



8 | 9 October 2021

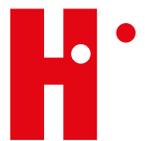
Virtual

# 20<sup>TH</sup> AUSTRALIAN CONFERENCE

ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

**EMBRACING A CHANGING WORLD**

# Abstracts & Handbook



HAEMOPHILIA FOUNDATION AUSTRALIA

# WELCOME

We welcome you to the fully virtual 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders. The conference theme of “*Embracing a Changing World*”, will give a focus to each session as we address advances in treatment and care, managing bleeds, diagnosing and treating VWD, specific issues for women and girls and young people, understanding and managing pain, sport and exercise, getting older, managing hepatitis C and HIV, mental health, managing change and optimising peer support.

We hope you enjoy the virtual conference and find it a stimulating and informative meeting.

We sincerely thank the Program Committee for their commitment to develop such an exciting conference program.

**Dr Ritam Prasad**  
Co-Chair  
Conference Program Committee

**Suzanne O’Callaghan**  
Co-Chair  
Conference Program Committee

**Gavin Finkelstein**  
President  
Haemophilia Foundation Australia

**Sharon Caris**  
Executive Director  
Haemophilia Foundation Australia

## Program Committee

Dr Ritam Prasad (Co-chair)	Australian Haemophilia Centre Directors’ Organisation (AHCDO)
Suzanne O’Callaghan (Co-chair)	Policy Research and Education Manager, Haemophilia Foundation Australia
Dr Simon Brown Australian	Haemophilia Centre Directors’ Organisation (AHCDO)
Julia Broadbent	Haemophilia Foundation Victoria
Sharon Caris	Executive Director, Haemophilia Foundation Australia
Nicoletta Crollini	Australia/NZ Haemophilia Social Workers’ & Counsellors’ Group
Alison Morris	Australian and NZ Physiotherapy Haemophilia Group
Joanna McCosker	Australian Haemophilia Nurses’ Group
Abi Polus	Australian and NZ Physiotherapy Haemophilia Group
Jane Portnoy	Australia/NZ Haemophilia Social Workers’ & Counsellors’ Group
Beryl Zeissink	Australian Haemophilia Nurses’ Group

# GENERAL INFORMATION

## Conference Organisers

Haemophilia Foundation Australia  
7 Dene Ave, Malvern East VIC 3145  
P: 03 9885 7800  
E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

W: [www.haemophilia.org.au](http://www.haemophilia.org.au)

## Disclaimer

All information in the Conference Program and Abstracts is correct at the time of printing. The organisers may alter the Conference Program in the event of unforeseen circumstances. Some abstracts may not have been available at the time of print.

## Log in Address

<https://haemophilia.delegateconnect.co/>

To log in use the link above and type in email and password. Use the menu bar on the left hand side to go to sessions, e-posters and virtual exhibitions.

## Need Help?

If you need help during the conference, click on the Need Help (pink button) in the left hand corner once you are logged in.

If you need any other assistance not related to the conference portal call or text 0403 538 109.

# SOCIAL PROGRAM

**Friday 8 October**

**Remembrance Service**

**18:00**

The Remembrance Service is a time to remember friends and family, and the people we have cared for. Please click this URL to join. <https://us06web.zoom.us/j/84850322433?pwd=NDF6Z0tad0x5OFV5WHUrSTJ0OXdJdz09>

**Battle of the Trivia**

**19:00**

Let's battle it out for a night of virtual fun.

Join Zoom Meeting <https://us06web.zoom.us/j/81403508398?pwd=eXJhRUVndWVpWkJlMVQrbURQWHlzQT09>

Meeting ID: 814 0350 8398

Passcode: 653880

# CONNECTING WITH THE COMMUNITY

Connect with one another and share your experiences! This has always been a key part of our national conferences. Even though we are virtual, there will still be plenty of opportunities for you to connect, share and have fun. Click on the Community Networking Tab to join in during all breaks.

# YOUTH WORKSHOPS

Together with Beautiful Minds, Haemophilia Foundation Australia is running virtual workshops in October to coincide with the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders. These workshops are targeting at anyone aged between 10-30 years and free to our community - young people with bleeding disorders, siblings, cousins and family. The 3 separate workshops will cover:

- Thurs 7/10, 7-8pm: Mind Fitness (separate guys and girls' sessions)
- Fri 8/10, 7-8pm: What is a Real Man? (for guys) | Inner Bully, Inner Bestie (for girls)
- Sat 9/10, 9-10am: Looking After Your Health (guys and girls together session).

For information contact Natasha E: [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) M:0403 538 109.

*This program is being run by HFA with the support of an education grant from CSL Behring*

# POSTER ABSTRACTS

You can view all Posters at the e-poster section.

Author	Co-Authors	Title	Topic Area
Cat Pollard		Ultrasound use in haemophilia care: An audit of physiotherapists using ultrasound imaging as standard care for people with haemophilia	Clinical Practice and care: Physiotherapy assessment and management of patients with haemophilia
Suzanne O'Callaghan		The Getting Older Info Hub: implementing a centralised online information hub for older people with bleeding disorders	Special projects
Suzanne O'Callaghan		Female Factors evaluation survey 2021	Special projects
Scott Russell	Simon Whitehart, Dr. Peter Window, Dr. Jane Mason.	Does the use of video-conferencing in physiotherapy consultations of adult patients with bleeding disorders change clinical recommendations when compared to audio-conferencing?	
Frankie Mullen	Abi Polus, Cathy Haley	Acquired Haemophilia and the role of Physiotherapy	Acquired haemophilia - Case Presentation
Abi Polus		The distribution of dedicated haemophilia physiotherapy service in Australia	The distribution of dedicated haemophilia physiotherapy service in Australia with relation to haemophilia population

**Cat Pollard**

Auckland Regional Haemophilia Treatment Centre, ADHB

E-mail: cpollard@adhb.govt.nz

**Title**

Ultrasound use in haemophilia care: An audit of physiotherapists using ultrasound imaging as standard care for people with haemophilia.

