



**18TH AUSTRALIAN & NEW ZEALAND CONFERENCE
ON HAEMOPHILIA & RARE BLEEDING DISORDERS**

LOOKING FORWARD TO CHANGE

Melbourne • 12-14 October 2017

Abstracts & Handbook



WELCOME

The 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders will be held at the Pullman Albert Park, Melbourne, 12-14 October 2017. The theme for the conference is **“Looking Forward to Change”**.

Our Conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and to plan for the future.

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives.

We look forward to an informative and educational conference.

Gavin Finkelstein
President
Haemophilia Foundation Australia

Deon York
President
Haemophilia Foundation of New Zealand

Dr Huyen Tran
Chair,
Conference Program Committee

Program Committee

Dr Huyen Tran	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Andrew Atkins	Australian Haemophilia Nurses' Group
Charlotte Bradley-Peni	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Sharon Caris	Executive Director, Haemophilia Foundation Australia
Cameron Cramey	Australian and NZ Physiotherapy Haemophilia Group
Leonie Demos	Community Member
Janine Furmedge	Australian Haemophilia Nurses' Group
Dr Jane Mason	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Loretta Riley	Australia/NZ Haemophilia Social Workers' & Counsellors' Group
Suzanne O'Callaghan	Policy Research and Education Manager, Haemophilia Foundation Australia
Hannah Opeskin	Health Promotion Officer, Haemophilia Foundation Australia
Megan Sarson	Australian Haemophilia Centre Directors' Organisation (AHCDO)
Deon York	Haemophilia Foundation of New Zealand

GENERAL INFORMATION

Conference Organisers

Haemophilia Foundation Australia
7 Dene Ave, Malvern East VIC 3145

P: 03 9885 7800

F: 03 9885 1800

E: hfaust@haemophilia.org.au

W: www.haemophilia.org.au

Venue

Pullman Albert Park
65 Queens Rd, Albert Park VIC 3004

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

Wireless internet is available for all conference delegates
HFA17

Registration and Information Desk

All enquiries should be directed to the Registration and Information Desk located in the Pullman foyer area (see attached venue map), which will be open at the times listed below:

Thursday 12 October 17:00-19:30

Friday 13 October 07:30-17:00

Saturday 14 October 07:30-15:35

Haemophilia Treatment Centres

Ronald Sawers Haemophilia Centre (adults)

The Alfred Hospital

1st Floor, South Block Commercial Road, Melbourne

T 03 9076 2178

Emergency 03 9076 2000 and page 4959

The Henry Ekert Haemophilia Treatment Centre (children)

Royal Children's Hospital

Flemington Road Parkville Vic 3052

T 03 9345 5099

Emergency 03 9345 5522 and page 4800

Childcare

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

SOCIAL PROGRAM

Thursday 12 October

Welcome & Exhibition Opening

18:30-19:30

Pullman Lobby

Come to see the exhibition and meet people before the conference. Free for all registered delegates.

Youth Meet and Greet

19:30 til late

Pullman Atrium Bar and Lounge

Youth are invited to meet others and connect before the conference program starts. Free to all registered youth delegates.

Friday 13 October

Remembrance Service

18:00-18:45

Lake Room

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 21:30

State Room

Come and join your fellow delegates for dinner onsite at the Conference venue. This will be an informal dinner giving people an opportunity to talk, share and meet others.

Dinner tickets must have been purchased in advance - no tickets will be available during the conference or on the night. The dinner will be free seating.

