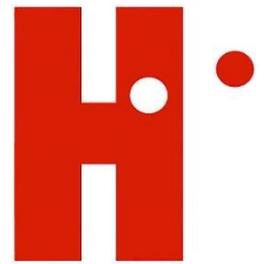


Contact



Newsletter of Haemophilia Foundation WA Inc.

February 2018



HAEMOPHILIA FOUNDATION WA INC.

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Your Committee

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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.

Cover picture

Two of our members at the women's High Tea at Henley Brook on Sunday, 11 February 2018.

PRINCESS MARGARET HOSPITAL CONTACT DETAILSWard 3B Outpatients **Ph: 9340 8682**Medical Staff: **Dr Tina Carter Ph: 9340 8682**Nursing Staff: **Natalie Gamble-Williams Ph: 9340 8682 or 0466 318 286**After Hours **Ph: 0410 717 816**Social Worker: **Charlotte Bradley-Peni (Monday to Thursday, 8:00 AM - 4:30 PM, adults and paediatrics, contact for appointment) Ph: 6152 6529**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: **Charlotte Bradley-Peni (Monday to Thursday, 8:00 AM - 4:30 PM, adults and paediatrics, contact for appointment) Ph: 6152 6529**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



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President's Report

Hi Folks

I hope everyone had a good festive season and a relaxing new year.

Well 2018 is well underway, school is back and we have lots coming up at HFWA.

The HTC at FSH had a transition clinic on Monday, 5 February 2018, and there were good numbers attending. Hopefully it was of benefit to those who attended. If you missed out and you or your child is due to transition (i.e. turning 17 or 18) then contact Charlotte on 6152 6529 to arrange an appropriate clinic time for you to transition.

For anyone attending clinic make sure you are registered on MyABDR. If not, it is simple to get signed up whilst you are there. It is important that all of us who use, have used or may use products (even rarely) are registered on MyABDR and use it to record product usage, especially for statistical and research purposes. It is not Big Brother keeping an eye on us it is our responsibility to account for product usage.

Please note the closing date for registration for the HFWA Community Camp is Wednesday, 28 February 2018. If you don't register before that date we will be unlikely to accept your registration due to a limit on the number of attendees, so don't be disappointed or miss out and get your registration in ASAP.

Remember that it is World Haemophilia Day on Tuesday, 17 April 2018. If you can get any landmarks to light up red on that day please do so. If you do, don't forget to send us the photos (the Perth Bell Tower and Trafalgar Bridge are lighting up).

It was disappointing that we had to cancel the Men's Breakfast on Sunday, 11 February 2018, due to lack of numbers. Please ensure that you RSVP by the due date as unfortunately some people RSVP'd after the due date and the breakfast had to be cancelled.

That's all for now and look forward to catching up with people at clinics, camp or any other activity.

Gavin Finkelstein
President

This newsletter is kindly printed by Fuji Xerox



**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 - Cheryl Ellis

In October 2017, I was fortunate enough to attend the 18th Australian and New Zealand Conference on Haemophilia and Rare Bleeding Disorders, in beautiful Melbourne.

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, busting myths, prophylaxis, the Australian Bleeding Disorders Registry (ABDR), women with bleeding disorders, ageing with haemophilia, pain, disclosure, and the future of bleeding disorder treatment.

The opening plenary on Friday morning was '21 days to a Happier Family', presented by Dr Justin Coulson. His talk, in a nutshell, gave us some advice that works for his family and most others – thriving families have a plan that centres around the principles of *love, limits and laughter*. Justin was the perfect opening keynote speaker; he was entertaining, knowledgeable and inspiring.

The second session I attended was the 'Youth Myth Busting' panel session, chaired by Dr Moana Harlen. The topics discussed in the session included 'Prophylaxis means that there are no more bleeding problems', 'tattoos are perfectly safe for people with a bleeding disorder', 'you don't have to tell your boss at work that you have a bleeding disorder', 'it is inappropriate to discuss sex and bleeds with a health professional at the treatment centre (HTC)' and 'treating yourself more than your HTC team has recommended is ok because you can never have too much treatment'. The panel was made up of three teams – the first team were HTC health professionals, the second team were youth representatives who have a bleeding disorder, and the third team were parents of young people with bleeding disorders. A few things I learned from the session are that most youth know they should treat regularly, but often don't; unless you are in the armed forces in Australia, you don't legally need to inform your employer about your bleeding disorder, but it may be in your best interests to inform them, particularly if you work in a potentially high-risk industry or need time off due to medical issues; and your HTC staff are there to help you to live the best and fullest life that you can live, and as a patient, you need to tell them if and when you have any problems, issues or questions.

