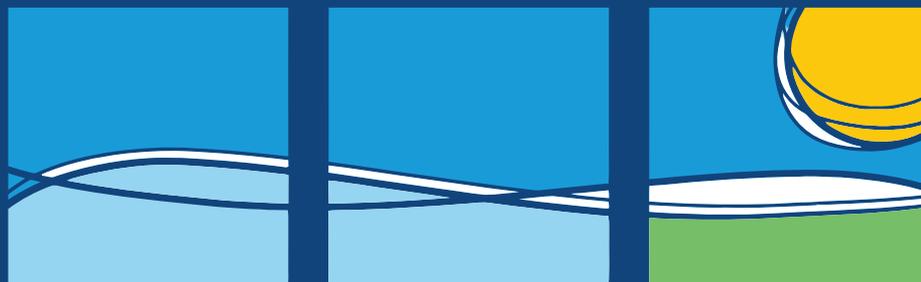


**17<sup>TH</sup> Australian & New Zealand Conference**  
on haemophilia & related bleeding disorders

*Facing the Future Together*



1 - 3 OCTOBER 2015 • GOLD COAST

**Conference Abstracts**  
and **Speakers**



# CONFERENCE PROGRAM

## THURSDAY 1 OCTOBER 2015

1830-1930	<b>Welcome and Exhibition Opening</b> Room: Longboard and Ballroom
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## FRIDAY 2 OCTOBER 2015

0900	<b>Official Conference Welcome ~ Gavin Finkelstein HFA President</b>		
0905-1030	<b>Plenary 1</b> <b>Comprehensive Care: the journey</b> Room: QT Ballroom		
	<b>Chair: Dr John Rowell</b>		
	The history of comprehensive care ~ Dr Alison Street The role of governments ~ Leigh McJames Panel discussion ~ Dr Chris Barnes, Dr John Rowell, Beryl Zeissink, Dan Credazzi (NSW)		
1030-1100	<b>MORNING TEA</b>		
1100-1230	<b>Concurrent 1</b> <b>von Willebrand disease</b> Room: Sunset	<b>Concurrent 2</b> <b>Mild Haemophilia</b> Room: Point Break	<b>Concurrent 3</b> <b>Hepatitis C</b> Room: Diamond Head
	<b>Chair: Dr Catherine Harris</b>	<b>Chair: Penny McCarthy</b>	<b>Chair: Suzanne O'Callaghan</b>
	Personal Stories ~ Bobby, ACT ~ Sally, NSW  Diagnosis and testing ~ Dr Ritam Prasad  Treatment and Management ~ Dr Susan Russell  Discussion	Mild Haemophilia across the life span ~ Penny McCarthy  Mild Haemophilia in Children ~ Dr Jamie Price  Personal story ~ Nathan, SA  Inhibitors, treatment in adults and genetic testing ~ Dr Simon McRae  Q&A	Hepatitis C: Medical issues for PWBD and treatment, incl direct acting antivirals ~ A/Prof Simone Strasser  Personal story of a person living with HCV ~ Dave, QLD  Hepatitis C progression - barriers to monitoring liver health and treatment ~ Mary Fenech ~ Beryl Zeissink Panel Discussion
1230-1330	<b>LUNCH</b>		
1330-1500	<b>Concurrent 1</b> <b>Youth</b> Room: Sunset	<b>Concurrent 2</b> <b>Inhibitors</b> Room: Point Break	<b>Concurrent 3</b> <b>HIV</b> Room: Diamond Head
	<b>Chair: Hannah Opeskin</b>	<b>Chair: Dr Chris Barnes</b>	<b>Chair: Leonie Mudge</b>
	Q&A panel with engaging topics including: • On the Move – moving out of home, travelling, work and study • Is there such a thing as a safe risk? • Disclosure – who to tell Panel: Physiotherapy ~ Cameron Cramey Nurse Perspective ~ Clare Waite Psychologist ~ Moana Harlen Young man's perspective ~ Tim D, VIC Young woman's perspective ~ Jade B, WA	Inhibitor Risk Factors ~ Dr Alfonso Iorio  The impact of product transition on the risk of inhibitor development in Australian patients with Haemophilia A ~ Dr Ann S Wilson  Personal experience ~ Andrew B, QLD  Treatment & Management of inhibitors ~ Dr John Rowell	The legacy of HIV for the bleeding disorders community ~ Leonie Mudge  HIV – An update on treatment and the burden of co-morbidities, including hepatitis C virus co-infection ~ Dr Krispin Hajkovicz  Ageing/disability, resilience and HIV – psychosocial issues ~ Lynne Heyes  HIV and mental health ~ Dr John Linnane

1500-1530	AFTERNOON TEA
1530-1700	<b>Plenary 2</b> Improving outlooks for pain in haemophilia Room: QT Ballroom
	<b>Chair: Abi Polus</b>
	Humans: The best protectors yet ~ Prof Lorimer Moseley Managing Pain in Haemophilia ~ A/Prof Carolyn Arnold
1815-1845	<b>Remembrance Service</b> Room: Malibu
1900 til late	<b>Conference Dinner</b> Room: QT Ballroom <i>*Tickets are \$35 and must be pre-booked*</i>

## FRIDAY 2 OCTOBER 2015

**0905- 1030**

### **Plenary 1**

#### **Comprehensive Care: the journey**

Room: QT Ballroom

#### **Chair: Dr John Rowell**

The history of comprehensive care ~ Dr Alison Street

The role of governments ~ Leigh McJames

Panel discussion ~ Dr Chris Barnes, Dr John Rowell, Beryl Zeissink, Dan Credazzi (NSW)

#### **The history of comprehensive care ~ Dr Alison Street**

*Alison was director of Ronald Sawers Haemophilia Centre at Alfred Health from 1986-2012.*

Comprehensive care is the practice of ongoing multidisciplinary management of a patient in both hospital and community settings. Haemophilia clinicians were pioneers of this model of care, now described as “chronic Disease management.” The earliest practitioners worked and published in Oxford U.K. and Los Angeles U.S.A. Their models developed as accurate laboratory diagnosis and specific plasma factor replacement therapies became available in the 1960s. The first Australian report describing adoption of the comprehensive care model and employment of specialty haemophilia clinical staff was published in 1971. With the subsequent local development of factor concentrates, which could be self-administered at home, patients with congenital bleeding disorders were increasingly dependent on review in non-inpatient settings. The associated transfusion transmission epidemics of Hepatitis B, Hepatitis C and HIV in the 1970s and 1980s put huge pressure on patients, their families and haemophilia centre resources. The advent of virus free recombinant factors through the 1990s with universal availability from early 2000s has satisfied the demand for product. The continuing challenges for haemophilia centres are to develop, maintain and assure clinical and cost effective models of care.

#### **The role of governments ~ Leigh McJames**

*Appointed in April 2012, Leigh McJames is the General Manager/CEO of the National Blood Authority (NBA). The NBA is an independent statutory authority responsible to all Australian and state and territory governments for the management of a budget of over \$1.2 billion to ensure the adequate, safe, secure and affordable supply of blood and blood products in Australia. The General Manager reports to the Commonwealth Minister for Health.*

Governments are committed to promoting safe, high quality management and use of blood products. This includes an objective that the arrangements for provision of blood products are sustainable. In support of this objective they have approved a wide ranging agenda to support improvements in the sector, encompassing research and development, haemovigilance, development and implementation of measures to improve clinical use of blood products, education and training and collection of data. This presentation outlines the current agenda with a focus on bleeding disorders.

