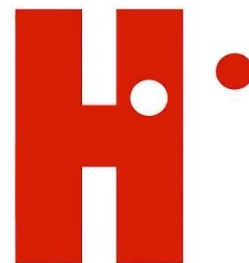


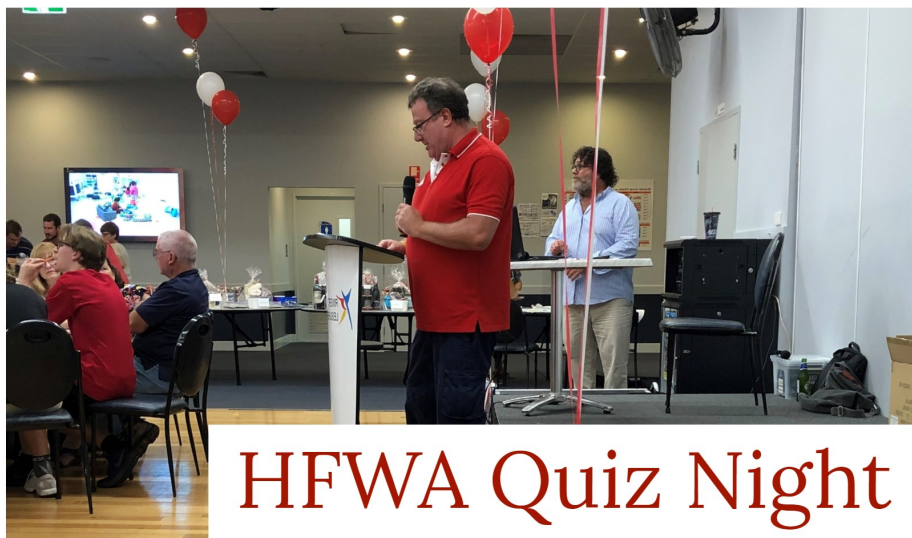
Contact



Newsletter of Haemophilia Foundation WA Inc.

December 2019

HFWA Quiz Night



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
Dale Spencer
Paul Keogh
Michelle Dinsdale

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

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

Cover picture

HFWA Quiz Night with Russell Woolf and Michelle Dinsdale

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

PERTH'S CHILDREN'S HOSPITAL CONTACT DETAILS

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

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

Nursing Staff: **Natalie Gamble-Williams and Stacey Hutchison** (Monday -

Thursday, 8:00am—4:30pm) Ph: 6456 0170 or 0466 318 286

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

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

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



FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**

Medical Staff: **Dr Stephanie P'ng** and **Dr Dominic Pepperell**

Nursing Staff: **Sandra Lochore, Lara Olson**

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

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



Entrance to the Cancer Centre is on the outside of the building
Haemophilia and Haemostasis Centre
Level 1 Cancer Centre
Fiona Stanley Hospital
102-118 Murdoch Drive
Murdoch WA 6150

Postal Address (address all correspondence as Private and Confidential);
Haemophilia and Haemostasis Centre
Level 1 Cancer Centre
Fiona Stanley Hospital
Locked Bag 100, Palmyra DC WA 6961

Opinions expressed in Contact do not necessarily reflect those of the Foundation. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFWA reserves the right to edit articles as it sees necessary. Material supplied on the internet is for information purposes only and is not to be used for diagnosis or treatment.

President's Report

2019

Hi All

I hope everyone is well into the hectic time for the end of year festivities and looking forward to catching up with family and friends over the coming weeks?

HFWA had a great Christmas End of Year function held at Adventure World in Bibra Lake, we had over 60 people attend and had some special visitors including Santa, and his able sidekick/elf (Sharri) (see page 7 for more photos from the day).

HFWA held our very hectic and successful annual Quiz night on Saturday 16 November. The event, which was hosted by the always entertaining Russell Woolf raised an amazing \$6,500 to help fund our Community Camp coming up in March 2020 (see page 8 for more on the night).

We look forward to seeing as many of you attend the camp as possible. The Community Camp always presents many great opportunities to meet new friends, reconnect with old friends, and see how members of our community deal with bleeding disorders and don't forget it is also a great opportunity to have a good time!

