National Haemophilia
Haemophilia Foundation Australia
www.haemophilia.org.au
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2019 CONFERENCE

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PROBE

Patient Reported Outcomes Burdens and Experiences Study

YOUR EXPERIENCES WILL MAKE THE DIFFERENCE

It's not too late to complete the PROBE (Patient Reported Outcomes Burdens and Experiences) questionnaire!

The survey is available at https://tinyurl.com/PROBE-Australia.

There is also a print version of the survey – contact Suzanne at HFA to have one posted to you.

HOW WILL PROBE HELP PEOPLE WITH HAEMOPHILIA?

PROBE is a multinational study where Australians can give evidence about living with haemophilia and the impact of different sorts of treatment on their bleeds, pain and quality of life.

HFA will use the data to better understand current issues - and this data is crucial for our treatment advocacy.

You are invited to complete the survey if you are an adult Australian and:

- **you have haemophilia**
- **or you DON'T have a bleeding disorder (as a comparison group)**

Consider being involved to help us with this important study!

ANY QUESTIONS?

For more information about PROBE in Australia, visit www.haemophilia.org.au/research/probe-study

Or contact Suzanne at HFA:
E: socallaghan@haemophilia.org.au
T: 1800 807 173

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

2019 CONFERENCE

It is hard to believe the Conference is over and it is December already. In this publication you will read my Conference reflections and the reports of some of the sessions presented. We are grateful for the Conference Program Committee, chaired by Dr Liane Khoo, and the speakers, chairs and others who made the Conference a success. If you missed out on getting to the Conference you can read many of the presentations on the HFA website. We haven't yet decided where the 2021 Conference will be located but will let you know as soon as we can.

HFA AWARDS

The HFA Awards Program recognises special service given to the bleeding disorders community in Australia. It was my great pleasure to announce three important Awards during the Conference dinner on 11 October.

HFA Volunteer Awards were given to Donna Field and Cheryl Ellis. Donna is a member of Haemophilia Foundation Victoria. She lives with her family live in Neerim South in country Victoria. Donna started a bleeding disorders awareness campaign there ten years ago for Bleeding Disorders Awareness Week. She called it **Paint the Town Red.** Donna and her family and friends bake red cakes and sell them along with a sausage sizzle to raise funds and community awareness about the impact of bleeding disorders on families. Further, through her work with the Bendigo Bank she has partnered with work colleagues to raise awareness and funds that have been channelled to the community for family camps and peer support. Donna was not present at the Conference, but her Award was later presented by Sharon Caris and Natashia Coco at a dinner held for Donna and her family with HFV representatives on 18 November.

The second HFA Volunteer Award was presented at the Conference dinner to Cheryl Ellis. Cheryl has served on the Haemophilia Foundation Western Australia (HFWA) management committee for 14 years and as the Vice President for ten of those. She has completed over 800 hours of voluntary service and has been a tireless fundraiser for HFWA. Both Donna and Cheryl are wonderful volunteers and have made a great difference in our community.

The HFA Ron Sawers Award is given to a doctor or scientist who has made a significant contribution towards improving the quality of life for people with bleeding disorders through dedicated work promoting and supporting clinical excellence or undertaking significant research. It is named after Dr Ron Sawers, who developed and championed high standards of haemophilia care throughout his 40 years of service at the Alfred Hospital in Melbourne. It was my great pleasure to present this award to Dr Simon McRae, Director of the Haemophilia Treatment Centre at the Royal Adelaide Hospital, for his leadership in South Australia and nationally as the Chair of the Australian Haemophilia Centre Director's Organisation (AHCDO) for several years.

2020 WFH WORLD CONGRESS

14-17 June 2020, Kuala Lumpur, Malaysia

We had a very special time in Australia when we hosted the 2014 WFH World Congress in Melbourne. The 2020 Congress is not in Australia, but it is close by. If you haven't made it to a World Congress and want to get to one in our region, why not think about attending the Congress in Kuala Lumpur. HFA will reimburse the registration fee for the first five community members who have registered for the Congress, and do not have any other funding support.

TREATMENT PRODUCTS

I am disappointed that the National Blood Authority (NBA) has not yet announced the outcome of tenders for clotting factor products which was called earlier this year. Following the recommendations of the Medical Services Advisory Committee (MSAC), extended half-life factor VIII and factor IX were included in this process and we have people awaiting the outcome and opportunity to use them for their treatment. The first of these products were registered for use in Australia in 2014 by the Therapeutic Goods Administration (TGA) yet they are still not available as a clinical choice for all who could benefit from them.

Fortunately, the NBA agreed to an expanded access program which enabled limited access, but there are many people who would benefit but do not have access as yet. There is no news either about Hemlibra which is a non-clotting factor registered in Australia for people with haemophilia A with and without inhibitors to factor VIII. This treatment has made a significant difference to the lives of many already through clinical trials or compassionate access, and HFA has made submissions to MSAC and directly to the Health Minister to seek funding. I truly hope this has been resolved before the next publication of *National Haemophilia*.

40 YEARS HAEMOPHILIA FOUNDATION AUSTRALIA

This year is the 40th year of Haemophilia Foundation Australia (HFA). Over the years we have represented and supported the bleeding disorders community in Australia and internationally. As a community we have worked together on the struggles and the achievements of those years and we invite you to join us in reflecting on them.

This article is a short summary of some of the key milestones, and we look forward to sharing more stories and reflections in the next 12 months.

By 1979, state/territory societies had been representing people with haemophilia locally in Australia for 20 years, and we still hear many stories of lasting friendship and peer support since that time.

From humble beginnings in former HFA Executive Director Jenny Ross's dining room, HFA has made an impact in many areas, affecting the lives of people living with a bleeding disorder and their families. Only recently, Jenny recalled the extraordinary time at the start of the AIDS epidemic in 1984 when HFA was suddenly transformed from a small national organisation to an active and respected member of national and international teams struggling to understand and deal with the issues – this was a time of great upheaval and sadness.

1. The HFA AIDS Press Conference in 1989
2. The first HFA meeting in 1979 at Jenny Ross's home (left to right Ted Troedson, Neville Acklom, Alison Bellamy, Bevlee Cassell,Jenny Ross AO, Alan Ewart inset)
3. Ita Buttrose opening the first HFA office in Hawthorn 1986

4. Our volunteers welcomed the world to Melbourne.

People are living longer than ever before and the future looks very different for many in our community.

Since then there have been advocacy campaigns for improved treatment and care, and many collaborations, some lead by our community to new address issues as they have occurred. While treatment for HIV and hepatitis C improved, the legacy of blood borne viruses has been profound.

Our older community members gave their blessing for children to have first access to treatment prophylaxis sooner to prevent or reduce bleeds. As a result, health outcomes and quality of life have been better for some people in younger generations, in comparison to those who lived through earlier times and experienced treatment product rationing due to supply shortages. Many people in our community still live with the complications of joint damage, poor mobility and pain. Since 2004 supply has been steady, and after a long campaign, we entered a new era of recombinant clotting factor for all, including prophylaxis for adults where this was appropriate.

A significant milestone for HFA was to win its bid to host the World Federation of Hemophilia World Congress in Australia and we had great pleasure introducing the global bleeding disorders community to Melbourne and Australia at the 2014 World Congress.