#### **Dr Chris Barnes**

*Dr Chris Barnes is the Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital*

**Dr John Rowell**

*Dr John Rowell is Director of Haematology at Pathology Queensland and Director of Queensland Haemophilia Centre at Royal Brisbane and Womens' Hospital. He is past Chairman of the Australian Haemophilia Centre Directors Organisation (AHCDO). Dr Rowell has been a member of the Council of the Australian and New Zealand Society of Blood Transfusion, was Chairman of the RCPA Transfusion Quality Assurance Program and an examiner in Haematology for the Royal College of Pathologists of Australasia. His major interests are in Haemophilia and other bleeding disorders, Genetics and Transfusion.*

**Beryl Zeissink**

*Beryl has worked with the Queensland Haemophilia Centre for 15 years. She has a Masters in Nursing and a Masters in Science (Genetic Counseling). She is interested in an historical perspective of where we have come from & changes within an ever changing health care system moving forwards and how we can all navigate this change. Also of interest are individuals own oral & written histories of how things have changed from a personal perspective over the years. If no one records this history there is risk of losing this knowledge.*

**Dan Credazzi**

*Dan has served on the NSW and National Boards of the Haemophilia Foundation for the past five years and is currently Vice President of Haemophilia Foundation of Australia and President of Haemophilia Foundation of NSW Inc. He has a young son with haemophilia.*

## FRIDAY 2 OCTOBER 2015

**1100-1230**

**Concurrent 1**

**von Willebrand disease**

Room: Sunset

**Chair: Dr Catherine Harris**

Personal Stories

~ Bobby, ACT

~ Sally, NSW

Diagnosis and testing ~ Dr Ritam Prasad

Treatment and Management ~ Dr Susan Russell

**Bobby, ACT**

*Bobby is a science communicator who creates film and multimedia for the Australian Government. Despite chronic conditions too numerous to mention, she thrives on sunlight, emerging technology, fine art and finding humour in the darkest of places.*

Diagnosed at birth with Von Willebrand's Disease, science communicator Bobby Cerini had a life characterized by love, laughter, and cutting-edge science facts. Everything was going well – that is, until she tried to have children, a wisdom tooth extraction and a PhD all at the same time. Inundated by Biostate and troubled by disturbing revelations not listed in the Women with Bleeding Disorders guide, reality eventually caught up with fantasy...and then overtook it.

In this short talk, Bobby shares her experiences of living with VWD and reveals the single fact that all women should know – that bleeding can, just sometimes, save your life...

**Sally, NSW**

*Sally is the mother of Cassie, an 11 year old with Type 3 vWD*

**Diagnosis and testing ~ Dr Ritam Prasad**

*Dr Prasad is haematologist at the Royal Hobart Hospital in Tasmania*

**Treatment and Management ~ Dr Susan Russell**

*Dr Russell is a Paediatric Haematologist Oncologist and is the Director of the Haemophilia Treatment Centre at the Sydney Children's Hospital, Randwick NSW*

## FRIDAY 2 OCTOBER 2015

**1100-1230**

**Concurrent 2**

**Mild Haemophilia**

Room: Point Break

**Chair: Penny McCarthy**

Mild Haemophilia across the life span ~ Penny McCarthy

Mild Haemophilia in Children ~ Dr Jamie Price

Personal story ~ Nathan, SA

Inhibitors, treatment in adults and genetic testing ~ Dr Simon McRae

Q&A

**Mild Haemophilia across the life span ~ Penny McCarthy**

*Penny is a Clinical Nurse Consultant at The Ronald Sawers Haemophilia centre at The Alfred which is the state wide referral centre for adults with Haemophilia and other inherited bleeding disorders. Penny has extensive experience caring for people with haemophilia and other bleeding disorders since 1998. She is actively involved in ongoing nursing education both nationally and internationally. Penny was formerly chair of the Australian Haemophilia Nurses Group (2000 -2002) and former secretary of the World Federation of Hemophilia nurses committee as the representative for Western Pacific and Oceania regions.(2008 - 2011)*

The complexity of managing bleeding in people with Mild haemophilia is often underestimated. The three case histories presented will illustrate some of the impact of bleeding at different life stages in people with mild haemophilia.

**Mild Haemophilia in Children ~ Dr Jamie Price**

*I have worked at Princess Margaret Hospital for Children for many years in Haematology and Oncology covering the whole spectrum of clinical disorders. Over the past 10 years my main focus has been with children with bleeding disorders. The preservation of joint function in patients with severe Haemophilia has been a prime objective and the introduction of aggressive prophylaxis and joint aspiration has been part of this focus*

Mild forms of Haemophilia make up around 40% of cases of Haemophilia both A and B. Presentations vary from a known family history to a presentation with bleeding either post traumatic or post-surgical. There may be a discrepancy between the one stage assay and the chromogenic assay which can have an impact on treatment. Inhibitors in mild Haemophilia A are uncommon in childhood but can convert the bleeding disorder to a severe bleeding condition.

**Personal story ~ Nathan, SA**

*Nathan is aged 19 and was diagnosed in 2009. He is currently studying Certificate III in disability*

**Inhibitors, treatment in adults and genetic testing ~ Dr Simon McRae**

*Dr McRae is the Director Haemophilia Treatment Centre. Royal Adelaide Hospital*

## FRIDAY 2 OCTOBER 2015

**1100-1230**

**Concurrent 3**

**Hepatitis C**

Room: Diamond Head

**Chair: Suzanne O'Callaghan**

Hepatitis C: Medical issues for PWBD and treatment, incl direct acting antivirals ~ A/Prof Simone Strasser

Personal story of a person living with HCV ~ Dave, QLD

Hepatitis C progression - barriers to monitoring liver health and treatment -

~ Mary Fenech

~ Beryl Zeissink

Panel Discussion

**Hepatitis C: Medical issues for PWBD and treatment, incl direct acting antivirals ~ A/Prof Simone Strasser**

*A/Prof Simone Strasser is a Senior Staff Specialist in the AW Morrow Gastroenterology and Liver Centre, and the Australian National Liver Transplant Unit at Royal Prince Alfred Hospital and the University of Sydney. She has a major clinical and research interest in a broad spectrum of liver diseases including viral hepatitis, advanced liver disease, liver cancer and liver transplantation. She is a regular speaker in national and local educational programmes for health care workers and consumers in many aspects of liver disease and is on multiple educational, advisory and administrative boards and committees in Australia and Internationally.*

Treatment of hepatitis C is currently undergoing a major revolution. The severity of liver damage can be accurately assessed using safe, non-invasive tools. New interferon-free all oral treatments, have very few side-effects and are effective in eradicating hepatitis C in over 90% of people. Response rates are high despite the presence of cirrhosis, HIV, particular HCV genotypes or prior treatment failure. These treatments are TGA approved, and are awaiting PBS listing. All people with haemophilia and hepatitis C should have their liver disease assessed, and should undergo treatment once these new treatments are available.

Once HCV is eradicated, the risk of complications of liver disease is markedly reduced, however those with cirrhosis continue to be at risk of developing liver cancer. They should continue to have liver ultrasounds every 6 months so that early tumours can be found and treated. Liver transplantation is an option for people with liver failure or early liver cancer.

