National Haemophilia
Haemophilia Foundation Australia
www.haemophilia.org.au
No. 207, September 2019

BLEEDING DISORDERS AWARENESS WEEK & RED CAKE DAY

13-19 OCTOBER 2019

CONTENTS

Photo: credits
Cover - April
p10 - Wojtek Gurak
P12 Sven Scheuermeir
p16 - Jimmy Baikovicius
p18 - Jorge Fernedez
p 20 - Lena
p26 - Patrick Amoy

Haemophilia Foundation Australia
Registered No.: A0012245M
ABN: 89 443 537 189
7 Dene Avenue Malvern East,
Victoria, Australia 3145
Tel: +61 3 9885 7800
Freecall: 1800 807 173
Fax: +61 3 9885 1800
hfaust@haemophilia.org.au
www.haemophilia.org.au
Editor: Suzanne O'Callaghan

Conference 2019

*The **19th Australian Conference on haemophilia, VWD & rare bleeding disorders** will be held at the Novotel Manly in Sydney from **10-12 October 2019**.*

Check out the program in this edition of *National Haemophilia* and you will see the variety of topics that are being covered and discussed over the two days.

And don't forget to register for the social functions – the Welcome & Exhibition Opening on Thursday evening (free-of-charge), Conference Dinner on Friday night and special Youth Meet and Greet on Friday night.

For the latest information visit www.haemophilia.org.au/conferences

or contact hfaust@haemophilia.org.au or call 03 9885 7800

It's not too late to register for the Conference! Register online at https://www.secureregistrations.com/HFA2019/ or download a registration form at www.haemophilia.org.au/conferences.

CONFERENCE PROGRAM

Subject to change

Times	THURSDAY 10 OCTOBER 2019		
0830- 1700	**Annual meetings** of AHCDO, AHNG, ANZHSWCG, ANZPHG, DMG (Health professionals' group members only)		
1830-1930	**Welcome and Exhibition Opening** – open to all registered conference attendees		
1930-2230	**Youth VIP Meet & Mingle** – for registered youth only		
	FRIDAY 11 OCTOBER 2019		
0820	Official Conference Welcome • Gavin Finkelstein, President HFA • Dr Teresa Anderson, Chief Executive RPAH		
0830-1000	Plenary 1: Improving outcomes - what has been achieved in the treatment of bleeding disorders? Chair: Dr Liane Khoo		
	• Dr Liane Khoo • Dr Alfonso Iorio ~ Optimising patient care through PK analysis (WAPPS) Q&A		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Addressing the challenges of inhibitors	Concurrent 2 Getting older	Concurrent 3 Looking after children who have a bleeding disorder
	Chair: Megan Walsh	Chair: TBC	Chair: Robyn Shoemark
	Dr Huyen Tran ~ a clinical overview Discussion and debate on immune tolerance induction therapy Andrew's personal journey	Emerging clinical issues Preetha Jayaram ~ Patient voices Penny McCarthy ~ Treatment and care at Haemophilia Treatment Centres TBC ~ HIV and hep C update for older people with bleeding disorders Greig Blamey ~ Maintaining independence and keeping up the exercise Marcia Fearn ~ Innovative ageing projects Q & A	Robyn Shoemark ~ Encouraging independence and overcoming barriers to self-infusion Liane Willis ~ Impact of a chronic illness on families Anne Jackson ~ Transition to adult Haemophilia Treatment Centres Alison Morris ~ Q&A on physiotherapy, joint health & sport

1215-1325	LUNCH		
1325-1455	Concurrent 1 360 ° on clinical trials	Concurrent 2 Reproduction and family planning	Concurrent 3 A healthy life for all ages
	Chair: Dr Tina Carter	Chair: Jaime Chase	Chair: Beryl Zeissink
	Dr Simon Brown ~ the role of your doctor in a clinical trial Stephen Mathews ~ the role of nurses Alicia ~ A family's experience of a clinical trial for children Dr Alfonso Iorio ~ What outcome information should we be considering Q& A	A joint presentation by a geneticist and a genetics counsellor • Kristi Jones ~ Geneticist • Lucy Kevin ~ Counsellor Personal Stories • Kara • TBC	Jules Aitken ~ managing a healthy diet and weight Greig Blamey ~ Exercising safely at all ages Tim's personal experience of managing haemophilia challenges and keeping fit and well Q&A
1455-1535	AFTERNOON TEA		
1535-1700	Plenary 2		
	Chair: Dan Credazzi		
	Dr Happy (Dr Tim Sharpe) ~ Challenging the status quo		
1800	Remembrance Service		
1900	Conference Dinner Tickets are $50 and must be pre-paid		
SATURDAY 12 OCTOBER 2019			
0700 - 0820	Men's Breakfast ~ Everything you wanted to know but were afraid to ask Tickets are $30 and must be pre-paid		
	Chair ~ Claude Damiani Panel: Greig Blamey, Tim, Dr Nalini Pati		
0700 - 0820	Women's Breakfast ~ Extraordinary women in leadership: some of the inspiring women I have met. Tickets are $30 and must be pre-paid		
	Chair ~ Sharon Caris Marie Ann Fernandes (World Federation of Hemophilia Regional Program Manager for Asia & Western Pacific) will share her experiences as a development worker around the world		
0830-1000	Plenary 3 Musculoskeletal challenges: joint care and treatment		
	Chair: Abi Polus		
	Greig Blamey ~ The importance of upper limb care throughout life Dr Rob Russo ~ Haemophilia Early Arthropathy Detection with Ultrasound TBC ~ Upper limb surgical options		

1000-1045	MORNING TEA		
1045-1215	**Concurrent 1** **Gene therapy de-mystified**	**Concurrent 2** **From girls to women**	**Concurrent 3** **Self-advocacy**
	Chair: Dr Suzanne Russell	**Chair: Susan Dalkie**	**Chair: Loretta Riley**
	Yvonne Brennan ~ Basic science about how blood clots and how this interacts with new therapies Dr Julie Curtin • How does non-factor replacement therapy work and gene therapy fit into this context • Explaining the jargon – what is gene therapy? How does it work? What is achieved?	Dr Jenny Curnow ~ Bleeding in females across the lifespan Dr Kim Mathews ~ the role of a gynecologist Joanna McCosker ~ Ages & stages – what do parents and daughters need to know? Personal stories: • Shauna • TBC Q&A	An interactive workshop: successful self-advocacy; identifying relevant skills and resources; barriers and overcoming them.
1215-1325	LUNCH		
1325-1455	**Concurrent 1** **Von Willebrand disease and rare bleeding disorders**	**Concurrent 2** **Youth**	**Concurrent 3** **What is comprehensive care today?**
	Chair: TBC	**Chair: Moana Harlen**	**Chair: Anne Jackson**
	Current issues in VWD - best practice and future treatment Alex Connolly ~ Developing an effective treatment plan Susie's personal experiences ~ living with VWD and a parent of a son with VWD Dr Heather Tapp ~ looking after people with rare bleeding disorders The personal experiences of living with a rare factor deficiency • Belinda ~ factor X deficiency • Stephanie ~ mother of daughter with factor VII deficiency	What's the risk? Panel discussion of scenarios, with audience input (Q&A style) - personal decision-making around visiting HTC for a bleed review; gym/sport-related injury; travel, insurance; disclosing – in sport, in relationships; work, challenges of becoming an adult. Panel: 2 young people with bleeding disorders (Alan and TBC) 2 adults – person with haemophilia and parent (Paul and Shane) Health professionals ~ Greig Blamey, Physiotherapist Jane Portnoy, Psychosocial worker Steve Matthews, Haemophilia Nurse	Dr Suma Sumakura ~ Healthy teeth Loretta Riley ~ Using other services & navigating the health system Dr Jane Mason, Loretta Riley, Joanna McCosker ~ QLD Haemophilia Centre's experience of telehealth – engaging with the rural, remote and regional inherited bleeding disorders community
1455-1535	AFTERNOON TEA		
1535-1700	**Plenary 4 New opportunities or is the status quo good enough?**		
	A panel discussion about what patients expect from their treatment in the future, how haemophilia treatment centres expect to be treating their patients, and what the issues are for governments.		

BLEEDING DISORDERS AWARENESS WEEK

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of **13-19 October 2019.**

This year the theme is CHALLENGING THE STATUS QUO.

What does challenging the status quo mean to you? Look out for the personal stories from the bleeding disorders community that we will publish during Awareness Week. We invite you to share these stories with other people you know: it's through sharing personal experiences that we can connect and increase understanding in the wider community.

To order your free promotional items, visit www.haemophilia.org.au/order

HFA can post out promotional packs for your event or awareness stand, such as stickers, balloons, tattoos, or colouring in sheets.