**Topic Area**

Clinical Practice and care: Physiotherapy assessment and management of patients with haemophilia.

**Abstract**

A large proportion of bleeding episodes experienced by a person with haemophilia occur within their muscles and joints, potentially leading to permanent changes to the synovium (layer surrounding the joint), cartilage and bone. Physiotherapists play an integral role in identifying and managing these bleeds, therefore reducing their long term consequences. Historically, physiotherapists have relied on physical assessment of the region. More recently, haemophilia physiotherapists in New Zealand have been able to employ ultrasound imaging allowing a more comprehensive and detailed appraisal.

In order to identify how useful this addition to practice has been, an audit within the Auckland Region (New Zealand) was performed over a 16 month period. During this timeframe, 67 first contact ultrasound assessments were performed, with 29 additional follow-up assessments.

The ultrasound was used for four purposes:

- (1) As part of the yearly joint health screening assessment using the Haemophilia Early Arthropathy Detection with Ultrasound protocol (38 cases)
- (2) For suspicion of a bleeding episode (24 cases)
- (3) To assess damage of a single joint (3 cases)
- (4) To monitor myositis ossificans (bone formation in a muscle, which can occur after trauma) (2 cases).

The ultrasound was shown to provide additional information to the assessment in many of these cases. In 12 instances, physical examination was normal but early joint damage was identified by ultrasound, prompting adjustments to treatment regimes. In four instances ultrasound was able to disconfirm a suspected bleeding episode, saving the need for additional factor replacement therapy (a cost saving between NZD\$15,360-\$21,040). Overall, the addition of ultrasound added substantial benefits to quality of care, improved outcomes and significant cost savings to the Health Service.

**Suzanne O'Callaghan**

Haemophilia Foundation Australia

E-mail: socallaghan@haemophilia.org.au

**Title**

The Getting Older Info Hub: implementing a centralised online information hub for older people with bleeding disorders.

**Topic Area**

Special projects.

**Abstract**

The Getting Older Info Hub was established on the Haemophilia Foundation Australia (HFA) website in June 2020. The Hub aims to centralise information and education about the special issues of growing older with a bleeding disorder and provide pathways and strategies for self-management. It is a response to the findings of the HFA Getting Older report. To ensure the information is relevant, accurate and delivered in an accessible and attractive way, HFA has involved a consumer focus group and expert health professionals to develop the Hub and the information on it.

Recent advances in treatment and care have resulted in a new phenomenon: a generation of people with bleeding disorders living into their senior years. Understanding the issues and impact of ageing with a bleeding disorder is new territory. In the HFA Getting Older report, all stakeholders identified information and education in this area as a priority. In the HFA Getting Older community survey, more than 85% of older people with bleeding disorders and their partners/family were active online daily. A centralised hub on the HFA website was recognised as an effective way to make information available for both the community and health professionals.

The concept and topics for the Info Hub were sourced from the Getting Older report findings. The HFA consumer focus group developed this further, mapping out a simple and accessible interface, with topics such as health and wellbeing, support, work, finances and a section for health professionals. Expert health professionals meet with HFA regularly to develop relevant information on these topics. The focus group continues to provide feedback. Uptake has been good, with more than 2300 page views to July 2021. Next steps include a community survey on user satisfaction and priority topics and wider promotion to the community and health professionals.

**Suzanne O'Callaghan**

Haemophilia Foundation Australia

E-mail: socallaghan@haemophilia.org.au

**Title**

Female Factors evaluation survey 2021.

**Topic Area**

Special projects.

**Abstract**

In 2021 Haemophilia Foundation Australia (HFA) undertook an evaluation of two Female Factors education resources for young women: Female Factors and Sport and exercise for girls and young women with bleeding disorders.

The HFA Female Factors education resources are intended to provide young women with bleeding disorders with high quality evidence-based information resources that they can use to inform themselves about their bleeding disorder and strategies to manage it. They include personal stories and tips from other affected women as peer education and support. The resources are presented in an attractive format and have details of evidence-based references and expert reviewers for credibility with health professionals.

There were 26 respondents to the national survey. 24 were female and 2 were male, from all age groups over 18 years, and were affected by a range of bleeding disorders. Most had a bleeding disorder themselves, with a small number being partners, parents, family or with a professional interest. Most had seen online versions; 23% had seen print versions. 50% had shown the resources to someone else, predominantly partners, family, friends and work to educate them and raise awareness about issues for girls and women. 27% had shown the resources to health professionals. Some commented that they were already well-educated in the area themselves but wanted to educate others.

63% of respondents said the resources were extremely/very useful and 75% said the design and layout was excellent/very good. Many commented that they were easy to read, age appropriate and informative. Suggestions included promoting them more - particularly specific sections - trialling different sizes and including more variety in the images.

The 2021 Female Factors survey has provided valuable feedback on user satisfaction with the resources, how they are used in the community and practical suggestions for developing and promoting resources for young women.

**Scott Russell**

Co-authors: Simon Whitehart, Dr. Peter Window, Dr. Jane Mason.  
QLD Haemophilia Centre, Physiotherapy Department RBWH  
E-mail: scott.russell@health.qld.gov.au

**Title**

Does the use of video-conferencing in physiotherapy consultations of adult patients with bleeding disorders change clinical recommendations when compared to audio-conferencing?

