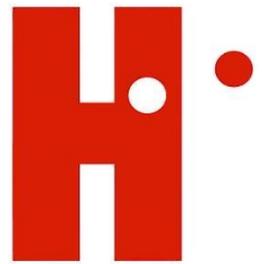


Contact



Newsletter of Haemophilia Foundation WA Inc.

April 2018



HAEMOPHILIA FOUNDATION WA INC.

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Your Committee

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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'.

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 Nursing Staff: **Natalie Gamble-Williams and Stacey Hutchison**
Ph: 9340 8682 or 0466 318 286
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FIONA STANLEY HOSPITAL CONTACT DETAILS



Clerk Front Desk: **08 6152 6542**
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 Nursing Staff: **Sandra Lochore, Lara Olson**

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);
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 Level 1 Cancer Centre
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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 all,

A big thank you to Pam, Brian, Sharri, Aaron, Roma, Cheryl, Susie and all those who helped to make HFWA's Community Camp such a great success. A great time was had by all (see photos and articles from the happy campers).

Unfortunately our office co-ordinator has left us for greener pastures, we currently have Kelly Cant filling in so feel free to contact Kelly and welcome her.

I hope everyone celebrated and recognised World Haemophilia Day on 17 April and lit everything up red. This year's theme is **Sharing Knowledge Makes Us Stronger**. This year HFWA was able to light up the Bell Tower on the Esplanade and Trafalgar Bridge in East Perth. Unfortunately they are servicing the lights at Council House so we were unable to light it up.

A late reminder for the Men's and Women's Breakfasts on Sunday, 29 April (see page 18 for details).

The World Federation of Haemophilia Congress is in May this year and there should be some great Updates or new research or treatment advances arising from that. I look forward to reporting on those in the next Newsletter.

If you have been sent out appointment letters and are unable to attend, it is most important that you advise the Haemophilia Treatment Centre (HTC) that you are unable to attend your appointment. The HTC can then re-book your appointment. If you miss three appointments, you will be required to get a new referral from your GP.

The staff at FSH Treatment Centre are meeting with the Dental services to confirm services to be provided to our community and there will be some changes. We will advise once we have heard the outcome of this meeting.

When attending clinics, take the opportunity to ask your health professionals about new products coming to market and advise them if you are interested in participating in any clinical trials that may be offered through your HTC.

Until next time.

Gavin

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Community Camp 2018 Feedback - Col Sternberg

My family and I had the great pleasure of attending the 2018 WA Haemophilia community camp held at the Swan Valley Adventure Centre.

This was the first time we had attended the foundation's camp, and we all agreed that it was a fantastic experience.

The opportunity to spend time with families living with haemophilia; talking and listening to their stories was really eye opening and gave us great insight into this blood condition and how it affects the day-to-day lives of families. The same can be said for the timeline presentation, which was a great education.

The camp itself was fantastic on many levels. The location was excellent with great facilities and activities to keep everyone continually engaged.

My daughters had loads of fun canoeing, riding the flying fox, running the muddy commando course, scaling the high ropes (although I could have done without that!!) and generally running amok.

It was so enjoyable to see all the kids make new friends and being so active over the weekend (no screens ☺). The spy theme and activities were fantastic and it was great fun to join in these with the kids.

The camp was really well organized and run, and all people involved should be very proud of what they achieved.

By far the biggest takeaway for my wife and I was witnessing, and feeling, the very strong sense of inclusiveness and support that was evident all weekend.

We both found the men's and women's meetings amazing events due to the people involved being so open and willing to educate, share and help each other, as well as going out of their way to make everyone feel welcome.

Overall, the camp was tremendous fun, lots of laughs and fun activities, a great education and a fantastic introduction to a wonderfully supportive community.

Looking ahead, we very much look forward to attending future camps and being more involved with HFWA.



Community Camp 2018 Report - Brian and Pam Wall

Yet another camp came and went. This year our spy theme 'Mission Possible' camp delivered many challenges in both code, puzzles and self. It was a fun weekend with a lot to do and set in an amazing green environment.

Thanks to all that came and made it another fun experience to get to know more about each other and for some to be introduced to HFVA camp life.