***Personal story of a person living with HCV ~ Dave, QLD***

David has been living with Von Willebrand Disease type 2 for some fifty eight years and was diagnosed at birth. David is originally from Florida in the United States and has lived in Australia for four years with his partner Judy.

David is currently undergoing hepatitis C treatment and will share his experiences.

***Hepatitis C progression - barriers to monitoring liver health and treatment -  
\* Mary Fenech***

**\* Beryl Zeissink**

*Beryl has worked with the Queensland Haemophilia Centre for 15 years. She has a Masters in Nursing and a Masters in Science (Genetic Counseling). Although Beryl does not work in the liver clinic, she sees the importance of the close links in communication between the haemophilia centre and the liver clinic. Although the journey is difficult this communication is also key, between pts and the clinical multidisciplinary team.*

## FRIDAY 2 OCTOBER 2015

**1330-1500**

**Concurrent 1**

**Youth**

Room: Sunset

**Chair: Hannah Opeskin**

Q&A panel with engaging topics including:

- On the Move – moving out of home, travelling, work and study
- Is there such a thing as a safe risk?
- Disclosure – who to tell

Panel:

Physiotherapy ~ Cameron Cramey

Nurse Perspective ~ Clare Waite

Psychologist ~ Moana Harlen

Young man's perspective ~ Tim D, VIC

Young woman's perspective ~ Jade B, WA

Young people with chronic disorders often engage in risky behaviours at typically higher rates than young people without, and with the potential for greater adverse health effects (Sawyer, Drew, Yeo, & Britto, 2007). Youth often struggle to find relatable information about their bleeding disorders and their lives and also to adhere to conservative health and medical advice. This panel session focuses on pressing issues in young people's lives including moving interstate, travel, moving out of home, sex and disclosure in the workplace and relationships and offers practical solutions. The panel session aims to address issues and anonymous questions that previously may have not been discussed.

The panel comprises of 3 health professionals and two youth representatives:

***Haemophilia physiotherapist – Cameron Cramey***

*Cameron Cramey is a senior Musculoskeletal Physiotherapist at the Royal Adelaide Hospital and a physiotherapist at the Royal Adelaide Hospital Haemophilia Treatment Centre. Cameron's special interest is in haemophilia, complex spinal injuries and exercise rehabilitation.*

***Haemophilia Nurse – Claire Waite***

*Clare Waite is a clinical nurse haemophilia nurse at Royal Prince Alfred Hospital in Sydney.*

***Senior Psychologist Haemophilia – Dr Moana Harlen***

*Moana is a senior Psychologist at the paediatric service of the Queensland Haemophilia Centre. The ultimate aim of Moana's psychosocial role is to help lessen the impact of haemophilia on the children and families and to utilise a preventative approach to enhance long term developmental outcomes of the children and adolescents of the Qld Haemophilia Centre.*

***Youth representative – Tim***

Tim has severe haemophilia A. Tim is a paramedic with a special interest in promoting physical health for all people living with haemophilia.

***Youth representative - Jade***

Jade has Von Willebrand Disorder and currently works as an Engagement Officer. Jade has a special interest in helping promote and encourage health and well-being in the community specifically among women.

## FRIDAY 2 OCTOBER 2015

**1330-1500**

**Concurrent 2**

**Inhibitors**

Room: Point Break

**Chair: Dr Chris Barnes**

Inhibitor Risk Factors ~ Dr Alfonso Iorio

The impact of product transition on the risk of inhibitor development in Australian patients with Haemophilia A ~ Dr Ann S Wilson

Personal experience ~ Andrew B, QLD

Treatment & Management of inhibitors ~ Dr John Rowell

***Inhibitor Risk Factors ~ Dr Alfonso Iorio***

*Prof Alfonso Iorio is the Deputy Chief of the Health Information Unit in the Department of Clinical Epidemiology and Biostatistics at McMaster University, Hamilton, Ontario, Canada. He is the current chair of the World Federation of Hemophilia Data and Demographics Committee.*

***The impact of product transition on the risk of inhibitor development in Australian patients with Haemophilia A ~ Dr Ann S Wilson***

*Ann Wilson first joined AHCDO as the project officer in March 2014. She has over 20 years research experience within the health sector both as a scientist and a social researcher. Fields of interest have included developing cancer diagnostics, genetic and epigenetic research, diabetes and pregnancy as well as developing online surveys and screening tools for young people seeking help and evaluating ways of improving clinical practice. Ann has been involved in education through teaching not just science but also research methods and improving nursing practice through understanding of both cultural and personal patient needs.*

The impact of product transition on the risk of inhibitor development in Australian patients with Haemophilia A.

McRae S<sup>1,2</sup>, Wilson A<sup>2</sup>, Tran H<sup>2,3</sup>.

<sup>1</sup>Royal Adelaide Hospital, Adelaide, SA, Australia; <sup>2</sup>Australian Haemophilia Centre Directors Organisation, Melbourne, Victoria, Australia; <sup>3</sup>The Alfred, Melbourne, Victoria, Australia.

There is conflicting and inconsistent evidence that “switching” factor VIII concentrate as treatment among patients with haemophilia A might be associated with an increased risk of inhibitor development. As a result, some clinicians and patients are hesitant to switch between products. However, the evaluation of more recent data does not support this finding. This study aims to evaluate the impact of switching factor VIII treatment products on inhibitor development among the severe haemophilia A patient population in Australia. This is done by analysing the data of patients who were recently involved in treatment product switching due to the National tender process.

***Personal experience ~ Andrew B, QLD***

***Treatment & Management of inhibitors ~ Dr John Rowell***

*Dr John Rowell is Director of Haematology at Pathology Queensland and Director of Queensland Haemophilia Centre at Royal Brisbane and Womens' Hospital. He is past Chairman of the Australian Haemophilia Centre Directors Organisation (AHCDO). Dr Rowell has been a member of the Council of the Australian and New Zealand Society of Blood Transfusion, was Chairman of the RCPA Transfusion Quality Assurance Program and an examiner in Haematology for the Royal College of Pathologists of Australasia. His major interests are in Haemophilia and other bleeding disorders, Genetics and Transfusion.*

## FRIDAY 2 OCTOBER 2015

**1330-1500**

**Concurrent 3**

**HIV**

Room: Diamond Head

**Chair: Leonie Mudge**

The legacy of HIV for the bleeding disorders community ~ Leonie Mudge

HIV – An update on treatment and the burden of co-morbidities, including hepatitis C virus co-infection ~ Dr Krispin Hajkowicz

Ageing/disability, resilience and HIV – psychosocial issues ~ Lynne Heyes

HIV and mental health ~ Dr John Linnane

***The legacy of HIV for the bleeding disorders community ~ Leonie Mudge***

*Leonie Mudge is the Haemophilia Social Worker at the Royal Prince Alfred Hospital in Sydney, at the Haemophilia Treatment Centre for Adults. Prior to this she had extensive experience as the Haemophilia Social Worker at the Ronald Sawers Haemophilia Treatment Centre at the Alfred Hospital in Melbourne. She has been Co-Chair of the Haemophilia Social Workers and Counsellors Professional Group, and participated at WFH Congress.*

***HIV – An update on treatment and the burden of co-morbidities, including hepatitis C virus co-infection ~ Dr Krispin Hajkowicz***

*Dr Krispin Hajkowicz is a staff specialist in infectious diseases at Royal Brisbane and Women's Hospital and a Board Member and Chair of the Viral Hepatitis Group of the Australasian Society for Infectious Diseases. He has a large HIV clinical practice, including many people living with haemophilia and HIV. He has a special interest in the management of HIV-HCV and HIV-HBV co-infection.*

As HIV has evolved from into a chronic disease requiring medical management, new challenges and risks have emerged. Landmark studies published in the last twelve months, including the START study, have substantially altered treatment strategies for HIV. The rise of co-morbidities such as diabetes, cardiovascular disease and other components of the so-called “metabolic syndrome,” as well as non-AIDS-defining cancers, now represent the most common cause of death for people living with HIV. Recent developments in the field of hepatitis C virus therapeutics has revolutionized the management of HIV-HCV co-infection. Special attention to disease progression, drug:drug interactions and complication screening is needed for people living with this “double-hit”.