Saturday 14 October

Men's Breakfast ~ Choosing a career path

07:00 - 08:20

Room: Lake 3&4

Women's Breakfast ~ Mindfulness

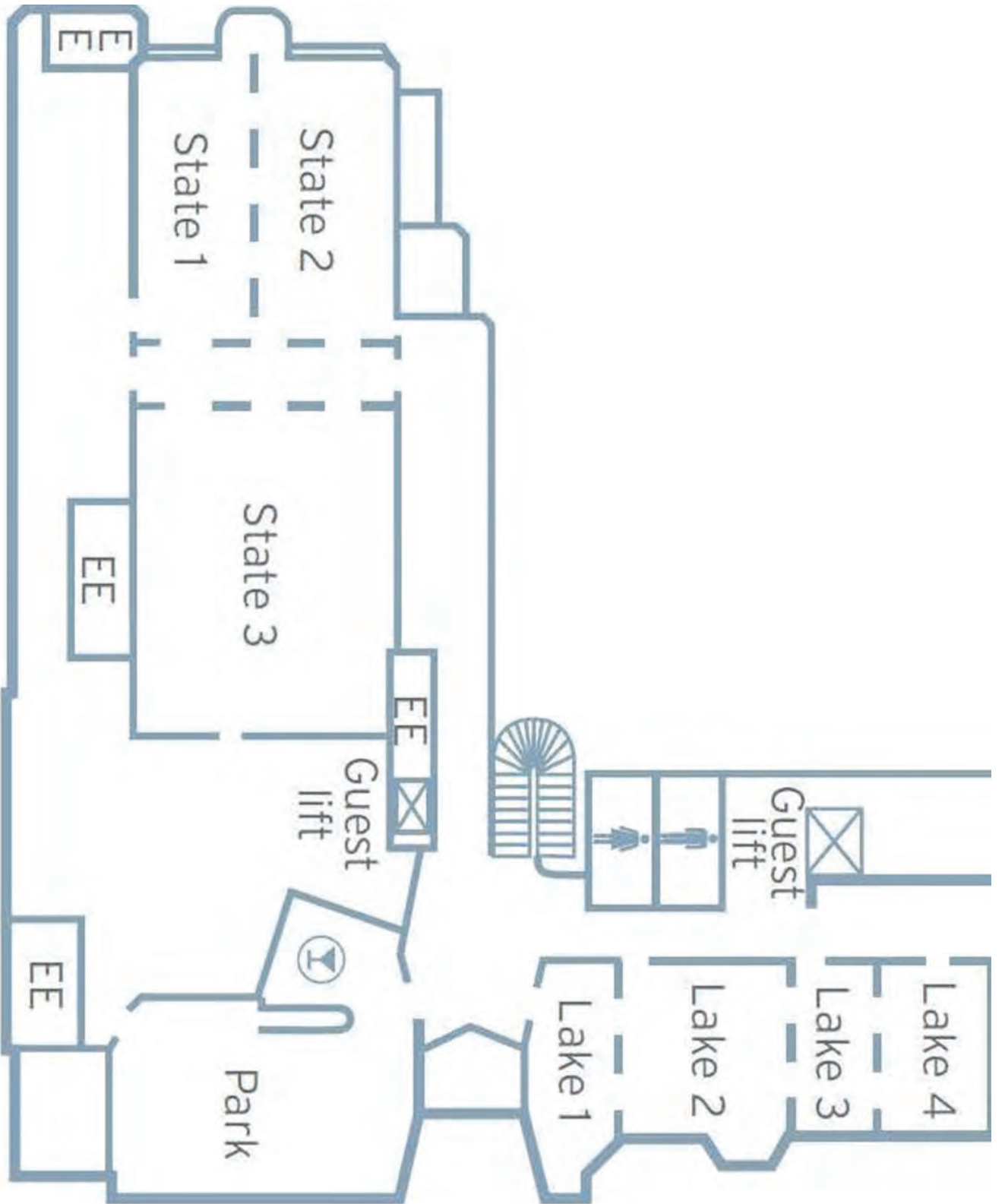
07:00 - 08:20

Room: Lake 1&2

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



SPONSOR AND EXHIBITION DIRECTORY

- PULLMAN LOBBY GROUND

Thank you to our sponsors and exhibitors

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38-42 Wharf Road, West Ryde NSW 2114

P: 02 9850 3333

Roche

Level 8, 30-34 Hickson Road, Sydney NSW 2000

P: 02 9454 9000

Shire

819, Grosvenor Place, Level 39, 225 George Street, Sydney NSW 2000

Medical information: 1800 012 612

Haemophilia Foundation Australia

7 Dene Ave, Malvern east VIC 3145

P: 03 9885 7800 Freecall: 1800 807 173

E: hfaust@haemophilia.org.au

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.

Friday 13 October

10.20-10.30 Saturday 14 October

10.20-10.30

POSTER 1 - Karl Archibald

New Zealand Advanced Youth Leadership Training Workshop: Building for the future

POSTER 2 - Hayley Coulson

*Physiotherapy rehabilitation of obturator externus muscle bleed:
A Case report.*

POSTER 3 - Johanna Newsom

Can You See It? Can You Score It?

POSTER 4 - Johanna Newsom

A Probing Issue

POSTER 5 - Dr Desdemona Chong

Painting the psychosocial landscape of individuals with haemophilia in Queensland

POSTER 6 - Suzanne O'Callaghan

What's stopping you from treatment? A health promotion strategy to eliminate hepatitis C in the bleeding disorders community

POSTER 7 - Hannah Opeskin

Connecting youth in leadership

POSTER 1

Name: Karl Archibald

Co-authors:

Institution/Organisation: Haemophilia Foundation of New Zealand

Title: New Zealand Advanced Youth Leadership Training Workshop:
Building for the future

The Haemophilia Foundation of New Zealand Inc. (HFNZ) has a proud history of developing young leaders and advocates who work together to deliver the best outcomes for our members. Over Waitangi weekend, 03-06 February 2017, HFNZ held its first ever Advanced Leadership Training (ALT) weekend in the central North Island.

ALT followed on from the HFNZ Youth Leadership Training weekend run in August 2014, and was targeted at specially selected young people from around New Zealand. Also included was a member from the Cambodian Hemophilia Association, which has twinned with HFNZ. These 18-30 year olds have stepped up into leadership roles in their organisations and have grown their involvement in their bleeding disorder communities. The ALT programme was designed specifically to enhance their leadership skills.

The challenges started the moment they landed in Auckland on day one. Split into two teams the groups had to problem-solve their way to the first night's base, 192km south. Here the leaders learnt about HFNZ's roots, history, sacrifices, shared personal stories, learned what it is like in a developing country, about not for profit leadership for tomorrow, social enterprise, and about building on the foundations set down before them.

On day two the teams had to make their way 150km east to Rotorua, where executive members of the HFNZ National Council discussed risk management, what the foundation is doing today and what could happen tomorrow. On day three the participants learned some higher-level advocacy strategies, and discovered ways to manage group conflict. The final day covered the global youth scene, some planning for tomorrow, and setting SMART goals.

There have been some great outcomes from the ALT. There is a higher level of engagement, with 13 foundation related goals or projects planned or completed. These include running local events and workshops, becoming a committee member, further leadership development, and greater advocacy through increased board involvement.

Overall, ALT has provided greater knowledge, increased confidence, and a better understanding of the impact that each person has on the future of the bleeding disorder community.

POSTER 2

Name: Hayley Coulson

Co-authors: Wendy Poulsen 1 , Anne-Maree King 1, Kellie Stockton 1

Institution/Organisation: Lady Cilento Children's Hospital Queensland

Title: Physiotherapy rehabilitation of obturator externus muscle bleed:
A Case report.

Haemophilia is a rare condition with a significantly smaller percentage of haemophilia males experiencing obturator muscle bleeds. The literature encourages continued investigation for unusual bleeding sites if symptoms persist, despite cover with factor and after excluding hip haemarthrosis or iliopsoas haematoma. A case of misdiagnosed obturator externus and the utilisation of magnetic resonance imaging (MRI) to guide physiotherapy rehabilitation will be discussed.

Case report: A teenage male with severe haemophilia and on regular prophylaxis was brought in to hospital following a sporting injury. He presented with pain and limited range of motion particularly with hip and knee extension, abduction, external and internal rotation of the hip. As evidence suggests limited hip range of motion is suggestive of iliopsoas haematoma, however initial ultrasound guided radiologic images provided no evidence of iliopsoas bleed even though clinical signs indicated. Over a two week period rehabilitation was carried out with progressive return to function with pain free range of motion. Seven weeks later, he demonstrated persistent hip and groin pain and greater restriction of range of motion. A magnetic resonance imaging (MRI) was performed and showed a large haematoma 4.8 x 2.6x 3.3cm of the externus obturator.