As facilitators of the camp, we work very hard and very mindfully trying to push boundaries, cushion experiences and test campers' abilities to try something different.

Big thanks to Sharri and Aaron Brodie, previous committee members and camp volunteers for spending the time and energy to deliver some amazing activities and code solving problems for camp.

To Roma and her sewing machine - many thanks for all your stitches of love.

To Lena, Courtney, Emily and Aaliyah - thanks for your time and effort of adding in your own specialised touches and knowledge to our camp connectedness.

To Cheryl and Susie - let's put our hands together for keeping our bellies full and putting together our sleeping arrangements.

From Brian and Pam - thanks for making our Haemophilia community AMAZEEEE ing!

Remember to be yourself, and keep in contact everyone. That's what's communities and families do!



Canoeing Youth Report - Belinda Broughton

Hi all,

W.A.Y held another youth event - this time it was combined with our camp. One of our main goals was to really focus on team work, and I believe the canoe activity helped achieve that.

Before we got into our canoes, our Swan Valley instructors told us we would need to work together as teams to turn and move the canoes the correct way. With groups of twos or threes, it was really about communicating well and relying on each other to guide the canoes the correct way.

Eager to jump in and start exploring the river, we lined up and dragged our canoes in one by one. It was really calm and peaceful rowing on the river, and after a while, we found a nice place to link up for some morning tea. A few thrill seekers got to stand up in their canoe and race along the river. It wasn't long before we had a few tipping their canoes over into the muddy water. To my displeasure, I was one of them, but I must admit the muddy water cooled us down and gave us something to laugh about.

We rowed for a few more hours and then eventually headed back to camp where we all made it back in one piece.



Camp Photos

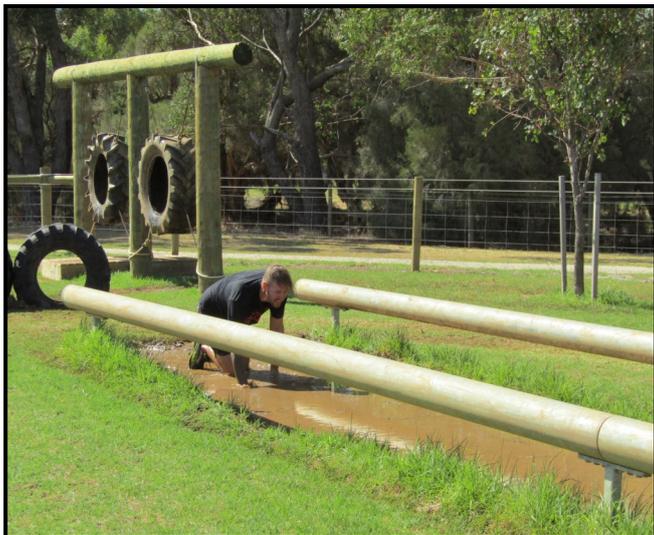


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Camp Photos



Camp Photos

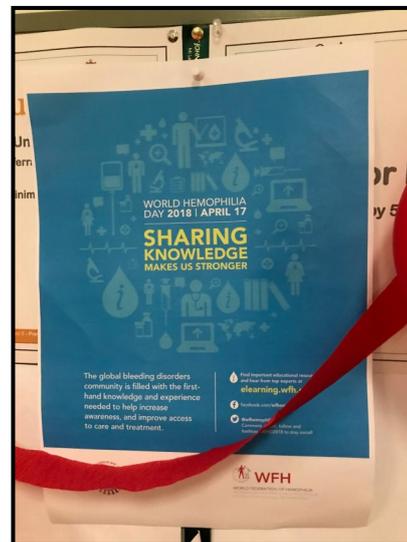


Camp Photos



World Haemophilia Day Morning Tea - Robin Dique

This morning my team at the Restorative Unit, St John of God Mt Lawley held a morning tea for World Haemophilia Day 2018. All of the staff pitched in to bake amazing cakes, slices and cupcakes raising \$240.85 by way of gold coin donations for Haemophilia Foundation of WA. We focused on the this year's theme **Sharing Knowledge Makes Us Stronger** and distributed resources from the World Federation of Hemophilia to all that attended. My team have shared our journey of Charlie's diagnosis of Haemophilia A and treatment, and continue to support us by raising awareness in the community.