RED CAKE DAY

HFA is calling on our friends and supporters to help us by taking part in Red Cake Day!

How can I get involved?

- Organise a Red Cake Day at your home, workplace, school, kindergarten or community group
- Order free napkins, pens, tattoos, stickers and colouring sheets and pencils to make your Red Cake Day special
- Display free posters, postcards, newsletters and raise awareness
- Tell your friends, family, colleagues about the week and encourage them to hold their own Red Cake Day event!

EVENTS

HFV will be hosting their Red Classic on Sunday 20 October at Albert Park. For more details visit www.hfv.org.au.

Other events will be posted on our social media pages and website. If you are hosting an event be sure to advise us so we can share.

Follow Red Cake Day!

Like HFA on Facebook
www.facebook.com/RedCakeDay

Follow HFA @Haemophilia_Au

And join the conversation at #redcakedayhaemophilia

FOR MORE INFORMATION

- visit **www.haemophilia.org.au/redcakeday**
- or call HFA on **1800 807 173**

or email **Natashia** on **ncoco@haemophilia.org.au.**

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT

Gavin Finkelstein

2019 CONFERENCE

It gets exciting as we come closer to our national conference. I missed the Melbourne conference in Melbourne in 2017 due to an unfortunate accident in the swimming pool I use regularly! But now well and truly recovered from that, I am looking forward to catching up with old and new friends in Sydney. Manly is not too far from the Sydney airport or a quick ferry ride from Circular Quay in the Sydney CBD. We are told the weather is usually lovely in October and with the conference venue right over the road from Manly Beach, we could not ask for a better location.

Opportunities for learning and development

The conference is a perfect opportunity to meet people who share similar experiences, and to learn from each other. Whether you are a parent of a child with a bleeding disorder or an adult with a bleeding disorder or someone you care for has a bleeding disorder, the program will have plenty of relevance to you. Conference sessions cover bleeding disorders from all angles – most sessions have personal stories of people living with bleeding disorders, or their families, as well as information from health professionals and others with experience and knowledge to support our personal journeys.

For many people in our community, the conference is one of the rare chances they have of meeting others who go through some of the same things - these days where people don't need to go to their Haemophilia Treatment Centre (HTC) as often as in the past, and they may never come across others with a bleeding disorder. In the old days we would meet up in hospital wards, and our parents would meet when they came to the hospital. Things have changed a lot – if all is going well, people may only need to visit their HTC once or twice a year, even though they are often in touch with their treating team by telephone, email or SMS. It's not uncommon for people to say at conferences, 'this has been fantastic, it's the first time I have met others like me, who know what it's like!'

We have a wealth of experience in Australia to develop a rich program. So many people have generously agreed to speak at the conference, and we also have invited three well-known and respected participants from further afield. Prof Alfonso Iorio is a clinician from McMaster University in Ontario, Canada who has a great interest in clinical research and improving and measuring treatment outcomes. We are also delighted that Greig Blamey has accepted our invitation to participate in the conference as well as attend the Australia New Zealand Physiotherapy Haemophilia Group Annual meeting as a guest speaker. Greig is a specialist physiotherapist who hails from Winnipeg in Canada. Greig is the Chair of the World Federation of Hemophilia (WFH) Musculoskeletal Committee and has a wealth of experience and knowledge. Our third international guest will be Marie Ann Fernandez, WFH Regional Program Manager for Asia & Western Pacific. Marie Ann will be sharing her experiences as a Development Worker at the Women's Breakfast.

GO FOR IT GRANTS

We are delighted that Pfizer has agreed to sponsor the Go For It Grants again in 2020. This awards program aims to inspire and support people affected by a bleeding disorder to achieve new personal goals. This might be in the area of study or to take on a new and challenging activity. Grants in previous years have given people affected by a bleeding disorder a chance to learn something new, by taking on an education or training course, a special challenge or setting goals they did not think would be possible for them to achieve without the support and encouragement of the grant that was awarded.

Applications must be received by **30 November 2019**. See the HFA website for details.

Preetha Jayaram is the HFA Getting Older Project Officer

GETTING OLDER PROJECT UPDATE

Where to from here?

Preetha Jayaram

Special thanks to all the community members, partners and family who have welcomed me since I took up the position of Getting Older Project Officer at HFA and for your participation in the project. There have been high levels of engagement and support from all and I appreciate your enthusiasm and courage to share your experiences and thoughts in interviews and when participating in the forums.

Getting Older is a priority project of Haemophilia Foundation Australia (HFA). HFA is committed to supporting active, independent and fulfilling lives for people in our bleeding disorders community. Since March 2019, I have been consulting with community members, state and territory foundations, medical specialists, haemophilia nurses, psychosocial workers and physiotherapists to explore current and emerging issues and how to 'future proof' as people grow older. I also had advice and guidance from experts in HFA's Getting Older Project Advisory Group.

COMMUNITY SURVEY

In the next stage of the project HFA will be administering a needs assessment survey to hear from the wider bleeding disorders community. This survey aims 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 asks questions about work/retirement, housing and insurance, aspirations for the future, information and education, computer use, support, and social connectedness.

Although the survey is voluntary, your participation would be appreciated. It is important that your voice is part of this project and that you share your thoughts about what is needed and the strategies and services that would help you. Survey responses will be treated confidentially. If you want to take part, you will be able to do the survey online or in print. Please check your mailbox in the coming months and let us know your concerns around getting older and what would help now and in the future!

If you know anyone else who might be able to complete the survey, please tell them about this. I am looking forward to hearing from you and finding out about the issues you and your partner and family see around getting older.

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

ISTH 2019 MELBOURNE JULY6-10 RESEARCH DISCOVERY OUTCOMES ISTH2019.ORG

Australia once again became the host for an international forum on bleeding disorders when ISTH 2019, the Congress of the International Society on Thrombosis and Haemostasis, was held at the Melbourne Exhibition and Convention Centre in July 2019. Thousands of the world's leading experts on haematology, thrombosis and related areas came together to present the most recent advances, exchange the latest science and discuss the newest clinical applications designed to improve patient care.

Presentations, scientific posters and exhibition stands covered an exciting range of new developments. New treatments for haemophilia and von Willebrand disease were well-represented. With several gene therapy clinical trials now reaching an advanced stage, ISTH has developed their own gene therapy education website portal and had an exhibition booth to demonstrate the portal with its webinars and links to research literature. The Congress also had a focus on haematology issues in obstetrics and women's health and discussed the ISTH work towards developing consistent approaches to classifications and best practice internationally.

ISTH includes sessions targeted at nurses and in this issue of *National Haemophilia* you will find a report from three of the haemophilia nurses who attended ISTH on the nursing forum and other sessions they found to be especially relevant or inspiring.

HFA was offered a stand in the trade exhibition to showcase our activities and education resources to haematologists and other health professionals from around the world. Delegates were interested in our approach to addressing the questions and concerns of people with bleeding disorders in our education materials, particularly our The Female Factors resources and our haemophilia guide for parents of a newly diagnosed child. We also took the opportunity to catch up with our colleagues from other international organisations who were represented at the Congress, such as the World Federation of Hemophilia, the European Haemophilia Consortium and the PROBE team.

HFA attendance at ISTH was funded by HFA. We thank ISTH for providing HFA with a complimentary trade exhibition stand

L-R Sharon Caris and Suzanne O'Callaghan at the HFA exhibition stand.

isth

A NURSING PERSPECTIVE

ISTH this year was themed ***Research, Discovery, Outcomes***, and there were a number of presentations outlining the proposed studies for gene therapy, and the real-world experience of the use of emicuzimab, including in surgery, and the local and global experience of extended half-life factor products. Other presentations included studies about quality of life and the burden of living with bleeding disorders, and comparative studies between people living with severe and moderate haemophilia.

MUSCULOSKELETAL ULTRASOUND

Andrew Atkins
Nurse Consultant, SA Adult Haemophilia Treatment Centre, Royal Adelaide Hospital

MSKUS – professional approach to new therapies
Mary Lesh, United States

Nurse forum sessions were held on two afternoons.

In one of the nurse forum sessions a nurse practitioner from San Francisco outlined a 5-year retrospective study on the use of musculoskeletal ultrasound in a haemophilia treatment centre (HTC) to affect clinical decision-making in acute bleeding events. The study included 26 children/adolescents with a mild/moderate (8) or a severe (17) bleeding disorder, and 1 platelet disorder. 16 were on a prophylaxis treatment regimen. There was a total of 97 ultrasounds performed for suspected bleeding events. Severe haemophilia represented 50% of the total patients and 42% of the total scans. By comparison, moderate haemophilia totalled 8% and 13%, and mild haemophilia 19% and 23% respectively.