The third session I attended was 'Starting the Journey with a Child Newly Diagnosed with a Bleeding Disorder'. The chair was Dr Julie Curtin, who outlined some history of bleeding disorders, and accentuated that parents need to tap into other peoples' experiences and knowledge, the need to use support networks to get your family through the highs and lows of your journey, and not to give up on your dreams for your child - anything is possible. Dr Moana Harlen talked about the stages of adjusting to your child's diagnosis and the need for family support. Moana outlined the Family First Parenting Program that is implemented in Queensland, different coping styles and some strategies to help such as mindfulness, relaxation, stress management, social and peer support networks such as family, friends, HTC staff and the state haemophilia foundations. The lovely Jacqui Bradshaw then talked to the audience very frankly about her and her family's experiences with having a son with a bleeding disorder.

The fourth session I attended covered 'Prophylaxis'. Dr John Rowell was the chair of this session. Dr Jane Mason outlined the definition, history, issues and types of prophylaxis, including individualised prophylaxis. Some interesting points that I noted from Dr Mason's talk were that arthropathy (joint damage) starts with ankle joints; primary prophylaxis ≠ perfect joints; arthropathy is found in people's joints who have mild and moderate bleeding disorders, as well as people with severe bleeding disorders. Dr Mason also spoke of the economic saving overall that needs to be taken into consideration - resulting from the increased quality of life of people utilising prophylaxis. National prophylaxis data is lacking outcome measures. Dr Mason's conclusion dovetailed nicely with Dr Sumit Parikh's talk on the ABDR Data Analytics. Australia is one of the few countries in the world that has a bleeding disorders registry, and this statistical data is crucial in illustrating the importance of prophylaxis.

A 'Mindfulness' session during Saturday's breakfast, chaired by the multi-talented Sharon Caris, and presented by Dr Ira van der Steenstraten, was excellent. I learnt that mindfulness is not just about meditation (which is used as a crucial tool, though), but about being aware, present and appreciative *at that*

present moment in your life. Ira has led a very interesting life so far, and as a health professional and a woman with a bleeding disorder herself, has a personal appreciation of what we live through as patients. I loved this session.

After breakfast, plenary three was 'Let's Talk Period: Women and Bleeding Disorders'. Dr Jenny Curnow was the chair, and Dr Paula James talked about women's issues. This plenary detailed the issue of menorrhagia mainly, and the ways in which it affects women. Menorrhagia was defined in this plenary as a loss of greater than 80mls of blood during the menstruation period. About 30 percent of women reported abnormal blood loss during their period, and about 5 to 10 percent of women seek medical advice. Dr James stated that 50 percent of causes were organic, 25 percent of cases were undiagnosed, and 15 -25 percent of women had an underlying bleeding disorder. Dr James also stated that 70 percent of women with von Willebrand Disease, and 60 percent of women with factor viii deficiency will experience menorrhagia, as compared with 30 percent of women in general population. The impacts of menorrhagia include work / study absenteeism, and a negative quality of life. Two thirds of hysterectomies performed on women of reproductive age are as a result of diagnosed menorrhagia. Dr James also talked about the 'Let's Talk Period' website, Instagram and Facebook page.