Every April 17 World Haemophilia Day is recognised worldwide to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH) which chose to bring the community together on April 17 in honour of WFH founder Frank Schnabel's birthday.

Conference 2017 Report - Janelle Coe

I was given an amazing opportunity to attend the 18th Australia and New Zealand Conference on Haemophilia and Rare bleeding disorders in October 2017. I arrived on Thursday in Melbourne and headed to the Pullman Hotel to check in for the Conference.

I was lucky enough to stay with a fellow mum, Jacqui, who I am very close with, so I felt blessed to be able to experience this with her.

Firstly, we were greeted by the lovely Natasha from HFA and got our info packs and passes. We walked through the Exhibition opening and met other members and employees of the foundation of many other states. It was amazing getting to know and see so many people living what we are going through. It was reassuring also, seeing all the amazing youth who attended. They are an inspiration for parents to see they are just like other youth, having fun with life along with the challenges that come with it.

At the meet and greet, Jacqui and I talked to many people including many whom are members of a Facebook page that we had created, called Haemophilia Families Australia. It was nice to put names to faces and actually meet some of these amazing people. We also met new people; inspirational people who I am forever grateful to have had the opportunity to meet. David, I'm talking about you.

On Friday it was a bright start with Dr Justin Coulsen – 21 Days to a happier family. His speech was based mainly around how his family work, live and enjoy life together. I took from his speech to enjoy the time we spend together, actually enjoy it, not on an iPad or watching TV but actually spending quality time with family. Go camping, read a book together, play, whatever it may be and however it works for your family just don't miss out. He was entertaining and well spoken, it was a good start to the first of many speakers.

After this was a quick break and catch up at morning tea, then off to the first of two concurrent sessions for the day; hardest part of these is choosing just one. The three choices were Hep C/HIV, Genetic Testing and Youth Myth Busting session. I was mixed with this lot as I wanted to see the genetic testing for more information towards my daughter and her future testing, but ended up going to the Youth Myth Busting session. This was a panel of youth, health and medical professionals discussing their views on myths surrounding bleeding disorders. It was very interesting how the view differed depending on who it was from. The medical professionals were direct and factual, the youth were more defiant and not wanting to be put into a separate category due to their conditions and the parents were, well parents :) Overall, another great session; entertaining and educational.

On to lunch, with a few more discussions around what we had seen and different opinions surrounding what we heard and took from each session. The next sessions to choose between were Von Willebrand disorder, Evolving Concepts in Pain Management and Starting the Journey with a child newly diagnosed with a bleeding disorder. I chose the Starting a Journey session. We although not so newly diagnosed, (4 years on), are still learning every day how to deal with our situation, so this was a great session discussing many valid points, including not blaming yourself as a parent about what your child is now going through. Personally as a mother, how can you not, right? Anyway, this was good in just discussing that we all go through those same feelings at the beginning and it is completely normal and ok. I enjoyed listening to Dr Julie Curtin and Moana discussing many topics including children self-infusing at such young ages, which although daunting to me, the determination and strength some of these kids have is awe-inspiring. Lastly in this session, I got to listen to my beautiful and brave friend Jacqui talk about her journey with their gorgeous boy, and how although they faced many challenges, she and her family deal with each one with such grace and support for one another. It was lovely to see, as family support and encouragement is a powerful tool to have.

Afternoon tea was served next, so a quick break and chat before heading onto the next plenary on prophylaxis – prophylaxis as we call it. This was a great topic as our son is currently on prophylaxis treatment and it was good to hear about the improved quality of life that people on these treatments have. Our son is on 2nd daily prophylaxis treatment, so this gave me great hope that it will not only assist in preventing his bleeds, but also decrease the impact when he does have them. The less pain the better, and regular prophylaxis treatment does just that.

Conference 2017 Report - Janelle Coe (continued)

The dinner held on Friday night was a great evening. I enjoyed the company of many amazing men and women. Some were living as I am - a parent or caregiver. Some were living with a bleeding disorder and others medical professionals. It was a night full of laughter, some tears and just an overall feeling of community. The bonds I have created with some of these people in such a small amount of time will last a lifetime.