The study assessed the use of ultrasound at follow up reviews in the HTC for ongoing pain/unsatisfactory progress.

15 patients had a total of 38 ultrasounds repeated, mostly within 2 weeks. 12 were for soft tissue bleeds, and 26 were for joint bleeds, with the ankle joint being the most common joint to be re-scanned. Interestingly over 40% of the repeated scans were in patients with mild bleeding disorders. Just over half of the repeated studies resulted in either not commencing treatment, stopping treatment, or reducing treatment. Nearly half of these were prescribed alternative therapy to factor replacement, such as anti-inflammatory medication.

This study highlights a potential benefit in having readily accessible ultrasound in the HTC to assist in monitoring the effect of treatment for bleeding events.

REACHING OUT: TREATMENT OF MATERNAL BLEEDING DISORDERS IN MOZAMBIQUE

Natalie Gamble-Williams, Clinical Nurse Manager, and Stacey Hutchison, Haematology Clinical Nurse, Perth Children's Hospital, WA

Maternal death and post-partum hemorrhage in Sub-Saharan Africa - A pilot study in metropolitan Mozambique

Annette Von Drygalski, United States

Dr Annette Von Drygalski from the University of California in San Diego presented a retrospective study of maternal death and post-partum haemorrhage (heavy bleeding after childbirth) in metropolitan Mozambique. Maternal mortality in Sub-Saharan Africa is 500-1000/100,000 births (compared to 5-20/100,000 in developed countries), and post-partum haemorrhage is a leading cause, accountable for 30-50% of deaths. Dr Annette Von Drygalski shared her personal experience of visiting Mozambique where she worked collaboratively with the local hospital staff to identify the risk factors of post-partum haemorrhage and implement small but key first world interventional strategies to reduce the devastatingly high mortality rate.

The data was gathered from January – July 2018 at Maputo Central Hospital, Mozambique. Results showed that 80% of women who developed post-partum haemorrhage were found to be severely anaemic and that HIV positive mothers who developed post-partum haemorrhage were at the highest risk of mortality. Furthermore, it was identified that age, increase in body temperature, high parity (the number of pregnancies reaching a viable gestational age), and short gestation (the time that a baby develops inside its mother's body until it is born) were additional risk factors in those who suffered post-partum haemorrhage. Therefore, implementation of a simple model using 'easy to obtain' parity parameters on admission, including temperature and gestation length can assist predict the risk of post-partum haemorrhage. Early detection of post-partum haemorrhage risk factors and treatment guidelines will help improve survival rates!

Observations from the study identified:

- A lack of education in the community and amongst health professionals about post-partum haemorrhage and sustainable preventive measures in metropolitan Mozambique
- Limited resources for reliable data collection
- Protocols for treatment of peri-partum (around the time of childbirth) blood loss volumes were not used consistently
- Pre-existing anaemia is a complicating factor associated with post-partum haemorrhage.

Interestingly, sub-Saharan Africa has very low blood donation rates and has no access to nucleic acid testing (NAT) to look for HIV in the blood. Access to cryoprecipitate and tranexamic acid is not readily available especially when required in an emergency situation.

Outreach programs giving minimal resources and advanced knowledge can have incredible impact. Twinning programs with developing countries are invaluable in identifying gaps in service and providing sustainable solutions to improving health care. Implementation of simple and cost-effective strategies for early detection and treatment of post-partum haemorrhage will help address the resulting high mortality rates in Sub-Saharan Africa. Education is paramount in raising awareness of the risks and complications associated with post-partum haemorrhage and this knowledge empowers patients and health professionals to advocate and initiate treatment plans.

Sam's experiences were originally published in *Factor Matters*, the newsletter of HFNSW (www.hfnsw.org.au), vol. 40, Winter 2019 and Leonie's reflections have been published in *The Missing Factor*, the newsletter of HFV (www.hfv.org.au), Spring 2019. They are adapted with permission.

Sam Duffield is a Haemophilia Foundation Australia Youth Leader

Leonie Demos is a delegate on Haemophilia Foundation Australia Council and President, Haemophilia Foundation Victoria

Twinning with Myanmar

Sam Duffield and Leonie Demos describe their experiences of representing HFA at the National Member Organisation Twinning Meeting with the Myanmar Haemophilia Patient Association in March 2019.

Their only access to clotting factor is through the WFH Humanitarian Aid Program. Many of the young men cannot work because of their bleeds.

MYANMAR TWINNING VISIT

Sam Duffield

Myanmar, formerly known as Burma, is found between Bangladesh, China, Laos & Thailand, with a population of approximately 55 million. In March 2019 Leonie Demos (HFV President and HFA Council Member) and I represented HFA at a series of meetings in Yangon (formerly known as Rangoon) with the Myanmar Haemophilia Patient Association (MHPA) to discuss the possibility of establishing a World Federation of Hemophilia (WFH) twinning partnership between each of the organisations. We were accompanied by Marie Ann Fernandez who is the WFH Regional Manager for Southeast Asia/Western Pacific.

PATIENT ORGANISATION TWINNING

The WFH Twinning Program aims to improve haemophilia care in emerging countries through a formal, two-way partnership between a patient organisation in an emerging country with a more experienced patient organisation. It has operated for more than 20 years and in that time there have been 215 partnerships across 113 countries. HFA had previously twinned with the Thai Patients' Club in Thailand from 2008-2011. WFH also has a program for haemophilia treatment centres (HTCs) to twin to help increase access where haemophilia diagnosis, treatment and care is limited because of economic and other circumstances.

HAEMOPHILIA IN MYANMAR

Over the course of five days, Leonie and I were introduced to the Council of driven young men and women who are working hard to improve the situation of those living with haemophilia in Myanmar. We also met with doctors at the hospital, which has recently opened a haemophilia treatment centre. We learned more about the difficulties for people living with haemophilia in Myanmar. Their only access to clotting factor is through the WFH Humanitarian Aid Program. Many of the young men cannot work because of their bleeds.

These challenges aside, the MHPA is working hard on behalf of those with haemophilia in order to provide improved access to information, treatment, hydrotherapy and opportunities. The doctors have also developed their expertise though participation in training programs where they could visit HTCs in the UK and learn more about diagnosis, treatment and care.

WORKING TOGETHER

During our discussions we talked about how the Myanmar group and HFA volunteers might work together to strengthen their advocacy skills so they can represent their needs to other organisations and the government to continue to improve the situation for people with haemophilia.

As with any organisation including our own haemophilia foundations, it's all about having a strong governance structure and driven leaders, and Myanmar has some very smart driven young leaders, who are looking to do more to help their community.

This is just a short snapshot of my recent trip to Myanmar, so please watch this space as the journey continues. The next step is for the two groups to apply to WFH to be formally recognised as twinning partners.

But this is also a small reminder to the community out there reading this, to be involved whenever possible, because without your involvement, your foundation doesn't know how to help you. Be involved, because you are not alone, there might not be a lot of us, but we all share a lot of the same experiences and can help each other and continue to improve the situation locally within Australia and globally.

>>

REFLECTIONS ON TWINNING WITH MYANMAR

Leonie Demos

1. Some young members of MHPA
2. Leonie and Sam with Marie Ann Fernandez and the MHPA group
3. The Haemophilia Treatment Centre in Yangon

As a mother of a son with haemophilia it has always been a double-edged sword for me. On one side it feels unfair and unjust that we as a family have had to watch him with his challenges in life and the times that pain has been his enemy. However, like most of us I have always been so grateful for the medical care and the support we have in Australia. Challenges are shared with amazing medical professionals and treatments are of a quality that were nothing but dreams to those generations before us. From diagnostics which we take for granted, public transport that is affordable and available to get to hospital if we need to, to government-funded treatment product in Australia, we are confident we will have access to high quality health care every day. This was highlighted again for me during my twinning visit to Myanmar.

1

Our new friends in Myanmar share a genetic disorder like us. They share a heart and passion to work together to support each other and provide support for the rough times they face. But they have great challenges every day in living with a bleeding disorder and much to do to achieve the level of diagnosis, hospital services and treatment they need to live well.


2

It is an exciting opportunity to plan for a twinning with Myanmar. They have been making strides ahead both with their haemophilia services and with their Patient Association. Sam mentioned that a haemophilia treatment centre has now been opened in Yangon and that the haematologists have undertaken further training on haemophilia management after an HTC twinning with the UK. The Patient Association has been meeting to discuss planning for future directions with members from both Yangon and the second largest city in Mandalay. They have been working closely with hospital teams to broaden their reach and address isolation issues. They have also had successful events to raise awareness with the public.


