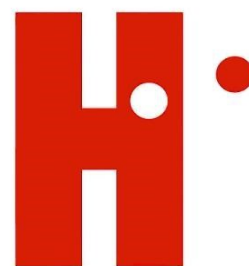


# Contact



**Newsletter of Haemophilia Foundation WA Inc.**

**February 2020**



— HAPPY NEW YEAR —

**HAEMOPHILIA FOUNDATION WA INC.**

City West Lotteries House, 2 Delhi Street, West Perth WA 6005  
P: 08 9420 7294 E: [office@hfwa.org](mailto:office@hfwa.org) W: [www.hfwa.org](http://www.hfwa.org)

**Inside This Issue**

President's Report	3
Introducing Michelle Dinsdale	3
Introducing Helena Reynolds	3
Men's & Women's Breakfasts	4
2019 Conference	5-6
Introducing Paul Keogh	6
Probe Study	7
Haemolympics Camp	8
Arved Wasser Memorial Fund	9-10
Gene Therapy	11
World Haemophilia Day	11
World Congress Application	12-13
Fundraising	14-15
What's On	16

**Your Committee**

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Shane Meotti (Secretary)	

Susie Couper  
Dale Spencer  
Paul Keogh  
Michelle Dinsdale

Profiles of committee members can be found on the website, [www.hfwa.org](http://www.hfwa.org) 'Your Committee'.

**HFWA Office Coordinator**  
**Haemophilia Foundation WA Office**  
**Ph: (08) 9420 7294**  
**Email address: [office@hfwa.org](mailto:office@hfwa.org)**

**Cover picture****Welcome to the new year**

HFWA is grateful to Fuji Xerox for their ongoing support in printing the Contact Newsletter.

**PERTH'S CHILDREN'S HOSPITAL CONTACT DETAILS**

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

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

Nursing Staff: **Natalie Gamble-Williams and Stacey Hutchison (Monday - Thursday, 8:00am—4:30pm) Ph: 6456 0170 or 0466 318 286**

After Hours (**EMERGENCIES ONLY**) **Ph: 0410 717 816**

Social Worker: **Helena Reynolds (Monday to Thursday, 8:00 AM - 4:30 PM, adults and paediatrics, contact for appointment) Ph: 6152 6527**

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

**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, Lara Olson**

Social Worker: **Helena Reynolds (Monday to Thursday, 8:00 AM - 4:30 PM, adults and paediatrics, 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.

## President's Report

Hi Folks

I hope everyone has had a great start to the year?

We are now back into the swing of things and have a busy year ahead with the men's and women's breakfast coming up first on 16 February, camp in March and the World Congress in June.

Please see the camp registration form in this newsletter to secure your spot at camp. It looks to be a fun camp with an Olympic theme, so get in quick so you don't miss out! For rural members, please call Mel in the office on 9420 7294 or email [office@hfw.org](mailto:office@hfw.org) if you require travel assistance to get to camp.

We have a small amount of funding available for people thinking of attending the Congress in Malaysia. HFWA may fund the registration fee for successful applicants. Please see the funding application form on page 13.

The 30th anniversary of World Haemophilia Day is on 17 April 2020. If you have any ideas of places or buildings that we can light up red, please drop Mel in the office a line to investigate.

The HFWA Management Committee will be holding a strategic planning workshop later in the year and we are keen to hear from the bleeding disorders community on ideas for the future of HFWA so please let us know either via email or come and have a chat to us at one of our activities.

Gavin Finkelstein  
President

## Introducing Michelle Dinsdale

Hi my name is Michelle Dinsdale, I'm married to Mark and we have three sons, Sam aged 25 and fraternal twins John and Michael aged 22. Sam and John are affected with severe Haemophilia A.

Quite a few years ago I was the HFWA Office and Committee Secretary, while the kids were young and still needed me to be around to do school drop offs and pick ups and sporting commitments etc. It worked well for me to be a part of the HFWA organisation way back then. However now after a long break I have decided to re-join the Committee to help out wherever I can. I am looking forward to meeting new and old community members at upcoming events.

## Haemophilia Social Worker

My name is Helena Reynolds I am a Senior Social Worker at Fiona Stanley Hospital. I have been working in the Cancer Centre since the hospital opened and have recently started in the Haemophilia Social Work role.

I am based in the Haemophilia Clinic on the 3<sup>rd</sup> floor of the Cancer Centre at FSH on Monday and Thursday mornings and all day on Fridays. If you are attending the clinic and wish to speak to me you can ask anyone in the clinic – reception, doctor or nursing staff. You can also phone ahead of time to book an appointment on 6152 4059.