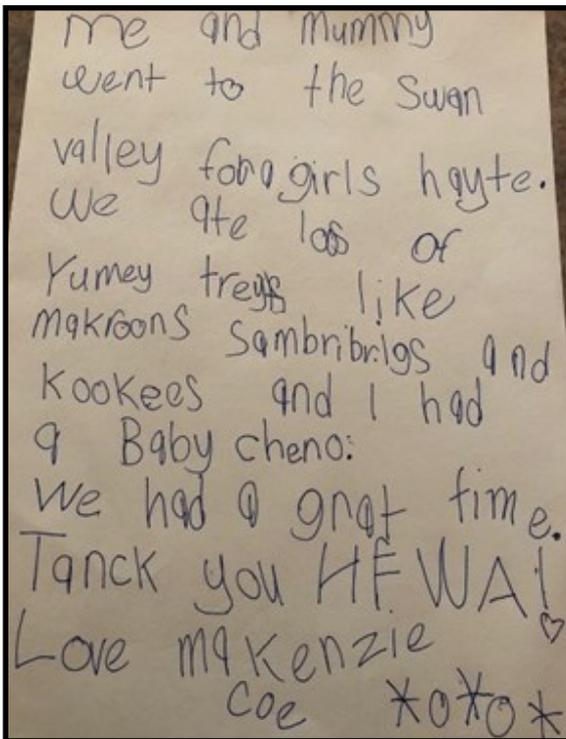
I attended the Concurrent 1 plenary 'Ageing' on Saturday after morning tea. Dr Huyen Tran's session about Ageing was entertaining and informative, giving an insight into the medical issues that people with bleeding disorders (PWBD) are likely to experience with ageing. The great news is that the life expectancy of people with bleeding disorders has caught up with the general population average, which is around 71 – 80 years of age. This is due to the availability of safe and effective therapies, surgical intervention, prophylaxis treatments, home therapy and comprehensive care. In the future, Dr Tran forecast that there may be a time when there are no bleeds in the new generations of PWBD. Other issues being explored include transition of care from independent care to aged care, and improved inhibitor management with the trials of Emicizumab, in the form of a subcutaneous injection once a week. Hepatitis C is also almost eradicated. These will impact on the health-related quality of life for PWBD. The flipside of the reduction of bleeding in ageing PWBD are the appearance of lifestyle-related disease and disorders such as obesity, cardio-vascular disease, strokes, diabetes and some cancers. Dr Tran advised everyone to look for a good GP, and to be diligent in your own health surveillance. The personal story from David was also interesting and enlightening. An overview of the NDIS by Leonie Mudge, and a talk from Josh Mennen regarding insurance and superannuation followed.

After lunch, I attended the Concurrent 2 plenary 'Women and Telling Others'. This plenary included a talk about employment and insurance, some personal stories about disclosing your bleeding disorder status to your co-workers and employer by Susie and Sharron and a question and answer and panel discussion to follow everything up. A key point I gained out of this plenary is that whilst it is not legally necessary, it may be in your best interests to inform your co-workers and employer that you have a bleeding disorder. Some reasons for this are that you don't have to explain too much about work absences related to you bleeding disorder, and it may just save your life if you have an accident at work. A discussion about the value of Medic Alert membership resulted from a random question.

Following afternoon tea, the conference was closed with the last plenary - 'What's Here Now and on the Horizon - New Treatment Therapies'. Paul talked about his experiences with an extended half-life product, John Cahill spoke of the funding considerations of new and (hopefully) upcoming products, Dr Huyen Tran talked about extended half-life products, and other new therapies such as Fitusiran, a synthetic, small molecule interfering RNA that targets antithrombin (AT). The working basis of Fitusiran is that haemophilia A and B results in an incomplete clot due to the insufficiency of thrombin. Fitusiran aims to allow enough thrombin production to enable haemostasis and prevent bleeding. It is administered via a subcutaneous injection and will not cause inhibitors. Exciting stuff, indeed. Dr John Rasko spoke of gene therapy, including a 'one shot and you're cured' living therapy that may be around the corner. 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!

Women's High Tea Report - Makenzie Coe and Cheryl Ellis



me and mummy
went to the Swan
valley for girls hqute.
We ate lots of
Yummy treats like
makroons sambriblogs and
kookees and I had
a Baby cheno:
We had a great time.
Tanck you HFWA!
Love Makenzie
Coe *o*o*o*

'Me and mummy went to the Swan Valley for a girl's high tea. We ate lots of yummy treats like macarons, sandwiches and cookies and I had a baby chino. We had a great time. Thank you HFWA'. Makenzie Coe (6)



I was lucky enough to have a reporter attend the women's high tea at the Cottage Garden Tea Rooms on Sunday, 11 February. Makenzie and her wonderful mum Janelle have kindly given permission for us to publish her report.



