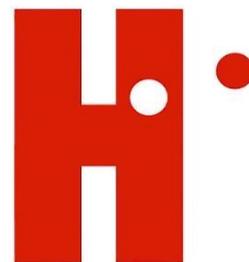


Contact



Newsletter of Haemophilia Foundation WA Inc.

December 2017



HAEMOPHILIA FOUNDATION WA INC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005
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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
 Belinda Broughton
 Pamela Wall
 Brian Wall
 Dale Spencer

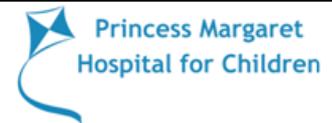
Profiles of committee members can be found on the website, www.hfwa.org. "Your Committee".

HFWA Office Coordinator
Deborah Barnes
Haemophilia Foundation WA Office
Ph: (08) 9420 7294
Email address: office@hfwa.org
Office Hours: Monday, Tuesday and Thursday: 10:00am - 3:00pm, Wednesday: 10:00am - 4:00pm.
Christmas Closing - HFWA office will be closed Friday 22 December 2017 to Sunday 7 January 2018.

Cover picture

HFWA Team relaxing at Adventure World, left to right, Dale Spencer, Pam Wall, Bob Butler, Cheryl Ellis, Santa's Elf (Sharri Brodie) and Gavin Finkelstein.

PRINCESS MARGARET HOSPITAL CONTACT DETAILS



Ward 3B Outpatients **Ph: 9340 8682**
 Medical Staff: **Dr Tina Carter Ph: 3940 8682**
 Nursing Staff: **Natalie Gamble-Williams Ph: 9340 8682 or 0466 318 286**
 After Hours **Ph: 0410 717 816**
 Social Worker: **Charlotte Bradley-Peni (Tuesday, Wednesday, Thursday) Ph: 6152 6529 or 0404 039 971**
 ABDR Data Manager: **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**
 Social Workers: **Charlotte Bradley-Peni (Tuesday, Wednesday, Thursday) Ph: 6152 6529 or 0404 039 971 and Sue Habersfeld (Monday, Thursday) - Ph: 6152 6525**
 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

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

A wet and wild time was had by all who attended the W.A.Y (West Australian Youth) / HFWA Xmas Function that was held at Adventure World on Sunday 3 of December. It was a great opportunity to catch up with the regulars and meet some new members. We had 85 people attend and we were visited by Santa's little helper / elf due to Santa being too busy on the day to visit us. Sharri (Where's Wally) did a wonderful job with assistance (see inside for more pictures and information). It was great to see members of the community and their families, and the effort made by Marina and Natalie, representing the treatment centres at FSH and PMH.

The move to the Perth Children's Hospital is "likely" to be May / June next year; we eagerly await this but are not holding our breath!

It has been a great year, and on behalf of your foundation I thank all those who volunteered for us during the year in whatever capacity, and all those who attended HFWA functions or activities.

We also greatly appreciate everyone who renewed or took up membership. It is important to us to have as many members (paid up) as possible, because it shows the support of the community for the organisation that represents all people in WA with bleeding disorders.

We look forward to 2018, beginning with Men's and Women's Breakfast on the Sunday 11 of February 2018 (see inside for further information).

If you are interested in attending the HFWA Community Camp from Friday 16 to Sunday 18 of March 2018, please complete the Community Camp Registration Form, page 14. It will be an experience not to be missed, especially based on the last one we held. Family Camp focuses on bringing everyone together in a community environment and is great fun; I can highly recommend it - an unbiased view!!!

Please note the HFWA Office will be closed from Friday 22 December 2017 and reopening Monday 8 January 2018.

On behalf of all of us at HFWA, I wish you and your loved ones a Merry Christmas (Happy Chanukah) and a happy, healthy 2018.

See you in 2018.

Gavin Finkelstein
President



Cheryl Ellis, Gavin, Marina Goruppi and Ann-Maree Foran at Adventure World, Sunday 3 December 2017.

This newsletter is kindly printed by Fuji Xerox

Conference 2017 Feedback Article - Shane Meotti

Well done and congratulations to the HFA Staff and Conference Program Committee on another excellent conference. The theme of this year's conference was "looking forward to change" and I certainly came away from the conference with a renewed sense of optimism about the future of haemophilia and bleeding disorder treatment and care.

