



THURSDAY 10 OCTOBER 2019

0830- 1700	Annual meetings of AHCCO, AHNG, ANZHSWCG, ANZPHG, DMG (Health professionals' group members only)
1830-1930	Welcome and Exhibition Opening – open to all registered conference attendees
1930-2230	Youth VIP Meet & Mingle – for registered youth only

FRIDAY 11 OCTOBER 2019

0820	Official Conference Welcome		
	<ul style="list-style-type: none"> • Gavin Finkelstein, President HFA • Dr Teresa Anderson, Chief Executive RPAH 		
0830-1000	Plenary 1: Improving outcomes - what has been achieved in the treatment of bleeding disorders? Chair: Dr Liane Khoo		
0835-0855	<ul style="list-style-type: none"> • Dr Liane Khoo • Dr Simon McRae and John's personal experience • Dr Alfonso Iorio ~ Optimising patient care through PK analysis (WAPPS) Q&A 		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Addressing the challenges of inhibitors	Concurrent 2 Getting older	Concurrent 3 Looking after children who have a bleeding disorder
	Chair: Megan Walsh Dr Huyen Tran ~ a clinical overview Discussion and debate on immune tolerance induction therapy Andrew's personal journey	Chair: Frankie Mullen TBC ~ Emerging clinical issues Preetha Jayaram ~ Patient voices Penny McCarthy ~ Treatment and care at Haemophilia Treatment Centres Greig Blamey ~ Maintaining independence and keeping up the exercise Marcia Fearn ~ Innovative projects in ageing Q & A	Chair: Robyn Shoemark Robyn Shoemark ~ Encouraging independence and overcoming barriers to self-infusion TBC ~ Impact of a chronic illness on families Anne Jackson ~ Transition to adult Haemophilia Treatment Centres Alison Morris and Jo Newsom ~ physiotherapy, joint health & sport Q&A
1215-1325	LUNCH		

1325-1455	Concurrent 1 360 ° on clinical trials	Concurrent 2 Reproduction and family planning	Concurrent 3 A healthy life for all ages
	Chair: Dr Tina Carter	Chair: Jaime Chase	Chair: Beryl Zeissink
	<p>Dr Simon Brown ~ the role of your doctor in a clinical trial</p> <p>Stephen Mathews ~ the role of nurses in trials</p> <p>Alicia ~ A family's experience of a clinical trial for children</p> <p>Hamish ~ an individual's experience of a clinical trial</p> <p>Dr Alfonso Iorio ~ What outcome information should we be considering</p> <p>Q&A</p>	<p>A joint presentation on reproduction and family planning</p> <ul style="list-style-type: none"> • Kristi Jones ~ Geneticist • Lucy Kevin ~ Genetics Counsellor <p>Personal Stories</p> <ul style="list-style-type: none"> • Kara • TBC 	<p>Jules Aitken ~ managing a healthy diet and weight</p> <p>Greig Blamey ~ Exercising safely at all ages</p> <p>Tim's personal experience of managing haemophilia challenges and keeping fit and well</p> <p>Q&A</p>
1455-1535	AFTERNOON TEA		
1535-1700	Plenary 2		
	Chair: Dan Credazzi		
	Dr Happy (Dr Tim Sharpe) ~ Challenging the status quo		
1800	Remembrance Service		
1900	Conference Dinner <i>Tickets are \$50 and must be pre-paid</i>		

SATURDAY 12 OCTOBER 2019

0700 - 0820	Men's Breakfast ~ Everything you wanted to know but were afraid to ask <i>Tickets are \$30 and must be pre-paid</i>		
	Chair ~ Claude Damiani Panel: Greig Blamey, Tim, Zev, Dr Nalini Pati		
0700 - 0820	Women's Breakfast ~ Extraordinary women in leadership: some of the inspiring women I have met		
	Chair ~ Sharon Caris Marie Ann Fernandes (World Federation of Hemophilia Regional Program Manager for Asia & Western Pacific) will share her experiences as a development worker in different parts of the world		
0830-1000	Plenary 3 Musculoskeletal challenges: joint care and treatment		
	Chair: Abi Polus		
	<ul style="list-style-type: none"> • Greig Blamey ~ The importance of upper limb care throughout life • Dr Rob Russo ~ Haemophilia Early Arthropathy Detection with Ultrasound • Mark Horsley ~ Surgical options 		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Gene therapy de-mystified	Concurrent 2 From girls to women	Concurrent 3 Self-advocacy
	Chair: Dr Susan Russell	Chair: Susan Dalkie	Chair: Loretta Riley
	<p>Yvonne Brennan ~ the basic science of blood clotting and how this interacts with new therapies</p> <p>Dr Julie Curtin</p> <ul style="list-style-type: none"> • How does non-factor replacement therapy work and gene therapy fit into this context? • Explaining the jargon – what is gene therapy? How does it work? What is achieved? 	<p>Dr Jenny Curnow ~ Bleeding in females across the lifespan</p> <p>Dr Kim Mathews ~ the role of a gynecologist</p> <p>Joanna McCosker ~ Ages & stages – what do parents and daughters need to know?</p> <p>Personal stories:</p> <ul style="list-style-type: none"> • Shauna • TBC <p>Q&A</p>	<p>An interactive workshop: successful self-advocacy; identifying relevant skills and resources; barriers and overcoming them.</p> <p>Session to be facilitated by Loretta Riley with Dr Liane Khoo, Nicoletta Crollini and Jane Portnoy</p>
1215-1325	LUNCH		

1325-1455	Concurrent 1 Von Willebrand disease and rare bleeding disorders	Concurrent 2 Youth	Concurrent 3 What is comprehensive Care today?
	<p>Chair: Dr Ritam Prasad</p> <p>Dr Ritam Prasad ~ Current issues and VWD - best practice and future treatment</p> <p>Alex Connolly ~ Developing an effective treatment plan</p> <p>Susie's personal experiences ~ living with VWD and as a parent of a son with VWD</p> <p>Dr Heather Tapp ~ looking after people with rare bleeding disorders</p> <p>The personal experiences of living with a rare factor deficiency</p> <ul style="list-style-type: none"> • Belinda ~ factor X deficiency 	<p>Chair: Moana Harlen</p> <p>What's the risk?</p> <p>Panel discussion of scenarios, with audience input (Q&A style) - personal decision-making around visiting HTC for a bleed review; gym/sport-related injury; travel, insurance; disclosing – in sport, in relationships; work, challenges of becoming an adult.</p> <p>Panel: Young people with bleeding disorders (Alan and TBC) Older person with haemophilia and parent (Paul and Shane) Health professionals ~ Greig Blamey, Physiotherapist Jane Portnoy, Psychosocial worker Steve Matthews, Haemophilia Nurse</p>	<p>Chair: Anne Jackson</p> <p>Dr Suma Sumakura ~ Looking after your teeth</p> <p>Loretta Riley ~ Using other services & navigating the health system</p> <p>Dr Jane Mason, Loretta Riley, Joanna McCosker ~ QLD Haemophilia Centre's experience of telehealth – engaging with the rural, remote and regional inherited bleeding disorders community</p>
1455-1535	AFTERNOON TEA		
1535-1700	Plenary 4 New opportunities or is the status quo good enough?		
	Chair: Dr Simon McRae		
	A panel discussion about what patients expect from their treatment in the future, how doctors and nurses expect to be treating their patients, and what the issues are for governments and suppliers.		