Abstracts & Handbook

HAEMOPHILIA FOUNDATION AUSTRALIA

WELCOME

Welcome to the 21st Australian Conference on haemophilia, VWD & rare bleeding disorders. We hope you enjoy the conference and find it a stimulating and informative meeting. We encourage you to participate actively to add to the richness of this exciting conference.

We sincerely thank the Program Committee for bringing what we hope will be a very exciting and informative meeting to you. Their hard work and professional commitment is greatly appreciated.

Gavin Finkelstein
President
Haemophilia Foundation Australia

Sharon Caris
Executive Director
Haemophilia Foundation Australia

Program Committee

Sharon Caris	Executive Director, HFA
Kara Cordiner	Clinical Nurse Consultant The Alfred, VIC
Lauren Green	Manager, HFQ
Andrea Johannessen	Executive Officer, AHCDO
Anne Jackson	Nurse Consultant Women's and Children's Hospital SA
Dr Liane Khoo	Haematologist Royal Prince Alfred Hospital, NSW
Alex Klever	Clinical Nurse Queensland Haemophilia Centre
Alison Morris	Senior Musculoskeletal Physiotherapist Perth Children's Hospital
Suzanne O'Callaghan	Policy Research and Education Manager, HFA
Abi Polus	Senior Clinical Physiotherapist The Alfred Hospital, Melbourne
Jane Portnoy	Social Worker, The Alfred
Dr Heather Tapp	Haematologist Women's and Children's Hospital SA

GENERAL INFORMATION

Conference Organisers

Haemophilia Foundation Australia
7 Dene Ave, Malvern East VIC 3145
P: 03 9885 7800 E: hfaust@haemophilia.org.au W: www.haemophilia.org.au

Venue
Pullman on the Park
192 Wellington Parade East Melbourne

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. Daily program changes will be notified during the Conference.

Mobile Phones
As a courtesy to delegates and speakers, please switch off or set your mobile phones to silent during all sessions. If you need to take a call please do not answer your mobile until you have left the room.

Name Tags
Entrance to the Exhibition area and Conference sessions will be limited to name tag holders only. If you misplace your name tag, please advise HFA staff at the Registration and Information Desk.

Internet
Wifi is complimentary for all delegates. Please follow the below steps to connect:

Step 1: Connect to Pullman in Wifi settings
Step 2: You will be redirected to a login page
Step 3: Select "Complimentary Internet"
Step 4: Scroll down to the bottom and type "Accept" into the box and connect

Onsite Parking
For conference delegates the Pullman offer a discounted self-park rate of $35.00 per vehicle,per day from 8am – 5.30pm.

The entrance to the car park is the main entrance of the hotel at 192 Wellington Parade, East Melbourne.

HFA funded parking:

- Collect your ticket and hand to HFA information desk. You will be given another ticket to exit.

If you are paying for parking:

- Guests will need to retrieve a ticket at the boom gate.
- Prior to exiting the building each guest will need to collect a validation ticket, from Concierge.
- To make payment, guests will need to go to the pay machine, located on level B1 of the car park.
- Guests will need to ensure the second ticket received from concierge is inserted into the machine following the original ticket, before making payment. This will ensure the discounted rate is applied.
- Once payment has been made, the guest will receive an exit ticket and receipt. Each guest will enter the hotel carpark via the driveway on Wellington Parade.

Registration and Information Desk

All enquiries should be directed to the Registration and Information Desk located in the main exhibition area and will be open at the times listed below:

Thursday 10 October	**17:00-19:30**
Friday 11 October	**07:30-17:00**
Saturday 12 October	**07:30-15:35**

Hospitals for haemophilia treatment

There will be no treatment room at the conference venue. Delegates must make their own plans for medical services and treatment. All Delegates should plan well in advance to bring sufficient supplies of haemophilia treatment products to meet treatment requirements.

The Alfred - Ronald Sawers Haemophilia centre
1st Floor, South Block Commercial Road, Melbourne Vic 3004
T 03 9076 2178
Emergency 03 9076 2000 (switchboard)
Fax 03 9076 3021

Royal Children's Hospital - the Henry Ekert Haemophilia Treatment centre
Flemington Road Parkville Vic 3052
T 03 9345 5099
Emergency 03 9345 5522 and ask for haematologist on call
Fax 03 9349 1819

Childcare

Childcare is not available at the Conference and children are not permitted in Conference sessions.

SOCIAL PROGRAM

Thursday 24 August

Welcome & Exhibition Opening
18:30-19:30
Exhibition
Come to see the exhibition and meet people before the conference. Free for all registered delegates.

Friday 25 August

Remembrance Service
18:00-18:45
Room: Latrobe
The Remembrance Service is a time to remember friends and family, and the people we have cared for. The service is non-religious and everyone is welcome.

Conference Dinner
19:00 til 23:00
Room: Junior Ballroom
Come and join your fellow delegates for an informal dinner, dancing and some presentations. The dinner will be free seating. Dinner tickets must have been purchased in advance - no tickets will be available during the conference or on the night.