Day two arrived very quickly and started with the Men's and Women's separate breakfasts. The women's breakfast topic was around Mindfulness and was run by Sharon Caris and Dr Ira van Der Steenstraten. Dr Ira has had an incredible life journey so far as a woman with a bleeding disorder herself, which she shared with us. She gave us tips for living the best life we can by being mindful of ourselves and our bodies and of those around us, be it through meditation or just simply being aware and living in each moment as it comes.

The first plenary of the day was Women and Bleeding disorders. Dr Paula James spoke about periods/ menstruation and the impact this has on our lives, such as missing work and school due to heavy bleeding, pain and other symptoms which we may have due to being a carrier or also having a bleeding disorder. I found this session amazing not only for myself, but also gave me hints and tips to look out for in my daughter in future years. Dr James discussed many issues which shocked me, including how many women may go undiagnosed with a bleeding disorder due to thinking that a heavy period is ok. I have started following her Let's talk Period webpage. There is a quiz which can advise if your bleeding is normal or if you should have some tests to follow up, and I have referred a few friends to this quiz.

Quick break for morning tea followed by the second last concurrent sessions. We could choose between Ageing and Improving Care through My ABDR. I attended the Ageing sessions which discussed things like living with inhibitors, insurances, superannuation and other medical issues that arise as we age not just because of the bleeding disorders but because we age. For some of these issues we may be more affected due to having a bleeding disorder, such as arthritis due to joint bleeds. Discussion included ways to improve your life as you age by keeping fit and healthy to decrease the risk of bleeds and other ideas for a greater quality of life.

Another amazing meal in lunch from the Pullman and it was onto the final concurrent for the conference. The choices were Healthy Joints, Women and Telling Others, Free Papers. I attended the Healthy Joints session spoken by Alison Morris & Abi Polus. This discussion spoke about what can occur in joints, causes and how they are treated. They spoke about different sports and what their risks or pros are and what sports are suggested and what are not. At the end of the day they advised if you're not sure or are wanting to do something that may be considered risky to discuss it with your HTC and decide an action plan between you. Not everything works the same for everyone; an individualised plan for each person is best, as what works for one doesn't always work for another.

Afternoon tea and the final plenary session to finish off the conference, and what better way to do so than to discuss the Here and Now of Upcoming Treatments. This session was made up firstly by Paul, who discussed his experience with being on extended half-life product, which decreases the frequency of infusions. Next was Dr John Cahill, who discussed the costs involved with the supply and purchasing of new treatments, cost effectiveness and a look into funding of new medicines. Dr Huyen Tran was up again to talk more about some of the upcoming treatments. He discussed further extended half-life factors, injections done subcutaneously (meaning not having to find a vein) and other new treatments which may become available in the near future. It was amazing to think of what it holds for our boys. Lastly was Professor John Rasko, who finished the session by talking about Gene Therapy. Effectively talking about a "cure" – along the lines of turning severe bleeding disorders into a mild or moderate category. Ultimately a great way to finish off the conference.

Finally it was onto many bittersweet 'goodbyes for now' and home to let the information all sink in. I am so grateful to have had the opportunity to attend the conference. If you've ever thought about it, all I can say is do it!! Meet some new people who genuinely get what you are going through and gain some valuable information through this amazing experience.

Our Haemophilia Camp Experience - Grit Andre

Our whole family was so excited when we got the email saying there would be another Haemophilia Camp this year. Not only did it mean we were off to Perth and could do some decent shopping, but we could also spend a fabulous weekend with our Haemophilia family.

On our way down to Perth 1600km+ (Aussie's would say "just down the road, mate"), we got into the spirit of things and decided our cool 'Spy names'. We wondered what the organizers would have in store for us this year.

We really liked the new location of the Swan Valley Adventure Camp. What bliss to see so much green around. Yes, we are deprived of that in Port Hedland. The location was beautiful and the set up of the whole camp was well laid out.

On arrival, we were lovingly greeted by everyone and quickly got reminded of this year's theme. It was just like a Saturday Night out with all the fingerprints and pictures taken! The kids loved it and started behaving like spies. We got to our dorm rooms and they started looking through the envelopes and goody bags for the next clue.