3

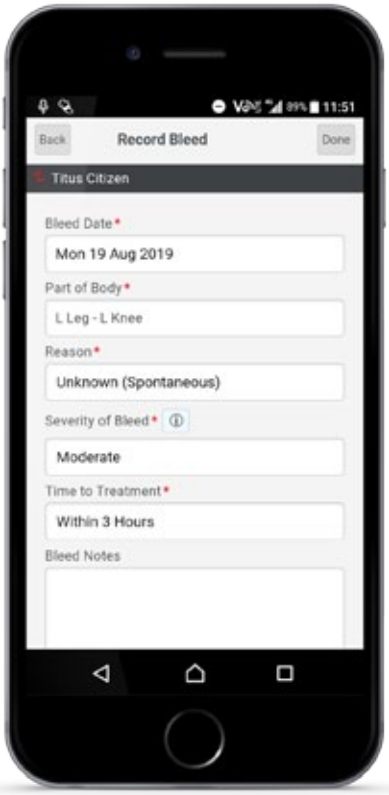
Sam and I felt our privilege in every way during our time in Myanmar. We also felt the hope and passion of a group of very special people who want to work together to improve treatment, care and peer support in their country. We have skills and experience to share and together we will work to do what we can knowing all our extended community is behind us.

Watch this space as the twinning takes off and consider the ways you can also step out of our shared privilege and support a beautiful community in Myanmar.

Dr Sumit Parikh is the AHCDO ABDR Senior Research Fellow

EXTENDED HALF-LIFE PRODUCT USE

Sumit Parikh



Accuracy of outcome data recording has greatly improved

In 2018, extended half-life (EHL) recombinant factor VIII and factor IX products became available in Australia to a limited number of haemophilia A and haemophilia B patients with high priority needs. The National Blood Authority (NBA) implemented this limited interim supply arrangements under the coordination and monitoring of the Australian Haemophilia Centre Directors' Organisation (AHCDO).

Currently AHCDO is undertaking a project to develop a better understanding of current clinical practices regarding the use of EHLs in haemophilia treatment centres (HTCs) across Australia. The project will also evaluate ABDR and MyABDR use, compliance with the product and examine various aspects of haemophilia care in Australia. Patients with at least 3 months of exposure to EHLs were included in the study to be able to determine the effectiveness of EHLs and the 'real-life' practice of physicians prescribing EHL products.

A total of 203 patients (139 with haemophilia A and 64 with haemophilia B) have commenced on EHL factor products for regular prophylaxis. There are 193 patients (131 with haemophilia A and 62 with haemophilia B) with 3 or more months of exposure to EHLs.

Whilst the data is still being reviewed, it was clearly evident that the interim program requirement for prompt data recording saw a significant increase in MyABDR uptake that coincided with commencing treatment with EHLs. Accuracy of outcome data recording has greatly improved, mainly related to specifics of the bleed, such as the Bleed Date, Dose and Body Location. Initial results also indicate better compliance to the prescribed regimen leading to reduced bleeds while on EHL products. However, identifying variables for the cause of bleed in some patients and categorising bleeds by their severity still needs further investigation. It was very reassuring to confirm that none of the patients tested developed a clinically significant inhibitor after switching to an EHL product.

As the project progresses further it will be a pleasure to update the community on the outcomes of the study.

Abi Polus is Senior Clinical Physiotherapist – Haemophilia, Alfred Health, Melbourne.
Lee Townsend is Haemophilia Physiotherapist, Christchurch Hospital, New Zealand.
Helen Dixon is Expert Physiotherapist Haemophilia, Wellington Hospital, New Zealand.
Abi, Lee and Helen are members of the Australian and New Zealand Physiotherapy Haemophilia Group

WFH Musculoskeletal Congress

Abi Polus, Lee Townsend and Helen Dixon

Three physiotherapists from Australia and New Zealand, Abi Polus, Lee Townsend and Helen Dixon, were fortunate to attend the World Federation of Haemophilia (WFH) Musculoskeletal Congress, held in Madrid, Spain in May 2019.

This was the largest ever Musculoskeletal Congress with 425 delegates from 76 countries coming together to discuss current and emerging evidence and best practice in the management of the musculoskeletal issues that arise due to haemophilia. It was agreed by the delegation that although haemophilia is a haematological condition, the musculoskeletal aspects currently appear to be the most challenging to manage overall.

There was a variety of sessions, from management of pain, the complexity of obesity, treatment strategies for joint pathology, nurturing the athlete, the use of ultrasound, outcome measures, and current research. Global areas of need were highlighted, which was especially humbling and made us very grateful for what we have available in Australia and New Zealand. Speakers were from a range of disciplines, including physiotherapists, orthopaedic surgeons, rehabilitation specialists, haematologists, researchers and patients, and were knowledgeable and engaging.

HIGHLIGHTS

LEE – THE MADRID APPROACH

The Congress began with the 'Madrid point of view' on musculoskeletal problems of haemophilia. Carlos Rodriguez-Merchan, an orthopaedic surgeon, and Hortensia de la Corte, a specialist in physical medicine and rehabilitation, spoke on their Haemophilia Treatment Centre's experience.

They described **radiosynovectomy** as a simple effective and safe procedure for the control of chronic haemophiliac synovitis. Their indication for this procedure was 2 or more episodes of haemarthrosis in 6 months and that patients can have up to 3 repeated injections every 6 months. They suggested that confirmation of synovitis must be by ultrasound and clinical examination. This is a common procedure in Madrid and is available in both Australia and New Zealand in specific Centres, when clearly indicated.

Other orthopaedic procedures carried out on patients with haemophilia described by the Madrid team were **knee, ankle and elbow operations** to improve function following joint arthropathy. They reported their statistics of the many total knee replacements that had been done with good outcomes.

Ankle arthrodesis (fusion) was their preferred operative option over ankle replacement as complications were about double with replacement compared to fusion. They noted that the literature suggests complications with total elbow replacements can be as high as 60% so they believe that the risks are too great to recommend them to the cohort in Madrid. It is well established in general literature that total elbow replacements can significantly decrease pain but function may be usually affected. In Australia and New Zealand it is suggested that elbow surgery should be decided on an individual basis, with collaboration with between the patient, surgeon, and haemophilia team.

The Madrid team have now started doing ultrasound guided evacuation of muscle haematomas to decrease the risk of pseudotumours. In Australia and New Zealand this is an extremely rare complication, often although not exclusively, linked with poor management of bleeds. In countries where factor replacement is unavailable or insufficient these are more common. The role of joint aspiration in acute haemarthrosis remains controversial. The blood must be in the liquid phase, joints assessed by ultrasound, be under factor cover and be performed under ultrasound guidance. The Madrid HTC carried out a study with patients assigned to either the

aspiration group or to the control group. There were 55 patients with acute joint bleeding episodes in the study. Joints treated with joint aspiration exhibited a significantly faster resolution of bleeding (15 less than control), 6 less days of factor treatment, 4 days less of pain, 10 less days to restore range of movement and 4 days less to return to work or school. They reported that there were no short or long-term complications. The Madrid group concluded that in their cohort, under their conditions, this is a safe and effective procedure that allowed faster recovery in their patients with haemophilia following an acute bleed. To achieve this, it must be done in a Haemophilia Treatment Centre with multidisciplinary input.

HELEN – OBESITY

A session on obesity was presented by Jens-Christian Holm, Consultant Paediatrician Denmark, Dari Di Minno, Professor of Medical Science, Italy, Nichan Zourikain, Physiotherapist, Canada, Mauricio Silva, Orthopaedic Surgeon, USA and Mathieu Jackson, Canadian Haemophilia Society. The World Health Organisation recognised obesity as a disease as long ago as 1948. As we all know, since then - and particularly over the last decade - this disease has grown at epidemic proportions, almost tripling since 1975.

L-R Helen Dixon, Abi Polus and Lee Townsend at the MSK Congress
Photo: Lee Townsend

Recognition and treatment of obesity in the haemophilia community is still not well documented or researched. The presenters pointed out a few studies that show the haemophilia population mirrors obesity trends in the general population.

Obesity does appear to have an impact on the health of people with haemophilia and particularly their joint health. When they are obese, there appears to be up to 30% more joint bleeds and an increase in the HEAD-US (Haemophilia Early Arthropathy Detection with Ultrasound) score as well as increased risk of musculoskeletal injury. There is also significantly more risk associated with surgery.

As factor replacement dosing is calculated on body weight, there was suggestion that this should be calculated on ideal body weight rather than actual weight in obese patients. This is more accurate for calculating circulating factor levels as adipose tissue does not circulate clotting factor. This should be confirmed with PK studies.

Overall, the presenters concluded that overweight and obesity represent major issues in people with haemophilia. Targeted prevention and treatment solutions need to be implemented for this group.

