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ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

It's only a couple of weeks until the next HFA biennial conference on haemophilia, VWD and rare bleeding disorders, to be held in Melbourne on 24-26 August. I'm really looking forward to it. Having been to the previous five conferences, I always find them informative, educational and somewhat uplifting when hearing about the latest treatment options under development. Further information about the conference is in this newsletter.

Also looking forward, HFACT is in full swing with planning for the next HFACT camp, to be held in October on the South Coast. Details about the camp, as well as the registration form to attend, are included in this newsletter. The last camp was a great success with a good turnout, lovely weather and a fun mix of activities for all ages. I'm confident this year's will be just as good (if not better!).

Finally, HFACT is continuing to engage with the Haemophilia Treatment Centre to find a suitable time to hold a meeting to discuss a range of issues of importance to the bleeding disorders community in the ACT and surrounding regions. This is just one way in which HFACT advocates on behalf of the community to ensure that community concerns around hospital treatment and care are addressed and opportunities are realised. I'll provide a summary of the meeting in the next newsletter.

Enjoy the rest of winter and hopefully see you at the HFA conference!

Claude Damiani

President

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TRIVIA NIGHT



Everyone loves trivia, right?

Well, there are a few keen ones in the ACT bleeding disorders community, and to cater for that love of trivia, HFACT entered a table in Canberra's more competitive trivia night (Tuesdays) at the Durham Hotel in Kingston in May.

HFACT has entered a table in a trivia night for a number of years now and while we have previously shown some glimpses of trivia talent, this year's performance under the team name of *"The Bleeding Obvious"* was probably best described as so-so, middle of the road, flying under the radar, not making waves, etc... you get the drift!



While we didn't go home with the win, one of the team did win the 'heads or tails' competition, which entitled us to a free shot of alcohol for everyone on our table. You can see below, Len Minty proudly displaying our liquid treasure cups before they were ceremoniously swilled in one smooth motion. Fair to say, we had a great time.

Until next year...we will be back!





HFACT Community Coastal Camp 2023

The HFACT Camp Committee is pleased to announce the details of the 2023 HFACT Community Coastal Camp!

Key Information

- **Date:** Friday 20th – Sunday 22nd October
- **Location:** NRMA Batemans Bay Holiday Resort (51 Beach Rd, Batehaven NSW)
- **Cost:** \$175 per family for HFACT financial members

After the resounding success of last year's camp, we have decided to return to the NRMA Batemans Bay Holiday Park for another unforgettable experience. Thanks to the subsidies provided by HFACT, and the proceeds from our recent Bunnings BBQ fundraising day, the camp will be heavily subsidised for HFACT financial members.

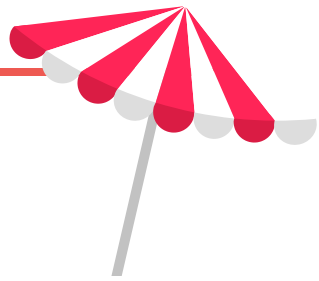
The weekend will be packed with a diverse range of activities suitable for all ages: relaxing on the beach, engaging in heartwarming conversations, participating in a group visit to the local aquatic centre where you can have a relaxing swim or experience the waterslides, and much more! There's guaranteed to be something for everyone.

Please submit your registration form (enclosed with this newsletter) and payment by **no later than Wednesday 23rd September**. For enquiries or further information about the camp, please contact the HFACT President, Claudio Damiani (0412 839 135) or HFACT Counsellor, Kathryn Body (0409 830 472).

We look forward to welcoming you at the coastal camp!

Warm regards,
HFACT Camp Committee





Some photos from the 2022 camp...



HFACT 2022



SANDCASTLE



COMPETITION





**SAVE THE
DATE**

SATURDAY 21 OCTOBER, 7PM

ANNUAL GENERAL MEETING

The 2023 HFACT Incorporated AGM will take place as part of the HFACT coastal camp at Batemans Bay for in-person attendees. Financial members not attending the camp can dial in via Zoom.

A formal agenda and call for nominations for HFACT Committee positions will be forthcoming closer to the date.

PLEASE CONSIDER ATTENDING!

The poster features a dark blue background with white decorative elements like stars and swirls. At the bottom, there are colorful hand silhouettes in red and yellow. The text is arranged in a clear, hierarchical layout with bold headings and a call to action.



Family event

Calling all families with children with a bleeding disorder...

You are invited to the residence of Claude and Julia for an afternoon BBQ. There will be fun games for the kids (and for adults) and plenty of food to share. It will be a great way to meet other families and share stories, learnings and concerns about your little ones in a relaxed and positive environment.

Date: Saturday 9 September
Time: 3pm
RSVP to Claude by 3 September (president@hfact.org.au or 0412 839 135)
Address to be provided on RSVP

The invitation features a white background with colorful watercolor splashes in shades of blue, green, pink, and yellow. The text is centered and uses a mix of bold and regular fonts. The overall aesthetic is warm and inviting.