I am happy to speak to you about something that is of concern to you – big or small! Social Workers can help with practical and emotional support, providing information and referrals to community resources and services or just listening!

# HFWA Women's Breakfast

On February 16, 2020, at 9 am  
Pagoda Resort & Spa  
112 Melville Parade, Como.

**RSVP: By 13 February 2020 to  
Mel on 9420 7294 or [office@hfwa.org](mailto:office@hfwa.org)**

Knowledge

Listening

Opportunity

Community

Sharing

Empowerment

Communication

Mentoring

Guidance

Experience

Connection

Acceptance

Understanding



## 2019 Conference

Hello, my name is Darren Ellis and would like to tell you about my experience at the 2019 Australian and New Zealand National Conference. The conference was held at the Novotel Manley, NSW, which was a beautiful venue right on the vibrant Manly beachfront.

I really did not know what to expect, being that this was the first conference I had attended. I attended the conference to find out about the latest treatments available and the treatments that are on the horizon. I am excited about the breakthrough technologies that will hopefully be available to everyone who needs them soon. My family is affected by haemophilia A. My two teenage sons both have severe haemophilia A and my wife is carrier.

There were so many sessions to attend on a variety of different subjects. Two of the sessions I attended were:

**Improving Outcomes** – this session covered how tailoring treatment for individual patients is possible through using PK (pharmacokinetic) information.

**Getting Older** – listening to an older generation of people affected by a bleeding disorder, I gained some insight into their day-to-day challenges and how they deal with joint deterioration and the related pain and reduction in mobility. Greig Blamey (a physiotherapist from Canada) talked about the importance of exercise and how using crutches for too long could lead to damage in unrelated areas, such as the shoulders.

I enjoyed meeting a variety of different people from around Australia and the world. Two men from Australia I talked to are currently taking part in gene therapy trials, and it was interesting listening to their experiences and remarkable results. I found it fascinating talking to health professionals from different areas such as treatment and research. It was a lot to take in, but I thoroughly enjoyed the experience. I would like to thank the HFWA for giving me the opportunity to attend the conference.

Darren Ellis

## 2019 Conference

In October 2019, I was fortunate enough to attend the 19<sup>th</sup> Australian and New Zealand Conference on Haemophilia and Rare Bleeding Disorders, in picturesque Manly, NSW.

I found most of the plenaries and session descriptions most interesting, and had trouble deciding which to attend. The sessions and plenaries I attended related to family issues, improving outcomes for people with bleeding disorders, clinical trials, gene therapy, comprehensive care, musculoskeletal care and challenges, ageing with haemophilia, considerations for girls and women with bleeding disorders, and the future of bleeding disorder treatment.

There are some important points I gained from the conference plenaries, including the importance of using individual pharmacokinetic (PK) profiling to tailor treatment, which enables clinicians to adjust dosages for each patient, resulting in “bespoke” treatment plans. PK profiling is now easier to perform and interpret, which makes it a user-friendly tool for treatment centre staff. Another point I gained is that it is crucial for us as members of the bleeding disorders community to participate in surveys such as PROBE and the Getting Older Needs Assessment Survey.



## 2019 Conference

The data from these surveys is used to formulate outcomes that give clinicians and treatment centre staff, national and state foundations and other decision-makers vital information such as the physical and psychological impacts of living with a bleeding disorder, what treatments and interventions work and how these change over time. Further points include the importance for girls, their parents or caregivers and women who have a bleeding disorder to utilise their treatment centre for education and care, and the importance of recording your bleeds and treatments, and keeping in touch with your treatment centre, particularly to find out about the new treatment products and trials available. Some of these treatments are life-changing; the future looks bright.

The congress was an ideal forum to meet and share information and experiences with other families and health professionals from all over the world who have something in common with us – they are affected by a bleeding disorder or strive to improve the lives of those who are affected. If you get a chance to attend a National Conference or World Congress, grab the opportunity. The next World Congress is in Kuala Lumpur in June this year, keep an eye out for more information if you are interested.

Cheryl Ellis

## Introducing Paul Keogh

I recently attended the National Haemophilia Conference held in Manly New South Wales as an ambassador for HFWA. I had always wanted to attend a conference believing through attendance I would be able to gain current information regarding new scientific breakthroughs that would help my son Blaize who faces the challenges that severe Haemophilia A presents. Well I can tell you that I received ground breaking information that will prove beneficial to assisting Blaize with the challenges he faces today and those that he will face into the future. What I didn't expect was the influence that the conference would have on me as a person.