Bradley remembers the kid's puzzles and games. He and Daddy played them, as I apparently, was having a good night with the other ladies. I sure did. It is always nice to just sit in a group with ladies and exchange stories, experiences and share advice on all things life.

Saturday started early, and after breakfast we were right back into problem solving and puzzle making. I remember two of our team members spent half the night on that big puzzle. Nothing scares us!

Romi got the opportunity to go canoeing on the Swan River. Her feedback was along the lines of: "I totally wanna do that again!" It was good that there were different activities for different age groups. Rubi and Bradley enjoyed kitchen gardening and planted seeds, followed by arts and crafts for the Movie Night later that evening.

I really enjoyed the Timeline workshop that the adults attended. It was interesting to go back into time and see how people with a bleeding disorder were living back then. The life expectancy in those days really shocked me, and it just shows how medicine has evolved over the years to give us access to factor now and doing treatment at home.



Cheating at it's finest



Andre Family starts camp



Code solving and puzzle making

Our Haemophilia Camp Experience - Grit Andre (Continued)

The afternoon was one we will not forget for a while. They said bring old clothes, but little did we expect to look and smell like little pigs. It was so worth it! Here was this 'Obstacle Course', like an army commando course, where you picture "The Rock smashing it and still looking good in his muddy half torn apart T-shirt". Well let me tell you, all teams smashed that course and most of us looked rather muddy and some of us lost some shoes to the track. I did ask the kids on our drive back to Hedland about this obstacle course and what they loved the most. "It was so much fun!" And "I loved the slip and sliding long run at the beginning", as well as "I loved the mud slide into the brown water", were some answers I got.

We also had Sister Lee visiting us that afternoon. It brought a smile to my face seeing all the kids giving her hugs and I could tell she enjoyed catching up with everyone.

After everyone got cleaned up and had some delicious dinner, we concluded the evening with our cheerleading abilities and talent show. The kids all got together with Popcorn and drinks for their movie night.

Sunday was truly Funday for the kids. My three chose Junior High Ropes and Flying Fox. You can't beat that. The smiles on the kid's faces said it all. After the kid's activities we all got together to figure out our last clue and celebrated another successful camp.

I am truly grateful for being able to participate in these camps. I remember six years ago when we attended the first one and did not know anyone or did not know what to expect from fellow Haemophilia families. After our first camp we felt part of this community, which go through up and downs in life just like any other family, but you always see a smile on their faces. The strength and support that comes from our community is second to none. Thank you to the Haemophilia Foundation WA for organizing events like this, for all the volunteers who work hard to make this happen, and our community for supporting each other. Can't wait for the next camp!



Romi & Youth Mentor Belinda casting off



Timeline adults session



Grit commando Style

Community Camp 2018 Feedback Article - Lena Smith and Paul Keogh, Blaize, Aurora and Phoenix

Wow! What an amazing camp, full of fun and adventure.

The achievements that Blaize, Aurora and Phoenix made in the activities were phenomenal!

The camp is like a family milestone for us, where we see the growth of our children. We saw Blaize break away from us to make his own friends, going non-stop on the flying fox and becoming an independent young man, with doing his own injections.

The girls were so proud of themselves doing the kids high ropes course and joining in with the cheerleading performance.

For Paul and I, it's especially important to feel connected with this community, talking to other families and learning about their experience because we find that is the most helpful support. Also finding out what new treatments are coming and any other information we may not have thought to ask about!

Above all, my favourite was not being pregnant! Being able to get involved with the physical activities, the mud run and the high ropes course.

At times, Blaize believes he is the only person with Haemophilia, so I find coming together like this helps him connect with the other boys which we call 'blood brothers'.

We have a rich family history of haemophilia, and its heritage can be traced. With having this particular gene, I love that we can follow who has the gene and that we can really appreciate that we have the same blood. Even though we may be distant relatives, our blood is the same and we have all been through these experiences, trials and joy (more trials in the past!) that are associated with having Haemophilia.

It was the best camp we have experienced and that is all because of the wonderful people and community we are a part of. So thank you Pam and Brian, Sharri, Aaron and family, and everyone who contributed to making this an amazing camp. We are very grateful for this entire community.

