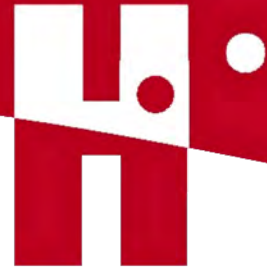


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Newsletter of Haemophilia Foundation WA Inc.

November 2022



Dear Community & Valued Supporters,

DOES THE HAEMOPHILIA FOUNDATION WA STAY OR CLOSE?

Over the last few months, the Haemophilia Foundation Western Australia (HFWA) Management Committee has been reviewing the services we offer to the community.

Currently we provide -

- Education to individuals, families and the wider community around the causes and impacts of bleeding disorders. This is done in person, by telephone, during community presentations or through the provision of written information and resources
- Peer support for individuals and families living with the impact of a bleeding disorder
- Advocacy to encourage the clear understanding of the specific needs of women with bleeding disorders, people with von Willebrand disease, and the lesser-known and understood range of very rare bleeding disorders
- Community fundraising events, regular breakfast events and camps that offer enjoyment and connection with other families and individuals, and allow connection and conversations, without the need to explain the challenges that we live with
- Advocacy, in conjunction with Haemophilia Foundation Australia. For new treatment products to be made available to individuals

The HFWA, in conjunction with the Haemophilia Foundation Australia, has been a strong and unrelenting voice for change in treatment and services over many years.

Over the past few years, the number of people attending our activities (other than a small core) has been getting smaller and there is less response to requests to become involved in the foundation. As a committee who are keen to make a difference, we are questioning whether we continue operating.

If you want this strong representation to continue, you need to tell us and more importantly, become involved. Yes, we know people are busy and guess what - so are we, the committee members. The choice is now yours; let us know.

The HFWA works hard to lobby for new and emerging treatments to be made available to the bleeding disorders community. This has resulted in huge changes in the opportunities for people with bleeding disorders to lead a productive, fulfilling and more pain-free lifestyle. This is very different from treatment that was available as little as ten years ago.

How HFWA can be of value to you and your family?

How will you become involved with your foundation?

How will you support the work we do?

The alternative is simple, we close the doors of the Haemophilia Foundation (WA) and the community is left to fend for themselves in accessing what we know are some new and exciting treatments in development for people with bleeding disorders.

Please remember that our current products and the newer opportunities being developed are very expensive, and governments and taxpayers need to be convinced about why they would want to spend more money on even better products if what we have is considered 'good enough'.

So over to you; what do you want? Please remember that your silence or lack of response is an answer that tells us to close the doors.

The Haemophilia Foundation of WA Committee



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YOUR COMMITTEE

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Cheryl Ellis (Vice-President)

Robert Butler (Treasurer)

Michelle Dinsdale (Secretary)

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Profiles of committee members can be found on the website, at www.hfwa.org/yourcommittee

PERTH CHILDREN'S HOSPITAL CONTACT DETAILS

Clinic H, Level 1 (Haematology/Oncology Outpatients: Ph: 6456 0170

Medical Staff: **Dr Tina Carter** - Ph: 6456 0170

Nursing Staff: **Natalie Gamble-Williams** and **Stacey Hutchison**

Social Worker: **Sarah Franz** (Three days per week, contact for appointment) Ph: 3456 0413

FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**

Medical Staff: **Dr Stephanie P'ng** and **Dr Dominic Pepperell**

Nursing Staff: **Sandra Lochore** and **Lara Olson**

Social Worker: **Helena Reynolds** (Mon and Thurs 9:00 am - 1:00 pm, contact for appointment)
Ph: 6152 6527

ABDR Data Manager and Clinical Trial Coordinator: **Marina Goruppi**

Entrance to the Cancer Centre is on the outside of the building
Haemophilia and Haemostasis Centre
Level 1 Cancer Centre
Fiona Stanley Hospital
102-118 Murdoch Drive
Murdoch WA 6150

Postal Address (address all correspondence as Private and Confidential);
Haemophilia and Haemostasis Centre
Level 1 Cancer Centre
Fiona Stanley Hospital
Locked Bag 100, Palmyra DC WA 6961

Opinions expressed in Contact do not necessarily reflect those of the Foundation. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFWA reserves the right to edit articles as it sees necessary. Material supplied on the internet is for information purposes only and is not to be used for diagnosis or treatment.

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These pages are blank to reflect the extent of communication and advice between HFWA and the Community should the Foundation close.

**HFWA is grateful to Fuji Film Australia for their ongoing support in printing
the Contact Newsletter**

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Peer Breakfast November 2022

It's been an extended period of time since we last got together for a Women's/Men's breakfast. So on Sunday 6 November 2022 we had a joint Men's & Women's breakfast at the Waterwall Restaurant in Como with 18 Attendees.

It was great to catch up again and most of us missed having the opportunity to regularly catch up and chat about the machinations of life living with a bleeding disorder and dealing with the vagaries of Covid-19 and how it has impacted our lives.

There was lots of discussion about solving all of the world's problems, interspersed with how people are managing with new innovative treatment products that we have access to, and the benefits to peoples' health as a consequence.

We look forward to catching up early in the new year and hope to have more members attend.





Sausage Sizzle 16 October 2022

We held our annual Sausage Sizzle fundraiser at Bunnings Homebase Wembley on a fine Sunday 16th October.

We sold approximately 440 sizzles with plenty of drinks also and the awesome “double doggers”.

It was a lovely day with a steady stream of customers. We gave away stickers and balloons to kids along with some fantastic shoelaces and great new Haemophilia Foundation Australia Frisbees.

The Committee would like to extend their gratitude to the following people who volunteered their time, equipment, donated beverages and financial donations for this event. Without all your help and commitment on and in the lead up to the day it would not have been possible.



A Huge thank you to:

Shane Meotti, Sheryl Butler, Jaspa Favero, Debbie Favero, Neil Venn, Jenny Garlinge, Grit Andre and family, Sharri, Aaron & Will Brodie, Roma Stokes, Victoria Foran, Pam & Bill Aitkins, Lena Smith, Paul Keogh, Cheryl Ellis & Family, Michelle Dinsdale, Susie Couper, Nici Burgess, The residents at Mandurah Gardens Estate.

Bleeding Disorders Awareness Month 2022

Thank you to Ally & Finn who held fundraising activities and The Dique family events for BDAM.

Please visit the HFWA website regularly for upcoming events and information about your foundation.

www.hfwa.org and www.haemophilia.org.au