During the conference I listened to many health professionals speaking on a range of topics such as the benefits of using ultrasound to monitor the health and deterioration of joints to an amazing mobile app which has been developed allowing people to monitor their levels of factor at any given time. I couldn't get enough information, I wanted more and as I listened I looked around the room and realised how many people had dedicated their lives to improving the lives of others on this rare genetic disorder. This was the moment I had decided that I wanted to do my part.

Over the many years attending HFWA events such as camps, Christmas parties and other social events, I have witnessed the great work and contribution from other parents, and without these wonderful people dedicating their time and effort, these events simply wouldn't happen. It has been roughly 8 years since we attended our first camp and we have watched the parents that so wonderfully welcomed us into this new community continue to support the community as their children have grown up and become young adults. While at the conference, I recognised that there is very limited representation on the HFWA committee when it came to Parents like my wife Lena and myself with children aged below 10.

Wanting to do my part, I have always wanted to help HFWA although my career for the past 17 years in FIFO work has not allowed me the time. I am happy to say I have recently joined the HFWA committee as my career has transitioned into a more permanent role in Perth. I am keen to assist where possible and give back to the HFWA community and do my part making this journey easier for others as others have done for my family. For me it is the dedication of these people that make HFWA what it is.

**It's not too late to complete the PROBE study! Your experiences can make the difference.**



Are you keen to help with advocacy on the impact of haemophilia and new treatments?

The [PROBE \(Patient Reported Outcomes Burdens and Experiences\) study](#) is a great opportunity for Australians to give high-quality evidence about what it's like to have haemophilia and the impact of different types of treatments.

## WHO CAN PARTICIPATE?

You are invited to complete the PROBE questionnaire if you are **an adult (18 years+) who lives in Australia** and:

**Have haemophilia or carry the gene OR Do NOT have a bleeding disorder.**

## HOW TO DO THE SURVEY

Contact [HFA](#) or [your local Foundation](#) for a print copy.

## WHAT IS PROBE?

PROBE is a multi-national validated research study ([www.probestudy.org](http://www.probestudy.org)) which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

## WHY IS IT IMPORTANT?

With new treatments becoming available high-quality evidence is particularly important. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

We also need good evidence to understand the different experiences of living with haemophilia – for example, women with haemophilia or who carry the gene, people with mild, moderate or severe haemophilia or inhibitors, getting older with haemophilia.

Statistics from Australians who complete the questionnaire will be provided to HFA by the international PROBE team for us to use in our advocacy and planning for the future.

## HOW CAN YOU HELP?

If you fit the criteria you can [complete the questionnaire](#).

- You may also like to **pass the survey on to your partner/wife/husband or other members of your family or interested friends**. If they don't have a bleeding disorder, their answers are also very valuable – we need equal numbers of people affected by haemophilia and people without a bleeding disorder.

We need a few hundred Australian participants for good quality results, so the more people who complete the survey, the better!

## WHAT HAPPENS TO YOUR DATA?

All responses are anonymous and confidential. They are combined as statistics and will not identify individuals. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

## MORE INFORMATION

Contact Suzanne at HFA:  
E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)  
T: 1800 807 173

## 2020 HFWA CAMP

# HFWA Haemolympics 2020



You **DO NOT** want to miss this one!!!!

This year's camp is going to be **amazables!!!!**

We have been inspired by the 2020 Olympic games in Tokyo and we will be hosting our own first ever HAEMOLYMPICS.

There will be bubble soccer, air hockey and foosball tournaments, tug of war challenges, ponycycle races, happy hopper relays, high ropes, flying fox, canoeing, disco, fancy dress and so much more. All ages catered for.

Get together with other families living with bleeding disorders and make friends, get educated, find support but mostly let yourself have some fun.

Spaces are limited so make sure you get your forms in ASAP and start training!  
Get ready to feel Haemolympic glory!





