



ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

As 2022 draws to a close, reflecting on the year brings a sense of relief and, heading into 2023, optimism.

The year started with COVID still in full swing but over the course of the year it has waned for various reasons – although it's concerning to hear reports of an impending fourth wave of infections.

During the year, HFACT was able to kick-start activities and events once more, beginning with an online trivia event, followed by a breakfast and finally, a community camp. The camp was a long time in coming, having twice needed to be cancelled due to COVID. But it was well worth the wait: a good turnout, great weather, a venue that catered to all age groups – making for a fantastic camp all round. HFACT intends to keep up the social activities in 2023, beginning with a community BBQ in February. We will also look to host a Bunnings BBQ, which is always a great fundraiser and an excellent way to connect with the community and friends.

In terms of the Haemophilia Treatment Centre (HTC), everything appears to be travelling along well and the community is in the fortunate position to now have a number of nurses (Jayne, Lauren, Lachlan) with experience in dealing with people with a bleeding disorder. The HTC is efficient in the services it provides to our community, and from my own experience, the nurses always show a genuine care for their patients.

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President's Report cont.

I'd like to thank the HFACT Committee for its hard work and dedication throughout 2022, as volunteers working to improve outcomes for people with bleeding disorders. The AGM confirmed the departure from the Committee of Rebecca Minty (who has been involved for several years, including as Secretary, Vice-President and newsletter editor), and Shauna Adams stepping down as Secretary into a committee member role. The Committee also welcomes two new members, Richard Laugesen (new Vice-President) and Nick Tining (Committee Member). It's great to have some fresh faces on the Committee and I look forward to their contributions.

Lastly, I'd like to wish you all a merry Christmas, safe travels if you'll be holidaying or visiting family and friends, and a happy and safe festive period. See you in 2023!

Claude Damiani

President



Camp Musings

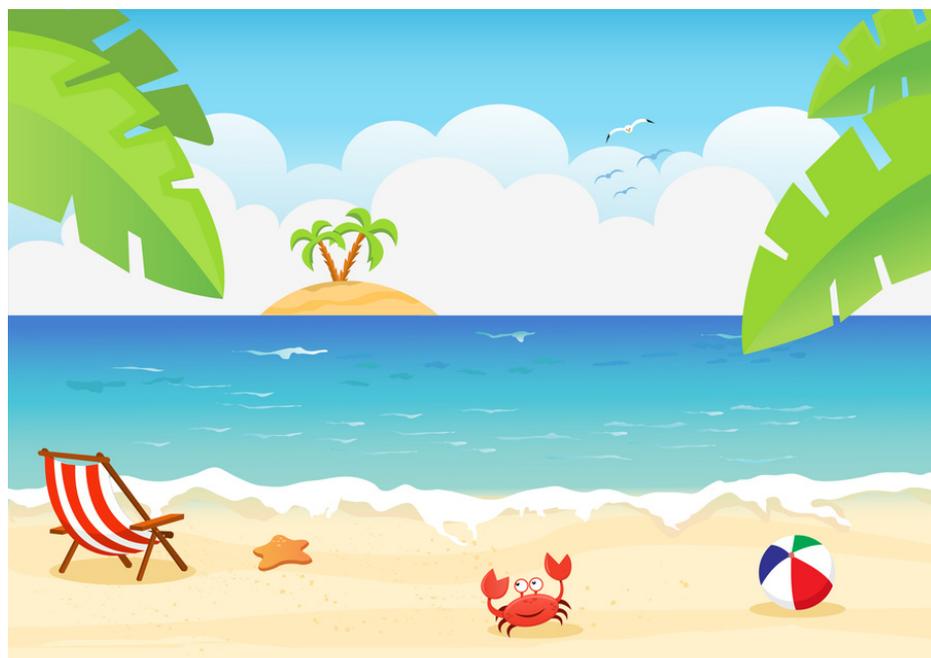
From Friday 14th to Sunday 16th October 2022, the Haemophilia Foundation of the ACT welcomed people with bleeding disorders and their families from the ACT and surrounds to a community camp. The camp was held at the amazing NRMA Batemans Bay Holiday Resort, about two hours from Canberra. A lovely beach setting awaited those who joined, after an adrenaline-filled drive dodging potholes from the recent rains. What followed was a relaxing weekend of family time in the cabins, planned activities, knowledge sharing and growing friendships.