NATIONAL HAEMOPHILIA

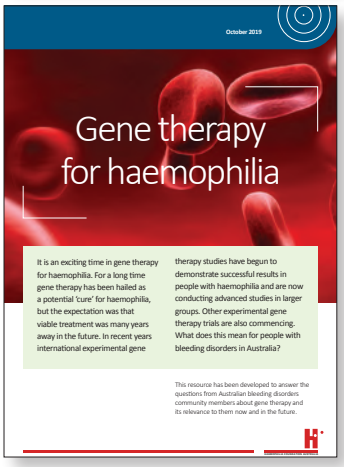
MAJOR TREATMENT PRODUCT BREAKTHROUGH

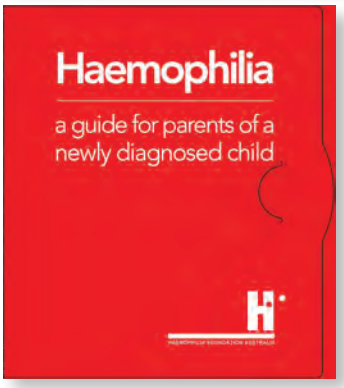
A NEW ERA FOR HAEMOPHILIA

We are entering a new decade. For people with bleeding disorders in Australia these are exciting times, with groundbreaking new treatments becoming accessible and gene therapy and other promising treatments in advanced clinical trials. People are living longer than ever before and the future looks very different for many in our community.

To all those who have contributed to HFA over the years and have made it the organisation it is now – thank you!

HFA will recognize the challenges and celebrate the successes of the past 40 years when it releases a series of short videos to mark the different chapters in our growth and development during the next year.





WORLD AIDS DAY 2019

World AIDS Day is marked globally on 1 December to raise awareness in the wider community about the issues surrounding HIV and AIDS.

In 2019 the World AIDS Day national theme was **Every journey counts**.

A TIME TO REMEMBER

In 2019 HIV continues to be a part of our community's experience.

The bleeding disorders community suffered greatly when it became known that HIV had been transmitted through blood products in the mid-1980s, resulting in illness and loss. Many individuals and their partners, families and carers still feel the effects of this. World AIDS Day is an opportunity for everyone in the community to reflect and to provide support.

For those of you who live on with the challenges of HIV, we recognise your strength and your determination to work together to create a supportive community for all affected by HIV.

UNAIDS' theme for World AIDS Day 2019 was **Communities make the difference**. It highlights the important role of the community as leaders to enable all people living with HIV to lead healthy and productive lives free from the harmful effects of stigma and discrimination.

For more information about World AIDS Day, visit www.worldaidsday.org.au.

NEW GENE THERAPY RESOURCE

HFA's new resource **Gene therapy for haemophilia** was developed to answer the questions from our community:

- What types of gene therapy are used in haemophilia?
- How does gene therapy work?
- Is it a cure?
- How safe is it?
- Who can have gene therapy?

The information includes diagrams to explain simply how genes and gene therapy work.

Our thanks to the bleeding disorders community members and expert reviewers and our designer, Ray Hehr, who made valuable contributions to this resource.

This resource was funded by an education grant from BioMarin.

Gene therapy for haemophilia is available on the HFA website and in print. A print copy has been included with this issue of *National Haemophilia*. To order more copies, contact HFA:

E: hfaust@haemophilia.org.au
T: 1800 807 173
W: www.haemophilia.org.au

Challenging the Status Quo
Bleeding Disorders Awareness Week
13-19 October 2019
Red Cake Day

BLEEDING DISORDERS AWARENESS WEEK

Bleeding Disorders Awareness Week and Red Cake Day was held this year from 13-19 October 2019. Haemophilia Foundation Australia and Haemophilia Foundations around the country worked together to raise awareness about bleeding disorders.

We had many supporters to help us fundraise and raise awareness over the week. Bendigo Bank branches across Victoria joined in partnership once again and schools, hospitals, libraries, families and local communities around the country also took part to help spread the message.

THANK YOU NEWSLETTER

A newsletter highlighting all the events held during the week will be distributed to participants soon and will be available on the HFA web site. If you wish to receive a copy, please email Natashia at: ncoco@haemophilia.org.au

Thank you to everyone who participated in Bleeding Disorders Awareness Week and Red Cake Day activities!

BLEEDING DISORDERS AWARENESS WEEK AROUND AUSTRALIA

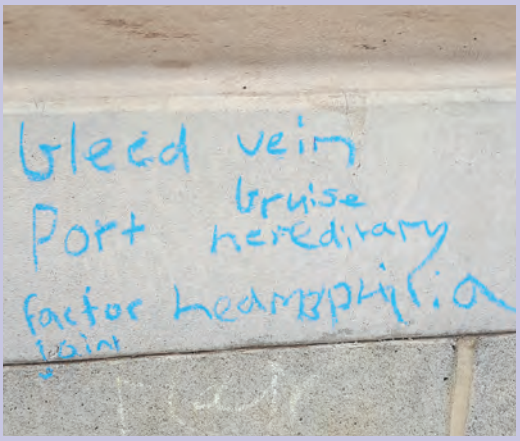
Hamlyn Banks Primary School

Today Hamlyn Banks Primary dressed in red. We are raising funds for Bleeding Disorders Awareness Week. The money that we raise will go to the Haemophilia Foundation Australia to put towards research.

At our school, we have two students who have haemophilia, Harrison and Callum. Their blood is different to other students because it does not clot, meaning the blood takes a while to stop. 'Every second day I have a small needle put into my vein, which feeds me the medicine and it helps my blood clot,' says Harrison.

During the week, all students have been learning how blood disorders affect people's lives.

Renee B – Grade 5 Hamlyn Banks Primary School



Red Classic, Albert Park Victoria

HFV hosted the Red Classic around Albert Park on a lovely Sunday afternoon. The sea of red looked great as people enjoyed a stroll and BBQ afterwards.

Paint The Town Red

Now in its 10th year, Paint the Town Red, was run by Donna Field and her family in Neerim South, Victoria. It was another successful day for Donna and family as they sold cupcakes, a sausage sizzle and anything red.

COLOURING-IN COMPETITION 2019

Congratulations to all the winners and thank you to everyone who participated.

Category **1**: children aged under 4 years - Benjamin NSW

Category **2**: children aged 5 to 8 years – Lilly Ann VIC

Category **3**: children aged 9 to 11 years – Ruby VIC

Preetha Jayaram is the HFA Getting Older Project Officer

GETTING OLDER PROJECT UPDATE

Preetha Jayaram

LET'S TALK ABOUT GETTING OLDER

My thanks to those who took the time to participate in our Getting Older Community Survey. This survey was part of our needs assessment and was a way to hear from the wider bleeding disorders community about what is needed and the strategies and services that would help with getting older. This survey was available online and in print and was mailed out to community members. It aimed to identify the range of related needs people with bleeding disorders and their partner/family or friends/carers may have as they get older. It asked questions about work/retirement, housing and insurance, aspirations for the future, information and education, computer use, support, and social connectedness.

We had a good response and are looking forward to the insights that will come from analysing your answers.

FOCUS GROUP WORKSHOP

In late November 2019 we held a community focus group workshop to consider online solutions, such as an online information hub on getting older with a bleeding disorder and digital peer support options.

It was productive day and the group gave valuable contributions about what an online hub should look like and include – and had some very creative ideas and frameworks. There was a lot of discussion about digital peer support options for the bleeding disorders community which left us with much to think about!

Thank you to the group for their hard work and inventiveness!

WHAT'S NEXT

HFA will be working on digital solutions for the focus group to test over the next few months and you will see the results of this in 2020.

The needs assessment report will be completed in February 2020 – watch this space for more information!