The program began with an excellent plenary by Dr Justin Coulson titled "21 days to a happier family". Apart from being quite an entertaining speaker, I also found what Justin had to say on parenting and family relationships very useful and the key takeaway for me was the three Ls; love, limits and laughter.

The next session I attended was the Hep C and HIV update. The clinical updates from Associate Professor Joe Sasadeusz and Dr Edwina Wright were excellent and the personal stories from Simon and Anthony about their journeys and treatment were very courageous and enlightening. The key message I took away from this session is that the new treatments now available in Australia for Hep C are true game changers and put this country in the forefront of global efforts to eliminate the virus. The role that Haemophilia Treatment Centres have with treatment and follow up screening is critical and was clearly highlighted.

One of the other standout sessions I attended was presented by Alison Morris and Abi Polus titled "Healthy joints in Adolescence for Life". The first part of the session focused on decision making in sport and physical activity and the second part on bleeds, arthritis and injuries. I was really encouraged by this presentation and felt it reflected a key theme that was prevalent throughout the conference regarding the personalisation of care. The key takeaway for me was that, with the right approach and care, many sports and activities that have been traditionally considered unsuitable for people with bleeding disorders can be enjoyed by them. The simple message from Alison and Abi is to ensure your HTC is involved so that health professionals fully understand the nature of the activity. By working together, an appropriate regime for the timing of treatment, emergency plans and a graduated training program can be put in place to ensure sports and activities can be enjoyed safely.

Another strong theme that crossed a number of the sessions I attended was the importance of the Australian Bleeding Disorders Registry and the role that it plays in improving care, both from an individual clinical perspective as well as providing evidence to support new treatments. Patient accountability through the use of MyABDR by patients and their carers was discussed on a number of occasions as it is critical in providing evidence of better patient outcomes. The ease of recording treatment using the app and website was highlighted by another of speakers.

Along with the excellent program, speakers and posters there was also a really good social program and opportunities to network and talk with others from the bleeding disorders community. As I have said in the past, the benefit of our community coming together for such events cannot be understated and I thank the HFWA once again for the opportunity to attend.



**WFH 2018
WORLD
CONGRESS**

Glasgow, Scotland • May 20-24

**THE LARGEST INTERNATIONAL
MEETING FOR THE GLOBAL
BLEEDING DISORDERS COMMUNITY**

GLASGOW, SCOTLAND • MAY 20-24, 2018

ORGANIZED BY: WORLD FEDERATION OF HEMOPHILIA
HOSTED BY: THE HAEMOPHILIA SOCIETY

Conference 2017 Feedback Article - Michelle Dinsdale

It's been a long while since I've been to a national conference, the last being when it was held in Fremantle. Our boys were young then so I went along to help the committee, help man the registration desk and then low and behold after that conference I was somehow on the committee (after being invited to attend a couple of committee meetings).

Our history - we have 3 boys - 23 year old Sam (affected), 20 year old twins John (affected) and Michael. I was on the committee for about 10 years being the Committee Secretary and I also worked in the office as the Secretary / Office coordinator.

Now to the conference - some of it was way over my head and some things I could relate to. I suppose it is hard to get an even spread of sessions when you are sharing information with health professionals and lay people. So here are some snippets that I took away from the conference and please remember this is from a mother's perspective!

Dr Justin Coulson - 21 days to a Happier Family

w: www.happyfamilies.com.au

f: happyfamilies.au

Justin is regarded as one of Australia's most respect relationship speakers, authors and researcher. He talked about keys to a happier family. It was a great light heartened start to the conference. Everyone could relate to something he said about their own families.

The big key to a happier family is to make time for your loved ones! I know I'm guilty of not doing this. We are all too busy working, maintaining the house, cooking, cleaning etc.

Try and get away from being on all the social media platforms - Facebook, Messenger, Twitter, Instagram. Have screen free time - especially when having the family meal - no television on in the background when eating, converse with your kids. Ask them how their day went, what was positive or negative with their day.

His three principles to a happier family are:

One Love

- Stop and pay attention.
- Chat with your children.
- Be "there".

Two Limits

- Getting relationships right - talk to your children about boundaries, include the kids in the negotiations, make them feel like they have contributed as well - not just mum and dad setting the rules, e.g. when young children / teenagers wanting Facebook, snap chat etc.