A reminder that the World Federation of Hemophilia Congress is being held in Kuala Lumpur, Malaysia from June 14 - 17, 2020. The World Federation of Haemophilia Congress, being the biggest bleeding disorder meeting for patients and community to attend, presents great opportunities to find out what is happening with treatment products including updates from other countries. It is always a wonderful event to meet those from all over the world, see how they live their lives and deal with their bleeding disorder - often using limited amounts of treatment products.

The team at HFWA are looking forward to a busy and productive 2020!

Wishing everyone a merry Christmas, happy Channuka or just a great opportunity to take a break and spend time with family and friends.

Gavin

HFWA Membership fell due on 30 June 2019

The HFWA membership period runs from 1 July 2019 to 30 June 2020. HFWA is committed to the promotion of Haemophilia and related bleeding disorders on a State, National and International level.

Being a member entitles you to:

- Membership to Haemophilia Foundation Australia
- Receive the quarterly newsletter
- Access to library resources
- Shoe subsidies
- Access to peer support activities
- Subsidised Medic Alert emblem

The cost of membership is \$25.00, payment can be made over the phone or online.

Please see enclosed the 2019/20 membership form

HFWA AGM and New Committee

The HFWA AGM was held on 19 September 2019. Sean Matthews from WA Primary Health Alliance spoke to members about My Health Record and the benefits of having the service, how to log onto the service and the security in place which protects your information. If you would like further information about My Health Record, please email Mel in the office at office@hfwa.org to receive some information.

It was pleasing to see a large contingency of members and stakeholders at this year's meeting. The President, Treasurer & Office Coordinator tabled their reports and it is good to see that the Foundation is ticking along quite nicely and in a comfortable financial position, which is encouraging in today's financial climate.

We received seven nominations for committee members at the AGM and all nominees were elected to the Management Committee for 2019/20. Positions and office bearers were elected at the first meeting following the AGM. There was nomination received at a later date which was also accepted.

Your current Management Committee comprises of:

Gavin Finkelstein, President; Cheryl Ellis, Vice President; Bob Butler, Treasurer; Shane Meotti, Secretary; Susie Couper; Michelle Dinsdale; Dale Spencer and Paul Keogh.

Please go to the HFWA website to view the 2018/19 Annual Report.

Bunnings Sausage Sizzle

We held our annual Bunnings sausage sizzle at Bunnings Homebase in Subiaco on Saturday 19 October 2019. This annual event has become a stalwart for Bleeding Disorders Awareness Week throughout the years and proves to be an effective way to raise awareness of haemophilia and other bleeding disorders.

Once again our many loyal volunteers turned up to cook and sell sausages in a bun and talk to the public about bleeding disorders. The staff at Bunnings Homebase are always happy to see us and keen to help us, especially once the onions start cooking.

Thank you to everyone who volunteered and those who donated drinks for us to sell—we can't do it without your help.

Pencil in Saturday 17 October 2020 for our next sausage sizzle— We look forward to seeing you there!



PROBE for real-world evidence



The real-world PROBE study is now available!

What is the impact of haemophilia and treatment on Australians? How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

The **PROBE (Patient Reported Outcomes Burdens and Experiences) study** is a great opportunity for you and others in our community to give this evidence.

What is PROBE?

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

You may have done the PROBE survey in the past. This was testing the survey. In 2015 Australia joined more than 20 other national haemophilia organisations around the world to successfully test and validate the questionnaire. The international PROBE team is led by well-respected haemophilia organisation and academic investigators.

This time the PROBE study is collecting real-world evidence. Statistics from Australians who complete the questionnaire will be provided to HFA by the international team for us to use in our advocacy and planning for the future.

How can you help?

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

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

You may also like to pass the survey on to your partner/wife/husband or other members of your family or interested friends.

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

Continued next page

Probe Study Continued**How to do the survey**

The questionnaire is available:

Online at <https://stage.mcmaster.plus/PROBE/>

Or ask your local Foundation or HFA for a print survey pack

**What happens to your data?**

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

More information

For more information about the **PROBE study in Australia**, visit

www.haemophilia.org.au/research

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173

HFWA Community Camp 2020

GREAT NEWS!!!!!!