Conclusions/outcomes

This case study will discuss in greater detail the gradual rehabilitation process closely guided by medical imaging and objective assessment which provided a slow return to full weight bearing status, with pain free range of motion.

Other sources of literature discuss obturator bleeds but provide minimal discussion on rehabilitation. In essence deep muscle bleeds such as obturator externus should have guided return to function with thorough musculoskeletal assessment and MRI to confirm definite resolution.

POSTER 3

Name: Johanna Newsom

Co-authors: Robyn Shoemark

Institution/Organisation: The Children's Hospital at Westmead

Title: *Can You See It? Can You Score It?*

The Haemophilia Early Arthropathy Detection with UltraSound (HEAD-US) protocol involves standardised imaging planes for elbows, knees and ankles. Several Healthcare Professionals (HCP's) from around Australia have had the opportunity to attend hands on training sessions over the last 3 years to learn to conduct the HEAD-US protocol. This has led to familiarity with the technique, and numerous Haemophilia Treatment Centres (HTCs) now have regular access to ultrasound machines. HCPs at these centres have since been honing their techniques - but it's not just about being able to do the ultrasound, it is also about being able to accurately interpret the pictures and then use that information for the benefit of the patient.

How can we achieve this?

It is proposed that once confident in their HEAD-US techniques, HCP's utilising the protocol will work together to benchmark and demonstrate consistency in interpreting their results. This will be achieved by sharing de-identified images to the HCP's and asking all to independently score the images.

What will we do with this information?

By sharing these images and scoring, we will be able to develop inter-rater reliability across Australia - allowing us to determine that all HTCs are using and interpreting the protocol in the same manner. Once assured we have this consistency, we can then confidently use the information gained from the HEAD-US assessment to complement our clinical decision-making processes. We can also devise guidelines that will indicate the best way to use ultrasound for patient care.

POSTER 4

Name: Johanna Newsom

Co-authors: Robyn Shoemark

Institution/Organisation: The Children's Hospital at Westmead

Title: *A Probing Issue*

Haemophilia is an everchanging field of medicine. Advances in treatment must come with changes for Health Care Professionals (HCPs) in assessing and looking after the patient. This is one Haemophilia Treatment Centre's (HTC) four year journey of change.

Assessment of haemophilia patients using point of care ultrasound has been a regular theme at recent conferences. Our ultrasound journey started in 2013 at a Global Summit

in Potsdam, with a one day seminar for Australian and New Zealand HCPs to provide an introduction to the Haemophilia Early Arthropathy Detection with UltraSound (HEAD-US) protocol. With the support of industry, the next step was a two day workshop in Melbourne 2015 where physiotherapists, nurses and doctors gained hands on experience using and interpreting the HEAD-US protocol.

With the support of our haematology department, the next step was to obtain an ultrasound machine for our HTC. This proved challenging as hospital executives needed to be persuaded and educated about the value and potential possibilities of non-imaging staff utilising point of care ultrasound. In 2016, Pfizer provided the funds for a 12 month lease for an ultrasound machine to support our HTC. This was accompanied by a session with an expert trainer in 2017. The next step was to start using the ultrasound on patients and honing our skills. A further 3 day inaugural global ultrasound summit was attended in Italy 2017 with additional hands on practice.

Where to from here?

We have plans to commence a Physiotherapist and Nurse lead clinic where patients will have a joint ultrasound using the HEAD-US protocol, in addition to other standard health assessments. This will be completed prior to their medical review so that all information can be used to determine an optimal individual treatment plan for the patient.

POSTER 5

Name: Dr Desdemona Chong

Co-authors: Loretta Riley, Dr John Rowell

Institution/Organisation: Royal Brisbane & Women's Hospital

Title: Painting the psychosocial landscape of individuals with haemophilia in Queensland

The current poster describes an on-going psychosocial study which started in 2015. The first phase of the study was completed at the end of 2016. The study collected information about one's self-esteem, self-efficacy, perceptions of health-related quality of life, treatment satisfaction, pain coping and pain acceptance using questionnaires that were either established, linguistically validated for the Australian haemophilia community (e.g. quality of life) or developed for the haemophilia population (e.g. pain coping). Respondents include individuals with mild, moderate and severe haemophilia, living across Queensland and northern New South Wales.

The poster will cover:

- Aims of study
- Method
- Participant pool
- Main results
- Discussion of preliminary findings
- Recommendations

POSTER 6

Name: Suzanne O'Callaghan

Co-authors: Hannah Opeskin

Institution/Organisation: Haemophilia Foundation Australia

Title: What's stopping you from treatment? A health promotion strategy to eliminate hepatitis C in the bleeding disorders community

In Australia approximately 1350 people with bleeding disorders acquired hepatitis C from infected clotting factor concentrate treatments before 1993, when blood supply testing and viral inactivation manufacturing processes had been introduced. By 2014 unpublished data suggested that more than a third still had chronic hepatitis C. With the risks of advancing liver disease in long-term infection, eliminating hepatitis C in this population is a priority.

A health promotion strategy was required to address this. In 2014 HFA convened a Think Tank of haemophilia and hepatitis specialists. Targeted health promotion messages have been developed in consultation with these medical specialists, Haemophilia Treatment Centres (HTCs) and local Haemophilia Foundations. HFA has also consulted regularly with HTCs about treatment uptake and barriers.

With access to new highly effective treatments in 2016, the strategy was reshaped to encourage all affected people with bleeding disorders to have treatment.

The intention is to eliminate hepatitis C from the bleeding disorders community.

A large proportion have now had or are undergoing treatment. However, some have not yet sought treatment. Two target groups have been identified for specific strategies: those who do not see their hepatitis C as a priority, or have psychosocial or access barriers; and people with mild bleeding disorders unaware of their hepatitis C status as they had few treatments prior to 1993 and do not know their risk of infection. One strategy involves communication targeted at those with hepatitis C and their partners and family. Treatment messages focus on treatment as a priority and include personal stories, practical strategies and tips from people with bleeding disorders. The other aims to raise awareness about the risk of hepatitis C in people with mild bleeding disorders among general practitioners treating them in the community.