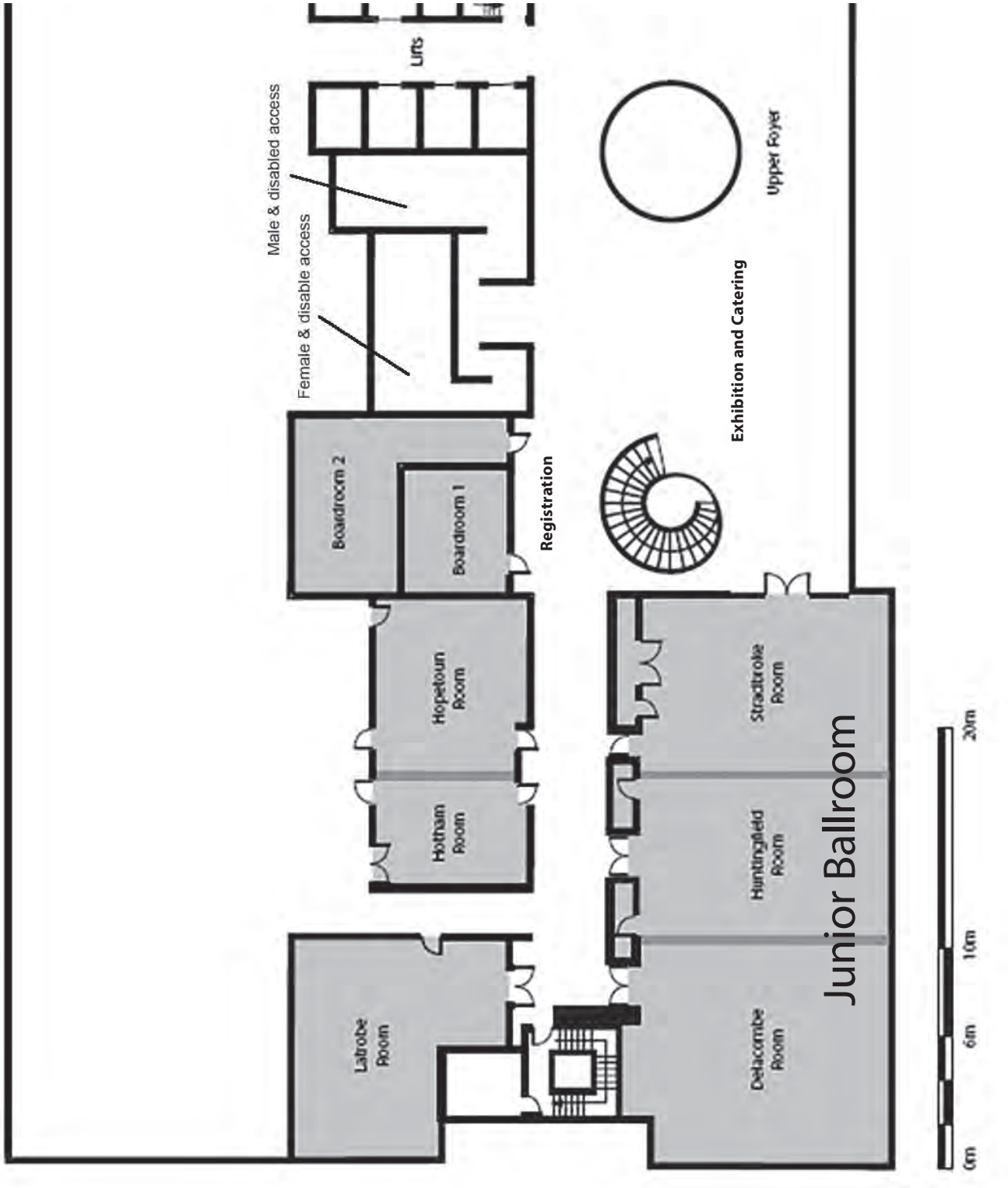
Saturday 26 August

Men's Breakfast - Ask me Anything
Chair: Dan Credazzi
Dr Glenn Pierce, Dale Spencer, Zev Fishman, Dr Chris Barnes
07:00 – 08:30
Room: Latrobe

Women's Breakfast – Mindfulness strategies on the go
Chair: Sharon Caris
07:00 – 08:30
Room: Hopetoun

Tickets to both the Men's and Women's breakfast must have been pre-purchased, no tickets are available during the conference.

CONFERENCE VENUE MAP – LEVEL 1



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NSW 2065
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NSW 2153
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Trade Displays/Exhibition Booths
Trade displays/exhibition booths are accessible to all conference delegates. Exhibitors in the trade display are required to be compliant with the Medicines Australia Code of Conduct, which prohibits promotion of prescription medicines to anyone who is not a registered Healthcare Professional. Therefore, it is unlikely that staff at company trade displays/ exhibition booths will be able to provide information about medicines to non-healthcare professionals.

Filming/Videography
No filming or recording is permitted at any conference sessions, trade displays, meal and break out areas held for the conference by any Delegates.
HFA may undertake filming for education purposes in certain circumstances.

Photography
HFA will have an official conference photographer onsite. Photographs will only be taken with your consent for use by HFA. Please advise photographer if you do not wish to be photographed.

POSTER ABSTRACTS

The poster display is in the main foyer area. All posters will be displayed for the duration of the conference. Poster authors will be available at their poster the following times for discussion and questions.

Name	Co-Authors	Title of Poster Abstract
Alex Klever	Beryl Zeissink	A Reflection of surgery performed in Queensland over the last 21 years
Elise Mosey	Hayley Coulson, Joanna McCosker, Nathan Morgan	Physiotherapy management of an atraumatic hamstring haematoma in a patient with no history of bleeding disorders: A Case Study
Yarrow Ruane		Emerging peer support needs in the Victorian bleeding disorders community
Alex Klever	Beryl Zeissink, Joanna McCosker, Tamara Shannen	Nursing Reflections of Transitioning Patients onto Hemlibra in Queensland

Name: Alex Klever
Co-authors: Beryl Zeissink
Institution/Organisation: Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital
Title: A Reflection of surgery performed in Queensland over the last 21 years

1. Outline and description of topic/content of presentation/project
The Queensland Haemophilia Centre has been keeping formal statistics of surgery since 2002. The Royal Children's Hospitals statistics are not included. People with Haemophilia or other Inherited Bleeding disorders, can experience excessive bleeding following surgery if untreated or inadequately covered with factor replacement therapy. The severity of the bleeding disorder, type of bleeding disorder and extent of surgery will have implications on the degree of bleeding and complications that can develop. With many advances in surgery plus an aging population, a growing number of surgeries and more complicated surgeries are being performed in patients with bleeding disorders. Most surgeries are planned; however, some surgeries occur under emergency circumstances. The expected outcome of any surgery is to extend life or relieve symptoms.

This poster will reflect upon surgery performed over the last 21 years with direct supervision or advice from the Queensland Haemophilia Centre. Over this time, there has been an increase in patient numbers generally, as well as identification of patients that were not originally included in numbers eg platelet defects. Challenges identified has been an increase in private and regional surgery, which required intensive planning, coordination and communication. New therapies have required a change of approach in how to manage surgery.

Surgery types have included Orthopaedics, Gastroenterology, Ear Nose & Throat, Vascular, Cardiac, Neurosurgery, Maxillo-Facial, etc.