**Abstract****Background**

Physiotherapists commonly assess patients with bleeding disorders to help determine appropriate management for bleeding episodes and other musculoskeletal issues.

Audio-conferencing (i.e telephone) has traditionally been used in this setting when patients are unable/unwilling to present to hospital, resulting in recommendations based solely on the verbal description provided by the patient. The additional visual information provided by video-conferencing has the potential to influence management decisions in this setting, but has not been formally evaluated.

**Aims**

To determine if video-conferencing impacts the physiotherapy management of adult patients with bleeding disorders when compared to audio-conferencing.

**Methods**

The project compared two modes of health service delivery: audio-conferencing and video-conferencing. Using a sample of 40 patient encounters, audio-conferencing was conducted and the subsequent physiotherapy management plan was recorded. Video-conferencing was then immediately utilized for the same encounter and a second management plan was devised based upon the additional visual information provided by the video-conference. These two management plans were then compared and examined for significant change.

**Results**

In 40% of the encounters, the visual information provided by video-conferencing resulted in a change in the physiotherapy management plan. Within the encounters where video-conferencing prompted a change in physiotherapy management, this was mostly prompted by visual information related to the location of the complaint (31.3%), swelling (31.3%) and range-of-motion (25%). The average clinician confidence in the management plan following audio-conferencing was 68.1%, compared to 90.8% following video-conferencing.

**Conclusion**

In situations where a patient's with bleeding disorders can not physically present for assessment, the additional information provided by video-conferencing has the potential to influence physiotherapy management when compared to audio-conferencing.

**Frankie Mullen**

Co-authors: Abi Polus, Cathy Haley  
The Alfred Hospital  
E-mail: f.mullen@alfred.org.au

**Title**

Acquired Haemophilia and the role of Physiotherapy .

**Topic Area**

Acquired haemophilia - Case Presentation.

**Abstract****Outline**

Acquired haemophilia (AH) is an extremely rare bleeding disorder (1.5/million diagnoses per year).

In contrast to Congenital Haemophilia (CH), AH occurs suddenly in subject, without a history of a bleeding disorder and of these more than 80% of the patients are elderly, males and females been equally affected, 20% are in the post-partum women and malignancies.

With the aging population the incidence of AH has proportionally increased and with it, the role of the Physiotherapist has expanded.

Once the patient has had a diagnosis of AH and is medically stable, the role of Physiotherapy follows the same criteria as that of CH. This involves education, exercise prescription and mobility targeting range of movement (joint) and strengthening. All aimed at maximizing independent function.

When seeing an AH patient it is important to recognize that as an elderly cohort, they may also have other pathologies that can delay their progress and discharge if not recognized.

We present the case of a patient who presented with Acquired Haemophilia, and was stabilized successfully with medical intervention. However, post medical stability it was difficult to get the patient moving to enable her to return home to live independently. If she could not achieve independence then she would have to be discharged into care.

With Physiotherapy intervention, it became evident that the patient also had severe osteoarthritis in her hip, and it was this pathology that was prolonging her hospital admission and may have meant she could not return to independent living.

On referral to the Orthopedic team, and post Total Hip replacement she was able to return home independently.

**Conclusion**

The Physiotherapy role in patients with Acquired Haemophilia involves not only managing the bleed and its consequences but often managing pathologies found in the elderly patient.

The Physiotherapist has the skill base to be the primary practitioner in the assessment and management of the elderly patient that present with Acquired Haemophilia.

**Abi Polus**

Alfred Health

E-mail: a.polus@alfred.org.au

**Title**

The distribution of dedicated haemophilia physiotherapy service in Australia.

**Topic Area**

The distribution of dedicated haemophilia physiotherapy service in Australia with relation to haemophilia population.

**Abstract*****Introduction***

It has been well documented that physiotherapy management is an integral part of the multidisciplinary care of people with Haemophilia, due to musculoskeletal knowledge and skill in assessing and managing the musculoskeletal effects of the disease (Mulder et al 2021, Srivastava et al 2020). A study was undertaken to review if this represented within Australia and is displayed pictorially.

***Methods***

A study of how much available dedicated, funded, physiotherapy for haemophilia patients was undertaken by collating data from the ABDR and contacting the HTC centres around the country. Whilst unable to obtain information for some, most are represented.

***Results***

The results from the centres demonstrate many have access to available dedicated, funded, physiotherapy for haemophilia patients. The average per patient also appears low. Further study is recommended to determine how this is efficiently used.

***Conclusion***

There does not appear to be a uniform amount of access to dedicated haemophilia physiotherapy for each state. There appear to be areas within Australia that do not have specific access to haemophilia physiotherapy at all, suggesting patients in these areas may not be getting benefit recommended by WFH. More investigation would be of benefit to deduce what role physiotherapists are managing within clinics.

