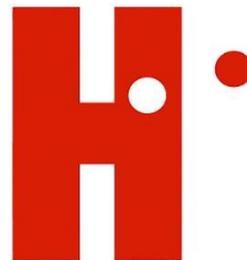


Contact



Newsletter of Haemophilia Foundation WA Inc.

June 2017



Women's Breakfast for World Haemophilia Day 2017

HAEMOPHILIA FOUNDATION WA INC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005

P: 08 9420 7294 F: 08 9486 8966 E: office@hfwa.org W: www.hfwa.org

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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
 Marcus West
 Pamela Wall
 Brian Wall
 Dale Spencer

Profiles of committee members can be found on the website, www.hfwa.org. "Your Committee".

HFWA Office Coordinator

Deborah Barnes
 Haemophilia Foundation WA Office
 Ph: (08) 9420 7294
 Email address: office@hfwa.org

Office Hours: Monday, Tuesday & Thursday: 10:00am - 3:00pm, Wednesday: 10:00am-4:00pm.

PRINCESS MARGARET HOSPITAL CONTACT DETAILS

Ward 3B Outpatients
 Nursing Staff: **Sister Lee and Natalie**
 Ph: **9340 8682 or 0466 318 286**



REMEMBER

Mark Sunday 27 August on your calendar for the City to Surf. See page 10 for more details.

FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**

Medical Staff: **Dr Stephanie P'ng & Dr Dominic Pepperell.**
 Nursing Staff: **Sandra Lochore**
 Social Workers: **Charlotte Bradley-Peni (Tuesday, Wednesday, Thursday) & Sue Haberfeld (Monday, Tuesday & Friday) - Ph: 6152 6529 or 0404 039 971**
 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 & 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

This edition of our newsletter finds us heading towards the end of the 2016/2017 financial year.

It will be interesting to see what outcomes we get from the NBA's (National Blood Authority) RFI (Request For Information) in relation to products used for our treatment. HFA vigorously advocated for inclusion of EHL (Extended Half Life) products to be added to the list, but we still wait on their announcement as to what the next couple of years hold for us.

For World Haemophilia Day on 17 April, Perth had 3 sites lit up red; these were the Bell Tower, Perth City Council House and Trafalgar Bridge in East Perth (See page 4 for photos).

HFWA held enjoyable and well-attended Men's and Women's Breakfasts to celebrate World Haemophilia Day. This time both Breakfasts were held at a shared venue in different dining areas, both breakfasts ran separately and very successfully.

As I said before, the end of June is the end our financial year. It is also the time to renew your HFWA membership (please see the Membership Form on page 6). Renewing your membership is important, as it shows that we have a strong state Foundation. So, to all our current members and our potential new members, I encourage you to complete and send in your HFWA Membership Form for the 2017/2018 year; it is well worth your while to do so.

If you are thinking of attending the Australia and New Zealand Haemophilia Conference in Melbourne from 12 to 14 of October 2017, and you wish to apply to HFWA for financial assistance to attend, Expressions of Interest close on the 30 of June 2017. Contact the Office by phone or email for an Expression of Interest Form.

We are looking to hold a Self-Infusion Workshop later this year so watch this space, also see the introduction from Charlotte Bradley-Peni, Snr. Social Worker, Haemophilia and Haemostasis (Paediatrics and Youth) on page 15.

Last but not least. We are once again fundraising with the sale of the Entertainment Book. Many thanks to those members who have already purchased these through HFWA and their friends and supporters. This is a great way for us to fundraise with a minimum of effort and with something that so many people will enjoy and get benefit from. On the back page of this Newsletter you will find the form and information to get your copy of this year's Entertainment Book, or ring Deb in the office. Enjoy!

Gavin Finkelstein
President

This newsletter is kindly printed by Fuji Xerox



**18TH AUSTRALIAN & NEW ZEALAND CONFERENCE
ON HAEMOPHILIA & RARE BLEEDING DISORDERS
Melbourne • 12-14 October 2017**

World Haemophilia Day - Some Photos around Perth

Hi Everyone. Some photos of the buildings and bridges around Perth that turned red this year for World Haemophilia Day on 17 April.