2. Conclusions/outcomes
A major role of the Haemophilia team is to liaise with the surgeon, anesthetist, and multidisciplinary team to optimize patient outcomes. It is therefore stressed that in order to avoid complications, patients play an important role in this process. It is important that patients indicate to their surgical team members their diagnosis and importance of making contact with the Haemophilia Treatment Centre.

Name: Elise Mosey
Co-authors: Hayley Coulson, Joanna McCosker, Nathan Morgan
Institution/Organisation: Queensland Children's Hospital
Title: Physiotherapy management of an atraumatic hamstring haematoma in a patient with no history of bleeding disorders: A Case Study

1. Outline and description of topic/content of presentation/project
Atraumatic muscle bleeds are uncommon, especially in patients that have no history of a bleeding disorder. This unusual presentation of an 8-year-old patient with pain limited range of motion of the right knee and minor swelling to the right posterior thigh underwent an extensive medical work up to exclude the presence of a neoplasm. He was subsequently diagnosed with two bleeding disorders, mild haemophilia A (FVIII 2%) and von Willebrand's Disease type 2M (VWD2M). The haematoma in the semitendinosus muscle in the posterior thigh was slow to recover following the initiation of factor 8 replacement. Best practice management of muscle bleeds involves timely physiotherapy intervention, however in this case given the lack of bleeding history, time to diagnosis and transfer to the Haemophilia centre, physiotherapy intervention was delayed 21 days.

2. Conclusions/outcomes
The initial diagnosis of a suspected haematoma was via CT scan. Serial MRIs were performed to monitor the resolution of the hamstring bleed which measured 13x15x55mm at 4-weeks post-injury, 11x44x10mm at 5-weeks, 22x3x4mm at 7-weeks, and was completely resolved by 13-weeks. Physiotherapy management acutely involved immobilisation via use of a wheelchair and a brief period of compression for swelling. After resolution of the bleed on imaging, post-acute physiotherapy intervention included provision of a range of motion knee brace for prevention of rebleeds on return to school and guidance regarding return to sport at 17 weeks post-injury. The haematoma resolution of 13 weeks is slower than expected and could be partially related to delay of initial physiotherapy treatment at the Haemophilia treatment centre. Delays in physiotherapy management can be associated with increased chances of rebleeds and poorer functional outcomes, subsequently a conservative approach to management was imperative to ensure optimal patient outcomes.

Name: Yarrow Ruane
Institution/Organisation: Haemophilia Foundation Victoria
Title: Emerging peer support needs in the Victorian bleeding disorders community

In the wake of the global COVID-19 pandemic and significant treatment changes for bleeding disorders, it is likely that the Victorian bleeding disorders community's needs have shifted. In 2023, Haemophilia Foundation Victoria (HFV) conducted a preliminary community needs assessment to identify areas of expressed need relevant to the foundation's peer support programming.

The community needs assessment is intended to provide preliminary insights into those social needs or issues among the Victorian bleeding disorders community which peer support programmes are well-placed to address. HFV's stated vision is to connect, support and empower Victorians with a bleeding disorder and their families. As a community-led organisation, peer support remains a key pillar of this vision. It is of ongoing importance to understand which community needs are best served by peer support and how that support should be delivered. This poster summarises HFV's findings to date.

Findings were synthesised from 2 digital surveys, 1 physical survey and 1 online forum. Data collection spanned from July 2021 to June 2023. Surveys were issued in the lead-up to or follow-up from HFV peer support events, while the online forum concerned HFV programming more broadly. A total of 30 people across a variety of ages, genders, and Victorian locations were surveyed, including 24 HFV members and 6 non-members of HFV.

Significant needs were expressed for:

(1) Peer-led discussions regarding new treatments and health management systems, among both adults and youths
(2) Social connection with both same-age peers and mentors, among youths
(3) Practical advice on navigating adulthood with a bleeding disorder, among youths

Several secondary needs were also expressed in the data, especially related to peer support accessibility across a number of axes.

These results provide scope for HFV peer support activities and program evaluations, while offering some insights relevant to the broader bleeding disorders community.

Name: Alex Klever
Co-authors: Beryl Zeissink, Joanna McCosker, Tamara Shannen
Institution/Organisation: Queensland Haemophilia Centre, Royal Brisbane & Women's Hospital & Queensland Haemophilia Centre, Queensland Children's Hospital
Title: Nursing Reflections of Transitioning Patients onto Hemlibra in Queensland

1. Outline and description of topic/content of presentation/project
On the 2nd of November 2020 the National Blood Authority (NBA) announced Hemlibra was available to people with severe and moderate Haemophilia A with or without inhibitors to factor VIII. Despite the challenges of the pandemic, the Queensland Children's Hospital (QCH) and Royal Brisbane and Women's Hospital (RBWH) started making plans to roll out Hemlibra to all the eligible patients.

This poster will outline the rationale for patient selection, practical educational requirements, mode of delivery of education, implementation, and reflection on outcomes.

The Haemophilia centre goal was to transition as many eligible patients onto Hemlibra within 12 to 18 months.

Patient selection was based on clinical need and opportunity including a) patients with chronic inhibitors b) difficult venous access and c) those with current appointments locally and at outreach sites. There was a small cohort of patients who had their transition to Hemlibra delayed due to prospective surgery due to limited real life experience managing surgery on Hemlibra. There were also those patients & families who were not currently engaged with the HTC and those who are slow adopters of change.

Nursing staff utilised varying modalities including face to face and telehealth to provide education and support to transition &/or initiate Hemlibra prophylaxis.

In general patients were seen for five weekly visits with some fast adopters only requiring a minimum of 2 sessions and phone follow up prior to first week maintenance. Dosing regimes were tailored to specific patient characteristics. In the paediatric setting the most common regime was fortnightly dosing whilst in the adult setting fortnightly or monthly were the norm.

2. Conclusions/outcomes
Most eligible patients in Queensland have now been transitioned to Hemlibra. These patients were transitioned onto Hemlibra within a 12-month period in both centres. Despite challenges of the pandemic, geographical locations, and remoteness of patient cohort the roll out was successful for patients and centre staff.