This poster will evaluate the evolution of these strategies during 2016-17.

POSTER 7

Name: Hannah Opeskin

Co-authors: Suzanne O'Callaghan

Institution/Organisation: Haemophilia Foundation Australia

Title: Connecting youth in leadership

Youth Lead Connect is a program developed by Haemophilia Foundation Australia (HFA) and focuses on developing leadership, mentoring and life skills among young people with bleeding disorders.

Beyond Prophylaxis (2012), a needs assessment of young people with bleeding disorders aged between 13-30 years, highlighted young people's beliefs that it was important to develop a group of older young people who could take on the role of

peer educators and mentors, with the potential for being community leaders in the future. However, engaging young people to be leaders and mentors in the community was proving to be difficult. Although young people desired to be involved in their local community, they lacked the skills, confidence and knowledge to do so effectively and as such, engagement was lacking across Australia.

The Youth Lead Connect program was developed by Haemophilia Foundation Australia (HFA) and focuses on developing leadership, mentoring and life skills among young people with bleeding disorders. This program builds these skills and aims to link the local community through Leadership Achievement Goal commitments.

In 2016, 10 youth participated in the YLC program.

Acceptance into the program was followed by a training weekend, held in Melbourne. As a commitment to the program youth develop Leadership Achievement Goals and complete these over a 12 month period. These Goals differ from person to person based on each participant's strengths and those they wish to grow. The youth participant and their state or territory Haemophilia Foundation, work together with HFA to devise achievable and realistic Achievements that work towards these goals.

Outcomes include youth taking on a leadership role at a foundation camp or activity including assisting their local foundation with leading, or planning an event (n=4); Youth contributed a personal story to Factored In (n=5); Youth promoted Factored In at a foundation camp (n=2); Youth are members of their foundation committee after joining the YLC program (n=2).

Through participating in the program, youth are now involved with their local community and Foundation at a higher level as leaders and mentors and have contributed to Factored In, highlighting the successfulness of the YLC program. The program will be continue to be run in 2017 and it is likely the program will be run every second year after 2017 to garner maximum demand among youth for future programs.

CONFERENCE PROGRAM

THURSDAY 12 OCTOBER 2017

- 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
Room: Pullman Lobby
- 1930-2230** Youth VIP Meet & Mingle - for registered youth only
Room: Pullman Atrium Bar and Lounge

FRIDAY 13 OCTOBER 2017

- 0830** Official Conference Welcome
Gavin Finkelstein
- 0830-1000** Plenary 1
Dr Justin Coulsen ~ 21 days to a Happier Family
Room: State
Dr Justin Coulsen is one of Australia's most respected relationship speakers, author, and researcher. He will talk about keys to being a "happier family".
- 1000-1045** MORNING TEA
Room: Pullman Lobby
- | | | |
|---|---|--|
| <p>1045-1215</p> <p>Concurrent 1
Hep C and HIV
Room: State 3
Chair:
Suzanne O'Callaghan</p> <p>A personal story of Hep C treatment
~ Simon</p> <p>Hepatitis C update
~ A/Prof Joe Sasadeusz</p> <p>HIV clinical update
~ A/Prof Edwina Wright</p> <p>A personal story about living with HIV
~ Anthony</p> <p>Panel Discussion</p> | <p>Concurrent 2
Genetic Testing
Room: State 1+2
Chair:
Andrew Atkins</p> <p>The pathway to genetic testing
~ Dr Matt Hunter</p> <p>Family planning and the role of the genetic counsellor
~ Carolyn Cameron</p> <p>Q&A</p> | <p>Concurrent 3
Youth Myth Busting Session
Room: Lake 2-4
Chair:
Moana Harlen</p> <p>Help a panel of three teams with young people, adults and health care professionals on each panel bust myths about living with a bleeding disorder. Topics include sport, employment and disclosure among many more!</p> |
|---|---|--|

1215-1325**LUNCH**

Room: Pullman Lobby

1325-1455**Concurrent 1
Von Willebrand
disorder
Room: State 3**Chair: Dr Mandy Davis
von Willebrand
disorder - diagnosis,
treatment and care

Dr Paula James

Living with vWD -
my personal story ~
Brendan

Dr Mandy Davis

**Concurrent 2
Evolving concepts in
pain management
Room: State 1+2
Chair: Cameron
Cramey**Understanding Pain ...
in less than 20'
~ Martina Egan-MoogEvolving concepts in
pain management
~ A/Prof Carolyn
ArnoldClinical application of
modern pain sciences
for PWBD, an "active
approach"
~ Catherine Pollard**Concurrent 3
Starting the Journey
with a child newly
diagnosed with a
bleeding disorder
Room: Lake 2-4
Chair: Dr Julie Curtin**From a clinical
perspective
~ Dr Julie CurtinAdjusting to diagnosis
and the need for
family support
~ Moana HarlenOne family's journey
with bleeding disorder
~ Jacqui**1455-1535****AFTERNOON TEA**

Room: Pullman Lobby

1535-1700**Plenary 2
Prophylaxis
Room: State
Chair: Dr John Rowell**Australian multicentre study of current real-world prophylaxis practice in
severe and moderate haemophilia A and B
~ Dr Jane MasonABDR Data analytics
~ Sumit Parikh**1800****Remembrance Service**

Room: Lake Room

1900**Conference Dinner**

Room: State Room (Tickets must be pre-booked)

SATURDAY 14 OCTOBER 2017

0700 - 0820 **Men's Breakfast ~ Choosing a career path** (Tickets must be pre-booked)

Room: Lake 3&4
 Chair ~ Jonathan Spencer
 Panel ~ David, Paul, Griffin

0700 - 0820 **Women's Breakfast ~ Mindfulness** (Tickets must be pre-booked)

Room: Lake 1&2
 Chair ~ Sharon Caris
 Speaker ~ Dr Ira van der Steenstraten

0830-1000 **Plenary 3 Women & Bleeding Disorders Room: State Chair: Dr Jenny Curnow**

Let's Talk Period: Women and Bleeding Disorders ~ Dr Paula James

Followed by Panel Discussion:
 Dr Jenny Curnow (Chair), Dr Chris Barnes, Dr Paula James,
 Dr Dominic Pepperell

1000-1045 **MORNING TEA** Room: Pullman Lobby

1045-1215 **Concurrent 1 Ageing Room: State 3 Chair: Leonie Mudge**

A personal story -
 living with inhibitors
 ~ David

Medical matters for people as
 they are ageing
 ~ Dr Huyen Tran

Issues for PWBD -an overview
 of NDIS, MyAgedCare
 ~ Leonie Mudge

Insurance and superannuation
 ~ Josh Mennen

Concurrent 2 Improving care through MyABDR Room: State 1+2 Chair: Dan Credazzi

Why do we use MyABDR?
 ~ Dr Chris Barnes

Working with the community
 ~ Suzanne O'Callaghan.