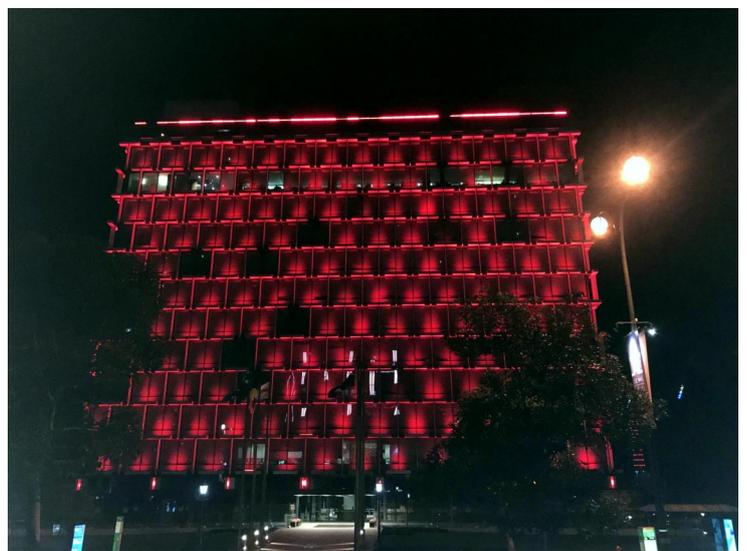
Many thanks to our keen amateur photographers.



Above: Trafalgar Bridge.

Left: Perth Belltower.

Below: Perth Council Building





Haemophilia Foundation WA Inc.

APPLICATION FOR 2017/2018 MEMBERSHIP

New

Renewal

TAX INVOICE
ABN 42 961 282 521
GST Registered

Please Complete Both Pages of This Membership Form

Title	
First Name	
Last Name	
Address	
Telephone	
Email	

To reduce costs and to save paper, our newsletter will be sent to you by email. If you require to receive the newsletter in hard copy please tick this box . Please be aware this will cost HFWA an extra \$12.00 per year per newsletter just for postage.

Please note, HFWA IS now ABLE to accept phone credit card payments for Memberships or Donations (ring Co-Ordinator, Deb in the HFWA office on 08 9420 7294).

PRIVACY:

HFWA respects member's privacy. Your details will NOT be forwarded to other organisations, bodies, or persons without your permission. Please refer to the privacy statement on the HFWA website for details,

<http://www.hfwa.org/> Please tick if you do NOT want your details forwarded to HFA.

Please indicate:

<input type="checkbox"/> Person with bleeding disorder	<input type="checkbox"/> Parent of Child
<input type="checkbox"/> Grandparents	<input type="checkbox"/> Doctor
<input type="checkbox"/> Nurse	<input type="checkbox"/> Special Interest
<input type="checkbox"/> Other	

Individual Family (includes immediate family members) - **Membership \$25.00 (GST inclusive)**

Extended family members need to take out their own membership.

Membership fee can be waived in special circumstances – Please contact Deborah Barnes on 9420 7294.

I would like to make a donation of:

\$25 \$50 \$100 or \$ **Donations over \$2.00 are tax deductible**

Direct Deposit Acct Name: The Haemophilia Foundation of WA Inc. Cheque enclosed

BSB: 086 488

Acct No: 03 523 3031

Reference: *Please include your name e.g. John Smith*

Signature: _____ Date: _____

OFFICE USE ONLY	RECEIVED	REC. NO.	ENTERED	HFA



Haemophilia Foundation WA Inc.

APPLICATION FOR 2017/2018 MEMBERSHIP Family History

Please list all family members to be included in HFWA membership.