We had thirteen women attend our high tea, including our roving reporter and her mum. The day was beautiful, as were the surrounds, the company, and most importantly (to me), so was the food. Our two tables discussed the upcoming camp, the treatment centres, our families, the need for being knowledgeable and pro-active when interacting with health care professionals outside the treatment centres (and sometimes, inside) and our busy schedules and work lives, all the while nibbling our way through a delicious and impressive assortment of goodies, tea and coffee. Next time, come and join us; there's always a seat at our table saved just for you!



Conference 2017 Feedback Article - Dale Spencer

Hello my name is Dale Spencer and I was lucky enough to be given the opportunity to attend the 18th Australian and New Zealand Conference on Haemophilia and Rare Bleeding Disorders as a WA Delegate. It was held at the beautiful Pullman Albert Park in Melbourne in October 2017.

The conference began on Thursday night with registration and welcome drinks, it was a great way to catch up with my fellow delegates and be introduced to some new ones.

A youth meet and greet was arranged for after registration, moving into the 'older' side of youth it was great to see so many new faces keen to be involved and share experiences.

Friday morning began with a great session ran by Dr Justin Coulsen titled '21 Days to a Happier Family'. As the father of (soon to be) 4 young kids it was great to hear that I'm not the only one who struggles sometimes and a lot of what you see on social media isn't as true as it portrays to be.

He taught us about Sunshine, storm clouds and rainbows as a way to ask your children about three parts of their day so they can reflect.

I also learnt that just having time for my kids and 'being there' can be the love they need.

After morning tea I sat in on Genetic Testing and its role in family planning, it was a very interesting session as I've had people close to me use genetic testing and it was great to get an understanding of what it entails.

After lunch I attended a pain management session and learned a lot about bleeds, arthritis and managing them together.

I also learned that medical professionals are trying to move away from the term 'spontaneous bleed' as it's now more often referred to as 'bleed from unknown origin'.

An afternoon session on prophylaxis and data analysis was followed by an hour break for everyone to get dressed up for the Gala Dinner.

My fiancée Shannon and myself got dressed to the nines and had a beautiful feed, a few drinks (Shannon's was non alcoholic) and a good chat with fellow delegates and health professionals. The amazing food was followed up with some amazing desserts. We left with very full stomachs.

Saturday morning began for me with a talk on improving care through MyABDR, and the future benefits that everyone being involved would bring to the community on a national level.

Following morning tea was 'Healthy Joints for Life'. It dealt with the unfortunate facts that certain sports can be a little too much for someone with a bleeding disorder although it doesn't mean you just have to settle for swimming (not that there is anything wrong with that). I enjoyed hearing about other people's experiences and endeavours in sport as it was a big part of my life growing up.

The last session of the day was the one a lot of people, including myself, were greatly looking forward to 'New Treatments'. It delved into longer half life products, sub cut products and the infamous gene therapy, one needle and your bleeding disorder is gone. After hearing about a lot of case studies I have hope for the future and it's amazing to see how far treatment has come and I just want to say a massive thank you to the older generation for fighting for what we have today.

All in all it was another successful conference and I hope everyone got out of it as much as I did.

Thank you



Haemophilia Western Australia presents...



Community Camp 2018

Our 2018 camp challenge is

16-18 March 2018



**Registrations close
Wednesday, 28 Feb.
Don't miss out!**

IF YOU CHOOSE TO ACCEPT OUR INVITATION YOU MUST:

Choose and record your spy alias name

Complete covert undercover missions

Contribute towards your team / agencies secret mission



FRIDAY

JUST A PEAK

Missions commence
Code breaking intro
Women and Mum's
Project 007 'M' huddle



SATURDAY

COVERT ASSIGNMENTS BEGIN

Kitchen garden 1 - 7yrs
River Canoeing 8 -18yrs
Men and Dad's Cone of Silence muster

SUNDAY

MISSION POSSIBLE SPY CAMP CHALLENGE

Mind, Body, Agency
Crack the final challenge for your agency

Register today, (form next page) Saturday day trip excursion available, funding assistance if required.
DON'T MISS OUT CONTACT US NOW! Phone: 9420 7294 or Email: office@hfwa.org



HFWA Community Camp – Registration Form
REGISTRATIONS CLOSE Wednesday, 28 February 2018

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@hfw.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

Conference 2017 Feedback Article - Deborah Barnes

I was one of those fortunate enough to be able to attend the Haemophilia and Bleeding Disorders Conference in Melbourne last year. I would like to extend my thanks for this opportunity to the HFWA Management Committee. It was a most rewarding and interesting experience.