>>

Haemophilic arthropathy
Another highlight was the session on haemophilic arthropathy. This was presented by Christian Carulli, Orthopaedic Surgeon, Italy, Maria Eulalia Landro, Biologist, Argentina, and Lize Van Vulpen, Haematologist, Netherlands.

Joint regeneration following blood induced damage and repair of articular cartilage is a great challenge as cartilage cells do not regenerate. Mild to moderate joint disease is difficult to treat as the treating team usually wait until it is severe and orthopaedic intervention is needed. Novel therapies such as bone marrow stimulation, stem cell injection, growth factor treatment, platelet-rich plasma injection and joint distraction all need further clinical trials to demonstrate safety and efficacy.

Intra-articular injection of hyaluronic acid has been shown to be helpful in a small number of patients in a few studies of mild to moderate arthropathy of the knee. However, it doesn't appear as effective as steroid injection for reducing pain in the short to medium term.

Intra-articular injection of platelet-rich plasma is thought to be anti-inflammatory, regenerational, anti-microbial and an immunomodulatory. All of these are very useful properties for the treatment of synovitis. A 3-year follow-up study based in Argentina with 84 patients and 144 joints showed a significant reduction in joint pain, number of bleeds and Haemophilia Joint Health Score and an increase in range of movement and joint function.

Clearly more research is needed in this very interesting and exciting area of joint arthropathy treatment.

ABI – NURTURING THE ATHLETE

A patient-focused session on nurturing the athlete brought together three high-achieving patients from three different countries, who presented their experiences and achievements in a panel discussion. The countries represented, it should be noted, allow them to have access to regular and tailored factor replacement or by-passing agents. The patients were Andrew Selvaggi, personal trainer, Australia; Clive Smith, Ironman triathlete, United Kingdom; and Pau Salva Martinez, competitive cyclist, Spain. Also on the panel was Dr Sebastien Lobet, haemophilia physiotherapist and researcher, Belgium.

Particularly interesting were the changes in medication, management and attitudes they highlighted that had come about within their lifespans thus far (of around 30-40 years). They discussed the attitudes of their respective Haemophilia Treatment Centres, both the positives and negatives, and described the importance of clinicians listening to and supporting their personal choices and managing their specific needs as paramount. Interestingly, they reported that they would have done these things anyway, regardless of their clinicians' support or the lack of. Thankfully they all

...weather for us, the food and drink was wonderful and we all were grateful for the opportunity to be able to discuss what we do with colleagues and musculoskeletal specialists from around the world...

Abi speaking at the MSK Congress
Photos: Abi Polus

reported support from their current physiotherapists (phew), but it did reiterate how we can guide, advise and educate but, most importantly, collaborate with our patients.

It also demonstrated that there are few limits to what people with haemophilia can achieve: overcoming physical impairments to embrace and promote physical career pathways; compete in an ironman or four (that's a 3.86 km swim, 180.25 km bicycle ride and then a 42.20 km marathon run, raced in that order and without a break) for fun; a race for your country in the toughest cycle ride in the world (and win!); an active dream-career, or choose whatever you put your mind to. A question at the end of the session was posed to each presenter: 'would you have achieved what you have if you did not have your bleeding disorder?' and each participant stated a resounding no.

MSK and the future of haemophilia

Musculoskeletal management and the future of haemophilia was an extremely interesting way to reflect forward to what changes may come. Gene therapy and new agents were discussed by Dr Maria E Mancuso, Italy, along with the effects they may have on joint protection and management of haemophilia. In an excellent presentation, Canadian physiotherapist Karen Strike discussed the use of an app which can monitor PK (pharmacokinetics) and looked towards the use of artificial intelligence in outcome measures and management strategies in the future.

The conference was extremely informative, Madrid put on spectacular weather for us, the food and drink was wonderful and we all were grateful for the opportunity to be able to discuss what we do with colleagues and musculoskeletal specialists from around the world to enhance our own practice and bring it to our own centres and patients.

Abi Polus was funded by Haemophilia Foundation Australia to attend the WFH Musculoskeletal Congress.

This article was published simultaneously in Bloodline, the magazine of the Haemophilia Foundation of New Zealand.

Cameron Cramey is Senior Musculoskeletal Physiotherapist at the Royal Adelaide Hospital

IMPROVE ARTHRITIC KNEE PAIN WITH EXERCISE

Cameron Cramey

Arthritis or arthropathy are generic terms used to describe conditions that affect the joints and surrounding tissues. Some common arthritic conditions you are probably familiar with include osteoarthritis, rheumatoid arthritis and haemophilic arthropathy. Although each are distinctly different clinical conditions, with variable medical and pharmacological management strategies, they all share common clinical features of synovial (or 'joint lining') inflammation and thinning or erosion of joint cartilage (a substance that cushions the ends of bones in a joint).

When considering management of osteoarthritis, there is a vast amount of research literature and consumer information available outlining recommended management approaches, particularly involving the knee (see the REFERENCES at the end of this article). Given the similarities between osteoarthritis and haemophilic arthropathy, there is an opportunity to 'tap in' to this existing and emerging body of evidence to improve the long-term outcomes of people with arthritis that has occurred as a result of joint bleeds.

BENEFITS OF EXERCISE AND EDUCATION

Recent studies of people with knee osteoarthritis have demonstrated that education and exercise can improve quality of life and pain by 33%.

A Victorian-based study at La Trobe University found that education combined with appropriately targeted exercise improves quality of life and pain in people suffering from knee osteoarthritis. This followed on from a Danish study that found similar results when education sessions were combined with an individualised rehabilitation program consisting of aerobic exercise, functional strengthening and cool down; and builds on existing evidence citing the benefits of exercise for osteoarthritis.

Other benefits noted during the La Trobe study included a reduction in sick leave and use of analgesia; and more than 30% of participants had increased their level of physical activity.

The secondary health benefits from physical activity shouldn't be underestimated. These include: improved psychological wellbeing, increased social interactions, and reduction in the risk of chronic diseases including heart disease, diabetes, stroke, falls and fractures.

HOW MANY PEOPLE EXERCISE?

The data is compelling and backed by national clinical guidelines recommending exercise as the frontline management option for osteoarthritis.

Yet despite this, research reveals that of the estimated 2 million Australians living with arthritis, just 1 in 20 perform any form of regular structured fitness activity - while only 1 in 5 will perform any form of strengthening exercise.

EXERCISE AND PAIN

The good news is that regardless of severity, exercise helps.

There seems to be a common misconception that exercise is dangerous for arthritis and pain equates to damage. To the contrary, it seems that moderate loading of joints improves joint health. Joint loading may not always be pain free. However, under appropriate supervision exercises can be safely prescribed at a level sufficient to achieve functional and strength gains.

JOINT SURGERY

Exercise in combination with education, weight reduction and simple analgesia can offer an effective and non-invasive approach to avoiding or delaying joint surgery. For those people who require joint replacement surgery participation in a pre-operative exercise program can hasten recovery.

FOR PEOPLE WITH BLEEDING DISORDERS

At the most recent annual meeting of Australian and New Zealand Physiotherapy Haemophilia Group Dr Christian Barton from La Trobe Sport and Exercise Medicine Research Centre provided an overview of current successful osteoarthritis exercise programs. The graded exercise programs are easily adaptable to suit individual patient characteristics. The Australian and New Zealand Physiotherapy Haemophilia Group anticipates that the benefits noted in recent studies would likely be similar for people suffering from haemophilic arthropathy.

If you would like to know how you can get started on an exercise program to improve your arthritis contact your local Haemophilia Treatment Centre and ask to speak with the Physiotherapist.

ACKNOWLEDGEMENT

Dr Christian Barton: Implementing appropriate education and exercise for osteoarthritis – GLA:D™ Australia. La Trobe University Sport and Exercise Medicine Research Centre, Melbourne.

REFERENCES

Alentorn-Geli E, Samuelsson K, Musahl V, et al. The association of recreational and competitive running with hip and knee osteoarthritis: a systematic review and meta-analysis. Journal of Orthopaedic & Sports Physical Therapy. 2017;47(6):373-390. doi:10.2519/jospt.2017.7137.

Australian Commission on Safety and Quality in Health Care. Osteoarthritis of the knee Clinical Care Standard. Sydney: ACSQHC; 2017. https://www.safetyandquality.gov.au/standards/clinical-care-standards/osteoarthritis-knee-clinical-care-standard

Hinman R, Nicolson PJ, Dobson F, Bennell K. Use of nondrug,nonoperative interventions by community-dwelling people with hip and knee osteoarthritis. Arthritis Care & Research. 2015;67(2):305-9. https://onlinelibrary.wiley.com/doi/full/10.1002/acr.22395

Shmerling, RH. Patient education: Arthritis (Beyond the Basics). UpToDate, June 2019. https://www.uptodate.com/contents/arthritis-beyond-the-basics

Skou ST, Roos EM. Good Life with osteoarthritis in Denmark (GLA:D™): evidence-based education and supervised neuromuscular exercise delivered by certified physiotherapists nationwide. BMC Musculoskeletal 2017;18:72. https://doi.org/10.1186/s12891-017-1439-y

WORLD HEPATITIS DAY

World Hepatitis Day is marked globally on 28 July. The World Hepatitis Alliance has committed to eliminating viral hepatitis by 2030.