Name
(From Front Page)

Date of Birth

Please indicate diagnosis details:

<input type="checkbox"/> Haemophilia A	<input type="checkbox"/> Haemophilia B
<input type="checkbox"/> von Willebrand Disorder	<input type="checkbox"/> Carrier
<input type="checkbox"/> Other Factor Deficiency	<input type="checkbox"/> No Bleeding Disorder
<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate
<input type="checkbox"/> Mild	<input type="checkbox"/> vWD Type

Name

Date of Birth

Please indicate diagnosis details:

<input type="checkbox"/> Haemophilia A	<input type="checkbox"/> Haemophilia B
<input type="checkbox"/> von Willebrand Disorder	<input type="checkbox"/> Carrier
<input type="checkbox"/> Other Factor Deficiency	<input type="checkbox"/> No Bleeding Disorder
<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate
<input type="checkbox"/> Mild	<input type="checkbox"/> vWD Type

Relationship to Member:

Name

Date of Birth

Please indicate diagnosis details:

<input type="checkbox"/> Haemophilia A	<input type="checkbox"/> Haemophilia B
<input type="checkbox"/> von Willebrand Disorder	<input type="checkbox"/> Carrier
<input type="checkbox"/> Other Factor Deficiency	<input type="checkbox"/> No Bleeding Disorder
<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate
<input type="checkbox"/> Mild	<input type="checkbox"/> vWD Type

Relationship to Member:

Name

Date of Birth

Please indicate diagnosis details:

<input type="checkbox"/> Haemophilia A	<input type="checkbox"/> Haemophilia B
<input type="checkbox"/> von Willebrand Disorder	<input type="checkbox"/> Carrier
<input type="checkbox"/> Other Factor Deficiency	<input type="checkbox"/> No Bleeding Disorder
<input type="checkbox"/> Severe	<input type="checkbox"/> Moderate
<input type="checkbox"/> Mild	<input type="checkbox"/> vWD Type

Relationship to Member:

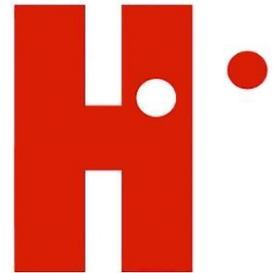
Bunnings Sausage Sizzle

Saturday 30 September 2017



Calling all volunteers and generous donors!

Come and have a fun time with HFWA at our annual Bunnings Sausage Sizzle. HFWA has been cooking up a storm and fundraising for the last umpteen years at **Bunnings Homebase in Subiaco** as part of World Haemophilia Week.



We would like to hear from those who can come along for a couple of hours to help on the day (any time between 7.30 am and 4.00 pm).

Everyone always has a great time.

We are also looking for generous people to donate soft drink cans, or bottles of water to sell on the day - Solo, Coke (any sort), Fanta, Lemonade or water.



REMEMBER we are fundraising for our Family Camp in 2018.

Plenty of volunteers are needed. Those 500 sausages won't cook themselves. Sign up early to get your preferred time - don't miss out!

To let us know how you can help, by volunteering or donating drinks: ring the office on 9420 7294, email the office at office@hfwa.org or complete the form below and return it to the office.

Above - Shane, Susie and Jenny, some of our happy volunteers at last year's very successful and fun sausage sizzle.

.....

I

- Would like to volunteer at the Bunnings Sausage Sizzle between the hours of
- I would like to donate soft drink or water, quantity

My contact details are:

.....

My Operation Experience - Sharri Brodie

Having a child with severe haemophilia I have had a fair few medical appointments, for him, in his almost 15 years, haematology, physio, pathology, dental, anaesthetist etc. etc. etc. ...

I never saw these appointments as anything other than what I had to do to make sure he always had what was best for him.

After he was diagnosed at a few days old and the dust settled (several years later) I took myself off to Royal Perth to get blood levels checked for the very first time (I didn't know I was a carrier before I had Willem).

My factor levels were 38% which I was told was not great but if I required any surgery probably best to check in with them first. I also trialled the DDVAP but it was decided this wasn't very effective for me. As I was fit and healthy, I was fairly sure any surgery was not in my plans for the next 20 or so years, so I just carried on not thinking about it much.

