work with people on a deeper more holistic level and have made the transition to counselling by studying a Masters at the University of Canberra while being a stay-at-home mum.

In my spare time I love to craft and you'll often find me knitting, drawing or painting – as I watch the NRL and AFL or listen to an audiobook.

I'm looking forward to working with you all, learning all I can about haemophilia and bleeding disorders, and hope that I can provide you with the support and care you deserve.





What does it take?

What does it take to change things?

What does it take to make things better?

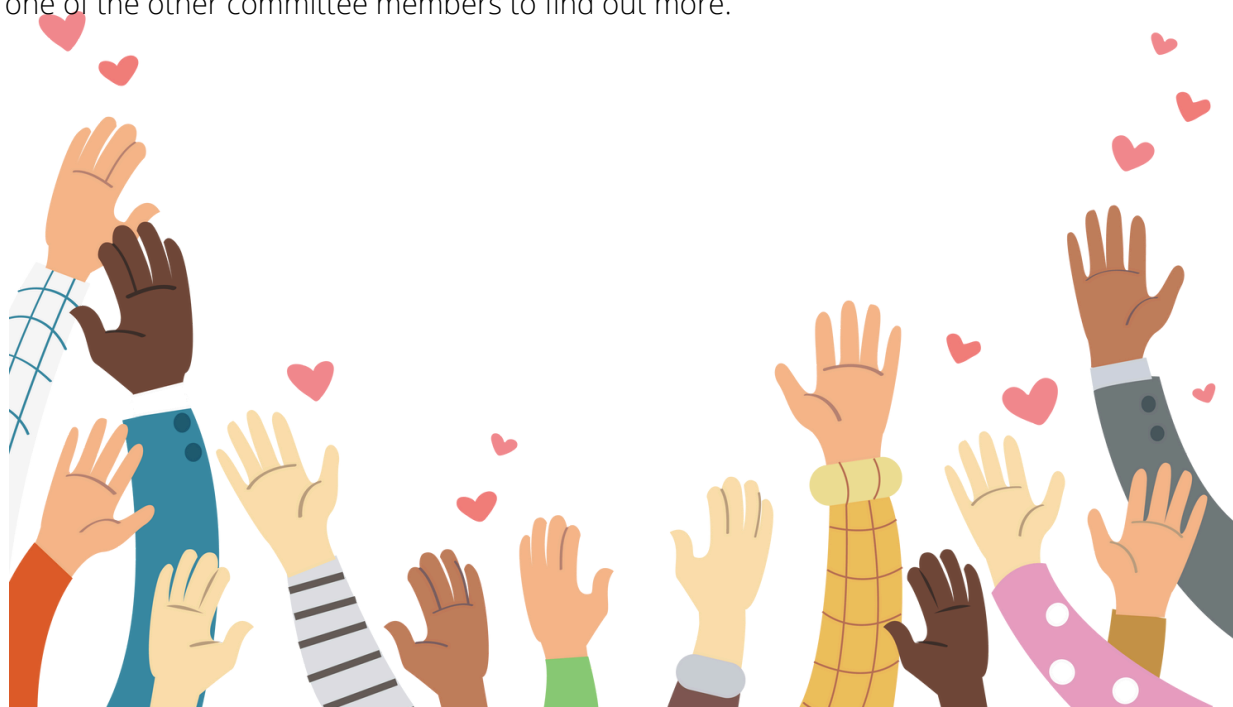
What is the haemophilia foundation anyway?

ANSWER

You, and your involvement! The haemophilia foundation consists of you, and others like you, who share a common interest, problems or issues associated with bleeding disorders such as haemophilia and von Willebrand Disease.

Things will only happen if you and others in the group participate, go to the functions, even join the committee! The opportunity for involvement is always there!

Do you have a skill or talent to offer? Are you simply prepared to help? If so, then you should consider joining the committee! The opportunity to do this comes around again at the Annual General Meeting which will be held in October. Details on the following page - or contact Claude or one of the other committee members to find out more.



Notice of HFACT 2024 AGM & call for nominations

The 2024 Annual General Meeting will take place at 7.30pm on Thursday 24 October at the home of Ron and Jenny Lees (48 Crowder Circuit Stirling). Nominations for the 2024-25 HFACT Committee are open until 16 October 2024 and should be forwarded to the Secretary at secretary@hfact.org.au. You may self-nominate. The following positions are available:

- President
- Vice President
- Secretary
- Treasurer
- general committee member

Agenda items should be submitted to secretary@hfact.org.au by 23 September 2024.

RSVP to treasurer@hfact.org.au or Jenny (0410 543 086) for catering purposes.