Three Laughter

- Have fun with your kids - be spontaneous.
- Set a particular day when you all do something as a family - even if it is just going to the local park for a picnic, kick the footy or play on the playground equipment.

We need to STOP, LOOK AND LISTEN to our kids.

I attended the Youth Myth Busting Session. The panel consisted of three groups of people - health professionals, youth and parents. The subjects they talked about:

- *Prophylaxis means that there are no more bleeding problems* - the consensus was it is a myth. It may reduce the number of bleeds that you have but you can also have breakthrough (micro) bleeds.
- *It is inappropriate to discuss sex and bleeds with a health professional at your HTC* - again it is up to the individual, how comfortable do you feel talking to your HTC nurse or doctor about this - but just remember - you are probably not the first to ask the nitty gritty questions!

Michelle Dinsdale cont.

- *Tattoos are perfectly safe for people with a bleeding disorder* - after discussion and allowing the audience to also participate - general consensus was that you had the same amount of risks whether you had haemophilia or not. However, it needs to be looked at by a case by case basis - what severity are you, what size tattoo are you thinking of getting - one, two or a sleeve's worth of tattoos? Should you discuss this with your HTC - some people said yes, some said no. I personally think that you should discuss this with your HTC, have a plan in place, but that's from a mother's viewpoint.
- *You don't have to tell your boss at work that you have a bleeding disorder because it is none of their business* - again the consensus was divided. I suppose it really depends on your relationship with your employer whether you wish to disclose or not. Apparently, the Defence Force is the only employer that you do have to disclose to.
- *Treating yourself more than your HTC has recommended is okay because you can never have too much treatment* - the discussion was more around adhering to your prophylactic treatment and don't undertreat!

Women's Breakfast – Mindfulness

w: www.breezelifecoaching.com

f: breezelifecoaching

Dr Ira van der Steenstraten from Breeze Life Coaching spoke to us over breakfast about mindfulness and practices to use to train your attention and thoughts by doing meditative exercises which can help you reduce stress, anxiety and to give you the ability to focus your attention on the now and present moment. Research has shown that it can reduce stress, anxiety, depression and even boost your immune system.

Ira showed us some techniques on practicing mindfulness - but it does take a lot of practice! To take the stress out of life - try yoga or colouring in books - give it a go.

Let's Talk Period: Women and Bleeding Disorders - Dr Paula James

w: www.letstalkperiod.ca

f: letstalkperiod

Dr Paula James, a Haematologist at Kingston General Hospital, in conjunction with her research program at Queen's University in Canada, spoke about her team's project called "Let's Talk Period" - designed to raise awareness of symptoms of bleeding disorders among women. Her research shows 1 in 1,000 individuals worldwide have an inherited bleeding disorder but don't know it. Women with heavy menstrual bleeding (which can also lead to low iron levels) may not know that they have a bleeding disorder, they just think it the norm.

Dr James and her team have developed a bleeding assessment tool called a Self-BAT which can help inform people about whether they may have a bleeding disorder and guide them toward the help they may need. The local impact of the Let's Talk Period website and women doing the Self-BAT test has seen her clinic have eight new referrals of patients since it launched in 2016. So, with the help of social media Dr James and her team are getting the message out there - the website was launched in May 2016, they have had 17,167 page views from 112 countries.

However, the above is for your information only and please be mindful that you should always consult with your local GP or your HTC.

Michelle Dinsdale cont.

What's here now and on the horizon - New Treatment Therapies

Mr John Cahill from the National Blood Authority (NBA) talked about the NBA's mission to ensure a safe, secure, adequate and affordable blood supply for Australia. Currently they have 14 contracts with suppliers and service providers. They manage a budget of about \$1.1 billion PA for all Australian governments, however about 15% of this budget (approx. \$166 million PA) is spent on clotting factor products.

ABDR data for 2015-6 shows:-

- almost 6,000 patients with bleeding disorders
- almost 5,000 of these patients have common hereditary bleeding disorders
- some 2,300 of these patients have haemophilia A (660 severe patients) and
- some 550 have haemophilia B (102 severe patients)

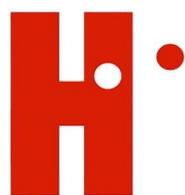
The data helps provide a focus for the NBA mission and the statistics are imperative to help governments deal effectively with new treatment therapies.