I continued my haematology checks and the last one at FSH had my factor levels at just 17% and I was also diagnosed as having mild von Willebrand disorder.

I still wasn't too worried as it didn't affect my day to day much as I had the Mirena® implant which managed the curse of menstruation.

This did take a bit of a twist this year as I needed to have surgery. I was booked in for a hysterectomy (due to prolapse), bladder lift/sling and a bit of renovation and nip tuck "down there" while they were in the region.

I told my surgeon of my blood issue and his clinic communicated with FSH haemophilia treatment centre. Turns out I definitely needed product and a pre and post-surgery treatment plan was written up. I required Biostate over the five days I was in hospital and could not go home until the last blood test said my levels were good and everyone was happy.

It's been three weeks since my surgery and physically I'm feeling great. Mentally I'm going crazy as I can't exercise, drive, or do house work and I am bored, bored, bored!! Netflix had been a real saviour. I am writing this article as I want to encourage women who are carriers to get your levels checked regularly as mine have changed a lot in only 12 years.

It has also been an interesting learning experience for me because for so long it has been all about Willem and managing *his* care, but this time (for the first time) it has been all about me.

thefemalefact^ors

Questions From Members

This is a new section we're introducing, it provides you with an opportunity to have questions answered by a community or committee member. Please remember that we aren't health care professionals so we won't be able to provide advice on your condition, treatment or recommended activities. We can share our perspectives on our experiences or provide details on where to go for more help or support though.

Our first question is "Why should I record on MyABDR – what's the point?"

There are many ways to answer this. From a parent's perspective, I think it offers a great record of treatment days and previous bleeds. We're all juggling so many activities and commitments MyABDR does the thinking for you. From a kid's perspective though, you can think about it as a high scoring game. Your doctors need your updates to help you, so the more entries that match what you're doing, the higher score you're getting. The home screen counts up the time since your last treatment, you can try and "beat the clock" to get your record updated before you get past your treatment schedule.

It all comes down to how you view it. Is MyABDR a tool for you? Yes. Is it a tool for your parents/partners/carers? Yes. Is it a tool for your doctors? Yes. Will it help researchers study trends to improve treatment and care? Yes. Will it help the government know what to keep in stock now and in the future? Yes.

What else do you want to know – send a question to office@hfwa.org and we'll put it out to the committee or other community members to answer in the next newsletter.



HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC

Thumbs Up From Members

This is a good news zone, another new section we are introducing, we hope it will become very popular, it is a place for members to contribute, in short form, an experience that made them smile, that made a positive difference, or just a way to say 'thanks' publicly.

Here is our first Thumbs Up.

Planning to succeed – when things just go right.

A recent scheduled surgery at PMH felt very different to so many other Ward 3B experiences. We had a plan, we had all the departments talking to each other. Pre-op conversations were thorough, details of the plan were checked and confirmed. A speed bump at admission was sorted with a compassionate response. The surgery itself was quite a big thing, but everything went like clockwork, even though there was more bleeding than expected.

Whilst on the ward, the right people came to check and confirm the plan was being followed and working. We went home with everything we needed – medications and our peace of mind intact! We actually had no problems – it sounds like no big deal but it was so satisfying. Thumbs up to Ward 3B.

City to Surf - Save the Date!

The Chevron City to Surf for Activ will be back in 2017, so mark Sunday 27 August in your diary!

The City to Surf has been a regular fixture on our fundraising calendar for a number of years now and it would be great to have a big group of runners and walkers from HFWA this year. Apart from the opportunity to raise some much-needed funds for the family camp next year, it is also a great opportunity to get into some regular exercise.

Not sure about how you will cope with a 10km run or walk? No problem, there is a 4km walk or run event which is perfect for families and those not quite up to a longer distance. There is also a 21km half marathon and a full marathon if you are really keen!