# PROGRAM

FRIDAY 8 OCTOBER 2021

0855	<b>Official Conference Welcome &amp; Acknowledgement of Country</b>	
	Gavin Finkelstein, President HFA and Dr Ritam Prasad, Conference Co-chair	
0900-1015	<b>Official Conference Welcome &amp; Acknowledgement of Country Chair: Dr Ritam Prasad</b>	
	<p>Short Personal Stories</p> <p>Overview of the Australian experience - spectrum of changes in bleeding disorders over the years ~ Prof Huyen Tran</p> <p>Are we there yet? The innovative future of bleeding disorders treatment ~ Dr David Lillicrap</p> <p>An overview of the impact of advances in treatment on quality of life and independence and on clinical practice. ~ Dr Liane Khoo</p> <p>Q&amp;A</p>	
1015-1045	<b>MORNING TEA</b>	
1045-1215	<b>Concurrent 1 - Managing bleeds under current new treatments</b>	<b>Concurrent 2 - Von Willebrand disease</b>
	<b>Chair: Jane Portnoy</b>	<b>Chair: Susie Couper</b>
	<p>The impact of new haemophilia treatments on people with haemophilia, parents and health professionals ~ Jane Portnoy</p> <p>Patient experiences</p> <p>Understanding bleeds under new treatments ~ Dr Julie Curtin</p> <p>Panel discussion and Q&amp;A Physiotherapist - Alison Morris Nurses - Joanna McCosker &amp; Beryl Zeissink</p>	<p>VWD personal experience ~ Perry</p> <p>VWD genetics, diagnosis and classification ~ Dr Simon McRae</p> <p>VWD personal experience ~ Simoni</p> <p>VWD treatment and future directions ~ Dr Nathan Connell</p>

1215-1325	<b>LUNCH</b>	
1325-1455	<b>Concurrent 3 - Sex, sexuality and intimacy</b>	<b>Concurrent 4 - Women and girls</b>
	<b>Chair: Scott Russell</b>	<b>Chair: Sharron Inglis</b>
	<p>Awkward conversations - Talking about sex and intimacy - Simone Sheridan</p> <p>WFH Ask Me Anything - can sex cause a bleed video - <a href="https://elearning.wfh.org/resource/ask-me-anything-can-sex-cause-a-bleed">https://elearning.wfh.org/resource/ask-me-anything-can-sex-cause-a-bleed</a></p> <p>Q&amp;A with panel of experts: Haematologist - A/Prof Chris Barnes Sexual health nurse consultant with disability expertise - Simone Sheridan Social worker - Alex Coombs Physiotherapist - Scott Russell Haemophilia nurse - Penny McCarthy</p>	<p>Introduction and personal story - Sharron Inglis</p> <p>Understanding, recording and reporting bleeding symptoms in girls and women - Joanna McCosker and Jaime Chase</p> <p>New clinical approaches in managing women and girls with bleeding disorders across the lifespan - Dr Mandy Davis</p> <p>Gynaecological issues for women and girls with bleeding disorders - Dr Angela Dunford</p> <p>Sport and exercise for girls and women - Hayley Coulson</p>
1455-1535	<b>AFTERNOON TEA</b>	
1535-1700	<b>Plenary 2 - Dealing with change</b>	
	<b>Chair: Sharon Caris</b>	
	<p>Dr Charlotte Keating is a psychologist, with a PhD in neuroscience, specialising in adolescents and executives. She is a passionate advocate for mental health, particularly for young people. Charlotte is a Member of the Australian Psychological Society and an Associate Member of the College of Clinical Psychologists.</p> <p><i>*This session will only be available live not on demand*</i></p>	
1800-1830	<p><b>Remembrance Service</b> A time for everyone to come together, reflect and remember family and friends in our community. Please click this URL to join. <a href="https://us06web.zoom.us/j/84850322433?pwd=NDF6Z0tad0x5OFV5WHUrSTJ0OXdjdz09">https://us06web.zoom.us/j/84850322433?pwd=NDF6Z0tad0x5OFV5WHUrSTJ0OXdjdz09</a></p>	
1900 - 2030	<p><b>Battle of the Trivia social activity on Friday night.</b> Join Zoom Meeting <a href="https://us06web.zoom.us/j/81403508398?pwd=eXJhRUVndWVPWkJIMVQrbURQWHIzQT09">https://us06web.zoom.us/j/81403508398?pwd=eXJhRUVndWVPWkJIMVQrbURQWHIzQT09</a> Meeting ID: 814 0350 8398 Passcode: 653880</p>	

**SATURDAY 9 OCTOBER 2021**

0900-1015	<b>Plenary 3 - Pain</b>	
	<b>Chair: Dr Liane Khoo</b>	
	<p>What's new in pain? Is it different now with new treatments? ~ Dr Liane Khoo</p> <p>Pain in haemophilia ~ Mr Paul McLaughlin</p> <p>A body and mind approach for pain management in people with bleeding disorders ~ A/Prof Carolyn Arnold</p> <p>Patient personal perspective on chronic pain ~ Dylan</p> <p>Osteoarthritis, exercise and pain: the GLA:D® program. ~ Dr Christian Barton</p> <p>Panel Q&amp;A</p>	
1015-1045	<b>MORNING TEA</b>	
1045-1215	<b>Concurrent 5 - Making the most of your health virtually</b>	<b>Concurrent 6 - Getting stronger safely</b>
	<b>Chair: Suzanne O'Callaghan</b>	<b>Chair: Abi Polus</b>
	<p>Embracing health care futures: Global trends in consumer health care innovation and where they're taking us ~ Dr Zaana Howard</p> <p>Future digital healthcare environment in Australia ~ Bettina McMahon</p> <p>New experiences with diagnostics and programs in bleeding disorders - Australian case studies: Telehealth and physiotherapy ~ Scott Russell Telehealth and infusion training ~ Erin Krake</p> <p>Panel discussion and Q&amp;A Nurses &amp; data manager - Janine Furmedge, Julia Ekert, Erin Krake Physiotherapist - Helen Dixon Social Worker - Sharon Danilovic Patient - Neil</p>	<p>Research into exercise for boys with haemophilia (DOLPHIN-II Trial) ~ Dr David Stephensen</p> <p>Less is more - getting the most out of limited time in the gym ~ Dr Mervyn Travers</p> <p>Panel Q&amp;A ~ Dr Merv Travers, Abi Polus and Tim</p>