PROGRAM

THURSDAY 24 AUGUST 2023

1830-1930	**Welcome and Exhibition Opening** **Room: Exhibition Space**

FRIDAY 25 AUGUST 2023

0845	**Official Conference Welcome**
	Hon Ged Kearney MP, Assistant Minister for Health and Aged Care Gavin Finkelstein, HFA President & Acknowledgement of Country
0850-1015	**Plenary 1** **Treatment landscape into the future** **Room: Junior Ballroom**
	From then to now – Gavin Finkelstein New and emerging treatments for bleeding disorders - what's in the pipeline/personalised medicine - what does this mean in the context of bleeding disorders/haemostasis and what it can mean for treatment – Dr Glenn Pierce Australian experience and challenges with new and emerging (inc clinical trials) haemophilia therapies, what needs to be managed differently - Dr Liane Khoo Access to new therapies, policy, regulation and funding – Jo Cameron Hopes for the future: reflections from a parent – Clare
1015-1045	**MORNING TEA**
1045-1215	**Plenary 2** **Gene Therapy** **Room: Junior Ballroom**
	Chair: Prof Huyen Tran
	Overview – Dr Glenn Pierce Psychological overview – Jane Portnoy Overview into AHCDO Gene therapy roadmap – Prof Huyen Tran Q&A
1215-1330	**LUNCH**

1330-1500	**Concurrent 1** **The impact of new treatments on children and families** **Room: Stradbroke**	**Concurrent 2** **Rare Bleeding Disorders** **Room: Huntingfield**	**Concurrent 3** **Making Career Choices** **Room: Delacombe**
	Chair: Anne Jackson	**Chair: Dr Jane Mason**	**Chair: Penny McCarthy**
	The impact of new treatments on children & families - Anne Jackson Non-factor treatment for Haemophilia A - new choices, new challenges - Janine Furmedge Physical activity in children - Nicola Hamilton Parent perspective: Impact of new treatment on family – Leanne Young adult and his mother's perspective: Catherine and Lachlan Q&A	Personal Experience - Chauntelle, FXIII Rare Bleeding Disorders - Dr Sally Campbell Personal experience - Jenny, acquired haemophilia A Acquired Haemophilia – can we do better with Emicizumab? - Dr Jane Mason Hereditary Hemorrhagic Telangiectasia – HHT - Nursing perspective - Alex Klever Q&A	Career choices over a lifetime. Do they change with new treatments? – Penny McCarthy Personal Stories Career Choices. Theories and strategies that can help - Jon Hazelton Employment: discrimination, disclosure and the law – Mark Waters Personal story - Dale Panel Discussion and Q&A: - Speakers and: - Nurse: Kara Cordiner - Physiotherapist: Abi Polus - Social worker: Nicoletta Crollini
1500-1530	**AFTERNOON TEA**		
1530-1700	**Plenary 3** **Women and girls with bleeding disorders** **Room: Junior Ballroom**		
	Chair: Dr Meredith Wiggins		
	Personal perspectives on the challenges and issues of living with a bleeding disorder - Shauna - Cheryl Medical perspectives on diagnosis, assessment, treatment and care - Haematologist: Dr Briony Cutts - Gynaecologist: Prof Sonia Grover Q&A		

1800	**Remembrance Service** **Room: Latrobe**
1900	**Conference Dinner** **Room: Junior Ballroom**

SATURDAY 26 AUGUST 2023

0700-0830	**Men's Breakfast - Ask me Anything**
	Chair: Dan Credazzi **Panel: Dr Glenn Pierce, Dale Spencer, Zev Fishman, Dr Chris Barnes** **Room: Latrobe**
0700-0830	**Women's Breakfast – Mindfulness strategies on the go**
	Chair: Sharon Caris **Room: Hopetoun**
0845-1015	**Plenary 4** **Managing Mild Haemophilia** **Room: Junior Ballroom**
	Chair: Dr Heather Tapp
	Mild Haemophilia – the new frontier – Dr Heather Tapp Personal perspective from a young adult and his dad - Louis and Tom Mild haemophilia in adults: medical issues – Dr Stephanie P'ng Nursing management, including surgery in mild haemophilia – Alex Klever Physical activities and sport across the lifespan – Abi Polus
1015-1045	**MORNING TEA**

1045-1215	**Concurrent 4** **Inheritance, genetics and family planning** **Room: Stradbroke**	**Concurrent 5** **Is it a bleed? MSK recovery** **Room: Huntingfield**	**Concurrent 6** **Getting older** **Room: Delacombe**
	Chair: **Dr Chris Barnes**	**Chair:** **Jo Newsom**	**Chair:** **Suzanne O'Callaghan**
	Personal story Genetics, Reproduction and Family Planning - Geneticist and Genetic Counsellor: A/Prof Kristi Jones and Lucy Kevin Q&A	Conditions that can mimic a bleed - Dr Rob Russo Recovering from a joint bleed – how long does it really take? - Ali Morris Muscle bleed recovery – Jarrad King Q/A panel	Personal story - Mike Medical issues - Dr Liane Khoo Hep C and liver health - Dr David Iser The power of friendship for older people - Marcia Fearn Panel discussion and Q&A:Speakers and Nurse: Jayne Treagust Physiotherapist: Cathy Haley Psychosocial worker: Kathryn Body

1215-1330	**LUNCH**		
1330-1500	**Concurrent 7** **Pregnancy, childbirth and newborns** **Room: Stradbroke**	**Concurrent 8** **VWD** **Room: Huntingfield**	**Concurrent 9** **Pain** **Room: Delacombe**
	Chair: Dr Jane Mason	**Chair: Dr Chee Wee Tan**	**Chair: Jonathan Spencer**
	Nursing perspective – pregnancy and delivery management - Robyn Shoemark Delivery and birth – Dr Iniyaval Thevathasan Best practice management of Previously Untreated Patients - Dr Simon Brown Personal Story – Rebecca Q&A	Personal stories: Man with severe VWD ~ Adam Woman with mild VWD ~ Susie VWD diagnosis - Dr Geoffrey Kershaw Guideline on Clinical Management of von Willebrand disease - Dr Nalini Pati Q&A	Better Pain Management for Haemophilia in the Future – Dr Carolyn Arnold Physiotherapy approaches to pain management in haemophilia care - Cat Pollard Strategies to manage procedural and acute pain in children – Michelle Perrin Q&A