Chelsea, Katherine and Kathryn did an amazing job organising activities for the children and tweens, with bubbles, balls, hoops, craft, outdoor games, team challenges and girls talk. The children also had a blast with the jumping pillow, mini golf, swimming pool, tennis court and foosball table. The movie night was a highlight for many of the children, with a chance to relax with new and old friends, playing games and chatting, while the adults had some downtime at the HFACT AGM (with cheese and wine!). Yasmin (10yo) said, "The jumping pillow was awesome! I really liked the movie night and hanging out with other girls my age."

It wasn't all for the children, though. Following a fun getting-to-know-you activity, the adults had plenty of time to share knowledge on navigating the Canberra and regional hospital settings, supporting children as they transition into adult settings, and discussing how treatment has changed over time. We were fortunate to be joined by HFA's Suzanne O'Callaghan, who shared some updates from HFA, including the different priority areas, advocacy work and evolving community needs. If all that wasn't enough, we also spent time on Corrigans beach, jumping waves and building sandcastles (see the great results below!). Families spent Sunday morning exploring Birdland and at an impromptu meet-up at the new Bay Pavilions Aquatic Centre, before the drive home.

The camp was made financially possible through funding from ACT Health and a small contribution from each family. However, it would not have happened without the generosity of the volunteers who helped weave all the threads together, most especially Kathryn and Jenny. We appreciate all their efforts, time and dedication to making the camp enjoyable for all.

Richard Laugesen



HFACT 2022



SANDCASTLE



COMPETITION



Transition to Hemlibra

My name is Alessandro Damiani. I started on Hemlibra two months ago and so far I've really enjoyed it. Here are some reasons why:

- It's a lot faster to set up and to do than prophylaxis (which I didn't do, but my brother did)
- It doesn't hurt at all because the needle is a lot thinner and the needle goes into your stomach or thigh, where the fat is, and not the vein
- Hemlibra is a lot easier to do than prophylaxis because you can do it yourself, whereas prophylaxis is a lot harder to do by yourself.



Overall, I'm finding my experience with Hemlibra a good one, and I'd like to continue.

AGM Wrap-Up

HFACT's Annual General Meeting took place during the October coastal camp. As the camp coincided with the time we usually hold our AGM, the opportunity to gather as many members as possible and hold a face-to-face meeting followed by a social get-together was too good to miss. We offered a hybrid meeting, giving those members not attending the camp the opportunity to join us via Zoom, but in the end all attendance was in-person. Thirteen members participated – significantly more than the virtual AGMs held in the past two years. In fact, given that we met in one of the camp's accommodation cabins, it was actually very cosy!

During the meeting the 2022 Annual Report and Financials were presented (available at <https://www.hfact.org.au/publications/annual-reports>) and the 2023 Committee was elected. Prior to the AGM, Rebecca Minty announced she was stepping down from her role as Vice-President and newsletter editor, and Shauna Adams stepped down from her position as Secretary and website editor. President Claude Damiani thanked them both for their service over recent years. While Rebecca is moving on to other interests, Shauna remains a general committee member in anticipation of taking up a role with the World Federation of Haemophilia.

The incoming Committee is:

- **President** Claude Damiani
- **Vice-President** Richard Laugesen
- **Secretary** *vacant* – HFACT was unsuccessful in filling the position of Secretary at the 2022 AGM so the Secretary's duties will be undertaken by other committee members, pending filling the Secretary position. If you are interested in helping HFACT by filling that role please contact the President
- **Treasurer** Jenny Lees
- **Other Committee Members** Shauna Adams , Ron Lees, Len Minty, Nick Tinling

After formally closing the meeting, we continued to socialise and enjoy some wine and cheese, catching up or making new acquaintances.

Your HFACT Committee in 2023

The Annual General Meeting on 15 October 2022 saw the HFACT office bearers for 2023 elected. It's exciting to welcome two new members to the Committee. And many thanks to the outgoing Vice-President, Rebecca Minty, for her valuable contributions over the last few years, and to Shauna Adams, who has served as Secretary for some years (and will remain on as a Committee Member).



Claude Damiani
President



Richard Laugesen
Vice-President



Jenny Lees
Treasurer



Nick Tinling
Committee Member



Shauna Adams
Committee Member



Ron Lees
Committee Member



Len Minty
Committee Member

Introducing the new Committee members

We are the Tinlings, new members of HFACT. Cass and I (Nick) have two wonderful sons Brody, (1yo) and Connor (3yo). Our family has recently become part of the bleeding disorders community as Brody has been diagnosed with Haemophilia A (severe). With no family history we were very surprised by Brody's diagnosis. We later discovered Cass carries the genetic alteration causing haemophilia.