1215-1325	<b>LUNCH</b>	
1325-1455	<b>Concurrent 7 - Youth - challenges, taboos and myths</b>	<b>Concurrent 8 - Getting older</b>
	<b>Chair: Robyn Shoemark</b>	<b>Chair: Jenny Lees</b>
	<p>Growing up ~ Dale's story</p> <p>Mother and son journey through teenage years ~ Heidi &amp; Sam</p> <p>Marina Passalaris</p> <ul style="list-style-type: none"> <li>• Resilience</li> <li>• How to deal with cyber bullying and communication</li> <li>• Looking after your mental health</li> </ul> <p>Panel Q&amp;A</p>	<p>Personal story ~ Zev</p> <p>Clinical issues with ageing ~ Prof Mike Makris</p> <p>Getting Older report - results and implementation ~ Suzanne O'Callaghan</p> <p><b>Panel Discussion</b> What are the issues and challenges ahead? Facilitator ~ Suzanne O'Callaghan Nurse ~ Stephen Matthews Physiotherapist ~ Frankie Mullen Psychosocial worker ~ Kathryn Body</p>
1455-1535	<b>AFTERNOON TEA</b>	
1535-1700	<b>Plenary 4 - Where to from here?</b>	
	<b>Chair: Dr Ritam Prasad</b>	
	<p>Haemophilia care in 2030 ~ Prof Mike Makris</p> <p>Where to from here? ~ Dr David Stephenson</p> <p>My vision of treatment and care into the future Patient/parent perspectives: Young man with severe haemophilia ~ Alan Parent of children with haemophilia ~ Claude Damiani Person with VWD ~ Shauna Adams</p> <p>Where to from here? Bleeding disorders treatment and care into the future ~ TBC</p> <p>Where to from here? Achieving the vision ~ Sharon Caris</p> <p>Panel discussion/Q&amp;A</p> <p>Wrap up and thank you!</p>	

# ABSTRACTS

**FRIDAY 8 OCTOBER**

**0900-1015**

**Plenary 1 – The changing world of bleeding disorders**

**Chair: Dr Ritam Prasad**

Short Personal Stories

**Overview of the Australian experience - spectrum of changes in bleeding disorders over the years**

**- Prof Huyen Tran**

*Director, The Ronald Sawers Haemophilia Treatment Centre, The Alfred Melbourne, VIC*

**Are we there yet? The innovative future of bleeding disorders treatment**

**- Dr David Lillicrap**

*Dr Lillicrap is a Professor in the Department of Pathology and Molecular Medicine at Queen's University, Kingston, Canada. He is a past member of the World Federation of Hemophilia's (WFH) Medical Advisory Board and Chair of the WFH's Research Committee.*

**An overview of the impact of advances in treatment on quality of life and independence and on clinical practice.**

**- Dr Liane Khoo**

*Haematologist, Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital, Sydney NSW*

**Q&A**

**FRIDAY 8 OCTOBER**

**1045-1215**

**Concurrent 1 - Managing bleeds under current new treatments**

**Chair: Jane Portnoy**

**The impact of new haemophilia treatments on people with haemophilia, parents and health professionals**

**~ Jane Portnoy**

*Social Worker, The Ronald Sawers Haemophilia Treatment Centre, The Alfred Melbourne, VIC*

**Patient experiences**

**Understanding bleeds under new treatments**

**~ Dr Julie Curtin**

*Dr Curtin is a Paediatric Haematologist with dual fellowship of the Royal College of Pathologists of Australasia and the Royal Australasian College of Physicians. She is currently a Senior Staff Specialist and Head of Haematology/Blood Bank at The Children's Hospital at Westmead (CHW). She is a Clinical Senior Lecturer of the Department of Paediatrics and Child Health of the University of Sydney. Dr Curtin has extensive experience in both clinical and laboratory paediatric haematology. She is the Director of the Kids Factor Zone Haemophilia Treatment Centre at CHW and has been on the executive committee of the Australian Haemophilia Centre Director's organisation since 2009.*

**Abstract -**

Over the past 5 - 10 years there has been a significant expansion in the available treatments for people with haemophilia. Some of these products are modified factor products with extended half-lives, others are non-factor products that may mimic the normal action of factor VIII (eg Emicizumab) or alter the coagulation pathway to reduce bleeding (eg Fitusiran). Gene therapy treatments for haemophilia are also in clinical trial. With each of these new products come improvement in quality of life for the patients, however breakthrough bleeds may still occur, be those traumatic or spontaneous. It is important to recognise these bleeds and treat in a timely manner with the appropriate product. Understanding how these new products work and how breakthrough bleeds need to be treated is important for patients and clinicians alike. An approach to the management of these bleeds for patients on the various categories of new treatments will be provided.