The HFWA have registered a team again this year so signing up and fundraising through EveryDayHero is easy. Registrations for this year's event are now open and instructions for registering with Team Haemophilia can be found on the following page. See how many people you can get involved to either join you on the day or donate.

With the weather cooling down there's no better time to hit the pavement than now so you're ready to blitz your running or walking goals come race day!

Marcus and Jenny's Training Tips:

- Put the date in your calendar and work out how many weeks to go.
- Ask your family and friends to join too.
- Agree on a time, the days & place to do your training together - it's always more fun as a group.
- Get started – don't put it off – do it today and back it up within 2 days.
- Make space in your calendar – book it in, if you have an electronic calendar, there is nothing like a reminder to help keep you on track.
- Build up – start with a walk or even a bike ride for a low impact option. Get used to getting out regularly. Whatever you do, don't try to break records on your first outing! Slow, steady and regular is a sure-fire recipe for success.
- Keep a log – if you have a smart phone, consider getting an app that tracks your progress. It's amazing how motivating seeing your sessions build up is. There are heaps of free ones available – just be aware that they do use data and will use battery charge.

Most importantly – enjoy yourself.

Please give it some serious thought and keep an eye out for the emails coming soon. Happy training!

See next page for details of how to participate.



City to Surf - Registration Process

Here are the registration steps:

- Go to the City to Surf website - <http://perthcitytosurf.com/>
- Select **Perth** under the '**Register**' menu.
- Pick the event you wish to participate in and select **adult** or **child**.
- Click **Join a Team** and then type in team name "Team Haemophilia" and click search.
- Click on the **Join** button next to **Team Haemophilia**.
- Complete the Entrant Details page with your details. Please note to select '**Find a Charity**' under the Fundraising section and enter "**Haemophilia Foundation of Western Australia Inc.**" for the name of the charity.
- Click on the '**Continue**' button.
- Select either **Postal Race Pack** or **Collect from Expo** and select any merchandise required then click on the '**Continue**' button.
- To register another person select '**Register Another**' otherwise check details and select '**Pay**.' (Please note we have selected for participants to pay individually for registration)
- Once payment is confirmed your eTicket and Receipt will be emailed to the email address you nominated. You can also download them from the Tiktok Dashboard.

Once you have registered you can then go to the **My Fundraising** tab on the Tiktok Dashboard and click on the '**go there**' button or go directly to the City to Surf fundraising page to build your own fundraising page - <https://chevroncitytosurf.everydayhero.do/>

- Click the '**Start Fundraising**' button.
- Sign Up to register or log in if you already have an everydayhero account.
- Create your fundraising page and select Haemophilia Foundation Western Australia Inc as your charity.
- Once you have set up a Fundraising page please join the Team Haemophilia 2017 fundraising page by going to - <https://chevroncitytosurf2017.everydayhero.com/au/team-haemophilia-2017> and clicking on the '**Join Team**' button.
- Encourage your supporters to donate to you by sending them the link to your supporter page or the Team Haemophilia 2017 page

Should you have any queries about this process, please feel free to contact Deborah at the HFWA Office on 9420 7294 or office@hfwa.org.

HFWA greatly appreciate your efforts to raise funds and awareness about Haemophilia and related bleeding disorders.

Remember – to get the Early Bird Discount you need to register by July 21.



Women's Lunch Invitation

Cheryl Ellis & Pamela Wall would like to invite you to a Women's Lunch, please see below for details:

VENUE: Buffet Amici, 923 Whitfords Ave, Woodvale WA 6026 (in shopping centre).

TIME: 12.30 pm

DATE: Sunday 30 July 2017

RSVP: by Tuesday 25 July 2017 to:
Deborah at the HFWA office on 9420 7294 or office@hfwa.org or
Cheryl Ellis on 0402033652 or vice_president@hfwa.org

This event is funded by HFWA and is free to current members



Please **NOTE** that the Men's and Women's events are free to current members, like most other events hosted by Haemophilia Foundation of Western Australia.