If you are interested in sharing your thoughts or have questions about the Getting Older Project, please contact Preetha Jayaram at HFA.
Phone: (03) 9885 7800
Email: PJayaram@haemophilia.org.au

The Getting Older Focus Group with Preetha and Suzanne

2019 CONFERENCE

The **19th Australian Conference on haemophilia, VWD & rare bleeding disorders** in October 2019 seemed to be enjoyed by all participants - in fact, informal feedback from delegates is rating it as one of the best!

The Conference was attended by people with bleeding disorders, their families and carers, health professionals, policy makers, industry representatives and other stakeholders who came together to meet, share information and learn from each other.

The diverse program was developed by a multidisciplinary committee chaired by Dr Liane Khoo and covered a range of interesting and challenging topics. We thank all the speakers and session chairs who contributed to our meeting.

CATCH UP ON THE PRESENTATIONS

Presentations and the abstract book are available to download from the HFA website - www.haemophilia.org.au/conferences.

CONFERENCE SPONSORS

Thank you to our conference sponsors and supporters.

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Conference Reflections

WHAT DID THE DELEGATES SAY?

'My second conference after Melbourne and the quality has been outstanding, probably the best one yet.'

'All sessions well planned, informative and thought-provoking.'

'Great topics, well-presented and informative for both professionals and patients. Loved the musculoskeletal as so relevant to all. And the speakers explained so well.'

'It is making me feel more connected to people with bleeding disorders. It has also helped me build on my confidence to advocate for my son.'

'Dr Happy made me think about developing a " happy goal".

'The titles of the sessions need to be more enticing. On paper it appeared quite boring, in reality the sessions were great.'

'As a health care professional, I found hearing the patient stories very motivating but also inspiring that we still need to do better. Opportunity to network is always invaluable professionally.'

'Was a fantastic three days, especially learning and meeting the new faces. Highly recommend to anyone thinking about coming to future conferences.'

HAEMOPHILIA HEALTH PROFESSIONALS REFLECTED ON THEIR EXPERIENCE AT THE CONFERENCE:

Conference

I was very lucky to have been able to attend the 19th Australian Conference on haemophilia, VWD and rare bleeding disorders in Sydney. As the Bleeding Disorders Nurse from the Northern Territory, I have always loved attending the HFA conferences, not only to update my knowledge of what is happening in the realm of bleeding disorders, but also to network with other health care professionals, patients and their families alike. The haemophilia conferences are the only medical conferences that I have attended that also invite patients and their families to join in. I think this is what makes the haemophilia community so unique and as a health professional, I find it incredibly inspirational to listen to the stories of patients and their family members.

Susan Dalkie, Bleeding Disorders Nurse – NT Royal Darwin Hospital

Remembrance service

This part of the conference program always moves me. We know that there are many people in our community who have been affected by loss due to a bleeding disorder. This service gives those people a chance to remember and acknowledge the loss of family and friends in our community.

I was touched by the readings, and the reflective space that the service created for all different members of the community to come together and remember. It is a way that we as a community can honour those who have died and those who have lost a significant other.

The bleeding disorders community has lived through a difficult time, and there are many friends and family members who are dearly remembered. As time passes those who remember can feel that others have forgotten. I felt the positive impact of sharing the memory of these people who have passed on.

Jane Portnoy, Social Worker – Haemophilia The Alfred hospital, Melbourne

Gavin Finkelstein is President, Haemophilia Foundation Australia

The 2019 Conference
- a foundation perspective

Gavin Finkelstein spoke with Suzanne O'Callaghan from HFA about his experiences at the Conference

SUZANNE:
WHAT WAS YOUR OVERALL IMPRESSION OF THE CONFERENCE?

GAVIN: It seemed to me that this Conference had something new and interesting for everyone who attended. The feeling was great. The venue lent itself to everyone engaging with each other and they really enjoyed that opportunity. Everyone was very excited and there was a real buzz. The theme of the Conference – **Challenging the status quo** – and the timing, and the topics and the way they were presented were all spot on.

Because there are now so many new types of treatments, and different types of treatments – bypassing agents, extended half-life treatments, gene therapy, to name a few – there is hope that treatment will be more precisely targeted at individual patients. Managing people's expectations will be important, and not just about whether there will be government-subsidised access to these new treatments. Not every treatment that is available is going to be suitable for every person: it's about targeting the right treatment to the right person.

..there is hope that treatment will be more precisely targeted at individual patients.

SUZANNE:

WERE THERE ANY SESSIONS THAT STOOD OUT FOR YOU?

GAVIN: I thought the ultrasound session was particularly good. For me it was the practicality - to see how it could be used clinically as a way to monitor joint deterioration over time and to take the opportunity to prevent further joint damage. Rob Russo demonstrated the ultrasound live on both a patient and a physiotherapist who volunteered to be on the stage. It was very visual: both the patient and the clinician share the diagnostic experience and I think seeing the evidence of the joint changes really hits home.

This to me is like the experience with MyABDR. You record your information into the system and you can track the details of your bleeds and treatments. With the graphs you can see for yourself the implications of treatments and bleeds. It makes it a lot more relevant to the patient and you can understand what is involved in your treatment regimen, what happens when you miss treatment and why it is so important to be compliant. It makes it a shared discussion about treatment and care between the patient and the clinician and has a two-way benefit. If you want a healthy and long life, you need to take some responsibility for managing yourself.

The happiness session with Dr Happy was also very good – enjoyable for everyone and gave some realistic options to pursue.

If you want a healthy and long life, you need to take some responsibility for managing yourself.

SUZANNE:

WHAT WAS YOUR TAKE HOME MESSAGE FROM THE CONFERENCE?

GAVIN: There are so many things happening across the board and a lot of it is really positive: there is gene therapy and other new treatment products, and for the first time we as a community are getting older. Our job isn't done. We need to make sure there is access to best practice treatment and care. This isn't just about access to the new treatments; if we are going to have best practice clinical care across Australia into the future, all HTCs need to be well-resourced.

There is a lot of work to do. It was great to see a new generation of young adults with bleeding disorders who are enthusiastic and doing well on treatment. They are now stepping up and wanting to be involved and take the advocacy work into the future – into the new world of the new treatments. And from my perspective this is really appropriate. My generation is getting older now and we have lived through a missing generation with HIV and hepatitis C that wasn't there to step into the breach with this work – it has been really hard to maintain the advocacy and representation through those losses and being tired and ill. This is a new world now and it is terrific to see young capable people who are prepared to take their life and their future into their hands.

Joshua Hutton and Joshua Wakefield are Physiotherapists, Royal Prince Alfred Hospital, Sydney, NSW

A physiotherapy perspective

Joshua Hutton and Joshua Wakefield

CHALLENGING THE STATUS QUO

The **19th Australian Conference on haemophilia, VWD & rare bleeding disorders** launched in a Galaxy Far, Far Away (the Manly Novotel) with Dr Liane Khoo's Star Wars flavoured opening address and recap of the history of management for people with bleeding disorders.

PLENARIES

The presentations across both days certainly kept true to the theme of the conference, **Challenging the status quo,** with extended crowd participation and engagement in many of the plenary sessions.

Plenary 1: Improving outcomes - what has been achieved in the treatment of bleeding disorders?
Professor Alfonso Iorio spoke about pharmacokinetic (PK) profiling software that utilises a vast database to accurately predict PK measures for individuals over time; a truly innovative and progressive development from the status quo.

Plenary 2: Dr Happy (Dr Tim Sharpe) – Challenging the status quo
Dr Happy (Dr Tim Sharpe) presented on the positive psychology movement and outlined 9 steps for leading a happy life. Intrigued by the prospect of 9 simple steps for happiness, members of the audience enquired further about the role of social media and technology in psychological wellbeing. Dr Happy outlined the need for perspective when using social media and highlighted the importance of mentoring and monitoring young people engaging with technology.