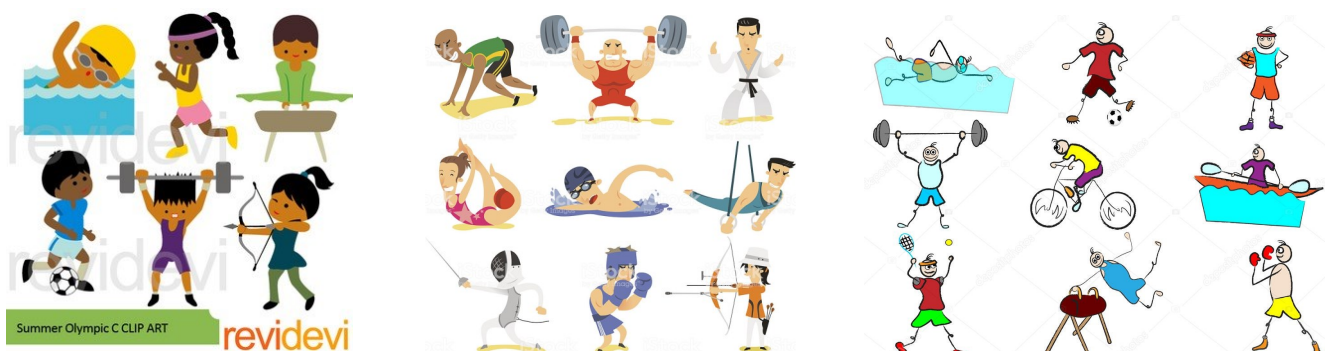
Thanks to a very successful quiz night and a handful of volunteers, camp 2020 is **BACK ON BABY!!!!**

The date for camp is March 20-22.

The camp theme is "THE RED OLYMPICS" so be prepared for some crazy sporty fun.

So we can organise the best activities around numbers and ages, please complete the expression of interest form over the page.

All HFWA members are welcomed and encouraged to attend.



HFWA Community Camp 2020 Expression of Interest

Expressions of interest are being sought for Camp 2020 at the Swan Valley Adventure Centre. This is an opportunity for you to catch up with the haemophilia and bleeding disorder community.

Please complete the form below to indicate your interest and return to:

Haemophilia Foundation WA
City West Lotteries House
2 Delhi Street
WEST PERTH WA 6005
Email: office@hfwaw.org

Name:			
Address:			
Phone:		Email:	
What information and activities would you like at camp? E.g. Services available, future products, venous access workshop, gene therapy.			

HFWA Nail Polish Gift Packs— perfect for Christmas!

Looking for that personalised gift with a real message for family and friends? Look no further! The perfect gift for Christmas is here, with single and three bottle packs of nail polish available.

Gift Packs

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



\$20 pack

Assorted Colours

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



\$10 each

HFWA End Of Year Christmas Party

This year HFWA hosted the End of Year/Christmas Party at Adventure World. Sixty community members attended on a lovely warm day.

The pools, waterslides and extreme rides were a hit with the kids (and the adults). We hired an area which had two nice shade sails and families brought along their beach tents. As usual Santa visited with the help of an elf and the kids had a great time opening their gifts and playing with them for the afternoon.

We would like to thank Adventure World for looking after our every need and a BIG THANK YOU to all our wonderful volunteers who helped with tasks on the day.



HFWA Quiz Night

HFWA's Quiz Night at the Riverton Leisureplex on Saturday 16th November was a cracker! In what is becoming a tradition for HFWA, this year's event did not disappoint. We were extremely fortunate to have Russell Woolf host the evening and keep everybody well entertained.

Thanks to the generosity of businesses and people listed below we had 90 silent Auctions and 30 raffles as well as games, lucky dips and plenty of give-aways during the evening, and not forgetting the fantastic quiz and door prizes. The Coin Toss game in the main break was very popular with a massive queue of people all wanting to win the bottle of Glenfiddich. The Reverse Raffle and Red Lolly Guessing were also very popular.

In total the quiz night raised approximately \$6,500 which will go toward running another fantastic family camp in March next year.