***Ageing/disability, resilience and HIV – psychosocial issues ~ Lynne Heyes***

***HIV and mental health ~ Dr John Linnane***

## FRIDAY 2 OCTOBER 2015

1530-1700

### Plenary 2

#### Improving outlooks for pain in haemophilia

Room: QT Ballroom

#### Chair: Abi Polus

Humans: The best protectors yet ~ Prof Lorimer Moseley

Managing Pain in Haemophilia ~ A/Prof Carolyn Arnold

#### ***Humans: The best protectors yet ~ Prof Lorimer Moseley***

*Lorimer is Professor of Clinical Neurosciences at the University of South Australia and Senior Principal Research Fellow at Neuroscience Research Australia. He has authored over 200 research articles and four books on pain. He was the inaugural winner of the International Association for the Study of Pain's Outstanding Clinical Science Prize, has won the Australian Government's prize for health and medical research innovation, and has been recognized for his contributions to the field by professional organisations on every continent. He was the first NHMRC Research Fellow to be made an Honoured Member of the Australian Physiotherapy Association. He has Honorary Professorships at leading universities in Europe and North America and has given over 30 plenary talks at major meetings in 26 countries. Lorimer is Chief Editor of the most influential web and social media presence in the clinical pain sciences – BodyinMind.org - and leads an interdisciplinary group of 30 researchers who are investigating the role of the brain and mind in chronic pain.*

Pain is a feeling perhaps more compelling than any other. It is unpleasant, terrifying at times, captures our awareness and does not let go. Like fear, it compels us to *do something* to protect ourselves from a situation that is dangerous to our body. Unlike fear, pain is always felt *somewhere* which is one reason it is so difficult to understand. That is, because pain is so clearly felt 'out there in the body' we tend to think that is where it is actually generated, which is not true. All pain, from that caused by a bee sting to that of cancer to that of haemophilia, is generated by the brain and serves to change our behaviour and promote our physical safety. In this talk, I will present some core concepts that I think are key to understanding pain and the fearful and wonderful complexity of humans as the ultimate self-protectors. I will present research that shows that understanding pain biology is not as difficult as you might think – there is certainly a massive amount of literature but it can be reasonably well distilled to some simple principles. I will suggest that actually understanding this helps us to realign the relationship between pain and what I call 'helpful protection'. I will touch on the latest developments in the science of pain and the best ways to promote understanding, use it to plan and guide your own pain management and rehabilitation, and to minimize the disruptive effects of flare-ups and setbacks.

#### ***Managing Pain in Haemophilia ~ A/Prof Carolyn Arnold***

*Carolyn is a Physician in Pain Medicine and Rehabilitation Medicine who works in Alfred Health managing both acute and chronic pain in PWH, working as part of a multidisciplinary team. She is also an Associate Professor in the Dept. of Anaesthesia and Perioperative Medicine of Monash University, and undertakes chronic pain clinical research. She has held leadership roles in the Australian Pain Society and the Faculty of Pain Medicine.*

It has been estimated that 32 to 50% of European people with Haemophilia (PWH) suffer chronic pain (Holstein 2012), arising principally from joint arthropathy, which is more common in those with severe haemophilia, or those without access to effective prophylactic factor replacement programmes.

Pleasingly the last 10 years has seen more scientific research into this problem, and many developments are promising that in the future pain will be better managed. Factors contributing to this improvement are not dissimilar to developments in the understanding and management of acute and chronic pain in other chronic conditions.

These factors include: better management of the underlying disease process- relevant both for bleeding and for managing the associated synovitis and degenerative joint condition, appropriate acute pain control, using a multifaceted approach to joint arthropathy pain, including expert rheumatology and orthopaedic surgery in joint care, physical re- activation through expert exercise prescription and physical therapy, orthotics, judicious use of analgesic medication supervised by those with pain medicine expertise, avoiding the hazards of chronic pain including mental health effects (for example depressed mood), physical inactivity, disengagement from work, and drug dependence. Negotiating the transition through adolescence from child to adult is also very important so that PWH can responsibly self-manage their health. This talk will outline a practical approach to the management of Pain in Haemophilia



## CONFERENCE PROGRAM

### SATURDAY 3 OCTOBER 2015

0700-0820	<b>Men's Breakfast</b> Facilitated by Tim Marchinton Room: Sunset 1 <i>*Tickets are \$25 and must be pre-booked*</i>			
0700-0820	<b>Women's Breakfast</b> MC: Leonie Demos Room: Sunset 2 <i>*Tickets are \$25 and must be pre-booked*</i>			
0830-0945	<b>Plenary 3</b> <b>Making informed family planning decisions</b> Room: QT Ballroom Chair: Dr Susan Russell			
	Prenatal/PGD testing ~ Peter Field A Journey Through Genetic Counselling and Prenatal Diagnosis ~ Pauline McGrath Role of Haemophilia Centres in genetic counselling ~ Robyn Shoemark			
0945-1000	<b>MORNING TEA</b>			
1000-1130	<b>Concurrent 1</b> <b>Genetic Counselling Services Workshop (Women Only)</b>  Room: Malibu Chair: Maureen Spilsbury & Dr Desdemona Chong	<b>Concurrent 2</b> <b>Family Matters: Tips, Tools &amp; Strategies to support your child</b>  Room: Sunset Chair: Moana Harlen	<b>Concurrent 3</b> <b>Getting Older</b>  Room: Point Break Chair: Leonie Mudge	<b>Concurrent 4</b> <b>Being Active for children, teenagers and young adults</b>  Room: Diamond Chair: Wendy Poulsen
	<i>The session will be facilitated by haemophilia social workers and a genetic counsellor and is for women. It will provide an opportunity for participants to think further about genetic issues and family planning.</i>  <i>The speaker's panel will also include women from the bleeding disorders community who will share their personal experiences.</i>	Back off bully ~ Sarah Elliott  Siblings – best of friends and rivals ~ Colleen McKay  Bouncing Back: Increasing Resilience in a child with a Bleeding Disorder ~ Linda Dockrill	Clinical issues ~ Dr John Rowell  GPs and Men's health checks ~ Olivia Hollingdrake  Personal experience ~ Mike, QLD  Falls prevention/keeping mobile~ Rebecca Dalzell	Purpose of prophylaxis treating after injury ~ Dr Chris Barnes  Adventure therapy success in supporting people living with a bleeding disorder ~ Tim Marchinton  Personal experience ~ Ben, VIC  Gym Training – What are the right exercises for me? ~ Cameron Cramey  Personal experience ~ Ty, SA
1130-1145	<b>BREAK</b>			