Associate Professor Huyen Tran spoke about the new therapies being clinically trialled in Australia at the moment - a once weekly emicizumab prophylaxis administered subcutaneously not intravenously! (*Emicizumab is an investigational monoclonal antibody for the treatment of haemophilia A*). How exciting - to think one injection a week!

The conference was an eye opener as to what is coming in the way of new gene therapies for our community. When we became a part of this bleeding disorder world quite a few years ago we were informed of gene therapy - it's happening but it will take about twenty years. It's probably not happening as fast as we would all like it to be going but it is getting there. So, one day.

Lastly, the dinner was a great opportunity to finally meet people face to face from other state foundations that I had liaised with when working for the foundation. It also gave me the opportunity to meet new parents whose children have only been newly diagnosed and young adults from all over Eastern Australia and New Zealand.

I hope one-day Western Australia will host a national conference again in Perth so that our families here can all have the opportunity to attend. Thank you to HFWA for giving me the opportunity to attend this conference and if it does look at coming to Perth, I would be only too happy to be on the committee to help organise it.



Haemophilia Foundation Western Australia
presents...

Community Camp 2018



SWAN VALLEY
ADVENTURE CENTRE



Youth Event Report - Pam Wall

We ended our 2017 WAY events by combining with the HFWA Christmas end of year party in a mega day at Adventure world.

It was a great way to gather everyone together and give the community an opportunity to see some of our youth at the Christmas event and to meet some new youth. What a great turn out. Combined with all of our families we had 85 attend.



Options for the 2018 WAY events were on display giving the Youth an opportunity to choose what they would like to do in 2018. Additionally we had on display some past camp information for those keen to see what we did in 2016. It's going to be another fabulous camp in 2018 with a new camp destination with even more HFWA community members combining to come on board.



Thanks for all your support in 2017. To all the WAY who participated in our events, to all our mentors and to the committee, thanks for another great year. Soooooo if your turning 10, in 2018, and looking for some cool things to do during the year be sure to get in touch youth@hfwa.org

See you in 2018!



Family Christmas Party at Adventure World - Deb Barnes

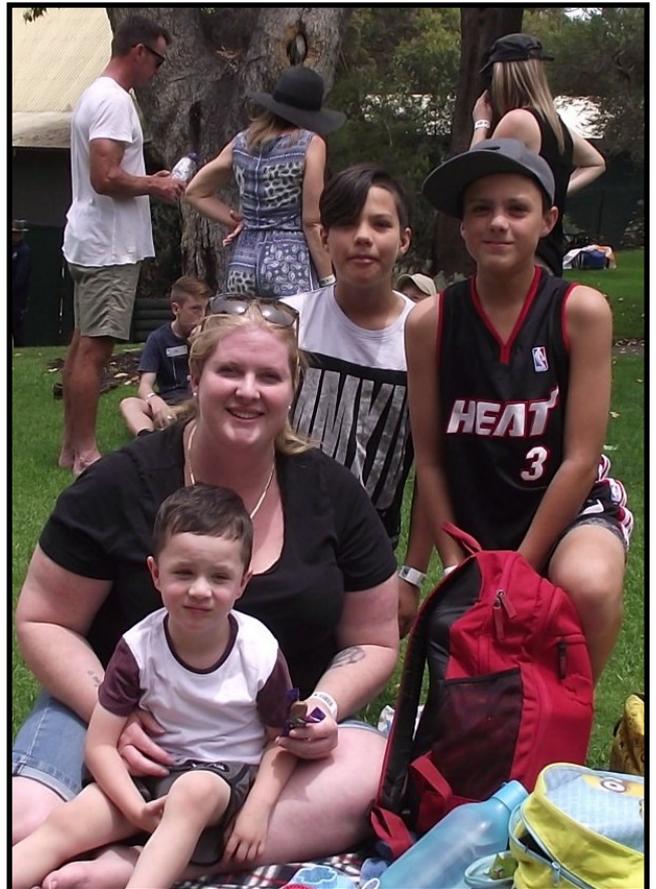
As Gavin said it was a wet and wild time at Adventure World on Sunday 3 December. Here are a few things people had to say about it.