**Panel discussion and Q&A**

**Physiotherapist ~ Alison Morris**, *Senior Musculoskeletal Physiotherapist, Perth Children's Hospital, WA*

**Nurses ~ Joanna McCosker**

*Haemophilia Nurse Practitioner, Queensland Children's Hospital, QLD*

**And Beryl Zeissink**

*Clinical Nurse Consultant, Haemophilia Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital, QLD*

**FRIDAY 8 OCTOBER**

**1045-1215**

**Concurrent 2 - Von Willebrand disease**

**Chair: Susie Couper**

**VWD personal experience**

**~ Perry**

**VWD genetics, diagnosis and classification**

**~ Dr Simon McRae**

*Clinical and laboratory Consultant Haematologist, Launceston General Hospital, TAS*

**VWD personal experience**

**~ Simoni**

**VWD treatment and future directions**

**~ Dr Nathan Connell**

*Dr. Nathan Connell is an associate physician in the Hematology Division at Brigham and Women's Hospital, Assistant Professor of Medicine at Harvard Medical School, and the Clinical Chief of Hematology at Brigham and Women's Faulkner Hospital. His clinical focus is thrombosis and hemostasis with interest in the spectrum of clinical disorders related to von Willebrand factor. He co-chaired the ASH ISTH NHF WFH Guideline Panels on the Diagnosis and Management on von Willebrand disease. In addition to experience in clinical practice guideline development and systems-resource utilization as a systems-based hematologist, his research evaluates cost-effective and quality strategies for care delivery for patients with blood disorders.*

**FRIDAY 8 OCTOBER**

**1325-1455**

**Concurrent 3 – Sex, sexuality and intimacy**

**Chair: Scott Russell**

**Awkward conversations – Talking about sex and intimacy**

**~ Simone Sheridan**

*Simone is a clinical nurse consultant who works with the Sexual Health Service at Austin Health (Victoria). Simone works with people whose sexual function has been impacted by illness or injury. She is passionate about training health professionals to have the confidence in opening conversations around sex and intimacy. Simone also works as a family violence nurse educator and was recently the subject of a book called ‘The Care Factor’ which was published earlier this year.*

**Q&A with panel of experts:**

**Haematologist ~ A/Prof Chris Barnes**

*Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children’s Hospital, Parkville, VIC*

**Sexual health nurse consultant with disability expertise ~ Simone Sheridan**

*Sexual Health Nurse Consultant – Austin Health*

**Social worker ~ Alex Coombs**

*Social Worker, Ronald Sawers Haemophilia Centre, The Alfred, Melbourne, VIC*

**Physiotherapist ~ Scott Russell**

*Physiotherapy, Royal Brisbane & Women’s Hospital, Brisbane QLD*

**Haemophilia nurse ~ Penny McCarthy**

*Haemophilia Nurse Consultant, Ronald Sawers Haemophilia Centre, The Alfred*

**FRIDAY 8 OCTOBER**

**1325-1455**

**Concurrent 4 - Women and girls**

**Chair: Sharron Inglis**

**Introduction and personal story**

**~ Sharron Inglis**

**Understanding, recording and reporting bleeding symptoms in girls and women**

**~ Joanna McCosker**

*Haemophilia Nurse Practitioner, Queensland Children's Hospital, Brisbane QLD*

and **Jaime Chase**

*Haematology Clinical Nurse Specialist, John Hunter Children's Hospital*

**New clinical approaches in managing women and girls with bleeding disorders across the lifespan**

**~ Dr Mandy Davis**

*Clinical Haematology, Laboratory Haematology, The Alfred, Melbourne VIC*

**Gynaecological issues for women and girls with bleeding disorders**

**~ Dr Angela Dunford**

*Dr Angela Dunford is an Obstetrician Gynaecologist working at John Hunter and John Hunter Children's Hospitals in Newcastle, NSW. She completed a Fellowship in Paediatric and Adolescent Gynaecology through the Royal Children's Hospital Melbourne under the supervision of Professor Sonia Grover. After her Fellowship she returned to Newcastle and established an adolescent gynaecology service.*

**Abstract -**

Menarche is often the first bleeding challenge for young women with bleeding disorders. The gynaecology team is uniquely placed to help recognise and manage heavy bleeding for young women. Abnormal periods, dysmenorrhea and endometriosis can have a very negative impact on quality of life and symptoms are usually evident in early adolescence. The aetiology of abnormal uterine bleeding differs greatly across the lifespan and it is important that we consider this when managing symptoms. Fortunately, hormonal options are evolving as is our comfort with use of these medications in younger patients.

**Sport and exercise for girls and women**

**~ Hayley Coulson**

*Hayley is a physiotherapist who works at the Queensland Children's Hospital, Brisbane, QLD. Hayley has been working with bleeding disorders since 2016. She has enjoyed learning about the changes to treatments and how this can positively impact the physical capabilities of her patients.*

**FRIDAY 8 OCTOBER**

**1535-1700**

**Plenary 2 - Dealing with change**

**Chair: Sharon Caris**

Dr Charlotte Keating is a psychologist, with a PhD in neuroscience, specialising in adolescents and executives. She is a passionate advocate for mental health, particularly for young people. Charlotte is a Member of the Australian Psychological Society and an Associate Member of the College of Clinical Psychologists.

*\*This session will only be available live not on demand\**

**SATURDAY 9 OCTOBER**

**0900-1015**

**Plenary 3 - Pain**

**Chair: Dr Liane Khoo**

**What's new in pain? Is it different now with new treatments?**

**~ Dr Liane Khoo**

*Haematologist, Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital, Sydney, NSW*

**Pain in haemophilia**

**~ Mr Paul McLaughlin**

*Paul McLaughlin works as a Clinical Specialist Physiotherapist in Haemophilia at the Katharine Dormandy Haemophilia Centre at Royal Free Hospital in London, United Kingdom. In 2000 he completed his undergraduate degree at the University of Ulster in Belfast, N Ireland, and his Master's degree in Advanced Physiotherapy (Neuromusculoskeletal Rehabilitation) at King's College London in 2009. He is currently undertaking a National Institute for Health Research (NIHR) funded PhD investigating the potential of exercise based rehabilitation in the management of chronic pain associated with haemophilic arthropathy.*