## Arved Wasser Memorial Fund

### INFORMATION AND APPLICATION FORM

*HFWA invites applications for the Arved Wasser Memorial Fund for the 2019/2020 financial year. If you would like to apply to the fund please complete the Standard Form of Application, and return to HFWA no later than Friday 29 May 2020.*

*The Fund was established to give people with a bleeding disorder access to limited financial assistance, should they wish to pursue any educational, recreational, or work related study or activity. Conditions are explained in the guidelines. Criteria for eligibility may loosely be described as any means of "self-betterment".*

#### Guidelines

1. a) For such time as the fund remains sustainable, a nominated sum (e.g. \$1,000) shall be made available each financial year. This amount may be reached by way of a single grant, or several smaller grants.
- b) These grants will consist of a nominated sum from the Arved Wasser Memorial Fund, and an amount being equal to this sum, (i.e. 50% of total) coming from HFWA general funds.
- c) Monies to be available for these grants, and any conditions hereto, shall be decided at the sole discretion of HFWA committee.
2. The recipient of any grant from this fund must reside in Western Australia, and have a bleeding disorder. Family members (including carriers) are not eligible.
3. a) Members will be invited to make application, (e.g. notice in newsletter) however; financial membership of HFWA shall not be a pre-requisite for any applicant.
- b) HFWA shall define a period of time in which applications should be lodged each year. At the conclusion of this period, fair and equal consideration will be given to all applications. If none are received, or approved within the allotted time, applications may be lodged any time until the end of the current financial year.
- c) If, in any financial year that the fund is operating, no grants are approved, or the total of those approved is less than the sum nominated by the HFWA committee, such monies shall remain in the fund to be "rolled over" into the following financial year. They shall not be available for any other purpose, unless so designated by HFWA committee.
4. Applications should be made by the person concerned or in the case of a minor, by a parent or legal guardian.
5. The sitting committee of HFWA shall consider each application according to individual circumstances. A decision on any application (s) shall be at the discretion of said committee. Any such decision will be final.
6. These grants are not intended to subsidise regular primary or secondary school fees, with regard to "every day" school curriculum. Additional tuition or courses, or skill building activities (e.g. photography, music or scuba diving) may qualify.
7. There shall be no restriction on how the grants may be used, with regard to further education, such as TAFE or university courses.
8. These grants are not intended for medical treatments or procedures.
9. These grants may be given for sporting or recreational activities. There shall be no restriction on how the grants may be used. However, preference will be given to an applicant seeking assistance (e.g. travel or equipment subsidy), in order to attend a special event such as a major championship, training facility, seminar or meeting, in relation to their chosen sport or activity.
10. Wherever and whenever possible, monies from these grants shall be paid directly to the "third party" involved (i.e. the person or body providing the goods or services being considered). Unless presented with exceptional circumstances, monies will not be paid to applicants.

## Arved Wasser Memorial Fund

### STANDARD FORM OF APPLICATION\*

- \* To be completed by the applicant (or parent / legal guardian if under 18 years of age) and returned to, HFWA City West Lotteries House, 2 Delhi Street, West Perth WA 6005.
- \* Please read grant guidelines carefully before completing.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Age: \_\_\_\_\_

Telephone: \_\_\_\_\_

Amount Requested: \$ \_\_\_\_\_

\*\*(Please give a brief explanation of how this money will be used).

If insufficient space, please attach a separate sheet.

- I make this application in good faith, having read and understood the guidelines pertaining to such.
- I shall accept and abide by any decision made by the Haemophilia Foundation Western Australia Inc. Management Committee, relating to this application.

Signature of Applicant (or parent/legal guardian if under 18 years of age).

\_\_\_\_\_  
Applicant/Parent/Legal Guardian

\_\_\_\_\_  
Date

## Gene Therapy for haemophilia

HFA have announced the release of a new gene therapy resource.

The resource aims to explain how genes and gene therapy works as well as answer questions raised by our community such as:

- What types of gene therapy are used in haemophilia?
- How does gene therapy work?
- Is it a cure?
- How safe is it?
- Who can have gene therapy?



The gene therapy resource is available to download as a PDF from the HFA website under publications:

<https://www.haemophilia.org.au/about-bleeding-disorders/gene-therapy>

or contact HFA for print copies on:

E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

T: 1800 807 173

W: [www.haemophilia.org.au](http://www.haemophilia.org.au)

## 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.



April 17, 2020 is the 30th anniversary of World Haemophilia Day! The longevity of this celebration is proof of the dedication and tight-knit nature of our community.

The theme of World Haemophilia Day in 2020 is “**Get+involved**”. Whether you are a patient, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world.

Watch this space for **Light it Up Red** locations and events!