Our first interaction with the HFACT community was at the recent camp at Batemans Bay. Thank you to everyone at the camp for making us feel so welcome. We were honestly a little nervous in the lead up to the camp – we had no clue what to expect but were eager to connect with the community and learn more about haemophilia. Cass and I are very grateful to the parents (and grandparents) who shared their experiences and insights on raising kids with bleeding disorders.

Our boys had a ball at the camp. Connor's highlights included attending the movie night (with his new friends) and getting a hole-in-one at mini golf! Brody especially enjoyed the sandcastle competition. Thank you to everyone involved in organising the camp.

I'm pleased to have become a member of the HFACT Committee and look forward to meeting the wider HFACT community in future.



Nick Tinling

I was diagnosed with Haemophilia A in New Zealand in the 1980s, when a cousin injured himself in a rugby match. We now know that my family has a complicated history with bleeding, going back a few generations and now including my tweens Yasmin and Maya.

Treatment was different back then and avoiding things that might cause a bleed became the leading approach. Navigating the AIDS epidemic as a teenager with Haemophilia was particularly confusing, although nothing compared to the very difficult time for others in our community. It's great that now many families with bleeding disorders enjoy a brighter future following all the amazing innovations from medical research and vibrant community support.

I'm excited to join the HFACT committee as Vice-President and look forward to helping our diverse community wherever I can. I hope that my background in science, and appreciation of the different experiences each of our members may have, can be of use.

Richard Laugesen

Save the date(s)...

A graphic invitation for a Summer BBQ. It features a dark blue background with a white scalloped border. At the top, the text "Late summer, but not too late..." is written in a cursive font. Below this, "COME ALONG TO THE HFACT" is written in a bold, red, sans-serif font. A large red banner with white text reads "SUMMER BBQ". The event details are listed: "NARA PARK (LENNOX GARDENS), YARRALUMLA" and "SUNDAY 19 FEBRUARY, 10AM". There are three blue stars below the date. The RSVP information is "RSVP TO CLAUDE DAMIANI @ 0412839135 BY 11 FEB". On the right side, there is an illustration of a red and blue barbecue grill with a fork holding a sausage over it.

Late summer, but not too late...

COME ALONG TO THE HFACT

SUMMER BBQ

NARA PARK (LENNOX GARDENS), YARRALUMLA
SUNDAY 19 FEBRUARY, 10AM

★ ★ ★

RSVP TO CLAUDE DAMIANI @ 0412839135 BY 11 FEB

*Food and drinks provided (including vegetarian).
Fun activities and games for kids and adults alike!*

A graphic for a Coastal Getaway. It features two green palm trees on either side of a yellow sun setting over blue waves. The text "COASTAL GETAWAY" is written in a bold, blue, sans-serif font. Below this, the date "MID-OCTOBER 2023" is written in a blue, sans-serif font, and "DETAILS TO COME" is written in a smaller, blue, sans-serif font.

**COASTAL
GETAWAY**

MID-OCTOBER 2023
DETAILS TO COME

Preparing for the Holiday Season

Hi all,

Just some news from the HTC.

Firstly some exciting news.... Jayne will be coming back into the Haemophilia Nurse role at the end of January 2023! I will be returning to my permanent role in the chemotherapy unit as planned. I would like to take this opportunity to thank you all for being so welcoming, I've really enjoyed the role.

Secondly, as the Christmas season is fast approaching, could I remind everyone to do a little stocktake of their medication. Please make sure you have enough of everything to get you through the Christmas period. The HTC is not open on public holidays and neither is the pharmacy, so any dispensing needs to be organised early! It's taking around a week for the Hemlibra to come in to the hospital, so please be mindful of that.

Wishing you all a safe and happy holiday season!

Lauren O'Connell
Haemophilia Treatment Centre Nurse



HFACT WISHES YOU ALL A

Merry Christmas

AND A HAPPY AND SAFE
FESTIVE SEASON!



DATES FOR THE DIARY

Contact HTC if you need product over

Christmas	ASAP
HFACT Summer BBQ	19/2
Bleeding Disorders Clinic	May (tbc)
HFACT Coastal Getaway	Oct (tbc)



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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