1500-1530	**AFTERNOON TEA**
1530-1700	**Plenary 5** **Working towards good health** **Room: Junior Ballroom**
	Chair: Sharon Caris
	Beyond resilience comes adaptability: thriving in a changing world - Dr Charlotte Keating Panel - What are the challenges we are facing, moving forward and how to keep connected Dr Glenn Pierce Prof Huyen Tran Dr Liane Khoo Dr Chris Barnes Claude Shauna

ABSTRACTS

FRIDAY 24 AUGUST 2023
0845 – 1015
Plenary 1: Treatment landscape into the future
Chair: David Fagan
Room: Junior Ballroom

Official Conference Welcome
Hon Ged Kearney MP, Assistant Minister for Health and Aged Care (Pre-recorded)
Gavin Finkelstein, HFA President & Acknowledgement of Country

From then to now – Gavin Finkelstein
Gavin is HFA and HFWA President

New and emerging treatments for bleeding disorders - what's in the pipeline/ personalised medicine - what does this mean in the context of bleeding disorders/ haemostasis and what it can mean for treatment – Dr Glenn Pierce MD PhD
Independent biotech consultant and former entrepreneur-in-residence at Third Rock Ventures. He serves on NHF-MASAC and is the elected VP Medical for WFH. Glenn splits time between La Jolla and San Francisco.

Australian experience and challenges with new and emerging (inc clinical trials) haemophilia therapies, what needs to be managed differently - Dr Liane Khoo
Haematologist Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital

Access to new therapies, policy, regulation and funding – Jo Cameron
Director, Commercial Blood Products, National Blood Authority

There are several pathways than can be used for the introduction of new products proposed for government funding. These include the Pharmaceutical Benefits Scheme (PBS), Medical Benefits Scheme (MBS), the National Health Reform Agreement (NHRA) and the National Blood Arrangements, managed by the National Blood Authority (NBA). Interested parties, including patient groups or suppliers, can propose changes to the products or services that are publicly funded under the national blood arrangements. Anyone wishing to make changes will be asked to provide evidence to support their proposal, including evidence-based evaluation of the product/service they nominate, as set out under Schedule 4 of the National Blood Agreement. In order to make the application process consistent, a comprehensive Multi-Criteria Analysis Framework has been developed to assess proposals. Where appropriate, the Commonwealth's Medical Services Advisory Committee (MSAC) health technology assessment process is also used to inform the cost effectiveness of proposals. Several proposals regarding new Haemophilia treatment products have been submitted over time and have been referred to MSAC for advice. This advice informs Government's decision making regarding the different funding pathways.

Hopes for the future – Clare Brunet
Claire is the mother of two young boys who have severe haemophilia. Her youngest boy was diagnosed at 6 months old, and her second was diagnosed at birth.

FRIDAY 24 AUGUST 2023
1045-1215
Plenary 2: Gene Therapy
Chair: Prof Huyen Tran
Room: Junior Ballroom

Science, Risks, benefits, outcomes, eligibility, clinical experience
Issues and challenges: immunity, children, inheritance, longevity of effect, retreatment, treat now or wait? – Dr Glenn Pierce MD PhD
Independent biotech consultant and former entrepreneur-in-residence at Third Rock Ventures. He serves on NHF-MASAC and is the elected VP Medical for WFH. Glenn splits time between La Jolla and San Francisco.

Psychological overview – Jane Portnoy
Jane is an Accredited Mental Health Social Worker and Family Therapist working at the Alfred in Melbourne as well as in private practice at Alma Family Therapy Centre.

Overview into AHCDO Gene therapy roadmap – Prof Huyen Tran
Director, The Ronald Sawers Haemophilia Treatment Centre, The Alfred Melbourne, VIC

Q/A Panel

FRIDAY 24 AUGUST 2023
1330-1500
Concurrent 1
The impact of new treatments on children and families
Chair: Anne Jackson
Room: Stradbroke

The impact of new treatments on children & families - Anne Jackson
Nurse Consultant – Haemophilia, Women's & Children's Hospital, SA

Access to new treatments for children with haemophilia opens up options to tailoring treatment to individual patients and their needs. The new treatments available currently and on the horizon bring new challenges and improvements in care. In this session we will explore the impact on children with haemophilia and their family, including the benefits and challenges of new treatments, different routes of administration as well as the impact on activities and joint health. We will hear directly from a parent and a young person with haemophilia how they have adapted to the new treatment.

Non-factor treatment for Haemophilia A - new choices, new challenges - Janine Furmedge
Haemophilia Clinical Nurse Consultant - The Royal Children's Hospital, Melbourne.

Non-factor treatment (Hemlibra) was funded in Australia in late 2020 for people with severe and moderate haemophilia A. This new treatment has brought many positive changes for children and young people. But change can also bring new challenges. This presentation will highlight the impact of a new subcutaneous treatment on children and young people, their parents and health care providers at a paediatric haemophilia treatment centre.

Physical Activity in Children - Nicola Hamilton
Physiotherapist - The Royal Children's Hospital, Melbourne

Physical activity, exercise and sport are recommended for all children and adolescents as part of day-to-day health and wellbeing. This talk explores safety, precautions or adaptations that need to be considered for those new to physical activity and sport as a result of new treatments, as well as some basic practical advice that should be considered when kids are active.

Parent perspective: Impact of new treatment on family – Leanne
Leanne is a mum of twins, Kai and Chloe who are 5 years old. Her son (Kai) was diagnosed with Severe Haemophilia A when he was 9 months old

Young adult Perspective: Catherine and Lachlan
Catherine has a family history of haemophilia A, she is the 3rd generation carrier in her family of severe haemophilia A. Lachlan is 16 years of age and has severe haemophilia A, he was diagnosed at 1 day old.