From Natalie Gamble-Williams, haematology clinical nurse coordinator, PMH. It was great to see the families outside of the hospital, engaging in conversation and the children playing with each other. The parents all seemed to be great supports especially for the newer families recently diagnosed. It was lovely to see how the other families sort of took them under their wing and gave them advice. It was also great to see some of the adult patients come along and the teenagers all getting along and having fun together. Thank you to HFWA for inviting me. I really enjoyed chatting with the families and some of our HFWA members outside of work.

From Darren. Kristy and I would like to say a big thank you for the Christmas party that you arranged. We had a lovely day and appreciate the effort by all to make the day a success.

From Sue-Ellen. Thank you all for the wonderful Christmas celebration. We all had a fabulous time and so appreciated all the efforts made to make us all feel special. Denver said it was the best one yet. It was terrific for him to meet some of the very friendly older teenagers, even if he did not join them on the thrill rides which he is not into. He really appreciated meeting them. He is looking forward to sharing more time with them in 2018. We had a hoot on the waterslides, bumper boats, go karts, and water playground. Thanks again for the opportunity to meet new and old members and share some much needed relaxation. It was a fantastic day. Warm wishes for a happy Christmas and 2018.

From Sister Lee. Sorry not to be with you all at Adventure World but overseas at present. Wishing everyone a very happy Christmas.



Photos from the Family Christmas Party at Adventure World.

See the next page for photos with Santa's Elf.

Family Christmas Party at Adventure World...

Santa's Elf was there to give out the Christmas presents - who do you recognise?



Men's Breakfast Invitation

Gavin Finkelstein would like to invite you to a Men's Breakfast

VENUE: Rendezvous Hotel - Restaurant, 148 The Esplanade, SCARBOROUGH 6019

TIME: 9:00am SHARP

DATE: Sunday 11 February 2018

RSVP: by Monday 5 February 2018 to:
Deborah Barnes - HFWA Office on 9420 7294 or office@hfwa.org
or Gavin Finkelstein on 0415 978 031 or gavfinkelstein@gmail.com



RENDEZVOUS
HOTEL
PERTH SCARBOROUGH



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.

Women's High Tea Invitation at Cottage Tea Rooms, Henley Brook

Cheryl, Pamela and Susie would like to invite you to our next Women's Event

VENUE: Cottage Tea Rooms, 8560 W Swan Rd, Henley Brook WA 6055

TIME: 2:00 pm - 4:00 pm

DATE: Sunday 11 February 2018

RSVP by Monday 5 February 2018 to:
Deborah at the HFWA office on 9420 7294 or office@hfwa.org
or Cheryl Ellis on 0402 033 652 or vice_president@hfwa.org



Men's Breakfast Report - Gavin Finkelstein

We had a good attendance of thirteen (would have been fourteen but someone slept in, no names....) gents who attended our breakfast at The Gate Bar and Grill, Cockburn. There was lively discussion as some of us hadn't seen each other for some time. We also had the opportunity to meet some new folk.

There was great interest in the new advances that were widely reported in the media last week, we look forward to accessing them when they are commercialised and approved by the TGA for use. There was much discussion about the services provided with a consistent issue being discussed that will be raised at FSH.



It was great to see so many attendees, and I look forward to catching up with as many of you as possible at our next breakfast Sunday 11 February 2018, at Observation City (or whatever it's called this week!!).

Women's Breakfast Report



We held the final Women's breakfast for 2017 at the Gate Bistro in Success on Sunday 10 December. While it was a small group, it was wonderful to have new faces at the table. It's always a pleasure to meet new people, hear their stories and provide some personal perspective in answer to questions. Coming together to provide support and a sense of community is an important feature of our Women's and Men's events. Seeing the smiles and active conversations makes me glad we continue to hold these events. If you meet people who would benefit from being a part of the HFWA community, bring them along; we're always happy to welcome new members.

Susie Couper

Attending events can be daunting as a new member; however, I was made to feel welcome from the moment I sat down. It was so comforting to hear other parents' stories regarding their child's treatment, inclusive of times where things did not go to plan but outcomes were still great. I learnt more about ports from first hand experience and now have less anxiety around my son having to have one.

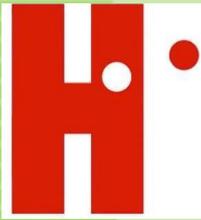
We discussed a range of topics including symptomatic gene carriers, differences between haemophilia A and Von Willebrand disorder, and our language around bleeding disorders. The committee members were a wealth of knowledge and were more than happy to answer questions. This was a fantastic experience to meet everyone and I look forward to future events!