Plenary 3: Musculoskeletal challenges: joint care and treatment
We were once again enthralled by Dr Rob Russo presenting on the benefits of ultrasound in assisting with diagnosis of bleeds and arthropathy. The real-time ultrasound demonstrations with both a patient and a physiotherapist volunteer captured the attention of patients, families and health practitioners. This is truly an exciting time to be part of the bleeding disorders community! Dr Mark Horsley had the enviable job of presenting after Dr Russo, but managed to keep the audience locked in with a presentation on surgical interventions for arthropathy. Dr Horsley continued with the narrative that ran throughout the conference that prevention is always better than cure, and encouraged all patients and families to remain diligent in bleed monitoring, treatment and exercise.

Plenary 4 - New opportunities or is the status quo good enough?
Claude Damiani gave an insightful presentation on the impact of the ever-changing treatment space from a parent perspective and encouraged us all to consider the individual in making key treatment decisions. Advances in extended half-life products and gene therapy were of particular interest to many in the room; however, it was acknowledged that there are significant barriers to treatment development and access. Dr Simon McRae spoke about some barriers to access experienced in Australia including payment models, regulatory and policy considerations and the need for comprehensive, methodologically sound studies and a framework of comparison. Robyn Shoemark, the CNC at Westmead Children's Hospital, spoke about the role of nursing moving into the future. Robyn highlighted the important role nurses will play in the future, particularly in regard to communication with patients in the ever-changing treatment landscape.

SELF-MANAGEMENT

In addition to these plenary sessions, there were several concurrent sessions that attendees raved about during the breaks. The concurrent session **A healthy life for all ages** was particularly interesting with a great mix of presenter personality and information. Jules Aitken spoke about the issues around obesity in people with bleeding disorders and gave some very helpful tips around diet (which were swiftly forgotten come lunch time). In this session we also heard from Greig Blamey and Tim, but a little bit more about them below. The **Self-advocacy** session was facilitated by social workers Loretta Riley and Nicoletta Crollini and Dr Liane Khoo and was well attended by healthcare professionals, patients and families alike. Patients sharing examples of how they advocated for themselves was both inspiring and informative. Barriers to self-advocacy were also discussed and provided valuable insights for clinicians on how to facilitate an open, welcoming environment where we can provide best care to achieve best outcomes.

THE PATIENT JOURNEY

Patient stories were also prominent in the conference this year, and provided a valuable insight into the patient journey. John spoke about living with haemophilia for over 50 years, and explained how advances in medications and treatment approaches have changed his quality of life and function. John gave a fantastic account

1. Jules Aitken presenting on managing diet and weight
2. Australian and New Zealand physiotherapists with Greig Blamey at the Conference

of what it was like growing up with haemophilia and the isolation he experienced at times when there were contraindicated activities. However, he reports today that he is now more active and engaged in physical activity than he ever has been.

PHYSIOTHERAPY

Patients and clinicians alike were thrilled to learn that Greig Blamey had agreed to come to the other side of the world to attend as a keynote speaker. Greig is a Canadian physiotherapist who works with people with bleeding disorders and is the current Chair of the World Federation of Hemophilia Musculoskeletal Committee. His passion for not only treating but advocating for people with bleeding disorders is truly infectious. During his presentations, Greig explained the important role physiotherapy plays in maintaining good joint health by engaging and monitoring resistance and aerobic activity. It was refreshing to hear that the Canadian health system has begun to focus on the multidisciplinary treatment of haemophilia. He also highlighted the importance of patients communicating regularly with the multidisciplinary team to ensure that any bleeding events can be actioned early to prevent or reduce joint damage.

Greig spoke about the importance of working with an experienced physiotherapist to find an activity, sport or exercise regime that reflects the individual's function, medical needs, goals and interests. Greig used the terms **independent, pre-dependent** and **dependent** to categorise functional status and highlighted how different levels of dependence require different management plans to compliment people's goals and needs. In essence, the treatment of people with haemophilia-related musculoskeletal conditions should not diverge from the principles of exercise whereby people undertake a frequency, intensity, duration and type of exercise that is specific to the demands of their sport, activities of daily living or goals.

A salient feature of Greig's presentation was that extraordinarily gifted athletes exist in all populations and why should they not be afforded the same opportunities as their peers? This was a theme which also arose in discussions at the Australia and New Zealand Physiotherapy Haemophilia Group (ANZPHG) meeting held at the conference. Some outstanding therapists from Australia and New Zealand presented cases of fantastic young athletes competing at the elite level in their respective sports.

This idea made a world of sense when I stood next to some very impressive athletes and members of the community living with bleeding disorders who described their journeys and how beneficial sport and resistance exercise have been from musculoskeletal and social perspectives. Tim is a formidable athlete living with haemophilia who enlightened the conference attendees with his story so far. He is capable of squatting up to 200 kilograms and bench pressing 160 kilograms! Interestingly, Tim reports he experiences less bleeds now that he is training regularly; real-world evidence of a shift away from the status quo perhaps? Not only has Tim developed an impressive physique, he also works full-time as a paramedic, a truly inspirational character indeed. Tim noted that his progress in the gym and in a physically demanding occupation was not an overnight process, and went on to emphasise the importance of working closely with his multidisciplinary team.

The presentations across the Conference by all parties were enlightening and informative.

Thank you to Haemophilia Foundation Australia and the sponsors for a conference that was thoroughly enjoyed by all.

A psychosocial perspective

HIGHLIGHTS

Jane Portnoy
Jane Portnoy, Social Worker – Haemophilia
The Alfred hospital, Melbourne

Youth – what's the risk?
Chair: Dr Moana Harlen

Risk taking was the topic: the audience were asked to decide if a particular action was high, medium or low risk, and then three groups, a group of health professionals, a group comprising a young woman and a young man with bleeding disorders and a third group of a parent and an adult with a bleeding disorder, were asked to decide if a certain decision was high risk, medium risk or low risk. This was an interesting session with lively discussion and strong audience participation.

While there was agreement for many of the activities, there were lots of differences in the way that we assessed risk between the groups. Interestingly there was a less conservative perspective in the voting from the professionals, who felt that many of the risk levels were lower than the audience and the other groups. Some considered the question in the context of the person's general health, and even factoring in their hopes and dreams, their mental health, and acknowledging the cost of 'missing out'. Of course, for many people with bleeding disorders 'missing out' is very familiar, with the associated frustration, and sometimes compounding to lead to rejection of treatment, long term dissatisfaction and heartbreak.

Even if the ultimate decision is to not take a risk, acknowledgement of these other costs makes the decision more acceptable and easier to live with.

Self-advocacy
Chair: Loretta Riley

Loretta Riley developed the concept and led the **Self advocacy** workshop. It was presented in a fun way that successfully inspired participation, using the notion of a 'café'. Four tables were presented with different menus. These were colourful café style sheets, with First course, Main Course and Dessert as well as Drinks options. It stimulated curiosity and interest as patrons/participants sat down. We all wanted to be in this Café.

Participants were asked:

> **Please describe a moment when self-advocacy worked well for you.**
>
> **What resources/skills do you use to advocate successfully for yourself?**
>
> **What makes self-advocacy difficult and what ways could these be overcome?**

There was interesting analysis and sharing of experience. Through this the groups came up with extensive collections of ideas to share. I have included some of these here.

What are the skills or resources that you use to advocate successfully for yourself?

