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Conference 2019

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

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

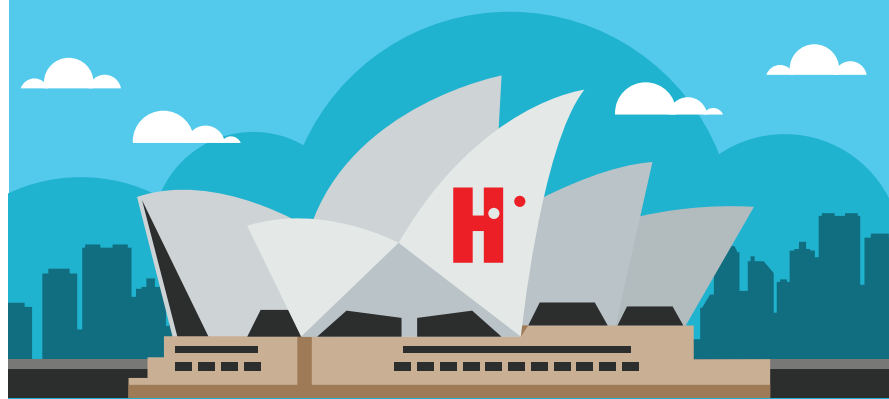
And don't forget to register for the social functions – the Welcome & Exhibition Opening on Thursday

evening (free-of-charge), Conference Dinner on Friday night and special Youth Meet and Greet on Friday night.

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

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

19th Australian Conference on haemophilia, VWD & rare bleeding disorders *Challenging the Status Quo*



~ 10-12 October 2019 ~

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

CONFERENCE PROGRAM

Subject to change

THURSDAY 10 OCTOBER 2019			
0830- 1700	Annual meetings of AHCDO, AHNG, ANZHSWCG, ANZPHG, DMG (Health professionals' group members only)		
1830-1930	Welcome and Exhibition Opening – open to all registered conference attendees		
1930-2230	Youth VIP Meet & Mingle – for registered youth only		
FRIDAY 11 OCTOBER 2019			
0820	Official Conference Welcome <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		
	<ul style="list-style-type: none"> Dr Liane Khoo Dr Alfonso Iorio ~ Optimising patient care through PK analysis (WAPPS) Q&A		
1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Addressing the challenges of inhibitors	Concurrent 2 Getting older	Concurrent 3 Looking after children who have a bleeding disorder
	Chair: Megan Walsh	Chair: TBC	Chair: Robyn Shoemark
	Dr Huyen Tran ~ a clinical overview Discussion and debate on immune tolerance induction therapy Andrew's personal journey	Emerging clinical issues Preetha Jayaram ~ Patient voices Penny McCarthy ~ Treatment and care at Haemophilia Treatment Centres TBC ~ HIV and hep C update for older people with bleeding disorders Greig Blamey ~ Maintaining independence and keeping up the exercise Marcia Fearn ~ Innovative ageing projects Q & A	Robyn Shoemark ~ Encouraging independence and overcoming barriers to self-infusion Liane Willis ~ Impact of a chronic illness on families Anne Jackson ~ Transition to adult Haemophilia Treatment Centres Alison Morris ~ Q&A on physiotherapy, joint health & sport

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

1000-1045	MORNING TEA		
1045-1215	Concurrent 1 Gene therapy de-mystified	Concurrent 2 From girls to women	Concurrent 3 Self-advocacy
	Chair: Dr Suzanne Russell	Chair: Susan Dalkie	Chair: Loretta Riley
	<p>Yvonne Brennan ~ Basic science about how blood clots 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>
1215-1325	LUNCH		
1325-1455	Concurrent 1 Von Willebrand disease and rare bleeding disorders	Concurrent 2 Youth	Concurrent 3 What is comprehensive care today?
	Chair: TBC	Chair: Moana Harlen	Chair: Anne Jackson
	<p>Current issues in 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 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 Stephanie ~ mother of daughter with factor VII deficiency 	<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:</p> <p>2 young people with bleeding disorders (Alan and TBC)</p> <p>2 adults – person with haemophilia and parent (Paul and Shane)</p> <p>Health professionals ~ Greig Blamey, Physiotherapist Jane Portnoy, Psychosocial worker Steve Matthews, Haemophilia Nurse</p>	<p>Dr Suma Sumakura ~ Healthy 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?		
	A panel discussion about what patients expect from their treatment in the future, how haemophilia treatment centres expect to be treating their patients, and what the issues are for governments.		