## World Congress Funding Application

### GUIDELINES

- An amount of funding to assist members to attend the WFH World Congress is determined by the HFWA committee each year there is a Congress.
- Each individual request will be considered on its merits and amounts provided may vary.
- Only financial members may apply to receive assistance from this fund.
- Members should not expect funding support as an automatic right.
- Assistance can be provided only if funds are available at the time of the request.
- Alternative avenues of funding assistance should be sought prior to requests being submitted to HFWA, i.e., family, workplace or supporters.
- Strict confidentiality is applied to all requests.
- HFWA may fund Congress registration.
- Previous applications for assistance will be taken into consideration.
- Payments will be made to a third party or will be paid once receipts have been provided. Discretion of the HFWA management committee can be applied at any time.
- All applications to be made using the attached form and sent to the Haemophilia Foundation WA Office via email - [office@hfw.org](mailto:office@hfw.org) or mail - 2 Delhi Street, West Perth WA 6005.
- Applications will be assessed by the HFWA management committee.
- Successful applicants will be notified by email.
- Further information may be requested by the HFWA Office Coordinator if required.
- Original application forms are stored securely at the HFWA office for accountability and auditing purposes only.
- Successful applicants are required to write an article about their experience at the congress for the HFWA newsletter.
- Applicants are encouraged to participate in fundraising activities to assist in covering costs.
- **Applications for the WFH 2020 World Congress are due by Friday 17 April 2020.**

**STANDARD FORM OF APPLICATION FOR FUNDING TO ATTEND  
WFH 2020 WORLD CONGRESS OF HEMOPHILIA KUALA LUMPUR**

**14 – 17 June 2020**

**To be completed by the applicant (or parent or guardian if under 18 years of age).**

**Application Due by FRIDAY 17 April 2020**

<b>NAME:</b>			
<b>ADDRESS:</b>			
		<b>POST CODE:</b>	
<b>AGE:</b>		<b>TELEPHONE:</b>	
<b>EMAIL:</b>			
<b>AMOUNT REQUESTED:</b>			\$
If you do not receive this amount from HFWA, will you still attend the Congress?			
Please give a brief description on how attending the World Congress would benefit you.			
If insufficient space, please attach a separate sheet.			
I make this application in good faith, having read and understood the guidelines pertaining to such.			
I shall accept and abide by the decision made by the Haemophilia Foundation Western Australia Inc. Committee, relating to this application.			
Signed   Email to: office@hfw.org  Post to: Haemophilia Foundation WA Inc. Reply Paid 83529 WEST PERTH WA 6005			Dated



HFWA are selling quality shopping bags to support our state programs.

To order your bags and arrange collection  
email: [office@hfw.org.au](mailto:office@hfw.org.au) or  
call: 9420 7294.



**Jute Large Shopping Bag**  
42cm W x 33cm H



**\$6.50**

**Red Shopping Bag**  
33cm W x 35cm H



**\$3.00**

I would like to order \_\_\_\_\_ Jute large bags

I would like to order \_\_\_\_\_ Red bags

**Total \$** \_\_\_\_\_ (postage can be arranged at extra cost).

Please complete credit card details below or deposit the total with your Surname as your reference to:  
Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**

**PLEASE NOTE THAT CREDIT CARD DETAILS WILL NOT BE RETAINED AFTER PROCESSING**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Card Type:

☐

Visa

☐

MasterCard

☐

AMEX

☐

Diners

Card Number:

















Expiry Date:





CVV:

Name on Card:

# HFWA NAIL POLISH GIFT PACKS

In Stock Now

Three bottle gift packs available.  
Looking for that personalised gift with a real message for family  
and friends? Look no further!

## Gift Packs

Gift packs contain Helen's Melons (red) and two colours of your choice.



**\$40.00  
Per Pack**

## Assorted Colours

Helen's Melons, Emerald Green, Rose Gold, Silver and White.



**\$20.00  
Each**

I would like to order \_\_\_\_\_ Gift Packs with the following colours:

\_\_\_\_\_

I would like to order \_\_\_\_\_ Bottles of the following colours:

\_\_\_\_\_

**Total \$** \_\_\_\_\_ (postage can be arranged at extra cost.)

Please deposit the total with your Surname and "Polish" as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.**

BSB: **086 488**

Acct No: **03 523 3031**

Phone the office: 08 94207294 to pay by credit card

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

**HURRY STOCK IS LIMITED!**

2019

WHAT'S  
ON?



Sunday, 16 February, 2020—Women's Breakfast

Sunday, 16 February, 2020—Men's Breakfast

Friday, 20—Sunday, 22 March, 2020—Camp

Wednesday, 17 April, 2020—World Haemophilia Day

Save the date

April 2020—Entertainment Books Fundraiser

Sunday 14—Wednesday, 17 June 2020—WFH Congress

March—HFWA Planning Day

September—HFWA AGM

October—Bleeding Disorders Awareness Week