Imagine a future without hepatitis C. Can we achieve this in the Australian bleeding disorders community?

HAVE YOU BEEN CURED?

The new hepatitis C treatments can cure nearly everyone and have few, if any, side-effects.

Haemophilia Treatment Centres are currently collecting data to check which of their patients have been cured of their hep C and their current liver health. You can help this work by making sure your HTC has your results for:

- your hepatitis C treatment
- your latest HCV PCR test
- your most recent liver health test/ fibroscan.

Ask your hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need to have liver health checks regularly.

Many people with bleeding disorders have been treated and cured but some might not even know they have hep C.

YOU COULD BE AT RISK

- If you ever had a blood product for treatment before 1993 – even as a baby
- If you have shared equipment that allows blood from an infected person to enter your bloodstream, eg injecting equipment, non-sterile tattooing, medical care overseas
- Still wondering? Take the Hepatitis Risk Quiz to see if you are at risk - www.worldhepatitisday.org.au/quiz
- Is this you or someone you know? Have you ever been tested for hep C? If not, now is the time to be tested - and have treatment to be cured, if you do have hep C!

As a Partner in the national World Hepatitis Day Campaign, HFA works with Hepatitis Australia and State and Territory Foundations on the annual national awareness campaign and is committed to making a difference on hepatitis C in Australia.

FOR MORE INFORMATION

Visit

- www.world.hepatitisday.org.au
- The HFA World Hepatitis Day page - https://tinyurl.com/HFAWHD19

Or talk to your hepatitis specialist, your HTC or your local doctor

Dr Emma Prowse is Clinical Psychologist at the Children's Cancer and Haematology Service, John Hunter Children's Hospital, Newcastle, NSW

QUALITY OF LIFE AND EMOTIONAL WELLBEING OF CHILDREN

Emma Prowse

THE CHALLENGES

According to the World Health Organisation, 'without mental health there can be no true physical health'. This is important to consider when a child's mental health or emotional wellbeing is complicated by a chronic illness such as haemophilia.

Children with haemophilia and other bleeding disorders are faced with a unique set of challenges, in addition to the typical challenges associated with growing up.

Developmentally, we would expect children and adolescents to be growing and undergoing physical changes, developing friendships, finding their place in the world and taking risks. However, a child with haemophilia carries a higher level of risk, leading to restrictions in activities that could increase the chance of injury leading to a bleed. Children with more severe bleeding disorders often feel excluded due to being unable to play contact sports, such as Rugby League or AFL, with Australian haemophilia management guidelines recommending that noncontact sports should be encouraged in preference to contact sports. Given the importance of sport in our Australian culture, this often has social ramifications, and can even lead to children not being invited to birthday parties if there is a perceived risk.

Children and adolescents may feel excluded from or feel different from their peers, whether this is due to stigma and/or limited understanding about the illness. Teachers may experience an increased sense of responsibility for children with bleeding disorders, which may lead to further social exclusion. The child may also miss days of school due to treatment or medical appointments; meaning that they have reduced opportunities to socialise or fall behind academically.

Parents are often required to be more vigilant, particularly of an active child, leading to hypervigilance, stress or fatigue. Children feeling that they are being treated differently to their peers can lead to increased conflict between parents and children, and can also lead to rule-challenging behaviours and other behavioural concerns.

Additionally, given the infusion-based nature of prophylaxis treatment administration for bleeding disorders at such a young age, and that young children are less likely to understand the need to sit still during procedures, have more energy than adults and generally have smaller veins, children are at a much higher risk of experiencing pain during medical procedures and are therefore at risk of developing develop procedural anxiety and needle phobias or experience trauma related to procedures.

>>

Finally, young women with bleeding disorders face unique challenges, impacting on their psychological wellbeing. It is hard enough being an adolescent girl in today's society, with the influence of social media and pressures to meet unrealistic body ideals, without the added embarrassment and discomfort associated with heavy menstrual bleeding.

WHAT CAN WE DO TO HELP?

Children are children - they explore, they get dirty, they get hurt. Even children with haemophilia!

Children need opportunities to explore and take risks in a safe and measured way. Talk to your specialist team about sports that are safe for your child/young person. Sport is not only good for your child's physical wellbeing, but it will also allow opportunities for friendships, the development of social skills and increased confidence. Ask questions about prophylaxis and have a plan in the event that your child is hurt.

School is important: it not only provides opportunities for academic development, but also allows social and personal development. Try to minimise the amount of school missed. This will reduce the impact of the bleeding disorder on the child's self-concept. Rather than being a chronically ill child with a bleeding disorder, they become a child who likes science and playing with friends, but just happens to have a bleeding disorder.

Emotional awareness and communication: talk to you child about their day and their emotions. Encourage the development of a vocabulary around a range of emotions. Help your child to feel that their emotions are OK.

When to get help: Look for signs that could indicate decline in emotional wellbeing. These include but are not limited to, changes in sleep and appetite, withdrawal from friends and previously enjoyed activities, complaining of headaches and stomach aches, increase in irritability or anger, fatigue, increase in rule-challenging behaviours, getting into trouble at school, difficulties concentrating or decline in school grades.

TAKE HOME MESSAGE

If you are worried about the emotional wellbeing of your child or young person, speak to your treating team or GP. Children may be eligible for psychology sessions under a Mental Health Care Plan and most schools have access to a School Counsellor. Support is out there!

REFERENCES

Australian Haemophilia Centre Directors' Organisation. Guidelines for the management of haemophilia in Australia. Canberra: National Blood Authority, 2016. < https://www.blood.gov.au/haemophilia-guidelines >

Berk LE. Child Development. Pearson international edn; 7th edn. Boston: Pearson Education, 2006.

Haemophilia Foundation of Australia. Beyond Prophylaxis Project: understanding and addressing the unmet needs of young people with bleeding disorders. Melbourne: HFA, 2012. < https://www.haemophilia.org.au/HFA/media/Documents/Young%20people/Beyond-Prophylaxis-HFA-Youth-Needs-Assessment.pdf >

Kolappa K, Henderson DC, Kishore S. No physical health without mental health: lessons unlearned? Bulletin of the World Health Organization 2013;91:3-3A. < https://www.who.int/bulletin/volumes/91/1/12-115063.pdf >

World Federation of Hemophilia. Guidelines for the management of haemophilia. Montreal: WFH, 2012. < https://www.wfh.org/en/resources/wfh-treatment-guidelines >

2020

Go For It Grants

Everyone experiences obstacles at some time, but you'll never know what you can overcome and achieve unless you Go for it!

The Haemophilia Foundation Australia's Go for it Grants program is open for applications!

WHO CAN APPLY?

If you have a bleeding disorder or are affected by a bleeding disorder, two Go For It grants of $2500 each are available.

The Go for it Grants can take you one step closer to realising your dream.

See the application form on www.haemophilia.org.au/awards.

Applications close on 30 November 2019.

The HFA Go For It Grants program is sponsored by Pfizer

Suzanne O'Callaghan is HFA Policy Research and Education Manager

The Female Factors survey 2019

Suzanne O'Callaghan

In July 2019 HFA undertook an evaluation survey of our two latest The Female Factors booklets, *Female Factors - information for young women with bleeding disorders* and *Telling others about bleeding disorders*. We are working on the next The Female Factors resources and wanted to have feedback on the booklets we have published and what improvements to make in the future.

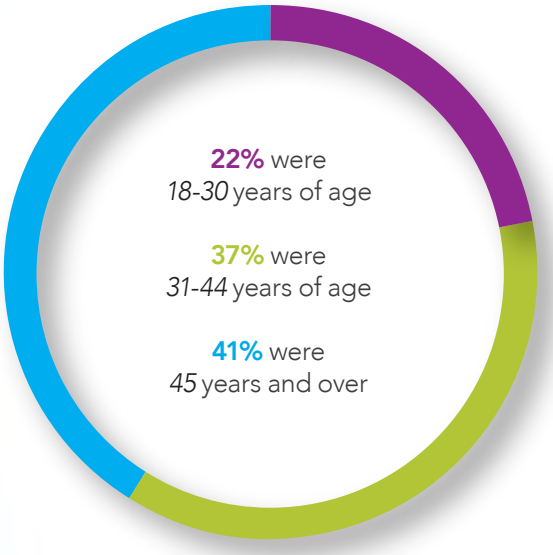
The Female Factors is the HFA women and girls project. The project is developing specific information resources for Australian women and girls affected by bleeding disorders to:

- Increase their understanding of their bleeding disorder, treatments and strategies to manage it
- Help them to feel more connected with each other by sharing personal stories and tips with others in similar situations
- Develop high quality, evidence-based information that they can show to other doctors, nurses, dentists, physiotherapists, etc who provide their care.