**A body and mind approach for pain management in people with bleeding disorders**

**~ A/Prof Carolyn Arnold**

*Carolyn Arnold is Head of Pain Management in Alfred Health Melbourne, VIC where she works with the Multidisciplinary Team in the Haemophilia Treatment Centre. She has qualifications in Pain Medicine & Rehabilitation Medicine and is an Adjunct Clinical Associate Professor in the Department of Anaesthesia & Perioperative Medicine of Monash University, with interests in teaching, pain service development and outcomes of multidisciplinary pain treatments.*

**Abstract:**

People with Haemophilia & Bleeding Disorders can now look forward to new therapies and many living into older age. Quality of life and reducing years lived with disability are important. PWBD are all familiar with acute pain from bleeding episodes particularly joint bleeds (hemarthroses) and muscle bleeds. Repeated hemarthroses set up synovial inflammation which may evolve into haemophilic joint disease ("arthropathy") associated with chronic pain and joint damage.

In Australia we are advantaged by factor replacement programmes offering prophylactic and on demand treatment, sophisticated diagnostic joint imaging such as MRI and point of care ultrasound, multidisciplinary treatments, and novel gene therapies available to some through Clinical Trials.

This short presentation focuses on chronic pain management. Thirty to 50% of PWBD suffer pain from arthropathy. Management starts with optimum prevention strategies and acute pain treatments. Most important is early and skilled rehabilitation aimed to restore function, wise use of medications, the right forms of exercise, mind based tricks to manage tricky pain, and non-drug treatments as part of a healthy, happy, resilient lifestyle approach.

**Patient personal perspective on chronic pain**

~ Dylan

**Osteoarthritis, exercise and pain: the GLA:D® program.**

~ Dr Christian Barton

*Associate Professor Physiotherapy Physiotherapy, La Trobe Melbourne*

**Panel Q&A**

**SATURDAY 9 OCTOBER**

**1045-1215**

**Concurrent 5 - Making the most of your health virtually**

**Chair: Suzanne O'Callaghan**

**Embracing health care futures: Global trends in consumer health care innovation and where they're taking us**

**~ Dr Zaana Howard**

*Dr Zaana Howard is a recognised leader with unique expertise and more than 10 years of global experience in driving human centred design, culture change, leadership development and capability building; focusing on developing more compassionate, inclusive and human centred leaders, organisations and systems. Zaana spent the last 5 years at McKinsey where she served as Leader for McKinsey Design in Australia New Zealand and a Leader for Customer Experience and Design in the Public, Social and Health sector practices across Asia. During this time she developed a global track record in driving human centric strategies and transformations for public, social and health services while also gaining broad industry experience. Prior to joining McKinsey, Zaana was a leader working in consultancies and internal teams to deliver human-centric transformations; build organizational capabilities in human centred leadership and design; and launched a leading human-centred design academy. Zaana is driven by empowering vulnerable communities and co-creating systemic change with and for them.*

**Future digital healthcare environment in Australia**

**~ Bettina McMahon**

*Bettina is the Chief Executive Officer of Healthdirect Australia - the leading provider of virtual health services in Australia - and Chair of the Australasian Institute of Digital Health - Australia's peak body for digital health, health informatics, digital health leaders and practitioners.*

*She has significant experience in digital transformation in the health sector and an extensive track record in delivering major reforms in complex regulatory and stakeholder environments. Prior to joining Healthdirect Australia, Bettina was the Interim Chief Executive Officer at the Australian Digital Health Agency (ADHA), where she had also held other executive roles since 2009. Prior to that she worked for federal and State departments on technology enabled reform in financial services, transport and environmental sectors.*

**New experiences with diagnostics and programs in bleeding disorders - Australian case studies:**

**Telehealth and physiotherapy ~ Scott Russell**

*Physiotherapy, Royal Brisbane & Women's Hospital, Brisbane QLD*

**Telehealth and infusion training ~ Erin Krake**

*Nurse, Henry Ekert Haemophilia Treatment Centre, Royal Children's Hospital, Parkville VIC*

**Panel discussion and Q&A**

**Nurses & data manager - Janine Furmedge, Julia Ekert, Erin Krake**

*Henry Ekert Haemophilia Treatment Centre, Royal Children's Hospital, Parkville VIC*

**Physiotherapist** ~ Helen Dixon

**Social Worker** ~ Sharon Danilovic

**Patient** ~ Neil

**SATURDAY 9 OCTOBER**

**1045-1215**

**Concurrent 6 – Getting stronger safely**

**Chair: Abi Polus**

**Research into exercise for boys with haemophilia (DOLPHIN-II Trial)**

**~ Dr David Stephensen**

*Physiotherapist, the Kent Haemophilia and Thrombosis Centre, and the Haemophilia Centre at the Royal London Hospital, United Kingdom.*

**Abstract:**

“What is the role of exercise for both prevention and treatment of joint damage in haemophilia?” is one of the top unanswered questions that concern patients, carers and healthcare professionals most. At present, there is a lack of robust evidence to determine whether muscle strengthening exercise can improve or negatively affect outcomes for young children with haemophilia. With the help of boys with haemophilia, their parents and physiotherapists we have developed an exercise programme designed to increase muscle strength. We recently showed the exercise programme had no harmful effects, was acceptable to children with haemophilia and that they were willing to participate in a study to answer the question, “does muscle strengthening help improve the long-term health of children with haemophilia?” To answer this question, we will allocate 66 boys with haemophilia to a group that is asked to complete the 12-week exercise routine to strengthen their leg muscles and another 66 boys to a group that does not do the exercises. The boys will be allocated at random, so that each boy has an equal chance of being in either group. We will monitor the boys throughout the study by measuring their muscle strength, how far they can walk in six-minutes, time taken to ascend and descend 12 steps, and how high and far they can hop and jump. We will also record how physically active the boys are using a wrist band as well as how satisfied they are with their health.