1145-1300	<b>Concurrent 1 Women Bleed too</b> Room: Sunset <b>Chair: Joanna McCosker</b>	<b>Concurrent 2 Managing your headspace for adults</b> Room: Point Break <b>Chair: Clare Reeves</b>	<b>Concurrent 3 Longer Acting Factors</b> Room: Diamond Head <b>Chair: Dr Jamie Price</b>	
	Managing bleeding problems: menorrhagia and pregnancy ~ Dr Stephanie P'Ng  Personal experience ~ Elyse S, QLD  Question and Answer Panel Nurse ~ Dale Rodney Outreach worker ~ Linda Dockrill	The new age challenge: Haemophilia and growing older ~ Sarah Elliott  Evidence Based Mindfulness and how it can help in your personal and professional life ~ Dr Ira Van der Steenstraten	Long Acting Clotting Factor Concentrates – How do they work? ~ Claire McGregor  What do we know so far about longer acting therapies – data ~ Dr Jamie Price  A family's experience – Helen and Felix, QLD	
<b>1300-1400</b>	<b>LUNCH</b>			
1400-1455	<b>Plenary 4 New therapies and future horizons</b> Room: QT Ballroom <b>Chair: Dr Simon McRae</b>			
	In this session, Dr Simon McRae will discuss the upcoming new Australian treatment guidelines for bleeding disorders, and their potential to improve care and services and optimise outcomes for patients and their families.  A Q &A Session with a multidisciplinary panel and community representative will look to the future as it responds to questions and comments from delegates.			
1455-1500	Closing remarks by HFA and HFNZ Presidents ~ Gavin Finkelstein and Deon York			
1500-1700	Concurrent Options <i>RSVP and bookings required</i>			
1500	<b>Workshop 1 1515-1615</b> Mindfulness ~ Dr Ira Van der Steenstraten Room: Sunset 1	<b>Catch up and chill out afternoon tea</b> 1500-1630 Room: Sunset Lounge	<b>Viewing of AFL Grand Final</b> 1500-1800 Room: Stringray	<b>My ABDR (Private closed group, not for public)</b> 1500-1630 Room: Sunset 2

## SATURDAY 3 OCTOBER 2015

0830-0945

### Plenary 3

#### Making informed family planning decisions

Room: QT Ballroom

Chair: Dr Susan Russell

Prenatal/PGD testing ~ Peter Field

A Journey Through Genetic Counselling and Prenatal Diagnosis ~ Pauline McGrath

Role of Haemophilia Centres in genetic counselling ~ Robyn Shoemark

#### ***Prenatal/PGD testing ~ Peter Field***

*Peter has been working at Queensland Fertility Group for the last 10 years, where he set up the Molecular Genetics lab to enable screening for genetic markers for fertility treatment and Preimplantation Genetic Diagnosis.*

An overview of genetic screening and Preimplantation Genetic Diagnosis (PGD), different methods implemented and approximate costs of treatment for a PGD cycle. PGD is not for everyone but it can be useful for some patients.

#### ***A Journey Through Genetic Counselling and Prenatal Diagnosis ~ Pauline McGrath***

*Pauline is a Human Genetics Society of Australasia Certified Genetic Counsellor. She has worked for Queensland Health since 1995 in this role. She has been responsible for the provision of prenatal and fetal medicine genetic counselling services as a staff member of Genetic Health Queensland since this time. She was recently awarded a Churchill Fellowship to explore the provision of counselling support for women accessing emerging pre-natal testing technologies.*

Each individual has different needs for their own journey through genetic counselling and/or prenatal diagnosis. Individuals and families require information and support to make their own decisions as to whether genetic testing is for them. The decision to use this information can be based on personal and familial experience of haemophilia, the severity of the condition within families matched with an individual beliefs, values, morals culture and religion. The decision to have carrier testing and the use of prenatal technologies presents challenges. Today many people may seek counselling prior to a pregnancy because of the concerns about the implications for their family. Genetic counselling regarding prenatal diagnosis can be complex and filled with powerful emotional responses. The role of the genetic counsellor is ensure those seeking genetic counselling, genetic testing, prenatal diagnosis or pre-implantation diagnosis have the facts that enable them to make their own decisions. However within this there remains the burden of decision making which includes the emotional strains and worries associated with the possibility of an affected newborn, and what the future may hold.

***Role of Haemophilia Centres in genetic counselling ~ Robyn Shoemark***

*Robyn Shoemark is the Clinical Nurse Consultant for Haemophilia from the Children's Hospital at Westmead in Sydney and has been in this role for the past 8 ½ years. She is the current Asia Pacific representative on the World Federation of Haemophilia Nurses Committee.*

As clinicians in a HTC, we are often asked about care and treatment for people with haemophilia. What is happening, what is new, what is out there? We are usually the first port of call for patients and their families for information about haemophilia.

But what about genetics? It is not just a case of taking the blood sample and sending it off for testing. There are many things to discuss and as the clinician who is there at the time, we are often asked questions about the testing process and what the results might mean for the patient and their families members.

This presentation will endeavour to cover some of those frequently asked questions and to pose questions about how to improve services and where do we go to from here?

## SATURDAY 3 OCTOBER 2015

**1000-1130**

Concurrent 1

### **Genetic Counselling Services Workshop (Women Only)**

Room: Malibu

**Chair: Maureen Spilsbury & Dr Desdemona Chong**

*The session will be facilitated by haemophilia social workers and a genetic counsellor and is for women. It will provide an opportunity for participants to think further about genetic issues and family planning.*

*The speaker's panel will also include women from the bleeding disorders community who will share their personal experiences*

***Maureen Spilsbury** is a Social Worker working at The Haemophilia Centre in Brisbane, Queensland. She has worked in the area of Haemophilia for over 18 years. Maureen initially worked at the QLD Paediatric Centre for 7 years then moved over to work at the Adult Haemophilia Centre. Maureen has a special interest in providing group work within the community.*

***Dr Desdemona Chong** is a clinical psychologist by training. She works with Maureen Spilsbury to provide psychosocial support and intervention to individuals receiving care at The Haemophilia Centre in Brisbane, Queensland. She has worked in the area of Haemophilia for about 5 years, starting initially at the QLD Paediatric Centre.*

## SATURDAY 3 OCTOBER 2015

1000-1130

Concurrent 2

**Family Matters : Tips , Tools & Strategies to support your child**

Room: Sunset

**Chair: Moana Harlen**

Back off bully ~ Sarah Elliott

Siblings – best of friends and rivals ~ Colleen McKay

Bouncing Back: Increasing Resilience in a child with a Bleeding Disorder ~ Linda Dockrill

### ***Back off bully ~ Sarah Elliott***

*Sarah Elliott is a registered Social Worker who has worked as an Outreach Worker for The Haemophilia Foundation of New Zealand for the last seven years. She is currently completing a Master's thesis in Social Work in the area of haemophilia through the University of Auckland.*

To investigate bullying and children with bleeding disorders workshops were held at two Haemophilia Foundation of New Zealand (HFNZ) events. The first included 13 parents of children with bleeding disorders at an HFNZ regional camp. The second included 20 children with bleeding disorders, or their siblings, and five youth leaders at the HFNZ National Families Camp. Discussion topics involved bullying in general (what is and is not bullying, types of bullying), specific discussion around bullying and bleeding disorders, and then appropriate strategies and tools to deal with bullying.