WHO COMPLETED THE SURVEY?

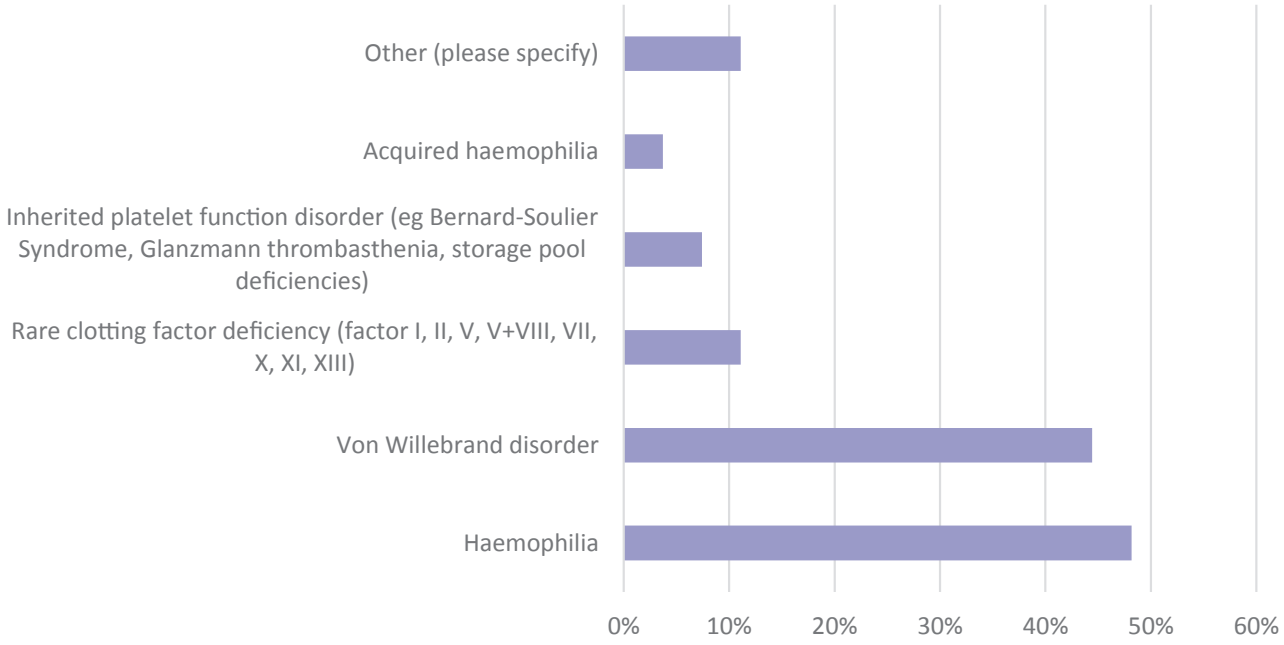
27 women completed the survey.

They were from all states and territories except South Australia and Tasmania (2 did not disclose where they lived).

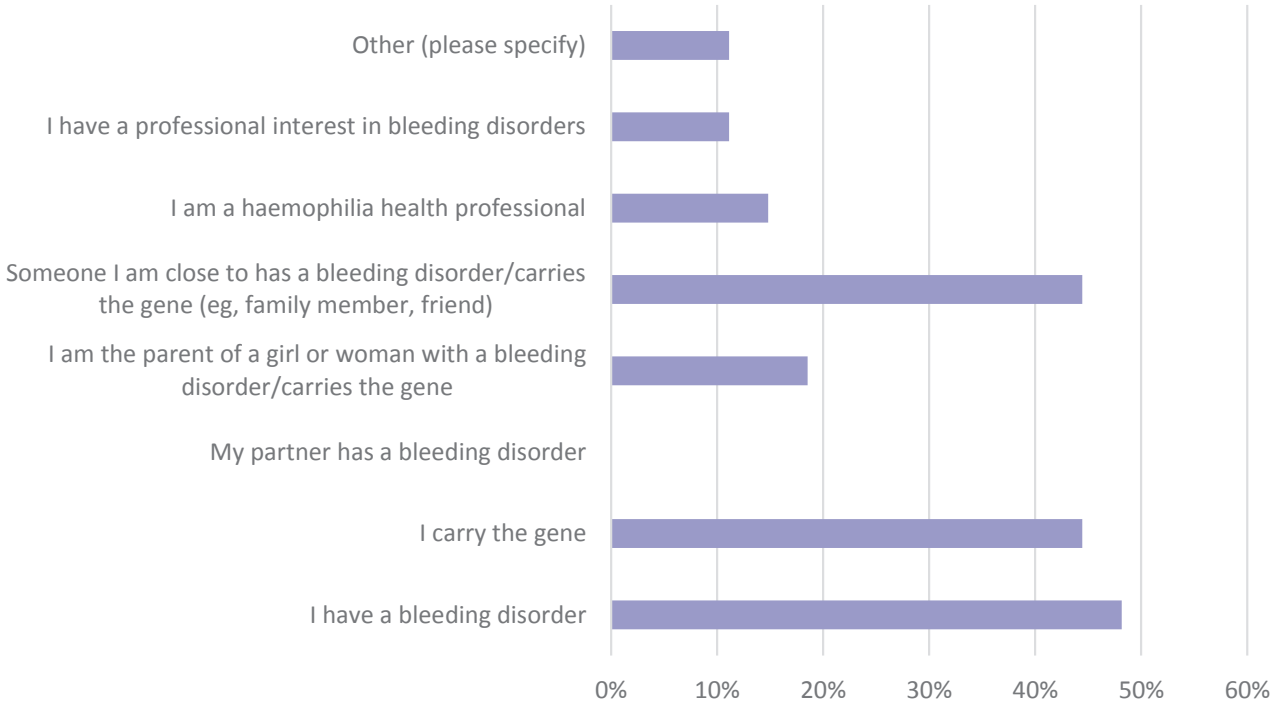


WHO COMPLETED THE SURVEY

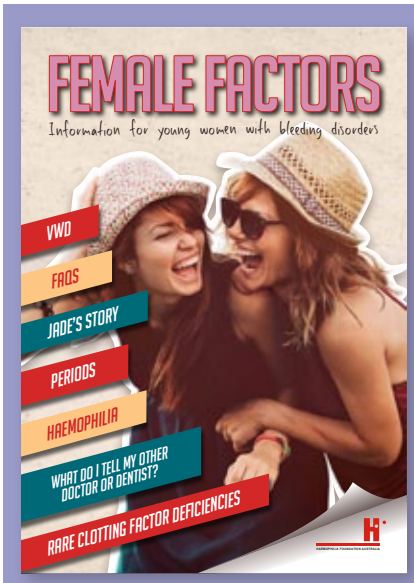
Bleeding disorder that applies to your situation



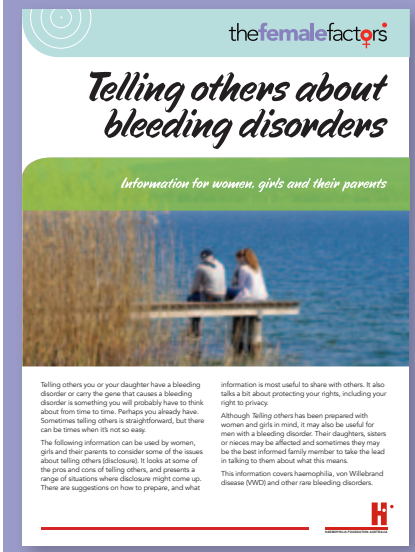
Please tick all the statements that apply to your situation



>>



- *Information about bleeding disorders in females for young women*
- *Working with HTCs and other health care practitioners*
- *Personal stories*



- Issues and strategies for telling others about your or your daughter's bleeding disorder
- Disclosure and protecting your privacy
- Personal stories

WHAT DID THEY THINK OF THE BOOKLETS?

92% had seen *Female Factors: for young women*

60% had seen *Telling others*

72% had seen the *print* version

60% had seen the *website* version

28% had seen the *online PDF* version

87% thought they were *very or extremely useful*

100% thought the *design* and *layout was very good or excellent*

What did they like?

- Lots of useful information, easy to read
- Design was contemporary, inviting, relaxed and colourful
- Engaging for the reader

Suggestions for improvement

- More information about women who are symptomatic, treatment for heavy periods
- More information on preparing for puberty
- Keep publishing updates.