**Less is more - getting the most out of limited time in the gym**

**~ Dr Mervyn Travers**

*Senior Research Scholar, School of Physiotherapy, The University of Notre Dame Australia, Perth, WA.*

**Abstract:**

Background: Despite a pressing societal need and increasing advocacy, many health professionals lack the knowledge and confidence to prescribe safe and effective resistance exercises for their clients. Similarly, many people attend the gym without the appropriate instruction to ensure that it is safe, efficient, and effective. What is often needed is guidance on what exercises to do, how much to lift, how many times and how often to do so.

**Aims / Objectives:** A key feature of a successful strength training programme is consistency. A major barrier to achieving this is time. This session will provide an update on contemporary strength training parameters so that you can spend the minimum time in the gym and still get strong.

**Approach:** A streamlined and user-friendly approach to gym-based exercise will be presented. This framework is based on synthesis of the most recent strength and conditioning evidence, rehabilitation frameworks and extensive clinical experience in gym-based rehabilitation. Video examples of patients implementing the above approach will punctuate this presentation.

Note: This presentation does not provide tailored exercise advice for any individual. People are advised to seek guidance of an appropriately trained health professional before commencing strength training.

**Panel Q&A**

**~ Dr Merv Travers, Abi Polus and Tim.**

**SATURDAY 9 OCTOBER**

**1325-1455**

**Concurrent 7 - Youth – challenges, taboos and myths**

**Chair: Robyn Shoemark**

This session will address some of the challenges for youth living with a bleeding disorder and their families. It will include personal experiences and how some of the challenges have been addressed.

**Growing up ~ Dale's story**

**Mother and son journey through teenage years ~ Heidi & Sam**

**Marina Passalaris**

- Resilience
- How to deal with cyber bullying and communication
- Looking after your mental health

**Panel Q/A**

**SATURDAY 9 OCTOBER**

**1325-1455**

**Concurrent 8 - Getting older**

**Chair: Jenny Lees**

### **Personal story**

#### **Clinical issues with ageing**

**~ Prof Mike Makris**

*Professor of Haemostasis and Thrombosis at the University of Sheffield, United Kingdom*

#### **Abstract:**

The availability of effective, safe medications to treat persons with bleeding disorders has resulted in improved life expectancy which, in the cases of mild bleeding disorders, is close to the general population. Persons with haemophilia have a reduced rate of heart disease but they are equally affected by the diseases found in the general population of similar age. Persons with haemophilia are likely to have worse joint disease due to recurrent bleeds as well as more frequent osteoporosis. Many persons with haemophilia were infected with chronic hepatitis C for which there is now safe and highly effective tablet treatment. All persons with chronic hepatitis C should be treated to eradicate the virus. All persons with a history of chronic hepatitis C which was eradicated with treatment, should have a fibroscan of their liver and those with cirrhosis should have regular ultrasound scans to screen for liver cancer. Once persons with haemophilia are over 80, the medical problems they will suffer from are likely to be more challenging than their haemophilia.

#### **Getting Older report – results and implementation**

**~ Suzanne O’Callaghan**

*Policy Research and Education Manager at Haemophilia Foundation Australia, East Malvern VIC*

#### **Panel Discussion**

##### **What are the issues and challenges ahead?**

**Facilitator ~ Suzanne O’Callaghan**

**Nurse ~ Stephen Matthews**

**Physiotherapist ~ Frankie Mullen**

**Psychosocial worker ~ Kathryn Body**

**SATURDAY 9 OCTOBER**

**1535-1700**

**Plenary 4 - Where to from here?**

**Chair: Dr Ritam Prasad**

**Haemophilia care in 2030 - Prof Mike Makris**

*Professor of Haemostasis and Thrombosis at the University of Sheffield, United Kingdom.*

**Abstract:**

Predicting the future is challenging but during this lecture I will make some educated guesses of what haemophilia care will look like in 2030. I believe all the current concentrates will still be available and will be joined in the next 2-3 years by a truly longer acting FVIII concentrate called BIVV-001. The bispecific antibodies such as emicizumab (Hemlibra) which are given subcutaneously will have a major presence and several new bispecific antibodies are likely to be available. A potential problem with persons growing up in the subcutaneous era will be individuals with severe haemophilia who will be unable to give themselves intravenous injections of concentrate to stop bleeding. Gene therapy is likely to be licensed for both haemophilia A and B, but I believe only a minority (<10%) of persons with severe disease in affluent countries are likely to have had it. It is likely that haemophilia care will be largely delivered by specialist haemophilia nurses who will be able to examine and prescribe drugs for the patients.

**Where to from here? - Dr David Stephenson**

*Physiotherapist, Kent Haemophilia and Thrombosis Centre, and the Haemophilia Centre at the Royal London Hospital, United Kingdom*

**My vision of treatment and care into the future**

**Patient/parent perspectives:**

**Young man with severe haemophilia - Alan**

**Parent of children with haemophilia - Claude**

**Person with VWD - Shauna**

**Where to from here? Bleeding disorders treatment and care into the future - TBC**

**Where to from here? Achieving the vision - Sharon Caris**

**Panel discussion/Q&A**

**Wrap up and thank you!**









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