I was very pleased to have opportunities to speak with the staff of HFA and many members and staff across all the Haemophilia Foundation organisations in Australia with whom I have interacted over the phone during the last two years. I found it a most interesting conference in that those attending came from across the spectrum of those with a bleeding disorder to those treating people with haemophilia and other associated bleeding disorders as well as those doing some really clever, sensible and cutting edge treatment and investigation. All designed to assist our members in the short and long term.

One thing that stood out for me was the increasing recognition of just how much bleeding disorders can vary between individuals who ostensibly share the same condition. I found it most interesting that several of the speakers acknowledged just how much a particular condition can shift genetically within any one family. The emphasis seems to be moving towards the treatment of individuals according to their particular needs, and according to the way they have been affected individually, physically etc. This move being driven as the medical analysis data moves forward and more meta data and more individual data is collected. Hence the extreme importance of MyABDR and the daily entering of data as discussed by several of the speakers. Australia's bleeding disorders registry is one of the few in the world. This makes the collection of this statistical data even more crucial and significant.

Dr Justin Coulsen presentation '21 Days to a Happier Family' was a great plenary session. He emphasised the importance of love, limits and laughter. He spoke about the importance of having fun with your family and how important it is to create your own family traditions like Super Saturday, camping trips and looking at what your family can spontaneously do together.

Dr Matt Hunter spoke on the 'Pathway to Genetic Testing'. He discussed mutation detection and carrier testing. He explained that today we can do accurate carrier testing. Prenatal non invasive testing is now available. It is possible, after ten weeks, to check the child's cells in the mother's blood and tell the sex of the child and if they have haemophilia. This session was wide ranging and most enlightening. The reasons for, and value of genetic testing and consent were discussed, these include; unclear diagnosis, identification of carriers, assistance in identifying the best medicine and correct dose, detecting potential allergic reactions to blood products and in the future, gene therapies. The role of a genetic counsellor and disclosure of results was covered. There were a wide range of issues mentioned as being raised, and dealt with positively in counselling sessions including; individual and family experiences, varying opinions amongst family members, beliefs regarding carrier status, and issues for women during pregnancy.

Over all the future is looking much brighter with the advent of genetic testing, even though the full benefits of this future may be a number of years away.



Above: It was great to catch up with Marina Goruppi and Dr Tina Carter, from Perth.

Martina Egan-Moog, Catherine Pollard and Associate professor Carolyn Arnold presented sessions about understanding pain and pain management. Martina talked about the explosion of pain research over the last 20 years, and that we have learnt that we can actually positively influence if and how we experience pain. She spoke about DIM (danger in me) and SIM (safety in me). DIM is anything that is a threat to you as a person in day to day functioning and causes you to experience pain at a higher level than SIM. SIM is anything that makes you stronger, better, safer and certain within yourself and consequently can lower chronic pain levels. Catherine explored some of the non-pharmacological options that are available for people with bleeding disorders.

Friday evening was an opportunity to dress up, relax and share a delicious meal with friends and acquaintances and to discuss some of the speakers presentations from the day and to anticipate what was to come on Saturday.

On Saturday during breakfast it was off to learn about 'mindfulness'. Mindfulness as if your life depended on it. Learning to ignore unproductive thought patterns and behaviours. Paying attention to the present moment rather than worrying or dwelling on the past or future. Developing an attitude of friendliness towards yourself instead of being critical and judgemental. To do this you have to learn to focus all five senses and practice, practice, practice. Yung observed 'what you resist persists'. Dr Ira van der Steenstraten explained the benefits of mindfulness meditation pain relief. It all has to do with the way you think about pain. Through mindfulness oriented intervention you can significantly decrease pain and develop a greater feeling of control over the pain.