'Think they're great.'

'Easy to read small sections meant I could absorb info more easily than long walls of text.'

'Topics previously avoided were addressed head on.'

'The front cover was inviting and the stories were great to read and not too long.'

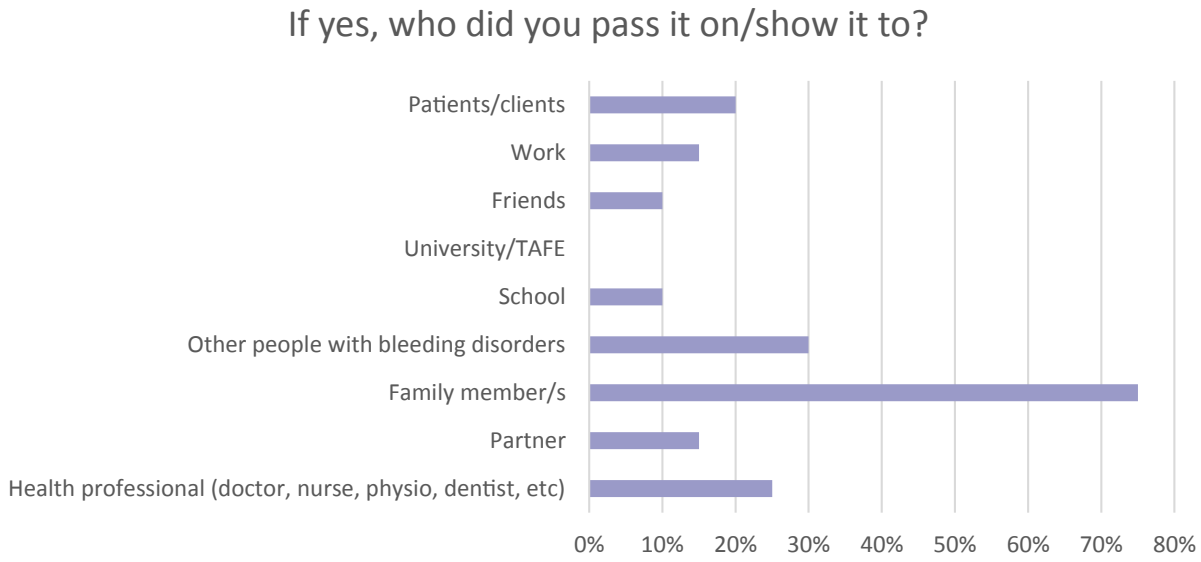
'Perhaps more information about women with haemophilia who are symptomatic to help address the stereotype that women can't have haemophilia.'

100%

thought the design and layout was very good or excellent

WHAT DID THEY DO WITH THE BOOKLETS?

72% passed booklets on or showed them to others



Why?

'To inform and reassure.'

'I knew some answers to questions were in there. I also hoped they were a good resource for them to share with their friends. I knew I could rely on it being a trustworthy source.'

'I was excited that there are new and relevant resources relating to my bleeding disorder and hoped others would learn from them too.'

'Informative for colleagues who have less knowledge on these disorders.'

'My daughter has just found out she is a carrier and my mother is a known carrier.'

'It was really good, gave it to my niece's parents (her dad has haemophilia and she is also a carrier).'

What was the impact for them?

'Great comments from young women about the information.'

'It's nice having a resource that helps explain things to others.'

'My husband feels much more informed about things that affect our daughter.'

'It's validated how I have felt for a while.'

'To know I'm not alone and we want more answers and any new info.'

'More confidence. Not ashamed.'

'Knowing there are a lot of us going through the same thing.'

WHAT'S NEXT?

HFA is working on the next two resources for The Female Factors project:

- Haemophilia diagnosis – factor level and genetic testing
- Family planning, pregnancy and birth.

We are using the feedback to develop the content and layout:

- Going the extra step to find out women's questions and answer them with the latest information
- Boxes with summary information
- Designed as an education tool both for women with bleeding disorders and their families and for others who are new to bleeding disorders
- Continuing to include personal stories and quotes.

Other resources in the pipeline:

- Symptoms, care and treatment, including self-management.

And we are always looking for women, teenage girls and parents of girls who are interested in contributing to the content with ideas or personal stories or reviewing drafts of the resources.

If you would like to be involved, contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173

YOUTH NEWS

Get out there and try new things. Live life to the fullest but be smart about it.

Joe Chivers tells his story of playing elite competition wheelchair football with VWD.

My name is Joe. I am from Tasmania, I am 31 years old and I have von Willebrand disease (VWD). Following a skydiving accident ten years ago I became a L1 incomplete paraplegic. I currently work for ParaQuad Tasmania as the Wheelchair Sport in Schools Facilitator.

I was in primary school and very young when I found out that I had VWD. I injured myself when I reached down to pick up a book under a tree. A stick pierced the top of my head which led to a large bleed and I was rushed to hospital. After my wound had been treated, I was tested for bleeding disorders and the test came back positive for VWD.

GROWING UP WITH VWD

Von Willebrand disease has impacted on my life in several ways. Some of the negative impacts have been easy bruising, internal injuries, complications during surgeries and a tendency to be injured easily during sport or physical activities. The positive impacts far outweigh the negative though. I have been able to understand myself and my boundaries far earlier in life. I have met a lot of fantastic people who live with bleeding disorders and learnt some fantastic life lessons from them.

PLAYING WHEELCHAIR SPORTS

I have played a lot of sport in my life. I am very lucky to be a talented athlete in numerous sports. I play wheelchair Aussie Rules Football and have been drafted by the Hawthorn Football Club to participate in the VWFL during its second season. I have also played Para Ice Hockey for Australia at the 2018 C-Pool World Championships.

I have always loved playing football. From a very early age, I wanted to play at an elite level. At the time of my accident, I was very fit and was training 5 to 6 nights per week. When I became a paraplegic, I thought my sporting days were over, which was extremely difficult for me to comprehend.

Fast forward a few years and here I am playing at an elite level for a great club in Hawthorn. It is such a fully inclusive sport and people can play regardless of their ability or whether they live with disability or not.

HOW DOES WHEELCHAIR FOOTBALL WORK?

We play on a basketball court, and there are 5 players per team. A handball counts as a kick and an underarm throw is a handpass. I play as a centre, meaning I can go anywhere on the court. The forwards are the only players who can score but both they and the defenders can only go into the first two-thirds of the court, like netball. Tackling is replaced with a touch on the shoulder to minimise contact and create a safer and fairer sporting environment.

The wheelchairs are specifically designed for use in sports. The wheelchairs that we use in everyday life are a lot more fragile and are susceptible to breaking during sporting activities, which would then impede our daily living. Sports chairs have a lot more camber on the wheels to make them more agile and safer. There are also 4 smaller anti-tip wheels attached to make them as safe as possible at high speeds. The frame of a sporting wheelchair is reinforced to bear the brunt of any big collisions and to make sure the user is safe.

PLAYING COMPETITION WHEELCHAIR FOOTBALL

1. Joe being awarded a silver medal for the national rowing championship in 2013 as part of the TA (Trunk and Arms) classification
2. Joe playing VWFL competition wheelchair football
Photos: Joe Chivers

I love the speed of the game as well as the physicality. Plus, to play at a high level, you need to be skilled in both operating a sports wheelchair and handling a football. We still need to bounce the ball, as able-bodied players do, and deliver precise hand balls and passes.

MANAGING MY VWD

My bleeding disorder hasn't been too difficult to manage during the season. I am very lucky that my treatment plan is very simple. I make sure that I have enough medication at home in case of an emergency. During competitions I have a letter from my haematologist and GP with me and have a card in my wallet with my medical details to assist medical professionals in the event that something does happen or I have a bleed. The club is aware of my medical history in case of an emergency.

WHAT I HAVE LEARNED

Get out there and try new things. Live life to the fullest but be smart about it. If there is a new activity that you would like to try, make an educated decision. Speak to current participants or people who have tried it before, research the activity and speak to medical professionals about whether it may or may not be suitable for you. Seek knowledge and you will discover so much about yourself and others in the process. And don't be afraid to fail. You will learn more by failing than you will by succeeding every time.

Live life to the fullest. Regardless of your ability in life, you can still live, love, laugh and learn.

CALENDAR

19th Australian Conference on haemophilia, VWD & rare bleeding disorders
Novotel Manly, Sydney
10-12 October 2019
www.haemophilia.org.au

Bleeding Disorders Awareness Week
13-19 October 2019
Tel: 03 9885 7800
Fax: 03 9885 1800
Email: hfaust@haemophilia.org.au
www.haemophilia.org.au

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

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

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