Robin Dique

I thought The Gate Coburn was one of the better venues at which the Women's Breakfast had been held. The subject of the recent media announcement regarding Gene Therapy for Haemophilia B came up. Great news! Hopefully there will be similar news for Haemophilia A in the near future.

Beryl Kerr





Haemophilia Foundation Western Australia presents...



SWAN VALLEY
ADVENTURE CENTRE



Community Camp 2018



For our community

This community camp is brought to you by the HFWA committee. We are all volunteers and feel very connected to those in our community with a bleeding condition. Join our family with your family. **Friday 16 to Sunday 18 March 2018.**

For the kids, boys, girls, teens, young adults, brothers, sisters, mothers, fathers, grandparents, aunts and uncles and the whole family.

We're all in this together

The amazing thing about camp is it brings out the best in everyone and you don't have to change who you are!

Games Galore

Family fun and team games. A little bit of challenge, a generous portion of competition and a heaping of laughter with fun on the side. Just when you thought you had it in the Then in springs the 'game changer'.

Family Ties

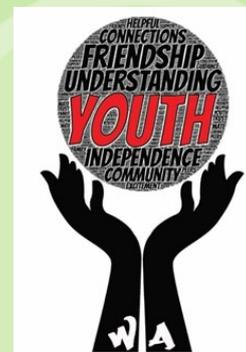
Peer support conversations with other mothers, fathers, women and men. Experiences and challenges.

As a mother/father I

When we go

What if they

Should we



W.A.Y.

Complete the Community Camp - Registration Form today - next page

HFWA Community Camp – Registration Form

HFWA is excited to invite you and your family to the
HFWA Community Camp - 2018

The Camp is open to people with bleeding disorders and their families and will provide an opportunity to meet new people and catch up with old friends.

All meals and accommodation are provided and included in the Camp costs. HFWA will continue to keep Camp fees the same as previous years, see fees below.

If you have any challenges in meeting these costs an application can be made for assistance by contacting the Social Worker or Vice President of HFWA, see details below. Travel assistance is also available to country campers.

Swan Valley Adventure Centre, 58 Yule Avenue, Swan Valley

Complete the form below to register and return to:

- Email: office@hfwa.org
- HFWA, 2 Delhi Street, West Perth WA 6005

Name	
Address	
Phone	
Email	
No. of adults and names	
No. of children and names	
Age of children	

Additional information

Allergies	
Dietary Requirements	
Friday Meal (strike)	I/We will/will not be attending the Friday night meal.
Photographs (strike)	I/We give permission for my/our photographs to be published in HFWA materials. YES/NO

Camp Fees and Payment

Camp Fees Members (circle)	Single \$50.00	Single under 18 \$40.00	Family \$150.00
Camp Fees Non-Members (circle)	Single \$80.00	Single under 18 \$40.00	Family \$180.00
Extra person after....	Each additional attendee \$40.00		
Payment Types (circle)	Cheque send to HFWA, 2 Delhi Street, West Perth WA 6005		
	Direct Deposit to National Australia Bank Account The Haemophilia Foundation WA Inc. BSB: 086488 Account: 035233031 Reference: Camp (your name)		
	Credit Card payment over the phone to Deb Barnes in the HFWA office		

OFFICE USE ONLY	RECEIVED DATE	PAYMENT TYPE	RECEIPT NO.	CONFIRM. SENT

2017/18

WHAT'S ON?



Friday 22 December 2017 to Sunday 7 January 2018

HFWA Office will be closed.

Ring Gavin on 0415 978 031 for any urgent queries during this time.

Sunday 11 February 2018

Men's Breakfast.

Rendezvous Hotel, Scarborough. See invitation page 11.

Sunday 11 February 2018

Women's High Tea.

Cottage Tea Rooms, Henley Brook. See invitation page 11.



SWAN VALLEY
ADVENTURE CENTRE

Friday 16 March to Sunday 18 March 2018

HFWA Community Camp.

See the Camp details on page 13.



2017:

 quarterly youth events
 quarterly men's group
 World Hemophilia Day

 quarterly women's group
 Bleeding Disorders Awareness Week
 parents and family meetings

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

Children's Page - Santa's Workshop