*Lots of Love,
Paul, Lena, Blaize,
Aurora & Phoenix*



Travelling with a bleeding disorder - Alannah Meotti

Being a carrier of both Haemophilia and Von Willebrand disorder, I guess it is no surprise that I am 'symptomatic'. My levels hover between 17% and 21%, so I often have issues that need treatment. I respond well to DDAVP, but in the past I have been guilty of putting off treatment simply to avoid the hassle of travel and the time-consuming drip that was required. I was thrilled to find out about the new sub-cutaneous injections, as they are so quick and easy to administer.

Recently, I was fortunate to take three months long service leave. Hubby and I planned a caravan holiday with a route that was taking us a long way from any Haemophilia Treatment Centre. I was a bit concerned at the possible implications. The haemophilia treatment centre at FSH kindly set me up with product and equipment, which really put my mind at ease. The vials are tiny, so I put them in a small Tupperware container to keep them safe in the Waeco fridge.

We followed the Murray River on our path east. After visiting Canberra and Sydney, we headed south then west, staying on the coast mostly for the return. Highlights for me included Bourke's Bend on the Murray River in VIC, Pretty Beach in NSW, Aire River in the Otway National Park in VIC, and Lucky Bay in the Cape Le Grande National Park in WA.

Alannah Meotti



Bourke's Bend – Murray River



Kayaking on the Murray River



Pretty Beach – NSW



Cape Le Grand - WA

MEN'S BREAKFAST INVITATION

Gavin Finkelstein & Dale Spencer would like to invite you to a Men's Breakfast
please see below for details:

VENUE: Waterwall Restaurant, Pagoda Resort, 112 Melville Parade, Como WA 6152

TIME: 8.30am

DATE: Sunday 29 April 2018

RSVP: by Tuesday 24 April

Kelly at the HFWA office on 9420 7294 or office@hfwa.org
or Gavin on 0415 978 031 or gavfinkelstein@gmail.com

The Men's Breakfast is funded by HFWA and free to financial 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 Kelly 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 BREAKFAST INVITATION

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

VENUE: Straits Café, Rendezvous Hotel, 40 The Esplanade, Scarborough WA 6019

TIME: 8.30am

DATE: Sunday 29 April 2018

RSVP: by Tuesday 24 April

Kelly at the HFWA office on 9420 7294 or office@hfwa.org
or Cheryl Ellis on 0402033652 or vice_president@hfwa.org

The Women's Breakfast is funded by HFWA and free to financial members



Disclosure and Telling Others - A Personal Story - Susie

Susie is an Australian community member. She has von Willebrand disorder (VWD) type 1 and her son has VWD type 3.

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

My nickname growing up was 'Susan Shut Up'. I even answered to it. I'm a talker, I talk with my hands. I love chatting, asking questions, sharing stories. But I want to tell you about when I couldn't talk. When as a person who speaks their mind and always seems to have something to say, I literally couldn't speak.

I work in a large office. It's not dangerous work. I don't have a risk of injury due to tools, danger, hazards. I don't need to wear protective equipment. But one day, I left the office in an ambulance. I fell down the stairs. I'd been walking down on my own, nothing in my hands, no distractions. As I fell, of course I thought I was only stumbling on one step and I'd right myself. But I didn't. When I came to a stop I realised I couldn't move. I couldn't call out. I could barely even breathe.

Luckily the stairs were internal stairs in our wonderful open plan office – glass surrounds and plenty of visibility. And luckily that day, I wasn't wearing a skirt.

People came running to my aid – thankfully I wasn't stuck there on my own in pain with no way out. But the thing was, I couldn't speak. I could not explain what had happened. I couldn't explain what I was feeling. What was wrong or what I needed. I was literally speechless. I couldn't say I'm OK, I couldn't say I'm not OK.

So, to go back a bit, I have von Willebrand's type 1. I was diagnosed only after my baby was diagnosed with type 3 and the doctors were wondering how that happened. I'm a classic case of plenty of symptoms but no diagnosis. I know now that I have a diagnosis, that I need check with my HTC in the event of injury. But when this happened I couldn't explain this to anyone.