This paper will review the current literature on bullying and bleeding disorders, present outcomes and comments from the two group discussions on bullying and the experiences of participants, and discuss tools and strategies to help people with bleeding disorders to cope with bullying.

### ***Siblings – best of friends and rivals ~ Colleen McKay***

*Colleen McKay has been involved with the Haemophilia Foundation of New Zealand (HFNZ) since 1983, initially as a volunteer. In 1996, she was employed by HFNZ as an Outreach Worker to provide education, support and advocacy for people with bleeding disorders and their families / whanau in the South Island. Since 2008 Colleen has had a new role - Manager of Outreach Services. In this position she both manages the small team of Outreach Workers and she takes responsibility for the co-ordination of educational Camps, Workshops and Events.*

In every family each child is an individual and with different needs. Children with bleeding disorders can often require greater time and attention of their parents. If the bleeding disorder becomes the focus of your family, siblings may feel left out and experience a range of feelings and sometimes challenging behaviours which can impact on the family unit. Within the family, the child with the bleeding disorder must have his / her medical needs met, and at the same time the other children in the family are entitled to parental care, love and attention. Managing these demands is a constant balancing act and takes considerable energy and skills, and a range of parenting strategies.

Brothers and sisters live closely together within the family unit, they affect each other's lives, and they often get angry and frustrated with each other. Siblings can sometimes compare themselves with each other and can become jealous, bossy, resentful and competitive, and they often test out their strengths and weaknesses on each other. These tensions are called Sibling Rivalry; a perfectly healthy process during which children learn positive skills about

getting along with other people. It is important that parents support and enhance the learning process.

This presentation will: highlight the good, the bad and the ugly aspects of sibling rivalry; explore the common feelings experienced by siblings of children with bleeding disorders; give helpful tips for parents to help siblings deal with these feelings and behaviours, and; identify red flags or warning signs that a child needs more help in dealing with their feelings or behaviours.

Sibling rivalry is generally manageable and, when managed well, children will learn very important life skills.

***Bouncing Back: Increasing Resilience in a child with a Bleeding Disorder ~ Linda Dockrill***

*Linda Dockrill is a Social Worker employed as the Southern Outreach Worker for the Haemophilia Foundation of New Zealand, working with families, individuals and groups in the South Island and nationally. She has worked for the foundation for the past 5-6 years and has taken responsibility for running the International Parents Empowering Parents programme in NZ. Linda is passionate about parenting issues and enjoys seeing the changes that can come about when a parent of a child with a bleeding disorder is able to embrace the challenges and enjoy the roller coaster ride that having a child with a potentially life threatening illness brings with it. She believes that parents are the experts about their own child and that with support parents have the skills to help their child become the independent, responsible, caring, resilient and happy adult that they picture in their mind. Linda is a parent to 3 adolescents and aims to walk the talk as often as possible! She learns a lot from the parents, children and families she works with everyday.*

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, or significant sources of stress — such as family and relationship problems or serious health problems. Research has shown that resilience is ordinary, not extraordinary. What studies also show is that resilience is not a trait that people either have or do not have. It involves behaviours, thoughts and actions that can be learned and developed in anyone. As a concept, resilience has considerable validity and application for children and parents of a child with a bleeding disorder. It is included as a component of Parents Empowering Parents (PEP), an international parenting programme for parents of a child with a bleeding disorder, for this reason. Increasingly families are being well supported by advancing medical practices but the challenges of parenting a child with a bleeding disorder are given less attention. This paper will define resilience as it relates to parenting a child with a bleeding disorder, acknowledge the role of parents in the development of resilience and identify the signs to look for when a child is in need of extra support. It will offer seven key parenting tasks that will help develop resilience in a child with a bleeding disorder and link these to developing resilience at each age and stage from pre-school to adolescence.

## SATURDAY 3 OCTOBER 2015

1000-1130

Concurrent 3

Getting Older

Room: Point Break

**Chair: Leonie Mudge**

Clinical issues ~ Dr John Rowell

GPs and Men's health checks ~ Olivia Hollingdrake

Personal experience ~ Mike, QLD

Falls prevention/keeping mobile~ Rebecca Dalzell

### **Clinical issues ~ Dr John Rowell**

*Dr John Rowell is Director of Haematology at Pathology Queensland and Director of Queensland Haemophilia Centre at Royal Brisbane and Womens' Hospital. He is past Chairman of the Australian Haemophilia Centre Directors Organisation (AHCDO). Dr Rowell has been a member of the Council of the Australian and New Zealand Society of Blood Transfusion, was Chairman of the RCPA Transfusion Quality Assurance Program and an examiner in Haematology for the Royal College of Pathologists of Australasia. His major interests are in Haemophilia and other bleeding disorders, Genetics and Transfusion.*

### **GPs and Men's health checks ~ Olivia Hollingdrake**

*Olivia Hollingdrake is a Clinical Nurse at the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital. Her areas of interest include chronic disease across the lifespan and preventative health.*

**Introduction:** As the life expectancy of men with haemophilia rises due to advances in treatment, the incidence of age-related comorbidities is also increasing. Current literature advocates prevention and early detection of age-related comorbidities for men with haemophilia. Little is known about whether this population is participating in recommended routine men's health checks.

**Aims:** To investigate whether men with haemophilia in Australia are aware of and participating in recommended men's health checks. To explore whether men with haemophilia have regular contact with a General Practitioner (GP) and seek men's perceptions of their GP's knowledge and communication around haemophilia.

**Methods:** All eligible men with haemophilia aged over 18 years in Queensland, Australia were sent a self-administered, anonymous survey. Descriptive statistical analysis was performed using Stata v13.1.

**Results:** The survey obtained a response rate of 106 (41%). One third of men reported attending the GP specifically for the purpose of a men's health check. Men who were unaware of recommended men's health checks were significantly less likely to participate in these checks. The majority of men (73%) reported regular attendance at the same GP clinic, and 46% of men indicated they always received the help they asked for. Many men perceived that their GP had some understanding of haemophilia in relation to their general health (90%), however over half the respondents had no knowledge of whether their GP contacted the haemophilia specialist if needed.

**Conclusion:** Clinicians at haemophilia treatment centres (HTC) are well placed to inform young men about recommended men's health checks aimed at preventing the onset of age-related comorbidities. Men are accessing GPs for their primary health needs, so collaboration between GPs and HTC staff and the men themselves is necessary to ensure men do not delay or avoid men's health checks.

**Keywords:**

Haemophilia, ageing, prevention, general practice, comorbidities, men's health

**Personal experience ~ Mike, QLD**

*Mike was born in 1948 and has severe haemophilia A (<1%). He is married with two adult children (daughter & son). After a career in senior management in sales and marketing with international consumer goods companies Unilever and Parmalat in Melbourne Sydney and Brisbane Mike is now retired with his wife Marie in their native city of Brisbane. His hobbies are art, aviation history and travel.*

The process of ageing and Haemophilia is entering new ground as it is the Baby Boomer generation of haemophiliacs who, due to medical technology and the availability of clotting factor products over the past 50 years, have the opportunity to live into their mature years. Consequently we now face a range of issues associated with ageing, while normal to the general mature population, are new to us eg; heart disease, blood pressure, cancer screening & diabetes.