If your membership has lapsed you are allowed to attend one further Breakfast or other event free. At that time you are required to ensure you are a current member to continue to attend HFWA hosted events for free. Please contact Deborah in the office on 9420 7294 or by email: office@hfwa.org if you are unsure whether your membership for the current year has been paid. You are able to pay your membership renewal at any of the HFWA events you attend, or to the office.

Men's Breakfast Invitation

Gavin Finkelstein and Marcus West would like to invite you to a Men's Breakfast on Sunday 30 July 2017;

VENUE: Waterwall Restaurant, The Pagoda, 112 Melville Parade, Como

TIME: 8.30am SHARP (**NOTE slightly earlier time than usual**)

DATE: Sunday 30 July 2017

RSVP: By Tuesday 25 July 2017 to:
Deborah Barnes - HFWA Office on 9420 7294 or office@hfwa.org or
Gavin Finkelstein on 0415 978 031 or gavfinkelstein@gmail.com

This event is funded by HFWA and is free to current members



Bring a Mate 8 Ball - Youth Event 28 May



Above: Who do you recognise?

The Bring a Mate 8 Ball Youth Event was held 28 May. An article and more photos will be coming in the next Newsletter. In the meantime here are some pictures to whet your appetite for more.

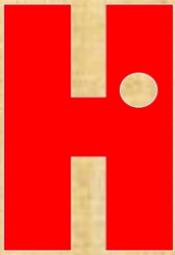


See next page for upcoming Youth Events.



ConnectGroups

helping support groups & individuals

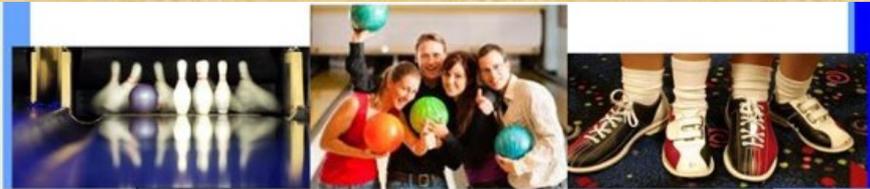


● HAEMOPHILIA FOUNDATION
WESTERN AUSTRALIA INC.

SEPTEMBER 2017

Super Bowl Warwick

12 Dugdale Street, Warwick - 9246 5088



Presented by W.A.Y Western Australia Youth - Event 10-25 years

FEATURING · Youth led discussions on current topics & FUN

DECEMBER 2017

Adventure World

351 Progress Drive, Bibra Lakes – 9417 9666



Presented by HFWA the ANNUAL Family Christmas event and W.A.Y.

FEATURING · Santa Claus and his red bag of goodies
Proud to be hosting another great Christmas event with all members welcome. A full day out we can't wait!

W.A.Y. - Western Australia Youth event held adjacent, giving all families an opportunity to see what an amazing bunch our youth are and see what's next for some of our younger members.

HFWA

We are a voluntary organisation of people with Haemophilia or a related bleeding disorder, their families, friends and anyone who is interested.

WHAT WE DO

- * PROVIDE PEER SUPPORT
- * PROVIDE INFORMATION
- * ADVOCATE & LIAISE
- * EDUCATION & WELFARE
- * SUPPORT RESEARCH
- * SUPPORT DEVELOPMENT
- * ENCOURAGE PUBLIC TO BECOME BLOOD DONORS

HFWA WEBSITE

Check out our sparkly new website at:

<https://www.hfwa.org/>

What would you like to see?

Can you please give us some feedback?

We are your community so let's make it a community voice.

MORE INFO...

Contact the office

Phone - 9420 7294

Email - office@hfwa.org

Self-Infusion Workshop - November 2017

Charlotte Bradley-Peni, Snr. Social Worker, Haemophilia and Haemostasis (Paediatrics and Youth)

This workshop aims to introduce self-infusion to community members of all ages.

Attendees are provided with the opportunity to meet other members of the bleeding disorders community and gain knowledge and confidence with self-infusion from Haemophilia health practitioners and 'seasoned self-infusers' in a safe environment.