A HTC Royal Children's Melbourne
 experience
 ~ Julia Ekert

MyABDR in the clinic and at
 home Paediatric - Dr Chris Barnes
 and Karan
 Adult - Andrew Atkins and Michael

Moving Forward with MyABDR
 ~ Dr Chris Barnes

Panel Discussion

1215-1325 **LUNCH**
Room: Pullman Lobby

1325-1455 **Concurrent 1**
Healthy joints for Life
Room: State 3
Chair: Nicola Hamilton

Decision Making
in Sport & Physical
Activity -
Not Everyone Wants
to Swim!!
~ Alison Morris /
Abi Polus

~ Bleed, Arthritis or
Something Else
~ Alison Morris /
Abi Polus

Q&A

Concurrent 2
Women and
telling others
Room: State 1+2
Chair: Sharron Inglis
& Kathryn Body

Navigating
employment
and insurance
~ Kim Shaw

Telling others -
Personal stories
- Sharron
VWD
- Susie

Panel discussion
and Q&A

Concurrent 3
Free Papers
Room: Lake 2-4
Chair: Dr Tina Carter

To Vein or Not to Vein?
~ Robyn Shoemark

A new transition model
from the Adult hospital
perspective
~ Jane Portnoy
and Alex Coombs

Real Benefits of New
Therapies for Children
with Haemophilia
~ Dr Julie Curtin

Peer Support in
Victoria
~ Julia Broadbent
and Andrea McColl

1455-1535 **AFTERNOON TEA**
Room: Pullman Lobby

1535-1700 **Plenary 4**
What's Here Now and on the Horizon - New Treatment therapies
Room: State 3
Chair: Claude Damiani

My experience with an extended half life product
~ Paul

Supply and purchasing, new treatments, cost effectiveness assessment/
funding pathways to new medicines
~ John Cahill

Extended half-life factors and other new therapies
~ Dr Huyen Tran

Gene therapy
~ Prof John Rasko

FRIDAY 13 OCTOBER 2017

0830-1000

Plenary 1

Dr Justin Coulson ~ 21 days to a Happier Family

Room: State

Dr Justin Coulson is one of Australia's most respected relationship speakers, author, and researcher. He will talk about keys to being a "happier family".

FRIDAY 13 OCTOBER 2017

1045-1215 CONCURRENT 1
Hep C and HIV
Room: State 3
Chair: Suzanne O'Callaghan

Hep C treatment personal story ~ Simon

Hepatitis C update ~ A/Prof Joe Sasadeusz

Hepatitis C virus (HCV) affected a large number of Australians with bleeding disorders via blood product administration prior to routine screening in 1990. In some cases it has led to cirrhosis, liver failure and liver cancer. Prior treatments had significant side effects, required prolonged courses of therapy and had poor efficacy (especially in genotype 1 infection) and this resulted in low uptake of therapy. Over the last few years several new treatments called direct acting antivirals (DAAs) have been developed and since March 2016 they have become available in Australia under the PBS. These drugs have minimal side effects, have very high level of efficacy of approximately 95% and usually require short course of therapy of only 12 weeks. They are also just as effective in HIV -infected individuals as in people without HIV. One does however need to be aware of drug-drug interactions between DAAs and other medications which may require modification or temporary discontinuation of concomitant medication. Australia has allowed open access to therapy with DAAs which puts it in the forefront of global efforts to eliminate HCV and this should also be the aim in the community of people affected by bleeding disorders.

HIV clinical update ~ Dr Edwina Wright

HIV personal story ~ Anthony

Panel Discussion

FRIDAY 13 OCTOBER 2017

1045-1215 CONCURRENT 2
Genetic Testing
Room: State 1+2
Chair: Andrew Atkins

The pathway to genetic testing ~ Dr Matt Hunter

Haemophilia is a genetic condition which follows an X-linked pattern of inheritance within families. There are 2 main forms: Factor 8 and Factor 9 clotting factor deficiencies. Usually the diagnosis is made by measuring the levels of these clotting factors. There are many other rarer clotting disorders. Genetic testing is used when couples want to prevent passing this on to their children or when there is uncertainty about a diagnosis, or where there is a family history. This presentation will be divided into two parts delivered by a genetic counsellor and a clinical geneticist. Subjects covered will include: the route to a genetic diagnosis, referral, reasons for genetic testing, the role of the genetic counsellor, consent to genetic testing, disclosure of results, family cascade testing, reproductive choices, testing in pregnancy, using IVF to select healthy embryos, the genes involved in haemophilia and rare clotting disorders, new emerging genetic therapies.

Family planning and the role of the genetic counsellor
~ Carolyn Cameron

Q&A

FRIDAY 13 OCTOBER 2017

1045-1215 CONCURRENT 3
Youth Myth Busting Session
Room: State 1+2
Chair: Moana Harlen

Help a panel of three teams with young people, adults and health care professionals on each panel bust myths about living with a bleeding disorder. Topics include sport, employment and disclosure among many more!