Hence it is vitally important to have a good patient /practitioner relationship with your GP and have regular checkups. It is also recommended to participate in some form of regular exercise to maintain muscle strength and joint mobility. The benefits of self infusion are covered plus the importance of mental and emotional health are discussed in terms of selecting a hobby or particular interest to exercise our faculties and maintain social interaction. Finally we look at the importance of planning for the next stages of our lives eg; "life style complexes" and levels of care.

**Falls prevention/keeping mobile~ Rebecca Dalzell**

*Rebecca Dalzell is the Physiotherapist for Adults at the Qld Haemophilia Centre, Royal Brisbane and Womens Hospital. She has a passion to help those with bleeding disorders to live active and fulfilling lives through optimizing their physical function and well-being. She has been involved in many initiatives that promote physical activity, falls prevention, bone loading and strength for those with bleeding disorders, including her DVD 'Inspire' and her latest program, 'Strong Bloody Men'....*

Growing older can present many new and complex challenges both for those with a bleeding disorder and their health professionals. Along with the co-morbidities and physical changes that are common in the later decades, the health of those with bleeding disorders can also be significantly impacted by other issues. Research reveals a higher incidence of osteoporosis in people with Haemophilia compared to the general population. Balance, mobility and strength have also been shown to be adversely effected. There is therefore a greater risk of falls and fracture. Arthritic pain, limitations in range of movement, and decreased mobility can be a challenge. General deconditioning and a lack of core muscle strength is also common and can cause other musculoskeletal challenges such as low back pain. This presentation will discuss these, and other, ageing related issues. It will also present new and positive management strategies that have been shown to significantly enhance health throughout the older years. The evidence shows that balance programs can indeed reduce the risk of falls. Bone loading and strengthening exercises can have a significant impact on bone density. There are new concepts emerging that promote core axial strength and can significantly improve posture and many musculoskeletal complaints. Indeed keeping active into the mature years has been shown to have many health benefits. Much can be done to promote a healthy, active and meaningful life. This talk will present the latest research, and aims to inspire both those with bleeding disorders, and those involved in their care, to adopt a comprehensive approach to ageing, and to pursue the many health benefits that are available to those who remain active.

## SATURDAY 3 OCTOBER 2015

**1000-1130**

Concurrent 4

### **Being Active for children, teenagers and young adults**

Room: Diamond

#### **Chair: Wendy Poulsen**

Purpose of prophylaxis treating after injury ~ Dr Chris Barnes

Adventure therapy success in supporting people living a bleeding disorder ~ Tim Marchinton

Personal experience ~ Ben, VIC

Gym Training – What are the right exercises for me? ~ Cameron Cramey

Personal experience ~ Ty, SA

Panel Discussion

#### ***Purpose of prophylaxis treating after injury ~ Dr Chris Barnes***

*Dr Chris Barnes is the Director of the Henry Ekert Haemophilia Treatment Centre at the Royal Children's Hospital*

#### ***Adventure therapy success in supporting people living with a bleeding disorder ~ Tim Marchinton***

*Tim loves sharing adventure with young people and believes in the magic of Adventure Based Experiential Learning (ABEL) in a camp environment.*

*He began focusing his career specifically on working with children living with a chronic or life threatening illness in 1992. He has delivered adventure therapy programs to children in 40 countries and during his career has held recreation management positions all over the world.*

*In 2002, he founded Purple Soup to provide challenging activity based programs for children and their families affected by serious illness. Specifically he set out to provide services to support families living with haemophilia. These programs are designed to rebuild confidence, self esteem, trust and courage in a safe, fun and supportive environment. Purple Soup have three times been awarded at the prestigious NACCHO conference for recognition as leaders in Adventure therapy programs specifically for people with a bleeding disorder.*

*Last year Tim and his team went to India to run a haemophilia family camp for the second time.*

*Tim holds a BA in Recreation Management, a Post Grad in Advanced Adolescent Counselling and instructor qualifications in many outdoor pursuits. The role of directing the organisation is varied and encompasses many roles however his preferred job title is "Game Maker-Upperer".*

*In his spare time he pursues his love for adventure, flying aerobatic planes, diving with sharks, riding motorbikes and despite these pursuits, he is terrified of even the smallest spiders but is on his way to conquering this fear after honeymooning with his wife Emma in the Amazon - surrounded by huge Tarantulas!*

#### Hypothesis

That Adventure Therapy specific residential camps and day programs contribute positively and in a unique way to all members of a family of somebody living with a bleeding disorder.

These programs benefit the family members on a wide variety of levels and areas including psychosocial, emotional and physical benefits.

### Conclusion

We have collected and will present the statistical data using pre and post participant surveys as well as anecdotal, qualitative and quantitative research that demonstrates the effectiveness of Adventure therapy as a way of improving adherence to medical regime including successful self vena puncture both for prophylaxis and also on demand treatment. Further there is strong evidence to support the benefits of these programs in fostering self efficacy, self esteem, applied resilience during transition into an adult care centre and further into tertiary studies, overseas travel and independent living skills.

### ***Personal experience ~ Ben, VIC***

*Ben is 21 years old and was diagnosed at birth with Haemophilia A. Ben currently studies full time at Monash University.*

### ***Gym Training – What are the right exercises for me? ~ Cameron Cramey***

*Musculoskeletal Physiotherapist, Royal Adelaide Hospital and Private Practice.*

*Working within the Haemophilia Treatment Centre at the Royal Adelaide for the past 5 years.*

*Special interest in haemophilia, complex spinal injuries and exercise rehabilitation.*

This presentation will discuss the basic principles of resistance training and their application across the lifespan. From building muscle bulk, maintaining or improving function for everyday activities, and rehabilitating joint and muscle bleeds.

Is it safe for adolescents to perform a gym programme? Why do we lose strength as we age? What can I do to help minimize my risk of bleeding? What are the benefits and risks of strength training? What does a good gym programme look like?

This session will aim to provide information to help you answer these questions and should prove relevant to anyone looking to maintain an active and healthy lifestyle.

### ***Personal experience ~ Ty, SA***

## SATURDAY 3 OCTOBER 2015

**1145-1300**

**Concurrent 1**

**Women Bleed too**

Room: Sunset

**Chair: Joanna McCosker**

Managing bleeding problems: menorrhagia and pregnancy ~ Dr Stephanie P'Ng

Personal experience ~ Elyse S, QLD

Question and Answer Panel

Nurse ~ Dale Rodney

Outreach worker ~ Linda Dockrill

***Managing bleeding problems: menorrhagia and pregnancy ~ Dr Stephanie P'Ng***

Dr P'ng undertook her medical degree at the University of Western Australia. She completed her physician training at Royal Perth Hospital in 2003 and underwent 4 years of haematology training in Royal Perth and Fremantle Hospitals and Royal Prince Alfred Hospital Sydney.

***Personal experience: Elyse S, QLD***

Elyse is a 16 year old student who was initially diagnosed with von Willebrand Disorder (vWD) following an injury at the age of 18months. Following her diagnosis, family testing highlighted that unbeknown to her parents, both her brothers were also positive for vWD. This diagnosis was changed to mild haemophilia A when she was about 5 and she had very few bleeding incidents for many years. In the past three years she has had numerous bleeding issues and has now been diagnosed with both vWD and mild haemophilia A. Despite this diagnosis she leads a full and active life including sporting and cultural activities.