As with these kind of events, success only comes after a lot of hard work. This year's event was put together by a small organising committee and some fantastic and hardworking helpers. Without doubt Jenny Holliday retains her crown as the undisputed Fundraising Queen of the world, followed very closely by Cheryl Ellis. Without Jenny and Cheryl organising prizes and donations the event simply would not have occurred. Joining them on the organising committee was Susie, Michelle, Mel, Shane and Gavin and a big thankyou goes out to Mark, Xavier, Sharri, Aaron, Will, Joss, Vince, Darren, Taj, Jake, Ben, Ann-Maree, Victoria, Pam, Bill, Christine, Neil & Jenny, Bob and Jennie for all their hard work to set up the venue, help during the event and pack up and clean at the end of the night.



The West Australian





**HFWA would like to thank YOU & the following generous Donors & Sponsors
(Please forgive us if we have forgotten anyone)**

Anaconda	Nextra Forum West Newsagency
Ann-Maree Foran	Nici Burgess
Anonymous HFWA Members & Friends	Noel Leerson
Araluen Botanical Park	Perth Explorer Tours
Aurora Pools	Perth Mint
Baker's Delight Kardinya	Perth Motorplex
Bill & Pam Aitkins	Perth Racing
Blue Steel Workboots	Perth Wildcats
Bob Butler	Porkies Bar-B-Que Gosnells
Brownes Dairy	Pot Black Cannington
Bunnings Homebase Subiaco	Red Rooster
BWS West Leederville	Retravisision Kardinya
Cockburn Ice Arena	Riverton Leisureplex
Coles Kardinya	Rockingham Wild Encounters
Craig Foran	Rollaways
Dome Café Kelmscott	Shane Meotti
Fogarty Wines	Sheryl Butler
Frame Sports	Speedo Australia
Fremantle Dockers Foundation	Steve Hindley
Fremantle Prison	Terry White Chemist Kardinya
Fremantle Tram Tours	The Gate Bar & Bistro
Gloucester Park Racecourse	The West Australian
Grand Cinemas Warwick	This Above All Hairdressing
Helen O'Gradys Drama Academy	Thornlie Automotives
Holliday Family	Tony & Sylvia James
Impressions Paint Store Kardinya	U Reeka No More Dog Grooming
Jungle Gym	WA News (Seven West Media WA)
Kmart Kardinya	WASO
Laser Blaze	Wizard Warehouse Pharmacy Booragoon & Kelmscott
Meotti Family	Woolworths Kelmscott
Muzz Buzz	



Haemophilia in the 21st Century - “Challenging the Status Quo”

My son Beau (4) was diagnosed with Severe Haemophilia A when he was eight months old. I attended the latest conference held in Sydney from 10-12 October 2019. It was a privilege to be a delegate at the conference to learn from global experts and see that patients can truly enjoy a quality life with the latest treatments and technology.

Haemophilia A&B was discovered in 1947. At the time, treatment was blood transfusions which took days and exposed patients to various risks associated to blood transfusions. Today, we have extended half-life and subcutaneous products and gene therapies becoming available, and medical advances continue. I was also very excited to learn that we will soon have access to an “app” called MYWAPPS to determine factor levels.

MYWAPPS was designed by a team of 15 people and two universities and is already in use by over 4,000 patients globally. There is no other database available like MYWAPPS for factor levels. MYWAPPS allows patients to determine factor levels and bleed rates which in turn allows for tailored treatment plans (with different protection levels) to suit individual needs. The App can give clear indications of predicted factor levels and can be configured to send reminders. I am looking forward to seeing it available for the patients in Perth soon.

We were able to attend various presentations that we felt would be suitable and having a four year old I think learning a lot about the time line of events - from being a toddler up to primary school when they start to do their own factor - has a lot of benefits as children with chronic illnesses usually have limited understanding in pre-school about their illness. Supporting your child by providing a supportive home and environment and playing a key role in emotional support is the way parents can assist. Parents also become the key link between the health professionals and the child. It is of vital importance to balance autonomy with independence and to help adolescents manage their own illness without conflict by making sure skills are transferred from parents to young adults once the bulk of the education is done early on in life.

A session was held on reproduction and family planning where young families that are looking to have more children or children can make use of genetic counselling that is available as each family is unique. If you are considering more children, non-invasive testing is also available, so please get in touch with your Haemophilia Treatment Centre (“HTC”) for more info.