FRIDAY 24 AUGUST 2023
1330-1500
Concurrent 2
Rare Bleeding Disorders
Chair: Dr Jane Mason
Room: Huntingfield

Personal Experience - Chauntelle, FXIII

Rare Bleeding Disorders - Dr Sally Campbell
Haematologist - Royal Brisbane & Women's Hospital, QLD Haemophilia Centre

Personal experience - Jenny, acquired haemophilia A

Acquired Haemophilia – can we do better with Emicizumab? – Dr Jane Mason
Consultant Haematologist & Acting Director – Royal Brisbane & Women's Hospital, QLD Haemophilia Centre

Acquired haemophilia A (AHA) is a rare potentially life-threatening disease caused by the development of autoantibodies against factor VIII (FVIII) that disproportionately affects elderly people. These patients are at high risk of life or limb threatening bleeding and the WFH recommends that AHA patients are managed under the care of the HTC. There is increasing interest in the role of Emicizumab for this rare group, with preliminary data suggesting haemostatic effect within days, with ability to cease bypassing agents sooner and earlier discharge. There is limited real-world experience with the use of this agent for AHA. We undertook a retrospective review of all patients with AHA receiving Emicizumab at the QLD Haemophilia Centre over a 2-year period and describe clinical features, outcomes and patient experience of this approach compared to our historic practice.

Hereditary Hemorrhagic Telangiectasia – HHT - Nursing perspective – Alex Klever
Clinical Nurse, Haemophilia - Royal Brisbane & Women's Hospital, QLD Haemophilia Centre

Q/A

FRIDAY 24 AUGUST 2023
1330-1500
Concurrent 3
Making Career Choices
Chair: Penny McCarthy
Room: Delacombe

Career choices over a lifetime. Do they change with new treatments? – Penny McCarthy
Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, Melbourne Australia.

Personal Story Compilation

Career Choices. Theories and strategies that can help ~ Jon Hazelton
Career development consultant, Bravo Careers.

What are some good ways to make meaningful career choices even when faced with challenges beyond our control? In this session we will explore some relatively modern career development theories (Design Thinking and Hope-Action Theory) as catalysts for considering our career choices with some exercises provided to help us reflect on our values, goals, and purpose in work/careers/life.

Employment: discrimination, disclosure and the law – Mark Waters
Partner, CIE Legal

Personal story – Dale
Living in WA with severe Haemophilia A. Qualified Electrician and working FIFO life.

Panel Discussion
Nurse – Kara Cordiner - *Clinical Nurse Consultant, Ronald Sawers Haemophilia Centre, Melbourne Australia.*
Physio - Abi Polus - *Senior Clinical Physiotherapist- Haemophilia - Ronald Sawers Haemophilia Centre, Melbourne Australia.*
Social worker – Nicoletta Crollini - *Haemophilia Social Worker, Royal Prince Alfred Hospital, NSW*

FRIDAY 24 AUGUST 2023
1530-1700
Plenary 3
Women and girls with bleeding disorders
Chair: Dr Meredith Wiggins
Room: Junior Ballroom

Personal perspectives on the challenges and issues of living with a bleeding disorder
- Shauna - von Willebrand disease type 3, member of the HFACT Committee and member of WFH Youth Committee 2022-2024 term
- Cheryl - affected by Haemophilia A and Vice President of HFWA

Medical perspectives on diagnosis, assessment, treatment and care
- Haematologist: Dr Briony Cutts
Obstetric medicine physician and haematologist, VIC

- Gynaecologist: Prof Sonia Grover
Paediatric and Adolescent Gynaecology, General Gynaecologist & Pain Medicine Specialist, VIC

Q&A

SATURDAY 25 AUGUST 2023
0845-1015
Plenary 4
Managing Mild Haemophilia
Chair: Dr Heather Tapp
Room: Junior Ballroom

Mild Haemophilia – the new frontier - Dr Heather Tapp
Paediatric Haematologist/Oncologist and Director of the Paediatric Haemophilia treatment centre at the Women's and Childrens hospital, Adelaide

People with mild haemophilia have a broad range of factor levels and varied bleeding phenotypes. They represent a diagnostic and management challenge and are rarely considered for clinical trials or access to novel therapies. Engagement with health care can be limited and the potential for unrecognized bleeding contributing to poor joint outcomes can be of concern. This session outlines some of these challenges and the potential benefits from international databases and further research into inhibitor risk, assay discrepancies, bleeding phenotype and novel therapies that should aid the optimal management of people with mild haemophilia.

Personal Speaker - Louis and dad Tom
Louis is 20 years old from Adelaide and was diagnosed with mild haemophilia when he was a baby. Tom is Louis' father.

Being diagnosed with mild haemophilia can imply that life will not be impacted significantly. The term 'mild' may not tell the whole story and for Louis and his family has meant re assessing the impact of haemophilia and adjusting life to help maintain independence, health and wellbeing.

Mild Haemophilia in adults, medical issues – Dr Stephanie P'ng
Clinical haematologist, Fiona Stanley Hospital, Western Australia

Management, including surgery in mild haemophilia – Alex Klever
Clinical Nurse, Haemophilia - Royal Brisbane & Women's Hospital, QLD Haemophilia Centre

Rehab, arthritis, physical activities and sport across the lifespan in mild haemophilia – Abi Polus
Senior Clinical Physiotherapist- Haemophilia - Ronald Sawers Haemophilia Centre, Melbourne Australia.

Q/A

SATURDAY 25 AUGUST 2023
1045-1215
Concurrent 4
Inheritance, genetics and family planning
Chair: Dr Chris Barnes
Room: Stradbroke

Introduction ~ Dr Chris Barnes
Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital, Parkville, VIC

Personal story

Genetics, Reproduction and Family Planning - A/Prof Kristi Jones and Lucy Kevin
Prof Kristi Jones, Paediatrician and Clinical Geneticist at the Children's Hospital at Westmead
Lucy Kevin, Human Genetic Society of Australia (HGSA) certified Genetic Counsellor at the Children's Hospital at Westmead

Haemophilia, VWD and other rare bleeding disorders are genetic health issues, therefore patients and family members frequently have questions about whether their own children could have a similar blood condition and whether there are any options available to them to either check for the condition during or before a pregnancy. Individuals and/or couples can be referred to their local genetic service to have these discussions. Conversations around reproductive planning can be both complex and emotional for some individuals and reproductive decisions are very personal to each couple. Genetic counsellors and clinical geneticists aim to provide information to families about genetics, genetic testing and reproductive options in a non-directive and non-judgmental manner so that clients can make informed decisions in keeping with their own values and beliefs. In this presentation we hope to present a brief overview of how the haemophilias, VWD and rare bleeding disorders are inherited and genetic testing for these conditions. We will also try and outline some of the reproductive technologies available to couples including non invasive prenatal testing (NIPT), prenatal diagnosis and pre-implantation genetic diagnosis (PGD).