- Information and knowledge
- Understanding your rights
- Verbal communication skills
- Collaboration
- Remain objective – as if you do not, it may push people away
- Channelling the right supports and guidance as needed, including support services
- Understanding how to achieve the outcome
- Acquiring perspective
- Have trust in staff – social worker, nurses, GPs
- Connecting to your community
- Being analytical about what you're putting forward.

The Self advocacy workshop allowed for a sharing of information: although everyone has certain skills, there was much to learn from others. The strategies, approach and techniques used were diverse and successful in different circumstances. The ability to use a variety of different approaches also allows for more success.

The strategies employed when there were barriers allowed for diverse and creative approaches. There was animated discussion and a level of energy that is often needed in these situations.

There were some Ah-Ha moments when members of the group realized that someone else's strategy could be used in their own situations. Preparation and support were two ways that people overcame barriers.

Here are some of the possible solutions/strategies to use when there are barriers:

- No issue too small
- Preparation – questions to take into clinic
- Support – e.g., peer worker
- Build slowly before transition and in early stages after transition
- Have a short blurb prepared, '30 second elevator speech'
- Practice
- Trouble shooting with others – peers, for example
- Use your Foundation (for example) to link with the team (HTC)
- Build relationships with the HTC
- Taking someone with you
- Calm yourself before
- Prepare dot points before calling
- Using Foundation counsellor/HTC Social Worker or Psychologist
- Knowing who to talk to
- Dot points with information you have heard back
- To say back what you have heard
- Solution focussed – have a goal for the conversation.

Self-advocacy is a really important skill, particularly if you have a chronic illness. There are skills which you can build, and it really helps if you get support to do this.

HAPPINESS

Moana Harlen
Dr Moana Harlen, Senior Haemophilia Psychologist
The Queensland Children's Hospital

Dr Happy (Dr Tim Sharpe) – Challenging the status quo

Dr Tim Sharp (aka Dr Happy) introduced himself as the Chief Happiness Officer (CHO) of The Happiness Institute. This cheerful yet humble title reflects Dr Sharp's passion for promoting positive psychology, which he explained is the academic study that helps people to do more than survive, but to thrive and flourish and to live a meaningful and purposeful life even in times of adversity.

His presentation described 9 Habits for Happiness.

Habit 1. Create your own definition of what happiness really means to you.

Dr Happy discussed the importance of adjusting your versions of happiness over time. When the audience was asked 'how many people would like to be happier?' unsurprisingly there was a majority show of hands. However, this changed when the question was posed 'how many of you have a happiness plan?'. I wonder whether my plans to go camping and boating could be considered a happiness plan?

Habit 2. Set and work towards meaningful goals

Dr Happy reiterated that the stepping stones to a great life consist of developing SMART goals. I think we are all familiar with these but as a reminder, here they are:

- Specific – what do you need to do? (e.g. increase, make, improve, reduce, save, develop something)
- Measurable – how will you measure your goal? (e.g. how much, how well)
- Achievable – is the goal realistic? (e.g. do you have the resources and skills needed?)
- Relevant – is this goal in keeping with your broader goals? (e.g. why is the result important?)
- Time-bound – what is the time frame to accomplish your goal? (e.g. tomorrow, next month, etc)

Habit 3: Laugh, play and have fun

Dr Happy discussed research that has shown when fun and play are used in constructive and appropriate ways, it can lead to positive outcomes such as increasing the likelihood of working through problems.

To demonstrate that positivity can increase desirable behaviours, he presented a video on 'fun therapy'. It gave an example where simply adding some novelty feedback in the form of

fun flashing lights and messages to a drink disposal container increased the number of times people disposed bottles into the container to more than 100 compared to a rather boring ordinary bottle disposal bin which was only used twice.

I liken this to how children can develop a love of reading simply by experiencing warm positive feelings when a parent reads to them at bedtime.

Habit 4: Jump out of an airplane
Dr Happy shared his own personal feeling of joy when he once did a tandem skydive. He later reflected on this incredible experience as helping him to create a positive reaffirming belief about himself, that is, 'If I can do that, what else can I do?'. He further explained that to live our best life we need to confront adversity, because if we never take any risks we never learn.

I like to think of this as stepping (or being pushed) outside of our comfort (what is familiar to us) zone into our uncomfortable (stress) zone or we could view it more positively as our learning zone, which eventually becomes part of our comfort zone.

Extending on this, Dr Happy commented that it's not possible for parents to protect their children from everything; children will more likely develop resiliency skills if they experience boredom and frustration at times.

I can tick this box and say I have also jumped out of a perfectly good plane and found it the most exhilarating experience of my life. What did I learn, you ask? On reflection, I realised that a far scarier thing for me to do would be to go into a small underground cave and confront my claustrophobia but then again, sometimes it's also good to play to your strengths, I say.

Habit 5: Exercise your right to be happy
I love Dr Happy's play on words here. He goes on to say that the simplest mood enhancer is exercise; it is a stress buster and enhances positive emotions. Bodies are made to move; find some way of moving that you enjoy.

On the other side of the coin to exercise is a healthy diet, which Dr Happy succinctly phrased as eating more real food and less processed foods.

Habit 6: Sleep your way to the top
Good quality and adequate sleep is important. It's hard to be happy if you're tired all the time.

Habit 7: Ask for help
Dr Happy suggested that women are better at asking for help. However, he pointed out, if we want to be the best we can be, we can't do it on our own.

The stigma of mental health disorders such as depression is a barrier to men asking for help. It is of great concern that suicide is the leading cause of death for men under 45 years.

How can we best help each other? Dr Happy described a study that analysed interactions between patients with chronic pain and their spouses. Being a carer is one of the most difficult tasks there is, and carers have higher rates of depression. The study asked, 'What was the impact of how carers responded to their partners?' More specifically it looked at 'how my wife responds to me about how dysfunctional I am.'

Three broad categories of responses were found:

1. Angry responses were found to not be helpful to the person with chronic pain.
2. Overly solicitous responses, that is, doing everything for the person with chronic pain, made him become more dysfunctional.
3. Supportive responses, were those such as, let me help you to help yourself.

Findings showed the best interactions were where people help one another to become the best people we can become.

An important contributor to longevity is the quality of relationships: 'other people matter'.

Habit 8: Give help
Research into volunteering shows that giving help and doing good for others increases our feeling of wellbeing and improves our health and happiness.

Habit 9: Choose your focus
Dr Happy recommended that we take care about what we focus on – that we be cautious of focusing on what's

wrong with the world versus what's right. He asked us to consider the news, for example: how much of it is bad news? Perhaps it is time to stop watching the news and actively seek out good news regularly – and focus on what is relevant or important. To prove his point, Dr Happy provided video footage showing the many acts of love, kindness and courage which exist aplenty in our world.

This was a powerful reminder of how easy it is to get a warped picture of what happens in the world by only focusing on the negative; but by choosing to focus on the positive qualities of humanity, it can help us to gain a more balanced and realistic view of the world.

Another important aspect of this raised by Dr Happy was the impact of comparing ourselves to what we see on social media posts: where people only post their best face and the smiling and beautiful moments of their lives and we don't see what didn't go right, or the lumps and bumps of the rest of their life. He explained that comparing our messy imperfect lives with this curated reality will only cause feelings of inadequacy and it is important to recognise social media for what it is.

Practicing gratitude has become very popular, but what does the research say about its benefits? Interestingly, studies have confirmed that people who practice gratitude are happier people. One technique is to ask, 'what's the three best things that happened today?'

A key to self-development and self-improvement is knowing your own character strengths. Dr Happy provided this website where you can complete a free survey to find out your particular strengths - www.viacharacter.org. Give it a go.