After two busy days and a lot of information, we had Dr Happy that came to remind us to be grateful again. I was grateful for Haemophilia and grateful to know that future treatment and research are in very capable hands.

“Challenging the status quo” can be a great way to get ahead.

Julene Bets

Attending the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders

My husband Dave and I attend the Sydney 2019 Conference. It was great to catch up with people I haven't seen for a while, and to meet new people from other states living with haemophilia.

I enjoyed learning about the current treatments/care and the future products to treat haemophilia. Listening to ageing with Haemophilia was very good, taking good care of your body, and slowing down (like that's going to happen, wives/ partners with older guys would know how hard it is to get them to slow down) Eating properly and losing weight helps their joints. I didn't know that when they have an elbow bleed, it bleeds into three joints. The humeraulnar, humeroradial, and proximal radioulnar, resulting in a loss of 50% motion and 80% function of the joint.

There was a lot of information about how gene therapy is being studied; it seems maybe in the near future they may find a cure. I hope so, I watch Dave every day in pain. I am glad that the younger guys don't have the pain and joint damage that the older guy's live with. It's good to hear that they can play sports and do exercise something Dave can't even think about doing, even when he was younger the joint bleeds/damage limited his physical ability.

I enjoyed the conference and learnt a lot, I would like to thank HFWA for the conference funding, the HFA, and everyone involved. And the food was great.

Tammy Bell

As it had been many years since I had attended a haemophilia conference, I took the opportunity to apply for the community conference funding through HFWA. I was successful in my application and was fortunate to attend the 19th Australian conference held in Sydney.

It was great catching up with a few old faces from my past involvement with the HFWA/HFA and meeting with other attendees. The venue was spot on with views overlooking the Manly beachfront, a very nice place to spend a few days. It was good to see the sandgropers in full force, with just over a dozen Western Australian members attending the conference.

As is the case at most conference's digesting and understanding the volume of information, presented at the sessions can be difficult. I won't pretend that I understood everything that I heard, but I did get a lot of things that I found of interest to me. The first session was improving outcomes; this was a timeline of the history of haemophilia and related treatments/current treatments that PWBD access today. There are exciting and interesting times ahead in gene therapy for the management/possible cure of bleeding disorders. I remember one of the speakers made a statement at the 1999 conference in Fremantle, that gene therapy was 10-15 years away; it seems it wasn't far off. Twenty years on and the general feel was it seems very close. Positive results and success in clinical trials are making inroads into this treatment pathway. With many members in the wider bleeding disorders community participating in these trials, may be one day we may be able to look forward to a future without haemophilia?

Focus on optimising patient care through PK testing was also discussed, with the focus on utilizing PK testing in conjunction with modern IT technology to calculate and tailor individual's treatment plan/dosage. Considerations in lifestyle/activity to help better manage bleeding episodes, and or enabling prophylaxis treatment to be more effective.

Continued next page.

Attending the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders cont.

Another session I attended was getting older. HFA are currently undertaking a needs assessment based on the ageing population within the bleeding disorders community. I found this very interesting as I am one of the current generations of people living/ageing with haemophilia. A bit of a catch 22....I feel it's a nice problem/challenge to have, given we are the first generation of PWBD to outlive our life expectancy.

Past generations living with haemophilia/bleeding disorders endured either no treatment/limited treatment, then able to access plasma derived products available in the 1960's-90's. As most would know the bleeding disorder community lost many members, due to the impact of HIV/Hep C in the 1980's passed on through blood products.

The evolution of safe treatment products and the advancements in medicine/care mean most of us now live a normal life. However this brings a new challenge, as the patient and health professionals now face the complexities of managing the bleeding disorder as well as the complications of other comorbidities, health conditions, surgical procedures etc. that the non PWBD ageing population also face.

Maintaining independence and keeping up exercise was discussed. As we all know the importance of trying to stay as active as possible, even given your joint limitations, it not only benefits our joint health, but our health overall. Growing older with your HTC was also discussed, as it plays a vital role in managing your bleeding disorder, but also creating an appropriate care plan. The HTC can liaise with your GP/health professionals to address any future health concerns/issues etc. Also the importance of mental health was discussed as this can also be impacted due to the overall decline in your health/loss of mobility/loss of independence/isolation and the associated impacts due to ageing.