Panel -

- James Slade
- Jane Portnoy
- Cameron Cramey
- Martin
- Heidi
- Jenny
- Megan
- Sam
- Cara

FRIDAY 13 OCTOBER 2017

**1325-1455 CONCURRENT 1
Von Willebrand disorder
Room: State
Chair: Dr Mandy Davis**

von Willebrand disorder - diagnosis, treatment and care

- Dr Paula James

Living with vWD - my personal story - Brendan

- Dr Mandy Davis

FRIDAY 13 OCTOBER 2017

1325-1455 CONCURRENT 2
Evolving concepts in pain management
Room: State 1+2
Chair: Cameron Cramey

Understanding Pain ... in less than 20' ~ Martina Egan-Moog

Understanding why we hurt helps us to hurt less, and abundant scientific research has convincingly shown that learning about pain is a powerful treatment in itself - this is the "Explain Pain Revolution". Explaining Pain involves teaching people that many things, happening both inside and outside of their bodies, can contribute to their pain, and importantly, that there are ways that we can positively influence these.

The "Explain Pain Revolution" has been built on the explosion of pain research in the last 20 years, research that has helped us to deeply understand many aspects of pain including the chemical processes that occur after injury, how 'danger messages' are sent to the spinal cord and then the brain, how these messages can be 'turned down' or 'turned up' depending on the situation, the widespread, complex processing of danger messages in the brain, and finally, the many ways in which this complex brain processing recruits multiple, powerful, protective systems including immune, hormonal, movement and pain systems.

This presentation aims to first provide an overview about the intricate interplay of these factors and how the brain will make pain when it concludes that body tissues are in danger and protective action is required. And secondly to offer an introduction to active treatment approaches that harnesses the power of "bioplasticity".

Evolving concepts in pain management ~ A/Prof Carolyn Arnold

My colleagues in this workshop will present on understanding pain sciences as applied to PWBD and an "active" approach to pain.

People WBD who are experience persistent pain have varied reasons for their pain. Some may have developed degenerative joint disease in joints exposed to bleeding over their lifetime, and variably according to the severity of bleeding experienced. This is called "nociceptive pain". Others may have nerve injuries from bleeding episodes in pain generated by nerve dysfunction, called "neuropathic pain". But sometimes these separations are not distinct, and the nervous system can modulate any pain experienced.

Like many medical problems, approaches are changing with better research, so what we did 20 years ago has changed, and similarly there is great hopes for better management in the future.

The major changes are a more wholistic approach to pain, that takes into account individual variability, as well as the importance of good function and quality of life even in the presence of some disability. And medication management is only one element in this approach.

This presentation will be an update of the benefits and in some cases hazards of medication, and a whole person approach to management over a lifetime.

Clinical application of modern pain sciences for PWBD, an “active approach”

~ Catherine Pollard

In order to minimize long term joint damage, people with haemophilia are taught to treat pain quickly with clotting factor replacement therapy. However, not all pain is related to a bleeding episode particularly as the individual ages. For many years we have considered that this chronic pain is secondary to tissue damage and have therefore focused on the periphery, attempting to fix the damaged tissues. As science progresses, we now have a better understanding of how pain is processed within the brain and nervous system and a deeper appreciation of how pain can be amplified irrespective of the peripheral stimulus seeming to initiate it. Changes affecting nervous system processing, along with influences from psychological and social factors all play important roles in the maintenance and augmentation of persistent pain. This knowledge has helped to extend our repertoire of techniques and strategies for managing pain. This talk aims to explore some of the non-pharmacological options available to people with bleeding disorders.

FRIDAY 13 OCTOBER 2017

1325-1455 CONCURRENT 3
Starting the Journey with a child newly diagnosed with a bleeding disorder
Room: Lake 2-4
Chair: Dr Julie Curtin

From a clinical perspective ~ Dr Julie Curtin

Adjusting to diagnosis and the need for family support ~ Moana Harlen

One family's journey with bleeding disorder ~ Jacqui

FRIDAY 13 OCTOBER 2017

1535-1700 **Plenary 2**
Prophylaxis
Room: State
Chair: Dr John Rowell

Australian multicentre study of current real-world prophylaxis practice in severe and moderate haemophilia A and B ~ Dr Jane Mason

Introduction

With the emergence of novel treatment products for haemophilia and an increasing focus on the benefits of pharmacokinetic driven individualized prophylaxis, robust national data with regards to current patterns of factor consumption and compliance are required.

Aim

To characterise current Australian practice with regards to use of prophylactic clotting factor infusions in patients with moderate or severe haemophilia A (HA) and haemophilia B (HB).

Methods

This was a retrospective, non-interventional study utilising Australian Bleeding Disorder Registry (ABDR) data collected over a 12 month period. Registered and consented patients with moderate or severe HA or HB without inhibitors were included.

Results

A total of 718 HA (551 severe, 167 moderate) and 166 HB (87 severe, 79 moderate) patients were included. Regular prophylaxis was prescribed in 453 patients (82%) with severe HA, 42 patients (25%) with moderate HA, 66 patients (75%) with severe HB and 11 patients (13%) with moderate HB. Near universal prophylaxis was achieved in the paediatric subgroup. The mean weekly dose of factor VIII in severe HA was 84 international units/kilogram/week (IU/kg/wk) versus 71 IU/kg/wk of factor IX in severe HB. Most patients on prophylaxis were treated ≥ 3 times/week (HA) or 2 times/week (HB). Non-adherence peaked in the 20-29 year age group. Older individuals on regular prophylaxis used more factor than was expected for their prescribed regimen.

Conclusion

Prophylaxis rates in severe haemophilia are comparable with other developed nations. The benefit of a national registry is demonstrable. Further research into the underlying reasons for non-compliance in young adults with haemophilia is required.

ABDR Data analytics ~ Sumit Parikh

The Australian Bleeding Disorders Registry (ABDR) is a secure online database designed to collect all clinical information related to the normal, routine and emergency treatment of patients with bleeding disorders. ABDR data, primarily used to monitor treatment product supply and use, also provides a unique opportunity to understand population characteristics, effects on patient well-being, improvements in treatment management, outcomes of preventative care, risk factors and treatment complications. However to measure any outcome it is imperative to have a good understanding of the minimum data set required for analysis. This presentation provides an overview of the measurable outcomes using ABDR data and highlights the importance of data quality and patient participation/involvement.