Dr Paula James followed this session with her presentation 'Let's talk period: Women and bleeding disorders'. She started by pointing out a few facts about menorrhagia in the past versus today. For example in the past women experienced about 160 menstrual cycles as compared to about 450 today. There used to be late menarche whereas today we have early menarche. In the past there was extended breastfeeding while today we have short breastfeeding. While we used to have early menopause today we have late menopause. Dr James explained about her 'Let's Talk Period' project that she set up in Canada. It has a website, Instagram and Facebook page that women from all over the world access. She is very enthusiastic that women with menorrhagia become aware that they have a condition and observed that accurate diagnosis of women with bleeding disorders is critically important in order to ensure proper management. On her website she points out that 1 in 1000 Canadian women have a bleeding disorder but most don't know it.

Dr Huyen Tran next presented a most interesting session on ageing with haemophilia, he began with a case study of a patient of 97 with haemophilia A. His conclusions were that significant improvements in haemophilia have led to a significant ageing population with haemophilia. That adult haemophilia patients are susceptible to non-haemophilia related illnesses in later life. Finally that haemophilia treatment centres remain an integral part of co-ordinating care to maintain a quality of life and independence.

Josh Mennen next gave a presentation on insurance and superannuation. He explained the difference between taking out an individual policy and being part of a group life policy. There apparently are differences and benefits to people with medical conditions in the group life policy that may not be available in an individual policy.

All the presenters at the Conference were most interesting to listen to, very approachable and happy to talk further on their chosen speciality. The HFA staff did a fantastic job in organising the Conference, many thanks and congratulations all round.



Dr Megan Sarson and Marina Goruppi between sessions in front of the HFA stand.

Hep C Treatment - A Personal Experience - Simon

Simon is an Australian community member with haemophilia who has been cured of hepatitis C. He is an architect, the co-director of an architecture design practice and a senior lecturer at a university where he is also doing his PhD.

This is a transcript of Simon's presentation at the 2017 Conference. It is reprinted from National Haemophilia No 200 December 2017 with permission.

Preparing this presentation began with me wondering what it was that I could bring to the Conference regarding my experience with hep C and its treatment. I mean, a guy in his mid forties takes a pill with no side effects for three months and is cured of a disease without any residual issues is hardly compelling listening. In conversation with Suzanne from HFA though, my jaw dropped when she told me that some people had not taken up treatment. I couldn't believe that anyone would refuse the opportunity to finally rid themselves of that bomb ticking away inside them.

So I thought, well then, this is going to be about me giving reasons, and experiences that you can relate to patients you encounter. Patients who may have reasons for avoiding or delaying taking up this quite amazing treatment. So I thought I'd imagine what those could be.

For those who are perhaps suspicious

As I, or I should say my mother and I, were in the early eighties, when all of a sudden treatment became dangerous. It was about 1984, a year or so after I had already contracted hep C from blood products taken for a couple of tooth extractions. Never mind the opportunity to contract HIV had probably already come and gone, the fact was that trust in treatment had evaporated.

So what to do? As a mild haemophiliac I had the option, for the most part, of just waiting out the slow healing of my joint trauma injuries. My mum, keen to find some way to ease my pain and bleeding from injuries to my joints looked into alternative medicines. Safe medicines, and as it turned out quite useless ones.

I recall lying on my couch strapping cotton wool soaked in arnica to my knee, or ankle, or elbow – tinctures - for years, of unnecessary pain and lost days suffered. It still makes me very angry to think someone, an adult, advised a haemophiliac child and their mother to undertake such nonsense.

So for those who are suspicious, I've tried things that don't work too, and I also had good reasons. This treatment we are talking about isn't that.

For those who have already lost time

I avoided any form of treatment for hep C following my ultimately unsuccessful interferon treatment in my early twenties. I had cleared the virus after the six month treatment. It was quite heartbreaking to discover it had returned in the sixth month following the end of treatment, and contributed to a period where I lost about a year of my studies - or of much of anything really - to that vague funk that accompanies interferon treatment, along with the distress of the unsuccessful aftermath that I found hard to take and the source of quite crippling anxiety.