Committee members for HFACT!

We need to have a functioning committee to enable us to advocate, put on functions and activities for members, employ a counsellor, and provide practical and emotional support to our members. Specifically, the Secretary position has not been filled for the past two years. We had a volunteer minute taker during 2023 which was a great help but have been without that assistance during 2024. This means the remaining three members of the Executive have had to take on additional duties.

We also need to find someone to train up into the Treasurer role. Jenny has announced her intention to step down at the AGM next year (2025). No Treasurer means no association as we cannot meet our legal obligations as an incorporated association or as a recipient of government grants. Much has been done to streamline the job of the Treasurer over the past ten years:

- we use MYOB software to manage our funds
- all banking activity is online
- reporting to the ATO is facilitated by the software
- wages and entitlements are calculated by MYOB
- regular payments are automated (Telstra, MYOB)
- audit preparation is well documented

For more information on either role, reach out to Jenny on 0410 543 086 or treasurer@hfact.org.au

Bunnings BBQ result

On 14 July, HFACT hosted a Bunnings BBQ fundraiser at the Tuggeranong Bunnings store. These BBQs are a great way to engage with others in the community and help HFACT raise funds to support people with bleeding disorders and the events we hold for our bleeding disorders community.

The event was a great success, raising \$1973. Money from this fundraiser will go towards our 'Staycation' later in the year. More details on that in this newsletter!

Big thanks must go to those who volunteered their time on the day - whether for an hour, or significantly more. Without your help, we could not have gone ahead with it. Your contribution is greatly appreciated.

We aim to hold these fundraising BBQs annually, so keep an eye out for notice of our next one in 2025. We look forward to more enthusiastic volunteers signing up!

**THANK
YOU!**

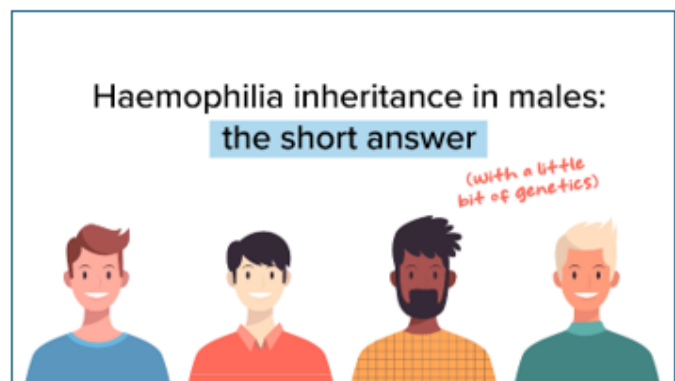
Haemophilia inheritance video

If you were born male and have haemophilia, will your children have haemophilia too?

This is a burning question for a lot of young men with haemophilia but the answer and explanation of why this occurs can be difficult to grasp.

HFA has developed a 2-minute video for teenage males with haemophilia who have questions about how haemophilia is passed on in a family. It covers:

- inheritance patterns for males with haemophilia
- a short and simple explanation of the genetics involved.



Watch the video

- on the HFA website - <https://tinyurl.com/haem-inherit-male-video>
- on the HFA YouTube channel - <https://tinyurl.com/YT-haem-male-inherit-video>

HFA is very grateful to the young people with haemophilia and their parents and the health professional experts who reviewed the video – particularly the HFV youth leaders who contributed valuable feedback and advice to its development.



Spring Soiree

WHEN: *Thursday 26 September, 6pm - 7:30pm*

LOCATION: *Allhomes office in Kingston (1/67 Eyre St, Kingston)*

Drinks and nibbles provided. RSVP for catering purposes to Jenny (0410 543 086) or Laura (0409 830 472) by 24 September.

This will be an opportunity to meet the new HFACT counsellor, Laura, and to hear from Martha Soria about her experiences at the Haemophilia World Congress earlier this year.

SAVE THE DATE



Staycation

Join the HFACT community for a day of locally-based fun activities in NOVEMBER!

- Treetops Adventure - 2 hours of outdoor adventures in Majura Pines, for kids and adults alike
- outdoor BBQ lunch - with playground facilities for the kids
- tenpin bowling - test your skills on the bowling alleys
- dinner at the Southern Cross Club

Come along to all or just a selection of the activities. All costs will be covered by HFACT.

Date and RSVP details will be emailed out soon.

DATES FOR THE DIARY

Spring Soiree	26 September
HFACT 2024 AGM	24 October
Staycation	November (date TBA)
Bleeding disorders clinic	22 November



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

Haemophilia contacts



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:
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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