SATURDAY 14 OCTOBER 2017

0830-1000 Plenary 3
Women & Bleeding Disorders
Room: State
Chair: Dr Jenny Curnow

Let's Talk Period: Women and Bleeding Disorders ~ Dr Paula James

Studies have shown that ~1 in 1000 individuals worldwide has an inherited bleeding disorder, however far fewer are actually diagnosed. Women with bleeding disorders are particularly at risk to go undiagnosed as there is a general lack of understanding about the difference between normal and abnormal bleeding, particularly menstrual bleeding, and social stigma preventing open discussion about the issue. There can often be a significant delay (up to 15 years) between the onset of bleeding symptoms and appropriate medical attention. During this presentation, Dr. James will talk about the challenges facing women with bleeding disorders, and her approach to assessing patients, including a review of the inheritance patterns of the most common bleeding disorders seen in women. Management strategies for heavy menstrual bleeding and other gynecologic problems will be addressed, as well as the importance of iron stores in a woman's health. Of critical importance to the bleeding disorders community is the distinction between the symptoms experienced by men and women; women cannot be "bleed free" and the approach to their care must take this into account. Dr. James will present her "Let's Talk Period" project and ongoing efforts to raise awareness about women and bleeding disorders using social media as a means of global communication.

Followed by Panel Discussion:

Dr Jenny Curnow (Chair), Dr Chris Barnes, Dr Paula James, Dr Dominic Pepperell

SATURDAY 14 OCTOBER 2017

1045-1215 CONCURRENT 1
Ageing
Room: State 3
Chair: Leonie Mudge

A personal story – living with inhibitors ~ David

Medical matters for people as they are ageing ~ Dr Huyen Tran

Issues for PWBD~ Leonie Mudge

The last few years have seen changes introduced to the Federal Government delivery of two major safety net programs with the rollout of the NDIS and changes to the delivery of aged care services for over 65 year olds. Both programs emphasize the importance of consumer directed care.

The introduction of both programs have brought pressures to upskill staff, and disruption and replacement of existing services. Consumers face the challenge of working through the maze of relevant information like traversing a minefield. When this new information needs to be absorbed at a time of poor health and family crisis, the pathway forward can seem overwhelming.

This presentation will provide basic information about the two programs to assist consumers and their carers to make important choices and prepare themselves ahead of time. It will draw on experiences of people with bleeding disorders, and their carers, who have recently applied to use these programs

Insurance and superannuation ~ Josh Mennen

This session will offer insights into the difficulties faced by haemophilia sufferers and their families when buying and claiming on insurance product including disability and travel insurance. It will offer practical suggestions about how best to deal with insurers to get the right cover and make sure it pays out on a valid claim. The key themes will include genetic testing issues, disclosure of pre-existing conditions, disability discrimination, and automatic insurance cover through superannuation membership.

SATURDAY 14 OCTOBER 2017

1045-1215 CONCURRENT 2
Improving care through MyABDR
Room: State 1+2
Chair: Dan Credazzi

Why do we use MyABDR? ~ Dr Chris Barnes

The MyABDR program has become an integral part of the haemophilia treatment centre at the Royal Children's Hospital. During the review of the patient, patient entered data is reviewed facilitating patient and family focused management. The session will describe the challenges and potential of using the myABDR application in the clinic room

Working with the community ~ Suzanne O'Callaghan

A HTC Royal Children's Melbourne experience ~ Julia Ekert

When MyABDR was launched in 2014 the RCH HTC decided to embrace the technology and encourage our families to record their treatment product usage. This decision was based on feedback we had deemed from a previous study in our centre in 2011. For this study we sent out 60 questionnaires asking questions about how, when and who records their clotting factor usage and how important it is. We received 30 questionnaires back with 22 indicating that they recorded their product usage and did not find it hard to do this. We followed up this study with phone interviews which led us to the conclusion that most people were willing to record their clotting factor usage if there was a good reporting tool available. Using this data we felt that with the launch of MyABDR it was the right time to encourage our patient population to start recording their clotting factor usage in earnest.

It is fair to say that our success in the uptake of MyABDR is largely down to a whole team effort. The in clinic support we have from our HTC director, nurse, registrars and data manager have been crucial achieving a 93% success rate. Although we have tied home delivery in with MyABDR usage it has turned out to be a "stick" we have not hardly had to use as our families have been able to see the advantages of recording when they come to clinic. Offering MyABDR support in the clinic setting has also helped with our uptake figures. Sometimes the help required is as simple as calling the NBA help desk during clinic to help explain the issue to them or helping the patient/parent to get through the password steps! Our main message is to not give up and that we are there to help and support because not only does it help the treating doctor but also the patient.

MyABDR in the clinic and at home
Paediatric - Dr Chris Barnes and Karan
Adult - Andrew Atkins and Michael

Moving Forward with MyABDR ~ Dr Chris Barnes

Panel Discussion

SATURDAY 14 OCTOBER 2017

1325-1455 CONCURRENT 1
Healthy joints in Adolescence for Life
Room: State 3
Chair: Nicola Hamilton

Decision Making in Sport & Physical Activity - Not Everyone Wants to Swim!!
~ Alison Morris / Abi Polus

Bleed, Arthritis or Something Else
~ Alison Morris / Abi Polus

Q&A

SATURDAY 14 OCTOBER 2017

1325-1455 CONCURRENT 2
Women and telling others
Room: State 1+2
Chair: Sharron Inglis & Kathryn Body

Navigating employment and insurance ~ Kim Shaw

This session will offer insights into the difficulties faced by people with hemophilia and their families when buying and claiming on insurance products including disability and travel insurance. It will offer practical suggestions about how best to deal with insurers to get the right cover and make sure it pays out on a valid claim. The key themes will include genetic testing issues, disclosure of pre-existing conditions, disability discrimination, and automatic insurance cover through superannuation membership.

Telling others - Personal Stories - Sharron
VWD - Susie

Panel discussion and Q&A

SATURDAY 14 OCTOBER 2017

1325-1455 CONCURRENT 3
Free Papers
Room: Lake 2-4
Chair: Dr Tina Carter

To Vein or Not to Vein? ~ Robyn Shoemark

For people with severe haemophilia prophylaxis has been the treatment of choice for many years. Haemophilia A is usually 3 times/week or every second day. Haemophilia B is usually 2 times/week or every 3 days. Peripheral venous access or a surgically implantable venous device (port) are the most common ways to administer factor. Deciding which type of venous access is dependent on many things including age, size, vein health and frequency of treatment.