Another session was managing a healthy diet and weight. We all know the importance of a healthy diet/weight. We all seem to go off track now and again with our eating habits. It was valuable hearing the nutritionist reinforcing the importance of a well-balanced diet and tools and tricks to help shed a few kilos and maintain a healthy weight, and to help avoid weight gain. Even a 5%-10% weight loss is clinically meaningful.

Exercising safely at all ages was discussed; I felt the session was very good for the younger generation with no joint damage. This demonstrated first hand results with the use of a HTC/physiotherapist educated personal trainer working with a PWBD, it was noted that factor usage and bleeds decreased in patients with a lifestyle change and regular exercise program. Dr Happy, aka Tim Sharp gave a talk on the importance of our mental health, and provided some examples, tools and tricks on maintaining a positive outlook in what can be a very challenging world that we live in today.

Joint care and treatment- surgical options were discussed, as I have had a few of the procedures that were discussed I found the session very interesting and informative. With the discussion on ankle fusion particularly interesting, as I maybe considering this in the not too distant future. Ultrasound has been recognised as a valuable tool in monitoring joint health. Ultrasound is a great tool for detecting early changes in joints and has the ability to detect visual synovitis. Ultrasound is inexpensive, accessible, provides early detection of changes, can confirm a bleed or arthritis? And is in real time as a HTC trained member can use the machine, enabling quarterly/annual or more frequent reviews in managing joints.

Continued next page.

Attending the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders cont.

Current treatments and the longer acting half-life products were discussed, as was future products. As mentioned before gene therapy was discussed with positive results. Non-factor replacement treatments are having very good results. Instead of replacing the factor that is deficient, these products increase thrombin levels in the blood, which mimic the factor clotting chain. Concizumab, Fitusiran and Hemlibra are some of the drug names from the different pharmaceutical companies, these products are all in the trial stage but they seem to be very successful. Interesting times ahead as these products are administered subcutaneously either weekly or monthly.

The conference theme was challenging the status quo, I feel that everyone who attended got the vibe that we may be very close to some big changes in the treatment of bleeding disorders in the very near future?

The conference sessions were very interesting and I enjoyed my involvement at the conference. I enjoyed the social/support sessions the most. I got a lot from them, and hopefully I gave back to others by sharing my own life experience/knowledge.

Thank you HFWA for the opportunity to attend.

Dave Bell

Getting Older Community Survey

Let's talk about getting older!

We invite you to take part in the HFA Getting Older community survey.

HFA wants to hear from:

- **people with bleeding disorders**
- **and their partner/family or friends/carers**

about the needs they may have as the person with a bleeding disorder gets older.

Let us know what your concerns are around getting older and what would help now and in the future!

Your answers to the HFA Getting Older survey will help us to understand and respond to the impact of getting older with a bleeding disorder.

You can do the survey online at <https://www.surveymonkey.com/r/GOPsurvey2019>

Prefer to do a print survey?

Contact Preetha at HFA to have a print survey posted to you, if you need help doing the survey, or if you have any other questions about the survey:

email pjayaram@haemophilia.org.au or phone 1800 807 173 (tollfree).

If you complete a print survey, please complete one print survey per person.



Women's Breakfast

Susie Couper, Cheryl Ellis and Michelle Dinsdale would like to invite you to a Women's Breakfast

Date: Sunday 16 February 2020
Time: 9:00 am
Location: TBA
RSVP: to Mel in the office on 9420 7294 or office@hfwf.org

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



Men's Breakfast

You are invited to a Men's Breakfast with Gavin, Shane, Dale and Paul from the HFWA Management Committee

Date: Sunday 16 February 2020
Time: 9:00 am
Location: The Waterwall Restaurant, Pagoda Hotel, 112 Melville Parade, Como
RSVP: to Mel in the office on 9420 7294 or office@hfwf.org

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



Save the date

Sunday 16 February 2020 Men's & Women's Breakfasts

Friday 20 to Sunday 22 March 2020 "The Red Olympics" Camp

Saturday 28 March 2020 HFWA Strategic Planning Day