There are other free tools and fact sheets on his website and he invited us to have a look if we want more information - www.drhappy.com.au

Habit 10: There's always more happiness than you think

This extra habit was a gift that Dr Happy gave to us in parting.

I left this presentation feeling inspired to make a happiness plan and to look at a meaningful way to apply the 10 habits.

Damon Courtenay Memorial Endowment Fund Funding Round Open

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established by Haemophilia Foundation Australia with financial support from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

A total amount of $20,000 is available as grants for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

WHO CAN APPLY?

- Anyone with a bleeding disorder or affected by a bleeding disorder who resides in Australia
- Patient support organisations in Australia, but preference may be given to individuals with high needs

The application form and guidelines for the Fund are available:

- On the HFA website - www haemophilia.org.au
- Or email hfaust@haemophilia.org.au for a copy
- Or telephone HFA on 1800 807 173.

The closing date for applications is **15 February 2020**.

Susan Dalkie is the Bleeding Disorders Nurse – NT, Royal Darwin Hospital

A nursing perspective

Susan Dalkie

The line-up of sessions provided at this Conference was one of the best that I have ever seen. There was a wide range of topics discussed, including future treatment options and clinical trials for patients with bleeding disorders, such as gene therapy for haemophilia. The challenges and issues faced with both the paediatric and aging populations with haemophilia were also interesting topics, along with joint care and healthy living options for all ages.

FROM GIRLS TO WOMEN

Chair: Susan Dalkie

Personal story: self-management, diaries, what a parent wants to know ~ Shauna
Female Factors - issues for different life stages and how to handle them ~ Dr Jenny Curnow
The gynaecologist and patients with bleeding disorders ~ Dr Kim Mathews
Carriers: What do parents, young girls and women need to know? ~ Joanna McCosker

I have a personal interest in women's health and bleeding disorders. Therefore, it was an honour to have been able to chair the Saturday morning session, **From girls to women**.

The session featured four different speakers who outlined issues that affect women and girls with bleeding disorders.

Shauna was our first speaker who shared her personal story with the audience regarding living with and managing her VWD. (see **Managing my VWD - Shauna's story** in this issue of *National Haemophilia*)

Shauna highlighted the fact that she was diagnosed with Type 3 VWD and with no apparent family history, her parents had to manage her symptoms the best they could along with support from their local HTC team.

Shauna pointed out the importance of keeping a record of her bleeding symptoms throughout the years to assist the HTC team in providing her with an appropriate and effective care plan.

Stepping into adolescence with Type 3 VWD as a girl was not easy. Shauna suffered from very heavy periods with haemorrhaging ovarian cysts. She voiced her gratitude to her women's health medical team working very closely with her HTC team in managing her symptoms.

She explained that over the years her treatment plan changed from her treating bleeds 'on demand' to changing over to 'prophylaxis' treatment. She pointed out that she had already suffered from previous joint bleeds, particularly into her knee which had caused significant damage. The decision to go onto prophylaxis treatment was to try to prevent any further joint damage and to manage her bleeding episodes more effectively.

Lastly, Shauna spoke about how she personally helps herself in dealing with the challenges she faces with living with VWD. She keeps herself well informed, she ensures she keeps the lines of communication open about her VWD, and most importantly she remains active, tries new things to see what helps her the most and continues on enjoying life.

Dr Jenny Curnow discussing the medical aspects

Both Dr Jenny Curnow and Dr Kim Matthews provided the audience with information on the issues women with bleeding disorders face during their lifetime; in particular, during the reproductive years. Dr Matthews also went into further detail, explaining from a gynaecological perspective the medical interventions available to help women manage menorrhagia, such as using the Mirena® IUD (intrauterine device) plus or minus in combination with the oral contraceptive pill and tranexamic acid.

Dr Matthews explained the importance of carefully monitoring these women during pregnancy and how having an effective treatment plan for the birth is imperative to prevent complications such as post-partum haemorrhage. She also mentioned that during the birthing process, due care must be taken to protect the baby in case he/she also has a bleeding disorder. Therefore, to prevent injury to the neonate, procedures such as suction and forceps delivery should not occur. Comprehensive care of the mother and baby will ensure the best outcome, which includes involvement from the paediatrics, haematology and obstetrics teams.

In my opinion, women with bleeding disorders are at times at a disadvantage due to the old fallacy 'women don't have bleeding disorders'; not all health professionals take their bleeding issues seriously. Luckily, this notion is slowly disappearing, but it is imperative that we continue to educate the wider community about these issues. I think both presentations by Dr Curnow and Dr Matthews covered this perfectly.

The last presentation of the session was by Joanna McCosker, Haemophilia Nurse Practitioner from the Queensland Children's Hospital. Many people are confused as to what defines a haemophilia carrier; however, Joanna's presentation beautifully explained the meaning of being a carrier in simple terms enabling everyone in the audience to understand. As with Dr Curnow's and Dr Matthews' presentations, Joanna pointed out the consequences of bleeding in this cohort of women and the importance of performing genetic testing early enough for them to manage and make informed decisions regarding their reproductive health.

One of the more important take home messages for me from this presentation was 'for every 1 male with haemophilia there are up to 5 female carriers!'

I thoroughly enjoyed chairing this session and found all four presentations excellent. It is reassuring to know that there are other clinicians around Australia advocating for women and young girls with bleeding disorders. With the provision of further support and education to patients, families and medical health professionals, these women have a bright future ahead knowing that their bleeding issues can and will be well managed.

'for every 1 male with haemophilia there are up to 5 female carriers!'

Shauna is an Australian community member with von Willebrand disease

Managing my VWD - *Shauna's story*

Shauna

This is a transcript of Shauna's presentation at the 2019 Conference

Hi everyone, thank you all for joining me today. I'm here to tell you a little about my experiences growing up as a severe bleeder and the challenges I have faced along the way.

As a baby learning to walk, I was progressively becoming covered in bruises with no known reason why. After I fell and cut my lip, the bleeding continued until I was taken to hospital via ambulance where I was diagnosed with type 3 von Willebrand disease. With no known family history of this condition, my parents carefully navigated through my upbringing, figuring things out along the way under the guidance of my haematology team.

GROWING UP

Growing up with von Willebrand's I've seen a great deal of change to my treatment plans over the years. My symptoms evolve as I age, and I have also experienced changes in my lifestyle that have required a different level of care. Keeping record of my changing symptoms helped establish new care plans, including updating contraceptive methods to manage bleeding, through to moving away from on demand treatment to a prophylactic routine to prevent ongoing joint damage.

As a child, my main causes for concern were nosebleeds, general knocks about, and weirdly enough, losing teeth. Much to the detriment of my parent's stress levels, though to my gain, they still allowed me to try out a great deal of activities, within reason. Contact sports were out of the question, but I dabbled in athletics, running and swimming until eventually finding a love for ballet, which kept me active and strong well into my early 20s. My parents were involved in educating my teachers on my bleeding disorder and ensuring I could also advocate for myself in an emergency if needed. Treating my bleeding disorder as an open topic for conversation has ensured those around me were aware of what help I may need.

Entering my teenage years saw huge changes in my bleeding concerns, facing heavy periods and haemorrhaging ovarian cysts. Fortunately, my HTC being based in the women's and children's hospital meant I had access to a great women's health team that could work closely in collaboration with my HTC. Once we found the right solution for me, I was able to get back on top of things and continue living a relatively normal life, as much as any teenager could say so! People often ask if this was difficult mentally, as most young women aren't thrilled about discussing the topic of their hormonal activity, especially with their parents. I consider myself lucky in some ways that this was my 'normal', because it meant there weren't any delays in seeking the right treatment. I also owe a great deal of thanks in that respect to my parents, who always faced the topic in an almost professional manner so that I never felt uncomfortable.