Any description of the treatments I've been offered over the years since involved lengthy commitments of up to twelve months, the possibility of side effects and unsatisfying cure rates, particularly for my genotype. I had already lost time and was not keen to lose more, to give up time that could be spent on my post-grad studies, or later the projects I was working on such as Federation Square, later the time for my business I was building. It just didn't seem worth it. I was yet to have a result from biopsy or ultrasound that showed the disease was doing any damage, so I waited. I am now glad I did for the total time lost to this treatment, the one that worked, would be three trips to the pharmacy and two to the hepatitis clinic.

For those who are avoiding it

That said, waiting was not so easy. It's a time spent wondering why I couldn't feel comfortable to tell people that I have this disease, and that's why I hide my toothbrushes away from accidental use by others.

The awkward explanations to new partners, when you aren't exactly sure how much risk you are asking them to take.

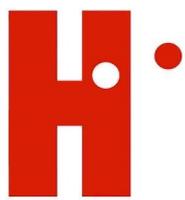
The mornings after too many drinks the night before when you wonder if this really was the time that you'd finally done it to yourself, that the next fibroscan would come with bad news.

And so, like most people faced with the fear of bad news, I tried avoiding it, missing scans and not chasing referrals, hoping my fears away. Finding out that I no longer have anything to avoid, no longer need to worry about some future where my luck runs out really was such a release.

The last reason...

The last reason I'll give is not really a specific argument against why a person might refuse to take treatment. It's really just to say that the moment when the specialist looked at my results and turned casually saying, yep, you're cured - there was a tone he had like there was never any other possibility - that was one of the most incredible moments of my life. Thirty-three years of carrying this disease with all the strange sense of shame, worry and wondering what might happen into the future evaporated like it never happened. And that's a feeling you really do want.

On reflection it's the lack of drama in this story that's the real point. After so many years the end was so easy and ordinary.



Haemophilia Foundation Western Australia
presents...

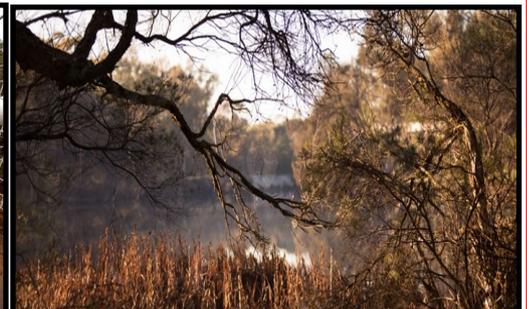
Community Camp 2018



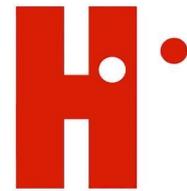
SWAN VALLEY
ADVENTURE CENTRE



W.A.Y.



Registrations close Wednesday, 28 February 2018.
Don't miss out!

2018**WHAT'S
ON?****Friday, 16 March to Sunday, 18 March 2018****HFWA Community Camp**

See the Camp details on page 8 and the Community Camp
Registration Form on page 9.

Come and join us - don't miss out!

**SWAN VALLEY
ADVENTURE CENTRE****Tuesday, 17 April 2018****World Haemophilia Day**

Trafalgar Bridge and Perth Bell Tower lit up!



2018:

 quarterly youth events	 quarterly women's group
 quarterly men's group	 Bleeding Disorders Awareness Week
 World Hemophilia Day	 parents and family meetings

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

Arved Wasser Memorial Fund - information and application form

HFWA invites applications for the Arved Wasser Memorial Fund for the 2017 / 2018 financial year. If you would like to apply to the fund please complete the application form on the next page. This must be returned to the HFWA office no later than Thursday, 31 May 2018.

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 below. Criteria for eligibility may loosely be described as any means of 'self-betterment'.

Arved Wasser Memorial Fund 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. Applications close Thursday, 31 May 2018. Funds will be approved and paid to recipients by Saturday, 30 June 2018.
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 (on the form on the next page or request an application form from the HFWA Office Coordinator on 9420 7294 or by email office@hfw.org) 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, 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