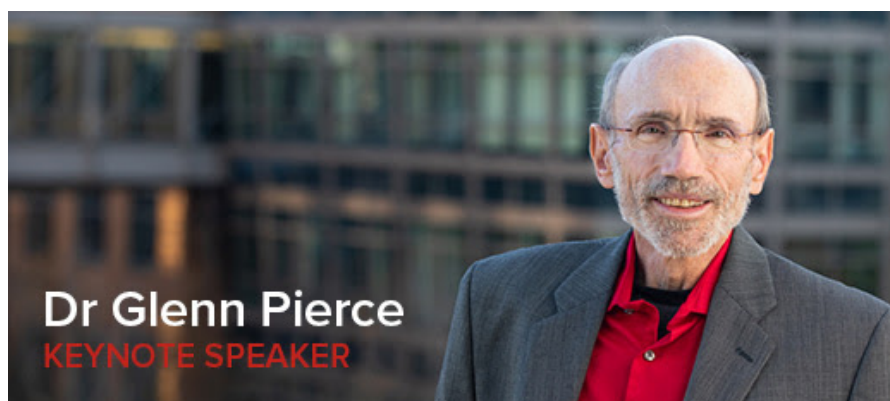
HFA Conference 2023

It's not too late to register!

The **21st Australian Conference on haemophilia, VWD & rare bleeding disorders** will be held in person at the Pullman on the Park, **Melbourne, 24-26 August 2023**. The venue has good access in and around the hotel and on the conference floor, with direct lift access. The hotel is suitable for people who use wheelchairs.

The multidisciplinary program will include presentations from people living with bleeding disorders, experts, as well as health professionals and other specialist speakers. There'll be something for everyone, with topics ranging from: new developments in care and treatment, gene therapy, women/girls with bleeding disorders, getting older with a bleeding disorder, managing pain, and much more.

The keynote speaker will be Dr Glenn Pierce. Dr Pierce currently serves on the World Federation of Hemophilia (WFH) as Vice-President Medical and WFH USA Board of Directors and NHF (US) Medical and Scientific Advisory Council. He is an Entrepreneur-in-residence at Third Rock Ventures USA, and a biotech consultant in the areas of gene therapy and haematology.



Registration link and details: www.haemophilia.org.au/conferences or email hfaust@haemophilia.org.au

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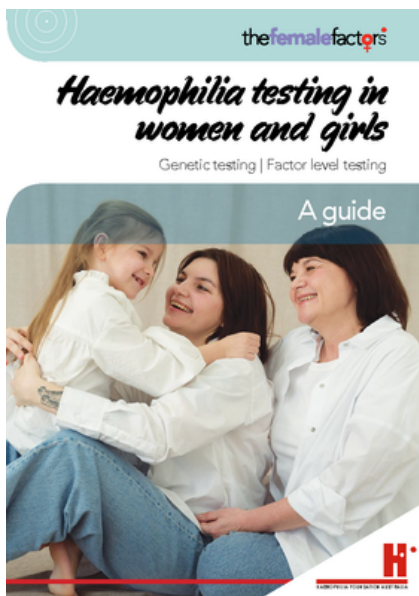


Supporter BIOMARIN

New HFA education resource: Haemophilia testing in women & girls

New simple haemophilia testing guide

Explaining genetic testing and factor level testing simply



Unsure about genetic testing and factor level testing in haemophilia and how it works in women and girls?

Haemophilia Foundation Australia has published a new education resource, **Haemophilia testing in women and girls: a guide**, to answer these questions simply and clearly.

The resource is aimed at women, girls and parents of girls and uses relatable stories, infographics and diagrams to tackle some complex information in an accessible way.

How does a woman or girl know if she is affected by haemophilia?

- What are genetic and factor level tests?
- Who should have these tests and when?
- How is haemophilia passed on in a family – and what if there is no family history?
- Why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the education resource in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. We would like to thank everyone involved for their advice and creative ideas!

HOW CAN YOU ACCESS THE RESOURCE?

Visit the HFA website page: <https://tinyurl.com/haemophilia-testing-simple>

- download the entire resource
- read it online magazine-style (ISSUU)
- download specific sections, e.g. genetic testing and counselling

Look out for the webpage version – coming soon! To request print copies (free):

- email HFA at hfaust@haemophilia.org.au
- call (03) 9885 7800



Membership renewal

It's Haemophilia Foundation ACT membership renewal time – fees for 2023-24 are now due.

The membership fee remains unchanged at just \$20 per annum. Donations are always welcome and are tax deductible. *This year we have introduced the option to pay for a three-year membership – taking you through to June 2026. A three-year membership costs just \$55.*

Membership fees can be paid by direct bank deposit (details below). Please include your name in the reference or payee field.

Westpac Bank
BSB: 032-778
Account number: 440919
Account name: Haemophilia Foundation ACT Incorporated

We now also have the ability to accept payment by credit card. Details of this payment option are on the 2023-24 Membership Application / Renewal Form (enclosed with this newsletter).

Membership renewal time is a good opportunity to inform us if any of your contact details have changed. You can do this on the Membership Form (included with this issue of ACTivated and also available on the HFACT website at www.hfact.org.au/join) or by using the change of details page on our website (www.hfact.org.au/update).

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.



Membership renewal...

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
- three 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, Haemophilia Foundation Australia
- representation and advocacy at the local and national level
- entitlement to vote at the HFACT AGM
- the option to 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 will enable us to:

- update our records
- ensure you get communications in the format most appropriate for you
- tailor our activities to our membership
- provide evidence to ACT Health about the size of our community to prove ongoing eligibility for the grant that covers Kathryn's services

Jenny Lees
Treasurer

Join us!

DATES FOR THE DIARY

HFA Conference	24-26/8
Family event	9/9
Coastal Camp registrations due	23/9
HFACT Coastal Camp	20-22/10
HFACT AGM	21/10
Bleeding disorders clinic	Nov (tbc)



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 (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



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

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