CHANGING TREATMENT PLANS

Due to a combination of the low frequency of my serious bleeding episodes as well as my families own personal choices, I grew up receiving factor on demand up until the age of 24. I had a relatively severe joint bleed in my left knee that reoccurred twice over the space of 6 months, and on investigation it was found that I had already started to develop osteoarthritis, probably from minor bleeds that went untreated over time in addition to the acute bleeding. Due to the restrictions this was already placing on my mobility I decided, with the advice of my HTC, that it was time to start a prophylactic routine to prevent any further damage to the joint.

While it is difficult to say how things might have been had I started prophylaxis earlier, I am in some ways glad that my treatment plan panned out that way. As I began treatment on my own terms, I see that this has helped with my compliance, there's no reason to rebel against the routine. It also means that I can more easily identify what is bleeding related or just a regular injury, because I can compare scenarios and how they felt without factor.

DEALING WITH CHALLENGES

In the same fashion as most of the bleeders we know, my life journey has been very unique, with treatment plans and self-management changing over time to suit my lifestyle. There is no one size fits all; however, there have

been some key points in my life that have prepared me to take on most challenges.

Education: Ensuring I can learn as much as possible about my bleeding disorder in order to advocate for myself if needed. Having the confidence to ask questions and knowing where to find the answers.

Communication: being open about my bleeding disorder has helped this be a normal part of my life for me and also those around me. No bleeding topic has ever been taboo and should always be considered.

Keeping active and trying new things to find what works for me. Having the freedom to take these challenges on has helped me into adulthood and developed my confidence in all areas of life.

Overall, there are always so many exciting new advances in medicine and I know that as my journey continues to change as I get older there will be so many opportunities for me to take on whatever challenges I face head on, with a positive attitude and hope for a great future.

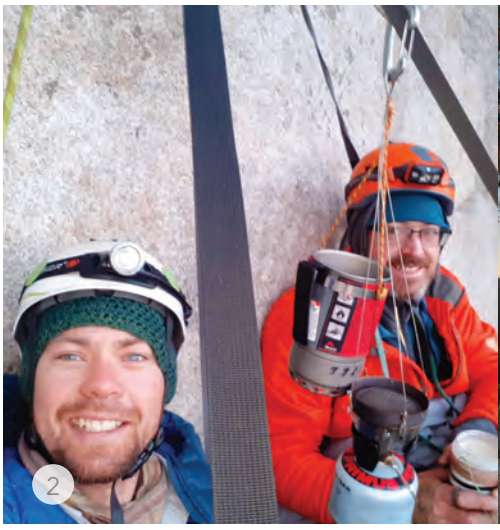
Shauna challenging herself with a trek in Canada

Photo: Shauna

Andrew and Scott are Australian community members with severe haemophilia A

Mission accomplished!

1. Andrew and Scott climbing El Capitan
2. Andrew and Scott having breakfast on the wall



Australian brothers Andrew, 30 and Scott, 37, took on the El Capitan climb at Yosemite National Park in California in September 2019. Andrew is an HFA youth leader. HFA has been following their preparation and adventures on Factored In and our social media. Scott tells the story of their grand adventure.

In September 2019 my brother Andrew and I travelled to California to pursue an audacious goal. It was one that we'd been working towards for months, and something that I'd been dreaming about for years. We wanted to climb a mountain called El Capitan, a 1000-metre-high granite monolith in Yosemite National Park, via the famous 'Nose' route, arguably the greatest rock climb in the world.

THE WALL

The Nose of El Cap is the quintessential 'big wall', a huge vertical cliff too big to climb in one day, requiring specialised technical climbing skills, endurance and commitment. On paper, the Nose doesn't sound that hard. The technical difficulty of the climbing is well within the capability of most competent climbers, but the sheer size of the wall, the complicated rope techniques required, the logistics involved in living on the side of a cliff for several days and the physical and psychological stamina required to keep going all add up to make it a serious undertaking. More than half of the climbers who start up the route turn around before making it a third of the way up the wall. Adding an extra dimension to the challenge was the fact that Andrew and I both have severe haemophilia.

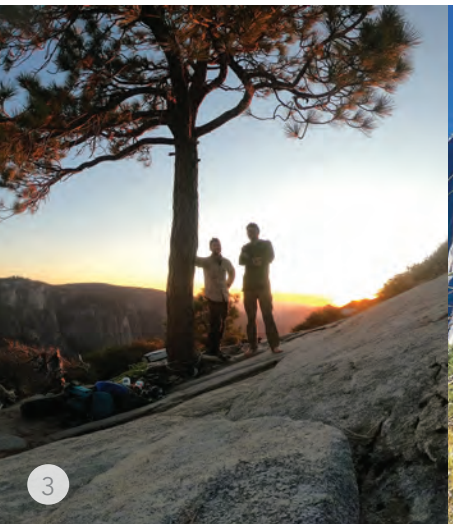
In the months leading up to the trip we'd practiced the rope techniques and climbed some smaller routes to get our systems working smoothly. We'd also done our best to train to prepare for what I was fully expecting would be the hardest physical thing that either of us had ever done. For me, this training hadn't gone very well. A series of injuries meant that I arrived in Yosemite feeling unfit and very anxious about how my body would hold up. My biggest fear was that the niggling back and shoulder injury that had been giving me trouble for weeks would develop into a bleed on the wall, necessitating a retreat from hundreds of metres above the ground.

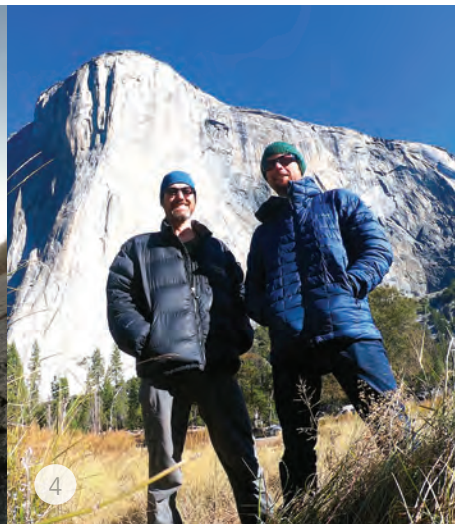
THE CLIMB

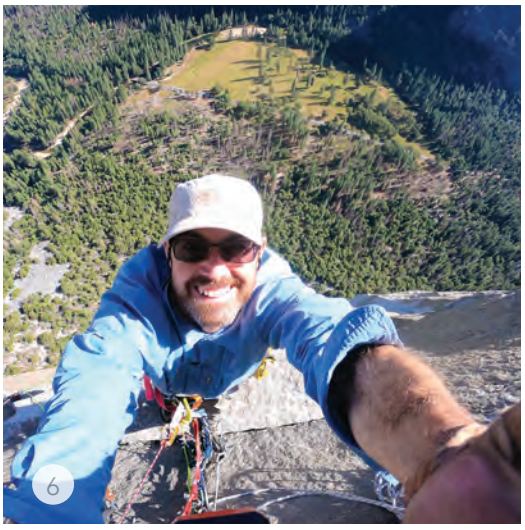
On our first attempt the climbing went smoothly enough, and physically we seemed to be doing OK, but the greatest rock climb in the world attracts climbers from everywhere, and the crowds were making things difficult. On our third day on the wall we found ourselves stuck at the back of a slow-moving convoy of four two-man teams, all chasing the same dreams of El Cap glory. We were still at the back of the queue when we reached one of the crux sections of the wall – the famous 'King Swing'. This section, located about 600 metres above the ground, involves lowering 20 metres down then running wildly back and forth on the vertical wall, swinging on the rope to reach a crack system far off to the side. Even after having read dozens of stories and watching all the online videos I was totally unprepared for how difficult and committing this manoeuvre would be. I tried multiple times, but I kept coming up short of the hold I was aiming for. On each one of these failed attempts, gravity would take over and send me swinging back across the wall at high speed. On one of these return swings I crashed awkwardly back into the rock, and felt a jarring pain in my hip and ankle. Luckily the