Q/A

SATURDAY 25 AUGUST 2023
1045-1215
Concurrent 5
Is it a bleed? MSK recovery
Chair: Jo Newsom
Room: Huntingfield

Case Study

Conditions that can mimic a bleed - Dr Rob Russo
Rheumatologist, Sydney Local Health District

Recovering from a joint bleed – how long does it really take? - Ali Morris
Senior Musculoskeletal Physiotherapist at Perth Children's Hospital in Western Australia

Haemophiliac arthropathy, as a result of joint bleeding, is a major cause of pain and reduced quality of life in people with bleeding disorders (PWBD). Despite recent advances in care, PWBD's continue to experience joint bleeds. This presentation will explore the physiotherapist's role in ensuring optimal recovery from a joint bleed, how recovery is determined and the time frames associated with this.

Muscle bleed recovery, athlete back to sport, sports physio – Jarrad King
Physiotherapist, Geelong

Q/A panel

SATURDAY 25 AUGUST 2023
1045-1215
Concurrent 6
Getting older
Chair: Suzanne O'Callaghan
Room: Delacombe

Personal story ~ Mike

Medical issues ~ Dr Liane Khoo
Haematologist Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital

Hep C and liver health ~ Dr David Iser
Gastroenterologist and Hepatologist, St Vincent's Private Hospitals, Melbourne

The power of friendship for older people ~ Marcia Fearn
Research Policy and Practice Fellow, Research Administration Officer - NARI, Melbourne

It has been reported that one in two Australians feel lonely at least once a week, while one in four feel lonely for three or more days a week. Loneliness and social isolation can be caused by a variety of factors, including mobility or health issues, living alone, losing a spouse or partner or close friends, living in rural or remote areas and limited access to transportation, and experiencing significant life changes such as retirement or a move into residential aged care. Loneliness has been linked to poorer physical health outcomes, including a higher risk of mortality as well as a higher risk of cognitive decline and dementia. In our BEFRIENDAS study, preliminary analyses examined whether loneliness, number of social networks and depression were associated. As part of the andomized control trial we conducted baseline interviews with over 300 older people using a structured interview schedule including the UCLA Loneliness scale and the Geriatric Depression Scale (Austin HREC/45941/Austin-2018). Older adults were aged between 60-102. We found a strong association between loneliness and depression as well as loneliness and social networks. Men had higher loneliness scores than women. The presentation will discuss the importance of social connections and friendship for older people and how these may reduce loneliness and social isolation, with updates from the recently completed BEFRIENDAS study.

Panel discussion

- **Nurse – Jayne Treagust** - *Haemophilia & Bleeding Disorders APN, Canberra Hospital*
- **Physio – Catherine Haley** - *Physiotherapist, Ronald Sawers Haemophilia Centre, Melbourne Australia*
- **Psychosocial – Kathryn Body** - *Counsellor, HFACT*

SATURDAY 25 AUGUST 2023
1330-1500
Concurrent 7
Pregnancy, childbirth and newborns
Chair: Dr Jane Mason
Room: Stradbroke

Introduction – Dr Jane Mason
Consultant Haematologist & Acting Director – Royal Brisbane & Women's Hospital, QLD Haemophilia Centre

Nursing perspective – pregnancy and delivery management ~ Robyn Shoemark
Clinical Nurse Consultant Haemophilia/Haematology, The Children's Hospital at Westmead

Having a baby. What you need to know for mother and baby to get you through your pregnancy and delivery safely.

Delivery and birth – Dr Iniyaval.Thevathasan
Maternal fetal medicine subspecialist obstetrician based in Melbourne

Best practice management of PUPs ~ Dr Simon Brown
Haemophilia Centre Director, Queensland Children's Hospital

Personal Story - Rebecca

Q/A

SATURDAY 25 AUGUST 2023
1330-1500
Concurrent 8
VWD
Chair: Dr Chee Wee Tan
Room: Huntingfield

Patient perspectives
Man with severe VWD ~ Adam
Woman with mild VWD ~ Susie

VWD diagnosis ~ Dr Geoffrey Kershaw
Senior Hospital Scientist, Institute of Haematology, Royal Prince Alfred Hospital NSW

Medical perspective and VWD clinical management ~ Dr Nalini Pati
Adult and Paediatric Haematologist, The Canberra Hospital

Guideline on Clinical Management of von Willebrand disease Medical perspective and VWD clinical management ~ Dr Nalini Pati
Adult and Paediatric Haematologist, The Canberra Hospital

Von Willebrand's disease is the most common inherited bleeding disorder known in humans. Accurate and timely diagnosis would help better management of these patients. The current classification includes types, 1 and 3 due to quantitative deficiency of Von Willebrand Factor (VwF). Types 2A, 2B, 2M and 2N are linked to qualitative deficiency of VwF. In terms of Symptoms of VWD, typically patients present with excessive mucocutaneous bleeding, including increased menstrual bleeding, recurrent epistaxis, gum bleeding, excessive bruising spontaneously or on trivial trauma. This could also be manifested with major bleeding, including gastrointestinal, bleeding following dental work, childbirth or surgical procedures. However the timely diagnosis of VWD remains a huge challenge for clinicians and patients as symptoms can be very mild and non-specific and awareness amongst medical professionals is scarce.