This year's workshop will be held in November at the Fiona Stanley Hospital HTC with the exact date yet to be confirmed. Refreshments will be provided by the HFWA.

Should you wish to attend or volunteer as a demonstrator please register your interest via email charlotte.bradley-peni@health.wa.gov.au or telephone 0404 039 971



Coming Soon to the HFWA website - Psychological Support Information

Charlotte Bradley-Peni, Snr. Social Worker, Haemophilia and Haemostasis (Paediatrics and Youth)

During the month of June the new hospital and psychosocial services section will be launched on the HFWA website. This new addition to the website will be located under *WA Health Social Work* in the *Support & Services Section* and an E-News announcement will be sent once the new section is live.

The information aims to provide families and individuals of all ages effected by a bleeding disorder a single point of reference pertaining to services offered by the adult and paediatric WA Health Clinical Social Workers and community service providers.

The website will direct you to helpful information regarding your treatment centre and team, WA Health services offered at both the paediatric and adult centres, hospital emergency procedures specific to those with a bleeding disorder and links to additional services outside WA Health.

We invite you, as members of the community to share providers and services that you have found helpful with the view of adding these resources to the website in the near future.

Email: charlotte.bradley-peni@health.wa.gov.au or phone: 0404 039 971



18TH AUSTRALIAN & NEW ZEALAND CONFERENCE ON HAEMOPHILIA & RARE BLEEDING DISORDERS Melbourne • 12-14 October 2017

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017.

The theme for the Conference is *“Looking Forward to Change”*.

Over the past 37 years HFA have been running conferences that provide current information and resources, discussion on topical issues and that look into the future.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and to plan for the future.

Chaired by Dr Huyen Tran, the program committee is developing a multidisciplinary program which will interest everyone. We are soon to confirm some of our local and international speakers. Some of the topics they will cover include:

- new treatments
- women/girls with bleeding disorders
- carrying the gene
- von Willebrand disease
- rarer bleeding disorders
- using data to improve treatment and care
- managing pain
- blood borne viruses
- ageing
- new diagnosis
- youth
- sport and physical healthy activities
- and.....the future?

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

Who should attend?

People with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners – all ages welcome from young adults to seniors!

Health professionals – doctors, nurses, physiotherapists, social workers/counsellors and other health care providers

Treatment product producers, suppliers and service providers

Policy makers and government officials

Haemophilia Foundation volunteers and staff

Costs and registration information has been available since March 2017. To be kept up to date email your details to ncoco@haemophilia.org.au.

“Haemophilia: Finding out you carry the gene” booklet

Finding out you carry the gene for haemophilia can raise a lot of different feelings, even in women and girls who suspected they might carry the gene.

“It wasn’t any great surprise – this just became a bit more information to help with decisions.”

“When I was diagnosed I felt gutted.”

“I found out that I carried the gene when I was 12 weeks pregnant. The stress was enormous as I had to make some important decisions fast.”

HFA’s new booklet ***Haemophilia: Finding out you carry the gene*** explores the responses of Australian women and girls. It covers:

- How to know if you carry the gene
- Common reactions to finding out you carry the gene
- Where to go for information and support

ACKNOWLEDGING THE EXPERIENCE OF WOMEN

The booklet topics and content were developed from the suggestions and feedback of the HFA Women’s Consumer and Health Professional Review Groups. These are volunteers, and include women who carry the gene and specialist health professionals, and we appreciate their time and expert advice greatly.

Quotes and personal stories contributed by Australian women who carry the gene form a very important aspect of the booklet. These acknowledge the varied experience of women and girls when they are diagnosed and the very strong impact that diagnosis can have. For the women who were involved in the booklet, sharing personal experiences is a powerful way of supporting each other and the wider community of women and girls who carry the gene. They were keen to share the message that women in this situation are not alone; and told their story and outlined the strategies they used to manage their diagnosis in the hope that it might be of value to other women. Our sincere thanks to these women for their generosity in sharing their experiences.