3. Andrew and Scott at the famous tree at the top of the Nose.
4. Victory photo after climbing El Cap.
5. Scott on the side of El Capitan.
6. Scott on the Boot Flake, about halfway up El Capitan

Photos: Scott and Andrew







climbers just in front of us were able to throw me a line so that I could pull myself across the swing, but with the painful hip I only managed two more rope lengths of climbing before throwing in the towel. After a long and involved retreat we found ourselves back on the ground, full of mixed feelings and wondering if we'd made the right decision to come down.

After a few days of rest and easier climbing my hip recovered and we started thinking about another attempt. The weather forecast looked less than ideal, with cold temperatures and possible snow, but we decided to take a chance and go anyway. Our plan this time was to avoid the King Swing by climbing a variation called the Jardine Traverse that weaved around to the left for about 100 vertical metres before re-joining the original route at the point we had retreated from last time.

I started to question the wisdom of our gamble with the weather while dangling 50 metres above the ground at 3 am on the first morning, being buffeted by freezing rain and wind. It soon cleared though and we found the wall that had been so crowded before was almost totally empty. Without the pressure of other teams on the route we could relax and enjoy the amazing climbing at our own pace.

On our second morning we reached the spot that we had bailed from before and kept climbing into new terrain. Above this point the wall gets steeper and the feeling of exposure from having so many hundreds of metres of air between us and the ground was exhilarating. We kept moving methodically up the wall one rope length at a time, following the same process over and over. Climb, fix rope, haul the bag, ascend the fixed line, climb, fix rope, haul the bag, ascend the fixed line. We had found the rhythm of the wall and we knew that this time we were going to make it to the top. With each pitch of climbing all the stress and anxiety about lack of fitness, and all the doubts and questions about whether we were good enough to be there faded further away. As we gained height the views of Yosemite valley gradually extended outwards to include more and more distant horizons. Then, on the afternoon of our fifth day we pulled over the top, and suddenly the vertical world that we had been living in shifted back to the horizontal.

THE SUMMIT

The last evening that we spent camped on the summit of El Cap was one of the best nights I can remember. We gazed out at the stars above the valley while we feasted on the last of our beef jerky, chocolate and freeze-dried rice and vegetables. I don't think anything had ever tasted so good. As I crawled into my smelly sleeping bag that night, I felt sore and tired, but profoundly satisfied.

We hope that by sharing this story we might inspire others with bleeding disorders to pursue their own big and physically challenging goals, whatever they may be. By climbing El Capitan Andrew and I proved to ourselves that haemophilia doesn't have to be a barrier to achieving something hard, and found out that we're capable of more than we suspected.

Scott and Andrew used their climbing challenge to fundraise for HFA. You can show your support of Scott and Andrew's efforts by donating at https://give.everydayhero.com/au/climbing-el-capitan-with-haemophilia.

YOUTH NEWS

You have started at uni and met some new people. You really enjoy hanging out with them and you have a lot of shared interests. You can see some good friendships coming out of this. Should you tell them about your bleeding disorder?

How would you decide the risk involved with different scenarios?

The Youth session at the Conference was a lively debate between three teams – young people with bleeding disorders, adults from the next generation, and health professionals. And the audience could vote on their phones and then join the discussion with their point of view as well. Chaired by Dr Moana Harlen, the Senior Haemophilia Psychologist from the Queensland Children's Hospital, the session bounced around the realities of life for a young person with a bleeding disorder. There were a few surprises – sometimes the young people were more cautious than the health professionals!

What did the young people and the next generation on the panel think about the session?

YOUNG PEOPLE

Alan has severe haemophilia and Sabrina has VWD.

What did you find most interesting about the Youth Session?

I feel that when the audience is interactive with the panel it makes it a bit more enjoyable, it allowed everyone to have a voice and say to the questions being asked.
Alan

The Youth session was most interesting to discover what other young adults go through with their blood disorder and how they cope with their bleeds, especially in regards to strategies and treatment plans. I didn't realise that my blood disorder, von Willebrands, is very different to haemophilia in terms of treating injuries and internal bleeds. Thus it was great to get different perspectives from other youths and how they manage their lives.
Sabrina

Did anything in the Youth Session surprise you?

I think I surprised myself and others with how open I was with day-to-day life, prophylaxis and haemophilia.
Alan

Yes! I didn't realise just how important it is to look after yourself when going through puberty. As a teenager, I told myself to 'get over it' or 'grit your teeth and put up with the blood'. However, it was surprising to hear at the Youth session that any bleed that is abnormal should be attended to and treated accordingly.
Sabrina

You are going on a school camp. You don't want to be excluded from activities and are already really cross that your action plan means you are not permitted to play hockey at camp. You decide to keep very quiet about your bleeding disorder and not tell anyone if you think you might be having a bleed – you will just deal with it yourself.

You are going to travel overseas in a couple of weeks and time has got away from you. You haven't talked to your HTC yet. Youknow they are very busy and will not be happy that you have left things to the last minute. You are wondering if you should just pack the treatment product you have in your fridge and hope for the best.

WHAT'S THE RISK?

THE NEXT GENERATION

Paul is a former member of the HFA Youth Committee and now an experienced community leader in South Australia. He describes himself as 'mid 20s trapped in a 43-year old's body'. Shane is the father of a young man with severe haemophilia.

What did you find most interesting about the Youth Session?

I thought there would be a greater divide between responses from the health professional, youth representatives, parents/older person with a bleeding disorder and the audience. However, everyone's responses were pretty consistent with each other.
Paul

I thought it was quite interesting that there was such a broad spread of opinions across a number of the topics covered, even at times between the health professionals. It was really good that the session focused on the 'risk' and what I learnt was that there is not necessarily a single or 'one size fits all' answer. From the broad spread of answers, it was clear that each scenario presented different risks to different people. The key takeaway for me was that assessing the risk and having a clear plan for treatment/management is what is really important.
Shane

CALENDAR

World Haemophilia Day
17 April 2020
www.wfh.org/whd

WFH World Congress
Kuala Lumpur, Malaysia
14-17 June 2020
www.wfh.org

Bleeding Disorders Awareness Week
11-17 October 2020
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

ACKNOWLEDGEMENTS

Haemophilia Foundation Australia (HFA) acknowledges funding grants received from the Australian Government Department of Health for communications and education activities undertaken by the HFA secretariat.

We thank the individuals, philanthropic trusts and companies which have made donations to support HFA programs, and the following companies that sponsor education programs, conferences or peer support programs run by the Foundation for the bleeding disorders community:

BIOMARIN | CSL BEHRING | NOVO NORDISK | PFIZER | ROCHE | SANOFI | TAKEDA

The HFA Council and Staff wish you a happy and safe festive season.

Thank you for your support during 2019 and we look forward to working with you again in 2020.

The HFA office will close on Tuesday 24 December and reopen Monday 6 January.
During that time if you have any queries or need to contact HFA call 0398857800. Messages during that time will be monitored.