Paediatric patients starting prophylaxis often meant going to theatre for a port. With the introduction of extended half-life (EHL) products through clinical trials this has made peripheral venous access a more accessible option.

This presentation showcases a 14 month old on clinical trial who was able to avoid having insertion of a port. Venepuncture was made possible due to factor only being needed 2 times/week and the willingness of this family to travel regularly to the hospital to attend venous access training.

With EHL's, patient/family willingness and consistent nursing staff to attend to venepuncture and provide patient/family support, we may see less need for ports for treatment of patients with haemophilia.

A new transition model from the Adult hospital perspective
~ Jane Portnoy and Alex Coombs

Transition is well known to be a risky time for young people. The costs of unsuccessful transition are experiences across their personal, family, financial, and health spheres. Adolescence is a time when there are physical and neurological changes, and in fact we now understand that at 18 the brain is not fully developed, particularly in the area of dealing with emotions and integrating them with reasoning and judgment.

Running a transition program is how we try to build our relationship with our future clients and reduce the challenges of having to move health care at a time when there are so many other changes happening. These changes are experienced across many aspects of a young person's life, often all at once.

We started from the position of having noticed that there is a group of our clients who really struggle to manage their own care. The impact is noticed in their quality of life, can cause them long term harm, and also leads to significant issues with their feelings about coming into an adult hospital.

We decided that we wanted to get to know these patients before they come to us, and to allow them to meet us. We have a multi pronged strategy.

- We ran an evening information session, personally contacting all our imminent transitionees.

- We also involved the HFA and HFV, made contribution to the HFV newsletter and HFA journal, and have met with representatives of HFA and HFV and other social workers and psychologists working in the area of bleeding disorders.
- We talked to our recent transitionees about what worked and what was problematic. (particularly getting input from those that struggle with our hospital or with their bleeding disorder.

Real Benefits of New Therapies for Children with Haemophilia ~ Dr Julie Curtin

Despite having very good treatments for the past 20 years, there remain a number of challenges in managing children with haemophilia. In recent years a number of new products have been developed that offer real potential to address a number of these issues. The holy grail of a “cure” for haemophilia remains, however, with progress being seen in Gene Therapy this Holy Grail may one day become a reality. However, it is likely to still be quite some time before gene therapy will become a standard therapy for patients with haemophilia. In the meantime, new products that are either extending the half-life of the factor product, working through alternative mechanisms, or delivered by alternative means, are much closer to a practical reality. A number of these products are now registered in Australia and others are undergoing clinical trials in Australia and elsewhere in the world. Some of these products are now available for use in the USA, Canada, Europe and other countries.

Current challenges in managing children with haemophilia include the need for intravenous injection; the development of inhibitors; traumatic bleeds in active children and issues of compliance (especially in adolescents). The new therapies that are now emerging potentially provide means to overcome these challenges. These new products offer real benefits such as reduced frequency of infusion and the reduced need for ports, improved trough levels (and therefore reduced rate of traumatic bleeds), alternative therapies (eg emicizumab) that work even in the presence of an inhibitor. Finally the delivery of these new products by subcutaneous means offers real promise to parents of small children where finding a vein can be a traumatic experience for all.

Overcoming these challenges by using these emerging therapies has the potential to revolutionise the treatment of children with haemophilia.

Peer Support in Victoria ~ Julia Broadbent and Andrea McColl

At Haemophilia Foundation Victoria peer support is an important goal of our programs and services we provide to the community. We are going to share the importance of programs; Family Camp, Grandparents group, Youth Camp, regional visits, Women’s group and Men’s group and how peer support connections work within them.

For example, the annual family camp is a unique opportunity for our community, especially families with young children to come together, support each other, establish and build relationships through interaction, casual conversations and guided activities with skilled professionals in adventure therapy. There is no doubt this activity is significant in helping HFV to meet its goals: to connect support and empower individuals and families affected by bleeding disorders.

SATURDAY 14 OCTOBER 2017

1535-1700 Plenary 4
What's Here Now and on the Horizon - New Treatment therapies
Room: State
Chair: Claude Damiani

My experience with an extended half life product
 ~ Paul

Supply and purchasing, new treatments, cost effectiveness assessment/funding pathways to new medicines ~ John Cahill

The healthcare for patients with bleeding disorders in Australia is largely provided through a model of coordinated care that was endorsed by Australian governments in 1998. This model is recognised as the optimal model of care in guidelines that were developed by the Australian Haemophilia Centre Directors' Organisation (AHCDO), with support and funding from Australian Governments through the National Blood Authority (NBA).

The NBA has helped to support the clinical care of people with haemophilia in Australia through the provision of a safe, secure, adequate and affordable supply of clotting factor products, since 2003, and recombinant products, since 2004. For the past ten years, the NBA has also supported the appropriate care and effective use of clotting factor products through the development and provision of systems such as the Australian Bleeding Disorder Registry and the MyABDR application.

Over recent years, and through constant horizon scanning, the NBA is aware of emerging new clotting factor products, including extended half-life (EHL) products and other new therapies, for people with bleeding disorders that are not available under the current supply arrangements.

Governments currently spend more than \$1 billion annually for the supply of blood and blood related products to meet the clinical needs of Australians. This level of increasing expenditure must be assessed against well-developed evidence.

In 2017 the NBA conducted a consultation process with clinical, patient and industry stakeholders that obtained useful information about the potential future availability of EHL clotting factor products and other new therapies for patients in Australia.

Australian governments have tasked the NBA with developing a coordinated health technology assessment process to consider the potential funding and availability of EHL products under national supply arrangements. The NBA is developing this process in conjunction with the Medical Services Advisory Committee in the Commonwealth Department of Health, and the Jurisdictional Blood Committee.

The NBA is also currently working with certain suppliers on temporary programs for the immediate and limited provision of EHL clotting factor products within national arrangements.

Extended half-life factors and other new therapies ~ Dr Huyen Tran

Gene therapy ~ Prof John Rasko

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