***Nurse ~ Dale Rodney***

*Dale Rodney is the Haemophilia Clinical Nurse Consultant, Haemophilia Treatment Centre, Calvary Mater Newcastle, NSW*

***Outreach worker ~ Linda Dockrill***

*Linda Dockrill is a Social Worker employed as the Southern Outreach Worker for the Haemophilia Foundation of New Zealand, working with families, individuals and groups in the South Island and nationally. She has worked for the foundation for the past 5-6 years and has taken responsibility for running the International Parents Empowering Parents programme in NZ. Linda is passionate about parenting issues and enjoys seeing the changes that can come about when a parent of a child with a bleeding disorder is able to embrace the challenges and enjoy the roller coaster ride that having a child with a potentially life threatening illness brings with it. She believes that parents are the experts about their own child and that with support parents have the skills to help their child become the independent, responsible, caring, resilient and happy adult that they picture in their mind. Linda is a parent to 3 adolescents and aims to walk the talk as often as possible! She learns a lot from the parents, children and families she works with everyday.*

## SATURDAY 3 OCTOBER 2015

**1145-1300**

Concurrent 2

### **Managing your headspace for adults**

Room: Point Break

#### **Chair: Clare Reeves**

The new age challenge: Haemophilia and growing older ~ Sarah Elliott

Evidence Based Mindfulness and how it can help in your personal and professional life ~ Dr Ira Van der Steenstraten

#### ***The new age challenge: Haemophilia and growing older ~ Sarah Elliott***

*Sarah Elliott is a registered Social Worker who has worked as an Outreach Worker for The Haemophilia Foundation of New Zealand for the last seven years. She is currently completing a Master's thesis in Social Work in the area of haemophilia through the University of Auckland.*

For the first time people who have haemophilia are facing the same aging issues as the general population. This brings new and unique challenges for this population that adds further complexity to their treatment, care and support. The existing literature on this topic is dominated by a medical perspective that focuses on treatments and haematological management of haemophilia and common co-morbidities. Very little investigation into the wider effect of the challenges of growing older with haemophilia on an individual's holistic wellbeing has occurred. The mixed-method research investigated the wider psychosocial experiences of older men with haemophilia in New Zealand using an exploratory sequential design; Literature review, focus group, and national questionnaire. This paper will focus specifically on the findings of holistic wellbeing of adult men with haemophilia in New Zealand; social and psychosocial support, mental and emotional wellbeing, spiritual wellbeing, and age related changes.

#### ***Evidence Based Mindfulness and how it can help in your personal and professional life ~ Dr Ira Van der Steenstraten***

*Dr Ira van der Steenstraten is trained as a psychiatrist, psychotherapist and family therapist at the University of Amsterdam and the Academic Medical Centre in Amsterdam, The Netherlands. She is currently working as a Life Coach at Breeze Life Coaching in Brisbane, Queensland. She is an experienced Mindfulness trainer, and has developed a number of innovative Mindfulness and Resilience programs for individuals and groups such as doctors, interns, physiotherapists, families, teachers and schoolchildren. She has over 20 years of experience working in various medical and therapeutic settings. At present she specializes in providing Mindfulness and Resilience training to adults and children. She also has personal experience with Haemophilia and knows from own experience how effective Mindfulness techniques can be to reduce discomfort.*

This presentation will explain the basic principles of Mindfulness and why it is thought to be effective.

Current research shows that by training your attention doing selected Mindfulness and meditative exercises, you can reduce stress, anxiety and depression, boost your immune system and strengthen your ability to focus your attention to where you want it to be. It has even been shown to change the architecture of your brain. This evidence has made meditation no longer only for "hippies", but its benefits have become widely accepted by scientists and the general public, both young and old. Mindfulness training programs have

been implemented in schools, hospitals, sports, the military and corporate businesses, showing huge benefits for participants.

Training your ability to be non-judgmental creates space to allow new opportunities to arise. If your mind or body is in discomfort and you try to ignore it, resist it, or ruminate on it, this will heighten your levels of stress. For most people it is difficult to accept something unpleasant for what it is. But opening up to reality and exploring how to be with it will give you a better chance of happiness, rather than trying to control it with thinking, or wishing things to be different. Mindfulness can help you to accept situations.

Mindfulness meditation exercises teach you that your thoughts are something you *have*, not what you *are*. You will learn that you cannot stop your thoughts, but you can gain control by learning to not listen to them. This can be especially effective for people suffering from chronic conditions like bleeding disorders but also for the people caring for them. .

*\*\* A follow on Mindfulness workshop will be held on Saturday 3 Oct from 1515-1615 in Sunset 1\*\**

## SATURDAY 3 OCTOBER 2015

**1145-1300**

Concurrent 3

### **Longer Acting Factors**

Room: Diamond Head

#### **Chair: Dr Jamie Price**

Long Acting Clotting Factor Concentrates – How do they work? ~ Claire McGregor

What do we know so far about longer acting therapies – data ~ Dr Jamie Price

A family's experience – Helen and Felix, QLD

#### ***Long Acting Clotting Factor Concentrates – How do they work? ~ Claire McGregor***

*Claire has worked as an adult Haemophilia Clinical Nurse Consultant since 2005. The Adult Haemophilia Treatment Centre in Perth, first at Royal Perth Hospital and more recently Fiona Stanley Hospital has participated in a number of long acting clinical trials and by being a part of those clinical trials, Claire has developed a good understanding of how these technologies work.*

The next wave of treatment for people with haemophilia A and B is closely approaching our shores. Modifications to current factor VIII and factor IX have allowed the life of these factors to last longer. There are a number of different technologies being employed to extend the half-life of factor VIII and factor IX including: pegylation, fc fusion and albumin fusion. Another technology being used is the modification of the structure of factor VIII into a single chain with the aim to make a more stable factor VIII. This presentation will provide a brief overview of the different technologies employed and how they make the factor concentrates last longer.

#### ***What do we know so far about longer acting therapies – data ~ Dr Jamie Price***

*I have worked at Princess Margaret Hospital for Children for many years in Haematology and Oncology covering the whole spectrum of clinical disorders. Over the past 10 years my main focus has been with children with bleeding disorders. The preservation of joint function in patients with severe Haemophilia has been a prime objective and the introduction of aggressive prophylaxis and joint aspiration has been part of this focus.*

#### ***A family's experience – Helen and Felix, QLD***

## SATURDAY 3 OCTOBER 2015

**1400-1455**

Plenary 4

### **New therapies and future horizons**

Room: QT Ballroom

#### **Chair: Dr Simon McRae**

In this session Dr Simon McRae will discuss the upcoming new Australian treatment guidelines for bleeding disorders, and their potential to improve care and services and optimise outcomes for patients and their families.

A Q &A Session with a multidisciplinary panel will look to the future as it responds to questions and comments from delegates.

## SATURDAY 3 OCTOBER 2015

### **Mindfulness Workshop**

1515-1615

Mindfulness ~ Dr Ira Van der Steenstraten

Room: Sunset 1

### **Catch up and chill out afternoon tea**

1500-1630

Room: Sunset Lounge

### **Viewing of AFL Grand Final**

1500-1800

Room: Stringray



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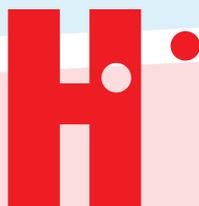
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