To help improve the care in VWD patients, ASH, ISTH, NHF and WFH developed a guideline on management of VWD forming an expert panel which was published in 2021. The panel kept the guideline very well balanced, keeping possible bias to very minimal. The panel prioritized clinical questions and tried to achieve at outcomes based on the available evidence and derived the recommendations. The guideline, addressed the common questions such as prophylaxis for frequent bleeders and in patients with severe phenotypes, use of desmopressin including the issues surrounding challenge tests, management in the context of neuraxial anaesthesia during labor and delivery, post-partum management as well as in perioperative management While this guideline has been adopted broadly by most advanced Bleeding Disorder centres, it is still interesting to see how this has brought into practice and used in day to day management of care of VWD patients, which would ultimately will bring huge change in the care of such complex and tricky patients. Care plan of VWD patients' needs to be individualised and developed keeping the patients in the midst of all the discussion, in a multidisciplinary model to make it more effective.

SATURDAY 25 AUGUST 2023
1330-1500
Concurrent 9
Pain
Chair: Jonathan Spencer
Room: Delacombe

Better Pain Management for Haemophilia in the Future – Dr Carolyn Arnold
Pain Medicine Specialist, Alfred Health, Melbourne and Monash University

Chronic pain is far more common in people with haemophilia (PWH), particularly those over 30 years (30 -80%) compared to 20% prevalence in the 'normal' adult population. The majority of chronic pain in PWH is from haemophilic arthropathy, affecting ankles, knees and elbows. This results in disability in mobility and upper limb function. In Australia the availability of prophylactic factor treatments in children and adults, and recently emicizumab a monoclonal antibody, offers prevention and reduction of bleeding. Less bleeding joint episodes can spare affected joints from the cascade of inflammatory processes following joint bleeds, which precedes development of arthropathy. In haemophilic arthropathy the cartilage and underlying bone of the joints are damaged. In Alfred Health in Melbourne, our patients are keen on accessing pain management strategies through the HTC multidisciplinary (MDT) clinics. In the clinics, clinicians together assess joints and function to determine presence or not of underlying bleeding, synovitis, target joints. We assess range of movement and gait as well as pain interference, and recommend many strategies in addition to wise use of medications. Planning is closely interwoven with the haematological management of bleeding control. The expert physiotherapists are key for rehabilitation and reconditioning, motivating patients to exercise, and monitoring function over time. The MDT clinic runs along interdisciplinary lines. This is a model adopted from Rehabilitation and Pain Medicine. The clinics are followed by a face-to-face case conference with the whole team together- haematology, nursing, physiotherapy rheumatology, pain medicine, social work. This allows all aspects of management to be weighed up together, and to create treatment plans with patients input. Interestingly participation of a Pain Medicine Consultant in the clinics leads many patients to discuss their pain more openly and seek additional psychosocial and lifestyle approaches to chronic pain.

Physiotherapy approaches to pain management in haemophilia care - Cat Pollard
Pain Specialist Physiotherapist, Te Whatu Ora, Te Toka Tumai New Zealand

The most common complication of haemophilia is musculoskeletal bleeding episodes. Bleeding into a joint can produce permanent damage and may lead to pain. However, pain sensations occur following complex interactions within the joint and as pain signals pass through the nervous system and the brain. Pain management approaches, therefore, involve targeting the local tissues and modulating signals as they pass through the nervous system and into the brain. Targeting all these areas together can improve our ability to manage pain more effectively. This talk will cover common strategies used within physiotherapy to manage pain associated with haemophilia providing real-life case examples of how these approaches are applied.

Strategies to manage procedural and acute pain in children – Michelle Perrin
Child Life therapist, John Hunter Children's Hospital

Optimal health care involves supporting the physical, emotional and psychological wellbeing of children and young people during treatment.

There can be long term implications for children and young people if medical procedures are not well managed. Medical experiences in early life can be stored as a traumatic memory (Parson, 2014), and may present as a trauma response later in life. The likelihood of this is increased if the child and/or family felt helpless, or if they were restrained (Levine & Kline, 2006). Single frightening events, or repeated procedures can cause treatment-related, or iatrogenic trauma (Forgey & Bursch, 2013). Children who are fearful of procedures are more likely to miss appointments and in some cases treatment may be delayed.
Similar to other chronic health conditions, children with haemophilia and other bleeding disorders require strong relationships with the healthcare team. The team have a responsibility to engage with children and families to empower them to feel safe in the health environment. This sense of safety extends to procedural care by enabling children and families to make meaningful choices and actively participate in their treatment plan.

This presentation will discuss how Child Life Therapy support children and families through play and individualised procedural care. Strategies such as medical play, therapeutic play, procedural preparation, procedural plans, diversion and refocussing will be explored.
References

Forgey, M., & Bursch, B. (2013). Assessment and management of pediatric iatrogenic medical trauma. Current Psychiatry Reports, 15(2), 1. https://doi.org/10.1007/s11920-0
Levine, P. A., & Kline, M. (2006). Trauma through a child's eyes: Awakening the ordinary miracle of healing. North Atlantic Books
Parson, J. A. (2014). Holistic Mental Health Care & Play Therapy for hospitalised, chronically ill children. In A. Myrick & E. J. Green (Eds.), Play therapy with vulnerable populations: No child forgotten (pp. 125–139). Rowman & Littlefeld Publishers.

Q&A

SATURDAY 25 AUGUST 2023
1530-1700
Plenary 5
Working towards good health
Chair: Sharon Caris
Room: Junior Ballroom

Overcoming challenges to work towards good health - Dr Charlotte Keating
Clinical Psychologist and has a PhD in Neuroscience. She currently works in her Sydney-based Private Practice on the Lower North Shore

What are the challenges we are facing, moving forward and how to keep connected
Panel

- **Dr Glenn Pierce** - *Independent biotech consultant and former entrepreneur-in-residence at Third Rock Ventures. He serves on NHF-MASAC and is the elected VP Medical for WFH. Glenn splits time between La Jolla and San Francisco.*
- **Prof Huyen Tran** - *Director, The Ronald Sawers Haemophilia Treatment Centre, The Alfred Melbourne, VIC*
- **Dr Liane Khoo** - *Haematologist Director, Haemophilia Treatment Centre, Royal Prince Alfred Hospital*
- **Dr Chris Barnes** - *Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital, Parkville, VIC*
- **Claude** - Father of 5 children, 4 boys all with haemophilia and a daughter, President of HFACT
- **Shauna** - *von Willebrand disease type 3, member of the HFACT Committee and member of WFH Youth Committee 2022-2024 term*

Notes

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