I spent a while on the stairs with work colleagues who came to my aid. They acted quickly and really quite confidently, assigning roles as per our Emergency Response Guidelines. They attempted to glean from me some info and were calmly checking for injuries. I could not fault the way my peers helped to work through what had happened and what I might need. As the plans progressed and it became clear that I needed medical assistance, something important happened.

My manager was there on the stairs with me and she was able to take the extra step of calling the HTC to speak with the Haemophilia Treatment Nurse to report my injuries and work out a plan. This is when disclosure helped me. And not filling out a form, tick a box. This kind of disclosure I mean is how I went about telling her. This had been a conversation that wasn't held only once. It had been a series of chats, and was varied.

We'd talked about my son with type 3. She had supported me when I needed to take time out for appointments. When I'd needed to field calls from his teachers. We had talked in general terms about my diagnosis journey. And these conversations weren't intrusive. They were caring, based on the facts of my situation, my needs at the time and her level of responsibility for me as well as interest.

Disclosure and Telling Others - A Personal Story - Susie (continued)

She was not only my manager but also the floor first aid officer so she had a vested interest in knowing what might be required of her in just such an event. During these conversations, she had asked simple questions about my condition, the treatments and response plans that helped put it into context. She had never dealt with a bleeding disorder before so she was learning, busting her own myths and misconceptions. I never felt I was being judged or penalised for having a condition that might need additional requirements.

The practical things we talked about were the different types of von Willebrands. What the severities meant. What the treatment options were and why some things helped in certain situations and why others didn't. We have an active blood donation program at work and we talked about how crucial that is to my son for a normal life and when I've received product too. We talked about the advances in treatments, or the lack of them. We talked about DDAVP. We talked about how simple first aid 'stepped up a notch' is a way to approach understanding treatment. We talked about the realities of symptoms and, how they for the most part, are confidently managed and don't take over my life.

But we also talked about risks about what can go wrong and why appropriate care and trauma response is so crucial.

So what else was going on here? I had already learned that as a person with a bleeding disorder I needed to be my own best advocate, both for myself and as a parent of a person with a bleeding disorder. But crucially, sometimes you need to plan and have contingencies for others to advocate for you. By having these conversations with my manager I had thought we were talking about my world my needs. I hadn't realised that by doing this I was helping her in her world, her needs, when they intersected with mine.



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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

2018

WHAT'S ON? H.

Tuesday, 17 April 2018

World Haemophilia Day

Trafalgar Bridge and Perth Bell Tower light up!



Pictures courtesy of the Scolaro family

Sunday, 29 April - 2018 Men's Breakfast - 8.30am

Waterwall Restaurant, Como WA 6152

Join Gavin & Dale for breakfast and a chat

Sunday, 29 April- 2018 Women's Breakfast - 8.30am

Straits Café, Rendezvous Hotel, Scarborough, WA 6019

Join Cheryl, Pamela & Susie for breakfast and a chat



2018:  quarterly youth events
 quarterly men's group
 World Hemophilia Day

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

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@hfwa.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

Entertainment Books 2018/2019

Haemophilia Foundation Western Australia Inc. is raising funds. Here's how you can help...

We're raising as much as we can to support Youth Group Activities and while the new 2018 | 2019 Entertainment Books will be available from 1st May 2018, the Entertainment Digital Memberships are here now. Instantly access hundreds of valuable offers OR pre-order your Entertainment Book today and receive over \$180 worth of Early Bird offers.



Haemophilia Foundation WA

Contact: Kelly Phone: 08 9420 7294 Email: office@hfwa.org

To order your Book or your Digital Membership securely online visit:

www.entbook.com.au/847b23

Alternatively, please complete your details below:

Name: _____ Phone: _____

Email: _____

Address: _____ State: _____ Postcode: _____

Perth Edition \$70 including GST: # _____ Book(s) &/or # _____ Digital Membership(s) \$ _____

Post my order \$12.00 TOTAL ENCLOSED \$ _____

Payment Type: CASH VISA MASTERCARD CHEQUE (payable to *Haemophilia Foundation WA*)

Credit Card Number: _____ / _____ / _____ / _____ Expiry Date: _____ / _____ CVV*: _____
*CVV is the 3 digits on the back of your credit card

Cardholder's Name: _____ Signature: _____