The booklet was launched by HFA on 11 April 2017 as part of the international World Haemophilia Day ***Hear Their Voices*** campaign, which aimed to show support for the millions of women and girls affected by bleeding disorders.

A copy of the booklet accompanies this newsletter.

HOW TO OBTAIN MORE COPIES OF THIS BOOKLET:

Download the ***Haemophilia: Finding out you carry the gene*** booklet from the HFA website - <https://tinyurl.com/carry-gene>

Contact your local Foundation
or HFA email hfaust@haemophilia.org.au
or phone 1800 807 173 for additional print copies



THE FEMALE FACTORS RESOURCES

(Continued from previous page)

This booklet is part of the suite of resources that will be published in the HFA *The Female Factors* project. Other resources cover:

A snapshot of bleeding disorders in females (published June 2016) **Additional copies are available for download from the HFA website or hardcopy from the HFWA office.**

And in development:

- Diagnosis
- Symptoms, treatment and care
- Family planning, pregnancy and birth
- Telling others
- Information for teenage girls and young women

For more information about the HFA *The Female Factors* project, contact HFA:

Suzanne O'Callaghan (adult women) – socallaghan@haemophilia.org.au

Hannah Opeskin (young women/teenage girls) – hopeskin@haemophilia.org.au

T: 1800 807 173

the female factors

We had two very successful Breakfasts, at Nicholson's Bar and Grill in Canning Vale, in April to celebrate World Haemophilia Day (17 April). For once the two groups shared a venue with each group dining in a separate area of the restaurant. This proved very successful and it is something we will do another time in the future.

The food was great and the company and conversations even greater. We had a wide age range in the attendance for both groups, and, except for eating, the talk, discussions and questions never stopped. There was terrific sharing of loads of knowledge and experience.

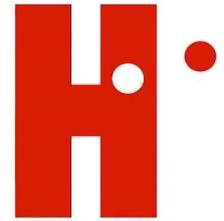
As you can see from the photo, a good time was had by all.



Above - Sharri, Pam and Cheryl at Nicholson's

2016/17

WHAT'S ON?



July

31 July

Men's and Women's Events

Men's Breakfast - Waterwall Restaurant, The Pagoda, Como.

Women's Lunch - Buffet Amici, Woodvale.

Please see invites on page 12 for details.

August

28 August

City to Surf

Get registered and start your fundraising page. See page 10.

September

Date to be confirmed

Youth Event - Superbowl Warwick

See page 14 and keep watching your inbox for more details.

October

12 - 14 October

18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders

See page 16 for more details. Also contact ncoco@haemophilia.org.au to be added to the conference mailing list.



2017:  quarterly youth events
 quarterly men's group
 parents and family

 quarterly women's group
 World Hemophilia Day
 meetings Haemophilia

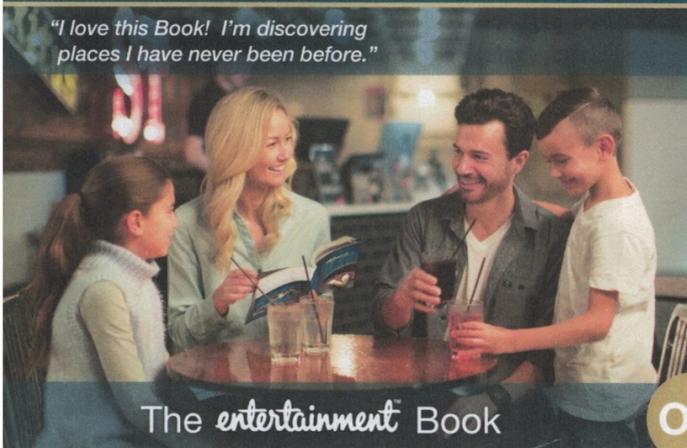
For more information please contact Deborah, Office Coordinator 9420 7294 or office@hfwa.org

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Contact: Deborah Phone: 0894207294 Email: office@hfw.org

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